Exploring a physiotherapy well-being review to deliver community-based rehabilitation in patients with pulmonary hypertension

KEEN, Carol <http://orcid.org/0000-0001-7803-1235>, HASHMI-GREENWOOD, Molly, YORKE, Janelle, ARMSTRONG, Iain, SAGE, Karen <http://orcid.org/0000-0002-7365-5177> and KIELY, David

Published version

KEEN, Carol, HASHMI-GREENWOOD, Molly, YORKE, Janelle, ARMSTRONG, Iain, SAGE, Karen and KIELY, David (2019). Exploring a physiotherapy well-being review to deliver community-based rehabilitation in patients with pulmonary hypertension. Pulmonary Circulation, 9 (4).

Research Article

Pulmonary Circulation

Exploring a physiotherapy well-being review to deliver community-based rehabilitation in patients with pulmonary hypertension

Carol Keen[1], Molly Hashmi-Greenwood[2], Janelle York[3], Iain J Armstrong[1], Karen Sage[2] and David Kiely[4]

[1]Pulmonary Vascular Diseases Unit, Sheffield teaching Hospitals NHS Foundation Trust, Sheffield, UK; [2]Sheffield Hallam University, Sheffield, UK; [3]School of Health Sciences, UoM, Manchester, UK; [4]Room M15, Ward M2 Royal Hallamshire Hospital, Sheffield, UK

Abstract

Background: Highly structured, supervised exercise training has been shown to be beneficial in patients with pulmonary hypertension. Despite evidence of the effectiveness of community-based rehabilitation in other cardiopulmonary diseases, there are limited data in patients with pulmonary hypertension.

Methods: This prospective study evaluated the intervention of a physiotherapist well-being review in patients with pulmonary hypertension who had been established on targeted drug therapy for between 3 and 12 months. The intervention included a detailed consultation assessing functional, social and motivational status to identify individual patient rehabilitation goals and facilitate tailored referrals to community-based services.

Results: One hundred and thirty-eight patients (79% pulmonary arterial hypertension, 17% chronic thromboembolic disease), age 67 ± 14 years, diagnosed over a one year period were evaluated between July 2017 and January 2018. Fifty-two per cent of patients were referred to community-based pulmonary rehabilitation programmes, 19% received other forms of community rehabilitation, 17% were given exercise advice, 5% had an assessment of social support and 7% declined any intervention. At the end of the study, 32% of patients were undertaking independent exercise.

Conclusion: This study has identified that the majority of patients with pulmonary hypertension who are optimised on targeted drug therapy have rehabilitation needs. The use of a physiotherapy well-being review can identify this need and facilitate access to community-based rehabilitation. Further research is required to evaluate the efficacy of such interventions in pulmonary hypertension.

Keywords

pulmonary hypertension, rehabilitation, community, physiotherapy

Date received: 8 August 2019; accepted: 4 October 2019

Pulmonary Circulation 2019; 9(4) 1–9

DOI: 10.1177/2045894019885356

Introduction

Pulmonary hypertension is a life-shortening condition, varying from rare forms such as pulmonary arterial hypertension (PAH) and chronic thromboembolic pulmonary hypertension (CTEPH) for which specific interventions exist to, usually milder, elevations of pulmonary artery pressure seen in cardiac and respiratory disease.[1,2] With the development of advanced drug therapies,[3] more people than ever are living with pulmonary hypertension and for longer.[4] However, improvements in symptoms and/or survival do not necessarily reflect the physical, emotional and psychological burdens of living with pulmonary hypertension.[5] This suggests the

Corresponding author:
Carol Keen, Sheffield Teaching Hospitals NHS Foundation Trust, Glossop Road, Sheffield S10 2JF, UK.
Email: carol.keen@nhs.net

need to consider wider rehabilitative approaches in what is now a chronic condition.

There has been increasing interest and a growing evidence base for exercise training in patients with pulmonary hypertension since the first randomised controlled trial in 2006.[6] It has now been established that exercise in patients with pulmonary hypertension is safe and leads to improvements in functional ability and quality of life.[7,8] While further work is required to fully understand the physiological effects of exercise training in patients with pulmonary hypertension,[9] change in skeletal muscle function and cardiac function as well as reversal of pre-existing deconditioning are potential mechanisms.[10,11] In a systematic review of studies of exercise therapy in pulmonary hypertension, Morris et al.[12] demonstrated improvements in six-minute walk distance of 60 m as well as significant improvements in quality of life and only a single adverse event (light-headedness during exercise) across 206 study participants. The recent European Respiratory Society Task Force on exercise training in pulmonary hypertension called for supervised exercise in physically stable, deconditioned patients and for wider commissioning of rehabilitation programmes in this patient group.[13]

To date, exercise studies have focused on rehabilitation conducted in specialist pulmonary hypertension centres, including a high number of inpatient rehabilitation programmes[14–16] which are not universally available and which potentially exclude patients whose lifestyles are unable to accommodate this approach. Consequently, provision of rehabilitation for patients with pulmonary hypertension is not yet universal standard care.[17] Establishing new in-patient rehabilitation programmes where they do not exist would have considerable cost implications. Community-based rehabilitation programmes, including pulmonary rehabilitation, are widely and successfully used in the care of patients with other respiratory conditions.[18] The potential for out-patient and home-based exercise training in pulmonary hypertension has been reported.[19,20] However, while such programmes can offer greater ease of access for patients, they are likely to be delivered by staff who lack specialist knowledge of pulmonary hypertension and may therefore provide rehabilitation which is sub-optimal.

