The parameter with the highest value explaining the necessity for improvement was the family perceived evaluation that the amount of prognosis information was insufficient (beta = 0.39, $P < 0.001$). Furthermore, family perception of loss of hope and usefulness of the prognosis in the preparation for patient death had significant direct effects on the necessity for improvement (beta = 0.21, $P < 0.001$ and beta = −0.18, $P < 0.001$, respectively). There were also three communication strategies that explained the necessity for improvement, as follows: "The physician said, 'I can do nothing for the patient any longer'" (beta = 0.11, $P = 0.005$), "The physician paced his/her explanation with the state of my/patient's preparation" (beta = −0.21, $P < 0.001$), and "The physician said, 'We will respect the patient's wishes'" (beta = −0.10, $P = 0.013$).

Discussion

In Japan, family members have a special role in communicating bad news, including predicted prognosis.[19] However, only a few empirical studies have specifically addressed the preferences and experiences of family members in receiving information about the patient's prognosis,[18] and familial views on optimal ways of presenting the prognosis have not

been explored. This is, to our knowledge, the first large, multicenter survey to investigate family reported experiences in receiving prognostic disclosure.

Our survey revealed the experience of families of patients with cancer in Japan in receiving prognostic disclosure. Over 80% of the families received prognostic disclosure. This agrees closely with results of a previous Japanese study.[19] The proportions of subjects who received each type of disclosure were told specific periods with some ranges or probability (40% in the previous survey vs. 52% in our survey) and told definite periods without ranges or probability (38% vs. 34%, respectively). In contrast, over 45% of the subjects answered that the patients were not told specific periods about their prognosis. These data support the view that Japanese family members have a special role in communicating prognosis, and it seems to be important for physicians to consider methods of communicating a patient's prognosis to family members. This study also demonstrated that 60% of family members reported that some, considerable, or much improvement was necessary in the methods of prognostic disclosure. This result suggests that methods in prognosis disclosure would need more improvement in general.
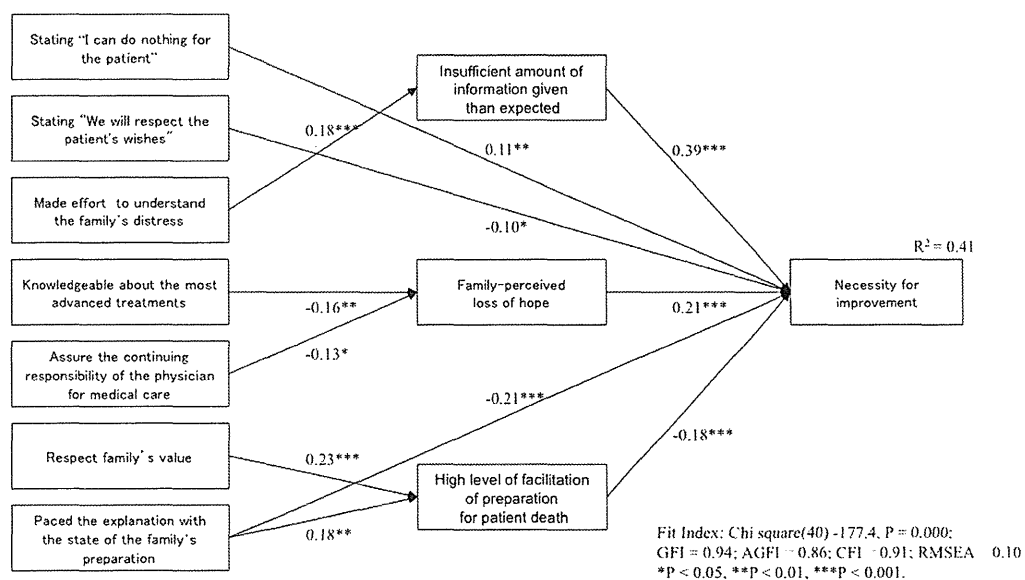

Fig. 1. Model for the relevant factors for family-perceived need for improvement.

The most important finding in the present study was the clarification of the determinants of the necessity for improvement in prognostic disclosure. Using path analysis, we determined that 41% of the variance for increased perceptions for the necessity for improvement was related mainly to the five variables: 1) insufficient amount of information given than expected; 2) loss of hope and failure in facilitation of preparation for patient death; 3) not providing information carefully in consideration of the family's preparation; 4) stating "Nothing can be done;" and 5) not stating "We will respect the patient's wishes."

First, the disclosure of an insufficient amount of information than expected had the largest effect on the necessity for improvement. In a previous study of parents of pediatric patients with cancer, almost all participants wanted as much information as possible about the prognosis, although they found the prognostic information very upsetting.[8] It also is said that 69.6% of caregivers of Korean cancer patients want to know their own terminal condition.[29] The results of the present study show that this may be similar in the case of Japanese adult patients. Physicians, therefore, should comprehend family members' needs and communicate as much information as the family members want.

Second, the results of this study suggested that maintaining the family's hope and facilitating their preparation for a patient's death have a significant and moderate effect on the family member's evaluation of the prognosis communication. In previous studies of patients with cancer, both maintaining patients' hope and helping them prepare for death were of great importance for patients.[5] The present study confirmed that these two factors are equally important in terms of the patient's family also. Maintaining hope while simultaneously preparing for a patient's death seems contradictory, and thus, it may represent a difficult issue for physicians. For patients, a useful way of accomplishing this task is to acknowledge all of the possible outcomes and to expand their planning goals to include both recovery and death.[5,20] In this study, loss of hope was significantly accounted for by the two descriptions: "The physician was knowledgeable about the most advanced treatments" and "The physician assured continuing responsibility as the physician for medical care." One possible interpretation of this result is that hope for family members means receiving assurance of continuing responsibility for medical care by a physician who is knowledgeable about up-to-date treatments. In addition, the type of disclosure they received affected the facilitation of preparation for patient death: "The physician paced his/her explanation with the state of my/patient's preparation" and "The physician respected my values." This finding means that although detailed prognostic information helps families in preparing for a patient's death, it is important to provide information with careful consideration for families' preferences and values. These results confirm that maintaining hope and preparing for death need not be mutually exclusive.[5]

Third, about 30% of the family members reported that the physician said she/he could do nothing for the patient, and this experience had a strong influence on the family-perceived necessity for improvement. This result was consistent with a finding from a previous study that indicated that both patients and families received the phrase from physician "I can do nothing for the patient any longer" with serious negative emotions when they were informed of the ending of cancer treatment.[19,30] From this finding, physicians are advised to emphasize what they can do, such as providing symptom control, instead of stating "nothing can be done" in the prognostic disclosure.

It is notable that family members who were told the physician will respect the patient's wishes reported a lower level of necessity for improvement. It is also noted that the disclosure of prognostic information as it corresponds to patient's values is essential for patients to make decisions about the terminal phase.[31] At the same time, over 70% of physicians in Japan have experience of not telling patients their prognosis according to the request of family members.[22] The results of the present study indicate the possibility that many family members have a conflict between their wish to respect the patient's wishes and their hesitancy about communicating the prognosis to the patient. Thus, in prognosis disclosure, physicians should assure the family of the intent to respect the patient's wishes while also conferring with the family on how to achieve this.

This study had several limitations. First, as the response rate was not very high (64%), the study subjects might not be representative of the population. Second, the study subjects were limited to the families of patients who had been admitted to PCUs, and the findings might not be applicable to families in other settings. Moreover, prognostic disclosure is sometimes required for admission to a PCU; thus, the amount of disclosure might be higher than in a general ward. The future survey of families of patients who had not been admitted to PCUs will be expected as the next step. Third, due to a lack of validated instruments, primary endpoints were measured without formal reliability and validity testing. Fourth, some factors that might be relevant, such as symptom distress and experience of anticancer therapy, were not analyzed as to whether they might influence the perception of prognostic communication. Fifth, this study depended on the retrospective evaluation of bereaved family members, and recall bias could exist. Confirmation of the findings will require prospective observational or interventional studies. Finally, due to the lack of comparable studies, we compared our results mainly with those of patient surveys, but preferences might be different between patients and families.

