

# Existential distress and associated factors in advanced cancer patients: A cross-sectional study

## Original Article

**Cite this article:** Xu G, Zheng J, Lin X, Wu H, Yang S, Xiao H, Lin X (2024) Existential distress and associated factors in advanced cancer patients: A cross-sectional study. *Palliative and Supportive Care* 22(5), 1094–1101. <https://doi.org/10.1017/S147895152400018X>


Received: 25 August 2023  
Revised: 14 November 2023  
Accepted: 24 January 2024

### Keywords:

Existential distress; advanced cancer; associated factors; cross-sectional study

### Corresponding authors:

Huimin Xiao;  
Email: [huimin\\_xiao@126.com](mailto:huimin_xiao@126.com);  
Xiaoyan Lin;  
Email: [13950482366@qq.com](mailto:13950482366@qq.com)

Guiru Xu, M.D.<sup>1</sup> , Jianwei Zheng, PH.D.<sup>2</sup>, Xiaodan Lin, M.D.<sup>1</sup>, Hong Wu, B.D.<sup>3</sup>, Shangwang Yang, M.D.<sup>4</sup>, Huimin Xiao, PH.D.<sup>1</sup> and Xiaoyan Lin PH.D.<sup>2</sup>

<sup>1</sup>School of Nursing, Fujian Medical University, Fuzhou, China; <sup>2</sup>Department of Oncology, Fujian Medical University Union Hospital, Fuzhou, China; <sup>3</sup>Fujian Provincial Hospice, Fuzhou, China and <sup>4</sup>Department of Oncology, Affiliated Rehabilitation Hospital of Fujian University of Traditional Chinese Medicine, Fuzhou, China

### Abstract

**Background.** Advanced cancer patients often experience existential distress (ED). However, the factors associated with ED remain unclear. This study investigated the current state of ED and identified the associated factors in Chinese patients with advanced cancer.

**Methods.** A cross-sectional study was conducted among 352 advanced cancer patients from 3 tertiary hospitals in Fujian, China. Participants were invited to complete the Existential Distress Scale, Number Rating Scale, Self-Perceived Burden Scale, Quality of Life Concerns in the End-of-Life Questionnaire, and Hospital Anxiety and Depression Scale.

**Objectives.** This study aimed to investigate the level of existential distress among advanced cancer patients in China and identify the associated factors.

**Results.** A total of 352 advanced cancer patients were recruited for this study. The average score for ED was  $8.48 \pm 7.12$  among the advanced cancer patients. Multiple regression showed that the associated factors included depression ( $\beta = 0.32, p = 0.000$ ), self-perceived burden (SPB) ( $\beta = 0.18, p = 0.001$ ), the presence of a spouse ( $\beta = -0.10, p = 0.050$ ), and reception of government subsidies ( $\beta = 0.17, p = 0.001$ ). The factors accounted for 30.1% of the total variance in ED ( $F = 8.472, p < 0.001$ ).

**Significance of results.** Among the advanced cancer patients queried, ED was found to be positively influenced by depression, SPB, and reception of government subsidies and negatively influenced by the presence of a spouse. Depression was the most important risk factor, and thus future ED interventions should target depression.

## Introduction

The global incidence and mortality rates for cancer have been steadily increasing. In 2020, the number of new cancer cases reached 19.3 million, with 10.0 million deaths attributed to the disease worldwide. China accounts for a significant proportion of these cases, with 4.5 million new cancer cases and 3.0 million cancer-related deaths that year (Sung et al. 2021). Facing deteriorating physical symptoms, psychological trauma, and impending death, advanced cancer patients often experience existential distress (ED). ED refers to the mental turmoil experienced by individuals who are approaching death (Kissane 2000). It is characterized by a state of profound psychological upheaval that is often accompanied by feelings of remorse, powerlessness, futility, and an overwhelming sense of meaninglessness (LeMay and Wilson 2008). Chen et al. (2022) identified 5 core attributes of this experience: feelings of meaninglessness, loss of autonomy, loss of dignity, hopelessness, and death anxiety. Empirical studies have shown that 53.4%–72.8% of advanced cancer patients report moderate to high levels of ED (Bovero et al. 2019; Vehling and Kissane 2018). Moreover, a considerable body of literature has linked ED to a range of adverse outcomes, including decreased psychological well-being, poor quality of life (QoL), suicidal ideation, and loss of the will to live (Bovero et al. 2023; Salander 2018; Vehling and Kissane 2018).

