Palliative care in India: Situation assessment and future scope

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Abstract
Palliative care is 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 problems – physical, psychosocial, and spiritual. It is estimated that in India the total number of people who need palliative care is likely to be 5.4 million people a year. Though palliative care services have been in existence for many years, India ranks at the bottom of the Quality of Death index in overall score. However there has been steady progress in the past few years through community-owned palliative care services. One of the key objectives of the National Programme for prevention and control of cancer, diabetes, cardiovascular diseases, and stroke is to establish and develop capacity for palliative and rehabilitative care. Community models for the provision of home-based palliative care is possible by involving community caregivers and volunteers supervised by nurses trained in palliative care. Training of medical officers and health care professionals, and sensitization of the public through awareness campaigns are vital to improve the scope and coverage of palliative care. Process of translating palliative care plan into action requires strong leadership, competent management, political support and integration across all levels of care.

Key Words: Need, palliative care, scope

Introduction
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 healthcare issue in India. Patients diagnosed with chronic conditions such as cancer, cardiovascular disorders, cerebrovascular disorders, chronic respiratory disorders, end-stage renal disease, leprosy, and HIV not only require physical control with their diseases and symptoms but also need help in coming to terms with their diseases. Increase in the geriatric population will have dramatic implications for governments around the world, particularly as aging populations put increasing pressure on existing services.

The ‘Quality of Death’ index measures the current end-of-life care environments across 40 countries. The index scores countries across four categories: Basic end-of-life healthcare environment; availability of end-of-life care; cost of end-of-life care; and quality of end-of-life care. The index ranks the United Kingdom and Australia as providing the world’s best ‘Quality of Death’, whereas countries such as Italy and South Korea are ranked much lower. The report identifies poor access to pain relief, a lack of palliative care at national policy level, and cultural taboos as the main barriers to countries providing a good ‘Quality of Death’ and thus 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 indicators. Furthermore, India ranks poorly regarding the knowledge of existence of hospice care, reflecting a general lack of awareness.

What is Palliative Care?
World Health Organization (WHO) defines 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 prevention and relief of suffering by means of early identification, assessment and treatment of pain, and other problems – physical, psychosocial, and spiritual. Palliative care starts as supportive care at the time of diagnosis of life-threatening illness and continues as terminal care if the illness progresses until death of the patient.

Palliative care aims to enhance the quality of life and positively influence the course of illness. Palliative care is used to describe supportive care when the disease is no longer responsive to curative treatment; thus, palliative care provides relief from pain and other distressing symptoms, affirms life, and regards dying as a normal process. It offers a support system to help patients live as actively as possible until death and uses team approach to address the needs of the patients and their families. Palliative care is applicable early in case of illness in conjunction with other therapies that are intended to prolong life such as chemotherapy and radiotherapy. Pain relief is an extremely important component of palliative care, especially in the treatment of cancers. Palliative care offers a platform for communication with patient and families, rehabilitation to maximize independence, continuity of care, coordination between services, terminal care, and a support system to help families cope during patient illness and in bereavement.

Need for Palliative Care
According to Worldwide Palliative Care Alliance (WPCA), although more than 100 million people across the world would benefit from hospice and palliative care annually (including family and carers who need help and assistance in caring), less than 8% of those in need access it. The exact need for palliative care is difficult to estimate because of flaws in disease registration, communication difficulties, and stigma attached to the diagnosis of cancer and AIDS. It is estimated that in India around 1 million people are diagnosed with cancer every year. Around 80% of all cancers are diagnosed in the advanced stage when treatment is less effective and palliative care becomes absolutely essential.
Palliative Care in India

Access to drugs and availability of carers are the most important practical issues in the management of end-of-life care. 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.[6] India is one of the largest legal producers of morphine, providing most of the morphine for pain relief across the world. Of the available drugs in the third rung of the analgesic ladder for pain relief in cancer patients (strong opioids), only morphine is available in India.[7] However, the use of morphine in India is determined by the restrictions in manufacture, sale, and possession of morphine by Narcotic Drug and Psychotropic Substance act of 1985.[8]

It is estimated that in India <3% of cancer patients have access to adequate pain relief. India ranks last in the list of 40 countries when it comes to the availability of painkillers for end-of-life care. Realizing the importance of making morphine available for pain relief, 14 states have amended the act to for easy availability of morphine in India.[2]

Though palliative care services have been in existence in India for many years, there has been steady progress in the past few years. According to the report by WPCA, India has moved from Group 2 countries (making capacity-building activities) to Group 3B countries for having generalized palliative care provision.[9] Although India ranks at the bottom of the Quality of Death Index in overall score, Kerala, an Indian state, is cited as a ‘beacon of hope’ for providing palliative care services. Constituting only 3% of India’s population, Kerala provides two-thirds of India’s palliative care services. The state has a formal palliative care policy in place and its government provides funding for community-based care programs. It was also one of the first of India’s states to relax narcotics regulations to permit use of morphine by palliative care providers. Recognizing the need of palliative care as primary healthcare and the importance of homecare services, the neighborhood network in palliative care was commenced as a community-run system that operated through local micro-donations.[2] The volunteers identify those in their community who need care and supplement the work of healthcare professionals linked to the state’s 230 local palliative care units covering a population of 12 million. The volunteers can provide psychological, social, and spiritual support after initial training.

