

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

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

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

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

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

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

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

Methods

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

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

Subjects

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

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

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

Measurements and Questionnaire

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

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

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

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

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

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

Statistical Analyses

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

Results

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

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

Table 1
Background of Respondents

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

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

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

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

95% CI = 95% confidence interval.

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

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

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

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

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

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

Discussion

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

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

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

95% CI = 95% confidence interval.

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

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

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

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

CI = 95% confidence interval.

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

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

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

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

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

95% CI = 95% confidence interval.

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

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

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

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

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

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

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References

- Steinhauser KE, Christakis NA, Clipp EC, et al. Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA* 2000;284:2476–2482.
- Miyashita M, Sanjo M, Morita T, Hirai K, Uchitomi Y. Good death in cancer care: a nationwide quantitative study. *Ann Oncol* 2007;18:1090–1097.
- Smeenk FW, van Haastregt JC, de Witte LP, Crebolder HF. Effectiveness of home care programmes for patients with incurable cancer on their quality of life and time spent in hospital: systematic review. *BMJ* 1998;316:1939–1944.
- Finlay IG, Higginson IJ, Goodwin DM, et al. Palliative care in hospital, hospice, at home: results from a systematic review. *Ann Oncol* 2002;13(Suppl 4):257–264.
- Ministry of Health, Labour and Welfare. Population survey report 2005. Available from <http://www.e-stat.go.jp/SG1/estat/List.do?lid=000001066473>. Accessed February 10, 2011.
- Cohen J, Houttekier D, Onwuteaka-Philipsen B, et al. Which patients with cancer die at home? A study of six European countries using death certificate data. *J Clin Oncol* 2010;28:2267–2273.
- Gomes B, Higginson IJ. Factors influencing death at home in terminally ill patients with cancer: systematic review. *BMJ* 2006;332:515–521.
- Fukui S, Fukui N, Kawagoe H. Predictors of place of death for Japanese patients with advanced-stage malignant disease in home care settings: a nationwide survey. *Cancer* 2004;101:421–429.
- Fukui S, Kawagoe H, Sakai M, et al. Determinants of the place of death among terminally ill cancer patients under home hospice care in Japan. *Palliat Med* 2003;17:445–453.
- Jack B, O'Brien M. Dying at home: community nurses views on the impact of informal carers on cancer patients' place of death. *Eur J Cancer Care (Engl)* 2010;19:636–642.
- Mitchell GK. How well do general practitioners deliver palliative care? A systematic review. *Palliat Med* 2002;16:457–464.
- Rhee JJ, Zwar N, Vagholkar S, et al. Attitudes and barriers to involvement in palliative care by Australian urban general practitioners. *J Palliat Med* 2008;11:980–985.
- Burt J, Shipman C, White P, Addington-Hall J. Roles, service knowledge and priorities in the provision of palliative care: a postal survey of London GPs. *Palliat Med* 2006;20:487–492.
- Groot MM, Vernooij-Dassen MJ, Verhagen SC, Crul BJ, Grol RP. Obstacles to the delivery of primary palliative care as perceived by GPs. *Palliat Med* 2007;21:697–703.
- Barclay S, Todd C, McCabe J, Hunt T. Primary care group commissioning of services: the differing priorities of general practitioners and district nurses for palliative care services. *Br J Gen Pract* 1999;49:181–186.
- Groot MM, Vernooij-Dassen MJ, Crul BJ, Grol RP. General practitioners (GPs) and palliative care: perceived tasks and barriers in daily practice. *Palliat Med* 2005;19:111–118.
- Burt J, Shipman C, Addington-Hall J, White P. Nursing the dying within a generalist caseload: a focus group study of district nurses. *Int J Nurs Stud* 2008;45:1470–1478.
- Dunne K, Sullivan K, Kernohan G. Palliative care for patients with cancer: district nurses' experiences. *J Adv Nurs* 2005;50:372–380.
- Miyashita M, Morita T, Uchida T, Eguchi K. Knowledge about opioid treatment in 97,961 Japanese physicians. [abstract]. *J Clin Oncol* 2010;28(Suppl):e16523.
- Japan Medical Association. Survey of physician attitude toward palliative care [in Japanese]. 2008.
- Yamagishi A, Morita T, Miyashita M, et al. Palliative care in Japan: current status and a nationwide challenge to improve palliative care by the Cancer Control Act and the Outreach Palliative Care Trial of Integrated Regional Model (OPTIM) study. *Am J Hosp Palliat Care* 2008;25:412–418.
- Ise Y, Morita T, Maehori N, et al. Role of the community pharmacy in palliative care: a nationwide survey in Japan. *J Palliat Med* 2010;13:733–737.
- Martin CM. Hypodermoclysis: renewed interest in an old technique. *Consult Pharm* 2010;25:204–206, 209–212.
- Alisky JM. Implantable central venous access ports for minimally invasive repetitive drainage of pleural effusions. *Med Hypotheses* 2007;68:910–911.
- Po CL, Bloom E, Mischler L, Raja RM. Home ascites drainage using a permanent Tenckhoff catheter. *Adv Perit Dial* 1996;12:235–236.
- Teunissen SC, Verhagen EH, Brink M, et al. Telephone consultation in palliative care for cancer patients: 5 years of experience in The Netherlands. *Support Care Cancer* 2007;15:577–582.
- Imura C, Fujimoto K, Nozue Y, et al. Outreach program of palliative care team. [in Japanese]. *Gan To Kagaku Ryoho* 2010;37:863–870.

