International Journal of Community Medicine and Public Health
Eliza SR et al. Int J Community Med Public Health. 2026 Aug;13(8):4307-4310
https://www.ijcmph.com
pISSN 2394-6032 | eISSN 2394-6040

DOI: https://dx.doi.org/10.18203/2394-6040.ijcmph20262706

Original Research Article

Profile and pattern of care among palliative home care patients under a tertiary care hospital in central Kerala, south India

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Received: 28 April 2026
Revised: 13 July 2026
Accepted: 15 July 2026

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ABSTRACT

Background: Increase in aging population and epidemiological shift in disease profile to non-communicable diseases have led to an increase in need for palliative care. But the high demand has not been met adequately with increase in palliative care service providers. The aim of this study was to describe the profile and pattern of care among palliative home care patients registered under a tertiary care private hospital in south India.
Methods: Data was extracted from the palliative home care case sheets regarding patient profile, analgesic usage, performance status (for oncology patients) and visit from other home care services. The patient case sheets were reviewed after 3 months to reassess the variables.
Results: Data was collected from 60 case sheets of patients registered under palliative home care department. After 3 months follow up 12 patients expired. Out of the total patients 75% of them (45) were geriatric patients with age more than 60 years. About half the patients were onco palliative patients (48.3%). The primary caretaker in most cases were children, as most persons were in the geriatric age group (41.6%). About half of the patients were not on any analgesics (55%). More than half of the palliative patients were utilizing services from government palliative care unit regularly (55%).
Conclusions: The study throws light into the profile of patients needing palliative care attached to a tertiary care private hospital and may be used as a basis for creating a sustainable model for providing palliative care services from other hospitals.

Keywords: Palliative care, Quality of life, Home based care

INTRODUCTION

Palliative care is 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] An unexpected health transition has occurred in India and Kerala over the past 20 years. The ratio of aging population seems to be increasing.[2] Epidemiological shift in the disease profile from communicable to non-communicable diseases contributes to the burden on family's economy as well as health care system.[3] In India, an estimated 59 lakh people are in need of such care but less than 2% are currently being catered to4. There is also a growing need for home based palliative care services which is being supported by the government palliative care program in Kerala. The lacunae in palliative care can be filled only by a greater number of service providers or by strengthening the community to support the palliative care needs of its people. The private health care sector has to develop a social commitment to complement the government palliative system to fill in these lacunae.

Kerala has remained unique in the palliative care journey through community based palliative care approach.

The objective of the study was to describe the profile and pattern of care among palliative home care patients registered under a tertiary care private hospital in south India.

METHODS

This was a record-based study.

All patients registered under palliative unit as on 1st of September 2024 was included into the study and none of them were excluded. Data was extracted from the palliative home care case sheets of the hospital regarding patient profile, frequency of home visit, primary caretaker, presence of Ryles tube/urinary catheters in situ, analgesic usage, performance status (for oncology patients) and visit from other home care services. The patient case sheets were reviewed after 3 months to reassess the variables.

ECOG PERFORMANCE STATUS*	
Grade	**ECOG**
0	Fully active, able to carry on all pre-disease performance without restriction
1	Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light house work, office work
2	Ambulatory and capable of all selfcare but unable to carry out any work activities. Up and about more than 50% of waking hours
3	Capable of only limited selfcare, confined to bed or chair more than 50% of waking hours
4	Completely disabled. Cannot carry on any selfcare. Totally confined to bed or chair
5	Dead

Figure 1: ECOG performance status.[7]

Statistical analysis

Quantitative data obtained was coded and entered into Microsoft Excel and analyzed using appropriate software. Descriptive statistics like mean, SD, median and range was calculated for continuous data and frequency and percentages for categorical characteristics of the study sample.

Ethical consideration

The Institutional ethics committee approval was taken before starting the study. Confidentiality of the patient was maintained at all stages.

RESULTS

Cross sectional data was collected from 60 case sheets of patients registered under palliative home care department. After 3 months follow up 12 patients expired.

Out of the total patients 75% of them (45) were geriatric patients with age more than 60 years. Mean age of the study population was 68.57 years with standard deviation 18.404 (range 7 years to 94 years). Gender distribution showed 61.7% females and 38.3% males. About half the patients were onco palliative patients (48.3%).

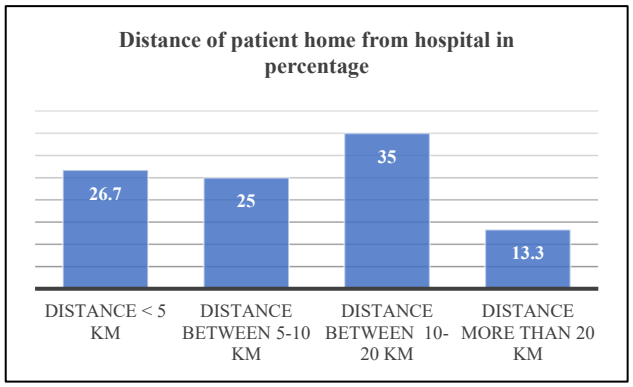

Figure 2: Distance of patient home from hospital.