Self-perceived burden (SPB) is a term used to describe the empathetic concern that arises from the impact of one's illness and care needs on others (McPherson et al. 2007). Due to the extensive care required, financial strain, and emotional toll, patients with advanced cancer often perceive themselves as a burden on their loved ones. Research has indicated that a significant number of patients with advanced cancer suffer from SPB (ranging from 50% to 73%) (Akazawa et al. 2010; Saji et al. 2022). Such feelings of guilt, shame, distress, and irresponsibility result from difficulties in restoring equity to the caregiving relationship (McPherson et al. 2007, 2010). Relying on others for daily life assistance inevitably causes such individuals to struggle with their self-concept, as they must to relinquish roles that once defined them

(Dempsey et al. 2012). When trapped with feelings of being burdensome, patients may believe that they are making life more difficult for their caregiver and their caregiver would be better off without them (Dempsey et al. 2012). These feelings result in an affective state of hopelessness and loss of meaning and purpose (Liu et al. 2022). However, the relationship between SPB and ED has yet to be empirically confirmed in advanced cancer patients.

QoL is a crucial measure of overall well-being and a central concept in palliative care. Advanced cancer patients often experience a significant reduction in QoL due to the physical, emotional, and spiritual effects of the disease and its treatment. Evidence has shown that the QoL of advanced cancer patients is affected by ED (Cohen et al. 1996). According to an Italian study by Bovero et al., ED was not only found to be associated with poor QoL across all domains but also identified as the most significant contributing factor to poor QoL in advanced cancer patients (Bovero et al. 2023). A study conducted in southern Europe has also confirmed that ED has a negative impact on advanced cancer patients' physical, functional, and psychological symptoms, leading to a poor QoL (Nanni et al. 2018). Recently, Chang et al. revealed that poor QoL conversely increased the level of ED in cancer patients. However, to date, the cause and effect relationship between ED and QoL has not been thoroughly documented (Chang et al. 2022).

Anxiety and depression are prevalent psychological disorders in advanced cancer patients. They can be caused by various factors such as physical symptoms, side effects of treatment, social isolation, uncertainty about the future, and fear of recurrence. A conceptual analysis of ED suggests that severe psychological disorders such as anxiety or depression may contribute to the development of ED in cancer patients (Chen et al. 2022). Several studies have also indicated that anxiety and depression exacerbate ED in patients with advanced cancer, but that research was focused on Spain and Germany (Belar et al. 2019; Mehnert et al. 2011; Rudilla et al. 2016). It is still unknown whether those findings can be generalized to advanced cancer patients in other countries such as China. Therefore, it is crucial to investigate whether anxiety and depression play a role in the development of ED in Chinese advanced cancer patients.

Previous research has provided initial insights into the correlation between ED and SPB, QoL, anxiety, and depression (Belar et al. 2019; Chen et al. 2022; Nanni et al. 2018). However, most studies have predominantly relied on theoretical perspectives to explain the relationship. To the best of our knowledge, no published research has yet explored the connections among ED, SPB, QoL, anxiety, and depression in Chinese patients with advanced cancer. The lack of understanding regarding these relationships may impede healthcare professionals seeking to develop and test culture-specific ED interventions for advanced cancer patients. Filling this knowledge gap is particularly significant for the future development of palliative care services for advanced cancer patients in China. Hospice care in China is still in an early stage, due to the taboo of death and a culture of filial piety. In order to promote the development of hospice care, the Chinese National Health Commission launched 3 hospice care pilot projects from 2017 to 2023. The Guidelines for Hospice Care Practice emphasize that healthcare professionals should provide psycho-spiritual care for hospice care patients in order to improve their QoL (National Health and Family Planning Commission of the People's Republic of China 2017). Therefore, the present study examines the current status of ED and its connection to SPB, anxiety, depression, and QoL in Chinese patients with advanced cancer.

## Method

### Participants and design

The present study used a cross-sectional design and convenience sampling method. The participants were recruited from 2 hospitals and 1 hospice in Fujian in the southeast of China, from June 2020 to January 2021. The criteria for participants included their being: (1) diagnosed with advanced cancer at stage III or IV, according to the TNM staging system; (2) aged 18 years or above; (3) aware of their diagnosis and treatment; and (4) without verbal communication or cognitive impairment. Participants were excluded if they were (1) severely disabled or critically ill (Karnofsky Performance Status <40) or (2) experiencing a visual, hearing, or psychiatric disorder.

### Data collection

Data collection was completed by 3 trained research assistants (RAs). After obtaining written informed consent, the participants were invited to individually complete questionnaires. The RAs guided participants in how to complete the questionnaires and if participants had difficulty reading or understanding the instrument, the RAs explained the items without offering any inducement. The questionnaires were distributed on location and collected and checked for missing items. It took participants 15–20 minutes to complete the survey. A total of 370 questionnaires were distributed, 18 (4.9%) of which were excluded due to incomplete data ( $n = 12$ ) or over-centralized responses ( $n = 6$ ). Finally, 352 valid questionnaires were recovered. The effective participation rate was 95.1%.

### Ethical approval and consent to participate

The study was approved by the biomedical ethics committee of Fujian Medical University (No. 20, 2018). Per the Declaration of Helsinki, all participants provided written informed consent prior to their inclusion. All data were kept confidential and anonymous and used exclusively for this research.

