

2.19 Arogyakeralam Palliative Care Project: Ensuring care and support for the chronically ill & infirm in Kerala

The Arogyakeralam project is based on a unique policy issue by the Government of Kerala in 2008 with the aim of providing medical care and support to every citizen in need of palliative care. Arogyakeralam emphasises a community-based approach to healthcare and considers home-based medical care to be the cornerstone of palliative care services. As of March 2014, the project had provided primary-level palliative care to an average of 48,339 and secondary-level care to an average of 2,419 beneficiaries each month since 2008.

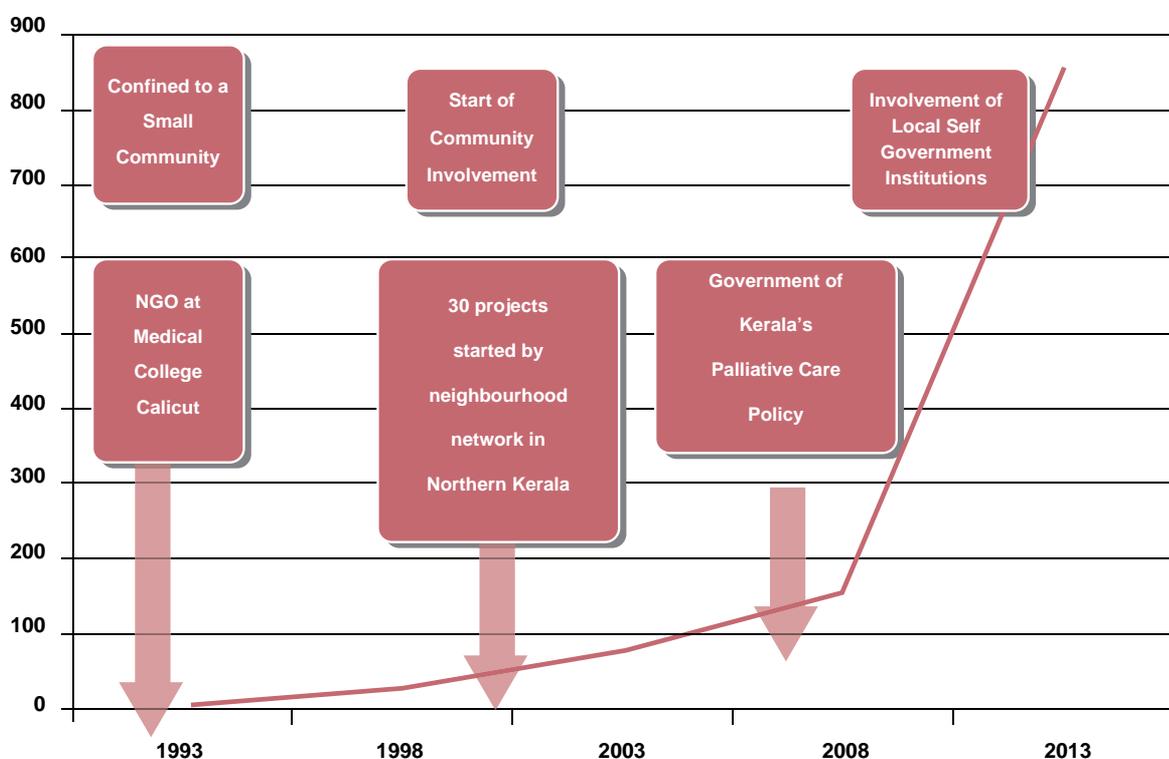
Rationale

Palliative care refers to healthcare for patients who are undergoing intense suffering as a result of their chronic medical conditions. It is a holistic approach to medical care, focussing not only on health concerns but also on the social, economic and psychological condition of a patient. Palliative care is required by cancer patients, HIV/AIDS patients, bedridden patients, paraplegics, geriatric cases, accident cases, cerebral palsy patients etc. In India, an estimated 59 lakh people are in need of such care but less than 2% are currently being catered to.¹

The first palliative care initiative in Kerala was started by an NGO in Calicut in 1993. Subsequently, four other NGOs, working in the districts of Malappuram, Wayanad and Kannur collaborated to form the Neighbourhood Network in Palliative Care (NNPC) in 1999. They provided palliative care through a network of volunteers, with the active support of the community.

