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How community palliative rehabilitation is delivered in the United Kingdom: a multiple case study

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Abstract

Background: Community palliative rehabilitation is an important part of palliative care.

Little is known about how this is delivered in practice.

Aim: To understand how community palliative rehabilitation is organised and delivered within different models of care in the United Kingdom (UK).

Methods: A contrasting mixed methods case study compared two separate models of community palliative rehabilitation in the UK: a specialist palliative care service (an independently funded hospice which relies on charitable donations), and a generalist community rehabilitation service delivered by the government-funded National Health Service (NHS). Data collection included: qualitative interviews with people with a life-limiting condition, caregivers, physiotherapists, occupational therapists, multidisciplinary therapy assistants, managers and commissioners (n=34); survey of therapy staff (n=46); routine service use data (n= 2966 service users); and documentary analysis of internal policy documents (n=14). Data were analysed within each case using reflexive thematic analysis and triangulation, followed by across case analysis.

Results: Therapists at both sites shared a commitment to holistic, person-centred rehabilitation, but delivery of this varied. Resources were limited in each site but clinicians in the specialist palliative care site described being able to spend time with service-users developing relationships and understanding what mattered to them, whereas clinicians at the NHS site reported a lack of time to do this due to waiting list and capacity pressures. Engagement between generalist and specialist teams in a 'layered model' where people with a life-limiting condition access different levels of care based on clinical need was limited, contributing to therapist-reported gaps in confidence and the need for training in palliative rehabilitation. Integration was improved through co-location of different services at both sites. However, the inability

to access shared records limited communication between different services at the specialist palliative care site. Access to palliative community rehabilitation appeared to be good, although early referral into the service appeared to be difficult. Formal education for people with a life-limiting condition and informal caregivers was largely absent. Differences between the two sites were driven by each service's organisational and funding context: charitable funding of hospices enabled a more flexible, proactive model at the specialist site, while NHS workforce and target pressures constrained time-dependent processes such as holistic assessment and training.

Conclusions: Enabling earlier referral, strengthening specialist-generalist integration, and improving information for people with a life-limiting condition and informal caregivers may help services better realise their shared aims of holistic, person-centred care.

Introduction

Palliative rehabilitation enables people with life-limiting illness to optimise their independence, function and wellbeing (1). Rehabilitation has an important role throughout the palliative care pathway rather than only at the end of life. Palliative rehabilitation can be delivered in inpatient settings such as hospitals and hospices, or in the community in outpatient settings or in a person’s home. Care provided in the latter settings of outpatient or home is called community palliative rehabilitation. Despite the World Health Organisation recognising the importance of palliative rehabilitation (2), the evidence base on community palliative rehabilitation is limited (3). These services can be complex in their design and vary considerably in how they

are organised, staffed and delivered (4). There is little evidence about which models of care – or features of models- may influence the quality or delivery of care.

A realist review by the authors developed a programme theory proposing how community palliative rehabilitation should work (3). The review identified five aspects of care that the evidence base suggests could improve outcomes in community palliative rehabilitation such as functional improvement, psychological wellbeing, and service efficiency. These aspects were: a layered model of care (where generalist therapists see a majority of people with a life-limiting condition but there is integration with specialist palliative care for more complex cases); straightforward and timely access to rehabilitation; integration and coordination of care between rehabilitation services, primary and community care, and specialist palliative care; holistic person-centred assessment; and education/information for both people with a life-limiting condition and their informal caregivers. These five aspects of care offer a useful framework for exploring how palliative community rehabilitation is delivered in practice in different contexts. The aim of this study was to understand how these aspects of community palliative rehabilitation are delivered within different models of care.

Methods

Methodology and study design

Case study methodology is well suited to exploring complex healthcare services because it allows researchers to examine how and why interventions work within their real-world settings (5,6). By drawing on multiple sources of evidence and considering the influence of context, case studies can generate a rich understanding of service

delivery (5). Using contrasting case studies enables similarities and differences between service models to be explored, as well as the reasons for any differences (5). A contrasting case study design was used here, with two models of rehabilitation purposefully selected as cases (7). Yin's approach to case studies was followed for this study (5).

Ethical approval

Ethical approval was obtained from the North of Scotland Research Ethics Committee (IRAS: 352035; REC reference: 25/NS/0019) on 9th April 2025.

Conceptual framework

In preparation for this primary research study, the authors conducted a realist review of the literature to identify aspects of community palliative rehabilitation that could improve outcomes (3). Five aspects of care were identified (see Figure XX), and these were used to structure the data collection and later parts of the analysis.

Case selection

A survey of models of community palliative rehabilitation in the UK previously published by the authors (4) indicated that specialist palliative care providers (also known as independently funded hospices) and palliative care providers within the government funded NHS described very different provision of community palliative rehabilitation. The survey findings were used to create a sampling frame for case selection. Details of the sampling decisions are documented in Supplementary Materials. In brief, the aim was to identify (1) an independent hospice with a community palliative rehabilitation

service and (2) an NHS community rehabilitation service, both of which were in England or Wales and covered both urban and rural areas.

Positionality

The lead researcher (JM) is an experienced community physiotherapist with a specialist interest in palliative rehabilitation. Her clinical background and commitment to improving community rehabilitation services led to this research. To enhance reflexivity, JM maintained a reflexive diary throughout data collection, documenting assumptions, decisions, and potential influences on the research process. Reflexive discussions were held regularly with the wider research team to challenge interpretations and minimise the impact of preconceptions arising from her clinical and personal experience.

Data collection

Data were collected between July 2025 and March 2026, with data collection in one case (the specialist palliative care provider) followed by data collection in the second case (the NHS provider). In each case data collection was partly sequential and partly concurrent: four components comprising an initial survey followed by two qualitative and one quantitative component collected concurrently. Methods were (1) a survey of therapy staff providing community palliative rehabilitation; (2) qualitative interviews with people with a life-limiting condition, informal caregivers, therapists (occupational therapists, physiotherapists, and multidisciplinary therapy assistants), service managers, commissioners and referrers into the service; (3) routinely collected data;

and (4) documentary analysis of relevant documents such as local guidelines, standard operating procedures, job descriptions, and service feedback.

