

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.¹⁶ 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 ± SD	33 ± 8.7
Median	31
Sex	
Female (%)	99
Number of years of clinical practice	
Mean ± SD	11 ± 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 ± SD	40 ± 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,^{10,16,17} 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,^{11,12,21} 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		
	β	SE	P Value	β	SE	P Value	β	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.¹⁶ 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.²² 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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Reliability Assessment and Findings of a Newly Developed Quality Measurement Instrument: Quality Indicators of End-of-Life Cancer Care from Medical Chart Review at a Japanese Regional Cancer Center

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ABSTRACT

Objectives: To assess the reliability of quality indicators of end-of-life cancer care (QI-EOL) and evaluate the quality of end-of-life cancer care in general wards by using QI-EOL.

Methods: A retrospective chart review study was conducted on patients with cancer who died in general wards ($n = 104$) and the palliative care unit (PCU; $n = 200$) between September 2004 and February 2006 at a regional cancer center in Japan. Herein, we measured QI-EOL, which was developed to evaluate the quality of end-of-life cancer care based on medical charts. We preliminarily assessed the interrater reliability of QI-EOL and subsequently compared the percentages of QI-EOL documented between settings.

Results: The reliability of QI-EOL was assured in 27 of 29 indicators ($\kappa > 0.40$ or agreement $> 90\%$). For the reliable indicators, we found wide variation in the percentages of QI-EOL documented, ranging from 0% to 98% in general wards. Thirteen of 27 indicators were significantly less documented in general wards than in PCU. Presence of delirium or agitation was less documented (15% in general wards, 55% in PCU, $p < 0.001$), although presence of pain (92%, 93%, $p = 1.000$) and dyspnea (78%, 78%, $p = 1.000$) were similarly documented. Observation and oral care (22%, 62%, $p < 0.001$) differed significantly. Patient's (29%, 45%, $p = 0.009$) and family's (30%, 45%, $p = 0.014$) preferred place of care were infrequently documented. For psychosocial and spiritual concerns, no significant differences were found.

Conclusion: QI-EOL is generally a reliable quality measure instrument. We found the need for improvements of end-of-life cancer care in general wards using the QI-EOL.

INTRODUCTION

MEASURING THE QUALITY OF CARE is an important issue for monitoring clinical practice and improving outcomes.¹⁻³ Although patient assessment is

the best quality measure, it is impractical to measure the quality of end-of-life care because of the difficulties of accurate prognostication for end-of-life and many patients are too ill to provide assessments.⁴ In contrast, several recent studies developed quality in-

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dicators (QIs) of palliative and end-of-life care, which assess the quality from existing sources such as administrative data or medical chart data.⁵⁻¹¹

Earle et al.⁵ identified QIs of end-of-life cancer care using administrative data that focused on the aggressiveness of care. In the United States, they analyzed Medicare claims and the Surveillance, Epidemiology and End Results registries between 1993 and 1996 and found that, near death, there were trends associated with increased chemotherapy uses, emergency department visits, hospitalizations, and intensive care unit (ICU) admissions.¹² Barbera et al.¹³ also reported on the poor quality of end-of-life cancer care using the Ontario Cancer Registry. However, databases do not include some important information such as psychosocial care, pain and symptom management, and advance directives.⁶ QIs from administrative data have the advantage of being readily available and inexpensive to collect, but they may be unreliable and lack detail.¹⁴⁻¹⁶

The Assessing Care of Vulnerable Elders (ACOVE) project developed a quality assessment system using the medical chart.¹⁷ The ACOVE QI set consisted of 22 conditions, including 14 indicators for end-of-life care such as surrogate decision makers, advance directives, care preferences, and symptom management.⁷ Wenger et al.¹⁸ measured the ACOVE QI set for vulnerable community-dwelling older patients in two managed care organizations in the United States. They reported wide variation in documentation of QIs among conditions from end-of-life care (9%) to stroke care (82%). Twaddle et al.⁹ developed 11 key performance measures to assess the quality of hospital-based palliative care and reported wide variability of palliative care in 35 teaching hospitals across the United States from retrospective chart reviews. Clark et al.¹⁰ identified QIs of end-of-life care in the ICU, and reported better practice in symptom management but inadequacies in spiritual support, communication, emotional support, and continuity of care in 15 ICUs.

In Japan, palliative care developed from inpatient care for terminal cancer patients in palliative care units (PCUs). In 1990, coverage of PCU was included in National Health Insurance and the number of PCUs has increased from 5 to 177 in 2007. Nevertheless, only 6% of all patients with cancer died in the PCU, while most (91%) died in the hospital in 2006.²⁰ In addition, interdisciplinary palliative care teams (PCTs) provide specialized palliative care in general wards in cooperation with attending physicians. These teams are still developing. Therefore, measuring the quality of end-of-life care in general wards is an important task to improve care for dying patients with cancer in Japan.

In Japan, using administrative data is difficult because the cancer registry is insufficient and medical claims are inaccessible. Additionally, the Japanese concept of quality of end-of-life is marginally different from Western countries.^{21,22} For these reasons QIs of end-of-life cancer care (QI-EOL) from medical chart review have been identified by using the consensus method in Japan.²³ QI-EOL consists of 30 indicators, which assess symptom control, decision making and preference of care, family care, and psychosocial and spiritual concerns. In order to offer valuable insights from the newly developed QI-EOL, these indicators must be reliable.^{15,16,24,25} Therefore, the purpose of this study was to assess the reliability of QI-EOL and evaluate the quality of end-of-life cancer care in general wards by applying QI-EOL.

