Original Article

Loss of Dignity in Severe Chronic Obstructive Pulmonary Disease

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Abstract

Context. The maintenance of dignity is an important concept in palliative care, and the loss of dignity is a significant concern among patients with advanced cancer.

Objectives. The goals of this study were to examine whether loss of dignity is also a concern for patients receiving interdisciplinary rehabilitation for Stage III or IV chronic obstructive pulmonary disease. We examined the prevalence and correlates of loss of dignity and determined whether it improves with treatment.

Methods. Inpatients underwent a structured interview inquiry around their sense of dignity and completed measures of pulmonary, physical, and psychological function at admission ($n = 195$) and discharge ($n = 162$).

Results. Loss of dignity was identified as a prominent ongoing concern for 13% of patients. It was correlated with measures of depression and anxiety sensitivity, but not with pulmonary capacity or functional performance. A robust improvement in loss of dignity was demonstrated, with 88% of those who reported a significant problem at admission no longer reporting one at discharge.

Conclusion. The prevalence of a problematic loss of dignity among patients with severe chronic obstructive pulmonary disease is at least as high as among those receiving palliative cancer care. Loss of dignity may represent a concern among people with medical illnesses more broadly, and not just in the context of "death with dignity" at the end of life. Furthermore, interdisciplinary care may help to restore a sense of dignity to those individuals who are able to participate in rehabilitation. J Pain Symptom Manage 2016;51:529—537. *© 2016 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.*

Key Words
Loss of dignity, chronic obstructive pulmonary disease, rehabilitation, depression, anxiety

Introduction

Chronic obstructive pulmonary disease (COPD) is the fourth leading cause of death in the U.S. and the sixth leading cause of years lived with disability.[1] For those with established COPD, the recommended treatment includes interdisciplinary rehabilitation that incorporates education about illness self-management and enhancement of functional performance.[2–6] Even with rehabilitation, however, COPD is not curable, and the underlying airways disease is generally irreversible.

Although there is evidence that those with severe COPD also could benefit from palliative care,[7–10] frameworks for its implementation are not well explored. Some investigators have suggested that models developed for patients with cancer represent a reasonable starting point for considerations of palliative care in COPD.[11] Where this has been done, studies have found that the symptom profile of COPD overlaps with that of lung cancer. Breathlessness is a common primary symptom, followed by drowsiness, lack of energy, and cough.[11] Although

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the prognosis of patients with severe COPD is less certain than for those with advanced cancer,[12] patients with Stage III and IV COPD survive nearly five times as long, on average. Thus, palliative care needs are likely to arise earlier in the disease trajectory.[7]

One unique aspect of palliative care is an emphasis on existential concerns. Although prominent existential crises are not universal among the terminally ill,[13–20] when they do arise, they can be difficult to manage.[21,22] Among existential sources of suffering, the loss of dignity has emerged as a central consideration in palliative care, as is reflected in the popular term "death with dignity." Dignity has been defined as "the quality or state of being worthy, honored, or esteemed."[23] Although the preservation of dignity is valued highly in the context of life-threatening illness, few studies have actually examined concerns about dignity from an empirical perspective.[14,15,20,24,25] This small body of research has found that the majority (54%–75%) of patients receiving palliative care for cancer report no loss of dignity, with another 15%–40% reporting a minor loss. Only 5%–10% of patients report that loss of dignity is a clinically significant and ongoing concern, which Chochinov et al.[14] have described as a "fractured" sense of dignity. Importantly, however, these individuals report more difficulties with self-care activities, are more likely to feel depressed and anxious, and to regard themselves as having become a burden to others.[14]

The disability caused by COPD, its symptomatic comparability to lung cancer, and a small body of qualitative research suggest that the loss of dignity may also be a concern for this population.[26–28] On the other hand, the longer survival expectancy with COPD, and the emphasis on active rehabilitation, indicates that the study of dignity could perhaps be broadened beyond an explicit focus on the end of life. In addition, there is no evidence as to whether the loss of dignity is amenable to change with appropriate intervention. These issues represent the main objectives of this study: 1) to examine whether loss of dignity is a relevant construct in COPD, by identifying its prevalence and correlates among individuals with severe airways disease, and 2) to examine whether the loss of dignity changes with pulmonary rehabilitation.

Methods

Participants

Study participants were 195 inpatients with Stage III (severe) or IV (very severe) COPD who were admitted to a pulmonary rehabilitation program. Program admission required at least one of the following criteria: 1) recent hospitalization or emergency visit because of dyspnea; 2) seeking improvement to quality of life affected by dyspnea; 3) forced expiratory volume in 1 second (FEV_1) between 15 and 70% of predicted values; or 4) supplemental oxygen use.

Design

Hospital records were reviewed for data concerning pulmonary, physical, and psychological function, both at program admission and discharge. Chart reviews included all eligible patients from 2007 to 2011, with approval from the Ottawa Health Science Network Research Ethics Board.

Program

The program was a structured interdisciplinary pulmonary rehabilitation program based on Global Initiative for Chronic Obstructive Lung Disease and Canadian Thoracic Society guidelines.[29,30] Patients were seen as inpatients over the course of four five-day weeks by clinicians from a range of rehabilitation disciplines, including respirologists, clinical dieticians, nurses, occupational therapists, psychologists, physiotherapists, respiratory therapists, and social workers.

Measurements

Pulmonary: spirometry. Spirometric measures included FEV_1 and forced vital capacity (FVC), which represent exhalation volumes in the first second after full inhalation and after complete exhalation. Predicted values of respiratory parameters (FVC%, FEV_1%) were based on a Canadian reference sample.[31]

Functional: Exercise Performance

Six-Minute Walk Test. The Six-Minute Walk Test (6MWT)[32] requires patients to walk unaccompanied for a period of six minutes on a flat 30-m surface, while distance is measured. Although slowing or resting is permitted, symptoms of chest pain, intolerable dyspnea, staggering, or pale or ashen appearance are contraindications for continuation of this test.[32] As contraindications were prevalent in this sample; only 66 patients completed the 6MWT at admission.

Non-Stop Walk Test. The Non-Stop Walk Test (NSWT) is an alternative measure of functional capacity used with patients for whom the 6MWT is contraindicated. Patients are asked to walk for 20 minutes at a self-selected pace without pauses, rests, or stops, while distance covered is measured. All 195 patients completed the NSWT at admission.

Stair Climbing. Stair climbing represents an important activity of daily living and can be used as a standard measure of functional capacity.[33] Patients are

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