

**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  $69 \pm 12$  years, males made up 57% of the total, the mean number of hospital days was  $41 \pm 37$ , and 71% of the patients died in the PCU. As for bereaved family members, the mean age was  $57 \pm 12$  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	%
<b>Patients</b>		
Age, y (mean±SD)	69±12	
<b>Sex</b>		
Male	108	57
Female	91	43
Hospital days (mean±SD)	41±37	
<b>Setting</b>		
General ward	55	29
Palliative care unit	134	71
<b>Bereaved family members</b>		
Age, y (mean±SD)	57±12	
<b>Sex</b>		
Male	63	33
Female	122	65
<b>Health status</b>		
Good	48	25
Moderate	106	56
Fair	28	15
Poor	5	3
<b>Relationship</b>		
Spouse	87	46
Child	64	34
Child-in-law	20	11
Parent	1	1
Sibling	11	6
Other	3	2
<b>Frequency of attending patient</b>		
Every day	133	70
4-6 days/week	17	9
1-3 days/week	26	14
Less than 1 day/week	9	5
<b>Presence of other caregivers</b>		
Present	131	69
Absent	54	29
<b>Living status</b>		
Living together	157	83
Not living together	30	16
<b>Religiousness</b>		
Much	14	7
Moderate	34	18
Fair	46	24
None	85	45
<b>Education</b>		
Junior high school	34	18
High school	82	43
College	40	21
University	31	16
<b>Household Income (thousand yen)</b>		
-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" ( $r=0.80$ ), "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=1.5)									
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 <sup>a</sup>	0.31 <sup>a</sup>	0.44 <sup>a</sup>	0.23 <sup>b</sup>	0.25 <sup>a</sup>	0.18 <sup>c</sup>	0.06	0.07	0.29 <sup>a</sup>	0.28 <sup>a</sup>
6. Physical and psychological comfort										
Place of care	0.35 <sup>a</sup>	0.33 <sup>a</sup>	0.40 <sup>a</sup>	0.29 <sup>a</sup>	0.37 <sup>a</sup>	0.34 <sup>a</sup>	0.22 <sup>b</sup>	0.15 <sup>c</sup>	0.27 <sup>a</sup>	0.30 <sup>a</sup>
1. Environmental comfort										
3. Dying in a favorite place	0.37 <sup>a</sup>	0.30 <sup>a</sup>	0.40 <sup>a</sup>	0.20 <sup>b</sup>	0.30 <sup>a</sup>	0.24 <sup>b</sup>	0.10	0.06	0.25 <sup>b</sup>	0.30 <sup>a</sup>
