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Differences between physician and patient in the perception of symptoms and their severity in COPD

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Summary

Chronic Obstructive Pulmonary Disease (COPD) impairs quality of life and presents symptoms that affect the lives of patients. Our study analysed the degree of concordance between the patients and their pulmonologists in the perception of the severity of symptoms. A cross-sectional, descriptive, multicentre study was conducted in patients with COPD. From a list of 10 symptoms (cough, dry mouth, chest pain, expectoration, wheezing/whistling in the lungs, depression/sadness/discouragement, fatigue/tiredness/general lack of energy, anxiety/nervousness, breathlessness/shortness of breath upon exertion and difficulty sleeping/sleep disorders) each investigator and patient assessed those which, in their opinion, most concerned or affected the patient. A total of 450 patients were included in the study (91.3% males, 66.7 years old (SD = 10.2), $FEV_1(\%)$ 51.7% (SD = 12.7%)). At an aggregate level, breathlessness/shortness of breath, fatigue/tiredness and coughing were identified by patients and physicians as being the most relevant symptoms. However, according to the concordance analysis conducted with individual pairs (each pulmonologist with his/her patient), only 52.8% coincided when identifying the symptom that most concerned or affected the life of the patient. The concordance analysed by the Kappa index between patients and physicians was poor (<0.42). The degree of physician–patient concordance was greater in patients with more

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severe COPD. The patients and their pulmonologists identified the same three main symptoms of COPD but showed low concordance when assessing the impact of the symptoms of the illness.

Introduction

Chronic obstructive pulmonary disease (COPD) produces a very relevant impact on the general well-being and quality of life of the patient who suffers from it [1,2]. Besides the known symptoms of the disease there are other aspects such as fatigue or sleep disorders that present significant daily challenges for patients with COPD, even though they may go unnoticed by the physician [3–5]. The cause of this lack of adequate recognition may lie in the physician interpreting these symptoms differently from the way the patient perceives them, and consequently may not give these symptoms the due importance in his/her clinical monitoring.

This differential perception of symptoms between the physician and the patient, within different health areas, has been named physician–patient concordance, and has generated growing interest in recent years. This is due to progressive changes within the healthcare model, giving greater importance to the patient and his/her opinion regarding the treatment of their disease and the healthcare they receive. Physician–patient concordance has been the subject of studies on such diverse aspects as patient quality of life [6], patient satisfaction regarding certain aspects of healthcare [7], symptomatic manifestations specific to certain populations such as elderly patients [8], primary care patients [9,10] and symptomatic manifestations associated with certain diseases such as cancer [11]. Generally speaking, these aspects have yielded low levels of concordance in terms of perception, which may reflect a problem in the physician–patient relationship and, consequently, in the monitoring of the illness.

So far the few studies on "physician–patient" concordance centred on the area of COPD have been exploratory in nature, with small sample sizes providing insufficient information [12,13]. However, to what extent the perception of the physician and the patient differs or agrees, with regard to the level of symptoms caused by COPD, would provide new knowledge that could help to more precisely identify the healthcare needs of the patient.

The present study proposes to quantify and compare the relative importance attributed by the patients as well as the specialists, who regularly attend them, with regard to certain symptomatic manifestations relating to COPD. It seeks to highlight the commonalities and differences between the perceptions of the physician and the patient with respect to a common reality.

Methods

This was a multicentre, observational, cross-sectional, descriptive study conducted in the Pneumology Services in hospitals throughout Spain. Information gathering was conducted during a single visit in which the principal sources of information were the patients themselves, along with their corresponding clinical histories and their physicians.

The patients included in the study had to comply with the following criteria: a) a diagnosis of moderate or severe COPD (post-bronchodilator FEV_1/FVC <0.70 and FEV_1(%) <80%); b) age ≥40 years old; c) smoker or ex-smoker of at least 10 pack-years; d) patients who were capable of understanding and filling out the questionnaires; and e) patients that had signed the informed consent form to take part in the study.

