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Understanding Breathlessness: Cross-Sectional Comparison of Symptom Burden and Palliative Care Needs in Chronic Obstructive Pulmonary Disease and Cancer

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Abstract

Background: Little is known about symptom burden and palliative care needs of breathless patients with advanced cancer and chronic obstructive pulmonary disease (COPD).

Objectives: We aimed to describe and compare symptoms and needs in these two groups in relation to survival.

Methods: Cross-sectional study of breathless patients with COPD III/IV or advanced cancer. Data were collected in an interview using the Memorial Symptom Assessment Scale short form (MSAS-SF), the modified Borg Scale, the Hospital Anxiety and Depression Scale, and the Palliative Care Outcome Scale (POS). Follow-up information was collected on survival.

Results: Forty-nine patients with cancer and 60 patients with COPD were recruited. Both groups had similar demographics and a similar high symptom burden: median number of 14 symptoms; most prevalent symptoms in both groups besides breathlessness were drowsiness, lack of energy, cough; median global symptom distress on MSAS-Global Distress Index MSAS-GDI 1.6 in cancer and 1.4 in COPD. HADS depression scores were higher than HADS anxiety scores. Palliative care needs were also similar in both groups. Median survival was 107 days in patients with cancer and 589 days in patients with COPD.

Conclusions: Symptom burden and palliative care needs of breathless patients with severe COPD are considerable and as high as among patients with advanced primary and secondary lung cancer although patients with COPD have a longer survival.

Introduction

BREATHLESSNESS is one of the most common and distressing but neglected symptoms in patients with severe chronic obstructive pulmonary disease (COPD) and advanced cancer.^{1,2} Solano et al.¹ postulated that breathlessness is one of the universal symptoms across diseases constituting a common pathway towards the end of life in terms of symptomatology but this has never been investigated. Overall, our understanding of breathlessness in advanced disease is still limited and little is known about the broader palliative care context of breathless patients.

Most evidence and experience in symptom management and palliative care derives from patients with advanced cancer but it has been widely acknowledged that palliative care should be offered beyond cancer to patients with advanced chronic respiratory disease.³⁻⁵ However, the best models and timing for palliative care in COPD have yet to be defined and models for patients with cancer can only serve as examples. There is some evidence that patients with more severe COPD have high palliative care needs, suffer on average from 7 to 11 symptoms, and have concerns about symptom relief, quality of life, satisfaction with care, information, and use of care facilities.⁶⁻¹⁰ Given that cancer models of palliative care are much better developed than COPD models, comparing the

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palliative care needs of patients with severe COPD with those suffering from advanced cancer could help to better plan palliative care for COPD patients but only few studies have compared these two groups^{6,11–13} The main focus of these studies was either quality of life and need for social and medical care¹¹ or patients' preferences for care and life sustaining interventions.¹³ Only Edmonds et al.⁶ described the detail of symptoms and palliative care needs but used proxy ratings rather than patient reported outcomes. With the exception of Edmonds' study⁶ none of the studies reported survival, so that symptom burden can be described in relation to time of death.

The study reported here is part of a wider study to describe and compare the course of breathlessness over time and towards the end of life in patients with advanced cancer and COPD. The aim of this study was to describe and compare the symptom burden, palliative care needs, and survival of breathless patients suffering from severe COPD or advanced cancer.

Patients and Methods

Setting, patients, and recruitment

We conducted a cross-sectional survey of patients with severe COPD and advanced cancer. Patients were included if they were suffering from breathlessness affecting their daily activities and suffering either from advanced primary or secondary lung cancer or COPD stage III/IV.¹⁴ Exclusion criteria were lack of capacity to give informed consent, too ill to be interviewed, or not fluent in German or illiterate.

Recruitment took place from the oncology and/or respiratory departments in three major hospitals (one tertiary respiratory hospital), a hospice home care service and two respiratory practices in Munich, Germany. Sites were chosen to represent the main settings in which patients are seen in the German Health Care System. Patients are usually referred to these sites by their family doctors, practice-based specialists, or other hospital departments. All recruitment sites screened patients regularly for inclusion criteria, and patients in the respiratory hospital were screened at regular weekly visits. Eligible patients were invited to participate by their treating physicians. Consenting patients were then contacted by the researchers and formal written consent obtained. Data were collected from June 2006 to November 2007. All participants were subsequently followed up for 6 months to assess breathlessness and other symptoms over time. This longitudinal data will be reported elsewhere although survival is reported in order to better understand the comparability of the two disease groups.

Data collection and measures

Patients completed the questionnaires in a face-to-face interview at a place of their choice, most often the recruitment site. Demographic and clinical data were obtained from the medical records and the participants.

