# **ORIGINAL ARTICLE**

# End-of-life care for patients with advanced lung cancer and chronic obstructive pulmonary disease: survey among Polish pulmonologists

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#### **KEY WORDS**

advanced chronic obstructive pulmonary disease, breathlessness, end-of-life communication, opioids, palliative care

#### **ABSTRACT**

**INTRODUCTION** There is evidence that people with nonmalignant disease receive poorer end-of-life (EOL) care compared with people with cancer.

**OBJECTIVES** The aim of the study was to assess the selected aspects of symptomatic treatment and communication between physicians and patients diagnosed with either advanced chronic obstructive pulmonary disease (COPD) or lung cancer.

RESULTS Properly completed questionnaires were returned by 174 respondents (27.2% of those proved to be contacted by email). In COPD, 32% of respondents always or often used opioids in chronic breathlessness and 18.3% always or often referred patients to a palliative care (PC) specialist. Nearly 80% of the respondents claimed that bedside discussions on EOL issues with people with COPD are essential, although only 20% would always or often initiate them. In people with lung cancer, opioids were routinely used for relief of chronic breathlessness by 80% of physicians; 81.7% referred patients to a PC specialist. More than half of the respondents always or often discussed EOL issues only with the patient's caregivers or relatives. Younger physicians, those at an earlier stage of their career, those caring for higher numbers of patients with lung cancer, and those who were better acquainted with Polish Respiratory Society recommendations for PC in chronic lung diseases seemed to provide better EOL care for COPD patients.

**CONCLUSIONS** Patients with COPD, as compared with patients with lung cancer, were less frequently treated with opioids to relieve chronic breathlessness or referred for a PC consultation. Discussing the EOL issues with a patient was generally found challenging by physicians, and most often pursued with caregivers instead. The COPD recommendations on PC may prove helpful in providing better EOL care by pulmonologists.

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**INTRODUCTION** A steadily rising number of patients diagnosed with chronic obstructive pulmonary disease (COPD), especially those at an advanced stage of the disease, has triggered an ongoing debate over palliative care (PC) for this particular group of patients. Numerous studies

revealed the burden of ineffectively controlled symptoms such as chronic breathlessness, depression, and anxiety among patients with end-stage COPD.<sup>1-3</sup> Compared with other life-limiting conditions, these patients experience lower quality of life, and yet they have limited access to PC or

TABLE 1 Participants' characteristics

Age, mean (SD)		49.2 (11)
Female sex		102 (58.6)
Years of practice	<5 years	6 (3)
	5–9 years	9 (5)
	10-19 years	48 (28)
	20–29 years	66 (38)
	>30 years	45 (26)
Specialty held	Respiratory medicine	156 (90)
	Allergology	21 (12)
	Palliative medicine	5 (3)
The main place of work	University hospital	50 (29)
	Another hospital	75 (43)
	Outpatient clinic	32 (18)
	Private practice	10 (6)
Number of COPD patients treated within a year	< 50	21 (12)
	50–200	81 (47)
	>200	72 (41)
Number of lung cancer	<50	76 (44)
patients treated within a year	50–200	80 (46)
you	>200	18 (10)
Number of category D	<30	52 (30)
patients with COPD treated during last year	30–100	90 (52)
treated during last year	>100	52 (18)
Knowledge of PRS	I know them and I have read them.	70 (40.2)
guidelines on PC in lung diseases	I have heard about them and looked through them briefly.	63 (36.2)
	I have heard about them, but not read them.	18 (10.3)
	I have never heard of them.	23 (13.2)
Religious beliefs	Christian	135 (77.6)
	Nonbeliever	21 (12.1)
	Buddhist	0
	Muslim	0
	Other	1 (1.7)
	I prefer not to answer.	15 (8.6)

Data are presented as number (percentage) unless otherwise indicated.

Abbreviations: COPD, chronic obstructive pulmonary disease; PC, palliative care; PRS, Polish Respiratory Society

even a PC consultation. 4-6 There is also evidence of ineffective communication between pulmonologists and people with COPD, especially on end-of-life (EOL) issues. 7-9 Patients usually expect their physicians to be able to explain to them the key aspects of their condition, including future care needs. On the other hand, patients usually do not initiate conversations about EOL issues themselves during a consultation. 10,11 Recently, international and local recommendations for PC in advanced nonmalignant lung diseases have been introduced, including guidelines of the Polish Respiratory Society (PRS). 12-16

We carried out a questionnaire survey among Polish pulmonologists 5 years after the publication of the Polish guidelines, with the aim to assess their understanding and uptake of specific recommendations in everyday clinical practice. We aimed to compare how attending pulmonary physicians treated symptoms and communicated with patients with advanced COPD and those with lung cancer. The comparison between COPD and lung cancer seems to be relevant since both conditions are characterized by common pathogenesis, 17 similar presentation, and comparable prognosis at their advanced stage.

