

Ⅱ. 緩和ケアプログラムによる地域介入研究 付帯研究のまとめ

- Burden in Terminally Ill Cancer Patients: A Categorization of Care Strategies Based on Bereaved Family Members' Perspectives. *J Pain Symptom Manage* 40: 224-234, 2010
27. Ando M, Morita T, Akechi T, Okamoto T; Japanese Task Force for Spiritual Care. Efficacy of short-term life-review interviews on the spiritual well-being of terminally ill cancer patients. *J Pain Symptom Manage* 39: 993-1002, 2010.
28. Morita T, Fujimoto K, Namba M, et al. Screening for discomfort as the fifth vital sign using an electronic medical recording system: a feasibility study. *J Pain Symptom Manage* 35: 430-436, 2008.

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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.

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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)

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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: Free from pain</i>	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: Able to stay at favorite place</i>	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: Have some pleasure in daily life</i>	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: Trust the physician</i>	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: Feeling a burden to others</i>	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: Spend enough time with family</i>	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: Independent in daily activities</i>	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: Live in calm circumstances</i>	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: Being valued as a person</i>	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: Feels that his or her life is fulfilling</i>	21% (n = 178)	30% (n = 262)	17% (n = 147)	15% (n = 130)	6.7% (n = 58)	3.2% (n = 28)	2.4% (n = 21)

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\* Domain names in italics

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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 current condition	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)

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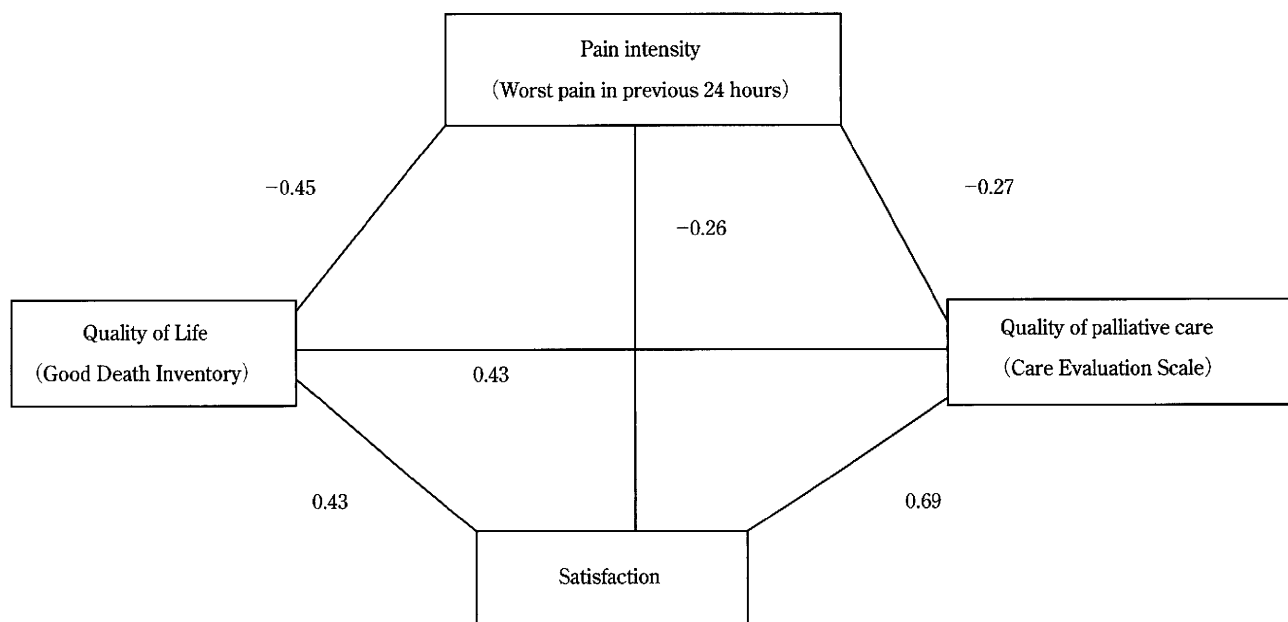
Table 5 Comparisons of patient backgrounds and patient-reported pain intensity, quality of life, quality of palliative care, and satisfaction

	Pain intensity (worst pain in previous 24 hours)		Good Death Inventory		Care Evaluation Scale		Satisfaction	
		P		P		P		P
<b>Gender</b>								
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	
<b>Age</b>								
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	
<b>Primary tumor sites</b>								
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	
<b>Living</b>								
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	
<b>Marriage status</b>								
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	
<b>Working</b>								
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	
<b>Performance status</b>								
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	
<b>Chemotherapy and/or radiotherapy</b>								
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.

