

Caregiver Burden Amongst Relatives of Terminally Ill Cancer Patients: A Pilot Study

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Abstract

Introduction: Caregiver burden is considered as a "multi-dimensional biophysical reaction resulting from an imbalance of care demands relative to caregiver's personal time, social roles, physical and emotional states, financial resources and formal care resources given the other roles they fulfil. Caregivers usually face multitude of strains, due to varied aspects of life affected by cancer including communication, nursing care, financial concerns and also emotional conflict. It is utmost importance to assess the caregiver burden levels amongst the relatives of cancer patients.

Material and Methods: Questionnaire based prospective study was conducted from January 2019 to May 2020. Descriptive statistics was used for correlation of caregiver burden with clinical and socio-demographic parameters and t-test for comparison of means and p value less than 0.05 was considered as statistically significant. Statistical analysis was done with IBM SPSS Statistics version 24.0.

Observation and Results: We found 50 caregivers with mean age of the 41.54 ± 13.35 years with male (64%) preponderance. Most of the individuals were kins and spouses. Majority had mild to moderate burden (56%). The mean caregiver burden was 33.22 which was significantly correlated with age of caregivers ($p=0.012$). However, statistically significant correlation was seen with caregiver relation to patient ($p=0.036$) and their education ($p=0.059$).

Conclusions: Majority caregivers had mild to moderate burden this implied that they were aware of the responsibility bestowed upon them. However, severe burden seen among children warrant urgent need of attention towards with counselling, interactive session. Proper counselling centers be set up in cancer hospitals and appropriate interventions and support groups be formed to help caregivers.

Keywords: Caregiver Burden; Relatives; Terminally Ill Cancer patients

Introduction

The global cancer burden is being estimated to have risen to 18.1 million new cases and 9.6 million deaths in 2018. Around One in every 5 men and one in every 6 women worldwide develop cancer during their lifetime, and one in every 8 men and one in every 11 women die from the disease. Worldwide,

total number of people who are alive with a cancer diagnosis, and 5-year prevalence, is estimated to be 43.8 million¹. Noncommunicable diseases (NCDs) are now considered responsible for majority of global deaths, and cancer is expected to rank as leading cause of death. Cancer being a condition associated with considerable, continuing and

fluctuating problems and special needs of patients. In our Indian scenario relatives form an important part of informal caregiving. The caregivers need to prepare themselves regarding facing the demands of the new roles and responsibilities at the same time also ensuring providing physical care accompanied with psychological, spiritual and social support to the patient². While adapting to this new role and responsibilities the caregivers are bound to burden themselves with caregiving and themselves land into stressful conditions hampering their physical and mental status. Family caregivers are usually expected to provide complex and multidimensional care in home with little preparation or support. When demands of caregiving roles exceed the caregivers limited resources, they feel overwhelmed and report high stress, leading to more caregiver burden³. Caregiver burden is considered as a "multi-dimensional biophysical reaction resulting from an imbalance of care demands relative to caregiver's personal time, social roles, physical and emotional states, financial resources and formal care resources given the other roles they fulfill⁴. According to Zarit et al caregiver burden is a state resulting from necessary caring tasks or the restrictions causing discomfort for the caregiver⁵. The caregivers usually face a multitude of strains, due to varied aspects of life affected by cancer which includes communication, nursing care, financial concerns and also emotional conflict⁶. In our Indian scenario informal caregiving by family members and relatives is taken upon as a responsibility put upon them by our cultural aspect and upbringing. The family caregivers put forth their entire effort while fulfilling the needs and demands of the patient. This vital role played by them is often well recognized but assessment of caregiving stress over caregivers is often neglected. Caregiver burden is defined as strain or load of distressful consequences associated with caring for a chronically ill family member⁷. Caregiver burden threatens psychological, emotional, functional, and even physical health of caregivers⁸. Usually while caregiving for the patient comes into role Family Adaptability. It is described usually as the family's ability of modifying the family dynamics such as roles and responsibilities as and when needed and to show flexibility for the same.⁹ Family maladaptation however can cause family distress,¹⁰ on the other hand, if flexibility of family and its adaptive function is impaired, the family certainly is unable to respond to wide variety of needs such as caregiver burden¹¹. The family adaptability to the new roles and responsibilities does help in appropriate patient care and support, while also

avoiding the situation of stress on an individual caregiver. Despite of the fact of increasing attention being given to caregivers and families in the cancer literature, some health professionals however still remain unaware of the fact that emphasises on the fact of patients and caregivers having an interdependent relationship, in terms of their quality of life (QoL), and therefore at times fail to address needs of caregivers as a part of the therapeutic strategy^{12,13}. So when vitality of caregiver role has been appreciated at the same time caregiver burden also needs to be assessed. In this study we assessed the caregiver burden amongst terminally ill cancer patients.

