Causes for lack of adherence to respiratory rehabilitation programs

Cauzele lipsei de aderență la programele de reabilitare respiratorie

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Abstract

The respiratory rehabilitation is a non-pharmacologic therapy recommended by international guidelines for the treatment of symptomatic patients with chronic obstructive pulmonary disease (COPD), but also for other respiratory diseases. The rehabilitation comprises a series of evidence-based medical interventions and is conducted by a multidisciplinary team. The benefits of rehabilitation are: a better exercise tolerance, a decrease of exacerbation episodes, shorter hospitalization time and an overall improvement of the quality of life. Thus, the patient is given the opportunity to be socially reintegrated. The benefits of respiratory rehabilitation depend on the patient's adherence to the program. We talk about adherence if the patient beliefs coincides with the medical advice. A non-adherent patient refuses to participate in a rehabilitation program or fails to complete the program. Non-compliance affects the efficacy and the medical results of the respiratory rehabilitation. We need a method to identify high-risk, non-adherent patients and to find methods to solve this problem.

***Keywords:* respiratory rehabilitation, non-adherence**

Rezumat

Reabilitarea respiratorie este o terapie nefarmacologică recomandată de ghidurile internaționale pentru tratamentul pacienților cu bronhopneumopatie obstructivă cronică (BPOC) simptomatici. Reabilitarea cuprinde un ansamblu de intervenții medicale bazate pe dovezi și este realizată de o echipă multidisciplinară. Beneficiile reabilitării respiratorii sunt reprezentate de creșterea calității vieții și a toleranței la efort, reducerea numărului de exacerbări, scăderea duratei spitalizării și, cel mai important, de reintegrarea socială a pacientului. Obținerea beneficiilor în urma programului de reabilitare respiratorie este direct proporțională cu aderența pacientului la program. Vorbim despre aderență atunci când viziunea pacientului coincide cu sfatul medical. Pacientul neaderent este acela care refuză includerea în programul de reabilitare respiratorie sau renunță pe parcurs la acesta. Necomplianța are repercusiuni atât asupra eficienței programului, cât și asupra rezultatelor științifice. Este neapărat necesară găsirea unei metode eficiente de identificare a pacienților neaderenți în scopul înlăturării acestei probleme.

***Cuvinte-cheie:* reabilitare respiratorie, neaderență**

Background

The respiratory rehabilitation is a non-pharmacologic therapy recommended by international guidelines for the treatment of symptomatic respiratory patients. The rehabilitation is based on a series of evidence-based medical interventions and is conducted by a multidisciplinary team[1,2,3].

The new definition of pulmonary rehabilitation from American Thoracic Society/ European Respiratory Society (ATS/ERS) 2013 is the following: "pulmonary rehabilitation is a comprehensive intervention based on a thorough patient assessment followed by patient-tailored therapies, which include, but are not limited to, exercise training, education, and behavior change, designed to improve the physical and psychological condition of people with chronic respiratory disease and to promote the long-term adherence to health-enhancing behaviors"[1]. The main factor which causes lack of physical activity in patients with chronic obstructive pulmonary disease (COPD) is dyspnoea, which further causes muscular weakness (peripheral and respiratory muscles) and limited exercise tolerance. These factors lead to the aggravation of dyspnoea and physical inability, a vicious cycle being thus created. The negative consequences of the lack of physical activity could be avoided by resuming it progressively, while also initiating physical training under medical supervision[1,2].

The rehabilitation program includes physical training, respiratory kinesiotherapy, patient education, nutritional advice, psychological and anti-smoking counseling. The rehabilitation benefits are: better effort tolerance, a decrease of relapses, shorter hospitalization time and an overall improved quality of life. Thus, the patient is given the opportunity to be socially reintegrated[2,3]. Although the respiratory rehabilitation benefits are based on a series of evidence, unfortunately, a considerable number of eligible patients never start or fail to complete the program.

Rehabilitation programs

The rehabilitation programs have a variable duration (4 weeks - 6 months), most commonly 8 weeks. The respiratory rehabilitation is mainly based on physical training (endurance and strength training) and respiratory physiotherapy. The additional therapy is represented by nutritional support, psychological counseling and smoking cessation counseling[1].

There are different types of respiratory rehabilitation programs, depending on location: inpatient, outpatient, home-based and community. The most common type of program is outpatient, with a 2-month duration (for example, 3 sessions per week; one session lasts one hour). But also an intensive program can be available, with 5 days a week (inpatient or outpatient).

Adherence/non-adherence to the rehabilitation program

The central position of adherence in the rehabilitation program is highlighted from the beginning of the ERS/ATS statement (2013). In this new definition, one of the main purposes is "to promote the long-term adherence"[1].

