



Contents lists available at ScienceDirect

## International Journal of Gerontology

journal homepage: [www.ijge-online.com](http://www.ijge-online.com)

Original Article

## Demoralization Syndrome Among Elderly Patients with Cancer Disease

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## ARTICLE INFO

Article history:  
Available online 1 March 2018

Keywords:  
aged,  
cancer,  
depression,  
hospice care/psychology,  
morale

## SUMMARY

**Background:** Demoralization is distinctive psychological distress that involves hopelessness, helplessness, loss of purpose and meaning, and existential distress. Cancer patients' demoralization has been well documented, but little is known regarding older cancer patients and the related factors. Therefore, this study evaluated demoralization syndrome in older cancer patients.

**Methods:** Cancer patients over 61 years old ( $n = 113$ , female 59.3%, mean age 65.7 years, range 61–80) diagnosed with heterogeneous types of cancer were recruited. They completed questionnaires in a hospital's inpatient and outpatient units. Their demoralization was measured using the Demoralization Scale-Mandarin Version (DS-MV). The Patient Health Questionnaire-9 (PHQ-9), Distress Thermometer (DT), Beck Scale for Suicide Ideation (BSS), and Posttraumatic Growth Inventory (PTGI) were used to measure other psychological statuses and the association with demoralization.

**Results:** The mean DS-MV score was 28.1 ( $SD = 16.3$ ). In this sample, 57.7% had moderate to high demoralization (18.6% had moderate demoralization, and 38.1% had high demoralization). Twenty-three percent reported a DT score of five and above, 5.5% reported a PHQ-9 score of 10 and above, and 23.9% reported a BSS score greater than zero. Demoralization was associated with suicide ideation, depression, distress, lower education, and the cancer site. Demoralization was not associated with posttraumatic growth, gender, work status, or religion.

**Conclusion:** More than half of older cancer patients have moderate to high demoralization and it is associated with depression, suicide ideation, and distress. Screening and interventions that are better tailored to older cancer patients could improve the quality of care in cancer treatment.

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## 1. Introduction

Demoralization has become a potential psychiatric diagnosis in the most recent decade, and it has gained much attention in palliative care for cancer patients.<sup>1</sup> The concept of demoralization provides an opportunity for the assessment of psychological distress in cancer patients falling outside of the classic diagnosis system.

Several scholars have consolidated the concept of demoralization; the most recent formulation was proposed by Clarke and Kissane from studies of suicide and desire for hastened death in medically ill or advanced cancer patients.<sup>2,3</sup> They define

demoralization as an affective state of loss of meaning and hopelessness, with thoughts of helplessness and personal failure, subjective incompetence, and social alienation.<sup>4</sup>

While demoralization shares the clinical symptom of dysphoric mood, scholars believe there are distinct differences between them.<sup>5–8</sup> A subgroup of patients with high demoralization did not meet DSM-IV criteria for major depressive disorder. In general, depression is characterized by anhedonia (loss of pleasure and interest), while demoralization is characterized by hopelessness, helplessness, and meaninglessness.<sup>5</sup> Demoralized people may experience pleasure from engaging in activities and have a full range of affect compared to depressive patients. However, demoralization is not a lighter state of depression. Demoralization is a spectrum from normal reactive response to an abnormal psychological state that impairs a person's coping and will to live.<sup>9,10</sup>

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Studies demonstrate that demoralization and depression are strongly and independently related to suicide ideation or desire for hastened death in the cancer population.<sup>8,11,12</sup> Kissane emphasized the need of recognized and provide treatment to demoralization symptom because it's an explanatory source of suicidal thinking in palliative care.<sup>4</sup> Some scholars considered demoralization as a symptom of adjustment disorder.<sup>13,14</sup> However, little research has been done demonstrating the validity or clinical merit in chronic or advanced medical ill patients, and the core feature of time-limited in adjustment disorder may different from the observed prolonged demoralization in advanced cancer patients.

