ORIGINAL RESEARCH

# Basic Determinants of Disease Knowledge in COPD Patients: Results from COSYCONET

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**Introduction:** In many chronic diseases, including COPD, the patients' basic knowledge of the disorder has been shown to be relevant for the course of the disease. We studied which clinical and functional characteristics were related to this knowledge as well as the patients' satisfaction with their knowledge about COPD.

**Methods:** The study population comprised 645 patients of GOLD grades 1–4 who participated in Visit 6 of the COSYCONET cohort (COPD and Systemic Consequences - Comorbidities Network). The assessments covered a broad panel of clinical and functional characteristics, including generic and disease-specific quality of life and the COPD Assessment Test (CAT). The study aim was addressed by two questions, referring to patients' knowledge of the meaning of  $FEV_1$  and the overall satisfaction with their knowledge of COPD.

**Results:** Knowledge of  $FEV_1$  was higher in patients of higher spirometric GOLD grades or exacerbation risk, in males, with higher educational level, and after participation in a prior educational training on COPD. Patients with more detailed knowledge showed a higher satisfaction with their knowledge. Satisfaction was associated with higher generic quality of life and a lower CAT score. Furthermore, satisfaction was higher in patients with a treatment plan but lower in patients with cardiac comorbidities. It appeared that females with basic education, high burden from COPD and low quality of life had the greatest knowledge deficits.

**Discussion:** The results suggest room for education programs adapted to the educational level of the participants. They also emphasize the major role of a disease management plan for the patients.

Keywords: chronic obstructive pulmonary disease, knowledge, education, satisfaction

#### Introduction

Patients with chronic obstructive pulmonary disease (COPD) show a large heterogeneity of their clinical condition that is commonly described by the categorization into GOLD grades 1–4 based on spirometry, and GOLD groups A to D based on symptoms and exacerbation history.<sup>1</sup> The respiratory condition and the frequent presence of comorbidities lead to extensive therapy.<sup>2</sup> It is reasonable to assume that the therapeutic success depends on patients' cooperation and possibly their understanding of the disease, both of which can be promoted by education and disease management programs. Indeed, self-management programs have been designed to improve patients' clinical status<sup>3</sup> through behavioral changes, optimized social, emotional and physical impairments.<sup>4,5</sup> Although \_ENREF\_6we did not find clinical status to be a major determinant of the

Patient Preference and Adherence downloaded from https://www.dovepress.com/ For personal use only. adherence to medication in a previous analysis,<sup>6</sup> this might be different with respect to the acquired knowledge about the disease and the need for further information expressed by the patients. This study aimed to investigate the relationship between disease-specific knowledge and clinical and functional characteristics of COPD patients. In an analogous manner, we analyzed patient satisfaction with COPD-specific knowledge to identify potential needs for action. To elucidate such associations and potential needs, we analyzed the responses to two basic questions on patients' knowledge and their satisfaction with their knowledge of the disease, using data from the large, multi-center German COPD study COSYCONET (COPD and Systemic Consequences - Comorbidities Network) addressing different aspects of COPD research.<sup>7–11</sup> These data comprised information on anthropometric, clinical and lung function characteristics, time since diagnosis, education level, participation in a disease management program, availability of a treatment plan and whether the treating physician was a pneumologist.

### **Materials and Methods**

#### Assessments

The observational German COPD cohort study COSYCONET ("COPD and SYstemic consequences-COmorbidities NETwork") investigates the interaction of lung disease, comorbidities and systemic inflammation and n=2741 patients with COPD were included into visit 1 of COSYCONET.<sup>12</sup> Details of the COSYCONET study have been published previously<sup>12</sup>. Inclusion criteria comprised aged 40 years and older, diagnosis of COPD (according to GOLD criteria) or chronic bronchitis, availability for repeated study visits over at least 18 months and exclusion criteria comprised having undergone major lung surgery, moderate or severe exacerbation within the last 4 weeks, having a lung tumor, physical or cognitive impairment resulting in an inability to walk or to understand the intention of the project.<sup>12</sup> Follow-up visits were performed after 6, 18, 36, 54 and 72 months. At the time of the 72-month visit, 776 patients still participated in the study. At this point in time, questions "Do you know the term  $FEV_1$  (forced expiratory volume in one second)" and "How satisfied are you with your knowledge and understanding regarding COPD?" were introduced into the COSYCONET questionnaires. Only patients of spirometric GOLD grades 1-4<sup>1</sup> were included in visit 6 (see Figure 1). At each visit, the assessments of COSYCONET comprised a detailed clinical history, anthropometric data, lung function, time since COPD diagnosis, comorbidities based on patients' reports of physician-based diagnoses, symptoms, exacerbation history, physical activity by the International Physical Activity Questionnaire (IPAQ), and quality of life via the visual analogue scale (VAS) of the EQ-5D-3L and the diseasespecific St George's Respiratory Questionnaire (SGRQ). All visits followed standard operating procedures (SOP).<sup>12</sup> Education level was grouped into three categories based on the number of years of education completed (basic education  $\leq 9$  years, secondary education 10 to 11 years, higher education >11 years).<sup>13</sup> Moreover, patients were questioned regarding participation in a disease management program, availability of a treatment plan and whether the treating physician was a pneumologist.

