

Research Article

A STUDY ON DEMOGRAPHIC, EPIDEMIOLOGICAL AND CLINICAL EVALUATION OF LOCALLY ADVANCED AND METASTATIC CANCER PATIENTS REGISTERED UNDER PALLIATIVE CARE UNIT IN A TERTIARY HOSPITAL IN UTTAR PRADESH

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Received 30th November 2020; Accepted 28th December 2020; Published online 30th January 2021

ABSTRACT

Aim & Objective: The main objective of this study is to assess demographic, epidemiological and clinical distribution of locally advanced and metastatic cancer patients using statistical analysis in the largest tertiary hospital of Uttar Pradesh state, India. **Study Protocol:** Each patient has been assessed through pre-coded Palliative preformed for disease and treatment related attributes. The parameters included age, sex, addiction history and presenting complaints. **Place and Duration of Study:** Palliative care unit of King George Medical University, Lucknow. **Methodology:** A retrospective observational study including demographic, epidemiological and clinical evaluation of patients has been conducted with a sample size of 1,600 patients from Feb 2017- Dec 2019. **Results and Discussion:** 71% patients were found to be of 30-60years' age group, head and neck malignancy was observed to be the most common one(c.50%). 76.1% of the patients were found to be of stage IV locally advanced and 23.9% as metastatic. Prevalence of tobacco & alcohol use was present in 70% of the sample size. All patients reported pain, 84% patients presented with loss of appetite and weight loss, 75% reported tiredness and fatigue, 36% had nausea & vomiting problems. Other problems reported included swallowing problem, bleeding, anaemia, altered bowel habit, depression and anxiety. Maximum cases were reported from central Uttar Pradesh. **Conclusion:** Palliative care needs and quality of life in Indian patients with advance cancer is of concern and need to be addressed with advanced developed frameworks.

Keywords: Palliative care, Demography, Epidemiology, Advance cancer, Quality of life

INTRODUCTION

Palliative care is an emerging discipline worldwide. The WHO define palliative care as "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual."^[1] The goal of palliative care is to improve the quality of life of both patients and families by responding to pain and other distressing physical symptoms, as well as to provide nursing care and psychosocial and spiritual support^[2] Globally, palliative care is sparsely distributed in developing countries including India where the need is immense. The International Agency for Research on Cancer GLOBOCAN project has predicted that the number of cancer patients will nearly double in the next 20 years.^[3] Patients with advanced cancer at the terminal stage of the disease suffer from a multitude of physical and psychosocial problems which when left unaddressed results in a debilitating quality of life. Among the various problems, pain is the most distressing symptoms followed by anorexia-cachexia, fatigue, anxiety and depression. Palliative care addresses these problems of the patients providing a holistic healing through a multidisciplinary team approach. Care that is aimed at control of symptoms whether from the cancer itself or the toxicity of treatment delivered concurrently with disease-directed therapies, is a key feature of patient-centred care. Early focus on care aimed at improving quality of life, survival and reduce overall costs of care.

Hospital palliative care unit (HPCU) is an inpatient unit within a general, secondary, or tertiary setting in the hospital, in which the patients are under the clinical direction of specialists within a Palliative care team^[4] HPCU in a cancer center deals with complex physical, psychosocial and spiritual needs of patients and their families.^[2,4] The research and analysis has been carried out on the patients in Palliative Care Unit of Radiotherapy Department, KGMU Lucknow, which was established in 2017. The unit consists of 10 beds, each attached with vital monitoring units and related infrastructure. The minimum stay of the patient is around 3 days or even more as per the requirement. The unit has been registering c.1,200 patients per year with help of dedicated staff trained in the field of palliative care. Pain is the most common complaint of advance cancer patient for which other than NSAIDS, easy access to opioids are provided as per requirement. The team is dedicated for proper counseling of patient as well as attendant about the disease status, dietary advice, various government run programs etc. The team work in collaboration with other department like anesthesia, general surgery, internal medicine, urology, interventional radiology and intensive care unit as per the patient's requirement. The palliative care unit in the department has been operational in collaboration with JivDaya Foundation (JDF), Dallas USA and is first of its kind in state of Uttar Pradesh, India. Advanced cancer patients experience many symptoms, including fear of the disease and death.^[4] The presence of various physical symptoms restricts the day-to-day activities of these patients.^[5,6] Studies related to need, problems, and quality of life^{[7],[8],[9],[10]} in advanced cancer patients receiving palliative care have been scarce in India. It is estimated that one million new cases of cancer occur each year in India, with over 80% presenting at stage III and IV^[11]. The need of palliative care in a developing country like India is of high importance and need of the hour. The study includes patients with advance or metastatic carcinomas of head and neck,

