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A study to assess the stressors faced by the care givers of patients suffering from oral cancer and their coping strategies at radiation oncology, SVIMS Hospital, Tirupati

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Abstract

The purpose of the study was to assess the stressors and coping strategies, and to find out the association between stressors and coping strategies.

Methods: The research approach was Quantitative approach and the research design was Descriptive cross sectional design which involves the assessment of stress and coping strategies at a single point of time among the caregivers of oral cancer patients, Non-probability convenience sampling technique was used which included 100 caregivers of oral cancer patients. Kingston caregiver stress scale [KCSS] and, Brief COPE inventory scale were used to assess stress and coping strategies.

Results: The findings of study revealed that Majority 52[52%] of caregivers had moderate stress, 25[25%] had some stress, only 23[23%] had a lot of stress, and 42[42%] are using coping strategies a little bit. 33[33%] were using in medium amount, 13 [13%] were not using coping strategy, 12[12%] were using a lot.

Conclusion: Major stressor 60[60%] was financial difficulties associated with care giving and Majority of caregivers were using positive coping strategies. Therefore, it is important to support the positive coping strategies and intervene in order to change the negative coping strategies.

Keywords: Stressor, caregivers, coping strategies, oral cancer

1. Introduction

Cancer is a class of diseases in which a cell or a group of cells display uncontrolled growth or division beyond the normal limits, invasion into adjacent tissues and sometimes metastasis to other locations in the body through lymph or blood. These three malignant properties of cancers differentiate them from benign tumors, which are self-limited and do not invade or metastasize. Oral cancer is any malignant neoplasm which is found on the lip, floor of the mouth, cheek lining, gingiva, palate or in the tongue. Tobacco chewing is the major etiological factor in its development. Other factors include alcohol, genetic factors, and diet lacking in micronutrients and vitamins. Oral cancer is among the top three types of cancers in India. Right from the diagnosis of the disease till the end care the patients are completely dependent on family members ^[1].

Cancer is the second most common cause of death worldwide, and the burden of cancer is increasing in all countries. This poses a rapidly growing threat to individuals, health systems, and economies globally. The global cancer burden is expected to reach 29 million new cancer cases per year by 2040, a 62% increase on the estimated 18.1 million cancers in 2018. The increases in the cancer incidence burden will affect all countries, but the predicted increases will be proportionately greatest in low-income countries, due to known infectious agents, chemicals including tobacco, and obesity ^[2].

According to GLOBOCAN 2018 data in 2018 there were 11,57,294 new cancer cases in India in both men and women, estimated oral cancer new cases were 1,19,992 and deaths are 72,616. In general, more men suffer and die from oral cancer than women. Risk of developing cancer before the age of 75 years Male: 9.81% Female: 9.42%3

Total deaths due to cancer in 2018

Total: 7,84,821

Men: 4,13,519

Women: 3,71,302

Care-giving is a job without clearly defined goals. Family caregivers usually begin care-giving without adequate training or expertise and are often expected to provide quality care without significant help. Consequently, a family caregiver ignores his/her own health by prioritizing the patient's needs and well-being. Today, numerous healthcare providers are eager to observe the symptoms of caregiver distress during the provision of cancer treatment to a patient. This is because caregiver strain reduces the effectiveness of care-giving, and consequently the patient suffers adverse effects. Therefore, helping the caregiver equates to helping the patient (National Cancer Institute 2012) [3].

Cancer patients experience various problems regarding both their disease and their treatment methods. Caregivers are directly affected by the change in the physical capability, body functions, appearance, job status, sexual functions and roles within the family and society of patients. Caregivers experience stress when patients cannot cope with the symptoms they are experiencing. The stress experienced by caregivers gives rise to psychological symptoms such as stress, depression, anxiety, fear, loneliness, psychosomatic symptoms and marital problems, and physical symptoms such as tiredness, anorexia, indigestion, constipation, serious sleeping disorders and pain. Family member caregivers have no idea how to carry out their carer role, how much care the patient needs and how to use current resources as they usually feel unprepared, have inadequate information regarding the disease and the care required and have limited support from health care givers. As a result, they neglect their own health and portray inadequate coping reactions. Coping is the process of managing requirements and difficulties caused by the individual's inner and outer world, expending cognitive and behavioral efforts to solve personal and interpersonal problems and seeking to control and reduce stress [4].