Survey

The aims of the questionnaire was to identify the types of services provided within community palliative rehabilitation, the number and duration of rehabilitation sessions, and therapists' confidence in communicating with and delivering rehabilitation to people with a life-limiting condition. The questionnaire was sent to the site principal investigator who then identified and sent it electronically to all therapists providing community palliative rehabilitation within the case study. It was sent four weeks prior to the lead author accessing the site, with one reminder at two weeks. This was extended by two weeks for the NHS site with an extra reminder sent due to the low response rate.

Routine data about service use

The aim of the aggregated routine data analysis was to describe service users and outcomes. Each site primary investigator was asked to provide routinely collected data extracted from their electronic patient record system. These data included primary diagnosis, number of visits by the therapist, performance status, and other outcomes if available for the period 1st January 2025 – 31st December 2025.

Qualitative interviews

The aim of the qualitative interviews was to gain insight into how the model of care was understood, experienced, and enacted by different interest holders. Participants were recruited via purposive sampling.

Participants were given the choice of in-person, online, or telephone interviews at a time and place to suit themselves. Prior to interviews commencing, written consent was obtained from all participants taking part in face-to-face interviews and audio consent was obtained from participants completing interviews virtually. Each interview was recorded using an encrypted device. Topic guides were developed based on the aspects of care that could improve outcomes derived from the realist review described earlier, and the findings from a nationwide survey of models of community palliative rehabilitation (4). Supplementary materials has an example topic guide. Interviews lasted an average of 40 minutes, ranging between 14 and 82 minutes. Interviews were transcribed verbatim. All participants were given pseudonyms, and no identifiable data was included on the transcripts. For further details on interview recruitment see supplementary materials.

Document Analysis

The aims of the document analysis were twofold: first, to enhance the lead researchers' understanding of the model of care delivered, through sources such as service maps, local guidelines, and standard operating procedures; and second, to complement qualitative interview data by examining compliments and complaints about the service. Therapists and service managers were invited to provide any documents they considered useful in enriching the understanding of the delivery of community palliative rehabilitation.

Data Analysis

Quantitative Data

Questionnaire responses were uploaded to Excel prior to the initial site visit. Descriptive statistics were calculated and issues identified for exploration in the interviews. The aggregated routine data were uploaded to an Excel spreadsheet and analysed using descriptive statistics at the end of the qualitative data collection.

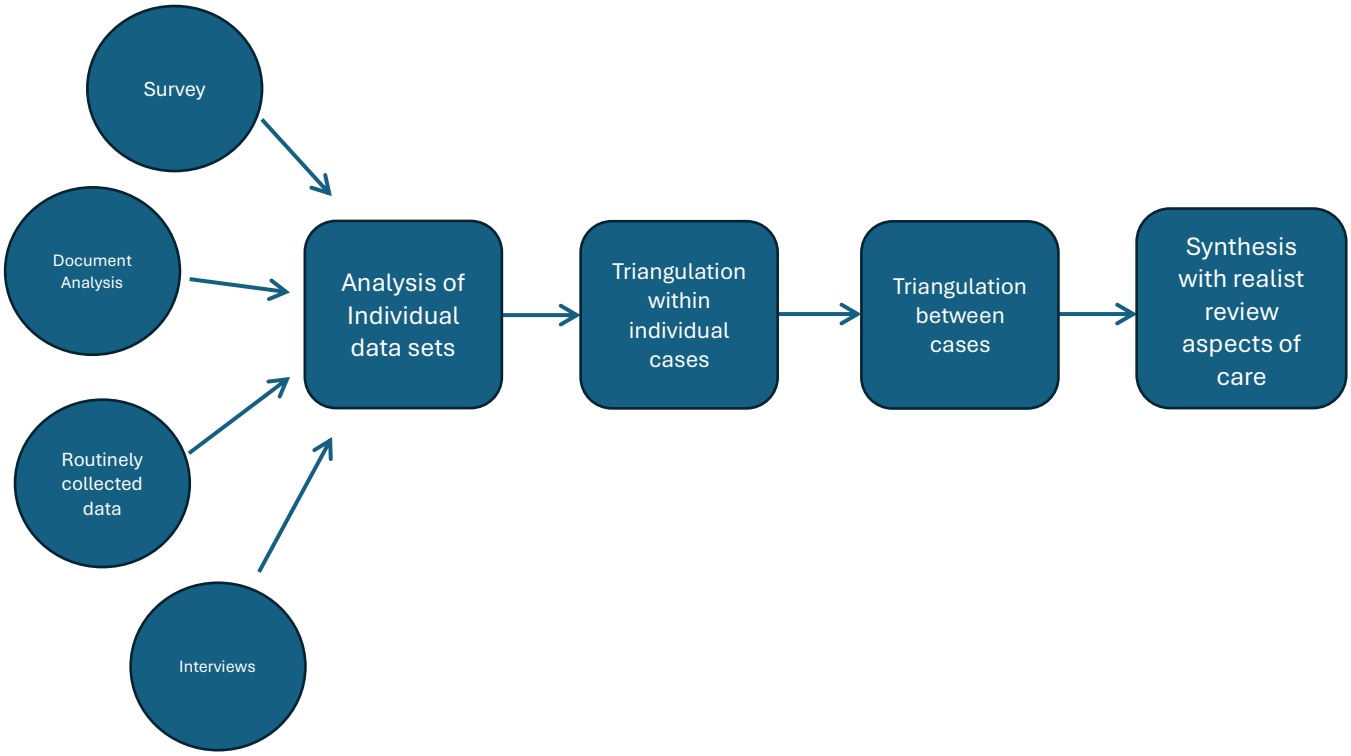
Qualitative Data

Qualitative interviews from each case study site were analysed using the six steps of reflexive thematic analysis (8). See Supplementary materials for details. In brief, an inductive approach to generating initial codes was used to ensure no important issues were missed. When themes were identified, their relationship with the five aspects of care from the realist review was considered. They fitted this framework well and the themes were named in line with these aspects of care. To further strengthen the analysis, service-user and caregiver transcripts were independently reviewed by a patient representative (JG), providing a patient perspective on the data. For the documentary analysis, documents were read and relevant content was extracted onto an excel spreadsheet.

