Caregiver burden among working women and homemakers taking care of psychiatric patients

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ABSTRACT

Background: Caregiver burden is defined as the physical, psychological or emotional, social, and financial problem that can be experienced by the members of family caring for impaired person. In India, women are twice more likely to become caregivers than men, despite emergence of men as caregivers. Aim: The aim of the study is to assess burden of illness among working women and homemakers taking care of psychiatric patients. Materials and Methods: This hospital-based, descriptive, cross-sectional comparative study was conducted on the caregivers who were recruited from outdoor patient department of psychiatry department of a tertiary care hospital attached to a medical college. Women who were 30–45 years old, working or homemakers and who were taking care of psychiatric patients diagnosed with schizophrenia and Bipolar affective disorder (BAPD) of either sex. Caregivers were first-degree relatives of patients. Sociodemographic data were recorded using a special performa and caregiver burden was assessed using caregiver burden questionnaire. Results: Overall mean caregiver burden scores in Group 1 and Group 2 were 55.66 ± 4.09 and 58.16 ± 3.97, respectively, with statistically significant difference (P < 0.05). Conclusion: Caregiver burden was more among working women compared to homemaker women.

Keywords: Caregiver burden, caregiver burden questionnaire, homemaker women, working women

Caregiver is defined as any person including parents and other family members who with or without payment provides care, support, or assistance to a person with disability. Caregiver is a relative who stays with the patient, involved in looking after patient’s daily needs, supervising medication, and accompanies him/her to the hospital. All over the world, women are the predominant providers of informal care for family members with mental illness; and they may be working women or homemakers. Women spend more time on caregiving than men, which interferes with their work and social life to a greater extent. Working women earn wages through regular employment outside the home and have to juggle her career with raising children and taking care of various domestic chores. Homemakers besides managing the household chores also take care of the sick and elderly. With the advancement of treatment modalities for the
management of psychiatric patients, there is an increase in trend toward home-based treatment.

Caregiver burden is defined as the physical, psychological or emotional, social, and financial problem that can be experienced by the members of family caring for impaired person. Women experienced greater mental and physical strain, caregiver burden, and higher levels of psychological distress while providing care. Burden among 30 caregivers of in patients with depression using burden assessment scale showed that mean burden level in female caregivers (17.3% or 56.7%) was significantly higher than in male caregivers (15.5% or 43.3%). Due to the paucity of Indian studies in this area, the present study undertaken to assess and compare caregiver burden among working women and homemaker women taking care of patients diagnosed with schizophrenia and bipolar affective disorder.

**MATERIALS AND METHODS**

This was a hospital-based, descriptive, cross-sectional comparative study. The caregivers were recruited from outdoor patient department (OPD) of psychiatry of a tertiary care hospital attached to a medical college. The study was conducted as per the good clinical practice guidelines and the Declaration of Helsinki’s Geneva with an approval of college ethical committee. All subjects gave written informed consent.

### Sample size estimation

Latest data from India reported moderate-to-severe levels of caregiver burden in 62% of the caregivers of psychiatric patients. Taking the effect size of 10%, at 5% error and 80% power of the study, the estimated sample size is 135 using the formula:

\[ n = \left( \frac{Z_{\alpha/2} + Z_{\beta}}{d} \right) \times \frac{PQ}{2}, \]

\[ n \rightarrow \text{Sample size} \]

\[ Z_{\alpha/2} \rightarrow Z \text{ value at } 5\% \text{ error } (1.96) \]

\[ P \rightarrow \text{average prevalence of the character}, \quad Q \rightarrow 1 - P \]

\[ d \rightarrow \text{the effect size}. \]

Hence, by rounding off, we calculated the total sample size to be 140 and formed two groups. 70 caregivers were homemakers and 70 were working women.

### Sample

Caregivers of patients diagnosed with schizophrenia and bipolar affective disorder were included in the study with the following criteria.