National Rural Health Mission has also initiated the development and expansion of community-owned palliative care services in collaboration with the state government of Kerala. The Arokya Keralam project for community-based care of the bedridden elderly is an example for integration of community-based palliative care.[10] In the state of Karnataka, Bangalore Hospice Trust, set up in 1994, is an independent, standalone institution that provides both homecare and institutional care.[11] The Government of Andhra Pradesh started a health insurance system for people below poverty line, wherein the insurance scheme also covers palliative care services.[12]

Capacity building is yet another essential factor in palliative care, from providing specialist education for physicians and nurses to better equipping volunteers and community workers. Indian Association of Palliative Care runs a certificate course in Essentials of Palliative Care for doctors and nurses in India, by distance education program through its 27 centers.[14]

Community-based Palliative Care

It is estimated that in India the total number of people who need palliative care is likely to be 5.4 million people a year, stressing on the need to expand the coverage of palliative care services and integrate services at all levels of care. Across the levels of care, services can be provided through inpatient care, outpatient care, and home-based care. 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, palliative care can be made effective by involving community caregivers and volunteers supervised by nurses trained in palliative care. Home-based care can be used to provide palliative care to everyone who needs it; this is often representative of the patients’ wish to breathe their last at home, which may be ignored in conventional curative medicine.

Home-based palliative care 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. It is generally delivered by an interdisciplinary team trained in palliative care, which includes doctors, nurses, paramedical staff, and volunteers. A multi-dimensional approach offers the best quality of care as no one member of the team has either the skills or the insights to provide comprehensive palliative care, which encompasses the physical, psychosocial, and spiritual, on their own. Home-based palliative care is suited to the convenience of both parties, tailored to meet the psychological, mental and physical health needs of the patients and families. The WHO India Country Office has developed guidelines for providing home-based palliative care.[14] The basic components of home-based palliative care include a willing and accessible patient, an available caregiver, a conducive home/live-in environment, a properly trained team, 24-h support, means of transport, network for supportive care, and a homecare kit. Advantages of home-based palliative care are the provision of comfort to patients in familiar surroundings, easy access, security, independence, increased effective care, and spreading awareness in the community. By increasing the proportion of community and homecare, palliative care can reduce costs associated with hospital stays and emergency admissions.
Program Perspectives

Palliative care is a key component of an overall cancer control program and it should be linked to cancer prevention, early detection, and treatment strategies; this will allow a seamless response to all the cancer priority requirements in a community and make the best use of scarce resources. One of the key objectives of the National Programme for prevention and control of cancer, diabetes, cardiovascular diseases, and stroke is to establish and develop a capacity for palliative and rehabilitative care.\(^\text{[15]}\) Ensuring the availability of palliative and rehabilitative services, including oral morphone, is one of the responsibilities of the District NCD Cell. The district hospital should provide home-based palliative care for chronic, debilitating, and progressive patients. The proposed structure under this program includes setting up facilities for patients requiring home-based care and day care. A team consisting of nurses and counselors should be trained in identifying symptoms, pain management, communication, psychosocial and emotional care, nursing needs of the terminally ill, and ethics of palliative care. A home care kit containing a stethoscope, blood pressure apparatus, torch, thermometer, tongue depressor, forceps, common medicines, and so on should be provided to this team. The activities at the state, district, Community Health Centre, and sub-center levels ought to be closely monitored through the NCD cell at different levels. The medical colleges in the country can function as resource centers for training in palliative care and assist in operational research on the various aspects of implementation and management.

Future Scope

- The process of translating palliative care plan into action requires strong leadership, competent management, and political support
- Community models for the provision of home-based palliative care need to be implemented all over the country
- Public education and information campaigns are therefore critical to changing public attitudes. Activities and education campaigns around ‘World Hospice and Palliative Care day’ (8th October) can increase awareness among the public
- 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
- Healthcare professionals should be trained adequately in palliative care and the foundation of sensitization can be laid by including palliative care in the MBBS curriculum
- Incorporating palliative care in existing health systems requires the training of medical officers at the primary health centers and community health centers and the provision of the minimum required facilities for provision of care
- Palliative care standards should be developed with the wide participation of stakeholders, to ensure fulfillment of minimum service requirements
- Evidence-based standards of palliative care services and research focusing on improving palliative care services are required in all settings.

Several of these initiatives have been initiated in India; however, concerted effort is required to bring palliative care into the forefront. Future scope for palliative care in the country lies in the provision of facilities and medicines, sustainability of services, support from the community, government, and media and team building for palliative care.

References


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