### Instruments

#### Sociodemographic and disease-related information

A personal information form was developed by the research team to collect participants' sociodemographic and disease-related information. Sociodemographic variables included age, gender, spouse (yes/no), education level, religion, co-residents, primary caregiver, health insurance, income source, and monthly income. The data were collected via this self-completed general information questionnaire. The disease-related variables included type of tumor, surgery (yes/no), chemotherapy (yes/no), radiotherapy (yes/no), use of analgesic (yes/no), pain intensity, and course of disease (months). This information was collected from the patients' medical records.

#### Existential Distress Scale (EDS)

The EDS was used to measure the ED of the advanced cancer patients. It was first compiled by Lo et al. (2017) and translated into and validated in Chinese by our research team. The Chinese EDS contains 10 items divided into 3 dimensions: meaninglessness, loneliness, and low self-worth. Responses are recorded on a 5-point scale ranging from 0 (unbearable distress) to 4 (no distress). The total EDS score ranges between 0 and 40, with higher scores representing greater ED. The Cronbach's  $\alpha$  for the Chinese EDS is

0.892 and ranges from 0.75 to 0.86 for its dimensions (Huimin *et al.* 2022).

### Number Rating Scale (NRS)

The NRS was used to evaluate the pain intensity experienced by the advanced cancer patients queried in this study (Jensen *et al.* 1986). It is an 11-point scale ranging from 0 (no pain) to 10 (worst imaginable pain). NRS categories include no pain (NRS = 0), mild pain (NRS = 1–3), moderate pain (NRS = 4–6), and severe pain (NRS = 7–10).

### Chinese Self-Perceived Burden Scale (SPBS)

The SPBS was initially developed by Cousineau *et al.* to measure SPB. The Chinese version (C-SPBS), translated by Zhang Qingna, was applied in the present study (QN 2013). The C-SPBS has 8 items and is scored on a 5-point Likert scale ranging from 1 (none of the time) to 5 (all of the time). The scale's total score ranges from 8 to 40, with higher scores indicating higher SPB. The scale's Cronbach's  $\alpha$  is 0.88.

### Quality of Life Concerns in the End of Life Questionnaire (QOLC-E)

QoL was measured by the QOLC-E, which contains 29 items (Pang *et al.* 2005). One of the items is used to measure overall subjective QoL on a numeric scale ranging from 0 (least desirable) to 10 (most desirable). The other 28 items are grouped into 4 positive ("support," "value of life," "food-related concerns," and "healthcare concerns") and 4 negative subscales ("physical discomfort," "negative emotions," "sense of alienation," and "existential distress"). It uses a 5-point scoring system ranging from 0 to 4, with higher scores indicating higher levels of satisfaction with QoL. The Cronbach's  $\alpha$  for the scale is 0.87 and ranges from 0.57 to 0.83 for its subscales.

### Hospital Anxiety and Depression Scale (HADS)

The HADS was used to assess the possible presence of anxiety and depression (Sun *et al.* 2017). The 14-item scale is divided into 2 subscales, the HADS-A for anxiety and HADS-D for depression. Each item is rated on a 4-point Likert scale ranging from 0 (as much as I always do) to 3 (not at all). Total scores range from 0 to 21, with higher scores indicating a higher probability of anxiety or depression. The Cronbach's  $\alpha$  of the HADS-A ranges from 0.80 to 0.93.

### Statistical analysis

Statistical analyses were carried out using SPSS 23.0. Normal distribution tests were verified using Kolmogorov–Smirnov. Continuous variables were expressed as mean  $\pm$  standard error ( $M \pm SD$ ) or medians with interquartiles, while categorical variables were reported as frequency and percentage (%). The Kruskal–Wallis nonparametric test was used to compare ED scores for patients' sociodemographic and disease-related characteristics. Spearman correlation analysis was employed to assess correlations among variables. Multivariate linear regression model was used to explore the associated factors of ED. The 2-sided  $P < 0.05$  was considered statistically significant.

## Results

### Participant characteristics

A total of 352 patients participated in the survey. More than half were male (64.8%), aged between 18 and 59 years (54.8%), and

lived with their spouses and/or adult children (50.0%). The participants were mainly cared for by their spouses (59.1%) and covered under resident health insurance (67.0%). Almost all of the participants were married (93.2%). Some participants had received an education below middle school (44.9%) and were affiliated with a religion (48.3%). A smaller proportion of participants had incomes derived from a salary or pension (38.3%), and 38% of the patients' monthly income per person was between 1,000 and 3,000 Ren Min Bi (RMB). Regarding the disease-related variables, over 50% of the participants suffered from digestive tumors (60.5%) and had not yet undergone surgery (51.1%). Additionally, more than half of the participants were diagnosed with cancer within the last 12 months (54.3%). Most participants had received chemotherapy (84.1%) but not radiotherapy (84.1%) or analgesics (81.0%). Finally, 35.8% reported no pain. For more information, refer to Table 1.

