CHRONIC OBSTRUCTIVE PULMONARY DISEASE

Self-management education for patients with chronic obstructive pulmonary disease: a systematic review

E Monninkhof, P van der Valk, J van der Palen, C van Herwaarden, M R Partridge, G Zielhuis

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See end of article for authors' affiliations

Correspondence to: MSc E Monninkhof, Department of Pulmonery Medicine, Medisch Spectrum Twente, P O Box 50000, 7500 KA Enschede, The Netherlands; emonninkhof@introweb.nl

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Background: The idea of self-management is to teach patients how to carry out the activities of daily living optimally in the face of their physiological impairment, and to prevent or decrease the severity of exacerbations by means of life style adaptation. In chronic obstructive pulmonary disease (COPD) the value of self-management education is not clear. This review was undertaken to clarify the effectiveness of self-management programmes in COPD.

Methods: A search was made of the Cochrane Airways Group trial registers, Medline, reference lists, and abstracts of medical conferences for controlled trials of self-management education in patients with COPD. Two reviewers independently assessed each paper for methodological quality and extracted the data.

Results: The reviewers included 12 articles describing eight randomised controlled trials and one controlled clinical trial in which self-management education was compared with usual care. The studies assessed a broad spectrum of outcome measures with different follow up times so meta-analysis could not be undertaken. Self-management education had no effect on hospital admissions, emergency room visits, days lost from work, and lung function. Inconclusive results were observed on health related quality of life, COPD symptoms, and use of healthcare facilities such as doctor and nurse visits. Self-management education reduced the need for rescue medication and led to increased use of courses of oral steroids and antibiotics for respiratory symptoms.

Conclusions: Insufficient data were obtained to make recommendations because of the wide variation in outcome measures used and other limitations to generalisations in the current published literature. Further research in this area is needed.

Chronic obstructive pulmonary disease (COPD) is a serious public health problem worldwide. The prevalence, morbidity, and mortality are expected to rise, especially in countries with a rapidly ageing population and even in populations with reduced smoking rates.[1] A study published by the World Bank/World Health Organisation reported that COPD is likely to rise from being the twelfth most burdensome disease in 1990 to the fifth in 2020.[2] This will place an enormous burden on the healthcare system and will also cause a loss in health related quality of life (HRQoL) for many patients with COPD. Treatment in COPD is often primarily aimed at improving airflow obstruction by bronchodilator and anti-inflammatory therapy, despite indications that airflow obstruction is irreversible and the apparent lack of effect of pharmacological interventions on the progressive decline in health status. Despite optimal pharmacological treatment, many patients with COPD experience substantial functional impairment.[3] However, airflow obstruction correlates poorly with disease perception by the patient.[4 5] COPD is a systemic inflammatory disease and, besides airflow limitation and hyperinflation due to loss of elastic recoil and intrinsic airway narrowing, systemic deficits such as skeletal and respiratory muscle dysfunction are prominent features. There is a growing need for other forms of treatment for COPD patients, not only to control and alleviate symptoms and complications of respiratory dysfunction but also to teach them how to carry out the activities of daily living optimally in the face of their physiological impairment.[6]

In asthma, patient education and self-management programmes have proved to be successful—at least when combined with regular review—in reducing the economic burden of disease and in improving quality of life and lung function.[7–10] In COPD, pulmonary rehabilitation has been shown to increase exercise tolerance and quality of life.[11] The drawback is that pulmonary rehabilitation programmes will normally be more expensive and time consuming for both professionals and patients than self-management programmes, and may be less widely available.

Worth and colleagues[12] were the first to describe the effectiveness of a programme aimed at acquiring self-management skills and behavioural change by patients with COPD. Unfortunately this pilot study was uncontrolled and studied only a small sample of patients (n=21). Impressive reductions in the frequency of exacerbations and home visits by the family doctor were observed, but no changes in lung function were found. Several controlled trials have been conducted to evaluate the effectiveness of COPD education and self-management education programmes. This review was conducted to examine the impact of these programmes on health outcomes and healthcare utilisation.

METHODS

Search of literature

Relevant studies were identified with assistance from the Cochrane Airways Group from the following sources: Cochrane Airways Group register derived from Medline (January 1985–October 2001), Embase (January 1985–October 2001), CINAHL (January 1985–October 2001), hand searched respiratory journals, and abstracts from meetings. The databases were searched using the following terms: "self-care" (keyword) *and* "lung-diseases-obstructive" (keyword) *and* ("COPD" *or* "chronic obstructive pulmonary disease" *or* "emphysema" *or* "chronic bronchitis") *and* ("patient-education" (keyword) *or* "self management" *or* "self-management" *or* "self management"). From these the bibliographic lists were hand searched for additional papers.

