

Life before Death in India: A Narrative Review

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ABSTRACT

Palliative care is an ever-increasing need in India, with its large population and rising burden of chronic illness. India ranks 67th out of 80 countries in the quality of death index, which measures the availability and quality of palliative care. Community-led projects in Kerala have proven successful in improving palliative care access with modest resources and volunteer involvement. In India, the number of hospice facilities is increasing; however, <1% of the Indian population has access to palliative care. Financial and human resources limitations in the health-care system, poverty and high health-care expenditure, the lack of awareness among the public about end-of-life care, hesitance to seek care due to social stigma, strict laws regarding opiates that hinder adequate pain relief and the apparent conflict between traditional social values and western values regarding death are the major obstacles to improving palliative care. Significant efforts focused on public awareness of end-of-life care and locally-tailored programmes with family and community involvement are necessary to address this issue and integrate palliative care into the primary care system. Furthermore, we discuss the effects of the COVID-19 pandemic that has been managed effectively by palliative care involvement.

Keywords: Palliative care in India, End of life, Hospice, Issues in palliative care in India, COVID-19 management with palliative care, Opiate issues, Spirituality, Ethics

INTRODUCTION

The World Health Organisation defines palliative care as an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness through the early identification, correct assessment and treatment of pain and other issues, whether physical, psychosocial, or spiritual.^[1] The concept of end-of-life care and palliative care is becoming more and more relevant with the increasing burden of chronic illnesses worldwide and it is being embraced as an integral part of the health-care system in countries with advanced health-care systems like the United States. As of 2019, 72% of hospitals in the United States with 50 or more beds had a palliative care team, with all but five of the 50 states having palliative care services in more than 40% of their hospitals.^[2] In India, the Global directory of palliative care institutions and organisations lists 151 facilities across the country, which shows that it is still a new and growing concept.^[3] Palliative care programmes have been shown to reduce rehospitalisation's by 50% and

decrease caregiver stress^[4] while lowering overall health-care costs.^[5]

HOSPICE VERSUS PALLIATIVE CARE

Palliative care is often misunderstood concept as only being relevant for dying people. It is a broad term that encompasses comfort and quality of life care for any chronic illness. Patients need not have a terminal illness and may continue to pursue curative therapy.^[6] It includes care for both the patient and the family. Palliative care begins at diagnosis of chronic disease and can continue into end-of-life care if the disease progresses to terminal stages and even after the patient's death as bereavement care. Palliative care alleviates suffering through holistic and compassionate care, which is an essential component of care for all patients with a life-threatening illness. Unlike hospice, palliative care does not depend on prognosis but on managing life in the context of a patient's wishes as the end of life approaches.

Hospice is a system of care that focuses on comfort and quality of care for patients with a life expectancy of fewer than 6 months

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who have stopped curative treatment. Patients are usually required to meet disease-specific criteria and the focus is on improving the quality of life rather than extending life expectancy. Hospice care can be provided at home or in an inpatient facility.

END-OF-LIFE CARE IN INDIA: ROOTED IN TRADITION

Traditional palliative care has been practiced in India for a long time in religious and cultural customs and rituals.^[7] India has a wide range of religious and cultural practices with different attitudes and rituals around illness and death. Karma and reincarnation are tenets of Hinduism, the major religion of India. Suffering is viewed as punishment for the past bad deeds and the balance between good and bad karma is believed to decide whether the rebirth will be good or bad. People are thus more accepting of death and suffering. The end of life is centred around detachment from the physical world and preparing for death by meditation, praying and atoning for bad deeds in life.^[8,9] Usually, Hindus prefer to die at home surrounded by family singing sacred hymns, praying, reading holy verses or chanting.^[10] Buddhism also teaches reincarnation and detachment from the material world. Towards the end of life, the use of narcotics is discouraged.^[11] In Christianity, the concept of sin and punishment is associated with suffering and death and it is believed that the soul lives on after death. Confession of one's sins with the priest is believed to absolve them. Islam views suffering as submission to god and allows the use of narcotics to manage severe pain in dying patients. Suicide and euthanasia are considered negatively by all major religions. While religion is an essential determinant in patients' end-of-life decisions, several factors other than religion affect patients' attitudes towards dying and their preferred methods or rituals.

