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Communication regarding sickness and end of life in patients with advanced chronic obstructive pulmonary disease: a multicenter questionnaire survey

Abstract

Background: Higher levels of knowledge about the disease among patients with chronic obstructive pulmonary disease (COPD) were shown to result in better physician-patient communication. Nonetheless, a sizable percentage of patients within this group continue to lack sufficient information about their disease and prognosis. The objective of this study was to collect the opinions of COPD patients regarding their knowledge of their condition, the sources of this knowledge, the most important barriers to end-of-life communication, and the needs regarding such communication from a pneumonologist.

Subjects and methods: A questionnaire survey was carried out among 474 patients with advanced COPD at three pneumonology centers in Poland (Gdańsk, Katowice, Toruń). The questionnaire consisted of a total of 25 questions. The article presents the conclusions of the part of the survey relating to the level of patients' knowledge of their condition and end-of-life communication with physicians.

Results: Slightly more than 40% of respondents declared their knowledge of the disease to be good or sufficient ("I have good knowledge or I have some knowledge"). The primary source of knowledge for survey participants was their physicians, albeit a vast majority of patients have not talked to their physicians about the subsequent course of their illness. The main barriers to end-of-life discussions as pointed out by the patients included insufficient time when visiting a specialist, the lack of notions regarding the further course of the disease, the lack of knowledge on the disease and end-of-life issues, or the reluctance to discuss such topics.

Conclusions: The analysis of the data confirms the continued deficit of knowledge regarding the future course of the disease among COPD patients as the majority of them have not discussed this issue with their physicians despite having identified them as the primary source of disease-related information.

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Keywords: COPD, end-of-life communication, end-of-life care

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Introduction

Building trust through good physician–patient communication is an important prerequisite for the patient’s compliance with recommendations and, consequently, for better control of disease symptoms [1]. Patients with chronic obstructive pulmonary disease (COPD), especially those in its advanced stages, are burdened by numerous symptoms and often complain of lacking knowledge regarding the further course of the disease and prognosis. This uncertainty can constitute an additional burden and exacerbate the anxiety and depressive disorders that are frequently encountered in these patients [2]. The expectations of COPD patients regarding end-of-life discussions are not always clear. On the one hand, patients declare that they want to be informed in detail about all aspects of their condition, while on the other hand, many of them are unwilling to broach the subject of an unfavorable prognosis [3]. The current study is part of a broader assessment of the course of treatment for advanced lung disease. The current part of the survey aimed to determine the patients’ views on their level of knowledge about their disease, the sources of this knowledge, the demand for end-of-life discussions, and the possible barriers to such discussions.

Subjects and methods

The study was conducted in 2017 and 2018 on a group of 474 patients with symptomatic COPD (moderate to very severe as per the GOLD 2017 guidelines) [4]. Patients were recruited from among those hospitalized in lung disease departments or presenting at pneumonology outpatient clinics in Toruń, Gdańsk, and Katowice. The questionnaires were completed anonymously and included a total of 24 closed-ended single- and multiple-choice questions encompassing several areas such as coping with daily life and support for the close ones, knowledge about the disease, consultations with the physicians, forms of support, and end-of-life problems. In the last, open-ended question, patients were asked to share their thoughts on end-of-life care after completing the questionnaire. Nine questions were included in the current analysis regarding the respondents’ level of knowledge about their disease, the sources of this knowledge, the demand for end-of-life conversations, and barriers to such conversations. The study protocol had been approved by the Bioethics Committee at the Nicolaus Copernicus University in Toruń, Collegium Medicum in Bydgoszcz (KB 667/2016).

Statistical analysis

Analyses were carried out using the SPSS (IBM SPSS Statistics 24.0.0; SPSS Inc., Armonk, New York, United States) software. The chi-square test of independence was used to look for statistically significant correlations between qualitative (nominal) variables. Correlations between quantitative variables were verified using Spearman’s rank correlation coefficient (the variables did not meet the condition of conformance with normal distribution). Correlations between rank variables were verified using Kendall’s tau-b correlation coefficient. The significance level was established at $p = 0.05$.

Results

Characteristics of study participants

Most of the patients (61%) were male, and the average age of the subjects was 69 (40 to 94) years. The characteristics of the study group are presented in Table 1.

