

# Exploring the Benefits to Caregivers of a Family-Oriented Pulmonary Rehabilitation Program

Daniela Figueiredo PhD, Joana Cruz MSc, Cristina Jácome MSc, PhD, and  
Alda Marques MSc PhD

**BACKGROUND:** COPD is a highly incapacitating disease, particularly among older people, implying significant burden for family caregivers. Involving caregivers in comprehensive pulmonary rehabilitation programs might benefit their functional coping to care demands; however, there is no objective evidence to sustain such assumption. This study is a secondary analysis aiming to analyze the effects of a family-based pulmonary rehabilitation program on close family caregivers of older subjects with COPD. **METHODS:** This is a mixed-method study. Family caregivers were randomly assigned to family-based (experimental) or conventional (control) pulmonary rehabilitation. Caregivers from the family-based pulmonary rehabilitation ( $n = 20$ ; 80.0% female; age  $63.1 \pm 9.5$  y) attended the psychoeducational component together with their relatives. In the conventional pulmonary rehabilitation, caregivers did not participate ( $n = 19$ ; 68.4% female; age  $53.6 \pm 11.3$  y). Self-rated instruments (Family Crisis Oriented Personal Scales, Depression Anxiety and Stress Scales, and Carers' Assessment of Difficulties Index) and focus group interviews were used to assess the intervention. **RESULTS:** Caregivers from the family-based pulmonary rehabilitation had significantly greater improvements in overall family coping ( $P = .01$ ), reframing ( $P = .01$ ), seeking spiritual support ( $P = .01$ ), and mobilizing to acquire help ( $P = .02$ ). No significant differences were found for emotional state. Significant improvements in overall burden ( $P = .01$ ), reactions to caregiving ( $P = .01$ ), physical demands of caring ( $P = .044$ ), and poor family support ( $P = .038$ ) were observed, although there were no significant between-group differences. Qualitative data sustained the benefits of involving family caregivers in pulmonary rehabilitation. **CONCLUSIONS:** The findings provide valuable evidence to recommend the inclusion of COPD family caregivers in comprehensive pulmonary rehabilitation. Family-oriented pulmonary rehabilitation maximizes caregivers' adaptive coping and potentially prevents negative psychological outcomes; however, further research is needed. *Key words:* burden; COPD; coping; emotional state; family caregiving. [Respir Care 2016;61(8):1081–1089. © 2016 Daedalus Enterprises]

## Introduction

COPD is a major cause of morbidity, mortality, and health-care costs in old age.<sup>1</sup> As the disease progresses, a number of symptoms, such as dyspnea, fatigue, and co-

morbidities emerge, and patients experience a gradual reduction in physical, emotional, and social functioning.<sup>2</sup>

Family is among the most important resources for these patients,<sup>3,4</sup> assisting with activities of daily living, managing complex treatment technologies and medica-

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Dr. Figueiredo is affiliated with School of Health Sciences, University of Aveiro, Aveiro, Portugal, and Center for Health Technology and Services Research (CINTESIS.UA), Portugal. Dr. Cruz is affiliated with Lab 3R–Respiratory Research and Rehabilitation Laboratory, School of Health Sciences, University of Aveiro (ESSUA), Aveiro, Portugal, and Institute for Research in Biomedicine (iBiMED), University of Aveiro, Aveiro, Portugal.

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Dr. Jácome is affiliated with Lab 3R–Respiratory Research and Rehabilitation Laboratory, School of Health Sciences, University of Aveiro (ESSUA), Aveiro, Portugal.

Dr. Marques is affiliated with Lab 3R–Respiratory Research and Rehabilitation Laboratory, School of Health Sciences, University of Aveiro (ESSUA), Aveiro, Portugal, and Institute for Research in Biomedicine (iBiMED), University of Aveiro, Aveiro, Portugal.

tion regimens, monitoring breathlessness, providing emotional support, participating in decision making, and facilitating communication with health-care providers.<sup>5,6</sup> Consequently, COPD caregiving can be a burdensome experience, with negative impacts on family caregivers' health, including poor self-rated mental health,<sup>4</sup> sleep problems,<sup>3</sup> and anxiety and depressive symptomatology.<sup>7</sup> The support given can also precipitate poorer dyad communication,<sup>8</sup> financial strain, and restrictions in social life.<sup>4-6,8</sup>

