

# Symptom Burden and Quality of Life in Advanced Head and Neck Cancer Patients: AIIMS Study of 100 Patients

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## ABSTRACT

**Aim:** Head and neck cancers (HNCa) are the most common cancers among males in India and 70-80% present in advanced stage. The study aims to assess symptom burden and quality of life (QOL) in advanced incurable HNCa patients at presentation.

**Materials and Methods:** One hundred patients were asked to fill EORTC QLQ-C15-PAL questionnaire, which consisted of Global QOL, physical functioning (PF), emotional functioning (EF), fatigue (FA), nausea-vomiting (NV), pain (PA), dyspnea (DY), sleep (SL), appetite (AP), and constipation (CO). Additional questions pertaining to swallowing (SW), hoarseness (HO), cough (CG), weight loss (WL), using pain killers (PK), taste (TA), bleeding (BL), hearing (HE), pain in neck lump (PALMP), opening mouth (OM), and oral secretions (OS) were asked based on a modified EORTC-HN35 questionnaire. Scoring was according to EORTC scoring manual. Mean, median and range were calculated for each item for the entire cohort.

**Results:** The female:male ratio was 17:83.42% of them were  $\geq 60$  years of age. Sixty-six patients had T4, 25 had T3, 36 had N2, and 33 had N3 disease. Median QOL was 50 (range 0-83.33) and PF was 77.78 (0-100). Median score for EF and FA was 50. Median score for PA, PK, and SL was 66.67 while that for AP was 33.33. Median value for SW, HO, WL, BL, PALMP, OM, and OS was 33.33 (100-0) while TA, CG, NV, DY, and HE had a median score of 0.00.

**Conclusion:** Advanced HNCa has a significant burden of symptoms. These results would help in giving patients better symptom directed therapies and improve their QOL.

**Key words:** Head and neck cancers, Palliative care, Quality of life, Symptom burden

## INTRODUCTION

Palliative care aims at ameliorating the distressing symptoms and improving the quality of life (QOL) in patients with malignancy or other chronic illnesses.<sup>[1,2]</sup> Studies of cancer-related symptoms in the palliative care setting have traditionally focused on isolated symptoms. However, cancer patients comprise of a population in which symptoms are numerous and intense,<sup>[3,4]</sup> which may

explain why treating one symptom may not necessarily improve QOL. The life of patients with end-stage head and neck cancer (HNCa) gets entangled in numerous physical and psychological symptoms. Previous studies have found pain (50-85%), dysphagia (30-55%), airway obstruction, fungating wound, and mucosal dryness to be the alarming problems in patients with HNCa.<sup>[5,6]</sup> Palliative care for such patients is utterly challenging because of the impact of tumor on the airway, the upper gastrointestinal tract, and other homeostatic mechanisms such as fluid-electrolyte imbalance, chronic mucosal inflammations, or infections due to immunosuppression, hearing, or voice production, etc. Communication plays a pivotal role in good palliative care. The provision of good pain and symptom control and psychosocial care is often difficult because of communication problems, especially for patients with

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DOI:  
10.4103/0973-1075.138389

HNCa, as a result of tracheostomy or obstruction of the upper airway due to a progressive tumor growth. A vivid, pertinent questionnaire sensitive to assess short-term HNCa symptoms could lead to their accurate identification and quantification, allow earlier interventions for individual patients, and serve as a research tool to compare the symptom burden associated with various treatment options. It should be specific for a particular set of population with regards to the site and stage of primary tumor and the demographic characteristics. Such studies on QOL and symptom burden can enlighten us with information that guides healthcare-related decision making on several levels.<sup>[7]</sup> It allows us to set-up a good liaison between the patient and the physician to address the symptoms and issues related to QOL since the very beginning. Thus, it ultimately results in better patient compliance and saves valuable time in a busy clinic. It can help shape public policy and healthcare decisions and also guide the research agenda of pharmaceutical companies and cooperative groups. The current study, first of its kind from India, aimed to determine the symptom burden amongst incurable advanced HNCa patients.

