

Awareness and Self Reported Utilization Pattern of Community Palliative Care Units in a Rural Area in Central Kerala

Bichu P Babu**, *Abyraj Kurinjikattil and
*Shaliet Rose Sebastian******

Palliative care is a specialty of health care that deals with not only the attitude and values of care, but caters to the patient dealing with chronic, debilitating, life-threatening illness from diagnosis till death. Kerala has been the pioneer for offering excellent palliative care in our country supported by government policy that ropes provision of palliative care through the public health system. Home-based palliative care is care provided to people with chronic, debilitating, and progressive diseases that are potentially life limiting, in the home or live-in environment of the patient. Advantages of home-based palliative care are the provision of comfort to patients in familiar surroundings, easy access, security, independence, increased effective care, and spreading awareness in the community. This study was conducted in 60 adults in Thiruvwarppu Panchayat using a

*** Medical Social Worker, Believers Church Medical College, St. Thomas Nagar, Kuttapuzha, Thiruvalla, Kerala- 689103 (India)**

**** Medical Social Worker & PRM, MarSleeva Medicity, Cherpunkal, Kerala- 686584 (India)**

***** MBBS, MD, PGDEPI, Believers Church Medical College, Thiruvalla, Kerala- 689103 (India) E-mail: <drshalieters@gmail.com>**

semi-structured questionnaire to assess the awareness about community palliative care services and to study the utilization pattern of the services by the community. Out of 60 study participants, 57(95%) of them had heard about community palliative care units. 93% had availed palliative care services for a family member. From the study, it was understood that the study population had good awareness about community palliative care services. Further improvement in the reach of services can be made possible by involvement of grass root level workers, conduct of community programs through schools, colleges, kudumbasree and other Self Help Groups and involvement of NGOs to provide better facilities to the patients.

[**Keywords** : Awareness, Palliative Care, Utilization Pattern, Kerala]

1. Introduction

Palliative care is a specialty of health care that deals with not only the attitude and values of care, but caters to the patient dealing with chronic, debilitating, life-threatening illness from diagnosis till death. It not only aims to provide optimal quality and organized care to these patients, but also helps in the bereavement of the family and caretakers after the death of the patient. The WHO defined 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, impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual.”¹ The UN Committee on Economic, Social and Cultural Rights reports that it is critical to provide “attention and care for chronically and terminally ill persons, sparing them avoidable pain and enabling them to die with dignity.”² Thus, palliative care has its sphere of influence not only at the physical and emotional needs of the patients and their relatives, but also aims to improve the physician-patient communication and provision of multispecialty coordinated care.³ The need for palliative care is ever increasing at a faster pace due to increase in aging population as well as increase in cancers and other NCDs. According to Worldwide Palliative Care Alliance (WPCA), although more than 100 million people across the world would benefit from hospice and palliative care annually, less than 8% of those in need access it.⁴ It is estimated that in India around 1 million people are diagnosed with cancer every year. Around 80% of all cancers are diagnosed in the advanced stage when treatment is less effective and palliative care becomes absolutely essential.⁵

The palliative care medicine gained its momentum in the early 1990s mainly driven by the nongovernmental sector promoting awareness and increasing avenues of care.⁶ The Pain and Palliative Care Society, Calicut, Kerala, formed in 1993, is one of the non-governmental organizations (NGOs) that have played a pioneering role in developing palliative care in the country.⁷ Kerala has been the pioneer for offering excellent palliative care in our country supported by government policy that ropes provision of palliative care through the public health system.^{8,9} At present, there are approximately 1000 palliative care units in India, with about 90% of these being located in Kerala which caters to only 3% of country's population.¹⁰

Home-based palliative care is care provided to people with chronic, debilitating, and progressive diseases that are potentially life limiting, in the home or live-in environment of the patient. It is generally delivered by an interdisciplinary team trained in palliative care, which includes doctors, nurses, paramedical staff, and volunteers.¹⁰ The WHO India Country Office has developed guidelines for providing home-based palliative care.¹¹ The basic components of home-based palliative care include a willing and accessible patient, an available caregiver, a conducive home/live-in environment, a properly trained team, 24-h support, means of transport, network for supportive care, and a homecare kit. Advantages of home-based palliative care are the provision of comfort to patients in familiar surroundings, easy access, security, independence, increased effective care, and spreading awareness in the community. By increasing the proportion of community and homecare, palliative care can reduce costs associated with hospital stays and emergency admissions. One of the key objectives of the National Program for prevention and control of cancer, diabetes, cardiovascular diseases, and stroke is to establish and develop a capacity for palliative and rehabilitative care.¹² The proposed structure under this program includes setting up facilities for patients requiring home-based care and day care. A team consisting of nurses and counselors should be trained in identifying symptoms, pain management, communication, psychosocial and emotional care, nursing needs of the terminally ill, and ethics of palliative care. The activities at the state, district, Community Health Centre, and sub-center levels ought to be closely monitored through the NCD cell at different levels. Earlier studies have reported that around 12-28% of patients chose to opt out of palliative care for various reasons

which increases with a decrease in social support from the clinic and the number of home visits by the physician.^{13,14} Understanding the patient characteristics, utilization of home-based palliative care and its predictors can assist service planners in the appropriate allocation of resources and service packaging to meet the complex needs of palliative care patients.¹⁵ However, there is limited information on general awareness about palliative care among the public and the utilization pattern of palliative care. This study was conducted to assess the awareness about community palliative care services and to study the utilization pattern of the services by the community

2. Materials and Methods

2.1 Study Design

The study design is exploratory in nature and uses cross sectional analysis.