METHODS

Study design

We conducted a chart review study in order to measure QI-EOL and evaluate the quality of end-of-life cancer care. Data were collected retrospectively on cancer patients who died in general wards and the PCU from September 2004 to February 2006 at a regional cancer center (Tsukuba Medical Center Hospital). This center has 409 beds, including 20 PCU beds, and plays a central role in cancer treatment, community health care and emergency medical care in Ibaraki prefecture, Japan. The inclusion criteria were as follows: died from cancer; aged 20 years or older at the time of death; and hospitalized for 3 days or more. The cancer sites could not be matched between settings due to the inclusion of data from various clinical departments, including respiratory medicine, general thoracic surgery, gastroenterology, gastroenterological surgery, general medicine, and palliative medicine. During the study period, these departments represented 88% of all cancer deaths in general wards and 100% of all deaths in the PCU.

The Japanese ethical guidelines for epidemiologic research restricts access to medical charts without disclosure of information to participants and a guarantee of their right to refuse participation.²⁶ Therefore, we mailed a letter to the bereaved families to inform them about the study and reviewed the medical charts for the patients whose bereaved families did not decline to participate. A qualified research nurse (K.S.) reviewed all medical charts under the supervision of a PCU doctor (S.Y.). An additional abstractor (M.M., also a research nurse) independently and randomly reviewed 10% of medical charts to assess interrater re-

liability. The abstracters were trained using abstraction guidelines with detailed definitions. The ethics committee of Tsukuba Medical Center Hospital approved the protocol of this study.

Measures

QI-EOL was developed in order to evaluate the quality of end-of-life cancer care based on medical chart review using the modified Delphi method. The development methods were previously described in detail.²³ Briefly, 96 potential indicators were proposed from a combination of systematic reviews and expert judgment. An expert panel comprised of 17 multiprofessional specialists, 5 palliative care physicians, a medical oncologist, a general medicine physician, 3 psycho-oncologists, 3 nurses, 2 sociologists, a medical ethicist, and an expert on Delphi methodology, rated potential indicators for appropriateness of quality end-of-life cancer care and feasibility for extraction from

medical chart review. Through 2 expert panels, 30 indicators within 4 domains were accepted, which included 8 indicators for symptom control, 5 for decision-making and preference of care, 11 for family care, and 6 for psychological and spiritual concerns. Because QI-EOL focus on the documentation of a general approach (e.g., documentation of the degree of pain) to care rather than practical action (e.g., documenting the degree of pain on a 0–10 numeric rating scale more than once a day), a set of abstraction guidelines was developed for the present study in cooperation with QI-EOL developers. An additional expert panel reviewed the guidelines and deleted or modified unmeasurable indicators from medical charts and divided the indicators with double-barreled questions. Finally, we used the modified QI-EOL as follows: 10 indicators focused on symptom control, 6 focused on decision-making and preference of care, 9 focused on family care, and 4 focused on psychological and spiritual concerns (Table 1). The patients who died were

TABLE 1. INTERRATER RELIABILITY OF QUALITY INDICATORS OF END-OF-LIFE CANCER CARE

	<i>Agreement (%)</i>	<i>κ coefficient</i>
Symptom control		
Presence or absence of pain	93	0.47
Degree of pain	80	0.53
Physician's prescription order for pain management	87	0.59
Physician's prescription order for first and second line pain management	90	0.80
Presence or absence of dyspnea	97	0.84
Physician's prescription order for dyspnea	80	0.59
Effect of rescue medication for any physical distress	90	0.63
Presence or absence of delirium or agitation	90	0.73
Physician's prescription order for delirium or agitation	90	0.79
Observation and care of mouth	77	0.54
Decision-making and preference of care		
Patient's preferred place of care	77	0.53
Patient's insight of disease	83	0.56
Explanation of medical condition to patient	83	0.65
Discussion with patient about goals of care	77	0.48
Discussion with patient about do-not-resuscitate order	97	0.65
Discussion of strategy of care among physicians and nurses	70	0.30
Family care		
Configuration of family relationships	97	0.65
Key person involved in patient care	97	0.65
Family's preferred place of care	77	0.52
Family's insight of disease	93	-0.03
Explanation of medical condition to family	100	1.00
Family's preferences or expectations	87	0.63
Discussion with family about goals of care	93	0.46
Discussion with family about do-not-resuscitate order	97	0.78
Explanation to family of patient's impending death	97	0.65
Psychosocial and spiritual concerns		
Degree and content of patient's anxiety	77	0.52
Patient's religion	83	0.66
Patient's preferences or expectations	80	0.53
Patient's preference for bowel and bladder excretion	63	0.22

Agreement between two different abstracters of 30 randomly selected medical chart reviews.

retrospectively identified (denominators) and inpatient medical charts were reviewed to clarify whether each indicator was documented on admission or within the last 2 weeks of the hospitalization (numerators). High percentages of documented QI-EOL indicated high quality of end-of-life cancer care.

Furthermore, data on patients' demographic and clinical characteristics were collected. Demographic characteristics included gender and age. Clinical characteristics included primary cancer site, stage, treatment (surgery, chemotherapy and radiotherapy), length of time since cancer diagnosis, hospital stay and PCU stay, documentation of do-not-resuscitate (DNR) order, patient or family consent to DNR, and length of time between documentation and death.