The aim of this study was to examine whether a specialist physiotherapist well-being review can identify the individual rehabilitation needs and goals of patients with pulmonary hypertension and investigate whether these needs can be addressed by referral to community-based services.

Methods

Setting

This was a prospective study of a new service that consisted of physiotherapy well-being reviews of patients with pulmonary hypertension under the care of a UK regional pulmonary hypertension specialist centre, which serves a referral population of in excess of 15 million, with more than 1600 patients receiving targeted drug therapies for pulmonary hypertension. Patients supported by the centre live in a mix of rural and urban areas, travelling up to 200 miles (approximately 6 hour commute) to attend appointments.

Study population

Patients who were commenced on targeted pulmonary hypertension drug therapy between October 2016 and October 2017 were considered for inclusion in the study. Patients underwent the initial physiotherapy well-being review between July 2017 and January 2018. Follow-up continued until the end of January 2019, 12 months after the last patient was enrolled.

Inclusion and exclusion criteria

Patient records were reviewed to identify patients suitable for physiotherapy assessment.

Patients included in the study were adults > 18 years diagnosed with pulmonary hypertension[21] who had been commenced on targeted pulmonary hypertension drug therapy within the study time period and had been established on treatment for at least 3 months but less than 12 months and attended clinic within the recruitment window. Patients were excluded from the study if they were on a pathway for pulmonary endarterectomy surgery, had recently undergone surgery, had uncorrected congenital heart disease or were seen by a shared care centre during the follow-up period (shared care arrangements exist between the specialist centre and nationally designated congenital heart disease centres). Patients who were identified, on screening, as not being stable were excluded, i.e. patients who had deteriorated since their last review or required change in their targeted pulmonary hypertension therapies. Disease severity or functional ability was not used as an inclusion or exclusion criteria.

Intervention

Physiotherapy well-being review. Patients meeting the inclusion criteria were approached by a physiotherapist specialising in pulmonary hypertension while they attended routine out-patient/day-case clinics at a pulmonary hypertension specialist centre.

Patients underwent a well-being[22] review conducted by the physiotherapist. This is a novel intervention newly devised for this study based on the clinical experience of the physiotherapist and other members of the multidisciplinary team. The physiotherapist conducted a well-being review which took the form of an individualised one-to-one clinical assessment capturing objective and subjective information to identify the patients' current functional ability and exercise activity. The information was assimilated to identify rehabilitation needs and

functional and rehabilitation goals before discussing and agreeing with the patient suitable options for onward rehabilitation referral. Well-being reviews typically lasted between 15 and 45 min depending on the individual patient.

The physiotherapist captured a detailed history including the presence or absence of comorbidities; social and economic status; functional ability, limitations and independence; weight and diet behaviour; current and previous levels of physical activity and exercise; emotional well-being; participation in work, education, training or recreation; experiences, beliefs and attitudes to exercise and physical activity; motivation for rehabilitation and change. Where available, information was also captured from carers to gain further detail and insight into the patients' experience of living with pulmonary hypertension and its impact on the lives of the patient and those around them.

Physical examination included height, weight, body-mass index, oxygen saturations, heart rate, blood pressure and assessment for the presence or absence of heart failure. WHO functional class,[2] emPHasis-10 quality of life score,[23] Incremental Shuttle Walking Test distance (ISWT)[24,25] and right heart catheter results were also noted.

All of the objective markers are clinical measures routinely used in the specialist centre in which the study was conducted. No additional assessments, beyond those which are routinely used in clinical assessment, were carried out for the study.

The well-being review offer and structured content was common for each patient, regardless of their diagnosis or WHO functional class. A universal structure was followed for every review; however, the detailed content of each individual's review and their expected outcomes varied in response to each patient's status and needs which were identified for each individual during the well-being review.

Community referral. The physiotherapist drew on the findings of the well-being review to identify primary patient characteristics and establish functional priorities and goals for rehabilitation. From this, discussions were held with patients to identify the most suitable method to address their rehabilitation needs and goals (Fig. 1). This could include onward referral to community rehabilitation (pulmonary rehabilitation, community or domiciliary therapy, musculo-skeletal physiotherapy), exercise advice or an assessment for social support. Full details of rehabilitation services used in the study are given in Table 1. Where patients declined support, advice or referral to rehabilitation, they were given written information on ways to increase levels of physical activity.

