

## Special Article

# Advances in palliative care in 2020: Palliative care and oncology in India - Looking ahead from 2020

Vidya Viswanath<sup>1</sup>, Seema Rajesh Rao<sup>1</sup>

Department of Palliative Medicine, Homi Bhabha Cancer Hospital and Research Centre, Visakhapatnam, Andhra Pradesh, <sup>1</sup>Department of Palliative Medicine and Supportive Care, Kasturba Medical College and Hospital, Manipal, Manipal Academy of Higher Education, Manipal, Karnataka, India

**Correspondence to:** Vidya Viswanath, E-mail: [drvidya21@gmail.com](mailto:drvidya21@gmail.com)

The papers in this perspective were selected by the authors as they discussed the relevance of palliative care and highlighted the importance of integrative practice with oncology among papers published in 2020.

“Some say that palliative care is the best kept secret in healthcare”.

This is the first line in the foreword of the Global Atlas of Palliative Care 2020-2<sup>ND</sup> edition by the Director General World Health Organization (WHO). This atlas is a source of essential information on the status of palliative care (PC) worldwide, and surveys PC needs based on the concept of serious health-related suffering (SHS) across age groups and disease types. It maps PC development in different countries, reviews models of care delivery across different resource settings, and identifies the barriers of care provision; thus serving as a contemporary baseline.<sup>[1]</sup>

The Global Atlas reveals that over 56.8 million people are in need of PC worldwide. Adults over 50 years account for 67.1%, with children accounting for 7.1%. Among the adults, the largest single disease group needing PC is cancer (28.2%). Among children, cancer accounts for 4.1% of PC needs. Across resource settings, 76% adults and >97% children (0-19 years) are from the low and middle income countries (LMIC). Regional distribution shows that 17.1% adults and 19.5% children needing PC are from the South East Asian Region (SEAR). SHS amenable to PC interventions is expected to increase by 87% by 2060.<sup>[1]</sup>

PC development follows the WHO public health model emphasizing policy, education, medication availability, and implementation laws that acknowledge and define that PC is part of the healthcare system.<sup>[1]</sup> There are only 55 countries in the world with a national strategy or plan for PC.<sup>[2]</sup> At the highest level, PC provision is available for only 14% of the global population and is concentrated in European countries.<sup>[1]</sup> Within Europe, there is a significant increase in specialist palliative care services, but this is in Western Europe and the high-income group region.<sup>[3]</sup> Approximately 84.25% of the world's population lack adequate access to opioid medications for pain control. Australia, Canada, New Zealand, the United States, and several European countries account for more than 90% of the global consumption of opioid analgesics, while LMICs, comprising 88% of the global population, consume only 10% of global opioids.<sup>[4]</sup>

India is among the 37 countries that are just making progress towards a national strategy for PC.<sup>[2]</sup> India is mapped at level 3a (level 1—no known PC activity to 4b—advance PC integration) where palliative care provision is isolated, activism is patchy, sources of funding are donor dependent, availability of morphine and the number of palliative care services in relation to the population is limited.<sup>[5]</sup>

In PC provision, lack of clear policies, education, research, medication, and resources coexist with distinct psychosocial and cultural barriers due to the fears associated with death and dying.<sup>[1]</sup>

This is an open access journal, and articles are distributed under the terms of the Creative Commons Attribution-NonCommercial-ShareAlike 4.0 License, which allows others to remix, tweak, and build upon the work non-commercially, as long as appropriate credit is given and the new creations are licensed under the identical terms.

**How to cite this article:** Viswanath V, Rao SR. Advances in palliative care in 2020: Palliative care and oncology in India - Looking ahead from 2020. Indian J Cancer 2021;58:45-7.

