


Lessons from Kerala: Community Engagement and Participation in Palliative Care

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All photographs have been taken and are shared with individuals' informed consent.

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1. About Me

Since 2023 I have been working as a Specialist Nurse in Palliative care at Community Hospice in South East London. I have a passion for community engagement and for championing equitable access to palliative care services for all local communities. I enjoy empowering and educating patients and their loved ones to manage life-limiting conditions at home, maximising their quality of life until the very end of their life.

2. Introduction

The World Health Organization (WHO) (2020) advises that access to palliative care improves the quality of life for people diagnosed with life-limiting conditions, and their families, by reducing physical, emotional, psychosocial and spiritual suffering. Access to timely palliative care is recognised as a human right; however, this is shown to be inequitable across the nation and the world.

Even in the UK, which is ranked highly for delivery of palliative and end of life care (Finkelstein et al, 2022), there are limitations in the palliative care resources and provision available depending on location. In the UK half a million people are expected to die every year. The Better End of Life report by Marie Curie (2024) highlighted gaps in community palliative care services, with many geographic areas not covered during out of hours periods (which accounts for around 75% of the week). GPs and district nurses, already stretched in their roles, are shown to be providing a substantial amount of support. However inappropriate hospital presentations still occur when patients reach a crisis point.

The National Palliative and End of Life Care Partnership (2021) has produced a framework with suggestions for improvements in palliative care with particular emphasis on community support, including community partnerships and empowering local people to recognise the role they can play to support others. Until now, there has been limited reliable non-clinical palliative support for patients across the country and their families despite evidence demonstrating the benefits of this. Developing community approaches in the UK and promoting general education on illness, death and dying would enhance the holistic support available to people and enable individuals to comfortably remain at home if this is their preference.

Despite contact with and input from healthcare professionals during illness, people spend the majority of their time at home with care support given by family or loved ones. However, these informal carers often lack confidence or skills in providing care for someone with an illness. In addition to this, lack of community input and support in the patient's palliative journey can contribute to feelings of isolation for carers (Watson and Jehan, 2019).

In contrast to this, Kerala in South India has drawn attention from the world for its innovative approach to community palliative care. Community-centred models of palliative care have been recognised for their value in supporting service delivery to patients and their caregivers. McDermott et al. (2008) identified that the state of Kerala had 83 of the 139 palliative care services in India despite only being home to 3% of the population. The formation of the Pain and Palliative Care Society (PPCS) in 1993 and subsequent development of the Neighbourhood Networks in Palliative Care (NNPC) have supported community-led centres to engage and train volunteers to identify and support local people needing palliative input. Programmes aim to sensitise local populations to palliative care and provide training to caregivers, whether they are volunteers or relatives. These initiatives have led to strong local support and development and active participation in provision of palliative care to communities.

3. Aims and Objectives

The aim of this Churchill Fellowship project was to observe palliative care provision, community initiatives and participation in Kerala. This report discusses approaches observed and seeks to start discussions on how these can be adapted and considered for use in the UK.

4. Approaches

My Fellowship project involved a six-week visit to three cities in Kerala, spending time with three differently sized palliative care organisations. The organisations were chosen following general online research of the services available across Kerala and contacting those who had received recognition for their community participation and support. During visits, I observed a mixture of home care provision, inpatient care, outpatient clinics, community engagement and palliative care workshops. The variety of experiences informed my learning about the background of palliative care in Kerala and the community support for services in different locations. During my time spent with organisations, I made notes, took photographs with consent and recorded several interviews.

Arike Palliative Homecare – Ernakulam

Arike is a small NGO founded in 2019 in Ernakulam. This organisation delivers palliative homecare services with a team of community palliative care nurses and doctors, social workers and volunteers, supporting over 200 patients a year. They have developed and deliver training and education to other palliative care organisations.

Institute of Palliative Medicine (IPM) – Kozhikode

IPM is the training, research and outreach arm of the Pain and Palliative Care Society. It was instrumental in development of the "Kerala Model" of palliative care. It is the first World Health Organization Collaborating Centre for Community Participation in Palliative and Long Term Care (WHOCC). It is estimated that they support over 20,000 patient contacts a year through their outpatient, inpatient and home care teams.

Pallium India – Thiruvananthapuram

Pallium India is a highly influential NGO established in 2003, headquartered in Thiruvananthapuram. This organisation is a leader in palliative care, offering comprehensive services, education, and advocacy to improve the lives of patients and their families across India. They are instrumental in policy change and training healthcare professionals nationwide. Pallium delivers inpatient, clinic and homecare services, and supports more than 3,000 patients a year – over 37,000 patient contacts in 2023-24 (Pallium India, 2024).

5. Findings

5.1 Community-led Services

The palliative care services I observed throughout my Churchill Fellowship in Kerala were considerably more inclusive than specialist palliative services in the UK with the cohorts of patients they provided support to. The organisations I spent time with filled vital gaps in health and care provision.

Although in Kerala, some government services exist to provide basic scheduled nursing home care for patients, for example catheter maintenance, there is no resource for urgent and unexpected care, or for complex symptoms. Patients who are housebound or have limited access to transport due to economical or geographical reasons may have no access to any other clinical care. Members of the Indian Medical Association in Kerala recognised this need for additional support in the community, and the importance of developing self-sustaining services.