The assumed basic knowledge of COPD was assessed based on the question "Do you know the term  $FEV_1$  (forced expiratory volume in one second)"; the answers were either yes or no. This was considered relevant as  $FEV_1$  plays a fundamental role in the categorization of COPD and could be assumed to be known to patients who had already performed a considerable number of lung function tests. The level of further information desired by patients was assessed by the question "How satisfied are you with your knowledge and understanding regarding COPD?"; answers were given on a Likert scale ranging from 0 (not at all) to 6 (very satisfied).

The COSYCONET study was approved by the Ethical Committee of the coordinating center (University of Marburg) and those of all study centers, as well as the respective data security authorities (data security agency of the federal states of Hesse, Baden-Württemberg, Lower-Saxony and Saarland). Moreover, it followed the declaration of Helsinki and Good Clinical Practice Guidelines. All patients gave their written informed consent. Clinical Trial registration: NCT01245933.

### Data Analysis

For descriptive purposes, median values [quartiles] and numbers or percentages were computed, depending on the type of data. Statistical comparisons between groups were performed using contingency tables and the chi-square statistics, or

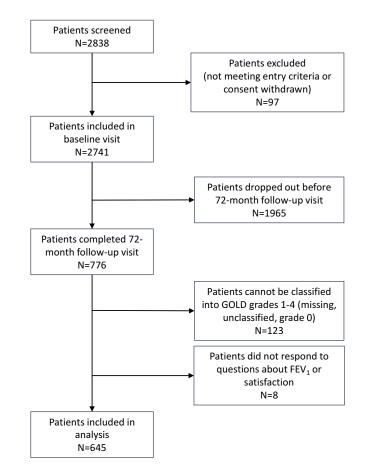


Figure I Flow-chart diagram of the study population.

the Mann–Whitney-*U*-Test, depending on the type of data and comparison. As only few patients showed low score points in the satisfaction with COPD knowledge, we defined a new binary variable comprising 0–4 versus 5–6 points based on ROC (receiver operator characteristics) analysis with knowledge as outcome. This simplification was done in order to make the analyses of satisfaction and knowledge more comparable.

Multiple binary logistic regression analysis was employed to identify statistically independent predictors of knowledge and satisfaction. The predictors used were age, sex, GOLD grades, symptoms (GOLD BD vs AC), exacerbations (GOLD CD vs AB), IPAQ, CAT, EQ-5D-3L VAS, patients' education category, participation in COPD education, participation in a COPD disease management program, a COPD treatment plan and the specialty of the treating physician (pneumologist vs others) as well as the comorbidities coronary artery disease (CAD), myocardial infarction (MI), heart failure (HF), hypertension, peripheral artery disease (PAD), diabetes, hyperlipidemia, hyperuricemia, osteoporosis, mental disorders, sleep apnea and asthma. The comorbidities were analyzed through four sum scores comprising the number of respiratory, cardiac, vascular and metabolic disorders, whereby osteoporosis was counted separately due to its special relation to COPD resulting from corticosteroid therapy. GOLD grades 1-4 were treated as categorical variables relative to grade 1. We omitted the SGRQ from the analysis due to its high collinearity with CAT and VAS. In case of knowledge, satisfaction was included as additional predictor, in case of satisfaction, knowledge. Analyses were performed using inclusion of all predictors and repeated with forward and backward selection to confirm that the set of predictors identified as significant was the same and thus the result could be considered as statistically reliable. For the sake of brevity, only the significant predictors are shown in the graphs, and the presented estimates refer to analyses restricted to these predictors. Statistical significance was assumed for p < 0.05. All analyses were performed using the software package SPSS (IBM SPSS Statistics for Macintosh, Version 28.0., Armonk, NY, USA).

