

Oncology-Based Palliative Care Development: The Approach, Challenges, and Solutions From North-East Region of India, a Model for Low- and Middle-Income Countries

Nandini Vallath, MD^{1,2}; Rewati Raman Rahul, MPH²; Tanma Mahanta, MBBS, DPM³; Dipankar Dakua, MBBS, CCPM, FPM³; Pranjali Protim Gogoi, MD³; Ramchandran Venkataramanan, MSc²; Lakshman Sethuraman, MBA^{2,3}; H. M. Iqbal Bahar, MD, PGDPM⁴; Kabindra Bhagabati, MBBS, PGDPM, MSc⁵; Dinesh Goswami, MD⁶; and Arnie Purushotham, MD^{2,7}

abstract

BACKGROUND Access to palliative care within healthcare systems of low- and middle-income countries (LMICs) has never been more pronounced than in current times. The Lancet Commission Report (2018) estimates that 80% of global serious health-related suffering (SHS), which demands access to palliative care for its relief, are in LMICs. Cancer is a major contributor to SHS and a rapidly growing burden in LMICs. Similar to many LMICs, cancer is a leading cause of death in India. The North-East Region (NER) of India has a high prevalence of cancer and paucity of services for cancer and palliative care.

OBJECTIVES To describe the strategies used to initiate and strengthen palliative care services integrated with the comprehensive cancer care initiatives in the state of Assam in NER.

METHODS After an initial assessment of the status of palliative care in the NER, a multipronged strategy was adopted that aligned with the WHO framework recommended for initiating palliative care services. A core team working with a government and private collaborative strategized and activated supportive policies, education, and training and improved access and availability to essential drugs, while implementing the components synchronously within the state.

SIGNIFICANCE This project demonstrates an informed regional adaptation of the WHO model. It highlights the strengths of integrating palliative care within cancer care program right from its inception. It emphasizes the sustainability of services activated across public healthcare systems, as compared with the donor- or champion-driven initiatives. The outcome of this project underlines the relevance of this model for LMIC regions with similar health systems and sociocultural and economic contexts.

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BACKGROUND

Palliative care is the active holistic care of persons with serious health-related suffering because of advanced progressive illnesses such as cancer. The care spans across the illness trajectory and lifespan of patients and includes end-of-life care. Palliative care reduces symptom burden, facilitates patient-prioritized care plan, and improves the quality of life of patients and their families.

In India, palliative care began in the mid-1990s with nongovernment organizations providing end-of-life care for patients with cancer. Since the launch of the National Program of Palliative Care in 2012, the field is witnessing a gradual expansion from champion- or donor-driven community-based facilities to integrated services within cancer and other healthcare

institutions.¹ The essential standards for palliative care services as laid out by the Indian Association of Palliative Care (IAPC) include the availability of trained, full-time professionals (doctor, nurse, and counselor); a system in place for whole patient assessment; documentation; and management protocols for managing symptoms and end-of-life care, uninterrupted supply of opioid analgesics, and processes for supporting the team, along with processes for continuity of care, as mentioned in Appendix I of the Data Supplement.^{2,3}

Relevance of palliative care within healthcare systems of low- and middle-income countries (LMICs) like India has never been more pronounced than in current times. The WHO estimates that 76% of adult population needing palliative care live in LMICs.^{4,5} The Lancet Commission Report (LCR) on Global Access to Palliative Care and Pain Relief defined and determined

ASSOCIATED CONTENT

Data Supplement

Author affiliations and support information (if applicable) appear at the end of this article.

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CONTEXT

Key Objective

To develop quality palliative care services in a region in a sustainable manner, through its integration within a public-private collaborative cancer care program.

Knowledge Generated

1. Successful implementation of the WHO-recommended framework for palliative care rests on the background study and field observations from the intended region.
2. Contextual flexibility in implementing each component of the framework is a significant contributor to success.

Relevance

Access to palliative care is the right of every patient with serious health-related suffering. Cancer patients have significant health-related suffering. We have used an opportunity presented, to integrate palliative care as part of developing cancer care in a region. Given the unmet need for palliative care in many long-term conditions, a feasible model for integrating with each is a step in the right direction, toward achieving universal coverage.

contributors to serious health-related suffering (SHS)—Appendix II of the Data Supplement.^{3,6} LCR estimates that LMICs account for 80% of global SHS, with India hosting 7.2 million of patients who are suffering.⁶ Appendix III of the Data Supplement compares the palliative care-related indicators along with the prevalence, incidence, and mortality of cancer in India, LMICs, and high-income countries (HICs).³

Cancer is listed as a major contributor to SHS.⁶ Cancer accounts for the escalating health and economic burden in many regions of LMICs.⁷ In India, it is the second leading cause of death and also the leading cause of catastrophic health expenditure.^{8,9}

The need for improving access to palliative care for patients with cancer is critical because the global cancer case prevalence is expected to double over the next two decades and half of these cases are expected in the LMICs.¹⁰ The mortality figures are disproportionately greater in several LMICs as a result of late-stage presentation of the disease and insufficient access to cancer treatment options.¹¹

The North-East Region (NER) of India has a high cancer incidence with 70%-80% presenting with advanced stage.^{7,12} Assam is one of the seven states of NER and represents 68% of NER population. Appendix IVa of the Data Supplement highlights NER and Assam on the world map depicting LMICs.³ The status of healthcare system of Assam is comparable with that of NER as shown in Appendix IVb of the Data Supplement.

