

**Title: Development of a family-based pulmonary rehabilitation programme: an exploratory study**

**Alda Marques**<sup>1,2</sup> Email: [amarques@ua.pt](mailto:amarques@ua.pt)

**Raquel Gabriel**<sup>1,2</sup> Email: [raquelgabriel@ua.pt](mailto:raquelgabriel@ua.pt)

**Cristina Jácome**<sup>1</sup> Email: [cristinajacome@ua.pt](mailto:cristinajacome@ua.pt)

**Joana Cruz**<sup>1,3</sup> Email: [joana.cruz@ua.pt](mailto:joana.cruz@ua.pt)

**Dina Brooks**<sup>4</sup> Email: [dina.brooks@utoronto.ca](mailto:dina.brooks@utoronto.ca)

**Daniela Figueiredo**<sup>1,2</sup> Email: [daniela.figueiredo@ua.pt](mailto:daniela.figueiredo@ua.pt)

<sup>1</sup> School of Health Sciences, University of Aveiro (ESSUA), Aveiro, Portugal

<sup>2</sup> Unidade de Investigação e Formação sobre Adultos e Idosos (UniFAI), Porto, Portugal

<sup>3</sup> Department of Health Sciences (SACS), University of Aveiro, Aveiro, Portugal

<sup>4</sup> Graduate Department of Rehabilitation Science, Department of Physical Therapy, University of Toronto, Toronto, Canada

**Corresponding author:**

Alda Marques, School of Health Sciences, University of Aveiro (ESSUA), Agras do Crasto  
- Campus Universitário de Santiago, Edifício 30, 3810-193 Aveiro, Portugal.

Telephone: 00351 234 372 462

Email: [amarques@ua.pt](mailto:amarques@ua.pt)

*Running head: family-based pulmonary rehabilitation programme*

**Keywords:** family, pulmonary rehabilitation, mixed-methods approach, delivery of health care

**Abstract**

**Purpose:** This study explored the expectations of patients with COPD and family members about a family-based pulmonary rehabilitation (PR) programme; developed and implemented a family-based PR programme and explored the impacts of the intervention on patients and family members.

**Method:** Patients with COPD and family members were interviewed. A family-based PR programme was designed. Patients' breathlessness, muscle strength, exercise tolerance, functional balance and health-related quality of life were collected pre/post-programme. Family coping and adjustment to illness were measured in patients and family members. Focus groups were conducted after the programme.

**Results:** Patients (n=35; 69±10 years; FEV<sub>1</sub> 62±15% predicted) and family members (n=35; 57±12 years) had similar expectations/needs about a PR programme. Nine dyads participated. Patients' quadriceps strength, exercise tolerance and functional balance improved significantly (all p values<0.023). Patients and family members seem to use more positive coping behaviours (p=0.026; p=0.011). Patients (n=7; 78%) and family members (n=8; 89%) considered having more knowledge about COPD and its management. Patients felt more functional (n=9; 100%) and reported their family members to be more active (n=3; 38%). In family members' perspective, their relationship with the care receiver was enhanced (n=2; 22%).

**Conclusions:** PR programmes, if inclusive of family members, may enhance the skills of the whole family to manage COPD.

### **Introduction**

Patients with chronic obstructive pulmonary disease (COPD) often need assistance from their significant others (family member) to cope with the impacts of the disease [1]. The need for informal care of patients with chronic lung disease has been estimated at \$1.8 to \$3.5 billion in invisible costs per year [2]. Family members, the most common carers, are therefore affected by patient's condition through role changes, impact on social activities, emotional stress and financial burden [3-5]. However, the impact of the disease on the family system is often neglected [6].

Pulmonary rehabilitation (PR) is an effective intervention for individuals with COPD which includes exercise training and psychosocial support and education to achieve the individual's maximum level of independence and function in the community [7]. The World Health Organization has recognised the importance of changing the focus of the interventions for patients with chronic diseases and has recommended family integration in rehabilitation programmes [8]. However, a focus on the family as a part of the patient's therapeutic plan of care is generally absent [9, 10]. Attending to patients and family members' needs, preferences and expectations has the potential to promote a more integrated and collaborative approach to care in COPD [11, 12], although little information exists on this topic. Furthermore, there are no studies describing and evaluating interventions designed to support family members of patients with COPD [13]. These interventions are essential to help family members to become more competent and confident, providing effective support to patients and, therefore, reducing the overall impact of COPD on both patients and family members' well-being.

Therefore, the aims of this study were three fold: 1) explore the expectations, needs and concerns of patients and family members about a family-based PR programme; 2) develop and implement a family-based PR programme; and 3) explore the impacts of the intervention on patients and family members.

## **Methods**

### **Study Design**

An exploratory study using a mixed methods approach was conducted with patients with COPD and their family members. The study received full approval from the Institutional Ethics Committee. In order to address the three aims, the study was carried out in three phases:

Phase 1: A qualitative design using individual interviews was conducted to assess the expectations and needs about a family-based PR programme.

Phase 2: A family-based PR programme was designed according to the findings from Phase 1 and a comprehensive literature review [6, 7, 13-19]. This programme was implemented in one primary care centre (the nearest from the research team) by a multidisciplinary team (a physiotherapist, a gerontologist, a physician, a nurse and a psychologist). Only ten dyads (10 patients and 10 family members) were invited to participate in this study phase, as in pilot studies participation of 10–15 participants per group has been described as a reasonable sample [20].

Phase 3: The impact of the family-based PR programme was assessed using a mixed-methods approach.

### **Participants**

The sample was recruited from two primary care centres. Dyads (patient/family member) were included if the patient was diagnosed with COPD according to the Global Initiative for Chronic Obstructive Lung Disease (GOLD) criteria [21] and if there was a family member identified by the patient, providing them care, assistance or support. Patients and family members were included if they: i) were  $\geq 18$  years old; ii) were able to understand the purpose of the study; and iii) voluntarily consented to participate. Dyads were excluded if: i) one of them presented severe psychiatric conditions and/or inability to understand and co-operate; or ii) one of them refused to participate. Potential participants were identified by the clinicians of the institutions involved in the study. The researchers contacted via telephone the potential eligible dyads, explained the purpose of the study and asked about their willingness to participate. When they agreed to participate, an appointment was scheduled at the primary care centres. Written informed consents were obtained prior to any data collection.

For Phase 2, additional exclusion criteria for patients were defined: exacerbations or hospital admissions one month prior to the family-based PR programme; and presence of severe neurologic/musculoskeletal conditions and/or unstable cardiovascular disease. Considering these criteria, 10 dyads were invited to participate in the family-based PR programme.

**Data collection**

**Phase 1.** Socio-demographic (gender, age, educational level and employment status) information was collected from patients and their family members. Clinical data, such as smoking habits, medication for the respiratory system and lung function

were also collected from patients. Patients reported their disability resulting from breathlessness using the Modified British Medical Research Council questionnaire (mMRC) questionnaire [22]. The mMRC questionnaire comprises five grades (range 0–4), with higher grades indicating greater perceived respiratory disability. This questionnaire is simple to administer and correlates significantly with measures of health status [22]. Additional questions about caregiving duration and the relationship with the patient were included.

Individual interviews were conducted using a semi-structured guide, with open-ended questions focused on expectations, needs and concerns about a family-based PR programme conducted in primary care. Two researchers were involved in conducting the interviews, one interviewed the patients and the other the family members. The individual interviews were performed in different physical spaces so patients and respective family members could talk openly. The interviews lasted on average 15 (6-28) minutes with the patients and 17(10-29) minutes with the family members and were digitally audio-recorded and transcribed for further analysis.

**Phase 3:** Data were collected before and after the family-based PR programme. Patients' disability resulting from breathlessness was assessed with the mMRC [22], quadriceps muscle strength with the 10 repetition maximum (10-RM) [23], exercise tolerance with the six-minute walk test [24], functional balance with the Timed Up-and-Go (TUG) test and health-related quality of life with the St. George's Respiratory Questionnaire (SGRQ) [25]. In this questionnaire, higher values indicate a poorer quality of life [25]. Both patients and family members filled in the Family Crisis Oriented Personal Scales (F-COPES) and the Psychosocial Adjustment to Illness Scale –

Self Report (PAIS-SR). These scales have been used to assess the impact of rehabilitation programmes [26-28]. The F-COPES identifies family coping patterns [29] and higher scores indicate more positive coping and problem-solving strategies. The PAIS-SR was used to assess psychosocial adjustment to illness [30, 31]. Higher scores indicate poorer adjustment.

After the programme, two focus group interviews were conducted, one with the patients and other with the family members. Interviews lasted around 65 minutes, were digitally audio-recorded and transcribed.

### **Data Analysis**

#### **Quantitative analysis**

Descriptive statistics were used to characterise the samples (phase 1 and phase 3). To analyse pre- and post- measures, paired *t*-tests and Wilcoxon signed-rank tests were performed using SPSS Statistics version 20.0 (IBM Corporation, Armonk, NY, USA). The level of significance was set at 0.05.

#### **Qualitative analysis**

Interviews were analysed using the procedures suggested by Ulin [32]. Five steps were followed: i) the transcripts of the interviews were read until researchers were intimately familiar with the content; ii) codes were attached to the words or parts of words of text that represented themes; iii) the information relevant to each theme was displayed; iv) the information was reduced to its essential concepts and relationships and v) the core meaning of the data was identified and explained. Focus groups were analysed using the same methodology [32] and according to pre-

established categories: i) impact of the intervention in individual and family lives and ii) opinion about the programme and suggestions for future interventions.

## Results

### Phase 1: Expectations and needs about a family-based PR programme

In total, 35 patients with COPD ( $69.4 \pm 10.2$  years old,  $FEV_1$   $62 \pm 15\%$  predicted) and respective family members ( $56.9 \pm 12.4$  years old) were interviewed. All patients used bronchodilators (inhaled beta2-agonists  $n=21$ , 60%; inhaled anticholinergics  $n=11$ , 31.4%; inhaled corticosteroids  $n=10$ , 28.6% and methylxanthines  $n=6$ , 17.1%) and only 6 were current smokers (17.1%). The majority of family members were spouses ( $n=22$ ; 63%) and were caring for more than 4 years ( $n=24$ ; 69%). Table 1 provides the socio-demographic characteristics of the sample.

