





Information Needs in COPD After an Educational Programme: Influence in Exacerbations and Admissions

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Carlos Antonio Amado ¹
Cecilia Pérez-García²
Begoña Tamayo Fernández ³
Juan Agüero-Calvo³
Pedro Muñoz-Cacho ⁴
Rafael Golpe ⁵

¹Hospital Universitario Marqués de Valdecilla, Servicio de Neumología, Universidad de Cantabria, Santander, Spain; ²Universidad de Cantabria, Santander, Spain; ³Hospital Universitario Marqués de Valdecilla, Servicio de Neumología, Santander, Spain; ⁴Servicio Cántabro de Salud, Santander, Spain; ⁵Hospital Universitario Lucus Augusti, Servicio de Neumología, Grupo C039 Biodiscovery HULA-USC, Instituto de Investigación Sanitaria de Santiago de Compostela (IDIS), Santander, Spain

Introduction: Improving patients' information needs (IN) may contribute to better control in COPD. This study analyses IN using Lung Information Needs Questionnaire (LINQ) following an educational intervention, evaluates how clinical characteristics modify IN, and studies high IN as a prognostic factor for COPD exacerbations and hospital admissions.

Methods: Cohort of 143 patients with initial diagnosis of COPD included in a structured educational program. Two months after completing the program, IN was assessed using LINQ. Correlations between IN and clinical variables of COPD and distribution of IN in different clinical groups were analyzed. Univariate and multivariate analysis was performed to determine influence of IN on exacerbations and COPD admissions over the following year.

Results: LINQ scored 6.3 ± 2.9 . There were no differences in LINQ scoring between different clinical groups, but LINQ score positively correlated with age ($r=0.184$, $p=0.029$). High IN was a predictor of COPD hospitalizations (HR 2.3 [95% CI 1.1–5.1] ($p=0.029$)) but not of less severe exacerbations ($p=0.334$).

Conclusion: IN was not associated with any clinical variables, but it correlated with age. High IN proved to be an independent predictor of admissions.

Keywords: COPD, education, COPD exacerbation

Introduction

Chronic Obstructive Pulmonary Disease (COPD) is one of the main causes of morbidity and mortality worldwide.¹ Exacerbation risk reduction is one of the key objectives for the management of the disease as stated by clinical guidelines.^{2,3} Exacerbations influence on the deterioration of respiratory function tests⁴ and on the disease prognosis.^{5,6}

COPD patient education programs improve self-management, exercise capacity, quality of life, levels of anxiety,⁷ and reduce treatment costs.⁸ Despite this, structured education programs in this disease and its evaluation are scarce. The Lung Information Needs Questionnaire (LINQ)⁹ is a self-administered questionnaire consisting of 16 questions divided into 6 domains: Knowledge about the disease, medications, self-management, exercise, diet and smoking. It has been used to evaluate respiratory rehabilitation programs,¹⁰ in other types of educational programs for patients with COPD in outpatient clinics^{11,12} or during hospital admissions.¹³ This questionnaire has been previously validated⁹ and translated into several languages including Spanish.¹⁴ However, the LINQ has never been

Correspondence: Carlos Antonio Amado
Servicio de Neumología, Hospital
Universitario Marqués de Valdecilla,
Avenida Valdecilla SN, Santander 39001,
Cantabria, Spain
Email carlosantonio.amado@scsalud.es

used to assess which COPD Characteristics are correlated with information needs (IN), nor how IN influence moderate COPD exacerbations or admissions due to exacerbations.

In our clinical setting patients receive a standard educational cycle on COPD performed by a specialized educational nurse based on recommendations from clinical guidelines^{2,3} and LINQ domains, assessing treatment posology and technique, self-management, diet, exercise, vaccination and progression of the disease. Two months after this intervention, patients are tested using the LINQ questionnaire.

