

Original Article

Understanding Long-Term Outcomes of Public Health Strategy in Palliative Care at Micro Level: Impact of Home-Based Palliative Care Services under Local Self-Government Institutions in Kerala, India

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ABSTRACT

Objectives: Palliative care units under Local Self-Government Institutions (LSGIs) are increasing in number in the state of Kerala, India, since the announcement of the Pain and Palliative Care Policy, 2008. Whether these units are functioning with a view to materialise the long-term objectives, following the guidelines stipulated by the Government of Kerala and serve the neediest patients with quality care are a matter of debate. Hence, a microlevel study of the palliative care unit is attempted. The aims of the study were to understand the extent to which the structure and nature of functioning of the Pain and Palliative Care Unit under LSGI comply with guidelines set by the Pain and Palliative Care Policy of the Government of Kerala and to check whether the palliative care services are reaching the needy and, if so, are they provided to patients in good quality.

Materials and Methods: The award winning Pain and Palliative Care Unit attached to LSGI is selected for analysis and a hybrid research design is followed. Data are collected from 25 patients and their caregivers selected randomly. Mean score of satisfaction level on the basis of Quality care questionnaire - Palliative care is used.

Results: Sample unit complies with the revised guidelines of 2015, Pain and Palliative Care Policy. It serves the neediest patients and the quality of care is satisfactory.

Conclusion: The study reaffirms the strength of the public health model in palliative care which can provide quality care to the neediest patients.

Keywords: Public health model, Home-based palliative care, Local Self-Government Institution, Quality care

INTRODUCTION

The necessity for palliative care services is increasingly recognised in developing nations, given the growing number of ageing population and rate of chronic illnesses.^[1] Following the public health model of palliative care initiated by the WHO, the state of Kerala, India, announced a pain and palliative care policy, whereby palliative care became the mandatory responsibility of Local Self-Government Institution (LSGI).^[2,3] Although palliative units are increasing in numbers over the years, whether these units are attaining the long-term expected outcomes of palliative policy which is a matter of debate.^[4,5] Hence, a microlevel study, analysing the compliance to policy and guidelines regarding the structure

of the unit and nature and monitoring of service delivery are attempted along with patient-reported quality of care.

Pain and palliative care policy in Kerala: An overview

The state of Kerala in India, hosted the WHO demonstration project by initiating Neighbourhood Network in Palliative Care and with the expertise gained, facilitated the introduction of the public health model in Kerala through the declaration of Pain and Palliative Care Policy, 2008, and the revised guidelines of 2013 and 2015.^[6,7] The policy envisaged providing medical care and support to every citizen in need of palliative care through adopting community-based approach in home care settings.^[8] The long-term objectives envisioned in policy require adherence to the guidelines stipulated in terms

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Received: 10 July 2021 Accepted: 30 November 2021 EPub Ahead of Print: 06 January 2022 Published: 24 March 2022 DOI: 10.25259/IJPC_4_21

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of structure, nature of services delivery, monitoring quality of care and responsiveness and ensuring the quality of life of patients and their families. The revised guidelines introduced in 2015 set up standards for palliative care project planning and implementation at the LSGI level, in which operational guidelines relating to the formation of the palliative care team (2.2.3), conduction of managerial committees (2.3 and 2.4), local resource mobilisation (2.6), service delivery (2.6.2) and coordination with other departments/institutions (2.11) were issued.^[3] The directives issued by Directorate of Health Services, Local Self-government Department, National Health Mission and Social Justice Department clearly demarcate roles and responsibilities of all stakeholders in each stage of project implementation.^[9] The apparent result was the establishment of palliative care units under LSGI, with medical officers at Primary Health Centres/Community Health Centres coordinating palliative care activities with the support of palliative care nurses, Accredited Social Health Activists (ASHAs) and elected members of LSGI, whereby the provision of palliative care services (medical as well as non-medical) became the responsibility of health department and resource mobilisation and allocation came under the purview of the LSGI.^[3]

Research findings are inconclusive regarding the impact of this public health strategy in palliative care in Kerala, where some find the fallacy in the aspects relating to the implementation of the Palliative Care Policy (2008 and its revisions in 2013 and 2015) at the local level.^[4,5,6,9] For instance, Jayalakshmi and Suhita (2017) state that 'the programme in two LSGIs is still short of a public health approach, and major guidelines of palliative care policy seem to have been given a miss'^[5] while analysing home-based palliative care services under LSGI and suggests for structural reconfiguration of the delivery system. Explicitly, this raises apprehensions relating to the effectiveness of palliative care programme to provide holistic care and the ability of the public health model to incorporate palliative care with due importance.

The present study is an attempt to re-examine the state of affairs, by investigating the structure and nature of the state award winning Pain and Palliative Care Unit under LSGI, functioning as per the same guidelines of the Government of Kerala, since 2009. The aim is to examine, whether the palliative care unit succeeds in meeting the long-term objectives envisioned in the public health strategy in palliative care in Kerala after a decade of its initiation. Moreover, this includes 2-fold objectives. First, to understand the extent to which the structure and nature of the functioning of the Palliative Care Unit under LSGI comply with guidelines set by the Pain and Palliative Care Policy of the state of Kerala. Second, whether these services are reaching the needy and if so, to what extent the unit succeeds in delivering palliative care with quality.

MATERIALS AND METHODS

As mentioned above, the pain and palliative care unit which has received the state award for the best palliative care unit continuously for the last 5 years is selected for detailed analysis. This unit named 'Kanivu' is attached to the Family Health Centre (FHC) under the purview of Kilimanoor LSGI (Gram Panchayat). Established in 2009, soon after the announcement of pain and palliative care policy by the state government, it is one of the pioneering Pain and Palliative Care Units controlled by LSGI and so provides an opportunity to assess the developments over a decade. The study used a hybrid research design, in which qualitative methods of research were used to understand the structure, organisation and compliance to policy and a primary survey of patients was conducted to capture the quality of care. Stakeholders including the medical officer in-charge of the palliative care unit, palliative care nurse, physiotherapist, President of LSGI, Secretary of LSGI, Chairman of Health Standing committee and 11 ASHA workers were interviewed to gather information about the origin and development of pain and palliative unit and the services provided by it. Twenty-five patients were randomly selected from a total of 274 patients registered currently in the unit, and data relating to socioeconomic status, palliative care services received, healthcare expenditure and quality of care were collected using an interview schedule during August 2020. The satisfaction index is worked out from quality care questionnaire for palliative care which is based on patient-reported assessment of the palliative care unit.^[10,11]

RESULTS

'Kanivu' Pain and Palliative Care Unit was initiated by the LSGI officials capitalising on the experience gained from the training programme at the Institute of Palliative Medicine during 2008. Started with a baseline survey to identify patients in need of palliative care in the area under concerned LSGI, the initiative has grown as a full-fledged palliative care unit serving a total number of 874 registered patients with an annual financial outlay of US\$ 19,069. Sustained over a period of 12 years of service, the pain and palliative care unit was able to realise the concept of community-based home care palliative care services, through the coordinated efforts of LSGI officials and medical/paramedical staff of health department and staff in the unit; currently, one doctor, nurse, physiotherapist and 22 ASHA workers act as caregivers. In addition, the nine-member Palliative Care Management Committee and Palliative Care Implementation Committee (PCIC) with 11 members, support and supervises the work of caregivers, and thus, the unit owns adequate skilled manpower to provide medical, psychosocial and spiritual support to patients. This is complemented by palliative care unit at the FHC with all facilities including the nursing station, observation room, inpatient ward, pharmacy, physiotherapy room and ambulance which are not common in other palliative care units under LSGI.^[5]

Organisation, structure and nature of service delivery: Compliance to guidelines

Revised guidelines introduced as a part of 12th Five-Year Plan of state of Kerala in 2015 clearly states the roles and responsibilities of LSGI in the planning, organisation, resource allocation, training and implementation of palliative care services and the guiding principle envisages, LSGI to coordinate with other departments/institutions/non-governmental organisations to develop community-based home care palliative care services. These guidelines were issued to meet the long-term objective of pain and palliative care policy to provide palliative care services to the neediest patients with good coverage and quality. The operational guidelines focus on procedures relating to the formation of a palliative care team, training of medical and paramedical personnel, home care visits, drug procurement and supply, appointment of palliative care nurse, physiotherapist and ambulance driver and monitoring activities. [Table 1] explains whether the pain and palliative care unit understudy adheres to the guidelines formulated in 2015.

