

Participant Characteristics. The patient's age, sex, hospital days, and care settings were extracted from medical databases. We asked the bereaved family member's age, sex, health status during the caregiving period, relationship with the patient, frequency of attending the patient, presence of other caregivers, living status with the patient, faith, education, and household income during the caregiving period.

Analysis

For item reduction, we first deleted attributes with 20% or more of the data missing or highly skewed distribution of the ratings, defined as "absolutely disagree" or "absolutely agree" in 80% of responses. We then used explanatory factor analysis, using the principle method with a promax rotation, for the 10 core domains and eight optional domains separately. According to the results of the factor analysis, attributes with factor loadings less than 0.4 (standardized regression coefficient) were deleted. In addition, we discussed the final adoption of attributes so that each domain had three items with regard to exhaustibility and clinical viewpoint.

To examine the validity and reliability of the GDI, we first examined factor validity with explanatory factor analysis, using the principle method with a promax rotation, for the final 30 attributes with the 10 core domains and 24 attributes with the eight optional domains separately. Second, to examine concurrent validity, we calculated the Pearson's correlation coefficients between each domain of the GDI and each item of the CES and overall care satisfaction. Third, for internal consistency and test-retest reliability, we calculated Cronbach's alpha coefficients (Cronbach's alpha) and intraclass correlation coefficients (ICCs).

Finally, we developed the short version of the GDI. We selected items for each domain using the standard regression coefficient in the factor analysis, Pearson's correlation coefficient between each item and domain score, and content representativeness. We calculated Pearson's correlation coefficient between selected items and overall each domain score that the item belonged to. In addition, Cronbach's alpha coefficient and ICC of the short version of the GDI were calculated. The inverse items were transformed before all

analyses. All analyses were performed using the statistical package SAS version 9.1 (SAS Institute, Cary, NC).

Results

There were 388 potential participants. Subjects were excluded for the following reasons: recruitment in another questionnaire survey for bereaved family members ($n = 23$), serious psychological distress as determined by the primary physician ($n = 8$), cause of death was treatment related or due to injury ($n = 4$), no bereaved family members older than 20 ($n = 4$), and other ($n = 5$). Of 344 questionnaires sent to the remaining bereaved family members, 11 were undeliverable and 215 were returned (response rate, 65%). Among these, 23 individuals refused to participate and three responses were excluded due to missing data. Thus, 189 responses were analyzed (effective response rate, 57%). As for the retest, of 175 questionnaires sent to bereaved families who responded during the study period, nine individuals refused to participate, and two responses were excluded due to missing data. Finally, 112 responses were analyzed (effective response rate, 64%).

Participant Characteristics

Participant characteristics are shown in Table 1. Patient characteristics were as follows: the mean age \pm standard deviation was 69 ± 12 years, males made up 57% of the total, the mean number of hospital days was 41 ± 37 , and 71% of the patients died in the PCU. As for bereaved family members, the mean age was 57 ± 12 years, 33% were males, 81% were in good or moderate health, spouses made up 46% of the total and children 34%, 69% claimed to be less religious (fair and none), 51% had a high school education or less, and the proportion with a household income of less than five million yen (US \$41,700) was 55%.

Factor Validity

In accordance with the above-mentioned item reduction procedure, 30 attributes for core domains and 24 items for optional domains were selected. The results of the factor analysis for core domains is shown in Table 2.

Table 1
Characteristics of Participants (n=189)

	n	%
Patients		
Age, y (mean±SD)	69±12	
Sex		
Male	108	57
Female	91	43
Hospital days (mean±SD)	41±37	
Setting		
General ward	55	29
Palliative care unit	134	71
Bereaved family members		
Age, y (mean±SD)	57±12	
Sex		
Male	63	33
Female	122	65
Health status		
Good	48	25
Moderate	106	56
Fair	28	15
Poor	5	3
Relationship		
Spouse	87	46
Child	64	34
Child-in-law	20	11
Parent	1	1
Sibling	11	6
Other	3	2
Frequency of attending patient		
Every day	133	70
4-6 days/week	17	9
1-3 days/week	26	14
Less than 1 day/week	9	5
Presence of other caregivers		
Present	131	69
Absent	54	29
Living status		
Living together	157	83
Not living together	30	16
Religiousness		
Much	14	7
Moderate	34	18
Fair	46	24
None	85	45
Education		
Junior high school	34	18
High school	82	43
College	40	21
University	31	16
Household Income (thousand yen)		
-249	31	16
250-499	74	39
500-749	37	20
750-999	21	11
1000-	16	8

Several total percents do not equal 100% due to missing values.

The following 10 domains were identified: (1) environmental comfort, (2) life completion, (3) dying in a favorite place, (4) maintaining hope and pleasure, (5) independence, (6) physical and psychological comfort, (7) good relationship with medical staff, (8) not being a burden to others, (9) good relationship with family, and (10) being respected as an individual. The cumulative proportion was 83%. The results of factor analysis for optional domains are shown in Table 3. Eight domains were identified, as follows: (11) religious and spiritual comfort, (12) receiving enough treatment, (13) control over the future, (14) feeling that one's life is worth living, (15) unawareness of death, (16) pride and beauty, (17) natural death, and (18) preparation for death. The cumulative proportion was 81%. These 18 domains coincided with the 18 hypothesized domains. The mean value of each domain score ranged from 2.7 to 5.5 and each standard deviation ranged from 1.1 to 1.8. We classified these 18 domains into four categories by discussion of researchers: (1) physical and psychological comfort, (2) decision making and relation to medical staff, (3) family relationship, and (4) psycho-existential issues.

Concurrent and Discriminant Validity

Table 4 shows the concurrent and discriminant validity demonstrated by the correlation between each domain of the GDI and the item of the CES. The figures represented by bold face were presumed correlations as concurrent validity. As for *physical and psychological comfort*, "physical and psychological comfort" of the GDI correlated with "physical care by physician" ($r=0.44$) and "physical care by nurse" ($r=0.23$) of the CES. As for *place of care*, "environmental comfort" correlated with "environment" ($r=0.34$), and "dying in a favorite place" correlated with "environment" ($r=0.24$). As for *decision-making and relation to medical staff*, "good relationship with medical staff" correlated with "help with decision making for patient" ($r=0.36$), "help with decision making for family" ($r=0.34$), "physical care by physician" ($r=0.44$), "physical care by nurse" ($r=0.23$), "coordination of care" ($r=0.40$), and "family burden" ($r=0.42$). "Receiving enough treatment" correlated with "help with decision making for patient" ($r=0.32$),

