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Local Government-led Community-Based Palliative Care Programmes in Kerala

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Abstract

This paper highlights aspects of community-based palliative care programmes in Kerala in the context of the increasingly aged population and the emergence of life style diseases. Kerala is the forerunner in community-based palliative care in India. With the involvement of local governments and public participation, the quality of palliative care programmes have improved quite significantly. Kerala, traditionally renowned for its high quality of life, is also proving to be the best place to die with a high quality of death index due to the prevailing palliative care programmes. Collating state level data available from the Information Kerala Mission, the author validates that all the three grassroots levels of local governments in Kerala, viz, the Grama Panchayats, Municipalities and Municipal Corporations are best placed to deliver palliative care services to the needy. A detailed account of palliative care programmes undertaken by Mullurkkara Grama Panchayat of Thrissur district, Kerala State, forms part of this article to give emphasis on the special role of local governments in palliative care management. The Grama Panchayat has carried out various care services including home care visits, supply of medicines, supply of aids and appliances, constitution of home care teams, and the appointment of palliative care nurses. The absence of social workers in the home care teams, inadequate financial resources, low service convergence and a lack of concurrent monitoring of services are the major gaps found in the palliative care programme. The author confirms that within a few years of intensive implementation, the programme has proved to be a most cost effective and decentralised public health model. However, the sustainability of such programmes depends on the capacity to mainstream community volunteerism.

Keywords

Grama Panchayat, decentralised public health, volunteerism, palliative care, Kerala

Introduction

Millions of people worldwide are affected by life threatening illnesses such as cancer, chronic kidney disorder and old age associated issues, which cause them and their families great suffering and economic hardship. The patients and their families are in need of financial, medical and psychological support to overcome this situation.

According to the World Health Organisation (WHO, 2012) the goal of palliative care is to improve the quality of life of both patients and families by responding to pain and other distressing physical symptoms, as well as to provide nursing care and psycho-social and spiritual support. Elsayem, et. al.(2004) state that palliative care means patient and family

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centered care that optimises quality of life by anticipating, preventing and treating suffering. According to Wikipedia, palliative care is a term derived from the Latin palliate, "to cloak". It refers to specialised medical care for people with serious illnesses. It is focused on providing patients with relief from the symptoms, pain and stresses of a serious illness whatever the prognosis.

According to Carlson et al. (1988) palliative care is a multidisciplinary approach to specialised medical care for people with serious illnesses. It focuses on providing patients with relief from the symptoms, pain, physical stress, and mental stress of a serious illness whatever the diagnosis. The goal of such therapy is to improve the quality of life for both the patient and the family.

Suffering at the end of life can be effectively reduced by sensitive care with effective control of physical symptoms, and good social, emotional and spiritual support. In modern times palliative care can be seen as a system of care aiming to improve the quality of life of the incurably ill, dying and bedridden people.

Palliative Care in India

Despite its limited coverage, palliative care has been present in India for about 20 years. In India, the earliest facilities to deliver palliative care within cancer centres were established in places like Ahmedabad, Bangalore, Mumbai, Trivandrum, and Delhi in the late 1980s and in the early 1990s (Mohanti, 2011). Palliative care was initiated in Gujarat in the 1980s with the opening of a pain clinic and palliative care service under the department of Anaesthesiology at the Gujarat Cancer and Research Institute (GC and RI). Later the GC and RI provided pioneering leadership for the formation of the Indian Association of Palliative Care (IAPC) which contributed to the development of palliative care programmes in India.

McDermott et al (2008) identified 138 organisations providing hospice and palliative care services in 16 states or union territories in India. These services are usually concentrated in large cities and regional cancer centres, with the exception of Kerala where services are more widespread.

Significance of Palliative Care in Kerala

Kerala is estimated to have more than 125,000 incurably ill, bedridden and dying patients in need of palliative care (Sanoj, et al., 2014). Kerala is the forerunner in community-based palliative care in India. Formal attempts to provide palliative care for the needy in Kerala were initiated by the Institute of Palliative Care Medicine in the early 1990s, a civil society organisation which led to the concept of the Neighbourhood Network in Palliative Care (NNPC). This approach, even though led by committed doctors and social workers, could expand to a few locations only. With the objective of ensuring wider participation of the community, the NNPC was floated. This resulted into a deeper level of community participation in the management of palliative care programmes, especially in north Kerala. With improved voluntarism and outreach programmes the quality of care also improved. This gained further momentum with institutional support, when the involvement of local governments started in 2007. Efforts in this direction received yet another boost with the starting of palliative care programmes by the National Rural Health Mission under the palliative care policy of the Government of Kerala.

