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What explains the development of Kerala's community-based palliative care model? A realist analysis of Witness Seminars on decentralization and health reforms in Kerala

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Abstract

Background

Palliative care needs are increasing in India, but access remains limited. Kerala is a notable exception, with a widely developed community-based, home-based palliative care approach. Its development coincided with governance reforms, particularly the People's Planning Campaign (PPC) in 1996, which decentralisation by transferring planning responsibility, decision space, and financial authority to Local Self-Governments (LSGs), while expanding participation in priority-setting. Although Kerala's palliative care outcomes are well documented, less is known about how decentralised institutions, political priorities, and local histories supported the model's emergence and scale-up. This study examines how LSG-level decentralisation created conditions for initiatives, what mechanisms sustained them, and how they gained policy legitimacy, from those who witnessed and shaped these developments.

Methods

We used Witness Seminar (WS) methods, an oral-history approach bringing together people who witnessed or influenced a historical development to reconstruct events and create an archival record. Three WS were held in 2021 with 22 participants from the health department, LSGs, bureaucracy, civil society, and PPC policy spaces. Inductive thematic analysis was applied to English transcripts using ATLAS.ti 9, followed by realist analysis to develop Context–Mechanism–Outcome (CMO) explanations linking decentralisation processes with the evolution of palliative care in Kerala.

Results

CMO configurations showed how decentralisation created contexts and mechanisms through which palliative care emerged as a community movement and later gained system-level support. The PPC enabled local planning, participation, and ownership, while community-based, volunteer-led home-care programmes developed across several panchayats. LSGs implemented these programmes through government Primary Health Centres transferred under decentralisation. As the value of the model became evident, the state health department scaled up palliative care, with finance and HRH support from the National (Rural) Health Mission proving critical.

Conclusion

Palliative care came to be viewed by stakeholders as central to health service delivery in Kerala, contributing to the State Palliative Care Policy in 2008. Decentralisation and sustained community participation can generate legitimacy and political commitment to embed such programmes within services. However, durable implementation also requires system-level enablers such as financing, human resources, and administrative support, alongside local relational foundations including trust, leadership, and shared ownership.

Introduction

The global burden of diseases continues to rise; reflected in increasing morbidity, disability adjusted life years (DALYS) and years lived with disability (YLDs), with more population living longer with serious chronic illnesses (1). This growing need has made palliative care essential. Recognized by the World Health Organization for its potential to improve the quality of life of patients facing challenges due to illness related to physical, psychological, social or spiritual and that of the carers, it is estimated that only 14% of population have access to palliative care services, further fewer in the low- and middle-income countries (2). Beyond their impact on health, these accessibility issues also slow progress toward key Sustainable Development Goals (SDGs). Palliative care is an important part of Universal Health Coverage under SDG goal- 3, helps protect families from falling into poverty, reduced inequalities in health, and depends on strong partnerships across sectors (3).

Globally, palliative care is now increasingly acknowledged as an important pathway to promote health equity alongside improved efforts to provision of curative health services (4). For decades, global inequities are apparent in the service provision and integration of palliative care with the mainstream healthcare system. A global monitoring report, 2021 founded only 43% of the countries availing palliative care, much of it is counted as high income countries (5). The gap between the need for and availability of palliative care in Low and Middle Income Countries (LMICs) remains stark, which are home to nearly 80% of individuals requiring such care (2, 4).

In common with other LMICs, India faces a substantial unmet need for palliative care, with estimates indicating that 7–10 million people require such services annually while less than 4% access them (6). A national systematic review further quantifies this burden with a pooled prevalence of 6.21 per 1,000 population, disproportionately affecting older adults, rural populations, and southern states (7). Although India launched the National Programme for Palliative Care (NPPC) in 2012 to embed palliative care across primary, secondary, and tertiary levels (8) implementation remains limited due to budgetary constraints (9). National access mapping of palliative care centres (2022) as per the directory of Pallium India reveals only 526 active palliative care centres with a density of four per ten million population and, with a median travel time of 118 minutes, reflecting significant rural–urban disparities in service reach (10). Despite supportive frameworks like the Health and Wellness Centre operational guidelines, progress is hindered by regulatory barriers, training gaps, and shortcomings in essential medicines lists particularly limited availability of opioids (6, 11).

