Australia, <sup>11</sup> and this value was 66% for Singapore. <sup>12</sup> Sixty-five percent of patients with cancer utilized hospice care in the United States in 2002. <sup>13</sup> We note that it is difficult to compare these data directly because the definitions and ways of providing the services were different among the countries.

Another important finding of this survey was that utilization of hospital-based palliative care teams was much more common than utilization of specialized palliative care services, palliative care outpatient clinics, or community palliative care. This situation has most likely arisen because the government policy for specialized palliative care service has been hospital oriented in Japan. In contrast, in the UK survey, <sup>10</sup> described above, almost the same proportion of patients with cancer utilized home palliative care as that which utilized a hospital-based palliative care team. We suggest that it would be beneficial to facilitate an intensive transition toward outpatient clinic and home care in Japan to provide continuity in the specialized palliative care service from the early stage of the disease.

This study had some limitations. First, the survey was conducted using a self-reporting questionnaire and, therefore, self-reporting bias would be present. Second, we might have overestimated the number of patients with cancer who utilized a specialized palliative care service because we could not avoid duplicates in this survey. Third, we might have underestimated the number of institutions providing specialized palliative care service and the utilization of specialized palliative care services among patients with cancer due to following reasons: (1) this survey did not cover home palliative care because of the lack of a definition or nationwide organization for this type of service and (2) this survey might not cover all institutions that provided specialized palliative care service although we made every effort to mail the survey questionnaire to as many institutions as possible.

In conclusion, the results of this first nationwide survey of specialized palliative care services in Japan suggest that about one-quarter of patients with cancer utilized a specialized palliative care service, and the types and quantity of specialized palliative care service have increased explosively in the past decade.

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The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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## The Palliative Care Knowledge Questionnaire for PEACE: Reliability and Validity of an Instrument To Measure Palliative Care Knowledge among Physicians

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#### **Abstract**

*Background:* In Japan, a nationwide palliative care education program for primary palliative care (the Palliative care Emphasis program on symptom management and Assessment for Continuous medical Education: PEACE) was established in 2008. Effective delivery of such programs relies on adequate evaluations of program efficacy; however, such an instrument does not exist.

Objective: This study aimed to develop and validate a measurement tool to quantify knowledge level of physicians about broader areas of palliative care, by which the effect of an education program could be measured.

Methods: We conducted a cross-sectional, anonymous, self-administered questionnaire survey with a group of 801 conveniently sampled physicians in October 2010. To examine the test-retest reliability of items and domains, the questionnaire was reissued two weeks after the first survey was completed. This study used psychometric methods, including item response theory, intraclass correlation coefficients, and known-group validity.

**Results:** The response rate was 54% (n=434). We included 33 items across the following 9 domains: (1) philosophy of palliative care, (2) cancer pain, (3) side effects of opioids, (4) dyspnea, (5) nausea and vomiting, (6) psychological distress, (7) delirium, (8) communication regarding palliative care, and (9) community-based palliative care. For these items, the intraclass correlation was 0.84 and the Kuder-Richardson Formula 20 (KR-20) test of internal consistency was 0.87. There was a significant difference in the scores between palliative care specialists and other physicians.

*Conclusions:* We successfully validated a newly developed palliative care knowledge questionnaire to evaluate PEACE effectiveness (PEACE-Q). The PEACE-Q could be useful for evaluating both palliative care knowledge among physicians and education programs in primary palliative care.

#### Introduction

PALLIATIVE MEDICINE has become an essential part of cancer care in the past 30 years. To achieve high-quality palliative care, education for physicians is crucial, but most physicians worldwide including in Japan agree that current undergraduate and postgraduate programs do not provide sufficient education on palliative care.

Recently, several countries established nationwide palliative care education programs. $^{3,4}$  In the United States, the

Education for Physicians in End-of-life Care (EPEC<sup>TM</sup>) Project<sup>3</sup> aimed to increase physician knowledge about palliative care, with 62% of the participants attaining improved knowledge. In Japan, the Palliative care Emphasis program on symptom management and Assessment for Continuous medical Education (PEACE) was established in 2008, <sup>2,5</sup> with more than 1000 PEACE education opportunities and more than 20,000 participating physicians reported throughout Japan from 2008 to 2010. <sup>6</sup> To sustain the efficacy and significance of such programs, timely adjustment based on adequate

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and ongoing evaluations of the program is essential. Such evaluations should assess participant achievement and the effectiveness of the program among participants.

To date, the palliative care knowledge test (PCKT) was developed to measure the levels of knowledge about palliative care. The PCKT consists of five domains: philosophy, pain, dyspnea, psychiatric symptoms, and gastrointestinal symptoms. However, the PCKT was originally designed to quantify knowledge about palliative care among general health care professionals, especially nurses; and consequently, the reliability and validity of PCKT was not formally investigated in physicians. In addition, existing measurement tools to measure the knowledge of physicians in palliative care literature focus on pain management, and no instruments have been established to measure knowledge level of physicians about broader areas of palliative care. 8–10

The primary aim of this study was to develop and validate a measurement tool to quantify knowledge level of physicians about broader areas of palliative care, by which the effect of education programs could be measured.

#### Methods

We conducted a confidential and anonymous questionnaire survey among physicians, consisting of two phases: (1) instrument development and (2) psychometric analysis and selection of the 33 items for the final instrument. The ethical and scientific validity of this study was approved by the institutional review board of Saku Central Hospital. Consent to participate was indicated by the completion and return of the questionnaire.

#### Development phase

Initially, 12 palliative care specialists generated a total of 83 items for an item pool based on all modules of the PEACE program. Each such module includes nine domains and thus we designed our measurement instrument to include all these domains: (1) concept and philosophy of palliative care, (2) cancer pain, (3) side effects of opioids, (4) dyspnea, (5) nausea and vomiting, (6) psychological distress, (7) delirium, (8) communication, and (9) community-based palliative care.

To confirm the content validity, we adopted a modified Delphi method<sup>11</sup> with another group of 10 physicians (9 palliative care specialists and 1 psychiatrist). The experts evaluated the appropriateness of each item according to nine grades from 1 (inappropriate) to 9 (appropriate). If a participant rated the grade as less than 6, we asked him or her the reason. Items rated by eight or more members at 7 or more were selected; the remaining items were modified according to the members' opinions and then reevaluated. Following two such content-setting rounds we generated a provisional version of the instrument, the 79-item PEACE-Q (palliative care knowledge questionnaire for PEACE). Each question requires potential responses of right, wrong, and unsure.

#### Validation phase

The survey was carried out in October 2010 on 735 physicians from 15 conveniently sampled hospitals. The inclusion criterion was registered physicians whose specialty was not palliative medicine. In addition, to explore the known-group validity, 66 palliative care specialists were recruited. For this

study, "palliative care specialist" was defined as a responsible physician in a certified palliative care unit belonging to Hospice Palliative Care Japan.

