



Taylor, Helen N. and Bryan, Karen ORCID logoORCID:
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Introduction

There are few physiotherapists with a registered special interest in palliative patients (204 of the Chartered Society of Physiotherapy's (CSP) registered 51,000 members¹), and out of 127 national research priorities identified by physiotherapists², palliative and cancer care were itemised only three times, despite the CSP³ and NICE⁴ identifying a lack of evidence-base in cancer and palliative rehabilitation almost a decade ago. Current government guidelines and policies for end of life care⁵ are resulting in many more palliative cancer patients being treated in their local hospitals and community rather than specialist centres, bringing physiotherapists into increasing contact with this patient population.

NICE^{4(p136)} recommends that all cancer patients should have access to rehabilitation services, 'when, and where they need them, and that services are provided without undue delay'; however recent studies^{6,7} have demonstrated that terminally ill cancer patients have difficulty accessing palliative rehabilitation. All physiotherapists possess skills to assist in the management of musculo-skeletal problems, pain, mobility, neurological dysfunction, and respiratory difficulties³ all of which can be experienced by terminally ill cancer patients, however, despite having the technical skills, it would seem that not all physiotherapists are suited to working in palliative cancer care.

Literature Review

Searches of Databases using BNI, CINAHL, Internurse, Medline, NHS Evidence, Nursing and Medical Cross Search, and PsycInfo from 1990 to 2013 revealed a paucity of literature relevant to attitudes towards palliative patients, with none specific to physiotherapists, other than anecdotal studies or personal opinions.

Search words used were physiotherapists, physiotherapy, palliative care, attitudes,

incurable, dying patients, palliative education, communication skills, allied health professionals, occupational therapists, oncology, nurses' perceptions, and professionals working with dying patients.

It is important to highlight many authors have identified that even professionals working within the field of palliative care do not understand that palliative care incorporates cancer and all life-limiting diseases, and that these professionals do not make the distinction between end-of-life care and palliative care^{8,9}

Palliative care is defined as;

“an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”¹⁰

End-of-Life Care (also known as Terminal Care) is an important part of palliative care and refers to the management of patients in the last few days, weeks or months of life when it becomes clear the patient is in a progressive state of decline⁸

It has been reported that palliative cancer patients find physiotherapy important in providing relief from distressing symptoms and regaining some control, but that communication skills could be improved to enhance patient outcomes and clinician confidence.¹¹⁻¹⁶ Ries,¹⁷ observed that physiotherapists have a magnified fear of cancer in their role particularly around issues such as the risks of fracture or cord compression: It was noted that palliative care is not the first practice setting physiotherapists think of.

A number of studies demonstrate gaps in learning across professional groups and only a small amount of time dedicated to palliative care education, with students remaining low in confidence when faced with working in palliative care.¹⁸⁻²² It has

been demonstrated that professionals and patients have expectations regarding what each profession should do Outcome of this is? Limit referrals? .²³

Current guidelines and policies identify that palliative care is the responsibility of every health care professional that comes into contact with people living with a life-threatening illness and not just the responsibility of palliative care specialists.²⁴ The CSP describes how all physiotherapists can support and rehabilitate people affected by cancer using seven principles which apply from diagnosis to end of life, describing physiotherapists as essential members of the multi-disciplinary team and that their absence would be detrimental to patients and their families.³ The main barriers to effective implementation of rehabilitation are stated to be as a result of attitudinal problems, poor knowledge about cancer rehabilitation, poor detection of rehabilitation problems, front-line practitioners frequently do not recognise patients' needs for rehabilitation, limited availability of Allied Health Professionals (AHP's), inadequate training of AHP's and delays in accessing equipment.^{3,4} NICE⁴ notes that rehabilitation interventions can also have major psychological, social and spiritual benefits and that all cancer patients are likely to need rehabilitation along their journey. NICE⁴ recommendations state that access to AHP's should be clearly defined via referral and treatment criteria and that evidence-based guidelines are developed, recommending the use of referral pathways, and that equipment requests for those who are dying should be met within 24 hours of the request. Training and education for all health care professionals to recognise cancer patients' rehabilitation needs is recommended.⁴

The purpose of this research was to acquire evidence and insight into the attitudes, beliefs and experiences of physiotherapists (who do not specialise in palliative

cancer rehabilitation), towards terminally ill cancer patients and has been reported using the COREQ guidelines.²⁵ Do they comply with COREQ guidelines?

