

# Caregiver Burden and Quality of Life among Family Caregivers of Cancer Patients on Chemotherapy: A Prospective Observational Study

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## Abstract

**Aim:** Informal caregivers of cancer patients have extensive burdens. They are susceptible for deterioration of their quality of life (QOL). We aimed to assess caregiver burden and QOL of family caregivers of cancer patients receiving chemotherapy admitted in the ward/intensive care unit/high-dependency unit. **Materials and Methods:** This prospective observational study including 178 caregivers was carried out in a tertiary care hospital. The assessment of caregiving burden was done using the Zarit Burden Interview and its impact on QOL using the WHO BREF QOL questionnaire. **Results:** The mean age and mean Zarit Burden score of caregivers were  $38.98 \pm 10.53$  and  $30.697 \pm 8.96$ , respectively. Of the total, 70.22% of caregivers reported mild-to-moderate burden and 21.38% reported moderate-to-severe burden. On assessment of QOL WHO BREF, the mean general score was  $5.79 \pm 1.84$ , physical health score was  $49.65 \pm 16.07$ , psychological health  $51.85 \pm 20.43$ , social relations  $59.38 \pm 21.43$ , and environmental  $58.73 \pm 17.51$ . The QOL scores were slightly better in mild-to-moderate burden compared to moderate-to-severe burden but not statistically significant except for social relations ( $P = 0.053$ ). We did not find any difference in burden scores or QOL between male and female caregivers. **Conclusion:** Mild-to-moderate burden was seen in 70.22% of caregivers and 21.38% had moderate-to-severe burden.

**Keywords:** Cancer, caregiving burden, family caregiver

## INTRODUCTION

Cancer is growing as a major cause of morbidity and mortality in the present time across the world including India. Chemotherapy regimens used for cancer treatment are immensely complex, and cancer patients are a susceptible population with little tolerance.<sup>[1]</sup> Patients who are highly symptomatic either due to cancer or due to side effects of chemotherapy need more constant and increased duration of caregiving time as compared to those with mild symptoms. Hence, caregivers taking care of highly symptomatic cancer patients are more prone to psychological, physical, financial, and social reactions. The caregiver burden increases even further if they themselves are underprivileged with limited resources and/or are in poor health.<sup>[2]</sup>

Caregivers of cancer patients are at risk of impairment of their quality of life (QOL) due to the caregiving burden. The

conditions predisposing the caregiver to an adverse outcome include poor physical health, inadequate social support, poor patient functionality, and patient's cognitive impairment.<sup>[3-5]</sup> In accretion, it has been seen that the caregivers' burden tends to accumulate and increases over time.<sup>[6]</sup> Subjective burden arising from caregiving mainly affects the mental health and is responsible for caregiver-related disruptions to the QOL. It has been found to be a major stressor affecting psychological health and causing depressive symptoms in caregivers.<sup>[7]</sup> Caregivers' symptom burden is increased in caregivers with preexisting

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comorbidities, young age, close relation to the patient, and higher level of education.

Caregivers are essential for the patients' recovery in daycare, inpatient, or in critically ill setup because they communicate well with the patient and the treating team, understand the patients' feelings, and motivate the patients in their struggle to survive critical illness. Hence, their health both physical and mental is of equal concern to us.

## MATERIALS AND METHODS

This prospective observational study was conducted in a tertiary care hospital after due permission from the institutional ethical committee. Informal caregivers of cancer patients receiving chemotherapy, 18–65 years of both sexes willing to participate in the study were assessed for the caregiving burden and impact on their QOL. The caregivers with inability to fill the questionnaires were excluded from the study. The assessment of caregivers' burden in cancer patients was done using the Zarit Burden Interview (ZBI) and WHO-QOL BREF questionnaire. A total of 178 caregivers were asked to fill the questionnaires for finding out the caregiving burden and its impact on their QOL. Apart from the questionnaire, demographic details of the patients and caregivers were obtained. Other information such as diagnosis, educational, and employment status of both patient and caregiver was also noted. The need for any respiratory support, inotropic support, hepatic derangement, and need for dialysis were also taken into account.

### Statistics

The patients who received chemotherapy on an inpatient basis were included in the study. The initial sample size of 187 was calculated based on a previous study<sup>[8]</sup> with caregiver burden of 63%, relative precision 10% using nMaster 2.0 developed by Biostatistics Resource and Training Centre, Department of Biostatistics, Christian Medical College, Vellore, India. However, due to incomplete information provided in the questionnaire, 22 caregivers were excluded. Thus, a total of 178 caregivers were included in the study. Categorical variables were expressed as frequency and percentage. Kruskal–Wallis and Mann–Whitney tests were used for quantitative analysis and Chi-square and Fisher exact tests for categorical variables.