Table 2
Factor Validity of the Good Death Inventory, Core 10 Domains

	Standardized Regression Coefficients										Communality
	F1	F2	F3	F4	F5	F6	F7	F8	F9	F10	
1. Environmental comfort (Mean=5.4, SD=1.3)											
Living in quiet circumstances	0.95	-0.09	0.07	-0.09	-0.02	0.08	-0.04	0.00	0.05	0.05	0.92
Living in calm circumstances	0.92	0.00	0.13	-0.03	0.00	0.02	0.02	0.07	-0.03	-0.07	0.88
Patient was not troubled by other people	0.84	-0.01	0.10	-0.11	-0.02	0.04	0.07	-0.04	0.12	0.02	0.85
2. Life completion (Mean=4.2, SD=1.6)											
Having no regrets	-0.10	0.90	-0.07	-0.04	-0.13	0.06	0.03	-0.04	0.16	-0.05	0.78
Feeling that one's life was completed	-0.09	0.88	0.13	0.00	0.06	0.01	0.02	0.00	-0.07	0.05	0.86
Feeling that one's life was fulfilling	0.11	0.87	0.14	-0.05	0.08	-0.06	-0.10	0.01	-0.01	0.05	0.87
3. Dying in a favorite place (Mean=4.9, SD=1.7)											
Being able to stay at one's favorite place	0.15	-0.01	0.80	0.13	-0.02	0.01	0.02	-0.03	0.00	-0.03	0.90
Being able to die at one's favorite place	0.08	0.08	0.80	0.09	0.03	0.06	0.01	-0.02	-0.04	-0.01	0.89
Met the patient's preference of place to die	0.11	0.15	0.73	0.10	-0.01	-0.05	0.08	-0.01	0.01	0.01	0.85
4. Maintaining hope and pleasure (Mean=1.0, SD=1.6)											
Living positively	-0.07	-0.03	0.07	0.91	0.04	-0.04	0.03	0.00	0.09	0.00	0.91
Having some pleasure in daily life	-0.08	-0.11	0.12	0.88	-0.03	0.04	0.01	0.03	0.12	0.01	0.87
Living in hope	-0.06	0.10	0.15	0.72	-0.08	0.21	-0.04	-0.03	0.01	-0.07	0.79
5. Independence (Mean=3.7, SD=1.8)											
Being independent in moving or waking up	-0.04	-0.08	0.04	0.03	0.93	0.09	-0.09	-0.08	0.06	-0.01	0.80
Being independent in daily activities	-0.03	-0.06	0.05	0.09	0.88	-0.11	0.03	0.07	-0.03	-0.06	0.85
Not being troubled with excretion	0.03	0.15	-0.09	-0.18	0.80	0.08	0.08	0.01	0.01	0.03	0.69
6. Physical and psychological comfort (Mean=4.9, SD=1.5)											
Being free from pain	0.09	-0.03	-0.02	0.02	0.00	0.93	0.00	-0.01	0.00	-0.01	0.92
Being free from physical distress	0.01	0.03	0.00	0.04	0.05	0.89	0.05	-0.02	-0.04	0.04	0.92
Being free from emotional distress	0.08	0.13	0.19	0.28	0.01	0.47	0.01	0.09	-0.05	0.00	0.78
7. Good relationship with medical staff (Mean=5.5, SD=1.1)											
Trusting physician	0.05	0.13	-0.01	-0.05	0.00	-0.08	0.90	0.03	0.05	-0.12	0.80
Having a professional nurse with whom one feels comfortable	0.01	-0.17	0.00	0.10	0.01	0.04	0.80	-0.06	0.05	0.07	0.76
Having people who listen	-0.03	-0.01	0.15	-0.03	-0.01	0.19	0.73	0.01	-0.07	0.07	0.79
8. Not being a burden to others (Mean=4.0, SD=1.5)											
Not being a burden to others	0.20	-0.01	-0.20	0.07	-0.05	0.03	-0.06	0.91	-0.10	0.00	0.86
Not being a burden to family members	0.03	0.07	-0.09	0.05	0.04	-0.06	0.02	0.87	0.04	-0.02	0.80
Having no financial worries	-0.28	-0.12	0.35	-0.15	0.01	0.03	0.02	0.79	0.10	0.05	0.80
9. Good relationship with family (Mean=5.0, SD=1.2)											
Having family support	0.11	-0.06	0.14	-0.02	0.00	-0.18	-0.02	-0.05	0.80	0.08	0.67
Spending enough time with one's family	-0.02	0.05	-0.11	0.17	0.03	0.10	0.02	0.02	0.72	0.02	0.72
Having family to whom one can express one's feelings	0.05	0.19	-0.12	0.14	0.02	0.06	0.05	0.07	0.72	-0.06	0.80
10. Being respected as an individual (Mean=5.8, SD=1.1)											
Not being treated as an object or a child	-0.13	-0.03	0.06	-0.24	-0.09	0.11	-0.05	0.03	0.12	0.96	0.82
Being respected for one's values	0.14	0.15	-0.09	0.29	0.04	-0.17	0.14	0.03	-0.18	0.66	0.82
Being valued as a person	0.29	-0.02	-0.07	0.20	0.07	0.01	-0.05	-0.05	0.06	0.65	0.82

Cumulative proportion, 82.7%

F# = Factor 1 to Factor 10.

Boldfaced numbers indicate attributes belonging to each domain.

“help with decision making for family” ($r=0.30$), “physical care by physician” ($r=0.37$), and “physical care by nurse” ($r=0.16$). “Unawareness of death” correlated with “help with decision making for patient” ($r=0.26$), and “help with decision making for family” ($r=0.25$). “Natural death” correlated with “help with decision making for

patient” ($r=0.38$) and “help with decision making for family” ($r=0.32$). As for *psycho-existential issues*, there were weak correlations between each domain and “psycho-existential care.” Finally, “not being a burden on others” correlated with “cost” ($r=0.25$).

Table 5 shows the correlation between each domain of the GDI and total score of the

Table 3
Factor Validity of the Good Death Inventory, Optional Eight Domains

	Standardized Regression Coefficients								Communality
	F11	F12	F13	F14	F15	F16	F17	F18	
11. Religious and spiritual comfort (Mean=2.7, SD=1.7)									
Supported by religion	0.98	-0.01	-0.02	0.02	-0.03	-0.02	-0.02	-0.01	0.94
Having faith	0.97	0.02	0.03	0.03	0.00	0.00	-0.03	-0.02	0.95
Feeling that one is protected by a higher power beyond oneself	0.90	-0.02	0.05	0.00	0.02	0.00	0.04	0.00	0.84
12. Receiving enough treatment (Mean=5.1, SD=1.5)									
Receiving enough treatment	-0.02	0.90	0.03	0.02	0.06	-0.01	0.02	-0.04	0.89
Believing that one used all available treatments	0.02	0.86	0.03	-0.06	0.13	-0.02	-0.01	0.05	0.85
Fighting against disease until one's last moment	0.00	0.86	0.10	0.08	-0.11	0.02	-0.02	0.04	0.80
13. Control over the future (Mean=4.0, SD=1.7)									
Knowing how long one will live	0.06	-0.01	0.92	-0.12	0.10	0.02	-0.03	0.06	0.84
Knowing what to expect about one's condition in the future	0.05	0.06	0.89	0.02	-0.07	0.01	0.01	0.04	0.90
Participating in decisions about treatment strategy	-0.06	0.18	0.70	0.15	-0.04	-0.04	0.05	-0.06	0.69
14. Feeling that one's life is worth living (Mean=5.2, SD=1.3)									
Feeling that one can contribute to others	-0.01	0.03	-0.01	0.94	-0.02	0.02	-0.12	0.04	0.87
Feeling that one's life is worth living	0.07	-0.04	0.02	0.86	0.11	-0.03	0.04	-0.05	0.79
Maintaining one's role in family or occupation	0.02	0.05	-0.03	0.75	-0.10	0.05	0.13	0.09	0.70
15. Unawareness of death (Mean=3.8, SD=1.5)									
Dying without awareness that one is dying	-0.05	-0.08	0.10	0.04	0.96	-0.02	-0.06	-0.07	0.83
Living as usual without thinking about death	-0.03	0.03	0.08	-0.01	0.88	0.00	-0.02	0.00	0.79
Not being informed of bad news	0.16	0.23	-0.35	-0.08	0.62	0.04	0.11	0.11	0.72
16. Pride and beauty (Mean=3.4, SD=1.4)									
Not having a change in one's appearance	0.06	0.07	-0.02	-0.08	-0.11	0.88	-0.05	0.03	0.83
Not receiving pity from others	-0.03	-0.01	0.05	0.10	0.15	0.86	-0.09	-0.02	0.75
Not exposing one's physical and mental weakness to family	-0.04	-0.07	-0.03	0.01	-0.04	0.85	0.12	-0.04	0.74
17. Natural death (Mean=5.4, SD=1.3)									
Not being connected to medical instruments or tubes	-0.01	-0.20	0.00	0.04	0.01	-0.03	0.93	0.09	0.82
Not receiving excessive treatment	0.02	0.21	-0.01	-0.08	-0.10	0.02	0.87	-0.10	0.81
Dying a natural death	-0.08	0.24	0.06	0.13	0.18	-0.02	0.56	0.00	0.73
18. Preparation for death (Mean=4.8, SD=1.4)									
Seeing people whom one wants to see	-0.03	0.13	0.06	-0.06	-0.06	-0.01	-0.01	0.85	0.64
Feeling thankful to people	-0.05	0.07	-0.11	0.16	-0.01	-0.05	-0.10	0.79	0.77
Saying what one wants to tell dear people	0.06	-0.18	0.21	-0.01	0.07	0.05	0.14	0.74	0.79

Cumulative proportion, 80.6%

F# indicates Factor 11 to Factor 18.

Boldfaced numbers indicate attributes belonging to each domain.

CES and overall care satisfaction. The correlation of each domain of the GDI and the total score of the CES ranged from $r=0.07$ to $r=0.42$. The correlation of each domain of the GDI and the overall care satisfaction ranged from $r=0.11$ to $r=0.55$. Most domains correlated with the CES and overall care satisfaction moderately. In addition, the GDI tended to more strongly correlate with overall care satisfaction than the CES. All 18 domains of the GDI correlated with the total score of the CES ($r=0.26$) and overall care satisfaction ($r=0.39$). The total of the 10 core domains of the GDI correlated with the total score of the

CES ($r=0.31$) and overall care satisfaction ($r=0.41$). The total of the eight optional domains of the GDI were not correlated with the total score of the CES and overall care satisfaction.

