

findings indicate that although team care is important in the care of terminally ill patients, its actual practice in Japan may be insufficient.

Artificial hydration is a common practice for terminally ill cancer patients. Guidelines developed by an expert committee sponsored by the European Association for Palliative Care for artificial nutrition versus hydration in terminal cancer patients defined the psychological attitudes of patients and families as one of 8 key elements to be considered in decision making on hydration.<sup>7</sup> Other researchers have also argued the relevance of considering the wishes of patients and families and of respecting these wishes.<sup>8-11</sup> Family members and loved ones play an important role in the care of terminal patients. For them, feeding is often one of their greatest concerns, and the need for ongoing hydration<sup>12</sup> or a lack of food intake often increases their anxiety.<sup>7</sup> Moreover, some patients and families may feel that the patient has been abandoned if hydration is withheld.<sup>13</sup>

In addition, attitudes toward hydration therapy differ between physicians and nurses.<sup>14-16</sup> Despite the importance of discussion by medical practitioners among patient-centered teams caring for terminally ill cancer patients and the conduct of decision making according to the individual patient's preference,<sup>10,16,17</sup> the decision-making process in artificial hydration remains unclear.

Only a few studies have investigated the decision-making process from the perspective of patients and families. Musgrave et al surveyed decision making for the administration of artificial hydration in Israel and reported that the majority of conscious patients (95%), family members (81%), and nurses (64%) played no role.<sup>18</sup> Scientific uncertainty regarding the effectiveness of terminal hydration,<sup>19,20</sup> as well as patient and family requirements<sup>9,11,21</sup> and their lack of involvement in medical decisions regarding terminal hydration,<sup>18</sup> might produce emotional distress in nurses in their dealing with this practice. To our knowledge, however, distress regarding artificial hydration among nurses has not been investigated.

The aims of the present paper were (1) to clarify nurses' views of discussions among nurses and physicians regarding artificial hydration for terminally ill cancer patients, and (2) to clarify nurses' distress arising from artificial hydration issues and to explore factors related to this distress.

## Methods

### Participants and Procedure

This is the second part of a survey on nurse attitudes toward terminal dehydration, which was started in October 2002.<sup>16</sup> Participants were recruited from 2 nationwide organizations, the Japanese Association of Clinical Cancer Centers and the Japanese Association of Hospice and Palliative Care Units. The former consists of 28 medical centers for cancer and adult disease that play leading roles in clinical oncology, and the latter of 80 hospitals with a variety of palliative care units or inpatient hospices. Sixteen cancer centers and 73 hospitals agreed to participate in the study, and an additional 4 general hospitals and a palliative care clinic from the Japan Palliative Oncology Study Group (J-POS), organized to investigate the effectiveness of artificial hydration in Japan,<sup>15,22</sup> were added. Representatives of each institution then identified potential participants working as nurses in units responsible for the care of terminally ill cancer patients. A total of 4210 nurses were recruited as a heterogeneous sample of nurses working at cancer centers, general hospitals, and palliative care units.

In Japan, the Ministry of Health, Labor, and Welfare has strongly supported the development of specialized palliative care services. With coverage of palliative care units provided under the National Medical Insurance system since 1991, the number of palliative care units has dramatically increased, from 5 in 1991 to 135 in 2004. In contrast, the growth of home-based palliative care programs has been slow, and palliative care teams were not covered by National Medical Insurance until 2002. The most common type of specialized palliative care service in Japan is therefore the palliative care unit (PCU). Here, we chose nurses belonging to general wards of cancer centers, general hospitals, and PCUs as study targets for this investigation.

### Questionnaire

The questionnaire (available from the authors) was developed by the J-POS group. Face validity of the questionnaire was confirmed by a pilot test using 15 nurses from oncology and palliative care settings.

*Nurse views of discussions regarding artificial hydration for terminally ill cancer patients.* Nurses responded

to 4 statements on the adequacy of discussion among physicians and nurses regarding artificial hydration using a 6-point Likert scale (from "strongly disagree" to "strongly agree"), as follows: "Patients and medical practitioners discuss the issue of artificial hydration adequately," "Medical practitioners discuss the issue of artificial hydration adequately," "Physicians respect the patient's/family's desires regarding artificial hydration," and "Physicians respect nurses' opinions regarding artificial hydration."

*Nurse distress arising from artificial hydration for terminally ill cancer patients.* Nurse distress arising from artificial hydration issues was evaluated from responses to 6 statements using a 4-point response scale of "none," "rare," "sometimes," and "frequently." Two categories each were evaluated for distress on behalf of patients/families who complained about the withholding of artificial hydration, and for distress for patients/families who refused artificial hydration, namely, "patient" and "family." Two further categories were evaluated for distress arising from disagreements among medical practitioners, namely, "withholding of artificial hydration by medical practitioners" and "refusing artificial hydration by patient and family."

