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Research Article

A Study to Assess the Caregiver Burden of the Caregivers of Post-Operative Patients with Oral Cancer in B.R.A Institute Rotary Cancer Hospital, All India Institute of Medical Sciences, New Delhi

Neenumol Paulose[1], Aditi Prashant Sinha[2], S. V. S. Deo[1]

[1]Department of Surgical Oncology, All India Institute of Medical Sciences, New Delhi, India, [2]Department of Medical Surgical Nursing, College of Nursing, All India Institute of Medical Sciences, New Delhi, India

ABSTRACT

Introduction: Cancer is a leading cause of death in both developed and underdeveloped countries. The Indian subcontinent accounts for one-third of the world burden of head-and-neck cancer. Caregivers of patients with oral cavity cancer experience heavy burden during and post-treatment period, which, in turn, may affect the caregiver's ability. **Aim:** This study aims to assess the caregiver burden (CB) of the caregivers of post-operative oral cancer patients. **Methodology:** The study was conducted at AIIMS, New Delhi. The data were collected by convenience sampling from 50 caregivers of the post-operative patients with oral cancer during June 2017 to December 2017. Self-developed CB assessment questionnaire was used to assess the perceived level of the CB during hospital stay and at 1 month follow-up. Ethical clearance was obtained from the Institutional Ethics Committee. **Results:** Half of the caregivers were male and half were female. Majority of the caregivers always perceived physical problem (70%, 55.8%), emotional problem (60%, 52.9%), logistical problem (64%, 55.88%), inadequate knowledge and skill (66%, 64.7%), and socioeconomic problem (56%, 73.5%) during hospital stay and 1 month follow-up, respectively. There was a significant decrease in the overall CB at 1 month follow-up (17.16 ± 8.19 and 14.96 ± 9.87) ($P = 0.04$). **Conclusions:** Reduction in CB was noted over the month. Future studies with larger sample over extended period will yield much.

Keywords: Caregiver burden, Oral cancer, Post-operative

Address for Correspondence: Aditi Prashant Sinha, Department of Medical Surgical Nursing, College of Nursing, All India Institute of Medical Sciences, Ansari Nagar - 110 029, New Delhi, India. Mobile: 011 2659445722. E-mail: aaditiprashant@gmail.com

Introduction

Cancer is a leading cause of death in both more and less economically developed countries in the world. In South Asia, oral cancers account for up to 40% of all cancers. The Indian subcontinent accounts for one-third of the world burden of head-and-neck cancer. Head-and-neck cancers account for one-fourth of all cancers in Indian males.[1]

There are three main methods for treating oral cancer; surgery, radiotherapy, and chemotherapy either used alone or in combination, depending on the type of cancer, location, extent of spread, patient's age, and general state of health. Surgery is the standard treatment of choice for head-and-neck cancers.[2]

The side effect of surgery includes esthetic and functional tissue loss requiring post-surgical rehabilitation. Recovering from oral cavity cancer and adjusting to life after treatment are different for each person, depending on the extent of the disease, the type of treatment, and many other factors.[3]

Surgical treatment for cancer of the oral cavity has important effects on the quality of life; this modifies the

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patient's self-perception and the ability to interact with others in daily social life.[4] Caregivers of patients with oral cavity cancer experience heavy burdens during the treatment and post-operative period, which, in turn, may affect the caregiver's ability to care for the patient. Social support is a significant factor for caregivers of patients with oral cancer and has been shown to act as a buffer against negative effects on caregiver caregiving.[4]

Caregivers are essential part of cancer care and the level of caregiving burden is high in those who care for cancer patients. Caregivers experience physical, psychological effects that adversely affect their health.[5] Caregivers with longer caregiving time are often dissatisfied when providing care for oral cancer patient. It was essential to explore the caregivers burden (CB) among the caregivers of the post-operative oral cancer. The aim of the present study was to assess the CB of the caregivers of post-operative oral cancer patients, while caring the patients during post-operative hospital stay and at home in B.R.A. Institute Rotary Cancer Hospital, All India Institute of Medical Sciences, New Delhi. The objectives of the study were (1) to assess the perceived level of CB of family caregivers of post-operative patients with oral cancer during hospital stay and 1 month of follow-up and (2) to compare the perceived level of CB of caregivers of post-operative patients with oral cancer during hospital stay and 1 month of follow-up.