The objective of this study is to determine whether IN after having been diagnosed and having received a standard educational cycle on their disease influence in respiratory exacerbations or admissions and to assess whether IN correlates with any clinical variable of the disease or if they are typical of any of the phenotypes described in the disease management guidelines.²

Methods

Retrospective longitudinal cohort study in which the medical records of patients treated consecutively in the COPD monographic clinics – which attend patients referred from Primary care or Hospitalization due to suspected COPD – from a Spanish third level hospital with 800 beds belonging to the public health system. This study was approved by the Ethics Committee of Cantabria (2019.112). Informed consent was obtained from participants to perform all procedures related to the study and it was conducted in accordance with the Declaration of Helsinki.

Participants

The patients included in the study had a COPD diagnosis confirmed by spirometry carried out according to SEPAR criteria¹⁵ with a post-bronchodilator FEV1/FVC ratio of less than 0.7. After the initial disease diagnosis, and after the indication of pharmacological treatment, patients attended a complementary nursing consultation, in which the educational programme was performed, addressing issues such as smoking, exacerbations, the use of inhaled therapy and other useful aspects in order to have better

self-management. Two months after this intervention, patients were tested using the LINQ questionnaire to determine their degree of knowledge about the disease and were included in the study.

The study was carried out between December 2016 and January 2018 with a subsequent review of the medical records to identify exacerbations and admissions during the year after completing the questionnaire.

Variables

Collected clinical variables (2 months after COPD diagnosis): Age, Sex, Post-bronchodilator spirometric variables: Maximum expiratory volume in the first second (FEV1), Forced Vital Capacity (FVC), FEV1/FVC, COPD Assessment Test (CAT) quality of life questionnaire,¹⁶ dyspnea according to the modified Medical Research Council (mMRC) dyspnea scale,¹⁷ number of moderate COPD exacerbations in the year prior to the visit (moderate exacerbations were defined as respiratory exacerbations which required antibiotic treatment and/or systemic corticosteroids recorded in patient's electronic medical records in the year prior to the LINQ questionnaire), number of admissions for COPD exacerbation in the year prior to the visit recorded in patient's electronic medical history, diagnosis of cognitive impairment prior to the visit, Pharmacological treatment for COPD, Charlson Comorbidity Index,¹⁸ LINQ questionnaire total score and in each of its 6 domains: Disease knowledge (questions 1 to 4 and score between 0 and 4 points), Medicines (questions 5 to 7 and score between 0 and 5 points), Self-management (questions 8 to 9 and score between 0 and 6 points), Smoking (questions 10 to 12 and score 0–3 points), Exercise (questions 13 to 15 and score between 0 and 5 points), Diet (question 16 and score between 0 and 2 points). The minimum score is 0 (it indicates lowest information needs), while the maximum score is 25 points (highest information needs).¹⁴

The number of moderate exacerbations and hospital admissions for COPD exacerbation during the year after the answer to the LINQ questionnaire were collected. The study schedule is shown in [Figure 1](#).

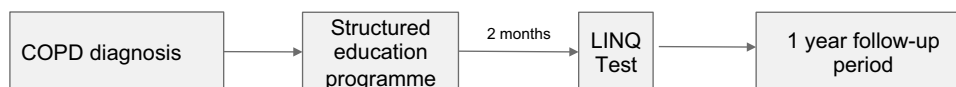


Figure 1 Study schedule.

Clinical Groups

The patients were divided into groups according to clinical variables proposed by the GesEPOC (Spanish COPD guidelines) and GOLD guidelines^{2,3} based on: FEV1: mild COPD (FEV1 \geq 80% of predicted value), moderate ($50\% \leq$ FEV1 $<$ 80% of predicted value), severe ($30\% \leq$ FEV1 $<$ 50% of predicted value), or very severe (FEV1 $<$ 30% of the predicted value). CAT: Non-symptomatic: score \leq 9 or less, symptomatic: $>$ 9 points. mMRC Dyspnoea score, dyspneic: score 2 or more. Non-dyspneic: score 0–1.

Patients with 2 or more exacerbations were considered exacerbators, patients with 1 or none were considered non-exacerbators.

Patients with a score higher than the 75th percentile of our sample on the LINQ questionnaire were considered patients with high IN.

