


Home-Based Educational Programs for Management of Dyspnea: A Systematic Literature Review

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Abstract

Dyspnea or breathlessness is a symptom of a plethora of diseases; despite that its management poses a challenge, it leads to frequent hospitalizations and a poor quality of life. In lung cancer, dyspnea may appear at any time of the disease but mainly during the end-of-life period. This article aims to explore the effectiveness of home-based educational programs for the management of dyspnea. This is a systematic review. The inclusion criteria were studies published between 2000 and 2018, and structured nurse-led home educational programs for the management of dyspnea due to cancer. The search via PUBMED, COCHRANE, EBSCO, and Google Scholar was worldwide for English- and Greek-language articles. The keywords included “education, program, intervention, patient, dyspnea, breathlessness, cancer, home, nurse.” The review was expanded to dyspnea being due to any chronic disease as it gave only one research article for lung cancer. The review identified seven research articles evaluating the effectiveness of various home-based educational programs for dyspnea management due to chronic obstructive pulmonary disease, heart failure, and lung cancer. They showed that a structured home-based educational program is of benefit for the patients by improving their dyspnea levels and their quality of life. There is the need to evaluate the benefits of home-based educational programs for cancer patients with dyspnea at home either as part of a symptom alone support program or as part of the general support given to cancer patients at home.

Keywords

education, program, patient, dyspnea, home, nurse

Introduction

Dyspnea is a common symptom for patients with cancer^{1,2} and is the commonest symptom of patients suffering from lung cancer³ and among patients in need of palliative care or with advanced cancer.^{4,5} As classified by the American Thoracic Society in 1999⁶ dyspnea is a subjective experience which entails difficulty in breathing that consists of qualitative distinctive sensations that differ in intensity. Dyspnea is caused by multiple physiological, psychological, environmental, and social factors.⁵⁻⁷

Dyspnea might be experienced by patients with various cancers either due to the disease itself or due to comorbidity like chronic obstructive pulmonary disease (COPD) and heart failure. As the disease progresses, dyspnea exacerbates and eventually becomes resistant to any intervention; this also signifies a negative prognostic factor.^{8,9} It is a symptom that is difficult to comprehend and not sufficiently managed for patients with cancer who are approaching the end of their life. It should be noted that dyspnea almost doubles in the last 6 months of someone’s life.¹⁰ Its frequent assessment is crucial in order for therapy to be accustomed and for the identification and management of anxiety of the patient

and family.¹⁰ The main reason for the inadequate management might be the secondary physiological and behavioral responses that can be caused by dyspnea.^{6,7}

Lung cancer remains the most complicated in relation to morbidity and mortality, and the families of patients feel isolated and remain invisible to health care professionals.¹¹⁻¹³ Dudgeon et al¹⁴ indicated that 46% of patients with cancer reported dyspnea, and 9.4% of those had lung cancer or lung metastasis. In a study by Corner et al¹⁵ following treatment, more than 90% of lung cancer patients reported that dyspnea posed a crucial problem for them. At the hospital level, the feeling of being safe and that someone would always be there when needed appeared to reduce the consequences of the disease on patients and their family. Moreover, within the hospital environment, complete care can be offered for dyspnea management compared with what family caregivers

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can offer at home mainly due to lack of knowledge.¹⁶ According to Malik et al,¹⁷ frequently problems emerge because care is left on the hands of people with none or limited education or experience concerning the issue. As mentioned by Bee et al,¹⁸ poor management at home creates complications in patients' care, affecting their quality of life (QOL) and increasing admissions to hospital. Moreover, it burdens family caregivers, and this is even worse during the end of life as the disease progresses.

For the management of dyspnea due to cancer, various successful educational and supportive programs from multidisciplinary teams exist at hospital level. The programs run in the outpatient services of the hospitals. Patients are referred by their physicians or nurses or they attend on their own through informational leaflets. The interventions used are pharmacological, nonpharmacological, or a combination of both, giving guidance to patients and family caregivers. The programs are organized by multidisciplinary teams but are mainly run by specialist nurses with the support of a physician and other health care professionals such as physiotherapists.¹⁹⁻²³

The aim of the article is to identify whether there are any home-based educational programs for the support of patients with dyspnea due to lung cancer run by nurses, as well as their effectiveness in managing patients' dyspnea outside the hospital environment.

