

Research Paper

## Comparative study on caregiver burden and their quality of life in caring patients of Schizophrenia and bipolar affective disorder

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### ABSTRACT

**Background:** With the advent of deinstitutionalization mentally ill patients are cared now being cared at community level by their families. Caregivers play an important and ever expanding role in caring mentally ill patients. Major mental illness like schizophrenia and bipolar disorder lead to great deal of morbidity and disability among the patients. **Aims and objectives:** -To determine the level of perceived burden and quality of life among caregivers of schizophrenia and bipolar patients. **Materials and methods:** Cross sectional study conducted in tertiary care center in Department of Psychiatry. Family Burden Interview Schedule Pai and kapur,1981 was used for burden assessment and WHOQOL BREF for quality of life assessment. **Results and conclusions:** More burden perceived by the caregivers of schizophrenia than bipolar patient's caregivers and the difference was statistically significant( $p=0.000$ ). Better quality of life is seen in caregivers of bipolar patients than schizophrenia. Negative correlation of burden perception with all quality of life domains.

**Keywords:** Caregiver burden, Quality of life, Schizophrenia, Bipolar disorder

Mental disorders have profound effect on health and well-being not only of individuals with the disorder but also of their families and entire community. Globally it is estimated that lifetime prevalence of mental health disorder to be between 18.1% and 36.1% and 10.6% in India<sup>1,2</sup>. With the advent of deinstitutionalization in 1955 due to introduction of antipsychotics chlorpromazine, most mentally ill patients are now being care at community level by their families. The negative effects of persons with a serious mental illness on their family members have been explored since 1950's and the term "caregiver burden" began to be used in 1970's this concept of caregiver burden was broadened after 1980's. Globally, it is recognized that caregivers will play a important role and ever-expanding role<sup>3</sup>. Major mental disorders like schizophrenia and bipolar disorder lead to a great deal of morbidity and disability in developing countries<sup>4</sup>. Caregiver experience play a vital role in mental health promotion. So, caregiver perception to mental illness is important in caring both positive and negative aspects of caregiving. According to World Federation of Mental

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Health,2010, caregiving burden involves physical, psychological, social, financial problems, experience by families in caring for their family members with mental illness. Due to chronic course of schizophrenia, at some point schizophrenic subjects may have impaired cognition, social functioning and live with residual symptoms, these could be an significant concern, with high stress in families<sup>5</sup>. Bipolar affective disorder is a mood disorder that alternates between two extremes –one of unproductive hyperactivity, distractibility and intrusions on others, and the other of inactivity, sadness, hopelessness and suicidal thoughts. Paradigm<sup>6</sup> shifts that have occurred in the treatment of bipolar disorder include:

1. A growing awareness that bipolar disorder is a chronic illness and needs long-term maintenance treatment,
2. A realization that the focus of treatment needs to be on the illness itself, not individual episodes, and
3. There cognition that full functional recovery, not just symptomatic recovery should be the goal of treatment.

Achieving these objectives when treating a patient with bipolar disorder calls for a careful combination of psychosocial and pharmacologic strategies on the part of the healthcare provider. An important aspect of long-term management that directly affects the effectiveness of treatment is the patient's adherence to his or her treatment regimen<sup>7</sup>, which universally is entrusted upon the primary caregiver in mental illnesses, solely due to gross insight deficits in the patients.

Studies indicate that people who take care of severe mentally ill suffers from significant stress and experience higher level of burden and responsibilities. This in turn compromise their own quality of life in every aspect (physical, social, emotional, and psychological).

### ***Burden of care has two components:***

**Subjective burden:** - It is the perception of the caregiver in context to his or her caregiving function. It is the mental health and subjective distress among family members<sup>8</sup>. Subjective burden resulting from social stigma included frustration, anxiety, low self-esteem and helplessness<sup>9</sup>.

**Objective burden:** - it relates to the patient's symptoms, behaviour, socio-demographic characteristics, familial, social relationship, work functions, and physical health<sup>10</sup>. Is the disruption in many aspects of family that is expressed and is arguable and agreeable as per Platt?

Quality of life (QOL) measures are potentially useful methods to demonstrate the impact of mental illnesses and the possible benefits of therapeutic interventions<sup>11</sup>. The Quality of life group of the World Health Organization(WHOQOL) elaborate quality of life as “the subjective perception of an individual, of his or her position in life-pertaining to the context of the prevailing value and culture systems in the milieu he or she thrives in, and in relative transgressions, short-term concerns and long term goals”<sup>12</sup>.