## MATERIALS AND METHODS

### Patient selection

Between August 2011-2012, 100 patients of locally advanced HNCa patients deemed unsuitable for curative cancer treatment were prospectively included in this observational study after informed consent. The patients were evaluated in a multidisciplinary HNCa clinic by a team comprising of an oto-rhino-laryngologist, a medical oncologist, and a radiation oncologist. The study was approved by the institutional review board and ethics committee.

### Instruments used

PAL\_ADD: Patients were asked to fill a pre-structured proforma (Appendix 1), which included information about patient demographics (age, sex, educational status, economic status, distance from institution, co-morbidities, addictions, histopathology, site of the disease, and Karnofsky performance status). Questions pertaining to swallowing (SW), pain in mouth/jaw/throat (PA), hoarseness (HO), cough (CG), weight loss (WL), use of pain killers (PK), taste (TA), bleeding from tumor (BL), hearing (HE), pain in neck lump (PALMP), opening mouth (OM), and oral secretions (OS) based on a modified abbreviated EORTC-HN35 questionnaire (European organization for research and treatment in cancer head and neck questionnaire no. 35-a 35-point module developed specifically for HNCa). Patients were asked to grade their

symptoms on a four point scale (4 = 'very much', 3 = 'quite a bit', 2 = 'a little', and 1 = 'not at all').

Patients were also asked to fill EORTC QLQ-C15-PAL (Version 1) (European organization for research and treatment in cancer, QOL questionnaire). The questionnaire is an abbreviated 15-item version of the EORTC QLQ-C 30 (a questionnaire used to assess the QOL of cancer patients) developed for only palliative care. It contains 2 questions for fatigue (FA) and pain (PA) each and 1 question each for nausea and vomiting (NV), dyspnea (DY), sleep (SL), appetite (AP), and constipation (CO). Additionally, it contains 3 questions pertaining to physical functioning (PF), 2 questions for emotional functioning (EF), and 1 question for global QOL. The response for all items except QOL are graded on a four-point scale (4 = 'very much', 3 = 'quite a bit', 2 = 'a little', and 1 = 'not at all'). QL is a graded on a seven-point scale (1-7, one for very poor and 7 for excellent).

### Statistical analysis and calculation

The scoring procedures for the questions included in both the questionnaires were done as per the EORTC scoring manual as described below.

Raw score (RS) is calculated by average of the items in a particular scale (for example, physical functioning includes 3 points and the raw score for PF is calculated as sum of score for point 1-3 divided by 3).

Score (S) is obtained by applying a linear transformation to 0-100:

Functional Scales (PF, EF):  $S = [1 - \{(RS-1)/range\}] \times 100$

Symptom scale:  $S = [(RS-1)/range] \times 100$

Global health status/QOL:  $S = [(RS-1)/range] \times 100$

Range is the difference between the maximum possible value of RS and the minimum possible value. Most items are scored 1-4, giving range 3. The global health status/QOL question is scored 1-7, giving range 6.

Mean, median, and standard deviation of the scores thus obtained were calculated.

## RESULTS

### Patient characteristics

Median age of the patient was 55 years (range 22-80 years) and male:Female ratio was 83:17. Median

monthly income of the patients was 4500 INR (range 0-27,000 INR). Median distance from institution was 100 kilometers (range 3-1500 kilometers). About 82% patients had education of below class 12; 16% patients had medical co-morbidities in the form of diabetes, tuberculosis, hypertension, hypothyroidism, asthma etc. About 75% patients were smokers (bidi/cigarettes), 27% were tobacco/gutkha chewer, 10% were addicted to alcohol, and 20% of the patients had more than one addiction. Median number of smoking pack-years was 17 (range 1-70). Rest of the patient characteristics are as summarized in Table 1.

Table 1: The patient characteristics	
Characteristics	Patient (n)
Age (years)	
<60	58
≥60	42
Sex	
Female	17
Male	83
Educational level	
Below 12 <sup>th</sup> grade	82
12 <sup>th</sup> grade and above	18
Disease site	
Oral tongue	12
Oral cavity except tongue	19
Oropharynx	46
Base of tongue	27
Tonsil	19
Larynx	14
Carcinoma unknown primary	05
Others	04
KPS	
<70	53
≥70	47
T stage	
TX	05
T2	04
T3	25
T4	66
N stage	
No	15
N1	16
N2	36
N3	33

KPS: Karnofsky performance status

### EORTC QLQ score according to QOL C-15 PAL questionnaire

Median QOL of the entire study cohort was 50 (Range 0-83.33) and PF was 77.78 (0-100).