*Attitudes of nurses toward artificial hydration for terminally ill cancer patients.* Fifteen further questions were asked regarding nurse attitudes toward artificial hydration, particularly symptom control and ethical issues. The descriptive statistics and 7 domains generated by the 15 questions have been detailed elsewhere.<sup>16</sup> Briefly, the 7 domains identified by explanatory analyses were as follows: "belief that artificial hydration palliates physical symptoms"; "belief that withholding artificial hydration palliates physical symptoms"; "perception of loss of trust by withholding artificial hydration"; "perception of guilt from withholding artificial hydration"; "belief that artificial hydration is a component of minimum care"; "perception of difficulty concerning decision making for artificial hydration"; and "belief that maintaining a venous route is a burden." The respondents were asked to evaluate each statement using a 6-point Likert scale (strongly agree to strongly disagree). Scores for each domain were summed and used for analysis.

*Demographics.* The respondents were first asked to describe their background, including number of years of clinical practice, clinical setting, and number

of cancer deaths that occurred in their unit during the preceding year.

### Statistical Analysis

Nurse views of discussions regarding artificial hydration were analyzed by calculating the overall percentage of "strongly agree," "agree," and "slightly agree" answers and comparing between clinical settings using the chi-square test.

Nurse distress arising from artificial hydration issues was analyzed by calculating the overall percentage of "frequently" and "sometimes" answers and comparing between clinical settings using the chi-square test. In addition, we performed an explanatory factor analysis using the principle component method and promax rotation for the following analysis. The data are shown in Table 1, presented according to the results of factor analysis and calculation of Cronbach alpha coefficient for each domain.

To explore factors related to these distresses, we performed multivariate analysis using a multiple linear regression model. Objective variables were "distress on behalf of patients/families who complain about withholding artificial hydration," "distress on behalf of patients/families who refuse artificial hydration," and "distress arising from disagreements among medical practitioners." These 3 variables were generated by summing the domain scores in Table 1. Explanatory variables were characteristics of respondents such as sex (1, female; 0, male), number of years of clinical practice, number of cancer deaths occurring in the unit during the preceding year and clinical setting (1, PCU; 0, oncology ward), 7 domain scores of attitudes toward artificial hydration, and nurse views of discussion on artificial hydration (summed scores of 4 statements in Table 2).

Two-sided *p* values were calculated for all statistical tests, and a *P* value < .05 was considered statistically significant. All analyses were performed using the Statistical Analysis System (SAS) statistical package (version 9.1, 2005, SAS Institute, Cary, NC).

## Results

### Subject Characteristics

A total of 3515 of 4210 nurses returned completed questionnaires. Since 187 responses contained missing values and were excluded from further analysis,

**Table 1.** Nurse Distress Arising from Artificial Hydration for Terminally Ill Cancer Patients

	Oncology Nurse (n = 2735)	PCU (n = 593)	P Value
Distress on behalf of patients/families who complain about withholding artificial hydration (alpha = 0.82)			
For patients	20	24	.049
For families	24	36	< .001
Distress on behalf of patients/families who refuse artificial hydration (alpha = 0.72)			
For patients	44	57	< .001
For families	19	28	< .001
Distress arising from disagreements among medical practitioners (alpha = 0.83)			
About withholding artificial hydration	48	47	.57
About refusal of artificial hydration by patient or family	44	43	.56

NOTE: The numbers denote the percentage of summed "sometimes" and "frequently" responses. Alpha indicates Cronbach alpha coefficient; PCU = palliative care unit.

**Table 2.** Nurse Views of the Adequacy of Discussions Regarding Artificial Hydration for Terminally Ill Cancer Patients

	Oncology Nurse (n = 2735)	PCU (n = 593)	P Value
Patients and medical practitioners discuss the issue of artificial hydration adequately.	39	78	< .001
Medical practitioners discuss the issue of artificial hydration adequately.	49	79	< .001
Physicians respect the patient's/family's desires regarding artificial hydration.	42	84	< .001
Physicians respect nurse opinions regarding artificial hydration.	36	68	< .001

NOTE: Values represent the percentage of summed "strongly agree," "agree," and "slightly agree" responses. PCU = palliative care unit.

3328 responses were finally analyzed (validated response rate, 79%). Background characteristics of the participants are shown in Table 3.

*Nurse views of discussions regarding artificial hydration for terminally ill cancer patients.* Nurse views of the adequacy of discussion regarding artificial hydration for terminally ill cancer patients are presented in Table 2. Regarding whether patients and medical practitioners discuss the issue of artificial hydration adequately, 39% of oncology nurses and 78% of PCU nurses agreed with the statement ( $P < .001$ ). Among other statements, 49% and 79% agreed that medical practitioners discuss the issue of artificial hydration adequately ( $P < .001$ ); 42% and 84% agreed that physicians respect the patient's/family's desires regarding artificial hydration ( $P < .001$ ); and 36% and 68% stated that physicians respect nurses' opinions regarding artificial hydration ( $P < .001$ ), respectively.

