



# Factors Associated with Choosing the Kerala Model of Palliative Care versus Standard Care among Indian Cancer Patients

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## Abstract

Patients who opt for the Kerala Model of Palliative Care (KMPC) report favorable psychological outcomes. Still, not all patients in Kerala prefer this treatment's approach. Hence, this study is aimed to examine the demographical, medical, pain, and psychological factors associated with cancer patients who choose the KMPC versus standard care (SC). Using a cross-sectional design and purposive sampling, 87 patients (SC = 40; KMPC = 47) residing in Kerala, India, responded to questionnaires on pain, anxiety, and depression, and quality of life (QoL). Data analysis was conducted using chi-squared and independent sample *t*-tests. Findings revealed that KMPC (vs. SC) patients had lower levels of education, were self-employed or homemakers, belonged to a middle or low socioeconomic status, received government aid or were financially self-supported, and were diagnosed for less than 1 year or less than 5 years. KMPC patients reported higher levels of pain, lower levels of anxiety and depression, better overall total QoL, physical health, social health, functionality capacity, and emotional health. These findings suggest the need for community awareness programs regarding the benefits of opting for the KMPC. Patients who chose KMPC reported higher levels of pain than SC patients, highlighting the need for the KMPC to improve its approach to pain management.

## Keywords

- ▶ palliative care
- ▶ pain management
- ▶ quality of life
- ▶ India

## Introduction

Palliative care aims to provide relief from pain and suffering and improve patients and their caregivers' quality of life (QoL).<sup>1</sup> Passed as a public health policy in Kerala, India, in 2008, the Kerala Model for Palliative Care (KMPC) aims to provide patients with optimal support and care throughout the cancer trajectory.<sup>2</sup> The model has a three-tier structure: (i) community and primary health centers offer medical and supportive care, (ii) a team of medical (physicians, nurses) and nonmedical (social workers, counselors) staff provide

weekly at-home care, and (iii) government-certified trainers host capacity and skill-building workshops and training sessions for community volunteers and medical staff.<sup>3</sup> Typically, physicians introduce patients to KMPC when diagnosed with a life-threatening or terminal illness,<sup>2</sup> offering assurances that standard care (SC) will be given as well and explaining that KMPC aims at providing holistic (e.g., psychological, spiritual, social), at-home care as per the preferences and needs of the patient, irrespective of the stage of their illness.<sup>4</sup>

Research has shown that this community-based KMPC provides a range of practical (e.g., wound dressing, free

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medication, financial support for the family) as well as psychosocial (e.g., psychoeducation, counseling) support for patients and their families.<sup>3</sup> Further, patients who availed the KMPC reported feeling more independent, self-reliant, and self-confident.<sup>4</sup> Yet, many cancer patients do not choose KMPC and continue to opt for SC.<sup>2</sup> While the factors of physicians, patients, and family might impact this decision, this study focuses only on patient factors.

Understanding the factors associated with choosing KMPC/SC might guide intervention efforts to assist patients in making informed choices about the type of care they prefer. To the best of our knowledge, no research in India has examined the differences between patients who choose KMPC versus SC.

Therefore, the current study examines the demographical, medical, pain, and psychological factors associated with patients residing in Kerala who selected KMPC or SC.

## Methods

### Study Design and Participants

Using a cross-sectional design and purposive sampling (to ensure an equal number of patients who had chosen KMPC versus SC were represented in the sample), 87 patients (SC = 40; KMPC = 47) diagnosed with any cancer and at any cancer stage were recruited from 5 hospitals in Kerala. Inclusion criteria for the patients were that (i) they are at least 18 years of age, (ii) could speak Malayalam (regional language), (iii) were aware of their diagnosis, and (iv) did not have any other comorbidities or psychiatric conditions (as reported by themselves). All procedures performed in the study involve human participants were in accordance with the ethical standards of the Indian Institute of Technology Hyderabad [IITH/IEC/2018/03/19 w.e.f 14/03/2018] and with 1964 Helsinki declaration and its later amendments or comparable ethical standards. Further, approval was provided by the medical officers of the hospitals involved in the study.

### Procedure

Eligible participants were approached by the first author (PG) at the oncology departments (SC patients) or the palliative care department within a hospital (KMPC patients).<sup>^</sup> Participants were introduced to the study, including a brief description of the study and the time it would take the patient to participate. If any patient expressed an interest in participating, PG elaborately explained the study details and answered any questions that the patient had regarding the study. Following this, written informed consent was obtained from the participants, their demographical and medical information were collected, and the questionnaires were administered by PG.