Noticing the success of palliative care services supported actively by local communities, the State government instituted an official policy - Pain and Palliative Care Policy - in 2008, declaring palliative care as part of primary healthcare and facilitating the development

Figure 1: Timeline of the development of palliative care services in Kerala



Source: OneWorld Foundation India, 2014

¹ The Institute of Palliative Medicine (IPM): 'Models of Delivering Palliative and End-of-Life Care in India'. Current Opinion Support Palliative Care. 2013. 7:216-222.

Foundational awareness campaigns on palliative care by *Malayalam Manorama* and the Institute of Palliative Medicine (prior to 2008)

- ❖ The initiative was kicked off with a pro-active campaign by *Malayalam Manorama*, a popular daily newspaper in Kerala and was later upscaled by the State government as a result of unprecedented People's support that it generated.
- ❖ A five-part series text campaign comprising print advertisements was launched in the newspaper. The campaign touched on what palliative care is, success stories in the northern districts where this initiative was carried out by various community based organisations and how the public can participate in providing palliative care.
- ❖ Four helplines were established at the Institute of Palliative Medicine (IPM), Calicut; these were serviced by student volunteers who worked to channelise the vast response from the community.

Thereafter, experts from IPM and *Malayalam Manorama* arranged and conducted training sessions in all 14 districts of the state.

- ❖ A campaign website aimed at establishing an online presence was maintained by *Malayalam Manorama*.
- ❖ A 15-minute documentary was created to promote volunteering among community members, especially among those unaware of the project.
- ❖ Campus campaigns were conducted with the help of IPM.
- ❖ Stories of community volunteers, such as that of an auto driver or a teacher helping in this programme, were showcased by the newspaper to elicit more participation from the community. As a result, a lot of motivated citizens from different walks of life, including women and retired officials, came forward as volunteers. Being a large and well-known media vehicle, *Malayalam Manorama* had a huge impact on people and institutions and garnered tremendous support. The newspaper invested about Rs. 55 lakh in conducting the awareness campaign and training programmes. The conclusion of *Malayalam Manorama's* role came with the handover of the list of all volunteers to the LSGI Minister in 2008. NRHM's presence in palliative care, therefore, came about in an atmosphere of general awareness and support for the cause.



Image 1: Lymphoedema care at Nedumangadu district hospital

Source: District Hospital, Nedumangadu

of community-based homecare initiatives under the leadership of local self governments.

The policy has received high-level support from all political parties in the state and is implemented by the state National Rural Health Mission (NRHM). The Arogyakeralam palliative care project has been formulated in consonance with this policy.

Objectives

The primary objective of the Arogyakeralam project is to provide palliative care to all the patients who are in need of this service. Its larger objective under NRHM is to ensure that palliative care becomes entirely self-subsistent and community-based.

The other major objective of the project is to ensure that palliative care becomes an integral part of the state's public health system.

Key Stakeholders

The key stakeholders for the project include NRHM and the Institute of Palliative Medicine (IPM) at the State level, District Project Managers and medical personnel at district level, Panchayat ward members, community nurses, medical personnel and patients and their families at the village level.

Figure 2: Key stakeholders in the Arogyakeralam Palliative Care Project

State

- ❖ **NRHM, Kerala:** Monitoring and evaluation of the project
- ❖ **Institute of Palliative Medicine:** State Resource and Coordinating Centre that plans the implementation of the project

District

- ❖ **District Project Managers:** Coordinating and monitoring implementation of the project
- ❖ **Medical personnel:** Handle patients in palliative care units in district and general hospitals

Village

- ❖ **Nodal implementing stakeholders:** Panchayat ward members, community nurses and other medical personnel, other NGO partners
- ❖ **Beneficiaries:** Patients and their families

Implementation Strategy

After the institution of the Pain and Palliative Care Policy, even Gram Panchayats where palliative care was unknown were institutionally brought into the fold. As per the policy, Local Self Government Institutions (LSGIs) in all 14 districts of the state are required to plan and implement palliative care projects.

