Original Article

Is the Kerala Model of Community-Based Palliative Care Operations Sustainable? Evidence from the Field

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Abstract

Background: The palliative care operation in Kerala, unlike other parts of India, is widespread. Kerala's community-based approach to palliative care is often recognized in the current literature as a sustainable model. However, the sustainability of palliative care operations is not empirically studied, and the domains of sustainability are not clearly explained in the current literature. **Aims:** The present study attempted to explore the following research questions. First, are the community-based palliative care operations in Kerala really sustainable? Second, what are the dimensions of sustainability? **Methods:** To answer these research questions, an empirical field-based investigation was carried out using the case study method. The study was conducted among ten selected palliative care units in the Malappuram and Palakkad districts of Kerala. The records of service delivery, reports, and other available documents were accessed. Interviews were conducted with the key functionaries and other staff of the individual palliative care units. **Results:** The result of the study indicates that palliative care is delivering uninterrupted and comprehensive care to the needy in the region. Three dimensions were evident as the sustainability of palliative care operation. **Conclusion:** The replication of this model requires an understanding of these dimensions.

Keywords: Community-based projects, Kerala model, palliative care, sustainability

Introduction

Palliative care plays a very crucial role in improving the quality of life of patients who are suffering from life-limiting severe illnesses, chronic conditions, and terminal illnesses. The services of palliative care are integral in the public health service delivery, but globally, only 14% of the people who require the service are able to access it.[1] The situation in India is also not different. It is estimated that in India, only 2% of people who require palliative care services are availing it.[2] However, the scenario of palliative care in the state of Kerala is unique, where almost universal access is evident.[3] Kerala is evolved as a unique model in the service delivery of palliative care through the community-based approach. The services are provided through community-led projects at free of cost. The services are provided in a home care model. Moreover, the services provided are holistic, which cover different aspects of the care of patients and families, including physical care, psychosocial, spiritual, and economic support.[4] The palliative care model in practice in the state of Kerala is ideally fit for the resource-poor setting like India due to its cost-effectiveness and community-based approach.[5] Voluntary efforts with multidisciplinary teams mostly manage the palliative care services in Kerala. A large number of palliative care units are able to deliver uninterrupted services to the needy throughout these years since its popularity in the late 1990s.

The evolution of Kerala's palliative care model in a community-led approach is considered as unique in the domain of sustainability as it could give coverage of care to a large volume of patients solely through voluntary efforts. The current literature emphasizes that Kerala model is sustainable. The Worldwide Hospice Palliative Care Alliance? and WHO attributed community involvement and ownership as the

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attributes of sustainability of the palliative care model of Kerala.[6] As the resources raised from the community itself, the Kerala model is highly sustainable.[7] The resources for the day-to-day functioning of palliative care are mainly mobilized from the community as micro-donation, and the innovations in resource mobilization make the model sustainable.[8] The volunteers contribute significantly to making the model sustainable.[2,9] The quality of death report 2010 also highlights the Kerala model of palliative care sustainable and attributed its services for improving the quality of life during the terminal stages of life.[10]

Although extensive literature is not available, the existing evidence suggests Kerala's community-based approach of palliative care as a sustainable model. However, the sustainability of palliative care operations is not empirically studied, and the domains of sustainability are not clearly explained in the current literature. In this context, the present study attempted to answer two core research questions. First, are the community-based palliative care operations in Kerala really sustainable? And second, what are the dimensions of sustainability? To be specific, the study attempts to explore what constitutes sustainability the palliative care operation. It is timely to explore these aspects in detail to generate empirically grounded evidence on the much highlighted Kerala model of palliative care.

Methods

A case study design was adopted in the present study to unveil the research questions posed. The unit of analysis considered for the study was the palliative care units. The study was conducted among the selected palliative care units in the Malappuram and Palakkad districts of Kerala. The selection of the palliative care units was based on inclusion criteria. Firstly, palliative care units operating at least for a period of five years without any interruption were only considered. Secondly, palliative care units operated by the NGOs/community-led projects were only selected. The selection of palliative care units operating under community-led projects or civil society organizations was only made because the government funds local self-government-run projects. Moreover, the issue of financial sustainability is not a major concern for government-run programs. However, it is pertinent to look at the sustainability issues of the community-based and civil society-run palliative care programs since the significant chunks of funding come from the community.

