



CARE GIVER BURDEN IN PATIENTS OF SCHIZOPHRENIA AND BIPOLAR DISORDER IN A RURAL AREA OF SOUTHERN KARNATAKA

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ABSTRACT

Background: It can be a difficult task to provide care to the patients living with psychiatric health issues, especially with chronic diseases such as schizophrenia and bipolar disorder where the patient loses touch with reality. Hence, our study aims to assess the perception of burden that caregivers endure while giving care to the patients of schizophrenia and bipolar disorder and to compare the difference in burden between these two conditions. The study also evaluated the factors affecting the caregivers' burden. **Materials and Methods:** This was a cross-sectional interview-based study conducted at the psychiatry department of a tertiary care hospital in Sullia, Dakshina Kannada, Karnataka among caregivers of schizophrenia and bipolar disorder. Each caregiver was given the Zarit-Burden Interview scale in a language they understand and asked to rate each statement from 0 to 4 where ratings were based on likert scale and the final scores were interpreted. Data of the burden score were expressed as mean and standard deviation and compared using unpaired t-test. Pearson's correlation coefficient was used for correlation between burden score and variables such as age, years of education, and duration of illness. The analysis was done using SPSS 21.0 version. **Results:** A total of 100 caregivers reported the interview scale completely, of which 50 caregivers belonged to schizophrenia group and 50 were related to bipolar disorder. Average of burden score was 64.89 ± 15.7 and 59.11 ± 17.8 (maximum score: 88) in schizophrenia and bipolar group, respectively, and difference between the group was statistically significant. In both the groups, it was found that, with increase in the age of patients, caregiver's burden significantly increased. **Conclusion:** Caregivers of schizophrenia and bipolar disorder patients feel a considerable burden of care with more burden felt by the caregivers of schizophrenia. The more vulnerable to burden are females, elderly, low-income groups, and patients in whom longer duration of care is required. The caregivers should receive an adequate support for maintaining their own mental health via adequate psycho education, counselling and psychiatric intervention if necessary.

KEYWORDS : Caregiver burden, Bipolar disorder, Schizophrenia

INTRODUCTION

Taking care of individuals with mental health concerns is incredibly demanding and difficult, especially in India where it is socially stigmatized to be called "Mentally unwell" even for seeking out a psychiatrist. In a study conducted at five major cities in India, participants displayed overall high levels of perceived stigma, with female participants showing higher levels of perceived stigma compared to male counterparts. [1] Such a level of stigma with a high prevalence of psychiatry disorders and gradual de-institutionalization of the treatment of psychiatry disorders can result in significant stress to the caregivers. [2]

In order to avoid burnout while providing care and maintaining their own mental health, caregivers also require social support. Therefore, in order to lessen the burden of care, we should be aware of its contributing aspects.

Numerous research have been carried out worldwide, including in India, to determine how the burden of care varies depending on the demographic type. Studies have shown that those who care for people with psychiatric illnesses experience more burden than those who care for people with other chronic medical conditions. [3-7]

Additionally, several studies revealed that caring for patients with psychotic symptoms causes caregivers to feel more burdened than caring for patients suffering from neurotic spectrum disorders or only mood symptoms. [8-11]

However, because of cultural and various other factors, burden becomes highly subjective and variable. For example, ethnic minorities such as Asians are more tolerant than the people from western parts to psychiatry patients in their families. [12] India is a country with wide cultural diversities. The studies in this regard are sparse in our region of southern Karnataka and to understand the burden that caregiver's feel

to a psychiatry illness is still open to in-depth study. Hence, the present study was designed to understand the difference between the burden felt by caregivers of schizophrenia patients and patient with bipolar disorders. We also tried to understand whether there is any relation between various patient and caregiver variables such as age, sex, years of education, occupation, and the burden a caregiver feels.

MATERIALS AND METHODS

The study design used was a hospital based, cross-sectional, observational study. The study was conducted at psychiatry outpatient department of a tertiary care Medical College level hospital. The healthy adult primary caregivers of patients with schizophrenia and bipolar disorder were included. The sampling method used was purposive sampling. Ethical committee clearance was taken beforehand from our institution.

