ORIGINAL ARTICLE

Integration of Palliative Care into the Management of Head and Neck Malignancies – One Year Experience from a Tertiary Care Hospital in Pakistan

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ABSTRACT

Background: Head and neck cancers represent the second most frequently diagnosed malignancy in Pakistan. Smokeless tobacco and tobacco chewing are identified as a significant etiological factor. Despite recent advances in therapeutic interventions, treatment often results in substantial adverse effects, leading to considerable physical and psychological distress for patients and their caregivers.

Objective: This study aimed to identify prevalent symptoms and assess the incorporation of palliative care in head and neck cancers using the American Society of Clinical Oncology (ASCO) palliative care quality indicators.

Methods: This retrospective study reviewed charts of all patients with head and neck cancers referred to outpatient palliative care services at Aga Khan University Hospital in 2022. Demographic data, tumor characteristics, symptom burden, and end-of-life care indicators were extracted. ASCO quality indicators used included timing of referral, continuation of oncologic treatment, emergency room visits, hospital admissions, home healthcare utilization, and place of death. Statistical analysis was conducted using SPSS version 26.0, with chi-square tests applied for categorical comparisons. P-value ≤0.05 was considered as statistically significant.

Results: A total of 84 patients were referred to outpatient palliative care services, with a mean age of 56 ±18 years. The majority of patients were male (67%). The most common reason for referral was a high symptom burden, with facial pain (60%). The average time from diagnosis to the first palliative care visit was 52 ± 12 weeks. The median follow-up duration after palliative care referral was 42 days, with a mean follow-up of 113±44 days. Of the total cohort, 30% of patients (30%) died, and of them, 18% died at home.

Conclusion: Patients who received four or more outpatient palliative care visits experienced better symptom control, higher rates of home-based end-of-life care, and fewer emergency room visits. Prolonged engagement with palliative care services was associated with improved coordination of end-of-life care and overall quality of care.

Keywords: *Head and neck cancer, palliative care, symptom management, end-of-life care, quality indicators.*

INTRODUCTION

Head and neck cancers rank as the second most common cancer in Pakistan and smokeless tobacco is the most significant contributor [1, 2]. Globally, oral cavity cancer is most prevalent and overall ranks sixth with approximately 630,000 diagnoses, causing 350,000 deaths [3].

In the last three decades, early detection and the availability of diverse treatment modalities—including advanced radiotherapy techniques (such as IMRT and proton therapy), improved surgical expertise, and the introduction of immune checkpoint inhibitors (ICIs) have significantly altered cancer outcomes [3, 4]. While these advances have improved survival rates, they are often associated with significant adverse effects, contributing to a high symptom burden and psychosocial distress among patients with the evolving landscape of oncology, the need for incorporating palliative medicine is supported by recent scientific evidence. Different treatment guidelines recommend the involvement of a palliative care team regardless of the cancer stage, type, and prognosis [4, 5].

Early integration of palliative medicine improves quality of life, controls bothersome symptoms, and alleviates pain and resilience [6, 7]. Early integration helps physicians navigate patients and their families through difficult decision-making and smoothen their cancer journey with care plans that are inclusive of patients' choices and values [6]. Especially when disfiguring surgeries, concurrent treatment modalities, and dependency on feeding tubes in most of the patients with head and neck cancers increase the chances of morbidity, repeated emergency presentations, and rate of hospitalization. All of this has a huge bearing on physical, and emotional well-being, and social needs [8].

There are only a few institutions providing specialized palliative care in Pakistan, that too with a limited bandwidth. Integrating the services as per American Society of Clinical Oncology (ASCO) guidelines is arduous [9], nevertheless Head and Neck Cancer patients can substantially benefit from an additional layer

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of support [10]. Recently, oncologists at our center have made deliberate efforts to refer head and neck cancer patients with significant symptom burden and emotional distress to outpatient palliative care clinics. However, despite these collaborative efforts, the impact of such referrals on patient outcomes and disease trajectory has not yet been systematically evaluated.

Our institution has recently promoted outpatient palliative care referrals for head and neck cancer patients. This study assesses the impact of these referrals over one year using ASCO's palliative care quality indicators: The indicators assessed in this study included Timing of referral to palliative care, Timing of referral to palliative care, Timing of referral to palliative care, Continuation of oncologic treatment while receiving palliative care, Frequency of emergency room visits, Number of inpatient hospital admissions, Utilization of home healthcare services and Place of death [10, 11]. These indicators were used to quantify the palliative care trajectory and outcomes, in line with ASCO guidelines for integrated oncology-palliative models [7].

