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

L. Wang, Y. Wei, L. Xue, Q. Guo, and W. Liu

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, 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. 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. Ho et al. 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 1 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 \( r = -0.184; 95\% \text{ confidence interval (CI)}: -0.317 \text{ to } -0.041 \), cancer stage \( r = 0.239; 95\% \text{ CI}: 0.138 \text{ to } 0.328 \), and KPS \( r = 0.462; 95\% \text{ CI}: 0.318 \text{ to } 0.595 \) 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 \( \geq 4 \)). Anxiety was being experienced by 36\% of the patients \( (\text{HADS-A} \geq 7) \), with 15\% reaching the diagnostic criteria for anxiety \( (\text{HADS-A} \geq 11) \). Depression was present in 34\% of the patients \( (\text{HADS-D} \geq 7) \), with 17\% reaching the diagnostic criteria for depression \( (\text{HADS-D} \geq 11) \).

### 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                 |                          |   |   |
| \( \leq 44 \text{ Years} \) | 18 (60.00)               | 12 (40.00) |
| 45–59 Years               | 67 (75.28)               | 22 (24.72) |
| \( \geq 60 \text{ Years} \) | 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                 |                          |   |   |
| \( \leq \text{Elementary school} \) | 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            |                          |   |   |
| \( \leq ¥1000 \)          | 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) |

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

### Symptom Burden and Loss of Dignity

With respect to the 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 \((r = 0.555; 95\% \text{ CI}: 0.439 \text{ to } 0.657)\), sadness \((r = 0.509; 95\% \text{ CI}: 0.382 \text{ to } 0.609)\) having significant moderately positive associations with loss of dignity (Table III).

With respect to the MDASI interference items, all 6 items were significantly correlated with loss of dignity, with enjoyment of life \((r = 0.589; 95\% \text{ CI}: 0.487 \text{ to } 0.676)\) and mood \((r = 0.568; 95\% \text{ CI}: 0.451 \text{ to } 0.669)\) 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).

### Associations of Quality of Life with Loss of Dignity

We observed a significant negative association between quality of life and loss of dignity \((r = -0.417; 95\% \text{ CI}: -0.541 \text{ to } -0.289)\). Of the 5 subscales on the 30-question core Quality of Life Questionnaire, physical function \((r = -0.566; 95\% \text{ CI}: -0.664 \text{ to } -0.464)\) and emotional function \((r = -0.524; 95\% \text{ CI}: -0.623 \text{ to } -0.427)\) 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 \((r = 0.55; 95\% \text{ CI}: 0.462 \text{ to } 0.656)\) (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

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\text{TABLE III} \quad \text{Correlation between symptom burden}^a \text{ and loss of dignity in 202 cancer patients}
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| 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.
The most common PD 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 Mehner9 found that the top 3 PD 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 PD 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 family10. 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 PD 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 isolation11,12.

Our study found that age, KPS, symptom burden, and anxiety were significantly related to loss of dignity, which is similar to findings in other studies5,7,13,14. 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 loss15. 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 and don’t feel too uncertain about diseases and treatment. As they are the “core force” in Chinese society, the loss of dignity would increase their sense of shame and isolation11,12.

In our study, the level of PD 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 number of PD problems was 8.7. 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.
Our study found that loss of dignity was significantly correlated with psychological distress such as anxiety, which is similar to findings in previous studies. In addition, of the 13 items on the MDAS, distress or feeling upset, followed by sadness, fatigue, and shortness of breath had significant moderately positive associations with loss of dignity. Oechsle et al. 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 ROI 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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