The palliative care movement in Kerala was subsequently started in 1993, initially developing support for people with chronic pain and cancer as a professionally run system. Slowly, communities began to help these organisations by providing funding, resources and manpower. By 2000, the Neighbourhood Network in Palliative Care (NNPC) was established, which aims to be a sustainable way to develop palliative services for local communities. The network focuses on training and empowering volunteers to identify issues for local people and to intervene. NNPC aims to move away from biomedically-focussed models of care, recognising that people with chronic or life-limiting illness need support which addresses their psychosocial, emotional and spiritual needs that cannot necessarily be addressed by institutionalised care. Dr Rajagopal, a leading palliative care physician in Kerala, states that dying is a “social issue with medical components, rather than a medical issue with social components”. The NNPC model of care used in Kerala integrates elements of social and healthcare whereas in the UK these are still very much separate entities, with ongoing efforts to streamline collaborative working.

Arike Palliative Homecare is a not-for-profit non-government organisation (NGO) founded in 2019 in Ernakulam. They provide nursing homecare services and doctor consultations for patients with palliative care needs and their families, with the aim of providing ‘total’ care and support covering physical, psychological, social and spiritual needs. They encourage the community to be aware of and involved in palliative care activities by providing sensitisation programmes and encouraging participation.

Dr Athul Manuel, Palliative Care Physician and co-founder of Arike, states that for an ordinary member of the public “there is no skill, only a feeling” when someone needs help and they hope to utilise this to further drive community participation and neighbourhood networks in their district. Arike encourage the community to contribute to the financial support required to provide palliative homecare services. For patients who are able and willing to contribute, they invoice them for services provided at a flat hourly rate which differs for a nurse or doctor visit. For patients without financial means, care is provided free of charge. They have some community members who ‘sponsor’ care of another, they receive charitable donations and they also encourage their paid staff to donate a small amount of earnings back into the organisation. Arike only covers about a 5km radius around the Ernakulam city limits and is neighboured by other community palliative care providers. They work to provide accredited training programmes to these other organisations to support their development.

The Institute of Palliative Medicine (IPM) in Kozhikode is a wider-reaching organisation, having been established for longer and with links to the original Pain and Palliative Care Society (PPCS). Their services include a large inpatient unit, daily outpatient clinics at their institute and delivery of palliative homecare nursing and doctor services. They have promoted the development of networks of community-led clinics covering wider-reaching and more rural areas of Kozhikode. The case study that follows describes one organisation which has developed as part of a network with the support of IPM and is driven by the community itself.

Case Study - Community Palliative Care Society at Malaparamba

In an area of Kozhikode with limited palliative homecare support unless privately funded, community-led organisations have been supported to develop for the benefit of local people. The Malaparamba Community Palliative Care Society was established in 2006 with 10 volunteers using a public library to discuss palliative homecare patients in their local community and how they could be best supported holistically by community volunteers. Over a period of 15 years, the organisation has grown to hire a rented office space, two homecare teams staffed by palliative care nurses and a doctor who supports with weekly visits as required, and telephone advice and support.

On asking what the biggest challenge of establishing the organisation was, Chairman Mr Suhas Nambath reports that initial lack of funding and lack of volunteers were barriers they have overcome. They addressed the funding issue by organising collections and fundraising as more people joined.

Now with around 60 registered volunteers, at least 30 of whom are actively supporting on a regular basis, the organisation runs regular sensitisation workshops for local people about the purpose of palliative homecare and the support they can provide. From these sensitisation sessions, for around 30 people held every two months, they usually recruit 1-2 new volunteers. Volunteers complete a caregiver's workshop, provided by IPM to gain a more comprehensive understanding of how they can provide care and support. The organisation holds a monthly meeting where they discuss new referrals, and volunteers are encouraged to actively seek people locally who may need support and to present their case at the meeting. From there, a homecare nurse will arrange a first assessment visit and ongoing support as required.

All palliative homecare services are provided as free to all. For medication costs, patients who have the means to pay for these will do so, but the organisation will cover costs for people who do not. They estimate their organisation spends between 50-60,000 Indian Rupees (INR) (£400-500) a month on medications for patients. For families in need, they provide a weekly food parcel. They have also developed a Palliative Care Patient Benefit Trust scheme for children of deceased patients, to fund their education. Around 35 children have completed their education with support of this bursary.

Pallium India in Thiruvananthapuram, a World Health Organization Collaborating Centre for Training and Policy on Access to Pain Relief, provides inpatient care, outpatient clinics and homecare services. Pallium coordinates its far-reaching community service using link centres. These are run by community volunteer groups who recognise and can advocate for needs of local people. Community nurses from Pallium are linked to a particular geographic area and link centre to provide homecare visits for patients in this catchment and/or outpatient clinics with a doctor. Services provided depend on the needs of the community. The community volunteers support with access to infrastructure to provide outpatient support, such as local libraries, schools, community or religious centres.

Malaparamba volunteers fundraising with a stall selling buttermilk, Indian snacks and plants.

From left: Malaparamba Chairman Mr Suhas Nambath, volunteer Mr E Premgiri and office staff member Ms Sumisha

Case Study – Murukumpuzha Community Outpatient Clinic

The outpatient clinic for this Pallium link centre in Thiruvananthapuram is held twice monthly at a local library and is staffed by a doctor, nurse, social officer and several link centre volunteers who prepare the space, greet patients and support the flow of patients through the clinic. Patients can attend to seek review of their symptoms or for discussion of other issues. Vital signs are monitored, and nurses also dispense one-month supply of regular medications. Several people attending were by proxy for a relative who is physically unable to attend the clinic.

Similar to my experiences in the UK, occasionally a palliative care assessment of these patients may flag a more general physical issue – such as hypotension in a patient needing review of their anti-hypertensive medication. In these cases, they would be directed to their general physician where possible. The majority of cases I observed would review management of common symptoms such as nausea, pain or breathlessness, and involved medication adjustments and non-pharmacological advice.

