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RESEARCH PAPER

Clinical profile of palliative care Patient at the state cancer institute of a North-eastern state of India: a cross-sectional study

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Background and aims: *With the patient's limited scope to palliative care in India's North-eastern state, this service has been a decade since it was available. The people of this region are unaware of this department's role at the State Cancer Institute (SCI) to promote life with a debilitating illness from diagnosis to death. Palliative care is one of the essential components of cancer care which has lots of ethical and legal issues and has been present in India for decades now but still limited data regarding palliative care from India's North-Eastern state. Therefore, we aimed to study the clinical profile of cancer patients in the palliative setting.* ***Material and Methods****: The present study was a cross-sectional study on patients attending the outpatient department (OPD) of the pain and palliative care of SCI, Gauhati Medical College and Hospital (GMCH), Guwahati, for twelve months from January 2020 to December 2020. In the study, we recorded the patient's age, sex, performance status, symptomatology and primary diagnosis during their visit to the pain and palliative care department. The data were analyzed using SPSS version 22. The ethical clearance was taken from the "Institutional Ethics Committee" of SCI of GMCH, Guwahati, Assam and India. Informed consent was also taken from the participating patient.* ***Results****: A total of 1002 cancer patients were included in the study. The median age of presentation was 41.5 years (range 18-86 years). The male and female ratio was 1:1.12. The majority, 443 out of 1002 patients, had Eastern Cooperative Oncology Group (ECOG) Performance Status (PS)-2, followed by ECOG PS-3 (32.2%) with 323 patients. Overall, head and neck cancer were the most common cancer (20.6%) with 206 patients, followed by 162 patients with carcinoma gall bladder (16.2%) and 132 patients with oesophagal cancer (13.2%), while in female, breast cancer was the most common and out of 101 breast cancer cases 97 were females. In the symptomatology, the pain was the most common symptom (82.1%), followed by anorexia (73.2%) and generalized weakness (66.7%). Most of the patients (45.9%) were assessed with severe pain. Skeleton was the most common site of metastasis (49.7%), followed by lung (24.1%) and liver (17.2%). Most patients attending the pain and palliative OPD were in stage IV (n=581,58%), followed by Stage III (n=290,29%) cancer.* ***Conclusion****: Pain was the most common symptom that adversely affects cancer patients' quality of life. Therefore, an early referral for palliative care needs to be ensured.*

Keywords*: Pain relief; terminally ill; clinical profile, quality of life.*

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INTRODUCTION

The World Health Organization (WHO) defines palliative care as "an approach that improves the quality of life of patients and their families facing the problem associated with a life-threatening illness, through the prevention and relief of suffering utilizing early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."[1] This care is required by patients suffering from various chronic diseases but has been most commonly used for cancer patients.[2] The concept of palliative care existed far back in history. Still, Dame Cicely Saunders has popularized the idea of modern palliative care with the setup of St Christopher's hospices in 1967 for end-of-life care.[3] Now, palliative care has broadened from diagnosis to beyond grief for the family.[4]In India, palliative care is still an emerging discipline.[5]

India has a high load of cancer patients. According to the estimates of the National Cancer Registry Programme Report 2020, released by the Indian Council of Medical Research (ICMR) in association with the National Centre for Disease Informatics and Research (NCDIR) Bengaluru, there will be about 1.39 million cancer cases in 2020, which is likely to increase to 1.57 million by 2025, based on current trends. There will be an estimated 12% rise in cancer cases in India in the next five years. While the need for palliative care is high in India, carrying many ethical and legal issues, there is minimal data on patients opting for palliative care in India. SCI, Guwahati, is one of India's North-Eastern region's tertiary care oncology centres, providing comprehensive oncology services to patients from entire North-Eastern areas. Thereby, we aimed to evaluate patients' clinical profile attending the pain and palliative care OPD at SCI of GMCH.

