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# Referral to palliative care in COPD and other chronic diseases: A population-based study



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## KEYWORDS

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Palliative care;  
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## Summary

**Aim:** To describe how patients with COPD, heart failure, dementia and cancer differ in frequency and timing of referral to palliative care services.

**Methods:** We performed a population-based study with the Sentinel Network of General Practitioners in Belgium. Of 2405 registered deaths respectively 5%, 4% and 28% were identified as from COPD, heart failure or cancer and 14% were diagnosed with severe dementia. GPs reported use and timing of palliative care services and treatment goals in the final three months of life.

**Results:** Patients with COPD (20%) were less likely than those with heart failure (34%), severe dementia (37%) or cancer (60%) to be referred to palliative care services ( $p < 0.001$ ). The median days between referral and death was respectively 10, 12, 14 and 20. Patients with COPD who were not referred more often received treatment with a curative or life-prolonging goal and less often with a palliative or comfort goal than did the other patients who were not referred.

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*Conclusion:* Patients with COPD are underserved in terms of palliative care compared to those with other chronic life-limiting diseases. Awareness of palliative care as an option for patients with COPD needs to increase in palliative care services, physicians and the general public.  
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## Introduction

Palliative care services have been demonstrated to improve the end of life of people suffering from chronic life-limiting illness [1,2]. Recent studies have also found that earlier referrals to palliative care improve quality of life [3,4]. Although chronic obstructive pulmonary disease (COPD), responsible for an increasing proportion of deaths [5], is a chronic life-limiting disease, the scarce data for COPD patients seem to indicate that many patients do not receive adequate palliative care which may leave them with reduced quality of life in the final months, weeks or days [6,7]. In contrast, patients with a cancer diagnosis relatively often receive palliative care [8–12]. Part of this inequality between disease groups is historical, due to the initial focus of palliative care on oncology in the countries in which it was first developed [13]; part of it is due to the difference in disease trajectories [14]. Prognostication of death, which often remains the basis for determining whether a person is eligible for palliative care [15], is in practice usually easier for cancer patients with a rapid decline and a distinct terminal phase than for those with conditions with a less-recognizable terminal phase e.g. COPD, heart failure or dementia [14,16]. Previous review studies [17,18], an interview study with informal carers [19] and a large scale survey study with proxies [20] and with patients [21] showed us that patients with advanced COPD experience many palliative care needs similar to those of advanced cancer patients, such as pain, insomnia, fatigue and low mood [18–21]. Dyspnea was even found to be more experienced in COPD patients than in patients with lung cancer [19]. This indicates that COPD patients would equally benefit from care with a palliative intent [22,23]. Research on referral to palliative care among patients with COPD is scarce and most has been limited to specific settings and small sample sizes [10,24].

Although fewer or later referrals may indicate a disadvantage or inequity, a lack of referral to palliative care services does not necessarily mean the patient did not get any form of care or treatment with a palliative or similar intent through which their potential palliative care needs may have been met [8]. Therefore, to evaluate and understand differences in palliative care referrals between disease groups it would also be important to look at what kind of care and treatments patients who are not referred to any palliative care service are receiving.

This population-based retrospective study aims to describe differences in the extent and timing of referrals to palliative care services for people dying from COPD compared with three other relevant disease groups: heart failure, following the same disease course with a comparable clinical picture, and dementia and cancer, following different disease courses [14]. The study also describes

treatment goals when not referred. The following research questions are addressed:

- 1) How often are patients with COPD, heart failure, dementia or cancer referred to palliative care services?
- 2) How long before death are these patients referred?
- 3) Which socio-demographic characteristics are associated with referral and timing of referral to palliative care services within those four disease groups?
- 4) What are the treatment goals for patients who were not referred to these services in the last three months of life?

## Methods

### Study design

We conducted a population-based retrospective survey studying deaths registered by a sample of general practitioners (GPs) in Belgium, i.e. the existing nationwide Belgian Sentinel Network of General Practitioners [25,26]. The Sentinel Network of General Practitioners is a relative stable network of practices or community-based physicians, operational since 1979. It has proved to be a reliable epidemiologic surveillance system for health care data e.g. on diabetes, stroke, cancer [27,28] and is representative for all Belgian GPs in terms of age, sex and geographical distribution [29,30]. In 2009 and 2010 it consisted of respectively 161 and 142 participating practices (both solo and group practices), covering respectively 1.8% and 1.5% of the Belgian population.

