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# Health literacy and health outcomes in chronic obstructive pulmonary disease



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#### ABSTRACT

Background: There is little information worldwide about the impact of health literacy (HL) on clinical outcomes of COPD. Our aim was to quantify inadequate HL in Spain, as measured by the Short Assessment of Health Literacy for Spanish Adults questionnaire, and to examine the associations between HL and both COPD outcomes and health status.

Methods: 296 COPD patients of 68(SD=9) years and a FEV<sub>1</sub>% predicted of 53%(SD=18%) were enrolled and followed-up for one year. 59% showed "inadequate" HL.

Results: Individuals with inadequate HL were older (70[SD = 9] vs 65[SD = 8] years; p < 0.001) and had less knowledge of their disease, as measured by the low HL-COPD questionnaire, (6.9[SD = 2.3] vs 7.5 [SD = 1.9]; p < 0.001). While their lung function was no different, they reported significant differences in mMRC (1.6[SD = 1] vs 1.4[SD = 1]; p < 0.001), CAT (19.2[SD = 8.1] vs 18.3[SD = 7.5]; p = 0.049), and EQ-5 (3.1[SD = 2.2] vs 2.3[SD = 1.9]; p < 0.00). Those with inadequate HL had also higher risk of having ≥2 comorbidities (OR = 1.87; 95%CI = 1.14−3.08), need of assistance (OR = 2.5; 95%CI = 1.5−4.2), anxiety/depression (OR = 1.9; 95%CI = 1.2−3.0), admissions or visits to the emergency department (OR = 1.70; 95%CI = 1.1−2.7), and all-cause deaths in the following year (3.8% (SE = 1.1%) vs 0%; p = 0.051). Conclusions: Inadequate HL is prevalent among COPD patients and it is related to health status and relevant clinical outcomes of the disease. HL needs to be considered when planning the care for COPD patients.

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#### 1. Introduction

Knowledge societies in the 21st century confront new health decision-making challenges for patients. People are increasingly encouraged to make lifestyle choices and offered the benefits of increasingly complex services such as telemedicine and domiciliary care. Moreover sophisticated equipment, for example oxygen concentrators and mechanical ventilation devices, which need

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certain skills to be handled self-sufficiently, has been made available for home treatment to a significant number of patients.

A key factor for taking full advantage of advanced medical treatments in today's health care environment is the ability of the patients and their families to understand health and medical information [1,2]. However, the impact on health outcomes of the communication gap between providers and health-care users is frequently neglected [1,3]. It is remarkable for example that neither the Global initiative Chronic Pulmonary disease (GOLD) [4] nor most of the proposed approaches to chronic care [5] address the impact of health literacy (HL) on the patient's management, in spite of the evidence that if patients cannot fully comprehend the

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messages from healthcare providers, they have are less likely to adhere to preventive measures [6], follow medical instructions and take prescriptions [2,6] and to carry out the required self-care for their chronic conditions [7]. The paradox of this disinterest is that if the patient's preparation and support to fully address their responsibilities in controlling and managing their sicknesses is insufficient, the chances of failure of otherwise effective therapies are greatly increased [8–10]. One of the barriers impeding the communication between providers and receivers in health systems is inadequate HL [3,11,12] However, there is very little specific information on HL regarding chronic respiratory diseases.

The primary objective of this study is to determine the prevalence of inadequate HL, as measured by the Short Assessment of Health Literacy for Spanish-speaking Adults (SAHLSA) questionnaire [13] among patients with COPD and to examine the associations between HL and both health status and disease outcomes.

#### 2. Material and methods

This is a cross-sectional analytical study to measure the prevalence of low HL and the relationship of HL with clinical outcomes, followed by an inception cohort study, with 12 month of follow-up, to establish the relationship between HL and emergency department visits, admissions and mortality. The study was conducted between January 2012 and December 2014. Participants were consecutively recruited at 102 centers across Spain. Patients were included if they had a diagnosis of COPD [4], were older than 40 years, their FEV<sub>1</sub> was lower than 80%, had no hearing or visual problems preventing them from reading, had no mayor psychiatric diseases, had no terminal illnesses, and had no cognitive impairment [14]. During the study, patients received the usual treatment decided by their physicians.

The promoter and the researchers abode by the World Medical Association Declaration of Helsinki and its amendments, the standards of good clinical practice and the Spanish and EU regulations in planning, conducting, recording and reporting of the study. The study was approved by local Human Research Ethics Committees and all the participants gave their informed consent before being enrolled.

