

ORIGINAL ARTICLE

To investigate the impact of caregiving for patients with schizophrenia and bipolar disorder on caregivers' burden, perceived stigma, and coping style

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ABSTRACT:

Aim: To investigate the impact of caregiving for patients with schizophrenia and bipolar disorder on caregivers' burden, perceived stigma, and coping style. **Materials and Methods:** This is a cross sectional hospital-based study. The caregivers of a total of 88 patients of which 50 with schizophrenia and 38 with Bipolar Mood Disorder were taken as participants. The semi structured Proforma, The Burden Assessment Schedule (BAS), Brief COPE and Perceived Discrimination Devaluation Scale (PDD) translated and validated in Hindi were administered. **Results:** The level of burden for schizophrenic caregivers is more as compared to the caregivers of BD. The caregivers of patients with schizophrenia were more stigmatized as compared to caregivers of BD patients. Females were more stigmatized than males in both the groups. The caregivers of both BD and schizophrenic patients used Active emotional coping to combat the situation.

Key words- Schizophrenia, Bipolar Disorder, Burden, Stigma, Coping.

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INTRODUCTION

Schizophrenia is one of the most burdensome and stigmatized illnesses in the world especially in the current era of de-institutionalization. Schizophrenia and Bipolar Disorder are two major psychotic disorders which cause considerable morbidity among the affected patients. The burden of care is more often defined by its impact on the caregivers. Other than the emotional, psychological, physical and economic impact, the concept of burden of care involves subtle but distressing ideas like shame, embarrassment, feelings of guilt and self-blame. The early concept of burden of care was divided into 2 distinct areas - objective and subjective. Objective burden of care is meant to indicate its effects on the household, like taking care of daily chores; whereas subjective burden indicates the psychological and emotional impact of mental illness on family members (including feelings of grief and worry). Living with a patient with schizophrenia can put considerable stress and limitations on the rest of the family. Since the mid-1950s, researches have been studying the effects of mental illness on patients caregivers, regarding the impairments and emotional distress that occur as a consequence of schizophrenia and a number of studies^[1] have documented high degree of objective and subjective burdens on near and dear ones of the psychiatric patients. The results of these studies also raise a query pertaining to the resilience of a family or caregiver lest they themselves become overburdened and require professional help. Strong evidence from previous research indicates that the care giving role is very demanding and may reduce one quality of life.

Stigma as defined by Goffman^[2] can be divided into physical, personal and social/ perceived stigma. The stigma attached to mental illness raises great concern to the patients and their families. The society that is seen as rejecting makes life difficult for the caregivers and families of people with suffering from major psychoses. Development and implementation of effective interventions to create a more supportive and understanding society would be a challenging task.^[3] The stigma, myths and misconceptions surrounding mental disorders have been identified as the major reason for a large number of patients not seeking treatment.^[4] Stigma contributes too much of the discrimination and human rights violations experienced by people with mental disorders.^[5] Stigma has been divided into public and self. Public stigma is the reaction that the general population expresses towards persons with mental disorders. Self-stigma is the prejudice which people with mental disorders turn against themselves. Both public and self-stigma may be understood in terms of three components: stereotypes, prejudice, and discrimination.

^[6] Most of the Indian research on stigma focuses on the attitudes and reactions of the general public towards mentally ill persons.^[7-9]

Folkman and Lazarus^[10] have defined coping as a person's constantly changing cognitive and behavioral efforts to manage a situation which is seen as stressful. The relationship between coping styles is complex because caregivers subjectively report 'burden'. The consensus report by Troop^[11] states that emotion-based coping is equivalent with an unsatisfactory outcome and problem-focused coping is

associated with more satisfactory outcome. Coping with patient having a serious mental disorder like schizophrenia or bipolar mood disorder in the family can be difficult, as one may use negative style of coping. [12]

Very few studies from India have compared the burden perceived by caregivers of schizophrenia and bipolar affective disorders; those that have been largely inconclusive. Some suggest that caregivers of bipolar affective disorder patients suffer the same degree of burden as caregivers of schizophrenia, [13] whereas others suggest that the burden is higher on the caregivers of schizophrenia. [14-17]

MATERIAL AND METHODS

This is a cross sectional, hospital based study. The caregivers of a total of 88 patients of which 50 with schizophrenia and 38 with Bipolar Disorder diagnosed according to DSM IV-TR [18] visiting the Psychiatry OPD of a tertiary care hospital during one year were the participants of the study. The caregivers were of either sex, aged 18 years and above, of patients who had total illness duration of more than 2 years. The written informed consent was obtained from the subjects either in English or Hindi after explaining them the purpose of the study. The semi structured Proforma was used for entering the Socio-demographic data and clinical details obtained from patients' caregivers or medical records. All the three scales -The Burden Assessment Schedule (BAS), Brief COPE and Perceived Discrimination Devaluation Scale (PDD) translated, back translated and validated in Gujarati were administered.