### Procedures

From 1 January 2009 to 31 December 2010 GPs registered weekly all deaths of patients in their practice on a standardized registration form providing information about care in the final three months of life. The registration form was first developed in Dutch and then forward–backward translated into French, as the study covers both language regions (Flanders and Wallonia) in Belgium. More details on this study protocol have been published elsewhere [26].

### Measurements

#### Referral and timing of referral to palliative care services

For each case the GP was asked to tick one or more of four possibilities: palliative care team at home, hospital-based palliative care team (excluding palliative care unit), inpatient palliative care unit or in-house palliative care in a

nursing home. The GP also indicated the timing of a referral i.e. the number of days between the first referral to a palliative care service and death.

### Treatment goals

The importance of three treatment goals i.e. cure, life-prolonging and comfort/palliation was judged by the GP for respectively the last week of life, second to fourth week before death and second to third month before death, on a 5-point Likert scale ranging from 1 (not at all important) to 5 (very important). Concurrence of more than one treatment goal was possible in each period.

### Socio-demographic and disease characteristics

GPs recorded the cause of death in a manner that is identical to that on the official death certificates in accordance to WHO guidelines: the GP was asked to fill in the immediate, intermediary and underlying causes of death. Causes of death reported by the GPs for our survey were thoroughly checked and encoded (International Classification of Diseases, 10th ed., ICD-10) by the Flemish Ministry of Welfare, Public Health and Family, who also process the official death certificates. Also GPs registered whether the patient suffered from severe, mild or no dementia, age, sex, main place of residence in the last year of life of the patients and whether they experienced symptoms (pain, breathing problems, feeling drowsy, feeling sad, feeling nervous) in the last week of life.

### Analysis

For this study we selected only those patients who were 18 years or older and had died from COPD, heart failure, cancer or had suffered from severe dementia. Patients were attributed to one of four disease groups based on the underlying cause of death (as registered by the GP and encoded by the Ministry of Health into ICD-10 codes), and on a question about whether the patient suffered from severe, mild or no dementia: COPD (ICD-10 codes J40-47), heart failure (ICD-10 codes I50, I110, I130, I132), cancer (ICD-10 codes C00-D48) or dementia (when the GP indicated that the patient suffered from severe dementia).

In order to explore differences between the four disease groups for referral to palliative care services we conducted Pearson chi square tests. Multivariate binary logistic regression was performed to control for confounding effects of sex, age and main place of residence. We evaluated differences between the disease groups in terms of time of onset of referral with the non-parametric Kruskal–Wallis test. We performed ordinal logistic regression to control for confounding effects.

In order to investigate the association between referral and age, sex and main place of residence within each disease group we performed Pearson chi<sup>2</sup> tests as well as multivariate binary logistic regression for each disease separately.

To further understand the differences in referral between the disease groups we explored treatment goals for patients who were not referred to palliative care services using Pearson chi<sup>2</sup> tests. All analyses were performed using SPSS (version 19.0).

### Ethical considerations

Anonymity of patient and physician was preserved. The study protocol was approved by the Ethical Review Board of Brussels University Hospital [26].

### Results

In total, GPs registered 2405 deaths of which 1197 were from COPD, heart failure, cancer or involved severe dementia (Table 1). The proportions of all deaths of the disease groups are comparable to the official death certificate data from 2008.

### Referral to palliative care services and timing of referral

In the last three months of life patients with COPD (20%) were less often referred to any type of palliative care service than were those with heart failure (34%), severe dementia (37%) or cancer (60%) (Table 2). Of all patients with COPD, 4% were referred to a palliative care team at home, 6% to a hospital-based palliative care team and 6% to an inpatient palliative care unit, all less often than cancer patients; 8% were referred to in-house palliative care in a nursing home, which was less often than patients suffering from dementia (25%). Multivariate logistic regression analyses confirmed the differences between the four disease groups in the chances of referral independently of sex, age and main place of residence.

Patients with COPD had a lower median number of days between referral and death (10 days) than those with heart failure (12 days), dementia (14 days) and cancer (20 days). However, this difference was not significant when controlled for sex, age and main place of residence.

### Socio-demographic characteristics associated with referral within the four disease groups

Female cancer patients were more likely to be referred to palliative care services than their male counterparts. Patients with heart failure and dementia were more likely to be referred when they lived in a nursing home than when they lived at home, while the opposite was found for cancer patients. No significant associations were found in the multivariate analyses for patients with COPD (Table 3). There were no significant associations between socio-demographic characteristics and the timing of onset of palliative care services for the four disease groups (not in table).