Data were collected first at a visit to participating clinics (crosssectional part) and 6 and 12 month afterwards to register the vital status of the patient and the number of emergency visits and exacerbations. At the baseline visit, patients were asked to fill the patient-reported-outcome (PRO) questionnaires, i.e the COPD assessment test<sup>TM</sup> (CAT) a specific instrument to measure health status in COPD patients [15] the EQ-5D 3LTM, a generic instrument designed to measure quality of life, consisting of 5-domains and a visual analogue scale [16]. and COPD knowledge questionnaire, an instrument designed to measure the knowledge about COPD by low literacy individuals [17]) with the help of the accompanying persons, typically the spouse or a younger relative. Later on during the visit, the anthropometric and clinical information (including the last spirometry available), the modified Medical Research Council scale for daily living breathlessness (mMRC) [4], the Charlson's index of comorbidity [18], dependence on extrinsic assistance (assessed in four grades: autonomous [do not require any help], low dependence [able to recognize and take medicines and to perform most activities by him/herself, help to solve complex situations or paperwork needed], moderate dependence [self-sufficient for personal care, help needed to prepare food and to take medicines], and high dependence [fully dependent on someone else]) were recorded. Finally a trained physician or nurse administered the SAHLSA questionnaire [13]. SAHLSA, requires examinees to read aloud a list of 50 medical terms (same as the test in the Rapid Estimate of Adult Literacy in Medicine, REALM [19]) and associate each term to another word similar in meaning to demonstrate comprehension [13]. The cut-off point for inadequate HL (i.e. <37 points) had been previously determined by the authors of the SAHLSA questionnaire [13]. We requested and obtained permissions to use all these measurement instruments in our study.

Statistical Analysis: Variables were described by their mean and standard deviation, median and interquartile range, or frequency with standard error. Comparisons between two groups were done by *t*-test, or Fisher exact test respectively depending on the nature of the variable. Association between two variables was studied using the correlation coefficient or the Spearman's rank correlation coefficient. Adjusted odds ratios (OR) were calculated by means of logistic regression.

#### 3. Results

Information was collected from 351 patients, of these 2 where excluded because of tobacco exposure <10 packet-year, 36 because  $FEV_1 < 80\%$ , 16 because the post bronchodilator  $FEV_1/FVC$  was >70% and 1 because he/her response to the questionnaire was illegible. Complete data on 296 participants were analyzed.

On average, patients were 68 (SD = 9) years old, predominantly males (80%), overweighed (body mass index = 27) and with an average Charlson comorbidity index of 2.4. Forty-six percent of patients were taking more than five medicines and around 15% took more than 10 pills plus their inhalers daily (Table 1). On average, patients were moderately obstructive (Table 1), with 52% in the severe or very severe range (Table 2), had a dyspnea level of 1.3 (mMRC), with 48% reporting a dyspnea levels  $\geq$ 2, the impact level of their disease (CAT) was 19 (medium). Patients rated their health status as 58 in the 0–100 visual analogic scale of the EQ-5 and about 50% had certain degree of anxiety/depression.

The mean SAHLSA score was 35 (SD = 8), the median was 35, and the 25% and 75% percentiles were 29 and 41 respectively (Fig. 1). About 58% of the patients had inadequate HL (i.e. < 37 points

Description of scale variables and comparisons between inadequate and adequate health literacy groups.

Variable	All	n = 296	IHL	n = 174	AHL	n = 122	p
	Mean	SD	Mean	SD	Mean	SD	
Age	68.0	(9.0)	69.9	(9.0)	65.3	(8.4)	0.000
BMI	27.2	(4.3)	27.6	(4.2)	26.5	(4.2)	0.000
N° of drugs	5.4	(2.7)	5.4	(2.7)	5.4	(2.7)	0.769
N° of pills	5.0	(3.8)	5.4	(4.2)	4.6	(3.2)	0.000
N° of inhalers	2.0	(0.6)	2.0	(0.6)	2.1	(0.7)	0.078
FEV <sub>1</sub> (%)	53.5	(18.2)	53.7	(16.9)	53.3	(20.0)	0.678
FEV <sub>1</sub> /FVC	58.2	(14.8)	57.8	(13.8)	58.9	(16.2)	0.284
Charlson Index	2.4	(1.6)	2.6	(1.7)	2.2	(1.4)	0.000
mMRC	1.5	(0.9)	1.7	(1.0)	1.4	(0.9)	0.000
SALHSA	34.8	(7.9)	29.5	(5.8)	42.3	(2.9)	
CAT	18.8	(7.9)	19.2	(8.1)	18.3	(7.5)	0.049
EQ_5D™	2.8	(2.1)	3.1	(2.2)	2.3	(1.9)	0.000
EQ_5D™ (utility)	0.58	(0.17)	0.62	(0.17)	0.56	(0.17)	0.000
COPD knowledge	7.2	(2.2)	6.9	(2.3)	7.5	(1.9)	0.000
All visits (12 m)	7.1	(5.9)	7.2	(6.6)	6.9	(4.9)	0.517
PC visits (12 m)	4.6	(4.9)	4.7	(5.4)	4.5	(4.2)	0.521
S visits (12 m)	1.7	(1.5)	1.6	(1.5)	1.7	(1.5)	0.220

Data are described as mean with standard deviation within parentheses. AHL: adequate health literacy; BMI: body mass index; CAT: COPD assessment test [15]; COPD: chronic obstructive pulmonary disease; COPD knowledge: as measured by the COPD knowledge questionnaire; EQ\_5D [16]; FEV1: forced expiratory volume in the first second; FVC: forced vital capacity; IHL: inadequate health literacy; N°: number; p = significance by the appropriate test; PC visits: visits to a primary care physician; SALSHA: Short Assessment of Health Literacy for Spanish-speaking Adults [13]; SD: standard deviation; S visits: visits to a pulmonologist or internal medicine specialist.

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