The following measures were selected for data collection to describe physical and psychological symptoms as well as palliative care needs. Patients rated their average severity of breathlessness over the last 24 hours on a modified Borg scale.^{15,16} The Memorial Symptom Assessment Scale short

form (MSAS-SF) was used to measure frequency and distress of 32 highly prevalent symptoms.^{10,12,17} The Palliative Care Outcome Scale (POS) assesses palliative care needs. POS covers, in 10 questions, physical and psychological symptoms, spiritual considerations, practical concerns, emotional concerns of the patient and family, and psychosocial needs of the patient and family.^{18,19} We adapted the POS for this patient group adding a question on breathlessness using the same wording as in the pain question (question no. 1) and called this score POS plus. The Hospital Anxiety and Depression Scale (HADS), a patient-completed questionnaire with 14 items—7 on anxiety and 7 on depression—was used to assess the psychological status of patients.²⁰

Sample size

It was estimated that 50 patients in each diagnostic group would be necessary to show a difference of one Borg score with a standard deviation of 1.8, a power of 80% and a 5% significance level.

Statistical analysis

Demographic and clinical characteristics were described using frequencies (%) and 95% confidence intervals for categorical variables, and means and standard deviations or medians and ranges/interquartile range for continuous variables, depending on the distribution of the data. As most data were not normally distributed nonparametric tests were conducted. χ^2 test was used for comparison of categorical variables. Patients were followed from study entry until death or over 6 months and Kaplan Meier survival estimates were calculated for cancer and COPD patients with log rank test for comparison. There was little missing data (0.05%) in this cross-sectional study and therefore no imputation procedures were performed. The significance level was set at 1% as multiple tests were conducted. The data were analyzed using the software package STATA IC10 (StataCorp, College Station, TX).

Ethics approval was obtained from the Research Ethics Committees at King's College London (CREC number 05/06-69) and Munich University (number 079-06).

Results

Forty-nine patients with cancer and 60 patients with COPD were recruited. The demographic and general clinical characteristics were similar in both groups (Table 1). As expected, respiratory characteristics were different. Patients with COPD had lower forced expiratory volume in 1 second (FEV₁) and FEV₁/forced vital capacity (FVC) % values, which were statistically significant at the 1% level and were more often on supplemental oxygen.

Number of symptoms and overall symptom distress

Patients from both disease groups reported a similar number of symptoms (median 14; Table 2). Overall symptom distress, as measured on the MSAS-GDI, revealed moderately high symptom distress in both groups, with comparable overall levels. Cancer patients had significantly more physical symptom distress than patients with COPD.

TABLE 1. DEMOGRAPHIC, CLINICAL AND RESPIRATORY CHARACTERISTICS WITH COMPARISON BETWEEN FORTY-NINE PATIENTS WITH CANCER AND SIXTY PATIENTS WITH COPD

Demographic characteristics		Cancer (n = 49)	COPD (n = 60)	Difference
Age	mean (SD)	63.9 (9.1)	65.2 (9.7)	<i>p</i> = 0.49
Gender	male/female	25/24	29/31	<i>p</i> = 0.78
Clinical characteristics				
Specific diagnosis		Primary lung cancer = 30 (21 NSCLC, 2 SCLC, 7 = unknown histology; stage III = 2, stage IV = 26, unknown stage = 7) mesothelioma = 4 lung sarcoma = 1 Metastatic lung cancer ^a = 14 (^a Primary diagnoses breast n = 5 gastrointestinal n = 4 other n = 5)	COPD III = 29 COPD IV = 31	
Comorbidities	Comorbidity (%)	35 (71)	51 (86)	<i>p</i> = 0.05
	Cardiac (%)	19 (39)	24 (41)	<i>p</i> = 0.84
	Gastrointestinal (%)	6 (12)	10 (17)	<i>p</i> = 0.49
	Endocrine (%)	15 (31)	26 (44)	<i>p</i> = 0.15
	Neurologic (%)	8 (16)	7 (12)	<i>p</i> = 0.50
	Other (%)	13 (27)	27 (46)	<i>p</i> = 0.04
KPS	Mean (SD)	66 (11.7)	62 (10.9)	<i>p</i> = 0.11
	≥70% (%)	23 (47)	19 (32)	<i>p</i> = 0.14
	60% (%)	21 (43)	30 (50)	
	≤50% (%)	5 (10)	11 (18)	
Marital status	Married (%)	29 (59.2)	28 (46.7)	<i>p</i> = 0.70
	With partner (%)	2 (4.1)	3 (5)	
	Divorced (%)	7 (14.3)	14 (23.3)	
	Widowed (%)	8 (16.3)	10 (16.7)	
	Single (%)	3 (6.1)	5 (8.3)	
Place of care at study entry	Home	3	11	
	Respiratory unit	1	49	
	Oncology unit	39	0	
	Palliative care unit	5	0	
	Outpatient clinic (gynecology)	1	0	
Respiratory characteristics				
FEV ₁ %	Median (range)	61.3 (39–96.2) (<i>n</i> = 38)	32.0 (12.6–61) (<i>n</i> = 55)	<i>p</i> = 0.00
FEV ₁ /FVC %	Median (range)	74.3 (46.4–94) (<i>n</i> = 38)	41.6 (22.9–72.3) (<i>n</i> = 54)	<i>p</i> = 0.00
SaO ₂ (%) ^a	Median (range)	93.7 (84–98) (<i>n</i> = 44)	92.7 (39–98) (<i>n</i> = 54)	<i>p</i> = 0.44
Supplemental oxygen	No oxygen (%)	24 (49)	4 (7)	<i>p</i> = 0.00
	<2 h/day (%)	7 (14)	4 (7)	
	2–6 h/day (%)	3 (6)	7 (12)	
	6–12 h/day (%)	5 (10)	5 (8)	
	>12 h/day (%)	10 (20)	40 (67)	

