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# Provision of Palliative Care in Patients with COPD: A Survey Among Pulmonologists and General Practitioners

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**Introduction:** Patients with advanced chronic obstructive pulmonary disease (COPD) experience significant symptom burden, leading to poor quality of life. Although guidelines recommend palliative care for these patients, this is not widely implemented and prevents them from receiving optimal care.

**Objective:** A national survey was performed to map the current content and organization of palliative care provision for patients with COPD by pulmonologists and general practitioners (GPs) in the Netherlands.

**Methods:** We developed a survey based on previous studies, guidelines and expert opinion. Dutch pulmonologists and GPs were invited to complete the survey between April and August 2019.

**Results:** 130 pulmonologists (15.3%; covering 76% of pulmonology departments) and 305 GPs (28.6%) responded. Median numbers of patients with COPD in the palliative phase treated were respectively 20 and 1.5 per year. 43% of pulmonologists and 9% of GPs reported some formalized agreements regarding palliative care provision. Physicians most often determined the start of palliative care based on clinical expertise or the Surprise Question. 31% of pulmonologists stated that they often or always referred palliative patients with COPD to a specialist palliative care team; a quarter rarely referred. 79% of the respondents mentioned to often or always administer opioids to treat dyspnea. The topics least discussed were non-invasive ventilation and the patient's spiritual needs. The most critical barrier to starting a palliative care discussion was difficulty in predicting the disease course.

**Conclusion:** Although pulmonologists and GPs indicated to regularly address palliative care aspects, palliative care for patients with COPD remains unstructured and little formalized. However, our data revealed a high willingness to improve this care. Clear guidance and standardization of practice are needed to help providers decide when and how to initiate discussions, when to involve specialist palliative care and how to optimize information exchange between care settings.

**Keywords:** COPD, palliative care, advance care planning, surprise question, organization

## Introduction

Chronic obstructive pulmonary disease (COPD) is the third leading cause of death worldwide.<sup>1</sup> In advanced stages, COPD is associated with a significant symptom burden and poor quality of life.<sup>2</sup> However, palliative care is often not provided to patients with COPD; discussions on palliative and end-of-life care rarely occur,<sup>3</sup> and access to specialist palliative care is limited and late.<sup>4</sup> This lack of palliative care is

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often attributed to the unpredictable disease course of COPD, making it hard to determine when to start palliative care.<sup>5</sup>

Consequently, physicians and policymakers increasingly acknowledge the need for better and timely palliative care provision for patients with COPD.<sup>6–8</sup> In the Netherlands, various efforts have been deployed to improve quality and timing of palliative care for patients with life-limiting diseases, including COPD. A national multidisciplinary guideline on this topic was published in 2011.<sup>9</sup> Furthermore, the Quality Framework Palliative Care was published in 2017, to incentivize implementation of palliative care in the Netherlands.<sup>10</sup> The framework describes the essential elements needed to deliver high-quality palliative care. In this framework, no distinction is made between oncologic and non-oncologic diseases, following the WHO definition of palliative care.<sup>11</sup>

Previous studies have highlighted that the provision of palliative care to patients with COPD is unstructured and often limited to terminal care only.<sup>3,12</sup> However, no study has yet examined the formalization and implementation of palliative care for patients with COPD in the Netherlands. Therefore, we developed a national survey to explore the current content and organization of palliative care for patients with COPD in primary and secondary care in the Netherlands.

## Materials and Methods

### Design

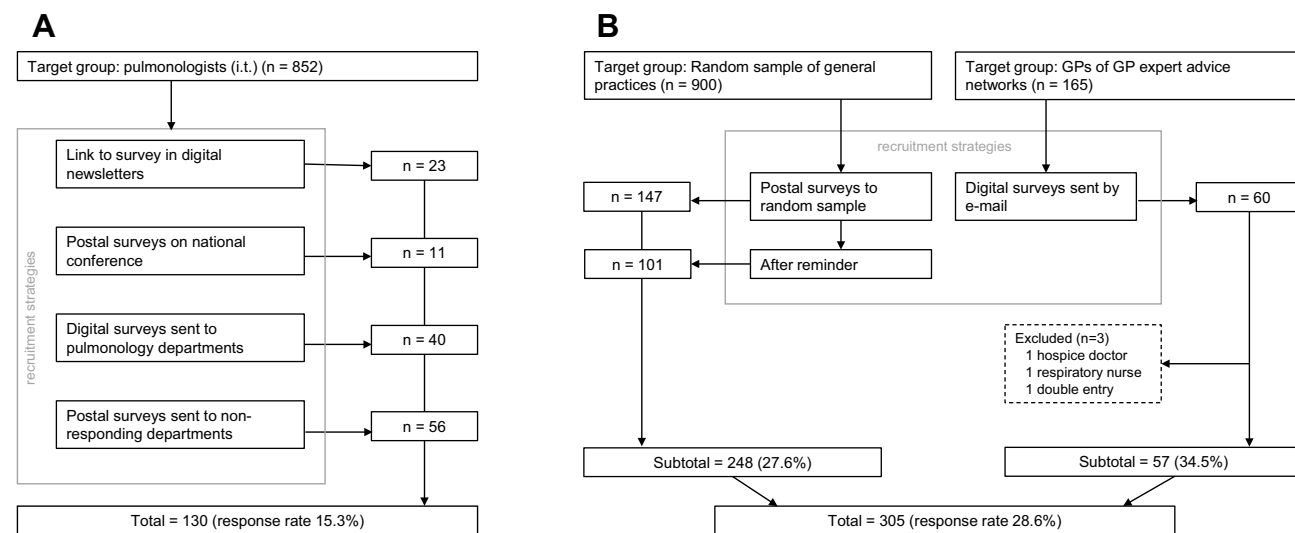
A national survey study was performed among pulmonologists and general practitioners (GPs) in the Netherlands, to examine both the primary and secondary palliative care provision to patients with COPD.

