

Progress in palliative care in India

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India is experiencing an epidemiological transition with non-communicable and chronic diseases becoming the leading causes of death. There are at least 1.5–2 million cancer cases; two-thirds of them are in an incurable stage of disease. The adult HIV prevalence is approximately 2.5 million. The development of palliative care has been patchy. Vast majority of India does not have access to palliative care but in a state like Kerala, effective coverage and involvement led to designation of centers such as Institute of Palliative Medicine (IPM), Calicut and Trivandrum Institute of Palliative Sciences (TIPS), Pallium India as the Collaborating Centers of WHO for Community Participation in Palliative Care and for Training and Policy on Access to Pain Relief, respectively. A lack of health policy, lack of training and awareness, and opioid availability are barriers to palliative care. India does not have a national policy on palliative care. The National Cancer and AIDS Control Programme mentions palliative care but with ineffective implementation. Kerala is the first state to introduce a state health policy. Andhra Pradesh includes palliative care for cancer in its state health insurance scheme. The major barriers to opioids availability include stringent regulatory issues, attitude, and knowledge. Efforts led to 14 states simplifying the regulations. Lack of training and awareness is a challenge. The Medical Council of India recently approved palliative medicine as a specialty. The *Indian Journal of Palliative Care* has become an indexed journal. Many International organizations such as the International Network in Cancer Treatment and Research (INCTR) and the International Association for Hospice and Palliative Care (IAHPC) are playing roles in bringing changes. Recognition of non-communicable diseases as a priority and palliative care as a specialty is expected to bring major change in palliative care scenario in India.

Keywords: India, Palliative care, Non-communicable diseases, Cancer, Policy, Opioid availability, Training and education

‘The Government of India calls for a comprehensive national program to prevent and control non-communicable diseases such as diabetes, cancer, cardiovascular diseases, mental health and stroke’.¹

‘Policy framework for prevention, control and universal coverage of Non Communicable Diseases in India is a clear need along with a multisectoral response to the problem of NCDs’, – Dr Nata Menabde, WHO Representative to India, National Summit on Universal Coverage for Non communicable Diseases, New Delhi, August 2011.¹

Background

India is a large democracy, with a population of 1.21 billion (Census, March 2011). The diversity in India in terms of its physical, religious, language, and racial variety is astounding and unique. With 28 states and 7 Union territories, each state or union territory of India has its own unique demography, history

and culture, dress, and festivals. A birthplace of Hinduism, Buddhism, Jainism, and Sikhism, religion still plays a central and definitive role in the life of its people. Hinduism is practiced by the majority (80.5%) followed by Islam (13.4%) and Christianity (2.3%).^{2,3}

More than 72% of the population lives in villages. Family plays a significant role in the Indian culture. For generations, India has had a prevailing tradition of the joint family system. However, in recent times, many families especially in urban areas have started turning nuclear. The caste system is very strong with its presence making its impact on several components of the society, like formation of governments and political affairs, social segregation, marginalization, poverty, and unemployment.

Health-care system in India

India has a universal health-care system. The national health policy by the government is primarily tailored to primary health needs of the large rural and poor population. Public health infrastructure in rural

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areas consists of a three-tier system, a sub-centre, a primary health centre, and a community health center. In urban areas, it is two-tier system with urban health centre followed by general hospital.⁴ In spite of efforts at increase in services and reach of these programs, many limiting factors like inadequate facilities, manpower, and resources still exists and force a large portion of population to seek medical care services from the private sector. Thus, the access to health becomes unaffordable and inaccessible to the majority as the expenditure is then mostly met by 'out-of-pocket'. Only 10% of the population is being covered under health insurance.⁴

Indigenous or traditional systems of medicine such as Ayurveda, Siddha, and Unani are popular and continue to be practiced.

Burden of disease

Like many other developing countries, India is also experiencing an epidemiological transition. It is reflected in a growing burden of non-communicable diseases (NCDs).⁵ Non-communicable and chronic diseases are becoming the leading causes of death in rural India.⁶ It was estimated that approximately 32% of all deaths could be due to the selected NCDs.

The implications of these findings are far reaching. First, the peak prevalence of many NCDs occurs at a younger age than in developed countries resulting in a major socio-economic impact. Second, it is a challenge to implement appropriate prevention strategies to halt the growing trend in NCDs against a background of infectious diseases which remain out of control.

Patients with NCDs typically require care over a long period of time, sometimes decades. Hence, there is a growing need to reorganize the health delivery system to control and manage the growing burden of NCDs in a population-based primary care setting.

