# Demography and treatment pattern of patients with head and neck carcinoma presenting to a tertiary care center in India: Need for urgent decentralization of cancer care

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## Abstract

**Aims:** This study aims to report on the demographic profile and treatment pattern of head and neck cancer patients and impact of an early treatment decision on treatment. This study also aims to suggest recommendations to improve treatment compliance. **Methods:** All new patients registered under the head and neck disease management group (DMG) over a period of 3 months at a single center were included. Their demographic details, time to treatment decision, and treatment compliance were determined. The findings were presented to head and neck DMG, and changes were implemented to patient workup with an aim to improve compliance. A reaudit was performed over a period of 3 months and results were compared. **Results:** Two thousand two hundred and forty patients were included in the analysis. Patients with a treatment decision at 1–4 weeks stood at 28.32%, 63.88%, 80.8%, and 89.87%, respectively. Dropout rate was 26%. About 50% of patients planned for surgical intervention could be treated within the institution. After implementation of changes as recommended by DMG, 2418 patients were analyzed and findings were compared to the previous audit. The dropout rate reduced to 17.57%. The number of patients with a treatment decision at 1–4 weeks were 51.26%, 77.42%, 89.46%, and 94.31%, respectively. **Conclusion:** Early treatment decision and referral could significantly improve patient dropout and possibly compliance to treatment. Decentralization of cancer care is urgently needed to manage the high numbers of patients presenting to tertiary care centers. Setting up of new regional cancer centers and increasing infrastructure in the existing centers should be the long-term goals.


**Key words**: Head and neck cancer, patient demography, treatment compliance

## Introduction

The GLOBOCAN series of the International Agency for Research on Cancer estimated 14.1 million new cancer cases and 8.2 million deaths due to cancer worldwide.[1] In India, this stands at one million new cases and 0.68 million deaths with a projected rise to 1.2 million deaths by 2035.[2] The mortality: incidence ratio of 0.68 for India is far higher than the very high human development index (HDI) countries (0.38) as well as high HDI countries (0.57).[3] Multiple factors account for this – variation in reporting systems, advanced stage at presentation, lack of access to cancer care, less availability of affordable treatment, and variations in practice of evidence-based medicine.

More than 80% of outpatient care and 40% of inpatient care in India are provided by private hospitals.[4,5] However, relatively higher number of patients diagnosed or suspected with cancer present to government hospitals. Cancer treatment is unique as it requires a multimodality approach with treatment to be administered in a timely fashion. This could result in higher treatment cost, especially if treatment is received away from home. Due to lack of a referral system in India combined with a paucity of tertiary care cancer hospitals, these centers cater to a high volume of patients. For instance, our institution had registered 30,000 new cancer patients in 2009, which increased to 38,000 in 2015, a 25% increase over a period of 7 years.

There have been no reports on measures to improve patient care, and planning is needed to tackle the increasing patient burden. An understanding of the demographic profile of patients, their stage at presentation, time taken for a treatment decision, and treating capacity of tertiary care institutions is important to understand the present day needs of treating hospitals and more so the patients. It would also aid in future planning and development required to provide affordable, quality cancer care, preferably close to home.[6,7] We report an audit on demographic and clinical characteristics of head and neck cancer patients registered at a tertiary cancer center, their treatment patterns within the hospital, and the possible effects of timely treatment decisions on patient care.

## Methods

An analysis of all patients registered under the head and neck disease management group (DMG) over a period of 3 months from March 1, 2014 to May 31, 2014 was performed. The demographic details, tumor characteristics, investigation details, treatment decisions, time taken for the same, and place of treatment received were also recorded. The institutional workup, diagnosis, and treatment protocol are outlined in Figure 1.

All patients registered with the DMG in private or general category (based on patient choice) underwent a preliminary clinical examination on the day of registration. Following this, patients were advised routine clinical investigations, imaging studies as required, and a biopsy for tissue diagnosis. If a biopsy report was available, it was either reviewed within the hospital or a biopsy was repeated as per institutional protocol. After necessary investigations for diagnosis and staging, the patients were discussed in the multidisciplinary tumor board (MDT) meeting. The MDT comprised of consultants from surgical oncology, medical oncology, radiation oncology, radiodiagnosis, and pathology.