Inclusion and Exclusion Criteria:

Accompanying adult healthy reliable caregivers of patients with a confirmed diagnosis of schizophrenia and bipolar disorder as per Diagnostic and Statistical Manual of Mental Disorders - V, in symptomatic phase, diagnosed and on continuous treatment for at least 6 months, aged >18 years, and willing to participate were included in the study. A primary caregiver is the person who takes primary responsibility for someone who cannot care for himself or herself.

In case, if more than one caregiver was accompanying, a primary caregiver who provides day-to-day care and support to patient, takes decisions regarding treatment, and is responsible for giving medicines to patient, was included. Caregivers of patients with a history of recent hospitalization, a major change in diagnosis and management within 3 months, and caregivers with diagnosed psychiatry illness were excluded. Subjects were enrolled in the study only after taking their written informed consent.

Tools used:

Zarit burden interview (ZBI) –

This scale is a self-reporting, structured scale where the caregivers are asked to rate 22 Questions from 0 to 4 – where – 0: never, 1: rarely, 2: sometimes, 3: quite frequently, and 4: nearly always, making a total score of 88. Dimensions reported include consequences of caregiving, patient's dependence, exhaustion and uncertainty, guilt or self-criticism, embarrassment/anger or frustration, psychological burden and emotional reactions, personal strain, and role strain. Here, we have restricted the interpretation of the global 22-item score only. The final score was interpreted as: 0–21- little or no burden, 21–40 – mild-to-moderate burden, 41–60 – moderate-to-severe burden, and 61–88 – severe burden. It is a prevalidated scale which has shown satisfactory psychometric properties such as internal consistency, convergent and discriminative validity, and sensitivity to change to assess the caregivers' burden. [13] The scale was translated into a language they understand and the subjects were given adequate time to understand the questionnaire and encouraged to ask the questions for any doubts regarding the study or questionnaire.

Statistical Analysis:

Data was entered into Microsoft Excel worksheet and statistical analysis was done using SPSS 21.0 version. Descriptive analysis was used as a tool for factors affecting caregivers' burden, unpaired Student's t-test was applied for comparison of burden score between schizophrenia and bipolar disorder. Pearson correlation coefficient was used for estimating the correlation between patient's age, education, caregivers' age, years of education, and duration of illness with the burden score. Chi-square test was used for comparing categorical variables. For all statistical tests, P < 0.05 was considered significant.

RESULTS

A total of 114 caregivers were provided with the ZBI scale, of which 14 interview survey forms were discarded due to missing information for evaluation. Thus, a total 100 survey forms were analyzed. Out of 100 caregivers, 50 were of patients of bipolar disorder and 50 caregivers were of patients of schizophrenia.

Demographic profiles of patients and caregivers are shown in Table 1. In both the groups, male caregivers were more than the female caregivers. Demographic characteristics were comparable between both the study groups as Mann-Whitney U-test applied between the group variables found the difference between groups to be statistically insignificant.

As shown in Table 2, average ZBI score (maximum score 88) was 59.11 (17.80) in caregivers of the bipolar disorder group and 64.89 (15.66) in caregivers of schizophrenia group. Thus, caregivers of both the groups felt moderate-to-severe burden. However, burden felt by caregivers of schizophrenic patients was significantly higher than the burden felt by caregivers of bipolar patients (P < 0.05).

Table 3 shows the relationship between ZBI scores and patient variables such as age, years of education, and duration of illness. In bipolar group, patient's age and duration of illness were significantly correlated with burden score (P < 0.05), meaning with increase in age of patients and increase in duration of treatment led to increase in burden of care, significantly. In the schizophrenia group, no significant correlation was found for any variable with burden score. Patient's sex was found not to have statistically significant correlation with burden in any group.

Table 4 shows the relationship between ZBI score and caregivers' variables. In bipolar group, with an increase in

age of caregivers, the burden was increasing, which was statistically significant (P < 0.05). In schizophrenia group, less duration of education was associated with significantly more burden in caregivers (P value < 0.05).