Conclusion

When receiving communication about a patient's prognosis, 60% of bereaved family members reported that some, considerable, or much improvement in the communication methods was necessary. Strategies for care providers to improve family perception include 1) providing as much prognostic information as families want; 2) supporting families' hopes by keeping up with up-to-date treatments and by assuring continuing responsibility as the physician for medical care; 3) facilitating the preparation for death by providing information in consideration of the family's preparations and values; 4) stressing what they can do instead of saying that nothing can be done for the patient; and 5) assuring the family that they will respect the patient's wishes. These suggested communication strategies should be tested in future prospective observational or interventional studies.

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ORIGINAL ARTICLE

A qualitative study of mindfulness-based meditation therapy in Japanese cancer patients

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Abstract

Purpose The primary objective of the study was to examine mindfulness-based meditation therapy qualitatively. A secondary goal was to examine the differences in themes selected by Japanese and Western patients receiving this therapy.
Methods The subjects were 28 patients who were undergoing anti-cancer treatment. The subjects participated in two sessions of mindfulness-based meditation therapy, including breathing, yoga movement, and meditation. Each patient was taught the program in the first session, then exercised at home with a CD, and subsequently met the interviewer in a second session after 2 weeks. Primary physicians recruited the patients and interviews were conducted individually by nurses or psychologists with training in the program. Patients provided answers to pre- and post-intervention interviews about the meaning of their illness.
Results Narrative data from the semi-structured interview were analyzed qualitatively. Pre-intervention, themes such as "*Effort to cope,*" "*Looking back,*" "*Spirituality,*"

"*Personal growth,*" and "*Suffering*" were often chosen. Post-intervention, themes such as "*Adapted coping,*" "*Personal growth,*" "*Positive meaning,*" "*Spirituality,*" and "*Negative recognition*" were more commonly chosen. *Conclusions* Mindfulness-based meditation therapy may be effective for producing adapted coping, including positive recognition and changes for an adapted lifestyle. There were some common aspects and some differences in the themes selected by patients in this study and Western patients received mindfulness therapy in other studies.

Keywords Meditation therapy · Cancer patients · Adapted coping style

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Introduction

Patients receiving anti-cancer treatment experience physical problems such as pain, fatigue, and nausea and psychological problems such as anxiety, depression, distress [1–3], and spiritual pain. A mindfulness approach is an effective intervention from a psychological perspective. The Mindfulness-Based Stress Reduction (MBSR) program was modeled on the work of Kabat-Zinn [4] and colleagues at the Center for Mindfulness-Massachusetts Medical Center. The program is based on the principal of mindfulness, defined as moment-to-moment, present-centered, purposive non-judgmental awareness. The goal of the MBSR program is to guide participants to achieve greater awareness of themselves, their thoughts, and their bodies through class discussion, meditation, and yoga exercises.

For cancer patients, Speca et al. [5] showed effects of the MBSR on mood disturbance and stress symptoms and Carson et al. [2] showed an effect on QOL and the immune profile. Monti et al. [6] showed that Mindfulness-Based Art-

Therapy, which includes mindfulness and art therapy, also produces a significant decrease in symptoms of distress and improvements in key aspects of health-related QOL. Garland et al. [7] examined the effects on spirituality, stress symptoms, and mood of a Healing Art program compared with MBSR Post-Trauma Growth (PTG). Improved growth, a relationship of PTG in MBSR with spirituality, and increased spirituality with related decreases in stress and mood disturbance were found in participants in both groups.

In contrast to these quantitative studies, there have been very few qualitative studies on the experience of participants in MBSR. Mackenzie et al. [8] evaluated nine cancer patients who received a semi-structured interview after an 8-week MBSR program, and five major themes emerged from the data: (1) open to change, (2) self-control, (3) shared experience, (4) personal growth, and (5) spirituality. This study showed that changes could be achieved through MBSR, but it is not clear if the same effects would be observed for Japanese patients. Since Mackenzie et al. performed the study in Western patients, it is also unclear if the same themes will present in Japan. We have previously examined the efficacy of mindfulness-based meditation therapy [9]. In the current study, our primary objective was to evaluate this therapy qualitatively, with a secondary goal of examining possible differences in themes as outcomes of the therapy in Japanese and Western patients.

Patients and methods

Participants

The participants were outpatients who were receiving anti-cancer chemotherapy, radiation, or medication at a general hospital in Western Japan. The patients were >20 years old and were able to undergo an interview for about 60 min in a session. Patients were excluded if they had cognitive impairment or mental disease. These conditions were rated using a numeric rating scale (0–10 points) and patients with a score of above 8 were excluded from the study. Thirty-two patients were registered, but four subsequently dropped out because of a decrease in physical strength. Therefore, a total of 28 patients (four males, 24 females) with a mean age of 60.0 ± 9.2 years old participated in the study. The primary tumor sites were the breast ($n=21$), colon ($n=2$), stomach ($n=2$), and bladder ($n=2$). The performance status ranged from 0 to 2 and all patients were able to visit the hospital.

Outcome measures, interventions, and procedure

We used a modified version of the Mindfulness-Based Stress Reduction Program [4, 10], in which we refer to cyclic meditation as that including both breathing and

meditation. During meditation, patients move their hands or legs to focus their attention (Fig. 1) [9]. The cyclic meditation program takes about 30 to 60 min per session and was conducted by nurses or a clinical psychologist who received training for at least 3 h. The training included basic communication skills and Yoga skills learned directly from a Yoga specialist or using a CD. A primary physician recruited the patients and a clerk obtained informed consent and asked the patients to complete questionnaires pre- and post-intervention. In the pre-therapy session, the patient learned the cyclic meditation program and it was recommended that they perform the therapy at home once a day. After 2 weeks, the patients met the interviewers in a second session to talk about their impressions in a semi-structured interview to establish the patient's "perception of the meaning of the illness". The study was approved by the appropriate institutional ethics committees and was performed in accordance with the ethical standards laid down in the Declaration of Helsinki.

Statistical analysis

The sentences in the patients' replies in the interviews were analyzed line by line and the content was extracted. This content was classified into codes and those with a common meaning were grouped together. Categories and sub-categories were then formed and integrated. Several meetings of investigators were held for this purpose. Strategies for increasing the reliability of the data and analysis included interviews conducted by each
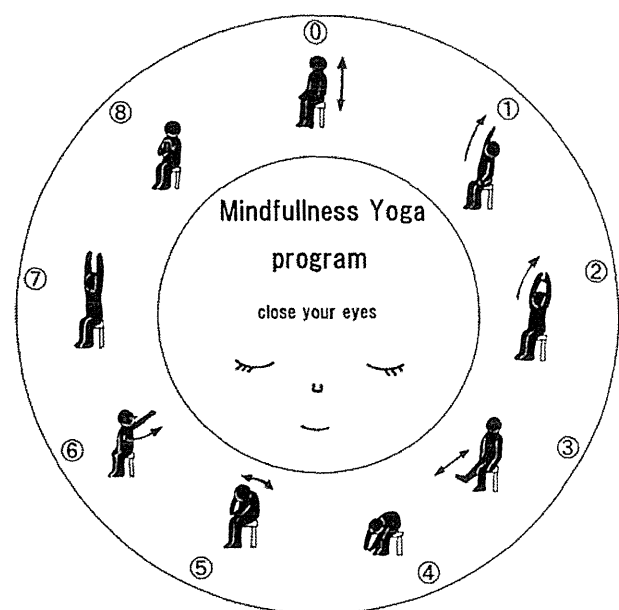

Fig. 1 The cyclic meditation program [9]

investigator, and concurrent data collection and analysis until the data were confirmed. Two researchers coded and categorized the data and the investigator obtained feedback and validation regarding the methods from experts in nursing and qualitative methodology.