The palliative care project has been improving its functioning over the years; the project outlay of US\$680 in 2009 has grown to of US\$ 19,069; patient base has increased from 45 to serving a total of 874 and this growth is the result of coordinated efforts of public institutions at the grassroot level. The LSGI provides all financial and administrative support to the unit to function effectively. In addition, it positively intervenes in the life of patients by providing livelihood support. Once the palliative team raises the need for livelihood support for patients, the LSGI takes all steps to provide it by including it in any of the government welfare programme for livelihood support. On the other hand, the FHC provides special care to palliative care patients at the hospital and doctor visits the patients in case of emergency. Medicines are provided to all patients free of cost and physiotherapy is done for patients who are in need. The success of the palliative care unit is this coordination of activities and division of work according to each institution's capacity. Both institutions try to invite the participation of the community in delivering the services and school students and other volunteers are given training which, in turn, makes the initiative community-owned.

An important feature of the palliative care policy in Kerala is that it succeeded in setting up an operational procedure in place that has to be followed while initiating palliative care units under the government sector, and the way in which 'Kanivu' Pain and Palliative care is organised and structured exemplify this. This has helped in guiding all stakeholders in relation to planning, finance allocation, quality standards, case management and direct health care service delivery in the sector. There are elaborations on each and every component item relating to palliative care starting from setting up committees to equipment to be kept at the home care kit. 'Kanivu' Palliative Care Unit has followed each

instruction and this ostensibly provides each stakeholder with a sense of responsibility and managerial freedom that contributes clarity in organisation and structure. Hence, contrary to the instances of conflicts reported among different stakeholders in other palliative units, 'Kanivu' Pain and Palliative Care Unit maintains sustainability because of adherence to the policy guidelines in terms of administrative structure, nature and monitoring of services.^[5]

Pain and palliative care service delivery: Beneficiary base, the sufficiency of services and quality of care

Identifying the needy patients and developing a personalised care plan for each patient are important in palliative care. Managerial independence and autonomy of palliative management committee and PCIC which ensure political non-interference relating to admission of patients, identification of beneficiaries for livelihood support, charting the house visits and distribution of medicines or other supplies make sure that the neediest patients are served. Detailed documentation of disease condition, medical treatment and socioeconomic backdrop and maintaining the stipulated registers and patient records help in developing a personalised care management plan for each patient and this is evidenced by the patient-reported quality of care.

Socioeconomic and demographic status of respondents shows that around 48% are below 60 years of age and 70% are not educated more than high school. About 72% of the population live below the poverty line, and most of the patients were either unemployed or worked as a casual labourer before becoming ill. This shows that the patients registered with the unit belong to the economically backward category in the society. There was a fall of average monthly per capita income to US\$110, from the pre-illness period of US\$243. Analysis of the pattern of consumption expenditure holds with the findings that the families experience iatrogenic poverty with health expenditure forming more than 20% of total consumption expenditure.

Regarding the disease profile of respondents, 92% are suffering from chronic illness against 8% of patients having problems relating to ageing. Accident, cancer and stroke are major diseases and around 40% of the patients are diagnosed with the disease before 2012. Treatment history, before referring to palliative care services, reveals that 52% of the patients have undergone surgery and 30% needed intensive care unit support, to deal with medical complications. The direct cost of average healthcare expenditure during the medical complication was estimated at US\$ 2559/- and the indirect cost amount was US\$299. Data relating to the chronicity of symptoms as reported by patients show that most of the patients experienced medium to high health problems relating to physical impairment, sensory loss, respiratory problems and memory loss.

DISCUSSION

In short, socioeconomic demographic data suggest that the pain and palliative care unit is reaching to patients of all

Table 1: Adherence to policy guidelines.

