Palliative and End of Life Care in India – Current Scenario and the Way Forward

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Abstract

India, being home to one-sixth of the world’s population has a huge burden of suffering from life limiting diseases. It is estimated that in India the total no. of people who need palliative care (PC) is likely to be 5.4 million people a year. Though PC was introduced nearly 30 years ago, it is still in its infancy with less than 1% of patients having access to PC. India ranks at the bottom of the Quality Of Death Index in overall score. Obstacles are too many and not only include factors like population density, poverty, geographical density, restrictive policies regarding opioid prescription, workforce development at base level but also limited national PC policy and lack of institutional interest in palliative care. However there has been a steady progress in the past few years through community owned PC services. South Indian state of Kerala which has 3% of Indian population, stands out in terms of achieving coverage of palliative care. On the national level recent years saw several palpable changes including the creation of a National Programme for Palliative care and also the Parliament amended India’s cumbersome Narcotic Drugs and Psychotropic Substances Act (NDPS) thus overcoming many of the legal barriers to opioid access.

Initially WHO and now the IAPC has taken over the responsibility of spreading the message of palliative care in India, but we still have a long way to go. Education of the professionals and sensitization of the public through awareness campaigns are vitals for improving access to PC in India. Process of implementing PC plan into action requires strong Advocacy, political support and integration across all levels of care.

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Introduction

India with a 1.2 billion population has a huge burden of suffering from life limiting diseases. Less than 1% of its population has access to pain relief and palliative care. The ‘Quality of death’ index measures the current end-of-life care environments across 40 countries. The report identifies poor access to pain relief, a lack of palliative care at national level and cultural taboos as the main barriers to countries providing a good ‘Quality of death’ and thus a good quality of life at the end of life. India ranks at the bottom of the Quality of Death Index in overall score and scores badly on many other indications. Furthermore, India ranks poorly regarding the knowledge of existence of hospice care, reflecting a general lack of awareness.

What is Palliative Care

The World Health Organisation defines palliative care (PC) as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through prevention and relief of suffering by means of early identification, assessment and treatment of pain and other distressing problems—physical, psychosocial and spiritual. Palliative Care starts as supportive care from the time of diagnosis of life-threatening illness and continues as terminal care if illness progress until death of the patient. In fact the need for emotional support may be most when the diagnosis is broken to the patient. It even extends beyond the death of the patient which is known as Bereavement Care. In PC the primary aim is not to prolong life but to make life which remains as comfortable as possible. Hence the goal is to improve quality of life (QOL) of both patients and families by responding to pain and other distressing symptoms as well as to provide a good nursing care and psychosocial and spiritual support.

Hospice care is comfort care without curative intent whereas PC is comfort care with or without curative intent. Objective of both hospice and palliative care is pain and symptom relief but the goal tends to be different. In hospice care goal is to provide comfort and QOL as well as to avoid aggressive futile care. PC involves an interdisciplinary multi-dimensional team including the patient, family, palliative medicine physician, primary care physician, nurses, social worker, pharmacists, spiritual leader, counsellor, speech, physical and occupational therapists, dieticians and volunteers. It can be given in patient’s home, at hospital, nursing home or private hospice facility.

PC improves health care quality in three domains: the relief of physical and emotional suffering, improvement and strengthening of the process of patient-physician communication and decision making and assurance of co-ordinated continuity of care across multiple health care settings: hospital, home, hospice and long-term care.

Need of Palliative Care in India

It is estimated that in India the total number of people who need PC is likely to be 5.4 million people a year, stressing on the need to expand the coverage of PC services and integrate services.

1. Late diagnosis and inadequate pain relief: It is estimated that in India around 1 million people are diagnosed with cancer every year with over 80% of cancer presenting at stage 3 and 4 when treatment is less effective and palliative care becomes absolutely essential. There is also a sizable number of patients with HIV/AIDS. It has been estimated that 60% of the people dying annually will suffer from prolong illness. That means there will be a sizable number of aged who will be needing palliative care. In fact according to WHO, there were 60 million people above 65 years of age in 2010 in our country and that this figure will increase to 227 million by 2050 constituting 20% of the total population. Non-communicable diseases (NCD) including injuries account for 62% of disease burden as on 2004 and contribute to half (50%) of all mortality in India. Long term care for such patients is emerging as a major health care issues in India. So all of them are in dire need of palliative care. Less than 3% of India cancer patients have access to adequate pain relief.