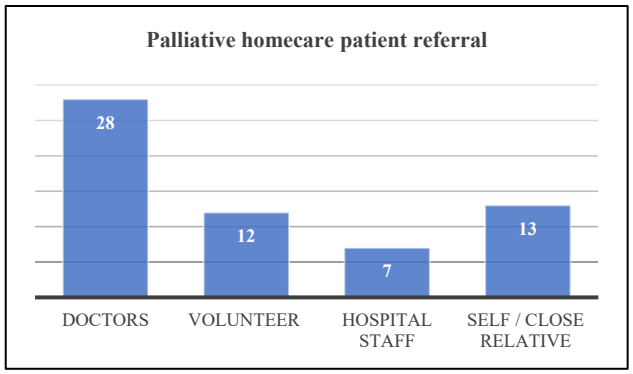

Figure 3: Reference to palliative home care services.

Most of the patients lived between 10-20 km from hospital (Figure 2). Most of the patients were referred to palliative home care service by the doctor (46.7%) and the rest were referred by volunteers (20%), self /relative of patient (21.7%) and hospital staff (11.7%) (Figure 3).

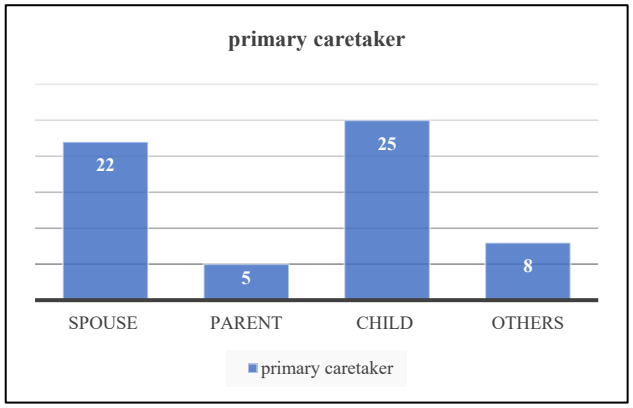

Figure 4: Distribution of palliative home care patients based on their primary care taker.

The primary caretaker in most cases were children, as most persons were in the geriatric age group (41.6%).

Of the total patients 68.3% were not seen by any other specialist and the rest have consulted other specialists including oncologists, psychiatrists, general physicians, neurologists etc. for management of specific comorbidities/medical events at least once during the past 6 months.

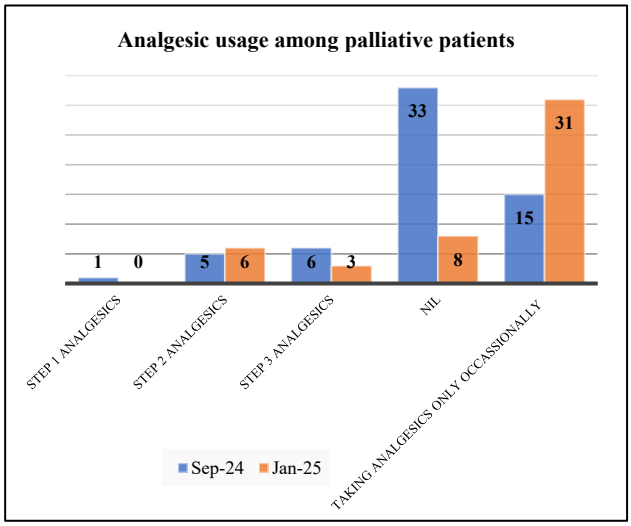

Figure 5: Comparison of analgesic usage in palliative patients.

12 patients expired/ shifted out during the follow up period.

About half of the patients were not on any analgesics (55%) and 25% were on analgesics which are being taken only during pain episodes (Figure 5).

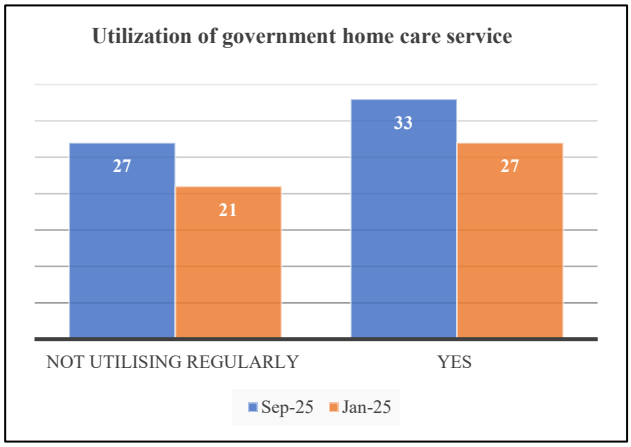

Figure 6: Utilization of government home care service by palliative home care patients

More than half of the palliative patients were utilizing services from government palliative care unit regularly (55%) and only 5 persons (0.08%) was using other private home care facilities which were used only during emergencies (Figure 6 and 7).