### Treatment goals for patients not referred to palliative care services

The proportion of patients not referred decreased as death approached. This was the case for all disease groups (Fig. 1). Of those not referred, patients with COPD received fewer treatments aimed at comfort/palliation than did other patients. Even in the last week of life 40% of patients with COPD were not given treatment with comfort or

**Table 1** Sample characteristics of deceased patients with COPD, heart failure, severe dementia and cancer (%).

Number (% of all deaths)	COPD 111 (4.6)	Heart failure N = 88 (3.7)	Dementia N = 325 (13.5)	Cancer N = 673 (28.0)	p-value
Sex					<0.001 <sup>a</sup>
Male	62.7	39.8	35.2	56.3	
Age at death, in years					<0.001 <sup>a</sup>
18–64 y	7.2	2.3	2.5	27.2	
65–84 y	63.1	33.0	38.9	53.7	
≥85 y	29.7	64.8	58.6	19.0	
Main residence last year of life					<0.001 <sup>a</sup>
Home	71.2	54.5	31.9	88.5	
Nursing home	27.9	42.0	65.6	9.4	
Other institute	0.9	3.4	2.5	2.1	
Symptoms in last week of life <sup>b</sup>					
Pain	29.1	27.0	30.8	55.4	<0.001 <sup>a</sup>
Breathing problems	88.4	75.3	46.1	56.3	<0.001 <sup>a</sup>
Feeling drowsy	54.4	52.0	69.7	76.0	<0.001 <sup>a</sup>
Feeling nervous	48.9	34.8	20.1	44.6	<0.001 <sup>a</sup>
Feeling sad	44.7	30.9	18.2	56.2	<0.001 <sup>a</sup>

Percentages are column percentages.

Other institute comprised (psychiatric) hospitals, rehabilitation center or monastery.

Symptoms in the last week of life were rated as present (yes) or not present (no) by the GP.

Eleven patients with COPD as an underlying cause of death also suffered from dementia and were allocated to the COPD group as this disease is the focus of our study.

Proportions of cause of death of all deaths from our study ( $n = 2405$ ) were compared with the proportion of cause of death from the most recent official death certificate data (2008) in Belgium ( $n = 101685$ ). The proportions in the latter were for COPD 4.5%, heart failure 4.4% and cancer 27.1%.

<sup>a</sup> Pearson  $\chi^2$  test testing for differences between the four disease groups.

<sup>b</sup> Missing values: for pain  $n = 193$  (16%); for breathing problems  $n = 171$  (14%); for feeling drowsy  $n = 179$  (15%); for feeling nervous  $n = 286$  (24%); for feeling sad  $n = 314$  (26%).

palliative intent. Patients with COPD more often received treatment aimed at cure and at life-prolonging throughout the last three months, up to the last week of life, than those with heart failure, dementia and cancer.

## Discussion

This retrospective study shows that patients with COPD (20%) were much less likely than those with heart failure (34%), severe dementia (37%) or cancer (60%) to be referred to any palliative care service. All patients were referred relatively late in the disease course. Patients with COPD who were not referred more often received treatment with a curative or life-prolonging goal and less often with palliative or comfort intent than did those with heart failure, dementia or cancer who were not referred.

To our knowledge this is the first study comparing the extent and timing of referral to palliative care services, as well as treatment goals of those not referred, for people with COPD, heart failure, dementia and cancer. Our retrospective design and the use of an established representative GP network allowed us to describe these differences on a population-based level in a representative sample of all deaths in Belgium. While retrospective designs may have their limitations to resurrect certain aspects of the treatment histories of dead patients [31] it is the most appropriate design to make population-based estimates about who received palliative care [32,33]. This study also

has several limitations. Inherent to retrospective designs, memory bias cannot be excluded. However, we limited recall bias by weekly registrations, leaving little time between death and registration [34]. Another possible weakness is that although GPs are often the main treating and coordinating physicians of patients nearing the end of life, they may not always fully be aware of all treatments and care their patients receive in the last months of life, particularly in institutional settings. With a low number of patients with COPD and heart failure referred statistical power for subanalyses for those patients (e.g. timing of referral) was low. While more disease groups are probably eligible for palliative care services [23] we chose to compare COPD patients with patient groups representing one of three typical end-of-life disease trajectories identified as eligible for palliative care in previous studies [14,16]. We did not measure whether patients or their families had expressed a preference for palliative care and it could well be that such preferences is one of the reasons (but not necessarily therefore a justification) for the unequal chances between disease groups of receiving palliative care. Additionally it should be kept in mind that patterns of referral are not necessarily a good basis on which to make inferences about the quality and appropriateness of the individual care needs of patients [35].

