

1 **Exploring the Benefits to Caregivers of a Family-Oriented Pulmonary Rehabilitation**

2 **Program**

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24

## Abstract

1  
2 **Introduction:** COPD is a highly incapacitating disease, particularly among older people,  
3 implying significant burden for family caregivers. Involving caregivers in comprehensive  
4 pulmonary rehabilitation (PR) programs might benefit their functional coping to care  
5 demands; however, there is no objective evidence to sustain such assumption. This study is a  
6 secondary analysis aiming to analyze the effects of a family-based PR program on close  
7 family caregivers of older subjects with COPD. **Methods:** This is a mixed-methods study.  
8 Family caregivers were randomly assigned to family-based (experimental) or conventional  
9 (control) PR. Caregivers from the family-based PR (n=20; 80.0% female; 63.1±9.5years)  
10 attended the psychoeducational component together with their relatives. In the conventional  
11 PR, caregivers did not participate (n=19; 68.4% female; 53.6±11.3years). Self-rated  
12 instruments (Family Crisis Oriented Personal Scales; Depression Anxiety and Stress Scales  
13 and Carers' Assessment of Difficulties Index) and focus group interviews were used to assess  
14 the intervention. **Results:** Caregivers from the family-based PR had significantly greater  
15 improvements in overall family coping (p=0.01), reframing (p=0.01), seeking spiritual  
16 support (p=0.01), and mobilizing to acquire help (p=0.02). No significant differences were  
17 found for emotional state. Significant improvements in overall burden (p=0.01), reactions to  
18 caregiving (p=0.01), physical demands of caring (p=0.04) and poor family support (p=0.04)  
19 were observed, though there were no significant between-group differences. Qualitative data  
20 sustained the benefits of involving family caregivers in the PR.

21 **Conclusions:** The findings provide valuable evidence to recommend the inclusion of COPD  
22 family caregivers in comprehensive PR. A family-oriented PR maximizes caregivers'  
23 adaptive coping and potentially prevent negative psychological outcomes, however, further  
24 research is needed.

- 1 **Key Words:** Burden; Chronic Obstructive Pulmonary Disease; Coping; Emotional state;
- 2 Family caregiving.

## Introduction

Chronic Obstructive Pulmonary Disease (COPD) is a major cause of morbidity, mortality and healthcare costs in old age<sup>1</sup>. As the disease progresses, a number of symptoms, such as dyspnea, fatigue and comorbidities emerge and subjects experience a gradual reduction in physical, emotional and social functioning<sup>2</sup>.

Family is among the most important resources for these subjects<sup>3, 4</sup>, assisting with activities of daily living, managing complex treatment technologies and medication regimens, monitoring breathlessness, providing emotional support, participating in decision-making and facilitating communication with healthcare 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>, anxiety and depressive symptomatology<sup>7</sup>. The support given can also precipitate poorer dyads' 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, symptoms 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 (PR) programs in COPD, alongside with exercise training, smoking cessation and nutrition counseling<sup>13, 14</sup>. Comprehensive PR has shown to reduce exacerbations, hospital admissions or anxiety/depressive symptoms in subjects with COPD, whilst improving overall functional status<sup>15, 16</sup>. Given the evidence of COPD impacts on caregivers, and the recognized

1 importance of family support, it would be expected to find a greater involvement of  
2 caregivers in PR. Instead, PR remains patient-centered and, to date, there is no objective  
3 evidence to sustain such recommendation. An encouraging exception is the study of  
4 Zakrisson et al.<sup>17</sup> aiming to explore the experience of a multidisciplinary PR for subjects with  
5 COPD from the perspective of the next kin. However, caregivers have only participated in  
6 one theoretical session and no quantitative outcome measures were collected.

7 Assuming that a chronic disease, like COPD, is a family disease<sup>18</sup> this study aimed to analyze  
8 the effects of a family-based PR on family caregivers of subjects with COPD. The study was  
9 guided by the McCubbin and McCubbin Family Stress Theory<sup>19</sup>. According to this theory,  
10 functional adaptation to chronic diseases is facilitated when family caregivers are able to:  
11 acquire new resources or coping skills not yet available; reduce the intensity of demands  
12 imposed by the illness; manage the tension associated with ongoing strains; and manage the  
13 meanings about their situation. It was therefore expected that, compared to a usual patient-  
14 centered PR, a family-oriented intervention would maximize caregivers' adaptive coping and  
15 emotional state and reduce burden.