Volunteers were observed to have good rapport with patients, and it was evident that being greeted by someone with shared local values in a local setting makes the clinic more inviting to patients who may be intimidated by palliative care support.

Staff nurse dispensing medication at a community outpatient clinic, held at Murukumpuzha Library and a palliative care van.

5.2 Holistic Approach to Suffering

There were geographical and socio-economic differences between all cities visited; however, it was evident that factors such as accommodation, mobility status, transportation and financial means all impacted some of the population's ability to access appropriate clinical care. Dr Athul Manuel, Director at Arike Palliative Homecare, references the World Health Organization's (2020) description of palliative care being an approach which 'addresses suffering'. He explains that inclusion criteria for their organisation and many others is the evidence of healthcare-related suffering – for the individual themselves or the caregiver.

IPM developed a community screening tool which they train volunteers and interns to utilise to identify people in need of palliative care. This is a holistic tool which focuses on mobility, ability to carry out their Activities of Daily Living (ADLs), oral intake, symptoms and levels of anxiety, depression or worry – considering domains over the last three months. Patients with scores above the threshold trigger clinical evaluation for palliative care needs. I observed the use of this in the outpatient clinic at IPM as part of the triage and registration process for new patients.

In the UK, the Supportive and Palliative Care Indicators Tool (SPICT) (Appendix A) is one of the most widely used to identify people with deteriorating health due to life limiting conditions. It focuses more on medical or functional changes specific to different groups of conditions and prompts review of current care needs and forward planning, either by palliative care professionals or primary or secondary care clinicians. The SPICT-4ALL was developed with simpler language to help people from a non-clinical background, such as family members and social staff, to identify potential palliative care needs and empower them to communicate these concerns to healthcare teams. The impact of this tool is currently being evaluated, whilst the SPICT tool is already validated for clinical use.

The shift in perspective from a biomedical focus of care recognises the multi-factorial suffering and supports teams to address patients' needs. I observed all staff and volunteers contributing equally to patient care. Volunteer drivers often joined homecare episodes, speaking and providing emotional support to family members or directly supporting care. I observed a range of holistic initiatives such as food parcel deliveries for people with low household incomes, or social support groups which provide companionship and reduce isolation.

5.3 Decentralisation and Local Autonomy

A key contributor to the difference in the palliative care models in Kerala and the UK is the differences in decentralised powers for spending.

Panchayats are democratically elected local governing bodies in Kerala, who have the autonomy to manage development and allocate funds based on local priorities. By actively involving local people and driving community participation, they ensure sustainability at local level for palliative programmes and raise awareness within their populations promoting greater equity in access. During my time observing organisations in the three different cities, I noted a huge difference in populations and cultural attitudes which impacted how people received palliative care. Decentralisation and empowerment of local bodies supports effective palliative care provision to ensure it is tailored to the people it is serving. Decision making in Panchayats often involves direct community input, allowing local needs and preferences to be considered. This differs to the UK, where decision making and commissioning responsibility for healthcare spending is primarily held by Integrated Care Boards (ICBs) for their geographical areas and is more centrally driven than the Panchayat system, with less

of a link to communities. Local authorities hold responsibility for social care service commissioning, under legal frameworks processes.

My observations in Kerala highlighted differences in the locus of control and participation in healthcare when compared to the UK. In the areas of Kerala I visited, there was a sense of community ownership and agency where individuals felt empowered to initiate and shape healthcare services at grassroots level. This was evident in the numerous initiatives I came across throughout my trip.

Conversely, my experience in the UK suggests that healthcare is heavily institutionalised, with centralised policy and bureaucratic processes. Whilst this contributes to quality and equity of services, the framework creates a 'red tape' and decision making distant from the immediate needs of local communities. The centralisation of services, whilst offering systematic oversight, has the consequence of potentially disempowering individuals from actively participating in the health and care needs of their neighbours and wider community. The structural difference suggests an area for reflection on how greater community engagement and centralised approaches may be fostered within more established healthcare systems.

5.4 The Pivotal Role of Community and Volunteers

As previously mentioned, community volunteers contribute heavily to the sustainability and provision of palliative care services throughout Kerala. Each organisation I observed utilised volunteers in different ways with varying levels of success. All three organisations mobilised volunteers for direct patient contact and care.

Recruitment of volunteers was acknowledged to be successful when organisations conducted sensitisation programmes or workshops (usually around an hour long) delivered to communities to raise awareness of palliative care, with opportunities for further training. The Sanjeevan Palliative Care Project (2022) (a joint venture between Sri Aurobindo Society and IPM) have developed and published a workbook to support structured training programmes for both family carers and community volunteers. The workbook has suggestions on how to structure sensitisation workshops, 'entry point' introductory training and more comprehensive training programmes for volunteer carers (see Appendix B). Palliative care is seen as a 'life skill' which can benefit volunteers both in their role with organisations and personally. At Arike, the social work team are active in delivering sensitisation programmes, particularly to colleges and local community groups. I observed one college workshop delivered to students aged 16-18. Topics discussed were interactive and educational, delivered by young members of staff who the students could clearly relate to. During discussions, they encouraged students to give opinions and agree or disagree with statements. Students identified people in their neighbourhoods who may need support and were encouraged to consider how they could make a difference in their communities. Following this workshop, a high proportion of students signed up for further introductory training to palliative care.

