



## Palliative care: A “missing chapter” in medical science

Debjani Nath\*, Ashutosh Ghosh and Nasima Khanam

Department of Zoology; University Of Kalyani, Kalyani Nadia, West Bengal Pin 741235

\*Correspondence: [nath\\_debjani@yahoo.co.in](mailto:nath_debjani@yahoo.co.in)

Palliative care is a method which provides special care to patients and families facing progressive and fatal diseases. This care emphasizes on giving relief from psychological problems, spiritual distress and physical symptoms. Understanding and learning of applying principles of palliative medicine are important in the field of palliative care. This review provides an idea about the status of palliative care, hospice care and integration of palliative care in the Indian curriculum of medical science. Many studies suggest that palliative care is appropriate in the care of chronic illness. But research and educational progress of palliative care are still scarce in present day technology based knowledge of medical biology. Our aim in this review is to focus the light on the dearth of knowledge for integrative palliative care needed for the medical professional of chronic diseases, researchers and others related to palliative care.

**Keywords:** palliative care, deadly diseases, India, medical biology, pain relief

### Introduction

“The purpose of a doctor or any human, in general, should not be to simply delay the death of the patient, but to increase the person's quality of life”- quality of life can be improved by essentially reducing the gap between aspirations and possibility. Palliative care is defined as an inter-professional discipline that improves the living condition of diseased persons and their families and is comparatively a new concept of modern medicine. Palliative care aims to reduce the complications associated with deadly diseases like cancer, advanced chronic pulmonary disease, extreme kidney insufficiency, severe heart insufficiency, dementia and other degenerative diseases and provides relief to patients from life–risk condition [1]. Considering individuals as holistic beings, health has moved away from the concept that restricted it from the mere treatment of diseases. The idea of health and healing are added at different levels of an individual's overall subjective satisfaction in life, such as social, spiritual and psychological which are recommended by palliative care rules [2]. For example, it is suggestive that the addition of special palliative care to routine cancer treatment is better than oncologic care alone. Cancer death follows a clear life pathway, from a long period of good physical condition to a steady, rapid decline towards death. Palliative cancer care is associated with improvement of life quality, treatment of end-of-life, depression reduction, illness understanding, and patient satisfaction [3, 4, 5, 6]. Neurological diseases, on the other hand, are mostly incurable, reduce life expectancy [7], and include depression, pain and other symptoms. Sometimes, the

norms of palliative medicine are applied by neurologists for the care of patients with chronic, progressive illnesses [8, 9]. This care meets their emotional, informational, spiritual, physical or social needs during their period of diagnostic, treatment, health promotion and prevention, survivorship, palliation and bereavement [10, 11]. Thus, palliative care becomes supportive care for patients who suffer advanced disease [12].

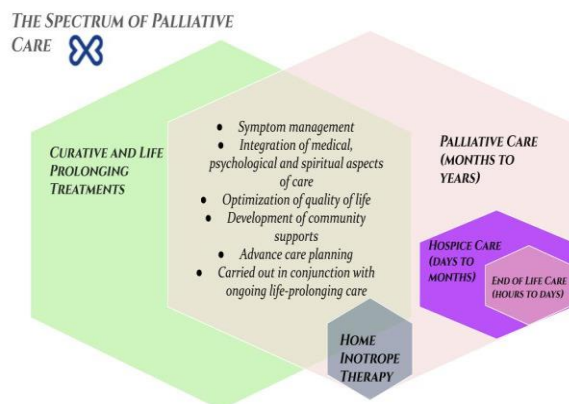
There is a misconception that palliative care is synonymous with hospice care. Patients who come to the end of life are actually suitable for palliative care, different from hospice care [13]. Similarly, some health care specialists think palliative care is service-less. When disease-modifying treatments are not available or not appropriate, then palliative care will be the main focus to handle the diseased condition. It is suggested that early palliative care may positively affect both quality of life and survival [14] and it is useful alongside curative treatments [15, 16, 17]. Palliative care is a special medical service which provides comfort to patients from the symptom, painful condition, and stress of a serious disease and is possible at any age and all stages in a serious illness, and can be given along curative treatment [18]. The spectrum of palliative care includes integration of psychological, spiritual and medical care along with the curative and life-prolonging care (Figure 1).