## 16 **Methods**

### 17 **Design and Participants**

18 This is a mixed-method study, which is a secondary analysis of an original study with a  
19 single-blinded, randomized controlled design (clinical trial registration at ClinicalTrials.gov -  
20 NCT02048306) where 69 family dyads (i.e., subjects with COPD and family caregivers) were  
21 screened and 56 randomly assigned to family-based PR (experimental) or conventional  
22 (control) PR<sup>20</sup>. The original study, conducted between January and December 2014, aimed to  
23 investigate the impacts of a family-based PR on both subjects with COPD and family  
24 members' coping and psychosocial adjustment, without interfering with subjects' benefits  
25 obtained from a conventional PR program in terms of exercise tolerance, functional balance,

1 muscle strength and health-related quality of life<sup>20</sup>. The current analysis, combining both  
2 quantitative and qualitative approaches, intended to extend our understanding about the  
3 benefits to close family caregivers – spouses and adult children caring for more than 1 year -  
4 of their involvement in PR. The selection of this specific caregiving group for the current  
5 analysis is due to the existing evidence that spouses and adult children provide assistance in a  
6 broader range of tasks and are much more likely to provide support with hands-on personal  
7 aspects of care compared to other family caregiver groups. Moreover, spouses and adult  
8 children caregivers have been identified as the highest risk group for burden and distress  
9 among all caregivers.

10 Participants were recruited from three primary care centers. Subjects with COPD were  
11 considered eligible if they: were  $\geq 18$  years old; had a clinical diagnosis of COPD according  
12 to the Global Initiative for Chronic Obstructive Lung Disease (GOLD) criteria<sup>14</sup>; were  
13 clinically stable; and voluntarily consented to participate. Caregivers were included if they  
14 were:  $\geq 18$  years old; the primary caregiver (i.e., the person who provided the largest amount  
15 of physical and/or supportive care without receiving any payment) of a relative with COPD  
16 who was living in the community; and voluntarily consented to participate. Caregivers were  
17 excluded if they presented severe psychiatric conditions and/or if their relative with COPD  
18 did not consent to participate. Dyads' randomization was performed by a computerized  
19 random number generator in random blocks of three. The allocation sequence was kept in  
20 sealed opaque envelopes by a researcher who was not involved in data collection. This  
21 researcher drew the envelope and scheduled dyads of both groups. Participants were blinded  
22 to group allocation. Approval was obtained from the Ethics Committee of the Center Health  
23 Regional Administration (28-02-2011). Written informed consent was obtained from all  
24 participants. More detailed information on the study design can be found elsewhere<sup>20</sup>.

## 1 **Intervention**

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

9 Sessions had two modules: educational and supportive. The educational module aimed to  
10 provide information about COPD, increase problem-solving skills to adjust to and to manage  
11 the disease. The supportive module intended to help managing the emotional demands of  
12 COPD, facilitate the communication within the family and with health/social services, and  
13 maximize a sense of family identity despite the disease.

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

## 21 **Measures**

### 22 *Participants' Characteristics*

23 Participants were assessed at primary care centers before and within three days after the  
24 program. Assessments of each subject with COPD and his/her family member were scheduled  
25 at the same time, but occurred in two distinct rooms. Socio-demographic data were collected

1 through a structured questionnaire. Participants were explained the aim of each questionnaire  
2 and they were asked to complete it by themselves. For participants who were unable read,  
3 questionnaires were interviewer-administered. Lung function of subjects with COPD was  
4 assessed to determine the COPD grade according to the GOLD classification<sup>14</sup>.