**METHODS** The online questionnaire was developed for the purpose of this research, based on a tool used in a Portuguese study by Gaspar et al, <sup>18</sup> but expanded to 2 patient populations, namely, those with advanced COPD and those with lung cancer. The questionnaire was divided into 5 thematic domains: symptom management, EOL communication, participants in EOL communication, obstacles to EOL communication, and a sense of dignity in a COPD patient.

With regard to the first 3 domains, a Likert scale was used to elicit respondents' opinions (1 - never; 2 - seldom; 3 - occasionally; 4 - often; and 5 - always). In the "obstacles to communication" category, respondents were asked to mark as many options as they deemed essential. Finally, there was an open question on how to support dignity in a patient with COPD at the end of life.

The questionnaire was loaded onto the Survio survey platform (https://www.survio.com). All members of the PRS who were also physicians were sent an email with an invitation to complete the questionnaire anonymously, and a reminder was sent 3 times within 4 months.

The study protocol was approved by the Bioethics Review Committee at Nicolaus Copernicus University in Toruń, Collegium Medicum in Bydgoszcz, Poland (Ref. No. KB 667/2016).

Statistical analysis The differences in the results between people with COPD and lung cancer measured on the ordinal scale were tested using the Mann–Whitney test. Nominal variables were assessed with the  $\chi^2$  independence test. Correlations between the variables were established with the Kendall's  $\tau$ -b correlation coefficient. The level of statistical significance was set at a P value of less than 0.01. The SPSS software (IBM SPSS Statistics 24.0.0; SPSS Inc., Armonk, New York, United States) was used for analyses.

RESULTS Study participants An invitation to participate in the study was sent to 958 email addresses from the database of the PRS; however, only 639 respondents were contactable by email (Supplementary material, Figure S1). A total of 176 members of the PRS completed the survey; however, 2 questionnaires were excluded from the analysis due to critical technical errors. Finally, 174 correctly completed questionnaires were received, yielding a response rate of 27.2% (174 of 639). The average age of respondents was 49 years (range, 28–86 years; TABLE 1) and 59% of respondents were women. Most people worked

TABLE 2 Relieving the symptoms in people with advanced lung cancer or advanced chronic obstructive pulmonary disease

		Lung cancer	COPD	P value	z score
Frequency of opioid use in relieving	1 – never	7 (4)	33 (19)	< 0.001	-11.69
severe to moderate pain in patients with advanced stages of the disease	2 – seldom	0	33 (19)	-	
with davanced stages of the disease	3 – occasionally	16 (9.2)	59 (33.9)	-	
	4 – often	63 (36.2)	41 (23.6)	-	
	5 – always	88 (50.6)	8 (4.6)	-	
	Median	5	3	-	
Frequency of opioid use in relieving	1 – never	9 (5.2)	29 (16.7)	< 0.001	-9.11
chronic breathlessness in patients with advanced stages of the disease	2 – seldom	9 (5.2)	34 (19.5)	- - - -	
with advanced stages of the disease	3 – occasionally	18 (10.3)	55 (31.6)		
	4 – often	69 (39.7)	44 (25.3)		
	5 – always	69 (39.7)	12 (6.9)		
	Median	4	3		
Frequency of concerns regarding opioid use in patients with chronic breathlessness in advanced stages of the disease	1 – never	102 (62)	31 (17.8)	<0.001	-9.27
	2 – seldom	47 (27)	60 (34.5)		
	3 – occasionally	14 (8)	43 (24.7)		
	4 – often	4 (2.3)	28 (16.1)		
	5 – always	1 (0.6)	12 (6.9)		
	Median	1	2	-	
Frequency of favorable effects of opioid	1 – never	_	12 (6.9)	_	_
use in COPD patients with chronic breathlessness	2 – seldom	_	11 (6.3)	-	
Diediliessiless	3 – occasionally	_	37 (21.3)	-	
	4 – often	_	95 (54.6)	-	
	5 – always	_	19 (10.9)	-	
	Median	_	4	-	
Frequency of recommending	1 – never	1 (0.6)	1 (0.6)	NS	-1.67
antidepressant or anxiolytic therapy in patients with depression or anxiety	2 – seldom	16 (9.2)	27 (15.5)	-	
disorders in advanced stages of	3 – occasionally	59 (33.9)	58 (33.3)	-	
the disease	4 – often	74 (42.5)	72 (41.4)	-	
	5 – always	24 (13.8)	16 (9.2)	-	
	Median	4	4	-	

Data are presented as number (percentage) unless otherwise stated.