*Nurse distress arising from artificial hydration for terminally ill cancer patients.* Nurse distress arising from artificial hydration for terminally ill cancer patients is shown in Table 1. Explanatory factor analysis clearly identified 3 domains (detailed data not shown). Regarding distress on behalf of patients/families who complain about withholding artificial hydration (alpha = 0.82), 20% of oncology nurses and 24% of PCU nurses experienced such distress for patients ( $P = .049$ ), and 24% and 36% did so for families ( $P < .001$ ), respectively. Among other statements, 44% and 57% experienced distress on behalf of patients who refuse artificial hydration (alpha = 0.72) ( $P < .001$ ), and 19% and 28% did so for families ( $P = .001$ ); 48% and 47% experienced ( $P = .568$ ) distress arising from disagreement among medical practitioners (alpha = 0.83) about withholding artificial hydration; and 44% and 43% did so ( $P = .556$ ) about patients or families refusing artificial hydration.

**Table 3.** Participant Characteristics (N = 3328)

Age	
Mean $\pm$ SD	33 $\pm$ 8.7
Median	31
Sex	
Female (%)	99
Number of years of clinical practice	
Mean $\pm$ SD	11 $\pm$ 8.6
Median	9
Clinical setting (%)	
General hospital	35
Cancer center	47
Perception of guilt from withholding artificial hydration	18
Number of cancer deaths that occurred in the unit during the preceding year	
Mean $\pm$ SD	40 $\pm$ 42
Median	22

*Factors related to nurse distress arising from artificial hydration for terminally ill cancer patients.* Results of the exploration of factors related to nurse distress arising from artificial hydration for terminally ill cancer patients are shown in Table 4. With regard to distress on behalf of patients/families who complain about withholding artificial hydration, associations were seen for the number of cancer deaths occurring in the unit during the preceding year ( $P < .001$ ) and perception of a loss of trust by withholding artificial hydration ( $P < .001$ ). For distress on behalf of patients/families who refuse artificial hydration, associations were seen for clinical setting ( $P < .001$ ), perception of a loss of trust by withholding artificial hydration ( $P = .045$ ), belief that artificial hydration is a component of minimum care ( $P = .022$ ), and belief that maintaining a venous route is a burden ( $P = .001$ ). For distress arising from disagreements among medical practitioners, associations were seen for a belief that artificial hydration palliates physical symptoms ( $P = .002$ ), belief that withholding artificial hydration palliates physical symptoms ( $P < .001$ ), belief that artificial hydration is a component of minimum care ( $P = .001$ ), perception of difficulty concerning decision making for artificial hydration ( $P < .001$ ), and nurses' views of discussion of artificial hydration ( $P < .001$ ).

## Discussion

This is the first nationwide survey on nurse attitudes toward terminal hydration in Japan. The most

notable finding was that almost half of the oncology nurses surveyed considered discussion regarding artificial hydration in general wards to be insufficient. In contrast, most PCU nurses evaluated discussion in the PCU positively. Although the importance of discussion by medical practitioners among patient-centered teams caring for terminally ill cancer patients and of individualized decision making is known,<sup>10,16,17</sup> our findings show that practice in general hospitals and cancer centers is poor and that there is room for improvement. Overall, although PCU nurses evaluated these factors positively, only 68% agreed that physicians respect nurse opinions regarding artificial hydration. Even in the PCU, nurses view nurse participation in the decision-making process as insufficient. Physicians should recognize that nurses seek to be more closely involved in the decision-making process than is the case now.

The second notable finding of this survey was that many nurses felt distress concerning artificial hydration for terminally ill cancer patients. Some 20% to 36% of nurses were distressed by patients/families who complain about withholding artificial hydration, whereas 19% to 57% were distressed by patients/families who refuse artificial hydration. PCU nurses were more distressed by patients who refuse artificial hydration because PCU inpatients tend to refuse medical treatment, placing nurses who are ordered by physicians to provide artificial hydration for symptom alleviation in an uncomfortable conflict. Generally, families request hydration therapy,<sup>11,12,21</sup> whereas patients sometimes refuse it, representing a source of nurse distress. Surprisingly, with regard to distress arising from disagreements among medical practitioners, no significant difference between the 2 settings was seen. Although PCU nurses evaluated discussion in the PCU positively, almost half were distressed by disagreements among medical practitioners. Sixty-eight percent were dissatisfied with respect for nurse opinions regarding hydration evidenced during communication with physicians, and disagreement might also occur among nurses in the PCU (Table 2). Even in the PCU, therefore, discussion and patient-centered decision making remain issues.

Several attitudes toward artificial hydration associated with distress were identified in 3 domains. Most of the associations identified in Table 1 appear clinically reasonable. For example, nurses who perceive a loss of trust by withholding artificial hydration

