

According to the vital statistics reported by the MHLW, the age-adjusted death rate in Aomori Prefecture (104 per 100 000 person) was 1.4 times that of Nagano Prefecture (76 per 100 000 person) in 2007 (13). In 2008, there were only four prefectures that had more than 20 beds (for hospice care) per 1000 cancer deaths in Japan. Totally, there are 4060 beds for hospice care and about 360 approved hospices by the MHLW in Japan in 2010. However, only 59 out of 377 approved oncology hospitals (16%) have a specially equipped ward for palliative care. Among these approved oncology hospitals, only 90 out of 377 (24%) have a palliative care team (14).

The Japan Hospice Palliative Care Foundation performed a survey using questionnaires for the general public about home care for the terminally ill in 2007 (15). About 900 people responded. More than 80% of responders wanted to receive care at home; however, about 60% of people thought it would be impossible because of burdens for care givers, lack of information regarding preparing for emergency situations, etc. It is mandatory to enlighten people's perception of palliative home care and expand resources of medical and nursing care services. The questionnaires for Japanese doctors who engaged in clinical practice for cancer medicine have been conducted by a task-force team of the Japan Medical Association in 2008 (16). About 46 000 doctors corresponded and it was the largest survey on doctors' perception for palliative cancer care in Japan. Doctors recognized well the importance of general aspects of palliative cancer care, but could not answer more specific questionnaires on skill and knowledge of palliative medicine. Education and training for medical and nursing staff will be mandatory for improvement and to overcome these issues. Whole aspects of better life for patients and

family in each community are shown in Fig. 1. The CCP declares that they should easily be able to find and reach various kinds of support and better management in every district of Japan within 5 years.

THE OUTREACH PALLIATIVE CARE TRIAL OF INTEGRATED REGIONAL MODEL STUDY IN JAPAN

The Outreach Palliative care Trial of Integrated regional Model (OPITM) study, supported by the MHLW, is a strategic interventional trial for 5 years to develop procedures and systems of community-scale palliative cancer medicine for patients and their families (17,18). The aim of the program includes (i) early intervention of palliative care for patients suffering advanced cancer and their families, and (ii) effective cooperation of various support staff, at the hospital, clinic, nursing center, pharmacy, home welfare services etc., in the area where patients spend their daily life. Four municipalities were selected as experimental fields, that is, an area with and without a network of activity in palliative care. In the 'with' areas, there are three types of core institute, such as a large general hospital, a medical association in a district and a center institute specialized for cancer medicine. The OPITM study is not a randomized controlled trial and applies a pre- and post-comparative design. It is to assess the efficacy of integrated intervention and organized network with human resources, tools and specific facilities. In the OPTIM study, the primary endpoint consists of QOL scores rated by patients and families, the frequency of use of specific palliative care services and the death rate at home, and the final report will be published in 2013. If our

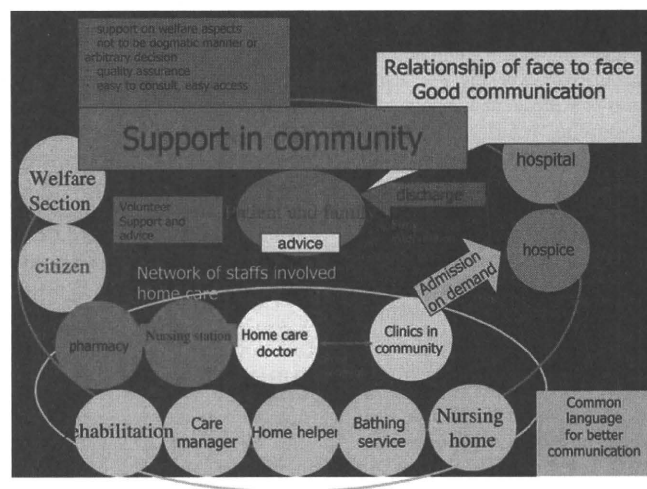


Figure 1. Network for community supported cancer care.



Figure 2. Practical education and training is mandatory for skill-up and maintenance of better communication of each staff in the community.

intervention study results in real improvement of the primary endpoint, we will recommend to the MHLW, a plan to conduct the system of palliative cancer care in each community of Japan under the guidance of procedures suggested in the OPTIM reports.

ENLIGHTENMENT AND EDUCATION OF PALLIATIVE CARE IN CANCER PATIENTS

Various educational events have been conducted for lay people by several societies, related to palliative care in Japan. Recently, patients' advocates have also been actively involved in these movements, cooperating with medical and nursing societies. Systematic educational programs for primary medical staff and special projects for training leaders and experts in palliative medicine are conducted by the above-mentioned societies (Fig. 2). Those are partly supported by the MHLW, such as the 'Orange balloon project' for lay people. The NPO-JSPM is conducting the PEACE (Palliative care Emphasis program on symptom management and Assessment for Continuous medical Education) project for trainers and regular seminars for medical students and for primary staff in cancer medicine using integrated curricula with the support of the MHLW (3). In 2009, about 10 000 doctors completed integrated educational courses such as the PEACE projects. The MECSSST supports projects conducted by consortiums of graduate schools of medicine, such as Gan (Cancer) professional training course (19).

Currently, there are only few chairs and courses for palliative medicine in universities and medical colleges in Japan. A major breakthrough will be sure to increase the number of courses and chairs for palliative medicine in most of the universities and medical colleges in Japan.

Continuous educational programs of primary palliative medicine for clinicians will be important and will urgently to be maintained by the cooperation of the trainers who graduate from the PEACE project. The JSPM will make efforts to increase the number of certified specialists for palliative medicine to a minimum of 2000 doctors within several years, expecting that each core hospital in a district should have two to three certified experts. These specialists will be anticipated to work in specific consultation cooperating with nursing specialists on active triages of patients in the community.

All medical staff should be aware of the importance and essence of palliative care in cancer medicine. We will continue our efforts to offer high-quality palliative care to improve and keep better QOL of cancer patients and their families.

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Conflict of interest statement

None declared.

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Pain intensity, quality of life, quality of palliative care, and satisfaction in outpatients with metastatic or recurrent cancer: a Japanese nationwide region-based representative survey

Abstract

Backgrounds: The aim of this study was to evaluate pain intensity, quality of life, quality of palliative care, and satisfaction reported by advanced cancer outpatients.

Patients and Methods: Questionnaires were sent to consecutive 1493 outpatients with metastatic or recurrent cancer from 4 regions in Japan, and 859 responses were analyzed (58%). Questionnaires included the Brief Pain Inventory, Good Death Inventory, Care Evaluation Scale, and 6-point satisfaction scale.

Results: About 20% of the patients reported moderate to severe pain. While more than 70% agreed or strongly agreed with “good relationship with medical staff”, and “being respected as an individual”, less than 60% agreed or strongly agreed with “free from physical distress”, “free from emotional distress”, “maintaining hope”, and “fulfillment at life’s completion”, and 54% reported some agreements with “feel a burden to others”. About 20% reported that improvement is necessary in physical care by physicians, physical care by nurses, psycho-existential care, help with decision making, and coordination/consistency of care; and 13% reported some levels of dissatisfaction.

Conclusions: A considerable number of outpatients with metastatic or recurrent cancer experienced pain, physical symptoms, emotional distress, and existential suffering, and advocated improvements in palliative care across multiple areas.

