



# Hospital-based pulmonary rehabilitation in patients with COPD in Sweden—A national survey



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## KEYWORDS

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## Summary

Pulmonary rehabilitation (PR) is an evidence-based, multidisciplinary and cost-effective intervention that leads to improved health in patients with chronic obstructive pulmonary disease, COPD. However, the availability of PR programs varies between and within different countries. The aim of this study was to investigate the availability and content of hospital-based PR programs in patients with COPD in Sweden.

A cross-sectional descriptive design was applied using a web-based questionnaire which was sent out to all hospitals in Sweden. The questionnaire consisted of 32 questions that concerned availability and content of PR in patients with COPD during 2011.

Seventy out of 71 hospitals responded the electronic survey. Forty-six (66%) hospitals offered PR for patients with COPD. Around 75% of the hospitals in southern and middle parts of Sweden and 33% of the hospitals in the northern part offered PR. Thirty-four percent of the patients declined participation. A total number of 1355 patients participated in PR which represents 0.2% of the COPD population in Sweden. All hospitals had exercise training as major component and 76% offered an educational program.

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Not even half a percent of the patients with COPD in Sweden took part in a hospital-based PR program during 2011. There was a considerable geographic discrepancy in availability over the country. To enable a greater part of the increasing number of patients with COPD to take part in this evidence-based treatment, there is a need of evaluating other settings of PR programs; in primary care, at home and/or over the internet.

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## Introduction

Dyspnea and exercise limitation are common complaints in patients with chronic obstructive pulmonary disease (COPD) and this often leads to decreased level of physical activity, exercise capacity and health related quality of life.<sup>1</sup> In addition to the personal suffering of each patient, COPD also places a significant burden on the Swedish health care system.<sup>2</sup> Pulmonary rehabilitation has successfully, and to an even greater extent than pharmacological treatment,<sup>3</sup> been shown to improve exercise capacity and quality of life in this patient group and is therefore recommended in treatment guidelines.<sup>4,5</sup> It has also been shown to be a cost effective intervention.<sup>6</sup>

The recommendations for comprehensive pulmonary rehabilitation include multidisciplinary patient assessment, exercise training, education, nutritional intervention and psychosocial support.<sup>4,5,7</sup> It is strongly recommended that patients with moderate, severe and very severe COPD participate in pulmonary rehabilitation<sup>8</sup> and it has been shown to be effective also in patients with only small increase in dyspnea.<sup>9</sup>

The number of patients with COPD is increasing worldwide. In Sweden the prevalence of COPD according to Global initiative for chronic Obstructive Lung Disease (GOLD)<sup>1</sup> in persons over the age of 45 is estimated to 17%<sup>10</sup> which corresponds to approximately 7,00,000 persons. However, the availability of pulmonary rehabilitation programs may not match the number of patients with COPD. In the UK and Canada, surveys regarding the availability of pulmonary rehabilitation, showed that less than 1% of the COPD population in the UK<sup>11</sup> and 1.2% in Canada had access to this treatment.<sup>12</sup>

The aim of this study was to investigate the availability and content of hospital-based, pulmonary rehabilitation programs for patients with COPD in Sweden.

## Methods

### Design

The study has a cross-sectional descriptive design involving a web-based questionnaire that was sent out to all hospitals in Sweden. Professionals responsible for pulmonary rehabilitation at each hospital were previously identified and contacted through e-mail and/or telephone. The manager of each participating clinic was informed about the survey. The web-based questionnaire was sent out in January 2012. It focused on pulmonary rehabilitation for patients with COPD during the past year. Two reminder e-mails were sent

out in February 2012. Those responders still not replying were contacted by telephone in March 2012.

### Survey instrument

The questionnaire consisted of a total of 32 questions regarding six different areas: caregiver and patient characteristics, extent and content of the rehabilitation program, evaluation of rehabilitation and other concerns such as waiting lists and collaboration with patient organizations. The questionnaire was developed from the one used in the study by Brooks et al.<sup>12</sup> It was translated, adjusted to Swedish conditions and further developed with input from one patient and one spokesman (administrator) from the Swedish Heart and Lung Association. After being pilot tested on one nurse and two physiotherapists, two questions were reformulated to facilitate better understanding.

