

Assessment of Care Giver Burden among Care Givers of Mentally Ill Patients

Abinayaa .A¹, Gopinath .S², Rajkumar .R³

¹Postgraduate, Sree Balaji Medical College and Hospital, Chrompet, Chennai, India

²Assistant Professor, Sree Balaji Medical College and Hospital, Chrompet, Chennai, India
Corresponding author Email id: gopi4863[at]gmail.com

³Professor, Sree Balaji Medical College and Hospital, Chrompet, Chennai, India

Abstract: Background: Caregiving psychiatric patients is a challenging task and has a great impact on the family caregiver's wellbeing. The current study to demonstrate the burden posed on them & variables associated with burden of caregiving. Materials and Methods: This cross-sectional study recruited 45 caregivers of psychiatric patients visiting the Department of Psychiatry at Sree Balaji Medical College & Hospital, Chrompet. Information was gathered from patients using a semi-structured proforma. Burden was assessed using Zarit caregiver burden scale. Patient's illness severity & functional status were assessed using Global Assessment of Functioning and Clinical Global Impression scale respectively. Results: Female caregivers experienced more caregiving burden. Severe the mental illness was associated positively with more severe caregiver burden. Lower the functioning of the individual, higher the caregiving burden. Caregiver burden score was high in caregivers whose relatives were on irregular treatment. Caregivers encountering more than 6 relapses in their relatives experience more burden. Conclusion: To conclude, caregiving mentally ill patients cause severe psychological distress in the caregiver. Hence, psychoeducation and support to the caregiver within mental health settings on a routine basis is beneficial which helps them to handle their worries and promote their coping abilities.

Keywords: Caregiver, Schizophrenia, Psychiatric patients, Caregiver burden

1. Introduction

Mental illness is characterised by marked disturbance in cognition, regulation of emotions and behaviour. It may result in an enormous social and economic burden to the individual affected by it and their families.^[1] According to National Mental Health Survey of India 2015-16, lifetime prevalence of any mental disorder is 13.67% and the prevalence of individual disorders like mood disorders is 5.61%, schizophrenia is 1.41%, Neurotic disorders is 3.70% and substance use disorders is 22.44%.^[11] Another study done by Sagar, Rajesh et al., reported that one in seven Indians were suffering from mental illness and the disease burden has doubled since 1990^[12].

With increasing global burden of mental illness, caretakers of the individuals with mental illness are also going through significant stress which is minimally explored and hardly intervened. Caregiver burden is defined as the degree to which a carer's emotional or physical health, social life or financial status suffered as a result of caring for their relative^[2]. In addition to this, there have been evidence to suggest that caregiving of psychiatric ill individuals were more burdensome than the caregiving of individuals with chronic medical condition^{[13][14]}. The psychological distress perceived by the caregiver depends upon his/her personality, severity of symptoms, extent of social support, financial resources etc.^[3] This dependency & responsibility for caring affects the caregiver's quality of life impacting their health, work, socializing, relationships which adds to their distress^[5]. Caregivers experience physical problems, fatigue, burnout, depression and other emotional disturbances, and feelings of resentment towards the patient.^{[4][5][6]} Hence, understanding about the caregiving burden among the caregivers of patients with psychiatric illness seems to be very important area to be explored.

2. Methodology & Materials Used

This cross-sectional study was carried out in psychiatry OPD of a general hospital setting. 45 caregivers were recruited, who were included if they taking care of the mentally ill patients for minimum duration of 6 months. After obtaining informed consent, semi-structured proforma was used which includes basic demographic details of the caregiver. Burden was assessed using Zarit caregiver burden scale which consists of 22-items. Clinical Global Impression scale was used to rate the severity of patient's illness and Global Assessment of Functioning was used to determine the psychological, social and occupational functioning. Descriptive statistics was analysed with appropriate statistical software. Chi-square test was used to determine the association between categorical variables. Mann-Whitney test was used to compare the means between continuous variables. Correlations were assessed using Pearson correlation analysis. $P < 0.05$ was considered as statistically significant.

3. Results

45 caregivers of psychiatric patients were recruited in the study. The sociodemographic profile and various variables assessed are shown in Table 1.

Table 1: Socio- Demographic Profile of Caregivers:

Variable	Frequency (%)
Age	
24-34	8(17.8%)
35-45	14(31.1%)
>45	23(51.1%)
Gender	
Male	16(35.6%)
Female	29(64.4%)

Education	
Primary	21 (46.7%)
Secondary	12(26.7%)
Graduate	8(17.8%)
Post graduate	4(8.9%)
Marital status	
Unmarried	4(8.9%)
Married	36(80%)
Widow/Widower	5(11.1%)
Employment status	
Unemployed	27(60%)
Employed	18(40%)
Residence	
Urban	38(84.4%)
Rural	7(15.6%)
Relationship with patient	
Parent	20(44.4%)
Sibling	11(2.2%)
Spouse	20(44.4%)

Children	4(8.9%)
Medical co-morbidities	
Yes	15 (33.3%)
No	30(66.7%)
Psychiatric co-morbidities	
Yes	2(4.4%)
No	43(95.6%)
Assistance of another caregiver	
Yes	21 (46.7%)
No	24(53.3%)

Among the study population, majority of the caregivers had completed only primary education (46.7%) with majority of them consisting of parents (44.4%) & spouses (44.4%) and most of them were unemployed (60%) as quoted in the table 1. Most of the study population belonged to upper lowerclass (37.8%) followed by lower middle class (28.9%) as depicted in Fig.1.