Synthesising findings within and across cases

In line with Yin's (5) emphasis on triangulation as a central action in case study data analysis, each dataset was initially analysed independently within its respective case. Triangulation protocol was used to integrate findings within each case (9,10). Following completion of the within-case analyses, a cross-case comparison was undertaken to identify areas of convergence, complementarity, discrepancy, and absence (silence) across the cases (10). Finally, the findings were considered in relation to the realist review five aspects of care (3). An overview of the data collection and analysis sequencing is presented in Figure 1. The triangulation protocol can be viewed in supplementary materials. The lead author discussed data and insights with the wider team throughout this process.

Chapter 6, figure 1 Data collection and analysis within and across case studies



Results

Characteristics of the cases and participants

The specialist palliative care site was situated in the Southwest of England and had a mixed urban and rural population (see chapter 6, table 1). They employed several specialist palliative care physiotherapists and occupational therapists within their rehabilitation team and only saw people with a life-limiting condition. The NHS site was situated in the North of England. It covered a large city but also serviced a large rural population. The site did not employ any specialist palliative care therapists and saw people with a variety of functional problems, not just those associated with a life-limiting condition.

Chapter 6, table 1 Case study site characteristics

Case study site	Location	Population size	Population density	Number of specialist physiotherapists	Number of Specialist Occupational Therapists	Patient population	Rehabilitation delivery models	Types of data included
Specialist palliative care	South West England	500,000-750,000	Mixed urban and rural	3 FTE	1.2 FTE	Solely people with a life-limiting condition	Home-based rehabilitation, 1:1 visits off site (e.g. day centre), 1:1 on hospice site, telerehab (virtual or telephone)	15 interviews with 17 participants, 16 survey responses, Routinely collected data from 652 patients, 7 internal documents

NHS	North of England	750,000-1,000,000	Mixed urban and rural	0 FTE	0 FTE	Mixed patient population including palliative care	Home-based rehabilitation, 1:1 off site (e.g. day centre), telerehab (virtual or telephone)	14 interviews with 17 participants 30 survey responses. Routinely collected data from 2314 patients, 7 internal documents

Twenty-nine semi-structured interviews were conducted with 34 participants (See chapter 6, tables 2 and 3). Most interviewees with a life limiting condition in the NHS site had a Parkinson's diagnosis whereas the specialist palliative care site had more participants with a diagnosis of cancer. This fits with the cohorts of patients reported by the different services in the national survey described earlier (4). Most therapists interviewed were female and there was a range of job roles and length of experience in palliative care at both sites.

Chapter 6, table 2 Characteristics of people with life-limiting condition and caregivers

Characteristic	People with a life-limiting condition (n=9)		Caregivers (n=5)	
	Specialist palliative care	NHS	Specialist palliative care	NHS
Sex				
- Female	2	1	1	2
- Male	2	4	0	1
Primary diagnosis (people with a life-limiting condition)				
- Cancer	3	2		

- Parkinson's - Pulmonary Fibrosis	0 1	3 0		

Chapter 6, table 3 characteristics of clinicians

Characteristic	Clinicians (n=20)	
	Specialist palliative care	NHS
Sex		
- Female	10	8
- Male	2	0
Profession		
- Physiotherapist	3	3
- Occupational Therapist	2	1
- Multidisciplinary Therapy Assistant	3	0
- Nurse/Matron	2	2
- Service Manager	1	1
- Commissioner of Service	1	1
Years of experience in current role		
- 6 months-1 year	1	0
- 1-3 years	4	3
- 3-5 years	2	2
- 5-10 years	1	3
- 10-20 years	2	0
- Over 20 years	2	0
Years of experience in palliative care		
- 6 months-1 year	0	0
- 1-3 years	2	2
- 3-5 years	0	1
- 5-10 years	2	2
- 10-20 years	4	1
- Over 20 years	4	2

Overview of themes

Therapists at both sites shared a commitment to holistic, person-centred rehabilitation, but delivery of this varied according to context. This is explored first through the theme Holistic Assessment, which describes how clinicians at the

specialist palliative care site described being able to spend time with people with a life-limiting condition, developing relationships and understanding what mattered to them, whereas clinicians at the NHS site reported a lack of time to do this due to waiting list and capacity pressures. The Layered Model theme then considers how integration between generalist and specialist teams, which intended to allow people with a life-limiting condition to access different levels of care based on clinical need, was limited in both cases. This contributed to therapist-reported gaps in confidence and a need for training in palliative rehabilitation. The theme Joined Up Working builds on this, showing how co-location of different services and shared electronic records shaped communication and co-ordinated care between teams. The theme Timely Access addresses referral pathways: access to palliative community rehabilitation was described as good, although early referral into the service was described as difficult in both cases. The theme Education and Information for Service-users and Caregivers describes how formal education was largely absent in both cases, although people with a life-limiting condition valued peer learning in the specialist case. Finally, consideration is given to why there were differences between the two cases. This appeared to be due to organisational conditions rather than the values of individual clinicians.

Holistic Assessment: Offering people time, access to services and opportunities for social connection to deliver holistic and person-centred care

Holistic assessments and care were valued by therapists in both services but appeared to be performed differently in practice. Clinicians within the specialist palliative care site routinely described working around “what matters to you” and tailoring

interventions to individual goals for people with life-limiting conditions. In contrast, NHS therapists often described pressures associated with workload, waiting lists and service targets, which appeared to limit opportunities for holistic assessment. Several explanations for this were evident from the triangulated data. First, therapists in the specialist palliative care site perceived that they had greater opportunity to spend time with people with a life-limiting condition, facilitating exploration of personal goals and concerns. Second, the specialist palliative care service therapists described close links with psychosocial and supportive services, potentially enabling more comprehensive responses to a person's needs. Third, people with life-limiting conditions attending the specialist palliative care service reported non-clinical benefits associated with group sessions (weekly sessions where people with a palliative condition would come together at the specialist palliative care site for group exercise, socialisation, craft activities, and individual clinical support). Having the opportunity for social interaction appeared to provide psychological and social benefits alongside rehabilitation outcomes. Such benefits were not described by service users and carers in the predominantly domiciliary NHS model.

