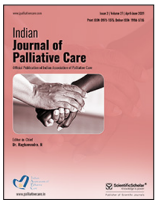
https://jpalliativecare.com/

Indian Journal of Palliative Care



Original Article

Patient satisfaction in Home care services through e-Palliative Care - An experience of tertiary cancer centre from Kerala

Satheesan Balasubramanian[1], M. S. Biji[2], M. K. Ranjith[3], S. S. Abhina[2]

Departments of [1]Surgical Oncology, [2]Cancer Palliative Medicine, [3]Health Information Technology, Malabar Cancer Centre, Thalassery, Kerala, India.

ABSTRACT

Objectives: e-palliative care (PC) is an evolving concept wherein technological interface is used to deliver PC to the patients with advanced cancer at their doorstep. This study aims to find out the level of satisfaction of patients receiving e-palliative homecare (e-PHC) service from a tertiary Cancer Center using the validated e-Palliative Patient Satisfaction Questionnaire –Malayalam (PSQM).

Materials and Methods: In this prospective study, patients/caregivers on home care were given the e - Palliative PSQM by the homecare nurse after the patient had consulted the doctor through e-PHC service. The questionnaire had 15 statements with response graded using Likert scale. Descriptive analysis was performed to compute the distribution of observed responses to obtain the level of satisfaction among patients or caregivers receiving e-PHC service.

Results: This study was done among 120 homecare patients whose median age was 69 (62-79) with almost equal prevalence of both genders. Stage 4 malignancy was seen in 107 (89.2%) patients with the commonest being gastrointestinal malignancy (N=34, 28.3%) The mean score of response for General satisfaction, Technical quality, Communication, Financial aspect, Time spent with doctor and Accessibility and convenience were observed as 4.52, 3.92, 4.48, 4.55, 4.52 and 4.49 respectively. The overall satisfaction was found to be 4.39.

Conclusion: The overall satisfaction of patients receiving e-PHC service from our Institution is seen to be high. e- palliative care is a feasible option for providing excellent PC in developing countries with limited resources and financial constraints.

Keywords: Palliative care, Patient satisfaction, e-palliative care, Home care

INTRODUCTION

In our institution, most of the patients suffering from cancer present in advanced stage when curative options are limited. Palliative care (PC) has been the most important yet underutilized modality for such patients.[1] PC aims to preserve the best possible quality of life of the patient whose disease is not responsive to curative treatment.[2] Improvements in PC usually focuses on pain and symptom management, use of standardized Assessment Tools care in the last days of life leading to a dignified death.[3,4] Studies have shown that cost-effective PC services can be provided by home based services. Palliative homecare (PHC) service provides psychological benefits to the patient, as the home environment enhances the patient's independence and quality of life.[5] Furthermore, studies have reported that if given good care, 60–70% of people would prefer to remain at home under care of their family doctor. Evidence also shows that well over 50% of people prefer to be cared for, and to die at home.[6-8] Literature mentions one of the most challenging obstacles in delivering cancer palliative home care service is the lack of knowledge on pain management techniques among community nurses and family physicians as compared to oncologist and cancer palliative specialists in modern cancer hospitals.[9] This lack of knowledge is one of the leading factors resulting in patient visit to modern cancer center.[10]

The homecare service provided by our Institution is Nurse-led and Physician assisted. The homecare team consisting of a PC trained staff nurse, a nursing assistant and a trainee social worker go for a scheduled home visit thrice in a week. The home care nurse interacts with the physician over phone for any doubts regarding the management of the patients. Most of the time, lack of a PC physician in the team causes dissatisfaction among patients and caregivers. This often led to frequent hospital visits by these patients. In a busy cancer hospital with limited human resources, such visits lead to

***Corresponding author:** M. S. Biji, Department of Cancer Palliative Medicine, Thalassery, Kerala, India. bijims@gmail.com

Received: 30 July 2021 **Accepted:** 07 September 2021 **EPub Ahead of Print:** 21 October 2021 **Published:** 29 July 2022 **DOI** 10.25259/IJPC_36_2021

difficulties for patients due to overcrowding and long waiting time at the outpatient clinics. Many patients have to travel long distances to get management for pain and other symptoms. The out-of-pocket expenditure and loss of work hours for the care giver too matters. To overcome this dissatisfaction, the institution decided to try the concept of e-PC wherein the patients can virtually see and interact with the PC physician who is physically present at the distant cancer hospital. In this study, apart from presenting the concept of e-PC, we also assessed the level of patient satisfaction of e-PHC services using a validated questionnaire.