^aTaken from patients independent if patients were on oxygen or not.

bold, significant difference.

COPD, Chronic obstructive pulmonary disease; SD, standard deviation; FEV₁, forced expiratory volume in 1 second; FVC, forced vital capacity.

Severity and distress of breathlessness

The severity of breathlessness was moderate and similar in both groups, with a median of 3 (range, 0–7) in patients with cancer and also 3 (range, 0–10) in patients with COPD. However, patients with COPD experienced more distress due to breathlessness measured on the MSAS-SF with a median of

4 (range, 0–4) compared to 3.2 (range, 0–4) in patients with cancer (*p* = 0.01).

Prevalence and distress of physical symptoms

To better understand which individual symptoms contributed to the global symptom burden, the prevalence of

TABLE 2. NUMBER OF SYMPTOMS AND OVERALL SYMPTOM DISTRESS WITH COMPARISON BETWEEN FORTY-NINE PATIENTS WITH CANCER AND SIXTY PATIENTS WITH COPD

No. symptoms	Cancer n = 49 median (range)	COPD n = 60 median (range)	Difference (Mann-Whitney U test)
All symptoms	14 (0–27)	14 (5–24)	<i>p</i> = 0.45
Physical symptoms	13 (0–23)	12 (4–20)	<i>p</i> = 0.35
Psychological symptoms	2 (0–4)	2 (0–4)	<i>p</i> = 0.88
Overall symptom distress			
MSAS-GDI (average of the frequency of 4 prevalent psychological symptoms and the distress associated with 6 prevalent physical symptoms)	1.6 (0–3.3)	1.4 (0.1–3.3)	<i>p</i> = 0.13
MSAS-PHYS (average of the distress associated with 12 prevalent physical symptoms)	1.5 (0–3.4)	1.1 (0.1–2.5)	<i>p</i> = 0.005
MSAS-PSYCH (average of the distress associated with 6 prevalent psychological symptoms)	1.1 (0–3.4)	1.3 (0.1–3.5)	<i>p</i> = 0.36
TMSAS (average of the symptom scores of all 32 symptoms)	1.1 (0–2.7)	1.2 (0.3–2.5)	<i>p</i> = 0.73

bold, significant difference.

MSAS-GDI, Memorial Symptom Assessment Scale Global Distress Index; MSAS-PHYS, Memorial Symptom Assessment Scale physical subscale; MSAS-PSYCH, Memorial Symptom Assessment Scale psychological subscale; TMSAS, Memorial Symptom Assessment Scale total score; COPD, chronic obstructive pulmonary disease.

individual symptoms was analyzed (Table 3). Overall, the prevalence of individual symptoms was very similar in both groups with only slight differences. Besides breathlessness, feeling drowsy, lack of energy and cough were highly prevalent in both groups. Patients with cancer complained specifically of lack of appetite and pain and patients with COPD of dry mouth and skin changes.

Patients also rated the distress that individual symptoms were causing them on the MSAS-SF. Severe distress scores (“quite a bit” and “very much”) for each symptom are shown in Figure 1. In patients with cancer, four of the most prevalent symptoms also caused most distress (shortness of breath, feeling drowsy, lack of energy, and lack of appetite). However, pain, which was the sixth most prevalent symptom,

TABLE 3. PREVALENCE AND NINETY-FIVE PERCENT CONFIDENCE INTERVALS OF TOP FIFTEEN PHYSICAL AND FOUR PSYCHOLOGICAL SYMPTOMS MEASURED ON MSAS-SF, WITH COMPARISON BETWEEN FORTY-NINE PATIENTS WITH CANCER AND SIXTY PATIENTS WITH COPD RANKED BY OVERALL PREVALENCE IN WHOLE GROUP

