

**Physiotherapy practice in pulmonary hypertension:
physiotherapist and patient perspectives**

KEEN, Carol, FOWLER-DAVIS, Sally <<http://orcid.org/0000-0002-3870-9272>>, MCLEAN, Sionnadh <<http://orcid.org/0000-0002-9307-8565>> and MANSON, Jane

Available from Sheffield Hallam University Research Archive (SHURA) at:
<http://shura.shu.ac.uk/21742/>

This document is the author deposited version. You are advised to consult the publisher's version if you wish to cite from it.

Published version

KEEN, Carol, FOWLER-DAVIS, Sally, MCLEAN, Sionnadh and MANSON, Jane (2018). Physiotherapy practice in pulmonary hypertension: physiotherapist and patient perspectives. *Pulmonary Circulation*, 8 (3), 1-9.

Copyright and re-use policy

See <http://shura.shu.ac.uk/information.html>

Physiotherapy practice in pulmonary hypertension: physiotherapist and patient perspectives

Carol Keen¹, Sally Fowler-Davis², Sionnadh McLean² and Jane Manson¹

¹Sheffield Teaching Hospitals NHS Foundation Trust, Royal Hallamshire Hospital, Sheffield, UK; ²Sheffield Hallam University, Sheffield, UK

Abstract

Pulmonary hypertension (PH) is a life-limiting disease affecting circulation to the lungs. The primary symptom of PH is breathlessness, yet research has shown that patients with PH can exercise safely and can benefit from exercise to improve exercise capacity and maintain quality of life. This study aimed to investigate the nature of physiotherapy delivered to patients with PH in the UK. This was a two-phase sequential, exploratory, mixed-methods study. Interviews were conducted with seven lead physiotherapists at specialist pulmonary hypertension centers and three patients. Survey data came from 63 physiotherapists caring for patients with PH in specialist and non-specialist settings. The findings from the two phases were triangulated and analyzed. Findings showed that physiotherapists and patients see the benefit and potential of physical activity for patients with PH to maintain functional wellbeing. However, current physiotherapy provision focuses on acute inpatient care and planning for discharge and is not therefore aligned with research evidence and clinical guidelines. In the absence of inpatient rehabilitation facilities, physiotherapists will occasionally access existing community services, e.g. pulmonary rehabilitation; however, specialist knowledge of this rare condition can be lacking in local services. There is aspiration among physiotherapists and patients for a new approach which supports patients from diagnosis with PH to end of life. This includes promoting and delivering rehabilitation and exercise interventions to achieve better health outcomes, in line with patient needs. Treatment would be commissioned and delivered within existing national health systems with physiotherapists developing strategies for health improvement.

Keywords

pulmonary hypertension, physical activity, physiotherapy, pulmonary rehabilitation, evidence-based practice

Date received: 22 January 2018; accepted: 21 May 2018

Pulmonary Circulation 2018; 8(3) 1–9

DOI: 10.1177/2045894018783738

Pulmonary hypertension (PH) is an increase of blood pressure in the pulmonary circulation, characterized by remodeling of the pulmonary vasculature, with mean pulmonary arterial pressure (mPAP) > 25 mmHg.¹ It can arise from a variety of causes and is classified according to cause as follows:

- Group 1: pulmonary arterial hypertension (PAH);
- Group 2: PH due to left heart disease;
- Group 3: PH due to lung diseases or hypoxia or both;
- Group 4: chronic thromboembolic PH (CTEPH);
- Group 5: PH with unclear multifactorial mechanisms.¹

It is a rare condition with an estimated prevalence in the range of 10–52 cases per million.²

PH was once viewed as an untreatable condition; however, more people than ever are living with the disease and they are living for longer.³ Breathlessness is the primary symptom in patients with PH, leading to reduced functional ability and diminished quality of life.¹ Medical management includes PH-targeted drug therapy and optimization of underlying conditions; in CTEPH patients, surgery is an option.¹

Undertaking exercise can be challenging for patients who suffer shortness of breath, yet literature shows that supervised exercise is safe and effective in patients with PH.^{4,5}

Corresponding author:

Carol Keen, Sheffield Teaching Hospitals NHS Foundation Trust, Glossop Road, Sheffield S10 2JF, UK.

Email: carol.keen@sth.nhs.uk



Creative Commons Non Commercial CC BY-NC: This article is distributed under the terms of the Creative Commons Attribution-NonCommercial 4.0 License (<http://www.creativecommons.org/licenses/by-nc/4.0/>) which permits non-commercial use, reproduction and distribution of the work without further permission provided the original work is attributed as specified on the SAGE and Open Access pages (<https://us.sagepub.com/en-us/nam/open-access-at-sage>).