Results

The main themes chosen from the data are shown in Tables 1 and 2. Pre-intervention, themes such as *"Effort to cope," "Looking back," "Spirituality," "Personal growth,"* and *"Suffering"* were mostly chosen. Post-intervention,

themes such as *"Adapted coping," "Personal growth," "Positive meaning," "Spirituality,"* and *"Negative recognition"* were commonly chosen.

Discussion

"Personal growth" and *"Spirituality"* were common themes that were chosen pre- and post-intervention. Some of the patients receiving anti-cancer treatment recognized the importance of health, paid attention to this after diagnosis, and appreciated their families and others (*Personal growth*). They also recognized the importance of limited

Table 1 Themes in replies of patients to interviews conducted before mindfulness-based meditation therapy

Small category	Sub-category	Large category
I believe that I will be cured Illness is my destiny	Effort for positive thinking	Effort to cope
I want to recover as soon as possible		
I have accepted my feeling of disbelief		
I feel the limitation of my life		
I try to think positively		
I try not to think deeply		
I want to devote myself to my anti-cancer treatment	Effort for concrete coping	
I am suffering at the moment		
I have to be energetic by myself		
I make my children look after themselves		
I try to enjoy my daily life and spend time fully		
I take care of my physical strength and health in daily life		
Illness is one of my life experiences	Looking back	Looking back
I have reviewed my life until now		
I have thought about my life		
I have lived somehow		
My view of my life has changed		
Illness is a good chance for me to look back at my health and my family		
I have recognized the importance of others	Recognition of importance of limited life or time	Spirituality
I feel the importance of family and people around me		
I recognize the importance of my life		
I value time		
I have begun to have a strong interest in my health and medicine	Paying attention to health	Personal Growth
Illness has been a wake		
A medical check		
I appreciate every day	Appreciation for other people	
I appreciate my family and others		
Why me?	Negative feeling	Suffering
I cannot believe that I have my illness		
I feel fear and anxiety		
I hate my life	Burden and suffering	
I have lost my job		
I worry about the future of my family		
I cannot die leaving my children		

Table 2 Themes in replies of patients to interviews conducted after mindfulness-based meditation therapy

Small category	Middle category	Large category
My grandchildren help me to overcome the illness	Positive recognition	Adapted coping
I was relieved about my treatment		
I recognized the illness positively		
I live with the illness positively		
I want to devote myself to my treatment		
I have kept a good relationship with my husband		
I want to teach things to my children to allow them to be independent		
I enjoy cooking or other things that I have not done before	Changes for an adapted life style	
I am relaxed		
I have put my affairs in order		
I exercise every day for an hour		
I prioritize what to do		
I sleep well with good music		
I spend the day taking care of myself		
The operation is a big event for me	Recognition of health	Personal Growth
I have been indifferent to my health		
I pay attention to my family's and my health		
I will have a medical check-up at any cost		
I appreciate my family and others around me	Appreciation of others	
I feel other people's tenderness		
My feelings toward my family have changed		
I have looked back at my character and behavior	Finding positive meaning	Positive meaning
The illness has shown me that I should rest more		
The illness experience has given me a chance to look back at myself and my family		
I feel the importance of my life	Recognition of the importance of limited life and time	Spirituality
I have been helped and my life is supported by others		
I value each day with thanks		
I was damaged by distrust of the treatment	Negative	Negative recognition
I did not know what to do		
I became ill because of my previous lifestyle		
I have a negative image of my illness		

life or time and relationships with families and others (*Spirituality*).

Pre-intervention, patients had negative feelings such as anxiety or fear, and felt a burden or suffering about their children or work (*Suffering*). They tried to find positive recognition of the illness or concrete coping strategies (*Effort to cope*). Through mindfulness-based meditation therapy, they were able to achieve positive recognition of their illness and to find coping strategies, such as sleeping well with good music, enjoying cooking, or physical exercise (*Adapted coping*).

"*Adapted coping*" includes sub-categories such as "Positive recognition" and "Changes for an adapted lifestyle"; therefore, after therapy the patients were able to positively recognize their illness, changed their lifestyle, and develop their own coping style. These changes can be understood based on the "*Self regulation theory*" of Shapiro [11]. In this model, using the "non-judgment" aspect of mindfulness, people respect each moment and gain access to more information. Conscious intention brings awareness (attention) and acceptance, and participants are better able to use a wider and more adaptive range of coping skills. The patients in the present study achieved insight through meditation and used a wide range of other information to see things from other points of view. Thus, they found their own coping style and achieved positive recognition of cancer, including living with cancer.

However, some patients still had psychological distress after the therapy. These patients had little belief or did not find coping skills. Thus, other therapies, such as cognitive behavior therapy or the problem-solving method, may be useful in these cases.

We found some commonality and some differences between Japanese and Western patients in terms of the themes chosen after therapy. *"Personal growth"* is a common theme seen in previous studies [7, 8, 12, 13]. Mackenzie et al. [8] showed that participants were able to see their illness in a different light, transforming the very meaning of illness through identification of some positive benefit, instead of entirely negative consequences. The *"Spirituality"* category includes dimensions such as achieving meaning of life, faith, purpose, and connection with others and a higher power [14, 15]. Spirituality also included spiritual and religious practice or self-prayer in Mackenzie et al. [8], but such categories were not observed in the present study. Instead, "limited life or time" was chosen by patients in *"Spirituality"*. Therefore, Japanese cancer patients may not think about the meaning of life or their purpose deeply at the stage of treatment; instead they accept their cancer and life naturally.

Moreover, *"Self-Control"* was not chosen in the present study, but was chosen in Mackenzie et al. *"Self-Control"* is defined as the ability of a patient to control their own behavior; for example, a participant in Mackenzie et al. said "I am in better control of myself physically and mentally." In Western culture, patients seem to confront their illness and control themselves, whereas the absence of this theme in the present study indicates that this does not occur in Japanese patients. An attitude of not confronting serious facts in Japanese patients has been found previously [16, 17], and the patients in the present study apparently did not try to control themselves intentionally.

Lastly, we note that cyclic meditation is very easy for patients. It may be hard to develop insight from meditation in usual mindfulness, whereas cyclic meditation therapy makes it easy to pay attention to the body through a focus on movement of the hands or body.

Conclusion

Mindfulness-based cyclic meditation may be useful for Japanese patients under anti-cancer treatment to allow them to find their own positive coping strategies and to adapt their life, although some patients have problems in achieving these goals. There are some commonalities and some differences in outcome themes between Japanese and Western patients.

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Efficacy and Undesirable Effects of Corticosteroid Therapy Experienced by Palliative Care Specialists in Japan: A Nationwide Survey

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Abstract

Background and Methods: Corticosteroids are commonly used for symptom relief in the treatment of patients with advanced cancer. Consistent efficacy of corticosteroid treatment in palliative care remains controversial. A cross-sectional anonymous survey was mailed to representative managing physicians in certified palliative care units in Japan to clarify the physician-perceived efficacy of steroid treatment on anorexia, fatigue, and dyspnea in terminal cancer patients, to clarify physicians' experience of side effects of corticosteroid use, and to determine the Japanese palliative care physician-reported predictive factors for efficacy and lack of efficacy.
Results and Conclusions: Many Japanese palliative care specialists perceived that corticosteroids are effective for each of the symptoms, are aware of the prevalence and importance of serious adverse effects, and predict the effectiveness of steroid therapy by etiological factors.