Safety and specialist support. To address the potential lack of knowledge of pulmonary hypertension in local rehabilitation programmes, detailed information concerning the patient and the condition were provided within referrals. This included information on the characteristics of pulmonary hypertension and specific guidance on any limitations to exercise for each patient. Additionally, each patient was advised on safe exercise practice for them. Community rehabilitation services have their own risk assessment and safety procedures in place which will be applied to all patients taking part in rehabilitation. The pulmonary hypertension specialist physiotherapist was available to service

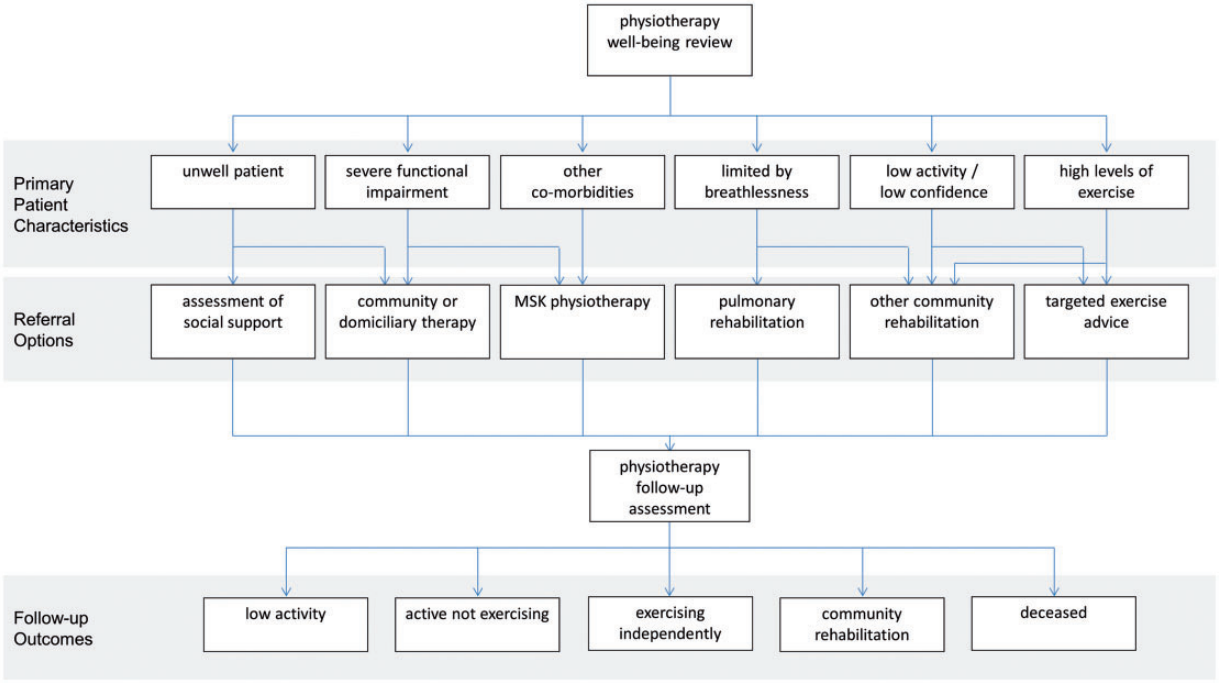

Fig. 1. Diagnostic process map.

Table 1. Referral options offered to patients during the study.

Referral options	Details
Pulmonary rehabilitation	Pulmonary rehabilitation is an interdisciplinary programme of care for patients with chronic respiratory impairment comprised of individualised exercise programmes and education.[26]
Community or domiciliary therapy	Patients with poor mobility, history of falls or with limited functional independence can benefit from a therapy assessment at home by physiotherapy or occupational therapy. This may result in, e.g. home adaptations or equipment provision; improved functional ability; referral to care services which can help to prolong independence and avoid hospital admission.
Musculo-skeletal physiotherapy	Some patients, while limited by breathlessness, cite other comorbidities which are the limiting factors in their physical activity, e.g. knee or back pain, which can be addressed through specialist physiotherapy assessment.
Other community rehabilitation	A wide range of rehabilitation programmes are provided by local authorities and charities which provide exercise, activity and social activity in a variety of community settings. Examples include exercise-on-prescription schemes, community walking groups, singing for health; tai chi groups etc.
Exercise advice – low level exercise	Patients with very sedentary lifestyles were offered advice on small incremental steps to becoming more active and supported to develop confidence in their physical capabilities, with a view to engaging them in other future rehabilitation activities.
Exercise advice – high level exercise	Patients who were already exercising regularly were given advice on guidelines regarding the amount and type of exercise recommended This needs to be added as a reference as follows: NHS England Physical Activity Guidelines (2018) https://www.nhs.uk/live-well/exercise/ and approaches to staying motivated and adapting exercise routines to change in circumstances.
Assessment of social support	Where patients were too unwell to undertake any form of rehabilitation, levels of home social and functional support were identified and addressed as needed.

providers and patients for any queries during the rehabilitation period, including those relating to patient safety during exercise. Data were not formally collected on the number and nature of these queries. Details of contacts with third parties were recorded in contemporaneous clinical patient notes.