© The Author(s) 2018.
Reprints and permissions:
sagepub.co.uk/journalsPermissions.nav
journals.sagepub.com/home/pul



This evidence is mostly focused on patients in PH Groups 1 and 4 and much of it is derived from inpatient programs, e.g. three weeks supervised inpatient rehabilitation with follow-up on discharge, which are common in some parts of Europe, but far less so in other parts of the world such as the UK, Australia, and the USA.⁵ Guidelines for the care of patients with PH in the UK⁶ and Europe⁷ recommend that patients are as active as their symptoms allow and suggest supervised rehabilitation, without further detail regarding the form that this should take.

While physiotherapists are skilled in the management of respiratory patients, with a range of strategies to support respiratory function, breathlessness, and exercise, historically physiotherapy involvement with patients with PH has been minimal and provision of exercise rehabilitation is not widespread.

The aim of this study was to investigate the nature of physiotherapy currently delivered to patients with PH in the UK.

Methods

Research design

This was a two-phase sequential, exploratory, mixed-methods study, selected to capture in-depth views of experts as well as the experiences of the wider physiotherapy community. Phase 1 was a qualitative study exploring views and experiences of physiotherapy experts in PH and patients. Phase 2 was a survey investigating specialist and non-specialist physiotherapists' perspective of the role of physical activity in patients with PH. Findings from phases 1 and 2 were synthesized using a triangulation framework described by Farmer et al.⁸

Phase 1: Qualitative study

Data collection and sampling. Phase 1 consisted of seven semi-structured interviews with physiotherapists specializing in PH, plus three patient interviews.

To improve the care of patients with PH, seven specialist adult centers have been established in the UK; all patients with PH are managed through one of these seven centers. The principal investigator (CK, a physiotherapist specializing in PH, with experience in qualitative research interviewing) contacted six of the specialist centers by phone or email. Through enquiry with physiotherapy managers and clinicians, CK identified the physiotherapist taking the lead role in physiotherapy care of patients with PH. The six therapists were contacted by phone or email to confirm that they were the physiotherapy lead for PH and to invite them to take part in the study. All six agreed to take part and CK was interviewed as the lead physiotherapist at the seventh site.

A database search of relevant literature was conducted to identify articles concerning PH with exercise and other

forms of physical rehabilitation. JM and CK reviewed the literature to identify common themes relevant to this study. These included:

- the amount of exercise prescribed;
- exercise intensity;
- the nature of the exercise;
- inclusion and exclusion criteria;
- benefits identified;
- safety issues considered or arising.

The themes arising from the literature were used to develop the topic guide for interviews which included the following:

- therapists' current role and experience;
- the setting in which they deliver care to their PH patients;
- the nature of their assessments and interventions;
- what onward referrals they made and difficulties encountered;
- barriers and enablers to the care they provide;
- any other issues going forward.

Interviews were conducted between December 2015 and July 2106. Participant information sheets were sent and written consent was obtained. Six telephone interviews were conducted by CK with participants in their work setting. The participants were not previously known to the interviewer. Interviews lasted 20–42 min; they were audio-recorded and transcribed in full.

As CK was the specialist therapist at the seventh center, a second researcher (JM) interviewed CK face-to-face. CK was interviewed first to avoid bias that might arise from information gathered in earlier interviews.

Phase 1 also involved three telephone interviews conducted by CK with patients with PH to capture their views and experiences of physiotherapy. Participants were asked to come forward through patient publications and networks. Three patients volunteered and all were included in the study; as they were volunteers and not recruited through health services, their medical records were not accessed. Participants were initially contacted by telephone, sent a participation information sheet, and written consent was obtained by post. Interviews lasted approximately 28–38 min by telephone, while the participant was at home, and audio-recorded and transcribed in full. Participants did not review the interview transcripts.

The topic guide for the patient interviews was derived from the physiotherapist topic guide and initial thematic analysis from the physiotherapist interviews.

Qualitative data analysis. Analysis of the qualitative data was based on the principles of framework analysis⁹ as follows:

- familiarization with the data through repeated reading of transcripts;

- developing an initial framework based on interview topic guides;
- indexing the transcripts to apply the framework to the data;
- sorting and summarizing the indexed transcripts to create thematic charts, building and refining categories and subcategories;
- mapping and interpreting the charted data to identify associations and strategies, linking to the original goals of the research.