2. Lack of palliative care facilities: In India the coverage of PC services is extremely patchy, services being concentrated in large cities and regional cancer centres with exception of Kerala, where the services are more widespread. The problem of inadequate pain relief is owing to the poor availability of morphine, lack of skills among professionals to prescribe morphine, fear of side effects and a fear of addiction of morphine among professionals, patients and their family.

3. Poor quality of death index: The economist intelligence unit has given India the lowest ranking in end-of-life care across the world among 40 countries. In India there is very little awareness about palliative and end-of-life care which is complicated by the perception that Hospice care is often
associated with giving up.

4. Lack of medical infrastructure: The majority of the urban poor to rely on government run hospitals, which are overcrowded and is the least of their priorities. It is natural that they would devote their limited resources to patients who can be cured. Again in the rural areas, the doctor and hospitals are few and far apart. The vast distance and poor transportation facility prevent these patients from getting medical relief.

**History of Palliative Care**

Hospices were originally the places of rest for the travellers/pilgrims in 11th century. In 17th century a religious order established hospices for the dying poor, where they offered food, clothing, shelter as well as minimal medical care. Modern hospice is relatively a new concept but originated and gained momentum in UK after the foundation of St. Christopher’s hospice in London in 1967.

Dame Cicely Mary Saunders is the founder of modern Hospice movement, who revolutionised PC in India and helped people to die with dignity free from fear and pain. She was originally a medical social worker, then she became a registered nurse, finally advanced her carrier to become a palliative care physician. She got inspired by a polish patient David Thasma who was dying from cancer to open St. Christopher’s hospice. She had three aims for foundation of hospice: to provide care in both hospice and patient’s home, to encourage teaching and training of doctors/nurses to promote research and in to the care and treatment of the dying. In 1986, Prof. D’Souza opened the first hospice in India ‘Shanti Avedna Ashram’.

**Timeline of Palliative Care Development in India (Figure 1)**

Concept of Palliative care is a relatively new in India, having been introduced over past 30 years. Since then hospice and palliative care services have been developed through the efforts of committed individuals including Indian health professionals as well as volunteers in collaboration with international organisations and individuals from other countries. The Government of India initiated a National Cancer Control Programme in 1975 which was modified in 1984 to make pain relief one of the basic services to be provided at the primary health care level.

Palliative care was born in India as the Shanti Avedna Sadan in Mumbai, a hospice in 1986. Over the next five years it established two more branches, one in Delhi and one in Goa but patients outside these institutions had no access to PC. Two major developments occurred in 1990s. One was the formation of Pain Palliative Care Society (PPCS) in Calicut, Kerala in 1993. The other was the formation of Indian Association of Palliative Care (IAPC) in 1994. PPCS was formed as a registered charitable trust based on purely volunteerism which grew up as an outpatient service latter adding on a home visit programme with the help of WHO in 2010, (Neighbourhood Network in Palliative Care).

PC was initiated in Gujarat under the department of Anaesthesiology at Gujarat Cancer and Research Institute (GCRI), a regional cancer centre in western India. One of the important steps in the history of palliative care development in India also began from here, formation of Indian Association of Palliative care (IAPC) with the help of WHO. Over the next few years, in the later part of 1990s, several new palliative care centres were started such as the Guwahati Pain and Palliative Care Society in Assam, Jivodaya Hospice in Chennai, Can support in Delhi, Lakshmi palliative Care in Chennai and Karunasraya hospice in Bangalore. Some regional centres like Trivendrum, Bangalore and Delhi which already had pain management programmes also included PC in their service. Though every year few centres were added, the growth was limited considering the enormity of Indian population. In 2003, a Non-Government Organisation called Pallium India under the chairmanship of Prof. M R. Rajagopal was initiated with the help of WHO to improve access to PC outside Kerala. In 2008, Kerala became the first state to declare a palliative care policy integrating it into health care.