Introduction

CORTICOSTEROIDS ARE COMMONLY USED for symptom relief in the treatment of patients with advanced cancer, with their initial use reported in the 1970s.[1–4] Indications for corticosteroid use in cancer patients differ according to the broad range of effects of this class of drugs. Specific indications include spinal cord compression, lymphatic carcinomatosis, and raised intracranial pressure, and nonspecific indications include pain, nausea, anorexia, fatigue, a general feeling of being unwell, and malaise. Treatment with corticosteroids is also sometimes associated with potentially serious side effects. Therefore, close monitoring of the patient using the minimum effective dose is recommended, with cessation if no benefit is obtained.

Consistent efficacy of corticosteroid treatment in palliative care remains controversial, with only limited evidence of efficacy from uncontrolled studies.[5,6] There are also only scant data[5,7] on physician-perceived effectiveness as well as side effects of corticosteroid therapy in palliative care settings nationwide. Assessment of treatment effectiveness in terminally ill cancer patients with severe symptoms and a short life expectancy is indeed difficult; thus, analysis of the clinical practice experience and perceptions of palliative care experts may be useful. The aims of this nationwide survey were to (1) clarify the physician-perceived efficacy of steroid treatment on anorexia, fatigue, and dyspnea in terminal cancer patients, (2) clarify physicians' experience of side effects of corticosteroid use, and (3) determine the Japanese palliative care physician-reported predictive factors for efficacy and lack of efficacy.

Materials and Methods

This was a cross-sectional, anonymous mailed survey of representative managing physicians in all 178 certified palliative care units in Japan. The questionnaires were sent out in November 2008, along with a cover letter explaining the purpose of the study. The respondents were requested to report their clinical practice experience and perceptions regarding corticosteroid treatment in terminally ill patients. We sent a reminder 1 month after the initial mailing. We chose this population as our study population because most palliative care units in Japan have a single or only a few physicians and representative physicians are usually involved in direct patient care.

Questionnaire

The authors developed a 15-item questionnaire (see Appendix) on the basis of a literature review and discussions with 3 palliative care physicians.[5,7,8]

The physicians were first asked to report their rate of agreement regarding corticosteroid therapy using a non-Likert-type

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scale and to report on their actual clinical experiences regarding corticosteroid treatment of adult cancer patients with an estimated survival of 6 months or less who were not on anticancer treatment. The questions focused on corticosteroid therapy for the specific symptoms of anorexia, fatigue, and dyspnea, which were the most common indications for steroid therapy reported in the literature, because we speculated that the physicians' attitudes might differ for each of these symptoms.[8,9] The questionnaire was divided into four sections.

The first section related to the physician-perceived efficacy. The respondents were asked to report the physician-perceived effective rate and timing and to evaluate the treatment effect. The physician-perceived effective rate was defined as the proportion of patients showing a positive effect that lasted at least a week among all patients treated for the particular indication. The evaluation of the treatment effect was not based on the patient's records, but on the clinical impression of the respondents.

The second section related to the side effects of corticosteroid therapy. The physicians were asked to report the physician-perceived rate of patients who experienced 10 major side effects within 1 week and over 1 month, and was defined as the percentage of patients who experienced each side effect among all the patients who had received corticosteroids. The evaluation of the side effects was based on the clinical impression of the respondents. Respondents were then requested to report their clinical experience of serious side effects. The definition of each side effect was based on the clinical diagnosis, and we had not provided any operational definitions, which are not clearly established.

In the third section, the participants reported the predictive factor(s) for efficacy or lack of efficacy, on an empirical basis, in relation to each symptom (e.g., the impression that corticosteroid therapy is effective for fatigue associated with hepatic failure). These questions were in a multiple-choice format, with additional open-answer questions.

Next, the respondents were asked to report the frequency of corticosteroid use. The frequency of corticosteroid use was defined as the percentage of patients receiving corticosteroid therapy among the inpatients.

Background data were obtained, including the characteristics of the participating institutions (average patient age, median death rate, median percentage of patients receiving chemotherapy, median length of hospitalization, availability of palliative care outpatient services, and availability of local guidelines).

Statistical analyses

All analyses were performed using the Statistical Package for the Social Sciences (version 12.0; SPSS Japan Inc., Tokyo, Japan).

Results

A total of 124 physicians returned the questionnaires (response rate 70%) by January 2009. The characteristics of the participating palliative care units are detailed in Table 1.

Prevalence of corticosteroid prescription

Corticosteroids were used at 123 institutions (99%). The reported reason for the lack of use of corticosteroids at 1% of the surveyed institutions was insufficient efficacy. The percentage of patients who received corticosteroids among all

TABLE 1. CHARACTERISTICS OF THE PARTICIPATING
INSTITUTIONS

Variable	
Average age of inpatients (years) ($n = 116$)	70 [4.3]
Median death rate ($n = 120$)*	90% (4.2–100)
Median percentage of patients receiving chemotherapy ($n = 115$)*	0% (0–90)
Median duration from admission to death (days) ($n = 119$)*	35 (2–87)
Availability of palliative care outpatient services	90% (111/124)
Availability of local guidelines on treatment with corticosteroids in terminal cancer	5.0% (6/121)

*Range in brackets.

terminally ill cancer inpatients ranged from 2% to 100% (average 71%).

Physician-reported efficacy

The highest physician-perceived effective rate as perceived by the responding physicians was for anorexia (57%), whereas more than 97% reported a positive effect within 7 days for each of the three symptoms (Table 2).

Side effects

The physician-perceived rates (%) of 10 common side effects as reported by the physicians are indicated in Table 3. The side effects seen in more than 10% of patients within 1 week of the start of treatment were insomnia and hyperglycemia, whereas those seen in more than 20% of patients after over 1 month of the start of treatment were oral candidiasis, moon face, and hyperglycemia.

Experiences with serious side effects were reported by 23% ($n = 28$) of the respondents, as follows: gastrointestinal bleeding ($n = 7$, 5.8%), gastrointestinal perforation ($n = 6$, 5.0%), potentially fatal hyperglycemia ($n = 10$, 8.3%), Pneumocystis jiroveci pneumonia ($n = 3$, 2.5%), potentially fatal bacterial pneumonia ($n = 2$, 1.7%), pulmonary tuberculosis ($n = 2$, 1.7%), sepsis ($n = 1$, 0.83%), serious delirium ($n = 3$, 2.5%), suicidal tendency ($n = 1$, 0.83%), severe myopathy ($n = 2$, 1.7%), and compression fracture ($n = 1$, 0.83%).

TABLE 2. RESPONSES REGARDING EFFICACY
OF CORTICOSTEROID USE ($N = 120$)

	Anorexia	Fatigue	Dyspnea
Average physician-perceived effective rate*	57 [21]%	50 [21]%	52 [22]%
Positive effect came			
Within 24 hours	7.5% ($n = 9$)	10% ($n = 12$)	37% ($n = 44$)
1–2 days	44% ($n = 53$)	34% ($n = 41$)	38% ($n = 45$)
3–7 days	48% ($n = 58$)	53% ($n = 63$)	24% ($n = 29$)
8–14 days	0%	2.5% ($n = 3$)	0.8% ($n = 1$)

Some percentages do not add up to 100% due to missing values.
*The empirical effective rate was defined as the proportion of patients showing a positive effect that lasted for at least 1 week among all patients treated for each indication.