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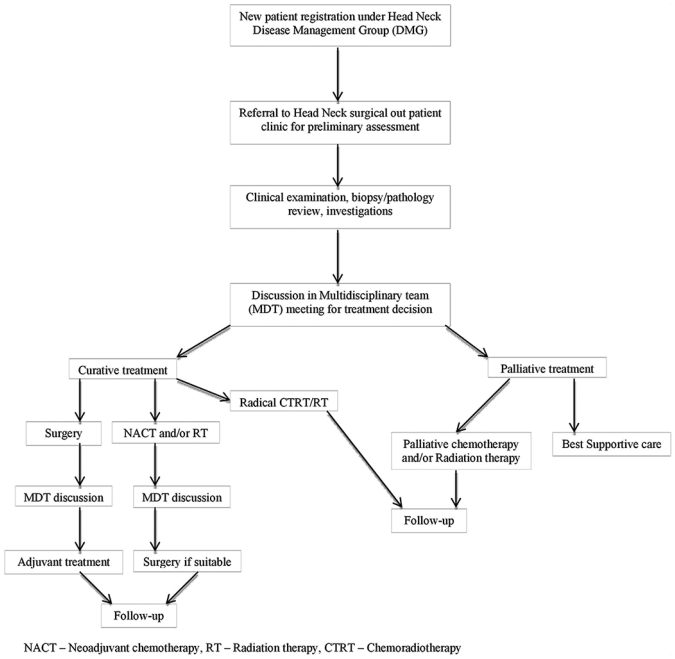


**Figure 1: Investigation and treatment flowchart for new patients with head and neck cancer**

After a treatment decision from the MDT, patients were referred for further treatment to the respective subspecialty. For example, patients were treated by medical oncology team under the head and neck DMG for chemotherapy and by the surgical oncology team for surgical treatment or procedures. Cancer staging was performed as per the 7th edition of American joint committee on cancer/union for international cancer control tumor-node-metastasis staging system.[8] All patient and treatment details were recorded from electronic medical records of the hospital. Patients who did not report to the outpatient clinic after registration or defaulted treatment before MDT decision were categorized as dropout patients. The time interval from date of registration to date of treatment decision was recorded as time taken for treatment decision. All patients with a MDT treatment decision were further followed up to see if the treatment was received within the institution. The primary end points of the initial audit were patient dropout rate, time taken to treatment decision, and number of patients treated within the hospital.

The results were presented to head and neck oncology departmental meeting. Recommendations were made by the DMG members with an aim to reduce patient waiting time for a treatment decision and possibly improve compliance. Based on the recommendations, changes were implemented to patient workup and investigation protocol from February 1, 2015. Two specific changes introduced in the system were to conduct an early MDT and treatment decision for patients and if clinically suitable, to not advise a repeat biopsy if performed elsewhere. Concept of a "first day MDT" was introduced, wherein patients were discussed on the day of registration if deemed suitable for a treatment decision. A further analysis was performed for a period of 3 months from February 10, 2015 to May 9, 2015 with similar end points. A comparison was made with the results from 2014.

**Table 1: Demographic details - 2014 and 2015**

| Demographic feature | Year, *n* (%) | |
|---|---|---|
| | 2014 | 2015 |
| Total patients | 2240 | 2418 |
| Category | | |
| General | 1470 (66) | 1619 (67) |
| Private | 770 (34) | 799 (33) |
| Sex | | |
| Male | 1696 (76) | 1883 (78) |
| Female | 544 (24) | 535 (22) |
| Median age (years) | 50 | 51 |
| State | | |
| Maharashtra | 915 (40.8) | 940 (39) |
| Uttar Pradesh | 414 (18.6) | 487 (20.1) |
| West Bengal | 206 (9.2) | 216 (9) |
| Madhya Pradesh | 153 (6.8) | 176 (7.3) |
| Bihar | 155 (6.9) | 164 (6.8) |
| Rest of India | 397 (17.7) | 435 (17.8) |
| Within Maharashtra | | |
| Mumbai/Thane | 485 (53) | 517 (55) |
| Rest of Maharashtra | 430 (47) | 423 (45) |
| Category distribution as per state (general: private) | | |
| Maharashtra | 81:19 | 82:18 |
| Rest of India | 55:45 | 57:43 |

