dose distribution characteristics of PBT over X-ray should minimize the risk of treatment-related bilateral visual impairment or treatment-related blindness.

Hasegawa *et al.* (16) showed that a certain degree of visual impairment had occurred in 28% of patients whose optic nerves were included in the irradiated volume in carbon ion radiotherapy. There is no report about a direct comparison between PBT and carbon ion radiotherapy.

Previous reports about various approaches to mucosal melanoma are summarized in Table 4.

Cervical lymph nodes were the most frequent site of first failure, and most patients who died finally had distant metastases. Several authors have suggested that aggressive local treatment should be initiated at the presentation of localized melanomas, on the basis that the achievement of local tumor control may increase in survival rate (6, 17). However, it remains controversial whether cervical lymph nodes should be included in the treatment field. We think that what we can do at present is to institute close follow-up after PBT and to detect signs of recurrence or regrowth as early as possible.

CONCLUSIONS

In conclusion, PBT for mucosal melanoma showed promising local control benefit and enough feasibility. To confirm the efficacy and safety, a phase II study of hypofractionated PBT for mucosal melanoma of the head and neck (UMIN-000001505) using the same treatment schedule as the present study is now ongoing in Japan.

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SUPPORTIVE CARE INTERNATIONAL

Family member perspectives of deceased relatives' end-of-life options on admission to a palliative care unit in Japan

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Abstract
Purpose Our goal was to better facilitate the desire of terminally ill patients to die in a favorite place, which may not always be the case for patients admitted to palliative care units. Our aims were to assess the perspectives of bereaved family members about (1) available and preferred places of care when their ill loved one was admitted to a palliative care unit and (2) why patients preferred to live at home but could not.

Methods A questionnaire was answered by 407 of 663 bereaved family members of cancer patients who were admitted to 95 inpatient palliative care units in Japan.
Results Seventy-three percent of respondents answered that a palliative care unit was the only available option. Patients lacking other places for care preferred their home (49%), a hospital (26%), or a long-term care facility (28%). Only 9% retrospectively considered that living at home was feasible for the following reasons: anxiety about the patient's deteriorating physical condition (85%), insufficient care at home compared to a hospital (84%), imminent hospitalization (63%), and the patient's concern about being burdensome (60%).
Conclusion Seventy-three percent of terminally ill cancer patients admitted to palliative care units had no other options for care. Improving outpatient treatment at palliative care units and establishing a palliative care system in patients' homes would greatly benefit patients and their families.

Keywords Attitude to death · Home care · Terminal care · Palliative care · Neoplasms · Retrospective studies

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Introduction

Dying in a favorite place is an important goal in achieving a good death [1–3]. In the Western countries and Japan, home is the most strongly preferred place to die [4–6], but this is not achievable by many patients [4, 5, 7–9]. In Japan, 55%, 15%, and 29% of 2,549 people chosen from the general population preferred the home, general hospital, or a palliative care unit mainly within a hospital as places to die of cancer, respectively [6]. In contrast, in 2009, the percentages of cancer patients dying at home, in a hospital, or at a

palliative care unit were 7%, 84%, and 7%, respectively [9, 10]. This large discrepancy between a person's wishes for a "good death" and actual circumstances must, therefore, be addressed by the health care community to provide patients with the best possible medical treatment and the most ethical and compassionate care.

A systematic review aimed at addressing this problem identified six factors strongly associated with patients' reasons for death at home: poor health, personal preference, intensity of home care, living with relatives, and extended family support [11]. In contrast, only a few individuals in the general population responded that living at home at end-of-life would be feasible if they became terminally ill [12]. Although several factors regarding patients and family members were significantly related to death at home, the evidence is insufficient with respect to the experiences of the patients and family members who preferred end-of-life home care even though it was not possible.