Statistical Analysis

The Kolmogorov–Smirnov technique was used to assess the data adjustment to a normal distribution. Parametric variables were presented as mean \pm standard deviation and non-parametric variables as median (interquartile range). T-student test for unpaired samples was used to establish the differences in variables with normal distribution, and the Mann–Whitney *U*-test was used to determine differences between variables with a non-parametric distribution. To study the

correlations between the different clinical variables, the Spearman test was used for non-parametric variables and the Pearson test for parametric variables. A univariate and multivariate analysis was implemented to determine which variables intervene as predictors of exacerbation and admission using the Cox regression test. Two-tailed tests were used and a level of $p < 0.05$ was considered statistically significant. Statistical analysis was developed with the SPSS program (version 25.0 for pc).

Results

A total of 170 medical records of patients seen in outpatient Pneumology clinics at the Marqués de Valdecilla University Hospital were analyzed. Twenty-seven patients were excluded from the study due to different reasons: Patients moved to other area (1 case), absence of subsequent follow-up at the referral hospital (6 cases), patients who did not answer the LINQ questionnaire due to presenting a previous diagnosis with moderate-severe cognitive impairment (5 cases), and patients whose LINQ questionnaire score had not been collected in the electronic history due to technical problems (15 cases). A total of 143 patients were finally included in the study. Seven patients did not complete the follow-up study due to death (four patients due to severe COPD exacerbations, two patients due to lung cancer and colon cancer in one patient). Six of the deceased patients

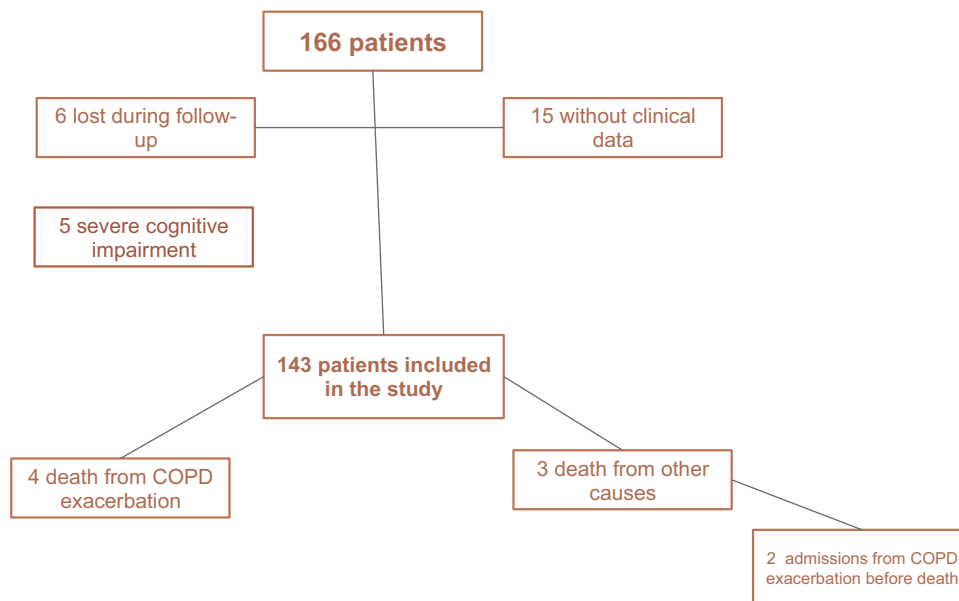


Figure 2 Flowchart of patient selection.

showed an admission due to COPD exacerbation prior to death (Figure 2).

Clinical Characteristics of the Patients Included in the Study

The most relevant characteristics of the patients included in the study are shown in Table 1. Four patients included in the study had mild cognitive impairment.

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Table 2 shows the IN of the patients included in the study estimated by LINQ. The total score and the score of the different LINQ domains are included.

