# DEMORALIZATION AFFECTS QUALITY OF LIFE IN TERMINAL CANCER PATIENTS IN PALLIATIVE CARE

**Valentina Tesio[1], Andrea Bovero[2], & Ada Ghiggia[3]**
[1]*Department of Psychology, University of Turin, Turin (Italy)*
[2]*Clinical Psychology Unit, AOU Città della Salute e della Scienza, Turin (Italy)*
[3]*Department of Life Sciences, University of Trieste, Trieste (Italy)*

## Abstract

Objective: Demoralization implies a persistent inability to cope with a stressful situation and is characterized by feelings of hopelessness and helplessness due to loss of purpose and meaning in life. Although years of research have demonstrated its clinical importance, there are few studies that deepen the relationship between demoralization and health-related quality of life (HRQoL) in terminal cancer patients in palliative care. The aim of this study is to specifically examine the prevalence of demoralization in a sample of terminally ill cancer patients and assess its independent effect on patients' HRQoL, controlling for other clinical and psychological variables.

Methods: Data were collected from 372 terminal cancer patients undergoing palliative care. The Edmonton Symptom Assessment System (ESAS) for symptoms of palliative care patients, the Hospital Anxiety and Depression Scale (HADS) for psychological distress, the Functional Assessment of Cancer Therapy Scale - General Measure (FACT-G) for HRQoL and the Functional Assessment of Chronic Illness Therapy - Spiritual Well-Being for spirituality (FACIT-Sp) were used. In addition, Demoralization was assessed using the Demoralization Scale - Italian version (DS-IT).

Results: According to the DS-IT, 48.4% of the recruited terminal cancer patients were severely demoralized, and 13.7% showed moderate demoralization. Demoralization was strongly correlated with HRQoL, which was severely impaired (mean FACT-G (SD) = 53.52 (14.7)). The regression analysis showed that psychological distress (HADS: $\beta = -0.42$, p<.001), as well as "Disheartenment" ($\beta = -0.21$, p<.001) and "Sense of Failure" ($\beta = -0.11$, p=.003) subscales of the DS-IT were the strongest contributors for HRQoL, followed by the "Dysphoria" subscale ($\beta = -0.07$, p=.034) of the DS-IT and the "Appetite" ($\beta = -0.09$, p=.012), "Lack of Well-Being" ($\beta = -0.08$, p=.032), and "Drowsiness" ($\beta = -0.07$, p=.035) subscales of the ESAS, with the final model explaining 70% of the variance of the FACT-G.

Conclusions: The results of the present study highlight the presence of high levels of demoralization in terminal cancer patients and show that psychological distress and demoralization are the main independent negative factors affecting HRQoL in these patients. From a clinical perspective, the high prevalence and impact on HRQoL highlight the need to adequately assess demoralization and psychological distress in terminal cancer patients and to identify psychological interventions that focus on preventing existential distress and thus improve the quality of life of dying patients and accompany them until the end of life.

*Keywords: Psycho-oncology, Demoralization, end-of-life, palliative care, quality of life.*

## 1. Introduction

Demoralization is characterized by feelings of hopelessness and helplessness due to the loss of meaning and purpose in life and implies a persistent inability to cope with a stressful situation (Kissane et al., 2001). In the context of distressing situations or circumstances that affect the patient's integrity, life and well-being, such as a chronic and/or progressive illness, patients may experience a spectrum of clinical manifestations ranging from an initial sense of discouragement to a deeper sense of hopelessness and failure to a strong sense of loss of meaning and purpose (Robinson et al., 2016). From a clinical perspective, demoralization is often dismissed or unrecognized, although it is associated with suicidal ideation and a desire to hasten death, and various therapies have been shown to help reduce it (Robinson et al., 2015; Gan et al., 2021).

Several studies have investigated the prevalence of demoralization in oncology and palliative care, with a recent literature review finding an average prevalence of 35.8% severe demoralization in cancer patients (Gan et al., 2021). The presence of demoralization is associated with the number and type of physical symptoms, and demoralized cancer patients have low levels of quality of life (QoL) (Robinson et al., 2015; Nanni et al., 2018; Gan et al., 2021), although no studies have delved into the relationship between demoralization and QoL in end-of-life cancer patients.