Psychoeducational interventions have been found to reduce caregivers' stress in dementia, cancer, or stroke.<sup>9-11</sup> These interventions include the provision of information about treatments, symptom management, and community resources; training to provide care and respond to disease-related problems; and problem-solving and emotional-management strategies for coping with the disease demands. The rationale is based on the importance of practical information, social support, and problem-solving assistance, through the predictable stressful moments that can be anticipated in the future course of a chronic condition.<sup>12</sup>

Psychoeducation is also a recommended component of comprehensive pulmonary rehabilitation programs in COPD, alongside with exercise training, smoking cessation, and nutrition counseling.<sup>13,14</sup> Comprehensive pulmonary rehabilitation has been shown to reduce exacerbations, hospital admissions, and/or anxiety/depressive symptoms in subjects with COPD while improving overall functional status.<sup>15,16</sup> Given the evidence of COPD impact on caregivers and the recognized importance of family support, one would expect to find greater involvement of caregivers in pulmonary rehabilitation. Instead, pulmonary rehabilitation remains patient-centered, and, to date, there is no objective evidence to sustain such recommendation. An encouraging exception is the study of Zakrisson et al,<sup>17</sup> which aimed to explore the experience of a multidisciplinary pulmonary rehabilitation for subjects with COPD from the perspective of the next of kin. However, caregivers only participated in one theoretical session, and no quantitative outcome measurements were collected.

Assuming that a chronic disease, like COPD, is a family disease,<sup>18</sup> this study aimed to analyze the effects of a fam-

## QUICK LOOK

### Current knowledge

Family caregivers provide the main source of support to patients with COPD, and it is known that this may constitute a stressful experience, likely to involve significant burden. Nevertheless, interventions to support COPD management remain patient-centered.

### What this paper contributes to our knowledge

After a family-oriented pulmonary rehabilitation program, caregivers showed greater improvements in functional coping. Family-centered interventions can foster caregivers' coping and adaptation to COPD demands and require further study.

ily-based pulmonary rehabilitation on family caregivers of subjects with COPD. The study was guided by the McCubbin and McCubbin family stress theory.<sup>19</sup> According to this theory, functional adaptation to chronic diseases is facilitated when family caregivers are able to acquire new resources or coping skills not yet available, reduce the intensity of demands imposed by the illness, manage the tension associated with ongoing strains, and manage the meanings of their situation. It was therefore expected that, compared with a usual patient-centered pulmonary rehabilitation, a family-oriented intervention would maximize caregivers' adaptive coping and emotional state and reduce burden.

## Methods

### Design and Participants

This was a mixed-method study, which was a secondary analysis of an original study with a single-blinded, randomized, controlled design (clinical trial registration at ClinicalTrials.gov number NCT02048306), where 69 family dyads (ie, subjects with COPD and family caregivers) were screened, and 56 were randomly assigned to family-based pulmonary rehabilitation (experimental) or conventional (control) pulmonary rehabilitation.<sup>20</sup> The original study, conducted between January and December 2014, aimed to investigate the impacts of a family-based pulmonary rehabilitation on both subjects with COPD and family members' coping and psychosocial adjustment, without interfering with the subjects' benefits obtained from a conventional pulmonary rehabilitation program in terms of exercise tolerance, functional balance, muscle strength, and health-related quality of life.<sup>20</sup> The current analysis, combining both quantitative and qualitative approaches, was

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Correspondence: Daniela Figueiredo PhD, School of Health Sciences, University of Aveiro (ESSUA), Agrad do Crasto-Campus Universitário de Santiago, Edifício 30, 3810-193 Aveiro, Portugal. E-mail: daniela.figueiredo@ua.pt.

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intended to extend our understanding about the benefits to close family caregivers (spouses and adult children caring for >1 y) of their involvement in pulmonary rehabilitation. The selection of this specific caregiving group for the current analysis is due to the existing evidence that spouses and adult children provide assistance in a broader range of tasks and are much more likely to provide support with hands-on personal aspects of care compared with other family caregiver groups. Moreover, spouses and adult children caregivers have been identified as the highest risk group for burden and distress among all caregivers.