#### 5 *Primary Outcome Measure*

##### 6 *Family Coping*

7 Caregivers completed the Family Crisis Oriented Personal Scales (F-COPES)<sup>24</sup>. The F-  
8 COPES measures problem-solving attitudes and behavior with which families respond to  
9 problems and difficulties. It identifies coping patterns used internally (between family  
10 members) and externally (outside the family)<sup>24</sup> and has been used to assess the impact of  
11 rehabilitation programs<sup>25, 26</sup>. F-COPES comprises five subscales: Acquiring social support,  
12 Reframing, Seeking spiritual support, Mobilizing family to acquire and accept help and  
13 Passive appraisal. Responders have to determine to what degree, on a 5-point Likert scale  
14 (from 1 “*totally disagree*” to 5 “*totally agree*”), they (dis)agree with the statement. Responses  
15 yield a total score and five subscale scores. Higher scores indicate more positive coping and  
16 problem-solving strategies. The F-COPES has demonstrated good internal consistency, with  
17 Cronbach’s alpha of 0.77 for the total score and 0.61-0.80 for the subscales<sup>27</sup>.

#### 18 *Secondary Outcome Measures*

##### 19 *Emotional State*

20 The Depression Anxiety and Stress Scales (DASS-21) was used<sup>28</sup> to assess family caregivers’  
21 emotional states. This version, adapted from Lovibond and Lovibond<sup>29</sup>, consists of a 21-item  
22 4-point Likert questionnaire which includes three self-report sub-scales designed to measure  
23 the negative emotional states of depression, anxiety and stress. Each of the three sub-scales  
24 contains 7 items and the responders are asked to rate the extent to which they have  
25 experienced each state over the past week, using a scale from 0 (“*Did not apply to me at all*”)

1 to 3 (“*Applied to me very much, or most of the time*”). The items are then summed and  
2 converted to the full scale of 42 items (DASS-42), by multiplying the scores by two. The  
3 scores for each sub-scale vary from 0 to 42, with higher scores indicating a more negative  
4 emotional state. A total score can also be calculated. The DASS-21 has good internal  
5 consistency, with Cronbach’s alphas between 0.74 and 0.85<sup>28</sup>.

### 6 *Caregiver Burden*

7 Burden was assessed with the Carers’ Assessment of Difficulties Index (CADI)<sup>30</sup>. This 30-  
8 item scale enables the assessment of the multidimensional burden<sup>31</sup> and comprises seven  
9 subscales: Caregiver–dependent relationships, Reactions to caregiving, Physical demands of  
10 caring, Restricted social life, Poor family support, Poor professional support and Financial  
11 consequences. Responders are asked to select, on a 4-point scale, if the statement: “*does not*  
12 *apply*” (0); “*applies, but not stressful*” (1); “*applies and finds it quite stressful*” (2); or  
13 “*applies and finds it very stressful*” (3). Score ranges from 0 to 120, and higher scores indicate  
14 greater burden. CADI has presented high internal consistency with a Cronbach’s alpha of  
15 0.92<sup>30</sup>.

### 16 *Perspectives about the Family-Based PR*

17 Three focus group interviews were conducted with the caregivers of the EG. A semi-  
18 structured guide was used to explore their perspective about: benefits and disadvantages of  
19 participation, functional aspects (e.g., contents and methodologies) of the program,  
20 expectations and suggestions for the future. Interviews lasted approximately 72 minutes and  
21 were digitally audio-recorded for further transcription and analysis.

## 22 **Data Analysis**

### 23 *Quantitative Analysis*

24 Descriptive statistics were performed to characterize the sample. Independent t-tests for  
25 normally distributed data, Mann Whitney U-tests for ordinal/non-normally distributed data

1 and Chi-square tests for categorical data were used to test any differences in the baseline  
2 characteristics of both groups. Normality of data was investigated with the Shapiro-Wilk test.  
3 A mixed-model analysis of variance (ANOVA) was used to determine whether the effects of  
4 time and interaction between time and group were statistically significant. The level of  
5 significance was set at 0.05. Effect sizes (ES) were computed using the partial eta squared  
6 ( $\eta^2_{\text{partial}}$ ), interpreted as: 0.01 small, 0.06 medium and 0.14 large effect<sup>32</sup>. Statistical analyzes  
7 were performed using IBM SPSS v20.0 (IBM Corp., Armonk, NY).