#### Procedures

The questionnaire with an accompanying cover letter was distributed to physicians by mail. Completed questionnaires were collected in a box specifically provided in each participating hospital. The survey for test-retest examination was conducted on the subjects who had consented to participate during the first survey in three institutions with two-week interval administrations. For the 79-item PEACE-Q, we then analyzed and compared physician backgrounds—i.e., age, gender, specialty, institutions, years of clinical experience, the number of terminally ill cancer patients seen in the past year, the number of cancer deaths per year, the number of patients they prescribed opioids to in the past year, and whether they participated in a PEACE program. No reminder or reward was used.

#### Statistical analysis and item selection

For analyses, 'unsure' responses were regarded as incorrect. First, to assess feasibility we calculated the percentage of missing data for each question; if the missing value accounted for more than 1% of all data, that item was regarded as inappropriate. Next, to assess sensitivity we calculated the percentage of correct answers for each question; if correct answers accounted for more than 90% of all data, that item was regarded as inappropriate. Third, to examine the testretest reliability of each item, the kappa coefficients were calculated (cutoff: kappa coefficient of 0.3). Fourth, we estimated the difficulty and discrimination based on the twoparameter logistic Item Response Theory (IRT) model. IRT models are used for the statistical estimation of parameters that represent the magnitude of a latent trait attributable to the items. An advantage of IRT is that it potentially enables a researcher to improve the precision and reliability of an assessment.12 We then determined the precision (cutoff: discrimination of 0.5). Finally, to confirm the content validity, the first 12 experts discussed the appropriateness of each item from both statistical and clinical viewpoints: (1) items in which sensitivity was likely to be higher and (2) items that could be viewed as providing lessons. Through this process, 33 items were selected to comprise the PEACE-Q.

#### Reliability and validity

Internal consistency was determined by calculating the Kuder-Richardson Formula 20 (KR-20) index. The test-retest reliability was explored by calculating intraclass correlation coefficients. To explore known-group validity, the unpaired t-test was used to determine a potential statistically significant difference in the total score of the PEACE-Q (33 items) and for each domain, between the palliative care specialists and the other physicians.

Statistical analysis was performed using statistical software SAS (SAS version 9.1; SAS Institute Inc., Cary, NC). The significance level was set at P < 0.05 (two-tailed).

#### Results

Among 801 physicians included in the validation study, 434 responses (54%) were obtained and analyzed. For the

test-retest investigation, 124 physicians agreed to participate and a total of 44 responses (35%) were obtained and analyzed.

The subject characteristics are summarized in Table 1. Approximately 70% were male, with an average of 16 years of clinical experience. Among them, 51% experienced more than 21 terminally ill cancer patients in the past year, while 17% cared for less than 5 cancer patients.

#### Item selection

Missing values totaled more than 1% in three items (1.2% each). However, we gave priority to content validity over psychometric properties based on the discussion among experts; thus, these three items were included in the PEACE-Q.

The percentage of correct answers ranged from 19% to 99% across the items, with the highest percentage of correct answers (99%) for, 'Oral care should not be offered to the patients with nausea and vomiting, because mouth stimulation causes vomiting.' Eighteen items showed a correct response rate of 90% or more, and these items were excluded. There were no items with 10% or less correct response rate.

The kappa coefficient in the test-retest reliability of each item ranged from -0.04 to 0.85, and was 0.3 or less for 14 items. However, we gave priority to content validity over psychometric properties based on the discussion among experts, and 6 out of these 14 items were included.

The results of the item analysis and IRT are shown in Table 2. The difficulty in all items ranged from -2.76 to 0.29, with a discrimination of 0.69 to 2.67. We determined that a subject who correctly answered an item with high discrimination would also have a high total score, whereas for an item with poor discrimination, the percentage of correct answers for that item would not relate to the total score.

Based on the item analysis, IRT, and expert discussions, we determined 33 items for inclusion in the final version of PEACE-Q across the following 9 domains: (1) philosophy of palliative care, (2) cancer pain, (3) side effects of opioids, (4) dyspnea, (5) nausea and vomiting, (6) psychological distress, (7) delirium, (8) communication, and (9) community-based palliative care.

#### Reliability and validity

The KR-20 index of internal consistency was 0.87, and the intraclass correlation in the test-retest examination was 0.84. Regarding the known-group validity, there was a significant difference in the score for each domain as well as in the total score between palliative care specialists and other physicians (see Figure 1).

#### Discussion

This study validated an instrument to measure the levels of knowledge about palliative care among physicians. This measurement tool enables us to evaluate the ongoing effectiveness of the PEACE program. The instrument showed good internal consistency, test-retest reliability, and knowngroup validity.

PEACE-Q would be useful for measuring the level of palliative care knowledge that all physicians engaged in cancer treatment should have. Furthermore, it could be used to measure the efficacy of undergraduate education programs about palliative care.

Previous measurement tools for quantifying the effect of palliative care education programs for physicians showed insufficient evaluation of reliability and validity, <sup>13–16</sup> and none other than the PCKT addresses a broad knowledge of palliative care. <sup>7</sup> However, the psychometric properties of the PCKT were formally evaluated only among nurses. The PEACE-Q is a specific measure for physicians in both patient care and symptom management.

This study has several limitations. The tool was developed only for physicians who attend a PEACE-based seminar. In addition, several questions (2, 3, 31, 32, 33) are specifically about the Japanese medical system, and thus are not suitable for physicians in other countries; this limits the instrument transferability.

Table 1. Characteristics of Participants (N=434)

		•
	п	% <sup>1</sup>
Age, mean±SD	42±11	
Gender		
Male	306	70
Female	95	22
Specialty		
Internal Medicine	121	28
Surgery	75	17
Resident	50	12
Gynecology	12	2.8
Urology	12 12	2.8 2.8
Anesthesiology Other	106	2.6
	100	24-34
Institution	37	8.5
University Hospital over 400 beds	235	54
Hospital under 200 beds	47	11
Clinic	30	6.9
Other	43	9.9
Years of clinical experiences,	$16\pm10$	
mean±SD Number of terminally ill cancer p	ationts in the na	et wear
None	20	4.6
1–5	54	12
6–10	37	8.5
11–15	33	7.6
16–20	18	4.2
21–	219	51
Number of patients prescribed op	ioids in the pas	t year
None	49	11
1–5	75	17
6–10	68	16
11–15	40	9.2 5.3
16–20 21–	23 125	29
		27
Number of cancer deaths per year	r 47	11
None 1–5	112	26
6–10	64	15
11–15	53	12
16–20	18	4.2
21-	89	21
Whether they participated in a PE	ACE program	
Yes	92	21
No	301	69
1		

<sup>&</sup>lt;sup>1</sup>The percentages do not add up to 100% due to missing values.