There were many palliative care units in both the districts which fit into the inclusion criteria mentioned above. However, to delimit the study, the researchers have chosen five palliative care units, each from both the districts randomly using the lottery method. The selected palliative care units were contacted for participation in the study. All the chosen palliative care units, which fit into the inclusion criteria, were agreed to participate in the study. Hence, the total number of palliative care studied constitutes ten.

After the selection of palliative care units, informed consent was taken from the concerned authority of the respective units to conduct the study. The confidentiality of information collected was ensured, and indications of the identity of the organizations were kept hidden by assigning numerals to each organization in this article. Multiple strategies were adopted for data accumulation. The official records like patient registers were accessed to understand the patient characteristics and magnitude of services provided. The financial aspects of the management of palliative care units were inquired by analyzing the annual and audit reports. The registers of the nurse's report and volunteers' reports were also accessed.

Apart from going through the accessible records, the first author has conducted a series of interviews with the key functionaries and volunteers of the palliative care units to understand the sustainability issues. The researcher also participated in the home visits of all the palliative care units studied at least twice or thrice to understand the nature of service delivery and the sustainability issues. The records, interviews, and field notes were analyzed to answer the core research questions posed in the study. A general inductive approach to qualitative analysis proposed by Thomas[11] was adopted for analyzing the interview data and presenting the reflections from the field notes.

Results

The study looked at the sustainability aspects of palliative care operations. The analyzed documents and interview excerpts are presented in the form of categories that carry the essence of studied phenomena. Three dimensions of sustainability of the community-based palliative care operations have emerged from the data. The palliative care operations are widespread in the two districts from the units that were selected, especially in the Malappuram district. As per the palliative care policy of the state and subsequent mandates by the government, palliative care is operated by all local self-governments in Kerala. In Malappuram district, there are around 112 such units existent, which is run by the panchayats and municipalities. In Palakkad, the number is approximately 95. Although most of the local self-governments have established palliative care, a substantial proportion of them are not actively involved in care delivery. On the other hand, the number of palliative care units run by the community, civil society, or nongovernmental organizations in the Malappuram district is around ninety. In Palakkad, it is about fifty.

Patient care and services

One of the most important indications of the sustainability evident from the analysis is the sustained services provided to the patients for a longer period of time since the inception of palliative care units. All the palliative care units reported that they had provided the services to the patients and families without any interruptions. It was also evident that the services provided were comprehensive and touched the lives of many.

Table 1: Patient services (n=10)

	n
Active patients at a time	
100-150	4
151-250	2
251-350	3
351 Above	1
Home care services	
Thrice in a week	1
4 days in a week	1
5 days in a week	2
6 days in a week	6
Outpatient services	
Yes	8
No	2
Rehabilitation service	
Yes	9
No	1

Table 1 indicates the major components of the services offered by the studied palliative care units. Based on the locality, the number of active patients varied from 100 to 500. The home care units operate thrice in a week to 6 days a week. Except for two palliative care units, all other units have the option of the outpatients' services. The special rehabilitation service for the patients who are economically weak and deprived is provided by all palliative care except one.

The palliative care units are engaged in providing services that help the patients to improve quality of life and reduce the treatment costs. All the studied palliative care has the provision of comprehensive care according to the needs of the patients and families. The care provision and different types of services provided are detailed in Table 2.

The key functionaries, staff, and volunteers narrated that they are providing comprehensive care that touches the different aspects of the patients and families. The home care units reach every patient at regular intervals based on the requirements of the patient. All the patients enrolled are provided with free medication, and whoever required is given nursing care. Similarly, some patients require medical equipment such as catheters, wheelchairs, crutches, water beds, and oxygen cylinders. However, many of them are not in a position to access or purchase those of their own. In such circumstances, the palliative care units provide such items to the patients. It was found that all the studied organizations have provided hundreds of such equipment to needy patients.

The patients who require to spend a huge amount of money on any surgical procedure or treatment are also supported based on the needs. Psychosocial support and family education is also a crucial part of palliative care interventions. This is potentially beneficial for the family members to understand more about the situation of the patients and to provide basic care. Palliative care is providing these services in the sustained mode for the last many years, and the patients and family members are getting benefits out of the same. The services are potentially reducing the treatment costs of the families.