Analysis was carried out by CK who developed the initial framework, based on themes generated from the data. These were then independently checked by SFD who suggested additional themes based on her reading and conscious of the risk of bias due to the dual role of CK as both participant and researcher. The themes were then compared and discussed with agreements resolved by mutual consent and/or additional nuance offered to each theme.

Phase 2: Survey

Data collection and sampling. Phase 2 involved the design and distribution of a survey instrument to capture the experiences of physiotherapists not specializing in PH, yet who are involved in their care, e.g. in community settings or general wards. The nature and size of this population of physiotherapists is not clearly defined or identifiable, since patients with PH could present to physiotherapists in any setting, for differing reasons, e.g. for cardiac or pulmonary rehabilitation, on an acute medical ward or intensive care at a local hospital or specialist center, or in an outpatient musculoskeletal clinic.

It was therefore decided to use an electronic survey that would be distributed using snowball methods to capture the wide range of therapists who might be involved in the care of these patients. The SurveyMonkey® method was deemed suitable to capture data in an expedient way, directly from a large group when individual contact could not be achieved. The method permitted self-selection and individual professional responses from a range of physiotherapists across different organizational and service contexts.

Questions for the survey instrument were derived from an initial thematic review of the interviews conducted in phase 1. The questions were transferred to SurveyMonkey® and tested on a sample of three respiratory physiotherapists by sharing the unique link to the survey.

Once tested, the survey was distributed using professional networks and associated social media. The survey link was directly shared through the following sources, with recipients invited to complete the survey and where appropriate to suggest further recipients or pass it on as a link:

- via email to the physiotherapist in the specialist centers and shared by them with colleagues and networks;
- on Twitter, via the researchers' own accounts;
- through the Internet forum of the UK professional body for physiotherapists;
- through physiotherapy special interest groups in cardiac rehabilitation and respiratory care, who shared the survey with their members.

The survey data were collected between August 2016 and November 2016. The survey was closed when the survey responses had slowed to a minimum. Sixty-three physiotherapists completed the survey.

Quantitative data analysis. Descriptive statistics were conducted on responses to the survey and a weighted score was applied to scaled responses (e.g. Never, Sometimes, Often, Always), with a higher score indicating a more preferred response.

Triangulation

The final step of the analysis was to triangulate the findings from the phase 1 qualitative data derived from patient interviews and specialist therapist interviews with the phase 2 quantitative data derived from the survey. The methodological triangulation sought to code and assess for convergence and divergence across the data sources.⁸

The themes, sub-themes, and categories from the patient and specialist therapist thematic charts were each attributed with a direction and summary statement.

For the survey, responses were given a weighted score, with a higher score indicating a more preferred response. The direction and summary statements from the patient and physiotherapy interviews, and the weighted scores from the survey, were then reviewed concurrently, to generate a summary statement for each theme, capturing information from all three sources.

Ethical approval

Ethical approval for the study was obtained from Sheffield Hallam University (reference no. HWB-HSC-44).

Public and patient involvement

Patient and public involvement in this study was obtained through consultation with Pulmonary Hypertension UK (PHA-UK) who are the patient organization for PH in the UK. In addition, there was a patient on the steering group for the project.

Results

Interviews

The physiotherapists in the interviews were Band 7 staff and above who were the lead physiotherapist at their

specialist center for PH. None of them worked exclusively in PH; they all had additional responsibilities for patients with other respiratory conditions. All of the therapists worked exclusively in acute inpatient settings – none of the specialist centers had physiotherapy provision for outpatients.

The sample size for the physiotherapy interviews was determined by the number of specialist centers; 100% of the specialist centers were included in the physiotherapy interviews. Data saturation was reached for themes emerging from the physiotherapy interviews.

Patient volunteers were sought through the PHA and three patients came forward; all were interviewed. As the patients volunteered to the study and were not recruited through health services, their medical records were not accessed. There were two female patients and one male patient (age range = 44–66 years). Medical history was discussed through the interviews but was not formally recorded. All the patients had stable PH and had been diagnosed 8–10 years previously.

All three patients described themselves as active, regularly exercising independently. One patient had been through a pulmonary rehabilitation program several years previously, whereas the others had had no physiotherapy input. Many common themes were identified across the participants, with new issues arising in all of the interviews, so it is unlikely that data saturation was reached in this limited sample.

Survey

A total of 63 participants responded to the survey, with demographics data shown in Table 1. Figure 1 shows participants' responses to the survey questions.

Triangulation

Table 2 shows the key themes and sub-themes that emerged once the data from the patient interviews, the therapist interviews, and the surveys had been triangulated. The key findings emerging from the triangulation, including the themes and statements of direction, are presented below under indicative headings.