High stress levels in caregivers can interfere with their ability to provide the emotional or logistical support patients need. Problematic family relationships that predate the onset of cancer also can lead to inadequate support from the family. Both of these situations can exacerbate the patient's stress, which in turn can contribute to the patient's poorer adjustment to the illness. Thus, attending to the needs of the families of patients not only will benefit family members but also may help patients with their own emotional responses and management of their disease. Families who sacrifice so much for the care of their loved ones deserve access to effective interventions and psychological care [5].

1.1 Objectives

- To assess the stressors and coping strategies of the caregivers of oral cancer patients.
- To find out the association between stressors and coping strategies of oral cancer caregivers with their selected demographic variables.

2. Methodology

2.1 Study design

This study was designed as a descriptive research approach. Design was Cross sectional descriptive research design. Prior permission was obtained from head of the department

of radiation oncology to conduct the study. 100 samples were selected by non-probability convenient sampling technique. The study was conducted in the radiation oncology, SVIMS, Tirupati. Data was collected from first degree relative[parent/spouse/children] taking care of patients. Before the study, participants were informed verbally about the aim of the study and took a written consent, then administered the questionnaire to the patients through interview schedule and the responses of the participants were recorded. After completion of data collection a information booklet was given on stress management and coping strategies to each participant for future references.

2.1.2 Data collection tool and techniques

Three scales and a demographic sheet were to be filled by the subjects. Socio demographic data of caregivers Consists of age, gender, religion, marital status, education, occupation, residence, type of family, monthly family income, relationship with patient, length of time involved in caregiving, government health benefits receiving by the patient, duration of work leaving, distance in kilometers from home to hospital, transportation cost, amount spent on cancer treatment, any information received on stress and coping. Kingston care giver stress scale (Hopkins & Kilik, 2004) was used to measure the stress of the care givers. This scale monitors changes in family care givers stress level over time. It has 10 items divided into three sub scales: care giving issues, family issues and financial issues. Brief COPE inventory scale [Carver, C.S.1997] was used to assess the coping strategies used by the caregivers of oral cancer patients. The Brief-COPE is a 28 item self-report questionnaire designed to measure effective and ineffective ways to cope with a stressful life event. Analysis of the data was done by using descriptive and inferential statistics.

3. Results

Frequency and distribution of Demographic variables showed that maximum sample belongs 39[39%] of caregivers are in age group of 26-35 years, 27[27%] were from 36-45 years, 56[56%] of caregivers were male 85[85%] of caregivers were hindus, 79[79%] were married, 36[36%] of caregivers were cooli, 74[74%] of caregivers were residents of rural area, 92[92%] of caregivers were from nuclear family, 41[41%] of caregivers family income is from 5000 – 10000, 42[42%] of caregivers were childrens of patients, 89[89%] of caregivers involved 0-6 months in caregiving, 96[96%] of patients were receiving arogyasri, 86.3[86.3%] of caregivers left <6 months work for caregiving, 26[26%] of caregivers travelling more than 150 km from home to hospital, 47[47%] of caregivers transportation cost is below 500, 27% of caregivers spent less than 10000 on treatment till date, 89% of caregivers have not received any information regarding stressors and coping strategies.