Abbreviations: NS, nonsignificant; others, see TABLE 1

in the profession for over 10 years, and nearly 90% of respondents held a specialization in pulmonology. For 29% of respondents, the main place of work was a university hospital, and for 43%, another type of hospital. The majority of respondents (88%) treated more than 50 people with COPD within a year, with 70% caring for 30 or more people with category D according to the Global Initiative for Chronic Obstructive Lung Disease classification in the preceding year. 19 More than half of respondents (56%) cared for at least 50 people with lung cancer within a year. Most of the pulmonologists who participated in the study were aware of the PRS guidelines on PC in chronic lung diseases: 40% of respondents had read them and 36% briefly reviewed them.

**Relief of symptoms** As to relieving moderate or severe pain, opioids were more often used in

patients with advanced lung cancer than in those with COPD (always or often, 86.8% and 28.2%, respectively; TABLE 2). As to relieving chronic breathlessness<sup>20</sup> in people with advanced lung cancer, opioids were used significantly more often than in advanced COPD (always or often, 79.4% and 32.2%, respectively). For people with COPD, the majority of physicians used opioids only occasionally (31.6%), or seldom or never (36%; TABLE 2).

The majority of study participants who used opioids to relieve chronic breathlessness in patients with COPD often or always noticed benefits (65.5%). More physicians never had any concerns that would made them reluctant to use opioids in chronic breathlessness while treating patients with lung cancer as compared with patients with COPD (62% and 17.8%, respectively).

Among 96 answers (given by 82 participants) to the open question about the fears connected

TABLE 3 Relationship between the variables and the frequency of opioid use, depression or anxiety treatment, favorable effects of opioids, and concerns regarding opioid use

Variables	Test	Frequency of opioid use in relieving severe or moderate pain		Frequency of opioid use in relieving chronic breathlessness		Frequency of recommending antidepressant or anxiolytic		Frequency of favorable effects of opioids in	Frequency of concerns regarding opioid use	
		Lung cancer	COPD	Lung cancer	COPD	Lung cancer	COPD	COPD patients with chronic breathlessness	Lung cancer	COPD
Ageª	Coefficient	-0.12	-0.24	-0.17	-0.21	-0.04	-0.08	-0.21	0.13	0.10
	Significance	NS	< 0.001	0.005	< 0.001	NS	NS	< 0.001	NS	NS
Sex <sup>b</sup>	Test value	-0.35	-1.29	-0.19	-0.17	-0.58	-0.60	-1.06	-0.69	-1.46
	Significance	NS	NS	NS	NS	NS	NS	NS	NS	NS
Work	Coefficient	-0.09	-0.22	-0.14	-0.21	-0.03	-0.09	-0.23	0.13	0.12
experience <sup>a</sup>	Significance	NS	< 0.001	NS	0.001	NS	NS	< 0.001	NS	NS
Number of	Coefficient	-0.02	-0.02	-0.06	-0.01	0.01	0.08	0.04	0.07	-0.03
COPD patients treated within a year <sup>a</sup>	Significance	NS	NS	NS	NS	NS	NS	NS	NS	NS
Number of lung	Coefficient	0.10	0.22	0.22	0.21	0.26	0.28	0.14	-0.02	-0.03
cancer patients treated within a year <sup>a</sup>	Significance	NS	0.001	0.001	0.001	<0.001	<0.001	NS	NS	NS
Knowledge of	Coefficient	-0.20	-0.22	-0.21	-0.23	-0.20	-0.17	-0.18	0.01	0.17
PRS guidelines <sup>a</sup>	Significance	0.004	0.001	0.001	< 0.001	0.003	NS	0.007	NS	0.008
Religious	Value of test	-0.97	-1.15	-0.94	-0.31	-0.78	-0.33	-0.61	-0.53	-0.24
beliefs (believer or nonbeliever) <sup>b</sup>	Significance	NS	NS	NS	NS	NS	NS	NS	NS	NS

a The Kendall's τ-b correlation coefficient was applied.

Abbreviations: see TABLES 1 and 2

with using opioids, the majority were related to the risk of respiratory depression (n = 56) and the balance with adverse effects such as constipation, nausea, or drowsiness (n = 12), and the potential for serious complications such as consciousness disturbances (n = 6) or development of opioid addiction (n = 4).

The correlation analysis revealed a significant relationship between the frequency of using opioids to relieve pain and chronic breathlessness and the following factors: age, work experience, number of people with lung cancer treated within a year, and knowledge of the PRS guidelines for PC in lung diseases (TABLE 3).

Study participants who had better knowledge of the PRS guidelines were more likely to use opioids for pain and chronic breathlessness in both groups of patients. Younger respondents and those treating higher numbers of patients with lung cancer were more open to the use of opioids to manage pain in people with COPD and to reduce chronic breathlessness in both patient groups.