Material and methods

Study Design: This was a Questionnaire based observational study for assessing caregiver burden amongst terminally ill cancer patient relatives done from January 2019 to May 2020.

Case Definition: Terminal illness is decline in functional status of patient. It is an advanced stage of a disease with an unfavourable prognosis. Terminally ill cancer patients show evidence of progressive malignancy, and in which therapy cannot realistically be expected to prolong survival significantly¹⁴.

Consent: An Informed consent was taken for the study, explaining them the whole procedure and the aim behind conducting the study. Relatives not giving consent were excluded. A total of 50 patients were included in the study.

Caregiver burden scale adapted from Zetiti SH et al questionnaire based observational study for caregiver burden scale in relatives of terminally ill cancer patients was conducted. Each case was asked to fill a pre-structured proforma regarding general information, standard questionnaire and validated Hindi version questionnaire and relevant information was collected for various scales to be used in study for computing and assessing caregiver burden. Descriptive chi-square statistics was used for the analysis of near death experience in terminally ill cancer patients with p value less than 0.05 considered as statistically significant. Statistical analysis was done with IBM SPSS Statistics version 24.0.

Observations and results

In the present study our aim was to assess the caregiver burden in the relatives of terminally ill cancer patients. For assessing the caregiver burden in the relatives of terminally ill cancer patients

validated Hindi and English format questionnaire was used. Total 50 caregivers were selected randomly who were taking care for terminally ill patients. Amongst 50 caregivers of terminally ill patient admitted over the study duration our department. The mean age of the caregivers was 41.54 ± 13.35 years with male preponderance (Table 1).

Table 1: Age wise distribution of relatives.

Age (relatives)	No. of Frequency	Percentage	Mean \pm SD
15 - 25	08	16 %	22.25 \pm 2.04
26 - 35	11	22 %	31.27 \pm 3.01
36 - 45	09	18 %	41.55 \pm 3.09
46 - 55	14	28 %	48.42 \pm 1.34
56 - 65	07	14 %	62.42 \pm 2.55
>65	01	02 %	66 \pm 0.00
Total	50	100 %	41.54 \pm 13.22

Most of the individuals were in age group of 46-55 years 28% (Figure 1).

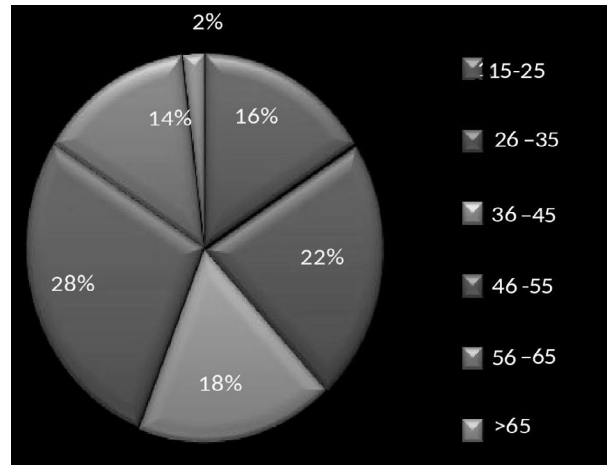


Fig. 1: Distribution based on age.

There were 64% male and 32% female (Figure 2), comprised of kins like children and parents, spouses and other relatives like brother, sister and other relatives. Most of the individuals were kins followed by spouses in majority (Figure 3).

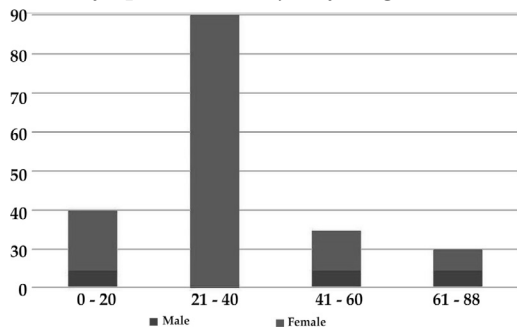


Fig. 2: Distribution based on gender.

