# Palliative and Supportive Care

# cambridge.org/pax

# **Original Article**

Cite this article: Burke S, Hopkins N, Divine A, Ebenso B, Allsop M (2023). Physical activity service provision in hospice care: A national mixed-methods study. *Palliative and Supportive Care*. https://doi.org/10.1017/S1478951523000822

Received: 22 January 2023 Revised: 31 March 2023 Accepted: 03 June 2023

#### **Keywords:**

Hospice care; Physical activity; Mixed methods; Quality of life; Symptom management; Barriers and facilitators

**Corresponding author:** Shaunna Burke; Email: S.Burke@leeds.ac.uk

# Physical activity service provision in hospice care: A national mixed-methods study

Shaunna Burke, PH.D.<sup>1</sup> D, Natalie Hopkins, M.SC.<sup>1</sup>, Alison Divine, PH.D.<sup>1</sup>, Bassey Ebenso, PH.D.<sup>2</sup> and Matthew Allsop, PH.D.<sup>2</sup>

<sup>1</sup>School of Biomedical Sciences, Faculty of Biological Sciences, University of Leeds, Leeds, UK and <sup>2</sup>Leeds Institute of Health Sciences, School of Medicine, Faculty of Medicine and Health, University of Leeds, Leeds, UK

#### **Abstract**

**Background.** Physical activity (PA) interventions help people with advanced incurable diseases to manage symptoms and improve their quality of life. However, little is known about the extent to which PA is currently delivered in hospice care in England.

**Objectives.** To determine the extent of and intervention features of PA service provision in hospice care in England alongside barriers and facilitators to their delivery.

**Methods.** An embedded mixed-methods design using (1) a nationwide online survey of 70 adult hospices in England and (2) focus groups and individual interviews with health professionals from 18 hospices. Analysis of the data involved applying descriptive statistics to the numeric items and thematic analysis to the open-ended questions. Quantitative and qualitative data were collected and analyzed separately.

**Results.** The majority of responding hospices (n = 47/70, 67%) promoted PA in routine care. Sessions were most often delivered by a physiotherapist (n = 40/47, 85%) using a personalized approach (n = 41/47, 87%) and included resistance/thera bands, Tai Chi/Chi Qong, circuit exercises, and yoga. The following qualitative findings were revealed: (1) variation among hospices in their capacity to deliver PA, (2) a desire to embed a hospice culture of PA, and (3) a need for an organizational commitment to PA service provision.

**Significance of results.** While many hospices in England deliver PA, there is considerable variation in its delivery across sites. Funding and policy action may be needed to support hospices to initiate or scale up services and address inequity in access to high-quality interventions.

#### Introduction

Physical activity (PA) can be defined as any voluntary bodily movement, produced by skeletal muscles, which results in energy expenditure (Caspersen et al. 1985). Based on the current evidence, adults should be encouraged to engage in regular PA (i.e., at least 150 minutes of moderate-intensity or 75 minutes of vigorous-intensity aerobic activity, with muscle strengthening on 2 or more days per week) (World Health Organization (WHO) 2020) and be advised to live as actively as possible, as any amount of activity is better than none at all. Recommendations also extend to people with advanced, progressive diseases. Studies show that PA is an important palliative rehabilitative strategy that can alleviate distressing symptoms (e.g., fatigue, shortness of breath) and improve quality of life (Kosmadakis et al. 2012; Vira et al. 2021). However, few adults with advanced, progressive diseases in England are active (Elshahat et al. 2021). Barriers to engagement arise not only from personal factors (e.g., low motivation, poor mobility) but also the social (e.g., lack of support from family and friends) and physical environment (e.g., limited access to interventions) in which people with advanced progressive disease inhabit (Burke et al. 2020). Finding solutions to support people who experience multiple complex barriers to PA engagement should be a key priority for palliative and hospice care services.

Hospices, which are a leading setting in which specialist palliative care is provided, can play a vital role in promoting PA. Evidence suggests that care settings (e.g., primary and secondary care) and health professionals (e.g., general practitioners, nurses, physiotherapists) who work within them have considerable influence on patients' health behavior and are well-positioned to promote PA (Cunningham and O'Sullivan 2021; Hassett et al. 2022). However, promoting PA in the health sector is often varied and dependent on multiple key enablers such as funding and available expertise (Albert et al. 2020). For the most part, care pathways have not formally embedded PA, with ad hoc and often limited provision within health service delivery (Bayly et al. 2022; Burke et al. 2020). Despite the increasing recognition of PA as an important palliative rehabilitative strategy for people living with advanced diseases, there is a dearth of evidence on the provision of PA in hospices in England. We address

© The Author(s), 2023. Published by Cambridge University Press. This is an Open Access article, distributed under the terms of the Creative Commons Attribution licence (http://creativecommons.org/licenses/by/4.0), which permits unrestricted re-use, distribution and reproduction, provided the original article is properly cited.





this gap in the literature through this study, which sought to investigate the extent of and intervention features of PA in hospice care in England alongside barriers and facilitators to their delivery.

