Monaldi Arch Chest Dis
2010; 73: 3, 130-134

Potential benefits of integrated COPD management in primary care

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ABSTRACT: ***Potential benefits of integrated COPD management in primary care. A.L. Kruis, N.H. Chavannes.***

Chronic obstructive pulmonary disease (COPD) represents a major and progressive cause of morbidity and mortality worldwide, resulting in an important financial and health burden in coming decades. Pulmonary rehabilitation (PR) has been proven to be the most effective treatment in all patients in whom respiratory symptoms are associated with diminished functional capacity or reduced quality of life. Nevertheless, despite wide recommendation and proven efficacy, the use of PR is limited in daily practice. Reasons for these include low accessibility and availability, high costs, and lack of motivation to continue a healthy life style after treatment. By contrast, it has been demonstrated that primary care patients can be reactivated by formulating personal targets and designing individualized treatment plans in collaboration with their general practitioner or practice nurse. Based on these personal plans and targets, specific education must be provided and development of self management skills should be actively encouraged. Ideally, elements of pulmonary rehabilitation are tailored into a comprehensive primary care integrated disease management program. In that way, the benefits of PR can be extended to a substantially larger part of the COPD population, to reach even those with milder stages of disease. Favorable long-term effects on exercise tolerance and quality of life in a number of studies have been demonstrated in recent years, but broad introduction in the primary care setting still needs further justification in the form of a proper cost effectiveness analysis.

Monaldi Arch Chest Dis 2010; 73: 3, 130-134.

Keywords: COPD, disease management, integrated care, pulmonary rehabilitation, primary care.

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Background

COPD is a smoke-related disease, characterized by largely irreversible airflow obstruction. Patients suffer from variable grades of impaired quality of life and the disease is often complicated by co-morbidities, making it one of the more complex chronic diseases seen by general practitioners.

Because of the complexity of the disease, diagnostic problems are common: symptoms are not always recognised by patients and health care workers, and patients greatly underestimate the severity of their disease [1]. Moreover, when diagnosed, patients frequently receive insufficient treatment [2].

COPD forms a major cause of chronic morbidity and mortality worldwide and, according to the WHO, will be the third leading cause of death in 2030 [3]. Given the rise in incidence, COPD constitutes an important financial and health burden in coming decades.

The most effective non-pharmacological and pharmacological treatment, besides smoking cessation, is pulmonary rehabilitation (PR), which has been widely recommended [4, 5]. PR refers to an integrated, multidisciplinary treatment of COPD, aiming at reducing dyspnoea and symptoms. Integrated into the treatment of the patient, PR is designed to optimize functional status, increase participation and reduce healthcare costs. Ideally, PR programs are individually tailored and designed to promote education and self-management skills in combination with personal exercise training [4]. Beneficial effects are well established in severe to very severe patients [6], and significant improvements in exercise capacity, dyspnoea and health-related quality of life have been reported [7-10].

Nevertheless, despite proven efficacy and wide recommendation [4, 5, 11, 12], PR is still not available in the vast majority of cases.

Capacity problems

Even though the benefits of PR are widely established, daily use is limited. There are several reasons for this.

First, access is poor and services are frequently unavailable for patients who would benefit from PR programs [13]. Overall, admission to a program is only considered for a small proportion of the COPD population, usually the most severely affected patients.

A disequilibrium between demand and supply of PR services is the result, and consequently, health care workers are confronted with capacity problems [13]. As a striking example, it was con-

cluded in a UK survey that only 1% of the COPD population had access to a PR program [14]. These results are confirmed in a more recent Canadian study, where it was found that only 1.2% of the COPD population was able to follow a PR program [15]. Availability of PR programs at hospital settings differs considerably among countries. A survey across North America, Europe and Japan in 1999 indicated that PR programs were available at 56% of hospitals in North America and 74% in Europe, but at only 20% of hospitals in Tokyo [16].

Second, due to its highly specialized setting, PR programs are costly (but cost-effective) interventions: each rehabilitation program (maximum of 20 patients) has been calculated to cost £ 12.120, equalling approximately € 14.280 per patient [17]. As a result of these high costs, services have often been available for those patients in whom quality of life has already deteriorated to a large extent only, and prognosis is dire.