As per WHOQOL, the quality of life concept comprises of at least 4 different major dimensions: the emotional and the physical health of the individual, his or her psychological and hence social wellbeing functional ability to normally conduct daily routines, and economic assurance and the fulfilment of individual goals and personal expectations.

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Since last two decades research methods have been developed to assess family burden among caregiver of patients diagnosed with schizophrenia and bipolar disorder. While very few studies are done on comparison of caregiver burden and their Quality of life while caring for schizophrenia and bipolar affective disorder.

### ***Aims & objectives***

1. To assess level of caregiver burden in caring patients with schizophrenia and bipolar affective disorder.
2. To determine the correlates of caregiver burden and also to examine perceived burden and its influence on the quality of life.
3. To find out the difference in burden and quality of life of the caregivers for schizophrenia and bipolar affective disorders.

### ***Study Design***

This will be cross-sectional study

### ***Study setting***

The study will be conducted at Department of Psychiatry, of a Medical College.

### ***Study sample***

70 participants (35 from each group), who gave the informed consent were included from caregivers of patients with schizophrenia and bipolar affective disorder based on diagnosis of International Classification of Disease (ICD-10)<sup>13</sup>.

### ***Inclusion criteria***

Caregivers giving informed consent

Caregivers age should be above 18years.

Caregivers living with patients for at least 1year.

### ***Exclusion criteria***

1) Caregivers suffering from any serious mental illness, comorbid physical illness and substance use disorders.

### ***Tools used are***

Structured Performa for sociodemographic details.

Family Burden Interview Schedule Pai and Kapur 1981<sup>14</sup> will be used to assess burden across Six domains. This is a semi-structured interview schedule comprising of 24 items grouped under 6 areas- 1) Financial burden, 2) Disruption of routine family activities, 3) Disruption of family leisure, 4) Disruption of family interaction, 5) Effect on physical health of others, 6) Effect on mental health of others.

World health organization quality of life (WHO QOL) BREF<sup>15</sup>, will be used to assess quality of life.

WHOQOL-100 is a 100 items scale measuring about 24 facets of life, with 4 questions in each. WHO QOL BREF is an abbreviated version with about 26 items measuring the quality of life across four domains viz, physical, psychological, social relationship and environmental domains. The responses range from 1 (very dissatisfied) to (very satisfied).

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### *Interview procedure*

All cases who are selected for study were interviewed in detail using the tool. Interview pattern was flexible to elicit maximum data. No time limit for interview of the patient was set.

### *Analysis of data*

Data was evaluated keeping the aims and objectives in mind with appropriate statistical method using SPSS version 21.

## RESULTS AND OBSERVATIONS

Table no.1 shows the frequency and percentage distribution of sociodemographic variables of caregivers of schizophrenia and bipolar patients. Findings reveal that more number of caregivers in schizophrenia i.e 13(37.1% ) are in the age group of 31-55 years .In bipolar group also more number of caregivers i.e 15(42.9%) are in same age group. There was no significant association between age groups of caregivers.

In relation to the gender, males were the more caregivers in both groups. Among the schizophrenic caregivers 29(82.9%) belonged to Hinduism while in bipolar caregivers group, Islam 19(54.3%) was the predominant religion and the difference was statistically significant. (p=0.00). Highest number of caregivers in schizophrenia group were from rural background 22(62.6%) while in bipolar group mostly from urban background 19(54.9%). Only 12 (34.3%) caregivers in schizophrenia group were educated up-to graduate level or above while in bipolar group 9(25.7%) were graduates or above.

Occupation of schizophrenia caregivers and bipolar caregivers were mostly farmers, 25.7% and 22.9% respectively, this reflects the sample characteristic of same area. Highest number of caregivers in both schizophrenia and bipolar groups are married i.e 65.7% and 80% respectively. There is significant association between marital status in both the groups. (p=0.027). Majority of the caregivers in schizophrenia belonged to joint family (54.3%) while in bipolar group caregivers were mostly living in nuclear family (60%). More number of caregivers in schizophrenia group are parents while in bipolar group mostly spouses (42.9%) were the caregivers.

In relation to socioeconomic status, most of schizophrenia caregivers were from lower middle class (31.4%) while in bipolar group most were from upper middle class (34.3%). Duration of caregiving is more in 6-10 years range in schizophrenia group (31.4%) while in bipolar group it is 11-15 years (31.4%).