**Table 4.** Factors Related to Nurse Distress Arising from Artificial Hydration for Terminally Ill Cancer Patients

Explanatory variables	Distress on Behalf of Patients/Families who Complain about Withholding Artificial Hydration			Distress on Behalf of Patients/Families who Refuse Artificial Hydration			Distress Arising from Disagreements among Medical Practitioners		
	$\beta$	SE	P Value	$\beta$	SE	P Value	$\beta$	SE	P Value
Intercept	2.73	0.52	< .001	3.51	0.53	< .001	4.31	0.52	< .001
Characteristics of respondents									
Sex (1, female; 0, male)	.28	0.23	.22	.13	0.24	.60	.42	0.23	.07
Number of years of clinical practice	.00	0.00	.16	.00	0.00	.31	.01	0.00	.07
Number of cancer deaths that occurred in the unit during the preceding year	.00	0.00	< .001	.00	0.00	.58	.00	0.00	.99
Clinical setting (1, PCU; 0, oncology ward)	.11	0.10	.25	.39	0.10	< .0001	.18	0.10	.07
Attitudes toward artificial hydration									
Belief that artificial hydration alleviates physical symptoms	-.01	0.01	.50	.00	0.01	0.83	-.04	0.01	.002
Belief that withholding artificial hydration alleviates physical symptoms	.00	0.01	.81	.00	0.01	0.76	.06	0.01	< .001
Perception of loss of trust by withholding artificial hydration	.08	0.02	< .001	-.03	0.02	0.045	.00	0.02	.77
Perception of guilt from withholding artificial hydration	.01	0.02	.34	.01	0.02	0.36	.01	0.02	.55
Belief that artificial hydration is a component of minimum care	-.05	0.02	.040	-.06	0.02	0.022	-.09	0.02	.001
Perception of difficulty concerning decision making for artificial hydration	.03	0.02	.05	.04	0.02	0.018	.10	0.02	< .001
Belief that maintaining a venous route is a burden	.04	0.02	.12	.08	0.02	0.001	.02	0.02	.30
Nurse views of discussion of artificial hydration*	-.01	0.01	.10	.01	0.01	0.16	-.11	0.01	< .001

\*Summed score of 4 statements in Table 2. PCU = palliative care unit.

would be embarrassed by patient/family complaints about such withholding. Alleviation of distress related to beliefs over the palliative value of providing or withholding artificial hydration requires evidence for the effectiveness of hydration therapy and its dissemination.<sup>16</sup> Furthermore, to alleviate distress over the belief that maintaining a venous route is a burden, nurses should contrive methods of hydration that minimize the burden on patients, such as intermittent hydration and subcutaneous transfusion. Morita et al developed a satisfaction scale regarding rehydration therapy and explored related factors, and found that "the presence of a nurse with primary responsibility in charge" was associated with patient satisfaction for hydration therapy.<sup>22</sup> Thus, nursing

care would contribute not only to patient care but also to alleviating the burden on nurses.

Belief that artificial hydration is a component of minimum care and the perception of difficulty concerning decision making for artificial hydration were associated with the domain of distress arising from disagreements among medical practitioners. Nurse views of discussion of artificial hydration were also associated with this domain. These findings suggest that discussion regarding artificial hydration in the ward is an important factor in nurses' distress, and furthermore, they also suggest the need for more active discussion and patient-centered decision making.

The present study has several limitations. First, questions concerning attitudes toward artificial

hydration may obscure answers that depend on individual scenarios, for example, complications such as bowel obstruction, ascites, or pleural effusion. Second, data were gathered on nurses' retrospective views only, which might have been subject to recall error. Discussion about artificial hydration may require a prospective survey.

## Conclusion

Discussion among physicians and nurses regarding artificial hydration is insufficient, particularly in general wards. Medical practitioners caring for terminally ill cancer patients should engage in greater discussion among patient-centered teams and facilitate individualized decision making. Many nurses experience distress concerning artificial hydration for terminally ill cancer patients. Discussion with and active participation by nurses in decisions regarding hydration therapy might not only contribute to patient care but also alleviate the burden on nurses.

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## Barriers to referral to inpatient palliative care units in Japan: a qualitative survey with content analysis

Mitsunori Miyashita · Kei Hirai · Tatsuya Morita ·  
Makiko Sanjo · Yosuke Uchitomi

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### Abstract

**Objectives** We investigated the barriers to referral to inpatient palliative care units (PCUs) through a qualitative study across various sources of information, including terminal cancer patients, their families, physicians, and nurses.

**Materials and methods** There were 63 participants, including 13 advanced cancer patients, 10 family members, 20 physicians, and 20 nurses in palliative care and acute care cancer settings from five regional cancer institutes in Japan. Semi-structured interviews were conducted regarding barriers to referral to PCU, and data were analyzed by content analysis method.

**Results** A total of 21 barriers were identified by content analysis. The leading barriers were (1) a negative image of PCUs by patients and families ( $n=39$ ), (2) delay of

termination of anti-cancer treatment by physicians in the general wards ( $n=24$ ), (3) unwillingness to end anti-cancer treatment and denial of the fatal nature of the disease by patients and families ( $n=22$ ), (4) patient's wish to receive care from familiar physicians and nurses ( $n=20$ ), and (5) insufficient knowledge of PCUs by medical staff in general wards ( $n=17$ ).

**Conclusions** To correct these unfavorable images and misconceptions of PCUs, it is important to eliminate the negative image of PCUs from the general population, patients, families, and medical staffs. In addition, early introduction of palliative care options to patients and communication skills training regarding breaking bad news are relevant issues for a smooth transition from anti-cancer treatment to palliative care.