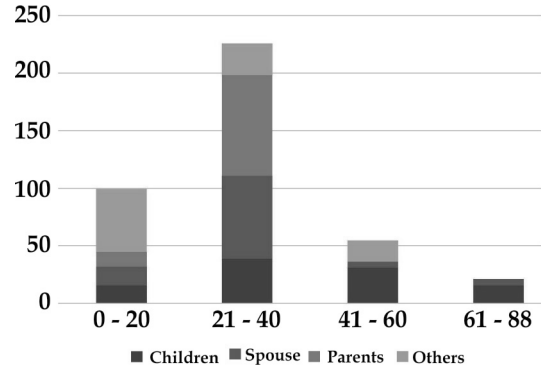


Fig. 3: Distribution based on relation to the patient.

Majority of them were educated, 48% upto high school and 36% above high school and only 16% were illiterate (Figure 4).

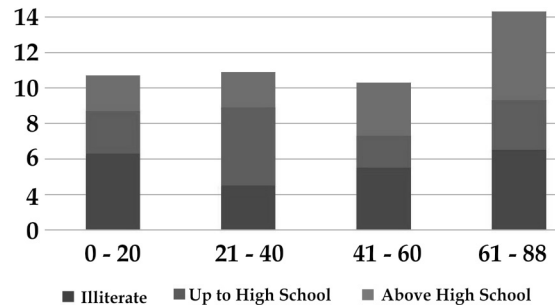


Fig. 4: Distribution based on education.

So, this implied that majority of caregivers were aware of the responsibility bestowed upon them as a result of caregiving. Majority of them were employed (76%) while there were around one-fourth (24%) individuals who were unemployed (Figure 5).

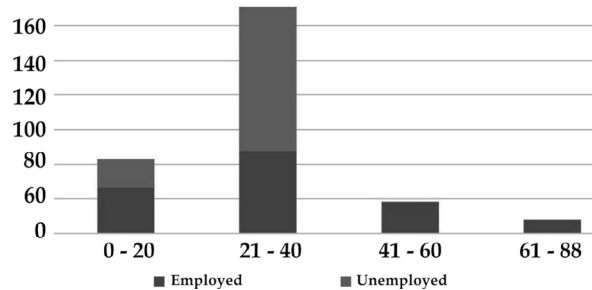


Fig. 5: Distribution based on employment.

The caregiver burden level was divided into four categories. The final scores range from 0 to 88. Further stratified into four categories, that is, score of 0-20 indicates no or minimal burden, 21-40 mild to moderate burden, 41-60 moderate to severe burden and 61-88 indicates severe burden. The majority of the sample population had mild to moderate burden, which was around 56% of the sample. However, there were also 24% population that had little to no burden. Moderate to severe and severe burden was observed in 14% and 6%

population respectively (Table 3) (Figure 6).

Table 3: Distribution of caregiver burden.

S. No.	Score	Interpretation	Total Patients
1	0-20	Little or no burden	12
2	21-40	Mild moderate burden	28
3	41-60	Moderate to Severe burden	7
4	61-88	Severe burden	3
Total			50

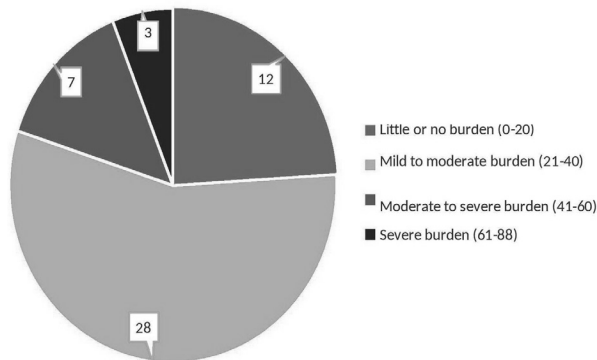


Fig. 6: Caregiver burden distribution.

The mean caregiver burden was 33.22. There was found to be significant association found between age of relatives to the care giver burden levels p value 0.012 (Table 4).

Table 4: Association of age with caregiver burden.

	N	Mean	Standard Deviation	P Value (T Test)
Age	50	41.54 years	13.35 years	0.012
Caregiver burden	50	33.22	15.65	

Also significant association (p value 0.036) was found with the relationship of caregiver to the patient and the level of caregiver burden levels (Table 2) owing to the proximity of the caregiver to the patient and hence the level of stress bestowed upon them as a result of caregiving. There was minimal association found regarding the education level and level of caregiver burden (Table 2) (p value 0.059)

Most of females (66.7%) and males (50%) had mild to moderate burden. Majority of children (38.5%), spouse (72.2%) and parents (87.5%) also had mild to moderate burden while other (54.5%) related people had mostly little or no burden. Mild to moderate burden was predominant among illiterate (75%), educated upto high school (66.7%) and above high school (33.3%). Also similar finding of mild to moderate caregiver burden was observed among majority of ether employed (47.4%) or unemployed

(83.3%) people.