**Submitted:** 14-Dec-2020

**Revised:** 20-Dec-2020

**Accepted:** 23-Dec-2020

**Published:** 24-Mar-2021

Access this article online	
<b>Website:</b> <a href="http://www.indianjancancer.com">www.indianjancancer.com</a>	<b>Quick Response Code:</b> 
<b>DOI:</b> 10.4103/ijc.IJC_1347_20	

Compounding the problem is the confusion associated with terminology and referral patterns to palliative care. From the modern hospice movement in the 1960s, PC has transitioned into a medical discipline, which is now a global priority. The evolving definitions, euphemistic terminology, upstream migration from end-of-life care to early palliative care, and the multidisciplinary approach has blurred boundaries and caused uncertainty within and between specialities in medicine.<sup>[6]</sup> Though PC has a positive effect on quality of life and medical costs,<sup>[7]</sup> it is an end speciality and physician views play a key role in triggering PC referrals and impacting care provision.

A recent globally highlighted systematic review explores how the oncologists' views impact referral to PC. Reluctance to refer to PC was triggered by the oncologist's inability to accept therapeutic failure and by the negative connotation that arises out of PC being associated with death and dying. For the oncologist, referral to PC symbolizes loss of hope and a breakdown of a long-standing therapeutic relationship. Along with lack of trust in the competence of the PC provider, these factors act as major barriers for successful integration of PC.<sup>[8]</sup> A survey of oncologists' views in China cited lack of knowledge regarding PC among oncologists in the developing world as a major factor that impedes referral. The inequitable distribution of power, with oncologists acting as gatekeepers for referral to PC, and their view of PC as a service to be offered only after cessation of cancer-directed therapy has further hindered referral to palliative care.<sup>[9]</sup> The sociocultural milieu, families' and patients' expectations and healthcare beliefs discourage discussion of death and dying and preclude healthcare providers', families', and patients' transition into PC.<sup>[10]</sup> In addition, organizational barriers, lack of legislative policies and legal guidelines, along with limited palliative care resources are major obstacles for PC referral.<sup>[8-10]</sup>

These obstacles though formidable, are not insurmountable. Majority of the oncologists' perceived PC to be beneficial to the patients and their families and have advocated for its integration into cancer care.<sup>[6]</sup> Salins *et al.* in their systematic review espouse co-management between PC and oncology teams as a way out of this conundrum.<sup>[8]</sup> This would involve transfer of knowledge and skills between the two teams, focused inter-team communication, and the development of standardized care pathways aligned to the context of care. In addition, enhancing awareness regarding PC through training, legislative policies to support PC programs, and a legal framework to guide

medical care and end-of-life-care (EOLC) decisions will facilitate better PC provision.<sup>[8-10]</sup>

These nuances of integrative practice are pertinent as India is working towards widening education and research in PC across the country and stepping up policies. The International Quality Improvement collaborative-Enable Quality, Improve Patient care—India (EQulP-India) has been integrated into the National Cancer Grid (NCG) paving the way for collaborative research and scaling up evidence-based practice in PC.<sup>[11]</sup>

Sustained, collective work by the Indian Association of Palliative Care, Indian Society for Critical Care Medicine, and the Indian Academy of Neurology<sup>[12]</sup> has resulted in the drafting of the DNAR—Do Not Attempt Resuscitation by the Indian Council of Medical Research in 2020.<sup>[13]</sup> This position paper guides physicians in making decisions on whether or not to perform cardio-pulmonary resuscitation (CPR) in terminally-ill patients. Some private and public institutions (Kasturba Medical College Manipal, All India Institute of Medical Sciences Delhi)<sup>[12]</sup> have developed practical procedural guidelines on limiting life sustaining treatment and providing EOLC for patients with terminal illness where continuing aggressive invasive interventions was considered futile. The state of Kerala in its government order has laid down guidelines for brain death declaration and listed the standard clinical procedures to be followed while withdrawing life-support in the event of brain death<sup>[12,14]</sup> Quality EOLC has also been mandated by the National Accreditation Board for Hospitals and Healthcare.