In April 2008, Kerala became the first state in India to announce a palliative care policy. The policy aims at facilitating engagement of local governments in the development of palliative care programmes. Home-based palliative care services are becoming increasingly popular, with care being taken to the doorstep of the patient. It is also well suited to conditions in India where a family member is usually available and willing to nurse the sick

person. The aim of home-based care is ultimately to promote, restore, and maintain a person's maximum level of comfort, function, and health, including care toward a dignified death.

Kerala is traditionally renowned for its high quality of life. Now, due to the interventions of local governments in the area of palliative care programmes, Kerala is also proving to be the best place to die due to its high quality of death index. Kerala's total population as per the 2011 census is 33.6 million, of which 12.6% were aged above 60 years. The state's elderly population is growing at a perpetual rate of 2.3%. The majority of diseases responded to under the palliative care programme in Kerala are largely life style diseases. Life style diseases are permanent and require long periods of intensive care and hence they are termed chronic diseases which put pressure on the health care system. Several population based studies and medical records in Kerala have identified the prevalence of both non-communicable and life style diseases in Kerala. Among the chronic illnesses, hypertension, diabetes and cardio vascular diseases are emerging as serious health problems. A sedentary lifestyle, lack of physical activity and obesity increase the risk of chronic diseases. All these trends call for the relevance of strengthening palliative care in Kerala.

Evolution of the Local Government-led Palliative Care in Kerala

Many local governments in the northern part of Kerala started supporting community projects in palliative care by 2000. Local governments became involved initially as donors, then as facilitators and finally as project leaders. With the issuing of new policy guidelines by Government in 2008, the local governments across 14 districts of Kerala started involving themselves in the programme.

The leadership of local governments in providing resources on a continuous basis gives the programme the much needed sustainability. The local governments also take up the co-ordination of different actors and thereby adding professionalism into it. Training of community nurses for home care is being supported by the Kudumbasree system. The high level political priority and social acceptance attached to this programme has eased resource mobilisation.

With the issuing of a circular by the Directorate of Health Services, the role clarity among different health functionaries became clearer. With the issuing of an exclusive circular by the Local Self Government Department (LSGD), Government of Kerala for palliative care management, local governments' active involvement was made visible. This gave more clarity to the role to be played by local governments in the planning process and service delivery arrangements, and imparted uniformity to programme implementation. The making of palliative care programmes, mandatory for local governments since 2015, gave much needed resource allocation for meeting the programmatic and human resources arrangements. The Departments of Health, Social Justice and Kudumbasree Mission are also extending the necessary support arrangements for the smooth translation of the policy guidelines into action.

Kerala demonstrates how the decentralised governance system can help needy persons to obtain the palliative care services. The services are managed through Primary Health Centres (PHC) where one female nurse is appointed exclusively for palliative care and the funding is provided by the local governments based on the proposals submitted. Palliative care services, as per the policy guidelines and practice, have become operational in the state at three levels, viz., the primary level of basic home-based care and support, the secondary level of specialty palliative care services and the tertiary level of advanced care and training and research activities.

1. *Primary Level*

Basic home-based care and support is given to the needy at the primary level. The basic steps and core components of home-based palliative care by local governments are given below:

- Formation of local government level project
- Meeting of agencies and individuals interested in the programme
- Formation of Palliative Care Project Management Committee
- Structured training for volunteers, health staff and people's representatives
- Identification of patients in need of care
- Initial home visits, assessment and documentation
- Regular home care support for the patients shortlisted.
- At least one full day home care per week accompanied by one Health Field Staff and volunteers
- Vehicle provided by Local Government
- Special Out-Patient facility conducted by the PHC Medical Officer for providing medicines, one day per week
- Support of accessory materials such as water beds, wheelchairs, commodes, etc.