Table 2. Item Analysis and Item Response Theory Analyses of the PEACE-Q (N=434)

			7 (C'-11		IRT
Questions		Correct answer (%)	k-coefficient (n = 44)	Difficulty	Discrimination
Philosophy of palliative care					
1 Palliative care is synonymous with terminal	care. F	88	0.69	-2.76	0.77
In Japan, 50% or less of the general population that, if they have cancer, they want to feel about receiving cancer treatment and living	secure	78	0.47	-1.54	0.97
severe pain.  The total consumption of opioids for pain is Japan than in the UK, Canada, and Germa		85	0.42	-1.48	1.49
Cancer pain					
When cancer pain is severe, one of the third-s of WHO's Pain Relief Ladder is used as a analgesic.	tep drugs T n initial	53	0.48	-0.15	1.41
5 When opioids are initially prescribed, all nor analgesics should be discontinued.	n-opioid T	87	0.49	-1.26	2.37
6 Morphine is used safely in a patient with ren	al failure. F	57	0.31	-0.32	1.20
7 The rescue dose of opioid is 5% of the total d	laily dose. F	64	0.74	-0.45	2.22
8 Because the tolerance does not occur for opi induced nausea, an antiemetic should be p	oid- F	83	0.43	-1.25	1.78
for all patients.  Total dose of daily opioids increases by 10% unpalliated.	if pain is F	55	0.85	-0.18	2.14
10 Opioid rotation or switching should be cons when it is difficult to increase the dose of due to adverse effects.		87	0.68	-1.20	2.67
11 About 10% of the patients with controlled by pain have breakthrough pain.	aseline F	49	0.58	0.00	2.57
12 Invasive dental procedures should be avoided bisphosphonate treatment.	ed during T	60	0.40	-0.68	0.69
Side effects of opioids					
13 Opioid-induced nausea and/or vomiting occord or more of patients taking opioids.		50	0.36	-0.04	1.11
14 It is necessary to use a laxative together with opioids, because most patients who take of experience constipation.	h oral T opioids	89	0.09	-2.12	1.13
15 Opioids cause addiction in 0.2% or less of capatients under careful monitoring.	ancer T	67	0.61	-0.59	1.73
Dyspnea			•		
16 If a patient has dyspnea, the PaO <sub>2</sub> of the patunder 60 Torr.	tient is F	76	0.39	-1.18	1.23
17 Morphine is effective for dyspnea.	T	67	0.58	-0.59	1.79
18 If room temperature is maintained higher (h patient with dyspnea often experiences rel	ot), a F lief.	41	0.47	0.29	1.52
Nausea and vomiting	-	=4	o Eo	1.05	1.00
The neurotransmitters in the vomiting center dopamine, histamine, acetylcholine, and se	erotonin.	71	0.59	-1.05	1.03
20 When the primary cause of nausea is hypero the administration of bisphosphonate is a treatment for alleviating nausea.		66	0.57	-0.53	1.99
21 Prochlorperazine sometimes causes akathisia	T. T	67	0.73	-0.55	2.03
Psychological distress When a patient has a high level of psychologistress, clinicians are recommended to exwhether the patient has suicidal ideation.	gical T amine	80	0.56	-1.87	0.84
When the patient has suicidal ideation, psyc consultation is recommended.	hiatric T	85	0.27	-1.95	1.04
24 An anxiolytic is one of the useful medication patients with psychological distress.	ns for T	86	0.34	-2.45	0.82

(continued)

Table 2. (Continued)

			Correct	k-coefficient		IRT
Que.	stions		answer (%)	(n=44)	Difficulty	Discrimination
Del	irium					
25	Delirium occurs due to drugs or physical etiologies.	T	70	0.22	-1.28	0.73
26	Benzodiazepines should be used first for delirium.	F	52	0.26	-0.11	1.48
27	It is better to make the room pitch black for a patient with delirium, so that he or she can sleep well.	F	71	0.46	-1.05	1.03
Con	nmunication					
28	An open-ended question means that it cannot be answered with a simple 'yes' or 'no,' and requires an unrestricted answer based on the subject's own feelings.	Т	82	0.08	-1.57	1.15
29	When physicians convey bad news, they should ask the patient's concern and understanding about the disease.	Т	88	0.25	-1.80	1.37
30	It is better to repeatedly use the word 'cancer' when telling the patient about his or her malignancy.	F	75	0.77	-1.58	0.78
Con	munity-based palliative care					
31	There is a consultation support center in all designated cancer centers.	T	56	0.38	-0.27	1.23
32	All terminally ill cancer patients 40 years of age can access long-term care insurance.	T	53	0.62	-0.17	1.16
33	All designated clinics with home hospice function have a 24-hour 7-day system.	T	73	0.37	-1.89	0.55

In conclusion, this study used psychometric methods to validate an instrument for evaluating palliative care knowledge among physicians who attend a PEACE-based seminar, which was developed as a nationwide education program in palliative care. This evaluation instrument was constructed to cover nine domains: philosophy of palliative

care, cancer pain, side effects of opioids, dyspnea, nausea and vomiting, psychological distress, delirium, communication, and community-based palliative care. The PEACE-Q could be useful for evaluating both knowledge among physicians and education programs in primary palliative

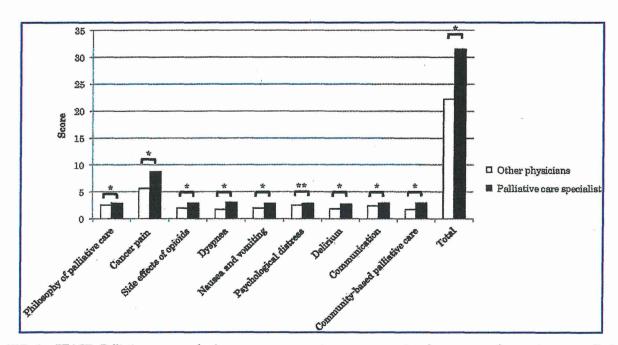


FIG. 1. PEACE, Palliative care emphasis program on symptom management and assessment for continuous medical education.

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# Palliative Care Physicians' Practices and Attitudes Regarding Advance Care Planning in Palliative Care Units in Japan: A Nationwide Survey

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#### **Abstract**

To clarify physicians' practices and attitudes regarding advance care planning (ACP) in palliative care units (PCUs) in Japan, we conducted a self-completed questionnaire survey of 203 certificated PCUs in 2010. Ninety-nine physicians participated in the survey. Although most Japanese palliative care physicians recognized the importance of ACP, many failed to implement aspects of patient-directed ACP that they acknowledged to be important, such as recommending completion of advance directives (ADs), designation of health care proxies, and implementing existing ADs. The physicians' general preference for family-centered decision making and their feelings of difficulty and low confidence regarding ACP most likely underlie these results. The discrepancy between physicians' practices and their recognition of the importance of ACP suggests an opportunity to improve end-of-life care.