Economic self-sufficiency

The second domain of sustainability identified in the study is economic self-sufficiency. The palliative care units studied are involved in providing a wide variety of services for large number of patients. These service deliveries bring a potential cost to the palliative care units. Most of the palliative care in the region, except government-run, is functions under the community-owned projects. Although there are no fixed sources of funding for these organizations, they are reaching a large number of patients every year with comprehensive care. All the studied palliative care was reported that they are financially sustainable in a way they could meet all the expenses of the palliative care operations from the fund they receive from different sources. The important characteristics of self-sufficiency of the palliative care units and the major source of income are detailed in Table 3.

The indications of economic sustainability are evident from the assets procured and regular income provisions. It was evident that out of the 10 palliative care units studied, seven had their own building while one was operating in a rented building. The other two units had the sponsorship for the rent of the building from the community. The building and infrastructure for palliative care were constructed through community support. All the studied palliative care had their own vehicle for the home care units. In all cases, except one, these vehicles are donated by different organizations of business community, service organizations, or individuals. Regular nurses (at least two) and a medical practitioner (part time or full time) were available in all studied palliative care units. All the units had permanent drivers. Three of the units appointed part-time physiotherapists for the service delivery, and two had qualified social workers.

The sources of funds play a crucial role in making palliative care sustainable. The entire activities of the organization purely depend on the funds received from different sources. All the palliative care units were reported that their primary source of funds comes from micro-donations. Donation boxes are kept at public places, including shops, hospitals, hotels, and recreational centers. The major expenses for the month could be met by these means. Apart from it, there are systems for monthly collections in which identified willing individuals or business firms contribute a fixed amount of money, which may range from Rs. 500 to 5000. In case of special circumstances (construction of the building, purchasing of a vehicle, or helping a patient's special medical needs), funds are raised at the macro level from people and business firms who can afford it.

Out of the ten palliative care units studied, seven were involved in social entrepreneurship. The purpose of the same is two-fold: first, to employ a family member of a patient who is economically deprived, and second, to act as a potential source of income for palliative care. The social entrepreneurship contributes to a potential source of income for the organization as well as the families of the patients. The expenses of the palliative care

Table 2: Services provided

Services provided	*n*
Free medication	10
Dressing of wounds and necessary nursing	10
Distribution of necessary medical equipment	10
Resource mobilization for major medical expenses	10
Psychosocial interventions, counseling, and family education	10
Economic support to the family	10
Travel support for treatment in distant places	10

Table 3: Characteristics of self-sufficiency and sources of income

	n
Characteristics	
Own building	7
Own vehicle for home care	10
Regular nurses	10
Medical practitioner (full/part-time)	10
Sources of income	
Micro-donations	10
Monthly collections	10
Macro donations	10
Social entrepreneurship	7
Donation as kind	10

units are also met through contributions in kind, which include medicine, medical equipment, food kits, and other necessities. For the functioning of palliative care, considerable amount is spent annually [Table 4]. The expenditure varies from 9 lakh to 30 lakh based on the locality, number of people served, and years of existence. All the palliative care units studied have emphasized that they are in a position to find the funds for the operation through the various means of funds.

Volunteering efforts

The third dimension found as the sustainability of palliative care was the volunteering efforts. The entire palliative care activities are based on voluntary efforts. The sustenance of volunteers' contributions highly determines the sustainability of palliative care operations. Volunteers play a significant role in the identification of patients, their requirements, resource mobilization, and the overall management of palliative care. All the studied palliative care units have emphasized on the importance of volunteers in the sustenance of palliative care activities. The number of active volunteers in each unit varies [Table 5].

The general public widely accepts the services of palliative care, and there is a social consensus for its contribution. The role of volunteers in familiarizing the palliative care activities to the public is very vital. In general, palliative volunteers hail from the respective areas, and they have a strong network with the local people. This would help them to directly involve in understanding the problems of patients and families and connecting them to resources.

