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Access, access, access: the Three A's of pulmonary rehabilitation – perspectives of patients, loved ones and healthcare professionals

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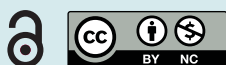
To the Editor:

Improving access to pulmonary rehabilitation (PR) is a worldwide priority [1]. Evidence suggests that those who are more symptomatic, with frequent hospitalisations and whose health status and ability to exercise and perform activities of daily living is worse, are also the ones who respond better [2] and should be referred/prioritised to PR [3]. We explored whether these criteria are aligned with the perspectives of people with chronic respiratory diseases (CRDs), their loved ones (LOs) and healthcare professionals (HCPs).

We conducted seven focus groups with people with CRDs (n=29), LO (n=5) and HCPs (n=16) recruited using purposive/snowballing sampling strategies from two hospitals, two primary healthcare centres and one institutional practice. Ethical approvals were obtained (UAI F 83/2019; P517-08/2018 and 086892). People with CRDs were eligible if they were adults with CRDs and had participated in PR at least once. LOs were eligible if they were adults having a significant/personal relationship with the person with a CRD and provided physical/practical, social, financial and/or emotional support [4]. HCPs were eligible if they had been involved in at least one PR programme. Participants were approached face-to-face and informed consents were obtained. Data collection occurred separately with each stakeholder in a different setting; no prior relationship with the interviewer existed; a semi-structured, pilot-tested interview guide was used; interviews were audio-recorded; and field notes were taken. Data were analysed with inductive thematic analysis. An external researcher reviewed the interview guide, code descriptions, themes/subthemes and participant quotations. Findings were: confirmed by two researchers, triangulating the method of collection (interviews and field notes); validated by participants (two people with CRDs and two HCPs); and discussed among team members and with the external researcher.

People with CRDs had a mean±SD age of 68±8 years, were mostly male (76%) and had a diagnose of COPD (82%) or interstitial lung disease (ILD) (17%). LOs were on average 67±8 years of age, female (100%), mostly spouses (80%) and had been caring for >4 years (80%). HCPs were on average 38±9 years, mostly female (75%) and had been working in hospitals for >14 years (63%). Focus groups lasted on average 47±15 min. Three common core themes were identified (figure 1).

All stakeholders felt that, in a favourable scenario, having criteria to access PR was somewhat unfair, and having a mix of less and more disabled people would be beneficial to their social experience. Nevertheless, HCPs felt it to be easier to work with homogeneous groups. They recognised the importance of comprehensive assessment and discussion with a multidisciplinary team, to guide personalised PR. Both HCPs and people with CRDs felt that it was important to start PR as early as possible (*i.e.* when diagnosed). HCPs also suggested that this would allow the opportunity to prompt a change in daily habits and behaviours, although adherence challenges were mentioned, especially in patients whose disease had less impact.



Shareable abstract (@ERSpublications)

Efforts need to be made to increase access to pulmonary rehabilitation as early as possible, prioritising those who are more symptomatic and have functional status limitations, and improving communication within and among healthcare services <https://bit.ly/3LMcLCU>

