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Caregiver burden and quality of life among primary caregivers of patients with head and neck cancer: A cross-sectional study.

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Abstract

Background

Caregivers of patients with head and neck cancer (HNC) may experience substantial burden and impaired quality of life due to prolonged caregiving demands. However, this association remains underexplored in Indian settings. **Objectives:** To assess caregiver burden and quality of life among primary caregivers of HNC patients and examine their association with sociodemographic and clinical variables.

Methods

This cross-sectional observational study was conducted over 18 months among 124 primary caregivers of histopathologically confirmed HNC patients admitted to a tertiary care institute in Rajasthan, India. Caregiver burden was assessed using the Zarit Burden Interview (ZBI), and caregiver quality of life using the Caregiver Quality of Life Index-Cancer (CQOLC). Data were analysed using IBM SPSS version 25. Mann-Whitney U, Kruskal-Wallis, Chi-square, Fisher's exact tests, and Spearman correlation were used, with $p<0.05$ considered significant.

Results

The mean ZBI score was 40.1 ± 15.9; 41.1% of caregivers reported mild-to-moderate burden, 21.8% moderate-to-severe burden, and 17.7% severe burden. The mean CQOLC score was 102.14 ± 27.59 and declined progressively with increasing burden, from 123.83 ± 11.24 among caregivers with little/no burden to 68.46 ± 26.18 among those with severe burden ($p<0.001$). ZBI score showed a strong negative correlation with CQOLC ($r = -0.708$, $p<0.001$). Caregiver burden was significantly associated with education, marital status, relationship to patient, socioeconomic class, patient care dependency, cancer stage, health insurance status, and treatment modality ($p<0.05$). CQOLC scores were significantly lower among caregivers of patients with greater care dependency, advanced cancer stage, absence of health insurance, and surgical treatment ($p<0.05$).

Conclusion

Caregiver burden is common among primary caregivers of HNC patients and is strongly inversely associated with quality of life.

Recommendation

Routine screening for caregiver burden and provision of psychosocial and financial support should be integrated into comprehensive HNC care.

Keywords: *Caregiver burden; Quality of life; Head and neck cancer; Zarit Burden Interview; Caregiver Quality of Life Index-Cancer; Psycho-oncology*
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Introduction

Head and neck cancer (HNC) is the seventh most common cancer worldwide, accounting for an estimated 947,211 new cases and 482,428 deaths in 2022.[1] India bears a disproportionately high burden, with HNC accounting for approximately 28% of all cancers in men and 7% in women. The high prevalence is largely attributed to tobacco and areca-nut use, poor oral hygiene, and delayed diagnosis. [2–4] HNC and its treatment, including surgery, radiotherapy, and chemotherapy, often result in disfigurement, dysphagia, speech impairment, and functional disability, leading to prolonged dependence on family members for daily care.[5] Primary caregivers, usually spouses or close relatives, provide physical assistance, communication support, and emotional care, frequently without formal training or adequate support.[6,7] These caregiving responsibilities can adversely affect caregivers' physical, psychological, social, and financial well-being, resulting in significant caregiver burden and reduced quality of life (QOL).[7,8]Caregiver burden has emerged as an important component of comprehensive cancer care because increased burden is consistently associated with poorer caregiver QOL and may adversely influence patient care. [8–10]

Caregivers of patients with HNC face additional challenges related to speech impairment, altered appearance, feeding difficulties, tracheostomy care, and prolonged rehabilitation, making them particularly vulnerable to caregiver burden. [10,11] Although several international studies have examined caregiver burden in cancer, evidence from India, particularly among caregivers of patients with HNC, remains limited. Furthermore, the influence of sociodemographic characteristics, disease severity, treatment modality, patient dependency, and financial factors on caregiver burden and QoL has not been adequately explored in the Indian setting. [11–13] Therefore, the present study was undertaken to assess caregiver burden and quality of life among primary caregivers of patients with head and neck cancer and to determine their association with selected sociodemographic and clinical variables.

Aim

- To assess caregiver burden and its impact on the quality of life among primary caregivers of patients with head and neck cancer.