> *I think we do a great job as to what we do and I think we listen and we don't rush people so I would go to someone and I wouldn't be in a rush to disappear, you know, I try to offer them as much time as possible for them to offload and discuss what they're going through at the time and create solutions, really. (C003-* therapist, specialist palliative care site)

> *And I enjoyed it at the end of the day, and it released, I suppose, a lot of other tensions that were there in my head. (*P003- Person with a life-limiting condition,

specialist palliative care site taking about the group sessions at the specialist palliative care site)

Layered model: limited inter-team engagement and disparities in training and confidence

The realist review indicated that a layered model of care - in which support workers and volunteers see the majority of people with a life-limiting condition, generalist therapists manage those requiring physiotherapy or occupational therapy input, and specialist palliative care therapists focus on people with complex, condition-related needs - may improve outcomes for this population. The review further suggested that such a model could provide a supportive and educational framework for generalist therapists. However, clinicians at both sites described limited engagement between generalist and specialist therapy teams. At the NHS/generalist site, therapists reported uncertainty around the scope of practice and referral criteria for the specialist palliative care team. At the specialist palliative care site, therapists noted that although people with a life-limiting condition were discussed between generalist and specialist teams, these discussions tended to centre on which team would take over the care of the person with a life-limiting condition, rather than on collaborative working based on the complexity of their needs.

> *Saying that, I don't actually think I know what their referral criteria is. (...) And I actually don't know if we can refer to them as therapists.* (C016, Therapist, NHS site)

This in turn appeared to have an impact on therapist-reported confidence levels in dealing with people with community palliative rehabilitation needs. Both the survey and

qualitative data indicated greater confidence levels within the specialist palliative care service than the NHS site. At the specialist palliative care site, all therapists (100% n=16) reported always or usually feeling confident discussing death and dying and discussing other palliative care services available to service-users; the majority also reported feeling confident with advance care planning (75% n=12) and providing psychological support (94% n=15). In contrast, at the NHS site, only 28% (n=8) therapists reported always or usually feeling confident discussing death and dying, advance care planning, or giving psychological support, and 24% (n=7) felt confident discussing other available palliative care services. Despite their higher overall confidence, a minority of specialist palliative care therapists (25% n=4) still reported always or usually needing further education or advice to have these conversations.

This contrast in confidence – which reflected an educational gap for therapists - appeared to relate to two factors: routine exposure to palliative conversations and differential access to training. Therapists within the specialist palliative care service described working exclusively or predominantly with palliative populations and had routine exposure to the complex conversations that are often needed, describing this as normalised through repetition. In contrast, some NHS therapists suggested that responsibility for these discussions with people with a life-limiting condition often rested with community nurses, and their limited interaction with the specialist palliative care therapy teams potentially limited opportunities for other members of the team to develop confidence and expertise in having such conversations.

> *remember that this is normal for us to talk about death and dying and pain and all those kinds of things*. C010 (therapist, specialist palliative care site).

> *I suppose where somebody's known to be palliative, they've often already come through the nursing or the matrons as well. And they often I think they've had more training, and they will do more of those conversations. (*C017- therapist, NHS site).

Training opportunities also appeared to differ between sites. At the specialist palliative care site, job descriptions in the document analysis, and therapists in interviews, identified the existence of regular, protected training. At the NHS site, however, a senior leader described training as one of the first things de-prioritised under workload pressures.

> *the reality of it is we're in a business continuity at the moment because we're in winter pressures and we've had to stand down all our training because we're so overwhelmed with referrals. (*C020 senior leader, NHS site).

Joined-Up Working: how co-location and shared records shape communication and co-ordinated care

Clinicians in both services valued integration between different parts of the health and care system. Across both sites, clinicians, including referrers, described the importance of close working relationships and effective communication between health and social care professionals. Clinicians at both sites described how co-location and joint working (including joint meetings and project working) facilitated a coordinated service by improving communication, strengthening professional relationships and improving understanding of each other's roles.

The NHS site described a shared electronic records system which supported communication and reduced duplication. However, at the NHS site, specialist palliative care services were excluded from this record creating uncertainty regarding referral criteria, service boundaries and responsibilities. This was a frustration echoed by the specialist palliative care site, who reported being unable to access communication from and contact other clinicians due to incompatible electronic systems.

> *It's so much easier, isn't it, to just ask someone in the same room rather than having to phone through and try and find the right person and see kind of who you need to deal with, (...) So if you if they're in the same hub as you in the same area as you, then that's really easy just to turn around and talk to them about something that's I suppose a bit more urgent rather than again trying to get through to someone of the phone (*C016- therapist, NHS site).

> *I'm probably even further from the hospice, the more specialist team, because they're a completely different service and I don't really know, I don't know what staff they have really. I know they have therapists, but I know even less probably about who their staff are and what their provision is. (*C019- referrer, NHS site).

Timely access: variety of access options but early referral is a challenge

The realist review suggested that flexible, accessible services throughout a person's disease trajectory may lead to improved outcomes for community palliative rehabilitation. Clinicians at both sites, including referrers into services, described services as easy to access, with referrals arriving from a wide range of sources. Therapists and managers perceived that caseloads were broadly representative of their

population, although neither collected demographic data to confirm this. The specialist palliative care site was flexible about who they accepted into the service but also wanted to keep some capacity in reserve so they could respond quickly when generalist colleagues needed specialist input — reflecting a tension between inclusivity in access and the need to remain selective enough to protect responsiveness.

Flexible access could include offering virtual as well as in-person contact. People with a life limiting condition and their caregivers at both sites were generally happy to have virtual or hybrid contact, provided it was offered alongside, rather than instead of, in-person options. The small number of NHS service users in the sample tended to be more cautious than their counterparts in the specialist site about these newer approaches, citing practical barriers and a preference for physical presence, particularly when being shown how to use equipment or devices. People with a life limiting condition accessing the specialist palliative care site, by contrast, expressed more acceptance of different formats, provided that the purpose and value of the contact was clear.

> *But it would be more the physical presence which really helped for a time but obviously that's not being possible on a long-term basis because now we are discharged* (CA003- caregiver, NHS site).

