Research article
Assessment of psychological stress among family care takers of cancer subjects in India-
A cross-sectional study
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ABSTRACT

Introduction and Aim: A rapid increase in cancer rate is one of major concerns in India. It is a well-known fact that family caretakers play an essential part in aiding cancer subjects who are in critical stage. But the psychological strain and economic impact on caretakers are not widely known. The present cross-sectional study assesses the relationship between various factors and higher burden among family caretakers of cancer subjects.

Materials and Methods: One hundred and ninety family caretakers of cancer patients who met inclusion criteria were recruited for study. A proforma was collected regarding the age, gender, social and economic status according to Modified Kuppuswamy Scale 2019, the type of family or the caregiver and their relation to the patient.

Results: Monthly income had an inter quartile range of Rs.10,000-25,000 with the median being Rs.14,000. Higher number of males participated (58.4%) as compared to the females (41.6%). Moderate to severe stress (53.3%), and severe stress (6.7%) was maximum in class 5 of the socio-economic classification. Lower income was found to be related to higher burden scores.

Conclusion: Present study showed that the burden was more among class 5 of the Kuppuswamy Socioeconomic classification. The findings suggest that education levels, occupation and monthly income are the major contribution for the burden among the caregivers.

Keywords: Cancer; family caregivers; psycho social burden.

INTRODUCTION

According to Indian Council or Medical Research (ICMR) India is a country with 2.25 million cancer cases with over 1 lakh new cases get registered every year. In India, overall cancer rates increasing rapidly along with risk of mortality. Hence, timely diagnosis and effective treatment is major public health priority (1). Due to the increasing incidence of cancer in India, the paucity of the specialist manpower and lack of proper structural facilities cue giving burden rests mostly on family caregivers/informal caregivers (2). A family caregiver is defined as “An individual who provides wide range of assistance to the person with disability or chronic illness without salary” (3).

It is well known fact that family caretakers play essential part in aiding cancer subjects who are in critical stage. But the psychological strain and economic impact on caretakers which affect their mental condition and health are least known. This psychological stress among family caretakers has indirect impact on health of cancer subjects (4). With minimum or no expertise, the family caretakers are asked to presume switching roles from routine responsibilities for management of drug administration, manifestations and side effects, consulting physician, taking appointment of necessary treatments, dealing with anxiety and fear and unpredictability in cancer like diseases and watching sufferings of cancer subjects (5).

In cancer, there is also the added difficulty of handling the news of diagnosis and rapid deterioration in health of the patient leading to high burden on the care given (6). In patients who are highly symptomatic, or undergoing chemotherapy experience a wide variety or symptoms for which the cure giver must be prepared for both psychologically, financially and be in constant vigilance. This can lead to anxiety and depression in caretakers mostly seen in the early months or diagnosis and treatment, which leads to poor quality of care given to the patient (7).
Older patients with advanced cancer led to higher caregiver burden rates. Burden is not always related to the hours of care giving (h). Various other factors including financial, social and support factors, occupational and educational factors can have an impact on the level s or burden. This study will be able to assess the correlation of these rectors and higher burden among the caregivers.

**MATERIALS AND METHODS**

A total of 190 family caretakers of cancer subjects who were admitted and outpatient department of tertiary care hospital were participated in this cross-sectional study. A pre-examined, pre certified semi structured questionnaire was utilized to evaluate the psychological strain by using Zarit Burden Interview (ZBI) scale. The present study was approved by Institutional Ethics Committee. A written informed consent was obtained from the subjects who participated in the study.

**Sample size**

The sample size was calculated to be 190. This was computed based on the previous study by Kim and Schuz, in which the percentage of caretakers with increased stress was found to be 67.3%. Using the formula $N = \frac{4pq}{d^2}$ and taking 10% as the relative precision and 95% confidence interval (13).