**Inclusion criteria**

1. Female participants who were either working or homemakers in the age group of 30–55 years and taking care of psychiatric patients of either sex brought to the psychiatry OPD
2. Caregiver who is a first-degree relative of the patient and staying with the patient at least for the past 2 years and not suffering from a mental or chronic physical illness
3. Caregivers who give written informed valid consent.

**Exclusion criteria**

1. Caregivers with significant medical, neurological, and endocrinological disorders
2. Pregnant women
3. Caregivers with intellectual disability, mental illness, or substance use disorder.

### Instruments

**Sociodemographic proforma**

A semistructured proforma was used to obtain information about the participants and gather sociodemographic details including age, marital status, gender, educational status, economic status, history of substance use disorder, and any psychiatric illness.

**Caregiver burden questionnaire**

The caregiver burden questionnaire (CBQ) contains 22 items which evaluates the burden experience resulting from taking care of a patient with chronic disease. The average score of 22 items represents the total score of caregiver burden and the highest score represents the greatest caregiver burden. The total score of caregiver burden can be divided into three levels: low burden (1.00–1.99), medium burden (2.00–2.99), and severe caregiver burden (3.00–4.00). Therefore, the score of 22–43 is accounted as low burden, 44–65 as medium burden, and 65–88 is considered as severe burden. Its reliability (82%) was obtained based on the internal correlation coefficient and using Cronbach’s alpha of 0.86.

### Procedure

Diagnosis of psychiatric illness was made as per the International Classification of Diseases-10 (ICD-10) criteria. A brief explanation about the study was given to the caregivers and informed consent was taken. The patients and caregivers identification data about sociodemographic status were recorded in a specially designed proforma. For assessment of caregivers’ burden, the CBQ was administered individually to the caregivers. The questionnaire was scored as per the manual.

### Statistical analyses

The data were analyzed with SPSS (IBM Corp., Armonk, NY, USA) using appropriate statistical tests.
RESULTS

Table 1 shows the comparison of sociodemographic data of Group 1 and Group 2 caregivers. No significant difference was found between the two groups when compared in relation to age group and relation but there were significant differences with regard to marital status, caregivers occupation, and education.

Table 2 shows the diagnostic classification of the psychiatric illness as per ICD-10. Overall, the study comprised of 57 schizophrenic patients (40.71%) and 83 (59.29%) bipolar affective disorder patients. The difference between the groups was no statistically significant. The subtypes of schizophrenia in both groups are given in Table 3. Table 4 shows the history of manic and depressive episodes in BAPD patients. The mean duration of psychiatric disorders and mean duration of treatment are given in Tables 5 and 6, respectively. Table 7 shows the total time spent by the caregiver on the psychiatry patient. Table 8 shows the caregiver burden score comparison among Group 1 and Group 2.

DISCUSSION

In India, the role of the family is vital in the care of persons with severe mental disorder. It includes supervising medications, arranging for follow-up, bringing the patient for inpatient care, staying with the patient, and providing financial support.[7] A study from Mysore (India) showed that the family provides care and assists the nurses during indoor care of psychiatric patients. In India, women are twice more likely to become caregivers than men.[8]
Approximately 55% of the caregivers were mothers of PMI while 31% were wives. Similar findings were reported by Aggarwal et al. and Darlami et al. who reported majority of the caregivers to be married 76% but only 36% of PMI were taken care by their spouses. Another study revealed that more than two-fifths of caregivers were parents, less than one-third were son and daughter, one-fourth were spouses, and only 4% of caregivers were siblings. The higher percentages of caregivers being parents can be explained due to fact that an early onset of mental illness, which hinders with the patient prospects of an early marriage. Hence, parents become the natural caregivers who bring their children for treatment. The Indian societal values are such that if a person becomes