Participants were recruited from 3 primary care centers. Patients with COPD were considered eligible if they were  $\geq 18$  y old, had a clinical diagnosis of COPD according to the Global Initiative for Chronic Obstructive Lung Disease criteria,<sup>14</sup> were clinically stable, and voluntarily consented to participate. Caregivers were included if they were  $\geq 18$  y old, the primary caregiver (ie, the person who provided the largest amount of physical and/or supportive care without receiving any payment) of a relative with COPD who was living in the community, and voluntarily consented to participate. Caregivers were excluded if they presented severe psychiatric conditions and/or if their relative with COPD did not consent to participate. Dyad randomization was performed by a computerized random number generator in random blocks of 3. The allocation sequence was kept in sealed opaque envelopes by a researcher who was not involved in data collection. This researcher drew the envelope and scheduled dyads of both groups. Participants were blinded to group allocation. Approval was obtained from the Ethics Committee of the Center Health Regional Administration (approval February 28, 2011). Written informed consent was obtained from all participants. More detailed information on the study design can be found elsewhere.<sup>20</sup>

### Intervention

In both groups, subjects with COPD underwent 12 weeks of pulmonary rehabilitation composed of exercise training (3 weeks) and psychoeducation (1 week).<sup>20</sup> Family caregivers randomized to the family-based pulmonary rehabilitation participated in the psychoeducational component together with their relative. Family caregivers assigned to conventional pulmonary rehabilitation did not attend any component of the intervention. Psychoeducation sessions were based on a comprehensive literature review on COPD rehabilitation,<sup>13,21</sup> interventions for subjects and families living with chronic conditions,<sup>22,23</sup> and needs of family dyads.<sup>2,4,5</sup>

Sessions had 2 modules: educational and supportive. The educational module aimed to provide information about COPD and increase problem-solving skills to adjust to and to manage the disease. The supportive module intended to

help with managing the emotional demands of COPD, facilitate communication within the family and with health/social services, and maximize a sense of family identity despite the disease.

The sessions lasted approximately 90 min and were conducted by the same physiotherapist and gerontologist, who assumed the role of facilitators by supporting participants in their doubts, encouraging them to share experiences, and validating and normalizing feelings. Various didactic methods were used (eg, group discussions, home tasks, role playing, and brainstorming). The detailed contents of each session are provided elsewhere.<sup>20</sup> On each session, a chapter with the most relevant information was provided, so participants could build a handbook during the pulmonary rehabilitation.

### Measurements

**Participants' Characteristics.** Participants were assessed at primary care centers before and within 3 days after the program. Assessments of each subject with COPD and his/her family member were scheduled at the same time, but occurred in 2 distinct rooms. Socio-demographic data were collected through a structured questionnaire. The aim of each questionnaire was explained to the participants; they were asked to complete it by themselves. For participants who were unable read, questionnaires were interviewer-administered. Lung function of subjects with COPD was assessed to determine the COPD grade according to the GOLD classification.<sup>14</sup>

**Primary Outcome Measurement.** Caregivers completed the Family Crisis Oriented Personal Scales (F-COPES) to assess family coping.<sup>24</sup> The F-COPES measures problem-solving attitudes and behavior with which families respond to problems and difficulties. It identifies coping patterns used internally (between family members) and externally (outside the family)<sup>24</sup> and has been used to assess the impact of rehabilitation programs.<sup>25,26</sup> F-COPES comprises 5 subscales: acquiring social support, reframing, seeking spiritual support, mobilizing family to acquire and accept help, and passive appraisal. Responders have to determine to what degree, on a 5-point Likert scale (from 1 [totally disagree] to 5 [totally agree]), they agree/disagree with the statement. Responses yield a total score and 5 subscale scores. Higher scores indicate more positive coping and problem-solving strategies. The F-COPES has demonstrated good internal consistency, with Cronbach's  $\alpha$  of 0.77 for the total score and 0.61–0.80 for the subscales.<sup>27</sup>

### Secondary Outcome Measurements

**Emotional State.** The Depression Anxiety and Stress Scales (DASS-21) was used<sup>28</sup> to assess family caregivers'

emotional states. This version, adapted from Lovibond and Lovibond,<sup>29</sup> consists of a 21-item 4-point Likert questionnaire, which includes 3 self-report subscales designed to measure the negative emotional states of depression, anxiety, and stress. Each of the 3 subscales contains 7 items, and the responders are asked to rate the extent to which they have experienced each state over the past week, using a scale from 0 (did not apply to me at all) to 3 (applied to me very much, or most of the time). The items are then summed and converted to the full scale of 42 items (DASS-42), by multiplying the scores by 2. The scores for each subscale vary from 0 to 42, with higher scores indicating a more negative emotional state. A total score can also be calculated. The DASS-21 has good internal consistency, with Cronbach's  $\alpha$  between 0.74 and 0.85.<sup>28</sup>