IPM in Kozhikode had the most established Students in Palliative Care (SIPC) programme, with large numbers of students completing a comprehensive 2-day workshop in palliative care for volunteers and then actively engaging in projects such as death cafes, fundraising and awareness events and being involved in patient contact and support. IPM also utilises interns from universities on placement to support inpatient, outpatient and homecare encounters. I observed interns greeting outpatients and gathering initial information for basic assessment which was used for triage prior to clinician contact. With large volumes of people attending the clinic, this supported prompt acknowledgement of attendance. Interns had an opportunity, once trained, to work autonomously in this role to help the patient flow through clinic. Many students I met were studying social work or other health disciplines and commented on the value of the learning and experience they were exposed to.

IPM also runs workshops for volunteers interested in companionship support or bereavement support. Well-established volunteers told me they were drawn to these programmes to develop their own skills and felt they could offer enhanced support to their community.

Volunteers at a palliative caregiver workshop

Volunteers who had successfully completed a recent Companionship workshop at IPM and were utilising enhanced skills to support patients with more complex psychosocial needs.

Palliative care workshop delivered by Arike Palliative Homecare team at Al-Ameen College, Kottayam

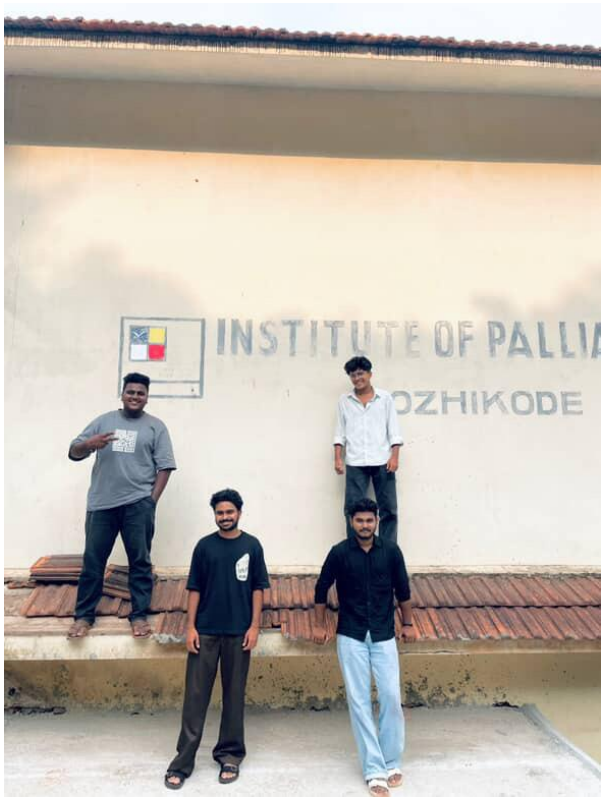
At Pallium India, volunteers significantly contribute to inpatient care by providing companionship and social support. I observed these volunteers actively participating in ward rounds and care discussions. Initially, I was concerned that this 'groupthink' approach might intrude on individual autonomy. However, it quickly became apparent that this collaborative model aligns well with the decision-making culture in Kerala. The volunteers, having established strong rapport with patients, effectively supported their care, demonstrating how this model enhances patient well-being within the local cultural context.

The population of Ernakulam, where Arike is based, is interesting as a main financial district of Kerala. Several staff I spoke to commented on the volume of young people who move to the area for work or education, yet may leave after a few years, which leads to a rapid turnover of volunteers. They also identify that other areas may have ageing populations with reduced local support from younger relatives due to this economic migration.

IPM, based in Kozhikode, serves a different population, which may be a key feature of why it is celebrated for its high levels of community participation. Compared with a more urbanised, diverse population in Ernakulam, Kozhikode has a more homogenous population, a Muslim majority, which can be helpful for building trust and shared goals in communities. Kozhikode locals also have a sense of strong cultural identity and there is a history of community-based initiatives, being in the founding city of PPCS and NNPC. This has led to deeply rooted traditions of community involvement in the area.

From my observation, Arike raises awareness through more formal channels such as education and sensitisation programmes, such as the workshop at Al-Ameen College. In contrast, some of the initiatives seen at IPM were less formal and utilised community leaders and networks to spread information. For example, IPM students in Palliative Care had identified a need and developed a project with a local wheelchair user group.

Thiruvananthapuram has a higher population density and is more urbanised as the state capital. I felt there may be less emphasis on community and grassroots involvement, as in Kozhikode. However, there are potential strengths in policy advocacy, training and more organised volunteer structures. It was noted by people I spoke to at Pallium that volunteer turnover is very quick – and their SIPC programme lasts only a year. Volunteers rarely stay on beyond this programme, which differs to Kozhikode where IPM student volunteers sometimes stayed on and engaged with the organisation long after leaving education. One individual, Musafa, had initially volunteered 7 years ago as a member of SIPC, and after completing his studies continued to support IPM in various roles. He now acts as a role model and mentor for younger volunteers, is involved in developing training programmes, and is on the management board for the organisation. It was clear to see how far-reaching his impact has been on other volunteers and to the organisation. He described the network as ‘a friendship group’ and spoke highly of the social benefits of being involved.



Students in Palliative Care at IPM and a training workshop for students held over two days.

5.5 The Nurse's Expanded Role and Caregiver Empowerment

"There are four kinds of people in the world:

Those who have been caregivers,

Those who are currently caregivers,

Those who will be caregivers,

And those who will need caregivers" – Rosalynn Carter

Previous research has found that many caregivers feel unprepared for the physical and emotional work of caring for someone at the end of life (Marie Curie, 2024), and there are many needs that remain unmet including psychological support, information and help with care tasks (Grande et al, 2009).

