

B. Neighbourhood Network in Palliative Care (NNPC)-Kerala, India ^{122 123}

The Neighbourhood Network in Palliative Care (NNPC) in Kerala, India has won the World Health Organisation (WHO) recognition as an exemplary model for community-led palliative care programs.

Kerala's experience demonstrates the implementation of a public health approach to palliative care, within a community-led operational structure supported by health system. This was achieved by means of:

- **Community mobilization and participation**- Identifying partners in the community to sets a common agenda and implement it through joint plans of action
- **Capacity development** - training and education of:
 - health care professionals,
 - community leaders,
 - community volunteers,
 - family caregivers.
- **Public awareness and promotion of palliative care.**

This section describes how palliative care in Kerala, India has evolved over the past 14 years to create a compassionate society accountable for the wellbeing its terminally ill citizens.

NNPC Philosophy

The Neighbourhood Network in Palliative Care (NNPC) was established in 2001 based on the notion that “there is enough social capital available in the community to build a ‘care net’ readily accessible and available to the terminally ill patients, who are in continuous need for social, psychological and spiritual support in addition to the medical and nursing care.”

The objectives of the Neighbourhood Network in Palliative Care (NNPC) were to:

- Engage and empower the local community to look after terminally ill patients;
- Develop a cost-effective method for the provision of palliative care in a community-based setting.

NNPC Structure:

- A network of trained volunteers in the community
- Community-based palliative care centres
- A support system of trained health care professionals and palliative care institutions

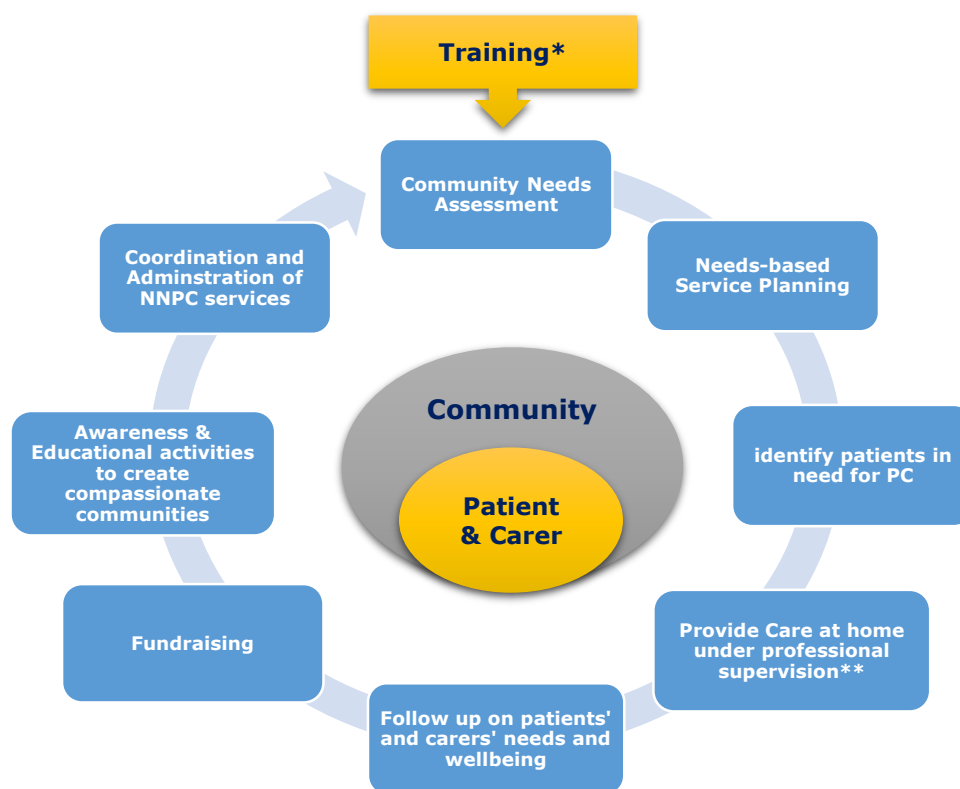
¹²² Sallnow L, Chenganakkattil S. The role of religious, social and political groups in palliative care in Northern Kerala. Indian J Palliat Care 2005;11:10-4

¹²³ Kumar S. Kerala, India: A Regional Community-Based Palliative Care Model. J Pain Symptom Manage 2007;33(5): 623-27

NNPC Operating Model

- Recruit people who can spare at least 2 hours per week to care for the sick in their community neighbourhood and enrol them in structured training,
- On successful completion of training, the volunteers form groups of 10–15 volunteers per community (NNPC groups),
- The NNPC groups work closely with existing palliative care facilities in their areas (see Figure 10 for the group’s typical activities),
- After gaining enough experience, the groups may set up and run palliative care centres.