Table 1 Characteristics of included studies

Reference	Design	N	Mean age I/C*	Sex (% male) I/C*	FEV_1 (%pred) I/C*	Recruitment	Follow up (months)	Outcomes
Gallefoss (1999a)†[8]	RCT	62	57/58	48/52	59/56	Outpatients	12	Health status
Gallefoss (1999b)†[15]	RCT	62	57/58	48/52	59/56	Outpatients	12	Compliance, courses of steroids, use of rescue medication
Gallefoss (2000)†[16]	RCT	62	57/58	48/52	59/56	Outpatients	12	Health status, hospital admissions, days lost from work, GP consultation, lung function
Blake (1990)[17]	RCT	94	63/64	80/82	?	Outpatients	12	Health status, hospital days, bed disability days, restricted activity days, physician visits
Cockcroft (1987)[18]	RCT	75	69/71	69/67	?	Outpatients	10	Health status, hospital admissions, deaths knowledge, symptoms
Emery (1998)‡[19]	RCT	50	67/67	67/67	43/39	Outpatients + GP patients, advertisements + word of mouth	2	Health status, knowledge, lung function
Gourley (1998)§[20]	RCT	98	69/69	100/100	?	Outpatients	6	Health status, patient satisfaction, knowledge
Solomon (1998)§[21]	RCT	128	69/69	100/100	50/50	Outpatients	6	Symptoms, hospital admissions, ER visits, other healthcare facilities
Howland (1986)[22]	CCT	659	59/60	54/51	?	Community patients	12	Health status, lung function
Littlejohns (1991)[23]	RCT	152	63/63	67/63	45/50	Outpatients	12	Health status, number of exacerbations, courses of steroids/antibiotics, hospital admissions, lung function, exercise capacity
Watson (1997)[24]	RCT	69	68/67	62/67	37/36	GP patients	6	Health status, symptoms, GP visits, courses of steroids/antibiotics, lung function

RCT=randomised controlled trial; CCT=controlled clinical trial.
*I=intervention group; C=control group.
†These papers were derived from the same study.
‡The third arm of this study was disregarded because it focused on pulmonary rehabilitation.
§These papers were derived from the same study.

Research groups in this field were also contacted for unpublished and non-registered ongoing trials.

Selection of literature

Two reviewers (EM and JvdP) independently selected studies for inclusion in the review. Studies were included if they were randomised controlled trials (RCT) or controlled clinical trials (CCT) which assessed the efficacy of self-management education in patients with COPD. We excluded studies with patients having asthma as the primary diagnosis, studies focusing mainly on pulmonary rehabilitation, and those performed before 1985 because before this date the treatment of COPD was not comparable with current practice.

The interventions were categorised according to whether or not they involved COPD education and/or self-treatment guidelines—that is, whether a personal action plan was issued. COPD education was defined as a programme which transfers information about COPD and treatment of COPD in written, verbal, visual, or audio forms. Minimal education included the provision of written material alone or a short structured verbal interaction between a healthcare provider and a patient. However, it had to be embedded in a formal programme where the primary goal was to improve the knowledge and understanding of COPD. The educational programme might be directed towards smoking cessation, improving exercise, nutrition, self-treatment of exacerbations, inhalation technique, or coping with the activities of daily living, or a combination of these. Self-treatment guidelines (action plan) were defined as a written plan produced for the purpose of patient self-management of COPD exacerbations which informs patients about when and how to adjust and/or start medication in case of an exacerbation.

Only COPD education studies which included any of the following outcomes were selected: health related quality of life scores, symptom scores, number and severity of exacerbations, courses of oral steroids or antibiotics, use of rescue medication, hospital admissions, emergency room visits, use of other healthcare facilities, days lost from work, lung function, and exercise capacity.

Data extraction and analysis

The data extraction and study quality assessment were independently performed by two reviewers (EM and JvdP). Agreement was examined; disagreement was resolved if possible by consensus and otherwise by consultation with a third reviewer (PvdV). Data were extracted using a standardised data abstraction form created for the study. Missing data from the primary study reports were requested from the investigators. The methodological quality of the included studies was assessed using the criteria list of Jadad *et al*.[13] The quality variables recorded in the criteria list of Jadad were the procedure of allocation, information regarding withdrawals and dropouts, blinding of patients, and outcome assessment. In general, a maximum of five points can be obtained using this criteria list but, as blinding is impossible when assessing behavioural interventions, the maximum score was limited to three points. A higher score indicated better methodological quality. In addition, information was extracted on the general quality of the data in the studies in terms of sample size, quality of the outcome assessment, and length of the follow up period.

