

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."¹ The ACP improves end-of-life care and patient and family satisfaction and reduces stress, anxiety, and depression in surviving relatives.² 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,⁵ working in a solo practice,⁵ female gender,⁵ 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 school⁴ and being a foreign medical graduate.⁵ The ACP is

supported by legislation in Australia, the United Kingdom, and the United States.² The ACP is spreading in Asia and has been governed by a national act in Taiwan since 2000.⁷

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.^{8,9} 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%.⁹

These previous studies^{8,9} 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.¹⁰ 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 certified 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 study⁴ 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 study⁴ 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 α 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

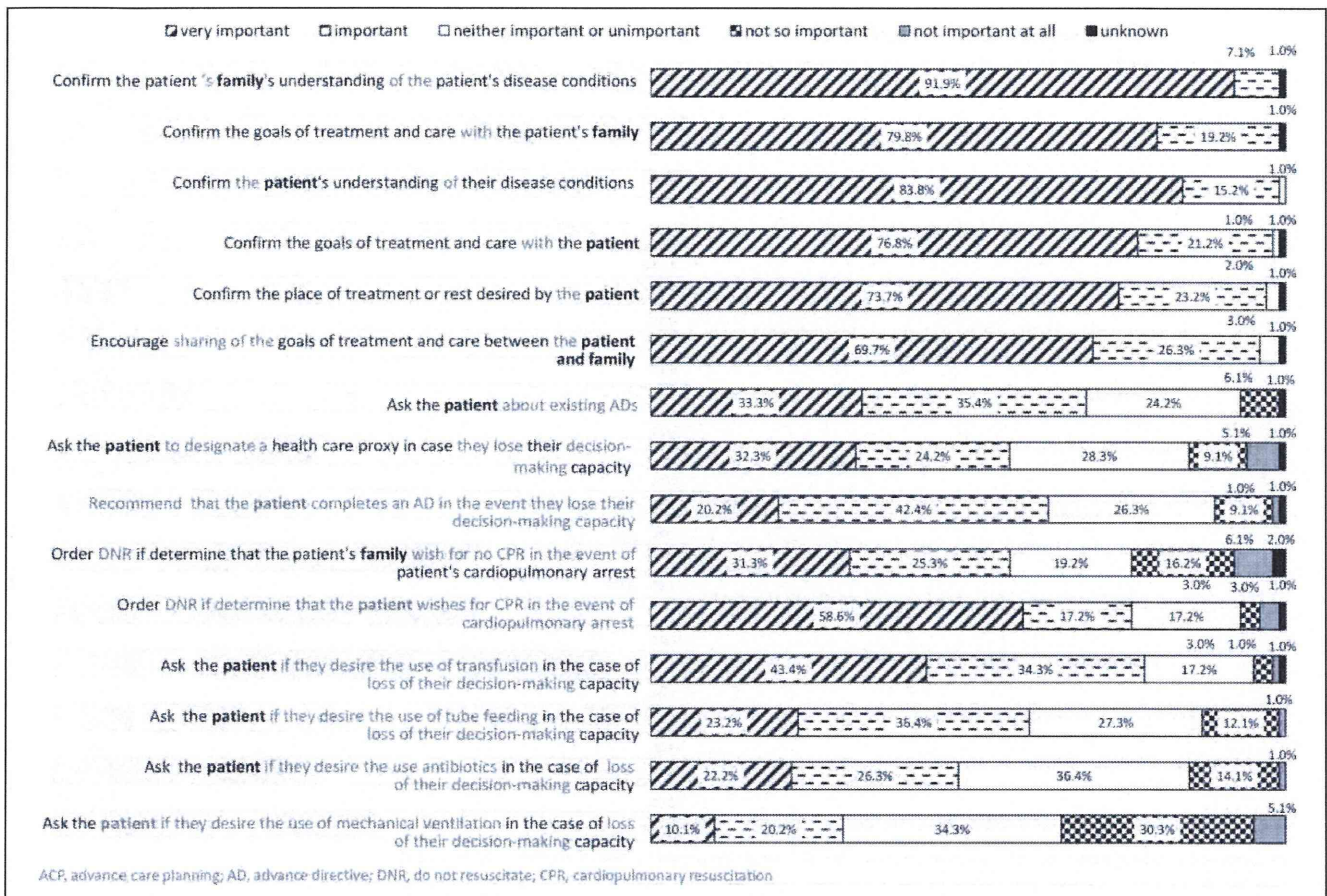


Figure 2. Physicians' recognition of the importance of ACP (N = 99). ACP indicates advance care planning.

ACP, their attitudes toward ACP and ADs (questions translated from Davidson et al⁴), 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.

