

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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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.

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	
Knowledge about opioids								
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
Beliefs about palliative care								
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
Concerns about receiving care at home								
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
Sense of security score (n=833)	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).

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 (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
Beliefs about palliative care										
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
Concerns about receiving care at home										
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
Sense of security score (n=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	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).

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.	P value
Knowledge about opioids				
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	
Beliefs about palliative care				
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	
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 ± 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 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 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 DNs 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.^{1,2} Specialized home-care services appear to be effective in improving the patient's quality of life and ability to stay at home,^{3,4} but the rates of home death vary among the countries, and in Japan only 6% of cancer deaths occurred at home in 2009.^{5,6} A number of significant determining factors for achieving a home death have been identified by multiple empirical studies, 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.⁷⁻¹⁰ These findings consistently stress the role of the community health care system in achieving home death, as well as the patient's and family's preference to stay at home, and thus the role of general practitioners (GPs) is a focus of recent palliative care research.¹¹⁻¹⁸ 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.¹¹ At the same time they experience the barriers of unfamiliar palliative care skills, medical technology, time constraints especially out-of-hours demands, lack of community services to reduce the family burden of caregiving, and lack of coordination and communication among community health care workers.¹¹

In Japan, palliative care is very strongly facilitated as a part of 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.^{19, 20} Only one nation-wide 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 nation-wide 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 representative 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 irrespective 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 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 elsewhere²¹.

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); Hamamatsu (820,000 population, Shizuoka prefecture); and Nagasaki (450,000 population, Nagasaki prefecture). Kashiwa and Hamamatsu have specialized hospital palliative care teams in a cancer center and general hospitals, respectively; Nagasaki have coordinated palliative care system for home patients in addition to hospital palliative care teams; and Tsuruoka has no formal specialized palliative care service at the time of survey.

For this survey, we identified 2 groups of study subjects; a group of GPs and a group of DNs. Inclusion criteria for the former were all GPs with 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 had 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 inclusion criterion for DNs was full-time work in a district nursing service, and we had investigated the number of nurses working at each district nursing service. In addition, we asked one representative DN from each district nursing service to answer questions relating to the service of the district nursing service.

Measurements and questionnaire

Due to a lack of validated tools and the explorative 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; 1 to 5 patients; 6 to 10 patients; 11 to 20 patients; or more than 20 patients per year. In addition, 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” is described as expert only in questionnaire, because some physicians may not know palliative care specialists.

Willingness to participate in new regional systems was measured using 2 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 4 regions.

In addition, we asked all the DNs to consider the reason for admission of terminally ill cancer patients that they had cared for at home and rate the frequency of each of the following reasons, using the 5-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 was also 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) and small sample size, and we determined to analyze the whole data for this study.

Results

Of the 1106 GPs clinics identified, a total of 235 (21%) responded. Responses were received from 22 out of 88 clinics in Tsuruoka, 41 out of 196 clinics in Kashiwa, 67 out of 331 clinics in Hamamatsu, and 105 out 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 40% cared for 1 to 10 cancer patients dying at home (Table 2). On the other hand, 30% of the district nursing services cared for 10 or more cancer patients dying at home per year, and 60% cared for 1 to 10 such patients. While 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 palliative care consultation service became available, the number of GPs and district nursing services who 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). On the other hand, the number of GPs and district nursing services who 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, while 34% of GPs reported oral opioids were unavailable and approximately 50% reported subcutaneous opioids or haloperidol were unavailable even if expert advice available (Table 3). Peripheral intravenous infusion was available from about 70% of GPs and about 90% of district nursing services, while 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.

About the out-of-hours cooperation among community health care providers, only 20% or less of GP clinics and district nursing services feeling "positive", and 35% of GPs reporting no interest (Table 4). On the other hand, 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

This survey we believe 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 across the world.

One of the most important results of this study was the finding that Japanese GPs had small exposure to cancer patients dying at home. This figure is comparable with 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 to results from studies in Canada, the UK, and Australia which showed that almost all GPs there 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 has no formal responsibility as 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 1 to 5 terminally ill cancer patients dying at home per year. This result is consistent with previous findings from the UK 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 service 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 UK 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 response to this question in our study. Taken together, these findings show about 70% of GPs across 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 due to the balance between other occupational and personal responsibilities and/or lack of interest.^{12, 13} Development of a regional system should therefore 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 interests 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. In this survey, district nursing services reported a variety of opioids available, but 35% of GPs reported oral opioids were unavailable even if expert advice available, and 50% reported subcutaneous opioids or haloperidol were unavailable. In contrast, previous studies from Australia and the UK 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 While 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 due to the fact that they are time-consuming procedures, and not only due to the 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:

basic education of GPs about opioids, psychiatric medications, and hypodermoclysis; developing a system to support home-care technology such as subcutaneous infusion; and 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 service 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, due to legal or political regulations, potential conflicts of interest, and personal conflicts. On the other hand, 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 a 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 of clinic physician backgrounds, and comparisons between respondents and non-respondents or all GPs is impossible. Second, as the study focused on cancer patients, we cannot conclude about the palliative care for non-cancer 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 and subcutaneous opioids and haloperidol were unavailable in 30% to 50% of GP clinics, while more than 90% of the district nursing services had access to them. GPs and DNs were willing to use community palliative care consultation service 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 of family members.

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Table 1. Background of respondents

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

Data are expressed as mean ± standard deviation

Table 2. The number of cancer patients dying at home seen by general practitioner (GP) clinics or district nursing services

Number of cancer patients dying at home	GP clinics (n = 235)		District nursing services (n = 56)	
	No. (%)	If out-of-hours cooperation among community health care providers and palliative care consultation service available No. (%)	No. (%)	If out-of-hours cooperation among community health care providers and palliative care consultation service available No. (%)
None per year	125 (53, 47-60)	113 (48, 42-55)	4 (7, 3-17)	6 (11, 5-22)
1 to 5 per year	80 (34, 28-40)	80 (34, 28-40)	19 (34, 23-47)	12 (21, 13-34)
6 to 10 per year	15 (6, 4-10)	19 (8, 5-12)	14 (25, 15-38)	13 (23, 14-36)
11 to 20 per year	7 (3, 1-6)	9 (4, 2-7)	10 (18, 10-30)	11 (20, 11-32)
20 or more per year	1 (0.4, 0-2)	6 (3, 1-5)	7 (13, 6-24)	13 (23, 14-36)

Percentages with 95% confidence intervals in the brackets.

Table 3. Availability of symptom control procedures for general practitioners (GPs) and district nursing services

	GP clinics (n = 235)			District nursing services (n = 56)		
	Unavailable No. (%)	Available if expert advice available No. (%)	Available No. (%)	Unavailable No. (%)	Available if expert advice available No. (%)	Available No. (%)
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)

Percentages with 95% confidence intervals in the brackets.

Table 4. Willingness to participate in out-of-hours cooperation and palliative care expert consultation

	General practitioners (n = 235) No. (%)	District nursing services (n = 56) No. (%)
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)

Table 5. Reasons for admission of terminally ill cancer patients after care at home from the district nurse's perspective (n = 115)

	None No. (%)	Rarely No. (%)	Sometimes No. (%)	Often No. (%)	Always No. (%)
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)

Preferred place of care and place of death of the general public and cancer patients in Japan

ABSTRACT

Dying at a favorite place is one of the important determinants for terminally ill cancer patients. The primary aim was to clarify 1) differences in preferred place of care and place of death among the general public across four areas across Japan, and 2) preferred place of care and place of death among community-representative cancer patients. A cross-sectional mail survey was conducted on 8000 randomly selected general population. We examined preferred place of care and place of death using two vignettes, and obtained a total of 3984 (50%) responses. For the pain scenario, approximately 50% of the general public throughout 4 areas chose home as their preferred place of care; and for the dependent-without-pain scenario, about 40% chose home as preferred place of care. In cancer patients, for both scenarios, approximately 40% chose home as the preferred place of care, and they were significantly less likely to choose home. The most preferred combination of place of care and place of death was home-hospice for both groups. Although there were statistically significant differences in preferred place of care and place of death among the four regions, the absolute difference was less than 8%. Independent determinants of choosing home as place of care included concern about family burden, and being unable to adequately respond to sudden changes out of working hours.

In conclusion, establishing more accessible home and hospice service is strongly required through arranging regional resources to reduce family burden, alleviating patient-perceived burdens, and improving 24-hour support at home.

Introduction

Dying at a preferred place is one of the most important determinants for terminally ill cancer patients in Japan and across the world^{1, 2}. Understanding the preferred place of care and place of death is therefore the first step in ensuring adequate resources for patients³⁻⁵, and multiple preference surveys in the UK, USA, and other countries have been conducted to clarify the preferred place of care and place of death⁶⁻⁸. In these surveys, general public and cancer patients generally chose home as preferred place of care and place of death⁶.

