



# Models of delivering palliative and end-of-life care in India

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## Purpose of review

India is home to one-fifth of the global population. This review aims to explore the structures, functions and relevance of palliative care services in India. Although palliative care has been initiated in India almost 3 decades ago, development of services has been patchy and inadequate. Some of the regions are well covered, but most are not. The Indian palliative care scene, with its diversity in approach and delivery of services, can offer valuable lessons to service development in low-income and middle-income countries.

## Recent findings

The number of people dying each year in India is more than 9.8 million. The number of people in need of palliative care will be around six million if we assume that 60% of all those who die would benefit from palliative care. Less than 2% of the needy have access to palliative care in India. The available services are very unevenly distributed with the state of Kerala with 3% of the country's population having more than 90% of the palliative care services in the country.

## Summary

The state of palliative care in India is discussed with particular attention to the successful Kerala Model in palliative care. Lessons learned from the experiment in Kerala are listed.

## Keywords

community participation, palliative care, public health

## INTRODUCTION

India is home to one-fifth of the global population. With a crude death rate of 8.2 per 1000, the number of people dying each year in India is more than 9.8 million. Noncommunicable diseases (NCDs), mainly cardiovascular diseases, respiratory diseases and cancer, account for more than half of these deaths in India. Like the rest of the world, NCDs are on the rise within the country. In terms of the number of lives lost because of ill health, disability and early death (disability-adjusted life years, NCDs (inclusive of injuries) accounts for 62% of the total disease burden, whereas 38% is from communicable diseases, maternal and child health and nutrition all combined. The total number of people in need of palliative care in the country is estimated to be more than 5.9 million.

There has been a steady rise in the percentage of elderly population in the total population over the decades. According to official population projections, the number of elderly persons will rise to approximately 140 million (approximately 10% of the population) by 2021 [1<sup>•</sup>]. NCDs largely affect middle-age and older populations, the groups

growing the fastest. About 64 per 1000 people ages above 60 in rural areas and 55 per 1000 in urban areas suffer from one or more long-term disabilities. The highest number of patients needing palliative care in the future will come from the terminally ill elderly people.

Seven out of every 10 Indians live in rural areas, which are served by about 2% of qualified medical doctors [2<sup>•</sup>] Despite efforts for almost three decades from various corners, palliative care services are nonexistent or minimally developed in most regions of the country. Although there are places where excellent palliative care is offered to a lucky few, less than 2% of those needing palliative care in the country receive it. The public health system

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## KEY POINTS

- Establishment of a sustainable public health model in palliative care by Kerala has effectively proved that it is possible to achieve good quality and coverage in palliative care even in low-income and middle-income countries.
- A clear national policy for palliative care, which can accommodate civil society and local government initiatives, can be a major step in this direction.
- Regulations for prescription of opioids are to be reviewed in many regions so that it will be easy to prescribe morphine for all appropriately trained doctors, enabling pain relief to be incorporated in the primary healthcare system.
- Advocacy and education of the politicians, social activists, healthcare professionals and the public are essential to ensure the success of the initiative.

units, spread from the village level up to the state level, have not started to focus attention on appropriate care of the incurably ill, chronically bedridden or dying patients except in the southern state of Kerala. Kerala is the one state that has a government policy that supports provision of palliative care through the public health system as discussed further below.

Available data on total amount of morphine released by the government alkaloid factory to palliative care units and pharmaceutical companies show that the consumption of morphine in India is very low. According to one estimate, more than seven million people with life-limiting illnesses need pain relief in India each year [3] Only a very small percentage of the needy have access to good pain relief, though opioids morphine sulphate and codeine phosphate are listed in the National List of Essential Medicines of India, 2011, compiled by the Ministry of Health of Health and Family Welfare, government of India. Procurement and distribution of morphine and other opioid analgesics are affected by the licensing requirements under the present Narcotic Drugs and Psychotropic Substances (NDPS) Act [4]. In its original form, NDPS Act makes it mandatory for palliative care units to acquire multiple licenses from different agencies. More than half of the states and union territories have modified NDPS Act to make medical use of opioids easier. Access to opioid analgesics for patients has not improved much even in many of these states, as morphine availability without bedside training in pain relief and palliative care or education of the doctors has been proved to be ineffective.