Follow-up outcomes. Patients were seen on their return to clinic (typically between three and six months after their initial physiotherapy well-being review) and reassessed by the physiotherapist. Repeat measures for ISWT and emPHasis10 were extracted from routine clinical data. Current levels of patient activity were subjectively assessed (Table 2) through clinical interview by the physiotherapist along with information regarding whether the patient had attended or completed any rehabilitation programmes and the reasons behind this. Where indicated by clinical assessment and discussion with the patient, referral to further rehabilitation services or targeted exercise advice was provided (Fig. 1). The physiotherapy goal was to continue to support patients until they were exercising independently or with the support of a long-term community rehabilitation programme, or until the physiotherapist judged that the patient was as active as they were likely to be within the constraints of their functional ability and motivation.

Additional data. Information was logged throughout the project to capture practical or process issues that limited or facilitated the smooth administration of the intervention. This was obtained through contemporaneous clinical notes which were taken at each patient clinic visit and also on any patient-related activity, e.g. patient phone calls, referral correspondence and contact with third parties involved in the patient care or provision of rehabilitation services.

Table 2. Levels of patient activity.

Activity levels	Details
Low activity	These patients would be largely based at home, rarely going out. They might perhaps be supported by carers and live on a single level or have a stair lift
Active not exercising	Patients who are able to get about and participate in domestic activities of daily living, social or work activities
Community rehabilitation	Regularly engaging in a community rehabilitation programme
Exercising independently	Going to the gym, carrying out a home exercise programme, regular walks for exercise

Statistical analysis

Descriptive statistics including mean, standard deviation and range were used to analyse patient demographic and outcomes from the physiotherapy well-being review.

Results

Study population

Of 310 patients screened for entry into the study, 172 were excluded (see Table 3 for reasons) leaving a total of 138 patients who received a physiotherapy well-being review.

Patient demographics are shown in Table 4. The majority of patients had PAH (79%), while 17% had a diagnosis of CTEPH, comprising either inoperable disease or residual disease following surgery and 4% had Group 5 pulmonary hypertension.[1]

The study population included patients with a wide range of disease severity and functional ability as shown by the variation in values at diagnosis for mPAP (25–81 mmHg), ISWT (0–720 m) and emPHasis10 (score of 2–50) as shown in Table 4.

Community referrals

The most common outcome from the physiotherapy well-being review was referral to local pulmonary rehabilitation programmes (52%). Referrals to other forms of community-based rehabilitation were made for 19% of patients; this included one patient who was initially referred for pulmonary rehabilitation but transferred to cardiac rehabilitation by the service provider and another who was referred to cardiac rehabilitation due to a myocardial infarction in the preceding three months. A further 17% of patients were given exercise advice and the 5% who were identified as being too unwell to benefit from rehabilitation had an assessment of their social support at home (Table 5). Seven per cent of patients had an identified rehabilitation need, but declined the opportunity of a referral and were instead given written advice on increasing their levels of physical activity.

During email or phone call contact regarding referrals or advice, clinicians in local services reported that they valued

Table 3. Reasons for exclusion from study.

Reason for exclusion n = 172	Number of patients (%)
Not reviewed/did not attend a clinic appointment within study time period	68 (39.5)
Seen by shared care centre (congenital heart disease)	59 (34.3)
On a pathway for pulmonary endarterectomy	33 (19.2)
Not stable on current PH treatment	6 (3.5)
Uncorrected congenital heart disease under local follow-up	4 (2.3)
Recently undergone surgery	1 (0.6)
Pregnancy	1 (0.6)

PH: pulmonary hypertension.

Table 5. Physiotherapy well-being review results.

Well-being review outcome, n = 138	Number of patients (%)
Pulmonary rehabilitation	72 (52.2)
Exercise advice given – high-level function	17 (12.3)
Community or domiciliary therapy	16 (11.6)
Patient declined support	9 (6.5)
Exercise advice given – low-level function	7 (5.1)
Other community rehabilitation	9 (6.5)
Assessment of social support	7 (5.1)
MSK physiotherapy referral	1 (0.7)

MSK: musculo-skeletal.

Table 4. Patient demographics at diagnosis.