### **Results** Study Population

In total, 645 patients of GOLD grades 1–4 participated in the 72-month follow-up visit and answered the questions regarding COPD knowledge and satisfaction (Table 1). Of these, 235 (36.4%) stated to be familiar with the term FEV<sub>1</sub>. Satisfaction with COPD knowledge at Likert points 0–6 was reported by 1.2, 3.4, 7.6, 26.4, 23.7, 24.0 and 13.6% of patients, respectively, resulting in 243 patients (37.7%) in the category of  $\geq$ 5 points.

# Associations of Reported Knowledge of FEV1

The results of univariate analyses using contingency tables and the Mann–Whitney-*U*-Test are summarized in Tables 2 and 3. There were associations with multiple variables that were checked in multiple logistic regression analyses for

| Variable  | Numbers (%)/ Median [Quartiles]         |  |  |
|---|---|--|--|
| FEV <sub>1</sub> % predicted (GLI)                            | 51.6 [38.5, 67.5]                       |  |  |
| FVC % predicted (GLI)   | 80 [66.5, 93]                           |  |  |
| EQ-5D-3L VAS (mm)   | 60 [40, 70]                             |  |  |
| CAT (score 0-40)  | 18 [13, 23]                             |  |  |
| SGRQ (score 0–100)  | 40,2 [25.7, 55.4]                       |  |  |
| mMRC (score 0-4)  | I [I, 2]                                |  |  |
| IPAQ (points)   | 2182 [693, 5610]                        |  |  |
| Reported knowledge of FEV <sub>1</sub> (yes) (%)              | 235 (36.4%)                             |  |  |
| High satisfaction with knowledge (score 5 or 6 among 0–6) (%) | 243 (37.7%)                             |  |  |
| Previous educational training on COPD (yes) (%)               | 278 (43.1%)                             |  |  |
| GOLD grades 1/2/3/4 (%)                                       | 70/274/242/59 (10.9%/42.5%/37.5%/9.1%)  |  |  |
| GOLD groups A/B/C/D (%)                                       | 381/66/131/64 (59.1%/10.2%/20.3%/9.9%)  |  |  |
| Number of cardiac comorbidities (0/1/2/3) (%)                 | 443/112/48/27 (69.0%/17.4%/7.5%/4.2%)   |  |  |
| Number of vascular comorbidities (0/1/2) (%)                  | 240/319/71 (37.4%/49.7/11.1%)           |  |  |
| Number of respiratory comorbidities (0/1/2) (%)               | 385/211/33 (60.0%/32.9%/5.1%)           |  |  |
| Number of metabolic comorbidities(0/1/2/3) (%)                | 233/243/134/22 (36.1%/37.7%/20.9%/3.4%) |  |  |
| Diagnosis of osteoporosis (yes) (%)                           | 144 (22.3%)                             |  |  |
| Treatment plan for COPD (yes) (%)                             | 129 (20.1%)                             |  |  |
| Participation in COPD disease management program (yes) (%)    | 150 (23.4%)                             |  |  |
| Time since diagnosis of COPD (years)                          | 12 [9, 16]                              |  |  |
| Treating physician pneumologist (yes) (%)                     | 478 (74.5%)                             |  |  |
| Education level (basic/secondary/higher)* (%)                 | 298/199/135 (46.2%/30.9%/21.0%)         |  |  |

 Table I Patient Characteristics (n=645) of the Study Cohort

Notes: Numbers and percentages or median values and quartiles [in brackets] are given. \*Educational level: basic (9 years), secondary (10 years), higher (12 years).

**Abbreviations:** BMI, body mass index; GLI, Global Lung Function Initiative; FEV<sub>1</sub>, forced expiratory volume in I second; FVC, forced vital capacity, EQ-5D-3L; VAS, Visual Analog Scale of the European Quality of Life 5 Dimensions 3 Level Version questionnaire; CAT, COPD Assessment Test; SGRQ, St George's Respiratory Questionnaire; mMRC, modified Medical Research Council; GOLD, Global Initiative for Chronic Obstructive Lung Disease.