Decision-making and relation to medical staff	0.36 <sup>a</sup>	0.34 <sup>a</sup>	0.43 <sup>a</sup>	0.33 <sup>a</sup>	0.36 <sup>a</sup>	0.28 <sup>a</sup>	0.19 <sup>c</sup>	0.15	0.40 <sup>a</sup>	0.42 <sup>a</sup>
7. Good relationship with medical staff										
12. Receiving enough treatment	0.32 <sup>a</sup>	0.30 <sup>a</sup>	0.37 <sup>a</sup>	0.16 <sup>c</sup>	0.25 <sup>a</sup>	0.17 <sup>c</sup>	0.10	0.11	0.22 <sup>b</sup>	0.22 <sup>b</sup>
15. Unawareness of death	0.26 <sup>a</sup>	0.25 <sup>a</sup>	0.26 <sup>a</sup>	0.13	0.19 <sup>b</sup>	0.11	0.13	0.14	0.15 <sup>c</sup>	0.17 <sup>c</sup>
17. Natural death	0.38 <sup>a</sup>	0.32 <sup>a</sup>	0.37 <sup>a</sup>	0.24 <sup>b</sup>	0.35 <sup>a</sup>	0.29 <sup>a</sup>	0.13	0.07	0.28 <sup>a</sup>	0.28 <sup>a</sup>
Family relationship	0.08	0.17 <sup>a</sup>	0.11	0.02	0.07	0.12	-0.08	-0.03	0.04	0.06
9. Good relationship with family										
Psycho-existential issues	0.24 <sup>b</sup>	0.20 <sup>b</sup>	0.22 <sup>b</sup>	0.10	0.16 <sup>c</sup>	0.07	0.02	-0.04	0.15 <sup>c</sup>	0.13
2. Life completion										
4. Maintaining hope and pleasure	0.34 <sup>a</sup>	0.29 <sup>a</sup>	0.34 <sup>a</sup>	0.21 <sup>b</sup>	0.23 <sup>b</sup>	0.18 <sup>c</sup>	0.06	0.09	0.20 <sup>b</sup>	0.25 <sup>a</sup>
5. Independence	0.07	0.00	0.08	0.04	0.05	0.08	0.05	0.18 <sup>c</sup>	0.07	-0.02
8. Not being a burden to others	0.14	0.18 <sup>a</sup>	0.14	0.17 <sup>a</sup>	0.20 <sup>b</sup>	0.14	0.25 <sup>b</sup>	0.09	0.09	0.05
10. Being respected as an individual	0.22 <sup>b</sup>	0.25 <sup>a</sup>	0.25 <sup>a</sup>	0.26 <sup>a</sup>	0.24 <sup>b</sup>	0.29 <sup>a</sup>	0.18 <sup>c</sup>	0.09	0.20 <sup>b</sup>	0.17 <sup>c</sup>
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 <sup>a</sup>	0.17 <sup>a</sup>	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 <sup>a</sup>	0.19 <sup>a</sup>	0.16 <sup>c</sup>	0.24 <sup>b</sup>	0.19 <sup>a</sup>	0.09	0.17 <sup>c</sup>	0.16 <sup>c</sup>	0.20 <sup>b</sup>
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 <sup>c</sup>	0.18 <sup>a</sup>	0.16 <sup>c</sup>	0.16 <sup>c</sup>	0.18 <sup>a</sup>	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.