Figure 1: Bar diagram of Socio-economic status among the study group

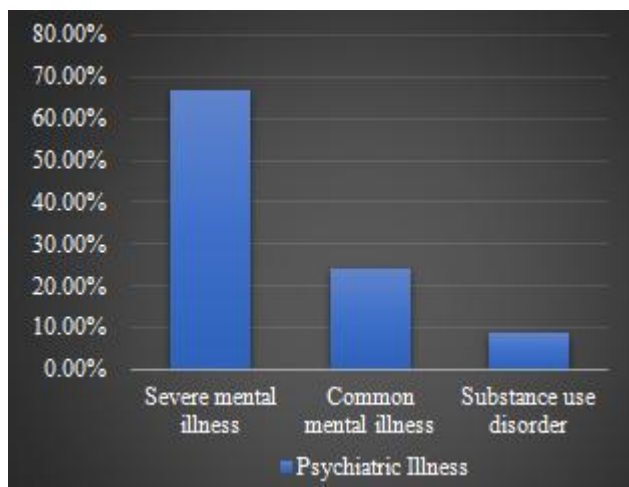


Figure 2: Bar-chart of Psychiatric illness in the study group

Table 2: Frequency of various psychiatric disorders in the study population:

Psychiatric disorders	Frequency (%)
Depression	8 (2.2%)
Mixed anxiety and depression	2 (4.4%)
Recurrent depressive disorder	1 (2.2%)
Acute Psychosis	1 (2.2%)
Psychosis NOS	1 (2.2%)
Schizophrenia	18 (40%)
Schizoaffective disorder	3 (6.7%)
Bipolar affective disorder	7(15.6%)
Alcohol dependence syndrome	4 (8.9%)

Table 3: Mean scores of caregiver burden among males and females

	Sex	N	Mean(\bar{x})	SD
Caregiver burden	Male	16	24.3750	11.56936
	Female	29	36.9655	16.76834

Caregiver burden score was significantly high among the female caregivers when compared to the male caregivers (Mean \pm SD = 36.96 \pm 16.76; Mean \pm SD = 24.37 \pm 11.56; P = 0.011) as described in the table 3.

Based on the CGI scores, the caregivers were divided into two groups based on the severity of the illness in their relatives. Individuals who were normal to mildly ill was categorized as one group and those with moderate to severe illness were grouped into another. Total score of caregiver burden was significantly high among the caregivers whose relatives had moderate to severe illness than the other group (Mean \pm SD = 35.16 \pm 15.95 ; Mean \pm SD=20.12 \pm 11.08 ; P=0.015).

Also, the caregiver burden score was significantly high among the caregivers whose relatives were on irregular treatment when compared to those who were on regular treatment. (Mean \pm SD = 43.57 \pm 14.70; Mean \pm SD = 30.44 \pm 15.76; P = 0.047).

As explained in table 4, caregiver burden score was significantly less among the caregivers of patients with <5 relapses compared to the caregivers of patients with 6-10 relapses (Mean \pm SD=26.16 \pm 14.57; Mean \pm SD =40.66 \pm 16.89; P=0.021) and >10 relapses (Mean \pm SD = 26.16 \pm 14.57; Mean \pm SD = 39.00 \pm 14.37;

P=0.017). Caregiver burden score was less among the caregivers of patients with >10 relapses than the group with 6-10 relapses (Mean \pm SD = 40.66 \pm 16.89 ; Mean \pm SD = 39.00 \pm 14.37, P=0.716). However the difference was not statistically significant.

Table 4: Comparison between groups of caregivers based on patient's number of relapses

Comparison between groups of caregivers of patients with numbers of relapses	Caregiver burden scores (Mean \pm SD)		P value
R1 and R2	26.16 \pm 14.57	40.66 \pm 16.89	0.021
R1 and R3	26.16 \pm 14.57	39.00 \pm 14.37	0.017
R2 and R3	40.66 \pm 16.89	39.00 \pm 14.37	0.716

*R1 < 5 relapses, R2 - 6-10 relapses, R3 - >10 relapses

On assessing the correlation between caregiver burden score and global functioning, we identified that the caregiver burden score negatively correlated with the patient's global level of functioning ($r = -0.611$, $P < 0.001$). It implies that the lower the functioning of the individual, higher the caregiving burden.

Medical and psychiatric co-morbidities in the caregivers did not have any significant association with the total scores of caregiver burden.