Aim

To explore the attitudes and beliefs experienced by physiotherapists who do not specialise in palliative cancer rehabilitation, towards terminally ill cancer patients.

Design

Semi-structured interviews analysed using Colaizzi's²⁶ method of analysis, reported using the COREQ²⁵ guidelines.

Setting

Acute Hospital in the UK

Participants

Purposive sampling was used to recruit physiotherapists at a large, UK acute hospital, to reflect physiotherapists across all specialities, at varying stages of their careers. The study was presented to prospective participants by the principal author/interviewer, at a meeting of the physiotherapy department. The author introduced herself as a researcher-physiotherapist in palliative care and distributed participant information sheets and consent forms. The author did not work at the study site. The participants were the first twelve volunteers who met the inclusion criteria of being qualified physiotherapists, Chartered, Health and Care Professions

Council registered and not specialising in palliative rehabilitation.²⁷⁻³² Demographics are presented in Table 1. Data saturation was reached within the first 10 interviews with one potential negative case. The potential negative case was heavily influenced by the participants' religious beliefs but cannot be discussed further to protect anonymity.

DEMOGRAPHIC DATA	
Characteristic	Variable
Number participants (n)	12
Number of years qualified	Range 1 to 28
Age	21 to 50 years
Sex	Male = 2 Female = 10
Band	Bands 5,6,7 and 8
Speciality	Out-patients = 2. Ward-based = 10
Palliative education at undergraduate	3
Palliative education post-graduate	6

Table 1 Demographic Data of Participants

Confidentiality was maintained by not including the participants' names, specialities or their location in the final report and all references made by participants to their location or persons were de-identified in the transcripts.

Interviews

The in-depth, semi-structured interviews were conducted a minimum of one week after the introduction of the study, by the principal author over a two week period during January 2012 at the participants' place of work, in a private room away from colleagues and patients and lasted between 16 and 50 minutes.^{27,33,34} There were no drop-outs. The author was able to bracket their own beliefs due to their 27 years' experience as a physiotherapist and reported feeling "outside the circle of physiotherapists" due to their own speciality of palliative care.

When considering the question 'why did only certain physiotherapists' volunteer for the study?' physiotherapists revealed to the researcher that this was partly due to physiotherapists at the study site not thinking a study about working with terminally ill cancer patients was relevant to them.

The two pilot interviews revealed confusion regarding terminology, hence the words "terminally ill" were selected for subsequent interviews, with the initial opening question; How did they minimise the confusion?

"What do you think physiotherapists in general think about working with terminally ill cancer patients?"

This was followed by a second question;

"Could you describe in as much detail as possible your personal view of working with terminally ill cancer patients?"

Prompts such as “Tell me more” were used as required. The interviews were audio-recorded and field notes made after each interview. The twelve interviews were listened to three times and then transcribed verbatim by the author and a transcriber. The author re-checked the transcripts of the transcriber. The fellow author listened to a sample of tapes against transcription to further check accuracy. Colazzi’s method of data analysis²⁶ was applied to identify clusters of themes (with the omission of stage seven to reduce un-necessary burden on the participants³⁵ due to staff shortages and work pressure constraints on physiotherapists at the time of the study.). The fellow author re-checked the themes against a sample of transcriptions. All participants were given the opportunity to contact the author direct throughout the course of the study, but none did.

All data has been stored in accordance with the Data Protection Act (1998)³⁶.

Results

Two themes of ‘Attitudes’ and ‘Issues’ emerged from the data, with sub-themes.