Similar to many LMICs, a cancer diagnosis is far more lethal in NER, because of late presentation, delay in diagnosis, and poor access to health care. A 5-year cumulative survival of head and neck cancer for early stage is 40% as compared with rest of India, which is 74%.^{12,13}

This article describes activation of palliative care services in the state of Assam using a collaborative venture between the state government and a nongovernment organization. From the comparisons of age-standardized cancer death

rate and the demographic indicators across Assam, North Eastern Region, India, and LMICs as depicted in Appendices V and VI of the Data Supplement, it may be surmised that the strategies used in Assam can have applicability across other regions of LMICs as well.³

The cancer care initiative began in the last quarter of 2017, when Tata Trusts (the Trusts), one of the largest philanthropic enterprises in India, collaborated with the state government of Assam to develop comprehensive cancer care services in the region. The vision was to provide accessible, affordable, patient-centered cancer care. The program emerged as a distributed model of care as depicted in Appendix VII of the Data Supplement.³ The vision and budget of this program integrated awareness, prevention, early detection, and provision of palliative care services across all tiers. This meant that the development of palliative care attracted as much attention as oncology, from the planning and funding perspective.

The strategies and activities related to palliative care were managed by an expert team, working with the Trusts (the core team). Details of their background, roles, and responsibilities are presented in Appendix VIII of the Data Supplement.³ The core team began by exploring the status of palliative care through field visits and discussions with hospital administrators and oncology and palliative care professionals of the state. Appendix IX of the Data Supplement³ tabulates activities of the palliative care units in the region, as assessed during these field visits. None of the existing services fulfilled the essential criteria of the IAPC standards audit tool. The main challenges faced were (i) lack of skilled professionals, (ii) inadequate administrative support and funding, and (iii) underutilization of services, because of poor awareness of the scope of palliative care among professionals and the public.

Oral morphine consumption is considered an established indicator of access to palliative care and pain relief in any

region.¹⁴ Table 1 compares the total amount of morphine dispensed at a tertiary cancer care center in Assam during the year 2017, with the need for morphine estimated based on the number of patients seen at that hospital during the same period.¹⁵ The difference between the actuals (1.890 kg) and the estimates (102.6 kg) demonstrates the massive gap in the access and availability to essential narcotic drugs (ENDs) in the state. It may be inferred that a majority of patients with cancer with severe pain had poor access to analgesics and suffered needlessly.

Although lack of awareness and misconceptions at professional and public levels played a significant role, the major barrier was regulatory. Several licenses with brief expiry periods, mandated and controlled by the state excise department, had to be maintained by an institution that required to stock these drugs. The state health department was unaware of the amendment of India's narcotic drug law in 2014-2015,¹⁶ and the modified rules had not yet been implemented in the state nor in the NER. Prohibitive regulations are a common concern restricting access to essential opioid analgesics in many LMICs.¹¹

The curricula of the medical and nursing colleges in the state did not feature concepts on palliative care. A 1-year fellowship program in palliative care in the tertiary cancer center had been discontinued for over 5 years. The essential certificate course in palliative care, a flagship 3-day awareness program of the IAPC, was conducted annually in the capital city and had a total of five participants in the year 2017.

Because of the formal engagement with the Trusts, activities related to the cancer care program became an important mandate for the state health departments. Officials were open, engaging, and helpful as they comprehended the seriousness of cancer as a disease. However, the scope of palliative care within the realm of cancer care was not fully appreciated. Palliative care was equated with care for the terminally ill and deemed out-of-bounds for state-level integration and funding. The state office of the National Health Mission (NHM) was unacquainted with the National Program of Palliative Care (NPPC) that came under their purview.¹

STRATEGIES AND INTERVENTIONS

After the exploration and collation of information, the core team chose the Public health model for palliative care development recommended by the WHO. WHO framework recommended simultaneous efforts through (1) policies, (2) education, (3) access to ENDs, and (4) facilitating implementation (Appendix Xa of the Data Supplement).³

The strategies adopted for Assam, categorized as per the WHO framework (Appendix Xb of the Data Supplement), are described below:

1. Activate supportive policies

- 1.1. Integrate palliative care within the mandates, funding, and activities of the bodies governing the state health systems
- 1.2. Initiate palliative care services within regions prioritized for healthcare development by the state government
2. Enable Education and Training
 - 2.1. Facilitate training and build capacity to provide palliative care
 - 2.2. Develop awareness on the scope of palliative care among the professionals and the public
3. Improve access and availability to essential drugs
 - 3.1. Improve access and availability to ENDs by addressing the regulatory barriers
 - 3.2. Implement the amended narcotics law in the state
4. Synchronous implementation
 - 4.1. Support centers of excellent standards providing quality palliative care
 - 4.2. Activate novel endeavors in response to field observations.

These strategies were designed to unfold simultaneously rather than sequentially. The team also chose indicators to assess and monitor the program.

Activating Supportive Policies

This objective aimed to include palliative care within the mandates of the top offices in the state health system.

The cancer care project of the Trusts was governed by the newly formed joint committee represented by the state government officials and the Trusts. A road map was presented to the governing body officials, clarifying the purpose, objectives, and expected outcomes for palliative care development in the state. Early engagement with decision makers promoted synchronous action across sections.

All government-supervised medical college hospitals worked under the Directorate of Medical Education (DME). An official directive from the DME,³ addressed to the principals of medical college hospitals, ensured support for the new palliative care units within their premises.

