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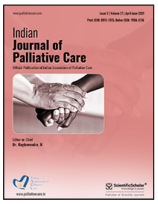

Original Article

Beneficiary's Satisfaction with Primary Palliative Care Services in Kerala – A Cross-Sectional Survey

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ABSTRACT

Objectives: Kerala was the first state to implement a community-based, sustainable primary palliative care (PC) home care (HC) model. Beneficiary satisfaction, an important indicator to assess the quality of service provision with the HC program, has not been assessed since the programme was launched 14 years ago. This study tried to assess the satisfaction of beneficiaries receiving primary PC services through the Kerala State PC programme and the factors associated with the same.

Materials and Methods: The cross-sectional survey was conducted among 450 patients registered under the Kerala State Primary PC Programme. Data were collected using a semi-structured questionnaire from October 2022 to January 2023. We summarised the data as proportions and performed Chi-square tests to make comparisons wherever applicable.

Results: Most of the beneficiaries (69.1%) were satisfied with HC services. The mean age of the beneficiaries was 65.51 ± 17 years. More than 80% of the participants (88.4%) were married, and the primary caregivers were wives (31.8%) and daughters/daughters-in-law (35.3%). The primary diagnosis of the beneficiaries was a cerebrovascular accident (27.4%), cancer (18.8%), and spinal cord injury (13.2%). The study examined the needs of beneficiaries and found that the top three requirements reported by the patients were the inclusion of doctor visits in HC (71.8%), medicine distribution at home (67.4%), and physical rehabilitation services at home with a minimum of three sessions per month (52.3%). The study found a statistically significant association ($P < 0.05$) between the Beneficiary's satisfaction and behaviour of PC nurses and certain services, including physiotherapy, procedural care specifically catheterisation and wound dressing, and health check-ups received through the HC program. Satisfaction was reported more in Thiruvananthapuram district, followed by Malappuram.

Conclusion: The overall satisfaction with the Kerala State Primary PC Programme was found to be high at about 69%. Despite the fact that the study identified significant relationships between nurses' behaviour, services provided (physical therapy, procedures, and health checks), and satisfaction, the findings suggested expanding the scope of the HC programme by including doctor visits and medicine delivery at patient's home.

Keywords: Palliative care, Home care, Beneficiary's satisfaction

'You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully but also to live until you die'. – Dame Cicely Saunders.

INTRODUCTION

Palliative care (PC), as defined by the World Health Organization (WHO), is 'an approach that improves the quality of life (QoL) of patients and their families who are facing problems associated with life-threatening illness.' [1] Globally, an estimated 56.8 million people, mostly from low- and middle-income countries, require PCs.[2] Only 14% (globally) and 2% (nationally) of those in need have access to such services.[2,3] Over the past 20 years, the State of Kerala has gained national and international acclaim for its distinctive PC model.[4] The hallmarks of the Kerala PC model include community ownership, involvement of local self-governments (LSGs), a meticulous state policy, and incorporation of PC into primary healthcare.[5] Estimates showed that Kerala, which makes up only 3% of the country's total population, provides nearly two-thirds of India's PC services.[2,3]

Home care (HC) programme

HC refers to the care provided to ill or infirm people in their homes with an aim to maintain their (QoL) and functional

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independence at home. It encompasses preventive, promotive, therapeutic, rehabilitative, long-term maintenance and PC. Similar to European and other Asian countries, Kerala's need for HC is being driven by epidemiological, demographic, and sociocultural transitions. In Kerala, HC services are provided by hospitals, private agencies, non-profit organisations, and nursing bureaus. They offer services ranging from routine to specialised nursing care, intensive care, geriatric care, and assistance with activities of daily living. The government and most non-profit organisations focus on PC geriatric care at home.[4]

