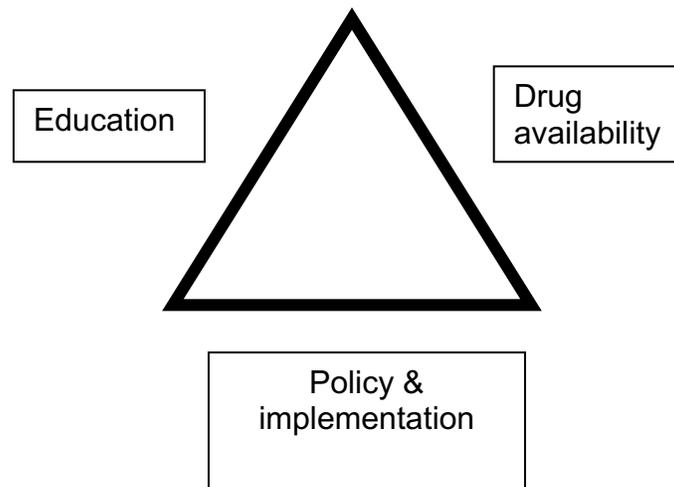


Developing a palliative care service suited to the Indian scene

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Of the 61 million people in serious health-related suffering around the globe¹, at least 7 million are estimated to be in India. Less than 4% of them have access to palliative care and are in needless pain and suffering. Any attempt at solving this problem has to take into account the enormity of numbers and should be realistic.

What can be done?



The World Health Organization recommends that all three sides of the triangle must be satisfied for a palliative care program to be successful.

¹ Knaul FM, Farmer PE, Krakeur EL et al. Alleviating the access abyss in palliative care and pain relief—an imperative of universal health coverage: the *Lancet* Commission report. *The Lancet* 2017; *The Lancet*, 391:10128

Education:

Change is always resisted. Existence of proof of scientific advances does not always get translated to change in practice. It needs persistent efforts to effect change. The following barriers to palliative care will have to be overcome.

1. Lack of awareness among professionals.
2. Lack of awareness among administrators.
3. Lack of awareness among the public.

People's voice matters. It is essential to educate the public. Public demand does persuade professionals and administrators to think. The media hence, have a large part to play.

Simultaneous educational programs will be necessary for professionals. One to three-year postgraduate programs for doctors have been recently started too. And from 2019, palliative care forms a part of undergraduate medical education in India. Pallium India offers physical and online courses for professionals.

Advocacy programs are essential to coax the administrators to help. Many institutions in India offer six weeks' course in palliative care to doctors and nurses and conduct volunteers' training programs.

Drug availability:

Morphine is the mainstay of cancer pain management. Its availability has been eased to a small extent by amendment of the Narcotic Drugs and Psychotropic Substances (NDPS) Act in 2014, but most states are yet to implement them. And the reality of poverty in our country mandates that the majority of patients will get pain relief only if essential drugs are dispensed free of cost. Experience in Western European countries and in some developing countries like Uganda and Kerala in India has shown that it is possible to ensure access to oral morphine for pain relief in the home setting without significant non-medical use, if essential documentation and control are implemented, while removing all needless procedural hurdles. The inexpensive methadone, another opioid belonging to the

same class of morphine, is available for use in anyone who does not respond well to morphine.

Policy (and its implementation):

A. Governmental policy.

In much of the world, palliative care came into being because of individual initiatives and action by Non-Government Organizations. However, to achieve national coverage, palliative care needs to be integrated into general health care delivery system. Experience from countries like Uganda has shown that even in resource-poor countries, Government action can result in effective action aimed at achieving coverage. Government action is also needed to remove barriers to access to morphine.

B. Institutional policy

It is essential for budding services to develop their own policies that can overcome any lacuna in available facilities. When we plan a palliative care service, we would do well to remember the following points.

- **The patients' needs should come first.** This almost sounds like a cliché; it needs clarification. Very often we strive for the success of an organisation, or a department, out of a sense of loyalty for it. If commitment to the organisation supersedes commitment to the patient, then we end up building monuments, eventually patients being considered an unavoidable nuisance.
- **A partnership in care needs to be established with the patient.** The average villager is quite capable of making brave and intelligent decisions regarding treatment options. Formal education and intelligence are not synonymous. Doctors have no right to force decisions on the patient. The family finances certainly need consideration before deciding on treatment options.

- **There should also be a partnership in care with the family.** Strong family structure is usually a major Asian strength. Most of the time relatives are available to care for the person, but often they don't know what to do. We can succeed only by working with the relatives, empowering the relatives to care for the patient establishing a partnership in care.
- **The palliative care delivery system should be realistic.** Our system of palliative care delivery has to be equitable and suitable to the Indian situation. There is injustice in giving royal treatment to 25 patients at an enormous cost, if 2500 others are kept outside denied of any help! The western hospice system cannot obviously be copied in its entirety in the Asian context. The Indian experience so far has shown that care at home, supported by an outpatient clinic is the most cost-effective in terms of achieving coverage, supported by home visits whenever possible. Needless to say, limited inpatient facility will be needed for those who are unable to attend the outpatient clinic or those who have difficult problems.
- **We have to make use of existing resources.** India has the advantage of a network of primary, secondary and tertiary health care centers. These have their advantages and their drawbacks. We need to use whatever the existing machinery has to offer. If we don't, we will end up spending too much and therefore, providing service only to a few.
- **Deficiencies in existing facilities need to be supplemented by the community and by NGOs.** We must find ways to supplement all shortcomings in the available machinery. If compassionate communities can be facilitated and if non-Government organizations (NGOs) can work with the Government machinery, it could prove to be of benefit to the patient.