Those not included in the study were: a) patients diagnosed with another chronic respiratory disease such as asthma or any serious comorbidity that might affect the interpretation of the outcomes, including sleep apnoea syndrome, uncontrolled cancer, symptomatic heart failure, dementia, depression, alcoholism or other addictions and moderate or severe kidney failure; b) hospitalised patients; c) patients who were taking part in any other clinical trial or research study; d) patients with COPD exacerbation at the time of inclusion; and e) patients requiring continuous oxygen therapy. The study was approved by the Clinical Ethics and Research Committee (CIEC) of the Hospital Universitari Vall d'Hebron (Barcelona, Spain) and all the patients gave written informed consent.

Data collection for the study was conducted between July and November 2008. During a single visit with the pulmonologist, each patient provided socio-demographic data (age, sex, level of education) and clinical data related to COPD (time since diagnosis, spirometry with bronchodilator test, smoking habits, COPD clinical symptoms, pharmacological treatment, comorbidity). The degree of dyspnoea was evaluated with the Medical Research Council's (MRC) scale [14]. Comorbidity was evaluated using the Charlson Index [15].

An ad-hoc list was prepared for the study that included the following COPD symptoms: cough, dry mouth, chest pain, expectoration, wheezing/whistling in the lungs, depression/sadness/discouragement, fatigue/tiredness/ general lack of energy, anxiety/nervousness, breathlessness/shortness of breath upon exertion and difficulty sleeping/sleep disorders. For each patient, the investigator identified the four symptoms that in his/her opinion most concerned or affected the patient's life at that time, scoring the symptoms from the greatest to the least impact. At the same time, the patient also indicated which 4 of the 10 symptoms affected him/her most. Moreover, the patient also evaluated the impact of the 10 symptoms on his/her daily life and how they were affected by means of a Likert-type ordinal scale of 5 response options ranging from "It doesn't affect me" to "It affects me a lot". The

assessment of the symptoms by the physician and the patient were conducted simultaneously and without the likelihood of interaction between the two. Questionnaires for patients and physicians had a different structure and design to make direct comparisons difficult in an attempt to prevent any potential biased responses.

Lastly, data relative to the study investigator was also collected, in particular: his/her age, sex, years of practice as a specialist, practice setting, monthly average of COPD cases he/she diagnosed as well as the average monthly number of COPD cases attended, for the purpose of assessing whether or not there was any kind of association between the level of concordance and the profile of the investigator.

Statistical analysis

Categorical variables have been described according to the number and percentage of subjects in each category. Continuous variables have been described using mean and standard deviation. Non-parametric tests (bilateral Kolmogorov—Smirnov tests with a confidence level of 95%) were conducted to assess the normal distribution of the questionnaire scores; therefore the bivariate analysis was carried out using the Mann—Whitney test (for two samples), the bilateral Kruskal—Wallis test with a confidence level of 95% (for 'n' samples) and Spearman Rho (for continuous variables). The use of these three non-parametric tests was determined on a case-by-case basis. The bivariate analyses between variables with normal distribution were conducted by means of the unilateral Fisher's Exact Test or the bilateral Chi-Square Test, both with a confidence level of 95%. In addition, the Kappa index [16] was obtained to assess the degree of concordance between two different observers (patient and physician) in order to assess to what extent Observer 1 and Observer 2 coincided in their measurement or assessment when using categorical variables. In this case, this index was used to measure the degree of concordance between the patient and his/her physician in identifying which of the 10 COPD symptoms studied concerns or affects the patient's life the most. The magnitude of the K coefficient, which ranges from 0 (without concordance) to 1 (maximum concordance) is usually interpreted as follows: poor concordance ($K < 0.20$), weak concordance (K between 0.21 and 0.40), moderate concordance (K between 0.41 and 0.60), good concordance (K between 0.61 and 0.80), and very good concordance (K between 0.81 and 1.00) [17]. Statistical analysis were carried out using specific SPSS software.

