

Assessment of Primary Caregiver’s Burden in Oral Cancer Patients: A Descriptive Study

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ABSTRACT

Aim: Caregiver burden refers to people’s emotional response to the changes and demands of giving support to another. This study aims to highlight the burdens faced by the primary caregiver of oral cancer patients and assess which amongst them contributes to the highest stress.

Materials and methods: The study was conducted at oncology ward of our hospital. The cross-sectional correlational study design was employed. The data was collected through a structured questionnaire. A total of 50 oral cancer patients’ primary caregivers consented to participate in the study. Two-step data analysis was done. First descriptive statistics were used to analyze the background characteristics. Then the patient’s overall burden was calculated based on the scoring system obtained from ZBI. In the second step, regression analysis was done to predict the burden degree and also to find the main cause of the burden.

Results: Binary logistic regression analysis revealed the following burdens (stressed managing to balance –0.896, embarrassed –0.896, no privacy –0.980 and uncomfortable about having friends –1.094) as statistically significant. Again with those significant variables, forward stepwise logistic regression was done which revealed the following burdens (not enough time for themselves –0.013 and uncomfortable about having friends –0.023) very significantly associated.

Conclusion: This study highlights that the caregivers, though burdened to some extent, wanted to take care of their relatives till the last day.

Clinical significance: The purpose of the study was to create awareness among the professionals to give more importance to the primary caregiver. The importance of primary caregiver in the life of the diseased is paramount because of the emotional attachment they share. So this inter-relationship between the doctor, the patient, and the primary caregiver will help in a significant way in the wellbeing of the patient.

Keywords: Burden, Oral cancer, Primary caregiver.

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BACKGROUND

Cancer is among the leading causes of death with cardiovascular diseases being the most prevalent. In 2015, over 8.7 million deaths were reported globally.¹ As a result of the multiple supportive care requirements of patients with cancer, they are more dependent on family caregivers, who are in turn affected by the psychological, psychosocial or physical burden of caring for the cancer patients. The subsequent emotional response of the caregiver to the changes and demands of a distressed person is discussed as the caregiver burden.² In this concept, the negative components of caregiving are emphasized more than positive elements, which may be an impetus for the caregiver.³ Caregivers are often deprived of physical and emotional health and report high levels of stress in addition to career sacrifices, financial losses, and workplace bigotry, loss of social harmony and embarrassment.⁴ Though the knowledge concerning the burden of caring for cancer/oncology patients is finite, the literature documents some of the challenges faced by family caregivers.⁵ Sharpe et al. stated that caregivers with a greater level of support had a lower burden of family subsistence and were less afflicted with financial difficulties.⁶ According to Goldstein et al., patients with constrained activities and their caregivers with less social backing were afflicted with high caregiving burden.⁷

Caregiving is alleged to be a major life stressor and considered a stress response process. Therefore, this study was derived from the conceptual basis of the Caregiving model.⁸ This study aims to highlight the burden faced by the caregivers and assess which amongst them contributes to the highest stress.

MATERIALS AND METHODS

Participants

The inclusion criteria for the study were

- All the caregivers of the patients who were receiving palliative care services for oral cancer;
- The primary caregivers who consented to participate in the study;

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- The caregivers who were aware of the cancer diagnosis of the patient;
- Caregivers who communicated orally or in writing.

The exclusion criteria were

- Nonconsenting patients or their caregivers;
- Caregivers of terminal stage diseased patients;
- Minors as the primary caregiver of the patients;
- Caregivers who cannot communicate verbally or orally.

Data Collection Process

The cross-sectional correlational study design was implemented. The clearance from the Institutional Ethics Committee (IEC) was obtained. The questionnaires were distributed to the patients' primary caregivers' only after obtaining written consent from them. Patients from the oncology ward at our tertiary care hospital were considered. A total of 50 oral cancer patients', (collected over a period of 6 months) primary caregivers' consented to participate in the study. A questionnaire consisting of few baseline details of the caregiver followed by structured 22 questions related to various psychological and psychosocial problems the caregiver might face while taking care of these unfortunate patients, were distributed to the primary caregiver of the respective patients. The questionnaire was obtained from the Zarit Burden Interview (ZBI).⁹

Scoring/Interpretation

A 5 point Likert scale, ranging from never to nearly always present was utilized to score each question with total scores ranging from 0 (low burden) to 88 (high burden).

The Burden Interview score was obtained by totaling the numbered responses of the individual items.