Study participants who were at earlier stages of their career were more likely to use opioids for pain and chronic breathlessness in people with COPD. Younger pulmonologists, those earlier in their career, and those with a better knowledge of the PRS guidelines were also more open to see favorable effects of opioids in patients with COPD and chronic breathlessness. A significant relationship was revealed between the frequency of concerns about the use of opioids in patients with COPD and lower familiarity with the PRS guidelines for PC in lung disease.

No significant difference was observed in the pulmonologists' attitude to the treatment of mood disorders in patients with COPD and lung cancer (TABLE 2). Prescribing antidepressants and anxiolytics in both groups of patients was correlated with the number of people with lung cancer treated within a year (TABLE 3). A significant relationship was also revealed between the frequency of recommending antidepressants and anxiolytics in patients with lung cancer and good knowledge of the PRS guidelines.

**End-of-life communication** Most of the respondents believed that discussions about the EOL issues with patients with COPD were essential (79%; TABLE 4), yet only 20% of respondents often or always initiated these conversations. Slightly

b The Mann-Whitney test was applied.

TABLE 4 End-of-life communication with people with advanced chronic obstructive pulmonary disease or advanced lung cancer (continued on the next page)

		Lung cancer	COPD	<i>P</i> value	z score
Frequency of initiating a talk	1 – never	22 (12.6)	26 (14.9)	0.001	-3.40
with patients regarding EOL issues	2 – seldom	42 (24.1)	64 (36.8)		
100000	3 – occasionally	42 (24.1)	49 (28.2)		
	4 – often	49 (28.2)	27 (15.5)		
	5 – always	19 (10.9)	8 (4.6)		
	Median	3	2		
requency of talks with patients o	on the subject of:				
Disease progression	1 – never	0	0	NS	-1.92
	2 – seldom	15 (8.6)	10 (5.7)		
	3 – occasionally	39 (22.4)	25 (13.2)		
	4 – often	74 (42.5)	89 (51.1)		
	5 – always	46 (26.4)	52 (29.9)		
	Median	4	4		
Everyday needs	1 – never	1 (0.6)	3 (1.7)	NS	-0.31
	2 – seldom	22 (12.6)	18 (10.3)		
	3 – occasionally	44 (25.3)	42 (24.1)		
	4 – often	63 (36.2)	77 (44.3)	<del></del>	
	5 – always	44 (25.3)	34 (19.5)	<del></del>	
	Median	4	4		
End-of-life symptoms	1 – never	18 (10.3)	24 (13.8)	0.004	-2.90
	2 – seldom	43 (24.7)	57 (32.8)		
	3 – occasionally	45 (25.9)	52 (29.9)		
	4 – often	49 (28.2)	31 (17.8)		
	5 – always	19 (10.9)	10 (5.7)		
	Median	3	3		
Religious/spiritual needs	1 – never	42 (24.1)	50 (28.7)	NS	-2.23
	2 – seldom	50 (28.7)	64 (36.8)		
	3 – occasionally	38 (21.8)	32 (18.4)		
	4 – often	29 (16.7)	20 (11.5)		
	5 – always	15 (8.6)	8 (4.6)		
	Median	2	2		
requency of making a suggestio	n to the patient that a decision (	needs to be made on:			
nvasive mechanical ventilation	1 – never	75 (43.1)	21 (12.1)	< 0.001	-7.13
	2 – seldom	47 (27)	37 (21.3)		
	3 – occasionally	26 (14.9)	54 (31)		
	4 – often	19 (10.9)	50 (28.7)		
	5 – always	7 (4)	12 (6.9)		
	Median	2	3		
Cardiopulmonary resuscitation	1 – never	85 (48.9)	42 (24.1)	< 0.001	-4.77
	2 – seldom	53 (30.5)	59 (33.9)		
	3 – occasionally	17 (9.8)	51 (29.3)		
	4 – often	12 (6.9)	19 (10.9)		
	5 – always	7 (4)	3 (1.7)		
	Median	2	2		
Place of dying	1 – never	42 (24.1)	65 (37.4)	< 0.001	-3.87
-	2 – seldom	46 (26.4)	56 (32.2)		
	3 – occasionally	38 (21.8)	30 (17.2)		
	4 – often	34 (19.5)	18 (10.3)		
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	5 – always	14 (8)	5 (2.9)		

TABLE 4 End-of-life communication with people with advanced chronic obstructive pulmonary disease or advanced lung cancer (continued from the previous page)

		Lung cancer	COPD	<i>P</i> value	z score
Frequency of referring a patient	1 – never	8 (4.6)	42 (24.1)	< 0.001	-11.41
for PC or to a palliative	2 – seldom	8 (4.6)	51 (29.3)		
medicine specialist	3 – occasionally	16 (9.2)	49 (28.2)		
	4 – often	81 (46.6)	26 (14.9)		
	5 – always	61 (35.1)	6 (3.4)		
	Median	4	2		
Whether the discussions on EOL	They are needed and important	_	137 (78.7)	_	_
with an advanced COPD patient are needed and	They are neither needed nor important	_	5 (2.9)		
important for the patient	I have no opinion	_	32 (18.4)		

Data are presented as number (percentage) unless otherwise stated.