Method

The systematic literature review was conducted from January 2016 until September 2018 and searched for articles from 2000 onward using the search engines PUBMED, COCHRANE, EBSCO, and Google Scholar. Initially, this search focused on the implementation of an educational program at home for people with dyspnea due to lung cancer using the following key words: "education, program, teaching, intervention, patient, patient information, dyspnea, breathlessness, lung cancer, cancer, home care, community nursing" and combination of these. However, a primary search produced no results; thus, it was broadened to include studies conducted with patients who experienced dyspnea due to chronic diseases. From the latter search, 162 articles were located.

The inclusion criteria were (1) implementation of a home-based educational program by nurses, (2) participants to be patients with dyspnea, (3) the educational program should include nonpharmacological interventions for dyspnea, and (4) research article in English or Greek language.

The exclusion criteria were (1) reviews, (2) studies that included one intervention for managing dyspnea and not an educational program, (3) educational program taking place at a hospital or any other health facility, and (4) educational program applied by another health care professional.

This resulted in seven research articles from studies conducted worldwide published from 2000 to 2018. Only one article referred to dyspnoea due to lung cancer (Figure 1).²⁴

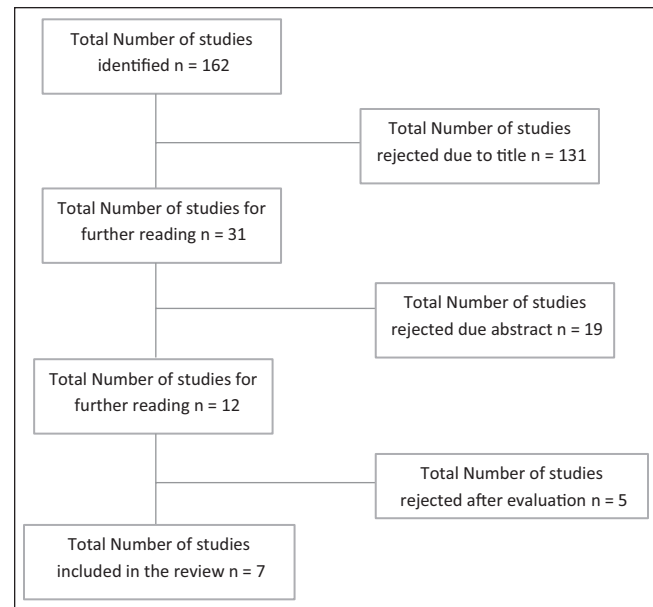


Figure 1. Systematic review flow chart.

Findings

The review included seven research studies which were all experimental studies published from 2000 till 2018 (Table 1). The studies had a different approach to managing dyspnea as part of their educational program offered mainly to patients in the intervention groups. There were differences in the various methods used to manage dyspnea, as pulmonary rehabilitation (PR), which included either breathing retraining (diaphragmatic breathing, inspiratory and/or expiratory muscle training, pursed-lip breathing, respiratory muscle stretching calisthenics) or breathing exercises or exercise training (stretching, walking, stairs climbing, upper and lower aerobic).^{24,25,28-30} The educational guide (leaflet) provided or education given (lectures, discussions) was either individualized or general with information about disease, dyspnea, management of disease and dyspnea, medication use, methods for protection against complications and early recognition to require care, energy conservation techniques, and so on. The educational program might also include normal care, management of daily living activities and energy conservation, or psychosocial care (relaxation, telephone calls).²⁴⁻³⁰

All but one study²⁴ included an intervention and a control group. COPD patients with dyspnea were the focus of five studies which attempted to assess the effectiveness of the home-based nursing program.^{25-27,29} In the study by Olivier et al,²⁴ the participants were patients with lung cancer or pleural malignant mesothelioma with dyspnea, and in the study by Padula et al,³⁰ the participants were patients with heart failure with dyspnea. In one research study, the two groups were different, with the intervention group consisting of patients with restrictive lung disease and the control group consisting of COPD patients with dyspnea.²⁸

Table 1. Characteristics of Included Studies.