Characteristics	PAH (n = 109)	CTEPH (n = 23)	Other (n = 6)	All (n = 138)
Age, mean (SD), y	66.4 (14.3)	73.3 (10.2)	63.7 (10.1)	67.5 (13.8)
Female, no. (%)	77 (70.1)	9 (39.1)	2 (33.3)	88 (63.8)
WHO FC, no. (%)				
Class II	1 (0.9)	1 (4.3)	0 (0)	2 (1.4)
Class III	85 (78.0)	21 (91.3)	6 (100.0)	112 (81.2)
Class IV	23 (21.1)	1 (4.3)	0 (0.0)	24 (17.4)
ISWT, mean (range), m	124 (0–590)	190 (0–720)	163 (40–320)	137 (0–720)
Haemodynamics				
mPAP, mean (SD), mmHg	49 (±12)	45 (±11)	42 (±5)	48 (±12)
mRAP, mean (SD), mmHg	11 (±6)	10 (±4)	9 (±8)	11 (±6)
PAWP, mean (SD), mmHg	11 (±5)	11 (±4)	10 (±4)	11 (±5)
CO (l/min)	3.85 (±1.69)	3.87 (±1.21)	3.5 (±1.07)	3.84 (±1.58)
CI (l/min/m^2)	2.09 (±0.83)	2.04 (±0.57)	1.64 (±0.39)	2.06 (±0.78)
PVR (dynes/m^2)	896 (±486)	672 (±306)	806 (±313)	855 (±459)
emPHasis10, mean (SD), score out of 50	31 (±11)	28 (±11)	29 (±5)	31 (±11)

WHO FC: World Health Organization functional class; PAH: pulmonary arterial hypertension; CTEPH: chronic thromboembolic pulmonary hypertension. Haemodynamics measure at right heart catheterisation: mRAP: mean right atrial pressure; mPAP: mean pulmonary arterial pressure; PAWP: pulmonary arterial wedge pressure; CO: cardiac output; CI: cardiac index; PVR: pulmonary vascular resistance.

the triage of patients by a physiotherapist specialising in pulmonary hypertension prior to referral as well as acknowledging that easy access to the expertise of the physiotherapist increased their understanding and confidence in rehabilitation of this patient group. Challenges arose when making referrals for six patients where pulmonary rehabilitation was the preferred referral option but was not commissioned for patients with pulmonary hypertension within their area. In three instances, this was resolved through discussion with service providers; where this was not possible, alternative rehabilitation arrangements were made.

Patients in the study lived in a wide geographical area, covering the centre of the UK, with the furthest patient living over 150 miles away. Reflective of this geographical spread, referrals were made to 69 rehabilitation services across the region.

Safety and specialist support

No safety issues were reported by patients during clinical assessments or by rehabilitation service providers during discussions of referrals or requests for advice, although information on adverse events was not actively sought. In some instances, providers of services contacted the referring physiotherapist to clarify guidance on rehabilitation protocols for individual patients or in general for patients with pulmonary hypertension.

Follow-up outcomes

Of the 74 patients referred to pulmonary or cardiac rehabilitation programmes, 36 (48%) completed the full rehabilitation programme, 14 (19%) started rehabilitation and did not complete, while 24 (32%) did not start. At follow-up assessment, common reasons given by patients for non-completion included other health problems, difficulty travelling to rehabilitation and lengthy waiting times to commence rehabilitation. Some patients with work or caring responsibilities reported that the timing of pulmonary rehabilitation classes (which tend to be during the working day) did not meet their needs, while others found the programmes to be targeted at patients with COPD and therefore not well suited to them.

Measurements for ISWT and emPHasis10 were taken for 104 patients before and after rehabilitation. These data were collected at routine clinic appointments and therefore do not directly coincide with start and end of rehabilitation; the time period between measures varied from 3 to 12 months. Fifty-eight (42%) patients showed an improvement in functional ability (increase in ISWT of $\geq$40 m) or an improvement in quality of life (increase in emPHasis10 of 6 or more (out of 50)).

At follow-up, clinical assessment was made by the physiotherapist of the patients' current level of activity (Table 6). The largest group (38%) were considered to be active, but not exercising, while 32% were exercising independently. Low levels of activity were identified in 21% of patients, while 6% were engaged in community rehabilitation.

Table 6. Follow-up outcomes.

Follow-up outcome n = 138	Number of patients (%)
Active, not exercising	52 (37.7)
Exercising independently	44 (31.9)
Low levels of activity	29 (21.0)
Community rehabilitation	6 (4.3)
Deceased	7 (5.1)

Discussion

Need for rehabilitation

This study has shown that the majority of patients with pulmonary hypertension receiving targeted drug therapy within the first year of diagnosis have rehabilitation needs. The use of a well-being review delivered by a physiotherapist specialising in pulmonary hypertension can identify this need and facilitate access to community-based rehabilitation.

To our knowledge, this is the first study to establish the extent of the need for rehabilitation in newly diagnosed patients with pulmonary hypertension who are optimised on targeted drug therapy. With 88% of patients receiving either referral for exercise rehabilitation or targeted exercise advice, the study results demonstrate a clear need for the provision of rehabilitation for patients with pulmonary hypertension to enhance their well-being. By engaging patients in rehabilitation once they are optimised on drug therapy, there is an opportunity to build on the functional gains that might be achieved through pharmaceutical support to achieve further improvements in well-being. Further work is required to identify optimal timing of these interventions and the nature and extent of change that can be made to patient well-being; however, Fig. 2 is an illustration which indicates the potential gains achievable through timely rehabilitation interventions.[12,27]