Generally speaking, it is considered a "last-ditch" effort for patients with only the most severe forms of COPD [18]. This is in contrast with the American Thoracic Society/European Respiratory Society (ATS/ERS) Statement on Pulmonary Rehabilitation and recent GOLD Guidelines, that actually recommend PR for all patients in whom respiratory symptoms are associated with diminished functional capacity or reduced quality of life [4, 19]. This recommendation is backed up by results of earlier studies, where PR has been proven to be effective, regardless of disease severity [20, 21]. In fact, especially improvements in milder stages of disease could slow down disease progression considerably.

In addition, exercise training on its own, which forms one of the major components of PR, has shown improvements in fitness of mild to moderate COPD patients [22].

A third problem with PR is the fact that it usually consists of a separate program running parallel to standard care. Furthermore, it is only administered during a limited period of time. Patients are frequently not motivated to continue a more active and healthy life style after returning home, and benefits usually dissolve over time. Ideally, when the general practitioner and/or practice nurse would be involved in the PR program, they could partake in counteracting this imminent lack of motivation, and could support the patient in maintaining physical exercise training on a daily basis. In reality, primary physicians are rarely involved in rehabilitative efforts, and as a result, largely unable to support program methods or integrate the program into their plans of continuous care [23]. What is needed for a successful long term effective intervention, accessible for all eligible patients in primary care, is to integrate the tools of PR into standard care, as was also suggested before by other authors [18, 23, 24], which will likely lead to substantial cost reduction. Our case would gain strength when it would no longer be doubted that home-based or outreaching PR programs can in fact be as efficacious as more traditional inpatient programs, and would be considered an equivalent alternative in less severe patients [7, 25].

Reactivation

In chronic disease conditions, patients not uncommonly express feelings of helplessness, negatively colored thoughts and a diminished belief in a useful and worthwhile future. Anxiety and depression appear frequently, and can even occur in mildly affected patients [26]. Illness perceptions in COPD patients have been proven to influence their quality of life: increased attention to symptoms, less positive beliefs about the effects and outcomes of illness and strong emotional reactions to the illness have found to be associated with lower quality of life scores [27]. In the same way, patients with a current depression, previous history of alcohol dependency and those who perceive that their actions have a low influence over their disease course may have difficulty with learning and applying self-management plans [28].

In COPD, there is a saddening lack of communication between healthcare providers and patients. As a striking example, up to 50% of COPD exacerbations are not reported to healthcare providers [29].This troublesome lack of communication could be the result of the negative spiral of dyspnoea, deconditioning and social deprivation that COPD patients find themselves in [30].

Through their daily decisions about taking medication, applying self-measurements and performing exercise, people with chronic diseases play a central role in determining the course of their disease [3, 32]. Because suboptimal adherence is associated with a significant health and economic burden in patients with COPD [33], efforts must be aimed at changing an attitude of perceived helplessness into an active approach, in order to break through this negative spiral. In other words, acquiring and applying self-management skills for an individual patient should be a crucial part of our treatment plan.

Ideally, patients and health care providers constitute partners in disease management, in order to take better control over daily symptoms and management. In these continuous decision-making processes, a clearly formulated written action plan in combination with approachable and committed health care providers can be a helpful and reliable instrument.

The concept of written action plans is based on their successful application in asthma patients, where programs that enable people to adjust their medication dosage using a written action plan appear to be more effective than other forms of asthma self-management [34]. In COPD, however, pharmacological treatment is considerably less effective than in asthma patients.

