Achieving universal health coverage for Palliative Care: A Case Study of integration of palliative care into Government primary healthcare from South-Central, India

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Background: Integrating palliative care into primary care is essential to achieving universal health coverage; however, there is limited evidence of models of primary palliative care in resource-limited settings. The existing literature describes small-scale programmes, most often funded by civil society organizations; and there is limited evidence describing the integration of palliative care into government primary health care systems, critical to reaching the entire population.

Setting: The state government primary healthcare system in the state of Telangana, in South-Central India (state population – 39.6 million).

Objectives: To describe the context, process, challenges, opportunities, and outcomes of a large-scale state-wide model integrating palliative care into government primary healthcare to achieve universal coverage.

Methods: This is a descriptive case study describing the implementation of a primary palliative care model.

Results: Thirty-three district palliative care centres were established within the government primary care system, at each of the district hospitals in the state. Each palliative care centre provided home-based care, as well as outpatient and inpatient palliative care (10 bed ward). Each district centre was staffed by a dedicated team of nurses, a physician, a physiotherapist, and support staff. Staff received palliative care training through a 4-week residential course delivered by an established palliative care organization, which participated in the initiative as a knowledge partner. The training included theoretical and clinical components and was followed by ongoing mentoring and clinical supervision. A statewide referral network was also established to support bi-directional referrals between district centres and tertiary health facilities. The programme cared for 29,000 patients in the first five years, and opioids availability increased at all 33 district hospitals.

Conclusion: It is possible to implement a model of primary palliative care which is integrated into the government primary healthcare system and covers a large population. The critical components of the model which enabled success included partnerships between the local government health system, civil society, and tertiary health facilities; high-quality staff training combined with ongoing clinical supervision; establishing referral pathways; and ensuring access to opioids and other essential medicines.

Significance of the results: This is the first study to describe a large-scale primary palliative care model in an low- and middle-income country (LMIC). The study is particularly important as it is the first to demonstrate a model integration into the government-funded primary health care system, ensuring population-level palliative care coverage. The study identifies the context and processes which support health system integration of palliative care and suggests a model which can be implemented more broadly in primary health care systems globally.

Keywords: Low- and middle-income countries, end-of-life care, palliative care, implementation study, primary healthcare, universal health coverage

Palliative care is an approach to address the needs of people with serious illnesses, focusing on improving quality of life by preventing and relieving physical, emotional, social, and spiritual suffering for patients and their families and caregivers. Globally, every year more than 70 million people, include 25 million in the last year of life, require palliative care *(1)*. Despite the substantial need, fewer than 12% of those needing palliative care can access it. Currently, most palliative care is being provided in high-income countries, while 80% of the need for palliative care is in low-and middle-income countries (LMICs), leading to huge burden of preventable serious health-related suffering *(1,2)*. The World Health Organization (WHO) has identified palliative care as an essential component of universal health coverage (UHC), which is best achieved through primary healthcare *(3)*.

In India, an ageing population and growing burden of non-communicable diseases is leading to a growing need for palliative care. For cancer alone, there are an estimated 916,000 deaths each year *(4)*. Many more patients with chronic heart, lung, and kidney diseases, HIV/AIDS, dementia, and other life-limiting conditions also need palliative care; however, palliative care reaches only 4% of patients needing it across India *(5)*. Moreover, palliative care services are not well distributed, with services concentrated at tertiary hospitals in urban areas, while 64% of the population lives in rural areas. Expanding access in rural areas is particularly important for palliative care, since patients with serious illnesses cannot easily travel beyond their local community and they spend most of their time at home *(6)*.

Primary palliative care, which is provided by non-specialists in primary care settings, is an important intervention which can meet the needs of patients and their families. For patients and their families, this model of care improves health, by treating physical symptoms and psychosocial distress, and it reduces direct and indirect healthcare costs for patients *(7,8)*. Primary palliative care offers additional benefits for health systems by improving the cost-effectiveness and sustainability of services *(9,10)*.