Physiotherapists work in acute settings and have a shared common practice

The specialist physiotherapists interviewed worked in acute regional specialist units where they managed unwell, deteriorating, or palliative patients in a ward environment. They described a range of common core interventions that contributed to acute patient recovery and discharge, including progressive walking programs; individualized bed- or chair-based exercise programs; chest treatment; breathing exercises; and advice on breathlessness. Specialist therapists also reported occasionally carrying out oxygen assessments,

Table 1 Demographic responses to survey.

Data	Respondents (%)
Geographic location	
England	95
Wales	5
Principal location of practice	
Specialist PH center	32
Primary care	30
Secondary care	27
Other	11
Years of experience	
<2	8
2–5	22
6–9	27
≥10	43
Highest qualification	
Diploma	3
BSc	65
MSc	32
PhD/Other	0
PH patients as proportion of caseload (%)	
<5	57
5–25	40
26–50	3
>50	0

providing treatment for relaxation, or encouraging static cycling activities.

“So along the general principles that they need to be a bit stronger, a bit fitter, and breathe a bit better...Everything else is tailored to them as an individual, what they're able to do, what they were doing before, where they want to be, and where they're at in terms of their ... wellness.” (P01 – Physio)

The physiotherapists who responded to the survey worked with patients with PH in primary and secondary care settings ranging from intensive care to community rehabilitation, with PH making up only a small proportion of their patient caseload. Their intervention choices were similar to those of specialist physiotherapists, with additional emphasis on self-management strategies and advice on pacing activities.

The underpinning reasons for therapists' choice of interventions ranged from research evidence, local protocols, local teaching or in-service training, Internet searches, British Thoracic Society (BTS) guidelines,¹⁰ advice from senior colleagues, and advice from specialist centers. Survey respondents relied principally on advice from senior colleagues.

“There is a growing research base out there to suggest that it is okay to rehab these patients, and that it's safe, and also that it's effective.” (P01 – Physio)