MATERIAL AND METHODS

The present study is a hospital-based cross-sectional study on 1002 patients who had attended the OPD of pain and palliative care at SCI of GMCH, Guwahati, for palliative care for 12 months from January 2020 to December 2020. The study included all patients of age more than 18 years attending OPD of pain and palliative care at the referral hospital with a confirmed cancer diagnosis. During their visit to the pain and palliative care department, the patient's clinical profile like age, sex, marital status, performance status, and primary diagnosis of the type of cancer, symptomatology, stage of cancer, and metastasis site, were recorded on a questionnaire developed by the researchers. To study the symptomatology of the cancer patients included in the study, a checklist of 32 symptoms was included in the questionnaire. The symptoms were assessed as per the patients' self-reporting during their visit to pain and palliative care OPD. As all symptoms reported by the patient were recorded therefore multiple counts of symptoms per patient were possible.

The patient's performance status was assessed using the ECOG PS[6] scale, which measures their level of functioning in their daily living abilities and physical activities with scores ranging from 0 to 5. The ECOG-PS scale was first published in 1982 and developed by the Eastern Cooperative Oncology Group (ECOG), now part of the ECOG-ACRIN Cancer Research Group.

Assessment of pain is essential for effective pain management. Various one-dimensional tools such as numerical pain intensity scale and visual analogue scale have been commonly used to assess the pain intensity at rest and during movement.[7]In the present study, pain intensity among the study participants was assessed using a numerical rating scale (NRS) ranging from 0-10. The numerical pain scores assigned were 0: No pain, 1-3: Mild pain, 4-7: Moderate pain and 8-10: Severe pain.

The data were analyzed using the Statistical Package for the Social Studies (SPSS) version 22 (IBM Corp., Armonk, New York). The ethical clearance was taken from the "Institutional Ethics Committee" of SCI of GMCH, Guwahati, Assam, and India vide ref: SCI/ECR/2020/16 dated 02/05/2020 before collecting the data. Informed consent was obtained from the study participants, and that the guidelines outlined in the declaration of Helsinki were followed.

RESULTS

The median age of presentation was 41.5 years (range 18 to 86 years). In the study, most patients were female, with a male and female ratio of 1:1.12. Twenty-one patients (2.1%) were unmarried. About 69.6% of patients were female in the 41-50 years age group, and 61.8% were male. The majority of patients attending pain and palliative OPD had an ECOG PS-2 (44.2%) followed by ECOG PS-3 (32.2%), as shown in **Table 1**.

Table 1 Clinical characteristics of palliative care patients

Sl.No.	Parameters	Number (%)
1.	Total number of patients included	1002
2.	Age of presentation in years	41.50years (range, 18-86)
3.	Sex: Male Female	 472(47.1%) 530(52.9%)
4.	Marital status Married Unmarried	 981(97.9%) 21(2.1%)
5.	ECOG PS: PS- 0 PS- 1 PS- 2 PS- 3 PS- 4	 50(5.0%) 125(12.5%) 443(44.2%) 323(32.2%) 61(6.1%)

In the study, we have found that overall, patients with head and neck cancer like oral carcinoma cavity, oropharynx, larynx attended to our OPD for palliation of their symptoms in maximum number followed by the carcinoma gall bladder, oesophagus, breast, lung and others. Head and neck cancer was the most common cancer in males gender-wise, followed by oesophageal, gall bladder, and lung cancer. Female breast cancer was the most common, followed by the gall bladder and gynaecological cancer, as shown in **Table 2**. The majority of head and neck cancer were related to tobacco use.