The higher the score, greater would be the caregiver distress:

- 0 to 20 Little or no burden
- 21 to 40 Mild to moderate burden
- 41 to 60 Moderate to severe burden
- 61 to 88 Severe burden

Data Analysis

Data analysis of this study was done in two steps. Firstly, to analyze the background characteristics and the caregiving burden of the primary caregiver, the descriptive statistics were employed. Subsequently, the overall burden was calculated based on the scoring system mentioned above. In the second step, regression analysis was done to predict the burden degree and also to find the main cause of the burden. First binary logistic regression was done with 16 independent variables. Then with 2 out

of the 16 significantly dependent variables, forward step-wise logistic regression analysis was done to determine the final burden.

Ethical and Humane Consideration

Ethical clearance for the study was procured from the Institutional Ethics Committee.

RESULTS

The caregivers' age ranged between 18 to 40 years with the average age being approximately 36 years. There was a male predilection in the caregivers' with 26 of the caregivers' being male (52%) while 24 were females (48%) as mentioned in Table 1. Majority of the caregivers' had either studied till high school or have received no formal education. Most of the caregivers' were either in the daily wages category or salaried category. Almost all the female caregivers' turned out to be in the household category. Around 10% population fell in the self-employed category. The family income was mostly in the <5000 p.m slab with 17 patients out of 50 being in the 5000–10000 p.m slab. A very low percentage was noted in the > 10000 p.m slab. (20%) Mostly the daughters turned out to be the primary caregivers' (52%), 26 out of 50 patients (Table 1).

Concerning the questionnaire results, to focus on the caregivers' caregiving process and to evaluate the burden, 22 questions were prepared. The first few questions represented the relationship of the patients' caregivers' with the patient, i.e., the caregivers' response to various

Table 1: Descriptive statistics of primary caregivers' background data

		Count	Column N %
Age	<20 years	6	12.0%
	21 to 30 years	16	32.0%
	31 to 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%
Occupation	Graduate	9	18.0%
	Daily wages	20	40.0%
	Self employment	5	10.0%
	Salaried	13	26.0%
Family income	Household	12	24.0%
	<5000 pm	23	46.0%
	5000 to 10000 pm	17	34.0%
Relationship to patient	> 10000 pm	10	20.0%
	Spouse	13	26.0%
	Daughter/son	26	52.0%
	Sibling	8	16.0%
	Others	3	6.0%

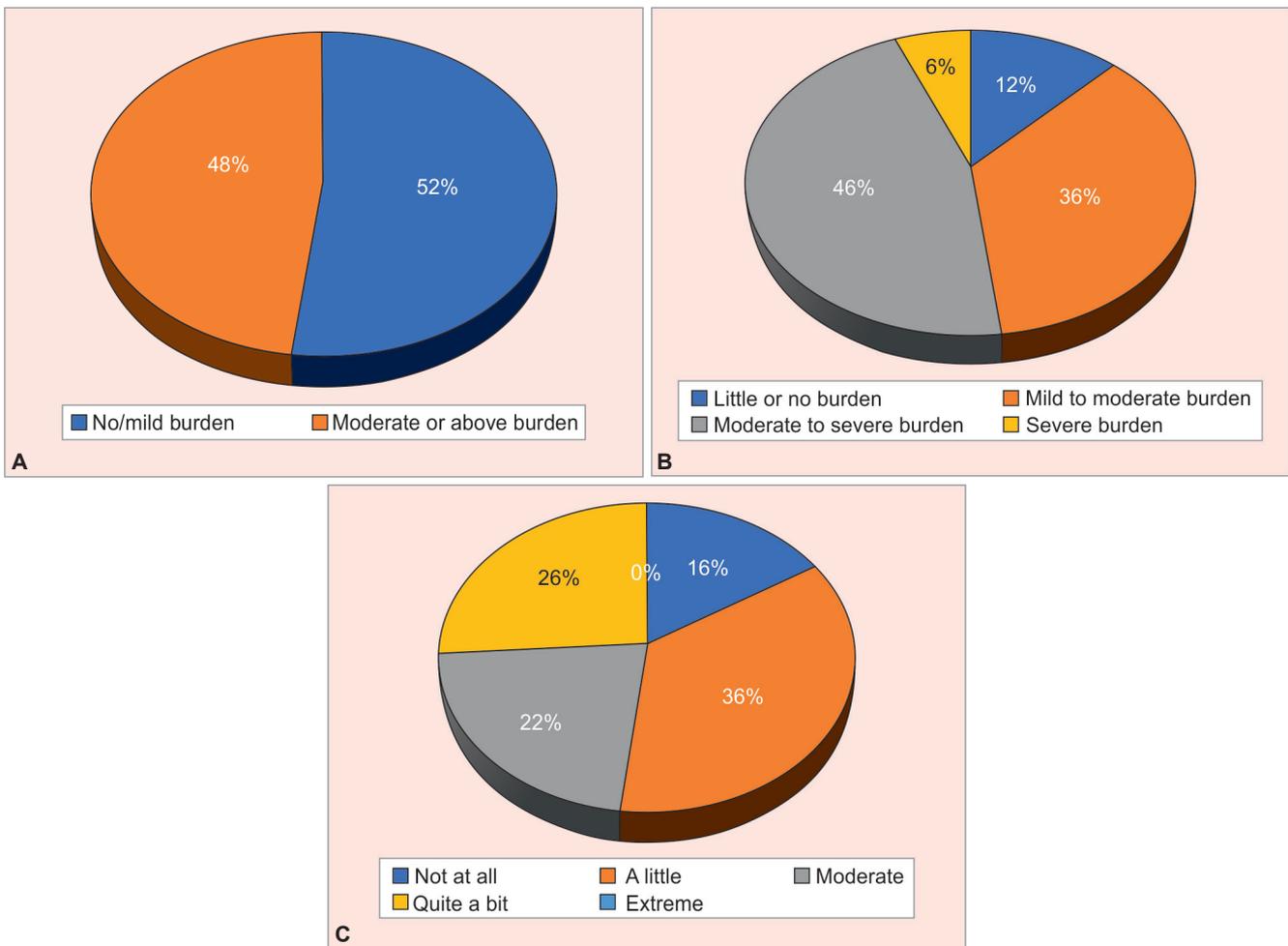
demands and behavioral tantrums of the diseased patient. A positive or negative response gave an insight into the significance of our study.