Distribution of sample according to stress level. [Fig 1] Stress level ranges from 1-50, 1 – 10 -No Stress, 11- 20 - Some stress, 21 – 30 -Moderate stress, 31 – 40 – A lot of stress, 41 – 50 extreme stress

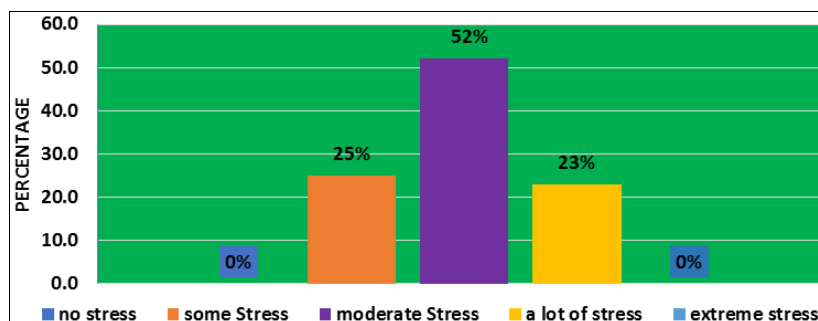


Fig 1: shows Majority of the caregivers 52[52%] were having moderate stress, 25[25%] were having some stress, only 23 [23%] having a lot of stress, none of them had no stress and extreme stress.

Table 1 shows that majority of caregivers 42[42%] were using coping strategies a little bit, 33[33%] were using in

medium amount, 13 [13%] were not using, 12[12%] were using a lot.

Table 1: frequency and percentage distribution of coping strategies

4-point likert scale of Coping strategies	frequency(f)	Percentage (%)
I haven't been doing this at all	13	13.0
I have been doing this little bit	42	42.0
I have been doing this a medium amount	33	33.0
I have been doing this a lot	12	12.0

Table 2 shows the Paired sample t-test shows that there is significant association between stress and coping significant at 0.01 level.

Table 2: Paired sample t-test

Paired Samples Statistics					t-test	Sig. (2-tailed)
	N	Mean	Std. Deviation	Std. Error Mean		
Paired	KCC	100	22.39	2.950	53.341**	0.000
	cope	100	50.17	4.120		

Association of demographic variables with the level of stress among the caregivers of oral cancer patients showed that, Age, gender, Marital status, education, type of family, monthly income, Relationship with patient, length of time involved in caregiving, duration of work leaving, transportation cost, amount spent on caregiving, significant at $p < 0.05$. Association of demographic variables with the coping strategies showed that Age, gender, monthly income, relationship with patient, duration of work leaving, distance, transportation cost, amount spent on cancer treatment till date shows significant association at $p < 0.05$ level other factors found to have no any significant association with coping strategies.

Table 3 Shows that the mean and standard deviation of total level of stress among the caregivers of oral cancer patients at radiation oncology was 24.86 ± 5.8 , for coping strategies 50.17 ± 4.120 .

Table 3: Mean and standard deviation for stress and coping strategies

Domains	Mean	Standard Deviation
Stress	24.86	5.847
Coping strategies	50.17	4.120

Item analysis of Kingston caregiver stress scale revealed that 41[41%] of caregivers have some stress regarding Feelings of being overwhelmed, or over worked and or overburdened, 54[54%] of caregivers have some stress about change in relationship with their spouse/relative,

47[47%] of caregivers have some stress regarding changes in their social life, 9[9%] of caregivers have some stress regarding Conflicts with their previous daily commitments, 45[45%] of caregivers have some stress regarding Feelings of being confined or trapped by the responsibilities Or demands of care giving. 52[52%] of caregivers have some stress regarding Feelings related to a lack of confidence in your ability to provide care, 38[38%] of caregivers have moderate stress Concerns regarding the future care needs of your spouse/relative. 53[53%] of caregivers have no stress regarding conflicts within their family over care decisions, 69[69%] of caregivers have no conflicts within their family over the amount of support and receiving in providing care. 60% of caregivers have moderate stress regarding financial difficulties associated with care giving.