### 8 *Qualitative Analysis*

9 The interviews were transcribed verbatim and participants' identification was coded to  
10 preserve anonymity (from C1 to C20). Transcripts were analyzed by two independent  
11 researchers using content analysis procedures and following several steps<sup>33</sup>. First, researchers  
12 read and re-read the transcripts to gain a sense of whole and highlighted phrases that captured  
13 the information related with the research question. Then, they took notes of the content area to  
14 which the highlighted phrases referred and grouped the content areas expressing similar  
15 concepts into categories. After, the categories were revised and previous categories were  
16 clustered or new categories were formulated. A hierarchical structure of areas was then  
17 performed, consisting of categories and subcategories, and a final checking of category  
18 overlaps to merge or to divide into subcategories was conducted. Finally, researchers  
19 registered their agreements and disagreements and reached a consensus on the major  
20 categories and subcategories. To ensure reflexivity, the researchers held regular group  
21 meetings with the research team to reflect about and discuss issues related to the study.

## 22 **Results**

### 23 **Participants' Characteristics**

24 Participants' enrolment and allocation into groups are summarized in figure 1. Baseline  
25 characteristics are provided in Table 1. Caregivers (n=39) had 59.0±11.2 years old, were

1 mostly female (74.4%) and caring for their spouse (71.8%) for 2-4 years (74.4%). From these,  
2 20 caregivers were included in the family-based PR group and 19 caregivers in the control  
3 group. Significant differences between groups were found only for age ( $p=0.01$ ) and marital  
4 status ( $p=0.02$ ). Regarding the characteristics of subjects with COPD, they had  $66.9\pm 10.6$   
5 years old (EG:  $68.5\pm 7.1$ ; CG:  $65.0\pm 13.5$ ) and were mostly male (EG:  $n=17$ ; CG:  $n=10$ ).  
6 Fourteen patients had mild (EG,  $n=7$ ; CG,  $n=7$ ), 15 had moderate (EG,  $n=7$ ; CG,  $n=8$ ) and 10  
7 had severe to very severe COPD (EG,  $n=7$ ; CG,  $n=3$ ). No significant differences regarding  
8 any of the baseline characteristics were found between subjects' groups.

9

10 *(insert figure 1 and table 1)*

## 11 **Impacts of the Intervention**

### 12 *Quantitative Assessment*

13 Table 2 presents the comparison between groups before and after the PR. Caregivers from  
14 both groups reported significant improvements in F-COPES global score ( $p=0.01$ ) and  
15 subscales ( $p<0.05$ ). However, the experimental group (EG) presented higher mean differences  
16 in the F-COPES global score (time\*group,  $p=0.01$ ) and in the subscales Reframing  
17 (time\*group,  $p=0.01$ ), Seeking spiritual support (time\*group,  $p=0.01$ ) and Mobilizing to  
18 acquire and accept help (time\*group,  $p=0.02$ ), when compared to the CG.

19 Results of the DASS total score and sub-scales showed that caregivers' emotional states did  
20 not change significantly as a result of the intervention or group allocation ( $p>0.05$ ). Regarding  
21 burden, CADI global score ( $p=0.01$ ) and the subscales Reactions to caregiving ( $p=0.01$ ),  
22 Physical demands of caring ( $p=0.04$ ) and poor family support ( $p=0.04$ ) were significantly  
23 improved, though there were no significant differences between groups.

24

*(insert table 2)*

1 *Qualitative Assessment*

2 Three significant categories had emerged: *Benefits of participation; Strengths of the PR* and  
3 *(Dis)Continuity of the PR.*

4 *Benefits of Participation*

5 *Self-benefits.* All caregivers reported that the PR helped them to understand and cope with  
6 COPD: “*Now I can give a better support because I already understand the disease. We can*  
7 *solve problems in a better way*” (C<sub>1</sub>); “*Before the program, I didn’t know how to deal with his*  
8 *disease*” (C<sub>2</sub>). Learning how to care during exacerbations was one of the greatest benefits  
9 (n=16; 80%): “*He had a severe crisis and what I’ve learned here was really helpful, I*  
10 *remembered how he had to breathe and the right position to be during the crisis.*” (C<sub>3</sub>)

11 Most caregivers reported that the PR contributed to a better management of family  
12 relationships because, by sharing this experience with their relative with COPD, they became  
13 closer and improved their relations (n=14; 70%): “*It helped creating complicity in our*  
14 *relationship and in issues related to the disease.*” (C<sub>4</sub>) Moreover, the program enabled the  
15 subjects’ awareness of the impact of COPD in the family life (n=9; 45%); and helped other  
16 family members to be aware of the health condition of their relative (n=6; 30%).