Results

A total of 77 pulmonologists from 63 hospitals evaluated 649 candidate patients to be enrolled in the study. Of these, 152 were excluded for non-compliance with any one of the inclusion or exclusion criteria and 47 for possessing insufficient data for analysis, so that the final evaluable sample consisted of 450 cases (69.3%).

Table 1 shows the socio-demographic and clinical characteristics of the patients included. There was a majority of males (91.3%) with a mean age of 66.7 years (SD = 10.2)

Table 1 Socio-demographic and clinical characteristics of the study sample (N = 450).

Age, mean (SD)	66.7 (10.2)
Sex, male, N (%)	411 (91.3)
Level of education, N (%)	
No formal education	88 (19.6)
Primary education	237 (52.7)
Secondary education	88 (19.6)
University or similar	35 (7.8)
Time (in years) since diagnosis, mean (SD)	7.7 (5.3)
Post-bronchodilator spirometry values, mean (SD)	
FVC (ml)	2836.8 (720.9)
FVC (%)	77.3 (17.4)
FEV_1 (ml)	1470 (449.5)
FEV_1 (%)	51.7 (12.7)
FEV_1/FVC	51.1 (10)
Smoking, N (%)	
Ex-smoker	346 (76.9)
Smoker	101 (22.4)
Pack-years, mean (SD)	49 (26.6)
Degree of dyspnoea, mean (SD)	2.5 (0.8)
Exacerbations in the last 12 months, mean (SD) [min, max]	1.67 (1.83) [0, 13]
Pharmacological treatment, N (%)	
Short acting beta 2 agonist	259 (57.5)
Long acting beta 2 agonist	390 (86.6)
Inhaled corticosteroids	374 (83.1)
Oral corticosteroids	10 (2.2)
Anticholinergics	383 (85.1)
Theophylline	38 (8.4)
Number of treatments indicated for COPD, mean (SD)	3.2 (1.04)
Number of concomitant treatments, mean (SD)	1.1 (1.4)
Charlson comorbidity index, mean (SD)	1.8 (2.7)

SD: standard deviation.

and with a low or very low level of education (72.3%). The mean time since diagnosis of the illness was 7.7 years (SD = 5.3). The mean FEV_1(%) post-bronchodilator was 51.7% (SD = 12.7%). 76.9% were ex-smokers with a mean tobacco consumption of 49 (SD = 26.6) pack-years. The mean degree of dyspnoea was 2.5 (SD = 0.8). The most used medication was long-acting beta 2 agonists (86.6%), anticholinergics (85.1%) and inhaled corticosteroids (83.1%). The mean Charlson index was 1.8 (SD = 2.7).

Table 2 shows the list of COPD symptoms which, according to both physicians and patients, most affected patients' lives. In general, the group of patients and physicians identified "breathlessness/shortness of breath upon exertion" as the symptom that most concerned or affected patients' lives, followed by "fatigue/tiredness/general lack of energy" and "cough". From there on patients and physicians differed in opinion. For example, according to

Table 2 Ranking of COPD symptoms that affect or concern[a] the study patients, according to the physician and according to the patient ($N = 450$).

