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Understanding the Challenges Experienced by COPD Patients: A Qualitative Study

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Abstract

Objective: The aim of this study is to investigate the difficulties experienced by COPD patients, understand their needs, and provide a reference for the content of COPD patient empowerment programs.

Method: In this study using phenomenological design, semi-structured individual in-depth interviews were conducted with 11 COPD patients using purposive sampling between May 2023 and July 2023. The transcribed interviews were transferred to the MAXQDA program for analysis. Thematic analysis was used to code the data and determine themes. The Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist was used as a guide to ensure the quality of the study.

Results: As a result of the analysis, five themes emerged regarding the challenges experienced in COPD: Perception of disease, difficulty in disease management, losses in lifestyle, emotional burden of the disease, need for information.

Conclusions: It is thought that the interventions to be implemented to strengthen COPD patients can increase their effectiveness by creating them within the scope of the themes obtained in this study.

Keywords: Chronic Obstructive Pulmonary Disease, Nursing, Qualitative Research

Öz

KOAH Hastalarının Yaşadığı Zorlukların Anlaşılması: Nitel Bir Çalışma

Amaç: Bu çalışmanın amacı, KOAH hastalarının yaşadığı güçlükleri keşfetmek, ihtiyaçlarını anlamak ve KOAH hastalarını güçlendirme programları içeriği için bir referans sağlamaktır.

Yöntem: Fenomenolojik tasarım kullanılan bu çalışmada, Mayıs 2023 ile Temmuz 2023 arasında, amaçlı örnekleme yöntemiyle seçilen 11 KOAH hastasıyla yarı yapılandırılmış bireysel derinlemesine görüşmeler yapıldı. Transkript edilen görüşmeler analiz için MAXQDA programına aktarıldı. Verileri kodlamak ve temaları belirlemek için tematik analiz kullanıldı. Niteliksel Araştırma Raporlama için Birleştirilmiş Kriterler (COREQ) kontrol listesi, çalışmanın kalitesini sağlamak için bir rehber olarak kullanıldı.

Bulgular: Analiz sonucunda KOAH'ta yaşanan güçlüklere ilişkin beş tema ortaya çıktı: Hastalık algısı, hastalık yönetiminde güçlük, yaşam biçiminde kayıplar, hastalığın duygusal yükü, bilgi ihtiyacı.

Sonuç: KOAH hastalarını güçlendirmeye yönelik uygulanacak girişimlerin, bu çalışmada elde edilen temalar doğrultusunda oluşturulmasıyla etkinliğinin arttırılabileceği düşünülmektedir.

Anahtar Kelimeler: Kronik Obstrüktif Akciğer Hastalığı, Hemşirelik, Kalitatif Araştırma

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INTRODUCTION

Chronic obstructive pulmonary disease (COPD) is a growing health problem worldwide. More than 10% of individuals aged 40 and over are affected by COPD (World Health Organization, 2020). COPD exacerbations, characterized by a sudden increase in cough, sputum, and shortness of breath, which are the main symptoms of the disease, frequently cause hospitalization and high costs (Strang et al., 2021). While the direct and indirect cost of chronic obstructive pulmonary disease is 2.1 trillion United States (US) dollars worldwide, according to 2010 data, it is estimated that this cost will increase to 4.8 trillion US dollars in 2030 (Bloom et al., 2011). In addition, COPD-related disabilities, workforce losses, and health expenditures emerge as a serious public health problem, causing a great economic burden and negative effects on society (Chen et al., 2023).

The fact that COPD symptoms seriously affect daily life makes it different from other chronic diseases (Bringsvor et al., 2019). Individuals with COPD experience increased shortness of breath, insufficiency in physical and social functions, loss of productivity, fatigue, insomnia, and limitations in performing daily life activities (Strang et al., 2021; Kochamat et al., 2024). This situation affects the individual in many social, spiritual, and economic aspects. In later stages, situations such as inability to fulfill their roles in family and society, social isolation, and decrease in quality of life are also observed (Kochamat et al., 2024; Hurst et al., 2020).

Issues such as disability, diminished quality of life, rising healthcare costs, and the complex needs of patients with COPD continue to pose challenges for patients, their families, and healthcare professionals. Brief encounters of healthcare professionals with patients in hospitals and other outpatient settings are insufficient to truly understand the challenges experienced by patients (Bringsvor et al., 2019). One of the most ideal methods to be used to see more clearly the challenges experienced by individuals with COPD in coping with the disease and adapting to treatment is individual in-depth interviews.

Listening to patients' experiences through in-depth interviews allows nurses to gain a new perspective to understand the challenges caused by progressive disease such as COPD. For nurses, such interviews are "critical sources of information about etiology, diagnosis, treatment, and prognosis from the patients' perspective" (Holloway and Galvin, 2023). Proposals for solutions to the challenges identified because of the interviews will strengthen patients by increasing treatment compliance and symptom control and can significantly reduce hospitalization and healthcare costs. The aim of this study is to explore the challenges experienced by COPD patients, understand their needs, and provide a reference for the content of COPD patient empowerment programs.