Table 1 Demographic Characteristics of Patients Included in the Study (N=143)

Variables	
Age (years)	70.1±10.6
Sex (Male) n (%)	110 (75.9%)
FVC (mL)	2759±993
FVC (%)	99.8±33
FEV ₁ (mL)	1446±505
FEV ₁ (%)	57.6±18.6
FEV ₁ /FVC	52±12
mMRC dyspnea score 0/II/III/IV	28/49/37/26/3
2 or more exacerbations during previous year n (%)	33 (23.1%)
1 or more admissions during previous year n (%)	32 (22.4%)
CAT score	15.5±7.5
Charlson	4.8±2.1
GOLD A/B/C/D	26/69/6/42

Abbreviations: FVC, forced vital capacity; FEV₁, forced expiratory volume in the first second; mMRC, modified Medical Research Council Dyspnea score; CAT, COPD assessment test.

Table 2 LINQ Score and Domains

Variables	Score Median (Rinterquartile Range)/Median ± SD	Highest Possible Score	% Median/Highest Score
LINQ Knowledge	1 (1–2)	4	25%
LINQ Medicines	0 (0–1)	5	0%
LINQ Self-management	2 (1–3)	6	33.3%
LINQ Exercise	1 (0–2)	5	20%
LINQ Diet	1 (0–1)	2	50%
LINQ Smoking	0 (0–1)	3	0%
LINQ Total score	6.3±2.9	25	24.8%

Abbreviation: LINQ, Lung Information Needs Questionnaire score.

LINQ Score Correlations with Relevant Clinical Variables

The LINQ score was weakly but significantly positively correlated with age ($r = 0.184$, $p = 0.029$) but not with CAT ($p = 0.180$), Charlson comorbidity index ($p = 0.878$), FEV₁ (%) ($p = 0.052$), number of previous admissions ($p = 0.477$), number of previous exacerbations ($p = 0.641$) or mMRC degree of dyspnea ($p = 0.510$). Figure 3 shows the scatter plot of the correlation between age and LINQ.

Differences in LINQ Score Between Different Clinical Groups

They are shown in Table 3. No statistically significant differences were found among the different clinical groups. There were also no statistically significant differences in the LINQ score in patients with different degrees of GOLD obstruction ($p = 0.141$) (Figure 4) or different GOLD ABCD classification ($p = 0.757$) (Figure 5).

LINQ Score as a Predictor of Exacerbations and Admissions per Year

During the follow-up period, 79 patients suffered a respiratory exacerbation and 38 were admitted to the hospital due to exacerbation of their COPD. The patients were divided according to their LINQ score into patients with high IN (patients with a LINQ score of 8 or more, corresponding to the upper quartile of the patients included in the study $n = 34$) and the rest of patients. Seventeen patients in the group with high IN presented an exacerbation of their COPD, while in the rest of the patients, 62 had COPD exacerbations. Thirteen patients with high IN were admitted, while 25 patients in the group without high IN showed an admission (Table 4).

Univariate analysis using Cox regression showed that Age ($p = 0.049$), FEV₁ ($p = 0.001$), the history of having presented 2 previous exacerbations ($p = 0.008$), or the mMRC degree of dyspnea ($p = 0.002$) were risk factors for COPD exacerbation, but gender ($p = 0.724$), high IN ($p = 0.425$), and Charlson ($p = 0.062$) were not. Multivariate analysis using Cox regression showed that FEV₁ ($p = 0.012$) was an independent risk factor for COPD exacerbation (Table 5).

Univariate analysis using Cox regression showed that high IN ($p = 0.008$), age ($p < 0.001$), previous admissions due to COPD exacerbation ($p < 0.001$), FEV₁ ($p = 0.006$), Charlson index ($p < 0.001$) and the mMRC dyspnoea score ($p < 0.001$) were risk factors for admission due to