#### **Methods**

# Research design

This study used an embedded approach (Creswell and Plano 2011; Green 2007), which can be defined as a mixed-methods design where one type of data (e.g., interview data) plays a supporting role in a study predominately based on the other data type (e.g., survey data). This approach included an online survey, to enable the collection of numerical data and free-text responses from a large group of respondents, alongside focus group discussions and individual interviews to provide a more nuanced exploration of perspectives on PA service delivery from a subgroup of survey respondents. The survey was the dominant method and was supported by the qualitative data. The quantitative and qualitative data were collected and analyzed simultaneously but separately (from July 2021 to January 2022), and then integrated to give insight into current PA service provision in hospice care in England. Mixed methods offer distinct yet complimentary data and provide a more comprehensive understanding than either data collection method alone can offer (Johnson et al. 2007). Ethical approval for this study was gained from the Faculty of Medicine and Health at the University of Leeds (MREC 20-052).

### **Quantitative methods**

#### Survey content

An anonymous online survey was developed by SB and BE specifically for this study using Online Surveys (formerly Bristol Online Surveys; BOS) platform (JISC 2020). The survey used adaptive questioning and contained 69 questions that were grouped into 3 main areas (see Table 1). The survey also included free-text responses asking participants to elaborate briefly on yes or no responses. The survey was piloted by 3 palliative care health providers (physiotherapists, based in 3 hospices) targeted by the survey, who reviewed items and provided minor suggestions on changes to questions to ensure they were easy to understand and

could be completed in less than 15 minutes. At the end of the survey, all participants were asked to provide their email address if they were willing to take part in a follow-up focus group. Before responding to the survey items, participants viewed an information sheet and indicated their informed consent.

#### Survey recruitment

An email was sent to the chief executive of adult hospices (n = 147)in England. The research team used a contact list of hospices held by the Academic Unit of Palliative Care, at the University of Leeds, which was developed through earlier national survey studies (Allsop et al. 2018; Birtwistle et al. 2022; Neoh et al. 2019). The list was developed to yield an even geographical spread of responses. We sought to recruit sites that were not National Health Service (NHS) hospices as these can be in hospital settings, often starting as hospital palliative care wards or units. Instead, we recruited across sites that reflect the most common hospice model that are independent organizations typically receiving a proportion of government funding supplemented by charity fundraising. The email sent to hospices contained detailed study instructions and a hyperlink to the online survey. The chief executive of each hospice was asked to identify 1 staff member who had oversight of PA provision or rehabilitative care (if PA was not delivered as part of hospice care) and share the email and link to the online survey (which was voluntary to fill in). A reminder email followed 3 and 6 weeks later and was sent to hospices who had not already completed the survey. We aimed to collect 1 response per hospice.

#### Survey analysis

Data were downloaded from Onlinesurveys<sup>\*</sup> into IBM SPSS software (version 26, IBM Corp, Armonk, New York) for analysis. Categorical responses were summarized using frequencies and percentages. Responses entered into text boxes were analyzed, using thematic analysis, to identify categories. All questionnaires were analyzed including those that were incomplete.

# **Qualitative methods**

#### Focus group and individual interview content

The focus groups (n = 4) and interviews (n = 3) followed a semistructured format and included questions (see Table 1) that were

Table 1. Survey and focus group and interview themes and example questions

Question themes	Example survey questions	Example focus group and interview questions
Frequency of PA promotion	Do you promote PA to service users in your hospice? How often (e.g., daily, 2-3 times per week) do you deliver PA sessions to service users in your hospice? Are there opportunities for service users at your hospice to engage in PA (e.g., Tai Chi/yoga sessions, circuit classes)?	Can you describe the extent to which you promote PA to service users in your hospice?
Delivery and features of interventions	Who (e.g., physio, occupational therapist) typically promotes PA to your service users? What mode (e.g., group-based, individual) of PA delivery do you tend to use? What types of PA do you offer at your hospice?	How do you promote PA to service users in your hospice? Can you explain who is responsible for the delivery of PA in your hospice?
Barriers and facil- itators to service provision	What factors (e.g., limited mobility, pain) tend to discourage/prevent service users from participating in PA in your hospice? Why (e.g., lack of trained staff, lack of time) do you think PA is not available to service users in your hospice? What is needed (e.g., access, support) to help your service users engage in PA?	What barriers prevent service users from engaging in PA in your hospice? What factors would help to support you to deliver PA in your hospice?

designed to elicit a nuanced exploration of participants' perspectives (n=19) on PA service provision in 18 hospices. The first author (SB) developed the interview guide based on the main areas targeted in the survey.

#### Focus group and individual interview recruitment

An email was sent to survey participants who had previously indicated their willingness to take part in an online (recorded using Zoom) focus group discussion or individual interview (i.e., convenience sampling). The email included detailed information (e.g., the purpose and duration of the focus groups and individual interviews). A time was scheduled with those participants who replied to the email and continued to express interest in taking part in the study. Three participants requested an individual interview and this was arranged. At the beginning of each focus group and interview, participants affirmed their consent to participate. A female PhD student (NH) conducted the focus groups and interviews alongside a senior member of the research team (SB or MA).

#### Focus group and interview analysis

The focus groups and interviews were transcribed by the first, second, and fifth authors and initially analyzed by 2 researchers (SB and NH), using Braun and Clarke's deductive thematic framework approach (Braun and Clarke 2006). Analysis was guided by the main thematic areas targeted in the survey. After reading each transcript, descriptive codes were generated and any segment of text coded multiple times was grouped and identified as a potential subtheme. A framework was developed to provide structure to the data in the form of codes, subthemes, and themes. The data were then moved from the transcript and placed in the framework (i.e., charting). For example, a desire to embed a hospice culture of PA was commonly reported and participants offered examples of how they believed this could be achieved. Data from the transcripts related to this theme were organized into 2 main codes: (1) creating an enabling environment for PA to occur and (2) adopting a joined-up multidisciplinary approach to PA provision. Next, the transcripts were re-examined to be certain no data were missed. A collaborative process that involved working with critical friends occurred (Smith and McGannon 2018) whereby alternative explanations for findings that were generated were suggested and discussed with the research team. A thick description of each theme was developed with supporting quotations selected from the original transcripts to build a complex, holistic picture. The research team ensured that data were collected to the point when no new information was discovered in the analysis (Fusch and Ness 2015).