<sup>a</sup>P<0.001.

<sup>b</sup>P<0.01.

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

Figures are Pearson's correlation coefficients.

<sup>a</sup> $P < 0.001$ .

<sup>b</sup> $P < 0.01$ .

<sup>c</sup> $P < 0.05$ .

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 $r^a$
<b>Core 10</b>	
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
<b>Optional eight</b>	
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
<b>Internal consistency</b>	
All 18 attributes	Alpha 0.85
Core 10 attributes	0.78
Optional eight attributes	0.69
<b>Test-retest reliability</b>	
All 18 attributes	ICC 0.71
Core 10 attributes	0.64
Optional eight attributes	0.59

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

<sup>a</sup>Pearson'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.<sup>25</sup>

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.<sup>26,27</sup> 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.<sup>28</sup> 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 Steinhilber et al.'s<sup>7</sup> 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.<sup>7,25</sup>

Although the domains of the GDI demonstrated sufficient internal consistency, reliability measured by ICC was of moderate value.<sup>29</sup> 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.<sup>20,30</sup> 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<br/>         Patient was free from pain.<br/>         Patient was free from physical distress.<br/>         Patient was free from emotional distress.</p> <p>II. Dying in a favorite place<br/>         Patient was able to stay at his or her favorite place.<br/>         Patient was able to die at his or her favorite place.<br/>         The place of death met the preference of the patient.</p> <p>III. Maintaining hope and pleasure<br/>         Patient lived positively.<br/>         Patient had some pleasure in daily life.<br/>         Patient lived in hope.</p> <p>IV. Good relationship with medical staff<br/>         Patient trusted the physician.<br/>         Patient had a professional nurse with whom he or she felt comfortable.<br/>         Patient had people who listened.</p> <p>V. Not being a burden to others<br/>         Patient was not being a burden to others (*).<br/>         Patient was not being a burden to family members (*).<br/>         Patient had no financial worries (*).</p> <p>VI. Good relationship with family<br/>         Patient had family support.<br/>         Patient spent enough time with his or her family.<br/>         Patient had family to whom he or she could express feelings.</p> <p>VII. Independence<br/>         Patient was independent in moving or waking up.<br/>         Patient was independent in daily activities.<br/>         Patient was not troubled with excretion.</p> <p>VIII. Environmental comfort<br/>         Patient lived in quiet circumstances.<br/>         Patient lived in calm circumstances.<br/>         Patient was not troubled by other people.</p> <p>IX. Being respected as an individual<br/>         Patient was not treated as an object or a child.<br/>         Patient was respected for his or her values.<br/>         Patient was valued as a person.</p> <p>X. Life completion<br/>         Patient had no regrets.<br/>         Patient felt that his or her life was completed.<br/>         Patient felt that his or her life was fulfilling.</p> | <p>XI. Receiving enough treatment<br/>         Patient received enough treatment.<br/>         Patient believed that all available treatments were used.<br/>         Patient fought against disease until the last moment.</p> <p>XII. Natural death<br/>         Patient was not connected to medical instruments or tubes.<br/>         Patient did not receive excessive treatment.<br/>         Patient died a natural death.</p> <p>XIII. Preparation for death<br/>         Patient met people whom he or she wanted to see.<br/>         Patient felt thankful to people.<br/>         Patient was able to say what he or she wanted to dear people.</p> <p>XIV. Control over the future<br/>         Patient knew how long he or she was expected to live.<br/>         Patient knew what to expect about his or her condition in the future.<br/>         Patient participated in decisions about treatment strategy.</p> <p>XV. Unawareness of death<br/>         Patient died without awareness that he or she was dying.<br/>         Patient lived as usual without thinking about death.<br/>         Patient was not informed of bad news.</p> <p>XVI. Pride and beauty<br/>         Patient felt burden of a change in his or her appearance (*).<br/>         Patient felt burden of receiving pity from others (*).<br/>         Patient felt burden of exposing his or her physical and mental weakness to family (*).</p> <p>XVII. Feeling that one's life is worth living<br/>         Patient felt that he or she could contribute to others.<br/>         Patient felt that his or her life is worth living.<br/>         Patient maintained his or her role in family or occupation.</p> <p>XVIII. Religious and spiritual comfort<br/>         Patient was supported by religion.<br/>         Patient had faith.<br/>         Patient felt that he or she was protected by a higher power.</p> |
|---|---|

(\* ) Inverse items.

## Measuring the regret of bereaved family members regarding the decision to admit cancer patients to palliative care units

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### Abstract

**Objective:** The purposes of this study were to develop a bereaved family regret scale measuring decision-related regret of family members about the admission of cancer patients to palliative care units (PCUs) and to examine the validity and reliability of this scale.

**Method:** Bereaved families of cancer patients who had died in one regional cancer center from September 2004 to February 2006 received a cross-sectional questionnaire by mail. The questionnaire contained seven items pertaining to decision-related regret about the patient's admission to the PCU, the Care Evaluation Scale (CES), an overall care satisfaction scale, and a health-related quality-of-life (QOL) scale (SF-8). One month after receiving a completed questionnaire, we conducted a retest with the respondent.

**Results:** Of the 216 questionnaires successfully mailed to the bereaved families, we received 137 questionnaires and were able to analyze the responses for 127 of them, as the other 10 had missing data. By exploratory factor analysis and confirmatory factor analysis, we identified two key factors: intrusive thoughts of regret and decisional regret. This scale had sufficient convergent validity with CES, overall care satisfaction, SF-8, sufficient internal consistency, and acceptable test-retest reliability.

**Conclusion:** We have developed and validated a new regret scale for bereaved family members, which can measure their intensity of regret and their self-evaluation about their decision to admit their loved ones to PCUs.