The budget for palliative care at state level was linked to the budget of the national noncommunicable disease program (NCD, including cancer) that came under the purview of the state office of the NHM. As part of the collaborative, the Trusts supported the NHM through dedicated personnel posted at their offices in districts of interest. The core team thus found a platform for their initiatives and helped the state NHM access federal budget earmarked for palliative care. In time, the state NHM became informed owners for operationalizing palliative care services at district and subdistrict levels through its Health & Wellness centers (HWCs) in state prioritized regions (Fig 1).

TABLE 1. Comparison of Estimated Annual Morphine Requirement v Actual Morphine Consumption (the Estimation Based on the Annual Patient Load and the Actual Amount of Morphine Dispensed for the Year 2017 for the Tertiary Cancer Hospital and Actual Morphine Consumption at a Tertiary Cancer Center in Assam)

Patients seeking cancer care at the center/year (A)	= 30,000 patients/year
Patients in advanced stages (B) = 80% of A	= 24,000 patients/year
Patients who need strong opioids for relieving moderate to severe pain (C) = 66% of B	= 15,840 patients/year
The estimated yearly requirement of morphine for this population C using ~ 72 mg/day/patient for at least 3 months = $C \times 72 \text{ mg} \times 90 \text{ days}$	= $15,840 \times 72 \times 90$, which is 102.6 kg/year
Actual morphine consumption at the center, a mere of the estimated consumption	= 1.890 kg for year 2017
The gap in kilograms, between actual morphine consumption and the estimated requirement based on patient load for the year 2017	= 100.71 kg

NOTE: Reference for the calculation method used for re-estimating need for morphine from cancer patient numbers: Joransen et al: [https://www.jpmsjournal.com/article/S0885-3924\(07\)00,121-2/pdf](https://www.jpmsjournal.com/article/S0885-3924(07)00,121-2/pdf).

Enabling Education and Training

To strengthen the overall palliative care capacity within the state, new palliative care services were established in the medical college hospitals at Dibrugarh and Jorhat and at the state cancer hospital (Kamrup), by recruiting, training, and mentoring of professionals. The in-person–certified training recommended by the NPPC for palliative care professionals was selected. Since there was no training capacity within NER, training centers from other regions in India, which fulfilled both the essential and desirable standards of the IAPC standards audit tool, were selected. Three palliative care doctors and twelve nurses were recruited and trained during the project period. Sensitization programs were conducted for healthcare professionals at host institutions, as part of the new initiative. The aim was to clarify the scope of the field, generate interest, elicit support for integration, and encourage appropriate referrals. The multiple activities undertaken for initiating palliative care services at a medical college are depicted in Figure 2.

Figure 3 shows the progress of palliative care service delivery across the newly activated centers in three hospitals in the state.

All functioning palliative care centers in the region were deemed as assets, and the core team strived to strengthen their capacity to achieve the essential and many of the desirable standards featured in the IAPC standards audit tool. Accordingly, the core team facilitated training for additional doctors, nurses, and multipurpose health workers for the palliative care units at Kamrup and Cachar districts. The aim was to strengthen and expand their services across all clinical settings including home-based care. A quality improvement project to enhance the coordination and communications between out-patient and in-patient settings was completed successfully at the Cachar center, under the aegis of EQUIP-India program, an immersion training program in healthcare improvement sciences, supported by the Trusts.¹⁷ Both centers now have all the essential and several desirable standards of the IAPC standards audit tool.

The awareness program of IAPC was initiated at the state cancer institute in June 2018, which has since become a popular annual event. Medical and/or nursing students are now being posted as observers at the palliative care units at Jorhat and Dibrugarh medical college hospitals.

FIG 1. Palliative care services within the cancer care institutions in the pre- and postintervention period. NHM, National Health Mission.

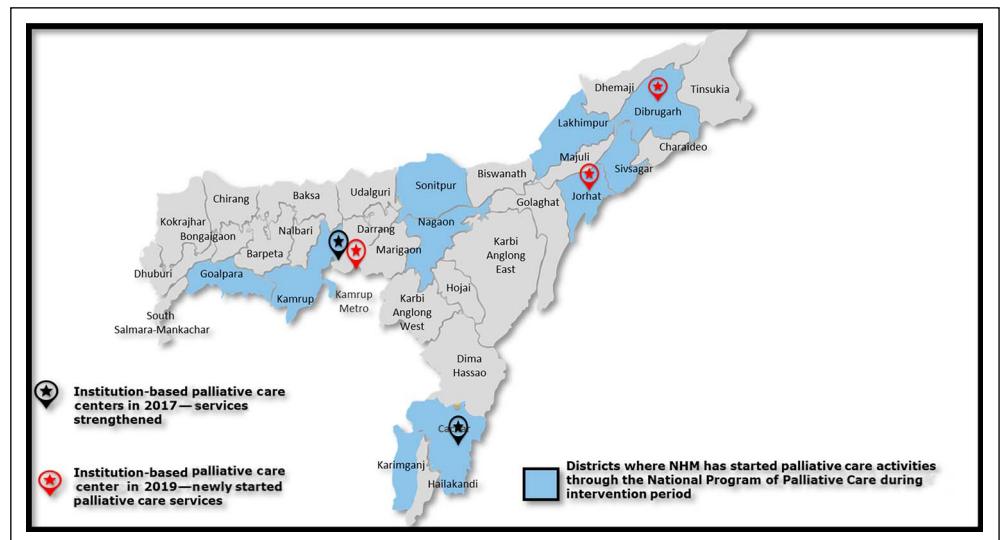
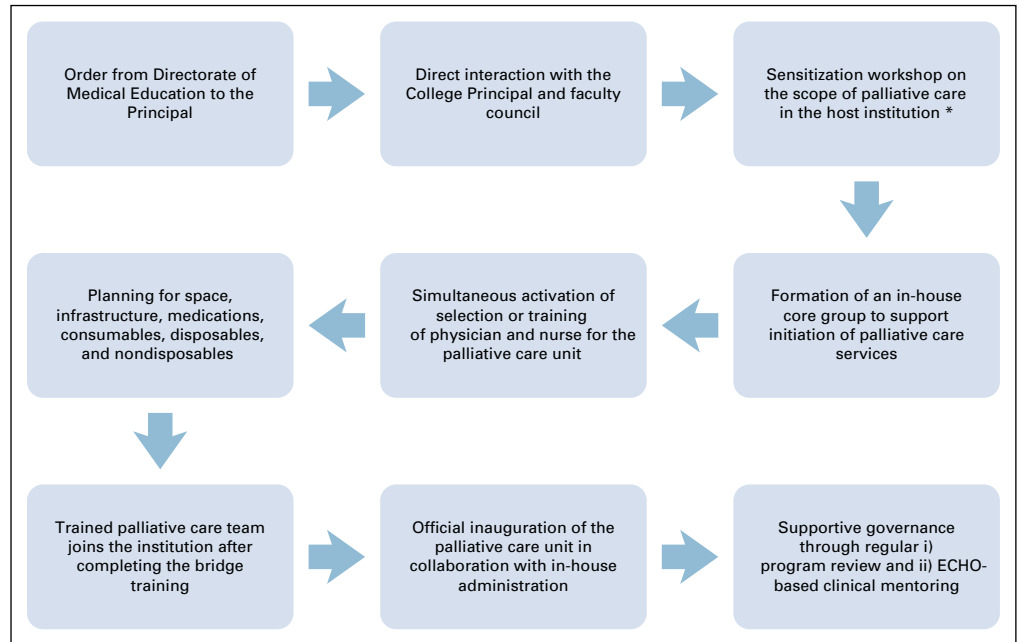


