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Dignity and its influencing factors in patients with cancer in North China: a cross-sectional study

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ABSTRACT

Background   Patients with cancer experience various levels of loss of dignity. Exploring levels of loss of dignity and the factors that influence such losses for patients with cancer is rare, but important in palliative care in China.

Methods   Participants were cancer patients with early and advanced cancer recruited from a tertiary cancer hospital in North China. Patients were surveyed to assess their level of loss of dignity and potentially relevant factors. Data were collected using the Patient Dignity Inventory, the MD Anderson Symptom Inventory–Chinese, the distress thermometer, the Hospital Anxiety and Depression Scale, and the 30-question core Quality of Life Questionnaire from the European Organisation for Research and Treatment of Cancer, and were analyzed using quantitative methods.

Results   The study included 202 cancer patients, 143 of whom experienced mild loss of dignity (71%); 37, moderate loss of dignity (18%); and 10, severe loss of dignity (5%). The problems with dignity were slightly different in patients with early-stage disease than in those with advanced-stage disease. Loss of dignity in the patients was significantly correlated with psychological distress, symptom burden, and quality of life ($p < 0.05$). Logistic regression showed that age, Karnofsky performance status, anxiety, and symptom burden were significant predictors of loss of dignity.

Conclusions   Most patients with early and advanced cancer experienced some level of loss of dignity. Loss of dignity was more likely for patients of younger age, high Karnofsky performance status, high symptom burden, and anxiety. Understanding the dignity of cancer patients and potentially relevant factors is of great value for implementing comprehensive palliative care in China.

Key Words   Dignity, loss of dignity, influencing factors, quality of life

INTRODUCTION

Palliative cancer care is no longer limited to the relief of pain and other distressing symptoms; maintenance of a patient's sense of dignity is considered of the same importance. The dignity of patients approaching death was proposed by Canadian scholar Chochinov as a subjective and multidimensional concept in the Dignity Model[1–5], which is composed of 3 primary domains that emerged as factors influencing a dying patient's sense of dignity. Those domains are

- illness-related factors (problems that arise from the illness itself, such as physical and psychological response);
- the dignity-conserving repertoire (internally held qualities or worldview of the patient and personal approaches that the patient uses to bolster or maintain their sense of dignity); and
- the social dignity inventory (quality of interactions with others, and external sources of distress that impinge on a patient's sense of dignity).

Given cultural differences between geographic regions, scholars from various countries have carried out region-specific and culture-specific studies of patient dignity based on the Dignity Model to further explore the meaning of dignity and its influencing factors. A study conducted by the American scholars Beach *et al.*[6] with 21

patients in an intensive care unit synthesized 7 aspects of dignity, including being treated as a person, the Golden Rule (treating others like oneself), acknowledgment, being treated as family or a friend, being treated as an individual, being treated as important or valuable, and being treated as equal. Patients also indicated that the behaviours of health care professionals such as listening, honesty or provision of information, and a caring manner can also affect the sense of dignity. A German study found that the sense of dignity in cancer patients was significantly associated with physical symptoms, psychological distress, Karnofsky performance status (KPS), and comorbidity[7]. Ho *et al.*[8] explored the meaning of dignity from the perspective of older terminally ill Asian patients in Hong Kong, and their findings were basically consistent with the 3 main aspects of the Chochinov Dignity Model, but varied in several subthemes. The 4 subthemes uncovered in the Chochinov Dignity Model were pain tolerance, morality inheritance, spiritual surrender, and trans-generational harmony.

Compared with Western culture or even Hong Kong culture, traditional Chinese culture has a certain uniqueness, such as a stronger sense of shame, more emphasis on family, weakness in self-expression and communication, and introverted personality, among others—all of which lead to a culture-specific meaning of dignity and its influencing factors for patients in Mainland China. However, few studies have examined the meaning of dignity from the perspective of cancer patients in Mainland China and factors influencing that sense of dignity. In the present study, we aimed to examine loss of dignity for patients with early and advanced cancer in Mainland China, to analyze factors that influence patient dignity, and to use survey questionnaires to explore correlations between a patient's level of dignity and psychological distress, symptom burden, and quality of life.

