Statistical Analyses

Before statistical analysis, an explanatory factor analysis with promax rotation was conducted to order the questions and help with their interpretation. These results were used to order the questions and word them as listed.

To compare attitudes between the 2 respondent groups, overall percentages of "strongly agree," "agree," and "slightly agree" answers were calculated and compared using the χ^2 test. Given the marked differences in responses depending on clinical setting,[13] responses were also compared by clinical setting by using the χ^2 test.

Data for physicians and nurses affiliated with cancer centers and general hospitals as oncologists and oncology nurses were aggregated and compared with those for physicians and nursing staffs of PCUs. For statistical tests, 2-tailed P values were calculated, with values of $P < .05$ considered statistically significant. Owing to the large sample size, we considered an absolute 20% difference in responses as clinically significant. All analyses were performed using the statistical package SAS 9.1 (SAS Institute, Cary, NC).

Results

Characteristics of Participants

Questionnaires were mailed to 1123 physicians, and responses were received from 595. Eleven did not meet the eligibility criteria and were excluded, leaving 584 responses for the final analysis (validated response rate, 53%). Questionnaires were mailed to 4210 nurses, and responses were received from 3515. A total of 187 were excluded because of missing values, leaving 3328 for final analysis (validated response rate, 79%). Participant characteristics are summarized in Table 1. General hospital settings accounted for a higher proportion of physicians (physicians, 46%; nurses, 35%), and cancer centers accounted for more nurses (physicians, 38%; nurses, 47%). The proportion of PCU settings was about the same (physicians, 15%; nurses, 18%).

Table 1. Participant Characteristics

Characteristic[a]	Physicians (n = 584)	Nurses (n = 3328)
Age	42 (43 ± 8.5)	31 (33 ± 8.7)
Sex		
Female (%)	6.0	99
Years of clinical experience	16 (17 ± 8.3)	9 (11 ± 8.6)
Clinical setting		
General hospital	46	35
Cancer center	38	47
Palliative care unit	15	18
Specialty (%)[b]		
Surgery	36	
Gastroenterology	16	
Internal medicine, hematology, medical oncology	15	
Palliative medicine	10	
Respiratory medicine	8	
Radiology	2.9	
Gynecology	2.7	
Urology	2.4	
Otolaryngology	1.9	
Orthopedics	1.7	
Anesthesiology	1.2	
Neurosurgery	0.3	
Dermatology	0.3	
Patient deaths during the past year (n)	10 (22 ± 35)	22 (40 ± 42)

a. Continuous data are presented as median ± SD.
b. Physicians only.

Attitudes Toward Terminal Hydration

When responses of nurses and physicians were compared (Table 2), more than 70% of physicians and nurses agreed with the statements "determining the medical indications for artificial hydration is difficult" and "patients have the right to refuse artificial hydration." In contrast, less than 30% agreed with the statements "artificial hydration alleviates delirium," "withholding artificial hydration leads to loss of patient trust," "withholding artificial hydration leads to loss of family trust," "withholding artificial hydration leads to undertreatment in compromised patients," "withholding artificial hydration shortens patient survival," and "withholding artificial hydration may be criticized by colleagues." Responses to the other statements differed between physicians and nurses, although with a clinically significant difference for 1 statement only, "artificial hydration alleviates the sensation of thirst" (difference, 23%; $P < .0001$). In addition, although not clinically significant, physicians tended to agree with the statement "artificial hydration is a component of minimum standards of care" (difference, 18%; $P < .0001$).

When responses from physicians were compared among clinical settings (Table 3), oncologists agreed to a clinically significant degree with the statements "artificial hydration alleviates the sensation of thirst"

Table 2. Attitudes Toward Artificial Hydration Therapy for Terminally Ill Cancer Patients Between Physicians and Nurses

	Physicians (Phy) (n = 584)	Nurses (N) (n = 3328)	Difference (Phy-N)	P
Belief that artificial hydration alleviates physical symptoms				
Artificial hydration alleviates the sensation of thirst	43	20	23	<.0001
Artificial hydration alleviates fatigue	34	19	14	<.0001
Artificial hydration alleviates delirium	20	11	10	<.0001
Belief that withholding artificial hydration alleviates physical symptoms				
Withholding artificial hydration alleviates the burden of urination	51	57	−7	0.002
Withholding artificial hydration alleviates nausea/vomiting	46	35	11	<.0001
Withholding artificial hydration alleviates cough/sputum/dyspnea	52	48	4	0.08
Perception of loss of trust by withholding artificial hydration				
Withholding artificial hydration leads to loss of patient trust	23	19	4	0.034
Withholding artificial hydration leads to loss of family trust	26	21	5	0.010
Perception of guilt with withholding artificial hydration				
Withholding artificial hydration leads to undertreatment in compromised patients	8	5	4	0.001
Withholding artificial hydration shortens patient survival	29	23	6	0.002
Withholding artificial hydration may be criticized by colleagues	10	5	5	<.0001
Belief that artificial hydration is a component of minimum care				
Artificial hydration is a component of minimum standards of care	40	22	18	<.0001
Perception of difficulty concerning decision making for artificial hydration				
Determining the medical indications for artificial hydration is difficult	72	72	0	0.81
Patients have the right to refuse artificial hydration	96	95	1	0.18
Belief that maintaining a venous route is a burden				
Maintaining a venous route is a burden on the patient	65	71	−6	0.003

NOTE: Values denote the proportion of summed "strongly agree," "agree," and "slightly agree" responses.