The median score for EF and FA was 50 in the entire cohort (range for both being 0-100). The median score for NV was 0 while that for PA was 66.67. The median score for DY and CO was 0 while that for SL and AP was 66.67 and 33.33, respectively. The range for all these items was 0-100. The details of the score sheet are available in Table 2.

### EORTC QLQ score according to the modified questionnaire (PAL\_ADD)

The median values for PA, SW, OM, HO, BL, PALMP, OS and WL were 33.33 while 0 was the median score for TA, HE and CG. Only PK had a median score of 66.67. The values range from 0-100 for all the items except PA for which the values range from 0-78. The details are shown in Table 3.

### Other important findings

Over all the top four symptoms in our study, cohort are pain ( $n = 98$ ), insomnia ( $n = 89$ ), loss of appetite ( $n = 89$ ), and fatigue ( $n = 84$ ). However, the common grade 3/4 symptoms were dysphagia ( $n = 73$ ) followed by pain (including PALMP) ( $n = 64$ ), oral secretions ( $n = 32$ ), and trismus ( $n = 21$ ).

### Discussion and review of literature

According to GLOBOCAN 2012, HNCa is the most common malignancy among males in India. The overall age standardized rates of incidence of oral cavity, nasopharynx, and other pharyngeal cancers are 7.2, 0.3, and 3.7, respectively. The distribution of site of involvement is markedly different from other parts of the world. While oral cavity is the most commonly involved site in India, pharyngeal primaries rank top in the developed countries. Similarly, nasopharyngeal cancer is highly prevalent in the south-east Asia region.<sup>[8]</sup> Approximately 80% of the HNCa patients in developing countries present in Stage III and IV disease, and roughly around 40% of these patients are suitable only for palliative radiotherapy. The time

**Table 2: The mean and median values of different parameters according to C15 PAL questionnaire**

Parameters	QOL	PF	EF	FA	NV	PA	DY	SL	AP	CO
Mean	50.84	68.93	52.36	48.48	9.76	60.10	20.54	49.83	31.65	21.21
Median	50	77.78	50	50	0	66.67	0	66.67	33.33	0

QOL: Quality of life, PF: Physical functioning, EF: Emotional functioning, FA: Fatigue, NV: Nausea and vomiting, PA: Pain, DY: Dyspnea, SL: Sleep, AP: Appetite, CO: Constipation

**Table 3: The mean and median values for different parameters according to modified questionnaire (abbreviated HN-35)**

Parameters	PA	SW	OM	CG	WL	BLE	HO	PALMP	HE	PK	TA	OS
Mean	29.89	38.22	37.67	24.00	49.00	26.67	35	47.67	11.67	62.33	20.67	40
Median	33-33	33-33	33-33	0.00	33-33	33-33	33-33	33-33	0	66.67	0	33-33

PA: Pain, SW: Swallowing, OM: Opening of mouth, CG: Cough, WL: Weight loss, BLE: Bleeding, PALMP: Pain in lump, HE: Hearing, PK: Pain killers, TA: Taste, OS: Oral secretions, HO: Hoarseness

consumed for pre-treatment evaluation and staging may be as long as 49 days.<sup>[9]</sup> Patient compliance varies significantly according to the intent of treatment: 712/1150 (62%), 406/755 (54%), and 91/262 (35%) in curative, palliative, and supportive care groups, respectively.<sup>[9]</sup>

Our study shows the prevalence of multitude of symptoms in a study cohort comprising of 100 patients of advanced incurable HNCa patients who were offered palliative radiation. The top 4 symptoms are pain, insomnia, loss of appetite, and fatigue. Difficulty in swallowing, problem with oral secretions, difficulty in opening mouth, and constipation are other significant symptoms in our cohort of patients. However, they report lower complaints of dyspnea, loss of taste, cough, loss of hearing, and nausea and vomiting. The median score for requirement of pain killers were 66.67. Similarly, the median intensity of insomnia was 66.67.