When the project was launched in 2008, it focussed on primary level care, involving nurse-led homecare. At least 5% of the Panchayat Plan Fund had to be allocated to this project. On their part, LSGIs took additional steps to procure external contributions to expand the project and elicit greater community participation. For example, families in Chemmarudi Panchayat (Thiruvananthapuram) decided not to consume fish for a day and instead donated the money to 11 palliative care patients. In 2013, the implementation mandate was expanded to cover the introduction of palliative care units in block (taluk), district and general hospitals.

The project provides for the delivery of free palliative care at different levels. At the primary level, homecare



Image 2: Palliative care team going to visit a patient

is given by community nurses with support from LSGIs. A homecare team, comprising trained palliative care nurses selected by LSGI, a medical officer-in-charge, local Accredited Social Health Activists (ASHAs), Junior Public Health Nurses and elected representative, visits the home of the patient at least once on fixed homecare days. The team assesses the medical, emotional and financial situation of the patient. Accordingly, medicines are given and visits, including for emotional counseling, are scheduled. Family members are also given advice on the basic care of bedridden patients.

In special cases, for example, as in the case of lymphoedema (a condition of localised fluid retention as in the case of cancer patients) or need for physiotherapy support, the homecare team refers patients for secondary-level care, which is provided at taluk, district and general hospitals. Palliative Care Units (PCUs) run an Out-Patient Department (OPD) at health facilities, where the assigned doctors and nurses support and monitor the condition of the patient.

At the tertiary level, training is given to healthcare workers such as Junior Public Health Nurses, ASHAs and Auxiliary Nurse Midwives (ANMs) at the district level. The training is given by a palliative care doctor, district-level palliative care coordinator, staff nurses and a physiotherapist. The training programmes include six-week courses for doctors and nurses; three-month courses for community nurses; 10-day foundation courses for doctors; foundation courses in palliative care for Ayurveda doctors; one month's basic course in community-based interventions in palliative care and long-term care for ASHAs; and short courses for healthcare workers.

Monitoring and evaluation of the project is undertaken and regular review meetings are conducted by NRHM and the State Resource and Coordinating Centre at the state level. At the district level, registers on the following components are documented and maintained by the

People speak...

Chandran, homecare patient, Kilimanoor, Thiruvananthapuram



“My medical problem is the lack of strength in my hands and the inability to walk without support. However, I can stand and move to a certain extent with the help of the walker provided by the PHC. The Palliative Care team

has been visiting me once a month for the past two to two-and-half years. The nurse changes the catheter each time I call when I have any difficulty. Medicines that would have otherwise cost approximately Rs. 1,900-2,000 are given to me free of cost.”

Aliyar Kunhu, homecare patient, Kilimanoor, Thiruvananthapuram



“I was diagnosed with multiple myeloma four years ago, and began to receive palliative care in 2011 after treatment at Trivandrum Medical College. The

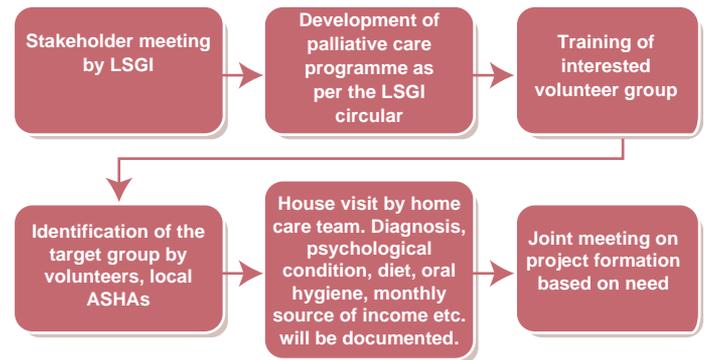
medicines provided by the team cost approximately Rs. 3,000 per month. Since we have financial difficulties, we would have been unable to continue the appropriate medical care without support. My wife is the main person in the house who helps me throughout the day. She has been given advice on my treatment by the homecare nurses.”