| Variable   | Reported Knowledge of FEV <sub>1</sub> (Yes) | p-value          |  |
|--|--|------------------|--|
| Sex (male/female)  | 38.5%/34.0%                                  | 0.238<br><0.001  |  |
| Age (years)  | 68.5 vs 72.0                                 |                  |  |
| GOLD groups A/B/C/D (%)  | 31.0/33.3%/45.8%/54.7%                       | <0.001           |  |
| GOLD grades 1/2/3/4 (%)  | 21.4%/26.8%/46.3%/60.3%                      | <0.001           |  |
| Number of respiratory comorbidities (0/1/2) (%)                      | 32.3%/40.8%/50.0%                            | 0.027            |  |
| Number of cardiac comorbidities (0/1/2/3) (%)                        | 38.1%/30.4%/31.3%/37.0%                      | 0.407            |  |
| Number of vascular comorbidities (0/1/2) (%)                         | 35.4%/38.6%/28.2%                            | 0.245            |  |
| Number of metabolic comorbidities without osteoporosis (0/1/2/3) (%) | 34.3%/37.4%/37.0%/31.8%                      | 0.870            |  |
| Diagnosis of osteoporosis (yes/no) (%)                               | 45.8%/33.1%                                  | 0.005            |  |
| CAT (score)  | 17.5 vs 18.0                                 | 0.485            |  |
| EQ-5D-3L VAS (mm)  | 60.0 vs 60.0                                 | 0.153            |  |
| SGRQ (score)   | 42.8 vs 38.9                                 | 0.94             |  |
| IPAQ (points)  | 1897.5 vs 2376.0                             | 0.146            |  |
| Time since diagnosis of COPD (years)                                 | 13.0 vs 11.0                                 | 0.047            |  |
| Participation in COPD education (yes/no) (%)                         | 51.1%/25.1%                                  | <0.001           |  |
| Participation in COPD disease management program (yes/no) (%)        | 56.7%/30.6%                                  | <0.001<br><0.001 |  |
| COPD treatment plan (yes/no) (%)                                     | 51.2%/32.7%                                  |                  |  |
| Treating physician pneumologist (yes/no) (%)                         | 36.4%/37.2%                                  | 0.857            |  |
| Educational level (b/s/h) * (%)                                      | 27.0%/43.4%/48.9%                            | 0.05             |  |
| High satisfaction with knowledge (yes/no) (%)                        | 52.9%/26.8%                                  | <0.001           |  |

Table 2 Associations of Reported Knowledge of FEV<sub>1</sub>

**Notes**: Results of univariate analyses of reported knowledge of FEV<sub>1</sub> using contingency tables and chi-square-statistics or Mann–Whitney *U*-tests, depending on the type of data and comparison. Statistically significant results are marked in boldface. \*Educational level: basic (9 years), secondary (10 years), higher (12 years).

Abbreviations: BMI, body mass index; GLI, Global Lung Function Initiative; FEV<sub>1</sub>, forced expiratory volume in I second; FVC, forced vital capacity, EQ-5D-3L; VAS, Visual Analog Scale of the European Quality of Life 5 Dimensions 3 Level Version questionnaire; CAT, COPD Assessment Test; SGRQ, St George's Respiratory Questionnaire; mMRC, modified Medical Research Council; GOLD, Global Initiative for Chronic Obstructive Lung Disease.

being statistically independent predictors. Male sex, GOLD grades 3 and 4 compared to grade 1, higher exacerbation score, previous education on COPD, osteoporosis, participation in a COPD disease management program, secondary and high compared to low education as well as satisfaction with knowledge were significant simultaneous predictors of greater knowledge (p<0.05 each), while CAT, EQ-5D-3L VAS, IPAQ and other comorbidity scores were not relevant. This was confirmed by forward and backward selection. The results are shown in Figure 2 in terms of odds ratios.

To elucidate whether the effect of educational training on the knowledge of FEV<sub>1</sub> was dependent on education, we repeated the analysis separately in patients with either basic education (N=298; 46.2%) or secondary/higher education (N=344; 53.3%). In both groups, GOLD grade 4, participation in a disease management program and satisfaction with COPD knowledge remained as predictors (p<0.05 each). In the group of basic education, exacerbations were additional predictors, in the group with secondary/higher education, osteoporosis, male sex and previous education on COPD (p<0.05 each). For the corresponding odds ratios see the <u>Supplemental Table S1</u>. The differences between groups were small, but the highest GOLD grades were linked to more detailed knowledge, primarily in patients with basic education.