- **Willing volunteers can be the backbone of the facility.** There are numerous individuals who are kind-hearted and are willing to help. This strong work force only needs to be trained, organized and channeled properly.
- **Advocacy is essential:** To influence policy and to improve availability of funds and drugs, we need a strategy – both directly approaching the decision makers and indirectly influencing them through the public. Mass media – the press, the television and radio all have an important role to play in this.

Palliative care in Kerala, India:

Kerala is a tiny overpopulated state in the South-West coast of India. It has about 1% of the geographical area of the country and 3% of the population. It has a high literacy state and is one of the more progressive states in the country. We formed a registered charitable organization called the Pain and Palliative Care Society (PPCS) in the year of 1993. In the coastal city of Calicut in Kerala, PPCS developed a palliative care center based in a Government Medical College Hospital. It found volunteers and provided essential staff, equipment, and drugs wherever the Government machinery fell short. By working in existing hospital facilities, initial cost of construction could be avoided and supportive facilities in the hospital could be made use of. The community is engaged so that people of any neighbourhood take responsibility for caring for people in their locality.

Most palliative care centers in Kerala work with a strong community participation. Many of them are initiated and run by lay volunteers. Volunteers undergo a training program – on an average about 18 hours of classroom sessions coupled with practical training. The practical training involves shadowing the palliative care team at both the hospital setting and during home visits. Trained volunteers act as an effective link between the patient and the medical system.

Most resources for the palliative care work in Kerala are raised locally. In one small town at the local bus station for example, the bus crew have clubbed together, each person donating five Rupees (about 8 cents of US money) a day. The total amount collected is sizeable and helps to buy free drugs for poor people. In one town, 1000 donation boxes kept in individual households, into each of which at least one Rupee goes in a day, find enough money for free palliative care medicines for the poor.

Realizing that the success of the Calicut experiment was mostly limited to Northern Kerala, some of us formed a registered charitable trust called Pallium India in 2003 to facilitate development of palliative care services in places which have little palliative care. Pallium India has catalysed the development of several palliative care training centers in various parts of the country. Working with some international agencies, Pallium India has also facilitated the development of palliative care services in 19 states.

To facilitate palliative care education, Trivandrum Institute of Palliative Sciences (TIPS) has developed six weeks' training programs for doctors, nurses and other professionals and also training programs for volunteers and palliative care assistants.

The work of NGOs in palliative care attracted so much public support that in 2008, Government of Kerala accepted Pallium India's proposal and declared a palliative care policy. In practice, it has incorporated palliative care at primary and secondary levels of care. Every one of more than 900 primary health centres in the state now employs one full-time palliative care nurse who makes at least one home visit every month to every bed-bound patient in the area. A growing number of doctors are now getting trained in palliative care.

What has been achieved in Kerala is remarkable: but it is so little compared with what needs to be done in the rest of the country. In most of India, even now,

palliative care access is limited to small pockets – mostly in major cosmopolitan cities. Progress can be achieved only when palliative care gets integrated into routine health care delivery system.

Action plan:

What exactly do we need to do, if we are to start a palliative care service? Of course, the basic principles and previous experience in the country have been explained already, but we still need to develop an action plan.

The action plan needs to include all three sides of the triangle described above. For example, it *has* to include finding answers to the following or take the following actions:

1. Policy and implementation:

- a. Where will the service start? Patient's home, outpatient, inpatient or a combination of some of them?
- b. What is the staffing that is available at the moment?
- c. What is the additional staffing necessary to make a beginning (take into consideration any service that can be provided by volunteers). This should include considering the following categories in the beginning stages:
 - i. Nurses
 - ii. Palliative care doctors
- d. Nursing auxiliaries
- e. If the service is going to be under another institution, how can the service get the support of the administration (like a charitable organization or a hospital)?
- f. How can we provide for free treatment for the poor? Can we find funds for supply of free palliative drugs for the poor?
- g. What will be the policy regarding referrals? Would your service accept patients who come on their own without a proper referral

(Most services in the country consider it essential to do away with too many formalities).

- h. It is good to put in a quality assurance program right from the beginning.
- i. Who will be in charge of the service?

2. Education and advocacy:

- a. Do we have at least one doctor and one nurse with practical hands-on training in palliative care? If not how can we get it done?
- b. Education of colleagues is essential. This can take the form of discussions of subjects related to palliative care at departmental meetings, at meetings of Indian Medical Association or at other professional bodies, continuing medical education programs for professionals etc.
- c. Public education: To recruit volunteers, to generate support in the form of good will as well as funds and to indirectly influence decision makers, public awareness is essential. Talks/video shows/presentations etc at public meetings, clubs, associations, schools, colleges etc achieve a significant lot.
- d. Media advocacy. Write ups on palliative care in newspapers and periodicals as well as programs on audiovisual media (radio & TV) can be invaluable to generate favourable public opinion.
- e. Governmental advocacy: For many matters connected with palliative care, including overcoming barriers to opioid availability to integration of palliative care into routine medical practice, support of the Government machinery is valuable. It may be difficult, but essential, to develop a good relationship with the Government.

3. Drug availability.

- a. Is there access to opioids of step III of the WHO ladder? If not, how can we obtain oral morphine?

- i. Has your state implemented the amended NDPS Act of 2014 and the relevant rules of 2015? (If you need information on this, please see <https://palliumindia.org/resources> and for more information, please email info@palliumindia.org)
 - ii. If your state still follows the old regulations, it would be necessary to find out how to obtain oral morphine and other opioids of that class.
- b. To overcome any problems with opioid availability over the long term, it would be necessary to assess existing barriers and make plans to overcome them.
- c. Affordability of drugs will always be a concern and will have to be taken into consideration when planning choice of drugs and formulations.

It is part of Pallium India's mission to work with anyone interested in starting palliative care services. Please email us at info@palliumindia.org.