For every outcome we assessed the effect of self-management compared with usual care. Outcomes were analysed as continuous and/or categorical variables using standard statistical techniques. For continuous outcomes the weighted mean difference or standardised mean difference with 95% confidence intervals were calculated as appropriate, and for rates the relative risks or odds ratios were pooled. In case conventional meta-analytical techniques could not be applied, the effects in both groups of studies were described.

RESULTS

The search identified 395 titles and abstracts (386 from the Cochrane database and nine by hand searching) which were screened to identify 33 potentially relevant articles about self-management education in COPD. Full text versions of these papers were obtained and independently assessed by two

Table 2 Characteristics of the self-management education intervention in each study

Reference	Group education	Individual education	Patient brochure	Audiotape	Exercise	Action plan	Smoking cessation	Nutrition
Gallefoss[8 15 16]	√		√			√	√	
Blake[17]		√	√	√				
Cockcroft[18]		√						
Emery[19]	√							
Gourley[20]/Solomon[21]		√						
Howland[22]	√				√		√	√
Littlejohns[23]		√						
Watson[24]			√		√	√	√	√

reviewers. Twenty one of the 33 articles were excluded for the following reasons: the design of the study was not a CCT or RCT (n=10); most of the included patients had asthma as the primary diagnosis (n=2); the studies were published before 1985 (n=2); the studies were primarily focused on pulmonary rehabilitation (n=6); and the outcome assessed was not appropriate (n=1). The reviewers included 12 articles describing eight RCTs and one CCT. Eight of the nine studies described COPD self-management education compared with usual care, and one study compared a rehabilitation programme without an exercise component with general health education.[14] This study was omitted from the review. The characteristics and type of interventions of the eight included studies are summarised in tables 1 and 2, respectively.[8 15–24] We contacted the authors of these studies for additional information but not all authors could provide the additional information requested.

A total of 1295 patients were randomised in the eight studies with 1106 patients completing the study. The dropout rates ranged from 0% to 22.4%. Five studies recruited their patients from outpatient clinics, one from general practice, one from the community, and one from a mix of these settings.

Only two studies[8 15 16 24] reported the use of an action plan for self-treatment of exacerbations in COPD embedded in a self-management programme. Although action plans and self-management education can be considered as separate interventions with different outcomes, we were not able to distinguish them in this review because the number of studies was too small.

Quality of data

The method of generating the randomisation sequence was not clear in one of the seven RCTs but was adequate in the other six RCTs. None of the interventions was double blind because blinding of patients with respect to study status is almost impossible in behavioural clinical trials. A description of withdrawals and dropouts was given in seven of the eight studies. Five studies[8 15–17 19 23 24] scored the maximum number of three quality points, two[18 20 21] scored two points, and one study[22] scored one point.

Outcomes

The results of the different outcome measures are summarised in table 3. HRQoL was measured in all eight included studies, but the instruments for HRQoL measurement differed widely among the studies. COPD specific HRQoL using the St George's Respiratory Questionnaire (SGRQ) was measured in two studies.[8 24] SGRQ total scores and domain scores were all lower (indicating a better HRQoL) in the self-management education groups, but these differences did not reach clinical significance. The SGRQ physical activity domain showed a significant and clinically relevant lower score (weighted mean difference (WMD) 10, 95% CI –18.5 to –2.0) indicating a better HRQoL in the self-management education group but there was significant heterogeneity between these two studies (χ^2=12.54, p<0.05).

General HRQoL was measured with the Sickness Impact Profile (SIP) in three studies.[17 19 23] Data from these three studies were not suitable for meta-analysis and showed incongruent results. One study[19] reported significant improvement in total function measured by the SIP for the control group. However, Tougaard and colleagues[17] found better physical function and total function in favour of the intervention group, and Littlejohns *et al*[23] showed a significantly greater improvement in physical function in the intervention group. Other studies used the Health Status Questionnaire 2.0,[20] the General Health Questionnaire,[18] and a self-designed questionnaire (consisting of elements of the health locus of control scale, respiratory health questionnaire, Zung scales, and SIP scales)[22] to measure general health status. In the latest two studies general HRQoL was not significantly different between the self-management education and control group, although Gourley *et al*[20] showed significantly improved scores for the well being dimension of the Health Status Questionnaire 2.0 in the intervention group.

