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Original Article

Bridging Inequities at End of Life: Community Perspectives on Palliative Care Access in Rural, Coastal, and Low-Income Settings

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Abstract

England's South-west Peninsula is predominantly rural, contains a large number of residents aged 65+, and includes several areas of rural and coastal deprivation. People living in rural and low-income areas often face significant disadvantages at the end of life. Yet, there is a very limited understanding of the specific support needs of rural, coastal, and low-income communities. To identify effective ways of building community support for good dying and grieving, a regional multi-sector research partnership designed and delivered a community engagement initiative. The program aimed to capture people's experiences of seeking help, the topics that mattered most to them, and the forms of community support they found most helpful. This paper reports participants' views on the roles communities can play in end-of-life care. It considers the key lessons from involving communities in open discussions about death and dying. The initiative used a range of community engagement activities, including: the 'Departure Lounge' interactive installation together with four focus groups held with interested people in different local venues; the joint development of a 'Community Conversation' toolkit used by Community Builders to hold discussions with individuals who had direct experience of end-of-life care and with their carers; one focus group involving Community Builders; and a storytelling project conducted with three people who had been bereaved.

Participants particularly appreciated community support during end-of-life situations or bereavement that created meaningful connections, offered impartial peer support, was flexible to personal needs, and assisted them in navigating services. Creative engagement approaches appear promising for enabling researchers and practitioners to gain deeper insight into the needs and priorities of underserved groups. Partnering with established community organizations proved essential for effective involvement, though local contextual factors influenced the number of participants. Local community organizations are ideally positioned to provide support to people at the end of life. The project demonstrated strong potential for collaboration between these organizations and palliative care and bereavement services. Such partnerships could help build local knowledge and capabilities while developing lasting, community-led solutions to address specific regional needs.

Keywords: Coastal, Community engagement, End-of-life, Low-income, Palliative care, Public health

Introduction

The South-west Peninsula (SWP) region of England (Devon, Cornwall, and Somerset) is a mostly rural area featuring a long coastline. Analysis carried out by the National Institute for Health Research (NIHR) Clinical Research Network (CRN) SWP Business Intelligence Unit [1-3] found that, in comparison with other CRN regions across England, the SWP recorded the highest share of people aged 65 years and over in 2018 (24.2%) and the highest national average index of multiple deprivation score among rural villages and dispersed populations (17.7%). The Chief Medical Officer's (CMO) 2021 Annual Report [4] highlighted that coastal areas

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experience the poorest health outcomes in England, marked by reduced life expectancy and a heavier load of illness across multiple conditions, including Coronary Heart Disease and Chronic Obstructive Pulmonary Disease. The report speaks of a persistent 'coastal excess' of disease that continues even after adjusting for age and deprivation. It stresses that coastal communities have been largely neglected for many years, with little research focused on their health and wellbeing. Problems with healthcare access in rural and remote locations become especially severe towards the end of life [5]. Both rural residents and those on lower incomes face inequalities not only in accessing healthcare [6] but also in broader end-of-life experiences (such as social isolation and financial strain) [7, 8]. In addition, these groups are frequently underrepresented in health and medical research, thereby reducing the influence of those bearing the heaviest burden of illness in studies seeking to address such inequalities [9].

Attention to public health strategies in palliative care has risen steadily, in part because involving local communities in caring for those who are dying or grieving offers one potentially lasting solution to the increasing demand for end-of-life support [10], especially for groups facing major structural obstacles to accessing healthcare [11]. Public health or health-promoting models of palliative care differ considerably in both the language they employ and the range of approaches they describe [10]. According to Sallnow and Paul [12], community engagement in end-of-life care can be understood as a collaborative process that helps communities and service providers jointly identify needs, strengthen local capacity, and tackle challenges in ways that enhance people's experience of dying, bereavement, and overall wellbeing. This engagement operates along a continuum, ranging from simply providing information to fully empowering communities, depending on factors such as the extent of local participation and the initiative's underlying goals.

Kellehear [13] proposed the 'compassionate communities' framework, which has achieved worldwide recognition as a public health model for palliative care and has been put into practice locally in various parts of the United Kingdom, including the Compassionate Inverclyde project [14]. In the South West Peninsula (SWP), St Luke's Hospice [15] worked with Plymouth City Council to launch an effort that made the area the first 'Compassionate City' in England. Additional examples of creative work include the activities of Torbay Community Development Trust (TCDT), which uses an Asset-Based Community Development approach to encourage healthy aging across neighborhoods. This project was featured as a case study in the Chief Medical Officer's Coastal Health report [4]. Nevertheless, Grindrod [11] points out that structured frameworks capable of driving policy and practice changes toward a public health model that specifically reaches disadvantaged populations are still at a very early stage. There remains a limited understanding of the particular requirements of rural, coastal, and low-income communities when applying public health principles to palliative care.

