# Effect of Palliative Care Interventions on Symptom Profile in Head Neck Cancers: A Prospective Observational Trial

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#### Summary

Head and Neck cancer patients often present with diversity of distressing physical and psychological symptoms, which significantly affect quality of their life. This study aims to assess effectiveness of palliative care interventions on symptom profile in Head and Neck cancer patients. This single centre prospective observational study was done on 173, adult patients with Head and Neck cancer, referred to Palliative Medicine outpatient department at a tertiary cancer hospital in India. Patients were regularly assessed as a part of routine protocol. Symptoms were assessed and compared by Edmonton symptoms assessment system at baseline which was considered day zero and at day seven. Palliative care was given in the form of symptomatic management and nursing care. Out of 173 patients, from 20 to 75 years of age with mean age of 48.15 years, 130 were male and 43 were female. Most common symptoms as mean ± standard deviation on Edmonton symptoms assessment scale were pain(5.86±2.30), fatigue(4.42±2.45), loss of appetite (4.54±2.69) and insomnia(3.54±3.03) on day zero. After seven days with palliative intervention, greater number of patients experienced improvement in their symptom profile like pain(1.50±1.61) (P < 0.0001), fatigue $(2.34 \pm 1.97)(P < 0.0001)$ , loss of appetite(1.86±1.83)(P<0.0001) and insomnia(1.24±2.02)(P< 0.0001). Feeling of well being had statistically very significant improvement (P<0.0001). All other symptoms were having mild to moderate scores on ESAS scale. Patients with advanced Head and Neck cancer have a significant burden of symptom. A palliative care intervention significantly reduces the symptoms burden and thereby improve the quality of life of patients and care givers.

**Key words:** Head and neck cancer, Symptoms burden, Palliative care intervention

## Introduction

Head and neck cancer (HNC) is the most prevalent and the most common cancer found in Indian population.<sup>1</sup> Standard treatment measures include surgery, radiotherapy and chemotherapy. Patients with HNC often present with spectrum of symptoms ranging from physical to spiritual issues.<sup>2</sup> Mixed type (Nociceptive and neuropathic) pain is seen in more than two third of patients. Changes in body images and involvement of nerves are responsible for severe pain and distress in such patients. This dramatically affects their physical, psychosocial functioning and thus quality of life. Previous studies showed positive effect of palliative care interventions in patients suffering from advanced cancers.<sup>3</sup> Hence, we decided to conduct an observational trial to see the effect of palliative care interventions on symptom profile in HNC patients at a tertiary cancer centre.

## **Material and Method**

This single-institutional, prospective, questionnaire-based study was conducted after Institutional Review Board approval. Consecutive patients who were referred to palliative medicine outpatient department (OPD) over a period of three months from first April to thirty first June 2018 were enrolled in this study. Inclusion criteria for study were, age between 20 to 75 years, able to understand Hindi or Gujarati language, clinical diagnosis of advanced head and neck cancer (stage III or IV) and consenting to participate in study. Patients with any psychiatric illnessor refusing to participate were excluded from study.

Patients were assessed for their symptoms using Edmonton Symptom Assessment System (ESAS) at baseline which was considered day zero and at day seven of starting Palliative care intervention.

Palliative care was given in the form of Symptomatic management, counselling to develop copping skill with psychological support, generalised nursing care and diet counselling regarding semi solid or liquid diet and nasogastric tube feeding.

Pain treatment was given according to WHO step ladder guideline. Generalised nursing care was taught to patient and care giver, e.g. dressing of wound, nasogastric tube feeding and oral hygiene.

## The ESAS tool

The ESAS is a ten-items symptom assessment questionnaire, where patients rate their symptoms from zero to ten on a visual analogue scale.<sup>4</sup> This questionnaire can be completed by the patient alone or with the assistance of a proxy. Although the reliability of the use of a proxy is questionable as many times the result is an assessment that underestimates patients' Quality of life (QOL). The assessed ESAS symptoms, that patient may be experiencing include pain, fatigue, nausea, depression, anxiety, drowsiness, breathlessness, appetite, insomnia, and other problems. A score of zero corresponds to the absence of the symptom, and ten corresponds to the symptom being of the worst

Table	1:	Demographic	data
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Characteristic	No of Patients
Study Duration	1st April to 31st July 2018
Total No of Patients	173
Age (Mean) years	48.152 (Range 20-75) <60 years – 136 >/=60 years – 37
Sex (M:F)	130:43
Education level <10th grade >10th grade	150 23
Socioeconomic status Poor Middle Upper	121 34 18

Table 2:	Diagnosis	of 173	patients
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Diagnosis	No of Patients and Percentage (%)	
Ca Tongue	59 (34.10)	
Ca Buccal Mucosa	42 (24.27)	
CaAlvelous	9 (5.20)	
Ca Larynx	5 (2.89)	
Ca Lip	3 (1.73)	
CaMaxila	7 (4.04)	
Ca Retro Molar Trigone	5 (2.89)	
Ca Pyriform Fossa	9 (5.20)	
Muo Neck	9 (5.20)	
Ca Post Cricoid	5(2.89)	
Tonsil	3(1.73)	
Ca Parotid	6 (3.46)	
Carcinoma with Unknown Primary	5(2.89)	
Ca Hard Palate	4 (2.31)	

possible severity. Feeling of well being is more at score zero and worst at score ten.

#### **Statistical Analysis**

Demographic information was summarized through descriptive statistics. Mean scores were compared at day zero and at day seven using paired t test. p value of <0.05 was considered as statistically significant. Statistical analysis was done using Graph Pad Quick Calcs online calculator.

#### Results

A total of 173 patients with head and neck cancer were enrolled during period of three months. All patients filled ESAS at baseline day zero and at follow up on day seven. Range of patients' age was from 20 to 75 years with mean age of 48.15years. 130 patients were male and 43 were female.(table1). Majority of them were from poor socio-economical class and were nongraduated (Table 1)

Primary sites of cancer were, tongue (59), buccal mucosa (42), retromolar trigone (5), larynx (5), parotid (6), post cricoid (9), maxilla (5), pyriform fossa (9), tonsil (3), MUO Neck (9), alveolus



**Figure 1:** Graphical presentation of Mean values of different parameter according to ESAS, on day zero and on day seven after palliative intervention

Table 3: Symptoms – Mean values ± standard deviation and P value of different parameter according to ESA	AS,
on day zero and on day seven after palliative intervention	

Symptoms	No of patients having moderate to severe symptoms	Day 0	Day 7	P value
Pain	142	5.86±2.30	1.50±1.61	0.0001
Fatigue	68	4.42±2.45	2.34±1.97	0.0001
Nausea	21	1.18±2.48	0.44±1.30	0.645
Depression	38	2.54±2.62	1.30±1.88	0.0077
Anxiety	31	2.80±5.17	0.92±1.41	0.0148
Drowsiness	13	0.96±1.87	0.46±1.05	0.1032
Breathlessness	22	1.28±2.16	0.42±1.30	0.0175
Anorexia	87	4.54±2.69	1.86±1.83	0.0001
Other (sleep disturbance)	65	3.54±3.03	1.24±2.02	0.0001
Feeling of Wellbeing	113	5.24±2.25	0.42±0.91	0.0001

(9), lip (3) carcinoma of unknown primary (5) (Table2) at baseline, most prominent symptoms were pain and fatigue. Mean scores for these symptoms were 5.86±2.30 and 4.42±2.45 respectively on day zero and 1.50±1.61 (P <0.0001) and 2.34±1.97 (P <0.0001) on day seven after palliative interventions. Most of the patients complained about mixed type of pain, i.e., both nociceptive and neuropathic pain. Other symptoms those relatively scored high on ESAS were sleep disturbances, loss of appetite, depression and anxiety with a mean score of 3.54±3.03, 4.54±2.69, 2.54±2.62 and 2.80±5.17 respectively on day zero, and those also had significant improvement on day seven, i.e. 1.24±2.02 (P<0.0001), 1.86±1.83 (P<0.0001), 1.30±1.88 (P<0.0077) and 0.92±1.41 (P<0.0148). As there were good symptom control, feeling of wellbeing had statistically very significant improvement (P<0.0001).All other symptoms were having mild to moderate scores on ESAS scale(Table 3).