> *But if that means, do I do it face to face or do a telephone, do I talk on the VR headset, is it done on a teams meet video call teams meeting, you know, whatever, that's absolutely fine. As long as (...) I can understand the value to me,*

> *and the benefit to me. What? Why am I doing this? What's the plus point? (*P001- person with a life-limiting condition, specialist palliative care site).

Care can be provided by individual therapists or in group sessions. Although both sites delivered individual domiciliary rehabilitation, the specialist palliative care site also delivered group-based rehabilitation from a static hospice site, supported by volunteers which gave therapists the opportunity to see several people in a short space of time. It also allowed people accessing the service the opportunity to be seen by many clinicians in one visit. But the rurality of some service users created its own access barrier, prompting discussion from therapists of the need for satellite locations. Domiciliary rehabilitation supported access for those unable to travel but clinicians at the specialist palliative care site highlighted that this constrained service capacity because they could only see one service-user per visit.

Both services valued proactive, early referrals, but achieving it appeared to be harder for the NHS site, where clinicians described how workforce pressures and waiting lists limited earlier intervention. In contrast, specialist palliative rehabilitation therapists described a stronger proactive ethos around early referral.

> *I think some patients are referred in really early, which is good because we can give them the information that they need at a good time and they can then use those kind of techniques when they need it. (*C008- therapist, specialist palliative care site)

This perception of having early referral into the specialist site was not wholly supported by the routine data which showed that people with a life-limiting condition were

referred to the specialist palliative care site with an average AKPS score (11) of 50–60 (a palliative care functional score; this category describes individuals as requiring assistance) and around 60% classified as in the “unstable” or “deteriorating” phase of illness (12), suggesting referral could still often occur relatively late.

Education and Information for Service-users and Caregivers: little formal provision, but value found in learning from peers

Education and information for service-users and caregivers throughout the palliative care journey was an aspect of community palliative associated with improved outcomes in the realist review. However, across the case studies, people with a life-limiting condition and their caregivers made no reference to receiving education or formal information in any form. Clinicians mentioned giving information about exercises and services in written form but did not discuss any other information or education delivery. The one exception was among individuals who attended group sessions at the specialist palliative care site, who consistently described learning from their peers in this setting.

> *I just felt a different person knowing that there's other people out there. I needed to speak to people who had it because I'd only picked up all the horrible things on Google, which I won't again.* (P002, person with a life-limiting condition, specialist palliative care site).

Why are the models so different?

An organisational driver not identified in the realist review, because it has not been mentioned previously in the palliative rehabilitation literature, appeared to explain why the two cases were so different. Managers and commissioners described different service expectations and performance pressures for each case, which appeared to shape how community palliative rehabilitation was delivered. The specialist palliative care site appeared to operate with more flexibility around person-centred goals, although capacity constraints were still in operation. Senior leaders there suggested that the service's funding source influenced its ability to choose its own drivers. Because the service was funded by charitable donations from service users and their families, it was a priority to meet the needs of that population through holistic assessment, proactive intervention and ongoing support.

> *Because of the difference in funding of Hospices and the NHS, (…) we can choose what services we have and the number of people in those services, and we can choose what a waiting list looks like, and we can choose what our service standards are. That is all part of this, which is why we are able to offer more.* (C012 Senior leader, Specialist palliative care site).

This was supported by the routine data: waiting times at the specialist palliative care site were 1–2 weeks on average (range 0–8 weeks), compared with 3–6 weeks (range 0–102 weeks) at the NHS site. Within the NHS site, by contrast, waiting lists, workforce shortages and performance targets were prominent concerns of the clinicians. These pressures meant that therapists were often trying to reduce waiting times by increasing

the throughput of service-users rather than addressing what matters to the person, even though they valued holistic, person-centred care.

> *I mean, our drivers are very much waiting times and reference costs pretty much. So how much does it cost to see this patient and how many wait weeks are they waiting? So, and we're under pressure every single day for that driver to reduce it and obviously trusts are looked at nationally as to their waiters and scrutinised quite severely. If they have patients waiting for longer than a certain time, so that is the focus. Quality of care is almost lower down on the focus, not for us as therapists. But it's not a key driver we keep.* C017 – Senior leader, NHS site

This contextual issue then seemed to affect the extent to which the five aspects of community palliative rehabilitation associated with improved outcomes were practised in each case.

Discussion

Across both sites, therapists aspired to deliver holistic, person-centred rehabilitation, yet how this was delivered differed considerably by site. While resource constraints affected both settings, clinicians at the specialist palliative care site were able to dedicate time to building relationships with people with a life-limiting condition and understanding their individual priorities, in contrast to the NHS site, where waiting list demands and capacity constraints left clinicians with insufficient time for this. Interaction between generalist and specialist teams within a 'layered model' remained limited in both sites and this was reflected in therapists reporting gaps in their

confidence and a need for further training in palliative rehabilitation. Although co-location of services at both sites strengthened integration, the specialist palliative care site's inability to access shared patient records hindered communication between services. While access to palliative community rehabilitation was generally good, referring people into the service early on did not necessarily occur. Structured education for service-users and informal carers was missing in both sites. These differences did not seem to come down to what clinicians valued as therapists at both sites wanted the same things for their service-users. Instead, they came down to what each service's funding and organisation allowed. In short, the two sites were not distinguished by different values, but by whether their staff had the conditions to act on those values.

Previous research into community palliative rehabilitation has highlighted the importance of integrated multidisciplinary working, early referral, holistic care and workforce capability as mechanisms in improving outcomes for people with life-limiting illness (2,3,13–19). However, the present findings suggest that these mechanisms cannot be considered in isolation. The case studies indicate that organisational factors, including commissioning arrangements, service priorities and workforce capacity, act as contextual conditions that enable (or constrain) the implementation of these mechanisms in practice.

The findings are consistent with growing evidence in the wider palliative care literature showing that community palliative care works best when organisations work closely together and share common goals (20–22). Where services operated separately, staff described uncertainty about referral pathways, service boundaries and professional

responsibilities, which made coordinated care more difficult. Limited integration between specialist and generalist therapy teams also restricted opportunities for shared learning and the exchange of knowledge. This contrasts with examples from other areas of healthcare, where collaboration between services has supported shared learning and more integrated care (23,24)

Providing holistic, person-centred rehabilitation was another clear difference between the two services with therapists at the specialist palliative care site highlighting the importance of psychological support for their people with a life-limiting condition. This adds to the growing evidence that rehabilitation for people with advanced illness is about much more than improving physical ability. It can also help people maintain their wellbeing, social connections and quality of life (25,26).