Following our previous work, in which we first examined the relationship between demoralization and QoL in a sample of 170 cancer patients in palliative care with a life expectancy of 4 months or less (Bovero et al., 2023), in the present study we explored this relationship in greater depth in a large sample. Specifically, we examined the independent impact of demoralization on patients' health-related QoL (HRQoL) in a larger sample of terminal cancer patients in palliative care, controlling for other clinical and psychological variables.

## 2. Methods

### 2.1. Participants and procedure

The participants were recruited at the "Città della Salute e della Scienza" hospital and the "V. Valletta" hospice in Turin. Hospitalized patients diagnosed with cancer and meeting the national criteria for access to palliative care were evaluated as potential candidates. Criteria for palliative care were end- stage disease, an unfavourable/poor prognosis or no possible or appropriate curative treatment, a Karnofsky Performance Status (KPS) of 50 or less and an expected life expectancy of 4 months or less. Other inclusion criteria were age over 18 years, ability to give informed consent and complete the test battery, sufficient knowledge of the Italian language and no history of neurological and/or severe psychiatric illness. Participants who met the inclusion criteria were invited to participate in the study and were enrolled after providing written informed consent.

The socio-demographic and clinical data were recorded by the palliative care physicians. The psychologist conducted the psychosocial assessment at the bedside and asked the patients to read and complete the test battery at their own pace and according to their needs.

The sample included in the present study consisted of 372 patients. The study was approved by the institution's ethics committee (protocol number 0034403, procedure number CS2/1178) and was conducted in accordance with the Declaration of Helsinki.

### 2.2. Measures

A test battery containing the Italian versions of validated self-report scales commonly used in the cancer population was used.

The Edmonton Symptom Assessment System (ESAS) was used to assess the presence and intensity of symptoms in palliative care patients on a Likert scale from zero (no symptom) to 10 (worst possible symptom).

The Hospital Anxiety and Depression Scale (HADS) was used to assess psychological distress (depressive and anxiety symptoms) during the last week; the total score ranges from 0 to 42, with higher scores indicating a high level of symptoms.

The Functional Assessment of Cancer Therapy Scale - General Measure (FACT-G) was used to assess HRQoL; the total score ranges from 0 to 100, with higher scores indicating higher HRQoL.

The Functional Assessment of Chronic Illness Therapy - Spiritual Well-Being (FACIT-Sp-12) was used to assess spirituality in the cancer setting; the total score ranges from 0 to 48, with higher scores indicating better spiritual well-being.

The Demoralization Scale - Italian Version (DS-IT) was used to assess demoralization on a Likert scale ranging from 0 (never) to 4 (always). The DS-IT is divided into five subscales: Loss of Meaning and Purpose in Life, Dysphoria, Disheartenment, Helplessness, and Sense of Failure. The total score ranges from 0 to 94, with a cut-off score of ≥37 and ≥31 indicating the presence of severe and moderate demoralization, respectively.

### 2.3. Data analysis

The Statistical Package for Social Sciences - 27.0 (IBM SPSS Statistics for Macintosh, Armonk, NY, USA: IBM Corp.) was used to perform the statistical analyses. All variables were normally distributed (all absolute values for skewness and kurtosis were below 3.0 and 8.0, respectively).

Hierarchical multiple regression analysis with stepwise method was performed to assess whether demoralisation was a significant predictor of HRQoL (FACT-G) in end-of-life cancer patients, controlling for other variables. The predictor variables (age, gender, cancer stage, KPS, ESAS symptoms, psychological distress, spiritual well-being and demoralization) were only included in the regression

models if they were significantly correlated with the outcome variable (Pearson and Spearman bivariate correlations) (p-value < 0.05). Collinearity was assessed using the statistical factors of tolerance and Variance Inflaction Factor.

