

# Hospital Based Cross Sectional Study on Caregiver Burden in Chronic Mentally Ill Patients in Northern Kerala

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## ABSTRACT

### BACKGROUND

Mental health is an important aspect of health, and it should be cherished, promoted, and conserved, to the maximum. World-wide, around 450 million people suffering from mental illness and contributing to important causes for years lived with disability. Caring is a fundamental issue in the treatment of a patient with mental illness. Majority of patients stay with their families and they have been the mainstay of care giving for patients with mental illness. Taking care of chronic mentally ill patients puts stress and burden on the caregivers. Caregivers use different methods of coping. This study was conducted to assess burden among caregivers of chronic mentally ill patients.

### METHODS

This is a hospital based cross-sectional study. A consecutive sample of 150 caregivers of both inpatients and outpatients who satisfy the inclusion criteria, attending psychiatry department were recruited in the study. Caregivers were assessed with socio-demographic proforma. The burden assessment schedule (BAS) developed by SCARF measures the burden experienced by caregivers of chronic mentally ill patients. Statistical analysis was done using statistical package for social sciences (SPSS). Categorical and quantitative variables were expressed as frequency (percentage) and mean  $\pm$  SD respectively. Chi-square test was used to association between categorical variables.

### RESULTS

Of the 150 participants, 16 % experienced mild burden, 57.3 % had moderate levels of burden and 26.7 % had severe burden levels.

### CONCLUSIONS

This study concluded that caregivers of the mentally ill individuals do undergo a lot of burden or strain. Highest areas of burden were seen in the areas of physical and mental health, external support, and spouse related. The caregivers are in need of support and understanding. Clinicians dealing with the caregivers of patients with chronic mental illness must systematically assess the coping mechanisms of caregivers and encourage the use of adaptive and problem-focused coping mechanism to improve the caregiving and patient related outcome. Hence, there is a need to develop strategies that can help them such as providing them with a support structure as well as counseling services.

### KEYWORDS

Caregiver, Burden, Mental Illness, Coping

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## BACKGROUND

In India about 20 % of the whole population has psychiatric disorders. According to National Mental Health Survey (NMHS), 2015 - 16 India, the overall weighted prevalence for any mental morbidity was 13.7 % lifetime and 10.6 % current mental morbidity.<sup>1</sup> Major problems faced in India are lack of mental health work force, financial aid, stigma and caregiver burden.<sup>2</sup> Half of the patients with psychiatric illness reported disability in all three domains of – work, social, and family. For these patients, care is necessary. As world health organization (WHO) recommended deinstitutionalization, the responsibility of care has then shifted mainly to the informal caregivers of the patients.<sup>3</sup> In India, majority of the patients stay with their families<sup>4</sup> and they have been the mainstay of care giving for patients with mental illness.<sup>5</sup>

A caregiver has been defined as a family member, who has been staying with the patient for more than a year and has been closely related with the patients daily living activities, discussions and care of health.<sup>6</sup> The world health organization defines caregiver burden as the emotional, physical and financial demands and responsibilities of an individual's illness that are placed on the family members, friends or other individuals outside the care system.<sup>7</sup> Caregivers are in charge of assisting people who are unable to recover or continue with treatment. The day-to-day needs of patients are taken care by caregivers. The family caregiver supervises treatment and provides emotional support to the patient. Caregiver's role in medical aspects include ensuring that patients take their medications and providing the doctors with information about recovery.<sup>5</sup> Taking care of chronic mentally ill patients puts stress and burden on the caregivers. The consequence of caregiver burden are depression, anxiety and burn out which is associated with higher levels of stress than compared to other chronic medical illnesses. As the severity of the psychiatric illness increases, it leads to increasing severity of burden on the caregiver which in turn leads to negative outcome on the patient's care. Caregiver burden in mental illness can be either subjective or objective. Subjective burden is defined as the caregiver's personal appraisals of the situation and the extent to which the person experiences the burden. Subjective burden includes emotional strain like sadness, fear, anger, guilt, loss, stigma and rejection. Objective burden is defined as observable, tangible costs to the caregiver resulting from the mental illness. Objective burdens are negative patient symptoms, disruption of caregiver's routine activities, leisure, social isolation, financial and employment difficulties.<sup>8</sup>

For caregivers of schizophrenia, providing care while attending to other family responsibilities caused a greater level of burden for caregivers. If sacrifices had to be made to provide care to the care recipient, the level of burden was higher because of the perception of sacrifice itself and it is associated with time, money, giving up luxury items, and the quality of relationships with others.<sup>9</sup>