[Received 19 Feb 2020; Accepted 26 March 2019; Published (online) 30 June 2020]

Publisher's Note: RCLSS stays neutral regard to jurisdictional claims published maps



Attribution 4.0 International (CC BY 4.0)



**Figure1.** Spectrum of palliative care.

The Lancet Commission on Access to Pain Relief and Palliative Care in 2017 states that 61 million people around the world have "serious health-related suffering" (SHS) which entails palliative care. India alone accounts for 10 million of them. The recommendation of the commission indicates the introduction of a low-cost essential palliative care package, which would be made affordable for palliative care and will be less expensive treatment near ‘the end of life’.

As mentioned by Dr M R Rajagopal (The Hindu, June 2018), father of palliative care in India, ‘just 1%-2% people have access to palliative care or pain management in India’. This country has a national programme but the medical students have little access to learn pain management through their curriculum. For most severe pain in two-third of cancers, major trauma, surgical pain, which can not be managed without opioids, reach less than 2% of the needy of the country. However, the country grows poppy, makes opium and exports it throughout the world. There is nothing for medical students to study pain management and the majority of students do not know anything about it. India needs three things- a policy and its plan of implementation, availability of essential medications to common people and public awareness. Health care expenses will drop significantly if palliative care is implemented.

The advancement of palliative care in India is obstructed by many factors like poverty, population density, geographical diversity, workforce development at the base level, restrictive policies regarding opioid prescription, limitations in national palliative care policy and lack of interest of the institutions in this particular subject [19].

### History of palliative care in Indian medical science

Even though developed nations have been advocating palliative care for almost 50 years, it is a comparatively new concept in India, having developed over the past 30 years. A National Cancer Control Programme was first initiated by the Government of India in 1975. The programme was reorganized to provide pain relief at the basic service level in 1984. But this policy was not converted into a large-scale service initiative [20]. The first Hospice facility was

established in Mumbai in 1986 in the Shanti Avedna Ashram. A UK charity, Cancer Relief India was founded in 1990 which intended on imparting the knowledge of palliative care to doctors and nurses for relief of cancer patients [21]. The Pain and Palliative Care Society (PPCS) was created in Calicut, Kerala in 1993. The India Association of Palliative Care (IAPC) was brought into by WHO in 1994. Anaesthetists all over the nation served as the initial founding members, they being the ones generally involved in palliative care of pain management. The National Palliative Care Strategy was formed by the joint action of the Ministry of Health and Family Welfare and Pallium (a charitable trust for Palliative Care in India founded in 2003), which paved the way for the formation of National Program of Palliative Care for India (NPPC)(2012-2017).

The objectives of the National Palliative Care Strategy are as follows.

“Improve the capacity to provide palliative care service delivery within government health programs such as the National Program for Prevention and Control of Cancer, Cardiovascular Disease, Diabetes, and Stroke; National Program for Health Care of the Elderly; the National AIDS Control Program; and the National Rural Health Mission”.

“Refine the legal and regulatory systems and support implementation to ensure access and availability of Opioids for medical and scientific use while maintaining measure for preventing diversion and misuse”

“Encourage attitudinal shifts amongst healthcare professionals by strengthening and incorporating principles of long term care and palliative care into the educational curricula (of medical, nursing, pharmacy and social work courses)”.

“Promote behaviour change in the community through increasing public awareness and improved skills and knowledge regarding pain relief and palliative care leading to community owned initiatives supporting health care system”.

“Develop national standards for palliative care services and continuously evolve the design and implementation of the National program to ensure progress towards the vision of the program.”

One of the important barriers was the budgetary allocation and the other issues faced by India in palliative care could be based on the caregivers – inability to prognosticate or psychological attachment to patients; or patient/family, fear of being unethical, legal litigation, ineptitude to accept that death is near, failure to realize the shortcomings of further aggressive medical care, hope for miracles or fear of religious or ethical impropriety etc. So patients will be unlikely to get the benefit from a dignified death without increasing awareness and education from the side of the provider itself. Pallium, India undertook the initiative in 2013 for promoting curricula for undergraduate medical and nursing courses. Medical Council of India together with the Indian Nursing Council will be the responsible board to consider that [22]. Palliative Care in India got leap forward in 2014 with the