A limited number of primary palliative care models have been described in LMICs, and these models have described small-scale programmes at one or several health facilities, usually with funding from civil society organizations *(7)*. There have been very few studies describing primary palliative care models which adopt a public health approach, seeking to ensure palliative care coverage for the population of an entire country or region. One example of population-level coverage is found in the southern Indian state of Kerala, where home-based palliative care is provided by health professionals and trained volunteers, funded by donations from the local communities. Kerala's unusually high literacy rates, long-standing decentralized governance, strong public health infrastructure, and distinctive political economy differ markedly from most Indian states and the expansion and scaling-up of the Kerala model will require adaption and contextualization. Further studies are needed to understand models of primary palliative care which can be integrated into the government primary healthcare systems and which can be scaled-up to cover the entire population *(11)*.

The purpose of this study is to describe the context, process, challenges, opportunities, and outcomes of a large scale, state-wide initiative integrating palliative care into government primary healthcare in the state of Telangana to provide coverage for the entire population. The study explores the adaption and performance of a novel model of primary palliative care, seeking to identify key insights that can be applied to government primary healthcare systems to provide palliative care coverage at a population-level.

India's economic, political, and social context

India is a lower-middle income country and government spending on healthcare is US$ 37 per capita, or 3.3% of GDP, compared to the global average of 10.4% *(6)*. India has a multi-payer universal healthcare model, which includes publicly insured services as well as government-regulated private insurance and out-of-pocket spending. Government healthcare in Telangana includes basic primary, secondary and tertiary care services for all state residents, and the system is largely free for users. However, due to long wait times and low quality care, higher income groups typically seek private care, and as a result out-of-pocket health spending makes up 49.8% of total health spending (6).

Organizational context

The Telangana primary palliative care programme was implemented by the state government in partnership with Pain Relief and Palliative Care Society (PRPCS), is a local civil society organization with 15 years' experience providing palliative care in Hyderabad, the capital of Telangana. PRPCS provides large home-based palliative care and runs a community-based hospice facility (12). In the Telangana primary palliative care programme, PRPCS was designated by the government as a "knowledge partner", providing training to programme clinical staff as well as ongoing mentorship and clinical support. Additional knowledge support was provided by Two Worlds Cancer Collaboration a Canadian charitable foundation with a long-standing partnership with PRPCS, which provided financial support for training clinical staff and service delivery. The annual patient care volumes for PRPCS are shown in Table 1.

Methods

This study employed a descriptive case study methodology,

Table 1: **Summary of annual palliative care services in 2024**

Pain relief and palliative care society

Type of visit	Children	Adults
Consultation (new patient)	180	1224
Hospice admissions	367	1039
Home-care visits	3738	12093

with findings reported in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist. The Consolidated Framework for Implementation Research (CFIR) guided the development of the research questions and the analytic approach.

Qualitative data were collected through semi-structured interviews with key stakeholders involved in the implementation process to explore the innovation, its context, and implementation processes, as well as perceived challenges and opportunities. Additional qualitative data sources included non-participant observations and document review to identify and triangulate key elements of the implementation process. Quantitative data were extracted from relevant programmatic databases to support reporting on programme outcomes.

Data analysis followed the review and recommendations of Ebneyamini et al. and involved iterative processes of data display, conclusion drawing, verification, and explanation building. Members of the research team synthesized and organized case study features – including context, process, challenges, opportunities, and outcomes – using CFIR constructs, with the aim of generating findings relevant to future research in this field.

Member checking was conducted by sharing analyzed findings with participants in written form. Participants who engaged in member checking were invited to join the research team to enhance global representation and contextual interpretation. All feedback received through this process was systematically reviewed and considered for inclusion in the final presentation of results.

Results

Developing and refining the Telangana primary palliative care model

In 2007, the first District Palliative Care Centre (DPCC) was created by PRPCS in partnership with the Department of Health and Family Welfare in Rangareddy, a rural district close to Hyderabad. A needs assessment was first conducted via household survey, identifying the characteristics and needs of local people with serious illnesses. The DPCC started by providing home-based care and then expanded to an outpatient clinic and an inpatient unit, located at the local government primary health centre. Programme staff eventually included nurses, support staff, a physician, and a van driver. A morphine licence was obtained, allowing opioids to be administered and dispensed.

