

Self-management programmes for COPD: Moving forward

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Tanja W Effing^{1,2}, Jean Bourbeau³, Jan Vercoulen⁴,
Andrea J Apter⁵, David Coultas⁶, Paula Meek⁷,
Paul van der Valk⁸, Martyn R Partridge⁹ and
Job van der Palen^{8,10}

Abstract

Self-management is of increasing importance in chronic obstructive pulmonary disease (COPD) management. However, there is confusion over what processes are involved, how the value of self-management should be determined, and about the research priorities. To gain more insight into and agreement about the content of programmes, outcomes, and future directions of COPD self-management, a group of interested researchers and physicians, all of whom had previously published on this subject and who had previously collaborated on other projects, convened a workshop. This article summarises their initial findings. Self-management programmes aim at structural behaviour change to sustain treatment effects after programmes have been completed. The programmes should include techniques aimed at behavioural change, be tailored individually, take the patient's perspective into account, and may vary with the course of the patient's disease and co-morbidities. Assessment should include process variables. This report is a step towards greater conformity in the field of self-management. To enhance clarity regarding effectiveness, future studies should clearly describe their intervention, be properly designed and powered, and include outcomes that focus more on the acquisition and practice of new skills. In this way more evidence and a better comprehension on self-management programmes will be obtained, and more specific formulation of guidelines on self-management made possible.

Keywords

COPD, behaviour, self-management, programmes, conformity

¹ Department of Respiratory Medicine, Repatriation General Hospital, Daw Park, Australia

² School of Medicine, Flinders University, Adelaide, Australia

³ Respiratory Epidemiology and Clinical Research Unit, Montreal Chest Institute of the Royal Victoria Hospital, McGill University Health Center, Quebec, Canada

⁴ Department of Medical Psychology and Department of Pulmonary Diseases, Radboud University Nijmegen Medical Centre, Nijmegen, The Netherlands

⁵ Section of Allergy and Immunology, University of Pennsylvania, PA, USA

⁶ Department of Medicine, The University of Texas Health Science Center at Tyler, TX, USA

⁷ College of Nursing, University of Colorado Denver, CO, USA

⁸ Department of Pulmonary Medicine, Medisch Spectrum Twente, KA Enschede, The Netherlands

⁹ Imperial College London, NHLI Division, South Kensington Campus, London, UK

¹⁰ Department of Research Methodology, Measurement and Data Analysis, University of Twente, AE Enschede, The Netherlands

Corresponding author:

Tanja W Effing, Department of Respiratory Medicine, Repatriation General Hospital, Daws Road, Daw Park SA 5041, Australia
Email: tanja.effing@health.sa.gov.au

Introduction

Self-management programmes are increasingly used in chronic obstructive pulmonary disease (COPD), but the interventions are diverse.¹ In general, COPD self-management programmes are programmes that aim to teach the skills needed to carry out medical regimens specific to a long-term disease and to guide behaviour change to help patients control their own condition and improve their well-being.² However, in the different guidelines several meanings have been attached to COPD self-management programmes. In the National Institute for Health and Clinical Excellence guidelines,³ self-management refers specifically to action plans for exacerbations; while in the Global Initiative for Chronic Obstructive Lung Disease guidelines,⁴ patient education is aimed at improving self-management. Similarly, the American Thoracic Society/European Respiratory Society Statement on pulmonary rehabilitation⁵ emphasises educational topics that will enhance self-management skills (including the use of action plans); and in the American College of Chest Physicians guidelines,⁶ education to enhance collaborative self-management is recommended without specifying the content except for prevention and treatment of exacerbations.

The term 'self' implies self-care and yet self-management always includes a partnership with a health care professional, with the latter providing a supportive role. Using the term 'self-management education programmes' may be misleading because self-management aims at behavioural change that requires specific interventions aimed at problem solving and gaining the confidence to deal with these problems. The interpretation of the term 'education' is often limited to transmission of knowledge, which will most of the times not lead to behavioural change. Because self-management should mainly be interpreted as developing skills and equipping patients to both manage and cope with their chronic illness, we strongly advise to use the term 'self-management' or 'self-management training' instead of 'self-management education' for future purposes.

