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# Building Community-Based Palliative Care Systems for Health Resilience: A Case Study from the Monaragala District, Sri Lanka

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## Abstract

Palliative care is a critical yet often under-integrated component of healthcare systems in low-resource settings. It enhances the quality of life for patients with life-limiting illnesses and offers essential support to their families and caregivers. In Sri Lanka, palliative care services remain limited, particularly at the community level. To address this gap, a district-level initiative was undertaken in Monaragala to establish a sustainable, community-based palliative care system under the leadership of the Regional Directorate of Health Services. The initiative involved a context-specific gap analysis, formation of a steering committee, training of multidisciplinary teams, and deployment of a low-cost, digital patient management platform using open-access tools. Over a five-month period, six palliative care teams were established, and 19 patients were enrolled and effectively managed, demonstrating improved care coordination and responsiveness. This model not only reduced unnecessary hospital admissions and patient travel burdens but also strengthened local health system capacity by mobilizing underutilized staff and infrastructure. The project highlights the role of community-based palliative care in building health systems resilience by improving continuity of care, optimizing resources, and fostering adaptability. It offers a replicable approach for other districts in Sri Lanka and similar low-resource settings. It is recommended that the Ministry of Health facilitate the development of a centrally guided, locally implemented national framework for palliative care to ensure equitable, accessible, and resilient service delivery.

*Key words: Palliative Care, Community-Based Palliative Care, Health Systems Resilience, Primary Healthcare, Sri Lanka*

## 1. Introduction

Palliative care is an approach that improves the quality of life for patients and their families who are facing problems associated with life-threatening illnesses (1). It is a specialized form of care that provides symptom relief, comfort, and support to people living with serious or chronic illnesses, and it offers support to caregivers and family (2). Studies have found that early delivery of palliative care reduces unnecessary hospital admissions and the use of health services (1). Pain and difficulty in breathing are among the most frequent and serious symptoms experienced by patients in need of palliative care (3). Incorporating palliative care into primary healthcare systems not only enhances patient well-being but also strengthens health system resilience by being responsive to evolving epidemiological and demographic challenges, reducing avoidable strain on tertiary services, improving continuity of care, and promoting community-based support models (4). In resource-limited settings, such integration can play a critical role in building adaptive and sustainable healthcare responses to chronic disease burdens.

It has been found that 35% to 96% of cancer patients experience pain, 32% to 90% experience fatigue, and 10% to 70% experience breathlessness (5). Therefore, it is essential to manage such symptoms effectively. If not properly managed, such symptoms can significantly affect patients' ability to function, their quality of life, and their adherence to anticancer treatments (6). The need for palliative care services will continue to grow, partly due to the rising prevalence of non-communicable diseases and the ageing of populations worldwide (7).

Therefore, national health systems need to include palliative care in the continuum of care for people with chronic, life-threatening conditions (8). It has been identified that worldwide, provision of palliative care must overcome significant barriers (7,8). A recent study on the status of palliative care in 234 countries, areas or territories found that it was well integrated into health care systems in only 20 of them; 42% have no delivery system for palliative care services, and in 32% service delivery reaches only a small percentage of the population (9). Various models for implementing palliative care exist, but the success factors include a multidisciplinary and multi-sectoral approach; adaptation to the specific cultural, social and economic setting; and integration into existing health systems, with emphasis on primary health care and community- and home-based care (7).

Globally, access to palliative care services remains a challenge, with only a few countries integrating it effectively into their health systems. A successful example of community-based palliative care comes from Kerala, India, where local health workers and trained community volunteers work together to care for seriously ill patients. This model has made palliative care more accessible, especially in rural areas, and is now seen as one of the best examples of how such care can be provided in low-resource settings (10) In Sri Lanka, Palliative care centers have been established at the Apeksha National Cancer Institute, Teaching Hospital Rathnapura, Teaching Hospital Ragama, Lady Ridgway Hospital for children, Colombo South Teaching Hospital Kalubowila and National Hospital Galle to provide services to patients admitted to their respective hospitals (11). Kandy District implemented a home-based care model for cancer patients, supported by the Palliative Care Association of Sri Lanka, showing improved symptom control and reduced institutional deaths also it shows a reduced hospital re-admissions among advanced cancer patients by 32% over 6 months. (12).