#### Keywords

advance care planning, advance directives, attitude, palliative medicine, palliative care, neoplasms, Japan

#### Introduction

Advance care planning (ACP) has been described as a process "whereby a patient, in consultation with health care providers, family members, and important others, makes decisions about his or her future health care, should he or she become incapable of participating in medical treatment decisions." The ACP improves end-of-life care and patient and family satisfaction and reduces stress, anxiety, and depression in surviving relatives.<sup>2</sup> Advance directives (ADs) are directions recorded by competent individuals to allow them to influence treatment decisions through ACP in the event of serious illness and subsequent loss of competence. Several previous studies focused on the completion of ADs and factors impacting on physicians' attitudes toward ADs, that is, cultural factors, autonomy, the patient's family, legal worries, the professional's fear of increased euthanasia, and individual subjective concerns.3 In these studies, the characteristics of physicians with a positive attitude toward ADs were experience with the use of ADs in practice,4 higher age,5 an earlier year of graduation from the medical school,<sup>5</sup> working in a solo practice,<sup>5</sup> female gender,<sup>5</sup> and working as a resident physician. 6 In contrast, the characteristics of physicians who have a negative attitude toward ADs were reported to be an early year of graduation from the medical school<sup>4</sup> and being a foreign medical graduate.<sup>5</sup> The ACP is

supported by legislation in Australia, the United Kingdom, and the United States.<sup>2</sup> The ACP is spreading in Asia and has been governed by a national act in Taiwan since 2000.<sup>7</sup>

In Japan, the term ACP is not popular with general citizens or health care professionals; however, ADs have received much discussion, especially in the case of living wills when life-sustaining treatment was administered to patients who were unlikely to recover. Previous studies have revealed that Japanese physicians have a positive attitude toward ADs in general. <sup>8,5</sup> However, because ADs are not mandatory documents in Japan, health care professionals do not often have the opportunity to see patients who have completed ADs in the

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physician's own clinical practice, even in palliative care units (PCUs) or hospices. A previous study in Japan indicated that the rate of completion of ADs was only 9%.

These previous studies<sup>8,9</sup> were small, and because they were published in 1998, they do not reflect more recent changes in practices and attitudes. No one has conducted a large size, multicenter, and systematic survey of practices and attitudes regarding ACP among palliative care physicians in Japan.

We therefore conducted a nationwide survey in Japan to examine the current status of ADs in PCUs and to determine palliative care physicians' practices and attitudes regarding ACP. We have already reported the survey results showing that the rate of completion of ADs is 18% to 48% in PCUs. <sup>10</sup> Here, we report the results of Japanese palliative care physicians' practices and attitudes regarding ACP, and the characteristics of physicians who have positive or negative practices concerning ACP.

#### Methods

#### **Participants**

Participants were responsible physicians from all 203 certificated PCUs that are members of Hospice Palliative Care Japan, which is the most respected and largest palliative care association in Japan and was established in 1991. The survey covered 93.5% of the total of 217 certified PCUs in 2010 in Japan.

#### Design

We conducted a nationwide cross-sectional survey from December 2010 to February 2011 by mailing a cover letter and questionnaire about ACP to a responsible physician in each of the 203 certified PCUs. The cover letter stated that the survey was anonymous and provided instructions for answering the self-completed questionnaires. Participating physicians answered their questionnaire and returned it in the envelope provided. The institutional review board of the Graduate School of Comprehensive Human Sciences, University of Tsukuba, approved the survey protocol.

#### Questionnaire

The questionnaire examined each participating physician's practices before and after a patient's admission to a PCU and their attitude toward ACP. Because most of the palliative care physicians were in charge of patients only after admission to PCUs, in the current study we have only reported question items concerning the physicians' practices after the patient's admission: examples are "Do you encourage sharing of the goals of treatment and care between the patient and family?" "Do you order do not resuscitate (DNR) if you determine that the patient wishes for no cardiopulmonary resuscitation (CPR) in the event of the patient's cardiopulmonary arrest?" and "Do you order DNR if the patient's family wish for no CPR in the event of the patient's cardiopulmonary arrest?" (Figure 1). We required the physicians to answer the questions regarding

their practices using a 5-point Likert-type scale: "always," "very frequently," "sometimes," "rarely," or "never".

The question items concerning each physician's attitudes toward ACP were separated into 2 parts (Figures 2 and 3). The first part examined the physicians' recognition of the importance of ACP and included question items such as "Is it important to confirm the patient's understanding of their disease conditions?" "Is it important to ask the patient about existing ADs?" and "Is it important to ask if the patient desires the use of transfusion in case they lose their decision-making capacity?" We required physicians to answer the questions using a 5-point Likert-type scale: "very important," "important," "neither important nor unimportant," "not so important," or "not important at all." The second part concerned the physicians' attitudes and difficulties toward ACP and ADs, such as "ACP is an effective way for patients to influence their medical treatment should they lose competence"; "In a catastrophic situation, I would have greater confidence in my treatment decisions if guided by an AD"; and "I have difficulty asking the patient, not their family, about the patient's desires concerning end-of-life care in ACP." We required the physicians to answer the questions using a 5-point Likert-type scale: "strongly agree," "agree," "undecided," "disagree," or "strongly disagree."

The questionnaire also examined each physician's demographic data including age, sex, clinical experience, length of time engaged in palliative care, and the type of medical facility in which they work. The types of medical facilities were designated cancer hospital, other hospital, clinic, and others.

The questionnaire was developed by 2 of the study's authors (YK and YA). The first part of the questionnaire, which concerned the physicians' practices before and after a patient's admission to a PCU and the physicians' recognition of the importance of ACP, was original items developed based on a literature review. 1,3-6,11 The second part of the questionnaire about the physicians' attitudes and difficulties toward ACP and ADs was developed with reference to a previous study.4 We translated all items about the physicians' attitudes toward ACP and ADs in the previous study<sup>4</sup> into Japanese, with the exception of 2 items pertaining to law, which we deleted because AD and ACP are not supported by law in Japan, and we thought the question would be inappropriate to ask. In addition, we changed the description of AD in the translation of the previous study<sup>4</sup> to ACP to avoid confusion regarding the definitions. Throughout this study, AD was defined as directions recorded by competent individuals to allow them to influence treatment decisions in the event of serious illness and subsequent loss of competence, and ACP was defined as the process of making decisions about patient's future health care by a patient in consultation with health care providers, family members, and important others, should he or she become incapable of participating in medical treatment decisions. We added another 3 items to the translated questionnaire to assess the physicians' difficulty in practicing ACP: "I have difficulty telling the patient directly about their disease conditions in ACP"; "I have difficulty assessing the patient's decision-making capacity in