In India, there is a strong cultural tradition of caring for elderly and unwell relatives, and it is common for family caregivers to take an active care role when someone is in hospital, even carrying out basic nursing tasks. This differs to the UK where care is provided by registered and unregistered professionals in an inpatient setting and where it is rare for relatives to take a very active role unless there is a long history of severe complex need. In the inpatient settings I visited in Kerala, all patient spaces had beds for caregivers which accompanied the patient bed space. This struck me as an important acknowledgement of the importance of their participation in the patient's care and is a holistic way of supporting the whole family unit.

During my time in all three cities, I observed nursing staff supporting family caregivers through the exchange of knowledge and practical skills. I observed nurses demonstrating pressure area care and educating relatives on the importance of skin care and repositioning. For a patient with a category 3 pressure ulcer, I joined a visit where a palliative care nurse reviewed the wound care and management by the patient's son. He had been taught how to clean, dress and monitor the pressure ulcer with support from the nursing team. In the village in Kozhikode where this took place, there was no other provider of homecare to give support and by empowering the son to take on this duty, nursing resources were freed for other urgent and complex needs. In the UK, district nurse teams aim to work in partnership with patients but they will, however, take main responsibility for pressure ulcers and wound care in the community. Families rarely have the opportunity, and generally may not wish, to be involved in aspects of nursing care. In the UK, there is a greater emphasis on seeking professional support due to the sense of disempowerment or fear of causing more harm.

In the UK and with many families I meet, there is a lot of anxiety about even making the call to district nurses for symptom control, as families often do not feel confident about their own assessment of this. With strong legislation and policy surrounding controlled drugs, it is understandable that responsibility for administration of these falls to registered healthcare professionals. However, this case study illustrates that families can be supported with knowledge and skills to identify and deal with presentation of symptoms. In more rural areas of the UK or where resources are limited, patients can wait up to several hours for a nurse to visit and administer injectable medications, leading to high levels of distress to the individual and their family.

Case Study – Mrs G

I observed a visit to a female patient, Mrs G, who was approaching the end of her life. In her late 80s with multi-morbidities, she had a total bowel obstruction and was experiencing pain and agitation. As she was no longer able to swallow any oral medicines and her symptoms were poorly controlled, it was decided that medicines for subcutaneous injection would be most appropriate. After a detailed discussion to educate family caregivers on the purposes of the anticipatory medicines and how these are prescribed, a demonstration followed of how to administer them. The nurse then drew up the remainder of the medication from the vial to the correct dose and left the family with clear guidelines of how and when to give it if required – with the guidance of calling the palliative care team in this instance once it had been given so it could be reviewed by the telehealth nurse on duty.
The family appeared confident with using this medication and were happy to have a plan of action if their relative became symptomatic again.

During my observations, I noted a significant number of patients nearing the end of life at home in Kerala had nasogastric tubes (NG tubes) in place. This contrasts sharply with practices in the UK community setting, where NG tubes are typically reserved for gastric drainage in cases of bowel obstruction or for enteral feeding. In Kerala, NG tubes are frequently inserted for patients with dysphagia, and caregivers are taught to administer small amounts of puréed food, water and medication through the tube.

Initially, I found this practice conflicting. In the UK, we dedicate considerable time to educating patients and their families about the physiological changes associated with the dying process, including reduced swallowing ability and decreased appetite. Artificial hydration and nutrition toward the end of life are generally understood to offer minimal physiological benefit, while posing risks such as aspiration, increased discomfort, and other complications. Our focus in the UK community is on symptom management, encouraging eating for pleasure while possible, and supporting excellent oral hygiene and care when patients can no longer eat or drink.

I discussed this with a doctor, querying the expectations surrounding NG tube use, especially since the small nutritional volumes provided would not prolong life. They explained that due to the profound cultural significance of food and drink in Kerala, families find comfort in having an alternative method to provide nourishment to their loved ones. This highlights the vital role of shared decision-making with families. As with any medical intervention, clinicians have a duty to weigh the perceived benefits and harms of nasogastric feeding and hydration. For this population, the spiritual and psychological impact of artificial feeding can be substantial, stressing the need for culturally sensitive care.

6. Lessons from Kerala's Palliative Care Model

My time in Kerala, observing community participation and palliative care service provision at Arike, IPM, and Pallium, offered profound insights and opportunities for reflection. The experience highlighted significant differences in how palliative care is approached in the UK, particularly regarding community involvement and local empowerment.

Decentralised Power and Community Autonomy

A striking difference between the UK and Kerala is the impact of decentralised power, where local self-governments (Panchayats) can allocate funds based on local priorities. This autonomy fosters inclusive, sustainable, and responsive services that genuinely reflect community needs. For instance, a notable portion of Kerala's healthcare budget is devolved to these local bodies, allowing them to directly fund initiatives like community palliative care units. This contrasts sharply with the heavily regulated and centrally controlled UK healthcare system, where local people often feel they have limited influence over decision-making. The National Health Service (NHS) operates under a more top-down structure, which, while ensuring national standards, can struggle to adapt to the diverse local requirements across the country.

In the UK, hospices operate with a mixed-funding model, receiving some government funding but often relying predominantly on charitable donations. They are independent from NHS organisations and have independent boards of trustees responsible for governance, strategy and financial oversight. This independence does offer hospices a degree of responsiveness to local needs, allowing them to work in partnership with local Integrated Care Boards (ICBs). However, the fundamental difference lies in the direct, democratic control seen in Kerala's panchayat system, which can empower communities to initiate and sustain services in a way that is less common in the UK.

