

## **Burden and perceived social support on primary caregivers of cancer patients**

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### **Abstract**

**Objective:** The role of caregivers is very demanding especially when the disease is Cancer. They have to look after the day-to-day needs of the patient, keep a track on the progression of his illness, supervise treatment, and provide emotional support to the patient in addition to their regular family duties. The caregiver becomes the recipient of the patient's frustration and misbehavior. Due to the lack of training, insignificant knowledge about the disease and the mental trauma of seeing their once so healthy and active relative now bed ridden these caregivers undergo a lot of stress and strain. These stressors cause psychological strain and impaired health in caregivers which may have a potential to culminate into severe illness and mortality.

1. To assess burden and its determinants on primary caregivers of cancer patients.

2. To evaluate the perceived social support by the primary care givers.

**Methodology:** A structured and validated questionnaire was used.

To assess the burden on the care givers – Zarit Burden Scale will be used

To assess the perceived social support- a multi-dimensional scale of Perceived social support by Zimet, Dahlem, Zimet & Farley 1988

**Results:** In the present study majority felt mild to moderate burden and the mean duration of care was 8 months with 12 hours per day. Majority of them felt that they received social support from their family and friends. Statistical significant association was found with

variables like duration of care relationship with the patient

**Keywords:** caregiver, Cancer, burden, support

### **Introduction**

Cancer is the second leading cause of death worldwide. According to GLOBOCAN, there are 32.6 million people (over the age of 15 years) alive who had a cancer diagnosed in the past five years. According to National Institute of Cancer Prevention and Research, there are about 2.7 million people living with cancer in India. In 2022, about 851,678 patients died due to cancer.<sup>1,2</sup>

Cancer is a chronic disease with a prolonged treatment. This leads to not only financial burden, but also, mental and social burden on the caregivers. Due to poor prognosis and lifelong treatment the disease has a bad impact on the patients and family<sup>3</sup>. It results in mental distress and burden among the family members, especially if they are caregivers<sup>4</sup>. Recent advances in the modalities of the treatment protocol have led to more ambulatory care on an outpatient basis. This has further increased the patient's dependency on the caregivers for symptomatic management, treatment, monitoring of medications and adverse reactions, and other daily routine and moral support.

The caregivers on the contrary are emotionally unprepared.<sup>5,6</sup> This makes them more vulnerable to physical, psychological, social, and financial burden. Caregivers do not have sufficient time for themselves and have to cut down on their various personal activities.<sup>7</sup> Family caregivers are forgotten patients and may have mood swing, fatigue, headaches, joint and muscle aches/pains, marital and family conflicts, and financial problems may be a reflection of caregiver stress in looking after a sick relative.<sup>3</sup>

In developed countries, studies have focused on caregiver's health perspectives.

However, there is paucity of the same in developing countries. In Indian culture, mostly the care to patients comes from families, extended families, and other care providers.<sup>8</sup>

Research has been shown that, lack of social support will lead to detrimental effects particularly that of stress and burden which lead to negative effects on the immune system. The stress-buffer hypothesis states that social support acts to protect people from the potentially harmful effects of stressful life events. Surprisingly family caregivers have received very little attention in published literature related to psychological effects of caring for a cancer patient.<sup>4</sup>

So the current study is undertaken with the aim to scrutinize the amount of burden and also map the relationship between the burden among family caregivers of cancer patients and the level of the perceived social support.

The study also measures the association of burden and perceived social support with socio-demographic variables of family caregivers. Findings of this study will have significance in the field of caregiving as it may help the future researchers to develop support interventions.

### **Materials and Methods**

**Study setting:** Study was conducted in a tertiary care hospital, multidisciplinary oncology specialty Centre, well known for its medical expertise and quality of care at an affordable cost. It also as a hospital-based cancer registry. It caters to the population not only within the state but also from other neighboring states.

### **Study design**

A hospital-based cross-sectional study

### **Study population**

Caregivers attending patients at the time of data collection.