Several studies have examined the prevalence of demoralization in clinical populations. In a systematic review of 25 studies, clinical prevalence rates for demoralization ranged from 13% to 18% in patients with progressive diseases like cancer.<sup>1</sup>

Cancer disproportionately affects the elderly. In 2009, 53.2% of new cancer diagnoses and 69.2% of cancer deaths occurred in the older U.S. population.<sup>15</sup> As the geriatric population is expected to grow worldwide, the study of psychological distress or older cancer patients' needs is an increasingly important health-care issue. Geriatric patients were not considered a specific group with different needs in medicine until gerontology and geriatric medicine were established as a separate discipline. Studies regarding age and demoralization are sporadic and inconsistent; positive, negative, or no associations with age have been found.

It is already known that the suicide risk is higher in older populations. Studies of hospitalized elderly people show that approximately one in four reports a high level of risk, and undergoing cancer treatment is one important factor associated with a higher risk. An Australian case-control psychological autopsy study reported a significantly lower prevalence of psychiatric disorders (62%) in older adults compared with middle-aged suicide cases (80%).<sup>16</sup> The risk factors other than current psychiatric diagnosis, especially demoralization, require more attention. To our knowledge, little is known about demoralization in elderly people. No study has investigated older cancer patients' demoralization. Thus, this study explored demoralization and its associated factors among older cancer patients.

## 2. Materials and methods

### 2.1. Participants and procedures

This is a secondary analysis study of a sample of cancer patients of all ages. In the original study, a convenience sample was recruited from inpatient and outpatient units for breast, digestive and liver, colorectal, neck and head, and gynecological cancers in a medical center in north Taiwan. The research assistants checked the daily inpatient and outpatient lists for patients diagnosed with these cancer types. They were approached and invited to participate by trained research assistants after a physician introduced them. The exclusion criteria included cognitive impairment and confusion. Written informed consent was obtained after the data collection's purpose and nature were explained.

The participants completed questions about their sociodemographic information (age, gender, education level, work status, marital status) and disease characteristics (cancer site, cancer stage), and a pack of questionnaires. The research assistants checked the cancer site and stage from the charts after the interview. They read the questionnaires aloud if participants had difficulty reading them. The Hospital Committee on Human Testing approved the study and passed the institutional review board's inspection to allow clinical research (12MMHIS008). The research assistants were one senior psychologist and two master's degree psychology students who received training and supervision by a

research psychiatrist during the study. The data were collected between March 2012 and March 2013. In total, we invited 470 participants to sign the informed consent and answer the demographic questions and questionnaires. Completed questionnaires were obtained from 350 patients. For this study's purpose of understanding the clinical picture of older adults, the data of 113 patients aged over 61 years were used.

### 2.2. Measures

#### 2.2.1. Demoralization Scale-Mandarin version

The Demoralization Scale-Mandarin Version (DS-MV) was translated from the Demoralization Scale,<sup>17</sup> which is the most widely used scale and it has been translated into several languages with appropriate validity.<sup>7,18,19</sup> The scales contain the same 24 items, with each rated on a five-point Likert scale, ranging from zero (never) to four (all of the time). The DS-MV had high internal reliability (Cronbach's alpha = 0.92) and convergent validity with the McGill Quality of Life Scale, Patient Health Questionnaire (PHQ-9), and Beck Hopelessness Scale in a study of cancer patients in Taiwan.<sup>20</sup> The DS-MV uses a five-factor model, the same as the DS, that includes loss of meaning and purpose ( $\alpha = 0.84$ ), dysphoria ( $\alpha = 0.77$ ), disheartenment ( $\alpha = 0.82$ ), helplessness ( $\alpha = 0.85$ ), and a sense of failure ( $\alpha = 0.68$ ). A cut-off DS score  $\geq 30$  was considered to indicate demoralization in the original study.<sup>17</sup> The German version chose a cut-off score of 30 to indicate moderate demoralization and of 36 to indicate a high level of demoralization in advanced cancer patients.<sup>7</sup> This study used a DS-MV cut-off score  $\geq 36$  to define high demoralization.

