# Awareness in patients with COPD about the disease and pulmonary rehabilitation: A survey

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# ABSTRACT

Background and Objective: Chronic obstructive pulmonary disease (COPD) is the fourth leading cause of death worldwide. It overloads the healthcare system and increase healthcare expenditure. As a patient's awareness enables him/her to acquire better self-management skills, it helps to reduce the severity and frequency of exacerbations, prevents hospitalizations, and improves health-related quality of life. The current study aims to assess the awareness amongst COPD patients about the disease itself and pulmonary rehabilitation. Materials and Methods: A cross-sectional survey was carried out in order to evaluate awareness through "a COPD awareness questionnaire". This was developed and validated for its content. A total of 21 questions were included in this questionnaire. These questions were divided into two domains that included pulmonary disease (1-12) and pulmonary rehabilitation (13-21). Results: Three hundred patients were recruited of which 282 were included in the study. The subject group consisted of 177 males and 105 females. The mean age of the subjects was 63.54 ± 10.656. Awareness in the "disease domain" was 47.84% and "pulmonary rehabilitation domain" was 25.14%. Awareness about the causes of COPD was 34.8%, of common symptoms was 83.0%, and of activities of daily living that could increase breathlessness was found to be 73.8%. The need to consult a physiotherapist was reported by only 26.2%. 81.2% of the subjects believed that breathing exercise could cause breathlessness; whereas, only 19.5% were aware of secretion removal techniques. Conclusion: The findings of the study suggest an imminent need to educate the public about the disease and the scope of pulmonary rehabilitation and its role in the management of COPD. The education of patients in this regard needs to be incorporated into standard health care practice in order to improve their self-management skills and their quality of life.

KEY WORDS: Awareness, chronic obstructive pulmonary disease, pulmonary rehabilitation, survey

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# **INTRODUCTION**

Chronic obstructive pulmonary disease (COPD) is a slowly progressing disease involving the airways or pulmonary parenchyma (or both) resulting in airflow obstruction. COPD is defined as a preventable and treatable disease, with some significant extrapulmonary effects that may contribute to the severity in individual patients. Its pulmonary component is characterized by

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airflow limitation that is not fully reversible. The airflow limitation is usually progressive, and associated with an abnormal inflammatory response of the lung to noxious particles or gases.<sup>[1]</sup>

COPD is the fourth leading cause of death worldwide.<sup>[2]</sup> It represents 5% of all deaths globally;<sup>[1]</sup> and by 2020, COPD will be the third leading cause of death worldwide.<sup>[1,3,4]</sup> In India, 30% of the patients seen in chest clinics on an outpatient basis and 1-5% of hospital admissions are patients of COPD.<sup>[5]</sup>

The most common factor leading to COPD is cigarette smoking,<sup>[1,6]</sup> hereditary deficiency of alpha 1-antitrypsin,<sup>[1,6]</sup> inhalational exposure to tobacco smoke,<sup>[1,3,6]</sup> and exposure to occupational dust and chemicals.<sup>[1,6]</sup> The symptom of COPD ranges from dyspnea, chronic cough with or without sputum production to poor exercise tolerance. Severity of the symptoms is increased during exacerbations.<sup>[7,8]</sup>

COPD may overload the healthcare system and increase healthcare expenditure. Studies have found that an Indian COPD patient spends about 30% of his income on disease management.<sup>[5]</sup> The management of COPD is symptomatic, and includes pharmacological and nonpharmacological treatment.<sup>[1,6,9]</sup> Along with pharmacological treatment, pulmonary rehabilitation is found to be cost-effective. It includes patient education, exercise training, and psychological intervention.<sup>[9]</sup> Studies have shown that patient education regarding their condition, warning signs and symptoms, pathology, and treatment is believed to be the key element of successful treatment of COPD.<sup>[10,11]</sup>

For patients to be better involved in self-management programs and to utilize action plans effectively, they must understand their illness and its treatment. These in turn prevent hospitalization and improve health-related quality of life.<sup>[10,11]</sup> A Canadian study on knowledge and attitude of COPD patients with regard to their disease found that, their knowledge was poor regarding the cause of their condition, the consequences of inadequate therapy and the management of exacerbation.<sup>[12]</sup>

