Brief Methodological Report

Multicenter Study of the Psychometric Properties of the New Demoralization Scale (DS-II) in Spanish-Speaking Advanced Cancer Patients

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Abstract

Context. Demoralization is a state of existential distress in patients with advanced illness, typically with coping difficulties, feelings of loss of sense, and purpose in life and despair, among other things. The New Demoralization Scale (DS-II) is an evaluation tool for this syndrome, which has recently been reformulated on a shorter scale.

Objectives. The objective of this study was to obtain a Spanish version of the DS-II and to assess its psychometric properties in advanced cancer patients in Spain and a number of Latin American countries.

Methods. Following a translation−back translation process, a validation study and a confirmatory analysis using structural equation models with their corresponding latent constructs were undertaken. Patients completed the DS-II in Spanish (DS-II (es)), the Hospital Anxiety and Depression Scale, and the Edmonton Symptom Assessment System−revised. Reliability was studied according to internal consistency; construct validity and concurrent validity with the Hospital Anxiety and Depression Scale and the Edmonton Symptom Assessment System−revised; discriminant validity using the Karnofsky Performance Status scale; and feasibility, with response ratio and required time. Cutoff points were established, and sensitivity and specificity were studied.

Results. The DS-II (es) was obtained. One hundred fifty patients completed the validation study. The confirmatory analysis showed coherence, and all items correlated positively with their subscales and with the overall scale. Cronbach's alpha for the DS-II (es) was 0.88, for the sense and purpose subscale 0.83, and for the coping ability 0.79. Demoralization correlated significantly with emotional distress (rho = 0.73, $P < 0.001$). The tool distinguished between patients with diverse functional levels (rho = −0.319, $P = 0.001$). Cutoff points at 10 and 20 out of 32 were established. The scale showed high sensitivity (81.97%) and specificity (80.90%). The prevalence of demoralization was 33% in our sample.

Conclusion. The Spanish version of the new Kissane DS-II demoralization scale has shown to be valid, reliable, and feasible with adequate psychometric properties. J Pain Symptom Manage 2019;57:627−634. © *2018 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.*

Key Words

Advanced cancer patients, validation, psychometric properties, demoralization scale, demoralization syndrome

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Introduction

Demoralization syndrome refers to a situation of existential distress in patients with advanced illness. It is characterized by a sense of feeling trapped which limits coping ability, accompanied by a loss of the sense and meaning of life, of hope, of one's value in life, low moral, and reduced optimism.[1–4] Over the last 2 decades, an increasing interest in demoralization syndrome has been noted.[5]

Its prevalence varies between 13% and 33.3% in patients with cancer or advanced illness, depending on the tools used in its evaluation.[5] Demoralization has negative consequences for the patient and is one of the factors that may be associated with the wish to die.[1,5] Some factors that may influence demoralization are as follows: the perception of loss of dignity and independence, social isolation, loss of purpose, and the growing feeling of dependence, accompanied by the perception of having become a burden.[6]

Demoralization is a treatable condition and its diagnosis may thus help prioritize interventions for its treatment.[5] There are different diagnostic tools: the Diagnostic Criteria for Psychosomatic Research,[7] the Subjective Incompetence Scale,[8] the Short Demoralization Scale,[9] the Demoralization Scale (DS)[1] and its new version, the DS-II.[2]

The Diagnostic Criteria for Psychosomatic Research[7] is a semistructured interview where the professional evaluates whether, over a period of one month or more, the patient has experienced a feeling of inability to cope, feelings of despair, or feelings of not living up to expectations placed in him or her by others.

The Subjective Incompetence Scale[8] diagnoses the incapacity of coping with adverse circumstances related to despair. The Short Demoralization Scale[9] is a five-item scale (loss of the meaning of life, despondency, discouragement, helplessness and the feeling of failure) scored from 0 to 4 on a Likert scale. This scale has only been validated in Spanish, although there is a proposed translation into English.