All respondents filled out information regarding hospitals' and informants' identification and whether or not the hospital offered pulmonary rehabilitation in the last year. The respondents in hospitals that did not offer pulmonary rehabilitation answered two questions regarding possibility to referral before ending the questionnaire. The hospitals which did offer pulmonary rehabilitation completed the whole survey which required approximately 20 min to be completed.

Pulmonary rehabilitation was, in this survey, defined as exercise training and one or more of the following activities: education, nutritional intervention, energy conservation techniques, or psychosocial support.<sup>7</sup>

### Data analysis

Simple descriptive statistics were used. Data is presented as frequency and percentage. Three hospitals had missing values for number of patients getting pulmonary rehabilitation in a stable phase. The mean value from the other responding hospitals (43 hospitals) served as imputed value in the calculation.

## Results

### Response rate and national distribution

Of the 71 hospitals contacted, 70 responded to the electronic survey. Of these, 46 (66%) hospitals reported offering pulmonary rehabilitation programs for patients with COPD during 2011. Twenty-four hospitals confirmed the absence of pulmonary rehabilitation programs. Of these, six hospitals reported referring patients to another hospital or to a

program in primary care. Eighteen hospitals did not refer patients to pulmonary rehabilitation elsewhere, Fig. 1. The national distribution of pulmonary rehabilitation programs for patients with COPD was: 5 out of 15 (33%) hospitals in the northern part of Sweden (Norrland), 17 out of 22 (77%) hospitals in the central part of the country (Svealand) and 24 out of 33 (73%) in the southern part (Götaland).

### Type of programs and total number of patients

All hospitals that reported having pulmonary rehabilitation programs ( $n = 46$ ) offered the program for patients with stable COPD. Nineteen hospitals (41%) offered pulmonary rehabilitation for patients with COPD after exacerbation. All hospitals allowed smokers to participate in the pulmonary rehabilitation programs and 38 hospitals (83%) offered or referred patients to a smoking cessation program. Eighteen hospitals (39%) reported having waiting list to their rehabilitation program and forty hospitals (87%) allowed patients to be re-admitted to the program. The total number of patients who participated in pulmonary rehabilitation programs during one year (2011) was 1328, which represents 0.2% of the COPD population in Sweden.<sup>10</sup> Of the 1328 patients, 1216 were in a stable phase of the disease and 112 had had a recent exacerbation.

### Patient characteristics

Most hospitals included patients from GOLD stages III and IV. Only one third of the hospitals included patients with GOLD stage I and two thirds of the hospitals included patients with GOLD stage II. The majority of the patients who participated in pulmonary rehabilitation were between 50 and 80 years old and 61% were women.

### Hospital structure

Of the 70 responding hospitals, 33 had respiratory physicians connected to the clinic responsible for the patients with COPD. Of the 46 hospitals offering pulmonary rehabilitation, 29 (63%) had respiratory physicians. Of the hospitals not offering any program, 17 percent had respiratory physicians connected to the responsible clinic. All eight

university hospitals in the country offered pulmonary rehabilitation.

### Components of the pulmonary rehabilitation programs

All centers had exercise training as the major component of the pulmonary rehabilitation program. The different exercise components offered by the pulmonary rehabilitation programs are described in Table 1. Most programs offered training in a group setting twice a week for a period of five weeks to six months. Patients who used supplemental oxygen during training were never discharged. Forty-five programs (98%) reported offering exercise training supervised by a physiotherapist. Twenty-five programs (54%) used Physical Activity by Prescription (FaR<sup>®</sup>).<sup>13</sup> FaR<sup>®</sup> is a system, developed in Sweden, in which health care professionals can prescribe physical activity and exercise for patients with different diseases. Other components of pulmonary rehabilitation programs are shown in Table 2. Two thirds of the hospitals reported partnering with patient organizations.