While there has been no published evidence since the realist review specifically exploring earlier referral, our findings suggest that early referral into rehabilitation may be beneficial. Even at the specialist palliative care site, despite a stronger proactive ethos around access, people with a life-limiting condition were typically referred only once functional decline had already occurred, rather than early enough to preserve independence. This aligns with evidence that functional decline in the final weeks of life is variable (27), and that referral prompted by deterioration rather than offered proactively is associated with shorter periods of rehabilitation support (28) and reduced goal attainment (29). People with a life-limiting condition and their caregivers also did not report receiving much formal information about palliative rehabilitation services which could present a barrier to them seeking timely support if there was deterioration in a person's condition. Together, these findings suggest that earlier referral may

maximise opportunities to maintain function rather than respond to decline, although this will depend on service-users and caregivers having enough information to recognise when support might help. However, achieving earlier referral is unlikely to be addressed through funding models alone. Instead, it may require system-level changes to commissioning priorities, referral criteria and clinicians' triggers for referral, so that rehabilitation is introduced proactively within the palliative pathway rather than as a response to established deterioration.

Strengths & Limitations

This study has several strengths. First, by comparing two different models of community palliative rehabilitation, it was possible to understand not only what rehabilitation looked like in each service, but also why differences existed. Second, including the views of people with a life-limiting illness, caregivers, physiotherapists, occupational therapists, multidisciplinary therapy assistants, referrers into service, service managers and commissioners provided a broad understanding of how rehabilitation was experienced and delivered from different perspectives. Third, having a patient representative analyse the service user and caregiver transcripts contributed to a broader interpretation of the findings and ensured that issues of particular importance to people with a life-limiting condition and caregivers were adequately represented. Finally, using interviews alongside surveys, routine service data and documentary evidence also helped build a more complete picture. There were five limitations. First, the study included two case study sites – both in the UK - so the findings may not reflect every model of community palliative rehabilitation and may not be transferable outside of the UK. However, the services were purposefully chosen

because they represent two contrasting approaches, allowing important differences to be explored in depth. Second, the therapist survey non-response was much higher at the NHS site than in the specialist site. This could create non-response bias where those therapists who did not respond may have held different viewpoints. Third, routine data were also reported differently across the two sites, making it difficult to compare processes and case mix directly. For example, stage of illness was routinely measured at the specialist palliative care site, but this was not measured at the NHS site. Fourth, neither site collected data on protected characteristics making it difficult to understand if the service delivered was representative of the population. Finally, demographic data were not formally collected for people with a life limiting illness who participated in the interviews. The lead researcher is confident that interviews reflected diverse service user background in terms of rurality and socio-economic status. However, all people with a life-limiting condition and their caregivers identified as White British meaning that perspectives from other ethnic backgrounds were not included.

From a positionality perspective, as a practising NHS physiotherapist, JM recognised the resource constraints affecting community palliative rehabilitation services and the frustrations that therapists face in this setting. She also values the physiotherapy profession, which made it difficult at times to report on gaps in service provision when she strongly believes that services are trying their best under difficult circumstances. Regular discussion with the wider team throughout the analysis process helped address this, ensuring that the results presented here reflect the data rather than JM's own professional sympathies.

Implications for policy and practice

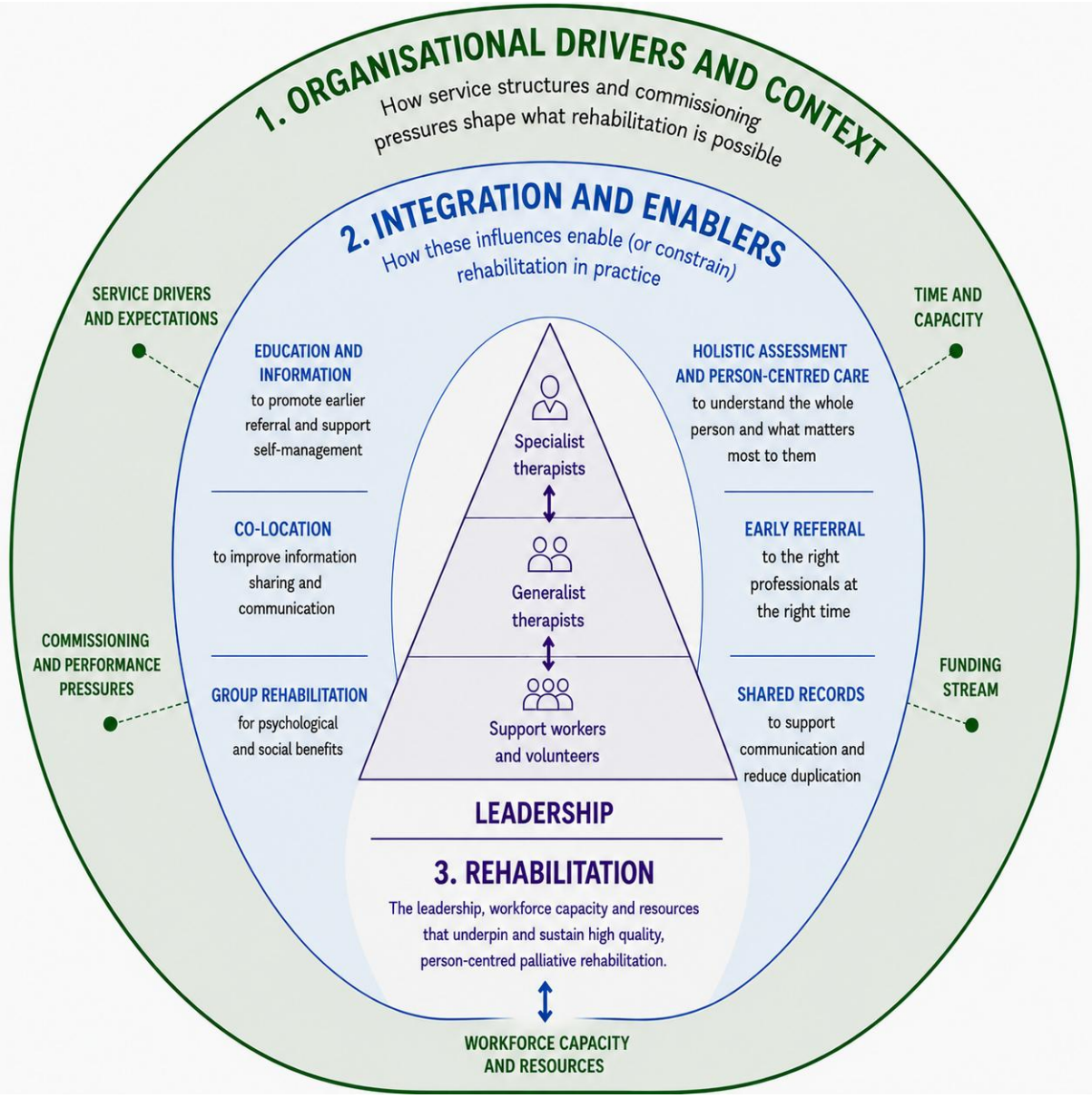
These findings have several implications for healthcare professionals, service managers and commissioners. As championed in the World Health Organisation policy brief (2), rehabilitation should be fully integrated into community palliative care services, with shared referral pathways, regular multidisciplinary meetings and electronic records that can be accessed across organisations. This would help reduce fragmentation and improve communication between teams. Commissioners should also consider measuring success using indicators that reflect the aims of palliative rehabilitation, such as timely access, person-centred care and person-reported outcomes, rather than focusing mainly on activity levels and waiting times. Earlier referral based on a person's need, rather than based on deterioration or prognosis, would allow rehabilitation to become proactive instead of reactive. Finally, continued investment in palliative care training for the rehabilitation workforce, opportunities for joint learning across professions, and access to specialist support would help increase therapists' confidence in providing palliative rehabilitation, particularly within generalist community services. A UK-wide repository of palliative rehabilitation resources for people with a life-limiting condition and their caregivers may also provide easy to access, consistent information.