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gynecological, breast, genitourinary, gastrointestinal and hepatobiliary, hematological, bone and soft tissue sarcomas, where potentially curative treatment options are unavailable or proven ineffective. The various parameter which are included in the study are the demographic, epidemiological and clinical evaluation of advance cancer patients.

AIM & OBJECTIVE:

The primary end point of the study is to evaluate demographic, epidemiological and clinical parameters of advance cancer patients.

MATERIAL AND METHOD

It was a retrospective observational study conducted from February 2017 to December 2019 with a sample size of 1,600 patients registered in palliative care unit in KGMU Lucknow. All these patients had been registered in hospital’s central registry as well as oncology department. The study population includes patients with histopathological confirmation of malignancy, who were harboring metastatic disease and also patients of locally advanced disease who were unfit for curative management. These patients were deemed unfit for radical treatment in view of performance status or advanced metastatic nature of their disease. A record was made of patients, disease, and treatment related attributes. The patient related parameters included age, sex, history of smoking, tobacco chewing, and alcohol intake, presenting complaints. Some other parameters included in the study are: zonal distribution of patients and financial support in terms of various schemes run by government. Inferences were drawn of these various attributes, and data from previously published similar studies were perused for comparison and discussion.

OBSERVATION & RESULT

The data was analyzed by SPSS software version 23. Age and sex of individuals are represented as mean with Standard deviation. Various topographical locations of tumour sites, histopathology, extent of disease, etiological factors, geographical distribution and financial help provided are presented in frequencies.

Demographic Profile

The study was conducted in 1,600 advanced cancer patients receiving palliative care. 1,036 (64.8%) were male and 564 (35.2%) were female. The age of patients ranged from 2 to 90 years with the mean age of 46.29 ± 14.59 years (table 1).

Table 1. Age and Sex: Mean age of cases was 46.29 ± 14.59 years Median of age was 47.

	Age			Sex	
	Range	Mean ± SD	Median	Male, N (%)	Female, N (%)
Cases (N=1,600)	2-90 years	46.29 ± 14.59	47	1036 (64.8%)	564 (35.2%)

We have categorized patients according to age groups ≤ 18 years, 18-30 years, 31-60 years & > 60 years as shown in (figure 1). Maximum patients belong to 31- 60 years’ age group i.e. 71%.

Age Distribution

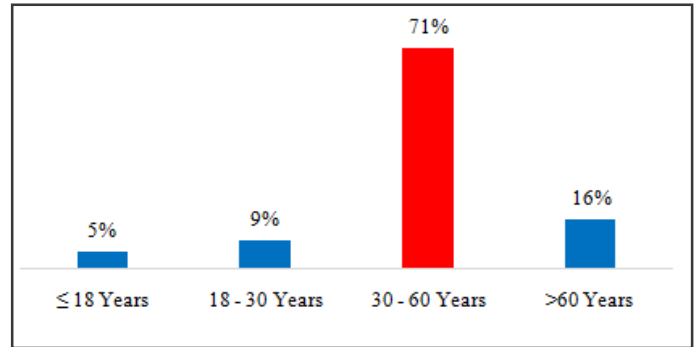


Fig 1. Distribution of cases according to different age groups defined

A total of 11 sites of lesion has been broadly included in the study i.e. malignancy of head and neck, gastrointestinal tract, genitor-urinary system, gynecological, hepato-biliary system, brain, breast, hematological, bone and soft tissue and few rare malignancies. Head and neck malignancies was the most commonly involved site (50.1%) followed by Gastro-intestinal malignancies and gynecological carcinomas (fig 2).

