

A Basic Question: Are Patients with Chronic Obstructive Pulmonary Disease Aware of Their Disease?

Fatma Işıl Uzel, Pelin Karadağ, Seda Tural Önür, Demet Turan, Esin Yentürk, Esin Tuncay

Department of Pulmonology, Yedikule Chest Diseases and Thoracic Surgery Training and Research Hospital, İstanbul, Turkey

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Abstract

OBJECTIVES: Increased awareness and understanding of chronic obstructive pulmonary disease (COPD) is important for its management, but there are limited data regarding the basic knowledge among patients with COPD. This study aimed to evaluate the basic information and knowledge of patients who were specifically provided with a medical exemption certificate for COPD.

MATERIAL AND METHODS: This cross-sectional, observational, single-center study was conducted at an outpatient clinic of our hospital and included 201 consecutive ambulatory patients who visited the outpatient clinic between January 01, 2015 and June 30, 2015. Data regarding sex, age, educational level, symptoms, smoking history, years since diagnosis, years since obtaining the exemption certificate, and COPD GOLD (Global Initiative for Chronic Obstructive Lung Disease-GOLD) stage were obtained. A questionnaire comprising 15 questions was used.

RESULTS: The question regarding the organ primarily affected by COPD was correctly answered as "lung" by 145 (72%) of patients. In addition, 152 (76%) patients declared that they knew the localization of the affected organ; only 44 (22%) patients correctly located the organ on an image. Only seven (3.5% of the total) patients could correctly write "chronic obstructive pulmonary disease."

CONCLUSION: The lack of awareness among patients with COPD emphasizes the lack in the field of patient education. Simple questionnaires can be used to determine and also to improve the awareness and basic knowledge among patients with chronic diseases.

KEYWORDS: Chronic Obstructive Pulmonary Disease, awareness of disease, patient education

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INTRODUCTION

Chronic respiratory diseases are a major cause of morbidity and mortality. According to the World Health Organization (WHO) fact sheet that was updated in January 2017, chronic obstructive pulmonary disease (COPD) claimed 3.2 million lives in 2015 and is projected to rank third in 2030, with 8.6% in burden of disease caused worldwide which is a modelling technique that combines multiple data sources to count and compare the total fatal and nonfatal health loss from diseases and injuries in a population [1]. In 2013, a survey regarding chronic diseases and risk factors conducted in Turkey reported that COPD prevalence based on self-reporting of a doctor's diagnosis or spirometry was 5.0% (4.9% in males and 5.1% in females). In addition, 46.1% of patients with COPD regularly used medication [2]. Many attempts are being made to mitigate the negative effects of COPD on the general health worldwide. Increasing the awareness level regarding the disease is one of the key components of these attempts. WHO established the Global Alliance Against Respiratory Disorders (GARD) project with the aim to reduce the global burden of chronic respiratory diseases. [3]. As a participant of GARD project, Turkey conducted studies to evaluate the knowledge and awareness regarding asthma and COPD in the general population [4]. Increased awareness and understanding of COPD is an important part of disease management, but there are limited data about the basic knowledge of the disease among patients with COPD. We often forget to ask the simple questions regarding the organ that is the main target of a specific disease.

This study aimed to evaluate the basic information and knowledge of patients with COPD with regard to the educational level and GOLD stages; these patients were specifically provided with a medical exemption certificate for COPD.

MATERIAL AND METHODS

Study Design

This was a cross-sectional, observational, single-center study that was conducted at an outpatient clinic of our hospital.

This study was presented at the 19th Annual Congress of Turkish Thoracic Society, 6-10 April 2016, Antalya, Turkey.

Address for Correspondence: Fatma Işıl Uzel, Yedikule Chest Diseases and Thoracic Surgery Training and Research Hospital, İstanbul, Turkey

E-mail: uzelisil@gmail.com

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Patients

A total of 201 consecutive ambulatory patients who visited the outpatient clinic between January 01, 2015 and June 30, 2015 and who were provided with a medical exemption certificate for COPD were included. This certificate is given to patients with chronic diseases with the approval of the relevant specialists in Turkey. In case of COPD, these specialist are either Internal Medicine or Pulmology specialists. This is a kind of proof that the patient suffers from this disease and needs lifelong treatment.