## Procedure

Pulmonologists (n=668) and pulmonologists in training (i.t.) (n=184) registered by the Netherlands Association of Physicians for Lung Diseases and Tuberculosis (NVALT) were recruited via various and subsequent strategies between April and August 2019, to maximize participation (see Figure 1). Both a digital link to the online survey and a paper version was used. A link to the survey was disseminated via two subsequent digital newsletters of the NVALT, a digital newsletter of the Lung Alliance Netherlands (LAN) and via e-mails to each pulmonology department (n=80) in the Netherlands. Also, pulmonologists visiting the annual Dutch pulmonologist conference were asked to complete a paper version of the survey. Subsequently, paper versions of the survey were sent to pulmonologists of departments of which no pulmonologist had responded yet.

GPs were recruited in two ways. First, postal surveys were sent to a random sample of 900 general practices in the Netherlands, obtained via the Netherlands Institute for Health Services Research (NIVEL). A reminder was sent to non-responding general practices after five weeks. Second, a digital link to the online survey was sent to 165 GPs via two GP expert advice networks on COPD/asthma care (CAHAG) and palliative care (PalHag).

All responses received before August 21, 2019 were included in the analysis. The online data management system Castor EDC was used for data collection. Consent to participate was implied by responding to the survey. This study was approved by the Medical Ethics Committee of the Radboud University Medical Center (number 2019–5021).



**Figure 1** Flowchart of recruitment strategies and numbers of responding pulmonologists (A) and general practitioners (B).

**Abbreviations:** GP, general practitioner; i.t., in training.

## Survey

The survey was developed based on previous studies<sup>7,13,14</sup> and national guidelines.<sup>9,10</sup> In several cycles, we presented drafts of the survey to care providers and experts for adaptations and improvements. The survey started with an introductory text explaining the definition of palliative care and the palliative phase in COPD according to the national guideline<sup>9</sup> ([Supplementary Table S1](#)). Then, questions were presented regarding the presence and plans for future development of any formalized agreements (i.e. a protocol or specific agreements) in their department or practice, and methods used to identify the palliative phase in patients with COPD. This was followed by a question on the level of experience with palliative care provision in COPD and a question on the estimated number of palliative patients with COPD the participant treated on average per year. Participants who had treated at least one such patient in the last year, were further inquired on the frequency of palliative care aspects provided and topics discussed in the previous year, and collaboration with and referral to other care providers. Answer options ranged from never to always on a 5-point Likert scale. Also, satisfaction with collaboration between pulmonologists and GPs was inquired. The next question of the survey was presented to all respondents and related to perceived barriers towards palliative care discussions; multiple answer entries were allowed on fourteen statements. Lastly, the following characteristics were questioned: age, gender, position, workplace, work experience and education.

## Statistical analysis

All data were analyzed using descriptive statistics. For each item, all available data were used. Therefore, the total number of respondents varied per item. Noncontinuous variables were reported as frequencies. Answers in free text boxes were inductively coded and categorized using Atlas.ti. Differences between 1) pulmonologists and GPs and 2) physicians with and without any form of palliative care training were tested using the Mann–Whitney *U*-test for categorical variables (using 5 answer categories) and the Chi-square test for dichotomous variables. Differences were considered significant if  $p < 0.05$ . Statistical analyses were performed with IBM SPSS Statistics, version 25.

## Results

### Study participants

In total, 130 pulmonologists (response rate of 15.3%), including four pulmonologists in training, and 305 GPs (response rate of 28.6%) responded to the survey between April and August 2019 ([Figure 1](#)). The responding pulmonologists were employed in 61 of 80 pulmonology departments (76%) in the Netherlands. The median number of COPD patients treated in the palliative phase was on average 20 per year for pulmonologists and 1.5 per year for GPs ([Table 1](#)). In the last year, three pulmonologists and sixty-five GPs had not treated any palliative patient with COPD. Non-response per item was on average 12.9% in returned surveys of pulmonologists and 6.0% in those of GPs ([Supplementary Table S1](#)).

**Table 1** Characteristics of participating pulmonologists and general practitioners

	Pulmonologists (n=130) n (%)	General Practitioners (n=305) n (%)
Age (years), mean (SD)	46.0 (8.9)	49.4 (9.6)
Gender, male	67 (59.3)	124 (43.5)
Work experience (years), mean (SD)	13.0 (8.8)	17.8 (9.7)
Workplace		
General hospital	54 (47.8)	N/A
Top clinical hospital	48 (42.5)	
University hospital	8 (7.1)	
Other	3 (2.7)	
Experience with PC provision in COPD*	97 (78.0)	105 (34.8)
Median number of palliative patients with COPD treated yearly	20 (range 0–1020)	1.5 (range 0–30)
Treated $\geq 1$ palliative patient with COPD last year	127 (97.7)	240 (78.7)
Education		
Palliative care training, any	36 (35.7)	93 (34.6)
Specialized training in palliative care	2 (1.7)	22 (7.4)
Specialized training in asthma/COPD	N/A	25 (8.9)

**Note:** \*Respondents with answers “a reasonable amount” and “a lot”.

## Structure of palliative care

Fifty-six pulmonologists (45.9%) reported that there were no formalized agreements on the palliative care provision to patients with COPD at their department and thirteen (10.7%) indicated did not know. Fifty-two pulmonologists (43.4%) reported that there were formalized agreements; most detailed the possibility to involve a specialist palliative care team (n=22; 18.0%). Sixteen pulmonologists (13.2%) indicated a hospital-specific care pathway was present, five of these were palliative sedation protocols or dying care pathways. Other agreements covered advance care planning discussions (n=9; 7.4%) and agreements on e.g. scoring symptoms or starting morphine (6; 5.0%). Half of the pulmonologists (n=60; 50.4%) indicated that their department had plans to establish formalized agreements in the future; fourteen (11.9%) referred to the development of a new protocol and eight (6.8%) to the adaptation of an existing protocol or care pathway.

