Clinical research

Subjective evaluation of the effectiveness of treatment of chronic obstructive pulmonary disease – a qualitative study (Warsaw, Poland)

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Abstract

Introduction: Chronic obstructive pulmonary disease (COPD) is accompanied by troublesome symptoms such as shortness of breath, and the disease can severely impair the patient's daily functioning. The treatment consists of many elements that together allow the patient to cope with the symptoms of the disease and the adverse effects of therapy, reducing the frequency of exacerbations. The aim of this qualitative study was to better understand the experiences of patients with COPD, especially their subjective assessment of the effectiveness of treatment.
Material and methods: This is a qualitative interview study. Data were analyzed using qualitative content analysis, with NVivo 12.2 Pro QRS International software.
Results: The study was conducted in a group of 50 patients (29 men, 21 women, mean age: 73.8 ±9.4 years), at the National Institute of Tuberculosis and Lung Diseases in Warsaw (Poland). According to the subjective opinion of the study participants, the applied treatment is effective. However, the patients report a significant negative impact of the disease on their everyday life and physical activity. The feeling of breathlessness makes them passive and avoid physical exertion. Treatment mainly consists of pharmacotherapy and oxygen therapy. In general, they do not perform breathing exercises. Exacerbations occur irregularly in some of the patients. The patients exhibit poor knowledge and skills necessary for effective self-management.
Conclusions: Despite the COPD patients' sense of good disease control, the treatment effectiveness is not satisfactory. There is a need to implement patient-centered comprehensive educational activities combined with behavioral strategies.

Key words: self-care, chronic obstructive pulmonary disease, coping styles, exacerbations, self-management, educational needs.

Introduction

Chronic obstructive pulmonary disease (COPD) is one of the most common chronic non-infectious diseases [1]. In Poland, patients with COPD may make up as much as 10% of the population [2, 3], and their number is systematically increasing. The main environmental cause of COPD is tobacco smoking [4]. The symptoms usually appear after 40 years of age [5], and the largest group of patients consists of geriatric

patients who often have concomitant diseases [6]. COPD shortens the patient's potential life expectancy by more than 14 years [7].

Currently, airflow limitation severity (grade 1-4 according to the Global Initiative for Chronic Obstructive Lung Disease (GOLD) classification) and, separately, the risk of exacerbations and intensification of clinical symptoms (groups A–D – based on the modified Medical Research Council (mMRC) or COPD Assessment Test (CAT) questionnaires) are assessed in COPD patients [1]. The initial pharmacological treatment for COPD is established based on the A–D classification [1]. The breathlessness of patients in Group A is treated with either a short- or long-acting bronchodilator. In Group B a long-acting bronchodilator, either a long-acting β2-agonist (LABA) or a long-acting muscarinic antagonist (LAMA), is used. Patients in Group C are administered a LAMA. Patients in Group D may be treated with a LAMA or with a combination of a LAMA and a LABA, or with an inhaled glucocorticosteroid (ICS) plus a LABA [1]. The aims of COPD treatment are: relieving the disease symptoms, improving exercise tolerance and the quality of life, and mitigating the risk of progression by reducing the number of exacerbations. Costs of treatment of COPD are high [8, 9]. The largest expenses are consumed by hospital treatment, which indicates the necessity of preventing exacerbations [8, 10, 11].

COPD patients are a varied group of people [12]. The majority of them are elderly people, with relatively low economic status, low-educated manual workers and people with a generally weak health condition. They need support in managing with the disease and motivation to comply with the doctor's recommendations [13]. Some studies indicate that in Poland many COPD patients do not know what this disease is, what its causes and consequences are and do not even know how to explain the "COPD" abbreviation [14]. Many patients do not stop smoking and take medications irregularly [15].

The chronic character of COPD, uncomfortable symptoms such as dyspnoea, and intermittent periods of exacerbations and remission cause that a condition for effective disease control is self-management [1], defined as "the ability of a patient to deal with all that a chronic disease entails, including symptoms, treatment, physical and social consequences and lifestyle changes" [16]. In the case of COPD, self-management is composed of many elements that, when taken together, enable a patient to manage with disease symptoms or adverse effects of therapy. Self-management in COPD includes health education, smoking cessation, recognition and management of exacerbations, management of breathlessness and other symptoms, inhaler technique and medication adherence, exercise, and respiratory muscle training [17]. Based on self-assessment of the health condition, a patient may establish treatment effectiveness, which is a very important element of self-management. Occurrence of exacerbations is most often a consequence of mistakes in self-management, particularly treatment non-adherence [13].