METHODS

Study Design

In this study, a qualitative research design, phenomenological design, was used to understand the difficulties experienced by COPD patients and individual in-depth interviews were conducted.

Sampling Strategy

Participants were individuals diagnosed with COPD who applied to a chest diseases hospital in Turkey between May 2023 and July 2023. Participation criteria included the following: (1) having a confirmed diagnosis of COPD for at least 5 years, (2) having the cognitive and mental competence to answer the questions, (3) disease symptoms being at a level that does not interfere with communication, (4) being COPD Stage 2 or Stage 3 according to GOLD criteria because their daily lives are more affected. According to the GOLD criteria, the staging of COPD is based on the percentage of the expected value of forced expiratory volume in one second (FEV1) after bronchodilator use. If an individual's FEV1 is 50-79% of the expected value, they are classified as Stage 2 moderate level, and if it is 30-49%, they are classified as Stage 3 severe level (GOLD, 2022). Maximum diversity sampling method, one of the purposeful sampling methods, was used. Diversity was achieved in terms of age, education, gender, profession and working status. The researcher, a clinic doctor, identified patients who met the inclusion criteria from the records of patients diagnosed with COPD. Patients were contacted by phone, informed about the study, and invited to participate. A date and time were determined for the patients who agreed to participate in the study and an interview appointment was made. Face-to-face interviews were held with 11 individuals with COPD who volunteered for the study. Data saturation was taken as the basis for terminating the interviews.

Data Collection Methods and Tools

Data were collected through semi-structured individual in-depth interviews. This method was preferred because it provides flexibility in data collection and the opportunity to analyze how participants make sense of the subject under study (Pope and Mays, 2006).

"Introductory Information Form" and "Semi-Structured In-Depth Individual Interview Questions", in which descriptive information was questioned, were used as data collection tools. Five main questions and sub-questions were prepared by the researchers for the interviews, based on an interview guide (Brinkmann and Kvale, 2018). The questions were also evaluated by experts on the subject. In-depth individual interview questions were as follows:

1. What do you know about COPD disease? How do you access information about your disease?

2. What do you think it is like to have COPD?

   -How does having respiratory distress affect you?

3. What effects does your disease have on your daily life/ what has changed in your life?

4. Could you please explain what you experienced in the management of your disease?

   -What did you experience during the adaptation process to treatment?

   -How do you access health services?

   -What do you experience when you have to make a decision about your illness?

Opinions of two experts were obtained for the semi-structured interview questions. A pilot test was conducted with individual in-depth interviews with 2 patients to determine the clarity and appropriateness of the questions. The appropriate day and time were determined for the interview with the patients who voluntarily agreed to participate in the study. All researchers are female researchers with COPD and qualitative work experience. ZA is a nurse academic who has worked clinically with COPD patients for a long time and has taken a course in qualitative research and MAXQDA training. SE is a nurse academic who specializes in qualitative research. ÖO is a physician who follows COPD patients. The interviews were conducted by the researchers in a calm and quiet room on the outpatient clinic floor of the hospital. The interview started by asking the individual to introduce themselves and a patient introductory information form was filled out in the form of a conversation. Afterwards, questions in the semi-structured in-depth individual interview form were asked. Patients were encouraged to talk through questions such as “Please give me more information” or “Can you explain?” to get more detailed information. All interviews were recorded on a voice recorder with permission from the participants. Interviews continued by asking probing questions, when necessary, until data saturation was achieved. The interviews lasted between 41 and 63 minutes, depending on the answers given by the participants. The interviews were conducted in Turkish and later translated into English.

Rigor and Trustworthiness

One of the most useful methods for reliability in qualitative studies is to explain in detail each stage of the research and the path followed. This method was followed in the study for reliability. For validity, the data was evaluated and compared by two different experts. To obtain participant confirmation, the interview recording was played to the participant after the interview and approval was obtained. Before the study began, the participants and the researchers had no relationship and did not know each other. At the same time, the researchers kept “notes” written on a piece of paper after each interview, through observations.

Ethical Considerations

This study was approved by the Istanbul Kent University Health Sciences Scientific Research and Publication Ethics Committee (Date: 25.05.2023, Decision no: 2023-04). The study was conducted in accordance with the principles of the Declaration of Helsinki (World Medical Association, 2013). Permission was obtained from the ethics committee of the hospital where the data was collected. Before the interview, participants were given verbal and written information about the study and signed written consent. Participants were assured of the confidentiality and anonymity of their responses. Information was given and permission was obtained for the audio recordings. In addition, participants were assured that their care would not be affected in any way whether they participated in the interview or not, and it was clearly stated that they could withdraw from the study at any time. To ensure anonymity in our findings, participants were quoted with an identifying number as “P1, P2”.