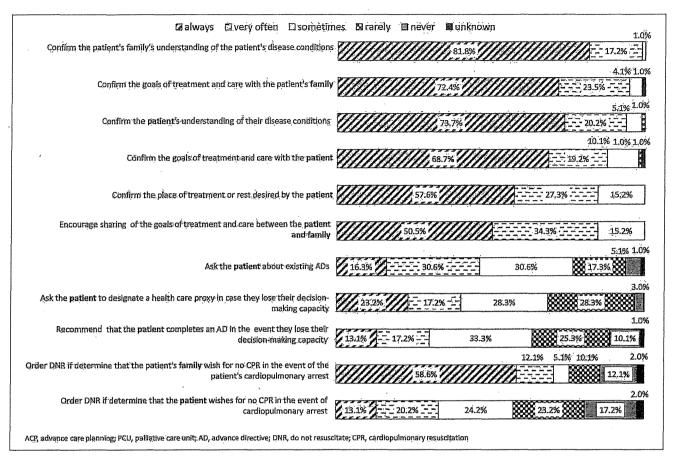


Figure 1. Physicians' practices regarding ACP in the PCUs (N = 99). ACP indicates advance care planning; PCUs, palliative care units.

ACP"; and "I have difficulty asking the patient, not their family, about the patient's desires concerning end-of-life care in ACP." The content and face validity of the survey instrument were confirmed by a convenience sample of 10 palliative care specialists. Reliability was checked by Cronbach  $\alpha$  coefficient. The full questionnaire used for the study is given in Appendix A.

#### Statistics

We summarized the demographic data by descriptive statistics. Either the chi-square test or Fisher exact test was used in univariable analyses comparing physicians with positive practices regarding ACP to those with negative practices. In this study, a physician with negative practices regarding ACP was defined as one who responded "sometimes," "rarely," or "never" to each of the following 3 questions, which were deemed the most fundamental after much discussion among the researchers: "Do you recommend that patients to complete an AD in the event they lose their decision-making capacity?" "Do you ask the patient to designate a health care proxy in the event they lose decision-making capacity?" and "Do you order DNR if you determine that the patient wishes for no CPR in the event of cardiopulmonary arrest?" Physicians who did not meet this definition for negative practices were classed as having positive

practices regarding ACP. *P* values less than .05 were considered statistically significant. Analysis was conducted using SPSS statistics 21 (IBM, Tokyo, Japan).

#### Results

Of the 203 certified PCUs, 99 (49%) returned responses to the survey. In total, we collected data from 99 responsible physicians.

#### Demographic Data

The characteristics of the respondents are listed in Table 1. The respondents were predominantly male, and their median age was 49.0 years (interquartile range [IQR], 12.0 years). The median length of time of the physicians' clinical experience and palliative care experience was 24.0 years (IQR, 14.0 years) and 7.0 years (IQR, 8.0 years), respectively. Approximately one-fourth of the physicians were engaged in a designated cancer hospital.

#### Reliability of the Questionnaire

Cronbach α coefficient for the parts of the questionnaire about the physicians' practices, their recognition of the importance of

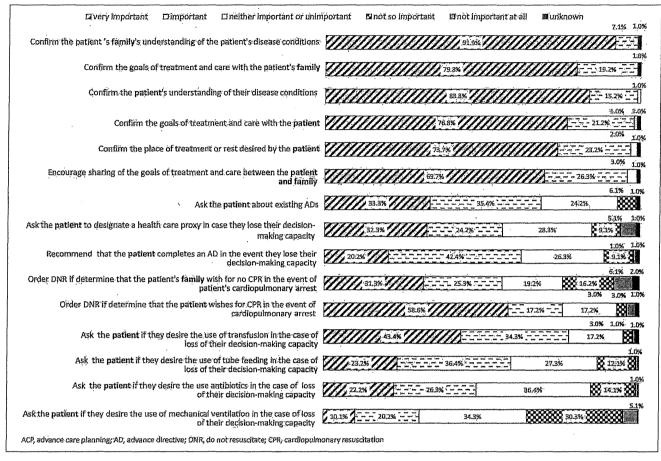


Figure 2. Physicians' recognition of the importance of ACP (N = 99). ACP indicates advance care planning.

ACP, their attitudes toward ACP and ADs (questions translated from Davidson et al<sup>4</sup>), and their attitudes toward ACP and ADs (original questions devised for this study) were 0.884, 0.881, 0.344, and 0.756, respectively.

#### Physicians' Practices Regarding ACP in the PCUs

Figure 1 shows the results for the physicians' practices regarding ACP in the PCUs.

The percentages of physicians who "always" or "very often" confirm the family's understanding of the patient's disease conditions, the goals of treatment and care with the patient's family, the patient's understanding of their disease conditions, and the goals of treatment and care with the patient were 99.0%, 95.9%, 93.9%, and 87.9%, respectively.

The percentages of physicians who "always" or "very often" ask the patient about existing ADs, the patient to designate a health care proxy in case they lose their decision-making capacity, and recommend that the patient completes an ADs in the event they lose their decision-making capacity were 46.9%, 40.4%, and 30.3% respectively.

The percentage of physicians who "always" or "very often" order DNR after asking the patient's family was

70.7%. The percentage of physicians who always or very often order DNR if they know that the patient wishes for no CPR in the event of cardiopulmonary arrest was 33.3%.

#### Physicians' Recognition of Importance of ACP

Figure 2 shows the results for the physicians' recognition of the importance of ACP. A physician was deemed to recognize the importance of a certain aspect of ACP if they responded "very important" or "important" in the survey.

The percentages of physicians who recognized the importance of confirming the family's understanding of the patient's disease conditions, confirming the goals of treatment and care with the patient's family, confirming the patient's understanding of their disease conditions, and confirming the goals of treatment and care with the patient were 99.0%, 99.0%, 99.0%, and 98.0%, respectively.

The percentages of physicians who recognized the importance of asking the patient about existing ADs, recommending that the patient complete an AD in the event they lose their decision-making capacity, and asking the patient to designate a health care proxy in case they lose their decision-making capacity were 68.7%, 62.6%, and 56.5% respectively.

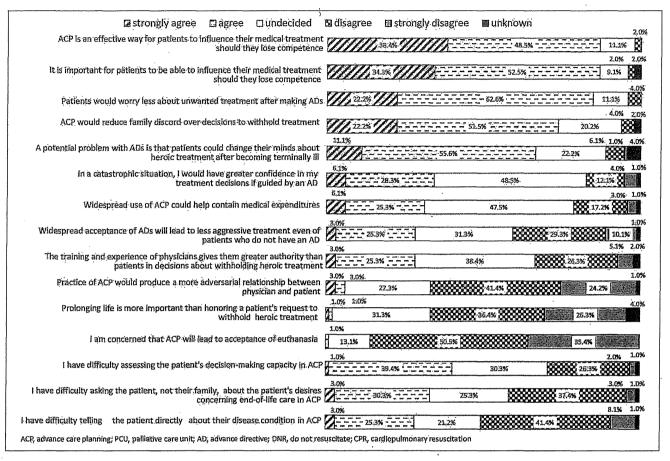


Figure 3. Physicians' attitude toward ACP and ADs (N = 99). ACP indicates advance care planning; AD, advance directive.

