

Exploring demoralization in end-of-life cancer patients: Prevalence, latent dimensions, and associations with other psychosocial variables

Original Article

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Abstract

Objective. Demoralization is an existential distress syndrome that consists of an incapacity of coping, helplessness, hopelessness, loss of meaning and purpose, and impaired self-esteem. It can affect cancer patients, and the Demoralization Scale is a valid instrument to assess it. The present study aimed to investigate the prevalence of demoralization in end-of-life cancer patients and its associations with the medical and psychosocial variables. In addition, the latent dimensions of demoralization emerging in this distinctive population were explored.

Method. The study is cross-sectional. The sample consisted of 235 end-of-life cancer patients with a Karnofsky performance status (KPS) lower than 50 and a life expectancy of a few weeks. For each patient, personal and medical data was gathered by a palliative physician and a set of validated rating scales, assessing demoralization, anxiety, depression, physical symptoms, pain, spiritual well-being, and dignity, was administered by a psychologist during the first consultation.

Result. Sixty-four participants (27.2%) had low demoralization, 50.2% ($n = 118$) had medium demoralization, and 22.6% ($n = 53$) had high demoralization. Factor analysis evidenced a five-factor solution that identified the following demoralization factors: Emotional Distress and Inability to Cope, Loss of Purpose and Meaning, Worthlessness, Sense of Failure, and Dysphoria. All the considered variables were associated with demoralization, except for pain, nausea, breathing problems, and sociodemographic and clinical variables.

Significance of results. End-of-life cancer patients showed higher levels of demoralization than has been reported in other studies with advanced cancer. These data could suggest that demoralization could increase in proximity to death and with impaired clinical condition. In particular, the five demoralization dimensions that emerged could represent the typical concerns around which the syndrome evolves in end-of-life cancer patients. Finally, spiritual well-being could play a protective role with respect to demoralization.

Introduction

In the past few years, an increasing number of studies has recognized demoralization as a relevant clinical dimension to assess and treat in cancer patients (Clarke & Kissane, 2002; Fang et al., 2014; Kissane et al., 2001).

Demoralization is defined as an existential distress syndrome that can arise from upsetting events or situations, such as the experience of chronic and progressive medical diseases that represents a threat to the patient’s integrity and life (Clarke & Kissane, 2002; Kissane et al., 2001; Vehling & Philipp, 2018). Demoralization arises from a persistent incapacity of coping, feelings of helplessness and hopelessness, loss of meaning and purpose, and impaired self-esteem (Clarke & Kissane, 2002; Norris et al., 2011; Robinson et al., 2015). All these phenomena should persist for more than two weeks and a major depressive or other psychiatric episode should not be present as the primary condition (Kissane et al., 2001).

Although mild demoralization may not be pathological and the syndrome is not included in the *Diagnostic and Statistical Manual of Mental Disorders*, cancer and its effects, as traumatic stressors, can affect patients’ lives and psychological well-being. It could provoke high emotional suffering and clinically relevant demoralization, which is significantly associated with potentiated risk for suicidal ideation (Grassi et al., 2017; Robinson et al., 2015; Vehling et al., 2017).

Demoralization can be distinguished from depression: in major depression, the source of distress is within oneself and is characterized by feelings of guilt, anhedonia, and no motivation. In contrast, demoralized patients give an external attribution to their distress, feel inability to cope instead of guilt, and do not experience anhedonia, but uncertainty about the direction of their actions; their motivation is, in fact, intact (de Figueiredo, 1993). Therefore, in demoralized patients, the ability to experience pleasure can be retained and drop in mood and loss of interest

are not necessarily present (Vehling et al., 2017). Numerous studies showed in a percentage of cancer patients moderate or severe demoralization in absence of depression (Grassi et al., 2017; Mehnert et al., 2011; Vehling et al., 2017). These evidences support the relevance of assessing demoralization as an autonomous clinical dimension.

Clinically relevant demoralization can affect cancer patients in all the disease stages, with an overall prevalence rate of 13–18% (Robinson et al., 2015). It can rise to 52.5% in advanced cancer patients, probably from their more severe clinical condition (Julião et al., 2016). The literature shows that demoralization is generally associated with impaired physical symptoms (Vehling & Mehnert, 2014), diminished quality of life, depression, anxiety, feelings of solitude, and reduced social functioning (Robinson et al., 2015). Additionally, demoralized patients can present with suicidal ideation and desire to die (Fang et al., 2014; Robinson et al., 2016). The previously mentioned associations can be also observed in the advanced phase of illness (Julião et al., 2016; Mehnert et al., 2011; Rudilla et al., 2016; Vehling & Mehnert, 2014).

