



Comparing the use and timing of palliative care services in COPD and lung cancer: a population-based survey

To the Editor:

Palliative care is a proven approach to enhance quality of life and care both for people with severe chronic obstructive pulmonary disease (COPD) [1] and those with lung cancer [2], and it is encouraged to start palliative care early in the disease trajectory [3, 4]. Similar symptoms occur in both diseases, such as pain, insomnia, fatigue, low mood and dyspnoea [5], with a study reporting even worse physical and emotional functioning for COPD than for lung cancer [6]. These symptoms signal palliative care needs [6], and require treatment focused on symptom management and psychosocial support for more than just the terminal phase. A high use of healthcare resources in COPD is found, related to a tendency towards aggressive and life-prolonging care [7]. Difficulties in predicting disease trajectories and unclear prognosis have been suggested as explanations for why people with COPD are referred less often for palliative care [8].

Previous studies comparing the timing and use of palliative care services for those with lung cancer and those with COPD have mostly been limited to specific settings [9] or small samples [6], while robust population-based studies on these topics are lacking. A population-based perspective is important to examine access and inequality in access to palliative care within a healthcare system. Our goal in this study was therefore to examine treatment goals in the last week of life, use and timing of palliative care services, and reasons for not referring people dying from COPD and lung cancer to palliative care services.

We conducted a nationwide mortality follow-back study based on a representative stratified sample of deaths ($n=6871$) of people aged ≥ 18 years from January 1 to June 30, 2013, representing 12% of all deaths in Flanders, Belgium, in 2013. The study design has been validated to evaluate palliative care [10]. For COPD, we selected cases where COPD was reported on the death certificate as the underlying, intermediate or associated cause of death (International Classification of Diseases 10th Revision (ICD-10) codes J40–J44) and where cancer (ICD-10 code C) was not an underlying cause. For lung cancer we selected deaths for which lung cancer was the underlying cause (ICD-10 codes C33–C34).

The questionnaire inquired whether death had occurred “suddenly and totally unexpectedly”. If not, referral to palliative care would not have been precluded, so the physician was asked to answer questions regarding the care provided to the patient. Data were weighted for disproportionate sampling and differences due to nonresponse between the response sample, and all deaths in terms of province and place of death. After weighting, no significant differences between response sample and all deaths for age, sex, marital status, province, cause and place of death were found.

Response rate for the deaths from COPD and lung cancer was 60.6% (3751 out of 6188), resulting in 251 (6.7%) deaths from COPD and 192 (5.1%) from lung cancer. Compared with people with lung cancer, those with COPD more often were female, older, living in an institution, and died in a nursing home and in a manner considered as sudden and unexpected by the physician ($p<0.001$) (data not shown).

Of all non-sudden deaths for COPD ($n=155$) and lung cancer ($n=154$), treatment goal in the last week of life was less often aimed at comfort/palliation for COPD (59.1%) than for lung cancer (92.1%) ($p<0.001$), confirmed by multivariable tests controlling for sex, age and living situation (OR 9.901, 95% CI 4.74–20.40). Use of any type of palliative care service happened less often for COPD than for lung cancer



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Palliative care services are used mainly as terminal care in lung cancer and COPD, with less and later use for COPD <http://ow.ly/j38v30jxbhv>

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(37.3% versus 73.5%) ($p < 0.001$) and this was also true for all types of palliative care service (palliative care support at home: 7.2% versus 35.5%; palliative care support in hospital: 18.8% versus 32.2%; palliative care unit in hospital: 2.6% versus 12.6%) except use of a palliative care reference person in a nursing home (11.7% versus 3.3%). This was confirmed by multivariable tests (OR 5.682, 95% CI 3.25–9.90) (table 1).

The median timing of the first palliative care service use for COPD was 6 days before death (interquartile range (IQR) 3–14 days, mean 13.30 days) and 16 days for lung cancer (IQR 7–54 days, mean 40.22 days). Multivariable tests showed that the first palliative care provision took place, on average, 28 days earlier for lung cancer than for COPD in relation to the moment of death (unstandardised B coefficient 28.25, 95% CI 3.45–53.40) (table 1). The main reason for non-referral indicated by physicians were less often in those with COPD that palliative care needs were already sufficiently addressed by regular care (39.8%) than in those with lung cancer (55.3%), a difference confirmed by multivariable tests (OR 2.44, 95% CI 1.05–5.68). Other reasons were that palliative care services were not (sufficiently) meaningful in COPD (36.0%) and lung cancer (18.4%), and not enough time to initiate it (23.0% in COPD and 23.4% in lung cancer) (table 1).

The considerably large discrepancies found between COPD and lung cancer in both use and timing of palliative care services are in line with previous research [2, 6, 9]. They could be due to physicians being more aware of the advantages of palliative care for cancer, which would confirm evidence that palliative care is still associated with cancer [11]. As palliative care needs are signalled for both diseases [6], and some needs are even higher in COPD [6], our findings that palliative care is more often viewed as not meaningful in COPD are striking. It suggests that physicians either do not recognise palliative care needs