METHODOLOGY

A retrospective chart review was carried out, including all patients diagnosed with head and neck malignancies who attended the outpatient palliative care clinic at Aga Khan University Hospital during the year 2022. An exemption from the Institutional review board as received 2023-8579-24800.

Electronic health records from the outpatient oncology department were reviewed to identify patients with head and neck cancers who received integrated palliative care services in 2022.

Two independent investigators examined the electronic medical records and patient files. The data collected encompassed demographic information (such as age, gender, type and site of malignancy, date of diagnosis, cancer stage, whether it was a new or recurrent diagnosis, and current treatment status) and clinical details (including timing of first palliative care integration, presenting symptoms at initial visits, number of outpatient clinic visits, and total duration of palliative care involvement). The EMR was used to gather information regarding the last oncological treatment received, the number of emergency room visits, and reason for presentation, utilization of home health services, and the place of death.

Statistical analyses used SPSS v26.0. Descriptive statistics summarized demographics, symptoms, and disease characteristics. Means and standard deviations were reported for continuous variables; frequencies and percentages for categorical variables. Chi-square tests were applied for comparisons with p-value ≤0.05 considered statistically significant.

RESULTS

In the year 2022, a total of 84 patients diagnosed with head and neck cancers were referred to the outpatient palliative care clinics at Aga Khan University Hospital. The mean age was 56±18years, with a male predominance (n = 56, 67%), while (n = 27, 32%) had recurrent disease. The most frequent primary site of malignancy was the buccal mucosa (n=31, 37%), followed by the tongue (n=12, 14%), oropharynx and larynx (n=8, 9.5%), lip and lower alveolar (=9, 10.7%) salivary gland tumors (n=5, 6%) hard palate (n=3, 3.5%), maxillary SCC (n=3, 3.5%), piriform (n=2, 2.3%), retromolar (n=2, 2.3%), and glottis SCC (n=2, 2.4%). The average time to palliative referral was 52±12 weeks. Major symptoms included facial pain (60%), mucositis (23%), fatigue (17%), chest secretions and infections (14%), and anxiety/depression (9%) as shown in **Fig. (1)**. Pain management improved symptoms in 67.8% of 51 patients over a mean follow-up of 113.2 ± 44.6 days. Nutritional support was provided to 71.4% (n=60); 52% showed subjective improvement.

At the time of initial palliative care consultation, out of 84 patients, the treatment intent in most cases (n=43, 51%) was palliative. Almost one-quarter of these patients (n=20, 23%) declined one or more treatment modalities, and n=11, 13%, of patients opted out of any form of oncological treatment altogether. Even among these individuals, the palliative care integration was late (29.75 ±16 weeks).

Moreover, in the year 2022, a total of 468 patients with head and neck cancers were registered in the AKU Cancer Registry. Of these, only 44 patients (9.4%) were referred to and integrated with the palliative care team during the same year, (**Table 1**), although the total referral for patients with head and neck cancer in the study period was 84 patients. The current analysis focuses on a cohort of 84 patients which also includes the above-mentioned 44 patients.

Among those referred, in-person consultations were predominantly favored over telemedicine visits. Most patients were accompanied by close family members—primarily spouses or children—who also commonly served as primary caregivers and surrogate decision-makers.

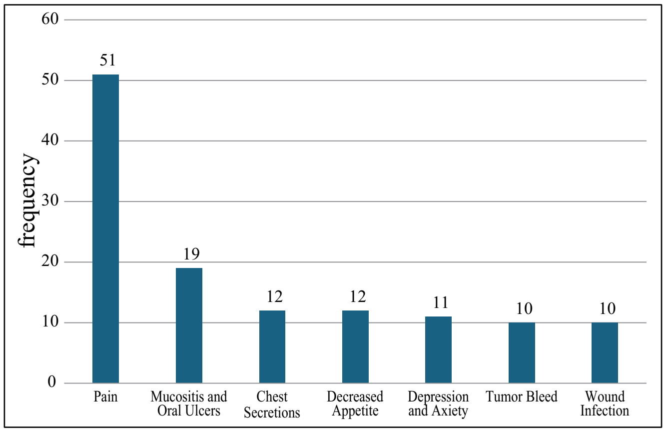

Fig. (1): Symptom burden among this patient cohort.

Table 1: The palliative integration in the year 2022 and ASCO quality indicators.

