Early View

Research letter

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3 A’s (Access, access, access) for 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 more symptomatic, with frequent hospitalisations, worse exercise and activities of daily living performance and health status are also the ones responding better[2] and should be referred/prioritise to PR[3]. We explored whether these criteria are aligned with the perspectives of people with chronic respiratory diseases (CRD), their loved ones (LO) and healthcare professionals (HCP).

We conducted seven focus groups with people with CRD (n=29), LO (n=5) and HCP (n=16) recruited with 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 CRD were eligible if they were adults with CRD and had participated in PR at least once. LO were eligible if they were adults having a significant/personal relationship with the person with CRD and provided physical/practical, social, financial and/or emotional support[4]. HCP were eligible if they had been involved in at least one PR programme. Participants were approached face-to-face and informed consents obtained. Data collection occurred separately with each stakeholder in the different settings, no prior relationship with the interviewer existed, a semi-structured interview guide pilot-tested 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/sub-themes and participant quotations. Findings were confirmed by two researchers, triangulating the methods collection (interviews and field notes); validated by participants (2 people with CRD and 2 HCP) and discussed among team members and with the external researcher.

People with CRD were on average 68±8 years, mostly male (76%) and had a diagnose of chronic obstructive pulmonary disease (COPD) (82%) or interstitial lung disease (ILD) (17%). LO were on average 67±8 years, female (100%), mostly spouses (80%) caring for more than four years (80%). HCP were on average 38±9 years, mostly female (75%), working in hospitals (63%) for more than 14 years. Focus groups lasted on average 47±15 minutes. Three common core themes were identified (Figure 1).

**Universal access**

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 for their social experience. Nevertheless, HCP considered to be easier to work with homogeneous groups.
They recognised the importance of comprehensive assessments and discussions with a multidisciplinary team, to guide personalise PR. Starting PR as early as possible (i.e., when diagnosed) was felt, by people with CRD and HCP, as important and HCP also considered it as the ideal timing to prompt change of daily habits and behaviours, although challenges to obtain adherence were mentioned, especially in patients with less impact of the disease.

“… 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

“… 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

**Priority to those struggling and motivated**

All stakeholders were aware that an ideal scenario is often absent from the real-world and were unanimous about giving priority to those more symptomatic, in terms of dyspnoea, fatigue and impaired in activities of daily living, family-, work- and leisure-related activities. HCP highlighted the importance of looking beyond lung function, which often was relatively preserved, when referring to PR.

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

“Priority should be given to those most in need, those who are more affected.” Loved one, female, 69 years “…to those who present symptoms of breathlessness” Loved one, female, 72 years “...and feel tired” Loved one, female, 53 years

“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

**Communication, dissemination and organisation as main keys**

All stakeholders felt that lack of local information/communication and dissemination were major obstacles to access PR, especially among primary healthcare. People with CRD and LO specifically expressed the need to increase their health literacy so they could take action; while
for HCP, communication and dissemination were essential to improve the quantity and timely referrals.

Lack of articulation between institutions and organisations also generated difficulties/logistic challenges and navigability issues to access PR according to HCP and people with CRD.

“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

 “[Limited access to PR]... it 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.

“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

Figure 1. Thematic map with the generated themes and subthemes about criteria to access pulmonary rehabilitation (PR) according to the perspectives of people with chronic respiratory disease (CRD), loved ones and healthcare professionals.
Perspectives of the different stakeholders were consensual. There should be “Universal access” to PR and “Priority to those struggling and motivated” should be given. “Communication, dissemination and organisation are main keys” to promote access to PR.

PR is a multicomponent intervention where the most appropriate strategy can be activated to address each person needs, with benefits for patients and their family[5,6]. Not surprising, all stakeholders wanted everyone to have access to it and as early as possible, irrespective of the disease-severity.

This universal access is, however, an intangible goal. Most PR has been conducted in hospital-based outpatient settings[7,8] and higher involvement of primary care is fundamental to expand access to PR, according to the levels of disease complexity[6], and overcome 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 more symptomatic and with limited functional status. Nevertheless, HCP felt it was important to incorporate motivation into the clinical-decision models. Whilst lack of motivation has been acknowledged as a barrier of adherence to PR[9], motivation can also be improved when benefits are experienced, and is not a prerequisite for PR[10].

Education and dissemination on PR were emphasised as needed by all stakeholders. Various strategies to improve access to PR, such as involving more HCP in the primary care; developing “try before you buy” sessions, initiatives with patients’ associations; use of technology/peer support have been discussed[11] and need implementation.

Limited communication and articulation among HCP, fragmented healthcare pathways and late referrals to PR due to lack of knowledge/operationalisation have also been acknowledged[12]. Integrated care models placing a strong emphasis on non-pharmacological interventions and improving communication among healthcare systems, have shown promising results in improving health status in those who received PR[12] and, seem fundamental for improving patients’ healthcare navigability.

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