Building on this national context, India's challenges in palliative-care delivery stand in contrast to the more advanced and community-oriented model seen in Kerala, which is widely recognized for achieving near-universal access through a dense network of palliative-care units and strong community engagement (10). Over the past three decades, it has developed a decentralised, home-based palliative care approach rooted in community participation and integrated with primary healthcare – widely recognised as the "Kerala model" of palliative care (12).

Kerala has sought to integrate community participation within a decentralised governance framework; possible because of the PPC for Decentralised Planning which emerged in the 1990s and became firmly established following India's 73rd and 74th constitutional amendments. Through PPC, the decentralisation process was expected to address the issues in quality of services in health and educational sectors (13). This landmark reform transferred significant financial resources and decision-making power to LSG Institutions, enabling the development of strong local systems for planning, intersectoral collaboration, and community engagement in health initiatives, which is a significant impact of the passing of the Kerala Panchayat Raj Nagara Palika Act (13–15). Kerala's decentralised architecture was crucial in shaping the state's approach to public health programs including palliative care.

The palliative care in Kerala is often cited as an example of community-based service delivery, particularly for its emphasis on volunteerism, home-based care, and integration with primary healthcare systems (12, 16), in contrast to global norms where palliative care delivery has traditionally been dominated by hospice- or institution-based models (17). At present, Kerala hosts one of the largest community-based palliative care systems globally, delivering home-based services to thousands of patients through a collaborative framework involving the government, local self-government institutions, and civil society organisations. The state's palliative care well developed, comprising 1,141 primary-level units and 113 secondary-level units based in major hospitals, along with 231 units in community health centres and eight medical colleges. The program is further strengthened by more than 500 NGOs and community-based organizations delivering home-based medical and nursing services. In 2022, a total of 114,397 bedridden patients were enrolled, including 80,214 older adults (18). The program has achieved substantial reach, supported 305,899 registered patients and delivering 1.34 million total visits, with services largely benefitting older adults- especially those aged 61–80 years and a predominantly female patient population (57%). It effectively addresses major palliative care needs such as hypertensive disorders, age-related frailty, and cerebrovascular accidents. Its strong community-based model is reflected in the delivery of 67,835 nursing examinations and nearly 19,000 catheter changes, demonstrating its capacity to provide comprehensive home-based palliative care at scale (19).

Despite Kerala's recognised success, little is known about how decentralised governance enabled the model's scale up, most literature focuses on program outcomes rather than the institutional processes, political priorities, and community histories that shaped it. Understanding these dynamics is essential for countries seeking to adapt similar community-oriented strategies. It may offer insights within Kerala on how future health system or community-based innovations may be fostered, particularly for home-

based and/or elderly care. This study therefor aims to examine the contextual factors that enabled Kerala's palliative care movement, the mechanisms that sustained it over time, how palliative care evolved into an innovation in decentralized health governance.

Methods

We carried out the novel method of Witness Seminar (WS) to archive the histories of decentralisation and health reforms in Kerala from its real time witnesses in which the events in history were discussed, debated or reconciled. We conducted three witness seminars between the months of June and September of 2021. All three WS were conducted virtually via zoom platform due to difficulties gathering participants during Covid-19 pandemic. The WS is an oral history technique where that focuses on a defined period of historical developments; individuals who directly witnessed and helped shape these events come together to describe their experiences and explain why they matter, thereby creating a record for the public archive (20). The detailed methodology of the WS is available elsewhere (21).

Persons who were involved with the PPC, N(R)HM, academia, elected representatives, and officials from the health department were invited to participate in the WS. Seminars were recorded, transcribed in English and Malayalam, and sent to participants for approval. Detailed annotations were carried out on transcripts and additional translations were made, as appropriate. WS transcripts were entered into the qualitative data analysis software ATLAS.ti 9 (22). Inductive thematic analysis of transcripts was carried out by three researchers in discussion with a fourth. We indexed and grouped codes, then explored analytical approaches to construct a realist framework.