| Variable   | High Satisfaction with Knowledge (Yes) | <b>p-value</b><br>0.511 |  |
|--|--|-------------------------|--|
| Sex (male/female) (%)  | 36.6%/39.2%                            |                         |  |
| Age (years)  | 69.0 vs 71.0                           | 0.011                   |  |
| GOLD groups A/B/C/D (%)  | 37.8%/30.3%/41.2%/37.5%                | 0.526                   |  |
| GOLD grades 1/2/3/4 (%)  | 37.1%/34.6%/39.3%/46.6%                | 0.343                   |  |
| Number of respiratory comorbidities (0/1/2) (%)                        | 36.4%/39.3%/38.2%                      | 0.779                   |  |
| Number of cardiac comorbidities (0/1/2/3) (%)                          | 41.8%/28.6%/29.2%/22.2%                | 0.010                   |  |
| Number of vascular comorbidities (0/1/2) (%)                           | 42.5%/37.6%/21.1%                      | 0.005                   |  |
| Number of metabolic comorbidities without osteoporosis $(0/1/2/3)$ (%) | 36.1%/39.1%/40.0%/22.7%                | 0.328                   |  |
| Diagnosis of osteoporosis (yes/no)                                     | 38.9%/37.2%                            | 0.716                   |  |
| CAT (score)  | 16.0 vs 19.0                           | <0.001                  |  |
| EQ-5D-3L VAS (mm)  | 66.5 vs 59.0                           | <0.001                  |  |
| SGRQ (score)   | 34.9 vs 42.4                           | <0.001                  |  |
| IPAQ (points)  | 2056.0 vs 2240.0                       | 0.818                   |  |
| Time since diagnosis of COPD (years)                                   | 12.5 vs 11.0                           | 0.016                   |  |
| Participation in COPD education (yes/no)                               | 45.1%/32.1%                            | <0.001                  |  |
| Participation in COPD disease management program (yes/no)              | 42.7%/36.3%                            | 0.161                   |  |
| COPD treatment plan (yes/no)   | 53.3%/33.7%                            | <0.001                  |  |
| Treating physician pneumologist (yes/no)                               | 37.4%/38.5%                            | 0.816                   |  |
| Educational level (b/s/h) *  | 34.1%/39.4%/44.4%                      | 0.595                   |  |
| Reported knowledge of FEV <sub>1</sub> (yes/no)                        | 54.5%/28.0%                            | <0.001                  |  |

| Table 3 Associations | of High | Satisfaction | with Knowledge | on COPD |
|----------------------|---------|--------------|----------------|---------|
|                      | •····   | •            |                |         |

Notes: Results of univariate analyses of high satisfaction with COPD knowledge using contingency tables and chi-square-statistics or Mann–Whitney U-tests, depending on the type of data and comparison. Statistically significant results are marked in boldface. \*Educational level: basic (9 years), secondary (10 years), higher (12 years).

**Abbreviations:** BMI, body mass index; GLI, Global Lung Function Initiative; FEV<sub>1</sub>, forced expiratory volume in 1 second; FVC, forced vital capacity, EQ-5D-3L; VAS, Visual Analog Scale of the European Quality of Life 5 Dimensions 3 Level Version questionnaire; CAT, COPD Assessment Test; SGRQ, St George's Respiratory Questionnaire; mMRC, modified Medical Research Council; GOLD, Global Initiative for Chronic Obstructive Lung Disease.

In patients without previous educational training, GOLD grade 3, exacerbations and satisfaction with knowledge were significant predictors (p<0.05 each). In patients with previous educational training, GOLD grade 4, secondary/higher education level, participation in a disease management program and satisfaction with COPD knowledge were significant predictors (p<0.05 each). For the corresponding odds ratios see the <u>Supplemental Table S1</u>. Differences were small, but participation in a disease management program was relevant only in patients with prior educational training.

#### Associations of Satisfaction with COPD Knowledge

Univariate analyses using contingency tables and the Mann–Whitney-U-Test yielded the results summarized in Table 2. These associations were checked in multiple logistic regression analysis for statistically independent predictors. The results showed statistical significance (p<0.05 each) for higher exacerbations, higher EQ-5D-3L VAS, lower CAT, the existence of a treatment plan, longer time since the diagnosis of COPD, lower cardiac comorbidities and reported knowledge. The corresponding odds ratios are shown in Figure 3.