The majority of GPs (n=269; 89.4%) reported that there were no formalized agreements. Twenty-six GPs (8.6%) reported that there were; most of them covered patient support by the GP, a practice nurse or palliative care nurse (n=11; 3.7%), and participation in a PaTz (palliative homecare) group (n=8; 2.7%). No protocols were reported. Thirty-five GPs (11.7%) indicated to have plans

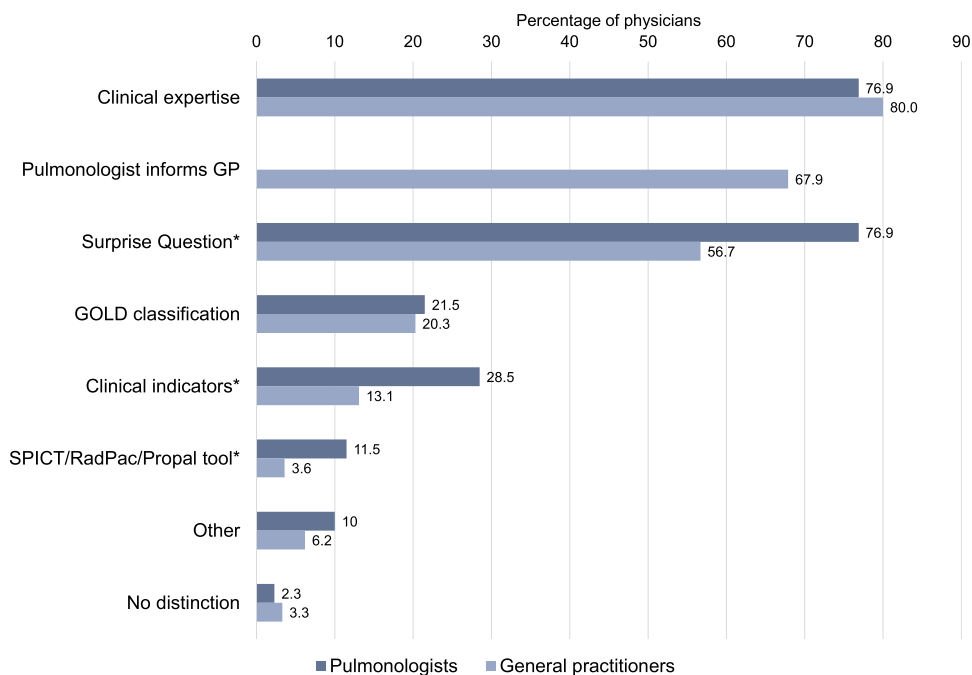
to formalize palliative care in COPD in the future, of which eight indicated they planned to establish a protocol.

## Identification of the palliative phase in patients with COPD

As reported by our respondents, the palliative phase in patients with COPD was most often determined based on clinical expertise or by using the Surprise Question (SQ) (Figure 2). The SQ reads “Would I be surprised if this patient were to die in the next twelve months?” More pulmonologists indicated to use the SQ than GPs (76.9% vs. 56.7%,  $p < 0.001$ ). Many GPs also determined the palliative phase based on information transfer or transfer of care from the pulmonologist to the GP. Thirteen participants (3.1%) indicated not to discern a palliative phase.

## Symptom management

Most respondents (n=283; 79.3%) reported to often or always administer opioids to treat dyspnea (Table 2). No significant differences in frequency were observed between pulmonologists and GPs nor between those with and without palliative care training. GPs prescribed pharmacological treatment for anxiety and depression more often than pulmonologists ( $p = 0.046$ ). Physicians with palliative care training more frequently provided non-



**Figure 2** Methods used by pulmonologists and general practitioners to identify the palliative phase in patients with COPD. \*Significant difference ( $p < 0.05$  using Chi-square test).

**Table 2** Symptom management in patients with COPD in the palliative phase that respondents had treated in the previous year, and comparison of pulmonologists and general practitioners