The definition and minimum requirements in term of process and content of COPD self-management programmes are not clear. Whereas the most recent update of the Cochrane review stated that COPD self-management was associated with a reduction in respiratory-related hospital admissions, data were still insufficient to enable programming choices.¹ Included studies used a wide variety of interventions

ranging from solely education to combinations of education, action plans, and community or home-based exercise programmes, and only a minority of studies were clearly aimed at behavioural change. Sub-analyses could not be performed in this review because of a lack of power.¹

A systematic review by Adams et al.⁷ concluded that self-management as part of multiple components (delivery system, decision support, and clinical information system) is an effective strategy to reduce health care use in COPD, while interventions that apply self-management alone are unlikely to show benefit on outcomes such as emergency department visits and hospital admissions.

Agreement about the content of self-management programmes is needed to guide future research on self-management of COPD. To help in this process, a group of interested physicians and researchers, who had all previously published on this subject and collaborated previously on projects in this and allied areas, convened a face-to-face workshop. Prior to the start of this workshop, topics of interest were defined. A selected number of attendees were asked to present background and current knowledge regarding each topic: (a) definitions of COPD self-management; (b) current state of knowledge around COPD self-management; (c) modifying health behaviours for better health outcomes; (d) methodological limitations of current research; and (e) desired outcomes and standardisation. After each presentation, the topic was discussed further in the group and key points and priority areas for future research were summarised by the chair.

Where COPD self-management should be situated in the COPD journey

Self-management is an aspect of the continuum of disease management (Figure 1) whose goal is to empower the patient at all stages of the disease. However, content and components of the programme will vary within the continuum, depending on the factors such as disease severity, co-morbidities, and ease of access to health care. Self-management programmes with minimal supervision, including care plans that promote a healthy lifestyle (e.g. smoking cessation and physical activity) can be offered to patients with less severe problems and those with capacity to manage their disease. In the more severe patients, who may have co-morbidities, pulmonary rehabilitation will assume greater importance and

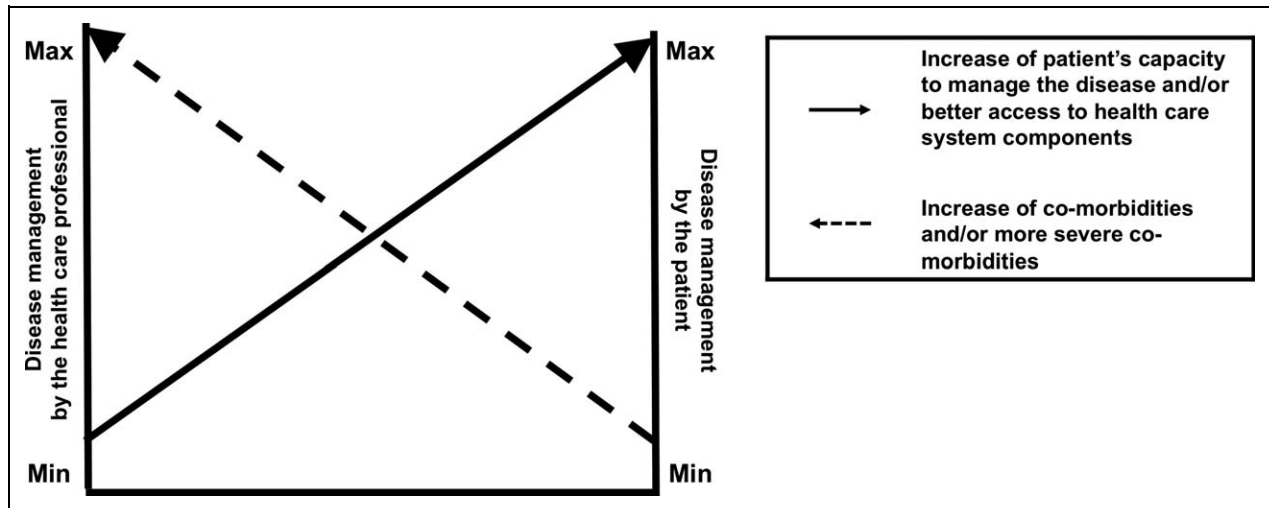


Figure 1. Continuum of disease management.

pulmonary rehabilitation that includes self-management is the most intensive method to increase self-help skills and healthy lifestyle better adapted to their daily needs.

Disease management by the patient will always be accompanied by disease management by health care providers. When patient management decreases (e.g. when the severity of illness increases as part of the trajectory of the long-term disease), management by health care providers will increase proportionally and vice versa (Figure 1). It should be noted that although patient management may decrease proportionately relative to management by the health care providers, in absolute terms management by both the patient and health care provider will most of the times increase with disease severity.