Table 3. Physician-perceived Rates of 10 Common Side Effects Related to Corticosteroid Therapy* ($N = 105$)

Side effect	Median rate within 1 week after initial administration (%)[†]	Median rate over 1 month after initial administration (%)[†]
Aggravated/triggered diabetes mellitus	10 (0–100)	20 (0–100)
Insomnia	10 (0–80)	10 (0–80)
Delirium	5 (0–50)	10 (0–80)
Oral candidiasis	1 (0–60)	30 (0–100)
Moon face	0 (0–20)	30 (0–100)
Depression	0 (0–30)	10 (0–50)
Electrolyte abnormalities	0 (0–20)	10 (0–40)
Peptic ulcer	0 (0–20)	7.5 (0–30)
Osteoporosis	0 (0–10)	5 (0–90)
Myopathy	0 (0–14)	5 (0–70)

*The physician-perceived side-effect rates were defined as the percentage of patients with the side effect among patients who received corticosteroids, based on the respondents' clinical impressions.
[†]Range in brackets.

Physician-reported predictive factors of effectiveness

The physician-reported predictive factors, on an empirical basis, for efficacy and lack of efficacy for each symptom are listed in Table 4. The predictive factors for efficacy against anorexia identified by more than 50% of the respondents were lung cancer and digestive cancer. For fatigue, tumor fever, digestive cancer, and lung cancer were identified as the predictive factors of efficacy, whereas liver failure, renal failure, and cachexia were identified as predictive factors for lack of efficacy. In relation to dyspnea, lymphantic carcinomatosis, airway obstruction, and multiple lung metastases were identified as predictive factors for steroid efficacy, whereas the predictive factor identified for lack of efficacy by 53% of the respondents was pleural effusion.

Discussion

To the best of our knowledge, this is the first representative nationwide survey to systematically investigate physicians' experience of corticosteroid therapy for terminally ill cancer patients. The important findings of this study were that many Japanese palliative care specialists (1) perceived that corticosteroids are effective for each of the symptoms, (2) are aware of the prevalence and importance of serious adverse effects, and (3) predict the effectiveness of steroid therapy by etiological factors.

In our study, more than 50% of the patients were assessed as showing good response to steroid treatment administered for different indications. Although a simple comparison is difficult because of differences in the study design, the results of our study are consistent with earlier findings.[1,4,10,11] Thus, corticosteroid therapy may be found to be generally effective for these indications in many terminally ill cancer patients.

Many respondents stated that a positive response was noted within 1 week in cases in which the treatment was effective, consistent with previous studies.[3,10,12] This finding may indicate that the efficacy of corticosteroid therapy should be evaluated within 1 week after it is initiated. This information is very useful in terms of the cost-effectiveness, economic resources, and prevention of unnecessary adverse effects.[12]

Large variations exist in physicians' estimation of side effects related to treatment with corticosteroids. As compared with previous reports,[7,13] the actual percentages of the side effects in our study were relatively low. In contrast, this study revealed that 23% of the respondents encountered serious side effects, and the side effects experienced by palliative care specialists were similar to those reported previously: gastrointestinal bleeding,[12] severe myopathy,[5,14] severe osteoporosis,[5] severe infection,[5] and severe neuropsychiatric complications.[15,16] To obtain the greatest benefit with the fewest adverse effects, a large prospective cohort study to clarify the frequency of side effects is strongly needed. However, it cannot be overemphasized that clinicians should carefully monitor and manage treatment-related complications on an individual basis to avoid side effects.

Table 4. Physician-reported Predictive Factors for the Empirical Effectiveness of Corticosteroid Treatment of the Three Symptoms

		Effective predictive factor (n = 111)		Ineffective predictive factor (n = 92)	
Anorexia					
	Lung cancer	64% (n = 71)	Cachexia	26% (n = 24)	
	Digestive cancer	58% (n = 64)			
	Cachexia	32% (n = 35)			
	<70 years old	28% (n = 31)			
Fatigue					
	Tumor fever related	69% (n = 75)	Liver failure	37% (n = 34)	
	Digestive cancer	53% (n = 58)	Renal failure	36% (n = 33)	
	Lung cancer	52% (n = 57)	Cachexia	36% (n = 33)	
	Chemotherapy induced	30% (n = 33)	Anemia	30% (n = 28)	
	Liver failure	29% (n = 30)	Depression	27% (n = 25)	
Dyspnea					
	Lymphangitic carcinomatosis	83% (n = 91)	Pleural effusion	53% (n = 47)	
	Airway obstruction	67% (n = 74)	Bronchial secretion	47% (n = 42)	
	Multiple lung metastases	66% (n = 73)	Anemia	42% (n = 37)	
	Weakness	32% (n = 35)	Pneumonia	40% (n = 36)	
	Bronchial secretion	27% (n = 30)	Weakness	39% (n = 35)	

The questions were multiple-choice models and open answers.
This table represents the opinions reported by more than 25% of respondents.

Although the present study identified some predictive factors that many respondents regarded as useful, opinions varied among physicians regarding other predictive factors. Predicting the effectiveness of steroid therapy would allow avoidance of unnecessary use in patients. A future prospective study is needed for investigation of each predictive factor; this would contribute to using steroid therapy to obtain maximum benefits with minimum adverse effects.

One of the limitations of this study is that it was based on reports of physicians rather than on assessments by patients. Because of this limitation, we need to be cautious in making conclusions on the basis of the findings of this study.

In conclusion, corticosteroids are frequently administered to terminally ill cancer patients in Japan. Of special interest among the findings of this study is that physicians often predict whether corticosteroids would be effective based on etiological factors. A future study to validate the identified predictive factors might allow avoidance of potential over-prescription of steroid therapy. Because palliative care specialists encounter serious side effects in clinical settings, a future controlled trial to determine the efficacy of steroid therapy for each symptom of homogeneous etiology, as well as a large cohort study to clarify the prevalence of serious side effects is strongly needed to obtain optimal effect of corticosteroid therapy and minimize the risk of development of side effects in terminal cancer patients.

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Author Disclosure Statement

No competing financial interests exist.

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APPENDIX. QUESTIONNAIRE SHEET

1. Please answer the following items about your palliative care unit.

   1) Average age of inpatients _____ years old
   2) Death rate _____%
   3) Percentage of patients receiving chemotherapy ____ %
   4) Duration from admission to death _____ days
   5) Is palliative care available for outpatients? Yes No
   6) Are local guidelines available on treatment with corticosteroids in terminal cancer? Yes No

2. Do you prescribe corticosteroids in terminal cancer? Yes No

   If "No," please select the reasons from the following:
   Worried about adverse effects of corticosteroids
   Insufficient efficacy of corticosteroids
   Other

   If "Yes," please continue to answer the questions below.
   If "No," your questionnaire is finished.

3. What percentage of the terminal cancer patients at your facility have been prescribed corticosteroids? _____ %

4. Please indicate the percentage of terminal cancer patients prescribed corticosteroids for the following three indications. This value is defined as the percentage of patients receiving corticosteroid therapy among patients who complain of each symptom.

   The percentage of patients with anorexia is _____ %
   The percentage of patients with fatigue is _____ %
   The percentage of patients with dyspnea is _____ %

5. The section in this question relate to your preferred administration method for each symptom (anorexia, fatigue, and dyspnea).

   1) Please select your preferred corticosteroid from the list below (please circle one).
      a. Betamethasone, b. Dexamethasone,
      c. Predonisoloned. Other (please state).
   2) Please select your preferred titration of corticosteroid from the list below (please circle one).
      a. Escalating the dose to a maintenance dose,
      b. Tapering the dose to a maintenance dose,
      c. Keeping a fixed dose.
   3) Please state initial dose and maximum dose.

6. When your patients are expected to live for less than 1 week, do you stop or reduce the dose of corticosteroid for the purpose of avoiding hyperactive delirium. Please circle the most appropriate statement.

   a. Stop, b. Reduce, c. Neither stop nor reduce.