### Table 3: As per the International Classification of Diseases-10 subtypes of F20 patients among both the groups (n=70)

| Subtypes                          | Group 1 (homemakers) (n=28), n (%) | Group 2 (working women) (n=29), n (%) |
|----------------------------------|------------------------------------|---------------------------------------|
| Paranoid schizophrenia (F20.0)  | 23 (82.14)                         | 27 (93.11)                            |
| Hebephrenic schizophrenia (F20.1)| 3 (10.71)                          | 2 (6.89)                              |
| Catatonic schizophrenia (F20.2) | 2 (7.14)                           | 0                                     |

ICD-10 – International Classification of Diseases-10

### Table 4: Past history of manic and depressive episodes of bipolar affective disorder patients in Groups 1 and 2

| BAPD                                | Patients in Group 1 (homemakers) (n=42), n (%) | Patients in Group 2 (working women) (n=42), n (%) |
|-------------------------------------|-----------------------------------------------|--------------------------------------------------|
| Manic episode                       |                                               |                                                  |
| 2 or more manic episodes with psychosis (F31.2) | 25 (59.52)                           | 18 (43.90)                                      |
| Single manic episode (F30)          | 17 (40.48)                                 | 23 (56.10)                                      |
| Depressive episode                  |                                               |                                                  |
| Depressive episode severe without psychosis (F31.4) | 19 (45.24)                           | 7 (17.07)                                       |
| Depressive episode severe psychosis (F31.5) | 23 (54.76)                           | 34 (82.93)                                      |

BAPD – Bipolar affective disorder

### Table 5: Frequency and mean duration of psychiatric illness (months) in Group 1 and Group 2 (n=70)

| Duration of psychiatry illness (months) | Group 1 (homemakers), n (%) | Group 2 (working women), n (%) | χ²  | P   |
|----------------------------------------|----------------------------|-------------------------------|-----|-----|
| <6                                     | 7 (10.00)                  | 10 (14.29)                    | 2.91| 0.27|
| 6–9                                    | 15 (21.43)                 | 18 (25.71)                    |     |     |
| 9–12                                   | 21 (30.00)                 | 22 (31.43)                    |     |     |
| 12–18                                  | 16 (22.86)                 | 13 (18.57)                    |     |     |
| 18–24                                  | 11 (15.71)                 | 7 (10.00)                     |     |     |
| Mean±SD (months)                       | 10.28±4.49                 | 11.38±5.17                    |     |     |

P>0.05, nonsignificant. SD – Standard deviation

### Table 6: Frequency and mean duration (months) of psychiatric treatment in Group 1 and Group 2 (n=70)

| Duration of treatment (months) | Group 1 (homemakers), n (%) | Group 2 (working women), n (%) | χ²  | P   |
|--------------------------------|----------------------------|-------------------------------|-----|-----|
| 1                              | 12 (17.14)                 | 10 (14.29)                    | 1.78| 0.36|
| 2–3                            | 24 (34.29)                 | 26 (37.14)                    |     |     |
| 4–5                            | 18 (25.71)                 | 16 (22.86)                    |     |     |
| 5–6                            | 16 (22.86)                 | 18 (25.71)                    |     |     |
| Mean±SD (months)               | 3.24±2.91                  | 2.31±2.29                     |     |     |

P>0.05, nonsignificant. SD – Standard deviation

### Table 7: Total time spent in caregiving by caregiver in Group 1 and Group 2 (n=70)

| Caregivers time spent (h) | Group 1 (homemakers), n (%) | Group 2 (working women), n (%) | χ²  | P   |
|---------------------------|----------------------------|-------------------------------|-----|-----|
| 1–8                       | 18 (25.71)                 | 42 (60)                       | 6.98| 0.02*|
| 9–14                      | 40 (57.14)                 | 27 (38.57)                    |     |     |
| >14–19                    | 9 (12.86)                  | 1 (1.43)                      |     |     |
| >19–24                    | 3 (4.29)                   | 0                             |     |     |

*P<0.05 significant
mentally ill, spouses might leave him, but parents rarely abandon their children.