To enable a shift towards more management by the patients, patients have to gain confidence, 'self-efficacy,' to apply the acquired skills on a daily basis and they have to be provided with the necessary tools (e.g. action plans and access to a case manager). In addition, it is very important that health care providers have a positive attitude towards disease management by the patient and recognise patients as experts on their own illness.⁸

Change of behaviour: The (only) way to achieve long-term improvement of health status

We believe that self-management interventions should be aimed at sustained behavioural change so that the beneficial effects do not decline after programmes have been completed. Self-management programmes

should therefore also incorporate interventions that are effective in achieving behaviour change and to ensure maintenance.

One important therapeutic technique that can be used for achieving behavioural change is cognitive-behavioural therapy.⁹⁻¹⁴ Cognitive-behavioural therapy is a structured, time limited, psychological intervention in which the patient works collaboratively with the therapist to identify the types, effects, and interactions of thoughts, interpretations on current symptoms, feeling states, and behaviour in relation to problem areas.¹⁵ Its aim is to develop skills to enable the patient to control their symptoms and manage their disorder, by utilizing a combination of behavioural and cognitive techniques to counteract problematic thoughts, interpretations, emotions, and behaviour. Shared decision making and motivational interviewing are examples of cognitive-behavioural therapy techniques that are crucial with regard to changing peoples' behaviours.¹⁵ Whereas these cognitive-behavioural therapy techniques may be successfully incorporated in any treatment of patients with COPD, to date there are only a few studies that have reported the use of these techniques.^{16,17}

In the last few decades, cognitive-behavioural therapy has achieved prominence because of its effectiveness in achieving behaviour change⁹⁻¹⁴ within a limited number of sessions. Whereas evidence for the latter is still limited in COPD, its benefits amongst non-COPD populations is so convincing that we recommend use and further evaluation of cognitive-behavioural therapy in all future COPD self-management programmes.

A fundamental psychological mechanism from cognitive-behavioural principles is 'operant conditioning' in which the re-occurrence of behaviour is dependent upon the consequences from this behaviour.¹⁸ A particular behaviour is most likely to re-occur if the person actually experiences positive effects of this behaviour. Positive effects in the short term are much more powerful than effects in the long term. For example, patients are more compliant with bronchodilator usage than with maintenance medication because bronchodilators have easily perceived immediate benefits. Negative effects of behaviour, both short term and long term, have little or no effects. Cognitive-behavioural interventions are aimed at encouraging the patient to actually experiment with adaptive behaviours. Experiencing the positive effects from these new behaviours will reinforce the continued adoption of this behaviour most powerfully.¹⁸ This explains why education alone is not effective in inducing structural behaviour change.

Another cognitive-behavioural approach is changing behaviour by changing a patient's cognitions. Cognitions are thoughts or interpretations a person has concerning the world in which he lives. Illness cognitions concern thoughts and interpretations regarding any aspect of health or illness.¹⁹ Illness cognitions are very diverse and include interpretations of physiological sensations, the causes and consequences of complaints, expectations about the future, or ideas about the controllability of the disease. Cognitions are very powerful in inducing negative emotions. Cognitions and emotions guide behaviour. The effectiveness of cognitive-behavioural interventions depends not only on well-chosen techniques but also upon motivating patients to take responsibility for their health and by increasing the patient's confidence that they can effectively manage their health (improvement of self-efficacy).^{20,21} In addition, the effectiveness of cognitive-behavioural interventions depends on the way these techniques are employed. A caregiver should not give advice about 'what to do' or how to solve a problem, but to ask the patient questions such as 'What do you want to achieve?' and 'How are you going to deal with this?' to encourage him to actually experiment with new behaviours.

Cognitive-behavioural interventions can be performed by nonpsychotherapists but training is crucial. In Table 1 some practical tips have been summarised.

Finally, the concept of 'motivation' is important in behaviour change. Poor motivation is sometimes

Table 1. Practical tips for stimulating behavioural change

- Formulate treatment goals into concrete and highly relevant goals in relation to the personal situation of the patient.
- Do not talk just about adaptive behaviours, but encourage patients to actually experiment with these adaptive behaviours in every day life to improve motivation and increase the likelihood of the new adaptive behaviours being adopted and maintained.
- Stimulate the patient to take responsibility for his health by asking questions instead of giving advice or solving the problem for the patient (to ensure he is proficient in problem solving and decision making).
- Focusing on positive effects of adaptive behaviours is more effective than focusing on negative effects of maladaptive behaviours.
- Self-efficacy is a powerful factor in inducing new behaviour. Experiencing beneficial effects of adaptive behaviours will in turn increase self-efficacy.
- Changing cognitions is a powerful way to change both negative emotions and inadequate behaviours. Increasing motivation and changing cognitions occur simultaneously with experiencing positive benefits from new adaptive behaviours in an interactive manner.

