Short Communication

Epilogue: Reflections from Stakeholders of a Facilitated Community Partnership Developed to Provide Palliative Care to a Vulnerable Population in Kerala

Anu Savio Savio Thelly[1], M. Jima Rose[2], Smriti Rana[3]

[1]Department of Palliative Medicine, Mahatma Gandhi Medical College and Research Institute, Puducherry, [2]Coastal Students Cultural Forum, [3]Pallium India Trust, Aisha Memorial Hospital Building, Thiruvananthapuram, Kerala, India.

ABSTRACT

Introduction: In mid-March 2020, the Kerala government implemented additional preventive measures to the steps already taken to reduce the transmission of COVID-19. Strategies were taken by a non-governmental palliative care organisation (Pallium India) with Coastal Students Cultural Forum – a coastal area-based collective of young educated people in the coastal region to address the medical needs of people living in this community. The facilitated partnership lasted 6 months (July–December 2020) and addressed the palliative care needs of the community in the selected coastal regions during the first wave of the pandemic. Volunteers sensitised by the NGO identified more than 209 patients. The current article highlights the reflective narratives of key players in this facilitated community partnership.

Materials and Method: The current article is dedicated to highlighting the reflective narratives of key players in this facilitate community partnership to the readers of this journal. The palliative care team's overall experience was collected from selected key participants to understand the program's impact, identify areas of improvement, and discuss possible solutions if there were any challenges. The contents below are their statements on the experience of the entire program.

Conclusion: Palliative care delivery programmes must be configured to respond to local needs and customs, be community-based and integrated with local health and social care and have accessible referral pathways between and across services. They must also be responsive to changing individual and population needs and shifts in local and national health structures.

Keywords: Community-based palliative care, Palliative care during COVID-19, Vulnerable population, Palliative care, Community partnership

INTRODUCTION

Palliative care emphasises the care of the whole person: Physical, psychosocial and spiritual care.[1] It also recognises that relationships are vital to wellbeing; that the unit of care is more than the person and extends to the broader family and social support systems. Holistic palliative care can be delivered effectively even in resource-poor settings. Inclusive and competent palliative care can become accessible by building on existing frameworks, ensuring services that are physically accessible and thinking creatively about the inclusion of marginalised communities. What is needed is a public health approach to enable and enliven this equitable provision, which should consider social and commercial determinants of health.[2,3] Proactively addressing the barriers to access and inclusion within existing palliative care services requires paying heed to the experiences of marginalisation that often results in differential treatment in healthcare, intentionally or unintentionally, directly or indirectly. Healthcare workers' attitudes, barriers posed by predetermined 'normal' care practices, stigma, insensitive public policies and the population's embodiment of all of these structural inequalities can increase vulnerability and overshadow the right to receive and access palliative care services. Such barriers get in the way of identifying when palliative care is necessary, who receives palliative care, where and what is needed to complement palliative care.[2]

Although Kerala is an Indian state that has demonstrated the integration of palliative care with the existing public health system,[4] the pandemic exposed gaps in care delivery to the fishermen in the coastal region. Fishermen are one of the

marginalised, neglected, marginalised and largely left out of the broad development activities groups in the state.[5,6]

In mid-March 2020, the Kerala government implemented additional preventive measures to the steps already taken to reduce the transmission of COVID-19,[7] causing a significant setback for the coastal communities in the state capital of Trivandrum. Following the declaration of Poonthura as a critical containment zone, the situation in the coastal area worsened.

The strategies taken by a non-governmental palliative care organisation (Pallium India) in a facilitated community partnership with Coastal Students Cultural Forum (CSCF) – a coastal area-based collective of young educated people in the coastal region, is described in '*Response to COVID-19 Crisis with Facilitated Community Partnership among a Vulnerable Population in Kerala*'.[8] The facilitated partnership lasted 6 months (July–December 2020) and addressed the palliative care needs of the community in the selected coastal regions during the first wave of the pandemic. Volunteers sensitised by the NGO identified more than 209 patients.

The palliative care team's overall experience was collected from selected key players after the project to understand the program's necessity, interventions and the way forward. The current article highlights the reflective narratives of key players in this facilitated community partnership. The narrative statements illustrate first-hand experiences, opinions and reflections about the program.

Response from CSCF Volunteer Lead – Mr. Thadeus, member of a coastal community and an active member of the youth club and regional political party. He led the activities of the CSCF within the community and coordinated with Pallium India.