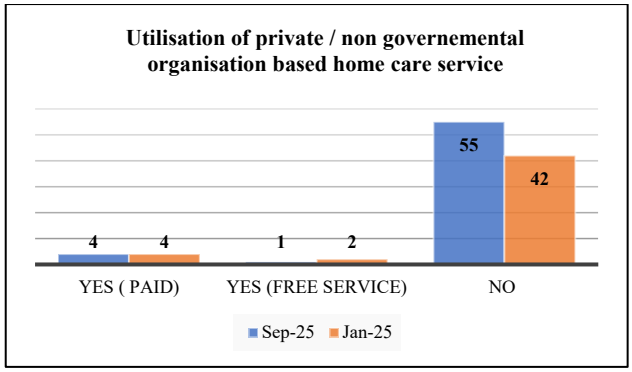

Figure 7: Utilization of private/non-governmental organization based home care service among palliative patients.

Among the 60 patients 8 had Ryles tube in situ (13.3%) and 33 had urinary catheters (55%). Four patients with Ryles tube and 10 patients with urinary catheters expired during the 3 month follow up.

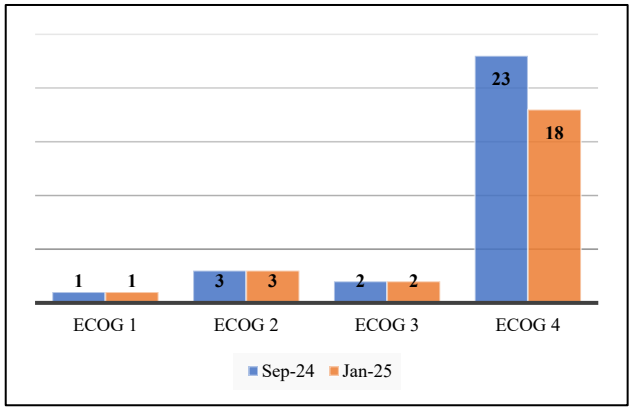

Figure 8: Comparison ECOG status among oncology patients in September 2024 and January 2025.

Five patients with cancer expired during the 5 month follow up.

ECOG (eastern cooperative oncology group) performance status was measured among oncology patient. Among the 29 cancer patients 23 of them (79.3%) were in grade 4 which means they are confined to bed.

DISCUSSION

Researchers across the world have identified the need for palliative care in improving the quality of life of its people especially those suffering from life threatening illness and thus suggesting policy changes to improve palliative care access among general public.[5]

This study throws light into the profile and pattern of care among palliative home care patients under a home care unit attached to a private hospital.

Palliative home care service is provided free of cost to the patients registered under our unit. It works on public

funding provided by well-wishers, cash boxes in shops etc.

The study shows that even patients living within 5 km from the hospital are seeking homecare service and prefers health care interventions at home for the comfort of the patient and bystander. Although the references to palliative care mainly comes from health care professionals, there is a need to expand the knowledge regarding palliative care among general public and health care professionals. Spouse and children of the palliative patient form the major group of caretakers and along with the palliative patients their needs and support should also be catered to. About half the patients were on analgesics and their dose and usage (including step 3 analgesics) need to be monitored by a trained health care professional, who has to be present during home visits.

More than half of the palliative patients were utilizing services from government palliative care unit regularly and their services need to be expanded to include other patients too. Lack of utilization was mainly due to the fact that their team does not always include a doctor.

Ryles tube and catheters were present in 13.3% and 55% of the patients respectively and their care and change of tubes poses a major difficulty among the caretakers.

ECOG (eastern cooperative oncology group) performance status was measured among oncology patient and most were in grade 4 category and shows the need for extra care required for these patients who are mainly bed ridden

Despite significant advances in medical field, palliative care remains an area which is poorly explored and accessed. Even in some of the most advanced countries in the world this lacuna in service persists.[6]

Private sector needs to go hand in hand to complement the public sector palliative care delivery.

The main limitation of this study is that it was done in the home care unit associated with a cancer institute and thus the data mainly focuses on cancer patients. There may be regional differences in the home care services from various governmental and non-governmental organizations and thus further study with a larger sample size including a larger geographical area may give a better picture of the home care service in the state.

CONCLUSION

The study throws light into the profile of patients needing palliative care attached to a tertiary care private hospital and may be used as a basis for creating a sustainable model for providing palliative care services from other hospitals.

Funding: No funding sources
Conflict of interest: None declared
Ethical approval: The study was approved by the Institutional Ethics Committee

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Cite this article as: Eliza SR, John M. Profile and pattern of care among palliative home care patients under a tertiary care hospital in central Kerala, south India. Int J Community Med Public Health 2026;13:4307-10.