It is felt that the awareness regarding the scope of palliative care and pain relief is low among professionals as well as the public. Most patients in India with moderate-to-severe pain from life-limiting diseases are unaware that there are effective medications for her/his pain and that it may be relieved. The situation, again, is different in the South Indian state of Kerala as explained below.

## HISTORY

The first formal palliative care service in India was initiated in 1986 as a hospice in Mumbai [5]. Pain clinics offering outpatient services were in existence in some of the cancer centers since late 1980s [6]. From the 1990s onwards, there was a significant increase in the momentum of development of hospice and palliative care provision. This was demonstrated through both an expansion in the number of services as well as other key events and initiatives. Pain and Palliative Care Society, a civil society organization, initiated an outpatient palliative care clinic and home care services in Calicut (Kerala) in 1993. Another NGO, CanSupport, founded in 1997 in Delhi started providing the first free palliative care home care support service in North India. Cipla Cancer Palliative Care Center was established in Pune, Maharashtra, (Central India). Four nongovernment organizations (NGOs) in Kerala joined together in 1999 to launch Neighborhood Network in Palliative Care (NNPC), a major community-owned initiative in palliative care [7]. NNPC continued to grow to become an extensive network covering most of Kerala. The government of Kerala took a major step to support development of palliative care by declaring palliative care as part of Primary Healthcare in the state through an official government policy in 2008. Indian Association of palliative Care, the umbrella organization for palliative care in the country, was formed in 1994 in consultation with World Health Organization and government of India.

There are several nonprofit NGOs that have palliative care as their primary mandate. Most NGOs providing for care are run by volunteers, with resources from charities, national/international funding agencies and other NGOs, and in some instances, through payments from patients. Institute of Palliative Medicine in Calicut (Kerala) was designated in 2010 as the first WHO collaborating center in palliative care in low-income and middle-income countries. This was followed an year later by designation of another palliative care center in the state as WHO Collaborating Center for Training and Policy on Access to Pain Relief

## DELIVERY OF PALLIATIVE CARE

There are less than 1000 palliative care units in India. Less than 10 of them are conventional hospices. The distribution of services, quality and access to care differs. Over 90% of all palliative care programs in the country are available in the state of Kerala with 3% of the country's population. There are few states in the country without a single center for palliative care service provision. It is estimated that less than 2% of patients in need of palliative care in the country receive it.

A study on 'quality of death' was carried out by Economist Intelligence Unit of 'The Economist in 2010 covering 40 countries, ranks India the last, below Mexico, Brazil, Uganda, among others [8<sup>11</sup>]. By the time the disease is pronounced to be incurable, most of the patients would have already spent a huge amount of money for treatment. In the absence of an accessible palliative care system to guide and treat the patients, most of them get drawn to inappropriate, futile and expensive treatments like futile chemotherapy, 'miracle cures', inappropriate hospitalizations and so on leading to further harm including financial liabilities. Lack of palliative care facilities lead to improper use of scarce resources meant for curative therapy and also blockage of hospital beds.

Local and state governments play a major role in running palliative care services in Kerala. In most of the other regions, services are managed by NGOs.

## TRAINING PROGRAMS

The on-going training programs in palliative care the country are:

- (1) Postgraduate degree courses in palliative care – currently only in Tata Memorial Hospital, Mumbai
- (2) One-year residential fellowship program – Christian Medical College, Vellore (Tamil Nadu), Kidwai Memorial Institute of Oncology, Bangalore (Karnataka) and Tata Memorial Hospital, Mumbai (Maharashtra)
- (3) One-year distance education fellowship program – Institute of Palliative Medicine, Calicut (Kerala)
- (4) Eight-week certificate course in essentials of palliative care by the Indian Association of Palliative Care with an optional clinical placement component happening simultaneously at 30 centers across India
- (5) Six-week and 4-week residential training programs for doctors and nurses at the WHO collaborating centers, Calicut and Thiruvananthapuram, Institute of Palliative Care, Trissur,

Kerala, District Hospital, Ernakulam (Kerala) and MNJ Institute of Oncology, Hyderabad.

First three training programs mentioned are for Doctors. Programs 4 and 5 are for doctors and nurses.