The distinctive characteristics of demoralization and their effect on the individual and on his or her adjustment to illness suggest the importance of adequate assessments and effective treatments (Kissane et al., 2001). The therapeutic intervention to treat demoralization should focus on restoring hope and exploring the meaning of personal relevant themes linked to the current situation, such as life and death, supporting the feeling of uncertainty to meet patient's unfulfilled needs, and promote realistic goals achievement (Breitbart et al., 2010; Clarke & Kissane, 2002; Dufault & Martocchio, 1985; Nunn, 1996; Thomas et al., 2014).

Considering its negative effect on patients' quality of life, the purpose of the present study was to assess the prevalence of demoralization in a population of end-of-life cancer patients (i.e., patients with a life expectancy of less than four months and a Karnofsky performance status [KPS] ≤ 50) (Karnofsky, 1949).

In fact, in previous research focusing on the concept of dignity in end-of-life cancer patients, we found that this specific sample has distinctive characteristics (Bovero et al., 2018a). To assess demoralization, we used the Demoralization Scale (DS) (Kissane et al., 2004a), a valid and reliable instrument that has been translated and validated in several countries (Costantini et al., 2013; Deng et al., 2017; Grassi et al., 2017; Mehnert et al., 2011; Mullane et al., 2009; Rudilla et al., 2016). In these studies, different factor structures emerged according to the specificities of the various samples: advanced cancer patients (Kissane et al., 2004a; Mehnert et al., 2011; Mullane et al., 2009), cancer and noncancer advanced patients receiving palliative care (Rudilla et al., 2016), inpatients recruited from a specialist tertiary level cancer hospital (Deng et al., 2017), and cancer patients at mixed stages (Costantini et al., 2013; Grassi et al., 2017). Therefore, in the present study, in addition to exploring the prevalence of demoralization in end-of-life cancer patients and its associations with a set of psychosocial variables, we explored the latent dimensions of demoralization emerging in end-of-life cancer patients.

Methods

Study design and participants

Participants were recruited from October 2016 to February 2018 at "Città della Salute e della Scienza" Hospital of Turin. Inclusion criteria were: diagnosis of cancer, being hospitalized, and meeting the criteria to access palliative care. These last, stated in Piedmont

Regional Legislative Decree no. 45/2002 and in the National Law on Palliative Care and Pain Treatment (no. 38/2010) are the following: presence of an advanced disease stage in its terminal phase, for which there are no possible or appropriate curative treatments and with unfavorable/poor prognosis, an estimated life expectancy less than four months, and KPS ≤ 50 . Exclusion criteria were not speaking Italian fluently, diagnosis for any severe psychiatric disorder, and having obtained a score ≤ 19 at the Mini Mental State Examination (Folstein et al., 1975), which implies not being able to provide valid informed consent and answers. There were 291 possible candidates: 26 did not meet the inclusion criteria (14 obtained a score ≤ 19 on the Mini Mental State Examination, five were not able to speak Italian fluently, and seven had a KPS ≥ 50), 25 refused to participate in the study because of severe distress resulting from the disease, and five passed away before the interview. The final sample included 235 end-of-life cancer patients. They were assisted by a multidisciplinary team composed of physicians, nurses, and psychologists trained in palliative care. All of them received psychological support and palliative care aimed at managing their symptoms and well-being, without any ongoing curative treatments, or palliative chemoradiotherapy.

A palliative physician gathered, for each patient, the sociodemographic and clinical data. He also estimated patients' life expectancy, based on the "surprise question" (Moss et al., 2010), the Palliative Prognostic Score (Maltoni et al., 1999), and his clinical experience. Then, participants were interviewed at their bedside during the first meeting with the psychologists. On this occasion, the established set of rating scales was administered and patients' awareness of diagnosis and prognosis was evaluated.

Measures

The Italian validated versions of the following instruments were used.

The Demoralization Scale-Italian version (DS-IT) (Costantini et al., 2013) is a self-report scale assessing demoralization, composed of 24 items on a 5-point Likert scale (0 = never, 4 = always). For the study, the following cutoff scores were used: 0–25th percentile, low demoralization; 25th–75th percentile, medium demoralization; and >75th percentile, high demoralization (Robinson et al., 2016).

The Hospital Anxiety and Depression Scale-Italian Version (HADS-IT) (Costantini et al., 1999) is a 14-item self-report scale that consists of two seven-item subscales related, respectively, to depressive and anxious symptomatology. The items are on a 4-point Likert scale, ranging from 0 to 3, rating the issue described in the item. Scores ≥ 8 on each subscale indicate clinically relevant symptomatology.

