

EDITORIAL

Varun Devraj

Department of Molecular Biology, Princeton University, Princeton, NJ, USA

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Corresponding Author:

Varun Devraj
Department of Molecular Biology
Princeton University
Princeton, NJ, USA
vdevraj@princeton.edu

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SUMMARY

The World Health Organization estimates that only 14 per cent of the 40 million people worldwide who require palliative care receive sufficient help. Many of the individuals in need of palliative care reside in developing nations, such as India. Due to opioid restrictions and societal stigma, as well as the COVID-19 pandemic, India has had difficulties delivering palliative care to its population. This editorial explores India's palliative care challenges, especially in the context of the pandemic and lockdown measures. To address these challenges, the author explores possible solutions that take advantage of the flexible nature of palliative care to extend its implementation across India.

Key Words

Palliative care; home-based care; barriers; India; COVID-19

INTRODUCTION

Amidst the COVID-19 pandemic, the specialty of palliative care has received more global attention. As defined by the World Health Organization (WHO), palliative care seeks to improve “the quality of life of patients and their families facing life-threatening illness” through the “treatment of pain and other problems, physical, psychosocial and spiritual”.¹ By involving caregivers in this process, palliative care emphasises a holistic approach towards treating a patient's suffering. Numerous palliative care models have been implemented around the globe. Arguably, one of the most well-known models is linked to hospice/hospital or “end-of-life” care, where specific centres exist to provide palliative care services. This model of palliative care operates in an institutional framework, where “around-the-clock” monitoring of patients is available.² Home-based care is an alternative model of palliative care now growing in popularity. It brings care directly into patients' homes, which allows palliative care teams to see the entire picture of the patient's life and how their illness impacts not only their physical body, but also the lives of those around them.

India exemplifies the need for palliative care services among a burgeoning and rapidly aging population. According to the WHO, an estimated 40 million people globally are in need of palliative care, yet only 14 per cent of them receive the care they need.³ Additionally, out of these 40 million people, 78 per cent of them are living in low- and middle-income countries such as India: in fact, a report mentions that an estimated 6 million people in India require palliative care services.³⁻⁴ Unfortunately, this need for palliative care is not being adequately addressed. Dr M.R. Rajagopal, founder of a palliative-care nongovernmental organisation based in Kerala, reports that only 1–2 per cent of patients in India needing palliative care actually receive it, which raises many questions about this paucity in Indian palliative care services.⁵ However, while understanding India's palliative care challenges, especially in the context of the COVID-19

pandemic, is important, it is also essential to discuss how home-based palliative care can be expanded in India through improved opioid access, increased funding, and enhanced education efforts.

A key component of palliative care is providing opioid-mediated pain relief for patients. India's stringent regulations, however, prevent doctors from prescribing these medications, despite the relatively inexpensive nature and ubiquity of opioids globally.⁶ Specifically, India's 1985 Narcotic Drugs and Psychotropic Substances Act (NDPS) implemented complex and often confusing guidelines for prescribing opioids, including the need for physicians to simultaneously obtain four to five licences to dispense painkillers.⁷ Even with recent amendments that have relaxed these stringent rules, many Indian healthcare professionals have not been trained in prescribing opioids, which means that they will be less likely to supply patients with them when needed.

Palliative care is also limited in India by local cultural stigmas and preconceived notions of palliative care being tied to the hospice setting. Since hospice care primarily revolves around end-of-life services, most people in India associate palliative care only with the final stages of a terminal illness and not with relieving pain earlier on. Cultural considerations in India, such as ayurvedic practices and beliefs in *karma*, also contribute to the stigmatisation of palliative care services, leading many patients to refuse services that could relieve their pain.^{6,8-9} In fact, even many Indian medical professionals believe that palliative care is an admission of defeat due to their lack of ability to cure patients. Additionally, the intrusive and expensive nature of hospice/hospital palliative care means that it is not a viable option for many less well-off or poor patients, who cannot afford the high costs of hospital treatment and transportation to reach hospital/hospice centres.