FIG 2. The sequence of activating a working palliative care at a state governed medical college hospital. *Heads of clinical and academic departments and nursing heads, medical social workers, pharmacy, rehabilitative sciences, medical and paramedical students, and administrators. ECHO, Extension for Community Healthcare Outcomes.



Community awareness programs were conducted through bike rallies, and focus group discussions, on the theme of cancer prevention, detection, and palliation. Coverage on palliative care activities through print, electronic, and social media further facilitated awareness.³

Improving Access and Availability to Essential Drugs

The Narcotics Drugs and Psychotropic Substances (NDPS) Act 1985 of India was amended in 2014 through a parliamentary action, to overcome regulatory barriers that

constrained the access and availability of narcotic analgesics for needy patients.¹⁶ The amended rules authorized the office of the State Drug Controller (SDC) to permit medical institutions to stock and dispense the controlled analgesics (ENDs).

The core team sensitized the SDC, elicited and resolved their questions, and supported implementation of the reformed drug law in Assam. The facilitated participation of a key official in a national opioid availability workshop (February 2019), through direct interactions with drug

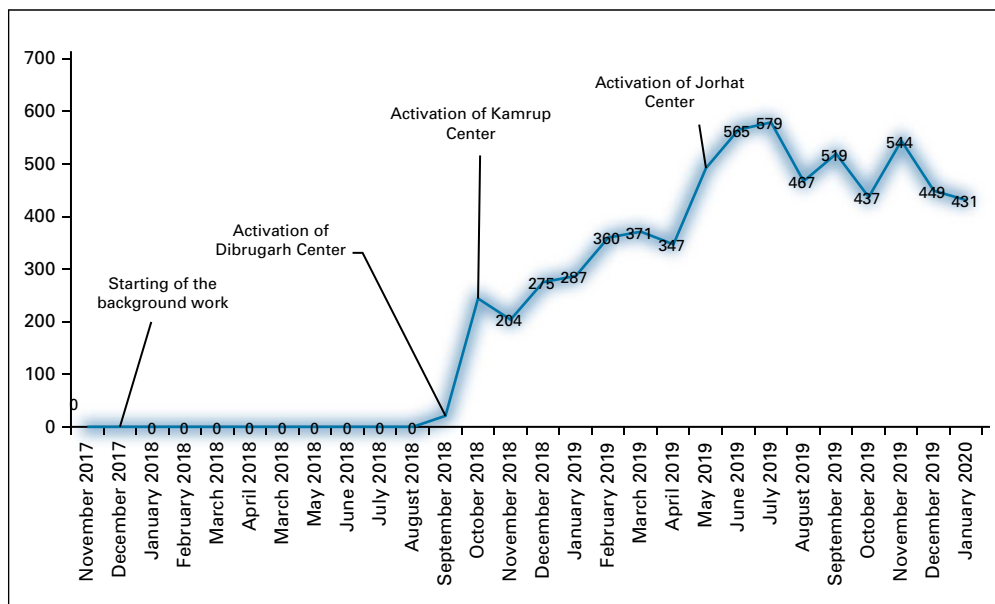


FIG 3. The run chart depicting the total number of patients seen across the newly activated palliative care services at Dibrugarh, Guwahati, and Jorhat (December 2017-February 2020).

policy experts and officials from other states holding similar responsibilities, triggered an attitudinal shift and catalyzed implementation of drug reform in the state. Submission of the NDPS Act/Rules with the amended sections, translated and highlighted in Assamese (local language), further supported the cause.

In June 2019, an official order from the Principal Secretary to the SDC, including official stakeholders, mandated seamless integration and implementation of the amended rules in Assam (Appendix XI of the Data Supplement).³ By December 2019, the palliative care units at Dibrugarh, and Jorhat and Kamrup, became the first set of centers in the state activated to stock and dispense ENDS, as per the amended regulations.