The Patient Dignity Inventory-Italian version (Bovero et al., 2018a) is a 25-item self-report that follows the Dignity Model (Chochinov, 2002). The items are on a 5-point Likert scale (1, not a problem; 5, an overwhelming problem). This version, validated for end-of-life patients, consists of five subscales (Psychological Distress, Social Support, Physical Symptoms and Dependency, Existential Distress, Loss of Purpose and Meaning).

The Functional Assessment of Chronic Illness Therapy – Spiritual Well-Being (FACIT-Sp-12) measures spirituality in cancer patients. It contains 12 items underlying the traditional religiousness dimension (Faith) and the spiritual one (Meaning/Peace) (Peterman et al., 2002). The wording of the items does not assume a belief in God, so it can be completed comfortably by both atheists and agnostics. The items are on a 5-point Likert scale, ranging from 0 (not at all) to 4 (very much).

The Edmonton Symptom Assessment System-Italian Version (Moro et al., 2006) assess nine common symptoms experienced by cancer patients: pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, well-being, and shortness of breath. In addition, patients can eventually report other symptoms. The symptoms severity is rated on an 11-point Likert scale, ranging from 0 (no symptom) to 10 (worst possible symptom).

The visual analog scale (VAS) for pain (Scott & Huskisson, 1976) explores patient's subjective pain perception. The patient indicates the intensity of his or her current pain with a cross on a horizontal line of 10 cm with specifications on each end ("no pain" on the left; "intolerable pain" on the right). The score is the distance between the left end of the line and the patient's cross.

Statistical analysis

To identify demoralization latent dimensions, the DS-IT factor structure was explored through principal component analysis (PCA) with oblique rotation and Kaiser normalization, on its 24 items. Sampling adequacy and assumption of sphericity were tested by calculating the Kaiser-Meyer-Olkin measure and the Bartlett test. The optimum number of factors was determined through Guttman-Kaiser criterion (eigenvalue of ≥ 1.00 as the cutoff point) and the scree plot visual examination.

To analyze the demoralization prevalence, the sample was divided into three subsets (low, medium, high demoralization), depending on the obtained DS-IT total score and Robinson et al. percentiles (2016). Sociodemographic, medical, and psychological variables were analyzed with respect to the three groups, through multivariate analyses of variance and chi-square test. Descriptive statistics included frequencies, *M*, and *SD*. All the tests were two-sided and all the tests assumptions were verified. *p* values < 0.05 were considered statistically significant. In analyses of variance, post hoc analyses with Bonferroni correction were performed. Statistical analysis was executed using the software SPSS Statistics, version 24.0 (IBM Corp. Armonk, NY).

Results

Participants' sociodemographic and medical characteristics

The final sample consisted of 235 patients. The average age was 68 years (range 30–91); 53.2% of participants were female and the majority of the sample was married. Only 5.5% were graduated and nearly 60% of the sample was retired. Almost 80% of patients were Catholics. Spouses and sons/daughters were the most frequent caregivers.

The KPS average score was 39.72 and the most frequent types of cancer were lung, hepatic-pancreatic-biliary, colorectal, and breast. In three-quarters of cases, the cancer stage was metastatic. According to the Palliative Prognostic Score, patients were classified in three groups on the basis of the risk of death: A, 54 (23.0%); B, 138 (58.7%); and C, 43 (18.3%), with C being representative of the highest risk. Most patients were not aware of their disease prognosis or overestimated it (63.8%, $n = 150$). The average expectancy of life was about 27 days, ranging from < 24 hours to 120 days (Table 1).

Demoralization prevalence and latent dimensions

The sample's average demoralization total score was 35.04 ($SD \pm 15.01$; $SE = 0.98$). Sixty-four participants (27.2%) had low

demoralization, 118 (50.2%) had medium demoralization, and 53 (22.6%) had high demoralization.

Regarding the factor analysis, the Kaiser-Meyer-Olkin measure of 0.90 verified the sampling adequacy for the analysis and the Bartlett test of sphericity chi-square ($276 = 3,165.01$, $p < 0.001$) indicated that the correlations between the items were sufficiently large for PCA. The optimum number of factors comprehended five components that together accounted for 64.30% of the variance. Table 2 shows the factor loading after the rotation and the emerged factors that represent the demoralization latent dimensions. Component 1 (items 5, 6, 8, 9, 12, 18, 21, 22, 24) was labeled "Emotional Distress and Inability to Cope"; component 2 (items 2, 3, 4, 7, 14, 20, 23) represents the loss of purpose and meaning; component 3 (items 1 and 19) refers to worthlessness; component 4 (items 10, 13, 17) corresponds to sense of failure; component 5 (items 11, 15, 16) was labeled "Dysphoria."

