

# Building Palliative care programme in developing countries and role of Home based care

---

Dr Suresh Kumar, WHO Collaborating Center for Community Participation for Palliative Care and Long Term Care, Institute of Palliative Medicine, Calicut, Kerala, India

## Key messages:

1. The unmet need for end of life care is enormous. The requirement is on the rapid rise due the increasing life span of people and global disease transition from communicable to non communicable.
2. Services in the area of palliative care are poorly developed in most regions of the world. This is particularly so in low and middle income countries.
3. Millions of people suffer unnecessarily because the available knowledge and skills in the area are not translated to services available and accessible to the needy.
4. Implementing the available knowledge and experience in a rational public health way can quickly and dramatically improve the quality of life of people with incurable diseases including dementia, patients dying of chronic diseases, the elderly terminally ill, people living with Multi Drug Resistant Tuberculosis and people living with AIDS
5. The public health approach in palliative care involves development of services including home based care as part of primary health care
6. Policies and recommendations for the implementation of palliative care as public health measures and a several detailed reports on how to put theory into practice for establishing such Palliative Care Programs are available.
7. What is needed is the political will to address unnecessary suffering at the end of life

## Summary:

Death is inevitable for all human beings. Only a small percentage of people die healthy. For the majority of people, death is preceded by a period of suffering. This can be for days, weeks, months or years, depending on the disease process. Most of the suffering the incurably ill, elderly or dying people currently undergo is preventable if the patient and family have access to good quality palliative care services. Such services need to be

comprehensive taking the socio cultural and economic milieu into consideration as issues related to illness, dying and death go beyond the medical domain. This will mean empowering the local community through sensitisation, training and networking and encouraging people with appropriate knowledge and skills to play their roles in the care of the incurably ill, chronically bedridden and dying patients. Though the number of people in need of palliative care services is huge, most of the possible interventions to improve the quality of life of these people are not complicated or high tech. Palliative care services need to be developed as part of primary health care to ensure continuity of services from prevention through early detection of diseases and curative treatment to palliation at the end. A primary health care approach is necessary also to make sure that the majority of the needy are covered in a meaningful way. Home based care should be the corner stone of such a community based palliative care as most patients have limited mobility. Development of palliative care in regions like Kerala (India) over the last two decades have proven that it is possible to develop palliative care services with good coverage at the grass root level with community participation even in low and middle income countries. A possible strategy for this is outlined in the light of experience from Kerala.

## **Introduction:**

Death comes to all of us. More than 50 million among us die every year. Less than 15% Of these people die suddenly, unexpectedly. Others die after a period of prolonged illness and debilitation. (1) Life with an incurable and debilitating disease is often associated with a lot of suffering. Most of the people with incurable or terminal illness spend their last days, months or years in misery. Pain, many other symptoms like breathlessness, nausea and vomiting, paralysis of limbs, foul smelling ulcers, pressure sores, incontinence etc can make life unbearable not only for that person, but also for the family. In addition to physical problems, they usually suffer from social, emotional, financial and spiritual issues caused by their condition. Suffering that the incurably ill, terminal and elderly people undergo can be effectively reduced by sensitive care with effective control of physical symptoms, good psycho social, emotional and spiritual support. The system of care aiming to improve quality of life of the incurably ill, dying and bedridden people is called palliative care.

## **Palliative Care:**

Palliative care relieves suffering and improves the quality of life of people living and dying with chronic and incurable illness. It improves the quality of life for cancer sufferers, other patients dying of chronic diseases, the elderly terminally ill and People Living with HIV/AIDS. Palliative care responds to physical, psychological, social and spiritual needs, and extends if necessary to support in bereavement. It aims to address suffering and hence is patient centred, and not disease-focused.

In 2002, the World Health Organization established a revised definition of palliative care for adults and a separate one for children: Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (2). Palliative care offers a support system to help patient's live as actively as possible until death and to help the family cope during the patients' illness and in their own bereavement. It uses a team approach to address these needs of patients and their families, including bereavement counselling, if indicated. It will enhance quality of life, and may also positively influence the course of illness and is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, and includes those investigations needed to better understand and manage distressing clinical complications. (3, 4)

Patients with a wide range of chronic conditions throughout the world have been recognised as benefiting from palliative care ( 5, 6, 7).This includes patients with dementias, cancer, cardiovascular diseases, and cirrhosis of the liver, chronic obstructive pulmonary diseases, diabetes, HIV/AIDS, end stage kidney disease, multiple sclerosis, Parkinson 's disease, rheumatoid arthritis and drug-resistant tuberculosis (TB) in adults(8). With the rapid ageing of the population occurring, the highest number of patients needing palliative care will in the future come from the elderly terminally ill. Cancer, cardiovascular diseases, cirrhosis of the liver, congenital anomalies (excluding heart abnormalities), blood and immune disorders, HIV/AIDS, meningitis, progressive kidney diseases, neurological disorders and fatal neonatal conditions have been identified as possible disease conditions requiring palliative care in children (8).