Introduction

Palliative care is an essential part of integrated cancer treatment¹. This is particularly so recently, as increasing numbers of patients with advanced cancer are receiving anticancer and/or palliative treatment in outpatient settings²⁻⁵.

While some studies were performed in outpatient settings to evaluate pain, quality of life, unmet needs, and concerns of cancer patients⁶⁻¹⁵, very few have focused on outpatients with advanced cancer. For example, a recent review on pain prevalence in cancer patients identified 52 relevant studies⁶. Of these, 22 studies specifically evaluated patients with advanced, metastatic or terminally illness, but only five specifically focused on outpatients with advanced cancer. Furthermore, to our best knowledge, there are no systematic region-based large surveys on advanced cancer outpatients to clarify not only symptom burden but quality of life and quality of care specifically designed to capture the experience of advanced cancer patients. Identifying symptom burden, quality of life, patient-perceived quality of care, and satisfaction would be useful to improve care for outpatients with advanced cancer as the region levels. In Japan, in addition, there have been no multicenter studies to assess the prevalence of pain, as well as quality of life and quality of palliative care, as reported by cancer patients themselves, despite a large amount of empirical data from nation-wide surveys of bereaved families¹⁶.

The primary aim of this region-based representative study was thus to assess pain intensity, quality of life, quality of palliative care, and satisfaction with medical care as recorded by outpatients with metastatic or recurrent cancer. Additional aim was to explore the correlations among the pain intensity, quality of life, quality of palliative care, and satisfaction.

Subjects and methods

A cross-sectional study was performed by sending questionnaires to consecutive outpatients with metastatic or recurrent cancer in four regions in Japan. This survey was part of the pre-intervention measurements collected for the regional

intervention trial, the Outreach Palliative Care Trial of Integrated Regional Model (OPTIM) study, and the study's methodology is reported in detail elsewhere¹⁷. The ethical and scientific validity of this study was confirmed by the institutional review board of the Japan Cancer Society, as well as by those of all participating hospitals.

Study subjects

Participating hospitals

Four study regions were chosen for intervention studies to cover a variety of areas with different palliative care systems across Japan: Tsuruoka (population 170000, Yamagata prefecture), Kashiwa (population 670000, Chiba prefecture), Hamamatsu (population 820000, Shizuoka prefecture), and Nagasaki (population 450000, Nagasaki prefecture). Kashiwa and Hamamatsu have specialized hospital palliative care teams in a cancer center and general hospitals, respectively; Nagasaki have coordinated palliative care system for home patients in addition to hospital palliative care teams; and Tsuruoka has no formal specialized palliative care service at the time of survey.

Due to the lack of an established method to identify all cancer patients living a specific area in Japan, we identified all hospitals in the study areas with reference to hospital lists from the Japan Hospital Association, the largest and authorized organization of hospitals in Japan, and the local resource information. Of 54 hospitals identified, we excluded 20 hospitals primarily treating psychiatric, rehabilitation, and geriatric non-cancer patients. We approached thus the remaining 34 hospitals (11033 beds), and a total of 23 hospitals (8964 beds, 81%) participated in this survey: 3 hospitals (Tsuruoka), 7 hospitals (Kashiwa), 8 hospitals (Hamamatsu), and 5 hospitals (Nagasaki).

Patients

Inclusion criteria for patients in this study were: 1) adult cancer patients with a primary tumor site in either the lung, esophagus, stomach, colon, rectum, pancreas, liver, biliary system, kidney, prostate, bladder, breast, ovary, or uterus, 2) presence of metastatic or recurrent cancer, 3) outpatient visits to the hospital between April and June 2008, and 4) disclosure of malignancy. Exclusion criteria included; 1) incapacity of the patient to complete the questionnaire (dementia, cognitive failure, or psychiatric illness), 2) severe emotional distress in the patient as determined by the principal treating, 3) poor physical conditions unable to complete questionnaire, and 4) language difficulty or visual loss. Patients were recruited consecutively, with hospitals either sending each eligible patient a questionnaire by mail or delivering it directly by hand to the patient.

Measurements

Data were collected on 1) pain intensity, 2) quality of life, 3) patient-perceived quality of palliative care, and 4) satisfaction.

Pain intensity

Pain intensity was measured using the Japanese adaptation of the Brief Pain Inventory, with a score given for the pain at its worst (0-10), at its least (0-10) and a score for the average pain felt (0-10) in the previous 24 hours¹⁸. The reliability and validity in Japanese populations has been established¹⁸. We had determined not to collect the data about other variables (e.g., current pain) or pain medication due to patient burden and cost.

Quality of life

Quality of life was measured using the Good Death Inventory (short version)^{19,20}. The Good Death Inventory was developed to specifically measure quality of life for Japanese patients with advanced cancer^{19,20}. We had determined to use the Good Death Inventory, not common tools such as EORTC or FACT, because we intended to investigate broader areas

of quality of life the Japanese patients regard important, especially psycho-existential components, beyond physical or functional areas. The full version of this scale consists of 10 domains (3 items for 8 domains and 2 items for 2 domains) with a 7-point Likert-type scale from “1: strongly disagree” to “7: strongly agree”: physical and psychological comfort, living in a favorite place, maintaining hope and pleasure, having a good relationship with medical staff, not feeling a burden to others, having a good relationship with family, having independence, having environmental comfort, being respected as an individual, and a feeling of fulfillment at life’s completion. For this study, we adopted the shortened version, in which each domain had one item (i.e. a total of 10 domains with 10 items). The reliability and the validity of both versions have been established^{19,20}. The total score of the Good Death Inventory was calculated as the total score of 10 items, potential ranges of 7 to 70, with higher scores indicating respondents who felt they had greater quality of life. In addition, we investigated full 3 items for “physical and psychological comfort” domain to allow detailed investigation of this attribute.

Patient-perceived quality of palliative care

Patient-perceived quality of palliative care was measured using the Care Evaluation Scale. The Care Evaluation Scale is a well validated and commonly used measurement tool in Japan to quantify the level of patient or family-perceived need for improvements in palliative care^{16, 21, 22}. The full version of the Care Evaluation Scale consists of 8 subscales (3 items for 7 domain and 2 items for 1 domain) with a 6-point Likert-type scale from “1: improvement is not necessary at all” to “6: highly necessary”: physical care provided by physicians, physical care provided by nurses, psycho-existential care, help with decision-making, coordination/consistency of care, environment, availability, and cost. For this study purpose, we used the first 5 subscales (15 items), because the study aim focused on interpersonal areas, not social areas (i.e., environment, availability, and cost). The reliability of the validity of each subscale has been established^{21, 22}. Each subscale score was calculated as an average of the items belonging the subscale, and the total score was calculated as an average of subscale scores. All scores are proportionally adjusted to range from 0 to 100 following the original studies^{21, 22}, and thus higher values indicate lower perception of necessity for improvement.

Satisfaction and demographic data

Satisfaction with their medical care was measured using a single item scale; “Are you satisfied with the medical care you currently receive?”. As in a previous study¹⁶, patient responses were selected from a 6-point Likert-type scale varying from “1: very dissatisfied” to “6: very satisfied”.