A realist informed approach is generally considered appropriate to look at complex health systems phenomena in qualitative research (23, 24) and was therefore considered uniquely appropriate for our analysis. Realist analysis explains causation through Context–Mechanism–Outcome (CMO) configurations (25, 26). Context refers to the social, institutional, and cultural conditions that shape how an intervention functions. Mechanisms are the underlying processes formed when people respond to the opportunities or resources an intervention provides, generating particular outcomes. Outcomes are the intended or unintended effects that result from these interactions. Identifying mechanisms is central to explaining how and why interventions produce different results across contexts. A team of three researchers include a male researcher and two female researchers indexed theme groups under Context, Mechanisms, and Outcomes (CMOs) to develop a configuration framework drawing from the Witness Seminar transcripts guided by Mays and Pope (27).

Review of analysis was carried out by a senior female health systems researcher. We iterated through several cycles of discussion, revision and re-mapping of findings, drawing on triangulation across witness seminars and participant accounts. We also engaged in a reflexive review of our positions (including our prior relationships with some witnesses and our historical awareness), which helped us scrutinise discrepant or countervailing accounts. Throughout, we aimed for fair dealing and to minimise undue influence from any single narrative or from our differing roles in each seminar (e.g., where one of us as the moderator). This process culminated in CMO configurations that we lay out in our results.

The study was approved by the Institutional Ethics Committee of the George Institute for Global Health (27/2020).

Results

A total of 22 participants took part in the three witness seminars, of whom five were women (see Table-1). Representation varied across stakeholder groups, which include academics, frontline public health staff and health administrators.

Table-1 Participant Characteristics

Participant type	Male	Female
Senior health administrators (Policymakers)	3	0
State program functionary N(R)HM	3	1
Elected representative	1	1
Medical officer	1	2
Academic	5	1
Frontline public health staff (department of health)	4	0
TOTAL	**17**	**5**

Note: the profiles included persons who were retired from service as well as those who remained in service. The profiles report positions and roles held at the time of the witness seminar.

To better understand how the palliative care program in Kerala progressed, from its early grassroots initiatives to its eventual recognition within state-level policy, we examined the program's evolution through the rich anecdotes shared by participants in our witness seminars. The various contexts-mechanisms-outcomes detailed in this results section is summarised in the below illustration (See figure-1)

Figure-1 CMO outline

Context – Mechanism – Outcome Configuration related to the evolution of palliative care program in Kerala

1. Context (C) Kerala's palliative care experience unfolded within a complex blend of historical, geographic, socio-political, and administrative conditions. These contextual features deeply shaped *how*, *where*, and *for whom* the programme operated.

C1. Historical roots and civic traditions fostered early innovation

The programme grew out of Kerala's long-standing culture of civic activism and social solidarity. Before any state mandate existed, community organisations-initiated services early 1990s. Participants emphasized that *"Kerala is undoubtedly the leader in India in respect of palliative care, initiated by pro-active members from the governmental system in the early 1990s"*

Another respondent recalled that *"…like all of us who have convened here already know, palliative care began in Calicut in 1996" and shortly after "a network of volunteers named 'Neighbourhood Network in Palliative Care' started in Malappuram"*. This history created a strong foundation: communities were already accustomed to volunteerism, mutual support, and local leadership, fertile ground for later scale-up. As informed by a participant

During 2000-01, a network of volunteers named 'Neighbourhood Network in Palliative Care' started in Malappuram. Through them, many clinics became more popular. The clinics that already existed under the leadership of the doctor in charge during that time happened to become more popular. So, people collected money from local residents and demonstrated how to run a palliative care clinic with the cooperation of residents. (MN_WS3)

C2. The political and administrative arrangements legitimised decentralised action and local focus was enhanced

A major contextual factor shaping expansion was Kerala's decentralized governance architecture, introduced through the People's Planning Movement. Respondents emphasized that decentralization created institutional space for innovations that could respond to local health needs. As one participant put it,

…. decentralization has given avenues for innovations in health care. And in fact, community-based Pain and Palliative Care programme...especially in northern Kerala…, community based palliative care was formulated and implemented in many of the north

Kerala districts. It was mostly in the form of Panchayat projects. (CKJ_WS1)

Reflecting on how Kerala's decentralised governance enabled the Panchayats to establish one of the world's first community-based palliative care institutions, demonstrating how local leadership could drive innovation, a participant noted that

When we talk about decentralization; it was in Kerala, for the first time in the world even, a quality institution of palliative care was developed. It was the neighbourhood initiative of Malappuram with the lead of the Panchayat, I think in 2003… (JTT_WS3)

C3. Local priorities and ground realities were highly variable, requiring myriad and dynamic development of strategy/ies