Abbreviations: EOL, end-of-life; others, see TABLES 1 and 2

more physicians initiated such conversations with patients with lung cancer (always or often, 39.1%).

With regards to patients with advanced COPD, the most frequently discussed topics were disease progression (81% of respondents discussed it always or often) and everyday needs (always or often, 63.8%). Discussion on the EOL symptoms were much less frequent (always or often, 23.5%), similarly to talks on religious or spiritual needs (always or often, 16.1%; TABLE 4). The same topics were also most frequently addressed in people with lung cancer. Mechanical ventilation was always or often discussed with people who had COPD by 35.6% of respondents. Patients with lung cancer were significantly less likely to have a discussion about mechanical ventilation (15%; TABLE 4). Only 12.6% of respondents discussed cardiopulmonary resuscitation with patients with COPD, and 10.9% with patients with advanced lung cancer. Conversations about the place of dying were rare in both patient populations. A higher number of people with COPD and lung cancer treated within a year positively influenced the initiation of EOL discussion by physicians (TABLE 5). A better knowledge of the PRS guidelines was related to more frequent initiation of a discussion on EOL issues with patients with COPD.

Pulmonologists who treated higher numbers of people with lung cancer were more inclined to initiate bedside discussions about the preferred place of dying with both patient groups (TABLE 5). Younger physicians and those earlier in their careers were more open to discuss this topic with people who had lung cancer. Physicians who cared for a higher number of people with COPD were more inclined to suggest to a patient with COPD the need for making a decision regarding invasive mechanical ventilation. Better knowledge of the guidelines was associated with more frequent initiation of discussion on the use of invasive ventilation and cardiopulmonary resuscitation with COPD patients (TABLE 5).

**Referral to specialist palliative care** People with lung cancer were more often referred for PC or a consultation with a palliative medicine specialist, with 81.7% of respondents always or often doing this. As to patients with COPD, only 18.3% of respondents (always or often) referred them for PC (TABLE 4).

Participants in end-of-life communication More than half of the respondents (often or always) discussed the EOL issues with the caregivers or the patient's family only, with the patient being excluded from the conversation (54%; TABLE 6). On the other hand, only 8.6% of respondents always or often made the decisions regarding the EOL of patients with COPD along with other health care specialists without including patients or their caregivers or relatives.

Obstacles to end-of-life communication The following key obstacles to initiating talks about the EOL issues with a patient who has end-stage COPD were identified: belief that a patient was not ready for such talk (68.4%); fear of stripping the patient of hope (64.9%); lack of the resources necessary to provide PC for the patient (49.4%); and certain inadequacies in training in this particular area (33.9%). More than 20% of respondents pointed to lack of clarity regarding the legal aspects of making medical decisions at the end of the patient's life (23.6%) and to difficulties in predicting the actual progression of the disease (20.1%; FIGURE 1).

Similar obstacles were identified for people with lung cancer: fear of stripping hope (62.1%); belief that a patient was not ready for such discussion (49.4%); inadequate training (28.2%); lack of the resources necessary to provide PC for the patient (21.3%); difficulties in predicting the actual progression rate of the disease (17.8%); and ignorance of pertinent legal aspects (13.2%; FIGURE 1).

More respondents recognized obstacles hampering communication on EOL issues in people

TABLE 5 Association between the variables and frequency of initiating discussions on end-of-life issues and of suggesting to a patient at an advanced stage of lung cancer and chronic obstructive pulmonary disease the need for making a decision regarding invasive mechanical ventilation, cardiopulmonary resuscitation, and a place of dying