Statistical analysis

Initially, to test interrater reliability, we calculated the agreement and κ coefficient of QI-EOL between two abstracters. According to the criteria of Landis and Koch, agreement was classified according to κ scores as poor (0–0.20), fair (0.21–0.40), moderate (0.41–0.60), substantial (0.61–0.80), and almost perfect (0.81–1.0).²⁷ We defined an indicator as reliable if κ was > 0.40 . Meanwhile, in a 2×2 table showing binary agreement of two observers, κ becomes unreliable when the distribution of the dichotomous variable is unbalanced; therefore, despite the high level of agreement, kappa would be very low.²⁸ Thus, we also defined an indicator as reliable if agreement was greater than 90% when κ was ≤ 0.40 .

Next, for the reliable indicators, we showed the percentages of QI-EOL documented separately from general wards and PCU. As PCU is the current gold standard for end-of-life care in Japan, bivariate analyses between settings were then conducted to assess the quality of end-of-life cancer care in general wards. For patients' demographic and clinical characteristics, percentages were calculated for categorical variables and the median, mean and standard deviation (SD) were calculated for quantitative variables. These characteristics were compared between settings and statistically were analyzed using Fisher's exact test, the Cochran-Armitage exact trend test, or the Wilcoxon test, when appropriate. A p value of < 0.05 was considered statistically significant. All statistical analyses were performed with SAS version 9.1 for windows (SAS Institute, Cary, NC).

RESULTS

Patients

During the study period, patients who died in general wards ($n = 160$) and PCU ($n = 228$) were iden-

tified as potential subjects meeting the inclusion criteria. Among potential subjects, 44 were excluded due to participation in the other study ($n = 23$ in general wards, $n = 0$ in PCU), serious psychological distress as determined by the attending physician ($n = 8$, $n = 0$), treatment or injury related deaths ($n = 3$, $n = 1$), no bereaved adult members ($n = 2$, $n = 2$) or other reasons ($n = 4$, $n = 1$). Subjects were also excluded because the bereaved families had no known addresses ($n = 3$, $n = 8$) or declined to participate ($n = 13$, $n = 15$) and one medical chart was missing in the PCU. Finally, we completed medical chart review for 104 (66%) and 200 (88%) patients.

Patient demographic and clinical characteristics are shown in Table 2. Among the patients whose medical charts were reviewed, 71% and 55% were male and mean age was 71 ± 9 and 68 ± 12 years old in general wards and PCU, respectively. Primary cancer sites were lung (41% in general wards, 15% in PCU), hepatobiliary and pancreatic (28%, 17%) and gastric (11%, 16%). Most patients (94%, 97%) had DNR orders and families, not patients, generally have consent (97%, 97%). Comparing general wards with PCU, there were significantly more males ($p = 0.007$), primary cancer sites were different ($p < 0.001$), cancer stages were less advanced ($p = 0.002$), experience of surgery ($p < 0.001$) or chemotherapy ($p = 0.014$) were less and lengths between cancer diagnosis and death ($p < 0.001$) were shorter.

Reliability of QIs

Agreement and κ for two abstracters of 30 randomly selected medical chart reviews are shown in Table 1. κ of three indicators was ≤ 0.40 and two agreements of those indicators were also $\leq 90\%$. "Discussion of strategy of care among physicians and nurse" (agreement, 70%; κ , 0.30) and "patient's preference for bowel and bladder excretion" (agreement, 63%; κ , 0.22) had poor interrater reliability in this study. These two indicators were excluded from the following results.

Quality of end-of-life cancer care

Documentation of QI-EOL is shown in Table 3. For symptom control, percentages of QI-EOL documented in general wards were from 15% (presence or absence of delirium or agitation) to 92% (presence or absence of pain). By comparing general wards to PCU, 5 of 10 indicators were significantly less documented and one was more frequently.

For decision-making and preference of care, percentages of QI-EOL documented in general wards were from 0% (discussion with patient about DNR or

TABLE 2. PATIENT DEMOGRAPHIC AND CLINICAL CHARACTERISTICS

	General wards (n = 104)		Palliative care unit (n = 201)		p
	n	(%)	n	(%)	
Gender, male	74	(71)	110	(55)	0.007 ^a
Age, years (Mean ± SD)	71 ± 9		68 ± 12		0.100
Primary cancer site					
Lung	43	(41)	30	(15)	<0.0001 ^b
Hepatobiliary and pancreatic	29	(28)	34	(17)	
Gastric	11	(11)	32	(16)	
Colorectal	7	(6.7)	35	(17)	
Head and neck	0	(0)	16	(8.0)	
Breast	1	(1.0)	15	(7.5)	
Other	13	(13)	39	(19)	
Cancer stage					
Local	7	(6.7)	2	(1.0)	0.002 ^a
Regional	19	(18)	26	(13)	
Distant	74	(71)	171	(85)	
Experience of cancer treatment					
Surgery	26	(25)	118	(59)	<0.0001 ^b
Chemotherapy	52	(50)	131	(65)	
Radiotherapy	45	(43)	93	(46)	
Length between cancer diagnosis and death, months (median, mean ± SD)	7,	14 ± 27	18,	32 ± 39	<0.0001 ^b
Length of hospital stay, (median, mean ± SD)	27,	37 ± 37	30,	45 ± 65	0.296
Length of palliative care unit stay, days (median, mean ± SD)	—	—	23,	37 ± 60	—
Documentation of DNR order	98	(94)	197	(98)	0.067
DNR order consented by family, not patient	95	(97)	192	(97)	0.307
Length of time between written DNR order and death, days (median, mean ± SD)	8,	17 ± 29	7,	20 ± 55	0.893

^ap < 0.01, ^bp < 0.001, ^cp < 0.05.

