

# Patients' Experiences of COPD Self-Management Challenges: A Qualitative Study

Fereshteh Najafi <sup>1\*</sup>, Najmeh Saberi <sup>2</sup>

## Abstract

**Background:** Patients with chronic obstructive pulmonary disease (COPD) should be able to manage this progressive disease. An analysis of patients' experiences of self-management barriers and challenges can help health managers and policymakers to address the challenges.

**Aim:** The present study was conducted with aim to explore COPD self-management challenges from the perspective of patients.

**Method:** This descriptive qualitative study was conducted in 2023 at Ali Ebne Abitaleb hospital in southeastern, Iran. The participants were 15 COPD patients admitted to the pulmonary ward who were selected through purposive sampling. The data were collected through semi-structured interviews and analyzed using conventional content analysis.

**Results:** The findings indicated that COPD management is a complex and multi-faceted process affected by several factors including personal patient factors (non-adherence to treatment, personal beliefs, stress, low health literacy, financial burdens/strains, occupation/role, and low self-efficacy), environmental factors (internal and external factors), and the COPD-related factors (progressive nature of COPD and cardiac comorbidities).

**Implications for Practice:** Based on the findings of the present study, healthcare providers and health policy makers can help patients improve their self-management skills and prevent disease progression by reducing barriers to self-management.

**Keywords:** Challenge, COPD, Qualitative study, Self-management

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1. Assistant Professor, Community Nursing Research Center, Zahedan University of Medical Sciences, Zahedan, Iran
  2. MSc in Medical-Surgical Nursing, Zahedan University of Medical Sciences, Zahedan, Iran

\* Corresponding Author Email: [Najafi.fe@gmail.com](mailto:Najafi.fe@gmail.com)

## Introduction

Chronic obstructive pulmonary disease (COPD) is a progressive disease that causes airflow to block the airway, lung parenchyma, or both. The disease is characterized by three main symptoms including chronic cough, sputum production, and shortness of breath (1, 2). These symptoms usually worsen over time (3). COPD often occurs in people over 40 years of age, and its prevalence increases with age. It is 5 times more prevalent in people over 65 than those aged less than 40 years. Active or inactive smoking or job exposure to risk factors increases the prevalence of COPD (4). COPD is the third leading cause of death after heart disease and cancer worldwide (1). The incidence of COPD is high due to the high consumption of cigarettes in developing countries and increased aging (5). The COPD among older adults in Iran has increased as the elderly population grows and COPD-related risk factors increase (6). Increasing the COPD incidence imposes a lot of economic costs on the health system (7). COPD progression is associated with performance restrictions, adverse quality of life, and frequent hospitalizations. The exacerbation of symptoms is the main cause of hospitalization. Readmission of COPD patients imposes huge costs on the health system (8). Overall, COPD negatively affects patients' physical and mental health and their social and family relationships (9). Since COPD is a chronic disease and has numerous psychosocial complications, affected patients should be able to take care of themselves (10). Global guidelines describe the self-management program as a vital part of COPD treatment (1). Self-management refers to the patient's ability to understand the disease, control behaviors, and maintain an attitude toward the management of the disease in chronic conditions (11). Self-management interventions for COPD patients increase the health-related quality of life and reduce hospital admissions and shortness of breath (12, 13). An important element of self-management is understanding of factors affecting the patient's self-management. Patients' subjective experiences in the management of the disease show their barriers and challenges which can serve as valuable findings to help healthcare workers (14, 15). A qualitative study of 21 healthcare staff who worked directly with COPD patients highlighted the vital role of patients' attitudes. Other challenges were treatment costs, numerous morbidities, peer support, and the lack of specialized knowledge in medical staff (16). Another study highlighted the significance of support consultations, patient access to routine and non-routine support by health caregivers, and effective patient-caregiver communication (17). Rafiei et al. (2024) in their research examined self-management barriers and facilitators from the perspective of COPD patients, family caregivers, and pulmonologists. Their findings showed that knowledge, education, experience, family participation, and financial support were as the facilitators of self-management, and lack of education, special nature of the disease, false beliefs, poor self-efficacy, and non-adherence to treatment were considered as the barriers of self-management (18). However, women's experiences with COPD were not explored. In addition, COPD-related health and cultural beliefs affect the self-management attitudes and behaviors in affected patients (15, 19, 20). To develop and implement effective self-management interventions, it is crucial to understand the challenges and barriers to self-management from the perspectives of stakeholders, including patients. Although many studies have examined patients' perceptions of these barriers and challenges, there is a paucity of research in Iran. Therefore, the present study was conducted with aim to explore patients' experiences of COPD self-management challenges.