Primary objectives

- To assess the level of caregiver burden among primary caregivers of patients with head and neck cancer using the Zarit Burden Interview (ZBI).
- To assess the quality of life of primary caregivers using the Caregiver Quality of Life Index–Cancer (CQOLC).
- To determine the association between caregiver burden and quality of life among primary caregivers of patients with head and neck cancer.

Secondary objective

To evaluate the association of caregiver burden and quality of life with the sociodemographic and clinical characteristics of patients and their primary caregivers.

Materials and methods

Study design and participants

This hospital-based cross-sectional observational study was conducted over a period of 18 months, from June 2024 to November 2025, at the Department of Psychiatry, in collaboration with the Department of Oncology, Ananta Institute of Medical Sciences & Research Centre (AIMS&RC), Rajsamand, Rajasthan, India. The study included 124 primary caregivers of adult patients (≥18 years) with histopathologically confirmed head and neck cancer involving the oral cavity, oropharynx, hypopharynx, larynx, nasal cavity, or paranasal sinuses. A primary caregiver was defined as the family member primarily responsible for the patient's daily care for at least three months after diagnosis. Caregivers aged ≥18 years who understood Hindi were eligible for participation.

Eligible patients and their primary caregivers who attended or were admitted to the Oncology Department during the study period were screened according to predefined inclusion and exclusion criteria. Primary caregivers who fulfilled the eligibility criteria and provided consent were recruited consecutively until the required sample size was achieved. Caregivers or patients with pre-existing psychiatric illness, substance use disorder other than nicotine, serious medical illness, significant physical disability, or malignancies other than head and neck cancer were excluded.

Study setting

The study was conducted at Ananta Institute of Medical Sciences & Research Centre (AIMS&RC), Rajsamand, Rajasthan, a tertiary-care teaching hospital providing multidisciplinary healthcare services. The institute provides comprehensive diagnostic, therapeutic, emergency, and specialty care through multiple clinical departments and associated support services. The Oncology Department provides multidisciplinary cancer care, including medical oncology, surgical oncology, and radiation oncology, along with diagnostic and supportive services. The Department of

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Psychiatry provides assessment and management of psychiatric and psychological disorders and collaborated with the Oncology Department for assessment of caregiver burden and quality of life in the present study.

Sample size

Sample size was calculated using Thrusfield's formula with an expected proportion of 65%, 95% confidence level, 5% precision, and a finite population of 150.[14] The minimum required sample size was 113. After allowing for a 10% non-response rate, 124 caregivers were recruited.

Bias

Potential sources of selection and measurement bias were addressed by using predefined eligibility criteria and consecutive recruitment of eligible caregivers during the study period. A standardised semi-structured proforma was used for the collection of sociodemographic and clinical information. Validated instruments, namely the Zarit Burden Interview and Caregiver Quality of Life Index–Cancer, were used to assess caregiver burden and quality of life, respectively. Caregivers and patients with conditions likely to independently influence caregiver burden or quality of life, including pre-existing psychiatric illness, substance use disorder other than nicotine, serious medical illness, and significant physical disability, were excluded. The same assessment procedures were followed for all participants.

Study measures

Sociodemographic and clinical information was collected using a semi-structured proforma. Socioeconomic status was assessed using the Modified Kuppuswamy Scale (2023 update). Caregiver burden was assessed using the 22-item Zarit Burden Interview (ZBI), with scores categorised as little/no burden (0–20), mild-to-moderate burden (21–40), moderate-to-severe burden (41–60), and severe burden (61–88).[15] Caregiver quality of life was assessed using the 35-item Caregiver Quality of Life Index–Cancer (CQOLC), with higher scores indicating better quality of life.[16,17]

Ethical considerations

The study was approved by the Institutional Ethics Committee of Ananta Institute of Medical Sciences & Research Centre, Rajsamand (IEC No. AIMS/Ananta IEC/2024/214, dated 20 May 2024). The study was conducted in accordance with the ethical principles of the Declaration of Helsinki. Written informed consent was obtained from all participants before enrolment. Participants were informed about the purpose and procedures of the study, the voluntary nature of participation, and their right to withdraw at any time without affecting their clinical care. Confidentiality and anonymity of participant information were maintained throughout the study.

Statistical analysis

Data were analysed using IBM SPSS Statistics version 25. Continuous variables are presented as mean ± standard deviation, while categorical variables are presented as frequencies and percentages. The Mann–Whitney U test was used for comparison of continuous variables between two independent groups, and the Kruskal–Wallis test was used for comparisons involving more than two independent groups. For categorical variables, the Chi-square test was used when the expected cell frequencies met the assumptions of the test, whereas Fisher's exact test was used when expected cell frequencies were insufficient for the Chi-square test. The association between ZBI and CQOLC scores was assessed using Spearman's rank correlation coefficient. A two-tailed P value <0.05 was considered statistically significant.

Results section

Participant flow

Potentially eligible patients/caregivers identified (n = 250)
↓
Assessed for eligibility (n = 250)
↓
Excluded (n = 126)

- Did not meet inclusion criteria (n = 74)
- Declined to participate (n = 28)
- Pre-existing psychiatric illness (n = 10)
- Serious medical illness/significant physical disability (n = 8)
- Substance use disorder other than nicotine (n = 4)
- Other malignancy/non-HNC diagnosis (n = 2)

↓
Eligible and recruited (n = 124)
↓
Completed study assessment (n = 124)
↓
Included in final analysis (n = 124)

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Table 1: Socio-Demographic and Clinical Characteristics of Patients and Primary Caregivers (N = 124)

Variable	Category	*n* (%)
Patient sex	Male	93 (75.0)
	Female	31 (25.0)
Patient age (years)	*M* ± *SD*	46.0 ± 9.3
Patient cancer stage	Stage I	64 (51.6)
	Stage II	16 (12.9)
	Stage III	16 (12.9)
	Stage IV	28 (22.6)
Treatment modality	Radiotherapy	49 (39.5)
	Chemotherapy	42 (33.9)
	Surgery	33 (26.6)
Health insurance/government benefit	Yes	112 (90.3)
Caregiver age (years)	*M* ± *SD*	40.4 ± 9.3
Caregiver relationship to patient	Husband	50 (40.3)
	Father	34 (27.4)
	Mother	19 (15.3)
	Wife	8 (6.5)
	Son	6 (4.8)
	Brother	5 (4.0)
	Daughter	2 (1.6)
Caregiver domicile	Rural	108 (87.1)
Socioeconomic class (Kuppuswamy)	Class I	18 (14.5)
	Class II	71 (57.3)
	Class III	31 (25.0)
	Class IV	4 (3.2)
Patient care dependency	Eating/drinking/toileting	65 (52.4)
	Hygiene and grooming	38 (30.6)
	All activities of daily living	21 (16.9)

Of the 124 patients whose caregivers were studied, 93 (75.0%) were male and 31 (25.0%) females, with a mean age of 46.0 ± 9.3 years; 87.9% were married. Just over half (51.6%) presented with Stage I disease, and 22.6% with Stage IV disease; radiotherapy (39.5%), chemotherapy (33.9%), and surgery (26.6%) were the treatment modalities received, and 90.3% had health insurance or government health-benefit coverage.

The 124 primary caregivers had a mean age of 40.4 ± 9.3 years (42.7% aged 41-50 years). Husbands (40.3%) and fathers (27.4%) constituted the largest relationship categories, followed by mothers (15.3%); 88.7% were married, 78.2% belonged to nuclear families, and 87.1% resided in rural areas. More than half (57.3%) of caregiver families belonged to socioeconomic Class II (Modified Kuppuswamy scale), and the caregiver was the family's major earning member in 60.5% of households. Care dependency of patients was substantial: 52.4% of patients required assistance with eating, drinking, and toileting, 30.6% with hygiene and grooming, and 16.9% were dependent for all activities of daily living.