MSAS-SF symptoms	Cancer		COPD		Difference (χ^2 – test)
	number (%)	95% CI	number (%)	95% CI	
Shortness of breath	42 (86)	73–94%	58 (97)	88–100%	<i>p</i> = 0.04
Feeling drowsy	43 (87)	75–95%	41 (68)	55–80%	<i>p</i> = 0.02
Lack of energy	41 (84)	70–93%	43 (72)	59–83%	<i>p</i> = 0.14
Dry mouth	32 (65)	50–78%	51 (85)	74–93%	<i>p</i> = 0.02
Cough	38 (78)	63–88%	37 (62)	48–74%	<i>p</i> = 0.07
Lack of appetite	36 (74)	59–85%	24 (40)	28–54%	<i>p</i> = 0.00
Pain	34 (69)	55–82%	26 (43)	31–57%	<i>p</i> = 0.01
Difficulty sleeping	25 (51)	36–66%	33 (55)	42–68%	<i>p</i> = 0.68
“I don’t look like myself”	26 (53)	38–67%	29 (48)	35–62%	<i>p</i> = 0.62
Changes in skin	17 (35)	22–50%	36 (60)	46–72%	<i>p</i> = 0.01
Weight loss	27 (56)	41–70%	23 (38)	26–52%	<i>p</i> = 0.06
Sweats	19 (39)	25–54%	30 (51)	37–64%	<i>p</i> = 0.21
Numbness hands/feet	18 (37)	23–52%	31 (52)	38–65%	<i>p</i> = 0.12
Problems with sex	28 (58)	43–72%	19 (32)	21–46%	<i>p</i> = 0.01
Feeling bloated	15 (31)	18–45%	31 (52)	38–65%	<i>p</i> = 0.03
MSAS-SF psychological symptoms					
Worrying	32 (65)	50–78%	39 (67)	54–79%	<i>p</i> = 0.83
Feeling nervous	23 (48)	33–63%	35 (59)	46–72%	<i>p</i> = 0.24
Feeling irritable	23 (47)	32–62%	29 (49)	36–62%	<i>p</i> = 0.82
Feeling sad	28 (57)	42–71%	23 (38)	26–52%	<i>p</i> = 0.05

bold, significant difference.

COPD, chronic obstructive pulmonary disease; MSAS-SF, Memorial Symptom Assessment Scale Short form.