The COVID-19 pandemic has compounded the already significant challenges associated with implementing palliative care. Palliative care has changed radically due to the social constraints brought about by the pandemic, where telehealth services are used more widely to minimise COVID-19 transmission risk. Physical contact between healthcare providers and their patients is a key component of palliative care—in this sense, lockdown restrictions have been challenging for palliative care physicians as they seek to provide effective services to patients.

The pandemic has created an additional concern—namely, the risk of COVID-19 infection present in hospitals and hospices for terminally ill patients. This infection risk is one reason why home-based palliative care services are so beneficial, as patients do not have to leave the safety of their home. However, COVID-19 lockdown restrictions have also meant that home-care teams are taking on more procedures inside patients' homes due to hospitals being unwilling to admit immunocompromised patients. Unfortunately, access to equipment and resources is still at pre-pandemic levels and is increasingly being stretched thin.

One way to improve access to palliative care is to educate more healthcare professionals about its benefits. Another way is to enable healthcare professionals to receive training in palliative care services. However, to date, Indian doctors and nurses have not been given adequate training or awareness about palliative care. The Medical Council of India only recognised palliative care as

a specialty and gave the distinction of an M.D. in Palliative Care in 2012. As a result, most Indian physicians wishing to further their education in palliative medicine continue to have to travel abroad for fellowships.⁴ Beyond physicians, palliative care will never be highly regarded in India unless the general population also gains greater awareness and access. In the last decade, there have been formal courses and information sessions designed to educate the public about palliative care. Regrettably, the COVID-19 pandemic upended the continuation of many of these courses, stressing the need for virtual forms of palliative care education. Using formal, online courses and mobile applications to deliver palliative care information will be essential to resuming educational services.

Due to the previously mentioned limitations in opioid prescription imposed by the 1985 NDPS Act, Indian doctors are limited in their attempts to provide painkillers to palliative care patients. Therefore, another key step in expanding access to palliative care services is for the federal government to make a greater effort to revise the complex opioid regulations stipulated in this act. To ensure that opioids are not only available but are prescribed properly, Indian doctors need to be trained to recognise medical cases in which prescribing painkillers is appropriate. This recommendation goes hand in hand with training more Indian doctors in the palliative care field. The combined impacts of opioid availability and greater palliative medicine education will lay the groundwork for further efforts to expand palliative care services across India.

For palliative care to be scaled up across the country, organisations and hospitals will require more funds. With no nationwide healthcare system and a lack of money from the private sector due to the pandemic, these resources are currently severely lacking in India.¹⁰ The best long-term solution for improving funding for palliative care services is for the government to take an active role in providing money to palliative care providers and organisations. Whether this is done through expanding health insurance or simply through increasing monetary support for palliative care, it is imperative that federal and state levels create this structural foundation.

Finally, home-based care is key to addressing the impact of palliative care in India, especially in a future where contagious diseases such as COVID-19 may continue to propagate. By ensuring that patients do not have to leave their homes to receive palliative care services, home-based models protect the health of many immunocompromised patients that would be unable to receive hospice/hospital-directed care. Due to their adaptable nature, these home-based services are also able to continue operating safely even in the face of COVID-19-related restrictions. The flexibility of home-based palliative care will help promote even more innovations in the organisation and provision of palliative care, some examples of which include maximising efficiency of care through triage systems or more closely involving family members in the care of patients that may need less involved interventions.

India presents an important study of the challenges and promises of palliative care in a modernising, more virtual world. Despite its unique cultural context and the continued challenges to effective implementation of palliative care, current developments in the field show promise for expanding access to these pain-relieving resources across the country. With greater focus on funding and opioid availability and more widespread education efforts, India has the potential to become an innovator in palliative care on a global scale.

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CONFLICTS OF INTEREST

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