**Caregiver Burden.** Burden was assessed with the Carers' Assessment of Difficulties Index (CADI).<sup>30</sup> This 30-item scale enables the assessment of the multidimensional burden<sup>31</sup> and comprises 7 subscales: caregiver-dependent relationships, reactions to caregiving, physical demands of caring, restricted social life, poor family support, poor professional support, and financial consequences. Responders are asked to select, on a 4-point scale, their assessment of a statement: does not apply (0); applies, but not stressful (1); applies and finds it quite stressful (2); or applies and finds it very stressful (3). The score ranges from 0 to 120, and higher scores indicate greater burden. CADI has presented high internal consistency, with a Cronbach's  $\alpha$  of 0.92.<sup>30</sup>

**Perspectives About the Family-Based Pulmonary Rehabilitation.** Three focus group interviews were conducted with the caregivers of the experimental group. A semi-structured guide was used to explore their perspective about: benefits and disadvantages of participation, functional aspects (eg, contents and methodologies) of the program, and expectations and suggestions for the future. Interviews lasted approximately 72 min and were digitally audio-recorded for further transcription and analysis.

### Data Analysis

**Quantitative Analysis.** Descriptive statistics were performed to characterize the sample. Independent *t* tests for normally distributed data, Mann-Whitney U-tests for ordinal/non-normally distributed data, and chi-square tests for categorical data were used to test any differences in the baseline characteristics of both groups. Normality of data was investigated with the Shapiro-Wilk test. A mixed-model analysis of variance was used to determine whether the effects of time and interaction between time and group were statistically significant. The level of significance was set at 0.05. Effect sizes were computed using the partial

eta squared ( $\eta^2_{\text{partial}}$ ), interpreted as follows: 0.01, small effect; 0.06, medium effect; 0.14, large effect.<sup>32</sup> Statistical analyses were performed using SPSS 20.0 for Windows (IBM Corporation, Armonk, New York).

**Qualitative Analysis.** The interviews were transcribed verbatim, and participants' identification was coded to preserve anonymity (from C<sub>1</sub> to C<sub>20</sub>). Transcripts were analyzed by 2 independent researchers using content analysis procedures and following several steps.<sup>33</sup> First, researchers read and re-read the transcripts to gain a sense of whole and highlighted phrases that captured the information related to the research question. Then they took notes of the content area to which the highlighted phrases referred and grouped the content areas expressing similar concepts into categories. Afterward, the categories were revised, and previous categories were clustered, or new categories were formulated. A hierarchical structure of areas was then created, consisting of categories and subcategories, and a final checking of category overlaps to merge or to divide into subcategories was conducted. Finally, researchers registered their agreements and disagreements and reached a consensus on the major categories and subcategories. To ensure reflexivity, the researchers held regular group meetings with the research team to reflect about and discuss issues related to the study.

## Results

### Participants' Characteristics

Caregivers' enrollment and allocation into groups are summarized in Figure 1. Baseline characteristics are provided in Table 1. Caregivers ( $n = 39$ ) were, on average,  $59.0 \pm 11.2$  y old, were mostly female (74.4%), and were caring for their spouse (71.8%) for 2–4 y (74.4%). From these, 20 caregivers were included in the family-based pulmonary rehabilitation group, and 19 caregivers were included in the control group. Significant differences between groups were found only for age ( $P = .01$ ) and marital status ( $P = .02$ ). Regarding the characteristics of subjects with COPD, they were, on average,  $66.9 \pm 10.6$  y old (experimental group:  $68.5 \pm 7.1$  y; control group:  $65.0 \pm 13.5$  y) and were mostly male (experimental group:  $n = 17$ ; control group:  $n = 10$ ). Fourteen subjects had mild (experimental group,  $n = 7$ ; control group,  $n = 7$ ), 15 had moderate (experimental group,  $n = 7$ ; control group,  $n = 8$ ), and 10 had severe to very severe COPD (experimental group,  $n = 7$ ; control group,  $n = 3$ ). No significant differences regarding any of the baseline characteristics were found between subjects' groups.



