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KERALA SUPPLEMENT

Palliative care management committees: a model of collaborative governance for primary health care

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SETTING: The community-based primary palliative care programme in Kerala, India, has received international acclaim. Programme functioning is supported through Palliative Care Management Committees (PMCs) at the local government (LG) level.

OBJECTIVE: To study the functioning of the PMCs within the decentralised governance space to identify achievements, gaps and notable innovations.

DESIGN: This qualitative study included seven key informant interviews (KIIs), 28 in-depth interviews and a review of relevant publicly available policies and documents. Major themes were recognised from the KII transcripts. Codes emerging from the document review and in-depth interview transcripts were mapped into the identified thematic areas.

RESULTS: Successful PMCs raised resources like money, human resource, equipment, had good skilled care options for symptom relief and facilitated reduced out-of-pocket expenditure by providing home care and free medicines, and improved access to interventions that addressed the social determinants of suffering like poverty. PMCs had varying managerial and technical capacities. In some LGs, the programme was weak and mostly limited to the supply of medicines, basic aids and appliances to patients' homes.

CONCLUSION: Despite varied implementation patterns, PMCs in Kerala are examples of state-supported, community-owned care initiatives, that can potentially address medical and social determinants of suffering.

> "It was once said that the moral test of government is how that government treats those who are in the dawn of life, the children; those who are in the twilight of life, the elderly; and those who are in the shadows of life, the sick, the needy and the handicapped." Hubert H Humphrey (1911–1978)

Conventional primary care models often neglect chronic care needs, particularly in low- and middle-income countries.[1] Non-relief from suffering is so high that provision of palliative care has become a human rights debate.[2] Futile care causes catastrophic health expenditure and further impoverishes families already affected by serious health-related suffering.[3] Kerala, a southern state in India, is renowned for its primary palliative care model, which has expanded service delivery over the past two decades. The hallmarks of this model include better opioid availability, community-driven care and a meticulous state policy.[4] An aspect that has been less addressed is the functioning of the governance model in all local government (LG) units in the state – the Palliative Care Management Committees (PMCs). The PMC is an example of a people-centred, health service activity based on stakeholder trust, co-learning and co-creation of services.[5,6]

The evolution of palliative care in Kerala is described in a recently published Lancet Commission Report.[7] The programme evolved from the Neighbourhood Network for Palliative Care (NNPC) through the first palliative care policy in the state in 2008 and the (then) National Rural Health Mission Palliative Care Project. The major components of the programme are community ownership, LG involvement and incorporation of palliative care into primary care.[4] Today, there are over 1,000 palliative care projects run by LGs in Kerala.[8]

As part of a broader qualitative study on decentralisation and health in Kerala, we explored the achievements, gaps and notable innovations in the functioning of the PMCs in the Kerala palliative care programme.

DESIGN AND METHODS

Design and data collection

Our approach was qualitative and included: 1) documents available at relevant government websites containing the text, or tagged, as "palliative".[9,10] We shortlisted and reviewed 37 policy documents, programme guidelines and government orders; 2) seven key informant interviews (KIIs) to learn about the evolution and important developments of the palliative care programme, followed by 28 in-depth interviews (IDIs) with stakeholders from LG palliative care units (see Figure 1 for the LG profile covered and Table 1 for the participant profile). We studied local stakeholders and processes, service provision, perceived challenges, and innovations if any (Figure 1; Table 1).

We started with the premise that the PMC structure had facilitated participatory palliative care. We did not aim for representativeness or generalisability of our findings in the quantitative sense. Sample size determination was pragmatic and aimed to check for data adequacy in terms of variety of evidence and discrepancy among cases, rather than quantity.[11] Also, as our formative assessments indicated that the palliative care nurse was the custodian of all records and registers pertaining to the PMC, the nurse was prioritised as the main candidate for information on PMCs.