	Patient's assessment		Physician's assessment		Spearman's Rho	Difference in means[b]
	Position in the ranking	Mean (SD)	Position in the ranking	Mean (SD)		
Breathlessness/shortness of breath upon exertion	1st	2.58 (1.04)	1st	3.05 (1.34)	0.29	<0.001
Fatigue, tiredness, lack of energy in general	2nd	2.23 (1.15)	2nd	1.67 (1.46)	0.30	<0.001
Coughing	3rd	1.81 (1.11)	3rd	1.53 (1.41)	0.29	<0.001
Anxiety/nervousness	4th	1.57 (1.27)	7th	0.49 (1.03)	0.34	<0.001
Expectoration	5th	1.56 (1.09)	4th	1.05 (1.28)	0.36	<0.001
Dry mouth	6th	1.45 (1.32)	9th	0.35 (0.94)	0.27	<0.001
Despondency, sadness or enervation	7th	1.43 (1.24)	5th	0.63 (1.13)	0.36	<0.001
Wheezing/whistling in the lungs	8th	1.32 (1.07)	6th	0.54 (1.03)	0.25	<0.001
Difficulty sleeping, sleep disorders	9th	1.32 (1.25)	8th	0.39 (0.90)	0.33	<0.001
Chest pain	10th	0.71 (0.95)	10th	0.19 (0.66)	0.28	<0.001

[a] The scale used ranges from 0 (doesn't affect/concern the patient) to 4 (affects or concerns the patient a lot).
[b] After conducting the Kolmogorov—Smirnov test a comparative analysis by means of non-parametric tests was conducted: test for 2 independent samples U Mann Whitney (confidence level of 95%).

patients, "anxiety and nervousness" was a symptom that concerned or affected them somewhat (appearing in 4th place), while the physicians considered it to be much less relevant (appearing in 7th position), which means a low correlation with regard to the importance attributed to each symptom by both physicians and patients (Spearman Rho = 0.29—0.30).

Fig. 1 and Table 3 show the results of the concordance analysis between the 450 pairs of observers (each patient with his/her corresponding physician). When asked which symptom most concerned or affected the patient's life, 238 pairs of observations coincided (52.8% of the total). In particular, for 258 patients "Breathlessness/shortness of breath" was the most distressing symptom. Concurrently, the physicians considered that this was the symptom that most concerned 204 of the assessed patients. However, when analysing these assessments for each pair of physicians/patients, only 159 of the assessments given by the physicians concurred with those of the patients (Cohen's Kappa value of barely 0.37). In terms of "Expectoration", it was the most distressing symptom for 24 patients and the physicians considered this symptom as being the greatest concern in 25 of the assessed patients. However, only 11 of these assessments coincided between physician and patient (Cohen's Kappa value of 0.42). When conducting a symptom-by-symptom assessment, Cohen's Kappa values ranged between 0.18 and 0.42.

Table 4 describes which characteristics of the patients and physicians were associated with patient—physician concordance with respect to identifying the COPD symptom that most concerns and affects the life of the patient. In the group of concordant pairs there was a greater frequency of patients with severe COPD ($p = 0.019$), patients with a higher degree of dyspnoea ($p = 0.002$), patients with

more exacerbations ($p = 0.026$) and those treated in hospitals ($p = 0.046$) and ex-smokers ($p = 0.004$), than in the group of non-coinciding patient—physician pairs. This trend was corroborated when obtaining Cohen's kappa values between patient—physician for the "breathlessness/shortness of breath" in patients who smoke (kappa = 0.19) and ex-smokers (kappa = 0.42), and in patients with severe (kappa = 0.39) and moderate dyspnoea (kappa = 0.31). At the same time, the symptom considered as most critical by both the patient and the physician was "breathlessness/shortness of breath", regardless of the degree of COPD severity (in terms of dyspnoea and stage of illness) and of whether they were active or ex-smokers.

Discussion

The present study was conducted to provide evidence to identify any similarities or disparities between physicians and patients in the perception of symptoms and the severity of COPD, not only from an aggregate perspective, but more importantly, at the level of inter-observer concordance; in other words, between each patient and his corresponding physician. As is shown in some other studies conducted in other therapeutic areas [18,19], patient—physician concordance could be vital in contributing to improved control of the patient's disease, amongst other things, because it would serve to adapt clinical management and treatment to the needs of each individual patient. On the other hand, poor concordance would encourage the physician to make decisions that did not conform to the patient's reality. The recently published Spanish guidelines [20—22] and the new GOLD document [23] recommend and insist on including symptom severity