Analysis and Evaluation of Data

The data were analyzed with thematic analysis and the following processes were followed respectively. The audio recordings of the interviews were listened to repeatedly and transcribed in Microsoft Word. The interviews were read repeatedly by ZA and SE to get a general picture of the interviews and to become familiar with them. The transcripts were transferred to the MAXQDA program (version 22.8; VERBI Software GmbH; Berlin, Germany) and analysis was started. Thanks to the MAXQDA qualitative analysis program, the analysis process is carried out more clearly and systematically, allowing the coding to be checked and making adjustments when necessary. Initial coding was done with some sentences and paragraphs that emerged based on the interview questions. The analyzes were last read by the third researcher ÖO.

A coding tree is a hierarchical structure used to systematically analyze raw data obtained in research and to identify the main themes. In other words, a coding tree is the process of identifying and hierarchically categorizing recurring themes and expressions in qualitative data analysis. While main codes represent major themes, sub-codes elaborate on the components of these themes, providing a more in-depth analysis (Braun and Clarke, 2006). In our study, each main code was supported by specific sub-codes, and significant trends within the data were analyzed. The entire data set was coded separately by two researchers, each of whom is an expert in the field and unaware of each other’s work. Approximately 50-53 codes were generated for the data sets analyzed by both researchers. The researchers combined their codes to form themes, reducing the total number of codes to 30. The codes created were grouped into 4-6 themes. The researchers then shared their themes and compared both the themes and the reasons behind their creation. As a result of these comparisons, common themes that both researchers agreed upon were established. Subsequently, a third researcher evaluated the themes. The patients participating in the study were asked to provide their opinions on the themes and sub-themes. All participants confirmed the themes.

RESULTS

The ages of the participants, four women and seven men, ranged from 41 to 74, with the average age being 55.2. Four of the participants were primary school graduates, two secondary school graduates, three high school graduates and two university graduates. The average disease duration was 12 years, and two participants were current smokers (Table 1).

The study initially yielded 53 codes. These codes were collected by researchers ZA and SE then evaluated by researcher ÖO. Five themes were discovered through interviews with participants (Table 2). These were "Illness perception", "challenge in disease management", "loss in lifestyle", "emotional burden of the disease" and "need for information". The patients participating in the study were asked to provide their opinions on the themes and sub-themes. The participants confirmed the themes.

Under the theme of "Illness perception", the sub-themes of not accepting the disease and ways of defining/interpreting the disease; under the theme of "challenge in disease management", the sub-themes are challenge in accessing healthcare, economic challenges, challenge in managing treatment, challenges due to device use and challenge in decision-making; Under the theme of "lifestyle losses", the sub-themes of losses in instrumental daily living activities, losses in basic daily living activities, losses in work life and social losses are; under the theme of "emotional burden of the disease", the sub-theme of negative emotions caused by the disease; under the theme of "need for information", sub-themes of inability to access accurate information about the disease and he need for information regarding maintaining treatment were found (Table 3).

Table 1. Sociodemographic characteristics of participants (n = 11)

Participant	Age	Gender	Educational Status	How many years have you had COPD?	Job	Smoking
P1	74	Female	Primary school	10	Tailor	No
P2	55	Female	Primary school	15	Housewife	No
P3	60	Male	Middle school	5	Logistics	No
P4	58	Male	High school	8	Welder	No
P5	72	Male	Middle school	36	Mine Retired	No
P6	55	Female	High school	18	Housewife	No
P7	45	Male	University	7	Artist	Yes
P8	41	Male	University	6	Teacher	No
P9	42	Male	High school	5	Machinery Manufacturer	Yes
P10	56	Male	Primary school	15	Retired	No
P11	50	Female	Primary school	7	Hairdresser	No

Table 2. Themes and subthemes ıdentified through ınterviews with COPD patients

Theme	Sub-theme
Illness Perception	Not accepting the disease
	Ways of defining/interpreting the disease
Challenge in Disease Management	Challenge in accessing health services
	Economic challenges
	Challenge in managing treatment
	Challenges related to device use
	Challenge in making decisions
Lifestyle Losses	Losses in instrumental activities of daily living
	Losses in basic activities of daily living
	Losses in work life
	Social losses
Emotional Burden of Illness	Negative emotions caused by the disease
Need for information	Inability to access accurate information about the disease
	The need for information regarding maintaining treatment