		All respondents	Pulmonologists	GPs	P-value <sup>a</sup>
Dyspnea using opioids	Never	6 (1.7)	0 (0.0)	6 (2.5)	0.077
	Rarely	8 (2.2)	4 (3.3)	4 (1.7)	
	Sometimes	60 (16.8)	18 (15.0)	42 (17.7)	
	Often	202 (56.6)	84 (70.0)	118 (49.8)	
	Always	81 (22.7)	14 (11.7)	67 (28.3)	
Dyspnea using non-pharmacological treatment	Never	12 (3.5)	1 (0.9)	11 (4.8)	0.142
	Rarely	35 (10.1)	9 (7.8)	26 (11.4)	
	Sometimes	112 (32.5)	37 (31.9)	75 (32.8)	
	Often	149 (43.2)	58 (50.0)	91 (39.7)	
	Always	37 (10.7)	11 (9.5)	26 (11.4)	
Pain using opioids	Never	24 (6.8)	6 (5.1)	18 (7.7)	0.625
	Rarely	84 (23.9)	26 (22.2)	58 (24.8)	
	Sometimes	146 (41.6)	54 (46.2)	92 (39.3)	
	Often	82 (23.4)	26 (22.2)	56 (23.9)	
	Always	15 (4.3)	5 (4.3)	10 (4.3)	
Anxiety/depression using pharmacological treatment	Never	23 (6.6)	9 (7.8)	14 (6.0)	0.046
	Rarely	50 (14.4)	22 (19.1)	28 (12.1)	
	Sometimes	155 (44.7)	51 (44.3)	104 (44.8)	
	Often	111 (32.0)	31 (27.0)	80 (34.5)	
	Always	8 (2.3)	2 (1.7)	6 (2.6)	
Anxiety/depression using non-pharmacological treatment	Never	20 (5.9)	5 (4.4)	15 (6.6)	0.665
	Rarely	63 (18.5)	25 (21.9)	38 (16.7)	
	Sometimes	149 (43.7)	48 (42.1)	101 (44.5)	
	Often	96 (28.2)	34 (29.8)	62 (27.3)	
	Always	13 (3.8)	2 (1.8)	11 (4.8)	

**Notes:** Data are expressed as absolute values and percentages. <sup>a</sup>P-values based on Mann–Whitney U-test.

pharmacological treatment for anxiety and depression ( $p=0.030$  for pulmonologists and  $p=0.011$  for GPs) than those without ([Supplementary Table S2](#)).

### Doctor-patient-family communication

Almost all respondents indicated to often or always discuss palliative treatment options for dyspnea ( $n=307$ ; 92.1%) ([Table 3](#)). Approximately a third of respondents rarely or never discussed non-invasive ventilation ( $n=112$ ; 33.4%) or spiritual needs ( $n=92$ ; 27.8%). GPs discussed seven topics more frequently than pulmonologists. Pulmonologists discussed non-invasive ventilation more often than GPs. Pulmonologists with palliative care training discussed six topics more often than pulmonologists without training ([Supplementary Table S3](#)): fear of choking ( $p=0.015$ ), fear of death/dying ( $p=0.025$ ), preferred place of death ( $p=0.005$ ), spiritual needs ( $p=0.007$ ),

caregiver burden ( $p=0.003$ ) and goals of care ( $p=0.020$ ). Within GPs, no differences were found between those with and without palliative care training.

Most GPs ( $n=200$ ; 91.7%) mentioned that, in the past year, they had often or always discussed treatment preferences at home; a minority ( $n=46$ ; 21.6%) discussed them at the practice. More than half ( $n=116$ ; 53.5%) often or always discussed these preferences shortly after a hospitalization for an acute exacerbation. Of the pulmonologists, 41.3% ( $n=43$ ) stated to have often or always discussed preferences when patients visited the emergency department, 66.3% ( $n=69$ ) during hospitalization and 52.4% ( $n=54$ ) at the outpatient clinic. More GPs ( $n=105$ ; 48.4%) than pulmonologists ( $n=23$ ; 21.9%) mentioned that they often or always planned an appointment specifically for these discussions; 24.4% of the GPs ( $n=53$ ) and 48.6% of pulmonologists ( $n=51$ ) never or rarely did so. The

**Table 3** Frequency of topics discussed by respondents in the previous year, and comparison of pulmonologists and general practitioners

		All respondents	Pulmonologists	GPs	P value <sup>a</sup>
Disease course and incurability	Never	2 (0.6)	0 (0.0)	2 (0.9)	0.014
	Rarely	4 (1.2)	2 (1.8)	2 (0.9)	
	Sometimes	39 (11.4)	13 (11.4)	26 (11.4)	
	Often	162 (47.4)	67 (58.8)	95 (41.7)	
	Always	135 (39.5)	32 (28.1)	103 (45.2)	
Life expectancy	Never	9 (2.7)	0 (0.0)	9 (4.0)	0.050
	Rarely	30 (8.9)	14 (12.5)	16 (7.1)	
	Sometimes	98 (29.0)	41 (36.6)	57 (25.2)	
	Often	133 (39.3)	39 (34.8)	94 (41.6)	
	Always	68 (20.1)	18 (16.1)	50 (22.1)	
Fear of choking	Never	1 (0.3)	0 (0.0)	1 (0.4)	0.065
	Rarely	10 (3.0)	3 (2.7)	7 (3.1)	
	Sometimes	53 (15.7)	18 (16.1)	35 (15.5)	
	Often	169 (50.0)	67 (59.8)	102 (45.1)	
	Always	105 (31.1)	24 (21.4)	81 (35.8)	
Fear of death/dying	Never	3 (0.9)	1 (0.9)	2 (0.9)	<0.001
	Rarely	13 (3.9)	7 (6.3)	6 (2.7)	
	Sometimes	64 (19.3)	37 (33.0)	27 (12.3)	
	Often	149 (44.9)	46 (41.1)	103 (46.8)	
	Always	103 (31.0)	21 (18.8)	82 (37.3)	
Advantages and disadvantages of life sustaining treatments	Never	0 (0.0)	0 (0.0)	0 (0.0)	0.456
	Rarely	7 (2.1)	1 (0.9)	9 (8.0)	
	Sometimes	30 (9.0)	6 (2.7)	21 (9.5)	
	Often	149 (44.7)	58 (51.8)	91 (41.2)	
	Always	147 (44.1)	44 (39.3)	103 (46.6)	
Advantages and disadvantages of non-invasive ventilation	Never	56 (16.7)	0 (0.0)	56 (25.2)	<0.001
	Rarely	56 (16.7)	5 (4.4)	51 (23.0)	
	Sometimes	88 (26.3)	28 (24.8)	60 (27.0)	
	Often	93 (27.8)	60 (53.1)	33 (14.9)	
	Always	42 (12.5)	20 (17.7)	22 (9.9)	
Desirability of hospitalization for acute exacerbation	Never	4 (1.2)	1 (0.9)	3 (1.3)	<0.001
	Rarely	14 (4.2)	11 (9.8)	3 (1.3)	
	Sometimes	64 (19.0)	39 (34.8)	25 (11.2)	
	Often	158 (47.0)	52 (46.4)	106 (47.3)	
	Always	96 (28.6)	9 (8.0)	87 (38.8)	
Palliative treatment options for dyspnea (e.g. morphine)	Never	0 (0.0)	0 (0)	0 (0)	<0.001
	Rarely	1 (0.3)	0 (0)	1 (0.4)	
	Sometimes	25 (7.5)	10 (9.1)	15 (6.7)	
	Often	161 (48.3)	73 (66.4)	88 (39.5)	
	Always	146 (43.8)	27 (24.5)	119 (53.4)	
Preferred place of death	Never	6 (1.8)	5 (4.6)	1 (0.4)	<0.001
	Rarely	28 (8.4)	21 (19.3)	7 (3.1)	
	Sometimes	61 (18.3)	36 (33.0)	25 (11.2)	
	Often	114 (34.2)	34 (31.2)	80 (35.7)	
	Always	124 (37.2)	13 (11.9)	111 (49.6)	