Citation	Participants	Methodology	Educational program	Assessment	Results
Olivier et al ²⁴ (France)	71 lung cancer or malignant pleural mesothelioma patients receiving chemotherapy or radiotherapy	47 completed the PR 8-week program with weekly retraining for 90 min Assessment at baseline and after 8 weeks	Retraining: exercise training, resumption of daily living physical activities, therapeutic education, psychological counseling, motivational communication and nutritional advice Daily exercise 5 days per week with personalized action plan lasting 30-45 min (endurance training, muscle strengthening exercises, activity of daily living, walking and learning to climb stairs)	Exercise capacity: six-minute walk test (6MWT) and six-minute stepper test (6MST). Lower limb muscle strength Timed Up and Go test (TUG) and a test of 10 chair stands (10CS) Dyspnea with modified Medical Research Council (mMRC) scale QoL and psychological State: Visual Simplified Respiratory Questionnaire (VSRQ) and Hospital Anxiety and Depression scale (HADS)	Significant attrition (56.6% retention) No change in 6MWT but increase in the 6MST number of steps especially for MPM Patients. No significant decrease in dyspnea or lower limb tiredness after 6MWT. Less time needed to achieve 10CS but not TUG. Dyspnea score was steady during follow-up. QoL improvement not significant but significant increase in global VSRQ in MPM patients. Significant decrease in the HADS anxiety score without decrease in the HADS depression score. No potential adverse events related to PR activities were reported
Bal Özkaptan and Kapucu ²⁵ (Turkey)	106 chronic obstructive pulmonary disease (COPD) patients from certain geographical region	53 intervention group: 4 visits in 3 months (2-1-1 per month) 53 control group: 2 visits (beginning and end)	Intervention: educational guide (first visit) and care, education and guidance according to individualized plan Control: educational guide given at last visit	Symptom evaluation form developed by researchers, MRC dyspnea scale, COPD Self-Efficacy Scale	Significant difference in MRC dyspnea scale, dyspnea level higher in the control group at last visit. Dyspnea level significantly lower in the intervention group than at the first visit. Wheezing and activity intolerance decreased in the intervention group but same for the control group. Self-efficacy also improved. Negative effect score, weather/environment effect score, and behavioral risk factors scores significantly higher in the control group. Emotional state and physical exertion scores higher in the intervention group
Eui-Geum ²⁶ (Korea)	34 COPD patients	15 intervention group (8-week home-based pulmonary rehabilitation program) 8 control group (educational advice at initial interview)	Intervention: education, inspiratory muscle training (Pflex), exercise training (stretching, walking, stairs climbing), psychosocial components (relaxation twice daily, telephone calls twice a week) Control: Educational advice on effective breathing methods	Lung function test with spirometry, dyspnea on exertion with Modified Borg Scale (mBorg), exercise tolerance, Health-Related Quality of Life (HRQOL) with the Chronic Respiratory Disease Questionnaire (CRDQ) (dyspnea, fatigue, emotion, mastery)	No difference among two groups on lung function test. Improvement of dyspnea in both groups (related to educational advice given to the control group). Exertional dyspnea and exercise tolerance improved in the intervention group. In HRQOL assessment, there was an increase in all dimensions assessed and not only for dyspnea
Hermiz et al ²⁷ (Australia)	177 COPD patients	84 intervention group (home visit 1st and 4th week) 93 control group. For 3 months	Verbal and written education, advice on stopping smoking, management of daily living activities and energy conservation, exercise, understanding and use of drugs, health management, early recognition of signs that require medical attention	St George's Respiratory Disease Questionnaire (SGRQ), frequency of hospital visits or readmissions and nurse and GP visits. Knowledge of illness, self-management, and satisfaction of care	No difference among the groups in admissions, visits, or functional status. Intervention: activity improvement, higher knowledge, more satisfaction Control: symptoms worsened. No difference in GP visits, self-management, or hospitalization
Kagaya et al ²⁸ (Japan)	66 restrictive lung disease patients and COPD patients	26 intervention group (PR and 45-min educational program) 40 matched COPD patients as control group. For 6 months	Pulmonary rehabilitation and educational program (disease, control of dyspnea, medication, equipment, nutrition, stress management, relaxation, exercises, benefits of PR)	FVC and FEV measures, P _{1max} and P _{Emax} , Borg scale, HRQOL with CRDQ and SF-36 (Short Form 36)	MRC scores lower in both groups but no significant difference in improvement was shown in repeated ANOVA measures. P _{1max} , P _{Emax} , 6MWD, dyspnea, emotional functions of the CRDQ, and social functioning and role-emotional subscales of the SF-36 were increased in the lung disease group. In comparison, FCV, P _{1max} , P _{Emax} , 6MWD, Borg score, dyspnea, fatigue, emotional functions and mastery subscales of the CRDQ, and role-emotional subscales of the SF-36 were increased in the COPD group