The DS[1] is self-administered and contains 24 items with scores on a Likert scale from 0 to 4. It is divided into five subscales: loss of purpose, dysphoria, discouragement, helplessness, and the feeling of failure. The same research group has recently validated a short demoralization scale (DS-II), applying a number of changes to the initial scale[2]: The number of items has been reduced from 24 to 16 and scored from 0 to 2 on a Likert scale (0 = never, 1 = sometimes, 2 = all the time), and items were divided into two subscales instead of five, referring to the loss of purpose and to the inability to cope with the illness. Finally, the initial version of DS[1] contained five items out of 24 with positive wording and 19 with negative wording. This fact might reduce the tool's reliability, and in the new validated version of DS-II, all items are negatively phrased. In psychometric tests, the new scale showed good internal consistency. In a systematic review,[5] the DS was the most commonly used scale for demoralization diagnosis.

The aim of our study was to obtain a Spanish language version of DS-II and to verify its psychometric characteristics in a population including patients from various Spanish-speaking countries. We intend to see if the scale is equally feasible, valid, and discriminant for Spanish and for Latin American patients and to study whether cutoff points can be established for different levels of demoralization. To provide evidence for concurrent validity, we expected high associations between emotional symptoms and low associations with physical symptoms. For discriminant validity, we expected lower scores of demoralization for high levels of functionality.

Secondary goals include gaining an insight into the prevalence of demoralization in the study group and examining relations between sociodemographic characteristics.

Methods

Translation and Cultural Adaptation

The process of translation and cultural adaptation was carried out using the procedure of the European Organization for Research and Treatment of Cancer.[10] This implies a process that involves translation and back translation: a translation is done by two bilingual persons, in this instance into Spanish, and a back translation from the same language into the original language by two different bilingual persons. After this process, consensus is sought between the translators until obtaining the Spanish version of the scale. During a pilot study ($n = 40$), a confirmatory analysis was performed using a structural equation model with latent constructs. Each item on the questionnaire was checked and thus, its assignation or not, to the subscales. When the confirmatory analysis detected errors in an item, the translation process was repeated, and further verification was carried out.

Participants

Patients with advanced cancer were recruited from five hospital centers, two in Spain and three in Latin America. The participating patients were seen at 1) Clínica Universidad de Navarra (CUN), 2) Hospital San Juan de Dios, Navarra (HSJD), 3) Hospital Pontificia Universidad Católica de Chile (HPUCC), 4) Hospital Universitario Austral in Buenos Aires (HUA), 5) The Palliative Care Team at Universidad Dr. José Matías Delgado in El Salvador (UJMD).

Selection criteria for the patients were as follows: 1) advanced oncological disease (Stages III and IV), 2)

over 18 years of age, 3) written informed consent, 4) conserved cognitive function according to clinical criteria, 5) able to read and understand Spanish. Those with physical or psychological incapacity to answer or those who did not consent to participate were excluded.

Sample Size Calculation

The sample size required for the validation of the scale was calculated according to the item-subject relationship rule mentioned in the study by Anthoine et al.,[11] which proposes a size of between 1.2 and 10 subjects per item. In our case, as the DS-II scale has 16 items, a minimum of 19 patients and a maximum of 160 patients would be considered. We proposed recruiting 30 patients per center.

Evaluation Tools

Patients completed the DS-II and two other questionnaires: the Edmonton Symptom Assessment System—revised[12] and the Hospital Anxiety and Depression Scale (HADS).[13] These two questionnaires were included to study associations between physical and emotional symptoms and demoralization, so as to estimate the concurrent validity with DS-II. The Edmonton Symptom Assessment System—revised consists of a scale evaluating 10 items (Analogue Visual Scale with scores between 0 and 10), of physical and psychological symptoms frequently seen in advanced cancer patients. The Spanish version of this questionnaire was validated in 2013 with patients from Spain and Guatemala (Cronbach's Alpha 0.86).[12] HADS is an anxiety and depression questionnaire. It consists of 14 items in total, of which seven refer to anxiety and a further seven to depression. Each item has a Likert score from 0 to 4 and a maximum of 21 points for each subscale. As in other studies,[14] the total score of anxiety and depression was used to measure the emotional distress. This tool was also validated in Spanish in 2003 (Cronbach's alpha 0.80—0.87).[13]

Sociodemographic data and clinical information were collected for each patient including the Karnofsky Scale[15] (see Table 1).

