Improving the wellbeing of caregivers of patients with COPD using a home-based pulmonary rehabilitation programme

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Abstract

Objectives The aim of this study was to evaluate the effects of a home-based pulmonary rehabilitation (PR) programme on anxiety and depressive symptoms, general fatigue and burden in informal caregivers of patients with COPD. We also evaluated the baseline characteristics of both patients and caregivers that contributed to the change in caregiver's outcomes after PR.

Methods In this retrospective study, patients with COPD were referred to an 8-week home-based PR programme consisting of a weekly supervised 90-min session. Informal caregivers were invited to participate in PR according to the patient's preference and its availability. Caregivers received educational support, behavioural therapies and self-management strategies using the same methods as for patients. Burden, anxiety and depressive symptoms, and general fatigue of caregivers were assessed at baseline and at the end of PR.

Results 241 patients with COPD and 138 (57.3%) caregivers were included. The majority of the caregivers were women (70.5%) and spouses (90.3%) and had at least three comorbidities (57.3%). A large proportion of caregivers showed baseline high burden, anxiety symptoms and abnormal fatigue (40%, 40% and 45%, respectively). Burden, anxiety and depressive symptoms, and general fatigue of informal caregivers were all improved after PR ($p<0.05$). Long-term oxygen therapy and/or noninvasive ventilation, coronaropathy and/or peripheral arterial disease and a higher baseline modified Medical Research Council Dyspnoea scale score in patients with COPD were associated with a decrease in caregiver's burden after PR.

Conclusion A large proportion of caregivers of patients with COPD showed anxiety symptoms, fatigue and a high burden. These outcomes were improved by integrating the caregiver into a home-based PR programme.

Introduction

In addition to dyspnoea, patients with COPD commonly show exercise intolerance, kinesophobia and anxiety and depressive symptoms, compromising daily physical activity, quality of life and even survival [1–3]. As the severity of the symptoms and the number of comorbidities increase, patients with COPD become care dependent with difficulties in fulfilling their daily life activities and experience social isolation [4].

Informal caregiver refers to an individual (commonly a spouse or a child) who provides unpaid care to persons with one or more disabilities to perform daily life activities and provide support for medical care and symptom management [5, 6]. Informal caregivers are of major importance for patients with COPD,
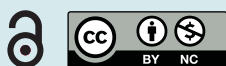
since they can facilitate and enhance adherence to COPD management behaviours, such as treatment adherence or increasing daily physical activity, possibly leading to a reduction in exacerbations and hospitalisations [7–9]. However, providing informal care to a patient with COPD can take a considerable toll on the caregiver's physical, psychological and social wellbeing [5, 10]. A large survey conducted in Spain reported that 35%, 83% and 38% of the informal caregivers caring for patients with COPD experienced health, social/leisure time and occupational problems, respectively [10]. Additionally, they may experience helplessness, powerlessness, anxiety, depression, vulnerability to fatigue, disability and/or burnout when trying to cope with the symptoms related to COPD [11–13]. The situation may be even worse for caregivers of patients with advanced COPD with higher risks of exacerbations, hospitalisations and even death compared to the less severe forms of the disease [14, 15].

Pulmonary rehabilitation (PR) is a cornerstone of treatment for patients with chronic respiratory disease [16, 17]. PR is effective at reducing symptom burden and improving exercise tolerance in patients with COPD [18]. Despite the undeniable burden placed on the informal caregiver, formal support for caregivers is lacking [19]. Few studies have included the patient–carer dyad in education and self-management sessions during PR, with conflicting results across studies [19–21]. These interventions focused on improving the caregiver's understanding of the disease and on coping strategies to adequately equip them for effectively supporting patients with COPD. Nevertheless, the informal caregiver should be also seen as a person to treat using a personalised intervention leading to improving their physical and psychological wellbeing. Relieving the caregiver's burden is critical to sustain and support the home-care network and might have a positive long-term impact on the economic burden of COPD by reducing the yearly number of exacerbations and hospitalisations [7, 8].

Furthermore, the main objective of this retrospective study was to evaluate the effectiveness of a home-based PR programme on the burden, anxiety and depressive symptoms and general fatigue in caregivers of patients with COPD. We also evaluated the baseline characteristics of both patients and caregivers that may have contributed to the change in caregiver's wellbeing after PR. Our hypothesis was that in addition to improving the physical and psychological wellbeing of patients with COPD, the home-based PR programme will be effective for improving the burden, anxiety and depressive symptoms and general fatigue of the informal caregivers. We also assumed that the baseline severity of the patient's disease (requiring long-term oxygen therapy, spirometry data, dyspnoea, comorbidities) will affect the changes in caregiver's wellbeing after PR.