Table 3. Themes and subthemes with quotes from COPD patients7

Quotes	Sub-theme	Theme
“One does not accept this disease easily.” (P5) *“It’s hard to get used to it and accept it, I can’t accept it...” (P9)* *“I denied and ignored my illness for a long time.” (P7)*	Not accepting the disease	**Illness Perception**
“COPD has no cure, it cannot be treated, it will always be with me like a friend. It is difficult to recover.”(P2) *“A person’s arm may be broken, but he will be fine. He will undergo surgery and the pain will go away. But there is no solution for COPD. There is no surgery in the first place. It is not a temporary condition. It will go away with you.” (P10)* *“They can’t do anything to you from the outside with this disease. If you manage yourself, you will be comfortable with this disease.” (P10)* *“Living with this disease is very, very difficult” (P8)* *“My life has completely faded away... We are now friends with these drugs.” (P11)* *“In COPD disease, I say first take a breath... Because if you don’t have breath, you are exhausted.” (P10)*	Ways of defining/ interpreting the disease	
“When there are indifferent healthcare personnel, I often think of quitting my medications because I will not be able to get better.” (P8) *“Of course, I understand, medical examination time is very limited. There is no environment where we can find answers to all our questions.” (P9)* *“Medical personnel are doing their best, I am grateful. Of course, sometimes they are busy and sometimes I cannot get answers to my questions. I understand them too, but it is difficult not to know about this disease. (P1)* *“I come for check-ups if I can find an appointment. But it is very difficult to find an appointment with the doctor who follows me. I have to wait for a very long time. Sometimes my medications run out. Then the disease gets out of control. Everything goes back to the beginning...” (P11)* *“If it was easy to make an appointment, we could control it better. But I can’t access healthcare.” (P4)* *“I cannot find an appointment. I have to wait 15 days even when I am at home in a very serious condition.” (P11)* *“I want home health care, but it is not possible. I don’t want to come to the emergency room when I have shortness of breath. The hospital environment affects me badly.” (P6)*	Challenge in accessing health services	**Challenge in Disease Management**
“But sometimes I have to buy extra, and since my insurance does not cover it, I pay for it. My financial situation is not very good. Naturally, it is a bit difficult” (P4) *“I use my medications and I have no problems. Sometimes the medications are just not enough. They run out early, I have to pay to get them, but insurance does not cover them.” (P3)* *“I also believe that alternative treatments will be good for COPD. Like aromatherapies. But they are very expensive and difficult to access.” (P8)* *“I have heard of pocket-sized oxygens. They would be very good for patients like me... They have very high prices. It is not possible for everyone to afford them...” (P9)* *“I do not have a regular income, and since I do not have insurance, I cannot afford my treatment” (P5)*	Economic challenges	
“My inhaler medication... is not enough. I have to use it when I have shortness breath. When I use it, it runs out early. Then I am left without medication. I see the doctor and he says he cannot prescribe any more. But I think doctors also need information from the patient. It is not enough, so I have to go and buy it myself... Do I have any other choice?” (P9) *“But they give different medicine every time. They say it’s the same medicine, but their usage techniques are different. So, I’m having a hard time.” (P5)* *“But to be honest, sometimes I forget to use my medications. When I get shortness of breath, I remember and use them immediately.” (P5)* *“Of course, I had problems using medication at first. I left the medications for a while. If I had been informed correctly, I would never have quit.” (P11)* *“...for example, you are in a group of people and you are shortness of breath, you cannot use your medications comfortably.” (P10)*	Challenge in managing treatment	

Table 3. Themes and subthemes with quotes from COPD patients7 (Continued)

Quotes	Sub-theme	Theme
"It is very difficult to be constantly connected to oxygen. I need oxygen and it needs to be with me everywhere" (P9) *"I always carry my device with me. That's why I don't leave the house much." (P4)* *"I cannot sleep while using the BIPAP device at night. The tubes came out once while I was using it. I was breathless and very scared. I also sweat a lot when using it at night. .... But I have to use this device." (P5)* *"When my doctor gave me this machine (BIPAP device), he said, 'Can you use it? Do you have a beef with machines?' (laughs). I asked what that meant and said of course I would use it." (P5)* *"I couldn't get used to the device, I had reservations for a long time" (P9)*	Challenges related to device use	**Challenge in Disease Management**
"So when I think about making a decision, the first thing that comes to my mind is losing weight. I shouldn't gain weight so that my shortness of breath doesn't increase. However, you can't exercise because you have shortness of breath. You need to eat well, and you can't lose weight at this point. It's a bit of a vicious cycle. That's why I think professional support is needed." (P8) *"...my daughter-in-law helps me a lot when I can't decide." (P4)* *"Hospitalization is a difficult decision. I have a hard time making a decision, so I talk to my doctor directly. If there is nothing left to recommend other than hospitalization, then I will use my decision in favor of hospitalization." (P7)* *"I thought a lot about whether I should do sports or not. But finally I decided to do sports." (P8)* *"I have a hard time making decisions on my own." (P8)*	Challenge in making decisions	
"I can't go shopping; I need someone else to buy what I need" (P7) *"I can't clean, I can't breathe when there's dust and smoke." (P1)* *"I can't clean." (P2)* *"The smell while cooking is very disturbing. It makes me feel stuffy." (P1)* *"I can't cook," (P2)* *"I cook my own food. I get short of breath when frying... "...when I open the lid of the pot, that steam takes my breath away." (P4)*	Losses in instrumental activities of daily living	**Lifestyle Losses**
"Even going to the toilet and kitchen are very complicated situations for me." (P7) *"For example, I can't even walk. It's the most normal thing, but when you have COPD, you can't even do that." (P9)* *"We are unable to walk or travel. For example, you have to carry a tube to go from one place to another. That's why I can't leave the house unless it's necessary." (P11)* *"I can't take a bath alone, I run out of breath." (P1)* *"I can't even go to the toilet without my daughter's support. Even going to the toilet destroys me." (P6)* *"I can't even go to the door alone; I feel so sad." (P6)*	Losses in basic activities of daily living	
"My business life was affected greatly. I retired. I could not go to work anymore." (P5) *"I had to quit my job after my illness because I was unable to continue." (P7)* *"My work-related travels have all stopped. I had to change positions. ...it is not tolerated at work after a certain point" (P9)* *"I had to take a lot of leave in my work life." (P10)* *"I sew to make a living. I have difficulty breathing while sewing. I have to sew... This is very difficult work for me." (P11)*	Losses in work life	