Uptake of rehabilitation

Along with high levels of need, there were high levels of engagement with rehabilitation in the study. Referrals to pulmonary rehabilitation were accepted by 54% of patients and to other community-based rehabilitation by 17% of patients. Despite reports from some patients that they found their pulmonary rehabilitation to be focused on COPD and therefore not always entirely suited to them, commencement and completion rates for pulmonary rehabilitation at 68% and 48%, respectively, are comparable with data for pulmonary rehabilitation in patients with

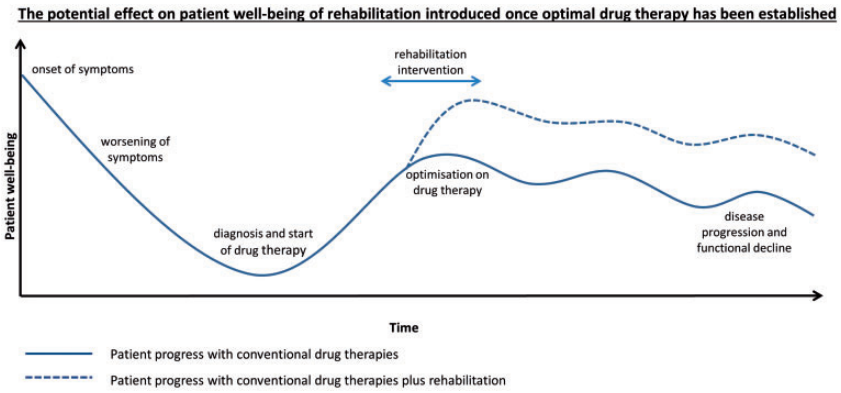

Fig. 2. The potential effect of rehabilitation on patient well-being.

COPD where 67% commenced and 46% completed rehabilitation.[28] Further research into the effectiveness and cost-effectiveness of pulmonary rehabilitation in patients with pulmonary hypertension is currently underway.[29]

The levels of physical activity at follow-up, with 32% of patients exercising independently and 6% participating in community rehabilitation programmes, are indicative of the potential for rehabilitation in patients with pulmonary hypertension. In studies of exercise training in patients with pulmonary hypertension, Chan et al.[30] and Weinstein et al.[31] both demonstrate significant increases in levels of physical activity in patients undergoing rehabilitation as measured by physical activity questionnaires. Further work is required to explore outcomes relating to physical activity, which might include patient report outcomes measures or wearable devices,[32] to determine their potential use in pulmonary hypertension rehabilitation.

The current study was universal in its inclusion, assessing and treating patients with even the most severe disease whose outcomes might be expected to be poor. Despite this, and despite the progressive nature of the disease, our data show some positive indications that the intervention can improve function and quality of life.

Inclusive rehabilitation

The intervention in this study was able to meet the diverse rehabilitation needs of this complex patient group. Patients with pulmonary hypertension vary significantly in terms of age, functional ability, disease history and severity. While some patients with pulmonary hypertension are significantly limited functionally, others might be in work or have caring responsibilities. This, combined with the wide geographical spread of patients from their regional specialist centres, can make delivery of rehabilitation challenging. Patients will have preferences for the time, location and nature of the rehabilitation in which they are prepared to engage. The physiotherapy well-being review and onward referral to community rehabilitation are able to accommodate this wider rehabilitation and thus suggest the requirement for rehabilitation solutions tailored to the individual rather than one-size-fits-all solutions.

This study was pragmatic in design and shows that it is feasible to deliver community-based rehabilitation to patients with pulmonary hypertension within existing healthcare service provision. Participants were not required to attend any additional appointments; instead, their well-being review took place around the normal clinical activity of a standard clinical visit. The rehabilitation services accessed by patients in this study were pre-existing and widely available in community settings, without the need to establish bespoke and potentially expensive services for patients with pulmonary hypertension.

Role of the physiotherapist

The expertise of the specialist physiotherapist was important in ensuring that the community-based rehabilitation met the needs of patients with pulmonary hypertension. Professionals delivering rehabilitation in community settings will be experts in rehabilitation, but may have limited knowledge of its application in this rare disease. The specialist physiotherapist role offers a combined expertise in pulmonary hypertension and rehabilitation along with access to the resources of a specialist pulmonary hypertension referral centre. They share a professional language and framework of understanding of rehabilitation with community providers. By delivering detailed expert referrals and being easily available for questions or concerns, the specialist physiotherapist has facilitated the provision of effective community-based rehabilitation to a complex patient group with a rare disease.

The specialist physiotherapist also had an important role to play in supporting the safety of the intervention. Within the physiotherapy well-being review, patients who were identified as higher risk for exercise were directed towards more closely supervised rehabilitation programmes, e.g. pulmonary rehabilitation which offers physiotherapy and nursing support to patients. Detailed information concerning the patient and the condition were provided in referrals, and patients were advised on safe exercise practice.

