

Brief Methodological Report

Validation of the Chinese Version of the Good Death Inventory for Evaluating End-of-Life Care From the Perspective of the Bereaved Family



Juanjuan Zhao, RN, PhD candidate, Frances Kam Yuet Wong, RN, PhD, FAAN, FHKAN (Education & Research), Liming You, RN, PhD, and Hongmei Tao, RN, MSN

School of Nursing (J.Z., L.Y.), Sun Yat-sen University, Guangzhou; School of Nursing (F.K.Y.W.), The Hong Kong Polytechnic University, Hong Kong, SAR; and Department of Nursing (H.T.), The Fifth Affiliated Hospital of Sun Yat-sen University, Zhuhai, China

Abstract

Context. It is essential to evaluate good death of patients with cancer. However, currently, there is no validated measurement tool available in Mainland China.

Objectives. To validate the Chinese version of the Good Death Inventory (GDI).

Methods. An online survey was distributed to the bereaved family members of patients with cancer (from 10 medical institutes) who died between January 2014 and December 2016. The survey included the demographic characteristics of the patients and their family members, the Chinese version of the GDI, overall satisfaction of family members regarding the end-of-life care, as well as the patients' overall quality of death and dying, and overall quality of life.

Results. A total of 305 valid responses were analyzed. The average score of the GDI was 241.20 ± 39.45 . The Cronbach's α coefficient of the GDI was 0.896 overall and ranged from 0.561 to 0.950 for the subdomains. The fit indices for the original 18-factor model were acceptable: root mean square error of approximation = 0.044, Comparative Fit Index = 0.900, Tucker-Lewis Index = 0.892, and standardized root mean square residual = 0.073. The total scores of the GDI were moderately correlated with overall satisfaction with medical care ($r = 0.411$, $P < 0.01$), patient's quality of life ($r = 0.468$, $P < 0.01$), and quality of death and dying ($r = 0.441$, $P < 0.01$).

Conclusions. The psychometric characteristics of the Chinese version of the GDI indicate that this questionnaire is reliable and valid. It can be used as a tool for the assessment of quality of death and dying of patients with cancer among the Chinese population. *J Pain Symptom Manage* 2019;58:472–480. © 2019 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words

Good death, cancer, end-of-life care, palliative care, validation

Introduction

In modern palliative care, a good death is an important goal and outcome for the evaluation of the quality of end-of-life care. However, thus far, there is no universal definition for a good death. According to the Institute of Medicine in America, a good death is one that is “free from avoidable distress and suffering for patients, families, and caregivers; in

general accord with patients' and families' wishes; and reasonably consistent with clinical, cultural, and ethical standards.”¹ In addition, Weisman defined a good death as one where a patient's suffering is reduced as much as possible and death is accompanied by dignity.² However, these definitions are conceptual and difficult to translate into practical guidance. Numerous investigators have explored the

Address correspondence to: Frances Kam Yuet Wong, RN, PhD, FAAN, FHKAN (Education & Research), Associate Dean, Faculty of Health & Social Sciences Professor, School of

Nursing, The Hong Kong Polytechnic University, Hungghom, Hong Kong SAR, China. E-mail: frances.wong@polyu.edu.hk

Accepted for publication: May 28, 2019.

components of a good death through qualitative research^{3–7} and literature reviews.^{8,9} The major components of good death identified in these studies were pain and symptom management, treatment preferences, emotional well-being, preparation for death, life completion, contributing to others, affirmation of a whole person, achieving a sense of control, and religious/spiritual comfort.

In 2014, a total of 3.804 million new cases of cancer were diagnosed, and 2.296 million cancer-related deaths were reported in China.¹⁰ Cancer is the leading cause of disease-related death, accounting for 26.11% and 23.07% of deaths reported in 2017 in urban and rural areas of Mainland China, respectively.¹¹ There are few hospice centers in China, and general hospitals/wards are the main institutions that manage cancer-related death.

In 2017, the Chinese government established *The Practice Guidelines to Palliative Care (trial)* to improve the quality of palliative care in China.¹² These guidelines focus on symptom control, comfort care, as well as psychological, spiritual, and social support. However, these guidelines did not include a validated standard for the assessment of quality. Furthermore, there is no research investigating the quality of death as an indicator of palliative care outcomes, and there are no relevant tools for evaluating good death in Mainland China.