The effects of self-management education on COPD symptoms were examined in two studies.[21 24] Solomon *et al*[21] assessed symptoms using the Borg scale to measure breathlessness on a 12-point scale and the Global Assessment Scale to measure symptom severity on a 6-point scale. Borg scale scores indicated a positive effect for self-management education on breathlessness, although no statistically significant differences were observed. The Global Assessment Scale showed a reduction which was not statistically significant in symptom severity in the self-management education group, while in the control group no reduction was observed. In the study by Watson *et al*[24] patients scored their respiratory status in symptom diaries on a 4-point scale (usual, mild, moderate, severe); no significant between-group differences were seen in the proportion of days rated as mild, moderate, and severe.

Three studies assessed the use of oral corticosteroids for respiratory problems.[15 23 24] Gallefoss *et al*[15] reported that 69% of patients in the intervention group used courses of steroids compared with 44% in the control group, with a median of three and four courses recorded during the study year, respectively. Littlejohns *et al*[23] found that 49% of the patients in the intervention group used oral steroids compared with 37% in the control group during the study year. Meta-analysis of these studies showed an increased use of oral steroid courses in the educated patients (RR 1.39, 95% CI 1.02 to 1.91). Watson *et al*[24] analysed from symptom diaries the days on prednisolone as a percentage of the days recorded. The intervention group spent 15% of the days recorded on prednisolone compared with 9% in the control group.

Use of antibiotics for respiratory problems was assessed in two studies.[23 24] Littlejohns *et al*[23] reported that 79% of patients in the intervention group were prescribed antibiotics during the study year compared with 52% in the control group. Watson *et al*[24] analysed from symptom diaries the days on antibiotics as a percentage of the days recorded and found that the intervention group spent 10% of the days recorded on antibiotics compared with 4% in the control group. Treatment differences in both studies were statistically significant.

Table 3 Results of different outcome measures: self-management compared with usual care

Outcome	No of studies	Meta-analysis	Results of the different outcome measures
General HRQoL	3[17 19 23] 1[20] 1[18] 1[8 24]	No	• SIP: incongruent results • Health Status Questionnaire 2.0: no difference in general; improved well being scores • General Health Questionnaire: no difference • Self-designed questionnaire: no difference
Disease specific HRQoL	2[8 24]	Yes[8 24]	• Meta-analysis SGRQ indicating better HRQoL but significant heterogeneity between studies; WMD = –10 (95% CI –18.5 to –2.0)
COPD symptoms	2[21 24]	No	• Borg scale: positive direction, not significant • Global Assessment Scale: reduction in symptom severity; not significant • Symptom diaries: no difference
Exacerbations	1[23]	No	• No comparison between groups could be made
Use of oral steroids	3[15 23 24]	Yes[15 23]	• Meta-analysis % patients who used oral steroids: increased use; RR 1.39 (95% CI 1.02 to 1.91) • Watson *et al*: increased number of days on prednisolone
Use of antibiotics	2[23 24]	No	• Increased use of the number of patients which used antibiotics • Increased number of days on antibiotics
Rescue medication	1[15]	No	• Reduction of short acting β agonist use
Hospitalisations	4[16 18 21 23]	Yes[16 23]	• Meta-analysis number of patients with one or more admissions: reduction, not significant; RR 0.80 (95% CI 0.43 to 1.50) • Solomon + Cockcroft: no difference
ER visits	1[21]	No	• No difference
Doctor/nurse visits	3[16 21 24]	Yes[16 21 24]	• Meta-analysis number of visits per year: non-significant reduction and significant heterogeneity between studies; WMD = –0.36 (95% CI –0.75 to 0.03)
Days lost from work	2[16 17]	No	• No difference
Lung function	4[16 19 23 24]	Yes[16 19 23 24]	• Meta-analysis FEV_1 % pred: no difference; SMD = –0.01 (95% CI –0.24 to 0.22)
Exercise capacity	0	–	–

WMD=weighted mean difference; SMD=standardised mean difference.

One study[15] reported on the use of short acting β_2 agonists as rescue medication. Use of rescue medication was coded as the defined daily dosages (DDD) for comparison of medications within the same chemical therapeutic group. In this study the educated patients received less than half the amount of rescue medication (median DDD=125) used by the control group (median DDD=209). This reduction is statistically significant.

No significant differences between self-management and usual care were found in number of hospital admissions, emergency room visits, doctor and nurse visits, days lost from work or in lung function (table 3).

One study[23] reported the number of exacerbations but no comparison could be made because only the number of acute exacerbations in the intervention group were given.

