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Palliative Care in India - The Need of an Hour

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According to The UN's State of World Population Report 2023 India will become the world's most populous country by mid-2023, surpassing China's 1.425 billion people by about 3 million. India is a developing country and presently facing a big demographic transition in terms of rising population size, population growth and increase in life expectancy. Though the working population is increasing (demographic dividend) but at the same time elderly population is also rising. Also, our country is facing the dual burden of diseases both communicable and non-communicable or lifestyle diseases. Keeping in view of the above scenario, inclusion of palliative care in the primary health care is the need of an hour.

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]. In other words, it is a holistic care that improves the quality of life of the patients as well as their families. Evidence from various studies reveal that more than 90% of the cancer patients spend most of their time in hospital during their terminal period and about 70% of them die in hospital settings without their nears and dears in front of them. These patients often get a curative care only and are usually devoid of the "total care" that includes physical, psychological and spiritual support.

India is a resource poor country; with shortage of manpower, money and materials in healthcare. Therefore, to deliver palliative care at the grassroot level for the rural poor population of India, it should be delivered by a multidisciplinary team comprising of family members, community volunteers, social workers, spiritual leaders in addition to the doctors and nurses who can provide symptomatic care to the patient. A good example of this is the Neighbourhood Network of Palliative Care (NNPC) in Kerala which is the first WHO Collaborating Centre for Community Participation in palliative care.

Though with limited awareness and coverage, history of palliative care in india dates back to 20 years or mid- 1980s when people used to think that palliative care is for cancer patients only. So, the first facilities to deliver palliative care in India were within cancer centres at places like Ahmedabad, Bangalore, Mumbai, Trivandrum, and Delhi. Another milestone in the history of palliative care development in India was establishment of Indian Association of Palliative Care (IAPC). The first hospice in India, Shanti Avedna Ashram, in Mumbai, Maharashtra, was opened by Professor D'Souza in 1986.

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Can Support in Delhi was established in 1997 which was the first centre in North India to deliver home care palliative care services. The availability of morphine was again a big hurdle in India. The Narcotic Substances and Psychotropic Substances (NDPS) act of India in 1985 further added to the difficulty in the procurement of morphine leading to a remarkable drop in its use in the subsequent years. In 1998 Indian government gave instructions to all state governments to amend their narcotic regulations, but the response was not good. Various workshops were held in lot of states regarding this issue and among them Kerala showed a significant improvement in access to opioids. Two important events that contributed to the progress of palliative care were designation of the Institute of Palliative Medicine at Calicut, Kerala, as a WHO Collaborating Centre for Community Participation in Palliative Care and Long-Term Care in 2010 and of Pallium India's Trivandrum Institute of Palliative Sciences (TIPS) as a WHO Collaborating Centre for Training and Policy on Access to Pain Relief in 2012 [2].

But inspite of increasing progress in the field of palliative care in India, only 1% of Indian population has access to it. India is rated lowest among all countries in the use of opioids. National programme for palliative care was formulated in 2012 but it is lost under lack of funds [3]. Need of an hour is to include palliative care in the primary health care so that it is accessible and affordable to all rich and poor. Not only the health care professionals but the general community should be made aware that palliative care is the continuum of care that should be started with the diagnosis of any long term or life limiting illness. Volunteers with leadership qualities should be included in the programme to enhance community participation and make the general community more receptive. The emphasis needs to be shifted from the quantity of life to the quality of life. Efforts have been started by the government and a lot of barriers have been overcome but still lot is needed to be done. The policies and programmes that are made need to be implemented stringently to bring about a change.

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