As Table 2 shows, the scores for ED, SPB, QoL, anxiety, and depression were  $8.48 \pm 7.12$ ,  $19.66 \pm 7.75$ ,  $81.69 \pm 10.28$ ,  $5.85 \pm 4.22$ , and  $6.87 \pm 4.88$ , respectively.

### ED's associations with sociodemographic, disease-related, and psychological characteristics

The Kruskal–Wallis nonparametric test (see Table 1) showed a significant difference in ED scores according to gender ( $Z = 1.895$ ,  $P = 0.058$ ), presence of a spouse ( $Z = 2.098$ ,  $P = 0.036$ ), education level ( $Z = 12.22$ ,  $P = 0.007$ ), source of income ( $Z = 17.166$ ,  $P = 0.004$ ), type of tumor ( $Z = 16.445$ ,  $P = 0.001$ ), and use of analgesic ( $Z = 4.434$ ,  $P = 0.001$ ).

The correlation analysis (see Table 3) revealed that ED was positively correlated with SPB ( $r = 0.372$ ,  $P < 0.01$ ), anxiety ( $r = 0.353$ ,  $P < 0.01$ ), and depression ( $r = 0.485$ ,  $P < 0.001$ ) and negatively associated with QoL ( $r = -0.368$ ,  $P < 0.01$ ).

### Multivariate linear regression analysis for ED

The regression analysis was conducted using ED as the dependent variable, and statistically significant variables from Tables 1 and 3 were included as independent variables. The resulting model was found to be statistically significant ( $R^2 = 0.301$ ,  $F = 8.472$ ,  $P < 0.001$ ). The analysis revealed that depression ( $\beta = 0.32$ ,  $P = 0.000$ ), SPB ( $\beta = 0.18$ ,  $P = 0.001$ ), presence of a spouse ( $\beta = -0.10$ ,  $P = 0.050$ ), and reception of government subsidies ( $\beta = 0.17$ ,  $P = 0.001$ ) were significant predictors of ED (see Table 4).

## Discussion

To the best of our knowledge, this is the first study to investigate ED and its influential factors in Chinese advanced cancer patients and thus will contribute to an understanding of advanced cancer patients' existential issues. Our study revealed that ED was significantly associated with depression, SPB, the presence of a spouse, and reception of government subsidies.

In this study, depression was found to be the greatest risk factor for ED in advanced cancer patients. The fact that depression is a critical element of ED in this group has already been reported in the literature. A German study found that depressive symptoms functioned as significant independent predictors of ED in advanced cancer patients (Quintero Garzón *et al.* 2018). A Canadian study by Lee *et al.* indicated that patients presenting with high levels of depression showed a 9.9-fold increase in ED (Lee *et al.* 2012). Depressive patients tend to perceive distress internally and often

**Table 1.** Demographic and disease-related variables related to ED (*N* = 352)

Variable	Frequency (%)	ED score $M$ (P25, P75)	$Z$	$P$
<b>Gender</b>				
Male	228 (64.8%)	7 (2, 12)	1.895	0.058
Female	124 (35.2%)	9 (3, 14)		
<b>Age</b>				
18–59	193 (54.8%)	7 (1, 14)	0.516	0.606
≥60	159 (45.2%)	8 (3.5, 12)		
<b>Spouse</b>				
No	24 (6.8%)	9 (6.5, 17)	2.098	0.036
Yes	328 (93.2%)	8 (2, 12.5)		
<b>Education level</b>				
Primary school or below	158 (44.9%)	9 (5, 13)	12.220	0.007
Middle school	89 (25.3%)	6 (2, 11)		
High school	61 (17.3%)	8 (3, 13)		
College or above	44 (12.5%)	3 (0, 10.5)		
<b>Religion</b>				
Yes	170 (48.3%)	8.5 (3, 13)	1.262	0.207
No	182 (51.7%)	7.5 (2, 13)		
<b>Co-resident</b>				
Live alone	7 (2.0%)	10 (6.5, 16.5)	8.849	0.076
Spouse	116 (33.2%)	8 (1.5, 12)		
Adult child	38 (10.8%)	9 (5, 14)		
Spouse and adult child	176 (50.0%)	7 (2, 12)		
Other	15 (4.0%)	12 (7.5, 15.5)		
<b>Major caregiver</b>				
Spouse	208 (59.1%)	8 (2, 12.5)	0.227	0.893
Adult child	76 (21.6%)	8 (3, 13)		
Other	68 (19.3)	7.5 (3, 13)		
<b>Health insurance</b>				
Employee health insurance	110 (31.25%)	7 (1, 12)	2.312	0.315
Resident health insurance	236 (67.04%)	8 (3, 13)		
Other	6 (1.71%)	8.5 (0, 10)		
<b>Source of income</b>				
Salary or pension	135 (38.3%)	8 (1, 11.5)	17.166	0.004
Allowance from adult child	114 (32.4%)	9 (4, 14)		
Household savings	39 (11.1%)	4 (1, 10)		
Gifts from relatives or friends	21 (6.0%)	9 (5, 17)		
Government subsidies	7 (2.0%)	20 (8.5, 23.5)		
Other	36 (10.2)	7.5 (2, 12)		
<b>Monthly income per person, RMB</b>				
<1,000	62 (17.6%)	8 (3, 12)	5.333	0.149
1,000–3,000	134 (38.0%)	9 (3, 13)		