A study by Kumar et al. reported that, the female spouses of schizophrenic patients primarily utilize projection as the defence mechanisms. The use of such projection increases the interpersonal conflict because of which the

female spouses find it difficult to get optimum external support.<sup>10</sup> Jagannathan et al. opined that, duration of illness and levels of psychopathology and disability had direct correlation with total burden score and perceived social support had significant inverse correlation with total burden score.<sup>11</sup>

A study conducted by Chakrabarthi et al. administered family burden interview schedule to the relatives of 78 patients with affective disorder (BPAD, Recurrent MDD) and 60 patients with schizophrenia and found that both the groups reported financial burden, disruption of family routine, family leisure and family interaction as burdensome. In the affective disorder group, maximum burden was experienced in the area of disruption of family routine and family interactions. Burden was principally felt in the areas of family routine, family leisure, family interaction and finances. Financial burden was primarily a direct outcome of loss of patient's income and is due to expenses of treatment. Disruption of family interactions was as a consequence of patient's illness. The emotional health of caretakers was affected in a number of cases, with many reporting loss of sleep or appetite and constant worrying.<sup>12</sup>

Conventional mental health services in our country do not offer any special strategy or interventions to address the issue of caregiver burden among individuals caring for patients with mental illness. There are only few studies regarding the assessment of stigma and unmet needs such as burden of patients and caregivers in the context of a developing country. Deinstitutionalization, restricted hospital admission and reduction of length of inpatient treatment also change the situation of relatives. Newer changes made them more involved in the care of patients.

Caregivers of patients face a lot of burden, ill health, and disrupted family life, with literature suggesting an increasing concern about their ability for coping. Mental health professionals should be more aware of and address the burden of the family in caring for patient with mental disease as they treat the patient. Burden can cause potential damage to physical and mental health of the carer and worsen the outcome of the patient. So, there is a need to examine both the prevalence as well as factors associated with caregiver burden, as this will serve to plan appropriate interventions.

We wanted to assess the burden among caregivers of chronic mentally ill patients.

## METHODS

This is a hospital based cross sectional study. Caregivers of inpatients and outpatients attending to Department of Psychiatry Government Medical College Kannur for a continuous period of 1 year from 1<sup>st</sup> February 2019 to 29<sup>th</sup> February 2020 after getting ethical clearance were included. Sample size of our study was 185 caregivers (sample size calculated using the formula  $Z^2 pq / d^2$  with an assured prevalence of 14 % for severe burden and a precision factor of five). But, a consecutive sample of 150 caregivers who satisfy the inclusion and exclusion criteria were recruited in the study.

**Inclusion Criteria**

1. Caregiver of patient aged between 18 - 65 years diagnosed with mental illness as per International Classification of Diseases 10
2. Those caregivers who are willing to give informed written consent.
3. Caregivers who were family members range between 18 - 65 years of age, male or female.
4. Patient who has been ill for one year and the caregiver staying with the patient for more than one year.

**Exclusion Criteria**

1. Patient with other chronic physical illnesses
2. Psychiatric illnesses in the caregivers prior to the illness of patient
3. Those were home nurses.

The samples were assessed using socio-demographic data and burden assessment schedule.

**Sociodemographic Data**

This data sheet was prepared by investigator for collecting and recording information regarding caregivers name, age, gender, educational status, occupation, socio-economic status, relation with patient, marital status, contact address, telephone number, and type of family.

**Burden Assessment Schedule**

The burden assessment schedule<sup>4</sup> developed by SCARF measures the burden experienced by caregivers of chronic mentally ill patients. It is a 40 item, 3-point rating scale with nine areas-spouse related, physical and mental health of caregivers, external support, caregiver’s routine, support of patient, taking responsibility, other relations, patient behaviour and caregiver’s strategy.

**Statistical Analysis**

Categorical and quantitative variables were expressed as frequency (percentage) and mean ± SD respectively. Chi-square test was used to find association between categorical variables. For all statistical interpretations, P < 0.05 was considered the threshold for statistical significance. Statistical analysis was performed by using a statistical software package SPSS, version 20.0.

**RESULTS**

Among 150 sample, 85 were females and 65 were males. Most of the patients belonged to the productive age group of 31 – 50 years (46.0 %), and were ever married (76.7 %). Majority of the participants were from rural background (58.0 %), nuclear family (54.0 %), belonged to middle class family (71.3), had an annual income > 10000 (54.0 %) and were unemployed (55.3 %). 46.7 % of the participants belonged to Muslim religion. 16 % experienced mild burden, 57.3 % had moderate levels of burden and 26.7 % had

severe burden levels. There was no significant association between caregiver burden and various socio-demographic variables like age, sex, education, marital status, work, occupation, background, socio-economic class and treatment setting. There was significant association between caregiver burden and socio demographic variables like religion and family income. The highest amount of burden was seen in the areas of physical and mental health, external support and spouse related.

