Original Article

Correlates and Predictors of Changes in Dyspnea Symptoms Over Time Among Community-Dwelling Palliative Home Care Clients

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Abstract

Context. Dyspnea is a frequently reported and highly distressing symptom for persons nearing end of life, affecting the quality of living and dying.

Objectives. This study described health and clinical characteristics of persons experiencing dyspnea who receive palliative home care services and identified factors affecting change in dyspnea over time.

Methods. Anonymized assessments (N = 6655 baseline; 959 follow-up) from the interRAI palliative care assessment instrument (interRAI PC) were collected during pilot implementation (2006−2011). Triggering of the interRAI PC dyspnea clinical assessment protocol was used to indicate presence of dyspnea. Bivariate and logistic regression analyses described risk and protective factors for developing new dyspnea and for recovery from dyspnea at follow-up.

Results. At baseline, 44.9% of persons exhibited dyspnea. Dyspnea was more prevalent among older adults, males, persons with shortened prognoses, and persons without cancer. Persons with dyspnea were more likely to experience functional impairment, moderate cognitive impairment, fatigue, weight loss, and urinary incontinence. Among persons with dyspnea at baseline, 31.5% recovered from dyspnea at follow-up. In contrast, 31% of persons without dyspnea at baseline reported new dyspnea at follow-up. Risk factors for developing new dyspnea included smoking, fatigue, and receiving oxygen therapy.

Conclusion. Results highlight that dyspnea is not inevitable as persons progress toward death. Accordingly, dyspnea should be identified and prioritized during the care planning process. Integrated approaches using the interRAI PC dyspnea clinical assessment protocol may assist clinicians to make informed decisions addressing dyspnea at the person-level and thereby improve quality of life at the end of life.   J Pain Symptom Manage 2015;■:■−■. © 2015 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words
interRAI palliative care assessment instrument, end of life, community-based care, shortness of breath, clinical assessment protocol

Introduction

Dyspnea, also referred to as breathlessness or shortness of breath, is a frequently reported and highly distressing symptom affecting multiple aspects of daily life for persons nearing end of life.[1−3] It can cause anxiety and fear for both the person and their significant others, which in turn increase risk of social isolation and adverse outcomes.[4,5] Estimated prevalence rates for dyspnea vary from 3% to 25% in the general population[6] and from 16% to 80% among persons with life-limiting illnesses.[1,7] In the last six weeks of life, it is estimated that 70% of persons receiving palliative care experience dyspnea, and this increases to 90% during the active dying phase.[8] Despite the high prevalence of dyspnea and the severity of distress it can cause, attention to dyspnea in the literature is lacking.[9,10]

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The philosophy underpinning many palliative care programs prioritizes that persons nearing end of life receive the highest quality of care possible to relieve pain and distressing symptoms such as dyspnea. The World Health Organization advocates that comprehensive assessment is essential to provision of person-centered care for the "total person" or "whole self."[11]

The subjective nature of dyspnea can make diagnosis of its underlying causes challenging. Moreover, the complex pathophysiology of dyspnea is still not fully understood, leaving its origins open to multiple interpretations. Dyspnea may result from interactions involving physiological, psychological, social, and environmental factors.[12] Currently, there is no clearly accepted ideal measurement scale for dyspnea for persons nearing end of life[13] and no universally recognized evaluation criteria.[14]

It is recommended that identification of dyspnea based on self-report by the person and, where possible, on physical assessment, consider onset and frequency of the experience, absence/presence of anxiety, and level of difficulty breathing.[15] Self-report is important to assess the severity of dyspnea and to determine any subjective effects it may have on the person's health and quality of life (QOL).[16] The American College of Chest Physicians noted that clinicians should routinely ask about and document client self-reported frequency and intensity of dyspnea and that assessment investigates not only distress but also meaning and unmet needs that accompany dyspnea.[16]

High-quality palliative care to address distressing symptoms relies on clinicians' ability to recognize and prioritize those symptoms. In the absence of detailed assessment, distressing symptoms, like dyspnea, may remain undetected.[17,18] During the care planning process, it is useful for clinicians to combine clinical judgment with a comprehensive, standardized assessment to identify distressing symptoms affecting both the persons with the life-limiting illness and their informal support network.[19] Reliance solely on self-report may not be adequate. White et al.[18] found that nearly two-thirds of all symptoms experienced at the end of life were not reported by patients. Among persons receiving palliative care, the number of symptoms detected using systematic assessment was 10 times higher than those volunteered during the initial patient interview. Therefore, comprehensive clinical assessment is a useful support to inform the care planning process; support a person-driven goal setting process; and improve care team communication with the persons and their informal support network.

This study aimed to 1) investigate the prevalence of dyspnea among persons who receive palliative home care services; 2) describe how those who experience dyspnea differ from those who do not; and 3) examine changes in dyspnea over time. Health and clinical characteristics, as well as levels of health service utilization associated with dyspnea, were examined, and predictive factors affecting development of new dyspnea and recovery from dyspnea over time are described.

Methods

This secondary analysis used de-identified interRAI palliative care (interRAI PC) assessment data for 6655 unique persons completed between 2006 and 2011 from palliative home care clients aged 18 years or older who resided in Ontario, Canada. Assessments were collected during regular clinical care across six Community Care Access Centres (CCACs) in Ontario, Canada as part of the pilot implementation of the interRAI PC. CCACs coordinate service allocation for persons requiring specialized services and support, including palliative care, connecting the person with the needed services and support. The six pilot CCAC sites each serve a different geographic region in the province of Ontario and include both rural and urban populations. Follow-up assessments were available for 959 persons.

The interRAI PC, a comprehensive, standardized assessment instrument, addresses 17 key domains, including demographic/intake information, diagnoses, health conditions, physical and psychological functioning, and social and emotional well-being, based on 280 unique assessment items.[20] Trained case managers complete assessments using information from multiple sources including communication with and direct observation of the person; consultation with members of the informal support network (family, caregivers) when appropriate; discussions with the health care team; and attention to personal health records. Previous studies have shown the interRAI PC has excellent inter-rater and test-retest reliability.[20,21]

The assessor first used client self-report to assess the level of dyspnea over the last three days: absence of symptom; absent at rest but present when moderate activities performed; absent at rest, but present when normal day-to-day activities performed; and present at rest. If the client was unable to self-report whether they were experiencing dyspnea, assessors were instructed to review available clinical records and consult with the client's health care team, family, and informal caregivers.[22]

For this study, presence or absence of dyspnea was based on triggering or not triggering the interRAI PC dyspnea clinical assessment protocol (CAP).[23,24] The dyspnea CAP assists clinicians in recognizing