Palliative Care in India: Current Progress and Future Needs

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ABSTRACT

Despite its limited coverage, palliative care has been present in India for about 20 years. Obstacles in the growth of palliative care in India are too many and not only include factors like population density, poverty, geographical diversity, restrictive policies regarding opioid prescription, workforce development at base level, but also limited national palliative care policy and lack of institutional interest in palliative care. Nonetheless we have reasons to be proud in that we have overcome several hurdles and last two decades have seen palpable changes in the mindset of health care providers and policy makers with respect to need of palliative care in India. Systematic and continuous education for medical staff is mandatory, and a major break-through for achieving this purpose would be to increase the number of courses and faculties in palliative medicine at most universities.

Key words: Challenges, Education, Hospice, India, Palliative care, Perspectives, Research

INTRODUCTION

Palliative care is a health care specialty that is both a philosophy of care and an organized, highly structured system for delivering care to persons with life-threatening or debilitating illness from diagnosis till death and then into bereavement care for the family. Palliative care 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 coordinated continuity of care across multiple healthcare settings—hospital, home, hospice, and long-term care. The WHO defined palliative care as “an approach that improves the quality of life of patients and their families facing the problems 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.”[1] The goal of palliative care is, therefore, to improve the quality of life of both patients and families by responding to pain and other distressing physical symptoms, as well as to provide nursing care and psycho-social and spiritual support.[2] This is why it is best administered by an interdisciplinary, multi-dimensional team, comprising doctors, nurses, counselors, social workers, and volunteers.

India is categorized as a developing country; however, over the past 20 years, increases in the aging population and prevalence of advanced cancer are common. Together with China, the country has the second largest population in the world. It is estimated that one million new cases of cancer occur each year in India, with over 80% presenting at stage III and IV.[3] The need of palliative care in India is immense.

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HISTORY OF PALLIATIVE CARE IN INDIA

The concept of palliative care is relatively new to India, having been introduced only in the mid-1980s. Since then, hospice and palliative care services have developed through the efforts of committed individuals, including Indian health professionals as well as volunteers, in collaboration with international organizations and individuals from other countries.[4] In 1975, the Government of India initiated a National Cancer Control Program. By 1984, this plan was modified to make pain relief one of the basic services to be delivered at the primary health care level. Unfortunately, this policy was not translated into extensive service provision.[5] The hospice and palliative care movement in India started tentatively in the mid-1980s and has slowly increased over the last two decades.

In India, the earliest facilities to deliver palliative care within cancer centers were established in some places like Ahmedabad, Bangalore, Mumbai, Trivandrum, and Delhi in the late 1980s and the early 1990s.[6] Palliative Care was initiated in Gujarat in 1980s with the opening of a pain clinic and palliative care service under the department of Anesthesiology at Gujarat Cancer and Research Institute (GCandRI) a Regional Cancer Centre in Western India. One of the important steps in the history of palliative care development in India was also began from here; forming of Indian Association of Palliative Care (IAPC). In 1986, Professor D'Souza opened the first hospice, Shanti Avedna Ashram, in Mumbai, Maharashtra, Central India.[7] At a similar time, pain clinics were established at the Regional Cancer Centre, Trivandrum, Kerala, with the assistance of a WHO subsidy, and at Kidwai Memorial Institute of Oncology, Bangalore, Karnataka. 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. CanSupport was founded in 1997 in Delhi which provided the first free palliative care home care support service in North India. In Pune, Maharashtra, central India, the Cipla Cancer Palliative Care Centre was established.

The IAPC was registered as Public Trust and Society in March 1994 in Ahmedabad. IAPC held its first international conference at Varanasi in January 1994 (with the assistance of WHO and Government of India) and adopted a constitution. The following year, the IAPC set up a Palliative Care Drugs Committee and Educational Task Force and held its Second International Conference in Ahmedabad, where 180 delegates attended.

Morphine availability was a considerable problem to the provision of hospice and palliative care. The Narcotic Substances and Psychotropic Substances (NDPS) act of India brought out in 1985 made procurement of morphine so difficult and had a negative impact such that use of morphine in the country dropped steeply in succeeding years.[8] The WHO Collaborating Center at Madison-Wisconsin has been working with Indian palliative care activists to improve access to opioids. The Government of India in 1998 gave instructions to all state governments to amend their narcotic regulations, simplifying them. But response from the state government was so poor such that workshops were done in many states in order to improve the situation.