Patients may experience problems when admitted to palliative care units. Specialized palliative care in Japan has been developed primarily in palliative care units since 1990 and expanded since 2002 to include palliative care teams in general wards. One of the aims of the Cancer Control Act implemented in 2007 was to promote early palliative care for more patients. Therefore, the health care system in 2008 required palliative care units to enhance cooperation with regional general practitioners (GPs) and district nurses. Most patients whose symptoms were relieved by treatment in a palliative care unit were nevertheless not discharged. Thus, a nationwide survey reported that, in 2009, 86% of patients admitted to palliative care units died there, and the mean length of stay was 42 days [9, 13]. Moreover, 49% of the 318 bereaved family members queried by the survey regarded the referrals to palliative care units as "too late" [14]. This indicates that admission to palliative care units often means a comparatively short stay until death. A negative image of palliative care units is held by terminal cancer patients [15, 16], family members [15, 16], physicians [16], nurses [16], and the general population [17]. Further, 39% of those surveyed were emotionally distressed by the information that they received regarding discontinuing cancer treatment and admission to a palliative care unit [18]. The Japanese national health care system has recently restricted prolonged and unnecessary hospitalization, making it difficult for advanced cancer patients to transfer to appropriate care facilities when their treatment ends. It is assumed that not all patients were admitted to their preferred palliative care units.

Therefore, our aims here were to assess the perspectives of bereaved family members about (1) available and preferred places of care upon admission of their relative to a palliative care unit and how the quality of care provides patients with a comfortable end-of-life and "good death" and (2) why patients preferred to live at home but could not.

Methods

Procedure

Our study was a component of a large cross-sectional anonymous nationwide survey, the Japanese HOspice and Palliative Care Evaluation study (J-HOPE study), of bereaved families of cancer patients, the latter having been admitted to 95 inpatient palliative care units in Japan and died between November 2004 and October 2006. Detailed methods have been described elsewhere [19]. Briefly, we mailed information and questionnaires to randomly selected bereaved family members in June 2007 and to nonresponders again in August 2007. Completion and return of the questionnaire was regarded as consent to participate. The institutional review board of each hospital confirmed the ethical and scientific validity of our study.

Participants

Primary physicians identified potential J-HOPE study participants according to these criteria: (1) bereaved family members of an adult cancer patient (one family member was selected for each patient), (2) age ≥20 years, (3) capable of replying to a self-administered questionnaire, (4) aware of the diagnosis of malignancy, and (5) no serious psychological distress. We identified up to 80 potential participants at each institution and admitted 7,892, of whom 663 were randomly allocated to this study.

Questionnaire

We used a two-part questionnaire that asked randomly allocated participants unique and common questions for all J-HOPE study participants. The unique questions inquired about available and preferred places of care on admission to palliative care units and the reasons why patients preferred to live at home but could not. Specifically, we asked whether they had alternatives to palliative care units. If they answered no, we then asked whether patients preferred home, a hospital offering

acute care, or a long-term care facility. If they preferred home, we asked whether this would have been feasible in retrospect, and why this was not possible. We show the questions in the "Appendix."

Common questions were designed to measure the quality of palliative care and dying. Respondents rated their *overall care satisfaction* (as defined in Morita et al. [20]): "Overall, were you satisfied with the care in the palliative care unit?" provided by palliative care units according to the following scale: 1=very dissatisfied to 6=very satisfied. In addition, respondents completed a subset of the Good Death Inventory (GDI), comprising 18 items (out of 54) in 18 domains to measure the quality of dying. The GDI has good psychometric properties. The subscale score ranged from 1=absolutely disagree to 7=absolutely agree [21]. We used "dying in a favorite place" domain to evaluate place of dying. The concepts of *overall care satisfaction* and GDI appear similar but are in fact different, with the former assessing care provided and the latter evaluating the quality of dying. Further, the Pearson's correlation coefficients showed only a medium effect size (r=0.39) [21].

The questionnaire also asked for each patient's gender, age, primary cancer site, length of time since referral, length of stay in a palliative care unit, and bereaved family members' gender, age, relationship, health status, number of visits to patients in the final week of life, and surrogate family caregivers.

Analyses

We calculated descriptive statistics for each variable. To compare the characteristics of respondents and nonrespondents, Fisher's exact test or Wilcoxon test was conducted as appropriate. To explore the significance of factors related to the perception of available alternatives to palliative care units, univariate analysis was conducted using a logistic regression model. Further, to assess the influence of available choices and preferences of care location on quality of care and dying, univariate analysis was conducted using the Wilcoxon test. We examined overall satisfaction with care in palliative care units and "dying in a favorite place" according to the GDI subscale. All analyses were performed using the SAS statistical package version 9.2 (SAS Institute, Cary, NC, USA).