### **Inclusion criteria**

Who consented for the interview.

### **Sampling**

Non-probability sampling (Convenient sampling)

### **Study duration**

Two months (April–May 2022)

### **Data collection tool**

A pre-tested, pre-validated semi-structured questionnaire was used. To assess the psychosocial burden, Zarit Burden Interview (ZBI) scale and multidimensional scale of perceived social support (Zimet 1988) was used.

### **Tool no. 1- Socio-demographic data sheet**

Variables of socio-demographic and care giving information of the family caregiver and their patients such as age, gender, marital status, religion, education, occupation, income, type of family and residence. Care giving information such as relationship with patient, duration of care giving in months, average no. of hours spent in care giving per day, any cut back in usual working hours, provision of unpaid help or paid help in, distance from treatment Centre, presence of any co-morbid chronic illness in caregiver.

### **Tool 2**

ZBI scale.<sup>9</sup>: It is a brief 22-item instrument (Cronbach's alpha: 0.92) with excellent psychometric property. Response is recorded using 5-point Likert-type scale. The score range depicts: 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 burden

### **Tool no. 3**

### **The multidimensional scale of perceived social support (Zimet 1988)<sup>10</sup>**

Perceived Social Support Assessment scale was used in this study to measure social support. It is a standardized, short-structured, self-report, 12 items multi-dimensional scale with a Cronbach's alpha =0.93 for the total score. Items are answered on a 7-point scale from very strongly disagree to very strongly agree.

All the items are positive statements. All items were only related to the self-acceptance aspect of social support and not with any others.

Scores range from 12 to 84. The higher the score indicates the higher is the perceived social support. For each assessment, there is an algorithm leading to one of three acuity ranges i.e. high acuity (total score 69-84), moderate acuity (total score 49-68) or low acuity (total score 12-48).

All the three tools were translated into Kannada and Hindi language by experts. Back translation in English was done to ensure the content and meaning. Pilot study was conducted to ensure the reliability and understanding of the tool and also the feasibility.

### **Ethical considerations**

An informed written consent form was signed by each subject before data collection. All the subjects were assured of confidentiality and anonymity. Permission was obtained from Institutional Ethical Committee to carry out the study.

Operational definition: Informal Caregiver: "A person who provides support and assistance, formal or informal, with various activities to a person with long term conditions without financial remuneration"<sup>11</sup>.

## **Data analysis**

Was done using SPSS version 25. Data was summarized using mean and percentages. Chi-square test was performed to find the association.

## **Results**

### **Socio-demographic characteristics**

As shown in table-1, the mean age of the family caregivers (N=150) was 40.98 (SD=12.2) years. The family caregivers were mostly female (59%), married (70%) and majority belonged to Hindu religion (84%) and literate (90%). Maximum participants were self-employed (42.4%), followed by agricultural profession (23.6%). Majority of them belonged to class 3 and 4 as per the Kuppuswamy socioeconomic classification. Majority of them belonged to nuclear family (55%) and were residing in rural areas (61%).

### **Care giving related characteristics**

As shown in table-2, majority (39%) caregivers were children, followed by spouse (22%). Caregivers were providing care for a mean duration of 8.7 months with an amount of care giving mean of 12.3 hrs/day. It was seen that majority (69%) of the care giving duration was less than 6 months. All 150 caregivers had to cut back number of working hours and also that they did not have time for any leisure activities or relaxation, due to their care giving responsibility. Majority (43%) participants reported to have no unpaid help. As the study was conducted in a tertiary apex institute, majority (70%) participants belonged to other districts. 20% participants were having at least one health professional in family whether it was a near or distant relative. Chronic disease was present in 12% whereas 55% participants had health problems in the past one month. None of the participants ever received any formal education or information to support their caregiving role. Most of (85%) patients

were receiving treatment for advance stage (stage III and IV) cancer.

Table-3 shows that 21% of the caregivers had no burden and 14.7% had heavy burden.