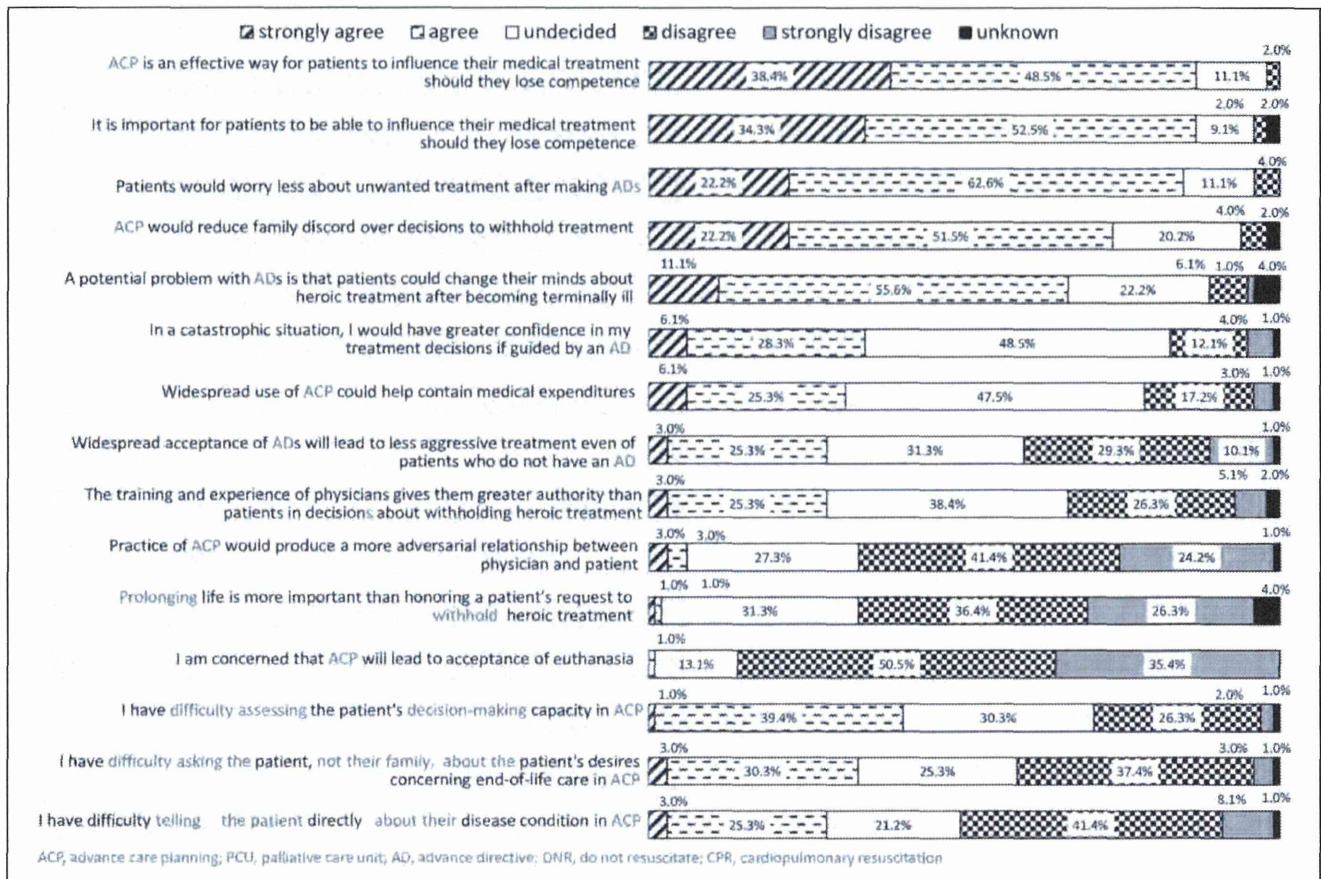


Figure 3. Physicians' attitude toward ACP and ADs (N = 99). ACP indicates advance care planning; AD, advance directive.

Table I. 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)

(continued)

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	1 (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.