During the early days the programme did not operate uniformly across the state. Regional disparities especially between high-capacity northern Panchayats and less-resourced one's shaped outcomes. In some northern Panchayats, strong governance led to exceptional service quality:

I have seen that in some Panchayats, the palliative care governance is excellent...And because of that, I have seen some kind of migration of families which is taking place in certain Panchayats to other Panchayats in search of better services from the BUDS school or the palliative care units. I would like to say that this is nothing but similar to a pattern of 'vote by feet. (JC_WS1)

These districts also served as early innovators, with the palliative care volunteers from North Kerala helping other regions adopt similar models. With implementation support from experienced palliative care volunteers from North Kerala, the new panchayat quickly demonstrated the value of home-based care, inspiring neighbouring Panchayats to adopt similar community-based models. A participant noted that, *"Muhamma was the first Panchayat in South Kerala to initiate a panchayat led community based palliative care program in August 2007…The palliative care volunteers from North Kerala facilitated the implementation process..." (SP_WS3)*

C4. Demographic and epidemiological pressures intensified demand

The epidemiological context further intensified demand. Several participants pointed to Kerala's ageing population, lifestyle shifts, and high burden of NCDs, and mental health disorders created a context of urgent need:

We are facing so many crises, we are moving through transitions from one epidemic to another etc., and our state average surpasses national and even world average. Especially hypertension and diabetes, it is a critical situation. Kerala's per capita alcohol consumption is also really high...(SA_WS2)

Coupled with the increasing morbid situation and number of bedridden patients, this produced a compelling need for community-based and home-based care. These demographic realities meant families increasingly required home-based and long-term care conditions that made community palliative care not only desirable but essential. This scenario was further explained by one of our witnesses as follows;

…The high rates of treatment expenditure caused by high rates of illness push many families into impoverishment and bedridden conditions...For a bedridden patient, these services should be provided by palliative care. The palliative services and survival support for the family also should be delivered to them. (SA_WS2)

C5. Administrative constraints limited the decisions and possibilities implementers and providers could proffer

Despite these enabling conditions, respondents also described persistent administrative and financial constraints. Audit fears and pressure to prioritize mandatory schemes created a climate of caution among frontline implementers:

Many implementing officers, especially medical officers have a major anxiety regarding implementation, whether they will face an audit objection. When we go for a working group meeting or project brainstorming meetings, medical officers usually say something: not to take up any projects that involve a lot of expenses. So, these mandatory projects and medicines purchase projects are enough…Most medical officers are sent with a request to not plan anything new. There are such situations like that in Kerala. (SKC_WS2)

2. Mechanisms (M)

M1. Feeling heard and respected: care-seekers felt they could meaningfully shape public services through decentralised planning spaces

Several respondents described that decentralised planning increased people's sense of being heard and directly benefited through improvements like medicine availability and permanent doctors. By asking communities to identify and prioritise their own problems, Panchayats created responsive models, such as palliative care, that felt locally owned. This sense of "these are our problems" fostered meaningful social change and strengthened trust in local governance.

The experience of Peoples' Planning brought about so much of a relief to the common man when they felt that someone is listening to me, that changes happened as per my suggestions, medicines are available in my hospital, we have a permanent doctor, I can avail treatment when I visit my hospital etc. These great models were made when problems were identified, prioritized and understood on how to support the LSGs to address these problems on the basis of that priority. The unique palliative care projects etc. are considered as such models. These should have been the byproducts of the freedom offered by decentralized planning. The feeling that these are our problems; these projects are being planned to address the crisis of patients admitted in our village have resulted in major social changes. (SA_WS2)

M2. Neighbourhood groups came together with shared responsibility and willingness to mobilise resources collectively

The creation of the 'Neighbourhood Network in Palliative Care' sparked a strong volunteer movement that not only increased the visibility of existing clinics but also demonstrated the community's willingness to participate actively in care provision. As people raised funds from the residents, and worked cooperatively to run clinics, they showcased a powerful model of grassroots ownership, where local solidarity, trust and collective responsibility became the driving forces behind expanding palliative care access.