### 1.1 Identification of the Gap

The gap in palliative care service delivery was particularly evident in Monaragala District, where no structured system existed to support chronically or terminally ill patients within their communities. This gap was identified through a series of structured stakeholder meetings and informal clinical discussions conducted with oncologists and anesthetists at the District General Hospital (DGH) Monaragala. These specialists provided qualitative insights into the volume, diagnostic profiles, and care trajectories of patients who would benefit from community-based support following hospital discharge. Additional inputs were gathered through consultative engagements with doctors and healthcare staff at rural divisional hospitals, who highlighted operational challenges and expressed the need for a coordinated follow-up mechanism at the community level. These discussions served as a formative needs assessment process that guided the design of the Community-Based Palliative Care (CBPC) service. Although no formal gap analysis tool or model was applied at the time, the approach was grounded in practice-based evidence and clinician consensus, allowing for the identification of priority training groups, service delivery bottlenecks, and feasible integration pathways within the existing primary healthcare system.

### 1.2 Rationale for Community-Based Palliative Care

The initiative to establish a sustainable CBPC service within the Monaragala District by 2024 emerged in response to significant gaps in patient care, particularly for those with chronic and life-limiting illnesses. Many individuals in the district experience unmet needs related to pain and symptom management, psychosocial support, and dignified end-of-life care. These challenges are compounded by the geographical isolation of rural communities in Monaragala, where limited transport, underdeveloped infrastructure, and distance from tertiary-level facilities hinder timely access to specialized services. Additionally, local health institutions such as divisional hospitals and primary healthcare units are underutilized, despite their potential to provide effective palliative care when empowered with the right training and resources. Prior to this initiative, the absence of a formal referral pathway and lack of community follow-up mechanisms further weakened care continuity. In response, the Regional Director of Health Services (RDHS) Monaragala has spearheaded the formation of locally embedded multidisciplinary teams to ensure sustained and holistic care delivery at the community level. This model not only bridges critical system gaps but also aligns with World Health Organization guidelines and national health sector priorities to strengthen primary care and chronic disease management in Sri Lanka.

### 1.3 Objectives

This case study documents the experience of a pioneering initiative undertaken by the RDHS Monaragala, with the overarching objective of establishing a sustainable community-based palliative care service in the district by 2024. The project aimed to ensure that individuals with life-limiting conditions receive accessible, patient-centered support within their own communities. To achieve this, several specific objectives were pursued: establishing dedicated palliative care centers in divisional hospitals across Monaragala; forming community-based multidisciplinary teams by assigning trained healthcare workers from local divisional hospitals and primary healthcare units to provide both institutional and home-based services; developing a structured patient referral system to identify and link individuals in need of palliative care with appropriate services; and strengthening the capacity of healthcare staff through targeted training in effective palliative care delivery. By embedding these services within the existing healthcare infrastructure and tailoring them to the geographic and social contexts of the district, the project offers a replicable model for decentralized and compassionate palliative care in resource-constrained settings.

## 2. Setting and Context

### 2.1 Geographic, Socio-Economic, and Health System Context

Monaragala is the second-largest district in Sri Lanka, spanning over 5,636 km2 (2,176 sq mi) with a population of approximately 451,000 (13). The economy is largely agrarian, with most of the population dependent on farming. However, the district faces widespread economic hardship, poor road networks, and limited infrastructure, making access to healthcare particularly challenging.

The district comprises 3 base hospitals, 14 divisional hospitals, 10 primary medical care units, and 11 Medical Officer of Health (MOH) areas. Despite this network, most primary-level facilities are underutilized, with patients often bypassing them to seek care at secondary or tertiary hospitals.

### 2.2 Community Profile and Health Needs

Monaragala has also been identified as an area with high prevalence of Chronic Kidney Disease (CKD) cases, particularly among farmers (14). In addition, the district sees a significant number of cancer cases, many of which present late due to delayed detection and poor access to treatment. With limited availability of specialized palliative care services, patients and their families often endure unnecessary suffering, making the need for a district-level intervention both urgent and necessary.

## 3. Program Design and Implementation

### 3.1 Description of the Palliative Care Model

The project established a district-wide community-based palliative care service under the leadership of RDHS Monaragala. The approach involved the creation of a multi-tiered system, including hospital-based palliative care teams, designated centers, and a digital referral and tracking platform to ensure continuity and coordination of care.

The following steps were implemented to establish palliative care services under RDHS Monaragala.

1. Establishment of a Steering Committee
2. Formation of Hospital-Based Palliative Care Teams
3. Setup of Designated Palliative Care Centers
4. Training of Multi-disciplinary Palliative Care Teams
5. Development of an Information Management System
6. Design of a Patient Management Framework
7. Sustainability Planning
8. Program Launch and Information Dissemination

### 3.2 Community Engagement and Stakeholder Involvement

The initiative was spearheaded by the Non-Communicable Disease (NCD) Unit and overseen by a steering committee composed of the RDHS, consultants, hospital directors, and key medical officers. Regular stakeholder meetings were held to gather feedback, mobilize support, and ensure alignment with existing services. Awareness programs and training sessions were conducted to sensitize healthcare workers and community members, ensuring broad ownership and sustainability.