Nevertheless, it has been demonstrated that action plans can be helpful in guiding COPD patients to recognize and react appropriately to an exacerbation, even in cases where limited COPD education is provided [35]. In practice, patients must be trained in adequate symptom recognition and encouraged to state individual goals for the coming six months, which should then be put on record. Information provided by general practitioners or

practice nurses through different stages of disease must be directed to these goals and can result in an individualized treatment plan, designed realistically in collaboration with the patient. When written and signed by the patient, patients will gain a greater feeling of self-efficacy and increase involvement to achieve these targets. For example, when the personal goal is formulated as 'to go biking for 30 minutes every other day' or 'play in the park with my grandchildren during weekends, without acute hindrance by feelings of breathlessness', efforts must be made to maximize exercise tolerance. If the target is 'to quit smoking within two weeks', different smoking cessation therapies and behavioral guidance strategies must be explored. When goals are chosen that are close to one's beliefs, needs and personal situation, the impact will be greater.

General practitioners and nurse practitioners have a unique position: they are often familiar with the patients' habitat, are easily involved in one's family situation and patients usually report a great trust in their general practitioner. It is essential for partners and relatives to be involved as they can offer support in achieving desired prospects in future. In keeping goals simple, realistic, relevant for daily life and patient-driven, patients' self-efficacy will be supported and, as a result, intrinsic motivation will increase. In formulating these relevant and realistic goals, modern techniques such as *motivational interviewing* can be very useful, but require additional training of practice nurses and/or other health personnel [36].

Self-management is a 'hot topic' in current COPD management, and an increasing number of healthcare professionals agree that patients suffering of a chronic disease should receive support to help them self-manage their disease as effectively as possible [32]. A well informed patient will be better enabled to make his or her own decisions and can assist in maintaining healthy behaviours during different stages and complications when disease progresses [32]. Self-management education has proven to be effective as it increases knowledge and enhances self-confidence [37]. Furthermore, proper self-management is associated with a reduction in COPD-related hospital admissions [38].

Integrated disease management programmes in primary care

At present, the majority of COPD patients present themselves in a primary care setting, of which an estimated 80% are suffering from mild to moderate disease (see table 1).

The World Health Organisation promotes primary care as the most viable cost-effective setting to combat non-communicable diseases on a global scale [39], anticipating a substantial need for chronic disease-management in coming decades. Due to the resulting large-scale shift of COPD patients from secondary and tertiary care to primary care, general practitioners and practice nurses find themselves at a focal point in the organisation of care for COPD patients.

COPD remains a complex disease to treat. Multidisciplinary collaboration can improve diagnosis and management of COPD in primary care [40]. To establish a program of interventions based on individual needs and strengths, sufficient cooperation within several disciplines in primary care and collaboration with secondary and tertiary care is necessary. As a result, a multidisciplinary team should be formed, in which different health care workers participate and contribute to the required care in their field of expertise, e.g. physiotherapists, general practitioners, pulmonary physicians, dieticians and practice nurses. Patients are at a central position and their role in achieving success is decisive. An integrated disease management (IDM) program, where the elements of PR are integrated into a tailor-made program consisting of self-management, regular exercise and individualized targets, can effectively introduce certain elements of pulmonary rehabilitation into the large population that can be reached by primary care (see figure 1). Patients are managed in their own home-setting, making the benefits accessible for all COPD patients eligible.

Table 1. - Current and expected rise in prevalence according to GOLD stage in the Dutch COPD population

Gold stage	Characteristics	Current prevalence and expected rise in coming decade
I Mild	$FEV_1/FVC < 0.7$ $FEV_1 > 80\%$	**28% → + 120%**
II Moderate	$FEV_1/FVC < 0.7$ $50\% \leq FEV_1 < 80\%$	**54% → + 27%**
III Severe	$FEV_1/FVC < 0.7$ $30\% \leq FEV_1 < 50\%$	**15% → + 30%**
IV Very severe	$FEV_1/FVC < 0.7$ $FEV_1 < 30\%$	**3% → + 120%**

FEV_1: Forced Expiratory Volume in 1 second; FVC: Forced Vital Capacity.

Modified from: Smeele IJ, van Weel C, van Schayck CP, van der Molen T, Thoonen B, Schermer T, *et al*. Dutch College of General Practitioners Guideline for COPD Diagnosis. *Huisarts Wet* 2007; 50 (8): 362-79.