Participants were excluded if they were diagnosed with dementia or mental illness or if they were illiterate because that would prevent them from answering the questionnaire. The participating physicians were trained to standardize the application of the questionnaire. The patients filled the forms themselves, and only simple objective answers were given

to them. All patients gave written informed consent to participate in the study. This study was approved by the ethical committee of our hospital (registration number 2015/38).

Measurements

Data regarding sex, age, educational level, COPD-related symptoms, smoking history, years since diagnosis, years since obtaining exemption certificate, and COPD GOLD stage were obtained. A questionnaire comprising 15 questions regarding COPD diagnosis, as well as the basic knowledge regarding the human body and health literacy, was used (Figure 1). The questionnaire required an average of 20 min for completion. Although the questionnaire is not validated, it includes questions about the main symptomatology of the disease, the beliefs related to the cause of COPD and its treatment, the location of lungs, and the meaning of COPD.

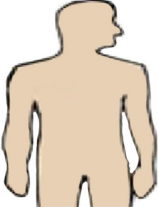
1-	When did you get the diagnosis of COPD?	a) 0-1 years	b) 2-5 years	c) 6-10 years	d) more than 10 years
2-	When did you get the medical exemption certificate for COPD?	a) 0-1 years	b) 2-5 years	c) 6-10 years	d) more than 10 years
3-	Do you cough on most days of the week?	Yes	No		
4-	Do you have sputum on most days of the week?	Yes	No		
5-	Do you have more shortness of breath when compared to persons of your age?	Yes	No		
6-	Did you smoke before or are you still smoking?	Yes	No		
7-	Do you know what COPD means? Can you write, what the acronym stands for?	Yes	No		
8-	Which organ is primarily affected by COPD?				
9-	Do you know the localization of this organ? If yes, please sign:				
					
10-	Do COPD drugs cause addiction?	Yes	No	I do not know	
11-	Do COPD drugs cause weight gain?	Yes	No	I do not know	
12-	Is COPD a contagious disease?	Yes	No	I do not know	
13-	Is COPD a treatable disease?	Yes	No	I do not know	
14-	What is the most important causal factor of COPD?				
15-	Did you make any information search for COPD (book/leaflet/internet)?	Yes	No		

Figure 1. The questionnaire

Table 1. Characteristics of the study patients

	n	%
Male:Female	179:22	89:11
Age group, yr		
40-49	12	6.3
50-59	57	29.8
60-69	81	42.4
≥70	51	21.5
Education		
Uneducated	24	12
Primary school	135	67.2
Secondary school	26	13
High school	13	4.5
University	3	1.5
Smoking status		
Current or ex-smoker	130	65
Never smoked	81	35
COPD history, yr		
<1	42	21
2-5	71	35
6-10	56	28
>10	30	15
Medical exemption certificate history, yr		
<1	52	26
2-5	80	40
6-10	57	28
>10	12	6
GOLD stage		
A	74	37
B	41	20
C	26	13
D	60	30

The educational level was categorized as follows: a) completed primary school (duration of 5 years), b) completed secondary school (duration of 8 years), c) completed high school (duration of 11 years), d) completed university, or e) uneducated (not attended any level of education). COPD stage was determined as combined assessment using symptoms, breathlessness, and risk for exacerbations according to the GOLD update 2016 [5]. The patients were first staged according to dyspnea using the modified Medical Research Council dyspnea scale, followed by risk assessments of exacerbations using spirometry for determining the GOLD grade of airflow limitation, the number of exacerbations the patient experienced in the previous 1 year, or if the patient had one or more hospitalizations owing to COPD exacerbation within 1 year, whichever was available. All the patients were classified as GOLD stage A, B, C, or D.

Statistical Analysis

Data was analyzed using Statistical Package for the Social Sciences version 20.0 (SPSS Inc.; Chicago, IL, USA).The

study findings were expressed as categorical variables. The values were presented as percentages for qualitative data. Descriptive statistics (counts and frequencies in percent) was used. The sample size was calculated for $\alpha=5\%$ and $\beta=20\%$. The sample size required for detecting a 10% difference of proportion according to the knowledge of COPD was calculated as 194 patients, with a focus on previous data of nearly 50% awareness that COPD patients have regarding their disease. Fisher's exact test was used to compare the educational level, GOLD stages, and awareness levels among the patients.