*(insert table 1 about here)*

**Patients' perspectives.** Almost all patients ( $n=32$ ; 91%) were interested in participating with their family member in a PR programme, if it was available in their primary care centre. In general, patients hoped to improve their health condition ( $n=19$ ; 54%). Specifically, they expected to acquire better knowledge about their disease ( $n=8$ ; 23%); increase their exercise tolerance during walking and basic activities of daily living ( $n=4$ ; 11%); improve their emotional state ( $n=4$ ; 11%) and well-being ( $n=3$ ; 9%); reduce their symptoms ( $n=3$ ; 9%); improve the relationship with their family member ( $n=3$ ; 9%) and be more able to leave the house and be more mobile ( $n=3$ ; 9%). Patients also believed that a PR programme could improve their family members' well-being and knowledge about COPD ( $n=2$ ; 6%).

*"I just wanted to be able to walk a bit, 1 or 2km...it was already good if I could do it daily, with a normal breathing" [Paul]*

*"I expect to improve my well-being and of my family (...) if I am well, I will surely treat better my family members" [John]*

Patients' main concerns regarding their participation were related to transportation difficulties, due to: i) dependence on family members (n=5; 14%) and fear of burdening them (n=4; 11%); ii) walking difficulties (n=4; 11%); and iii) financial restrictions (n=2; 6%). Some patients also reported concerns about the programme schedule (n=2; 6%).

*"I have to ask my daughter to bring me, I will give her a lot of work and she already works a lot." [Margaret]*

*"I don't have my own transport and I don't have money to pay for a taxi" [Jacob]*

**Family members' perspectives.** All family members (n=35; 100%) were interested in participating in a PR programme if their care receiver agreed to participate. In all family members' opinion, COPD can cause emotional distress not only on the person who experiences the disease, but also on their family. Therefore, family members expressed the need for: i) information and skills to manage the disease (n=19; 54%); ii) opportunities to share experiences and coping strategies with other family members (n=4; 11%); and iii) emotional support to deal with the adversities of the experience of care (n=7; 20%).

*"I have no knowledge about the disease, but we learn throughout our lives until old age. In relation to the disease of my wife, I am interested in knowing and learning everything I can." [Brian]*

*"Sometimes a hug, a smile or a kiss, it helps a lot, it helps us to forget..." [Dawn]*

Family members also believed that the PR programme could provide to the patient: i) an appropriate treatment, which could lead to an improvement in their symptoms and consequently in their quality of life (n=10; 29%); ii) increased social engagement, contributing to their psychological well-being (n=6; 17%); iii) strategies to accept and deal with the disease (n=2; 6%); and iv) awareness to the impact of COPD in their family life (n=3; 9%).

*"He needs better knowledge to help him breathe and more health services support!"*

*[Charlotte]*

*"The support is everything. We need to talk about the disease and not make it a bad situation. Learning to have a positive thought!" [Sara]*

Several family members reported no concerns in participating in the PR programme (n=11; 31%). The ones that had some concerns, were related to: i) their availability to participate in the PR programme (n=9; 26%); ii) the lack of interest of the care receiver to participate (n=7; 20%); and iii) the potential negative impact of interactions with patients in more advanced grades of COPD (n=4; 11%).

*"I need to see the schedule of the programme. It depends on my job." [Peter]*

*"I'm afraid he doesn't want to participate because he is reserved! He might not know the other participants." [Judith]*

## **Phase 2: Development and implementation of the family-based PR programme**

Given the feedback and a comprehensive literature search, a 12-week family-based PR programme was developed consisting of two components: psychosocial

support and education for both patients and family members (once a week during 90 minutes) and exercise training for patients (3 times a week during 60 minutes).

The psychosocial support and education component (Table 2) aimed to empower the family with strategies to facilitate a functional and healthy adjustment to the disease. The educational module intended to: i) provide information about the disease; ii) increase the skills and sense of self-efficacy of the family to manage COPD; and iii) promote adherence to therapy and healthy lifestyles. The psychosocial support module aimed to: i) empower the family with strategies to prevent and cope with stress and anxiety; ii) facilitate communication within the family and with health and social services; and iii) develop a sense of family identity enhancing its cohesion.

*(insert table 2 about here)*

Each session of exercise training comprised 5 components: warm up, endurance training, resistance training, balance training and cool down (Table 3). The warm up and cool-down period included mainly range-of-motion, stretching, low-intensity aerobic and breathing exercises. The endurance and resistance training were designed according to international guidelines [7]. A specific component of balance training was also added since most patients were older than 60 years old and recent evidence showed that patients with COPD have impaired balance and are at high risk of falling [33, 34].