In Japan, a series of national surveys was conducted by the Ministry of Health, Labor, and Welfare in 2008 to reveal the preferred place of care and place of death⁸. Home was the preferred place of care in general, with 29% of respondents reporting that they wanted to receive care at home and be admitted to a hospice if necessary, and 23% preferring to receive care at home and be admitted to hospital if necessary. Another 11% chose home until death, while a considerable number of respondents reported that they want to be admitted to hospice earlier and stay until death (18%) or be admitted to hospital earlier and stay until death (10%). In summary, 63% of the general public chooses home as place of care, and as place of death if physical and social conditions were acceptable if presented with terminal cancer. At the same time, this survey also demonstrated that less than 10% believed home death is achievable; the reasons listed included burden to family (80%), concerns about sudden changes in physical conditions (54%), cost (33%), unavailability of physicians visiting home (32%), unavailability of emergency hospital beds (32%), unavailability of nurses visiting home (19%), inadequate home environment (16%), lack of around-the-clock services (15%), and lack of family caregivers (15%). The absolute figures of each response did not change compared with the same surveys in 1998.

The findings provide useful insights about the preferred place of care and place of death of Japanese cancer patients, but existing studies have major limitations. First, there have been no surveys specifically targeted at cancer patients, thus it is difficult to apply the results from the general population directly to cancer patients. Second, considerable differences may exist among various areas in Japan in medical resources, social resources, the delivery system of palliative care, and

cultural backgrounds, rendering the findings from a national representative sample may not be always applicable to specific regions such as urban vs. rural areas^{9, 10}. We thus believe that comparing the preferred place of care and place of death among different areas in Japan and clarifying the preferred place of care and place of death in cancer patients specifically are both of value.

In addition, although identifying predictors of preference about place of care and place of death is helpful for understanding how patients decide where they live at the end of their life, only a few studies have examined such determinants^{6, 11-14}. In particular, it would be important to clarify the impact of concerns about home care on the preference of place of care and place of death, because large surveys in Japan revealed that excessive apprehension significantly contributed to late referrals to specialized palliative care services¹⁵, and few empirical studies have specifically addressed this topic^{6, 11-14}.

The primary aim of this study was to clarify 1) the differences in preferred place of care and place of death of the general public among different areas in Japan, and 2) preferred place of care and place of death of cancer patients. Additional aims include clarifying concerns and values about home care of the general public and cancer patients, and examining the effects of such concerns on preferred place of care and place of death.

Subjects and methods

We conducted a cross-sectional mail survey of the general public as part of a larger regional intervention trial, the Outreach Palliative Care Trial of Integrated Regional Model (OPTIM) study. This survey was performed at the initial phase of the OPTIM study, the details of which are reported elsewhere¹⁶. The institutional review board for the OPTIM study approved the ethical and scientific validity.

Study subjects

This survey was conducted in four regions where the OPTIM study was employed. These areas were selected based on different palliative care system development across Japan: Tsuruoka (170000 people, Yamagata prefecture), Kashiwa (670000 people, Chiba prefecture), Hamamatsu (820000 people, Shizuoka prefecture), and Nagasaki (450000 people, Nagasaki prefecture). The systems in Kashiwa, Hamamatsu, and Nagasaki provide palliative care led by a national cancer center, a general hospital, and a general practitioner association, respectively, while the system of palliative care in Tsuruoka is not organized.

For this survey, we initially identified 8000 subjects in the general population by a stratified two-stage random sampling method of residents of the four areas. We selected 50 census tracts for each area and then selected 25 individuals, aged 40-79 years, within each census tract, thus identifying 2000 individuals for each area. The census tracts usually cover 200 families to conduct national census surveys in Japan. We randomly sampled 50 census tracts in each prefecture, and then sampled 25 individuals in each census tract according to the national census method in Japan.

We mailed questionnaires to potential participants in June 2007, and sent a reminder postcard two weeks later.

Questionnaire

To enable comparisons with previous findings using a national sample, we decided to use the same questionnaire used by the Ministry of Health, Labor, and Welfare⁸. This questionnaire surveyed the respondents about preferred place of care and place of death using two brief scenarios. The first scenario described a terminally ill cancer patient with pain and given a prognosis of 6 months or less (the pain scenario), while the other scenario described a terminally ill cancer patient without pain, but dependent on others in their daily activities (without pain and dependent scenario). Choices with

simplified combination definitions were: 1) home until death (home-home), 2) receive care at home, and admitted to hospice if necessary (home-hospice), 3) receive care at home, and admitted to hospital if necessary (home-hospital), 4) admitted to hospice earlier and stay until death (hospice-hospice), 5) admitted to nursing home and stay until death (nursing home-nursing home), 6) admitted to hospital and stay until death (hospital-hospital), or 7) receive aggressive treatment at cancer center (cancer center-cancer center)¹⁷. Hospice meant in this study palliative care units or inpatient hospice, and home-based hospice was regarded as home.