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**Keywords:** regret; the bereaved family; decision-making; cancer; oncology

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### Introduction

Researchers into end-of-life issues have recognized the value of what they have called a 'good death'. Critical to achieving a 'good death' is the 'completion of life,' which entails one's being prepared for dying, a feeling that one's life has been completed, no regrets about one's death, and family members who also have no regrets about one's death. Thus, minimizing the regret of cancer patients and their families is an important issue for achieving a 'good death' [1, 2]. However, bereaved

family members who have lost a loved one may find themselves experiencing self-blame feelings of regret along the lines of, 'I may have had to do it for my loved one' or 'I may not have had to do it for my loved one' [3].

Such feelings are a component of regret, the painful sensation that can result from recognizing that 'what is' compares unfavorably with 'what might have been' [4]. Early regret studies have found that a bad outcome resulting from action seemed more regrettable than the same bad outcome resulting from inaction [5] and that regretta-

ble feelings may exhibit a temporal reversal, with action evoking more regret in the short term and inaction evoking more regret in the longer term [6]. Subsequent research has categorized regrets in the daily decision context into three types according to their target: outcome regret, option regret, and process regret [7]. For each of these regret types, researchers have examined the effects of anticipated regret on decision-making as well as the effect of decision-making on experienced regret. Investigators have explored various theories and models to try to explain decision-related regret. Connolly and Zeelenberg, for instance, have recently proposed a new model called decision justification theory (DJT) [8]. DJT postulates two core components of decision-related regret: evaluation of the outcome and the feeling of self-blame for having made a poor choice. The overall feeling of regret at the decision is the combination of these two components. Thus DJT might offer a new explanation as to how people still feel regret even when they experience a situation in which the actual outcome is good. In contrast, most regret studies to date have evaluated regret by examining either the past decision or the self-blame feeling.

With respect to cancer patients, regret studies have typically focused on fatal decisions regarding what course of treatment to follow, e.g. [9] or whether to undergo a screening test [10]. Several studies of prostate cancer patients have established that patients can feel substantial regret following their cancer-related fatal decisions [11–13] and that such treatment-related regret is associated with worse current health-related quality of life (QOL) [11] and with worse quality of life and emotional well-being [12]. Future research should further explore how aspects of the fatal decision process affect later regret in cancer patients and their families.

Family members will face various decisions as well as the cancer patients themselves during the course of illness. However, no reports are available regarding decision-related irremediable regret among family members within bereaved families. Cohesiveness and control are much greater within Japanese than within western families [14]. Also, the opinions of family members tend to exert greater influence on clinical decision-making in Japan than in the United States [15, 16]. The assessment of current irremediable regret can retrospectively color past decision-making processes. Current irremediable regret also can strongly affect future psychological status. Developing a vigilant decision-making model focused on the regret of bereaved family could help provide useful information for improving decision-making by cancer patients and their families. One important area of decision-making for cancer patients and their families involves the decision process by which physicians

initially refer patients to palliative care units (PCUs) [17]. This study thus endeavored to develop a bereaved family regret scale measuring irremediable regret regarding the decision to admit cancer patients into PCUs and to examine the validity and reliability of this scale.

## Methods

### Participants and procedure

Our initial set of potential study participants comprised family members of patients who had died from September 2004 to February 2006 in Ibaraki prefecture, Japan. Inclusion criteria were as follows: the patient had died in a PCU; the patient was 20 years of age or older; and the patient had been admitted to the PCU at least three days prior to death. Exclusion criteria were as follows: the family member participant had already been recruited for another questionnaire survey for bereaved family members; the family member's primary physician determined that the participant would suffer serious psychological distress from participation in the study; the patient's cause of death was either directly treatment related or secondary to a treatment-related injury; or no member of the bereaved family was 20 years of age or older, capable of replying to a self-reported questionnaire, or aware of the patient's diagnosis of malignancy.