THEMES AND SUBTHEMES
<p>A. ATTITUDES</p> <ol style="list-style-type: none"> 1. The influence of terminology upon attitudes 2. Physiotherapists’ perceptions and attitudes towards their contribution when working with terminally ill cancer patients. 3. Other professionals perceived attitudes toward physiotherapists’ contribution to terminally ill cancer patients 4. Patients and their families perceived attitudes toward physiotherapists’

contribution to terminally ill cancer patients

B. ISSUES

1. Communication
2. Education
3. Emotions
4. Boundaries
5. Referring onward from the acute setting
6. Time

Table 2 Clusters of Themes (Colaizzi stage 4)

ATTITUDES

The influence of terminology

The following participant quote sets the context for the perspectives described subsequently. *“It’s such a, the BIG C word is such a ... a thing, I think that it overtakes everything else.” (A12/2 6:141-142)*

Six of the participants described difficulties with the words ‘palliative’, ‘terminally ill’, ‘hospice’ and ‘palliative rehabilitation’ describing an uncertainty about what they meant and hence what would be expected of physiotherapists and how they would manage palliative patients. Participants noted the word ‘palliative’ was associated with no expectation of improvement, which influenced the low prioritisation of terminally ill cancer patients.

“ I think a lot of the time as soon as a lot of physio’s hear the word ‘palliative’ they’re like well ‘they’re dying. I’ll see this patient that’s doing a lot better, after this patient.’ And they can often be put at the bottom of the list, ” (A8/2 12:284-288)

Three participants highlighted the perception that the words ‘terminally ill’ and ‘palliative’ conjure up a short prognosis.

“ I think if you talk about terminally ill or palliative I think people automatically think that’s end of life.” (A2/2 5:123-124)

However, several participants acknowledged that patients can be deemed palliative and yet still have months to live.

Two of the physiotherapists stated the word ‘hospice’ was an unpopular word, and the perception that a hospice was inaccessible.

“also for them to go to a hospice or palliative, they have to be within DAYS of death ... and it’s so HARD ...unless it’s their only problem, which it very rarely is, it’s very hard to say ‘yes they’re going to die within a week’.” (A5/2 12:273-276)

Reluctance on the part of other clinicians (these words repeated in actual quote) to use the word ‘palliative’ was acknowledged.

“I still think amongst GP’s, other consultants, professionals that people still think it’s that terminal door closed, we’ve shut the door behind them now.” (A10/2 21:513-515)

One of the physiotherapists questioned the term ‘palliative rehabilitation’ and how it would be perceived by patients and family, identifying it as an oxymoron.

“does that not cause questions among people all the time when you put those two words together, because they ...?” (A9/2 9:219-220)

The confusion and uncertainty experienced by physiotherapists regarding terminology impacts patients as they are perceived to be unable to benefit from physiotherapy.

Physiotherapists' perceptions and attitudes towards their contribution

Five of the twelve participants responded that physiotherapists in general would question the benefit of physiotherapy with terminally ill cancer patients, – You can remove this as it is stated in the quote below. A further participant responded that most physiotherapists did not think working in this field was relevant to them.

“In general... I'd say there are a LOT of physio's that think it's probably a little bit ... pointless, for want of a better word. ...why would you work with someone that's dying, what are you going to bring them back to? That kind of attitude: What are you actually rehabilitating?” (A8/2 1:3-6)

Four of the twelve participants described their personal experiences as very rewarding. Three of the twelve participants commented that working with terminally ill cancer patients is not why students tend to go into physiotherapy.

“when they qua-, y'know go into training and things like that, I think a lot of people think it's backs, hips, knees and they don't think about physiotherapists working in cancer care” (A3/2 2:27-30)

It was noted by six of the participants that physiotherapists had to alter their perspective from one of aiming to *restore* patients' function, to one of *facilitating*, to enable this group of patients to achieve smaller, realistic goals.

“It's really hard to kind of drop into that mind-set that we're not getting them back to doing what they were doing before – we're getting them functionally ... just doing

SOMETHING functional as opposed to getting them back to ... running, swimming, whatever.” (A8/2 2:46-50)

Seven of the twelve participants raised concerns regarding being perceived as the ‘bad guy’, ‘taking away hope’, and about ‘unrealistic expectation’ with the ensuing breaking of bad news that patients were not going to achieve their physical aspirations.