More recently, several tools were specially developed to assess good death internationally. These tools included the McGill Quality of Life Questionnaire,¹³ Quality of Dying in Long-Term Care,¹⁴ Quality of Life at the End of Life,^{15,16} Quality of Death and Dying questionnaire,¹⁷ Good-Death Scale,¹⁸ and Good Death Inventory (GDI).¹⁹ In Western countries, the most widely used among these tools is the Quality of Death and Dying questionnaire. The GDI is a relatively new tool based on a national qualitative study of the attributes of a good death from the perspective of members of bereaved families in Japan. The psychometric properties of the original version of the GDI were satisfactory.¹⁹ A subsequent Korean version of the GDI also demonstrated good reliability and validity.²⁰

Dying patients may be unable to communicate, and nonresponse bias is a major challenge in this population.²¹ Therefore, retrospective interviews of family members may be a strategy for the collection of information regarding the quality of care at the end of life.²² After reviewing the literature, we selected the GDI to evaluate the quality of palliative care from the perspectives of family members, based on the greater acceptability of this tool in the Asian culture. This study evaluated the psychometric properties of a Chinese version of the GDI and assessed its appropriateness in evaluating the outcomes of palliative care in Mainland China.

Methods

Measurements

The GDI consists of 18 domains, totaling 54 items (i.e., three items per domain).¹⁹ The domains are divided into 10 core and eight optional domains. The 10 core domains included “*environmental comfort*,” “*life completion*,” “*dying in a favorite place*,” “*maintaining hope and pleasure*,” “*independence*,” “*physical and psychological comfort*,” “*good relationship with medical staff*,” “*not being a burden to others*,” “*good relationship with family*,” and “*being respected as an individual*.” The eight optional domains included “*religious and spiritual comfort*,” “*receiving enough treatment*,” “*control over the future*,” “*feeling that one’s life is worth living*,” “*unawareness of death*,” “*pride and beauty*,” “*natural death*,” and “*preparation for death*.”^{19,23} Each item is scored using a seven-point Likert scale: 1 = *absolutely disagree*, 2 = *disagree*, 3 = *somewhat disagree*, 4 = *unsure*, 5 = *somewhat agree*, 6 = *agree*, and 7 = *absolutely agree*. The total score was calculated by summing all items, with a higher score indicating higher quality of good death.

Cross-Cultural Adaptation

Cross-cultural adaptation of the GDI was performed according to the guidelines established by the American Association of Orthopaedic Surgeons Outcomes Committee.²⁴ With permission from original author, the questionnaire was initially translated by four translators (two conducting forward and two backward translations). A synthesized version was submitted to an expert committee comprising a nursing education expert, a public health management expert, an oncology nurse specialist, a clinical nurse manager, a medical English expert, and a rehabilitation medicine expert to evaluate the semantic equivalence and relevance of the content. Both the item-level content validity index and average scale-level content validity index were 1.0. Moreover, the average semantic equivalence score was 93.5% (range: 66.7%–100.0%). Several item statements were slightly adjusted, and a final Chinese version of the GDI was formed.

Pilot testing involved 49 family members of deceased adult patients with cancer. Three options (online survey, email survey, and face-to-face interview) were offered. Each family member selected one of these means to complete the questionnaire. The pilot study confirmed that all questionnaire instructions, questions, and response options were clearly understood by the participants. In addition, the questionnaire could be completed within 30 minutes. Online survey was the most popular choice (69.4% vs. 6.1% for email survey and 24.5% for face-to-face interview).

Participants

A multicenter cross-sectional online survey was conducted to examine the psychometric characteristic of the GDI from January to December 2017. For the estimation of the sample size, a subject-to-item ratio of minimum 5:1 is recommended to meet the requirements of factor analysis.²⁵ The desired sample size for the 54-item GDI was ≥ 270 . Finally, the estimated minimum number of participants was 297, including an additional 10% to account for nonresponders. Convenience sampling was applied to recruit participants from 10 medical institutes (seven general hospital-based oncology departments, one community hospital, one palliative care unit, and one cancer center), which provided care to patients with terminal cancer.

The inclusion criteria of patients and family members were as follows: deceased cancer patients aged ≥ 18 years, who had been hospitalized (excluding patients in the intensive care unit) for ≥ 72 hours; members of the bereaved families should be self-proclaimed main caregivers for the patients, aged ≥ 18 years, with good ability in reading and writing in Chinese, and physically and mentally able to complete the questionnaire. The exclusion criteria were as follows: patients who died because of treatment-related conditions (surgical complication, severe drug allergy, etc.); members of the bereaved families were incapable of completing the self-reported questionnaire, could not be contacted via telephone, or refused to participate in this study.

Procedures and Questionnaires

One nurse from each of the participating institutions received training (i.e., communication skills) related to the interaction with members of the bereaved families. They contacted the potential participants via telephone, explained the aim of the survey, and noted the phone number or email address of those who consented to participate. Subsequently, the research team sent a text message to the participants including a link to the survey website. The participants could complete the online survey through their personal electronic devices at their convenience. The material of the online survey included a cover letter, an informed consent statement, and the questionnaires. The participants provided informed consent before completing the questionnaires. The questionnaires included the Chinese version of the GDI, evaluation of demographic characteristics, and the following three overall questions: “Overall, were you satisfied with the medical care that the patient received during his/her last days?” (0 = absolutely dissatisfied to 10 = absolutely satisfied); “According to your experience, how would you

rate the quality of death and dying of the patients overall in the last moment of death?”; and “According to your experience, how would you rate the quality of life of the patients overall in the last month of life?” (0 = terrible experience to 10 = almost perfect).