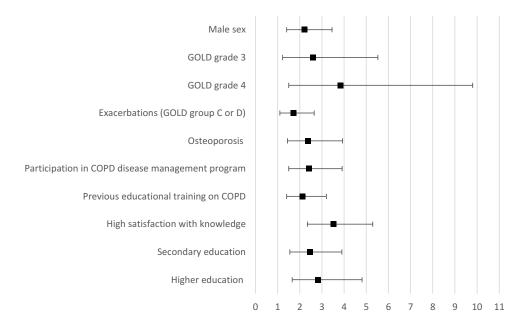


Figure 2 Odds ratios and 95% confidence intervals obtained from logistic regression analysis of the reported knowledge of FEV<sub>1</sub> versus a comprehensive set of predictors (see Methods). The figure shows the result restricted to those predictors that were consistently found significant with inclusion as well as forward and backward selection. The effects of GOLD grades 3 and 4 were relative to grade 1.

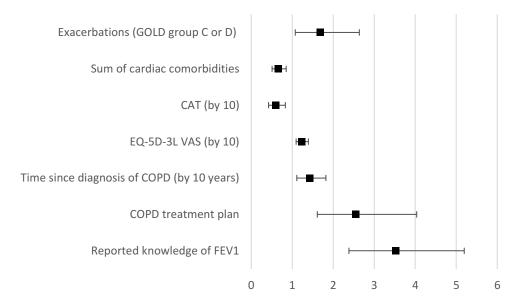


Figure 3 Odds ratios and 95% confidence intervals obtained from logistic regression analysis of the reported higher satisfaction with COPD knowledge versus a comprehensive set of predictors (see Methods). The figure shows the result restricted to those predictors that were consistently found significant with inclusion as well as forward and backward selection. For better readability, the effects of CAT, EQ-5D-3L VAS and the duration of COPD since diagnosis are given for changes in 10 units of the respective variable.

In patients with basic education a higher EQ-5D-3L VAS, the existence of a treatment plan and knowledge of FEV<sub>1</sub> were linked to more satisfaction (p<0.05). In patients with secondary/higher education, a higher EQ-5D-3L VAS, the existence of a treatment plan, lower cardiac comorbidities and knowledge of FEV<sub>1</sub> were associated with higher satisfaction (p<0.05). In patients without previous educational training, a lower CAT, the presence of a treatment plan, lower cardiac comorbidities and the knowledge of FEV<sub>1</sub> were significant predictors of satisfaction (p<0.05 each). In patients with previous educational training, higher EQ-5D-3L VAS, the presence of a treatment plan, longer time since

COPD diagnosis and the knowledge of  $FEV_1$  were significant predictors of satisfaction (p<0.05 each). From the <u>Supplemental Table S2</u> it can be seen that for both subcategorizations the differences in odds ratios were small irrespective of statistical significance.

### Discussion

The present analysis addressed COPD-relevant knowledge and satisfaction with this knowledge in relation to basic characteristics of patients including educational level and previous participation in educational programs on COPD. The aim was to get hints on the characteristics of patients who lack information and conversely benefit most from educational training. For this purpose, we used two simple questions that had been introduced into the COSYCONET cohort at one of the follow-up visits; these questions referred to the knowledge of the meaning of  $FEV_1$  and to the overall satisfaction with the knowledge about COPD.

As expected, the reported knowledge depended on the educational level and the participation in a prior educational training on COPD. Interestingly, it also was higher in patients of higher spirometric GOLD grades or exacerbation risk, as well as in males. Additionally, patients who participated in a disease management program as well as patients with the diagnosis of osteoporosis reported better knowledge. Neither the clinical state as measured by the CAT, nor generic quality of life, reported daily activity, nor the presence of comorbidities played a role. Patients with reported knowledge of  $FEV_1$  were also more satisfied with their general knowledge about COPD, suggesting that the specific knowledge regarding  $FEV_1$  was considered a relevant part of knowledge.

Satisfaction with the knowledge showed a different pattern of predictors. It depended on the reported knowledge as well as a higher exacerbation score but not on GOLD grades or sex or age. Conversely, it was associated with less COPD complaints in terms of the CAT and higher generic quality of life. Moreover, the presence of cardiac comorbidities was associated with less satisfaction with the knowledge about COPD. Additionally, the presence of a COPD treatment plan as well a longer time since the diagnosis of COPD had a positive effect on the patients' satisfaction.