Several total percentages are not 100% due to missing values.

DNR, do-not-resuscitate; SD, standard deviation.

der) to 56% (patient's insight of disease). Two of 5 indicators were significantly less documented in general wards than PCU.

For family care, percentages of QI-EOL documented in general wards were from 30% (family's preference of place of care) to 98% (key person involved in patient care). Six of 9 indicators were significantly less documented in general wards than PCU.

For psychosocial and spiritual concerns, percentages of QI-EOL documented in general wards were documented from 34% (degree and content of patient's anxiety) to 65% (patient's preferences or expectations). No significant differences were seen between settings.

DISCUSSION

We preliminarily assessed the interrater reliability of QI-EOL and affirmed that many indicators had moderate or substantial interrater reliability.

Subsequently, we found several features and concerns about current clinical practice for dying cancer patients by measuring the reliable QIs. Many indicators were less documented in general wards than PCU. Our findings indicated the need for improvements in assessment of delirium, mouth care and discussion about preferred place of care. Despite their importance in end-of-life care, these aspects were not well assessed by previous QIs.⁵⁻¹¹ QI-EOL is a useful instrument to assess the quality of end-of-life cancer care, which has comprehensive concepts and methodological advantages such as relative ease and fewer difficulties with measurement.

For symptom control, assessment of delirium was insufficient in general wards. Presence of delirium or agitation was documented 15% in general wards, although delirium was observed in 63%–90% of patients with cancer prior to death.²⁹⁻³¹ While nurses should play a key role in recognition of delirium, delirium was often unrecognized by nurses.³² When terminally ill patients with cancer experienced delirium, families

TABLE 3. DOCUMENTATION OF QUALITY INDICATORS OF END-OF-LIFE CANCER CARE IN GENERAL WARDS AND PALLIATIVE CARE UNIT

	General wards (n = 104)		Palliative care unit (n = 201)		p
	n	(%)	n	(%)	
Symptom control					
Presence or absence of pain	96	(92)	185	(93)	1.000
Degree of pain	57	(55)	119	(60)	0.464
Physician's prescription order for pain management	79	(76)	174	(87)	0.023 ^a
Physician's prescription order for first and second line pain management	62	(60)	88	(44)	0.011 ^a
Effect of rescue medication for any physical distress ^d	52	(73)	162	(92)	<0.0001 ^b
Presence or absence of dyspnea	81	(78)	155	(78)	1.000
Physician's prescription order for dyspnea	39	(38)	86	(43)	0.391
Presence or absence of delirium or agitation	16	(15)	109	(55)	<0.0001 ^b
Physician's prescription order for delirium or agitation	31	(30)	109	(55)	<0.0001 ^b
Observation and care of mouth	23	(22)	124	(62)	<0.0001 ^b
Decision-making and preference of care					
Patient's preferred place of care	30	(29)	89	(45)	0.009 ^c
Patient's insight of disease	58	(56)	144	(72)	0.005 ^c
Explanation of medical condition to patient	18	(17)	48	(24)	0.191
Discussion with patient about goals of care	18	(17)	42	(21)	0.453
Discussion with patient about do-not-resuscitate order	0	(0)	4	(2.0)	0.303
Family care					
Configuration of family relationships	100	(96)	198	(99)	0.186
Key person involved in patient care	102	(98)	195	(98)	1.000
Family's preferred place of care	31	(30)	89	(45)	0.014 ^a
Family's insight of disease	78	(75)	195	(98)	<0.0001 ^b
Explanation of medical condition to family	98	(94)	199	(100)	0.007 ^c
Family's preferences or expectations	66	(63)	170	(85)	<0.0001 ^b
Discussion with family about goals of care	87	(84)	185	(93)	0.029 ^a
Discussion with family about do-not-resuscitate order	79	(76)	168	(84)	0.091
Explanation to family of patient's impending death	88	(85)	185	(93)	0.044 ^a
Psychosocial and spiritual concerns					
Degree and content of patient's anxiety	35	(34)	91	(46)	0.050
Patient's religion	66	(63)	116	(58)	0.389
Patient's preferences or expectations	68	(65)	144	(72)	0.239

^a $p < 0.05$, ^b $p < 0.001$, ^c $p < 0.01$.

^dPercentages were calculated from patients with rescue medication (71 in general wards, 176 in palliative care unit). Whether each indicator was documented in inpatient medical charts on admission or within the last 2 weeks of life.

experienced high levels of distress³³; therefore, appropriate assessment and treatment of delirium are needed to reduce patients' and families' distress. Second, mouth care was also insufficient in general wards. Dry mouth is a common symptom observed in 60%–70% of patients with cancer prior to death.^{34,35} Good nursing care can relieve this distressing symptom,³⁶ so nurses should document assessment and care of the mouth to provide continued care and symptom relief. Third, assessment of pain and dyspnea was relatively well documented but minor improvements could be made in the management of physical symptoms. Twaddle et al. measured the quality of palliative care for patients with cancer in 35 teaching hospitals using medical chart review and reported assessment of pain (98%) with a numeric pain scale (82%) and dys-

ypnea (90%).⁹ Our results for assessment of pain (92%), degree of pain (55%), and dyspnea (78%) in general wards were common with PCU but less than in the United States. In addition, effect of rescue medication in general wards (73%) was documented less than PCU (92%). Assessment and management of physical symptoms have room for improvement.