METHODS

Study Design

A cross-sectional survey design was used for the study. Participants were recruited from Hebei Tumor Hospital (one of the largest cancer centres in North China) between December 2016 and January 2017. Patients were included if they had (according to the American Joint Committee on Cancer staging system, version 7.0) early-stage (stages I–III, operable) or advanced-stage disease (stages III–IV, inoperable), with a specific pathology or cytology diagnosis; if they were 18 years of age or older; if they were able to speak and read Chinese; if they were well-informed about the cancer diagnosis, showing no evidence of confusion or delirium based on clinical consensus; and if they were able to provide informed oral and written consent. Ethics approval was obtained from the ethics committee at the participating hospital. Written informed consent was obtained from all participants.

Data Collection

Data were collected using these instruments:

- A questionnaire designed to obtain demographic information and clinical and pathologic features.

- The Patient Dignity Inventory (PDI), a tool to measure dignity-related distress in palliative care. It consists of 25 items in 5 dimensions, including symptom distress, existential distress, dependency, peace of mind, and social support.
- The MD Anderson Symptom Inventory–Chinese (MDASI-C), a multi-symptom patient-reported outcome measure for clinical and research use that assesses the severity of symptoms in cancer patients and interference with daily living.
- The distress thermometer, a rapid screening tool for assessing psychological distress in people affected by cancer.
- The Hospital Anxiety and Depression Scale, a commonly used instrument to determine the levels of anxiety and depression that patients are experiencing.
- The 30-question core Quality of Life Questionnaire from the European Organisation for Research and Treatment of Cancer. This tool assesses the quality of life of cancer patients.

Data Analysis

Descriptive statistics are used to describe demographic data. Logistic regression analysis was used to predict factors influencing patient dignity. Spearman rank correlation was used to analyze correlations between level of dignity and psychological distress, symptom burden, and quality of life. A 2-sided *p* value less than 0.05 was considered statistically significant. The IBM SPSS Statistics software application (version 24.0: IBM, Armonk, NY, U.S.A.) was used for the data analysis.

RESULTS

Loss of Dignity

Table I shows the demographic characteristics and clinical features of the 202 patients who participated in the study. In terms of loss of dignity, 12 patients did not report loss of dignity (PDI score: 0–25), 143 patients (71%) experienced a mild loss of dignity (PDI score: 26–50), 37 (18%) experienced a moderate loss of dignity (PDI score: 51–75), and 10 (5%) experienced a severe loss of dignity (PDI score: 76–125). Dignity-related distress was demonstrated in items on the PDI, where scores of 3 and higher indicate that the individual is experiencing a problem. Patients with early and advanced disease reported an average of 4.5 PDI problems. The top 3 most common PDI problems overall and for patients with advanced cancer were "experiencing physically distressing symptoms" (68 of 202, 33.7%, and 67 of 151, 44.4%, respectively), "worrying about future" (64 of 202, 31.7%, and 57 of 151, 37.7%) and "feeling like I am no longer who I was" (59 of 202, 29.2%, and 51 of 151, 33.8%). The top 3 problems of patients with early cancer were "not being treated with respect or understanding by others" (8 of 51, 15.7%), "feeling like I am no longer who I was" (8 of 51, 15.7%), and "worrying about future" (7 of 51, 13.7%). Of the 5 dimensions of the PDI, symptom distress, existential distress, and dependency were the dignity-related distresses most likely to be experienced by patients with early and advanced cancer.

Associations of Demographic and Clinical Characteristics with Dignity

General Condition and Loss of Dignity

Age [$r = -0.184$; 95% confidence interval (CI): -0.317 to -0.041], cancer stage ($r = 0.239$; 95% CI: 0.138 to 0.328), and KPS ($r = 0.462$; 95% CI: 0.318 to 0.595) were significantly correlated with loss of dignity (Table II).

Psychological Distress and Loss of Dignity

The incidence rate of psychological distress in our patient cohort was 50% (distress thermometer ≥ 4). Anxiety was being experienced by 36% of the patients (HADS-A > 7), with 15% reaching the diagnostic criteria for anxiety (HADS-A $\geq$ 11). Depression was present in 34% of the patients (HADS-D > 7), with 17% reaching the diagnostic criteria for depression (HADS-D $\geq$ 11).

