

the completion and returning of the questionnaire as consent to participate. The ethical and scientific validity of this study was confirmed by the institutional review board independently from the research project, which was organized by the Japan Cancer Society, the organization responsible for conducting the OPTIM study.

Population and Procedures

We identified 8000 subjects, 40–80 years of age, within the general population, using a stratified two-stage random sampling of residents in the four regions (2000 subjects in each area). We mailed questionnaires to potential participants in July 2007, and if the questionnaire was not returned, we sent a reminder postcard.

Measurements

We developed a questionnaire regarding the sense of security through discussions based on previous studies.^{12–14} The questionnaire comprised five statements about the characteristics of health care professionals who provide adequate treatment and care (“competent professionals”) and adequate access to health care resources to feel supported (“timely access to needed care”), which are components indicated by Funk et al.¹² We did not include the “caregiver’s identity and self-worth¹²” in the questionnaire because the intended use of this scale in the OPTIM study was to measure the change in the level of competency of professionals and timely access to needed care as a result of the intervention for improving regional palliative care. The face validity of the questions was assessed based on full agreement of the authors.

The questionnaire statements were as follows: If I get cancer 1) I would feel secure in receiving cancer treatment, 2) my pain would be well relieved, 3) medical staff will adequately respond to my concerns and pain, 4) I would feel secure as a variety of medical care services are available, and 5) I would feel secure in receiving care at home. The translation from Japanese to English was done by a translation/back-translation procedure as follows: the questions were translated into English by a proficient translator; this translation was supervised by a bilingual person and modified. Subsequently, this prototype was translated

into Japanese by two researchers other than the authors. The back-translation was compared with the original Japanese questionnaire, and the authors approved it. We asked participants to rate their level of agreement with the statements on a seven-point Likert scale (1: strongly disagree, 2: disagree, 3: slightly disagree, 4: not sure, 5: slightly agree, 6: agree, and 7: strongly agree).

The demographic data, such as area where the respondent lived, age, gender, duration of residence in the region, current treatment of health problems, diagnosis of cancer (during or after treatment), family members’ experiences of cancer, and knowledge about palliative care also were included in the questionnaire.

Statistical Analyses

First, we conducted descriptive analyses of demographic data and responses concerning the sense of security regarding cancer care in the designated region.

Scale Development. To examine feasibility, we considered the rate of missing data for questions regarding sense of security. We then used exploratory factor analysis using the principal factor method for questions on sense of security; the factorial validity of the scale was examined. To assess the reliability of the scale, we calculated Cronbach’s α coefficients.

The scale score was calculated by summing the points for the five items because the score was regarded as normally distributed. We set 25 points, which is the sum of five Number 5 ratings (“slightly agree”), or more as the cutoff on the sense of security scale to identify persons who felt secure.

Related Factors. To identify factors associated with a sense of security, univariate analyses were conducted using analysis of variance, the unpaired *t*-test, Pearson product-moment correlation coefficient, and Spearman rank correlation coefficient, where appropriate. Thereafter, the association of each hypothesized factor with the sense of security score was determined using multiple regression analysis.

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

Results

Characteristics of Participants

Of the 8000 questionnaires sent out, 26 were undeliverable and 3984 were returned. Among the respondents, 254 were excluded because of missing data for items regarding sense of security, and 3730 responses were analyzed (effective response rate: 46.8%). There was a significant difference in the response rate among the areas (Yamagata, 47%; Chiba, 53%; Shizuoka, 44%; and Nagasaki, 42%; Chi-squared test, $P < 0.001$). Table 1 summarizes the characteristics of the respondents.

Distribution of the Sense of Security in the Region

Table 2 shows the distribution of responses regarding the sense of security. Although about 60% of the respondents (sum of “strongly agree,” “agree,” and “slightly agree”) believed that they would be treated appropriately for cancer, less than half of the respondents believed that the treatment for pain and distress and the availability of health care services, including home care, would be sufficient.

Feasibility

The rate of missing values for the five items regarding the sense of security was 1.5%–3.5%.

Exploratory Factor Analysis

According to the results of the exploratory factor analysis, the five items regarding the sense of security were aggregated into one factor (Table 3). Cronbach’s α was 0.91.

Table 1
Characteristics of Respondents (n = 3730)

Characteristic	n (%)
Area	
Yamagata	943 (25)
Chiba	1061 (28)
Shizuoka	877 (24)
Nagasaki	849 (23)
Gender	
Male	1648 (45)
Female	2012 (55)
Age (years), mean (\pm SD)	59.6 (\pm 10.5)
Duration of residence in the region	
Less than one year	42 (1)
One to five years	141 (4)
More than five years	3457 (95)
Treated for health problems	1959 (54)
Have cancer	177 (5)
Family members’ experiences of cancer	2008 (55)
Awareness of palliative care	523 (15)

SD = standard deviation.
Percentages for each item were calculated after excluding missing values.