Item	Guidelines	Compliance
Structure (administrative)		
2.1.1 Palliative care project	Mandatory projects each year in annual plan of LSGI	Yes
2.2.2 Planning	Annual meeting for planning activities – medical officers, field workers, LSGI officials, NGOs, volunteers, etc.	Yes
2.2.3. Home care team formation	The team to include doctor (1), palliative care nurse (1), physiotherapist (1), ASHA workers and volunteers	Yes
2.2.4 Training	One day training programme for all stakeholders	Yes
2.3. PMC	A committee consisting of LSGI President, Health Standing Committee Chairman, Welfare Committee Chairperson, LSGI Secretary, Nominated Members, Chairperson and Secretary of Community Development Society, Medical Officers and Palliative Care Nurse to meet once in 2 months	Yes 15 member committee joins once in 2 months
2.4. PCIC meeting	Monthly meeting to approve expenses and plan activities	Yes
Nature of service delivery		
2.5 Patient registration	Keep and update nominal register, patient status report, follow-up home care register and present it before PCIC	Yes
2.6 Home care visit	Up to 3 days ASHA, ward member to accompany nurse, eight homes per day, verification of Annexure 3 Form by medical officer, maintaining online report and volunteer register.	5 days Yes
2.6.4 Home care kit	Maintain home care kit with essential supplies	Yes
2.6.5 Home care vehicle	Display of name of palliative unit, Hospital Management Committee as custodian of vehicle and driver on daily wage	Yes
2.6.6 Coordination	Act as mediators to secondary/tertiary institutions	Yes
2.6.7 Medicine	OP for palliative care patients – to maintain OP register and treatment record, distribution of free medicine	Yes
2.6.8 Assistive devices	Wheelchairs, walker, water beds, colostomy bags and hearing aids made available with the help of public/project fund	Yes
2.6.11 Social support with community's help	Food distribution/educational help	Food kits to needy patients
2.6.12 Rehabilitation activities	With the support of LSGI	Yes
Monitoring quality of care and responsiveness		
2.6.14 Continuing education	Training for nurse, ASHA workers and students from nearby schools	Yes
2.10 Review	Monthly review meetings	Yes
2.8 Appointments	Nurse Qualification: GNM/BSc Nursing with BCCPN Physiotherapist: BPT	Yes (GNM with BCCPN), BPT

LSGI: Local Self-government Institution, PC: Palliative care, NGO: Non-government organisation, ASHA: Accredited social health activist, PMC: Palliative management committee, PCIC: Palliative care implementation committee, OP: Outpatient, GNM: General nursing and midwifery, BCCPN: Basic certificate course in palliative nursing, BPT: Bachelor of physiotherapy

age groups, who are suffering from chronic illness and have been trapped into the cycle of iatrogenic poverty for pretty long periods. The palliative care facility attached to the FHC seems to be the only healthcare facility option to the patients. Regarding the services provided, the palliative care team visited all the respondents once in every month, and patients in need of catheter care or wound dressing were given the services whenever needed. The medical services included the provision of medicines, pain relief tablets, assistive devices and routine check-up along with caregiver services. Data show that 92% of patients received medicines free of cost, and all patients in need of pain relief tablets, routine check-up, catheter care and nursing services were provided with the

services. Similarly, all patients below the poverty line received monthly food kits, and more than 60% got financial help from the pain and palliative care unit. However, with regard to daily life skill support and bystander facility, patients' needs were not fully met. The level of satisfaction plotted by the patients implies that they were satisfied with the medical and non-medical services provided by the unit. Sufficiency of services is measured on the basis of demand for services and availability of care from the beneficiary's opinion. The frequency of the provision of services to address problems relating to daily life skills, personal transportation, physical symptoms, autonomy, social, psychological, spiritual and financial issues that are to be

taken care to deliver an effective care plan is evaluated. Results are given in [Table 2].

Measuring the sufficiency of services, the experience of patients shows that most of the patients were taken care effectively according to their needs and aspirations which suggest the existence of a personalised plan of care for each patient and continuity of palliative care services.

Patient-reported assessment of the quality of palliative care is done under four domains – (a) communication with the palliative care team, (b) value of life and goals of care,

(c) support and counselling for needs of holistic care and (d) accessibility and sustainability of care. A Likert scale of 5 points is used where 1 indicates the least level of satisfaction and 5, the highest level of satisfaction. Results are given in [Table 3]. The index scores show that palliative care team members maintained clarity and empathy in conversations relating to formulation and implementation of the care plan and in this, the values of the patient were given adequate importance. Furthermore, patients received psychological support through counselling whenever necessary, and

Table 2: Sufficiency of palliative care services.