(continued)

Table 1. (continued)

Citation	Participants	Methodology	Educational program	Assessment	Results
Akinci and Olgun ²⁹ (Turkey)	32 COPD patients	16 intervention group (patient education and exercise program on 1st visit. Assessment 2nd and 3rd visit) 16 control group. For 3 months	2-3 times education (2-3 hr) personalized booklet (disease, drugs, and instructions, breathing control, relaxation techniques, airway clearance techniques, modifications on daily living activities, energy conservation techniques, exercises and methods for smoking cessation). Exercises: Upper and lower aerobic and breathing (diaphragmatic breathing and pursed lip) Walking and breathing exercises daily for 30 min each. Control group standard care	FEV and FVC. HRQOL measured with the SGRQ modified for Turkey patients. Dyspnea level with Baseline Dyspnea Index (BDI). Functional capacity measured with the 6MWT	No changes in pulmonary function test, arterial blood gases improved in both groups but statistical importance in the intervention group. QOL improved only in the intervention group. Functional capacity increased significantly in the intervention group
Padula et al ³⁰ (USA)	32 COPD patients	15 intervention group (IMT training 7 days/week). 17 control group (educational booklet) 12-week program	IMT training, education booklet with information on anatomy and physiology of the heart, diet, medication regimen, sleep, rest, and activity patterns	Vital signs seen in weeks 1-3-6-9-12. CRDQ and self-efficacy on weeks 1-6-12	P _{max} higher in the IMT group but unchanged in the control group even after repeated measures. Significant improvement in dyspnea from 1 to 12 weeks. Certain activities with significant improvement in the IMT group but caused increased SOB, which needed to be dealt with pacing. HRQOL showed no significant difference among the two groups

PR = pulmonary rehabilitation; 6MWD = six-minute walk distance; MPM = malignant pleural mesothelioma; QOL = quality of life; GP = general practitioner; FEV = forced expiratory volume; FVC = forced vital capacity; ANOVA = analysis of variance; IMT = Internal Medicine Training; SOB = shortness of breath.

All studies aimed to identify the effectiveness of their educational program on relieving dyspnea and its effects on daily living. This seems to be shown from participants' lung function improvement (including lung function tests or arterial blood gases or functional capacity), lower level of exertion dyspnea, increased exercise tolerance, improvement of inspirational/expirational muscle strength, and greater improvement of general health-related quality of life (HRQOL).^{26,29,30} Furthermore, in the study of Olivier et al,²⁴ the safety of the PR program was also assessed. Various assessment scales were used, such as the modified Medical Research Council (mMRC), Modified Borg Scale (mBorg), Chronic Respiratory Disease Questionnaire (CRDQ), St George's Respiratory Disease Questionnaire (SGRQ), Short Form 36 (SF-36), Visual Simplified Respiratory Questionnaire (VSRQ) for assessing dyspnea and QOL, or the Hospital Anxiety and Depression scale (HADS) or the COPD Self-Efficacy Scale (CSES) for assessing the effectiveness of the program on patients.²⁴⁻³⁰

The research studies covered a range of countries, with two conducted in Turkey,^{25,29} one in Korea,²⁶ one in Australia,²⁷ one in Japan,²⁸ one in the United States,³⁰ and one in France.²⁴ Participation ranged from a minimum of 32²⁹ to a maximum of 177.²⁷ Participants were selected from the hospitals' outpatient department in three studies:^{25,26,29} one from the Pulmonary and Oncology Department,²⁴ one with referral from hospital physicians,²⁶ and in the study conducted by Hermiz et al,²⁷ from the hospitals' records.

Only in the study by Padula et al³⁰ were the participants recruited from physicians' offices, home care agencies, provider referrals, and newspaper advertisement. The distribution between the intervention and the control group, in the above studies, was either by matching criteria or by random assignment. Important attrition was noted in three studies: seven of 30 in Eui-Geum,²⁶ 24 of 71 in Olivier et al,²⁴ and 19 of 52 in Akinci and Olgun.²⁹ The reasons for the attrition were acute exacerbation of the disease,^{24,26,29} noncompliance in following the guidelines (exercise, visitations, follow-up) which might be due to lack of motivation,^{24,26,29} excess of constrain,²⁴ or even death.²⁹