Related Factors

Univariate Analyses. The association of each demographic factor with the sense of security score, which was calculated by summing the points of the five items, was examined using univariate analyses, and the results are shown in Table 4. The difference in the sense of security among the areas was significant ($P < 0.001$). Other factors associated with a higher score for the sense of security were an older age ($P < 0.001$), current treatment for a health problem ($P < 0.001$), having cancer ($P < 0.001$), and no family history of cancer ($P = 0.005$). When examining correlations among variables, a family history of cancer was associated with gender (females had more

Table 2
Distribution of Responses for Sense of Security Regarding Cancer Care (n = 3730)

If I get cancer:	Strongly Disagree (%)	Disagree (%)	Slightly Disagree (%)	Not Sure (%)	Slightly Agree (%)	Agree (%)	Strongly Agree (%)	Total Agreement ^a (%)
(1) I would feel secure in receiving cancer treatment.	3	10	9	17	26	30	6	61
(2) My pain would be well relieved.	4	18	13	24	23	17	2	41
(3) Medical staff will adequately respond to my concerns and pain.	3	14	13	23	26	19	2	46
(4) I would feel secure as a variety of medical care services are available.	5	17	14	29	21	12	2	35
(5) I would feel secure in receiving care at home.	9	26	16	26	15	7	1	23

Percentages for each item were calculated after excluding missing values.
^aSum of “slightly agree,” “agree,” and “strongly agree.”

Table 3
Exploratory Factor Analysis (n = 3587)

If I get cancer:	Factor 1	Communality
(1) I would feel secure in receiving cancer treatment.	0.82	0.67
(2) My pain would be well relieved.	0.88	0.77
(3) Medical staff will adequately respond to my concerns and pain.	0.91	0.83
(4) I would feel secure as a variety of medical care services are available.	0.90	0.82
(5) I would feel secure in receiving care at home.	0.77	0.59

Proportion of variance explained = 73.5%.

experiences of family cancer) and having a health problem was associated with age and having cancer ($P < 0.001$, respectively).

Multiple Regression Analyses. The results of multiple regression analyses are shown in Table 5.

Table 4
Factors Related to Sense of Security According to Univariate Analyses (n = 3587)

Variable	Sense of Security Score	
	Mean (SD)	P-value
Area		
Yamagata	17.7 (7.1)	<0.001 ^a
Chiba	19.8 (6.3)	
Shizuoka	21.3 (6.2)	
Nagasaki	19.9 (6.6)	
Gender		
Male	20.0 (6.2)	0.571 ^b
Female	20.1 (6.3)	
Age	0.225 ^c	<0.001
Duration of residence in the region	-0.015 ^d	0.373
Treated for health problems		
Yes	20.6 (6.3)	<0.001 ^b
No	19.5 (6.2)	
Have cancer		
Yes	23.1 (5.7)	<0.001 ^b
No	19.9 (6.3)	
Family members' experiences of cancer		
Yes	19.5 (6.4)	0.005 ^b
No	20.1 (6.2)	
Awareness of palliative care		
Yes	20.1 (6.7)	0.666 ^b
No	20.0 (6.2)	

SD = standard deviation.

^aAnalysis of variance.

^bt-test.

^cPearson product-moment correlation coefficient.

^dSpearman rank correlation coefficient.

Table 5
Factors Related to Sense of Security According to Multiple Regression Analyses (n = 3419)

Independent Variable	β	P-value
Area		
Yamagata	Reference	—
Chiba	0.143	<0.001
Shizuoka	0.242	<0.001
Nagasaki	0.140	<0.001
Gender		
Male	Reference	—
Female	0.035	0.035
Age	0.155	<0.001
Duration of residence in the region		
Less than one year	Reference	—
One to five years	0.023	0.436
More than five years	-0.004	0.898
Treated for health problems	0.015	0.389
Have cancer	0.090	<0.001
Family members' experiences of cancer	-0.028	0.096
Awareness of palliative care	-0.011	0.528

Determination coefficient: $R^2 = 0.068$.

The Yamagata area showed a significantly smaller score for the sense of security compared with the other areas ($P < 0.001$). Female gender ($P = 0.035$), older age ($P < 0.001$), and diagnosis of cancer ($P < 0.001$) were associated with a high score for sense of security. The associations of these variables, other than the area and age, were not strong, and the determination coefficient was small (0.068).

Discussion

In this study, we developed a scale to evaluate the general population in regions of Japan to assess their feelings of support and security regarding cancer care. The scale was constructed using one factor, and showed good face validity based on the full agreement of the authors, and factorial validity and internal consistency on factor analysis. The sense of security in the Yamagata area was poor compared with that in the other three areas. Being female, of an older age, and having cancer were associated with a strong sense of security. Additionally, more than half of the respondents felt uneasy (i.e., "strongly disagree," "disagree," "slightly disagree," and "not sure") about the availability of adequate treatment for pain and distress caused by cancer and of the types of health

care services available (e.g., home care). These responses suggest that many people were unsure about the adequacy of regional cancer care.

To our knowledge, this is the first study to evaluate the sense of security regarding cancer care from the perspective of the general population. In the Yamagata area, where specialized palliative care services were not available at the time of the survey, the sense of security was relatively poor. This result suggests that the scale could reflect the adequacy of the regional system for providing health care services, thus suggesting good known-group validity.

In the scale developed in this study, the sense of security of the general population comprised trust in health care professionals to adequately respond to patients' pain and distress from cancer, and feeling that various medical and care services are readily available, even at home.¹² To improve the sense of security in a region, it is important for the general population to feel supported; thus, health care professionals should be educated in cancer and palliative care, palliative and other care services should be available, and these services should be accessible to the general population. This new scale would be a useful endpoint for evaluating the comprehensive sense of security in the general population of a region. It also may be used as an indicator of the adequacy of health care services (including the competency of health care professionals and accessibility to care) provided in the region and awareness of the services among the general population.