For decision making and preference of care, many indicators were relatively less documented in both settings. This indicated the possibility of poor advanced communication with patients. Several studies indicated that in Japan the preference of families, not patients, determines the end-of-life decision-making more than in Western countries.^{37–39} Furthermore, many patients lost communication capacity in the last two weeks due to decreased consciousness, appearance

of delirium or induction of palliative sedation.^{29-31,40} For these reasons, discussion with patients about their illness and preference were avoided by health care professionals and sometimes impossible because of the patient's condition.

For family care, the family's preferred place of care was documented remarkably infrequently. The multicenter survey in Japan revealed that half of the bereaved families of patients with cancer considered the referrals to PCU to have been too late and such family-perceived late referrals were associated with insufficient discussion with physicians about preferred end-of-life care.⁴¹ Short length of stay in hospice was associated with lower satisfaction of care,^{42,43} therefore, health care professionals in general wards may improve the quality of end-of-life cancer care by discussing preferred place of care earlier and more frequently. Meanwhile, the other indicators were well documented, although less frequently than PCU. This indicated the good advanced communication with families, whereas the frequency of family consented DNR orders (97%) may improve the apparent percentages.

For psychosocial and spiritual concerns, no significant differences were detected, although these concepts are central to palliative care. We propose two reasons for this gap. In Japan, compared to Western countries, patients with cancer view religious support as less important.^{21,22} In addition, religious or spiritual care was sometimes not provided even if was considered important.⁴⁴ The study PCU did not provide chaplain care; psychosocial and spiritual care may be insufficient even in PCU. However, these indicators may not be sensitive enough to detect changes.

This study has several limitations. First, documentation in medical charts may not reflect actual practice. However, documentation itself is also important in the sharing of information and ongoing assessment; therefore, QI-EOL was developed for assess the quality by focusing on documentation. Second, interrater reliability of many indicators was moderate (κ , 0.41-0.60). Stricter guidelines and training of abstracters is necessary to further enhance the reliability. With regards to this study, the results were reliable for a single abstracter who reviewed all medical charts. In addition, QI-EOL focused on general approach to care rather than practical action. This ambiguity complicated the measurement process and resulted in the modification of the original indicators in order to establish more feasible indicators. Third, this study was conducted in a single center. Extrapolation of our findings is difficult, so further multicenter studies are necessary to assess the quality of end-of-life cancer care in Japan. Moreover, this study could not include all

potential subjects due to strict adherence to ethical guidelines. Families of patients who received poor quality end-of-life care may be more likely to decline to participate in such a study; therefore, the differences between settings may have been underestimated. Despite the limited sample, we do not believe that the results have been significantly effected. Fourth, QI-EOL was developed by expert panels that did not include patients or family members; thus, QI-EOL may have poor content validity. Finally, the number of nurses and some characteristics of patients are different between general wards and PCUs. The difference between settings may be overestimated.

CONCLUSIONS

We initially found that QI-EOL was a generally reliable quality measure instrument. Subsequently, using QI-EOL, we found that the quality of end-of-life cancer care was less adequate in general wards when compared to that provided in PCU. In particular, our findings indicated the need for improvements in assessment of delirium, oral care, and discussion about preferred place of care. Educational intervention focusing on these perspectives could improve the clinical practice for dying patients with cancer in general wards.

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Original Article

Perceptions of Specialized Inpatient Palliative Care: A Population-Based Survey in Japan

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Abstract

This study aimed to clarify and compare the awareness and perceptions of the specialized inpatient palliative care service. A cross-sectional questionnaire survey was performed on the general population selected by stratified two-stage random sampling (n = 2,548) and bereaved families who actually received specialized inpatient palliative care at 12 palliative care units (PCUs) in Japan (n = 513). The respondents reported their awareness and perceptions of PCUs. Thirty-eight percent of the general population answered that they had "considerable" or "moderate" knowledge of PCUs, but 24% answered that they had "no" knowledge. Bereaved families who received PCU care (PCU-bereaved families) were likely to have better perceptions of PCUs than the general population: "alleviates pain" (68% of the general population and 87% of PCU-bereaved families agreed), "provides care for families" (67% and 86%, respectively), and "provides compassionate care" (67% and 87%, respectively). Both groups, however, expressed concerns about PCUs: "a place where people only wait to die" (30% and 40%, respectively) and "shortens the patient's life" (8% and

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17%, respectively). These perceptions were associated with overall satisfaction with received care, and differed among the 12 PCUs. In conclusion, public awareness of PCUs was insufficient in Japan. Although PCU-bereaved families were generally likely to have better perceptions of PCUs than the general population, both groups shared concerns that a PCU was a place where people only wait to die. To facilitate appropriate use of specialized palliative care services, more efforts to inform the general population about the actual palliative care system are needed. In addition, the role of PCUs might be reconsidered in terms of the continuum of cancer care. *J Pain Symptom Manage* 2008;35:275–282. © 2008 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Key Words

Palliative care, end-of-life care, neoplasm, health knowledge

Introduction

The numerous barriers to quality end-of-life care are related to patients, families, medical professionals, and the health care system itself.^{1–3} One recognized impediment to palliative care is that the general population has insufficient knowledge about palliative care and hospices.^{3–8} Population-based surveys have revealed that although the majority of the general population had heard of specialized palliative care, many are relatively ill-informed about what it comprises.^{8,9} In Japan, the most common type of specialized palliative care service is inpatient care, that is, care provided in palliative care units (PCUs), because home-based specialized palliative care programs and palliative care teams are still being developed.^{10–12} Although the number of PCUs has increased dramatically from only five in 1991 to 135 in 2004, no population surveys have been conducted to clarify the public awareness and perceptions of PCUs in Japan.