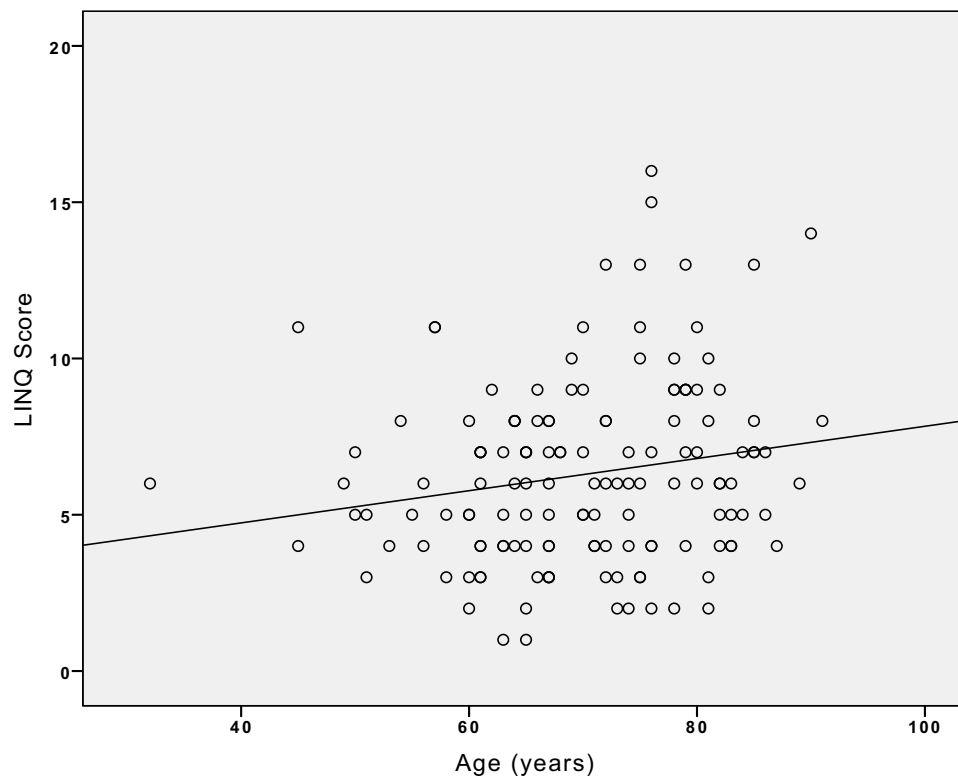


Figure 3 Scatter plot showing correlation between age and LINQ score.

exacerbation of COPD, but not sex ($p = 0.884$). Multivariate analysis using Cox regression showed that high need for information ($p = 0.029$), age (0.01), Charlson ($p = 0.026$) and the history of previous admissions ($p = 0.004$) were independent risk factors for admission due to COPD exacerbation (Table 6, Figure 6).

Discussion

COPD is a disease associated with a high consumption of health resources and which has a great impact on the quality of life and patient survival, so it is essential to control all its dimensions that are susceptible to improvement. Biosanitary education is a key element in the

management of these patients. It aims to achieve a proactive attitude towards their pathology, but its influence on clinical results has not been sufficiently investigated. This study has found that our educational program is similar in terms of educational results to programs carried out in other countries such as Canada or Sweden,^{11–13} despite the fact that patients included in our study, had a recent diagnosis and had not received information previously about their disease. The domains of the questionnaire in which patients have the greatest IN are “Diet” and “Self-care”. These results are similar to previously presented data¹⁹ and highlight the need to have a more exhaustive impact on this information.

Table 3 LINQ (Lung Information Needs Questionnaire) Score in Different Clinical Groups

Clinical Characteristics	Number of Patients with Characteristic	LINQ in Patients with Characteristic	LINQ in Patients without Characteristic	p
Dyspneic	65	6.3±2.7	6.3±3.1	0.961
Symptomatic	107	6.07±2.9	6.92±3	0.131
High risk of exacerbation	51	6.31±3.1	6.26±2.9	0.918
Sex (Male)	108	6.15±2.9	6.69±3.1	0.346

Note: High risk of exacerbation= patients with 2 or more exacerbations during previous year.

Abbreviation: LINQ, Lung Information Needs Questionnaire score.