1. '*Already, we have many problems in the community. From being vulnerable to climate and calamity, changes in fish yield, to being exploited by many. It is significant to notice the plight of vulnerable groups in our community – like the elderly and chronically ill. Fish selling is the only source of income for almost all families, and that's stopped during the 1st weeks of the pandemic. Fish vendors from the coastal community were being avoided by the mainstream society citing various reasons like corona might spread through fish or from the vendors*'.

2. '*There were instances of denial of basic healthcare (even for other disease conditions) and food for women and students from the coastal community due to the stigma that was created and propagated in the society. People outside the coastal community fear that we are the ones who spread COVID-19. We used to do many types of social work to help our community by mobilising resources, shifting patients to hospitals and giving blood to patients. But this time, the problems were different, and we were unable to respond to all their needs. Furthermore, the demands were increasing day by day. However, we*

tried our best, but we could not do it. We always thought health-related problems could be solved only by medical people. We never knew that we could do so much to reduce someone's suffering. The response and feedback we got from the patients were rewarding after the initiation of palliative care services with the support of Pallium India. Arranging medicines for all was complex, and with their support, we were able to provide all the medication to the needy. We are so grateful for this association and hope this will be continued'.

The narrative shows that this community is hugely disadvantaged in terms of discrimination, social stigma, effects of prejudice and trauma associated with the provision of care for this population from social/health institutions. These discriminatory beliefs or stereotypes effectively diminish their autonomy, access to resources, equitable healthcare and living a so-called normal life. This, further, creates significant barriers to identifying patients in need of palliative care, to improve their quality of life and access to end-of-life care. Vulnerable populations living with life-limiting/threatening and terminal illnesses often are identified late, and their health declines rapidly without access to high-quality palliative care[9] Most families had difficulties in affording medicines and other health-care aids. Thus, health-care needs should be assessed in the frame of their life context and experience.

Response from the social worker who led the helplines – Ms Gayatri, one of the three social workers from Pallium India who coordinated the helplines. They were dedicated to attending to the requests from the coastal area and coordinated activities with volunteers in the community. They registered the patients and collected general information. All three have completed their post-graduation in social work.

1. '*The entire process was challenging. Most of the problems they shared were similar and associated with their community – poverty and lack of access to palliative care. The COVID-19 lockdown had isolated many patients further. In a way, their problems were tougher than others who called us for help from elsewhere. The issues were not just a result of an illness. Being in a marginalised community complicated their care needs. Using dedicated tele-helplines, we assessed and addressed their needs. We addressed their medical needs by coordinating with the medical (division of palliative care) team here at Pallium India. We also provided psychological support, information and guidance and assured their families. We must explore the possibility of teleconsultation further as it has proved successful with our experience*'.

2. '*Even though integrating the helpline system has proved vital in addressing issues from bread to blood, training social workers and nurses to communicate, assess symptoms, provide necessary care and guidance and maintain impeccable documentation is challenging. On-*

going training and formative evaluation are required for successful and widespread uptake to be achieved'.

Their odds of accessing palliative care services were determined by their social position, which was determined by the intersectionality of their location, sociocultural factors, illness, functional status, occupation, literacy, insensitive policies and discrimination. Only a combined effort by all stakeholders will be able to overcome these complex and interconnected inequities in access to high-quality healthcare. Due to stringent constraints, in-person visits with patients identified by the CSCF were not possible; nevertheless, this problem was overcome using a tele-helpline and virtual meetings with patients, caregivers, and CSCF members. This illustrates that if we are willing to put effort, there will always be a way out of the challenges we confront in every context, especially when humans are advancing to a world of increasingly sophisticated technology.

Response from Nurse – Ms Bessy member of this coastal community, identified by CSCF, appointed as a community nurse by Pallium India after the initiation of this project. She holds a diploma in nursing (General Nursing and Midwifery) and later completed the certificate course in palliative care.

1. *'As I live in this area, I could easily locate the patients whenever I got their details from Pallium India. I know where their relatives are, so it was easy to share the information. When I shared a few older women's needs, my church friends offered help. A few of them have visited some patients who provided bedsheets. Patients have learned how to manage their symptoms and when to call us for help. They were comfortable in sharing their problems with me'.*
2. *'The ASHA worker (grass root-level health worker) shared information about a few patients, which helped me provide support and medicines in time. I could coordinate the activities so well with the volunteers as we all belonged to the same area'.*

The World Health Organisation suggests that adding the nursing component to community-based palliative care delivery and capacitating them with palliative care training is feasible and sustainable. Training the nurse from the community improved care coordination, enhanced patient education in their vernacular language, respecting the culture, mobilising the available resources and better networking within the community.

Response from Programme Coordinator from Pallium India – Mrs. Vyshnavi, a Project Officer, deputed to supervise and coordinate the program.