Vellarada Panchayat members, Thiruvananthapuram

“We began palliative care in June 2012 and have 59 patients under the programme. A hired vehicle has been made available for homecare visits. We have distributed wheelchairs, waterbeds and walkers. On special occasions such as Christmas and Onam, we give care packages of rice/oats to the needy families.”

staff at PCUs²: monthly review meetings, appliances, stock and sub-stock, follow-up, homecare report, special outpatient (OP) attendance and OP registers.

Figure 3: Process flow for delivering Palliative Care in Kerala



Source: The Institute of Palliative Medicine (IPM)

Resources Utilised

Basic implementation of the Arogyakeralam palliative care project is done using the existing healthcare infrastructure. Additional infrastructure, in the form of OPDs, has been set up for secondary-level care, where existing facilities are not sufficient. At both primary and secondary levels, a medical kit is assembled by the healthcare staff for use during patient visits. In some cases, LSGIs also arrange a vehicle exclusively for palliative care services. The cost of monitoring and training is borne by the State government.

Funds for expenditure, primarily on medicines, nurses salaries, transport and additional provisions like walkers and waterbeds, are allocated from every Panchayat’s Plan Fund and from external contributions by community members. The collection of funds and their use depends upon the enterprising nature and strategy adopted by the respective Panchayats. For example, the Kilimanoor Panchayat collected Rs. 50,000 in its first year, Rs. 5 lakh in the second year and Rs. 7 lakh in the third year. Given the availability of funds, this Panchayat is now considering expansion of the project to include an SMS feature in services.

The local ASHAs, who identify patients for palliative care in a Panchayat, are incentivised by being given Rs. 100 for every first visit to a patient’s home. Also, the Junior Public Health Nurse (JPHN)/community nurses who are part of the homecare team receive approximately Rs. 6,000 per month as honorarium. Government doctors are first inducted into the project by the LSGI and later called upon for palliative care services based on patients’ needs.

² About 97% units maintained nominal register, follow-up register and homecare register. State Resource Centre in Palliative Care, Institute of Palliative Medicine, WHO Collaborating Center for Community Participation in Palliative Care and Long Term Care. ‘Evaluation of Local Self Government Institutions based Home Care in Kerala’. September 2013.

Impact

Healthcare to those with chronic illnesses: The Arogyakeralam project is making a big difference in the lives of many bedridden people with chronic illness or old age infirmity. As of March 2014, the project had provided primary-level palliative care to an average of 48,339 beneficiaries each month and secondary-level care to an average of 2,419 beneficiaries each month. Details of state-wide coverage are presented in *Table 1*. Findings from an evaluation study³ of the project offer evidence of the positive impact it has had, which are highlighted in *Table 2*.

Table 1: State-wide coverage (as of March 2014)

Indicators	Numbers
Average number of patients under primary care every month	48,339
Average number of patients under secondary care every month	2,419
Number of LSGIs currently implementing PC in Kerala	875 (out of 1,000)
Number of Palliative Care Units in selected major hospitals in each district	74
Number of Training Centres (adopted from one of the above PCUs in each district)	15

Source: OneWorld Foundation India, 2014

Table 2: Evaluation Study Findings (September 2013)⁴

Indicators	Response (in %)
Reduction in treatment-related expenses	86% reported reduction
Patients' opinion about palliative care	51.9% very satisfied, 46.6% satisfied, 0.1% dissatisfied and 1.3% no comments
Carer's ability to cope	93% reported better ability to cope
Change in overall quality of life of patient	93% responded little better/much better

Source: OneWorld Foundation India, 2014

³ *Ibid.*

⁴ State Resource Centre in Palliative Care, Institute of Palliative Medicine, WHO Collaborating Centre for Community Participation in Palliative Care and Long Term Care. 'Evaluation of Local Self Government Institutions based Home Care in Kerala'. September 2013.