(Continued)

**Table 1.** (Continued.)

Variable	Frequency (%)	ED score $M$ (P25, P75)	Z	P
3,001–6,000	128 (36.4%)	7.5 (3, 12)		
>6,000	28 (8.0%)	3.5 (0, 11)		
Type of tumor				
Digestive tumor	213 (60.5%)	8 (1, 12)	16.445	0.001
Respiratory tumor	93 (26.5%)	5 (3, 12)		
Reproductive tumor	29 (8.2%)	3 (1, 14)		
Other	17 (4.8%)	10 (7, 15)		
Stage of tumor				
III	71 (20.2%)	7 (1, 10.5)	1.563	0.118
IV	281 (79.8)	8 (3, 13)		
Surgery				
Yes	172 (48.9%)	8 (2.5, 12)	0.369	0.712
No	180 (51.1%)	8 (2.5, 13)		
Chemotherapy				
Yes	296 (84.1%)	9 (4.5, 12)	-1.191	0.234
No	56 (15.9%)	8 (2, 13)		
Radiotherapy				
Yes	62 (17.6%)	8 (3, 13)	-0.350	0.726
No	290 (82.4%)	8 (2, 14)		
Use of analgesic				
Yes	67 (19.0%)	7 (1, 12)	4.434	<0.001
No	285 (81.0%)	11 (7, 15)		
Pain intensity				
No pain	126 (35.8%)	7.5 (2, 12)	6.122	0.106
Mild pain	128 (36.4%)	7.5 (2.5, 12)		
Moderate pain	62 (17.6%)	8 (3, 13)		
Severe pain	36 (10.2%)	11 (5.5, 11.5)		
Course of disease (month)				
1–12	191 (54.3%)	8 (2, 12.5)	1.582	0.663
13–24	63 (17.8%)	8 (3, 12)		
25–36	40 (11.4%)	9 (3, 13.5)		
≥37	58 (16.5)	8 (3, 12)		

**Table 2.** Descriptive statistics for ED, SPB, QoL, anxiety, and depression ( $N = 352$ )

Variable	Mean	SD	Range
ED	8.48	7.12	0–38
SPB	19.66	7.75	8–40
QoL	81.69	10.28	41–106
Anxiety	5.85	4.22	0–20
Depression	6.87	4.88	0–20

**Table 3.** Correlations for ED, SPB, QoL, anxiety, and depression ( $N = 352$ )

	ED	SPB	QoL	Anxiety	Depression
ED	1.000				
SPB	0.372**	1.000			
QoL	-0.368**	-0.414**	1.000		
Anxiety	0.353**	0.453**	-0.631**	1.000	
Depression	0.485**	0.381**	-0.640**	0.645**	1.000

Note: \*\* $P < 0.01$  (2-tailed).

**Table 4.** Multiple regression analysis predicting ED ( $N = 352$ )

Variable	<i>B</i>	SE	$\beta$	<i>t</i>	<i>p</i>
Constant	10.663	1.524		6.999	0.000
Spouse (ref: no)	-2.668	1.354	-0.095	-1.970	0.050
Source of income (ref: salary or pension)					
Government subsidy	8.422	2.458	0.165	3.427	0.001
SPB	1.269	0.385	0.178	3.298	0.001
Depression	2.287	0.533	0.321	4.295	0.000

lack motivation, pleasure, and interest in the present (Jacobsen et al. 2007). According to previous studies, such a mental state could cause cancer patients to lose their sense of meaning and dignity, become disheartened, and develop a sense of failure, leading to ED (Nanni et al. 2018; Rudilla et al. 2016; Liu et al. 2020).

Our study found a significantly adverse effect of SPB on ED in advanced cancer patients. Similarly, Grandi et al. (2010) identified the association of SPB with existential issues. Another study reported that the prevalence of SPB in cancer patients in China was higher than in other countries (Liu et al. 2022). This is because Chinese patients' perceptions of over-benefiting or under-investing may result in feelings of being a burden on their caregivers (Yeung et al. 2019). Furthermore, economic burden could be another reason for the increase of SPB (Liu et al. 2022). SPB is considered a key antecedent of ED in cancer patients, based on the conceptual framework of SPB developed by Chen et al. (2022). This can also be explained by McPherson's equity theory (McPherson et al. 2010). Advanced cancer patients may be unable to retain a balance between giving and taking in the caregiving relationship, due to their deteriorating physical condition. Such feelings of being a burden on others may lead to ED.