## 3. Results

The terminally ill cancer patients (men: 189 (50.8 %); women: 183 (49.2 %)) had an average age of 67.1 (12.3) years, and most patients were married or in a partnership (226 (60.9 %)) and had a middle (138 (37.1 %)) or high school degree (123 (33.1 %)). The mean KPS score was 40.65 (8.8), and the most common cancers were lung cancer (83 (22.4%)), hepatic-pancreatic cancer (54 (14.6%)) and breast cancer (46 (12.4%)), with 259 (70.8%) of patients having metastatic cancer.

Mean and standard deviations of the physical and psychological symptoms and their correlation with Health-Related Quality of Life were listed in Table 1. Anxiety, lack of well-being, fatigue and depression were the most distressing symptoms in ESAS. The high level of psychological distress symptoms was confirmed by the HADS total score, with 287 (77.2%) patients reporting a score ≥15, indicating a clinically relevant level of psychological distress. The FACIT-Sp12 indicated low spirituality, and the FACT-G total score indicated that HRQoL was severely impaired.

The DS-IT data showed high level of demoralization, with "Disheartenment", "Helplessness" and "Sense of failure" being the most affected domains: 180 (48.4%) patients reported a score indicating the presence of severe demoralization, and 51 (13.7%) patients showed moderate demoralization.

*Table 1. Data regarding physical and psychological symptoms and their correlation with Health-Related Quality of Life (FACT-G) (N=372).*

|  | Mean (SD) | Pearson's r coefficients |
|---|---|---|
| FACT-G | 53.52 (14.7) |  |
| KPS | 40.65 (8.8) | .236* |
| ESAS_Pain | 1.84 (2.7) | -.181* |
| ESAS_Fatigue | 4.86 (2.8) | -.438* |
| ESAS_Nausea | 1.4 (2.5) | -.171* |
| ESAS_Depression | 4.39 (2.6) | -.627* |
| ESAS_Anxiety | 5.07 (2.5) | -.386* |
| ESAS_Drowsiness | 2.66 (3) | -.378* |
| ESAS_Appetite | 2.73 (3) | -.403* |
| ESAS_Lack of Well-Being | 4.69 (2.7) | -.556* |
| ESAS_Shortness of Breath | 1.97 (3) | -.234* |
| HADS | 19.5 (6.7) | -.779* |
| FACIT-Sp12 | 23.7 (7.7) | .586* |
| DS-IT | 36.09 (14.4) | -.735* |
| DS-IT_Loss of meaning and purpose | 5.3 (4.4) | -.539* |
| DS-IT _Dysphoria | 6.15 (3.3) | -.514* |
| DS-IT _Disheartenment | 12.83 (4.2) | -.716* |
| DS-IT _Helplessness | 6.31 (3.6) | -.686* |
| DS-IT _Sense of failure | 5.63 (2.3) | -.537* |

Note. *p-value < .001. FACT-G: Functional Assessment of Cancer Therapy-General scale; ESAS: Edmonton Symptom Assessment System; HADS: Hospital Anxiety and Depression Scale; FACIT-Sp12: Functional Assessment of Chronic Illness Therapy–Spiritual Well-Being Scale; DS-IT: Demoralization Scale-Italian version.

To investigate whether demoralization is a significant predictor of HRQoL (FACT-G) in end-of-life cancer patients, a hierarchical multiple regression analysis was performed. Age, gender and cancer stage did not correlate with FACT-G. The KPS and ESAS scores were entered into the first regression block, the HADS and FACIT-Sp12 score into the second block and the DS-IT subscales scores into the third block. The final model (Model 9 – Table 2) explained 70% of the variance of the FACT-G ($F_{(9,362)} = 97.9$, $p < 0.001$). Psychological distress ($\beta = -0.401$, $t(362) = -8.7$, $p < 0.001$) and the dimensions "Disheartenment" ($\beta = -0.211$, $t(362) = -4.5$, $p < 0.001$) and "Sense of failure" ($\beta = -0.114$, $t(362) = -3.0$, $p = 0.003$) of demoralization were the strongest and statistically significant influencing factors for HRQoL, followed by the "Dysphoria" subscale ($\beta = -0.07$, $t(362) = -2.1$, $p=.034$) of the

DS-IT and the "Appetite" (β = -0.09, t (362) = −2.5, p=.012), "Lack of Well-Being" (β = -0.08, t (362) = −2.1, p=.032), and "Drowsiness" (β = -0.07, t (362) = −2.1, p=.035) subscales of the ESAS.