Palliative care: need and availability

According to the National Cancer Registry program, there are at least 1.5–2 million cancer cases at any given point of time; two-thirds of them present in an incurable stage of disease.⁷ Today, a child diagnosed with cancer in a developed country has an 80% chance of being cured. Unfortunately, this is not true for India where, of the 75 000 children with recorded cancer every year, <20% survive.

The national adult HIV prevalence in India is approximately 2.5 million. The risk is higher for the younger population. 3.8% of HIV infections are noticed to be in the under 14 category.⁸

More than seven million people with various progressive, incurable, and life-limiting illnesses need palliative care services each year⁹ with pain being the symptom for immediate attention. Around one million cancer patients¹⁰ and an unestimated huge percentage

of people with HIV infection and AIDS-related disease suffer pain (moderate to severe) each year.¹¹

Current status of palliative care services in India

Palliative care as a movement in India gained its momentum in early 1990s. The first hospice started in Shanti Avedna, Mumbai way back in 1986. Much of the progress in palliative care has largely been driven by the non-governmental sector and has resulted in slow but steady spread of palliative care awareness and delivery across the country. The Pain and Palliative Care Society, Calicut, Kerala, formed in 1993, is one of the non-governmental organizations (NGOs) that has played a pioneering role in developing palliative care in the country.¹²

According to global mapping of levels of palliative care development, 2011, India is in the category 3b, generalized palliative care provision.¹³ In a state like Kerala with two-thirds of the country's 300 palliative care centers and where service is available in every district, it is in the category of approaching integration.¹⁴

The vast majority of India's population, however, still does not have access to palliative care services: such services exist in only 14 of India's 35 states and territories, according to Pallium India, one of India's leading palliative care organizations. Even in regions where it is available, they are usually concentrated in large cities, regional cancer centers, and medical institutions and unavailable in communities.¹⁵

The WHO has urged countries to take action in three areas – policymaking, education, and drug availability – that it sees as fundamental for the development of palliative care and pain management services.¹⁶ Major gaps exist in all these areas in India. Barriers like low priority in government policy, dearth of manpower and resources, lack of training of health-care workers, difficulty in procuring morphine impedes the development of palliative care. Specific ethical issues related to limitation of resources and vast population of the country and some that are specific to a traditional society, such as the joint or extended family system, religious and cultural belief system, societal and spiritual issues, and issues related to unorthodox medical systems make delivery of palliative care a complex issue.¹⁷

Policy and programs

Policy in palliative care

India does not have a national policy or program on palliative care even though WHO has recommended that each country should have a national palliative care policy. The Indian Association of Palliative Care (IAPC) established in 1994 is the national organization, which is actively engaged in enhancing palliative care through its activities of awareness, advocacy, training, policy, and program development.

Majority of the one million patients with cancer reporting to cancer care facilities across the country are incurable at the time of diagnosis. The estimated cure rate now is only 10% and 0.5–0.8 million patients are estimated to die of cancer every year. The National Cancer Control Program of India¹⁸ since 1987 has referred to palliative care as a priority. The program for 2007–2011 had a taskforce for palliative care specifically, to put up recommendations to the Government. But still most large cancer hospitals in India, including 18 of 29 government-designated lead cancer centers do not have personnel trained to administer palliative care or morphine and other pain medications. There is no separate allocation of funds for palliative care in this program clearly reflecting inadequate implementation of the policy. Palliative care programs specially designed to address the needs of children are few and far between. Centers such as Tata Memorial Hospital, Mumbai and MNJ Institute of Oncology, Hyderabad have taken initiatives to develop a dedicated pediatric palliative care service and training of professionals.

Health is a state subject, responsibility for its delivery being with the State Government rather than with the Union Government of India. The performance of State Governments has varied across the country with only a few states taking an active role. The State Government of Kerala came out with the palliative care policy in 2008, which paved the way for initiation of home care programs at Panchayat level (Local Self-Government Institution) for the care of the patients suffering from incurable illnesses and those who are bedridden and training of health-care professionals and volunteers across the state.¹⁹

The Government of Andhra Pradesh has a health insurance system for the poor. In this system, the government insures all the members of the households below poverty line for major illnesses. In a landmark decision, the insurance also included palliative care for cancer bringing a major recognition and sustainability to palliative care program in the state.²⁰ The Government of Andhra Pradesh has also given an official recognition to the palliative care program of its regional cancer center by creating faculty position, releasing funds for the staff position, essential drugs, and the infrastructure.