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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<sup>1</sup>. 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 care<sup>2-19</sup>. 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-shortening<sup>2-7</sup>. Negative beliefs about palliative care were also one of the significant determinants of the potential underuse of specialized palliative care services<sup>8-12</sup>. 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 homecare<sup>13-19</sup>.

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 families<sup>20-23</sup>. 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 individuals<sup>20</sup>. 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 elsewhere<sup>24</sup>. 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 region<sup>23</sup>. The statements were: “If I get cancer”, (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 hours<sup>25</sup>. Its reliability and validity in Japanese populations has been established<sup>25</sup>. 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<sup>26, 27</sup>. 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 ( $\leq 59$ , 60-74,  $\geq 75$ ); 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 ( $\leq 49$ , 50-79,  $\geq 80$ ). 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  $\pm$  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  $\pm$  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%)<sup>2,5,7</sup>; and somewhat lower than some studies (i.e., 70%)<sup>4,6</sup>. 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<sup>3,5</sup>, 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 professionals<sup>8-11</sup>. 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<sup>12,28</sup>. 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 conditions<sup>15</sup>, 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<sup>18, 29, 30</sup>. 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<sup>31, 32</sup>. 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 care during the entire course of a disease, and realistic information about homecare is of marked importance to achieve the optimal quality of life for cancer patients.

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#### Conflict of interest

None.

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Ⅱ. 緩和ケアプログラムによる地域介入研究 付帯研究のまとめ

Table 1. Participant characteristics (N=833)

	N	%
Age (years)		
<60	208	25
60-74	405	49
75 or over	220	26
Sex		
Male	473	57
Female	360	43
Region		
Yamagata	135	16
Chiba	137	16
Shizuoka	302	36
Nagasaki	259	31
Family living with participant		
Yes	771	93
No	61	7
Performance status (EORTC)		
0	234	28
1	367	44
2	174	21
3 or 4	52	6
Current medical status		
Receiving chemotherapy or radiation therapy	491	60
Average pain score in previous 24 hours		
0-4	721	89
5-10	92	11

Percentages do not always add to up 100% due to missing values.

II. 緩和ケアプログラムによる地域介入研究 付帯研究のまとめ

Table 2. Knowledge about opioids, beliefs about palliative care, and concerns about receiving care at home

	All subjects	Age (years)			P	Sex		P
		<60	60-74	75+		Male	Female	
<b>Knowledge about opioids</b>								
Opioids can relieve most pain caused by cancer (n = 743)	545 (73%)	143 (71%)	272 (75%)	130 (74%)	0.620	320 (77%)	225 (69%)	0.018
Opioids are addictive and/or shorten life (n = 718)	202 (28%)	40 (20%)	105 (30%)	57 (34%)	0.007	126 (32%)	76 (24%)	0.002
<b>Beliefs about palliative care</b>								
Palliative care relieves pain and distress (n = 753)	570 (76%)	155 (77%)	280 (75%)	135 (76%)	0.905	313 (74%)	257 (79%)	0.105
Palliative care is provided along with chemotherapy and/or radiation therapy (n = 742)	474 (64%)	124 (62%)	230 (63%)	120 (69%)	0.278	147 (35%)	121 (37%)	0.578
Palliative care is only for terminally ill patients (n = 727)	377 (52%)	97 (48%)	187 (52%)	93 (55%)	0.436	216 (53%)	161 (50%)	0.508
<b>Concerns about receiving care at home</b>								
Pain can be alleviated as effectively through home-visit services as it can at the hospital (n = 748)	286 (38%)	67 (33%)	144 (39%)	75 (42%)	0.203	171 (41%)	115 (35%)	0.006
Home-visit services cannot respond to sudden changes in a patient's condition (n = 744)	452 (61%)	103 (52%)	241 (66%)	108 (61%)	0.004	256 (62%)	196 (59%)	0.442
It is hard to find home-visiting physicians (n = 742)	419 (57%)	113 (57%)	215 (59%)	91 (51%)	0.191	227 (55%)	192 (58%)	0.354
Being taken care of at home puts a burden on the family (n = 748)	557 (75%)	152 (76%)	274 (75%)	131 (73%)	0.811	303 (73%)	254 (76%)	0.309
<b>Sense of security score (n = 833)</b>	27.0 ± 5.6 (n = 833)	25.5 ± 5.5 (n = 208)	27.3 ± 5.6 (n = 405)	27.8 ± 5.1 (n = 220)	<0.001	27.4 ± 5.4 (n = 473)	26.4 ± 5.8 (n = 360)	0.009

Each column indicates the number (percentage) of respondents who agreed or strongly agreed with the statement, except for the last column, which indicates the mean ± S.D. (number of subjects).