In Kerala, the concept of HC under PC was sprouted from an innovative social approach called Neighbourhood Network in PC, a community-based network established in 2001 to empower community members to identify problems of those in need of PC and consecutively intervene with the support of trained community volunteers and professionals.[5-7] The Government of Kerala declared the PC policy (the first in Asia) and implemented the PC programme under the National Rural Health Mission PC project – '*Arogyakeralam*.' HC provided through structured home visits by the team led by a trained community nurse appointed by the corresponding Local Self Government Institutions (LSGIs) is the cornerstone of Kerala's PC program.[8] The expenditure in connection with HC visits is met by community donations and LSGI funds on an average of rupees 5 lakhs per local body annually.[9] This was funded initially through community donations. Later, the PC project was implemented through LSGI projects. At present, there are 1110 primary PC projects run by LSGIs in Kerala.[9,10] The traditional indicators that are used to assess the quality of healthcare, such as recovery rates, disease progression, or death, are not suitable for PC. Thus, it is vital that alternative indicators for the same are identified and used. Patient satisfaction assessment is considered one of the main indicators for assessing the quality of PC services. In published literature so far, there is no uniform definition for patient satisfaction, with different studies using different structural, process, and outcome indicators to assess the same.[11] Very few studies have assessed the satisfaction of beneficiaries with the HC programme in Kerala. Still, most of them were conducted in Community-Based Organisations, thus resulting in a dearth of literature regarding potential ways to improve the Government's HC Programme.[12] This study attempted to assess the satisfaction of beneficiaries receiving HC services through the Kerala State PC programme and its associated factors. This could aid in translating study implications into policy actions in the context of the new PC policy action plan, which is currently being drafted.

MATERIALS AND METHODS

A cross-sectional survey was conducted among beneficiaries who were the patients receiving HC services, through Kerala State primary PC program. The sample size was estimated using OpenEpi Version 3.0. Anticipating that 44% of the beneficiaries are satisfied with pain and PC services,[13] assuming 5% absolute precision and design effect 1, the sample size was estimated to be 379 at a 95% confidence interval. Assuming a 10% non-response rate, the sample size was rounded to 450. The study was conducted in selected districts of Kerala using a two-stage cluster sampling method. Three blocks were randomly selected from five randomly selected districts. The list of primary PC units was collected from concerned district PC coordinators and used as a sampling frame. From each block, nine PC units were selected [Figure 1]. From the HC registry of each selected unit, ten beneficiaries were randomly selected, and the gate keeper consent was obtained through a community nurse. Then principal investigator of the study and the trained field investigators visited the beneficiaries' residences,

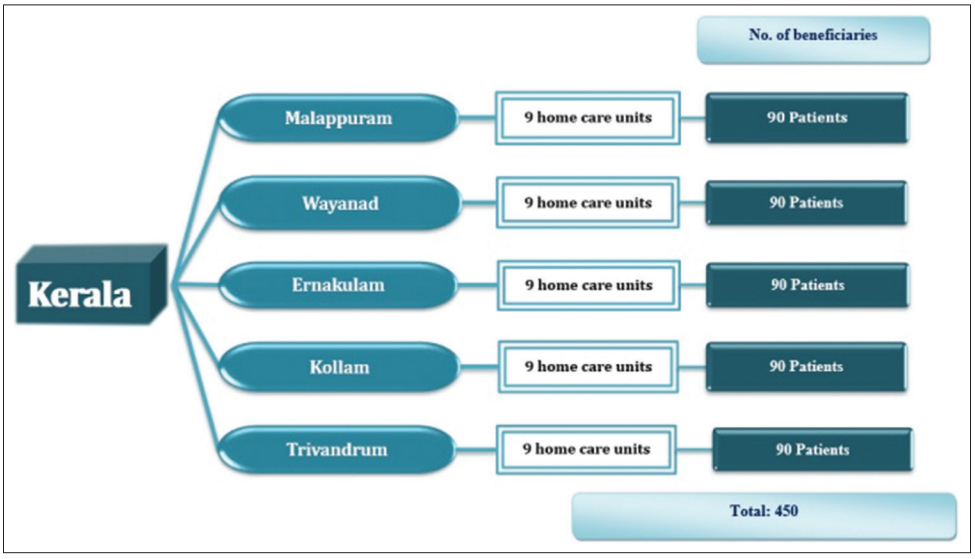

Figure 1: Sampling strategy.

obtained consent from the study participants and then the data were collected using a semi-structured questionnaire [Annexure 1]. The field investigators were given an orientation session and included in a pilot survey to get them acquainted with the project. The questionnaire had five sections – (i) sociodemographic characteristics, (ii) clinical information, (iii) type of services received through the HC programme, (iv) beneficiary's satisfaction, and (v) suggestions to improve the HC programme. The satisfaction component was captured using three domains – aspects of care provided in terms of professionalism, communication skills of nurses, and time spent by the HC team with patients. Each domain had four to five statements and three options for responses, with agreement indicating satisfaction in each main. In this study, beneficiaries' satisfaction is defined as the satisfaction with all facets/domains of HC services, including clinical and rehabilitation services they received, interpersonal relationships between patients and the HC team, communication skills of nurses, and time spent by the HC team. The study was undertaken from October 2022 to May 2023.

