

Quality of Life and Functional Status in Advanced Cancer Patients and its Association with Caregiver Burden: A Cross-sectional Study

ARTH JAYESHKUMAR SHAH¹, NIMESHKUMAR HIMMATBHAI PATEL², BHALENDU SURYAKANT VAISHNAV³, AJAY GAJANAN PHATAK⁴, DINESH KUMAR⁵, NIRAV NIRANJAN ASARAWALA⁶, ALPABEN NIMESHKUMAR PATEL⁷



ABSTRACT

Introduction: The incidence of cancer is likely to increase from 1.46 million in 2022 to 1.57 million in 2025 in India. Majority of the cancer patients are diagnosed at the locally advanced stage. Symptoms experienced by patients are multi-dimensional and not only impacts patients' Quality of Life (QoL) and function but also increase caregiver burden. There is scarcity of evidence encompassing the intricate relationship between QoL, Functional status, symptoms and its association with caregivers' burden.

Aim: To assess the symptom burden, performance status and QoL among patients suffering from advanced malignancy and its correlation with caregivers' burden.

Materials and Methods: The present cross-sectional survey was conducted at Cancer Centre of Shree Krishna Hospital, a rural Tertiary Care Teaching Hospital between December 2018 and August 2020. All or simultaneous non-oncological critical illness were excluded. Detailed history and primary oncological diagnosis with staging were noted. Questionnaires viz. Edmonton symptom assessment system, EORTC QLQ-C30, Karnofsky Performance status, Zarit Burden Interview (ZBI) and Caregivers Strain Index (CSI) were administered by the investigator. Descriptive statistics, Analysis of Variance and correlation coefficient were employed to explore participant's

profile and association of patient characteristics with QoL and caregivers' burden as well as their interactions. STATA (14.1) was used for the analysis. A p-value of less than 0.05 was considered statistically significant.

Results: Out of 138 eligible patients, 125 (90.6%) participated. Majority of the participants were from age group 41-60 {72 (57.6%)}, had stage 4 disease {93 (74.4%)} and suffered from Head and Neck or breast cancer {71 (56.8%)}. The mean (SD) QoL summary score was significantly higher in patients experiencing up to 3 symptoms as compared to those experiencing 4 or more {82.29 (10.49) vs. 65.41 (11.50), $p < 0.001^{**}$ }. The domains, global health status and financial difficulties and symptoms viz. fatigue, appetite loss and pain hampered the QoL. The mean (SD) Caregivers Strain Index (CSI), Zarit score and QoL summary score were 5.49 (3.00), 27.63 (12.75) and 77.1 (13.3), respectively. The CSI and Zarit score correlated significantly { $r = 0.69$, $p < 0.001^{**}$ }. The CSI score showed significant negative correlation with Quality-of-life summary score { $r = -0.29$, $p = 0.01^{*}$ }.

Conclusion: Despite advanced cancer staging, most patients remained functionally independent. QoL in advanced cancer patients was found inversely related with symptom burden and early palliative care may reduce caregiver burden.

Keywords: Health status, Neoplasm, Palliative care, Tertiary care centres

INTRODUCTION

In India, the incidence of cancer cases is projected to increase from 1.46 million in 2022 to 1.57 million in 2025. The national average crude incidence rate for 2022 was 100.4 (95.6% for males and 105.4% for females). Lung (10.6%) and head and neck cancers (mouth 8.4%, tongue 5.9%, larynx 4%) are the leading sites among men, while breast (28.8%) and cervix (10.6%) are the most common among women [1]. In India, the majority of patients with common cancers, such as breast (57.0%), cervix uteri (60.0%), head and neck (66.6%), and stomach (50.8%), are diagnosed at a locally advanced stage. Furthermore, distant metastasis is predominant in lung cancer among both males (44.0%) and females (47.6%) [2].

Thus, approximately 50% of patients have advanced cancer at the time of diagnosis, with many more progressing to advanced stages during treatment. With the increasing cancer incidence and more patients undergoing treatment, both disease-related and treatment-associated morbidity are on the rise. A random-effects model found the pooled estimate of palliative care needs to be 6.21 per 1000 population (95% CI: 2.42-11.64), with a higher need among female patients [3]. As cancer is a chronic, and sometimes incurable, disease, the caregivers of patients also suffer from a considerable

psychological burden. The symptoms experienced by patients are multidimensional, and they not only impact the patient's QoL and function but also increase the caregiver burden [4].

While many studies in India have focused on symptom burden or QoL in patients or caregiver burden in relatives [5-9], very few have examined the correlation between the patient's symptom burden, functional status, and QoL with their caregiver's burden in advanced stages of cancer [10]. This highlights the need for early palliative care for these patients, which in turn can help reduce the burden on their caregivers.

Therefore, the aim of the present study was to assess the symptom burden, performance status, and QoL among patients with advanced malignancy and to examine their correlation with the burden on their caregivers.