…Neighbourhood Network in Palliative Care' started in Malappuram. Through them, many clinics became more popular. The clinics that already existed under the leadership of the doctor in charge during that time happened to become more popular. So, people collected money from local residents and demonstrated how to run a palliative care clinic with the cooperation of local residents. (MN_WS3)

M3. Trust was fostered between local self government leaders and health professionals, combined with control over local funds and flexibility in implementation, enabled sustained programmatic investment

The development of trust between the Panchayat president and the health professional became a crucial mechanism that allowed ideas, which initially seemed out of reach, to be taken up and implemented. Through this trusted partnership many interventions, all financed through Panchayat plan funds were implemented collaboratively ensuring participation of the local community. This trust appears to have created a mechanism of confident decision-making. When leaders trust implementers, they are more willing to approve projects, allocate budgets, and defend innovative work.

After associating with a few programs, he (panchayat leader) developed a trust in me. Even today, I really don't know how that happened. At that time, it was like a dream for us to get the Panchayats to implement innovative public health projects based on our ideas. …We did a number of innovative public health projects in that Panchayat from 2003 onwards. Like establishing outreach BP clinics, community-based morbidity management clinics for filarial lymphedema patients, providing nutrition to persons on treatment for tuberculosis etc. All these projects were done with the help of Panchayat plan fund and implemented with the help of Community Health Centers' health team and the community (SP_WS3).

3. Outcomes (O)

O1. Community members saw tangible benefits and became advocates of home-based care where family members were involved

The community members' recognition of the clear benefits of home-based palliative care, particularly the noticeable improvement in the quality of life of bedridden patients, generated strong local support for the programme. This positive perception encouraged acceptance and trust in the model, enabling the LSGs to emerge as a trendsetter that other LSGs sought to follow. As mentioned by

a witness, *"the people discerned the benefit of home care to bedridden in influencing their quality of life and the Panchayat became a trend setter for other panchayats with regard to community based palliative care program". (SP_WS3)*

Expansion of palliative care services facilitated sharing familial responsibility of care giving for elderly with formal palliative care units. This also reflected a growing dependency on formal care and a cognitive shift in how caregiving responsibilities are perceived. As mentioned by one of the participants, "*For a bedridden patient, services should be provided by palliative care personals…All this has to happen under the vigilant leadership of LSGs and elected representatives." (SA_WS2)*

Eventually, the growth of home-based palliative care shifted how families responded to everyday care needs for older and bedridden family members. Care that was once handled within households increasingly became shared, with families expecting trained palliative care workers to support (and at times undertake) routine personal care tasks. Witnesses suggested this institutional support also interacted with changing social norms among the younger generation, including reduced willingness or confidence to provide intimate elder care, prompting renewed calls to strengthen caregiving values and skills within families.

What is palliative? They call up and ask when are you coming to bathe my father or maybe mother? That is a major issue with palliative care. We used to bathe elderly people in our houses...We used to give them treatment with the help of our family doctor. Now we are witnessing a situation where people are waiting for palliative workers to bathe their parents, to tie their hair, or to apply some powder on a bed sore. That is not how Kerala should become. I strongly believe that we need to go back. I agree we need the services of our palliative care but to what extent? I think we need to train our children and inculcate a mindset to take care of the elderly at our home. (MR_WS2)

O2. Virtuous cycle of trust across community members, local leaders, as well as health providers and system actors, focused on public service design, investment, provision and utilisation

Public reliance on Kerala's government health system has grown substantially over the 25 years since the start of People's Planning, rising from about one-third of the population to nearly half, and likely even higher during COVID-19. This shift reflects improved service quality and the success of decentralised planning in institutionalising comprehensive primary health care including preventive, promotive, rehabilitative and palliative services. Examples such as Muhamma's pioneering palliative care model and Malappuram's "Parireksha" campaign illustrate how active Panchayat engagement has strengthened community participation and contributed to this broader transformation.

At the beginning of Peoples Planning, 32% of people used to depend on our public health facilities. When I say public health facilities, it includes even Primary Health Centers as well. Now when it is turning 25 years, it has increased to 46% as per the latest study report... Other than that, we know that the movement was successful in bringing in the concept of Comprehensive Health Care throughout Kerala. It is very important that the LSGs be able to implement preventive, promotive, rehabilitative and palliative concepts with people's participation. (SB_WS2)

Overtime, mandatory budget allocations for palliative care and increasing interest in new health programmes led to a substantial rise in local health spending. Panchayat contributions grew from a few hundred crores to nearly INR 950 crores annually, indicating a long-term outcome where sustained local commitment and decentralised decision-making dramatically expanded financial investment in the health sector.