Figure 11 Kerala’s Experience: Typical activities of NNPC volunteer groups



*Training: 16 hours of interactive theory plus 4 days of clinical practice under supervision, with an evaluation at the end of the training.

**Care: is provided under professional guidance and support from trained primary care doctors and nurses, addresses patient’s financial problems, emotional, spiritual and social needs, may include basic medical care such as: bed sore prevention and mobility.

NNPC Approach

The NNPC engaged already existing local volunteer groups providing palliative care in their communities. Examples provided below:

Not-for-profit organizations- Examples.

- A large state-sponsored not for profit women's organization, working in health awareness and poverty reduction.
- Aspire, a support group for people affected by quadriplegia and paraplegia.
- National Literacy Movement, volunteers from the Literacy Movement help with fundraising, administration tasks, and community needs assessment studies.
- Other groups: local libraries, sports and arts clubs, political parties- *examples*:
 - The Bankmen's club is heavily involved in fundraising and many of its retired members volunteer in NNPC.
 - The Forest Protective Staff Association took the initiative of planting trees around the Institute of Palliative Medicine (IPM) in Calicut and maintaining its gardens. After seeing the work carried out at the IPM, many of the members became NNPC volunteers.

Religious groups Various religious groups/organizations (Hindu/Muslim/Christian) in Kerala play a pivotal active role in raising public awareness, fundraising, and recruiting new volunteers and running clinics and inpatient centres. Religious-based groups helped palliative care to make inroads into the tribal population.

University students. The 'Palliative Care in Campus' initiative" is the outcome of a formal collaboration between NNPC and the National Social Scheme (a community-service-promoting organization). The student led initiative provides training to students, coordinates NNPC activities on campus and raises funds.

NNPC Achievements ¹²⁴**1. Palliative care in Kerala has become a social movement.**

- A regional Palliative Care Day marked on 15 January every year
- The media endorses the movement. The largest circulating newspaper in India with an estimated readership of over 9 million, ran an **award winning campaign** for 3 months entitled "**We are with you**"- over 100,000 people participated in it.
- Palliative care has become a politically attractive topic for politicians.

2. Maximized access to good palliative care by:

- Increasing availability of care. In 2010, NNPC has grown into a huge network of **230 palliative clinics** caring for around 25,000 patients at any point in time. In some districts this translates to **coverage of over 60%** of those in need of care. Most of the care is delivered in the home.

¹²⁴ Sallnow L, Kumar S, Numpeli M. Home-based palliative care in Kerala, India: the Neighbourhood Network in Palliative Care. *Progress in Palliative Care* 2010;18(1): 14-17

- Providing a holistic type of care by addressing the medical and non-medical needs of patients and families.
- Providing care that is free to patients at all care setting.
- Linking chronic/terminally ill patients to the centres in their community;
- Reaching inaccessible populations through religious groups;

Community-based palliative care (NNPC) in Kerala Workforce	2010
Full time doctors(<i>n</i>)	85
Nurses (<i>n</i>)	350
Trained volunteers (<i>n</i>)	>10,000
Patients	
Patients care for at any point of time (<i>n</i>)	25,000
Cancer patients (%)	30%
Terminal non-cancer patients (%)	50%
HIV/elderly (%)	20%
Coverage of patients in need for palliative care (%)	>60%

3. **Reduced unnecessary hospital admissions and ER visits** by providing good care to the terminally ill patients in their own homes.
4. **Created a compassionate caring society with empowered individuals** (in terms of knowledge, skills and confidence).
5. **Enhanced social capital** by pooling and efficiently using the community's resources
6. **Created social pressure that prompted structural changes such as policy and service reorientation:**
 - Pain and Palliative Care Policy –issued by the Government of Kerala in 2008. The policy emphasizes a community-based approach to palliative care and highlights the need to integrate palliative care with primary healthcare.
 - Palliative Care Practice Guidelines – issued by Local Self Government Department and -Health Department in 2009.
 - Integration of social health services into the community-based palliative care units.

Conclusion

So far, Kerala's model represents the most developed version of the health promoting palliative care/compassionate communities concept.¹²⁵ The Neighbourhood Networks in Kerala offers palliative care to more than 12 million people, liaising with medical services. Kerala's model demonstrated that raising the social capital of a community and moving beyond the traditional institutional and biomedical models of palliative care can bring tremendous improvements in access to underserved populations and the provision of holistic care in a truly meaningful sense.

¹²⁵ Abel J., et al. Compassionate community networks: supporting home dying. *BMJ Supportive & Palliative Care* 2011; 1:129–133.