## Methods

This qualitative-descriptive study was conducted in 2023 on 15 COPD patients admitted to Ali Ebne Abitaleb hospital in southeastern, Iran. The participants were selected through purposive sampling that continued until data saturation was achieved. To gain a variety of experiences, the participants were selected with maximum diversity in terms of age, gender, severity and duration of COPD, number of hospital admissions, education, and occupation. The inclusion criteria were the age of over 18 years, a history of hospital readmission due to exacerbation of COPD three times over two years, Gold Stage II and III, and stable clinical conditions. The exclusion criterion was the unwillingness of patients to continue the interview. The patients' experiences of COPD self-management challenges were explored through in-depth structured interviews. Examples of the interview questions were: "How is life with COPD? Can you describe it?" "What problems do you have in managing the disease and its complications?", and "How do you manage the disease when it exacerbates? Probing questions such as "Can you explain more?" and "Can you give an example?" were also asked for further

clarification. All interviews were conducted in the pulmonary ward when the patient's condition was stable. In the case of the deterioration of the disease and shortness of breath, the interview was stopped immediately and resumed after the patient's stability. The data from the initial interviews guided the selection of subsequent participants. For instance, the patients frequently pointed to non-adherence to treatment and irregular use of medicines. These issues were addressed in the subsequent interviews. The interviews continued until data saturation was reached. In addition, written consent was obtained from the participants. The interviews were recorded upon the participants' permission. They were also assured that their information would be kept anonymous and confidential and their participation would be voluntary and they would be free to leave the study at any stage.

The data were analyzed following Lundman and Graneheim's content analysis method (21, 22). Qualitative content analysis reduces the data and gives them structure and order. To this end, the audio files of the interviews were first transcribed verbatim. The transcripts were then reviewed several times to get a better understanding of content. The meaning units were then extracted and the data were summarized, condensed, and coded. The codes were placed into different categories based on similarities and differences, and eventually, the main categories and themes were extracted.

The rigor of the findings was checked using the four criteria proposed by Lincoln and Guba (23). The dependability of the data was ensured through prolonged engagement and interaction with participants to confirm the findings. To enhance the credibility of the findings, the extracted themes and categories were reviewed by some participants to evaluate if they matched their experiences. A thorough description of the steps taken to collect and analyze the data was provided to check the confirmability of the data. The transferability of the findings was enhanced by selecting participants with a wide range of backgrounds and characteristics and a detailed description of the research procedure. Moreover, the coding scheme and the findings were reviewed by some subject-matter experts to ensure their accuracy.

### Ethical Consideration

This study was approved by the Ethics Committee of Zahedan University of Medical Sciences (ethical code: IR.ZAUMS.REC.1401.148).

### Results

The mean age of participants was  $67.66 \pm 11.64$  years and the mean duration of the disease was  $15.20 \pm 7.76$  years. Other demographic characteristics are displayed in Table 1. Data analysis revealed 376 primary codes. The content analysis of the data also showed 1 theme, 3 categories, and 11 subcategories (Table 2).

**Table 1: Demographic characteristics of participants**

No.	Age (years)	Gender	Occupation	Educational level	Disease duration (years)
1	63	Female	Housewife	Illiterate	20
2	59	Male	Driver	Primary school	10
3	58	Male	Retired	Diploma	20
4	50	Female	Housewife	Illiterate	8
5	78	Female	Housewife	Illiterate	10
6	60	Male	Employee	Primary school	6
7	80	Male	Employee	Primary school	13
8	78	Female	Housewife	Illiterate	20
9	76	Male	Employee	Primary school	9
10	67	Male	Rancher	Diploma	14
11	51	Female	Driver	Diploma	20
12	87	Male	Rancher	Illiterate	30
13	70	Male	Farmer	Illiterate	8
14	80	Male	Farmer	Illiterate	30
15	58	Female	Babysitter	Primary school	10

**Table 2: Main theme, categories, and subcategories extracted from the COPD patients' experiences of self-management challenges**