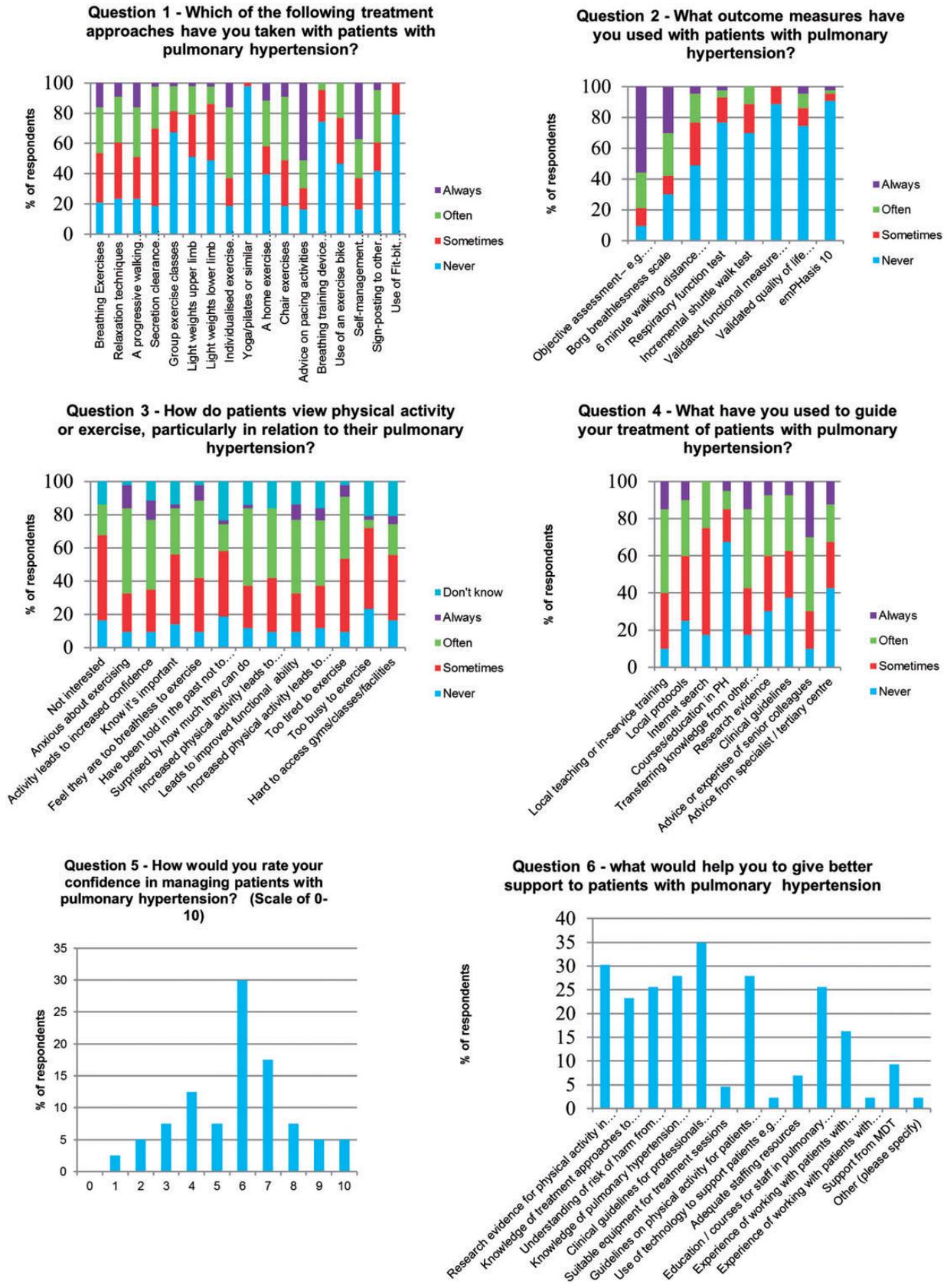


Fig. 1. Questionnaire responses.

Table 2 Themes associated with physiotherapy practice in PH.

Theme	Sub-theme
Role of physiotherapy	<ul style="list-style-type: none"> ● Which patients do you see? ● What interventions do you use? <ul style="list-style-type: none"> ○ Exercise ○ Respiratory ○ Other ● Onward referrals
Potential for physiotherapy	<ul style="list-style-type: none"> ● Opportunities ● Barriers ● Facilitators
What guides your practice?	<ul style="list-style-type: none"> ● Therapist knowledge and skills ● External resources ● Measuring effectiveness of treatment
Patient attitude to physical activity and exercise	<ul style="list-style-type: none"> ● Perceived benefits ● Triggers/motivators/influencers ● Self-efficacy for exercise ● Social relationships

Physiotherapists undertook assessments based on their clinical judgement, incorporating functional ability, mobility, and breathlessness.

The patient representatives in this study had not experienced inpatient physiotherapy and had received minimal physiotherapy input since their diagnosis with PH. Specialist therapists were primarily involved only in acute ward-based care of more unwell patients and so therefore reflected on the limited extent of their role and involvement in supporting patients through the lifespan of their disease. They also discussed the potential for increased physical activity in patients with PH.

“I suppose getting in there a little bit earlier, and then being able to work with them to increase their exercise tolerance, rather than it just being a discharge kind of thing.” (P06 – Physio)

Patients and physiotherapists view physical activity favorably

The potential to increase physical activity in this patient group was recognized by physiotherapists and patients. They believed that physical activity could help to control disease progression, moderate functional decline, and increase patient confidence and independence. The patients who took part in this study were all active and exercised regularly; they expressed social benefits, a feeling of increased self-control, enjoying the challenge, and feeling better from exercise. They believed that exercise contributed to their relative PH stability and helped to moderate disease progression.

“Personally, I do do quite a bit of exercise, but I also feel that is why I am stable.” (P09 – Patient)

These active patients were confident in their ability to exercise. They described knowing how much exercise to do, trying different things, and feeling motivated in their exercise. They had learned to make adjustments to their activities, medication, and environment to accommodate their physical activity.

“I have always been a very confident person and I have to be with the job I had, so yes, and I can do things on my own. I’ll just take myself off for a walk.” (P08 – Patient)

By contrast, physiotherapists reported managing patients who did not see that exercise would benefit them. Their patients were often anxious about exercising and uncertain about how much exercise to do. They could have pre-existing negative ideas about the effects of physical activity, having been told in the past to avoid over-exertion; they may have previously experienced severe breathlessness and they felt exercise could cause them harm.

“They have a natural anxiety that comes from ... something that’s made them so out of breath that they really feel ... they’re not going to get the next breath. And I think that then makes them think that they don’t want to do anything that would make them feel like that again.” (P01 – Physio)

In addition to patient anxiety, physiotherapists encountered families and carers who were anxious and protective of their relatives regarding physical activity; they did not want to see their relative suffer any more. Where families did get involved and were supportive, it was helpful. Active patients often exercised in groups or with the support of family.