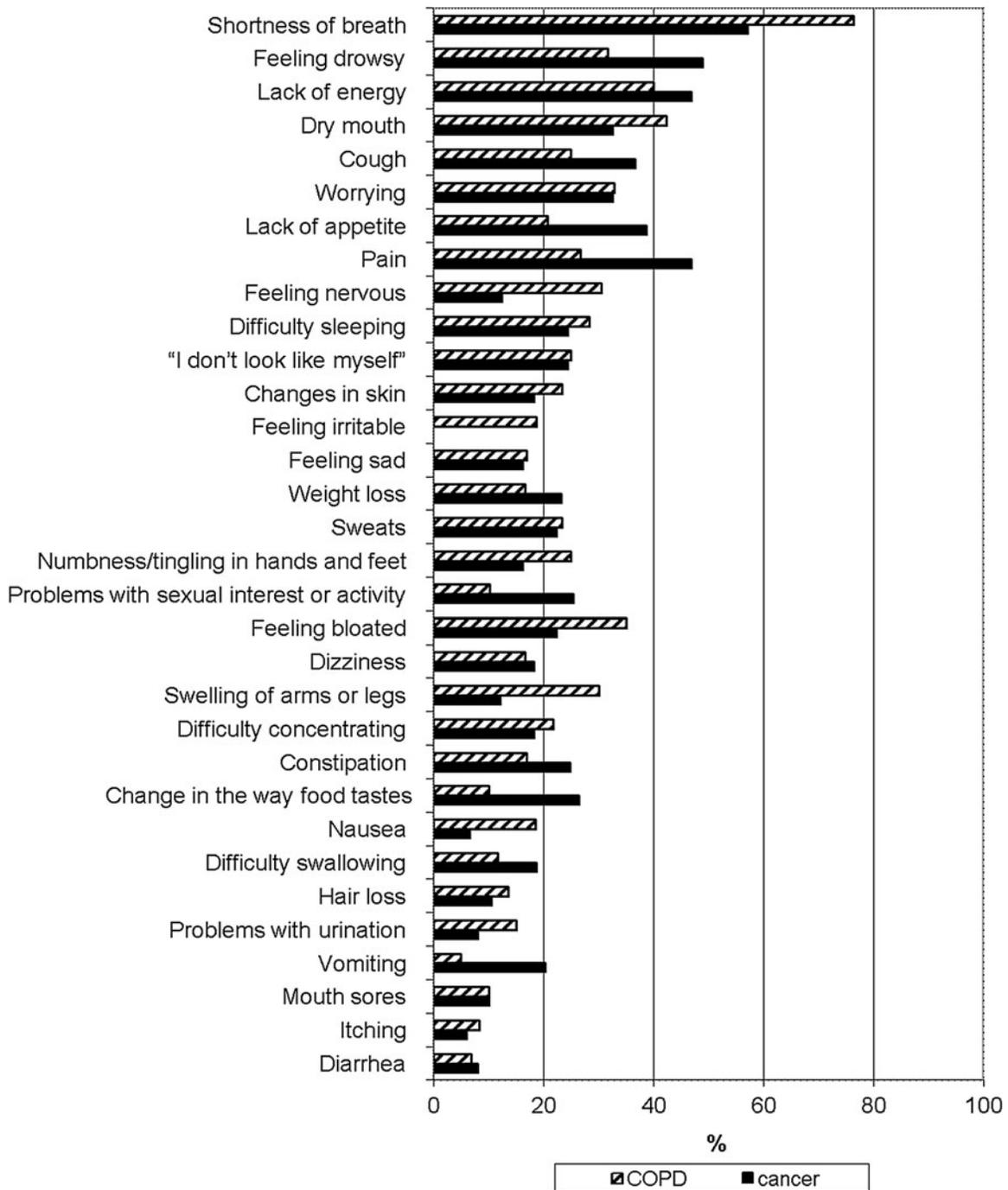


FIG. 1. Severe (quite a bit/very much) distress scores of individual symptoms rated on the Memorial Symptom Assessment Scale short form (MSAS-SF) by 49 patients with cancer and 60 patients with chronic obstructive pulmonary disease (COPD) ranked by overall prevalence in whole group.

caused more distress than cough. Patients with COPD were most distressed in the most prevalent symptoms with the same order: shortness of breath, dry mouth, lack of energy, feeling drowsy, and cough.

Shortness of breath caused the highest distress in both patient groups and was higher in patients with COPD. Otherwise, distress levels appeared to be slightly higher in patients with cancer compared to patients with COPD.

Prevalence and distress of psychological symptoms

Worrying, as measured on the MSAS-SF, was the psychological symptom most prevalent (>65%) in both disease groups (Table 3), and also the psychological symptom causing most distress (Fig. 1). Measured on the HADS, depression scores were higher than anxiety scores in both groups (Fig. 2).

