

Differences in content and organisational aspects of pulmonary rehabilitation programmes

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ABSTRACT The aim was to study the overall content and organisational aspects of pulmonary rehabilitation programmes from a global perspective in order to get an initial appraisal on the degree of heterogeneity worldwide.

A 12-question survey on content and organisational aspects was completed by representatives of pulmonary rehabilitation programmes that had previously participated in the European Respiratory Society (ERS) COPD Audit. Moreover, all ERS members affiliated with the ERS Rehabilitation and Chronic Care and/or Physiotherapists Scientific Groups, all members of the American Association of Cardiovascular and Pulmonary Rehabilitation, and all American Thoracic Society Pulmonary Rehabilitation Assembly members were asked to complete the survey *via* multiple e-mailings.

The survey has been completed by representatives of 430 centres from 40 countries. The findings demonstrate large differences among pulmonary rehabilitation programmes across continents for all aspects that were surveyed, including the setting, the case mix of individuals with a chronic respiratory disease, composition of the pulmonary rehabilitation team, completion rates, methods of referral and types of reimbursement.

The current findings stress the importance of future development of processes and performance metrics to monitor pulmonary rehabilitation programmes, to be able to start international benchmarking, and to provide recommendations for international standards based on evidence and best practice.



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Introduction

Pulmonary rehabilitation is defined as a comprehensive intervention based on thorough patient assessment followed by patient-tailored therapies that include, but are not limited to, exercise training, education and behaviour change. These are designed to improve the physical and psychological condition of people with chronic respiratory disease and to promote the long-term adherence of health-enhancing behaviours [1]. Pulmonary rehabilitation has consistently shown that individuals with chronic respiratory disease experience: a decrease in daily symptoms of dyspnoea, fatigue, anxiety and depression; improvements in exercise performance, self-efficacy and health status; and a decrease in healthcare utilisation [2–9]. As pulmonary rehabilitation addresses the symptoms, activity limitations and reduced health-related quality of life associated with chronic respiratory disease, it is now considered a fundamental component of the integrated disease management of individuals with chronic respiratory disease [10].

Although pulmonary rehabilitation should be made available to all individuals with chronic respiratory disease who still suffer from daily symptoms despite optimal medical therapy [1], there are still marked shortfalls in the provision of this intervention [11–15]. Moreover, there is variability in content and organisational aspects among pulmonary rehabilitation programmes at a national level [11, 14–17]. This is most probably the result of local conditions, and not a reflection of an evidence-based organisational model. Differences in content and organisational aspects may partially explain the differences in reported outcomes following pulmonary rehabilitation [18].

To date, neither the content nor the organisational aspects of pulmonary rehabilitation programmes have been studied worldwide during the same period of time. As international differences may limit international benchmarking [19], the overall content and organisational aspects of pulmonary rehabilitation programmes from a global perspective were studied to get an initial appraisal on the degree of heterogeneity worldwide.

Methods

Study design

An existing survey on pulmonary rehabilitation was made available for this project by BROOKS and coworkers [11, 16]. The survey was shortened to 12 questions. The response format was either a checkbox or free text option (see online supplementary material). From September 2012 to February 2013, pulmonary rehabilitation programmes that previously participated in the European Respiratory Society (ERS) COPD Audit, were asked to complete this survey (n=384). Moreover, all ERS members affiliated with the ERS Rehabilitation and Chronic Care and/or Physiotherapists Scientific Groups (n=983), all members of the American Association of Cardiovascular and Pulmonary Rehabilitation (AACVPR, n=1628), and all American Thoracic Society (ATS) Pulmonary Rehabilitation Assembly members (n=486) were asked to complete the survey via multiple e-mailings. There may have been overlap as people can be affiliated to two or more of the abovementioned groups. Moreover, not all recipients of the e-mail work in a pulmonary rehabilitation setting. Surveys were returned by e-mail or post. All data were inserted into an Excel (Microsoft Corporation, Redmond, WA, USA) database. Respondents were contacted via e-mail if data were missing. Pulmonary rehabilitation programmes starting after 2011 were excluded. Only complete surveys were used for further analyses. Only one survey per pulmonary rehabilitation programme was included in the analyses (i.e. only the first completed received survey per pulmonary rehabilitation programme was used).