Implications for the programme theory for community palliative rehabilitation

The model developed in the realist review can be updated based on this primary research (see chapter 6, figure 1). This new model extends the realist review model by suggesting that organisational drivers may represent an important contextual

mechanism underpinning all five aspects of care, helping to explain why there are different models of community palliative rehabilitation services.

Chapter 6, figure 1 Updated programme theory for community palliative rehabilitation



Future research

Future research should explore whether these findings apply to other community palliative rehabilitation services, including those in different parts of the UK and in other

healthcare systems. Studies involving a larger number of services would help determine whether the organisational factors identified in this study consistently influence how rehabilitation is delivered and experienced. Research is also needed to test whether changes such as closer multidisciplinary working, earlier referral to rehabilitation and better information sharing between services improve outcomes in practice.

Conclusion

The findings suggest that successful community palliative rehabilitation depends not only on the commitment of individual therapists but also on the organisational conditions in which care is delivered. Earlier referral, stronger integration between specialist and generalist services, and better access to information and support for people with life-limiting conditions and their caregivers may help services deliver more timely, holistic and person-centred care. Achieving this requires attention to the wider factors shaping service delivery, including workforce capacity, funding and organisational priorities. These findings highlight the importance of addressing both how services work together and the resources and structures needed to support responsive, coordinated rehabilitation.

Declarations

Ethical Approval and Consent to Participate

Ethical approval was obtained from the North of Scotland Research Ethics Committee (IRAS: 352035; REC reference: 25/NS/0019) on 9th April 2025. The study was conducted in accordance with the Declaration of Helsinki and all subjects gave their informed consent for inclusion before they participated in the study.

Consent for publication

Not applicable

Data availability

The datasets generated and analysed during the current study are available on the University of Sheffield data repository (ORDA) https://orda.shef.ac.uk/. Please contact rdm@sheffield.ac.uk for access to this data.

Funding and Conflict of interest

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References

1. Tiberini R, Turner K, Talbot-Rice H. Rehabilitation in palliative care. In: MacLeod R, Van den Block L, editors. Textbook of Palliative Care. Springer; 2019.

2. World Health Organisation. Policy brief on integrating rehabilitation into palliative care services [Internet]. 2023 Mar. Available from: https://www.who.int/europe/publications/i/item/WHO-EURO-2023-5825-45590-68173#:~:text=World%20Health%20Organization%20(%E2%80%8EWHO,systems%20using%20a%20multiprofessional%20workforce.

3. Manson J, Taylor P, Mawson S, Bayly J, Keen C, Gath J, et al. Identifying aspects of physiotherapy and occupational therapy provision in community palliative rehabilitation that could improve outcomes: A realist review. Palliat Med. 2025 Jul;39(7):734–49. doi:10.1177/02692163251331166

4. Manson J, Taylor P, Mawson S, O'Cathain A. What models of community palliative rehabilitation exist for adults in the United Kingdom? – a national cross-sectional survey. BMC Palliat Care. 2026 Mar 13;25(1):100. doi:10.1186/s12904-026-02027-x

5. Yin RK. Case study research and applications: design and methods. Sixth edition. Los Angeles: SAGE; 2018. 319 p.

6. Walshe CE, Caress AL, Chew-Graham C, Todd CJ. Case studies: a research strategy appropriate for palliative care? Palliat Med. 2004 Dec;18(8):677–84. doi:10.1191/0269216304pm962ra PubMed PMID: 15623163.

7. Patton MQ. Qualitative research & evaluation methods: integrating theory and practice. Fourth edition. Los Angeles London New Delhi Singapore Washington DC: SAGE; 2015. 806 p.

8. Braun V, Clarke V. Thematic analysis: a practical guide. London ; Thousand Oaks, California: SAGE; 2022. 338 p.

9. Farmer T, Robinson K, Elliott SJ, Eyles J. Developing and Implementing a Triangulation Protocol for Qualitative Health Research. Qual Health Res. 2006 Mar;16(3):377–94. doi:10.1177/1049732305285708

10. O'Cathain A, Murphy E, Nicholl J. Three techniques for integrating data in mixed methods studies. BMJ. 2010 Sep 17;341:c4587. doi:10.1136/bmj.c4587 PubMed PMID: 20851841.