Telemedicine can be defined as the use of telecommunication technologies to provide medical information and services.[11] The widespread adoption of telemedicine in PC is a major yet underdeveloped challenge that needs to be strengthened through new research directions.[12] e-PC is a specialized form of telemedicine that uses technology to provide real-time visual and audio patient evaluation, assessment, and management. This novel innovative idea was probably the first of its kind in India, when it was started in August 2014. Although telemedicine has been used in various countries including India in patient care, the concept of e-PC is to bring the doctor to the bedside of a patient in his home setting.

The e-PC system is dedicated only for the patients who are bedridden or those who avail of PC services from our institution through our home care services. One of the key components in PC is communication.[13] The e-palliative system serves as an effective means of communication between the patients, care givers, and the PC Team. This concept was developed indigenously by the IT department and the PC Team at our Institution

MATERIALS AND METHODS

After Ethics Committee approval, this prospective study was done among 120 patients with advanced Cancer under PHC. The homecare team led by a PC trained nurse visits the patients, with a camera integrated laptop and e-PC software application installed in it. The laptop is placed at the bedside of the patient and then connected to the PC physician stationed in the hospital so that the patient and caregivers can see and communicate with their PC physician who in turn gets an alert in the hospital system in his/her out-patient department, once the home care team comes online. The doctor then documents the consultation in the patient case record kept in the hospital and the homecare team documents the consultation in the homecare file.

At the end of the consultation, after providing the information sheet and getting a written informed consent,the e-Palliative Patient Satisfaction Questionnaire – Malayalam is given to the patient to assess their satisfaction level with this mode of online consultation. If a patient could not read or was not in a state to comprehend the questionnaire, it was given to the close caregiver who explained to the patient and recorded the responses. The questionnaire concentrates on six subscales, namely, patient's General satisfaction, Technical quality, Communication aspects, Financial aspects, Time spent with doctor, Accessibility and convenience. It consists of 15 statements with five response options where agreement reflects satisfaction. These subscales were measured using Likert scale of 1 to 5 with 5 representing maximum satisfaction except question 14 which had reverse scoring. The homecare team visits 4 to 5 patients per day, thrice in a week.

The validation of questionnaire was conducted in two phases. In the first phase, a total of 25 statements tapping six aspects of satisfaction with e-PHC service were framed in Malayalam language based on similar questionnaires used in earlier studies.[14] These statements were forwarded to 10 experts in PC who were also fluent in Malayalam. Based on the expert's opinion, only 15 most relevant statements were selected for validation. In the second phase, Cronbach's alpha technique was adopted to finalize the most relevant statements from the questionnaire. Only statements that passed the 0.8 cutoff value were considered into the validated questionnaire. A pilot study was first initiated in 30 patients. Using the results from the pilot study, the minimum sample size was calculated to be 70 at level of significance 5% and absolute allowable error 10%. The study was then expanded to include 120 patients.

Basic descriptive analysis was performed to compute the distribution of observed responses to obtain the level of satisfaction of patients receiving e-PHC service.

The mean and median scores were calculated for each subscale. Out of the 15 statements in the questionnaire, the 1st, 4th, 5th, 8th, and 15th statements reflected general satisfaction, the 3rd, 13th, and 14th statements were related to technical quality (clarity of visual and verbal communication using the gadgets, and net connectivity), the 2nd statement was related to communication aspect, the 12th statements reflected the financial aspects (financial burden incurred for the family during patient transportation and stay in the hospital), and the 6th and 10th statements captured the time spent with doctor and the 7th, 9th, and 11th statements were related to the accessibility and convenience.