Table 5 shows the relationship of caregiver's occupation with the ZBI score. In schizophrenia group, the highest burden was felt by laborers and housewives than other groups. In the bipolar group, the highest burden was felt in retired/unemployed and students than other groups. Table 6 depicts the relationship between caregivers' burden and relation of caregiver with the patients. In the schizophrenia group, the highest burden was felt when the caregiver is children of the patients, lowest when the caregiver is a sibling of the patient. In bipolar disorder, the highest burden was felt when a caregiver is children of the patient, the lowest when a caregiver is the parent of the patient.

DISCUSSION

In this study, the significant burden of care was noted in both the groups. The average ZBI score (maximum score 88) was 59.11 in caregivers of the bipolar disorder group and 64.89 in caregivers of schizophrenia group. Thus, both the groups showed that they feel the burden of care of a patient with a psychiatry disorder to the level of moderate to severe This was in accordance with the previous studies[9-11] where the results shown that the families of both group experience considerable burden with a slightly higher burden in the schizophrenia group. Findings of the current study are in contrast with Zhou et al., where the author noted that the family burden was greater in caregivers of acute bipolar disorder than among caregivers of schizophrenia. [14]

Table 1: Demographic Variables Of Patients And Caregivers Of Both Groups

	Schizophrenia (n=50)	Bipolar disorder (n=50)
Patient variables		
Age (mean, years)	35.94	41.28
Years of education (mean, years)	13.20	16.10
Duration of illness (mean, years)	7.78	6.59
Male (%)	65.00	63.00
Female (%)	35.00	37.00
Caregiver variables		
Age (mean, years)	35.80	44.40
Years of education (mean, years)	14.10	17.10
Male (%)	56.00	55.00
Female (%)	44.00	45.00

Table 2: Comparison Of Burden Of Care In Both Groups

	Mean ZBI Scores	SD	t-value (df)	p - value
Bipolar Disorder	59.11	17.80	-2.42(208)	0.01
Schizophrenia	64.89	15.66		

SD Standard deviation; ZBI – Zarit burden interview; Df – Degree for freedom

Table 3: Relation Of Caregiver Burden With Patient's Variables

	Bipolar disorder (N=50) Pearsons/chi2 p value	Schizophrenia (N=50) Pearsons/chi2 p value		
Age	0.32	0.01	0.33	0.11
Sex*	0.19	0.92	0.23	0.96
Education	0.11	0.27	-0.01	0.31
Duration of illness	0.40	0.01	0.08	0.06

*value is for chi square test

Table 4: Relation Of Caregiver Burden With Caregiver's Variables

	Bipolar disorder (N=50) Pearsons/chi2 p value		Schizophrenia (N=50) Pearsons/chi2 p value	
Age	0.23	0.01	0.06	0.53
Sex*	0.06	0.94	1.12	0.29
Education	0.07	0.49	-0.23	0.01

*value is for chi square test

Table 5: Relation Between Caregivers' Burden And Caregiver's Occupation

	Schizophrenia (N=50)		Bipolar Disorder (N=50)	
	Pearsons/chi2	p value	No. of cases	Avg ZBI scores
Students	3	70.6	5	68.7
Farmer	3	56.8	2	64.8
Private Job	12	62.0	12	62.3
Govt Job	6	55.6	4	52.0
Unemployed/retired	1	62.0	2	71.5
Household worker	13	71.1	15	57.9
Skilled laborer	6	60.0	4	59.5
Laborer	6	76.7	6	60.8

Table 6: Relation Between Caregivers' Burden And Relation With Patients

	Schizophrenia (N=50)		Bipolar disorder (N=50)	
	No. of cases	Avg ZBI scores	No. of cases	Avg ZBI scores
Parents	14	59.00	13	57.80
Siblings	10	55.35	7	57.90
Spouse	15	67.54	18	61.05
Children	10	70.30	10	62.61
Others	1	72.00	2	46.00

This may be due to cultural and familial differences between two geographical areas. This basic difference between the bipolar disorder and schizophrenia may be due to the chronicity and the social exclusion of the patient due to their poor social functioning. One more reason for the difference in burden between two groups can also be that schizophrenia patients also require care even during the remission period. Researchers have found that people with schizophrenia and psychosis require the same amount of social care during the remission phase that is why they feel more burden. [15]

In this study, there is a statistically significant increase in the burden with an increase in age of patient in bipolar group, however, not in schizophrenia group. This may be because the schizophrenia patient group is younger in comparison to the bipolar group.