## KERALA MODEL

The state of Kerala has managed to develop an integrated health service delivery model with community participation in palliative care. The evolving palliative care system in Kerala tries to address the problems of the incurably ill, bedridden and dying patients irrespective of the diagnosis. It is also expanding to areas of community psychiatry and social rehabilitation of the chronically ill. The primary healthcare system in Kerala plays a major role in these activities. The 'Quality of Death' study by Economist Intelligence Unit states that 'Amid the lamentably poor access to palliative care across India, the southern state of Kerala stands out as a beacon of hope.' Although India ranks at the bottom of the index in overall score, and performs badly on many indicators, Kerala, if measured on the same points, would buck the trend. With only 3% of India's population, the tiny state provides two-thirds of India's palliative care services [8<sup>11</sup>].

This model is discussed in detail in view of its relevance and implications in other low-income and middle-income countries.

The main components of Kerala's program are:

- (1) Community mobilization and ownership by the local community
- (2) Involvement of the local self-government institutions (LSGIs)
- (3) Incorporation of palliative care in the primary healthcare system

The major player in development of this public health model in palliative care in Kerala has been LSGIs in the state.

## EVOLUTION OF THE MODEL

Formal attempt to provide palliative care for the needy in Kerala was initiated by a civil society organization in Calicut in early 1990s. This approach, even though led by committed doctors and social workers, could expand to only 30 projects by the year 2000. After great deal of discussion and analysis, it was decided by a group of people involved that a paradigm shift is necessary by involving the community. With this objective, NNPC, a concept of wider and deeper participation

by the community, was floated. Community initiatives in line with within the conceptual framework NNPC started getting established in northern part of Kerala. Though the services expanded, it was still too local and suffered for want of resources and want of effective political leadership. Long-term sustainability and institutionalization of the program without losing its spontaneity were also major challenges. It was at this point of time in 2007 that attempts at the second paradigm shift in palliative care in Kerala took place by getting the local governments involved in the initiative. Efforts in this direction received a major boost through a media campaign by the most popular newspaper in Kerala, a policy decision by government of Kerala and the subsequent palliative care project by National Rural Health Mission (NRHM) in Kerala to implement the policy.

### COMMUNITY PARTICIPATION IN PALLIATIVE CARE

The main strategy in palliative care in Kerala has been to encourage local people to address the social needs of patients and families, train community volunteers to offer emotional support, facilitate the development of locally sustainable home care programs and to establish a network of nurses and doctors with expertise in palliative care to support these initiatives. The program has been very popular with the community.

Community volunteers in palliative care have been responsible for setting up most of the existing palliative care units in civil society sector in Kerala. The trained volunteers:

- (1) help in identifying need and in initiating and running palliative care units in their locality,
- (2) visit patients at home (both with the home care unit and on their own),
- (3) help at the outpatient clinic (keeping the patients comfortable, talking to them, helping with clerking, and so on),
- (4) do administrative work (including clerical work and account keeping),
- (5) raise funds for the unit, and
- (6) mobilize support for the patients from the various governmental and nongovernmental agencies.

Most patients are visited at home by community volunteers. In addition, the palliative care units linked with community initiatives offer regular nurse-led home care services, supplemented by home visits by trained nurses and doctors. Services

offered by outpatient clinics and professional home care units include medical consultations, medicines, procedures like tapping of ascetic fluids and wound care.

In addition to the medical and nursing services offered, the palliative care units in the community also offer:

- (1) Regular supply of food for the starving families. This usually comes as a weekly supply of rice and other items collected from individuals and shops in the neighborhood. 'Rice for the family' has become an important component of total care for patients in the region as a good percentage of families are financially broken by the cost of prolonged treatment by the time the patient registers with the palliative care unit.
- (2) Support for children from families of poor patients to continue their education. The support is mainly in the form of books, uniforms and umbrellas at the time of opening of the school. Students tend to drop out at the beginning of academic year because the parents are not able to afford the one-time expenses on books and uniforms. Intervention by the palliative care units at that point keeps them going. Also, some students are being supported for their university education.
- (3) Transport facilities to referral hospitals. In most situations, this is in the form of a vehicle offered free of charge for a follow-up visit/admission to the Medical College hospital or for an admission to the Institute of Palliative Medicine. The trip otherwise would have cost the family a month's income.
- (4) Rehabilitation. There is a regular attempt to encourage/train/support patients/family members in income-generating activities. The programs include support/training in making handicrafts, paper bags/envelopes and so on, and support in rearing chicken, keeping cattle and setting up small shops. Training workshops are organized for patients and family members.
- (5) Financial support. Most units provide finances to very poor patients in emergency situations.
- (6) Community volunteers trained in psychosocial support interacting with patients and family to offer emotional support.
- (7) Community-based programs try to link their patients with local, social or religious organizations supporting the marginalized.
- (8) They also link the patient with local government to identify benefits from government schemes. These include support for the destitute, electricity connection to homes of cancer

patients, pension for cancer patients and so on [9].