About 36% of the patients' caregivers' neither felt discomfited over their relative's health nor were they strained or losing out on personal time (Graph 1). Anger was not an issue among the caregivers except 10 cases, in which the caregivers were young individuals and were monetarily compromised, giving rise to the agitation. Nearly 34% of the caregivers' were anxious and ambiguous of their relative's future. Around 12% of the patients were educationally sound, so they knew about the prognosis of the disease and either never or rarely afraid or uncertain about their relative's future. Strain and health was not an impeding factor in 13 patients. The remaining felt strained when they were around their relative. Money factor was an important issue in this study as most of the caregivers' earning was found to be less than Rs 5000 per month. But currently, there is various insurance scheme for the cancer patients which lightens the caregivers' financial burden to a certain extent. Almost 88% of the caregivers wanted to do a better job as they thought that the care they are providing to their relative was insufficient. Issues with social and private life was an important burden for the caregiver. Nearly 62% of

the caregivers' perceived to have lost control of their social and private life. About 78% of the caregivers' thought that their relative expected of only him/her to look after him/her. Merely three caregivers believed to be burdened with the patient and therefore want to hand over the patient to someone else for caregiving. The well-educated and the well-placed ones felt very lightly burdened because of their knowledge of the disease per se.¹⁰ Thirty-six percent caregivers quite frequently wanted to do a better job for their relatives. Three caregivers' thought that they have had enough with the patient and left the rest to the Almighty (Table 2).

The overall burden of the patient was calculated based on the burden interview scoring chart as mentioned above. Twenty-six caregivers with 52 N % felt that there was no/mild burden. 24 caregivers with 48 N % felt the moderate burden. On further calculation with four independent variables, six caregivers experienced little or no burden, 18 caregivers with mild to moderate burden, 23 caregivers with moderate to severe burden and 3 caregivers experienced severe burden (Table 3).

On the basis of regression analysis, numerous significant factors were identified and found to be related to the primary caregivers' burden (Table 4).