*(insert table 3 about here)*

### **Phase 3: Impact of the family-based PR programme**

One dyad dropped out due to patient's professional life. Therefore, 9 dyads completed the family-based PR programme. Patients were  $69.6 \pm 7.7$  years old (7 males; 77.8%), their FEV<sub>1</sub> was  $69 \pm 25\%$  of the predicted and none was currently smoking. According to the GOLD [21], 4 (45%) patients had mild, 2 (22%) moderate and 3 (33%) severe COPD. All patients used bronchodilators (inhaled beta2-agonists n=4, 44.4%; inhaled anticholinergics n=3, 33.3%; inhaled corticosteroids n=3, 33.3% and methylxanthines n=1, 11.1%) and maintained their medication during the study period. Family members were  $63.8 \pm 11.3$  years old (1 male; 11.1%) and 6 (67%) provided care for more than 4 years.

#### **Quantitative assessment**

After the family-based PR programme, significant improvements were noted in quadriceps muscle strength (pre  $3.4 \pm 1.9$  Kg post  $6.5 \pm 2.4$  Kg,  $p=0.002$ ), six-minute walking distance (pre  $393.7 \pm 46.3$  m post  $420.5 \pm 42.9$  m,  $p=0.023$ ) and TUG score (pre  $8.2 \pm 0.7$  s post  $6.7 \pm 1.2$  s,  $p=0.002$ ) in patients with COPD. There was no improvement in the mMRC (pre 2[1, 3] post 1[1, 2],  $p=0.129$ ) and SGRQ total score (pre  $42.1 \pm 22$  post  $39.4 \pm 19.6$ ,  $p=0.624$ ). Regarding family coping, both patients and family members used more positive coping behaviours after the programme (Patients - pre  $91.3 \pm 15.1$  post  $105.4 \pm 14.2$ ,  $p=0.026$ ; Family members - pre  $96.4 \pm 15.1$  post  $106.7 \pm 12.1$ ,  $p=0.011$ ). There was no significant improvement in psychosocial adjustment (Patients - pre  $31.9 \pm 19.5$  post  $27 \pm 12.4$ ,  $p=0.178$ ; Family members - pre  $29.9 \pm 13.9$  post  $25.8 \pm 12.1$ ,  $p=0.242$ ). A detailed description of these data can be found in Table 4.

*(insert table 4 about here)*

### Qualitative assessment

**Patients' perspectives.** Patients reported that the programme: i) helped them to be more functional (n=9; 100%) and manage their dyspnoea and fatigue in daily life (n=7; 78%); ii) enabled them to perform activities of daily living they no longer did or performed with difficulty, such as climbing stairs with/without carrying weights (n=2; 22%); iii) promoted a more healthy and active lifestyle (n=7; 78%), specifically the inclusion of a healthy diet and hydration (n=2; 22%), of exercise training such as walking, riding a bike or gardening (n=2; 22%) or of breathing control techniques (n=3; 33%); and iv) helped them to cope with the disease and live better, thus improving their comfort and well-being (n=2; 22%).

*"I do not feel so suffocated, so breathless. Because before I did, but it does not have happened lately..." [Tom]*

*"In the past, I sometimes felt tired and I had to stop in the middle. Now, I climb the stairs carrying weights and I can reach the top without feeling that effort I used to feel. So much has changed in my life." [David]*

*"Since I came here, it seems that it [the programme] sparked my interest to do some things at home [that I used to do] (...) It seems that one person feels better and more predisposed to do activities that he/she had stopped doing." [Margaret]*

Two patients, who were already exercising out of the programme, mentioned they would continue to do it regularly. However, others (n=3; 33%) admitted that including exercise in their schedule would be a difficult task because of the lack of supervision and that they would probably return to the baseline levels of physical activity.

Two patients highlighted that the inclusion of the family member had an impact on family life, specifically because it enabled their family member not to worry so much:

*“The main change is that my spouse does not worry so much and also lives happier (...) she thinks it [the programme] was worthwhile” [Keith]*

*“When I was hospitalised, I was anxious and she handled the situation (...) she calmed me down” [David]*

Overall, patients perceived the programme as being very helpful to manage their disease (n=8, 88.9%).

*“I learned to cope better with the disease and breathlessness. Though I feel the same shortness of breath (...), I know how to handle things better (...) I do not feel so suffocated, so breathless.” [Bill]*

They highlighted the importance of the professionals involved in the sessions to help them acquire the information and motivate them to improve their performance (n=3; 33%). Specifically about the exercise training component, all patients (n=9; 100%) reported that some exercises required a great effort and were performed with difficulty, such as the endurance training (n=6; 67%) and some resistance exercises (n=2; 22%).

*“In the bicycle, unless accompanied, I felt like giving up. But here I had the [professionals’] incentive ‘No, you must continue! You are doing very well!’ (Laugh) And then I made a bit more effort and went until the end [of the training]!” [Chris]*

All patients (n=9; 100%) expressed their wish for the programme to continue for longer or be replicated at regular intervals.