The length of the educational programs ranged from 8 weeks^{24,26} to 3 months^{25,27,29,30} and 6 months.²⁸ The intervention group received different numbers of home visits for the implementation of the intervention according to the required level as identified by the researchers or as requested by the patients participating in the study. There were either two to three visits^{27,29} or five visits,³⁰ with the ability of contact in between in all the above studies. Also, there were four home visits (2-1-1 per month) in the study conducted by Bal Özkaptan and Kapucu,²⁵ six visits in the study conducted by Kagaya et al,²⁸ or eight visits in the study conducted by Olivier et al.²⁴ In the study by Eui-Geum,²⁶ the number of home visits, to apply the educational program, was not mentioned, but telephone contact carried out twice weekly was offered by the nurse in charge of the study for dealing with questions and problems.

The control group received two visits at the beginning and at the end^{25,27} and was offered intervention during the last visit.²⁵ In two studies, patients received an educational advice/booklet at initial interview^{26,30} and one standard of care.²⁹ In the study by Kagaya et al,²⁸ the control group also received the intervention and received the same amount of home visits.

In the study by Bal Özkaptan and Kapucu,²⁵ family caregivers were mentioned at the end of the study as if they were included in the process even though they were not mentioned within the study methodology.

Effect on Dyspnea and Lung Function

The results of the studies showed significant benefits for the intervention group in improving dyspnea not only in relation to the initial assessment but also compared to the control group.²⁵⁻³⁰ This was evident by the significant differences in the dyspnea scales used to assess,²⁵ as well as differences in other assessments, for example, $P_{I_{max}}$, $P_{E_{max}}$, functional capacity, exercise tolerance, and six-minute walk distance (6MWD),²⁵⁻³⁰ compared to the control group. In the study by Olivier et al,²⁴ improvement of six-minute walk test (6MWT) and a test of 10 chair stands (10CS) was shown without decreasing dyspnea significantly. In another two studies, there were no changes in the Pulmonary Function Test even though dyspnea improved,^{26,29} and in one there was increased physical exertion in the intervention group.²⁵ Remarkably, the results of some of the studies showed improvements both in the intervention and in the control group. In the study by Akinci and Olgun,²⁹ arterial blood gases improved in both groups but with statistical importance only in the intervention group. In the study conducted by Kagaya et al²⁸ where both groups received the intervention, it showed that there were improvements either in the same parameters ($P_{I_{max}}$, $P_{E_{max}}$, 6MWD) or in different ones. In the study by Eui-Geum,²⁶ there was improvement in both groups, but this might be due to the fact that the control group received educational advice on effective breathing methods which can be considered as an intervention. In contrast to all the above, in the study carried out by Olivier et al,²⁴ no remarkable improvement was seen in the dyspnea level of cancer patients, which remained steady in the follow-up.

Effect on QOL

QOL and functionality showed improvement among the participants, but not in all studies and not at all aspects.^{25,27-29} Akinci and Olgun²⁹ measured QOL with the use of the SGRQ, which is a disease-specific QOL questionnaire measuring three domains: symptoms, activity, and impacts. Improvement was shown in all domains in the intervention group. Self-efficacy has also improved in the intervention group. In the study by Eui-Geum,²⁶ HRQOL was assessed with the use of the CRDQ measuring physical function (dyspnea and fatigue) and emotional function (emotion and mastery). There was an

increase in all dimensions assessed and not only in dyspnea. Kagaya et al²⁸ in their study assessed HRQOL using CRDQ together with the SF-36 that measures physical/functional and psychosocial dimensions. HRQOL, perception of dyspnea, and social functioning and role-emotional subscales of the SF-36 were increased in the lung disease group. No significant difference in HRQOL among the two groups was shown by Padula et al³⁰ in their study which used the SF-36 for assessment. In the study conducted by Bal Özkaptan and Kapucu,²⁵ the emotional state was higher in the intervention group, whereas the negative effect score, the weather/environment effect score, and the behavioral risk factors scores were significantly higher in the control group when assessed using the CSES. For assessing QOL, Olivier et al²⁴ used the VSRQ and the HADS, whereas Hermiz et al²⁷ used the SGRQ. No changes in QOL were noted in the studies by Olivier et al²⁴ and Hermiz et al,²⁷ with the latter showing no differences among the intervention and control groups in presentation or admission to hospital or in overall functional status. In the same study, there were no differences in general practitioner visits or management or hospitalization during the 3 months of follow-up in both groups.