The Professionalisation of Death and Community Engagement

The professionalisation of death in the UK, following palliative medicine's recognition as a specialty, has shifted care responsibilities from communities to professionals (Kellehear, 2005). While this ensures coordinated and more consistent approaches, it can limit broader community engagement as people fear overstepping into professional's domains. Kellehear (2005) suggests that generally people have a desire to be involved in and support needs in their community. He explains that Western societal structures channel this into formal, professionally supervised projects such as support groups or fundraising. Volunteers are reporting to professionals and rarely have much autonomy to take initiative.

In Kerala, I witnessed direct community action, powerfully illustrated by the establishment of community-led clinics such as the one in Malaparamba. This demonstrates a powerful model of local empowerment. Volunteers described remarkably collapsed hierarchy systems even when collaborating with palliative care professionals, with their contributions recognised as having equal value and impact on care. This level of intrinsic community ownership and direct participation in care delivery is a significant differentiator.

While the UK may not always see the same extensive levels of community action, hospices across the nation often boast deep, meaningful histories intertwined with their local areas. This rich heritage frequently cultivates powerful connections with residents. For instance, many patients I meet vividly recall the original fundraising drives that led to the building and establishment of the Greenwich and Bexley Community Hospice in 1994. They can recount stories of friends or family members who either worked at the hospice or received compassionate end-of-life care within its walls. This shared history

fosters a profound sense of connectedness and loyalty to the organisation, often translating into a greater willingness to volunteer time or donate much-needed funds.

Strengthening Localised Care in the UK: the Role of Volunteers

One-way localised care could be strengthened in the UK is by improving the ties between primary care and volunteer networks. This has already been demonstrated well with the introduction of Social Prescribers, who have been a vital link between primary care and voluntary, community and social enterprise sectors. There is potential for development of pathways in which volunteers could support primary care with their palliative patients including identifying people in need of support, practical assistance, health promotion and education. Regular joint meetings between volunteers, practices and palliative care teams would strengthen integration, communication and problem-solving, creating a more cohesive support system.

The National Neighbourhood Palliative Care (NNPC) in Kerala champions the training and development of volunteers to support local palliative care. This aligns with findings from the Worldwide Hospice Palliative Care Alliance (2020), which identifies education as a key barrier to palliative care development and stresses the importance of community awareness and education in fostering participation. The Kerala model of 'sensitisation' and volunteer development is clearly pivotal in establishing and delivering palliative care services across the region.

Globally, over 1.2 million volunteers contribute to palliative care, underscoring their critical role in supporting service delivery and fostering community awareness (Worldwide Hospice Palliative Care Alliance, 2020). The organisations I observed in Kerala showcased how volunteers actively contribute to direct patient care and community engagement, acquiring valuable knowledge and skills that benefit both themselves and their social networks. This model offers a compelling blueprint for how the UK could further leverage its existing volunteer base.

Integrating Health and Social Care: A Holistic Approach

People needing palliative support in the UK often face multi-faceted challenges with their health and social care needs. At present, the two systems operate with different funding streams, eligibility criteria and administrative processes. This can make navigating these systems complex for patients and their families, who may struggle to understand who is responsible for different aspects of their needs. In addition to this, some people are known to be less likely to have equitable access to care. For example, people from poorer socioeconomic backgrounds, people with lower-level health literacy or language barriers, some minority ethnic groups and LGBTQI+ people face additional barriers.

Kerala's health and social care systems appear to be remarkably well-integrated, recognising the inherent overlap between medical and social issues. Dr Rajagopal's perspective — describing dying as "a social issue with medical components, rather than a medical issue with social components" — perfectly encapsulates this approach. Such a holistic view of palliative care values contributions from both community members and professionals, fostering a more comprehensive and person-centred support system.

At the onset of developing NNPC in Kerala, community input and decision making was minimal and volunteers carried out limited support roles or were involved in simple fundraising or donation of resources. Once it was noted that this was not a sustainable model, palliative care centres began to develop programmes which empowered communities to take active roles in identifying patients, completing training programmes and developing link centres or services. This approach does not seek to replace clinical input but to supplement and enhance the social, psychological, spiritual and

emotional support available to patients it has also resulted in improvement in early reporting of symptoms and better concordance with medications or clinical advice (Kumar, 2007).

Community engagement in the UK is vital for building relationships with communities who may face barriers to accessing care and support. Abel et al (2021) recognise that a lot of the work on reducing barriers to palliative care access focuses on expansion of services, rather than how the strengths of communities themselves can be utilised.

Engagement with local communities at Community Hospice In South East London has supported learning about what is important when a member is diagnosed with a life-limiting illness, and how we can best support them in a person-centred way. Continued efforts in this area are crucial to addressing existing inequities but it is important to recognise that engagement is two-directional, with communities receiving but also providing services, exchanging knowledge and there being a mutual participation in development (Abel et al, 2021). At Community Hospice there has been an effort to engage with various important community groups such as faith and minority ethnic or cultural groups. These interactions have focussed on *what is important* to individuals in specific groups and *what they want* from a service. The Community Engagement team have sought to learn about how these communities support one another and this sets good foundations for how we can cooperate as a palliative care provider.

Empowering Families and Caregivers

While acknowledging population differences across the cities visited, a key takeaway is the active empowerment of families and caregivers in Kerala. This contrasts with the UK where professional responsibility, while essential, can sometimes lead to anxiety or disempowerment among those providing informal care. The Kerala model demonstrates a highly collaborative approach, where community members are not just recipients of care but active participants and providers, significantly bolstering the palliative care workforce and its reach. This is particularly relevant given the increasing demand for palliative care services; the number of people requiring palliative care in the UK is projected to rise by around 25% over the next decade.