### 3.4 Service Delivery Structure

The service delivery structure of the community-based palliative care initiative in Monaragala District was designed to provide comprehensive, accessible, and patient-centered support through a combination of home visits, institutional care, and community volunteer engagement. Three palliative care centers were integral to this structure: one at Divisional Hospital (DH) Madagama, which has been completed, and two others at DH Buttala and DH Thanamalwila, both planned for completion through the Primary Healthcare System Enhancing Project (PHSEP) funding. These centers served as hubs for both institutional and home-based care delivery. Trained multidisciplinary teams coordinated care using a standardized referral and communication system leveraging digital platforms such as Google Forms, Telegram, and WhatsApp, enabling real-time data sharing and case follow-up. Home visits formed a critical component of the model, with patients stratified based on their clinical needs to determine whether they required ongoing care at home or at the institutional level.

Figure 1: Reaching-out to Patients by Palliative Care Teams with Community Volunteers

Figure 2: Palliative Care Teams Serving Patients at the Warmth of their Homes

This blended model ensured continuity of care, responsiveness to local contexts, and optimal use of limited healthcare resources.

### 3.5 Workforce

Palliative care service teams were established in each divisional hospital and primary medical care unit, initially comprising Public Health Nursing Officers. The head of the institute, or a nominated medical officer, was designated as the officer in charge of each palliative care unit. Each team included nursing officers and healthcare assistants assigned by the head of the institution. In addition, the support of the community volunteers was also obtained in the service provision at different stages of the service provision.

Teams were trained using multiple methods—Zoom lectures, workshops, and field visits to National Hospital Galle and RDHS Kandy—supported by funds from the Asian Development Bank.

### 3.6 Digital Patient Management System

To streamline care coordination and enhance efficiency, the program implemented a Google-based digital patient management system tailored to the needs of community-based palliative care. This system comprised two key Google Forms and a centralized Google Sheet database.

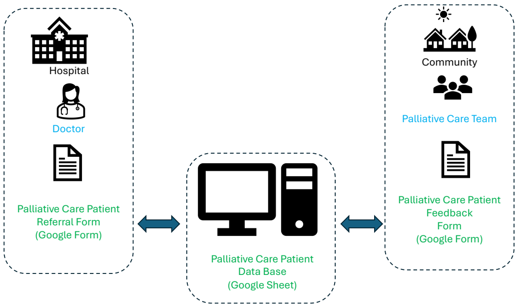

Figure 3: Digital Patient Management System

The Palliative Care Patient Referral Form was completed by the referring doctor at the hospital, while the Palliative Care Patient Feedback Form was used by the community-based palliative care teams to provide follow-up updates. All data flowed into a color-coded Palliative Care Patient Database, maintained on Google Sheets, which was accessible by relevant teams in each MOH area. The database captured a comprehensive set of patient details, including referral date, demographic information, baseline severity score, diagnosis and comorbidities, treatment history, symptom burden, level of family support, care requirements, and follow-up notes. Each patient was assigned a unique ID, and data sharing was conducted securely using encrypted platforms. Real-time updates were facilitated through a dedicated Telegram group, while WhatsApp served as a platform for clinical discussions and specialist input, ensuring rapid decision-making and collaborative care. This digital system allowed for timely, coordinated, and geographically sensitive palliative care delivery across the Monaragala District.

## 4. Enablers and Challenges

### 4.1 Enablers

Several key facilitators contributed to the successful implementation of the community-based palliative care initiative in Monaragala District. Foremost among them was the strong leadership provided by the RDHS and the NCD unit, which offered strategic guidance and administrative backing. The project also benefited from robust multi-sectoral support, including active involvement from hospitals, medical consultants, and external partners, fostering a collaborative environment. Community trust emerged as a critical enabler, with patients and families displaying high levels of cooperation and engagement in care activities. Moreover, the effective utilization of previously underused infrastructure and local healthcare personnel helped optimize system efficiency and extend service reach. The integration of digital tools further enhanced program operations by streamlining referral, follow-up, and monitoring processes—ensuring timely responses and continuity of care across institutional and home-based settings. These enablers collectively strengthened the foundation for a sustainable and responsive palliative care model.

### 4.2 Challenges

Despite the notable progress made in establishing a community-based palliative care model in Monaragala, several challenges hindered smooth implementation and service delivery. Geographical and infrastructural barriers posed significant difficulties, particularly poor road networks that complicated access to patients in remote areas during home visits. Communication was another major hurdle, as weak mobile and internet connectivity in rural regions disrupted coordination and delayed data sharing. Human resource constraints also emerged, with a limited pool of trained staff available at the district level to manage the increasing demand for palliative care. Logistical limitations, such as the absence of official vehicles for field visits, forced teams to depend on personal or occasionally donated transport, impacting reliability and safety. Additionally, data management processes suffered due to staff shortages and a lack of technical training, creating inconsistencies in patient monitoring and reporting. These barriers underscore the need for sustained investment in infrastructure, workforce development, and digital capacity to ensure the long-term viability of the program.

