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REHABILITATION IN CHRONIC RESPIRATORY DISEASES

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Organizational aspects of pulmonary rehabilitation in chronic respiratory diseases

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ABSTRACT

Adult patients with chronic respiratory diseases may suffer from multiple physical (pulmonary and extrapulmonary), emotional and social features which necessitate a comprehensive, interdisciplinary rehabilitation programme. To date, pulmonary rehabilitation programmes show a lot of variation in setting, content, frequency and duration. Future projects should strive for a standard set of assessment measures to identify patients eligible for pulmonary rehabilitation, taking disease complexity into consideration, which should result in referral to an appropriate rehabilitation setting. Local circumstances may complicate this crucial endeavour.

Key words: chronic obstructive pulmonary disease, home-based, pulmonary rehabilitation, setting.

INTRODUCTION

Adult patients with chronic respiratory diseases, such as chronic obstructive pulmonary disease (COPD), asthma and interstitial lung disease (ILD), may suffer from multiple physical (pulmonary and extra-pulmonary), emotional and/or social limitations which necessitate a comprehensive, interdisciplinary pulmonary rehabilitation programme. Indeed, the integrated care of these complex patients should reach beyond regular pulmonary drug treatment(s), as this will have no or only a partial effect on the physical, emotional and social conditions of these patients, and the burden of disease to patients and society is high. In this review, we share our views on some of the organizational aspects of a pulmonary rehabilitation programme, including its setting.

PULMONARY REHABILITATION

In 2013, an Official Task Force of the American Thoracic Society (ATS) and the European Respiratory Society (ERS) defined pulmonary rehabilitation as a comprehensive intervention based on a thorough patient assessment followed by patient-tailored therapies, which include, but are not limited to, exercise training, education and behaviour change, designed to improve the physical and psychological condition of patients with chronic respiratory disease and to promote the long-term adherence of health-enhancing behaviours. Despite the formal approval of this definition by the ATS Board of Directors and the ERS Executive Committee, large differences still exist (internationally, nationally and regionally) in the content and organizational aspects of rehabilitative interventions for adults with chronic respiratory disease.

SETTINGS FOR PULMONARY REHABILITATION

To date, most pulmonary rehabilitation programmes have been offered in a hospital-based outpatient setting. However, rehabilitative interventions have also been provided in an inpatient setting, a community-based setting and at the patient’s home. To date, clear evidence is lacking to allocate the most appropriate patient, to the most appropriate setting, for the most appropriate rehabilitative treatment, including medical and non-medical patient-tailored therapies. Internationally, there is also no expert consensus, mainly due to large differences in local situations. Historically, the degree of airflow limitation has been used to select patients with COPD for pulmonary rehabilitation. However, just using the degree of lung function impairment is not enough to truly understand the physical, emotional and social conditions of adults with a chronic respiratory disease. Indeed, dyspnoea, fatigue,
dynamic hyperinflation, a reduced physical capacity, an impaired disease-specific health status and social deprivation already occur in patients with a mild degree of airflow limitation. Moreover, the degree of lung function impairment at entry to the pulmonary rehabilitation cannot forecast the efficacy of the programme.

The degree of disease complexity, derived from a comprehensive initial assessment, should determine the type of intervention as well as the rehabilitation setting. Only then we can make the next step towards personalized medicine within the field of pulmonary rehabilitation. Figure 1 is an example of how patients with chronic respiratory disease, based on the degree of complexity, can be referred to the most appropriate type of care. So, patients without clear symptom burden and limitations during the performance of activities of daily life should receive healthy lifestyle recommendations and should be followed up over time to determine the degree of disease stability. Fast-developing e-health/m-health applications can support patients, family members and healthcare providers to monitor these well-functioning patients in their home environment.

Patients who despite optimal medical therapy have a single physical, emotional or social limitation should be referred to an allied respiratory professional in primary care (i.e. physiotherapist, or psychologist, or dietician or social worker, etc.) for a targeted therapy. Patients with multiple physical, emotional and/or social limitations should be considered candidates for a comprehensive, hospital-based intervention, where interdisciplinary care can be provided by a dedicated and skilled team. The degree of care-dependency (including patients with chronic respiratory failure in need of non-invasive ventilation, or patients in the direct post-hospitalization phase) should then be used as criteria to refer patients to inpatient pulmonary rehabilitation programmes in specialized centres. Obviously, the proposed model needs to be substantiated by additional research projects, and its success also depends on the local availability of the different pulmonary rehabilitation settings. However, this approach is in line with new initiatives, such as COPDnet, where patients with COPD are referred to different care settings with a different treatment modality and intensity after an extensive screening in the secondary care setting.