Domains	Problem		Frequency of provision					
	Yes		Always		Sometimes		No	
	F	%	F	%	F	%	F	%
Daily life skills	9	36	5	55.6	3	33.1	1	11.1
Personal transport	6	24	2	33.3	3	50	1	16.7
Physical symptoms								
Pain	7	28	6	85.7	1	14.3	0	0
Fatigue	7	28	7	100	0	0	0	0
Sleeplessness	5	20	2	40	3	60	0	0
Breath problems	3	12	3	100	0	0	0	0
Skin infections	8	32	8	100	0	0	0	0
Autonomy								
Difficulty to continue daily activities	25	100	18	72	5	20	2	8
Difficulty to give tasks out of hand	22	88	15	68.2	4	18.2	3	13.6
Feeling dependent	13	52	11	84.6	2	15.4	0	0
Loss of control of life	9	36	7	77.8	2	22.2	0	0
Social issues								
Problems with relatives	10	40	7	70	0	0	3	30
Do not find anyone to talk	4	16	3	75	0	0	2	25
Difficulty in sharing disease details to relatives	6	24	6	100	0	0	0	0
Does not want to share pain	10	40	10	100	0	0	0	0
Psychological problems								
Depression	9	36	9	100	0	0	0	0
Fear	13	52	13	100	0	0	0	0
Difficulty to show emotions	7	28	7	100	0	0	0	0
Difficulty to cope up with unpredictable nature of future life	13	52	13	100	0	0	0	0
Spiritual problems								
Unable to engage life usefully	24	96	20	83.3	2	8.3	2	8.3
Difficulty to be available for others	8	32	7	87.5	0	0	1	12.5
Financial problems								
Additional expense due to disease	20	80	3	15	14	70	3	15.0
Loss of income due to disease	21	84	3	14.29	17	80.95	1	4.76
Lack of information	8	32	1	12.5	6	75	1	12.5

F: Frequency

Table 3: Quality of palliative care services.

Domains of quality of care	N	Minimum	Maximum	Mean	S. D
Communication with palliative care team	25	4	5	4.88	0.30
Value of life and goals of care	25	3.56	5	4.86	0.36
Support and counselling for needs of holistic care	25	4.29	5	4.97	0.14
Accessibility and sustainability of care	25	4	5	4.69	0.40
Overall quality of care	25	4.07	5	4.85	0.23

the care services provided were in lieu with the interest of patients and their families.

CONCLUSION

'Kanivu' Pain and Palliative Care Unit, through gaining recognition at the state level in Kerala for the best palliative unit, sets an example for initiating a successful public health model in palliative care. Abiding to the guiding principle of palliative care policy, 2008, the unit materialised the envisioned public health governance, with LSGI taking up the financial and managerial agency and health department complementing the efforts, by entering into effective implementation of the projects at the grass root level. The case of 'Kanivu' Pain and Palliative Care Unit needs special mention for its ability to bring in LSGI representatives, medical and paramedical professionals of the Health Department and National Health Mission officials together, in planning, implementation and monitoring of the project. Unlike the typical disagreements relating to sharing of power and responsibility among different stakeholders, roles and responsibilities are correctly demarcated and followed by each institution. Thus, the underlying idea of this public healthcare strategy to generate linkages in the health system and to create awareness relating to palliative care among the local population became fruitful.

The unit has a clear implementation strategy and quality monitoring mechanism in place, with an average number of patients to be covered each day and additional services to be provided to each person. The holistic nature of services – along with home care visits, daily life skill training, distribution of food kit, financial and livelihood support and outpatient clinic services – and the annual meet of patients and their families create a sense of trust and dependence in patients to the palliative care team which, in turn, makes the palliate management plan flawless. The beneficiary sample survey undoubtedly shows that the palliative care unit serves the neediest and provides sufficient palliative care services of good quality.

In short, the experience of the poorest patients getting palliative care services with good coverage and quality from the pain and palliative care unit under LSGI throws light on the possibilities of successfully integrating palliative care systems with the public health structures. This quintessentially requires the establishment and functioning of units strictly following the guidelines issued by the government in terms of administrative structure, nature of service delivery and monitoring quality of care and responsiveness.

Declaration of patient consent

Patient's consent not required as there are no patients in this study.

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

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How to cite this article: Nair M, Augustine A. Understanding long-term outcomes of public health strategy in palliative care at microlevel: Impact of home-based palliative care services under local self-government institutions in Kerala, India. *Indian J Palliat Care* 2022;28:7-12.