Ethical considerations

This study was carried out as part of a larger study titled 'Evaluation of Kerala State PC Programme,' which was approved by the Institutional Ethics Committee of General Hospital, Thiruvananthapuram – Kerala. While interviewing the beneficiaries, privacy and confidentiality were ensured. The study came under the category of less than minimal risk according to the National Ethical guidelines of the Indian Council of Medical Research.[14]

Statistical analysis

The data were entered into Microsoft Excel version 365 and then exported to IBM SPSS statistics version 27. Twenty participants were dropped from the study since they had no interest in taking part in the research activity and were not willing to respond to all the questions due to their poor health condition during the day of data collection. Hence, the details of 430 beneficiaries were included for analysis. The data were summarised as mean with standard deviation and proportions. The variables were coded, and a Chi-square test was performed to test the significance of the association.

RESULTS

Sociodemographic and clinical profile of participants

The mean age of the participants was 65.51 ± 17 years. Just over half were females (50.9%). More than 80% (88.4%) were married. One-fourth of the participants (27%) had no formal schooling, and the majority (67.9%) belonged to below the poverty line (BPL). Most of the participants (66.3%) were unemployed, and almost one-fifth (17.19%) were homemakers [Table 1]. The primary source of income of beneficiaries was an old-age pension of about Rs. 1,600/month, which is not received on a regular basis (80%). The majority of the participants (98.6%) had female primary caregivers, specifically daughter/daughter-in-law.

Table 1: Sociodemographic profile of study participants.

Characteristics	Frequency (*n*=430)	Percentage
Age		
<30 years	16	3.7
30–60 years	127	29.5
61–90 years	276	64.2
>90 years	11	2.6
Gender		
Female	219	50.9
Male	211	49.1
Marital status		
Single	49	11.4
Married	296	68.8
Widowed	80	18.6
Separated/divorced	5	1.2
Education		
None	116	27
Elementary school	178	41.4
High school	92	21.4
Higher secondary and above	44	10.2
Economic status		
No ration card	4	0.9
APL	134	31.1
BPL	292	67.9
Individual income		
Yes	345	80.2
No	36	8.4
Not responded	49	11.4
Occupation		
Employed	143	33.3
Unemployed	285	66.3
Students	2	0.4

APL: Above poverty line, BPL: Below poverty line

Stroke was the most common primary diagnosis found (27.4%), followed by cancer (18.8%) and spinal cord injury (13.2%) [Figure 2]. More than one-quarter (26.3%) of the participants had multiple comorbidities. Around 60% of the participants had partial or full mobility but were home-bound.

Details of HC service

Most of the participants were enrolled in HC services for more than two years (43.3%). Most of the beneficiaries (84%) stated that they received one HC visit per month, while 11% received two to three visits per month due to medical emergencies. The beneficiaries received various types of services, including blood pressure (BP) checks (56.6%), random blood glucose tests, and various procedures (35.8%), including catheterisation, Ryles tube insertion, stoma care, enema, and wound care. Some of the beneficiaries (26.7%) reported that they got only a few medicines, such as Paracetamol, Diclofenac, and Pantoprazole,

through the HC programme [Figure 3]. However, these medicines were not being distributed at home. The caregiver needs to go to the nearest healthcare facility to collect medicines which is extremely challenging.

Satisfaction with HC services

Nearly 70% of the beneficiaries (69.1%) were satisfied with the services provided by the HC team. District-wise comparisons revealed that beneficiaries in Thiruvananthapuram district (25.5%) showed the highest satisfaction, while Kollam showed the lowest (11.3%) [Figure 4].

The study also examined the needs of beneficiaries and found that home delivery of medicines (67.4%), physical therapy (PT) (52.3%) at homes (minimum three/month), and inclusion of doctor's visits (49.8%) in HC [Figure 5] were the main requirements.

Association between Beneficiary's characteristics and satisfaction

The study could not find any statistically significant association between satisfaction and sociodemographic characteristics. Males (71.1%) expressed higher levels of satisfaction. Participants without spouses (70.9%) and those who belonged to BPL (70.5%) were more satisfied with HC services [Table 2].