Moreover, patients are concerned about transition to palliative care services based on the perception that palliative care equates to imminent death,¹³ and families fear that palliative care shortens the patient's life before determining the use of PCUs.¹⁰ These concerns may impede appropriate referrals. Nonetheless, retrospective surveys of bereaved families who had actually chosen PCUs as a place of end-of-life care and received specialized inpatient palliative care showed that these negative perceptions of PCUs improved markedly after using the service.¹⁰ Given the necessity of providing sufficient and correct information about PCUs, it is important to understand

the differences in perceptions of PCUs between the general population and bereaved families who have actually received specialized palliative care (PCU-bereaved families). Although a recent qualitative study suggested that negative perceptions of PCUs, for example, "a place where one dies" and "somewhere from which you can never return," were associated with dissatisfaction with received care among PCU-bereaved families,¹⁴ this association has not yet been quantitatively investigated. Clarifying the association between the perception of PCUs and overall satisfaction with received care can provide valuable clues as to how health care providers should offer information about PCUs and issues that should be addressed when providing end-of-life care.

This survey, therefore, had the following aims: 1) to clarify the awareness and perceptions of PCUs among a representative sample of the Japanese general population and PCU-bereaved families, 2) to clarify the differences in perceptions of PCUs between these two groups, and 3) to explore the association between perceptions of PCUs and overall satisfaction with received care among PCU-bereaved families.

Methods

Subjects

This study was part of a nationwide survey, and the protocol has been described in detail previously.¹⁵ We initially identified four target areas to obtain a wide geographic distribution for the nationwide sample; these comprised an urban prefecture (Tokyo) and three mixed

urban-rural areas (Miyagi, Shizuoka, and Hiroshima). A cross-sectional questionnaire survey was performed in a sample of the general population selected by stratified two-stage random sampling and a sample of bereaved families who actually received specialized inpatient palliative care at one of 12 PCUs (PCU-bereaved families). We initially identified 5,000 subjects within the general population (that is, the nonbereaved general population and the bereaved general population) using stratified two-stage random sampling of residents in the four areas. We mailed questionnaires to potential participants in March 2004 and sent a reminder postcard two weeks later.

To identify bereaved family members, we initially identified all 37 PCUs in the four areas as potential participating institutions. We then approached the 18 PCUs with available collaborative researchers. Ultimately, 12 of the PCUs (two in Miyagi, five in Tokyo, two in Shizuoka, and three in Hiroshima) agreed to participate in the survey. Primary care physicians identified bereaved families in which the caregiver fulfilled the following inclusion criteria: 1) primary caregiver of an adult patient with cancer, 2) older than 20 years, 3) capable of replying to a self-reported questionnaire, 4) aware of the diagnosis of malignancy, and 5) without serious psychological distress as determined by the physician. We mailed self-report questionnaires to potential participants in August 2004, and resent them in October 2004 to those who did not respond; we requested that the primary caregiver filled in the questionnaire.

The protocol was approved by the institutional review board of each participating PCU, and met the requirements of the Helsinki Declaration.

Questionnaire (Available from the Authors)

The questionnaire was constructed through an extensive literature review,^{4-9,13} expert consensus among the authors, and on the basis of a previous study.¹⁰ We investigated three topics in this survey: 1) public awareness of PCUs, 2) perceptions of PCUs, and 3) overall satisfaction with received specialized inpatient palliative care. In addition, we investigated respondents' age and gender. The general population was asked whether they had been bereaved through cancer within the previous 10 years. PCU-bereaved families were asked about length of

hospital stay, time since the patient's death, and the level of the patient's physical distress on a five-point Likert-type scale (1: not distressed at all, 2: not too distressed, 3: unsure, 4: distressed, 5: very distressed). Despite the possibility of a recall bias, we selected 10 years as the limit of experience of bereavement through cancer in the general population, because a limit of five years yielded essentially the same conclusion in this survey.

We asked the general population to rate their level of awareness of PCUs on a four-point Likert-type scale (1: no knowledge, 2: some knowledge, 3: moderate knowledge, 4: considerable knowledge).

We asked participants who identified themselves as having at least some knowledge of PCUs to rate their levels of agreement with 10 statements regarding a PCU on a five-point Likert-type scale (1: strongly disagree, 2: disagree, 3: unsure, 4: agree, 5: strongly agree). The statements were "supports patients in living peacefully," "supports patients in living with dignity," "provides care for families," "provides compassionate care," "alleviates pain," "expensive," "provides no medical treatments," "a place where patients are isolated from the community," "a place where people only wait to die," and "shortens the patient's life."