Statistical analyses

GraphPad Prism 5 (GraphPad Software Inc., La Jolla, CA, USA), Excel (Microsoft Corporation) and SPSS (SPSS Inc., Chicago, IL, USA) were used for the statistical analyses. Median (interquartile range (IQR)) and proportion were calculated as appropriate. *A posteriori* differences between Europe and North America were analysed using a Wilcoxon rank-sum test or Chi-squared test as these were the two continents with the highest number of completed surveys. The findings of the remaining continents were not clustered as the number of surveys was rather limited. *A priori* the level of significance was set at $p \le 0.05$.

Results

General characteristics

A total of 481 surveys were returned from 40 countries. After excluding all surveys with missing data or overlapping pulmonary rehabilitation programmes, 430 surveys were available for the final analyses. Most surveys were affiliated with pulmonary rehabilitation programmes from Europe (43.7%) or North America (43.5%). The remaining programmes were from Oceania, Asia, South America or Africa (fig. E1).

Setting

Most commonly, centres offered structured outpatient pulmonary rehabilitation programmes (262 (60.9%) centres), 41 (9.5%) centres offered inpatient programmes, and 106 (24.7%) centres offered both. The remaining 21 (4.9%) pulmonary rehabilitation programmes offered rehabilitation in the home setting (including tele-rehabilitation) or the primary care setting. Most of these programmes (17 of 21) were offered in combination with an inpatient or outpatient hospital-based pulmonary rehabilitation programme. Most programmes in Europe and North America were outpatient programmes (table 1).

Types of reimbursement

A small number (six (1.4%)) of programmes did not receive any reimbursement for providing pulmonary rehabilitation. The remaining pulmonary rehabilitation programmes were funded by one or more sources (range: 1–5): individuals' insurance (58.8%), government (54.8%), individuals' own money (25.6%), workplace insurance (10.2%), or others including, but not limited to, departmental funding, research grants, external funding, personal efforts and private donations. Programmes were more likely to be reimbursed in Europe by the government, while in North America the programmes were more likely to be reimbursed by the patient's insurance or own money (table 1).

Team members

Pulmonary rehabilitation teams consisted of a median (IQR) of 5 (4–7) healthcare professionals (fig. 1a). Chest physicians (70.7%), dieticians (70.2%), nurses (66.7%) and physiotherapists (61.4%) were the most prevalent team members (fig. 1b). Chest physicians, physiotherapists, occupational therapists, social workers, psychologists and cardiologists were more frequent participants in Europe than North America. In North America, dieticians, exercise physiologists and respiratory therapists were more common (table 1).

Referral sources

Individuals with chronic respiratory disease were referred by a median (IQR) of 2 (2–3) referral sources. Chest physicians and general practitioners referred individuals with chronic respiratory disease to 95.3% and 73.3% of the pulmonary rehabilitation programmes, respectively. Interestingly, self-referral was possible in 29.8% of the pulmonary rehabilitation programmes (fig. 2). It was more common for programmes in North America to report referrals from general practitioners, self-referrals or cardiologists than in Europe (table 1).

Patient volumes and completion rates

The respondents estimated that a total of 34 890 individuals with chronic respiratory disease enrolled in pulmonary rehabilitation programmes in 2011 (median 40 to 75 enrolled individuals per programme) (fig. 3a). The median proportion of individuals with a chronic respiratory disease that completed a pulmonary rehabilitation programme in 2011 was estimated to be 75–90% (fig. 3b). More patients were enrolled from Europe in 2011 than North America (table 1).

Case mix

The case mix of individuals with chronic respiratory disease consisted of a median (IQR) of 6 (4–7) different primary diagnoses (fig. 4a). Most pulmonary rehabilitation programmes received referrals of individuals with "stable" chronic obstructive pulmonary disease (COPD) (97.4%), COPD during and/or directly following an exacerbation (74.9%), restrictive lung disease (including interstitial lung disease and thoracic wall diseases; 73.7%), asthma (71.9%) or post-thoracic surgery (71.9%) (fig. 4b). Programmes from North America reported more frequent referrals for restrictive lung disease, asthma and post-thoracic surgery than those from Europe (table 1).