Patients’ feedback

Respondents’ level of knowledge about the further course of the disease

With regard to the question in which the survey participants were asked to rate their knowledge on the subsequent course of the disease, the options “I have absolutely no knowledge” and “I don’t have much knowledge” were selected by 10.1% and 22% of subjects, respectively. Thus, one in three participants badly assessed their level of knowledge on the index topic. A slightly larger group (42.1% in total) have provided positive estimations of their knowledge, with the answer “I have some knowledge” being indicated by 31.3% and the answer “I have much knowledge” — by 11%, the remaining 25.6% of respondents having difficulty in providing an answer. Patients of younger age, those with higher educational backgrounds, and those reporting fewer exacerbations provided better estimations of their knowledge regarding the progression of the disease. Correlational analysis revealed a significant relationship between age ($p = 0.017$), educational background ($p = 0.001$), number of COPD exacerbations requiring oral steroids ($p = 0.005$), and the self-assessed knowledge of disease progression.

Sources of knowledge about the disease

In the next two questions, patients were asked to indicate the sources of knowledge regarding their condition that were most important to them. In

Table 1. Characteristics of the study group

Characteristics		Percentage of responses	Number of respondents
Average age	68.9 (from 40 to 94)		
Gender	Male Female	61% (290) 39% (184)	n = 474
Educational background	Elementary Vocational High school University	16% (72) 35% (155) 35% (155) 15% (66)	n = 448
Smoking status	Currently smoking Ex-smoker Never a smoker	34% (163) 60% (285) 6% (26)	n = 474
Current residence	Home Hospital — COPD exacerbation Hospital — other reasons Other	48.5% (230) 37.6% (178) 13.5% (64) 0.4% (2)	n = 474
Comorbidities (multiple choice)	Hypertension Heart diseases Diabetes Cancer Other	69.6% (329) 49% (232) 28% (133) 12% (57) 18.2% (86)	
Average number of exacerbations in the previous year	Requiring an antibiotic Requiring a systemic steroid Requiring hospitalization	1.2 0.7 0.7	
Home oxygen therapy	Yes No	22.2% (105) 77.8% (369)	n = 474
History of pulmonary rehabilitation to date	None Yes — once Yes — more than once	72.1% (341) 15% (71) 12.9% (61)	n = 473

COPD — chronic obstructive pulmonary disease

both the multiple-choice and single-choice options, physicians ranked first by a wide margin (85.2% and 73.7%, respectively). In the multiple-choice version, this response was followed by family (27.5%), information brochures (24.4%), and nurses (24.2%), as well as other patients, friends, the Internet, television, books, newspapers/magazines, and radio. In the single-choice version, sources other than the physician included the family (6.2%), friends (4.5%), and the Internet (3.2), followed by other patients, television, nurses, information brochures, books, newspapers/magazines, and radio. In the multiple-choice option, the possibility of knowledge being obtained from the Internet was indicated as one of the sources by 17.2% of respondents. These were mostly people under the age of 70. According to the analysis, one in four patients in this age bracket (25%) used the Internet to gain knowledge about their disease. The Internet was a clearly less frequent source of information for those over 70 years of age ($p < 0.001$). It was also the more common source of knowledge for those with university (24%) and high school (23%)

educational background as compared to vocational (13%) and elementary (8%) educational background, the differences being significant ($p = 0.01$).

Conversations regarding the end stage of illness and life

The next questions concerned conversations about the end stage of the disease and the end of life as held by the patients with their lung specialists. To the question of whether the patient had ever discussed this topic with a pneumonologist, a negative answer was provided by a vast majority of respondents (75%). In the group of patients who had raised this topic in their conversations with the specialist, good marks were given in a majority of cases with regard to the atmosphere of such conversations and the knowledge provided by the physician. More than one-half of all respondents (58%) expressed no desire to have such conversations in the future (by having chosen the options "I don't want to talk about it" or/and "I'd rather not talk about it"). The interest in such conversations ("I'd rather like to talk about it" or "I want to

talk about it") was expressed by a total of nearly 42% of patients. A vast majority of patients (91.5%) had not brought up these topics in conversations with physicians of other specialties as well.

Correlational analysis revealed a significant relationship between the respondents' evaluation of the end-of-life conversation with their physician in terms of the knowledge provided ($p = 0.007$) and the atmosphere of the conversation ($p = 0.008$) vs. their willingness to continue with such conversations. Respondents who had engaged in end-of-life conversations had high opinions about the content and atmosphere of such conversations and were more likely to be willing to discuss the end stage of their illness and life in the future.