Methods

Study design and participants

This was a retrospective study conducted on prospectively collected data. Data were collected from January 2018 to December 2019. Details regarding the referral and criteria selection of the patients with COPD and the home-based PR programme can be found elsewhere [22, 23]. Briefly, patients with COPD performed an 8-week home-based PR programme, consisting of a weekly supervised 90-min home session, during which supervised physical training, education and self-management strategies were implemented. Prior to starting the programme, an evaluation of the patient's needs and expectations was performed for designing a personalised intervention. Personalised exercise and daily physical activity training, educational, motivational and self-management plans were implemented through a collaborative process between the PR team, the patient and their caregiver. Apart from the weekly visit of the team member, participants were expected to perform, on their own, personalised physical training and self-management plan the rest of the week. A cycle ergometer (Domyos essential 2; Decathlon, Villeneuve-d'Ascq, France) and/or or a stepper (Go Sport, Grenoble, France) were available at home to perform physical exercise during the 8-week training component of the programme.

The caregiver helped in the design of the personalised patient's action plan according to the patient's preference and its availability and could express not only what he/she expected for the patient from the home-based PR but also for him/herself. Caregivers who attended the weekly visits of the PR team member could not only share their difficulties regarding helping the patient during daily life activities, but also their own feelings and emotions. Since caregivers (a person) experienced a similar burden to that of patients (a person) with COPD [11, 12], the same educational supports, behavioural therapies and self-management strategies were also applied to caregivers to meet their own needs and expectations by using personalised interventions. To reduce the burden and anxiety symptoms of the caregivers when caring for their loved one, cognitive behavioural therapy, counselling, motivational support, mindfulness meditation and cardiac coherence techniques were specifically offered to the caregivers. Motivational communication was used at each home session and was frequently re-evaluated and readjusted [24].

PR team members received training in the principles of behaviour change and motivational communication skills.

Regarding the education, the following topics were systematically discussed with the patients and their caregiver: management of dyspnoea, exacerbations, medication, exercise training and daily physical activities. End of life and fear of dying was also addressed according to the needs of the patient–carer dyad. Smoking cessation or cessation of other unhealthy behaviours (alcoholism, drug addiction, nutritional issues) were discussed with both the patient and the caregiver if necessary. When the caregivers also presented these issues, the same support was offered to him/her. During the 8-week programme, these topics were discussed in order of the patient's and caregiver's needs and goals as certain supports were more required depending on how the participants were progressing on a week-to-week basis. In the absence of medical contraindications, caregivers could also perform the physical exercises training with the patients. They were also encouraged to increase independent leisure activities outside the family home and to not hesitate to seek additional assistance in caring for the patient.

The study was approved by the observational research protocol evaluation committee of the French Language Society of Pulmonology (CEPRO, number: 2021-054). All participants (patients with COPD and their caregiver) signed a written informed consent prior to the start of the programme which included their approval to use the collected data for research purposes. The study was conducted according to the principles of the Declaration of Helsinki.

Assessments

Comorbidity data of the patients with COPD were collected from the individual's medical record provided by the pulmonologist. Comorbidities data of the caregivers were only collected from those who participated in the study using a questionnaire completed with the PR team member during the first visit. Patients with COPD and their caregivers were evaluated at home at the beginning (M0) and at the end of the PR programme (M2).

The burden of the informal caregivers was self-assessed using the Zarit Burden Interview (ZBI) (22 items with a test score ranging from 0 to 88; lower is better) [25]. The ZBI measures subjective burden in terms of the degree (from "never=0" to "almost always=4") to which the caregiver experiences physical, psychological, emotional, social and financial problems as a result of their care-giving role [25]. A ZBI score >24 was considered a high burden [26]. The anxiety and depressive symptoms and the general fatigue of the informal caregivers were self-assessed with the Hospital Anxiety and Depression (HAD) scale (14 items: seven each for anxiety and depression with minimum and maximum subscores of 0 and 21; lower is better; an anxiety or depressive symptoms score $\geqslant 11$ indicates a probable clinical diagnosis of anxiety or depression) [27], and the Fatigue Assessment Scale (FAS) (10 items: five reflecting physical fatigue and five reflecting mental fatigue with a test score ranging from 10 to 50; lower is better; a score $\geqslant 22$ suggests abnormal fatigue) [28], respectively. The minimal clinically important difference (MCID) of the ZBI, HAD scale and FAS has never been documented in informal caregivers.