One hundred and two patients were approached (SC = 52; KMPC = 50) by PG, of whom 15 declined participation (SC = 12; KMPC = 3) citing the following reasons: (i) caregivers refused patient's participation (commonly, in India, family caregivers play a considerable role in medical decision-making),<sup>5</sup> (ii) lack of time, (iii) too tired to participate, (iv) wanted the researcher to provide an incentive for participa-

tion which was not within the scope of this study, or (v) desired privacy. These reasons suggest that SC patients were less willing to participate in the study, warranting further attention. Consequently, the total number of participants for this study was 87 (SC = 40, KMPC = 47).

### Measures

**Pain<sup>6</sup>:** Pain was assessed using a 11-point self-reporting Numeric Rating Scale, with the values of 0 representing "no pain" and 10 representing "worst pain imaginable."

**Anxiety and depression (Hospital Anxiety Depression Scale (HADS)<sup>7</sup>:** The HADS is a 14-item Likert scale that assesses psychological distress in nonpsychiatric patients and consists of 2 sub-scales of anxiety (7 items) and depression (7 items). The HADS has been used extensively in Indian cancer populations and reports good validity and reliability.<sup>5,8,9</sup> The Cronbach  $\alpha$  score for the current study is 0.805, indicating a good reliability.

**Quality of life (Functional Assessment of Cancer-General; FACT-G)<sup>10</sup>:** The FACT-G is a 27-item Likert scale designed to measure four domains of health-related QoL in cancer patients, namely physical (7 items), social (7 items), emotional (6 items), and functional well-being (7 items). The FACT-G has been used in Indian cancer populations and reports good validity and reliability.<sup>11-13</sup> The Cronbach  $\alpha$  score for the current study is 0.789, indicating a good reliability.

### Analysis

To differentiate between the KMPC/SC groups, chi-squared test was used for the demographic and medical variables, which were categorical in nature. Independent sample *t*-tests were conducted for the psychological variables, which were continuous in nature.

## Results

### Participants' Characteristics

KMPC patients ( $n = 47$ ; mean age = 48.2 years) were primarily male, married, had an undergraduate degree, in Stage IV of cancer, and were diagnosed with cancer for between 1 and 5 years. SC patients ( $n = 40$ , mean age = 50.2 years) were primarily male, married, in Stage IV of cancer, and diagnosed with cancer for less than 1 year. ► **Table 1** describes patients' demographical and medical details per group.

### Differences between the KMPC and SC Patient Groups

Significant differences between patients who chose KMPC versus SC were found with KMPC patients reporting higher levels of pain, lower levels of anxiety and depression, better overall total QoL, physical health, social health, functioning capacity, and emotional health. ► **Table 1** shows the results of group comparisons between the demographic, medical, and psychological outcomes.

## Discussion

This study aimed to examine the factors that differentiated cancer patients who chose KMPC over SC residing in Kerala,

**Table 1** Patients' details and comparisons between the KMPC and SC patients

Variables		Treatment style				Test statistics	
		SC		KMPC		X <sup>2</sup>	p-Value
		n	%	n	%		
Gender	Male	23	57.5	31	65.9	0.657	ns
	Female	17	42.5	16	34.1		
Marital status	Unmarried	0	0	2	4.2	3.31	ns
	Married	39	97.5	41	87.3		
	Widowed	1	2.5	4	8.5		
Religion	Hinduism	20	50	24	51.1	2.67	ns
	Christianity	11	27.5	7	14.9		
	Islam	9	22.5	16	34		
Caste	SC/ST <sup>a</sup>	1	2.5	4	8.5	1.74	ns
	OBC <sup>b</sup>	14	35	13	27.6		
	General	25	62.5	30	63.9		
Education	Illiterate	0	0	3	6.38	17.39	0.05
	Until 5 <sup>th</sup> grade	0	0	6	12.7		
	10 <sup>th</sup> grade	8	20	13	27.6		
	12 <sup>th</sup> / diploma	2	5	8	17		
	Undergraduate degree	22	55	14	29.7		
	Postgraduate degree	8	20	3	6.3		
Occupation	Government	9	22.5	3	6.4	16.63	0.05
	Private	12	30	8	17		
	Business	3	7.5	4	8.5		
	Self	4	10	16	34		
	Homemaker	4	10	12	25.5		
	Student	4	10	3	6.4		
	Retired	4	10	1	2		
Socioeconomic status	Low	8	20.9	15	31.2	6.93	0.05
	Middle	15	37.5	24	51		
	High	17	42.5	8	17		
Source of financial support	Self	25	62.5	22	47	7.86	0.05
	Government	3	6.3	15	31		
	Private	12	25.5	10	22		
Stage of cancer	Stage I	3	7.5	11	23.4	5.74	ns
	Stage II	14	35	11	23.4		
	Stage III	10	25	7	14.8		
	Stage IV	13	32.5	18	38.2		
Time since diagnosis	<1 year	23	57.5	19	40.4	6.50	0.05
	<5 years	17	42.5	22	46.8		
	>5 years	0	0	6	12.8		
Family history of cancer	Parents	2	5	2	4.3	6.43	ns
	Siblings	1	2.5	3	6.3		
	Relatives	10	25	3	6.3		
	No history	27	67.5	39	82.1		