Barriers to end-of-life conversations

In the last of the multiple-choice questions analyzed, patients were asked to indicate the barriers that hindered conversations about the end stage of their illness and life from being held during their meetings with the pulmonologists. The lack of time during their visit to the specialist was the answer provided by the largest percentage of respondents (26.6%), followed by the lack of notions regarding the further course of the disease (25.7%), the lack of knowledge about the disease and end-of-life matters (23.2%), as well as unwillingness to discuss such topics (23.2%). Slightly less frequently, patients indicated their own being unprepared for such conversations (19.4%), their fear of losing hope (13.5%), the physician's being unprepared to discuss such topics (10.3%), or, finally, the physician's fear of taking away the patient's hope (8.9%). The opinion of no barriers to having such conversations being present whatsoever was expressed by more than 12% of survey participants. The questions, along with the response options provided by the patients, are shown in Table 2.

Discussion

With the growing global population of COPD patients and the continued search for optimum solutions regarding their care, there is a growing recognition of the importance of disease awareness being promoted as an important factor in improving treatment outcomes [5–7]. The importance of tests that take into account patients' own assessment of the course of their disease and treatment is growing [8, 9]. The impact of the level of knowledge on the patient's ability to self-manage the disease is also important [5, 10], as the deficits in this knowledge not only limit this ability but also exacerbate frustration and discouragement on behalf of the patient as well as their caregivers

[11]. The deficits of COPD-related knowledge have also been confirmed by Polish observations [12], the published recommendations highlighting the need to raise awareness of the disease among the Polish public [13]. The previous observations in this regard have been confirmed by the results of this study. Good or at least satisfactory knowledge of the further course of the disease has been declared by less than one-half of the respondents.

Interesting data have been provided with regard to the sources of patients' knowledge, the physician being the main source of disease-related information for the vast majority of subjects. This imparts a major responsibility on the pulmonologists, as well as on the physicians of other specialties, who should be urged to undertake greater educational efforts with their patients. This is especially important in light of the disturbing reports regarding the deficiencies in this area among the physicians in Poland. In a 2015 report on physician attitudes, negative responses to the question "Do physicians know how to talk to their patients?" amounted to nearly 70% [14]. The statistics published in the report by the Organization for Economic Cooperation and Development (OECD) for the same year are also overwhelming. Polish physicians infamously ranked last among the physicians from all countries included in the ranking in terms of providing patients with the ability to ask questions, devoting adequate time to patients during consultations, or explaining medical problems in a comprehensible manner as assessed by patients in the outpatient setting [15].

The analysis also confirms that the Internet is a fairly popular source of knowledge, albeit only for younger subjects. Therefore, physicians should not feel relieved of their duties by online portals for the next few years, given that the majority of the COPD patient population are elderly individuals unaccustomed to using these sources of knowledge. In contrast, a significant proportion of subjects drawing information from the Internet in younger age groups indicates the need to post reliable and easily accessible COPD-related information data on online platforms addressed to patients and their close ones, as well as to the general public.

Initiating conversations about the end stage of illness and life appears to be a particularly problematic issue for physicians. Most respondents had not talked to their lung specialist about this topic, even though a significant percentage of patients expected such discussions to take place.

This finding is supported by data from a survey of Polish pulmonologists. When asked whether conversations about end-of-life problems are needed in COPD patients, nearly 80% of specialists provided

Table 2. Questions from the questionnaire for patients with advanced COPD (n = 474)