#### 2.2.2. Patient Health Questionnaire-9

Depression was assessed using the Diagnostic and Statistical Manual of Mental Disorders-based depression module of the PHQ-9.<sup>21,22</sup> It is a nine-item scale that uses a four-point Likert scale ranging from zero to three. It is a validated screening instrument for depression in the general population, primary care patients, and cancer patients.<sup>22-24</sup> In the Chinese population, the Chinese version has satisfactory psychometric properties for the detection of major depressive disorder among the elderly with acceptable internal consistency ( $\alpha = 0.77$ ), test-retest reliability, and concurrent validity with HAMD.<sup>22</sup> A meta-analysis of studies using the PHQ-9 in medical settings, with cut-off scores  $\geq 10$  for major depressive disorder, showed a pooled sensitivity (0.80) and specificity (0.92).<sup>23</sup>

#### 2.2.3. Beck Scale for Suicide Ideation

The Beck Scale for Suicide Ideation (BSS) was used to measure the severity of suicide ideation during the past week.<sup>25</sup> The BSS has 17 items that use a three-point Likert scale, plus two additional items that assess the number of previous attempts and strength of the intent to die during the last attempt. The score range of each question is 0-2 points. There is no cut-off score. All scores above zero indicate the presence of suicide ideation. A higher score indicates stronger suicide ideation. The internal reliability, test-retest reliability, and concurrent validity have been established.<sup>26</sup>

#### 2.2.4. Posttraumatic growth inventory

Posttraumatic growth (PTG) represents positive psychological change as a result of struggling with a highly challenging life event or traumatic experience. PTG has been demonstrated in various cancer types and is associated with physical and mental well-being. The Posttraumatic Growth Inventory (PTGI) is the most widely used instrument to evaluate PTG.<sup>27</sup> It is a 21-item questionnaire with answers rated from 0 to 5 (zero meaning "I did not experience this as a result of my crisis" and five meaning "I experienced this to a

**Table 1**  
Demographic characteristics of the study participants and descriptive statistics for demoralization.

Variables	n	%	Demoralization frequency (DS-MV $\geq$ 36)			
			n	%	$\chi^2$	P-value
Total	113	100	43	38.1		
Gender					4.71*	0.030
Male	46	40.7	12	26.1		
Female	67	59.3	31	46.3		
Age (years)					0.202	0.653
61–70	95	84.1	37	38.9		
71–80	18	15.9	6	33.3		
Education					7.01**	0.008
Junior high and lower	78	69.0	36	46.2		
High school and above	35	31.0	7	20.0		
Work					0.94	0.331
No	78	69.0	32	41.0		
Yes	35	31.0	11	31.4		
Religion					2.04	0.153
No	11	9.7	2	18.2		
Yes	102	90.3	41	40.2		
Cancer type					15.01**	0.005
Colorectal	28	24.8	7	25.0		
Digestive and liver	25	22.1	5	20.0		
Head and neck	21	18.6	7	33.3		
Breast	19	16.8	5	26.3		
Gynecological	20	17.7	13	65.0		
Depressed					10.32**	0.001
No	107	94.7	37	34.6		
Yes	6	5.3	6	100.0		

\*  $p < 0.05$ ; \*\*  $p < 0.01$ . DS-MV = Demoralization Scale-Mandarin Version.

very great degree as a result of my crisis"). The Chinese version has good internal consistency ( $\alpha = 0.86$ ) and validity in cancer patients.<sup>28,29</sup>

### 2.2.5. Distress Thermometer

The Distress Thermometer (DT) is an ultra-short screening instrument that assesses psychological distress. It is a self-assessment tool that uses a visual analog scale in the form of a thermometer, which ranges from zero (no distress) to 10 (extreme distress). It is the most widely utilized screening instrument in cancer care.<sup>30</sup> A cut-off score of five has optimal sensitivity and specificity among Taiwanese cancer patients.<sup>31</sup>

### 2.3. Statistical analysis

Standard descriptive statistics were used to characterize the sample's demographic, disease, and psychological distress variables. The differences between a demoralization group and non-demoralization group were analyzed using the chi-square test. Correlations were computed using Pearson's correlation analysis, and  $p < 0.05$  was considered statistically significant. The influences of age, gender, education, cancer type, work, and religion, and the BSS, PHQ-9, and DT on demoralization were analyzed using multiple linear regression. The data were analyzed using SPSS version 18.0 (SPSS Inc., Chicago, IL, USA).