Our study shows that palliative care services still serve mainly cancer patients in comparison with others [9,12,23], despite the World Health Organisation [36] calling for palliative care for all chronic life-limiting diseases and the

**Table 2** Referral to and time of onset of palliative care services in the last three months of life for the four disease groups

	COPD N = 111		Heart Failure N = 88		Dementia N = 325		Cancer N = 673		p-value
	%	OR (95% CI) <sup>d</sup>	%	OR (95% CI) <sup>d</sup>	%	OR (95% CI) <sup>d</sup>	%	OR (95% CI) <sup>d</sup>	
<i>Referral to palliative care services (any type)</i>	20.0	Ref cat	34.1	<b>1.99 (1.02–3.90)</b>	37.4	<b>2.32 (1.34–4.02)</b>	60.3	<b>6.07 (3.64–10.13)</b>	<0.001 <sup>b</sup>
Palliative care support at home	3.6	Ref cat	5.9	1.55 (0.37–6.49)	6.0	2.61 (0.85–8.04)	28.7	<b>8.56 (3.08–23.76)</b>	<0.001 <sup>b</sup>
Hospital-based palliative care service (excl. palliative care unit)	5.5	Ref cat	3.5	0.73 (0.17–3.05)	3.5	0.85 (0.29–2.47)	20.3	<b>3.53 (1.50–8.32)</b>	<0.001 <sup>b</sup>
Palliative care unit	5.5	Ref cat	7.1	1.64 (0.50–5.40)	2.8	0.68 (0.23–2.07)	21.7	<b>4.06 (1.73–9.54)</b>	<0.001 <sup>b</sup>
In-house PCS in a nursing home	8.2	Ref cat	21.2	2.23 (0.85–5.83)	26.4	<b>2.41 (1.08–5.40)</b>	6.1	1.49 (0.64–3.45)	<0.001 <sup>b</sup>
<i>Time of onset of palliative care services<sup>a</sup></i>	Median (P25–75)	OR (95% CI) <sup>e</sup>	Median (P25–75)	OR (95% CI) <sup>e</sup>	Median (P25–75)	OR (95% CI) <sup>e</sup>	Median (P25–75)	OR (95% CI) <sup>d</sup>	p-value
Days prior to death	10 (7–30)	Ref cat	12 (6–35)	1.34 (0.58–3.09)	14 (7–30)	0.92 (0.31–2.72)	20 (8–45)	1.20 (0.48–2.99)	<0.05 <sup>c</sup>

Abbreviations: Ref cat = reference category; OR = odds ratio; CI = confidence interval; P25–75 = percentile 25 to 75.

Percentages are column percentages. Percentages may not add up to total percentage of referrals because more than one palliative care service was used in some cases.

<sup>a</sup> Calculations for only patients with a referral to palliative care services.

<sup>b</sup> Pearson  $\chi^2$  test testing for differences in referral between the three disease groups.

<sup>c</sup> Kruskal–Wallis test testing for differences in time of onset between the four disease groups.

<sup>d</sup> Odds ratios with 95% confidence intervals from multivariate binary logistic regression analyses with palliative care services as dependent variable (referral vs no referral). Controlled for sex, age and main place of residence. Bold denotes significant differences with COPD at  $p < 0.05$ .

<sup>e</sup> Odds ratios with 95% confidence intervals from ordinal logistic regression analyses with time of onset of palliative care services as dependent variable (ordinal variable with 3 categories: 1–7 days (ref), 2–4 weeks and 2 or more months). Controlled for sex, age and main place of residence.



**Table 3** Proportion<sup>a</sup> and chances<sup>b</sup> of referrals to palliative care services by socio-demographic characteristics for the four disease groups