*"I learned things that will be really helpful in my lifetime, I think this is important and I feel sorry that will not continue so we can learn even more and live better." [Tom]*

*"People should be invited to attend again, it doesn't mean that it has to be so assiduously, but let's say once or twice a week... to remember the programme and for the person to continue [exercising]..." [Margaret]*

**Family members' perspectives.** With the participation in the programme, the majority of family members reported self-benefits (n=6; 67%) and also benefits to the care receivers (n=5; 56%). Regarding self-benefits, family members described that the programme: i) gave them competences to help the care receiver during exacerbation episodes (n=3; 33%) and to control their breathing in their daily life (n=2; 22%); ii) contributed to a better management of their relationship with the care receiver, specifically the session about emotions management (n=2; 22%); and iii) helped other family relatives, such as their children, to be more aware of the health condition of the care receiver (n=2; 22%).

*"He had a very strong crisis, and what really helped me was reminding him on how to breathe, the positions to reduce breathlessness." [Lindy]*

*"Our relationship has changed. Before this programme, we did not know how to deal with the disease". [Patrick]*

*"Even my children were involved in the programme, they asked for information to help us." [Karen]*

Family members believed that after the programme the individual with COPD: i) was able to better cope with the symptoms of the disease (n=3; 33%); ii) was more frequently in a good mood (n=2; 22%); and iii) changed nutritional habits, such as

reducing the quantity and improving the quality of food intake (n=3; 33%). Family members reported that they will apply the knowledge acquired during the programme (n=3; 33%).

*"They feel a good mood; I have noticed that they are better prepared. In the case of my husband, he feels happier" [Dawn]*

*"He [husband] learned to use the breathing technique when he feels tired." [Jessica]*

Most family members reported that the programme was very useful (n=7; 78%) and they perceived the session about breathing control techniques as the most important (n=6; 67%).

*"... I think it was the second session, when they [the professionals] started to explain how we should breathe." [Patrick]*

Family members also stressed the importance of its continuity to help themselves and their care receivers (n=2; 22%). They highlighted the innovative nature of the PR programme in primary care (n=2; 22%).

*"It was good and I feel sorry that the programme does not continue. My husband and I would be happy if it continued." [Lorraine]*

*"My friends were amazed because the programme was performed at the primary care centre. It's not common to conduct these programmes in primary care centres." [Claire]*

Family members mentioned the factors that motivated them to adhere to the programme: i) the attitudes of the professionals involved (n=4; 44%), specifically the empathy and receptivity shown on the first contact and through the sessions; ii) the recognition of their needs (n=3; 33%); and iii) the incentive given by their clinicians (n=3; 33%).

*"The receptivity of the professionals was very important, the phone calls that they made us." [Lorraine]*

*"The professionals worried a lot with our family! I received a call from them asking if I was better." [Claire]*

As suggestions, family members proposed to replicate the programme at regular intervals (n=3; 33%).

*"Everything I have learned here, they [the programme sessions] should be more regular! People who suffer from this disease should be closely monitored." [Lindy]*

*"This would help us, if we had this monitoring at least once a month." [Karen]*

### **Discussion**

To the best of our knowledge, this exploratory study is the first to develop and implement a family-based PR programme for COPD. We found that patients and family members had similar expectations and needs about a PR programme, with some minor differences in their perspectives. Both expected to learn more about COPD management, but also expected the programme to provide an opportunity for improving their emotional state, social relationships, quality of life and well-being. The need for information and disease management but also for emotional support is well documented in the literature among patients with COPD [16, 18, 35]. These needs have also been found among family members [35-38], given that they face challenges in providing physical and emotional support to their care receiver [18, 38]. However, patients' needs were focused around themselves, e.g. their restrictions in daily life, and family members were more focused on the needs of the patient, e.g. expected the

PR programme to help their care receiver to accept the disease and be more aware of its impact on all family. Difficulties of patients to adjust to lifestyle change and to the disease have been previously reported in the literature [39-41].

In the present study, disability resulting from breathlessness did not change. This was to be expected as the sample from this study had mainly mild to moderate COPD and, therefore, low levels of breathlessness were already present at baseline. Nevertheless, improvements on patients' muscle strength, exercise tolerance and functional balance were similar to other PR programmes [7, 42, 43]. These findings are in line with other research studies which found that PR is beneficial even for those with mild COPD [44, 45]. Additionally, its implementation at earlier grades of the disease is currently advocated by the PR international guidelines [7]. However, these PR programmes have been neglecting the role of the family [7]. The family-based PR programme developed was considered, by the family dyads participating in this exploratory study, to be beneficial for their day-to-day lives (e.g. lifestyle change). Patients believed to be more functional, active and less anxious and reported their family members to be more active, less worried and living happier. Family members adhered to the programme and reported similar perspectives and perceived benefits to the patient. The significant differences in family coping behaviours seem to strengthen these qualitative perspectives. Therefore, the family-based PR programme may address the important aspects of disease management: i) to help families as a unit to cope with and manage the challenges and stress imposed by the disease; ii) to mobilise the patient's support system to enhance family closeness, increase

interactions and build additional support, improving the health and well-being of patients and all family members [6, 14].

This exploratory study has some limitations. A small sample of patients (most of them male and with early COPD), who have family members caring for them and easy access to a primary care centre, was included. Therefore, the findings cannot be generalised to female patients, patients who are at more severe grades of the disease, living alone or in remote settings. Furthermore, a control group was absent which will be needed in future research to strengthen these results. Finally, the long-term effects of this programme will need to be assessed as well as the economic cost and other benefits of integrating the family member within PR programmes.