It was made compulsory that 5% of their budget should be compulsorily allocated to palliative care. Along with that they used to take much interest and actively participate in the new health projects as well, whenever they were introduced… the annual budget contribution went up to Rs. 600 [crores] from Rs. 200–400 crores. Last year it even further went up to Rs. 960 crores. Panchayats contribution is above Rs. 950 crores in the health sector, which is really huge. (SK_WS3)

O3. Growing legitimacy led to statewide institutionalisation of palliative care

The decentralised governance system in Kerala enabled early high-quality, Panchayat-led palliative care initiatives to emerge through neighbourhood networks. This local innovation served as a proof of concept, helped build legitimacy for palliative care as a public responsibility, and contributed to Kerala being viewed as a reference point for community-based palliative care. As noted by a participant "*That's why we could become a model for the world". (JTT_WS3)*

Building on this legitimacy, the expansion of palliative care gained momentum when local governments began actively steering the programme, strengthening it through dedicated staffing, collaboration with community networks (women's self-help group-Kudumbasree), and mobilisation of local support systems. Their coordinated involvement created an environment for larger uptake and revealed how empowered local governance can drive successful implementation and inform future strategies for scaling other health initiatives in the state.

It took off in 2009 under the leadership of local governments. All local governments appointed a palliative care nurse in their institutions and used Kudumbashree for the initial identification and planning process. They also succeeded in mobilizing the local civil society for outreach and material support. This has lot of lessons for further scaling up and involvement of local governments in other health aspects. (SMV_WS1)

Discussion

Kerala's decentralised palliative care trajectory illustrates how governance reform can enable community health innovations to emerge and institutionalise. Using a realist analysis lens, this study explains how a long-standing civic activism and early volunteer-led efforts created fertile conditions for locally owned palliative care, while the PPC expanded panchayats' decision space and resources to adopt and adapt home-based models. The pathway to scale-up depended on key mechanisms included communities feeling heard through decentralised planning, collective action through neighbourhood networks, and trust-based partnerships between elected leaders and health professionals that reduced perceived risk and enabled sustained investment. Rising demographic and epidemiological pressures like ageing, Non Communicable Disease burden, and growing dependency intensified demand and widened acceptance of shared caregiving. These dynamics supported statewide scale-up, improved utilisation of public services, and increased local health spending, while also introducing tensions as earmarked funds and audit anxieties constrained flexibility for future innovation. Overall, the study findings show that decentralization did not automatically improve services, instead, it created space for local actors to act on problems they recognized as urgent and meaningful; similar conclusions are reported in prior analyses of Kerala's health reforms, which emphasise the importance of local initiative alongside policy support (14, 28).

An important contribution of realist analysis is explaining why similar decentralized structures produced different outcomes across panchayats. Where decentralized authority was combined with capable leadership, social trust, and active community participation, palliative care expanded more rapidly and with better quality. In such settings, mechanisms such as trust between elected representatives and health professional, community ownership, and shared responsibility for care were more easily activated – echoing earlier work that highlights relationships and volunteer engagement as central to Kerala's palliative care movement (29, 30, 31). Our analysis extends this literature by showing how these social mechanisms interacted with formal governance structures to support scale up.

A key finding of this study is the central role of trust. Trust between health professionals and Panchayat leaders reduced hesitation around innovation and encouraged confident decision making, including allocating plan funds for palliative care. Similar trust-based relationships have been noted in earlier studies of decentralized health planning in Kerala, where collaborative leadership enabled local experimentation (32, 33). Our study suggests that trust bridged LSG leaders and health system implementors, enabling translate seemingly impossible ideas into practice. Trust also grew between communities and local governments as people experienced tangible benefits such as improved quality of life for bedridden patients, medicine access, and regular home visits, they developed confidence in both palliative care and the public health system. This, in turn, mobilised volunteering, local financial contributions and political backing. Earlier studies of the NNPC similarly describe how visible improvements in care strengthened community engagement and sustained volunteering (12, 34, 35), and further suggest that these early community-led models built the social and political legitimacy that later enabled institutionalisation through LSGs and state policy frameworks (12, 29).