1. *'The volunteers identified more than 200 patients. Our team is now visiting the registered patients on a priority basis. Requests for home visits are increasing day by day. Due to financial and availability issues, people have many difficulties getting their medicines'.*

Unni and Edasseri reported that socioeconomic status might determine the utilisation of palliative care. Patients with low socioeconomic status are more likely to access home-based palliative care services.[10] The preference for home care in the coastal regions can also be attributed to the free supply of medication at their doorstep, making health-care affordable and accessible.

2. *'Volunteers delivered the medicines and food kits and built relationships between patients and the palliative care team. Volunteers took lead roles in direct patient assistance, providing medicines and supplies, connecting them with the palliative care team and psychosocial support. They played a significant role in facilitating the entire program. However, ongoing volunteer training is a challenge to be overcome, and there is a need to develop a greater support network for all volunteers.*

This facilitated community partnership affirmed that community volunteerism enables care to more patients, because care is decentralised and professional staff workload is reduced.[11]

Response from Public Health Professional – Ms TS Sumitha, connected the CSCF with Pallium India.

1. *'People in coastal areas are very closed communities. They live together. But there is a difference in the context, dialect and health literacy. Many patients do not know about government benefits and lack necessary documents. That may be why they couldn't follow the guidelines initially when the government announced lockdown'.*
2. *'We knew there is inequity in delivering health care, especially palliative care. The existing system needs to be prepared to function and support the vulnerable during a humanitarian crisis. This involvement of trained volunteers from the community made a significant transition from the system provided care to community-initiated care. Expanding palliative care in the community should be a leading strategy in policymaking. It is vital to engage the community and empower them to meet their health care needs'.*
3. *'When the community is empowered to actively participate in the continuum of care, unmet needs will be minimal. Better health-care provisions will slowly be demanded as they have explored realistic solutions to their earlier unmet needs. The integration of knowledge and understanding about palliative care in the general training of Local Self Government is strategic. We thus expect these interventions to ensure better palliative and end-of-life care for everyone within the community'.*

Designing, delivering and evaluating high-performing palliative care services for complex and vulnerable subpopulations are challenging endeavours. The complexity of providing and evaluating palliative and end-of-life care services requires understanding the active components of an

intervention to be delivered.[12] Engaging and empowering volunteers can be an essential strategy to deliver more integrated and comprehensive palliative care,[13] which is culturally and socioeconomically appropriate and acceptable. Volunteer training and capacity building can be developed for those interested in providing palliative care services. Materials and training workshops in the vernacular can enhance the effectiveness in raising awareness.[14] Freeman *et al.* (1998) proposed establishing education and coordinating a network of palliative care volunteers to deliver non-clinical services as a solution to overcome the challenges in delivering palliative care to remote areas.[15]

Response from the Director of Pallium India – Dr MR Rajagopal The entire project was steered by the Director of Pallium India. He guided in overcoming the challenges of improving coverage and ensuring quality.

1. '*The socioeconomic impact of an advanced illness can be anticipated, especially marginalised people. CBPC services reduce avoidable spending on healthcare. Addressing palliative care needs is essential to reduce unnecessary suffering of patients and their families*'.

There is evidence of the socioeconomic impact of advanced and progressive illness in a family, including loss of livelihood, selling off assets and taking loans. Palliative care can reduce the most desperate poverty in India caused by chronic illness.[16] Rahman and Bai (2019) described that most families in Kerala's fisherman community do not have any savings or money put aside for emergencies. Almost half of their study, participants were found owing money to someone.[17] Lack of quality palliative care services in coastal regions may result in significant costs being absorbed by the individual, family and local community. This perpetuates financial losses passed on to future generations and catalysts in the poverty cycle while stunting regional economic growth.[18]

2. '*More than sixty per cent of the population of the world die due to non-communicable diseases. Existing palliative care services need to be extended to people with Alzheimer's, Parkinson's, chronic respiratory diseases, severe kidney disease, heart failure, end-stage lung disease, progressive neurological diseases and other life-limiting illnesses. We need to reorient the existing palliative care delivery model to address the needs of the elderly population. Future service provisions for community-based palliative care should acknowledge the increasing service demands and chronicity of the patient population and the socioeconomic consequences of the ageing population*'.

During the last century, Kerala witnessed improved longevity, indicating slow progress toward the high prevalence of non-communicable diseases.[18] Individuals from marginalised communities have fewer resources and poorer health outcomes.