This is in contradiction to previous studies [16,17] where no statistically significant difference between the socio demographic variable of either group of patient or their caregivers was observed, while others found a statistically significant increase in the burden of caregivers with an increase in the age of elderly mentally ill patients,[3,18,19] which makes sense since the older patients need care for their physical health too, which adds up to the demands of the patient care. In the current study, patient sex has no significant relation to the burden of care.

In Ayalew et al. and Eloia et al.,[20,21] the authors found that burden score was more in taking care of male patients than

female patients. This may be because male patients are generally more demanding and because of the male dominance in society may be enjoying undue privileges.

The mean years of education were 16.10 and 13.20 years in patients with bipolar disorder and schizophrenia, respectively. No statistical significance was found between years of education of patients and caregivers' burden which is in accordance with Gupta et al.[19] This may be justified in schizophrenia because of early-onset symptoms of patient may not be able to continue his studies further. However, in general, sense-educated patients should be easy to take care by their caregivers, so this needs further elaboration by study with large sample size.

In the current study, a statistically significant increase in burden in both the groups with an increase in the duration of illness was found, which is in accordance with previous studies. [3,19,22] With longer duration of illness, there is usually exhaustion on part of the caregivers, particularly emotional and economical exhaustion plays a role because of the chronicity of these diseases. In Kuchhal et al., no significant difference was noted for the duration of illness and burden score. [17]

In bipolar group, there was a statistically significant increase in burden felt by caregivers with increase in caregivers' age, which was in accordance to Gupta A et al. [19] and Prashant et al. [20] This difference between the two groups may be because with increase in the age of the caregiver as his ability to cope up with the physical and mental stress start diminishing. [20]

In general, female caregivers have less mean burden score compared to male caregivers, but this finding was not statistically significant. It is generally thought that female caregiver because of their natural role of caring in society should make it easy for females to take care of sick family members, but it not so found in psychiatry patients.

In this study, caregiver education was positively correlated with burden score in schizophrenia group which was statistically significant but not in bipolar group In Siddiqui and Khalid [22] and Kuchhal et al.,[17] authors noted less educated had more burden compared with caregivers with high education.

Educated caregivers are able to understand the disease better and also can add to the compliance of the patient to treatment. Educated caregivers may also be better at communicating with others regarding the perceived stress and so may feel relief in their burden.

In the current study, in schizophrenia group, the most burden was felt by children of the patient and least by siblings. In bipolar group, less burden was felt by parents of the patients. This is in contradiction with Kuchhal et al., author noted parents having more burden than a spouse. [17] In Gupta et al. [19] and Jungbauer and Angermeyer [22] highest burden was felt by spouses. The structure of the family as well as their life stage as a family, for example, elderly parents caring for an adult with severe mental illness, will have its effect on the caring. [24]

In this study, most burdens were felt by laborer and least by government employees In bipolar group, the most burden was felt by unemployed and least by government employees This is in accordance with Siddiqui and Khalid and Ayalew et al. [3,22] This may be because of additional financial burden faced by laborers, unemployed that may be added to the burden as a caregiver. Low-income groups also have to take care of their daily income, which may be impacted if they have to spare time taking care of patient at home.

Limitations

Sample size was less for the present study. Sample was selected from one tertiary care hospital of a rural medical college in Dakshina Kannada, Karnataka . Hence, finding of this study restricts the generalizability to the general population. Causal inference cannot always be deduced since this was a cross-sectional study. Only global interview score was considered in the present study, there is a need for a detailed analysis of all the domains of ZBI.

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Conflicts Of Interest

Nil.

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