

# Relationship between demoralization and quality of life in end-of-life cancer patients

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## Abstract

**Objective:** To examine the relationship between demoralization and health-related quality of life (HRQoL) in a sample of end-of-life cancer patients with a life expectancy of 4 months or less undergoing palliative care, controlling for socio-demographic, clinical, and psychological variables.

**Methods:** Sociodemographic, clinical, and psychological data from 170 end-of-life cancer patients were collected using the following scales: Edmonton Symptom Assessment System for palliative care patients' symptoms; Patient Health Questionnaire-9 (PHQ-9) for depressive symptoms; Functional Assessment of Cancer Therapy Scale - General Measure (FACT-G) for HRQoL; Functional Assessment of Chronic Illness Therapy - Spiritual Well-Being for spirituality (FACIT-Sp); Demoralization Scale - Italian Version (DS-IT) for demoralization.

**Results:** The DS-IT showed that 51.8% of cancer patients were severely demoralized. In addition, 36.5% of the sample had clinically significant depressive symptoms and QoL was severely impaired (FACT-G). The result of regression analysis showed that demoralization (especially "Disheartenment" and "Sense of failure") was the strongest contributor for HRQoL, followed by ESAS\_Lack of Well-Being and depression (PHQ-9), with the final model explaining 66% of the variance of the FACT-G.

**Conclusions:** The results highlight a very high prevalence of severe demoralization in end-of-life cancer patients. Moreover, demoralization was not only associated with patients' HRQoL, but it was also the most important contributing factor. This finding underscores the need to identify preventive or therapeutic psychological interventions that focus on preventing existential distress, and thus improve the QoL of dying patients in their last days of life.

## KEYWORDS

cancer, demoralization, end-of-life, oncology, palliative care, Psycho-oncology, quality of life

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## 1 | BACKGROUND

Although not being formally included among the psychiatric diagnoses, years of research have proven and continue to confirm the importance of the clinical concept of demoralization, which is characterized by feelings of hopelessness and helplessness due to loss of purpose and meaning in life.<sup>1</sup> As a possible manifestation of psychological and existential distress, demoralization implies a persistent inability to cope with a stressful situation, usually occurring in the context of troubling situations or circumstances, such as a chronic and/or progressive illness that affects the patient's integrity, life, and well-being.<sup>2,3</sup> The clinical manifestation of demoralization encompasses a spectrum of severity, ranging from an initial sense of disheartenment to a deeper sense of hopelessness and failure, to a strong sense of loss of meaning and purpose.<sup>4</sup>

Demoralization has been observed in various clinical populations, with both physical and mental illnesses.<sup>1,5,6</sup> Although it is considered a treatable clinical condition and several therapies have been shown to be effective in reducing it,<sup>6-9</sup> it is often dismissed or unrecognized as an individual's understandable reaction to the circumstances of their medical condition.<sup>1</sup> However, because demoralization is associated with suicidal ideation and the desire to hasten death,<sup>5,10,11</sup> it is important to address this syndrome and its impact on patient well-being and quality of life (QoL). Despite their consistent comorbidity and to properly target treatment interventions,<sup>11-13</sup> it is also important to distinguish depression from demoralization, which involves a loss of hope and meaning, with a loss of anticipatory pleasure rather than general anhedonia.<sup>1,2</sup>

Most studies have focused on demoralization in oncology and palliative care settings.<sup>6</sup>

A recent literature review revealed a mean pooled prevalence of 35.8% severe demoralization in cancer patients,<sup>6</sup> ranging from 16% to 57.6%. The wide variability in prevalence can be explained by many factors, such as worsening clinical condition and increase in physical discomfort and loss of functioning in the last weeks of life,<sup>14</sup> palliative treatment,<sup>15</sup> high level of psychological distress,<sup>13</sup> or desire for death.<sup>4</sup>

Several studies have highlighted that demoralization is associated with the number and type of physical symptoms such as fatigue, limited mobility and activity, respiratory problems, constipation, memory or concentration problems, and pain.<sup>6,10,16,17</sup> Inconsistent associations between sociodemographic factors and demoralization have been identified,<sup>6,10</sup> while consistent data seem to suggest that demoralized cancer patients have low levels of QoL.<sup>18,19</sup>

