

Informal carers and peer support in pulmonary rehabilitation: an underutilized resource?

Patel, Suhani; Man, William D-C; Roberts, Nicola J.

Published in:
Current Opinion in Supportive and Palliative Care

DOI:
[10.1097/SPC.0000000000000517](https://doi.org/10.1097/SPC.0000000000000517)

Publication date:
2020

Document Version
Author accepted manuscript

[Link to publication in ResearchOnline](#)

Citation for published version (Harvard):
Patel, S, Man, WD-C & Roberts, NJ 2020, 'Informal carers and peer support in pulmonary rehabilitation: an underutilized resource?', *Current Opinion in Supportive and Palliative Care*, vol. 14, no. 3, pp. 213-218.
<https://doi.org/10.1097/SPC.0000000000000517>

General rights

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

Take down policy

If you believe that this document breaches copyright please view our takedown policy at <https://edshare.gcu.ac.uk/id/eprint/5179> for details of how to contact us.

Engagement of informal carers and peer support in pulmonary rehabilitation.

Miss Suhani Patel¹ s.patel1@rbht.nhs.uk

Dr William D-C Man^{1,2} w.man@rbht.nhs.uk

Dr Nicola Roberts³ nicola.roberts@gcu.ac.uk

Affiliations:

1. Harefield Respiratory Research Group, Harefield Hospital, UK
2. National Heart and Lung Institute, Imperial College London, UK
3. School of Health and Life Sciences, Glasgow Caledonian University, UK

Word count: 918/2500

Informal carers provide support to the elderly, disabled or unwell in a non-professional capacity. This may include help with household tasks, such as shopping or cleaning, helping with medical procedures or medications at home, personal care, as well as emotional support. This care is provided at no additional cost to the National Health Service, and represents work worth in the region of £132 billion per year (1). However, despite this huge contribution, the importance of informal care is often overlooked. With the increasing shift towards caring for people in the community, rather than an admission to secondary care, such as hospital-at-home and early supportive discharge initiatives, where there is a reduced burden on healthcare services, this may in part be transferred to the informal carer or family member.

Additionally, the role of the caregiver may include providing transport (2), which is pertinent in the context of pulmonary rehabilitation, where lack of appropriate transport is a significant barrier to attendance and completion of a course. Engagement of the caregiver in understanding the benefits of pulmonary rehabilitation, and the associated reduction in input required from them in the longer term may encourage supporting attendance at a programme. Peer social support has been highlighted as a

theme from focus groups investigating factors that patients perceive as important in maintaining an active lifestyle after completing a course of pulmonary rehabilitation (3).

Acting as a carer for another can be detrimental to the caregiver themselves, where they may experience high levels of stress and may neglect their own healthcare needs in lieu of prioritising those of the person they care for.

A few studies have explored the impact of engaging informal carers in pulmonary rehabilitation, including having family members attend once-weekly for psychosocial support and education sessions during a 12-week exercise training programme (4). The authors reported excellent compliance to the programme in the intervention group, with a mean attendance rate of 92%. This was found to improve the coping strategies of the family, as well as the patient, as measured using the Family Crisis Orientated Personal Scale (F-COPES). However, this group was primarily limited to those with moderate breathlessness and mild-to-moderate COPD, and may not reflect the additional burden that might be expected as the patient deteriorates or ages and additional support is required. Further work looking at interventions to support informal carers of those with more severe disease, or those in the post-acute exacerbation period would be valuable. The study reports a single-blinded, randomised controlled trial, however it is difficult to understand how blinding of the participants was achieved, in light of either being involved in the psychosocial support and education sessions, or not.

However, this intervention may not suit all carers, particularly those who are still working, as it requires a significant additional time commitment. Attendance of a patient at a pulmonary rehabilitation course may represent a reduced burden on the caregiver, in knowing that they are in a safe environment being supervised by healthcare professionals, and provide a small amount of respite for the carer. Provision of a condensed programme may be an alternative method that should be assessed for efficacy.