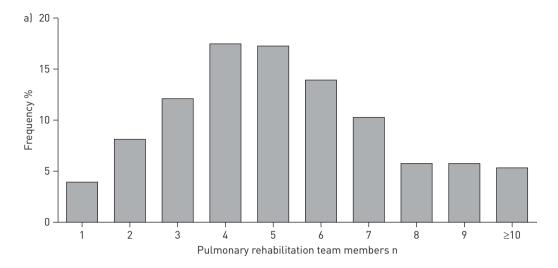
Duration and frequency

The median (IQR) length of the pulmonary rehabilitation programmes was 9 (8–12) weeks. Individuals with a chronic respiratory disease attended a median (IQR) of 2.5 (2–3) pulmonary rehabilitation sessions per week, for a median (IQR) duration of 1.5 (1–2) h per session. The median (IQR) number of hours of pulmonary rehabilitation dosage (number of weeks × number of sessions per week × number of hours per session) was similar for government funded programmes (32 (24–48) h), insurance funded programmes (36 (27–54) h), or a combination thereof (36 (27–48) h; p=0.31). Programmes in North America were longer in duration compared to European programmes, while the number of sessions per week was greater and the duration of sessions was longer for European programmes. In turn, the total median hours of pulmonary rehabilitation dosage provided in Europe or North America was similar (table 1).

TABLE 1 European versus North American pulmonary rehabilitation programmes

	Europe	North America	p-value
Subjects n	188	187	
Setting			
Outpatient	48.9	71.7	< 0.001
Inpatient	16.0	3.7	
Both	29.3	23.0	
Other	5.8	1.6	
Types of reimbursement#			
Own insurance	38.3	92.5	< 0.001
Government	62.8	38.5	<0.001
Own money	10.6	43.3	< 0.001
Work insurance	3.7	19.3	< 0.001
Not funded	2.7	0.5	0.22
Other		0.5	0.50
Pulmonary rehabilitation team members ¶			
Chest physician	87.8	62.0	< 0.001
Physiotherapist	95.2 36.2	17.1 17.1	<0.001 <0.001
Occupational therapist Social worker	42.6	24.1	<0.001
Psychologist	53.7	8.6	<0.001
Dietician	76.1	93.5	< 0.001
Exercise physiologist	25.5	62.6	< 0.001
Internist	11.7	8.0	0.30
Cardiologist General practitioner	43.0 18.1	20.0 13.4	<0.001 0.26
Pharmacist	22.9	18.2	0.20
Nurse	68.1	64.2	0.45
Respiratory therapist	1.6	59.9	< 0.001
Number of team members Referral sites#	6 (4–8)	4 (3–6)	<0.001
Chest physicians	96.8	95.7	0.60
General practitioners	55.9	92.5	< 0.001
Self-referral	21.3	33.7	0.008
Specialist respiratory nurse Cardiologist	12.2 1.1	3.7 9.1	0.001 <0.001
Median number of individuals per pulmonary rehabilitation programme ⁺	76 to 105	46 to 75	<0.001
Estimated total pulmonary rehabilitation enrolments in 2011 n	19 515	11 475	<0.001
Median percentage of pulmonary rehabilitation completers Case mix#	76 to 90	61 to 75	<0.001
Stable COPD	95.7	98.9	0.11
Unstable COPD	74.5	75.9	0.81
Restrictive lung disease [§]	66.5	82.4	0.001
Asthma Rect theresis surgery	63.3 61.7	82.9 85.0	<0.001 <0.001
Post-thoracic surgery Length of pulmonary rehabilitation programme weeks	8 (5.6–12)	11 (8–12)	<0.001
Number of pulmonary rehabilitation sessions per week	2.5 (2-4)	2.5 (2–3)	0.005
Duration of pulmonary rehabilitation session h	2 (1.3–2)	1.5 (1–1.5)	< 0.001
Total pulmonary rehabilitation h ^f Most important outcomes [#]	39.3 (25.0–62.5)	36 (30–48)	0.33
Quality of life	81.4	83.4	0.68
6-min walk test	33.0	53.5	< 0.001
Dyspnoea	48.4	35.8	0.016
Depression	3.2	9.1	0.019
Physical activity Self-management skills	33.5 33.5	21.9 30.5	0.02 0.58
Smoking cessation	5.9	16.0	0.002
Activities of daily living	28.7	36.4	0.12
Interventions#			
Outdoor walking	43.6	5.9	< 0.001
Treadmill walking	68.6	97.9	< 0.001
Stationary cycling	89.4	97.3	0.003
Resistance training using training apparatus Resistance training using handheld weights	62.8 71.3	67.9 93.6	0.33 <0.001
Education	89.9	73.6 98.9	<0.001
ECT/ADL training	64.9	94.7	< 0.001
Self-management training	75.5	85.0	< 0.001
Nutritional support	76.1	93.6	< 0.001
Inspiratory muscle training	54.8	49.7	0.35
Neuromuscular electrical stimulation Breathing exercise including PLB	29.3 86.7	1.6 97.9	<0.001 <0.001
Smoking cessation	76.6	97.9 83.4	0.12
Psychosocial support	64.9	81.8	< 0.001
Number of types of interventions	10 (8-12)	11 (10–12)	0.0041

