

# Role of Early Palliative Care in Advanced Head-and-Neck Cancers Patients

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## Abstract

Head-and-neck cancers (HNCs) are significant in India. Poverty, illiteracy, lack of access to healthcare, and poor treatment infrastructure pose a major challenge in the management of these cancers. The majority of these patients present with advanced stage and are not amenable to curative treatment. The majority have the potential to benefit from palliative care (PC) interventions. Our experience has been that usually the referrals from HNC clinic for PC are at the end-of-life or terminal stage. Unfortunately, in the state of intractable suffering, it is difficult for patients to understand and fully benefit from the role of PC. Developing an effective working relationship and communication between the PC service and referring surgeons or oncologists is a key to foster more timely, appropriate referral, as both patients and clinicians often misunderstand or fail to recognize the role of PC. In preparation for a quality improvement project to improve access to PC for HNC patients at the All India Institute of Medical Sciences, we reviewed the needs, challenges, conceptual models, and potential of early integration of PC in advanced HNC patients.

**Keywords:** Early palliative care, head-and-neck cancer, palliative care referral

## INTRODUCTION

Head-and-neck cancers (HNCs) pose a significant healthcare burden in India. Over two lakh people are diagnosed with HNC every year.<sup>[1]</sup> HNC constitutes nearly one-third of the total Indian malignancies. Most patients present in an advanced stage of disease due to delays in diagnosis.<sup>[2]</sup> Psychosocial, emotional, and existential distress and other physical symptoms concurrently experienced by patients hamper their quality of life (QOL).<sup>[3]</sup> The integration of palliative care (PC) as a supportive therapy provided along with antineoplastic treatment during the disease trajectory provides holistic patient care and improves the overall well-being in non-small cell lung cancer. On the basis of several such trials, there have been calls generally for the integration of early PC in advanced solid tumors.<sup>[4,5]</sup> Unfortunately, we have observed that patients with advanced head-and-neck malignancies are typically referred for PC only when curative treatments are no longer possible. In the state of intractable suffering, it is difficult for patients to understand the role of PC, and many of the potential benefits of PC such as pain management or family support are lost or delayed. Due to India's unmet need for PC and high burden of

HNC, there is a need for early integration of PC with oncology care in this group. With this article, we aim to review the literature about the role of early PC in advanced HNC patients.

## SYMPTOM BURDEN FOR HEAD-AND-NECK CANCER PATIENTS

The prime aim of PC is to provide symptomatic relief and improve QOL in patients suffering from life-threatening illnesses.<sup>[6]</sup> Symptom burden for HNC patients is high and is due to the tumor itself or acute/chronic complications of treatment.<sup>[7]</sup> HNC patients experience an extensive range of distressing symptoms, some of which are common to other carcinomas and some of which require special considerations.<sup>[7]</sup>

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Murphy *et al.*<sup>[8]</sup> categorized late effects in HNC patients as general or specific functional deficits such as frailty and difficult speech/swallowing, respectively, and musculoskeletal impairment. Literature depicts varying prevalence rates of symptoms associated with HNC patients during various stages of disease trajectory. Hanna *et al.*<sup>[9]</sup> reported pain, fatigue, distress, and difficult sleep as severe symptoms in pretreatment phase. Gandhi *et al.*<sup>[6]</sup> demonstrated pain, insomnia, appetite loss, and fatigue as the most prevalent symptoms in advanced HNC patients in our institute. Symptoms experienced during the end-of-life phase among HNC patients in decreasing order of prevalence are pain, dysphagia, anorexia, fatigue, and dyspnea.<sup>[10]</sup> Oral complications arise as a result of cancer itself or due to its treatment. Those arising due to cancer therapies are summarized in Table 1.<sup>[11]</sup>

Significant symptom burden is experienced by these patients during all phases of their disease trajectory. This clearly signifies the role of PC for symptomatic relief.

### CHALLENGES FOR INTEGRATION OF PALLIATIVE CARE WITH STANDARD ONCOLOGY CARE

Scarcity in four main areas restricts access to PC as follows: access to essential medicines, education/knowledge about PC, resources to develop PC, and government policies.<sup>[12]</sup> The barriers to PC are related to the following domains:<sup>[13]</sup>

1. Education: perception of PC as the end-of-life care by both public and healthcare providers, and inadequate training and education of residents and fellows
2. Policy: lack of funds and reimbursement, regulatory barriers, and fragmented healthcare structure
3. Implementation: lack of standardized criteria for PC referral, scarcity of trained PC professionals, and cultural barriers.