Internal Consistency and Reliability

Table 6 shows the internal consistency (Cronbach's alpha) and test-retest reliability (ICC). Cronbach's alpha ranged from 0.74 to 0.95. The Cronbach's alpha coefficient of the total score was 0.94; of the 10 core domains, it was 0.92; and of the eight optional domains, it was 0.87. The ICC ranged from 0.44 to 0.72

Table 4
Concurrent and Discriminant Validity with Each Item of the Care Evaluation Scale

	Care Evaluation Scale									
	Help With Decision Making for Patient	Help With Decision Making for Family	Physical Care by Physician	Physical Care by Nurse	Psycho-Existential Care	Environment	Cost	Availability	Coordination of Care	Family Burden
Physical and psychological comfort	0.40 ^a	0.31 ^a	0.44 ^a	0.23 ^b	0.25 ^a	0.18 ^c	0.06	0.07	0.29 ^a	0.28 ^a
Place of care										
1. Environmental comfort	0.35 ^a	0.33 ^a	0.40 ^a	0.29 ^a	0.37 ^a	0.34 ^a	0.22 ^b	0.15 ^c	0.27 ^a	0.30 ^a
3. Dying in a favorite place	0.37 ^a	0.30 ^a	0.40 ^a	0.20 ^b	0.30 ^a	0.24 ^b	0.10	0.06	0.23 ^b	0.30 ^a
Decision-making and relation to medical staff										
7. Good relationship with medical staff	0.36 ^a	0.34 ^a	0.43 ^a	0.33 ^a	0.36 ^a	0.28 ^a	0.19 ^c	0.15	0.40 ^a	0.42 ^a
12. Receiving enough treatment	0.32 ^a	0.30 ^a	0.37 ^a	0.16 ^c	0.25 ^a	0.17 ^c	0.10	0.11	0.22 ^b	0.22 ^b
15. Unawareness of death	0.26 ^a	0.25 ^a	0.26 ^a	0.13	0.19 ^b	0.11	0.13	0.14	0.15 ^c	0.17 ^c
17. Natural death	0.38 ^a	0.32 ^a	0.37 ^a	0.24 ^b	0.35 ^a	0.29 ^a	0.13	0.07	0.28 ^a	0.28 ^a
Family relationship										
9. Good relationship with family	0.08	0.17 ^c	0.11	0.02	0.07	0.12	-0.08	-0.03	0.04	0.06
Psycho-existential issues										
2. Life completion	0.24 ^b	0.20 ^b	0.22 ^b	0.10	0.16 ^c	0.07	0.02	-0.04	0.15 ^c	0.13
4. Maintaining hope and pleasure	0.34 ^a	0.29 ^a	0.34 ^a	0.21 ^b	0.23 ^b	0.18 ^c	0.06	0.09	0.20 ^b	0.25 ^a
5. Independence	0.07	0.00	0.08	0.04	0.05	0.08	0.05	0.18 ^c	0.07	-0.02
8. Not being a burden to others	0.14	0.18 ^c	0.14	0.17 ^c	0.20 ^b	0.14	0.25 ^b	0.09	0.09	0.05
10. Being respected as an individual	0.22 ^b	0.25 ^a	0.25 ^a	0.26 ^a	0.24 ^b	0.29 ^a	0.18 ^c	0.09	0.20 ^b	0.17 ^c
11. Religious and spiritual comfort	0.04	0.09	0.04	0.04	0.01	0.03	0.06	0.02	-0.01	0.11
13. Control over the future	0.15	0.17 ^c	0.17 ^c	0.14	0.14	0.12	0.02	0.07	0.08	0.09
14. Feeling that one's life is worth living	0.14	0.18 ^c	0.19 ^c	0.15 ^c	0.24 ^b	0.19 ^c	0.09	0.17 ^c	0.16 ^c	0.20 ^b
16. Pride and beauty	0.11	0.06	0.12	0.09	0.09	0.05	0.15	0.09	-0.01	-0.05
18. Preparation for death	0.15 ^c	0.18 ^c	0.16 ^c	0.16 ^c	0.18 ^c	0.13	0.04	0.03	0.13	0.12

Figures are Pearson's correlation coefficients.
 Boldfaced numbers indicate attributes assumed to correlate with each item of the Care Evaluation Scale.
^aP<0.001.
^bP<0.01.
^cP<0.05.

Table 5
Concurrent and Discriminant Validity with Total Score of Care Evaluation Scale and Satisfaction

	Total score of CES	Overall care satisfaction
Physical and psychological comfort		
6. Physical and psychological comfort	0.32 ^a	0.47 ^a
Place of care		
1. Environmental comfort	0.39 ^a	0.42 ^a
3. Dying in a favorite place	0.32 ^a	0.50 ^a
Decision-making and relation to medical staff		
7. Good relationship with medical staff	0.42 ^a	0.55 ^a
12. Receiving enough treatment	0.28 ^a	0.50 ^a
15. Unawareness of death	0.23 ^b	0.35 ^a
17. Natural death	0.34 ^a	0.45 ^a
Family relationship		
9. Good relationship with family	0.07	0.18 ^c
Psycho-existential issues		
2. Life completion	0.15 ^c	0.33 ^a
4. Maintaining hope and pleasure	0.27 ^a	0.33 ^a
5. Independence	0.08	0.11
8. Not being a burden to others	0.19 ^c	0.14
10. Being respected as an individual	0.27 ^a	0.28 ^a
11. Religious and spiritual comfort	0.05	0.12
13. Control over the future	0.14	0.25 ^a
14. Feeling that one's life is worth living	0.22 ^b	0.28 ^a
16. Pride and beauty	0.09	0.16 ^c
18. Preparation for death	0.16 ^c	0.27 ^a
All 18 domains	0.26 ^a	0.39 ^a
Core 10 domains	0.31 ^a	0.41 ^a
Optional eight domains	-0.02	0.10

Figures are Pearson's correlation coefficients.

^aP<0.001.

^bP<0.01.

^cP<0.05.

except for "not being a burden for others" (ICC = 0.38). The ICC of all 18 domains was 0.52; of the total of the 10 core domains, it was 0.59; and of the total of the eight optional domains, it was 0.50.

Development of Short Version of the GDI

In accordance with the process described in the Analysis section, we selected 18 attributes for each domain to create the short version of the GDI (Table 7). Pearson's correlation coefficient between each attribute and the final domains ranged from 0.80 to 0.97. The Cronbach's alpha coefficient of all 18 attributes

Table 6
Internal Consistency and Reliability

Domains	Alpha	ICC
Core 10 domains		
1. Environmental comfort	0.92	0.57
2. Life completion	0.87	0.63
3. Dying in a favorite place	0.94	0.68
4. Maintaining hope and pleasure	0.91	0.67
5. Independence	0.82	0.52
6. Physical and psychological comfort	0.92	0.44
7. Good relationship with medical staff	0.83	0.87
8. Not being a burden to others	0.83	0.38
9. Good relationship with family	0.79	0.44
10. Being respected as an individual	0.74	0.58
Optional eight domains		
11. Religious and spiritual comfort	0.95	0.58
12. Receiving enough treatment	0.90	0.59
13. Control over the future	0.87	0.72
14. Feeling that one's life is worth living	0.86	0.60
15. Unawareness of death	0.81	0.53
16. Pride and beauty	0.84	0.51
17. Natural death	0.74	0.50
18. Preparation for death	0.78	0.61
All 18 domains	0.94	0.52
Core 10 domains	0.92	0.59
Optional eight domains	0.87	0.50

Alpha = Cronbach's alpha coefficient; ICC = Intraclass correlation coefficient.

was 0.85; of the 10 core attributes, it was 0.78; and of the eight optional attributes, it was 0.69. The ICC of all 18 attributes was 0.71; of the 10 core attributes, it was 0.64; and of the eight optional attributes, it was 0.59.

Discussion

We validated the GDI in Japanese bereaved family members. This assessment will allow us to evaluate end-of-life care from the bereaved family's perspective. The most useful finding is in regard to concurrent validity. Some GDI domains measuring end-of-life care that focus on structure and process of care correlated with the CES. However, other domains did not correlate with the CES or overall care satisfaction. This means that the GDI might measure different aspects of end-of-life care and that the results are consistent with the hypothesis that the GDI explains a significant portion of the bereaved family member's overall satisfaction.

As for the factor validity, we identified 18 possible domains. We conducted a nationwide opinion survey on this topic preceding the present study. The results of the present study

Table 7
Short Version of the Good Death Inventory

Attributes	Pearson's r^a
Core 10	
Living in calm circumstances	0.93
Feeling that one's life was completed	0.92
Having some pleasure in daily life	0.94
Being able to stay at one's favorite place	0.96
Being independent in daily activities	0.87
Being free from physical distress	0.96
Trusting physician	0.87
Not being a burden to others	0.89
Spending enough time with one's family	0.89
Being valued as a person	0.83
Optional eight	
Supported by religion	0.97
Receiving enough treatment	0.92
Knowing what to expect about one's condition in the future	0.95
Feeling that one's life is worth living	0.88
Dying without awareness that one is dying	0.87
Not exposing one's physical and mental weakness to family	0.87
Dying a natural death	0.80
Saying what one wants to dear people	0.87
Internal consistency	Alpha
All 18 attributes	0.85
Core 10 attributes	0.78
Optional eight attributes	0.69
Test-retest reliability	ICC
All 18 attributes	0.71
Core 10 attributes	0.64
Optional eight attributes	0.59

Alpha = Cronbach's alpha coefficient; ICC = Intraclass correlation coefficient.