### **Conclusions**

Family-based PR programmes may be feasible to implement within the primary care context and seem to enhance the skills of the whole family to manage COPD. Patients with COPD and family members seem to have relatively similar expectations and needs regarding a PR programme and similar perspectives and perceived benefits from participating. However, these are preliminary results and a study conducted with a control group is deemed necessary to confirm these findings. As family members are key elements on helping patients manage the disease, their active participation seems crucial towards a more comprehensive model of healthcare.

### **Acknowledgements**

The authors would like to acknowledge all institutions (Unidade de Saúde Familiar Moliceiro and Unidade de Saúde Familiar Flor de Sal), patients and family members involved, for their participation in this research. We are also very grateful to Ana Luísa Barbosa and Ana Pereira for their contributions in the design and implementation of the intervention.

### **Declaration of Interest**

This work was supported by Portuguese National Funds through FCT - Foundation for Science and Technology [grant number RIPD/CIF/109502/2009]. The authors report no conflict of interest.

**References**

1. Kanervisto M, Paavilainen E, Astedt-kurki P. Impact of chronic obstructive pulmonary disease on family functioning. *Heart Lung*. 2003;32:360-7.
2. Langa KM, Fendrick AM, Flaherty KR, et al. Informal caregiving for chronic lung disease among older Americans. *Chest*. 2002;122:2197-203.
3. Figueiredo D, Gabriel R, Jácome C, et al. Caring for relatives with chronic obstructive pulmonary disease: How does the disease severity impact on family carers? *Aging Ment Health*. 2013.
4. Hynes G, Stokes A, McCarron M. Informal care-giving in advanced chronic obstructive pulmonary disease: lay knowledge and experience. *J Clin Nurs*. 2012;21:1068-77.
5. Spence A, Hasson F, Waldron M, et al. Active carers: living with chronic obstructive pulmonary disease. *Int J Palliat Nurs*. 2008;14:368-72.
6. Weihs K, Fisher L, Baird M. Families, health and behaviour *Fam Syst Health*. 2002;20:7-46.
7. Spruit MA, Singh SJ, Garvey C, et al. An Official American Thoracic Society/European Respiratory Society Statement: Key Concepts and Advances in Pulmonary Rehabilitation. *Am J Respir Crit Care Med*. 2013;188:e13-e64.
8. World Health Organization. *Active Ageing. A Policy Framework*. Madrid: World Health Organization. 2002.
9. Chodzko-Zajko WJ, Proctor DN, Fiatarone Singh MA, et al. Exercise and Physical Activity for Older Adults. *Med Sci Sports Exerc*. 2009;41:1510-30.
10. Buist AS, Bailey W, Hurd SS. National COPD conference summary. *COPD*. 2004;1:293-302.
11. Simpson AC, Rocker GM. Advanced chronic obstructive pulmonary disease: rethinking models of care. *QJMed*. 2008;101:697-704.

12. Kaptein AA, Scharloo M, Fischer MJ, et al. 50 years of psychological research on patients with COPD - Road to ruin or highway to heaven? *Respir Med.* 2009;103:3-11.
13. Caress A-L, Luker KA, Chalmers KI, et al. A review of the information and support needs of family carers of patients with chronic obstructive pulmonary disease. *J Clin Nurs.* 2009;18:479-91.
14. Fisher L, Weills KL. Can addressing family relationships improve outcomes in chronic disease? *Fam Pract.* 2000;49:561-6.
15. Boyle AH. An integrative review of the impact of COPD on families. *Southern online journal of nursing research.* 2009;9:1-6.
16. Bulley C, Donaghy M, Howden S, et al. A prospective qualitative exploration of views about attending pulmonary rehabilitation. *Physiother Res Int.* 2009;14:181-92.
17. Caress A, Luker K, Chalmers K. Promoting the health of people with chronic obstructive pulmonary disease: patients' and carers' views. *J Clin Nurs.* 2010;19:564-73.
18. Gardiner C, Gott M, Payne S, et al. Exploring the care needs of patients with advanced COPD: An overview of the literature. *Respir Med.* 2010;104:159-65.
19. Chiquellho R, Neves S, Mendes A, et al. ProFamilies: a psycho-educational multi-family group intervention for cancer patients and their families. *Eur J Cancer Care (Engl).* 2011;20:337-44.
20. Hertzog MA. Considerations in determining sample size for pilot studies. *Res Nurs Health.* 2008;31:180-91.
21. Vestbo J, Hurd SS, Agustí AG, et al. Global Strategy for the Diagnosis, Management, and Prevention of Chronic Obstructive Pulmonary Disease. *Am J Respir Crit Care Med.* 2013;187:347-65.