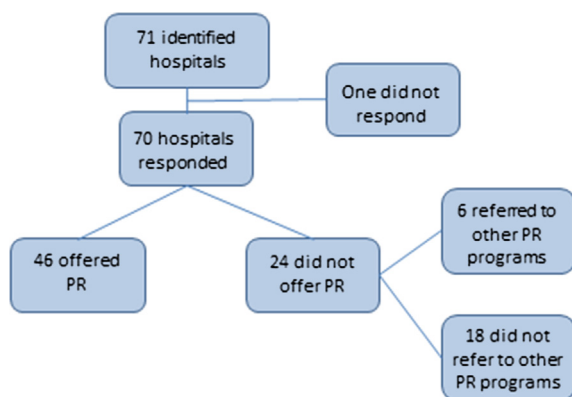
Education was included in 35 programs (76%). Table 3 shows the components of the educational program offered by these centers. The total hours of the educational program ranged from 10 to 20 h and were offered over a period of 4–10 weeks. Twenty-nine centers (63%) allowed members of the family to participate in the education sessions. Fifty-one percent of the education was given as lectures, 32% as group discussions and 27% as individual instructions. Most programs offered the education in a group setting.

### Assessment

Forty hospitals (87%) used outcome measures to evaluate the effect of pulmonary rehabilitation. The most commonly used measures were the 6 min walk test<sup>14</sup> and lower limb muscle strength test. Other outcome measures used by the pulmonary rehabilitation programs are shown in Table 4.

### Follow-up

Nineteen hospitals (41%) reported following-up of the patients after they completed the rehabilitation program.



**Figure 1** Flow chart of response rate for included hospitals. PR: pulmonary rehabilitation.

**Table 1** Exercise components of pulmonary rehabilitation programs,  $n = 46$ .

Component	N (%)
Aerobic exercise (cycling)	44 (96)
Resistance training (lower extremity)	44 (96)
Aerobic exercise (treadmill)	28 (61)
Water training	10 (22)
Breathing exercises	7 (15)
Inspiratory muscle training	7 (15)
Aerobic exercise (walking)	6 (13)
Range of motion exercises	6 (13)
Resistance training (upper extremity)	5 (11)

**Table 2** Other components of pulmonary rehabilitation programs, *n* = 46.

Component	<i>N</i> (%)
Nutrition counseling/treatment	39 (85)
Assistive device testing	36 (78)
Psychosocial counselling	35 (76)
Energy conservation technique	34 (74)
Smoking cessation	32 (70)
Relaxation technique	23 (50)
ADL training	16 (35)
Education	12 (26)

Follow-up was performed at two, three, six or twelve months. Two hospitals reported that they never discharged the patients. The follow-up consisted of telephone calls (*n* = 12), new tests (*n* = 11) and/or supervised exercise (*n* = 4).

### Health care professionals

All hospitals reported having a physiotherapist as a member of the team. Forty hospitals (87%) included a nurse as a member of the team, 38 (83%) had an occupational therapist and a dietitian, 38 (83%) had a physician, the same number had a social worker and seven (15%) had a nurse assistant. None of the hospitals reported having a psychologist as part of the team. Physiotherapists were the most frequent professionals that were responsible for the program (*n* = 19), followed by nurses (*n* = 8) and physicians (*n* = 3). Two hospitals reported that the whole team was responsible for the program. Ten hospitals reported having both physiotherapists and nurses as co-managers,

**Table 3** Components of the educational programs included in pulmonary rehabilitation, *n* = 46.

Subject	<i>N</i> (%)
Lung anatomy and physiology	35 (76)
COPD disease	35 (76)
Energy conservation technique	35 (76)
Effect of exercise and physical activity	34 (74)
Effects of medication	34 (74)
Nutrition	34 (74)
Inhalation techniques	33 (72)
Self-management	30 (65)
Signs of infections	27 (59)
Leisure activities	25 (53)
Relaxation	23 (50)
Strategy for changing behavior	22 (48)
Family role	19 (41)
Oxygen therapy	16 (35)
Sleep	14 (30)
Travel	11 (24)
Air pollution (indoor and outdoor)	7 (15)
Sexuality	4 (9)
Advanced health care planning	0 (0)
End life decision	0 (0)