Four symptoms and feeling of wellbeing demonstrated statistically significant improvement at day seven. Some of the symptoms showed mild to moderate improvement. (Figure 1)

## Discussion

The National Cancer Institute defines head and neck cancer as "cancer that arises in the head or neck region (in the nasal cavity, sinuses, lips, mouth, salivary glands, throat or larynx)". Most head and neck cancers are squamous cell carcinomas.<sup>5</sup> Globally it is ninth most common cancer and cause of cancer mortality.<sup>6</sup> and remains a potentially disfiguring disease.<sup>7</sup> Head and neck cancers are the most common cancers in developing countries.<sup>1</sup> Gujarat is one of the most affected states in India.<sup>8</sup> In our study Head and neck cancers are more common in males compared to females and same results have been given by Mohammad ShadabAlam and team in their study 'Epidemiological profile of head and neck cancer patients in Western Uttar Pradesh and analysis of distributions of risk factors in relation to site of tumor.<sup>9</sup>

This is mainly attributed to tobacco, areca nut, alcohol, etc. Poverty, illiteracy, presentation at advanced stage, lack of access to health care and poor treatment infrastructures are the major challenges in management of head and neck cancers.<sup>9</sup> Level of education is directly related to consumption of tobacco and related products. Use of tobacco is more popular in the developing countries.<sup>10</sup> It is more prevalent among men, rural population, illiterates, poor, and vulnerable section of the society.<sup>11</sup> Patients with advanced HNC often presents with numerous symptoms which include variety of physical symptoms and psychological issues and social problems. Common symptoms and signs observed in such patients are pain, oral mucositis, insomnia, fatigue, fungating wound, oral dryness, dysphasia, weight loss, communication difficulties, feeding difficulties, halitosis, loss of appetite and fatigue.<sup>2</sup> According to WHO, palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with lifethreatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.<sup>12</sup> Palliative care takes a holistic approach. Treatment modalities which may be appropriate to palliative care include oncological and surgical approaches, drug management, psychological support, and complementary therapies. It is important to make effective decision in palliative care setting. Patient and family should have adequate information about disease status and prognosis. The team should not convey any unrealistic hope simply because the goal is not indefinite survival. Hope can be maintained accordingly to the patient's own goals whether they are physical (symptom relief), psychological (distress, fear of bleeding and unbearable pain in end of life) or social (desire to witness a family event).<sup>12</sup>

Pain is the most common symptom according to our study. Gellrich et al reported that 54% of oral cancer patients had "some type of pain".<sup>14</sup> the head and neck area is highly sensitive to pain due to rich nervous supply and the confinement of many anatomical structures to a small space. HNC is the most common cause of neuropathic pain. It has been suggested that the etiology of pain in head and neck cancer patients is multifactorial, and that pain can be due to a direct tumor effect or as a result of cancer treatment or may be factors unrelated to cancer like age, gender, ethnicity, smoking or drinking. Structural alteration and chronic pain among post treatment survivors of head and neck cancer is very common.15 Due to advanced cancer treatment modalities, the numbers of cancer survivors are increasing but their Quality of life would be affected at the same time if pain is not properly assessed and treated. Therefore, screening programs for timely and early identification of pain are necessary. Epstein et al., who pointed out that orofacial pain improves following treatment and, in many cases, does not return to its baseline value.<sup>16</sup> Clinicians must use a screening tool like Questionnaires for assessing and treating cancer pain at an early stage of the treatment and assessment must include the presence of 'total pain' i.e. physical, spiritual, psychological and social issues. WHO pain ladder should be used to treat pain and for refractory pain specialized pain management services should be considered early in pain palliation. In our study VAS was 8-9 in many of the patients but after effective pain management VAS comes down to 2-3 in same population of patients.

