

Original Research Article

QUALITY OF LIFE IN ENHANCING CANCER **PATIENTS:** RETROSPECTIVE STUDY PALLIATIVE CARE SERVICES TERTIARY IN Α **GOVERNMENT CANCER HOSPITAL**

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ABSTRACT

Background: Palliative care is an approach that improves the quality of life of patients and their families. Quality of life is a broad ranging concept incorporating in a complex way the persons' physical health, psychological state, level of independence, social relationships, personal beliefs and their relationships to salient features of the environment. Early integration of palliative care for patients with advanced cancers showed clinical benefits in survival and improvement in quality of life. Worldwide, only about 14% of people who need palliative care currently receive it. The need for palliative care was found to be 6.21/1,000 population in India. In Andhra Pradesh, due to increased demand and fewer resources integrated palliative care services are yet to be developed in many centres and reach those in need. The main objective of this study is to audit our institutional experience since the initiation of delivering palliative care services and home care services through which quality of life is improved in cancer patients. This is a descriptive study conducted by analyzing data retrospectively from the registers between March 2023 and February 2024.

Material and Methods: At Government General Hospital, Guntur, palliative care services were started in the Department of Oncology in March 2023, and home care visits since April 2023. The palliative care team at our institution includes Oncologists, Anesthetists, Nurses, Physiotherapists, Social workers, and Counselors who were specially trained. Since the beginning of palliative care services, the team provided pain management, wound care, tracheostomy care, colostomy care, etc. to various patients. Also, bereavement counseling is provided to family members of patients. The services are extended to debilitating patients within the Guntur district in the form of home visits with end-of-life care. Patients from other districts are given care by the village health clinics managed by Mid-level health providers (MLHPs) who are trained by our team.

Results: A total of 744 patients were included in the study. Of which 692(93%) were registered under pain and palliative care hospital services from the beginning of March 2023 till February 2024. Home visits and end-of-life care included a total of 52(7%). The median age of the patients was 53 years (SD: 39-67 years). Males and females were of equal percentage. Gastrointestinal & hepatobiliary cancers constituted the highest percentage of patients under our palliative care with 25.94 % followed by Head and neck cancers (25%), breast (13.98%), lung (13.04%), gynecological malignancies (12.09%) and other malignancies cumulatively constituted 9.95%. Total 665

patients were on Morphine with a median of 76 per month. All the 744 patients registered were assessed for distress scoring through NCCN distress tool initially before initiation of palliative care services. However, less than fifty percent patients were available as lost to follow up for review assessment of the distress scoring system.

Conclusion: With the increasing burden of cancer patients, there is an increase in the need for multidisciplinary management in which palliative care services play an important role. Providing these services to patients within the hospital and extending them with home visits is one of the first of its kind in Government set up in the state of Andhra Pradesh. We as a team are working to reach furthermore patients who need evidence-based palliative care services and improve the quality of life of patients.

Keywords: Palliative care, Home care, Cancer, India, Andhra Pradesh.

INTRODUCTION

The World Health Organization (WHO) describes 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 through early identification and impeccable assessment and treatment of pain, illnesses including other problems whether physical, psychosocial, and spiritual".^[1] Quality of life is defined by the WHO as "individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns". Quality of life is a broad ranging concept incorporating in a complex way the persons' physical health, psychological state, level of independence, social relationships, personal beliefs and their relationships to salient features of the environment.^[2] Palliative care is specifically designed to improve the quality of life for both patients with serious illnesses and their families, by managing symptoms and supporting patients through treatment.^[3,4,5] It also addresses the emotional, social, and spiritual challenges associated with chronic diseases or end-of-life care.^[6,7,8] Palliative care teams work in a multidisciplinary manner to provide comprehensive care aiming to relieve suffering and provide the best possible quality of life for patients and their families.^[9] Early integration of palliative care for patients with advanced cancers showed clinical benefit on survival and improvement in quality of life.^[10,11] Each year an estimated 56.8 million people need palliative care, most of whom live in low- and middle-income countries. Worldwide, only about 14% of people who need palliative care currently receive it.[12] Systematic review and meta-analysis by Chandra et al revealed the need for palliative care was found to be 6.21/1,000 population in India. Subgroup analyses indicated a higher prevalence in the southern region and rural areas.^[13] The introduction of palliative care in India dates back to the 1980s followed by the formation of the Indian Association of Palliative Care (IAPC) in 1994.^[14] Palliative care services within the state of Andhra Pradesh were initiated a decade ago in 2012 by the Sneha Sandhya Age Care Foundation (SSACF) through the home and hospice

care provision. From the year 2015, a dedicated Palliative Medicine Department with full-day outpatient services began functioning at HBCHRC (Vishakhapatnam). In the year 2019 Government General Hospital (GGH) in Kurnool started palliative care services.^[15] Of the 26 districts of Andhra Pradesh palliative care services are in reach to the public in a few centres. Evidence-based palliative care services should be provided in all the districts in the state. At Government General Hospital, Guntur palliative care services were started in the Department of Oncology in March 2023, and home care visits since April 2023. In Andhra Pradesh, integrated palliative care services are yet to be developed in many centres and reach those in need, due to increased demand and fewer resources. The main objective of this study is to audit our institutional experience since the initiation of delivering palliative care services and home care services through which quality of life is improved in cancer patients.