MATERIALS AND METHODS

The present cross-sectional study was conducted at MS Patel Cancer Centre attached to a Rural Tertiary Care Teaching Hospital viz., Shree Krishna Hospital in Central Gujarat, India, between December 2018 and August 2020, with consecutive sampling of 125 patients. Informed consent was obtained from all patients and

caregivers and patient information sheet was provided to each patient in vernacular language (Gujarati). The Institutional Ethics Committee approve the study vide letter no. IEC/HMPCMCE/105/Faculty/4/121/19.

Sample size calculation: The main aim was to find association between caregiver's burden and QoL summary score using Karl Pearson's correlation coefficient. Correlation coefficient of 0.25 and above was considered clinically important (so that variability in QoL explains at least 6 % variability in caregiver's burden). For estimating the correlation coefficient of 0.25, a sample of size 123 was required to achieve 80% power and allowing for 5% Type I error.

Inclusion and Exclusion criteria: All patients aged above 18 and having stage IV cancer who were receiving treatment at the study site were included in study. Patients who had multiple cancers or simultaneous non oncological critical illness requiring admissions in Intensive Care Units (ICUs) were excluded.

Study Procedure

Demographic information including age, gender, site and stage of cancer, any presenting symptoms, vitals, systemic examination, co-morbidities, significant past history, significant family history, treatment details and primary oncological diagnosis with staging was noted. The staging was done by Senior Oncologist using standard Tumour Node Metastasis (TNM) classification.

EORTC QLQ C-30, Edmonton Symptoms Assessment System (ESAS) and Karnofsky Functional Assessment Scale (KPS) were used to assess the QoL, Symptoms experienced and functional status of the patients. Caregiver strain index CSI and ZBI were used to access caregivers' burden.

Edmonton Symptoms Assessment System (ESAS); developed by Bruera E et al., is a simple ten-point visual analog scale to assess severity of symptoms in cancer patients [11]. It allows for simple, rapid and pragmatic assessment of multiple patient reported symptoms at the same time. It is one of the first quantitative symptom assessment batteries and also is psychometrically validated by multiple groups. That includes nine symptoms for which patients had to score from 0 to 10 as per the severity of each of the symptom. Zero meaning that the symptom is absent and 10 that it is of the worst possible severity. The patient and the caregiver are taught how to complete the scales [11]. The original scale was translated to Gujarati and then back-translated to English by two independent cancer physicians conversant with both the languages. The back-translation and the original questionnaire was compared and consensually validated (for translation quality) by three cancer specialists. A score of more than four was considered significant for that particular symptom whereas patients suffering from four or more significant symptoms were considered to have significant symptom burden.

The EORTC QLQ-C30 is a widely used, 30-item questionnaire developed by the European Organisation for Research and Treatment of Cancer (EORTC) to assess the QoL of cancer patients [12]. It covers various aspects of their well-being, including physical, emotional, and social functioning, as well as symptoms and global health status. The QLQ-C30 includes: Five Functional scales: Physical, role, cognitive, emotional, and social functioning. Nine Symptom Scales: Fatigue, pain, nausea/vomiting, dyspnoea, sleep disturbances, appetite loss, diarrhoea, constipation, financial difficulties and Global Health Status/ QoL Scale- measures the overall impact of cancer on the patient's well-being. It is an integrated system designed to assess QoL of cancer patients. Scoring, interpretation and analysis of QLQ C 30 is very complicated. It is streamlined with the scoring manual, which explains how exactly to calculate the raw QLQ C 30 scores and how it can be transformed to scores ranging from 0 to 100 [13].

Functional scales reflect high levels of functioning, while symptom scales/single items indicate higher levels of symptomatology. A high score on the Global Health Status/QoL scale represents a high-

perceived QoL. For the symptom scales, the scores need to be reversed to create a consistent direction across all scales. This is done by subtracting the score from 100. Higher scores indicate better HRQoL [13].

Patient assessment process was supplemented with help of Karnofsky Performance Status (KPS) to record the functional status of the patient along with his QoL and palliative care symptoms [14]. Patient's functional status is described as a comprehensive 11-point scale correlating to percentage values ranging from 100% (no evidence of disease, no symptoms) to 0% (death). Moreover, it plays an independent role in treatment modality decisions and works as a salient prognostic factor in a variety of tumour entities. In most serious stages of the diseases, lower score predicts the worse the likelihood of survival. The percentages of the KPS describe three states (conditions):

A (100-80%) - Able to carry on normal activity and to work; no special care needed.

B (70-50%)- Unable to work; able to live at home and care for most personal needs; varying amount of assistance needed.

C (40-0%)- Unable to care for self; requires equivalent of institutional or hospital care; disease may be progressing rapidly.

Karnofsky scale was administered by the clinician using a standard Gujarati translation by an expert and consensually validated.

ZBI is a simple 5-point likert scale tool to assess caregivers' burden [15] it consists of 22 questions for which the caregivers had to answer from a scale of 0 (Never) to 4 (Nearly Always).

- 0: Never

- 1: Rarely

- 2: Sometimes

- 3: Quite frequently

- 4: Nearly always.