Physiotherapists share a vision for new interventions and roles to enhance health outcomes

Patients and therapists saw an important role for physiotherapists in supporting patients to increase their physical activity. This would involve providing education, signposting to local services, and advice on pacing activities. Specialist therapists wanted to be involved in treating not only inpatients, who are acutely unwell, but also supporting outpatients to become more physically active. Participants saw a role for physiotherapy in developing patient motivation and self-management with regard to exercise.

“I think in an ideal world to be able to see more of the patients and be able to see them more consistently ... you want to give them exercise advice, you want to give them breathlessness advice ... you want to do everything and we’re not going to take that on ... in the half an hour before they’re about to be discharged from the ward. So, it would be really nice to be able to follow those patients up more consistently to carry on with treatment.” (P05 – Physio)

Specialist physiotherapists saw opportunities to develop physiotherapy roles but could be inhibited by a lack of capacity to focus exclusively on PH and to develop new

services. Nevertheless, one specialist center was exploring the possibility of a pilot physiotherapy outpatient service focused on physical activity.

“We’re talking about the possibility of creating a clinical specialist post . . . to demonstrate that it could be effective in the long term, and cost-effective and make a difference to patients, and maybe save the unit some money as well.” (P01 – Physio)

The specialist therapists could articulate the range of additional resources that would allow them to develop further interventions including research evidence, health economic evidence to support a business case, and clinical guidelines and standards.

At one center, a research study was underway to replicate the inpatient rehabilitation model described in the research literature.⁴

Physiotherapists can enable patients with PH to access local services for health improvement

Care for this patient group is complicated by their wide geographical spread; with only seven adult specialist centers supporting patients in the UK, patients can live a significant distance from their specialist center. Physiotherapists were therefore dependent on onward referral to local services for rehabilitation. They found, however, that knowledge of PH and confidence in how best to manage patients with PH is at times limited among physiotherapists providing local services. This problem is further exacerbated by a lack of specific clinical guidelines for therapists.

Pulmonary rehabilitation is a widely researched intervention for different respiratory conditions and is available throughout the UK and other countries.¹⁰ Physiotherapists and patients had experience of pulmonary rehabilitation referrals and recognized its value for patients with PH. However, specialist physiotherapists reported that patients can fail to meet the criteria for acceptance into pulmonary rehabilitation groups or are considered to be too high-risk to take part.

“If there’s an exercise referral scheme in the area; otherwise I’d just go for a home-based exercise program where possible . . . but a lot of them because they seem to be more funded for assisting discharge from hospital . . . I’ve had problems with them accepting referrals previously. Because we want a longer-term kind of consistent input really.” (P05 – Physio)

Patients also reflected on the variability of provision of services that would support health improvement. Physiotherapists and patients would like to see improved referral pathways to services such as pulmonary rehabilitation for patients with PH.

Discussion

This study was based on a review of existing literature and evidence of physiotherapy practice in the assessment,

treatment, and management of PH patients. This demonstrated current practice of acute inpatient physiotherapy intervention predominantly focused on functional outcomes and rapid discharge from hospital, in contrast to research evidence which describes the benefits of rehabilitation in the stable PH patient.^{4,5} This sits alongside aspiration from patients and professionals for enhanced physiotherapy provision. This study suggests that physiotherapists could enhance their practice with this patient group and, as a consequence, benefit patients with PH by: (1) exploring the translation of existing rehabilitation research evidence into clinical practice; and (2) designing PH physiotherapy services to cater to patients’ changing needs.

Exploring the translation of existing rehabilitation research evidence into clinical practice. Physiotherapy practice in PH in the UK, in common with other countries, cannot currently align with the existing research evidence regarding rehabilitation. This research has, to date, typically evaluated exercise programs of three weeks duration as an inpatient with 12 weeks follow-up at home.^{4,5} It has been conducted in countries and health settings where inpatient rehabilitation is a well-established practice for patients with a range of different conditions. Such rehabilitation programs, while common in some countries, are virtually non-existent on others, including the UK^{4,5} where health systems seek to promote health improvement in long-term conditions based on increasing out-of-hospital care, patient empowerment, and self-management.¹¹

Despite the potential benefits of increased physiotherapy interventions,^{4,5} and enthusiasm among patients and professionals in this study for a greater emphasis on physical activity and rehabilitation, there are few examples in PH of community-based, self-management that matches the intensity of inpatient rehabilitation support by the evidence to date.⁵ There are, however, opportunities for physiotherapists to develop physical activity interventions based on a greater understanding of the existing evidence by extending their use of existing exercise and rehabilitation provision in local facilities in collaboration with the exercise and health communities, e.g. through pulmonary rehabilitation.^{5,12} Further research is required to explore the safety and efficacy of such interventions; a commissioned call by the National Institute for Healthcare Research is currently underway which may address this issue.¹³