Graph 1: Pie chart representation of overall burden score

Table 2: Descriptive statistics of primary caregivers' burden

	never	Rarely	Some- times	Quite frequently	Nearly always
Patient asking for more help	8 (16%)	16 (32%)	17 (34%)	8 (16%)	1 (2%)
Not enough time for themselves	8 (16%)	18 (36%)	12 (24%)	12 (24%)	0 (0%)
Stressed managing to balance	7 (14%)	7 (14%)	24 (48%)	10 (20%)	2 (4%)
Embarrassed	15 (30%)	18 (36%)	12 (24%)	5 (10%)	0 (0%)
Angry	13 (26%)	15 (30%)	12 (24%)	10 (20%)	0 (0%)
Affecting relationships in negative way	8 (16%)	11 (22%)	24 (48%)	6 (12%)	1 (2%)
Afraid what future holds for your relative	4 (8%)	1 (2%)	11 (22%)	17 (34%)	17 (34%)
Relative's dependance on you	2 (4%)	4 (8%)	16 (32%)	17 (34%)	11 (22%)
Strained when you are around your relative	4 (8%)	9 (18%)	32 (64%)	5 (10%)	0 (0%)
Health has suffered because of involvement with relative	9 (18%)	12 (24%)	23 (46%)	5 (10%)	1 (2%)
No privacy	12 (24%)	14 (28%)	15 (30%)	9 (18%)	0 (0%)
Social life	8 (16%)	19 (38%)	17 (34%)	5 (10%)	1 (2%)
Uncomfortable about having friends	15 (30%)	9 (18%)	18 (36%)	6 (12%)	2 (4%)
Expectation of taking care	4 (8%)	7 (14%)	18 (36%)	18 (36%)	3 (6%)
Not enough money	4 (8%)	6 (12%)	15 (30%)	12 (24%)	13 (26%)
Unable to take care much longer	7 (14%)	10 (20%)	13 (26%)	16 (32%)	4 (8%)
Have lost control of your life	8 (16%)	11 (22%)	20 (40%)	11 (22%)	0 (0%)
Wish to leave the care to someone else	22 (44%)	13 (26%)	12 (24%)	2 (4%)	1 (2%)
Uncertain about your relative	8 (16%)	4 (8%)	16(32%)	14(28%)	8(16%)
Should be doing more	3 (6%)	3 (6%)	25(50%)	12(24%)	7(14%)
Better job	0 (0%)	6 (12%)	23(46%)	18(36%)	3(6%)

Table 3: Calculating the overall burden

	Overall burden	Column N %
Not at all	8	16.00%
A little	18	36.00%
Moderate	11	22.00%
Quite a bit	13	26.00%
Extreme	0	0.00%
No/mild burden	26	52.00%
Moderate or above burden	24	48.00%
	Total score	Column N %
Little or no burden	6	12.00%
Mild to moderate burden	18	36.00%
Moderate to severe burden	23	46.00%
Severe burden	3	6.00%

When a binary logistic regression is performed with all the burden variables the odds ratio was found to be the highest with the situation of embarrassment, lack of privacy and uncomfortable about having friends. None of these variables were however statistically significant on the performance of forwarding stepwise Logistic regression 3.537 and 2.564 respectively with p-value less than 0.05 (Table 5).

DISCUSSION

Earlier studies prove that oral cancer patients need higher levels of patient care as compared to patients with cancer of the bowel, prostate or melanoma.¹¹ Support is all they need during the diagnosis and treatment plan of these patients. Along with moral support, the information needs of the patients are higher as well. Preceding

studies have concluded post-surgical discomfort as one of the major factors in patients' emotional bearings during this phase.¹² Moreover, there is a very short period between the treatment planning and surgery in these patients, so healthcare professionals should give utmost importance to the patients' psychological needs at this phase; and what better tools do we have than the caregivers.

There are studies pertaining to the role of spouse caregivers' burden in cancer patients. Higher caregivers' attachment anxiety and avoidance were associated with more depression.¹³ Spouse caregivers' burden was also related to the troubled marital relationship. This study is exclusive, as the comparison was done between the caregivers of all age groups and considered only oral cancer patients.

This study revealed that the major burden faced by the family caregivers were, insufficient time for themselves and uncomfortable having friends. Other studies presented various burden factors which were also evaluated in this study through the questionnaire, but the results were statistically insignificant.¹⁴ The social life of the caregivers was severely compromised, but they were happy to take care of their relatives and were even ready to give more effort to give comfort to the patients. Studies suggest that a "caregiver support group" should be formed as a portal to share each other's feelings to overcome this burden.¹⁵ Patients' performance index is one of the major factors in estimating primary caregivers' caregiving burden. Sharpe et al. observed that a negative relationship between the patients and their caregivers can predict a

Table 4: Binary logistic regression, balance, embarrassment, loss of privacy and friends are the main aspects which increases burden