**Methods of data collection**

A pre-examined, pre certified semi structured questionnaire was utilized to evaluate the psychological strain by using Zarit Burden Interview (ZBI) scale. Each one was asked to the caretaker in sentence form, and feedback was recorded using a 5-point Likert-type scale ranging from 0 to 4. Different score ranges indicates the severity burden and is classified as follows: 0 to 21 little or no burden, 21 to 40 mild to moderate burden, 41 to 60 moderate to severe burden, and 61 to 88 severe burdens. A proforma was collected regarding the age, gender, socio-economic status (as per the Modified Kuppuswamy Scale 2019) the type of family of the caregiver and their relation to the patient. The questionnaire and proforma was provided to caregivers in local vernacular languages.

**Statistical analysis**

Statistical analysis was performed using SPSS version 17. Continuous data was calculated as mean and standard deviation, Categorical data was calculated as frequency and percentage. $p$ value $<0.05$ was considered as statistically significant.

**RESULTS**

A total of 203 subjects were approached for the study, of which 190 consented and provided completely filled forms. The age of the caregivers ranged from 18 to 74 years, the mean age being 38.18±12.483. Monthly income had an interquartile range of Rs.10,000-25,000 with the median being Rs.14,000. Higher number of males participated (58.4%) as compared to the females (41.6%). Majority of the participants had basic graduation certificate (39.4%), over 80% had completed secondary schooling, and only 2.1% had no educational background. Most of the caregivers accompanying the patient were their children, among which sons were the majority (35.8%). Around 57.4% of the participants hailed from a rural background, and only 41.1% were living in a joint family (Table 1). Major portion of the participants were caregivers of breast cancer patients (24.7%) and gynaecological cancer patients (15.2%; Fig. 1). When classified according to Kuppuswamy classification, 79 (41.6%) belonged to class 3, and 49 (25.8%) belonged to class 4 forming the majority of the total population. Further the socio-economic distribution of the population is displayed in Fig. 2.

| Variables               | Frequency | Percentage (%) |
|-------------------------|-----------|----------------|
| 1) Education            |           |                |
| None                    | 4         | 2.1            |
| Primary                 | 8         | 4.3            |
| Middle School           | 22        | 11.6           |
| Secondary               | 58        | 30.6           |
| Higher Secondary        | 23        | 12             |
| Graduate & Postgraduate | 78        | 39.4           |
| 2) Relation to the patient |       |                |
| Brother                 | 14        | 7.4            |
| Brother-in-Law          | 1         | 0.5            |
| Cousin                  | 2         | 1.1            |
The participants’ scores were categorized as trivial or no burden (0-21), mild (22-41), moderate (42-61) and severe burden (62-88). 47.9% of the participants showed minimal burden, with the Zarit Burden interview score ranging from 0-21, mild to moderate burden was observed in 34.7% (Table.2).

**Table 2:** Psycho-social burden among study participants(n=190)

| Category(score) | Level of Burden | Frequency(N) | Percentage in % |
|-----------------|-----------------|--------------|-----------------|
| 1(0-21)         | No Burden       | 91           | 47.9            |
| 2(22-41)        | Mild Burden     | 66           | 34.7            |
| 3(42-61)        | Moderate Burden | 30           | 15.8            |
| 4(61-88)        | Severe Burden   | 3            | 1.6             |
The relationship between burden and various factors that could be affecting the amount of burden that caregivers face was as follows. Moderate to severe burden (53.3%), and severe burden (6.7%) was maximum in class 5 of the socio-economic classification. (Table 3). Monthly income of the family (p=0.001) and socio-economic status according to Kuppuswamy classification were correlated. Lower income was found to be related to higher burden scores (Correlation coefficient = 0.340). The other socio-demographic factors like gender, place, type of family, type of cancer were found to be non-significant (Table 4).