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

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

1 Caregivers also noted that their relatives were more frequently in good mood (n=13; 65%)  
2 and changed lifestyle behaviors (n=12; 60%). *“He used to spend too much time at home and  
3 now he's more encouraged to walk, he feels capable of doing multiples tasks, he lost some  
4 weight, and he breathes more easily!”* (C7).

#### 5 *Strengths of the PR*

6 *Strategies to engage participants.* Some factors led participants to adhere to the program: the  
7 incentive given by their general practitioners (n=20; 100%); the empathetic attitudes of the  
8 professionals involved (n=17; 85%); the innovative nature of the PR in primary care (n=11;  
9 55%); and the recognition of participants' needs (n=7; 35%). *“When they [professionals of  
10 the PR] called me, they were very friendly and it helped me to decide”* (C9); *“The first contact  
11 was made by a trustful institution, my primary care center, and this was very important.”*  
12 *(C6).*

13 *Strengths of the psychoeducation.* All psychoeducational sessions were considered relevant,  
14 nonetheless, caregivers identified the “management of respiratory symptoms” as the most  
15 useful as they learned and trained breathing control techniques (n=20; 100%). Caregivers also  
16 recognized that the “management of stress and anxiety” session was essential to cope with  
17 COPD (n=13; 65%), helping them to improve the relationship with the cared-for person: *“It is  
18 normal that we get involved in family problems, like diseases, and we start to feel anxious.  
19 With this knowledge, we have learned to use strategies to overpass problems.”* (C10); *“People  
20 don't value the emotional management and it's very important for this disease.”* (C2)

21 The PR handbook was identified as an important resource (n=16; 80%): *“When we forgot the  
22 techniques, we use the handbook at home to remember them.”* (C4).

#### 23 *(Dis)Continuity of the PR*

24 *Expectations and suggestions for future interventions.* All caregivers stressed the relevance of  
25 the program continuity to help themselves and their relatives, as well as to support other

1 families: *“People with COPD and family members should attend these programs.”* (C<sub>11</sub>);  
2 *“The program should be longer, it’d be good if it could continue...”* (C<sub>6</sub>)  
3 Some caregivers expressed concerns about the discontinuity (n=9; 45%). Although they  
4 believed that their relative would apply the acquired knowledge, they were afraid that the  
5 cared-for person returned to his/her previous lifestyle: *“He did exercise on a regular basis*  
6 *during the program, now it is going to be hard to keep him doing that.”* (C<sub>12</sub>)  
7 For future interventions, caregivers suggested (n=11; 55%) a longer duration and being held  
8 fortnightly. *“I would change one thing: the frequency [of the psychoeducation sessions], they*  
9 *should be conducted fortnightly”* (C<sub>13</sub>); *“The group started to encourage itself, so more weeks*  
10 *of program would be nice.”* (C<sub>5</sub>)  
11 Caregivers suggested replicating the PR program at regular intervals to allow the monitoring  
12 of participants’ health status (n=16; 80%): *“It should be done every year! There should be a*  
13 *follow up, because we can lose what we’ve gained here.”* (C<sub>15</sub>) This suggestion highlights  
14 their expectations of ongoing support to help themselves and their cared-for person over time.  
15 *Future plans.* Caregivers wished to continue applying the acquired knowledge and to make  
16 changes in their lifestyle (n=14; 70%): *“We will do what we’ve learned!”* (C<sub>16</sub>); *“We want to*  
17 *have a gym at home.”* (C<sub>11</sub>) The group also expressed the desire to organize outdoor activities  
18 (n=8; 40%): *“We have all the contacts and we are trying to organize some group outdoor*  
19 *activities.”* (C<sub>2</sub>) *“It would be necessary to have someone assuming the responsibility of*  
20 *organizing the activities, at least in the beginning.”* (C<sub>17</sub>)

## 21 **Discussion**

22 Overall, the results support the initial hypothesis that a family-based approach in PR could  
23 have more benefits for close family caregivers than a patient-centered one. Although the  
24 patient-oriented PR improved caregivers’ family coping, findings were more significant when  
25 family caregivers were included. Specifically, the EG showed greater improvements on