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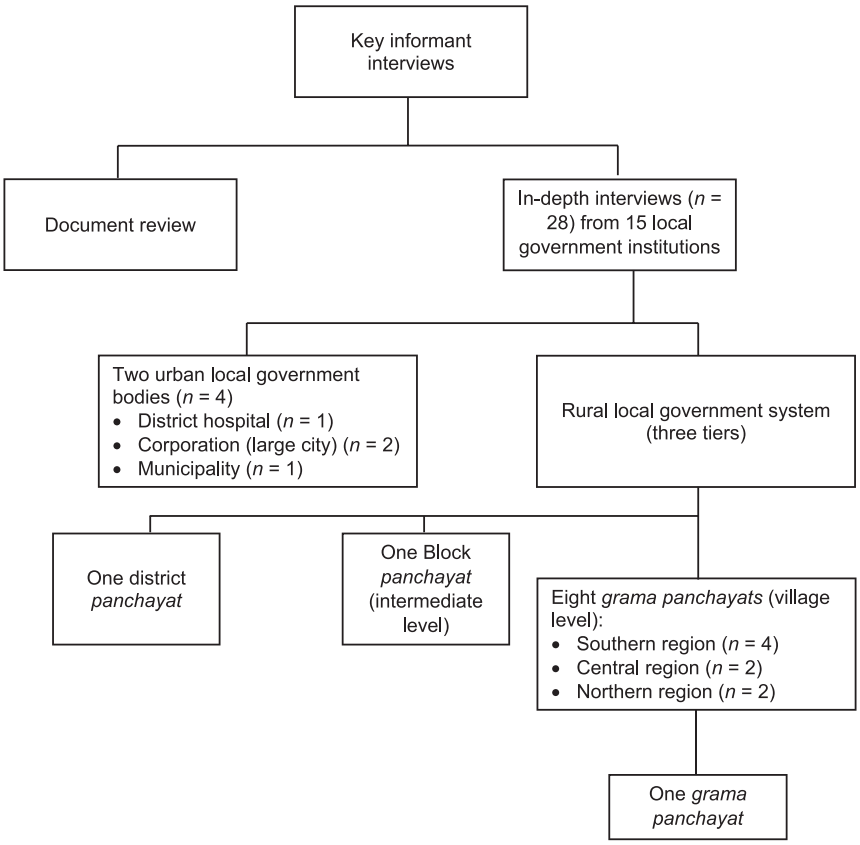

FIGURE 1 Schematic of data collection: document reviews and in-depth interviews.

Analysis

All interviews were transcribed and translated verbatim. KII transcripts were coded inductively to identify broad themes for categorising codes from documents and IDI transcripts.

Ethical considerations

All interviews were conducted electronically due to COVID-19 restrictions after documentation of consent in line with the Indian Council of Medical Research (New Delhi, India) recommendations.[12] The protocol and tools received ethical clearance from the Institutional Ethics Committee of the Health Action by People, Thiruvananthapuram, India (Letter number IEC No EC2/P1/Sep/2020/HAP, dated 10 December 2020).

TABLE 1 Profile of participants of in-depth interviews

Participant profile	Number interviewed
Palliative care nurse	14
Physiotherapist (palliative care)	1
Elected representatives	5
District-level officer (National Health Mission)	1
Other health professionals Medical Officer Ayurveda Medical Officer Field staff of health centres	6
Volunteers	1 (one former representative)
Total	28

RESULTS

The document review showed that the pain and palliative care policy for Kerala declared in 2008 was immediately implemented. Guidelines were periodically released in 2009, 2010, 2015 and 2019 to streamline implementation. The 2012 guidelines made palliative care a compulsory programme for all LGs. Funds were to be earmarked from the state-allocated annual budgetary plans of each LG (Table 2).

All 1,200 LGs in Kerala administer the programme in their various jurisdictions, which include the three rural tiers of district, block (intermediate level) and village panchayats, as well as urban administration authorities such as municipalities and corporations. The programme is accountable to both the health department and the LG, and is participatory at all levels, from home care to the PMC. Figure 2 shows the programme structures from the perspective of the LGs. We report the axial codes from IDIs in Table 3.