	COPD N = 111		Heart failure N = 88		Dementia N = 325		Cancer N = 673	
	Referred (%)	OR (95% CI)	Referred (%)	OR (95% CI)	Referred (%)	OR (95% CI)	Referred (%)	OR (95% CI)
<b>Sex</b>								
Male	19.1	Ref cat	36.4	Ref cat	31.2	Ref cat	57.7	Ref cat
Female	22.0	1.26 (0.46–3.51)	32.7	0.49 (0.16–1.48)	40.9	1.49 (0.88–2.53)	63.5	<b>1.46</b> (1.05–2.05)
<b>Age</b>								
18–64 y	25.0	Ref cat	0	Ref cat	25.0	Ref cat	62.6	Ref cat
65–84 y	17.4	0.60 (0.11–3.40)	33.3	n.a.	39.8	1.90 (0.36–10.05)	60.5	0.96 (0.65–1.42)
≥85 y	24.2	1.03 (0.16–6.54)	35.7	n.a.	36.6	1.42 (0.27–7.49)	54.9	0.83 (0.50–1.38)
<b>Main residence last year of life</b>								
Home/with family	20.5	Ref cat	<b>23.9</b>	Ref cat	<b>28.3</b>	Ref cat	<b>61.7</b>	Ref cat
Nursing home	16.1	0.62 (0.19–2.00)	<b>44.4</b>	<b>3.33</b> (1.07–10.43)	<b>41.6</b>	<b>1.75</b> (1.02–2.99)	<b>47.5</b>	<b>0.55</b> (0.31–0.99)

Abbreviations: OR = odds ratio; CI = confidence interval; Ref cat = reference category; n.s. = not significant.

Percentages and odds ratios of patients being referred to palliative care services for each disease separately.

Bold denotes significant at  $p < 0.05$ .

<sup>a</sup> Pearson  $\chi^2$  test testing for differences in referral between characteristics for each disease group.

<sup>b</sup> Multivariate binary logistic regression analyses with palliative care services as dependent variable (referral vs no referral) and sex, Age and main place of residence as independent variables.

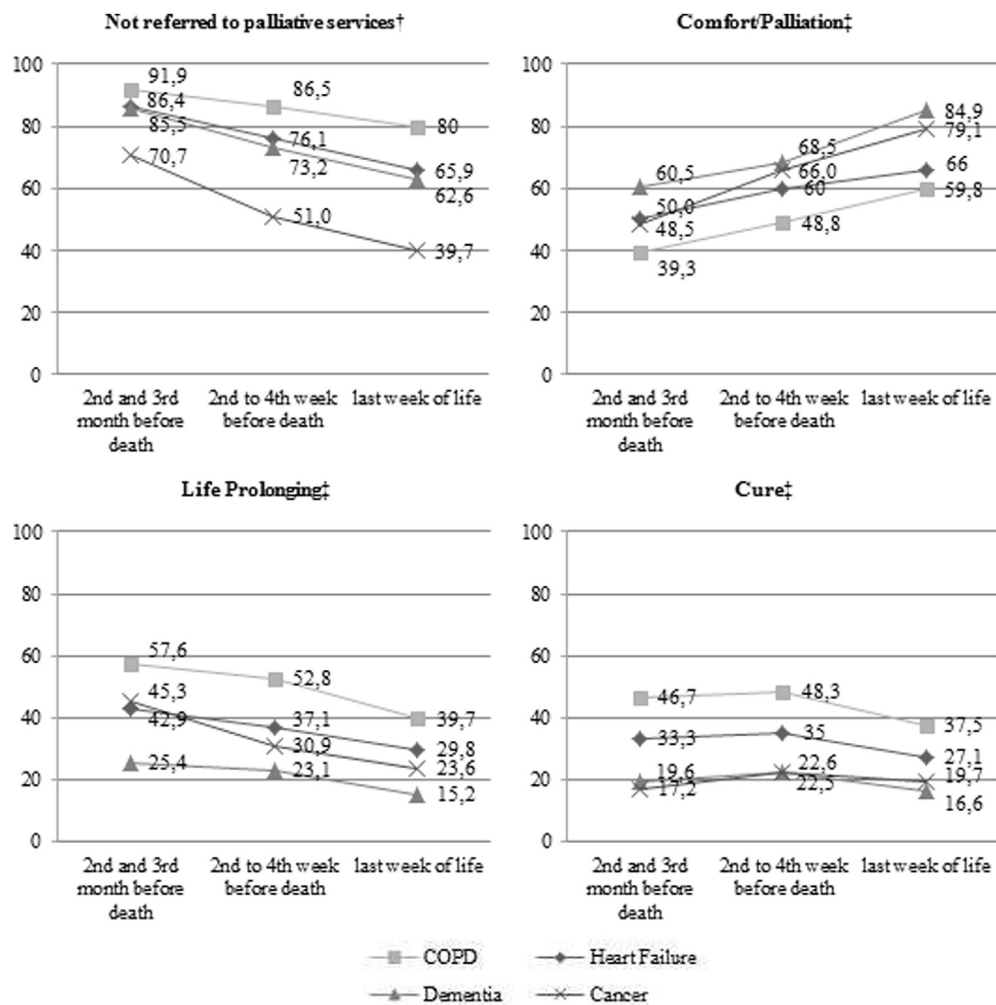
Belgian law on palliative care which gives equal rights to all patients to use palliative care services and regulates its equal availability across the country [37]. The historical focus on cancer and the easier predictability of the cancer disease trajectory may explain the emphasis on cancer [38], but it is particularly remarkable that COPD, with disease symptoms and a trajectory comparable to heart failure and an unpredictable prognosis comparable to dementia, has a significantly lower proportion of referrals than do those patient groups and differs a great deal in terms of treatment goals at the end of life. A possible explanation is that many patients with COPD and their caregivers do not consider the disease to be life-threatening or to be suitable for palliative care [39,40]. As a result, curative or life-prolonging treatments more often are continued until the last days of life in patients with COPD [41]. Even when treatment is not primarily curative or life-prolonging, the absence of noninvasive ventilation in many palliative care settings [6], as opposed to in pulmonology wards [42], may additionally lead physicians to less often consider referring patients with COPD to palliative care services.

