



Palliative Care in India: Past, Present, and Future

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Abstract

Over the last 4 decades, palliative care in India had steady growth and development from the early hospice movement in the 1980s to specialist and subspecialist palliative medicine in the 2020s. In the first decade, sustainable service delivery by capacity building, novel contextual community networking models, education facilitated by international collaboration, efforts towards opioid access, and nationwide networking through the formation of an association kindled the grand beginning of palliative care in India. Over the next 2 decades, palliative care in India evolved and developed as a speciality, disseminated across the nation, found its place in all clinical settings, engaged with specialities and subspecialities, developed its own specialist training program, and focused on indigenous research enabled through its own journal. Furthermore, end-of-life care awareness, training, advocacy, and initiatives towards policy and legislation reaped huge dividends in terms of improving the quality of dying in India. Generalist training through short and intermediate courses enhanced the knowledge and interest of the primary health care providers and non-palliative care specialists and education through international collaboration both in-person and distance learning modes augmented these efforts. In 2019, most elements of palliative care are part of the undergraduate medical curriculum. Policy initiatives by state and central governments and the inclusion of palliative care in the National Health Policy of 2017 offer hope for the future. In the last decade, we think that palliative care has found its footing and is ready to emerge as one of the dominant clinical specialities. Moreover, it is time for it to broaden its horizon, scope, and realm by developing into subspecialist verticals, being ubiquitous in all clinical spaces, focusing on robust evidence-based approach and research grounded in the Indian practice context.

Keywords Palliative · Hospice · India · Growth · Development

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The Genesis of Palliative Care in India

Dawn of Hospice Movement

In 1986, Dr Lusito D'Souza, a surgical oncologist, established the first hospice called Shanti Avedana in Mumbai (then Bombay) on a plot of land donated by the Archdiocese of Bombay. Severe suffering, caregivers' inability to manage dying patients at home, and persistent requests for euthanasia among cancer patients in the early 1980s prompted Dr D' Souza to establish a hospice [1]. He was ably supported by dedicated nuns from the sisters of The Holy Cross. During the same period, Ms Gilly Burns, who served as an advisor to the World Health Organisation (WHO), conducted education tours across India, disseminating palliative care knowledge in various hospices [2]. Subsequently, Sevagram Trust started palliative care services in Kerala [3]. In 1992, Cipla Cancer and AIDS Foundation developed a hospice with an original concept of a living palliative care centre [4]. Simultaneously, Jivodaya Hospice, Pain and Palliative Care Society, and Word and Deed Hospital commenced palliative care services in Kerala. The Indian Cancer Society and Rotary Bangalore Indiranagar were instrumental in setting up a hospice in Bangalore called Karunashraya in 1994 [3]. CanSupport in Delhi, Guwahati Pain and Palliative Care Society in Assam, and Lakshmi Palliative Care in Chennai were the other initial champions providing palliative care in India.

Origin of Oncology Palliative Care

In 1985, the first oncology palliative care was provided through Tata Memorial Centre, Mumbai. During those days, advanced cancer patients with severe pain received a tablet called A and O (aspirin and opium) prepared by Haffkine Institute, Mumbai, exclusively available in Tata Memorial Centre for cancer pain management. From 1986 to 1987, initial discussions were held with Maharashtra's Food and Drug Administration and pharmaceutical industries to make morphine available at Tata Memorial Centre. In 1987, a license to procure, store, and dispense oral morphine for cancer pain was obtained. Intractable cancer pain was then managed with neurolytic blocks using phenol and absolute alcohol [5].

Furthermore, in the 1990s, India's National Cancer Control Program initiated the first guidelines for cancer pain relief [6]. In the 1990s, apart from the twelve regional cancer centres, oral morphine was available for pain management in Mumbai, Bangalore, Manipal, Trivandrum, Ahmedabad, and the All-India Institute of Medical Sciences (AIIMS), Delhi [1]. A pain clinic at the Regional

Cancer Centre, Trivandrum, Kerala, established with WHO subsidy in 1986, had demonstrated that adequate pain control could be achieved for outpatients [7]. Likewise, an outpatient palliative care clinic established by a nongovernmental organisation (NGO) at the Calicut Medical College showed similar results [3].