“try and kind of almost reflect it back on them like ‘well what do YOU think from what we’ve done so far, what do you think, what do you think we’re going to achieve?’ So that I’m not the bad guy telling them ‘no you’re not, you’re not going to walk’.” (A8/2 5:116-119)

It was noted that many physiotherapists do meet and treat terminally ill cancer patients in their daily work but do not recognise them as such, and carry on without difficulty: Very interesting! How much does that label of palliative influence care a person receives (just my thoughts and not for text ☺)

“but they may see them along the way with other issues ... so I think, erm people don’t realise what’s under their noses sometimes” (A10/2 2:44-48)

Other professionals perceived attitudes toward physiotherapists’ contribution

Participants believed many other professionals did not recognise palliative cancer patients’ physiotherapy needs, failing to refer. When front-line referrers did refer, participants noted referrers inadvertently gave false hope to patients, implying that physiotherapists are able to restore function. There was an emphasis on inappropriate requests for chest physiotherapy to deal with respiratory secretions in the terminal phase.

“Sometimes consultants, SOMETIMES CAN BE SLIGHTLY UNREALISTIC ABOUT what expectations should be regarding rehabilitation” (A1/2 2:46-47)

Patients and their families perceived attitudes toward physiotherapists’ contribution

All of the participants described experiencing concerns as a result of public perception of their role and profession. One participant described how physiotherapists can be perceived by patients almost as bullies, others perceived to view themselves as ‘enablers’, facilitating discharge and some improvement in function.

“I think they [patients] perceive us as people that are going to get them going, erm, and people that will help, help them to do what they need to do, erm and very often the doctors will put their head ‘so when the physio’s are happy, you can go home’ or ‘when the physio’s have sorted this out, this can happen’. So I think they look at us as people that are going to enable them to do something.” (A6/2 6-7:148-153)

Several participants noted that the general view of physiotherapists was to associate them with sports and musculo-skeletal problems and returning patients to full fitness. It was noted that these perceptions of physiotherapists could lead to difficulties when working with terminally ill cancer patients because of the expectations that both patients and their families placed upon them.

Meeting family expectations was experienced as more difficult than meeting patient expectations.

“the patient may or may not have an understanding of what’s happening, but the, the relatives want ... the rehabilitation they want you to be fixed, and they, yeah, of course there’s a huge pressure on that.” (A1/2 16:381-384)

ISSUES

Communication

All twelve participants described concerns regarding communication with terminally ill cancer patients, seeing it as an essential part of their role but causing much personal uncertainty due to lack of training.

“if you could just be very OBJECTIVE and just treat the symptoms and what you see ... it’s a little bit easier, but if you’ve got that in your head that somebody’s DYING and they might be asking you QUESTIONS about it at the end of their LIFE, generally feeling unprepared for that, that part of it.” (A5/2 1-2:18-25)

Participants highlighted physiotherapists create the ideal opportunity for patients to talk by often treating them one-to-one, developing a relationship in a dedicated physiotherapy space.

Education

All twelve participants described their under-graduate preparation for working with terminally ill cancer patients as either insufficient or non-existent compared to other specialisms. Working with this group of patients is considered to be highly specialised and not the norm in the discipline of physiotherapy.

“I’m sure some undergraduate study would be useful, but how many people are actually going to end up working in that field? Not many; and probably sitting down in a classroom probably isn’t the best way and it probably is something, I think that you’d have to choose to do it.” (A3/2 20:439-443)

Of the teaching available, training in breaking bad news and communication skills improved physiotherapists' confidence most. They highlighted that lack of training can lead to physiotherapists becoming 'rail-roaded' by relatives and other professionals during clinical decision making.

"[regarding bronchial stenting] who's right to help them make that decision ... we're then prolonging their life, they're going to have three or four more pneumonias because they're not walking around as much. I think it does have a detrimental effect on you, potentially, ... if you haven't got the right training, you can get railroaded by relatives or other people into trying to help, sort of do the right thing" (A10/2 18-19:440-447)

Emotions, Boundaries and Time

Eight participants described feelings, with three using the word 'scared', three talked of the work being 'emotionally draining' and two describing 'distress and trauma'. Feelings of apprehension, trepidation and foreboding were described at going onto a cancer ward or being asked to assess deteriorating cancer patients. Another participant described feeling guilty at potentially wasting a patients' precious time with exercises.