(Continued)

**Table 3** (Continued).

		All respondents	Pulmonologists	GPs	P value <sup>a</sup>
Spiritual and existential needs	Never	25 (7.6)	15 (13.8)	10 (4.5)	<0.001
	Rarely	67 (20.2)	40 (36.7)	27 (12.2)	
	Sometimes	119 (36.0)	36 (33.0)	83 (37.4)	
	Often	85 (25.7)	14 (12.8)	71 (32.0)	
	Always	35 (10.6)	4 (3.7)	31 (14.0)	
Caregiver burden	Never	3 (0.9)	1 (0.9)	1 (0.9)	<0.001
	Rarely	25 (7.6)	20 (18.5)	5 (2.2)	
	Sometimes	97 (29.3)	51 (47.2)	46 (20.6)	
	Often	147 (44.4)	32 (29.6)	115 (51.6)	
	Always	59 (17.8)	4 (3.7)	55 (24.7)	
Goals of care	Never	21 (6.4)	1 (0.9)	20 (9.0)	0.702
	Rarely	35 (10.7)	12 (11.2)	23 (10.4)	
	Sometimes	131 (39.9)	49 (45.8)	82 (37.1)	
	Often	102 (31.1)	35 (32.7)	67 (30.3)	
	Always	39 (11.9)	10 (9.3)	29 (13.1)	

**Notes:** Data are expressed as absolute values and percentages. <sup>a</sup>P-values based on Mann–Whitney U-test.

majority of pulmonologists (n=92; 86.8%) and GPs (n=159; 72.3%) reported that they never or rarely discussed preferences with a family member without the patient being present. Bereavement support to relatives after the patient deceased was provided more frequently by GPs (n=175; 84.5%) than pulmonologists (n=20; 20.4%).

## Collaboration between healthcare providers

When caring for palliative patients with COPD in the past year, pulmonologists indicated they most often collaborate with a specialized COPD-nurse in the hospital (n=82 answered often or always; 77.4%) and GPs most often with a district nurse (n=168 answered often or always; 78.9%) (Figure 3). According to the respondents, patients were most frequently referred to a physical therapist or dietician (Figure 4). Involvement of specialized palliative care providers varied. Almost one-third of pulmonologists (n=33; 31.4%) reported that they often or always refer their palliative patients with COPD to a palliative care consultant; a quarter (n=26; 24.8%) of them referred hardly any. A quarter of GPs (n=55; 25.6%) mentioned to collaborate often or always with a palliative care nurse and more than half never or rarely (n=117; 54.4%).

More than half of the pulmonologists (n=59; 52.7%) and GPs (n=141; 61.8%) were satisfied with the collaboration between pulmonologists and GPs. Satisfaction about the information exchange between the hospital and primary care differed; more GPs were satisfied (n=130; 57.0%) than pulmonologists (n=34; 29.8%).

## Barriers to palliative care discussions

The most frequently reported barrier to discuss palliative and end-of-life care topics with patients with COPD was the difficulty in predicting the disease course (Figure 5). The second reported barrier by pulmonologists was lack of time (n=72; 63.7%), whereas only 14.8% (n=43) of the GPs mentioned this barrier. Lack of a clear definition of the palliative phase in COPD was more often indicated as a barrier by GPs than by pulmonologists (n=158; 54.3% vs n=44; 38.9%,  $p=0.008$ ). Further, patients' difficulties to specify what future care they want in case of disease deterioration was named as a barrier by both groups (n=88; 30.2% of GPs and n=47; 41.6% of pulmonologists).