## RESULTS

The age distribution of patients whose caregivers were included in the study was mainly above the age of 15 years. Only 15.17% were pediatric patients. The patients recruited had an equal male-to-female ratio with 48.31% females and 51.69% males. Only 23.03% of patients were employed, whereas 55.62% were educated above the 10<sup>th</sup> standard. Two-third of patients recruited were married with only 33.15% being unmarried, whereas majority of caregivers were married (88.20%). About 19.5% of caregivers were parents, 34.8% were spouse, 17.3% were siblings, and 28.4% were children. Other comorbidities were seen in 20.79% of patients, whereas 13.48% of caregivers had some illness. Of the patients

recruited on chemotherapy, 67.42% had metastatic disease. All patients had received chemotherapy as part of therapy with 44.94% having received surgery and 15.73% radiotherapy as part of treatment during the entire disease course. A total of 25.28% of patients needed some form of respiratory support ranging from facemask, noninvasive ventilation, and invasive ventilation. Other critical care supportive measures required such as inotropic support (11.8%), dialysis (2.81%), and hepatic derangement (5.06%). A total of 53.93% of caregivers were in the age range from 18 to 40 years and 43.82% from 40 to 60 years and only 2.25% were elderly. There were 53.37% female caregivers and 46.63% male caregivers. However, the difference was not significant. There were 76.40% of caregivers were literate with only 41.57% working [Table 1].

The mean Zarit Burden Score of caregivers was  $30.697 \pm 8.96$ . Of the total, 70.22% of caregivers reported mild-to-moderate burden, but 21.38% reported moderate-to-severe burden with 8.43% having minimal burden [Table 2].

We studied the effects on the QOL of the caregivers, while QOL WHO BREF mean general score was  $5.79 \pm 1.84$ , physical health score was  $49.65 \pm 16.07$ , psychological health  $51.85 \pm 20.43$ , social relations  $59.38 \pm 21.43$ , and environmental  $58.73 \pm 17.51$ .

The difference in the male and female caregivers in moderate-to-severe burden was significant,  $P = 0.005$ . The unemployed caregivers were significantly more in moderate-to-severe burden group as compared to employed caregivers.  $P = 0.013$  [Table 3].

There is no significant difference in the level of burden based on marital status, education level, and caregiver age group. There was no significant difference in the burden depending on the type of relationship of the caregiver with the patient.

**Table 1: Demographic characteristics of the patients and their caregivers**

Characteristics	Patient	Caregiver
Mean age $\pm$ SD	37.67 $\pm$ 18.55	38.98 $\pm$ 10.53
Duration of illness	13.426 (11.38)	-
Education (above matric) (%)	55.62	76.40
Married (%)	66.85	88.20
Employed (%)	23.03	41.57
Gender (%)		
Male	51.69	46.63
Female	48.31	53.37
Comorbidities (%)	20.79	13.48

SD: Standard deviation

**Table 2: Burden in caregivers on Zarit Burden Interview**

Level of burden	n (%)
Minimal	15 (8.43)
Mild to moderate	125 (70.22)
Moderate to severe	38 (21.35)

The WHO QOL physical health, psychological health, social relations, and environment were comparable across the minimal, mild-to-moderate, and moderate-to-severe burden groups [Table 4].

## DISCUSSION

Informal caregivers of cancer patients have extensive burdens due to the morbidity associated with the disease and side effects of chemotherapeutic drugs. The burden also adds with the need for multiple hospital visits, inpatient admissions, and need for assistance at home when caring for symptomatic patients. There is adverse effect on their physical, psychosocial, and emotional well-being of the caregiver. This also has a bearing on their mental health, QOL, occupation, and financial condition.

In our study, a total of 178 caregivers were included, of which 53.37% were female and 46.63% caregivers being males. Majority of caregivers in the present study were either spouses or children with one-third being either parents or siblings. We did not see a significant difference in the burden depending on the type of relationship. The burden and its psychological outcome can be variable depending on the disease stage, caregivers' social support, and duration of illness. Moreover, Huang *et al.* suggested that longer duration of caregiving may have fewer symptoms of distress because of the time they get to adjust the caregiving role to their goals.<sup>[9]</sup> Hence, although there have been previous reports suggesting higher caregiver burden in spouse, it seems more like an interplay of various factors that determine the burden and its effect on QOL.

Of the caregivers included in our study, only 8.43% reported minimal burden. About 70.22% of caregivers reported mild-to-moderate burden and 21.38% reported moderate-to-severe burden. This correlates with the study done in Iranian caregivers where a significant percentage (48.1%) of caregivers reported high burden. Mirsoleymani *et al.*<sup>[10]</sup> conducted this study in cancer patients referred to the outpatient chemotherapy wards, using the caregiver burden

inventory. In contrast, Likhmana *et al.*<sup>[11]</sup> in their study also used ZBI, but in outpatient cancer patient caregivers which suggested that 56.5% of family caregivers had no or minimal burden due to caregiving and 43.5% had burden varying from mild to moderate to severe while caring for cancer patients.