Table 1
Characteristics of the Patients ($N = 150$)

Total Patients	$N = 150$	%
Age (*n*, range)	62 (22—97)	
Sex female	71	47.33
Occupation		
Retired	58	38.67
Employed	59	39.33
Homemaker	21	14.0
Other	12	8.0
Educational level		
Without studies	11	7.33
Primary school	39	26.0
Vocational training	27	18.0
High school	17	11.33
University	56	37.33
Marital status		
Single	25	16.67
Married or with a partner	91	60.67
Widower	11	7.33
Separated, divorced	17	11.33
Other	6	4.0
Religious practice		
Practicing and believer	79	52.67
Nonpracticing and believer	61	40.67
Not believer	10	6.67
History of depression	33	22.0
History of anxiety disorder	31	20.67
Functional status (Karnofsky)		
>50	11	7.33
50—70	94	62.67
>70	45	30
Primary tumor		
Gastrointestinal system	49	32.67
Respiratory system	44	29.33
Reproductive system	32	21.33
Excretory system	8	5.33
Hematological	6	4.0
Others	11	7.3
Information		
Suspect or known diagnostic but does not speak	8	5.34
Diagnostic but not prognostic	41	27.33
Diagnostic and prognostic	101	27.33
Treatment received (last three months)		
None	30	20
QT or QT + RT	62 + 17	53
RT	15	10
Other	26	17.33

QT = chemotherapy; RT = radiotherapy.

Data Collection

The study was approved by the Clinical Research Ethical Committees at each of the centers. Data were collected between October 2017 and February 2018. Questionnaires were administered using a personal interview conducted by a researcher who was an expert palliative care health professional (PCHP). In those interviews, the patient scored the items from his or her own perspective and the PCHP interviewer made note of his subjective perception of the interviewee's degree of demoralization (DM-RP) based on the evaluation of the entire interview and without knowing the total questionnaires' scores beforehand. All PCHP researchers were given initial training on demoralization to use similar criteria when noting the degree of demoralization, based on response quality, spontaneous remarks, and the patient's general attitude, particularly regarding their state of mind. In this way, the degree of demoralization was classified as 1) nonpresent demoralization, 2) moderate demoralization, and 3) severe demoralization.

Psychometric Analysis

The reliability of the global scale and of the two subscales (sense-purpose subscale and coping subscale) was estimated by calculating the internal consistency with Cronbach's alpha. Construct validity was verified by studying subscale distribution with confirmatory

analysis using a structural equation model with latent constructs (conducted again to verify that the corrections made after the pilot study were adequate). Concurrent validity was measured between the DS-II (es) and the Edmonton Symptom Assessment System (scores on the overall total and for each item), and the DS-II (es) and the HADS (total HADS score and for each subscale) with Spearman's coefficient correlation. Discriminant validity was estimated by studying the relation between the DS-II (es) and the Karnofsky's index with Spearman's coefficient correlation. The tool's feasibility was studied by examining the response ratio and the time required to complete the scale. Moreover, consideration was made of whether all the people who began the interview actually finished it.

The intention was to establish cutoff points to use as guidelines for the intensity of the syndrome which would add value to the tool as a screening tool. To do this during each interview, the researcher who was a PCHP from each center applied the common criteria mentioned earlier. With Spearman's coefficient between the DS-II (es) and the DM-RP, the strength of association of the two measurements was established. Cutoff points on the scale were then established by means of logistic regression, using as its variable the response classification of degree of demoralization, noted by the PCHP researchers.

