Brief Methodological Report

Demoralization Scale in Spanish-Speaking Palliative Care Patients

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Abstract

Context. Among the approaches to the demoralization syndrome, the one proposed by Kissane et al. is prevalent in the literature. These authors developed the Demoralization Scale (DS) to assess emotional distress, conceived as demoralization.

Objectives. To present the Spanish adaptation of the Demoralization Scale in palliative care patients, with a new and more comprehensive approach to its factorial structure.

Methods. A cross-sectional study was carried out in 226 Spanish palliative care patients in three different settings: hospital, home care unit, and continued care unit. Outcome measures included the DS and the Hospital Anxiety and Depression Scale. Analyses comprised confirmatory factor analyses to test the original, German, and Irish structure of the DS, exploratory structural equation modeling (ESEM), estimations of internal consistency, and multivariate analyses of variance for criterion-related validity.

Results. The confirmatory factor analyses showed inappropriate fit for the previous structures when studied in the Spanish version of the DS. With ESEM, the best fitting structure was the five-factor solution, without item 18. Reliability results offered good estimations of internal consistency for all the dimensions except for sense of failure. Cronbach alpha coefficients were appropriate for the dimensions of loss of meaning (0.86), helplessness (0.79), disheartenment (0.88), and dysphoria (0.80), but low reliability was found for sense of failure (0.62). Convergent and discriminant validity showed positive correlations between demoralization, anxiety, and depression. Patients with higher levels of anxiety had higher scores on every dimension of demoralization, and those with higher levels of depression had higher scores on loss of meaning, disheartenment, and sense of failure, but not on dysphoria or helplessness.

Conclusion. The Spanish adaptation of the DS has shown appropriate psychometric properties. It has been useful to differentiate between depression and the demoralization syndrome, pointing to helplessness and dysphoria as unique characteristics of demoralized palliative care patients. J Pain Symptom Manage 2016;51:769–775 © *2016 Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine.*

Key Words
Demoralization, depression, confirmatory factor analyses, exploratory structural equation models

Introduction

Demoralization has been a topic of discussion in palliative care for the last few years. Several authors have devoted great efforts to consolidate the concept of demoralization, posing its existence as a psychiatric syndrome.[1–9] These works have pointed out the need of advances in the assessment, diagnosis, and treatment of demoralization in palliative care.[2,3] According to Clarke et al.,[4] the concept of demoralization was originally proposed by Jerome Frank, who described such patients as impotent, isolated, despairing, alienated, rejected, and with low self-esteem. To further characterize the concept of demoralization, De Figueiredo and Frank[5] proposed that the clinical hallmark of demoralization is "subjective incompetence." As such, demoralization involves this subjective incompetence and symptoms of distress, such as depression,

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anxiety, resentment, or anger. In this line, some definitions have been offered to differentiate demoralization from similar constructs.[6,7] Despite its prevalence, which has ranged from 20.6% to 33.3% in different studies,[3] demoralization has not been included in the traditional psychiatric classification system.[8] Consequently, demoralization is a hurdle when facing existential threat, constituting a problem for clinicians in their efforts to restore patients' morale, meaning, and purpose.[7–9]

The availability of a psychometric measure of demoralization is essential for the accurate diagnosis of this condition and inform about treatment success.[7,10] Taking this into account, several authors have developed a wide range of demoralization assessment instruments, for example, the Psychiatric Epidemiology Research Interview,[11] the Minnesota Multiphasic Personality Inventory, version 2,[12] the Diagnostic Criteria for Psychosomatic Research,[13] and the Demoralization Scale (DS).[14] Among them, Kissane et al.'s DS is the most used for demoralization assessment in palliative care.

The DS is a five-point Likert-type scale used to measure how strongly the respondent agrees with each of the items. The DS was designed to explore the existence of demoralization and assist treatment[14] and was initially tested in 100 patients with advanced cancer. Its factor structure involved five facets: loss of meaning in life, dysphoria, disheartenment, helplessness, and sense of failure. Additional studies on the DS's reliability and validity have been done,[15–18] and the scale has been translated and adapted to several languages: Dutch, German, Hungarian, Italian, Mandarin, Lithuanian, and Portuguese. Most of the studies have found adequate levels of internal consistency. Kissane et al. found a Cronbach alpha of 0.94 for the whole scale, and alphas of 0.71–0.89 for the different dimensions.[14] Other evaluations have found similar results, between 0.72 and 0.93 or 0.76–0.88.[15,16] However, the Italian version showed lower levels of internal consistency, with values for the different dimensions ranging from 0.50 to 0.84.[18] The establishment of criterion-related validity also has remained a problem, as there is a high level of convergence between depression and demoralization, and different studies have used different instruments.

Much of the controversy appears when the factorial structure is under study. In its original development, Kissane et al.[14] found a five-factor structure and proposed the dimensions of loss of meaning and purpose, dysphoria, disheartenment, helplessness, and sense of failure. Mullane et al.,[15] and Hung et al.,[17] when adapting the DS for Irish and Mandarin, respectively, again found a five-factor structure, but with variations in the items that composed each dimension. The German version, presented by Mehnert et al.,[16] reduced the structure to four dimensions, by redistributing the items of helplessness, together with other changes in the rest of factors. Overall, the DS has shown appropriate psychometric properties, but with some contradictory results regarding its structure.

Further research on the DS structure should be done focusing on the statistical approach and the problematic factorial stability. To date, DS research has relied on exploratory factor analysis (EFA), but confirmatory factor analyses (CFAs) have not been considered. Additionally, the DS structure has been studied using procedures designed for continuous items, although the response format is a Likert-type one. Thus, new analyses would clarify the factorial validity of the scale.

From a new and more comprehensive approach to the study of the factor structure, the aim of the present study was to offer confirmatory evidence on the adaptation of the DS, in its application to a sample of Spanish-speaking palliative care patients.

Methods

Sample

In this cross-sectional study, data were collected from 226 cancer and noncancer palliative-assisted patients in different settings: hospital (Oncology, Internal Medicine, Pneumology, etc.), home care unit, and continued care unit, of the Hospital General Universitario de Valencia. Once we obtained permission from the Hospital Ethics Committee and patients and relatives gave their informed consent, 226 patients were assessed for eligibility. The inclusion criteria were as follows: 1) patients who had been identified as palliative, admitted to hospital; 2) adult patients (18 years or older); and 3) patients with advanced/terminal illness. The exclusion criteria were as follows: 1) less than two weeks of predicted survival and 2) cognitive impairment (comprehension/expression problems).

Instruments

Participants completed a survey, which included, among other tools, the DS. The DS was adapted to Spanish with the forward-backward translation method by bilingual speakers, as recommended by the European Organization for Research and Treatment of Cancer.[19] The Spanish version of the DS is available in Appendix.

The original DS comprises 24 items, forming five factors: loss of meaning and purpose, dysphoria, disheartenment, helplessness, and sense of failure. They are measured using a five-point Likert scale,