Data are presented as % of pulmonary rehabilitation programmes or median (interquartile range), unless otherwise stated. COPD: chronic obstructive pulmonary disease; ECT: energy conservation techniques; ADL: activities of daily life; PLB: pursed lips breathing. **: sum of proportions exceeds 100% as respondents were allowed or asked to choose more than one option; **: pulmonary rehabilitation team members with a prevalence of \geq 10% in one or both continents; *: 50% of the programmes enrolled 76 to 105 patients (Europe) or 46 to 75 patients (North America) or more in 2011; **: always including interstitial lung disease and sometimes including thoracic wall diseases; **:weeks \times sessions \times time per session.



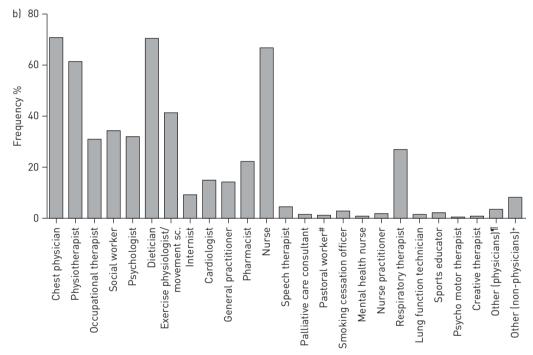


FIGURE 1 a) Number of pulmonary rehabilitation team members. b) Frequency of healthcare professionals. Movement sc.: movement scientist. *: includes, but not limited to, chaplain, parish nurse and pastoral worker; *: includes, but not limited to, geriatrician, neurologist, physiatrist, rheumatologist, surgeon and endocrinologist; *: includes, but not limited to, citizens advisor, volunteers, welfare rights advisor, council development worker, lung foundation support representative, dental hygienist, diabetes educators and alternative medicine practitioner.

Most important outcomes

Quality of life (82.1% of the respondents), 6-min walk test (45.8%) and dyspnoea (41.4%) were identified as the three most important outcomes of pulmonary rehabilitation (fig. 5). Quality of life remained one of the three most important outcomes after stratification for Europe or North America (table 1). Programmes in Europe reported on dyspnoea and physical activity more often than in North America. North American programmes reported outcomes on the 6-min walk test, depression and smoking cessation more frequently than European programmes (table 1), although neither continent reported on depression and smoking cessation frequently.

Interventions

The median (IQR) number of types of interventions within the pulmonary rehabilitation programmes was 11 (9–12). The most common interventions were education (94.4%), stationary cycling (92.6%), breathing

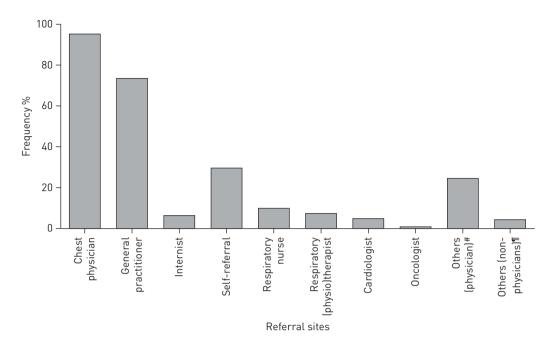


FIGURE 2 Pulmonary rehabilitation programme referral sources. *: includes, but not limited to, physiatrist, surgeon, "medical staff", "hospitalist", geriatrician and paediatrician; **!: includes, but not limited to, waiting list from other pulmonary rehabilitation programme, community staff, occupational therapy, personal trainer, lung foundation and nutritionist

exercises including pursed lips breathing (91.6%) and nutritional support (84.4%) (fig. 6). Outdoor walking and neuromuscular electrical stimulation were more commonly reported by programmes in Europe, while treadmill walking, stationary cycling, resistance training with handheld weights, education, training in activities of daily living, self-management, nutritional support, breathing exercises and psychosocial support were more commonly reported in North America (table 1). However, these differences were not great. For example, 89.4% of programmes in Europe reported on stationary cycling versus 97.3% in North America (table 1).

