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UTILIZATION AND CHALLENGES IN HOME-BASED PALLIATIVE CARE IN A RURAL AREA OF KOZHIKODE DISTRICT-A MIXED METHOD STUDY

Community Medicine

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ABSTRACT

Background: The palliative care approach significantly enhances the quality of life for patients and their families, serving as an indispensable component of a comprehensive response to non-communicable diseases (NCDs). In Kerala, where the prevalence of NCDs is high, Pain and Palliative Services began in 1993 at Government Medical College Calicut, evolving into widespread home-based care integrated into primary healthcare across most panchayats. **Objectives:** To study the utilization of palliative care services among patients in a rural area of Kozhikode from January 1 to December 31, 2022, and to identify the challenges faced by palliative care service providers at the palliative care unit. **Materials and Methods:** A mixed-method study was conducted in the palliative care unit of Mavoor Panchayat a rural area of Kozhikode district in Kerala in two phases. The first phase addressed the quantitative components of the study. Demographic details, symptoms and services received by patients registered in 2022 from palliative care health records were collected. The second phase addressed qualitative component of the study by conducting In-depth interview among healthcare providers to identify challenges in implementation. **Results:** Among the 113 patients newly registered in 2022, 58% were females, and the median age was 74yrs. Multimorbidity (24%) was the predominant condition for which palliative care was sought. Main services availed were blood pressure monitoring (43%) and training of care givers in provision of giving bath to bedridden patients (49%). Major challenges faced by healthcare providers included a shortage of trained staff. **Conclusion:** Palliative care services are being provided mainly for non-communicable diseases. Strengthening and expanding trained human resources will ensure more frequent and higher-quality care for patients. The involvement of medical and paramedical students in palliative care as part of their curriculum will contribute to sustained and continuous care.

KEYWORDS

Home-based palliative care, non-communicable disease, multimorbidity.

INTRODUCTION

In 2002, the World Health Organization (WHO) defined Palliative Care as an approach dedicated to improving the quality of life for patients and their families facing the challenges associated with life-threatening illnesses [1]. Palliative care is a vital component of comprehensive care for individuals dealing with complex chronic or acute, life-threatening, or life-limiting health conditions, and it is meant to be practiced by all healthcare and social care providers, including palliative care specialists. Furthermore, palliative care can be administered in any healthcare setting [2].

The growing significance of palliative care is evident in the global surge of Non-Communicable Diseases (NCDs) and the subsequent rise in the number of patients requiring long-term care for chronic conditions [3]. It is essential across a spectrum of diseases, encompassing chronic conditions like cardiovascular diseases, cancer, chronic respiratory diseases, AIDS, and diabetes [1].

The introduction of home-based models has transformed the concept and accessibility of palliative care within the public sphere. This approach optimizes the use of specialist palliative care expertise, with various models, including specialist consultative services, inpatient palliative units/beds, or nurse practitioner models being adopted in palliative services [4][5].

In India, the Government of Kerala declared a Pain and Palliative Care policy, marking the initiation of community-based home care initiatives. Majority of local self-governments are now integrating home-based palliative care as part of primary healthcare in Kerala [6]. The Neighbourhood Network in Palliative Care, recognized as a successful model not only in India but also in the entire developing world, strives to develop a free-of-charge, sustainable, community-led service capable of offering comprehensive long-term care and palliative care [7][8].

Palliative care services were initiated in Kerala as an outpatient unit at Government Medical College, Calicut in 1993 [9]. The home-based palliative care initiative was launched in Mavoor Panchayat of Kozhikode district in 2010. Since its inception, 1323 patients have been registered over the years. Presently, 371 patients are actively availing palliative care services. There is a need to evaluate the palliative services offered and identify challenges in implementation to ensure adequate utilization.

MATERIALS AND METHODS

The study was conducted at the Palliative Care Unit of Mavoor Panchayat, attached to the Community Health Centre of Cheruppa, a rural area within the Kozhikode district. The area encompasses a population of 31,977. The home-based palliative care approach in Mavoor Panchayat was initiated in 2010, facilitated by a special fund established by the Local Self Government (LSG).

A mixed-method study was conducted in the Palliative Care Unit of Mavoor Panchayat over one month. In the first phase (Quantitative component), demographic details of patients, reported symptoms, and services received by patients registered from 1st Jan 2022- 31st Dec 2022 were collected from palliative care health records at the health centre. Data were entered into MS Excel and analysed using SPSS statistical software version 18.0.

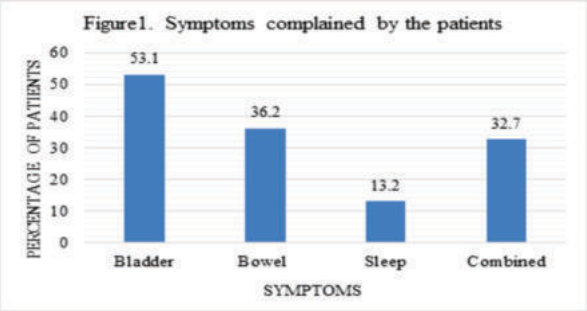
The second phase (Qualitative component) involved collecting information on challenges faced by healthcare providers involved in palliative care. In depth interview was conducted among doctors (2), palliative care nurse (1), and ASHAs (accredited social health activists) (3) and transcribed. Qualitative data were analysed through content analysis, identifying codes and categories using an inductive method.