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

17 Considering the functional aspects of the program, the qualitative analysis suggested its  
18 adequacy regarding the contents and didactic methods. The sessions targeted to the  
19 “management of respiratory symptoms” and “the management of stress and anxiety” were  
20 highly valued, which is in line with the caregivers’ needs already evidenced in terms of useful  
21 information to control COPD symptoms and emotional coping<sup>3, 6</sup>. Qualitative data provided  
22 valuable information about the recruitment and engagement, which has been described as one  
23 of the most difficult issues in the implementation of interventions and a significant threat to  
24 studies’ internal and external validity<sup>36</sup>. Facilitative factors have been identified by caregivers,  
25 namely: a PR conducted in a familiar location (primary care centers); being recommended to

1 participate by someone they trust (their general practitioner); the personalized attention and  
2 empathetic attitude of the professionals involved; and the acknowledgement of their own  
3 needs. These strategies were effective ensuring participants' engagement, as the dropouts  
4 were not significant, and were in line with those recommended previously<sup>37</sup>. It is, therefore,  
5 important to explore participants' perspectives to minimize potential barriers to participation  
6 in future interventions.

7 Qualitative analysis also provided important information regarding the maintenance of the PR  
8 benefits. Concerns about relatives' non-adherence to physical exercise after the PR were  
9 reported by 45% of the caregivers. Studies suggest that improvements in exercise capacity  
10 and health condition after short-term PR are maintained for approximately 6 months but  
11 diminish in the following 6-12 months<sup>13</sup>. To maintain the health benefits acquired, subjects  
12 with COPD need to remain physically active. Follow-ups to monitor relatives' condition and  
13 motivate their physical activity were proposed by caregivers. However, post-rehabilitation  
14 strategies that include regular supervised sessions and repeated PR show modest effects on  
15 long-term outcomes<sup>13</sup>. It has been argued that family-oriented interventions are more likely to  
16 enhance adherence to treatment regimens and physical activity than interventions directed at  
17 subjects with COPD alone<sup>38, 39</sup>. Further investigation is needed to verify this hypothesis  
18 within the context of comprehensive PR.

19 Some limitations need to be acknowledged. First, although in the original study the sample  
20 size estimation has been adequate for F-COPES (the primary outcome measure)<sup>20</sup>, probably it  
21 was relatively small to detect more subtle differences between groups regarding DASS or  
22 CADI subscales. Furthermore, the significant differences between groups in their baseline  
23 socio-demographic characteristics in terms of age and marital status may also account to  
24 explain the results. Second, the facilitators of the psychoeducational sessions were also the  
25 evaluators of the study, thus, they were not blinded to group allocation. This may have added

1 some bias in the results obtained favoring the family-based group. However, all questions  
2 were standardized and researchers were previously trained to minimize the possibility of  
3 occurring bias. Studies with larger samples controlled for socio-demographics and with a  
4 double-blinded design should be conducted to clarify the extent of the findings. Third, the  
5 study failed to consider how the benefits differed according to the COPD grade (e.g., early  
6 grades *versus* advanced grades). Future research is needed to more clearly determine under  
7 what conditions a family-based PR is likely to be more effective. Fourth, the direct financial  
8 costs were not analyzed.

9 Nonetheless, the current study provides valuable evidence to recommend the inclusion of  
10 family caregivers in PR. Consistent with the McCubbin and McCubbin Family Stress  
11 Theory<sup>19</sup>, the overall results sustain that compared to a usual patient-centered PR, a family  
12 oriented intervention can maximize family caregivers' ability to understand and manage  
13 COPD-related stress, mobilize external and internal coping resources, reframing the meaning  
14 of their situation, and develop family open communication. The findings highlight the  
15 potential benefits of family-based PR to prevent burden and other negative psychological  
16 outcomes, however further research in this area is warranted.

17

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6

7

1 **Table 1** - Family caregivers' characteristics (n=39).