CURRENT FACILITIES AND PROVISIONS

McDermott *et al*. identified 138 organizations currently providing hospice and palliative care services in 16 states or union territories. These services are usually concentrated in large cities and regional cancer centers, with the exception of Kerala, where services are more widespread.[4]

The Kerala network has more than 60 units covering a population of greater than 12 million and is one of the largest networks in the world.[9] In April 2008, Kerala became the first state in India to announce a palliative care policy. The Calicut model has also become a WHO demonstration project as an example of high quality, flexible, and low cost palliative care delivery in the developing world and illustrating sound principles of cooperation between government and NGOs.[10] CanSupport has 11 home care teams, each consisting of doctors, nurses, and counselors trained in palliative care, to cover the different parts of Delhi and National Capital Regions. They visit the homes of approximately 80-85 patients with advanced cancer every week.[11] In addition to home care program, it also has day care service for people with cancer. CanSupport is a different form of home-based service to the Kerala-based model. Harmala Gupta, the founder of CanSupport, has raised criticisms regarding the suitability of community-based palliative care delivery.[12,13] She questions whether quality palliative care can be provided by volunteer-led teams, and has generated a debate, within India and internationally, regarding community participation in palliative care. The Guwahati Pain and Palliative Care Society (GPPCS) in Assam, North East India, is a good example of the ways in which palliative care services have developed in different states and provinces. A registered NGO, it was the first service in North East India providing palliative care to people with advanced cancer. The GPPCS is now run by 3 doctors, 2 nurses, voluntary nurses, 30 volunteers, and an office assistant.[4] GPPCS now has established link centers in three towns in Assam (Rangia, Digboi, and Hojai). Karunashraya Bangalore Hospice Trust is a 55-bedded hospice with a homecare service and hospital facilities nearby. Bangalore Hospice Trust's unique strength lies in the fact that it provides an entire circle of care to the patient. The Chandigarh Palliative Care service was started with the aim of integrating palliative care into comprehensive cancer care and providing continuity in care to the cancer patients. It is a joint project of Department of Radiotherapy, Postgraduate Institute of Medical Education and Research and Chandigarh branch of Indian Red Cross Society (NGO).[14] The palliative care team shares the same outpatient department and patients are familiar with the team even when they are on anti-cancer treatment. It also provides home care service not only in Chandigarh but also in neighboring towns of Mohali and Panchkula. Similarly, Kidwai Memorial Institute of Oncology has been providing palliative care services for more than a decade. The majority of the doctors, nurses, and paramedical professionals working in these centers have rendered exemplary services to deliver palliative care to cancer and other terminally ill patients, raise awareness about palliative care practice and educate others.[4] At present, the IAPC is in its 18th year, and there are more than 150 centers actively engaged in palliative care delivery.

Cancer and other Non Communicable Diseases have emerged as major public health problems in India. The National Cancer Control Program of the Government of India is a laudable initiative and constitutes one of the very few such models in the world. Cancer control needs a multidisciplinary approach and palliative care is an important component of this approach. Despite its limited coverage, palliative care has been present in India for about 20 years. The past two decades have seen palpable changes in the mindset of healthcare providers and policy makers with respect to the urgency of providing palliative care. Every hour more than 60 patients die in India from cancer and in pain. Moreover, with a population of over a billion, spread over a vast geo-political mosaic, the reach of palliative care may appear insurmountable. It is estimated that in India the total number who need palliative care is likely to be 6 million people a year. These figures are likely to grow because of the increasing life span and a shift from acute to chronic illnesses. It is estimated that 60% of the people dying annually will suffer from prolonged advanced illnesses. This means there will be a sizeable population of the aged who will have several spells of hospitalization interspersed with long periods of being confined to their beds at home. In addition to the challenges posed by illnesses, many of the patients in India are extremely poor and do not have access to clean water, food, or even shelter. When chronic or life-threatening illnesses strike, it is a crippling blow for them and their families. There is therefore a crucial need for a system of care at home that can best be built by a community-based palliative care movement.