Bivariate analysis showed that satisfaction was higher among cancer patients (72.8%), but a statistically significant association was not found. Those who received PT through HC were two times more satisfied than those without received PT ($P < 0.05$). The study also found a statistically significant association between beneficiaries' satisfaction and health check-ups (BP and blood glucose) ($P < 0.001$) [Table 3].

For analysis, the nurse's behaviour was classified into four subcomponents. The study found a statistically significant association between satisfaction levels and nurses' friendly relationship with beneficiaries, the length of time spent with beneficiaries, nurses' listening behaviour, and communication skills ($P < 0.01$) [Table 3].

DISCUSSION

This present study is one of the first state-wide studies in Kerala to assess the satisfaction level of beneficiaries with HC services received through the Kerala State PC Programme.

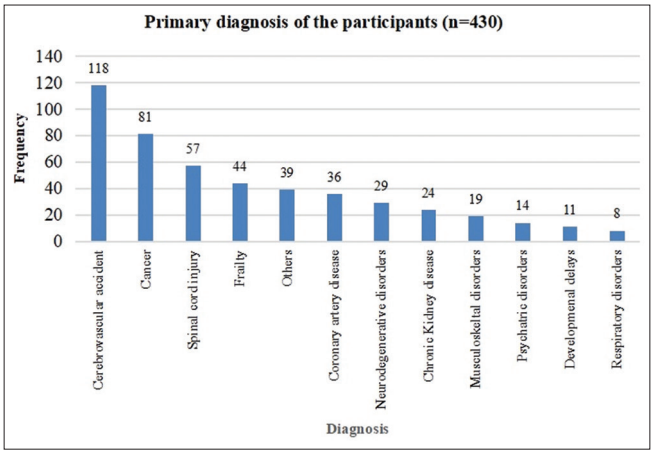

Figure 2: Distribution of primary diagnosis.

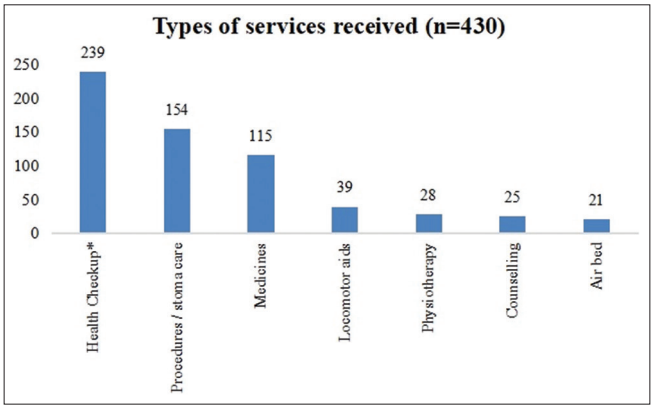

Figure 3: Services received through primary palliative care program. *Health check-up of blood pressure and random blood sugar.

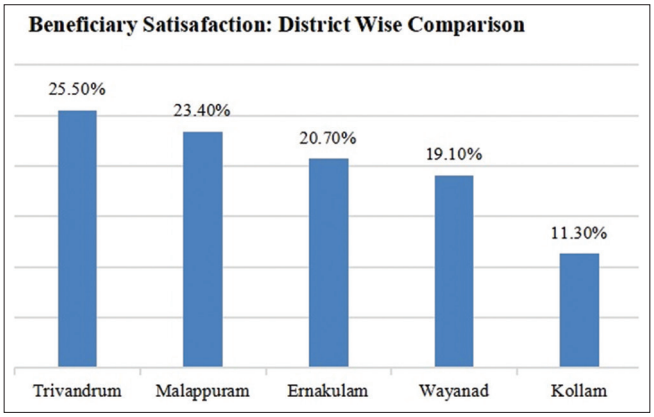

Figure 4: District-wise comparison of satisfaction.

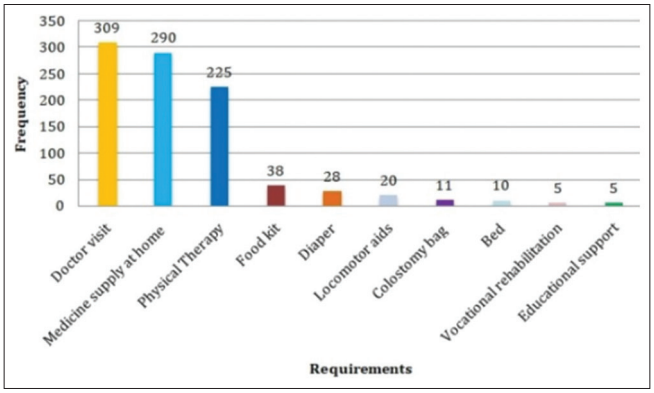

Figure 5: Requirements reported by beneficiaries.