4. Discussion

Majority of the caregivers in our study population experienced mild to moderate level of caregiving burden (46.7%) followed by moderate to severe level of burden (24.4%). In our study, female caregivers experienced more burden than the male caregivers (Mean \pm SD = 36.96 \pm 16.76; Mean \pm SD = 24.37 \pm 11.56; $P = 0.011$) which is in line with the earlier studies. Studies conducted by Sharma N et al. and Penning MJ et al. independently demonstrated that women caregivers were experiencing more caregiving burden & reported greater strain and distress than men^{[4][7]}.

Generally, women caregivers were predominantly either mothers or spouses. They enter the role in a caregiving by default. In spite of emerging men caregivers, the traditional cultural value of women as a natural caregiver remains the same. Women tend to get more involved with household chores and had very minimal time to do exercise or hardly could involve in other recreational activities which are very well known to alleviate stress. Earlier literature had proposed that the aforementioned reasons could possibly lead them to perceive more stress and henceforth more caregiving burden as they could feel overwhelmed with more responsibilities in addition to their existing routine^[16].

In our study, caregivers of individuals with moderate to severe illness experienced significantly more burden than the caregivers of individuals with mild illness (Mean \pm SD = 35.16 \pm 15.95 ; Mean \pm SD = 20.12 \pm 11.08 ; $P = 0.015$). Apart from this, caregivers of individuals who were on regular treatment had significantly reduced caregiver burden as against the caregivers of individuals who were irregular to treatment (Mean \pm SD = 30.44 \pm 15.76; Mean \pm SD = 43.57 \pm 14.70 ; $P = 0.047$). These findings had been

corroborated by earlier studies such as, S.P. Chaukimath et al. & Ohaeri JU^{[8][15]} which suggested illness severity as an important predictor for the caregiving burden. This could possibly be due to various factors involved in caregiving of severely ill psychiatric patients which includes multiple symptom exacerbations of the illness, poor functional outcome of the individual which might lead to financial burden and they had to deal with other social factors like stigma in the community and hospital visits and admissions. In addition to this, in our study population, we identified that majority of the individuals who were on irregular treatment had moderate to severe illness. Hence, we reiterate that with effective symptom control and ensuring adherence can minimize the caregiver burden as it is very well established that there could be a considerably increased caregiver burden as the severity of illness increases.

In our study, caregivers of individuals who had <5 relapses experienced significantly lesser caregiver burden when compared to the caregivers of the individuals who had 6-10 or more relapses. On the contrary, we identified that the individuals with 6-10 relapses had a slightly higher caregiver burden than the group with >10 relapses. However, the difference was not statistically significant. This finding from our study is partly in line with earlier studies, which elicited higher family burden in patients with high relapse rates and the relapse incidence were more when the caregivers experienced burden^[9].

Although, the caregivers of individuals with 6-10 relapses and >10 relapses perceived a moderate to severe caregiver burden, we could not establish a linear relationship between the caregiver burden and the number of relapses possibly due to the relationship of the caregiver with the individuals having different types of psychiatric illnesses. In our study sample, we identified that caregivers of patients with 6-10 (66.7%) and more than 10 (58.3%) relapses were parents. As parents, they might be feeling it as more of a responsibility than a burden due to social and cultural factors and due to their experience of handling the issue they would be aware of the availability of healthcare services to access at times of symptom exacerbation or relapse. This could have facilitated the caregivers of individuals with 6-10 relapses and >10 relapses to accept the illness dimensions and the caregiving responsibility with perceiving not more than slight burden than the other.

In our study, we identified that when the functional status of the individual with psychiatric illness when declined, their caregivers perceived greater burden ($r = -0.611$, $P < 0.001$) which is in line with the earlier studies. Salma Siddiqui et al and S.P. Chaukimath et al found that decline in the functional status of the patient posed enormous burden on the caregiver.^{[10][8]} This could possibly be explained by excessive worry about the future of their relatives with psychiatric illness having inadequate functioning. This might lead to mental and physical exhaustion experienced by the caregivers on meeting the demands of their relatives, thereby increasing their burden.

5. Limitations

Unlike earlier studies, we did not find any significant association between the age of the caregiver, years of

caregiving, presence and absence of medical or psychiatric co-morbidities in the caregiver with the caregiving burden. We attribute it to the smaller sample size and acknowledge as a limitation of our study.

6. Conclusion

To conclude, this study proves that caregiving mentally ill family member is a challenging task and the caregiver had to undertake this stressful task at the cost of their own needs. Most of the caregivers are ignored and receive very little recognition for their valuable effort they make. Hence, treating the psychiatric condition effectively and minimizing the illness severity may play a significant role in reducing the caregiver burden. We also submit that effective psychoeducation of the caregivers on a regular basis about the nature & the course of psychiatric illness, addressing caregivers' perceptions of the patient's deviant behaviour, issues related to relapse and the importance of drug compliance is beneficial which might empower them to cope with the caregiving burden effectively.

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