^aPearson's correlation coefficient with each domain total score.

confirm the findings of the preceding study and confirm that a good death concept in the Japanese population is constituted by these 18 domains.²⁵

As for the concurrent and discriminant validity, physical and psychological comfort, environmental comfort, dying in a favorite place, good relationship with medical staff, receiving enough treatment, unawareness of death, and natural death were correlated with presumed items of the CES. However, good family relationship, life completion, maintaining hope and pleasure, independence, not being a burden to others, being respected as an individual, religious and spiritual comfort, control over the future, feeling that one's life is worth living, pride and beauty, and preparation for death either were not correlated or were weakly correlated with the items of the CES. These domains cover psycho-existential and

spiritual concerns in the Japanese population.^{26,27} As the CES measures the structure and process of care, these results are considered reasonable. The GDI might be able to measure outcomes of care based on individualized important issues in the dying process. In addition, as a whole, the domains of the GDI were more correlated with overall care satisfaction than with the CES. This means that the GDI might cover more comprehensive aspects of end-of-life care outcomes than the CES. The concept of satisfaction of bereaved family members is still unclear and using satisfaction as a measure of quality of care contains unresolved problems.²⁸ The results of our study would provide more information of the understanding of care satisfaction from bereaved family members' perspectives.

Some might consider it odd that domains XIV (control over the future) and XV (unawareness of death) would coexist in the Japanese concept of a good death. However, our previous study found that the Japanese population emphasized both concepts. Actually, these two domains are part of the eight optional domains. These optional domains are thought to be concepts with lesser importance to the individual. In contrast to Steinhäuser et al.'s⁷ good death study, the Japanese population does not consider control over the future as important as the US population. The less autonomous attitude in the dying process might be unique to Japanese culture.^{7,25}

Although the domains of the GDI demonstrated sufficient internal consistency, reliability measured by ICC was of moderate value.²⁹ We think the reasons for moderate reliability would be as follows: (1) the period of test-retest was over one month; (2) we recruited participants until two years after death, so memory might be vague; (3) although we asked the primary caregiver to answer the questionnaire, we could not be sure that the identical person filled out the two questionnaires; and (4) the family member's assessment of the GDI might change over time. However, the moderate reliability of the study of bereaved family members is consistent with previous work.^{20,30} Therefore, these moderate ICCs would not be crucial drawbacks of the GDI. The relatively low ICC of "not being a burden to others" is reasonable because it is difficult for family members to infer the patient's viewpoint. Instead, we might appreciate

the sufficient internal consistency as a measure of reliability for a cross-sectional study.

In addition, we developed a short version of the GDI. Depending on the study objective, an investigator might be reluctant to use the full version. In that situation, the investigator would be able to use the short version. The psychometric properties of the short version of the GDI have been shown. This short version of the GDI could be used in any study setting.

Limitations and Future Perspectives

The limitations of this study are as follows: First, the response rate was 57%. We believe, however, this is not a fatal flaw because the objective of this study was to validate a scale, not to survey actual conditions. Second, this study was conducted at one regional cancer center. The results of this study might not be generalizable to other settings. Third, this study did not examine criterion validity. It is difficult to examine criterion validity, however, because the gold standard for measuring a good death has not yet been established.

In future studies, we would like to conduct a nationwide survey of the achievement of a good death using this scale. In addition, we should investigate the national level of a benchmark of the achievement of a good death and differences in the achievement of a good death among institutions or care settings. Furthermore, we should identify barriers to achieving a good death and develop methods for eliminating these barriers in all Japanese end-of-life care settings.

Conclusions

In conclusion, we validated the GDI as a measure for evaluating a good death from the bereaved family's perspective. The GDI has sufficient factor validity, concurrent validity, internal consistency, and acceptable test-retest reliability. The GDI is a valid scale for measuring comprehensive end-of-life care outcomes from the bereaved family members' perspective in Japan. In future studies, we would like to conduct a nationwide survey of the achievement of a good death using this scale. In addition, we should identify and eliminate barriers to achieving a good death in all Japanese end-of-life care settings.

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Appendix

Good Death Inventory (GDI)

How do you think the patient felt during the end-of-life period? Please place the appropriate number next to each statement: 1: absolutely disagree, 2: disagree, 3: somewhat disagree, 4: unsure, 5: somewhat agree, 6: agree, 7: absolutely agree.

- | | |
|---|--|
| <p>I. Physical and psychological comfort
Patient was free from pain.
Patient was free from physical distress.
Patient was free from emotional distress.</p> | <p>XI. Receiving enough treatment
Patient received enough treatment.
Patient believed that all available treatments were used.
Patient fought against disease until the last moment.</p> |
| <p>II. Dying in a favorite place
Patient was able to stay at his or her favorite place.
Patient was able to die at his or her favorite place.
The place of death met the preference of the patient.</p> | <p>XII. Natural death
Patient was not connected to medical instruments or tubes.
Patient did not receive excessive treatment.
Patient died a natural death.</p> |
| <p>III. Maintaining hope and pleasure
Patient lived positively.
Patient had some pleasure in daily life.
Patient lived in hope.</p> | <p>XIII. Preparation for death
Patient met people whom he or she wanted to see.
Patient felt thankful to people.
Patient was able to say what he or she wanted to dear people.</p> |
| <p>IV. Good relationship with medical staff
Patient trusted the physician.
Patient had a professional nurse with whom he or she felt comfortable.
Patient had people who listened.</p> | <p>XIV. Control over the future
Patient knew how long he or she was expected to live.
Patient knew what to expect about his or her condition in the future.
Patient participated in decisions about treatment strategy.</p> |
| <p>V. Not being a burden to others
Patient was not being a burden to others (*).
Patient was not being a burden to family members (*).
Patient had no financial worries (*).</p> | <p>XV. Unawareness of death
Patient died without awareness that he or she was dying.
Patient lived as usual without thinking about death.
Patient was not informed of bad news.</p> |
| <p>VI. Good relationship with family
Patient had family support.
Patient spent enough time with his or her family.
Patient had family to whom he or she could express feelings.</p> | <p>XVI. Pride and beauty
Patient felt burden of a change in his or her appearance (*).
Patient felt burden of receiving pity from others (*).
Patient felt burden of exposing his or her physical and mental weakness to family (*).</p> |
| <p>VII. Independence
Patient was independent in moving or waking up.
Patient was independent in daily activities.
Patient was not troubled with excretion.</p> | <p>XVII. Feeling that one's life is worth living
Patient felt that he or she could contribute to others.
Patient felt that his or her life is worth living.
Patient maintained his or her role in family or occupation.</p> |
| <p>VIII. Environmental comfort
Patient lived in quiet circumstances.
Patient lived in calm circumstances.
Patient was not troubled by other people.</p> | <p>XVIII. Religious and spiritual comfort
Patient was supported by religion.
Patient had faith.
Patient felt that he or she was protected by a higher power.</p> |
| <p>IX. Being respected as an individual
Patient was not treated as an object or a child.
Patient was respected for his or her values.
Patient was valued as a person.</p> | |
| <p>X. Life completion
Patient had no regrets.
Patient felt that his or her life was completed.
Patient felt that his or her life was fulfilling.</p> | |
- (* Inverse items.

Factors contributing to evaluation of a good death from the bereaved family member's perspective

Mitsunori Miyashita^{1*}, Tatsuya Morita², Kazuki Sato¹, Kei Hirai^{3,4}, Yasuo Shima⁵ and Yosuke Uchitomi⁶

¹ Department of Adult Nursing/Palliative Care Nursing, School of Health Sciences and Nursing, Graduate School of Medicine, The University of Tokyo, Tokyo, Japan

² Department of Palliative and Supportive Care, Palliative Care Team and Seirei Hospice, Seirei Mikatahara Hospital, Shizuoka, Japan

³ Center of the Study for Communication Design, Psychology and Behavioral Sciences, Graduate School of Human Sciences, Osaka University, Osaka, Japan

⁴ Department of Complementary and Alternative Medicine, Graduate School of Medicine, Osaka University, Osaka, Japan

⁵ Department of Palliative Medicine, Tsukuba Medical Center Hospital, Ibaraki, Japan

⁶ Psycho-Oncology Division, Research Center for Innovative Oncology, National Cancer Center Hospital East, Chiba, Japan

*Correspondence to:
Department of Adult Nursing/
Palliative Care Nursing, School
of Health Sciences and
Nursing, Graduate School of
Medicine, University of Tokyo,
7-3-1 Hongo, Bunkyo-ku,
Tokyo 113-0033, Japan.
E-mail: miyashita-ky@umin.net

Abstract

Background: Although it is important to achieve a good death in Japan, there have been no studies to explore factors associated with a good death. The aim of this study was to explore factors contributing to a good death from the bereaved family members' perspectives, including patient and family demographics and medical variables.