Predominance of mild to moderate burden may be attributed to increasing level of awareness among caregiver, feasibility of communication with treating physician and increasing quality of healthcare standards for severe diseases.

Discussion

With the high ratio of mortality and morbidity, cancer is being taken up as a challenging ailment that is adversely affecting physical and emotional wellness of not only the patients but also their families (Terakye, 2011; Oksuz et al., 2013). As number of people with cancer living their lives as patients demonstrates an upward trend globally, the number of family members who take care of them and live with them rises (Cameron et al., 2002). Owing to the mortality and morbidity of cancer patients and uncertainty of the future of patient because of disease nature the levels of burden on caregivers of cancer patients have been observed to be greater than those of other diseases¹⁵. Evidence based studies have also shown that the caring burden can be related to numerous factors that may negatively impact caregivers in various psychological, physical and social aspects of their lives¹⁵.

This setting of caregiving for cancer patient, brings to notice that burdens of family caregivers may include not only physical and financial tasks but also emotional distress, which caregivers usually tend to neglect their own needs on behalf of the patient¹⁶. Many a times in the process of caregiving the caregivers don't even realise the intensity of the situation and stressful situations they themselves are facing, also they feel it unnecessary at times to share their condition or seek intervention into it. However this practice does affect the mental health of the caregivers and at times they themselves end up landing into conditions like depression, anxiety.

The study population consisted of informal caregivers accompanying the patient. With mean age of 41.54 years and age range from 19 years to 66 years. Most of the individuals were 46-55 years. There was statically significant association between the mean age and mean caregiver burden with a p value of 0.012. Hence it could be put forth that age is an important factor for caregiver burden. Similar to the study by Bhaskaran Unnikrishnan et al 2019; and also study by Ting-Chua et al. 2016, the mean age calculated in our study was almost similar to these studies observation. In the study by Bhaskaran Unnikrishnan et al. 2019, age of the caregiver was observed as a modality associated

with the caregiver burden levels. The observation in our study was also similar with age of the caregiver being a factor guiding levels of caregiver burden. In a separate study by Hiremath et al 2017 there was similar finding of age being a factor for caregiver burden levels. Also in study by Souza et al 2017, age of caregiver was observed as a factor for significance.

We observed male predominance among caregivers with 64% males and 36% females. There was no statistical significance of this gender distribution in our study. In a study by Lukhmana et al 2015, it was brought into observation that female caregivers usually present with higher burden levels. The reason behind this observation was brought up as females play a larger role in the family so they are bound to be more affected with condition of the patient and the need for caregiving the patient usually due to this factor results in them being at higher burden levels. Also female caregivers usually are more emotionally affected by the condition of the patient so they are likely to experience probably higher burden levels of caregiving.

The caregivers were related to the patient either as spouses, kin (comprised of either parents or children of the patient) and others (it comprised of relatives other than the immediate family). The majority of sample comprised of the kins like either the parents or children of the patient for a total of 42% of the study population, this was followed by spouses comprising 36% of sample. There was statistically significant correlation between the relation of caregiver with patient and caregiver burden experienced by them with a p value of 0.036. In a study by Lukhmana et al 2015; the factor of relationship to the patient was found out to be a factor of significance. The reason behind the significance being that the kins or the spouses of the patient are very closely related to the patient. They understand the needs of the patient, and also understand responsibilities of the caregiving. So these individuals are bound to have higher burden levels of caregiving owing to the proximity to the patient.

We also studied literacy level of caregivers as it is an important indicator of understanding among caregivers. Most had education levels up to the high school level and above it. Less than one-fifth of the sample was illiterate. Because the sample had a majority of educated individuals there understanding about the disease and also regarding the needs and better approaches to providing support to the patient is better understood. There was nearly statistically significant association

between the education level and caregiver burden with a p value of 0.059. Also the responsibility bestowed upon them of caregiving is fulfilled in a channelized way without the caregiver taking stress of caregiving upon themselves.