Materials and Methods

Descriptive prospective study design was selected. The study was conducted at B.R.A.I.R.C.H, cancer hospital of All India Institute of Medical Sciences, a tertiary care hospital with various specialty and super specialty, New Delhi. Ethical clearance was obtained from the Institutional Ethics Committee (IECPG-85/22.03.2017). The caregivers of the patients diagnosed with oral cancer and underwent surgery for that during the study period (July 2017–December 2017) which were enrolled for the study. Inclusion criteria were as follows: Caregivers of patients with histopathologically proven diagnosis of oral cancer, caregivers of patients underwent surgery for oral cancer, a family member, those who give informed consent, and caregivers who can read Hindi or English. However, disoriented caregivers were excluded from the study. The sample size was calculated based on the pilot study at α 5% and power 90%. Out of the total 55 caregivers of the post-operative patients with oral cancer and who enrolled for the study, 5 were excluded as 4 of them were not meeting inclusion criteria and 1 was not willing to participate in the study. Hence, 50 were allocated for the study. Data were collected from them at two point of time: One during hospital stay and second at 1 month follow-up. Sixteen caregivers lost to follow up. The reasons losing the follow-up for patients were 9 caregivers could not be contacted and for others the reason was lost follow-up of the patient. The data were collected by convenience sampling from 50 caregivers. Demographic profile and clinical profile of the post-operative patients with oral cancer and demographic profile and care characteristics of the caregivers were obtained during hospital stay after surgery.

CB assessment tool is a self-developed tool by the researcher. It is a 22-item self-reporting questionnaire which measures the perceived level of CB of the caregivers of the post-operative patients with oral cancer in five domains: Physical problems, emotional problems, logistical problems, inadequate knowledge and skill, and socioeconomic problems. Higher score indicates a higher CB. For each item, the scales ranged from 0 "never,"1 "sometimes," to 2 "always." Tool translated into Hindi and validated by experts. The Cronbach's alpha value of the tool is 0.86.

Statistical analysis

The data were analyzed using SPSS software version 16. Descriptive statistics, frequency, mean, and standard deviation were used for describing the demographic variables and paired "*t*-test" for normal distribution and Wilcoxon sign-rank test for non-normality distribution was used to compare the perceived level of CB of caregivers of the post-operative patients with oral cancer during hospital stay and 1 month follow-up. Inferential statistics, the level of significance was taken as <0.05 based on the objectives of the study.

Results

In Table 1, the age of the patients with oral cancer was between 28 and 66 years. Majority (80%) were male and 56% of them belonged to nuclear family while 44% of them were from joint family. Half of the patients (50%) were from rural area and 50% were from urban area and majority of them (98%) were married. With regard to education, majority of the patients (58%) educated up to middle class and majority were employed (78%). Among all patients, 44% of the post-operative patients with oral cancer were earning <5000 rupees per month.

Table 2 shows the clinical characteristics of the post-operative patients with oral cancer. As shown in the table, 34% of the post-operative patients with oral cancer were diagnosed with cancer buccal mucosa followed by cancer alveolus and cancer tongue (22% each). About 6% of the patients had cancer retromolar trigone and the same percentage had cancer gingivobuccal mucosa. Among all patients studied, 4% had cancer mandible, 2% had cancer maxilla, and 2% presented with cancer in multiple sites. The duration of illness for most of the patients (76%) was <1 year and only 22% had a history of cancer more than 1 year. With regard to the staging, majority of the post-operative patients with oral cancer (52%) presented with Stage 4 disease. Majority of operative patients with oral cancer underwent mandibulectomy (including all types) (66%) and modified neck dissection (including all types)

Table 1: Demographic profile of post-operative patients with oral cancer (*n*=50)