RESULTS

Characteristics of COPD Patients

Five pulmonologists provided data of 201 patients who visited the outpatient clinic of our hospital. The characteristics of the patients are described in Table 1.

Regarding symptoms, dyspnea was more prevalent than cough and sputum production (60% vs. 36% vs. 38%).

Knowledge of and Beliefs Regarding COPD and Lungs

The first part of question 7, i.e., "Do you know what COPD means? Can you write what the acronym stands for?" was answered as "no" by 156 (78%) patients. Of the remaining 45 patients, only seven (3.5% of the total) could correctly write "chronic obstructive pulmonary disease." There was no statistically significant association between the GOLD stages and the lack of knowledge ($p=0.678$). Patients in all COPD stages were equally unaware of the meaning of COPD. Conversely, having graduated from primary school and the lack of knowledge were statistically significantly associated ($p=0.002$).

The question regarding the organ that was primarily affected by COPD was correctly answered correctly as "lung" by 145 (72%) patients. Forty (20%) patients did not know the correct answer and did not mention another organ. Of 40 patients, 22 (55%) belonged to the GOLD stage A. The difference between the "knowing" and "not knowing" groups with regard to the GOLD stages was statistically significant ($p=0.052$). When the answer to the same question was compared between two age groups, namely ≤ 60 and ≥ 60 years, the difference was not statistically significant ($p=0.098$). Hence, age did not play a role in the awareness about the affected organ.

Of all patients, 152 (76%) declared that they knew the location of the affected organ; only 44 (22%) patients correctly located the organ on an image. The location was decided to be correct if both lung fields were marked in the thoracic region. Sixty-three (31%) patients indicated the thoracic region but did not fulfill this criterion.

Twenty-four (12%) patients believed that the drugs used for treating COPD caused addiction, whereas 101 (50%) patients had no idea regarding this issue.

With respect to the question about the causal association between COPD drugs and obesity, 40 (20%) patients gave a positive response, whereas 98 (49%) gave a negative response ("no"); 63 (31%) patients did not have an answer.

Only nine of 201 (4.5%) patients considered COPD to be a contagious disease; 132 (66%) patients answered that COPD was not contagious, whereas 46 (23%) patients had no idea regarding the same.

More than half of the patients (n=106; 53%) responded that COPD was a treatable disease.

Cigarette smoking was mentioned as the most important causal factor of the disease by 118 (59%) patients; 41% of patients with COPD did not mention cigarette smoking as a causal factor.

Furthermore, 132 (66%) patients did not research regarding their disease, thus reflecting the health literacy in this population.

DISCUSSION

Our study population only comprised specialist-diagnosed patients with COPD. Being unable to correctly write down the name of the disease, not knowing the main target organ, and being unaware of cigarette-COPD association were considered to be thought provoking. This lack of awareness and basic knowledge among patients who visit a reference hospital in the biggest city of our country was the most striking result of our study.

While there was no statistically significant association between GOLD stages and the lack of knowledge ($p=0.678$), having graduated from primary school and a lack of knowledge were statistically significantly associated ($p=0.002$).

Awareness and basic knowledge regarding the disease, in the general population and in patients with the specific disease, are important factors in the management of the chronic disease. Many studies in Turkey and worldwide have been designed to identify and fill the gap regarding the awareness of COPD.

A study, designed and performed as the GARD project in Turkey, revealed that 49.6% of the population of subjects aged >15 years was aware that COPD was a lung disease and that the most important causal factor was cigarette smoking [4]. Only 25.2% of the population accepted COPD to be a treatable disease. Ersu et al. [6] investigated the awareness regarding COPD among primary care doctors in Turkey who were not previously provided any education. More than half of them correctly responded to the questions regarding the awareness and 83.4% of them considered spirometry to be a diagnostic tool.

There are many studies attempting to investigate the awareness about COPD in the general population or doctors. On the other hand, studies that shed a light on the awareness of patients with COPD themselves are scarce [7-9].

Some questionnaires have been developed to evaluate the level of knowledge of patients with COPD, and one of them is the Bristol COPD Knowledge Questionnaire [10], which examines the level of knowledge and the effects of education. We developed a simple questionnaire comprising 15 questions, because there is no validated tool for generally assessing COPD knowledge in our country, we developed a simple questionnaire comprising 15 questions.