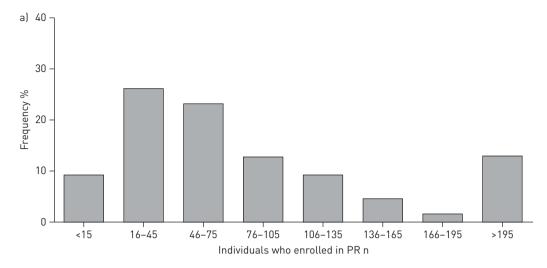
Discussion

This is the first global survey on content and organisational aspects of pulmonary rehabilitation. It was completed by representatives of 430 centres from 40 countries and, as expected, the findings clearly show key similarities, as well as substantial differences, between pulmonary rehabilitation programmes across continents. The observed differences make (inter)national benchmarking difficult, and suggest caution in generalisation of research findings between such different pulmonary rehabilitation programmes.

Differences in content and organisational aspects

Pulmonary rehabilitation for individuals with chronic respiratory disease is recommended by national and international guidelines and statements [1, 20]. The current findings show differences in each of the categories surveyed: the setting, the case mix of individuals, the composition of the team, completion rates, methods of referral, and types of reimbursement. These findings corroborate previous reports performed at a national level [11, 14–17, 21].

An encouraging finding was the use of health-related quality of life as the primary outcome of programmes, irrespective of jurisdiction. This reflects an evidence-based approach to evaluating the most important endpoint of pulmonary rehabilitation. Unfortunately, the current survey did not allow us to identify which questionnaires are used to assess health-related quality of life in daily clinical practice. Nevertheless, multiple options are available [22]. Approximately one-third of programmes employed measures of self-management as part of their primary outcomes which, given the growing interest in self-management, especially around medication use and recognition of COPD exacerbations, is encouraging. Similarly, an awareness of the impact of pulmonary rehabilitation on activities of daily living was reflected by a number of programmes in both major jurisdictions using it as an outcome. Just over half of the programmes in North America utilise the 6-min walk test as a field measure of exercise capacity. Whereas this test is far less common in other parts of the world, the survey did not enable us to evaluate the frequency of alternative



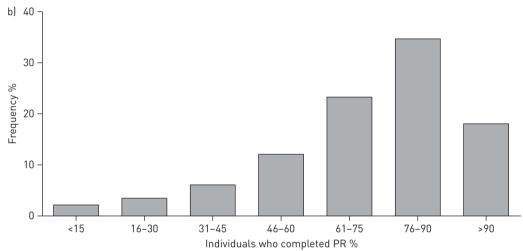


FIGURE 3 a) Estimated number of individuals who enrolled in each pulmonary rehabilitation (PR) programme in 2011. b) Estimated proportion of individuals who completed a PR programme in 2011.

field tests such as the shuttle walk test, which has become more popular in the past decade [23]. A small percentage of respondents included lung function as one of the three most important outcome measures for pulmonary rehabilitation. Such changes, as might occur, almost certainly reflect optimisation of pharmacotherapy, which should occur prior to programme enrolment. Disappointingly, few programmes identified the important psychological secondary impairments of anxiety and depression as part of their primary outcome measures. Given the prevalence of these symptoms and the positive impact that exercise has on them, increasing their use as outcome measures would be helpful [24, 25]. The limited use of healthcare resource utilisation (0.7%), despite clear evidence of the impact of rehabilitation on this outcome, was also unfortunate as the latter provides powerful reasons in support of programme funding related to significant reductions in healthcare costs among individuals with COPD [26]. Longitudinal data collection of healthcare resource utilisation, currently most likely to occur primarily in academic programmes, should be encouraged for community- and home-based environments.

Patient satisfaction and programmes safety, efficiency and accessibility were not identified as one of the top three most important outcomes of pulmonary rehabilitation. Even though this may not be recognised to be as important as performance metrics, it will provide detailed information about the pulmonary rehabilitation process. Moreover, healthcare facilities are increasingly being required to demonstrate these metrics as a condition of ongoing funding.