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

Kei Hirai, Ph.D.,¹ Tadashi Kudo, M.A.,² Miki Akiyama, Ph.D.,³ Motohiro Matoba, M.D., Ph.D.,⁴
Mariko Shiozaki, Ph.D.,⁵ Teruko Yamaki, B.A.,⁶ Akemi Yamagishi, R.N., Ph.D.,⁷
Mitsunori Miyashita, R.N., Ph.D.,⁸ Tatsuya Morita, M.D.,⁹ and Kenji Eguchi, M.D., Ph.D.¹⁰

Abstract

Background: This study explores the distribution of public awareness, knowledge of availability, and readiness for palliative care services, and the perceived reliability of information resources as part of a nationwide palliative care implementation intervention in Japan (Outreach Palliative Care Trial of Integrated Regional Model [OPTIM]).

Methods: A cross-sectional anonymous questionnaire survey was conducted, and 3984 responses were used in the final analysis.

Results: A total of 63.1% of respondents admitted having no knowledge about palliative care, while 0.5% of respondents were using palliative care services. Respondents who knew about palliative care services, yet did not know about their availability were 18.6% of all respondents. Respondents who had cancer-related experiences were more likely to be aware of palliative care compared to the general population and availability of palliative care services. Only awareness of palliative care was significantly associated with two typical images, while cancer-related experiences were not.

Conclusion: Findings show that the public awareness of palliative care services and their availability is insufficient, and cancer-related experiences affect awareness of cancer palliative care but not directly related to typical images for palliative care such as care for patients close to death.

Introduction

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

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

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

¹Center for the Study of Communication Design, ²Graduate School of Human Sciences, ⁶Graduate School of Human Sciences, Osaka University, Osaka, Japan.

³Faculty of Policy Management, Keio University, Japan.

⁴Department of Palliative Medicine and Psycho-Oncology, Palliative Care Team, National Cancer Hospital, Japan.

⁵Faculty of Applied Sociology, Kinki University, Japan.

⁷Department of Adult Nursing/Palliative Care Nursing, School of Health Sciences and Nursing, Graduate School of Medicine, The University of Tokyo, Tokyo, Japan.

⁸Department of Palliative Nursing, Health Sciences, Tohoku University Graduate School of Medicine, Japan.

⁹Department of Palliative and Supportive care, Palliative Care Team and Seirei Hospice, Seirei Mikatahara Hospital, Shizuoka, Japan.

¹⁰Department of Internal Medicine and Medical Oncology, Teikyo University School of Medicine, Japan.