Decentralized also governance played an important role in enabling these community model's spread. The Peoples Planning Campaign transferred ownership of planning and financial resources to the LSGs, allowing them to prioritize and implement programs based on the local needs (13). This aligns with broader literature on Kerala's decentralization reforms, which highlights how local governments were able to design context specific health interventions (14). However, our findings also echo earlier critiques that decentralization alone does not ensure uniform or equitable outcomes (14, 28). Differences in leadership quality,

administrative capacity, and social capital led to wide variation in service quality across panchayats, despite operating within a common decentralised framework which was also resonated across various studies (29, 36, 37).

Some LSGs in north Kerala which had earlier exposure to community based palliative care, often became centres of innovation and learning. Volunteers and health professionals from these regions supported the introduction of similar models in other parts of the state. This pattern of horizontal learning and diffusion supports existing research as suggested by Thomas and Rajesh in their paper, that peer to peer support between local governments can be a powerful mechanism for scaling health innovations (14). Our study adds to this literature by showing how decentralized governance structures made such diffusion possible.

Demographic and epidemiological changes also played a major role in shaping the programme's trajectory. Kerala's ageing population, high burden of non-communicable diseases, and increasing number of bedridden patients created strong demand for long-term and home-based care. These trends have been well documented in the literature (38, 39). World Health Organisation observed globally, where ageing populations drive demand for integrated, home-based care models (40). Our study findings shows that palliative care gained traction partly because it responded directly to these pressures and aligned with changing expectations of care. Families increasingly struggled to manage care alone, and community-based palliative care offered practical support that reduced caregiver burden. Dewhurst et al reported a similar shift towards shared responsibility for care in his study on ageing societies (41).

Importantly, the study shows that the success of palliative care also depended on a cognitive shift in how caregiving responsibilities were understood. Over time, care for elderly and bedridden individuals came to be seen not only as a family duty but as a shared social and governmental responsibility. Earlier research on Kerala's health system has described similar shifts in public expectations regarding state involvement in health and social care (13, 15). A comparable reflection was observed from our findings as well where decentralised palliative care programmes both reflected and reinforced this changing social contract.

As palliative care expanded, state-level policy decisions played a key role in institutionalising services. Making palliative care a mandatory project for LSGIs and earmarking a fixed share of local budgets helped ensure statewide coverage, dedicated staffing, and long-term sustainability. Furthermore, the policy supported implementation of palliative care programme under the National Rural Health Mission palliative care project – '*Arogyakeralam*' where LSGI was given power to appoint trained community nurse for their home care program under palliative care (42). Several studies have identified this policy decision as a major strength of Kerala's palliative care model, particularly in enabling integration with LSGs to ensure dedicated financing and supporting long-term sustainability of services (16, 29). Our study aligns with this assessment, showing that mandatory allocations increased investment and normalised palliative care as a core public service.

However, the study also highlights important tensions associated with institutionalisation. Mandatory funding requirements, combined with rising salary commitments under other health programmes, reduced financial flexibility at the local level. Many Panchayats reported having little room to plan new or innovative health initiatives once required expenditures were met. While earlier literature has largely celebrated earmarked funding as enabling sustainability (14, 16, 29), our findings suggest that it may also limit local discretion and experimentation. Frenk expressed a similar concern in health financing, where rigid, vertical funding mechanisms can crowd out local priorities and reduce system adaptability (43).

Administrative constraints further shaped local action. Fear of audit objections and pressure to prioritise mandatory schemes created a cautious environment among frontline implementers. Similar concerns have been raised in studies of decentralised planning in Kerala, where accountability mechanisms sometimes discouraged innovation (14, 44). In this context, our findings suggest that while decentralisation initially encouraged creativity, increasing bureaucratic oversight gradually shifted local decision making towards compliance and risk aversion.

Despite these constraints, the long-term outcomes of Kerala's palliative care programme remain significant. Increased public trust in government health services, rising local health expenditures, and the integration of palliative care into comprehensive primary health care reflect a broader transformation of the health system. Previous work, including our study by Surendran et al., has documented growing utilisation of public health facilities in Kerala (45). Our results underscore that decentralised initiatives such as palliative care contributed to this trend by demonstrating responsiveness to community needs.