In the current study, the presence of a spouse was also a statistically significant predictor of ED in advanced cancer patients. However, the mean differences between the spouse and non-spouse groups were not clinically significant. Furthermore, our study did not identify significant correlations among ED, spouse co-resident, and spouse caregiver. Though in our study patients with spouses had lower levels of ED, one should be cautious drawing conclusions regarding its impact. More thorough, large-scale, and probing research is needed to fully delineate the SPB-ED link.

Lastly, our study found that advanced cancer patients receiving government subsidies reported higher levels of ED. According to the General Office of the State Council of the People's Republic of China, government subsidies are granted to low-income people, including the elderly, disabled, and households with dependent children (General Office of the State Council of the People's Republic of China 2021). In our study, patients received government subsidies because of their low income and diagnosis of cancer. Although the majority of patients had corresponding health care in China, there is still a large part of the cost that is borne by the family. Cancer treatments often result in huge economic pressure on ordinary families, so patients feel the heavy economic burden (Xiao et al. 2020). As reported in previous studies, the combination of medical expenses and low income adversely affect the psychological, emotional, and overall distress experienced by cancer patients

(Carrera et al. 2018; Meeker et al. 2016). Various studies have demonstrated that these types of distress are associated with ED (Chin et al. 2021; Fang et al. 2014). Thus, ED could further be mitigated by social support, especially financial assistance (Li et al. 2020; Shao et al. 2023). As a result, the current findings serve as evidence that the financial burden could affect the level of ED.

### Study limitations

Firstly, as a cross-sectional study, this work was unable to establish a causal relationship or investigate the long-term effects of ED and other factors on advanced cancer patients. Consequently, future longitudinal studies are necessary to confirm these findings. Secondly, the primary psychological variables used herein were self-reported, which could have introduced reporting bias. Additionally, the use of convenience sampling may have affected the generalizability of our findings and introduced sampling bias, thereby failing to accurately represent the targeted population. Moreover, the sample regarding government subsidies was small and may have contained significant outliers that influenced the results. Future research should more comprehensively address this issue.

### Clinical implications

Our study established a baseline for ED in advanced cancer patients and highlighted the significant impact of factors such as depression, SPB, the presence of a spouse, and reception of government subsidies on ED. Identifying the factors related to ED could facilitate early recognition and the development of interventions to ultimately enhance QoL and health services for patients. Routine screening tests to identify depression, SPB, and ED should be implemented by healthcare professionals when caring for patients with advanced cancer. Such measures would enable timely referrals to mental health specialists for patients displaying ED.

### Conclusion

In summary, the level of ED in advanced cancer patients was found to be relatively high. ED was positively influenced by depression, SPB, and the reception of government subsidies. In the future, multifaceted interventions should be implemented to reduce depression and SPB and thus alleviate ED. Mobilizing family and social resources around patients may also enhance social support, decrease the financial burden, and ultimately relieve ED.

**Data availability statement.** The data upon which the results are based are available upon request from the corresponding author. The data are not publicly available due to privacy and ethical restrictions.

**Acknowledgments.** The authors sincerely thank the patients who participated in our study, the National Hospice Service Program, and Li Ka Shing Foundation.

**Author contributions.** Jainwei Zheng: designing and implementing the study and writing the manuscript. Xiaodan Lin: designing and implementing the study. Huimin Xiao: designing the study and writing the manuscript. Hong Wu and Shangwang Yang: recruiting eligible participants and implementing the study. Guiru Xu and Xiaoyan Lin: supervising the study and critically reviewing the manuscript. All authors contributed intellectually to this research and read and approved the final manuscript.

Huimin Xiao and Xiaoyan Lin contributed equally as a corresponding author of this study.

**Funding.** Humanities and Social Sciences Issues of the Ministry of Education of China (18YJA190017).

**Competing interests.** The authors declare no potential conflicts of interest concerning this article's research, authorship, and publication.