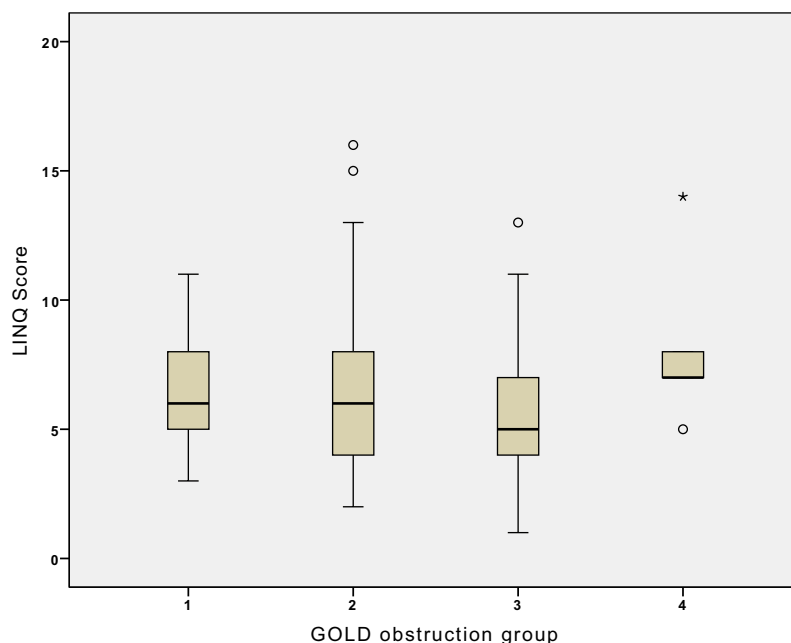


Figure 4 LINQ score in different GOLD Obstruction patients. *Outlier.

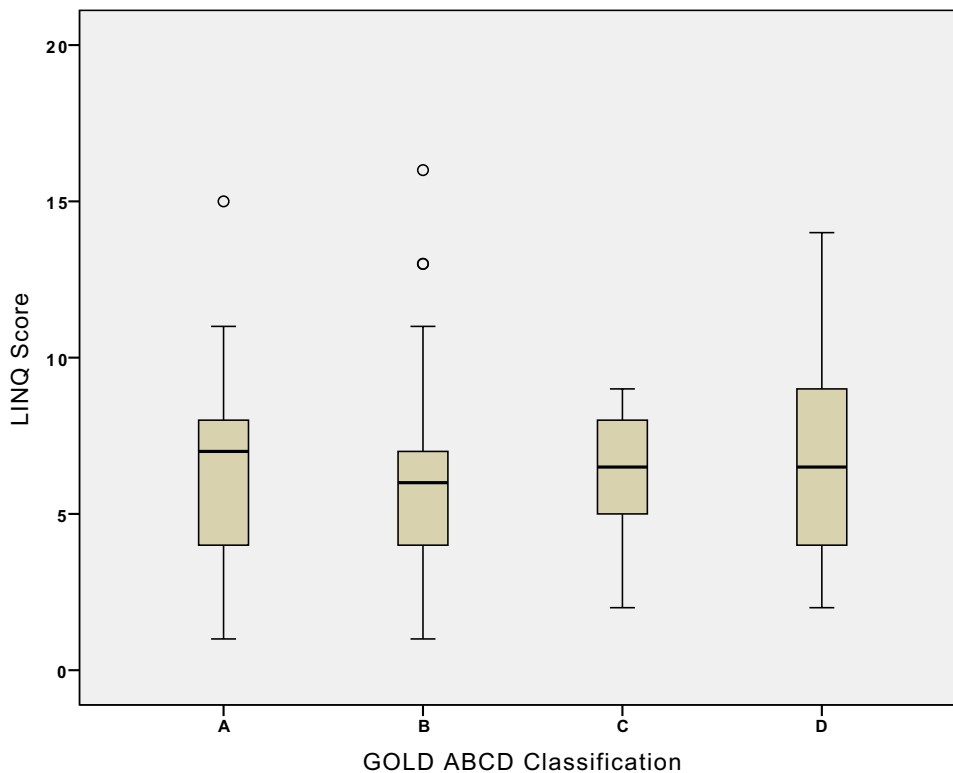


Figure 5 LINQ score in different GOLD ABCD Classification patients.