Developing the Rangareddy DPCC helped develop and refine a contextualized model for providing palliative care at the primary care level in Telangana. In 2017, the government created eight DPCCs in other districts, eventually opened DPCCs in all 33 districts over the next two years. PRPCS collaborated with the government throughout this expansion, training DPCC staff and providing ongoing mentorship and support to address implementation challenges, with a particular focus on supporting opioid access.

PRPCS provided practical guidance about infrastructure, recruitment and training of staff and supported government health planners as they developed a shared understanding of how palliative care could be integrated into primary care.

Characteristics of the Telangana primary palliative care model

Core components of the DPCC

Each DPCC consists of an inpatient ward, an outpatient clinic, and a home-care service. The DPCC is physically located within the local district government hospital. Each DPCC provides core palliative care services, including treatment of pain and other common physical symptoms (e.g., nausea, dyspnea) and psychosocial and spiritual support for patients and families. Each DPCC also included clinics for lymphoedema, wound and stoma care, and cancer survivorship.

Physical space and supplies

Each DPCC inpatient wards has 10 beds and provides a bed for one family member to stay overnight, encouraging family presence. A kitchen was available where caregivers could prepare food, as well as an office and training space for staff. Food, essential medicines, basic medical supplies, all visits (outpatient or home), and admissions were provided free of charge. Each DPCC had a van stocked for home-care, and staff could dispense essential medicines and supplies during home visits.

Essential medicines and opioid access

DPCCs were required to obtain a morphine licence and have opioids available on site, thus avoiding the need for patients to travel to urban centres for medicines. Initially, opioid licensing was a significant challenge because each district drug inspector had an individual interpretation of the licensing process. To speed up licensing, PRPCS worked with the state drug controller to develop a common checklist and process,

Table 2: Essential elements of the checklist for obtaining opioid approval at DPCC, based on the Narcotic Drugs and Psychotropic Substances Act

Pharmacy: Establish and document pharmacy processes for maintaining accurate records of opioid procurement, safe storage, and dispensing.
Physician: Documentation of physician training through 1-month certificate course from PRPCS and MNJIO.
Prescribing: Develop appropriate prescribing documentation and ensure safe storage on ward.
Following submission of proper documentation, the district drug inspector conducts a site visit, prepares a report, and, providing all the elements are satisfactory, approval will be granted.

thereby standardizing the process for all districts (Table 2).

Health workforce and training

The DPCC dedicated staff team included full-time clinical and support staff of five nurses (inpatient [3], home-care [1], relief coverage [1]), three support stuff, a physiotherapist, a physician, and a driver. All staff were government employees.

Clinical palliative care training

All clinical staff completed the Basic Certificate in Palliative Care, a 1-month residential course, delivered by PRPCS. This standardized national course is delivered at palliative care centres across India, includes clinical training in the management of common physical, psychosocial, and emotional problems. The training emphasizes multidisciplinary care and the integration of palliative care into serious illness management. Training was delivered in Hyderabad with clinical exposure to home and facility-based palliative care, as well as classroom teaching and learner assessments.

Mentorship and clinical supervision

To provide additional support, PRPSC palliative care physicians and nurses provided DPCC staff with regular support through daily checks, virtual case conferences, and monthly site visits. Virtual case conferences consisted of monthly online teaching and case discussion sessions *(13)*. Daily checks were done by phone call or instant messaging with the DPCC team, reviewing admissions and clinical concerns. These three supports were continued until the end of 2021, when PRPCS staff determined that DPCC were functioning independently, and ongoing clinical support was transitioned to the referral network (see section below).

Community empowerment and awareness

Raising awareness about palliative care within the local communities was an important component of the programme, and awareness sessions (3 hours) were conducted in all districts. The sessions targeted government health administrators, primary care health workers (nurses and doctors), accredited social health activists (ASHAs), and auxiliary nurse midwives (ANMs).