2.2 Study Setting

Thiruvārppu Panchayat, Kottayam District of Kerala State, India is study setting.

2.3 Study Population

Adults aged 18 years and above who are permanent residents of Thiruvārppu Panchayat constitute the universe of this study.

2.4 Study Tool

A pre-tested semi-structured questionnaire has been used in the study.

2.5 Sample Size and Sampling Technique

Sample size of this study is 60 and technique used to select respondents is convenient sampling.

2.6 Data Analysis

The data collected from the study was entered into Microsoft Excel and analyzed. The results have been expressed in percentages and proportions.

3. Results

Out of 60 study participants, 57 (95%) of them had heard about community palliative care units. The main source of their

information was their health worker (87%), followed by television (13%). The socio-demographic details of the study participants is given in the following table :

Table-1 : Socio-demographic profile of study participants

Variable	Frequency	Percentage
Age group		
18-30 years	3	5.0
31-45 years	19	31.7
Above 45 years	38	63.3
Total	60	100.0
Gender		
Male	8	13.3
Female	52	86.7
Total	60	100.0
Religion		
Hindu	32	53.3
Christian	19	31.7
Muslims	9	31.7
Total	60	100.0
Educational qualification		
Illiterate	13	21.7
Primary	5	8.3
High school	11	18.3
Degree	31	51.7
Total	60	100.0
Type of family		
Nuclear family	53	88.3
Joint family	7	11.7
Total	60	100.0
Occupation		
Government job	5	8.3

Private job	12	20.0
Unemployed	19	31.7
Others	24	40.0
Total	60	100.0
Economic status		
BPL	13	21.7
APL	47	78.3
Total	60	100.0

Majority of study participants (77%) believed palliative care was a health service provided (Table-2). Out of the total study population, 93% had availed palliative care services for a family member. Majority of the respondents (71.7 percent) were aware that palliative care services are not only for the bedridden patients. It was understood that more than one-third of the respondents (35 percent) knew that, for availing the services, the beneficiary needs to be registered at the PHC. While 95% of the beneficiaries opined a prompt service and uninterrupted supply of medicines, a small percentage suggested that services could be better (Table-2).

Table-2 : Awareness about community palliative care units

Awareness	Frequency	Percentage
Heard about community Palliative care units?		
Yes	57	95.0
No	3	5.0
Total	60	100.0
What you mean by palliative care?		
Health service	46	76.7
Health awareness program	14	23.3
Total	60	100.0
Does care helps to reduce the health problems in the society?		
Yes	55	91.7
No	5	8.3
Total	60	100.0

Does palliative care services reduce the burden of the family?		
Yes	56	93.3
No	4	6.7
Total	60	100.0
Do Palliative care staff visit houses in your area?		
Yes	53	95.0
No	7	5.0
Total	60	100.0
Does palliative care provide any equipment for the patients?		
Yes	56	93.3
No	4	6.7
Total	60	100.0
Does Palliative care unit provide services to the only bed ridden patients?		
Yes	17	28.3
No	43	71.7
Total	60	100.0
Have you received any medical benefits through the palliative care unit?		
Yes	56	93.3
No	4	6.7
Total	60	100.0
Prompt Services of doctors and other staff:		
Yes	53	94.6
No	3	5.4
Total	56	100.0
Uninterrupted supply of medicine from palliative care units:		
Yes	55	98.2
No	1	1.8
Total	56	100.0
Services received through palliative care units:		
Water bed	9	16.1
Walking Stick	14	25.0

Urine bag	10	17.9
Medical help	16	28.6
Wheel chair	7	12.5
Total	56	100.0
Do you feel improvement of quality is needed in palliative care services?		
Yes	59	98.3
No	1	1.7
Total	60	100.0

4. Discussion

In our study, only 95% of people had heard about palliative care. In a study done by Kolchakova¹⁶, 15% of people heard about palliative care. In another study done by Canadian Hospice Palliative Care Association,¹⁷ as much as 53% of people have heard about palliative care. Of them, 30% of people had some knowledge about palliative care. Other studies have reported that home-based palliative hospice care being associated with reduced hospitalizations.^{18,19,20} This association of community-based palliative care with reduced hospital admissions was consistent regardless of the underlying cause of death, be it cancer, COPD, organ failure or neurological conditions.