% [0Affects less - 100 Affects more]
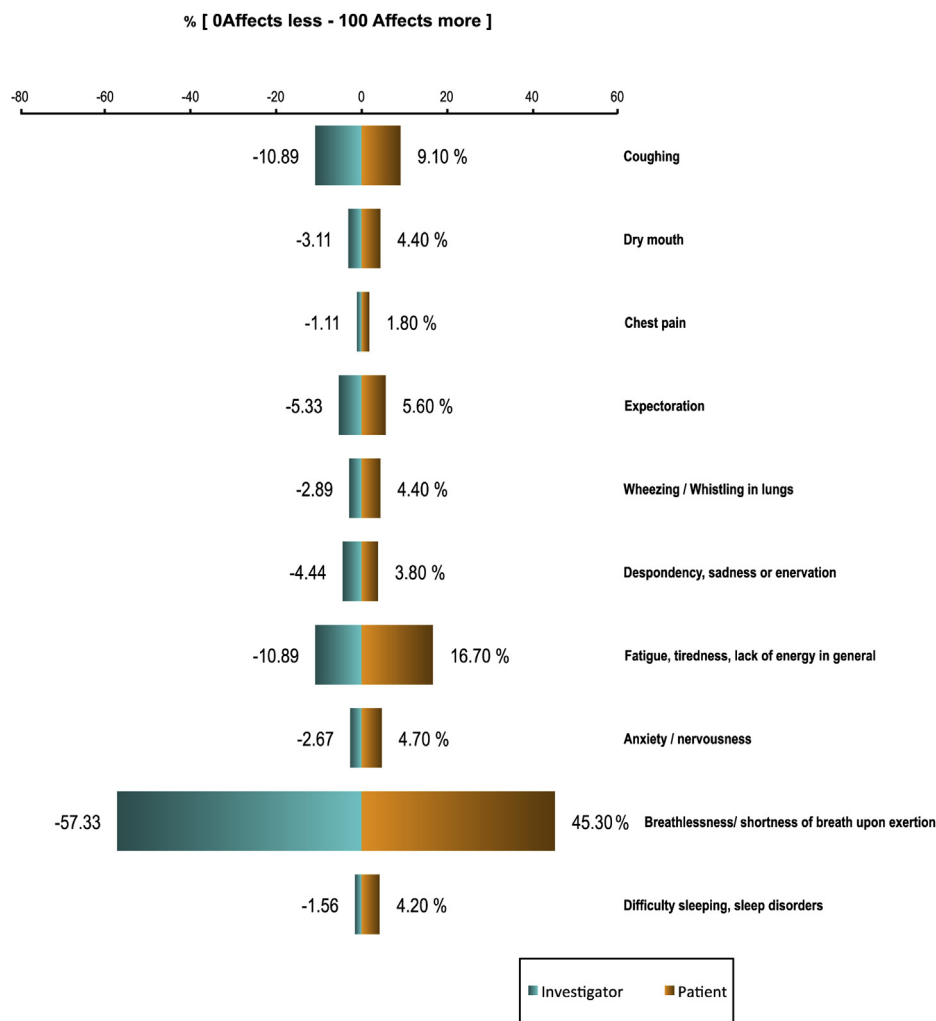
Figure 1 Degree of physician—patient concordance to identify which COPD symptom most affects the life of the patient (*N* = 450).

ratings to guide treatment. The introduction of the COPD Assessment Test (CAT) and the COPD Clinical Questionnaire (CCQ) in the new recommendations is an attempt to improve patient—physician communication, but their implementation in primary care in most countries is still very limited. The results of this study shed more light upon the little data available at the present time, with regard to the degree of patient—physician concordance within the scope of COPD [12,13] for the purpose of designing potential remedial strategies.