At this time, access to opioids was not easy. In 1985 Narcotic substances and psychotropic substance (NDPS) Act of India was formed which had a negative impact. In the 13 years which followed the enactment of the NDPS Act, morphine consumption in the country fell by an alarming 94% from around 600 kg to mere 48 kg. In 1997, India’s per capita consumption of morphine ranked among the lowest in the world (113th of 131 countries). During the same period, global consumption of morphine had increased by 437%. The Government of India in 1998 gave instruction to all government to amend their narcotics regulation, simplifying them. But the response from state government was so poor such that workshops were done in many states to improve the situation.

If we take morphine consumption in the country as the index for access to palliative care, there has been little progress in last few years as can be seen in the Figure 2. In 2000, the peak was caused by large scale purchase of morphine by the Government of India using funds from WHO for free distribution to Regional cancer centres. The bulk of it was never used and was eventually destroyed after expiry date. The drop in consumption from 2002 to 2006 was caused by a breakdown in the Government opium and alkaloid factory following which production of
morbidity was reduced.

Current Facilities and Provisions

In a study published in 2008, MC Dermott E. et al, identified 139 palliative care services in India serving 1.2 billion people out of which 83 centres in Kerala which contains 3% of India’s population. These services are usually concentrated in large cities and regional cancer centres with the exception of Kerala where it is more widespread. As of 2014 in Kerala, more than 170 institutions stock and dispense morphine. NNPC in Kerala is often cited as only “beacon of hope” contributing to two third of India’s palliative care services and one of the largest network in the world. India has a huge burden of suffering from life limiting diseases. It is estimated that 5.4 million people in a year are in need of palliative care in India.

Challenges to Progress of Palliative Care in India

1. Challenges before us is to reach people living with chronic incurable diseases in the background of poverty and apparent lack of resources. When chronic life-threatening illness strikes, it becomes a crippling blow for them. In low resource settings where the number of people requiring care is high and the number of doctors and nurses available to provide care is low, PC can be effective by involving community caregivers and volunteers supervised by nurses trained in palliative care. Therefore there is crucial need of community or home-based palliative care with care being taken to the door step of the patient. A study conducted at Cipla palliative care in Pune showed that 83% of people in India would prefer to die at home surrounded by their loved ones.

Home based PC is care provided to people with chronic debilitating and progressive diseases that are potentially life limiting (cancer, end stage cardiac, renal and respiratory diseases, HIV/AIDS and chronic neurological and psychiatric disorders) in the home or live-in environment of the patient.

Advantages of home-based PC are provision of comfort of patients in familiar surroundings, increased effective care and spreading awareness in the community. It can also be cost-effective as it doesn’t entail doctor and nurses fees and travelling to the hospital repeatedly for follow up visits and unnecessary investigations and treatments. However, due to lack of PC at end of life, patients receive inappropriate aggressive medical interventions at the end of life which drains the resources of patients and family and has forced up to 78% of patients in advanced stages of illness to leave hospital and ICUs against medical advice (LAMA). 80-85% of the population in India spend out of pocket for their health related expenses. Around 40-60 million families are becoming poorer every year to increasing health related costs and most of these costs related to aggressive medical interventions at last few days of life. This ultimately results in “holistic suffering” instead of “holistic care” for the dying person and the family.

2. Recent trends in health care decreases the chances of cancer patients having access to PC. These range from the limited availability of PC services to the philosophy of patient care that dominates our health care system that is mostly disease oriented.

3. Another aspect of care that is currently lacking in current health care system is communication about patient goals and preferences for care. When patients are asked what kind of care they want when serious life-threatening diseases occurs, their preferences include pain and symptom control, avoidance of prolongation of the dying process, sense of control, concern for family burden and an opportunity to strengthen relationships with loved ones. However research does not demonstrate that patient’s preferences are adequately met. An early and effective communication help both patient and family digest and accept the diagnosis and gives them a direction to move in.

4. Consent for PC must be obtained from competent patients and should not be assumed. Full disclosure is required so that the patient realises that he or she will be cared by a multidisciplinary team.

5. Limited evidence for palliative care needs more of studies that will provide strong evidence to guide better decisions regarding symptom management, different health care models, decision-making approaches about treatment options, communication on sensitive topics such as death and support for family/caregivers. In fact evidence based palliative care is need of the hour.