Beginning of Community Palliative Care

The Pain and Palliative Care Society (PPCS), started in Calicut, Kerala, in 1993, evolved from a pain clinic situated at the Calicut Medical College [3]. In 1995, the WHO declared PPCS a demonstration project, making it a model for palliative care delivery in developing countries [8]. Initially, only outpatient services were offered, which soon incorporated home visits and later in-patient facilities and independent link centres in neighbouring towns [9]. The Neighbourhood Network in Palliative Care (NNPC) program was initiated in 2000 to facilitate and foster a sustainable, community-led service capable of providing palliative care to all those in need. In this program, volunteers from the local community were trained to identify problems of the chronically ill in their area and intervene effectively, with active support from a network of trained professionals. By 2007, it had more than 60 units covering a population of more than 12 million and was probably the largest community-owned palliative care network in the world [10]. This program facilitated enormous social mobilisation, which was possible within the socially conscious State of Kerala. Community-owned units were set up in rural areas with the help of the PPCS. This program was supported by a large volunteer force enthusiastic about learning about palliative care. The Network covered the entire state, with over 60 doctors, 350 nursing staff, and over 10,000 volunteers catering to clinical conditions like chronic end-stage organ impairment, cancer, and HIV [11, 12].

The Bangalore Hospice Trust has been providing home care for the terminally ill since 1994. The home care team consisted of trained nurses, counsellors, and social workers who used a three-wheeler autorickshaw to visit terminally ill cancer patients in their homes and provide emotional support and advice about symptom relief [3]. CanSupport, a nongovernmental organisation based in Delhi, was formed in 1996. They offered home-based services by multidisciplinary teams consisting of physicians, nurses, and social workers trained in palliative care [13].

Start of Palliative Care Education in India

Cancer Relief India (CRI), in collaboration with the Cancer and Palliative Care Unit of the WHO, the International School for Cancer Care, the Macmillan Cancer Relief Fund, and Global Cancer Concern organised palliative care

training for many healthcare professionals throughout India [3]. Between 1993 and 1995, CRI and Cancer Relief Macmillan Fund, in collaboration with WHO, facilitated the training of doctors and nurses in palliative care courses in the UK during a 3-year Indo-British project. CRI also supported four doctors in completing the Diploma of Palliative Medicine at the University of Wales College of Medicine. In 1999, a nurse from Kerala was sponsored by CRI to be the first nurse from India to complete the Diploma in Palliative Nursing at Oxford Brookes University [7]. Furthermore, in collaboration with Bruce Davis Trust and Sir Michael Sobell House in the UK, PPCS conducted educational programs for volunteers, nurses, and doctors, including a 6-week certificate course for doctors [8]. The Indian Association of Palliative Care initiated the first significant systematic effort for nationwide training of doctors and nurses through its Project Kiran in association with HelpAge India in 2008 [14].

Creation of Palliative Care Network and Standards in India

Palliative care 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 essential steps in the history of palliative care development in India also began from here, that is, the formation of the Indian Association of Palliative care (IAPC) with the help of WHO. The IAPC is a registered Public Trust and Society formed on 16 March 1994 in Ahmedabad in consultation with the WHO and the Government of India as a national forum to connect, support, and motivate individuals and institutions involved in palliative care [3]. Over the years, IAPC has fulfilled the role of a common platform for the involvement of all those interested in palliative care. It has been involved in advocacy, establishing standards, organising training programmes, enunciating policy decisions and position statements, and working with the government to facilitate the spread of palliative care services in India. The IAPC has been working as a national umbrella organisation for palliative care in India. It has over 2500 registered life members, including individual, institutional, and overseas members.