Table-4 shows the scores of MSPSS, that 68% of them had a score of 5.1 to 7 that indicated that they had high support from family and friends.

The mean (SD) of burden was 56.91 (17.35). Similarly, mean (SD) of perceived social support was 64.89 (15.92) and it ranged from 16 to 73. The correlation between burden and perceived social support was calculated with Pearson's correlation and it was found that burden had large negative correlation with perceived social support at 0.01 level of significance ( $r = -0.578^{**}$ ), indicating that as the perceived social support increased, burden levels went down.

Table-5 shows that there was no statistically significant association of burden with socio-demographic characteristics of caregivers like age, gender, marital status, religion, education. However there was statistically significant association with socio-demographic characteristics like occupation, SES, type of family, relationship with the patient, residence and duration of care giving. There was also significant association of burden with unpaid help, health professional in family, presence of chronic disease in caregiver, current health problems of the caregiver in the last month. Patient's diagnosis, stage and type of current treatment had no relationship with burden.

In our study it was seen that the duration of care giving had a significant correlation with burden ( $r = -0.186$ ,  $p = 0.01$ ) whereas amount of care giving had significant, moderately positive correlation with burden ( $r = 0.182^{**}$ ,  $p = 0.01$ ). Hence, it can be concluded that as the duration

and the amount of care giving increased, the burden among caregivers also increased

Table-6 indicated that there was no significant association of perceived social support with socio-demographic characteristics of caregivers age, gender, marital status, religion, education, occupation and relationship with the patient. However there was significant association of perceived social support with family income, type of family and residence, relationship of caregiver and patient and unpaid help, health professional in family, presence of chronic disease, present health problem of caregiver in last month.

### Discussion

Diagnosis of cancer in a family member is by itself a major event. Due to the nature of the disease and its prognosis, it effects not only the patient but also the family and the caregivers. In developing countries the level of the burden is not properly assessed which has led to no intervention under health programmes. The current programmes are designed with more emphasis on curative services and less on preventive and counselling services and even those being focused mainly towards the cancer patients. Also in countries like India, due the societal and cultural construct, the responsibility of taking care automatically falls upon the kin, mostly spouses or children and in some cases friends and neighbors.<sup>11</sup>

The present study highlights the burden among caregivers because of care giving and they should be given the due importance. The findings were similar to a study where they found that most of the caregivers had no to mild burden<sup>4</sup>, and studies conducted outside India showed levels of mild to moderate degree of burden.<sup>12</sup> A case-control study done in Iran among caregivers of

breast cancer showed highest levels of psychosocial burden, contrastingly a no to mild level was found among the caregivers.<sup>13</sup>

These different levels of burden between various countries across the globe could be because of difference in the health care services and family culture. Taking the above observations into consideration, there is a need for interventions, tailor made to reduce the burden among caregivers.

The mean (*SD*) age of caregivers was 40.98 (12.2) years, more or less similar to the studies done in Delhi and South india.<sup>4,13</sup>

However, the age group of caregivers in the western world is on the higher side.<sup>12</sup> In other studies, the age of caregivers was found to be significantly associated with levels of burden and it increased as age advanced.<sup>14,15</sup> unlike the present study. Older caregivers usually find themselves less energetic with health issues of their own. This might cause higher burden among older caregivers. In this study, most of the caregivers were female (58%) similar to most studies. Although, some studies showed male caregivers in a majority.<sup>4,14</sup> But the burden of care giving was felt more by female because women's coping mechanism is not much effective to mitigate the burden. This could be because females have a larger role to play in a family and do multitasking.

In present study, most of the caregivers were married when compared with other studies.<sup>4,12</sup> Married caregivers felt more burdened than others because of the dual responsibility. Few studies showed that unmarried caregivers face excess burden due to lack of support and the lack of their partner to share problems.<sup>16</sup>

In this study, most of the caregivers were employed as in other studies.<sup>4,13</sup> Most of them were the sole earning member in the family. However, burden was more

among the unskilled workers which could be due to additional economic burden. Similar findings were also found in studies conducted by Maheshwari P S, and Unnikrishnan et al.<sup>14,15</sup>

There was significant association of burden with unpaid help, relationship of caregiver with cancer patient, provision of paid help, health professional in family, presence of chronic disease and current health problems of the caregiver which was quite similar to the findings in the other studies.