Designing PH physiotherapy services to cater to patients’ changing needs. The data clearly demonstrate that current physiotherapy provision contributes to acute care and is predominantly focused on functional outcomes and rapid discharge from hospital. On the whole, physiotherapy is available only during an acute hospital admission; it is not focused on health improvement strategies and longer-term planning for rehabilitation in the form of supervised physical activity in patients with PH as has been shown to be a safe and effective in managing their condition.^{4,5} Furthermore, this limited amount of physiotherapy is further restricted to those who are admitted to hospital; those

who have never had an acute admission do not typically benefit from physiotherapy input of any type.

Research evidence from similar long-term conditions is overwhelmingly supportive of physical activity and exercise as strongly indicative of better outcomes¹⁴ and there is clearly an opportunity for the physiotherapy profession to use this evidence to support improved service models and offer a range of interventions that offer advice and guidance along the lifespan of this long-term condition.

There is clear aspiration among physiotherapists and patients in this study for a physiotherapy service that goes beyond current practice and current research evidence.^{4,5} Such a service would support patients throughout the lifespan of their PH, from diagnosis to end of life: a model of care that offers rehabilitation throughout patients' experiences of living with PH; appropriate to patient needs at that point in time; and facilitating self-management at all times.¹⁴ Direct evidence for this approach is not yet available in PH and would need to be developed. However, drawing on evidence from other long-term conditions such as cancer, cystic fibrosis, or chronic obstructive pulmonary disease (COPD), it is possible to envisage physiotherapy services in PH which are able to:

- support newly diagnosed patients in learning to manage their symptoms, e.g. breathlessness within their functional activities;¹⁵
- provide early rehabilitation and enablement of acutely unwell patients during inpatient admissions;¹⁶
- promote physical activity and exercise as part of self-management of their condition;¹⁰
- enable exercise rehabilitation for patients with PH in settings that suit them, e.g. pulmonary rehabilitation;⁵
- offer ongoing support to patients to manage functional and physical changes as their disease progresses, including end-stage disease;¹⁵
- deliver pre-habilitation (exercise before intervention) to patients awaiting transplantation surgery.^{17,18}

This study suggests the need to explore options for models of patient care and patient enablement that are feasible from a practical, commissioning, cost and health culture point of view. For example, the patients contributing to this study reflected on their motivation to remain well and endorsed a shift towards health improvement and self-management with the support of physiotherapists and other healthcare professionals, in spite of their experience of physiotherapy being limited. The professional view was that patient outcomes and experience are essential to provide measures of effectiveness of physiotherapy interventions and to advance the health outcomes of a population group who have only latterly been recognized as having greater potential for longevity and quality of life. The shared vision is for health improvement whereby the patient is enabled to live better with their disease with best support from across the multidisciplinary team.

Enhanced collaboration and knowledge exchange between community and specialist PH services is required to provide the physiotherapy care that meets patient needs in the most appropriate setting. This challenges PH services to plan for integrated, multidisciplinary services that span organizational boundaries and move out of the traditional modes of delivery, and to consider opportunities for patients in alternative, non-hospital venues, e.g. community health services, sport and exercise venues, and other community facilities.¹⁴ This planning should be underpinned by professional guidelines and consensus on the use of wider evidence to support the specific needs and interventions for the PH population, in addition to enhanced educational support from specialist centers to multidisciplinary teams in local services.

Conclusion

Current UK physiotherapy for patients with PH is focused on delivery of care to acutely unwell patients in inpatient settings. Therapists would like to do more to achieve better health outcomes with this population. Functional assessment and early rehabilitation (i.e. standing, walking, and physical activity with the purpose of self-care) are important contributions but are currently limited to those PH patients admitted to specialized units. There are opportunities to intervene earlier with these patients and deliver a wider range of interventions, based on evidence of effectiveness of physical activity and health improvement for those with other long-term conditions.

For those patients who are not acutely unwell, health improvement practices and holistic functional assessment should be integral to patient care, from diagnosis to the end of life. Physiotherapy for patients should promote physical activity, functional independence, and self-management as routine management of their PH. This will require physiotherapy to apply the existing research evidence and collaborate with local services to deliver quality care in line with patient needs, throughout the lifespan of their disease.