In a state like Kerala, adequate coverage and the network led to the designation of centres such as the Institute of Palliative Medicine (IPM), Calicut and Trivandrum Institute of Palliative Sciences (TIPS), and Pallium India as the Collaborating Centers of WHO for Community Participation in Palliative Care and Training and Policy on Access to Pain Relief, respectively [15]. In 2006, Pallium India assembled a working group at the national level to develop minimum standards. The standards were to be used for self-evaluation by palliative care services in the country. The working group prepared a standards document with two parts—the first

composed of eight essential components and the second, 22 desirable components [16].

Initial Efforts Towards Opioid Availability

In 1985, India's Narcotic and Psychotropic Substances (NDPS) Act negatively impacted opioid access. In the 13 years that followed the NDPS Act's enactment, annual morphine consumption in the country fell by an alarming 92%, from 600 to a mere 48 kg. In 1997, India's per capita consumption of morphine ranked among the lowest globally (113th of 131 countries). During the same period, global consumption of morphine increased by 437%. In 1994, the Director of WHO's Cancer Unit in Geneva explored morphine unavailability in India, the need for opioids, and barriers to availability and patient access.

The WHO collaborating centre for policy and communication in cancer care, along with the Indian Association of Palliative Care (IAPC) and the Pain and Palliative Care Society (PPCS), Calicut, participated in two national meetings in 1994 and 1995, sponsored by the Ministry and the WHO in New Delhi to review policies governing the availability of opioids. Following consultation with the IAPC Committee, a proposal to simplify India's narcotic control policies was prepared with expert advice from the WHO Collaborating Centre at Pain and Policy Studies Group, Madison-Wisconsin. The proposal was sent to the national revenue secretary with a graph showing the decreasing use of morphine. On 8 May 1998, the revenue secretary sent the model rule to the heads of all state and territorial governments with instructions to amend state rules. The first state workshop on morphine availability was held on 24 June 1998 in Thiruvananthapuram. The Government of Kerala adopted and published the model rule in 1999. Using the Kerala workshop as a model, the collaborators sponsored and participated in 11 workshops between 1998 and 2002 in several Indian states [17]. However, the states were not legally obliged to follow the instruction of the revenue secretary, and progress was minimal. Following sustained advocacy by the palliative care community, the Indian Parliament amended the NDPS Act in 2014, creating a category of "Essential Narcotic Drugs" (ENDs), transferring powers for legislation regarding ENDs from the states to the central government, and simplifying the procedure. All states and union territories had to follow a single process. The drug controller was the single authority for approving recognised medical institutions (RMIs) having the licence for stocking and dispensing ENDs [18]. It is hoped that this will facilitate the better availability of opioids in India. This was possible with the involvement of all stakeholders, the government, the palliative care community and the manufacturers of opioids and narcotics.

Development of Palliative Care in India

Specialist Palliative Medicine Education in India

In 2010, the Medical Council of India (MCI) recognised palliative care as a medical subspecialty. The Specialist Palliative Medicine training (MD Palliative Medicine) in India is a 3-year onsite supervised training program offered at a Medical Council of India (MCI) recognised department in a medical college. The first specialist Palliative Medicine training commenced at Tata Memorial Hospital, Mumbai, in 2012. Specialist Palliative Medicine training involves 24 months of broad training (core training) in palliative medicine and 12 months of related speciality/subspecialty training (non-core training) in oncology specialities, general medicine and related subspecialty, paediatrics, public health, and allied health. MCI created the curriculum for a competency-based postgraduate training program for MD Palliative Medicine with the help of an expert group of palliative medicine professionals. This paved the way for many palliative medicine departments across India to initiate efforts towards starting the MD Palliative Medicine program [19]. Furthermore, in 2021, the National Board of Examinations (NBE) approved Diplomate in National Board (DNB) in Palliative Medicine. In 2022, five institutes are offering the MD Palliative Medicine Program, and five are offering the DNB Palliative Medicine Program.