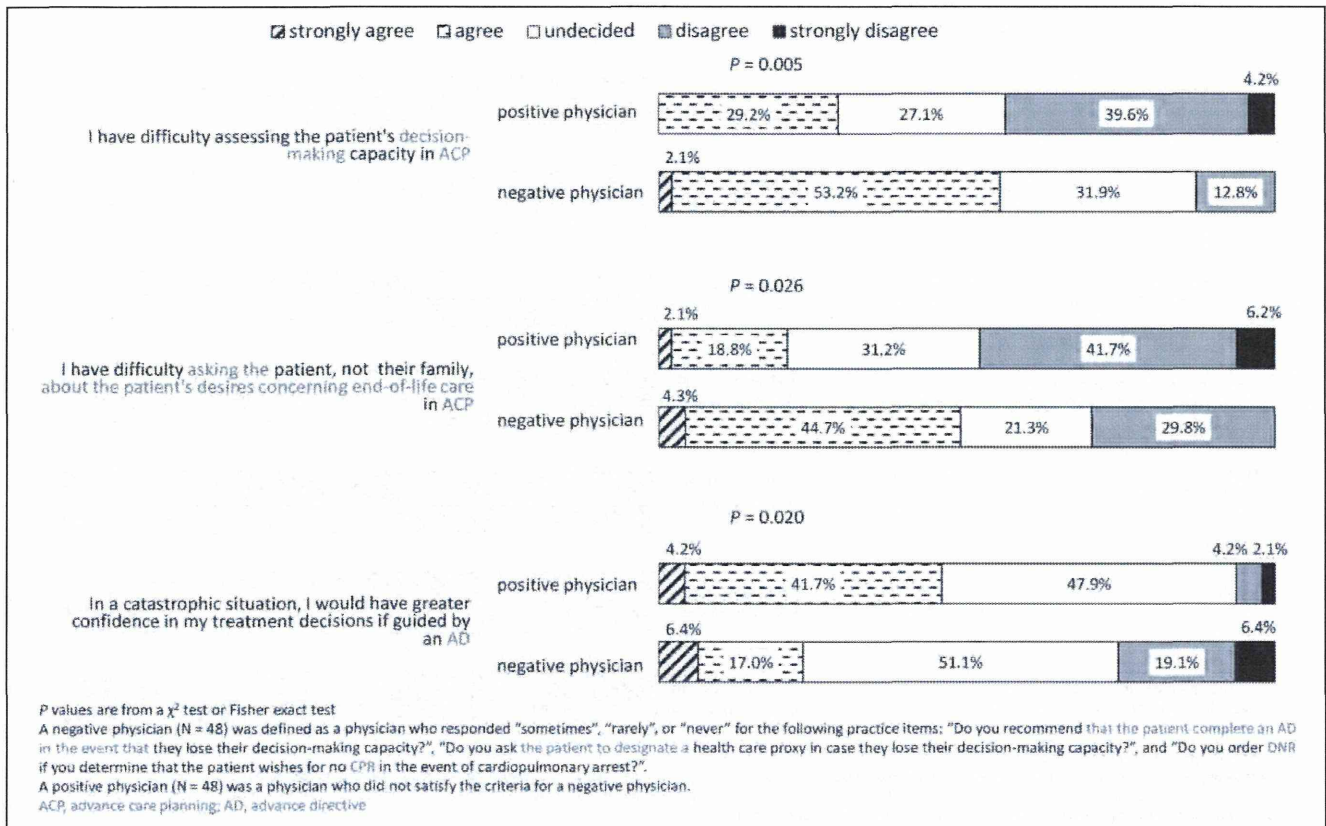


Figure 4. Self-assessment of skill and confidence with respect to ACP and AD among physicians with positive practices regarding ACP compared to physicians with negative practices. ACP indicates advance care planning; AD, advance directive.

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” ($P = .036$) 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

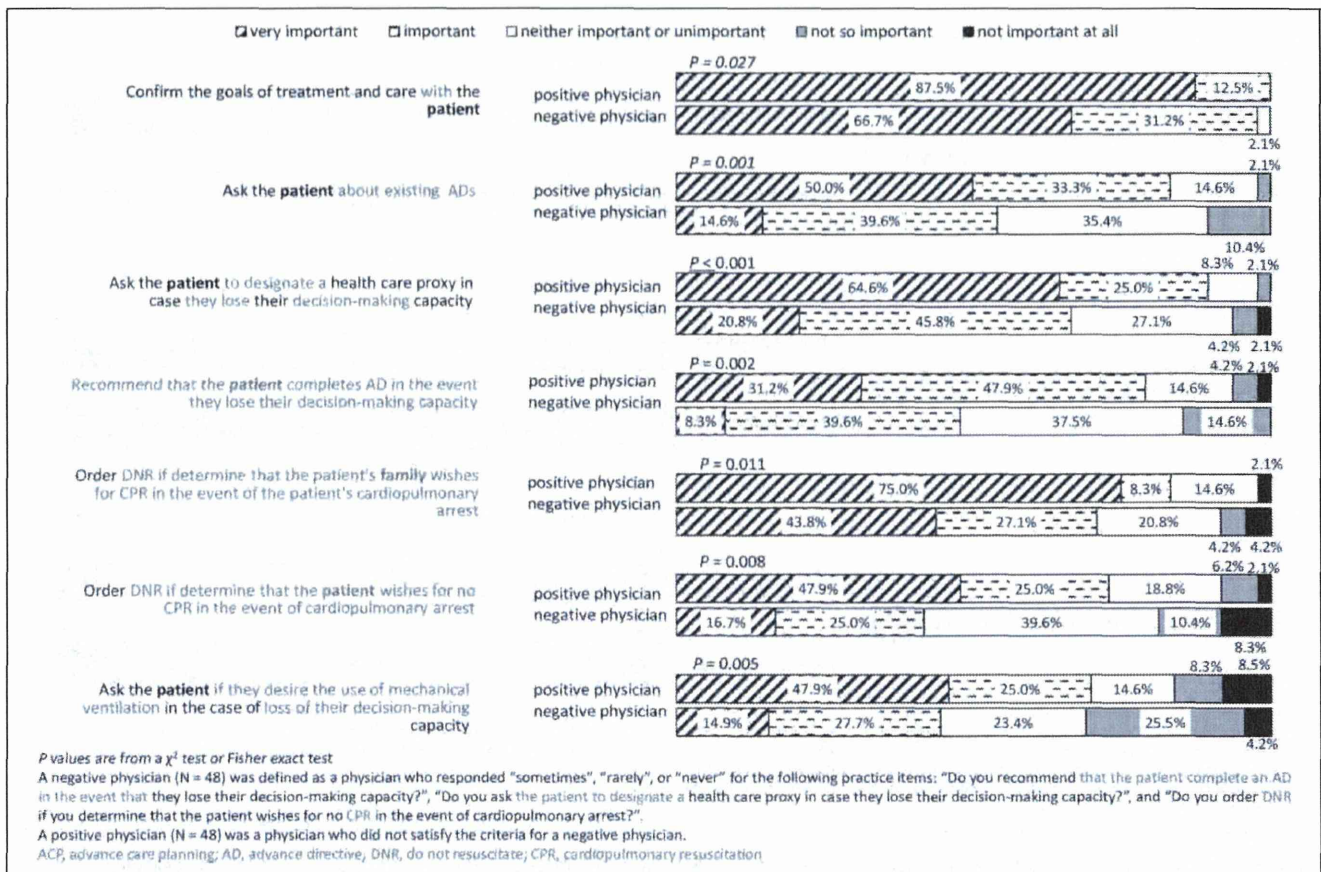


Figure 5. Comparison between the physicians who had positive or negative practices regarding ACP in terms of their recognition of the importance of ACP items. ACP indicates advance care planning.

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 family-centered decision making near the end of life. These findings were expected in view of the results of Sanjo et al¹² 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 communication¹³ 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 decision-making 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%),^{4,7,8,11} 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.