Ethical Considerations

This research study was approved by the Ethical Committee of the School of Nursing, Sun Yat-sen University (Guangzhou, China) and the ethical committees of all institutions participating in this study.

Statistical Analysis

We used the Mplus 7.0 and SPSS 20.0 to conduct the analyses. A significance level of 0.05 (two-sided test) was used. First, descriptive statistics were used to analyze the demographic characteristics. Pearson's chi-squared test or Fisher's exact test was used to compare the characteristics between respondents and nonrespondents and refusals. Analysis of variance or Student's t-test was used to analyze the variation of the GDI total score according to demographic and other characteristics. Second, Cronbach's α values ≥ 0.70 and ≥ 0.60 were considered satisfactory²⁶ and acceptable for the internal consistency of the GDI,²⁷ respectively. Third, the construct validity was examined through confirmatory factor analysis (CFA) to evaluate the fitness of the 18-factor GDI model. The Mplus yields the root mean square error of approximation (RMSEA), the Comparative Fit Index (CFI), the Tucker-Lewis Index (TLI), and the standardized root mean square residual (SRMR). A model with SRMR and RMSEA < 0.08 and CFI and TLI ≥ 0.90 shows a good fit.²⁸ Three classification levels of factor loading were adopted: low (< 0.30), mid-range (0.30–0.59), and high (≥ 0.60).²⁹ Finally, a concurrent validation of the GDI was performed through Pearson correlation analysis between the total score of the GDI and overall satisfaction regarding the end-of-life care, overall quality of death and dying, and overall quality of life.

Results

A total of 1912 family members of deceased cancer patients were identified. Of those, 703 (36.8%) could not be contacted and 510 refused to participate (42.2%). Questionnaires were distributed to 699 members of bereaved families who agreed to participate, and 313 of those returned the completed survey (response rate = 44.8%). Eight questionnaires were excluded because of missing ($> 50\%$) data. Finally, 305 questionnaires were analyzed (effective response rate = 43.6%) (Figure 1). There was no significant difference in the patients' age and gender between respondents, nonrespondents, and refusals (Table 1).

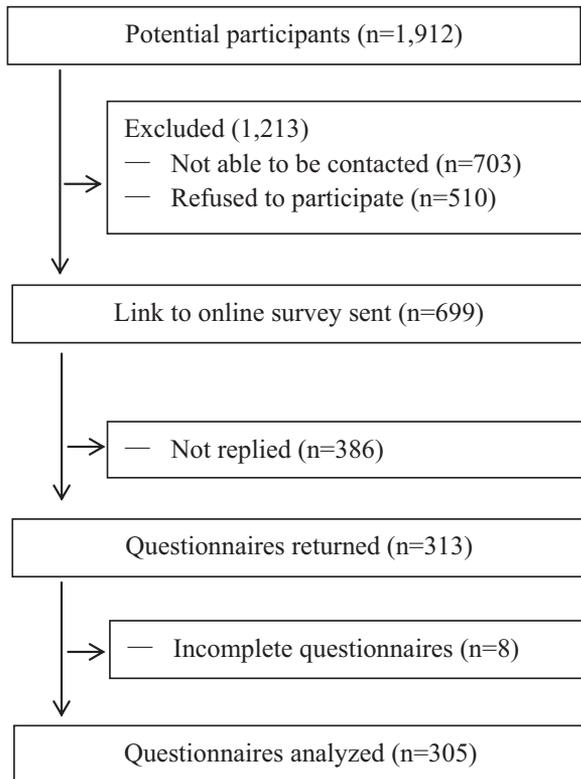


Fig. 1. Flowchart of recruitment.

Characteristics of Participants

Surveys were conducted between 1.6 month and 3.5 years after death (mean: 548.0 ± 332.7 days; range: 47–1288 days). The mean age of the 305 patients was 64.54 ± 12.55 years (range: 18–96 years). The majority were males (62.3%) and died in the oncology unit of general hospitals (76.1%). The average length of stay of last admission was 35.0 ± 42.7 days (range: 3–365 days). For the family members, the mean age was 42.53 ± 10.99 years (range: 19–84 years). The majority were females (55.7%), employed (85.9%), and highly educated (college or higher) (70.2%), with a monthly family income per capita of 5000 yuan (US \$700) (58.4%). The majority (71.1%) were the children of patients (Table 2).