**Table 4** Outcome measures included in pulmonary rehabilitation programs, *n* = 46.

Outcome measures	<i>N</i> (%)
Tests of exercise capacity	
6MWT	38 (83)
ISWT	3 (7)
ESWT	0 (0)
Endurance test (cycle ergometer or treadmill)	6 (13)
Muscle strength tests	
Lower limb	20 (43)
Upper limb	8 (17)
Other functional tests	
TUG	4 (9)
Step test	1 (2)
Dyspnoea and general assessment	
CAT	8 (17)
BODE-index	3 (7)
Dyspnea during daily life (MRC scale)	0 (0)
HRQL	
CCQ	12 (26)
SGRQ	3 (7)
SF-36	3 (7)
CRQ	0 (0)

Abbreviations: 6MWT: 6 min walking test; ISWT: Incremental shuttle walking test; ESWT: Endurance shuttle walking test; TUG: Timed up and go; CAT: COPD Assessment test; BODE-index: an index combining measures of body mass, obstruction, dyspnea and exercise; MRC: Medical research council dyspnea scale; CCQ: Clinical COPD questionnaire; SGRQ: St Georges respiratory questionnaire; SF-36: Short form-36; CRQ: Chronic respiratory disease questionnaire.

one hospital had a physiotherapist and an occupational therapist in charge of the program and another hospital had a physiotherapist and a physician as co-managers for the programs. Two hospitals did not specify who supervised the program.

### Program completion and barriers to participation

The proportion of patients that completed the entire program in each hospital ranged from 20 to 99%. Thirty-four percent of the patients in stable phase decline participation in any program. The most frequently listed barrier to participation in pulmonary rehabilitation programs were exacerbation (*n* = 28), travel to and from the hospital (*n* = 27) and lack of motivation (*n* = 21). Ten hospitals reported that cost was one of the barriers related to non-compliance.

### Discussion

The questionnaire had a response rate of 99%. This enables us to give a fairly accurate picture of the availability of pulmonary rehabilitation programs in Sweden. The survey revealed that only 0.2% of patients with COPD in Sweden received hospital-based pulmonary rehabilitation in 2011. This is striking considering the strength of available

evidence and cost effectiveness of pulmonary rehabilitation.<sup>6,7</sup> In Sweden there is, to our knowledge, only one hospital offering inpatient pulmonary rehabilitation. Therefore this survey did not investigate availability of inpatient rehabilitation programs. These results demonstrate that pulmonary rehabilitation is even more uncommon, compared to the previous Canadian<sup>12</sup> and British<sup>11</sup> studies. This implies that an effective treatment strategy is not available for the majority of the Swedish COPD population.

The difference in availability of pulmonary rehabilitation across the country is remarkable and could not be explained by regional differences in disease prevalence. In the Northern part of Sweden only one third of the hospitals offered pulmonary rehabilitation resulting in a decreased access for patients living in this part of the country. Similar results were found in the Canadian survey where some of the more rural regions had no pulmonary rehabilitation programs.<sup>12</sup> It is obvious that a respiratory physician connected to the clinic responsible for patients with COPD, increase the probability of having a pulmonary rehabilitation program.

The majority of the programs in this survey included patients from GOLD stages III and IV. This diverges to some extent with guidelines that recommend that also symptomatic patients with moderate disease, GOLD-stage II, should be included in pulmonary rehabilitation.<sup>3-5,7,8</sup> One reason why we found a minority of patients with Gold-stage II in the hospital-based programs might be explained by the new Swedish recommendations that COPD patients with milder disease should be taken care of in primary care. Only 112 patients with recent exacerbation were included in pulmonary rehabilitation programs. It is of utmost importance to spread information about the positive effects of pulmonary rehabilitation during or close to an exacerbation, as recommended in recent literature.<sup>8</sup> All programs included smokers which is in line with the recommendations.<sup>5</sup> The fact that sixty-one percent of the patients participating in pulmonary rehabilitation were women is in line with previous studies on the effect of exercise training of patients with COPD in Sweden.<sup>15,16</sup> Even though the prevalence and incidence of COPD is higher in males,<sup>17</sup> female patients seem to be more prone to approve participation in rehabilitation programs.