Severity of Burden	Count	Percent
Mild	24	16.0
Moderate	86	57.3
Severe	40	26.7

**Table 1. Percentage Distribution of the Sample According to Severity of Burden**

		Mild		Moderate		Severe		χ <sup>2</sup>	P
		Count	%	Count	%	Count	%		
Age	18 - 30	5	14.7	23	67.6	6	17.6	4.1	0.393
	31 - 50	12	17.4	34	49.3	23	33.3		
	> 50	7	14.9	29	61.7	11	23.4		
Sex	Male	8	12.3	43	66.2	14	21.5	3.67	0.160
	Female	16	18.8	43	50.6	26	30.6		
Education	Primary	10	21.7	26	56.5	10	21.7	2.41	0.661
	Secondary	7	11.5	36	59.0	18	29.5		
	University	7	16.3	24	55.8	12	27.9		
Occupation	Work	15	22.4	35	52.2	17	25.4	3.71	0.156
	Not work	9	10.8	51	61.4	23	27.7		
Religion	Hindu	8	17.0	22	46.8	17	36.2	10.92*	0.027
	Muslim	12	17.1	48	68.6	10	14.3		
	Christian	4	12.1	16	48.5	13	39.4		
Marital status	Single	7	20.0	21	60.0	7	20.0	1.27	0.529
	Ever married	17	14.8	65	56.5	33	28.7		
Family income	0 - 5000	6	66.7	2	22.2	1	11.1	19.43	P < 0.01
	5001 - 10,000	9	15.0	37	61.7	14	23.3		
	> 10,000	9	11.1	47	58.0	25	30.9		
Background	Rural	14	16.1	53	60.9	20	23.0	4.07	0.397
	Semi urban	7	17.5	23	57.5	10	25.0		
	Urban	3	13.0	10	43.5	10	43.5		
Family type	Nuclear	10	12.3	50	61.7	21	25.9	2.17	0.704
	Joint	9	20.0	24	53.3	12	26.7		
	Extended	5	20.8	12	50.0	7	29.2		
Socio economic status	Lower	3	10.0	13	43.3	14	46.7	8.17	0.086
	Middle	18	16.8	66	61.7	23	21.5		
	Higher	3	23.1	7	53.8	3	23.1		

**Table 2. Association of Burden with Selected Background Characteristics of Caregivers of Mentally Ill Patients**

Of the 150 participants, 16 % experienced mild burden, 57.3 % had moderate levels of burden and 26.7 % had severe burden levels. There was no significant association between caregiver burden and various socio-demographic variables like age, sex, education, marital status, work, occupation, background, socio-economic class and treatment setting. There was significant association between caregiver burden and socio demographic variables like religion and family income.

**DISCUSSION**

Our study is set in a tertiary care hospital in northern Kerala. All the patients were living with their families and being cared by them and therefore the sample is representative of the majority of patients receiving treatment in Kerala. Our study included 150 caregivers of age group 18 - 65 years who were staying with the patients for more than 1 year. Among the sample, 85 were females and 65 were males.

Most of the patients belonged to the productive age group of 31 – 50 years (46.0 %), and were ever married (76.7 %). This was similar to the findings in a study conducted by Walke et al.<sup>6</sup> Majority of the participants were from rural background (58.0 %), nuclear family (54.0 %), belonged to middle class family (71.3), had an annual income >10000 (54.0 %) and were unemployed (55.3 %). 46.7 % of the participants belonged to Muslim religion.

Caregivers, who take majority of responsibility of caregiving for a chronic mentally ill individual, have to undergo severe burden.<sup>13</sup> Also, patients can dominate them, which causes distress, and it may affect their ability to handle the crisis.<sup>14</sup> In this study, moderate burden due to caregiving accounted for 57.3 % and severe burden was found among 26.7 %, which is comparable to a cross-sectional study conducted by Walke et al. in Udupi taluk. 6 Mandal et al. in a tertiary care general hospital in northern India among thirty caregivers of schizophrenic patients.<sup>15</sup> Kaur et al.<sup>14</sup> In New Saini Psychiatric Hospital, Hoshiarpur, Punjab, also reported similar findings in their study done among 100 caregivers of schizophrenic patients with moderate burden experienced by 50 % of caregivers and severe burden by 49 % of caregivers.