Primary caregiver (is defined as an adult relative living with a patient, in the same environment, for at least 12 months and was involved directly in giving care to the patient and most supportive either emotionally or financially, i.e felt most responsible for the patient), Males and females of 18 years and above taking care of a patient who is diagnosed having Schizophrenia and Bipolar disorder as per the DSM-IV-TR criteria, Person including spouse taking care of a patient who is on medication and on regular follow up in outpatient department for atleast last 2 years and Patients with bipolar disorder who have atleast one episode in past 2 years of illness period prior to assessment were included.

Patients with chronic physical illnesses, co-morbid psychiatric conditions, organic brain syndromes, and substance abuse/ dependence except nicotine dependence, If the patient was not on medications, If the caregiver was not living with the patient for at least 2 years prior to intake and If the caregiver had a history of psychiatric disorder before being a caregiver were excluded from the study.

TOOLS

Socio-demographic profiling sheet- The sheet includes both the sociodemographic and clinical variables.

Burden Assessment Schedule (BAS)-developed by Thara et al, 1998 [19] at Schizophrenia Research Foundation (SCARF) is based on principle of 'stepwise ethnographic exploration' described while studying affected families in an effort to gauge the meaning, of giving care to a chronic psychotic person. This is a semi- quantitative, 40-item scale measuring 9 different areas of objective and subjective caregiver burden. Each item is rated on a 3 point scale. Scores range from 40 to 120 with higher scores > 80 indicating greater burden. Internal consistency for the full scale is 0.80 as measured by the alpha coefficient. Four items are to be rated by the spouse.

Perceived Devaluation and Discrimination Scale- This scale has been developed by Link, [20] It consists of 12 items which were asked on a 6 point -strongly agree to strongly disagree Likert format. The scale which ranges from 1- 6 is rated by summing up all the items and dividing them by 12. It shows adequate reliability overall (alpha=0.78) as well as among first treatment contact patients (alpha=0.82), former patients (alpha= 0.83) untreated community cases (alpha=0.73) and as well as members of the community (alpha=0.73) In the items marked R the scoring will be reversed.

Brief COPE (Carver, 1997) [21] The Brief COPE is a 28-item measure of coping style use derived from the longer COPE inventory. It is a self administered scale translated in validated in Gujarati. The Brief COPE uses a 4-point Likert scale (I haven't been doing this at all to I've been doing this a lot). It includes 14 sub scales of two items each grouped into three coping categories by summing items accordingly (with higher scores indicating greater intensity of use of the coping strategy). The three coping strategies and their associated sub scales were problem-focused coping (active coping, planning, instrumental support, and religion scales; alpha .80); active emotional coping (venting, positive reframing, humour, acceptance, and emotional support scales; alpha .81); and avoidant emotional coping (self-distraction, denial, behavioural disengagement, self-blame, and substance use scales; alpha.88) [22]

STATISTICAL ANALYSIS

Statistical analysis was done using the SPSS software package for Windows, version 15.0. Descriptive analysis was computed in terms of mean, standard deviation and statistical tests t test, F ratio, Pearson's correlation coefficient were calculated. X2 test was calculated for dichotomous and polychotomous nominal categorical variables.