To clarify concerns about home care, we asked the respondents to rate the levels of agreement on the 5 point Likert-type scale from 1: disagree to 5: strongly agree for 5 items: concern of being unable to achieve adequate pain relief, unable to adequately respond to sudden changes in out-of-hours care, family physician visiting home is unavailable, family burden is heavy, and home care is too expensive. In addition, to explore respondent values about home care, we also asked the respondents to select one of three choices that best suited their chosen scale value to describe living and dying at home: 1) “dying at home is the best, if family respite and expert advice available”, 2) “dying at home is undesirable despite any health care systems, due to perceived heavy burden to family”, and 3) “unsure”.

To establish the respondent background, we asked the respondents to report age, gender, length of stay in that region, and presence or absence of family members with cancer. To identify cancer patients, we asked the respondents to report whether they suffered from any of a list of 15 specific diseases including cancer.

Statistical analyses

Data distributions were calculated separately for the general public from each region and for cancer patients. Comparisons were performed using the chi-square test.

To explore the predictors of choosing home as preferred place of care, we compared the subject backgrounds and concern items about home care between those who chose home as place of care (i.e., home-home, home-hospice, home-hospital) and those who chose a place other than home (i.e., hospice-hospice, nursing home-nursing home, hospital-hospital, cancer center-cancer center) for each scenario. We then performed a multivariate logistic regression analysis of the dependent variable of choosing home as preferred place of care using all variables identified by univariate analyses as statistically significant ($P < 0.05$).

Results

Of 8000 questionnaires sent out to the general population in the four regions, we obtained a total of 3984 (50%) responses, distributed as follows: 994 (50%, Tsuruoka), 1106 (55%, Kashiwa), 947 (47%, Hamamatsu), and 937 (47%, Nagasaki). Of these, 189 responses were classified as “cancer patients”. Table 1 summarizes the demographic variables of all respondents.

There were statistically significant differences in preferred place of care and place of death for the general public across regions for both scenarios ($P < 0.001$). In general, however, these differences were small (Table 2), with the absolute difference in percentages for each item among the regions less than 8%.

For the with-pain scenario, approximately 30% of all respondents chose home-hospice, while about half chose home as preferred place of care. For the dependent-without-pain scenario, approximately 20% of the respondents across regions chose one of home-hospice, hospice-hospice, or nursing home-nursing home, while approximately 40% chose home as preferred place of care.

For both scenarios, approximately 40% of the cancer patients chose home as preferred place of care, and 20-25% chose home-hospice the preferred place of care-place of death (Table 3). There was a statistically significant difference in

preferred place of care and place of death between cancer patients and the general public ($P < 0.001$ for both scenarios): lower percentages of home-home choice (e.g., 4.2% of cancer patients vs. 9.7% of general public for the with-pain scenario, and higher percentages of hospital-hospital choice (e.g., 20% of cancer patients vs. 8.0% of general public for the with-pain scenario).

Regarding concerns about home care, approximately 80% of both the general public and cancer patients agreed or strongly agreed that family burden is heavy, and approximately 70% agreed or strongly agreed that they were unable to adequately respond to sudden changes in out-of-hours care (Table 4). In addition, more than half of respondents agreed or strongly agreed that family physician visiting their home was unavailable and home care was too expensive, while approximately 40% agreed or strongly agreed that they were unable to achieve adequate pain relief at home.

In addition, the scale values ascribed to home care were split among the responses. Approximately 40% of respondents believed that dying at home is the best option if family respite and expert advice is available, while a similar number believed that dying at home is undesirable despite any health care systems due to the perceived heavy burden to family (Table 4).

The respondents who chose home as place of care in with pain scenario were significantly more likely to be younger, and significantly less likely to have concern of being unable to achieve pain relief, of being unable to adequately respond to sudden changes in out-of-hours, that family burden is heavy, and that home care is too expensive (Table 5). Independent determinants of choosing home as place of care were; age, concern of being unable to adequately respond to sudden changes in out-of-hours, and concern family burden is heavy.

The respondents who chose home as place of care when presented with the dependent-without-pain scenario were significantly more likely to be male, and significantly less likely to be concerned about being unable to adequately respond to sudden changes in out-of-hours care and a heavy family burden (Table 5). Independent determinants of choosing home as place of care with the dependent-without-pain scenario were male, concern of being unable to adequately respond to sudden changes in out-of-hours care, and concern about family burden.