Main theme	Categories	Subcategories
Complex and multifaceted process of self-management	personal patient factors	Non-adherence to treatment Personal beliefs Stress Low health literacy Financial burdens/strains Occupation/role Low self-efficacy
	Environmental factors	Internal factors External factors
	COPD-related factors	Progressive nature of COPD Cardiac comorbidities

### **Complex and multifaceted process of self-management**

The findings suggested that the management of COPD and its symptoms is influenced by several factors, including personal patient factors (physical, psychological, and economic factors, health literacy, beliefs, and attitudes), environmental factors, and COPD-related factors. The complex and multifaceted nature of disease management can make patient self-management a challenging issue.

### **Personal patient factors**

The findings showed that several personal patient factors can affect self-management skills in COPD patients; these factors include non-adherence to treatment, personal beliefs, stress, low health literacy, economic problems, jobs/roles, and low self-efficacy.

#### **• Non-adherence to treatment**

Most of the participants reported that they did not comply with medicinal instructions, did not change or modify their lifestyles, and did not abandon high-risk behaviors that exacerbated COPD symptoms and shortness of breath, which led to frequent hospitalizations. One of the participants said in this regard:

“...Every time I go to the doctor, the doctor asked me not to smoke hookah. But when I took some medicines and felt well, I started smoking hookah again and I felt really bad”. (Participant No. 11).

Another participant stated:

“...I will stop taking the drugs when I feel well, and most of the time I take drugs when I feel bad. I take medicines and stop them on my own will but not with the doctor's consultation !!”. (Participant No. 5).

#### **• Personal beliefs**

Most of the patients stated that their false beliefs about controlling COPD symptoms or complications worsen the disease and exacerbate its symptoms. In this regard, one of the participants reported:

“...I wondered if I wanted to use inhalers regularly, I would be addicted to them and I should always use them, so I wouldn't always use them”. (Participant No. 1).

The other participant said:

“...The doctor asked me to use inhalers every 12 hours but I didn't do it because I thought I had to use them forever. That's why my shortness of breath became more severe”. (Participant No. 7).

#### **• Stress**

Most of the patients stated that stress exacerbates shortness of breath and the inability to manage the disease. Several factors led to stress and they often used inefficient methods that sometimes exacerbated shortness of breath. This process continued as a defective cycle. In this regard, one of the participants said:

“...If I don't smoke cigarettes and hookah, I will have stress and anxiety but smoking itself will increase my shortness of breath”. (Participant No. 10).

Another participant stated:

“...When I am happy and don't have stress I feel better and I get less shortness of breath, but when I'm unhappy I feel terrible”. (Participant No. 4).

- **Low health literacy**

A majority of the patients highlighted their inadequate knowledge and information about COPD, how it is managed, how medication is taken, and how to control the disease in situations where shortness of breath is exacerbated. Most of participants said that doctors and nurses did not give them enough training. One of the patients stated in this regard:

“...They can teach us how to use oxygen and how to measure blood oxygen levels or how to do blood oxygen therapy”. (Participant No. 9).

The other patient said:

“...I don't know how to use the medicines. I wish there was a consultant to say how to take care of myself”. (Participant No. 6).

- **Financial burdens/strains**

Given the chronic nature of COPD, one of the major challenges reported by most patients was their poor economic situation for drug and oxygen supply. This led to a temporary or periodic use of medication or oxygen that exacerbated the disease. A participant said in this regard:

“...I have financial problems; I can't fill the oxygen capsule. I don't use it during the day, so I can use it at night”. (Participant No. 4).

Another patient stated:

“...I have financial problems so I cannot afford medication and oxygen” (Participant No. 15).

- **Occupation/role**

Some participants stated that their roles or jobs led to the development and aggravation of COPD which was difficult for them to manage the disease. In this regard, one of the participants said:

“...At my mother-in-law's house, I used to bake bread in a traditional oven and I started developing shortness of breath. Every time I went to the oven, my shortness of breath got worse”. (Participant No. 1).

The other patient stated:

“...I had a lung problem due to complications caused by chemical weapons during the war. Because my job was to clean minefields, I developed severe shortness of breath”. (Participant No. 3).