These results are in line with the known positive effect of disease knowledge on the course of COPD.<sup>4</sup> They furthermore provide insight into which particular patients lack knowledge and suggest that these are females with basic education, high burden from COPD, low quality of life and cardiac disease. Lower educational level is a proxy of socioeconomic status that has been shown to be associated with poorer COPD outcomes,<sup>13,14</sup> therefore these patients might benefit from COPD education.

The fact that the estimated effect of previous education on COPD was low in patients with basic education also points towards education programs that are adapted to the needs and understanding of these patients. Thus, different courses might be offered for different levels of education. This could easily be implemented in online courses which not only could help to reconcile the participation with work but also might avoid problems arising from a slower rate of understanding in a group.

Previous studies already investigated the distribution of patients' disease-specific knowledge in COPD<sup>15–17</sup> or other chronic diseases such as diabetes.<sup>18,19</sup> These studies often used extensive panels designed for covering a broad spectrum of knowledge. In the present study, we used only two questions. The reason was that the extensive study protocol of COSYCONET<sup>12</sup> and the restrictions of time prevented the introduction of more detailed assessments or specific tests to verify the claimed knowledge.

Despite these limitations, the results seem plausible and the questions suitable  $FEV_1$  is the basic variable used to categorize COPD into GOLD categories 1–4. These categories are known to the great majority of patients and treating physicians including non-specialists. Moreover, patients are commonly monitored over time involving repeated assessments of lung function and often ask doctors and technicians for the measured values. It therefore appeared reasonable to utilize the knowledge of  $FEV_1$  as a proxy of basic knowledge on the disease, similarly to that of HbA1c or glucose levels in diabetes.<sup>20</sup> Knowledge on COPD was also related to the presence of osteoporosis. This is known to many patients as a risk of treatment with corticosteroids and of advanced age which is relevant as COPD is primarily a disease of the elderly. Indeed, a great number of patients in COSYCONET are treated with corticosteroids, irrespective of the conformity with treatment recommendations.<sup>2</sup>

The question regarding satisfaction with the knowledge of COPD did not address a specific topic and covered the whole area of COPD. It is therefore plausible that high satisfaction correlated with other broad-band measures such as CAT and generic quality of life. Satisfaction was lower in patients with a history of cardiac diseases. Experience shows that such diseases are considered as a threat<sup>21</sup> which is also reflected in the high adherence to cardiac medication.<sup>6</sup> In view of the close link between COPD and cardiac diseases, the feeling of insufficient knowledge seems understandable as patients may put their primary focus on the cardiac disease rather than COPD. Conversely, higher exacerbations and longer duration of COPD seemed to favor satisfaction with COPD knowledge, possibly based on more experience with the successful management of the disease. Another interesting finding was that while the existence of a COPD treatment plan was associated with higher satisfaction, this was not true for the mere participation in a disease management program.

#### Limitations

This is a cross-sectional study, as the question on knowledge about  $FEV_1$  and the question on satisfaction with knowledge was introduced in the course of the COSYCONET study. In the study population, a total of 40% of COPD patients received disease-specific education. This number is likely to be higher than in real-life situations, since participation in an intensive observational study such as COSYCONET should have a selection effect. It can therefore be assumed that COPD-specific knowledge in the general population is lower. Moreover, the single question regarding  $FEV_1$  was considered as indicator question for the level of COPD knowledge; this was probably justified as it is a simple, intuitive parameter and many patients are aware of lung function being used for COPD grading. The advantage of this study is the detailed knowledge about the clinical characteristics, thus it was possible to identify patients with the largest gaps of knowledge.

### Conclusion

We found that patients with greater disease-specific knowledge in terms of  $FEV_1$  had higher satisfaction with their knowledge. Satisfaction was lower in patients with cardiac comorbidities and higher in patients with a treatment plan. Higher satisfaction corresponded to a higher generic quality of life and a lower score in the COPD Assessment Test. It appeared that females with basic education, high burden from COPD and low quality of life had the greatest deficits in knowledge. The results suggest room for education programs that take into account the educational level of the participants and emphasize the role of a disease management plan for the patients.

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### **Data Sharing Statement**

The basic data are part of the German COPD cohort COSYCONET (<u>www.asconet.net</u>) and available upon request. The website of the network provides a detailed procedure for respective applications. The data can be obtained after submission of a proposal that is evaluated by the steering committee. All results to which the manuscript refers, are documented appropriately in the text, figures or tables.