The study has important implications for policy and practice. It shows that scaling community-based palliative care requires more than technical guidelines, staffing norms, or dedicated budgets. Social and relational factors like trust, leadership, and community engagement are equally critical. Policymakers seeking to replicate Kerala's experience should recognise decentralisation as an enabling context, not a guaranteed solution, and invest in local capacity, relationship-building, and supportive accountability. The findings also underscore balancing sustainability with flexibility. While institutionalisation secures continuity and coverage, excessive rigidity can suppress innovation. Allowing some discretionary space in local health budgets may help Panchayats respond to emerging needs amid the context of ageing populations and shifting disease patterns.

Limitations

This study has limitations. The witness seminar approach focused broadly on decentralisation and health reforms in Kerala and did not include all key pioneers of the palliative care movement. This study is based on retrospective accounts from witness seminars and maybe influenced by recall bias and participant perspectives. Additionally, the absence of patient and caregiver perspectives limits understanding of lived experiences and demand-side dynamics and historical part of it. Future research incorporating user perspectives could provide a more comprehensive account of how community engagement shaped program evolution. And finally, the findings are deeply context-specific and may not be fully generalisable to other settings without similar socio-political and institutional conditions.

Conclusion

Kerala's community-based palliative care programme represents a contextually embedded governance innovation shaped by civic activism, decentralised authority, and evolving health needs. Its development reflects not only policy design but the activation of trust-based relationships, local leadership, and collective ownership of care. The lessons from Kerala are therefore best understood not as a fixed model to be copied, but as guiding principles for how governance, communitisation, and health systems can work together to develop responsive, community-oriented health services.

Abbreviations

1. People's Planning Campaign (PPC)
2. Local Self-Governments (LSGs)
3. Witness Seminar (WS)
4. Context–Mechanism–Outcome (CMO)
5. Disability Adjusted Life Years (DALYS)
6. Years Lived with Disability (YLDs)
7. Sustainable Development Goals (SDGs)
8. Low and Middle Income Countries (LMICs)
9. National Programme for Palliative Care (NPPC)

Declarations

Ethics approval and consent to participate:

We obtained informed consent from all participants while conducting WS. The study was approved by the Institutional Ethics Committee of the George Institute for Global Health (27/2020).

Consent for publication:

Not applicable.

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Author Contribution

GB: Data collection and validation, data analysis and manuscript preparation. JJ: Analysis, manuscript preparation HS: Study design, Data collection, Analysis, manuscript review. DN: Fund acquisition, conceptualization, study design, supervision, manuscript preparation and review. All the authors read and approved the manuscript.

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Data Availability

The full dataset generated or analysed during the current study is available at: https://www.georgeinstitute.org.in/our-impact/policy-and-recommendations/community-action-for-health-evidence-from-india

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Figures

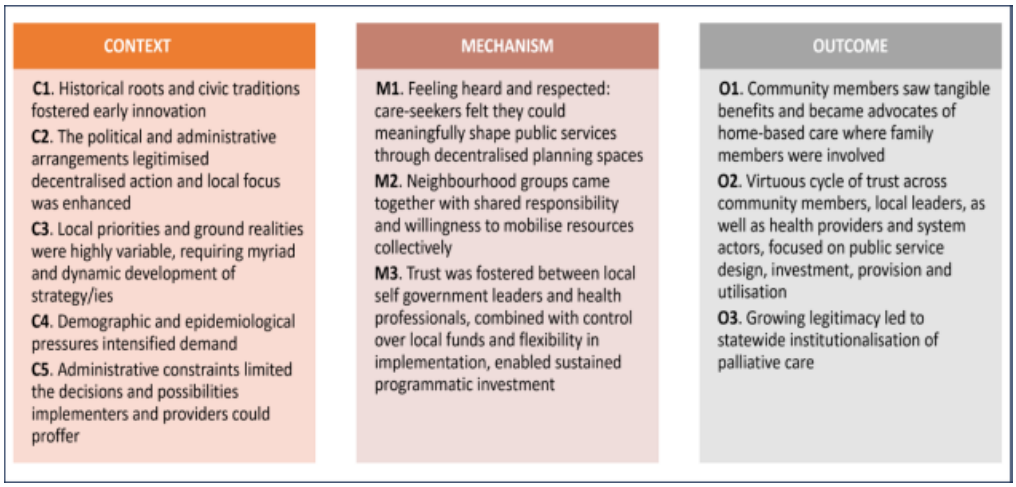


Figure 1

CMO outline