Synchronous Implementation

Early engagement with the opinion leaders in each region on the scope of palliative care facilitated co-ownership and early integration.

The core team ensured participation of the regional palliative care champions in the interactions with the government and in the public platforms. They readily engaged with the awareness and educational programs for professionals, administrators, bureaucrats, and the public and in the advocacy and implementation activities of the amended drug law in the state.

The opportunities presented during the project period were noticed and translated to design innovative methods for sustainable impact in the region. The Preventive, Early-detection, and Palliative (PEP) care activities within the training and community-based activities was one such unique opportunity for integrating care and; reduce the overall burden of cancer. The model focused primarily on building capacity of the community-based team.¹⁸

Health and wellness centers are the public healthcare services closest to the community, at the village level. The PEP concept was piloted at the HWCs in Sonitpur district, for oral, cervical, and breast cancers. For the pilot, the Trusts collaborated with a nongovernmental organization working on NCDs in the region. From the 2,106 households surveyed, 13 patients were identified for in-depth evaluation for oral or cervical cancer and 11 home-bound patients were found requiring palliative care services. The pilot confirmed the feasibility of the PEP model for wider implementation.

Coincidentally, during this period, the federal government announced prevention and palliation of cancer as mandates of HWCs across the country. The PEP concept that aligned well with the strategies and activities of the NHM now found federal budget support. It has since become the field model for cancer-related capacity building of HWCs in the state, using the integrated PEP training schedule conceived by the core team, to upskill their staff (Appendix

XIII of the Data Supplement).³ Districts with well-staffed HWCs, having the capacity to escalate care to oncology or palliative care units in the region, have been prioritized for PEP implementation in the state. Considering that the operational guidelines for the comprehensive primary healthcare program for HWCs mandate prevention, early detection, and palliation;¹⁹ this NHM-owned PEP model at Assam has wide applicability in India.

For early integration of palliative care services within the upcoming new cancer care centers, an innovative fellowship was developed for new entrant medical and nursing professionals entering this field. The program comprises of a credit-based training in three phases: (i) in-person intensive training for 3 months at selected training centers combining theory, practice, and hands-on experience; (ii) 9-month virtual credit-based assignments, while the candidates initiate palliative care services at their host institutions; and (iii) final week-long intensive with an exit examination at the end of fellowship year. The candidates have assigned mentors to interact with, across the fellowship period. Modules for the fellowship were developed through participation of national faculty. This program is ready for launch.

OUTCOMES

Indicators of impact for the interventions between December 2017 and end of February 2020 (including February) are depicted in [Table 2](#). The number of major institutions providing daily palliative care services in the state has increased from two to eight during the study period. Four of these fulfill the essential standards as per the IAPC standards audit tool. The state has implemented the amended narcotic regulation, which in-turn has improved access to essential analgesics for patients with cancer. Nine centers stock and dispense opioids without interruption in supplies. The annual consumption of morphine in the state has increased from 3.72 kg to 6.8 kg. The state now has six services, with the capacity to conduct foundation training programs and awareness activities, and 26 professionals from the state have completed the IAPC essential certificate course. A total of 108 frontline health workers have been sensitized and trained under the aegis of the NHM, to screen for palliative care needs in their community and provide basic services.

There have been other nonquantifiable, yet meaningful outcomes of these operations. The project has successfully showcased palliative care services at key educational institutions at tertiary, secondary, and primary levels, within the public health system of Assam. This is more likely to support sustainability, as compared to a donor- or champion-driven initiative. The administrators, the patient and/or family units receiving the care, the departments referring the patients, and the medical and nursing students observing the scope of palliative care are the new ambassadors for the field. Professionals from the region expressed

TABLE 2. Comparison of the Selected Indicators From November 2017 (Before the Interventions Began), Compared With the Collated Data at the End of February 2020 (Including February) After 27 Months of Applying Interventions

Indicator	November 2017	By March 2020
Palliative care service capacity		
Number of units with institution-based palliative care in the state	2	5
Number of institutions fulfilling all the essential standards as per the IAPC care audit tool	Nil	5
Opioid availability		
Number of medical institutions recognized to stock and dispense essential narcotic drugs as per the NDPS regulations (RMIs)	Nil	3 (4 are in the process of becoming RMIs)
Palliative care units having access and availability to essential opioids for cancer pain relief	3	7
Quantity of morphine consumption in the state	3.72 kg	6.8 kg
Educational activities in palliative care		
Number of institutions with in-house capacity for training in generalist palliative care	3	6
Number of professionals who completed structured residential training programs for 6 weeks at Apex Cancer Care Centers	6 doctors	9 doctors 14 nurses and 2 community health workers
Nurse trainers in palliative care nursing (through ELNEC) ^a	Nil	3
Virtual academics through ECHOs (Extension for Community Healthcare Outcomes)	Nil	Open, online bimonthly ECHO-based training programs
Institutions with ongoing sensitization sessions for healthcare professionals about the scope of palliative care	One (Kamrup)	6 (3 cancer care centers and 3 medical colleges)