In addition, background data were obtained from patients and included age, gender, living status, marriage status, working status, levels of daily activity, and whether they were receiving radiotherapy or chemotherapy. To measure levels of daily activity, patients evaluated their own European Organization for Research and Treatment of Cancer (EORTC) Performance status: 0 (no symptoms, able to carry on all activities without restrictions), 1 (mild symptoms but ambulatory and able to carry out work of a light or sedentary nature), 2 (ambulatory and capable of self care for more than 50% of their waking hours), 3 (laying in a bed or sitting in a chair for more than 50% of their waking hours), and 4 (laying in a bed or sitting in a chair for the entire day). The primary sites of medical care for patients were obtained from their medical charts.

Statistical analyses

As our primary aim was to understand overall experience of the patients, data distributions were analyzed for each item, not using the mean values or summarizing values. For comparisons, pain intensity was classified into 4 groups following the previous systematic review: no pain, 0; mild, 1 to 4; moderate 5 to 6; severe, 7 or more⁶. In addition, the proportion of the patients with pain of 5 or more was calculated as “substantial pain” to compare the results with other studies^{7,8}.

Pain intensity, total score for the Good Death Inventory, total score for the Care Evaluation Scale, and satisfaction were compared between groups of patients with different backgrounds. Intergroup differences were examined with post-hoc tests using the Sheffe's test. To explore the correlations among the pain intensity, quality of life, quality of palliative care, and satisfaction, we calculated the Spearman's correlation coefficients among these variables.

The difference among the regions of primary end-points was not statistically significant, and we thus determined to analyze the whole data for this study.

Results

Of 1880 patients who met the inclusion criteria, 182 patients were excluded due to 1) incapacity of the patient to complete the questionnaire such as dementia, cognitive failure, or psychiatric illness (n=87), 2) severe emotional distress (n=48), 3) poor physical conditions (n=28), and 4) language difficulty or visual loss (n=5), and unspecified reasons (n=14). During the procedure, 75 patients died, admitted, or changed hospitals; and responsible physicians unavailable for technical reasons in 30 patients. In addition, 100 patients refused to receive questionnaire. Questionnaires were thus sent to 1493 patients, and 5 returned due to wrong address. A total of 859 responses (58%) were obtained. Table 1 summarizes the patient backgrounds.

Approximately 60% of patients reported some level of pain, with approximately 20% reporting moderate to severe pain (Table 2). If the cut-off points are determined as 5, 17% of patients had a pain intensity of 5 or more for their worst pain in the previous 24 hours, and 11% of patients had this pain level as the average in the previous 24 hours.

In the items of the Good Death Inventory (Table 3), more than 70% of the patients "agreed" or "strongly agreed" with living in a favorite place (74%), having a good relationship with medical staff (77%), having independence (77%), having environmental comfort (71%), and being respected as an individual (73%). On the other hand, more than half but less than 60% of patients "agreed" or "strongly agreed" with "free from physical distress" (58%), free from emotional distress (52%), maintaining hope and pleasure (53%), and feeling of fulfillment at life's completion (51%). Furthermore, approximately 50% of the patients "slightly agreed", "agreed", or "strongly agreed" with the statement "I feel a burden to others".

Approximately 20% of patients reported that improvement is "necessary", "substantially necessary", or "highly necessary" in all five subscales; physical care by physicians, physical care by nurses, psycho-existential care, help with decision-making, and coordination/consistency of care (Table 4).

Satisfaction levels were; strongly dissatisfied in 1% (n=9), dissatisfied in 2% (n=19), slightly dissatisfied in 9.5% (n=82), slightly satisfied in 27% (n=231), satisfied in 49% (n=420), and strongly satisfied in 10% (n=88).

Analysis of patient background data showed working status was significantly associated with intensity of pain, and total score from the Good Death Inventory (Table 5). Patient reported performance status was significantly associated with pain intensity, total score for the Good Death Inventory, total score for the Care Evaluation Scale, and satisfaction levels. Intergroup difference existed in performance status 0 vs. 1-4, 1 vs. 2-4 (pain intensity); 0 vs. 1-4, 1 vs. 2-4, 2 vs. 3, 4 (Good Death Inventory); 0 vs. 2, 3 (Care Evaluation Scale); and 0 vs. 1, 2, 4 (satisfaction).

There were significant but mild to moderate correlations among the pain intensity, total score for the Good Death Inventory, total score for the Care Evaluation Scale, and satisfaction levels (all $P < 0.001$, Figure 1), except for the relatively high correlation between the total score for the Care Evaluation Scale and satisfaction levels. The correlation coefficients between satisfaction and subscales of the Care Evaluation Scale were; physical care by physicians ($\rho = 0.63$), physical care by nurses ($\rho = 0.59$), psycho-existential care ($\rho = 0.63$), help with decision-making ($\rho = 0.66$), and coordination/consistency of care ($\rho = 0.62$).

Discussion

This is the first region-based representative survey systemically evaluating pain intensity, quality of life, quality of palliative care, and satisfaction as reported by outpatients with metastatic or recurrent cancer as an international level. In addition, this is the first nation-wide multicenter survey about pain experience of cancer patients in Japan. Significant but modest correlations among these variables indicated that they are overlapped but different concepts, and measuring them as at the same time could be useful for understanding patient overall experience. The strengths of this study include the large number of patient responses analyzed, patient representation from multiple regions across the country (covered hospitals 81% as inpatient bed-based), and use of well validated measurement tools of quality of life and quality of palliative care specifically developed for Japanese advanced cancer patients. These measures enable us to capture the broader areas of patient quality of life especially psycho-existential components beyond functional status, in addition to patient-perceived quality of care.

Approximately 60% of the patients in this study had some level of pain, which is similar to figures of 59 to 74% reported in similar Western populations⁶. Approximately 20% of the population in this study had moderate to severe pain, with corresponding Western figures varying between 20 to 49%⁶. Likewise, the population in this study with “substantial” pain, defined as pain intensity of 5 or more, was approximately 20%, compared with 20% in a survey from the Netherlands⁸. These findings confirm that at least 20% of advanced cancer patients in outpatient settings experience moderate to severe pain, and pain management is still one of the most important area for outpatient cancer care.

Quality of life reported by the patients generally were high in this survey, particularly living in a favorite place, having a good relationship with medical staff, having independence, having environmental comfort, and being respected as an individual. These findings reflect that the patients studied in this survey were under being treated on an outpatient basis with relatively good performance status. On the other hand, patients reported relatively lower quality of life scores in three domains; 1) physical distress other than pain, 2) emotional distress, and 3) existential components such as maintaining hope, feeling of life completion, and feeling a burden to others. These findings are consistent with previous study findings in which the most frequent concerns for outpatient cancer patients included physical distress other than pain (i.e. fatigue and gastrointestinal symptoms such as appetite loss, nausea, and taste changes); psychological distress (i.e. anxiety, fear, and depression); and existential components (i.e. uncertainty, fears about their cancer spreading, concerns about their future, the unpredictability of their existence, their dependence on others, and feeling a burden to others)¹⁰⁻¹⁴. This study and others thus provide strong support for the urgent need for research to develop appropriate assessment tools and effective interventions to palliate physical distress other than pain (e.g., fatigue, appetite loss), emotional distress including depression, and existential suffering specifically targeting to maintaining hope, life completion, and alleviating patient-perceived burden to others²³⁻²⁵.