**Impacts of the Intervention**

**Quantitative Assessment.** Table 2 presents the comparison between groups before and after pulmonary rehabilitation. Caregivers from both groups reported significant improvements in F-COPES global score ( $P = .01$ ) and subscales ( $P < .05$ ). However, the experimental group presented higher mean differences in the F-COPES global score (time  $\times$

group,  $P = .01$ ) and in the subscales reframing (time  $\times$  group,  $P = .01$ ), seeking spiritual support (time  $\times$  group,  $P = .01$ ), and mobilizing to acquire and accept help (time  $\times$  group,  $P = .02$ ), when compared with the control group.

Results of the DASS total score and subscales showed that caregivers' emotional states did not change significantly as a result of the intervention or group allocation ( $P > .05$ ). Regarding burden, CADI global score ( $P = .01$ ) and the subscales reactions to caregiving ( $P = .01$ ), physical demands of caring ( $P = .044$ ), and poor family support ( $P = .038$ ) were significantly improved, although there were no significant differences between groups.

**Qualitative Assessment.** Three significant categories emerged: benefits of participation, strengths of the pulmonary rehabilitation, and (dis)continuity of the pulmonary rehabilitation.

**Benefits of Participation: Self-Benefits and Benefits for the Cared-for Person.** All caregivers reported that pulmonary rehabilitation helped them to understand and cope with COPD: "Now I can give a better support because I already understand the disease. We can solve problems in a better way" ( $C_1$ ); "Before the program, I didn't know how to deal with his disease" ( $C_2$ ). Learning how to care during exacerbations was one of the greatest benefits ( $n = 16$ ; 80%): "He had a severe crisis, and what I've learned here was really helpful. I remembered how he had to breathe and the right position to be during the crisis" ( $C_3$ ).

Most caregivers reported that pulmonary rehabilitation contributed to better management of family relationships because, by sharing this experience with their relative with

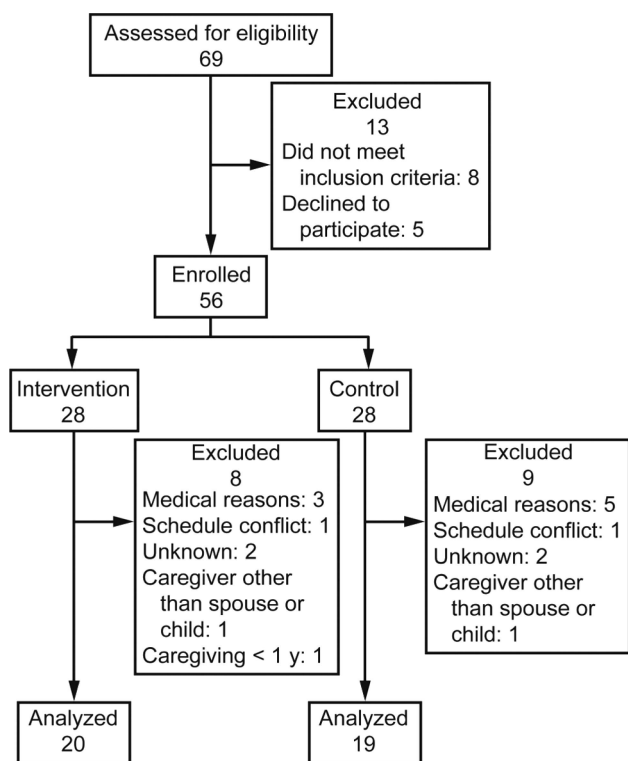


Fig. 1. Flow chart.

Table 1. Family Caregivers' Characteristics

	Total (N = 39)	Experimental Group (n = 20)	Control Group (n = 19)	P
Age, mean $\pm$ SD y	59.0 $\pm$ 11.2	63.1 $\pm$ 9.5	53.6 $\pm$ 11.3	.01
Female sex, n (%)	29 (74.4)	16 (80.0)	13 (68.4)	.46
Educational level, n (%)				
No qualifications/Primary	16 (41.1)	10 (50.0)	6 (31.6)	.32
Secondary	7 (17.9)	4 (20.0)	3 (15.8)	
High school	7 (17.9)	2 (10.0)	5 (26.3)	
University	9 (23.1)	4 (20.0)	5 (26.3)	
Marital status, n (%)				
Married/living as a couple	32 (82.1)	19 (95.0)	13 (68.4)	.02
Divorced/single	7 (17.9)	1 (5.0)	6 (31.6)	
Relationship with the subject, n (%)				
Couple	28 (71.8)	17 (85.0)	11 (57.9)	.052
Son/Daughter	11 (28.2)	3 (15.0)	8 (42.1)	
Caregiving period (y), n (%)				
1-2	10 (25.6)	4 (20.0)	6 (31.6)	.46
2-4	29 (74.4)	16 (80.0)	13 (68.4)	