DISCUSSION

This review has systematically evaluated eight studies of self-management education for patients with COPD compared with usual care. The studies showed no effect of self-management education on hospital admissions, emergency room visits, days lost from work, and lung function. Inconclusive results were observed on HRQoL. One possible reason for the absence of convincing effects on HRQoL is the limited use of COPD specific instruments; general HRQoL instruments may not be sensitive enough to detect differences in COPD patients. The studies using the disease specific SGRQ showed a trend towards better quality of life in the educated patients.

Days lost from work might not be an adequate outcome in patients with COPD because many are in the older age groups and are often retired. Since only a minority of patients in most COPD studies undertake paid work, we think restricted activity days—indicating days in which the normal activities are reduced by the disease—would be a better outcome measure.

We did not expect to find that self-management education had an effect on lung function. It is very difficult to affect the accelerated decline in pulmonary function in patients with COPD; smoking cessation is the only treatment that has so far been able to reduce this accelerated decline.[25] Inconclusive results were observed on COPD symptoms and use of other healthcare facilities.

Self-management education did reduce the need for rescue medication. This may indicate that self-management education leads to better disease control in patients with COPD, but the use of rescue medication was measured in only one study so the strength of evidence for this observation is poor.

Self-management education led to an increase in the use of courses of oral steroids and/or antibiotics for respiratory symptoms; however, this apparent paradox does not mean that self-management education leads to worsening of respiratory symptoms. Seemungal *et al*[26] showed in a well designed study that 50% of the exacerbations in patients with COPD were not reported to a doctor. Thus, it is likely that the educated patients were more conscious of the worsening of their symptoms and that the threshold for seeking help was decreased. In future studies it will be important to investigate the potential beneficial effects (on HRQoL and/or prevention of hospital admissions) and also the side effects of increased use of prednisolone in the long term. To answer these questions large studies with a long follow up period are needed.

This review also identified a number of limitations in the current published literature which need to be considered.

(1) The studies in this review assessed a broad spectrum of outcome parameters with different follow up periods. Meta-analytical comparisons could not readily be made. For the main part we have therefore been limited to describing the effects of self-management education on the different outcome parameters.

(2) The COPD population was defined in varying detail and included different diagnostic criteria. This could have led to heterogeneity in disease severity. The mode of the self-management education programmes varied from group

education to individual education to written education material only. Use of an action plan for self-treatment of exacerbations was assessed in only one study but it could be an important part of a self-management education programme based on a review of asthma self-management.[7] This review showed positive effects on health outcomes of self-management interventions including an action plan and regular health practitioner follow up in adult asthma patients, whereas interventions without action plans were not always of obvious benefit.

(3) A number of changes in the educational content, mode of delivery, and background treatment will have been introduced during the 14 years over which the trials were conducted. Most studies were not aimed at improving self-management skills or behavioural change, but self-management involves the transfer of knowledge as well as the acquisition of certain important skills by the patient leading to changes in their behaviour. This is the only way education can have a long term impact on the daily life of the patient with COPD, because knowledge of the disease does not directly lead to behavioural change. A theoretical model of behaviour and behavioural change such as the ASE model[27] can be very helpful in designing a self-management programme. The programme should be focused on the core elements of behaviour change in the theoretical model—for example, enhancing self-efficacy expectations or social support.

In addition to these limitations, the absence of positive results in most of the self-management education studies could also be caused by non-reversibility of the disease. COPD is a less variable disease than asthma, for example, and it is a disease where the scope for therapeutic interventions is much more limited and therefore it is intrinsically harder to show positive results. Furthermore, patients with COPD are older and may have more difficulty in understanding the issues of an educational programme. The effects of education can also be influenced by the fact that patients with COPD are more prone to anxiety and depression.[28]

The data abstracted by this review form an insufficient basis for the formulation of recommendations regarding the effectiveness of self-management education for patients with COPD because of the broad range of outcome parameters and other important limitations in the published literature. Further research on the effectiveness of self-management education programmes should be focused on behavioural change evaluated in well designed randomised controlled trials with a long follow up period so that definite conclusions can be made. Standardised outcomes designed for use in COPD and outcomes such as anxiety and depression need to be addressed. In addition, there is a need for studies specifically directed at the use of guided self-treatment action plans.

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Authors' affiliations

E Monninkhof, P van der Valk, J van der Palen, Department of Pulmonary Medicine, Medisch Spectrum Twente, Enschede, The Netherlands
C van Herwaarden, Department of Pulmonary Medicine, University Medical Centre Nijmegen, The Netherlands
M R Partridge, Imperial College of Science Technology and Medicine, Charing Cross Hospital Campus, London, UK
G Zielhuis, Department of Epidemiology and Biostatistics, University Medical Centre Nijmegen, The Netherlands

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