3. '*In Kerala, every local self-government body in the state has mandatory palliative care service delivery projects through the clinical team of primary health centres (PHCs). Through this program, we found that coverage of palliative care services is inadequate in the coastal hamlets. Further steps should be initiated so that the PHCs in the marginalised communities would be equipped to provide better coverage and quality palliative care services and reduce preventable crisis care*'.

Jayalakshmi *et al.* (2016) assessed the End-of-life Characteristics of the Elderly in two rural panchayats in Kerala. They concluded that home-based palliation in its present form does not promote good end-of-life care for the senior population. A restructuring of the existing palliative programme is needed to have the home as the locus of ageing and dying for marginal populations.[19]

The great majority of people who need palliative care prefer to remain at home, which needs palliative care to be provided in the community as part of primary healthcare. Thus, efficient integration of palliative care into public health-care systems is essential to address people's health-related suffering.[20]

DISCUSSION

COVID-19 poses significant and unique challenges to providing necessary health-care services for patients, especially people living in marginalised communities. Vulnerable populations like the coastal community are at risk for disparate health-care access and outcomes due to economic, cultural, ethnic or health characteristics. Members of such vulnerable populations may often have health conditions exacerbated unnecessarily due to lack of access to or inadequate healthcare, resulting in poor health outcomes and greater risk for chronic illnesses and mental illnesses. Understanding their social determinants of health and well-being and the nature of access to appropriate end-of-life care services for this group are essential. The pandemic proved that access to palliative care during a crisis is insufficient.

Although constructed differently, this programme focused on delivering culturally and contextually appropriate care to the needy and attempted to support more than symptom relief and medical support. The programmes faced several challenges: how to provide healthcare in the face of COVID-19, encourage identification of patients who would benefit, support basic needs and the needs of the family and develop effective referral systems which reflect their values and choices. The rapid response with limited resources to expand our services to meet community needs depended heavily on volunteers and technology. Our experience is that even people living in marginalised communities can receive palliative care with a facilitated partnership that is cost-effective and predominantly community-driven.

COVID-19 has caused a quantum leap in digitally-enabled remote care, or telemedicine, which is increasingly becoming

essential to health-care delivery, particularly in the area of chronic disease and cancer care.[2,3] The existing helpline system at Pallium India was used to expand and coordinate the activities to the coastal region. We found helplines to assess needs successfully, monitor, provide psychological support, information and guidance, plan intervention in real-time. This was a minimally burdensome, maximally accessible approach. Most registered patients did not own a smartphone or have broadband access. However, volunteers helped overcome this 'digital divide' and supported them by sharing their details with Pallium India. The efficacy of helplines should be explored in providing palliative care services.

Palliative care needs are universal, tangible and omnipresent. The entire process proved that opportunities exist to overcome obstacles such as lack of guidance and expertise in palliative care, access to medication and cultural specificity around death and dying to provide palliative care in humanitarian crises. An efficient combination of administrative leadership, political commitment, community cooperation and the health systems resilience is required to have a minimally interrupted provision of healthcare, especially palliative care, in this marginalised population. A facilitated partnership should coevolve in improving provision to ensure the delivery of context-specific, affordable palliative care at the doorstep, a creative and flexible concept of accessibility.

We propose to develop context-appropriate policies and guidelines to support individuals and families with palliative needs during a humanitarian crisis, especially in vulnerable regions like the coastal areas. The facilitated partnership could ensure that resources are matched to patient and family needs and priorities, providing palliative care services at substantially lower costs.

To realise the motto 'health for all', we should start utilising the potential of youngsters at the ground level. Low- and middle-income countries are likely to see a dramatic rise in 'serious health-related suffering' in the coming years.[21] In coastal regions, where specialist care is absent or not affordable, creating and strengthening civic, community and professional care may have to coevolve. We also propose to initiate steps to empower the community members to support their vulnerable sections during a humanitarian crisis.

CONCLUSION

Palliative care service delivery programmes must be configured to respond to local needs and customs, be community-based and integrated with local health and social care, along with accessible referral pathways between and across services. They must also be responsive to changing individual and population needs, and shifts in local and national health structures.

A public health approach with participation from the community, integrated into government policy and primary health service provision, is necessary to impact the burden of palliative care needs, especially in marginalised communities across the globe. While this programme evolved organically to respond to a felt need, we recognise its positive impact on the cohort it served. Further, work is required to identify interventions in a wider community and test models of care regarding the program's clinical impact, assess for gaps in care, healthcare savings, sustainability, coverage and quality and community participation. We also propose a system to evaluate effectiveness of existing services and efficient planning of future context specific programme expansion.

Declaration of patient consent

Patient's consent not required as patients identity is not disclosed or compromised.

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Conflicts of interest

There are no conflicts of interest.

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