The mean score of the GDI was 241.20 ± 39.45 (range: 90–333; minimum–maximum: 54–378).

There were significant differences in the GDI total score according to patient's religion ($P = 0.031$), patient's relationship with the family ($P = 0.000$), age of family member ($P = 0.001$), and member's relationship with the patient ($P = 0.008$). Religious patients and those enjoying a good relationship with their families tended to have higher GDI scores; family members who were spouses of patients and aged ≥ 40 years rated higher GDI scores of patients. There were no significant differences in the GDI scores according to patient's age, gender, diagnosis, place of death, gender of family member, educational level, income, etc (Table 2).

Reliability

The Cronbach's α coefficient was 0.896, 0.864, and 0.764 for the total score, 10 core domains, and eight optional domains, respectively. The Cronbach's α value for "natural death," "preparation for death," and "unawareness of death" was 0.561, 0.676, and 0.689, respectively. Values for all other domains were >0.70 (Table 3).

Construct Validity

The results of the CFA are shown in Figure 2. According to the standardized factor loadings of the domains by overall good death (i.e., correlations of the observed good death domain with overall good death), nine, seven, and two domains showed high (0.61–0.81), mid-range (0.34–0.58), and low factor loadings (0.11–0.24), respectively. The fit indices for the 18-factor model were acceptable: RMSEA = 0.044, CFI = 0.900, TLI = 0.892, and SRMR = 0.073.

Concurrent Validity

The results of the concurrent validity analysis are shown in Table 4. The total score of the GDI was moderately correlated with overall satisfaction with medical care ($r = 0.411$, $P < 0.01$), patient's quality of life ($r = 0.468$, $P < 0.01$), and quality of death and dying ($r = 0.441$, $P < 0.01$).

Table 1

Comparison of Respondents, Nonrespondents, and Refusals (N = 1,201)

Patient Characteristics	Respondents (n = 305)		Nonrespondents (n = 386)		P-value	Refusals (n = 510)		P-value
	n	Mean (SD) or %	n	Mean (SD) or %		n	Mean (SD) or %	
Age	305	64.54 (12.55)	386	64.65 (11.57)	0.905	510	62.76 (14.58)	0.067
Gender					0.428			0.091
Male	190	62.30	229	59.30		287	56.27	
Female	115	37.70	157	40.70		223	43.73	

SD = standard deviation.

Table 2
The GDI Total Score According to the Characteristics of Patients and Members of Bereaved Families (N = 305)

Variables	n (%)	GDI Total Score	
		Mean ± SD	ANOVA/t-test (P-value)
Patients			
Age, y (mean ± SD, range)	64.54 ± 12.55 (18–96)		
Hospital days (mean ± SD, range)	34.95 ± 42.67 (3–365)		
Age, y			0.204
18–39	13 (4.3)	247.23 ± 30.39	
40–49	27 (8.8)	255.89 ± 42.50	
50–59	54 (17.7)	239.17 ± 42.73	
60+	211 (69.2)	239.47 ± 38.76	
Gender			0.118
Male	190 (62.3)	238.46 ± 41.83	
Female	115 (37.7)	245.74 ± 34.88	
Religion			0.031
Yes	52 (17.0)	251.92 ± 40.46	
No (atheist)	253 (83.0)	239.00 ± 38.96	
Primary site of cancer			0.332
Lung	88 (28.8)	244.42 ± 35.38	
Esophagus and stomach	27 (8.8)	230.70 ± 41.03	
Liver/pancreas/gallbladder	47 (15.4)	242.72 ± 40.45	
Colorectum/rectum	35 (11.5)	236.46 ± 37.72	
Leukemia/lymphoma	17 (5.6)	250.59 ± 47.59	
Gynecological	13 (4.3)	234.46 ± 29.09	
Breast	7 (2.3)	255.71 ± 23.81	
Head and neck	22 (7.2)	238.41 ± 32.34	
Urinary	9 (3.0)	260.11 ± 46.65	
Prostate	5 (1.6)	206.80 ± 39.26	
Others	35 (11.5)	240.77 ± 49.68	
Place of death			0.609
Oncology unit of general hospital	232 (76.1)	242.27 ± 40.61	
Cancer center	20 (6.6)	230.05 ± 40.56	
Community center	19 (6.2)	238.95 ± 21.34	
Palliative care unit	34 (11.1)	241.74 ± 38.91	
Patient's relationship with family			0.000
Good	270 (88.5)	244.29 ± 38.51	
Moderate	29 (9.5)	216.41 ± 40.50	
Bad	6 (2.0)	222.17 ± 34.18	
Patient's relationship with friends or colleagues			0.072
Good	274 (89.8)	242.94 ± 39.28	
Moderate	27 (8.9)	225.44 ± 38.10	
Bad	4 (1.3)	228.50 ± 45.10	
Bereaved family members			
Age, y (mean ± SD, range)	42.53 ± 10.99 (19–84)		
Age, y			0.001
18–39	121 (39.7)	232.44 ± 41.16	
40–49	118 (38.7)	243.21 ± 36.30	
50+	66 (21.6)	253.68 ± 38.37	
Gender			0.848
Male	135 (44.3)	241.69 ± 39.30	
Female	170 (55.7)	240.82 ± 39.69	
Education			0.645
Elementary school	4 (1.3)	266.25 ± 31.63	
Middle school	26 (8.5)	243.46 ± 46.51	
High school	61 (20.0)	244.36 ± 37.63	
College	90 (29.5)	240.28 ± 37.80	
University or higher	124 (40.7)	239.04 ± 40.33	
Religion			0.240
Yes	58 (19.0)	246.69 ± 40.98	
No (atheist)	247 (81.0)	239.91 ± 39.06	
Relationship with patients			0.008
Spouse	59 (19.3)	253.98 ± 39.44	
Child	228 (74.8)	237.18 ± 39.06	
Other	18 (5.9)	250.28 ± 35.82	
Health status during caregiving period			0.298
Good	173 (56.7)	243.31 ± 41.04	
Moderate	123 (40.3)	239.50 ± 37.55	
Poor	9 (3.0)	224.00 ± 30.98	