TABLE I Characteristics of the 202 study participants

Characteristic	Dignity loss [n (%)]	
	None-to-mild	Moderate-to-severe
Sex		
Men	83 (74.77)	28 (25.23)
Women	72 (79.12)	19 (20.88)
Age group		
≤44 Years	18 (60.00)	12 (40.00)
45–59 Years	67 (75.28)	22 (24.72)
≥60 Years	70 (84.34)	13 (15.66)
Marital status		
Unmarried	2 (40.00)	3 (60.00)
Married	144 (77.01)	43 (22.99)
Divorced	3 (75.00)	1 (25.00)
Widowed	6 (100.00)	0 (0)
Education		
≤Elementary school	38 (84.44)	7 (15.56)
Junior high school	54 (70.13)	23 (29.87)
Technical secondary school or high school	44 (78.57)	12 (21.43)
College or bachelor degree	19 (82.61)	4 (17.39)
Master's degree and above	0 (0)	1 (100.00)
Career		
Worker	19 (82.61)	4 (17.39)
Farmer	76 (76.00)	24 (24.00)
Cadre	13 (81.25)	3 (18.75)
Teacher	6 (100.00)	0 (0)
Business	3 (75.00)	1 (25.00)
Housework	2 (100.00)	0 (0)
Health worker	0 (0)	1 (100.00)
Retirement	32 (72.73)	12 (27.27)
Other	4 (66.67)	2 (33.33)
Monthly income		
≤¥1000	56 (70.89)	23 (29.11)
¥1001–3000	63 (86.30)	10 (13.70)
¥3001–5000	29 (76.32)	9 (23.68)
¥5001–7000	5 (55.56)	4 (44.44)
>¥7000	2 (66.67)	1 (33.33)

Characteristic	Dignity loss [n (%)]	
	None-to-mild	Moderate-to-severe
Children		
0	2 (33.33)	4 (66.67)
1	46 (76.67)	14 (23.33)
2	65 (79.27)	17 (20.73)
3	27 (77.14)	8 (22.86)
≥3	15 (78.95)	4 (21.05)
Payment method		
Self-pay	16 (69.57)	7 (30.43)
Public fee	1 (50.00)	1 (50.00)
Medical insurance	68 (79.07)	18 (20.93)
Rural cooperative medical care	69 (76.67)	21 (23.33)
Other	1 (100.00)	0 (0)
Cancer site		
Lung	37 (74.00)	13 (26.00)
Esophagus or stomach	34 (79.07)	9 (20.93)
Colon or rectum	36 (83.72)	7 (16.28)
Liver	4 (80.00)	1 (20.00)
Breast	19 (90.48)	2 (9.52)
Genitourinary system	10 (62.50)	6 (37.50)
Blood system	1 (20.00)	4 (80.00)
Others	4 (21.05)	15 (78.95)
Time since diagnosis		
≤3 Months	43 (86.00)	7 (14.00)
>3, ≤12 Months	57 (74.03)	20 (25.97)
>12, ≤24 Months	17 (62.96)	10 (37.04)
>24, ≤36 months	15 (71.43)	6 (28.57)
>36, ≤60 Months	9 (81.82)	2 (18.18)
≥60 Months	14 (87.50)	2 (12.50)
Cancer staging		
Early	107 (70.86)	44 (29.14)
Advanced	48 (94.12)	3 (5.88)
Karnofsky performance status		
10–50	6 (30.00)	14 (70.00)
60–70	25 (58.14)	18 (41.86)
80–100	124 (89.21)	15 (10.79)

Overall, loss of dignity and psychological distress were significantly correlated ($r = 0.363$; 95% CI: 0.362 to 0.612). Specifically, anxiety ($r = 0.495$; 95% CI: 0.235 to 0.477) and depression ($r = 0.451$; 95% CI: 0.310 to 0.579) were both significantly positively correlated with loss of dignity (Table II).