amendment of Narcotic Drugs and Psychotropic Substances Act (NDPS) 1985. Access to opioids was a major barrier to Palliative Care services in India, which was under the control of states of India. A Human Rights Council reported stating “In 2008, India used an amount of morphine that was sufficient to adequately treat during that year only about 40,000 patients suffering from moderate to severe pain due to advanced cancer, about 4% of those requiring it” [23, 34]. Only a few states of India, i.e. Delhi, Karnataka, Kerala and Tamil Nadu have progressed in access to opioids. Now it is up to the state governments to spread awareness of the newly amended act amidst healthcare providers to extend benefits pharmacists and the general public. Now the Palliative Care is a part of the ‘Mission Flexipool’ under National Health Mission (NHM).

**Ethics and social issues in palliative care**

Many of the contemporary debates in bioethics are the direct result of advancement in scientific and medical knowledge and technology. With these new advances, the human race is not only morally challenged as to the basic nature of life and death but also about the power the social structure can assert over those in need who do not have the means to pay for it. Clinical decision-making in hospices and palliative care has relied on bioethical principles as a guide. These principles – beneficence, non-maleficence, autonomy and justice - assist the palliative care practitioner to assess issues that are often very emotive and to use a framework to guide the patient, family members and care team to a practical decision which is open to review as the patient’s condition or wishes change. It was reported that European physicians used to make end-of-life decisions in roughly 81–93% of cases [25]. In contrast in India, it is thought to be difficult to take these decisions due to a number of issues like lack of awareness of ethical issues, a tradition of heroic “fighting till the end,” inefficient orientation of palliative care and legal and administrative mind locks [26, 27]. Recently, the Economist Intelligence Unit (EIU) ranked India’s participation of end-of-life care horribly [28] and India was reported to have scored poorly in all of the indices: basic end-of-life care environment, availability, cost and quality of End Of Life Care (EOLC). Except for Kerala, which garners community-driven hospice service, the rest of India has been reported to have “lamentably poor” palliative care facilities by EIU.

The palliative and hospice care movement is needed to face the social and legal reform in India [29] to reduce the financial burden to the average people as healthcare expenses [30]. Lack of appropriate policies for distribution of life support system in a populous country like India and the current cultural traditions and views take away the serenity and dignity of death [31, 32]. The community related to policymakers should include the regulators, pharmacists, drug regulators, all law enforcement agents, community leaders, administrators to educate the people and health care providers through media and other mediators (Figure 2).

In the context of India with its unique cultural, social, economic and legal complexities “End Of Life in Dementia”

(EOLD) have not yet been adequately studied. There is a dread paucity of creation and management of logical data related to the life support system in Indian ICUs. The Indian physician’s attitude [33] is severely hampered in practice by the lack of safeguards in the form of legal guidance. But the ISCCM (Indian Society of Critical Care Medicine) took significant steps towards improving EOLD by providing a clearly stated professional position in 2005. The “left against medical advice (LAMA)” in India generally refers to the situation in which the patient’s family unilaterally withdraws due to insupportable financial and other burdens [33], especially since the health-care delivery is dominated by the private sector [30]. Physicians may implicitly endorse this method as the only course to counter perceived social and legal complications. Whereas out of the 48 deaths in the Netherlands [35] and Tunisia [35, 36] preceded by certain constraints of treatment, 38 (79%) used to discharge as Planned discharges for terminally ill patients for assuring “good death”.

There are several other misconducts to improve in critical care norms in India: Patients are usually approached in the “ paternalistic” way since the notion of autonomy is very poor in the contemporary cultural ethos. Medical education trains the physicians to concentrate on the curative rather than the palliative aspects of illnesses overlooking the phase of the illness. Physicians run the risk of being wrongly blamed for not carrying out their duties well or of possible criminal liability for restricting needless therapies. Adding to his predicament there is, in essence, an absence of legal guard in the guidelines (relating to deaths in intensive care units) in India. It was found that the most significant factor for obstruction of relevant EOLDs and “good patient death” was legal concerns [37].