In January 2022, the South-west Peninsula Palliative Care Research Partnership (SWPPCRP) was launched to build a strong cross-sector collaboration capable of pinpointing and addressing regional palliative care research priorities. The group placed special emphasis on discovering effective ways to nurture community-based support for good dying and healthy grieving. Supported for 15 months by the NIHR, the partnership united researchers and frontline practitioners from four universities and seven hospices, along with representatives from voluntary organizations and individual community members active in health and social care. To explore the support needs of people living in underserved rural, coastal, and low-income areas at the end of life, SWPPCRP participants conducted a scoping review of published evidence on public health palliative care initiatives that empower communities to support dying individuals and their carers [16]. The partnership also created a community engagement program to investigate the following questions:

- Which concerns matter most to local people when they reflect on death and dying?
- What kinds of information or assistance are residents looking for?
- To what extent do people consider existing local resources and services accessible, practical, and appropriate?
- Which particular challenges and contextual elements connected to rural, coastal, and low-income settings shape individuals' end-of-life experiences?
- In what ways can these insights guide the setting of future research priorities in the region?

Findings focused on people's experiences of obtaining healthcare and support near the end of life, together with information about the partnership's development. The planned next steps are presented in a separate publication [17]. Because the community engagement program was modest in scale and offered only a brief snapshot, no formal evaluation was conducted. However, given the scarcity of published accounts of informal community engagement efforts—especially those conducted in rural and coastal areas—we believed it would be useful to report the lessons we learned from this work. The purpose of this paper is therefore to convey what participants shared about the potential contribution of communities at the end of life, while also reflecting on the process of involving local people in open discussions about dying.

Although academic writing and clinical practice frequently differentiate between 'end-of-life care' (support provided in the final months, weeks, or days of life) and 'palliative care' (earlier intervention following a life-limiting diagnosis), much of the material gathered for this article concerned broader discussions about living with serious illness, approaching death, and bereavement. In these conversations, participants seldom drew clear boundaries between the two concepts. Consequently, we have applied the terms ‘end-of-life care’ or ‘palliative care’ only when the data explicitly referred to a defined service, and have used broader phrases such as ‘support at end of life’ to capture the wider context in which people described their experiences.

Materials and Methods

Our community engagement strategy

We organized a variety of activities over the course of 10 months. The goal was to connect with people who had no current involvement with palliative care services and little awareness of them, as well as those who had personal experience of receiving end-of-life support or dealing with bereavement. Choices about methods were driven by practical constraints, including the tight schedule, very limited staffing (only one researcher available for 1 day each week), the resources we could access [including the Departure Lounge kit], and the chance to leverage pre-existing ties between the research team and local community groups while creating fresh connections through members of the partnership.

Phase I of the program ran from January to August 2022 and emphasized relaxed, open-ended engagement and simple observation. Phase II, from July to October 2022, allowed us to examine emerging topics more thoroughly through focus groups and storytelling.

Phase I

The Departure Lounge

The Departure Lounge is a temporary pop-up display developed by the Academy of Medical Sciences. Its purpose is to spark open dialogue about death and dying through the imagery of an airport departure area. The exhibit includes a variety of visual aids, such as suitcase labels, postcards, and printed towels, that help share information and stimulate discussion. Researcher LH set up this display at multiple sites throughout the region, intentionally selecting a mix of rural, urban, coastal, and inland settings. Locations were proposed by partnership members or people within their networks. LH reached out to potential host organizations to gauge their interest and suitability, then scheduled visits only with those who expressed willingness to host. In total, nine separate visits occurred. Four took place during organized events: a bereavement open day in a cathedral, a Dying Matters Awareness Week session at a health center, a combined neighborhood family fun day on school grounds, and a Public and Patient Involvement (PPI) group meeting (see below). For the other visits, the display remained in place at everyday venues (for instance, community cafés or charity shops) while regular activities continued around it. After every session, LH recorded anonymized field notes that captured the degree and style of interaction with the materials as well as the subjects people chose to discuss.

Community conversations

The Community Conversations aimed to gather thoughtful reflections from individuals with firsthand experience of end-of-life care and their family carers. Extending this activity across the whole peninsula was not realistic, so the work focused on Torbay. This area was selected because TCDT – an active member of the partnership – already had well-established community links there, and because the local authority is ranked as the 48th most deprived district in England (out of 317) [3]. TCDT worked with a familiar local creative production company, Filament, to design a practical tool that could be taken into people’s homes to encourage meaningful conversations. Filament prepared a vintage suitcase packed with everyday objects and straightforward creative tasks intended to prompt discussion. The tasks centred on seven key questions covering topics such as personal identity and self-image, personal encounters with end-of-life care, the network of support surrounding the person, how living locally had shaped their experience, the different kinds of help needed (physical, emotional, spiritual, financial or practical), hopes for others facing similar situations, and the fundamental ingredients required for strong, connected community support at the end of life. People taking part could skip any question they preferred not to answer or talk through their thoughts without using the creative elements.

TCDT maintains a group of Community Builders (CBs) whose main task is to become fully integrated into local neighborhoods, encouraging social bonds, promoting activity, and building mutual assistance. These CBs attended a dedicated training session to test the suitcase resource. An early version was tested with three people and then improved based on their feedback. Following this, six CBs carried out the actual conversations. They used their existing local contacts to identify suitable participants, explained the project’s purpose, and invited them to join. Twenty-six people agreed to take part and provided informed consent. Most sessions lasted 90 to 120 minutes, though one conversation spanned three meetings and totaled 5 hours. The CBs noted participants’ responses in writing during the discussion. These records were later anonymized using pseudonyms and added to a database. LH then created concise summaries for each participant under five consistent headings that matched the main research questions: background context, central issues raised, positive elements, aspects that could be improved, and the core requirements for effective community support at the end of life. Once all conversations had been completed, the six CBs joined a focus group to share their observations on the main themes that had surfaced and reflect on what it had been like to facilitate the sessions. Everyone of the six took part.

