

Original Article

Relationship Between Symptom Burden, Distress, and Sense of Dignity in Terminally Ill Cancer Patients

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Abstract

Context. Maintaining a sense of dignity in terminally ill patients and enabling a dignified dying are important aims of palliative care.

Objectives. To evaluate the impact of symptom burden, distress, overall condition, and individual patient characteristics on self-perceived dignity in terminally ill cancer patients.

Methods. In this cross-sectional study, 61 patients were recruited through a palliative care inpatient ward within 48 hours after admission. Patients completed the Patient Dignity Inventory, a modified version of the Memorial Symptom Assessment Scale, the National Comprehensive Cancer Network Distress Thermometer, and a single-item scale rating subjective of overall condition. Sociodemographic parameters and performance status were taken from the patients' records.

Results. Dignity total score correlated highest with lack of energy ($P < 0.001$), anxiety ($P < 0.001$), sadness ($P = 0.002$), pain ($P = 0.009$), shortness of breath ($P = 0.019$), irritability ($P = 0.023$), thirst ($P = 0.029$), and tiredness ($P = 0.041$). Psychological symptoms showed more consistent associations with the different dignity dimensions than physical symptoms except for the dependency dimension. Psychological distress correlated with all dignity dimensions: symptom distress ($P < 0.001$), existential distress ($P < 0.001$), dependency ($P = 0.020$), peace of mind ($P < 0.001$), and social support ($P = 0.024$). Overall condition was significantly associated with existential distress ($P = 0.013$), but not with symptom distress, dependency, peace of mind, or social support. Performance status showed significant association with dependency ($P = 0.001$).

Conclusion. Self-perceived dignity in terminally ill cancer patients is significantly associated with physical as well as psychological symptoms, distress, overall condition, performance status, and comorbidities. Knowledge of these specific interactions is essential for adequate, comprehensive palliative

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Key Words

Dignity, self-perceived dignity, dignity-related distress, terminally ill, advanced cancer, palliative care, symptom burden, distress

Introduction

In the palliative care setting, maintaining a sense of dignity is essential for patients and caregivers, given the physical and psychosocial changes involved with illness experience.^{1,2} A growing body of research has conceptualized and investigated the states of psychological and existential distress in patients with severe physical illness to increase our knowledge and ensure comprehensive end-of-life care.^{3–9} According to Steinhäuser et al^{10,11} as well as Proulx and Jacelon,¹² a “good death” is characterized by adequate pain and symptom management, clear decision making, preparation for death, completion, contributing to others, and affirmation of the whole person, as well as to be treated with continuous respect for the patients’ and caregivers’ needs including physical, psychological, social, and spiritual aspects.^{13,14} Allowing the patient to die with dignity is a fundamental value of comprehensive palliative and end-of-life care and contributes to a good death.¹⁵

In contrast to the high relevance of dignity in the individuals’ perspective on their own dying and previous efforts to characterize perceived sense of dignity,^{2,16} there are little empirical data on the perception of dignity among dying patients. Obviously, psychological states such as feelings of help- and hopelessness, despair, and loss of sense of dignity are closely interrelated, yet the association between sense of dignity, demographic factors, and psychosocial factors has been little examined so far in patients with advanced cancer.

In the last decade, Chochinov et al² have systematically analyzed dignity in terminally ill patients. In a cross-sectional study, 50 terminally ill cancer patients receiving specialized palliative care on an inpatient or outpatient basis were interviewed consecutively over a time period of 15 months. They were asked about their subjective definition of dignity with respect to their disease experience, as well as about the factors or experiences that have

increased or decreased their own perception of dignity.^{16,17} Based on this study, Chochinov et al¹⁶ developed an empirical model of dignity in terminally ill patients including three categories of factors determining dignity, namely: illness-related concerns including the level of independence and physical and psychological symptom distress, dignity-conserving repertoire, and social dignity inventory.^{2,18,19} Based on this model, Chochinov et al²⁰ designed and validated a dignity assessment tool for terminally ill patients, the Patient Dignity Inventory (PDI), and developed a psychotherapeutic intervention, which became to be known as dignity therapy, in terminally ill patients with proven benefit for the patients’ distress and end-of-life experiences.^{21–28}

The purpose of this study was to analyze the relationship between physical and psychological symptom burden, distress, the patient’s overall medical condition, individual patient characteristics, and the sense of dignity in terminally ill cancer patients. We aim to further elucidate the complex system of individual, disease-related, symptom-related, and psychosocial factors interacting with the patient’s subjective perception of dignity.

Methods

Inclusion Criteria

Patients suffering from incurable and progressive cancer who were admitted to the inpatient palliative care ward of the University Medical Center Hamburg-Eppendorf, Germany, were eligible for the study. Admission to the inpatient palliative care ward was possible for incurably ill patients with the presence of significant physical and psychosocial symptoms prohibiting further care at home or in nonspecialized inpatient wards. Patients were excluded if they were delirious or otherwise cognitively impaired (based on clinical consensus) and unable to read or speak

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