Results

The questionnaire was answered by 407 (61%) out of 663 bereaved family members of cancer patients. Table 1 summarizes the characteristics of the patients and those of their bereaved family members. The mean age of the patients was 70±12 years; 53% were male; and primary cancer sites were gastrointestinal tract (26%), lung (24%), liver, and pancreas (16%). The mean age of family members was 58±13 years; 34% were male; and spouses and children accounted for 45% and 43% of the total, respectively. No significant difference of patients' characteristics was seen between respondents and nonrespondents, except that the respondents stayed significantly longer at palliative care units.

Available and preferred places of care

Seventy-three percent of bereaved family members thought that their only option was a palliative care unit (Table 2). Of those for which no other options existed, respondents indicated that patients preferred home (49%), acute hospital (26%), or a long-term care facility (28%). Of those who preferred home, only 9% of respondents retrospectively thought that this was feasible.

Reasons why patients preferred to live and die at home but could not

Respondents frequently indicated the following reasons for patients not being able to live at home as they desired: anxiety about worsening physical condition (85%), insufficient care at home compared to a hospital (84%), anxiety about immediate hospitalization (63%), and concern about being a burden to the family (60%) (Table 3).

Factors related to the perception that only palliative care units were available

Univariate logistic regression analysis showed that older family members thought that palliative care units were the only option (odds ratio (OR)=1.25, p=0.03), but no other significant relationship was found between the characteristics of patients and those of their bereaved family members related to their perception of available places of care (Table 4).

Influence of available and preferred places of care on quality of care and dying

The Wilcoxon test showed no significant differences in overall satisfaction with care (p=0.46) and evaluation of dying in a favorite place (p=0.28) compared with care

Table 1 Characteristics of patients and their bereaved family members

	Respondents		Nonrespondents		*p* value
	Number	Percent	Number	Percent	
Patients					
Gender (male)	217	53	144	56	0.40
Age (years, mean±SD)	70±12		69±13		0.52
<60	86	21	59	23	
60–69	86	21	51	20	
70–79	131	32	86	34	
≥80	99	24	60	23	
Cancer site					0.93
Gastrointestinal tract	107	26	66	26	
Lung	96	24	64	25	
Liver and pancreas	64	16	36	14	
Head and neck	28	7	17	7	
Gynecology	26	6	14	5	
Others	81	20	59	23	
Time at palliative care unit (days, mean±SD)	44±72		41±73		0.02
<15	112	28	98	38	
15–29	91	22	54	21	
30–59	103	25	61	24	
≥60	96	24	43	17	
Bereaved family members					
Gender (male)	139	34	–		
Age (years, mean±SD)	58±13		–		
<50	102	25			
50–59	110	27			
60–69	103	25			
≥70	88	22			
Relationship to patients					
Spouse	185	45	–		
Child	174	43			
Others	46	11			
Health status when caring for dying patients					
Good	79	19	–		
Moderate	219	54			
Fair	85	21			
Bad	19	5			
Number of visits during patients' final week of life					
Daily	282	69	–		
4–6 days	56	14			
1–3 days	54	13			
None	11	3			
Surrogate family caregivers					
Yes	292	72	–		
No	111	27			

Not all percentages add up to 100% due to missing values

SD standard deviation

options other than a palliative care unit (Table 5). In contrast, bereaved family members' responses indicated that the quality of dying in a favorite place was decreased if patients preferred to be at home ($p<0.001$). However, the overall satisfaction with care was not significantly different ($p=0.73$).

Table 2 Available and preferred places of care other than palliative care units

	Number	Percent
Available places of care other than palliative care units		
Only palliative care unit was available	296	73
Other places were available	111	27
Preferences for other places for care (n=296)[a]		
Home	144	49
Acute hospital	78	26
Long-term care facility	82	28
Feasibility to live and die at home in retrospect		
Feasible	13	9
Not feasible	130	90

Not all percentages add up to 100% due to missing values

[a] Bereaved family members with only the option for admission to a palliative care unit

Discussion

Our findings reveal that 73% of terminally ill cancer patients admitted to palliative care units do not have the ability to select where they wish to live out their tragically shortened lives. There was no significant correlation between the status of patients and their families and the types of available care facilities, indicating that this represents a shared problem among the general population. We found that the quality of dying was poorer when patients preferred to live and die at home, even though they were equally highly satisfied with their care received at palliative units. This would suggest the need for ongoing assessment of their preferred place of dying. To our knowledge, this is the first study to explore these aspects of terminally ill cancer patients' experiences with Japan's health care systems for providing end-of-life care.