Phase II: July–october 2022

Focus groups

Participants for the four focus groups were recruited through convenience sampling. Community organizations already connected to the partnership were contacted and invited to host a focus group. Those who showed interest were contacted again, with deliberate effort made to select venues across varied geographical settings and socio-economic contexts, including one group specifically for carers. The hosting venues were as follows:

- a local support group helping residents on low incomes in a small coastal town
- a care provider based in a small market town that serves the surrounding rural inland communities
- a carers' support organization located in a coastal city
- a community café situated in a low-income neighborhood within a coastal town

Host organizations promoted the sessions under the title 'Dying and Bereavement Focus Groups'. They invited people who had personal experience of, or strong opinions on, receiving care or assistance while living with a life-limiting condition, looking after someone nearing the end of life, obtaining help in rural, coastal, or low-income settings, dealing with financial, housing, or other practical concerns at the end of life, or exploring how local communities might provide better support. Individuals who expressed interest were asked to contact either the host organization or the researcher, after which they received a detailed information sheet. In total, 22 people took part. Informed consent was collected at the start of each session. The duration of the focus groups ranged from 66 to 116 minutes. All discussions were audio-recorded and later fully transcribed.

Storytelling

Filament was asked to collaborate more closely with three individuals who had already joined the Community Conversations. The goal was to develop personal narrative stories describing their experiences of living with or supporting someone with a life-limiting illness. Community Builders identified and approached participants whose accounts they believed would reflect a broad spectrum of end-of-life care experiences. Three people agreed to take part, and their stories were gathered during individual meetings with a professional storyteller. Work on the creative presentation of these stories is continuing.

PPI group

While the SWPPCRP was being established, partner organizations promoted the new partnership and the chance to join a Public and Patient Involvement (PPI) group among members of the public they already knew. The main purpose of this group was to bring the direct perspectives of people who had used palliative care services into the Steering Group's discussions, planning processes, and decision-making. Eight people expressed interest and were invited to an introductory meeting to learn more about the partnership and explore what the group might do. Six individuals attended this first meeting and went on to take part regularly (five from different hospices and one from a community organization). Every member had personal experience of caring for a relative at the end of life. To acknowledge the time they contributed to partnership activities, PPI members received payment of £25 per hour. They were invited to attend all Steering Group meetings (held online) and decided to organize additional in-person meetings. PPI members played an active role in designing the community engagement events, assisted in facilitating the workshop outlined below, and delivered a training session to share their insights with the wider partnership on the most important issues faced by people seeking support at the end of life.

Sense-checking workshop

In October 2022, the partnership organized a 'sense-checking' workshop. This event presented the main findings from the community engagement activities together with key points from the earlier scoping review. Invitations were extended to Steering Group members and to other organizations that had shown interest in the partnership's activities. Twenty-seven people attended in total: 11 staff members from 5 hospices, 5 PPI representatives, 7 academics from 4 universities, 2 representatives from community organizations, and 2 individuals from end-of-life charities. Those present reviewed the findings and discussed priorities for future research and improvements in service provision.

Analysis

All field notes gathered from the Departure Lounge visits, written records of the Community Conversations, notes from the PPI meeting and the sense-checking workshop, along with the complete transcripts of the focus groups, were systematically coded using Lumivero's NVivo 11 Software. The analytical process combined a deductive framework guided by the core research questions and the focus group discussion guides with an inductive approach that allowed fresh codes to arise naturally from the material itself. Given the strong alignment between the codes on community support emerging from direct community input (focus group transcripts and Community

Conversation records) and those identified in the reflective field notes, a unified structure of main themes and sub-themes was developed. Reflections on the engagement process are therefore integrated with the primary data findings in the sections that follow.

What did we learn about the role of communities in supporting dying and grieving well?

Participants described a wide range of personal circumstances and varying degrees of available support, yet several consistent patterns surfaced regarding the elements they found most helpful. These same patterns also appeared in the feedback gathered throughout our engagement activities. Insights about the engagement process have therefore been interwoven with the data findings presented here. The following section specifically explores how the creative resources we introduced supported open dialogue and identifies both enablers and obstacles to participation.

Connection

Building relationships with others helped ease feelings of loneliness, and this effect was especially noticeable among family carers and those who had experienced bereavement. During the focus groups and Community Conversations, some individuals spoke of feeling reassured or comforted when they could share their situation with people facing similar challenges; they referred to carers' groups or other local community gatherings. Others emphasized the importance of joining ordinary neighborhood activities. The advantages of social interaction — particularly in environments where it felt safe and normal to talk openly about illness, dying, and loss — were also reflected in how some people responded to joining the engagement activities. Several Community Builders noted that the conversations had been beneficial for those taking part. One CB remarked in the focus group:

"I sometimes find it quite healing for the person because it gives them an opportunity. For example, one woman told me, 'You know what? This is the first time in a long while that I've actually talked about it, so it seemed to do her a lot of good."