## Discussion

This is the first study giving a comprehensive overview of the palliative care provision for patients with COPD in primary and secondary care in the Netherlands. In contrast with previous studies conducted in other countries,<sup>3,14,15,16</sup> we found that the majority of physicians regularly discuss

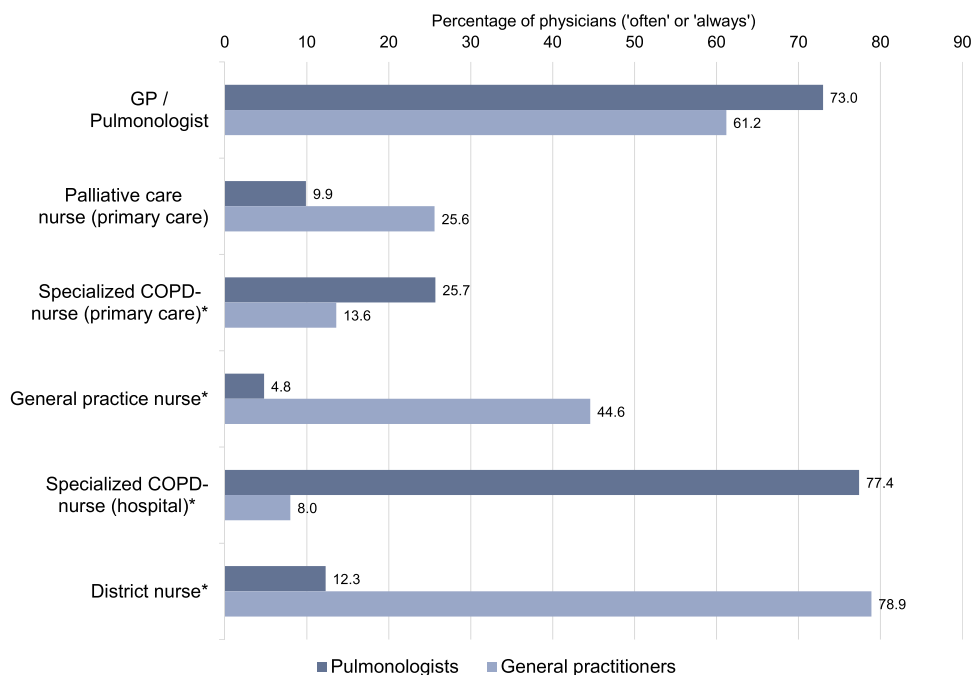


palliative care topics with their patients with COPD. In a 2009 study, Dutch pulmonologists reported discussing life-sustaining treatments with 20% of their patients and life expectancy with 16%; the rates found in our study are higher.<sup>17</sup> Interestingly, we found that pulmonologists who had received a training in palliative care were more likely to discuss some important topics, such as spiritual needs, caregiver burden and end-of-life related topics than those without training. These findings may underscore the usefulness of palliative care education. Additionally, almost all participants, following guideline recommendations, reported to frequently prescribe opioids to treat dyspnea. In comparison, in a survey among Dutch pulmonologists in 2012, half of the participants hardly ever prescribed opioids in COPD patients with refractory dyspnea.<sup>19</sup>

It is plausible that the publication of the Dutch guideline in 2011,<sup>9</sup> and to a lesser extent the Quality Framework in 2017,<sup>10</sup> may have had a positive impact on these care practices. Similarly, an increase in palliative care support was seen in the UK following the introduction of the End of Life Care strategy.<sup>18</sup> Furthermore, a Dutch survey study in 2015 revealed that almost half of the pulmonologists reported no involvement of a specialist palliative care team to treat their COPD patients.<sup>7</sup> Our study showed that this percentage had dropped considerably: only a quarter of

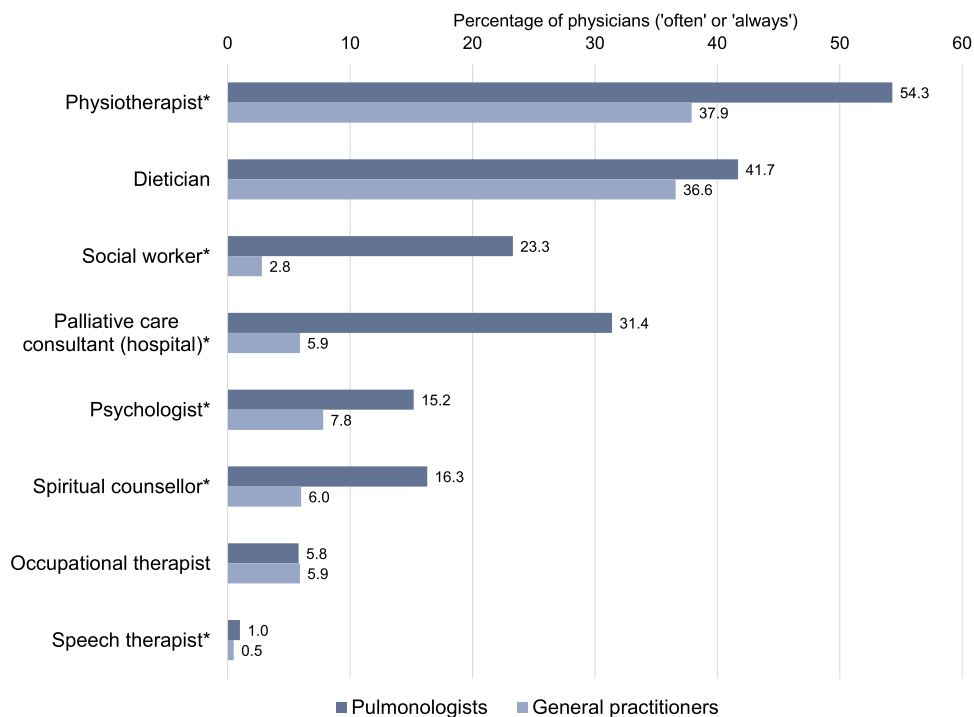
pulmonologists hardly ever referred patients to a specialist palliative care team. This may be explained by the requirement for Dutch hospitals to have installed a specialist palliative care team since 2017.<sup>20</sup> Although this requirement concerns oncological palliative care, these teams can also be consulted for non-oncological patients. Involvement of such teams in the care of patients with COPD was found to have a positive effect on advance care planning documentation.<sup>21</sup>