Quality of life is a central concept of palliative care, which aims not only at pain management, but also at the best possible physical, psychological, social and spiritual well-being of terminally ill patients and their families.<sup>20</sup> However, no studies deepen our understanding of the relationship between demoralization and QoL in cancer patients at the end-of-life, that is, patients with few weeks of life expectancy, which have unique characteristics.<sup>14,21</sup>

Thus, the main objective of the present study was to examine the relationship between demoralization and QoL in a sample of end-of-life cancer patients with a life expectancy of 4 months or less undergoing palliative care. Following our previous work on this specific population, which investigated the prevalence of demoralization and its associations with different medical and psychosocial variables,<sup>14</sup> in the present study we specifically aimed to assess the independent effect of demoralization on patients' health-related quality of life (HRQoL), controlling for clinical (such as functional status, physical symptoms, or prognosis awareness) and psychological (i.e., depressive symptoms, spiritual well-being) variables.

## 2 | METHODS AND MATERIALS

Participants in this study were recruited in the Palliative Care and Medical Oncology departments of the "Città della Salute e della Scienza" Hospital and the "V. Valletta" Hospice of Turin. Hospitalized patients diagnosed with cancer and meeting national criteria for access to palliative care were assessed as potential candidates. According to Piedmont regional legislative Decree n.45/2002 and the National law on palliative care and pain treatment (n.38/2010) the palliative care criteria are the following: terminal stage of the disease, with an unfavorable/poor prognosis or without possible or appropriate curative treatments; a Karnofsky Performance Status (KPS) of 50 or lower<sup>22</sup>; a presumed life expectancy of 4 months or less as evaluated by the patient's palliative physician. The exclusion criteria were age under 18, inability to give informed consent or to complete the rating scales, insufficient knowledge of the Italian language, a history of neurological and/or severe psychiatric pathologies. Participants who met the inclusion criteria were invited to participate in the study and enrolled after written informed consent.

Palliative care physicians recorded sociodemographic and clinical data and assessed whether or not the patient was aware of the diagnosis and/or prognosis during a clinical interview with patients and caregivers. A score of 0 was assigned if the patient did not know or overestimated the prognosis, whereas a score of 1 was assigned if he/she knew the prognosis. During the psychosocial assessment, which was conducted at the bedside, the psychologist reassessed the patient's prognosis awareness. Patients were asked to read and complete a test battery, and they were encouraged to ask questions if in doubt. To avoid overwhelming the patients, the assessment was based on the patients' rhythm and needs.

A total of 245 patients were identified as possible candidates: 32 patients did not want to take part in the study, due to lack of motivation or to their physical or emotional state; 8 did not meet the inclusion criteria, 3 did not speak Italian; 7 had incomplete data and 25 died before data collection. The final sample consisted of 170 patients. The present study was approved by the Institutional Ethics Committee (protocol number 0034403, procedure number CS2/1178) and conducted in accordance with the Declaration of Helsinki.

### 3 | MEASURES

The Edmonton Symptom Assessment System (ESAS)<sup>23</sup> is a self-administered scale, developed to assess the presence and intensity of nine palliative care patients' symptoms (pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, lack of well-being, and shortness of breath) on an 11-point Likert scale, ranging from zero (no symptom) to 10 (worst possible symptom).

The Italian version of the Patient Health Questionnaire-9 (PHQ-9), a reliable tool with good psychometric properties, was used to assess the severity of depressive symptoms during the last 2 weeks<sup>24</sup>

The Functional Assessment of Cancer Therapy Scale - General Measure (FACT-G) is a 27-item scale divided into four QoL domains: physical well-being, social/family well-being, emotional well-being, and functional well-being (FWB). Patients provide responses on a 5-point scale ranging from 0 (not at all) to 4 (very much). The total FACT-G score is the sum of the scores for the four subscales: higher scores indicate higher HRQoL.<sup>25</sup>

The Functional Assessment of Chronic Illness Therapy - Spiritual Well-Being (FACIT-Sp-12) is a 12-item scale that includes 3 spirituality factors (Meaning, Comfort and Faith) and is widely used in cancer setting.<sup>26</sup> Higher scores indicate better spiritual well-being.