7. When your patient who has an estimated prognosis of less than 2 weeks cannot take corticosteroid orally due to dysphagia with the progression of the underlying disease, do you stop or switch to other administration route for each symptom (anorexia, fatigue, and dyspnea)? Please circle the most appropriate statement.

   a. Stop, b. Switch to parenteral administration, c. Switch to suppository.

8. We would like to determine the timing of predicted survival for starting corticosteroid therapy in terminal cancer patients with anorexia, fatigue, and/or dyspnea. Please circle the most appropriate statement.

   a. Within 6 months, b. Within 3 months, c. Within 1 month, d. Within 1 week, e. Independently of predicted survival.

9. What percentage of the cancer patients who showed a positive effect from corticosteroid therapy for the following symptom did you see? This empirical effective rate is defined as the proportion of patients showing a positive effect that lasted for at least 1 week.

   The empirical effective rate for anorexia is _____ %.
   The empirical effective rate for fatigue is _____ %.
   The empirical effective rate for dyspnea is _____ %.

10. When do you see a positive effect of corticosteroid after initial administration if the patient has a positive effect for each symptom (anorexia, fatigue, and dyspnea)? Please circle the most appropriate statement.

    a. Within 24 hours, b. 1-2 days, c. 3-7 days, d. 8-14 days.

11. Do you prescribe a gastroprotector in patients treated with corticosteroids? Please circle the most appropriate statement.

    a. No preventive prescribing of gastroprotector, b. Principally prescribe gastroprotector, c. Prescribe gastroprotector only for with concomitant nonsteroidal anti–inflammatory drugs (NSAIDs), d. Prescribe gastroprotector only for a patient with a past history of peptic ulcer.

    If you prescribe a gastroprotector, please select your preferred drug from the list below (please circle one). If other, please specify.

    a. Mucoprotective agent, b. Histamine H2-receptor antagonist, c. Misoprostol, d. Proton pump inhibitor, e. Other (please specify).

12. What percentage of the cancer patients who have the following side effects of corticosteroid therapy do you see within 1 week and for more than 1 month?
    Oral candidiasis, Peptic ulcer, Aggravated/triggered diabetes mellitus, Depression, Electrolyte abnormalities, Delirium, Insomnia, Myopathy, Moon face, Osteoporosis

13. Did your patients experience serious adverse side effects associated with corticosteroid treatment? Yes No
    If "Yes," please state your experiences.

For example, *Pneumocystis jiroveci* pneumonia, coma due to hyperglycemia, and so on.

14. Do you prescribe corticosteroid to terminal cancer patients with the following complications and history? Please circle the appropriate answer.
Diabetes mellitus (diet therapy alone, require oral hypoglycemic agent and insulin therapy); Peptic ulcer (past history and present complication); Past history of tuberculosis; Depression (past history and present complication); Delirium (hyperactive type and hypoactive type). Answer

a. Principally not prescribe, b. Prescribe with careful management of the side effect, c. Prescribe without careful management of side effect.

15. What kind of predictive factors do you consider that indicate the effectiveness of corticosteroids? Please select from the table below as either effective or ineffective. If other, please specify.
For example, corticosteroid is effective for fatigue due to hepatic failure, but corticosteroid is ineffective for fatigue due to depression, and so on.

	Effective predictive factors	Ineffective predictive factors
Anorexia	Digestive cancer, Lung cancer, Chemotherapy induced, Hepatomegaly, Hypercalcemia, Depression, Cachexia, Over 70 years old, Less than 70 years old, Male, Female, Predicted survival, Others (please state)	Digestive cancer, Lung cancer, Chemotherapy induced, Hepatomegaly, Hypercalcemia, Depression, Cachexia, Over 70 years old, Less than 70 years old, Male, Female, Predicted survival, Others (please state)
Fatigue	Digestive cancer, Lung cancer, Chemotherapy induced, Liver failure, Renal failure, Depression, Tumor fever, Elevated C-reactive protein, Anemia, Cachexia, Over 70 years old, Less than 70 years old, Male, Female, Predicted survival, Others (please state)	Digestive cancer, Lung cancer, Chemotherapy induced, Liver failure, Renal failure, Depression, Tumor fever, Elevated C-reactive protein, Anemia, Cachexia, Over 70 years old, Less than 70 years old, Male, Female, Predicted survival, Others (please state)
Dyspnea	Multiple lung metastasis, Air way obstruction, Pleural effusion, Lymphangitic carcinomatosis, General weakness, Bronchial secretion, Pneumonia, Anemia, Others (please state)	Multiple lung metastasis, Air way obstruction, Pleural effusion, Lymphangitic carcinomatosis, General weakness, Bronchial secretion, Pneumonia, Anemia, Others (please state)

Public Awareness, Knowledge of Availability, and Readiness for Cancer Palliative Care Services: A Population-Based Survey across Four Regions in Japan

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Abstract

Background: This study explores the distribution of public awareness, knowledge of availability, and readiness for palliative care services, and the perceived reliability of information resources as part of a nationwide palliative care implementation intervention in Japan (Outreach Palliative Care Trial of Integrated Regional Model [OPTIM]).
Methods: A cross-sectional anonymous questionnaire survey was conducted, and 3984 responses were used in the final analysis.
Results: A total of 63.1% of respondents admitted having no knowledge about palliative care, while 0.5% of respondents were using palliative care services. Respondents who knew about palliative care services, yet did not know about their availability were 18.6% of all respondents. Respondents who had cancer-related experiences were more likely to be aware of palliative care compared to the general population and availability of palliative care services. Only awareness of palliative care was significantly associated with two typical images, while cancer-related experiences were not.
Conclusion: Findings show that the public awareness of palliative care services and their availability is insufficient, and cancer-related experiences affect awareness of cancer palliative care but not directly related to typical images for palliative care such as care for patients close to death.

Introduction

PALLIATIVE CARE for patients with cancer in Japan has rapidly progressed in the past decade, but many critical issues still need to be resolved. To improve overall cancer care (including palliative care) throughout Japan, the Cancer Control Act was established in April 2007. To facilitate the dissemination of palliative health services, the Ministry of Health, Labour, and Welfare focuses on palliative care concerns, and has launched a multiple nationwide project for community-based intervention trials in four areas in Japan, as described via the Outreach Palliative Care Trial of Integrated

Regional Model (OPTIM) study.[1] The study includes creating community-based specialized palliative care teams, developing educational materials, educating community medical staff on palliative care, and campaigning to disseminate knowledge relevant to specialized palliative care programs to patients, families, and the general public.

The reason that this trial includes the campaign is that the general public does not have adequate knowledge about palliative care concepts.[1] For example, only 34% of the general population knows about palliative care units in Japan, whereas the rate of knowledge in the United Kingdom is 70%.[2,3] Of note, although 32% of the Japanese general public

believes that palliative care units are places where patients simply wait for death, these misperceptions are significantly decreased after individuals actually use a specialized palliative care service.[3,4] Thus, the lack of knowledge and general misperceptions regarding palliative care are considerable barriers to palliative care and appropriate pain control, and further education of the general public would be of great value.

This research has revealed prevalence and relationships among general knowledge and perceptions for barriers but has not clarified intentions, acceptance, and knowledge of the availability if the people use the services in a local region. To develop effective strategies to promote the enhanced utilization of palliative care services, we must explore the demographics (such as gender, age, or residential status) and barriers related to not only general public awareness of palliative care, but also intention for use, knowledge of the availability, and actual rate of service utilization. As the previous study revealed,[3,4] it is also expected that opinions of palliative care, which are supposed to be formed from personal experiences, affected not only general awareness but intention or readiness. In particular, sources to form opinions of cancer palliative care are supposed to be cancer-related experiences as the patient themselves or as the patient's family members.[5]

This article, therefore, has the following aims: (1) to clarify the distribution of public awareness, knowledge of availability, and readiness for palliative care services, (2) to clarify the differences in awareness, knowledge, and readiness among demographic variables and between healthy individuals and those who have cancer-related experiences (either personally or via family), (3) to clarify the differences of typical opinions of palliative care in awareness, knowledge, and readiness, in relation to cancer-related experiences and other demographics.

