CHEST

Family-Based Psychosocial Support and Education as Part of Pulmonary Rehabilitation in COPD

A Randomized Controlled Trial

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BACKGROUND: Involving family as part of the patient's rehabilitation plan of care might enhance the management of COPD. The primary aim of this study was to investigate the impact of a family-based pulmonary rehabilitation (PR) program on patients and family members' coping strategies to manage COPD.

METHODS: Family dyads (patient and family member) were randomly assigned to family-based (experimental) or conventional (control) PR. Patients from both groups underwent exercise training three times a week and psychosocial support and education once a week, during 12 weeks. Family members of the family-based PR attended the psychosocial support and education sessions together with patients. In the conventional PR, family members did not participate. Family coping and psychosocial adjustment to illness were assessed in patients and family members of both groups. Patients' exercise tolerance, functional balance, muscle strength, and health-related quality of life were also measured. All measures were collected pre/post-program.

RESULTS: Forty-two dyads participated (patients: FEV_1, 70.4% ± 22.1% predicted). Patients ($P = .048$) and family members ($P = .004$) in the family-based PR had significantly greater improvements in family coping than the control group. Family members of the family-based PR had significantly greater changes in sexual relationships ($P = .026$) and in psychologic distress ($P = .033$) compared with the control group. Patients from both groups experienced significant improvements in exercise tolerance, functional balance, knee extensors strength, and health-related quality of life after intervention ($P < .001$).

CONCLUSIONS: This research supports family-based PR programs to enhance coping and psychosocial adjustment to illness of the family system.

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ABBREVIATIONS: 10-RM = 10-repetition maximum; αf = αfamily member; αp = αpatient; CONSORT = Consolidated Standards of Reporting Trials; F-COPES = Family Crisis Oriented Personal Scales; PAIS-SR = Psychosocial Adjustment to Illness Scale-Self Report; PR = pulmonary rehabilitation; SGRQ = St. George's Respiratory Questionnaire

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Pulmonary rehabilitation (PR) has been demonstrated to be effective for patients with COPD during stable periods or shortly after an exacerbation.[1] This intervention has been also acknowledged as an important component of integrated care to manage COPD.[1] However, successful integrated care interventions demand the involvement of both patients and family members in care planning, implementation, and oversight.[2-4]

The impact and challenges of living with a patient with COPD at all grades are well described,[5-9] including physical and emotional burden and distressing symptoms (eg, anxiety and depression).[5,10,11] Moreover, in some research, families have expressed the need for more information about disease management and for emotional support (eg, how to handle breathlessness, exacerbations, and anxiety symptoms).[8,10-12] Attending to patients' and family members' needs, preferences, and expectations might have potential to promote a more integrated and collaborative approach to care in COPD.[13,14]

Family interventions have been shown to improve family coping in chronic diseases such as diabetes,[15] cardiovascular disease,[16] and breast cancer,[17] but their impact has received limited investigation in COPD. Furthermore, the use of more positive coping and problem-solving strategies has been associated with better health outcomes, namely less depression and anxiety[18-20] and improved exercise tolerance[20] and quality of life[19] in patients and better self-rated physical and mental health in family members[5] living with COPD. However, only one study was identified that tested benefits of including family members in a multidisciplinary PR program.[21]

Therefore, the primary aim of this study was to investigate the impact of a family-based PR program on patients and family members' coping strategies to manage COPD. It was hypothesized that participation in a family-based PR program would improve coping strategies of the family system without interfering with patients' benefit obtained from a conventional PR program. The secondary aims were to explore its impact on family psychosocial adjustment to illness and patients' exercise tolerance and health-related quality of life.

Materials and Methods

Study Design

This was a single-blinded, randomized controlled trial. Family dyads (ie, patient with COPD and family member) were randomly assigned to family-based PR (experimental) or conventional PR (control) and were unaware of group allocation. Participants were only told that they were entering a PR program that involved the family and that, depending on group allocation, the involvement of the family member would differ.

The outcome measures were collected from patients and family members 3 days before and after the PR program. The family-based PR was conducted at a different time than the conventional PR. Randomization was performed by a computer-generated schedule in random blocks of three. 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. Approval for this study was obtained from the Center Health Regional Administration (2011-02-28) and national data protection committee (8940/2012). Written informed consent was obtained from each participant. This study was reported according to CONSORT (Consolidated Standards of Reporting Trials) recommendations.[22]

Participants

Consecutive patients with stable COPD were recruited from three primary care centers. Patients were considered eligible for the study if they (1) were diagnosed with COPD according to the GOLD (Global Initiative for Chronic Obstructive Lung Disease) criteria; (2) had a family member $\geq$ 18 years old who provided physical and/or supportive care, without receiving any payment; and (3) were able to provide informed consent to participate in the study. Patients were excluded if they had exacerbations or hospital admissions 1 month prior to the study, severe neurologic/musculoskeletal conditions, and/or unstable cardiovascular disease. Dyads were excluded if one of them presented severe psychiatric conditions or inability to understand and cooperate or if one of them refused to participate.

Intervention

In both groups, patients underwent 12 weeks of PR composed of exercise training and psychosocial support and education, conducted in primary care centers. Family members assigned to the family-based PR participated in the psychosocial support and education component together with patients. Family members randomized to conventional PR did not attend the sessions with patients, with the exception of sessions used to obtain baseline and post-intervention assessment data.

Exercise Training: Training frequency was three sessions per week. Sessions lasted 60 min and were delivered by the same physiotherapists in both groups, ensuring a consistent and uniform training among all patients. This component is described elsewhere.[23]

Psychosocial Support and Education: Sessions were designed based on a comprehensive literature review on COPD rehabilitation,[24-26] needs of families living with COPD,[7,27,28] and interventions for families living with other chronic diseases.[29,30] Education aimed to provide information about COPD, increase the skills of the family to adjust to and manage the disease, and promote adherence to therapy and healthy lifestyles. Psychosocial support intended to help the family to manage the emotional demands of living with COPD, facilitate the communication within the family and with health/social services, and develop a sense of family identity, enhancing its cohesion.

Weekly sessions, lasting approximately 90 min, were conducted by a multidisciplinary team (physiotherapist, gerontologist, psychologist, nurse, and clinician). These professionals assumed the role of facilitators by supporting participants in their doubts, encouraging them to share experiences, normalizing emotions, and assuming an empathic attitude. Several didactic methods were used during the sessions, such as group discussions, home tasks, role playing, and brainstorming.