There is a further need to design and test physiotherapy interventions for physical activity in PH that can be delivered within a variety of healthcare systems and strategies.

Strengths and limitations

This study was undertaken using purposive sampling and achieved a wide range of perspectives from physiotherapists specializing in PH, physiotherapists caring for patients with PH in non-specialist settings, and a group of active patients. While the number of physiotherapy interviews conducted was small, it included all the lead physiotherapists involved in the care of patients with PH in the seven UK specialist centers.

The patient perspective, while not representative of the whole patient population, was nevertheless informative about the aspiration to self-manage and undertake physical activity and recognized physiotherapy as a key professional group to advocate in this area.

Conflict of interest

The author(s) declare that there is no conflict of interest.

Funding

This work was supported by a grant from the Chartered Society of Physiotherapy Charitable Trust (grant no. PRF14B08).

References

1. Kiely DG, Elliot CA, Sabroe I, et al. Pulmonary hypertension: diagnosis and management. *Br Med J* 2013; 2028(April): 1–12.
2. Galiè N, Hooper MM, Humbert M, et al. European guidelines for the diagnosis and treatment of pulmonary hypertension: the Task Force for the Diagnosis and Treatment of Pulmonary Hypertension of the European Society of Cardiology (ESC) and the European Respiratory Society (ERS), endorsed by the International Society of Heart and Lung Transplantation (ISHLT). *Eur Heart J* 2009; 30(20): 2493–2537.
3. Health and Social Care Information Centre. National audit of pulmonary hypertension for 2016. 2017.
4. Babu AS, Padmakumar R, Maiya AG, et al. Effects of exercise training on exercise capacity in pulmonary arterial hypertension: a systematic review of clinical trials. *Heart Lung Circ* 2016; 25(4): 333–341.
5. Morris NR, Kermeen FD and Holland AE. Exercise-based rehabilitation programmes for pulmonary hypertension. *Cochrane Database Syst Rev* 2017; 1): CD011285.
6. National Pulmonary Hypertension Centres of the UK and Ireland. Consensus statement on the management of pulmonary hypertension in clinical practice in the UK and Ireland. *Thorax* 2008; 63(Suppl 2): ii1–ii41.
7. Task Force for the Diagnosis and Treatment of Pulmonary Hypertension of the European Society of Cardiology (ESC), European Respiratory Society (ERS), International Society of Heart and Lung Transplantation (ISHLT), et al. Guidelines for the diagnosis and treatment of pulmonary hypertension. *Eur Respir J* 2009; 34(6): 1219–1263.
8. Farmer T, Robinson K, Elliott SJ, et al. Developing and implementing a triangulation protocol for qualitative health research. *Qual Health Res* 2006; 6: 377–394.
9. Ritchie J, Spencer L and O'Connor W. Carrying Out Qualitative Analysis. In: Ritchie J and Lewis J (eds). *Qualitative Research Practice*. London: Sage, 2003.
10. Bolton C, Bevan-Smith EF, Blakey JD, et al. British Thoracic Society guideline on pulmonary rehabilitation in adults: accredited by NICE. *Thorax* 2013; 68: ii1–ii30.
11. NHS England. *Five Year Forward View*. London: NHS, 2014. Available at: <http://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf>.
12. Keen C. A small dot on a long line – physiotherapy in patients with pulmonary hypertension. In: National Centres for Sports and Exercise Medicine National Conference. Loughborough; 15 September 2017.
13. Health Technology Assessment Programme. *Commissioning Brief-Exercise Training for people with pulmonary hypertension*. Leeds: NIHR, 2017. Available at: <https://www.nihr.ac.uk/funding-and-support/documents/current-funding-opportunities/hta/17-129> Exercise training for people with pulmonary hypertension.pdf.
14. NHS England. *Commissioning Guidance for Rehabilitation*. London: NHS England, 2016.
15. Chartered Association of Physiotherapists in Cystic Fibrosis. *Standards of Care and Good Clinical Practice for the Physiotherapy Management of Cystic Fibrosis*. London: Cystic Fibrosis Trust, 2011.
16. National Cancer Action Team. *Cancer Rehabilitation: Making Excellent Cancer Care Possible*. London: National Cancer Action Team, 2013.
17. Silver JK and Baima J. Cancer prehabilitation. *Am J Phys Med Rehabil* 2013; 92(8): 715–727.
18. Tew GA, Ayyash R, Durrand J, et al. Clinical guideline and recommendations on pre-operative exercise training in patients awaiting major non-cardiac surgery. *Anaesthesia* 2018; 73(6): 750–768.