(Continued)

Table 2
Continued

Variables	n (%)	GDI Total Score	
		Mean ± SD	ANOVA/t-test (P-value)
Living status with patient			0.630
Living together	204 (66.9)	241.97 ± 41.01	
Not living together	101 (33.1)	239.65 ± 36.26	
Presence of other caregivers			0.814
Present	279 (91.5)	241.37 ± 39.78	
Absent	26 (8.5)	239.46 ± 36.47	
Family per capita monthly income (yuan)			0.292
<1000	3 (1.0)	223.00 ± 37.36	
1000–1999	16 (5.2)	247.25 ± 24.06	
2000–2999	26 (8.5)	232.65 ± 47.43	
3000–3999	33 (10.8)	229.73 ± 45.99	
4000–4999	49 (16.1)	241.20 ± 36.96	
≥5000	178 (58.4)	244.34 ± 38.52	

GDI = Good Death Inventory; ANOVA = analysis of variance; SD = standard deviation.

Discussion

In this study, the psychometric characteristics (i.e., reliability, construct validity, and concurrent validity) of the Chinese version of the GDI were confirmed to be applicable to members of bereaved families in Mainland China. The preliminary analysis of data also reflected that the GDI scores of Chinese patients with cancer were comparable with those previously reported in Japanese studies involving patients who died in hospitals.³⁰ Moreover, the present study revealed associations of the GDI with several demographic variables.

The reliability of the Chinese version of the GDI was good, with an overall Cronbach's α of 0.896. This indicated a good internal consistency of all items comprising the concept of good death. Regarding the subscales, all domains were acceptable (Cronbach's α range: 0.676–0.950), except the domain of "natural death" (Cronbach's α : 0.561). The relatively lower α in this domain may be attributed to an item stating "Patient was not connected to medical instruments or tubes." Connecting tubes for intravenous infusion and nasogastric feeding until death is very common for patients with cancer in Chinese hospitals.³¹ Thus, it may not be regarded as a measure against natural death by the patients and families.

We subsequently assessed the validity of the construct validity through a CFA, confirming that the original 18-factor model was valid. Sixteen domains showed medium to high factor loadings, and only two domains (i.e., "religious and spiritual comfort" and "pride and beauty") showed low factor loadings. The results suggested that most of the components included in the 18-factor model reflected good death among Chinese patients with cancer. The domain of "religious and spiritual comfort" showed a low factor loading; this may be related to the absence of religious beliefs in >80% of the patients and family members in this study. All items included in the

domain of "pride and beauty" referred to patients' burden in exposing one's changes of physical and mental conditions.¹⁹ This phenomenon is uncommon among Chinese patients with cancer.³² The importance of these two domains in this setting requires further investigation.