Methods

Subjects

This study was a part of OPTIM, and the overall protocol has been provided in detail elsewhere.[1] Our investigation was a survey of the general population, including patients with cancer and their families in four regions from the OPTIM study. These consisted of a large urban area (Chiba), an urban area (Shizuoka), and two rural areas (Nagasaki and Yamagata). The first three areas are places in which palliative care services are available and the last one (Yamagata) is, in comparison, a location in which services are practically unavailable.

A cross-sectional anonymous questionnaire survey was conducted in a sample of the general population selected by stratified two-stage random sampling in each area (2,000 subjects in each of four regional areas). As a result, this sample included cancer patients (outpatients receiving or having received cancer treatment). We mailed a total of 8,000 questionnaires to these potential participants in June 2007 and on a later date sent a reminder postcard. On the questionnaire, we explained the aim of the study and regarded completion and return of the questionnaire as consent for participation in this study. The institutional review boards of Tokyo University confirmed the ethical and scientific validity.

Questionnaire

We developed our own questionnaire on the basis of the aims of OPTIM and through literature reviews, existing sur-

veys, and consensus among the authors as follows. On the cover page of the questionnaire, palliative care was defined as: attempts to make patients with cancer and their family less anxious or to experience less pain, to immediately start consultations about anxiousness and pain regardless of the state of cancer development, and in addition to treatment, to facilitate the teamwork of doctors and nurses in the practice of treating patients who are suffering from the physical and/or emotional effects of cancer.

The questionnaire included three parts. First, it included questions covering the demographic information of the subjects (age, gender, length of living in each area) and whether subjects are undergoing (or had undergone) cancer treatment or had family members who had experiences of undergoing cancer treatment. Second, it included an item originally designed to determine the extent of public awareness, knowledge of availability, and readiness and actual utilization of palliative care service. We asked the participants to choose only one option from six sequential options regarding palliative care and such services: (1) no knowledge (I have no knowledge regarding palliative care; I); (2) lack of knowledge of availability (I have heard of palliative care, but I do not know if there are any available facilities in my municipality; II); (3) no interest (I know about palliative care and its availability in my residential area, but I have no interest in the service; III); (4) no intention (I know about palliative care and its availability in my residential area, and have an interest, but I have no intention of using the service as a patient or for a family member; IV); (5) preparation (I am preparing to use palliative care services; V); (6) under utilization (I currently use palliative care services; VI; Fig. 1). We converted the subjects' responses for these responses (I to VI) into a numeric
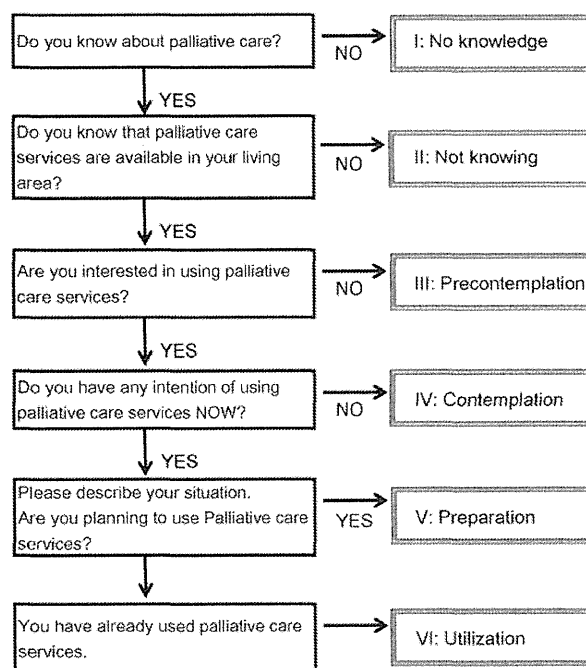

FIG. 1. Public awareness and readiness for palliative care services.

TABLE 1. DEMOGRAPHIC BACKGROUND OF THE RESPONDENTS

	Total		General population		Those who have experienced cancer	
	(n = 3190)		(n = 1330)		(n = 1860)	
	n	%	n	%	n	%
Age years						
40–49	705	22.1	302	22.7	403	21.7
50–59	1020	32.0	404	30.4	616	33.1
60–69	898	28.2	385	28.9	513	27.6
70-	567	17.8	239	18.0	328	17.6
Gender						
Male	1,426	44.7	666	50.1	760	40.9
Female	1,764	55.3	664	49.9	1100	59.1
Region (Prefecture)						
Chiba	945	29.6	413	31.1	532	28.6
Shizuoka	785	24.6	364	27.4	421	22.6
Nagasaki	733	23.0	274	20.6	459	24.7
Yamagata	727	22.8	279	21.0	448	24.1
Length of living in each area						
<1 year	38	1.2	22	1.7	16	0.9
1–5 year	131	4.1	60	4.5	71	3.8
>5 year	3,021	94.7	1,248	93.8	1,773	95.3

scale ranging from 1 to 6 points. Finally, three items related to palliative care beliefs/concepts ("Palliative care relieves pain and distress"; "Palliative care is used with chemotherapy and radiotherapy"; "Palliative care is for patients close to death.")[3,5] were presented, and responses were measured on a five point Likert-type scale from 1) strongly disagree to 5) strongly agree.

Analysis

Descriptive analyses were carried out summarizing the subjects' backgrounds, awareness of palliative care and utilization of such services, and scores for reliable media source opinions for total and each sampled area. Then we explored

the distribution of knowledge and readiness of palliative care and utilization of the service associated with each sampled area and experiences of having cancer. These analyses were performed after dividing subjects into two groups (the general population and cancer patients/survivors) and we used the χ^2 test and Cramer's V to clarify relations between categorical variables and using coefficient correlation and relations between two categorical variables and ordered variables two-way analysis of variance (ANOVA). We conducted all statistical analyses using the Statistical Package for the Social Sciences (version 15.0.1.1J, SPSS Inc., Chicago, IL) software package. The significance level was set at $p < 0.05$ (two-tailed).

Results

Of the 8000 questionnaires delivered to the sampled subjects, 26 were returned as undeliverable and 3984 were returned (response rate, 49.8%). Of those returned, 3190 were considered valid for statistical analyses. The rest (n = 794) were invalid and were excluded from the analyses since major information was lacking. Thus, the final rate of valid replies was 39.9%.

A total of 1860 respondents (58.3% of all respondents) were identified as "those having experienced cancer" and the rest were identified as belonging to the "general population." Table 1 summarizes the background of respondents.