We talk about adherence if the patient beliefs coincide with the medical advice. The adherence to rehabilitation is the degree to which a patient "sticks" to his rehabilitation program. An adherent patient is a voluntary one, active, open to collaboration. This is the first essential condition to obtain therapeutic results after a respiratory rehabilitation program. From the beginning, the patient must understand that the program is a helpful therapy, that adherence will not be a barrier in quality improvement[1,8,12,16].

The non-adherence has two components: the first one - patient do not attend the program; and the second one - patient do not complete it.

The ratio of non-adherence varies from study to study, from 10% to 32%[1]. The reasons for non-attendance and non-completion in respiratory rehabilitation program have not been well studied. A small number of studies were published and revealed a variety of factors that decreased the adherence. The causes of non-attendance can be different from the causes of non-completion.

The causes of non-adherence

Non-attendance

■ *Barriers to setting up the respiratory rehabilitation (RR) program*: the most important barrier is represented by a lack of medical knowledge about what RR represents and the benefits of RR, or the referring doctor thinks that the respiratory rehabilitation is not useful. The doctor's persuasion skills and more information about what is respiratory rehabilitation can remove this barrier. The aim of a study performed in 2016 in Saudi Arabia was to determine the barriers to setting up the RR program. It was a cross-sectional study and 123 health care providers were recruited (physicians - 44; nurses - 49; respiratory therapists/technicians - 30). For these people, the team used a questionnaire in wich the most important question was if they had heard until that time about the respiratory rehabilitation program. Out of them, 3.2% had never heard about respiratory rehabilitation programs before.

The conclusion of this study was that the most important barriers were a lack of hospital capacity (75.6%), the lack of trained health care providers (72.4%), and of funds (48%)[22].

Another qualitative study was published in 2009 and a small number of patients who had been referred to RR program were interviewed. The interview focused on three themes; the third one was called "Attributing value to pulmonary rehabilitation". At this part of interview the patient's answer was that the main reason for attending RR program was health care providers influence. The conclusion was that the information and enthusiasm of referring clinician can have a strong positive impact on the adherence[9].

■ *No hospitals and specialized medical team*, due to the limited number of RR centers[22].

■ *Disruption in daily routine:* most of the patients already have a daily schedule and routine represents the central word. They are not willing to lose their time and attend the RR program.

Some patients need to take care of a family member, this also representing a reason for non-attendance[10,11].

■ *Travel and transportation:* the distance from home to the rehabilitation center and the lack of public transport represent a barrier for attendance. A great number of patients are unable to move without help. Respiratory failure and the lack of oxygen therapy during transportation to the RR center are also a barrier[10,11,12,13,16].

A study published in 2007 had the purpose to identify why patients declined to take part to the respiratory rehabilitation program. Thirty-nine patients were interviewed on several themes, among wich travel to and location of the RR center. Nineteen patients answered that they were unable to travel alone because they had restricted mobility and they needed oxygen therapy, also they had problems with public transport and they didn't have a place of parking at the RR center. Also, they said that the distance between home and hospital was too high[10].

■ *Inconvenient schedule of the RR program:* some patients prefer to make exercises in the morning, others in the afternoon, because in the first part of the day they need to take their medicine or they have problems to wake up[16,18].

■ *Program unlikely to be helpful:* the stage of the disease is very severe and the patients do not expect to have benefits, or they think that the program is useless.

Another qualitative study (2007), using home interviews regarding participation and drop out RR programs (12 patients with COPD referred to RR), showed that the first reason to drop out was the difficulty of the program, the second was transportation, the third was that they didn't notice any improvement and the last were psychosocial factors – e.g., conflict with other patients[11].

■ *The lack of time:* some patients are still working and the RR program overlaps the working hours.

■ *Financial reasons:* patients do not have money for public transport in countries where this transportation is not covered by the insurance.

■ *Status of marriage*: one study showed that married people had a higher ratio of attendance compared with divorced or widowed one.

A study published in *ERJ* (2009) in New Zealand compared two groups of patients – an adherent one (n=55) and a non-adherent group (n=36) – to find the predictors of non-adherence to respiratory rehabilitation. One of the objectives was to assess marriage status: in the non-adherent group the patients were more likely to be divorced (22% vs. 2%), to live alone (39% vs. 14%) and to live in rented accommodation (31% vs. 6%)[12].

■ *Other reasons*: illness and comorbidities, the lack of social support, current smokers, discussions with other patients who attended the RR program and found it unuseful. Respiratory rehabilitation is a group activity and many people prefer individual exercise[7,15,17].

Non-completion

■ *Illness and comorbidities:* the most important reason they did not complete the program was exacerbations or other comorbidities associated with COPD[5,6,19,21].

A study published in January 2017 about the impact of exacerbation on adherence and outcomes of RR program in patients with COPD showed that patients with mild to moderate acute exacerbation did not drop out of the RR program and acute exacerbation did not affect the response to respiratory rehabilitation. On the contrary, patients with severe acute exacerbation dropped out of RR[21].