The average scores on the emerged five factors were, respectively, 18.8 ± 6.8 (range 0–36) for "Emotional Distress and Inability to Cope"; 7.4 ± 6.0 (range 0–24) for "Loss of Purpose and Meaning"; 3.2 ± 1.3 (range 0–8) for "Worthlessness"; 2.1 ± 1.9 (range 0–12) for "Sense of Failure"; 4.9 ± 2.6 (range 0–12) for "Dysphoria." In "Low," "Medium," and "High" demoralization groups, the items of the DS-IT with the highest mean scores were 18, 19, 21, 22, and 24. They all belong to factor 1: "Emotional Distress and Inability to Cope" Likert point 4, corresponding to the "always" answer, was not the highly frequent for any items, but 18, 21, and 24 were the items with the highest frequencies of answers "often." "Never" was the most frequent answer given to items 2, 3, 4, 7, 10, 14, 15, 20, and 23 (Table 3).

Associations between demoralization and the medical, sociodemographic, and psychological variables

Using Pillai's trace, we found a significant association between the demoralization severity and the scores of the other continuous variables, $V = 0.67$, $F(28,000) = 5.66$, $p < 0.001$.

Specifically, separate univariate analysis of variance evidenced that the group means of almost all the variables consistently increased, passing from low to high demoralization, and decreased for both the FACIT-Sp-12 subscales and the FACIT-Sp-12 total score. There was no significant between-group difference respect to VAS and Edmonton Symptom Assessment System-Italian Version-Nausea, Well-being, and Shortness of Breath. None of the sociodemographic and medical variables were significantly associated with demoralization (Table 3).

To compare demoralization and depression, DS scores and "Depressive symptomatology" HADS subscale were analyzed. Participants were divided into three groups according to 33th and 66th percentiles to identify, in our sample, the group of patients with the lowest level of depressive symptomatology (scores ≤ 8), the group with moderate levels (scores 9–12) and the group with the highest level (scores ≥ 13). Thirty-five patients with high demoralization presented also high levels of depression, and only two patients showed high demoralization with a low level of depressive symptomatology (Table 4).

Discussion

The present study aimed to investigate the prevalence of demoralization in end-of-life cancer patients and its associations with a set of medical and psychosocial variables. In addition, following the results of a previous research, which showed that end-of-life

Table 1. Sociodemographic and clinical characteristics of the sample (*N* = 235)

Characteristics	<i>N</i>	%
Age, y	68 ± 13.82	
Sex		
Male	110	46.8
Female	125	53.2
Marital status		
Married	145	61.7
Single	26	11.1
Divorced	13	5.5
Widow(er)	51	21.7
Education		
Primary school	66	28.1
Middle school	83	35.3
High school	73	31.1
Graduate	13	5.5
Profession		
Unemployed	14	6.0
Employed	60	25.5
Freelance	15	6.4
Housewife	8	3.4
Retired	138	58.7
Caregiver		
Spouse	102	43.4
Partner	5	2.1
Son/daughter	80	34.1
Relative	29	12.3
Friend	2	0.9
Other	4	1.7
Nobody	13	5.5
Religious affiliation		
Catholic	184	78.3
Atheist	32	13.6
Other	19	8.1
Type of cancer		
Colon-rectal	30	12.7
Breast	31	13.2
Uterus-ovary	11	4.7
Gastric	19	8.1
Lung	58	24.7
Hepatic-pancreatic-biliary	32	13.6
Prostate	15	6.4
Other cancers	39	16.6
Awareness		
No diagnosis, no prognosis	34	14.5

(Continued)

Table 1. (Continued.)

Characteristics	<i>N</i>	%
Diagnosis	61	26
Diagnosis, prognosis overestimation	88	37.4
End-of-life, no diagnosis	6	2.6
Total	46	19.5
Karnofsky performance status stage	39.72 ± 9.2	
Local	28	11.9
Locoregional	27	11.5
Metastatic	180	76.6

cancer patients show distinctive characteristics (Bovero et al., 2018a), we explored the demoralization latent dimensions emerging in this distinct population.