Policy-Level–Integration Within Health System Policies of the State

Directives, Orders, and Sanctions	Purpose
Directive by Principal Secretary to State Drug Controller	State-level implementation of the amended drug laws
Order from Directorate Medical Education	Integrate palliative care services within medical colleges
Sanction of the budget for developing palliative care available from the National Health Mission, through the Program Implementation plan (PIP) of noncommunicable diseases	Sanctioned and used the palliative care budget available from the central government for 2019 (i) Capacity building of government doctors from 10 district hospitals through the Essential Certificate Program on palliative care by the Indian Association of Palliative Care (IAPC) (ii) Trained 76 Accredited Social Health Activist (ASHA), 10 Community Health Officers (CHOs), and 18 Multipurpose Workers (MPWs)
Activation of the office of the State Drug Controller as the single agency for implementing NDPS rules in the state	Clarified the procedure to recognize Medical Institutions to stock and dispense essential narcotic drugs
Novel endeavors	
The PEP Project	Helped integrate preventive, early detection, and palliative care activities at the grassroots Health & Wellness Centres within the NHM network
In-depth competence training through an innovative fellowship	Readiness for structured training in palliative care for doctors and nurses

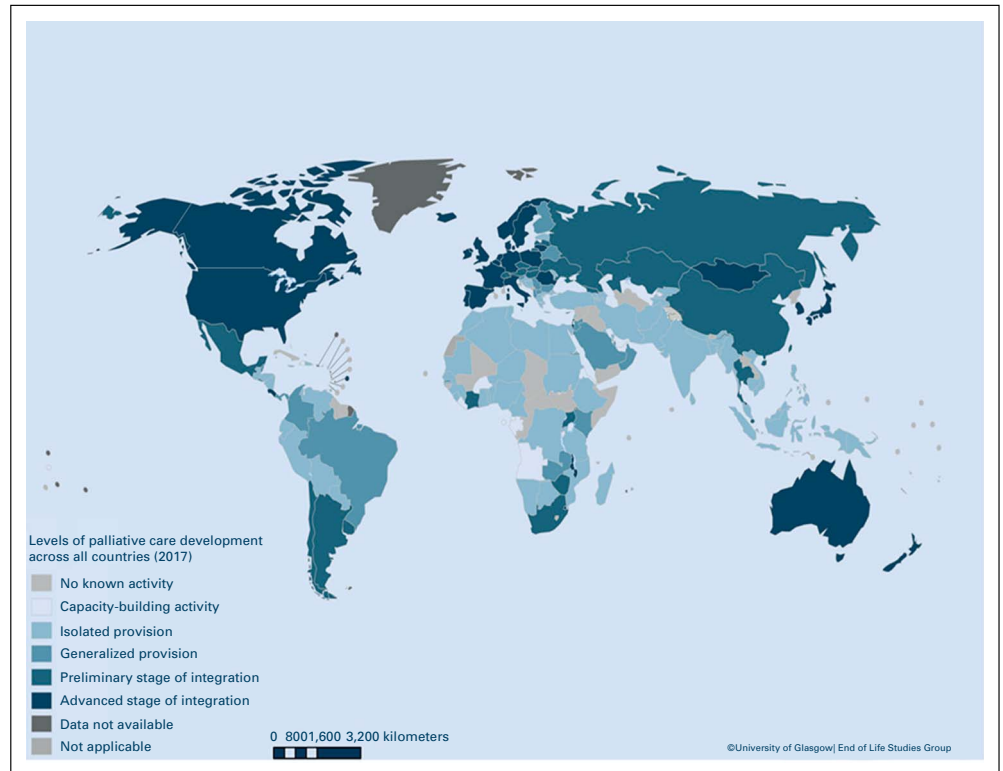
Abbreviation: NHM, National Health Mission.

^aEnd-of-Life Nursing Education Consortium: <https://advancingexpertcare.org/elnec>.

their new-found solidarity by hosting a successful international conference in February 2020, attended by 640 national and 60 international delegates. The publicity

accorded to the conference has given a further boost to the speciality. Palliative care is no longer an unknown field in the region.

FIG 4. Levels of palliative care development across different regions of the world. Note. Published with permission from The Worldwide Hospice Palliative Care Alliance.



DISCUSSION

SHS is a major challenge for LMICs, where the population is growing and aging.²⁰ Palliative care mitigates SHS.²¹ Access to the palliative care, including access to pain relief, is acknowledged as a human right.²²

Despite multilevel efforts, there is gross disparity between access and availability to palliative care across the globe.⁵ The Worldwide Palliative Care Alliance in 2020 mapped levels of palliative care development across the globe and categorized countries across a spectrum, starting with level 1 with no known activity and ending at level 4b, where palliative care services are at a stage of advanced integration into mainstream healthcare service provision (Fig 4). SAARC countries, (Afghanistan, Bangladesh, Bhutan, India, Maldives, Nepal, Pakistan, and Sri Lanka that belong to the South Asian Association of Regional Cooperation—SAARC Countries) are LMICs and host one fourth of the global population. Of these, Afghanistan, Bangladesh, India, Pakistan, and Sri Lanka are categorized level 3a, with isolated palliative care provision and Bhutan and Maldives are categorized as level 1, as there is no known hospice or palliative care activity.²³ Although India has been categorized at level 3a in this map, it would be apt to describe its development as a range: the state of Kerala is at level 4a with early integration of services into mainstream service provision, and few regions like the state of Telangana are at level 3b with generalized palliative care provision. Many regions in India, including NER, are between levels 1 and 3a, with some capacity building activities, community-based

activities, and isolated provision of services based on donor-driven funding. Some regions have nil activity.