Methods: A cross-sectional anonymous questionnaire survey for bereaved family members of cancer patients who had died in a regional cancer center and a medical chart review were conducted. We measured the results from the Good Death Inventory and family demographics. In addition, we extracted patient demographics, medical variables, and medical interventions in the last 48 h before death from a medical chart review.

Results: Of the 344 questionnaires sent to bereaved family members, 165 responses were analyzed (48%). We found, first, that death in the palliative care unit was more likely to be described as a good death compared with death on a general ward. Some significant characteristics were 'environmental comfort,' 'physical and psychological comfort,' 'being respected as an individual,' and 'natural death.' Second, we found that a patient's and family member's age and other demographic factors significantly correlated with an evaluation of a good death. In addition, life prolongation treatment and aggressive treatment such as chemotherapy in the last 2 weeks of life were barriers to attainment of a good death. Moreover, appropriate opioid medication contributed to a good death.

Conclusion: Withholding aggressive treatment and life-prolonging treatment for dying patients and appropriate opioid use may be associated with achievement of a good death in Japan.

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Introduction

One of the most important goals of palliative care is achieving a 'good death' or a 'good dying process.' In Western countries, elaborate efforts have been devoted to conceptualizing a good death using qualitative [1–4] and quantitative research [5, 6]. In addition, Steinhilber *et al.* have measured the achievement of a good death by terminally ill patients [7, 8]. Moreover, Yun *et al.* have assessed patient-reported quality of end-of-life care and explored correlations of quality-of-life measures in Korea [9].

However, interviewing or administering a questionnaire to vulnerable terminally ill patients is burdensome, and may result in biased conclusions

due to nonresponse because of physical status. Therefore, many studies to evaluate end-of-life care have been conducted with bereaved family members [10–14]. To accomplish this, measures for bereaved family members were developed in Western countries [13, 15, 16].

In Japan, although Morita *et al.* developed the Care Evaluation Scale focusing on structure and process of end-of-life care [17], only a few studies have investigated a good death [18, 19]. In order to establish a goal of palliative care in Japan, it is important to conceptualize what constitutes a good death in Japan. Therefore, for the first step, we conducted a nationwide qualitative study to explore attributes of a good death in Japan for a total of 63 participants including advanced cancer

patients, their families, physicians, and nurses [20]. For the second step, we conducted a quantitative study to determine what attributes were considered necessary for a good death, using a large nationwide sample of the general population and bereaved family members [21]. Our third step was to develop a Good Death Inventory (GDI) as a measure for evaluating a good death from the bereaved family member's perspective, and we examined its validity and reliability [22].

Although there are measures to evaluate a good death from the bereaved family member's perspective, few studies exploring contributing factors have been conducted. Teno *et al.* showed that the last place of care influenced the achievement of a good death [12]. However, the correlations between other variables such as patient and family demographics, medical variables, and the achievement of a good death were still unclear. It is important to describe the factors contributing to achieving a good death. It is especially relevant to identify medical variables that contribute to a good death because of the implications for improving clinical interventions by medical practitioners.

The Japanese Ministry of Health, Labor, and Welfare has strongly supported dissemination of specialized palliative care services, with coverage of palliative care units (PCUs) by National Medical Insurance since 1990. The number of PCUs has dramatically increased from 5 in 1990 to 163 in 2006. In contrast, the growth of home-based palliative care programs has been slow, as inpatient palliative care teams were not covered by National Medical Insurance until 2002. Therefore, the most common type of specialized palliative care service in Japan is the PCU. Although the number of PCUs has increased, they cover only 6% of all cancer deaths. In 2004, only 6% of cancer deaths occurred in the home and over 80% of cancer deaths occurred on general wards. Therefore, death on general wards is an important issue in Japan. However, the comparison of the achievement of a good death between these care settings has not been done. Therefore, we aimed in this study, first, to compare the achievement of a good death between inpatient PCUs and general wards; and second, to explore factors including patient and family demographics and medical variables that may contribute to a good death from the bereaved family member's perspective in Japan.

Methods

Participants and procedures

A cross-sectional anonymous questionnaire was administered to bereaved family members of cancer patients who had died in a regional cancer center's general wards and inpatient PCU in Ibaraki

prefecture, Japan. In addition, medical chart review was conducted for these patients with the permission of bereaved family members.

To find potential participants, we identified bereaved family members of patients who died from September 2004 to February 2006. The inclusion criteria were as follows: (1) patient died in PCU or died on the general ward from lung cancer or gastrointestinal cancer; (2) patient was aged 20 years or more; and (3) patient was hospitalized at least 3 days. The exclusion criteria were as follows: (1) participant was recruited for another questionnaire survey for bereaved family members; (2) participant would have suffered serious psychological distress as determined by the primary physician; (3) cause of death was treatment related or due to injury; (4) there was no bereaved family member who was aged 20 years or more; (4) participant was incapable of replying to a self-reported questionnaire; and (5) participant was not aware of the diagnosis of malignancy.

We mailed questionnaires to potential respondents in October 2006 and a reminder was sent in November 2006 to those who did not respond. We asked the primary caregiver to complete the questionnaire. If the respondents did not want to participate in the survey, they were asked to return the questionnaire with 'no participation' indicated, and a reminder was not mailed to them. In addition, we asked the participant to give permission for a medical chart review in accordance with Japanese guidelines for protection of individual information. The ethical and scientific validity of this study was approved by the institutional review boards of Tsukuba Medical Center Hospital.

Measurements

Good death inventory

The GDI evaluates end-of-life care from the bereaved family member's perspective. Fifty-four attributes of a good death were asked using a 7-point Likert scale (1: absolutely disagree, 2: disagree, 3: somewhat disagree, 4: unsure, 5: somewhat agree, 6: agree, 7: absolutely agree). The attributes were generated based on a previous qualitative study [20], quantitative study [21], and literature review [5, 6, 12, 13, 15–17, 23]. The validity and reliability of the GDI have been examined and 18 domains were confirmed [22]. The GDI consisted of 10 core domains including: '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,' and eight optional domains including: '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.' The eight optional domains were not important for all Japanese, however, some Japanese emphasized that these domains were significant. We calculated the domain score by summing up attributes. The range of each domain score was from 7 to 21. A high score indicated the achievement of a good death in each domain. The content validity of the GDI was ensured by our previous qualitative and quantitative studies. The GDI has sufficient factor validity and concurrent validity with overall satisfaction. The Cronbach's alpha of the GDI ranged from 0.74 to 0.95. The intraclass correlation coefficients (ICC) for test-retest reliability ranged from 0.44 to 0.72 except for 'not being a burden for others' (ICC = 0.38). The ICC of all 18 domains was 0.52; of the total of the 10 core domains it was 0.59 and of the total of the eight optional domains it was 0.50 [22]. The questionnaire and domains of the GDI are described in the Appendix.

Patient and family demographics

The patients' age, sex, and marital status were extracted from medical chart. We asked the bereaved family member's age, sex, health status during the caregiving period, relationship with the patient, frequency of attending the patient, religiousness, education, and household income during the caregiving period.

Medical variables and medical intervention in the last 48 h

The medical variables extracted from the charts were: place of care (PCU or general ward), type of room (private or not), duration since diagnosis, number of hospital days, short stay at home in the last 30 days, cancer stage, site of cancer, treatment experience, Do-Not-Resuscitate order (present or absent), cardiopulmonary resuscitation, and chemotherapy in the last 14 days. Medical interventions in the last 48 h that were extracted were: use of oxygen, palliative sedation, insertion/placement of tubes, parenteral medication, nonparenteral medication, artificial hydration, intravenous hyperalimentation, vasopressor, antibiotic, blood transfusion, and opioid medication. Palliative sedation was defined as a sedative drug such as midazolam or haloperidol that was administered to the patient with the aim of sedation and was recorded by the physician in the medical chart. The details of medical variables and medical interventions in the last 48 h in this regional cancer center have been described in another paper [24]. At the beginning of the review, 20 randomly selected medical charts were independently abstracted by two researchers

to assure inter-rater reliability. The average accordance rate was 93%.