Another study on patients of the same nationality aimed at assessing information needs and the knowledge of patients with COPD, concluded that there was need for more information, and that a knowledge gap was identified in self-management strategies.<sup>[13]</sup> The existing literature suggests that the prevalence of COPD is high amongst the Indian population and shows a variation among different geographical areas of the country.<sup>[2]</sup>

Nevertheless, there is a paucity of studies assessing the level of awareness about the disease itself and about pulmonary rehabilitation. The current study was aimed to assess the awareness amongst COPD patients about disease and pulmonary rehabilitation. In spite of a growing recognition of COPD as an important health problem, there was no retrievable study to identify the depth of patient's awareness about COPD and pulmonary rehabilitation in India. The aim of the study is to evaluate the awareness about the disease and pulmonary rehabilitation amongst COPD patients.

The objective of the study is to design and validate a questionnaire to determine current awareness about the disease and pulmonary rehabilitation in the case of COPD and to determine awareness about the disease and pulmonary rehabilitation amongst patients with COPD.

# MATERIALS AND METHODS

#### Study design and protocol

Approval was obtained from the scientific research committee and Institutional Ethics Committee of Kasturba Medical College, Manipal University, Mangalore. Patients diagnosed with mild to severe COPD (as per Global Initiative for Chronic Obstructive Lung Disease gold criteria) referred by pulmonologists and physicians were included in the study. Those with a perceived inability to complete the questionnaire were excluded.

A questionnaire with a total of 22 questions was developed at the Department of Physiotherapy, Kasturba Medical College, Manipal University in Mangalore, and used for the same. Content validation of the questionnaire was carried out before being administered among the subjects for survey.

### **Content validation**

For content validation, the questionnaire with a total of 22 questions was presented to 23 experts including three pulmonologists, 10 physicians, and 10 physiotherapists. They used their experience of teaching and treating patients with lung problems to finalize the topics and the content of the questions. The questionnaire which was originally developed in English was translated into local languages Kannada and Malayalam for the ease of understanding by the subjects. Translated versions of the questionnaire were further validated following the standard procedure of translation and back translation into English language.

### Multiple choice questionnaire

Multiple choice questions were designed to test awareness of the chosen topics. The respondents were required to answer whether each statement was 'yes', 'no', or that they did not know. The 'don't know' option was included in order to avoid forcing the patient to guess the answer. A total of 21 questions were included in this questionnaire. The questionnaire itself was divided into two domains that included: Pulmonary disease (1-12) and pulmonary rehabilitation (13-21).

The questions were formulated so that approximately two-third of the statements have the correct answer 'yes', and the others 'no'. Positive scoring was used with a mark being given for a correct answer, but no mark awarded for an incorrect answer or for a 'don't know' response.

# Application of the questionnaire

The information sheet was given to each patient. This described the purpose of the questionnaire. Their written consent was obtained. Baseline information was recorded and the questionnaire was completed in the presence of the researcher. No help was offered or given regarding the correct answers. The time taken for completion of the questionnaire was approximately 20-25 min.

# DATA ANALYSIS

Responses were analyzed to obtain descriptive summaries and frequency analysis of the data using Statistical Package for Social Sciences (SPSS) version 17. The magnitude of awareness was considered to be 'below average' if <33%of the responses in the completed questionnaire were appropriate. Whereas, 33-66% of appropriate responses was considered to be 'average' and >66% considered to be 'above average'.

#### RESULTS

A total of 282 COPD patients responded to the COPD awareness questionnaire. Demographic details of the subjects are mentioned in Table 1. The gender distribution constituted (n = 177 (62.8%)) males and (n = 105 (37.2%)) females. Mean age of the subjects was 63.54 ± 10.656.

#### About the disease

The overall awareness of the "disease domain" was found to be 47.84% (n = 282) mentioned in Figure 1. Details about each question are mentioned in Figure 2. Of the total number of subjects, 47.5% (n = 134) were aware of the term COPD; whereas, 42.6% (n = 120) subjects were aware which organ it affected. Awareness of the causes of COPD evident in only 34.8% (n = 98) of the subjects and 46.5% (n = 131) of the total subjects believed that smoking was a contributing factor for COPD. 56.7% (n = 160) of the population knew the meaning of the phrase 'shortness of breath'; while 36.9% (n = 104) believed that a heavy meal could aggravate breathlessness.