Public awareness, knowledge, and readiness for palliative care

A total of 63.1% of respondents admitting to having "no knowledge" of palliative care while 0.5% of respondents were actually using palliative care services. Respondents who knew about palliative care yet did not know about the availability of palliative care in their living area were 18.6% of all respondents. Female respondents were more likely to know about palliative care than male respondents ($\chi^2 = 55.09$, $df = 1$, $p < 0.001$, Cramer's V = 0.131), while age and length of living in each area were not significantly associated with

TABLE 2. PUBLIC AWARENESS AND READINESS FOR PALLIATIVE CARE SERVICES

	Total		General population		Those who have experienced caner		Chiba		Shizuoka		Nagasaki		Yamagata	
	(n = 3190)		(n = 1330)		(n = 1860)		(n = 945)		(n = 785)		(n = 733)		(n = 727)	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%
I: No knowledge	2012	63.1	909	68.3	1,103	59.3	546	57.8	518	66.0	482	65.8	466	64.1
Having Knowledge	1178	36.9	421	31.7	757	40.7	399	42.2	267	34.0	251	34.2	261	36.0
II: Not knowing	593	18.6	230	17.3	363	19.5	201	21.3	96	12.2	115	15.7	181	24.9
III: Not interseted	24	0.8	13	1.0	11	0.6	5	0.5	12	1.5	5	0.7	2	0.3
IV: No Intention	499	15.6	167	12.6	332	17.8	171	18.1	142	18.1	116	15.8	70	9.6
V: Preparation	46	1.4	10	0.8	36	1.9	18	1.9	14	1.8	10	1.4	4	0.6
VI: Under Utilization	16	0.5	1	0.1	15	0.8	4	0.4	3	0.4	5	0.7	4	0.6

Cancer experience×Awareness (No knowledge vs. Having knowledge): $\chi^2 = 27.24$, $df = 1$.
$p < 0.01$, Cramer's V = 0.092.
Four areas×Awareness (No knowledge vs. Having knowledge): $\chi^2 = 16.83$, $df = 3$, $p < 0.01$, Cramer's V = 0.073.
Within People who Knew Palliative Care:
Cancer experience×Availability: $\chi^2 = 4.83$, $df = 1$, $p < 0.028$, Cramer's V = 0.064
Four areas×Availability: $\chi^2 = 61.88$, $df = 3$, $p < 0.01$, Cramer's V = 0.229.
Availability: No awareness of availability vs. awareness of availability.

either awareness, knowledge or readiness. Respondents who had cancer-related experiences (either themselves or via family members) were more likely to be aware of palliative care compared to the general population ($\chi^2 = 27.24$, $df = 1$, $p < 0.001$, Cramer's V = 0.092). Also among people who knew palliative care, there was a significant association between cancer experience and knowledge for availability or readiness ($\chi^2 = 4.83$, $df = 1$, $p = 0.028$, Cramer's V = 0.064). Table 2 also shows that awareness and knowledge of and readiness for palliative care was significantly different among each area ($\chi^2 = 16.84$, $df = 3$, $p < 0.001$, Cramer's V = 0.073). Particularly, respondents in Chiba-city have more knowledge about palliative care than individuals from the other three areas.

Typical images of palliative care

Table 3 indicates the results of two-way ANOVA for responses on three typical images of palliative care using awareness and cancer experiences as dependent variables, when age, gender, and area were controlled. First, the analysis revealed the differences in perception for three common images of palliative care between individuals having no knowledge of palliative care and those who had knowledge. Significant differences were observed between them in terms of images of palliative care in the following dimensions: "Palliative care relieves pain and distress" (general population; $F(1, 3186) = 33.02$, $p < 0.001$, Those having experienced cancer; $F(1, 3186) = 60.85$, $p < 0.001$) and "Palliative care is for patients close to death" (general population; $F(1, 3186) = 13.62$, $p < 0.01$, Those having experienced cancer; $F(1, 3186) = 13.00$, $p < 0.01$). People who know about palliative care have an overall positive image of it, tend to think that palliative care brings symptom control to the patients, and is specialized for terminally ill patients. There were no significant differences between the general population and cancer-experienced individuals on the three typical opinions of palliative care, and there were no significant interactions between cancer experience and knowledge of palliative care.

Discussion

This study is the first attempt to understand the public awareness of palliative care and utilization of services based on a nationwide sample in Japan. A clarification of these findings will hopefully contribute to understanding general perception of cancer palliative care and its variations by experiences related to cancer.

The primary aim of this study was to clarify the distribution of public awareness, knowledge of availability, and readiness for palliative care services. Per the results of the survey, 63.1% of all the participants had no knowledge of palliative care services. These results demonstrate a low public awareness of the Japanese palliative care services compared with other countries.[2,3] Moreover, among those who did possess knowledge about palliative care in general, 18% did not know about the specific availability of the service in their region. These results indicate that over 80% of people do not have sufficient knowledge of palliative care to take advantage of its services, and it is therefore important to promote a more comprehensive understanding of palliative care (including availability) to the general population.

Second, our data clarified that cancer experiences were related to a greater knowledge of and readiness for palliative

TABLE 3. MEAN SCORES OF IMAGES OF PALLIATIVE CARE BY AWARENESS AND EXPERIENCE OF CANCER

Awareness		General population						Those who have experienced cancer						Main effect							
		Total		No knowledge		Having knowledge		Total		No knowledge		Having knowledge		Exp. Cancer		Awareness		Interaction	
Experience of Cancer	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD	F	p	F	p	F	p
Palliative care relieves pain and distress	3.81	0.80	3.72	0.83	4.00	0.70	3.88	0.85	3.76	0.88	4.06	0.76	2.75	.07	74.73	.00	0.08	.78
Palliative care is used with chemotherapy and radiotherapy	3.51	0.90	3.53	0.85	3.47	1.00	3.51	0.97	3.50	0.94	3.52	1.02	0.18	.68	0.04	.85	1.09	.30
Palliative care is for patients close to death	3.19	1.22	3.12	1.12	3.34	1.26	3.22	1.29	3.15	1.27	3.32	1.30	0.01	.91	15.30	.00	0.36	.55

The results by two-way analysis of variance (ANOVA) were shown when age, gender, and area were controlled as covariates.

care, but did not significantly relate to specific images commonly associated with palliative care. From our data it is difficult to strictly compare patients with cancer with the overall population since the sample surveyed in this study was from the general population, and therefore only a small number of patients with cancer were included. However, people who had experiences with cancer (either personally or via family members) recognized both the term and meaning of palliative care. Also, people who had knowledge of palliative care have an overall positive image of it, tend to think that palliative care brings symptom control to the cancer patients, and is specialized for terminally ill patients. Generally, as the images will be reinforced by actual experiences, those who experienced as patients with cancer or as family members might see or hear the care at late stage of the cancer process. This indicated current situation that palliative care for patients with cancer in general Japanese hospitals was mainly provided for late-stage cancer and that contributed to form the general opinions of palliative care. Also, the perception that palliative care is primarily for terminally ill patients care may cause late referrals to palliative care services.[5,6] These suggest that images derived from actual experiences will have strong impact for actual decision making for choosing or readiness for the services when the patients need. Therefore, it is important to provide proper and detailed information about palliative care services, as well as information regarding the availability of services, within areas of residence. We still have very big challenges to modify the general perception of cancer palliative care, because there is no known effective method to achieve this. Educational approaches in community may become one of the solutions, and will especially be needed to help people recognize that palliative care services accept even patients with early-stage cancer.

This study has several limitations. First, this study did not include measurements for the effectiveness of each medium and we cannot discern which media sources and what kind of information directly led individuals to be more aware of palliative care and to use these services. Second, we did not explore the possible associations between the awareness of palliative care and amounts of actual cancer treatment undergone. A more detailed survey will need to be conducted in order to clarify the above items. Moreover, it would be useful to better explore the insights of specific populations. In future surveys, it should be possible to design more directed questionnaires to support hypothesis-based studies.

In conclusion, the public awareness of palliative care services and their availability is insufficient. Those with cancer experiences were more aware of palliative care and their availability than the general population. Only people who were aware of palliative care developed two typical images, while those with cancer-related experiences did not. Approaches to inform the general population (including those with cancer-related experiences) about palliative care have already been taken in Japan. However, more effective methods should be developed. We feel that it is possible to eliminate many existing barriers to the improvement of end-of-life quality, and the dissemination of knowledge related to such care and treatment in Japan should be a top priority.

Author Disclosure Statement

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