The Demoralization Scale - Italian Version (DS-IT) is a self-report scale.<sup>27</sup> It contains 24 items on a 5-point Likert scale, ranging from 0 (never) to 4 (always), and is divided into five subscales: loss of meaning and purpose in life, dysphoria, disheartenment, helplessness, and sense of failure. The cut-off score of  $\geq 37$  and  $\geq 31$  were used to indicate high and moderate demoralization, respectively.<sup>4,6</sup>

### 4 | STATISTICAL ANALYSES

Statistical analyses were performed using the Statistical Package for Social Sciences - 26.0 (IBM SPSS Statistics for Macintosh, Armonk, NY, USA: IBM Corp.). The assumption of normality was met for all variables (all absolute skewness and kurtosis values lower than 3.0 and 8.0, respectively).<sup>28</sup>

Student independent-samples *t* tests were used to assess differences in demoralization by gender, marital status, place of admission and prognosis awareness. Pearson and Spearman bivariate correlations were used to analyze the relationship between variables. Hierarchical multiple regression analysis was performed to examine whether demoralization was a significant predictor of HRQoL (FACT-G) in end-of-life cancer patients. To avoid unnecessary reduction in statistical power, predictor variables (age, gender, cancer stage, KPS, prognosis awareness, ESAS symptoms, depressive symptoms, demoralization, and spiritual well-being) were included in the regression models, with stepwise method, only if they were significantly correlated with the outcome variable ( $p$  value < 0.05). Collinearity was assessed using the statistical factors of tolerance and Variance Inflation Factor.

### 5 | RESULTS

#### 5.1 | Sociodemographic and clinical characteristics

The end-of-life cancer patients had an average age of approximately 69 years (Table 1). Two-thirds of the sample were male, and most patients had a middle or primary school degree. Regarding cancer-related variables, the average KPS score was around 40, 75% of patients had metastatic cancer, and the most common cancers were lung, hepatic-pancreatic, colon-rectal and kidney cancer (Table 1). The average life expectancy was about 27 days, ranging from <24 h to 120 days.

According to ESAS scores, lack of well-being, fatigue, and anxiety were the most debilitating symptoms (Table 2). In addition, more than one-third of patients had clinically significant depressive symptoms on the PHQ-9, with 20.6% having mild/moderate and 15.9% having severe depression (Table 2). On average, HRQoL was severely impaired (FACT-G total score), with FWB being the most impaired domain (mean (SD) = 8.1 (3.8)). Patients' spiritual well-being was also low, especially for the "Faith" (mean (SD) = 4.12 (3.5)) and "Peace" (mean (SD) = 6.7 (3.1)) FACIT-Sp-12 subscales (see Table 2).

The demoralization data showed that more than 51% and 14% of the sample had severe or moderate demoralization, respectively, highlighting "Disheartenment" and "Sense of failure" as the most critical DS-IT domains (Table 2).

#### 5.2 | Demoralization associations with sociodemographic, clinical and psychological characteristics

*t*-test comparisons showed that there were no statistically significant differences in DS-IT scores between male and female (37.7 (13.8) versus 35.4 (13.9), respectively;  $p = 0.300$ ); married/cohabiting patients and patients who were single, divorced, or widowed (36.3 (14.8) versus 38.5 (11.9), respectively;  $p = 0.310$ ); hospital inpatients and hospice patients (36.1 (14.5) versus 38.8 (12.5), respectively;  $p = 0.201$ ); or between patients with no awareness or overestimating the prognosis and patients with good awareness of the prognosis (36.9 (13.2) versus 37.1 (15.6), respectively;  $p = 0.949$ ).

The correlation analyses between demoralization and the other continuous variables are shown in the Supplementary Material. There were no significant correlations between demoralization and age and only a small negative correlation between demoralization and KPS. Among the physical and psychological symptoms assessed with the ESAS, depression, lack of well-being, and fatigue were the symptoms with the highest correlation coefficients: the higher the symptoms, the higher the level of demoralization. The pain symptom showed only a weak positive correlation with the "Dysphoria" subscale of the DS-IT. A significant correlation was found between depression (PHQ-9) and demoralization. Finally, demoralization was negatively correlated with almost all domains of HRQoL: the higher the level of demoralization, the lower the QoL.