5. Conclusion

From the study, it was understood that the study population had good awareness about community palliative care services. Also majority of the study population was satisfied with the quality of care received through palliative care services. Further improvement in the reach of services can be made possible by involvement of grass root level workers, conduct of community programs through schools, colleges, kudumbasree and other Self Help Groups and involvement of NGOs to provide better facilities to the patients.

References

1. World Health Organization *Definition of Palliative Care*. Geneva: World Health Organization. Available from: <http://www.who.int/cancer/palliative/definition/en>

2. World Health Organization and World-Wide Palliative Care Alliance (WPCA), *Global Atlas of Palliative Care at End of Life*. Available from: http://www.who.int/nmh/Global_Atlas_of_Palliative_Care.
3. Sullivan, R., Badwe, R. A., Rath, G. K., Pramesh, C. S., Shanta, V., Digumarti, R., et al., "Cancer research in India : National priorities, global results", *Lancet Oncol*, 2014, 15, e213-22.
4. The quality of death ranking end-of-life care across the world [Internet]. London: Economist Intelligence Unit, Lien foundation: 2010. Available from: [http:// graphics. eiu.com/upload/QOD_main_final_edition_ Jul12_toprint.pdf](http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf).
5. World Health Organization, *Cancer control: Knowledge into Action : WHO Guide for Effective Programmes* [Internet]. Geneva: ; 2008. Available from: [http:// www. who.int/cancer/modules/FINAL_ Module_4.pdf](http://www.who.int/cancer/modules/FINAL_Module_4.pdf).
6. Khosla, D., Patel, F. D., Sharma, S. C., "Palliative care in India : Current progress and future needs", *Indian J Palliat Care*, 2012, 18, 149-54.
7. Bollini, P., Venkateswaran C, Sureshkumar K., "Palliative care in Kerala, India : A model for resource-poor settings", *Onkologie*, 2004, 27, 138-42.
8. Kumar, S., "Models of delivering palliative and end-of-life care in India", *Curr Opin Support Palliat Care*, 2013, 7, 216-22.
9. Duthey, B., Scholten, W., "Adequacy of opioid analgesic consumption at country, global, and regional levels in 2010, its relationship with development level, and changes compared with 2006", *J Pain Symptom Manage*, 2014, 47, 283-97.
10. Philip, et al., "Twenty years of home-based palliative care in Malappuram, Kerala, India: a descriptive study of patients and their care-givers", *BMC Palliative Care*, 2018, 17, 26 DOI 10.1186/s12904-018-0278-4.
11. *Comprehensive Community and Home-based Health Care Mode* [Internet]. New Delhi: World Health Organization; 2007. Available from:[http://www.searo.who.int/entity/nursing_midwifery/docume nts/ea_40/en/index.html](http://www.searo.who.int/entity/nursing_midwifery/documents/ea_40/en/index.html).
12. *National Programme for prevention and control of Cancer, Diabetes, Cardiovascular Diseases and Stroke (NPCDCS)*, Directorate General of Health Services Ministry of Health and Family Welfare, Government of India; 2010. Available from: [health.bih.nic.in/ Docs/ Guidelines- NPCDCS.pdf](http://health.bih.nic.in/Docs/Guidelines-NPCDCS.pdf)
13. Thayyil, J., Cherumanalil, J. M., "Assessment of status of patients receiving palliative home care and services provided in a rural area-kerala, India", *Indian J Palliat Care*, 18(3), 2012, 213-8.
14. Unni, K., Edasseri, D., "A prospective survey of patient drop-outs in a palliative care setting", *Indian J Palliat Care*, 18, 2012, 27-30.

15. Rajagopal, M. R., "The challenges of palliative care in India", *Natl Med J India*, 2001, 14, 65-7.
16. Kolchakova, P., Petroniya, K., *Proceedings of the connecting diversity 10th congress of The European Association For Palliative Care*, Budapest, Bulgaria: 2007. Jun 7, How far the population in Bulgaria is informed about hospice and palliative care.
17. *Living lessons campaign*. Canada : 2006. Canadian hospice palliative care association. Available from: <http://www.living-lessons.org>
18. Brumley, R. D., Enguidanos, S., Cherin, D. A., "Effectiveness of a home-based palliative care program for end-of-life", *Journal of Palliative Medicine*, 2003, 6(5), 715-24. Epub 2003/11/19. pmid:14622451
19. Riolfi, M., Buja, A., Zanardo, C., Marangon, C. F., Manno, P., Baldo, V., "Effectiveness of palliative home-care services in reducing hospital admissions and determinants of hospitalization for terminally ill patients followed up by a palliative home-care team: a retrospective cohort study", *Palliative Medicine*, 28(5), 2014, 403-11. pmid:24367058
20. Costantini, M., Higginson, I. J., Boni, L., Orengo, M. A., Garrone, E., Henriquet, F. et al., "Effect of a palliative home care team on hospital admissions among patients with advanced cancer", *Palliative Medicine*, 17(4), 2003, 315-21. pmid:12822847 ★