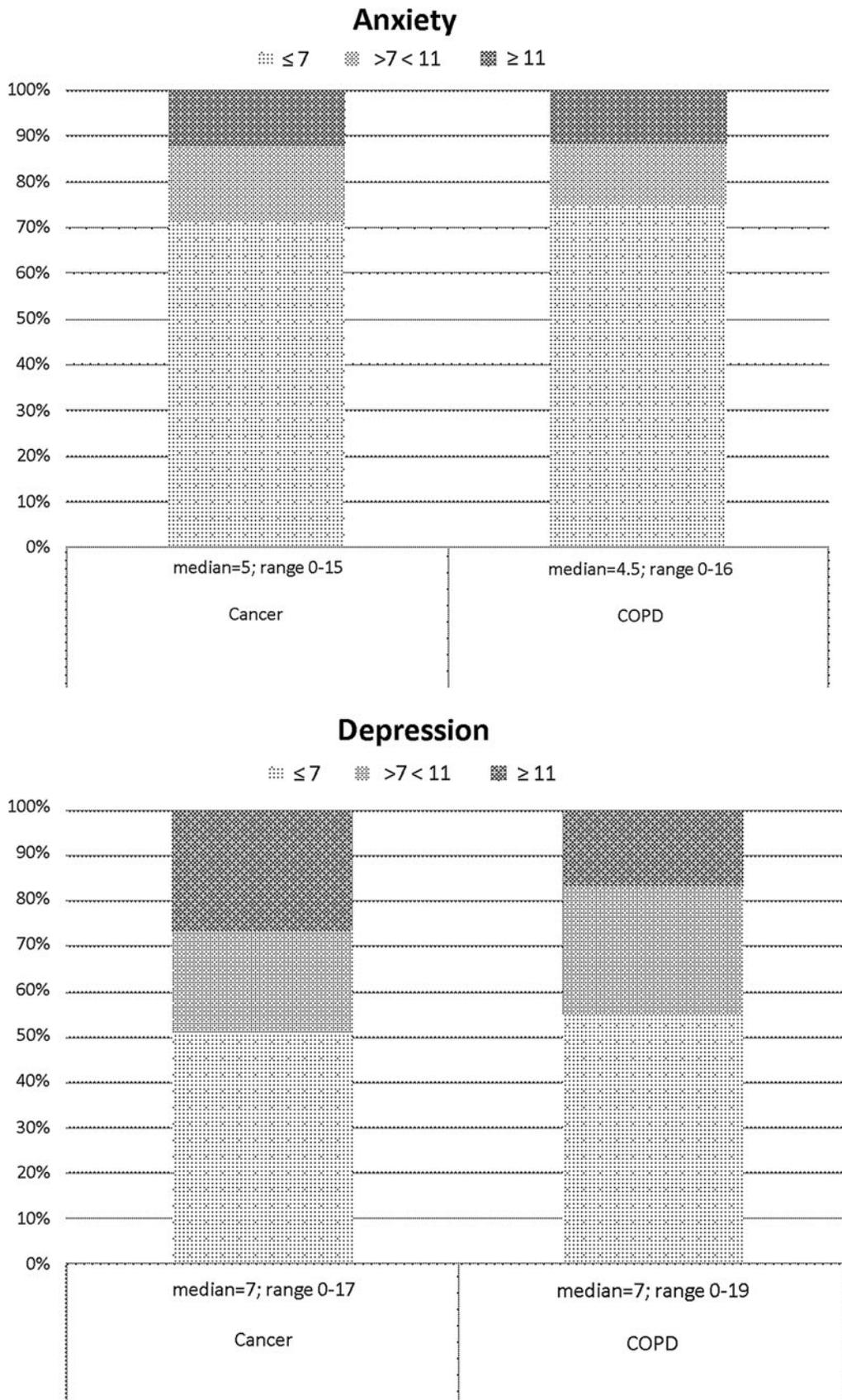


FIG. 2. Anxiety and depression subscores in 49 patients with cancer and 60 patients with chronic obstructive pulmonary disease (COPD); proportion of normal range (subscale scores ≤ 7), suggestive presence (subscale scores $> 7 < 11$) and probable presence of mood disorder (subscale scores ≥ 11).

On the anxiety subscale, about a quarter of patients in each disease group scored higher than 7 indicating the suggestive (score $> 7 < 11$) or probable presence (scores > 11) of anxiety. On the depression subscale, scores were even higher with almost half of the patients in both groups scoring higher than 7.

Palliative care needs

Overall, the POS sum scores appeared slightly higher in patients with cancer than in patients with COPD, but this difference was not statistically significant on the 1% level (Table 4). When palliative care needs were considered in more detail there were similarities between patients with COPD and patients with cancer. For 5 of 10 items the median scores were similar: breathlessness, getting information, sharing feelings, wasted time, and practical matters. In addition to breathlessness, family anxiety scored highest in both groups. Patients with cancer reported more problems with pain, other symptoms, patients' anxiety, and feeling good about yourself. Overall POS scores were moderate in both groups.

Survival

During the 6 months of data collection, 30 of 49 patients with cancer (61%) and 6 of 60 patients with COPD (10%) died. After the end of data collection another 9 patients with cancer and 9 patients with COPD had died by end of April 2008. The Kaplan-Meier survival estimates (Fig. 3) show the difference of survival between the two groups. Patients with COPD had a significantly longer median survival with 589 days (range, 8–692) compared to patients with cancer with 107 days (range,

4–671; log rank test $p = 0.00$). Median survival for was significantly shorter in patients with cancer with $KPS \leq 60$ compared to $KPS > 60$ (63 versus 240 days; log rank $p = 0.007$) but not in patients with COPD (median 589 days for $KPS \leq 60$ versus 615 days for $KPS > 60$; log rank test $p = 0.89$).

Discussion

The results of this study suggest that patients with breathlessness due to severe COPD have a considerable symptom burden beyond breathlessness and unmet palliative care needs comparable to breathless patients with advanced cancer. This supports Solano et al.'s hypotheses of a common pathway towards the end of life in patients with breathlessness.¹ However, there was a significant difference in survival in the two patient groups and the symptoms and needs of patients with COPD were experienced earlier in the disease trajectory indicating that patients with COPD have to cope much longer with this situation compared to patients with cancer.

How do our results compare with others?

Our sample had a higher symptom burden than previous studies in COPD and cancer.^{6,10,12,17} Despite the fact that they were earlier in their trajectory, patients with COPD in this study complained of an even higher number of symptoms ($n = 14$) compared to an average of 7 to 11 symptoms in other studies.^{6,17} This also applies to patients with cancer in whom the number of symptoms was higher than 7 to 9 symptoms reported before.^{6,21–23} Symptom distress measured on the MSAS-GDI in both groups was moderately high but again higher than in other studies of patients with cancer and patients with COPD using the MSAS-SF.^{10,23–25} It should be noted that breathlessness is not included in the Global Distress Index (MSAS-GDI) of the MSAS-SF and thus the reported symptom burden is due to symptoms other than breathlessness. The prevalence and distress of individual physical symptoms was high and rather similar in patients with COPD and in patients with cancer. Therefore, our results seem to suggest that breathless patients experience a particularly high symptom burden, irrespective of whether the breathlessness is due to cancer or COPD.