***Table no.1 Association of socio-demographic variables of caregivers of schizophrenia and bipolar patients.***

Sl no.	Sociodemographic variables	Schizophrenia (n=35)	Bipolar (n=35)	P-value
1	Age			.946
	18-30 years	8(22.9%)	6(17.1%)	
	31-45 years	13(37.1%)	15(42.9%)	
	46-60 years	12(34.3%)	12(34.3%)	
	>60 years	2(5.7%)	2(5.7%)	
2	Sex			.060
	Male	22(62.9%)	29(82.9%)	

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Sl no.	Sociodemographic variables	Schizophrenia (n=35)	Bipolar (n=35)	P-value
3	Female	13(37.1%)	6(17.1%)	
	Domicile			
	Rural	22(62.6%)	16(45.7%)	
	Urban	13(37.1%)	19(54.9%)	
4	Religion			.000*
	Hindu	29(82.9%)	13(37.1%)	
	Islam	6(17.1%)	19(54.3%)	
	Others	0	3(8.6%)	
5	Education			.092
	Illiterate	5 (14.3%)	8(22.9%)	
	Upto primary school	7(20%)	10(28.6%)	
	Upto high school	5(14.3%)	5(14.3%)	
	Upto higher secondary	6(17.1%)	3(8.6%)	
	Graduate & above	12 (34.3%)	9 (25.7%)	
6	Occupation			.230
	Student	1(2.9%)	1(2.9%)	
	Daily labourer	3(8.6%)	3(8.6%)	
	Unemployed	5(14.3%)	7(20%)	
	Farmer	9(25.7%)	8(22.9%)	
	Servicemen/profession	5(14.3%)	7(20%)	
	Businessmen	8(22.9%)	1(2.9%)	
	Housewife	3(8.6%)	3(8.6%)	
	Retired	1(2.9%)	5(14.3%)	
7	Marital status			.027*
	Single	9(25.7%)	4(11.4%)	
	Married	23(65.7%)	28(80%)	
	Widow/widower	0	3(8.6%)	
	Separated/divorce	3(8.6%)	0	
8	Family type			
	Nuclear	16(45.7%)	21(60%)	
	Joint	19(54.3%)	14(40%)	
9	Relation with patient			.384
	Father	10(28.6%)	4(11.4%)	
	Mother	5(14.3%)	9(25.7%)	
	Spouse	11(31.4%)	15(42.9%)	
	Siblings	6(17.1%)	3(8.6%)	
	Daughter	0(0%)	3(8.6%)	
	Son	1(2.9%)	0(0%)	
daughter-in-law	2(5.7%)	1(2.9%)		
10	Total annual income			.069
	<20,000	9(25.7%)	14(40%)	
	20,000-40,000	16(45.7%)	13(37.1%)	
	40,000-60,000	0(0%)	2(5.7%)	
	60,000-1,20,000	6(17.1%)	2(5.7%)	
	1,20,000-1,80,000	1(2.9%)	4(11.4%)	
	>1,80,000	3(8.6%)	0(0%)	
11	Socioeconomic status			
	Lower class	9(25.7%)	11(31.4%)	

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Sl no.	Sociodemographic variables	Schizophrenia (n=35)	Bipolar (n=35)	P-value
	Lower middle	11(31.4%)	9(25.7%)	.477
	Upper middle	8(22.9%)	12(34.3%)	
	Upper class	7(20%)	3(8.6%)	
12	Duration of care			.542
	1-5years	5(14.3%)	6(17.1%)	
	6-10 years	11(31.4%)	8(22.9%)	
	11-15 years	7(20%)	11(31.4%)	
	16-20 years	8(22.9%)	4(11.4%)	
	>20 years	4(11.4%)	6(17.1%)	

Perception of burden among caregivers of schizophrenia and bipolar patients is shown in table no.2. As mean burden score of the schizophrenia patients caregivers was more compared to bipolar patient’s caregivers. So, more burden was perceived among the caregivers of schizophrenia patients and the difference observed was statistically significant (p = 0.000).

**Table no. 2 Perception of burden among caregivers of schizophrenia and bipolar patients.**

Total fbis score	Schizophrenia caregivers	Bipolar caregivers
	Frequency	Frequency
N	35	35
Mean	41.68	37.00
Median	41.0	37.0
Standard deviation	3.668	3.556
T-value	4.784	
P-value	0.000	

In Table no. 3 we have seen the comparisons of quality of life score among the caregivers of schizophrenia and bipolar patients.

In all the domain of WHOQOL BREF, Bipolar patient’s caregivers have better quality of life than schizophrenia patient’s caregivers except in domain 3. There was better quality of life in caregivers of bipolar affective disorder with the highest mean score  $\pm$  SD of  $22.914 \pm 4.111$  in the physical domain of quality of life and the least score of  $6.657 \pm 0.683$  in the social domain of quality of life. Significant association (p-value = .009) is found in domain 2 QOL among caregivers of schizophrenia and bipolar patients.

