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## **BURDEN AMONG CAREGIVERS OF PERSONS WITH MENTAL ILLNESS: A STUDY AMONG THE RURAL COMMUNITY FROM MADURAI EAST BLOCK, TAMIL NADU**

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### **Abstract**

*The family constitutes an important support system in the care of the mentally ill in the community. Mental health professionals need to be aware of and address the stress borne by the family in caring for patients with mental illness as they treat the patient.*

*To assess burden among caregivers of mentally ill patients and associated factors in a rural area in Madurai East Block.*

*Caregivers of mentally ill patients were selected from a registry of a Community Based Mental Health Programme of M.S. Chellamuthu Trust & Research Foundation, in a rural area in Madurai East Block in September 2017. A 20-item interviewer-administered Burden Assessment Schedule was used to assess caregiver burden. Burden was scored based on impact on 5 domains with a maximum score of 12, high scores indicating a high burden.*

*62 caregivers consented to participate in the study, 48 (77.42%) were females. The average score for caregiver wellbeing was  $6.00 \pm 1.81$ , for marital relationships was  $6.53 \pm 1.37$ , appreciation for care giving was  $6.07 \pm 1.40$ , for perceived severity of disease was  $5.99 \pm 1.90$ , and for relations with others was  $5.64 \pm 1.59$ , the last of which was significantly associated with type of mental illness ( $p < 0.05$ ). The burden among caregivers in general was lower than expected, probably due to the interventions made in the community based program by the Institution.*

### **Introduction**

In India one in four patients attending primary care clinics has a mental disorder. Successful management of mental illness in the community relies significantly on an informal or non-professional network of caregivers. The family constitutes a major support system in the continuing care of the mentally ill in the community. Although any families show a strong resilience in caring for an ill relative, their share of physical and emotional distress cannot be ignored.

A caregiver has been defined as a family member who has been living with the patient, and has been loosely involved in his/her activities of daily living, health care, and social interaction for more than a year. Burden may be defined as the presence of problems, difficulties or adverse effects which affect the lives of psychiatric patients' caregivers. In an effort to provide the best possible care for a family member, caregivers often sacrifice their own physical and emotional needs and the emotional and physical experiences involved with providing care can strain even the most capable person.

Almost one-third of all caregivers are balancing employment and care giving responsibilities, and of this group, two-thirds report conflicts in roles that require them to rearrange their work schedules, work fewer than normal hours, and/or take unpaid leaves of absence. The emotional impact of any psychiatric disorder on family or primary caregivers can vary from frustration, anxiety, fear, depression and guilt to grief. Because care giving is such

an emotionally draining experience, caregivers have high rates of depression when compared to the general population. Research on family caregivers of mentally ill relatives has historically focused on negative aspects of care giving, often described as caregiver burden.

The World Health Organization (WHO) states caregiver burden as the "the emotional, physical, financial demands and responsibilities of an individual's illness that are placed on the family members, friends or other individuals involved with the individual outside the health care system". Family caregivers play a major role in providing care giving assistance to ill persons and their families. The effect of stressors on family members caring for an ill person in the family has been referred to as caregiver's burden. Chronic diseases place a considerable burden on family caregivers who take the sole responsibility for caring for chronically ill patients.

Caregiver burden in mental illness can either be objective or subjective. Objective burdens are defined as readily verifiable behavioural phenomena, e.g. negative patient symptoms; disruption of the caregiver's domestic routine social activities and leisure; social isolation; and financial and employment difficulties. Subjective burdens comprise of emotional strain on caregivers, e.g. fear, sadness, anger, guilt, loss, stigma and rejection. The shift towards community care for patients with mental illness has resulted in transferring responsibility for day-to-day care of patients to their family members, which has led to

profound psychosocial, physical and financial burdens on patients' families.

There is a dearth of information on burden among caregivers of patients with mental illness in developing countries, especially in community based settings. It is crucial for mental health professionals to be sensitive to the stress and burden experienced by families, in order to plan and implement a comprehensive treatment programme. This would also facilitate enhancing the quality of life of both- the mentally ill, and their families.

### Objectives:

To assess burden among caregivers of mentally ill patients and to assess the factors associated with the burden in rural areas of Madurai east Block.