[CB Focus Group]

The research activities themselves appeared to open up valuable opportunities for meaningful social connection. In every focus group, participants mentioned that the sessions had provided a much-needed chance to discuss dying and bereavement — an opportunity they rarely found elsewhere in their lives. Comments included:

"It has really helped me personally — I can't speak for the others here — but I'll leave feeling much lighter, because I don't usually talk about this with anyone outside my family; I simply don't have the time."

"I've been treading so carefully because I had no idea what to do or say […] But I really needed someone to talk to. I didn't want to burden [name] since I knew what she was dealing with, and I couldn't think of anywhere else to turn."

"This is the first time I've come to something like this, and already I feel as if a huge burden has been taken off my shoulders."

[Participants from 3 Focus Groups]

Peer support and feeling accepted

The opportunity to share feelings openly without worrying about being judged stood out as another vital part of effective community support. Several carers, for instance, spoke about the strong sense of relief that came from discussing their frustrations and sense of guilt with others facing the same difficulties:

R1 It hits me that I'm not alone in this. That's the big thing — it's not only me. 'Oh my God, she actually gets it!'
R2 Nobody else is going through this by themselves!
R1 That's right.
R2, saying how I feel doesn't make me a terrible person.
[Focus Group 4]

In the two focus groups in low-income neighborhoods, attendees described locally run community groups — staffed or supported by people from the same area — as environments free of judgment. Because of this, they felt much more comfortable reaching out for help there than turning to bigger institutions or formal professional services:

R1 This place gives us room to talk about what we've been through without feeling criticized. That's exactly how it feels to me.
R2 Anything you say here comes across as ordinary, if that makes any sense.
R1 No one has to act cheerful or pretend to be someone they're not, or do specific things to belong, or have extra money. All those typical obstacles stay outside when you walk in.
[Focus Group 3]

One group shared their views on a nearby care charity that seemed mainly focused on residents who could afford to give donations. Even though the charity offered options for those unable to pay, many in the group believed people on limited incomes often felt out of place and were reluctant to ask for assistance because they sensed they did not belong — 'you don't feel like you fit in'. They contrasted this with their own model of reciprocal peer support and developing skills among community members. Beyond helping people become more resilient, some felt the assistance exchanged within the group had a different and often richer quality than professional help, largely because the voluntary nature of the relationship created a stronger sense of equality.

Similarly, other participants mentioned support services or charities that had failed to help them because the people involved did not share comparable life experiences or backgrounds:

"But I tried [bereavement charity], and an older volunteer came round. There was no real connection at all. I couldn't relate to her, and she couldn't understand how I had lost my partner. So it wasn't any use, and I had to go all the way to [city] before I found a group where, as soon as I stepped inside, I knew the people there truly understood what I was dealing with."

[Focus Group 2]

Responding to individual needs

Support proved more effective when groups or organizations adapted to the specific needs and concerns of the person rather than sticking to a fixed, organization-driven routine. One individual, for example, appreciated the assistance from a local carers' group because it provided flexible help that people could accept or turn down as they wished, allowed time for genuine listening without intrusion, and focused on hearing rather than trying to solve everything.

Community groups working in low-income areas stressed that offering adaptable, personalized assistance — often delivered in person — was essential for reaching individuals who struggled to ask for help or felt discouraged by the bureaucratic systems of larger bodies. One volunteer drew a comparison with her own group's everyday drop-in sessions, where anyone could arrive for a free coffee and conversation, and volunteers would address whatever issues came up:

"So then you're looking at making an appointment that you might not be ready for in seven to ten working days, filling out paperwork, and meeting certain requirements. Here we have no requirements for whoever walks through the door — you don't need to check any boxes to match what we provide."

[Focus Group 3]

In a different focus group, another attendee explained how this kind of relaxed style made getting help much easier:

"Yes, and [name] and [name], who were here earlier, always step in to help with filling out forms. I find paperwork really difficult […]. They suggest doing it online, but I can't manage that because I only have an iPad, and the systems often don't work well on it. It's so much better to talk face-to-face. You walk in, have a cup of tea, coffee, juice, or whatever, and nobody pushes you to speak if you don't want to."

[Focus Group 1]

During a focus group in a rural setting, a community worker emphasized the need to recognize why some individuals hesitate to seek assistance. Drawing from her own observations, she noted that people who had negative past experiences with services often found it especially hard to ask for support when bereaved. The group explored the drawbacks of applying a uniform 'one size fits all' model to community help and highlighted the value of providing several different routes for people to connect:

"So it's not like ordering a delivery or getting a leaflet through the letterbox. It needs many different layers within the community and people's personal networks. That way, if one option doesn't work for someone, another might catch them, so the whole system stays much more adaptable."

[Focus Group 2]

Independence

In addition to the role community groups play in building connections for individuals who may be unaware of or uneasy about approaching formal services, participants highlighted that voluntary sector organizations often act as advocates when people struggle to obtain the help they require. Many described having to 'battle' to secure suitable healthcare, care services, or welfare benefits while supporting a family member with a life-limiting illness. Some volunteers and staff within the voluntary and community sector believed they were well placed to advocate in these circumstances. Their position outside statutory services allowed them to challenge organizations that were failing to meet a person's needs.

Others spoke about the benefit of discussing their emotions and experiences with individuals beyond their close family or usual social circle. This tendency to seek emotional support outside the family was frequently driven by a desire to shield loved ones from further distress or by disagreements or strained relationships within the family. Many were reluctant to feel they were 'burdening' friends or work colleagues by seeking emotional support from them.