Previous DS validations were performed in patients in an advanced illness stage (Kissane et al., 2004a; Mehnert et al., 2011; Mullane et al., 2009); with a KPS ≥ 80 (Grassi et al., 2017) or >50 (Costantini et al., 2013); with mixed tumor stages (Deng et al., 2017); and cancer/noncancer patients receiving palliative care (Rudilla et al., 2016), but no studies focused specifically on end-of-life patients. The results of the present PCA, performed on cancer patients with an average life expectancy of 27 days and a KPS average value of 39.72, suggest a new DS structure, that might represent the most salient demoralization aspects in this specific population. The PCA highlighted a factor structure at five factors (i.e., Emotional Distress and Inability to Cope, Loss of Purpose and Meaning, Worthlessness, Sense of Failure and Dysphoria) which showed two main differences compared with the previous validations (Costantini et al., 2013; Grassi et al., 2017; Kissane et al., 2004a; Mehnert et al., 2011; Mullane et al., 2009; Rudilla et al., 2016). First, “Emotional Distress and Inability to Cope” clusters items belonging to “Helplessness” (items 5, 8, 9), “Disheartenment” (items 6, 18, 21, 22, 24), and “Sense of Failure” (item 12) dimensions of the original DS. Second, “Worthlessness” encompasses two items of “Sense of Failure” original factor (items 1 and 19). “Loss of Purpose and Meaning,” “Dysphoria,” and “Sense of Failure” factors were similar to the ones reported by the previously mentioned other validations. The emerged factors could represent the dimensional nature of cancer patients’ demoralization at the end of life. Based on the clinical practice and on Clarke and Kissane’s evidence (2002), it can be speculated that the demoralization course might begin with inability to cope with the situation, followed by emotional distress, which might then evolve into dysphoria. Later, this psychological distress could lead to experience a sense of failure, which could pave the way to a condition of adverted loss of worth. Finally, all of these elements could generate a more spiritual and existential crisis characterized by all those feelings which represent the loss of purpose and meaning. It might be the final step of a process, originating from the confrontation with an impairing medical condition as well as the increasing severity of the dying patients’ medical status. These speculations should be verified through tailored longitudinal researches, which might reveal precursors indications for the healthcare professionals on how to assist demoralized dying patients (Clarke & Kissane, 2002).

With respect to sample’s demoralization prevalence, DS-IT mean score was higher than the ones reported in previous

Table 2. Summary of the exploratory factor analysis: PCA, oblique-rotated, five-component solution ($N = 235$)

Item	Rotated factor loadings: pattern matrix (structure matrix)				
	F1: Emotional Distress and Inability to Cope $\alpha = .91$	F2: Loss of Purpose and Meaning $\alpha = .89$	F3: Worthlessness $\alpha = .61$	F4: Sense of Failure $\alpha = .61$	F5: Dysphoria $\alpha = .60$
IT1 There is a lot of value in what I can offer.	.093 (.322)	-.120 (-.308)	.754 (.804)	.042 (.176)	-.025 (.081)
IT2 My life seems to be pointless.	.058 (.442)	-.733 (-.830)	.175 (.342)	.007 (.201)	.136 (.368)
IT3 There is no purpose to the activity in my life.	.165 (.431)	-.662 (-.727)	-.154 (.026)	.048 (.211)	.081 (.326)
IT4 My role in life has been lost.	.239 (.516)	-.666 (-.766)	-.140 (.051)	-.049 (.144)	.161 (.426)
IT5 I no longer feel emotionally in control.	.651 (.776)	-.096 (-.413)	-.028 (.172)	.171 (.369)	.129 (.428)
IT6 I am in good spirits.	.744 (.748)	.147 (-.196)	.324 (.466)	-.061 (.141)	-.002 (.257)
IT7 No one can help me.	.169 (.521)	-.440 (-.638)	.065 (.238)	.305 (.465)	.216 (.439)
IT8 I feel that I cannot help myself.	.375 (.639)	-.399 (-.626)	.137 (.324)	.105 (.309)	.120 (.394)
IT9 I feel hopeless.	.526 (.750)	-.389 (-.650)	.182 (.391)	.014 (.254)	.060 (.383)
IT10 I feel guilty.	.088 (.288)	.088 (-.121)	.021 (.109)	.669 (.693)	.145 (.228)
IT11 I feel irritable.	.020 (.390)	-.111 (-.347)	-.044 (.033)	.165 (.267)	.749 (.803)
IT12 I cope fairly with life.	.462 (.582)	-.287 (-.480)	.231 (.389)	-.052 (.142)	-.087 (.177)
IT13 I have a lot of regret about my life.	.101 (.211)	-.251 (-.371)	-.044 (.078)	.800 (.823)	.045 (.159)
IT14 Life is no longer worth living.	.060 (.302)	-.887 (-.877)	.120 (.275)	-.076 (.098)	.016 (.233)
IT15 I tend to feel hurt easily.	.014 (.226)	-.049 (-.190)	.086 (.106)	-.127 (-.048)	.521 (.530)
IT16 I am angry about a lot of things	.060 (.387)	.096 (-.186)	.028 (.078)	.181 (.266)	.793 (.810)
IT17 I am proud of my accomplishments.	.088 (.220)	.158 (-.036)	.522 (.568)	.550 (.583)	-.187 (-.115)
IT18 I feel distressed about what is happening to me.	.668 (.714)	.096 (-.218)	-.180 (-.026)	-.008 (.161)	.329 (.557)
IT19 I am a worthwhile person.	.012 (.299)	-.097 (-.304)	.669 (.694)	-.040 (.088)	.312 (.357)
IT20 I would rather not be alive.	.119 (.211)	-.863 (-.814)	.080 (.219)	-.015 (.126)	-.057 (.135)
IT21 I feel sad and miserable.	.801 (.857)	-.124 (-.446)	.125 (.339)	-.001 (.239)	-.054 (.299)
IT22 I feel discouraged about life.	.775 (.875)	-.139 (-.474)	.036 (.250)	-.047 (.199)	.123 (.462)
IT23 I feel quite isolated or alone	.097 (.349)	-.582 (-.639)	-.065 (.107)	.318 (.438)	-.108 (.122)
IT24 I feel trapped by what is happen to me.	.762 (.720)	.018 (-.252)	-.163 (.024)	.084 (.254)	-.043 (.253)
Eigenvalues	9.26	2.069	1.636	1.411	1.054
% of variance	38.591	8.619	6.815	5.880	4.391