Administrative oversight by the PMCs

The PMCs are expected to be reconstituted annually and to meet once every 2 months, under the chairmanship of the political head of the LG (President for

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Conflicts of interest: none declared.

TABLE 2 Codes from document review: implementation of decentralised primary palliative care programme

Local self-government department	Health department
1 Palliative Care Management Committee • Formation • Roles and responsibilities 2 Palliative Care Implementation Committee • Formation • Roles and responsibilities 3 Palliative care nurse • Selection • Qualifications needed • Benefits 4 Training 5 Home care • Team composition • Home care kit • Transport of home care team 6 Beneficiary identification 7 Services to be provided 8 Social security measures • Child's education • Nutritional support for poor families • Social security pension for eligible persons 9 Caregiver education 10 Maintenance of cash and assets • Registers 11 Contracting physiotherapists if needed 12 Restrictions on home quarantine in households of palliative care patients	1 National Rural Health Mission/National Health Mission involvement – *Arogyakeralam* Palliative Care Project 2 Guidelines for collaboration of health institutions with local governments for implementation 3 Modifications to usual care of primary health centres • Exemption from obtaining out-patient tickets • Medicines dispensed for up to 6 weeks at a time for palliative care patients • Space at the health centre for maintaining equipment stock and registers 4 Medicines for palliative care 5 Training of staff

the panchayat institutions, Chairman or Mayor of urban entities). The Medical Officer of the local primary health centre is usually the Member Secretary. Members include administrative personnel, elected representatives from within the same LG and from other tiers in that area, Medical Officers of traditional systems of medicine, physicians and members of non-governmental palliative units registered and working in the LG area, volunteers, Chairperson of the local Community Development Society of the *Kudumbashree* mission (a women empowerment programme implemented by the State Poverty Eradication Mission, Government of Kerala) and the palliative care nurse. All of the PMCs (15 in number) included in this study were formed in accordance with their guidelines but there were marked differences in their functioning, ranging from exemplary to suboptimal.

> Well-functioning PMCs meet regularly and have expanded in scope in the last 10 years.

…first we kept 30,000 rupees (in 2012), but now we can keep up to 1,000,000." (Indian rupees [INR] 100 ~ 1.3 United States dollar) (ID26)

We interviewed a palliative care nurse immediately after the first meeting of a newly constituted PMC.

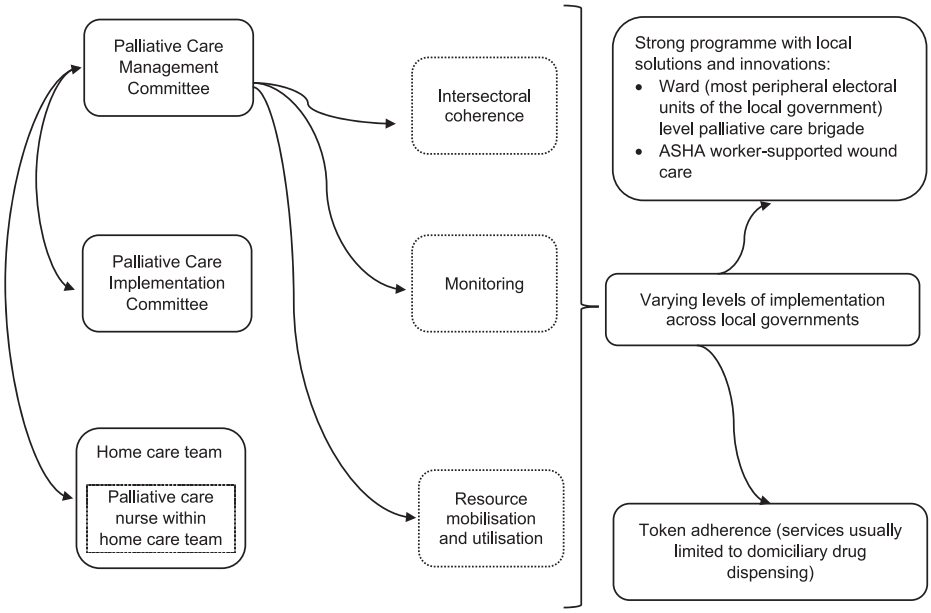

FIGURE 2 Organisation of primary palliative care programmes of local governments in Kerala. ASHA = Accredited Social Health Activist.