	<b>Total (n=39)</b>	<b>Experiment al group (n=20)</b>	<b>Control group (n=19)</b>	<b>p-value</b>
<b>Age (years)</b>	59.0±11.2	63.1±9.5	53.6±11.3	0.01*
<b>Gender (female)</b>	29 (74.4%)	16 (80.0%)	13 (68.4%)	0.46
<b>Educational level</b>				
No qualifications/Primary	16 (41.1%)	10 (50.0%)	6 (31.6%)	0.32
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%)	
<b>Marital status</b>				
Married/Living as a couple	32 (82.1%)	19 (95.0%)	13 (68.4%)	0.02*
Divorced/ Single	7 (17.9%)	1(5.0%)	6 (31.6%)	
<b>Relationship with the patient</b>				
Couple	28 (71.8%)	17 (85.0%)	11 (57.9%)	0.05
Son/Daughter	11 (28.2%)	3 (15.0%)	8 (42.1%)	
<b>Caregiving period (years)</b>				
1-2	10 (25.6%)	4 (20.0%)	6 (31.6%)	0.46
2-4	29 (74.4%)	16 (80.0%)	13 (68.4%)	

2 Results are presented as mean ± standard deviation or n(%). Significant values are presented  
3 with \*.

4

1 **Table 2** - Comparison of the scores of family coping, emotional state and caregiver burden  
 2 between the experimental and control groups (n=39).

	<b>Experimental group</b>		<b>Control group (n=19)</b>		<b>p-value<sup>a</sup></b>	<b>p-value<sup>b</sup></b>	<b><math>\eta^2_{partial}</math></b>
	<b>(n=20)</b>						
	<b>Pre-intervention</b>	<b>Post-intervention</b>	<b>Pre-intervention</b>	<b>Post-intervention</b>			
<b>F-COPES global score</b>	93.1±12.9	110.4±11.2	92.5±20.3	92.5±17.0	0.01*	0.01*	0.26
Acquiring social support	28.9±6.7	32.5±7.2	27.5±8.7	28.1±7.1	0.06	0.16	0.06
Reframing	29.4±4.6	33.2±4.0	31.5±4.7	30.5±5.2	0.06	0.01*	0.26
Seeking spiritual support	12.0±4.1	14.4±4.0	10.9±5.3	11.1±5.7	0.01*	0.01*	0.18
Mobilizing to acquire and accept help	10.9±3.1	14.1±3.7	11.9±2.1	12.6±3.3	0.01*	0.02*	0.17
Passive appraisal	12.7±2.2	10.8±3.1	11.3±4.3	9.9±3.7	0.01*	0.46	0.02
<b>DASS total, mean (SD)</b>	21.2±15.5	18.8±18.6	20.1±24.6	19.4±33.6	0.62	0.77	0.01
DASS Depression , mean (SD)	7.7±6.9	6.8±6.9	8.5±9.3	6.9±10.7	0.30	0.76	0.01
DASS Anxiety, mean (SD)	8.1±5.2	6.1±6.0	6.4±7.6	5.5±10.9	0.24	0.64	0.01
DASS Stress, mean (SD)	8.3±7.4	6.8±6.9	8.0±8.6	6.2±10.8	0.17	0.91	0.01
<b>CADI global score</b>	11.3±11.9	7.2±8.1	10.5±16.4	5.8±8.3	0.01*	0.83	0.01
Caregiver-dependent relationship	2.6±3.5	1.7±2.3	2.2±4.2	1.1±2.3	0.09	0.85	0.01

Reactions to caregiving	3.6±4.1	1.5±2.0	2.9±4.5	1.9±2.7	0.01*	0.29	0.03
Physical demands of caring	1.6±2.3	1.2±1.9	1.5±2.8	0.5±0.8	0.04*	0.40	0.02
Restricted social life	1.4±2.1	1.0±1.3	1.4±2.4	0.6±1.3	0.11	0.72	0.01
Poor family support	0.8±1.4	0.4±0.5	0.9±1.6	0.6±1.4	0.04*	0.80	0.01
Poor professional support	0.7±1.5	0.5±0.9	0.6±1.3	0.2±0.6	0.12	0.48	0.02
Financial consequences	0.9±1.5	0.7±1.0	1.0±1.4	0.8±1.3	0.26	0.90	0.01