22. Bestall JC, Paul EA, Garrod R, et al. Usefulness of the Medical Research Council (MRC) dyspnoea scale as a measure of disability in patients with chronic obstructive pulmonary disease. *Thorax*. 1999;54:581-6.
23. American College of Sports Medicine. ACSM's resource manual for guidelines for exercise testing and prescription 8th ed. Philadelphia: Lippincott Williams & Wilkins; 2009.
24. American Thoracic Society. ATS Statement: Guidelines for the Six-Minute Walk Test. *Am J Respir Crit Care Med*. 2002;166:111-7.
25. Jones PW. St. George's Respiratory Questionnaire: MCID. *COPD*. 2005;2:75-9.
26. Bailey A, Starr L, Alderson M, et al. A comparative evaluation of a fibromyalgia rehabilitation program. *Arthritis Care Res*. 1999;12:336-40.
27. Dracup K, Moser DK, Marsden C, et al. Effects of a multidimensional cardiopulmonary rehabilitation program on psychosocial function. *Am J Cardiol*. 1991;68:31-4.
28. Trappenburg JC, Troosters T, Spruit MA, et al. Psychosocial conditions do not affect short-term outcome of multidisciplinary rehabilitation in chronic obstructive pulmonary disease. *Arch Phys Med Rehabil*. 2005;86:1788-92.
29. McCubbin HI, Larsen A, Olson DH. Family crisis oriented personal evaluation scales. In: Olson DH, McCubbin HI, Barnes H, Larson A, Muxen M, Wilson M, editors. *Family Inventories: Inventories Used in a National Survey of Families Across the Family Life Cycle*. Minneapolis: University of Minnesota; 1982.
30. Derogatis LR. The Psychosocial Adjustment To Illness Scale (PAIS). *J Psychosom Res*. 1986;30:77-91.
31. Instituto Superior de Psicologia Aplicada. *Escala de Ajustamento Psicossocial à doença*. Lisboa: Instituto Superior de Psicologia Aplicada, 1993.

32. Ulin PR. Qualitative methods in public health: a field guide for applied research 1st ed: Jossey-Bass; 2005.
33. Beauchamp M, Hill K, Goldstein R, et al. Impairments in balance discriminate fallers from non-fallers in COPD. *Respir Med*. 2009;103:1885-91.
34. Jácome C, Cruz J, Gabriel R, et al. Functional Balance in Older Adults With COPD. *J Aging Phys Act*. 2013.
35. Jones I, Kirby A, Ormiston P, et al. The needs of patients dying of chronic obstructive pulmonary disease in the community. *Fam Pract*. 2004;21:310-3.
36. Woolfe P, McMillian M, Conway J. The needs of caregivers of people with COPD: a study. *Aust J Prim Health*. 2007;13:28-35.
37. Currow DC, Ward A, Clark K, et al. Caregivers for people with end-stage lung disease: characteristics and unmet needs in the whole population. *Int J Chron Obstruct Pulmon Dis*. 2008;3:753-62.
38. Simpson AC, Young J, Donahue M, et al. A day at a time: caregiving on the edge in advanced COPD. *Int J Chron Obstruct Pulmon Dis*. 2010;3:141-51.
39. Leidy NK, Traver GA. Adjustment and social behavior in older adults with chronic obstructive pulmonary disease: the family's perspective. *J Adv Nurs*. 1996;23:252-9.
40. McCathie HCF, Spence SH, Tate RL. Adjustment to chronic obstructive pulmonary disease: the importance of psychological factors. *Eur Respir J*. 2002;19:47-53.
41. Boot CRL, van der Gulden JWJ, Vercoulen JHMM, et al. Knowledge about asthma and COPD: associations with sick leave, health complaints, functional limitations, adaptation, and perceived control. *Patient Educ Couns*. 2005;59:103-9.
42. Beauchamp M, O'Hoski S, Goldstein R, et al. Effect of pulmonary rehabilitation on balance in persons with chronic obstructive pulmonary disease. *Arch Phys Med Rehabil*. 2010;91:1460-5.

43. Ries A, Bauldoff G, Carlin B, et al. Pulmonary Rehabilitation: Joint ACCP/AACVPR Evidence-Based Clinical Practice Guidelines. *Chest*. 2007;131:4S-42S.
44. van Wetering CR, Hoogendoorn M, Mol SJ, et al. Short- and long-term efficacy of a community-based COPD management programme in less advanced COPD: a randomised controlled trial. *Thorax*. 2010;65:7-13.
45. Jacome C, Marques A. Impact of Pulmonary Rehabilitation in Patients With Mild COPD. *Respir Care*. 2014.
46. Sousa L, Mendes A, Relvas A. *Enfrentar a velhice e a doença crónica*: Lisboa: Climepsi; 2007.
47. Jenkins S, Hill K, Cecins NM. State of the art: How to set up a pulmonary rehabilitation program. *Respirology*. 2010;15:1157-73.
48. Rose DJ. *Fall Proof: A comprehensive balance and mobility training program*. 2nd ed: Champaign USA: Human Kinetics; 2010.

Table 1 - Socio-demographic characteristics of the sample in phase 1 of the study.