Most common symptoms of COPD were known to 83.0% (n = 234) of the participants. The significance of the color of sputum was known to 34.0% (n = 96).

Table 1: D	Demograp	hic details of	COPD patie	nts
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	N	Percentage (%)
Age (mean)		
63.54±10.65	282	100
Gender		
Male	177	62.8
Female	105	37.2
Duration of COPD		
<2 years	28	9.9
Between 2 and 10 years	170	60.2
>10 years	84	29.8
Smoking history		
No H/O smoking	105 female	86.0
c	17 male	13.9
Still smoking	37 male	13.1
e	0 female	0.0
Stopped smoking	123 male	43.6
	0 female	0.0
Other relevant history		
H/O cooking fire	30	10.4
Beedi worker	15	5.67
H/O tambakoo	07	3.90
Education		
Uneducated	74	26.2
Below 10 <sup>th</sup>	85	30.1
Higher secondary	67	23.7
Graduate	39	13.8
Postgraduate	17	6.0
Total	282	
Income		
50,000 and below	34	12.1
50,001-75,000	38	13.5
75,001-100,000	75	26.6
100,001-150,000	48	17.0
150,001-200,000	42	14.9
Above 200,000	45	16.0
Total	282	100

COPD: Chronic obstructive pulmonary disease, H/O: History of

73.8% (n = 208) of the subjects believed that the performance of activities of daily living could increase breathlessness/breathing problems. 53.9% (n = 152) believed that lung disease could lead to easy fatigability. That lung disease could influence the quality of one's life was accepted by 38.3% (n = 108). The need to consult a physiotherapist for lung or breathing problems was affirmed by 26.2% (n = 74).

#### About pulmonary rehabilitation

According to the study, an awareness of the pulmonary rehabilitation domain was 25.14% (n = 282) as mentioned in Figure 1. Of the total number of subjects, 51.1% (n = 144) believed COPD to be a treatable disease. Details about each question are mentioned in Figure 3. That treatment for COPD is limited to medicine was accepted by 78.7% (n = 222), while 25.5% (n = 72) believed that any form of exercise could increase breathlessness. As many as 81.2% (n = 229) of the subjects believed that breathing exercises could aggravate breathlessness. Only 16.3% (n = 46) deemed that relaxation exercise were related to the patient's condition.

That positional variations like sitting or lying down could affect breathlessness was reported by 29.1% (n = 82);

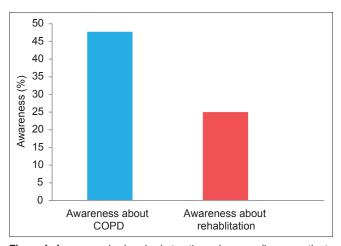


Figure 1: Awareness in chronic obstructive pulmonary disease patients about "disease domain" and "pulmonary rehabilitation domain"

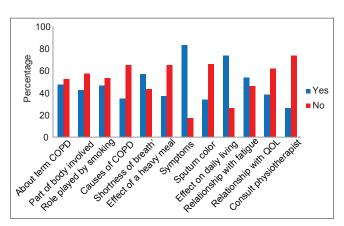


Figure 2: Awareness in COPD patients about "disease domain"

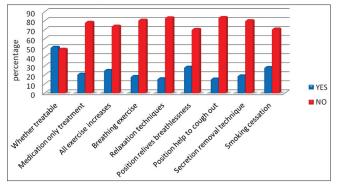


Figure 3: Awareness in COPD patients about "Pulmonary rehabilitation domain"

whereas, 16.0% (n = 45) subjects reported an awareness of any specific positions which could help the patient expectorate. 19.5% (n = 55) of the subjects were aware of secretion removal techniques and 28.7% (n = 81) of the subjects believed smoking cessation had an impact on the patient's condition.