"and it's quite scary ... environment. It's perceived as being quite an emotionally tense and upsetting environment." (A12/2 1:5-8)

Two participants acknowledged the boundaries of insufficient time

"I am working out of my job description and therefore I am going to get pulled up for spending too much time with a patient" (A2/2 8:184-185)

Two participants spoke of issues around stopping treatment when they became inappropriate, and the need to be honest with patients, whilst a further two participants spoke of boundaries between being the professional and being a person;

“you have to be professional, you have to be able to be a support for those (families), it’s no good if they’re upset and you’re upset.” (A3/2 9:191-192)

Referring on

Ten of the participants raised issues around discharging terminally ill cancer patients from the acute setting in particular they highlighted the difficulties in working with community services and not knowing who or where to refer on to as there are no established pathways for palliative cancer rehabilitation, unlike falls or stroke.

“[knowing] what community help is available for the patient. Y’know, if somebody’s come in with falls or a stroke y’know who to refer to in the community but,..., I don’t really know anything about the community from a physio point of view.” (A7/2 9:213-215)

Two participants believed cancer was seen differently to other terminal conditions such as heart failure with many more services available to cancer patients.

Contrary to this other participants believed that having the diagnosis of cancer proved to be a barrier in obtaining on-going rehabilitation in the community.

“I think actually CANCERS can be seen a bit differently ... rightly or wrongly, than other terminal diseases ... it’s a bit more ... it’s a bit more ...in VOGUE isn’t it, it’s a bit more ... better UNDERSTOOD, in, in, SOME WAYS comparative to other end of life things an it’s often, ... I think there’s MORE RESOURCES available for cancer patients (A1/2 6-7:140-145)

“certain places are very resistant to have them because they have cancer.” (A12/2 9:209-211)

Conclusions and Implications for Practice

EXPERIENCES AND BELIEFS DEMONSTRATED IN THIS STUDY
<ul style="list-style-type: none"> Some physiotherapists have a positive attitude and perceive they can improve quality of life for palliative cancer patients.
<ul style="list-style-type: none"> Some physiotherapists find working with terminally ill cancer patients rewarding. (Can this be incorporated into the one above?)
<ul style="list-style-type: none"> An additional set of skills is required to effectively manage this group of patients, including communication skills and counselling skills.
<ul style="list-style-type: none"> Negative connotations of the words ‘terminally ill’ and ‘palliative’ in the context of physiotherapy can result in the view that palliative cancer patients are unable to improve or benefit from physiotherapy.
<ul style="list-style-type: none"> Several participants believed that physiotherapists have little to contribute to terminally ill cancer patients, seeing their involvement as ‘pointless’ with patients not being able to be ‘rehabilitated.’ When I read this without “participants’ it could read as a generalisation about all PTs, see comment below. OR you could have a starting sentence at the conclusion that highlights these are participants perspectives about physiotherapists in general. Where this falls down is some of their comments are related to their own experiences.
<ul style="list-style-type: none"> The majority of participants noted involvement with terminally ill cancer patients was not relevant to them. Can this be incorporated into the one above? You need to be explicit that this is the perception of this particular group of participants and while the above is highly

likely you can't make that inference from your findings
<ul style="list-style-type: none"> • Other clinicians appear to be uncertain about the scope and role of physiotherapists in the management of terminally ill cancer patients.
<ul style="list-style-type: none"> • Participants believed doctors, nurses and other professionals to be unaware of the benefits of physiotherapy to terminally ill cancer patients
<ul style="list-style-type: none"> • Physiotherapists do not recognise they encounter terminally ill cancer patients away from the specialist setting.
<ul style="list-style-type: none"> • Physiotherapists can be perceived as 'the bad guy' taking away hope.
<ul style="list-style-type: none"> • Physiotherapists find dealing with the expectations of patients' families more challenging than those of the patients.
<ul style="list-style-type: none"> • Physiotherapists in acute settings do not have the time available to spend with complex terminally ill cancer patients.
<ul style="list-style-type: none"> • Physiotherapists are not aware of who to turn to for supervision and specialist support in the community and acute setting with palliative cancer patients.