1. Age	() age
2. Gender	1) man 2) woman
3. Clinical experience	() years
4. Palliative care experience*	() years

*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	1	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	1	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	1	2	3	4	5
Ask the patient about existing advance directives	1	2	3	4	5
Recommend that the patients 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	1	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	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	1	2	3	4	5
Encourage sharing of the goals of treatment and care between the patient and family	1	2	3	4	5
Confirm the place of treatment or rest desired by the patient	1	2	3	4	5
Ask the patient about existing advance directives	1	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	1	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	1	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	1	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	1	2	3	4	5
Encourage sharing of the goals of treatment and care between the patient and family	1	2	3	4	5
Confirm the place of treatment or rest desired by the patient	1	2	3	4	5
Ask the patient about existing advance directives	1	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
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	1	2	3	4	5

	Very important	Important	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	1	2	3	4	5
Ask the patient if they desire the use of antibiotics in case they lose their decision-making capacity	1	2	3	4	5
Ask the patient if they desire the use of tube feeding in case they lose their decision-making capacity	1	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	1	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	1	2	3	4	5
Advance care planning would reduce family discord over decisions to withhold treatment	1	2	3	4	5
I am concerned that advance care planning will lead to acceptance of euthanasia	1	2	3	4	5
Widespread use of advance care planning could help contain medical expenditures	1	2	3	4	5
It is important for patients to be able to influence their medical treatment should they lose competence	1	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	1	2	3	4	5
Patients would worry less about unwanted treatment after making advance directives	1	2	3	4	5
Prolonging life is more important than honoring a patient's request to withhold heroic treatment	1	2	3	4	5
A potential problem with advance directives is that patients could change their minds about heroic treatment after becoming terminally ill	1	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	1	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	1	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	1	2	3	4	5

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One-year Follow-up of an Educational Intervention for Palliative Care Consultation Teams

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Objective: This study explored how an educational intervention affects interdisciplinary palliative care consultation teams.

Methods: A pre-post questionnaire survey conducted before the intervention, as well as immediately, 3, 6 and 12 months later. The outcome measurements were behavior (four domains—17 items) and confidence (one domain—6 items).

Results: Of the 252 workshop participants (63 teams), 248 submitted a pre-intervention response, 240 responded immediately after, 198 after 3 months, 197 after 6 months and 184 after 12 months. The behavior domain score significantly increased from pre- to 12 months post-intervention, as follows: 'regional partnership and consultation availability from medical personnel in region', from 15.0 to 17.8 ($P < 0.001$, effect size = 0.59); 'direct practice or care by member', from 12.8 to 13.4 ($P < 0.001$, effect size = 0.26); 'provision of information to patient and family', from 11.4 to 12.5 ($P < 0.001$, effect size = 0.42). The confidence score for palliative care consultation teams activities significantly increased from 18.5 pre-intervention to 20.2 at 12 months later ($P < 0.001$, effect size = 0.37). By the analysis according to the profession of the team member, the score changes for physicians and psychiatrists were larger than that for nurses and pharmacists.

Conclusions: Participant behavior and confidence scores significantly increased after the educational intervention for the interdisciplinary team. In particular, physicians and psychiatrists showed the largest change. Future studies are needed to confirm the findings.

Key words: palliative care – interdisciplinary team – educational intervention – evaluation – questionnaire – Japan

INTRODUCTION

Palliative care consultation teams (PCTs) were established from the early 1990s in Western countries. The concept of PCTs has widened further in the 20 years hence, with the aim of maximizing symptom palliation, and these teams are

playing important roles in the UK, USA, Canada and Australia (1–4). The effectiveness of PCTs has been investigated by systematic review (5), randomized controlled trials (6,7), historical control studies (8–11), audit surveys of symptom severity (12,13), descriptive studies of PCT

recommendations (14–16), satisfaction surveys of relevant medical staff (17,18), an examination of changes in patient insight (19) and cost-effectiveness analysis (20).

In Japan, hospital-based PCTs are playing an increasingly important role, with several hospitals routinely reporting PCT activities and effectiveness (21,22). The National Cancer Program strongly supports the dissemination of palliative care (23). Since National Medical Insurance started to cover inpatient palliative care units for terminal cancer patients in 1990, such units have dominated palliative care service. However, more than 90% of cancer deaths occur in hospitals (24), and the adequacy of cancer patient care in these settings has been questioned (25–27). In response to the needs of cancer patients, the National Medical Insurance scheme began to cover palliative care consultation services in 2002. In addition, Designated Cancer Hospitals were required to establish PCTs from 2006. Consequently, the number of PCTs established in Japan rapidly increased following the change in government policy, and the number of Designated Cancer Hospitals reached 351 in 2008 (28). The government released the following statements for establishing a PCT (29): (i) a PCT should include a palliative care physician, psychiatrist, nurse and pharmacist and provide palliative care for cancer patients; (ii) palliative care can be provided at outpatients; (iii) the PCT holds care meetings to discuss patient symptom management at least once a week; (iv) sufficient information is provided to cancer patients; (5) the attending physician and the PCT provide patients with information and education regarding palliative care before discharge, collaborating with their home care doctor and (6) a palliative care network with other hospitals and home care agencies in the same region is established. However, the statement lacked enough detail for the PCT to entirely understand their required roles and activities in palliative care. In a previous study, 30% of Designated Cancer Hospitals in Japan reported that PCT consultation services were unavailable for more than 50% of the business hours on weekdays (30). The issue now is to improve quality and effectiveness of PCT activities.