It is important to explore which patient features are associated with a greater or lesser degree of IN, after a first educational visit. This would be very useful to design custom-made educational programs which affect those

groups with less knowledge of their pathology, allowing health resources to be managed more efficiently, and to advance in medical care customization to which precision medicine aspires. This study has not shown differences in

Table 4 Number of exacerbations and hospital admissions according to LINQ score.

	Exacerbation	Exacerbation Free	Hospital Admission	Hospital Admission Free
LINQ \geq 8	17	11	13	15
LINQ < 8	62	53	25	90
Total	79	64	38	105

Abbreviation: LINQ, Lung Information Needs Questionnaire.

Table 5 Cox Regression Analysis of Predictors of COPD Exacerbation

	B	p	HR	95.0% CI	
				Inferior	Superior
High information needs	0.289	0.334	1.335	0.743	2.399
High risk of exacerbation	-0.155	0.609	0.857	0.474	1.549
FEV₁%	-0.020	0.012	0.980	0.965	0.996
Age	0.011	0.470	1.011	0.981	1.043
Sex (male)	-0.267	0.349	0.766	0.438	1.338
mMRC dyspnea score	0.176	0.171	1.192	0.927	1.533
Charlson	0.111	0.146	1.118	0.962	1.299

Notes: High information needs LINQ Score \geq 8. Bold font indicates statistical significance.

Abbreviations: FEV₁, forced expiratory volume in the first second; mMRC, modified Medical Research Council Dyspnea score.

Table 6 Cox Regression Analysis of Predictors of Hospitalization Due to COPD Exacerbation

	B	p	HR	95.0% CI	
				Inferior	Superior
High information needs	0.855	0.029	2.352	1.091	5.070
Previous admission	-1.012	0.004	2.754	1.373	5.507
FEV ₁ %	-0.021	0.054	0.979	0.958	1.000
Age	0.053	0.010	1.054	1.013	1.097
SEX (male)	-0.673	0.130	0.510	0.214	1.218
mMRC Dyspnea	0.310	0.097	1.364	0.945	1.967
Charlson	0.210	0.026	1.234	1.026	1.484

Notes: High information needs LINQ Score \geq 8. Bold font indicates statistical significance.

Abbreviations: FEV₁, forced expiratory volume in the first second; mMRC, modified Medical Research Council Dyspnea score.

IN, evaluated with the LINQ questionnaire, among different groups, defined by clinical variables commonly used in subjects with COPD categorisation (eg, degree of dyspnea or bronchial obstruction). This result contrasts with a previous study¹² which found that patients with a higher degree of bronchial obstruction had greater information needs. The different setting of that study (primary care) and the different evaluation strategy of the patients with respect to our study (subjects in different phases of clinical follow-up, and not exclusively assessed after the disease diagnosis) could explain these differences. This suggests that it is daring to generalize the results of educational programs in COPD, and that these should be evaluated in the specific area in which they will be implemented.

However, our study found that age correlates with knowledge needs. Younger patients had less IN, after initial education, than older subjects. The practical implication would be that older patients would need more intensive educational programs. The explanation for this, possibly lies in sociocultural factors, or in undetected cognitive disorders. Therefore, our results suggest that sociodemographic aspects could influence the acquisition of knowledge about COPD more than clinical variables. A single previous study has analyzed this aspect and, consistent with this hypothesis, showed that the knowledge of the disease (in this case evaluated with the Mount Sinai Hospital Questionnaire) was higher in patients who had completed secondary education studies.¹⁹ Also, it has been shown that Patients' knowledge can be improved in