There is ongoing discussion about family and caregiver administered anticipatory medicines in the UK, with mixed opinions and policies across the country. In more rural areas where district nurses cover large geographical areas, some palliative care teams support this. Others argue that in urbanised areas with good district nurse provision, this is not needed. From observation in Kerala and subsequent learning, it appears that empowering families who are competent and confident to give anticipatory medicines for symptoms can support timely symptom control as well as giving people a role and means to alleviate suffering for their loved one if needed.

It is acknowledged that many caregivers are concerned about making decisions about identifying symptoms and administering appropriate medications (Letizia et al., 2004). In Kerala, this was overcome by personalised education to family caregivers and hands-on training (demonstrating subcutaneous injection and supporting them to administer under supervision if required) as well as providing non-pharmacological techniques to manage symptoms. Families were given basic training on how to identify symptoms even if a patient is not able to verbally communicate (for example, nonverbal indicators of pain), and were advised to call in to the office and speak to the duty clinician to advise when giving an injection. This supported timely reassessment of the patient's needs and a home visit review if needed. Crucially, it also supported caregivers to feel confident in their judgement and actions.

In the UK, there needs to be clear policies within organisations to support staff with educating and empowering caregivers to administer anticipatory medicines. Embracing this approach more widely could significantly enhance timely symptom management and empower families, aligning with a more person-centred model of care.

Summary of recommendations

- Improvement of ties between primary care and volunteer networks to strengthen localised care and ensure it suits local community's needs.
- Improvement of engagement between communities and healthcare providers, particularly palliative care organisations. This would support identification and reduction of barriers to accessing care and support.
- Development of clear policies within organisations to support staff to empower and educate caregivers to administer anticipatory medications.

7. Conclusion

My Churchill Fellowship experience in Kerala unveiled a powerful paradigm of palliative care, deeply rooted in community participation and local empowerment. The striking contrast with the UK lies in Kerala's decentralised power structures, where community-led initiatives and volunteer engagement are not just supplementary but fundamental to service provision. While the UK's professionalised healthcare system ensures consistency, it often struggles with the same level of community integration and local autonomy witnessed in Kerala, where volunteers actively participate in direct care with a flattening of traditional hierarchies. The holistic integration of health and social care in Kerala, exemplified by Dr Rajagopal's perspective, offers a potent lesson for the UK, where navigating disparate systems can be a significant burden, particularly for vulnerable populations. Empowering families and caregivers with education and confidence in symptom management, as demonstrated effectively in Kerala, presents a tangible opportunity to enhance timely care and alleviate suffering in the UK. Ultimately, by learning from Kerala's emphasis on community ownership, integrated approaches, and caregiver empowerment, the UK has a significant opportunity to strengthen its palliative care provision, making it more responsive, equitable and person-centred.

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Appendices

Appendix A – Supportive and Palliative Care Indicators Tool

Supportive and Palliative Care Indicators Tool (SPICT)

University of St Andrews

NHS SCOTLAND

The SPICT is used to help identify people whose health is deteriorating. Review unmet palliative care needs. Plan current and future care with them.

Look for any general indicators of poor or deteriorating health.

- Urgent or emergency hospital admission(s) or visits.
- Functional ability is poor or deteriorating, with limited reversibility. (eg The person often stays in bed or in a chair for more than half the day.)
- Depends on others more for care due to increasing physical and/or mental health problems. Person's carer needs more help and support.
- Progressive weight loss; remains underweight; low muscle mass.
- Persistent symptoms despite optimal treatment of health condition(s).
- The person (or family) asks for palliative care; chooses to reduce, stop or not have treatment; or wishes to focus on quality of life.

Look for clinical indicators of life shortening conditions.

Cancer

Functional ability deteriorating due to progressive cancer.

Too frail for cancer treatment or treatment is for symptoms.

Dementia or frailty

Unable to dress, walk or eat without help.

Eating and drinking less; difficulty with swallowing.

Urinary and faecal incontinence.

Not able to communicate by speaking; little social interaction.

Frequent falls; fractured femur.

Recurrent febrile illnesses or infections; aspiration pneumonia.

Neurological disease

Progressive deterioration in physical and/or cognitive function despite optimal therapy.

Speech problems with increasing difficulty communicating and/or progressive difficulty with swallowing.

Recurrent aspiration pneumonia; breathless or respiratory failure.

Ongoing disability with worsening physical and/or mental health after a major stroke or multiple strokes

Heart or vascular disease

Heart failure or extensive, untreatable coronary artery disease; breathlessness or chest pain at rest or on minimal effort.

Severe, inoperable peripheral vascular disease.

Respiratory disease

Severe, long term lung disease; breathlessness at rest or on minimal effort between exacerbations.

Persistent hypoxia needing long term oxygen therapy.

Has needed ventilation for respiratory failure or ventilation is contraindicated.

Kidney disease

Stage 4 or 5 chronic kidney disease (eGFR < 30ml/min) with deteriorating health.

Kidney failure complicating other life shortening conditions or treatments.

Stopping or not starting dialysis.

Liver disease

Cirrhosis with one or more complications in the past year:

- diuretic resistant ascites
- hepatic encephalopathy
- hepatorenal syndrome
- bacterial peritonitis
- recurrent variceal bleeds

Liver transplant is not possible.

Other conditions

Deteriorating with physical or mental illnesses, multiple conditions and/or complications that are not reversible; best available treatment has poor outcome.

Review current care and care planning.