# Integration of quantitative and qualitative data

Integration of quantitative and qualitative data occurred on multiple levels. First, integration occurred at the study design level by using an embedded approach. Second, it occurred at a methods level by (a) linking the 2 databases through sampling (i.e., focus group and interview participants were selected from the population of survey respondents); (b) collecting qualitative data using parallel questions to survey questions; and (c) merging data whereby analysis involved side-by-side comparisons so qualitative findings (i.e., themes, subthemes) were compared to the survey results. This explored the alignment of quantitatively assessed measures of participants' PA practices with their perceptions by adding context to survey results. Third, a contiguous approach to integration was used whereby study findings were presented within a single manuscript, but the survey and focus group and interview findings are reported in different sections. Integration provides study rigor

by significantly enhancing the value of mixed-methods research (Fetters et al. 2013). Reporting is aligned with the CHERRIES checklist for survey reporting (Eysenbach 2004) and COREQ for the focus groups and interviews (Tong et al. 2007).

#### Results

Quantitative and qualitative results are presented separately. The qualitative themes support and provide context for the survey results.

#### Survey results

#### Participant and hospice characteristics

In total, 147 hospices in England were approached for this study. From this, 70 (47.62%) completed the online survey. Respondents included physiotherapists (n=42/70; 60%), occupational therapists (n=15/70; 21.4%), nurses (n=8/70; 11.4%), directors or heads of hospices services (n=2; 2.9%), health-care/therapy assistants (n=2/70; 2.9%), and a consultant (n=1/70; 1.4%). Participants were from 70 hospices representing all 9 regions of England (Table 2).

#### PA service provision

The majority of responding hospices (n = 47/70; 67%) promoted PA as part of routine care. Among these 47 hospices, PA was delivered to outpatients (n = 39/47; 83%), inpatients (n = 38/47; 80%), and community-based patients (n = 29/47; 62%) using a range of modalities including resistance/thera bands, Tai Chi/Chi Qong, circuit exercises, and yoga (Table 3). PA was typically delivered in a seated position (n = 43/47; 61%), or by standing (n = 26/47; 37%), with only a few hospices offering interventions while laying down (n = 7/47; 10%). Sessions were most often

**Table 2.** Demographics of respondents (n = 70)

Profession	N (%)		
Physiotherapist	42 (60.0)		
Occupational therapist	15 (	15 (21.4)	
Nurse	8 (:	11.4)	
Consultant	1 (	1.4)	
Director or head of services	2 (	2.9)	
Health-care or therapy assistant	2 (	2.9)	
Location	Physical activit	Physical activity service provision	
	Yes	No	
North West	9	3	
Yorkshire	5	3	
East Midlands	5	1	
West Midlands	3	1	
South East	11	1	
South West	3	6	
East of England	4	1	
London	4	2	

**Note**: For location 2 missing responses (n = 68)

Table 3. Types of physical activity provision

Types of physical activity	N <sup>a</sup> (%)
Tai Chi/Chi Qong	26 (55.3)
Yoga	18 (38.3)
Circuit exercises	22 (47.0)
Pilates	3 (6.4)
Dance	2 (4.3)
Resistance/thera bands	27 (57.4)
Other	26 (55.3)
Gym (treadmills/bikes/free weights)	8 (30.8)
Seated movements	11 (42.3)
Balance, strength, falls prevention	4 (15.4)
Individual prescriptions/plans	4 (15.4)
Mobility	2 (7.7)
Walking outdoors	5 (19.2)
Aquatic	1 (3.9)
Virtual classes	2 (7.7)

**Note:**  $({}^{a}N = 47)$ , other (n = 26).

Table 4. Physical activity provision frequency and mode

Frequency of physical activity sessions delivered	Na (%)	
Daily	16 (34.0)	
Once weekly	13 (27.7)	
2 to 3× weekly	12 (25.5)	
>3× weekly	6 (12.8)	
Mode of physical activity delivery		
Supervised group-based exercise delivered in hospice	34 (72.3)	
Supervised individually tailed exercise delivered in the hospice	41 (87.2)	
Unsupervised home-based exercise	30 (63.8)	
Physical activity in the home environment delivered using technology	27 (57.4)	

Note:  $^{a}N = 47$ .

delivered by a physiotherapist (n=40/47;85%) and included individually tailored exercises delivered in the hospice (n=41/47;87%), supervised group-based exercises (n=34/47;72%), unsupervised home programs (n=30/47;64%), and home programs delivered using technology (n=27/47;57%; Table 4). Service provision varied by region (Fig. 1), with more hospices in the South East (n=11/47;16%) delivering PA as part of their care service.