Generalist Palliative Care Education in India

The Certificate Course in Essentials of Palliative Care was started by the Indian Association of Palliative Care in 2007. Several thousand candidates all over the country have completed the course. The course aims to inculcate the principles of palliative care and thereby improve patient care through proper communication and effective management of complex symptoms. The system helps to popularise palliative care in India by spreading the message among doctors and nurses and encouraging them to practice palliative care. Doctors with MBBS/BDS and nurses with BSc Nursing or GNM are eligible to apply. The course has two components: part A and an optional part B (Hands-on Training in Palliative Care). Part A consists of a contact session of 15 h, in the beginning, followed by 8 weeks of distance learning. Other agencies offering regular short (3–7 days) and intermediate (4–6 weeks) training programs for doctors and nurses include the Institute of Palliative Medicine (Kerala), Pallium India (Kerala) and MNJ Institute of Oncology and Regional Cancer Centre (Hyderabad). Furthermore, MNJ Institute also runs a regular Fellowship Program in Paediatric Palliative Care.

The National Fellowship in Palliative Medicine (NFPM) has been a postgraduate training program in palliative medicine for medical professionals in India since 2004. The Institute of Palliative Medicine Kozhikode launched this one-year distance education program jointly with the Christian Medical Association of India. NFPM is designed to equip interested and committed candidates in palliative medicine, build the capacity of healthcare professionals and institutions and prepare them to render much-needed palliative care services to the people of this country. One-year fellowships in palliative medicine are offered in centres like the Kidwai Memorial Institute of Oncology Bengaluru and the Christian Medical College in Vellore, South India. Furthermore, Tata Memorial Hospital Mumbai offers a 2-year residential fellowship program in Palliative Medicine.

Undergraduate Palliative Care Education in India

As part of the 2018 Competency-Based Medical Education (CBME) curriculum for MBBS, the AETCOM (Attitude Ethics Communication) competencies were developed. It is 34 h in professional year 1, 37 h in professional year 2, 25 h in professional year 3, and 44 h in professional year 4. Out of 140 plus hours of AETCOM training in MBBS, 87 h are related to palliative care. Furthermore, the general CBME curriculum for MBBS has 34 h of palliative care topics [20].

International Collaborations Towards Palliative Care Education in India

For the past 25 years, the Cardiff University Diploma and MSc Programme in Palliative Medicine and Care has delivered distance learning education to those pioneering palliative care services in India and worldwide. Scholarships from the Commonwealth Scholarship Commission have enabled funding for the diploma and MSc course fees for approximately 90 Indian doctors. In addition, a 20-module, free online resource for palliative care in India is available with the help of e-cancer. The partnership between the Cardiff University Diploma and MSc Programme, the Bangalore Hospice Trust, and the Commonwealth Scholarship Commission has significantly influenced the promotion of research, evidence-based practice, and good palliative care within India over the past decade.

Indo-American Cancer Association (IACA), and the John and Editha Kapoor Foundation, in association with Pallium India, launched a 6-week certificate course in palliative care for doctors and nurses starting January 1, 2015, at several palliative care centres across India. IACA Scholarship is available for ten pairs per year, consisting of one doctor and one nurse at the six palliative care centres across India.

EPEC-India program was developed in collaboration with the Northwestern University of Chicago to create palliative

care trainers across India. After a long hiatus, the EPEC training of the trainer's conference was revived in Feb 2016 with the help of distinguished EPEC faculty members. Subsequently, adults and paediatric EPEC programs were conducted every year.

Extension for Community Health Outcome (ECHO) was an innovative program initiated by Dr Sanjeev Arora in New Mexico. Numerous virtual education programs have been introduced in various parts of the country, collaborating with ECHO International. Thousands of health care providers have received palliative care training through this initiative.

Paediatric Palliative Care

The common life-limiting illnesses seen in the paediatric age group are numerous, i.e., childhood cancer, haemolytic anaemias, inoperable congenital heart diseases, HIV/AIDS, chronic kidney diseases, neurologically handicapped, and the various chromosomal anomalies. There is no data bank available in India regarding these illnesses. Secondly, few trained personnel take up the Paediatric Palliative Care (PPC) [21]. Paediatric palliative care in India is at the capacity building stage. Although it began 2 decades ago, its growth is restricted to less than ten cancer centres with minimal community paediatric palliative care activity [22]. Wherever PPC centres are developed, they are mostly attached to medical colleges, regional cancer centres, or centres of excellence in health like AIIMS, etc. PPC is still cancer centred, which is a serious obstacle to developing palliative care services for children with life-limiting illnesses. Paediatric palliative care programmes are available in Tata Memorial Hospital Mumbai, Can Kids Delhi, MNJ Institute of Oncology Hyderabad, and Government Medical College Calicut in Kerala [23].