TABLE 1 Sociodemographic and clinical characteristics

	N	N (%)	Mean (SD)	Min-Max
Age	168		68.76 (13.1)	33–96
Gender	169			
Male		108 (69.9)		
Female		61 (36.1)		
Educational level (years)	162			
Primary school		40 (24.7)		
Middle school		59 (36.4)		
High school		52 (32.1)		
Graduate		11 (6.8)		
Marital status	166			
Single/Divorced/Widow(er)		53 (31.9)		
Married/Cohabiting		113 (68.1)		
Work status	157			
Employed		38 (24.2)		
Unemployed		10 (6.4)		
Retired		109 (69.4)		
Religious affiliation	162			
Catholic		147 (90.7)		
Atheist		12 (7.4)		
Other		3 (1.9)		
Religious practice	155			
Prayer		47 (30.3)		
Not prayer		108 (69.7)		
Type of cancer	169			
Lung		40 (23.7)		
Hepatic-pancreatic-VBC		30 (17.8)		
Colon-rectal		14 (8.3)		
Kidney		14 (8.3)		
Breast		11 (6.5)		
Other		61 (35.4)		
Stage	164			
Local		9 (5.5)		
Loco-regional		33 (20.1)		
Metastatic		122 (74.4)		
Karnofsky performance status	163		39.79 (9.5)	20–50
Prognosis awareness	170			
No awareness/prognosis overestimation		121 (71.2)		
Prognosis awareness		49 (28.8)		
Place of admission	169			
Hospice		66 (39.1)		
Hospital		103 (60.9)		

**TABLE 2** Data regarding physical and psychological symptoms, health-related quality of life (HRQoL) and demoralization ( $N = 170$ ).

	Mean (SD)	N (%)
ESAS		
Pain	3.16 (2.9)	
Fatigue	4.60 (2.5)	
Nausea	1.66 (2.5)	
Depression	3.68 (2.4)	
Anxiety	4.10 (2.7)	
Drowsiness	3.19 (2.7)	
Appetite	2.80 (2.8)	
Lack of well-being	4.79 (2.5)	
Shortness of breath	2.02 (2.8)	
PHQ-9	8.1 (5.5)	
Subclinical depression (score $\geq 5$ , $\leq 9$ )		52 (30.6)
Mild-moderate depression (score $\geq 10$ , $\leq 14$ )		35 (20.6)
Severe depression (score $\geq 15$ )		27 (15.9)
FACT-G	51.82 (12.3)	
PWB	15.38 (5.3)	
SWB	15.74 (5.17)	
EWB	12.64 (4.5)	
FWB	8.06 (3.8)	
FACIT-Sp12	22.29 (6.9)	
Meaning	11.48 (2.6)	
Peace	6.7 (3.1)	
Faith	4.12 (3.5)	
DS-IT	36.95 (13.9)	
Moderate demoralization		25 (14.7%)
Severe demoralization		88 (51.8%)
Loss of meaning and purpose	5.13 (4.3)	
Dysphoria	6.42 (3.3)	
Disheartenment	12.84 (4.2)	
Helplessness	6.07 (3.2)	
Sense of failure	6.49 (2.2)	

Abbreviations: DS-IT, Demoralization Scale-Italian version; ESAS, Edmonton Symptom Assessment System; EWB, emotional well-being; FACIT-Sp12, Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being; FACT-G, Functional Assessment of Cancer Therapy-General scale; FWB, functional well-being; PHQ-9, Patient Health Questionnaire: Depression Module; PWB, physical well-being; SWB, social/family well-being;