Table 4: Annual expenditure of the palliative care

Palliative care	Expenditure (In lakh for the financial year-2019-2020)
Palliative care-1*	18.25
Palliative care-2	11.30
Palliative care-3	30.5
Palliative care-4	9.70
Palliative care-5	13.2
Palliative care-6	15.26
Palliative care-7	14.78
Palliative care-8	27.33
Palliative care-9	9.15
Palliative care-10	17.65

*Name is not mentioned to keep the anonymity of the studied palliative care

Table 5: Volunteers (*n*=10)

Number of active volunteers	*n*
20-30	1
31-50	3
51-75	5
76-100	1
100 above	1

The role of volunteers in the mobilization of funds is very crucial. The volunteers generally manage fundraising activities. Most of the volunteers in palliative care are trained volunteers who can address the psychosocial needs of the patients and families to a great extent. The volunteers are a diverse group who hails from different walks of life. The major chunk of volunteers constitutes youngsters, people in services, retired officials, students, elected representatives of panchayats, and the general public. The involvements of volunteers significantly influence the other two domains of sustainability: patient care and services and economic self-sufficiency.

Discussion

The study was designed to investigate the sustainability aspects of the Kerala model of palliative care and its potential dimensions. The results of the study were insightful and suggested that the Kerala model of community-based palliative care is sustainable to a great extent in its operations. The studied palliative care units are able to provide uninterrupted services to the needy patients in a comprehensive manner. The study could locate three domains of sustainability. The first domain identified was patient care and services. Most of the palliative care units were able to provide comprehensive care to the patients for many years. The care provisions touch different aspects, which include physical, psychological, spiritual, and economical. The services are provided free of cost through the home care units. Previous studies also have shown that Kerala's model constitutes a cost-free approach that provides comprehensive care.[12,13] The services available from palliative care significantly reduce the treatment costs of the patients and families. The wide range of

services provided to the patient community uninterruptedly throughout the years remains as the major indication of sustainability.

The second dimension of sustainability identified from the study was the economic self-sufficiency. All the palliative care units studied were reported that they are able to meet all the expenses of the operation by different sources of funds. The major source of income for most of the palliative care was the micro-donations through active community participation. The economic self-sufficiency of the model as a result of community involvement was documented in the previous literature.[8,14] Innovative approaches such as social entrepreneurship were also adopted as a mechanism for funding. Previous researches also support that socially innovative ideas developed by palliative care in Kerala contribute to economic self-sufficiency.[15-17] Since the funds are generated from the community in a voluntary mode, all the key functionaries of the palliative care units are sure about the sustained funding. The financial security is an important factor for the survival and sustainability of any community-based project. In the case of community-based palliative care operations, economic sustainability is ensured to a great extent through various means, and it acts as the major factor for overall sustainability.

The third dimension of sustainability evident was volunteering efforts. Volunteers are actively engaged in patient care and support services. The major actors of fundraising in palliative care operations are the volunteers. They involve in the management and service delivery of palliative care along with the multidisciplinary team. All the palliative care units are able to find enough volunteers throughout time. The diversity of palliative volunteers is also evident. The experience and expertise of the volunteers in their respective field is contributing to the effective service delivery in palliative care.

The volunteers potentially contribute to the other two dimensions of sustainability by their active services. The volunteers and their efforts are considered as the backbone of the Kerala model,[9,2] and their support is comprehensive that touches the different aspects of palliative care interventions, including fundraising and psychosocial interventions.[18,19] The enthusiastic engagement of volunteers positively contributes to the sustainable provision of providing palliative care. In a recent study, the perspectives of social work professionals on the sustainability of palliative care intervention were explored in the context of Kerala, and the factors found were the sociopolitical environment, holistic care, community participation, resource mobilization, and volunteerism.[20]

Conclusion

The study sheds light upon confirming the sustainability of the Kerala model of community-based palliative care. The uninterrupted patient services, economic-self sufficiency, and volunteering efforts are contributing to the overall sustainability of palliative care operations. The factors found as the dimensions of sustainability are mutually inclusive and specific to Kerala's model of community palliative care. The replication of the Kerala model of palliative care in the other localities must consider these dimensions for successful implementation. Future researches can focus on exploring the economic aspects of sustainability more comprehensively through quantitative measures. Further, the sociocultural aspects that set the context of identified dimensions of sustainability also require a detailed examination from a sociological point of view.

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Conflicts of interest

There are no conflicts of interest.

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