Clinical Note

Community Engagement in Palliative Care: A Lesson From the Lakshadweep Islands

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Abstract

A palliative care organization on the remote Lakshadweep Islands on the coast of India disrupts the Global North paradigm for palliative care by a thoughtful response to the needs of the community. In this community effort to bring those who need dialysis back to their home islands, the palliative care organization, Thanal, illustrates how palliative care can reduce health-related suffering in innovative ways and enhance the lives and health of the community that they serve. The Global South provides lessons for global palliative care, including the Global North, in its focus on community needs and social networks. J Pain Symptom Manage 2025;000:e1−e4. *Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine.*

Key Words

Community, global south, social capital, dialysis, India, low resource

Key Message

This article describes how a remote palliative care team in the Global South met the needs of their community in an intervention that is alien to Palliative care in the Global North but meets the World Health Organization definition of Palliative Care.

Introduction

In a collection of islands called Lakshadweep (Fig. 1), off the southwest coast of India in the Arabian Sea, people earn their subsistence living by extracting coconut oil and fishing as their ancestors have done for generations. Lakshadweep is a union territory of India (under the direct administrative control of Government of India). It is an archipelago of 36 islands, with a total population of about 64,000. The geographic isolation from the mainland has had its influence in its social, cultural and economic development. Even the dialects or slang spoken on each island are unique to that island. The predominantly insular culture of these islands is protected through restrictions on visitors and tourism. With the distance from the mainland and the restriction on visitors, a culture of self-reliance has emerged. Access to health care is limited. For tertiary healthcare, patients have to be transported, often by helicopter, to the only airport on one of the islands and then to the mainland.

Palliative care activists on these islands from the non-government organization (NGO) Thanal work with volunteer nurses and physicians to meet the needs of older adults and others with serious illness and frailty. Thanal was started by a secondary school teacher (AHM), who recruited volunteers to provide home visits every afternoon to attend to wounds, physical and emotional support for children and elders with cancer, dementia and chronic disease.[1] The nearby Indian state of Kerala, has a rich history of volunteer or community-led palliative care which addresses medical needs but also the lack of social support, including funds for the education of patients' children, employment for the caregiver, repairs for the home, food kits, counseling and legal supports.

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Accepted for publication: 10 June 2025.

Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine.

0885-3924/$ - see front matter
https://doi.org/10.1016/j.jpainsymman.2025.06.006

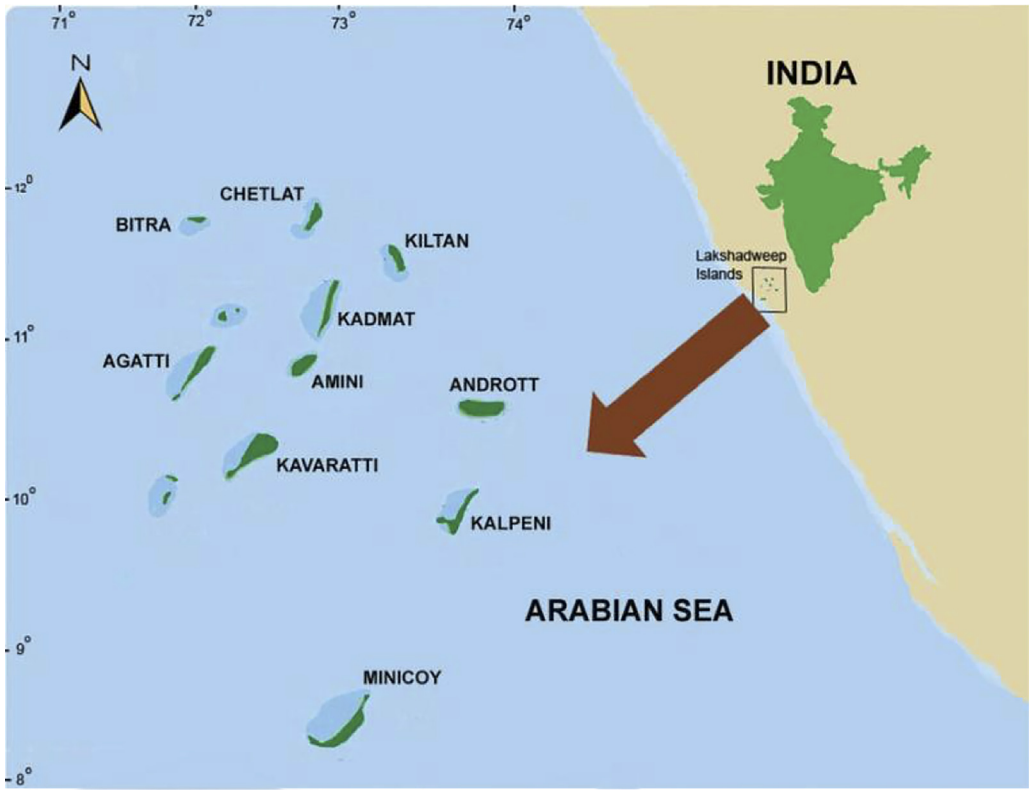

Fig. 1. Map of Lakshadweep Islands. Obtained under Creative Commons 4.0.