## Results

### 2014

In the given study period, 2240 patients were registered under the head and neck DMG. The demographic characteristics are presented in Table 1. The median age was 50 years, and 76% of patients were males. About 41% of the patients presented from within the state of Maharashtra and an additional 41.5% hailed from Uttar Pradesh, West Bengal, Madhya Pradesh, and Bihar. Thus, the above 5 states contributed about 82.5% of patients with remaining states across the country contributing only 17.5%. The category distribution of patients from within the state revealed a general: private category registration ratio of 4:1 as compared to 1.2:1 from other states. Thus, it is difficult for poorer patients to travel long distances for treatment.

About 55% of cancers were oral cavity primary tumors, and 61% of patients were presented with locally advanced or metastatic cancers. The tumor characteristics and treatment details are given in Table 2. About one-third of the patients required additional imaging studies. Remaining patients did not need one or had them performed before registering with the hospital. Less than 10% of imaging studies were performed within the institution and 90% patients were referred to imaging centers in view of a long waiting time. About 84% of the patients were treated with a curative intent. Of all patients with a treatment decision, about 50% were planned for upfront surgery and about 25% with nonsurgical treatment with a curative intent. This included chemotherapy and/or radiation therapy as treatment modalities.

Specific end points as mentioned in the methodology were noted. Dropout rate was quite alarming at 26%. Thus, one of every four patients registered to the hospital under head and neck DMG did not have a treatment decision or receive any form of treatment at the hospital. Of these, about 2%

**Table 2: Clinicopathologic characteristics, treatment statistics (2014 and 2015)**

| Parameter | Year, *n* (%) | |
|---|---|---|
| | 2014 | 2015 |
| Site | | |
| Oral cavity | 1223 (54.59) | 1304 (53.92) |
| Oropharynx, hypopharynx | 327 | 323 |
| Thyroid, parathyroid | 179 | 167 |
| Larynx | 155 | 186 |
| Paranasal sinuses, skull base | 55 | 96 |
| Unknown primary | 39 | 59 |
| Nasopharynx | 37 | 50 |
| Salivary glands | 26 | 47 |
| Parapharyngeal tumors | 10 | 8 |
| Others | 68 | 6 |
| Not known* | 121 | 172 |
| Stage | | |
| I | 201 (8.97) | 204 (8.44) |
| II | 165 (7.36) | 199 (8.23) |
| III | 241 (10.75) | 274 (11.33) |
| IV | 1129 (50.40) | 1213 (50.16) |
| Not available | 504 (22.52) | 528 (21.84) |
| Imaging advised | | |
| Yes | 773 (34.51) | 886 (36.64) |
| No | 1027 (42.79) | 1176 (48.64) |
| Not available | 440 (22.7) | 356 (14.72) |
| Imaging done in institute | | |
| Yes | 76 (9.83) | 332 (37.47) |
| No | 697 (90.17) | 554 (62.53) |
| MDT decision details | | |
| Dropout rate | 584 (26.07) | 425 (17.57) |
| Patients with a treatment decision | 1631 (72.81) | 1976 (81.72) |
| Decision not entered online | 25 (1.12) | 17 (0.71) |
| Time taken for treatment decision (days) | | |
| 0-7 | 462 (28.32) | 1013 (51.26) |
| 8-14 | 580 (35.56) | 517 (26.16) |
| 15-21 | 276 (16.92) | 238 (12.04) |
| 22-28 | 148 (9.07) | 96 (4.86) |
| >28 | 165 (10.13) | 112 (5.68) |
| Intent of treatment | | |
| Curative | 1380 (84.61) | 1568 (79.35) |
| Palliative | 238 (14.59) | 327 (16.54) |
| Not applicable/not available | 13 (0.80) | 81 (4.11) |
| Treatment category | | |
| Surgery | 836 (51.25) | 907 (45.90) |
| Nonsurgical curative | 410 (25.13) | 504 (25.50) |
| Nonsurgical palliative | 226 (13.86) | 297 (15.03) |
| Others† | 159 (9.76) | 268 (13.57) |
| Patients treated within institute surgery | | |
| Yes | 473 (55.91) | 456 (48.92) |
| No | 373 | 476 |
| Not applicable | 785 | 1044 |
| Adjuvant treatment | | |
| Yes | 99 (28.21) | 100 (28.65) |
| No | 252 | 249 |
| Not applicable | 1280 | 1627 |
| Nonsurgical (curative/palliative) | | |
| Yes | 180 (34.61) | 239 (39.11) |
| No | 340 | 372 |
| Not applicable | 1111 | 1365 |