Material and methods

This is a qualitative interview study, conducted in order to better understand the experiences of patients with COPD, particularly their subjective evaluation of the effectiveness of treatment. The investigator (DP), aided by the questionnaire, took the medical history that was recorded with the patient's consent. Based on the recordings, transcriptions of the interviews were prepared. Data were analyzed using qualitative content analysis using NVivo 12.2 Pro QRS International software [18].

Study group

Patients of the Home Oxygen Therapy Outpatient Clinic of the National Institute of Tuberculosis and Lung Diseases in Warsaw, Poland, as well as patients hospitalized at that institute were invited to participate in this study. The inclusion criteria were diagnosis of COPD and expressed informed consent to participate in this study. The study was reported to the Ethics Committees at the Medical University of Warsaw and the Institute of Tuberculosis and Lung Diseases (acceptance statement no. KBE/050/2017).

The interviews were coded with consecutive numbers and the letter I (I1, I2, I3, etc.). Any comments on the conversations were placed in square brackets.

Results

Characteristics of the studied patients

Forty-seven patients of the Home Oxygen Therapy Outpatient Clinic of the National Institute of Tuberculosis and Lung Diseases in Warsaw as well as 3 patients hospitalized at this institute were included in this study. The interviews were conducted from 13 to 30 March 2017. The mean age of the study participants was 73.8 years (standard deviation: 9.4). Study participants are characterized in Table I.

The majority of patients taking part in the study (70%) claimed that the current treatment is effective – their disease is controlled and symptom intensity is at a stable level.

"[medications] help me a lot. It has totally changed my life. Of course, it was not all of a sud-

Table I. Characteristics of the study participants (n = 50)

Parameter	Value
Sex, *n* (%):	
Women	21 (42%)
Men	29 (58%)
Age range (median) [years]	54–94 (73)
Pharmacotherapy, *n* (%)*:	
SAMA	4 (8)
SAMA and SABA	4 (8)
LAMA	4 (8)
LABA	1 (2)
LAMA and LABA	7 (14)
ICS and LABA	5 (10)
ICS and LAMA	5 (10)
ICS and LAMA and LABA	19 (38)
ICS and LAMA and LABA and PDE-4	1 (2)
Other treatments, *n* (%):	
SABA	29 (58)
SAMA	11 (22)
Theophylline	21 (42)
Carbocysteine	5 (10)
N-acetylcysteine	1 (2)
Oxygen therapy (proportion) [h]	4–24 (median: 15)
Using oxygen therapy:	44 (88%)
Oxygen therapy < 15 h	15 (34.1%)**
Oxygen therapy ≥ 15 h	25 (56.8%)**
Continuous oxygen therapy	4 (9.1%)**
Lack of oxygen therapy	6 (12%)
BMI [kg/m^2], *n* (%):	
< 18.5 – underweight	2 (4)
18.5–24.99 – normal value	10 (20)
25.0–29.99 – overweight	10 (20)
≥ 30.0 – obesity	13 (26)
No answer	15 (30)
Tobacco smoking, *n* (%)***:	38 (76)
Currently	5 (10)
In the past	42 (84)
Never	3 (6)
Passive tobacco smoking	2 (4)

**The values do not add up to 100%, because the participants could report more than one medication taken. **The proportions reported in relation to all the patients using oxygen therapy (n = 44). ***The values do not add up to 100%, because the participants could report more than one risk factor of the disease. LABA – long-acting β agonists, LAMA – long-acting muscarinic antagonists, ICS – inhaled corticosteroids, PDE – phosphodiesterase, SABA – short-acting β agonists, SAMA – short-acting muscarinic antagonists.*

den, day by day, but after a month I felt an improvement." (I2)

Two female patients (I37, I46), who received the treatment which was changed to umeclidinium bromide + vilanterol, evaluated the therapy with this combined medication as more effective compared to the previously used drugs.

"This drug [umeclidinium bromide + vilanterol] appears to me as more effective, though". (I46)

A few patients claimed that they did not feel the effects of treatment. These were the patients who took both the traditional and modern medications, at various stages of progression the disease. The majority of them do not do breathing exercises.