Emotional impact of providing informal support

Volunteer and paid community workers who joined the focus groups openly acknowledged that supporting people at the end of life or during bereavement could sometimes feel emotionally draining. At times, this stemmed from worries that they might not offer the right kind of help or that adequate support might not be available:

"I think one of the hardest parts of being involved in these communities is that we put so much energy into holding everyone else together that we can start to fall apart ourselves behind the scenes. We're constantly questioning whether we're doing enough or handling things the right way."

[Focus Group 1]

Community workers recognized that offering this kind of support brought both rewards and difficulties. One worker explained how her own experiences had inspired her to organize a grief café, yet she still found the work demanding:

"It's an amazing thing to be involved in. But I find it really tough. The last few weeks have been hard because of my own grief, and I've caught myself wondering why I'm doing this twice a year. Then I come back to moments like this and remember how valuable it is. It genuinely helps turn people's grief around."

[Focus Group 2]

This mixed feeling was also evident in the reflections of the Community Builders (CBs). Several described the experience of talking with people about death as an 'honor' and noted that it had been a valuable learning process that enriched their own practice:

"Going through that process alongside them has actually helped me, too, in thinking about death. I asked [name], 'Have you ever seen someone pass away?' She replied, 'Oh yes, loads of times.' [Laughter] […] It makes you realize that this really is just the natural cycle of life […]. So it's made me reflect on my own views and what might be missing from them."

[CB Focus Group]

The CBs recognized that while the conversations had generally been a positive experience, they could also be upsetting and emotionally tiring:

"Because of what I went through myself last year, there was a moment in the middle of one conversation where I almost broke down in tears and had to pull myself together. It came out of nowhere — just something she said that I strongly related to […]. So I have found it quite challenging at times […]. But overall it was still really worthwhile."

[CB Focus Group]

The CBs noted that taking part in the partnership project had allowed them to build new skills, gain experience, and feel more confident when discussing dying and bereavement. However, the tight schedule set by the research project proved unhelpful, as it led some CBs to conduct as many as eight conversations in a short period, increasing the pressure they felt.

The group also agreed that collaborating on the project had been beneficial. They appreciated learning together and having the chance to debrief after the conversations. All felt that anyone undertaking similar community work — whether practitioners or volunteers — would need access to supervision or peer support to protect their own wellbeing and make the role sustainable:

"They would need someone to check in with them afterward. If there were a volunteer coordinator, it would help to have a person at the end who could ask, 'How did that go? Are you okay? How are you feeling?' Because we've had each other to lean on […], so I think being able to reflect with someone at the end of the day would be really valuable."

[CB Focus Group]

What did we learn about engaging underserved populations in end-of-life conversations?

Using creative tools

The community conversations suitcase

TCDT originally planned for the Conversations to be delivered by both Community Builders (CBs) and any existing volunteers who wanted to join the training. The training was offered to 15 CBs and 4 volunteers. In the end, six CBs participated while no volunteers chose to take part. Those who declined cited reasons such as lack of available time, discomfort with the topic, belief that the people they worked with would not want to participate, or reluctance to recruit participants themselves.

In general, the CBs found recruiting participants quite challenging. Only 26 conversations took place, falling short of the original target of 40 that the CBs had considered realistic. All conversations were conducted with individuals with whom the CBs already had an established relationship. Because of their close involvement in local neighborhoods, the CBs were familiar with people's personal situations, could judge whether the activity would be suitable, and often carefully weighed whether to extend an invitation (for example, considering how much time had passed since a bereavement). The CBs noted that the short three-month timeframe partly caused recruitment difficulties. They were also conscious of other potential participants who might have been approached successfully in later months.

During their focus group, the CBs reflected on the design of the Conversation tool. They agreed that the suitcases helped open discussions about dying and bereavement, a subject they felt could otherwise be hard to introduce. They observed that the creative tasks served as effective prompts that encouraged deeper reflection by "putting ideas into people's minds and encouraging them to consider specific topics." Some participants appreciated having a physical object to hold or an activity to occupy their hands (such as knot-tying) while discussing difficult matters. Playful items like Lego could "lighten the atmosphere" during conversations and sometimes brought humor, which helped create a stronger connection:

"When I began taking the objects out, I said something like 'Just bear with me for a moment, this will start to make sense soon.' [Laughter] We're not actually building anything here. And they looked a bit puzzled at first, like 'What is this all about?' It definitely shifted the mood in a good way."

[CB Focus Group]

The CBs believed the suitcases worked best when used by experienced facilitators who could read the participant's reactions to the different tasks and adjust them accordingly so the person remained comfortable:

"Everything inside is quite useful, but when you're someone who regularly talks with all kinds of people […], you can adapt it on the spot. You get a sense of what's working […], and if something isn't helping in that particular conversation, you can set most of it aside […], rather than treating it as a fixed list where every single item has to be used."

[CB Focus Group]

One CB felt the activities would be more valuable when speaking with people she did not already know, but could seem unnecessary or even distracting with those she had an existing relationship with:

"Most of the people I spoke with I already knew, and they would have been perfectly happy to just chat with me directly […]. They didn't really need any of the props. In fact, a few of them joked, 'Come on, what's all this about?' Sometimes I would respond by saying 'There might not be an object for this, but look around your room — is there something that reminds you of…?' […]. On the whole, though, I found it more of a distraction."