Table 2: Sociodemographic characteristics and satisfaction.

Variables	Categories	Satisfaction		Total	OR (95% CI)	*P*-value
		Yes	No			
Age	≤60 years	98 (67.8)	46 (36.2)	144	1.08 (0.70–1.67)	0.71
	>60 years	199 (69.6)	87 (30.4)	286		
Gender	Male	150 (71.1)	61 (28.9)	211	0.83 (0.55–1.25)	0.37
	Female	147 (67.1)	72 (32.9)	219		
Living arrangement	With spouse	202 (68.2)	94 (31.8)	296	0.88 (0.56–1.37)	0.58
	Without spouse	95 (70.9)	39 (29.1)	134		
Education	No formal schooling	76 (65.5)	40 (34.5)	116	1.2 (0.79–1.96)	0.33
	Elementary school and above	221 (70.4)	93 (29.6)	314		
Occupation	Employed	95 (66.4)	48 (33.6)	143	1.20 (0.78–1.84)	0.40
	Unemployed	202 (70.4)	85 (29.6)	287		
Economic status	APL	87 (64.9)	47 (35.1)	134	1.29 (0.83–1.99)	0.24
	BPL	206 (70.5)	86 (29.5)	292		
Income	≤5000	219 (70.2)	93 (29.8)	312	0.82 (0.52–1.30)	0.41
	>5000	78 (66.1)	40 (33.9)	118		

OR: Odds ratio, CI: Confidence interval, APL: Above poverty line, BPL: Below poverty line

Table 3: Association between types of services received through primary palliative care programme, nurse's behaviour and satisfaction.

Categories	Satisfaction		Total	OR (95% CI)	*P*-value
	Yes	No			
Type of services receiving					
Symptom control	84 (73.0)	31 (27.0)	115	1.29 (0.8–2.8)	0.28
Locomotor aids	31 (79.5)	8 (20.5)	39	1.82 (0.81–4.0)	0.14
Physical therapy	24 (85.7)	4 (14.3)	28	2.83 (0.96–8.34)	**<0.05**
Health check-up (blood pressure and blood glucose)	189 (79.1)	50 (20.9)	239	2.90 (1.90–4.43)	**<0.001**
Procedures	106 (76.6)	32 (23.4)	137	1.72 (1.08–2.74)	**<0.05**
Friendly relationship between nurse and beneficiaries					
Yes	281 (79.6)	72 (20.4)	353	14.87 (8.09–27.33)	**<0.01**
No	16 (20.8)	61 (70.2)	77		
The nurse spends plenty of time with beneficiaries					
>20 min	262 (81.4)	60 (18.6)	322	9.1 (5.57–14.88)	**<0.01**
10–20 min	35 (32.4)	73 (67.6)	108		
Nurses listen to beneficiaries					
Yes	285 (78.3)	79 (21.7)	364	16.32 (8.28–31.83)	**<0.01**
No	12 (18.2)	54 (81.8)	66		
Communication skill of nurses					
Yes	236 (82.5)	15 (70.5)	286	6.42 (4.09–10.07)	**<0.01**
No	61 (42.4)	83 (57.6)	144		

OR: Odds ratio, CI: Confidence interval

Measuring patients' satisfaction provides insightful data on patient's service experience, identifies underlying issues, assesses the performance of the HC team, and acts as a source of motivation for those who deliver the service.[14-16] In the present study, 69.1% of the patients are satisfied with HC services. This is comparatively lower than the satisfaction level reported in Bangladesh.[11,17,18] The operational definition used in this study was more stringent than those employed in other studies in terms of the availability of medicines and rehabilitation services. This may be one of the reasons leading to the lower reported satisfaction level. The majority of patients showed satisfaction with HC services, which is consistent with earlier research pointing to greater patient satisfaction with HC compared to traditional healthcare.[19] Similar to a study conducted in Norway, this study could not find any statistically significant association between sociodemographic features and satisfaction.[20] However, we found that the majority of the beneficiaries of the HC programme were elderly, unemployed, and belonged to poor socioeconomic status. Males were found to be more satisfied

with PC services. This contrasted with the study by Asthana *et al.* and Balasubramanian *et al*., which reported higher satisfaction levels in females.[21,22] The findings that individuals from poor socioeconomic backgrounds exhibited higher satisfaction with the services are encouraging. This is particularly important as earlier research indicates that socioeconomically disadvantaged individuals are disproportionately impacted by limited access to PC. Furthermore, previous studies showed that those from lower socioeconomic classes are more likely to lack an informal caregiver.[23]