According to the study results, at the aggregate-level, both the participating patients and physicians coincided in considering that breathlessness/shortness of breath, fatigue/tiredness and cough, in this order, were the three symptoms that most concerned and affected the lives of patients with COPD. However, a detailed analysis of the concordance between each patient and his/her physician suggests that the office visit with the pulmonologist does not provide a sufficiently precise idea of the impact of the symptoms on the patient's life. This is true, if we bear in mind that barely 53% of the physicians were correct in identifying the symptom that most concerned or affected

each patient's life. In fact, the same occurred when the concordance analysis was conducted differentially for the 10 assessed symptoms: in both the 5 patients who considered chest pain to be the symptom that most concerned them and the 258 patients that considered breathlessness/shortness of breath to be the most distressing symptom, the physician's rate of accuracy was poor, obtaining concordance indexes of less than 0.42. There was a tendency for greater concordance when the symptom referred to as the most critical for the patient could be detected as a sign the diagnosis of the disease (for example breathlessness, coughing, expectoration or wheezing) instead of being more subjective (as in nervousness, anxiety, fatigue or dry mouth).

There are very few studies dealing with patient—physician communication in the field of COPD. A previous study performed in the US in a population of 342 veterans with COPD showed that better communication between patients and clinicians was associated with quality of care and confidence in dealing with breathing problems and the specific clinicians' behaviours, with larger associations with higher quality care including listening, caring and

Table 3 Degree of concordance between physician—patient when identifying the COPD symptom that most affects the patient's life (N = 450).

	Symptom that most concerns or affects the patient's life at the moment			
	According to the patient, N(%)	According to the physician, N(%)	Coincidence between both observers, N(%)	Kappa index between assessors
Coughing	49 (10.9)	41 (9.1)	20 (4.4)	0.383
Dry mouth	14 (3.1)	20 (4.4)	6 (1.3)	0.328
Chest pain	5 (1.1)	8 (1.8)	2 (0.4)	0.298
Expectoration	24 (5.3)	25 (5.6)	11 (2.4)	0.417
Wheezing/whistling in the lungs	13 (2.9)	20 (4.4)	7 (1.6)	0.403
Despondency, sadness or enervation	20 (4.4)	17 (3.8)	8 (1.8)	0.408
Fatigue, tiredness, lack of energy in general	48 (10.7)	75 (16.7)	17 (3.7)	0.183
Anxiety, nervousness	12 (2.7)	21 (4.7)	4 (0.9)	0.216
Breathlessness, shortness of breath upon exertion	258 (57.3)	204 (45.3)	159 (35.3)	0.369
Difficulty sleeping, sleep disorders	7 (1.6)	19 (4.2)	4 (0.9)	0.292
Total	450 (100%)	450 (100%)	238 (52.8)	

Table 4 Clinical characteristics of the patient according to the degree of concordance with his physician regarding the symptom that most concerns him/affects his life (N = 450).

	Degree of concordance between the two observers (physician and patient)		p-Value
	With concordance (N = 238)	Without concordance (N = 212)	
Years of evolution of COPD, mean (SD)	7.9 (5.3)	7.4 (5.4)	0.315[a]
Stage of the illness, N (%)			
Moderate	117 (48.3)	125 (51.7)	0.019[b]
Severe	119 (58.6)	84 (41.4)	
Degree of dyspnoea, mean (SD)			
0—1	103 (45.6)	123 (54.4)	0.002[b]
2—4	132 (59.7)	89 (40.3)	
Number of outpatient treated exacerbations, in the last 12 months, mean (SD)	1.2 (1.3)	1 (1.2)	0.071[a]
Number of exacerbations requiring hospital admission, in the last 12 months, mean (SD)	0.6 (1)	0.5 (1.4)	0.046[a]
Total number of exacerbations, mean (SD)	1.8 (1.8)	1.5 (1.9)	0.026[a]
Charlson's index of comorbidities, mean (SD)	1.6 (2.7)	1.9 (2.8)	0.298[a]
Currently a smoker, N (%)			
No	195 (56.4)	151 (43.6)	0.004[b]
Yes	41 (40.6)	60 (59.4)	