**Extent of the problem:**

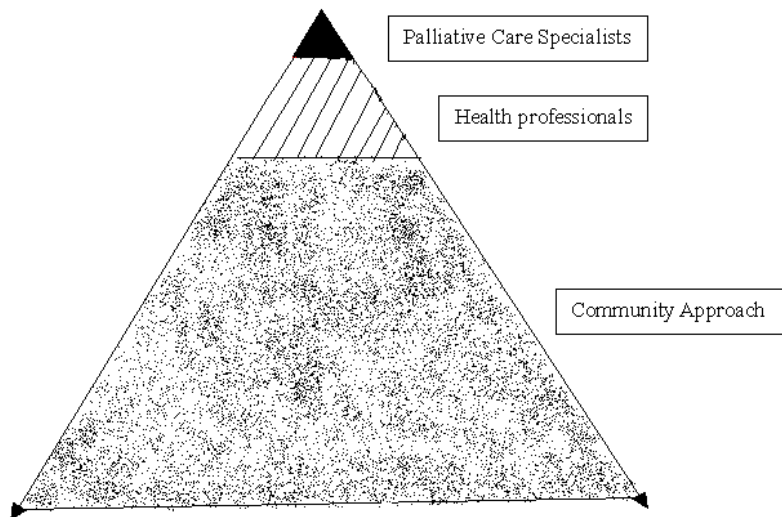
By 2030, the number of people aged 65 and older is projected to reach one billion (or one in eight of the global population). The rise in older population is sharper (by 140%) in developing countries than in developed countries (9). As the population ages, providing care for citizens who are living longer but doing so in fragile health will be major task for the governments, local communities and families. In addition, by 2030, according to the World Health Organisation (WHO), non-communicable conditions which often need palliative care towards the end are projected to account for more than three-quarters of all deaths (10)

Globally, in 2011, over 29 million people died from diseases requiring palliative care. The estimated minimum number of people in need of palliative care now is 20.4 million. The biggest proportion, 94%, corresponds to adults of which 69% are over 60 years old and 25% are 15 to 59 years old. 6% of all people in need of palliative care are children. The great majority, 78%, of adults in need of palliative care at the end of life belong to low and middle-income countries (8).

In most regions of the world, palliative care services are either non-existent or in its infancy. Lack of national policies, inadequate education and training facilities and non availability of essential medicines have been identified as some of the major barriers for development of palliative care services in these regions (8). According to the World Health Organization, about five billion people currently live in countries with insufficient or no access to medications to control severe or moderate pain (11).

**Possible solutions:**

Palliative Care need to be developed ideally as part of a system of seamless care from prevention of disease, early detection and management of diseases, palliation of symptoms to terminal care, all in a supportive environment. In view of the nature, number and geographical distribution of patients involved, the system of care, to be meaningful, should be developed keeping universal availability and accessibility in mind.



*Fig 1: Public Health Approach in Palliative Care*

*(With permission from Stjernsward J Palliative Care: The Public Health Strategy Journal of Public Health Policy (2007) 28, 42–55)*

Palliative care need to be provided at the place where the person’s care takes place, whether this is the patient’s own home or a treatment/ care facility. Since patients requiring palliative care are spread out in the community and tend to spend most of their time at home, a ‘palliative care approach’ by all healthcare professionals is needed in addition to specialist centres for training and referral. This will mean that all the health care professionals need to be educated and skilled through appropriate training. For maximum effectiveness in terms of quality and coverage, the health care professionals offering palliative care at the primary care level need have a supportive environment in the community. This can be made possible by empowering the community to effectively intervene in psychosocial and spiritual issues and reorienting the health care system to work with the community. Such a system of care should also be supported by specialist palliative care centres for referral of patients and training for health care professionals and community volunteers.

A lot of work has already gone into this area. It is unethical to let a huge number of patients suffer unnecessarily when relatively simple and affordable methods to address suffering at the end of life exist. Policies and recommendations for the implementation of palliative care are available (12, 13). Several detailed reports on how to put theory into practice when establishing National Palliative Care Programs or Initiatives are also available (14, 15). What is given below is the road outline of activities based on the existing knowledge and experience in the public health approach in palliative care.

### **National Strategy document:**

The national strategy should aim at establishing foundation measures (policies, education and training, drug availability and sensitisation) in the country in a coordinated way. A detailed realistic action plan should be part of the vision document generated for the purpose. The aim should be to integrate palliative care into the health care system at all levels and to create a supportive environment for meaningful care in the community. The action plan should address legislative changes needed, availability of drugs, plans for education and training including training of the trainers and also set the guidelines for local action. The outcome measures and indicators need to be identified. The plan should be to introduce palliative care covering all the target groups that need palliative care in a phased manner into all levels of the health care system. Capacity building (finances, training, drugs and equipment) at the primary health care level and at the specialist centre level is the most important components of this initiative for integrated palliative care services.