The present study also highlighted that the burden increased with an increase in the duration of care giving. Similar findings were found in Kahrman F, Millbury et al studies.<sup>15</sup> Few other studies like Ferrel et al<sup>17</sup> and Maheshwari P S<sup>14</sup> reported that as the duration increased, burden decreased. Few studies have found that cancer diagnosis, treatment and stages of disease have influence on caregiver burden which was not found in our study.

In this study, the relationship of caregiver, age, gender and other socio-demographic characteristics of family caregivers had no relationship with perceived social support. Similar findings have been reported stating the same.<sup>4,15,16</sup> In the current study, family income, SES, occupation, type of family had a significant impact on social support. This highlights that as Indian families are bound by some societal rules which invariably provide some form of support to the aggrieved family. The support might be emotional and sometimes also financial. It is of no doubt that family support plays a vital role in helping individuals cope with stressful or worrisome situations.

Results of the study also revealed that there is a significant relationship between burden and perceived social support and caregivers with low perceived social

support have high burden. This is consistent with previous research studies which reported the similar findings. A good understanding and family support evidenced lesser burden.

### **Implications and Recommendations**

The present study highlights the importance of the role of supportive measures that are to be integrated in the management of chronic diseases like cancer in order to decrease the burden among family caregivers. Caregiver assessments should be carried out at regular intervals to detect the psychological and physical impact at the earliest, followed by timely interventions to cater to the needs of the caregiver. Health professionals should be trained in conducting family caregiver assessment and conducting focused group discussions.

Social support networks should be improved at family and community level to help caregivers. They should be encouraged to give more importance to their health and to avail professional help when needed. The caregivers should also be counseled about stress management. They should be encouraged to join caregiver support groups and spare sufficient time for themselves. A regular screening test to assess the caregiver's health might also prove to be beneficial. A longitudinal study may also be conducted on a large sample to note the effects of various supportive interventions that may improve the outcome of care giving.

### **Conclusion**

Strengthening family relationships and supporting their efforts should be done via community based formal and informal support services. Community based support interventions should exist in order to help the caregivers combat with poor social support and high burden. It can provide good social support thus lowering their burden and improving their quality of life. It is also

recommended to have a counselling Centre at all cancer hospitals and public healthcare facilities (those providing cancer related services) for caregivers, which can reduce their psychosocial burden.

An analytical multi-centric study design should be conducted to find out the determinants of psychosocial burden among caregivers of cancer patients over a long term.

### Limitations

The study is limited to a single setting and to the caregivers of cancer patients during the time when the patients were undergoing treatment. These caregivers may not be representatives of the entire family caregiver population. This study was conducted in a hospital setting, hence the results can be generalized to the same population characteristics.

Self-report method was used to collect data in current study. Use of objective methods could strengthen the study. Finally, researcher acknowledges the limitations of cross-sectional design with respect to temporal relationship and imputation of causality of study findings.

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**Tables**

Table 1: socio demographic characteristics of caregivers

|     |       |    |      |
|-----|-------|----|------|
| Age | 15-25 | 36 | 24.0 |
|     | 26-35 | 21 | 38.0 |
|     | 36-45 | 36 | 24.0 |
|     | 46-55 | 15 | 10.0 |