Furthermore, the scale, although developed to target the general population, also could be used with cancer patients and their families. Whereas the questionnaire queried the general population about a hypothetical diagnosis of cancer, the surveys of cancer patients and their families using this instrument could collect more practical data on the sense of security based on care already received.

We also identified factors other than "area" that are associated with a sense of security, to be able to apply the OPTIM model effectively to other regions of Japan in the future. Older age, female gender, and a diagnosis of cancer were associated with a strong sense of security; having health problems and a family member's experience of cancer, which were associated with a sense of security on univariate but not

multivariate analysis, might be confounding factors of age and having cancer, and gender, respectively.

First, the results for age and gender were comparable to previous studies regarding patient satisfaction with health care, which indicated that older patients were more satisfied with their care than younger ones, but the association of gender and satisfaction differed.¹⁷⁻¹⁹ Our results showing that older people had a strong sense of security are supported by the results of a previous study in which older individuals remembered an earlier less accessible health care system and so were less ready to criticize, and that they did not have high expectations.¹⁸ Additionally, because many older persons lead a community-based life compared with younger ones, they may have easy access to regional health care; consequently they may feel more secure regarding its accessibility. For gender, a previous study put forward a reason why females may be more satisfied with the health care they have received than males; the level of communication with health care staff affected patient satisfaction, and females communicated more with staff than males.²⁰ In the present study, however, the scores for sense of security were almost equal between males and females, and the standardized partial regression coefficient of the multiple regression analysis was small. Further analyses regarding the influence of gender are needed.

Second, the subjects with cancer felt more secure regarding cancer care than those without cancer. This result suggests that, whereas a person without cancer may feel a vague anxiety about cancer and its care, once a person gets cancer and has experienced receiving care, he or she may feel secure because the level of individual treatment and care in Japan is of a relatively high quality. On the other hand, subjects with a family member who had cancer had a poor sense of security compared with those without such experience, although the difference was not significant on multivariate analysis. This situation might be a result of experiencing earlier cancer care in Japan, which was poor. Doctors did not tell patients they had cancer, and pain control was inadequate. Consequently, many patients died a painful death. The result may suggest that individuals who lost a family member (mostly parents) to cancer, in times past, saw their pain and distress; therefore, they have

the impression that cancer causes great distress and so a poor sense of security regarding cancer care. However, in Japan, palliative care teams became covered by National Medical Insurance in 2002, and the Cancer Control Act was established in 2007; as a result, palliative care has progressed so that more effective treatments are available.

Nonetheless, the association of each variable with a sense of security was not strong, and the determination coefficient was small. There should be factors associated with a sense of security other than those measured in this study. To identify effective strategies for improving the sense of security in the general population within a region, future studies should look at the association of more detailed characteristics of the respondents with the sense of security. For example, if persons with negative perceptions about palliative care (such as “a place where people only wait to die”)²¹ have a low sense of security, strategies that specifically educate about palliative care and improve the perceptions of such persons would be needed. Also, if persons who do not know of the availability of specialized palliative care services and other care resources (e.g., home care) in the region have a low sense of security, strategies that disseminate knowledge on the availability of services would be needed.

This study had several limitations. First, the content validity and test-retest reliability were not confirmed; further study is needed. Generally, the reliability of a scale should be verified using the test-retest method. However, Cronbach's α (internal consistency) also can be used as an indicator of reliability; if Cronbach's α is high, the coefficient of test-retest reliability also would be expected to be high.

Second, although we considered that the scale for the sense of security could be a measure of the adequacy of the system for providing health care services and the awareness among the population of the services, the construct validity has not been confirmed. Future studies should compare the sense of security with other indicators regarding the quality of the regional health care system, such as death at home, the number of patients receiving specialized palliative care, and evaluation of patients and the bereaved family, which were not measured during the study period but are measured now in the OPTIM study.¹⁵

Third, the response rate of the survey was not high, the difference in response rate among the areas was significant, and we could not clarify the characteristics of nonresponders; therefore, a response bias may exist. However, because the response rate of opinion surveys in the general population in Japan is generally about 50%,^{8,22–24} the response rate of the study may be acceptable.

In conclusion, this study developed a new scale to evaluate feelings of support and security regarding cancer care in regions of Japan. This scale may be a useful endpoint for studies on the comprehensive sense of security, as well as adequacy of the system for providing health care services for cancer in a region, and awareness among the general population of the services. The OPTIM study is an intervention trial for improving these endpoints; we are awaiting the results of this intervention.

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Original Article

Providing Palliative Care for Cancer Patients: The Views and Exposure of Community General Practitioners and District Nurses in Japan

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Abstract

Context. The role of general practitioners (GPs) and district nurses (DNs) is increasingly important to achieve dying at home.

Objectives. The primary aim of this region-based representative study was to clarify 1) clinical exposure of GPs and DNs to cancer patients dying at home, 2) availability of symptom control procedures, 3) willingness to participate in out-of-hours cooperation and palliative care consultation services, and 4) reasons for hospital admission of terminally ill cancer patients.

Methods. Questionnaires were sent to 1106 GP clinics and 70 district nursing services in four areas across Japan.