Sensitivity and specificity of the DS-II was studied, to detect or reject patients both with and without demoralization, using a single cutoff point (demoralization—no demoralization).

The total demoralization score for the subgroups in each center was compared by means of analysis of variance. Where significant differences were detected, subgroup characteristics were compared using analysis

DS-II (es) SCALE

Por favor indique cuantas veces se ha sentido de esta manera durante las dos últimas semanas rodeando el número correspondiente en cada una de las afirmaciones que siguen:

Afirmaciones	Nunca	Algunas veces	Todo el tiempo	Subescala
1. Lo que puedo ofrecer a otros tiene poco valor	0	1	2	S
2. Mi vida parece no tener sentido	0	1	2	S
3. He perdido mi papel o rol en la vida	0	1	2	S
4. Siento que no tengo control sobre mis emociones	0	1	2	A
5. Nadie me puede ayudar	0	1	2	S
6. Siento que no puedo ayudarme a mí mismo	0	1	2	S
7. Me siento sin esperanza	0	1	2	S
8. Me siento irritable	0	1	2	A
9. No afronto bien la vida	0	1	2	A
10. Lamento muchas cosas de mi vida	0	1	2	A
11. Tiendo a sentirme dolido fácilmente	0	1	2	A
12. Me siento angustiado por lo que me está pasando	0	1	2	A
13. No soy una persona valiosa	0	1	2	S
14. Preferiría no estar vivo	0	1	2	S
15. Me siento bastante aislado o solo	0	1	2	A
16. Me siento atrapado por lo que me está ocurriendo	0	1	2	A
Puntuaciones			**Obtenidos**	**Totales**
A: subescala de capacidad de afrontamiento				**16**
S: subescala de sentido y propósito de la vida				**16**
Desmoralización (<10 ausente, 10-19 moderada, >20 severa)				**32**

Fig. 1. DS-II (es) Scale.

of variance. Finally, correlations between sociodemographic variables and demoralization were compared using Spearman's correlation coefficient.

All statistical analyses were undertaken using STATA 15 (StataCorp LP, College Station, TX). Results with P value < 0.05 were considered significant; in each analysis, the size of the effect was added, for example, Spearman's correlation coefficient (rho).

Results

The Spanish Version of the New DS-II (es)

The pilot study of the first Spanish version was carried out with 40 advanced cancer patients from Navarra and it helped verify the comprehension of the scale (DS-II (es)). Nevertheless, when results were analyzed using the structural equation model with latent constructs, it was seen that Item 10 ("I have a lot of regret about my life" translated as "*tengo muchos remordimientos sobre mi vida*") was the only one which was not significant. The translation–back translation process was repeated, and a new Spanish version of the item was obtained ("lamento muchas cosas de mi vida"). In this way, the final version of the new tool in Spanish was established (DS-II (es)) as seen in Figure 1.

Validation Study and DS-II (es) Psychometric Properties

Each center organized data collection as for their convenience, on a periodical basis (always the same day/second of the week), reviewing the patients that were seen in the service. Then they assessed if they met the inclusion criteria to be offered participation in the study. The study was proposed to a total of 153 patients and 150 completed the validation study (98%). The clinical and sociodemographic characteristics of the patients are shown in Table 1. The average age of the participants was 62 years. The most frequent primary tumors were gastrointestinal (33%) and respiratory (29%). The average Karnofsky index score was 66. The average time since diagnosis was 3.5 years.

Good reliability was obtained for both the complete scale and for the subscales[16]: Cronbach's alpha for the DS-II (es) was 0.88, 0.83 for the sense and purpose subscale, and 0.79 for the coping ability subscale.