More than three fourth of the study sample was employed and only less than one fourth was unemployed. Employment status of the caregiver lessens the financial burden of caregiving and to there are less chances of caregiver burden regarding the same reason. We could not find statistical significance between the employment and caregiver burden. Though, the coverage with health insurance is low, in our country there are many national programmes and health schemes to support the terminally ill cancer patient and this privilege provides significant psychosocial motivation to caregiver with sense of financial burden and social security. We highly appreciate the scope and initiatives of all such programmes.

The caregiver burden scale being a 5-point scale ranges from 0 upto 88; it mainly assesses five main domains of burden namely health, psychological well-being, finances, social life and relationship with the patient. It was observed that the mean caregiver burden was 33.22.

Most of the study sample observed for little to moderate burden. More than half (56%) of the sample had mild to moderate burden levels. However, 6% of the sample population also depicted severe to very severe burden levels which is a significant number emphasizing the need for caring for the mental status of the caregivers as well. Our findings are similar to Goldstein et al 2004; in their study they found mostly minimal to moderate levels of caregiver burden in most people similar to our study (28/50). Also in a study by Higginson and Gao 2008; these findings were consistent with minimal to moderate caregiver burden most prevalent.

We observed that of cases who had little or no burden most of them were male (28.1%), having relation other (54.5%) than children, spouse or parents with patient, educated upto high school (25%) or illiterate (25%) and employed (26.3%). Cases with mild to moderate burden mostly were females (66.7%), who were parents (87.5%), illiterate (75%) and unemployed (83.3%). We emphasize here illiteracy and unemployment was more prevalent with mild to moderate caregiver burden which may be due to lesser awareness related to outcome of terminal illness, however, as they tend to spend more time with the patient and frequent communication between them might

not create dilemma of burden and worry that is seen in employed cases who tend to spend more time in workplace and have lesser interactions with terminally ill patient. We advise then to find adjusted working hours so as to take care of patient closely and it will decrease the burden of frequent worrisome thought in their mind.

Moderate to severe burden was mostly seen among males (15.6%), children (30.8%), having education above high school (27.8%) and employed (18.4%). While, severe burden was seen mostly in males (6.3%), children (15.4%), educated people above high school (16.7%) and employed (7.9%). Children usually have sensitive thoughts and emotionally attached to parents hence must be having severe burden and also worried about their future socioeconomic security. Hence, we must provide extra attention and psychological support to children.

Further most of the interviewed caregivers were observed to be in concern for the future of their patient. The disease process with its high morbidity and mortality rates and chances of recurrences all these factors led the caregivers to be concerned for the future of the patient. Most of the caregivers were also burdened owing to the fact of their insufficiency of financially being able to provide the best possible treatment and support to their patients. This factor led to a point of concern in majority of them and leading to a stressful situation for the caregiver.

Also many of the individuals concerned and were burdened owing to the fact of them not being able to do sufficient and support the patient to the best of the possible ways. Few individuals also felt that their patient was completely dependent on them adding to the burden over them, there was also a feeling of the patient expecting more of the support which the individual is not able to fulfil adding up the burden of caregiving among them. Some also experienced the need for not being able to get enough time for their own needs to be fulfilled leading to a state of stress among the caregivers.

Conclusions

The cancer diagnosis and its treatment process not only affects the patient but also affects the caregiver of the patient. Usually the vital role of caregivers is appreciated and taken into notice, however need for assessing their burden or stress level is often not looked into. The caregivers during the time of caregiving for the patient not only go through financial and physical stress but a real somentally

stressed. So assessing the caregivers burden is also of importance. In our study we assessed for the caregiver burden amongst relatives of terminally ill cancer patients. Minimal to moderate level of burden was found amongst the caregivers.

The caregivers were mostly concerned regarding the future of the patients and for not being able to provide the maximum effort to providing the best possible support for the patient. Also some of them did agreed to the feeling of their patient completely being dependent on them and hence also expecting too much from the caregivers. This again burdened the caregivers because of them not being able to fulfil all these needs of the patient. Higher burden levels were found in the children and spouses of the patient because of their proximity to the patient. In accordance with the treatment process of the cancer patient there is need to also look into mental stress of the caregivers and also it needs to be assessed and intervened timely.

Also Proper counselling centers be set up in cancer hospitals and appropriate interventions and support groups be formed to help caregivers cope and deal with wretched multifaceted burden. In Indian society where family forms backbone of support system, caregiver receiving little attention, this issue should be extensively addressed by clinicians and public health physician.

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