		<i>Variables in the Equation</i>					<i>95% C.I. for odds ratio</i>		
		<i>B</i>	<i>S.E.</i>	<i>Wald</i>	<i>df</i>	<i>Sig.</i>	<i>Odds ratio</i>	<i>Lower</i>	<i>Upper</i>
Step 1A	Patient asking for more help	0.304	1.035	0.086	1	0.769	1.355	0.178	10.301
	Not enough time for themselves	0.651	1.017	0.409	1	0.523	1.917	0.261	14.082
	Stressed managing to balance	0.896	0.867	1.070	1	0.301	2.450	0.448	13.391
	Embarrassed	0.896	0.891	1.011	1	0.315	2.450	0.427	14.060
	Angry	0.275	0.871	0.100	1	0.752	1.317	0.239	7.267
	Affecting relationships in negative way	0.180	0.894	0.041	1	0.840	1.198	0.208	6.910
	Strained when you are around your relative	-0.766	1.095	0.489	1	0.484	0.465	0.054	3.975
	Health has suffered because of involvement with relative	0.361	0.935	0.149	1	0.699	1.435	0.230	8.968
	No privacy	0.980	0.910	1.160	1	0.281	2.664	0.448	15.838
	Social life	-0.771	0.927	0.691	1	0.406	0.463	0.075	2.849
	Uncomfortable about having friends	1.094	0.742	2.174	1	0.140	2.985	0.698	12.772
	Expectation of taking care	-1.243	0.790	2.474	1	0.116	0.289	0.061	1.358
	Not enough money	-0.577	0.632	0.835	1	0.361	0.561	0.163	1.936
	Unable to take care much longer	0.684	0.667	1.050	1	0.306	1.981	0.536	7.329
	Have lost control of your life	-0.618	0.935	0.437	1	0.508	0.539	0.086	3.367
	Wish to leave the care to someone else	-0.303	0.674	0.202	1	0.653	0.739	0.197	2.770
	Constant	-2.139	1.957	1.194	1	0.275	0.118		

A. Variable(s) Entered in Step 1: Patient asking for more help, Not enough time for themselves, Stressed managing to balance, Embarrassed, Angry, Affecting relationships in negative way, Strained when you are around your relative, Health has suffered because of involvement with relative, Noprivacy, Social life, Uncomfortable about having friends, Expectation of taking care money issues, Not enough money, Unable to take care much longer, Have lost control of your life, Wish to leave the care to someone else.

Table 5: Significant variables i.e., not enough time for themselves

		<i>Variables in the Equation</i>					<i>95% C.I. for odds ratio</i>		
		<i>B</i>	<i>S.E.</i>	<i>Wald</i>	<i>df</i>	<i>Sig.</i>	<i>Odds ratio</i>	<i>Lower</i>	<i>Upper</i>
Step 2B	Not enough time for themselves	1.263	0.506	6.235	1	0.013	3.537	1.312	9.536
	Uncomfortable about having friends	0.941	0.415	5.141	1	0.023	2.564	1.136	5.784
	Constant	-3.450	1.009	11.690	1	0.001	0.032		

a. Variable(s) entered on step 1: Not enough time for themselves.

b. Variable(s) entered on step 2: Uncomfortable about having friends.

greater caregiver self-esteem burden.¹⁶ The caregivers' caregiving experience depends directly on the unmet supportive care needs of the patient. The clinical implication of this study is to make the clinicians aware of the primary caregiver's importance. They should conduct symposiums, and role plays, personal counseling, etc., involving the primary caregiver to make him/her understand their role in the pre and postoperative care of cancer patients. The healthcare professionals should be supportive by assessing the possible workload behavior because at the bedside, irrespective of being reported by the caregivers or not, the caregivers' burden might indicate overload. Therefore, training in caregiving skills, respite services, reconnecting the social network,

and developing hospital discharge programs during the postoperative period, should be implemented by the healthcare professional.

CONCLUSION

This study highlights that the caregivers, though burdened to some extent, wanted to take care of their relatives till the last day. The love and emotional attachment which the primary caregiver has with the patient makes them stretch themselves to the limit in providing primary care. We, as a clinician should set a trend by giving more importance to the primary caregiver, by encouraging them, monitoring them and help them get through their burden in this difficult juncture of their life.



CLINICAL SIGNIFICANCE

The purpose of the study was to create awareness among the professionals to give more importance to the primary caregiver. The importance of primary caregiver in the life of the diseased is paramount because of the emotional attachment they share. So this inter-relationship between the doctor, the patient, and the primary caregiver will help in a significant way in the wellbeing of the patient.

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