[CB Focus Group]

Most of the CBs particularly appreciated the final activity, where participants planted sunflowers and selected five 'essential elements' for good end-of-life care. They valued how it allowed them to summarise the discussion and confirm they had understood correctly, while also leaving the participant with a positive gift that symbolized life and growth. Many participants seemed eager to contribute to change by clearly stating what had helped them and what could have been improved. For some, the sunflower also became a natural reason for continued contact with the CB:

"The nicest part, as you mentioned, was the sunflower at the end. They've all come back to me saying, 'Oh, my sunflower is growing well,' [laughter] which is really lovely. So you're giving them something tangible — which was the intention — but the fact that it was something living and growing felt like a thoughtful touch, and I think people really appreciated it."

[CB Focus Group]

Although the suitcase itself was chosen partly because opening and closing it could symbolically contain the conversation safely, the CBs found this aspect less relevant. The Community Builders (CBs) felt that their relational skills were what truly enabled them to discuss with sensitivity and care. The CBs were mindful that they were inviting people to talk about an emotional subject that could bring up feelings of grief, so they made sure to close each session thoughtfully:

"Toward the end, after we had finished with everything in the case, I would also ask something like 'So what are your plans for this evening? Do you have anything lined up?' I tried to check that they had people around them or something to do, so they wouldn't be left sitting alone thinking about everything."

[CB Focus Group]

The CBs considered it essential to follow up each conversation with a phone call a few days later to see how the participant was doing.

Overall, the CBs described using the suitcase as a worthwhile experience and felt the discussions it generated provided valuable material for the research. Some noted that having an official "mandate" to talk about dying and bereavement gave them both permission and confidence to raise what is often seen as a delicate subject, along with practical tools to support those conversations.

The 'Departure Lounge' installation

The exhibit stands out for its large size and vibrant colors, which often catch people's eyes in busy public areas. However, the extent of actual interaction varied considerably by setting (see below). Because the display used an airport 'Departure Lounge' concept, most visitors did not instantly recognize its true topic when they first came closer. This element of surprise encouraged curiosity and created natural opportunities for conversation. Reactions to the theme itself were varied: some found it light-hearted or engaging, while a small minority found it insensitive or in poor taste. These mixed views were also expressed in the PPI group, where certain members appreciated the idea. Still, others felt the wording could seem blunt or upsetting, especially for anyone who had lost a loved one recently.

In practice, the resource worked best as an initial prompt to begin conversations. In some instances, visitors picked up leaflets and asked questions, allowing the display to serve an informational purpose. No one participated in the interactive components, such as filling out a postcard with personal experiences or wishes, although a few people took the postcards home. The tool also proved useful for uncovering specific support needs across different environments (for example, people asked for advice on helping bereaved children or on managing legal matters such as wills or power of attorney with limited funds). Such inquiries could then be addressed through more personalized follow-up support. Representatives from several organizations (including a hospital chaplaincy team and a community association) noted that a similar resource would be valuable for initiating discussions about death and dying in their own settings.

Facilitators and barriers to engagement

Place and context

People interacted more readily with the Departure Lounge in relaxed, everyday settings they already knew well, such as community cafés, where casual conversation is common. Engagement dropped noticeably in places like charity shops or the health center, where visitors had a clear, specific reason for being there. When choosing venues, it is therefore essential to consider who typically uses the space and what they expect to do while there.

Given that a public activity focused openly on dying is uncommon, some individuals questioned whether the display had a religious or commercial purpose (for instance, promoting funeral services or a particular faith). This impression could be strengthened by the choice of location, such as a church hall or shopping center. It is therefore equally important to think about how the setting might shape people's assumptions about the exhibit's intentions. The associations linked to a particular venue or group were also explored in one focus group, where a community worker described how opinions of a grief café changed when different people took over the running of it:

"Having us take charge has actually made a positive difference, because when the church was running it, some people stayed away. They assumed there would be a strong religious element, and we've managed to remove that, which has been helpful."
[Focus Group 2]

Relationships

In every engagement activity we carried out, success depended heavily on collaboration with individuals and community groups who already had deep, long-standing connections within local neighborhoods and who served as trusted intermediaries. In the Departure Lounge, the session with the highest participation was held at a small community café. The researcher had met with the café's staff and volunteers beforehand to explain the project in detail. The community workers knew which residents had recently experienced bereavement or were living with life-limiting conditions and thought they might welcome the chance to talk. They promoted the event in advance through personal networks and social media and actively invited people to attend. The community worker stayed throughout the session and personally introduced the researcher to residents, which helped create a comfortable atmosphere where people felt safe sharing their experiences with both the researcher and one another. Some visitors came specifically hoping to find information.

Recruitment for the focus groups was also managed through organizations with established community ties. Three of the groups achieved higher attendance (six or seven participants each), while the fourth had three. In two of these groups, most attendees already knew one another because they belonged to established community groups, and in the third, they were all part of a well-known carers' network. This pattern indicates that familiarity with the group and confidence in the hosting organization played a significant role in encouraging people to take part. Pre-existing relationships were similarly crucial when recruiting participants for the Community Conversations.