TABLE 3 Axial codes from in-depth interviews – implementation of decentralised primary palliative care programme

PMC	Local government functionaries
Functions: • Plan, implement and monitor the project • Support Hospital Management Committee for vehicle/transport for home care • Connect stakeholders from multiple sectors • Planning and review of care • Decisions on support, and judicious use of equipment • Organise events and gatherings • Rehabilitation/recreation/livelihood enhancement services Gaps: • Minor issues with duality of control • Urban projects are weaker • Limited involvement of some Medical Officers	Functions: • Identification and referral of beneficiaries • Connect various stakeholders • Accompany home care team • Communicate with general public • Facilitate local resource mobilisation • Review programme working Gaps: • Face difficulty when non-poor people ask for resources
Palliative care nurse	**Civil society members/volunteers**
Functions • All home care services, referral • Coordinate with health field workers, LG members, biomedicine and traditional medicine professionals, volunteers • Assist in convening PMC Gaps • Burn out • Irregular receipt of salaries • Varying levels of political commitment • Difficulties coordinating with multiple teams and levels	Functions • Accompany home care team • Arranging medical care • Arranging institutionalization • Generating resources • Procurement and distribution of resources Gaps • Communication issues between some groups

LG = local government; PMC = Palliative Care Management Committee.

> Today, since it is a new PMC, they called everybody – not just the PMC members, but all LG and health staff. (ID24)

Some elected representatives were extremely devoted to the programme.

> He (the panchayat president) considers the palliative care (programme) as though it is a part of his body. (I01)

In Table 4, we present quotes from interviewees indicating the active role played by PMCs in generating financial resources and leveraging equipment or services for patient care.

Achievements of Palliative Care Management Committees

Implementation was participatory and not secondary to state pressure even in places with no legacy of care like the NNPC (e.g.,

TABLE 4 Selected quotes on mobilisation of financial resources and equipment for local palliative care programmes

Sub-theme	Quotes
Financial resource mobilisation: "Mostly there will be shortage of funds." (ID4; urban palliative care nurse who had a different narrative than their rural counterparts)	"We collect (money from donation boxes) once in 3 months and deposit in the PMC fund. It is a joint account held with the President and the Medical Officer… We have a vehicle for our own (for home care). We collected funds … with receipt, with up to a maximum of INR5,000 from one person, and purchased the vehicle." (I02) "There is a scheme called *otta nanaya padhathi* (one coin scheme). We keep one box for putting one-rupee coins in local shops and schools." (ID27) "Actually, there were no difficulties in getting the funds. If the management committee is interested, there will not be any difficulty. We can easily get the funds from different areas." (I18)
Leveraging equipment and materials through partnerships: "The problem with the (usual Government system) is that if we (request something) now, we will receive it only after two years. But the equipment may be required immediately for a patient …" (ID4)	"There is a voluntary organisation called <organisation name>…they are about 200 persons … Every month they collect a fixed amount…they have purchased two oxygen concentrators. They maintain a register and provide (the equipment) to patients needing them (based on our request)" (ID02) "There is a scheme from IMA called PEPS (Professional Equipment & Employment Protection Scheme). They will provide the equipment at subsidised rates. We provide braces like knee braces and ankle braces for the patients, protective footwear, nebulisers, etc. We even bought one oxygen concentrator … We lend that equipment for a minimal amount ... Instead of INR3,000-4,000 for using the equipment, we collect a nominal amount like INR500 from the patient. If the patient is very poor, then we will not take any money." (ID7) "If I say I do not have a walker, if I make a call from the patient's house, by the next morning I would get that thing." (I02)

INR = Indian rupee (INR1 = USD75)

Idukki District in Kerala). Statements like "this is not managed by a single person" and "it is a joint programme" were made by almost all the participants interviewed.