These woeful symptoms have affected the normal functioning of the patients miserably. Emotional functioning was affected by 50%, while physical functioning was affected by almost 23% in 50% of the population. The halving of the value of global QOL may be attributed to these diversified symptoms.

Studies assessing symptom burden or QOL parameters have been reported. Studies have shown that various symptoms can be present in patients with advanced malignancies. These symptoms are influenced by primary cancer site, gender, age, and Eastern Cooperative Oncology Group performance status, and they may play a role in overall prognostication of the disease.

A study by Jimenez *et al.*<sup>[10]</sup> have shown that a reduced survival was observed for patients included in the neuropsychological (35 days vs. 21 days;  $P < 0.05$ ) or gastrointestinal symptoms (62 days vs. 36 days;  $P < 0.001$ ).

Lin *et al.*<sup>[11]</sup> assessed the pattern of symptoms in patients of advanced HNCa in Taiwan. In this single institutional retrospective study, the most common symptom experienced was weight loss, followed by pain, cough, dysphagia, feeding difficulties, and communication

difficulties. A statistically significant association of communication difficulties was found with presence or absence of a tracheostomy. The median equivalent dosage of morphine at first hospice admission and expiration was 70 mg/day (range 0-1080) and 160 mg/day (range 0-1600), respectively. In our study, 65-70% of the patients required pain killers at the time of presentation.

The current study has its own limitations. Symptom and QOL assessments have been conducted only at a single point of time. Therefore, one cannot assess the impact of short course palliative radiation on improvement of symptoms and QOL. We also did not analyze the difficulties faced during communication with the patients or the impact of adjunct therapies such as pain medications. The strength of this study lies in its homogenous population of patients, stressing upon almost all symptoms, which are attributable to advanced head and neck malignancies, and thus rules out any bias or heterogeneity in the result. Finally, in a developing nation like ours where the health resources are already taxed with the heavy burden of advanced malignancies, palliative care has a paramount importance from the time of diagnosis, and analysis of symptom burden should be the first step towards establishing a successful palliative therapy. One must not forget the hurdles of communication, which is considerably common especially for HNCa, as most of the patients belong to low socioeconomic strata and have a poor educational background. Therefore, a simple and explicit questionnaire such as the one we used in our study may be the answer to this intriguing problem. Though not proven yet, a thorough and fruitful communication with patients using such instruments may also lead to a better compliance to anti-cancer therapy and may improve the overall dismal prognosis of malignancies in our country.

## CONCLUSION

Advanced HNCa has a significant burden of symptoms at presentation. They lose their global QOL and emotional functioning by about 50%, though they maintain their physical functioning at a higher level. The top 4 symptoms in decreasing order of frequency in our cohort of patients

are pain, insomnia, loss of appetite, and fatigue. A simple and explicit questionnaire, as used in our study could help in quickly screening for the symptom burden and QOL in this group of patients and this would definitely help in delivery of better symptom directed therapies and achieving the holy goal of palliative care.

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**How to cite this article:** Gandhi AK, Roy S, Thakar A, Sharma A, Mohanti BK. Symptom burden and quality of life in advanced head and neck cancer patients: AIIMS study of 100 patients. *Indian J Palliat Care* 2014;20:189-93.  
**Source of Support:** Nil. **Conflict of Interest:** None declared.

<b>Appendix I: Study proforma</b>						
Name		Questions	Not at all	A little	Quite a bit	Very much
Age		Pain in mouth				
Sex		Pain in jaw				
Employment status	(Please tick one) Employed/Homemaker/ Retired without pension/Retired with pension/Medical leave/Unemployed	Soreness in mouth				
Educational status	(Please tick one) 12 <sup>th</sup> standard and below/ Above 12 <sup>th</sup> standard	Pain in throat				
Economic status		Difficulty in swallowing solids				
Personal Income/Month		Difficulty in swallowing liquids				
Family Income/Month		Difficulty in chewing				
Address		Difficulty in opening mouth wide				
(Distance from institution in kilometers)		Cough				
Co-Morbidities		Hoarseness of voice				
Addictions		Bleeding from wound/tumor				
Site of Disease		Lump in the neck				
Histopathology		Difficulty in hearing				
Stage	T N M	Weight loss				
		Need of painkillers				
		Decreased taste of food				
		Problems with oral secretions				