## References

- Akazawa T, Akechi T, Morita T, *et al.* (2010) Self-perceived burden in terminally ill cancer patients: A categorization of care strategies based on bereaved family members' perspectives. *Journal of Pain and Symptom Management* 40(2), 224–234. doi:10.1016/j.jpainsymman.2009.12.015
- Belar A, Arantzamendi M, Rodríguez-Núñez A, *et al.* (2019) Multicenter study of the psychometric properties of the new Demoralization Scale (DS-II) in Spanish-speaking advanced cancer patients. *Journal of Pain and Symptom Management* 57(3), 627–634. doi:10.1016/j.jpainsymman.2018.11.016
- Bovero A, Botto R, Adriano B, *et al.* (2019) Exploring demoralization in end-of-life cancer patients: Prevalence, latent dimensions, and associations with other psychosocial variables. *Palliative and Supportive Care* 17(5), 596–603. doi:10.1017/S1478951519000191
- Bovero A, Opezzo M and Tesio V (2023) Relationship between demoralization and quality of life in end-of-life cancer patients. *Psychooncology* 32(3), 429–437. doi:10.1002/pon.6095
- Carrera PM, Kantarjian HM and Blinder VS (2018) The financial burden and distress of patients with cancer: Understanding and stepping-up action on the financial toxicity of cancer treatment. *CA: A Cancer Journal for Clinicians* 68(2), 153–165. doi:10.3322/caac.21443
- Chang T-G, Huang P-C, Hsu C-Y, *et al.* (2022) Demoralization in oral cancer inpatients and its association with spiritual needs, quality of life, and suicidal ideation: A cross-sectional study. *Health and Quality of Life Outcomes* 20(1), 60. doi:10.1186/s12955-022-01962-6
- Chen W, Chen Y and Xiao H (2022) Existential distress in cancer patients: A concept analysis. *Cancer Nursing* 45(2), E471–E486. doi:10.1097/NCC.0000000000000925
- Chin HL, Ng CG, Thong KS, *et al.* (2021) Demoralisation in cancer patients: The association with distress, depression and positive emotion. *Medicine & Health* 16, 108–122. doi:10.17576/MH.2021.1601.10
- Cohen SR, Mount BM, Tomas JN, *et al.* (1996) Existential well-being is an important determinant of quality of life: Evidence from the McGill quality of life questionnaire. *Cancer: Interdisciplinary International Journal of the American Cancer Society* 77(3), 576–586. doi:10.1002/(SICI)1097-0142(19960201)77:3<576::AID-CNCR22>3.0.CO;2-0
- Dempsey LE, Karver MS, Labouliere C, *et al.* (2012) Self-perceived burden as a mediator of depression symptoms amongst individuals living with a movement disorder. *Journal of Clinical Psychology* 68(10), 1149–1160. doi:10.1002/jclp.21901
- Fang C-K, Chang M-C, Chen P-J, *et al.* (2014) A correlational study of suicidal ideation with psychological distress, depression, and demoralization in patients with cancer. *Supportive Care in Cancer* 22, 3165–3174. doi:10.1007/s00520-014-2290-4
- General Office of the State Council of the People's Republic of China (2021) Opinions on improving the medical insurance and assistance system for major and serious diseases. [http://www.gov.cn/zhengce/content/2021-11/19/content\\_5651446.htm](http://www.gov.cn/zhengce/content/2021-11/19/content_5651446.htm) (accessed 17 April).
- Grandi S, Sirri L, Tossani E, *et al.* (2010) Psychological characterization of demoralization in the setting of heart transplantation. *The Journal of Clinical Psychiatry* 71(5), 16094. doi:10.4088/jcp.09m05191blu
- Huimin X, Xiaodan L, Hong W, *et al.* (2022) Translation and validation of the Existential Distress Scale in Chinese advanced cancer patients. *Journal of Nursing Science* 2022, 74–77. doi:10.3870/j.issn.1001-4152.2022.09.074
- Jacobsen JC, Maytal G and Stern TA (2007) Demoralization in medical practice. *Primary Care Companion to the Journal of Clinical Psychiatry* 9(2), 139. doi:10.4088/PCC.v09n0208
- Jensen MP, Karoly P and Braver S (1986) The measurement of clinical pain intensity: A comparison of six methods. *Pain* 27(1), 117–126. doi:10.1016/0304-3959(86)90228-9
- Kissane D and Patsy Y (2000) Psychological and Existential Distress. *Palliative Care Nursing*, 229–243. doi:10.4324/9781315378473-16
- Lee C-Y, Fang C-K, Yang Y-C, *et al.* (2012) Demoralization syndrome among cancer outpatients in Taiwan. *Supportive Care in Cancer* 20, 2259–2267. doi:10.1007/s00520-011-1332-4
- LeMay K and Wilson KG (2008) Treatment of existential distress in life threatening illness: A review of manualized interventions. *Clinical Psychology Review* 28(3), 472–493. doi:10.1016/j.cpr.2007.07.013
- Li J, Liu X, Xu L, *et al.* (2020) Current status of demoralization and its relationship with medical coping style, self-efficacy and perceived social support in Chinese breast cancer patients. *The European Journal of Psychiatry* 34(4), 211–218. doi:10.1016/j.ejpsy.2020.06.007
- Liu B, Lee K, Sun C, *et al.* (2022) Systematic review on factors associated with self-perceived burden among cancer patients. *Supportive Care in Cancer* 30(10), 8417–8428. doi:10.1007/s00520-022-07129-9
- Liu ST, Xia W, Wang N, *et al.* (2020) Serial multiple mediation of demoralization and depression in the relationship between hopelessness and suicidal ideation. *Psychooncology* 29(8), 1321–1328. doi:10.1002/pon.5439
- Lo C, Panday T, Zeppieri J, *et al.* (2017) Preliminary psychometrics of the Existential Distress Scale in patients with advanced cancer. *European Journal of Cancer Care* 26(6), e12597. doi:10.1111/ecc.12597
- McPherson CJ, Wilson KG and Ann Murray M (2007) Feeling like a burden: Exploring the perspectives of patients at the end of life. *Social Science & Medicine* 64(2), 417–427. doi:10.1016/j.socscimed.2006.09.013
- McPherson CJ, Wilson KG, Chyurlia L, *et al.* (2010) The balance of give and take in caregiver-partner relationships: An examination of self-perceived burden, relationship equity, and quality of life from the perspective of care recipients following stroke. *Rehabilitation Psychology* 55(2), 194. doi:10.1037/a0019359
- Meeker CR, Geynisman DM, Egleston BL, *et al.* (2016) Relationships among financial distress, emotional distress, and overall distress in insured patients with cancer. *Journal of Oncology Practice* 12(7), e755–e764. doi:10.1200/JOP.2016.011049
- Mehnert A, Vehling S, Höcker A, *et al.* (2011) Demoralization and depression in patients with advanced cancer: Validation of the German version of the demoralization scale. *Journal of Pain and Symptom Management* 42(5), 768–776. doi:10.1016/j.jpainsymman.2011.02.013
- Nanni MG, Caruso R, Travado L, *et al.* (2018) Relationship of demoralization with anxiety, depression, and quality of life: A Southern European study of Italian and Portuguese cancer patients. *Psychooncology* 27(11), 2616–2622. doi:10.1002/pon.4824
- National Health and Family Planning Commission of the People's Republic of China (2017) Practice guide for palliative care (Trial). <http://www.nhc.gov.cn/zyygj/s3593/201702/83797c0261a94781b158dbd76666b717.shtml> (accessed 17 April).
- Pang SMC, Chan K-S, Chung BPM, *et al.* (2005) Assessing quality of life of patients with advanced chronic obstructive pulmonary disease in the end of life. *Journal of Palliative Care* 21(3), 180–187. doi:10.1177/082585970502100311
- QN Z (2013) Evaluation of the measurement of self-perceived burden for cancer patients and study on the influence factors of self-perceived burden. Anhui Province, China: Anhui Medical University.
- Quintero Garzón I, Koranyi S, Engelmann D, *et al.* (2018) Perceived doctor-patient relationship and its association with demoralization in patients with advanced cancer. *Psychooncology* 27(11), 2587–2593. doi:10.1002/pon.4823
- Rudilla D, Galiana L, Oliver A, *et al.* (2016) Demoralization Scale in Spanish-speaking palliative care patients. *Journal of Pain and Symptom Management* 51(4), 769–775. e1. doi:10.1016/j.jpainsymman.2015.11.019
- Saji A, Oishi A and Harding R (2022) Self-perceived burden for people with life-threatening illness: A qualitative systematic review. *Journal of Pain and Symptom Management* 65(3), e207–217.
- Salander P (2018) “Spirituality” hardly facilitates our understanding of existential distress-but “everyday life” might. *Psychooncology* 27(11), 2654–2656. doi:10.1002/pon.4784