The Economic Intelligence Unit (2015) evaluated 80 countries using 20 quantitative and qualitative indicators across five categories: palliative and healthcare environment, human resources, affordability of care, quality of care, and level of community engagement to measure quality-of-death index.²⁴ Several countries from South-East Asia, the SAARC group including India, rate poorly on this index (Appendix XII of the Data Supplement).³ Besides, in 2018, the International Narcotics Control Board observed that 79% of the global population hosted in LMICs consumed 13% of the total licit morphine, which is 1% of the 388 tons of morphine manufactured worldwide, for pain relief and palliative care.²⁵

In response to these global inequities, the 67th World Health Assembly passed the landmark resolution encouraging member states to strengthen palliative care as an essential component of comprehensive care, within their public health systems.²⁶ The resolution provides recommendations with specific measures, strategies, and an implementation model to facilitate the development of the field. The Lancet Commission report also presents essential palliative care packages to mitigate the serious health-related suffering, affordable for even LMICs.⁶

Regional initiatives to improve access to palliative care serve as development models for other LMICs with comparable contextual background. Historically, integration of palliative care has begun in patients with cancer or HIV

diagnosis. Cancer, specifically, has well-demarcated stages of progression, deterioration, and terminal phase. However, the gradual decline of systemic dysfunctions, with uncertain prognosis and nebulous terminal phase, makes it more complex to integrate palliative care in noncancer disease conditions. Also, modern palliative care, including access to opioid medicines and other methods of pain control, has often developed, even in HICs, as an adjunct to cancer care programs.¹¹ Oncology-based palliative care, by demonstrating the scope of the field, allows for gradual expansion of services to include nononcology conditions as well.

Assam was a relatively uncharted landscape for palliative care development. Through this project, we present the implementation process of a multipronged approach aligned with the WHO-recommended framework, aimed to fulfill the humane and ethical obligation to ensure access to palliative care. An analysis of palliative care development using macroindicators in Latin America found statistically significant associations with three variables: (i) proportion of medical schools with palliative care integrated, (ii) number of accredited physicians working full time in palliative care, and (iii) opioid consumption per capita.²⁷ These findings align well with the focus areas for improvement in Assam.

The Trusts core team composition that represented subject expertise, pedagogics skills, communications and management skills, and policy- or funding-related acumen, enriched with a public health perspective, was a major strength. Other key ingredients that contributed to the progress were

1. The vision to integrate palliative care right from the inception of a funded cancer care program
2. Public-private collaboration to implement care across public healthcare systems

AFFILIATIONS

¹Quality Improvement Hub-India, National Cancer Grid, Tata Memorial Centre, Mumbai, India

²Tata Trusts Cancer Care Program, Mumbai, India

³Assam Cancer Care Foundation, Guwahati, India

⁴Cachar Cancer Hospital and Research Centre, Silchar, India

⁵Dr B. Borooah Cancer Institute, Guwahati, India

⁶Guwahati Pain and Palliative Care Society, Guwahati, India

⁷King's College London, London, United Kingdom

CORRESPONDING AUTHOR

Nandini Vallath, MD, National Cancer Grid, Tata Memorial Centre, Dr Ernest Borges Rd, Parel East, Parel, Mumbai 400012, India; e-mail: aanandini@gmail.com.

AUTHOR CONTRIBUTIONS

Conception and design: Nandini Vallath, Rewati Raman Rahul, Ramchandran Venkataramanan, Lakshman Sethuraman, Dinesh Goswami, Arnie Purushotham

Administrative support: Kabindra Bhagabati

Provision of study materials: Tanma Mahanta, Dipankar Dakua, H. M. Iqbal Bahar, Kabindra Bhagabati

3. Explorative study of ground level conditions before planning strategies
4. Structured sharing of strategies with the government, for timely policies, directives, and government orders that facilitated support for the new initiatives
5. Contextual adaptation of the WHO public health framework for developing palliative care
6. Synchronous commencement of all components, allowing progress in one realm to influence another
7. Thoughtful selection of training centers, which also served as demonstration projects
8. Ongoing mentorship at clinical and programmatic levels, for the new palliative care teams.

The wider lens of a comprehensive cancer care collaborative allowed for exploration, planning, and a monitored execution. The model demonstrates interrelatedness of the fields, inclusivity, and sharing of resources: human technological and spatial. The strategies facilitated smoother, faster integration, unlike the donor- or champion-driven community-based initiatives.

Creative collaboratives, such as described above, which link the development of palliative care with that of cancer care or other NCD and/or HIV care programs strategized as per the WHO-recommended framework and aligned with resources and groundwork, provide a valuable model for planning activities in other regions. Based on similar parameters in terms of cancer incidence, prevalence, relative mortality, and the limited healthcare facilities and funding (Appendices III-VI of the Data Supplement),³ the implementation process at Assam may find application in different regions of India and in other LMICs with similar sociopolitical context and economic background.

Collection and assembly of data: Nandini Vallath, Rewati Raman Rahul, Tanma Mahanta, Pranjal Protim Gogoi, H. M. Iqbal Bahar, Kabindra Bhagabati, Arnie Purushotham

Data analysis and interpretation: Nandini Vallath, Rewati Raman Rahul, Dinesh Goswami, Arnie Purushotham

Manuscript writing: All authors

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AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

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Open Payments is a public database containing information reported by companies about payments made to US-licensed physicians (Open Payments).