Factor loadings $>.40$ appear in bold type.

validations. Also, the percentage of patients with high demoralization (23.8%) was higher than the one reported in other studies with advanced cancer patients, in Ireland (14%), Germany (15.7%), and Italy (17%). These results could be explained by considering the differences among countries with regard to cancer and death-related cultural aspects and by the fact that our sample consisted of patients at the end of life. In fact, physical discomfort, loss of functioning, and an increased dependency on others seem to be key factors for eliciting demoralization in dying cancer

patients (Lichtenthal et al., 2009). The data could highlight that end-of-life patients might have higher levels of demoralization than patients at previous illness stages. In this regard, there is no evidence in literature that indicates a direct association between demoralization and the illness stage. In particular, cancer patients can manifest existential distress in each disease stage, because existential stressors can be present throughout the illness course (Vehling et al., 2012). However, patients who are closer to death are often confronted with limited lifetime, growing physical

Table 3. Levels of demoralization in the sample and their associations with the other continuous variables

Item DS-IT	Low Demoralization (0–24) n = 64	Medium Demoralization (25–48) n = 118	High Demoralization (49–96) n = 53	ANOVA (F)
	M (SD)	M (SD)	M (SD)	
IT1. There is a lot of value in what I can offer others.	.84 (.79)	1.15 (.71)	1.66 (.73)	
IT2. My life seems to be pointless.	.14 (.50)	.83 (.87)	2.25 (.85)	
IT3. There is no purpose to the activities in my life.	.23 (.68)	1.19 (.98)	2.11 (.78)	
IT4. My role in life has been lost.	.50 (.82)	1.82 (1.15)	3.06 (.91)	
IT5. I no longer feel emotionally in control.	1.00 (.87)	1.97 (.70)	2.87 (.71)	
IT6. I am in good spirits.	1.25 (.62)	1.97 (.74)	2.55 (.85)	
IT7. No one can help me.	.17 (.49)	.94 (.88)	2.19 (.59)	
IT8. I feel that I cannot help myself.	.50 (.91)	1.55 (.86)	2.68 (.55)	
IT9. I feel hopeless.	.44 (.71)	1.53 (.88)	2.77 (.70)	
IT10. I feel guilty.	.25 (.62)	.36 (.71)	1.11 (1.31)	
IT11. I feel irritable.	.75 (.82)	1.76 (1.03)	2.34 (.90)	
IT12. I cope fairly well with life.	1.03 (.69)	1.54 (.62)	2.11 (.51)	
IT13. I have a lot of regret about my life.	.22 (.60)	.71 (.88)	1.21 (.95)	
IT14. Life is no longer worth living.	.09 (.53)	.55 (.83)	1.81 (1.06)	
IT15. I tend to feel hurt easily.	1.05 (1.24)	1.75 (1.27)	2.17 (1.25)	
IT16. I am angry about a lot of things.	.81 (.87)	1.68 (1.07)	2.34 (.90)	
IT17. I am proud of my accomplishments.	.73 (.78)	.90 (.70)	1.23 (.82)	
IT18. I feel distressed about what is happening to me.	2.11 (.76)	2.96 (.71)	3.34 (.62)	
IT19. I am a worthwhile person.	1.63 (.86)	1.96 (.69)	2.53 (.70)	
IT20. I would rather not be alive.	.19 (.53)	.81 (1.07)	1.77 (1.15)	
IT21. I feel sad and miserable.	1.22 (.97)	2.39 (.74)	3.11 (.51)	
IT22. I feel discouraged about life.	1.00 (.99)	2.41 (.75)	3.19 (.62)	
IT23. I feel quite isolated or alone.	.19 (.61)	.98 (1.00)	1.89 (1.27)	
IT24. I feel trapped by what is happening to me.	1.61 (1.16)	2.46 (.85)	3.08 (.73)	
Anxiety (HADS)*	6.72 (2.37)	9.81 (2.73)	11.33 (2.83)	48.13 [†]
Depression (HADS)*	5.70 (3.50)	10.04 (3.69)	13.73 (3.18)	77.65 [†]
Psychological Distress (PDI-IT) [‡]	13.00 (4.43)	16.61 (5.30)	18.68 (6.24)	17.93 [†]
Social Support (PDI-IT)*	3.34 (1.01)	4.10 (1.46)	4.89 (1.96)	16.07 [†]
Physical Symptoms and Dependency (PDI-IT)*	11.19 (3.43)	12.88 (3.55)	14.63 (3.52)	14.35 [†]
Existential Distress (PDI-IT)*	14.94 (4.92)	17.74 (5.09)	22.07 (7.52)	23.51 [†]
Loss of Purpose and Meaning (PDI-IT)*	6.22 (2.40)	7.58 (2.51)	8.66 (2.83)	13.79 [†]
Meaning/peace (FACIT-Sp-12)*	24.14 (4.06)	18.91 (3.55)	13.41 (3.76)	123.47 [†]
Faith (FACIT-Sp-12) [‡]	5.97 (4.19)	4.04 (3.43)	3.00 (2.75)	11.46 [†]
Spirituality (FACIT-Sp-12 total score)*	30.09 (6.30)	23.00 (5.19)	16.41 (4.87)	95.39 [†]
Pain (VAS)	1.27 (1.46)	1.71 (2.64)	2.21 (2.47)	1.98
Tiredness (ESAS) [‡]	3.84 (2.79)	5.37 (2.56)	5.93 (3.38)	7.16 [†]
Nausea (ESAS)	1.63 (2.80)	2.18 (2.92)	1.00 (2.30)	2.65
Drowsiness (ESAS) [§]	1.80 (2.63)	2.94 (2.99)	3.98 (3.37)	6.08
Loss of Appetite (ESAS) [‡]	1.88 (2.85)	3.51 (3.31)	4.00 (2.72)	6.56
Well-being (ESAS)*	3.02 (2.73)	5.15 (2.38)	7.02 (2.43)	29.72 [†]
Shortness of Breath (ESAS)	1.39 (2.94)	1.97 (2.96)	3.34 (3.81)	4.49

