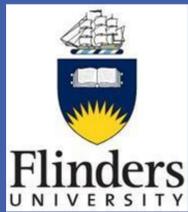


Breathlessness During the Last Week of Life in Palliative Care

An Australian prospective, longitudinal study

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Abstract

Context: Breathlessness is a major cause of suffering and distress and little is known about the trajectory of breathlessness near death.

Objectives: To determine the trajectory and clinical-demographical factors associated with breathlessness in the last week of life in specialist palliative care.

Methods: Prospective, longitudinal cohort study using national data in specialist palliative care from the Australian Palliative Care Outcomes Collaboration (PCOC). We included patients in PCOC who died between 1 July 2013 and 30 June 2014 with at least one measurement of breathlessness on a 0–10 numerical rating scale (NRS) in the week before death. The trajectory and factors associated with breathlessness were analyzed using multivariate random effects linear regression.

Results: A total 12,778 patients from 87 services (33,404 data points) were analyzed. The average observed breathlessness was 2.1 points and remained constant over time. Thirty-five percent reported moderate to severe distress (NRS ≥ 4) at some time in their last week. Factors associated with higher breathlessness were younger age, male gender, cardiopulmonary involvement, concurrent fatigue, nausea, pain, sleeping problems, higher Australia-modified Karnofsky Performance Status, and clinical instability in the multivariate analysis. Respiratory failure showed the largest association (mean adjusted difference 3.1 points; 95% confidence interval, 2.8 to 3.4).

Conclusion: Although breathlessness has been reported to worsen in the last months, the mean severity remained stable in the final week of life. In specialized palliative care, one in three people experienced significant breathlessness especially in respiratory disease.

Objectives

1. To describe the patterns of breathlessness by underlying life-limiting illness in the last week of life, and;
2. To identify any sub-populations who may be at particular risk of more severe breathlessness.

Methods

Design: Prospective, longitudinal cohort study using data from the Australian Palliative Care Outcomes Collaboration (PCOC) of specialist palliative care services across Australia including inpatient and community-based care.

Ethics: The PCOC was approved by the Human Research Ethics Committee of the University of Wollongong (approval ID: HE06/045).

Inclusion criteria: patients cared for by services registered in PCOC, dying between 1 July 2013 and 30 June 2014, who had at least one breathlessness measurement during the final seven days of life.

Assessments: Demographics, underlying disease, setting of care, and clinical assessments at each change in the Palliative Care Phase (herein ‘phase’), with services assessing patients each day they are seen.

- Distress from each of seven symptoms (bowel problems; breathing problems; fatigue; nausea; pain; and difficulty sleeping) over the previous 24 hours on a numerical rating scale (NRS) between 0 (“absent or no distress”) and 10 (“worst possible distress”). Scores were by self-report if possible or by proxy.

Statistical analyses:

Associations with breathlessness (0–10 NRS) were estimated using uni- and multivariate random effects linear regression, accounting for repeated measurements. Variables to include in the final model were selected based on subject matter knowledge.

For time-varying covariates, we estimated the association for differences *between* patients by regressing on each patient’s covariate mean, and the association *within* patients (longitudinal change between measurements) by centering each measurement on the covariate mean for each patient. Time-varying variables were AKPS, symptoms, and phase.

Results

We included 12,778 patients from 87 palliative care services across Australia, providing 33,404 data points during the last week of life. Forty-nine percent of patients had two or more breathlessness measurements during the last seven days.

- The mean breathlessness was 2.1 points on a 0–10 NRS (median 0; interquartile range 0 to 4)
- The mean breathlessness from the beginning of the last week of life did not change as death approached
- 54 % reported breathlessness (NRS ≥ 1) and 35% had moderate to severe levels (NRS ≥ 4) at some time during their last week

Table 1. Baseline characteristics

Characteristic	All, n (%)
Age, yrs, mean (SD)	73 (14)
Male gender	6922 (54)
Malignant disease (n = 12,720)	9872 (78)
Primary diagnosis	
Lung cancer	2195 (17)
Colorectal cancer	1168 (9)
Other gastrointestinal cancer	963 (8)
Breast cancer	715 (6)
Neurologic disease ^a	754 (6)
Hematological cancer	661 (5)
Pancreas cancer	614 (5)
Prostate cancer	552 (4)
Cardiovascular disease	554 (4)
Other non-malignancy	422 (3)
Respiratory failure	380 (3)
Other diagnoses ^b	3742 (29)