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REFERENCES

1. Director General of Health Services, Ministry of Health and Family Welfare, Government of India: National Programme for Palliative Care. https://dghs.gov.in/content/1351_3_NationalProgramforPalliativeCare.aspx
2. Indian Association of Palliative Care: IAPC Standards Audit Tool. <http://palliativecare.in/wp-content/uploads/2015/02/Standards-Tool.pdf>
3. Supplementary file supporting the JGO Assam palliative care article. <https://efficiency365.com/wp-content/uploads/2021/01/Supplementary-Data-for-Assam-Paper-JCOGO-V3.pdf>
4. World Health Organization: Palliative Care: Key Facts. <https://www.who.int/news-room/fact-sheets/detail/palliative-care>
5. Worldwide Hospice Palliative Care Alliance, World Health Organization: Global Atlas of Palliative Care (ed 2), 2020. <https://www.thewhpc.org/resources/global-atlas-on-end-of-life-care>
6. Knaul FM, Farmer PE, Krakauer EL, et al: Alleviating the access abyss in palliative care and pain relief-an imperative of universal health coverage: The Lancet Commission report. *Lancet* 391:1391-1454, 2018 [Erratum: *Lancet* 391:2212, 2018]
7. Knaul F, Horton S, Yerramilli P, et al: Financing cancer care in low-resource settings, in: Gelband H, Jha P, Sankaranarayanan R, et al (eds): *Cancer: Disease Control Priorities, Volume 3 (ed 3)*. Washington, DC, The International Bank for Reconstruction and Development/The World Bank, 2015. <https://www.ncbi.nlm.nih.gov/books/NBK343629/> doi: 10.1596/978-1-4648-0349-9_ch17
8. Office of the Registrar General and Census Commissioner, India, Ministry of Home Affairs, Government of India: Causes of Death Statistics. http://www.censusindia.gov.in/vital_statistics/causesofdeath.html
9. Kastor A, Mohanty SK: Disease-specific out-of-pocket and catastrophic health expenditure on hospitalization in India: Do Indian households face distress health financing? *PLoS One* 13:e0196106, 2018
10. B Hannon, C Zimmermann, FM Knaul, et al: Provision of palliative care in low- and middle-income countries: Overcoming obstacles for effective treatment delivery; *J Clin Oncol* 34:62-68, 2016
11. J Cleary, H Gelband, J Wagner: Cancer pain relief, in *Cancer: Disease Control Priorities, Volume 3 (ed 3)*. <https://www.ncbi.nlm.nih.gov/books/NBK343627/>
12. National Centre for Disease Informatics and Research: A Report on Cancer Burden in North Eastern States of India. Bengaluru, India, National Cancer Registry Programme (NCRP-ICMR). https://www.ncdirindia.org/Reports_NE/NE2012_2014/Files/NE_2012_14.pdf
13. P Mathur, K Sathishkumar, M Chaturvedi, et al: Cancer statistics: Report from National Cancer Registry Programme, National Centre for Disease Informatics and Research, India. *JCO Glob Oncol* 6:1063-1075, 2020
14. Global Health Observatory, World Health Organization, World Health Data Platform/GHO/Indicators: Annual consumption of morphine. <https://www.who.int/data/gho/indicator-metadata-registry/imr-details/2289>
15. Rajagopal MR, Joransen DE: India: Opioid availability. An update. *J Pain Symptom Manage* 33:615-622, 2007
16. Vallath N, Tandon T, Pastrana T, et al: Civil society-driven drug policy reform for Health and Human Welfare-India. *J Pain Symptom Manage* 53:518-532, 2017
17. National Cancer Grid India: Quality Improvement Program. <https://tmc.gov.in/ngc/index.php/activities-ngc/q1-india>
18. Hariprasad R, G Palat, Mehrotra R, et al: The PEP project: Synergistic community based action in prevention, early detection and palliative care, to impact the cancer burden in India. *Indian J Palliat Care* 24:349-354, 2018
19. National Health System Resource Centre, Ministry of Health and Family Welfare, Government of India: Ayushman Bharat, Comprehensive Primary Health Care Through Health and Wellness Centres: Operational Guidelines. <http://nhsrcindia.org/sites/default/files/Operational%20Guidelines%20For%20Comprehensive%20Primary%20Health%20Care%20through%20Health%20and%20Wellness%20Centers.pdf>
20. Poudel A, KC Bhuvan, Shrestha S, et al: Access to palliative care: Discrepancy among low-income and high-income countries. *J Glob Health* 9:020309, 2019
21. Malhotra S, Ulep R: Palliative medicine, in *Clinical Approaches to Hospital Medicine: Advances, Updates and Controversies*. Cham, Switzerland, Springer, 2017, pp 121-132
22. Lohman D, Amon JJ: Evaluating a human rights-based advocacy approach to expanding access to pain medicines and palliative care: Global advocacy and case studies from India, Kenya, and Ukraine. *Health Hum Rights* 17:149-165, 2015
23. Singh T, Harding R: Palliative care in South Asia: A systematic review of the evidence for care models, interventions, and outcomes. *BMC Res Notes* 8:172, 2015
24. The Economist Intelligence Unit: The 2015 Quality of Death Index: Ranking Palliative Care Across the World, London, United Kingdom, The Economist Intelligence Unit, 2015
25. International Narcotics Control Board, United Nations: Narcotic Drugs, Estimated World Requirements for 2020, Statistics of 2018, United Nations Publications. https://www.incb.org/documents/Narcotic-Drugs/Technical-Publications/2019/Narcotic_Drugs_Technical_Publication_2019_web.pdf
26. Sixty-Seventh World Health Assembly: Strengthening of Palliative Care as a Component of Comprehensive Care Throughout the Life Course. WHA67.19, 2014. https://apps.who.int/gb/ebwha/pdf_files/WHA67/A67_R19-en.pdf?ua=1
27. Pastrana T, Torres-Vigil I, De Lima L: Palliative care development in Latin America: An analysis using macro indicators. *Palliat Med* 28:1231-1238, 2014