Although palliative care services have been shown to improve the quality of care [3], not all patients need specialized care and it would be unrealistic to refer all patients with a life-limiting chronic disease to palliative care services [43]. Many palliative care needs can be managed by GPs or respiratory specialists. Our findings, however, show that people with COPD are less likely than those with other chronic life-limiting diseases to receive generalist treatment with a palliative or comfort intent. There is evidence that COPD patients experience similar palliative care needs in their last months of life to patients

with other chronic life-limiting diseases such as cancer [19,21]; we found high frequencies of pain, feelings of drowsiness and sadness and even higher frequencies of nervousness and difficulties breathing in the last week of life, which suggests referral to a palliative care service or at least changing treatment to include palliative or comfort intents may be of benefit to them [7,14,44,45].

Another important finding, applicable to all disease groups but perhaps most particularly so for COPD patients, is that palliative care is still seen mainly as terminal care. Half of the referred patients were referred to a palliative care service less than 10–20 days before death. This is considerably shorter than the time between referral and death found in studies of cancer patients in the US (42 days) and Australia (54 days) [46,47]. These late referrals may imply that the services used did not have time enough to achieve the goals of palliative care [36]. An over-optimistic prognosis and the attitude of physicians and patients to their disease [38,39], in combination with a reimbursement criterion in Belgium that stipulates that a 'palliative patient' should have a predicted survival time of less than three months, may impede early referral to palliative care. These barriers may apply particularly to COPD patients.

People with COPD receive palliative care less often than those with other chronic life-limiting diseases, both in terms of referral to specialist palliative care services and in terms of receiving generalist care aimed at comfort. An increasing awareness of palliative care services as an option for COPD patients is needed. However, bearing in mind that involving specialist palliative care services may not necessarily be required or realistic for every patient with a chronic life-limiting disease it is also particularly important that palliative care expertise and knowledge is cascaded to



**Figure 1** Proportion of patients not referred to palliative care services and their treatment goals\* over the course of the last three months of life (%). Missing values (not responded) for comfort/palliation, life-prolonging and cure in month 2–3, week 2–4 and the last week ranged from 9% to 11%. † Percentages of patients that were not referred to any palliative care service at the time given. ‡ Percentages of patients for which GP indicated a score of 4 or 5 on a 5-point Likert scale ranging from 1 (not at all important) to 5 (very important) for the question: ‘How important were the following aspects of patients care according to you?’ are displayed. These results are for patients that were not referred to palliative care services at the time given. Multiple treatment goals were possible per period. Differences between disease groups for each treatment goal and for proportion of referral for each time category were calculated using Pearson  $\chi^2$  test. All *p*-values were significant  $p < 0.01$

professional groups such as GPs and respiratory physicians. By combining the skills of general practitioners, respiratory physicians and palliative care services, the care of patients with COPD can be advanced.

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## Author contributions

KB, JC, LV and LD conceived the idea of the study and JC, LV and LD obtained funding. LV and KV contributed to the planning of the data collection and the actual collection of data. KB and KV were responsible for the integration of the data and KB and JC for the analyses on this file. KB and JC led the writing of the paper. All listed authors contributed to the writing of the article and approved the final version of the manuscript.

## Guarantor

KB has full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

## Conflict of interest

No conflict exist for the specified authors.

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