M in bold type are the highest in low, medium, and high demoralization.

DS-IT, Demoralization Scale-Italian version; ESAS, Edmonton Symptom Assessment System-Italian Version; FACIT-Sp-12, Functional Assessment of Chronic Illness Therapy – Spiritual Well-Being; HADS, Hospital Anxiety and Depression Scale; PDI-IDT, Patient Dignity Inventory-Italian version; VAS, visual analog scale.

*Significant difference among all three groups.

[†]p < .01.

[‡]Significant difference between low and medium and between low and high demoralization.

[§]Significant difference between low and high demoralization.

||p < 0.05.

Table 4. Contingency table between Demoralization and Depressive Symptomatology

Demoralization	Low Level (≤8)	Moderate Level (9–12)	High Level (≥13)	Total
Low level (≤24)	50 76.9% 55.6% 21.3%	14 21.5% 17.3% 6.0%	1 1.5% 1.6% 0.4%	65 100% 27.7% 27.7%
Moderate level (25–47)	38 33.3% 42.2% 16.2%	48 42.1% 59.3% 20.4%	28 24.6% 43.8% 11.9%	114 100% 48.5% 48.5%
High level (≥48)	2 3.6% 2.2% 0.9%	19 33.9% 23.5% 8.1%	35 62.5% 54.7% 14.9%	56 100% 23.8% 23.8%
Tot	90 38.3% 100% 38.3%	81 34.5% 100% 34.5%	64 27.2% 100% 27.2%	235 100% 100% 100%

For each cell, the first value is the absolute frequency, the second value is the row percentage, the third value is the column percentage, and the fourth value is the total percentage.

constraints, and increasing existential distress (Clarke et al., 2005), and this could increase demoralization and reduce existential well-being (Bovero et al., 2018b; Lichtenthal et al., 2009). These suppositions are not in contrast with the fact that our research did not evidence a significant relationship between demoralization, KPS, disease stage, and pain. Indeed, such associations were not significant, probably because of our sample's homogeneous nature: all the patients had a very low KPS score, 76.6% of them had a metastatic stage, and VAS scores were low for almost all the patients, indicating an overall condition of controlled pain. Nevertheless, the comparison between the demoralization prevalence in our sample with those of other studies suggest an association between demoralization and patients' clinical condition. Further studies specifically targeting this topic could provide evidences about this interesting relationship.