Analysis

We first described participant characteristics such as patient and family demographics, medical variables, and medical interventions in the last 48 h. Second, we compared the evaluation of a good death between PCUs and general wards using Welch's *t* test. Finally, to explore factors contributing to a good death from the bereaved family member's perspective, we conducted multiple regression analyses. The dependent variables were 18 domains of the GDI. The explanatory variables were patient and family demographics, medical variables, and medical interventions in the last 48 h. Because of the distorted distribution, we did not use the following variables as explanatory variables: cardiopulmonary resuscitation, intravenous hyperalimentation, and blood transfusion. We adopted the backward variable selection method in the multiple regression analyses and we set the significance level to be included in the model as $P < 0.05$. The place of death was included in the model because medical treatment would be different between the two settings. All analyses were performed using the statistical package SAS version 9.1 (SAS Institute, Cary, NC).

Results

There were 388 potential participants. Subjects were excluded for the following reasons: recruitment in another questionnaire survey for bereaved family members ($n = 23$), serious psychological distress as determined by the primary physician ($n = 8$), cause of death was treatment related or due to injury ($n = 4$), no bereaved family members older than 20 ($n = 4$), and other ($n = 5$). Of 344 questionnaires sent to the remaining bereaved family members, 11 were undeliverable and 215 were returned (response rate, 65%). Among these, 23 individuals refused to participate and three responses were excluded due to missing data. In addition, 24 individuals refused the medical chart review. Thus, 165 responses were analyzed (48%).

Participant characteristics

Participant characteristics are shown in Table 1. Patient characteristics were as follows: the mean age \pm standard deviation age was 70 ± 11 , males made up 56% of the total, and 73% of the participants were married. As for bereaved family members, the mean age was 57 ± 13 , and 33% were males. As for medical variables, 74% of the patients were cared for in the PCU, the mean number of hospital days was 41 ± 38 , 21% of the

Table 1. Characteristics of participants (N = 165)

	n	%
<i>Patient demographics</i>		
Age, years (mean ± SD)	70 ± 11	
Sex (male)	92	56
Marital status (married)	121	73
<i>Bereaved family member demographics</i>		
Age, years (mean ± SD)	57 ± 13	
Sex (Male)	54	33
<i>Health Status</i>		
Good	42	25
Moderate	94	57
Fair	23	14
Poor	4	2
Relationship (spouse)	77	47
<i>Frequency of attending patient</i>		
Every day	119	72
4–6 days/week	14	8
1–3 days/week	21	13
Less than 1 day/week	8	5
<i>Religiousness</i>		
None	75	45
Fair	40	24
Moderate	28	17
Much	12	7
<i>Education</i>		
Junior high school	28	17
High school	69	42
College	36	22
University	30	18
<i>Household income (thousand yen)</i>		
–249	24	15
250–499	64	39
500–749	34	21
750–999	19	12
1000–	15	9
<i>Medical variables</i>		
<i>Place of care</i>		
General ward	43	26
Palliative Care Unit	122	74
Type of room (private)	145	88
Duration from diagnosis, m (mean ± SD)	27 ± 33	
Hospital days (mean ± SD)	41 ± 38	
Short stay at home in the last 30 days	14	8
<i>Cancer stage</i>		
Local	4	2
Regional	25	15
Distant metastasis	133	81
<i>Site of cancer</i>		
Lung	35	21
Gastrointestinal	82	50
Other	48	29
<i>Treatment experience (multiple answer)</i>		
Surgery	82	50
Chemotherapy	103	62
Radiotherapy	74	45
Do-Not-Resuscitate order (present)	160	97
Cardiopulmonary resuscitation	1	1
Chemotherapy in the last 14 days	7	4
<i>Medical intervention in the last 48 h</i>		
Oxygen inhalation	143	87
Palliative sedation	32	19
Insertion/placement of tubes	30	18
Parenteral medication	159	96

Table 1. (continued)

	n	%
Nonparenteral medication	78	47
Artificial hydration	140	85
Intravenous hyperalimentation	4	2
Vasopressor	12	7
Antibiotic	58	35
Blood transfusion	3	2
Opioid medication	143	87

Note: Several total percent do not equal 100% due to missing values.

total had lung cancer, and 50% had gastrointestinal cancer. As for medical interventions in the last 48 h, 19% received palliative sedation, 85% artificial hydration, 7% vasopressors, 35% antibiotics, and 87% received opioid medications.

Comparison of an evaluation of a good death between PCU and general wards

We show the comparison of evaluations of a good death between PCUs and general wards in Table 2. For patients whose last place of care was a PCU, participants evaluated that patients were more likely to achieve a good death for the domains 'environmental comfort' ($P < 0.001$), 'physical and psychological comfort' ($P = 0.04$), 'being respected as an individual' ($P = 0.01$), and 'natural death' ($P = 0.02$).

Factors contributing to evaluation of a good death (10 core domains)

We show the results of multiple regression analyses regarding 10 core good death domains in Table 3. 'Environmental comfort' correlated with place of care (PCU, $P < 0.001$), family member's older age ($P < 0.001$), and family member's poor health ($P = 0.03$). 'Life completion' correlated with patient's older age ($P < 0.001$), and family member's relationship (spouse, $P < 0.001$). 'Dying in a favorite place' correlated with patient's older age ($P = 0.003$), family member's relationship (spouse, $P < 0.001$), and family member's education ($P = 0.005$). 'Maintaining hope and pleasure' correlated with patient's older age ($P = 0.04$), early cancer stage ($P = 0.01$), duration since diagnosis ($P = 0.04$), and not receiving vasopressors ($P < 0.001$). 'Physical and psychological comfort' correlated with place of care (PCU, $P = 0.01$), patient's older age ($P = 0.02$), family member's older age ($P < 0.001$), not receiving palliative sedation ($P = 0.03$), and not receiving antibiotic ($P < 0.001$). 'Good relationship with medical staff' correlated with patient's older age ($P = 0.04$), family member's older age ($P = 0.01$), early cancer stage ($P < 0.001$), and receiving opioid medication ($P = 0.003$). 'Not being a burden to others' correlated with patient's older age ($P = 0.005$) and treatment experience (no

Table 2. Evaluation of good death in PCU and general wards

	PCU		General wards		P-value
	Mean	SD	Mean	SD	
<i>Ten core domains</i>					
1. Environmental comfort	5.7	1.0	4.7	1.5	<0.001
2. Life completion	4.1	1.7	4.3	1.6	0.60
3. Dying in a favorite place	5.0	1.5	4.5	1.9	0.05
4. Maintaining hope and pleasure	4.1	1.5	3.8	1.7	0.31
5. Independence	3.6	1.8	4.0	1.8	0.10
6. Physical and psychological comfort	5.0	1.5	4.5	1.7	0.04
7. Good relationship with medical staff	5.6	1.0	5.3	1.3	0.07
8. Not being a burden to others	4.0	1.5	3.8	1.3	0.19
9. Good relationship with family	5.1	1.2	4.8	1.2	0.18
10. Being respected as an individual	5.9	0.9	5.4	1.3	0.01
<i>Eight optional domains</i>					
11. Religious and spiritual comfort	2.5	1.6	3.0	1.8	0.12
12. Receiving enough treatment	5.1	1.5	5.0	1.6	0.90
13. Control over the future	4.0	1.7	3.9	1.7	0.76
14. Feeling that one's life is worth living	5.2	1.3	5.2	1.3	0.89
15. Unawareness of death	3.6	1.4	4.0	1.5	0.10
16. Pride and beauty	3.4	1.3	3.5	1.6	0.83
17. Natural death	5.5	1.2	5.0	1.4	0.02
18. Preparation for death	4.8	1.4	4.8	1.3	0.92

Note: Statistical test comparing two places of care was by Welch's *t* test. PCU: Palliative Care Unit.

surgery, $P = 0.01$). 'Good relationship with family' correlated with place of care (PCU, $P = 0.007$), low household income ($P = 0.02$), type of room (private, $P = 0.03$), and not receiving artificial hydration ($P = 0.02$). 'Being respected as an individual' correlated with place of care (PCU, $P = 0.04$), patient's older age ($P = 0.003$), patient's marital status (not married, $P = 0.04$), family member's relationship (spouse, $P = 0.02$), early cancer stage ($P = 0.008$), treatment experience (chemotherapy, $P = 0.004$), type of room (private, $P = 0.03$), not receiving chemotherapy in the last 14 days ($P = 0.002$), and palliative sedation ($P = 0.03$).