Table 3: Training and awareness activities linked to DPCC (2019–2024)

Training: Certificate in Palliative Care (1-month residential course)

Type of health worker	N
Nurses	195
Doctors	42
Physiotherapists	35
Total	**272**

Awareness Sessions (3 hours)

Type of health worker	N
Accredited social health activists (ASHA) Workers	8,500
Mid-level health providers	2,450
Auxiliary nurse midwives (ANMs)	900
Primary healthcare physicians	750
Total	**12,600**

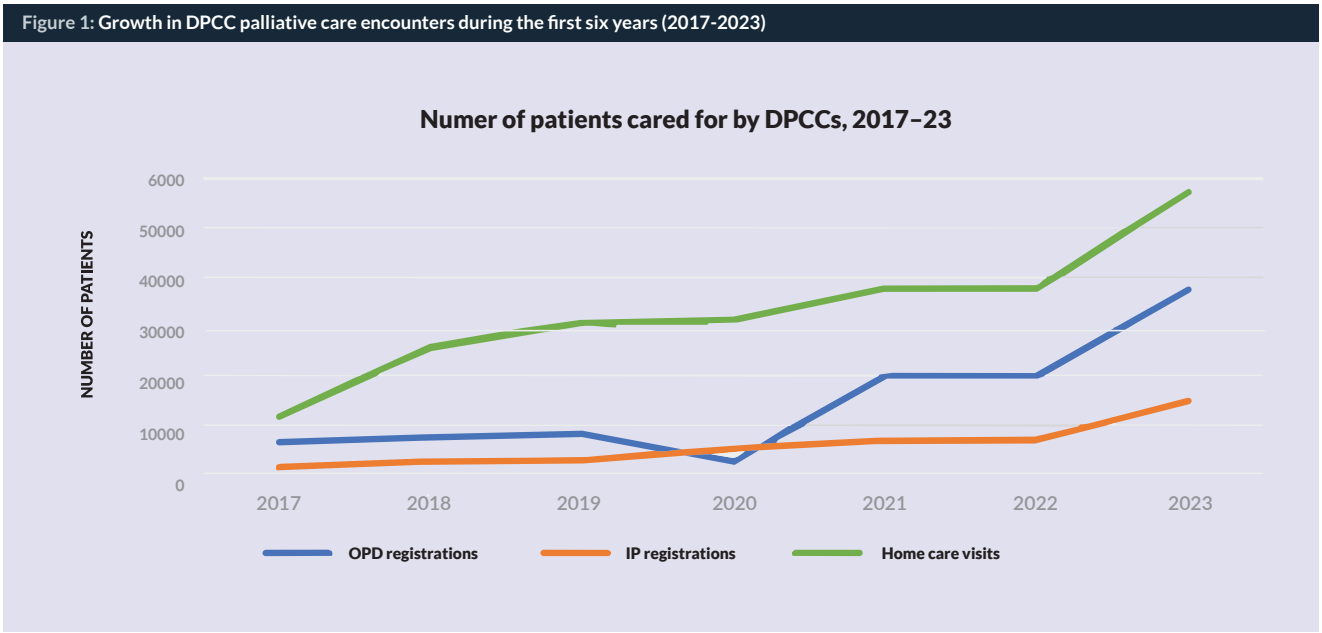
ASHAs and ANMs are community health workers providing the first point of contact for health and social care in rural areas. The awareness sessions focused on how to identify and refer people with a serious illness and how palliative care could help. Table 3 shows the number of health and social care workers who participated in training and awareness activities.

The DPCC programme was positively received in the local communities and strong government awareness about palliative care developed beyond the department of health, as government administrative staff frequently moved to other parts of the government, and in this way, awareness spread throughout the government.

Policies and administrative structure

Within the Department of Health and Family Welfare, a palliative care team was established. The team consisted of a state programme officer and three deputy programme officers who oversaw administration of the DPCCs. Working with district programme officers, this team supervised staffing, funding, medicines, equipment, data collection, evaluation and reporting. Standard monthly reporting templates were developed for DPCCs, and reporting audits were regularly conducted. The government set performance targets of 25–30 admissions and 200 home care visits per month for each DPCC.