## 5. Early outcomes

### 5.1 Service Delivery

By June 2025, the community-based palliative care initiative in Monaragala had registered 26 patients in its database, reflecting growing awareness and demand for supportive care services. Of these, 9 patients were under regular follow-up by the multidisciplinary palliative care teams, receiving home-based or institutional support tailored to their clinical and psychosocial needs. Six patients received end-of-life care and passed away with dignity, while two showed clinical improvement and one experienced deterioration. Referrals were received from 9 out of the 11 MOH areas in the district, indicating wide geographic coverage, with the highest number of referrals originating from Monaragala and Medagama. Most patients had cancer diagnoses, predominantly breast, lung, and ovarian cancers. These early outcomes demonstrate the program's reach, responsiveness, and capacity to deliver patient-centered care, while also highlighting the critical role of palliative services in improving quality of life across diverse stages of illness.

### 5.2 Patient and Caregiver Feedback

Though systematic feedback wasn't captured in this phase, anecdotal reports suggest that families appreciated the home visits, reduced hospital travel, and empathetic care. Consultants were better able to manage cases with real-time updates from the field.

## 6. Implications

### 6.1 System-Level and Cost Implications

Although no formal cost assessments or economic evaluations were conducted, several system-level implications of the community-based palliative care initiative in Monaragala can be observed. The program contributed to reduced hospital admissions and lowered travel burdens for patients and their families by shifting care closer to home. It also promoted better utilization of existing local staff and healthcare facilities, optimizing underused resources without requiring significant new infrastructure investments. Additionally, the integration of simple, scalable digital tools and the formation of decentralized, team-based care models laid a strong foundation for future expansion and replication. While more rigorous cost-effectiveness studies would be valuable in the future, early indications suggest promising potential for efficiency and sustainability within the primary care system.

### 6.2 Practice and Policy Implications

The Monaragala palliative care initiative offered several valuable lessons that can inform future programs. Foremost among them is the importance of strong local leadership and robust cross-sector engagement, which played a critical role in overcoming resource and system constraints. The use of simple, open-access digital tools such as Google Forms and Sheets proved transformative in managing referrals and patient follow-up, enabling real-time communication and data-driven decision-making. The project also demonstrated that, even in the absence of large funding streams, underutilized divisional hospitals and existing healthcare staff can be effectively mobilized to deliver meaningful, compassionate care. However, sustaining such initiatives requires ongoing capacity-building and motivational support for frontline teams, emphasizing the need for continuous training and supervision mechanisms.

### 6.3 Scalability and Sustainability

This model holds strong potential for scalability and long-term sustainability. Its design aligns well with the national health strategy to strengthen primary healthcare and decentralize services, especially in rural areas. By relying on low-cost infrastructure and accessible digital platforms, the approach remains affordable and adaptable to various district contexts. Institutional mechanisms such as bi-monthly steering committee meetings and regular district-level review meetings are essential to maintain momentum, monitor progress, and resolve operational bottlenecks. These built-in feedback loops enhance accountability and ensure continued stakeholder engagement.

## 7. Recommendations for Policy and Future Practice

To further strengthen and institutionalize community-based palliative care across Sri Lanka, several policy-level actions are recommended. First, the establishment of a centralized national framework would provide consistent guidance and standards for local programs. Investment in training and transport infrastructure is also vital to enhance the reach and efficiency of district-level palliative care teams. Moreover, palliative care should be formally integrated into the routine service packages of divisional hospitals to ensure it becomes a standard part of chronic disease management. Finally, this Monaragala model offers a compelling case for replication in other rural districts using similar resource-optimized strategies, expanding the reach of palliative care to underserved populations nationwide.

## 8. Conclusion

The Monaragala community-based palliative care project demonstrates that a sustainable, patient-centered care model can be implemented even in resource-constrained settings. The initiative successfully addressed a long-standing gap in rural health services, reduced suffering among terminally ill patients, and strengthened health system responsiveness. This model showcases the potential of locally-led, digitally-enabled, and community-engaged palliative care, offering valuable lessons for broader adoption in Sri Lanka and similar low-resource contexts. By embedding palliative care within primary healthcare, the initiative contributed to building a more resilient health system—one that is better equipped to adapt, absorb shocks, and provide continuous care for vulnerable populations.

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