The results show that there is a role for nurses, and specially community nurses, in addressing the problem of dyspnea faced by patients at home. Dyspnea is a symptom which appears to be mistreated at home, leading patients to seek hospitalization for support and care.²⁷ In the study conducted by Hermiz et al,²⁷ patients were more satisfied by the care offered by nurses than with the care offered by their general practitioner. One is not expecting that the structured intervention will solve the problem of dyspnea without any effort on the patient's behalf, so there are definitely negative consequences during the process. This is shown in the above studies, and thus, nurses need to be vigilant and offer all the necessary support to patients and family caregivers. Moreover, it is obvious that not every patient manages to tackle dyspnea successfully and not every intervention is going to be beneficial for the patients; thus, careful and individualized planning is required. Furthermore, Akinci and Olgun²⁹ stated that the cost of the intervention in their study was too high and suggested that this is a fact that should be taken into consideration in planning lung rehabilitation programs.

Limitations of the studies

The main limitation of the studies was the small number of participants in five of the seven studies ($n = 32-66$), preventing the generalization of the results.^{24,26,28-30} However, Padula et al³⁰ mention that their small number of participants is bigger than in other studies, and Kagaya et al²⁸ mention that including the results of participants who did not complete the 6 months of PR might have an effect on their positive findings. Moreover, attrition was considered as a major problem by Olivier et al²⁴ and in the included studies ranged from 23% to 36%.^{24,26,29}

Discussion

The review stressed that by establishing either an intervention or a structured multi-intervention program for improving dyspnea, nurses can assist patients to deal with their daily issues at home, specifically caused by dyspnea. The cause of dyspnea appears to be important because lung cancer patients showed no remarkable improvement in dyspnea level compared with COPD or heart failure patients. However, further research is required to justify any effectiveness of such programs for patients with lung cancer, taking into account the prognosis³¹ and the successfulness of programs taking place at the hospital level.³²⁻³⁴

The period of follow-up or the number of visits by the nurses appears to be irrelevant to dyspnea improvement in the studies, because effectiveness was also present in the programs lasting only for 8 weeks^{24,26} or the ones with the fewer visits.^{27,29} From the above review, it is also obvious that lung function may or may not improve regardless of the effect on patients' breathing ability. Some improvement in dyspnea was also identified in the control group, which might be due to the fact that patients with dyspnea were given attention or even just information as in studies by Eui-Geum²⁶ and Akinci and Olgun.²⁹ The improvement of QOL in the included studies, even though it was not achieved in all studies and in all the parameters, is important for patients' life and their well-being. Social functioning and emotional state increased in the patients receiving the intervention, as shown in the studies by Kagaya et al²⁸ and Bal Özkaptan and Kapucu,²⁵ which is a step toward the achievement of patients' independence within the community they live, despite the detrimental effects that dyspnea causes. However, the inability to reduce the number of hospital visits or readmissions as shown by the study conducted by Hermiz et al²⁷ is very crucial because this is a negative effect not only for the patients and their family caregivers but for the health care services as well.

Conclusion

Studies show that nurse-led educational programs with tailored exercise intensity have positive effect on patients with dyspnea due to COPD, lung cancer, and heart failure.²⁴⁻³⁰ Community nurses need to establish a well-structured PR program with all the necessary support, which will involve family caregivers as they are the crucial part for patients to follow all the instructions and achieve the goals set. Community nurses and home care nurses have a central role as they are familiar with the home establishment of patients and the support system they have or do not have at home, which has a vital role in the success of any program. As shown, tackling dyspnea improves patients' QOL, which is the ultimate goal for all efforts made by health care services and health care professionals, especially in cases where the disease has progressed, as it is in almost all the cases where dyspnea appears.

According to the guidelines of the American Thoracic Society,⁶ a PR program is considered successful when it meets realistic individual goals. More research is needed to establish the effectiveness of such home-based educational programs on patients with lung cancer with simultaneous assessment of the family caregivers who at the moment seem to be neglected and also to set a framework on the time that this intervention can be best used. Olivier et al²⁴ state that such programs are feasible and safe for cancer patients, so they should be assessed in line with all health care offered to cancer patients at home (if exists) to establish complete and holistic and personalized home care not only by nurses but from the whole multidisciplinary team involved.

Declaration of Conflicting Interests

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