Demographic variables	Category	*n* (%)
Age	28–66	50 (100)
Sex	Male	40 (80)
	Female	10 (20)
	Others	0
Type of family	Nuclear	28 (56)
	Joint	22 (44)
Area of residence	Rural	25 (50)
	Urban	25 (50)
Marital status	Married	49 (98)
	Unmarried	1 (2)
Educational status	Illiterate	7 (14)
	Up to middle	29 (58)
	Senior secondary	8 (16)
	Graduate	4 (8)
	Postgraduate	2 (4)
Occupation	Student	1 (2)
	Employed	39 (78)
	Unemployed	10 (20)
Monthly income	<5000 rupees	22 (44)
	5000–10,000 rupees	16 (32)
	10,000–15,000 rupees	4 (8)
	>15,000 rupees	8 (16)

Table 2: Clinical characteristics of post-operative patients with oral cancer (*n*=50)

Clinical variables	Category	*n* (%)
Diagnosis	Cancer lip	1 (2)
	Cancer gingivobuccal sulcus	3 (6)
	Cancer buccal mucosa	17 (34)
	Cancer alveolus	11 (22)
	Cancer palate	0
	Cancer tongue	11 (22)
	Cancer maxilla	1 (2)
	Cancer mandible	2 (4)
	Cancer retro molar trigone	3 (6)
	Multiple sites	1 (2)
Duration of illness	<1 year	38 (76)
	>1 years	11 (22)
	Not known	1 (2)
Stage of the cancer	1	4 (8)
	2	7 (14)
	3	9 (18)
	4	26 (52)
	Not known	4 (8)
Type of surgery	Wide local excision	4 (8)
	Mandibulectomy	33 (66)
	Glossectomy	12 (24)
	Maxillary resection	1 (2)
	Neck dissection	
	Modified neck dissection	30 (60)
	Supraomohyoid neck dissection	5 (10)
	Radical neck dissection	1 (2)
	Bilateral neck dissection	9 (18)
	Reconstruction	
	No	18 (36)
	Local flap	4 (8)
	Regional flap	28 (56)
Duration of stay in hospital	<10 days	25 (50)
	10–20 days	21 (42)
	>20 days	4 (8)
Tubing's present	Nasogastric tube	42 (84)
	Both tracheostomy tube and gastrostomy tube	2 (4)
	Both nasogastric and tracheostomy tube	6 (12)

(60%) and had regional flap (56%) reconstruction. Half of the post-operative patients with oral cancer stayed in the hospital for <10 days, 42% stayed more than 10 days but <20 days and 8% happened to stay for more than 20 days after surgery. Most of the patients (84%) discharged with nasogastric tube while 6% of the patients were discharged with both tracheostomy tube and gastrostomy tube. The age of the caregivers was between 14 and 64 years [Table 3]. Majority of them (78%) were married and half of the caregivers (50%) were male and half were female. About 52% of the caregivers belonged to nuclear family while 48% of them belonged to joint family. With regard to the area of residence, 54% of the caregivers were from rural area and 46% were from urban area. With respect to the education, 42% of the patients educated up to middle class, 32% were graduates, 14% were studied up to senior secondary level, 6% of them were illiterate, and 4% had postgraduation. With regard to the employment, majority of the caregivers were employed 56%, 8% were studying, and 34% of them had no job. In case of monthly income, 44% of the caregivers were earning <5000 rupees per month, 34% were earning between 5000 and 10,000 rupees, while only 22% had income above 10,000 rupees.

In Table 4, 48% of the caregivers were spouse, 34% of the caregivers were children of the patients, 6% were siblings, 4% were parents, and 8% were cousins or niece or uncle. Many of the caregivers (46%) were providing care for 6–12 months while 20% were providing care for more than 12 months. About 18% of caregivers were providing care for 3–6 months, 8% for 1–3 months, and 6% for <1 month. With regard to time spending daily in taking care of the patients, majority of them (80%) were spending more than 8 h, 12% spent 6–8 h while 6% spent 4–6 h. Most of the caregivers (68%) had no previous experience in taking care of seriously ill patients. Only 30% of the caregivers had previous experience in taking care of chronically ill patients. Majority of the caregivers of post-operative patients with oral cancer [Table 5] always perceived physical problem during hospital stay (70%) and 1 month follow-up (55.8%), emotional problem during hospital stay (60%) and 1 month follow-up (52.9%), logistical problem during hospital stay (64%) and 1 month follow-up (55.88%), inadequate knowledge and skill during hospital stay (66%) and 1 month follow-up (64.7%), and socioeconomic problem during hospital stay (56%) and 1 month follow-up (73.5%).