### Table 3: Burden of care givers based on socio economic status (n=190)

| Socio economic class (1-5) | Total | Burden Category          |
|----------------------------|-------|--------------------------|
|                            |       | little or no burden | mild to moderate burden | moderate to severe burden | Severe burden |
| 1                           | Number | 12 | 9 | 3 | 0 | 0 |
| %Within Socioeconomic class | 100.0% | 75.0% | 25.0% | 0.0% | 0.0% |
| 2                           | Number | 35 | 19 | 14 | 2 | 0 |
| %Within Socioeconomic class | 100.0% | 54.3% | 40.0% | 5.7% | 0.0% |
| 3                           | Number | 79 | 44 | 28 | 7 | 0 |
| %Within Socioeconomic class | 100.0% | 55.7% | 35.4% | 8.9% | 0.0% |
| 4                           | Number | 49 | 19 | 15 | 13 | 2 |
| %Within Socioeconomic class | 100.0% | 38.8% | 30.6% | 26.5% | 4.1% |
| 5                           | Number | 15 | 0 | 6 | 8 | 1 |
| %Within Socioeconomic class | 100.0% | 0.0% | 40.0% | 53.3% | 6.7% |

Table showing socio economic burden on family care givers. Data expressed in frequency and percentage.
DISCUSSION

The present study was carried out to analyse the prevalence and demographic stress of family caretakers of cancer subjects. Due to the financial constraints, lack of facility and also due to lack of formal caregivers, the role of care giving falls mostly to the blood relatives. The caregivers also have to face the day-to-day challenges of livelihood along with taking care of their cancer patients. The present study focused on the burden of caregivers based on their socioeconomic status and type of cancer. In addition to this, an attempt was made to calculate the average burden in caregivers who belonged to the study location. More number of male caregivers were present for the interview than female caregivers. This is contradictory to many other studies which find women playing this role. It is believed that women embrace this role far easier than men (15). This finding may be due to the fact that male family members accompany the patients more than females in the present study. Women were hesitant to participate even if they are the primary caregiver. The study found the mean of the burden score to be 24.62±13.652. The highest burden score was 67. This signifies mild to moderate burden when the average population was considered. This is in accordance with findings demonstrated by Harding et al in a comparative study of burden in cancer, dementia and acquired brain injury (16). Higher burden was found in study conducted on caregivers of chemotherapy undergoing patients by CMC Vellore (17).

Higher burden was also found in studies conducted in Saudi Arabia and in Nigeria (10,11). Lower rate of stress was seen in some studies done among more developed as well as urban areas (19,4). More than half of the study population faced some kind of burden. Little or no burden was found in 48% of the study population, whereas 1.6% of the study population had heavy burden according to the ZBI questionnaire. 35% faced mild to moderate burden similar to the study conducted in a South Indian tertiary care centre.18 In another Indian study done by CMC Vellore, burden was found in 91% of the study population. High levels of burden were predominantly seen in the study done in Sub Saharan region and Iran, which may be due to financial and medical facilities (15,19). Different levels of burden might be due to the developmental status of the nation, the regional facilities available and type of cultural practices that exist in the family. It may also be due to the unavailability of specialty care and understanding in palliative care and guidance in the same. Factors affecting the burden in present study, the mean age of the caretakers found to be 38.18±12.483. Age was found to be a significant

Table 4: Socio-demographic factors associated with psycho-social burden among the study participants(n=190)