Figure 1: **Growth in DPCC palliative care encounters during the first six years (2017-2023)**



A palliative care referral network

A referral network connecting the government cancer and children's hospitals in Hyderabad and the DPCCs was established. This network provided DPCC clinicians with rapid access to the palliative care specialists in Hyderabad for clinical questions and to clarify shared care plans. Gradually, other hospitals in Hyderabad began to use this network to referring patients to DPCCs.

Patients who had come to Hyderabad for care were referred to the local DPCC at the time of discharge or when they were returning home. The local DPCC team would then conduct a home visit to make the patient aware of the local DPCC services emphasizing that the DPCC was their primary point of contact. The DPCC and Hyderabad palliative care teams conducted monthly joint case review meetings to review and coordinate care. For patients coming home from Hyderabad with advanced progressive illness the teams coordinated end-of-life care, with the Hyderabad palliative care team developing an end-of-life care plan which was then reviewed with the DPCC team by phone. Following an initial home visit by the DPCC team, an update was sent back to the referring team in Hyderabad and the DPCC clarified the care plan as needed.

An additional element of the referral network was from community health workers (e.g., ANM, ASHA) who were encouraged to refer patients who they felt could benefit from palliative care.

Performance of the intervention

At the end of the study timeframe, the centres were well established and confident in providing core palliative care services. Morphine was available in all districts, ensuring access in all areas of the state. There were 330 palliative care inpatient beds at the primary care level, with 1,500 admissions per month and more than 300 home-based care visits occurring daily. Between 2017 and 2024, there were more than 330,000 palliative care clinical encounters in DPCCs, with a steady increase in the number of patients seen (Figure 1).

Discussion

The case study describes the development and implementation of a state-wide primary palliative care programme, a model for integration of palliative care within the existing government health and social care system to achieve population-level coverage, in this case for almost 40 million people. The "Telangana model" demonstrates that primary palliative care can be provided alongside active disease treatment, using a combination of in-patient outpatient, and home-based care. A skilled and trained health workforce is an essential component of the programme, with a team of full-time primary care providers in each district in the state providing palliative care. Health policies including morphine licensing and a statewide referral network to facilitate transitions between tertiary hospitals, district health facilities, and patients' homes improves care coordination. The Telangana model shows that it is possible to support patients needing palliative care in rural areas, including supporting end-of-life care closer to home, reducing reliance on tertiary health facilities and palliative care specialists.

Globally, the development of primary palliative care remains limited, with few successful large-scale initiatives having been described in the literature. Successful primary palliative care health service integration should consider key elements from the WHO health system building blocks, which include health workforce education and training, essential medicine

availability, health policies, empowering communities, and service delivery *(14)*. These building blocks have been organized into the WHO conceptual model of palliative care development (Figure 2). This model, which was developed through a structured, evidence-based consultative process with global experts and pilot testing in diverse country contexts, provides an outline of the core health systems considerations for primary palliative care service delivery models *(15)*.

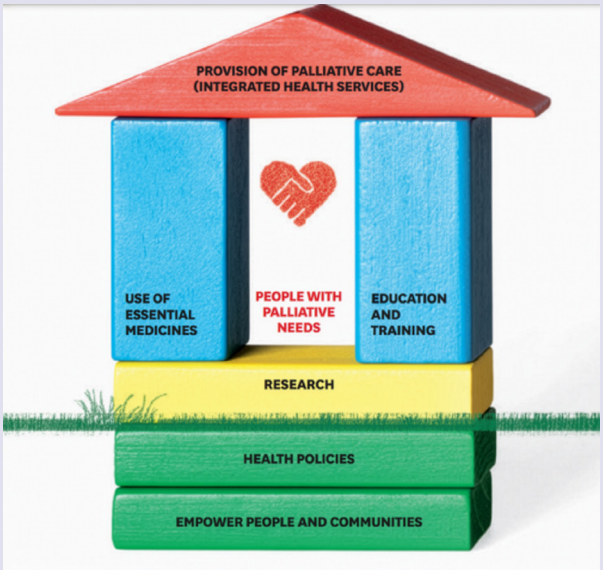
Provision of palliative care (integrated health services)