Despite these positive changes, palliative care for patients with COPD remains largely unstructured. The minority of respondents reported scheduling appointments specifically to discuss advance care planning. Furthermore, half of the responding pulmonologists and most GPs reported that their department or practice did not have any form of protocol nor specific agreements. This is comparable to findings from studies performed in the UK, Spain and Sweden.<sup>13,14,22</sup> Moreover, some responding pulmonologists mentioned protocols related to palliative sedation and the dying phase, suggesting that in those cases palliative care is focused on terminal care only. Nevertheless, half of the pulmonologists and one-tenth of GPs said to have the intention to establish a protocol or agreements in the future, acknowledging the need to formalize palliative care in COPD. Though these intentions



**Figure 3** Collaboration with healthcare providers by pulmonologists and general practitioners. Percentages of physicians with answer often or always. \*Significant difference ( $p < 0.05$  using Mann–Whitney  $U$ -test).

**Abbreviations:** GP, general practitioner; PC, palliative care.



**Figure 4** Referral to healthcare providers by pulmonologists and general practitioners. Percentages of physicians with answer often or always. \*Significant difference ( $p < 0.05$  using Mann–Whitney  $U$ -test).

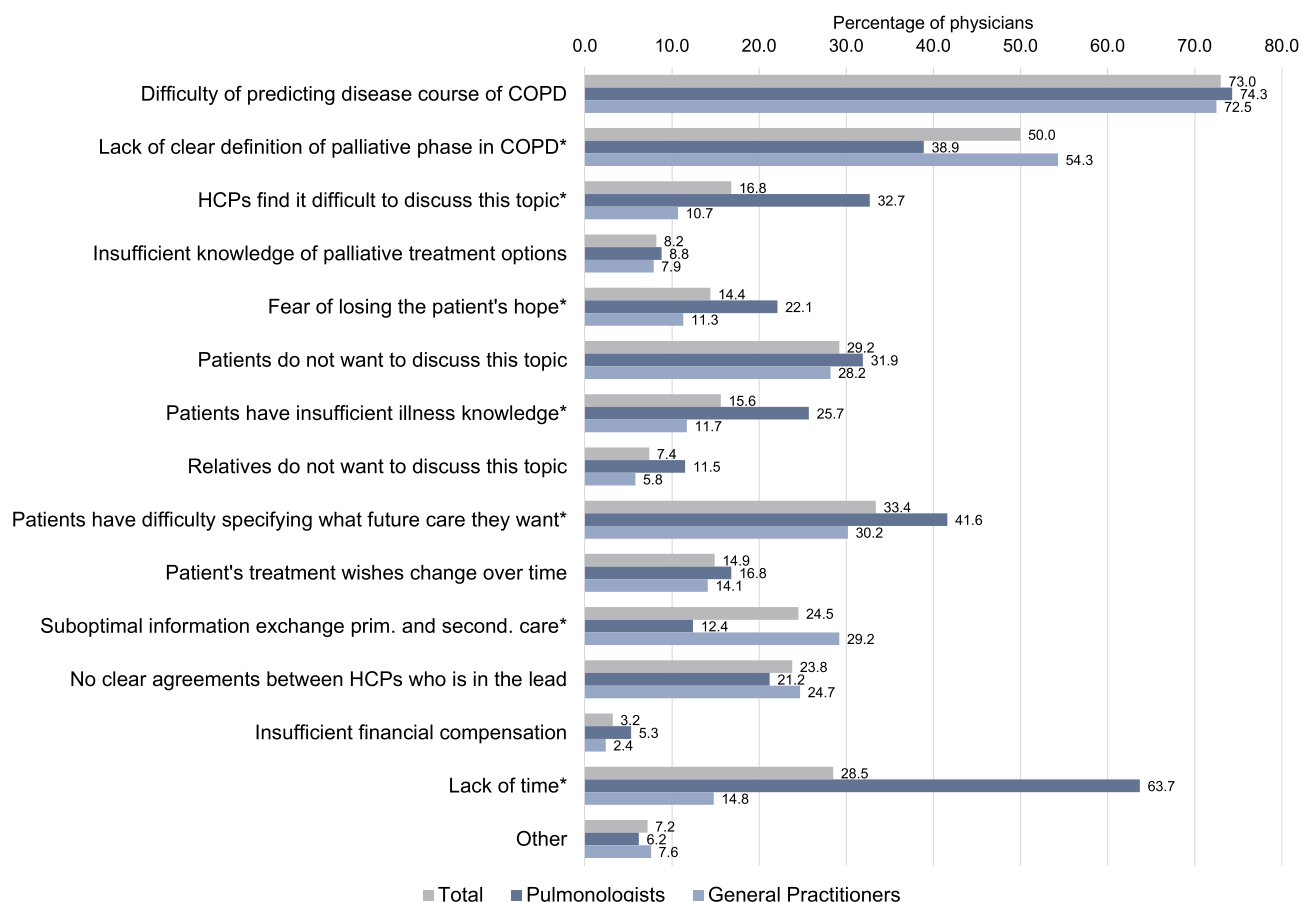
**Abbreviation:** PC, palliative care.

are promising, the explanations of their plans were non-specific. As was highlighted earlier, guidelines provide insufficient clear guidance on when and how this care can be best provided.<sup>6</sup> Therefore, more practical knowledge is needed. Examples may be a fixed time in the week scheduled for palliative care consultations, appointment of a care coordinator, clear criteria for (timely) involvement of specialist palliative care, and regular multidisciplinary meetings to discuss palliative patients with COPD.