Our findings also indicated that only a few bereaved family members retrospectively perceived home as a

Table 3 Reasons why patients preferred to live and die at home but could not

	Number	Percent
Anxiety about deteriorating physical condition	123	85
Insufficient care at home compared to hospital	121	84
Anxiety about immediate hospitalization	91	63
Patient's concern about burdening the family	86	60
Inadequate living environment	71	49
24-h consultation not available	67	47
Absence of family care	64	44
Absence of visiting physician/nurse	55	38
Financial burden	39	27

Not all percentages add up to 100% due to missing values. Bereaved family members of patients who preferred to, but could not choose end-of-life home care (n=144)

Table 4 Factors related to the perception of no other choices other than palliative care

	OR	95% CI	p value
Patients' characteristics			
Gender (reference = "male")	1.24	0.79–1.93	0.35
Age	1.19	0.98–1.45	0.08
Cancer site (reference = "gastrointestinal tract")			
Lung	1.50	0.80–2.81	0.40
Liver and pancreas	1.14	0.58–2.25	0.78
Head and neck	1.12	0.45–2.79	0.80
Gynecology	1.49	0.55–4.04	0.63
Others	1.20	0.63–2.27	0.92
Time at palliative care unit	1.05	0.87–1.28	0.60
Bereaved family members' characteristics			
Gender (reference = "male")	0.91	0.57–1.44	0.68
Age	1.25	1.02–1.53	0.03
Relationship to patients (reference = "spouse")			
Child	0.82	0.51–1.34	0.68
Others	0.83	0.45–1.53	0.75
Health status when caring dying patients	1.00	0.75–1.33	1.00
Number of visits for patients last week	1.09	0.83–1.44	0.52
Surrogate family caregivers	0.90	0.55–1.46	0.67

OR >1 means no other available choices than palliative care units

OR odds ratio, *CI* confidential interval

Table 5 Influence of available choices and preferences of place on quality of care and dying

	Overall satisfaction		Dying in a favorite place	
	Mean±SD	p value	Mean±SD	p value
Available places of care other than palliative care units				
Only palliative care unit was available	5.0±0.9	0.46	5.1±1.5	0.28
Other places were available	5.0±0.9		5.4±1.3	
Preferences for other than palliative care units				
Home	5.0±0.9	0.73	4.7±1.5	<0.0001
Other than home	5.0±1.0		5.6±1.4	

SD standard deviation

feasible alternative. Our survey of 595 subjects in the general population found that only 9% answered "possible" to the feasibility of dying at home [12]. In Japan, almost all bereaved family members we studied and, by inference, those in the general population think that living at home while suffering a terminal illness was impossible. Bereaved family members pointed out that their inability to provide adequate practical care and support were the major reasons that prevented patients from remaining home until they died. Therefore, we propose two strategies for allowing terminally ill cancer patients to be dying at home. The first strategy involves improving outpatient care at palliative care units. This will enable patients to stay at home as long as possible and then be admitted to palliative care units as inpatients when death is imminent. The second strategy aims to improve the palliative care system in the home. The latter is a social infrastructure problem. Home palliative care services are well established in the USA and in some European countries such as the UK, Sweden, Italy, and Spain [22, 23]. At present, Japan is still in the developmental stage of providing this type of care. The first strategy, therefore, is more feasible than the second one for immediately and significantly improving end-of-life care.

Factors affecting the implementation of the first strategy include late referrals to palliative care [14, 24–27] and palliative care units not providing adequate treatment at home or at outpatient facilities [9]. Providing patients with specialized palliative care services at home or at outpatient facilities could provide substantial benefits before admission to a facility. Palliative care units must shift focus more on palliation from care for imminently dying patients [13] and caring for terminally ill cancer patients at home for as long as possible. The hypothesis that a prolonged stay at home would contribute to quality of dying is supported by evidence that the general population's preferences for places to live at the end-of-life and to die are different [6]. Improvements in outpatient care may also contribute to removing the negative image of palliative care units as the final residence for these patients [15–17].

We suggest that health care professionals should undertake the following measures: (1) facilitate coping as the patient's condition deteriorates and alleviate family anxiety, (2) alleviate burdens on the family by, for example, using regional resources including respite and day care as well as improvements in managing symptoms, and (3) provide sufficient palliative home care including managing symptoms, helping with living arrangements, and offering 24-h consultation and family care. Yamagishi et al. [28] concluded that the current quality of palliative home care at the regional level is insufficient. For example, Japanese GPs have little experience in providing home care for terminal cancer patients, and 35% and 50%, respectively, could not administer oral or subcutaneous opioids or haloperidol. The authors indicated the importance of the following activities: (1) educating GPs about managing symptoms, (2) providing available palliative care consultation services, (3) establishing systems to support home care technology, and (4) helping coordinate systems to alleviate burdens on family. The views of bereaved family members that we report here support these proposals.