Results. Two hundred thirty-five GPs and 56 district nursing services responded. In total, 53% of GPs reported that they saw no cancer patients dying at home per year, and 40% had one to 10 such patients. In contrast, 31% of district nursing services cared for more than 10 cancer patients dying at home per year, and 59% had one to 10 such patients. Oral opioids, subcutaneous opioids, and subcutaneous haloperidol were available in more than 90% of district nursing services, whereas 35% of GPs reported that oral opioids were unavailable and 50% reported that subcutaneous opioids or haloperidol were unavailable. Sixty-seven percent of GPs and 93% of district nursing services were willing to use palliative care consultation services. Frequent reasons for admission were family burden of

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caregiving, unexpected change in physical condition, uncontrolled physical symptoms, and delirium.

Conclusion. Japanese GPs have little experience in caring for cancer patients dying at home, whereas DNs have more experience. To achieve quality palliative care programs for cancer patients at the regional level, educating GPs about opioids and psychiatric medications, easily available palliative care consultation services, systems to support home care technology, and coordinated systems to alleviate family burden is of importance. *J Pain Symptom Manage* 2012;43:59–67. © 2012 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Key Words

Home, general practitioner, district nurse, palliative care, community

Introduction

Dying at a preferred place is an important outcome for terminally ill cancer patients, and many patients prefer home as place of death across the world and in Japan.^{1,2} Specialized home care services appear to be effective in improving the patient's quality of life and ability to stay at home,^{3,4} but the rates of home death vary among countries. In Japan, only 6% of cancer deaths occurred at home in 2009.^{5,6}

A number of significant determining factors for achieving a home death have been identified by multiple empirical studies. These include patient and caregiver preference, intensity of home care services, and level of family support, as well as disease characteristics, patient's functional status, availability of hospital beds, rural or urban environment, and historical trend.^{7–10} These findings consistently stress the role of the community health care system in achieving home death, as well as the patient's and family's preference to stay at home.

Given the importance of community health services, the role of general practitioners (GPs) has become the focus of recent palliative care research.^{11–18} In these studies, current availability, barriers, and promising effective regional systems have been investigated using surveys of GPs and district nurses (DNs). On the whole, many GPs are willing to participate in palliative care and, in reality, see a relatively small number of palliative care patients each year.¹¹ At the same time, they experience the barriers of unfamiliar palliative care skills, medical technology, time constraints (especially out-of-hours demands), lack of

community services to reduce the family burden of caregiving, and lack of coordination and communication among community health care workers.¹¹

In Japan, palliative care is very strongly facilitated as a part of the government's cancer policy. Palliative care is increasingly seen as a part of comprehensive cancer treatment, and developing a regional model is urgently needed. Nonetheless, there have been very few large surveys about the availability of palliative care from community health care providers.^{19,20} Only one nationwide survey involved over 50,000 GP clinics and investigated their clinical exposure to palliative care, general willingness to be involved in palliative care, and knowledge about palliative care. In that survey, 60% of GPs had no experience in caring for cancer patients dying at home and 82% had no experience in prescribing opioids during the year but 47% expressed a willingness to provide medical care for terminally ill cancer patients dying at home. Furthermore, less than 20% were confident about palliative care skills, and less than half had correct knowledge about opioids.

This survey provides a nationwide overview of palliative care from the point of view of GPs, but the perspective of other professionals, especially DNs, is lacking; there are no data about the availability of symptom control procedures and willingness to participate in specific programs; and no region-based representative survey exists. We believe that gathering the views of GPs and DNs working from the same region is another valuable method to help understand

the reality and difficulties involved in palliative care for cancer patients at the regional level.

Therefore, this region-based comprehensive survey aimed to clarify 1) clinical exposure of GPs and DNs to cancer patients dying at home, 2) availability of symptom control procedures, 3) willingness to participate in out-of-hours cooperation and palliative care consultation services, and 4) reasons for admission of terminally ill cancer patients. The hypotheses of this study are that 1) in GPs, clinical exposure to cancer patients dying at home is not so high and some symptom control procedures are often unavailable, 2) in DNs, clinical exposure is high and symptom control procedures are generally available, 3) both GPs and DNs are willing to participate in out-of-hours cooperation and palliative care consultation services, and 4) DNs list various reasons for admission beyond medical reasons.

Health Care System Related to GPs, DNs, and Palliative Care in Japan

In Japan, there is no formal “family practice” or “general practitioner” system. Many clinic physicians functioning as GPs in the community are actually specialists, and after working at hospitals as specialists, they open their clinics under two or more specialty names irrespective of their certifications (e.g., a gastroenterologist usually can open a clinic under the names of “internal medicine,” “pediatrics,” and “gastroenterology”). The total number of clinics was about 90,000 in 2010, and all patients can visit any clinic and hospital they choose; they are not confined to their city or prefecture of residence.

Home nursing in Japan is provided through district nursing services. The number of district nursing services was 5763 in 2010. No expert palliative care nursing service (e.g., Macmillan nursing service) exists.

Since 1990, specialized palliative care service has been provided through palliative care units and inpatient hospices. The number of palliative care units was 208 (4153 beds) in 2010. Hospital palliative care teams are increasingly disseminated through cancer centers and general hospitals functioning as local cancer centers. The number of palliative care teams was about 500 in 2010. No community palliative care teams exist. Many health care professionals have regarded palliative care as a part of cancer

care. Although the concept of palliative care is not limited to cancer patients, we decided that this study should focus on palliative care for cancer patients.