To improve the activities of PCTs, we implemented educational workshops for an interdisciplinary team with the National Cancer Center for PCTs within Japanese Designated Cancer Hospitals. The effectiveness of interdisciplinary education has been investigated in the USA (31–33). These studies showed that an interdisciplinary educational intervention improves role understanding and strengthens participants' confidence and comfort. To develop a useful educational program, this study evaluated the effectiveness of an educational intervention delivered to a palliative care team, measuring self-perceived changes in behavior, and learner's confidence.

METHODS

DESIGN

This study design was a one-group pre- and post-survey with 1-year follow-up.

PARTICIPANTS AND PROCEDURES

The subjects of the surveys were participants of a PCT workshop that we implemented four times from December 2008 to August 2009. The PCTs voluntarily enrolled in this workshop across the country in response to announcements by prefectural government and on the National Cancer Center homepage. The subjects received the questionnaire and were informed of the survey protocol. Consenting participants replied to the survey anonymously.

The study comprised five surveys (pre-intervention, as well as immediately, 3, 6 and 12 months after the interventions) to examine the time course of measured changes appearing after the educational intervention. The surveys were conducted from December 2008 to September 2010 using the outcome measurements that we developed. We distributed the pre-intervention questionnaire at the workshop, and the other questionnaires were mailed to all participants. Reminders were sent to subjects that had not responded within 1 month.

INTERVENTION

Table 1 outlines the PCT educational program, which aimed to improve the quality of PCT activities. The program was developed based on literature review and expert opinions (five palliative care specialized physicians, five psycho-oncologists, four board-certified pharmacist in Palliative Pharmacy, two certified nurse specialists in Cancer Nursing and four certified nurse specialists in Palliative Care). The educational intervention was run for the interdisciplinary team over 2 days. In this program, we made four members into the unit of the team, with the precondition that four PCT members with different professions participated (palliative care physician, psychiatrist, nurse and pharmacist) to promote the team building and to enhance a cooperative relationship. For the group work, 'experts', as defined above, were placed in each group as facilitator.

QUESTIONNAIRE

We developed novel instruments to quantify the behavior and confidence of workshop participants regarding PCT activities because no such measurement was available.

First, we generated items based on literature reviews and focus group interviews with 12 past workshop participants (three physicians, three psychiatrists, three pharmacists, three nurses). Second, to examine content validity, we adopted a modified Delphi method one-phase measure conducted by 10 PCT 'experts' (four palliative care specialized physicians, one psycho-oncologist, three certified nurse specialists in Palliative Care, one board-certified pharmacist in Palliative Pharmacy and one psychotherapist) (34). More importantly, these PCT 'experts' were not involved in developing the educational program. Third, we did a development phase test of the preliminary items using past workshop participants 179 (response rate 70%). The authors then discussed the items based on the development test results and reduced the number. Finally, we

Table 1. PCT workshop programme

Session	Programme/outline	Method	Time (min)
Day 1			
1	Key note speech Orientation	Lecture	15
2	Palliative care overview Review principles of palliative care and roles of PCT	Lecture	45
3	Ice braking Introduction of someone else in a group	Group work	15
4	Clarifying issues related to consultation activities Identify problems and issues that PCTs have in group work by the KJ method (brain storming)	Group work	75
5	The group work according to the specialty Recognize each specialized role and discuss ways to play the role	Group work	120
Day 2			
6	The review of consultations See the trigger video about difficult situations on which to provide consultation for palliative care and discuss how to rectify these situations and presentation through role play	Group work and role play	120
7	A method to provide palliative care in community How to encourage regional collaboration	Lecture	75
8	The goal setting of the team Based on PCT's problems and issues and make some concrete action plan	Group work	120

PCT, palliative care consultation team.

conducted a validation test of two measurements using past workshop participants 182 (response rate 97%). The reliability and validity of our two measurements were confirmed.

BEHAVIOR REGARDING CHANGE IN PCT ACTIVITIES

The measurement to quantify participant behavior with respect to PCT activities comprised four domains: discussion of therapeutic measures used by the PCT and recommendation to clients; regional partnerships and consultations available with local medical personnel regarding palliative care; direct practice or care by PCT member; provision of palliative care information in a popular way to patients and their families, with 17 items (Cronbach's alpha coefficients 0.78–0.88, intraclass correlation coefficients 0.73–0.81, goodness of fit index = 0.87, adjusted goodness of fit index = 0.83). This measurement was evaluated by agreement with statements on

a Likert-type scale from 1 (never) to 5 (always). A higher score indicated a higher level of behavior.

CONFIDENCE ABOUT PCT ACTIVITIES

To quantify confidence in PCT activities, our measure comprised six items for the four domains of the behavior measure and the overall team activities (Cronbach's alpha coefficients 0.75, intraclass correlation coefficients 0.86). This measurement was evaluated by agreement with statements on a Likert-type scale from 1 (not confident at all) to 5 (very confident). A higher score indicated a higher level of confidence.

ACTIVITY STYLE OF PCT MEMBER

To evaluate activity style after the educational intervention, we asked the respondents about their working style as a PCT member and the number of patients consulted as PCT member in the past year.

STATISTICAL ANALYSES

Descriptive statistics were calculated regarding participant characteristics. The time change in behaviors and confidence were analyzed using a generalized estimating equation method, and we calculated the effect size of changes from pre-intervention to 12 months after. The relationships between behaviors and confidence before and after the intervention was estimated by dividing the change in behavior into three groups (behavior total score mean difference between before educational intervention and 1 year later; activities ± 0 = lowest–0, activities $+$ = 0–4 (median), activities $++$ = 4–highest), and comparing the confidence score mean difference between before educational intervention and 1 year later: of each group.

Statistical analysis was performed using SAS ver. 9.1. The significance level was set at <0.05 (two-tailed).