Factors contributing to evaluation of a good death (optional domains)

We show the results of multiple regression analyses regarding eight optional good death domains in Table 4. 'Religious and spiritual comfort' correlated with family member's younger age ($P = 0.01$) and family's religiousness ($P < 0.001$). 'Receiving enough treatment' correlated with patient's older age ($P = 0.03$), family member's older age ($P = 0.01$), and opioid medication ($P = 0.009$). 'Feeling that one's life is worth living' correlated with the duration since diagnosis ($P = 0.04$). 'Unawareness of death' correlated with family member's older age ($P = 0.002$), patient's marital status (not married,

Table 3. Factors contributing to a good death (10 core domains)

	β	P-value
1. <i>Environmental comfort</i> ($R^2 = 0.219$)		
Place of care (PCU)	1.05	<0.001
Family member's age	0.03	<0.001
Family member's health	-0.31	0.02
2. <i>Life completion</i> ($R^2 = 0.257$)		
Place of care (PCU)	0.55	0.06
Patient's age	0.08	<0.001
Family relationship (spouse)	1.01	<0.001
3. <i>Dying in a favorite place</i> ($R^2 = 0.307$)		
Place of care (PCU)	0.10	0.76
Patient's age	0.03	0.003
Family relationship (spouse)	0.89	<0.001
Family member's education	-0.36	0.005
4. <i>Maintaining hope and pleasure</i> ($R^2 = 0.168$)		
Place of care (PCU)	0.34	0.32
Patient's age	0.02	0.04
Cancer staging	-0.72	0.01
Duration from diagnosis	0.01	0.04
Vasopressor	-2.21	<0.001
5. <i>Independence</i> ($R^2 = 0.018$)		
Place of care (PCU)	-0.54	0.11
6. <i>Physical and psychological comfort</i> ($R^2 = 0.312$)		
Place of care (PCU)	0.71	0.01
Patient's age	0.02	0.02
Family member's age	0.04	<0.001
Palliative sedation	-0.64	0.03
Antibiotic	-0.85	<0.001
7. <i>Good relationship with medical staff</i> ($R^2 = 0.196$)		
Place of care (PCU)	0.22	0.26
Patient's age	0.02	0.04
Family member's age	0.02	0.01
Cancer staging	-0.69	<0.001
Opioid medication	0.82	0.003
8. <i>Not being a burden to others</i> ($R^2 = 0.115$)		
Place of care (PCU)	0.52	0.06
Patient's age	0.03	0.005
Treatment experience (surgery)	-0.61	0.01
9. <i>Good relationship with family</i> ($R^2 = 0.115$)		
Place of care (PCU)	0.76	0.007
Household income	-0.18	0.02
Type of room (private)	0.87	0.03
Artificial hydration	-0.65	0.02
10. <i>Being respected as an individual</i> ($R^2 = 0.302$)		
Place of care (PCU)	0.48	0.04
Patient's age	0.02	0.003
Patient's marital status (married)	-0.46	0.04
Family relationship (spouse)	0.51	0.02
Cancer staging	-0.48	0.008
Treatment experience (chemotherapy)	0.52	0.004
Type of room (private)	0.73	0.03
Chemotherapy in the last 14 days	-1.31	0.002
Palliative sedation	0.46	0.03

Note: Multiple regression analyses with backward variable selection method ($P < 0.05$). Place of death was included in the model absolutely. PCU: Palliative Care Unit.

$P = 0.006$), family member's sex (female, $P = 0.01$), and not receiving palliative sedation ($P = 0.001$). 'Pride and beauty' correlated with patient's older age ($P < 0.001$), and opioid medication ($P = 0.003$). 'Natural death' was correlated with patient's marital status (not married,

Table 4. Factors contributing to a good death (8 optional domains)

	β	P-value
11. <i>Religious and spiritual comfort</i> ($R^2 = 0.369$)		
Place of care (PCU)	-0.25	0.35
Family member's age	-0.02	0.01
Family member's religiousness	0.99	<0.001
12. <i>Receiving enough treatment</i> ($R^2 = 0.137$)		
Place of care (PCU)	0.03	0.92
Patient's age	0.02	0.03
Family member's age	0.03	0.01
Opioid medication	1.10	0.009
13. <i>Control over the future</i>		
Place of care (PCU)	0.45	0.16
14. <i>Feeling that one's life is worth living</i> ($R^2 = 0.034$)		
Place of care (PCU)	0.06	0.83
Duration from diagnosis	0.01	0.04
15. <i>Unawareness of death</i> ($R^2 = 0.162$)		
Place of care (PCU)	0.31	0.23
Family member's age	0.03	0.002
Patient's marital status (married)	-0.70	0.006
Family member's sex (male)	-0.59	0.01
Palliative sedation	-0.72	0.001
16. <i>Pride and beauty</i> ($R^2 = 0.187$)		
Place of care (PCU)	-0.34	0.18
Patient's age	0.05	<0.001
Opioid medication	1.02	0.003
17. <i>Natural death</i> ($R^2 = 0.143$)		
Place of care (PCU)	0.26	0.27
Patient's marital status (married)	-0.72	0.002
Opioid medication	1.06	0.001
18. <i>Preparation for death</i> ($R^2 = 0.100$)		
Place of care (PCU)	-0.11	0.68
Patient's age	0.02	0.02
Frequency of family attending to patient	-0.32	0.02
Oxygen inhalation	-0.66	0.04
Opioid medication	0.72	0.05

Note: Multiple regression analyses with backward variable selection method ($P < 0.05$). Place of death was included in the model absolutely. PCU: Palliative Care Unit.

$P=0.002$) and opioid medication ($P=0.001$). 'Preparation for death' correlated with patient's older age ($P=0.02$), high frequency of family attending to patient ($P=0.02$), oxygen use ($P=0.04$), and opioid medication ($P=0.05$).

Discussion

This is the first study to explore factors contributing to the evaluation of a good death from the bereaved family member's perspective using reliable measures. We found, first, that death in the PCU was described as a good death for some aspects including 'environmental comfort,' 'physical and psychological comfort,' 'being respected as an individual,' and 'natural death.' These results suggest that Japanese inpatient PCUs provide the dying patient not only environmental comfort but also whole person care. On the other hand, there were no differences for the other good death domains. The preference for place of care

was influenced by the patient's concept of a good death [25]. The referral to a PCU should be according to the patient's preferences and provision of information regarding the merits of the PCU. Second, we investigated many factors contributing to evaluation of a good death including not only patient and family demographics but also some medical variables. We found that patient's and family member's age and other demographic factors correlated with the evaluation of a good death. In addition, we found that life prolongation treatment and aggressive treatment such as chemotherapy in the last 2 weeks were barriers to attainment of a good death.

The patient's and family member's age was correlated with many aspects of a good death. Tsai *et al.* reported that patient age was not associated with a good death by proxy (medical practitioner) good death assessment [26]. This discrepancy may be due to the person doing the rating. Japanese bereaved family members evaluate a good death for older patient age. In other words, these results suggest that death at younger ages tended to be evaluated as a bad death. The older the family member, the more positively the family would look on the patient's death. The patient's marital status (not married) was associated with several good death domains. This might be because the mean age of unmarried patients was higher than married patients (76 vs 67). The reason for the mean age difference would be from including 'widow' in the unmarried population. In addition, several other demographic variables contributed to a good death. We should note that demographic variables influenced the evaluation of a good death from the bereaved family member's perspective, and for the proper evaluation of the intervention for a good death, we ought to adjust for these variables in the analysis.

Life-prolonging treatments such as vasopressors, antibiotics, and artificial hydration were barriers to achieving a good death. According to a nationwide opinion survey, most Japanese do not desire unnecessary life-prolonging treatment [27]. Withholding this type of treatment might contribute to a good death in Japan. Chemotherapy in the last 2 weeks was also a barrier to a good death. In Western countries, aggressive treatment for the dying cancer patient was identified as an indicator of poor quality [28–30]. Our results confirmed these previous studies. Withholding aggressive treatment for the dying patient contributes to a good death.

Opioid medication was positively associated with a good death. In Japan, opioid consumption per capita is significantly lower than in Western countries [31]. Appropriate opioid medication might contribute to a 'good relationship with medical staff' and 'receiving enough treatment' in the good death domains because bereaved family

members valued appropriate medical treatment. In addition, opioid use contributed to a good death in the domains of 'pride and beauty,' 'natural death,' and 'preparation for death.' In Japan, although there are misconceptions regarding opioid medications, use of opioids might contribute to a good death from the bereaved family's perspective [32].