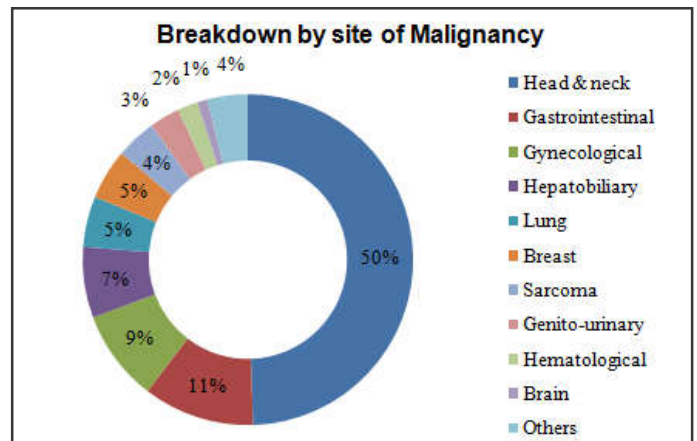


Fig 2. Distribution of study samples according to site of Malignancy

Histopathologically maximum cases were of squamous cell carcinoma (63.2%) followed by adenocarcinoma (20.9%), because most of the patients registered were of head and neck malignancies (Table 2).

Table 2: Distribution of cases according to histopathology:

Histopathology	Number	Percentage
Adenocarcinoma	334	21%
Squamous Cell Carcinoma	1,012	63%
Infiltrating Ductal Carcinoma	74	5%
Round Cell Tumour	66	4%
Soft Tissue Sarcoma	26	2%
Other Rare Histopathologies	88	6%

Majority of the cases studied were non metastatic locally advance stage IV (76.1%) followed by stage III (17.8%). The most common site of metastasis in metastatic patient was liver (10.3%) followed by bone (6.3%).

Epidemiology

Prevalence of tobacco use, in the form of smoking and tobacco chewing was present in almost 70 % of patients (Fig. 3). This could probably be explained by the profile of patients treated. Most of the patients are from a rural background and lower socio economic class where tobacco chewing and smoking is very common especially in the male population.

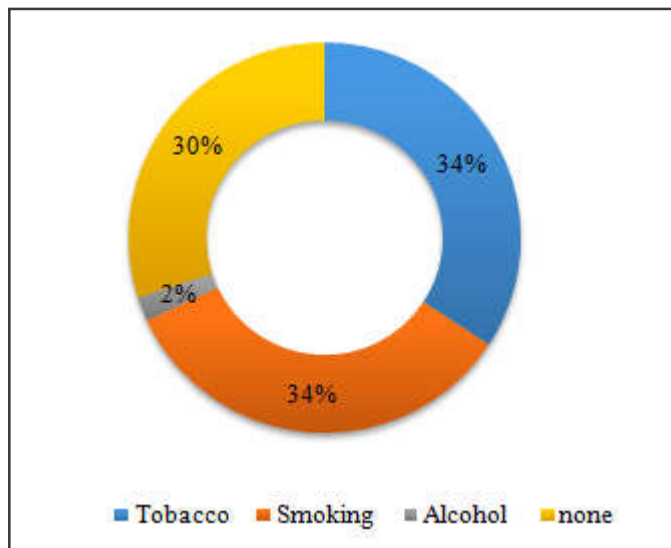


Fig 3: Distribution of cases according to Etiological Factors: alcohol, smoking, tobacco chewing etc.