- Review current treatments and medication; minimise polypharmacy. Shared decision making about treatment and care.
- Review holistic care – symptoms; emotional, social, financial, spiritual needs. Support families and carers.
- Ask for specialist advice or a review if symptoms or other problems are difficult to manage.
- Agree a current and future care plan with the person/family. Discuss future decision making (e.g. Power of Attorney).
- Record, share, and review care plans.

SPICT 2025 Please register on the SPICT website (www.spict.org.uk) for information and updates.

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Appendix 2

Proposed modules for sensitization and training programmes

INTERACTIVE TRAINING PROGRAMME FOR CARERS INCLUDING VOLUNTEER CARERS (20 HOURS)

1. What is palliative care?
   a. A brief 15-minute presentation on what is palliative care, focusing on issues relevant locally.
   b. Sharing of experiences with incurable illness in the family/friend circle, etc., by 3–4 participants.
2. Carer's responsibilities to patients/community participation in palliative care
3. Knowing about the patient's biomedical, psycho-social and spiritual status

Interactive sessions on problems faced by advanced, chronically bedridden and terminal patients and possible areas of interventions

i. Socioeconomic issues: Knowledge, skills and attitude
   1. Dependence & issues related to dependence:
      a. Mobility /lifting and moving
      b. Activities of daily living
      c. Financial
   2. Personal relationships—Importance
   3. Social activities—Importance/how to organize?
   4. Social support—Importance/What is possible?
   5. Health and social care—Accessibility and quality
      a. Description of healthcare and formal social support systems: What is available? How to access?
   6. Transport
      a. Description of transport systems: What is available? How to access?
   7. Work/capacity to work
   8. Home environment
      a. Disruptions due to disease

b. Carer issues
c. How to evaluate? How to intervene?

9. Sexuality

ii. Physical Issues: knowledge, skills and attitude

1. Energy and fatigue: Issues/assessment/principles of non-medical interventions
2. Pain: Discomfort and other symptoms
   a. Symptom/assessment/tips for non-medical interventions until professional help is available
3. Sleep and rest: Issues/assessment/principles of non-medical interventions
4. Prognosis:
5. Know how to administer medicines prescribed:

iii. Emotional Issues: Knowledge, skills and attitude

1. Feelings: Negative and positive/attitude to the world
2. Distress/assessing distress:
3. Body image and appearance:
4. Self-esteem:
5. Thinking, learning, memory and concentration:
6. When to seek professional help?
   a. Psychiatric disorders associated with advanced illness

iv. Spiritual Issues: Knowledge, skills and attitude

1. Spirituality/definition/concepts/ religion and spirituality/spirituality as part of life
2. Taking a spiritual history/assessment of spiritual pain
3. Death and dying/being mortal
4. Knowing how to communicate to the patient in a supportive way
   a. What are the skills and knowledge that a carer in palliative care needs? (Brainstorming to create a first list of skills/ knowledge. To be prioritized by the mentor explaining the reasons for prioritisation.)
   b. The carer should know how to communicate to the person in a supportive way
      i. Discussion following the 'empathy' video
   c. Barriers to communication (Group work on what are the barriers to proper communication to patients?)

d. Importance of listening skills?
    i. Group work: Attributes of good listener: (each group with 5–6 people) How do you want the listener to listen when you talk to him/her? (Discussion in groups followed by reporting.)
    ii. Group work: Attributes of good speaker: (each group with 5–6 people) How do you want the speaker to speak when he/she talks to you? (Discussion in groups followed by reporting.)

OR

    iii. Group exercises: In pairs with an attentive listener vs. an inattentive listener. (Feedback on what the speaker felt.)
e. The process of visiting patients/dos and don'ts in communication with patients. (Discussion after showing a video on a badly done visit.)
f. Exercises on exploring one's own communication style

5. Know the basics of nursing care
    a. Prevention of pressure sores
    b. Sterilization, asepsis, universal precautions
    c. Cleaning and dressing of wounds
    d. Stoma care
6. Know when and where to seek help, for the patient and also oneself
    a. Coping with illness/distress/ distress thermometer
    b. Helpful agencies in the neighbourhood
    c. Self-care
        i. Need for self-care
        ii. Knowing one's own strengths and weaknesses
7. Practical issues (Discussions to generate locally relevant information)
    a. Relief from difficult symptoms
        i. Who can help? How can we facilitate it?
    b. Emotional support
        i. Someone to talk/listen to
            1. Who can help? How can we facilitate it?
    c. Social support
        i. Help with daily living, better social interactions, financial support
            1. Who can help? How can we facilitate it?

d. Spiritual support
    i. Meaning of life, religious issues
        1. Who can help? How can we facilitate it?

8. Grief and bereavement (30 minute presentation followed by discussions)

SENSITIZATION PROGRAMME (1 HOUR)

What is palliative care?

a. A brief 15-minute presentation on what is palliative care, focusing on issues relevant locally.

b. Sharing of experiences with incurable illness in the family/friend circle, etc, by 3–4 participants.

c. What can we do as individuals? (Discussion 20 minutes)

d. Summarizing/giving details about further training programmes. (10 minutes)

INTRODUCTORY TRAINING (3 HOURS)

1. What is palliative care? (30 minutes)
    a. A brief 15-minute presentation on what is palliative care, focusing on issues relevant locally, followed by discussion
2. Carer's responsibilities to patients/community participation in palliative care (60 minutes)
3. Knowing how to communicate to the patient in a supportive way (90 minutes)
    a. What are the skills and knowledge that a carer in palliative care needs?
    b. Barriers to communication
    c. Importance of listening skills
    d. The process of visiting patients/dos and don'ts in communication with patients

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