|                |               |     |      |
|----------------|---------------|-----|------|
|                | 56-65         | 5   | 3.3  |
|                | 66-75         | 1   | .7   |
| Gender         | F             | 88  | 58.7 |
|                | M             | 62  | 41.3 |
| Religion       | Christian     | 1   | .7   |
|                | Hindu         | 127 | 84.7 |
|                | Muslim        | 22  | 14.7 |
| Marital status | Married       | 105 | 70.0 |
|                | Unmarried     | 45  | 30.0 |
| Education      | Illiterate    | 15  | 10.0 |
|                | Primary       | 3   | 2.0  |
|                | middle school | 24  | 16.0 |
|                | high school   | 40  | 26.7 |
|                | college       | 31  | 20.7 |
|                | professional  | 37  | 24.7 |
| Occupation     | housewife     | 85  | 56.7 |
|                | unskilled     | 23  | 15.3 |
|                | clerical job  | 8   | 5.3  |
|                | professional  | 31  | 20.7 |
|                | Business      | 3   | 2.0  |
| Family Income  | >10000        | 21  | 6.7  |
|                | 10001- 20000  | 55  | 18.0 |
|                | 20001-30000   | 34  | 15.3 |
|                | 30000-40000   | 40  | 14.0 |
| Type of family | Nuclear       | 82  | 55   |
|                | Joint         | 68  | 45   |
| Residence      | Rural         | 91  | 61   |
|                | Urban         | 59  | 39   |

Table 2: care giving related variables

|                            |         |     |      |
|----------------------------|---------|-----|------|
| Relationship with patient  | Child   | 59  | 39.3 |
|                            | Spouse  | 33  | 22.0 |
|                            | Parent  | 21  | 14.0 |
|                            | Sibling | 37  | 24.7 |
| Duration of care in months | < = 6   | 103 | 68.7 |
|                            | 6- 12   | 25  | 16.7 |
|                            | 12 - 18 | 7   | 4.7  |



|                               |                 |          |     |
|-------------------------------|-----------------|----------|-----|
|                               | 18 – 24         | 3        | 2.0 |
|                               | above 24        | 12       | 8.0 |
| Duration of care in months    | Mean SD         | 8.7      |     |
| Amount of care in hours/ day  | Mean SD         | 12.<br>3 |     |
| Unpaid help                   | No              | 65       | 43  |
|                               | Minimum Help    | 53       | 35  |
|                               | sufficient help | 32       | 21  |
| paid help                     | No              | 126      | 84  |
|                               | Yes             | 24       | 16  |
| distance from hospital        | Local           | 45       | 30  |
|                               | Other district  | 105      | 70  |
| Health problems of care giver | Yes             | 82       | 55  |
|                               | No              | 68       | 45  |
| Type of cancer                | Breast          | 12       | 8   |
|                               | Bone            | 11       | 7   |
|                               | Reproductive    | 22       | 15  |
|                               | G I             | 60       | 40  |
|                               | Others          | 45       | 30  |

|                 |               |     |    |
|-----------------|---------------|-----|----|
| stage of cancer | Initial stage | 23  | 15 |
|                 | advance       | 127 | 85 |
| Treatment       | Chemotherapy  | 52  | 35 |
|                 | radiation     | 57  | 38 |
|                 | combination   | 41  | 27 |

Table 3: Mean ZBI scores of the care givers

| Care burden    | range | n  |      |
|----------------|-------|----|------|
| no care burden | 0-20  | 31 | 20.7 |
| Mild           | 21-40 | 65 | 43.3 |
| Moderate       | 41-60 | 32 | 21.3 |
| Heavy          | 61-88 | 22 | 14.7 |

Table 4: Mean MSPSS scores of the care givers

| social support | Range  | N   |      |
|----------------|--------|-----|------|
| Low            | 1-2.9  | 7   | 4.7  |
| Moderate       | 3....5 | 41  | 27.3 |
| High           | 5.1-7  | 102 | 68.0 |