Simultaneously, palliative care should also be introduced at the community level through sensitisation and structured training programs. Such a capacity building initiative in the community is expected to ensure active participation of the community in the care of the patients.

### **Local Action:**

The success of the program in terms of quality and coverage depends on the meaningful involvement of maximum number of stakeholders. Since the problems of the patient are multiple including physical, psycho social, emotional and spiritual, it is possible to start action at any point depending on availability of the resources and build capacity in other necessary areas in a phased manner.



Matrix of community Based Palliative Care services – One can start with any component and build the other components in due course

**Guidelines on developing community based services: (16)**

**Step I: Sensitisation:** In any region, there will be people interested in helping others. Many of them might already have been helping others in their individual capacities. The idea is to sensitize them to the problems of patients with incurable diseases and also to get as many of them together as possible. The first step is to get those who are likely to be interested to an awareness meeting / discussion. This will be the responsibility of the local lead. All the groups / organisations involved in social / health care activities in the region are to be invited. This meeting should ideally be convened by a 'neutral' local group or institution to ensure participation from the different interest groups/ organizations in the region. Explain the issue of incurably ill / bed ridden patients in the region. Discuss possible way to help them. Register those who are willing to spend a couple of hours every week for such patients as volunteers.

Sensitise health care workers in the region

**Step II:** Establish a home care program to as a demonstration project in the region

**Step III:** Train those who are willing to get trained in basic nursing care and communication skills / emotional support. The training should be done locally and also at a time and venue convenient to the majority of the participants. Get the trained volunteers to document the problems of bed ridden / incurably ill patients in their neighbourhood (Use a proper form like the community volunteers patient care protocol). It is important to have weekly review meetings of the new volunteers at this stage. These review meetings can be used to discuss solutions to the problems documented by the volunteers. Initiate a social support program to support food for starving families, educational support to the patients' children, emotional support to patients and families by trained volunteers etc. Establish a contact point for giving and taking information. A space available with one of the new volunteers or well wishers can be used (for example, a local shop, public library premises etc.) Start collecting money, manpower and other resources. Link with the nearest palliative care unit if one is available.

Train health care workers in the region.

**Step IV:** Adding a nursing component to the program is the next step. It may take 1-2 months for the local group to establish a stable social support system and to raise money to employ a part time nurse. Getting the services of a nurse in the neighbourhood is the best option from the long term point of view. Encourage the nurse to get trained in palliative care. Initiate nurse led home care programs under supervision of the project team. In certain situations, help from the nurse from a nearby palliative care unit might be available. Use the nurses' protocol as guide to nurse led home care. Establishing a culture of meticulous documentation and review is important.

**Step V:** Getting the medical component in is very often the most difficult part due to 'scarcity' of trained doctors. One possible option is to get help from a local doctor in medical issues. Self study by the doctor can be facilitated by regular supply of reading material and availability of the doctor in the project team to guide. Encourage the doctor to get formal training in palliative care.

**Step VI:** Once the home care service starts getting established, there will be a need for a regular outpatient clinic. Availability of trained doctor and nurse is a pre requisite.



Remember that starting an institution (Outpatient clinic / Inpatient services) is more expensive than initiating a home care program. The facility can very often be linked to a local hospital.

**Step VII:** Establish a system of regular review and evaluation. Any palliative care or supportive service usually generates good appreciation from the local people. It is important to not to get carried away by the good words. Active attempts at identifying areas for improvement should always be there.

**Step VIII:** Continue with steps I and II in a nearby area with the help of the team already established.

**Guidelines on establishing Specialist Centres:** (Adapted from WHO (India) Report 2011 - APW 2010/ 144887- Unpublished)

A specialist centre can be a 'stand alone' centre or a palliative care unit attached to a secondary or tertiary care health care institution. The Specialist Center should have Outpatient, Inpatient and Home Care services in addition to facilities for education and training. A specialist palliative care centre developed as part of secondary / tertiary care has the advantage of being seen as part of the mainstream system and hence better chance of positively influencing the system. An institutional Protocol for identification of patients, referrals and palliative care services is the first step towards establishing a palliative care centre as part of an existing hospital.