M. Miyashita (✉) · M. Sanjo  
Department of Adult Nursing/Palliative Care Nursing,  
School of Health Sciences and Nursing,  
Graduate School of Medicine,  
The University of Tokyo,  
7-3-1 Hongo, Bunkyo-ku,  
Tokyo 113-0033, Japan  
e-mail: miyasita-ky@umin.net

K. Hirai  
Graduate School of Human Sciences, Osaka University,  
Osaka, Japan

T. Morita  
Department of Palliative and Supportive Care,  
Palliative Care Team and Seirei Hospice,  
Seirei Mikatahara Hospital,  
Shizuoka, Japan

Y. Uchitomi  
Psycho-Oncology Division,  
Research Center for Innovative Oncology,  
National Cancer Center Hospital East,  
Chiba, Japan

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### Introduction

Palliative care specialists are faced with extensive barriers to providing effective end-of-life care [1, 14, 15, 30]. It is important to explore barriers to referral to hospice because late referral results in low family satisfaction with care [25]. Many studies have been done regarding obstacles to hospice referral [3–6, 10, 13, 19, 21, 23, 29], and various barriers have been identified. They include the difficulty of predicting prognosis [3, 29], lack of physician acceptance of terminal diagnosis and death [1, 6, 14], physician's unwillingness to refer to hospice service [1, 5], physician's unfamiliarity with hospice [5], physician's negative opinion of hospice service [5], insufficient knowledge of physician about hospice service [1], insufficient education for physi-

cians about palliative care [1, 6, 14], a medical system that does not include hospice as standard care [14, 30], patient's and family's unwillingness to use hospice [1, 19, 23], patient's and family's desire for life-prolonging treatment [29], lack of acceptance of a terminal diagnosis by the patient and family [23, 29, 30], insufficient knowledge by the general population and patients and families about hospice service [10, 13], and social attitudes toward death [30].

In Japan, the Ministry of Health, Labor, and Welfare has strongly supported the dissemination of specialized palliative care services. National Medical Insurance has covered inpatient palliative care units (PCUs) for terminal cancer patients since 1991, and the number of PCUs has dramatically increased from 5 in 1991 to 162 in 2006. On the other hand, the growth of home-based palliative care programs has been slow, and 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 [7, 9, 17]. Although western studies are focused on referral to home hospice, in Japan, referral is usually to the PCU. As there is a difference in medical systems and cultural background, Japanese barriers to referral to the PCU should be examined [27].

Morita explored reasons for late referral to the PCU in Japan and found misconceptions about palliative care among families, inadequate communication with physicians, and insufficient preparation of the family for the deterioration of the patient's condition [17]. However, Morita's study sample included only bereaved family members of PCU patients. He did not include the families of patients who were not referred or were denied admittance to the PCU. About 5% of cancer deaths occur in PCUs in Japan. Many patients who should have been referred to the PCU are assumed to have died in general wards. Nonetheless, in Japan, there has been no research exploring barriers to referral to the PCU. Therefore, we investigated the barriers to referral to inpatient PCUs using a qualitative study across various sources of information, including terminal cancer patients and their families, physicians, and nurses.

## Materials and methods

### Participants

Participants were advanced cancer patients, their family members, physicians, and nurses in palliative care and acute care cancer settings of five regional cancer institutes in Japan (Ibaraki, Gunma, Shizuoka, Hiroshima, and Yamaguchi prefectures). We predetermined that we needed to recruit 20 participants in each group as the sufficient number required for a qualitative study. Then 16 participants (four for each group) were allocated for each institution, and

the patients who met the following conditions were recruited: having incurable advanced cancer, knowing their diagnosis, having no cognitive impairment, and being aged 20 to 80 years. The physicians and the nurses in acute care settings were required to have had more than 2 years of clinical experience in cancer treatment. The physicians and nurses in palliative care settings were also required to have had more than 2 years of clinical experience in specialized palliative care service. We obtained written informed consent from all the participants.

### Interview procedure

Semi-structured interviews were conducted by five interviewers, including the authors of this article (M. M. and K. H.), two graduate school students of psychology, and one research nurse. The interview followed guidelines developed by the authors through careful consideration of the purpose of this study. There were two sets of questions. One set contained predetermined, open-ended questions for patients and family members, such as the following: "If you were offered referral to the PCU, what would be the barriers to admittance to the PCU?" The other set included predetermined, open-ended questions for physicians and nurses, as follows: "What do you think are barriers to referral of patients to the PCU?" For both procedures, the participants were asked to respond freely to the questions.

### Analysis

All the interviews were audiotaped and transcribed. Content analysis was performed on the transcribed data [11]. First, a research nurse (M. M.) and a psychologist (K. H.) extracted all statements from the transcripts related to the study topics, such as barriers to referral to inpatient palliative care units. Then, under the supervision of an experienced palliative care physician (T. M.), they carefully conceptualized and categorized the attributes from the transcripts based on similarities and differences in the content and created definitions for all the attributes. Finally, two coders among the research nurses independently determined whether each participant had made remarks that belonged to any of the attributes according to the definitions. When their coding was inconsistent, a third coder was the final judge. The concordance rate and Kappa coefficient by the two independent coders were 89% and 0.55, respectively.