### 5.3 | Regression analyses

Hierarchical multiple regression analysis was performed to investigate whether demoralization is a significant predictor of HRQoL (FACT-G) in end-of-life cancer patients. Age, gender, cancer stage, and prognosis awareness did not show a significant correlation with the FACT-G total score and were therefore not included in the regression analysis (see Table 3). The KPS, ESAS, and PHQ-9 scores were entered into

the first regression block, the DS-IT subscales scores into the second block, and the FACIT-Sp12 total score into the third block. The result of the regression analysis is shown in Table 4. Demoralization and, in particular, the dimensions "Disheartenment" and "Sense of failure" appeared to be statistically significant contributing factors for HRQoL, with the final model (Model 5) explaining a significant proportion (66%) of the variance of the FACT-G ( $F(5,157) = 64.3$ ,  $p < 0.001$ ). "Disheartenment" was the strongest contributor ( $\beta = -0.35$ ,  $t$

	FACT-G	PWB	SWB	EWB	FWB
Age <sup>a</sup> (N = 168)	-0.089	0.007	-0.215**	0.043	-0.056
Gender <sup>b</sup> (N = 169)	0.064	0.037	-0.029	0.127	0.062
Stage <sup>b</sup> (N = 164)	0.069	0.048	0.049	0.100	-0.007
KPS <sup>a</sup> (N = 163)	0.243**	0.309***	-0.024	0.116	0.255**
Prognosis awareness <sup>b</sup> (N = 170)	0.143	0.044	0.06	0.041	0.237**
ESAS <sup>a</sup> (N = 170)					
Pain	-0.213**	-0.504***	0.162*	-0.127	-0.059
Fatigue	-0.474***	-0.554***	0.029	-0.389***	-0.342***
Nausea	-0.326***	-0.530***	0.044	-0.245**	-0.086
Depression	-0.506***	-0.383***	-0.063	-0.597***	-0.310***
Anxiety	-0.289***	-0.242**	0.031	-0.428***	-0.129
Drowsiness	-0.360***	-0.422***	-0.050	-0.196*	-0.280***
Appetite	-0.330***	-0.353***	-0.134	-0.181*	-0.181*
Lack of well-being	-0.617***	-0.648***	-0.026	-0.606***	-0.343***
Shortness of breath	-0.126	-0.258**	0.105	-0.128	-0.041
PHQ-9 <sup>a</sup> (N = 170)	-0.615***	-0.576***	-0.148	-0.481***	-0.419***
FACIT-Sp12 <sup>a</sup> (N = 170)					
Meaning	0.501***	0.300***	0.303***	0.310***	0.426***
Peace	0.686***	0.397***	0.172*	0.738***	0.557***
Faith	0.220**	0.052	0.070	0.302***	0.182*
DS-IT <sup>a</sup> (N = 170)					
Loss of meaning and purpose	-0.462**	-0.419**	-0.124	-0.384**	-0.288**
Dysphoria	-0.513**	-0.518**	-0.032	-0.571**	-0.218*
Disheartenment	-0.721**	-0.450**	-0.273**	-0.741**	-0.454**
Helplessness	-0.613**	-0.420**	-0.224*	-0.613**	-0.365**
Sense of failure	-0.606**	-0.297**	-0.338**	-0.427**	-0.582**

Abbreviations: DS-IT, Demoralization Scale-Italian version; ESAS, Edmonton Symptom Assessment System; EWB, emotional well-being; FACIT-Sp12, Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being; FACT-G, Functional Assessment of Cancer Therapy-General scale; FWB, functional well-being; KPS, Karnofsky Performance Status; PHQ-9, Patient Health Questionnaire: Depression Module; PWB, physical well-being; SWB, social/family well-being.

<sup>a</sup>Pearson's *r* coefficients.

<sup>b</sup>Spearman' rho coefficients.

\**p*-value < 0.05; \*\**p*-value < 0.01; \*\*\**p*-value < 0.001.

(157) = -5.34, *p* < 0.001), followed by ESAS\_Lack of Well-Being ( $\beta = -0.253$ , *t* (157) = -4.60, *p* < 0.001), "Sense of failure" ( $\beta = -0.222$ , *t* (157) = -3.87, *p* < 0.001), PHQ-9 ( $\beta = -0.171$ , *t* (157) = -2.86, *p* = 0.005), and KPS ( $\beta = 0.105$ , *t* (157) = 2.25, *p* = 0.026).