Figure 1. Severity of breathlessness during the last week of life by diagnosis, adjusted for the factors in Table 2

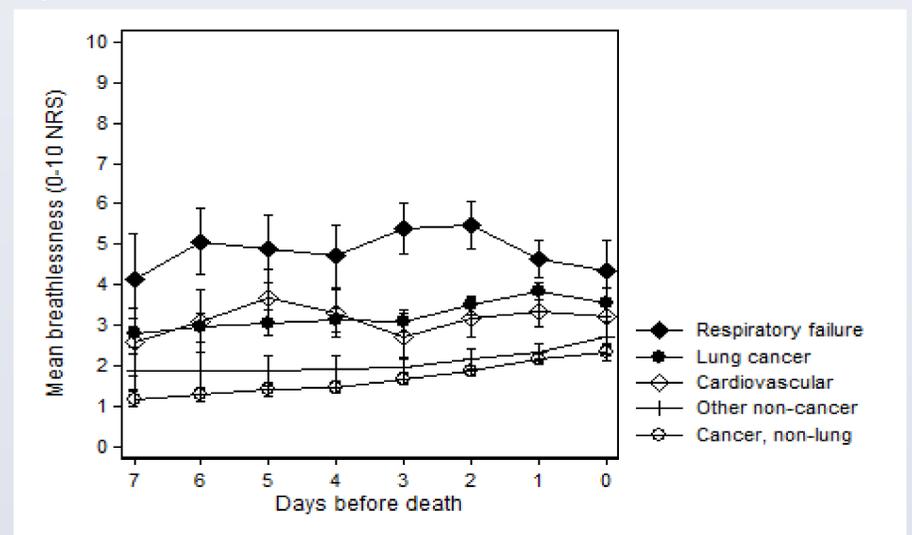


Table 2. Independent predictors of severity of breathlessness
(multivariate linear regression)

Variable	Change in Mean Breathlessness	95% CI	P-value
Day nearer death	0.14	0.12 to 0.17	<0.001
Male gender	0.12	0.02 to 0.22	0.022
Age (per yr)	-0.01	-0.01 to 0.00	0.001
Primary diagnosis			
Cancer, nonlung	Ref		
Lung cancer	1.64	1.46 to 1.74	<0.001
Cardiovascular	1.40	1.15 to 1.64	<0.001
Respiratory failure	3.08	2.79 to 3.36	<0.001
Other noncancer	0.35	0.20 to 0.49	<0.001
AKPS (per 10 points)	0.22	0.18 to 0.26	<0.001
Nausea (per point)	0.12	0.09 to 0.14	<0.001
Pain (per point)	0.17	0.16 to 0.19	<0.001
Phase			
Stable	Ref		
Unstable	0.60	0.42 to 0.77	<0.001
Deteriorating	0.35	0.19 to 0.52	<0.001
Terminal	-0.04	-0.23 to 0.15	0.690
Model intercept			
Intercept	0.30	-0.08 to 0.68	0.117

AKPS = Australia-modified Karnofsky Performance Status; IQR = interquartile range.
Associations with average breathlessness on a 0–10 numerical rating scale in palliative care patients (n = 9759; 13,171 observations) during the last week of life. Associations are estimated using multivariate random-effects linear regression and are adjusted for all other variables in the model.

Conclusion

In specialized palliative care, one in three people experienced significant breathlessness especially in respiratory disease in the final week of life. The mean severity of breathlessness remained stable. Breathlessness was more severe in men, people with lung cancer, better functional status, concurrent nausea, pain, and in clinically unstable patients.

Acknowledgements

Conflicts of interest: None relevant for this work.

The study was recently published: Ekström M, Allingham SF, Eagar K, Yates P, Johnson C, Currow DC. J Pain Symptom Manage 2016; 51(5):816-823.