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Table 2. Distribution of caregiver burden (Zarit Burden Interview) among primary caregivers (N = 124)

Variable	Category	*n* (%)
Zarit Burden level	Little/no burden	24 (19.4)
	Mild-to-moderate burden	51 (41.1)
	Moderate-to-severe burden	27 (21.8)
	Severe burden	22 (17.7)
ZBI total score	*M* ± *SD*	40.1 ± 15.9

The mean ZBI total score was 40.1 ± 15.9. Little/no burden was reported by 19.4% of caregivers, mild-to-moderate burden by 41.1%, moderate-to-severe burden by 21.8%, and severe burden by 17.7%, indicating that nearly 40% of caregivers experienced at least moderate-to-severe burden.

Table 3. Association between caregiver Quality of Life (CQOLC) and Zarit burden levels

Zarit burden level	CQOLC score, *M* ± *SD*
Little/no burden	123.83 ± 11.24
Mild-to-moderate burden	116.00 ± 8.39
Moderate-to-severe burden	84.11 ± 26.28
Severe burden	68.46 ± 26.18
Total	102.14 ± 27.59
Overall *p-value*	<.001

The overall mean CQOLC score was 102.14 ± 27.59. Mean CQOLC scores declined progressively and significantly with increasing caregiver burden: 123.83 ± 11.24 in the little/no burden group, 116.00 ± 8.39 in the mild-to-moderate group, 84.11 ± 26.28 in the moderate-to-severe group, and 68.46 ± 26.18 in the severe-burden group ($p<0.001$) (Table 3).

Table 4. Association of selected sociodemographic and clinical variables with Zarit burden levels

Variable	Comparator categories	*p*
Caregiver age group	≤30 to 51–60 years	.449
Caregiver sex	Male vs. female	.478
Caregiver–patient relationship	Husband, mother, father, wife, etc.	.038*
Caregiver marital status	Married, never married, widowed	.036*
Caregiver education	Illiterate to graduate	<.001*
Caregiver occupation	Homemaker, labour, salaried, student	.087
Family type	Nuclear, joint, extended	.112
Domicile	Rural vs. urban	.195
Socioeconomic class (Kuppuswamy)	Class I–IV	<.001*
Patient care dependency	Basic care to all-activity dependence	<.001*
Patient cancer stage	Stage I–IV	.015*
Health insurance/government benefit	Yes vs. no	<.001*
Treatment modality	Chemotherapy, radiotherapy, surgery	.015*
Duration of caregiving	<6, 6–12, >12 months	.980

**Statistically significant, $p<0.05$.*

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Original Article

Caregiver burden showed no significant association with caregiver age (p=0.449), sex (p=0.478), occupation (p=0.087), family type (p=0.112), or domicile (p=0.195). However, statistically significant associations were observed with caregiver-patient relationship (p=0.038; highest burden among spouses), marital status (p=0.036; all widowed caregivers reported severe burden), educational status (p<0.001; higher burden with lower education), and socioeconomic class (p<0.001; disproportionate severe burden in Class I and Class IV).

On the patient side, caregiver burden was strongly associated with patient care dependency (p<0.001; 57.1% severe burden among caregivers of totally dependent patients versus 6.2% among those assisting only with eating/drinking/toileting), cancer stage (p=0.015; highest burden with Stage IV disease), absence of health insurance or government health benefits (p<0.001), and treatment modality (p=0.015; highest burden among caregivers of surgically treated patients). Duration of caregiving and duration since diagnosis were not significantly associated with burden level (p=0.980 and p=0.159, respectively).