2. *Secondary Level: Specialty Palliative Care Services*

Specialty palliative care services are being developed in government taluk/district/general hospitals with the following activities supported by the corresponding Local Government:

i. In-Patient Care is given utilising the existing system in the hospital. Patients with palliative care needs are admitted to various specialty wards according to their requirements. Palliative care service for the needy patients will be organised by the nurse and doctor specially trained in palliative care. Follow-up of the patients is ensured through coordination with primary level programmes.
ii. Special Out-Patient Care is conducted at least once per week by a doctor trained in palliative care for patients with palliative care needs like those who are suffering from cancer, renal disorders and patients facing problems associated with other non-communicable diseases and the elderly
iii. Specialised home care support is given for patients referred by regular home care units of local governments within the area of service.

3. *Tertiary Level: Advanced Care and Training and Research Activities*

Tertiary level care includes regular professional training activities in addition to delivery of specialist palliative care. Professional training activities includes training programmes for doctors, nurses and community nurses. Tertiary level care is given by all government Medical Colleges, the National Health Mission at district levels and General Hospitals.

District and Local Body-wise Palliative Care, 2015–2016

As per the guidelines issued by Government of Kerala, every local government should mandatorily form a project for palliative care since 2015. As indicated in Table 1, there are 1,385 palliative care units at local government level. The total number of grassroot level local governments in Kerala at the level of Grama Panchayats (941), Municipalities (87) and Corporations (6) is 1034. The total fund spent by these units is Rs.443,050,553. This means each local government had spent Rs.42,848,215 on average. Based on the number of registered patients, a single local government can have more than one palliative care unit. This has currently proved to be one of the most effective decentralised and community-based palliative care practices.

Table 1. District wise Local body type wise palliative care details during 2015–2016

District	Local body Type	Approved		Expenditure	
		No of Projects	Amount Allocated (Rs.)	No of Projects	Amount Expended (Rs.)
Thiruvananthapuram	Municipalities	5	3750000	5	3408700
Thiruvananthapuram	Corporation	2	10031710	2	2499466
Thiruvananthapuram	Grama Panchayat	93	39308095	93	36878923
Kollam	Muncipality	8	2907165	8	2684644
Kollam	Corporation	7	3636012	7	2362319
Kollam	Grama Panchayat	88	30958135	84	28335890
Pathanamthitta	Municipalities	4	3069600	4	2988950
Pathanamthitta	Grama Panchayat	62	25588823	60	23281907
Alappuzha	Municipalities	9	2945797	9	2221039
Alappuzha	Grama Panchayat	87	27994408	88	23570597
Kottayam	Muncipality	6	2773500	6	2577230
Kottayam	Grama Panchayat	93	30218902	89	24315270
Idukki	Municipalities	5	2225000	5	1768400
Idukki	Grama Panchayat	80	28192069	77	26009893
Ernakulam	Municipalities	19	8272037	18	6957617
Ernakulam	Corporation	1	588707	1	571151
Ernakulam	Grama Panchayat	103	34549123	102	31360904
Thrissur	Municipalities	11	4334600	11	4017909
Thrissur	Corporation	1	8000000	1	7713360
Thrissur	Grama Panchayat	106	38215720	103	31470250
Palakkad	Municipalities	10	4986313	10	3832446
Palakkad	Grama Panchayat	119	38770799	114	31143431
Malappuram	Municipalities	24	8873618	24	8177057
Malappuram	Grama Panchayat	147	53912307	134	44927238
Kozhikode	Municipalities	8	4155000	8	3088640
Kozhikode	Corporation	2	2110000	2	1495734
Kozhikode	Grama Panchayat	85	27479705	82	22472455
Wayanad	Municipalities	6	2117656	5	1629638
Wayanad	Grama Panchayat	34	12929176	33	10741211

Kannur	Municipalities	11	6078105	11	5315111
Kannur	Corporation	8	2627941	7	1677426
Kannur	Grama Panchayat	84	32405170	84	24449225
Kasargod	Municipalities	5	2432192	5	2274555
Kasargod	Grama Panchayat	52	21705046	50	16831967
Total		1385	528142431	1342	443050553