In patients with COPD, in addition to anxiety and depressive symptoms and general fatigue, dyspnoea, health-related quality of life and exercise tolerance were also assessed using the modified Medical Research Council Dyspnoea scale (mMRC) [29], the Clinical COPD questionnaire (CCQ) [30] and the 6-min stepper test (6MST) [31], respectively. In COPD, the MCID of the HAD anxiety and depression scores, the CCQ and the 6MST is considered to be a change of 1.5 units [32], 0.4 unit [33] and 40 strokes [34], respectively. The MCID of the FAS has not been documented in COPD but is considered to be a change of 4 points in patients with sarcoidosis [35].

Statistical analyses

Statistical analyses were performed using SAS V9.4 (SAS Institute, Cary, NC, USA) and significance threshold was considered at 0.05. Quantitative variables are expressed as means±SD in the case of normal distribution or median (interquartile range, IQR) otherwise. Categorical variables are expressed as numbers (percentage). Normality of distributions was assessed using histograms and the Shapiro–Wilk test. Non-normally distributed data were log-transformed before analysis.

Changes between M0 and M2 in the study assessments of the patients with COPD and their informal caregivers were analysed using paired t-test. A linear regression model adjusted on baseline value of each score was performed to evaluate the baseline characteristics of both patients with COPD and caregivers that contributed to the change in caregiver's burden, anxiety and depressive symptoms and general fatigue after PR. To evaluate whether the number of sessions attended by the caregivers impacted their

improvements after PR, a one-way ANOVA with anxiety symptoms, depression symptoms, FAS and ZBI scores as dependent variables was performed. Baseline characteristics of the caregivers who attended more than half of the home visits (five to eight visits) were compared to those of caregivers who attended four or fewer visits using a one-way ANOVA.

Baseline characteristics of the patients with COPD who dropped out during PR were compared to those who finished PR using standardised difference analysis (SDA). A standardised difference >20% was considered important [36].

Results
Baseline characteristics
From January 2018 to December 2019, 241 patients with COPD were included in the PR programme. The majority were male (61.8%) and former smokers (75.1%), and had severe airway obstruction (forced expiratory volume in 1 s (FEV_1), 39.0±18.5% predicted value) and at least three COPD-associated comorbidities (87.2%), and 59.3% patients required long-term oxygen therapy (table 1).

Among the 241 patients with COPD, 47 (19.5%) patients did not report a caregiver and 56 (28.9%) caregivers refused to participate in the study (figure 1). The baseline characteristics of the remaining 138 (57.3%) caregivers are presented in table 1. The majority of them were female (70.3%), spouses (87.7%) and had at least three comorbidities (57.3%). Among the caregivers, 56 (40.6%) and 16 (11.6%) individuals had a probable clinical diagnosis of anxiety and depression (score ⩾11) respectively, 63 (45.6%) individuals had an abnormal fatigue score (⩾22) and 54 (39.1%) individuals reported a high burden (score >24). Twenty-three (16.7%) informal caregivers attended the eight home visits, 34 (24.6%) attended four to seven visits, 44 (31.9%) attended one to three visits and 37 (26.8%) caregivers did not attend any visit with an exception for the first diagnostic evaluation session. Caregivers who attended more than half of the home sessions (five to eight) were younger (p=0.002), more often female (p<0.001) and had higher baseline anxiety symptoms (p=0.009) than caregivers who attended zero to four visits.

PR effectiveness
Among the 241 included patients with COPD, 25 (10.3%) patients did not complete PR (figure 1). These patients had lower BMI (SDA=51%), 6MST score (SDA=76%) and CCQ total score (SDA=51%), and higher depression symptoms (SDA=58%) and fatigue score (SDA=33%) compared to those who