Symptom Burden and Loss of Dignity

With respect to MDASI symptom items, patients reported high scores for fatigue, lack of appetite, disturbed sleep, distress or feeling upset, dry mouth, and pain. The average number of moderate-to-severe symptoms was 5.24 for our participants. The clinical symptom burden was significantly correlated with loss of dignity, with distress or feeling upset ($r = 0.555$; 95% CI: 0.439 to 0.657), sadness ($r = 0.553$; 95% CI: 0.440 to 0.648), and fatigue ($r = 0.509$; 95% CI: 0.382 to 0.609) having significant moderately positive associations with loss of dignity (Table III).

With respect to MDASI interference items, all 6 items were significantly correlated with loss of dignity, with enjoyment of life ($r = 0.589$; 95% CI: 0.487 to 0.676) and mood ($r = 0.568$; 95% CI: 0.451 to 0.669) showing significant moderately positive associations with loss of dignity (Table III).

Predictive Factors for Loss of Dignity

Results of a multivariable logistic regression showed that age, KPS, anxiety, and symptom burden were significant predictors for loss of dignity in all patients. Patients who were younger, who had a lower KPS and a higher level of anxiety, and who had a higher symptom burden were more susceptible to loss of dignity (Figure 1).

TABLE II Correlations between dignity loss and clinicopathologic features in 202 cancer patients

Feature	*r*	95% CL	*p* Value
Sex	−0.051	−0.186, 0.083	0.469
Age	−0.184	−0.317, −0.041	0.009
Marital status	−0.137	−0.262, 0.011	0.052
Education	0.019	−0.110, 0.148	0.788
Career	0.049	−0.083, 0.193	0.486
Monthly income	−0.035	−0.192, 0.120	0.617
Number of children	−0.067	−0.207, 0.079	0.341
Insurance	−0.031	−0.177, 0.110	0.658
Cancer site	0.041	−0.107, 0.186	0.562
Time since diagnosis	0.071	−0.060, 0.197	0.317
Cancer stage	0.239	0.138, 0.328	0.001
Karnofsky PS	0.462	0.318, 0.595	<0.001
Anxiety	0.495	0.362, 0.612	<0.001
Depression	0.451	0.310, 0.579	<0.001
Psychological distress	0.363	0.235, 0.477	<0.001
Symptom burden	0.592	0.456, 0.716	<0.001

CL = confidence limits; PS = performance status.

Associations of Quality of Life with Loss of Dignity

We observed a significant negative association between quality of life and loss of dignity ($r = −0.417$; 95% CI: −0.541 to −0.289). Of the 5 subscales on the 30-question core Quality of Life Questionnaire, physical function ($r = −0.566$; 95% CI: −0.664 to −0.464) and emotional function ($r = −0.524$; 95% CI: −0.623 to −0.427) showed significant moderately negative associations with loss of dignity. As for items within the symptom subscales, fatigue was most correlated with dignity, showing a significant moderately positive association with loss of dignity ($r = 0.55$; 95% CI: 0.462 to 0.656; Table IV).

DISCUSSION

Many studies have focused on the dignity of patients who are terminally ill; however, more recently, attention is increasingly being paid to the dignity of patients with early and advanced cancer who are receiving anticancer treatment. In the present study, patient data were collected from one of the largest cancer centres in North China. Most patients experienced mild-to-moderate loss of dignity (89%), with an average total score of 42.0 and an average of 4.5 problems on the PDI. Similarly, a study in Germany by Vehling and Mehnert[9] of cancer patients with early and advanced disease showed that, on the PDI, the average total score was 42.1, and the average number of problems was 4.7. However, results from another German study that included only patients with advanced cancer demonstrated that, on the PDI, the average total score was 51.6, and the average

TABLE III Correlation between symptom burden[a] and loss of dignity in 202 cancer patients

Symptom	*r*	95% CI	*p* Value
Pain	0.457	0.344, 0.562	<0.001
Fatigue	0.509	0.382, 0.609	<0.001
Nausea	0.385	0.246, 0.506	<0.001
Disturbed sleep	0.436	0.321, 0.544	<0.001
Distress or feeling upset	0.555	0.439, 0.657	<0.001
Shortness of breath	0.475	0.362, 0.576	<0.001
Difficulty remembering	0.353	0.226, 0.474	<0.001
Lack of appetite	0.480	0.371, 0.580	<0.001
Drowsiness	0.430	0.297, 0.552	<0.001
Dry mouth	0.439	0.326, 0.537	<0.001
Sadness	0.553	0.440, 0.648	<0.001
Vomiting	0.400	0.271, 0.522	<0.001
Numbness or tingling	0.422	0.291, 0.543	<0.001
Activity	0.496	0.382, 0.605	<0.001
Mood	0.568	0.451, 0.669	<0.001
Working	0.490	0.373, 0.592	<0.001
Relations with other people	0.463	0.341, 0.574	<0.001
Walking	0.439	0.310, 0.547	<0.001
Enjoyment of life	0.589	0.487, 0.676	<0.001