Palliative Care Programme in Mullurkkara Grama Panchayat

This section deals with details of the palliative care programme in Mullurkklara Grama Panchayat of Thrissir district, Kerala state. The Mullurkklara Grama Panchayat, Thrissur district initiated the palliative care programme in November 2010. One Auxiliary Nursing Midwifery (ANM) was appointed for general palliative care services, homecare visits and for special Out-Patient care. Rs.333,836 was allotted and spent by the Grama Panchayat during 2015–16 as per the project prepared by the health working group convened by the Medical Officer. This project included services like homecare visits, supply of medicines, aids and appliances, food and travel expenses of the homecare team, meeting expenses, registers, papers, and the salary of the palliative care nurse.

The Panchayat has a palliative care management committee which conducts meetings once every three months. The management committee has the following members:

- Panchayat President
- Health and Education Standing Committee Chairperson
- Welfare Standing Committee Chairperson
- Block Panchayat members representing the locality
- Two Panchayat members (1 should be a woman)
- Medical Officers (allopathic, ayurveda and homeopath)
- Panchayat Secretary
- Community Development Society (CDS) chairperson
- Two volunteers
- Health Inspector
- One Auxiliary Nursing Midwifery (ANM)

Details of Palliative Care Patients and Services Provided by the Unit

The total number of registered palliative care patients in the Grama Panchayat was 172. The majority of them belonged to the 70–90 age group. As the data shows, 60% of the patients were females. There were 12 women above the age of 90 receiving support. The number of male patients above 90 years of age receiving support was zero. Five patients were below 18 years of age.

Table 2: Age category of patients receiving palliative care

Age Category	Frequency			Percentage		
	Male	Female	Total	Male	Female	Total
0–10	1	0	1	1.47	0.00	0.58

10–18	1	3	4	1.47	2.88	2.33
18–30	5	0	5	7.35	0.00	2.91
30–50	7	7	14	10.29	6.73	8.14
50–70	27	32	59	39.71	30.77	34.30
70–90	27	50	77	39.71	48.08	44.77
Above 90	0	12	12	0.00	11.54	6.98
Total	68	104	172	100.00	100.00	100.00

Table 3. Classification of patients based on type of illness

Illness/condition	Frequency	Percentage
CVA hemiplegia	38	22.49
Old age	37	21.89
Cancer (14 types)	26	15.38
CAD (CAD+HTN, CAD+CKD)	14	8.28
Multiple issues including Meningitis and paraplegia	8	4.74
Parkinson's disease	7	4.14
Paralysis	7	4.14
Arthritis	7	4.14
Accident (fracture)	7	4.14
CP + MR	7	4.14
COPD (COPD+ HTN)	6	3.55
Chronic kidney disease on dialysis	3	1.78
Kidney failure (no dialysis)	2	1.18
Total	169	100.00

Notes: CVA Hemiplegia (Cardio Vascular Accident Hemiplegia), CAD (Coronary Artery Disease), HTN(hypertension), CKD (Chronic Kidney Disease), CP (Cerebral Palsy)+ MR (Mental Retardation), COPD (Chronic Obstructive Pulmonary Disease)

As Table 3 shows, the majority of the patients were suffering from cardio vascular accident hemiplegia, old age related disorders and cancer. Five children received services on account of physical and mental disability such as cerebral palsy with mental retardation and locomotor disability.

Monthly Care Plan for Palliative Care

As indicated by Table 4, the palliative care team provides multiple services to the patients based on needs assessment. Each patient is given an average of 2–3 services every month. Psychological support is given to almost 89 of the patients. Appliances like wheelchair tricycles, water beds, air beds, commode chairs, and walking sticks and elbow crutches are also given to patients.

Table 4: Care plan for palliative care

Care plan	Frequency	Percentage
Psychological support	150	33.70
Voluntary health care	112	25.17
Nursing heath care	60	13.49
General health care	60	13.49
Medicine support	49	11.01
Aids and equipment	14	3.14
Total	445	100.00

Nursing health care includes mouth care, catheterisation including condom catheterisation, bladder wash, wound care/dressing, tracheotomy care and physiotherapy. Voluntary health care includes hairdressing and bathing to keep the patient in a hygienic environment. In addition to local contributions, the palliative care unit of this panchayat also facilitates access to pensions and allied benefits available with local, state and central governments like aaswasakiranam, cancer suraksha, old age pensions, disability pensions, widow pensions, unmarried pensions, agricultural pensions, unemployment pensions, ashraya schemes, housing schemes, toilets, and beneficiaries under the Chief Minister's welfare scheme.