Variables	Statistics
Number of Patients referred to Palliative Outpatients in 2022	n=84
Palliative Care integration in newly diagnosed cancer patients in 2022 [n=patient referred/total registry, (%)]	44/468 (9.4%)
Duration of Palliative Care Received, mean ± SD	113 ± 44 days
Palliative integration from time of diagnosis, mean ± SD	52 ± 12 weeks
Inpatient admissions in palliative, n(%)	14 (17%)
Emergency presentation, n(%)	
Less than 3	29 (34%)
3 and more	4 (5%)
Patient on curative treatment at first palliative contact, n(%)	41 (49%)
Patient with ongoing oncological treatment till last palliative visit	35 (42%)
Place of death (total number of patients died=25), n(%)	
At Home	16 (64%)
In the Hospital	6 (24%)
Home Health Care Services Utilized, n(%)	24 (29%)

The average duration of palliative care follow-up for referred patients was relatively short, with a mean of 113 ± 44days. During the same year, 25 patients (30%) died, while 33 patients (39%) were lost to follow-up.

For analytical purposes, patients were categorized based on the number of clinic visits: fewer than four visits and four or more visits as illustrated in Table **2**.

The majority (n= 61, 73%) had less than four clinical encounters. Out of the 84 patients, a total number of (n=19, 23%) patients received coordinated end-of-life care either at home or in the hospital, according to their families' preferences.

Table 2: A comparative analysis of patients who attended less than 4 visits to those to attended 4 or more visits.

Variable	**Palliative Care Received**		**p-value**
	4 and More Visits n(%)	**Less than 4 Visits n(%)**	
Age (in years)			
Mean (SD)	52.9 (16.3)	58.1 (15.7)	0.185
Gender			
Male	17 (73.9)	39 (63.9)	0.545
Female	6 (26.1)	22 (36.1)	
Type			
Newly Diagnosed	15 (65.2)	35 (57.4)	0.793
Recurrent Disease	7 (30.4)	22 (36.1)	
Relapsed Disease	1 (4.3)	4 (6.6)	
Extent			
Local	2 (8.7)	2 (3.3)	0.362
Locally Advanced	14 (60.9)	32 (52.5)	
Metastatic	7 (30.4)	27 (44.3)	
Intent			
Curative	12 (52.2)	29 (47.5)	0.893
Palliative	11 (47.8)	32 (52.5)	
Treatment Refusal			
No	19 (82.6)	44 (73.3)	0.550
Yes	4 (17.4)	16 (26.7)	
Ongoing Treatment			
No	11 (47.8)	37 (61.7)	0.371
Yes	12 (52.2)	23 (38.3)	
ER visit			
No	12 (52.2)	41 (67.2)	0.308
Yes	11 (47.8)	20 (32.8)	
Inpatient Admission			
No	11 (47.8)	36 (59.0)	0.500
Yes	12 (52.2)	25 (41.0)	
Palliative Medicine Admissions			
No	18 (78.3)	52 (85.2)	0.662
Yes	5 (21.7)	9 (14.8)	
Feeding Tube			
No	3 (13.0)	21 (34.4)	0.096
Yes	20 (87.0)	40 (65.6)	
Tracheostomy			
No	17 (73.9)	42 (68.9)	0.853
Yes	6 (26.1)	19 (31.1)	
Home health Integrated			
No	16 (69.6)	44 (72.1)	0.986
Yes	7 (30.4)	17 (27.9)	
Patient Status			
Alive	11 (47.8)	15 (24.6)	0.009
Dead	9 (39.1)	16 (26.2)	
Loss to Follow up	3 (13.0)	30 (49.2)	
Palliative Care Integration (in weeks)			
Mean (SD)	51.7 (112.7)	55.9 (88.5)	0.862

A significant proportion of patients required medical interventions such as feeding tube placement (n= 60, 72%) and tracheostomy (n= 25, 30%). The most frequent reason for emergency department visits was feeding tube complications, such as leakage or dislodgement (n= 7, 33%).

Among patients who attended four or more palliative care clinic visits, 11 (47.8%) had ER visits compared to 20 (32.8%) in the <4 visit group (p = 0.308). Similarly, inpatient admissions occurred in 12 (52.2%) of the ≥4 visit group versus 25 (41.0%) of the <4 visit group (p=0.500) (**Table 2**).

Utilization of home healthcare services in 29 patients (34.5%) was most common for feeding tube care and symptom monitoring. These individuals also had fewer emergency department visits and inpatient admissions under palliative care (**Table 2**). Out of 84, 14 (16.7%) patients were admitted under the palliative care service, with 13 (93%) admitted specifically for end-of-life care (**Table 2**). Among the 25 patients who died, 9 (33%) passed away at home, while 6 (22%) were brought dead to the hospital emergency department (**Table 1**).