### **MEDIA CAMPAIGN TO FACILITATE COMMUNITY PARTICIPATION IN PALLIATIVE CARE**

Media has been supportive of palliative care all the time. But a major target-oriented project in this area was by Malayala Manorama, the largest circulating regional newspaper in India. In April 2008, a large-scale awareness and training campaign was launched in Kerala in collaboration with Institute of Palliative Medicine. The aim of the campaign was to create mass awareness about palliative care in Kerala, particularly of the role that communities play in developing palliative care services for the needy in their communities.

District-level awareness seminars and training classes for the new volunteers have been conducted throughout Kerala as part of the campaign. The list of 3000 volunteers completing the formal volunteers training was handed over to the Minister of Local Government Department for follow-up [10]. Malayala Manorama campaign has been instrumental in reaching out to new groups and regions, previously not involved in palliative care and generating an awareness and level of interest not seen before.

### **LOCAL SELF-GOVERNMENT INSTITUTIONS IN KERALA**

It was in 1997 that the nationally acclaimed Peoples Plan campaign was launched in Kerala, which resulted in the empowerment of local governments – politically, administratively, financially and developmentally. Nearly 30% of the state plan came to be prepared by the local governments with nearly three quarters of this amount being handled by cutting-edge local governments, both rural and urban. A highly participatory planning methodology was put in place providing space for local needs to be factored in and local expertise to flow into.

Powerful and active local governments and the widespread community-based organizations found palliative care as a social priority to be addressed. Thus, planning and implementation of palliative care became part of the local development efforts of the Panchayath Raj and Nagarpalika institutions. This resulted in a remarkable scaling up of palliative care activities and in sustainably institutionalizing it in a short period of time. Facilitation of this process was by the Palliative Care Project by NRHM in Kerala working within a

framework set by government of Kerala's Pain and Palliative Care Policy.

### **GOVERNMENT OF KERALA'S PALLIATIVE CARE POLICY**

In 2008, the Government of Kerala declared a pain and palliative care policy highlighting the concept of community based care and giving guidelines for the development of services with community participation for the incurably ill and bedridden patients. The generation of this document was the result of a series of discussions between the government and the various initiatives in palliative care in the state [11].

The central purpose of the new policy was to cover as many needy as possible. The core themes of this policy were home-based care, palliative care as part of general healthcare and adequate orientation of available manpower and existing institutions in the healthcare field. The government specified that it aimed to work in harmony with community-based organizations (CBOs) and NGOs, which had acquired training in delivery of palliative care. In practical terms, it aimed to mobilize volunteers, providing them with training in palliative care, thus empowering them to work with the healthcare system. The policy also aimed at facilitating engagement from the LSGIs in development of home-based palliative care programs. The policy aimed to provide community-based palliative care programs with home care services available to most of the needy in the state with active participation of CBOs, NGOs and local healthcare programs, and to develop common bodies/platforms in LSGIs to coordinate the activities of these agencies.

The policy asserts that 'the three-tier governance system in Kerala, in which healthcare institutions up to the district level are transferred to the LSGIs, gives good opportunity for them to facilitate the development of pain and palliative care services through the existing network of institutions in co-ordination with community-based organizations and community in general'. The government policy advocated a three-level healthcare system for efficient and effective service delivery.

### **PROCESS ENGINEERING – NATIONAL RURAL HEALTH MISSION PALLIATIVE CARE PROJECT IN KERALA**

NRHM Palliative Care Project was initiated by NRHM (Kerala) in 2008 with the aim of facilitation of development of a public health model in palliative care in Kerala in line with the Palliative Care policy of government of Kerala. The project has

been trying to establish the primary, secondary and tertiary care facilities for all the bedridden, incurably ill and dying patients in Kerala (estimated to be 125 000 at any point of time) with community participation.

### **LOCAL SELF-GOVERNMENT-LED HOME-BASED PALLIATIVE CARE PROGRAM**

As per the government policy, the Department of Local Self-government got palliative care included in the decentralized system and helped taking it to the whole of the state with the support of NRHM project.