Table 3. Themes and subthemes with quotes from COPD patients7 (Continued)

Quotes	Sub-theme	Theme
“There is nothing in my life other than traveling between the hospital and the house. I can’t go to anyone. I can’t visit my relatives. I have no life left.” (P6) *“Even light perfume scent makes me feel stuffy in crowded places.” (P10)* *“I can’t do anything outside with my children. For example, there is a picnic, but I can’t go.” (P3)* *“I used to exercise regularly, running at least three days a week. Now I barely leave the house.” (P7)* *“Simply put, I try to lie down and my breath gets short even when I cover myself.” (P8)* *“I feel like I’m not alive now. I was a very active person before this disease. Walking in a park or on the beach is such a wonderful thing. Now I understand.” (P9)* *“For example, you cannot go for a walk when the weather is cool. I cannot go out even when there is a slight wind.” (P10)* *“If I go out of the city, I have to go by private car. I feel very bad when I go on a public bus for even two hours.” (P10)*	Social losses	
“There is also a psychological burden. Will I stay like this or will it progress? It’s a very bad situation if it progresses.” (P8) *“Of course, my psychology was also very affected. Sometimes I hurt the people around me for no reason. I can’t cope, this situation is very difficult.” (P9)* *“I smoked a lot, I wish I hadn’t. I regret it very much.” (P3)* *“I gave up my life, but I’m afraid I won’t be able to see my grandchildren.” (P4)* *“Sometimes I wonder if my life would be better if it ended. Because that can’t be called living.” (P7)* *“There are literally so many times when I don’t know what to do.” (P8)* *“I wish they would tell me how to deal with this disease. I feel so helpless.” (P9)* *“I don’t want to come to the check-ups because I’m afraid. I’m afraid that if I come, I’ll be hospitalized.” (P2)* *“I try not to forget to change my oxygen tube. Thanks to my friends, they help me too, but most of the time I feel like I’m a burden.” (P11)*	Negative emotions caused by the disease	**Emotional Burden of Illness**
“Most of the time, people do not know where to get accurate information.” (P7) *“To be honest, I only had problems with the medical staff in accessing the correct information... I did not come across anyone competent who gave me information. I would like to be able to access the correct information.” (P8)* *“Sometimes I think I wish I knew more about the disease. Maybe it would be better.” (P4)* *“You can’t do exercise. They say exercise is good for the disease, but exercise also makes you short of breath. I really don’t know what to do.” (P11)* *“Just maybe more information could be given. One does not know what to do when alone with this disease.” (P11)* *“I don’t know about the disease, and I couldn’t get proper information.” (P9)* *“If I had known more at the time that this disease would be like this, maybe it would have been much better...” (P10)* *“I have never done any research on COPD. My asthma had progressed, and this was its last stage. I am learning about the disease from the people around.” (P11)* *“I learned by experiencing the disease I suffered from for years. As I said, we learned about the disease because we suffered from it.” (P10)*	Inability to access accurate information about the disease	**Need for information**
“I stopped taking medications for a while. If I had been informed correctly, I would never have stopped....” (P11) *“In the first few uses (inhaler drugs), I wondered if the medicine stuck in my throat or went to my lungs? How am I supposed to know for sure? I had those kinds of concerns.” (P8)* *“I had hard time using inhaler medications for the first time... Has the medicine arrived? Did I use it? What is the effect? It takes a long time to understand and get used to it. I got used to it over time. I also had technical problems. But then I researched it on the internet and found out. (P9)* *“Of course, as I said, I am having problems in medicine supply. It’s not enough, the medicines run out early. I must buy it myself.” (P9)* *“But they give different medicine every time. They say it’s the same medicine, but their techniques are different. So, I’m having a hard time too...I want the medicine I know how to use.” (P5)*	The need for information regarding maintaining treatment	