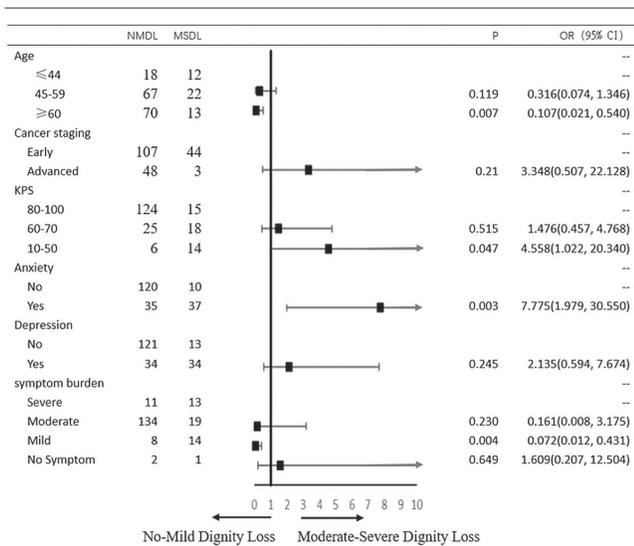[a] Measured using the MD Anderson Symptom Inventory–Chinese.

FIGURE 1 influencing factors for loss of dignity. NMDL = none-to-mild dignity loss; MSDL = moderate-to-severe dignity loss; OR = odds ratio; CI = confidence interval; KPS = Karnofsky performance status.

TABLE IV Correlation between quality of life and loss of dignity in 202 cancer patients

Item on the QLQ-C30	*r*	95% CI	*p* Value
Overall quality of life	–0.417	–0.541, –0.289	<0.001
Physical function	–0.566	–0.664, –0.464	<0.001
Role function	–0.46	–0.572, –0.330	<0.001
Emotional function	–0.524	–0.623, –0.427	<0.001
Cognitive function	–0.428	–0.544, –0.288	<0.001
Social function	–0.485	–0.582, –0.375	<0.001
Fatigue	0.55	0.462, 0.656	<0.001
Nausea and vomiting	0.41	0.292, 0.529	<0.001
Pain	0.49	0.378, 0.590	<0.001
Dyspnea	0.401	0.277, 0.506	<0.001
Sleep	0.29	0.161, 0.409	<0.001
Appetite	0.474	0.360, 0.573	<0.001
Constipation	0.311	0.228, 0.480	<0.001
Diarrhea	0.209	0.107, 0.387	<0.001
Financial difficulties	0.428	0.250, 0.503	<0.001

QLQ-C30 = 30-question core Quality of Life Questionnaire from the European Organisation for Research and Treatment of Cancer.

number of problems was 8.7[7]. Those contrasting results indicate that loss of dignity differs for cancer patients according to the stage of their disease. The more advanced the disease stage, the greater the loss of dignity and the more dignity-related problems that patients experience. Consistent with those findings, our study revealed that the level of loss of dignity differed statistically significantly for patients with early and advanced cancer, with more loss of dignity being experienced by patients with advanced cancer than by patients with early-stage cancer.