Palliative care needs have been evaluated in patients with advanced cancer^{23,26} and COPD⁸ but despite the value of comparisons in understanding how models of care may be transferable or not comparatively little is known about the comparison of these two groups. Only two studies contrasted patients with COPD and patients with lung cancer and found that patients with chronic lung disease have worse activities of daily living and physical, social, and emotional functioning whilst having less support from a district or palliative nurse.^{6,11} Patients lacked information regarding prognosis and future management. The study reported here is the first using a specific palliative care measure, the POS, in patients with COPD. These data highlight patients' concerns about the anxieties of their families. This was the main concern for patients with cancer and the second for patients with COPD. This worry is particularly important as patients with chronic disease (including respiratory disease and cancer) identify family and friends as their main source of support in providing physical and emotional care.^{27,28}

TABLE 4. PALLIATIVE CARE OUTCOME SCALE INDIVIDUAL ITEMS AND SUM SCORE IN FORTY-NINE PATIENTS WITH CANCER AND SIXTY PATIENTS WITH COPD

POS item	Cancer median (IQR)	COPD median (IQR)	Difference (Mann-Whitney U test)
Pain	1 (3)	0 (2)	$p = 0.00$
Shortness of breath	2 (2)	2 (2)	$p = 0.18$
Other symptoms	1 (2)	0 (1)	$p = 0.01$
Feeling anxious or worried	1 (3)	0.5 (2)	$p = 0.01$
Family anxious	3 (2)	2 (4)	$p = 0.16$
Information	0 (0)	0 (2)	$p = 0.05$
Sharing feelings	0 (1)	0 (1)	$p = 0.93$
Life worthwhile	0 (1.5)	1 (2)	$p = 0.56$
Feeling good	1 (2)	0 (1)	$p = 0.05$
Wasted time	0 (2)	0 (0)	$p = 0.00$
Practical matters	0 (0)	0 (0)	$p = 0.49$
Total POS score (max score = 40)	11 (8)	8 (5)	$p = 0.02$
Total POS plus score including breathlessness (max score = 44)	12 (7)	10 (7)	$p = 0.03$

Bold, significant difference. Note: higher scores indicate more problems for all items.

COPD, chronic obstructive pulmonary disease; PDS, Palliative Care Outcome Scale; IQR, interquartile range.

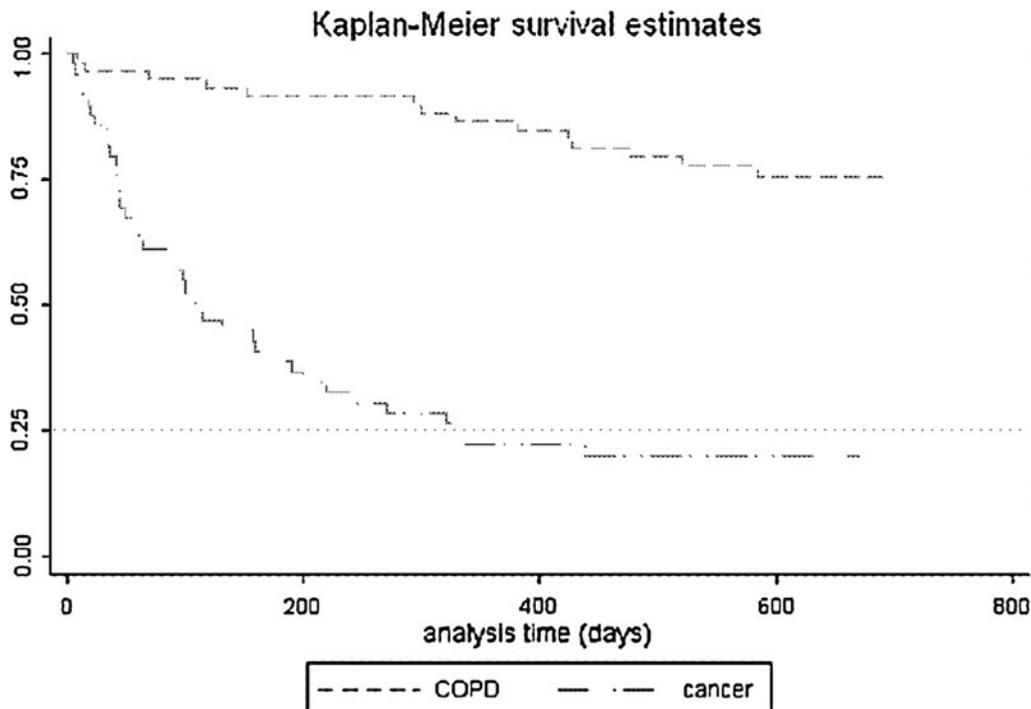


FIG. 3. Kaplan-Meier Survival estimates for 49 patients with cancer and 60 patients with chronic obstructive pulmonary disease (COPD).