## 6 | DISCUSSION

This study aimed to assess the independent effect of demoralization on HRQoL in a sample of end-of-life cancer patients, also examining its relationship with various sociodemographic, clinical, and psychological variables. As previous studies have shown, end-of-life cancer patients,

that is, patients in the very last stage of advanced cancer with a life expectancy of 4 months or less, have unique characteristics.<sup>14,21</sup> Recognizing the role that demoralization plays in affecting QoL of patients in their last days of life is of paramount importance to identify preventive or targeted therapeutic interventions.

Our results suggest a very high prevalence of demoralization (66.5% including moderate-to-severe demoralization), which is higher than that found among terminal cancer patients in Portugal (52.5%),<sup>13</sup> and in advanced-stage cancer patients in Taiwan (27.55%)<sup>17</sup> and Germany (39.1%),<sup>12</sup> but consistent with the prevalence recently found in palliative care patients in Hong Kong (64.8%).<sup>29</sup> "Disheartenment" and "Sense of failure" emerged as the most important aspects of

TABLE 3 Variables correlations with the health-related quality of life (HRQoL) (Cancer Therapy Scale - General Measure (FACT-G))

**TABLE 4** Hierarchical multiple regression with health-related quality of life (HRQoL) (Cancer Therapy Scale - General Measure (FACT-G)) as dependent variable ( $N = 163$ ).

	Predictor	R <sup>2</sup>	Adj R <sup>2</sup>	F	F- ΔR <sup>2</sup>	B	SE B	β	P
1	(Constant)	0.38	0.38	98.79**	98.79**	63.19	1.34		<0.001
	PHQ-9					-1.36	0.14	-0.617	<0.001
2	(Constant)	0.51	0.50	82.02**	40.82**	69.31	1.53		<0.001
	PHQ-9					-0.96	0.14	-0.434	<0.001
	ESAS_Lack of well-being					-2.00	0.31	-0.399	<0.001
3	(Constant)	0.53	0.53	60.79**	9.56*	60.3	3.28		<0.001
	PHQ-9					-0.92	0.14	-0.417	<0.001
	ESAS_Lack of well-being					-1.98	0.31	-0.395	<0.001
	KPS					0.22	0.07	0.168	0.002
4	(Constant)	0.64	0.63	70.38**	46.71**	72.17	3.37		<0.001
	PHQ-9					-0.50	0.13	-0.225	<0.001
	ESAS_Lack of well-being					-1.28	0.29	-0.256	<0.001
	KPS					0.16	0.06	0.125	0.011
	DS-IT_Disheartenment					-1.28	0.19	-0.438	<0.001
5	(Constant)	0.67	0.66	64.27**	14.97**	76.70	3.44		<0.001
	PHQ-9					-0.38	0.13	-0.171	0.005
	ESAS_Lack of well-being					-1.27	0.28	-0.253	<0.001
	KPS					0.14	0.06	0.105	0.026
	DS-IT_Disheartenment					-1.02	0.19	-0.35	<0.001
	DS-IT_Sense of failure					-1.23	0.32	-0.222	<0.001

Note: \* $p$ -value < 0.05; \*\* $p$ -value < 0.001.

Abbreviations: DS-IT, Demoralization Scale-Italian version; ESAS, Edmonton Symptom Assessment System; KPS, Karnofsky Performance Status; PHQ-9, Patient Health Questionnaire: Depression Module.

demoralization in our sample. The inability to cope with terminal cancer and the perception of an uncontrollable future may contribute to symptoms of demoralization such as discouragement and sense of failure. The emotional distress associated with this sense of discouragement and failure that dying patients experience after failing to cope with the threat and the resulting feelings of incompetence and diminished self-esteem, should therefore be the therapeutic target of psychological interventions. Existential and meaning focused therapeutic interventions can help patients cope with disease-related losses and worries about the future.<sup>7,30</sup>

Demoralization was associated with patients' functional impairment (KPS) and with the majority of physical symptoms assessed by the ESAS: the higher are the physical symptoms and functional impairment, the higher are the levels of demoralization. Consistent with the literature,<sup>6,10,16</sup> these results confirm that physical symptoms are a key factor of existential distress in end-of-life cancer patients and should therefore be carefully managed. In contrast, the lack of correlation with pain symptoms is not unexpected, considering that palliative care is quite effective in minimizing this symptom.