Policy	Drug Availability	Implementation	Education
<ul style="list-style-type: none"> <li>Palliative care part of national health plan, policies, related regulations</li> <li>Funding/ service delivery models support palliative care delivery</li> <li>Essential medicines</li> </ul> <p>(Policy makers, regulators, WHO, NGOs)</p>	<ul style="list-style-type: none"> <li>Opioids, essential medicines</li> <li>Important quota</li> <li>Cost</li> <li>Prescribing</li> <li>Distribution</li> <li>Dispensing</li> <li>Administration</li> </ul> <p>(Pharmacists, drug regulators, law enforcement agents)</p>	<ul style="list-style-type: none"> <li>Opinion leaders</li> <li>Trained manpower</li> <li>Strategic &amp; business plans - resources, infrastructure</li> <li>Standards, guidelines measures</li> </ul> <p>(Community &amp; clinical leaders, administrators)</p>	<ul style="list-style-type: none"> <li>Media &amp; public advocacy</li> <li>Curricula, courses - professionals, trainees</li> <li>Expert training</li> <li>Family caregiver training &amp; support</li> </ul> <p>(Media &amp; public, healthcare providers &amp; trainees, palliative care experts, family caregivers)</p>

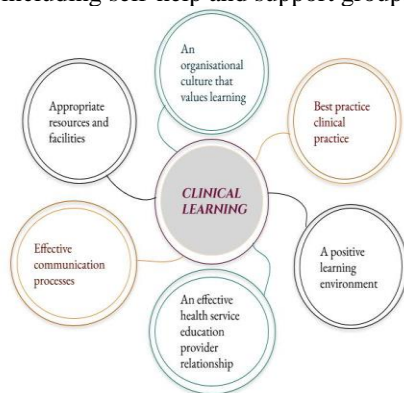
**Figure 2. Policies of palliative care. Possibilities of complementary and alternative medicine for palliative care in India:**

Making decisions on the appropriate provision of complementary therapy services for patients with deadly diseases is difficult. A considerable proportion of patients express interest in the use of complementary therapies and a significant number report they have used complementary

therapies for their condition. Yet there is little conventional evidence on the effectiveness of these therapies for the relief of pain, anxiety or distress, or for improving quality of life. In addition, some complementary therapies may present risks to patients, as well as benefits.

For providing psychological and emotional support by alleviating symptoms, complementary therapies are employed along with the orthodox treatment methods.

Complementary therapies encompass a diverse range of interventions, including physical, psychological and pharmacological therapies. Therapies may be considered as self-care approaches (meditation, for instance), as techniques (massage) or as interventions with a range of clinical applications (Ayurveda, homoeopathy, etc.). All are used in this context in addition to, rather than in place of, orthodox cancer treatments to help with symptom control and to enhance general wellbeing. The most extensively used complementary therapies with cancer are the touch therapies (aromatherapy, reflexology and massage) and psychological interventions (relaxation, meditation and visualisation). Patients with cancer may access complementary therapy services from a variety of sources in the statutory, voluntary and independent sectors. They are delivered in settings such as general practices, hospitals, hospices and diverse community locations, including self-help and support groups.



**Figure 3.** Different aspects of clinical learning of palliative care.

Recommendations can be made for the judicial supervision of acupuncture and herbal medicine, with the government expected to produce a document for consultation in the near future. Work is in hand to strengthen the voluntary regulation of aromatherapy, homoeopathy, massage, reflexology and others, based on the adoption of national occupational standards. Government should approve the policies on qualifications, professional registration and indemnity in

#### Author Disclosure Statement

No competing financial or academic interests exist.

#### Acknowledgement

relation to complementary therapies. These are not unique to cancer services. It is widely acknowledged that issues relating to training, qualifications and competence should be addressed at the national level to ensure safety for patients. Best practice clinical learning should include all infrastructural facilities available to the service providers who are enriched with effective communication process to reach the people (Figure 3).

#### Research and education

The need for palliative care is rising within the patient’s community suffering from critical diseases. Several gaps are present in the palliative care research which includes:

Physicians are alerted by advancement and evaluation of more specific prognostic predictors.

Better identification of high-risk patients and caregivers for palliative care referrals.

Clinical trials including implementation studies are required to improve the management of non-motor symptoms.

Patient-centred studies to identify and characterize palliative care needs in neurology and patient preferences for addressing these needs.

Cost-effectiveness and outcome studies of palliative care interventions.