PCU-bereaved families were asked to rate the levels of overall satisfaction with received specialized palliative care on a seven-point Likert-type scale (1: very dissatisfied, 2: dissatisfied, 3: somewhat dissatisfied, 4: unsure, 5: somewhat satisfied, 6: satisfied, 7: completely satisfied).

Analyses

Initially, we clarified public awareness of PCUs using descriptive statistics. Then, we confirmed similar distributions of variables between the four areas sampled, and explored factors associated with public awareness of PCUs using univariate and multivariate regression analyses. The independent variables were age, gender, and experience of bereavement through cancer. Next, perceptions were analyzed using descriptive statistics for the two study groups (the general population and PCU-bereaved families) and compared the mean between two groups using a *t*-test. We explored the factors that affect perceptions of PCUs using *t*-tests, linear regression, and

analysis of variance, as appropriate. The independent variables were age and gender (for both groups), levels of awareness of PCUs and experience of bereavement due to cancer (only for the general population), and length of PCU stay, time since the patient's death, institution (as data were collected regarding 12 PCUs), and level of patient's physical distress (only for PCU-

bereaved families). These analyses were conducted separately for the general population and PCU-bereaved families. Finally, we explored the correlation between perceptions of PCUs and overall satisfaction with received care using Spearman's rank correlation. As a large sample size may result in an excess of statistically significant results ($P < 0.05$), we have mainly described "clinically significant" results for which the effect size (ES) was over 0.5.¹⁶ This criterion indicates that the mean value difference as an absolute figure between two extreme categories was over half of the pooled standard deviation.

All analyses were performed using the SAS Statistical Package (version 9.1). Significance level was set at $P < 0.05$ (two-tailed).

Results

Of the 5,000 questionnaires sent to the general population, 26 were undeliverable and 2,670 were returned to the authors. Among these respondents, eight refused to participate, 14 were excluded due to missing data, and 2,548 responses were analyzed (effective response rate, 51%). Among the respondents from the general population, 25% ($n = 649$) had lost family members from cancer during the previous 10 years. There were no differences in gender and age between these respondents and the general population according to the vital statistics data for 2003.¹⁷

Among the 866 respondents from PCU-bereaved families considered as potential participants, 72 were excluded due to serious psychological distress ($n = 30$), lack of competent adult family members ($n = 17$), and other reasons. Of 794 questionnaires sent to the remaining bereaved families, 56 were undeliverable and 552 were returned to the authors. Within this group, 27 individuals refused to participate, 12 were excluded due to missing

data, and 513 responses were analyzed (effective response rate, 70%). Comparing the backgrounds of respondents and nonrespondents revealed no differences in gender, age, or time since patient's death, but a significant difference in the length of patient's hospital stay (mean = 44 vs. 36 days). Table 1 summarizes the backgrounds of the respondents.

Public Awareness of PCUs (Table 2)

Although 4.3% of respondents answered "very knowledgeable," 34% answered "moderate knowledge," 38% reported having "some knowledge," and 24% had "no knowledge" of PCUs. Female respondents were more likely to be knowledgeable about PCUs (standardized partial regression coefficient; $\beta = 0.18$, $P < 0.001$), while experience of bereavement due to cancer was not significantly associated with knowledge of PCUs ($\beta = 0.02$, $P = 0.15$).

Perceptions of PCUs (Table 3)

Overall, 67%–72% of the general population and 75%–87% of PCU-bereaved families agreed that a PCU "supports patients in living peacefully," "supports patients in living with dignity," "provides care for families," "provides compassionate care," and "alleviates pain." On the other hand, approximately 30% of the general population and 30%–45% of PCU-bereaved families agreed that a PCU "provides no medical treatments," "isolates patients from the community," and "is a place where people only wait to die." In addition, 61% of the general population and 41% of PCU-bereaved families agreed that PCUs were "expensive" and 8% of the general population and 17% of PCU-bereaved family thought that they "shorten the patient's life." PCU-bereaved families were clinically significantly more likely than the general population to agree that a PCU "provides care for families," "provides compassionate care," "alleviates pain," and "provides no medical treatments." However, they were less likely to agree that PCUs are "expensive."

Factors Associated with Perceptions of PCUs

Among the general population, better awareness of PCUs was clinically significantly associated with agreement that PCUs "provide care for families" (ES = 0.53, $P < 0.001$), while other factors (i.e., age, gender, and

Table 1
Demographic Backgrounds of the Respondents

	General Population (n = 2,548)		Bereaved Families from PCUs (n = 513)	
	%	n	%	n
Age (years)				
<49	25	613	21	104
50–59	30	758	29	144
60–69	28	710	29	146
>70	17	420	22	110
Gender				
Male	47	1,186	32	158
Female	53	1,326	68	343
Bereavement experience ^a	25	649	100	513
Length of hospital stay: days (mean ± SD/median)			44 ± 49/29	
Time since patient's death: months (mean ± SD/median)			28 ± 7/28	
Satisfaction with received care				
Very dissatisfied			1.4	7
Dissatisfied			1.6	8
Somewhat dissatisfied			2.8	14
Unsure			7.5	37
Somewhat satisfied			15	76
Satisfied			32	160
Very satisfied			27	134
Completely satisfied			12	60

SD = standard deviation; PCUs = palliative care units.

^aExperience of losing a family member from cancer during the previous 10 years.

bereavement experience) were not significantly associated with perceptions (data not shown).