Home care Services Provided by the Unit

Out of 169 patients registered for palliative care, 36% (62) received home care support. Among them, 48% belonged to the 70–90 age group, 32% to the 50–70 age group and 7% were above 90 years of age. Of these, 65% were females and 35% males. While one can say that palliative care is beneficial to aged women, it also brings to light the fact that the high life expectancy of women in Kerala is a burden on women. The Grama Pacnhayat has 14 wards. Each ward had an average of 5–7 persons receiving home care support.

Each of the home care visit teams had a minimum of 3 persons comprising a nurse, Accredited Social Health Activists (ASHA), volunteers, a Panchayat member of the respective ward and health staff. The team conducts 8–12 home care visits every month. Home care visits were held every Tuesday, Thursday and Saturday. An average of 6–7 patients were visited daily by the team as per the need of the patients. However the team is available for emergency calls. The patients registered for home care service receive different types of services as detailed in Table 4. The nurse and the palliative care team have a good rapport with the patients and their families. In addition to medical and psychological support to the patients and family members, the bedridden ones get the chance to live in a hygienic environment.

Conclusions

The absence of social workers in the home care teams, inadequate financial resources, low service convergence and the lack of concurrent monitoring of services are seen as major gaps in the palliative care programme. There is a necessity for mainstreaming the community volunteerism to provide regular social and psychological support as well as in facilitating access to schemes and other services.

All the grassroot level local governments in Kerala *viz*., Grama Panchayats, Municipalities and Corporations are now providing palliative care to needy people which has enabled the Kerala State to secure first place in the quality of death index. Within a five-year period of intensive implementation, the programme has proved to blend professionalism with volunteerism and has proved to be a cost effective and workable public health model. The programme has also blended the visible elements of care and compassion in the public health delivery system. The programme has tested the capacity of local governments to leveraging of resources both human and financial. The programme has proved to be a good example of a bottom up approach in planning and implementation.

One of the innovative aspects of the palliative care programme is the decentralisation of health care. As delivery of palliative care services is made mandatory for local governments, there has been a significant impact in relation to the maximisation of the coverage of palliative services. The programme has also led to new lessons in convergence and networking as it collaborates with different organisations like the National Health Mission, the Kudumbasree, health departments and non-governmental organisations.

The impact of the palliative care programme is beyond quantitative measurement. The network of palliative care in the local government context alone is currently above 1,000. It is estimated that local government alone is meeting the care needs of 60 of the needy. As a result, Kerala, with 3% of national population, now has more than 90 palliative care units in the country.

References

Carlson, R., Devich, L., and Frank, R. (1988). Development of a comprehensive supportive care team for the hopelessly ill on a university hospital medical service. *The Journal of the American Medical Association, 259*(3), 378–383.

Elsayem, A.1., Swint, K., Fisch, M.J., Palmer, J.L., Reddy, S., Walker, P., Zhukovsky, D., Knight, P., and Bruera, E. (2004). Palliative care inpatient service in a comprehensive cancer center: Clinical and financial outcomes. *Journal of Clinical Oncology*, *22*(10), 2008–14.

McDermott, E., Selman, L., Wright., M., and Clark, D. (2008). Hospice and palliative care development in India: A multi-method review of services and experiences. *Journal of Pain and Symptom Management, 35*(6), 583–593.

Mohanti, B.K. (2011). Research focus in palliative care. *Indian Journal of Palliative Care, 7(Suppl)*, 8–11.

Sanoj, A.K., Biju, P.C., and Suresh Kumar, K. (2014). Five years of National Rural Health Mission Project in palliative care in Kerala. *Indian Journal of Palliative Care, 20*(1), 66–87.

WHO (2012). Cancer Pain Relief and Palliative Care. Report of WHO an Expert Committee. Geneva: WHO.

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