*Unknown primary or primary site not reported on the system, †Benign conditions, observation, referral to other specialty

of patients did not present to the clinics after registration. The other 24% had initial investigations but no treatment decision. Thus, most of them would have had a preliminary assessment, initial investigations, and biopsy as they were performed on the very 1st day but were not discussed at the MDT meeting. The dropout rate was not different among general or private category patients. Of the patients with a treatment decision, a decision was made in ($n$ = 1631) 28.32% of patients within a week of registration. The corresponding figures at 2, 3 and 4 weeks were 63.88%, 80.80%, and 89.87%, respectively [Table 2 and Figure 2a, c]. The time for treatment decision was significantly different among general and private category patients. Among general category patients, numbers were 18.53%, 56.14%, 76.16%, and 87.15% at 1–4 weeks, respectively. The figures for private patients were 47.21%, 78.81%, 89.7%, and 95.15%, respectively, for the same time points. Of the patients planned either for upfront or postneoadjuvant treatment surgery, about 55.9% were operated within the hospital. Similarly, about 28.21% of patients planned for adjuvant treatment and 34.6% of patients planned for upfront nonsurgical treatment, received the same within the institution. The remaining patients had to be referred to other hospitals for treatment in view of a long waiting period.

## 2015

After implementing the changes as recommended by the head and neck DMG, 2418 patients were analyzed from February 10 to May 9, 2015. The demographic features are given in Table 1. The demographic profile and tumor characteristics were comparable to patients from 2014 [Tables 1 and 2]. A significant difference was noted in the imaging performed within the institution, which increased to 37% in 2015 as compared to 9% a year ago. This was due to a rise in the number of computed tomography (CT) and magnetic resonance imaging scanners in the hospital. Although the DMG committee recommended against routine confirmation of biopsy at the institution, this was not uniformly followed across all the units. However, a treatment decision was given while a biopsy review was awaited, based on clinical examination.

The dropout rate reduced to 17.57%. The time to treatment decision was also reduced significantly. Treatment decision was made in ($n$ = 1976) 51.26% of patients within a

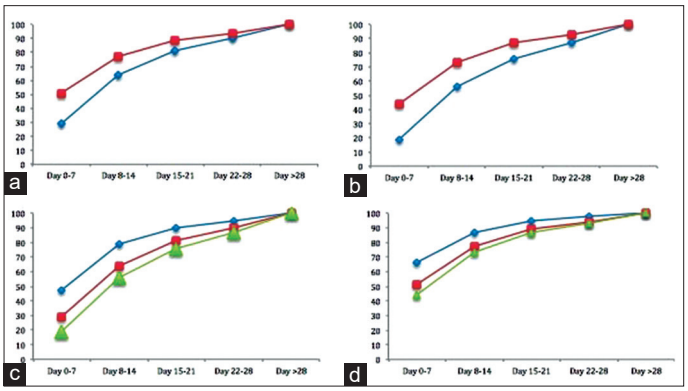


**Figure 2: Time trends for treatment decision. (a) 2014 (blue), 2015 (red). (b) General category 2014 (blue), 2015 (red).(c) As per category (2014) – general (green), private (blue), average (red). (d) As per category (2015) – general (green), private (blue), average (red)**