⁵ *Ibid.*

Additional services: Following the success of the palliative care project, additional services and programmes have been launched for this beneficiary segment. Vocational rehabilitation programmes were started in 2013 in all the districts to engage them in simple activities like making paper bags and umbrellas. The purpose is to offer a way out of emotional distress, enable them to earn some money and become meaningfully engaged. The programmes, still being firmed up, are run by local Panchayats. In 2013, the State government started another initiative – the DISHA helpline (toll-free # 1056) – to complement the emotional counselling services offered by the palliative care project.

Key Challenges

Awareness about palliative care is critical to the success of such a project. This posed a challenge as palliative care was almost unknown in the southern districts of Kerala as compared to the northern districts where the project was started by various community-based organisations. The awareness campaign by *Malayalam Manorama* and IPM, which was carried out in 2006-08, played an important role in garnering community attention and support for palliative care. At least two-three training sessions were also conducted for healthcare staff in every district to attend to the immense demand from communities and in shaping up the project across the state.

The retention of doctors continues to pose a challenge. Doctors in PHCs are subject to transfers and postings, which requires LSGIs to induct new doctors into the project. The nature of the project is such that the motivation of the doctors and their conviction in its utility is critical in ensuring the quality of services provided. The induction of the doctors in the philosophy and functioning of the project may take time. At times, such situations cause differences between the LSGIs and the Directorate of Health Services, affecting the smooth functioning of the project.

Addressing the issues arising out of integration and coordination between public sector facilities and NGOs poses more challenges. Additionally, sometimes there are differences between government entities and NGOs who run a number of palliative care services, which take time to resolve.

The availability of quality kits and other services are also issues that need attention. Only 36% of the patients have homecare kits that meet the guidelines, and only 6% have been offered rehabilitation services.⁵

Replicability and Sustainability

Sustainability of the palliative care project is high because of the support it has received from both higher echelons of power as well as the grassroots. Government policy has facilitated scaling up of the project and the participation of the community in delivering palliative care. However, reliance on community participation also means that there may be pockets that are not as active/ participative as expected. This is where facilitation by the government becomes essential. Financially, the communities have been able to access sufficient funds from the Plan Fund and from external contributions.

Factors for replication that must be focussed upon and strengthened include active community participation; smooth integration into the government healthcare system and continuous follow ups; adequate medical infrastructure comprising well-functioning PHCs and well-equipped staff of community nurses; capacity building of medical staff at primary, secondary and tertiary levels; high level of commitment, especially among health workers like ASHAs; coordinated effort at the government level; and efficient streamlining of drug procurement.

While palliative care is practised in different forms across the world, the Kerala model is being replicated on a smaller scale in Tamil Nadu and Pondicherry, and internationally in Bangladesh, Thailand and Sri Lanka by IPM. Based on their knowledge, a few Keralites have also set up the Delhi Institute of Palliative Medicine in New Delhi. The Kerala Police has also supported the project by training one police officer from each station under the Janamaithri programme for providing palliative care services.

Conclusion

Palliative care is an important area that remains to be integrated into the Indian healthcare system. The National Palliative Care Policy that is currently being drafted must take into consideration the lessons learnt so far in the state of Kerala. The Arogyakeralam project has been widely appreciated and represents a viable model for providing palliative care. As Richard Smith, Editor, *British Medical Journal* (June 2011), put it: "The Kerala model does provide a feasible way of achieving the vision of palliative care covering all patients, all diseases, all nations, all settings, and all dimensions. It's hard to see how it will be achieved in another way."

Fact Sheet

Theme	Health
Nodal Implementing Agency	National Rural Health Mission, Kerala, and Local Self-Government Institutions
Geographical Coverage	All districts of Kerala State
Target Groups	General population
Years of Implementation	2008 - Present