### Material and Methods

This is a cross sectional study. We selected the subjects – the care-givers of mentally ill patients, from among those registered under the CMHP Project - the Community Based Mental Health Programme, M.S. Chellamuthu Trust & Research Foundation, Madurai, and we interviewed them individually between September and October, 2017. We selected a total of 62 subjects from 24 villages, based on the following inclusion criteria:

Caregivers of patients with affective disorders (depression, mania, bipolar affective disorder),

Neuroses (obsessive compulsive disorder, generalized anxiety disorder) and

Psychoses (schizophrenia, paranoid states) were included.

We included only those patients who had been ill for more than 1 year, and were in active treatment during the study. We administered a 20-item Burden Assessment Schedule developed by H. Sell et al in association with SCARF (Schizophrenia Research Foundation), and Regional Office for South-East Asia of WHO (SEARO) which measures subjective caregiver burden to each caregiver.

We identified each caregiver with the assistance of our health care workers who are intimately connected with the families in the villages, spend time with them, and help in the treatment routine. We translated the questionnaire into the local language, Tamil, and back translated into English to ensure validity. This questionnaire measures the degree of burden in several important areas such as:

1. Impact on well being: Any feelings of frustration, exhaustion, depression, and impact on health in general, as a result of caring for the patient.

2. Impact on marital relationships: (if the care-giver is the spouse) this reflects the ability of the mentally-ill patient to give adequate attention and affection to other members of the family, and to satisfy the emotional needs of his/her partner.
3. Appreciation for care-giving: a positive factor, this reflects the satisfaction received from the appreciation and acknowledgement for care-giving, from family and friends.
4. Impact on relations with others: refers to disruption of family, and other social relations, as a consequence of the presence of a mentally-ill patient.
5. Perceived severity of the disease: is in the care-giver's opinion.

Subjective caregiver burden refers to the caregiver's emotional reactions (e.g., reduced morale, anxiety and depression). Objective caregiver burden refers to the practical problems associated with care giving (e.g., difficulties with neighbors and police, disrupted family relationships). Four of the questions are exclusively for care giver spouses, i.e., Impact on marital relationship.

The schedule uses a 3-point scale for each question and scores 1 for 'not at all', 2 for 'some extent' and 3 for 'very much'. Thus the maximum score in each area of burden is 12 with higher scores indicating high degree of burden. We entered the data on Microsoft Excel, and analyzed those using standard statistical packages and with tests like measures of central tendencies, frequencies, independent "t" test and ANOVA.

### Results

It has been found that 88 caregivers fulfilled the inclusion criteria. Of those, 26 were unavailable at their houses after three visits and were dropped from the study. The remaining 62 were available and consented to participate in the study. Thirty six (58.06 %) of the 62 caregivers were in the age group of 15 - 35 years (Mean age = 23.7; SD = ±5.03). Majority of the caregivers were females (77.42%); 90.4% of the caregivers were gainfully employed in an occupation. Seventeen (27.42 %) of the caregivers belonged to the spouse category while 45 (72.58%) were non- spouses, of whom 20 (44.4 %) were sons/daughters of the mentally ill. A majority of caregivers belonged to a nuclear family (59.7%). Fifty- five (88.70%) caregivers belonged to the high socio economic status based on the Standard of Living Index.

### Socio-demographic profile of the caregivers

Sl. No	Age in Years	N	%
1	15-25	15	24.19
2	25 - 35	21	33.87
3	35 - 45	14	22.58
4	45- & Above	12	19.36
	Total	62	100.0

### Gender

Sl. No	Gender	N	%
1	Male	14	22.58
2	Female	48	77.42
	Total	62	100.0

### Socio Economic Status (SLI)

Sl. No	Socio Economic Status	N	%
1	Low	34	54.84
2	Middle	16	25.81
3	High	12	19.35
	Total	62	100.0

### Education Status

Sl. No	Education status	N	%
1	Primary	28	45.16
2	Middle & High School	20	32.26
3	Above High School	14	22.58
	Total	62	100.0

Fourteen (22.58 %) mentally ill patients were in the age group of 35 – 45 years (Mean age = 44.1; SD =  $\pm 12.73$ ), 48 (77.42 %) being females. Forty nine patients (79.03 %) were diagnosed to have an affective disorder, 4 (6.4 %) to have psychosis, and 10 (16.12 %) to have neurosis. The mean score in the area of Impact on well being was  $6.0 \pm 1.81$ ; impact on marital relationships was  $6.53 \pm 1.37$ . Appreciation for care giving was  $6.07 \pm 1.40$ ; impact on relations with others was  $5.64 \pm 1.59$ ; perceived severity of the disease was  $5.99 \pm 1.90$ .