BENEFITS TO CAREGIVERS OF PULMONARY REHABILITATION

Table 2. Comparison of the Scores of Family Coping, Emotional State, and Caregiver Burden Between the Experimental and Control Groups

	Experimental Group (n = 20)		Control Group (n = 19)		P*	P†	η <sup>2</sup> <sub>partial</sub>
	Pre-Intervention	Post-Intervention	Pre-Intervention	Post-Intervention			
F-COPES Global Score	93.1 ± 12.9	110.4 ± 11.2	92.5 ± 20.3	92.5 ± 17.0	.01	.01	0.26
Acquiring social support	28.9 ± 6.7	32.5 ± 7.2	27.5 ± 8.7	28.1 ± 7.1	.063	.16	0.06
Reframing	29.4 ± 4.6	33.2 ± 4.0	31.5 ± 4.7	30.5 ± 5.2	.056	.01	0.26
Seeking spiritual support	12.0 ± 4.1	14.4 ± 4.0	10.9 ± 5.3	11.1 ± 5.7	.01	.01	0.18
Mobilizing to acquire and accept help	10.9 ± 3.1	14.1 ± 3.7	11.9 ± 2.1	12.6 ± 3.3	.01	.02	0.17
Passive appraisal	12.7 ± 2.2	10.8 ± 3.1	11.3 ± 4.3	9.9 ± 3.7	.01	.46	0.02
DASS total	21.2 ± 15.5	18.8 ± 18.6	20.1 ± 24.6	19.4 ± 33.6	.62	.77	0.01
Depression	7.7 ± 6.9	6.8 ± 6.9	8.5 ± 9.3	6.9 ± 10.7	.30	.76	0.01
Anxiety	8.1 ± 5.2	6.1 ± 6.0	6.4 ± 7.6	5.5 ± 10.9	.24	.64	0.01
Stress	8.3 ± 7.4	6.8 ± 6.9	8.0 ± 8.6	6.2 ± 10.8	.17	.91	0.01
CADI global score	11.3 ± 11.9	7.2 ± 8.1	10.5 ± 16.4	5.8 ± 8.3	.01	.83	0.01
Caregiver-dependent relationship	2.6 ± 3.5	1.7 ± 2.3	2.2 ± 4.2	1.1 ± 2.3	.09	.85	0.01
Reactions to caregiving	3.6 ± 4.1	1.5 ± 2.0	2.9 ± 4.5	1.9 ± 2.7	.01	.29	0.03
Physical demands of caring	1.6 ± 2.3	1.2 ± 1.9	1.5 ± 2.8	0.5 ± 0.8	.044	.40	0.02
Restricted social life	1.4 ± 2.1	1.0 ± 1.3	1.4 ± 2.4	0.6 ± 1.3	.11	.72	0.01
Poor family support	0.8 ± 1.4	0.4 ± 0.5	0.9 ± 1.6	0.6 ± 1.4	.038	.80	0.01
Poor professional support	0.7 ± 1.5	0.5 ± 0.9	0.6 ± 1.3	0.2 ± 0.6	.12	.48	0.02
Financial consequences	0.9 ± 1.5	0.7 ± 1.0	1.0 ± 1.4	0.8 ± 1.3	.26	.90	0.01

\* Time.

† Interaction time × group.

F-COPES = Family Crisis Oriented Personal Scales

DASS = Depression Anxiety and Stress Scales

CADI = Carers' Assessment of Difficulties Index

COPD, they became closer and improved their relations (n = 14; 70%): “It helped creating complicity in our relationship and in issues related to the disease” (C<sub>4</sub>). Moreover, the program enabled the subjects’ awareness of the impact of COPD on family life (n = 9; 45%) and helped other family members to be aware of the health condition of their relative (n = 6; 30%).

Caregivers believed that pulmonary rehabilitation also improved the exercise habits of the family (n = 11; 55%): “Before starting our jogging, I do some warm up exercises, and he says ‘You have to do it [the exercise] like that,’ and I follow his commands” (C<sub>5</sub>).