**Suggestions on Human Resources for the Specialist Centre:** Adequate human resources are essential for delivering quality palliative care service. It is recommended that for every 100 beds for Non Communicable Diseases in an institution there must be following dedicated personnel for palliative care.

i) Doctor: One. The doctor should be a graduate in Modern Medicine with a Post Graduate Degree/ Diploma in Palliative Medicine. Since long term post graduate courses in palliative medicine are not common in most of the low and middle income countries, minimum of 4 – 6 weeks hands on training from a recognized Institution providing Palliative Care services and training can be kept as the minimum qualification in the initial phase

ii) Nurses: A minimum of three nurses with formal training in palliative care. They should have either B. Sc. or Diploma in nursing with a minimum of 4 – 6 weeks training from a recognized Institution providing Palliative Care services and training.

iii) Social Worker: One

iv) Pharmacist: 10% of the dedicated time of a pharmacist should be ear marked for palliative care related work.

v) Programme manager: One program manager will be needed to coordinate the activities and to liaison with the Civil Society Organisations.

Specialist Centres can collaborate with Civil Society Organisations in establishing home care programs, generating social support for patients, rehabilitation activities for the patient, Information, Education and Communication (IEC) activities, and sensitisation and training activities for volunteers

### **Best Practice Model: Palliative Care in Kerala (17)**

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 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 players in development of this public health model in palliative care in Kerala have been layperson volunteers in the community and Local Self Government Institutions in the state through a program facilitated by National Rural Health Mission (NRHM)

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.

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. NRHM Palliative Care Project was initiated by National Rural Health Mission (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 with community participation.

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. All the Local Self Government Institutions in Kerala now have home care programs in palliative care in their regions. These home care programs are linked to the Primary Health Centers to integrate them to the primary health care system. 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.

In addition to the three Specialist Centers in the Civil Society Organization sector, training and referral centers are being developed in all the secondary and tertiary care hospitals in the Government sector in Kerala.

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

## **References:**

1. Lynne J Handbook for Mortals : Guidance for People Facing Serious Illness, Oxford University Press, USA 2001
2. WHO definition of palliative care. Geneva, World Health Organization, 2010 (<http://www.who.int/cancer/palliative/definition/en>, accessed on 31 March 2014).
3. Gomez-Batiste X, Martinez-Munoz M, Blay C, Espinosa J, Contel JC, Ledesma A. Identifying needs and improving palliative care of chronically ill patients: a community-oriented, population-based, public-health approach. *Current opinion in supportive and palliative care* 2012; 6(3):371-8.

4. Temel JS, Greer JA, Muzikansky A, Gallagher ER, Admane S, Jackson VA, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med* 2010; Aug 19;363(8):733-42.
5. Seamark DA, Seamark CJ, Halpin DM. Palliative care in chronic obstructive pulmonary disease: a review for clinicians. *J R Soc Med* 2007; 100(5):225-33
6. National Health and Medical Research Council. Living well with an advanced chronic or terminal condition. Australia: Australian Government publication, 2011.
7. Kane PM, Vinen K, Murtagh FE. Palliative care for advanced renal disease: A summary of the evidence and future direction. *Palliative Medicine* 2013
8. Global Atlas of Palliative Care at the End of Life, Geneva, World Health Organization, 2014
9. Why Population Aging Matters: A Global Perspective, National Institute on Aging, National Institutes of Health, US Department of Health and Human Services, and the US Department of State, 2007
10. The Global Burden of Disease: 2004 Update, Geneva, World Health Organisation, 2008
11. Access to Controlled Medications Programme, World Health Organisation Briefing Note, Geneva, World Health Organization, February 2009
12. Cancer Pain Relief and Palliative Care. WHO Technical Report Series 804, Geneva, World Health Organisation 1990
13. Stjernsward J and Clark D:” Palliative Medicine-a Global Perspective” in Oxford Textbook of Palliative Medicine, 3<sup>rd</sup> Edition Eds. Doyle D, Hanks G et al Oxford University Press, Oxford. 2005
14. Gomez-Batiste X, Porta J, Tuca A, Carrales E, Madrid F, Treils J, Fontanals D, Borrás J,Stjernsward J, Salva A, Rius E. “Spain: The WHO Demonstration Project of Palliative Care Implementation in Catalonia. Results at 10 years (1991-2001).” *Journal of Pain and Symptom Management*, 2002; 24(2):239-44
15. 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)
16. Appendix 4: An action plan for the initiation of a palliative care in the service in the community. *International Perspectives on Public Health and Palliative Care* Ed: Sallnow, Kumar, Kellehear - Routledge 2011

17. Kumar Suresh. "Models of delivering palliative and end-of-life care in India"  
Supportive and Palliative care 2013;7(2):216-222

### **Suggested Reading:**

1. Global Atlas of Palliative Care at the End of Life, Geneva, World Health Organization, 2014
2. Dying Healed: Transforming End-of-Life Care Through innovation <http://www.wish-qatar.org/reports/2013-reports>
3. Ranking care for the dying: *Quality of death*, The *Economist* 2010  
[www.economist.com/node/16585127](http://www.economist.com/node/16585127)