Ahmed *et al.*<sup>[14]</sup> also reported lack of healthcare professionals' education and absence of standardized criteria for screening patients with symptomatic needs as barriers to their referral for PC. In addition, Love and Liversage<sup>[15]</sup> demonstrated that preference for curative treatment and communication skills impact PC referrals. These referrals are mainly for physical symptom control, while psychosocial issues usually get neglected.<sup>[16]</sup>

Although PC has been referred to as human right,<sup>[17]</sup> the services are not being adequately provided to HNC patients. Two broad reasons for this are inadequate access and suboptimal referral to PC. Geographical and policy-related barriers have been a significant hurdle in the Indian PC scenario.<sup>[18]</sup> At Indian hospitals, including All India Institute of Medical Sciences in the recent past, we have observed that PC referrals are suboptimal and inappropriate, with the majority being only for pain management.<sup>[19,20]</sup>

### ROLE OF EARLY PALLIATIVE CARE FOR ADVANCED HEAD-AND-NECK CANCER PATIENTS

When a patient diagnosed with advanced cancer presents at oncology clinic, the focus of care is usually developing a treatment plan for cancer cure. Such patients often experience spiritual and emotional distress along with distressing physical symptoms. The frequency and intensity of these symptoms increase with both chemoradiation and also as a patient approaches end of life. Oncologists often do not routinely screen patients for psychosocial-emotional distress.<sup>[21]</sup>

PC team is trained to provide symptomatic care and psychosocial-spiritual support.<sup>[21]</sup> Integrating PC soon after the diagnosis of advanced cancer can be beneficial in the following ways:<sup>[21-23]</sup>

1. Bridging the gaps in cancer care by providing both antineoplastic and supportive care together
2. Communicating realistic prognostic information
3. Empowering patients and families for shared treatment decision-making about whether to receive symptom-directed care or cancer-focused therapy
4. Encouraging end-of-life discussions, deciding preferences for care, and providing better quality of death
5. Mitigating inappropriate, costly investigations, cancer treatments, and hospitalizations that are unlikely to benefit the patient and inconsistent with goals
6. Improved QOL and satisfaction.

Difficult conversations such as communicating prognosis, clarifying treatment decisions, and identifying and managing patients' evolving symptomatic need benefit from multiple sessions between the PC team and patients. Involving PC teams

**Table 1: Oral complications due to cancer therapies**

Radiation therapy		Chemotherapy	Hematopoietic Stem Cell Transplantation
Acute	Chronic		
Oral mucositis	Osteoradionecrosis	Oral and Gastrointestinal mucositis	Oropharyngeal mucositis
Salivary gland dysfunction-Sialadenitis	Dysgeusia and Ageusia	Neuropathies	Bleeding
Muscular or cutaneous fibrosis	Mucosal fibrosis and atrophy	Hemorrhage	Ulceration
Infection (bacterial, viral or fungal)	Dental caries	Infection (bacterial, viral or fungal)	Dental caries, gingivitis, periodontitis
Xerostomia	Soft tissue necrosis	Xerostomia	Pain
Taste dysfunction	Infection (bacterial, viral or fungal)	Taste dysfunction	Temporomandibular dysfunction
	Xerostomia		Infection (bacterial, viral or fungal)
	Taste dysfunction		Xerostomia
			Taste dysfunction

helps oncology and surgical teams in communicating realistic and accurate details.

## MODELS TO PROMOTE INTEGRATION OF PALLIATIVE CARE WITH ONCOLOGY CARE

Hui and Bruera<sup>[24]</sup> have proposed the following conceptual models for integration:

1. Time based: emphasizes chronological integration
2. Palli-centric (provider-based): based on the level of patients' complexity and settings, it consists of primary, secondary, and tertiary PC teams/providers
3. Oncocentric (issue based):
  - a. Solo practice: provided by oncologist only
  - b. Congress practice: oncologist refers patients for subspecialty care addressing their specific needs
  - c. Integrated care: collaboration between oncology and PC team allows routine referrals.
4. Patient centric (system based): consists of contemporary and integrated models based on eligibility/screening criteria for PC referral.

The application of conceptual models to various clinical settings emphasizes approaches to promote collaboration and communication in clinical practice, provides information about the clinical outcomes of integration, and demonstrates the logistical challenges.<sup>[24]</sup> Based on the clinical structure, the integration can also be classified into the following:

1. Presence of outpatient clinic, inpatient team, and community based<sup>[24]</sup>
2. Stand-alone, colocated, and embedded clinics.<sup>[21]</sup>

## FUTURE RECOMMENDATIONS FOR PATIENT CARE

Recognizing the high physical symptom burden and common psychosocial morbidity of HNC patients undergoing treatment or with advanced disease, PC referral for both physical and psychosocial-spiritual needs is suggested. Early integration of PC for addressing such needs along with antineoplastic treatment is recommended. Gaps in the current state of referrals which may hinder patient care need to be recognized. This may be done by identifying oncologists' perceptions toward PC referrals, addressing their misconceptions, and training them through educational programs and workshops. Processes and guidelines for patient screening for referral to PC should be developed. Defined screening criteria will act as important indicators for adequate resource allocation and will not increase the workload on oncologists and PC physicians in our time-constrained environment.

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### Conflicts of interest

There are no conflicts of interest.

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