MATERIAL AND METHODS

At Government General Hospital, Guntur palliative care services were started in the Department of Oncology in March 2023, and home care visits since April 2023. The palliative care team at our institution includes Oncologists, Anaesthetists, Nurses, Physiotherapists, Social workers, and Counsellors who were specially trained. Since the beginning of palliative care services, the team provided pain management, wound care. tracheostomy care, colostomy care, etc to various patients. Also, bereavement counselling is provided to family members of patients. The services are extended to debilitating patients within the Guntur district in the form of home visits with end-of-life care. Patients from other districts are given care by the village health clinics managed by Mid-level health providers (MLHPs) who are trained by our team. Pain Management includes pain assessment with a visual pain analogue scale, [16] and then treatment according to the WHO 3-step analgesic ladder. ^[17] For the colostomy care the stoma and parastomal area are cleaned with sterile dry gauze and then assessed for healthy stomal signs like pink to red colour of stoma, moist and slightly shiny. Post assessment a skin barrier cream as pH buffer is applied over peristomal skin for better healing and finally a colostomy ring is secured around the stoma and a colostomy bag is attached. For wound care wound is flushed with diluted betadine, hydrogen peroxide, and normal saline. Metrogyl powder is used after cleaning and then the wound is closed with a sterile pad. In the case of maggots, turpentine oil is used. For the tracheostomy care the inner cannula of the tracheostomy tube is removed initially and cleaned followed by suctioning with sodium bicarbonate and normal saline. Finally, the stomal site is cleaned with betadine gauze and the stomal site is secured with a sterile gauze piece. Palliative care services are extended to debilitating patients with home care within the Guntur district to places like Dasaripalem, Mamillapalli, Maruthinagar, Gorantla, Koppuravuru, Ananda Theertha Agraharam, SVN colony, Munipalle, Sangadigunta, etc. For the patients who are not reachable telemedicine facility is provided. The NCCN distress management tool was used to address distress measure which considered practical concerns (e.g., housing, insurance, physical symptoms), family problems, and emotional and spiritual or religious concern. ^[18] Every patient was assessed with NCCN distress score at the time of registration and accordingly counselled. Inclusion criteria for the study were patients who are diagnosed with cancer in advanced stages who are excluded from radical curative treatment irrespective of their age. All other cancer patients undergoing curative treatment were excluded. This is a descriptive study conducted by analyzing data retrospectively from the registers between March 2023 and February 2024. This study was approved by the Institutional Ethics Committee before initiation and patient consent has been taken. **Statistics**

The data was analyzed using the IBM SPSS® software version 23. The descriptive data was represented as mean, median, and standard deviation.

RESULTS

A total of 744 patients were included in the study. Of which 692(93%) were registered under pain and palliative care hospital services from the beginning of March 2023 till February 2024. Home visits and end-of-life care included a total of 52(7%). The median age of the patients was 53 years (SD: 39-67 years). Males and females were of equal percentage. Gastrointestinal & hepatobiliary cancers constituted the highest percentage of patients under our palliative care with 25.94 % followed by Head and neck cancers (25%), breast(13.98%), lung(13.04%), gynecological malignancies(12.09%) and other malignancies cumulatively constituted 9.95%. (See table 1 for the demographic data). Total 665 patients were on Morphine with a median of 76 per month. All the 744 patients registered were assessed for distress scoring through NCCN distress tool initially before initiation of palliative care services. However, less than fifty percent patients were available as lost to follow up for review assessment of the distress scoring system.

Characteristics	Number	Percentage
Total	744	
Pain& Palliative care services at hospital	692	93%
Home care services	52	7%
Age		
<15 yr	18	2.4%
15-44yr	119	16%
45-59yr	347	46.7%
60-79yr	246	33%
$\geq 80 \mathrm{yr}$	14	1.9%
Diagnosis		
GI & Hepatobiliary malignancies	193	25.94%
Head & Neck malignancies	186	25%
Breast	104	13.98%
Lung	97	13.04%
Gynaecological malignancies	90	12.09%
Other malignancies	74	9.95%

DISCUSSION

Palliative care services play a crucial role in the multidisciplinary management of cancer patients, especially with the increasing burden of cancer cases. These services not only aim to provide relief from physical symptoms but also address the emotional, psychological, and spiritual needs of patients. However, there are significant disparities in the provision of palliative care services worldwide and in India, with only a small percentage of those in need receiving it. In South India, Kerala state with its Kerala model showed a tremendous improvement in its palliative care services. [19] Other states in south India are yet to develop palliative care services on par with Kerala. In Andhra Pradesh, though the palliative care services were started in a few centres it is yet to be reached to the patients in need in most of the districts. In the district of Guntur at Government General Hospital palliative care services and home care services were initiated in March 2023. As mentioned by Gregory B. et.al, ^[20] interdisciplinary teamwork is an integral part of providing palliative care for a better quality of life. We at our tertiary government cancer hospital incorporate Oncologists, Anaesthetists, Nurses, Physiotherapists, Social workers, and Counsellors who are specially trained in our palliative care team. All the patients who are registered under palliative care services were provided with pain management, wound care, tracheostomy care, psychological counselling and also bereavement counselling for the family members. There was a significant improvement in the pain scoring post-pain management according to the WHO 3-step analgesic ladder which added to their better quality of life. As it is a retrospective study we were able to assess quality of life in terms of pain, wound care, tracheostomy care and NCCN distress scoring the data we obtained from the registers. So, limitations of our study include study being retrospective, outcomes in palliative care can be subjective and may rely on patient or caregiver reporting, which can introduce bias. Without a comparison group, it is difficult to determine if the outcomes can be directly attributed to the palliative care interventions.

CONCLUSION

In developing country like India being capital for non-communicable diseases like cancer there is need for improved social policies and increased access to comprehensive and integrated palliative care services. Providing these services to patients within the hospital and extending them with home visits is one of the first kinds of Government set up in the state of Andhra Pradesh. We as a team are working to reach furthermore patients who need evidence-based palliative care services and improve the quality of life of patients.

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