Theme 1: Illness Perception

Illness perception provides a framework for an individual's thoughts and feelings about their illness, how they choose coping strategies, and how they carry out their actions. During the in-depth interviews, it was observed that the participants denied the disease for a long time and had challenge accepting it. Participants expressed this situation as follows: *"I denied and ignored my illness for a long time" (P7)* and *"People do not accept this disease easily" (P5)*. The way participants defined/interpreted the disease centered around the fact that the disease is not a temporary condition, there is no treatment, and the challenges caused by experiencing shortness of breath. They also said, *"COPD has no cure, it cannot be treated, it will always be with me like a friend. It is difficult to recover." (P2)* and *"We are friends with these drugs now."* As seen in the statements of *(P11)*, it was seen that they integrated with the disease and described them as friends. This situation may sometimes reflect individuals' confrontation with their illness, acceptance of the illness, and their lifestyle.

Theme 2: Challenge in Disease Management

Under this theme, subcategories of challenge in accessing healthcare, economic challenges, challenge in managing treatment, challenges due to device use and challenge in decision-making were discovered. Participants requested home health care services, stating that they had challenge accessing health services and finding an appointment. It caused serious situations such as not being able to find an appointment, not being examined for a very long time, or a deterioration in general condition due to not being able to get their medications prescribed. Participants expressed challenges due to the indifference of healthcare personnel, limited examination times, and not being able to find an appointment with the physician they are followed-up by. In addition, one participant stated that disease management would be easier with increased access to appointments. *"If it was easy to make an appointment, we could control it better. But I can't access healthcare." (P4)*. It was observed that some participants described the hospital environment negatively and tended to postpone emergency room admission and hospitalization. Being able to receive health care at home was a good alternative for them.

For instance, *"I want home health care, but it is not possible. I don't want to come to the emergency room when I have shortness of breath. The hospital environment affects me badly."* (P6) (Table 2).

Under the sub-theme of economic challenges, it was discovered that they experienced obstacles in accessing devices that make life easier, such as paid purchases, alternative treatments such as aromatherapy, and pocket-sized portable oxygen, due to lack of regular income/insurance or premature use of medications. *"I do not have a regular income, and since I do not have insurance, I cannot afford my treatment" (P5)*

"I have heard of pocket-sized oxygens. They would be very good for patients like me... They have very high prices. It is not possible for everyone to afford them..." (P9), (Table 2).

It was also stated that technical differences in inhaler drug equivalents make usage challenge.

One participant expressed this situation as follows:

"But they give different medicine every time. They say it's the same medicine, but their usage techniques are different. So, I'm having a hard time." (P5).

The importance of initial training at the beginning of inhaler treatment also drew attention.

Some of the participants were using more than the recommended dose of inhaler medications because they had severe respiratory distress. This caused the inhaler drugs to run out earlier and negatively affected the drug treatment.

"My inhaler medication... is not enough. I have to use it when I have shortness breath. When I use it, it runs out early. Then I am left without medication. I see the doctor and he says he cannot prescribe any more. But I think doctors also need the patient's information. It is not enough, so I have to go and buy it myself... Do I have any other choice?" (P9). One participant reported that they forget to use medications, five participants reported that they were reluctant to use inhaler medications in public, and one participant reported that they did not go out without inhaler medications. Three participants stated that they found physical activity effective in managing COPD, but they had challenge deciding to start physical activity because they experienced increased shortness of breath with movement. Their lack of support in this regard was one of the factors that made disease management challenge. Not being able to get used to Bi-level Positive Airway Pressure (BIPAP) and sleep problems due to night use were other challenges experienced.

Continuous oxygen and BIPAP device use were the most life-limiting factors for them. One participant expressed this situation as follows:

"It is very difficult to be constantly connected to oxygen. I need oxygen and it needs to be with me everywhere" (P9)

Theme 3: Lifestyle Losses

Shortness breath has been shown to have profound negative effects on instrumental and basic daily living activities, work and social life. Participants were dependent and limited in their daily lives. It was observed that their work lives were negatively affected after the disease, and they experienced situations such as not being able to continue working, having to retire, change positions, and take frequent leave from work. At the same time, their social life was limited to home, and many of them experienced shortness breath even when walking at home. They were unable to fulfill their social roles such as attending weddings and funerals.

Participants also reported that shortness of breath made activities such as cleaning, cooking, shopping, going to the toilet, and bathing challenge. One participant said, *"…when I open the lid of the pot, that steam takes my breath away." (P4)* and explained the challenges he had in cooking.

The participants who said, *"Even when I try to simply lie down and cover myself, I get short of breath." (P8) "Even going to the toilet and kitchen are very complicate situations for me," (P7)* said the participants and shed light on how serious the impact of shortness of breath is on their lives. The participants stated that they could not walk or move due to their shortness of breath. Patients using oxygen had to carry the oxygen tube wherever they went.