Consistent with Japanese thinking that fighting vigorously against cancer is an important component of a good death [1] was our finding that 26% of terminally ill cancer patients preferred acute hospital care. However, many palliative care units in Japan have admissions policies requiring patients to discontinue cancer therapy. Some patients and family members complained about this policy [15–17] and, therefore, preferred acute hospital care.

This study has several limitations. First, our survey represents the retrospective views of bereaved family members regarding end-of-life choices and patients' preferences of places of care. Consequently, our findings may be subject to recall bias. However, bias from surrogate respondents can be justified because end-of-life decision-making is more often entrusted to families rather than to patients in Japan [29–31]. Second, there was insufficient information regarding physical and psychological symptoms. This may influence the feasibility of living at home during terminal disease. Third, the subjects were limited to the bereaved family members of patients who had been admitted to palliative care units. Our findings might not be applicable to families in other settings.

In conclusion, 73% of terminally ill cancer patients admitted to palliative care units did not have access to other facilities. For patients to die at home in relative comfort and with dignity, we propose two strategies aimed to improve outpatient care at palliative care units, thereby prolonging residence at home and enhancing the home palliative care system.

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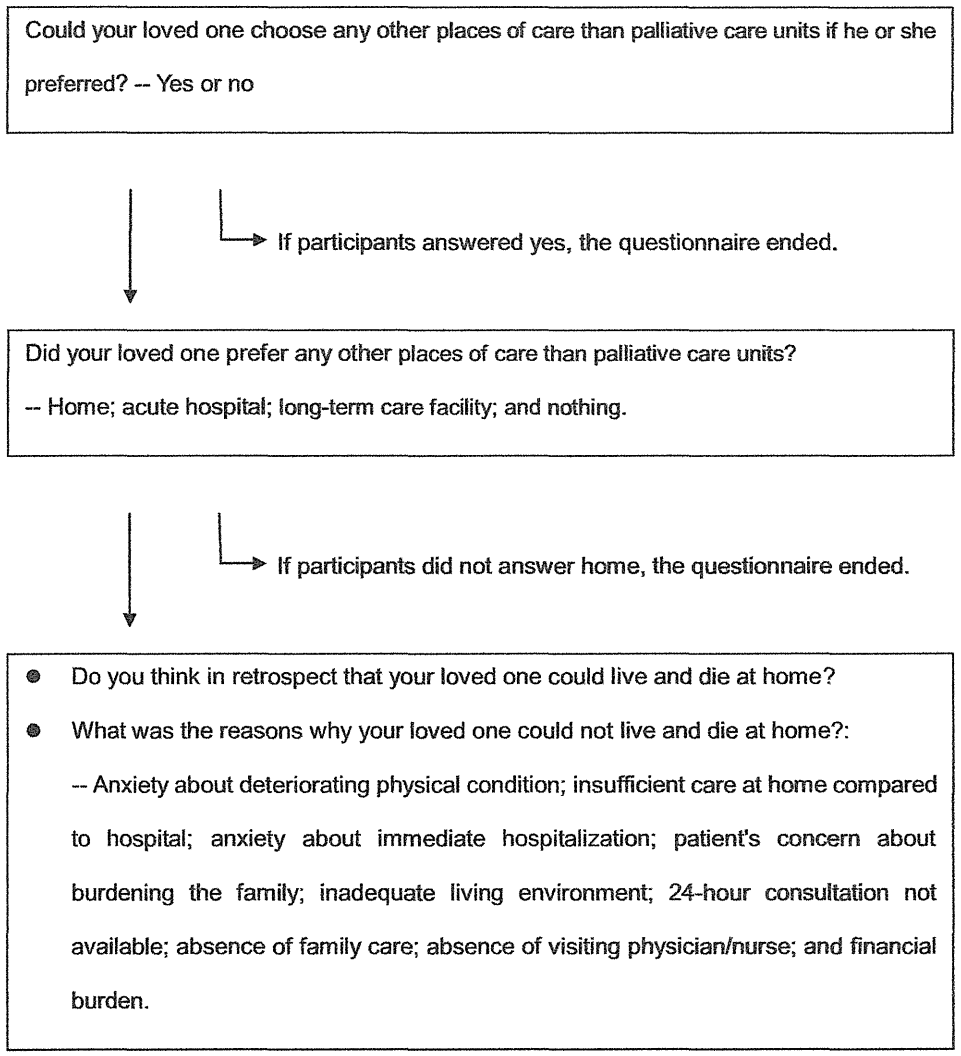
Conflict of interest None.