Table 5: ZBI scale and socio demographic variables

|                |                  | no burden | Mild | Moderate | Heavy | p value |
|----------------|------------------|-----------|------|----------|-------|---------|
| Age groups     | less than 25     | 9         | 15   | 9        | 3     | 0.545   |
|                | 25 to 50         | 21        | 47   | 21       | 19    |         |
|                | > 50 years       | 1         | 3    | 2        | 0     |         |
| Gender         | Male n=          | 15        | 26   | 17       | 4     | 0.61    |
|                | female n=        | 16        | 39   | 15       | 18    |         |
| Marital status | Married          | 19        | 44   | 23       | 19    | 0.246   |
|                | Unmarried        | 12        | 21   | 9        | 3     |         |
| Religion       | Hindu            | 27        | 57   | 29       | 14    | 0.086   |
|                | Muslim           | 4         | 7    | 3        | 8     |         |
| education      | Illiterate       | 2         | 8    | 4        | 1     | 0.04    |
|                | Upto high school | 11        | 24   | 16       | 16    |         |
|                | Graduate         | 18        | 33   | 12       | 5     |         |

|                           |              |    |    |    |    |       |
|---------------------------|--------------|----|----|----|----|-------|
| Relationship with patient | Child        | 14 | 29 | 11 | 5  | 0.008 |
|                           | Spouse       | 10 | 14 | 8  | 1  |       |
|                           | Parent       | 11 | 8  | 4  | 9  |       |
|                           | Sibling      | 5  | 1  | 9  | 7  |       |
| SES                       | Lower        | 4  | 19 | 11 | 13 | 0.001 |
|                           | Middle       | 12 | 29 | 13 | 9  |       |
|                           | Upper        | 15 | 17 | 8  | 0  |       |
| Duration in months        | Less than 6  | 23 | 47 | 26 | 7  | 0.05  |
|                           | 6 to 12      | 6  | 6  | 4  | 9  |       |
|                           | 12 to 24     | 1  | 5  | 0  | 4  |       |
|                           | More than 24 | 1  | 7  | 2  | 2  |       |

Table 6: MDSSP scale and socio demographic variables

|                   |                  | Low | Moderate | High | p value |
|-------------------|------------------|-----|----------|------|---------|
| Age groups        | less than 25     | 1   | 9        | 26   | 0.812   |
|                   | 25 to 50         | 6   | 31       | 71   |         |
|                   | > 50 years       | 0   | 1        | 5    |         |
| Gender            | Male             | 3   | 16       | 43   | 0.939   |
|                   | female           | 4   | 25       | 59   |         |
| Marital status    | married          | 6   | 31       | 68   | 0.372   |
|                   | unmarried        | 1   | 10       | 34   |         |
| Religion          | Hindu            | 4   | 36       | 87   | 0.27    |
|                   | Muslim           | 3   | 5        | 14   |         |
| Education         | illiterate       | 0   | 4        | 11   | 0.843   |
|                   | Upto high school | 3   | 19       | 45   |         |
|                   | graduate         | 4   | 18       | 46   |         |
| Occupation        | unemployed       | 7   | 23       | 55   | 0.578   |
|                   | employed         | 0   | 18       | 47   |         |
| SES               | lower            | 3   | 10       | 34   | 0.05    |
|                   | middle           | 4   | 17       | 42   |         |
|                   | higher           | 0   | 14       | 26   |         |
| type of family    | Nuclear          | 4   | 21       | 57   | 0.001   |
|                   | joint            | 5   | 43       | 20   |         |
| relationship with | child            | 2   | 13       | 44   | 0.374   |

|                  |                   |    |    |    |       |
|------------------|-------------------|----|----|----|-------|
|                  | parent            | 2  | 5  | 14 |       |
|                  | sibling           | 3  | 13 | 21 |       |
|                  | others            | 0  | 10 | 23 |       |
| Residence        | Local             | 2  | 25 | 32 | 0.05  |
|                  | Outside Bangalore | 12 | 37 | 42 |       |
| Duration of care | < 6 months        | 2  | 27 | 74 | 0.245 |
|                  | 6-12 months       | 2  | 8  | 15 |       |
|                  | 12-18 months      | 1  | 2  | 4  |       |
|                  | 18-24 months      | 0  | 0  | 3  |       |
|                  | >24 months        | 2  | 4  | 6  |       |