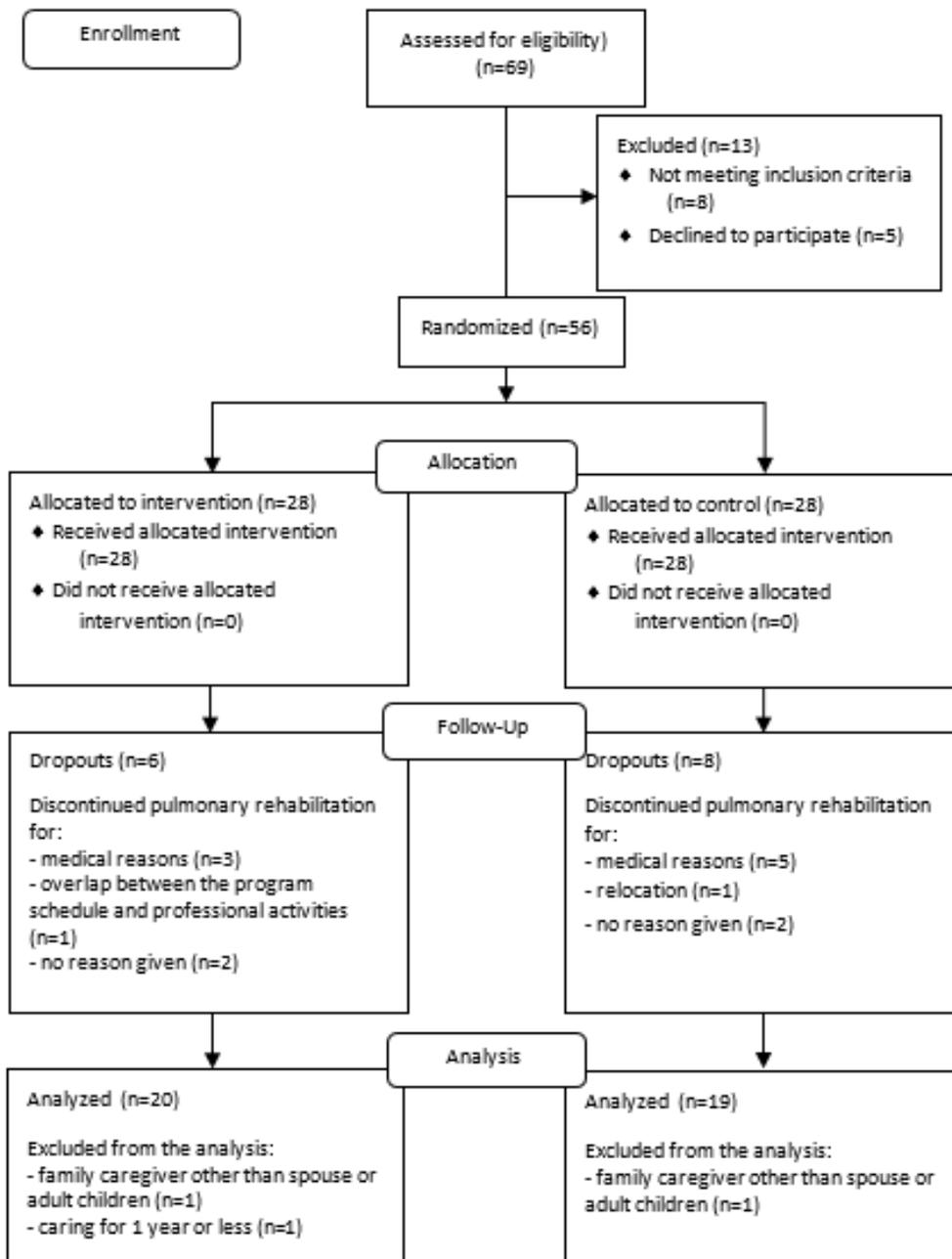
1 Results are presented as mean ± standard deviation. Significant values are presented with \*.

2 <sup>a</sup>Time; <sup>b</sup>Interaction Time\*Group. Abbreviations: CADI, Carers' Assessment of Difficulties

3 Index; DASS, Depression Anxiety and Stress Scales; F-COPES, Family Crisis Oriented

4 Personal Scales.

1 Figure legends:



2

3 Figure 1 - Flow diagram.

4

1        **Quick Look**

2        **Current Knowledge:**

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

6

7        **What This Paper Contributes To Our Knowledge:**

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

11