In addition, we conducted descriptive analyses on the frequencies of the attributes. We summarized four groups into non-medical populations (patient and family) and medical staff (physician and nurse), and Fisher's exact test was used to test group differences in the responses for each attribute. Significance level was set 0.05, and a two-tailed test was conducted. All statistical analyses were performed



using statistical package SAS for Windows version 9.1 (SAS Institute, Cary, NC).

## Results

### Respondent characteristics

There were a total of 63 participants, including 13 patients, 10 family members, 20 physicians (10 PCU, 10 general ward), and 20 nurses (10 PCU, 10 general ward; Table 1). In several institutions, the enrollment of non-medical populations was insufficient because of the absence of suitable participants. Although several institutions did not recruit the required number due to the absence of suitable participants during the study periods, we did not recruit additional participants because the number of extracted attributes was satisfactorily saturated by the end of the planned study period. Fifty-seven percent of the participants were female, and the mean age was 45 years. The patients' primary sites of cancer were the lungs ( $n=5$ ), pancreas ( $n=5$ ), liver ( $n=2$ ), and others ( $n=2$ ). Patient expected survival time from interviews was 1-3 months ( $n=6$ ), 3-6 months ( $n=2$ ), 6 months-1 year ( $n=3$ ), and unknown ( $n=2$ ). Patient performance status (ECOG PS) was 0 ( $n=2$ ), 1 ( $n=3$ ), 2 ( $n=4$ ), 3 ( $n=3$ ), and 4 ( $n=2$ ).

### Barriers to referral to PCU in Japan

A total of 21 barriers were identified by content analysis. We classified these barriers into three categories: (1) patient- and family-related barriers, (2) medical staff-related barriers, and (3) PCU system-related barriers. Their frequency is shown in Table 2. The leading attribute was a negative image of the PCU by patients and families ( $n=39$ ). Second was delaying the termination of anti-cancer treatment by general ward physicians ( $n=24$ ). The third barrier was unwillingness to end anti-cancer treatment and denial of the fatal nature of the disease by patients and families ( $n=22$ ). Fourth was the patient's wish to receive care by the accustomed physician and nurse ( $n=20$ ). And the fifth barrier was insufficient knowledge of PCUs by medical staff in the general ward ( $n=17$ ).

**Table 1** Participants' demographics

	Patient ( $n=13$ )	Family ( $n=10$ )	Physician ( $n=20$ )	Nurse ( $n=20$ )
Age, mean (SD), year	62.2 (11.7)	54.4 (11.5)	38.6 (6.5)	34.9 (7.6)
Male, $n$ (%)	7 (53)	1 (10)	19 (95)	0 (0)
Professional career, mean (SD), year	NA	NA	13.3 (6.1)	12.8 (6.6)

**Table 2** Barriers to referral to PCU in Japan ( $n=63$ )

	Number	Percent
Patient- and family-related barriers		
(1) Negative image of PCU among patients and family members	39	62
(2) Unwillingness to end anti-cancer treatment and denial of the fatal nature of the disease by patient and family	22	35
(3) Patient's wish to receive care by accustomed physician and nurse	20	32
(4) Family's request for patient not to be admitted to PCU	10	16
(5) Insufficient knowledge of the PCU among patients and family members	8	13
General ward medical staff-related barriers		
(6) Delaying the termination of anti-cancer treatment by the physician in the general ward	24	38
(7) Insufficient knowledge of PCU among medical staff in general ward	17	27
(8) Failing to communicate a bad prognosis by the medical staff in the general ward	15	24
(9) Insufficient explanation of PCU by medical staff to the patients and families in general ward	13	21
(10) Not proposing PCU as an alternative by medical staff in the general ward	11	17
(11) Negative image of PCU by medical staff in general ward	10	16
(12) Desire of medical staff in general ward to care for patient until death	10	16
(13) Insufficient communication skills of medical staff in general ward	6	10
(14) Uncertainty of limits of anti-cancer treatment by medical staff in general ward	5	8
PCU-related barriers		
(15) Poor access to PCUs (shortage of PCUs, inconvenient locations)	12	19
(16) Environment of PCU (private room, loneliness, and isolation from general ward)	10	16
(17) Poor communication between PCU staff and medical staff in general ward	9	14
(18) Discontinuation of anti-cancer treatment in PCU	7	11
(19) Economic problems (expensive private room fee, expensive hospital bill)	6	10
(20) Doctrinaire beliefs of PCU (emphasis on philosophy, stringent rules for admission)	5	8
(21) Prospective payment system of PCU	3	5

### PCU Palliative care unit

Table 3 shows the differences in responses among groups. For patients, families, and nurses, a negative image of the PCU by patients and families was the leading barrier. For physicians, however, it was delaying the termination of anti-cancer treatment. The following barriers were significantly different among the studied groups: (1) negative image of PCU among patients and family members, (2) insufficient knowledge of the PCU among patients and