> …everyone knows (of) palliative care 'If my mother is bedridden, I don't know who to (ask)'…such a problem is not at all there in our panchayat. (I02)

The governance structure provided legitimacy for community engagement and resource mobilisation, but with flexibility. Vulnerability assessment and support of individuals and households are built into the programme. There was some reduction in out-of-pocket expenditure; essential medicines and home care service are totally free, although not all medicines are provided.

> Dialysis patients … have requirement of erythropoietin around 8 per week, which (is costly) … if a patient is taking around 15 medicines, all except one or two medicines (will be arranged from) our side. (I01)

There is choice of biomedicine and traditional medicine for patients of home care programmes. Sectoral structures such as the National Health Mission, educational institutions, law enforcement institutions, and *Kudumbashree* were all are involved in the programme. A variety of collectives –monastic, rationalist and religious, professional and philanthropic – have all figured in the narratives. The palliative care network also facilitated a more equitable access to COVID-19 related interventions like home-based vaccination for palliative care patients, and uninterrupted supply of medicines and food.

Notable innovations

We came across several notable efforts from the various LGs and report two of these: 1) "*Ashadeepam*" – two Accredited Social Health Activists (ASHA) were trained in home-based wound dressing of foot ulcers in diabetic foot, peripheral vascular disease, etc.; funds were mobilised through collection boxes, which supported honoraria and fuel expenses; 2) a Palliative Care Brigade comprising volunteer committees were formed in each ward (the most peripheral electoral unit in the LG system, comprising about 2,500 persons). Fund generation, registrations and decisions using instant messaging apps were carried out at the ward level, and only those decisions that required a higher level of support, reached the PMCs.

Gaps in programme implementation

There is clear heterogeneity in managerial capacity of PMCs. Several PMCs exhibited suboptimal performance, as evidenced by a "business as usual" meeting tone, a lack of registers and reports, and a lack of funds. Some PMCs were hesitant in taking new initiatives.

> Many times, we have placed this proposal in the panchayat (but was never approved) …In our panchayat there are eight paraplegic patients, but our panchayat is not interested in (vocational rehabilitation being practiced in neighbouring LGs) (I28)

The technical competence of service providers varied, with some programmes delivering only a few medications to patients' homes and replacing some basic equipment (waterbeds, bed pans, etc.). Even in effective programmes, extensive medicine distribution to patients with multiple morbidities but no urgent symptoms left the nurse with less time for patients who require symptom alleviation. Urban areas had poorer implementation than rural areas. Interventions to tackle unfavourable social determinants were limited to distribution of food and clothes for festivals or marriages. Even though documents suggested that the coverage of the programme was expanding, there were no definite indicators to ascertain the quality of the services provided.

When commenting about the work, travel, meeting people, how they were perceived by patients and their families, as well as community and LG support, participants in initiatives that performed effectively were quite emotional. Having highly-trained human resources, notably the physician, and several initiatives that performed successfully in the health industry appeared to favour strong performance. The secondary-level programme was strengthened by the National Health Mission, consequent to the National Programme for Palliative Care in 2016 and the 2019 revised state policy. LG representatives were very positive about the sustainability of the programme.

> As long as the Panchayathi Raj System (name of the decentralised LG system) is present, nobody can move back from these activities. If any failure happens in palliative care, then it can lead to widespread issues. (I02)