Univariate analysis was performed to find out the association between factors and patient satisfaction. A p value of less than 0.05 was considered statistically significant

RESULTS

A total of 120 patients were included in the study. The median (IQR) age was 69 (62–79). Among these 63 (52.5%) were males, 91 (75.8%) came from families below poverty line. Stage 4 malignancy disease was seen in 107 (89.2%) cases. The most common malignancy was gastrointestinal malignancy 34 (28.3 %) [Table 1].

The number of responses received against each statement of the sub scales are described in [Table 2]. The mean score of response for general satisfaction was observed as

4.520. The mean score of response for Technical quality, Communication, Financial aspect, Time spent with doctor, and Accessibility and convenience were observed as 3.922, 4.483, 4.550, 4.521, and 4.492, respectively [Figure 1]. The overall satisfaction was found to be 4.394.

The median score of response for General satisfaction, Technical quality, Communication, Financial aspect, Time spent with doctor and Accessibility and convenience were observed as 5, 4, 4, 5, 5, and 5, respectively [Table 3].

Univariate analysis was performed to find out the various factors associated with patient satisfaction with e-palliative service, of which none of the factors (age, gender, and socioeconomic status) were found to be statistically significant [Table 4].

DISCUSSION

PC focuses on preventing and relieving the suffering of patients in all disease stages, including those undergoing treatment for curable illnesses and those living with chronic diseases. Palliative medicine utilizes a multidisciplinary team consisting of physicians, nurses, social workers, psychologists, and other allied health professionals in formulating a plan of care to relieve suffering in all areas of a patient's life as well as their families' need. This multidisciplinary approach allows the PC team to address the various physical, emotional, spiritual, and social concerns that are associated with advanced illnesses. This care includes the pharmacological management of pain and other symptoms, care giver empowerment and counseling for psychosocial and spiritual issues; help with advance directives, and family support and education.[15] The e-palliative system is a means to overcome the lack of communication between the doctor and the patient when the home care team does not have a doctor.

This e-palliative system is a joint collaboration by the Healthcare Delivery System and Health Information Technology to enhance the quality of PC activities among cancer patients. In this system, the doctors stationed in our institution provide consultatory service and needed advice through online as a real-time communication. The advantages of this system includes, simplicity of using it, limiting hospital visits of the patient/caregiver, ensuring patient data security, round the clock accessibility and flexibility. Moreover, the visual features enhance communication and allow a close connectedness between the patient and the doctor. This system is an online web based application with registration module, PC unit, messaging to specialists, online consultation, discussion, and resource modules. The online consultation is a specialized type of telemedicine that uses technology to provide real-time visual and audio patient assessment at a distance.[16] e-PC service is an innovative method facilitating a doctor's virtual presence and care at the patient's bedside in his home. This is a gigantic leap in the PC delivery system.

Table 1: Socio-demographic and clinical profile of patients in e-palliative home care service of a Tertiary Cancer Centre (n=120).

Socio-demographic and clinical details	Number	Percentage
Age group in years		
<65	38	31.7
≥65	82	68.3
Gender		
Male	63	52.5
Female	57	47.5
Socio-economic status		
APL	29	24.2
BPL	91	75.8
Stage of malignant disease		
Stage 2	1	0.8
Stage 3	12	10.0
Stage 4	107	89.2
ECOG Performance status		
2	2	1.7
3	78	65.0
4	40	33.3
Diagnosis of cancer		
GIT	34	28.3
Head and neck	30	25.0
Lung	16	13.3
Female Genito urinary	14	11.7
Male Genito urinary	9	7.5
Breast	8	6.7
Unknown primary	6	5.0
CNS tumor	1	0.8
Hematological malignancy	1	0.8
Sarcoma	1	0.8

In a study done by Tsai *et al*, the mean score of elderly people's overall satisfaction levels with telecare was 4.25, indicating that telecare services mainly satisfied their needs.[17] Our study also showed a median score of 4.0 for elderly people's overall satisfaction levels with e-PC. In addition, our study also showed that there was no statistically significant difference in the mean score of younger and older age group [Table 4].