Table 2 Type of cancer seeking palliative care

Cancer	Male	Female	Total Number
Head and Neck Cancer	147(14.7%)	59(5.9%)	206(20.6%)
Ca Gall Bladder	69(6.9%)	93(9.3%)	162(16.2%)
Ca Oesophagus	83(8.3%)	49(48.9%)	132(13.2%)
Ca Lung	59(5.9%)	43(4.3%)	102(10.2%)
Ca Stomach	37(3.7%)	30(3.0%)	67(6.7%)
Ca Breast	4(4.9%)	97(95.0%)	101(10.1%)
Gynaecological malignancy	-	95(9.5%)	95(9.5%)
Colorectal cancer (CRC)	25(2.5%)	19(1.9%)	44(4.4%)
Others	48(4.8%)	45(4.5%)	93(9.3%)
Total	472(47.1%)	530(52.9%)	1002(100%)

The six most common symptoms were pain (82.1%), anorexia (73.2%), generalized weakness (66.7), weight loss (56.6%), dysphasia (43.1%) and nausea and vomiting (40.1%), as shown in **Figure 1.** Patients having skeletal metastasis mainly reported pain as a disturbing symptom.

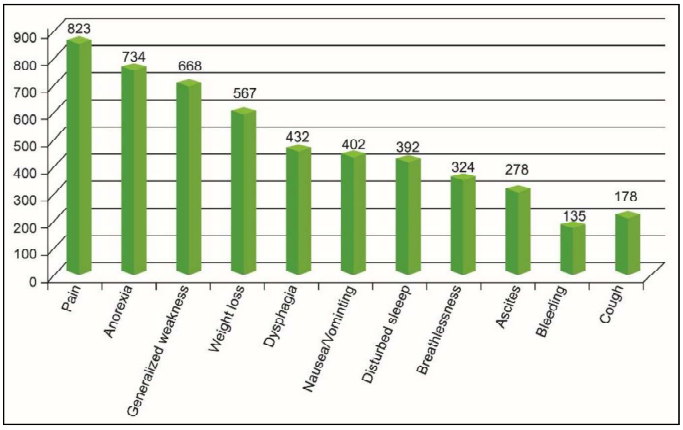

Figure 1 Symptomatology of patients attending pain and palliative department

Referrals to the pain and palliative care were most common in stage IV patients, i.e., metastatic disease (58%), followed by patients with stage III, i.e., locally advanced disease (29%). Patients with stage I or II disease accounted for only 13% of referrals. The condition is very early and usually has symptoms in a well manageable state (**Figure 2**).

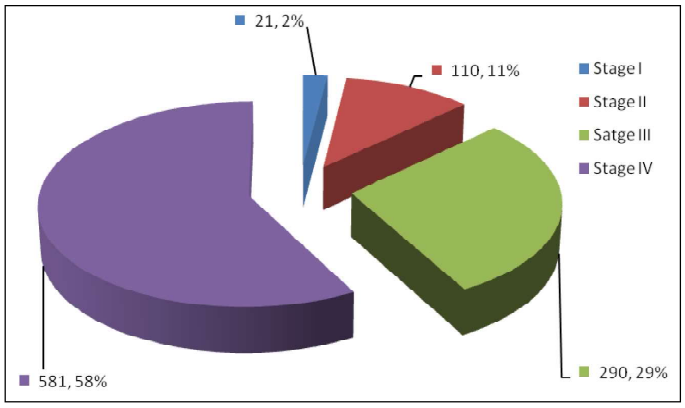

Figure 2 Stage-wise referral to pain and palliative care OPD

Skeleton (49.7%) was the most common site of metastasis in the patients, followed by lung (24.1%) and liver (17.2%) (**Figure 3**). The axial skeleton was the more common site of metastasis than the appendicular skeleton.

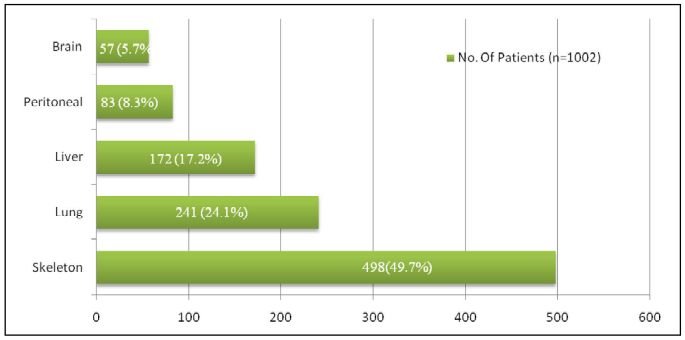

Figure 3 Sites of metastasis

Out of the 1002 cancer cases,823 (82.1%) patients reported pain as the most common symptom. Most of the cases (45.9%) were assessed with severe pain by NRS, followed by 32.2% with moderate pain (**Table 3**).