Presenting Complaints

Among the presenting complaints and sufferings of the patients, **Pain** is one of the most common symptoms experienced by patients in the study (100%, Figure 4), because most of the patients are either having locally advance or metastatic disease.

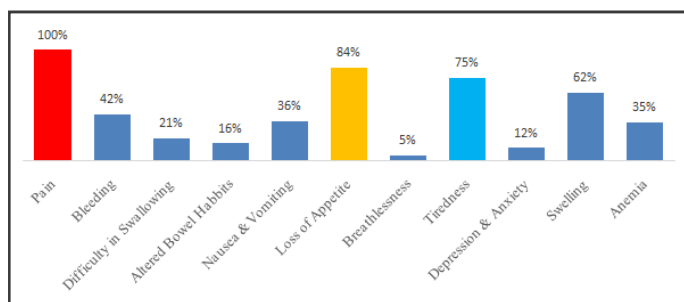


Fig.4: Distribution of patients according to presenting complaints

The loss of taste of food and **loss of weight** are the hallmark of cancer, the magnitude of which is associated with the severity of disease. In the study, almost 84% of the patients had complaint of loss of appetite at the time of registration. Loss of appetite can occur either early or late in the course of certain gastrointestinal cancers, such as those of the esophageal, stomach, colon, rectum and pancreas, and may be the sole presenting symptom in early disease.

Nausea and vomiting can be distressing and debilitating, and can have a significant effect on patient’s quality of life. In the study, 36% of the patients presented complaints of nausea and vomiting. 61.5% patients complained **swelling**, because c.50% patients registered in palliative are of locally advance head and neck malignancy with

almost all patient presented with neck swelling as a result of cervical lymphadenopathy. Bleeding is a frequent problem for patients with advanced cancer especially in head and neck malignancies, gastrointestinal and gynecological malignancies. These episodes may range from low-grade oozing to major episodic bleeding or even catastrophic bleeds. Bleeding can be caused by the cancer itself, as with local tumour invasion, abnormal tumour vasculature, or tumour regression. In the study, c.42.5% of the patients were found to have complain of bleeding.

Cancer-Related Anemia (CRA) is a common sign occurring in more than 30% of cancer patients at diagnosis before the initiation of antineoplastic therapy. Cancer-related anemia has a significant clinical impact in cancer patients: it is related with an important decline in performance score and quality of life (QOL), with progressive worsening of cognitive function and energy-activity levels [12,13]. Patients with CRA (Hb range, 8–10 g/dL) exhibit fatigue, lethargy, dyspnea, anorexia, and have difficulty concentrating, which can compromise their overall functional status and significantly reduce adherence to anticancer regimens [14]. It is more often detected in patients with advanced stage disease, where it represents a specific symptom of the neoplastic disease, as a consequence of chronic inflammation. In the study, almost 35% patients presented anemia at the time of initial registration. Other symptoms in the study include difficulty in swallowing (21%), altered bowel habit (16%), depression & anxiety (12 %) and breathlessness (5%) The study sample has been categorized according to the zonal distribution of patients. Maximum patients registered are from Uttar Pradesh (UP) followed by few patients from Bihar, Madhya Pradesh, Jharkhand and Uttarakhand etc. Since there are c.75 districts in Uttar Pradesh, the state has been divided into sub regions (Figure 5) as Central Uttar Pradesh, Eastern Uttar Pradesh and Western Uttar Pradesh to identify the patient’s footprint. The patients from other states have been categorized as “others”. The districts included in various zones/ sub- regions are:

- **Central UP:** Lucknow, Kanpur, Lakhimpur, Malihabad, Hardoi, Ambedkar Nagar, Amethi, Ayodhya, Behraich, Balrampur, Banda, Basti, Barabanki, Bulandshahar, Chitrakoot, Fatehpur, Hamirpur, Jalaun, Kannauj, Orai, Raebareli, Santkabir Nagar, Sarawasti, Sitapur, Sultanpur, Tanda, Unnao, Utraula
- **Eastern UP:** Allahabad, Azamgarh, Balia, Bhadoi, Deoria, Gazipur, Gonda, Gorakhpur, Jaunpur, Kunda, Kushinagar, Maharajanj, Mau, Mirjapur, Pratapgarhand Siddharth Nagar
- **Western UP:** Agra, Aligarh, Auraiya, Badaun, Bareilly, Bijnore, Etah, Etawah, Farrukhabad, Firozabad, Jhansi, Lalitpur, Mahoba, Mainpuri, Pilibhit, Rampur, Saharanpur and Shahjahanpur

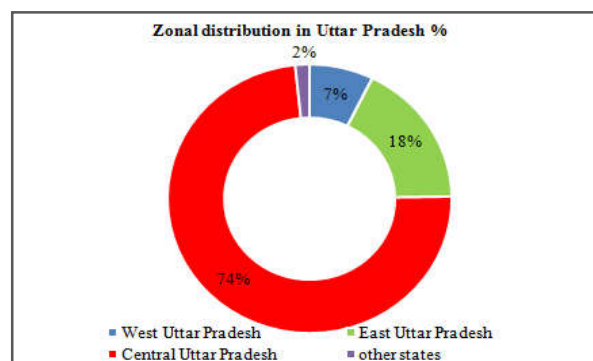


Fig 5: Distribution of cases according to epidemiological distribution

Almost 74% patients (Figure 5) belong to various district of central Uttar Pradesh followed by Eastern Uttar Pradesh followed by Western Uttar Pradesh. The large footfall from Central UP is due to close proximity and relatively easy connectivity of the palliative care unit from these districts. A patient can avail one of several schemes (Asadhya card, Ayushman Bharat card, CM Funds, Vippana) to ease some of the financial load which they may have to bear during the course of treatment. The financial schemes launched by state and central government play an instrumental role in helping the patients, since most of the patients registered in the palliative unit / department belong to low income group. The schemes have not only helped in monetary terms but also helped in increasing regularity of patients in form of follow ups and other compliance measures.

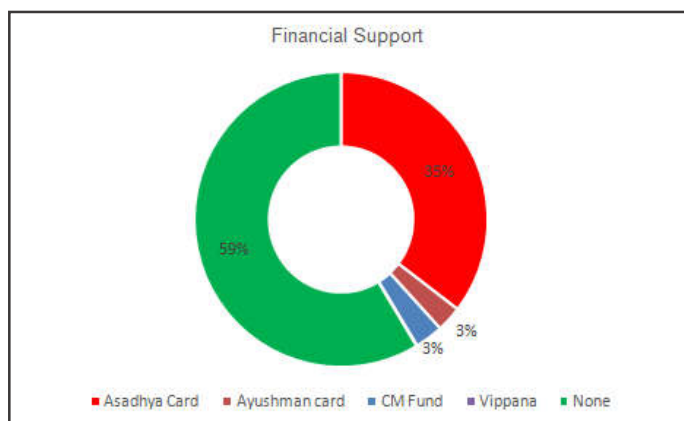


Fig 6: Distribution of patient provided with financial support.

Almost 35% (Figure 6) of the low income group patients were issued Asadhya card based on the income certificate produced by the patient. The cards have helped to easily avail various types of diagnostic workouts, medicines etc.