Table 1. Characteristics of palliative care physicians.

Variable	N = 99 n (%)
Gender	
Female	12 (12.1)
Male	87 (87.8)
Age, years	
20-29	1 (1.0)
30-39	13 (13.1)
40-49	38 (39.4)
50-59	36 (36.4)
60-69	10 (10.1)
70-79	1 (1.0)
Clinical experience, years	
<10	3 (3.0)
10-19	31 (31.3)
20-29	36 (37.4)
30-39	28 (28.3)
40-49	1 (1.0)
Palliative care experience, years	
<4	30 (30.3)
5-9	37 (37.4)
10-14	21 (21.2)
15-19	10 (10.1)
20-24	1 (1.0)

Table I. (continued)

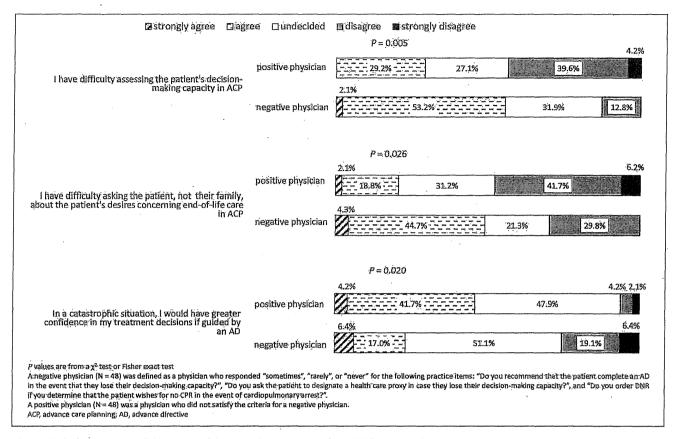
Variable	N = 99 n (%)
Type of medical facility	•
Cancer hospital	25 (25.3)
Other hospital	72 (72.7)
Clinic	0 (0.0)
Others	1 (1.0)
Unknown	l (1.0)

#### Physicians' Attitudes Toward ACP and ADs

Figure 3 shows the results for physicians' attitudes toward ACP and ADs.

The percentages of physicians who answered "strongly agree" or "agree" to the following statements: "ACP is an effective way for patients to influence their medical treatment should they lose competence"; "It is important for patients to be able to influence their medical treatment should they lose competence"; and "Patients would worry less about unwanted treatment after making an AD" were 86.9%, 86.8%, and 84.8%, respectively.

(continued)



**Figure 4.** Self-assessment of skill and confidence with respect to ACP and AD among physicians with positive practices regarding ACP compared to physicians with negative practices. ACP indicates advance care planning; AD, advance directive.

The percentages of physicians who answered "strongly agree" or "agree" that they have difficulties assessing the patient's decision-making capacity in ACP, asking the patient, not their family, about the patient's desires concerning end-of-life care in ACP, and telling the patient directly about their disease conditions in ACP were 40.4%, 33.3%, and 28.3%, respectively.

#### Characteristics of Palliative Care Physicians Who Have Positive or Negative Practices Regarding ACP

Of the 99 physicians, 48 had negative practices regarding ACP and 48 had positive practices regarding ACP; 3 physicians were eliminated from the comparison of physicians with positive or negative practices because of missing data. No demographic data were significantly different between physicians who had positive practices regarding ACP and those who had negative practices.

Figure 4 shows the results of the self-assessment of skill and confidence with respect to ACP and AD among physicians with positive practices regarding ACP compared to physicians with negative practices. Physicians who had negative practices experienced significantly more difficulties in assessing the patient's decision-making capacity (P = .005) and asking the patient about their wishes for end-of-life care (P = .026). In

addition, the physicians who had negative practices showed significantly lower confidence in treatment decisions guided by an AD in a catastrophic situation (P = .020).

Among the items concerning the physicians' attitude toward ACP and ADs, significantly more physicians with positive practices gave a favorable response to "ACP would reduce family discord over decisions to withhold treatment" (P=0.036) compared to physicians with negative responses. Items pertaining to the recognition of the importance of ACP items that were significantly different between physicians with positive practices and those with negative practices are shown in Figure 5.

#### Discussion

Here, we report the results of a multicenter and systematic survey of palliative care physicians' practices and attitudes regarding ACP in Japan. In addition, we reveal the characteristics of physicians who have positive practices regarding ACP and compare them to those who have negative practices regarding ACP. We revealed the following 2 important findings.

First, the results showed that there were discrepancies between the physicians' practices and their recognition of the importance of ACP (Figures 1 and 2). The largest discrepancies were found in ordering DNR after asking the patient (75.8% of

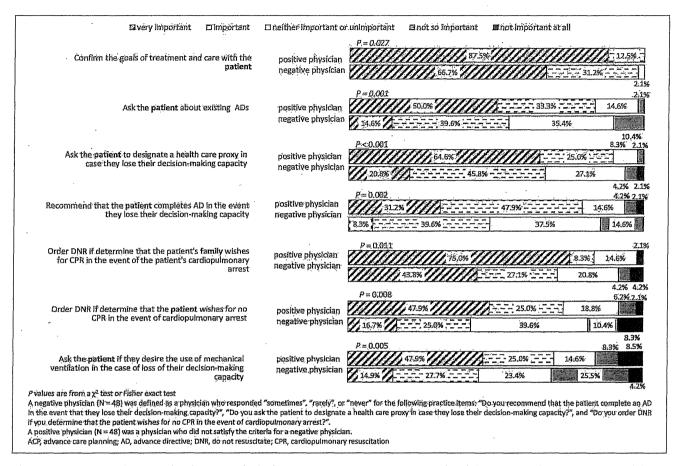


Figure 5. Comparison between the physicians who had positive or negative practices regarding ACP in terms of their recognition of the importance of ACP indicates advance care planning.

physicians recognized its importance but only 33.3% practiced it) and in recommending that the patient complete an AD (62.6% of the physicians recognized its importance but only 30.3% practiced it). By contrast, there was relatively less difference in asking the patient to designate a health care proxy (56.5% of physicians recognized its importance but 40.4% practiced it), and the relationship was reversed for ordering DNR after asking the patient's family (56.6% of physicians recognized its importance but 70.7% practiced it). We consider that these findings might reflect a cultural preference for familycentered decision making near the end of life. These findings were expected in view of the results of Sanjo et al<sup>12</sup> who reported that unawareness of death is one of the major contributors to good death in Japan and that there is a significant correlation between unawareness of death and traditional Japanese style of death. Other previous studies also indicated cultural differences in end-of-life care preferences between Western countries and Japan. 9,13-15 More specifically, Japanese patients may be more likely to feel free from the burden of difficult decision making by trusting their family9 to use nonverbal communication<sup>13</sup> and to cope with their distress by denying their terminal condition. 14,15 However, it is important that we develop improved communication skills focusing on the daily concerns

and short-term goals required for a patient's good death, because many Japanese palliative care physicians appear to have a dilemma between the patient's right to self-determination and unawareness of death.