TABLE 1 Use and timing of palliative care (PC) services

	COPD	Lung cancer	Bivariate p-value	OR (95% CI)
Deaths	155	154		
Treatment goal in the last week of life			<0.001 [#]	
Cure/life prolongation	40.9%	7.9%		
Comfort/palliation	59.1%	92.1%		9.901 (4.74–20.41) ^{¶¶} ($p < 0.001$)
Referral to PC services				
Any type	37.3%	73.5%	<0.001 ⁺	5.682 (3.26–9.90) ^{¶¶} ($p < 0.001$)
PC support at home	7.2%	35.5%	<0.001 ⁺	6.757 (3.14–14.49) ^{¶¶} ($p < 0.001$)
Hospital-based PC service [§]	18.8%	32.2%	<0.009 ⁺	1.946 (1.08–3.51) ^{¶¶} ($p < 0.027$)
PC unit	12.6%	12.6%	<0.001 ⁺	5.988 (1.91–18.87) ^{¶¶} ($p < 0.002$)
PC reference person in a nursing home	11.7%	3.3%	<0.008 ⁺	0.639 (0.19–2.17) ^{¶¶} ($p < 0.472$)
Timing of PC service^f days prior to death			<0.001 ^{##}	
Median (interquartile range)	6 (3–14)	16 (7–54)		28.248 (3.45–53.40) ^{¶¶¶} ($p < 0.025$)
Mean (range)	13.30 (1–90)	40.22 (1–666)		
Reasons for not using PC services (% deaths without referral to PC services)	96 (62.7%)	40 (26.5%)		
PC needs addressed	39.8%	55.3%	0.122 [#]	2.439 (1.05–5.68) ⁺⁺ ($p < 0.039$)
Not meaningful	36.4%	18.4%	0.059 [#]	0.385 (0.14–1.04) ⁺⁺ ($p < 0.059$)
Not enough time	22.7%	23.4%	>0.999 [#]	0.899 (0.35–2.38) ⁺⁺ ($p < 0.828$)
Patient did not want	5.7%	15.8%	0.086 [#]	3.155 (0.82–12.20) ⁺⁺ ($p < 0.095$)
Family did not want	4.4%	10.3%	0.243 [#]	3.226 (0.68–15.15) ⁺⁺ ($p < 0.139$)
PC services not available	3.4%	0%	0.553 [#]	
Not take away hope	1.1%	2.6%	0.522 [#]	1.209 (0.06–22.73) ⁺⁺ ($p < 0.899$)
Other	1.1%	0%	>0.999 [#]	

Percentages are column percentages; percentages may not add up to total percentage of referrals because more than one PC service was used in some cases or more than one reason for non-referral was given. Missing values for PC referral (four out of 149) and reason for not using PC (10 [7.3%] out of 136; lung cancer, two out of 40; chronic obstructive pulmonary disease (COPD), eight out of 96). #: Pearson Chi-squared test testing for differences in treatment goal and opiate use between the two illnesses. ¶: odds ratio (95% CI) from complex samples multivariable logistic regression with dependent PC referral (no referral versus referral) as dependent variable, and cause of death, living situation, sex and age as independent variables, with COPD as the reference category. +: Pearson Chi-squared test testing for differences in referral between the two illness groups. §: excluding palliative care unit. f: calculations only for patients with a referral to PC services (only available for non-sudden deaths); missing values for timing of PC service (lung cancer, 15 out of 114; COPD, six out of 58). ##: Kruskal–Wallis test testing for differences in time of onset between the two illness groups. ¶¶: unstandardised B coefficient (95% CI) from complex samples multivariable linear regression with dependent timing of referral (i.e. days prior to death) as dependent variable, and cause of death, living situation, sex and age as independent variables, with COPD as the reference category. ++: odds ratio (95% CI) from complex samples multivariable logistic regression with dependent PC referral (no referral versus referral) as dependent variable, and cause of death, living situation, sex and age as independent variables, with COPD as the reference category; calculations only for decedents not referred to PC services).

in COPD or view palliative care as not useful for COPD, which could imply that COPD patients are being deprived of adequate care.

Furthermore, the focus on life prolongation into the last week of life in 40% could indicate that physicians perceive COPD as a chronic disease requiring ongoing therapeutic care, and only intervene reactively in response to acute exacerbations rather than proactively based on a care plan [9]. This could impede the integration of holistic, comfort-focused palliative care for COPD, perhaps further corroborated by the outdated view that palliative care is merely end-of-life care [12]. Research [13] has also found that people with COPD themselves often do not fully understand the severity of COPD, and do not know which kind of care they would want in the future [14].

The difficulties of predicting illness progression may also explain these results. In lung cancer, a period of fairly good functioning is followed by a rapid decline and a relatively predictable death. COPD is characterised by a gradual but steady decline accompanied by exacerbations which can lead to an unexpected death [8]. Research shows that prognostication difficulties impact on communication about palliative care and what dying might entail [15], which might complicate discussions of and referral to palliative care more in COPD than in lung cancer.

Regardless of the differences between the disease groups, one similarity is worth noting, *i.e.* that the timing of referral was very close to death (median of 6 days for COPD and 16 days for lung cancer). This indicates that palliative care services are still seen mainly as care at the very end of life, despite studies showing important benefits of early palliative care for lung cancer [3] and for COPD [4]. Better training for professional caregivers about palliative care needs and multidisciplinary deliberation between professional caregivers, the person with COPD and the informal caregivers might facilitate the integration of palliative care and could be useful if there are differences of opinions about further care.

We conclude that while palliative care services are used mainly as terminal care in both diseases, our study shows less and later palliative care service use for COPD. This suggests a need for more demonstration of the benefits of palliative care and its value in the pre-terminal phase, particularly for COPD.

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