*Table 2. Final model of the hierarchical multiple regression with Health-Related Quality of Life (FACT-G) as dependent variable (N=372).*

|   | Predictor | $R^2$ | Adj $R^2$ | F | F- $\Delta R^2$ | B | SE B | β | P |
|---|---|---|---|---|---|---|---|---|---|
| 9 | (Constant) | 0.71 | 0.70 | 97.92** | 4.53* | 86.368 | 4.463 | | <.001 |
| | ESAS_ Lack of Well-Being | | | | | -0.455 | 0.211 | -0.084 | .032 |
| | ESAS_ Drowsiness | | | | | -0.348 | 0.164 | -0.070 | .035 |
| | KPS | | | | | 0.056 | 0.050 | 0.034 | .259 |
| | ESAS_ Appetite | | | | | -0.428 | 0.169 | -0.088 | .012 |
| | HADS | | | | | -0.888 | 0.102 | -0.402 | <.001 |
| | FACIT-Sp12 | | | | | 0.094 | 0.082 | 0.049 | .254 |
| | DS-IT_Disheartenment | | | | | -0.749 | 0.165 | -0.211 | <.001 |
| | DS-IT_Sense of failure | | | | | -0.735 | 0.248 | -0.114 | .003 |
| | DS-IT_ Dysphoria | | | | | -0.334 | 0.157 | -0.074 | .034 |

Note. *p-value < .05; **p-value < .001

ESAS: Edmonton Symptom Assessment System; KPS: Karnofsky Performance Status Scale; HADS: Hospital Anxiety and Depression Scale; FACIT-Sp12: Functional Assessment of Chronic Illness Therapy–Spiritual Well-Being Scale; DS-IT: Demoralization Scale-Italian version.

## 4. Discussion and conclusion

In the present study, we delved into the relationship between demoralization and QoL in a sample of end-of-life cancer patients in palliative care, controlling for other clinical and psychological variables. In a previous work, where we examined this relationship for the first time in a smaller sample of 170 terminally ill cancer patients, we found a high prevalence of severe demoralization, and the data showed that demoralization was also the most important factor influencing patients' HRQoL (Bovero et al., 2023).

The results of the present study indicate that while physical symptoms are adequately managed in palliative care, much remains to be done regarding the management of psychological and emotional distress symptoms. Indeed, not only did patients report higher psychological symptom scores on the ESAS, but the HADS showed that two-thirds of the sample reported clinically significant psychological distress. In addition, the present results confirmed the very high prevalence of demoralization in end-of-life cancer patients, with a cumulative prevalence of 62.1% moderate to severe demoralization, which is consistent with the prevalence recently found in palliative care patients in Hong Kong (64.8%) (Chan et al., 2022). The perception of an uncontrollable future and the inability to cope with the terminal phase of the disease may lead to demoralization symptoms such as discouragement, helplessness and sense of failure, which emerged as the most important aspects of demoralization in our sample.

From a clinical perspective, the high prevalence of psychological and emotional distress in end-of-life cancer patients suggests that these aspects are not always adequately addressed and that there is still much to be done in palliative care in terms of prevention and therapeutic interventions. According to the present findings, psychological therapeutic interventions should address the emotional distress and feelings of discouragement and failure that dying patients experience, leading to feelings of incompetence and diminished self-esteem, by helping patients cope with illness-related losses and worries about the future (Vehling & Philipp, 2018).

Consistently with the few other studies on advanced cancer patients, the present data confirmed that demoralization was associated with poorer QoL in end-of-life cancer patients (Bovero et al., 2023; Robinson et al., 2017; Tang et al., 2020). The regression analysis showed that not only demoralization was associated with patients' HRQoL, but that the demoralization dimensions "Disheartement" and "Sense of Failure" were the most important predictors of HRQoL, in addition to psychological distress. The fact that HRQoL was mainly predicted by the psychological symptoms and not by the cancer-related variables, and only marginally by the physical symptoms, underlines the need for the health care system to adequately assess psychological distress and demoralization in dying cancer patients.