In spite of the improvement of palliative care training, only 52% of programs offer an educational experience in end-of-life and palliative care, and less than 8% provide clinical knowledge [38]. These data support the continuing need for enhanced palliative care training of critical disease specialists [39]. Conferences, journals, and other medical education programmes may provide benefit to the palliative care specialists. Specialized training is required for specialists to manage critical patients. Finally, patients and specialists require more data about palliative care and hospice.

#### Conclusion

In the past, palliative care is derived from a philosophy of care in the way of professional discipline. In hospitals, the integration of normal treatment and palliative care can help the doctor to cure the fatal disease. But a difference is present between the model of integration of palliative care and disease in small, ill-developed health centre and large cancer research institute. Treatment of patients affected with cancer and any other fatal diseases depends on the quality of palliative care. Integration of disease treatment into both primary and special palliative care at proper times improves life span, life quality, and survivability rate of patients. Many studies suggest that optimization of patient care is governed by palliative care specialists, researchers, students, doctors, management of hospitals, funding agencies, professional institution and governments. In future, modern problems of integration and delivery of palliative care into patients will be solved by valuable researches on palliative care.

All authors gratefully acknowledge the University of Kalyani, Kalyani Nadia, WB, India for financial support.

#### References

- [1]. World Health Organization. (2002). WHO definition of palliative care. Geneva. Retrieved September 28, 2009, from <http://www.who.int/cancer/palliative/definition/en/>
- [2]. "WHO | WHO Definition of Palliative Care". WHO. Retrieved 2019-12-
- [3]. Bakitas M, Lyons KD, Hegel MT, et al. "The project ENABLE II randomized controlled trial to improve palliative care for rural patients with advanced cancer: baseline findings, methodological challenges, and solutions." *Palliat Support Care*, 7, 75-86, 2009.
- [4]. Temel JS, Greer JA, Muzikansky A, et al. "Early palliative care for patients with metastatic non-small-cell lung cancer." *N Engl J Med*, 363, 733-42, 2010.
- [5]. Temel JS, Greer JA, Admane S, et al. "Longitudinal perceptions of prognosis and goals of therapy in patients with metastatic non-small-cell lung cancer: results of a randomized study of early palliative care." *J Clin Oncol*, 29, 2319-26, 2011.
- [6]. Zimmermann C, Swami N, Krzyzanowska M, et al. "Early palliative care for patients with advanced cancer: a cluster-randomised controlled trial." *Lancet*, 383, 1721-30, 2014.
- [7]. Hoyert DL, Xu JQ. "Deaths: Preliminary Data for 2011. National Vital Statistics Reports", vol. 61, no. 6. Hyattsville, MD: National Center for Health Statistics; 2012
- [8]. Palliative care in neurology. The American Academy of Neurology Ethics and Humanities Subcommittee. *Neurology*. 46, 870–872, 1996.
- [9]. Foley KM, Carver AC. "Palliative care in neurology." *Neurol Clin*, 19, 789–799, 2001.
- [10]. Hui D, De La Cruz M, Mori M, et al. "Concepts and definitions for "supportive care," "best supportive care," "palliative care," and "hospice care" in the published literature, dictionaries, and textbooks." *Support Care Cancer*, 21, 659-85, 2013.
- [11]. Page B. "What is supportive care?" *Can Oncol Nurs J*, 4, 62-3, 1994.
- [12]. Hui D. "Definition of supportive care: does the semantic matter?" *Curr Opin Oncol*, 26, 372-9.
- [13]. Jablonski A. "Palliative care: misconceptions that limit access for patients with chronic renal disease." *Semin Dia*, 21, 206–209, 2008.
- [14]. Temel JS, Greer JA, Muzikansky A, et al. "Early palliative care for patients with metastatic non-small-cell lung cancer." *N Engl J Med*, 363, 733–742, 2010.
- [15]. Bunting-Perry LK. "Palliative care in Parkinson's disease: implications for neuroscience nursing." *J Neurosci Nurs*, 38, 106–113, 2006.
- [16]. WHO(2013) World Health Organization. Definition of palliative care. Accessed December 11,
- [17]. Bernat JL. "Ethical and legal issues in palliative care." *Neurol Clin*. 19, 969–987, 2001.
- [18]. Center to Advance Palliative Care. Defining palliative care. Accessed March 14, 2014.
- [19]. Khosla D, Patel F D and Sharma S . "Palliative Care in India: Current Progress and Future Needs." *Ind J of Palliative Care*, 18(3), 149-54, 2012.
- [20]. Rajagopal MR, Venkateswaran. "Palliative care in India: successes and limitations." *J Pain Palliat Care Pharmacother*, 17:121-128, 2003.
- [21]. Webb PA. "Cancer relief in India." *Eur J Cancer Care*, 2, 2, 1993.
- [22]. Rajagopal MR. "The current status of Palliative Care in India." *Cancer Control*, 57-62, 2015.
- [23]. Human Rights Council. Report of the special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Manfred Nowak, A/HRC/10/44, para 72. 2009 Jan 14. Available from: <http://www2.ohchr.org/english/bodies/hrcouncil/docs/10session/A.HRC.10.44AEV.pdf>.
- [24]. Bandewar SV. "Access to controlled medicines for palliative care in India: gains and challenges." *Indian J Med Ethics*, 1-6, 2015.
- [25]. Sprung CL, Woodcock T, Sjobqvist P, Ricou B, Bulow HH, Lippert A, et al. "Reasons, considerations, difficulties and documentation of end-of-life decisions in European intensive care units: The Ethicus Study." *Intensive Care Med*, 34, 271–7, 2008.
- [26]. Mani RK. "End of life care in India." *Intensive Care Med*, 32, 1066–8, 2006.
- [27]. Barnett VT, Aurora VK. "Physician beliefs and practices regarding end of life care in India." *Indian J Crit Care Med*, 12, 109–15, 2008.
- [28]. Economist Intelligence Unit. Commissioned by LIEN Foundation. The quality of death: ranking end of life care across the world. [accessed in 2010]. Available from [www.eiu.com/sponsor/lienfoundation/qualityofdeath](http://www.eiu.com/sponsor/lienfoundation/qualityofdeath).
- [29]. Maceden S. "Moving towards a National policy on Palliative and end of care." *Indian J Palliat Care*, (suppl):s42–44, 2011.
- [30]. Jayaram R, Ramakrishnan N. "Cost of critical care in India." *Indian J Crit Care Med*, 12, 55–61, 2008.
- [31]. Firth S. "End of life: A Hindu view." *Lancet*, 366, 682–6, 2005.
- [32]. Bülow HH, Sprung CL, Reinhart K, Prayag S, Du B, Armaganidis A, et al. "The world's major religions' points of view on end-of-life decisions in the intensive care unit. *Intensive Care Med*, 34, 423-30. [PubMed][Google Scholar], 2008.

