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End-of-life care in oxygen-dependent COPD and cancer: a national population-based study

To the Editor:

Chronic obstructive pulmonary disease (COPD) is the third leading cause of mortality worldwide [1], and is associated with high morbidity and poor symptom control for long periods of time as the disease progresses [2]. At the end of life, COPD patients have a symptom burden comparable to, and often greater than that associated with cancer [3]. Comparison between COPD and cancer is relevant because cancer patients have well-established palliative care programmes. Despite having extensive and similar end-of-life (EOL) needs to cancer patients, studies report unrelieved symptoms and low referral rates to palliative care in advanced COPD patients [4].

Knowledge about symptoms and symptomatic treatments near death are vital to identify healthcare inequalities, and to identify ways to improve EOL care in advanced COPD. The aim of this study was to estimate the prevalence of symptoms and their management in the last week of life in people with oxygen-dependent COPD or cancer.

This was a nationwide registry-based cohort study including all patients starting long-term oxygen therapy (LTOT) for physician- diagnosed COPD in the national Swedevox register who died between January 1, 2011 and October 14, 2013. The Swedevox register prospectively includes patients starting LTOT in Sweden with a population-based coverage of ~85% [5]. Details of the register are described elsewhere [6].

Data on people with oxygen-dependent COPD were cross-linked using each patient's unique Swedish identification number with data in the Swedish Register of Palliative Care (SRPC). Patients in SRPC who died from cancer during the same time period were included as the comparator group. SRPC is a national quality register of the care of patients during their last week of life regardless of place of care or diagnosis, with a coverage of 87.4% of all cancer deaths nationwide in 2013 [7].

The SRPC collects data through an end-of-life questionnaire (ELQ) completed retrospectively by the responsible nurse and/or physician within a week of the patient's death, based on the patient record and also experience of the care that may not have been documented, preferably after a team discussion, therefore including the experience of all team members. The ELQ includes data on the presence of breathlessness, pain, death rattle, nausea, anxiety and confusion, and prevalence of prescribing "as-needed" medications for pain, nausea, anxiety and death rattle during the last 7 days of life. A previous study supported the validity of the ELQ [8].

Prevalence was considered for each symptom in the questions of the ELQ: "Were any of the following symptoms prevalent at some time during the last week of life" (yes or no). For any reported symptom, the level of symptom relief was graded as relieved, partially relieved, or unrelieved. Prevalence of as-needed medication prescriptions was analysed among symptomatic patients for each identified symptom according to the question "Was medication

prescribed for use ‘as needed’ in the form of injections before death for pain, death rattle, nausea and anxiety” (yes or no).

The study was approved by local ethics committee (LundDNr 2013/379; University of Lund, Lund, Sweden). Statistical methods included standard descriptive statistics, t-test and chi-square tests as appropriate using Stata version 12 (StataCorp LP; College station, TX, USA).

A total of 1128 COPD patients (mean±SD age 78±8 years at death; 60 % women) and 56843 cancer patients (age 75±12 years at death; 49% women) were included. Of LTOT patients from Swedevox, 59% were registered in SPRC and included in the study. Characteristics were similar between LTOT patients who were and were not included in terms of age, sex, lung function, body mass index and arterial blood gas levels, supporting the external validity of the study.

Compared to patients with cancer, COPD patients suffered from more breathlessness (73% versus 22%) and anxiety (63% versus 54%) but less pain (52% versus 81%) and nausea (11% versus 23%) during the last week of life (figure 1a). COPD patients had lower rates of complete relief from breathlessness (22% versus 37%), anxiety (52% versus 61%) and death rattle (33% versus 44%) than cancer patients (figure 1b) ($p<0.001$ for all comparisons).

Prescription of as-needed medications during the last week of life was significantly lower in COPD than cancer for all symptoms: anxiety (76% versus 89%), death rattle (75% versus 88%), pain (80% versus 96%) and nausea (46% versus 77%) ($p<0.001$ for all comparisons). Furthermore, COPD patients had fewer as-needed medications prescribed to address specific symptoms when these were recorded: for anxiety (82% versus 95%), death rattle (89% versus 95%), pain (93% versus 97%) and nausea (64% versus 89%) ($p<0.001$ for all comparisons).