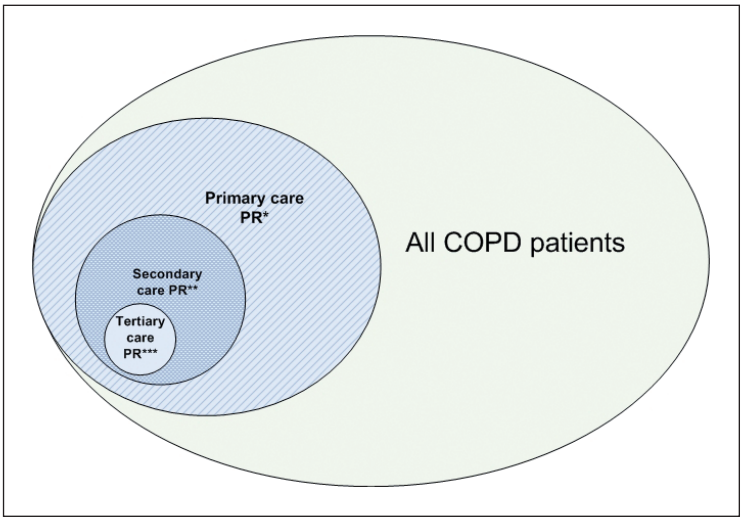

Fig. 1. Estimated yield of patients with potential benefits of pulmonary rehabilitation. PR = pulmonary rehabilitation. * Proportion of potential COPD patients that could benefit from PR in primary care; ** Proportion of COPD patients referred to secondary care PR for workup and guidance; *** Proportion of COPD patients referred to intensive tertiary care PR programs.

It is likely that costs will be lower while patients are helped at an earlier stage, possibly reducing decline and disease progression in the long term [41].

In past few years, we have demonstrated favourable results in applying primary care integrated disease management (IDM) programs. In the Picasso Bocholtz study, 150 primary care patients were followed up for two years during which the intervention group received an IDM program and the control group received usual care. The program consisted of exacerbation management, physical reactivation, and optimal medication. After one year, the results revealed a significant and clinically relevant improvement of quality of life in favour of the IDM group, being strongest in patients with MRC-dyspnoea score >2 [41]. The long-term results of this study are expected soon.

Based on the experiences of this study, the Kroonluchter disease management program was initiated in Rotterdam, the Netherlands. In this implementation programme, over 200 primary care COPD patients have been treated since 2005, aimed at tailored COPD rehabilitation in primary care. Depending on their individual disease burden, patients may receive optimization of their medication by their primary care physician, a tailored 6-month specific training program with a physiotherapist, or medication compliance monitoring and repeated inhalation instruction by a pharmacist. Drop out rates are very low (12%) and the majority of participants report perceptible and measurable improvements in exercise tolerance after two years follow-up. Furthermore, a strong collaboration has developed between primary care providers, patients and secondary care [30]. These results are consistent with another two-year randomized controlled trial, the INTERCOM study, in which patients were included with less advanced airflow obstruction but impaired exercise capacity. In this study, the intervention group received exercise training, education, nutritional therapy and smoking cessation counselling in a community-based, multidisciplinary setting. Quality of life, functional exercise capacity, and breathlessness remained significantly favourable in the intervention group versus usual care over the entire two-year intervention [42].

Despite encouraging results in earlier studies as described above, more research is needed. We recommend large pragmatic randomized controlled trials, addressing the costs and long-term clinical effectiveness of an IDM program in primary care.

Conclusion

PR has proven to be the most effective treatment for COPD patients [4, 5, 11, 12], but its use in daily practice is limited due to low availability and accessibility, high costs and short duration of administration [13-17]. When a program is provided where the elements of PR are integrated into a tailor-made program consisting of proper self-management, regular exercise and based on individualized targets, people can be managed in their home environment, while primary care providers are more involved and in the position to coach this process directly [41]. Training in motivational interviewing techniques is a prerequisite to actively include personal goals and stimulate the patients' intrinsic motivation. Our aim should be to make the benefits of PR available to the large population of eligible COPD patients, and possibly diminish disease progression in less severe patients at an earlier stage. Encouraging results have been published [30, 41, 43], but more research is needed in the form of a proper cost-effectiveness analysis.

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