6. Medical insurance does not play a significant role in hospice and palliative care provision in India

Milestones Achieved

1. Designation of the Institute of Palliative Medicine (IPM) at Calicut, Kerala as a WHO collaborating centre for community participation in palliative care and long term care in 2010 and pallium India’s Trivendrum Institute of Palliative Sciences(TIPS) as a WHO collaborating centre for training and policy on access to pain relief in 2012 were two significant events contributing to further progress.

2. Recognising the education of professionals was the key to improvement of PC in the country. PC activists after several trials the six week course in ‘Essentials of palliative care’ for doctors and nurses started by PPCS became widely popular and has been replicated in 33 institutes in the country at present. One year fellowship programme was also started by several institutes. Continued advocacy by PC community in 2010 Medical Council of India accepted palliative medicine as a medicine speciality and announced a postgraduate course in the subject. Subsequently in 2012, the first MD course was started at the Tata Memorial Hospital, Mumbai with two places per year. Subsequently IRCH, New Delhi and recently GCRI, Ahmadabad has started the course.

3. NDPS Act has been amended by the Parliament in February 2014 which enables Registered Medical Institutes (RMI) to procure morphine by obtaining a single license for the state drug controller rather than five. This is a huge step forward.

4. National Programme in Palliative Care (NNPC), twelfth 5 year plan in 2012 makes a special provision for PC is an important and essential part of cancer care therapy. At least 10% of the budget needs to be earmarked for their services at all level of cancer care. For palliative care, there will be dedicated 4 beds, at the district hospital. Doctors, nurses and health workers will be trained in basics of palliative care.

5. Indian society of critical care medicine as instrumental in initiating decision on EOLC (end-of-life care) in advanced critically ill patients. Initial work published in 2005, highlighted on
limiting life-prolonging interventions and providing interventions and providing PC towards end of life, in intensive care units.14 The consensus ethical position statement on guidelines for end of life and palliative care in Indian intensive care was published in 2012. Recently in March 2019, KMC, Manipal published a document on “guidelines on limitation of life sustaining treatment” named as BLUE MAPLE by Salins N et all. It is an attempt to improve quality of care of the dying with an ethical framework and through a professional and family/ patient concuss process. Before life ends, understand and evaluate the choice of medical treatment offered, methodised action plan for limitation of life sustaining treatment and end of life care.

6. If we take per capita consumption of opioids as a criterion for access to PC, this has been on plateau for many years now. There has been a lot of progress in PC in India but the fact remains that despite the passing of almost 30 years of palliative care activity in the country, even today it reaches only about 1% of the people in India.

The Way Forward…

1. Each state need to develop its own policy that suits its needs and its social and cultural background. Community models for the provision of home-based PC need to be implemented all over the country. Empowerment of family members and volunteers to be effective palliative caregivers might prove to be the most realistic approach for meaningful coverage, especially in rural areas.

2. A change in health care to include PC early in the course of cancer care can begin to familiarise the family with PC services, start communication about death earlier in the course of cancer treatment and provide an opportunity for discussion of goals of care among the physician, patient and family.

3. Though some major barriers to access to PC in India have been overcome but implementation of created policies and laws still requires massive efforts by both the government system and Non-Government Organisations. Five years after the amendment of NDPS Act in 2014 opioids like oral morphine remain inaccessible for 98% of the population of India.

4. There is an acute shortage of trained PC physicians, so clinicians should attend local and national presentations on PC to increase their knowledge base.

5. Introduction of palliative medicine into the curriculum of undergraduate education of doctors and nurses is recommended as an efficient way to broaden the base of PC coverage at the national level.

6. Research in PC is very much essential to deliver a high quality palliative care. In fact many of the developments like megestrol for cancer cachexia, biphosphonates for pain in bone metastasis, opioids for palliation of breathlessness in terminal illness have come from research in palliative care.

Future scope for PC in the country lies in the provision of facilities and medicines, sustainability of services, support from the community, government, media and team building for palliative care. Recent declaration by the WHA( World Health Assembly) asking all member states to integrate PC with routine health care comes as a major tool in advocacy and hopefully will boost the current efforts.

References