The Institutional Review Board of the National Cancer Center approved the ethical and scientific validity of this study.

RESULTS

Of the 252 study participants (across 63 teams), 248 submitted a pre-intervention response, 240 responded immediately after the educational intervention, 198 after 3 months, 197 after 6 months and 184 after 12 months. Table 2 summarized the characteristics of the respondents, of which 54% had <2 years experience in the PCT. There were nine physicians who make palliative care a specialty (18.3%), whereas 32 nurses received the Certified Nurse and Certified Nurse Specialist education about palliative care (65.3%). There were no significant differences between these characteristics at pre–post and follow-up.

ACTIVITY STYLE OF PCT MEMBER

The changes over time in the PCT member's activity style are outlined in Table 3. PCT duties as a percentage of the

Table 2. The characteristics of participants (*n* = 248)

	<i>n</i> (%)
Sex	
Male	130 (52)
Female	117 (47)
Age	
20s	12 (5)
30s	105 (42)
40s	92 (37)
50s	34 (14)
≥60	3 (1)
Professions	
Physician	63 (25)
Psychiatrist	60 (24)
Nurse	62 (25)
Pharmacist	63 (25)
Clinical experience/year	
1–4	10 (4)
5–9	47 (19)
10–19	108 (44)
20–29	69 (28)
≥30	10 (4)
Experience of activities in PCT/year	
0	6 (2)
<2	128(52)
2–4	72 (29)
4–6	28 (11)
6–8	9 (4)
>8	1 (0)
Training attendances in past year about palliative care per total time	
0	54 (22)
1–4	106 (43)
5–9	38 (15)
≥10	47 (19)

participant’s total duties significantly increased ($P = 0.003$), while 51% or more of the PCT duties ratio varied from 28% at pre-test to 36% after 12 months. The number of patients consulted by the PCT member as a percentage of their total patient consults in the past year also significantly increased ($P = 0.002$), with reports of 100 or more ranging from 22% at pre-test to 34% after 12 months.

BEHAVIOR ABOUT PCT ACTIVITIES

Table 4 shows the changes over time in behavior regarding the PCT activities. The domain score of regional partnership and consultation availability from medical personnel in the region

Table 3. The changes over time of PCT member’s activity style

		Percent				<i>P</i> -value ^a
		Pre- intervention (<i>n</i> = 248)	After 3 months (<i>n</i> = 198)	After 6 months (<i>n</i> = 197)	After 12 months (<i>n</i> = 184)	
Working style as PCT member						
Full time	22	23	26	28	0.113	
Part time	79	77	74	71		
PCT duties/total duties (%)						
0	2	1	2	2	0.003	
1–25	50	55	51	44		
26–50	18	16	14	16		
51–75	9	8	8	9		
76–100	19	21	24	27		
The consulted number of patients as PCT member in past 1 year/case						
0	4	1	1	1	0.002	
1–9	12	13	10	9		
10–49	40	35	35	34		
50–99	21	21	21	21		
≥100	22	30	31	34		

^aGeneralized estimating equation method.

significantly increased from 15.0 at before to 17.8 at after 12 months across all professions ($P < 0.001$, effect size = 0.59), while the domain score of direct practice or care by palliative consultation team changed from 12.8 at before to 13.4 at after 12 months across all professions ($P < 0.001$, effect size = 0.3), and the domain score of provision of information in a recognizable way to patient and family about palliative care changed from 11.4 at before to 12.5 at 12 months across all professions ($P < 0.001$, effect size = 0.4). The changes in domain score were larger for physicians and psychiatrists than for nurses and pharmacists.

CONFIDENCE ABOUT PCT ACTIVITIES

Table 5 lists the changes over time of confidence in PCT activities. The total score significantly increased from 18.5 at before to 20.2 at after 12 months across all professions ($P < 0.001$, effect size = 0.4). By the type of profession, the changes in the total score of physicians and psychiatrists were larger than those of nurses and pharmacists. In addition, the change in confidence score was bigger when the change of the behavior was also bigger (Fig. 1).

DISCUSSION

Herein, we report a pre–post survey study to evaluate the effects of an educational intervention on behavior and confidence