The National AIDS Control Programme²¹ (NACP) Phase-III (2007–2012) gives high priority on preventive efforts and aims for integration with care, support, and treatment. Evidence has shown that majority of people on antiretroviral therapy (ART) continue to experience pain and other symptoms and that simultaneous delivery of palliative care and ART improves treatment adherence. In India, one study that looked at prevalence of pain and other symptoms among people living with HIV found that

only about a quarter of HIV patients reporting pain had received any kind of pain treatment.¹¹ There are a few NGOs offering training and palliative care services for the care of people with HIV and AIDS but most palliative care services in India are for patients with cancer.

Two centers have recently achieved remarkable success in terms of policy making, training, and advocacy. Institute of Palliative Medicine (Policy, research and training institution of Pain and Palliative Care Society, Calicut, Kerala) has been designated as a World Health Organization Collaborating Center (WHOCC)²² for Community Participation in Palliative Care and Long Term Care. The Trivandrum Institute of Palliative Sciences (TIPS), the flagship program of Pallium India, has been named a WHOCC for ‘Training and Policy on Access to Pain Relief.’²³

Models of care

Most palliative care centers have given importance to developing palliative care as a specialty looking into the total care of the patients with chronic illnesses in distress, and their caregivers. Even smallest centers work with a multidisciplinary team and are usually supported by volunteers to address challenging psychosocial issues along with difficult physical symptoms.

Kerala leads the country by establishing a community-based model of delivery of care, essentially led by the people in the community. It exemplifies the partnership model of the NGO and people in the community with the government.^{12,24} This outreach program through an outpatient-based and home-based cares, wherever required, is cost-effective in providing both the coverage and the quality. Continuity of care by empowering the families to take care of patients at home is the essence of the model.²⁵ The effectiveness led to a very successful integration of the program into the mainstream health program of the government.

CanSupport, an organization based in New Delhi is another model of care in an urban setting which has mostly grown as a home-based care providing care for patients and their families in their home setting.²⁶ A few stand-alone hospices like the Bangalore Hospice Trust offer hospice-based palliative care to patients. Many other health-care institutions work in a determined manner to provide palliative care as outpatient clinics, inpatient care (includes few hospices), and home care programs.¹⁵

Drug availability

The WHO regards morphine as the mainstay of cancer pain relief and recommends it to be listed as an ‘essential drug’. It also considers a country’s morphine

consumption to be an important indicator of progress in pain relief.

In India, the opioid analgesics available for prolonged pain are codeine, dextropropoxyphene, tramadol, buprenorphine, fentanyl, and morphine. Morphine is the only oral opioid available for severe pain. Methadone is only available as substitution therapy for opioid dependence in designated centers. Legally, any registered medical practitioner can prescribe morphine using a prescription in duplicate, but they are almost always unavailable in pharmacies. Morphine and fentanyl are scheduled drugs and need special licensing under The Narcotic Drugs and Psychotropic substances (NDPS) Act of India.²⁷

India legally cultivates poppy, extracts opium, and exports the raw materials for medical use to the rest of the world. It is indeed paradoxical that two decades after 'hospice' or 'palliative care' was introduced in India, most people in pain in a major opium exporting country have no access to oral morphine.¹⁰ In 1997, India's per capita consumption of morphine ranked among the lowest in the world (113th of 131 countries). During the same period, global consumption of morphine increased by 437%.²⁸ During the five-year period between 2000 and 2004, the average annual quantity of morphine sold by the factories supplying raw material to various pharmaceutical companies was 142.32 kg – a mere 0.4% of the possible need.²⁹

As a result, the International Narcotics Control Board, called attention to the decline in consumption of morphine in India and made a recommendation: 'As the domestic consumption of morphine has decreased to an extremely low level over the last few years, the Government of India should take effective measures to ensure its adequate availability for medical purposes.'³⁰

The major barriers that have prevented access to opioids for medical use include the following:

1. Regulatory issues
 - (a) Stringent NDPS rules to curb misuse vary from state to state and require cumbersome licensing procedures. As many as three or four licenses are typically needed to procure every consignment of morphine. Several agencies, including the Excise, Drug Control, and Health Departments, are involved in the process of licensing to obtain morphine.
 - (b) Harsh punishment prescribed in the NDPS Act (e.g. 10 years of rigorous imprisonment even for minor offenses) has had the effect of alienating pharmacists and most pharmacies have stopped ordering opioids.
2. Problems related to attitude and knowledge
 - (a) Through decades of strict regulation, medical professionals have developed a fear of morphine; they would not use it and teach students

to avoid it. This attitude has come out of exaggerated fears of addiction and respiratory depression and was reinforced by an unbalanced regulatory environment governing opioids.