#### DISCUSSION

Available methods of testing awareness were considered while we designed the questionnaire. It was deemed important to have a sufficient number of incorrect responses to each question and so, we did not consider a multiple choice type of questionnaire with single correct response to each question.<sup>[14]</sup> It was decided that open-ended and leading questions would allow more flexibility to the respondents and lead to evaluation of beliefs rather than facts.<sup>[14]</sup> Further, multiple-choice questions with a single right answer were excluded because they would require rigid guidelines for answering the questions and detailed answer keys for marking them.<sup>[14]</sup>

So, we decided that questions with 'yes/no/don't know' as the answer options would be more acceptable for patients, easy to score and therefore, suitable for routine use in both clinical and research settings,<sup>[14]</sup> the chosen topics included in the questionnaire were those that a patient with COPD were expected to be aware of logically. In order to avoid 'forced' and 'virtually meaningless' responses, a third option 'don't know' was included.<sup>[14]</sup>

The questionnaire was divided into two domains the 'disease domain' and the 'pulmonary rehabilitation domain'. The global awareness score for "the disease domain" was 47.84%. We got 'above average' responses when questions pertaining to symptoms (83.0%) and activities of daily living (73.8%) were asked. Average responses were received for questions like organ affected in COPD (42.6%), contribution of smoking to the disease and its progression (46.5%), relationship of disease to easy fatigability (53.9%), and about shortness of breath (56.7%). These findings could be attributed to the fact that subjects become more aware of the symptoms or complaints that

affect their day-to-day life, and opt for a consultation with a physician.

We obtained an average response rate for the questions about the causes of COPD (34.8%), the effect of a heavy meal on the symptoms (36.9%), the importance of observing the color of the sputum (34.0%), and how the quality of life can be affected by the disease process (38.3%). These findings may point towards insufficient importance being given to patient education<sup>[11,15]</sup> as a part of healthcare intervention for COPD.

The lack of awareness in these subdomains may lead the affected population to be less alert in identifying the warning signs of exacerbation of their disease,<sup>[11]</sup> as well as deprive them of the skills to self-manage their condition.<sup>[15]</sup>

Awareness of the role of the physiotherapists in the management of COPD was found to be significantly low (26.2%, below average). This may be attributed to several factors like primary consultants being averse to a physiotherapist referral and a lack of awareness among the general population about the role of the physiotherapists in the management of pulmonary conditions.

Similar outcomes were observed in a study carried out in Bristol, UK where knowledge of the condition among patients with COPD was found to be 54.7%.<sup>[14]</sup> A study carried out in France concluded that there was poor knowledge of COPD, its causes, clinical signs, diagnostic procedures, and treatment among people with or at risk of the disease.<sup>[16]</sup>

The level of awareness in the domain "pulmonary rehabilitation" was found to be only 25.14%. Of the total number of subjects 51.1% considered COPD to be treatable disease, but as high as 78.7% (n = 282) believed medication to be the only available treatment for the disease. The considerable lack of awareness about pulmonary rehabilitation and options available for treatment may be because, as the severity and chronicity of the disease increases, the patient's exposure is limited to the primary consultants and the objectives of consultation would be mere symptom relief.

The results showed that a majority of subjects were not aware of positioning (70.9%), secretion removal techniques (80.5%), relaxation techniques (83.7%) and smoking cessation (71.3%). The findings may be attributed to pulmonary rehabilitation being emphasized less than it should be in the existing healthcare system and the ambitions of the subject population being limited to just the control of symptoms rather than regaining the lost quality of life.

Limitations of this study include the possibility that participants responded to question in the survey questionnaire with perceived ideal answers, thereby giving what they considered to be the best or more appropriate answer to each question. The content validation was performed for the COPD awareness questionnaire, but the other psychometric properties are yet to be established. The components of the disease and pulmonary rehabilitation can be modified and elaborated to seek more information from the patients. Future research on similar grounds can be carried out in subjects suffering from other pulmonary conditions and across various geographical locations.

#### CONCLUSION

The findings of the study suggest an imminent need to educate the public about the disease, the scope of pulmonary rehabilitation, and its role in the management of COPD. Patient's education needs to be incorporated into the standard healthcare practice through which the patients can improve their self-management skills and quality of life.

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