Of special note was the very high prevalence (approximately 50%) of Japanese outpatients with advanced cancer who perceived themselves to be a burden to others. This was despite the fact that more than 90% of the patients were independent in their daily lives. Several studies from Western countries revealed that being burden to others is also one of the biggest concerns for cancer outpatients^{13,14}. A large survey performed in Japan on terminally ill cancer patients also indicated that one of the most common suffering was perceived burden to others, and that this was not always associated with objective evidence of any impairment in the patients' activities²⁶. Recent studies on Japanese patients succeed to identify potentially useful care strategies to palliate patient perception of being a burden including practical, cognitive, and emotional approaches^{26,27}. Further studies should be encouraged to explore the better interventions for relieving patient-perceived burden to others in physically independent outpatients with advanced cancer.

Regarding the patient perceived quality of care, 20% of patients in this study reported there was some need for

improvements in all five subscales assessing the quality of palliative care, however less than 5% of patients rated the need as “highly necessary”. This is similar to the findings of another study using the same questionnaire for bereaved family members of cancer patients who died in certified palliative care units, in that study, less than 5% of respondents reported improvements in the palliative care was “highly necessary”. In contrast though, the percentage of respondents who reported that “no improvement was necessary” ranged 23 to 38% in the palliative care unit survey, versus 20% or less in this survey¹⁶. This suggests that outpatients in the current study evaluated the quality of the palliative care they received as generally acceptable (i.e., not completely satisfied), and some improvement was desired in all areas, including physical care by physicians, physical care by nurses, psycho-existential care, help with decision-making, and coordination/consistency of care.

Performance status was the strongest predictor of patient reported severe pain intensity, poor quality of life, low quality of care, and low satisfaction. This suggests disease progression causes the development of multiple symptoms and a variety of needs. As the full assessment of the palliative care needs of all patients is not practical in many outpatient settings due to the limited availability of time and resources, an easily applicable screening tool for outpatients targeted to those with considerable decreases in performance status could identify patients who should be candidates for intensive palliative care interventions^{9, 28}. Feasible and effective strategies to identify the outpatients with lower performance status and unmet needs should be urgently tested.

This study had several limitations. Firstly, the response rate was moderate of 58%, and no analysis was possible to compare respondents and no respondents due to lack of patient consent for using no respondents data. We cannot conclude therefore the response bias might make either over or under estimation of the results possible. Second, we adopted the mail survey for study methods instead using face-to-face or telephone interview due to cost reasons, and the possibility that different approach might obtain different results cannot be denied. One study performed in a similar setting in the Netherlands, however, demonstrated no statistically significant difference in the prevalence of pain when comparing data collected using either an interview or a mail survey⁸. We thus believe the method of questionnaire distribution was unlikely to alter the overall conclusion. Third, although the patients in this study came from a variety of locations and hospitals within the regions studied (more than 80% of inpatient beds are covered in each area), not all hospitals participated in the survey, particularly small hospitals. We believe however the number of the patients receiving cancer treatments in such hospitals is small, and this bias does not influence the conclusions. Finally, as we did not obtain the data about medical treatments the patients actually received, we cannot conclude the appropriateness of care they received.

In conclusion, at least 20% of outpatients with metastatic or recurrent cancer experience moderate to severe pain, physical symptoms other than pain, emotional distress, and existential suffering such as maintaining hope, life completion, and feeling a burden to others; and reported that the quality of palliative care is necessary for improvement in multiple areas. Palliative care for Japanese outpatients with recurrent or metastatic cancer should be further improved.

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Table 1 Patient backgrounds (n = 859).

Background characteristic of patients	n	%
Gender (male, %)	474	55%
Mean age (standard deviation)	67 (11)	
Primary tumor sites		
Lung	221	26%
Breast	148	17%
Colon, rectum	131	15%
Prostate	86	10%
Stomach	75	8.7%
Liver	39	4.5%
Pancreas	30	3.5%
Bladder	25	2.9%
Uterus	24	2.8%
Ovary	21	2.4%
Esophagus	19	2.2%
Bile duct	12	1.4%
Kidney	11	1.3%
Others (independent cancer in two organs)	16	1.9%
Living		
Not alone	789	91%
Alone	66	7.6%
Marriage status		
Married	700	81%
Divorced	100	12%
Not married	49	5.7%
Working		
Not working	660	76%
Full time	122	14%
Part time	65	7.5%
Performance status		
0	243	28%
1	373	43%
2	184	21%
3	37	4.3%
4	14	1.6%
Chemotherapy and/or radiotherapy		
Receiving	500	58%
Not receiving	346	40%

The percentages do not sum up 100% due to missing values.

Table 2 Pain intensity measured by the Brief Pain Inventory

	No pain	Mild (1 to 4)	Moderate (5 to 6)	Severe (7 to 10)
Worst pain	43% (n=374)	36% (n=315)	8.6% (n=74)	7.7% (n=66)
Average pain	43% (n=373)	42% (n=364)	7.7% (n=66)	2.7% (n=23)
Least pain	51% (n=437)	40% (n=348)	3.0% (n=26)	1.5% (n=13)

The percentages do not sum up 100% due to missing values

Table 3 Quality of life measured by the Good Death Inventory

Items in the Good Death Inventory*	Strongly agree	Agree	Slightly agree	Unsure	Slightly disagree	Disagree	Strongly disagree
<i>Physical and psychological comfort:</i>							
Free from pain	25% (n=216)	43% (n=372)	12% (n=106)	6.1% (n=53)	4.5% (n=39)	3.0% (n=26)	2.2% (n=19)
Free from physical distress	18% (n=158)	40% (n=348)	16% (n=140)	8.6% (n=74)	5.7% (n=49)	4.5% (n=39)	2.5% (n=22)
Free from emotional distress	17% (n=145)	35% (n=302)	20% (n=175)	11% (n=91)	6.8% (n=59)	4.9% (n=42)	1.7% (n=15)
<i>Living in a favorite place:</i>							
Able to stay at favorite place	29% (n=252)	45% (n=386)	9.5% (n=82)	6.3% (n=54)	2.0% (n=17)	2.3% (n=20)	1.2% (n=10)
<i>Maintaining hope and pleasure:</i>							
Have some pleasure in daily life	19% (n=162)	34% (n=292)	16% (n=141)	11% (n=94)	5.7% (n=49)	5.4% (n=47)	2.7% (n=23)
<i>Good relationship with medical staff:</i>							
Trust the physician	37% (n=318)	40% (n=349)	11% (n=94)	4.3% (n=37)	2.1% (n=18)	0.8% (n=7)	1.3% (n=11)
<i>Not being a burden to others:</i>							
Feeling a burden to others	11% (n=97)	19% (n=160)	24% (n=203)	9.0% (n=78)	8.6% (n=74)	13% (n=116)	9.6% (n=83)
<i>Good relationship with family:</i>							
Spend enough time with family	28% (n=242)	38% (n=330)	13% (n=110)	8.7% (n=75)	3.7% (n=32)	2.5% (n=22)	1.6% (n=14)
<i>Independence:</i>							
Independent in daily activities	39% (n=338)	38% (n=329)	9.5% (n=82)	3.5% (n=30)	2.3% (n=20)	1.7% (n=15)	2.3% (n=20)
<i>Environmental comfort:</i>							
Live in calm circumstances	30% (n=255)	41% (n=350)	14% (n=123)	6.0% (n=52)	1.9% (n=16)	1.6% (n=14)	2.1% (n=18)
<i>Being respected as an individual:</i>							
Being valued as a person	29% (n=246)	44% (n=381)	12% (n=104)	7.2% (n=62)	1.2% (n=10)	1.0% (n=9)	1.5% (n=13)
<i>Life completion:</i>							
Feels that his or her life is fulfilling	21% (n=178)	30% (n=262)	17% (n=147)	15% (n=130)	6.7% (n=58)	3.2% (n=28)	2.4% (n=21)