Among the PCU-bereaved families, the respondents who thought their patient had experienced less pain were clinically significantly likely to agree that a PCU "alleviates pain" (ES = 0.56, $P < 0.001$). There were also significant differences among institutions with regard to perceptions that a PCU was "a place where people only wait to die" (ES = 1.02, $P < 0.001$), was "expensive" (ES = 1.01, $P < 0.001$), "provides no medical treatments" (ES = 0.94, $P < 0.001$), "isolates patients from the community" (ES = 0.82, $P = 0.02$), "supports patients in living with dignity" (ES = 0.73, $P = 0.005$), "supports patients in living peacefully" (ES = 0.72, $P = 0.03$), and "shortens the patient's life" (ES = 0.70, $P = 0.01$). Other variables, such as age and gender, were not significantly associated with agreement with any statement (data not shown).

Association Between Perceptions of PCUs and Overall Satisfaction with Received Care (Table 4)

Four statements of perception of PCUs had moderate correlations with overall satisfaction:

"provides compassionate care," "provides care for families," "supports patients in living peacefully," and "supports patients in living with dignity." Another four statements had weak correlations with overall satisfaction: "alleviates pain," "a place where patients are isolated from the community," "shortens the patient's life," and "a place where people only wait to die." Neither agreement with "expensive" nor with "provides no medical treatments" was significantly correlated with overall satisfaction.

Discussion

This study is, to our knowledge, the first large population-based survey to clarify the

Table 2
General Population Awareness of PCUs (n = 2,548)

Awareness of PCUs	%	n
No knowledge	24	591
Some knowledge	38	936
Moderate knowledge	34	855
Considerable knowledge	4.3	106

PCUs = palliative care units.

Table 3
Perceptions of PCUs

	General Population (n = 2,548)				Bereaved Families from PCUs (n = 513)				PValue ^a	ES
	Agree (%)	Somewhat Agree (%)	Mean	SD	Agree (%)	Somewhat Agree (%)	Mean	SD		
Supports patients in living peacefully	37	35	4.03	1.06	45	30	4.12	1.23	0.067	0.09
Supports patients in living with dignity	32	38	3.94	0.93	38	38	4.12	0.84	<0.0001	0.19
Provides care for families	29	38	3.90	1.32	54	33	4.38	1.38	<0.0001	0.53
Provides compassionate care	28	39	3.88	1.18	56	30	4.36	1.21	<0.0001	0.52
Alleviates pain	32	36	3.87	1.03	57	30	4.40	0.85	<0.0001	0.52
Expensive	30	31	3.79	0.94	18	23	3.14	0.98	<0.0001	-0.58
Provides no medical treatments	12	20	3.00	1.03	29	25	3.59	1.32	<0.0001	0.49
Isolates patients from the community	7.5	21	2.80	0.90	8.4	21	2.75	0.81	0.40	-0.04
A place where people only wait to die	11	20	2.76	1.19	18	22	3.03	1.24	<0.0001	0.20
Shortens the patient's life	2.8	5.3	2.27	0.92	7.4	9.2	2.44	0.87	0.006	0.15

PCUs = palliative care units; SD = standard deviation; ES = effect size.
^at-test.

levels of awareness and perceptions of PCUs in Japan. Interpretation of the findings depends first on an understanding of the health care system and palliative care system in Japan.

In Japan, each person is obligated to enroll in a national health insurance system. The system is designed so that if a person moves, the insured person is expected to pay the same amount for the same amount of care. Medical fees are set and regulated by the government, and the maximum out-of-pocket cost for the patient is 30% of any such fee. In addition, to curb the expense of high-cost care, the government has instituted a monthly cap of 80,100 yen (670 US\$) co-payment. Meals and extra charges for private rooms are not

covered by the national health insurance system. The system provides the insured person with total freedom to choose any physician, hospital, or clinic.

Enhancement of palliative care for any Japanese citizen with cancer is a priority in Japan; thus, the Ministry of Health, Labor and Welfare supports dissemination of specialized palliative care services, with services provided by PCUs. PCUs have been covered by national medical insurance since 1991. To be approved as a PCU, institutions must fulfill the ministry's requirements regarding staff numbers, facilities, and equipment.

PCUs provide intensive symptom control and end-of-life care for patients with incurable cancer and their families, and the amount of money paid by national health insurance to medical institutions is fixed, irrespective of the treatment provided to patients. An approved PCU is reimbursed at the rate of 37,800 yen (315 US\$) per patient per day by the health insurance system. The maximum out-of-pocket cost for the patient is 30%, 11,340 yen (95 US\$). The majority of PCUs belong to general hospitals and have interdisciplinary teams, including attending physicians, nurses, and other specialists.¹⁸

Consistent with previous findings in Canada in 2004,⁹ public awareness of specialized palliative care services has remained insufficient in Japan. Moreover, experience of bereavement

Table 4
Association Between Overall Satisfaction with Received Care and Perceptions of PCUs

	n = 513	
	R ^a	P-value
Provides compassionate care	0.49	<0.0001
Provides care for families	0.49	<0.0001
Supports patients in living peacefully	0.43	<0.0001
Supports patients in living with dignity	0.40	<0.0001
Alleviates pain	0.30	<0.0001
Isolates patients from the community	-0.27	<0.0001
A place where people only wait to die	-0.27	<0.0001
Shortens the patient's life	-0.23	<0.0001
Expensive	-0.11	0.01
Provides no medical treatments	-0.06	0.19

^aSpearman's rank correlation coefficient.