Variable	Test	Frequency of initiating a talk on EOL issues		Frequency of suggesting to a patient at an advanced stage of the disease the need for making a decision regarding:						
					nechanical tilation		ulmonary citation	Place o	of dying	
		Lung cancer	COPD	Lung cancer	COPD	Lung cancer	COPD	Lung cancer	COPD	
Ageª	Correlation coefficient	-0.10	-0.09	0.01	0.11	0.04	0.00	-0.20	-0.14	
	Significance	NS	NS	NS	NS	NS	NS	< 0.001	NS	
Sex <sup>b</sup>	Test value	-1.47	-1.07	-0.64	-0.46	-0.44	-1.24	-0.36	-0.35	
	Significance	NS	NS	NS	NS	NS	NS	NS	NS	
Work experience <sup>a</sup>	Correlation coefficient	-0.10	-0.10	0.04	0.10	0.02	0.00	-0.21	-0.14	
	Significance	NS	NS	NS	NS	NS	NS	0.001	NS	
Number of COPD patients treated within a year <sup>a</sup>	Correlation coefficient	0.18	0.18	0.13	0.25	0.08	0.10	0.12	0.11	
	Significance	0.006	0.007	NS	< 0.001	NS	NS	NS	NS	
Number of lung cancer patients treated within	Correlation coefficient	0.18	0.24	-0.04	0.10	0.05	0.13	0.20	0.19	
a yearª	Significance	0.005	< 0.001	NS	NS	NS	NS	0.003	0.005	
Knowledge of Polish guidelines <sup>a</sup>	Correlation coefficient	-0.16	-0.21	-0.09	-0.25	0.07	-0.30	-0.10	-0.07	
	Significance	NS	0.001	NS	< 0.001	NS	< 0.001	NS	NS	
Religious beliefs (believer or	Test value	-1.87	-0.72	-0.06	-0.66	-0.50	-0.45	-1.00	-1.37	
nonbeliever) <sup>b</sup>	Significance	NS	NS	NS	NS	NS	NS	NS	NS	

a The Kendall τ-b correlation coefficient was applied.

Abbreviations: see TABLES 1, 2, and 4

 TABLE 6
 Participants in end-of-life communication

	1 – never	2 – seldom	3 – occasionally	4 – often	5 – always	Median
Frequency of EOL discussions with the caregivers or relatives only, without the patient's participation	7 (4)	27 (15.5)	46 (26.4)	71 (40.8)	23 (13.2)	4
Frequency of decisions on EOL issues regarding patients with end-stage COPD made by the respondent, along with other specialists, without including patients or their caregivers or relatives	47 (27)	64 (36.8)	48 (27.6)	14 (8)	1 (0.6)	2

Data are presented as number (percentage) unless otherwise stated.

Abbreviations: see TABLES 1 and 4

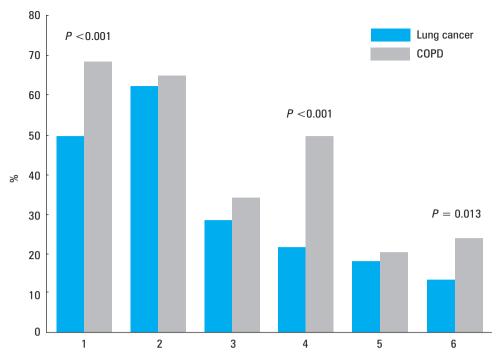
with COPD than lung cancer: the impression that patients are unprepared for facing such issues (68.4% and 49.4%, respectively) and lack of the resources necessary to provide PC for a patient (49.4% and 21.3%, respectively).

**Dignity in patients with chronic obstructive pulmonary disease** Finally, an open question was posed on how to effectively enhance dignity in people with COPD approaching the end of life. We received 108 answers, and the need for better access to PC centers or home PC was highlighted most often (n = 24). There were also numerous suggestions for more person-oriented treatment in terms of

better sharing of information about the nature of their disease and encouraging their informed involvement in making pertinent therapeutic decisions (n=15). Respondents also highlighted the importance of caring for patients' families (n=14), better access to psychological services (n=13), and more empathy from attending physicians (n=8).

**DISCUSSION** Caring for people with advanced chronic obstructive pulmonary disease Despite Polish and other guidelines on COPD that recommend PC approach including efficient management of symptoms and advance care

b The Mann-Whitney test was applied.



**FIGURE 1** Answers to a question on obstacles to communication about the end-of-life issues with regard to patients with end-stage chronic obstructive pulmonary disease (COPD) and lung cancer (multiple responses possible). 1 — impression that the patient is unprepared for facing such issues; 2 — fear of taking away all hope from a patient; 3 — deficits in professional training in this area; 4 — no resources to facilitate end-of-life or palliative care for a patient; 5 — difficulty in predicting progression of the disease; 6 — no command (or unclear view) of attendant legal aspects of making medical decisions at the end of one's life (eg, witholding invasive mechanical ventilation)

planning, 12-16,19,21-22 chronic breathlessness remains undertreated, physicians rarely initiate discussions on EOL issues and seldom refer their patients to a PC specialist. 18,23-26 A total of 19% of respondents reported that they never prescribe opioids to people with chronic breathlessness and COPD, which is similar to the results from a study among Dutch chest physicians.24 Although the beneficial effects of opioids<sup>27-32</sup> and their general safety (assuming that small, regular doses are prescribed) in relieving chronic breathlessness have been confirmed in various clinical trials,33-35 a significant percentage of the respondents still express serious reluctance to use them in practice. A similar attitude of pulmonologists was observed in a Portuguese study by Gaspar et al, 18 in which 30% of respondents never or seldom used opioids in chronic breathlessness in patients with COPD.