week of registration while at 2–4 weeks, about 77.42%, 89.46%, and 94.31% patients had a treatment decision [Table 2 and Figure 2d]. There was a significant improvement in time to treatment for general category patients with 43.98% patients having a treatment decision within 7 days as compared to 18.53% in 2014 [Figure 2b]. These numbers increased to 72.59%, 86.67%, and 92.65 at weeks 2–4. The corresponding figures for private category patients were 65.95%, 87.17%, 95.11%, and 97.7% at weeks 1–4, respectively.

Of the patients planned for surgical excision either upfront or after neoadjuvant treatment, 48.92% had their surgeries performed within the institute. Similarly, 28.65% of patients planned for adjuvant treatment and about 39.11% of patients requiring nonsurgical treatment received the same within the hospital. The remaining patients in each category were referred to other institutions for their treatment.

## Discussion

Head and neck cancers are the most common cancers in men in developing nations. About 25% of patients with a new cancer diagnosis are registered with the head and neck DMG in our institution. There have been reports on head and neck cancer patients looking at treatment decisions, compliance, and outcomes of treatment. These included about 500–2000 patients and have been reported from centers based in northern states of India. A common outcome in all studies was that of a high dropout rate and poor compliance with only up to 50% of patients completing their treatment protocols.[5,9,10] Our study included 4658 patients with head and neck cancers registered within a 6-month period. Our study is the largest study looking at patient demographics and the only study to implement changes to patient workup and suggest recommendations so as to possibly improve treatment compliance.

Most of our patients were from lower socioeconomic strata with 65% of them registered in general category wherein they receive subsidized treatment. About 60% of patients hailed from states other than Maharashtra. Of these, 43% are from Uttar Pradesh, Bihar, Madhya Pradesh, and West Bengal. This is probably due to a higher incidence of head and neck cancers in these regions and paucity of Regional Cancer Centres (RCC) in these states. There were fewer patients from southern states of the country, which could probably indicate a lower incidence of head and neck cancers or relatively higher number of patients being treated regionally. The population- and hospital-based cancer registries support this fact and have reported higher incidence of head and neck cancers in Maharashtra, Ahmedabad, Bhopal, Delhi, and Kolkata as compared to those from southern parts of the country. More than one-fifth of patients registered in cancer centers in North India have a head and neck primary with the highest incidence reported in Nagpur, a city in Maharashtra (36%).[11,12] About 50% of patients in our study from within the state of Maharashtra hail from distant regions within the state. These patients could hugely benefit if treated closer to their home, as they would be eligible for state healthcare schemes if applicable. This would need adequate RCC, where patients can be referred with a treatment decision taken at a tertiary cancer hospital. About 80% of patients from within the state register in general category, thus decentralizing cancer care within the state would benefit them the most.

About 61% of the patients presented with locally advanced or metastatic cancers. This is in concurrence with studies reported from other centers.[5,9,10] About 85% of these patients were eligible for treatment with curative intent. They would need multimodality treatment for advanced cancers, which means longer treatment time and need for adequate supportive care. Treatment could be expensive combined with economic loss due to the absence from work. This is an important consideration in the Indian context where most patients are from lower socioeconomic strata and are not insured for their treatment. This could be a major factor leading to poor treatment compliance. Treating patients closer to their homes will reduce expenses and possibly improve treatment compliance and outcomes.