The mean Zarit Burden Score of caregivers in our study was  $30.697 \pm 8.96$ . The results of our study are similar to that of Harding *et al.*<sup>[12]</sup> who also reported lower burden using ZBI in caregivers of cancer patients with mean 23.3. This was lower than that of caregivers of patients with dementia and acquired brain injury seen in their study. The caregivers were pooled from multicenter evaluation of palliative daycare for advanced cancer patients, evaluation of a supportive intervention group for the caregivers of palliative care patients with advanced cancer.

The present study included a small percent of inpatients who were critically ill. Of the total inpatients, only 25.28% of patients were on respiratory support ranging from facemask to noninvasive ventilation to invasive ventilation in few. About 11.8% needed inotropic support, 2.81% dialysis, and 5.06% had hepatic derangement. Since they contributed to a smaller population of the total, our study is not a true representation of burden in critically ill.

Cameron *et al.*<sup>[13]</sup> in 2016 studied critically ill patients' caregivers and reported that a high percentage had depressive symptoms. A total of 67% of caregivers reported depressed mood on initial assessment and 43% on follow-up at the end of 1 year. Beusekom *et al.*<sup>[14]</sup> reviewed 28 studies and reported that psychological burden was the most common burden in caregivers of intensive care unit (ICU) survivors. The other prevalent symptoms reported by informal caregivers were anxiety (15%–24%), depression (4.7%–36.4%), and posttraumatic stress disorder (35%–57.1%) even after 6 months of ICU discharge.<sup>[14]</sup>

The QOL scores did not show much difference in the minimal to mild/moderate to moderate/severe burden group in respect to physical health. The psychological, social, and

**Table 3: Relation of caregiver burden to caregiver occupation and patient gender**

Level of burden	Male caregiver	Female caregiver	Unemployed	Employed
Minimal	9	6	9	6
Mild to moderate	65	60	65	60
Moderate to severe	9	29	30	8
<i>P</i> value for moderate-to-severe burden group		0.005		0.013

**Table 4: WHO quality of life of caregivers in relation to their burden**

WHO QOL score	Minimal burden	Mild-to-moderate burden	Moderate-to-severe burden
Physical health	47.73±14.13	50.53±16.52	47.53±15.35
Psychological health	57.2±19.79	52.87±20.65	46.42±19.33
Social relations	59.93±16.44	61.37±21.52	52.66±21.98
Environment health	56.8±20.09	59.93±17.58	55.55±16.14

QOL: Quality of life

environment showed a slight decrease in the QOL scales from mild-to-moderate to moderate-to-severe burden group. This difference was, however, not significant.

Khan *et al.*<sup>[15]</sup> studied QOL, spirituality, and social support among caregivers of cancer patients. Physical well-being on the WHO QOL scale was comparable between caregivers and the control group (who were noncaregivers from the general population). Psychological well-being, social relationships, and environment showed a significant difference between caregivers and the control group.

Caregivers of cancer patients spend a lot of time taking care of their relatives and go through a lot of stress. However, in our study, most caregivers only reported a mild-to-moderate burden only. This could be attributed to the type of family set up that Indians live in. A good social support is an important predictor of better physical and mental health of the caregiver.<sup>[16]</sup>

The concept of joint family that is prevalent in many parts of India is known for providing its members with a good social and economic support. It also compensates for its members during the time of illness or any crisis and has the capacity to tolerate any deviant behavior.

Leff *et al.*<sup>[17]</sup> studied the caregivers of mentally ill patients and observed that joint families help in dispersion of the caregiving burden and also have a substantial role in predicting good outcome and course of mental disorders.

It has been suggested in some studies that the use of problem-oriented coping strategy along with a good social support in the Indian setup is useful in predicting a better caregiving experience.<sup>[18]</sup>

The burden in our study was mainly mild to moderate in spite of the increased disease burden suggesting that it is because of the Indian family setup that caregivers support each other in the time of crisis and assume roles to compensate for the ill member of the family. This is supported by the studies mentioned above most of which have, however, been done in the field of psychiatry.

The few limitations of the present study were inability to assess the economic burden by the scales used in the present study. Furthermore, the inpatient population recruited was not uniform in terms of patient symptoms and duration of illness. Hence, this heterogeneity could not help us analyze the real burden in the population who was critically ill as it was only 25% of the total study participants. Another factor which might have limited the results is the small study group based on a single center which might not be a true representation of the population.

## CONCLUSION

There was mild-to-moderate caregiver burden in 70.22% of caregivers and 21.38% had moderate-to-severe caregiver burden. The QOL scale (WHOQOL) was comparable between

mild-to-moderate and moderate-to-severe caregiver burden group. Indian family setup acts as a support system leading to better caregiver mental and social health.

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## Conflicts of interest

There are no conflicts of interest.

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