Characteristics	Patients (n=35)	Family members (n=35)
Age	69.4±10.2	56.9±12.4
Female	11(31.4%)	31(88.6%)
Marital status		
Single	2(5.7%)	3(8.6%)
Married	26(74.3%)	31(88.6%)
Divorced	2(5.7%)	1(2.9%)
Widowed	5(14.3%)	-
Educational level		
No qualifications	-	3(8.6%)
Primary school	26(74.3%)	30(85.7%)
Secondary school	9(25.7%)	2(5.7%)
Current occupation		
Employed	1(2.9%)	16(45.7%)
Unemployed	4(11.4%)	5(14.3%)
Retired	30(85.7%)	14(40%)
mMRC, M[IQR]	1[1, 2]	-
FEV <sub>1</sub> % predicted	62.2±15.2	-

Values shown as mean±SD or n(%), unless otherwise indicated. M, median; IQR, interquartile range.

Table 2 – Themes of the psychosocial support and education component of the family-based PR programme.

Sessions	Themes
1	Information about COPD Impact of COPD on family life
2	Respiratory symptoms management Energy conservation techniques
3	Family identity
4	Medication and oxygen therapy in COPD
5	Management of stress and anxiety
6	Healthy lifestyles - Physical activity and exercise
7	Healthy lifestyles - Nutrition and sleep
8	Resources available in the community Emotions management
9	Fall prevention Communication of feelings, needs and concerns
10	Develop a COPD action plan
11	Problem solving techniques Unpredictability and future fears
12	Ritualisation <sup>a</sup>

<sup>a</sup>The ritualisation is the final session symbolising the end of the programme. It aims to remember participants of their participation as a positive experience and stimulate the maintenance of contacts between participants beyond the programme [46].

Table 3 - Description of an exercise training session.

<b>Exercise component</b>	<b>Description</b>
Warm up and Cool down	5 to 10 minutes  Range-of-motion exercises  Breathing exercises (pursed lips breathing, body positions, diaphragmatic breathing, airway clearance techniques);  Stretching exercises (static and with PNF techniques)  Low-intensity aerobic exercises  Relaxation therapy
Endurance training	20 minutes  Walking  60-80% of the 6MWT [47]
Resistance training	15 minutes  Elastic bands and free weights  7 exercises/session, using the major muscle groups of upper and lower limbs  2 sets of 10 repetitions  50-85% 1RM
Balance training	5 minutes  Upright positions and exercises  4 progressive levels of difficulty (adapted from Rose) [48]

Abbreviations: PNF - proprioceptive neuromuscular facilitation; 6MWT - 6-minute walk test;

1RM – 1 repetition maximum.

Table 4 – Impact of the family-based PR programme on patients and family members.

Variable	Patients (n=9)			Family members (n=9)		
	Pre	Post	p-value	Pre	Post	p-value
mMRC	2[1, 3]	1[1, 2]	0.129	-	-	-
10-RM quadriceps strength (kg)	3.4±1.9	6.5±2.4	0.002	-	-	-
6MWD (m)	393.7±46.3	420.5±42.9	0.023	-	-	-
TUG (s)	8.2±1.7	6.7±1.2	0.002	-	-	-
SGRQ total score	42.1±22	39.4±19.6	0.624	-	-	-
F-COPES - Acquiring social support	24.4±8	32.4±6	0.018*	30±6.5	31.8±6.4	0.137
F-COPES - Reframing	32.1±3.1	31.4±5.6	0.741	28.8±6.3	32.2±5	0.136
F-COPES - Seeking spiritual support	13.7±4	14.2±4.2	0.647	13.2±4.7	15.3±4.1	0.118
F-COPES - Mobilizing to acquire and accept help	9.6±4.3	13.8±3.4	0.027*	11.9±3.5	13±3	0.384
F-COPES - Passive appraisal	11.6±2.2	13.6±1.4	0.043*	12.6±3.6	14.3±3.2	0.043*
F-COPES - Total score	91.3±15.1	105.4±14.2	0.026*	96.4±15.1	106.7±12.1	0.011*
PAIS-SR - Health care orientation	7.6±4	6.3±4	0.320	7.8±3.1	6.7±3	0.366
PAIS-SR - Domestic environment	5.9±5.8	4.7±3.3	0.401	3.8±3.4	4.2±4.2	0.569
PAIS-SR - Sexual relationships	5±5.6	4.2±4.4	0.228	6.4±4.5	4.7±4.2	0.013*
PAIS-SR - Extended family relationships	2±3.5	1±1.1	0.353	1±0.8	1.1±1.1	0.813
PAIS-SR - Social environment	6.3±3.6	5.7±4.2	0.518	3.6±3.2	4.3±3.5	0.560
PAIS-SR - Psychological distress	5.1±2.8	5±2.4	0.799	6.4±3.2	4.6±2.5	0.012*
PAIS-SR - Total score	31.9±19.5	27±12.4	0.178	29.9±13.9	25.8±12.1	0.242

p<0.05. Values shown as mean±SD or Median[interquartile range]. Abbreviations: mMRC,

Modified British Medical Research Council; 10-RM, 10 repetition maximum; 6MWD, six-minute walking distance; TUG, Timed Up-and-Go; SGRQ, St. George's Respiratory Questionnaire; F-COPES, Family Crisis Oriented Personal Scales; PAIS-SR, Psychosocial Adjustment To Illness Scale – Self Report.