described as being a feature of patients with COPD.²² In addition, it is not unlikely that the level of patient motivation will influence the chance to be included in a self-management programme. However, motivation can increase as the patient experiences benefits from new adaptive behaviours.¹⁸ In this respect, it is crucial not only to formulate general goals such as increasing exercise capacity or improving health status, but goals should be concretised in such a way that these are highly relevant for the individual patient. From the above-mentioned description of cognitive-behavioural processes, it should be clear that motivation to adopt new adaptive behaviours is synergistic with the whole process. Therefore, in our opinion, high motivation is not a prerequisite for treatment but one of the treatment goals.

Different components within COPD self-management programmes

From the literature on long-term conditions, it has been demonstrated that self-management needs to be in-depth and ongoing and usually provided by a multidisciplinary team including a case manager and peers.²³⁻²⁵ The patient is the key person collaborating with clinicians, nurses, physiotherapists, and other health care providers, who can all be seen as facilitators.

The precise content depends on the severity of COPD, presence of physical and/or psychosocial comorbidities, the patient's capacity to manage his or her disease (self-efficacy, literacy, and numeracy), and access to health care. A case manager (for example, a respiratory nurse) can serve as the patient's companion within the complicated world of health care. This case manager works in close collaboration with the physician and should also have easy access to the other health care providers and medical data.

The use of action plans can be very useful in helping the patient to define adaptive behaviours and to choose behaviours depending on specific situations. Self-management programmes should be tailored to the individual patients and therefore numerous factors should be taken into account (e.g. severity of COPD, co-morbidities, smoking status, physical, and cognitive limitations). A detailed assessment of the patient prior to the start of the programme is essential.²⁶ The self-management sessions should at a minimum include the aims of advancing disease knowledge, promoting healthy habits, optimizing medication and compliance to medication, recognizing exacerbations and having the possibility of acting promptly, and themes such as problem solving, decision making, resource use, and formation of effective patient-provider partnerships.

The following are specific components utilised within self-management programmes:

- (1) *Smoking cessation advice and support.* Smoking cessation is proven to prolong the life of COPD patients and delay progression at all stages of the disease.²⁷
- (2) *Self-recognition and treatment of exacerbations.* Guidelines for the self-treatment of exacerbations summarised in personalised action plans are considered as an essential component of self-management. Long-term benefits are still unclear, but self-treatment action plans in conjunction with other modalities of care seem to reduce exacerbation days, health care contacts, and costs.^{28–30}
- (3) *Exercise and increased physical activities.* Many COPD patients benefit from exercise programmes as part of pulmonary rehabilitation.^{31–35} However, the effects of these programmes may diminish with time because the level of physical activity in daily life may only be modestly influenced by the exercise programme.³⁶ This may lead to a decline in exercise tolerance due to a deconditioning effect.³⁷

Behavioural change with regard to exercise should therefore be an important goal in exercise programmes. The training intervention and exercise environment should be structured in a way that enables the shift from exercising with the physiotherapist to exercising at home or in their community (e.g. incorporation of home exercises and increasing functional physical activity).^{38,39}

A recent study showed positive effects of a home-based exercise programme in addition to self-management on quality of life and cycle endurance time.⁴⁰

- (4) *Nutritional advice.* Poor nutritional status is associated with increased morbidity and mortality in patients with moderate-to-severe COPD.⁴¹ Although, according to a review by Ries et al.⁶ studies have not proven the effectiveness of dietary interventions in COPD patients, actions to improve nutritional status (e.g. behavioural weight management) might nevertheless be valuable in some COPD patients.
- (5) *Dyspnoea management.* Breathlessness is inherent in COPD but may increase over time due to the progression of the disease, de-conditioning, an exacerbation, or co-morbidity, such as chronic heart failure. Teaching the patient how to discriminate between causes of increased dyspnoea and how to take appropriate action is essential. Energy-saving strategies, breathing-regulation training,^{42,43} and mitigation of concomitant anxiety are important interventions.⁴⁴