About 50% of patients registered with head and neck DMG were planned for upfront surgery. Only about 50% of these could be operated within the hospital. More than 150 head and neck cancer surgeries are performed per week at our institution, and if we have to accommodate all patients planned for surgery, this would mean almost doubling the operating theater strength for head and neck cancer patients with a parallel rise in inpatient beds. With at least four theaters dedicated per day to head and neck cancer, increasing the numbers to twice is quite challenging. In addition, we need long-term planning to cater to a 4% rise in new patient registrations per year to the hospital. For radiation therapy facilities, we have five telecobalt units, six linear accelerators, two tomotherapy units, and six brachytherapy units with two CT simulators and two conventional simulators within the hospital. We are currently able to treat about 400–450 patients per day with about 8–10 new patients enrolled for radiation therapy everyday. To accommodate all patients planned for adjuvant or definitive radiotherapy, the radiation facilities need to be increased by at least three times. Radiation therapy typically extends for 5–6 weeks and patients are required to stay close to the hospital for daily visits. This is a major concern as 80% of the patients hail from regions outside the city or from other states. It is thus more cost-effective for patients to take treatment closer to their homes and this might increase treatment compliance. Neoadjuvant chemotherapy, adjuvant chemotherapy, or intravenous palliative chemotherapy is required in about 40% of patients. Apart from administering chemotherapy, a significant proportion of hospital bed consumption is accounted for supportive treatment and management of chemotherapy-associated morbidity and complications. At present, about 39% of patients requiring any form of chemotherapy can be treated at the hospital. Although administering chemotherapy to larger numbers of patients would be feasible by increasing day care units, it would require planning to cater the rise in treatment-associated morbidity.

Annual registrations at the hospital have increased at a rate of 4% per annum over the last 7 years, from about 30,000 in 2009 to 38,000 new registrations in 2015. This highlights the need for tremendous infrastructure planning in the coming

years to cater to ever-increasing patient numbers. This would mean attending to a higher number of patients in outpatient clinics, increased number of inpatient beds, operating theaters, radiation and medical oncology facilities, support system, and follow-up care.

The possible means to try and take charge of the situation would be to reduce the inflow of patients or increase the numbers we treat. The fact that we can currently treat less than half of the registered patients catering to more patients in future will be a major undertaking. Reducing the inflow is not possible due to lack of a referral system and inability to restrict registrations. Another possible solution would be increasing the number of RCC, and this could possibly prevent patients from migrating long distances. Again, this will take time. Decentralizing health care is the need of the hour, and early treatment decision and referral would keep patients motivated for treatment and possibly improve compliance. Based on the DMG recommendations, we implemented 1st day MDT decision and early referral of patients to other hospitals for further treatment. This itself reduced the dropout rate from 26% to about 17%. About 84% of the patients with oral or oropharyngeal cancers could be given a treatment plan on the very 1st day. These are the most common subtype of head and neck cancers, thus making an early referral possible, as all patients cannot be accommodated for treatment.

It could be argued that early treatment decision and referral does not ensure treatment compliance. However, patients would possibly be more comfortable with an early referral rather the same done after weeks of investigations and waiting. It is also difficult to choose patients for referral. Those affording treatment at private hospitals and patients who might benefit from health schemes with treatment closer to home would be the best candidates. Increasing numbers of trained oncologists in different regions of the country makes decentralization feasible and ensures the quality of treatment.

Our study is the only study to the best of our knowledge that has looked at the demographic profile and treatment waiting times of patients at a tertiary cancer center and to demonstrate that measures taken within the existing setup have shown a significant reduction in patient dropout rate, helped them with an early treatment decision and referral and possibly improved treatment compliance. The study also provides an insight to future planning needed to cater to a rise in cancer patients registering to the hospital. Our study does have some drawbacks. An early referral to another hospital does not necessarily ensure treatment compliance. It could be argued that treatment quality could be compromised. The patients were referred to trained oncologists for treatment with a hospital referral letter and treatment decision, thus minimizing errors or quality compromise. The hospital would not necessarily have the treatment details of the patients referred elsewhere although the patients could consult back for treatment outcomes and further decisions on additional treatment if needed. The patients also have access to their electronic medical records and treatment decisions.

## Conclusion

An early treatment decision significantly reduced the patient dropout rate, and an early referral would possibly improve treatment outcomes for head and neck cancer patients. Decentralization of cancer care is urgently needed to manage the high numbers of patients presenting to tertiary care centers. Setting up of new RCC and increasing infrastructure in the existing centers should be the long-term goals.

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### Conflicts of interest

There are no conflicts of interest.

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