The ongoing role of volunteers follows the guidelines recommended by the WHO.[2]

The community on the Lakshadweep Islands had a very serious need—dialysis for people with kidney failure. Changes in diet have accelerated the rate of diabetes and hypertension, which are the major causes of chronic renal failure on the Lakshadweep Islands. The Marshall Islands, located in the Micronesia region of the Pacific Ocean, also faced this dramatic increase in hypertension and diabetes, and resulting renal failure. Nephrologists from Hawai'i supported the team on the Marshall Islands for a decade, flying patients back to Hawai'i if complications occurred. The dialysis team struggled to keep maintain supplies, and eventually the dialysis clinic closed. Concerns were raised about whether the high financial burden of dialysis would be better spent in population strategies, to control the major causes of renal failure on the island, diabetes and hypertension.[3] On the Lakshadweep Islands, those who needed dialysis were practically living in exile on the Indian mainland or the main island of Kavaratti—separated from their families and community, with rare visits to their home island. Trained dialysis technicians originally from the islands could only find work on the mainland. The community had come to trust Thanal and pressed them to meet this community need.

The incorporation of dialysis into palliative care services may seem incredulous under the current paradigm of palliative care, set by the Global North. However, we challenge this model: Thanal shows reducing health related suffering entails a tailored response to the needs of the population we serve. In the US and in much of the Global North (US, Europe, Australia, New Zealand), there have been nephrologists to meet the growing needs of kidney failure patients after the board exam was developed in 1972. Prior to that, family medicine physicians often met the need for dialysis in their rural communities. But in the Global South, the WHO definition of palliative care has broad implications for the palliative care field—the prevention and relief of suffering through early identification, assessment and treatment of pain and other symptoms, whether physical, psychosocial or spiritual.[4] In an environment without specialists, reducing health-related suffering becomes is the starting point for palliative care in the Global South.

Historically, palliative care came into being to fill a gap in the prevailing healthcare system in the United Kingdom, namely relief from pain and other suffering. Today's palliative care providers in the Global South often find preventable gaps in the healthcare system such as a person with diabetic gangrene or uncontrolled hypertension following a stroke. Palliative care

addresses this need in the absence of accessible specialty care and primary care services.

According to the report of the Lancet Commission on Access to Palliative Care and Pain Relief: "Suffering is health-related when it is associated with illness or injury of any kind. Suffering is serious when it cannot be relieved without medical intervention and when it compromises physical, social, and emotional functioning."[5] Understandably, the health conditions that cause this will depend on the level of primary, secondary and tertiary healthcare that is available which vary widely in every country. Globally, in rural regions where no tertiary healthcare is available, management of many health conditions will involve delays, major financial implications and social disruption associated with transportation to medical centers, often with presentation at a later stage of disease. Hence, many chronic conditions which may not cause serious health related suffering in the urban Global North, have serious consequences in the Global South or in rural areas in the Global North.

Thanal initially resisted the community pressure because the dialysis initiative appeared too ambitious, but the organization eventually started to explore what it would need to build the program from scratch. They started with the remote island of Amini, and after multiple attempts, were able to buy a dialysis machine in December 2022 with funds donated by a bank. A dialysis building was constructed by Thanal volunteers, and a water treatment facility was installed for desalination and contaminant removal using reverse osmosis. Renal dialysis became functional in Amini in February 2023 with two dialysis machines, two trained dialysis technicians and the Thanal team serving along with nurses and physicians, with virtual consultation with a nephrologist from the mainland. Volunteers collect donations from each household every month, covering the daily expenses of the dialysis unit. Currently 6 patients receive dialysis at the Amini center, with a projected need in the next year of 15 patients.

On the island of Andrott, with a population of 12,000, the patient load was higher than on Amini. Thanal bought land with the generosity of well-wishers, and construction started with the help of government employees. A women's self-help group contributes monthly to cover operating expenses. A dialysis machine and water treatment facility were installed in January 2024, and the dialysis unit has been fully operational since February 2024. There are two machines at the Andrott center with two technicians and one trained water technician. Currently 5 patients receive dialysis at the Andrott center with a projected need of 12 patients in the next year.