**Table 1** (Continued)

Variables		Treatment style				Test statistics	
		SC		KMPC		X <sup>2</sup>	p-Value
		n	%	n	%		
		Mean	SD	Mean	SD		
Age (years)		50.2	10.4	48.2	8.7	-0.506	ns
Pain		2.35	1.64	2.89	1.56	-1.57	0.05
Anxiety and depression	Anxiety	9.98	4.41	8.21	4.11	1.91	0.05
	Depression	7.93	4.17	7.32	4.89	0.623	0.05
	Total	17.65	8.15	15.32	8.10	1.33	0.05
Quality of life	Physical well-being	16.25	5.30	17.44	5.24	-1.05	0.05
	Social well-being	13.30	3.17	16.25	3.78	-3.96	0.01
	Emotional well-being	12.45	4.01	14.14	4.40	-1.88	0.05
	Functional well-being	10.32	3.05	12.55	4.51	-2.72	0.05
	Total	52.32	10.92	60.40	14.86	-2.91	0.05

Abbreviations: KMPC, Kerala Model of Palliative Care; ns, not specified; SC, standard care; SD, standard deviation.

<sup>a</sup>SC = scheduled caste/ST = scheduled tribe.

<sup>b</sup>OBC = other backward caste.

India. KMPC patients were found to have lower levels of education, were self-employed/homemakers, belonged to a low or middle socioeconomic status, used government aid or personal finances for their cancer-related expenses, and were diagnosed with cancer for either less than 1 year or for 5 years as compared with SC patients. Taken together, these variables are either directly or indirectly linked to one's financial background.<sup>14</sup> Therefore, factors determining the patient's financial ability may have differentiated between the two groups in this study. Furthermore, despite the positive psychosocial outcomes of utilizing the KMPC,<sup>4</sup> patients may negatively perceive it as a facility for the poor and needy, thus misunderstanding the cost-effective aspects of this model of care.<sup>4</sup> Consequently, in the current study, those who could afford cancer treatment expenses may have chosen SC.

KMPC patients had higher levels of pain than SC patients in this study. Most KMPC patients were diagnosed for 5 years. Therefore, the long and exhausting treatment for cancer may have increased KMPC patients' pain.<sup>15</sup> These findings align with existing western research reporting that patients who receive hospice or PC care report higher pain levels,<sup>16</sup> indicating that patients may have chosen KMPC to alleviate their high levels of pain or as a more appropriate method of pain management as opposed to their SC counterparts who reported lower levels of pain. It is also possible that the KMPC approach was not optimally managing the patient's pain bearing capacity as compared with SC treatment. Indeed, despite being the largest producer and exporter of opioids and 5.4 million Indians requiring palliative care every year, India offers less than 1% of its population access to reliable and sustainable sources of morphine for pain relief.<sup>3</sup>

In the current study, patients receiving KMPC had lower levels of anxiety and depression than SC patients. These findings are in line with recent research from Kerala, where-

in cancer patients reported high levels of anxiety due to the side effects of treatment.<sup>17</sup> Owing to the home-based, holistic care provision, the KMPC responds to the psychological distress patients undergo during treatment<sup>3,16</sup>, while psychological support services are lacking/inadequate in Indian cancer hospitals.<sup>17</sup> This may explain why SC patients in the current study reported higher levels of anxiety and depression than their KMPC counterparts.

KMPC patients in this study reported higher levels of QoL and its subdomains of physical, emotional, social, and functional well-being compared with their SC counterparts. These findings add to existing literature indicating that palliative care improves QoL by preventing and relieving physical suffering by assessment, early identification, and pain treatment.<sup>18</sup> KMPC patients might have had better physical health and functional capacities because they were treated at home per the model's protocol, which may have allowed the patients increased autonomy to engage in household chores and activities.<sup>15</sup> This study found that the KMPC group experienced increased emotional fulfillment and stability than the SC group, contrasting with existing research, which identified high emotional distress or lowered emotional health among cancer patients undergoing palliative care.<sup>19</sup> This difference maybe because KMPC patients can be recruited into care at any stage of the treatment process rather than only when the patient is at the terminal stage or on the deathbed,<sup>4</sup> as opposed to traditional palliative care provision worldwide.<sup>20</sup> Therefore, patients choosing KMPC may be better emotionally adapted to cancer and its treatment. In addition, the current study found that patients from the KMPC group had increased positive social interactions as opposed to their SC counterparts. The unique community-owned, home-based approach of care practiced in the KMPC is reported to significantly improve the patient's family well-being, enhance the

patient's social network, increase the community's understanding, and ability to support the patient.<sup>3</sup>