Palliative Care Capacity Building

The National Cancer Grid (NCG) is a union of cancer centres in the country, which aims to provide uniform high standards of cancer care, follow uniform evidence-based guidelines for the management of patients, develop trained human resources, and conduct collaborative clinical research. It ensures that patients from any part of the country are given the same quality of care without travelling long distances, regardless of their ability to pay for treatment, achieved by following the same evidence-based management guidelines, which are implementable in all cancer centres. National Cancer Grid can be an effective portal for developing high-quality uniform palliative care delivery across India. In the 2016 annual meeting of NCG, it was decided to initiate palliative care services in centres networked through NCG. The NCG palliative care conducted a gap analysis survey in the 2018 group, which demonstrated significant

gaps in palliative care delivery in the cancer centres across India [24].

The Cancer Treatment Centres (CTC) Palliative Care Training Program is a collaborative project of Asia Pacific Hospice Palliative Network, Singapore; All India Institute of Medical Sciences, New Delhi; and Manipal Academy of Higher Education, Manipal, supported and funded by Lien Collaborative for Palliative Care. This program was started in 2016 with the primary aim of building capacity to provide palliative care in CTCs in India. Three training programs have been successfully conducted in the last 3 years (2016–2019), CTC1, CTC2 and CTC3 and successfully established palliative care services in 23 CTCs in India. During the 2021–2022 CTC4 program was ongoing. This program aims to establish a sustainable, integrative palliative care service model in cancer treatment centres for palliative care service delivery.

End-of-Life Care Awareness and Advocacy

IAPC has collaborated with the Indian Society of Critical Care Medicine and the Indian Academy of Neurology and constituted the End-of-Life Care in India Taskforce (ELICIT). This task force is working towards a robust ethical and legal framework for facilitating good end-of-life care. In the wake of the Economist Intelligence Unit's 2010 quality of death report ranking India 40 out of 40 countries studied, an end-of-life care consortium was created in April 2014 to develop and promote end-of-life care in India. The key objectives were to create a position statement and policy guidelines, influence policymakers, and create an end-of-life care awareness amongst health care providers and the public. A position statement and policy guidelines were developed in 2014 [25, 26]. End-of-life care awareness programs were initiated across India with the help of CMEs and webinars. The consortium had several meetings with the National Accreditation Board of Hospitals (NABH). It successfully influenced NABH to bring critical changes to the fourth and subsequent editions of the NABH accreditation manual on end-of-life care.

To facilitate the end-of-life care delivery across India, a foundation course on the International Collaborative on the best care of the dying was held at the Bangalore Baptist Hospital, Bengaluru, from 11 to 13 January 2016. Professor John Ellershaw and Dr Susie Wilkinson from the Marie Curie Palliative Care Institute, Liverpool, conducted this program. Thirty participants from 16 Institutions involved in palliative care from all over India attended the foundation course. This program aimed to disseminate knowledge and improve end-of-life care practices across India. After the 2018 supreme court judgement favoured rules surrounding the limitation of treatment, the Indian Council of Medical Research (ICMR) convened an expert group to standardise terms and develop

protocol and procedures surrounding resuscitation in an end-of-life setting. A standard set of 25 terms were defined and explained, which came out as an ICMR booklet and published in 2018 [27]. Furthermore, a protocol for limitation of treatment was developed and published by the ICMR in 2020 [28]. Concurrently procedural guidelines on limiting life-sustaining treatment were developed by Manipal Hospitals titled “BLUE MAPLE”, Federation of Indian Chamber of Commerce and Industry (FICCI) and All India Institute of Medical Sciences (AIIMS), Delhi.