RESULTS

During the one-year period of the study 113 patients had newly registered at the palliative care unit.

Profile of Patients:

Among the study participants, proportion of females were more (58%) when compared to males (42%). The median age was 74yrs (Range 41-98yrs). The majority of patients (48.7%) belonged to three-generation families, 30.1% were from nuclear families, and the remaining 21.2% were from joint families. The mean family size was 4.8±1.6. For 99% of the patients, care givers were household members, and home nurse for the rest. 38.1% were bedridden, 56.6% were unable to perform daily activities and 42.5% expired during the same year. Majority of patients (53.1%) complained bladder issues followed by bowel (36.2%) (Figure 1).



Services availed by the patients:
Majority of patients were receiving palliative care for multimorbid condition (23.9%), followed by cancer (13.3%) (Table 1).

Table 1. Conditions for which receiving palliative care

CONDITION	PERCENTAGE
Multimorbidity	27(23.9%)
Cancer	15(13.3%)
Fracture	15(13.3%)
Hypertension alone	13(11.5%)
Debilitated elderly	12(10.6%)
Cerebrovascular accident	9(8.0%)
Dementia	5(4.4%)
Diabetes alone	5(4.4%)
Chronic obstructive pulmonary disease	4(3.5%)
Coronary artery disease	3(2.7%)
Chronic kidney disease	3(2.7%)
Parkinsonism	2(1.8%)

The majority (68%) of patients received 2-4 visits from healthcare providers (HCPs) within one year. Eighteen percent of patients received 5-7 visits, 10% had one visit, and 3% received 8-10 visits in a year. Only 1% received more than 10 visits. The visits are routinely done by the palliative care nurse and ASHA worker. Medical professionals provide care in emergency circumstances and for selected patients. 70% patients receiving care from palliative nurse and ASHA, 24% patients receive services of doctor and 6% patients receives physiotherapists services additionally. The patients receive services according to their health condition. Patients received services mainly as BP monitoring (92%), training of care givers in provision of care, example: giving bath (49%), toilet of intimate parts (43%) and oral care (35%) for those bedridden/ debilitated patients (Figure 2).

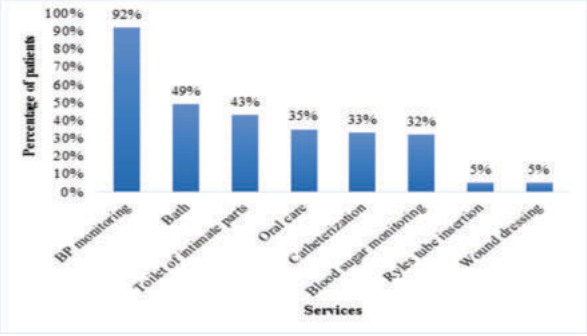


Figure 2: Services availed by the patients in the year 2022

Patients receive different social securities like old age pension (52%), Widow pension (16%), Farmers welfare pension (10%), Service pension (8%) and Others (4%).

Challenges Faced by Health Care Providers:
In-depth interviews were conducted among health care professionals involved in palliative care - two doctors, three ASHA workers, and one palliative care nurse. Two major themes were identified as programme related factors and patient related factors.

1)Programme related factors:
Healthcare providers highlighted program-related challenges, categorized into logistics, infrastructure, time resources, and human resources.

Logistics: Lack of essential drugs emerged as a major issue as mentioned by all health care providers. Palliative care nurse mentioned the requirement for certain essential medicines, especially for conditions like chronic kidney disease, coronary artery disease and cirrhosis, which patients sometimes have to purchase from private sector. As per the nurse's statement "*financial support from government was regular and there is enough money to buy equipment's, walking aids, to pay transport fee"*.

Nurse also added the lack of provision in providing essential medicines at patient's door steps. Since significant number of patients are suffering from multimorbidity, drugs that specifically prescribed for their conditions (example: combination drugs) are not freely available at the health centre. Moreover, irregular government supply of drugs at the CHC further aggravates the problem.

Infrastructure: Under infrastructure, lack of computerized system for documentation was stressed by doctors. Challenges for maintaining records of patients was highlighted by palliative nurse and also suggested computerised system for documentation. ASHA workers pointed out the absence of a 24-hour ambulance service for emergencies.

Time resource: Under time resource time constraints for each patient found to be a main problem and the doctor proposed one doctor exclusively for palliative care to ensure each patient receives proper attention. Palliative nurse also mentioned about additional care/time for patients with multiple problems.

Human resource: Under human resource shortage of trained nursing staff emerged as major issue.