The percentages do not sum up 100% due to missing values

*Domain names in italics

Table 4 Patient-reported quality of palliative care as measured by the Care Evaluation Scale

Items in the Care Evaluation Scale *	Improvement is: Not necessary	Rarely necessary	Some necessary	Necessary	Considerably necessary	Highly necessary
<i>Physical care by physicians:</i>						
Tried to relieve physical discomfort	17% (n=150)	38% (n=327)	18% (n=151)	16% (n=135)	5.7% (n=49)	1.6% (n=14)
Dealt promptly with symptoms	19% (n=166)	36% (n=309)	17% (n=146)	15% (n=133)	5.2% (n=45)	2.4% (n=21)
Had adequate knowledge and skills	21% (n=184)	34% (n=292)	15% (n=127)	15% (n=131)	5.3% (n=46)	2.7% (n=23)
<i>Physical care by nurses:</i>						
Responded promptly to needs	18% (n=151)	34% (n=297)	20% (n=175)	14% (n=123)	4.2% (n=36)	1.5% (n=13)
Had adequate knowledge and skills	14% (n=122)	35% (n=299)	23% (n=194)	14% (n=124)	4.4% (n=38)	1.2% (n=10)
Helped the patient to enjoy daily life	16% (n=134)	34% (n=297)	22% (n=188)	16% (n=135)	3.4% (n=29)	0.9% (n=8)
<i>Psycho-existential care:</i>						
Helping to relieve concerns	17% (n=148)	35% (n=303)	22% (n=186)	15% (n=127)	4.6% (n=40)	0.6% (n=5)
Appropriate when depressed	16% (n=134)	37% (n=318)	21% (n=183)	13% (n=116)	5.1% (n=44)	1.0% (n=9)
Tried to keep the patient hopeful	18% (n=158)	36% (n=309)	19% (n=168)	14% (n=117)	5.4% (n=47)	1.0% (n=9)
<i>Help with decision making</i>						
Sufficient explanation about the current condition	23% (n=198)	30% (n=257)	21% (n=178)	13% (n=109)	7.1% (n=61)	3.2% (n=28)
Sufficient explanation about the expected outcome	15% (n=131)	33% (n=285)	25% (n=212)	12% (n=104)	7.3% (n=63)	2.3% (n=20)
Patient could participate in the selection of treatment	21% (n=179)	34% (n=296)	19% (n=167)	13% (n=113)	4.3% (n=37)	2.1% (n=18)
<i>Coordination/consistency of care:</i>						
Cooperation among staff members	17% (n=148)	36% (n=307)	18% (n=154)	15% (n=125)	4.7% (n=41)	1.6% (n=14)
Same doctors and nurses provided care	24% (n=203)	33% (n=281)	15% (n=132)	16% (n=136)	4.1% (n=35)	1.7% (n=15)
Planned with consideration for the previous course of the disease	20% (n=171)	33% (n=288)	18% (n=157)	12% (n=104)	4.5% (n=39)	1.6% (n=14)

The percentages do not sum up 100% due to missing values *Domain names in italics

Table 5 Comparisons of patient backgrounds and patient-reported pain intensity, quality of life, quality of palliative care, and satisfaction

	Pain intensity (worst pain in previous 24 hours)		Good Death Inventory		Care Evaluation Scale		Satisfaction	
		P		P		P		P
Gender								
Male (n=474)	1.8 ± 2.4	0.42	55 ± 9.5	0.88	68 ± 21	0.27	4.6 ± 0.97	0.47
Female (n=376)	1.9 ± 2.5		55 ± 9.2		70 ± 20		4.5 ± 0.95	
Age								
Patient 75 years or older (n=248)	2.0 ± 2.5	0.44	54 ± 10	0.19	69 ± 21	0.72	4.7 ± 0.90	0.003
Patient <75 years (n=649)	1.8 ± 2.4		55 ± 9.0		69 ± 20		4.5 ± 0.98	
Primary tumor sites								
Lung (n=221)	1.9 ± 2.6	0.47	54 ± 9.5	0.79	69 ± 21	1.00	4.5 ± 0.9	0.93
Breast (n=148)	1.9 ± 2.4		56 ± 9.1		69 ± 19		4.6 ± 0.9	
Colon, rectum (n=131)	1.6 ± 2.3		55 ± 9.0		69 ± 21		4.6 ± 1.0	
Stomach (n=75)	2.1 ± 2.7		55 ± 9.2		69 ± 20		4.5 ± 1.0	
Liver, Pancreas, Bile duct (n=81)	2.1 ± 2.7		54 ± 8.3		69 ± 23		4.5 ± 1.1	
Prostate (n=86)	1.4 ± 2.0		56 ± 11		68 ± 21		4.5 ± 0.9	
Urogenital (n=81)	2.0 ± 2.6		54 ± 8.9		70 ± 21		4.4 ± 1.0	
Living								
Not alone (n=789)	1.9 ± 2.5	0.82	55 ± 9.2	0.21	69 ± 20	0.029	4.5 ± 0.95	0.77
Alone (n=66)	1.9 ± 2.6		53 ± 9.5		63 ± 23		4.5 ± 1.0	
Marriage status								
Married (n=700)	1.8 ± 2.5	0.36	55 ± 9.3	0.25	70 ± 20	0.23	4.5 ± 0.95	0.15
Divorced (n=100)	2.0 ± 2.4		53 ± 10		66 ± 23		4.6 ± 0.89	
Not married (n=49)	2.3 ± 2.7		55 ± 8.0		67 ± 22		4.3 ± 1.2	
Working								
Not working (n=660)	2.0 ± 2.6	0.001	54 ± 9.7	0.001	69 ± 21	0.72	4.5 ± 0.98	0.68
Full-time (n=122)	1.4 ± 2.1		57 ± 8.0		70 ± 19		4.5 ± 0.85	
Part-time (n=65)	1.1 ± 1.9		57 ± 7.7		67 ± 19		4.4 ± 1.0	
Performance status								
0 (n=243)	0.48 ± 1.2	<0.001	60 ± 7.8	<0.001	74 ± 19	<0.001	4.7 ± 0.89	<0.001
1 (n=373)	2.0 ± 2.3		55 ± 8.5		69 ± 20		4.5 ± 0.98	
2 (n=184)	2.8 ± 2.8		51 ± 9.0		65 ± 21		4.5 ± 0.92	
3 (n=37)	3.9 ± 3.3		44 ± 10		61 ± 20		4.3 ± 1.0	
4 (n=14)	4.8 ± 3.4		43 ± 6.6		56 ± 27		3.8 ± 1.3	
Chemotherapy and/or radiotherapy								
Receiving (n=500)	1.9 ± 2.4	0.36	55 ± 9.0	0.37	69 ± 20	0.56	4.5 ± 0.93	0.76
Not receiving (n=346)	1.8 ± 2.5		55 ± 9.8		68 ± 21		4.5 ± 1.0	

Values are mean ± standard deviations.