**Table 3** Differences in responses among groups

Barriers	Patient (n=13)		Family (n=10)		Physician (n=20)		Nurse (n=20)		P value
	N	%	n	%	n	%	n	%	
<b>Patient- and family-related barriers</b>									
(1) Negative image of PCU among patients and family members	7	54	3	30	11	55	18	90	0.006
(2) Unwillingness to end anti-cancer treatment and denial of the fatal nature of the disease by patient and family	3	23	2	20	10	50	7	35	0.33
(3) Patient's wish to receive care by accustomed physician and nurse	2	15	1	10	9	45	8	40	0.12
(4) Family's request for patient not to be admitted to PCU	0	0	1	10	4	20	5	25	0.24
(5) Insufficient knowledge of the PCU among patients and family members	0	0	0	0	8	40	0	0	0.001
<b>General ward medical staff-related barriers</b>									
(6) Delaying the termination of anti-cancer treatment by the physician in the general ward	0	0	0	0	13	65	11	55	0.001
(7) Insufficient knowledge of PCU among medical staff in the general ward	0	0	1	10	8	40	8	40	0.013
(8) Failing to communicate a bad prognosis by the medical staff in the general ward	0	0	0	0	8	40	7	35	0.006
(9) Insufficient explanation of PCU by medical staff to the patients and families in general ward	0	0	0	0	4	20	9	45	0.003
(10) Not proposing PCU as an alternative by medical staff in the general ward	0	0	0	0	6	30	5	25	0.047
(11) Negative image of PCU by medical staff in general ward	0	0	0	0	4	20	6	30	0.051
(12) Desire of medical staff in general ward to care for patient until death	0	0	0	0	4	20	6	30	0.051
(13) Insufficient communication skills of medical staff in general ward	0	0	0	0	4	20	2	10	0.24
(14) Uncertainty of limits of anti-cancer treatment by medical staff in general ward	0	0	0	0	4	20	1	5	0.19
<b>PCU-related barriers</b>									
(15) Poor access to PCU (shortage of PCUs, inconvenient location)	2	15	1	10	6	30	3	15	0.59
(16) Environment of PCU (private room, loneliness, and isolation from general ward)	2	15	1	10	4	20	3	15	0.96
(17) Poor communication between PCU staff and medical staff in general ward	0	0	0	0	4	20	5	25	0.12
(18) Discontinuation of anti-cancer treatment in PCU	2	15	0	0	3	15	2	10	0.77
(19) Economic problems (expensive private room fee, expensive hospital bill)	0	0	1	10	1	5	4	20	0.27
(20) Doctrinaire beliefs of PCU (emphasis on philosophy, stringent rules of admission)	0	0	0	0	2	10	3	15	0.43
(21) Prospective payment system of PCU	0	0	0	0	2	10	1	5	0.77

PCU Palliative care unit

family members, (3) delaying the termination of anti-cancer treatment by the physician in the general ward, (4) insufficient knowledge of the PCU among medical staff in the general ward, (5) failing to communicate a bad prognosis by the medical staff in the general ward, (6) insufficient explanation of the PCU by medical staff to the patients and families in the general ward, and (7) not proposing PCU as an alternative by medical staff in the general ward. The comparison between PCU staff (PCU physicians and nurses) and general ward staff (general ward physicians and nurses) was not significantly different for any attributes (data not shown).

## Discussion

This is the first study to investigate the barriers to referral to the inpatient PCU in Japan. A negative image of the PCU is

recognized as the most important barrier by patients, families, and medical staffs. They described the PCU as a place of death in that once a patient was admitted to the PCU, he or she could not be discharged alive. They also believed that the PCU shortens the patient's life, isolates patients from the community, and does not offer medical treatment. The opinion that the PCU shortens the patient's life coincides with the findings of Morita's study of late referral [17]. Sanjo reported that the belief that the PCU isolates patients from the community contributes to avoidance of the PCU [24].

Although PCUs are recognized by the general Japanese population and bereaved family members as services that provide compassionate care, helping patients die peacefully and with dignity, providing care for families, and alleviating pain, they still view the PCU as a place that shortens patients' lives and isolates dying patients from the community and as an expensive place where people are

only waiting to die (Sanjo et al., submitted for publication). In addition, Shiozaki investigated dissatisfaction of bereaved family members in the PCU and reported a negative image of the PCU as one of the major reasons for dissatisfaction [26]. Of note, many medical staff reported that the dissemination of these unfavorable images was by patients to patients and families to families. Patients admitted to the general wards and their families were told that the PCU was a place of death by other patients and families. Although some of these images were true [26], Morita showed that the unfavorable opinions could be changed through the experience of being cared for in the PCU [17]. Therefore, of these negative images, several are misconceptions or misunderstandings. To correct these misconceptions, it is important to disseminate accurate information about PCUs to the general population, patients, and families [18].

Delay in ending anti-cancer treatment by physicians in the general ward could be due to the difficulty of predicting prognosis [3, 29]. In addition, it may be associated with the physician's lack of acceptance of the patient's terminal diagnosis and death [1, 6, 14]. Several study participants in the general wards said that even if a physician recognized that a patient might be in a terminal phase, the introduction of palliative care is postponed by the patient's desire for anti-cancer treatment and the uncertainty of the prognosis made the physician. In Japan, the palliative care option is seldom introduced to patients who are receiving anti-cancer treatment. Therefore, it is difficult for the physician to have the opportunity to communicate bad news, especially because physician education in this area is so poor. In addition, determining the time to stop anti-cancer treatment is difficult for the oncologist. Therefore, early introduction of the palliative care option to the patient [8] and communication skills training regarding breaking bad news are relevant issues [2, 20].