TABLE 1 Baseline characteristics of patients with COPD and their caregivers		
Characteristics	**Patients with COPD**	**Caregivers**
Subjects n	241	138
Age years	66.0±12.1	60.3±14.8
Sex, male	149 (61.8)	41 (29.7)
BMI kg·m^{-2}	26.5±7.7	27.3±5.8
Smoker status		
Current	39 (16.2)	30 (21.7)
Former	181 (75.1)	27 (19.6)
Never	17 (7.1)	68 (49.3)
FEV_1 % of predicted	39.0±18.5	
FEV_1/FVC % of predicted	56.3±19.7	
LTOT	143 (59.3)	
NIV	85 (35.3)	
Marital status		
Married/living as a couple	153 (63.5)	
Widowed	38 (15.8)	
Separated/divorced	35 (14.5)	
Single	15 (6.2)	
Kin relationship with the patients		
Spouse		121 (87.7)
Son/daughter		11 (8.0)
Other		6 (4.3)

Data are presented as mean±SD or n (%) unless otherwise stated. BMI: body mass index; FEV_1: forced expiratory volume in 1 s; FVC: forced vital capacity; LTOT: long-term oxygen therapy; NIV: noninvasive ventilation.
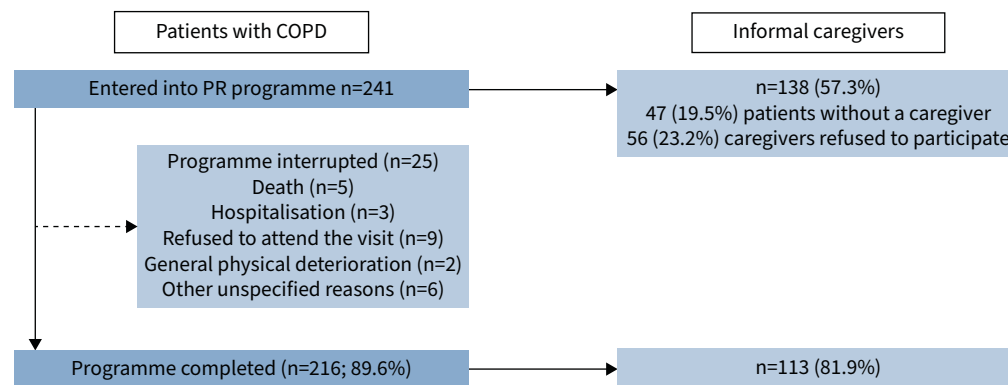
FIGURE 1 Flow chart of patients with COPD and their informal caregivers. PR: pulmonary rehabilitation.

completed PR. Caregivers of these 25 patients had higher anxiety symptoms (SDA=41%), depression symptoms (SDA=50%) and fatigue score (SDA=48%) compared to the caregivers of patients who completed PR.

The effects of the home-based PR programme are presented in table 2. All study assessments were improved at the end of PR in both patients with COPD and informal caregivers (p<0.05) (table 2). Patients with COPD reporting a caregiver had a higher decrease in anxiety symptoms (p=0.015) and general fatigue score (p=0.039) after PR compared to patients without a caregiver. The number of sessions attended by the caregivers was not associated with their improvements observed in burden questionnaire (p=0.915), anxiety symptoms (p=0.474), depressive symptoms (p=0.073) and fatigue questionnaire (p=0.317).

Correlates of the changes in caregiver's burden, anxiety and depression symptoms and general fatigue

Table 3 reports correlation parameters between baseline characteristics of both patients with COPD and their caregivers and changes in the burden, anxiety symptoms, depression symptoms and general fatigue of caregivers, from baseline to M2. Long-term oxygen therapy and/or noninvasive ventilation, coronaropathy and/or peripheral arterial disease and a higher baseline mMRC score in patients with COPD were associated with a decrease in caregiver's burden after PR. A higher baseline Charlson Index in patients with COPD was associated with a diminution in caregiver's depressive symptoms after PR (0.018), while decrease in caregiver's general fatigue was associated with baseline FEV_1 of patients with COPD.

TABLE 2 Effectiveness of the home-based pulmonary rehabilitation (PR) programme in both patients with COPD and their informal caregivers				
Assessments	Baseline M0	End of PR M2	ΔM2 – M0	p-value
Informal caregivers				
Anxiety symptoms	9.5±4.7	8.5±4.9	−0.9±3.5	0.006
Depressive symptoms	5.2±4.1	4.3±3.5	−0.6±3.1	0.047
FAS score	21.9±7.7	20.1±7.2	−1.4±6.6	0.026
ZBI score	21.6±15.1	18.9±15.0	−2.5±11.4	0.024
Patients				
Anxiety symptoms	9.5±4.7	8.0±4.2	−1.5±3.6	<0.001
Depressive symptoms	8.0±3.9	5.8±4.0	−2.0±3.4	<0.001
FAS score	27.7±8.2	22.7±7.4	−4.6±7.0	<0.001
mMRC score	3.0±1.1	2.4±1.2	−0.5±0.8	<0.001
CCQ total score	3.1±1.1	2.3±1.1	−0.7±0.8	<0.001
6MST, strokes	302±157	398±172	83±61	<0.001