We mailed questionnaires to potential respondents in October 2006 and mailed reminders in November 2006 to those who had not responded. We asked respondents who did not wish to participate in the survey to indicate that they did not wish to participate and to return the questionnaire. To examine test-retest reliability, we sent a follow-up questionnaire one month after we received a completed questionnaire. The institutional review boards of Tsukuba Medical Center Hospital approved the ethical and scientific validity of this study.

Of the 224 questionnaires sent to eligible bereaved families, eight were undeliverable. We received 137 of the remaining 216 questionnaires, among which we had to exclude 10 due to missing data. Thus, we analyzed 127 responses (effective response rate, 59%). Among these 127 respondents who submitted analyzable test questionnaires, we sent retest questionnaires to the 121 bereaved families who responded during the study period; the other six families submitted their test responses too late to be included in the retest program. We received 82 retest questionnaires, among which we excluded 11 due to missing data. In total, we analyzed 71 retest questionnaires (effective response rate, 59%).

## Measures

### Decision-related regret about admission to PCUs

The questionnaires asked participants to rate on a 5-point self-reported Likert scale (strongly disagree–strongly agree) their level of agreement with each of seven possible regrets that they may have experienced regarding their decision-making in the past about admitting their loved ones to a PCU. Most previous studies have evaluated regret only for single statements, such as 'how do you feel regret concerning XX'. In addition, we collected from prior studies three statements measuring the evaluation of decisions in the past [11, 18] and three other statements measuring severity and intensity of regret [19]. The evaluation-of-decision statements included, 'I made the right decision' and 'I would make the same decision if I had to do it again'. The severity and intensity of regret statements included, 'Once I start thinking about possible outcomes had I made a different decision, I find it difficult to think about other matters' and 'I had difficulty concentrating on daily activities because thoughts about regret kept entering my mind'. We constructed the wording of these statements based upon the palliative physicians' and psychologists' comments regarding understandability and wording.

### Care evaluation scale, short version

We used the Care Evaluation Scale (CES), short version, to examine concurrent validity [20]. The questionnaire design has the respondent evaluating the necessity of improvement for each item on a 6-point Likert scale (improvement is not necessary–highly necessary). The short version of CES used in this study comprises 10 items covering the following 10 domains: 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, and family burden.

### Overall care satisfaction

We assessed overall care satisfaction as part of our examination of concurrent validity by asking the following question, developed in a previous study [21]: 'Overall, were you satisfied with the care provided in the hospital?' The participant again responded on a 6-point Likert scale.

### Health-related QOL

We used the SF-8 Japanese version [22], the short form, which is derived from the health-related QOL scale called the MOS 36-Item Short Form Health survey (SF-36). The eight items cover the eight concepts measured by the SF-36 (one item per concept), using a 5- or 6-point Likert scale. The

SF-8 provides two summary scores for physical and mental health: a Physical Component Scale and a Mental Component Scale. Scores for each item and summary measurements range from 0 to 100, with higher scores indicating better health. This scale includes questions such as the following: 'Overall, how would you rate your health during the past 4 weeks'; 'During the past 4 weeks, how much did physical health problems limit your usual physical activities (such as walking or climbing stairs)'; and 'During the past 4 weeks, how much difficulty did you have doing your daily work, both at home and away from home, because of your physical health?'

### Participant characteristics

We extracted information concerning the patient's age, sex, and hospital days from a medical database. We asked the respondent bereaved family members to provide the following personal information about themselves: age, sex, health status during caregiving period, relationship with patient, frequency of attending the patient, presence of other caregivers, living status with patient, faith, education, and household income during the caregiving period.

### Analysis

We utilized the Statistical Package for SPSS for Windows (Version 14.0) for all data analyses. To examine validity of our regret scale, we conducted an exploratory and a confirmatory factor analysis along with correlation analyses of our regret scale vs CES, overall satisfaction, and QOL. To examine the reliability of the regret scale, we assessed the internal reliability of its two subscales with Cronbach's  $\alpha$  coefficients. We used correlation coefficients to assess test–retest reliability.