One of the principal functions of PC is the prevention and control of distressing symptoms.[24] A structured method of symptom assessment is necessary for efficient PC service delivery because the identification and management of symptoms are very important for improving the QoL of patients. Similar to Biswas *et al*., beneficiaries who reported higher satisfaction levels were those with better symptom control from the HC team.[11] Patients who underwent procedures such as catheterisation, stoma care, and wound care, as well as those who had their BP or blood sugar checked, expressed significantly higher satisfaction.

Ideally, the PC team is a multidisciplinary team addressing various concerns that are associated with illnesses.[10] Kerala is the only state where PT is offered as part of the PC program. A physical therapist visits patients' homes on a monthly basis to deliver rehabilitation services tailored to their requirements. Even though the study found a statistically significant association between PT and satisfaction, increasing the number of PT sessions each month was one of the most pressing needs listed by the beneficiaries. This is because the fee for a home visit by a private physical therapist ranges from Rs. 500 to 800/session, which is unaffordable. Earlier studies showed that the availability of PT plays a key role in improving patient satisfaction.[23,24]

The primary needs highlighted in the South African palliative HC team were similar to those in our study: supply of medicines at home and inclusion of doctor visits in HC.[25] Given that the average age of study participants was above 65 years and a significant majority came from lower socioeconomic backgrounds, implementing these measures can be perceived as enhancing PC, consequently leading to improved patient satisfaction. According to Subramanian *et al*., individuals receiving PC exhibited unmet demands for financial assistance and drug supply.[12]

The role of nurses was found to be fundamental to patient satisfaction.[26] Studies reported that continuous interaction and communication are essential elements of patient satisfaction and recovery. According to Berman and Chutka, effective communication skills are essential to make patients feel appreciated and cared for. The allocation of sufficient time for talking and listening to patients ensures that patients are less stressed, more engaged, and well-adjusted.[27] Respondents who have experienced humanistic interactions with PC nurses have reported higher psychological well-being in previous studies. In our study, patients were cared for by nurses who spent more time with them and listened to them. They kept cordial relationships with both patients and their families and reported higher levels of patient satisfaction than those cared for by other nurses. A study in Iran reported a statistically significant correlation between nurse behaviour and patient happiness. The nurse plays a pivotal role in the primary PC programme, contributing to the state's remarkable achievements due to their positive attitude and amiable approach.[27] Therefore, if any state or country hopes to increase the standard of its PC initiatives, it is imperative to develop nurses with empathy, professionalism, and communication skills.

CONCLUSION

- The overall satisfaction with the government's primary PC programme was 69.1%. Patients belonging to poor socioeconomic status reported higher satisfaction, but a significant association has not been found.
- The beneficiaries were satisfied with procedural care, blood glucose/pressure check and PT and found a statistically significant association.
- The study also found a significant association between satisfaction and nurse's communication skills, listening behaviour and time spent by the nurses.
- The findings highlight the need to expand the provision of medicine distribution to patients at their homes and the scope of rehabilitation services.
- The study findings were used during the preparation of an action plan for Kerala state PC policy 2019, and steps were taken to ensure the distribution of medicines at home and the inclusion of doctor's visit in HC for the patients who are in need.
- The main requirements reported by the beneficiaries were communicated on a real-time basis to the Principal Secretary (Health), Government of Kerala and the Ministry of Health to take corrective actions.

Limitations of the study

Since this is a quantitative study, the patient's interactions and experiences with the HC team were not explored in depth. The sense of satisfaction among the patients cannot be tracked over time because this survey is cross-sectional.

Ethical approval

The research/study is approved by the Institutional Ethics Committee at General Hospital,Thiruvananthapuram, number (19/03/02/21-GHEC).

Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent.