The concurrent validation of the GDI was performed using the GDI total score and three global items related to satisfaction of end-of-life care, quality of death and dying, and quality of life, and significant correlation was found. This further confirmed that the Chinese version of the GDI is valid and can be used as

Table 3
Reliability of Good Death Inventory

Domains	Mean ± SD ^a	Cronbach's α ^b
Core 10 domains		
Physical and psychological comfort	2.55 ± 1.67	0.842
Dying in a favorite place	4.07 ± 1.80	0.868
Maintaining hope and pleasure	5.28 ± 1.53	0.860
Good relationship with medical staff	5.02 ± 1.40	0.774
Not being a burden to others ^c	3.46 ± 1.79	0.806
Good relationship with family	5.84 ± 1.25	0.721
Independence	3.16 ± 2.06	0.929
Environmental comfort	4.81 ± 1.75	0.950
Being respected as an individual	5.71 ± 1.25	0.774
Life completion	4.12 ± 1.69	0.860
Optional eight domains		
Receiving enough treatment	5.48 ± 1.30	0.737
Natural death	4.55 ± 1.54	0.561
Preparation for death	5.48 ± 1.28	0.676
Control over the future	4.38 ± 1.56	0.728
Unawareness of death	4.05 ± 1.64	0.689
Pride and beauty ^b	4.49 ± 1.64	0.827
Feeling that one's life is worth living	5.08 ± 1.32	0.747
Religious and spiritual comfort	2.87 ± 1.71	0.804
All 18 domains	4.47 ± 0.73	0.896
Core 10 domains	4.40 ± 0.84	0.864
Optional eight domains	4.55 ± 0.74	0.764

SD = standard deviation.

^aMean score on item-level.

^bCronbach's α values > 0.70 indicate scale reliability.

^cDomain composited by inverse items.

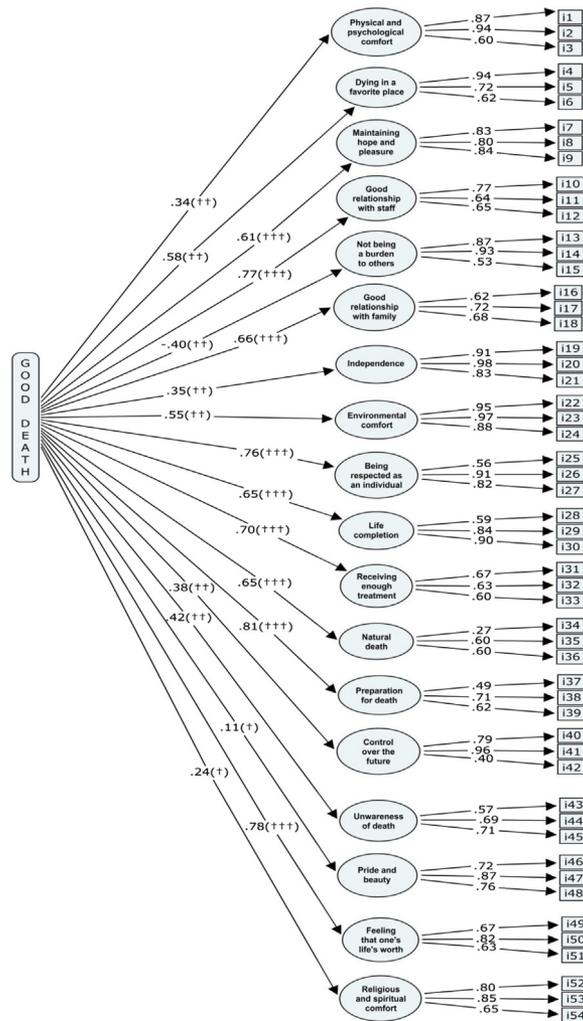


Fig. 2. The structure of Chinese version of Good Death Inventory. ††† high factor loading; †† mid-range factor loading; † low factor loading.

an instrument to evaluate good death of patients with cancer in Mainland China from the perspective of members of bereaved families.

In the present study, the mean score of the GDI was comparable with those reported in patients who died in hospitals in Japan.³⁰ This indicated that patients with cancer who died in general hospitals had similar quality of death. However, the score was markedly lower than that reported in patients who died in palliative care units or at home.³⁰ Thus, the quality of death and dying of patients with cancer in general hospitals requires improvement. In the future, we propose to provide professional palliative care service to patients with cancer in general hospitals and home hospice care for those who choose to pass away at home in Mainland China.

Several demographic factors were associated with positive ratings of good death, including religion, relationship with family, age, and relationship with