The optimal model of rehabilitation in pulmonary hypertension has yet to be determined and may vary according to country or setting,[10] but it is likely that any sustainable expansion of rehabilitation in pulmonary hypertension will require an associated expansion of physiotherapy provision for patients with pulmonary hypertension and in education and access to resources for community-based rehabilitation services. This study demonstrates a model of care for rehabilitation which allows patients to access a community rehabilitation service local to them while maintaining the support and access to the expertise of their specialist centre. The tailored, individualised approach allows the best rehabilitation solution to be delivered to patients based on their needs, rather than offering a one-size-fits-all solution. Physiotherapy skills and knowledge have been at the core of the intervention and its outcomes.

Next steps

The positive indication for the outcomes of functional ability and quality of life and the practical success of the study suggests that more work should be done to establish its effectiveness in comparison to a control group. The next step would be to undertake a feasibility study of a randomised controlled trial of the intervention to establish efficacy of the intervention and benefit to patients. The acceptability of the intervention to patients and clinicians would also need to be examined along with the outcome measures best-suited to capturing the impact of such interventions. It is important to explore the importance of patient well-being and rehabilitation in the commissioning of pulmonary hypertension specialist services.

Limitations

The pragmatic nature of this study leads to limitations which are manifest in the variable timeframes over which follow-up outcomes were collected. Outcomes were not uniformly separated by time, nor specifically aligned with the start and finish of patient rehabilitation which may detract for their effectiveness in detecting change. Levels of physical activity were not captured at the outset of the study, and therefore it was not possible to compare values before and after the intervention, which would have enhanced the study results. Reflective of the real-world nature of the study, there is no control of the content or quality of the rehabilitation undertaken by patients. While no major adverse events were reported by rehabilitation providers or patients, we cannot rule out the occurrence of minor events; this would be better addressed in a controlled trial.

Conclusion

The study has identified an unmet need in the provision of rehabilitation to patients with pulmonary hypertension who are optimised on targeted drug therapy. The use of a physiotherapy well-being review can identify this need and facilitate access to community-based rehabilitation. Further research is required to evaluate the efficacy of such interventions in pulmonary hypertension.

Authors' contribution

Carol Keen: Made a substantial contribution to the concept or design of the work; or acquisition, analysis or interpretation of data, drafted the article or revised it critically for important intellectual content; approved the version to be published.
Molly Hashmi-Greenwood: Made a substantial contribution to the concept or design of the work.
Janelle Yorke: Revised the article critically for important intellectual content; approved the version to be published.
Iain Armstrong: Revised the article critically for important intellectual content; approved the version to be published.
Karen Sage: Made a substantial contribution to the concept or design of the work; revised the article critically for important intellectual content; approved the version to be published.
David Kiely: Made a substantial contribution to the concept or design of the work; revised the article critically for important intellectual content; approved the version to be published.

Conflict of interest

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

Ethical approval

This study was conducted under the service evaluation framework of Sheffield Teaching Hospitals. Access to additional clinical data was obtained through the ASPIRE data registry which has ethical approval via the UK NHS Health Research Authority (16/YH/0352).

Clinical consent was obtained prior to each patient's well-being review.

Funding

Carol Keen was funded by an unrestricted educational grant from PHA UK (the UK patient charity for pulmonary hypertension) and Actelion Pharmaceuticals during the time that the service evaluation was conducted.

Guarantor

All authors take full responsibility for the integrity of the submission as a whole.

ORCID iD

Carol Keen https://orcid.org/0000-0001-7803-1235

References

1. Kiely DG, Elliot CA, Sabroe I, et al. Pulmonary hypertension: diagnosis and management. *Br Med J* 2013; 346(7904): 31–35.