DISCUSSION

Using a qualitative methodology, we investigated the operation of PMCs in Kerala and identified achievements, shortcomings, and innovations. In this section, we explore whether this was a model imposed by necessity or a genuinely participatory process. We also share our views on whether the PMCs can be considered as a model for the delivery of primary healthcare in resource-constrained settings. There was an element of obligatory enforcement of the PMC structure within LGs. Implementation, however, was more than a formal enforcement of the guidelines. The policy documents and guidelines were quite consistent with home care goals and those at a higher administrative level, suggesting a natural evolution of a participatory palliative care movement in a decentralised governance context. Other studies have also considered statutory policy implementation as participatory when they are informed by previous experiences and depend on local political processes for implementation.[13] The policy and guidelines provided a rubric for participatory structuring of the PMCs while facilitating subsidiarity, meaning that decisions that can be made at the peripheral level get decided there. Central structures, such as the National Health Mission, have to perform only what was necessary at their level. Non-uniformity of services that could arise in the decentralised systems were minimised by the bringing in a generic implementation framework. Ground-breaking interventions of palliative care such as the NNPC could be considered as an emergence of a social compact focusing on caring that emerged when conventional family structures changed with the increase in the number of elderly and persons living with severe chronic illness. The palliative care policy, and palliative care provision becoming a mandatory requirement for LGs, and sustaining in this form for a decade reflects processes of exchange of knowledge and resources across levels in society to meet critical needs and to define roles and responsibilities.[14] This is also a reflection of Kerala's "iterated cycles of social mobilisation and state responses", as described by Heller.[15]

The participatory governance model for primary healthcare

The translation of palliative care services through community-owned initiatives based on the Kerala experience is being attempted elsewhere.[7,16] The programme can potentially inform primary healthcare programmes in similar settings. Buse and Hawkes call for a paradigm shift in the approach to healthcare in the Sus-

tainable Development Goals, are yet to be achieved.[17] Among the several aspects described in the proposed shift, the PMCs are a realisation of at least four: 1) leadership for intersectoral coherence; 2) coordination of efforts to address some of the structural drivers, 3) greater civic engagement; and 4) accountability. The palliative care nurse represents a primary level health worker who is not a standalone agent, but is part of a broader team integrated within a system that aims to address equity issues beyond the immediate medical condition and its treatment.[18] Fostered by local contexts and actors and superintended by the LG, the PMCs have generated economic capital as well as social capital. Health professionals and organisations continue to hold much sway in health-related decision-making, but the spaces and players for engaging with health issues have expanded considerably and now include homes, neighbourhood groups, children's gatherings, and meetings of local formal and informal groups. This approach is conceptually comparable to the participatory primary healthcare experiments attempted by the UK National Health Service in the early 2000s that tried to reduce the predominance of the health paradigm over the patient.[19] The number of similar community-owned initiatives in developing countries is limited, an example is a maternity waiting home model in Zambia.[20]

These PMCs represent a progression in the decentralisation movement in Kerala. Venugopal and Yilmaz have described LGs as citizens bodies that monitor service provision.[21] The mandate of PMCs is not limited to monitoring, ranging from planning to resource generation, implementation and administration. The PMCs have considerable power and an active role in decision-making. The formation and processes facilitate reciprocity between services and peoples' expressed needs. In practise, the knowledge of the marginalised, has the same potential as that of the dominant institutions. The programme engenders the values the local administration strives for – transparency, flexibility, sustainability and managerial efficiency that helped the state machinery use existing networks extensively during the COVID-19 pandemic.[22]

Sustainability and quality of care

Sustained service delivery, financial independence and volunteerism have been proposed as factors that contribute to the sustainability of community-based palliative care organisations.[23] Quality of care is likely to be poor in some areas where PMC involvement was limited to medicine distribution and fund shortage. A previous study of two LG-run palliative care projects also found issues with the quality of care.[24] Availability of morphine, an important indicator of the success of palliative care programmes, was also quite low in LG-run projects. However, as opioids are controlled substances, their placement at levels where pharmacological controls can be effectively administered is justifiable. There was limited discourse about services requiring considerable medical skills such as physiotherapy, rehabilitation, management of emergencies and interventional pain management. These gaps have been identified in the 2019 palliative care policy, which mentions strengthening community health centres for better palliative care, greater coordination with all accredited and registered care providers in each LG area, better convergence of systems of medicine, livelihood support through *Kudumbashree* and better training courses.[25] Urban projects were weaker, possibly due to poor convergence between health and participatory local governance structures. The causes of urban–rural differences in health outcomes in Kerala are under-explored but have been mentioned in earlier studies.[26]