Table 4
Concurrent Validity of the Good Death Inventory

Domains	Overall Satisfaction	Overall Quality of Life	Overall Quality of Death and Dying
Core 10 domains			
Physical and psychological comfort	0.232 ^a	0.353 ^a	0.352 ^a
Dying in a favorite place	0.259 ^a	0.308 ^a	0.325 ^a
Maintaining hope and pleasure	0.050	0.170 ^a	0.170 ^a
Good relationship with medical staff	0.477 ^a	0.352 ^a	0.334 ^a
Not being a burden to others	-0.072	-0.101	-0.146 ^b
Good relationship with family	0.151 ^a	0.190 ^a	0.174 ^a
Independence	0.054	0.136 ^b	0.100
Environmental comfort	0.322 ^a	0.379 ^a	0.346 ^a
Being respected as an individual	0.232 ^a	0.259 ^a	0.196 ^a
Life completion	0.323 ^a	0.341 ^a	0.427 ^a
Optional eight domains			
Receiving adequate treatment	0.377 ^a	0.324 ^a	0.277 ^a
Natural death	0.330 ^a	0.263 ^a	0.301 ^a
Preparation for death	0.298 ^a	0.278 ^a	0.276 ^a
Control over the future	0.204 ^a	0.165 ^a	0.188 ^a
Unawareness of death	-0.030	0.091	0.008
Pride and beauty	0.110	0.153 ^a	0.139 ^b
Feeling that one's life is worth living	0.200 ^a	0.280 ^a	0.221 ^a
Religious and spiritual comfort	0.086	0.085	0.095
All 18 domains	0.411 ^a	0.468 ^a	0.441 ^a
Core 10 domains	0.379 ^a	0.455 ^a	0.435 ^a
Optional eight domains	0.379 ^a	0.398 ^a	0.366 ^a

Figures are Pearson's correlation coefficients.

^aP < 0.01.

^bP < 0.05.

patient. Consistent with previous findings, religious patients had higher GDI scores than nonreligious patients.³³ Religion and spirituality are important for individuals to find meaning, purpose, and value in their life.³⁴ Family members reporting good relationships with patients rated higher GDI scores than those who did not. This suggests that good family relationships may increase the patients' emotional support.³² Spouses provided higher GDI scores than patients' children. In Mainland China, a spouse is a close partner, intimate caregiver, and main decision-maker regarding cancer patients' end-of-life care.³¹ The GDI score may reflect the common

understanding of death and the final journey they share. Consistent with previous evidence from China,¹⁸ our findings showed that age did not affect the GDI score. However, family members aged ≥ 40 years rated higher GDI scores of patients. Younger individuals may have difficulty accepting death, and their GDI scores may reflect their limited experience in dealing with this process.³⁵

Demographic factors may affect the evaluation of good death of patients with cancer from the perspective of members of bereaved families. Thus, appropriate consideration should be given to these factors, when evaluating the effect of interventions on quality of death in future studies.

This study had three limitations. First, most of the data were obtained from the oncology departments of seven general hospitals. Therefore, the results may be less generalizable to other types of institutions. Second, the total effective response rate was 43.6%, which may limit the representativeness of the sample. Third, the online survey was convenient and ensured response to each item. However, it also limited the participants within a group of individuals able to use electronic devices. In our study, the average age of family members was 42.53 ± 10.99 years. Moreover, over 70% of family members were highly educated, and nearly 60% had upper-middle or higher monthly per capita income. Therefore, these results may not be generalizable to populations with different characteristics.

Disclosures and Acknowledgments

The authors declare no conflicts of interest. This work was supported by the China Medical Board (grant 10-021), Guangzhou, China. The authors express great gratitude to the family members who participated in this study, hospital managers who supported and permitted this study, and trained nurses who contacted the potential participants.

Supplementary Data

Supplementary data related to this article can be found at <https://doi.org/10.1016/j.jpainsymman.2019.05.014>.