We were pleased to see that most of the programs had a multi- and interdisciplinary approach and besides exercise training, these programs offered components such as nutrition and psychosocial counseling, assistive device testing, energy conservation techniques, smoking cessation and patient education.<sup>4</sup> Many of the programs also included strategies for self-management and behavior change, i.e. they aimed at teaching the patient ways to handle the disease and to become more physically active and less sedentary on a long-term basis.<sup>3</sup> Three fourths of the programs offered education. This is an area of improvement since lower health literacy has been found to be associated with poorer health status and outcomes in patients with COPD.<sup>18</sup>

The content of exercise training in the programs was relatively good compared to a recent state-of-the-art review.<sup>5</sup> All programs offered some kind of aerobic training, 96% offered aerobic exercise on a bicycle. Resistance training for lower extremity was also offered in most

programs but, despite evidence of positive effect<sup>7,19</sup> there were few programs offering resistance training for upper extremities.

Regarding assessment tools the majority of programs (83%) used the 6 min walk test for assessment of aerobic capacity, which is in line with the Canadian data.<sup>12</sup> Only 13% performed an endurance test on bicycle or treadmill which can be compared to 43% in the study by Brooks et al.<sup>12</sup> This could be an area of improvement considering the fact that many patients with COPD also have cardiac problems.<sup>20</sup> However, adverse events during pulmonary rehabilitation, even when the program is performed during an acute exacerbation, are rare.<sup>21</sup> Ninety-six percent of the programs did offer lower limb muscle training but only half of those programs evaluated the intervention.

Only 41% of the hospitals offered some kind of formal follow-up. This is an important observation since we know that many patients lose the effect they gained in pulmonary rehabilitation within 12 months if no maintenance intervention is carried out.<sup>22,23</sup>

Exacerbations, travels to and from the hospital and costs were reported as factors that might hinder patients from completing their pulmonary rehabilitation program. Furthermore, it was reported in the survey that 34% of the COPD patients in a stable phase of the disease were not willing to even start pulmonary rehabilitation. This is in line with Thorpe et al. who studied barriers for the patients to join pulmonary rehabilitation programs. They found personal factors, health status, external factors like costs, and distance as common factors.<sup>24</sup> It is a challenge for patients living in areas with no pulmonary rehabilitation to take part in programs available at hospitals in other geographic areas. Another barrier identified for patients to attend pulmonary rehabilitation can be found in the other end of the health care system. Perez et al. studied adherence to guidelines among general practitioners in New York City. They found that only 5.4% followed the recommendation to refer patients to pulmonary rehabilitation.<sup>25</sup> This is an area of possible improvement. Home-based rehabilitation has been evaluated and may be an alternative to outpatient pulmonary rehabilitation.<sup>26</sup> Simpler internet-based programs have also been investigated with positive results.<sup>27,28</sup> Thus, as health professionals we will have to further investigate each patient's needs and expectations regarding their disease to be able to offer the type of rehabilitation that would suit each patient best.

This study presents some limitations. The survey included only hospitals and some patients might have been offered pulmonary rehabilitation programs in primary care. Though, since the responsibility for pulmonary rehabilitation programs, until just recently, has been in the hospital setting, the number of pulmonary rehabilitation programs in primary care is probably scarce. However, a survey studying the availability of pulmonary rehabilitation programs in primary care during the same time period is being performed.

## Conclusion

Less than half a percent of the patients with COPD in Sweden took part in a hospital-based outpatient pulmonary

rehabilitation program during 2011. There was a considerable geographic discrepancy in availability of programs over the country. The content of the rehabilitation programs offered followed the available guidelines for the most part regarding exercise training, though only one fourth of the programs offered education. Considering the effectiveness of this treatment, there is a vast need for increased availability of pulmonary rehabilitation programs in Sweden. To enable more patients with COPD to take part in this evidence-based treatment, there is a need to evaluate other settings of pulmonary rehabilitation programs such as, primary care, at home and/or over the internet.

## Conflict of interest

The authors report no conflicts of interest.

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