- (b) The general public, including government officials, associates morphine with addiction and are reluctant to accept the drug for medical needs. Yet, extensive, carefully documented clinical experience even in Indian population has shown that these fears are unfounded.^{30,31}

Efforts are being made by many individuals and various national organizations such as the Indian Association of Palliative Care (IAPC) and Pallium India and international organizations such as Pain and Policy Studies Group, Madison, Wisconsin, USA and the International Network in Cancer Treatment and Research (INCTR) to overcome the aforementioned barriers and to improve the availability of oral morphine for medical use. The active advocacy resulted in the Government of India coming out with a recommendation to adopt a simplified rule, to enable easy licensing and procurement of oral morphine in all the states.

Fourteen of the 28 states and 7 union territories have so far implemented the simplified rule. The amendment shifts the licensing responsibility to one licensing body namely, the Drugs Controller in the State Health Department. Once approved by the agency, the palliative care program gets 'Recognized Medical Institution' (RMIs) status and is allotted an annual quota to buy morphine. The following states in India simplified their narcotic rules namely, (1) Arunachal Pradesh, (2) Delhi, (3) Goa, (4) Dader and Nagar Haveli, (5) Jammu and Kashmir, (6) Karnataka, (7) Kerala, (8) Madhya Pradesh, (9) Orissa, (10) Andhra Pradesh, (11) Sikkim, (12) Tamil Nadu, (13) Tripura, and (14) Mizoram.¹⁰

There is also widespread effort by various organizations like the IAPC and the Indian Society for Study of Pain (IASP) along with other institutions to conduct training and education of health professionals and public in pain management and palliative care. The increased demand has resulted in an increased interest by various pharmaceutical companies to manufacture oral morphine at much lower costs.

Recently, a Public Interest Litigation filed by the IAPC representative, a cancer survivor, and a pharmacologist in the Supreme Court of India has resulted in more widespread recognition of the problem.¹²

Education

WHO recommends that when initiating a palliative care program in a low- or middle-income country, education and training should be provided for all health workers in the target area. The extent of knowledge may range from simple awareness of the availability

of palliative care through to the highly specialized skills required for referral practice.³²

It is the general practitioners (GPs) and generalist hospital doctors who provide long-term care and terminal care for the patients with incurable illnesses in the community. Several studies have revealed problems with symptom control and communication in these settings and inadequate training for doctors and nurses. A study in one of the premier hospital in India has shown a similar need for clinicians in India. The study recommends focused skills and training for them to be able to deliver quality palliative care to the large number of patients with incurable cancer and it should be an integral part of clinical residency programs.³³

Lack of training and awareness among professionals in pain management and palliative care still remains as one of the biggest challenges in India. Undergraduate and postgraduate curricula in medical schools place greater emphasis on disease pathophysiology and treatment. Little attention is paid to pain management, principles of symptom control, communication, and end-of-life care. Palliative care is not included as part of the undergraduate or postgraduate medical curricula. Pain management is included in anaesthesiology training curriculum and some medical colleges have included palliative care principles in Community Health education.³⁴ One major barrier to developing an effective curriculum with inclusion of modules on such essential topics is non-recognition of Indian Medical or Nursing Council of palliative medicine as a specialty.

Thanks to the work of many pioneers in India, innumerable informal educational modules and manuals have been developed for the wide range of health-care professionals who are involved in palliative care. Institutions conducting training for undergraduate and postgraduates have their own training curricula. Essentials of Palliative Care manual by the IAPC,³⁵ The Education of Physicians in End of Life Care (EPEC), India,³⁶ Handbook on Palliative Care by the INCTR³⁷ and Training tool kit by the Help the Hospice,³⁸ Guidelines for setting up of palliative care, opioid availability, and home care by the WHO-India office³⁹ are some of the educational tools widely used by the professionals and public in their training and educational activities.

The existing training programs are conducted at several levels as basic foundation courses, six-week intensive certificate courses and a diploma/fellowship in palliative care by various organizations and institutions. The one-year fellowship program in palliative care for doctors by the Christian Medical College, Vellore and the post-doctoral fellowship in pediatric palliative care by the MNJ Institute of Oncology, Hyderabad are some of the notable examples.