Data are presented as mean±SD. p-values were obtained using paired t-test. FAS: Fatigue Assessment Scale; ZBI: Zarit Burden Interview; mMRC: modified Medical Research Council scale; CCQ: Clinical COPD questionnaire; 6MST: 6-min stepper test.

TABLE 3 Association between baseline characteristics of both patients with COPD and caregivers and changes in caregiver's burden, anxiety and depressive symptoms, and general fatigue after pulmonary rehabilitation (PR)

Caregivers	Burden ΔM2 – M0		Anxiety symptoms ΔM2 – M0		Depressive symptoms ΔM2 – M0		General fatigue ΔM2 – M0	
	Estimate (SE)	p-value	Estimate (SE)	p-value	Estimate (SE)	p-value	Estimate (SE)	p-value
Baseline characteristics of patients								
Age >70 years	1.63 (2.20)	0.46	0.35 (0.67)	0.61	0.02 (0.55)	0.96	0.79 (1.21)	0.51
FEV_1 % of pred value increase	0.01 (0.06)	0.80	−0.03 (0.02)	0.098	−0.01 (0.01)	0.27	−0.06 (0.03)	0.046
BMI >30 kg·m^{-2}	0.66 (2.30)	0.77	−0.66 (0.68)	0.36	−0.46 (0.54)	0.40	−1.49 (1.19)	0.21
LTOT or NIV	−7.51 (2.19)	0.042	0.69 (0.66)	0.30	0.50 (0.53)	0.35	1.18 (1.15)	0.31
Charlson index, 1-point increase	0.62 (0.38)	0.11	−0.14 (0.12)	0.23	−0.22 (0.09)	0.018	−0.19 (0.20)	0.35
Coronaropathy/peripheral arterial disease	−4.82 (2.33)	0.041	−0.44 (0.72)	0.55	−0.30 (0.58)	0.61	0.38 (1.28)	0.77
Sex, female *versus* male	0.51 (2.32)	0.83	0.90 (0.69)	0.20	0.51 (0.55)	0.34	0.31 (1.21)	0.80
Anxiety score ⩾11	0.46 (2.13)	0.83	0.22 (0.65)	0.73	−0.14 (0.53)	0.79	−0.27 (1.15)	0.81
Depression score ⩾11	4.44 (2.45)	0.073	0.54 (0.77)	0.49	0.99 (0.61)	0.11	−0.71 (1.35)	0.60
FAS score ⩾22	−0.73 (2.55)	0.77	1.11 (0.74)	0.13	−0.07 (0.60)	0.90	−0.65 (1.32)	0.62
6MST, 50 strokes	0.35 (0.39)	0.36	−0.04 (0.11)	0.73	−0.07 (0.09)	0.46	−0.03 (0.19)	0.89
mMRC, 1-point increase	−2.51 (1.00)	0.014	0.24 (0.32)	0.45	−0.17 (0.25)	0.49	−0.27 (0.55)	0.63
Baseline characteristics of caregivers								
Age >70 years	0.85 (2.47)	0.73	0.53 (0.76)	0.48	−0.06 (0.60)	0.92	1.35 (1.33)	0.31
Sex, female *versus* male	−1.17 (2.41)	0.63	−1.25 (0.72)	0.084	−0.92 (0.56)	0.10	−1.10 (1.27)	0.39
Anxiety score >11	4.55 (2.61)	0.083			−0.06 (0.68)	0.94	0.44 (1.48)	0.77
Depression score >11	6.54 (3.57)	0.094	−1.66 (1.26)	0.19			−1.12 (2.36)	0.63
FAS score ⩾22	0.16 (2.30)	0.94	0.42 (0.74)	0.56	0.75 (0.62)	0.23		
ZBI >24			2.13 (0.75)	0.005	0.83 (0.60)	0.17	1.78 (1.28)	0.17

Estimate (SE) and p-values were obtained using linear regression model adjusted on baseline score values of caregivers. SE: standard error; FEV_1: forced expiratory volume in 1 s; BMI: body mass index; LTOT: long-term oxygen therapy; NIV: noninvasive ventilation; FAS: Fatigue Assessment Scale; 6MST: 6-min stepper test; mMRC: modified Medical Research Council scale; ZBI: Zarit Burden Interview.