Table 3: Demographic profile of caregivers of the post-operative patients with oral cancer (*n*=50)

Demographic variables of caregiver	Category	*n* (%)
Age	16–64 years	50 (100)
Sex	Male	25 (50)
	Female	25 (50)
	Others	0
Type of family	Nuclear	26 (52)
	Joint	24 (48)
Area of residence	Rural	27 (54)
	Urban	23 (46)
Marital status	Married	39 (78)
	Unmarried	11 (22)
Educational status	Illiterate	3 (6)
	Up to middle	21 (42)
	Senior secondary	7 (14)
	Graduate	16 (32)
	Postgraduate	2 (4)
	Not known	1 (2)
Occupation	Student	4 (8)
	Employed	28 (56)
	Unemployed	17 (34)
	Not known	1 (2)
Monthly income	<5000 rupees	22 (44)
	5000–10,000 rupees	17 (34)
	10,000–15,000 rupees	3 (6)
	>15,000 rupees	8 (16)

In Table 6, there was a significant decrease in the overall CB of the caregivers of post-operative patients with oral cancer at 1 month follow-up (17.16 ± 8.19 and 14.96 ± 9.86) as compared to during hospital stay with $P = 0.04$. There was also a significant decrease found in the physical problem at 1 month follow-up (4.31 ± 2.63 and 3.49 ± 3.01) as compared to during hospital stay with $P = 0.05$. However, there was no significant difference with regard to the CB of the caregivers of post-operative patients with oral cancer in emotional problem, logistical problem, inadequate knowledge and skill, and socioeconomic problem during hospital stay and 1 month follow-up.

Discussion

In the present study, most of the caregivers of post-operative patients with oral cancer always perceived physical problem, emotional problem, logistical problem, inadequate knowledge and skill, and socioeconomic problem during hospital stay and 1 month follow-up. Sherrod *et al.* in 2014 also reported similar findings where the family caregivers had moderate problem in providing emotional support, preparing foods, helping to make medical decisions, monitoring mental status, communicating with insurers, aiding mobility, managing fatigue, assisting with finances, monitoring swallowing, managing constipation, managing pain, helping with medications, tracheostomy care, managing percutaneous endoscopic gastrostomy (PEG) problems, and ensuring safety.[5] Similar findings reported by Chen *et al.* in 2014 which said family caregivers reported the need for more information and health-care services after a family member has had oral surgery.[6]

Table 4: Care characteristics of caregivers of the post-operative patients with oral cancer (*n*=50)

Clinical variables	Category	*n* (%)
Whether caregiver related to patient	Yes	50 (100)
	No	0
Relationship	Spouse	24 (48)
	Children	17 (34)
	Parents	2 (4)
	Siblings	3 (6)
	In-laws	0
	Others	4 (8)
Duration of providing care	<1 month	3 (6)
	1–3 months	4 (8)
	3–6 months	9 (18)
	6–12 months	23 (46)
	12> months	10 (20)
	Not known	1 (2)
Time spent daily in taking care of patients	4–6 h	3 (6)
	6–8 h	6 (12)
	> 8 h	40 (80)
	Not mentioned	1 (2)
Any previous experience in taking care of chronically ill patients	Yes	15 (30)
	No	34 (68)
	Not mentioned	1 (2)

The present study showed a significant decrease in the physical problem of the caregivers at 1 month follow-up as compare to the hospital stay. However, no significant difference found with regard to the CB in emotional problem, logistical problem, inadequate knowledge and skill, and socioeconomic problem during hospital stay and 1 month follow-up. Emotional problem in caregivers continues even at 1 month follow-up. Longacre *et al.* in 2012 reported that caregivers experienced poorer psychological health, high levels of anxious symptoms, and fear of patient cancer recurrence during 6-month period after the diagnosis of head-and-neck cancer.[7]