Unwillingness to end anti-cancer treatment and denial of the fatal nature of the disease by the patient and family are major problems. Some patients with terminal cancer seek out anti-cancer treatment even if the possibility of cure is low [12, 28]. In addition, a Japanese study revealed that a number of bereaved families experienced serious emotional burden with the ending of anti-cancer treatment and transition to palliative care [16]. Early introduction of the palliative care option and careful and sophisticated communication with the patient and family are important [16]. To that end, it is necessary for the medical staff in the general ward to have accurate information about the PCU and palliative care.

In our study, although most of the barriers to inpatient PCU care are similar to those reported by western countries, several issues unique to Japan were found. Ten participants

told of the family's request for the patient not to be admitted to the PCU. In Japan, it is traditional for the family to intervene in decision-making [22]. Twelve participants told of poor access to a PCU. Only 5% of cancer deaths occur in the PCU. Therefore, the number of PCUs is insufficient and many patients die in the general ward while awaiting admission to the PCU. In addition, some PCUs have stringent admission rules, such as compelling the patient to recognize the diagnosis or prognosis, restrictions on the patient's physical and cognitive condition, and a correct understanding of the purpose of the PCU by patients. The shortage of PCUs is an important barrier to providing specialized palliative care in Japan. An increase in the number of PCU beds and the development of home hospices are needed to deliver palliative care to all dying patients.

The barriers to PCU admission significantly differed according to the group. Patients and families were not aware of physicians' attitudes and were not familiar with their barriers. This indicates an asymmetry of information regarding medical systems among patients, families, and medical staffs.

Our study has several limitations. First, we surveyed a limited number of institutions, and all participating institutions were hospitals with PCUs. If patients, families, and medical staff in general wards with non-PCU hospitals had participated, there may have been more emphasis on access to PCUs. Therefore, generalizing the present results is difficult. Second, barriers identified by patients and families were of low frequency. It was difficult to elicit barriers from patients in terminal stages of cancer and their families. Therefore, a study targeting an earlier phase might be required. Third, although we predetermined that we needed to recruit 20 participants for each group, we could not achieve such number among patient and family member groups. However, we believe that the variety of participants would assure the content validity of this study. Finally, because the number of participants in the four groups were different, determining the importance of each barrier by summing up the answers of the four groups might be not conclusive.

## Conclusions

In conclusion, we identified 21 barriers to referral to the PCU and determined the frequency of these barriers. The leading barriers were a negative image of the PCU by patients and families, delaying the termination of anti-cancer treatment by general ward physicians, unwillingness to end anti-cancer treatment and denial of the fatal nature of the disease by patients and families, the patient's wish to receive care by the accustomed physician and nurse, and

insufficient knowledge of PCUs by medical staff in the general ward.

To correct these unfavorable images and misconceptions of PCUs, it is important to eliminate the negative image that the general population, patients, families, and medical staff have of PCUs. In addition, early introduction of palliative care options to patients and communication skills training regarding breaking bad news are relevant issues for a smooth transition from anti-cancer treatment to palliative care.

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

Mitsunori Miyashita<sup>1\*</sup>, Tatsuya Morita<sup>2</sup>, Kazuki Sato<sup>1</sup>, Kei Hirai<sup>3,4</sup>, Yasuo Shima<sup>5</sup> and Yosuke Uchitomi<sup>6</sup>

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

<sup>2</sup> Department of Palliative and Supportive Care, Palliative Care Team and Seirei Hospice, Seirei Mikatahara Hospital, Shizuoka, Japan

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

<sup>4</sup> Department of Complementary and Alternative Medicine, Graduate School of Medicine, Osaka University, Osaka, Japan

<sup>5</sup> Department of Palliative Medicine, Tsukuba Medical Center Hospital, Ibaraki, Japan

<sup>6</sup> 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: miyasita-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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**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

## Factors contributing to a good death

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  $70 \pm 11$ , 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	%
<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



## Factors contributing to a good death

**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)

	$\beta$	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)

	$\beta$	P-value
11. Religious and spiritual comfort ( $R^2 = 0.369$ )		
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. Receiving enough treatment ( $R^2 = 0.137$ )		
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. Control over the future		
Place of care (PCU)	0.45	0.16
14. Feeling that one's life is worth living ( $R^2 = 0.034$ )		
Place of care (PCU)	0.06	0.83
Duration from diagnosis	0.01	0.04
15. Unawareness of death ( $R^2 = 0.162$ )		
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. Pride and beauty ( $R^2 = 0.187$ )		
Place of care (PCU)	-0.34	0.18
Patient's age	0.05	<0.001
Opioid medication	1.02	0.003
17. Natural death ( $R^2 = 0.143$ )		
Place of care (PCU)	0.26	0.27
Patient's marital status (married)	-0.72	0.002
Opioid medication	1.06	0.001
18. Preparation for death ( $R^2 = 0.100$ )		
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

## Factors contributing to a good death

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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