Second, although 86.9% (86 of 99) of the physicians answered that ACP is an effective way for patients to influence their medical treatment should they lose competence (Figure 3), approximately 50% (48 of 99) of the Japanese palliative care physicians have negative practices regarding ACP, that is, they don't recommend that patients complete an AD in the event they lose their decision-making capacity, ask the patient to designate a health care proxy in case they lose their decisionmaking capacity, or order DNR if they determine that the patient wishes for no CPR in the event of cardiopulmonary arrest. Furthermore, physicians who had negative practices regarding ACP had more difficulties in assessing the patient's decision-making capacity and in asking the patient about their desires concerning end-of-life care, and they had low confidence in treatment decisions guided by ADs in catastrophic situations (Figure 4). Difficulties in assessing the patient's decision-making capacity and in conducting end-of-life communication, and low confidence in having their clinical practices guided by ACP, may be the reasons for the gap between

the Japanese palliative care physicians' practices and their attitude regarding ACP. From our results, education focusing on patient-centered ACP, especially in regard to communication and assessment of decision-making capacity, may be an effective way to disseminate ACP practices in Japan.

The study has several limitations. First, the response rate of 49% was slightly lower than that achieved in previous studies (56%-71.8%),<sup>4,7,8,11</sup> and response bias would exist. Second, we proposed an original definition for physicians who have positive or negative practices regarding ACP, because a gold standard definition has not been established. We reviewed this definition many times and gave higher importance to basic practices regarding ACP. Third, the reliability of the translated part of the questionnaire about physicians' attitudes toward ACP and ADs was low. We consider that this problem may be derived from the difficulty to answer for the physicians in understanding the original concept and the English–Japanese

translation. Fourth, because this survey was a cross-sectional survey, the results do not prove a causal relationship.

In conclusion, among Japanese palliative care physicians, noteworthy discrepancies were found between the ACP practices and attitudes toward ACP. These findings may reflect the Japanese cultural preference for family-centered as opposed to patient-centered ACP. Approximately 50% of the physicians had negative practices regarding ACP, and these physicians experienced more difficulty and lower confidence regarding ACP than those who had positive practices. To disseminate ACP practices in Japan, education focusing on patient-centered ACP, especially end-of-life communication and assessment of decision-making capacity, may be effective. Further study is required to determine whether training in ACP principles and practices positively affects perceptions of ACP and increases the performance of patient-centered ACP among Japanese palliative care physicians.

#### Appendix A

The Survey for Advance Care Planning in Hospices and Palliative Care Units

I. First, Please Answer the Following Questions About Yourself.

I. Age	( ) age  1) man 2) woman  ( ) years  ( ) years		
2. Gender	I) man	2) woman	
3. Clinical experience	( ) years	3	
4. Palliative care experience <sup>**</sup>	( ) years	3	

\*Palliative care experience is defined as working in a palliative care unit or palliative care team (full time service over 50%)

- 5. Please answer the following questions about your institute.
  - 1: Cancer hospital 2: Other hospital (200 or more beds)
  - 3: Other hospital (Less than 200 beds) 4: clinic
  - 5: Others(

II. Please Answer the Following Questions About Your Practices Before a Patient's Admission to Your Hospice or Palliative Care Unit. Please Select the Most Appropriate Number (1 to 5).

	Always	Very often	Sometimes	Rarely	Never
Confirm the patient's understanding of their disease conditions	I	2	3	4	5
Confirm the patient's family's understanding of the patient's disease conditions	1	2	3	4	5
Confirm the goals of treatment and care with the patient	I	· 2	3 ·	4	5
Confirm the goals of treatment and care with the patient's family	1	2 .	3	4	5
Confirm the place of treatment or rest desired by the patient	I	2	. 3	4	5
Ask the patient about existing advance directives	l l	2	3	4	5
Recommend that the patients complete an advance directive in the event they lose their decision-making capacity	·	2	3	4	5
Ask the patient to designate a health care proxy in case they lose their decision-making capacity	I	2 ·	3	4	5

III. Please Answer the Following Questions About Your Practices After a Patient's Admission in Your Hospice or Palliative Care Unit. Please Select the Most Appropriate Number (1 to 5).

	Always	Very often	Sometimes	Rarely	Never
Confirm the patient's understanding of their disease conditions	1	2	3	4	5
Confirm the patient's family's understanding of the patient's disease conditions	1	2	<b>,</b> 3	4 -	5
Confirm the goals of treatment and care with the patient	ı	. 2	3	4	. 5
Confirm the goals of treatment and care with the patient's family	1	2	3	4	5
Encourage sharing of the goals of treatment and care between the patient and family	I	2	3	4	5
Confirm the place of treatment or rest desired by the patient	I	2	3	4	5
Ask the patient about existing advance directives	l	2	3	4	5
Recommend that the patient complete an advance directive in the event they lose their decision-making capacity	. 1	2	3	4	5
Ask the patient to designate a health care proxy in case they lose their decision-making capacity	l	2	3	4	5 ,
Order do not resuscitate if determine that the patient wishes for no cardiopulmonary resuscitation in the event of the patient's cardiopulmonary arrest	l	2	3	4	5
Order do not resuscitate if determine that the patient's family wish for no cardiopulmonary resuscitation in the event of the patient's cardiopulmonary arrest	·I	2	3	4	5

IV. Please Answer the Following Questions About Your Recognition of the Importance of Advance Care Planning. Please Select the Most Appropriate Number (1 to 5).

	Very important	Important	Neither important or unimportant	Not so important	Not important at all
Confirm the patient's understanding of the patient's disease conditions	1	2	. 3	4	5
Confirm the patient's family's understanding of the patient's disease conditions	I	2	3	4	5
Confirm the goals of treatment and care with the patient	1	2	3	4	5
Confirm the goals of treatment and care with the patient's family	I	2	3	4	5
Encourage sharing of the goals of treatment and care between the patient and family	I	2	3	4	. 5
Confirm the place of treatment or rest desired by the patient	I	2 .	3	4	5
Ask the patient about existing advance directives	I	2	3	4	5
Recommend that the patient complete an advance directive in the event they lose their decision-making capacity	ı	2	3	. 4	5
Order do not resuscitate if determine that the patient wishes for no cardiopulmonary resuscitation in the event of the patient's cardiopulmonary arrest	1	2	3	4	5
Order do not resuscitate if determine that the patient's family wish for no cardiopulmonary resuscitation in the event of the patient's cardiopulmonary arrest	I	2	3	4	5

	Very important	lmportant	Neither important or unimportant	Not so important	Not important at all
Ask the patient if they desire the use of mechanical ventilation in case they lose of their decision-making capacity	I	2	. 3	4	5
Ask the patient if they desire the use of antibiotics in case they lose their decision-making capacity	I	2	3	4	5
Ask the patient if they desire the use of tube feeding in case they lose their decision-making capacity	l	2	. 3	4	5
Ask the patient if they desire the use of transfusion in case they lose their decision-making capacity	1	2	3	. 4	5
Ask the patient to designate a health care proxy in case they lose their decision-making capacity	l	2	3	4	. 5

V. Please Answer the Following Questions About Your Attitude Toward Advance Care Planning and Advance directives. Please Select the Most Appropriate Number (1 to 5).