In another study by Iqbal *et al*., where an aggressive outpatient telephone follow-up was done, the mean score of overall satisfaction was found to be 4.6 while our study showed mean score of 4.3 with e-PC.[18]

The patients' satisfaction level was found to be high as evident from our study. The homecare service of our institution which was once nurse led has now become "doctor led" which, in turn, increased the efficiency and effectiveness of home care service. As this initiative requires only one time financial input, it is sustainable financially and can be replicated in other government hospitals too. Patients or their family do not have to spend any money either for travel or consultation thereby providing huge financial benefits to the patients and their family.

Table 2: Number of responses and satisfaction score against each statement of the sub scales (n=120).

Subscale	Statements	Satisfaction Score					Mean Score
		5	4	3	2	1	
General satisfaction	1. I feel confident when I see my doctor at the other end	66	52	2	0	0	4.533
	4. I am able to adjust with this type of treatment	60	59	1	0	0	4.492
	5. I get the same feel as if the doctor is speaking after coming home	65	52	3	0	0	4.517
	8. My family is satisfied with this type of treatment	62	57	1	0	0	4.508
	15. This facility is useful	66	54	0	0	0	4.550
Technical quality (application quality)	3. I am able to show my wound to my doctor directly	50	63	6	1	0	4.350
	13. This type of facility should be incorporated in every homecare service of our district	73	47	0	0	0	4.608
	14. A lot of time is wasted in getting online connectivity	9	11	61	26	13	2.808
Communication	2. Doctors are good explaining about any of my distress	59	60	1	0	0	4.483
Financial aspects	12. My financial burden is less	68	50	2	0	0	4.550
Time spend with doctor	6. Doctor is able to spend sufficient amount of time with me	59	59	2	0	0	4.475
	10. I am able to explain all my distress to the doctor	69	50	1	0	0	4.567
Accessibility and convenience	7. I had always wished this type of facility in the homecare service	53	60	7	0	0	4.383
	9. I wish I get this type of care frequently	63	55	2	0	0	4.508
	11. I feel this type of care is comfortable than coming to the hospital	73	44	3	0	0	4.583

Table 3: Mean, median, and standard deviation of satisfaction score of each sub scale.

	General satisfaction	Technical quality	Communication	Financial aspect	Time spent with doctor	Accessibility and convenience
Mean	4.520	3.922	4.483	4.550	4.521	4.492
Median	5.000	4.000	4.000	5.000	5.000	5.000
SD	0.523	1.084	0.518	0.532	0.525	0.564

Table 4: Factors associated with median overall satisfaction of patients in e-palliative homecare service of a Tertiary Cancer Centre.

Factors	Median overall satisfaction	χ^2	*P*-value
Age group in years			
<65	4	0.021	0.886
≥65	4		
Sex			
Male	4	0.083	0.370
Female	5		
Socioeconomic status			
Above poverty line	4	0.188	0.664
Below poverty line	4		

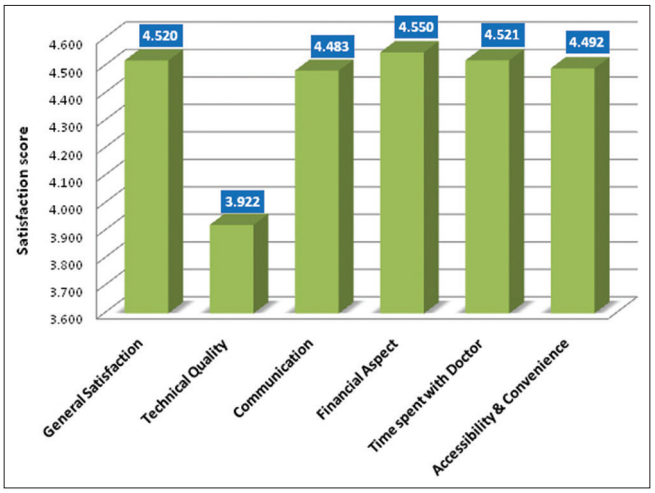


Figure 1: Mean satisfaction scores of sub scales.