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

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

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

Methods

Subjects

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

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

Questionnaire

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

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

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

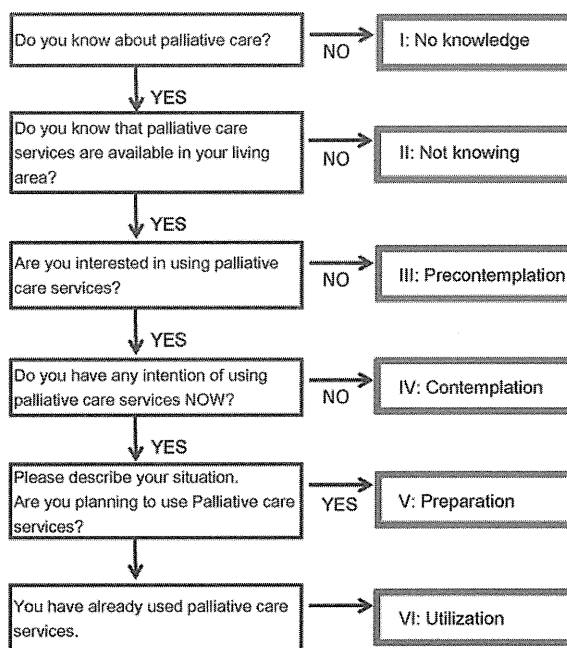


FIG. 1. Public awareness and readiness for palliative care services.

TABLE 1. DEMOGRAPHIC BACKGROUND OF THE RESPONDENTS

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

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

Analysis

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

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

Results

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

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

Public awareness, knowledge, and readiness for palliative care

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

TABLE 2. PUBLIC AWARENESS AND READINESS FOR PALLIATIVE CARE SERVICES

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

Cancer experience \times Awareness (No knowledge vs. Having knowledge): $\chi^2 = 27.24$, $df = 1$, $p < 0.01$, Cramer's V = 0.092.

Four areas \times Awareness (No knowledge vs. Having knowledge): $\chi^2 = 16.83$, $df = 3$, $p < 0.01$, Cramer's V = 0.073.

Within People who Knew Palliative Care:

Cancer experience \times Availability: $\chi^2 = 4.83$, $df = 1$, $p < 0.028$, Cramer's V = 0.064

Four areas \times Availability: $\chi^2 = 61.88$, $df = 3$, $p < 0.01$, Cramer's V = 0.229.

Availability: No awareness of availability vs. awareness of availability.

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

Typical images of palliative care

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

Discussion

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

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

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

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

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

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

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

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

In conclusion, the public awareness of palliative care services and their availability is insufficient. Those with cancer experiences were more aware of palliative care and their availability than the general population. Only people who were aware of palliative care developed two typical images, while those with cancer-related experiences did not. Ap-

proaches to inform the general population (including those with cancer-related experiences) about palliative care have already been taken in Japan. However, more effective methods should be developed. We feel that it is possible to eliminate many existing barriers to the improvement of end-of-life quality, and the dissemination of knowledge related to such care and treatment in Japan should be a top priority.

Author Disclosure Statement

No competing financial interests exist.

References

1. Yamagishi A, Morita T, Miyashita M, Akizuki N, Kizawa Y, Shirahige Y, Akiyama M, Kei Hirai, Kudo T, Yamaguchi T, Fukushima A, Eguchi K: Palliative care in Japan: Current status and a nationwide challenge to improve palliative care by the Cancer Control Act and the Outreach Palliative Care Trial of Integrated Regional Model (OPTIM) study. *Am J Hosp Palliat Care* 2008;25:412–418.
2. Koffman J, Burke G, Dias A Raval B, Byrne J, Gonzales J, Daniels C: Demographic factors and awareness of palliative care and related services. *Palliat Med* 2007;21:145–153.
3. Sanjo M, Miyashita M, Morita T, Hirai K, Kawa M, Ashiya T, Ishihara T, Miyoshi I, Matsubara T, Nakaho T, Nakashima N, Onishi H, Ozawa T, Suenaga K, Tajima T, Hisanaga T, Uchitomi Y: Perceptions of specialized inpatient palliative care: A population-based survey in Japan. *J Pain Symptom Manage*. 2008;35:275–282.
4. Morita T, Akechi T, Ikenaga M, Kizawa Y, Kohara H, Mukaiyama T, Nakaho T, Nakashima N, Shima Y, Matsubara T, Uchitomi Y: Late referrals to specialized palliative care service in Japan. *J Clin Oncol* 2005;23:2637–2644.
5. Miyashita M, Hirai K, Morita T, Sanjo M, Uchitomi Y: Barriers to referral to inpatient palliative care units in Japan: A qualitative survey with content analysis. *Support Care Cancer* 2008;16:217–222.
6. Morita T, Miyashita M, Tsuneto S, Sato K, Shima Y: Late referrals to palliative care units in Japan: nationwide follow-up survey and effects of palliative care team involvement after the Cancer Control Act. *J Pain Symptom Manage* 2009;38:191–196.