| Variables               | Little to No Burden (0-21) [n&%] | Mild Burden (22-41) [n&%] | Moderate Burden (42-61) [n&%] | Severe Burden (62-88) [n&%] |
|-------------------------|----------------------------------|----------------------------|-------------------------------|-----------------------------|
| Age                     |                                  |                            |                               |                             |
| <30                     | 35(18.4%)                        | 20(10.5%)                  | 6(3.1%)                       | 0                           |
| 31-40                   | 29(15.2%)                        | 23(12.1%)                  | 7(3.6%)                       | 1(0.52%)                    |
| 41-60                   | 12(6.3%)                         | 13(6.8%)                   | 9(4.7%)                       | 0                           |
| >60                     | 15(7.8%)                         | 10(5.2%)                   | 8(4.2%)                       | 2(1%)                       |
| Gender                  |                                  |                            |                               |                             |
| Male                    | 59(31%)                          | 36(18.9%)                  | 16(8.4%)                      | 0                           |
| Female                  | 32(16.8%)                        | 30(15.7%)                  | 14(7.3%)                      | 3(1.5%)                     |
| Place                   |                                  |                            |                               |                             |
| Urban                   | 17(8.9%)                         | 13(6.8%)                   | 2(1.0%)                       | 1(0.52%)                    |
| Semi-Urban              | 25(13.1%)                        | 16(8.4%)                   | 6(3.1%)                       | 1(0.52%)                    |
| Rural                   | 49(25.7%)                        | 37(19.4%)                  | 22(11.5%)                     | 1(0.52%)                    |
| Type of Family          |                                  |                            |                               |                             |
| Joint                   | 38(20%)                          | 27(14.2%)                  | 13(6.8%)                      | 0                           |
| Nuclear                 | 53(27.8%)                        | 39(20.5%)                  | 17(8.9%)                      | 3(1.5%)                     |
| Type of Cancer          |                                  |                            |                               |                             |
| Ca Breast               | 24(12.6%)                        | 15(7.8%)                   | 7(3.6%)                       | 1(0.52%)                    |
| Ca Head and Neck        | 16(8.4%)                         | 4(2.1%)                    | 7(3.6%)                       | 0                           |
| Ca Lung                 | 5(2.6%)                          | 5(2.6%)                    | 3(1.5%)                       | 0                           |
| GI malignancy           | 8(4.2%)                          | 12(6.3%)                   | 8(4.2%)                       | 1(0.52%)                    |
| Gynecological Cancers   | 14(7.3%)                         | 11(5.7%)                   | 10(5.2%)                      | 1(0.52%)                    |
| Other Malignancy        | 20(10.5%)                        | 15(7.8%)                   | 3(1.5%)                       | 0                           |
| Unknown                 | 4(2.1%)                          | 4(2.1%)                    | 1(0.52%)                      | 0                           |

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factor in contributing to higher levels of burden (Correlation coefficient=0.142). A study done by a dental college in Tamil Nadu had a mean age of 45 years. The burden was found to be maximum among the age groups of 40-50 years, indicating increased levels of stress which may be due to providing for their family along with care giving. Difficulty to adapt to change and their own personal health may also be the reason for the higher levels of burden (11,20,21). 78 of 190 participants hailed from a joint family, and the rest from a nuclear family. No significant change in burden patterns were noticed as previously found by the study conducted in Delhi (9). This may be due to the fact that there is a sharing of workload and care even in a nuclear family, and with nuclear families being found more in urban places where palliative care is gaining importance. Higher burden was found among lower socio-economic groups, classified according to Kuppuswamy classification. Around 60% of Class 5 of Kuppuswamy had moderate to severe burden. Education, occupation and income levels were taken into account for classifying, which signifies the role of these factors in higher burden levels. Higher the family monthly income less was the burden (Correlation Coefficient= -0.340). It was found that caregivers with higher educational levels were found have better coping mechanisms and thus deal better with the stress of caregiving (17). Caregivers with formal education have more chances of understanding the disease, more awareness about managing the cancer and would be able to understand the different modalities of treatment. In present study 87% of the participants were employed, which was in accordance with the studies of Garlo et al., and Liu et al.,(22,23). Most of them were bread winners of the family, especially when place of residence was considered. Rural caregivers who were the sole earning members faced higher burden levels, but maximum burden levels were found in unemployed. Proper education and working facilities provide stability, reduce anxiety and provide for a stable living condition while facing major health issues like cancer. Knowledge about different healthcare insurances could not be measured since awareness about this was limited. This could affect the burden scores as financial help from these insurances can lower burden significantly. Since the study was cross sectional in nature, the cases could not be followed up to note any variation in burden scores. No intervention of palliative care and counselling therapy could be done, which may lead to lesser burdens on the caregivers. Furthermore, depression questionnaires and anxiety scores could be calculated in the caregivers to assess the mental health of these caregivers.

CONCLUSION

The major finding in the present study was that the burden was more among Class 5 of the Kuppuswamy Socioeconomic classification. The finding suggests that education levels, occupation and monthly income are the major contributors for the burden among the caregivers. However, the study could not assess the relationship between amount of burden and stage of cancer due to uneven number of samples in each type of cancer. Information regarding staging of the cancer was not collected, which could also be a contributing factor for the burden.

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CONFLICT OF INTEREST

Authors have no competing interests to declare that are relevant to the content of this article.

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