Methods

This study was a cross-sectional mail survey of GPs and DNs in Japan and was a part of a regional intervention trial, the Outreach Palliative Care Trial of Integrated Regional Model (OPTIM) study. It was performed at the initial phase of the OPTIM study to explore the intervention protocols likely to be effective in each region; an overview of the OPTIM study is reported elsewhere.²¹

Questionnaires were sent to all GPs and DNs who met the inclusion criteria. No reminder or incentive was used. The ethical and scientific validity of this study was confirmed by the institutional review board.

Subjects

The survey was performed in four regions where the OPTIM study was used. Four areas with different palliative care systems were selected from across Japan: Tsuruoka (population 170,000, Yamagata prefecture); Kashiwa (population 670,000, Chiba prefecture); Hamamatsu (population 820,000, Shizuoka prefecture); and Nagasaki (population 450,000, Nagasaki prefecture). Kashiwa and Hamamatsu have specialized hospital palliative care teams in a cancer center and general hospitals, respectively; Nagasaki has a coordinated palliative care system for home patients in addition to hospital palliative care teams; and Tsuruoka had no formal specialized palliative care service at the time of the survey.

For this survey, we identified two groups of study subjects; a group of GPs and a group of DNs. The GPs all had a specialty of internal medicine, surgery, respiratory medicine, gastroenterology, urology, or gynecology. As there is no formal “family practice” or “general practitioner” system in Japan, we decided to include all specialties usually treating cancer patients. One questionnaire was sent to each GP clinic because many GP clinics are solo practice in Japan. The DNs comprised those working full time in a district nursing service. We had investigated the number of nurses

working at each district nursing service. Furthermore, we asked one representative DN from each district nursing service to answer questions relating to the service.

Measurements and Questionnaire

Because of a lack of validated tools and the exploratory nature of this study, the questionnaire was developed for this survey through literature review and discussions among authors.⁷⁻¹⁸ The clinical exposure of GPs and DNs to cancer patients dying at home was measured by 1) the number of cancer patients dying at home per year seen by each service (GP clinic or district nursing service), and 2) the predicted number of cancer patients dying at home likely to be seen by each service if out-of-hours cooperation among community health care providers and palliative care consultation services were available. The selected choices were none; one to five patients; six to 10 patients; 11 to 20 patients; or more than 20 patients per year. Furthermore, we investigated whether each service was available 24 hours a day.

The availability of symptom control procedures was measured using the choices "unavailable," "available if expert advice available," and "available" for each procedure, including oral opioids, subcutaneous opioids, subcutaneous haloperidol, home parenteral nutrition, peripheral intravenous infusion, hypodermoclysis, drainage of ascites or pleural effusion, and transfusion. "Expert" was described as expert only in the questionnaire because some physicians may not know palliative care specialists.

Willingness to participate in new regional systems was measured using two potential systems: out-of-hours cooperation among community health care providers (positive, neutral, and not interested), and palliative care consultation service in the community (want regular outreach visits, want on-demand consultation, and not interested). At the time of this study, neither system (out-of-hours cooperation among community health care providers, palliative care consultation in the community) was available in any of the four regions.

In addition, we asked all the DNs to consider the reason for admission of terminally ill cancer patients who they had cared for at home and rate the frequency of each of the following reasons, using a five-point Likert-type scale (1: none to 5: always): physical symptoms,

delirium, concern about out of hours, unexpected change in physical condition, family physician absent or inaccessible out of hours, unavailability of home care nurses, lack of informal caregivers, and family burden of caregiving.

Background data also were obtained from DNs concerning their age, clinical experience as a nurse, and their clinical experience as a DN. Data requested from GPs included their age, clinical experience, and whether their GP clinic was a certified home care clinic. Certified home care clinics are a recently developed medical system in Japan, whereby if the GP clinic has a 24-hour on-call system for patients at home, the clinic receives more payments from the national health care insurance.

Statistical Analyses

Data distributions, as well as 95% confidence intervals of the percentages, were calculated for all items. The difference among the regions was not statistically significant (data not shown) with the sample size small, and we determined to analyze all the data for this study.

Results

Of the 1106 GP clinics identified, a total of 235 (21%) responded. Responses were received from 22 of 88 clinics in Tsuruoka, 41 of 196 clinics in Kashiwa, 67 of 331 clinics in Hamamatsu, and 105 of 491 clinics in Nagasaki. Of the 70 district nursing services identified, a total of 56 services (80%) responded; a total of 115 responses were obtained from 270 DNs identified. Table 1 summarizes the background of the respondents.

Half of the GPs reported that they saw no cancer patients dying at home per year, and

Table 1
Background of Respondents

Characteristic	n ± SD
General practitioners (n = 235)	
Age (y)	57 ± 11
Clinical experience (y)	30 ± 11
Certified home care clinic, n (%)	30 (13)
District nurses (n = 115)	
Age (y)	42 ± 7.7
Clinical experience as a nurse (y)	18 ± 7.5
Clinical experience as a district nurse (y)	6.7 ± 4.5

Data are expressed as mean ± standard deviation unless otherwise noted.