The main limitation of our study was that data collection was electronic due to pandemic-related restrictions. Physical visits, review of programme records and reflective observations may provide greater information than qualitative interviews. Addition of initial quantitative electronic surveys, would have provided information to assist in the purposive selection of PMCs for in-depth analysis. Nevertheless, palliative care is an activity deeply ingrained in the discourse at the primary healthcare level in Kerala and we have no reasons to believe that our findings are untenable. Findings from a recent study in Kerala that explore one LG project in depth, mention the organisation and contributions of the PMC within the project and support our findings.[27] The emergence of palliative care in Kerala has been possible as a result of remarkable contributions from several individuals and institutions, including the media.[7] Within the state, there are two WHO-collaborating facilities for palliative care that provide appropriate leadership. The National Health Mission continues to give high priority to the programme.[28] The Kerala Institute of Local Administration has also developed training programmes to support LGs in implementing their programmes.[29]

CONCLUSION

In our qualitative exploration of the functioning of PMCs of LGs in Kerala, we found the implementation level of palliative care activities to be quite varied within the state. Some LGs had highly successful activities, with ample locally generated revenue, sharing of non-financial resources and good participation of technical, administrative and civic players in decision-making, while others were restricted to home drug dispensing. Weak projects may not be able to effectively address patients' suffering. The documents reviewed clearly indicate that the information system is too weak to determine the quality of care. However, the state palliative care policy and guidelines, do ensure micro-level interactions that make the PMC a participatory governance model. Important local stakeholders are part of the PMC, and it was formed as a decision-making body. Participatory governance models like the Palliative Care Management Committees in Kerala may be a solution for low- and middle-income countries grappling with high disease and disability due to ageing and non-communicable diseases.

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CONTEXTE : Le programme communautaire de soins palliatifs primaires du Kérala, Inde, a été applaudi sur la scène internationale. Le fonctionnement du programme est soutenu par des Comités de gestion des soins palliatifs (PMC) au niveau des gouvernements locaux (LG).

OBJECTIF : Évaluer le fonctionnement des PMC au sein de l'espace de gouvernance décentralisée, afin d'identifier les réussites, les lacunes et les principales innovations.

MÉTHODES : Dans le cadre de cette étude qualitative, sept entretiens avec des informateurs clés (KIIs), 28 entretiens approfondis et une analyse des politiques et documents accessibles au public ont été réalisés. Les transcriptions des KII ont permis de faire émerger les thèmes principaux. Les codes émergeant de l'analyse documentaire et des transcriptions des entretiens approfondis ont été associés aux domaines thématiques identifiés.

RÉSULTATS : Les PMC les plus performants ont pu mobiliser des ressources, telles que de l'argent, des ressources humaines ou des équipements. Ils proposaient également des options de soins de qualité pour soulager les symptômes, facilitaient la réduction des frais à la charge du patient en fournissant des soins à domicile et des médicaments gratuits, et ont permis d'améliorer l'accès aux interventions qui s'attaquaient aux déterminants sociaux de la souffrance, tels que la pauvreté. Les capacités techniques et de gestion variaient d'un PMC à l'autre. Le programme de certains LG était faible, principalement limité à la fourniture de médicaments et d'aides et de matériels de base pour le domicile des patients.

CONCLUSION : Malgré des schémas de mise en œuvre variés, les PMC du Kérala sont des exemples d'initiatives communautaires de santé soutenues par l'état qui peuvent potentiellement s'attaquer aux déterminants sociaux et médicaux de la souffrance.

Public Health Action (PHA) welcomes the submission of articles on all aspects of operational research, including quality improvements, cost-benefit analysis, ethics, equity, access to services and capacity building, with a focus on relevant areas of public health (e.g. infection control, nutrition, TB, HIV, vaccines, smoking, COVID-19, microbial resistance, outbreaks etc).