In the present study, unemployed patients were more in Group 1 (homemakers) (45.71%) as compared to Group 2 (working women) (12.86%). In both the groups, more than 70% were literate. Maximum caregivers in homemakers were housewives or doing household work (100%) and 87.14% were literate whereas among working women only 1.43% of the subjects were doing household work and 81.42% were literate, with statistically significant differences. Earlier studies also found that that most of the caregivers were literate and educated up to secondary level.[12,13] Another study found that majority of the caregivers were employed 19 (55.88%), 12 (35.29%) were homemakers, and 3 (8.8%) were unemployed.[14]

In Group 1, 57.14% (n = 40) caregivers spent 9–14 h per day in caregiving. However, in Group 2, 60% spent 1–8 h per day in caregiving. The difference in time spent in caregiving role was statistically significant among the groups which is in agreement with the findings of an earlier study.[12] This high time requirement may be because of the chronic nature and severity of symptoms that characterize mental illness, which require constant care and supervision. In today’s scenario, the husband and wife both work together to create a balance between their work life as well as at home but still it is very difficult for working women to play multiple roles of a cook, mother, wife, a nurse as well as cater to the demands of office work. Hence, working women are not able to spend much time on caregiving as she has to fulfill the demands both at work and home or caregiving.

In the present study, severe, medium, low, and no care burden score was found among 40%, 20%, 34.29%, 5.71% and 48.57%, 31.43%, 20%, 0% of the caregivers in Group 1 (homemakers) and Group 2 (working women), respectively. These findings are in agreement with an earlier study[12] which found that there was a highly significant relationship between caregiver burden and their occupation, as the caregivers who work experienced higher burden compared with other caregivers. In this respect, one study found that caregivers commonly give up their jobs, or, in some extreme cases, caregivers have been dismissed from their full-time positions.[13] In agreement with our findings, few previous studies showed that caregivers who are unemployed experienced a higher level of burden compared to the caregivers who have a full-time job.[15,16] As opposed to this, few workers stated that there was no statistically significant effect of employment on caregiving burden.[17,18] The finding of severe burden scores in 40% and 48.57% of homemaker and working women caregivers in the current study is consistent with the finding that 44.6% of caregivers had high level of burden score in an earlier study.[13] This elevated level of burden might be due to the physical and emotional drain and exhaustion by caregiving process. Similar findings were also reported by other studies.[18,19] Caregiver burden is higher among working women because working women perform a combination of multiple concurrent full-time roles such as wife, mother, worker, homemaker, and caregiver so they are doubly-burdened with the responsibility of fulfilling both their domestic, caregiving, and career obligations.

Limitations
The study is limited by the small sample size and its cross-sectional design. The caregivers were screened for the presence of a psychiatric disorder using a clinical interview and a formal assessment was not carried out.

CONCLUSION
Caregiver burden was more among working women as compared to homemaker women. The reason for this can be that working women perform a combination of multiple concurrent full-time roles such as wife, mother, worker, homemaker, and caregiver so they are doubly-burdened with the responsibility of fulfilling both their domestic, caregiving, and career obligations.

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Conflicts of interest
There are no conflicts of interest.

Table 8: Comparison of caregiver burden score in Group 1 and Group 2

| Caregiver burden score | Group 1 (homemakers) | Group 2 (working women) | χ² | P |
|------------------------|----------------------|-------------------------|----|---|
| (n=70), n (%) | Mean±SD | (n=70), n (%) | Mean±SD |
| Severe (65-88) | 28 (40.00) | 73.1±13.46 | 34 (48.57) | 72.29±13.76 | 4.71 | 0.04* |
| Medium (44-65) | 14 (20.00) | 58.64±13.56 | 22 (31.43) | 59.3±14.31 | | |
| Low (22-43) | 24 (34.29) | 37.45±5.87 | 14 (20.00) | 32.5±4.93 | | |
| No burden | 4 (5.71) | 15.6±3.61 | 0 | 0 | | |
| Overall burden | 55.66±4.09 | 58.16±3.97 | | | |

*P<0.05 significant. SD – Standard deviation
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