(difference, 26%; $P < .0001$), "artificial hydration alleviates fatigue" (difference, 24%; $P < .0001$), "withholding artificial hydration shortens patient survival" (difference, 23%; $P < .0001$), and "artificial hydration is a component of minimum standards of care" (difference, 30%; $P < .0001$). In addition, PCU physicians agreed to a clinically significant degree with the statements "withholding artificial hydration alleviates the burden of urination" (difference, −38%; $P < .0001$), "withholding artificial hydration alleviates nausea/vomiting" (difference, −50%; $P < .0001$), and "withholding artificial hydration alleviates cough/sputum/dyspnea" (difference, −46%; $P < .0001$).

For nurses, PCU nurses agreed to a clinically significant degree with the statements "withholding artificial hydration alleviates nausea/vomiting" (difference, −34%; $P < .0001$) and "withholding artificial hydration alleviates cough/sputum/dyspnea" (difference, −43%; $P < .0001$).

Discussion

This study details the broad range of attitudes toward artificial hydration for terminally ill cancer patients obtained by using an identical questionnaire sent to physicians and nurses working in a variety of clinical settings. Several responses differed significantly between professions and among clinical settings.

A higher percentage of physicians than nurses answered that artificial hydration alleviates the sensation of thirst. Given that several studies have shown that the sensation of thirst is not improved by hydration therapy,[6,22] this result indicates a misconception on this point among Japanese physicians, particularly oncologists. The reason for the nurses' low agreement might be due to clinical experience that mouth care or sips of liquids are an effective intervention.[1] It is important to educate physicians that mouth care is more effective than artificial hydration in alleviating the sensation of thirst.

Table 3. Attitudes Toward Artificial Hydration Therapy for Terminally Ill Cancer Patients (Comparison Among Clinical Settings)

	Physicians, Oncologist (O) and PCU				Nurses, Oncology (O) and PCU			
	Onc (n = 493)	PCU (n = 90)	Diff (O-PCU)	*P*	O (n = 2735)	PCU (n = 593)	Diff (O-PCU)	*P*
Belief that artificial hydration alleviates physical symptoms								
Artificial hydration alleviates the sensation of thirst	47	21	26	<.0001	21	17	4	.028
Artificial hydration alleviates fatigue	37	13	24	<.0001	21	13	8	<.0001
Artificial hydration alleviates delirium	21	18	3	0.52	11	9	2	.15
Belief that withholding artificial hydration alleviates physical symptoms								
Withholding artificial hydration alleviates the burden of urination	45	82	−38	<.0001	55	66	−11	<.0001
Withholding artificial hydration alleviates nausea/vomiting	39	89	−50	<.0001	29	63	−34	<.0001
Withholding artificial hydration alleviates cough/sputum/dyspnea	45	91	−46	<.0001	41	83	−43	<.0001
Perception of loss of trust by withholding artificial hydration								
Withholding artificial hydration leads to loss of patient trust	25	11	14	0.004	21	11	10	<.0001
Withholding artificial hydration leads to loss of family trust	28	17	11	0.025	23	16	7	.001
Perception of guilt with withholding artificial hydration								
Withholding artificial hydration leads to undertreatment in compromised patients	9	3	6	0.06	5	4	1	.18
Withholding artificial hydration shortens patient survival	33	10	23	<.0001	25	15	10	<.0001
Withholding artificial hydration may be criticized by colleagues	9	17	−8	0.025	5	3	2	.09
Belief that artificial hydration is a component of minimum care								
Artificial hydration is a component of minimum standards of care	45	14	30	<.0001	24	12	12	<.0001
Perception of difficulty concerning decision making for artificial hydration								
Determining the medical indications for artificial hydration is difficult	74	66	8	0.11	72	70	2	.24
Patients have the right to refuse artificial hydration	96	98	−2	0.40	95	95	0	.70
Belief that maintaining a venous route is a burden								
Maintaining a venous route is a burden on the patient	63	78	−15	0.007	73	66	7	.001

NOTE: PCU = palliative care unit.