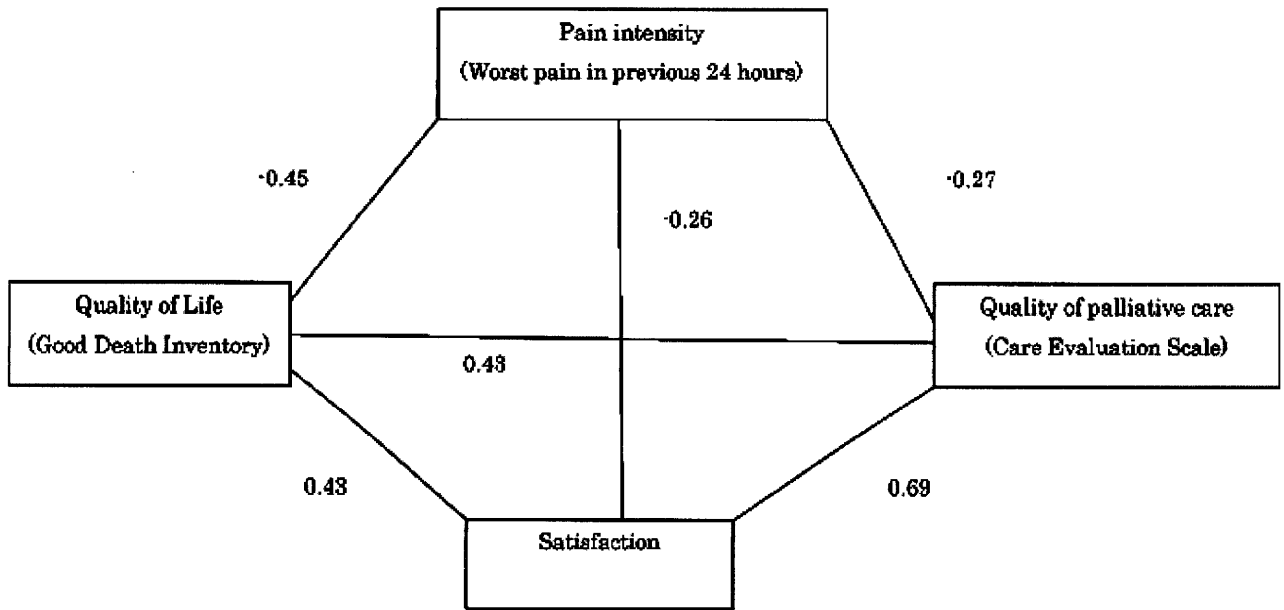


Figure 1 Correlations among patient-reported pain intensity, quality of life, quality of palliative care, and satisfaction

Knowledge, beliefs, and concerns about opioids, palliative care, and homecare of advanced cancer patients: A nationwide survey in Japan

Abstract

PURPOSE: Patients' knowledge, beliefs, or concerns about opioids, palliative care, and homecare can be potential barriers to providing quality palliative care. The primary aim of this study was to clarify knowledge about opioids, beliefs about palliative care, and concerns about homecare in advanced cancer patients.

METHODS: An anonymous questionnaire was sent to 1,619 outpatients with advanced cancer at 25 hospitals in 4 different regions of Japan. The respondents were asked to report their knowledge about opioids, beliefs about palliative care, and concerns about homecare, in addition to the levels of their sense of security regarding receiving cancer care in the region.

RESULTS: A total of 925 responses were received. In total, 28% believed that opioids are addictive and/or shorten life; 52% believed that palliative care is only for terminally ill patients; 75% agreed that being taken care of at home puts a heavy burden on the family; and 61% agreed that home-visit services cannot respond to sudden changes in a patient's condition. Levels of patients' sense of security were significantly higher in those who agreed that "opioids can relieve most pain caused by cancer" "palliative care relieves pain and distress", "palliative care is provided along with chemotherapy and/or radiation therapy", and "pain can be alleviated as effectively through home-visit services as it can at the hospital", and those who disagreed with the statements that "home-visit services cannot respond to sudden changes in a patient's condition" and "being taken care of at home puts a burden on the family".

CONCLUSIONS: Advanced cancer patients frequently had incorrect knowledge about opioids, a belief that palliative care is only for terminally ill patients, and concerns about homecare, especially the family burden and responses to sudden changes. Providing appropriate information about the safety of opioids, the availability of palliative care during the entire course of the disease, and realistic information about homecare is of marked importance to promote patients' sense of security.

Introduction

The numerous barriers to quality end-of-life care are related to patients, families, medical professionals, and the health care system itself^f. Among them, multiple empirical studies have identified knowledge, beliefs, or concerns about opioids, palliative care, and homecare in the general population and cancer patients as potential barriers for quality palliative care²⁻¹⁹. Many surveys have shown that incorrect knowledge about cancer pain and opioids could interfere with optimal pain management, especially an unrealistic fear of addiction and life-shortening²⁻⁷. Negative beliefs about palliative care were also one of the significant determinants of the potential underuse of specialized palliative care services⁸⁻¹². Moreover, many patients have concerns and difficulties about homecare, such as the burden on the family, concerns about sudden changes in physical conditions, and the unavailability of physicians visiting their home, and these could influence patients' decisions regarding whether or not to receive homecare¹³⁻¹⁹.

These findings indicate that providing appropriate information is of marked importance to achieve optimal palliative care, but, to our best knowledge, no large systematic large survey has been performed to clarify the knowledge about opioids, beliefs about palliative care, and concerns about homecare in a representative sample of advanced cancer patients.

In addition, a sense of security is being acknowledged as a very important concept for cancer patients and their families²⁰⁻²³. The sense of security is evaluated from the perspective of patients living in a region, and these perspectives reflect the quality of the regional system for providing healthcare services and awareness among the population of the services provided by the system. Funk and colleagues indicated that a feeling of security consisted of trust in competent professionals; timely access to necessary care, services, and information; and a sense of their own identity and self-worth as caregivers and individuals²⁰. Despite the increasingly perceived importance of the concept of a sense of security, to date,

no empirical studies have measured sense of security levels in advanced cancer patients, and explored the potential association between the levels and patients' knowledge, beliefs, and concerns.

The primary aim of this study was therefore to clarify the knowledge about opioids, beliefs about palliative care, and concerns about homecare in advanced cancer patients. Secondary aims included: 1) to clarify the levels of a sense of security, 2) to explore factors associated with knowledge, beliefs, and concerns, and 3) to explore the potential associations between the levels of a sense of security and knowledge about opioids, beliefs about palliative care, and concerns about homecare.

Subjects and Methods

A cross-sectional study was performed by sending questionnaires to consecutive outpatients with metastatic or recurrent cancer in four regions of Japan. This survey was part of the pre-intervention measurements collected for the regional intervention trial, the Outreach Palliative Care Trial of Integrated Regional Model (OPTIM) study, and the study's methodology is reported in detail elsewhere²⁴. The ethical and scientific validity of this study was confirmed by the institutional review board of the Japan Cancer Society, as well as by those of all participating hospitals (protocol registration number, UMIN000001274 of the University hospital Medical Information Network Clinical Trials Registry).