Theme 4: Emotional Burden of Illness

All participants expressed negative emotions caused by the disease. Negative emotions sometimes resulted in hurting the people around them. Feelings of regret and guilt about smoking were intense. All participants stated that they felt helpless due to the disease. They felt helplessness the most when they experienced shortness of breath and described shortness of breath as very frightening, unbearable. One participant stated that they might choose to end their life due to the severity of their symptoms. Not being able to enjoy life and feeling like a burden were other emotions expressed. Fears about the progression of the disease created a serious emotional burden. Other situations that caused fear were health checks and hospitalization. It was discovered that fears, especially those related to hospitalization, resulted in the behavior of postponing hospital admissions and health checks. *"I don't want to come to the check-ups because I'm afraid, I'm waiting. I'm afraid that if I come, I'll be hospitalized." (P2)*

Theme 5: Need for Information

Patients' knowledge about COPD, its course and management generally consisted of their own experiences. It was discovered that participants needed information about accessing accurate information about the disease and maintaining treatment. There were participants who stated that they could not access accurate information about COPD, that they learned about the disease by experiencing it, that they did not know that the disease process would progress like this, and that they learned about the disease from the environment. Some participants also stated that they received information from health professionals or the internet. A participant who stated that being informed about the disease process would have positive effects on disease management said, *"If I had known more in time that this disease would be like this, maybe it would have been much better..." (P10).* They especially needed information on maintaining inhaler therapy. There were participants who stated that they stopped or took a break due to not receiving sufficient information when they first started using inhaler medications or because they were not sure whether they were taking the medication.

DISCUSSION

This research focused on discovering the challenges experienced by individuals with COPD and understanding their needs. Participants described COPD as a disease that has no cure, will continue until death, and is challenged to accept. The vulnerability and decline in functionality that developed with the disease negatively affected their perception of the disease. Challenges caused by shortness of breath caused negative consequences and a feeling of stigmatization in all areas of their lives.

In Seamark et al.'s (2004) study, one of the participants stated that they thought they would die due to the illness. In our study, similar to previous research results (Giacomini et al., 2012; Disler et al., 2014), participants stated that it was not possible to get rid of this disease, that it was not a temporary situation, and that they thought the end of the disease was death.

It was discovered that after the diagnosis of COPD, the participants denied the disease for a long time. It was observed that those who accepted the disease described the disease and the medications as a friend. A patient's perception of his illness as a friend is described with terms such as "pathological friendship" or "integration with the disease". Seeing the disease as a friend may be a reflection of the person's process of coming to terms with his illness and adapting to this situation (Giacomini et al., 2012).

In our study, participants expressed challenges due to the indifference of health professionals, limited examination times, and not being able to find an appointment with the physician they are followed-up by. A study reported that these challenges are a common problem and can hinder both the continuity of treatment and the relationship between the patient and healthcare professionals (Hurst et al., 2020).

It is reported in the literature that the expensive nature of inhaler drugs and limited insurance coverage are factors that make access to treatment challenge (Disler et al., 2014; Svedsater et al., 2017). In our study, it was observed that patients who did not have social security or who used their medications more frequently than the recommended dosages procured medications for a fee and experienced economic challenges.

It has been reported in the literature that there are seven different inhaler devices available for COPD, individuals may need to use more than one device, and this may cause technical challenges (National Jewish Health, 2018).

In parallel with these findings, two participants in our study stated that they experienced challenges due to technical differences in inhaler drug equivalents. At the same time, participants were not sure whether they were taking the drug or not. These situations reveal the importance of communication with patients and healthcare professionals and training in inhaler drug use techniques. It is thought that repeating the training may be useful when switching to a different inhaler medication.

Another factor affecting compliance with treatment was avoiding using inhalers in public. The visibility of the inhaler medication negatively affects medication use in public and the inability to hide medication use. This causes stigma associated with the disease and negatively affects quality of life and compliance with treatment (Svedsater et al., 2017). Decreased compliance with treatment results in higher healthcare costs, more hospitalizations, and worse disease control (Strang et al., 2021).

It is reported in the literature that experiential knowledge helps disease management in patients with chronic diseases (Paterson, 2001). In our study, participants explained their knowledge about the disease through their experiences and stated that they learned about the disease by experiencing it. Although this situation draws attention to the contribution of experiential knowledge, it suggested that the instructions that should be given by health professionals may have been ignored. One study reported that having a disease caused by an individual's own behavior, such as smoking, causes feelings of shame and guilt (Jerpseth et al., 2021). This situation has been shown to be one of the factors that delay the information-seeking process, and it has also been reported that it may reduce active participation in the care process and cause poor self-management (Giacomini et al., 2012; Williams et al., 2014; Disler et al., 2014). Therefore, it is important for health professionals to understand these experiences of shame and guilt (Disler et al., 2014; Jerpseth et al., 2021).