- Shao Q, Li Y, Lin L, et al.** (2023) Demoralization syndrome and its impact factors among cancer patients in China. *Journal of Psychosocial Oncology*, 1–16. doi:10.1080/07347332.2023.2249895
- Sung H, Ferlay J, Siegel RL, et al.** (2021) Global cancer statistics 2020: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA Cancer Journal for Clinicians* **71**(3), 209–249. doi:10.3322/caac.21660
- Sun ZX, Liu HX, Jiao LY, et al.** (2017) Reliability and validity of hospital anxiety and depression scale. *Chinese Journal of Clinicians (Electronic Edition)* **11**(2), 198–201. doi:10.3877/cma.j.issn.1674-0785.2017.02.005
- Vehling S and Kissane DW** (2018) Existential distress in cancer: Alleviating suffering from fundamental loss and change. *Psychooncology* **27**(11), 2525–2530. doi:10.1002/pon.4872
- Xiao M, Yi YL and Wei BB** (2020) The effect of self-management efficacy on self-perceived burden of lung cancer patients undergoing chemotherapy. *Nursing Research* **34**, 835–841. doi:10.12102/j.issn.1009-6493.2020.05.022
- Yeung NCY, Lu Q and Mak WWS** (2019) Self-perceived burden mediates the relationship between self-stigma and quality of life among Chinese American breast cancer survivors. *Supportive Care in Cancer* **27**, 3337–3345. doi:10.1007/s00520-018-4630-2