Construct validity and concurrent validity were verified with other variables. Confirmatory analysis showed the significant relationship ($P = 0.00$) of all the items in each subscale and the relation between the two subscales. The degree of depression and the degree of demoralization were significantly related ($P < 0.001$, Table 2). There was evidence of very strong relationship between demoralization and emotional distress (sum of anxiety and depression) (rho = 0.73; $P < 0.001$) (Table 3). There was an elevated relationship between demoralization, depression and anxiety (rho = 0.67–0.68, $P < 0.001$) (Table 3). Discriminant validity was shown by observing an inverse correlation with functional status (rho = −0.3198; $P = 0.001$), indicating that a better functionality supposes less demoralization (es) and vice versa.

Table 2
Contingency Table of Depression and Demoralization

	Level of Demoralization			
	Absent	Moderate	Severe	Total
Level of depression				
Normal				
n	85	14	2	101
%	84.16	13.86	1.98	100.00
%	85.00	34.15	22.11	67.33
Moderate				
n	12	13	4	29
%	41.38	44.83	13.79	100.00
%	12.00	31.71	44.44	19.33
Clinical problem				
n	3	14	3	20
%	15.00	70.00	15.00	100.00
%	3.00	34.15	33.33	13.33
Total				
n	100	41	9	150
%	66.67	27.33	6.00	100.00
%	100.00	100.00	100.00	100.00

Chi-square: <0.001.

The DS-II (es) displayed high feasibility. The questionnaire was completed in less than 10 minutes. All the patients who started the questionnaire answered all the questions. None required specialized psychological support after the performance of the scale.

The total scores from the DS-II (es) correlated significantly with the researchers' perceptions about the level of demoralization (rho = 0.64; $P = 0.000$). After verifying significant correlation between them, logistic regression was established with cutoff points at 9/32 and 19/32. In the study population, patients who scored between 10 and 19 were considered as

Table 3
Correlation of Demoralization With Different Clinical Aspects Studied

Clinical Feature	Spearman Correlation Rho	*P*-value
Demoralization (researcher perception)	0.64	<0.001
Anxiety (HADS-A)	0.67	<0.001
Depression (HADS-D)	0.68	<0.001
Emotional Distress (total score of HADS)	0.73	<0.001
Functional status (KPS)	−0.31	<0.001
ESAS total	0.49	<0.001
ESAS depression	0.52	<0.001
ESAS anxiety	0.38	<0.001
ESAS well-being	0.35	<0.001
ESAS drowsiness	0.27	<0.001
ESAS tiredness	0.22	<0.05

HADS = Hospital Anxiety and Depression Scale; ESAS = Edmonton Symptom Assessment System; KPS = Karnofsky.

Table 4
Prevalence of Demoralization in the Populations Studied

	No Demoralization		Mild Demoralization		Severe Demoralization		Total	
Group	*n*	%	*n*	%	*n*	%	*n*	%
HPUCC	24	80%	4	13%	2	7%	30	100%
UJMD	20	67%	9	30%	1	3%	30	100%
HUA	18	60%	10	33%	2	7%	30	100%
CUN	24	80%	5	17%	1	3%	30	100%
HSJD	14	47%	13	43%	3	10%	30	100%
Total	100	67%	41	27%	9	6%	150	100%

HPUCC = Hospital Pontificia Universidad Católica de Chile; UJMD = Universidad Dr. José Matías Delgado en El Salvador; HUA = Hospital Universitario Austral en Buenos Aires; CUN = Clínica Universidad de Navarra; HSJD = Hospital San Juan de Dios.

having moderate demoralization; above 20 was considered severe demoralization. The sensitivity of the DS-II (es) to detect demoralized patients was 81.97% and the specificity was 80.90%, having used a single cutoff point (demoralization—no demoralization) for statistical analysis.

Demoralization Syndrome in the Study Population

In the sample studied, 27% displayed moderate demoralization and 6% severe demoralization (Table 4). Within subpopulations, a significant difference was seen ($P = 0.034$) between results for the DS-II (es) between patients from CUN and HSJD (data not shown).

In Table 5, associations are shown between the DS-II and different variables studied. Significant association was detected with low correlation between demoralization and greater religious practice ($P = 0.01$; rho = −0.20), anxiety ($P = 0.00$; rho = 0.23), and a history of depression ($P = 0.05$; rho = 0.15).

