RESEARCH PAPER

# Assessment of Caregiver Burden Among Primary Caregivers of Oral Cancer Patients: A Cross-Sectional Study in Rajasthan

**Dr. Jai Kishan Meena[1*], Dr. Anup N[2], Dr. Vikas Jeph[3], Dr. Swasti Tambi[4], Dr. Ashfaq Mohammed[5], Dr. Shivangi Maletia[6]**

[1*]MDS Final Year, Public Health Dentistry, Jaipur Dental College, MVGU University, Jaipur
Email: jaikishan7770@gmail.com
[2]Professor and Head, Public Health Dentistry, Jaipur Dental College, MVGU University, Jaipur
[3]Professor, Public Health Dentistry, Jaipur Dental College, MVGU University, Jaipur
[4]Professor, Public Health Dentistry, Jaipur Dental College, MVGU University, Jaipur
[5]MDS Final Year, Public Health Dentistry, Jaipur Dental College, MVGU University, Jaipur
[6]MDS Final Year, Public Health Dentistry, Jaipur Dental College, MVGU University, Jaipur

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**Abstract**

**Background:** Oral cancer affects not only patients but also their family members who provide continuous physical, emotional, and social support. Caregiving responsibilities may result in considerable psychological and psychosocial burden. Therefore, assessment of caregiver burden is important for providing comprehensive cancer care.

**Objective:** To assess the level of caregiver burden among primary caregivers of patients with oral cancer and to identify factors associated with caregiver burden.

**Methods:** A cross-sectional observational study was conducted among 50 primary caregivers of histopathologically confirmed oral cancer patients attending tertiary cancer hospitals in Rajasthan. Eligible caregivers were those who provided care, were aware of the patient's cancer diagnosis, consented to participate, and could communicate orally or in writing. Data were collected through face-to-face interviews. Caregiver burden was assessed using the 22-item Zarit Burden Interview. Regression analysis was performed to assess factors associated with caregiver burden.

**Results:** Among the 50 caregivers, 52.0% were male, and 48.0% were female. The majority were aged 31–40 years (56.0%). Based on the Zarit Burden Interview, 12.0% of caregivers had little or no burden, 36.0% had mild-to-moderate burden, 46.0% had moderate-to-severe burden, and 6.0% had severe burden. Overall, 48.0% of caregivers experienced moderate or higher levels of burden. Insufficient time for oneself and discomfort related to having friends were among the major concerns reported by caregivers. Regression analysis was performed to identify variables associated with caregiver burden; however, the variables assessed in the stepwise regression were not statistically significant.

**Conclusion:** A substantial proportion of primary caregivers of oral cancer patients experienced moderate-to-severe caregiver burden. The findings emphasise the need for early identification of caregiver distress and provision of appropriate psychological, social, and supportive care interventions. Integrating caregiver support into routine oral cancer and palliative care may improve the well-being of both caregivers and patients.

**Keywords:** Oral cancer; Caregiver burden; Primary caregivers; Zarit Burden Interview; Palliative care; Psychosocial distress.

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## Introduction

Oral cancer is a major global public health problem and contributes substantially to cancer-related morbidity and mortality. Recent global estimates indicate a considerable burden of oral cancer, with marked variations across regions and countries. India carries a substantial proportion of the global oral cancer burden, making oral cancer an important public health concern in the country [1].

The impact of oral cancer extends beyond the patient and significantly affects family members who provide day-to-day care. Primary caregivers are often responsible for assisting with feeding, personal care, medication, hospital visits, emotional support, and other healthcare-related needs. Studies have demonstrated that caregivers of oral cancer patients experience a considerable caregiving burden, particularly in relation to self-esteem, social functioning, and the demands associated with the patient's physical and psychological needs [2].

In the Indian context, oral cancer caregiving has been associated with substantial psychosocial consequences. Family caregivers may experience changes in their physical health and lifestyle, emotional distress, disruption of family and social

relationships, financial difficulties, and changes in occupational functioning [3]. A cross-sectional study from Wardha also reported that oral cancer had a significant psychosocial impact on family caregivers, with emotional stress and disruption being important aspects of caregiver burden [4].

Caregiver burden may also manifest as anxiety, depression, and perceived stress. Evidence from a tertiary care hospital in Central India demonstrated that family caregivers of oral cancer patients experienced significant psychological distress, emphasising the need to recognise and address caregivers' mental health along with the treatment of the patient [5].

The caregiving burden can be particularly challenging when patients require prolonged care at home or supportive and palliative services. Studies among family caregivers of oral cancer patients have reported that the complications and treatment-related effects of oral cancer can place a substantial burden on caregivers and affect their quality of life [6].