The most common PDI problems for cancer patients in the present study were "experiencing physically distressing symptoms," "worrying about future," and "feeling like I am no longer who I was." The study by Vehling and Mehnert[9] found that the top 3 PDI problems for patients with early and advanced cancer were "experiencing physically distressing symptoms," "feeling uncertain about my health and health care," and "feeling like I am no longer who I was," which resembled our findings, except for the second most common PDI problem, which can probably be explained by differences in culture between the two countries. Some Asian cultures, including traditional Chinese culture, value familial and social harmony more than individual preference. Thus, family is more important than the individual, and worry about the future for Chinese patients is not only about the future of one's own life, but also largely about the future of the whole family[10]. In Chinese culture, family plays a more important role than the individual in decision-making. At diagnosis of a terminal illness, clinicians are therefore more likely to provide that information—and information about treatment and care—to family members. Furthermore, the Chinese traditional death-taboo culture prevents patients from knowing their health condition, especially when the illness is not curable. Thus, of all Chinese patients, about half know little about their diagnosis, treatment, and prognosis; instead, they rely on their family to make decisions and don't feel too uncertain about diseases and treatment.

The top 3 PDI problems are slightly different for patients with early- and advanced-stage cancer. Patients with early-stage cancer were not constantly disturbed by "experiencing physically distressing symptoms," but by "not being treated with respect or understanding by others." That difference probably reflects the likelihood that patients with early-stage cancer might have less physically distressing symptoms or be more able to tolerate pain; instead, they experience more psychological distress and are more sensitive to changes caused by illness and treatment, such as violation of privacy, appearance change, changes in familial and social roles, and loss of independence in daily living, which would increase their sense of shame and isolation[11,12].

Our study found that age, KPS, symptom burden, and anxiety were significantly related to loss of dignity, which is similar to findings in other studies[7,13,14]. However, in a previous study, gender was shown to be significantly related to a patient's sense of dignity, with women being more likely than men to experience dignity loss[15]. In contrast, we observed no statistically significant influence of gender on the dignity of cancer patients in the present study. However, we did observe that age was related to loss of dignity for patients with early and advanced cancer, with young and middle-aged patients experiencing more loss of dignity than older patients did. That finding could be explained by the fact that young and middle-aged people are the "core force" in Chinese society and the "backbone" of a family; they play an extremely important role in working and in caring for both children and aged parents. If they are terminally ill, their social and familial roles change significantly, placing substantial pressures on the family and themselves, leading to much psychological and financial distress and, accordingly, loss of dignity.

Our study found that loss of dignity was significantly correlated with psychological distress such as anxiety, which is similar to findings in previous studies[14,16]. In addition, of the 13 items on the MDASI, distress or feeling upset, followed by sadness, fatigue, and shortness of breath had significant moderately positive associations with loss of dignity. Oechsle *et al.*[7] conducted a detailed analysis of the relationship between symptom burden and sense of dignity, finding that the symptoms most associated with dignity are psychological symptoms, especially anxiety and sadness.

Strengths and Limitations

This cross-sectional study had a relatively small sample size and thus is relatively insufficiently representative of the overall population of patients with cancer. Assessing the differences in dignity between patients with early- and advanced-stage cancer in more detail was therefore impossible. We are collecting more data, especially for patients with early-stage cancer, to conduct a more detailed and representative analysis. Meanwhile, sequential analyses based on stage of treatment, treatment type, and prognosis were not carried out, and more detailed statistical subgroup analyses and quantitative analyses were therefore impossible. A multicentre longitudinal study with a larger sample size will be needed to dynamically evaluate levels of dignity loss, change in dignity loss, and the associated influencing factors at various stages of illness. In the present study, age, KPS, symptom burden, and anxiety were found to be significantly correlated with loss of dignity. However, the causal relationship between dignity and those factors has to be further explored.

CONCLUSIONS

Chinese patients with early and advanced cancer experience varying levels of dignity loss, which are related to psychological and physical symptoms. Loss of dignity is more likely to be experienced by patients of young age and by those with a high KPS, high symptom burden, and anxiety. The problems most commonly reported on the PDI by cancer patients in China differ slightly from those reported by patients in Western countries, an observation that is potentially explained by the effects of Chinese culture and the country's social environment. To provide dignity-conserving care, health care providers have to pay attention not only to the functional state and physical symptoms of patients, but also to their psychological symptoms, especially in young and middle-aged patients. Gaining a better understanding of the factors that influence patient dignity and, in the meantime, taking Chinese culture into account are indispensable for providing comprehensive palliative care to Chinese patients.

CONFLICT OF INTEREST DISCLOSURES

We have read and understood *Current Oncology's* policy on disclosing conflicts of interest, and we declare that we have none.

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