Discussion

After a rigorous translation and validation process, the first Spanish version of the DS-II was obtained and its psychometric properties were evaluated. Our study was undertaken with Spanish and South and Central America patients. The fact that centers were selected for inclusion does not suppose a restriction as regards the tool's validation because participants included represent a population group with diverse sociodemographic characteristics. All the interviewed patients completed it quickly and in full, with no reports of distress. The results of the validation of the Spanish version of the DS-II can be generalized for Spanish-speaking patients.

Table 5
Association Between Demoralization and Sociodemographic and Clinical Characteristics

Clinical Feature	Spearman Correlation Rho	*P*-value
Age	−0.06	0.45
Sex	−0.03	0.68
Marital status	−0.09	0.26
Educational level	−0.04	0.57
Occupation	0.10	0.18
Religious practice	−0.21	<0.05
Illness	−0.02	0.78
History of depression	0.16	<0.05
History of anxiety	0.23	<0.05
Degree of information	−0.03	0.73

We carried out an extensive study on the psychometric properties of the new scale. The feasibility data are excellent and comparable with the original English version,[2] showing almost identical internal consistency, both for the complete scale and for each of the subscales. It was seen that all the items added value on their own subscale and both subscales added to the general scale. It may be considered that the construct in Spanish is equivalent to the English version. Our study, like many others,[17–25] found a very close relationship between demoralization and emotional distress and somewhat less between depression and anxiety. The difference between both constructs was already established when presenting the original DS version,[1] and the same authors recently recalled the utility of demoralization in diagnosis specified for major depression and adjustment disorders.[4] Notwithstanding, construct complementarity with the new tool has been verified because the conditional percentages show, for instance, that the probability of being highly depressed among highly demoralized patients is 33.33%, whereas the probability of being highly demoralized among highly depressed patients is 15%. In our sample, there was also significant, if moderate, correlation detected, with symptomatic load and as expected, demoralization presented itself as a factor that was closer to the emotional component rather than to the physical component. The DS-II discriminated well, with demoralization intensity being significantly inverse to functional levels.

In the obtained sample, the majority of patients, despite being in an advanced stage of illness, presented functional states of between 50 and 70 in the Karnofsky Scale. The negative association between functionality and demoralization might be due to

the fact that one of the factors that may lead to demoralization in the patient refers to the feeling of being a burden or the loss of independence.[6]

Based on the expert researcher's clinical impression arising from the interview on symptoms, state of mind, coping, and the meaning of life, the study suggests that the DS-II might be used as a screening method. It would offer good sensitivity and specificity characteristics with established cutoff points. The way in which the professional's subjective impression of the degree of the patient's demoralization was gathered was independent of the test result because the researcher's clinical impression stated the evaluation of the interview itself.

In the studied populations, between 3% and 10% presented severe demoralization and between 13% and 34% presented moderate levels. Earlier studies reported a prevalence of demoralization of between 13% and 33%, depending on the measurement tool.[5] The DS-II (es), a short questionnaire, makes it possible to identify that group of patients.

Among possible concurrent factors with demoralization, just as in the studies by Mehnert[22] and Passik,[26] religious practice is associated with lower levels of demoralization, although one study did not find that association.[17] Our study shows, for the first time, that an existing history of depression or anxiety disorder is a predisposition for demoralization in advanced illness. Future research may confirm this finding.

The limitations of the study are that on the days when data were collected, the patients admitted to the hospital were not registered, neither the patients excluded nor the reasons of exclusion. Consecutive recruitment would allow finer adjustment of prevalence data, thus avoiding potential selection bias. Other studies should establish the utility of the scale in different groups, with older people or non−life-threatening chronic illnesses.

In conclusion, the Spanish version of the new Kissane DS-II demoralization scale has been shown to be valid, reliable, and feasible with adequate psychometric properties in advanced cancer patients.

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