GPs less frequently encountered a patient with COPD in the palliative phase than pulmonologists, but when they did, they discussed palliative care topics and scheduled these discussions more often than pulmonologists. These findings are not surprising, as advance care planning is considered by GPs a typical GP task.<sup>23</sup> Further, the setting enables them to have these conversations at the patient's home. However, the risk is that patients with COPD with palliative care needs may not be timely recognized by GPs, since they have only one or two per year in their practice at most. GPs find advance care planning more challenging in patients with COPD and heart failure.<sup>23</sup> Many GPs reported that they use the moment a pulmonologist informs the GP about the dire situation of the patient as a starting point. Together with

the fact that in the Netherlands most patients with advanced COPD are under treatment of the pulmonologist, it may be more appropriate to consider the identification of patients with palliative care needs primarily the responsibility of a pulmonologist.

To identify those patients, the SQ was, next to clinical expertise, most often used by our participants. Noppe et al showed that using the SQ in recently hospitalized patients for an acute exacerbation of COPD is a useful and quick method.<sup>24</sup> However, not all patients with palliative care needs were identified with this method. The structural use of symptom assessment tools such as the Edmonton Symptom Assessment Scale<sup>25</sup> might have added value and could facilitate palliative care discussions with patients. Our results emphasize yet again that determining the most appropriate timing to start palliative care is difficult and perceived as an important barrier by most care providers. There is no consensus on when palliative care topics should be discussed and when specialist palliative care should be involved.<sup>6</sup> We found that responding pulmonologists frequently held advance care planning discussions on the emergency department and during hospitalization. In an acute setting, these discussions may be limited to preferences regarding cardiopulmonary resuscitation and mechanical



**Figure 5** Barriers of palliative care discussions with patients with COPD, as indicated by pulmonologists, general practitioners and all respondents. \*Significant difference between pulmonologists and GPs ( $p < 0.05$  using Chi-square test).

**Abbreviation:** HCP, healthcare provider.

ventilation, while this is only one aspect of advance care planning.<sup>26</sup> Additionally, it means that patients are confronted with these questions by a physician unfamiliar to them. During a planned visit to their regular physician in a non-acute setting, there is more opportunity to discuss the patient's wishes, values and preferences for future care with the patient and his/her family.

Since primary, as well as secondary care, are involved in COPD-care, a well-established collaboration between these settings is crucial. Although satisfaction about the collaboration between pulmonologists and GPs was reasonably high, information exchange between primary care and the hospital was viewed as problematic. This finding is consistent with previous literature.<sup>27</sup> It is not merely a COPD specific problem: also letters from medical specialists to the GP about advanced cancer patients seldom contain advance care planning items.<sup>28</sup> Establishing work agreements between pulmonologists and GPs may help to determine what and when to

communicate. A shared medical record, whether integrated into an electronic medical record system or via a standardized paper form, is a prerequisite. After a pulmonologist identifies a patient with COPD in the palliative phase, contact should be initiated with his/her GP to discuss the patient's situation, options for future care and alignment of responsibilities.

## Limitations

This study had some limitations. We asked participants to provide estimates on the frequency and content provided to patients with COPD in the palliative phase in the previous year. While this was a feasible and straightforward method to obtain an approximation of the provided care, it might not be an accurate reflection of the actually provided care because of recall bias and social-desirability bias. Neither does it provide insights into the quality nor the timing of the provided care, e.g. whether treatments and discussions took place in the terminal or

dying phase rather than early in the palliative phase. Although we achieved 76% coverage of pulmonology departments in the Netherlands, the response rate obtained among pulmonologists was lower than in previous studies.<sup>7,14,19</sup> Also, we faced significant item non-response for unknown reasons. Additionally, respondents may be more concerned with palliative care than the general population of physicians, which could have influenced the results. Therefore, caution is warranted when extrapolating the results to all pulmonologists and GPs in the Netherlands. Finally, we did not include specialized COPD-nurses or advanced nurse practitioners in the study, even though they play an essential role in the care of patients with COPD. Their views and practices should be investigated in future research.

## Conclusions

Most pulmonologists and GPs regularly discuss palliative care topics, use opioids to treat dyspnea and involve specialist palliative care consultants, probably with increasing frequency compared to a decade ago. However, palliative care for patients with COPD remains unstructured and little formalized, and advance care planning discussions frequently take place in an acute care setting. Nevertheless, there seems to be a high willingness to improve this care. To continue the upward trend, clear guidance and standardization of practice may help to decide when and how to initiate discussions, when to involve specialist palliative care and how to optimize information exchange between care settings. Furthermore, training in palliative care communication can empower healthcare providers to discuss end-of-life related topics, caregiver burden and spiritual needs.

## Abbreviations

COPD, chronic obstructive pulmonary disease; GP, general practitioner; SQ, surprise question.

## Data Sharing Statement

All relevant data are within the manuscript. Any other data are available upon request from the corresponding author.

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## Author Contributions

All authors made substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data; took part in drafting the article or revising it critically for important intellectual content; agreed to submit to the current journal; gave final approval of the version to be published; and agree to be accountable for all aspects of the work.

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