Table 2
Number of Cancer Patients Dying at Home Seen by GP Clinics or District Nursing Services

Number of Cancer Patients Dying at Home (Per Year)	GP Clinics (n = 235)		District Nursing Services (n = 56)	
	n (%), 95% CI	If Out-of-Hours Cooperation Among Community Health Care Providers and Palliative Care Consultation Service Available, n (%), 95% CI	n (%), 95% CI	If Out-of-Hours Cooperation Among Community Health Care Providers and Palliative Care Consultation Service Available, n (%), 95% CI
None	125 (53, 47–60)	113 (48, 42–55)	4 (7, 3–17)	6 (11, 5–22)
1–5	80 (34, 28–40)	80 (34, 28–40)	19 (34, 23–47)	12 (21, 13–34)
6–10	15 (6, 4–10)	19 (8, 5–12)	14 (25, 15–38)	13 (23, 14–36)
11–20	7 (3, 1–6)	9 (4, 2–7)	10 (18, 10–30)	11 (20, 11–32)
20 or more	1 (0.4, 0–2)	6 (3, 1–5)	7 (13, 6–24)	13 (23, 14–36)

95% CI = 95% confidence interval.

40% cared for one to 10 cancer patients dying at home (Table 2). Of the district nursing services, 30% cared for 10 or more cancer patients dying at home per year, and 60% cared for one to 10 such patients. Although 96% of district nursing services (n = 54) were available 24 hours a day, only 38% of GP clinics (n = 90) were available 24 hours a day.

If out-of-hours cooperation among community health care providers and a palliative care consultation service became available, the number of GPs and district nursing services that reported they would not see any cancer patients dying at home did not change considerably (53% to 48% for GP clinics, and 7% to 11% for district nursing services (Table 2). However, the number of GPs and district nursing services that reported they would see 20 or more cancer patients dying at home per year increased considerably, from 0.4% to 2.3% for GP clinics and 13% to 23% for district nursing services.

Oral opioids, subcutaneous opioids, and subcutaneous haloperidol were available from more than 80% of district nursing services if expert advice was available, whereas 34% of GPs reported oral opioids were unavailable, and approximately 50% reported subcutaneous opioids or haloperidol were unavailable, even if expert advice was available (Table 3). Peripheral intravenous infusion was available from about 70% of GPs and about 90% of district nursing services, whereas hypodermoclysis was available from less than 60% of GP clinics and about 70% of district nursing services. Drainage of ascites or pleural effusion and transfusions were rated as unavailable by

more than 50% of GP clinics and district nursing services.

Concerning the out-of-hours cooperation among community health care providers, only 20% or fewer of GP clinics and district nursing services reported feeling “positive,” and 35% of GPs reported no interest (Table 4). However, palliative care consultation service in the community was regarded as more necessary, with about half the GP clinics and district nursing services wanting on-demand consultation, and an additional 24% of GPs and 41% of district nursing services reporting that they wanted regular outreach visits.

Reasons for admission of terminally ill cancer patients that DNs had cared for at home are shown in Table 5. Family burden of caregiving was the most frequent reason given by DNs, with about 60% reporting this as “often” or “always.” The next most frequent reason was unexpected change in physical condition (about 40%), followed by uncontrolled physical symptoms (about 30%), and delirium (about 30%). Concern about out of hours, the family physician absent or inaccessible out of hours, lack of home care nurses, or lack of informal caregivers was infrequently listed.

Discussion

We believe this survey provides useful insights into the development of community palliative care services in Japan and also helps us understand how to deliver more effective palliative care through existing community health care services around the world.

Table 3
Availability of Symptom Control Procedures for GPs and District Nursing Services

Procedure Variation	GP Clinics (n = 235)			District Nursing Services (n = 56)		
	Unavailable n (%; 95% CI)	Available if Expert Advice Available n (%; 95% CI)	Available n (%; 95% CI)	Unavailable n (%; 95% CI)	Available if Expert Advice Available n (%; 95% CI)	Available n (%; 95% CI)
Oral opioids	81 (34, 29-41)	85 (36, 30-43)	59 (25, 20-31)	1 (2, 0-10)	30 (54, 41-66)	24 (43, 31-56)
Subcutaneous opioids	121 (51, 45-58)	82 (35, 29-41)	23 (10, 7-14)	6 (11, 0-22)	42 (75, 62-85)	6 (11, 5-22)
Subcutaneous haloperidol	113 (48, 42-55)	90 (38, 32-45)	24 (10, 7-15)	6 (11, 0-22)	42 (75, 62-85)	5 (9, 4-19)
Home parenteral nutrition	116 (49, 43-56)	68 (29, 23-35)	43 (18, 14-24)	3 (5, 2-15)	21 (38, 26-51)	32 (57, 44-69)
Peripheral intravenous infusion	57 (24, 19-30)	63 (27, 22-33)	104 (44, 38-51)	2 (4, 1-12)	18 (32, 21-45)	35 (63, 49-74)
Hypodermoclysis	95 (40, 34-47)	100 (43, 36-49)	33 (14, 10-19)	15 (27, 17-40)	35 (63, 49-74)	5 (9, 4-19)
Drainage of ascites/pleural effusion	118 (50, 44-57)	56 (24, 19-30)	52 (22, 17-28)	31 (55, 42-68)	20 (36, 24-49)	5 (9, 4-19)
Transfusion	131 (56, 49-62)	49 (21, 16-27)	47 (20, 15-26)	28 (50, 37-63)	24 (43, 31-56)	4 (7, 3-17)

95% CI = 95% confidence interval.