Many qualitative studies indicate that patients have a lack of knowledge about the disease and a low level of health literacy (Disler et al., 2014; Williams et al., 2014; Wahl et al., 2021). In this study, the participants also lacked information on how and from whom to obtain accurate information. Participants reported that their disease management could be better if they had more knowledge about the disease. It is reported in the literature that health-related behaviors, disease adaptation, and self-management skills can improve with an increase in the level of knowledge (Williams et al., 2014).

In COPD, movement restrictions occur from the moment oxygen is needed. Initially, movements outside the home are affected, later movements within home are also determined by the oxygen supply (Giacomini et al., 2012; Disler et al., 2014). In this study, participants stated that they had challenges in basic activities such as walking, cleaning, cooking, going shopping, going to the toilet and bathing. Participants' continuous use of oxygen and/or bilevel positive airway pressure (BIPAP) device was one of the most life-limiting factors for them (Giacomini et al., 2012; Marx et al., 2016).

It is stated in the literature that COPD patients continue to work even though they encounter challenges, and that they have to leave work in the advanced stages of their disease (Marx et al.,2016). It is also reported that the disease affects individuals' ability to perform group activities and social roles (Giacomini et al., 2012; Williams et al., 2014) and causes loss of productivity (Giacomini et al., 2012; Disler et al., 2014; Marx et al.,2016). In our study, the participants stated that they could not participate in activities with relatives, friends and family members such as weddings, funerals and picnics, and that their lives had completely changed.

It is reported in the literature that feelings of powerlessness, helplessness, hopelessness, (Disler et al., 2014; Hurst et al., 2020) sadness, deep regret, shame and guilt are common in patients with COPD (Jerpseth et al., 2021). It is also stated that anger, disappointment and irritability increase in COPD (Disler et al., 2014; Marx et al.,2016). It is reported that COPD patients with a history of smoking generally experience this (Giacomini et al., 2012). In our study, feelings of regret and guilt were especially intense among smokers. Participants stated that they sometimes unintentionally hurt their loved ones and this made them sad.

In our study, it was discovered that fears related to hospitalization resulted in the behavior of postponing hospital admission and health checks. It is reported in the literature that patients may be reluctant to consult healthcare professionals when they experience an exacerbation (Giacomini et al., 2012; Disler et al., 2014). Patients often seek medical help only when they reach a crisis point. Nevertheless, studies have reported that patients feel safe when treating their exacerbations at home (Lahham et al., 2020). This suggests that self-management is a viable option. In our study, participants stated home health care as a good alternative.

Patients with COPD have significantly lower daily physical activity levels than healthy individuals (Disler et al., 2014; Hurst et al., 2020). In our study, participants had fears of experiencing shortness of breath during physical activity.

That's why they stated that they could not decide to start physical activity. It is important for COPD patients to realize that avoiding physical activity may further exacerbate dyspnea (Hurst et al., 2020). Therefore, COPD patients should be helped to overcome the fear of experiencing shortness of breath during physical activity. Health professionals should discuss with patients the behaviors they restrict themselves from and provide information about the benefits of physical activity (Disler et al., 2014).

CONCLUSIONS

In this study addressing the challenges experienced by COPD patients, it was seen that dyspnea was the symptom that most challenged the patients, both physically and emotionally. The fact that they denied the disease for a long time and had challenge accepting it revealed the need to develop awareness and support programs on this issue. There were challenges in accessing health services, the appointment system, and the provision of health services. This situation revealed the need for improvements in the appointment system and health service delivery.

Patients needed support and resources for a better quality of life and disease management. It is recommended that healthcare systems, healthcare professionals, and society collaborate to meet the needs of COPD patients. It is thought that the challenges experienced in the use of inhaler drugs arise from lack of information, and training and information programs will be effective in this regard. The limitation of access to alternative treatments and devices can be resolved through public and private sector collaboration. Access to rehabilitation programs and support groups can be facilitated to alleviate the effects of shortness of breath on daily living activities and work life. Patients had serious fears that shortness of breath would increase with physical activity. In order to eliminate this common misconception, it is important to raise patients' awareness that lung capacity will improve, and shortness of breath will decrease with safe physical activity. Cigarette addiction caused patients a deep sense of guilt and negatively affected their self-management. To make quitting smoking easier, patients should be directed to support groups and smoking cessation programs. Participants' knowledge about COPD disease, its course and management generally consisted of their own experiences. Educational programs and information materials should be developed to ensure that patients have access to accurate and up-to-date information from the moment they are first diagnosed. At the same time, the needs of COPD patients for home care and palliative care also attract attention.

As a result, creating interventions to strengthen COPD patients within the scope of the themes illness perception, challenge in disease management, lifestyle losses, emotional burden of the disease and emotional burden obtained in this study may increase effectiveness.

Limitations

Due to the nature of qualitative research, findings are limited to participants' statements. To reveal the participants' perspectives as they are, the researchers paid utmost attention to validity and reliability measurements.

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