**Insomnia** increases cancer symptom burden and impairs quality of life. It is common complaint in head and neck cancer patients with an incidence reported ranging from 30% to 75% and it includes early awakening, excessive day time sleep, difficulty falling asleep, poor sleep efficacy, difficulty in maintaining sleep. It affects quality of life, decrease work attentively, decrease mental health, and serve as a consequence of other complications.<sup>17</sup> Insomnia is correlated with pain, fatigue, anti-cancer treatment and depression in most of the patients. The correlation between pain and insomnia in head and neck cancer patients has been previously demonstrated by Rogers LQ, Courneya KS, Robbins KT, et al.in their study 'Factors associated with fatigue, sleep, and cognitive function among patients with head and neck cancer'.<sup>18</sup> Management includes Systematic screening, Pharmacological and Non-pharmacologic therapies like cognitive behavioural therapy. Management of associated symptoms like fatigue, pain, and hot flashes with appropriate symptom-specific agents is important.<sup>19</sup> Successful management have shown a significant positive impact on global quality of life in our study.

Fatigue or cancer related fatigue [CRF] is defined by The National Comprehensive Cancer Network (NCCN) as "a distressing persistent, subjective sense of physical, emotional and/or cognitive tiredness or exhaustion related to cancer or cancer treatment that is not proportional to recent activity and interferes with usual functioning".<sup>20</sup> It is more common in patients on chemotherapy and radiotherapy.<sup>21</sup> Fatigue affects the patient's physical and psychosocial well being and ability to work. Assessment of fatigue includes 1-laboratory studies ,2-disease status and treatment given and 3-fatigue characteristics like severity, onset, duration, exacerbating and alleviating factors and impact on quality of life. Psychosocial interventions and Pharmacological treatments help in patients with fatigue.

**Loss of appetite** or anorexia may be simply defined as either loss of appetite or reduced caloric intake. It is always associated with weight loss. It is a common concerning symptom among patients with cancer, particularly those with advanced-stage disease and may result from disease itself, chemotherapy, radiation or a variety of other causes, including physical and psychological causes. Reduced calorie intake, alterations in basal energy expenditure, alterations in nutrient metabolism and emotional stress may be the cause of weight loss. Management of Cancer-related anorexia and weight loss includes appetite stimulants, anti-catabolic agents and addressing the psychological issues.<sup>22</sup> As the patient has already experienced a lot of complex issues throughout the trajectory of the disease, an individualized, comprehensive, and interdisciplinary approach is needed to reduce patient suffering and ensure appropriate symptom management and support from the time of diagnosis to end of life. Patients provided with early palliative care can experience relief of symptoms and improvements in quality of life, mood, satisfaction, resource use, and advanced care planning.<sup>3</sup> For an effective palliative care, it is important for oncologists to be familiar with the principles of primary palliative care and interdisciplinary team-based approaches to palliative care. Palliative care is a key component of oncologic care, and we highly recommend that it should be integrated into the plan of care for patients with advanced cancer.<sup>23</sup> A number of trials indicates that early palliative care interventions in patients of incurable cancer, who is suffering physically and psychologically have shown more improvements in QOL and symptom intensity than among those given standard cancer care.<sup>24</sup>

## Conclusion

Palliative care takes a holistic approach addressing physical, psychological, social and spiritual needs of the patient, their care givers and family. Head and neck cancer patients present with many physical and psychological symptoms. In our study we found that with intervention of palliative care greater number of patients experienced significant improvement in pain, fatigue, anorexia and insomnia. They also had improvement in depression, anxiety and overall welling.

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## " Great things are done by a series of

small things brought together. "

Vincent Van Gough