Among those hospices (n=47) where PA is promoted as part of routine care, the main barriers that participants reported as discouraging or preventing service users from engaging in PA were low motivation (n=41/47; 87%), pain/discomfort (n=37/47; 79%), poor functional mobility (n=25/47; 53%), low confidence (n=19/47; 40%), and fear of falling (n=9/47; 19%). The majority of respondents (n=29/47; 61%) from these hospices indicated that the most important benefit for service users was an increase in

general well-being and quality of life. Table 5 presents a summary of the perceived benefits and barriers to PA participation.

Most respondents (n=45/47; 96%) who worked at hospices where PA was promoted as part of routine care indicated that their PA service provision changed because of COVID-19, with 2 (n=2/47; 4%) indicating there was no change. The most frequently reported change to services was a switch of delivery from in-person hospice-based sessions to online sessions accessed by patients in their home environment (n=35/47; 75%). Other changes included the promotion of self-initiated home-based (15/47, 32%) and suspension of all services (n=9/47, 19%), with 1 hospice adding PA service delivery during the pandemic.

# A lack of PA service provision

A third of participants (n=23/70; 33%) indicated that there was no PA provision in their hospice. The majority of these participants (n=15/23; 65%) reported 2 or more barriers to promoting PA including lack of trained staff (n=14/23; 61%), lack of time (n=10/23; 43%), lack of policy and/or guidelines (n=10/23; 43%), concerns around the safety of service users (n=6/23; 26%), lack of demand from service users (n=4/23; 17%), and lack of funding and resources (n=2/23; 9%). The majority of respondents (n=20/23, 87%) believed that colleagues and staff within their hospice would benefit from access to resources on how to prescribe, monitor and design sessions, with 78% (n=18) indicating that their staff would be interested in attending a training course.

# Focus group and interview findings Participant and hospice characteristics

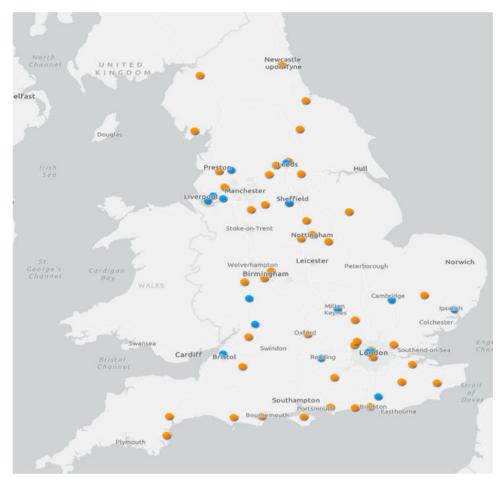
At the end of their survey, 30 participants expressed willingness to participate in an interview, and 19 responded to the invitation. All participants were currently involved in the delivery of PA at their hospice. Focus groups and interviews were on average 48 minutes, with a range of 38–65 minutes. Analysis of the data revealed 3 broad emergent themes: (i) variation in capacity to deliver PA, (ii) a desire to embed a hospice culture of PA, and (iii) a need for an organizational commitment to PA, each of which had 2 subthemes. Supporting quotes for each are provided in Table 2.

#### Variation in capacity to deliver PA

The capacity (i.e., funding, staffing, and resources) to deliver PA differed considerably among hospices. While some health professionals reported adequate staffing and ample opportunity for patients to consistently and safely engage in exercise, most health professionals reported limited funding, understaffing, and inadequate space to deliver high-quality PA provision.

#### Limited funding, understaffing, and inadequate physical space

Most participants spoke about underinvestment in the number of trained staff (i.e., therapists) needed to deliver PA in routine care. While most leadership and hospice management teams understood the importance of therapy services including PA provision, funding to staff these services adequately was not a priority (e.g., Table 6; quote 1). Underinvestment in staff to deliver therapy services was, seen by participants as, a barrier to making a positive impact on patient outcomes as well as the delivery of high-quality PA services. One participant noted that their hospice did not have a physiotherapist and therefore struggled to deliver PA. Others barriers to the delivery of PA in routine care included a lack of



**Figure 1.** The delivery of physical activity in hospice care across England. Orange represents hospices that promote physical activity as part of their service provision. Blue represents hospices that do not promote physical activity as part of their service provision.

Table 5. Benefits and barriers to physical activity service provision

Benefits of physical activity	N <sup>a</sup> (%)	
Improve or prevent the decline of physical function without increasing fatigue	11 (23.4)	
Reduce symptom burden	4 (8.5)	
Maintain personal independence	4 (8.5)	
Improve general well-being and quality of life	43 (91.5)	
Other: All indicated all of the above	8 (17.0)	
Barriers to participation		
Poor functional mobility	25 (53.2)	
Fear of falling	9 (19.1)	
Low motivation/lack of energy	41 (87.2)	
Low confidence	19 (40.4)	
Pain/discomfort	37 (78.7)	
Other	9 (19.1)	

**Note**: ( ${}^{a}N=47$ ) Other included not wanting to be in a group, do not want to engage with the hospice, disease progression, difficulty accessing for outpatients, being put off by family or other professionals.

staff time due to high caseloads and inadequate space for patients to move freely (e.g., Table 6; quote 2).

#### Adequate staffing and opportunities

Some participants reported sufficient numbers of suitably qualified and skilled therapists for PA provision. For example, 1 participant spoke about having 4 full-time equivalent senior therapists to deliver PA (e.g., Table 6; quote 3). Health professionals from hospices who had sufficient numbers of trained therapists to deliver PA, reported ample opportunities for their service users to engage in PA at their hospice (e.g., Table 6; quote 4).