Table 5. Association between caregiver Quality of Life (CQOLC) and clinical variables

Variable	Category	CQOLC, *M* ± *SD*	*p*
Patient care dependency	Eating/drinking/toileting	113.4 ± 18.9	<.001*
	Hygiene and grooming	102.1 ± 21.3	
	All activities of daily living	67.4 ± 32.1	
Patient cancer stage	Stage I	109.8 ± 22.3	<.001*
	Stage II	95.3 ± 28.6	
	Stage III	111.6 ± 15.4	
	Stage IV	83.1 ± 33.5	
Health insurance/government benefit	Yes	106.1 ± 24.1	<.001*
	No	65.5 ± 31.9	
Treatment modality	Chemotherapy	109.9 ± 21.3	.004*
	Radiotherapy	104.3 ± 23.8	
	Surgery	89.1 ± 35.1	

**Statistically significant, p<0.05.*

CQOLC scores mirrored the pattern seen for burden. Scores declined significantly with increasing patient care dependency, from 113.4 ± 18.9 (assistance with eating, drinking, and toileting only) to 67.4 ± 32.1 (dependence for all activities of daily living) (p<0.001). Caregivers of Stage IV patients reported markedly lower CQOLC scores (83.1 ± 33.5) than those caring for Stage I patients (109.8 ± 22.3, p<0.001). Absence of health insurance or government health benefits was associated with substantially poorer quality of life (65.5 ± 31.9 versus 106.1 ± 24.1 with coverage, p<0.001), and CQOLC scores were lowest among caregivers of surgically treated patients (89.1 ± 35.1) compared with those of patients receiving chemotherapy (109.9 ± 21.3) or radiotherapy (104.3 ± 23.8, p=0.004).

Table 6. Correlation of Caregiver Burden (ZBI) and Quality of Life (CQOLC) with Age Variables (Spearman's r)

Variable pair	*r*	*p*
ZBI–CQOLC	−.708	<.001*
ZBI–Patient age	.066	.465
ZBI–Caregiver age	.059	.512
CQOLC–Patient age	−.101	.262
CQOLC–Caregiver age	−.095	.296

*ZBI = Zarit Burden Interview; CQOLC = Caregiver Quality of Life Index–Cancer. *Statistically significant, p<0.05.*

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Original Article

Zarit Burden Interview total score showed a strong, statistically significant negative correlation with CQOLC score ($r=-0.708$, $p<0.001$), confirming that higher caregiver burden was consistently associated with poorer caregiver quality of life. Neither patient age nor caregiver age showed a significant correlation with ZBI or CQOLC scores, indicating that the burden-quality of life relationship was independent of age.

Discussion

The present study demonstrated that caregiver burden is common among primary caregivers of patients with head and neck cancer (HNC) and is strongly associated with poorer caregiver quality of life. Nearly 40% of caregivers experienced moderate-to-severe or severe burden, and caregiver burden showed a strong inverse correlation with quality of life ($r = -0.708$, $P < 0.001$). These findings emphasise the substantial psychosocial impact of HNC caregiving and highlight the need for routine caregiver assessment as part of comprehensive cancer care.

The mean ZBI score observed in the present study (40.1 ± 15.9) was higher than that reported by Miguel et al., who found a mean score of 26.8 ± 11.8 among HNC caregivers, but was comparable to the findings of Ramasamy et al. In caregivers of patients with advanced HNC. [10,13] The relatively higher burden observed in this study may be attributed to the predominantly rural population, lower socioeconomic status, and the inclusion of caregivers across different stages of disease and treatment modalities. These findings suggest that caregiver burden is influenced not only by disease characteristics but also by socioeconomic and healthcare-related factors.

Among sociodemographic variables, caregiver education, marital status, socioeconomic status, and caregiver–patient relationship were significantly associated with caregiver burden, whereas age, sex, occupation, family type, and domicile were not. Similar associations between lower educational status, socioeconomic disadvantage, and higher caregiver burden have been reported in previous studies among caregivers of patients with cancer. [12,18] Spousal caregivers experienced greater burden than other family members, consistent with earlier reports indicating that emotional attachment and greater caregiving responsibilities increase caregiving stress.[8,19]

Patient-related clinical factors had a greater influence on caregiver burden than caregiver characteristics. Greater patient dependency, advanced disease stage, lack of health insurance, and surgical treatment were all associated with significantly higher caregiver burden. These findings are consistent with previous studies demonstrating that functional dependency and treatment-related morbidity substantially increase caregiving demands and financial stress.[7,10,20]

Caregiver quality of life declined progressively with increasing caregiver burden. Caregivers with severe burden had markedly lower CQOLC scores than those with little or no burden, confirming a strong inverse relationship between burden and quality of life. Similar findings have been reported among caregivers of patients with HNC and other advanced cancers.[10,21–25] The strong negative correlation observed in the present study reinforces caregiver burden as an important determinant of caregiver well-being.