To run a hospital-based pulmonary rehabilitation programme for the most complex patients with COPD, the involvement of multiple, skilled healthcare professionals with COPD-specific knowledge seems imperative. For example, physiotherapists should be aware of the various treatment possibilities, including neuromuscular electrical stimulation and exercise training combined with non-invasive ventilation; or dieticians should be trained to modulate patient’s nutritional pattern, taking body composition abnormalities (i.e. cachexia and obesity) and cardiovascular risk factors (i.e. hypertension, hyperglycaemia and hyperlipidaemia) into consideration. However, multiple surveys show a huge variation in the number of healthcare disciplines available within and between countries. Moreover, the content of pulmonary rehabilitation programmes as well as its frequency and duration vary to a great extent. These disparities may, at least partially, be caused by differences in the local reimbursement of pulmonary rehabilitation services, ranging from paying out of pocket by the patient up to full reimbursement by insurance, employer and/or government. This will complicate benchmarking of key indicators of structure, process and performance, and, in turn, confuse quality control of existing and new pulmonary rehabilitation services.

**HOME-BASED PULMONARY REHABILITATION**

Home-based ‘pulmonary rehabilitation’ is emerging as a new format of pulmonary rehabilitation, which mostly consist of a home-based exercise training programme (i.e. walking, stationary cycling and/or resistance exercises using body weight, resistance bands and/or water-filled bottles), education by providing a self-management manual and sometimes coaching using motivational interviewing. This approach, applying some of the core components of pulmonary rehabilitation, confers short-term improvements in the level of breathlessness, exercise tolerance and disease-specific quality of life, with no significant difference compared to outpatient pulmonary rehabilitation. To date, however, it is not possible to exclude non-inferiority. The development of home-based intervention is, at least in part, the result of (i) a lack of financial resources to start up new rehabilitation locations in

**Figure 1** The most appropriate setting for pulmonary rehabilitation based on patient’s level of disease complexity.

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**Care setting**

- Hospital-based inpatient
- Hospital-based inpatient or outpatient
- Primary care
- Healthy lifestyle + E-health

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rural areas; (ii) local healthcare policies; (iii) initiatives by local researchers/clinicians; (iv) the unwillingness of payers to expand the capacity of existing programmes; (v) a reduction of costs of healthcare in general, and pulmonary rehabilitation in particular; (vi) patient choice; and/or (vii) ignoring the complexity and heterogeneity in a subgroup of patients with high degree of unpredictability of the clinical course.

While the home-based approach seems worth pursuing in patients with a chronic respiratory disease who are not too complex, multiple questions remain unanswered. Is the training intensity during the home-based programme intense enough to improve exercise capacity in COPD patients with a mildly impaired exercise tolerance at the start of the intervention? Does an exercise-based intervention in the patient’s home deal with the complexity that patients with chronic respiratory disease may experience? Is a home-based intervention also feasible, safe and effective in patients with chronic respiratory disease other than COPD? Does a home-based exercise training programme qualify as a pulmonary rehabilitation programme? Indeed, the term ‘home-based pulmonary rehabilitation’ seems erroneously chosen. A true comprehensive pulmonary rehabilitation programme is like a Swiss army knife. At first, a Swiss army knife looks just a simple pocket knife. However, if you look carefully, it is much more than just a knife and you have to be an expert to carefully apply all its features (Fig. 2). The same is true for pulmonary rehabilitation. At first, pulmonary rehabilitation seems just to be exercise training, providing some educational sessions and a self-management manual. However, based on comprehensive assessment at the start of the programme, physical, emotional and social treatable traits can be identified, which can be addressed by a dedicated, interdisciplinary pulmonary rehabilitation team using targeted therapies. Here, we should never forget the wise words of Aristotle: ‘The whole is greater than the sum of its parts’.

As stated before, the choice of treatment (monodisciplinary vs interdisciplinary) and the location of treatment (home- vs hospital-based) should be made on well-defined criteria, and should not be determined by local limitations. To date, daily clinical practice is not organized in such way. Obviously, if the choice for a home-based exercise training is necessary due to lack of other settings and/or the preference of the patient, this seems much better than doing nothing. However, it is appreciated that a home-based exercise training programme will not be able to cover all needs and preferences of patients with complex chronic respiratory disease and, in turn, causes a fragmentation of necessary interdisciplinary care. Indeed, the effects of a conventional, home-based exercise training programme on the performance of activities of daily life and daily symptoms beyond dyspnoea (i.e. anxiety, depression and fatigue) remain unknown, while this is clearly shown following a comprehensive, hospital-based pulmonary rehabilitation programme. The home-based approach does also not allow to truly target the training interventions to the possibilities/limitations of each individual patient. The one-size-fits-all approach (i.e. a home-based walking programme) seems acceptable for patients with a mild degree of complexity. However, for patients with hypercapnia, hypoxaemia, very severe dyspnoea and/or recently hospitalized/frail patients, this approach seems to ignore many available possibilities, including but not limited to exercise training (on a stationary bicycle or treadmill, to really target and monitor the optimal training intensity) combined with non-invasive ventilation or without oxygen supplements; neuro-muscular electrical stimulation for severely dyspnoic and weakened patients; whole-body vibration; resistance training using adequate apparatus; etc.