Case mix

The case mix of individuals with chronic respiratory diseases referred for pulmonary rehabilitation is highly variable, but indicates that the majority of the pulmonary rehabilitation programmes, in addition to

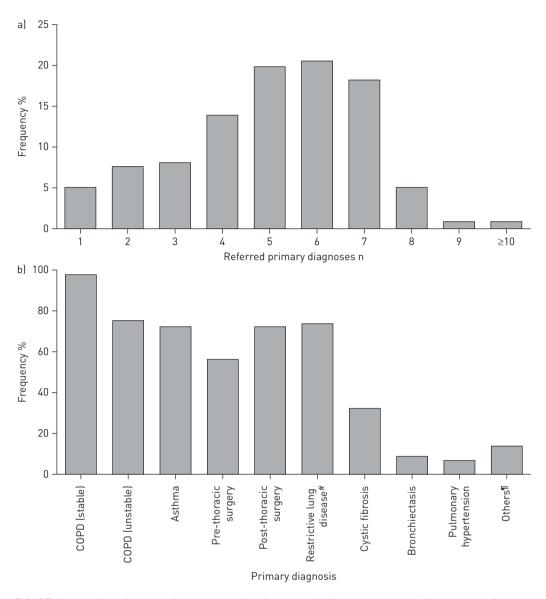


FIGURE 4 a) Number of primary diagnoses in each pulmonary rehabilitation programme. b) Frequency of primary diagnoses. #: includes, but not limited to, interstitial lung diseases such as sarcoidosis and idiopathic pulmonary fibrosis, and chest wall disease such as kyphoscoliosis; ¶: includes, but not limited to, neuromuscular disease, diaphragm paresis, hyperventilation, chronic heart failure, post-intensive care unit, obesity, pre-bariatric surgery and post-bone marrow transplantation.

enrolling stable COPD patients, will also enrol individuals during or directly after a COPD exacerbation. Many also enrol individuals with a chronic respiratory disease other than COPD in keeping with the evolving scope of pulmonary rehabilitation [5, 9, 27–29]. Obviously, the primary respiratory diagnosis (*i.e.* COPD) does not provide healthcare professionals with enough phenotypic information to come up with a patient-tailored pulmonary rehabilitation programme. Therefore, a broad initial assessment is inevitable [30].

Pulmonary rehabilitation teams

An interdisciplinary pulmonary rehabilitation team should include physicians and skill sets associated with other healthcare professionals, such as physiotherapists, respiratory therapists, nurses, psychologists, behavioural specialists, exercise physiologists, nutritionists, occupational therapists and social workers [1]. The number and type of healthcare professionals varied amongst pulmonary rehabilitation programmes (fig. 1a and 1b), with physical therapists being especially popular in Europe and respiratory therapists (who do not exist in Europe) dominating North American programmes. In keeping with the interdisciplinary nature of pulmonary rehabilitation, available skill sets rather than specific healthcare professionals extends the programme capability. It seems that some tasks are interchangeable with other healthcare professionals

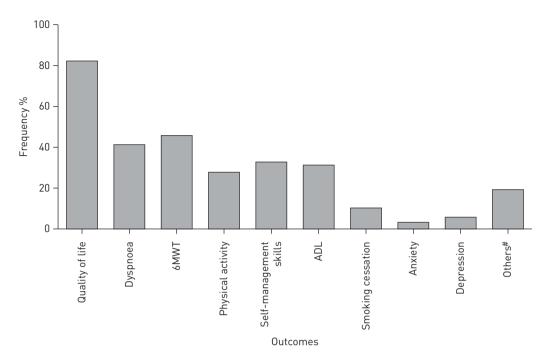


FIGURE 5 Frequency of the most important outcomes in the pulmonary rehabilitation programme. 6MWT: 6-min walk test; ADL: activities of daily living. #: includes, but not limited to, lung function, body composition, drug use, shuttle walk test, lower-limb muscle strength, upper-limb muscle strength and patient goals.

in daily clinical practice. For example, energy conservation techniques and/or activities of daily living training were available in 79.8% of the programmes, while an occupational therapist was only available in 30.9% of programmes.