Address correspondence to:

Kei Hirai, Ph.D.

Center for the Study of Communication Design

Osaka University

1-2 Yamadaoka, Suita,

Osaka, 567-0871

Japan

E-mail: khirai@grappo.jp

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

Miki Akiyama · Toru Takebayashi · Tatsuya Morita · Mitsunori Miyashita · Kei Hirai · Motohiro Matoba · Nobuya Akizuki · Yutaka Shirahige · Akemi Yamagishi · Kenji Eguchi

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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 four 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

M. Akiyama (✉)
Faculty of Policy Management, Keio University,
5322 Endo, Fujisawa,
Kanagawa 252-0882, Japan
e-mail: miki@sfc.keio.ac.jp

T. Takebayashi
Department of Preventive Medicine and Public Health,
School of Medicine, Keio University,
35 Shinanomachi, Shinjuku,
Tokyo 160-8582, Japan

T. Morita
Department of Palliative and Supportive Care, Palliative Care
Team, and Seirei Hospice, Seirei Mikatahara General Hospital,
3453 Mikatahara-cho, Hamamatsu,
Shizuoka 433-8558, Japan

M. Miyashita
Department of Palliative Nursing, Health Sciences,
Tohoku University Graduate School of Medicine,
2-1 Seiryomachi, Aoba-ku, Sendai,
Miyagi 980-8575, Japan

K. Hirai
Graduate School of Human Sciences, Osaka University,
1-2 Yamadaoka, Suita,
Osaka 565-0871, Japan

M. Matoba
Division of Palliative Medicine, National Cancer Center Hospital,
5-1-1 Tsukiji, Chuo-ku,
Tokyo 104-0045, Japan

N. Akizuki
Psycho-Oncology Division, Chiba Cancer Center,
Chiba City, Chiba 260-8717, Japan

during the entire course of the disease, and realistic information about homecare is of marked importance to promote patients' sense of security.

Keywords Cancer · Palliative care · Homecare · Knowledge · Opioids

Introduction

The numerous barriers to quality end-of-life care are related to patients, families, medical professionals, and the health care system itself [1]. 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 [2–19]. 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-shortening [2–7]. Negative beliefs about palliative care were also one of the significant determinants of the potential underuse of specialized palliative care services [8–12]. 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 homecare [13–19].

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 families

[20–23]. 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 individuals [20]. 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 study, and the study's methodology is reported in detail elsewhere [24]. 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).

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, which are relatively large urban cities, 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

Y. Shirahige
Shirahige Clinic,
1-13-28 Katafuchi, Nagasaki,
Nagasaki 850-0003, Japan

A. Yamagishi
Department of Adult Nursing/Palliative Care Nursing, School
of Health Sciences and Nursing, Graduate School of Medicine,
The University of Tokyo,
7-3-1 Hongo, Bunkyo-ku,
Tokyo 113-0033, Japan

K. Eguchi
Department of Internal Medicine and Medical Oncology,
Teikyo University School of Medicine,
2-11-1, Kaga, Itabashi-ku,
Tokyo 173-8606, Japan

Tsuruoka, which is a typical rural town, 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 in 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 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 three 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 five 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 five-item scale to assess feelings of support and security about cancer care in a region [23]. The statements were: (1) “I would feel secure in receiving cancer treatment”, (2) “my pain would be well-relieved”, (3) “medical staffs will adequately respond to my concerns and pain”, (4) “I would feel secure as a variety of medical care services are available”, (5) “I would feel secure in 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 five 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 h [25]. Its reliability and validity in Japanese populations has been established [25]. 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 eight subscales (three items for seven domains and two

items for one 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 five 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 Organization for Research and Treatment of Cancer 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 two 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. 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. 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, adjusting for age and sex, because these two factors were significant

covariates for confidence levels. As the results were essentially the same across the four 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 endpoints.