[a] Mann—Whitney non-parametric bilateral test for two independent samples (confidence level of 95%).
[b] Fisher's Exact unilateral test (level of confidence 95%).

attentiveness [24]. The poor concordance between COPD patients and their physicians has different explanations. One reason is the absence of a systematic procedure to assess the patient's symptomatology during the clinical visit. The absence of a list of questions encourages the omission of relevant symptomatic aspects. On the other hand, even if the physician does not formulate a question, the patient can explain the symptoms that affect him/her, but this spontaneous explanation on behalf of the patient will vary according to the planning of the visit, memory and personal and emotional factors. The time that the physician can devote to the patient during an office visit is also another factor to be borne in mind. Therefore, a symptom that may concern the patient could be passed over during a rushed visit. Moreover, the fact that on many occasions the patients treated are stable and/or long-term ones instead of recently diagnosed patients would contribute to the office visits being more routine and would induce a certain assimilation on the patient's behalf of what his illness is and what COPD means, which would lead to a lesser predisposition to explain any changes in the symptoms suffered [8].

A "fair" degree of concordance was observed when the patient presented severe versus moderate COPD, when the dyspnoea levels are worse and the patient has a greater number of exacerbations or hospitalisations. These factors have also been identified in previous studies about other diseases [8,11] and their influence on concordance could be put down to the physician attending these seriously ill patients more often and therefore being more informed about their status. Moreover, it is reasonable to believe that patients with more advanced COPD experience more abundant and intense symptoms and, therefore, these are more easily described by the patient and recognisable to the physician. It can also be assumed that as COPD advances, the patient will more openly express anything relating to the illness and how he/she deals with it on a day-to-day basis, so that patient–physician communication will be more effective and sincere. All this is consistent with previous studies, according to which patient–physician communication is associated with the quality of the health care received [24]. Therefore, strategies to promote this therapeutic communication could positively affect the care received by patients with COPD.

Lastly, when the patient is an ex-smoker versus a smoker, patient–physician concordance also improves somewhat. The negative influence of active smoking within concordance is probably due to the patient's awareness of not following the physician's indications or recommendations, which may sway him/her towards secrecy and the tendency to underestimate the symptoms.

The study also presents some limitations to be considered. On the one hand, the participating physicians were aware of the objectives of the study being conducted, meaning that they may have made a special effort to make assessments that coincided in great part with the patient's perceptions. However, because of this, the study results acquire greater relevance with regard to the discrepancies between patients and physicians. Another limitation to be borne in mind is that the study was conducted in the field of outpatient hospital care by pulmonologists. We do not know if these results can be extrapolated to other fields such as out-patient primary care centres, where the time available

for attending to patients may be even more limited. We used a questionnaire developed ad hoc for the purpose of the study. This questionnaire did not follow any formal validation process because it was not intended to be used for any scoring system or guiding in any management decisions. Comorbidities may have influenced the intensity and perception of symptoms; however, we only focused on the concordance between patients and clinicians in the interpretation of symptoms irrespective of the causes. Finally, another limitation is the low number of female patients. The gender distribution in our study corresponds to the gender distribution of COPD in Spain where most patients with moderate to severe COPD are males [2]. Therefore, extrapolation to women must be made with caution.

In conclusion, although patients and clinicians identified the same three main symptoms of COPD, this study provides further evidence regarding the low level of concordance existing between the COPD patient and the physician at the time of assessing the impact of disease symptoms on the patient's life, although this concordance was higher when the case assessed presented more severe disease. In light of these results, it would be recommendable to define strategies to encourage specialists to take a closer and more accurate view of the impact of the symptoms of the disease on the patient's life and adapt it to the clinical management of the patient's reality as much as possible.

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Conflicts of interest

Acknowledgements

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