RESULTS

The present study has a sample size of 50 caregivers of patients suffering with Schizophrenia and 38 caregivers of patients with Bipolar Disorder. The mean age of the patients of schizophrenia was less than that of the Bipolar Disorder group, although the difference was not significant. Age of onset of the

disease was less in Schizophrenia. Males outnumbered females in both the groups. Participants in both groups had a mean of about 10 years of education; the number of years of education between the groups is not significant. Most of the patients came from lower socioeconomic status. The caregivers of patients with bipolar mood disorder were significantly younger than the caregivers of patients with schizophrenia. The majority of the primary caregivers of patients with schizophrenia were fathers, whereas those of patients with bipolar Mood disorder were husbands, the majority of the caregivers in both the groups were parents. Most of the caregivers in either group were married and employed. Most of the caregivers belonged to nuclear families in both the groups. Being a tertiary care hospital most of the patients were from the rural background (63%). Duration of illness was

more than 5 years. In both the groups most of the patients were married for more than 30 years followed by unmarried caregivers and then divorced. Equal number of caregivers had knowledge about the illness and same numbers were not told about it before marriage. In rest of the cases illness developed at a later age. Duration of care is more for Schizophrenic patients. Among the patients with Bipolar disorder I, 23 were in a manic episode and 8 were in a depressive episode, with Bipolar disorder II, 4 were in a hypomanic and the remaining 3 were depressed at the time of assessment. In Table 3, the level of burden for schizophrenic caregivers is more as compared to the caregivers of BD. But in two subareas, i.e. taking responsibility and caregivers strategy the level of burden is more in BD.

Table-1 Socio-demographic variables (N/%)

		BD n=38	Schizophrenia n=50	χ^2	Significance
Age of onset	18-39	13(34.2)	10(20.0)	2.856	0.239
	40-59	15(39.5)	20(40.0)		
	60 & above	10(26.3)	20(40.0)		
Sex	Male	32(49.2)	33(50.7)	3.709	0.027*
	Female	6(26.1)	17(73.9)		
Relationship	Husband	12(52.2)	11(47.8)	9.311	0.156
	Wife	4(80)	1(20)		
	Mother	3(21.4)	11(78.6)		
	Father	10(40)	15(60)		
	Siblings	5(38.4)	8(61.5)		
	Daughter	0(0)	2(100)		
Socioeconomic status	Son	4(66.6)	2(33.3)	1.08	0.5827
	>2000	6(37.5)	10(62.5)		
	2000-4000	12(52.2)	11(47.8)		
	<4000	20(40.8)	29(59.2)		
Duration of care	0-2	8(57.1)	6(42.8)	7.395	0.11
	2-5	5(22.7)	17(77.3)		
	5-10	13(48.1)	14(51.8)		
	10-15	4(33.3)	8(66.6)		
	>15	8(61.5)	5(38.4)		

Table 2 Current Clinical state of the patients

	N(%)
BD I	
Manic	23(23.7)
Depressed	8(8.2)
BD2	
Hypomanic	4(4.1)
Depressed	3(3.1)
Schizophrenia	50(51.5)

In Table 4, perception of stigma is significantly different in BD and Schizophrenia for males and females. Females are more stigmatized than males. The caregivers of patients with schizophrenia were more stigmatized as compared to caregivers of BD patients. Habitat has not played a significant role in both BD and Schizophrenia. There is no significant

difference between the perceptions of stigma in people belonging to different socioeconomic status but difference is not significant in both the conditions. Different Relationship has a different perception of stigma which is not significant when both BD and Schizophrenia are compared.

Table 3 Level of burden in caregivers

Diagnosis type/BASS domains	Spouse related M(SD)	Physical and mental health	External support	Caregivers routine	Support of patients	Taking responsibility	Other relations	Patients behaviour	Caregivers strategy
Schizophrenia	4.37 (4.31)	12.08 (3.40)	9.42 (2.54)	8.68 (2.51)	11.16 (2.28)	9.92 (1.28)	5.74 (1.72)	6.55 (2.14)	8.29 (1.47)
BD	3.28 (3.73)	13.32 (3.09)	9.72 (2.07)	9.48 (2.40)	10.52 (2.10)	10.10 (1.34)	5.90 (1.69)	6.92 (1.98)	9.28 (1.64)
T test	1.266	-1.78	-.608	-1.51	1.36	-.631	-.445	-.833	-2.93
Level of Significance	.209	.078	.545	.135	.178	.530	.658	.407	.004*

Table 4 Perception of Stigma in caregivers

	t/F statistic	Significance
BD	t value	p
Sex	-3.714	.003
Habitat	.730	.479
	F value	P
SE status	.020	.980
Relationship	4.832	.022
Schizophrenia	t value	P
Sex	.313	.756
Habitat	.493	.626
	F value	P
SE status	3.563	.042
Relationship	.541	.707