Financial support and sponsorship

The study was funded by National Health Mission (NHM), Kerala.

Conflicts of interest

There are no conflicts of interest.

Use of artificial intelligence (AI)-assisted technology for manuscript preparation

The authors confirm that there was no use of artificial intelligence (AI)-assisted technology for assisting in the writing or editing of the manuscript and no images were manipulated using AI.

REFERENCES

1. Palliative Care-An Overview-Sciencedirect Topics. Available from: https://www.sciencedirect.com/topics/psychology/palliative-care [Last accessed on 2023 Jul 06].
2. Palliative Care. Available from: https://www.who.int/news-room/fact-sheets/detail/palliative-care [Last accessed on 2023 Jul 06].
3. Khosla D, Patel FD, Sharma SC. Palliative Care in India: Current Progress and Future Needs. Indian J Palliat Care 2012;18:149-54.
4. Gupta P, Randhava S. Home Health Care Emerging Phenomenon in India. New Delhi: Health System Transformation Platform; 2023.
5. Gómez-Batiste X, Porta-Sales J, Pascual A, Nabal M, Espinosa J, Paz S, *et al*. Catalonia WHO Palliative Care Demonstration Project at 15 Years (2005). J Pain Symptom Manage 2007;33:584-90.
6. Kumar S. Models of Delivering Palliative and End-of-Life Care in India. Curr Opin Support Palliat Care 2013;7:216-22.
7. Sallnow L, Smith R, Ahmedzai SH, Bhadelia A, Chamberlain C, Cong Y, *et al*. Report of the Lancet Commission on the Value of Death: Bringing Death Back into Life. Lancet 2022;399:837-84.
8. Philip RR, Philip S, Tripathy JP, Manima A, Venables E. Twenty Years of Home-based Palliative Care in Malappuram, Kerala, India: A Descriptive Study of Patients and their Caregivers. BMC Palliat Care 2018;17:26.
9. Kumar S. The Neighbourhood Network in Kerala. In: Sallnow L, Kumar S, Kellehear A, editors. International Perspectives on Public Health and Palliative Care. London, New York: Routledge; 2012. p. 98-109.
10. Directorate of Health Services, Government of Kerala; 2020. Last accessed on 2023 December 2023. Available from: https://dhs.kerala.gov.in/. [Last accessed on 2023 Sep 28].
11. Biswas J, Faruque M, Banik PC, Ahmad N, Mashreky SR. Satisfaction with Care Provided by Home-based Palliative Care Service to the Cancer Patients in Dhaka City of Bangladesh: A Cross-sectional Study. Health Sci Rep 2022;5:e908.
12. Subramanian S, Sarkar S, Vijayageetha M, Adhinarayanan S. Experiences of Volunteers and Patient Satisfaction in Home Based Palliative Care, Puducherry, South India-A Descriptive Qualitative Study. J Palliat Care 2022;37:164-9.
13. Saraswathy S. Patient Satisfaction with Pain and Palliative Care Services in Kerala. Int J Res Soc Sci 2014;4:663-77.
14. ICMR National Ethical Guidelines. Available from: https://ethics.ncdirindia.org/asset/pdf/icmr_national_ethical_guidelines.pdf [Last accessed on 2023 Jul 07].
15. Al-Abri R, Al-Balushi A. Patient Satisfaction Survey as a Tool towards Quality Improvement. Oman Med J 2014;29:3-7.
16. Alshammary SA, Duraisamy BP, Salem L, Altamimi A. Integration of Palliative Care into Primary Health Care: Model of Care Experience. Cureus 2020;12:e8866.
17. Andaleeb SS, Siddiqui N, Khandakar S. Patient satisfaction with Health Services in Bangladesh. Health Policy Plan 2007;22:263-73.
18. Chand P, Gabriel T, Wallace CL, Nelson CM. Inpatient Palliative Care Consultation: Describing Patient Satisfaction. Perm J 2013;17:53-5.
19. O'Brien V, Jenkins LS, Munnings M, Grey H, North Z, Schumann H, *et al*. Palliative Care Made Visible: Developing a Rural Model for the Western Cape Province, South Africa. Afr J Prim Health Care Fam Med 2019;11:e1-11.
20. Kerr CW, Tangeman JC, Rudra CB, Grant PC, Luczkiewicz DL, Mylotte KM, *et al*. Clinical Impact of a Home-based Palliative Care Program: A Hospice-Private Payer Partnership. J Pain Symp Manag 2014;48:883-92.e1.
21. Asthana S, Bhatia S, Dhoundiyal R, Labani SP, Garg R, Bhatnagar S. Quality of Life and Needs of the Indian Advanced Cancer Patients Receiving Palliative Care. Cancer Res Stat Treat 2019;2:138-44.
22. Balasubramanian S, Biji MS, Ranjith MK, Abhina SS. Patient Satisfaction in Home Care Services through e-Palliative Care-An Experience of Tertiary Cancer Centre from Kerala. Indian J Palliat Care 2022;28:250-5.
23. Wang Y, Li J, Ding L, Feng Y, Tang X, Sun L, *et al*. The Effect of Socioeconomic Status on Informal Caregiving for Parents among Adult Married Females: Evidence from China. BMC Geriatr 2021;21:164.
24. Kittelson SM, Elie MC, Pennypacker L. Palliative Care Symptom Management. Crit Care Nurs Clin North Am 2015;27:315-39.
25. Drenth C, Sithole Z, Pudule E, Wüst S, GunnClark N, Gwyther L. Palliative Care in South Africa. J Pain Symptom Manage 2018;55:S170-7.
26. Sekse RJ, Hunskår I, Ellingsen S. The Nurse's Role in Palliative Care: A Qualitative Meta-synthesis. J Clin Nurs 2018;27:e21-38.
27. Berman AC, Chutka DS. Assessing Effective Physician-patient Communication Skills: "Are You Listening to Me, Doc?" Korean J Med Educ 2016;28:243-9.