11. Abernethy AP, Shelby-James T, Fazekas BS, Woods D, Currow DC. The Australia-modified Karnofsky Performance Status (AKPS) scale: a revised scale for contemporary palliative care clinical practice [ISRCTN81117481]. BMC Palliat Care. 2005 Nov 12;4:7. doi:10.1186/1472-684X-4-7 PubMed PMID: 16283937; PubMed Central PMCID: PMC1308820.

12. Mather H, Guo P, Firth AM, Davies JM, Sykes N, Landon A, et al. Phase of Illness in palliative care: Cross-sectional analysis of clinical data from community, hospital and hospice patients [Internet]. 2018 [cited 2026 Aug 4]. Available from: https://journals.sagepub.com/doi/10.1177/0269216317727157

13. Tiberini, R, Richardson H. Rehabilitative palliative care: Enabling people to live fully until they die. Hospice UK; 2015.

14. Carson K, Mcllfatrick S. More than physical function? Exploring physiotherapists' experiences in delivering rehabilitation to patients requiring palliative care in the community setting. J Palliat Care. 2013;29(1):36–44. PubMed PMID: 23614169.

15. Badger S, Macleod R, Honey A. "It's not about treatment, it's how to improve your life": The lived experience of occupational therapy in palliative care. Palliative & Supportive Care. 2016 Jun;14(3):225–31. doi:10.1017/S1478951515000826

16. Welford J, Rafferty R, Short D, Dewhurst F, Greystoke A. Personalised Assessment and Rapid Intervention in Frail Patients With Lung Cancer: The Impact of an Outpatient Occupational Therapy Service. Clinical Lung Cancer. 2023 Jul;24(5):e164–71. doi:10.1016/j.cllc.2023.03.009

17. Phipps K, Cooper J. A service evaluation of a specialist community palliative care occupational therapy service. Progress in Palliative Care. 2014 Dec 1;22(6):347–51. doi:10.1179/1743291X14Y.0000000104

18. Chow JK. How the Utilization of Occupational Therapy in End-Of-Life Care Is Determined [Ph.D.] [Internet]. [United States -- Texas]: Texas Woman's University; 2020 [cited 2023 Nov 28]. Available from: https://www.proquest.com/docview/2647130141/abstract/562F589487F34DF0PQ/1

19. Edmonds P. Poor workforce planning blocks access to palliative care. BMJ. 2025 May 15;389:r979. doi:10.1136/bmj.r979 PubMed PMID: 40374296.

20. Belrhiti Z, Bigdeli M, Lakhal A, Kaoutar D, Zbiri S, Belabbes S. Unravelling collaborative governance dynamics within healthcare networks: a scoping review. Health Policy Plan. 2024 May 1;39(4):412–28. doi:10.1093/heapol/czae005

21. den Herder-van der Eerden M, van Wijngaarden J, Payne S, Preston N, Linge-Dahl L, Radbruch L, et al. Integrated palliative care is about professional networking rather than standardisation of care: A qualitative study with healthcare professionals in 19 integrated palliative care initiatives in five European countries. Palliat Med. 2018 Jun;32(6):1091–102. doi:10.1177/0269216318758194 PubMed PMID: 29436279; PubMed Central PMCID: PMC5967037.

22. Lalani M, Marshall M. Co-location, an enabler for service integration? Lessons from an evaluation of integrated community care teams in East London. Health Soc Care Community. 2022 Feb;30(2):e388–96. doi:10.1111/hsc.13211 PubMed PMID: 33152144; PubMed Central PMCID: PMC9290730.

23. Johansen ML, Ervik B. Teamwork in primary palliative care: general practitioners' and specialised oncology nurses' complementary competencies. BMC Health Serv Res. 2018 Mar 7;18(1):159. doi:10.1186/s12913-018-2955-7 PubMed PMID: 29514681; PubMed Central PMCID: PMC5842567.

24. Gardiner C, Gott M, Ingleton C. Factors supporting good partnership working between generalist and specialist palliative care services: a systematic review. Br J Gen Pract. 2012 May;62(598):e353–62. doi:10.3399/bjgp12X641474 PubMed PMID: 22546595; PubMed Central PMCID: PMC3338057.

25. Montagnini M, Wilson CMM. Editorial: Rehabilitation within the context of palliative care. Front Rehabil Sci. 2024 Sep 18;5. doi:10.3389/fresc.2024.1490057

26. Swarnakar R, Yadav SL. Integration of rehabilitation and palliative care in cancer management: A futuristic model. World J Clin Cases. 2025 Apr 26;13(12):102326. doi:10.12998/wjcc.v13.i12.102326 PubMed PMID: 40291584; PubMed Central PMCID: PMC11718568.

27. Soeda R, Ishikawa A, Oyamada S, Mitsuhashi M, Okano S, Yokosawa A, et al. Trajectories of Activities of Daily Living in the Last Eight Weeks of Life Among Patients With Terminal Cancer in a Palliative Care Unit: A Retrospective Study. Palliat Med Rep. 2024;5(1):63–9. doi:10.1089/pmr.2023.0043 PubMed PMID: 38406210; PubMed Central PMCID: PMC10890944.

28. Ayalew AA, Poudel A, Johnson K, Thepsourinthone J, Heer S, Redwood L, et al. Utilization and Post-Admission Duration of Palliative Care Among General Practitioner–Referred Patients: A Retrospective Cohort Study. Journal of the American Medical Directors Association. 2026 Jun;27(6):106187. doi:10.1016/j.jamda.2026.106187

29. Maddocks M, Fettes L, Takemura N, Bayly J, Talbot-Rice H, Turner K, et al. Functional goals and outcomes of rehabilitation within palliative care: a multicentre prospective cohort study. BMC Palliat Care. 2025 Jul 1;24(1):172. doi:10.1186/s12904-025-01816-0 PubMed PMID: 40597966; PubMed Central PMCID: PMC12210815.

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