Study subjects

Participating hospitals

Four study regions were chosen for intervention studies to cover a variety of areas with different palliative care systems 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 survey.

Due to the lack of an established method to identify all cancer patients living a specific area in Japan, we identified all hospitals in the study areas with reference to hospital lists from the Japan Hospital Association, the largest authorized organization of hospitals in Japan, and local resource information. Of the 54 hospitals identified, we excluded 20 hospitals primarily treating psychiatric, rehabilitation, and geriatric non-cancer patients. We approached the remaining 34 hospitals (11,033 beds), and a total of 23 hospitals (8,964 beds, 81%) participated in this survey: 3 hospitals (Tsuruoka), 7 hospitals (Kashiwa), 8 hospitals (Hamamatsu), and 5 hospitals (Nagasaki).

Patients

Inclusion criteria for patients in this study were: 1) adult cancer patients with a primary tumor site in either the lung, esophagus, stomach, colon, rectum, pancreas, liver, biliary system, kidney, prostate, bladder, breast, ovary, or uterus, 2) presence of metastatic or recurrent cancer, 3) outpatient visits to the hospital between April and June 2008, and 4) disclosure of malignancy. Exclusion criteria included: 1) incapacity of the patient to complete the questionnaire (dementia, cognitive failure, or psychiatric illness), 2) severe emotional distress of the patient as determined by the principal treating physician, 3) poor physical condition unable to complete the questionnaire, and 4) language difficulty or visual loss. Patients were recruited consecutively, with hospitals either sending each eligible patient a questionnaire by mail or delivering it directly by hand to the patient.

Measurements

Data were collected on: 1) knowledge about opioids, beliefs about palliative care, and concerns about homecare, 2) sense of security, 3) pain intensity, and 4) patient-perceived quality of palliative care. The questionnaire (available from the authors) was constructed based on an extensive literature review, expert consensus among the authors, and a previous study [2-23, 25-27].

Knowledge about opioids, beliefs about palliative care, and concerns about homecare

We asked the respondents to rate the extent to which they agreed with the statements about their knowledge of opioids, beliefs about palliative care, and concerns about homecare on a 5-point Likert-type scale (1: strongly disagree, 2: disagree, 3: unsure, 4: agree, 5: strongly agree) [2]. Knowledge about opioids was examined using two items: “opioids can relieve most pain caused by cancer” and “opioids are addictive and/or shorten life”. Beliefs about palliative care were examined using 3 items: “palliative care relieves pain and distress”, “palliative care is provided along with chemotherapy and/or radiation therapy”, and “palliative care is only for terminally ill patients”. Concerns about homecare were examined based on 5 items: “pain can be alleviated as effectively through home-visit services as it can at the hospital”, “home-visit services cannot respond to sudden changes in a patient’s condition”, “it is hard to find home-visiting physicians”, and “being taken care of at home puts a burden on the family”.

Sense of security about cancer care in the region

The sense of security was measured using the 5-item scale to assess feelings of support and security about cancer care in a region²³. The statements were: (1) “I could feel secure on receiving cancer treatment”, (2) “pain could be well-relieved”, (3) “medical staff adequately responded to concerns and pain”, (4) “I could feel secure as a variety of medical care services are available”, (5) “I could feel secure on receiving care at home”. We asked participants to rate their level of agreement with the statements on a 7-point Likert scale (1: strongly disagree, 2: disagree, 3: slightly disagree, 4: not sure, 5: slightly agree, 6: agree, 7: strongly agree). The total score of 5 items, ranging from 5 to 35, quantifies the levels of the sense of security; a higher score indicates higher sense of security levels. Factor validity was established based on the emergence of one factor by explanatory factor analysis, and a high Cronbach’s alpha coefficient (0.91) demonstrated sufficient internal consistency. Criterion-related validity established a significant difference among the total scores of general populations from several areas with various health care services in Japan.

Pain intensity

Pain intensity was measured using the Japanese adaptation of the Brief Pain Inventory, with a score given for the pain at its worst (0-10), at its least (0-10), and a score for the average pain felt (0-10) in the previous 24 hours²⁵. Its reliability and validity in Japanese populations has been established²⁵. For this study, average pain was used for analyses.

Patient-perceived quality of palliative care

Patient-perceived quality of palliative care was measured using the Care Evaluation Scale^{26,27}. The Care Evaluation Scale is a well-validated and commonly used measurement tool in Japan to quantify the level of patient or family-perceived need for improvements in palliative care. The full version of the Care Evaluation Scale consists of 8 subscales (3 items for 7 domains and 2 items for 1 domain) with a 6-point Likert-type scale from “1: improvement is not necessary at all” to “6: highly necessary”: physical care provided by physicians, physical care provided by nurses, psycho-existential care, help with decision-making, coordination/consistency of care, environment, availability, and cost. For this study purpose, we used the first 5 subscales (15 items), because the study aim focused on interpersonal areas, not social areas (i.e.,

environment, availability, and cost). Each subscale score was calculated as an average of the items belonging to the subscale, and the total score was calculated as an average of subscale scores. All scores were proportionally adjusted to range from 0 to 100 following the original studies, and, thus, higher values indicate a lower perceived necessity for improvement.

In addition, information about the subjects' demographic characteristics (age, sex, and family), performance status, and medical status was collected through self-administered questionnaires. The performance status was measured using the European Organisation for Research and Treatment of Cancer (EORTC) performance status: 0 (no symptoms, able to carry out all activities without restrictions), 1 (mild symptoms but ambulatory and able to carry out work of a light or sedentary nature), 2 (ambulatory and capable of self-care for more than 50% of their waking hours), 3 (laying in bed or sitting in a chair for more than 50% of their waking hours), and 4 (laying in bed or sitting in a chair for the entire day).

Statistical analysis

The 5-point scale to measure patients' knowledge, beliefs, and concerns was simplified into 2 categories ("strongly agree" and "agree" vs. others). As the age, sex, and regions of the subjects were considered to affect the knowledge, beliefs, and concerns, they were selected *a priori* as explanatory variables. The chi-square test was used to examine the rate of "agree" responses in relation to the age, sex, and region. The total sense of security scores were examined employing Student's t-test and analysis of variance (ANOVA). To elucidate the influence of the age, sex, pain level, and patient-reported quality of palliative care on patients' knowledge, beliefs, and concerns, multiple logistic regression analyses were performed to determine odds ratios (ORs). With sense of security scores, multiple linear regression analyses were used. All models included the following covariates selected *a priori*: age in years (≤ 59 , 60-74, ≥ 75); sex; region; number of family members living with the participant; performance status; current medical status; pain level; and the patient-reported quality of care measured by the Care Evaluation Score (≤ 49 , 50-79, ≥ 80). Trend analysis was conducted, and the Care Evaluation Score was included as an ordinal variable. Comparisons were performed with analysis of covariance (ANCOVA), adjusting for age and sex, because these 2 factors were significant covariates for confidence levels. As the results were essentially the same across the 4 regions (data not shown), we report only the overall results. All analyses were carried out using STATA ver. 9.1 (College Station, TX, USA).