## Implications

Although patients who selected the KMPC reported lower anxiety and depression and improved QoL, they experienced higher levels of pain than their counterparts receiving SC in this study. These findings suggest that the KMPC may need to improve access to and utilization of pain relief medication, such as morphine, prevalent in India.<sup>18</sup> Therefore, future research should explore meticulously the barriers and facilitators to pain management among patients choosing the KMPC. Further, the current study revealed that patients' financial background might play a role in their preference of KMPC over SC, indicating the need to reduce the stigma associated with their opting for KMPC. This can be done by raising community awareness of KMPC to sensitize and educate the wider public of the possible psychological benefits to patients who use these services. Further qualitative research to explore this aspect could increase our understanding of this issue.

## Strengths and Limitations

The current study has many strengths. First, to our knowledge, this is the first study that attempted to compare cancer patients who selected the KMPC or SC. Second, this study explored a range of psychological variables that may be associated with the choice of treatment style, thereby providing a broader understanding of factors that differentiate between the KMPC and SC groups. Third, by using purposive sampling, this study was able to recruit a comparable and representative sample per group, thus allowing meaningful interpretations of the findings.

These strengths notwithstanding, this study has some limitations. First, multiple stakeholders (e.g., family, physicians) who might play a role in selecting treatment style were not included. Second, owing to the study's cross-sectional design, it is difficult to assess whether there were any changes in patients' group membership. Therefore, future research should use a longitudinal method to trace any changes over time. Third, more SC (vs. KMPC) patients declined participation in this study. Given the reasons for nonparticipation, some suggestions to overcome this issue for future research are (i) sharing/keeping study's information in accessible yet discrete locations for potential participants to read at their convenience, (ii) underscoring that interviews can take place telephonically thereby addressing privacy concerns, and (iii) using a physician/healthcare worker referral system wherein they identify eligible patients who may otherwise decline participation (e.g., due to increased distress) and inform them about the study. Fourth, the sample size for the current study was small as the time duration for data collection was short and in-keeping with the academic schedule of the first author, PG. Therefore, due to the small sample size, generalization of the findings is

not possible. Future studies need to include a larger sample to better understand the relationship between a range of variables and patients who choose either KMPC/SC.

## Conclusion

This study reported that patients who choose KMPC belong to an overall lower financial status, have lower levels of anxiety and depression, higher levels of QoL and its sub-domains, and higher levels of perceived pain compared with patients who choose SC. These findings highlight the need to improve the patient's pain management efforts by the KMPC professionals. Additionally, this study's findings indicate the need to reduce stigma related to selecting the KMPC by increasing wider community awareness and sensitivity to this treatment.

### Footnote

✓ SC consists of treatment protocols for a specific illness that are accepted and followed by the treating physician. In the case of this study, SC refers to the standard medical care protocols for the treatment of cancer that are followed by the oncologist.

Reference: Standard of care. National Cancer Institute of health. Accessed September 15, 2021. <https://www.cancer.gov/publications/dictionaries/cancer-terms/def/standard-of-care>

✓ The hospitals where patients were recruited include:

- Ernakulam General Hospital (total = 46; SC = 17; KMPC = 29)
- Anwar Memorial Hospital (total = 12; SC = 5; KMPC = 7)
- Lakshmi Hospital (SC = 8)
- Government Hospital Aluva (total = 21; SC = 10; KMPC = 11)

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### Authors' Statement

This manuscript has been read and approved by all the authors, the requirements for authorship have been met, and each of the authors believe that the manuscript represents our honest work.

### Authors' Contribution Details (ticked as applicable)

P.N.G. was involved in conceptualization, designing, definition of intellectual content, literature search, data acquisition, data analysis, statistical analysis, manuscript preparation, manuscript editing and review. M.P.G. was involved in conceptualization, designing, definition of intellectual content, literature search, data analysis, statistical analysis, manuscript editing and review. S.C. was involved in definition of intellectual content, manuscript preparation, manuscript editing and review. M.C. was involved in definition of intellectual content, literature

search, manuscript preparation, manuscript editing and review. S.C. is guarantor for this manuscript.

#### Conflict of Interest

None declared.

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