## Results

### Characteristics of participants

Table 1 shows the demographic characteristics of the 127 participants included in the development analysis. We compared the demographic characteristics of these 127 participants with those of the 71 participants included in the validation analysis. We identified no significant differences between the two groups with respect to all demographic characteristics. Table 1 also shows descriptive statistics of decision-related regret, CES, overall satisfaction, and health-related QOL.

### Validity

All of the seven items had a moderate degree of variance, and no item evidenced bias. Using these

**Table 1.** Characteristics of the bereaved family and patient

	N = 127 Patient numbers or mean $\pm$ SD	%
<i>Bereaved family</i>		
Age	55.85 $\pm$ 12.11	
Sex, male	44	34.6
<i>Health status during caregiving period</i>		
Good	33	26
Somewhat good	71	55.9
Bad	20	15.7
Strongly bad	2	1.6
<i>Relationship to patient</i>		
Spouse	61	48
Parent	42	33.1
Parent-in-law	13	10.2
Others	10	7.9
<i>Frequency of attending patient</i>		
Everyday	96	75.6
4-6 days/week	11	8.7
1-3 days/week	15	11.8
None	3	2.4
Presence of other caregivers living with patient	89	70.1
	106	83.5
<i>Education</i>		
Less than high school	17	13.4
High school	56	44.1
Some college	28	22
Postgraduate	25	19.7
<i>Household income during caregiving period</i>		
Less than 250	13	10.2
250-500	58	45.7
500-750	25	19.7
750-1000	14	11
More than 1000	14	11
Care Evaluation Scale	75.49 $\pm$ 17.63	
Overall satisfaction	4.76 $\pm$ 0.96	
SF8: Physical Component Scale	48.78 $\pm$ 7.81	
SF8: Mental Component Scale	48.52 $\pm$ 6.37	
<i>Patient</i>		
Age	68.12 $\pm$ 12.28	
Sex, male	68	53.5
Hospital days	41.63 $\pm$ 33.90	

seven items, we conducted an exploratory factor analysis with promax rotation and the maximum-likelihood method. A minimal eigenvalue  $>1$  yielded a 2-factor solution (Table 2), in which these two factors explained 74% of the variance. The correlation coefficient between the two factors was 0.32 ( $p < 0.01$ ). Factor 1, which measured the degree of focus on regret, we named 'intrusive thoughts of regret'; factor 2, which measured evaluation of decision-making in the past, we named 'decisional regret.'

Then, to confirm the adequacy of the scale structures, we conducted a confirmatory factor analysis with these seven items. The results

indicated that item 3 was the item with highest factor loadings for both factors 1 and 2. We then constructed two models, shown in Figure 1, and compared the fit indexes of the two models. We adopted model 2 because its fit index was higher than that of model 1.

Table 3 contains the Pearson correlation coefficients showing the correlation between the scores of regret subscales and scores for CES, overall care satisfaction, and health-related QOL. As expected, the scores for CES and overall care satisfaction negatively correlated with each regret subscale. Physical QOL and mental QOL correlated with only the intrusive thoughts subscale.

### Reliability

We assessed the internal reliability of the two subscales with Cronbach's  $\alpha$  coefficients. Internal consistency was high for both 'intrusive thoughts of regret' ( $\alpha = 0.85$ ) and 'decisional regret' ( $\alpha = 0.79$ ) subscales. We then defined the sums for each sub-factor as the intrusive thoughts of regret score and the decisional regret feeling score, respectively. Using these scores, we assessed test-retest reliability using correlation coefficients. Among the 71 participants who responded in both surveys, correlation coefficients among subscales were moderately high for factor 1 ( $r = 0.69$ ,  $p < 0.01$ ) and factor 2 ( $r = 0.70$ ,  $p < 0.01$ ).