Results

Of 2,087 patients who met the inclusion criteria, 367 patients were excluded due to: 1) mental incapacity of the patient to complete the questionnaire such as dementia, cognitive failure, or psychiatric illness (n=137), 2) patient death, admission, or changing hospitals during the procedure (n=101), 3) severe emotional distress (n=52), 4) responsible physicians unavailable for technical reasons (n=30), 5) poor physical conditions (n=28), 6) language difficulty or visual loss (n=5), as well as other unspecified reasons (n=14). In addition, 101 patients refused to receive the questionnaire. Questionnaires were thus sent to 1,619 patients, and 5 returned due to being sent to the wrong address. Overall, 925 responses (57%) were obtained, and 833 responses were finally analyzed due to missing values for some of the primary end-points.

Participant characteristics

The participant characteristics are summarized in Table 1. The mean age \pm standard deviation (SD) was 67 ± 11 years, and 57% were men. The performance status was 0 or 1 in about 70% of the respondents, and 60% were receiving

chemotherapy and/or radiation therapy.

Knowledge about opioids, beliefs about palliative care, and concerns about receiving care at home

As shown in Table 2, about 30% of the patients believed that opioids are addictive and/or shorten life, and about half believed that palliative care is only for terminally ill patients. Regarding concerns about receiving care at home, 75% agreed or strongly agreed that being taken care of at home puts a heavy burden on the family, and about 60% agreed that home-visit services cannot respond to sudden changes in a patient's condition.

Sense of security

The mean score of the sense of security was 27 ± 5.6 (Table 2). The proportions of respondents who agreed (i.e., scored 5 or greater on the 7-point Likert-type scale) with each statement were: 82% ("I could feel secure on receiving cancer treatment"), 78% ("pain could be well-relieved"), 78% ("medical staff adequately responded to concerns and pain"), 59% ("I could feel secure as a variety of medical care services are available"), and 75% ("I could feel secure on receiving care at home").

Factors associated with the patients' knowledge about opioids, beliefs about palliative care, and concerns about homecare (Table 3)

Men, older respondents, and patients who reported lower-level quality of palliative care they received were significantly more likely to have incorrect knowledge about opioids. Patients' beliefs about palliative care and concerns about homecare were not significantly influenced by age and gender, while the patient-reported quality of palliative care was significantly associated that positive beliefs about palliative care ("palliative care relieves pain and distress") and lower levels of concerns about homecare ("pain can be alleviated as effectively through home-visit services as it can at the hospital").

Associations between the sense of security and knowledge about opioids, beliefs about palliative care, and concerns about homecare

Sense of security levels were significantly higher in patients who agreed that "opioids can relieve most pain caused by cancer", "palliative care relieves pain and distress", "palliative care is provided along with chemotherapy and/or radiation therapy", and "pain can be alleviated as effectively through home-visit services as it can at the hospital", as well as in the patients who did not agree that "home-visit services cannot respond to sudden changes in a patient's condition" and "being taken care of at home puts a burden on the family" (Table 4).

In addition, higher senses of security levels were significantly associated with an older age, male gender, lower pain intensity, and higher patient-reported quality of palliative care (Table 3).

Discussion

This is the first large-scale survey designed to clarify knowledge about opioids, beliefs about palliative care, and concerns about homecare in advanced cancer patients as a representative sample of multiple regions, in addition to the sense of security; the factors associated with knowledge, beliefs and concerns; and associations between the sense of security levels and knowledge and beliefs.

The most important findings of this study involved clarification of the patients' knowledge about opioids, beliefs about palliative care, and concerns about homecare.

First, about 30% of advanced cancer patients believed that opioids are addictive and/or shorten life. This figure is very

close to that in previous surveys of the general population in Japan and other countries (i.e., 30-40%)^{2, 5, 7}; and somewhat lower than some studies (i.e., 70%)^{4, 6}. In addition, this study revealed that older and male patients were significantly more likely to have incorrect knowledge about opioids. As many studies have identified misconceptions about opioids as dominant barriers to optimal pain control^{3, 5}, these results confirm that providing appropriate information about opioids, especially to older male patients, is of considerable importance to achieve maximum pain control.

Second, this study revealed that about half of the patients believed that palliative care is only for terminally ill patients, while similar percentages of the patients believed that palliative care is provided along with chemotherapy and/or radiotherapy. The findings are consistent with previous studies that revealed a negative image of palliative care among both patients and healthcare professionals⁸⁻¹¹. In Japan, a strong policy change from end-of-life care to “early” palliative care resulting in the involvement of palliative care teams was significantly associated with patient- and family-perceived appropriate referrals to specialized palliative care services^{12, 28}. These findings suggest that, along with ongoing efforts of disseminating palliative care teams not only for terminally ill patients but also those with intense symptoms and suffering irrespective of disease stages, providing information about the emerging concept of palliative care to patients themselves is another area to be improved to maximize palliative care use for enhancing patients’ quality of life

Third, this study revealed a high level of concern among advanced cancer patients about receiving homecare. The concerns most commonly reported included family burden, being unable to adequately respond to sudden changes in out-of-hours care, and availability of family physicians visiting the home. These figures are very close to data provided by the Ministry of Health, Labour, and Welfare whereby the most common difficulties with homecare surround concerns about the burden to the family and sudden changes in physical conditions¹⁵, and this is also consistent with Western studies which identified that concern about burden is a major factor affecting a cancer patient’s decision regarding homecare^{18, 29, 30}. The family burden is one of the most relevant issues in this population, and this includes the patient-perceived burden and actual family burden in caregiving. Multiple studies have indicated that the patient-perceived burden has one of the largest impacts on suffering in terminally ill cancer patients, even if family members do not report an actual caregiving burden^{31, 32}. These findings indicate that clinicians should alleviate patient concerns about burden when they receive homecare through the provision of psychological support for patients themselves, as well as arranging regional resources to reduce the actual family burden.

Another important finding of this study was clarification of the levels of a sense of security and the significant association between the sense of security and patients’ knowledge, beliefs, and concerns. To our best knowledge, this is the first reported study to demonstrate the significant association between the sense of security and patients’ knowledge, beliefs, and concerns. This finding suggests that a sense of security is shaped at least partly by knowledge and beliefs, and providing appropriate information could be of marked importance to enhance patients’ sense of security.

Despite the strengths of this study, including obtaining a relatively large number of patients from multiple regions of Japan and regional representative sampling, there are some limitations. First, it was a cross-sectional study, and, thus, the observed associations among variables might not be causal. Second, the response rate was moderate and no data were collected from the non-respondents. This could be a potential selection bias which may distort the study results. Third, unmeasured confounding factors, such as educational levels, could have distorted the study results, although adjustment was made for the confounders measured in the multivariate analyses. Finally, patients’ knowledge, beliefs, and concerns are inevitably influenced by the social and cultural views in the societies they live in.

In conclusion, advanced cancer patients frequently had incorrect knowledge about opioids, a belief that palliative care is only for terminally ill patients, and concerns about homecare, especially the family burden and responses to sudden changes. The knowledge, beliefs, and concerns were significantly associated with the sense of security levels regarding receiving cancer care in the region. Providing appropriate information about the safety of opioids, availability of palliative