One of the most important results of this study was the finding that Japanese GPs had little exposure to cancer patients dying at home. This figure is comparable to the largest survey conducted to date in Japan, which reported that 60% of all GPs had no experience in caring for cancer patients who died at home.¹⁹ This is different than results from studies in Canada, the U.K., and Australia, which showed that almost all GPs in those countries have some experience in caring for terminally ill cancer patients dying at home.¹¹ One possible interpretation of our results is that many GPs in Japan are former "specialists" who worked in hospitals, and a considerable number of physicians are unfamiliar with managing cancer patients (e.g., cardiology). In addition, Japanese GPs have no formal responsibility in the health care system for caring for patients in the community of their clinics, and cancer patients usually receive medical treatments in hospitals. Nonetheless, a third of Japanese GPs had experience in caring for one to five terminally ill cancer patients dying at home per year. This result is consistent with previous findings from the U.K. and Australia, where a GP sees about five terminally ill cancer patients per year.¹¹ Our results highlight the difficulties faced by Japanese GPs in learning up-to-date skills in palliative care when they only have minimal exposure to terminally ill cancer patients. This finding suggests that easily available on-demand consultation services from palliative care experts are necessary.

In this survey, hypothetical out-of-hours cooperation among community health care providers and the availability of palliative care consultation services in the region did not noticeably increase the number of GPs that intended to see terminally ill cancer patients at home. In addition, 30% of GPs reported no interest in participating in or developing such regional palliative care services. This figure is very close to the finding from an Australian survey, which identified lack of interest as one of the most frequent reasons for GPs not participating in palliative care.¹² Similarly, a U.K. survey reported that about 30% of London GPs believed "palliative care at home should be handed over to specialists."¹³ In contrast, the number of GP clinics and district nursing services that reported they would care for 20 or more cancer patients dying at home considerably increased in

Table 4
Willingness to Participate in Out-of-Hours Cooperation and Palliative Care Expert Consultation

Item	GPs (n = 235), n (%), 95% CI)	District Nursing Services (n = 56), n (%), 95% CI)
Out-of-hours cooperation among community health care providers		
Positive	33 (14, 10–19)	11 (20, 11–32)
Neutral	106 (45, 39–52)	40 (71, 58–82)
Not interested	82 (35, 29–41)	5 (9, 4–19)
Palliative care consultation service		
Want regular outreach visits	56 (24, 19–30)	23 (41, 29–54)
Want on-demand consultation	101 (43, 37–49)	29 (52, 39–64)
Not interested	63 (27, 22–33)	4 (7, 3–17)

CI = 95% confidence interval.

response to this question in our study. Taken together, these findings show that about 70% of GPs around the world believe that palliative care is one of their essential tasks, but the remaining 30% are unwilling to care for terminally ill cancer patients because of the balance between other occupational and personal responsibilities and/or lack of interest.^{12,13} Development of a regional system, therefore, should be intended to support those GPs who already care for terminally ill cancer patients at home or are interested in caring for such patients so that they see more patients with a minimum increase in their workload. To increase the total number of GPs in the community with interest in palliative care might require political or social intervention strategies.

The second important finding of this study is the clarification of the availability of symptom control procedures in Japan. District nursing services reported a variety of opioids available, but 35% of GPs reported that oral opioids were unavailable, even if expert advice was available, and 50% reported that

subcutaneous opioids or haloperidol were unavailable. In contrast, previous studies from Australia and the U.K. demonstrated that GPs were, in general, familiar with the use of opioids but less confident or experienced difficulties dealing with psychiatric symptoms and/or the use of home care technology.^{11,12,14} Possible interpretations of these findings are the strict regulation of opioids in the community in Japan, the lack of opportunity in medical education regarding opioid medications, and the lack of a coordinated system to support home care technology.²² Although peripheral intravenous infusion was available in many situations for medically assisted hydration at home, hypodermoclysis was less readily available despite existing evidence that hypodermoclysis is more convenient and safer than intravenous access.²³ In addition, the fact that drainage of ascites or pleural effusion and transfusions were unavailable in 50% of GP clinics and district nursing services could be partly because they are time-consuming procedures and not only the result of

Table 5
Reasons for Admission of Terminally Ill Cancer Patients After Care at Home From the District Nurse's Perspective (n = 115)

Reason for Admission	None n (%), 95% CI)	Rarely n (%), 95% CI)	Sometimes n (%), 95% CI)	Often n (%), 95% CI)	Always n (%), 95% CI)
Physical symptoms	9 (8, 4–14)	28 (24, 17–33)	32 (28, 20–37)	32 (28, 20–37)	5 (4, 2–10)
Delirium	17 (15, 9–22)	38 (33, 25–42)	24 (21, 14–29)	27 (23, 17–32)	9 (8, 4–14)
Concern about out of hours	48 (42, 33–51)	17 (15, 9–22)	18 (16, 10–23)	18 (16, 10–23)	5 (4, 2–10)
Unexpected change in physical condition	6 (5, 2–11)	20 (17, 12–25)	32 (28, 20–37)	41 (36, 27–45)	8 (7, 4–13)
Family physician absent or inaccessible out of hours	46 (40, 31–49)	25 (22, 15–30)	19 (17, 11–24)	15 (13, 8–20)	4 (4, 1–9)
Lack of home care nurses	67 (58, 49–67)	21 (18, 12–26)	11 (10, 5–16)	7 (6, 3–12)	1 (1, 0–5)
Lack of informal caregivers	38 (33, 25–42)	32 (28, 20–37)	25 (22, 15–30)	8 (7, 4–13)	4 (4, 1–9)
Family burden of caregiving	5 (4, 2–10)	17 (15, 9–22)	24 (21, 14–29)	55 (48, 39–57)	10 (9, 5–15)