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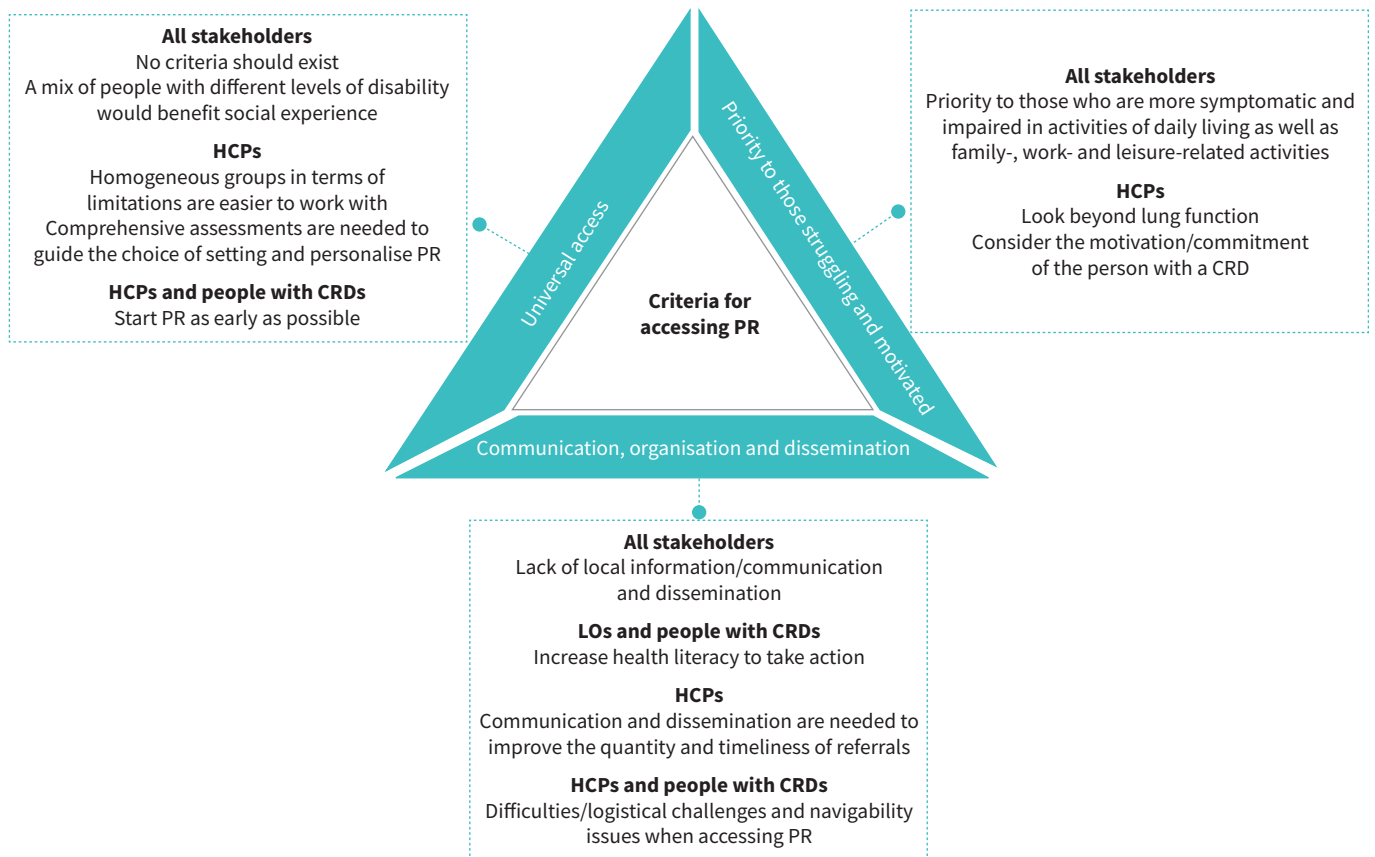


FIGURE 1 Thematic map presenting the generated themes and subthemes regarding criteria around accessing pulmonary rehabilitation (PR), according to the perspectives of people with chronic respiratory diseases (CRDs), loved ones (LOs) and healthcare professionals (HCPs).

It should not exist a criterion, because then we will have only those very sick or those who have been recently diagnosed... and I think a mixture of people is important and all can benefit hence, no criteria should be in place.

Person with COPD, female, 69 years of age

As soon as the diagnosis is established and we are informed about the disease we should also be informed and have access to PR.

Person with ILD, female, 45 years of age

All stakeholders were aware that an ideal scenario often isn't available in the real-world and were unanimous about giving priority to those who were more symptomatic, in terms of dyspnoea, fatigue, impaired activities of daily living, and impaired family-, work- and leisure-related activities. HCPs highlighted the importance of looking beyond lung function, which often was relatively preserved, when referring to PR.

For HCPs, fairness/personalisation were at risk when establishing criteria to access to PR without considering the motivation/commitment of the person with a CRD. Intrinsic motivation was considered key to going beyond the "one size fits all" model when referring patients to PR, and questioned its role in clinical-decision algorithms.

Priority should be given to those most in need, those who are more affected.

LO, female, 69 years of age

To those who present symptoms of breathlessness.

LO, female, 72 years of age

And feel tired

LO, female, 53 years of age

A fundamental criterion needs to be motivation. It cannot be only the clinical parameters, otherwise we can be at risk of many patients not being motivated and not allowing others highly motivated to access the programme.

Medical doctor, male, 27 years of age

All stakeholders felt that a lack of local information/communication and dissemination were major obstacles to accessing PR, especially among primary healthcare. People with CRDs and their LOs specifically expressed the need to improve their health literacy so that they could take action; while for HCPs, communication and dissemination were essential to improving the quantity and timeliness of referrals.

According to HCPs and people with CRDs, a lack of articulation between institutions and organisations also generated difficulties/logistical challenges and navigability issues when accessing PR.

It is dependent of primary healthcare centres... more information should be available, may be on the television or in primary healthcare centres ... because if we were conscious of what we have [available], we didn't even need the doctor to tell us.

Person with COPD, female, 68 years of age

[Limited access to PR] comes from lack of information too... Primary healthcare centres, which are so physically near to people, should be knowledgeable and inform about this therapy [PR]

LO, female, 69 years of age

Within each institution, among institutions or even in the community, we should be communicating more among each other. It is important to know the different healthcare pathways so we know how to better guide our patients.