Indian Journal of Palliative Care

The Indian Journal of Palliative Care (IJPC) is an interdisciplinary, peer-reviewed journal published quarterly under the aegis of the Indian Association of Palliative Care. The journal is Scopus Indexed and has been indexed by several international agencies. IJPC came into existence in 1995, and it has been online since 2007. According to the 2022 Google Scholar Metrics, IJPC ranks 8th among all indexed palliative care journals globally, with an h5-index score of 25 and an h5-median score of 40.

Engagement with the Government and Policies

In 2008, the Government of Kerala announced a palliative care policy, the first government in a low or middle-income country to have such a policy. Consequently, every one of about 900 primary health centres in Kerala had at least one full-time palliative care nurse providing home visits to every non-ambulant patient at least once a month. Secondary level government institutions, including taluk and district hospitals, provided consultation-liaison palliative care services [29]. The policy was reviewed and revised in 2019 [30]. In 2012, the Government of India announced a National Program in Palliative Care (NPPC) [31]. The state government can apply for funds for palliative care development by submitting program implementation plans. A new national health policy announced by the Government of India in 2017 includes palliative care [32]. As part of its implementation at the primary level, training modules and videos have been prepared, and central and state-level trainers have been trained. The latter is expected to train healthcare providers in 50,000 family wellness centres. Apart from Kerala, a few states in India have developed their state palliative care policies.

Future of Palliative Care in India

Subspecialist Palliative Medicine

There are several initiatives toward subspecialist palliative medicine development in India. Along with the

international neuro-palliative care society, the neuro-palliative care clinical services are starting to develop. Likewise, there are sporadic activities toward developing kidney supportive care and ICU-palliative care services in India. The development of clinical services is complemented by education and research in these niche areas. In a decade, these might evolve as subspecialist verticals of palliative care.

Evolution of Palliative Medicine as a Dominant Speciality

We might see similar trends in India analogous to high-income countries, where palliative medicine has already evolved as a preferred and dominant speciality. Already we are seeing a gradual change towards that where palliative medicine specialists are finding footing in both oncology and non-oncology spaces in public, private, and corporate clinical settings. Palliative medicine specialists might become ubiquitous in every clinical environment soon.

Early Palliative Care Models

To ensure that patients receive the best care throughout their disease trajectory, palliative care must be initiated early alongside standard medical care. Integration of modern medical science and practices into the current model of palliative medicine provision is quintessential for better patient outcomes. This helps palliative medicine be accepted as a broad speciality by other health care professionals as the one that provides essential treatment in situations with life-limiting illnesses and not just the care. In India, a feasibility trial on early palliative care (EPC) in lung cancer and head and neck cancer is complete, and EPC in various other settings is ongoing or planned.

Lessons Learnt and the Way Forward

The 4 decades of our experience in palliative care development in India have taught us several valuable lessons. Initiatives such as integrated palliative care in the oncology space, specialist education, opioid policies, and community networking facilitated palliative care growth in India. However, standalone hospices and palliative care policies did not have the same impact or reach in certain states. The government might systematically augment palliative care development in India by having palliative medicine services in all the medical colleges. It could be achieved by public-private partnerships and involving all the country's palliative care stakeholders.

Conclusion

In summary, palliative care in India had a great beginning and sustained linear growth over the first 3 decades. The pioneering work by the initial champions and the international support reaped great dividends. This period highlighted the early hospice movement, community palliative care networks, and home-based palliative care services. In the last decade, the growth of palliative care development in India was exponentially marked by specialist palliative medicine services and education, integration with oncology and non-oncology specialities, widespread dissemination of palliative care knowledge through short and intermediate courses and several capacity building initiatives as well as the incorporation of palliative care in National Health Policy. The future of palliative care in India looks bright and promising. It is poised to reach a substantial proportion of the needy in the country. It will probably emerge as one of the significant specialities over the next decade, with several subspecialties originating from palliative medicine.

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Declarations

Competing Interests The authors declare no competing interests.

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