Question	Response options	Percentage of responses	Number of respondents
What are the sources of your knowledge about your illness? (multiple choice)	Conversations with the physician Conversations with the family Information brochures Conversations with nurses Conversations with other patients Chats with friends Internet TV Books Newspapers and magazines Radio Other	85.2% (399) 27.5% (129) 24.4% (114) 24.2% (113) 19.1% (89) 18.9% (88) 17.2% (80) 12.9% (60) 8.9% (42) 8.3% (39) 5.3% (25) 1.3% (6)	n = 468
What is the most frequent source of your knowledge about your illness? (single choice)	Conversations with the physician Conversations with the family Chats with friends Internet Conversations with other patients TV Conversations with nurses Information brochures Books Newspapers and magazines Radio Other	73.7% (348) 6.2% (29) 4.5% (21) 3.2% (15) 3.2% (15) 2.1% (10) 2.1% (10) 2.1% (10) 1.5% (7) 0.4% (2) 0.4% (2) 0.6% (3)	n = 472
How do you assess your knowledge about the further course of your illness?	I have no knowledge I don't have much knowledge It's hard to say I have some knowledge I have good knowledge	10.1% (48) 22.0% (104) 25.6% (121) 31.3% (148) 11.0% (52)	n = 473
Has your lung specialist ever talked to you about the end stage of your illness and life?	Yes, he/she has No, he/she hasn't	74.6% (352) 25.4% (120)	n = 472
How do you rate this conversation in terms of the knowledge delivered (e.g., what might happen, what you should be prepared for, what issues need to be dealt with and fixed)?	Very good Good Satisfactory Poor Very poor	26.6% (32) 51.6% (62) 18.5% (22) 2.4% (3) 0.8% (1)	n = 120
How do you rate this conversation in terms of general atmosphere, respectful attitude, time for questions, and time to think?	Very good Good Satisfactory Poor Very poor	37.0% (45) 43.4% (53) 16.4% (20) 2.4% (3) 0.8% (1)	n = 122
Do you want your lung specialist to talk to you about the end stage of your illness and life?	I don't want to talk about it I'd rather not talk about it I'd rather like to talk about it I want to talk about it	28.8% (135) 29.3% (137) 24.1% (113) 17.7% (83)	n = 468
Has any other physician talked to you about the end stage of your illness and life?	No Yes	91.5% (428) 8.5% (40)	n = 468
What obstacles hinder your conversations with your lung specialist regarding the end stage of your illness and life (multiple choice)	No time for such conversations during a visit to a specialist No idea about the further course of the disease Lack of disease and end-of-life knowledge Reluctance to talk about such topics Patient not ready for such a conversation Patient's fear of losing hope Physician's not being ready for such a conversation Physician's fear of taking away the patient's hope No obstacles to holding such conversations	26.6% (126) 25.3% (120) 23.2% (110) 23.2% (110) 19.4% (92) 13.5% (64) 10.3% (49) 8.9% (42) 12.3% (58)	n = 474

positive answers whereas only 20% of them had actually initiated these conversations [16]. It seems that the burden of such conversations rests with the lung specialists, since, according to respondents to the current survey, physicians of other specialties are unlikely to discuss these issues. Patients who had had such conversations with their physicians had a decidedly positive view of them in terms of the overall atmosphere and the knowledge delivered; as also evident from the correlative analysis, they were more likely to expect such conversations in the future. With regard to the obstacles hindering such conversations, the respondents' indications were fairly evenly distributed across several problems, with the dominant ones being the lack of time during the visits and the aforementioned deficiencies in knowledge and ideas regarding the further course of the disease among COPD patients. This can be a significant impediment to the introduction of any standards of end-of-life care planning in this patient group. Above all, however, inadequate awareness of one's condition and the course of the disease can generate anxiety, which is in line with observations suggesting that the lack of knowledge does not improve comfort, but instead creates anxiety and uncertainty that further burden the patient [17].

The influence of socioeconomic status, including the level of general and health-related knowledge, has also been noted in other serious lung diseases. Observations on lung cancer confirm the influence of educational background on the incidence of the disease. This is most frequently associated with awareness of health-promoting behaviors, including the impact of smoking on the risk of the disease [18–20]. The level of knowledge and ability to communicate with the physician can also facilitate diagnostic decision-making and patients being more active about participation in lung cancer screening [21]. The level of awareness about the disease, its progression, and prognosis may also influence early planning of end-of-life care. This has been supported by observations regarding other pulmonary conditions fraught with unfavorable prognoses, such as idiopathic pulmonary fibrosis. Patients who are aware of the prognosis and have the difficult but necessary knowledge of the likely course of their disease can express their wishes regarding the scope of medical actions to be undertaken, avoiding medically futile management in the future [22, 23].

Summary

The study has provided some important information on the researched patient population with advanced COPD. The analysis of data confirms observations

from similar studies concerning the deficits in disease awareness and appropriate conversations with physicians that would allow these patients to participate in the process of future care planning. The fact that the physicians remain the primary source of knowledge for the patients should mobilize efforts to combat any barriers to proper communication — particularly about adequate time being allowed during the visits to lung specialists and gradual education of the patient so that they can become a more mature partner in disease management.

Article information and statements

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None.

Data availability statement

The authors declare that the data supporting the findings of this study are available within the article.

Ethics statement

Consent of the bioethics committee: Bioethics committee of Collegium Medicum in Bydgoszcz, Nicolaus Copernicus University of Toruń, Poland (KB 667/2016). The study was conducted in accordance with the Declaration of Helsinki.

Authors' contributions

Concept and design, data collection, data analysis, manuscript writing — BB; data collection, data analysis — SS; concept and design — IDK; concept and design, data analysis — EJ; concept and design, data analysis — MK.

Conflict of interest

All authors declare no conflicts of interest.

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Supplementary material

None.

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