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Annexure 1: Interview schedule for beneficiaries

Unique id:
Date:

Name of the district:
Name of Panchayat:

Sociodemographic information	
1. Age	
2. Gender	Male Female
3. Marital status	Unmarried Married Widowed Separated/divorced
4. Current living status	With spouse Without spouse Not applicable
5. Primary caregiver	Spouse (h/w) Parents (f/m) Children (son/son in law/daughter/daughter in law) Siblings Others
6. Education of the patient	None Elementary school High school Higher secondary Graduate Postgraduate and above
7. Economic status	BPL APL
8. Mobility status of patient	Bed bound Home bound Mobile with assistance Independent/fully mobile
9. Occupation	Employed full time - outside home fulltime Employed part-time - outside home part Homemaker Unemployed Retired Students
10. Does patient have monthly income?	Yes No If yes, please mention the source of income: Does that income regular? Yes No
11. Income of patient per month	<5000 5000–10000 >10000
Home care details	
12. Enrolled in home care (years)	<1 year 1–2 years >2 years

13. Frequency of home care team visit per month	One visit per month Two visits per month Three visits per month
Clinical information	
14. Primary diagnosis *Please put tick marks in relevant columns*	Cancer Chronic Kidney disease Stroke Spinal cord injury HIV/AIDS TB Frailty Lymphoedema Others If others, please specify:
Details of services receiving as part of home care	
15. What are the services you are receiving through the home care programme? *Please put tick marks in relevant columns*	Blood pressure check Random blood glucose check Ryles tube insertion Catheterisation Colostomy Bladder wash Tracheostomy care Wound dressing Bath Enema Mouth care Others If others please specify:
16. Did you get medicines as part of home care	Yes No If yes, please elaborate:
Information related to satisfaction	
17. Please listen to each question carefully regarding the palliative care services receiving now	
17.1. You are very satisfied with the care you receive.	Strongly agree' Uncertain Strongly disagree
17.2. Nurses are good about explaining the procedures to you before performing	Strongly agree' Uncertain Strongly disagree
17.3. Do you think that your home care team has everything needed to provide care	Strongly agree' Uncertain Strongly disagree
17.4. Do you think that the current home care services need to be improved?	Strongly agree' Uncertain Strongly disagree
17.5. Your nurse treats you in a very friendly and courteous manner.	Strongly agree' Uncertain Strongly disagree
17.6. Nurses usually give you advise about the necessary precautions that you should follow	Strongly agree' Uncertain Strongly disagree
17.7. Nurses listen carefully to what you have to say	Strongly agree' Uncertain Strongly disagree
17.8. Nurses usually spend plenty of time with you	Strongly agree' Uncertain Strongly disagree
Pressing needs to improve primary palliative care programme	
18. Please tell me your needs or services to improve the state primary palliative care programme	