The purpose of another study (2010-USA) was to determine the impact of COPD exacerbation on RR program adherence. On an 8-week outpatient program, 146 patients started respiratory rehabilitation, and 112 completed it.

Thirty patients had at least one exacerbation during the program, and 10 dropped out the program. The results showed that the exacerbators who completed the program had the same results compared with non-exacerbators. It is better to advise patients to continue the RR program after exacerbation[5].

■ *Current smokers*: the index of packet years represents an increased risk factor in non-completion at active smokers (higher index - higher non-completion)[5].

■ *Travel and transportation:* the same reasons to non-attendance. The patients who usually complete the RR program are living near the RR center.

■ Other barriers in non-completion are represented by *depression and lack of motivation*. This type of patient is also less compliant in other health care activities[16,20].

■ It is difficult to maintain self-motivation when patients have a *lack of social support*.

■ The patients who attend the RR program think that the results will appear quickly, *but a lack of perceived benefits* makes some participants stop the exercises[16].

■ *The difficulty of the RR program* (the complexity of procedures) represents another reason for non-completion[10].

Discussion

The two components of the non-adherence – non-attendance and non-completion – have for the most part common reasons. All these factors described above must be carefully analyzed in order to find the optimal method to minimize their effects to adherence.

One of the most common reasons is represented by travel and transportation to RR centers. Taking into account that the RR programs are mostly of outpatient type, we think that, in order to increase the adherence, it may be better to use an inpatient program, especially for patients with difficulties in transportation and mobility, with lack of financial support and respiratory failure. The lack of knowledge about what RR represents and about the benefits of RR, or the opinion of the referring doctor that respiratory rehabilitation is not useful, the discussions with other patients who attended the RR program and found it unuseful are the main reasons for failing to attend RR. This must be combated through better dissemination of knowledge about rehabilitation among health care providers and the general population[9,22].

Also, depression, lack of motivation, current smokers and lack of perceived benefits make patients to not complete the program. Using specific questionnaires to identify these cases may help further to refer the patients to psychological counseling. Currently there are no routine methods of non-compliant patients detection. In 2014, a clinical study showed that Adherence to Pulmonary Rehabilitation Questionnaire (APRQ) may be a valid method to screen adherence in patients with chronic lung disease. This questionnaire is designed on 6 main issues: disease management, treatment benefits, emotional factors, perceived severity of the disease, barriers towards treatment and coping attitude. 109 patients participated in this study, which analyzed the 18 items of APRQ. The conclusion of the study was that APRQ may be a valid method to identify non-adherent patients[4]. Non-adherence represents a serious problem that affects the efficacy of respiratory rehabilitation program. Almost 10-32% of patients referred to respiratory rehabilitation programs are non-adherent[1].

Conclusions

In conclusion, a high number of respiratory disease patients do not complete or attend the RR program. There is no universally valid method to solve this problem and each case must be carefully analyzed, in order to find personalized solutions to non-adherence effects on the efficacy and the medical results of the respiratory rehabilitation. We need a method to identify high-risk, non-adherent patients in order to find methods for solving this problem. APRQ questionnaire may be a valid way to screen the adherence of the chronic lung disease patients, but other studies are also needed[4].

Another potential tool that can be used is telemedicine, especially in home-based pulmonary rehabilitation. Individual approaches as e-mail or telephones can be used as well[14]. It is also important to increase the awareness of the health care providers on the pulmonary rehabilitation (medical conferences, Internet and educational materials). ■