Physicians tended to answer that artificial hydration represented a minimum standard of care.[23] Physicians often consider that hydration therapy has a symbolic role as a personal intervention by the medical expert for the terminally ill patient.[8,24] In contrast, nurses would more likely attempt other nursing interventions to alleviate the burden of artificial hydration. These differences of view might arise from a difference in attitudes toward minimum standards of care. Results for several of the statements show a lack of concordance among physicians and nurses.[25] These differences of belief would result in differences in the conduct of artificial hydration.[12,13] Effective hydration therapy thus requires discussion among patient-centered teams and an emphasis on individualized decision making.[15,19,26]

Among physicians, responses to several statements differed between oncologists and PCU physicians. The PCU physicians more clearly recognized that withholding artificial hydration palliates physical symptoms such as cough/sputum/dyspnea and nausea/vomiting, likely because of their greater first-hand experience with the effectiveness of withholding hydration therapy for terminally ill patients. The PCU physicians also disagreed that hydration therapy represents a minimum standard of care. The PCU physicians would similarly be more skilled in other medical or nonmedical treatments for patients than oncologists. Japanese oncologists might not only prescribe medications and fluid but might also have views on caring for patients that would in turn allow them to realize again their own role for terminally ill patients through the provision of alternative methods of hydration, alternative care, and in-depth communication as holistic care. In addition, data on artificial hydration is still insufficient, and further evidence from randomized clinical trials or well-designed observational studies is required.[3]

Among nurses, PCU nurses had greater recognition that withholding artificial hydration palliated physical symptoms such as cough/sputum/dyspnea and nausea/vomiting. Similar to physicians, oncology nurses require greater understanding of the effectiveness of withholding artificial hydration. In contrast to physicians, however, oncology and PCU nurses showed only small differences in their understanding of the clinical effectiveness of hydration therapy, likely because of their greater personal contact with patients.

The present study has several limitations. The response rate for physicians was relatively low. Nevertheless, this figure is common in Japanese opinion surveys of physicians. Further, questions concerning general attitudes may be confounded by answers that depend on individual scenarios, including the care of patients with complications such as bowel obstruction, ascites, and pleural effusion.

Conclusion

Our results show that attitudes toward several statements on artificial hydration differ between physicians and nurses and among clinical settings. They further emphasize the importance of discussion among patient-centered teams and of individualized decision making. As the differences are attributable to knowledge of artificial hydration for terminal cancer patients, oncologists should place greater emphasis on the opinions of palliative care specialists. Overall, medical practitioners caring for terminal and palliative care patients should consider not simply the providing or withholding of hydration therapy, but rather a broader range of views on hydration therapy, with a focus on effective alternative interventions.

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

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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.

Keywords Palliative care · Hospice · Neoplasms · Referral and consultation · Qualitative research

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-

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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*	%	
Patient- and family-related barriers									
(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
General ward medical staff-related barriers									
(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
PCU-related barriers									
(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 falleviating 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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Nurse Views of the Adequacy of Decision Making and Nurse Distress Regarding Artificial Hydration for Terminally Ill Cancer Patients: A Nationwide Survey

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We evaluated nurse views on the adequacy of decision-making discussion among nurses and physicians regarding artificial hydration for terminally ill cancer patients and nurse distress arising from artificial hydration issues, as well as factors related to this distress. A self-administered questionnaire consisting of 4 questions about nurse views of discussions regarding artificial hydration and 6 questions about nurse distress arising from artificial hydration issues was distributed in participating institutions in October 2002 and returned by mail. A total of 3328 responses (79%) were analyzed. Almost half of the nurses felt that discussion of terminal hydration issues was insufficient. Among responses, 39% of oncology nurses and 78% of palliative care unit (PCU) nurses agreed that patients and medical practitioners discuss the issue of artificial hydration adequately, and 49% and 79%, respectively, agreed that medical practitioners discuss the issue of artificial hydration with other physicians adequately. As for distress on behalf of patients and families who refuse artificial hydration, 44% of oncology nurses and 57% of PCU nurses experienced such distress for patients, and 19% and 28% did so for families, respectively. Furthermore, 48% of oncology nurses and 47% of PCU nurses experienced distress arising from disagreements among medical practitioners about withholding artificial hydration, whereas 44% and 43% experienced distress about medical practitioners refusing artificial hydration, respectively. Discussion among care providers 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.

Keywords: palliative care; attitude; fluid therapy; nurses; decision making; questionnaires

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The views expressed in this article are those of the authors alone.

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Nurses encounter many difficulties in the care of terminally ill patients.[1-4] In Japan, Sasahara et al reported that 92% of nurses were distressed by insufficient opportunities to discuss care with physicians. Morita et al investigated the emotional burden faced by nurses in palliative sedation therapy and emphasized the importance of a team approach to resolving conflicting opinions, especially between physicians and nurses.[5] Regarding the team approach to care, Maeyama et al reported that perceptions of the practice of team care differ between physicians and nurses and that nurses regarded team care as insufficient in Japan.[6] Together, these 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.[7] Other researchers have also argued the relevance of considering the wishes of patients and families and of respecting these wishes.[8-11] 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[12] or a lack of food intake often increases their anxiety.[7] Moreover, some patients and families may feel that the patient has been abandoned if hydration is withheld.[13]

In addition, attitudes toward hydration therapy differ between physicians and nurses.[14-16] 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,[10,16,17] 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.[18] Scientific uncertainty regarding the effectiveness of terminal hydration,[19,20] as well as patient and family requirements[9,11,21] and their lack of involvement in medical decisions regarding terminal hydration,[18] 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.[16] 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,[15,22] 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.[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 = pallative 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

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

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Abstract

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

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

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

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

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

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