In our survey, 1 in 4 participants always or often expressed concerns regarding opioids that make them reluctant to use those drugs in people with COPD and chronic breathlessness, which is consistent with other studies reporting that 15% to 56% of physicians were afraid of respiratory depression as an adverse effect of opioids in patients with COPD.<sup>24,36-38</sup> A recent meta-analysis showed no evidence of significant respiratory depression due to opioids used regularly at low doses for chronic breathlessness.<sup>35</sup> Besides the lack of knowledge among physicians on when and how to use opioids, also preexisting fears contribute to doctors' reluctance to prescribe opioids for

chronic breathlessness, especially in COPD. Recently, we showed high incidence of opiophobia in Poland both among palliative care patients and physicians, creating an additional barrier to optimal treatment of chronic breathlessness. <sup>39,40</sup> Half of Polish pulmonologists from the present study always or often prescribed antidepressant or anxiolytic therapy in people with advanced COPD experiencing depression or anxiety disorders, similarly to Portuguese study (60%). <sup>18</sup> Further work is required to understand why 50% of pulmonologists did not.

Our survey revealed opportunities for better communication between pulmonologists and people with advanced COPD. Only 20% of respondents (always or often) initiated a discussion about EOL issues, which was comparable with results from a Portuguese study (13.2%). Few clinicians initiated such conversations including the topic of advance care planning. Clinicians avoided bringing up end-of-life symptoms, mechanical ventilation, or cardiopulmonary resuscitation. Respondents attributed barriers in an effective EOL approach to their belief that the patients were unprepared for facing such issues or that they did not want to destroy patients' hopes.

A perceived lack of resources for providing PC for patients with COPD was also reported. A recent systematic review of studies on the practice of advance care planning among patients with chronic lung disease confirmed that it is uncommon, possibly due to the complex course of

**TABLE 7** Communication on end-of-life issues and symptom management provided by pulmonologists for patients with advanced chronic obstructive pulmonary disease and advanced lung cancer

Selected aspects of treatment and		)isease	χ² test		
communication; "often" or "always" responses	COPD	Lung cancer	χ²	P value	
Application of opioids for relieving	49	151	122.32	< 0.001	
moderate or severe pain	(28)	(87)			
Application of opioids for chronic	56	138	78.32	< 0.001	
breathlessness	(32)	(79)			
Concerns regarding	40	5	31.27	< 0.001	
the application of opioids in patients with chronic breathlessness	(23)	(3)			
Ordering antidepressant or	88	98	1.15	NS	
anxiolytic treatment	(51)	(56)			
Initiating a talk on EOL issues	35	68	15.02	< 0.001	
	(20)	(39)			
Referring a patient for PC or to	32	142	139.08	< 0.001	
a PC specialist consultation	(18)	(82)			

Data are presented as number (percentage).

Abbreviations: see TABLES 1, 2, and 4

the disease and ambivalence of both patients and clinicians about engaging in these processes.<sup>41</sup>

Interestingly, in a recent multinational survey, nearly all pulmonologists and PC specialists from Australia, New Zealand, and United Kingdom participating in the study reported that they would initiate a discussion with the person described in a case vignette regarding prognosis and advance care planning.42 While physicians of both specialties pointed at similar topics that need to be covered in advance care planning, palliative medicine physicians were more likely to discuss death and dying issues, prognosis, treatment limitations, and the place of future care. Researchers proposed the complementarity of a pulmonologist and PC specialist, in which the former should initiate these discussions and the latter then develop and expand the conversations according to each patient's needs and wishes, as the illness progresses.42 The cooperation between respiratory medicine and PC has been recommended by international guidelines, which pointed at early implementation of the PC approach in parallel with disease-directed therapy. 15,19 The ideal model should be based on good cooperation between the pulmonologist and PC specialist as well as an easy access to PC care for COPD patients. There is also a steadily growing body of evidence for the benefits offered by PC, even in the early stages of the disease.43 However, in the majority of countries referral to PC specialist services is still rare. 44,45 In the United States, only 1.7% of patients with end-stage COPD who were dependent on home oxygen were referred to a PC specialist when admitted with an exacerbation.<sup>45</sup> In Poland there are no legal restrictions on access to PC by patients with advanced COPD. However, there are no models of care for advanced COPD patients apart from a few pilot programs such as the Integrated Care Model developed in Gdańsk, Poland. 46,47