END-OF-LIFE CARE IN INDIA: MODERN ADVANCES

The concept of end-of-life care as part of the health-care system is relatively new in India, having been introduced in the 1980s. The first hospice in India was established in 1986 in Mumbai.^[12] A 2008 review found 138 hospice and palliative care services in 16 states and union territories, which were primarily concentrated in large cities.^[13] A review published in 2013 found that palliative care was available to < 2% of those in need in India.^[14] In 2016, there were over 900 palliative care centres in India, accessible to <1% of the Indian population.^[15]

In 2015, the Economic Intelligence Unit published a report titled 'The 2015' quality of death index with the aim to rank the availability and quality of palliative care in 80 countries. They compared the countries in different qualitative and quantitative indices in five categories: Palliative and health-care environment, human resources, affordability of care, quality of care, community engagement and demand and

supply of palliative care. India ranked 67th among the 80 countries and 14th out of the 21 low-income countries. Approximately 5.4 million people in a year are estimated to require palliative care in India.^[12] While end-of-life care is growing rapidly in the country, the massive discrepancy between the supply and demand shows that a lot of work still needs to be done to deliver quality palliative care to the majority of the Indian population.

Data on hospice utilisation are scarce in India and limited to single-centre reports.^[16,17]

EUTHANASIA AND WITHDRAWAL OF CARE

Passive euthanasia was legally upheld by the Supreme Court of India in 2018.^[18] Patients with a terminal illness or in a persistent vegetative state, passive euthanasia is permitted by the withdrawal of life support. However, active euthanasia by any method is illegal. 'Leaving against medical advice' is a concept widely used in India whereby a patient with chronic illness leaves the hospital accepting full responsibility for his health and discontinuing any medical treatment.

THE NNPC MODEL

The Neighbourhood Network in Palliative Care project was initiated in Kerala, India, in 2001 to facilitate a sustainable community-led service capable of providing palliative care to those in need.^[19] Volunteers from the local community are trained to attend to the palliative care needs of people within their community, with active support from healthcare workers.^[20] The project was highly successful. Within 5 years of its initiation, 68 community-based palliative care initiatives were established in Kerala, in an area covering 12 million people, providing coverage of more than 90% in palliative care within the region.^[20] Kerala is thus the region with the most availability of palliative care in India. Expansion of this model to other regions with support from the local governments could be a way forward for India to bring itself on par with the rest of the world in terms of palliative care, although the process is not without potential issues.

ISSUES WITH PALLIATIVE CARE IN INDIA

Lack of resources and inequity of health-care services is one of the major challenges in providing end-of-life care in India. Health-care expenses are very high, and almost 75% of health-care expenditure comes from the patient's pockets and chronic or life-threatening illnesses can quickly send the whole family into a spiral of poverty.^[21,22] Low health-care utilisation by a majority of Indians means that chronic illnesses are usually at advanced stages of their natural history when they are identified. In addition to the financial burden, it also adds to the demand for hospice services. Hospice care and relative services tend to be highly costly, further adding to the already massive health-care costs. To compound matters, especially in low-resource settings within

the country, the number of people requiring care for chronic diseases far outweighs the capacity of the existing health-care infrastructure to deliver it. The involvement of community health-care providers and facilities to provide palliative care can be an effective way to mitigate this.