Higher scores indicate greater burden Interpretation of score is done as below:

- 0 - 20: Little or no burden

- 21 - 40: Mild to moderate burden

- 41 - 60: Moderate to severe burden

- 61 - 88: Severe burden

A validated version of ZBI in Gujarati is available and it was administered after written permission to use it.

Caregiver Strain Index (CSI) assesses the strain perceived by the caregiver objectively [16]. The CSI is a tool that can quickly identify families with caregiving concerns. It is a twelve-question tool measuring strain related to care provision on caregiver. There is at least one question for each of the following major domains: Employment, Financial, Physical, Social, Time. The caregiver has to answer a set of twelve questions in either yes or no. Seven or more positive responses indicate a higher level of strain. Irrespective of age, any individuals who has taken upon himself to care for an older adult can be assessed by this instrument. Being a simple binary response scale, it was translated to Gujarati, back-translated to English and the contextual quality of translation was consensually validated.

STATISTICAL ANALYSIS

Data was captured on hard copy and entered into Microsoft Excel sheet. Descriptive statistics {Mean (SD), Frequency (%) etc.,} was used to present sociodemographic and clinical profile of the participants, QoL, functional status as well as caregiver's burden. Analysis of Variance was performed to assess QoL across sociodemographic variables. Karl Pearson's correlation coefficient was used to measure association between QoL and caregiver's burden. Analysis was performed using STATA version 14.2. A p-value of less than 0.05 was considered statistically significant.

RESULTS

A total of 138 eligible patients visited the cancer centre during the study period. Seven patients could not be contacted by the investigator due to late communication by the front desk operators. Out of 131 patients contacted, six patients refused to participate mainly due to time constraint. Thus, 125 (90.58%) of the eligible patients participated in the study. The Mean (SD) age of the participants was 50.75 (12.13) years.

Majority of the participants were from age group 41-60 {72 (57.6 %)}, had stage 4 disease {93 (74.4%)} and suffered from head and Neck {47 (37.6%)} or breast cancer {24 (19.2 %)}. The gender distribution of the participants was similar. About 10% participants had co-morbidities viz., hypertension, diabetes or both. No participant had known history of previous malignancy and two participants had family history of malignancy [Table/Fig-1].

Parameters	Frequency (%)
Age (in years)	
≤40	28 (22.4)
41-60	72 (57.6)
61-70	25 (20.0)
Sex	
Male	67 (53.6)
Female	58 (46.4)
Site of cancer	
Head & neck	47 (37.6)
Breast	24 (19.2)
GI tract	16 (12.8)
Lung	15 (12)
Others	23 (18.4)
Stage	
4	93 (74.4)
4A	22 (17.6)
4B	10 (8.0)
Co-morbidities	
Hypertension	6 (4.8)
Diabetes	1 (0.8)
Both	5 (4.0)
Family history (Yes)	2 (1.6)

[Table/Fig-1]: Demographic profile of the study participants (n=125).

Tiredness (40.8 %) followed by pain (38.4 %) were the two most common symptoms observed in both the genders, thus making these symptoms most prevalent regardless of gender and cancer type. The authors found that females had higher prevalence of symptoms such as pain, tiredness, depression, anxiety whereas there was no gender differences observed for other symptoms [Table/Fig-2].

Overall, 38 (30.4%) patients experienced significant symptom burden (i.e., 4 or more symptoms with symptom scores of greater than 4).

The mean (SD) QoL score was 77.1 (13.3). The domains Global health status and financial difficulties hampered the QoL the most. Similarly, the symptoms viz., Fatigue, appetite loss and pain predominantly hampered the QoL [Table/Fig-3].

The mean (SD) QoL summary score was significantly greater in males as compared to females {81.17 (11.67) vs 72.52 (13.61), $p < 0.001^{**}$ }.

However, the Mean (SD) QoL score was similar across stages 4, 4A and 4B {75.63 (13.86) vs 82.47 (11.74) vs 79.58 (6.75), $p = 0.08$ } as well as age groups 0-40, 41-60 and 61 and above {79.73 (12.65) vs 76.51 (13.23) vs 76.14 (14.27, $p = 0.51$ }.

ESAS Components	Mean (SD)	Frequency (%) of patients with Significant Burden for particular symptom (score>4)		
		Male (N=67)	Female (N=58)	Overall
Pain	3.82 (2.6)	18 (26.87)	30 (51.72)	48 (38.4)
Tiredness	3.87 (2.73)	20 (29.85)	31 (53.45)	51 (40.8)
Nausea	1.38 (1.93)	2 (2.99)	8 (13.79)	10 (8)
Depression	3.39 (2.68)	12 (17.91)	27 (46.55)	39 (31.2)
Anxiety	3.36 (2.82)	14 (20.9)	26 (44.83)	40 (32)
Drowsiness	1.73 (2.33)	8 (11.94)	9 (15.52)	17 (13.6)
Lack of appetite	3.2 (2.74)	18 (26.87)	19 (32.76)	37 (29.6)
Wellbeing	3.42 (2.14)	17 (25.37)	23 (39.66)	40 (32)
Shortness of breath	0.9 (1.84)	3 (4.48)	5 (8.62)	8 (6.4)
Others	0.46 (1.77)	5 (7.46)	0 (0)	5 (4)

[Table/Fig-2]: Burden of various symptoms among study participants as assessed by Edmonton Symptom Assessment Scale (ESAS).