Patient perspective

The patient's perspective regarding the selection of topics within disease management is important, especially with respect to motivating patients to adapt to their illness. The patient's perspective may not completely fit into the professional's perspective and may change during the different stages of COPD. In general, patients may lack understanding about severity, prognosis, medical treatment of COPD,^{45,46} and benefits of adaptive behaviours. Patients who participated in a pulmonary rehabilitation programme mentioned 'control of dyspnoea' and 'how to adapt to restrictions of COPD' as the prominent topics.⁴⁷ Patients discharged from hospital following an exacerbation of their condition reported feelings of anxiety and fear, uncertainty as to when to call for help, feelings of isolation, a need for support for care at home from family

and social services, and concerns about why oxygen was not provided post hospitalisation.⁴⁸

Literacy and numeracy

Self-management programmes need to also be concerned with health literacy (which includes numeracy). Literacy might be a problem in COPD because we are often dealing with an older population with a lower average socioeconomic status.^{49,50} Functional impairment of literacy is often unrecognised and may lead to problems with access to health care and poorer understanding of treatment.⁴⁹ The relationship between health literacy and the capacity to learn COPD self-management skills is hardly explored,⁵¹ but literature suggest that inadequate health literacy is a surmountable barrier to learning and remembering key asthma self-management skills.⁵²

Numeracy (the ability to understand and act on numerical directions) might also present problems.⁵³ Many patients have difficulties with interpreting percentages and risks and information about scheduled appointments.^{54,55} There is limited research on the impact of poor numeracy on health and no tool has been developed that assesses numeracy skills related to COPD.

One should offer information materials that are easy to interpret. Materials which have a predominantly written component should be tested for level of readability.⁵⁶ Pictorial representations may be a preferable method of offering information⁵⁷ and aid understanding even amongst the literate. This subject has recently been reviewed.⁵⁶

Measuring the effects of self-management programmes

Self-management includes interventions aimed at optimizing physiological functioning and adaptation to the illness in order to cause improvements in health status. Until now, most of the studies¹ have focussed on measuring ultimate outcomes such as patient health status and health service utilization (emergency department visits and hospital admissions).

Assessment should include not only ultimate outcome measures but also measurement of specific behaviour change and process variables (e.g. change in self-efficacy, attitude, and social support). With respect to outcome measures, many good quality instruments (with regard to validity, reproducibility, and responsiveness) are available for evaluation of

physiological (e.g. lung function testing and walking tests) and health status components (complaints, functional impairment, and quality of life). However, good instruments to evaluate important process variables with regard to self-management such as self-efficacy in patients with COPD are scarce.⁵⁸

Many commonly used disease-specific instruments measure subjective experiences of the patient.⁵⁹ Although these represent important aspects of health status, subjective change does not directly indicate actual behaviour change. Discrepancies are reported between what the patient is able to do (e.g. cycle ergometry), what he really does (e.g. accelerometry), and what he subjectively believes he can do (the patient's cognitions about his activity level, measured by questionnaires).⁵⁹⁻⁶¹ The final selection of instruments will depend on primary and secondary study aims.

In addition to questionnaires, self-registration techniques might also be useful in COPD patients.⁶² Self-registration techniques are structured and predefined diaries, specifically designed to measure outcome variables and process variables. Self-registration techniques can assess cognitions, emotions, and behaviour. These techniques can also be used as part of interventions (monitoring progress and to identify barriers).

Future studies

Published studies and reviews suggest that self-management is now an important part of the management of COPD but to be broadly applicable, further research is needed and should involve larger, high-quality studies using proper and well-described self-management interventions aimed at behavioural change. Because of the latter, behaviour change should be required as an outcome measure and follow-up also needs to be sufficiently long (minimum of 1 year and ideally beyond).

When designing future studies, a number of issues have to be taken into account. First, the concealment of allocation should be performed correctly and trials need to be powered adequately, and with less than 50 patients per group it is unrealistic to expect to find significant results, in spite of meaningful effect sizes. The self-management intervention including the material, the case manager and their interventions (visits, telephone, or other support to the patient), and training of the health professional needs to be described in detail. In addition, patient characteristics

and reasons for refusal need to be specified. Finally, the selection of sensitive and appropriate outcomes is essential (e.g. behaviour intent to change with the self-management programme), and not only assessing patient health and health care system benefit.

Conclusion

This report is a step towards more conformity in the field of self-management. The evaluation of high-quality self-management programmes within properly designed studies should be strived for. In this way, more evidence about self-management programmes is gained and the formulation of guidelines on self-management programmes in COPD will be possible.

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