Discussion

This prospective interventional study originally integrated the caregivers of patients with COPD into an 8-week home-based PR programme. Although caregivers are usually poorly involved in traditional PR, with a participation rate of 70%, this study demonstrated the strong interest of the caregivers to be integrated in the patient's care. Almost half of the caregivers reported an impaired wellbeing (anxiety, fatigue, burden) at the beginning of PR, showing the importance of recognising their difficulties and needs when caring for their loved one. Integrating the caregivers of patients with COPD in a personalised PR programme was effective for improving at short-term their burden, anxiety and depressive symptoms and general fatigue. Since only 40% of the caregivers attended at least half of the home-based sessions, the present positive results may suggest that only a few sessions were sufficient for improving caregivers' wellbeing when adequately targeting their needs. This is supported by a recent cluster randomised trial showing that only 90 min of structured nurse-led advance care planning was effective for improving anxiety symptoms of the caregivers of patients with COPD [37]. However, because of the design of the present study and the absence of a control group of caregivers not participating in the PR programme, caution needs to be taken when interpreting the results. Therefore, we cannot conclude whether the benefits observed in the caregivers are a consequence of their participation in the PR programme or whether they are an indirect consequence of the physical and psychological improvements of the patients with COPD. Moreover, linear regression models showed that the caregivers of patients with severe COPD (requiring long-term oxygen therapy and/or noninvasive ventilation, reporting heart diseases and severe baseline dyspnoea) were more likely to better improve their burden after PR. Confirming our previous studies, patients with COPD benefited from the home-based PR by significantly and clinically (reaching the respective MCID of each assessment) improving anxiety and depressive symptoms, general fatigue, health-related quality of life and exercise tolerance. The decrease in anxiety symptoms and general fatigue after PR was even higher in patients with COPD reporting a caregiver compared to those without one. Taken all together, these results support the importance of integrating the caregivers into the patient's care, which should be routinely considered when designing future PR programmes.

Characteristics of the included caregivers are consistent with previous studies in patients with chronic lung disease: they are mainly spouses with a significant proportion having health issues including anxiety

symptoms and general fatigue [11, 12, 21]. Anxiety and depressive symptoms are common in both patients with COPD and their caregivers, and often result from the difficulty in managing dyspnoea and fear of the future [12, 13]. With a cut-off score >8 in the HAD subscores, the prevalence of anxiety and depressive symptoms in people with COPD and their caregivers was 46.4% and 42.9% and 46.0% and 23.0%, respectively [38]. Using the same cut-off, we confirmed the previous results (patients with COPD: 54.4% and 44.9%, respectively; caregivers: 54.5% and 20.9%, respectively), highlighting the importance of providing personalised psychological and physical care for both the patient and their caregiver. Additionally, more than a third of the caregivers reported that caring for their sick loved one was a high burden (ZBI score >24 points). Nevertheless, the mean ZBI score of 21.6±15.1 points was relatively low compared to a recent study reporting a mean ZBI score of 52.4±14.6 points in 201 caregivers of hospitalised patients with COPD [39]. However, since patients with COPD were hospitalised, we can assume that they had more severe disease compared to the patients in the present study, which could explain the higher caregiver burden score. Moreover, in the study by Yi et al. [39], caregivers were mostly the patients' children (66%). It could be more difficult for the spouse (87% in the present study) to admit that their husband/wife is a burden. Nevertheless, whether they are spouses or children, the burden of the caregiver will take a considerable toll on their physical (fatigue), psychological (anxiety and depression symptoms) and social/financial (isolation, difficulty in communication, loss of employment) wellbeing [10, 12, 40]. A recent interesting study reported that patients with COPD living with a physically active caregiver had higher levels of physical activity and a higher likelihood of being physically active compared to patients living with a physically inactive caregiver [9]. This result highlighted the importance of engaging the caregiver as part of the PR programme as they can help their sick loved one to engage in healthy behaviours.