There were also benefits for the cared-for person. Caregivers considered that pulmonary rehabilitation provided their relative with appropriate treatment, leading to improvements in their symptoms and, consequently, in the quality of life of the whole family. Participants stressed that relatives learned several disease-management strategies and were able to cope better with COPD: “Sometimes he is anxious and I realize that he is using the breathing techniques learned here, and I’m less concerned! So it [the program] was really useful” (C<sub>6</sub>).

Caregivers also noted that their relatives were more frequently in a good mood (n = 13; 65%) and changed lifestyle behaviors (n = 12; 60%). “He used to spend too much time at home and now he’s more encouraged to

walk, he feels capable of doing multiple tasks, he lost some weight, and he breathes more easily!” (C<sub>7</sub>).

**Strengths of Pulmonary Rehabilitation: Strategies to Engage Participants and Strengths of the Psychoeducation.** Some factors led participants to adhere to the program: the incentive given by their general practitioners (n = 20; 100%), the empathetic attitudes of the professionals involved (n = 17; 85%), the innovative nature of the pulmonary rehabilitation in primary care (n = 11; 55%), and the recognition of participants’ needs (n = 7; 35%). “When they [professionals of the pulmonary rehabilitation] called me, they were very friendly and it helped me to decide” (C<sub>9</sub>); “The first contact was made by a trusted institution, my primary care center, and this was very important” (C<sub>6</sub>).

All psychoeducational sessions were considered relevant; nonetheless, caregivers identified the management of respiratory symptoms as the most useful because they learned and trained with breathing control techniques (n = 20; 100%). Caregivers also recognized that the session on management of stress and anxiety was essential to coping with COPD (n = 13; 65%), helping them to improve the relationship with the cared-for person: “It is normal that we get involved in family problems, like diseases, and we start to feel anxious. With this knowledge, we have learned to use strategies to overpass problems”

(C<sub>10</sub>); “People don’t value the emotional management, and it’s very important for this disease” (C<sub>2</sub>).

The pulmonary rehabilitation handbook was identified as an important resource ( $n = 16$ ; 80%): “When we forgot the techniques, we used the handbook at home to remember them” (C<sub>4</sub>).

**(Dis)Continuity of Pulmonary Rehabilitation: Expectations and Suggestions for Future Interventions and Future Plans.** All caregivers stressed the relevance of the program continuity to help themselves and their relatives as well as to support other families: “People with COPD and family members should attend these programs” (C<sub>11</sub>); “The program should be longer, it’d be good if it could continue ...” (C<sub>6</sub>).

Some caregivers expressed concerns about the discontinuity ( $n = 9$ ; 45%). Although they believed that their relative would apply the acquired knowledge, they were afraid that the cared-for person would return to his/her previous lifestyle: “He did exercise on a regular basis during the program; now it is going to be hard to keep him doing that” (C<sub>12</sub>).

For future interventions, caregivers suggested ( $n = 11$ ; 55%) a longer duration and with sessions being held every 2 weeks. “I would change one thing: the frequency [of the psychoeducation sessions]; they should be conducted fortnightly” (C<sub>13</sub>); “The group started to encourage itself, so more weeks of program would be nice” (C<sub>5</sub>).

Caregivers suggested replicating the pulmonary rehabilitation program at regular intervals to allow monitoring of participants’ health status ( $n = 16$ ; 80%): “It should be done every year! There should be a follow-up, because we can lose what we’ve gained here.” (C<sub>15</sub>). This suggestion highlights their expectations of ongoing support to help themselves and their cared-for person over time.

Caregivers wished to continue applying the acquired knowledge and to make changes in their lifestyle ( $n = 14$ ; 70%): “We will do what we’ve learned!” (C<sub>16</sub>); “We want to have a gym at home” (C<sub>11</sub>). The group also expressed the desire to organize outdoor activities ( $n = 8$ ; 40%): “We have all the contacts and we are trying to organize some group outdoor activities” (C<sub>2</sub>); “It would be necessary to have someone assuming the responsibility of organizing the activities, at least in the beginning” (C<sub>17</sub>).