Table 5 Caregivers Coping patterns and its associated factors

Diseases	Coping Patterns	Relationship		Gender	
		F ratio	p	T statistic	p
BD	PF	.775	.575	.407	.687
	AE	1.078	.391	-.406	.687
	AVE	.679	.643	-3.003	.005
Schizophrenia	PF	.752	.611	-1.114	.271
	AE	.585	.740	-.278	.783
	AVE	.743	.618	-.330	.743

In Table 5, Male Caregivers of BD patients used-Active Emotional Coping followed by Problem Focused Coping while Females used Active Emotional coping followed by Avoidant Emotional Coping. Caregivers of Schizophrenic patients used Active Emotional coping followed by Problem Focussed coping irrespective of the gender. In Table

6, The Facets of burden which were affected in caregivers of patients with BD who used Problem Focussed Coping are-Physical and mental health, caregivers routine, other relations while for those who used Active emotional coping are-External support, other relations and those who used Active emotional coping are-caregivers strategy.

Correlation between scores on Burden factors and coping strategies in BD and Schizophrenia (Pearson correlation)

Burden domains	Problem focused (PF)				Active emotional (AE)				Avoidant emotional(AVE)			
	Schiz		BD		Schiz		BD		Schiz		BD	
	r	Level of sign										
Spouse related	.214	.135	.034	.838	.049	.736	.115	.494	.177	.219	.253	.126
Physical and mental health	.004	.979	.363	.025	.011	.941	.133	.426	.185	.198	.169	.309
External support	.205	.154	.249	.132	.087	.550	.458	.004	.119	.409	.229	.167
Caregivers routine	.192	.183	.362	.026	.049	.734	.164	.324	.178	.216	.215	.196
Support of patients	.148	.304	.083	.622	.223	.120	.100	.551	.099	.495	.063	.709

Taking responsibility	.065	.651	.142	.396	.025	.863	.071	.673	.075	.602	.132	.429
Other relations	.113	.433	.448	.005	.014	.926	.419	.009	.203	.157	.165	.321
Patients behaviour	.059	.686	.283	.085	.024	.868	.108	.520	.056	.697	.204	.219
Caregivers strategy	.037	.801	.040	.813	.072	.619	.055	.745	.100	.491	.381	.018

DISCUSSION

The emotional health of the family was relatively untouched and the impact on physical health of the caring relatives due to burden of care was almost negligible. The pattern of burden was, however, almost similar in both the groups. ^[23] In a study conducted to assess and compare the extent and pattern of psychosocial dysfunction and family burden in schizophrenia and obsessive-compulsive disorder, it was found that OCD group showed a significant positive correlation between dysfunction and all areas of family burden except physical and mental health. Schizophrenic group showed a significant positive correlation between dysfunction and disruption of family interaction. ^[24] Subjective and objective burdens of the carers of schizophrenic and bipolar affective disorder patients were assessed which found that burden was higher among the carers of schizophrenic, young, male, low income and unemployed patients. ^[25] Ampalam et al ^[26] did a study to compare the caregiver burden in psychiatric illness and chronic medical illness and the association of caregiver burden with demographic factors like age, gender, duration of caregiving. The caregiver burden scores in the caregivers of psychiatric patients were significantly higher than that of chronic medical illness. The caregiver burden was found to increase with the duration of illness as well as with the age of caregiver.

The present study found that in the caregivers of BD patients, a positive correlation was observed between use of positive coping methods and various burden facets. Facets with high positive correlation were found in caregivers of patients with BMD. Those who used problem focused coping are-Physical and mental health, caregivers routine, other relations while for those who used Active emotional coping are-External support, other relations and those who used Avoidant Emotional Coping are-caregivers strategy. Similar studies were done and it was seen that in comparison with schizophrenia group, caregivers in OCD group had significantly high mean scores for the domains, spouse-related factor and caregiver's strategy of BAS. Spouses and unemployed caregivers in OCD group had significantly elevated mean total burden scores. ^[27] The comparative burden on families of schizophrenics and patients with chronic lung disease and the areas affected by it was studied and it revealed more burden on families of schizophrenic patients in the financial area, effects on family leisure, family routine, family interaction and mental health of other family members. Among the schizophrenic's families more financial burden was seen where male member had the illness. ^[28]