#### A desire to embed a hospice culture of PA

Most participants talked about a desire to embed PA provision in the organizational culture or fabric of hospice care. It was important to participants that a PA ethos that permeated the day-to-day delivery of care was adopted by the wider palliative care team. In particular, they expressed a need for their hospice to create an enabling environment for PA to occur and adopt a joined-up multidisciplinary approach to PA provision.

Table 6. Themes, subthemes, and example quotes reflecting participants' perspectives on physical activity service delivery in hospice care

Thoma	Cuhthama	Evample quetes
Theme	Subtheme	Example quotes
Variation in capacity to deliver PA	Limited funding, understaffing, and inadequate physical space	#1. "I think from the standpoint of the whole organization, our managers and service leads know the benefits of therapies and speak about the importance of it [PA] but when you look at our staffing levels, it does not reflect that. That [therapy] is not where they [management] think about putting their money. With how much we know about the benefits of self-management and keeping people independent, you would need so much more than what we have." (HCP 8, FG 2)
		#2. "We only offer a limited number of [exercise] sessions due to our high caseloads, and we can only have a certain amount of patients in the gym at a time due to a lack of space for patients to move around." (HCP 13, FG 3)
	Adequate staffing and opportunities	#3. "I don't know of any other hospice that has the same investment in the physio service as we have. We have four full-time equivalents, which is a lot and they are all senior therapists involved in the delivery of PA" (HCP 3, FG 1).
		#4. "Prior to Covid, we had lots and lots of gym classes running and we had a lot of patients coming in. Our gym was running for two hours, four days a week and we had about 10 – 15 and sometimes up to 20 patients coming in within a two-hour period. And patients were just coming and going as they pleased. They could come anytime within the two hours. They had a program. And, they used to come in the same days as their friends came and sit in our day therapy unit and have coffee and then go and have lunch in the canteen together. And it was a really social aspect to the hospice." (HCP 19, Interview 3)
A desire to embed a hospice culture of PA	Creating enabling environments	#5. "We have an old-fashioned day-hospice type service where patients come in, have a nursing assessment and sit there for the day. They might do a quiz, might have a massage, or some might attend a physio session like an exercise group, but it is not a very enabling environment at all. It is more an environment that fosters dependency. They [patients] would come in and just sit there and lunch would be served. It is not a great setup for promoting PA and independence. So Covid has almost come as a welcome opportunity. So when we go back to the building that we were in before we can make changes and create a more enabling environment." (HCP 16, FG 4)
	Adopting a joined- up multidisciplinary team approach to PA provision	#6. "I guess nurses tend to be automatically very caring and do everything for patients and as therapists, we tend to stand back and say, 'okay you do this and tell me when you need some help.' So I guess we need to ask nurses to kind of think about that [promoting PA] as part of their care and adopt more of a rehab outlook." (HCP 11, FG 3)
		#7. "I mean we are not represented enough as physio- and occupational therapists and we can't carry all the work of PA. It [PA] has to be a whole team decision to invest in itit is not just about having a policy about it [PA]. It really is about embedding a culture of PA." (HCP 2, FG 1)
A need for an organi- zational commitment to PA service provision	Recognition of and commitment to PA	#8. "We need a commitment to a palliative rehabilitation approach to how we look after patients from a higher level. We need recognition from commissioners and directors saying that this is an important part of healthcare so let us invest in it and let us get more professionals working in this areaand official training of staff around that kind of approach [palliative rehabilitation] to patient care and the importance of PA." (HCP 6, FG 2)
		#9. "How much value we are deemed to have within the whole hospice is difficult to say because of all the other priorities at the moment. Sometimes you feel that your value is almost non-existent because out of all of our service teams, we [therapists] sit in a cupboard with no ventilation in our offices and everybody else has a nice office. So you think maybe we're not very valued by the leadership team." (HCP 9, Interview 1)
	Guidance and benchmarking	#10. "every hospice is so different. We are all so different. We all have different priorities, but I think if you had national guidance or a framework that could influence hospices across the country. It [national guidance] would help us all to do similar things. And have standards that we would all need to work to. That would have more impact than local policies." (HCP 7, FG 2)

#### Creating enabling environments

Participants talked about wanting to improve the physical environment in which they delivered care to better enable and support patients to be more physically active and independent. While some participants reported that their hospice was set up to promote healthy and active living, other participants were concerned that the setting in which patients were receiving care was contributing to sedentary behavior and dependency as patients were encouraged to be sedentary and reliant on staff (e.g., Table 6; quote 5).

#### Adopting a joined-up multidisciplinary team approach

Most participants reported a need for a joined-up multidisciplinary team (MDT) approach to PA provision. While most members (i.e.,

therapists) of the MDT took an active role in promoting PA, participants reported that nurses were more likely to adopt a caring approach (i.e., supporting patients to be comfortable and completing tasks for them such as getting dressed and undressed) rather than encouraging patients to move and undertake activities for themselves (e.g., Table 6; quote 6). It was important to participants that all staff who provided care to patients adopted a rehabilitation outlook and worked together to achieve common goals related to the delivery of PA (e.g., Table 6; quote 7). While most participants expressed a desire for nurses to take more of an active role in promoting patients to move more, 1 participant reported that their entire MDT including nurses promoted PA. The therapy team worked with their nurses encouraging them to complete

a measure of performance in activities of daily living (i.e., a Barthel index) regularly to ensure that PA promotion was embedded in routine care.