### **Statement of Ethics**

All assessments were approved by the central (Marburg [Ethikkommission FB Medizin Marburg]) and local (Bad Reichenhall [Ethikkommission bayerische Landesärztekammer]); Berlin (Ethikkommission Ärztekammer Berlin); Bochum (Ethikkommission Medizinische Fakultät der RUB); Borstel (Ethikkommission Universität Lübeck); Coswig (Ethikkommission TU Dresden); Donaustauf (Ethikkommission Universitätsklinikum Regensburg); Essen (Ethikkommission Medizinische Fakultät Duisburg-Essen); Gießen (Ethikkommission Fachbereich Medizin); Greifswald (Ethikkommission Universitätsmedizin Greifswald); Großhansdorf (Ethikkommission Ärztekammer Schleswig-Holstein); Hamburg (Ethikkommission Ärztekammer Hamburg); MHH Hannover/Coppenbrügge (MHH Ethikkommission); Heidelberg Thorax/ (Ethikkommission Universität Heidelberg); Homburg (Ethikkommission Saarbrücken); Immenhausen Uniklinik (Ethikkommission Landesärztekammer Hessen); Kiel (Ethikkommission Christian-Albrechts-Universität zu Kiel); Leipzig (Ethikkommission Universität Leipzig); Löwenstein (Ethikkommission Landesärztekammer Baden-Württemberg); Mainz (Ethikkommission Landesärztekammer Rheinland-Pfalz); München LMU/Gauting (Ethikkommission Klinikum Universität München); Nürnberg (Ethikkommission Friedrich-Alexander-Universität Erlangen Nürnberg); Rostock (Ethikkommission Universität Rostock); Berchtesgadener Land (Ethikkommission Land Salzburg); Schmallenberg (Ethikkommission Ärztekammer Westfalen-Lippe); Solingen (Ethikkommission Universität Witten-Herdecke); Ulm (Ethikkommission Universität Ulm); Würzburg (Ethikkommission Universität Würzburg) ethical committees and written informed consent was obtained from all patients. The ethics application for the COSYCONET study which was approved by all of the above mentioned central and local committees, includes the consent of the patients that their data may be used for further future analyses of any kind. The current study is a secondary analysis of COSYCONET and therefore the study did not require separate ethical approval. The following statement (translated from the original patient informed consent), which was approved by all of the above mentioned ethical committees, confirms that the patient informed consent includes the consent to have their data used in any future study based on COSYCONET data.

I also consent to the recording of disease data as part of the study and to its storage and disclosure in accordance with Patient Information IV.

I agree that blood samples, respiratory samples and urine samples may be taken for research purposes as part of my participation in the study and that these samples may be used for current and future research into COPD and may also be passed on to other researchers outside COSYCONET in an anonymous form in this context I consent to my data and biomaterial samples being used for an indefinite period.

I am aware that my data and biomaterial samples can be used for a very long time. The right to use my data and biomaterial samples persists after my death.

I also agree that in the event of death, an independent committee consisting of three experts and appointed by the management of the Asthma/COPD Competence Network may view my medical records and contact the treating physicians to determine the cause of death. In this case, I release my treating doctor from his duty of confidentiality."The study was based on 2741 patients recruited within the COSYCONET framework (ClinicalTrials. gov, Identifier: NCT01245933). For further information see Karch A, Vogelmeier C, Welte T, Bals R, Kauczor HU, Biederer J, Heinrich J, Schulz H, Glaser S, Holle R et al: The German COPD cohort COSYCONET: Aims, methods and descriptive analysis of the study population at baseline. Respir Med 2016, 114:27–37.

For further information see:

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#### **Consent for Publication**

Within the ethical approval of COSYCONET, the participants of the study gave their consent to publish the data collected without reference to their person.

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# **Author Contributions**

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

### Disclosure

Professor Robert Bals reports grants from BMBF, during the conduct of the study; grants, personal fees from Various, outside the submitted work. Dr Claus F Vogelmeier reports grants from German Ministry of Education and Science (BMBF), during the conduct of the study; personal fees from Aerogen, grants, personal fees from AstraZeneca, grants, personal fees from Boehringer Ingelheim, grants, personal fees from Chiesi, grants, personal fees from CSL Behring, grants, personal fees from GlaxoSmithKline, grants, personal fees from Grifols, personal fees from Menarini, grants, personal fees from Novartis, personal fees from Nuvaira, outside the submitted work. The authors declare that they have no other competing interests with regard to this study.

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