DISCUSSION

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification, assessment and treatment of pain and other problems, physical, psychosocial and spiritual^[15,16]. Ideally, palliative care services should be provided from the time of diagnosis of life-threatening illness, adapting to the increasing needs of cancer patients and their families as the disease progresses into the terminal phase. It has been observed and analyzed that the palliative care needs in advance cancer patients were significant and need further attention for optimal care. In India, incidence of cancer is 11,57,294 yearly, prevalence (5 years) is 22,58,208 and death yearly due to cancer 7,84,821 which is c.37.4% if we compare with the prevalence. In India presently only around 1% patients have access to palliative care in view of lack of knowledge. Study was conducted in 1,600 advance cancer patients receiving palliative care. 1,036 (64.8%) were males and 564 (35.2%) were females. 11 sites of histopathologically proven primaries has been included in the study where head and neck malignancy accounts for 50%, gastro-intestinal 11%, gynecological 9%, hepato-biliary 7% etc. where palliative care is of utmost importance. In another similar study by Sharma et al. in 152 patients, most of the primaries were of head and neck region (60%) followed by gastrointestinal malignancies in 14% and lung cancer in 11% cases^[17]. In another study by Signal et al., 44% of patients had primary malignancy of head and neck, 14% of cervical, 17% of lung cancer, 6% of breast, and 5% of colon^[18]. In terms of complaints, almost 100% patients reported pain followed by loss of appetite in

84%, tiredness in 75%, swelling in 61%, bleeding in 42%, nausea vomiting in 36%, anemia in 26% and difficulty in swallowing 21%. Other earlier surveys for palliative care need assessment have reported similar results. A survey from the OPD of a regional cancer centre found that 90% patients were suffering from pain and weight loss^[19]. A study from Turkey on palliative care needs of gynecological cancer patients also reported many issues in patients such as tiredness, depression, and problems in performing physical activity.^[20] Pain, tiredness, and depression were found to be independent factors for suffering from advanced cancer in Saudi Arabia.^[21] Palliative care services are one of the important aspects in the treatment of advanced cancer patients. These services are needed in every trajectory of the patient's illness.^[22] In the present study, 1,015 patients were offered palliative radiotherapy (PRT) for pain relief at primary or metastatic sites. The patients receiving PRT should be adequately attended for pain and symptom relief.^[23] In this study, patients have revealed good symptomatic relief for most of the symptoms for which they were treated, when first reviewed 2–4 weeks after PRT. This high percentage can be explained by the fact that the study was conducted in a multispecialty hospital where patients received multimodal palliative care along with PRT, such as palliative chemotherapy, steroids, regional nerve blocks, and assisted feeding. More than 60% of patients reported more than 50% of pain relief in this study. This is in accordance with the existing data which have documented partial pain relief of 60%–80% and complete pain relief of 30%–50% in patients 3–4 weeks after initiation of external beam PRT^[24]. In a similar multi-centric study by van Oorschot et al., PRT led to a significant improvement of well-being (35% of patients) and reduction of symptoms, especially with regard to pain (66%), dyspnea (61%), and neurological deficits (60%).^[25]

CONCLUSION

The palliative care needs in developing countries like India must be further assessed for formulating an optimal plan for provision of universal palliative care to all advanced cancer patients. Presently, there is gross absence of accessibility to prompt and effective treatment for these advanced chronic diseases including advanced cancers. The development of palliative care through effective, low-cost approaches is usually the only feasible alternative to respond to the urgent needs of the sick and improve their quality of life.^[26] Integrating the oncology and palliative care services can be one such measure.^[27] For improving access to palliative care in India, education of professionals and public awareness is emphasized.^[28] There has to be strong fusion of robust patient care framework, awareness among the masses and government initiatives to make a pragmatic impact in order to improve the patient care.

ACKNOWLEDGMENT

Foremost, I would like to express my sincere gratitude to my advisor Prof Rajendra Kumar for the continuous support and guidance throughout the study. My co-author, Rashmi Gupta has been instrumental in carrying out various studies and analysis throughout the study period. The constant support of medical staff as well as the patients has been very important as the patient's history play a base for carrying out any study and analysis. I am thankful to the Patient Record Section of Radiotherapy Department, KGMU for compilation of the data used in the study. Finally, I would like to acknowledge the important contribution of my husband, who spent couple of weekends to read every version of this paper and helped in brainstorming various topics and issues.

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