Peer support is the provision of help from an equal; in the context of the pulmonary rehabilitation setting, this may be through simply attending the course, where patients necessarily find themselves

in a cohort with other patients with a lung condition, who they may otherwise not come across. Due to their breathlessness limiting their ability to socialise, patients with COPD may find themselves isolated not only from others living with the same condition, but also in the wider community (5).

Peer support may also lend benefits to a pulmonary rehabilitation programme, with an exploratory focus group of patients with COPD concluding that a peer-support model may be a viable means of improving long-term outcomes (6). Despite this, a study implementing telephone-based support delivered by a peer educator as a post-pulmonary rehabilitation maintenance programme was not more effective than usual care in maintaining 6-minute walk distance or health-related quality of life, measured using the St George's Respiratory Disease questionnaire (7). It is important to note that telephone support from a respiratory healthcare professional was also found to be no different than usual care, which might suggest that the intervention, rather than the person delivering it, is the more important factor. This is emphasised in the difficulties in maintaining the established benefits of pulmonary rehabilitation in the long-term without continued healthcare worker input.

The engagement of patients with COPD with prior experience of pulmonary rehabilitation as lay health workers has been explored in a feasibility trial, which demonstrated that this population can be recruited and trained in supporting newly referred patients with COPD through a course of pulmonary rehabilitation (8). The lay health workers were provided with training in confidentiality and had ongoing support from the study team in the form of eight mentoring meetings over the course of the intervention. An important consideration for this type of intervention is the changing circumstances of the lay health worker; of 20 patients offered training, 12 were able to support patients newly referred for pulmonary rehabilitation, and 10 were retained until the end of the study. Additionally, while the study demonstrated that a study incorporating this intervention was feasible and acceptable to both patients and the lay health worker, there was no reference to whether the preliminary data showed a trend towards improving uptake and completion of pulmonary rehabilitation in the newly referred patient group, however the full-scale trial will address this.

1. State of Caring. A snapshot of unpaid care in the UK. 2019 July 2019. Report No.: UK4079_0719.
2. Harris D, Hayter M, Allender S. Improving the uptake of pulmonary rehabilitation in patients with COPD. qualitative study of experiences and attitudes. 2008;58(555):703-10.
3. Hogg L, Grant A, Garrod R, Fiddler H. People with COPD perceive ongoing, structured and socially supportive exercise opportunities to be important for maintaining an active lifestyle following pulmonary rehabilitation: a qualitative study. *Journal of Physiotherapy*. 2012;58(3):189-95.
4. Marques A, Jácome C, Cruz J, Gabriel R, Brooks D, Figueiredo D. Family-based psychosocial support and education as part of pulmonary rehabilitation in COPD: a randomized controlled trial. *Chest*. 2015;147(3):662-72.
5. Williams V, Bruton A, Ellis-Hill C, McPherson K. What really matters to patients living with chronic obstructive pulmonary disease? An exploratory study. *Chronic respiratory disease*. 2007;4(2):77-85.
6. Poureslami I, Camp P, Shum J, Afshar R, Tang T, FitzGerald JM. Using Exploratory Focus Groups to Inform the Development of a Peer-Supported Pulmonary Rehabilitation Program. *Journal of cardiopulmonary rehabilitation and prevention*. 2017;37(1):57-64.
7. Wong EY, Jennings CA, Rodgers WM, Selzler A-M, Simmonds LG, Hamir R, et al. Peer educator vs. respiratory therapist support: Which form of support better maintains health and functional outcomes following pulmonary rehabilitation? *Patient education and counseling*. 2014;95(1):118-25.
8. White P, Gilworth G, Lewin S, Hogg L, Tuffnell R, Taylor SJ, et al. Improving uptake and completion of pulmonary rehabilitation in COPD with lay health workers: feasibility of a clinical trial. *International journal of chronic obstructive pulmonary disease*. 2019;14:631.