#### A need for an organizational commitment to PA

Most participants talked about a need for the directors and senior management team at their hospice to demonstrate an organizational commitment to PA service provision. Participants wanted PA to be given equal priority as other services within their hospice. They also communicated a desired for guidance and benchmarking at the national level to support health professionals when delivering PA.

#### Recognition and commitment to PA

For most participants, their organization needed to demonstrate a stronger commitment to and investment in PA service provision (e.g., Table 6; quote 8). Participants discussed the need for more funding and training to support the delivery of PA. In particular, they wanted their hospice to invest in the number of trained staff needed to deliver PA. Some participants shared that they felt undervalued by their organization and wanted to be treated equally to other staff within their hospice (e.g., see Table 6; quote 9).

#### Guidance and benchmarking

For some participants, benchmarks were deemed to be important for providing the MDT with guidance and structure around PA provision as well as ensuring consistency in delivering PA to patients (e.g., Table 6; quote 10). Benchmarks at the national level were seen as important for consistency of PA service delivery across the nation.

#### **Discussion**

This mixed-methods study provides the first comprehensive description of PA service provision across hospices in England. While almost two-thirds of participating hospices in England promoted PA in routine practice, not all provided this service mainly due to a range of barriers at the organizational level (e.g., a lack of trained staff, lack of time). This finding aligns with other studies determining variation across the types of services (e.g., physiotherapy, occupational therapy, respite management, rapid response, bereavement care) provided to patients and families across hospices in the UK (Carlson 2007; Finucane et al. 2021; Keeble et al. 2022; Mitchell et al. 2020). Drivers of disparity in PA service provision across England may be due to a lack of sustainable funding for the hospice care sector (Oliver 2019). PA promotion in health-care settings generally can be hindered by funding pressures, workforce shortages, and lack of training (Albert et al. 2020) which may contribute to inequalities in the quality of care provided to patients (Hasson et al. 2022; Kates et al. 2021). A better understanding of the causes of variation in service delivery including their impact on patient and family outcomes and satisfaction with hospice care is an important area for future research.

Among those hospices that promoted PA, qualitative findings suggest that there is variation in capacity to consistently deliver interventions in hospice care. Given the significant psychosocial and physical benefits (e.g., reduced fatigue, improved mobility) of engagement in patients with advanced, incurable diseases (e.g., Bradshaw et al. 2020; Miller et al. 2018), it is important for hospices

to address the barriers that prevent patients from being able to access continued support for PA engagement. Patients who receive hospice care face unique challenges to engagement (e.g., multimorbidities, dyspnea, frailty, sarcopenia) and require professional support, personalized advice, and easy access to interventions (e.g., convenient locations) (Burke et al. 2020). For these reasons, hospices are ideally placed to provide patients with the support they require to engage in PA. Hospices have the potential to reach a large proportion of the population living with advanced, incurable diseases and therefore should consider investing in interventions as a priority within routine care.

The most common types of PA delivered in hospice care included resistance/thera bands, Tai Chi/Chi Qong, circuit exercises, and yoga. These modalities are safe, acceptable, and effective for improving symptoms, functional capacities, and quality of life in people with advanced, incurable cancer (Toohey et al. 2022). However, safety considerations and measured precautions should be taken when prescribing PA to people with advanced, incurable diseases as they are a vulnerable population and improving their quality of life is of utmost importance. Health professionals should prescribe exercises based on the preference and motivation of the patient and adjust the intensity to the abilities of the person (Burke et al. 2020). Moreover, certain activities may not be suitable for all patients (e.g., high-impact exercise may not be suitable for patients with comprised bone strength).

Survey results showed that 85% of physiotherapists delivered sessions to patients. This result is consistent with other studies which have found that physiotherapists, across diverse healthcare settings (e.g., general practice, cancer care), have expertise and knowledge in PA promotion and typically integrated some form of discussion about activity with their patients (Albert et al. 2020; Hassett et al. 2022). Physiotherapists agree that PA promotion should be part of their clinical role (Aweto et al. 2013; Freene et al. 2017; Hassett et al. 2022; Mouton et al. 2014; Shirley et al. 2010). Our qualitative findings confirm those of previous research; yet, participants in our study felt that all members of the MDT should prioritize and take an active role in encouraging patients to move more. Participants believed that PA delivery should involve a collective team effort (whereby professionals from different disciplines work together to achieve common goals) and also be embedded within an organizational culture of "moving more" that supports everyone's efforts to promote active lifestyles.

Participants in this study believed that health professionals could benefit from more guidance and support to deliver PA in hospice care. Many participants felt that benchmarks at the national level would not only help with ensuring that PA was delivered consistently across hospices but also act as a best practice tool to structure and guide assessment, prescription, and monitoring. Benchmarking (i.e., structured comparison of outcome indicators and the sharing of best practices across organizations) has been used as a tool to help identify strengths and weaknesses in the health-care system (Willmington et al. 2022). Applying benchmarks to deliver PA in hospice care may be an important quality improvement tool (Ettorchi-Tardy et al. 2012). At the organizational level, hospices may benefit from methods (i.e., benchmarking) to formalize how best practice is developed, compared, and shared. Moreover, benchmarking may provide a mechanism to identify differences in PA practices and outcomes between different geographical areas where hospice care services are provided in England (Willmington et al. 2022) as well as promote the reduction of variation across sites.