"*I am the single person posted here for the past 12 years"* palliative care nursed raised her concern. Doctors and ASHA workers also emphasized the shortage of trained staff for home care. Doctor suggested that

"*It will be better to post one doctor only for palliative care and visits, thus every patient will get the opportunity to look after by the doctor*". Doctor also emphasized the absence of a permanent physiotherapist despite the substantial need for regular physiotherapy.

2) Patient Related Factors:
Challenges related to patients were identified, focusing on accessibility factors and financial issues.

Accessibility factors: Under accessibility factors distance to health care centre and dependence on others for collection of drugs were pointed out by nurse and ASHAs as a major issue.

Financial issue: Financial constraints of the patients emerged as another problem. Purchase of drugs due to unavailability and travel expenses contribute to significant out-of-pocket expenditure of patients. ASHA workers emphasized the financial struggles of elderly patients

"*Almost all patients are in their old age and depends on others for money. So those from financially backward houses struggles more"* and suggested fund raising through NGOs and community organizations. All core problems (codes), their respective categories, and themes are detailed in Table 2.

Table 2: Core problems and challenges identified in Health Care Providers

CORE PROBLEMS (CODES)	CATEGORIES IDENTIFIED	THEMES
Deficiency of essential drugs in health centre	Logistics	Programme related factors
Lack of computerized system for documentation Lack of 24hour ambulance service	Infrastructure	
Time constraints for each patient. Additional care/time needed for few patients with multiple problems	Time resource	
Shortage of trained nursing staffs for palliative care Lack of permanent physiotherapist	Human resource	

Distance to health care centre for getting medications and dependence on others for getting drugs	Accessibility factor	Patient related factors
Out of pocket expenditure for drugs prescribed by specialists	Financial issues	

DISCUSSION

The launch of home-based palliative care in Mavoor Panchayat in 2010 has shown substantial engagement, with 1323 patients registered during this time period since 2010. In the year 2022, 113 patients newly registered, surpassing the expected estimate based on population projections [10]. The program's acceptance seems positive, particularly in a community where 84% of the population falls into the >60 age group.

The demographics reveal a lower proportion of male patients, possibly influenced by higher life expectancy among females. Life expectancy of females in Kerala is 76.9 years, which is higher than the national [15]. The average family size corresponds with a value for the area of 4.8 people/house, comparable to study done in the same area in 2011 [6]. Most of the patients were from three generation family may be one of the reasons for the caregivers being household members themselves (99%). A descriptive study conducted by Philip RR et al in Malappuram showed for 96% of patient's family member itself as care givers [7]. Urinary complaints, particularly the need for frequent catheter changes, were prevalent, higher requirement for catheter changes among males, indicates issues such as acute urinary retention in older men [11].

The predominant presence of patients with multiple non-communicable diseases underscores the evolving impact of lifestyle changes [12]. Palliative care, traditionally associated with cancer, is increasingly needed for a spectrum of non-communicable diseases, aligning with the global shift in healthcare priorities [7]. However, the limited utilization of services from doctors and physiotherapists poses a notable challenge. Strengthening these aspects is crucial for optimal palliative care delivery.

Challenges identified in the provision of palliative care include a pronounced shortage of trained staff, particularly palliative care nurses. The intermittent involvement of doctors and the temporary nature of physiotherapist recruitment further compound the issue. A study conducted by Mayank Sharma et al also found out the issue of lack of trained staffs [13]. From patients' point of view, high out-of-pocket expenditure and dependence on other sources for medicine. 50% of them are dependent on others for activities of daily living, which may increase the burden in the household member who is care giver. As per Kerala's palliative care policy, it is essential to improve access to essential medicines needed for pain and palliative care [14]. This financial strain aligns with broader challenges in ensuring access to essential medicines, emphasizing the need for policy measures to address such issues. Time constraints for the health care providers in home care is go in hand with the study conducted by Agarwal US et al [16].

The study emphasizes the critical need to enhance capacity for documentation, research, and development in the palliative care sector. The identified challenges, especially the shortage of trained staff and financial constraints, underscore the importance of a comprehensive and sustained approach to address the multifaceted needs of patients requiring palliative care in the community.

LIMITATIONS

The descriptive details collected were primarily derived from records, which might have limitations in capturing the complete spectrum of information.

CONCLUSION

Home-based palliative care is primarily catering to patients with non-communicable diseases. The significant challenge faced by healthcare providers (HCPs) is the shortage of trained staff, impacting the frequency of visits and creating difficulties in accessing essential medicines. The limited availability of trained personnel raises concerns about the ability to meet the growing demand for palliative care services.

RECOMMENDATION

Collaborate with medical and paramedical educational institutions to incorporate palliative care into the curriculum and involve students in palliative care settings. Establish a systematic and ongoing process for monitoring and evaluating the home-based palliative care program. Address the issue of shortage of trained staff by new recruitment and providing training opportunities and workshops. Foster community engagement by raising awareness about the importance of palliative care and promote research initiatives in palliative care.

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ETHICAL CONCERNS

The study was approved by the Institutional Ethics Committee –Government Medical College Kozhikode (IEC No: GMCKKD/RP 2023/IEC/141)

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Nil

CONFLICTS OF INTEREST

There are no conflicts of interest

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