Therefore, assessment of caregiver burden is an important component of comprehensive cancer care. Identifying the extent and determinants of caregiver burden can help healthcare professionals provide appropriate counselling, psychosocial support, education, and supportive interventions to caregivers. In the present study, caregiver burden was assessed among primary caregivers of patients with oral cancer using the Zarit Burden Interview to identify the level of burden and factors contributing to caregiver distress [7]. The present study is particularly relevant because its caregiver burden assessment was based on a structured 22-item approach.

**Methodology**

A cross-sectional observational study was conducted among 50 primary caregivers of histopathologically confirmed oral cancer patients attending tertiary cancer hospitals in Rajasthan. The caregivers of oral cancer patients receiving palliative care services were included in the study. Only primary caregivers who consented to participate, were aware of the patient's cancer diagnosis, and were able to communicate orally or in writing were included. Non-consenting patients or caregivers, caregivers of terminal-stage patients, minors serving as primary caregivers, and caregivers unable to communicate verbally or orally were excluded.

Data were collected through face-to-face interviews. A questionnaire containing baseline details of the caregiver, followed by 22 structured questions, was used to assess the psychological and psychosocial problems experienced by caregivers while caring for oral cancer patients. Caregiver burden was assessed using the Zarit Burden Interview (ZBI). The total burden score was calculated by summing the individual item scores. A higher score indicated greater caregiver distress. Scores of 0–20 were categorised as little or no burden, 21–40 as mild to moderate burden, 41–60 as moderate to severe burden, and 61–88 as severe burden.

Regression analysis was performed to identify factors associated with caregiver burden. Binary and stepwise logistic regression were used to assess the relationship between burden-related variables and caregiver burden.

**Results**

A total of 50 primary caregivers of patients with oral cancer were included in the study. The demographic characteristics of the caregivers are presented in Table 1. The majority of caregivers were aged 31–40 years (56.0%), followed by 21–30 years (32.0%). Males constituted 52.0% of the study population, while females constituted 48.0%. About educational status, 40.0% of caregivers had completed high school, 24.0% had no formal education, and 18.0% each had primary or graduate-level education. Regarding occupation, 40.0% were daily-wage workers, 26.0% were salaried, 24.0% were engaged in household activities, and 10.0% were self-employed. Nearly half of the caregivers (46.0%) reported a family income of less than ₹5,000 per month. Regarding relationship with the patient, daughters/sons constituted the largest group (52.0%), followed by spouses (26.0%), siblings (16.0%), and others (6.0%).

**Table 1. Sociodemographic characteristics of primary caregivers (N=50)**

| Variable | Category | n | % |
|---|---|---|---|
| **Age** | <20 years | 6 | 12.0 |
| | 21–30 years | 16 | 32.0 |
| | 31–40 years | 28 | 56.0 |
| **Gender** | Male | 26 | 52.0 |
| | Female | 24 | 48.0 |
| **Educational status** | No formal education | 12 | 24.0 |
| | Primary | 9 | 18.0 |
| | High school | 20 | 40.0 |
| | Graduate | 9 | 18.0 |
| **Occupation** | Daily wages | 20 | 40.0 |
| | Self-employed | 5 | 10.0 |
| | Salaried | 13 | 26.0 |
| | Household | 12 | 24.0 |

| Variable | Category | n | % |
|---|---|---|---|
| **Family income/month** | <₹5,000 | 23 | 46.0 |
| | ₹5,000–10,000 | 17 | 34.0 |
| | >₹10,000 | 10 | 20.0 |
| **Relationship to patient** | Spouse | 13 | 26.0 |
| | Daughter/son | 26 | 52.0 |
| | Sibling | 8 | 16.0 |
| | Others | 3 | 6.0 |

The overall caregiver burden was assessed using the Zarit Burden Interview. The PPT showed that 52.0% of caregivers had no/mild burden, whereas 48.0% had moderate or above burden.

**Table 2. Overall caregiver burden among primary caregivers (N=50)**

| Caregiver burden category | n | % |
|---|---|---|
| No/mild burden | 26 | 52.0 |
| Moderate or above burden | 24 | 48.0 |
| **Total** | **50** | **100.0** |

Among the different levels of caregiver burden, 12.0% had little or no burden, 36.0% had mild to moderate burden, 46.0% had moderate to severe burden, and 6.0% had severe burden.

**Table 3. Distribution of caregivers according to level of burden (N=50)**

| Level of caregiver burden | n | % |
|---|---|---|
| Little or no burden | 6 | 12.0 |
| Mild to moderate burden | 18 | 36.0 |
| Moderate to severe burden | 23 | 46.0 |
| Severe burden | 3 | 6.0 |
| **Total** | **50** | **100.0** |

The study also assessed specific aspects of caregiver burden. The findings indicated that insufficient time for oneself and feeling uncomfortable about having friends were among the major burdens reported by family caregivers.

Regression analysis identified several variables associated with caregiver burden. In binary logistic regression, the highest odds were observed for embarrassment, lack of privacy, and feeling uncomfortable about having friends. However, the PPT reports that these variables were not statistically significant in the forward stepwise logistic regression analysis.