#### **Strengths and limitations**

This mixed-methods study combined quantitative and qualitative data. The strength of this approach was that quantitative variables can be explained and contextualized alongside the qualitative data. This provides us with a comprehensive account of PA provision in hospice care in England and highlights the facilitators and barriers to this provision. In addition, the sample included hospices across all regions of England, which provides representation across geographical regions. There are limitations of this study that should be considered. While respondents were from across the regions of England, they represented around half of all hospices contacted which may have led to a response bias. However, among the responding hospices, there was substantial variation within the provision of PA. Additionally, NHS hospices were not included. The findings may therefore not be generalizable to NHS hospice care settings.

#### **Conclusion**

There is increasing evidence that shows the positive role that PA plays in the management of advanced incurable diseases. However, there is considerable variation in the current delivery of services across hospices in England. Policy action may be necessary for PA provision to be incorporated into the fabric of the hospice care delivery system sustainably and to break down the barriers that impede integration. Findings highlight the need for a PA care pathway that includes guidance and benchmarking at the national level as well as, resource allocation including funding, education, and knowledge transfer.

**Data availability statement.** The anonymized dataset is available from the corresponding author on reasonable request.

**Acknowledgments.** The authors are grateful to all the health professionals who completed the survey and participated in the focus groups and interviews.

**Authors' contributions.** SB and BE developed the online survey questions. SB developed the focus group and interview guide. SB, NH, and MA conducted the focus groups and individual interviews and transcribed the data. NH and AD analyzed the online survey data. SB and NH analyzed the qualitative data. SB and MA supervised data analysis. SB drafted the paper. All authors read, revised, and approved the final manuscript.

**Funding.** The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This study was funded by Research England.

**Competing interests.** The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

# References

- Albert FA, Crowe MJ, Malau-Aduli AEO, et al. (2020) Physical activity promotion: A systematic review of the perceptions of healthcare professionals. International Journal of Environmental Research and Public Health 17(12), 4358. doi:10.3390/ijerph17124358
- Allsop MJ, Ziegler LE, Mulvey MR, et al. (2018) Duration and determinants of hospice-based specialist palliative care: A national retrospective cohort study. Palliative Medicine 32(8), 1322–1333. doi:10.1177/0269216318 781417
- **Aweto HA, Oligbo CN, Fapojuwo OA**, *et al.* (2013) Knowledge, attitude and practice of physiotherapists towards promotion of physically active lifestyles in patient management. *BMC Health Services Research* **13**(1), 21. doi:10. 1186/1472-6963-13-21

Bayly J, Bradshaw A, Fettes L, et al. (2022) Understanding the impact of the Covid-19 pandemic on delivery of rehabilitation in specialist palliative care services: An analysis of the CovPall-Rehab survey data. Palliative Medicine 36(2), 319–331. doi:10.1177/02692163211063397

- Birtwistle J, Millares-Martin P, Evans CJ, et al. (2022) Mapping and characterising electronic palliative care coordination systems and their intended impact: A national survey of end-of-life care commissioners. *PLoS ONE* 17(10), e0275991. doi:10.1371/journal.pone.0275991
- **Bradshaw A, Phoenix C and Burke SM** (2020) Living in the mo(ve)ment: An ethnographic exploration of hospice patients' experiences of participating in Tai Chi. *Psychology of Sport and Exercise* **49**, 101687. doi:10.1016/j. psychsport.2020.101687
- Braun V and Clarke V (2006) Using thematic analysis in psychology. Qualitative Research in Psychology 3(2), 77–101. doi:10.1191/1478088706q p063oa
- Burke S, Utley A, Belchamber C, et al. (2020) Physical activity in hospice care: A social ecological perspective to inform policy and practice. Research Quarterly for Exercise and Sport 91(3), 500–513. doi:10.1080/02701367.2019.
- Carlson AL (2007) Death in the nursing home: Resident, family, and staff perspectives. *Journal of Gerontological Nursing* 33(4), 32–41. doi:10.3928/ 00989134-20070401-05
- Caspersen CJ, Powell KE and Christenson GM (1985) Physical activity, exercise, and physical fitness: Definitions and distinctions for health-related research. *Public Health Reports* **100**(2), 126–131.
- Creswell JW and Plano CV (2011) Designing and Conduciting Mixed Methods Resaerch, 2nd edn. Thousand Oaks, CA: Sage Publications Inc.
- Cunningham C and O'Sullivan R (2021) Healthcare professionals promotion of physical activity with older adults: A survey of knowledge and routine practice. *International Journal of Environmental Research and Public Health* **18**(11), 6064. doi:10.3390/ijerph18116064
- Elshahat S, Treanor C and Donnelly M (2021) Factors influencing physical activity participation among people living with or beyond cancer: A systematic scoping review. *International Journal of Behavioral Nutrition and Physical Activity* 18(50), 1–20. doi:10.1186/s12966-021-01116-9
- Ettorchi-Tardy A, Levif M and Michel P (2012) Benchmarking: A method for continuous quality improvement in health. *Healthc Policy* 7(4), e101–e119.
- Eysenbach G (2004) Improving the quality of web surveys: The Checklist for Reporting Results of Internet E-Surveys (CHERRIES). *Journal of Medical Internet Research* **6**(3), 1–6. doi:10.2196/jmir.6.3.e34
- Fetters MD, Curry LA and Creswell JW (2013) Achieving integration in mixed methods designs - Principles and practices. *Health Services Research* 48(6 Pt 2), 2134–2156. doi:10.1111/1475-6773.12117
- **Finucane AM, Swenson C, MacArtney JI**, *et al.* (2021) What makes palliative care needs "complex"? A multisite sequential explanatory mixed methods study of patients referred for specialist palliative care. *BMC Palliative Care* **20**, 18. doi:10.1186/s12904-020-00700-3
- Freene N, Cools S and Bissett B (2017) Are we missing opportunities? Physiotherapy and physical activity promotion: A cross-sectional survey. BMC Sports Science, Medicine and Rehabilitation 9, 19. doi:10.1186/s13102-017-0084-y
- Fusch PI and Ness LR (2015) Are we there yet? Data saturation in qualitative research. *The Qualitative Report* **20**(9), 1408–1416. doi: 10.46743/2160-3715/2015.2281.
- Green JC (2007) Mixed Methods in Social Inquiry. San Fransisco, CA: Jossey-Bass
- Hassett L, Jennings M, Brad B, et al. (2022) Brief physical activity counselling by physiotherapists (BEHAVIOUR): Protocol for an effectivenessimplementation hybrid type II cluster randomised controlled trial. Implementation Science Communications 3(39), 1–18. doi:10.1186/s43058-022-00291-5
- Hasson R, Sallis JF, Coleman N, et al. (2022) COVID-19: Implications for physical activity, health disparities, and health equity. American Journal of Lifestyle Medicine 16(4), 420–433. doi:10.1177/155982762110 29222
- JISC (2020) Jisc online surveys. Jisc, Bristol, UK. https://www.onlinesurveys.ac. uk/ (accessed 20 November 2022).