Margaret *et al.* in their study in 2012 clearly mentioned that caregivers of elderly cancer patients are faced with unrelenting stress which adversely affect their health which, in turn, affect the caregiving quality. The diagnosis of cancer to their loved ones, treatment modalities, and side effects of treatments causes fears, anxiety, and emotional disturbances. These findings very much support the present study finding which says during immediate post-operative period the caregivers experiences emotional disturbances.[8]

Ronald *et al.* in 2014 studied the risk factors for CB of caregivers of lung cancer patients and found out that female sex, lack of knowledge, staying with the care recipient, time spent in caregiving, depression, social isolation, financial

Table 5: The perceived level of CB of caregivers of post-operative patients with oral cancer during hospital stay (T1) and 1 month follow-up (T2) (n=50)

CB	Never		Sometimes		Always	
	T1 n=50 n (%)	T2 n=34 n (%)	T1 n=50 n (%)	T2 n=34 n (%)	T1 n=50 n (%)	T2 n=34 n (%)
Physical problem	2 (4)	10 (29.4)	13 (26)	5 (14.7)	35 (70)	19 (55.8)
Emotional problem	3 (6)	9 (26.4)	17 (34)	7 (20.5)	30 (60)	18 (52.9)
Logistical problem	6 (12)	8 (23.5)	12 (24)	7 (20.5)	32 (64)	19 (55.88)
Inadequate knowledge and skill	7 (14)	11 (32.3)	10 (20)	1 (2.9)	33 (66)	22 (64.7)
Socioeconomic problem	3 (6)	6 (17.6)	19 (38)	3 (8.8)	28 (56)	25 (73.5)

CB: Caregiver burden

Table 6: Comparison of perceived level of CB of caregivers of post-operative patients with oral cancer during hospital stay and 1 month follow-up (n=50)

CB	During hospital stay n=50	1 month follow-up n=34	P-value
	Mean±SD	Mean±SD	
Physical problem	4.31±2.63	3.49±3.01	0.05*
Emotional problem	4.11±2.95	3.31±2.98	0.06
Logistical problem	2.83±1.38	2.34±1.58	0.06
Inadequate knowledge and skill	2.31±1.7	2.25±1.91	0.76
Socioeconomic problem	4.31±1.95	3.61±2.42	0.16
Overall CB	17.16±8.19	14.96±9.86	0.04*

CB: Caregiver burden, paired t-test, Wilcoxon sign-rank test, *significant $P<0.05$

stress, etc., are some factors directly related to the caregiving burden. Similar findings could be seen in the present study. Lack of knowledge, financial problems, loss of job, etc., were the important CB found.[9]

Grunfeld *et al.* in 2004 found that the CB of the caregivers of the breast cancer patients was very high and it led to anxiety and depression. They mentioned that job loss was one of the major stressor occurred as the result of caregiving responsibilities. The present study also concluded that the inability to work by the caregivers increases the financial burden for them. Hence, it is very essential to take some strategies to reduce the psychosocial, occupational, and economic burden associated with caregiving.[10]

Head-and-neck cancer care should be a separate specialty in oncology nursing to provide quality care to post-operative oral cancer patients and to support their caregivers. This study also shows the need for integrated oral health-care management. Support and teaching to the caregivers should be taken as an important part of cancer care.

Although the study could include all the caregivers of post-operative patients with oral cancer during the study period in B.R.A.I.R.C.H, the other centers like head-and-neck center could not be included. In the present study, only one follow-up could be taken to assess the CB. But for better results, long-term follow-up at least 1 year should be taken.

Caregivers of the post-operative patients with oral cancer perceived physical problem, emotional problem, logistical problem, inadequate knowledge and skill, and socioeconomic problem during hospital stay and 1 month follow-up. Long-term study can be done and study with larger sample size from multiple centers will yield more results. Experimental study with a structured teaching can be done to assess the impact of intervention in the caregiver's problems while providing care to the patients. Comparative study with other type of cancer is essential to compare the problems faced by caregivers during the treatment period of the patients. Further studies are needed to find out the factors associated with CB of the cancer patients.

Conclusions

Caregivers of the post-operative oral cancer experience immense problems during immediate post-operative period although some decreasing trend could be found later. It is very essential to support the caregivers as well during post-operative period.

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