Table 3 Assessment of pain among palliative care patients

Pain score	Numerical pain scale	Frequency (%)
Total cases with pain		823
Mild pain	1-3	180(21.9%)
Moderate Pain	4-7	265(32.2%)
Severe Pain	8-10	378(45.9%)

DISCUSSION

Palliative care is an integral part of cancer care that needs to be provided throughout the care continuum, not just end-of-life care. Early integration of palliative care with standard oncologic care results in a clinically meaningful improvement in life quality. At the SCI, GMCH, we provide

comprehensive palliative care to patients with different cancer at different stages of their illness, thereby generating our data regarding palliative care in this part of the country.

Jivarajani PJ[8] et al., in their study, found that the maximum number of cases were in the 35-64 years of age group. The proportion of cancer cases was 62.59% and 71.20% in males and females, respectively, in this age group. There was an overall female preponderance in the age group 35-64 years, but the male majority was found in the age above 65. These findings were similar to the results of our study.

Jivarajani PJ[8] et al., in their study, found that the leading sites of cancer in males were mouth (14.56%) followed by the tongue (13.17%), lung (8.37%), oesophagus (6.26%), hypopharynx (4.22%), larynx (3.78%), tonsil (2.62%) and prostate (2.47%), i.e., head and neck cancer were most common in male. The leading sites among females were breast (24.85%) followed by the cervix (15.11%), ovary (5.38%), head and neck cancer, oesophagal cancer (3.45%) and lung (2.03%). These findings were similar to the results of the present study.

In the present study, we have found that pain was the most common symptom, followed by anorexia, dysphasia, weakness and sleeplessness. These findings were similar to a survey done by Naveh *et al*., who reported that 66% of the patients had severe pain and Iyer *et al*. found that more than 90% of the patients expressed pain, weakness and anorexia.[9,10] Nilmana *et al*., and Harding *et al*., reported in their study that most of the cancer patients had pain (87.5%), weakness (77.7%).[11,12] Jivarajani PJ et al., in their research, also found that the majority of the patients studied had pain (77%), tiredness (96.5%), disturbed sleep (96.4%), weight loss (63.3%) and irritability (85.7%).[8]

Limitation: The present study included only the physical symptomatology of the patients, and the patient spontaneously reported the symptoms. However, social and psychological symptoms directly affect the quality of life of critically ill patients like those who have cancer and needs palliative care and consultation. A broader study for assessing those symptoms among patients may help the caregivers better manage the patients in providing better care.

CONCLUSION

This study revealed that cancer patients experience many symptoms which affect their quality of life. The management of cancer pain is a critical issue in caring for patients with cancer. All professionals must ensure that patients receive an early and timely referral for palliative care at their disease's initial stage. A relatively large number of patients in our study presented to palliative care at an advanced stage of disease when symptoms become severe, debilitating, multiple, and difficult to manage, indicating a lack of awareness of palliative care in medical professionals and the general population. More efforts need to be put into creating awareness, training in palliative care.

Ethical Corrections

All data of the cases were treated with confidentiality, following the declaration of Helsinki.

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Disclosure

The authors report that there are no conflicts of interest in this work.

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Authors' contributions

DS, DA, DH conceived the content, retrieved the data, wrote the manuscript, and approved the final version. DD, DS and SP extracted the data, wrote the paper, and approved the final version. SDG retrieved the data, wrote the manuscript, and approved the final version.

Data Availability

The data used to support the findings of this study are included in the article.

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