- [33]. Mani RK. “Limitation of life support in the ICU.” *Indian J Crit Care Med*, 7, 1112-7, 2003.
- [34]. Beuks BC, Nijhof AC, Meertens JH, Ligtenberg JJ, Tulleken JE, Zijlstra JG. “A good death.” *Intensive Care Med*, 32, 752-3, 2006
- [35]. Kallel H, Dammak H, Bahloul M, Ben Hamida C, Chelly H, Rekik N, et al. “ A good death: Another break in the wall.” *Intensive Care Med*, 32, 1915-6, 2006.
- [36]. Boussarsar M, Bouchoucha S. “Dying at home: Cultural and religious preferences.” *Intensive Care Med*, 32, 1917-8, 2006.
- [37]. Mani R.K., Amin P., Chawla R., Divatia J.V., Kapadia F, Khilnani P, Myatra, S.N. Prayag S., Rajagopalan R., Todi S.K., and Uttam R. “Guidelines for end-of-life and palliative care in Indian intensive care units: ISCCM consensus Ethical Position Statement.” *Indian J Crit Care Med*. 2012 Jul-Sep, 16(3): 166-181.
- [38]. Creutzfeldt CJ, Gooley T, Walke M. “ Are neurology residents prepared to deal with dying patients?” *Arch Neurol*, 66, 1427-1428, 2009.
- [39]. Barclay S, Moran E, Boase S, et al. “Primary palliative care research: opportunities and Challenges” *BMJ Supportive & Palliative Care*, 9,468-472, 2019.