In summary, the present findings underscore the need for adequate assessment of demoralization in cancer patients at the end of life, both because of its high prevalence and because it independently affects multiple aspects of patients' HRQoL. As the disease progresses, alongside helplessness, poor coping and giving up, a sense of futility may emerge and patients may become hopeless, socially isolated and suffer from feelings of shame and personal failure (Clarke & Kissane, 2002; Robinson et al., 2015). Psychological interventions should focus on preventing existential distress and demoralization triggered by physical discomfort and loss of function, recognizing their existential suffering and supporting the meaning of life in the therapeutic relationship, in order to optimize their QoL (Breitbart et al., 2018).

*References*

Bovero, A., Opezzo, M., & Tesio, V. (2023). Relationship between demoralization and quality of life in end-of-life cancer patients. *Psycho-Oncology*, *32*(3), 429-437.

Breitbart, W., Pessin, H., Rosenfeld, B., Applebaum, A. J., Lichtenthal, W. G., Li, Y., Saracino, R., Marziliano, A. M., Masterson, M., Tobias, K., & Fenn, N. (2018). Individual meaning-centered psychotherapy for the treatment of psychological and existential distress: A randomized controlled trial in patients with advanced cancer. *Cancer*, *124*(15), 3231-3239.

Chan, W. C. H., Yu, C. T. K., Kwok, D. K. S., & Wan, J. K. M. (2022). Prevalence and factors associated with demoralization in palliative care patients: A cross-sectional study from Hong Kong. *Palliative & Supportive Care*, 1-9.

Clarke, D. M., & Kissane, D. W. (2002). Demoralization: its phenomenology and importance. *Australian & New Zealand Journal of Psychiatry*, *36*(6), 733-742.

Gan, L. L., Gong, S., & Kissane, D. W. (2021). Mental state of demoralization across diverse clinical settings: a systematic review, meta-analysis and proposal for its use as a 'specifier' in mental illness. The *Australian and New Zealand Journal of Psychiatry, 8*(9), 1104-1129.

Kissane, D. W., Clarke, D. M., & Street, A. F. (2001). Demoralization syndrome--a relevant psychiatric diagnosis for palliative care. *Journal of Palliative Care, 17*(1), 12-21.

Nanni, M. G., Caruso, R., Travado, L., Ventura, C., Palma, A., Berardi, A. M., Meggiolaro, E., Ruffilli, F., Martins, C., Kissane, D., & Grassi, L. (2018). Relationship of demoralization with anxiety, depression, and quality of life: A Southern European study of Italian and Portuguese cancer patients. *Psycho-Oncology*, *27*(11), 2616-2622.

Robinson, S., Kissane, D. W., Brooker, J., & Burney, S. (2015). A systematic review of the demoralization syndrome in individuals with progressive disease and cancer: a decade of research. *Journal of Pain and Symptom Management*, *49*(3), 595-610.

Robinson, S., Kissane, D. W., Brooker, J., & Burney, S. (2016). A review of the construct of demoralization: history, definitions, and future directions for palliative care. The *American Journal of Hospice & Palliative Care*, *33*(1), 93-101.

Robinson, S., Kissane, D. W., Brooker, J., Hempton, C., & Burney, S. (2017). The relationship between poor quality of life and desire to hasten death: a multiple mediation model examining the contributions of depression, demoralization, loss of control, and low self-worth. *Journal of pain and symptom management*, *53*(2), 243-249.

Tang, L., Li, Z., & Pang, Y. (2020). The differences and the relationship between demoralization and depression in Chinese cancer patients. *Psycho-Oncology*, *29*(3), 532-538.

Vehling, S., & Philipp, R. (2018). Existential distress and meaning-focused interventions in cancer survivorship. *Current Opinion in Supportive and Palliative Care*, *12*(1), 46-51.