- Johnson RB, Onwuegbuzie AJ and Turner LA (2007) Toward a definition of mixed methods research. *Journal of Mixed Methods Research* 1(2), 112–133. doi:10.1177/1558689806298224
- Kates J, Gerolamo A and Pogorzelska-Maziarz M (2021) The impact of COVID-19 on the hospice and palliative care workforce. Public Health Nursing 38(3), 459–463. doi:10.1111/phn.12827
- Keeble E, Scobie S and Hutchings R (2022) Support at the end of life: The role of hospice services across the UK. Research report, Nuffield Trust. www.nuffieldtrust.org.uk/research/supportat-the-end-of-life (accessed 15 November 2022).
- Kosmadakis GC, John SG, Clapp EL, *et al.* (2012) Benefits of regular walking exercise in advanced pre-dialysis chronic kidney disease. *Nephrology Dialysis Transplantation* **27**(3), 997–1004. doi:10.1093/ndt/gfr364
- Miller B, McCarthy A and Hudson S (2018) The impact of physical activity on self-management in palliative patients: A collaborative service evaluation and a step towards becoming research active. *Progress in Palliative Care* 26(3), 142–147. doi:10.1080/09699260.2018.1467604
- Mitchell SL, Volandes AE, Gutman R, et al. (2020) Advance care planning video intervention among long-stay nursing home residents: A pragmatic cluster randomized clinical trial. JAMA Internal Medicine 180(8), 1070–1078. doi:10.1001/jamainternmed.2020.2366
- Mouton A, Mugnier B, Demoulin C, *et al.* (2014) Physical therapists' knowledge, attitudes, and beliefs about physical activity: A prerequisite to their role in physical activity promotion? *Journal of Physical Therapy Education* **28**(3), 120–127. doi:10.1097/00001416-201407000-00013
- Neoh K, Stanworth S and Bennett MI (2019) Blood transfusion practice in the UK and Ireland: A survey of palliative care physicians. *BMJ Supportive & Palliative Care* 9(4), 474–477. doi:10.1136/bmjspcare-2019-001779

- Oliver D (2019) David Oliver: £25m for hospices won't go far. *BMJ* **366**, l5520. doi:10.1136/bmj.l5520
- Shirley D, van der Ploeg HP and Bauman AE (2010) Physical activity promotion in the physical therapy setting: Perspectives from practitioners and students. *Physical Therapy* **90**(9), 1311–1322. doi:10.2522/ptj.20090383
- Smith B and McGannon KR (2018) Developing rigor in qualitative research: Problems and opportunities within sport and exercise psychology. *International Review of Sport and Exercise Psychology* 11(1), 101–121. doi:10. 1080/1750984X.2017.1317357
- Tong A, Sainsbury P and Craig J (2007) Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care* 19, 349–357. doi:10. 1093/intqhc/mzm042
- **Toohey K, Chapman M, Rushby AM**, *et al*. (2022) The effects of physical exercise in the palliative care phase for people with advanced cancer: A systematic review with meta-analysis. *Journal of Cancer Survivorship: Research and Practice* **17**(2), 399–415. doi:10.1007/s11764-021-01153-0
- Vira P, Samuel SR, Amaravadi SK, et al. (2021) Role of physiotherapy in hospice care of patients with advanced cancer: A systematic review. American Journal of Hospice and Palliative Medicine\* 38(5), 503–511. doi:10.1177/1049909120951163
- Willmington C, Belardi P, Murante AM, et al. (2022) The contribution of benchmarking to quality improvement in healthcare. A systematic literature review. BMC Health Services Research 22(1), 139. doi:10.1186/s12913-022-07467-8
- World Health Organization (WHO) (2020) Guidelines on physical activity and sedentary behaviour. Geneva, Switzerland: World Health Organisation. https://apps.who.int/iris/rest/bitstreams/1315866/retrieve (accessed 14 October 2022).