Better end-of-life care for patients with lung cancer than for those with chronic obstructive pulmonary disease When compared with patients with advanced lung cancer, patients with advanced COPD are prescribed fewer opioids for the relief of moderate or severe pain and chronic breathlessness, and pulmonologists less often initiate bedside discussion on the EOL issues, refer them to PC, or ask PC specialist for consultation (TABLE 7). Concerns regarding the use of opioids, as expressed by physicians, were also more often related to patients with COPD, but such fears do not reflect the available evidence. Further, pulmonologists more often talk about EOL symptoms and initiate a discussion on the place of dying with patients with advanced lung cancer. Discussions about invasive mechanical ventilation and cardiopulmonary resuscitation are more frequent in people with advanced COPD, but even then are initiated only by a minority of physicians. Significantly more respondents recognized obstacles hampering communication on EOL issues in patients with COPD than with lung cancer, especially because of concerns that patients are unprepared for facing such issues and lack of the resources required to provide PC. Respondents highlighted the need to facilitate better access to PC centers and recognition of the patient's rights to honest, factual information about their medical condition.

Why are people with COPD referred for PC less often? A recent population-based survey from Belgium by Scheerens et al<sup>48</sup> showed that treatment goals in the last week of life were less often aimed at comfort or palliation for COPD (59.1%) than for lung cancer (92.1%), and the use of any type of PC service was less common in COPD than in lung cancer (37.3% and 73.5%, respectively; P < 0.001). In addition, the timing of referral was very close to death: a median of 6 days for COPD and 16 days for lung cancer. There is a need to define the indications for referral of patients with COPD for PC based on the level and complexity of needs and to demonstrate the benefits of early integration of PC into their care.<sup>49</sup>

Who should the doctor talk to about end-of-life issues? More than half of the respondents (often or always) discussed EOL issues only with the caregivers or the patient's family, with the patient being excluded from the conversation (54%). It is one of the most surprising results of this survey. In the Portuguese study, 18 only 8.1% of respondents (often or always) had such conversations without the patient. Further studies should clarify whether respondents understood correctly that they were being asked about situations in which patients were still able to make their own decisions. If yes, then such physicians' attitude to discuss EOL issues with the family or

caregiver while excluding the most important person, the patient, needs to be carefully explored.

Professional factors related to care that was more aligned with the Polish Respiratory Society Guidelines Four professional factors were significantly associated with the increased use of opioids. Respondents at a younger age and earlier in their career were more likely to use opioids to relieve chronic breathlessness in people with COPD and more frequently observed favorable effects of opioids in breathless patients with COPD. In a recent survey involving pulmonologists from Australia and New Zealand, a similar observation was made. It is probable that we are observing positive changes in a new generation of doctors, who are more open to the use of regular low-dose morphine for symptom management.

A higher number of patients either with lung cancer or COPD treated within a year positively influenced the initiation of EOL talks by the physicians. The higher number in the COPD group was also related to the frequency of suggesting the need for making decision regarding invasive mechanical ventilation to a patient with COPD. However, caring for people with lung cancer also appears to be an important predictor of using opioids in patients with COPD and lung cancer to relieve chronic breathlessness. It may also predict ordering antidepressant or anxiolytic therapy in these patient populations and discussing the need for deciding on the place of dying. Caring for patients with cancer may make doctors more sensitive to the suffering of people with COPD, helping them not only to discuss EOL problems with patients, but also to introduce symptom management.

Better knowledge of the PRS guidelines was associated with the increased use of opioids in all patients, and the frequency of initiation of discussions on EOL issues and of addressing invasive ventilation and cardiopulmonary resuscitation in people with COPD. Respondents who did not know the PRS guidelines had concerns regarding the use of opioids in COPD patients more frequently. This observation seems to support the role of practice guidelines in improving the quality of patient care.

Limitations The Polish Respiratory Society sent the invitation to participate in the research to all email addresses which had been collected in their database. Not knowing how many addresses were still active, we finally assumed the number of going to the website as a total number of doctors who received the invitation. The overall response rate is at the level expected for online surveys of professionals, reflecting results in similar studies. 18,24,36 The survey assessed respondents' self-reported attitudes and knowledge, and thus might not reflect actual clinical practice in an objective way.

**Conclusions** The results of this study highlight a great need to improve the procedures for relieving the symptoms and communicating more effectively with patients with advanced lung diseases. Palliative care standards for these patient groups should be more widely promoted, and a more compassionate, whole-person care should be developed. 50 Models of integrated care including partnership between pulmonologists and PC clinicians should especially address the unmet needs of patients with advanced COPD. It is of particular interest to find out whether the results of this survey are typical of Polish pulmonary physicians only, or perhaps indicative of a more universal phenomenon, so it would seem prudent to initiate a pan-European research project in this area.

## SUPPLEMENTARY MATERIAL

Supplementary material is available at www.mp.pl/paim.

#### ARTICLE INFORMATION

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