### Burden among the care-givers Areas of Burden

Sl. No	Factors	Mean
1	Impact on well being	6.00
2	Impact on marital relationships	6.53
3	Appreciation for care giving	6.07
4	Impact on relations with others	5.64
5	Perceived severity of the disease	5.99

We found a significant association between type of mental illness and impact on relations with others (ANOVA,  $p < 0.05$ ), and type of mental illness and impact on marital relationships (Independent Sample t - test,  $p < 0.05$ ). There was no significant association between age, gender, type of family, educational status, occupational status, socioeconomic status of the caregiver and the areas of burden (Independent Sample t - test ,

$p > 0.05$ ). There was no significant association between age, gender of the mentally ill and the areas of burden (Independent Sample t - test,  $p > 0.05$ ).

### Discussion

This study may be called as the first study that has tried to assess the level of burden among caregivers of mentally ill patients in a rural area. A hospital based study conducted at Agra among caregivers of schizophrenic patients showed that the mean score for impact of well being was 8.43, impact on marital relationships was 10.60, and impact on relations with others was 6.36, and perceived severity of disease was 8.76. Levels of burden in the present study were lower in all the areas as compared to the above study.

This could be because of personalized care we offer to our rural patients. Several aspects of our care delivery model are unique: patients are evaluated at the Trust, for medical problems first before being evaluated for psychiatric conditions; they are introduced to 4 of our trained, high school educated, closely supervised community health workers (HWs) who live in the villages; these workers speak the local languages, are well respected women in the community; they provide regular outreach, visit patients in their homes, interact with the Womens' cooperatives; enable the patients to visit the clinic, supporting compliance. Patients and care givers get to interact with HWs in settings outside of hospital (like village market, fair price shop, milk dairy, SHG meetings etc) where they share and discuss problems. The weekly clinic is also run in an informal setting wherein the patients and/or caregivers assist the staff. Medications are also dispensed at the clinic at reduced rates or free of cost.

In a hospital based study done in Orissa, the burden among caregivers of in patients with mental illness was assessed. Both subjective and objective burden was found to be 53.33%. It was also observed that Subjective Burden was positively associated with younger age group and being female. Nuclear family and years of education and negatively correlated with marital and employment status. We found no such associations in our study.

In a study done in a tertiary care hospital to assess burden among caregivers of patients with schizophrenia, it was observed that primary caregivers were both parents and spouses. Perceived burden was higher in the parent group and in female caregivers. Seventy percent of the caregivers experienced moderate degree of burden, and 30% a severe degree of burden according to the burden assessment schedule. In our study, the caregiver burden

was lower most likely due to the predominant diagnoses being depression or dysthymia rather than schizophrenia. The negative symptoms of schizophrenia could increase the severity of the burden among caregivers. Another possible explanation is that our study was based in a rural community, whereas the study conducted by others were done in a tertiary care hospital, where more severely ill patients are treated.

The shift to the community based psychiatry services has formalized the role of the caregiver. The family and the caregiver's roles have thus been integrated in the treatment plans and in policy making. The role of a family becomes crucial in a country like India with a population of more than one billion people, where there is a paucity of trained personnel.

The number of mental health professionals for the country does not exceed 5000, a number that is grossly inadequate in both services and care providers. Consequently, a large part of mental health care occurs in the community, with family members playing a pivotal role. It is therefore important to assess the burden among the caregivers in order to treat them and prevent burnout.

### Conclusion

Although mental illnesses affect individuals directly, it affects their caregivers indirectly. Therefore healthcare services for mental illness should also incorporate aspects of wellbeing of caregivers. In this study the burden among caregivers was lower than expected, and lower in comparison to studies done in hospital settings earlier. Our explanation is that the care model used previously is unique in its comprehensiveness, the use of highly-trained community health workers who provide active outreach, decreased costs, integration into primary care, and early intervention. Additionally, an approach that emphasizes empathy and empowerment of affected individuals and family members in health care delivery is a driving principle that has sustained the project successfully for over a decade.

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