Ⅱ. 緩和ケアプログラムによる地域介入研究 付帯研究のまとめ

Table 3. Factors associated with knowledge and beliefs about palliative care, and sense of security by multivariate analysis

	Age(Years)			Sex		Pain	Care evaluation score (Total)			
	<59	60-74	75+	Male	Female	Pain score	-49	50-79	80+	Trend P
<b>Knowledge about opioids</b>										
Opioids can relieve most pain caused by cancer (n=743)	1	1.1 0.7-1.6	0.9 0.6-1.5	1	0.6* 0.4-0.8	1.1 0.6-2.0	1	1.1 0.7-1.7	2.3* 1.4-3.7	P<0.001
Opioids are addictive and/or shorten life (n=718)	1	1.8 1.1-2.7	2.4* 1.4-4.0	1	0.7 0.5-1.0	1.3 0.7-2.2	1	0.6 0.4-1.0	0.6* 0.4-0.9	P=0.04
<b>Beliefs about palliative care</b>										
Palliative care relieves pain and distress (n=753)	1	0.9 0.6-1.4	1.1 0.6-1.9	1	1.2 0.8-1.7	0.9 0.5-1.5	1	1.4 0.9-2.3	2.4* 1.5-4.0	P<0.001
Palliative care is provided along with chemotherapy and/or radiation therapy (n=742)	1	1.0 0.7-1.5	1.4 0.9-2.2	1	0.9 0.7-1.3	0.8 0.5-1.3	1	1.1 0.7-1.6	1.4 0.9-2.2	P=0.11
Palliative care is only for terminal patients (n=727)	1	1.2 0.8-1.7	1.4 0.9-2.2	1	0.9 0.7-1.3	0.9 0.9-1.5	1	0.8 0.5-1.2	0.8 0.5-1.2	P=0.39
<b>Concerns about receiving care at home</b>										
Pain can be alleviated as effectively through home-visit services as it can at the hospital (n=748)	1	1.1 0.7-1.6	1.2 0.7-1.9	1	0.8 0.5-1.0	0.6 0.3-1.0	1	0.8 0.5-1.3	1.7* 1.1-2.6	P=0.002
Home-visit services cannot respond to sudden changes in a patient's condition (n=744)	1	2.1* 1.4-3.0	1.8* 1.1-2.8	1	1.0 0.8-1.4	0.9 0.5-1.5	1	1.1 0.7-1.8	0.7 0.5-1.1	P=0.07
It is hard to find home-visiting physicians (n=742)	1	1.2 0.8-1.7	0.9 0.6-1.3	1	1.0 0.8-1.4	1.0 0.6-1.6	1	1.1 0.7-1.6	0.8 0.5-1.3	P=0.22
Being taken care of at home puts a burden on the family (n=748)	1	0.9 0.6-1.4	0.9 0.6-1.5	1	1.1 0.8-1.6	1.5 0.8-2.7	1	1.2 0.7-1.9	1.1 0.7-1.7	P=0.92
<b>Sense of security score (n=833)</b>	-	+1.5* 0.6, 2.3	+2.4* 1.3, 3.4	-	-0.8* -1.5, -0.1	-1.8* -2.9, -0.7	-	+0.9* -0.1, 1.8	+4.4* 3.4, 5.3	P<0.001

Values in the table indicate odds ratios and 95% confidence interval. \*, p<0.05; Multiple logistic regression analysis for knowledge about opioids and beliefs about palliative care indicates adjusted odds ratio and P-value; Multiple linear regression analysis for sense of security score indicates adjusted difference in score; all models include age (<60, 60-74, 75+; <60 as reference category), sex (male as reference category), region of residence, family living with participant, physical activity status, current medical status, average pain score in previous 24 hours, and care evaluation score (<50, 50-79, 80+; <50 as reference category).

II. 緩和ケアプログラムによる地域介入研究 付帯研究のまとめ

Table 4. Associations between the levels of feeling secure and knowledge about opioids, beliefs about palliative care, and concerns about homecare

		N	Mean ± S.D.	Pvalue
<b>Knowledge about opioids</b>				
Opioids can relieve most pain caused by cancer	Yes	545	27.9 ± 6.5	<0.001
	No	198	25.8 ± 5.9	
Opioids are addictive and/or shorten life	Yes	202	27.2 ± 5.8	0.857
	No	516	27.3 ± 6.9	
<b>Beliefs about palliative care</b>				
Palliative care relieves pain and distress	Yes	570	28.3 ± 8.0	<0.001
	No	183	25.6 ± 6.1	
Palliative care is provided along with chemotherapy and/or radiation therapy	Yes	474	28.1 ± 6.5	<0.001
	No	268	25.9 ± 6.1	
Palliative care is only for terminal patients	Yes	377	27.3 ± 6.4	0.684
	No	350	27.2 ± 6.4	
<b>Concerns about receiving care at home</b>				
Pain can be alleviated as effectively through home-visit services as it can at the hospital	Yes	286	29.3 ± 5.7	<0.001
	No	462	26.1 ± 6.4	
Home-visit services cannot respond to sudden changes in a patient's condition	Yes	452	27.1 ± 6.4	0.026
	No	292	27.9 ± 6.1	
It is hard to find home-visiting physicians	Yes	419	27.2 ± 6.5	0.193
	No	323	27.7 ± 6.1	
Being taken care of at home puts a burden on the family	Yes	557	27.1 ± 6.8	0.027
	No	191	28.1 ± 5.7	