- **Low self-efficacy**

Some participants did not believe in their ability to manage the disease. The dependence on help and support from other family members and the inability to abandon the habits exacerbating the disease or adopt a healthy lifestyle were some challenges reported by the participants. In this regard, one of the patients reported:

“...There should be someone helping me because I can't take care of myself alone”. (Participant No. 11).

Another patient said:

“...I can't quit smoking so easily. Both smoking and stopping smoking bother me” (Participant No. 6).

### **Environmental factors**

The participants stated that environmental factors, including internal and external factors exacerbated COPD that are sometimes out of the patient's control.

- **Internal factors**

Some participants reported that some home-related factors worsen their shortness of breath and make them unable to manage the disease. The factors include any odor or substance that stimulates the respiratory system. In this regard, one of the participants said:

“...I feel terrible in winter when I use the oil-burning heaters”. (Participant No. 15).

The other patient stated:

“...Wild rue smoke, the smell of cologne, and spicy smells like food fried in the house worsen my shortness of breath” (Participant No. 7).

- ***External factors***

The majority of patients pointed to the environmental conditions worsening COPD and shortness of breath. These factors made disease management a serious challenge for the patient and often led to frequent hospitalizations. A patient stated in this regard:

“...The shortness of breath depends on the weather. Dust always makes me feel worse” (Participant No. 3).

Another participant said:

“...In winter, my cough and shortness of breath will worsen”. (Participant No. 4).

### **COPD-related factors**

Factors related to COPD and its nature causing the symptoms worse include the progressive nature of the disease and its comorbidities.

- ***Progressive nature of COPD***

Most of the patients stated that by development of COPD, the disease was getting worse year by year and this has increased their fear and limitations. A patient said in this regard:

“...I feel bad from time to time and the disease is getting worse”. (Participant No. 8).

The other patient stated:

“...After a few years, I was getting worse and worse, as if the medicines were no longer effective and I have been hospitalized several times” (Participant No. 12).

- ***Cardiac comorbidities***

Another challenge for COPD management by affected patients was cardiac comorbidities, which acted as a defective cycle and made the disease symptoms more complicated. In this regard, one of the participants reported:

“...Heart disease appeared after lung problems, which itself has worsened lung problems”. (Participant No. 1).

Another participant stated:

“...My lung problem is getting much worse. The doctor told me that I have a heart problem, and I should take care of it”. (Participant No. 12).

### **Discussion**

The present study aimed to explore the experiences of patients with COPD regarding self-management challenges. The findings showed that COPD management is a complex and multi-faceted process that is affected by several factors, including individual, environmental, and disease-related factors. Identifying the related factors can promote self-management among people with chronic diseases (24).

The data in this study indicated that personal patient factors affecting COPD management are non-adherence to treatment, personal beliefs, stress, low health literacy, economic problems, jobs/roles, and low self-efficacy, leading to low self-management ability and consequently frequent hospitalizations. Failure to follow instructions provided by medical staff, including physicians and nurses, on regular use of medicines, modification of lifestyle, and abandoning high-risk behaviors would lead to some challenges for COPD patients. Various and complex patient-related factors can affect the condition of patients with COPD (25). A study revealed that compliance with medicinal instructions and following the guidelines provided by health providers were as the key issues for disease self-management (26). Thus, identifying these problems and planning to remove them can help promote treatment as a key component of patient self-management.

In the present study, the personal beliefs of patients, which were often inaccurate and led to noncompliance with treatment, were another important factor affecting COPD self-management. The patients falsely believed that prolonged use of drugs or oxygen therapy would lead to dependence and

addiction, or that it was better to follow medical instructions only when symptoms exacerbate. This led to exacerbation of shortness of breath and hospitalization. Most people with COPD have a limited understanding of the disease and its medications (27). Some beliefs can weaken or inhibit coping efforts. Personal and cultural beliefs also determine how one evaluates what happens or is about to happen (19). Shum et al. (2020) reported that patients' beliefs and attitudes toward the treatment regimen and its effectiveness, such as fear of being addicted to inhaled drugs, are the obstacles for their self-management (28).