WHO and other international organizations lay emphasis on providing physical, psychosocial, and spiritual needs and to help patients achieve quality of life with supportive families. It was to address such needs and so provide holistic care that the concept of friendly neighbours who have been trained in palliative care took shape and so the Neighbourhood Network of Palliative Care (NNPC) was formed in 2001.[15] This is a joint venture with four NGOs and eight palliative care centers which attempts to develop a sustainable "community led" service capable of offering comprehensive Long Term Care (LTC) and Palliative Care (PC) to those in need.[16] NNPC proved the theory that community ownership can work wonders even in financially poor communities. Indian palliative care development at its most successful has innovated and produced services like NNPC which provides an exemplar model of community-based palliative care for low-resource countries worldwide. The NNPC is designated a WHO Demonstration Project for providing cost-effective community-based home care for late stage cancer patients.

Home-based palliative care services are becoming increasingly popular with care being taken to the doorstep of the patient. Ideally, this is where people are most comfortable at the end of their lives, surrounded by their loved ones. It is also well suited to conditions in India where a family member is usually available and willing to nurse the sick person. The aim of home-based care is ultimately to "promote, restore, and maintain a person's maximum level of comfort, function, and health, including care toward a dignified death." Home-based care models are also generally person-centered and comprehensive, with the aim to take into account factors such as culture, religion, and value systems, and respect people's rights to privacy and dignity, which fits in well with its "community-driven" philosophy.[17] It is also cost-effective as it does not entail doctors and nurses' fees and travelling to the hospital repeatedly for follow up visits and unnecessary investigations and treatments.[2] McDermott *et al*. identified 88 home care programs across the subcontinent.[4] These are specific home care programs rather than services that provide occasional home visits.

Palliative care in India is still at an early stage of development and faces numerous problems. The WHO step ladder pattern has been a landmark, a watershed, a milestone in the pain management timeline. The availability, accessibility, and effectiveness of modern methods of pain control make it a moral mandate for every physician to be knowledgeable in the use of analgesics. It is estimated that less than 3% of India's cancer patients have access to adequate pain relief.[8] Inadequate attention to pain relief is tantamount to moral and legal malpractice and is a violation of the principle of beneficence. The medicinal use of opioids such as morphine is highly regulated by the Indian Narcotic Drugs and Psychotropic Substances Act (NDPS), and to dispense morphine to patients the hospitals must be registered with the government and adhere to a set procedure.[18] Procurement of oral morphine for treatment of pain in terminal cancer patients is another problem because of cumbersome legislation.[19] These rules vary from state to state and involve separate licensing agencies, each with numerous levels of review and approval in the bureaucracy. Despite some success at increasing availability, progress is slow and opioid accessibility continues to remain a constant problem for the providers of palliative care in India.

Palliative care is an important and essential part of cancer care therapy and twelfth 5-year plan makes a special provision for it. At least 10% of the budget needs to be earmarked for these services at level of cancer care services. For palliative care there will be dedicated 4 beds at the district hospital. Doctors, nurses, and health workers will be trained in basic palliative care. One of the doctors in the District hospital needs to have a 2 weeks training in palliative care.[20]

EDUCATION, TRAINING, AND RESEARCH

Approaches to improve the application of palliative care include education, training, and research endeavors. Educational efforts in palliative and end-of-life care have targeted nurses, physicians, and other disciplines associated with clinical care. WHO recommended three foundation measures for developing Palliative care—Governmental policy, Education, and Drug availability. They are important for establishing a sustainable Palliative care, and achieving meaningful coverage. The introduction of Palliative care into the curricula of the under graduate education of all doctors and nurses is recommended as an efficient way to broaden the base of Palliative care coverage at the national level. A milestone has been achieved in Palliative care as MCI has recognized MD in Palliative Medicine from this year and this will help it to develop as a specialty in our country.[21] IAPC has worked for this since many years.

A number of trends in health care today decrease the chances of cancer patients having access to palliative care. Reasons for the late transfer to palliative care and hospice include difficulty in switching to a non-treatment mode, inability to have the conversation about death with the patient and family, and reluctance of the patient and family to give up the search for a cure. A change in health care to include palliative care early in the course of cancer can begin to familiarize the family with palliative care services, start the communication about death earlier in the course of cancer treatment, and provide an opportunity for a discussion of goals of care among the physician, patient, and family.