Variables	Mean (SD)	Median (Range)
Global health status	54.2 (22.3)	50 (0,100)
Physical functioning	69.68 (22.7)	73.33 (33.33,100)
Role functioning	84.8 (17.2)	83.33 (33.33,100)
Emotional functioning	66.8 (25.8)	75 (8.33,100)
Cognitive functioning	84.67 (16.5)	83.33 (33.33,100)
Social functioning	74.4 (17.4)	66.67 (33.33,100)
Symptoms		
Fatigue	43.73 (24.9)	33.33 (0,100)
Nausea and vomiting	7.87 (15.7)	0 (0,100)
Pain	29.2 (22.5)	16.6 (0, 83.33)
Dyspnoea	8.53 (20.2)	0 (0,100)
Insomnia	26.4 (31.2)	33.33 (0,100)
Appetite loss	30.4 (29.3)	33.33 (0,100)
Constipation	24.8 (30.8)	0 (0,100)
Diarrhea	6.4 (16.2)	0 (0,100)
Financial difficulties	50.6 (25.2)	66.67 (0,100)
Summary Score	77.1 (13.3)	77.7 (38.9, 100)

[Table/Fig-3]: Distribution of Mean(SD) scores of various domains of QoL among the study participants based on EORTC-QLQ-30 scores.

Edmonton symptom assessment revealed that tiredness, pain, wellbeing and depression pose significant burden. This finding closely corroborates with symptoms assessed through quality-of-life questionnaire, with a caveat that QoL focused more on physical symptoms [Table/Fig-2,3].

A clear pattern emerged between number of symptoms with significant burden and summary score of QoL. In general, the mean (SD) QoL summary score was significantly higher in patients experiencing up to three symptoms with significant burden as compared to patients experiencing 4 or more {82.29 (10.49) vs. 65.41 (11.50), $p < 0.001^{**}$ }. It is noteworthy that the mean (SD) QoL score was impressive for patients experiencing up to three symptoms with significant burden [Table/Fig-4].

The {Mean(SD), Median (Q1, Q3)} KPS was {71.36 (10.03), 70.0 (60,80)}. The KPS was in concordance with mean QoL summary

Number of symptoms	Number of patients	Percentage	EORTC QLQ-30 summary score
None	32	25.60	89.05 (7.82)
One	26	20.80	82.67 (9.13)
Two	17	13.60	75.45 (9.17)
Three	12	9.60	73.08 (8.82)
Four Or more	38	30.40	65.41 (11.50)

[Table/Fig-4]: Table depicting trend in QoL (based on EORTC QLQ-30) and number of symptoms as per ESAS among study participants.

score. As the functional status improves (from 50-90%), the QoL summary score also improves organically. This also explains better overall QoL summary score as almost all patients were functionally independent [Table/Fig-5].

Karnofsky performance status	Frequency (%)	Mean(SD) QoL Summary Score
50: Requires considerable assistance and frequent medical care.	5 (4.0)	58.96 (13.40)
60: Requires occasional assistance but is able to care for most personal needs.	30 (24.0)	68.02 (13.09)
70: Cares for self; unable to carry on normal activity or to do active work.	43 (34.4)	76.52 (9.67)
80: Normal activity with effort; some signs or symptoms of disease.	37 (29.6)	84.24 (10.03)
90: Able to carry on normal activity; minor signs or symptoms of disease.	10 (8.0)	90.20 (10.08)
100: No complaints; no evidence of disease.	0 (0)	---

Note: None of the participants has performance status score of less than 50

[Table/Fig-5]: Distribution of the Karnofsky Performance Status (KPS) score and Mean(SD) Quality of Life (QoL) summary scores among the study participants.

The mean (SD) CSI was 5.49 (3.00) whereas the mean (SD) Zarit score was 27.63 (12.75). Most of the caregivers {83 (66.4%)} reported low strain as assessed by CSI. Similarly, most caregivers {108 (86.4%)} reported nil to moderate burden as assessed by Zarit burden scale [Table/Fig-6].

Parameters	Values
Caregivers Strain Index (CSI) {Mean (SD)}	5.49 (3.0)
Caregivers Strain Index (CSI) Classification	Frequency (%)
Low strain (CSI score <7)	83 (66.4)
High strain (CSI score ≥7)	42 (33.6)
Zarit Burden Scale (Mean (SD))	27.63 (12.75)
Zarit Burden Scale Classification	Frequency (%)
Nil to mild (0-20)	39 (31.2)
Mild to moderate (21-40)	69 (55.2)
Moderate to severe (41-60)	16 (12.8)
Severe (>60)	1 (0.8)

[Table/Fig-6]: Summary of caregivers' strain and burden as assessed by Caregivers Strain Index (CSI) and Zarit Burden Scale.