Both patients with COPD and their caregivers benefited significantly from PR. The anxiety symptoms and general fatigue improvement after PR was even higher in patients reporting a caregiver compared to those without one. This result highlights the importance of considering the caregiver as part of the intervention to improve outcomes in patients with COPD. However, despite that caregivers might play a crucial role in patient's adherence to new health behaviours (smoking cessation, physical activity training, symptom management including dyspnoea, medications adherence) [7], the literature regarding this topic is scarce [19], and clinically relevant changes are not documented in caregivers. MARQUES et al. [21] reported that 12 weeks of a family-based PR programme was effective in enhancing the coping strategies of both the patients and their family members. The experimental group performed one session a week in a primary care centre, during which psychological support and education were given to both the patients and their caregivers [21]. An overall adherence rate of 92% was found, but details regarding caregivers' attendance were not provided. In a pragmatic randomised control design, JONSDOTTIR et al. [20] showed that a 6-month partnership-based self-management programme had benefits on the intrusiveness of the disease and its treatment in patients with mild to moderate COPD. Nevertheless, the impact of the caregiver in these positive results is questionable as only one quarter of the patients were accompanied by a family member during the intervention [20]. Although the clinical relevance of the caregiver's improvements after PR is questionable, the decrease of −0.9 and −0.6 in the anxiety and depressive symptoms score, respectively, are similar to those reported by HOUBEN et al. [37] offering one home-based session of structured advance care planning to patients with COPD and their loved one. Comparison regarding the improvement of the burden and fatigue of the caregivers after PR is impossible since no study has ever investigated it. A few literature reviews have highlighted the importance of educating the informal caregivers for managing the patient's disease but also highlighted the need to provide them with specific physical and psychological support [13, 41–43]. By evaluating the burden, anxiety and depressive symptoms and general fatigue of the caregivers, the present study is a first step towards assessing the abilities and needs of caregivers leading to appropriate support.

Linear regression models showed that the caregivers of patients with a severe stage of the disease (requiring long-term oxygen therapy and/or noninvasive ventilation, reporting heart diseases and severe baseline dyspnoea) were more likely to better improve their burden after PR. On the one hand, the improvement in the patient's exercise capacity and general fatigue after PR making them less dependent on their caregiver could explain this result. On the other hand, we largely believe that educating both the patients and their caregivers on managing dyspnoea, exacerbations, end of life and fear of dying may have positively impacted the burden of the caregivers of the more severe patients. Educating caregivers regarding the management of the patient's dyspnoea through increasing caregivers' confidence and/or control and helping patients better self-manage breathlessness may reduce hospital admissions [44] and anxiety and depressive symptoms of both patients and their caregivers [37].

Strengths and limitations

We must recognise that the home-based PR programme was primarily designed for patients with COPD. However, the caregivers were integrated into PR sessions by encouraging them to share their difficulties regarding helping the patient during daily life activities. This real-life study could be the foundation of more robustly designed randomised and controlled studies aiming to better support the caregivers. The monocentric, non-randomised nature of this study and the absence of a control group may limit the scope of the present results. A three-arm randomised controlled trial that compared the effectiveness of an intervention targeted at the patients with COPD only, at the caregivers only and at the patient–caregiver dyad will be an ideal future study. This would provide high-level evidence of the benefit of incorporating caregiver support as a core component of care. Another aspect that should be investigated by future studies is the additional healthcare cost of integrating the caregiver into PR. Since caregivers can facilitate and enhance adherence to COPD management behaviours [7–9], the possible long-term positive economic effect of integrating the caregiver into PR needs to be evaluated. Another limitation of the study was that the specific attendance to each component of PR (physical training, education sessions and self-management strategies) was not documented. Since not all caregivers performed the physical training with their sick loved one, we can only assume that the present positive results are mainly the consequence of the education sessions and self-management strategies. Because of the study design, we did not collect data on the 56 caregivers who refused to participate in the intervention, preventing a comparison with the caregivers who participated. Nevertheless, the present data were collected systematically and consistently as an integral part of the home-based PR including a large number of non-selected participants and conducted by the same trained team. By improving external validity and establishment in usual care, real-life studies are useful to complement the results of randomised controlled trials [45].

Conclusion

Supporting a previous randomised controlled trial, the present real-life study showed that integrating the caregivers of patients with COPD into an 8-week home-based PR programme may be effective for improving the burden, anxiety and depressive symptoms and general fatigue of the caregivers. Although the present results should be taken cautiously, this study could be the foundation of more robustly designed randomised and controlled studies aiming to better support the caregivers. In this context, we believe that integrating the caregiver of patients with chronic respiratory disease into a PR programme should be more consistently considered when designing future interventions.

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