Research in Palliative care is very essential to deliver high-quality palliative care. Finding and using the best available evidence should be part of our professional lives. Evidence-based palliative care is need of the hour. We need to do high quality trials in palliative care. Many developments like Megestrol for cancer cachexia, Biphosphonates for pain in bone metastasis, Opioids for the palliation of breathlessness in terminal illness have come from the research in palliative care. There is good scope for developing a research culture in the Indian palliative care scenario. Sustainable and quality research in India will be possible by establishing a network of individuals—doctors, nurses, paramedics, other professionals, institutions, and organizations, including commercial establishments who have a stake in the palliative care practice. The issues that can improve the palliative care delivery and the areas where evidence of practice is still weak can be identified by forming network and collaborative groups for the application of study and research methods in India.[6]

CHALLENGES TO IMPLEMENTATION OF PALLIATIVE CARE

A number of trends in health care today decrease the chances of cancer patients having access to palliative care. These range from the limited availability of palliative care services to the philosophy of patient care that dominates our health care system. Most patient care is disease-oriented. Palliative care can assist in changing from a disease-focused approach to a patient-centered philosophy, where the needs of the patient and the patient/family goals are essential to planning care. Patient-centered care broadens the focus and requires clear coordination across specialties and disciplines and access to palliative care physicians and nurses. The goal of palliative care should continue to focus on the relief of suffering and the improvement of the quality of life for patients with advanced illnesses.

Another aspect of care that is clearly lacking in current health care systems is the communication about patient goals and preferences for care. When patients are asked what kind of care they want when serious and life-threatening disease occurs, their preferences include pain and symptom control, avoidance of prolongation of the dying process, a sense of control, concern for family burden, and an opportunity to strengthen relationships with loved ones. However, research does not demonstrate that patients' preferences are adequately met. Every patient has the right to know about his illness (patient autonomy is an important aspect of medical ethics) but the way to tell them is important—neither telling the diagnosis abruptly nor hiding the truth, but gently breaking the news on a need to know basis. Early and effective communications help both patient and family "digest" and accept the diagnosis and gives them a direction to move in. Breaking bad news is a complex communication task that requires expert verbal and non-verbal skills. This complexity can create serious miscommunications, such as the patient misunderstanding the prognosis of the illness or purpose of care.[22,23] It is rightly said "Break bad news well and you will always be remembered, break bad news badly and you will never be forgotten." Truth is one of the most powerful therapeutic agents available to us, but we still need to develop a proper understanding of its clinical pharmacology and to recognize its optimum timing and dosage in its use. Similarly, we need to understand the closely related metabolisms of hope and denial.[24]

The other issues which need to be addressed are that consent for palliative care must be obtained from competent patients and should not be assumed. Full disclosure is requisite so that the patient realizes that he or she will be cared by a multidisciplinary team.

An additional challenge to implementation of palliative care is the limited evidence for this specialty. Studies are needed that provide 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. The existing strength in India, i.e. IAPC, the Indian Journal of Palliative Care, palliative care facilities, experts and professionals in this field should be jointly utilized to mount coordinated research activities in palliative care.

Medical insurance does not play a significant role in hospice and palliative care provision in India. With a small number of healthcare professionals struggling to attend to millions and millions with various diseases, it is difficult for the average doctor to set aside time from his curative practice for palliative care.

FUTURE NEEDS

How can patients receive integrated high-quality palliative care wherever they are in India? Unfortunately, there are various obstacles to fulfilling patients' and their families' hopes because of the heterogeneity of various geographical, social and medical backgrounds among the various districts. One model cannot fit all. Given the diversity in India, each state will need to develop its own policy that suits its needs and its social and cultural background. And the central government will have to develop a policy which would provide guidelines for general application and provide an umbrella of support, especially in matters relating to opioid availability and education. Coordination and partnerships with hospice programs is a major feature as palliative care continues across the trajectory of disease. As an interdisciplinary endeavor, the field of palliative care includes medicine, nursing, social work, psychology, nutrition, and rehabilitation although depth of support available from each discipline varies from institution to institution.

Palliative care does require passion and commitment. Clinicians are urged to learn more about palliative care in order to overcome some of these barriers. Therefore, attending local and national presentations of palliative care to increase the knowledge base is an essential initial step. This can occur through local presentations, national meetings, on-line courses, and individual reading and exploration.

Educating people in palliative care through programs offered overseas can be useful in some instances, but it is not always an ideal solution. The way forward is to draw on the existing, successful models that have been described, to develop usable and dynamic educational initiatives within India itself, from model palliative-care teaching centers attached to inpatient or community units, thereby making close and relevant partnerships between theory and practice.[25] The centers for palliative care teaching should be culturally sensitive and relevant to the Indian situation. Collaborations between the government of India, Indian Association of Palliative care and WHO, provide further optimism regarding future development. India has the potential to lead the way and enlighten others rather than being subservient to those countries that enjoy resource wealth.