2. Galiè N, Humbert M, Vachiery J, et al. 2015 ESC/ERS Guidelines for the diagnosis and treatment of pulmonary hypertension. *Eur Heart J* 2016; 37(1): 67–119.
3. Simonneau G, Montani D, Celermajer DS, et al. Haemodynamic definitions and updated clinical classification of pulmonary hypertension. *Eur Respir J* 2019; 53: 1801913.
4. McGoon MD, Benza RL, Escribano-Subias P, et al. Pulmonary arterial hypertension: epidemiology and registries. *J Am Coll Cardiol* 2013; 62(25): D51–D59.
5. McGoon MD, Ferrari P, Armstrong I, et al. The importance of patient perspectives in pulmonary hypertension. *Eur Respir J* 2019; 53(1): 1801919.
6. Mereles D, Ehlken N, Kreuscher S, et al. Exercise and respiratory training improve exercise capacity and quality of life in patients with severe chronic pulmonary hypertension. *Circulation* 2006; 114(14): 1482–1489.
7. Leggio M, Fusco A, Armeni M, et al. Pulmonary hypertension and exercise training: a synopsis on the more recent evidences. *Ann Med* 2018; 50(3): 226–233.
8. Benjamin N, Marra AM, Eichstaedt C, et al. Exercise training and rehabilitation in pulmonary hypertension. *Heart Fail Clin* 2018; 14(3): 425–430.
9. 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.
10. Johnson MK and Peacock AJ. Treating pulmonary arterial hypertension with exercise: the role of rehabilitative medicine. *Adv Pulm Hyperten* 2019; 18(2): 56–62.
11. Nogueira-Ferreira R, Moreira-Gonçalves D, Santos M, et al. Mechanisms underlying the impact of exercise training in pulmonary arterial hypertension. *Respir Med* 2018; 142: 70–78.
12. Morris N, Kermeen F and Holland A. Exercise-based rehabilitation programmes for pulmonary hypertension. *Cochrane Datab Syst Rev* 2017; 1.
13. Grünig E, Eichstaedt C, Barberà J, et al. ERS statement on exercise training and rehabilitation in patients with severe chronic pulmonary hypertension. *Eur Respir J* 2018; 53: 1800332.
14. Grünig E, Lichtblau M, Ehlken N, et al. Safety and efficacy of exercise training in various forms of pulmonary hypertension. *Eur Respir J* 2012; 40(1): 84–92.
15. Grünig E, Ehlken N, Ghofrani A, et al. Effect of exercise and respiratory training on clinical progression and survival in patients with severe chronic pulmonary hypertension. *Respiration* 2011; 81(5): 394–401.
16. Ehlken N, Lichtblau M, Klose H, et al. Exercise training improves peak oxygen consumption and haemodynamics in patients with severe pulmonary arterial hypertension and inoperable chronic thrombo-embolic pulmonary hypertension: a prospective, randomized, controlled trial. *Eur Heart J* 2016; 37: 35–44.
17. Keen C, Fowler-Davis S, McLean S, et al. Physiotherapy practice in pulmonary hypertension: physiotherapist and patient perspectives. *Pulm Circ* 2018; 8(3): 2045894018783738.
18. Rochester CL, Vogiatzis I, Holland AE, et al. An official American Thoracic Society/European Respiratory Society policy statement: enhancing implementation, use, and delivery of pulmonary rehabilitation. *Am J Respir Crit Care Med* 2015; 192: 1373–1386.
19. Babu AS, Padmakumar R, Nayak K, et al. Effects of home-based exercise training on functional outcomes and quality of life in patients with pulmonary hypertension: a randomized clinical trial. *Indian Heart J* 2019; 71: 161–165.
20. Bussotti M, Gremigni P, Pedretti RFE, et al. Effects of an outpatient service rehabilitation programme in patients affected by pulmonary arterial hypertension: an observational study. *Cardiovasc Hematol Disorder Drug Targets* 2017; 17: 3–10.
21. Simonneau G, Gatzoulis MA, Adatia I, et al. Updated clinical classification of pulmonary hypertension. *J Am Coll Cardiol* 2013; 62: D34–D41.
22. Department of Health and Social Care. Care Act Statutory Guidance, October, https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance.
23. Yorke J, Corris P, Gaine S, et al. emPHasis-10: development of a health-related quality of life measure in pulmonary hypertension. *Eur Respir J* 2014; 43(4): 1106–1113.
24. Billings CG, Hurdman JA, Condliffe R, et al. Incremental shuttle walk test distance and autonomic dysfunction predict survival in pulmonary arterial hypertension. *J Heart Lung Transplant* 2017; 36(8): 871–879.
25. Billings CG, Lewis R, Hurdman JA, et al. The incremental shuttle walk test predicts mortality in non-group 1 pulmonary hypertension: results from the ASPIRE Registry. *Pulm Circ* 2019; 9(2): 1–9.
26. Bolton CE, Bevan-Smith EF, Blakey JD, et al. British Thoracic Society Guideline on Pulmonary Rehabilitation in adults. *Thorax* 2013; 68: ii1–ii30.
27. Pandey A, Garg S, Khunger M, et al. Efficacy and safety of exercise training in chronic pulmonary hypertension: systematic review and meta-analysis. *Circ Heart Fail* 2015; 8(6): 1032–1043.
28. Garrod R, Marshall J, Barley E, et al. Predictors of success and failure in pulmonary rehabilitation. *Eur Respir J* 2006; 27: 788–794.
29. McGregor G. Supervised Pulmonary Hypertension Exercise Rehabilitation (SPHERe) trial, www.journalslibrary.nihr.ac.uk/programmes/hta/1712902/#/ (2019, accessed 16 October 2019).
30. Chan L, Chin LMK, Kennedy M, et al. Benefits of intensive treadmill exercise training on cardiorespiratory function and quality of life in patients with pulmonary hypertension. *Chest* 2013; 143(2): 333–343.
31. Weinstein A, Chin L, Keyser R, et al. Effect of aerobic exercise training on fatigue and physical activity in patients with pulmonary arterial hypertension. *Respir Med* 2013; 107: 778–784.
32. Sehgal S, Chowdhury A, Rabih F, et al. Counting steps: a new way to monitor patients with pulmonary arterial hypertension. *Lung* 2019; 197(4): 501–508.