To evaluate the robustness of the findings, we compared symptom prevalence among patients for whom the symptom severity was rated according to the ELQ using a validated instrument. Results were similar for all symptoms, except that the relief of pain was higher in both groups, which supports the robustness of the findings.

Death was expected among 80% of COPD patients and 95% of cancer patients. However, COPD patients died more often in hospital (49% versus 28%) and received less specialized palliative home care (4% versus 14%). Fewer COPD patients had an EOL discussion (33% versus 61%) ($p<0.001$ for all comparisons).

Our study shows that patients with oxygen-dependent COPD suffered from a high symptom load with poor symptom control in the last week of life. Breathlessness was three times more common in oxygen-dependent COPD than cancer patients. Breathlessness was fully relieved for only 22% of patients. Prescription of as-needed medications for all symptoms was significantly lower among COPD patients than in patients with cancer.

These findings are in line with previous reports that COPD patients suffer from a high burden of symptoms, especially breathlessness, at the end of life [9]. We have expanded previous findings with data on prescription of palliative medications during the last week in advanced COPD specifically and comparing it with a cancer cohort who usually receives higher-quality EOL care.

Another finding is that COPD patients still have limited access to specialised care services and receive less palliative care than patients with cancer, consistent with previous reports [10, 11].

The limited specialised health and social care received by most COPD patients highlights the unequal distribution of specialised resources at end of life depending on the underlying disease.

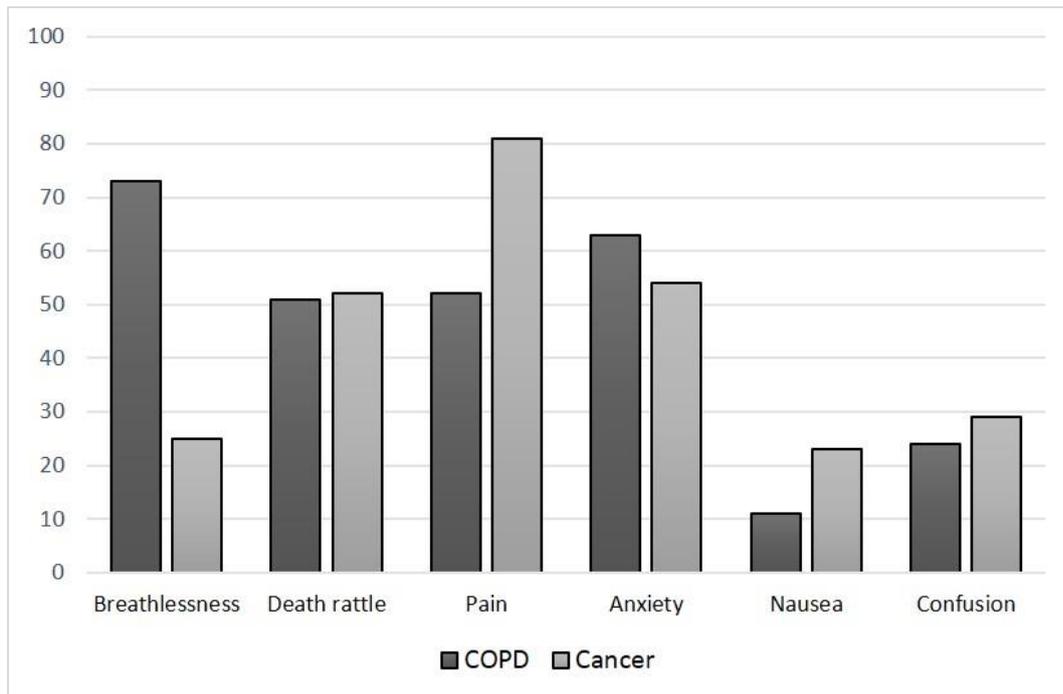
Strengths of the present study include its national population-based design and inclusion of the largest cohort to date of patients with oxygen-dependent COPD and cancer. Few previous studies included the very last days of life and most studies were old or involved small cohorts [10, 12]. We report population-based, real-world data, and the findings probably have high external validity due to the national setup.