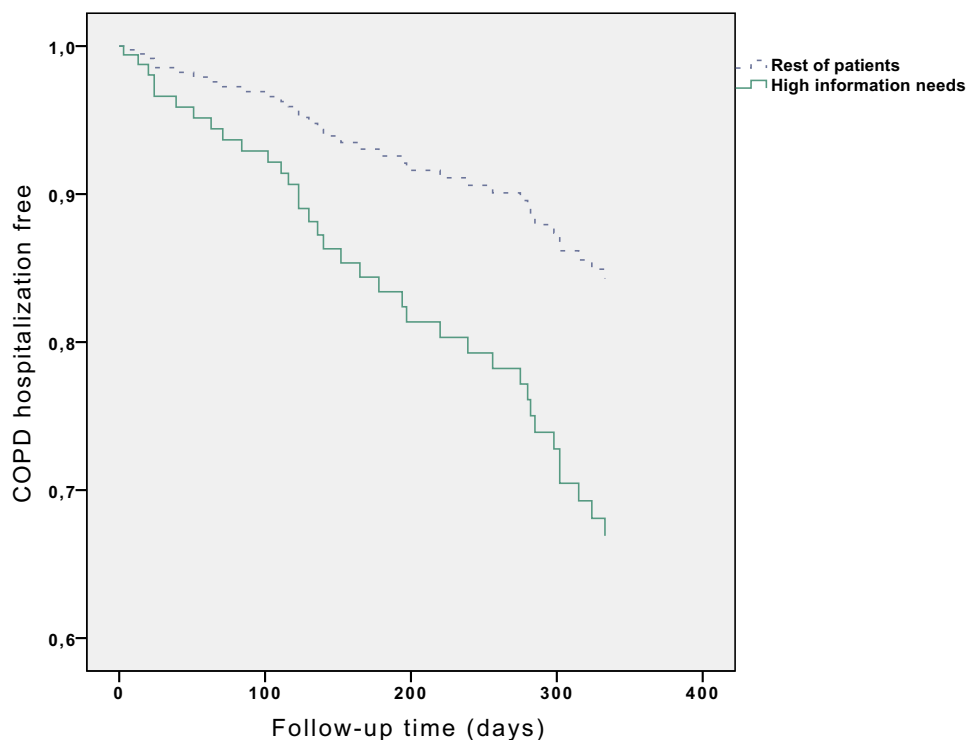


Figure 6 The curve representation for hospitalization due to COPD exacerbation. High information needs=LINQ Score ≥ 8 .

older patients with COPD using specific rehabilitation programmes.²⁰

One of the most relevant results of this study is the finding that high IN predicts an increased risk of severe COPD exacerbations (exacerbations resulting in hospital admissions). The potential implications of this observation to design follow-up strategies (intensive educational programs, early referral to respiratory rehabilitation . . .) which decrease the future risk of patients is evident. On the contrary, we did not find a significant relationship with the risk of suffering moderate exacerbations. When interpreting this last result, we must highlight that our study used an operational definition of moderate exacerbation, based on the prescription of antibiotics or steroids. Although this definition is widely used, it is not suitable, and in some studies, it has been observed that up to 50% of exacerbations, the patient does not look for medical attention and these are not treated, impacting despite this on the quality of life.²¹ It is plausible that subjects with poorer information about the disease are those who are less likely to consult the doctor when presenting exacerbation symptoms, so they would not receive treatment and exacerbations would not be detected by a retrospective study like this one. Hypothetically, some of these exacerbations not treated early could end up in hospital admission.

Our study has several limitations. Retrospective design implies a risk of information bias. In fact, the number of variables collected has been limited, and has not considered the socioeconomic or cultural level of the subjects studied, being only representative of public health patients. This potential confounding factor could influence both the baseline knowledge of the disease,¹⁹ the learning capacity and the risk of exacerbations and admissions.^{22–25} The scope of performance (monographic clinics, when the patient is first diagnosed by the specialist) also means a risk of selection bias, which limits the generalization of our findings.

In conclusion, IN in our setting were similar to other education programmes from other locations. Age influences negatively in IN, although other important COPD clinical outcomes were not correlated with IN. High IN is an independent predictor for hospital admission due to COPD exacerbation. These results may constitute the starting point for new studies investigating whether the modification of the knowledge of the disease through educational programs can reduce the number of admissions for exacerbation of COPD.

Disclosure

The authors report no conflicts of interest for this work.

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