DISCUSSION

Head and neck cancers represent a significant proportion of malignancies in the region, necessitating a multidimensional approach to symptom management that encompasses not only physical but also psychosocial domains including advance care planning [12-14]. Although many patients maintain partial independence in activities of daily living and mobility, they frequently experience complications such as facial disfigurement, severe weight loss due to impaired oral intake, and dependence on enteral feeding, which collectively heighten their susceptibility to infections and overall physical frailty [15]. Despite the presence of multidisciplinary care frameworks involving oncologists, surgeons, and nutritionists, the role of palliative care remains under-recognized and insufficiently integrated [10, 15]. This study presents a focused analysis from a tertiary care institution where palliative care services are available and in the process of progressive integration. At our institution, the overall referral rate to palliative care among patients with head and neck cancer was 9.4%, which is consistent with international findings indicating limited palliative care utilization within this patient population. In many cases, referrals are delayed, often occurring nearly a year after [16]. Significantly higher referral rates can be achieved through the implementation of structured referral pathways, improved availability of resources, and the integration of palliative care into routine oncology practice. Significant higher referral rates are expected if there are structured pathways, greater availability of resources, and integration of palliative care as part of standard oncology practice. This highlights both the need and opportunity to improve palliative care utilization in head and neck cancer.

On average, patients were engaged with palliative care services for approximately seven weeks, with most referrals occurring late in the disease trajectory. This reflects both a delayed integration of palliative care and an added financial burden due to the necessity of additional consultation. In resource-constrained settings such as ours, the high cost of cancer care remains a significant barrier to timely palliative care integration. Other than this lack of knowledge and no legal standing for advance care planning contribute to underutilization of the service [17]. Patients who remain under the care of the patients were more likely to access home-based services which are cost-effective and patient-centered [18]. However, the considerable symptom burden, particularly related to oral and chest secretions, recurrent aspiration, the risk of tumor-related bleeding, and dislodgement of tubes — often necessitates inpatient care and results in frequent emergency department visits [19].

Effective pain management in patients with head and neck cancers is essential. In our cohort, opioids were prescribed according to WHO guidelines. While follow-up notes indicated improvement in pain symptoms for many patients, the absence of standardized pain scores limited the ability to quantify sustained relief. Additionally, literature from similar settings has documented that opioid availability and regulatory barriers can impact long-term pain control, which may have influenced care in our context. Effective pain management in patients with head and neck cancers is essential; however, it is frequently compromised due to limited access to opioids and recurring shortages of controlled substances [20]. As a result, sustained pain relief is rarely achieved, with many patients experiencing persistent pain despite temporary alleviation. Nutritional concerns were also prominently raised by caregivers, particularly in cases where patients did not have feeding tubes, highlighting the ongoing challenges in maintaining adequate nutritional support [21]. Formal symptom assessments, including standardized pain and nutrition scores, were not consistently recorded in patient charts. As a result, symptoms in our study are based on subjective clinical documentation rather than validated tools. The psychological and emotional needs of the patients were reviewed during every visit however no interventions were documented in the charts.

This study focused exclusively on head and neck cancer patients referred to outpatient palliative care clinics, with the aim of evaluating the utility of palliative care services in this population. It did not include inpatient palliative care consultations, which are typically reserved for end-of-life care. The limitation of the study is that it is a retrospective chart review, the study was limited to information documented in patient records. The total number of patients' cohort was too small to have a significant result however the finding was meaningful and an area of future research. Future prospective studies are warranted to evaluate and compare clinical outcomes between head and neck cancer patients who receive palliative care and those who do not. Furthermore, investigating the multidimensional concept of total pain through prospective research is critical for informing the development of comprehensive psychosocial care models tailored to the needs of both patients and their families. Such evidence will also contribute to the formulation of context-specific guidelines for symptom management within our population.

CONCLUSION

The integration of palliative care can significantly improve the overall quality of care by addressing the multifaceted physical and emotional challenges experienced by patients with head and neck cancers. However, in most cases, this integration occurs late in the disease course. There is an urgent need for a structured, context-specific care framework tailored to the unique needs of head and neck cancer patients and their families, ensuring comprehensive support throughout the illness trajectory.

ETHICS APPROVAL

This study received an exemption from the Institutional Review Board as received 2023-8579-24800. All procedures performed in studies involving human participants followed the ethical standards of the institutional and/ or national research committee and the Helsinki Declaration.

CONSENT FOR PUBLICATION

Not applicable.

AVAILABILITY OF DATA

The data is available with the corresponding author on reasonable request.

FUNDING

None.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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Declared none.

AUTHORS' CONTRIBUTION

AI: Study concept and design, data acquisition, analysis, and data interpretation and manuscript drafting, AFK: Data acquisition and data interpretation YR: Manuscript drafting and critical revision NZ: Analysis and data interpretation, manuscript drafting & statistical analysis MAW: Study concept and design, analysis and data interpretation and final approval.

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