## 3. Results

### 3.1. Demographics and disease characteristics

Patients were aged between 61 and 80 years old (Table 1). The mean age was 66.7 years ( $SD = 4.8$ ). Sixty-seven patients (59.3%) were female. The education data were collected in the following categories: no education (9.7%,  $n = 11$ ), elementary school (39.8%,  $n = 45$ ), junior high school (19.5%,  $n = 22$ ), senior high school

(16.8%,  $n = 19$ ), college (12.4%,  $n = 14$ ), and master's degree (0.9%,  $n = 1$ ). The education level was divided into two groups: junior high and lower ( $n = 78$ ; 69.1%) and senior high and above ( $n = 35$ ; 31.0%). There was a high proportion of religious patients (90.3%).

### 3.2. Psychological variables

The mean DS-MV score was 28.1 ( $SD = 16.3$ , range 0–78). Of the sample, 18.6% ( $n = 21$ ) had moderate demoralization ( $30 \leq DS-MV < 36$ ) and 38.1% ( $n = 43$ ) had high demoralization ( $DS-MV \geq 36$ ), resulting in 56.7% of patients having moderate to high demoralization. The DT's mean score was 2.21 ( $SD = 2.44$ , range 0–8). Twenty-six participants (23%) reported a DT score of five or above. The PHQ-9's mean score was 4.07 ( $SD = 3.625$ , range 0–18). Using a cut-off score of 10, 5.5% ( $n = 6$ ) were considered to have major depressive disorder. The BSS's mean score was 0.65 ( $SD = 1.777$ , range 0–11), and 23.9% ( $n = 27$ ) reported suicide ideation ( $BSS \geq 1$ ). Comparing the prevalence of depression and demoralization, about 14% of patients with high demoralization had depression; however, 100% of the depressive patients had high demoralization.

### 3.3. Bivariate correlations between demoralization and the independent variables

Bivariate correlations were used to examine the relationship between demoralization and each variable. The patients were divided into a demoralization group and non-demoralization group using the DS-MV score  $\geq 36$ . We found significant correlations between demoralization and education, gender, cancer type, and depression. A lower education level, being female, having gynecological cancer, and depression were associated with demoralization. Female patients had almost double the prevalence rate than male patients (46.3% and 26.1% respectively). Demoralization was not associated with older patients' age, work status, or being religious.

### 3.4. Correlations

The DS-MV was correlated with the PHQ-9 (0.57), DT (0.42), and BSS (0.34) ( $p < 0.001$ ) but not with the PTGI (0.03) (Table 2).

### 3.5. Multivariable regression

Education, depression, suicide ideation, distress, and cancer type were significantly independently associated with the DS-MV. Female patients showed a higher DS-MV score, but the gender difference was minimal and not significant. Patients with gynecological cancer scored 9.31 points more than the reference group (colorectal cancer) (Table 3).

**Table 2**  
Correlations between the Demoralization Scale-Mandarin Version and mental health variables ( $n = 113$ ).

Variables	DS-MV	PHQ-9	BSS	DT	PTGI
DS-MV	–	0.568***	0.340***	0.422***	0.025
PHQ-9	0.568***	–	0.305**	0.476***	0.117
BSS	0.340***	0.305**	–	0.182	–0.031
DT	0.422***	0.476***	0.182	–	0.026
PTGI	0.025	0.117	–0.031	0.026	–

\*\*  $p < 0.01$ ; \*\*\*  $p < 0.001$ . BSS = Beck Scale for Suicide Ideation; DS-MV = Demoralization Scale-Mandarin Version; DT = Distress Thermometer; PHQ-9 = Patient Health Questionnaire; PTGI = Posttraumatic Growth Inventory.

**Table 3**  
Multivariable regression analysis for variables predicting older patients' Demoralization Scale-Mandarin version score ( $n = 113$ ).