Motivating factors for individual engagement

Those who chose to get involved with activities such as the Departure Lounge often explained that a personal connection — for example, having cared for someone with a life-limiting illness or having gone through a bereavement — made them feel it was worthwhile to discuss the subject of dying. Some were currently facing related challenges and saw the activity as a useful opportunity to gather information or discuss their own circumstances. Another frequent reason was personal concern about future care arrangements, either for themselves or for family members such as elderly parents.

Some people decided against engaging with the Departure Lounge and walked away as soon as they realized the topic. They explained that they did not need or wish to talk about death. While individual attitudes clearly played a major part, there were also signs that local and cultural backgrounds could influence responses. For instance, in the community café, a newly formed bereavement support group had held its first meeting only the day before the Departure Lounge visit, which had already sparked more open conversations among regular visitors about dying and loss. In contrast, at a lively community fun day involving many local organizations, a representative from a local Chinese Community Association showed interest in adopting the display for use within her own group. She felt the subject was often treated as taboo in her community and wanted to help encourage more open dialogue.

Possible barriers to engagement

While stronger participation at some Departure Lounge sessions could clearly be traced to pre-existing relationships, the reasons for reduced involvement at other sites can only be cautiously inferred from what was observed. For example, at the Dying Matters event in a health center, the limited space was largely occupied by service providers operating stalls. This setup made it awkward for ordinary visitors to start private conversations and may have felt intimidating or overwhelming when trying to explore the available information.

Language issues surfaced as a possible obstacle at multiple events. One community worker noted that using the phrase ‘palliative care’ on a flyer tended to put off people who did not understand the term. On several occasions during focus groups and Departure Lounge sessions, attendees noted that the word ‘hospice’ is commonly interpreted as ‘the place where you go to die’, instead of an organization that offers information and assistance to those living with life-limiting conditions.

During the CBs’ focus group, one Community Builder recounted how a participant had shared her positive experience of the Conversation at a local coffee morning. The CB knew that several people at the gathering had gone through bereavement and hoped this might inspire others to join. Instead, the subject elicited uncomfortable responses from several former carers. The CBs concluded that some viewed the coffee morning as a place to ‘escape’ from painful memories, making any talk of end-of-life matters feel unwelcome:

R1 ‘It was simply a coffee morning, yet quite a few attendees had lost loved ones and dealt with end-of-life situations.’
R2: But they try to put all that behind them.
R1: Exactly.
R2: The purpose of that group seems to be moving on and leaving those experiences aside, but she introduced the topic, and it just didn’t belong there.
R1: No, they come to enjoy themselves, share laughs, and spend time with friends.
[CB Focus Group]

This incident further illustrates how the unwritten social rules and overall atmosphere of a group or setting heavily influence whether people feel comfortable addressing subjects connected to dying and bereavement.

Limitations

The central goal of our engagement program was to identify which issues related to dying and bereavement matter most to people in rural, coastal, and low-income communities, to guide future research priorities. These observations, therefore, stem from direct fieldwork and group reflection rather than a formal assessment of various engagement methods.

With the limited resources at our disposal, covering the full expanse of the South-west Peninsula was not realistic. We therefore deliberately selected participants from targeted locations (coastal zones, rural inland areas, small towns, and cities) where established community networks were already present. Time and funding constraints also prevented us from reaching residents in the most remote rural areas, where existing community infrastructure is limited. Future studies should prioritize these areas, especially those that are especially isolated, and allow adequate time to develop trusted relationships that can support genuine involvement.

Although the Community Conversations were intentionally focused on the Torbay area — enabling CBs to draw on their long-established local connections with individuals and organizations for recruitment — we recognize that the resulting group was more likely to include people who already had social links in their neighborhoods, and may therefore have overlooked the most isolated residents.

The storytelling component required an extension beyond the original schedule due to difficulties in finding participants and the importance of allowing a natural, iterative co-creation process at a pace that suited those involved. This experience highlights the importance of building plenty of flexibility into timelines when planning sensitive engagement activities with people who may be navigating difficult personal situations, such as bereavement.

Key learning points and ideas for building community capacity

Valuing and supporting existing community assets

Conversations and direct observations revealed that numerous community ‘assets’ — while helping people in day-to-day life — also play a significant role in supporting individuals through dying and bereavement. Examples included community cafés and wellbeing hubs, churches and faith-based groups, and less obvious sources such as libraries. At one event, a library staff member mentioned that their ‘Better with a book’ sessions regularly attract people who have experienced bereavement. She suggested this may be because the sessions offer a low-pressure space to connect with others without the explicit focus on grief support. This observation aligns with earlier research indicating that robust community connections are a crucial element of end-of-life care for both patients and their caregivers in rural settings [8].

The findings point to the value of complementing specialist services — such as dedicated bereavement groups and grief cafés — with opportunities for existing community groups and volunteers already rooted in local neighborhoods to strengthen their knowledge and abilities. Strengthening the capacity of these community groups and volunteers would enable them to provide thoughtful support to people nearing the end of life and their carers. The experiences reported by the CBs reinforce this model: giving those already active in the community access to training and practical resources appears to boost their confidence in raising conversations about dying and bereavement while deepening their insight into individual needs.