"It's hard to say [whether the medications help or not]. Probably they do, but it starts to deteriorate slowly, my organism is getting used to them. This one [formoterol] with [ipratropium bromide] I've been taking for 10 years." (I41)

"In my opinion there is no improvement. It chokes and chokes and chokes." (I16) [The patient is taking indacaterol and glycopyrronium bromide]

"It's worse when compared to 5 years ago, for sure, but it's like a normal situation. Does the treatment help? No, I can't evaluate that." (I39)

Some patients are afraid of adverse effects which, according to them, may limit the benefits of pharmacotherapy:

"I: Do the medications help relieve disease symptoms? P: It's hard to say. There are a lot of side effects. Such an enormous brochure." (I14)

In general, the patients did not know the adverse effects of medications used in COPD therapy. However, many of them actually experienced such symptoms as dry mouth, hoarseness, voice change, scratchy throat, etc.:

"Dry mouth. And my voice has changed a lot as well. The tone of my voice has changed and has become weaker; moreover, hoarseness appeared." (I20)

One of the patients admitted to not taking the drug containing glucocorticosteroid due to a significant rise in appetite and constant body weight gain that was difficult to stop.

"I stopped taking the second one (Asaris) because I had a huge appetite after it; my weight increased from 120 kg to 160 kg in a short period of time." (I10)

At the same time, many patients did not take any actions to prevent the adverse effects; primarily, they did not rinse their mouth after using inhaled steroid medications. According to some patients, nobody has ever recommended them to rinse their mouth and several patients found it difficult because they had movement problems. In several cases it ended up with oral mycosis treated with nystatin.

"I have a hoarse voice all the time. The doctor says that Candida has started to appear in my mouth." (I3)

The patients declared themselves as people observing medication adherence.

„ (...) I don't change anything; I take them as you prescribed." (I16)

However, several patients admitted that they did not adhere to the doctor's recommendations due to the problems with memory or their own conviction that they do not need to take the medication as often as the doctor told them to.

"The doctor recommended me to take this 4 times per day, but I usually take it just when I remember." (I21)

"The doctor prescribed me [glycopyrronium bromide] once per day but I don't always inhale it, I don't need to do it. I don't always take [formoterol] either." (I50)

"I just take it when I need it. This one [ipratropium bromide] I take 2-3 times per day. Sometimes I don't take it for 3 days or so. But I take [fluticasone + salmeterol] just as I should do." (I27)

Breathing exercises

Only 9 patients participating in the study did breathing exercises, one person did not answer the question, and 30 patients did not do breathing exercises. Causes of giving up breathing exercises reported by patients were: lack of strength, motivation and willingness to do such exercises or lack of time to do them due to a need to perform inhalations frequently. Some patients claimed that breathing exercises were not recommended to them. The most common type of breathing exercises which was mentioned by the patients was blowing with a straw into a bottle of water. Among 11 patients who indicated lack of effectiveness of COPD treatment, seven did not perform breathing exercises.

"I blow into a bottle, but I do this rarely. This is an extremely boring activity. They recommended me diaphragmatic breathing as well, but with a belly such as mine, this is not an option." (I26)

Frequency of disease exacerbations

Assessing the frequency of disease exacerbations was very difficult for the patients. In the vast majority of the studied patients they did not occur regularly.

"Maybe once a year, when I catch a cold. I have not stayed at the hospital due to this." (I2)

"I usually have to stay for some time here, at the department, every two years. Besides, I feel well." (I7)

"They have not occurred for two years. The last one was at the turn of 2015 and 2016. I stayed at the hospital for the last time in 2014. During this time, I have just been saving myself from going into hospital. I have an antibiotic prescribed, to take it in case something starts happening." (I20)

"Breathlessness attacks are rarer since I've had an oxygen concentrator. But it occurs, sometimes, that I have to go to hospital to get an injection or something. I just feel good for two days, but on the third day something goes wrong." (I49)

Some patients considered that they did not have exacerbations at all and their disease was stable.

"They generally do not occur. The disease is controlled." (I6)

Some patients observed exacerbations depending on the season and air quality.

"Recently they have been occurring very often, basically this is the worst period. Autumn and spring." (I33)

"Exacerbations may occur not only as a result of an activity, but they may be caused by an external factor as well, for example, this smog at the moment." (I18)

Effect of the disease on everyday life and physical activity

Patients felt that their activity was limited by COPD. Disease symptoms (mainly fatigue) did not allow the patients to perform simple everyday life activities at home, such as cooking and cleaning as well as doing shopping on their own.