SUMMARY

The palliative care movement is one example of how health services can go well beyond the biomedical model of health and be seen as an affirmative act of living with dignity even whilst accepting that death is an inevitable part of life. Continued efforts are needed to overcome the barriers to successful implementation of palliative care. Ways to integrate current palliative care knowledge into care of patients include multidisciplinary educational initiatives, research endeavors, and clinician resources. Still, a lot needs to be done for creating awareness and training in Palliative Care.

Let's hope for a pain free India.

"Together everyone achieves more."

REFERENCES

1. "WHO Definition of Palliative Care". Geneva, World Health Organization. Available from: http://www.who.int/cancer/palliative/definition/en [Last accessed on 2012 Mar 02].
2. Guidelines for Home-based Palliative Care-IAPC and CanSupport. New Delhi. Developed under the government of India-World Health Organisation Collaborative Programme 2006-2007. Ishtihaar.
3. Seamark D, Ajithakumari K, Burn G, Saraswalthi Devi P, Koshy R, Seamark C. Palliative care in India. J R Soc Med 2000;93:292-5.
4. McDermott E, Selman L, Wright M, Clark D. Hospice and palliative care development in India: A multimethod review of services and experiences. J Pain Symptom Manage 2008;35:583-93.
5. Rajagopal MR, Venkateswaran C. Palliative care in India: Successes and limitations. J Pain Palliat Care Pharmacother 2003;17:121-8.
6. Mohanti BK. Research focus in palliative care. Indian J Palliat Care 2011;17:8-11.
7. de Souza LJ, Lobo ZM. Symptom control problems in an Indian hospice. Ann Acad Med Singapore 1994;23:287-91.
8. Rajagopal MR, Joranson DE, Gilson AM. Medical use, misuse, and diversion of opioids in India.Lancet 2001;358:139-43.
9. Kumar SK. Kerala, India: A regional community-based palliative care model. J Pain Symptom Manage 2007;33:623-7.
10. Rajgopal MR, Kumar S. A model for delivery of palliative care in India-the Calicut experiment. J Palliat Care 1999;15:44-9.
11. Hind B. Touching lives. New Delhi: CanSupport India; 2004.
12. Gupta H. How basic is palliative care? Int J Palliat Nurs 2004;10:600-1.
13. Gupta H. Community participation in palliative care: A comment. Indian J Palliat Care 2005;11:19-21.
14. Bansal M, Patel FD, Mohanti BK, Sharma SC. Setting up a palliative care clinic within a radiotherapy department: A model for developing countries. Support Care Cancer 2003;11:343-7.
15. Growing focus on palliative care. Available from: http://www.indiatogether.org/2010/mar/hlt-palliate.htm/[Last accessed on 2012 Jul 25].
16. Kumar S. Learning from low income countries: What are the lessons? Palliative care can be delivered through neighbourhood networks. BMJ 2004;329:1184.
17. Department of Health. Department of Health National Guideline on Home-Base Care/Community-Based Care-December 2001. Pretoria: Department of Health; 2001.
18. Sharma DC. Poor palliative care in India. Lancet Oncol 2008;9:515.
19. Ghooi RB, Ghooi SR, Chaturvedi HK. Pain relief in India.Lancet 1999;354:677.
20. Report of the Working Group on Disease Burden for 12th FiveYear Plan. WG3 (2): Non Communicable Diseases. Available from: http://www.planningcommission.nic.in//WG_3_2non_communicable.pdf/[Last accessed on 2012 Jul 08].
21. Medical council of India Postgraduate medical education Regulations. 2000. Available from: http://www.mciindia.org/rules-and-regulation/Postgraduate-Medical-Education-Regulations-2000.pdf, page 37/[Last accessed on 2012 Jul 14].
22. Hoy AM. Breaking bad news to patients. Br J Hosp Med 1985;34:96-9.
23. Davis H. Breaking bad news. Practitioner 1991;235:522-6.
24. Simpson M. The facts of death. A Complete Guide for Being Prepared. Englewood Cliffs, New Jersey: Prentice-Hall; 1979.
25. Shanmugasundaram S, Chapman Y, O'Connor M. Development of palliative care in India: An overview. Int J Nurs Pract 2006;12:241-6.

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