Appendix. Questionnaire of this study



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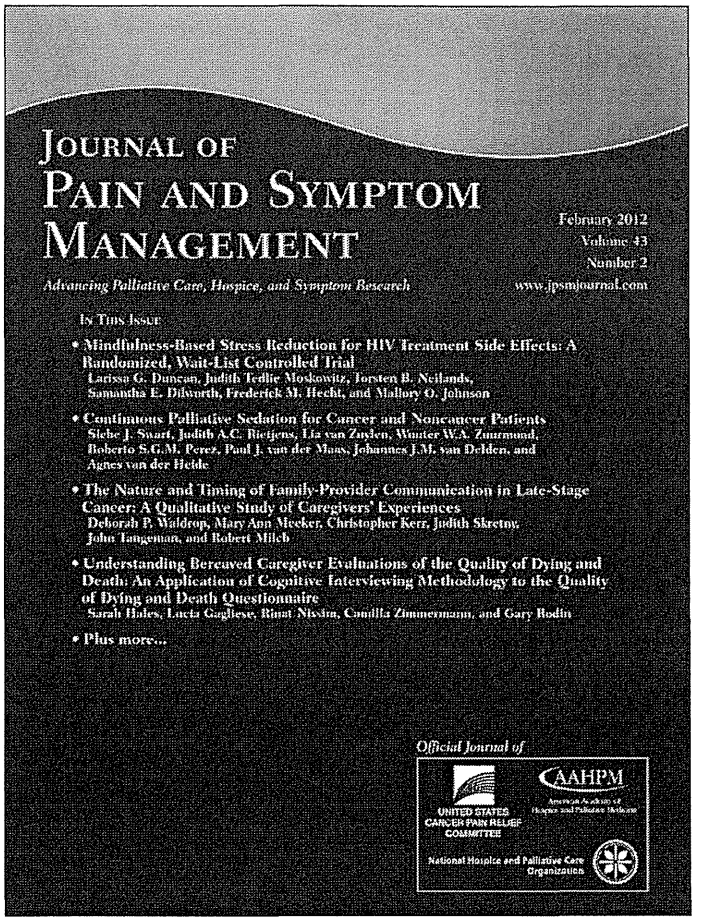

Original Article

A Scale for Measuring Feelings of Support and Security Regarding Cancer Care in a Region of Japan: A Potential New Endpoint of Cancer Care

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Abstract

Context. Having a sense of security about the availability of care is important for cancer patients and their families.

Objectives. To develop a scale for the general population to evaluate feelings of support and security regarding cancer care, and to identify factors associated with a sense of security.

Methods. A cross-sectional anonymous questionnaire was administered to 8000 subjects in four areas of Japan. Sense of security was measured using five statements and using a seven-point Likert scale: "If I get cancer 1) I would feel secure in receiving cancer treatment, 2) my pain would be well relieved, 3) medical staff will adequately respond to my concerns and pain, 4) I would feel secure as a variety of medical care services are available, and 5) I would feel secure in receiving care at home." We performed an exploratory factor analysis as well as uni- and multivariate analyses to examine factors associated with such a sense of security.

Results. The five items regarding sense of security were aggregated into one factor, and Cronbach's α was 0.91. In the Yamagata area where palliative care services were not available, the sense of security was significantly lower than in the other three regions. Female gender ($P = 0.035$), older age ($P < 0.001$), and having cancer ($P < 0.001$) were significantly associated with a strong sense of security.

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Conclusion. A new scale that evaluates sense of security with regard to cancer care was developed. Future studies should examine whether establishing a regional health care system that provides quality palliative care could improve the sense of security of the general population. J Pain Symptom Manage 2012;43:218–225.