Local governments have a fully functional system of reaching out to every deserving individual and providing a package of assured care services. Participation of local governments in delivery of palliative care services has resulted in coverage of about 70% of the needy the state in collaboration with civil society organizations. Local government projects in palliative care cover 60% of the state on their own. The coverage is the best anywhere in low-income and middle-income countries and comparable with coverage in any high-income country.

The combination of economic, social, psychological and medical approaches has ensured all-round care of the patients and support to their families, thereby increasing the quality of life and also the quality of death. The efficiency is increased by volunteerism and community involvement. This has facilitated home-based care, which otherwise would have been costly. The clear care and treatment protocols and the rational hierarchy of service provision have contributed to both efficiency and effectiveness. Capacity building with focus on attitudinal changes has further improved the project performance. The high local political priority of the program and its social acceptability and feasibility has helped to pool in other resources – human and financial – to contribute to efficiency.

### **INSTITUTIONAL MECHANISMS**

The guidelines for the implementation of pain and palliative care policy were given by the Directorate of health services through a circular on 29 July 2009. This gave a concrete idea about the role of staff and institutions in the government health system, so that effective healthcare may be achieved. It instructed the inclusion of palliative care review in general primary healthcare administration.

Further, it got fully institutionalized with the exclusive circular on palliative care issued by the Department of Local-self Government on 2 November 2009 [12], a culmination of its efforts

to canvas the active involvement of Local Governments. This gave more clarity to the role played by local governments in planning process and service delivery. It imparted uniformity to the local governments' programs.

Local governments are responsible for planning, implementation and review. They co-ordinate all the stakeholders and ensure public participation. Their ownership is the most critical element in the success of the initiative. The district governments monitor the program. Department of local-self government, at the apex level, plays the most critical and pivotal role in the initiative. It integrates the program into the decentralized development process by issuing suitable instructions. It motivates local governments to join and sort out all operational issues. But for its continuing activist role of co-ordination and guidance, the scheme could not have achieved the scale and momentum, which are there now.

### **SENSITIVE DELIVERY OF CARE**

Home care units have revolutionized the health-care system of the state. It helps to provide target-specific care with greater understanding of the circumstances.

Institution-based palliative care mostly overlooks the home condition of the patient, whereas the home care programs involve not only the family members but also a strata of compassionate community members. The local governments provide a common platform for their interaction and co-ordination. The central idea of this innovative healthcare model is home care units lead by trained health professionals and supported by volunteers. The efficient implementation of palliative care programs may be attributed to the flexibility of the organization setup and the ability to tailor patient-specific programs through participation of all the stakeholders. The local governments play the lead role in planning process by providing a common platform for different stakeholders. The local governments take initiative for organizing home care units, starting with the formation of a project management committee for planning and co-ordination.

### **FACTORS CONTRIBUTING TO SUCCESS OF THE MODEL**

The following factors seem to have contributed to the success of the program:

- (1) Improved awareness among general public as a result of efforts by various civil society

organizations in the field, regular support by the media and sensitization programs by NRHM.

- (2) High-level policy recognition resulting from awareness at the political level.
- (3) State funding for palliative care through NRHM, Ministry of Health and local self-government.
- (4) NRHM's innovative project in Palliative Care with the agency acting as facilitator, coordinating different governmental and nongovernmental agencies and working with a broad vision and long-term commitment.
- (5) Decentralized system of Governance in Kerala.
- (6) Home care with nurse as the lead helped in taking the care from institutions to patient's homes and also in better utilization of nurses as healthcare professionals.

The Kerala model may offer solutions to many of the issues in palliative care in low-income and middle-income countries.

## CONCLUSION

Palliative care services are poorly developed in India, the second most populous country in the World. Barriers exist at various levels like in most of the other low-income and middle-income countries. At the same time, the South Indian state of Kerala has managed to develop a unique public health model in palliative care, which looks very promising.

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## Conflicts of interest

*The author has been involved in developing palliative care services in many states including Kerala. The author has also advised Government of Kerala on issues related to palliative care in the state and been involved in the National Rural Health Mission Project in Palliative Care*

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## REFERENCES AND RECOMMENDED READING

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- of special interest
- of outstanding interest

Additional references related to this topic can also be found in the Current World Literature section in this issue (p. 242).

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