"I'm weak, I get tired easily, I don't have the energy for anything." (I25)

"I can't bend down; it's very difficult to put my socks on or tie my shoes." (I19)

Discussion

A vast majority of patients taking part in the study have been treated with traditional medications: cholinolytics and β_2-agonists (76%). A few study participants used new medications in the therapy. That might be caused by high costs of the new drugs or the fact that they have been less common in the period of conducting the study. Due to their short-lasting action, the traditional medications have to be taken several times per day in order to maintain the appropriate drug concentration in the organism. Patients suffering from COPD are usually elderly people who encounter a wide range of problems hindering the proper taking of medications (such as multi-medication, limited motor and manual skills, memory problems, etc.) [19]. Changing the therapy to long-acting new generation drugs that may have been taken only once a day could have a positive impact on the entire course of treatment and its effectiveness.

The majority of patients treated both with traditional medications and with new generation drugs indicated that, in their subjective opinion, the therapy was effective; however, not all of them were satisfied with the results of pharmacotherapy. It should be emphasized that the majority of the patients who considered the therapy ineffective or less effective did not do breathing exercises. That might affect the course and control of the disease. Dissatisfaction of this group of patients might also result from high expectations for pharmacotherapy, e.g. a complete elimination of breathlessness. Problematic are also patients' difficulties with performing everyday life activities, which may affect the effectiveness of therapy, e.g. limiting the possibility of taking medications regularly and undertaking actions in order to prevent the occurrence of adverse effects, such as mouth rinsing after using an inhaled glucocorticosteroid [19].

A tendency to introduce changes in COPD pharmacotherapy by a trial implementation of new long-acting drugs is visible in the study. Seven patients who expressed their consent and could afford the financial costs have been prescribed with the new medications, which had to be taken for one month prior to the following doctor's appointment. The effectiveness of this new way of treatment will be assessed using objective methods – spirometry and blood gases examination.

It seems that in the study there emerges an urgent necessity to implement comprehensive self-management interventions, because the patients are lacking knowledge and skills needed to achieve effective treatment, disease control and improvement in well-being. The patients too easily gave up breathing exercises, physical exercises and preventive actions, such as influenza and *S. pneumoniae* vaccinations. Breathing rehabilitation is considered the most effective therapeutic strategy to improve the patient's health condition and exercise tolerance as well as reducing breathlessness [20]. Vaccinations reduce mortality, the frequency of disease exacerbations and hospitalizations among the COPD patients [21, 22].

The patients often do not associate the observed symptoms with taking COPD medications [23], which also indicates poor knowledge on the recommended medications, including the adverse effects caused by them. Frequently, despite their awareness of the necessity to undertake the preventive actions, these people lack motivation to overcome the encountered difficulties, e.g. associated with their limited physical performance.

Due to their irregularity, establishing the frequency of COPD exacerbations was very difficult for the study participants. Moreover, the patients defined exacerbation in various manners, e.g. as increased shortness of breath after each major physical exertion. Some of the patients declared that disease exacerbations did not occur at all and that the severity of disease symptoms had remained constant.

The results of the present study are in line with the tendency observed in other studies, indicating the necessity to adopt a holistic, patient-centered perspective [24]. Patients' statements suggest the need for support in disease management [25]. They try to adhere to the recommended therapy, especially concerning the use of medications and the time of applying oxygen therapy. The principal motivation of the patients is fear of increasing breathlessness. However, too often they lack knowledge on the disease and factors modifying its course, as well as relationships between factors/actions taken and the observed symptoms, including the exacerbations that occur. The patients also lack some skills, e.g. effective use of inhalation devices, dyspnoea/symptom management, including chest clearance techniques, recognition and management of exacerbations [26]. It is essential to implement self-management interventions in which educational activities will be combined with behavioral strategies, including the implementation of exercise and breathing techniques targeted at reducing dyspnoea, fatigue, as well as changed perception of restrictions in everyday life [17]. When designing and implementing the self-management interventions it is necessary to consider the risk of exacerbations, including the number of hospitalizations.

In conclusion, according to the subjective opinion of the study participants, the applied treatment is effective. However, it is important to talk to patients about their well-being and their perception of treatment effectiveness. The patients exhibit poor knowledge and skills necessary for effective self-management, which indicates the need to implement patient-centered comprehensive educational activities combined with behavioral strategies.

Conflict of interest

The authors declare no conflict of interest.

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