Item analysis of brief cope inventory revealed that shows that 53[53%] of caregivers are using self distraction, 68[68%] of caregivers are using active coping, 12[12%] of caregivers are using denial 5[5%] of caregivers are using substance use, 82[82%] of caregivers are using emotional support, 52[52%] of caregivers are using instrumental support, 39[39%] of caregivers are using Behavioural disengagement, 48 [48%] of caregivers are using venting, 57[57%] of caregivers are using positive reframing, 75[75%] of caregivers are using planning, 100[100%] of caregivers are using humor, 12[12%] of caregivers are using acceptance, 9[%] of caregivers are using religion, 16 [16%] of caregivers are using self blame. Shown in fig 2 and 3

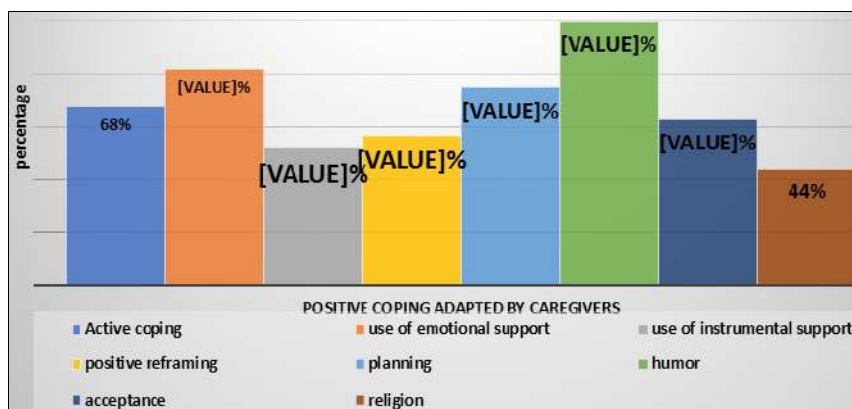


Fig 2: Positive coping adapted by Caregivers

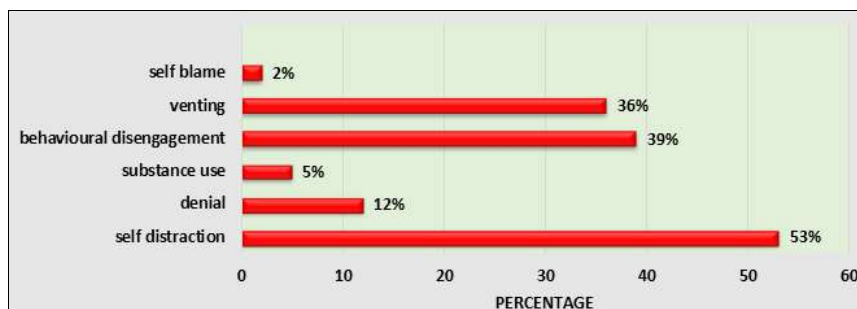


Fig 3: Negative coping adopted by caregivers

4. Discussion

Basit Ansari, Sara Sitara Qureshi, Conducted a study on stress and coping in caregivers of cancer patients in University of Karachi. The objective of the study is to explore the level of stress and coping ways in caregivers of cancer patients. The total sample size includes 200 caregivers both male and female. The findings of the study reveals that there are significant differences in the level of stress, coping and social support between the caregivers of nuclear and joint family system as $P < 0.05$. Hence proving that, a strong social support from family and friends plays a crucial role in the wellbeing of patients^[4].

Lovely Antony, Linu Sara George, Tessy Treasa Jose, conducted a study on Stress, coping, and lived experiences among caregivers of cancer patients on palliative care. The sample size for quantitative approach was eighty and qualitative approach was eight. The results showed that 74% of the participants were females and 30% of them belong to the age group between 51 and 60 years. Fifty-four percent of them belong to Hindu religion and 40% were unemployed. Sixty-two percent of the patients were dependent on caregivers for all activities of daily living. Assessment of stress revealed that 82% of the participants had moderate stress and 18% had severe stress. Participants adopted both negative and positive coping. There was a significant negative correlation ($r = -0.722$, $P = 0.001$) between stress and coping^[5].

5. Conclusion

The study findings revealed that majority of caregivers were having Moderate stress. Major stressor found was financial difficulties. Majority of caregivers were using positive coping strategies, but there were still caregivers that displayed negative coping strategies. Therefore, it is important to support the positive coping strategies and intervene in order to change the negative coping strategies.

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