The Mean (SD) CSI {5.34 (3.06) vs 5.66 (2.94)} as well as Mean (SD) Zarit score {25.99 (12.18) vs 29.53 (13.23)} was similar in male patients as compared to females. The Mean (SD) CSI and Zarit scores were similar across age groups as well as type of cancer as well as stage of cancer (data not shown).

The CSI and Zarit score correlated significantly { $r=0.69$, $p<0.001^{**}$ }. The CSI score showed significant negative correlation with QoL summary score { $r=-0.29$, $p=0.01^{*}$ } whereas the total Zarit score also showed negative correlation but not statistically significant ($r=-0.15$, $p=0.09$).

DISCUSSION

Patients in the present study, aged 18-77 years (mean 50.8±12.1), reflected India's cancer burden, where half of cases occur in the 40-64 age group, contrasting with the global trend of 65+ [1]. The male-to-female ratio was 1.16, slightly higher than the 0.95 reported by the National Cancer Registry Program (NCRP) of India [2]. Head and neck cancer was the most common in the present study (37.6%), likely due to high local tobacco use in the Charutar area, followed by breast cancer (19.2%). This aligns with state-wise distribution data from the National Cancer Registry Program (NCRP) [2].

This study identifies tiredness and fatigue as the most prevalent symptoms, followed by pain, lack of well-being, depression, and anxiety. This finding is consistent with an Indian study by Lamba

N et al., which showed that early palliative care can improve a patient's QoL and better manage distressing symptoms [17]. Other international studies also support this symptom pattern [18,19], finding no significant association with gender or age. Early initiation of palliative care is crucial for reducing symptom burden and enhancing QoL.

Among the largest patient groups- head and neck cancer and breast cancer- the study found that both pain and tiredness were common and severe. Pain was reported by 36.2% of head and neck cancer patients and 50% of breast cancer patients, while tiredness affected 21.3% and 54.2%, respectively. A Canadian study by Chow S et al., found that pain, tiredness, and anxiety were significant predictors of QoL in breast cancer patients [20]. Similarly, pain and fatigue are major symptoms in head and neck cancers, and palliative care interventions have been shown to improve them [21,22].

The study noted that symptoms with a significant burden (score >4) were more common in females. The mean QoL (QoL) score was significantly higher in males (81.17±11.67) compared to females (72.52±13.61; $p<0.001$). Similar gender-based differences in QoL have been reported in studies from Poland [23] and Pakistan by Tarar AH et al., suggesting that female cancer patients may experience a lower QoL than their male counterparts [24]. These findings highlight the need for gender-specific considerations in palliative care.

The overall mean QoL score, as measured by the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ C-30), was 77.1±13.3. Domains such as global health status and financial difficulties, along with symptoms like fatigue, appetite loss, and pain, significantly impacted QoL. The study revealed a significant inverse relationship between the number of symptoms assessed by the ESAS and the QoL score from the EORTC QLQ C-30. This is supported by a Spanish study by Valero-Cantero I et al., ($r=-0.511$, $p<0.001$) and a Brazilian study by Paiva CE et al., both of which found that an increase in the number and severity of symptoms leads to a decrease in QoL [25,26].

A study from Madhya Pradesh, India, by Agarwal AK et al., found a lower mean QoL score of 52.34, possibly due to their patient cohort being in earlier stages of cancer (73.5% in stages I and II) and undergoing active treatment like chemotherapy (52%) [27]. This suggests that cancer treatment-related symptoms can profoundly and negatively affect QoL. A East Indian study by Snehapriya S et al., reported an EORTC QLQ C-30 score of 58.1±17.2, with social functioning having the lowest mean functional score (57±19.8) [28]. Consistent with other research, fatigue and pain were the most prominent symptoms. This home-based study found that common symptoms, global health state, and financial difficulties significantly impacted overall QoL. When compared to pooled data from 34 countries [29], this study's EORTC QLQ C-30 data was equivalent for all functioning scales, with fatigue and pain remaining major concerns.

The KPS scores in this study aligned with the summary QoL scores, indicating a good QoL. Over half of the patients had KPS scores above 80, suggesting they were independent, while another 34% had scores between 70 and 80. These findings are similar to an Indonesian study by Perwitasari DA et al., where most patients had KPS scores above 80 [30]. In contrast, a German palliative care study by Jocham HR et al., reported a much lower mean KPS score of 48.5, likely because it included a higher number of patients with end-stage malignancy [31].

A worsening physical status, as indicated by a lower KPS score, is associated with increased 30-day mortality in patients with advanced incurable cancer receiving systemic therapy [32]. KPS is a reliable predictor of survival in advanced cancer, either alone or with other prognostic markers, and is strongly linked to deteriorating QoL [33]. Thus, KPS, along with ESAS and EORTC QLQ C-30, is a crucial tool for monitoring and prognostication.