References

1. Nici L, Donner C, Wouters E, Zuwallack R, Ambrosino N, Bourbeau J, et al. American Thoracic Society/ European Respiratory Society statement on pulmonary rehabilitation. *Am J Respir Crit Care Med*, 2006; 173: 1390-1413.
2. Croitoru A, Bogdan MA. Evidences related to pulmonary rehabilitation in the respiratory pathology. *Pneumologia*, 2014 Apr-Jun; 63(2):88-90, 92-5.
3. Croitoru A, Ioniţă D, Stroescu C, Pele I, Gologanu D, Dumitrescu A, Marinescu L, Anghelescu D, Alexandru M, Bogdan MA. Benefits of a 7-week outpatient pulmonary rehabilitation program in COPD patients. *Pneumologia*, 2013 Mar-Jun; 62(2):94-8, 101.
4. Ayiesah R, Leonard JH, Chong CY. Development and validation of non-adherence to pulmonary rehabilitation questionnaire: a clinical tool for patients with chronic obstructive pulmonary diseases. *Clin Ter.* 2014; 165(3):123-8.
5. Steele BG, Belza B, Cain K, Coppersmith J, Howard J, Lakshminarayan S, Haselkorn J. The impact of chronic obstructive pulmonary disease exacerbation on pulmonary rehabilitation participation and functional outcomes. *J Cardiopulm Rehabil Prev*. 2010 Jan-Feb; 30(1):53-60.
6. Crisafulli E, Costi S, Luppi F, Cirelli G, Cilione C, Coletti O, Fabbri L M, Clini EM. Role of comorbidities in a cohort of patients with COPD undergoing pulmonary rehabilitation. *Thorax*. Volume 63, Issue 6.
7. Arnold E, Bruton A, Ellis-Hill C. Adherence to pulmonary rehabilitation: A qualitative study. *Respiratory Medicine October* 2006, Volume 100, Issue 10, pages 1716–1723.
8. Guo Su-Er, Bruce A. Improving Understanding of and Adherence to Pulmonary Rehabilitation in Patients with COPD: A Qualitative Inquiry of Patient and Health Professional Perspectives. *PLoS O.* Nov. 9(10), 2014.
9. Bulley C, Donaghy M, Howden S, Salisbury L, Whiteford S, Mackay E. A prospective qualitative exploration of views about attending pulmonary rehabilitation. *Physiother Res Int.* 2009 Sep; 14(3):181-92.
10. Taylor R, Dawson S, Roberts N, Sridhar M, Partridge MR. Why do patients decline to take part in a research project involving pulmonary rehabilitation? *Respir Med.* 2007 Sep; 101(9):1942-6.
11. Fischer MJ, Scharloo M, Abbink JJ, Thijs-Van A, Rudolphus A, Snoei L, Weinman JA, Kaptein AA. Participation and drop-out in pulmonary rehabilitation: a qualitative analysis of the patient's perspective. *Clin Rehabil.* 2007 Mar; 21(3):212-21.
12. Young P, Dewse M, Fergusson W, Kolbe J. Respiratory rehabilitation in chronic obstructive pulmonary disease: predictors of nonadherence. *Eur Respir J.* 1999 Apr; 13(4):855-9.
13. Almadana Pacheco V, Pavón Masa M, Gómez-Bastero Fernández AP, Muñiz Rodríguez AM, Tallón Moreno R, Montemayor Rubio T. Patient Profile of Drop-Outs From a Pulmonary Rehabilitation Program. *Arch Bronconeumol.* 2016 Jul 29. pii: S0300-2896(16) 30193-4.
14. Marquis N, Larivée P, Saey D, Dubois MF, Tousignant M. In-Home Pulmonary Telerehabilitation for Patients with Chronic Obstructive Pulmonary Disease: A Pre-experimental Study on Effectiveness, Satisfaction, and Adherence. *Telemed J E Health*. 2015 Nov; 21(11):870-9.
15. Fischer MJ, Scharloo M, Abbink JJ, Thijs-Van A, Rudolphus A, Snoei L, et al. Participation and dropout in pulmonary rehabilitation: a qualitative analysis of the patient's perspective. *Clin Rehabil* 2007; 21: 212-221.
16. Sabit R, Griffiths TL, Watkins AJ, Evans W, Bolton CE, Shale DJ, et al. Predictors of poor attendance at an outpatient pulmonary rehabilitation programme. *Respir Med* 2008; 102: 819-824.
17. Fischer MJ, Scharloo M, Abbink JJ, van 't Hul AJ, van Ranst D, Rudolphus A, et al. Drop-out and attendance in pulmonary rehabilitation: the role of clinical and psychosocial variables. *Respir Med* 2009; 103:1564-1571.
18. Young P, Dewse M, Fergusson W, and Kolbe J. Respiratory rehabilitation in chronic obstructive pulmonary disease: predictors of nonadherence. *Eur Respir J*, 1999; 13: 855-859.
19. Crisafulli E, Costi S, Luppi F, Cirelli G, Cilione C,Coletti O, et al. Role of comorbidities in a cohort of patients with COPD undergoing pulmonary rehabilitation. *Thorax* 2008; 63: 487-492.
20. Withers NJ, Rudkin ST, and White RJ. Anxiety and depression in severe chronic obstructive pulmonary disease: the effects of pulmonary rehabilitation. *J Cardiopulm Rehabil* 1999; 19: 362-365.
21. Braeken DC, Spruit MA, Houben-Wilke S, Smid DE, Rohde GG, Wouters EF, Franssen FM. Impact of exacerbations on adherence and outcomes of pulmonary rehabilitation in patients with COPD. *Respirology.* 2017 Jan 31.
22. Alsubaiei ME, Cafarella PA, Frith PA, McEvoy RD, Effing TW. Barriers for setting up a pulmonary rehabilitation program in the Eastern Province of Saudi Arabia. *Ann Thorac Med.* 2016 Apr-Jun; 11(2):121-7.

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