### Discussion

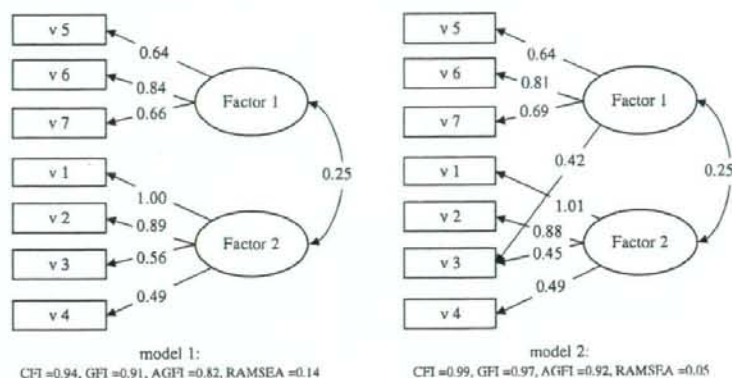
The purpose of this study was to develop a PCU's admission-related regret scale for the bereaved family and to identify its validity and reliability. Among the bereaved families, decisional-related regret was irretrievable. Furthermore, most families had thought that their past decision was fatal for the patients. By exploratory factor analysis and confirmatory factor analysis, we identified two key factors: intrusive thoughts of regret and decisional regret. This study provided good evidence of the reliability and validity of these two factors within this Japanese population. Using these two factors, we developed a new regret scale for bereaved family members, which was able to measure their intensity of regret and their self-evaluation about their decision to admit their loved ones to PCUs. Since this regret scale contains a small number of items and a simple structure, the scale is open to broad use.

We were able to delineate the structure of our two factors, intrusive thoughts of regret and decisional regret. These two factors appear to correspond to the two core components of DJT (intensity of regret and their self-evaluation) [8]: Intrusive thoughts of regret correspond to intensity of self-blame feelings, and decisional regret corre-

**Table 2.** Results of exploratory factor analysis

Items	Mean $\pm$ SD	Factor loadings		Communality
		F1	F2	
Once I start thinking about possible outcomes had I made a different decision, I find it difficult to think about other matters (v6)	1.88 $\pm$ 1.15	<b>0.90</b>	0.22	0.67
I had difficulty concentrating on daily activities because thoughts about regret kept entering my mind (v7)	1.72 $\pm$ 1.10	<b>0.83</b>	0.18	0.62
I could not stop thinking that the situation might have changed if I had made a different decision (v5)	2.03 $\pm$ 1.16	<b>0.81</b>	0.33	0.59
It was the right decision (v1*)	1.63 $\pm$ 0.75	0.30	<b>0.99</b>	0.82
I would make the same decision if I had to do it again (v2*)	1.73 $\pm$ 0.90	0.25	<b>0.89</b>	0.79
I regret the decision that was made (v3)	1.69 $\pm$ 0.08	0.56	<b>0.57</b>	0.48
I am satisfied with the decision (v4*)	2.06 $\pm$ 1.04	0.12	<b>0.49</b>	0.26

\*Reversed item.

**Figure 1.** The results of confirmatory factor analysis and fit indices**Table 3.** Criterion validity as measured by Pearson correlations

Scales	CES	Overall care satisfaction	Physical QOL	Mental QOL
F1: intrusive thoughts about regret	-0.33**	-0.33**	-0.22*	-0.37**
F2: decisional regret	-0.27**	-0.46**	-0.08	-0.09

\* $p < 0.05$ . \*\* $p < 0.01$ .

sponds to evaluation of decision-making and subsequent outcome. Each of the two factors contained four of the seven statements; one statement overlapped both factors. The overlapping statement, 'I regret the decision that was made', directly represented the overall regret of bereaved family members about their decision-making. Our regret scale could thereby measure three aspects of the bereaved families' regret: overall degree of regret, evaluation of decisional regret, and severity of intrusive thoughts about regret. Evaluation of the details of regret assists greatly in formulating an appropriate plan of regret management and therapy. Several recent studies have examined regret management and therapy for cancer patients [23,24]. However, to develop better evidence-based regret management or regret therapy, future research should explore the effects of

the decision-making process or options on subsequent irremediable regrets. We believe that psychosocial theories such as reference comparisons theory or justifications theory can provide a basis for utilizing our new scale to establish effective regret management and therapy.