Public awareness of hospice as a concept and the availability of hospice services is shallow in India. This causes delays in bringing patients to palliative care facilities and potentially prevents it altogether. In addition, there is usually a higher willingness to discuss death and also a higher cultural acceptance of death among the elderly population. However, people overwhelmingly tend to prefer to die at home.^[23] Compared with western societies, larger family units are more common in India and the family is more involved in the health-care decisions of the patients. A review published in 2019 highlighted the lack of basic living amenities for terminally ill patients the inability of Indians to cope with the financial burdens of terminal illness and death.^[24] They also found that most people prefer to die at home surrounded by family and patients tend to hide their emotions and suffering from their family and caregivers to not add to their burden of care. In a 2022 study done among cancer patients in six developing countries, including India, 35% of patients reported experiencing at least one facet of cancer-related stigma often, while 60% reported experiencing it occasionally; those who perceived stigma were less likely to opt for life-extending treatments.^[25]

COVID-19 PANDEMIC AND PALLIATIVE CARE ISSUES

COVID-19 infection has presented as typical flu-like symptoms to rapid clinical deterioration from breathlessness and severe conditions involving cardiopulmonary issues such as myocardial injury, acute respiratory distress syndrome, neurological complication, hypercoagulability, Multisystem Inflammatory Syndrome in Children and post-COVID sequela syndrome. Strict social distancing regulations to slow disease transmission have led to patients dying from COVID-19 without caregiver/loved ones by their side, who, in turn, were not able to say their final bye or undertake traditional grieving rituals. Those who survived have psychological impacts from the disease and social isolation, causing post-traumatic stress disorder in survivors and prolonging grief and bereavement to family and caregiver.

During the pandemic, access to essential palliative care at the end of life, including bereavement support, was limited in the face of high demands in all over the countries. Clinician and family/caregiver communication was essential and played a critical role from the early hospitalisation state. Family/caregiver visitation was restricted and hospitals had limited personal protective equipment. Patients who had active cancer or critical illness or other life-threatening conditions requiring palliative needs were also affected due to these

regulations. Patients with the acute disease were dying alone and families/caregivers were distressed as they were grieving for their loved ones from a distance.

COVID-19 INFECTION MANAGEMENT WITH THE HELP OF PALLIATIVE CARE IN THE UNITED STATES

In the United States, palliative care, a major subspecialty and division in most hospitals, has been the front line in advance care planning for critically ill patients. High-quality communication with patients and caregivers on goals of care has helped mitigate the pandemic. Many clinicians used video visits to communicate with caregivers. It helped to form face-to-face communication and allowed multiple health-care professionals to engage patients/families/caregivers simultaneously, which can be a challenge in person. In addition, early palliative care services were initiated, which helped in advance care planning and provided psychosocial support to patients and family to address the fear of contracting COVID-19 and the emotional burden during diagnosis.

They identified and respected the patient's care preferences (decisions expressed by the competent patient were honoured) and focused on addressing patients' quality of life. Setting a regular time for in-person video meetings/setting expectations for the family early on helped communicate and establish shared decision-making for end-of-life discussion. Family meetings between family members, nurses, physicians/providers, social workers and Chaplain have improved clinical outcomes and decreased the psychological burden associated with the diagnosis and family decision-making at the end of life. A multidisciplinary approach for decisions to withhold or withdraw ventilatory/life support was made after discussing how to respond to requests for futile and potentially inappropriate therapies and other palliative care issues that may arise in the patients treated in the ICU. Palliative care practitioners offered expertise in managing complex symptoms, including dyspnoea, anorexia, delirium and various other symptoms. Palliative care comanagement of these symptoms reduces patient care's burden on primary treating teams. At the same time, delivering excellent symptom management to patients provided emotional relief for the health-care providers that care for patients with COVID-19 without a cure.^[26] Patients who developed post-traumatic stress disorder during survivorship were also supported with behavioural therapy and support groups.^[26] Opiates were considered for COVID-19-induced breathlessness, common palliative care intervention.^[27] Support for healthcare workers with peer counselling, regular check-ins with social support networks, self-monitoring, combined emotional and physical wellness programs to mitigate the impact of continued exposure to death, dying and suffering was deployed across health systems.^[27]

A 2021 survey found that two out of three palliative care centres in India had adapted their protocols after the pandemic for infection control and more than half of the facilities had plans to redeploy staff and resources in case of outbreaks.^[28] Incorporation of palliative care into pandemic planning has been suggested to equip the health-care providers better and could definitively be helpful in the context of India.^[29] We learn that palliative care implementation as a major subspecialty in hospitals will be essential in mitigating pandemics and life's of critically ill patients in a very comforting and dignified way.