Key Words
Sense of security, palliative care, region, quality of care, general population

Introduction

Cancer is a serious disease affecting the lives of many people. In Japan, cancer affects half of the population (55% of males and 41% of females) throughout their lifetime[1] and is the cause of about 30% of all deaths.[2] It is essential that quality care is available for cancer patients. Outcomes of care for cancer patients have been measured using various indicators such as symptoms,[3,4] prognosis, quality of life,[5,6] quality of care,[7,8] patient satisfaction,[9,10] and family satisfaction;[11] however, there are no indicators that assess the overall availability of care, which could be used, for example, to compare regions.

Having a sense of security about the availability of high-quality care is very important for cancer patients and their families.[12] A sense of security should be evaluated from the perspective of the general population living in a region, in addition to cancer patients and their families. These perspectives reflect the quality of the regional system for providing health care services, and the awareness among the population of the services provided by the system. As part of quality assurance of regional cancer care, a sense of security among the general population is important.

Regarding the concept of a sense of security, Funk et al.[12] indicated that a feeling of security among family caregivers of cancer patients consisted of trust in competent professionals; timely access to needed care, services, and information; and a sense of their own identity and self-worth as caregivers and individuals. The domain of "access to care" encompasses a sense of feeling supported and the perceived access to care.[12] Milberg et al.[13,14] also suggested that having competent staff with a good attitude, access to care 24 hours a day, and being at home contributed to a feeling of security among family caregivers. According to these proposed concepts, security is not only just trust in an individual health care professional but also a generalized sense of institutional trust in the health care system that makes people feel supported.[12] However, the concept of a sense of security has not been explicitly validated.

The aims of this study were 1) to develop a scale for the general population in regions of Japan that evaluates the sense of feelings of support and security regarding cancer care, and 2) to identify factors associated with a sense of security in those regions. This study is new in that the scale to assess the sense of security is measured from the perspective of the general population in a region and includes both trust in competent health care professionals and in the regional health care system, as proposed by Funk et al.[12]

Methods

This study was conducted as a part of the Outreach Palliative Care Trial of Integrated Regional Model (OPTIM) study, launched by the Ministry of Health, Labor, and Welfare in Japan.[15,16] The OPTIM study is a regional intervention trial with the aim of establishing a regional palliative care model in four areas of Japan: a large urban area (Chiba: Kashiwa, Nagareyama, and Abiko City), a smaller urban area (Shizuoka: Hamamatsu City), and two rural areas (Nagasaki: Nagasaki City, and Yamagata: Tsuruoka and Mikawa City). In Chiba, Shizuoka, and Nagasaki, palliative care services are available; in Yamagata, such services are sparse.

We administered a cross-sectional anonymous questionnaire. In the questionnaire, we explained the aim of the study and regarded

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

Population and Procedures

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

Measurements

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

The questionnaire statements were as follows: If I get cancer 1) I would feel secure in receiving cancer treatment, 2) my pain would be well relieved, 3) medical staff will adequately respond to my concerns and pain, 4) I would feel secure as a variety of medical care services are available, and 5) I would feel secure in receiving care at home. The translation from Japanese to English was done by a translation/back-translation procedure as follows: the questions were translated into English by a proficient translator; this translation was supervised by a bilingual person and modified. Subsequently, this prototype was translated into Japanese by two researchers other than the authors. The back-translation was compared with the original Japanese questionnaire, and the authors approved it. We asked participants to rate their level of agreement with the statements on a seven-point Likert scale (1: strongly disagree, 2: disagree, 3: slightly disagree, 4: not sure, 5: slightly agree, 6: agree, and 7: strongly agree).

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

Statistical Analyses

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

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

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

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

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

Results

Characteristics of Participants

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

Distribution of the Sense of Security in the Region

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

Feasibility

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

Exploratory Factor Analysis

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

Table 1
Characteristics of Respondents ($n = 3730$)

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

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

Related Factors

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

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

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

Percentages for each item were calculated after excluding missing values.
[a]Sum of "slightly agree," "agree," and "strongly agree."

Table 3
Exploratory Factor Analysis ($n = 3587$)

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

Proportion of variance explained = 73.5%.

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

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

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

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

SD = standard deviation.
[a]Analysis of variance.
[b]*t*-test.
[c]Pearson product-moment correlation coefficient.
[d]Spearman rank correlation coefficient.

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

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

Determination coefficient: $R^2 = 0.068$.

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

Discussion

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Disclosures and Acknowledgments

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Original Article

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

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Abstract

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

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

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

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

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

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

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

Introduction

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

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

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

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

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