Variables (reference group)	<i>B</i>	<i>SE B</i>	$\beta$	<i>t</i>	<i>P-value</i>
Intercept	24.83	5.74		4.32***	>0.001
Gender (female)					
Male	-1.40	2.72	-0.04	-0.52	0.608
Education (junior high or lower)					
High school and over	-6.54	2.56	-0.19	-2.56*	0.012
Working status (no work)					
Work	-4.19	2.75	-0.12	-1.52	0.131
Religion (no religion)					
Religion	-0.23	3.98	0.00	-0.06	0.954
PHQ-9 score	1.69	0.38	0.38	4.45***	>0.001
BSS score	1.75	0.67	0.19	2.63**	0.010
DT score	1.38	0.56	0.21	2.48*	0.015
Cancer type (colorectal)					
Digestive and liver	6.66	3.58	0.16	1.86	0.066
Head and neck	1.54	4.04	0.04	0.38	0.704
Breast	-1.49	3.43	-0.04	-0.44	0.664
Gynecological	9.31	3.96	0.22	2.35*	0.021

\*  $p < 0.05$ ; \*\*  $p < 0.01$ ; \*\*\*  $p < 0.001$ . BSS = Beck Scale for Suicide Ideation; DT = Distress Thermometer; PHQ-9 = Patient Health Questionnaire.

#### 4. Discussion

The present study aimed to gain better understanding of demoralization in older cancer patients and the factors associated with it. Based on the cut-off value of  $\geq 30$  for moderate demoralization and  $\geq 36$  for high demoralization, we found that 56.7% of our sample had moderate to high demoralization. The prevalence of demoralization was high in our sample compared with previous studies of cancer patients of all ages, which reported it in 42% of cancer patients in Taiwan ( $DS \geq 30$ ), 39.1% of advanced cancer patients in Germany ( $DS \geq 30$ ), and 28.8% of advanced cancer patients in Italy.<sup>7,11,32</sup>

Our study shows that education level, cancer type, depression, suicide ideation, and distress are independent factors associated with demoralization. In older cancer patients, women have a higher risk of demoralization, which may be explained by the above factors because a significant gender difference was not found after controlling these factors. Education is known to affect people's psychological well-being, such as depression, and quality of life. Our study demonstrated the similar influence of education on demoralization in older patients. People with higher education may have better psychological and social resources to cope with cancer challenges. Controlling other socioeconomic variables, such as household income and financial status, in future studies may help to understand the effect of education on demoralization.<sup>33</sup>

The sample showed a low percentage of major depressive disorder (5.5%). Only 14% of the high demoralization patients ( $DS-MV \geq 36$ ) had major depressive disorder. This finding supports the hypothesis that demoralization, despite overlapping with depression, is a distinct concept from depression. In this study, 23.9% of patients reported suicidal thoughts. The BSS was most related to demoralization in this sample, which is similar to a study of cancer patients of all ages that demonstrated a stronger association between demoralization and suicide ideation than between depression and suicide ideation.<sup>11</sup> Demoralization may be a valuable clinical red flag for suicide screening and intervention.

In this study, gynecological cancer had higher demoralization than the other four types, even when gender was controlled. It is the fourth most frequently diagnosed cancer in women worldwide.<sup>34</sup> Studies of gynecological cancer patients have identified significantly higher levels of psychological distress compared to other cancers, which may be related to unique physical burdens following treatment.<sup>35</sup> The majority receives radical pelvic and

genital surgeries in addition to subsequent radiation or chemotherapy treatment and there are high rates of bladder, urinary tract, and bowel complications.<sup>36</sup> The loss of a sense of coherence has been reported in gynecological cancer patients, which is believed to be associated with demoralization.<sup>37</sup>

This study's limitations should be noted. The participants were those who were willing to finish the instruments and provide informed consent, and they were recruited from one hospital setting and only five cancer types were included, which limits the generalization of the results to the whole population. In summary, demoralization is a common clinical phenomenon in older cancer patients. A lower education level, distress, depression, and suicide ideation are the demographic and clinical factors associated with demoralization in older patients. Screening demoralization and interventions that are better tailored to older cancer patients would improve the quality of care in cancer treatment.

#### Funding/Support

This work was supported by Mackay Memorial Hospital Research Funding 12MMHIS008.

#### Conflicts of interest

The authors have no conflicts of interest to declare.

#### Acknowledgment

The authors declare no conflicts of interest. The authors thank the recruiting clinicians and all patients.

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