Table 4. The changes over time in behaviour regarding PCT activities

Domain	Domain score mean ^a (± SD)				Effect size ^b	P-value ^c
	Pre- intervention (n = 248)	After 3 months (n = 198)	After 6 months (n = 197)	After 12 months (n = 184)		
Discussion about therapeutic measures in PCT and recommendation to clients (range 6–30)						
Total	24.5 (± 3.7)	24.7 (± 3.9)	25.4 (± 3.5)	25.4 (± 3.7)	0.23	0.026
Physicians	25.2 (± 3.5)	25.4 (± 3.9)	25.8 (± 3.3)	26.1 (± 2.8)	0.28	0.263
Psychiatrists	24.4 (± 4.3)	25.0 (± 3.5)	25.7 (± 3.8)	25.9 (± 3.2)	0.39	0.280
Nurses	24.1 (± 3.7)	24.1 (± 3.5)	24.7 (± 3.6)	24.3 (± 4.1)	0.07	0.553
Pharmacists	24.5 (± 3.4)	24.3 (± 4.5)	25.6 (± 3.1)	25.3 (± 4.5)	0.20	0.320
Regional partnership and consultation availability from medical personnel in region about palliative care (range 5–25)						
Total	15.0 (± 5.2)	16.0 (± 4.8)	16.9 (± 4.3)	17.8 (± 4.0)	0.59	<0.001
Physicians	15.5 (± 5.4)	15.6 (± 5.5)	16.8 (± 4.9)	18.0 (± 3.8)	0.53	<0.001
Psychiatrists	14.4 (± 4.9)	16.1 (± 4.8)	17.2 (± 4.0)	19.2 (± 3.7)	1.13	<0.001
Nurses	14.4 (± 5.5)	16.0 (± 4.6)	16.1 (± 4.5)	16.0 (± 4.2)	0.32	0.046
Pharmacists	15.9 (± 4.8)	16.3 (± 4.4)	17.8 (± 3.7)	18.4 (± 3.6)	0.59	<0.001
Direct practice or care by PCT member (range 3–15)						
Total	12.8 (± 2.7)	12.8 (± 2.8)	13.2 (± 2.4)	13.4 (± 2.4)	0.26	<0.001
Physicians	12.4 (± 3.1)	12.7 (± 2.8)	13.2 (± 2.5)	13.4 (± 2.4)	0.37	<0.001
Psychiatrists	12.7 (± 2.8)	13.0 (± 2.8)	13.2 (± 2.3)	13.4 (± 2.3)	0.24	0.441
Nurses	13.1 (± 2.6)	13.0 (± 3.1)	13.1 (± 2.8)	13.6 (± 2.3)	0.21	0.887
Pharmacists	12.8 (± 2.3)	12.5 (± 2.5)	13.3 (± 1.9)	13.3 (± 2.7)	0.20	0.009
Provision of information in a recognizable way to patient and family about palliative care (range 3–15)						
Total	11.4 (± 3.2)	11.8 (± 3.0)	12.4 (± 2.5)	12.5 (± 2.5)	0.42	<0.001
Physicians	11.5 (± 3.1)	11.8 (± 3.1)	12.2 (± 2.4)	12.9 (± 2.1)	0.54	0.020
Psychiatrists	10.6 (± 3.3)	11.7 (± 3.3)	12.7 (± 2.3)	13.0 (± 2.2)	0.90	<0.001
Nurses	11.3 (± 3.5)	11.8 (± 3.1)	12.1 (± 2.8)	12.0 (± 2.9)	0.20	0.536
Pharmacists	11.9 (± 2.6)	12.0 (± 2.6)	12.6 (± 2.4)	12.3 (± 2.7)	0.14	0.281

SD, standard deviation.

^aEach domain score was calculated as the total score of each item from 'never' (1) to 'always' (5).

^bChange from pre-intervention to 12 months later.

^cGeneralized estimating equation method.

regarding PCT activities over time. The major findings were that participant's behavior and confidence scores both significantly increased after the educational intervention, and particularly among physicians and psychiatrists. Second, the PCT duties ratio to total duties and the consulted number of patients as PCT member in the past year increased over time.

ACTIVITY STYLE OF PCT MEMBER

A previous study associated the presence of a full-time physician with the number of referrals to a PCT (30). However, the findings of this study suggested that the activity of the team increased independently of working style of the PCT members (full time vs. part time). There is a limit to the number of members who can be secured for full-time duties

with any given PCT. Therefore, an educational program that improves the quality of consultation services the PCT can provide regardless of time and resource limits is clearly necessary.

BEHAVIOR REGARDING PCT ACTIVITIES

The all-domain score regarding PCT activities in this study also significantly increased after the educational intervention, and this increase was more pronounced among physicians and psychiatrists compared with nurses. This finding could reflect that many nurses in this study already had an advanced education in palliative care gained through their nursing certification specialty, whereas physicians and psychiatrists have insufficient access to education about palliative medicine in Japan.

Table 5. The changes over time in confidence regarding the PCT activities

	Total score mean ^a (\pm SD) (range 6-30)					Effect size ^b	P-value ^c
	Pre- intervention (n = 248)	Immediately after (n = 240)	After 3 months (n = 198)	After 6 months (n = 197)	After 12 months (n = 184)		
Total	18.5 (\pm 4.2)	18.2 (\pm 4.0)	19.2 (\pm 4.3)	19.8 (\pm 4.7)	20.2 (\pm 4.8)	0.37	<0.001
Physicians	20.0 (\pm 3.9)	19.5 (\pm 4.0)	20.5 (\pm 3.9)	21.5 (\pm 4.3)	22.6 (\pm 4.1)	0.66	<0.001
Psychiatrists	18.3 (\pm 4.1)	18.7 (\pm 3.8)	20.4 (\pm 4.4)	20.6 (\pm 4.1)	20.8 (\pm 4.3)	0.59	0.003
Nurses	17.8 (\pm 4.2)	17.4 (\pm 3.7)	18.4 (\pm 3.9)	18.9 (\pm 4.7)	19.0 (\pm 4.0)	0.28	0.112
Pharmacists	17.8 (\pm 4.4)	17.2 (\pm 4.1)	17.7 (\pm 4.6)	18.2 (\pm 5.1)	18.1 (\pm 5.3)	0.06	0.493

^aTotal score was calculated as the total score of each item from 'not confident at all' (1) to 'very confident' (5).

^bChange of from pre-intervention to 12 months later.

^cGeneralized estimating equation method.

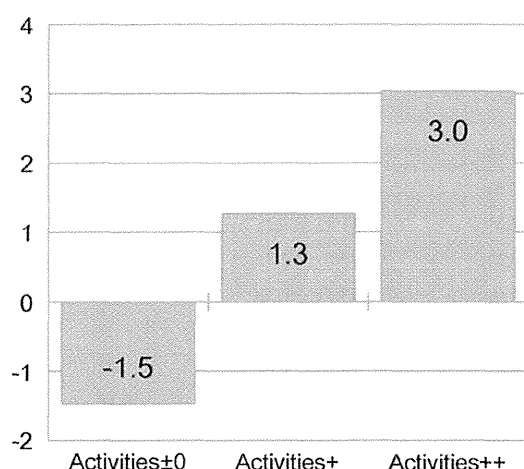


Figure 1. Comparison of confidence score mean difference before intervention and 1 year later by the activities categories. Activity categories: Behavior total score mean difference between before educational intervention and 1 year later: Activities \pm 0, Lowest-0, Activities+ = 0-4 (median), Activities++ = 4-Highest.