The development of the Telangana model of primary palliative care began with development and refining of the pilot DPCC in Rangareddy in 2007. The pilot phase was critical for the future success and scaling up of the model because the pilot phase allowed government and civil society partners to test and refine components of this new model in a real-world setting. By monitoring the programme and its impacts, the team was able to identify core palliative care interventions which could be provided within the local primary care model, ensuring that the supports were practical, culturally appropriate and meeting local needs and priorities. An important action in this phase was to conduct a household needs assessment survey to develop an in-depth understanding of the types of illnesses which were present in the local population and characterize their palliative care needs. Over time, clinical services were adapted to better meet local needs, with expansion from exclusively home-based care to include an outpatient clinic and eventually an inpatient palliative care unit. This reflects previous experiences from Malawi, where patients and caregivers preferred to receive palliative care either at home and from local health posts or clinics *(16)*. The pilot phase also allowed government and civil society to collaborate closely and build trust, through co-design of the project and joint problem-solving. These early actions created a strong foundation for the larger partnership during scaling up of the model.

Education and training

Clinical staff in the Telangana model were provided with high-quality palliative care training along with ongoing mentorship and sustained clinical supervision, which were key elements which leading to the programme's success. The initial training of DPCC staff used a standardized national course, thereby ensuring that all clinical staff had baseline competency with core palliative care skills. PRPCS's support as a knowledge partner was particularly important in ensuring that the training was not only clinical-relevant and context specific, while also providing health workers with hands-on experience to build clinical competence. The quality of training was particularly important for primary palliative care service expansion, since

Figure 21: Conceptual model of palliative care development



palliative care was not incorporated into undergraduate medical training for doctors in India until 2019. In 2021, palliative care was added to undergraduate nursing training, with a 20-hour mandatory module. The training delivered through the Telangana model also recognized that beyond one-time training, health workers require ongoing mentorship and clinical supervision to support practice change to deliver palliative care *(17)*. The model incorporated longitudinal support via monthly online teaching and case discussions, by connecting clinicians with expert faculty from their initial training. Connecting clinicians with familiar faculty from PRPCS further enhanced the support, helping participants to feel more comfortable posing clinical questions and sharing insights from their experiences. Daily checks via phone or messaging provided a low-cost, efficient solution to further support DPCC clinicians, providing ongoing connecting to faculty for clinical support. Further efforts to increasing health workforce capacity include regular certified training courses and standardized management protocols and guidelines, which could further support DPCC teams to provide optimal palliative care.

Health policies

Expanding palliative care within primary care to provide population-level covered for almost 40 million people was feasible only by addressing critical aspects of health policy and system, to ensure that the resources and activities of the health system were aligned with the initiative. Creation of a statewide referral network was essential for ensuring good coordination of care and reducing the need for patients to travel to Hyderabad for care. This reflects a key element from the Kerala model, which recognizes that people with a serious

illness spend most of their time at home, and that the local community should be the primary location of care. Addressing inconsistency in opioid licensing requirements was critical to ensuring essential medicine access in Telangana, which reflects the global palliative care literature which consistently identifies access to controlled medicines, particularly morphine, as indispensable to effective palliative care *(5,18)*.

Conclusions

The Telangana Model of DPCC represents one of the first initiatives describing the scaling up of primary palliative care services within government primary care, through collaboration between state government and civil society. Successful primary palliative care initiatives which achieve population coverage require a health systems approach, which incorporates the WHO conceptual model of palliative care development. These initiatives should consider service delivery models which include home- and facility-based care which is practical, culturally appropriate and addresses local needs and priorities. Additional considerations include providing ongoing clinical support from local experts beyond initial palliative care training, as well as considering solutions to address the need for referral networks and access to opioids.

Ethics Declaration: *This research was conducted in accordance with the World Medical Association Declaration of Helsinki. The study design and data analysis are based on publicly available information. The study does not involve direct interaction with human subjects or access to confidential information.*

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Data analysis and interpretation: GP, VR, MD, SB
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