OPIATE RELATED ISSUES IN INDIA

While opioid overuse and potential for dependence is a major current issue in the western world, the underuse of opioids is a significant concern in India since there are strict regulations imposed on narcotics by the federal and state government.^[30] The Narcotic Drugs and Psychotropic Substances Act of 1985, in particular, has been criticised as being draconian and reducing the consumption of medical morphine in the country.^[31] Strict laws on controlled substances like oral morphine make it harder to provide adequate analgesia to patients, and as a result, people tend to suffer more towards the end of their lives. This could be another factor predisposing patients to want to stay at home and not visit health-care centres in the final stages of terminal illnesses since prolonging life frequently means prolonged suffering, a bargain they might not be willing to accept. People with chronic diseases value the avoidance of pain and suffering very highly.^[32] Efforts have been made to improve the availability of opioids, including amendments to state and central laws to facilitate the availability of morphine and morphine substitutes such as methadone.^[31]

The existence of multiple alternative medical practices such as ayurvedic and traditional healthcare is likely contributing to the decreased utilisation of allopathic palliative care in India since they are often presented as more compassionate and holistic approaches.^[33] Since people who have been given a terminal prognosis tend to view it as a failure of 'western medicine', they might be more inclined to adopt these alternative methods in the final stages of their lives instead of modern medicine. However, the impact of these practices in place of or in addition modern palliative care on their quality of life is not well understood and is an area worth investigating in the future.

LOOKING FORWARD

Like most other health-care challenges facing India, there are no easy and straightforward answers to most of these issues. Due to its unique demographics and large population with a wide range of socioeconomic variability, programs that have proven effective in other countries and even in some regions within India cannot be directly applied to the whole country. Instead, the best way forward may lie in local solutions

tailored to the community's needs. Providing training to family members, community health workers and volunteers can help implement such programs locally, especially in rural and low-resource areas. A 2019 qualitative study conducted in the rural area surrounding Kolkata found that using community health workers to facilitate the delivery of palliative care is a feasible model in low-resource settings.^[34] In 2018, the Indian Association of Palliative Care and Academy of Family Physicians of India issued a joint position statement on the way forward for developing community-based palliative care programs throughout India.^[32] Their recommendations included integration of palliative care into all levels of primary care with clear referral pathways, a collaboration between palliative care specialties and family physicians and generalists in community settings, including palliative care as mandatory components of medical education, improving access to necessary medications, providing relevant training to all levels of service providers and generating public awareness about palliative care and providing support for those choosing to die at home. The inclusion of the palliative care concept in undergraduate and postgraduate medical education could help increase the general awareness among the health-care providers and improve service delivery to the patients. Amending existing laws to allow easier access to opiates to cancer patients can help improve their quality of life. Concerns regarding potential opiate overuse issues can be mitigated by proper training to physicians on opioid prescription and safety and strict monitoring.

Knowledge gaps still exist in palliative care in India, especially in palliative care facilities and patient outcomes. The future research should focus on filling those gaps to form a clearer picture of the state of palliative care across the whole nation. The model of palliative care in the United States has worked, as proven by the availability of palliative care in more than 70% of US hospitals and emulating the palliative care model of the United States could help with the availability and cost. However, the unique set of problems facing India in this field merit a more tailored solution. Integrating traditional end-of-life measures into palliative care is something to consider, as it might make patients more accepting of modern palliative care and ultimately improve their quality of life.

CONCLUSION

End-of-life practices in India have historically been closely linked to spirituality and religion. Despite increased recent attention and promising advancements, modern palliative care in India remains a luxury only afforded to a small minority of its population, whereas it is an absolute indispensable thing. Significant efforts are necessary at the local and central level to make palliative care accessible and affordable to the ever-increasing people that need it. Focusing on local-level projects with government support and community involvement and integration of palliative

care into medical education and the primary care system could prove helpful.

Declaration of patient consent

Patient's consent not required as there are no patients in this study.

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Conflicts of interest

There are no conflicts of interest.

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