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, nearly 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

Table 1 Participant characteristics ($N=833$)

	Number	Percent
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^a		
Yes	771	93
No	61	7
Performance status (EORTC)^b		
0	234	28
1	367	44
2	174	21
3 or 4	52	6
Current medical status		
Receiving chemotherapy and/or radiation therapy	491	60
Average pain score in previous 24 h		
0–4	721	89
5–10	92	11

^a $n=832$, due to missing values

^b $n=827$, due to missing values

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

Older respondents and patients who reported lower-level quality of palliative care they received were significantly more likely to have incorrect knowledge about opioids (Table 3). Although male patients were significantly more likely to know that opioids can relieve most pain caused by cancer, they were more likely to have incorrect knowledge that opioids were addictive and/or shorten life ($p=0.03$). 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 and male patients, is of considerable importance to achieve maximum pain control.

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

	All subjects	Age (years)			P value	Sex		P value
		<60	60–74	75+		Male	Female	
Knowledge about opioids								
Opioids can relieve most pain caused by cancer (<i>n</i> =743)	545 (73%)	143 (71%)	272 (75%)	130 (74%)	0.620	320 (77%)	225 (69%)	0.018
Opioids are addictive and/or shorten life (<i>n</i> =718)	202 (28%)	40 (20%)	105 (30%)	57 (34%)	0.007	126 (32%)	76 (24%)	0.002
Beliefs about palliative care								
Palliative care relieves pain and distress (<i>n</i> =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 (<i>n</i> =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 (<i>n</i> =727)	377 (52%)	97 (48%)	187 (52%)	93 (55%)	0.436	216 (53%)	161 (50%)	0.508
Concerns about receiving care at home								
Pain can be alleviated as effectively through home-visit services as it can at the hospital (<i>n</i> =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 (<i>n</i> =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 (<i>n</i> =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 (<i>n</i> =748)	557 (75%)	152 (76%)	274 (75%)	131 (73%)	0.811	303 (73%)	254 (76%)	0.309
Sense of security score (<i>n</i>=833)	27.0±5.6 (<i>n</i>=833)	25.5±5.5 (<i>n</i>=208)	27.3±5.6 (<i>n</i>=405)	27.8±5.1 (<i>n</i>=220)	<0.001	27.4±5.4 (<i>n</i>=473)	26.4±5.8 (<i>n</i>=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)

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)			Trend P
	<59	60–74	75+	Male	Female	Pain score	<49	50–79	80+	
Knowledge about opioids										
Opioids can relieve most pain caused by cancer (<i>n</i> =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	<i>P</i> <0.001
Opioids are addictive and/or shorten life (<i>n</i> =718)	1	1.8 1.1–2.7	2.4* 1.4–4.0	1	0.7* 0.5–0.9	1.3 0.7–2.2	1	0.6 0.4–1.0	0.6* 0.4–0.9	<i>P</i> =0.04
Beliefs about palliative care										
Palliative care relieves pain and distress (<i>n</i> =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	<i>P</i> <0.001
Palliative care is provided along with chemotherapy and/or radiation therapy (<i>n</i> =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	<i>P</i> =0.11
Palliative care is only for terminal patients (<i>n</i> =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	<i>P</i> =0.39
Concerns about receiving care at home										
Pain can be alleviated as effectively through home-visit services as it can at the hospital (<i>n</i> =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	<i>P</i> =0.002
Home-visit services cannot respond to sudden changes in a patient's condition (<i>n</i> =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	<i>P</i> =0.07
It is hard to find home-visiting physicians (<i>n</i> =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	<i>P</i> =0.22
Being taken care of at home puts a burden on the family (<i>n</i> =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	<i>P</i> =0.92
Sense of security score (<i>n</i>=833)	–	+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	<i>P</i><0.001

Values in the table indicate odds ratios and 95% confidence interval. 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 h, and care evaluation score (<50, 50–79, 80+; <50 as reference category)

**p*<0.05

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 [8–11]. 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 conditions [15], and this is also consistent with Western studies which identified that

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

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

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 and family forms, 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.