The study found a lower caregiver burden, with a mean Zarit Burden Interview (ZBI) score of 27.63. This is consistent with an Indian study on older cancer patients by Menon N et al., where the burden was "little/none" for 76.4% of caregivers [34]. Other hospital-based studies from Delhi by Mishra S et al., and a study on informal caregivers of patients on chemotherapy by Lukhmana S et al., also reported similar results using the ZBI [8,35]. International studies also show comparable mean ZCI scores, such as in Mediterranean countries [36], the US [37], and Malaysia [38]. A Thai study reported a mean ZBI of 19 [39]. These findings suggest shared factors contributing to caregiver burden across different cultures.

In this study, 33% of caregivers had a high burden (score >7) on the CSI. This differs from a study by Hsu T et al., which reported a high burden in only 15% of caregivers. The CSI and ZCI scores correlated well with each other, and the CSI score showed a negative correlation with the patient's QoL score [40]. The top three stressors for caregivers were personal adjustments, family adjustments, and financial strain. Studies by Nayak MG et al., and Manir KS et al., on caregivers in India confirm these stressors [41,42]. Managing patient symptoms, physical mobility, and emotional health, including anxiety and depression, can significantly reduce caregiver burden.

Limitation(s)

Being a single centre cross-sectional study in India, the generalisability of the study findings may be limited. Further, the alterations in QoL and its linkage with various treatments will provide a holistic view of QoL over time.

CONCLUSION(S)

Fatigue and pain were main symptoms in advanced cancer. The QoL summary score was significantly worse in patients experiencing up to 4 symptoms or more as compared to those experiencing three symptoms. The domains Global health status and financial difficulties and symptoms viz., fatigue, appetite loss and pain hampered the QoL. Functional independence is maintained in advanced cancer in most patients. Caregiver burden scale ZBI and CSI correlated significantly and CSI score showed significant negative correlation with QoL summary score. Thus, improving palliative care of advanced cancer patients which is holistic which includes symptoms management, emotional and psychological support, financial support including improving government facilities for subsidised cancer care shall in turn relieve care giver burden also. This will improve QoL for both the patients and their caregivers.