The burden assessment scale showed that highest amount of burden was seen in the areas of physical and mental health domain which assessed the caregiver burden resulting from the feelings of depression, anxiety, frustration and tiredness, spouse-related domain which related to the help received from the spouse, and burden in areas of external support such as support and appreciation from family, relatives, and friends. Least amount of burden was seen within the areas of support of the patient like the necessity to support the patient and other relations like disruption of family activities and effect on other relations. These findings were similar to a study conducted by Gandhi and Thennarasu<sup>16</sup> in a tertiary care neuropsychiatric hospital at Bangalore in the year 2012 which was done on thirty caregivers of inpatients diagnosed with depression and another study done by Walke et al.<sup>6</sup> A study by Swapna et al. in caregivers of bipolar affective disorder and alcohol dependence syndrome patients recruited from the psychiatric outpatient department of hospitals which provided clinical services to J.J.M. Medical College also found that domains such as physical and mental health, caregiver's routine, and spouse related showed highest amount of burden, followed by external support, patient behaviour, caregiver's strategy, taking responsibility, and support of patient. Least burden was seen in the areas of other relations.<sup>17</sup>

These findings show that the perception of burden by caregiver in the last decade remains the same with almost similar burden experienced by caregivers in 2004, 2014, 2019. Medical services in our country are mainly focused on patients alone during admissions, without an emphasis on a long-term holistic approach that benefits both the patient and caregiver. The findings from our study and similar research in past on the experience of caregiver burden underlines the necessity to address caregiver burden especially on a long-term basis beyond periods of acute exacerbation or hospitalization.

Providing caregiving while addressing other family responsibilities adds to the burden experienced by the caregivers. Caregiving is time consuming, creates social, emotional, behavioural and financial problems and cause limitations in their personal life.<sup>18</sup> Symptoms that were considered as burden were patients being a danger to themselves or others and issues with neighbours as a result of the patient's behaviour.

Our study evaluated that there is no significant association between socio-demographic variables like age, sex, education, marital status, occupation and burden. But shows a significant association with income. Unlike other studies socio-demographic variables show significant association with burden. A community based study by Shabna et al. conducted in southern Kerala found that the female and illiterate caregivers reported significantly more burden and the levels of caregiver burden were not associated with any other clinical or socio-demographic variables.<sup>19</sup> Our study found that there is significant association between high per capital income and religion with burden. Although no significance was found in relation to whether the patient was employed or unemployed, but the patient's income level was found to be significant. In a study conducted in the cities of Derince and Sakarya in Turkey, among caregivers of patients diagnosed with schizophrenia and who were being treated at Community Mental Health centers, they also noticed that caregiver burden was negatively correlated with income level and functionality of the patients.<sup>20</sup> So many studies exploring the relationship between economic condition and caregiver burden had shown that a lower socio-economic level is associated with increased caregiver burden.<sup>21</sup>

## CONCLUSIONS

Caregiver burden may be a significant clinical issue that unfortunately isn't routinely addressed in busy, under-resourced clinical settings. The aim of this study was to assess the burden among caregivers. This study concluded that caregivers of mentally ill individuals do undergo tons of burden/strain. Hence, there's a requirement to develop strategies which will help them like providing them with a support structure also as counseling services. The caregivers are in need of support and understanding. Clinicians handling the caregivers of patients with chronic mental disease must systematically assess the coping mechanisms of caregivers and encourage the utilization of adaptive and problem-focused coping mechanism to enhance the caregiving and patient related outcome.

### Strengths of the Study

The study was performed in an important area of need, which is largely not addressed, caregiver burden in families of people living with major psychiatric illness. The study population was representative of the people receiving treatment in the country, given that it was conducted in an outpatient as well as inpatient setting of a tertiary care center. The study was conducted in a semi-rural setting and majority of our samples are from rural areas while most

studies in the country have been conducted in urban settings and the majority of the Indian population lives in rural and semi urban areas. Consecutive sampling was used which reduces the chance of selection bias. Standardized instruments which have been widely used in similar populations were employed.

### Limitations of the Study

Caregivers who were motivated participated in the study as they were approached while waiting to seek care in the outpatient department. Language, literacy, and stigma related to caregivers suffering from mental illness were the main barriers faced while conducting the study. The study may not have been powered to examine the correlation of all the factors with caregiver burden. Factors such as personality or psychiatric morbidity among caregivers which could have impacted on caregiver burden were not examined. The study cannot be generalized to the community as the study population was from a hospital-based population.

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