This educational intervention was designed to provide interdisciplinary learning for an interdisciplinary team, and this approach has distinct advantages. First, the team members can together explore similarities and differences in roles, skills, knowledge and ideologies. Second, they can begin to recognize the complementary skills and resources of different provisions. They are also placed in a position whereby they can learn to acknowledge parity of esteem for their contributions to the care of patients and their carers. Finally, interdisciplinary education also provides scope for greater open communication by all members within a group (35). These advantages might have influenced the reported effects.

In addition, experts acted as facilitators in this educational intervention. Such an approach can enhance both individual and group learning, through more flexible learning opportunities during the workshop and increased relevance to the participant's different learning needs overall. The close

tutoring of participants by facilitators was viewed as a particular strength of this educational intervention.

CONFIDENCE REGARDING PCT ACTIVITIES

After the educational intervention, confidence scores increased significantly. A similar increase in confidence after interdisciplinary training was also identified by previous research (32). The participants recognized that increased cooperation within the PCT during the workshop might have influenced this observed increase in confidence, in that PCT members were better equipped to work together to solve clinical problems and support each other following the educational workshop. Relationships among the team members and PCT communication in general were also enhanced through the group work, which could also have increased the participants' confidence in team activities.

This study has several limitations. First, we measured self-reported outcomes. It is hard to judge the effects of educational intervention using only the participants' evaluation. To evaluate the effects of educational intervention correctly, we should independently examine both consultation user outcomes and patient outcomes including the change of clinical symptoms and quality of life, as well as the relationship between improvement in participants' self-reported score and these outcomes. It will be necessary to conduct these surveys in the future. Moreover, the quality of palliative care as a real outcome of the educational intervention care should be evaluated against patient or bereaved family outcomes (36-38). Second, this study could have a potential selection bias of participants that might limit the generalizability of the findings in other populations. On the pre-intervention survey, about half of PCTs played an active role only in a quarter of the work hours. Thus, many PCTs were unfamiliar with how to consult in their hospitals. The natural process of team building or the effects of on-the-job experience for 1 year might have influenced the change in self-reported outcomes. To exclude these factors, it may be valid to conduct

a control trial. However, we believe that this is an unlikely possibility and conclude instead the changes were due to not only the team-building outcome, but also the significant changes in other outcomes.

CONCLUSION

The educational intervention would be improved by enhancing the participant's behavior and confidence regarding PCT activities. In particular, physicians and psychiatrists showed the largest change. It will be necessary to confirm the findings in future and to determine an objective outcome measures.

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Conflict of interest statement

None declared.

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APPENDIX

Measurement items of behavior about PCT activities

Discussion about therapeutic measures in PCT and recommendation to clients

- We discuss the division of each role with PCT members
- We discuss the issues and the policy of PCT with PCT members
- When the opinion is divided among PCT members, we discuss until get it
- When PCT members do the assessment and the recommendation, we confirm needs and intentions of clients
- When PCT members do the recommendations, we aim for what primary team can practice
- When we recommend the methods to relieve a symptom, we present some choices

Regional partnership and consultation availability from medical personnel in the region about palliative care

- We exchange information about patients on telephone or conference with clinic, home-visit nursing station or hospice in region
- We hold a conference with healthcare workers in region to become 'the relations to be able to see of the face'
- We hold a workshop or a seminar about palliative care more than once a year for healthcare workers in the region
- We provide consultation for healthcare workers in region
- Consultation is available during night-time and holiday by on call or surrogation

Direct practice or care by palliative consultation team member

- Somebody of PCT members goes the direct rounds on inpatients more than once a week
- Somebody of PCT members can do the direct care on inpatients during business hours on weekdays
- When consultation is complicated, somebody of PCT members goes the direct care on the patient every day

Provision of information in a recognizable way to patient and family about palliative care

- A pamphlet about palliative care is put in an obvious place for outpatients
 - We inform the patients and the family clearly about accessing the PCT
 - We inform the patients and the family clearly about the PCT activities by pamphlet, poster and online
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Original Article

Changes in Quality of Care and Quality of Life of Outpatients With Advanced Cancer After a Regional Palliative Care Intervention Program

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Abstract

Context. A recent mixed-methods study to evaluate the effects of a comprehensive regional palliative care program, the Japan Outreach Palliative Care Trial of the Integrated Model study, achieved broad positive outcomes at a regional level. This is a secondary analysis of patient outcomes.

Objectives. The primary aims were to explore: 1) the changes in domains of patient-reported quality of care and quality of life after interventions, and 2) the changes in quality of care and quality of life of patients with different characteristics (i.e., performance status, age, and anticancer treatment).

Methods. A region-representative sample of metastatic/locally advanced cancer patients in outpatient settings participated in questionnaire surveys before and after regional intervention. Responses were obtained from 859 of 1880 and 857 of 2123 in the pre- and postintervention surveys, respectively.

Results. All subdomain scores of the quality of care, except for help with decision making, significantly improved in the postintervention survey. The percentages of the patients who reported that improvement was necessary decreased from 13% to 5.0%. Although there were no or only a marginally

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