REFERENCES

- [1] Sathishkumar K, Chaturvedi M, Das P, Stephen S, Mathur P. Cancer incidence estimates for 2022 & projection for 2025: Result from National Cancer Registry Programme, India. *Indian J Med Res.* 2022;156(4&5):598-607.
- [2] Mathur P, Sathishkumar K, Chaturvedi M, Das P, Sudarshan KL, Santhappan S, et al. Cancer statistics, 2020: Report from national cancer registry programme, India. *JCO Global Oncology.* 2020;6:1063-75.
- [3] Chandra A, Debnath A, Nongkynrih B. Palliative care need in India: A systematic review and meta-analysis. *Indian J Palliat Care.* 2023;29(4):375.
- [4] Dionne-Odom JN, Hull JG, Martin MY, Lyons KD, Prescott AT, Tosteson T et al. Associations between advanced cancer patients' survival and family caregiver presence and burden. *Cancer Medicine.* 2016;5(5):853-62..
- [5] Kumar K, Mittal A, Kamboj D, Goel GS, Mittal A, Garg SK. Factors affecting quality of life of cancer patients in North India. *Asian Pac J Cancer Prev.* 2023;24(2):641-48.
- [6] Asthana S, Bhatia S, Dhoundiyal R, Labani SP, Garg R, Bhatnagar S. Quality of life and needs of the Indian advanced cancer patients receiving palliative care. *Cancer Res Stat Treat.* 2019;2:138-44.
- [7] Rohith KP, Patel A. The burden of cancer caregivers: Time to acknowledge and start caring for the carers. *Cancer Res Stat Treat.* 2022;5:309-11.
- [8] Mishra S, Gullia A, Satapathy S, Gogia A, Sharma A, Bhatnagar S. Caregiver burden and quality of life among family caregivers of cancer patients on chemotherapy: A prospective observational study. *Indian J Palliat Care.* 2021;27(1):109.
- [9] Soni N, Banerjee J, Saravanan M, Rao AR, Upadhyay AD, Dey AB. Health-related quality of life in treatment-naive, older patients with cancer from India: A prospective observational study. *Cancer Res Stat Treat.* 2022;5(3):474-81.
- [10] Manivannan M, Karunanithi G, Lakshminarayanan S. Correlation between quality of life and burden in caregivers of advanced stage cancer patients on best supportive care. *Indian J Palliat Care.* 2023;29(1):89-93.
- [11] Bruera E, Kuehn N, Miller M, Selmsler P, Macmillan K. The Edmonton Symptom Assessment System (ESAS): A simple method for the assessment of palliative care patients. *J Palliat Care.* 1991;7(2):06-09.
- [12] Aaronson NK, Ahmedzai S, Bergman B, Bullinger M, Cull A, Duez NJ, et al. The European Organization for Research and Treatment of Cancer QLQ-C30: A quality-of-life instrument for use in international clinical trials in oncology. *J Natl Cancer Inst.* 1993;85(5):365-76.
- [13] Fayers P, Aaronson NK, Bjordal K, Sullivan M. EORTC QLQ-C30 scoring manual. European Organisation for Research and Treatment of Cancer; 1995.
- [14] Karnofsky DA, Abelmann WH, Craver LF, Burchenal JH. The use of the nitrogen mustards in the palliative Treatment of Carcinoma - with Particular Reference to Bronchogenic Carcinoma. *Cancer.* 1948;1(4):634-56.
- [15] Zarit S, Reeve K, Bach-Peterson J. Relatives of the impaired elderly: Correlates of feelings of burden. *The Gerontologist.* 1980;20(6):649-55.
- [16] Sullivan MT. Caregiver Strain Index (CSI). *Home Healthc Nurse.* 2003;21(3):197-98. doi:10.1097/00004045-200303000-00024. PMID: 12637827.
- [17] Lamba N, Makkar R, Gupta N, Sarna S, Khandelwal S. Comparative analysis of patient outcomes while receiving early palliative care in patients with cancer using ESAS Score. *J Mahatma Gandhi Univ Med Sci Tech.* 2021;6(1):01-02.
- [18] Salminen E, Clemens KE, Syrjänen K, Salmenoja H. Needs of developing the skills of palliative care at the oncology ward. *Supportive Care in Cancer.* 2008;16(1):03-08.
- [19] Karaman E, Sayin Kasar K, Deniz K, Yildirim Y. Symptoms, performance status and quality of life in cancer patients receiving palliative care. *EJM.* 2022;61(1):64-72.
- [20] Chow S, Wan BA, Pidduck W, Zhang L, DeAngelis C, Chan S, et al. Symptoms predictive of overall quality of life using the Edmonton Symptom Assessment Scale in Breast Cancer patients receiving radiotherapy. *Clin Breast Cancer.* 2019;19(6):405-10.
- [21] Singh Richa T, Patel Bhavna C, Sanghavi Priti R, Queenjal A, Himanshu P. Effect of palliative care interventions on symptom profile in head neck cancers: A prospective observational trial. *Gujarat cancer Res Soc J.* 2019;21(2):16-20.
- [22] Ostwal SP, Singh R, Sanghavi PR, Patel H, Anand Q. Correlation between symptom burden and perceived distress in advanced head and neck cancer: A prospective observational study. *Indian J Palliat Care.* 2021;27(3):419-25.
- [23] Gliwka E, Głabka D, Zaczek Z, Sobocki J, Guzek D. Multifactorial analysis of influences on quality of life in cancer patients. *Nutrients.* 2024;16(18):3207. https://doi.org/10.3390/nu16183207.
- [24] Tarar AH, Shaloom A. Cancer and quality of life: Importance of gender and marital adjustment in psycho-social oncology. *Pakistan Armed Forces Medical Journal.* 2020;(3):734.
- [25] Valero-Cantero I, Casals C, Espinar-Toledo M, Barón-López FJ, Martínez-Valero FJ, Vázquez-Sánchez MÁ. Cancer patients' satisfaction with in-home palliative care and its impact on disease symptoms. *InHealthcare* 2023;11(9). https://doi.org/10.3390/healthcare11091272.
- [26] Paiva CE, Manfredini LL, Paiva BS, Hui D, Bruera E. The Brazilian Version of the Edmonton Symptom Assessment System (ESAS) is a feasible, valid and reliable instrument for the measurement of symptoms in advanced cancer patients. *PloS one.* 2015;10(7):e0132073. https://doi.org/10.1371/journal.pone.0132073.
- [27] Agarwal AK, Yadav A, Yadav C, Mahore R, Dixit P. Assess and evaluation the Quality Of Life (QoL) among cancer patients undergoing treatment by using EORTC QLQ-30 Scale. *Natl J Community Med.* 2022;13(2):64-73.
- [28] Snehapriya S, Giri PP, Subba SH, Parida SP. Unveiling Health-Related Quality of Life (HRQoL) and sociodemographic factors predicting HRQoL among cancer patients in eastern India: A community-based cross-sectional study. *Asian Pacific journal of cancer prevention: APJCP.* 2025;26(3):819-27.
- [29] Quinten C, Coens C, Ghislain I, Zikos E, Sprangers MA, Ringash J, et al. The effects of age on health-related quality of life in cancer populations: A pooled analysis of randomized controlled trials using the European Organisation for Research and Treatment of Cancer (EORTC) QLQ-C30 involving 6024 cancer patients. *European Journal of Cancer.* 2015;51(18):2808-19.
- [30] Pervitasari DA, Atthobari J, Dwiprahasto I, Hakimi M, Gelderblom H, Putter H, et al. Translation and validation of EORTC QLQ-C30 into Indonesian version for cancer patients in Indonesia. *Jpn J Clin Oncol.* 2011;41(4):519-29.
- [31] Jocham HR, Dassen T, Widdershoven G, Halfens R. Reliability and validity of the EORTC QLQ-C30 in palliative care cancer patients. *Cent. Eur J Med.* 2009;4(3):348-57.
- [32] Wallington M, Saxon EB, Bomb M, Smittenaar R, Wickenden M, McPhail S, et al. 30-day mortality after systemic anticancer treatment for breast and lung cancer in England: A population-based, observational study. *The Lancet Oncology.* 2016;17(9):1203-16.
- [33] Laird BJ, Fallon M, Hjermstad MJ, Tuck S, Kaasa S, Klepstad P, et al. Quality of life in patients with advanced cancer: Differential association with performance status and systemic inflammatory response. *J Clin Oncol.* 2016;34(23):2769-75.
- [34] Menon N, Patil VM, Ramaswamy A, Gattani S, Castellino R, Dhakale R, et al. Caregiver burden in older Indian patients with cancer- Experience from a tertiary care center. *J Geriatr Oncol.* 2022;13(7):970-77.
- [35] Lukhmana S, Bhasin SK, Chhabra P, Bhatia MS. Family caregivers' burden: A hospital based study in 2010 among cancer patients from Delhi. *Indian Journal of Cancer.* 2015;52(1):146-51.
- [36] Alsirafy SA, Nagy R, Hassan AD, Fawzy R, Abdelhafeez AA, Husein MO, et al. Caregiver burden among family caregivers of incurable cancer patients in two eastern Mediterranean countries. *BMC Palliative Care.* 2021;20(1):163.
- [37] Semere W, Althouse AD, Rosland AM, White D, Arnold R, Chu E, et al. Poor patient health is associated with higher caregiver burden for older adults with advanced cancer. *Journal of geriatric oncology.* 2021;12(5):771-8.