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Advance care planning is an effective way for patients to influence their medical treatment should they lose competence	1	2	3	4	5
Practice of advance care planning would produce a more adversarial relationship between physician and patient	ı	2	3	4	5
Advance care planning would reduce family discord over decisions to withhold treatment	I	2	3	4	5
I am concerned that advance care planning will lead to acceptance of euthanasia	I	2	3	4	5
Widespread use of advance care planning could help contain medical expenditures	I	2	3	4	5
It is important for patients to be able to influence their medical treatment should they lose competence	I	2	3	4	5
Widespread acceptance of advance directives will lead to less aggressive treatment even of patients who do not have an advance directive	I	2	3 .	4`	5
Patients would worry less about unwanted treatment after making advance directives	I	2	3	4	5
Prolonging life is more important than honoring a patient's request to withhold heroic treatment	I	2	3	4	5
A potential problem with advance directives is that patients could change their minds about heroic treatment after becoming terminally ill	, l	2	3	4	5
The training and experience of physicians gives them greater authority than patients in decisions about withholding heroic treatment	1	2	3	4	5
In a catastrophic situation, I would have greater confidence in my treatment decisions if guided by an advance directive	ı	2	3	4	5
I have difficulty telling the patient directly about their disease conditions in advance care planning	1	2	3	4	5
I have difficulty assessing the patient's decision-making capacity in advance care planning	ı	2	3	4	5
I have difficulty asking the patient, not their family, about the patient's desire concerning end-of-life care in advance care planning	ı	2	3	4	5

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#### Original Article

### The Activity of Palliative Care Team Pharmacists in Designated Cancer Hospitals: A Nationwide Survey in Japan

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#### Abstract

**Context.** The role of pharmacists in palliative care has become more important now that they are able to provide medication review, patient education, and advice to physicians about a patient's pharmacotherapy. However, there is little known about pharmacists' activity on palliative care teams.

**Objectives.** The present study aimed to examine the clinical, educational, and research activities of pharmacists on palliative care teams and pharmacist-perceived contributions to a palliative care team or why they could not contribute.

**Methods.** We sent 397 questionnaires to designated cancer hospitals, and 304 responses were analyzed (response rate 77%).

Results. Of the pharmacists surveyed, 79% and 94% reported attending ward rounds and conferences, respectively. Half of the pharmacists provided information/suggestions to the team about pharmacology, pharmaceutical production, managing adverse effects, drug interactions, and/or rotation of drugs. In addition, 80% of the pharmacists organized a multidisciplinary conference on palliative care education. Furthermore, 60% of the pharmacists reported on palliative care research to a scientific society. Seventy percent of the pharmacists reported some level of contribution to a palliative care team, whereas 16% reported that they did not contribute, with the main perceived reasons for no contribution listed as insufficient time (90%) and/or staff (68%).

Conclusion. In Japan, pharmacists exercise a moderate level of clinical activity on palliative care teams. Many pharmacists believe that they contribute to such a team and generally place more emphasis on their educational and research roles compared with clinical work. J Pain Symptom Manage 2013; ... — ... © 2013 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

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#### Key Words

Palliative care team, pharmacists, designated cancer hospital, questionnaire, nationwide survey, Japan

#### Introduction

Pharmacists can now provide medication review, patient education, and suggestions to physicians about patient pharmacotherapy. 1-4 These altered responsibilities have made the role of pharmacists in palliative care even more important. However, few nationwide investigations have examined pharmacists' activities on a palliative care team.

In preliminary surveys from Australia and Canada, approximately 70% of hospital pharmacists provided specific advice on pharmacotherapy, drug administration, patient treatment, adverse effects of therapies, and drug incompatibilities as part of a palliative care team;1 however, this study involved only a small sample size. In Sweden, pharmacists' expertise was used on palliative care teams to contribute valuable advice regarding drugrelated problems and stock management, although only one institution was involved and thus the results could not be generalized.2 Therefore, it remains worthwhile to investigate pharmacists' roles on palliative care teams nationwide, including their clinical, educational, and research activities.

In Japan, the Ministry of Health, Labour, and Welfare<sup>5</sup> has strongly supported the dissemination of specialized palliative care as part of the National Cancer Program. Consequently, palliative care consultation services have been covered by National Medical Insurance since 2002, and designated cancer hospitals (currently numbering 397) were required to establish palliative care teams.<sup>6</sup> In addition, standards for hospital-based palliative care teams were recently developed, including the involvement of pharmacists in the team's care provision.<sup>7</sup> Nevertheless, few nationwide investigations have focused on the pharmacist's role on a palliative care team.

Thus, the aims of the present study were to examine the clinical, educational, and research activities of pharmacists on a palliative care team and pharmacist-perceived contributions to a palliative care team and why

pharmacists believed that they could not contribute to such a team.

#### Methods

This study used an anonymous, questionnaire-based, postal survey, which was approved by the Ethical Review Board of the Nippon Medical School Hospital. We identified all 397 designated cancer hospitals across the country, and questionnaires were mailed to all these centers from November 2012 to January 2013. No reminders were sent, and no compensation was offered.

#### Questionnaire

Owing to the lack of validated instruments, the questionnaire used in the present study was developed after a systematic literature review and discussions among the authors. 1,2 The face validity of the questionnaire was confirmed in a pilot study involving 10 palliative care team pharmacists (convenience sample). The survey included queries about clinical activity on a palliative care team, educational and research activities about palliative care, pharmacist-perceived contributions to a palliative care team or the reasons why pharmacists believed that they could not contribute, and personal background information.

Clinical Activity of Pharmacists on a Palliative Care Team. We asked pharmacists to comment on their clinical experience on a palliative care team, for example, direct counseling to patients, provision of information/suggestions to palliative care team staff, and the team's primary physician, nurse, and pharmacist. Clinical activity was rated on a five-point Likert-type scale as not at all, rarely (one day per month), sometimes (one day per week), often (three to five days per week), or always (every day).

Educational and Research Activities of Pharmacists About Palliative Care. We asked pharmacists to