Physiotherapist, female, 33 years of age

The perspectives of the different stakeholders were consensual. There should be “universal access” to PR and priority should be given to “those struggling and motivated”. “Communication, dissemination and organisation are the main keys” to promoting access to PR.

PR is a multicomponent intervention in which the most appropriate strategy can be activated to address each person’s needs, with benefits for both the patient and their family [5, 6]. Unsurprisingly, all stakeholders wanted everyone to have access to it and as early as possible, irrespective of disease severity.

Universal access is, however, an intangible goal. Most PR is conducted in hospital-based outpatient settings [7, 8]; increased involvement of primary care is fundamental to expanding access to PR, according to the levels of disease complexity [6], and to overcoming the barrier of distance from home. Models of PR referral using criteria based on disease stability, burden and physical capacity/activity have been proposed [3]. Our stakeholders were also unanimous in giving priority to those who were more symptomatic and those who had limited functional status. Nevertheless, the HCPs felt it was important to incorporate motivation into the clinical-decision models. Whilst a lack of motivation has been acknowledged as a barrier to adherence to PR [9], it can be improved when benefits are experienced, and is not a prerequisite of PR [10].

All stakeholders emphasised the need for education on and dissemination of information about PR. Various strategies to improve access to PR have been discussed [11] and need implementation. These

include: involving more HCPs in primary care; developing “try before you buy” sessions; initiatives with patient associations; and the use of technology/peer support.

Limited communication and articulation among HCPs, fragmented healthcare pathways and late referral to PR due to a lack of knowledge and integration among healthcare tiers have also been acknowledged [12]. Integrated care models that place a strong emphasis on non-pharmacological interventions and improving communication between healthcare systems, have shown promising results in improving health status in those who received PR [12]; they seem fundamental to improving patient healthcare navigability.

Stakeholders’ perspectives corroborate findings from the literature. Efforts need to be made in increasing access to PR as early as possible, prioritising those who are more symptomatic and functionally limited, as needed, and improving communication within and among healthcare services.

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References

- 1 Troosters T, Casaburi R. Interview with Prof. Dr Richard Casaburi, Presidential Awardee 2020. *Breathe* 2020; 16: 200249.
- 2 Spruit MA, Augustin IM, Vanfleteren LE, *et al.* Differential response to pulmonary rehabilitation in COPD: multidimensional profiling. *Eur Respir J* 2015; 46: 1625–1635.
- 3 Spruit MA, Van't Hul A, Vreeken HL, *et al.* Profiling of patients with COPD for adequate referral to exercise-based care: the Dutch model. *Sports Med* 2020; 50: 1421–1429.
- 4 Roth DL, Fredman L, Haley WE. Informal caregiving and its impact on health: a reappraisal from population-based studies. *Gerontologist* 2015; 55: 309–319.
- 5 Marques A, Jácome C, Cruz J, *et al.* Family-based psychosocial support and education as part of pulmonary rehabilitation in COPD: a randomized controlled trial. *Chest* 2015; 147: 662–672.
- 6 Spruit MA, Wouters EFM. Organizational aspects of pulmonary rehabilitation in chronic respiratory diseases. *Respirology* 2019; 24: 838–843.
- 7 McCarthy B, Casey D, Devane D, *et al.* Pulmonary rehabilitation for chronic obstructive pulmonary disease. *Cochrane Database Syst Rev* 2015; 2: CD003793.
- 8 Souto-Miranda S, Rodrigues G, Spruit MA, *et al.* Pulmonary rehabilitation outcomes in individuals with chronic obstructive pulmonary disease: a systematic review. *Ann Phys Rehabil Med* 2021; 65: 101564.
- 9 Oates GR, Niranjana SJ, Ott C, *et al.* Adherence to pulmonary rehabilitation in COPD: a qualitative exploration of patient perspectives on barriers and facilitators. *J Cardiopulm Rehabil Prev* 2019; 39: 344–349.
- 10 Spruit MA, Singh SJ, Garvey C, *et al.* An official American Thoracic Society/European Respiratory Society statement: key concepts and advances in pulmonary rehabilitation. *Am J Respir Crit Care Med* 2013; 188: e13–e64.
- 11 McNamara RJ, Dale M, McKeough ZJ. Innovative strategies to improve the reach and engagement in pulmonary rehabilitation. *J Thorac Dis* 2019; 11: S2192–S2199.
- 12 Koolen EH, van den Borst B, de Man M, *et al.* The clinical effectiveness of the COPDnet integrated care model. *Respir Med* 2020; 172: 106152.