## Providing palliative care for cancer patients: the views and exposures of community general practitioners and district nurses in Japan

### Abstract

#### *Background*

The role of general practitioners (GPs) and district nurses (DNs) is increasingly important to achieve dying at home. The primary aim of this region-based representative study was to clarify: 1) clinical exposure of GPs and DN 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 service; 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 4 areas across Japan, and 235 GPs and 56 district nursing services responded.

#### *Results*

In total, 53% of GPs reported that they saw no cancer patients dying at home per year, and 40% had 1 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 1 to 10 such patients. Oral opioids, subcutaneous opioids, and subcutaneous haloperidol were available in more than 90% of district nursing services, while 35% of GPs reported oral opioids were unavailable and 50% reported subcutaneous opioids or haloperidol were unavailable. 67% of GPs and 93% of district nursing services were willing to use palliative care consultation services. Frequent reasons for the admission were: family burden of caregiving, unexpected change in physical condition, uncontrolled physical symptoms, and delirium.

#### *Conclusions*

Japanese GPs have little experience in caring cancer patients dying at home, while DN have more experience. To achieve quality palliative care program for cancer patients as 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 important.

### Introduction

Dying at preferred place is an important determinant for terminally ill cancer patients, and many patients prefer home as place of death across the world and in Japan.<sup>1,2</sup> Specialized home-care services appear to be effective in improving the patient's quality of life and ability to stay at home,<sup>3,4</sup> but the rates of home death vary among the countries, and in Japan only 6% of cancer deaths occurred at home in 2009.<sup>5,6</sup> A number of significant determining factors for achieving a home death have been identified by multiple empirical studies, and 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.<sup>7-10</sup> 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, and thus the role of general practitioners (GPs) is a focus of recent palliative care research.<sup>11-18</sup> In these

studies, current availability, barriers, and promising effective regional systems were 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 relatively a small number of palliative care patients each year.<sup>11</sup> 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.<sup>11</sup>

In Japan, palliative care is very strongly facilitated as a part of cancer policy of the government. Palliative care is increasingly seen as a part of a 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.<sup>19,20</sup> Only one nationwide survey involved over 50000 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. In addition, less than 20% were confident with 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 is no data about the availability of symptom control procedures and willingness to participate into 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 as the region 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 service; and 4) reasons for admission of terminally ill cancer patients. The hypotheses of this study is that, 1) in GPs, clinical exposures to cancer patients dying at home are not so high and some symptom control procedures are often unavailable; 2) in DNs, clinical exposures are high and symptom control procedures are generally available; 3) both GPs and DNs are willingness to participate in out-of-hours cooperation and palliative care consultation service, 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 specialists in actual, and after working at the hospitals as specialists and open their clinics under usually 2 or more specialty names irrespe-

ctive of their certifications (e.g., a gastroenterologist usually can open the clinic under the names of “internal medicine”, “pediatrics”, and “gastroenterology”). The total number of clinics is about 90000 in 2010, and all patients can visit any clinics and hospitals as they choose beyond their living city or prefecture. On the other hand, home nursing is provided through district nurse services, and the number of district nurse services is 5763 in 2010. No palliative care expert nursing service (e.g., Macmillan nurse service) exist.

Specialized palliative care service has been provided through palliative care units and inpatient hospice from 1990, and the number of palliative care units is 208(4153 beds) in 2010. Hospital palliative care teams are increasingly disseminated through cancer centers and general hospitals functioning as local cancer centers, and the number of palliative care teams is about 500 in 2010. No community palliative care teams exist. Many health care professionals regarded palliative care as one part of cancer care, although the concept of palliative care is limited to cancer patients. We had decided thus that this study should focus on palliative care for cancer patients.

## **Subjects and methods**

### *Methods*

This study was a cross-sectional mail survey of GPs and DNs as a part of a regional intervention trial, the OPTIM study. This survey 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<sup>21</sup>.

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

### *Subjects*

This survey was performed in 4 regions, where the OPTIM study was employed. Four areas with different palliative care systems were selected from across Japan: Tsuruoka (170,000 population, Yamagata prefecture); Kashiwa (670,000 population, Chiba prefecture);