References

- Institute of Medicine, Committee on care at the end of life. Approaching death: improving care at the end of life. In: Field MJ, Cassel CK, eds. Washington, DC: National Academies Press (US), 1997:4.
- Weisman AD. Appropriate death and the hospice program. *Hosp J* 1988;4:65-77.
- Singer PA, Martin DK, Kelner M. Quality end-of-life care: patients' perspectives. *JAMA* 1999;281:163-168.
- Steinhauser KE, Clipp EC, McNeilly M, et al. In search of a good death: observations of patients, families, and providers. *Ann Intern Med* 2000;132:825-832.
- Hughes T, Schumacher M, Jacobs-Lawson JM, et al. Confronting death: perceptions of a good death in adults with lung cancer. *Am J Hosp Palliat Care* 2008;25:39-44.
- Chao CS. The meaning of good dying of Chinese terminally ill cancer patients in Taiwan (Chinese). *Hu Li Za Zhi* 1997;44:48-55.
- van Soest-Poortvliet MC, van der Steen JT, Zimmerman S, et al. Measuring the quality of dying and quality of care when dying in long-term care settings: a qualitative content analysis of available instruments. *J Pain Symptom Manag* 2011;42:852-863.
- Kehl KA. Moving toward peace: an analysis of the concept of a good death. *Am J Hosp Palliat Med* 2006;23:277-286.
- Meier EA, Gallegos JV, Thomas LPM, et al. Defining a good death (successful dying): literature review and a call for research and public dialogue. *Am J Geriatr Psychiatry* 2016;24:261-271.
- Chen W, Sun K, Zheng R, et al. Cancer incidence and mortality in China, 2014. *Chin J Cancer Res* 2018;30:1-12.
- National Health Commission of the People's Republic of China. China Health Statistical Yearbook. Beijing: Peking Union Medical College Press, 2018:285-299.
- Chinese National Health and Family Planning Commission. The Practice Guidelines to Palliative Care (*trial*). (in Chinese) 2017. Available from <http://www.nhc.gov.cn/yzygj/s3593/201702/3ec857f8c4a244e69b233ce2f5f270b3.shtml>. Accessed February 1, 2019.
- Cohen SR, Mount BM, Strobel MG, et al. The McGill Quality of Life Questionnaire: a measure of quality of life appropriate for people with advanced disease. A preliminary study of validity and acceptability. *Palliat Med* 1995;9:207-219.
- Munn JC, Zimmerman S, Hanson LC, et al. Measuring the quality of dying in long-term care. *J Am Geriatr Soc* 2007;55:1371-1379.
- Steinhauser KE, Bosworth HB, Clipp EC, et al. Initial assessment of a new instrument to measure quality of life at the end of life. *J Palliat Med* 2002;5:829-841.
- Steinhauser KE, Clipp EC, Bosworth HB, et al. Measuring quality of life at the end of life: validation of the QUAL-E. *Palliat Support Care* 2004;2:3-14.
- Curtis JR, Patrick DL, Engelberg RA, et al. A measure of the quality of dying and death. Initial validation using after-death interviews with family members. *J Pain Symptom Manag* 2002;24:17-31.
- Tsai J, Wu C, Chiu T, et al. Fear of death and good death among the young and elderly with terminal cancers in Taiwan. *J Pain Symptom Manag* 2005;29:344-351.
- Miyashita M, Morita T, Sato K, et al. Good Death Inventory: a measure for evaluating good death from the bereaved family member's perspective. *J Pain Symptom Manag* 2008;35:486-498.
- Shin DW, Choi J, Miyashita M, et al. Measuring comprehensive outcomes in palliative care: validation of

- the Korean version of the good death inventory. *J Pain Symptom Manag* 2011;42:632–642.
21. Steinhilber KE, Clipp EC, Tulsky JA. Evolution in measuring the quality of dying. *J Palliat Med* 2002;5:407–414.
 22. Fowler FJ Jr, Coppola KM, Teno JM. Methodological challenges for measuring quality of care at the end of life. *J Pain Symptom Manag* 1999;17:114–119.
 23. Miyashita M, Morita T, Sato K, et al. Factors contributing to evaluation of a good death from the bereaved family member's perspective. *Psychooncology* 2008;17:612–620.
 24. Beaton DE, Bombardier C, Guillemin F, et al. Guidelines for the process of cross-cultural adaptation of self-report measures. *Spine (Phila Pa 1976)* 2000;25:3186–3191.
 25. Hatcher L. A Step-by-step approach to using the SAS system for factor analysis and structural equation modeling, 1st ed. Cary: SAS Publishing, 1994:73.
 26. Calefato J, Nippert I, Harris HJ, et al. Assessing educational priorities in genetics for general practitioners and specialists in five countries: factor structure of the Genetic-Educational Priorities (Gen-EP) scale. *Genet Med* 2008;10:99–106.
 27. Polit DF, Beck CT. *Nursing research: Principles and methods*, 7th ed. Philadelphia: Lippincott Williams & Wilkins, 2003:418.
 28. Wang J, Wang X, Jiang B. *Structural equation models: Methods and applications*. Beijing: Higher Education Press, 2011:20–21.
 29. Kamaruzzaman S, Ploubidis GB, Fletcher A, et al. A reliable measure of frailty for a community dwelling older population. *Health Qual Life Out* 2010;8:123.
 30. Kinoshita H, Maeda I, Morita T, et al. Place of death and the differences in patient quality of death and dying and caregiver burden. *J Clin Oncol* 2015;33:357–363.
 31. Gu X, Chen M, Liu M, et al. End-of-life decision-making of terminally ill cancer patients in a tertiary cancer center in Shanghai, China. *Support Care Cancer* 2016;24:2209–2215.
 32. Hsu C, O'Connor M, Lee S. Understandings of death and dying for people of Chinese origin. *Death Stud* 2009;33:153–174.
 33. Choi JY, Chang YJ, Song HY, et al. Factors that affect quality of dying and death in terminal cancer patients on inpatient palliative care units: perspectives of bereaved family caregivers. *J Pain Symptom Manag* 2013;45:735–745.
 34. Emanuel EJ, Emanuel LL. The promise of a good death. *Lancet* 1998;351(suppl II):21–29.
 35. Asadpour M, Sabzevari L, Ekramifar A, et al. The attitude of medical students toward death: a cross-sectional study in Rafsanjan. *Indian J Palliat Care* 2016;22:354–361.