Clinical and service implications

This study has several implications for the care of breathless patients both for clinicians and service providers. As many patients with breathlessness are seen by generalist clinicians rather than palliative care specialists, education and skill development with regard to palliative care has to be emphasized for all clinicians. Hence, the presence of breathlessness in patients with cancer and patients with COPD could be a useful trigger for full assessment of symptoms and palliative care needs or may be valuable to trigger referral to palliative care. Clinicians should actively assess and manage other physical and psychological symptoms if a patient presents with breathlessness as the dominant symptom. However, even the presence of breathlessness may not be taken for granted as this symptom has been described as invisible even in patients with severe COPD.²⁹ Additional symptoms may be highly prevalent and distressing and add considerably to patients' suffering. Special attention should be paid to screening for depression and anxiety. Therefore, systematic assessment using a generic symptom assessment tool such as the MSAS-SF can reveal considerable symptom burden.³⁰ Regular symptom assessment is paramount in hospice and palliative care services but should also be integrated in respiratory medicine as it has been proposed for other areas such as renal medicine.³⁰

Data from this study underpin the need for palliative care models for patients with advanced COPD. COPD can serve as a model for palliative care needs for other long-term organ failure conditions. As symptom burden and palliative care needs in patients with severe COPD seem to be very similar to patients with cancer, lessons can be learned from the palliative care model for patients with cancer such as the need for

symptom control, attention to psychosocial issues, and advance care planning. However, as symptom burden and palliative care needs were documented well before the end of life of patients with COPD, timing of palliative care may be very different from patients with cancer and more difficult to determine; there is more uncertainty in predicting prognosis for patients with COPD.⁴ Late referral of a patient in the last weeks of life will not meet the patients' and families' needs sufficiently. Therefore palliative rather than only end-of-life care is needed for these patients.⁴ Palliative care models might be more appropriate as short and early palliative interventions rather than ongoing care over a long time. This might be similar to the short-term palliative care service tested among people with progressive multiple sclerosis.³¹ Also, joint respiratory and palliative care services may be an option to provide better palliative care to these patients. Besides the question how and when palliative care services are best introduced to patients with COPD, there are some practical implications for respiratory physicians. The systematic screening for problems using tools such as the POS would be helpful to identify patients' needs. There are educational implications also. More efforts are necessary to train and educate professionals working in the respiratory field to deliver holistic care and better symptom control, especially in the advanced stages of patients' illness. This may be aided by the development of clinical guidelines. Equally palliative care physicians may need to learn more about how to manage patients with long-term conditions. Working in a multidisciplinary team and developing links to specialist services (e.g., palliative care, psychology) can be a first step toward this.

As patients with COPD experienced high symptom burden and palliative care needs long before death future research needs to follow-up these patients until death to determine

whether breathlessness and symptom burden remains stable closer to death, fluctuates, or increases.

Limitations

Because this study lacks information on the denominator population the generalizability of findings could be questioned. However, we compared the demographic and clinical data of our sample with other studies that revealed similar characteristics.^{6,7,11,13} There was only a slight difference in the age distribution: patients in our study were in their mid-sixties whereas most patients in other studies were in their seventies, e.g., the mean age in Gore et al.¹¹ study was 71 years and in Edmonds et al.⁶ retrospective study more than 80% of patients in both groups were over 65. The majority of patients were recruited in an in-patient setting which may also reduce the generalizability of the data. However, within patients with advanced stages of cancer and COPD there is obviously a group with high symptom burden and palliative care needs and it has long been recognized that need and not diagnoses or disease stage should be the driver for palliative care involvement.

Conclusions

In conclusion, this study demonstrated that the symptom burden in patients with severe COPD is even higher than previously thought and comparable to breathless patients with cancer. Patients with COPD had a longer survival and thus experienced these symptoms and palliative care needs much earlier in their disease trajectory and for a longer time. Breathless patients appear to have high levels of palliative care needs. Clinical services and education needs to be developed for this group. Future research is necessary to better understand symptoms and needs of patients over time, to develop and evaluate new models of palliative care services for patients with COPD and to test treatments in breathless patients.

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