Data on prevalence also showed that "Emotional Distress and Inability to Cope" is the most salient demoralization aspect for end-of-life patients. In fact, the scores obtained by participants at the items of this factor are the highest among all the DS items. So, the emotional and existential dimensions of distress could be clinically crucial for end-of-life patients. In this regard, the key characteristics of demoralization in our sample were the self-perception of being incapable to face a progressive illness, a sense of discouragement, and feeling worthwhile, trapped, and sad. Finally, we can support that low self-esteem, poor social connection, and a general sense of vulnerability could be specific predictors for demoralization in end-of-life patients. Terminal cancer patients show a weakened sense of connection to others because physical disability progressively limits their capacity to engage in valued social and community activities, have less access to and ability to make use of supportive relationships, and a reduced sense of purpose in life, as rooted in the experience of meaningful relationships.

Furthermore, only 19.5% of patients are totally aware of their medical condition, and most of the sample overestimated the prognosis. Awareness level likely could affect the psychological attitude toward the illness, acting on person's capacity of acceptance, planning, active coping, and use of emotional support.

These data might suggest that, for terminal patients, not being informed on end-of-life issues and some aspects of the relationship with healthcare providers, as feelings of not having control, not being involved in decision making, and not being seen as a human being, could lead to an increased existential distress. Therefore, clinicians should attempt to establish close rapport with patient and ensure an emphatic and attentive approach.

Regarding the comparison between demoralization and depression, data confirm previous evidence supporting the notion that demoralization is a different construct with respect to depression (Costantini et al., 2013; Grassi et al., 2017; Kissane et al., 2004b; Lee et al., 2012; Mehnert et al., 2011). At the same time, only two patients showed low depressive symptomatology and high demoralization. These data are lower than that reported by Kissane et al. (2004a) (i.e., 7–14%) and the percentage of patients with high demoralization and high depression is high. These data are probably the result of patients' critical clinical status, which can lead to a major overlap between these conditions. Perhaps unrecognized and poorly treated depression in the previous illness stages might increase anhedonic states, lower morale, and elicit helplessness and hopelessness, which can ultimately favor demoralization.

About relationships with the other variables, the positive association between "Physical Symptoms and Dependency" Patient Dignity Inventory-Italian version factor, and demoralization indicates the link among dignity, demoralization, and physical problems shown by Vehling and Menhert (2014). In fact, at the end of life, the constant presence of physical symptoms can compromise a patient's sense of dignity, leading to feelings of dependency or being a burden to others (Bovero et al., 2018b; Chochinov, 2002), which may heighten existential distress and demoralization.

Moreover, the relationship between demoralization, dignity-related loss of purpose and meaning, and existential distress as well as the dimensions of spiritual well-being may underline the protective function of the latter on demoralization against the existential concerns. This result also supports the usefulness of considering the spiritual well-being when assessing patients' quality of life (Bovero et al., 2016). Without also knowing a patient's level of faith, peace, and meaning, the healthcare provider might miscalculate the burden of the illness for the patient.

The considerable number of patients in this sample suffering from demoralization strengthen the need for psychological interventions to reduce the existential distress at the end of life, focusing on finding meaning and detecting spiritual concerns. Individual or group interventions applied to dying cancer patients (Breitbart et al., 2010), have shown great success in impacting patients' existential well-being and other psychological issues, such as demoralization, elevating a positive growth, tapping inner peace, and strengthening religious coping style.


This study has limitations. First, the study is cross-sectional, measuring variables in a single cohort time, and essentially descriptive. This method does not allow to assess if terminally ill patients experienced changes in the demoralization dimensions while approaching death. Future studies should conduct longitudinal assessment of demoralization, but the difficulties in recruiting and of losing patients over time will continue to be a challenge for end-of-life research.

When patients could not autonomously fill in the rating scales, they were helped to complete them by the psychologist. Of course, it would have been better if the patients had completed the tools by themselves, but this limitation is strictly connected to the sample's clinical condition.

The strength of this research is that it represents the first Italian study that assesses the prevalence of demoralization and

the specific DS factor structure in end-of-life cancer patients with a life expectancy of few weeks. A larger population would reinforce the results achieved in this study, and future research could explore the associations between demoralization and quality of life in these patients. Moreover, this study should be replicated with the DS-II.

Our findings also suggest that, in this illness phase, there is a strong overlap between depression and demoralization. Thus, attention should be paid to this vulnerable population. Finally, the DS-IT can help to assess the demoralization level in patients nearing death, with few weeks of life remaining, contributing to identify their existential suffering and promoting clinical approaches to optimize their quality of life.

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