**Table no. 3 Comparisons of quality of life score among the caregivers of schizophrenia and bipolar patients.**

	Caregivers	N	Mean	Sd	P-value
Domain1 whoqol bref	Schz	35	22.371	6.682	.671
	Bpd	35	22.914	4.111	
Domain2 whoqol bref	Schz	35	13.944	3.171	.009
	Bpd	35	15.628	1.895	
Domain3 whoql bref	Schz	35	7.144	1.240	.084
	Bpd	35	6.657	0.683	
Domain4 whoqol bref	Schz	35	21.628	3.614	.589
	Bpd	35	21.629	.7314	

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There is a negative correlation of the perception of burden with all the quality of life domains. But this correlation is significant in domain 2 (psychological domain) at level .040 and domain 4 (environmental) at level .030. As shown in table no.4. With increase in burden among caregivers their quality of life deteriorates.

Table no.5 shows the correlation of duration of illness with perception of burden. There is comparatively strong positive correlation between duration of illness and perception of burden among caregivers of bipolar patients but this correlation is not statistically significant.

**Table no.4 Correlation of burden and quality of life among the caregivers.**

Whoqol bref domains	Total fbis score			
	Schizophrenia caregivers		Bipolar Caregivers	
	Pearson correlation	Sig. (2-tailed)	Pearson correlation	Sig. (2-tailed)
Domain 1 whoqol	-.052	.768	-.105	.550
Domain 2 whoqol	-.074	.672	-.061	.727
Domain 3 whoqol	-.326	.040*	-.157	.367
Domain 4 whoqol	-.240	.030*	-.113	.518

**Table no.5 Correlation of duration of illness with perception of burden.**

Duration of illness		
	Schizophrenia caregivers	Bipolar caregivers
Pearson correlation	.201	.756
P-value	.05	.22

## DISCUSSION

Most caregivers feel burdened and their quality of life deteriorates in caring for relatives with major psychiatric illness. Caregivers have reported physical symptoms, psychological distress, feeling of stigma, limited leisure time in caring for mentally ill patients<sup>19,20</sup>. In our study we have found that more number of caregivers were in age group of 31-55 years in both the groups, while in the study by Kaushik et al had most caregivers in age group of 18-37 years in both the groups. Gender of the caregivers contributes to the burden in following areas: external support, financial support, patients behaviour and daily routine activities. Females get less external support and perceive more psychological stress. Mors et al<sup>21</sup> reported if patient is male then family stress is significantly higher. Caregivers in both the groups were different, in schizophrenia group parents were the main caregivers while in bipolar groups spouses were the main caregivers, this corresponds to high frequency of unmarried status in schizophrenia while bipolar patients are mainly cared by spouses. So perception of burden among the caregivers was different. There was more burden among the caregivers of schizophrenia, this is in accordance with study by Chakraborty et al<sup>22</sup>, financial and physical health of family was most affected in schizophrenia group while family routine and family leisure were affected the most in bipolar caregivers. Both objective and subjective burden were more in schizophrenia caregivers which was in accordance to study by Chakraborty et al<sup>22</sup>. The chronicity of schizophrenia in contrast to discrete nature of bipolar affective disorder causes more burden in caregivers<sup>23</sup>.The comparatively better quality of life in caregivers of bipolar patients can be attributed to the discrete nature of illness and a resumption of normal level of functioning in between episodes while in

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schizophrenia progressive deterioration causes detrimental effects on the quality of life of family. This finding is concurrent with the findings of study by Prabhat et al<sup>24</sup> in which bipolar group had better quality of life. In our study there was significant correlation between perceived burden and duration of illness which was concordant with the findings by Srivastava et al<sup>25</sup>, Nirmala et al<sup>26</sup>. There was comparatively strong correlation between duration of illness and perceived burden in bipolar group because of more number of episodes and hence more stress in family.

### *Limitations of the study*

The major limitation of the study was its small sample size. The study was done in a single tertiary centre have particular characteristics of population so results cannot be generalised. Employment status of the patient was not assessed which can affect the burden perception in caregivers. In our study burden perceived was not correlated with bipolar subtypes separately. Adherence to treatment was not taken into consideration is a limitation of the study. Comorbid medical illness which influence burden were not considered. Functioning capacity of patients was not compared with burden perception.

## CONCLUSION

In the era of shift in focus from treatment and management to the strategies towards quality of life improvements this study emphasizes need for assessment of these variables among caregivers. Lowering the caregiver burden expedites the integration of patients in the community and live a better life.

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***Conflict of Interest***

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