Training in communication issues has been given priority by all programs.⁴⁰ There has been effective integration of training in communication skills and advanced issues in psycho-oncology in almost all training programs. Research in psychological aspects related to oncology and palliative care has been an active area of interest.^{41,42}

The IAPC has also been responsible for training and imparting basic information to an increasing number of doctors and nurses on palliative care. Several international universities are also offering fellowship, diploma, and masters training in palliative care to health professionals in India.

The range of education providers and course offerings reflects the diversity of palliative care. There is a need for developing national level guidelines and position statements to bring a national standard in palliative care education and practice. Also, it is essential to ensure that appropriately trained program managers and health-care practitioners exist across all levels of care. Because the complexity, scope, and coverage of care differ at different levels of services, health-care providers working at different levels need different types of training.

The workforce shortage often makes it difficult to release health professionals to participate in ongoing education. Strategies that develop more flexible approaches, capabilities in self-directed learning, and mentoring are integral to the delivery of quality palliative care training.

Some of the recent landmark developments are going to bring major changes in the education and training scenario and credibility to palliative care as a specialty in India. The Medical Council of India, the statutory body that controls medical education in the country, has approved palliative medicine as a medical specialty and initiated steps to start postgraduate courses about the subject.¹² The National Accreditation Board for Hospitals & Healthcare Providers (NABH) a constituent board of Quality Council of India establishes and operates accreditation program for health-care organizations. These standards focus on patient safety and quality of care. One of the standards for accreditation is to have a pain and end-of-life-care policy in the hospital.⁴³

Research

The knowledge base to support the basic elements of palliative care clinical practice (i.e. pain and symptom management, communication skills, and care coordination) is small and inadequate in India. Most evidence existing in palliative care is often based on studies of patients in developed countries. This results in treatment protocols that are not necessarily applicable in this country. Majority of the journals are published in developed countries and the

high subscription costs makes information inaccessible to most health workers in India.⁴⁴

It is essential to organize and conduct biomedical, clinical, behavioral, and health services research for patients with serious and chronic illness in an Indian setting and contribute to bringing an evidence-based approach to palliative care practice.

The *Indian Journal of Palliative Care* is an indexed interdisciplinary, peer-reviewed journal published under the aegis of the IAPC.⁴⁵ The journal has played a key role in bringing out many research articles based on work happening in different parts of India and also at international level. The subscription to journal is free thus making it widely accessible to health workers and the community. Many palliative care experts from India are increasingly contributing to evidence-based clinical practice in palliative care, as is evident from increasing number of scientific papers being published in Indian and different international journals.

A recent effort by the International Association for Hospice and Palliative Care (IAHPC)⁴⁶ to make access free to all important international journals to the members of the IAHPC is also contributing greatly to improving information access and advances in palliative care.

Ethical issues

There has been no specific focus on ethical issues in palliative care except clinical practice. As mentioned earlier there has been an End-of-Life-Care Policy issued by the NABH. Training in palliative care routinely includes medical ethics but this has not significantly extended to research. There is also no separate ethical committee at the national level for research. Individual institutions have their own ethical committees to regulate their research activities.

Role of international organizations

International organizations have played a significant role in facilitating service development, training, and advocacy from the beginning of palliative care movement in India. Development of guidelines and position statements by the WHO, setting up services by the INCTR and Indo-American Cancer Association (IACA),⁴⁷ education and scholarships by the IAHPC training and advocacy by the Help the Hospices and Cairdeas, UK,⁴⁸ opioid availability by the Pain and Policy Study Group, Madison, Wisconsin⁴⁹ are some of the examples of huge contributions by the international organizations in the growth of palliative care in India.

Future implications

With the Government of India recognizing and calling for action for the universal coverage of non-

communicable diseases as a priority, with plans to commission the health programs focusing on improving care for such illnesses, and the Indian Medical Council approving palliative care as a medical specialty, the palliative care scene in India would see a brighter and more effective journey ahead in the coming decade. In the global mapping of levels of palliative care development, even though India is approaching integration, the access to care still remains patchy. Having a national level health policy on palliative care, essential integration of palliative care in all undergraduate and postgraduate medical and nursing training curriculum, inclusion of oral morphine in the national and state level essential drug list and enforcement of centralized opioid-related regulations are highly recommended to improve the access to palliative care across the country. The concerted effort of interested individuals, national and international organizations toward a shared goal looks promising for the future of palliative care in India. India, with its growth in palliative care, is also playing a role in facilitating initiatives in neighboring south-east Asian and African countries.

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