Table 3; Experiences of non-specialist physiotherapists with terminally ill cancer patients

It could be concluded from the results that the majority of physiotherapists view terminally ill cancer patients as 'dying from' rather than 'living with' their diagnosis. *I don't believe you can draw this conclusion. You can say this is the belief of your participant group about physiotherapists' perceptions in general but not that the majority of physiotherapists believe this. It might look like splitting hairs when your clinical experience backs it up (as does mine) but this paper is reporting on your findings. You do note this in limitations but it needs to be consistent throughout.*

This perception may have been influenced by confusion of terminology, and the words chosen in the two interview questions. Participant responses highlight the importance of educating current and future physiotherapists to ensure that the profession meets the NICE⁴ guidelines making rehabilitation services accessible to all cancer patients, when and where they need them, and improve care of dying in the community.^{5, 37} Participants identified most valued areas of education being in communication, and counselling skills. A positive attitude from senior physiotherapists and provision of clinical supervision to address issues of emotion, time-management and communication would support current physiotherapy staff in acute hospitals.

There is a need to establish referral protocols to physiotherapy for terminally ill cancer patients both within a hospital and between acute and community services to maximise windows of opportunity for improved quality of life. Referral protocols could lead to reduced negativism, improve professionals understanding of the benefits of palliative rehabilitation, reduce the burden of false expectation, and facilitate communication.^{3,9,10,14,20} Service agreements and Integrated Care Pathways between charitable organisations such as hospices and Macmillan organizations and the acute and community sectors would enhance terminally ill cancer patients access to appropriate rehabilitation services in accordance with NICE⁴ guidelines.

Recommendations for further research;
<ul style="list-style-type: none"> • To explore in more depth physiotherapists' attitudes towards palliative cancer patients across community, acute and charitable sectors, to establish if there is a variance in willingness to work with this group of patients alongside variables such as age, education, experience, culture etc.
<ul style="list-style-type: none"> • How do community services identify palliative cancer patients physiotherapy needs if they are not being referred from the acute sector?

<ul style="list-style-type: none"> • How do palliative cancer patients currently access physiotherapy?
<ul style="list-style-type: none"> • Do physiotherapists have the same attitudes and experiences with other palliative non-cancer diagnoses, such as Motor Neurone Disease?
<ul style="list-style-type: none"> • Further qualitative and quantitative studies to establish if issues and experiences raised by this study are generalizable to provide an evidence base for future physiotherapists.
<ul style="list-style-type: none"> • Why is there an apparent shortage of physiotherapists for palliative cancer patients? Is it through lack of jobs, funding, understanding of value to patients etc?
<ul style="list-style-type: none"> • What are the perceptions of front-line referrers as to the value of physiotherapy for palliative cancer patients?
<ul style="list-style-type: none"> • How do we engage physiotherapists and physiotherapy students to meet the needs of the growing population of patients living longer with a palliative cancer diagnosis?

Table 4: Recommendations for further research

This initial study has provided insight into the experiences, attitudes, beliefs and issues of physiotherapists' with palliative cancer patients. The barriers to palliative cancer patients having easy access to physiotherapists are described as being the same as those identified by the CSP³ and NICE⁴ a decade ago; these coupled with the described experience that this group of physiotherapist participants regard patients as 'dying from' rather than 'living with' a terminal diagnosis, and confusion regarding terminology, lead the majority of these participants to believe they have little to offer this group of patients. Physiotherapists possess many beneficial skills

that can easily be adapted to meet the newer clinical guidelines and improve the lives of the increasing numbers of palliative cancer patients.

Limitations

Should limitations sit before the conclusion? Seems a negative way to finish a paper.

This study included a sample of physiotherapists of both sexes with a range of ages and experience, however findings cannot be generalised as the population sampled is small, and was biased towards ward-based physiotherapists. The sample did not include physiotherapists from ethnic minorities. Physiotherapists may have different attitudes towards other palliative conditions.