## Discussion

Overall, the results support the initial hypothesis that a family-based approach in pulmonary rehabilitation could have more benefits for close family caregivers than a patient-centered one. Although the patient-oriented pulmonary rehabilitation improved caregivers’ family coping, the findings were more significant when family caregivers were included. Specifically, the experimental group showed

greater improvements in overall coping, specifically in the use of external (seeking spiritual support and mobilizing to acquire and accept help) and internal (reframing) coping. These results were reinforced by the qualitative data, because most participants from the experimental group reported that the intervention helped them to understand and cope with COPD as well as to better manage exacerbations and to improve open communication within the family, 2 of the most stressful events related to COPD.<sup>34</sup> The findings are consistent with previous studies in non-respiratory conditions, which showed that providing psychoeducational support to family caregivers facilitates an adaptive coping to caregiving demands.<sup>10,35</sup> Nevertheless, there were no significant improvements in depression, anxiety, and stress, and improvements in CADI were found for both groups, with no significant differences. This might call into question the validity of DASS and CADI in the specific context of COPD caregiving, despite their good psychometric properties. This result might be also explained by the family-based design of the intervention. During the psychoeducation sessions, family caregivers may not wish to disclose issues in the presence of their relatives, like concerns about their declining condition. Future interventions may need to occasionally involve caregivers separately from their relatives, since their perceptions may differ.<sup>8</sup>

Considering the functional aspects of the program, the qualitative analysis suggested its adequacy regarding the contents and didactic methods. The sessions targeted to the management of respiratory symptoms and the management of stress and anxiety were highly valued, which is in line with the caregivers’ needs already evidenced in terms of useful information to control COPD symptoms and emotional coping.<sup>3,6</sup> Qualitative data provided valuable information about the recruitment and engagement, which has been described as one of the most difficult issues in the implementation of interventions and a significant threat to studies’ internal and external validity.<sup>36</sup> Facilitative factors have been identified by caregivers, namely: a pulmonary rehabilitation conducted in a familiar location (primary care centers), being recommended to participate by someone they trust (their general practitioner), the personalized attention and empathetic attitude of the professionals involved, and the acknowledgment of their own needs. These strategies were effective at ensuring participants’ engagement, because the dropouts were not significant, and were in line with those recommended previously.<sup>37</sup> It is therefore important to explore participants’ perspectives to minimize potential barriers to participation in future interventions.

Qualitative analysis also provided important information regarding maintenance of the pulmonary rehabilitation benefits. Concerns about relatives’ non-adherence to physical exercise after pulmonary rehabilitation were re-

ported by 45% of the caregivers. Studies suggest that improvements in exercise capacity and health condition after short-term pulmonary rehabilitation are maintained for approximately 6 months but diminish in the following 6–12 months.<sup>13</sup> To maintain the health benefits acquired, patients with COPD need to remain physically active. Follow-ups to monitor relatives' condition and motivate their physical activity were proposed by caregivers. However, post-rehabilitation strategies that include regular supervised sessions and repeated pulmonary rehabilitation show modest effects on long-term outcomes.<sup>13</sup> It has been argued that family-oriented interventions are more likely to enhance adherence to treatment regimens and physical activity than interventions directed at subjects with COPD alone.<sup>38,39</sup> Further investigation is needed to verify this hypothesis within the context of comprehensive pulmonary rehabilitation.

Some limitations need to be acknowledged. First, although in the original study, the sample size estimation was adequate for F-COPES (the primary outcome measure),<sup>20</sup> probably it was relatively small to detect more subtle differences between groups regarding the DASS or CADI subscales. Furthermore, the significant differences between groups in their baseline socio-demographic characteristics in terms of age and marital status may also explain the results. Second, the facilitators of the psychoeducational sessions were also the evaluators of the study; thus, they were not blinded to group allocation. This may have added some bias in the results obtained favoring the family-based group. However, all questions were standardized, and researchers were previously trained to minimize the possibility of occurring bias. Studies with larger samples controlled for socio-demographics and with a double-blinded design should be conducted to clarify the extent of the findings. Third, the study failed to consider how the benefits differed according to the COPD grade (eg, early grades vs advanced grades). Future research is needed to more clearly determine under what conditions a family-based pulmonary rehabilitation is likely to be more effective. Fourth, the direct financial costs were not analyzed.

### Conclusions

Despite its limitations, the current study provides valuable evidence to recommend the inclusion of family caregivers in pulmonary rehabilitation. Consistent with the McCubbin and McCubbin family stress theory,<sup>19</sup> the overall results sustain that compared with a usual patient-centered pulmonary rehabilitation, a family oriented intervention can maximize family caregivers' ability to understand and manage COPD-related stress, mobilize external and internal coping resources, reframe the meaning of their situation, and develop family open communication. The findings highlight the potential benefits of family-based

pulmonary rehabilitation to prevent burden and other negative psychological outcomes; however, further research in this area is warranted.

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