Discussion

This is the first survey, to our knowledge, that compares preferred place of care and place of death of the general public among multiple areas in Japan, and that addresses preferred place of care and place of death in cancer patients.

One of the most important findings was of minimum difference in preferred place of care and place of death of the general public among all respondents and across all regions surveyed in this study. Indeed, the data in this study were similar to those from the national sample surveyed by the Ministry of Health, Labor, and Welfare⁸. One difference was our finding that regional demographic characteristics such as availability of beds, hospital provision, and differences between rural and urban areas are significant determinants of actual place of death⁹, although this is not unexpected given that the Japanese health care system is of a similar standard and scope throughout the country. The fact that four areas with quite different characteristics in terms of urban-rural areas and existing palliative care systems produced essentially the same results suggests that preference regarding place of care and place of death would be similar among the general population throughout Japan.

The second important finding of this study was the clarification of preferred place of care and place of death for cancer patients as a representative sample of each community. The place of care and place of death preferences of cancer patients surveyed in this study were basically similar to those of the general public, although fewer cancer patients chose home-home and more chose hospital-hospital compared to the general public. These findings are consistent with previous similar studies,^{6, 11} although recent studies also indicated that preference about preferred place of care and place of death is not a

steady concept, and can change over time through discussions between health care professionals and patients^{18,19}. Our findings therefore indicate that preference surveying among the general population could provide an alternative to patient surveying as a representative sample of the community as a whole. However, patient surveys on homogeneous samples of a certain clinical stage and/or qualitative longitudinal studies are still needed in the future to more accurately estimate preferences in cancer patients and to obtain deeper insights about preferred place of care and place of death. In the meantime, establishing more accessible and higher quality home care and hospice service is of great importance given the finding that almost half of our surveyed cancer patients preferred home as place of care and a considerable number of cancer patients preferred hospice²⁰.

This study also revealed a high level of concern among the general public and cancer patients about dying at home, and that this concern significantly affected the preferred place of care and place of death. The concerns most commonly reported across all respondents included family burden (80%), being unable to adequately respond to sudden changes in out-of-hours care (70%), availability of family physicians visiting home (60%), and expense (50%). These figures are again very close to data provided by the Ministry of Health, Labor, and Welfare that the most common difficulties with home care surround concerns about the burden to family and sudden changes in physical conditions⁸. Our results also correspond to the previous finding that significant determinants of actual home death include the levels of caregiving at home, such as living with relatives, expanded family support, and caregiver's preference⁹. A small number of studies also identified predictors of patient preference for home as place of care or place of death to be lower levels of concern about being a burden to family and availability of informal caregiver, in addition to younger age, male, better physical health, family physician visiting home available, and the concept of a good death^{6, 7, 11-14}. The findings of this study is also generally consistent with previous studies from Western countries, and confirmed that many among the general public and patient population have similar concerns about home care and that this significantly contributes to the expressed preference¹¹⁻¹⁴.

Family burden in this context includes patient-perceived burden and actual family burden in caregiving. Multiple studies indicate that patient-perceived burden is one of the most serious stressors in terminally ill cancer patients, even if family members do not report actual caregiving burden^{21,22}. Other studies confirmed that perceived burden is a major component in a cancer patient's decision regarding home care^{23,24}. On the other hand, family may experience actual burden from caregiving at home regardless of the levels of patient-perceived burden, especially in caring patients with low functional status^{25,26}. In addition, meta-analyses identified inadequate information including emergency measures and out-of-hour support as unmet needs of informal caregivers^{27,28}, and that educational intervention alone achieves minimum beneficial effects on the concerns of family burden and being unable to adequately respond to sudden changes out-of-hours. These findings suggested that clinicians should alleviate such concerns through on-going continual support in how to address problems at home, arranging regional resources to reduce actual family burden, and the provision of psychological support for patient-perceived burden²⁷⁻³⁰.

This study had several limitations. The response rate of 50% was not particularly high, and thus the findings are not easily applicable. We believe, however, that this is an acceptable limitation, because other population-based surveys conducted by the Ministry of Health, Labor, and Welfare obtained similar results⁸.

In conclusion, there was minimum difference in preferred place of care and place of death among the general public across four regions, cancer patients were less likely to report home as preferred place of care than the general public, and among of cancer patients at least 40% preferred home as place of care and a considerable number preferred hospice. The major concerns significantly associated with preferred place of care were concern about family burden and being unable to adequately respond to sudden changes out-of-hours. Home care and hospice service in Japan needs to be more accessible and of good quality. In addition, clinicians should alleviate patient concerns about burden to their family and being unable to adequately respond to sudden changes out-of-hours by on-going continual support regarding home problems, arranging