As most of the patients in the study were in Stage 4 malignancy (89.2%), it was difficult to transport them to the hospital. Hence, this model of care was very useful and effective in this group of patients. The main highlight of this system is that patient is able to interact with the doctor at his own home just as he would have done visiting the doctor in the hospital. Moreover, the patient does not have to travel to the hospital with distressing symptoms thereby reducing the waiting time

and hospital stay. With this mode of consultation a significant proportion of patients expressed that they felt confident on seeing their doctor at the other end and as if the doctor had visited them at home. There was high level of acceptance for e-PC, and only 0.8% (1/120) was unsatisfied with the technical quality of the consultation in our study. This was lesser than that found in a study done by Müller *et al*. which showed that 1% were unsatisfied with the technical quality.[19] This model of PHC service can be extended to other PC units also. Using this system, local palliative volunteers can share information about patient care to doctors and get advice from them and expert doctor's service can be made available in remote villages. As it is possible to store the previous treatment details of the patients, a better understanding of the patient can be done during each consultation and would help the physician to take a better treatment decision. There can be better co-ordination of patient care activities and multiple doctors' consultation and discussion can be made available at the same time if required for patient care. This model of e-PHC service utilizing the Health Information Technology can be an effective way of delivering PC services. The wide spread use of smart phone would hopefully make this concept more socialistic and acceptable. The importance of the use of technology in PC in low- and middle-income group countries is decreasing unnecessary patient visit to hospital. It definitely reduces the additional out-of-pocket expenditure for patients for whom hospital care is not required and also the physical and psychological stress on patients. It offers a potential solution in not only improving the access to PC but also enhancing the quality of care for those in rural settings.

CONCLUSION

The overall satisfaction of patients receiving e-PHC service from our institution is high. e-PC is a feasible and cost-effective option for providing excellent PC in developing countries with limited resources and financial constraints. High speed internet connectivity is bound to be the major constraint in the widespread implementation of e-PC service.

Limitations of the study

This is an observational study. The attitude of the visiting homecare team members toward the patient could affect their level of satisfaction. This has not been studied. Future research incorporating the visiting homecare teams attitude into the factors determining the patients' satisfaction can be done. There is a likelihood of response bias since the collection of responses was not anonymized. Also a mixed method study exploring the experience of patients availing e-PHC service is recommended.

Recommendations

Our e-palliative system requires minimum essential items such as a laptop, a camera, and the e-palliative software application. The main highlight of this system is the ease with which it can be used and tight patient data security. As it requires only one time financial input, it can easily be considered in other PC settings with homecare services. However, high speed internet connectivity needs to be ensured in the patients' location. This can be overcome by employing the wireless internet connectivity of two different service providers.

Acknowledgments

The authors thank the staff of this institution for their assistance in data collection and the staff of Centre for Development of Imaging Technology, Thiruvananthapuram for their assistance in developing the e-palliative software. The authors also thank the patients (and their caregivers) registered in home care service of this institution whose data helped us to carry out this research. The authors acknowledge Dr. Mohandoss Murugesan and Dr. V.P Praveen Kumar Shenoy for their inputs in writing the manuscript.

Availability of data and materials

The data are available with the corresponding author and can be shared on request.

Ethics approval

This study was done in accordance with the protocol, the ethical principles laid down in the Declaration of Helsinki, International Council for Harmonization of Technical Requirements for Pharmaceuticals for Human Use and Good Clinical Practice (ICH GCP) after IRB/IEC (1617/IRB-IEC/13/MCC/22-01-16/1) approval.