**MANAGEMENT FOR CHRONIC LUNG DISEASE IN PRIMARY CARE**

The current trend is to move the disease management of patients with chronic respiratory disease more and more towards primary care and the home setting. However, timely referral by the general practitioner

| Condition | Proposed management |
|-----------|---------------------|
| Cachexia | Nutritional supplements / anabolic agents |
| Obesity | Diet and meal replacements |
| Exercise intolerance | Exercise training (+ pursed lips breathing) |
| Muscle weakness | Exercise training |
| Depression/anxiety | Cognitive behavioural therapy |
| Poor coping skills | Education + goal setting |
| Co-morbidities | Specific co-morbidity treatment |
| Physical inactivity | Physical activity coaching |
| Current smoking | Supervised daily outdoor walks |
| Excessive mucus | Smoking cessation |
| Inspiratory muscle weakness | Mucus evacuating techniques |
| Poor exacerbation management skills | Inspiratory muscle training |
| Poor inhalation technique | Education + skills training |
| Problematic ADL | Home adaptations and aids |
| | ADL training / energy conservation technology |

![Figure 2](image-url) The multitarget approach during pulmonary rehabilitation. ADL, activity of daily living.
(GP) to the next level of care (horizontally or vertically) is imperative. Accumulating evidence shows that there is still room for major improvement. To date, only a minority of outpatients with severe to very severe COPD attending an outpatient clinic are referred for respiratory primary care (i.e. nurse specialist (35%); physiotherapist (53%); and occupational therapist, dietician, social worker or psychologist (all <15%)) while they clearly are in need of such support and care. Indeed, fatigue was reported by 89% of the patients, while muscle weakness was reported by 75%; 47% of the patients had an abnormal low or obese BMI; 45% were dependent on personal care; 52% had a low mood and 85% of the patients had self-perceived mobility problems.58

Upon referral by the GP to a hospital-based, outpatient consultation by a chest physician, 50% of the patients with COPD (mean forced expiratory volume in 1 s (FEV1): 56% predicted) had clear exercise intolerance, physical inactivity and multiple exacerbations in the last 12 months.57 These data suggest that GP-guided medical care to patients with COPD is insufficient to stabilize (or even improve) patients’ physical, emotional and/or social condition. So, patients with mild to severe COPD can already enter the vicious dyspnoea–inactivity circle in the primary care setting, without being recognized.58

WHAT DO PATIENTS WANT?

Home-based exercise training programmes are well perceived by patients with COPD. Besides the increased exercise capacity, patients report that the intervention is flexible and convenient, as it reduces travel burden, and training can be done at a suitable time.43 Then again, starting the home-based intervention can be challenging due to the persistent inactive lifestyle; some patients report physical limitations that clearly limited their capability to perform walking exercises at home; and doing the same exercise each day is somewhat uninteresting.43

So, walking programmes in the home-based setting seem feasible, safe and effective to increase exercise performance to some extent. Nevertheless, patients with chronic respiratory disease state that hospital-based pulmonary rehabilitation programmes are indispensable as (i) the social aspect of exercising together with other patients is anticipated as enjoyable; (ii) patients can learn from each other’s experiences; (iii) the dedicated staff members quickly understand the patient; (iv) patients receive and provide emotional support from peers; and (v) the supervised setting was thought of as a safe environment.59 So, besides the proposed stratification of patients based on the degree of complexity (Fig. 1), patients’ preferences should also be added to the equation.

Self-referral to pulmonary rehabilitation is only possible in about one-third of the pulmonary rehabilitation programmes, and is more common in North America compared to Europe.3 Therefore, patients are still relying on the referral by healthcare professionals, who really have to start thinking about referral for an initial screening in patients with clear daily limitations.60

Approximately two-fifths of patients with chronic respiratory disease stated that their healthcare provider had never told them about pulmonary rehabilitation or its benefits51. This explains, at least in part, that currently <2% of the patients with chronic respiratory disease are referred to some kind of rehabilitative intervention.36 To conclude, patients and healthcare professionals have to combine the most appropriate pulmonary and extra-pulmonary targeted therapies, for patients with a chronic respiratory disease who are still symptomatic despite otherwise optimal medical therapy, aiming at relevant outcomes. Local circumstances may complicate this crucial endeavour.

The Authors

Professor Dr M.A.S. (1975) published >250 peer-reviewed articles mainly on pulmonary rehabilitation and physical inactivity in patients with chronic lung disease. He was the lead author on the 2013 ATS/ERS Statement on Pulmonary Rehabilitation; the ERS awarded him the ERS COPD Research Award in 2013; and he was elected Fellow of the ERS in 2016. Professor Dr E.F.M.W. (1953) published >700 peer-reviewed articles on extra-pulmonary treatable traits and the integrated care of complex patients with COPD. He is Head of the Department of Respiratory Medicine, Director of the Centre for Chronic Diseases at Maasstricht University Medical Centre and Chairman of the Board of Directors of CIRO. He was elected Fellow of the ERS in 2014.

Abbreviations: ADL, Activity of daily living; ATS, American Thoracic Society; BMI, body mass index; ERS, European Respiratory Society; GP, general practitioner.

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