- [38] Ahmad Zubaidi ZS, Ariffin F, Oun CTC, Katiman D. Caregiver burden among informal caregivers in the largest specialized palliative care unit in Malaysia: A cross sectional study. *BMC Palliative Care*. 2020;19(1):186.
- [39] Chindaprasirt J, Limpawattana P, Pakkaratho P, Wirasorn K, Sookprasert A, Kongbunkiat K, et al. Burdens among caregivers of older adults with advanced cancer and risk factors. *Asian Pacific Journal of Cancer Prevention*. 2014;15(4):1643-48.
- [40] Hsu T, Loscalzo M, Ramani R, Forman S, Popplewell L, Clark K, et al. Factors associated with high burden in caregivers of older adults with cancer. *Cancer*. 2014;120(18):2927-35.
- [41] Nayak MG, George A, Vidyasagar MS. Perceived barriers to symptoms management among family caregivers of cancer patients. *Indian J Palliat Care*. 2018;24(2):202-06.
- [42] Manir KS, Ghosh S. Assessment of caregivers' strain during radiation therapy of head-and-neck cancer patients: An institutional report using modified caregivers' Strain Index Scale. *Indian J Palliat Care*. 2019;25(2):228-31

PARTICULARS OF CONTRIBUTORS:

1. Senior Resident, Department of Neurology, Shree Krishna Hospital and Pramukhswami Medical College, Bhaikaka University, Karamsad, Anand, Gujarat, India.
2. Associate Professor, Department of ENT, Shree Krishna Hospital and Pramukhswami Medical College, Bhaikaka University, Karamsad, Anand, Gujarat, India.
3. Professor and Head, Department of Medicine, Shree Krishna Hospital and Pramukhswami Medical College, Bhaikaka University, Karamsad, Anand, Gujarat, India.
4. Professor of Bio-Statistics, Department of Central Research Services, Pramukhswami Medical College, Bhaikaka University, Karamsad, Anand, Gujarat, India.
5. Professor, Department of Community Medicine, Pramukhswami Medical College, Bhaikaka University, Karamsad, Anand, Gujarat, India.
6. Consultant, Department of Medical Oncology, Shree Krishna Hospital and Pramukhswami Medical College, Bhaikaka University, Karamsad, Anand, Gujarat, India.
7. Professor, Department of Medicine, Shree Krishna Hospital and Pramukhswami Medical College, Bhaikaka University, Karamsad, Anand, Gujarat, India.

NAME, ADDRESS, E-MAIL ID OF THE CORRESPONDING AUTHOR:

Alpaben Nimeshkumar Patel,
41, Professor Society, Mota Bazar, VV Nagar, Anand-388120, Gujarat, India.
E-mail: alpa.leuva75@gmail.com

PLAGIARISM CHECKING METHODS: [Jan H et al.]

- Plagiarism X-checker: Jan 01, 2025
- Manual Googling: Oct 09, 2025
- iThenticate Software: Oct 11, 2025 (2%)

ETYMOLOGY: Author Origin**EMENDATIONS:** 7**AUTHOR DECLARATION:**

- Financial or Other Competing Interests: None
- Was Ethics Committee Approval obtained for this study? Yes
- Was informed consent obtained from the subjects involved in the study? Yes
- For any images presented appropriate consent has been obtained from the subjects. NA

Date of Submission: **Dec 27, 2024**Date of Peer Review: **Mar 18, 2025**Date of Acceptance: **Oct 14, 2025**Date of Publishing: **May 01, 2026**