95% CI = 95% confidence interval.

difficulties in monitoring potential adverse effects. This survey thus suggests that potentially useful strategies to increase the availability of palliative care procedures at home should include 1) basic education of GPs about opioids, psychiatric medications, and hypodermoclysis; 2) developing a system to support home care technology, such as subcutaneous infusion; and 3) research to establish feasible methods to manage ascites or pleural effusion at home.^{24,25}

The third important finding of this study related to the level of willingness of GPs and DNs to participate in out-of-hours cooperation among community health care providers and palliative care consultation services in the community. In general, responses were more positive with the latter rather than the former. Taking into account the fact that concern about out of hours and family physician absence or inaccessibility out of hours were not listed as main reasons for admission in this survey, the development of a system of cooperation among community health care providers out of hours would be difficult because of legal or political regulations, potential conflicts of interest, and personal conflicts. Yet, community palliative care consultation service is one of the most commonly demanded services by GPs,^{13,15} and some research evidence has recently emerged about the effectiveness of community-based palliative care consultation activities.^{26,27} Development of a community palliative care team and continuing information is vital because one study revealed that GPs are often unaware of such regional consultation systems even after they are established.¹³

The fourth important finding of this study clarifies the views of DNs regarding reasons for admission of terminally ill cancer patients after they have been cared for at home. In this survey, the most frequent reason for admission was family burden of caregiving, followed by unexpected change in physical condition, uncontrolled physical symptoms, or delirium. This finding is generally consistent with previous views suggesting that useful strategies to avoid unnecessary admission to hospital include alleviating the family caregiving burden. For example, the comprehensive arrangement of regional resources including respite care and day care as well as improvements in symptom

control has been previously suggested.^{7,10,14,15} Our findings stress that, in addition to symptom control, alleviating the burden of family care is essential for the development of a community palliative care program.

This study has several limitations. First, the response rate of this study, especially from GPs, was low. Our findings, therefore, are possibly not representative of all Japanese GPs and DNs. This can be a significant cause of bias, but we believe there would be no reliable means to increase the response rate because national physicians surveys, even conducted by the Japan Medical Association (representative organization of the GPs), obtained a generally low response rate (37%).¹⁹ In addition, we have no accessible data on clinic physician backgrounds, and comparisons between respondents and non-respondents or all GPs are impossible. Second, as the study focused on cancer patients, we cannot make conclusions about palliative care for noncancer populations.

In conclusion, in Japan, over half the GPs have no exposure to cancer patients dying at home per year, and the remaining half see a small number of terminally ill cancer patients at home. Oral opioids, subcutaneous opioids, and haloperidol were unavailable in 30% to 50% of GP clinics, whereas more than 90% of the district nursing services had access to them. GPs and DNs were willing to use community palliative care consultation services if available, and common reasons for admission to hospital were the family burden of caregiving and uncontrolled symptoms. Potentially effective strategies to develop a regional palliative care program should include basic education of GPs about opioids and psychiatric medications, easily available on-demand consultation services from palliative care experts, a system to support home care technology such as subcutaneous infusion, and development of a community care system to alleviate the burden of care for family members.

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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

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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

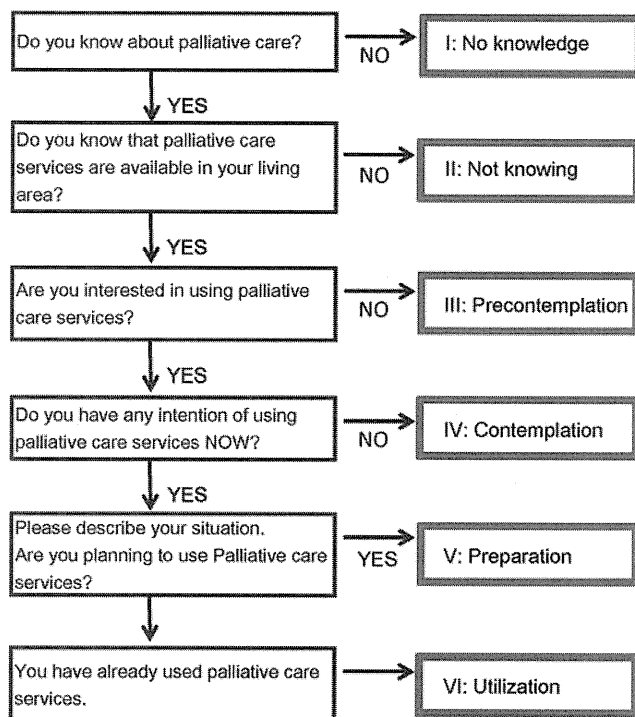


FIG. 1. Public awareness and readiness for palliative care services.

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 cancer		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	
	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. Ap-

proaches 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

No competing financial interests exist.

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