The way forward would be to integrate with all specialities, not just oncology, to strengthen and expand the existing framework and complement services. Then PC could step up from being a secret in healthcare to becoming the secret of better healthcare!

#### Peer-review:

This article was peer-reviewed by an external referee.

#### Financial support and sponsorship

Nil.

#### Conflicts of interest

There are no conflicts of interest.

#### ORCID iDs

Vidya Viswanath: <https://orcid.org/0000-0002-2035-7467>

Seema Rajesh Rao: <https://orcid.org/0000-0001-8278-3640>

#### References

1. Connor S. Global Atlas of Palliative Care. 2<sup>nd</sup> ed. London, UK: World Hospice and Palliative Care Alliance; 2020. 1–119 p.
2. Clelland D, van Steijn D, Whitelaw S, Connor S, Centeno C, Clark D. Palliative care in public policy: Results from a Global Survey. Palliat

Advances in palliative care in 2020

- Med Rep 2020;1:183-90.
3. Arias-Casais N, López-Fidalgo J, Garralda E, Pons JJ, Rhee JY, Lukas R, *et al.* Trends analysis of specialized palliative care services in 51 countries of the WHO European region in the last 14 years. *Palliat Med* 2020;34:1044–56.
  4. World Drug Report 2020: Other Policy Issues. UNODC Research, United Nations Office on Drug and Crime, Vienna. Downloaded 23 June 2020. [https://wdr.unodc.org/wdr2020/field/WDR20\\_BOOKLET\\_6.pdf](https://wdr.unodc.org/wdr2020/field/WDR20_BOOKLET_6.pdf)[Last accessed on 2020 Jan 13].
  5. Clark D, Baur N, Clelland D, Garralda E, Lopez-Fidalgo J, Connor S, *et al.* Mapping levels of palliative care development in 198 countries: The situation in 2017. *J Pain Symptom Mgmt* 2020;59:794-807.
  6. Ryan S, Wong J, Chow R, Zimmermann C. Evolving definitions of palliative care: Upstream migration or confusion? *Curr Treat Options Oncol* 2020;21:20.
  7. Huang YT, Wang Y, Chi C, Hu W, Lin R Jr, Shiao C, *et al.* Differences in medical costs for end-of-life patients receiving traditional care and those receiving hospice care: A retrospective study. *PLoS One* 2020;15:e0229176.
  8. Salins N, Ghoshal A, Hughes S, Preston N. How views of oncologists and haematologists impacts palliative care referral: A systematic review. *BMC Palliat Care* 2020;19:1-9.
  9. Wu X, Zhang X, Zhang J, Cui X. Analysis of knowledge, attitude and behavior of oncology medical staff in palliative care. *Ann Palliat Med* 2020;9:985-92.
  10. Alshehri HH, Olausson S, Öhlén J, Wolf A. Factors influencing the integration of a palliative approach in intensive care units: A systematic mixed-methods review. *BMC Palliat Care* 2020;19:1-8.
  11. Lorenz KA, Mickelsen J, Vallath N, Bhatnagar S, Spruyt O, Rabow M, *et al.* The Palliative Care–Promoting Access and Improvement of the Cancer Experience (PC-PAICE) project in India: A multisite international quality improvement collaborative. *J Pain Symptom Manage* 2021;61:190-7.
  12. Gursahani R, Simha S, Mani RK. Legislation for end-of-life care in India: Reflections on 5 years of the end-of-life care in India taskforce journey. *Indian J Palliat Care* 2020;26:269-70.
  13. Mathur R. ICMR Consensus Guidelines on ‘Do Not Attempt Resuscitation’. *Indian J Med Res* 2020;151:303-10.
  14. Available from: <https://www.mohanfoundation.org/images/BRAIN-STEM-DEATH-CERTIFICATION-GUIDELINES-KERALA.pdf>. [Last accessed on 2020 Dec 22].