Original Article

Breathlessness, Functional Status, Distress, and Palliative Care Needs Over Time in Patients With Advanced Chronic Obstructive Pulmonary Disease or Lung Cancer: A Cohort Study

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Abstract

Context. Breathlessness is a distressing symptom in advanced disease. Understanding its patterns, burden, and palliative care (PC) needs over time is important to improve patients' quality of life.

Objectives. To describe and compare the courses of refractory breathlessness, functional status, distress, and PC needs in patients with advanced chronic obstructive pulmonary disease (COPD) or lung cancer (LC) over time.

Methods. This was a cohort study of patients with COPD (Stage III/IV) or LC. Data were assessed monthly with up to 12 telephone interviews, using the modified Borg Scale, Karnofsky Performance Status Scale, Distress Thermometer, and Palliative care Outcome Scale as outcomes measures. Descriptive analysis compared all outcomes between COPD and LC at baseline and over time (forward from study entry and backward from death).

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Results. A total of 82 patients (50 COPD and 32 LC), mean (SD) age of 67.2 (7.8), and 36% female were included (8 COPD and 23 LC deceased). The patients with COPD perceived higher levels of breathlessness and distress at lower functional status steadily over time. The LC patients' breathlessness, distress, and PC needs increased, whereas functional status decreased toward death. The PC needs were similar between disease groups. Breathlessness was negatively correlated with functional status (COPD = mean r = -0.20, P = 0.012; LC = mean r = -0.277, P = 0.029) and positively correlated with PC needs in COPD patients (mean r = 0.343, P < 0.001). Death was significantly predicted by diagnosis (LC: hazard ratio = 7.84, P < 0.001) and functional status (10% decline: hazard ratio = 1.52, P = 0.001).

Conclusion. The PC needs of patients with advanced COPD are comparable with LC patients, and breathlessness severity and distress are even higher. The care for COPD patients requires further improvement to address symptom burden and PC needs. J Pain Symptom Manage 2014; ■. ■ ■. © 2014 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Key Words

Dyspnea, functional status, distress, needs assessment, palliative care, chronic obstructive pulmonary disease, lung cancer, cohort study

Introduction

Symptoms such as pain, breathlessness, or nausea are common in patients with lifelimiting diseases and can have a substantial impact on functional status and quality of life. 1-4 Previous research examining the prevalence and impact of symptoms in palliative care (PC) settings has predominantly focused on patients with cancer. However, awareness of the high symptom burden and PC needs of patients with life-limiting noncancer diseases, pulmonary chronic obstructive (COPD), is growing, as recent data suggest that symptom burden and negative impact on quality of life associated with COPD are similar to and perhaps greater than those associated with cancer.⁵ The need for a PC approach for this population has become more and more evident.^{5–8} The COPD is highly prevalent worldwide, causing major morbidity and impact on quality of life when associated with somatic symptoms, distress, and loss of function. 9-11 Breathlessness (dyspnea, shortness of breath, or difficult breathing) is a common, complex, and distressing symptom in advanced diseases and is probably the most dominant symptom in COPD and also common in lung cancer (LC), with prevalence increasing up to 94% in advanced COPD and 70% in LC. 1,9,12,13 Breathlessness is defined as "a subjective experience of breathing discomfort

that consists of qualitatively distinct sensations that vary in intensity. Experience derives from interactions among multiple physiological, psychological, social and environmental factors and may induce secondary physiological and behavioral responses." ¹⁴ Breathlessness is considered refractory when it persists despite optimal treatment of the underlying condition; it may occur as continuous (breathless all the time) or episodic breathlessness. ^{15–17}

Understanding the patterns of breathlessness, functional performance, distress, and PC needs over time is important to provide needsbased care and to improve quality of life for all people living with life-limiting diseases toward the end of life. Results of a previous observational study assessing breathlessness in cancer compared with COPD patients suggested that trajectories differ between the disease groups and, moreover, between population and individual levels. However, the time frame of observation was limited to six months; additional information on the impact and PC needs of patients over time is warranted.

The present cohort study was initiated to fill this gap. The primary objective of this study was to describe and compare the courses of refractory breathlessness in patients with advanced COPD or LC over time. The secondary objective was to explore the relationships

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