Limitations of our study include that data on palliative care in SRPC were collected retrospectively. The difficulties of predicting the prognosis in advanced COPD would make prospective data collection near death problematic among severely ill patients. The ELQ was answered by staff, which could be affected by recall or reporting bias. However, staff proxy assessments of symptoms in patients with advanced disease might be a valid alternative, especially for the detection of breathlessness [13].

For clinicians, this study highlights the need for adequate end of life care among patients with advanced COPD. This includes symptom management, the need for integrated respiratory and palliative care, and increased access to specialised palliative care services [14]. Breathlessness is very common in advanced COPD and poor symptom control remains a significant problem before death. At present, there is substantial evidence in favor of treatment with opioids, as randomised trials have shown that oral sustained-release morphine can relieve chronic refractory breathlessness [15]. A recent study by our group supports the safety of low-dose opioids in severe COPD [16].

In conclusion, this study identifies areas for improvement of the quality of EOL care received by COPD patients. Further engagement of health service providers and policy makers is necessary in order to provide these patients with equal and decent EOL care.

a)



b)

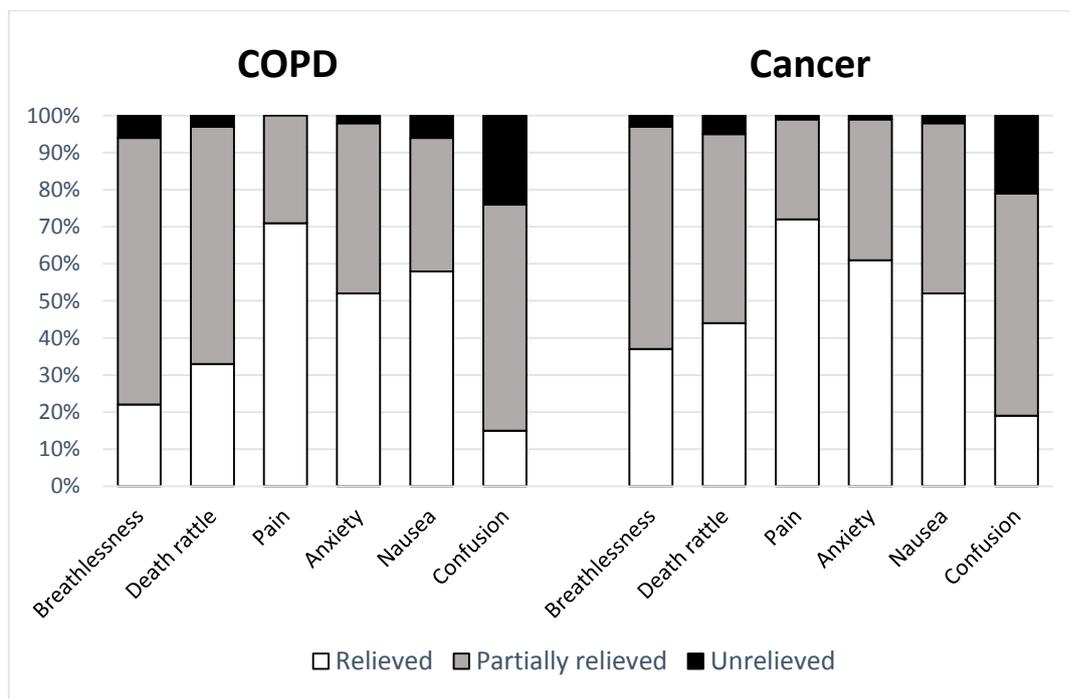


Figure 1. Patients with oxygen-dependent chronic obstructive pulmonary disease (COPD) (n=1128) or cancer (n=56843). The prevalence of (a) symptoms, and (b) relieved, partially relieved, and unrelieved symptoms in symptomatic patients during the last week of life in Sweden.

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