**Discussion**

The present study assessed caregiver burden among 50 primary caregivers of patients with oral cancer. The findings demonstrated that caregiver burden was an important concern, with 48% of caregivers experiencing moderate or higher levels of burden. Specifically, 46% experienced moderate-to-severe burden, 6% experienced severe burden, 36% experienced mild-to-moderate burden, and 12% reported little or no burden. These findings indicate that caregiving for patients with oral cancer can have a substantial psychosocial impact on family members.

Family caregivers of patients with oral cancer experience multiple challenges related to the physical, emotional, and social demands of caregiving. Liang et al. reported that caregivers of patients with oral cancer face difficulties performing caregiving tasks and managing the challenges of caring for patients at home [8]. These findings are consistent with the present study, in which a considerable proportion of caregivers experienced moderate-to-severe or severe burden. The demanding nature of oral cancer care may contribute to restriction of caregivers' personal activities and social life.

Cheng et al. emphasised that family caregivers of patients with oral cancer require adequate caregiving skills and confidence to manage patient-related problems, particularly nutritional issues, decision-making, resource acquisition, and sudden or uncertain patient conditions [9]. In the present study, the presence of considerable caregiver burden may similarly reflect the demands of providing continuous support to patients with oral cancer. This highlights the importance of caregiver education and supportive services as part of comprehensive cancer care.

The use of the Zarit Burden Interview in the present study is supported by previous research. Galindo-Vazquez et al. evaluated the psychometric properties of the Zarit Burden Interview among caregivers of cancer patients and demonstrated its applicability for assessing caregiver burden in cancer caregiving populations [10]. Similarly, Bachner reported satisfactory psychometric properties of an abridged Arabic version of the Zarit Burden Interview among caregivers of cancer patients, further supporting the instrument's usefulness for evaluating caregiver burden [11].

Kühnel et al. further demonstrated that the Zarit Burden Interview is useful in palliative care settings. Their study found that the ZBI-7 had good structural validity and internal consistency for measuring caregiver burden, supporting the use of ZBI-based assessment in palliative care [12]. This is

particularly relevant to the present study because the caregivers included were caring for patients with oral cancer receiving palliative care services. The present study also identified insufficient time for oneself and discomfort with having friends as important aspects of caregiver burden. These findings are consistent with the broader literature showing that caregiving may interfere with caregivers' personal time and social relationships. Liang et al. described multiple challenges experienced by family caregivers of patients with oral cancer, emphasising the impact of caregiving responsibilities on caregivers' daily lives [8].

Kudrick et al., in a longitudinal study of caregivers of patients with head and neck cancer, highlighted that caregiver burden is an important and persistent concern and emphasised the need for multidisciplinary recognition and supportive interventions for caregivers [13]. The findings of the present study similarly indicate that caregiver needs should be considered alongside the clinical needs of patients with oral cancer. Social support may play an important role in reducing caregiver burden. Yuen et al. found that greater perceived social support and social connectedness were significantly associated with lower caregiver burden, and both were independent predictors of caregiver burden [14]. In the present study, discomfort with having friends and limited personal time were among the major concerns reported by caregivers. This suggests that maintaining social relationships and strengthening social support may be important components of interventions aimed at reducing caregiver burden.

The findings of the present study are also comparable with research conducted among family caregivers of cancer patients receiving chemotherapy in India. Mishra et al. reported that 70.22% of caregivers had mild-to-moderate burden and 21.38% had moderate-to-severe burden, with caregiver burden assessed using the Zarit Burden Interview [15]. Although the patient populations and treatment settings differed between the two studies, both demonstrate that cancer caregiving can result in clinically relevant levels of burden.

Overall, the findings indicate that caregiver burden should not be overlooked in the management of oral cancer. Healthcare professionals should recognise caregivers as an important part of the cancer-care team and provide appropriate counselling, education, psychosocial support, and opportunities for respite and social support. Early identification of caregivers experiencing moderate-to-severe burden may help facilitate timely supportive interventions and potentially improve the well-being of both caregivers and patients.

**Conclusion**

The present study demonstrates that caregiver burden is an important concern among primary caregivers of patients with oral cancer. Nearly half of caregivers (48%) experienced moderate or higher burden, with 46% experiencing moderate-to-severe burden and 6% experiencing severe burden. Major concerns included inadequate personal time and discomfort in maintaining social relationships. These findings highlight the need to consider caregivers as an integral part of the oral cancer care team. Healthcare professionals should routinely assess caregiver burden and provide appropriate counselling, psychological support, caregiver education, and social support. Early recognition of caregiver distress may help prevent worsening of burden and improve the overall quality of care provided to patients with oral cancer. Further studies with larger sample sizes and longitudinal designs are recommended to understand better the factors influencing caregiver burden and to evaluate interventions aimed at reducing caregiver distress.

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