The international BREATHE study was conducted among the populations of 10 countries in the Middle East and North Africa [7]. It identified subjects aged ≥ 40 years who fulfilled the epidemiological definition of COPD and examined their perceptions regarding the disease, as well as their attitudes and beliefs. It was found that 19.3% of patients had a university degree and 31.6% had a high school degree, whereas in our study, the population had a much lower education level, with only 1.5% having a university degree and 3.5% being high school graduates. Overall, 50.3% of patients identified smoking to be the underlying cause, which was in concordance with our result of 59% of patients. The educational level of our patients was not high; thus, their intellectual ability was not good. Compared with the general Turkish population according to the 2013 data of Turkish Statistical Institute, our study population had a lower education level, with 80% of our patients having less than a high school education level compared with 54% of the general population. This can be attributed to the fact that COPD affects people with lower socioeconomic status and that these patients frequently visit state hospitals.

Another study that examined comorbidities, patients' knowledge, and disease management of patients with COPD in a national sample in USA showed that patients with COPD had a much better recall of their blood pressure and cholesterol levels than their FEV₁. This was considered interesting as lung function is a stronger independent predictor of survival than blood pressure or cholesterol levels [8]. This again underlines the need for a more public education of COPD.

In Korea, with a COPD prevalence of 17.2%, a nationwide survey was developed to explore the behavior of patients with COPD [9]. The proportion of well-educated respondents among the 300 subjects was low, similar to our study population. Furthermore, 42 % of the subjects did not know the exact diagnosis of their condition, with the percentage decreasing to 30% among very severe patients. Low awareness appears to be a global problem with regard to such an important disease.

A striking fact is that 41% of our patients were unaware about the association between cigarette smoking and COPD. After evidence was found that tobacco package health warnings increased the consumers' knowledge about the health consequences of tobacco use, Turkey was one of the countries that transferred this into practice in 2010. There is actually no package warning mentioning COPD in our country and this could explain the basic lack of knowledge regarding this association. Adding warnings about COPD on cigarette packages could be a simple method of increasing attention to this disease.

Many programs have been developed worldwide to improve patients' education and awareness regarding chronic diseases. The International COPD Coalition was organized in 2001 to improve awareness regarding COPD.

A survey completed in 41 countries showed that there was a global increase in awareness since 2001, with almost 37% of the countries reporting a public awareness of $\geq 20\%$ [11].

Health literacy is defined as the degree to which individuals can obtain, process, and understand basic health information and use this information to make appropriate health decisions. A study that investigated the health literacy among patients with cardiac disorders using the Short Test of Functional Health Literacy in Adults found out that inadequate or marginal health literacy was a risk factor for re-hospitalization owing to heart failure or all-cause mortality among rural patients with heart failure [12]. Although we did not use a specific tool to determine the health literacy level of our study population, 132 (66%) patients did not research regarding their disease, reflecting the lack of health literacy in this population.

This study has some limitations. Because the study was a single-center study, its generalizability was limited. The awareness level of patients visiting a teaching and reference hospital should be a reference point for other facilities, emphasizing the importance of general education for patients with COPD. The questionnaire that we used in this study was not a validated one. Furthermore, we did not perform a pilot study to evaluate its appropriateness. The majority (80%) of our patients were either uneducated or only completed primary school. Hence, a comparison regarding awareness among different educational levels was not possible. We did not assess the financial burden of medications or hospital admissions, which increase the costs of the healthcare system.

There is a lack of awareness and knowledge regarding the disease among patients with COPD regardless of the disease stage. Being unable to write down the name of the disease may be attributed to the general low educational level of the patients, but the ability to name the target organ and the awareness of the association between cigarette and COPD should be achieved for these patients. An educational program should be developed, which can be extended to the majority of patients with COPD, and further studies should be designed with a large number of patients, which evaluate the status before and after educational intervention.

Practice Implications

Simple questionnaires can be used to improve the awareness and basic knowledge of patients, particularly those with chronic diseases. This may be very helpful in directing our efforts to improve disease management.

Ethics Committee Approval: Ethic committee approval was received for this study from the Ethics Committee of Yedikule Chest Diseases and Thoracic Surgery Training and Research Hospital (Decision No: 2015/38).

Informed Consent: Written informed consent was obtained from the participants for this study.

Peer-review: Externally peer-reviewed.

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