Engaging underserved communities in research

As noted earlier, participation levels rose markedly — especially in low-income neighborhoods — when the researcher first invested time in speaking directly with local community workers and volunteers about the project. These early discussions enabled the researcher to benefit from their insights on appropriate timing and suitable venues, while also securing their active assistance with recruitment and the consent process. Discussions with these experienced workers shaped data collection in other practical ways as well. For instance, focus groups were deliberately kept informal, so participants could arrive or leave at any point during the session, and a familiar person was always on hand to assist with information sheets and consent forms. The value of collecting additional demographic details was carefully weighed against the risk of creating excessive paperwork or making people feel questioned, so only essential data was gathered. This lighter approach seemed to work well in boosting involvement: both recruitment for focus groups and interaction with the Departure Lounge were noticeably stronger in locations where the researcher had built these relationships with community workers in advance.

Potential for partnership

In their report on ‘Accessing quality care in rural areas’, Marie Curie [18] highlights an innovative model used in rural Scotland. There, community nurses collaborate closely with stakeholders, including care homes and statutory services — including transport planners — to create more flexible and responsive support. Our own findings strongly endorse this kind of collaborative working and emphasize the added value of involving local, neighborhood-based groups in such partnerships, particularly to reach communities that are often overlooked.

At the same time, it is essential to recognize that not every community worker will feel ready or willing to engage with subjects such as dying or bereavement. A worker’s willingness to engage with these topics may depend on their personal beliefs and life experiences. Even those who are willing can face challenges, whether due to limited knowledge of specialist services they could refer people to or because of the emotional weight of the work. Organizations specializing in palliative and bereavement care, therefore, play an important role in strengthening local capacity for end-of-life support. Such support could involve providing training for community workers and volunteers on how to talk about dying and grief, arranging ongoing supervision or peer support groups, or creating straightforward pathways to specialist advice and resources.

Co-creating sustainable and local solutions

Several groups put forward practical ideas for local initiatives that could strengthen community capacity to tackle the issues they had raised. In one group, carers proposed setting up a free advice clinic where people could receive help with claiming disability benefits or arranging power of attorney. Another group highlighted widespread misunderstandings about the role of their local hospice, which many saw simply as ‘the place you go to die’ rather than a source of information and support for people with life-limiting illnesses. They suggested that regular visits by hospice volunteers to grassroots community organizations could help close this perceived gap. While some of these ideas may involve modest resource implications and could be difficult for small community groups to implement on their own, they sparked useful discussions about realistic future projects that could be taken forward within the wider partnership.

An Australian study of rural palliative care services observed that the strongest service models often depended on ‘ad hoc and informal relationships’ [19]. It noted that while such complex informal networks are a common feature of rural healthcare, there remains a need to integrate them with standardized guidelines for routine care. Although integrating guidelines is clearly vital for improving clinical quality, it may also be worth recognizing the significant potential of these informal networks to build broader community capacity to support people at the end of life. Similarly, a UK study examining urban and rural differences in access to palliative care recommended that end-of-life policies take account of variations in settlement types, including rurality [20]. Findings from both our engagement activities and the scoping review [16] suggest that efforts to strengthen community support should focus on developing tailored, locally responsive solutions.

In their discussion of community engagement in end-of-life care, Sallnow and Paul [12] distinguish between community engagement (where professionals mainly share knowledge or raise awareness) and community development (which aims to bring about genuine change at both individual and collective levels). A systematic review by D'Eer *et al*. [21] of civic engagement initiatives in palliative care found that projects not initiated by or deeply involving local communities were less sustainable. Our program included a range of engagement approaches, but those developed in close partnership with embedded community workers are most likely to have a lasting impact. The CBs themselves expressed interest in further developing their skills in addressing end-of-life and bereavement needs, having seen through the research how much value this could bring to their everyday work. As a direct result, the umbrella organization supporting them — TCDT — has established a new collaboration with a cancer charity to explore community support needs in greater depth.

Leonard *et al*. [22] emphasize that death education within community development should focus more on 'creating sustainable collaborations' than on traditional didactic methods of simply informing or consulting people. Their work on death literacy portrays it as a kind of 'practice wisdom', in which carers, for example, actively participate in a critical learning process to acquire the knowledge and skills required for their role, then share that knowledge through their own support networks. On a modest scale, our PPI group illustrated this process. As experts by experience, they drew on their personal insights to inform and educate partnership members about community needs from their unique perspective. The partnership's funding provided the necessary infrastructure to foster connections among community partners, academics, and clinical expertise. While this support has been extremely valuable in achieving the partnership's goals, it also raises important questions about how such community engagement can be sustainably funded and resourced as part of ongoing service development and research.

Conclusion

Perhaps the most important takeaway from our engagement program is that anyone seeking to advance a public health approach to palliative care must carefully consider how to create opportunities for organizations with specialist palliative and bereavement expertise to connect with existing community groups with a broader community development focus. The aim should be to foster a shared understanding of each other's strengths and roles, and to collaborate effectively to increase local capacity to support the dying and the bereaved. Rather than searching for a single universal model, the most promising path lies in creating multiple layers of support that respond to specific local needs and service gaps, while building on the community's existing assets. This approach can offer several different points of access and deliberately target groups — such as those in rural and coastal areas — that conventional healthcare models frequently underserve.

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All Community Conversation, focus group, and storytelling participants provided written consent before participating in this study. The consent form explicitly outlined that participants' anonymized verbatim quotes may be used in academic publications.

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