Palliative sedation was negatively associated with the evaluation of a good death. Many patients with palliative sedation probably suffered from physical and psychological symptoms. Therefore, the bereaved family members would evaluate this situation as a bad death for these patients. As a result, palliative sedation would be negatively associated with physical and psychological comfort. That is to say, physically and psychologically distressed patients would be more likely to receive palliative sedation. In addition, Morita reported that 25% of bereaved family members were distressed with palliative sedation therapy [33], expressing guilt, helplessness, and physical and emotional exhaustion [34]. The distress of family members might have influenced the rating of a good death. On the other hand, palliative sedation was positively associated with 'being respected as an individual.' This might indicate that the family felt that the palliative sedation was alleviating the patient's symptoms. In Japan, clinical guidelines for palliative sedation therapy have been established [35]. In accordance with these guidelines, it is important to provide sufficient information about palliative sedation to the patient and family and to allow for discussion.

Having a private room was positively correlated with a 'good relationship with family' and 'being respected as an individual.' Staying in a private room enhanced the family relationships and patient's dignity. Cancer staging was correlated with 'maintaining hope and pleasure,' 'good relationship with medical staff,' and 'being respected as an individual.' Communication with advanced-stage cancer patients and their families is a relevant issue in Japan [36].

The limitations of this study are as follows: First, the response rate was 48% of potential participants. We believe, however, this is not a fatal flaw because the objective of this study was to explore factors contributing to evaluation of a good death. Second, this study was conducted at one regional cancer center. Third, although over 80% of deaths occurred on general wards in Japan, only 26% of the deaths in this institution occurred on general wards. Therefore, the results of this study might not be generalizable to other settings. Lastly, R^2 values of multiple regression analyses are generally low. This implies that other potential variables associated with a good death exist. It is necessary to explore these factors in further research.

Conclusions

In conclusion, we found that death in the PCU achieved a good death for some domains including 'environmental comfort,' 'physical and psychological comfort,' 'being respected as an individual,' and 'natural death'. We found that the patient's and family member's age and other demographic factors, life-prolonging treatment, and aggressive treatment were barriers to attainment of a good death. Moreover, opioid medication might have contributed to a good death. Withholding life-prolonging treatment and aggressive treatment from the dying patient and appropriate use of opioids may be associated with the achievement of a good death in Japan.

Appendix

Good Death Inventory (GDI)

How do you think the patient felt during the end-of-life period? Please check the appropriate number. 1: absolutely disagree, 2: disagree, 3: somewhat disagree, 4: unsure, 5: somewhat agree, 6: agree, 7: absolutely agree.

- I. Physical and psychological comfort
 - Patient was free from pain.
 - Patient was free from physical distress.
 - Patient was free from emotional distress.
- II. Dying in a favorite place
 - Patient was able to stay at his or her favorite place.
 - Patient was able to die at his or her favorite place.
 - The place of death met the preference of the patient.
- III. Maintaining hope and pleasure
 - Patient lived positively.
 - Patient had some pleasure in daily life.
 - Patient lived in hope.
- IV. Good relationship with medical staff
 - Patient trusted the physician.
 - Patient had a professional nurse with whom he or she felt comfortable.
 - Patient had people who listened.
- V. Not being a burden to others
 - Patient was not being a burden to others. (*)
 - Patient was not being a burden to family members. (*)
 - Patient had no financial worries. (*)
- VI. Good relationship with family
 - Patient had family support.
 - Patient spent enough time with his or her family.
 - Patient had family to whom he or she could express feelings.
- VII. Independence
 - Patient was independent in moving or waking up.
 - Patient was independent in daily activities.
 - Patient was not troubled with excretion.

- VIII. Environmental comfort
 Patient lived in quiet circumstances.
 Patient lived in calm circumstances.
 Patient was not troubled by other people.
- IX. Being respected as an individual
 Patient was not treated as an object or a child.
 Patient was respected for his or her values.
 Patient was valued as a person.
- X. Life completion
 Patient had no regrets.
 Patient felt that his or her life was completed.
 Patient felt that his or her life was fulfilling.
- XI. Receiving enough treatment
 Patient received enough treatment.
 Patient believed that all available treatments were used.
 Patient fought against disease until the last moment.
- XII. Natural death
 Patient was not connected to medical instruments or tubes.
 Patient did not receive excessive treatment.
 Patient died a natural death.
- XIII. Preparation for death
 Patient met people whom he or she wanted to see.
 Patient felt thankful to people.
 Patient was able to say what he or she wanted to dear people.
- XIV. Control over the future
 Patient knew how long he or she was expected to live.
 Patient knew what to expect about his or her condition in the future.
 Patient participated in decisions about treatment strategy.
- XV. Unawareness of death
 Patient died without awareness that he or she was dying.
 Patient lived as usual without thinking about death.
 Patient was not informed of bad news.
- XVI. Pride and beauty
 Patient felt burden of a change in his or her appearance. (*)
 Patient felt burden of receiving pity from others. (*)
 Patient felt burden of exposing his or her physical and mental weakness to family. (*)
- XVII. Feeling that one's life is worth living
 Patient felt that he or she could contribute to others.
 Patient felt that his or her life is worth living.
 Patient maintained his or her role in family or occupation.
- XVIII. Religious and spiritual comfort
 Patient was supported by religion.
 Patient had faith.
 Patient felt that he or she was protected by a higher power.
 (*) Inverse items

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Effect of a population-based educational intervention focusing on end-of-life home care, life-prolonging treatment and knowledge about palliative care

M Miyashita, K Sato Department of Adult Nursing/Palliative Care Nursing, School of Health Sciences and Nursing, Graduate School of Medicine, University of Tokyo, Tokyo, **T Morita** Department of Palliative and Supportive care, Palliative Care Team and Seirei Hospice, Seirei Mikatahara Hospital, Shizuoka and **M Suzuki** Fukushima Division, Soshukai Okabe Clinic, Fukushima

The effectiveness of population-based educational interventions in palliative care is unclear. We conducted an educational intervention study for the general public focusing on end-of-life home care, life-prolonging treatment and knowledge about palliative care and measured the change in perception about these issues. Participants were recruited from the 11 districts of Fukushima City, Japan. One-hour educational lectures were conducted in each district from April 2006 to March 2007. Meetings were held in a community centre or hall in each district. We asked participants to fill in a questionnaire before and after the educational lecture. Of 607 participants, 595 (98%) answered both pre- and post-intervention questionnaires. The feasibility of a home death changed from 9% before to 34% after the intervention ($P < 0.001$). In addition, preference for life-prolonging treatment and attitudes toward end-of-life care including symptom management at home, misconceptions about opioids, artificial hydration and communication issues between patient and medical practitioners were significantly improved after the intervention. Factors that were significantly associated with changing perceptions about the feasibility of a home death were male gender, change in beliefs regarding burden to family caregivers, anxiety regarding admission to the hospital with worsening physical condition and fear that pain would not be relieved at home. This population-based educational intervention was effective in changing beliefs regarding the feasibility of home care, preference for life-prolonging treatment and attitudes toward end-of-life care. *Palliative Medicine* (2008); 22: 376–382

Key words: barriers; education; home death; intervention studies; palliative care

Introduction

It is important for terminal cancer patients to be able to remain in their favourite place.¹ Over half of Japanese would like to be cared for at home.² However, in Japan, the growth of home-based palliative care programs has been slow.^{3,4} As a result, in 2004, only 6% of cancer deaths occurred in the home and over 90% occurred in hospitals.

There are many barriers to home care for end-of-life cancer patients.^{5–12} For example, previous studies have suggested that sex,¹² age,^{8,12} burden to the family^{6,7,12} and the ability of the family to care for the patient^{11,13} were factors associated with home care of terminal patients.

There are also many barriers to receiving appropriate palliative care for end-of-life cancer patients.^{14,15} For

instance, misconceptions about analgesics,^{16–19} misperceptions about life-prolonging treatment^{20–22} and lack of communication between patient and medical practitioner^{23,24} were reported to be potential barriers to palliative care.

In a large population-based survey of Japanese, we found many misconceptions about pain and opioids, communication with health care professionals, hydration and nutrition and legal issues about end-of-life options.²⁵ In addition, our previous study showed that misconceptions regarding opioid use and life-prolonging treatment prevented members of the general public from believing that they could live at home until death.²⁶

To overcome these barriers, it is important to provide appropriate education for the general public.¹⁵ Although education for cancer patients and their families has been conducted,^{27–33} educational interventions about palliative care for the general public have not been reported except for one regarding attitudes about cardiopulmonary resuscitation,³⁴ and a Canadian study using a trade show to educate the general public.³⁵ The effectiveness of population-based educational interventions is still

Correspondence to: Mitsunori Miyashita, RN, PhD, Department of Adult Nursing/Palliative Care Nursing, School of Health Sciences and Nursing, Graduate School of Medicine, University of Tokyo, 7-3-1 Hongo, Bunkyo-ku, Tokyo 113-0033, Japan. Email: miyasita-ky@umin.net