Clinical factors influencing caregiver burden similarly affected quality of life. Caregivers of patients with advanced-stage disease, greater functional dependency, absence of health insurance, and those undergoing surgery reported significantly poorer quality of life. These observations suggest that increasing physical care requirements and financial burden adversely affect multiple dimensions of caregiver well-being and should be considered during treatment planning and supportive care.

The findings of this study have important implications for palliative and supportive oncology care. Routine screening of caregivers using simple validated instruments such as the Zarit Burden Interview may facilitate early identification of caregivers at risk of poor quality of life. Multidisciplinary interventions, including caregiver education, psychosocial counselling, rehabilitation support, and financial assistance, may reduce caregiver burden and improve both caregiver and patient outcomes.

Generalizability

The findings of this study may be particularly relevant to tertiary-care oncology settings in Rajasthan and other Indian regions with similar sociodemographic and healthcare characteristics. The predominance of caregivers from rural areas and representation of different socioeconomic groups provide useful insights into caregiver burden in settings where access to healthcare and social-support resources may be limited. However, generalisation of these findings to urban populations, other geographic regions, community-based settings, or healthcare systems with different cancer-care and social-support structures should be undertaken cautiously. The findings may also not be directly applicable to caregivers of patients with malignancies other than HNC, as the physical, functional, and psychosocial demands associated with HNC may differ from those of other cancers.

Conclusion

Caregiver burden is prevalent among primary caregivers of head and neck cancer patients and is strongly and inversely associated with their quality of life. Burden is driven less by

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Original Article

caregiver demographic characteristics than by the clinical realities of caregiving - patient care dependency, advanced cancer stage, absence of health insurance, and caregiver-patient relationship - and these same factors also independently erode caregiver quality of life. These findings support the integration of routine caregiver burden and quality-of-life screening and financial-protection measures into comprehensive head and neck cancer care, to safeguard both caregiver well-being and the quality of care ultimately received by patients.

Limitations

This study has several limitations. Its cross-sectional design precludes causal inference regarding the direction of the burden-QOL relationship. The study was conducted at a single tertiary-care centre, which may limit generalisability, particularly to primary-care or purely urban populations. Self-reported questionnaires are susceptible to recall and social-desirability bias. The absence of a longitudinal follow-up component precludes assessment of how burden and quality of life evolve over the disease and treatment trajectory, and the absence of a comparison group (e.g., caregivers of patients with other cancers) limits comparative interpretation. Finally, potential confounders such as prior caregiving experience and pre-existing caregiver vulnerability were not comprehensively assessed.

Recommendation

Routine screening for caregiver burden and provision of psychosocial and financial support should be integrated into comprehensive HNC care.

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List of abbreviations

AIMS&RC — Ananta Institute of Medical Sciences & Research Centre
CQOLC — Caregiver Quality of Life Index–Cancer
HNC — Head and Neck Cancer
IEC — Institutional Ethics Committee
SD — Standard Deviation
ZBI — Zarit Burden Interview

Ethical approval and consent to participate

This study was approved by the Institutional Ethics Committee of Ananta Institute of Medical Sciences & Research Centre, Rajsamand (IEC No. AIMS/Ananta IEC/2024/214, dated 20 May 2024) and was conducted in accordance with the Declaration of Helsinki. Written informed consent was obtained from all participants.

Consent for publication

Not applicable.

Availability of data and materials

The datasets generated and/or analysed during the current study are available from the corresponding author on reasonable request.

Conflict of interest

The authors declare that they have no conflict of interest.

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Author contributions

All the authors contributed to study conception and design, data collection, analysis, drafting, and critical revision of the manuscript, and approved the final version for submission.

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