Another COPD management challenge for patients in the present study was stress that, like a defective cycle, exacerbated shortness of breath and shortness of breath as the consequence of poor self-management increased stress. Often, fear of possible shortness of breath, along with everyday life stressors, exacerbates patients' stress (9). Although stress is a personal challenge, it is the responsibility of nurses and healthcare staff to train patients on how to cope with stress more effectively (29). Low health literacy was another challenge that played a decisive role in the quality of COPD self-management in the current research. Sami et al. (2023) reported that most patients did not understand the importance and necessity of self-management at home and had limited motivation to take care of themselves (25). Lack of knowledge and disease management skills worsens the physical condition of patients (26). According to Rafiei et al. (2024), the more COPD patients have information about different aspects of their illness, the better they can manage it (18). The content of the counseling must be comprehensive and person-centered (17). Another reason for the low health literacy of COPD patients is that training and follow-up services are not provided after discharge by health caregivers to enhance the patients' knowledge and health literacy associated with COPD self-management at home (30).

The poor economic situation also had a direct relationship with compliance to the treatment regimen, management of the disease, and prevention of shortness of breath. Most patients were from lower-class socioeconomic groups and had low education and inadequate income. Therefore, they were unable to supply the inhaled drugs and oxygen makers or capsules. Given the chronic and progressive nature of COPD, most patients face economic challenges, and inadequate family and social support resources weaken the ability to manage the disease and reduce the quality of physical and emotional life (31). Loss of jobs, absence from work, early retirement due to the exacerbation of the illness, and inability to permanently supply drugs and oxygen impose financial burden on patients (31, 32). Thus, sustainable financing by the health system and support resources at the community level are required to address the financial concerns of patients for drug provision. Some patients could not manage the disease effectively due to their jobs or roles at home. Jobs such as keeping animals, farming, or cooking traditionally at home exacerbated the patient's shortness of breath. Low self-efficacy was another challenge faced by COPD patients in the present study. Indeed, self-efficacy is the main stimulus of self-management behaviors. Therefore, knowledge and adherence to self-management behaviors in the absence of self-efficacy are less sustainable (33).

The data in this study also showed that environmental factors including internal and external factors can affect COPD patients' self-management skills. As confirmed in previous studies (34-36), these factors, including the smoke or smell of food stimulating the respiratory system at home, and the presence of environmental pollutants such as dust, and cold and dry air, exacerbated shortness of breath, which was sometimes out of the patient's self-management capability (34-36). Improving health literacy, high self-efficacy, adherence to treatment regimens, and promoting sound beliefs about COPD can help patients control environmental challenges.

The progressive nature of COPD and cardiac comorbidities were other disease-related challenges in this study. Previous studies have shown that the progressive nature of COPD is a major challenge for patient self-management that reduces the patient's ability and complicates their conditions (6). Thus, the patient becomes frustrated with recovery and develops anxiety and depression (34). Cardiac diseases can act as both COPD antecedents and consequences, leading to the deterioration of the patient's condition and frequent hospitalizations (37, 38). These findings confirm the devastating nature of COPD, which, in advanced stages, exposes patients to serious disease management challenges. High levels of self-efficacy and self-management skills in the early stages of COPD can slow the progression of the disease and its adverse consequences.

This study had some limitations. First, the study only focused on the experiences of COPD patients admitted to the hospital. Other COPD patients who were not hospitalized during the study or were not

admitted to the hospital three times over the past two years, as well as family caregivers and healthcare providers may have different experiences about self-management challenges in COPD patients. In addition, the participants were selected from only one hospital. These limitations can reduce the generalizability of the findings. However, one of the strengths of the present study was the deep exploration of the perceptions of patients who were hospitalized frequently due to poor self-management. Moreover, the maximum diversity in sampling was effective in discovering patients' experiences.

### **Implications for practice**

The results of this study help better understand the COPD self-management challenges from the perspective of affected patients. The complex and multifaceted nature of the disease leads to multidimensional interventions to improve the management of the disease by patients. Identifying and promoting self-management strategies may improve health outcomes and increase personal independence. Nurses, as one of the main health workers, as well as other healthcare providers and health planners, can help patients improve self-management skills and prevent disease progression by removing self-management barriers. Further research is needed for monitoring and examining COPD patients and formulating strategies for effective self-management.

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### **Conflicts of interest**

The authors declared no conflict of interest.

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### **Authors' Contributions**

Fereshteh Najafi: Conceptualization, Investigation, Methodology, Administration, Writing-review & editing, Supervision. Nejme Saberi: Investigation, Administration, Writing-review & editing. All authors contributed to the writing of the manuscript and discussed the manuscript.

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