Declaration of patient consent

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

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

REFERENCES

1. Smith CB, Nelson JE, Berman A, Powell CA, Salazar-Schicchi J, Halm EA, *et al*. Underutilization of palliative care referral in lung cancer patients. Am J Respir Crit Care Med 2011;183:A3374.
2. Radbruch L, Payne S. White Paper on standards and norms for hospice and palliative care in Europe. Part 1. Eur J Palliat Care 2009;16:278-89. Available from: https://www.researchgate.net/publication/279547069_White_paper_on_standards_and_norms_for_hospice_and_palliative_care_in_Europe_Part_1. [Last accessed on 2021 Jul 29].
3. Temel JS, Greer JA, Muzikansky A, Gallagher ER, Admane S, Jackson VA, *et al*. Early palliative care for patients with metastatic non-small-cell lung cancer. N Engl J Med 2010;363:733-42.
4. Sigurdardottir KR, Haugen DF, Bausewein C, Higginson IJ, Harding R, Rosland JH, *et al*. A pan-European survey of research in end-of-life cancer care. Support Care Cancer 2012;20:39-48.
5. Hinton J. Can home care maintain an acceptable quality of life for patients with terminal cancer and their relatives? Palliat Med 1994;8:183-96.
6. McMillan SC, Small BJ, Weitzner M, Schonwetter R, Tittle M, Moody L, *et*

al. Impact of coping skills intervention with family caregivers of hospice patients with cancer: A randomized clinical trial. Cancer 2006;106:214-22.
7. Hughes S, Cummings J, Weaver F, Manheim L, Braun B, Conrad K. A randomized trial of the cost effectiveness of VA hospital-based home care for the terminally ill. Cochrane Database Syst Rev 1992;26:801-17.
8. Walsh K, Jones L, Tookman A, Mason C, McLoughlin J, Blizard R, *et al*. Reducing emotional distress in people caring for patients receiving specialist palliative care. Randomised trial. Br J Psychiatry 2007;190:142-7.
9. Abu-Odah H, Molassiotis A, Liu J. Challenges on the provision of palliative care for patients with cancer in low-and middle-income countries: A systematic review of reviews. BMC Palliat Care 2020;19:55.
10. Markkanen P, Quinn M, Galligan C, Chalupka S, Davis L, Laramie A. There's no place like home: A qualitative study of the working conditions of home health care providers. J Occup Environ Med 2007;49:327-37.
11. Sood S, Mbarika V, Jugoo S, Dookhy R, Doarn CR, Prakash N, *et al*. What is telemedicine? A collection of 104 peer-reviewed perspectives and theoretical underpinnings. Telemed J E Health 2007;13:573-90.
12. Zanaboni P, Wootton R. Adoption of telemedicine: From pilot stage to routine delivery. BMC Med Inform Decis Mak 2012;12:1.
13. Capurro D, Ganzinger M, Perez-Lu J, Knaup P. Effectiveness of eHealth interventions and information needs in palliative care: A systematic literature review. J Med Internet Res 2014;16:e72.
14. Thayaparan AJ, Mahdi E. The patient satisfaction questionnaire short form (PSQ-18) as an adaptable, reliable, and validated tool for use in various settings. Med Educ Online 2013;18:21747.
15. Bruera E, Yennurajalingam S. Palliative care in advanced cancer patients: How and when? Oncologist 2012;17:267-73.
16. Kitamura C, Zurawel-Balaura L, Wong RK. How effective is video consultation in clinical oncology? A systematic review. Curr Oncol 2010;17:17-27.
17. Tsai CH, Kuo YM, Uei SL. Influences of satisfaction with telecare and family trust in older Taiwanese people. Int J Environ Res Public Health 2014;11:1359-68.
18. Iqbal A, Raza A, Huang E, Goldstein L, Hughes SJ, Tan SA. Cost effectiveness of a novel attempt to reduce readmission after ileostomy creation. JSLS 2017;21:e2016.00082.
19. Müller KI, Alstadhaug KB, Bekkelund SI. Acceptability, feasibility, and cost of telemedicine for nonacute headaches: A randomized study comparing video and traditional consultations. J Med Internet Res 2016;18:e140.

How to cite this article: 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.