17 "pulmonary rehabilitation teams" consisted of only one type of healthcare professional. This is somewhat surprising, as individuals with chronic respiratory disease can be very complex and need an integrated approach. Indeed, individuals with a chronic respiratory disease may present with multiple extrapulmonary features and comorbidities, such as symptoms of anxiety and depression, body composition abnormalities, cognitive dysfunction, lower-limb muscle weakness, cardiovascular disease and problematic activities of daily life [31–35]. These extrapulmonary features and comorbidities as well as poor self-management skills also need to be addressed during a comprehensive pulmonary rehabilitation programme [36, 37]. Indeed, many programmes offered speciality components addressing extra-pulmonary features and/or comorbidities, *e.g.* 84.4% nutritional support, 79.8% energy conservation techniques and/or activities of daily living training, and 72.3% psychosocial support. Moreover, 80% of the programmes offered self-management training, which is believed to be necessary to achieve a meaningful and sustainable behaviour change [1].

International benchmarking

The observed differences in content and organisational aspects of pulmonary rehabilitation make benchmarking difficult among the various jurisdictions. Major differences in content and organisation were identified between programmes located in Europe and North America. It is unlikely that these differences are reported in clinical studies of rehabilitation and it is unknown as to whether variables such as team composition, skill mix, location and sources of payment have a direct impact on primary outcomes. Indeed, it is not clear whether extrapolating evidence from randomised controlled trials designed around a particular model of pulmonary rehabilitation may be generalised to other models.

The development of uniform performance and process metrics will enable more meaningful comparisons among programmes in different jurisdictions. It will also allow quality control to ensure appropriate standards for pulmonary rehabilitation. As a result, international scientific groups, such as the ERS Pulmonary Rehabilitation and Chronic Care and Physiotherapists groups, the AACVPR and the ATS Pulmonary Rehabilitation Assembly would greatly benefit from discussing future steps on how to compare the processes and results of other pulmonary rehabilitation programmes to one's own results. An international benchmarking approach could even be used to set aspirational targets. Obviously, the number of performance and process metrics need to be limited to retain manageability [38]. However, a

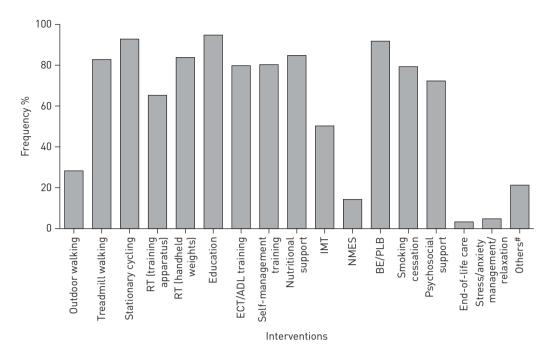


FIGURE 6 Frequency of the types of interventions in the pulmonary rehabilitation programme. RT: resistance training; ECT: energy conservation techniques; ADL: activities of daily life; IMT: inspiratory muscle training; NMES: neuromuscular electrical stimulation; BE: breathing exercise; PLB: pursed lips breathing; **: includes, but not limited to, other types of physical exercise training, goal setting, airway clearance techniques, water therapy, psychomotor therapy, enhanced art therapy, arm cranking and support group.

performance dashboard which produces reports easily using standardised metrics can generate insights between performance and process metrics that are currently lacking in the field of pulmonary rehabilitation.

Methodological limitations

Although the total number of pulmonary rehabilitation programmes present worldwide is unknown, it is undoubtedly substantially greater than 430. Therefore, we acknowledge that, since many pulmonary rehabilitation programmes did not share their details, our study results may be subject to selection bias. We believe some of the reasons behind non-response to our inquiry may have been that some healthcare professionals involved in pulmonary rehabilitation: were not proficient in English (especially in Asia, South America and Africa); were not aware of this survey; or were too busy to reply. Therefore, the current findings must be considered hypothesis-generating rather than definitive. Based on the current findings, it is not possible to ascertain whether regional differences in pulmonary rehabilitation programmes are due to genuine differences in approach to pulmonary rehabilitation, health inequalities, differences in local healthcare systems, or other unrecognised factors. Nevertheless, this survey can be seen as the first step towards possible future uniformity concerning performance and process metrics in pulmonary rehabilitation.

In conclusion, large differences exist in content and organisational aspects among pulmonary rehabilitation programmes worldwide. The current findings stress the importance of the future development of process and performance metrics to monitor pulmonary rehabilitation programmes, to be able to start international benchmarking, and to provide recommendations for international standards based on evidence and best practice. Differences in content and organisational aspects of pulmonary rehabilitation programmes suggest caution in generalisation of research findings.

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