Thanal, a palliative care organization in a remote area, learned about dialysis to reduce health-related suffering in their community. They receive no government funding for the $25,000 annual budget. For each dialysis center, there is an ongoing need to raise funds to support the salaries of technicians and cleaning staff, to provide maintenance of the dialysis machines and water treatment facilities, and to provide medicines for the patients. These funds are also needed to provide logistical support for the patients and staff. Thanal anticipates an increase in this need due to the rising rates of diabetic kidney disease. In addition to the medical needs of the patients with end stage renal disease, the community led palliative care team assesses the patients for other needs including funds for children's education, employment for patients and caregivers, food kits, and counseling about diabetes, hypertension and legal needs. Thanal volunteers from each community address the broader social, cultural and psychological landscapes of the patients and their families through regular home visits, informal gatherings and community conversations, and events to reduce social isolation. To date, no dialysis patients at Thanal have died, or stopped dialysis.

The community pressed Thanal to expand its notion of palliative care to meet the needs of the people with an illness that limited their ability to fully live their lives in all domains—"life-limiting." Will the community also rally behind prevention and early treatment of diabetes and hypertension, also a component of the WHO Palliative Care definition? The experience in the Marshall Islands led its dialysis team to address the need for prevention of diabetic kidney disease with public health measures and better treatment for diabetes given the enormous financial burden of dialysis for the islands.[2]

While the Global North does not need palliative care teams to run dialysis centers, global solutions could emerge from lessons from the Global South. First, through systematic inquiry at the community level, individual countries might find serious health-related suffering[5] that is not apparent from palliative medicine clinic visits in the medical centers, e.g. loneliness or abandonment of the social context for patients, in favor of a focus on physical symptoms.[6] Second, community volunteers can form and drive the social network that supports high quality medical care The Indian state of Kerala has championed these community-led palliative care networks.[7] In this way trained volunteers become part of social capital[8] networks, reinforcing connections within the community to address the needs of the patients and families. The small community on the Lakshadweep Islands model this approach with their profound sense of community and empathy for their fellow citizens.

1. Ms. Nadira*, who grew up on Andrott Island worked on the mainland as a dialysis technician, earning a low salary. Her accommodation and food expenses were financially taxing. She is

eager to care for kidney patients on her home island, as she can speak their language and understands their needs. Her family was happy to have her at home. "*I am proud to be a part of this organization. I have a very good working environment and much-needed support from my colleagues. I believe that the health and safety of my patients are ensured in my hands. Considering all the efforts and struggles to make a venture like this possible, I try to get my work done in the right way. An initiative like this is also a relief for many people. I consider this opportunity to serve my community and build my career. Thank you for believing in me for this.*"

2. Mr. Ramees*, 25 years old, is from Andrott Island and has chronic kidney disease. His family is poor, with no income. He has been away from his family for the last five years, receiving hemodialysis on the distant island of Kavaratti and on the mainland. In Kavaratti, he had to pay 800 rupees ($10) per day for room and board. In Kerala, he was getting free dialysis but had to rent a home, leading to a financial burden for food and accommodation. He had to depend on others for financial help. When Thanal completed the dialysis center at Andrott, Mr. Ramees moved back home, and he has now completed many cycles of dialysis there. "*For the past 5 years being away from my family on Kavaratti Island and the mainland was physically and emotionally exhausting and a financial burden. The new dialysis center at Andrott has truly transformed my life. Being able to return home, surrounded by the love and warmth of my family, has brought me immense relief and happiness.*"
3. Mrs. Fatima*, 70 years old, from Amini Island, has kidney disease, for which she received dialysis on Kavaratti and the mainland. Her son's education was often interrupted by frequent travel to the mainland and Kavaratti to support his mother during dialysis. She did not think she could attend her daughter's wedding due to her distant dialysis sessions. She learned that Thanal was establishing a dialysis center at Amini. She was so happy and prayed for it to open soon. She kept asking everyone when it would start. After a few months, the center became fully operational. She was the first patient to receive dialysis there. Thanal transferred her from Kavaratti to Amini via helicopter, accompanied by a dialysis technician. She needed three dialysis sessions every week. A huge crowd gathered to witness this historical moment. She emerged with a glow on her face, making everyone happy. Her daughter's marriage date was set, and the volunteers from Thanal were special guests at the wedding. *"I was overjoyed to learn about the new center, as it not only gave me hope of attending my daughter's wedding but also reduced the strain of travel. I deeply appreciate Thanal's efforts, including the thoughtful arrangement of my transfer from Kavaratti to Amini via helicopter, with your invaluable accompaniment. Your presence here helps me stay here on my home island with all memories of my forefathers and... I enjoy being here with my grandkids."*

*Fictitious name.

Disclosures and Acknowledgments

The authors wish to thank the following readers of the manuscript: Drs. M.R. Rajagopal, Sloka Iyengar and Ramya Sampath, Ms. Smriti Rana and Ms. Claire Perlman. We are also grateful to the dialysis technician and dialysis patients for their narratives and enthusiasm. There are no conflicts of interest.

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