In a study done on the burden of care experienced by family members of patients with major affective disorder, it was found that the burden was significantly more among families of bipolar patients than those of major depression. Prolonged illness and high levels of dysfunction among patients correlated consistently with severity of burden. Severity of illness, higher age of the patient and number of episodes of the illness also influenced the extent of burden. Variables such as gender of the patient, religion, education, occupation, family type and size and the locus of control of both patients and relatives did not influence the extent of burden significantly. ^[29] As part of the WHO Collaborative Study on Strategies for Extending Mental Health Care, 259 families in four developing countries (Colombia, India, Sudan and the Philippines) were screened with regard to the social burden caused by mental illness of one of its members. Levels of subsistence, previous illness, financial burden, personal relations and social acceptance were studied. The social burden was greatest in the urban areas. ^[30] It was noted that behaviour of the patients with schizophrenia related to activity and self-care were perceived to be most distressful, and not aggressive or psychotic behaviour by the relatives. Distress was more often reported by younger relatives and those with more education.

^[31] Similarly a study was conducted to examine burden and coping in parents and spouses of persons with schizophrenia. Spouses reported greater emotional burden. Parents used more of denial as a coping strategy, while spouses used more of negative distraction strategies.

^[32] Education of caregivers, coping strategies used by the caregivers and available social support influence the final appraisal of care giving ^[33] Depressive Disorders were higher among caregivers (18.33%) than control group (3.33%) when caregivers of schizophrenic patients were evaluated. The most common Depressive Disorders among the caregivers group was Adjustment disorder with mixed anxiety and depressed mood (6.67%). Depressive symptoms were associated with increased number of hours per week for providing care, older age of the caregiver and duration of care giving. ^[34]

In 2007 an index study was designed to investigate the effects of socio-demographic variables on spousal burden of schizophrenic patients. The results indicated significant effects of gender and family type on spousal burden. ^[35] The subjective burden levels caregivers of in-patients with depression suggest moderate burden perception by the caregivers. Individual domain standardized percentage scores indicated highest burden in the domain of physical &

mental health (67.9), taking responsibility (67.5), patients' behaviour (63.8), and caregivers' routine (61.3). Mean Burden level in female caregivers (17.3) was significantly higher than in male caregivers (15.5).^[36] The burden perceived by the relatives of schizophrenics was more closely related to the patients' personal/social disability than that reported by the relatives of neurotic patients. The psycho pathological features of schizophrenic patients that were perceived as the most burdensome were "negative" symptoms, whereas the burden reported by the relatives of neurotic patients was predominantly related to obsessive/compulsive and anxiety symptoms.^[37] The present study shows that the perception of stigma is significantly different in BD and Schizophrenia for males and females. Females are more stigmatized than males. The caregivers of patients with schizophrenia were more stigmatized as compared to Caregivers of BD patients. Habitat has not played a significant role in both BD and Schizophrenia. There is no significant difference between the perceptions of stigma in people belonging to different socioeconomic status but the difference is not significant in both the conditions. Different Relationship has a different perception of stigma which is not significant when both BD and Schizophrenia are compared.

It was found in a study that stigma scores were significantly higher in the younger age group patients, males, patients with a continuous illness and symptomatic patients. Substance dependence patients had significantly higher stigma than patients with psychiatric illnesses. Among persons with depression, stigma was positively correlated with severity of illness.^[38] The findings of a study showed that psychiatric patients perceive higher stigma and report lower degree of self-esteem and personal growth than diabetic patients. Results further indicated that perceived stigma is negatively associated with self-esteem and personal growth, and this relationship is higher for psychiatric patients than diabetic patients.^[39]

In the present study Bipolar disorder Males used-Active Emotional coping followed by Problem Focused Coping while Females used Active Emotional Coping followed by Avoidant Emotional Coping. Schizophrenia caregivers used Active Emotional Coping followed by Problem Focused Coping irrespective of the gender. Chakrabarti^[14] found that caregivers used a wide variety of coping strategies, both problem and emotion-focused. In bipolar disorder, demographic parameters, illness duration, levels of dysfunction, burden and social support, and appraisal by caregivers demonstrated significant associations with coping styles of caregivers. Problem- focused coping strategies were more common in caregivers of bipolar patients and emotion-focused strategies in caregivers of schizophrenic patients.

CONCLUSION

It can be concluded that the level of burden for schizophrenic caregivers is more as compared to the caregivers of BD. The caregivers of patients with schizophrenia were more stigmatized as compared to caregivers of BD patients. Females were more stigmatized than males in both the groups. The caregivers of both BD and schizophrenic patients used Active emotional coping to combat the situation.

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