However, the variables that correlated most strongly with demoralization were psychological variables, that is, depression and spiritual well-being. Although a significant correlation was found

between demoralization and depression, 42% (37 out of 88) of patients with severe demoralization had no depressive symptoms, and 27.3% (24) had only mild to moderate depression. Consistent with some previous studies,<sup>30-32</sup> these findings seem to confirm that demoralization and depression are distinct constructs, although there is some overlap. From a clinical perspective, the high prevalence of psychological distress in end-of-life cancer patients suggests that it is not being addressed by all available means and that there is still much to be done in palliative care in terms of prevention and therapeutic interventions.

The most important finding of the present study is that demoralization was associated with poorer QoL in all domains: physical, social, emotional, and FWB were indeed negatively associated with demoralization. This confirms the few other studies that report that advanced cancer patients with demoralization have poorer QoL.<sup>19,33</sup> Patients closer to death often face limited lifespan, increasing physical symptoms, and increasing psychological distress, which could heighten demoralization and decrease well-being.<sup>23,34</sup> QoL is a global measure of well-being and has been associated with the desire for a hastened death in end-of-life patients.<sup>33,35-37</sup>

Not only was demoralization associated with patients' HRQoL, but regression analysis showed that demoralization, and specifically the

dimensions of 'Disheartenment' and 'Sense of Failure', was the most significant predictor of HRQoL, even after controlling for other potential predictors. This finding confirms the significant association between existential distress and QoL in dying cancer patients. In the context of terminal illness, when physical problems increase with disease progression, a sense of pointlessness can arise alongside helplessness, poor coping, and given up states of mind.<sup>4,10</sup> Furthermore, if the patient cannot find help from others, he or she may become hopeless and socially isolated and suffer from feelings of shame and personal failure.<sup>2</sup> This finding underscores the need for psychological interventions, that is, meaning targeted interventions that focus on preventing existential distress. According to the predictors of this study, psychological interventions could reduce the demoralization triggered by physical discomfort and loss of functioning, and support the meaning of life in the therapeutic relationship.<sup>38</sup>

## 6.1 | Study limitations

This study has some limitations. Because of the cross-sectional methodology, measuring variables in a single cohort period, the study is essentially descriptive in nature, allowing inferences to be drawn but not truly verifying whether terminally ill patients experience changes in the dimensions of HRQoL and demoralization as they approach death. As recently reported,<sup>39</sup> although recruitment difficulties and loss of patients over time continue to challenge end-of-life research, future studies should conduct a longitudinal assessment of demoralization to fully examine how it develops as patients approach the end of life and how it relates to their QoL.

## 6.2 | Relationship between demoralization and quality of life in end-of-life cancer patientsClinical implications

The strength of this study is that it is one of the few studies to examine possible associations between demoralization and QoL in dying cancer patients, thus expanding knowledge of the mechanisms underlying the relationship between physical suffering and psychological outcome in terminal cancer patients. The findings underscore the need for the health care system to adequately assess demoralization in terminal cancer patients, not only because of its high prevalence, but especially because it independently affects multiple aspects of patients' HRQoL, including mental and physical health, even controlling for physical and psychological problems.

Physical problems could play a central role in the process of demoralization by affecting the sense of mastery and competence at the end of life. On the one hand, this result highlights the great need to adequately treat physical symptoms in terminal cancer patients, as their significant impact on psychological well-being is amplified. On the other hand, the strong association between demoralization and physical problems should encourage healthcare providers to assess the presence of demoralization in terminally ill patients who are close

to death and have only a few weeks to live and who face difficult physical symptoms, to recognize their existential suffering and promote clinical approaches to optimize their QoL.

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## CONFLICT OF INTEREST

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

## DATA AVAILABILITY STATEMENT

All relevant data are within the manuscript. The dataset used and/or analyzed during the current study is available from the corresponding author on reasonable request.

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## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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