We found good evidence for the reliability and validity of our regret scale. Examination of the convergent validity of this scale determined that the score of CES and overall satisfaction negatively correlated with each regret subscale, indicating that this regret scale could adequately measure regrets regarding decision-making about admission to PCUs. On the other hand, both physical and mental QOL scores did not correlate with decisional regret but correlated only with intrusive thoughts of regret. This pair of findings indicates that the bereaved family's QOL is not influenced by

how much they regret their decision but rather by how often their regretful thoughts come to mind. The finding that intrusive thoughts of regret were associated with health-related QOL is in accord with the results of previous studies among adults [25]. We believe that decisional regret and intrusive thoughts of regret comprise different concepts and thus should be measured separately. Our findings suggest that intrusive thoughts of regret have the potential to affect the health-related QOL of bereaved family members.

One limitation of our study is the somewhat small sample size of our study, especially for the retest survey. We sent out retest questionnaires one month after we received a completed questionnaire. Although our study design assumed that the regret of the bereaved family did not change during this one-month period, empirical confirmation of this assumption is lacking. Our analysis of test-retest reliability yielded correlation coefficients among subscales that were moderately high.

Utilizing this new scale to assess the regret of the bereaved family should help clinicians evaluate decision-making about the admission of cancer patients into PCUs retrospectively. Use of this scale in multi-institutional outcome surveys should assist evaluation of quality differences between institutions in the decision-making process. Developing a vigilant decision-making model of cancer patients and their families and examining the association of this model with irremediable regret will require future studies in order to provide useful information about decision-making aids. Our new scale thus represents the first step for these future studies.

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

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### 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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**Keywords:** palliative care; end-of-life care; cancer; hospice; good death

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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, Steinhauser *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, religiosity, 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  $70 \pm 11$ , males made up 56% of the total, and 73% of the participants were married. As for bereaved family members, the mean age was  $57 \pm 13$ , 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  $41 \pm 38$ , 21% of the

Table 1. Characteristics of participants (N = 165)

	n	%
<b>Patient demographics</b>		
Age, years (mean ± SD)	70 ± 11	
Sex (male)	92	56
Marital status (married)	121	73
<b>Bereaved family member demographics</b>		
Age, years (mean ± SD)	57 ± 13	
Sex (Male)	54	33
<b>Health Status</b>		
Good	42	25
Moderate	94	57
Fair	23	14
Poor	4	2
Relationship (spouse)	77	47
<b>Frequency of attending patient</b>		
Every day	119	72
4-6 days/week	14	8
1-3 days/week	21	13
Less than 1 day/week	8	5
<b>Religiosity</b>		
None	75	45
Fair	40	24
Moderate	28	17
Much	12	7
<b>Education</b>		
Junior high school	28	17
High school	69	42
College	36	22
University	30	18
<b>Household income (thousand yen)</b>		
<249	24	15
250-499	64	39
500-749	34	21
750-999	19	12
1000-	15	9
<b>Medical variables</b>		
<b>Place of care</b>		
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
<b>Cancer stage</b>		
Local	4	2
Regional	25	15
Distant metastasis	133	81
<b>Site of cancer</b>		
Lung	35	21
Gastrointestinal	82	50
Other	48	29
<b>Treatment experience (multiple answer)</b>		
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
<b>Medical intervention in the last 48 h</b>		
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