Original Article

Breathlessness During the Last Week of Life in Palliative Care: An Australian Prospective, Longitudinal Study

Magnus Ekström, MD, PhD, Samuel F. Allingham, BMath(Hons), Kathy Eagar, MA, PhD, FAFRM(Hon), Patsy Yates, PhD, RN, FAAN, FACN, Claire Johnson, PhD, RN, and David C. Currow, BMed, MPH, PhD, FRACP, FAHMS

Discipline, Palliative and Supportive Services (M.E., D.C.C.), Flinders University, Adelaide, South Australia, Australia; Division of Respiratory Medicine & Allergology (M.E.), Department of Clinical Sciences, Lund University, Lund, Sweden; Palliative Care Outcomes Collaboration (S.F.A., K.E.), Australian Health Services Research Institute, University of Wollongong, Wollongong, New South Wales; School of Nursing (P.Y.), Institute of Health and Biomedical Innovation, Queensland University of Technology, Brisbane, Queensland; and The Cancer and Palliative Care Research and Evaluation Unit (C.J.), School of Surgery, The University of Western Australia, Perth, Western Australia, Australia

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-demographic factors associated with breathlessness in the last week of life in patients receiving specialist palliative care.

Methods. This was a prospective, longitudinal cohort study using national data on specialist palliative care from the Australian Palliative Care Outcomes Collaboration. We included patients in the Australian Palliative Care Outcomes Collaboration who died between July 1, 2013 and June 30, 2014 with at least one measurement of breathlessness on a 0−10 numerical rating scale 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 (numerical rating scale ≥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, 2.8−3.4).

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. J Pain Symptom Manage 2016;■:■−■.

Key Words

Dyspnea, mortality, palliative care, terminal care, respiratory insufficiency, risk factors, cohort studies

Introduction

More than 50% of people experience breathlessness at the end of life (EOL).[1] These people have a range of life-limiting illnesses, not limited to cardiorespiratory diseases. Many people at the EOL have several clinical conditions that contribute to progressive breathlessness.[1] The prevalence and severity of

Address correspondence to: Magnus Ekström, MD, PhD, Discipline of Palliative and Supportive Services, Flinders University, Adelaide, South Australia, Australia. E-mail: pmekstrom@gmail.com

Accepted for publication: December 2, 2015.

0885-3924/$ - see front matter
http://dx.doi.org/10.1016/j.jpainsymman.2015.12.311

breathlessness at the EOL varies widely between individuals with apparently similar disease processes.[2]

Breathlessness is a feared symptom at the EOL, especially in people with respiratory disease.[3] It impairs quality of life, well-being, and function.[4,5] For patients and their caregivers, it is a symptom that continuously reminds people of impending death.[6] Breathlessness has been reported to worsen in people with advanced disease especially in the last months of life despite evidence-based, symptomatic treatments.[4,5,7] People with worsening breathlessness particularly fear that they may suffocate.[7] Half of all caregivers perceive that the person for whom they were caring was "uncomfortable" or "very uncomfortable" in the last two weeks of life.[8]

Little is known about breathlessness in the last week of life, including any factors that may help to predict higher levels of symptom prevalence or distress.[9,10] Understanding the temporal patterns of breathlessness at the EOL and clinical-demographic factors associated with breathlessness could help to improve the quality of care that is offered.

Previous studies have focused on breathlessness over longer periods, often with few observations in the last hours or days of life. From a large, representative, prospectively collected longitudinal database, are there factors that a clinician could identify that put people at higher risk of more severe breathlessness at the EOL? Such knowledge would be important to ensure optimized symptom control. The aim of this study was to describe the patterns of breathlessness by level of distress and underlying life-limiting illness in the last week of life and to identify any subpopulations that may be at particular risk for more severe breathlessness. The null hypothesis was that there are no identifiable factors associated with worse breathlessness in the last week of life.

Methods

Study Design and Population

This was a prospective, longitudinal cohort study using data from the Australian Palliative Care Outcomes Collaboration (PCOC).[11] The PCOC is funded by the Australian Government Department of Health and collects point-of-care data in specialist palliative care services across Australia including inpatient and community-based care.[11] Data were included from all participating services that routinely collected symptom severity data. The database has been used in previous reports.[11,12]

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

Data Collection

Services participating in the PCOC (inpatient, consultative, and community settings) provided data for each patient's demographic characteristics, underlying disease, setting of care, and clinical assessments at each change in the Palliative Care Phase (hereinafter "phase"), with services assessing patients each day they were seen.

Phase includes four clinically relevant categories that describe each patient's palliative care trajectory: stable; unstable; deteriorating; and terminal. The criteria for the start and end of each phase were recently validated and updated, and the latest version was used in this study.[12] A new phase was assigned whenever a clinical change required patient/family reassessment or modification of the care plan.[11,12]

The standardized assessment included functional status (Australia-modified Karnofsky Performance Status [AKPS]),[13] and distress from each of seven symptoms using the Symptoms Assessment Scale: appetite problems; bowel problems; breathing problems; fatigue; nausea; pain; and difficulty sleeping.[14] The Symptoms Assessment Scale measures the severity of the distress from each symptom over the previous 24 hours on a numerical rating scale (NRS) between 0 ("absent or no distress") and 10 ("worst possible distress").[14] Scores were rated by self-report if possible or by proxy.[15,16] Some symptom assessments (6%) were recorded using the Edmonton Symptom Assessment System (0−10 NRS of severity) because of local routines. The Edmonton Symptom Assessment System assessments were included as a sensitivity analysis; including/excluding them yielded consistent findings.

Ethical Considerations

The PCOC was approved by the Human Research Ethics Committee of the University of Wollongong (approval ID: HE06/045). As routine clinical data were collected, separate consent was not required.

Statistical Analyses

Data were tabulated using frequencies and percentages for categorical variables, or mean with SD, and median with range or interquartile range for continuous variables with normal and skewed distribution, respectively.

The primary outcome was distress from breathlessness during the seven days before death. All measurements for all patients were included in the analysis. Patients with only one measurement were included as they contributed to the estimation of the average breathlessness level and association for factors that vary between patients. No data were imputed.

Breathlessness was analyzed in two ways: as average scores and as percentages of the distress categories: