

Original Article

Perceptions of Specialized Inpatient Palliative Care: A Population-Based Survey in Japan

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Abstract

This study aimed to clarify and compare the awareness and perceptions of the specialized inpatient palliative care service. A cross-sectional questionnaire survey was performed on the general population selected by stratified two-stage random sampling ($n = 2,548$) and bereaved families who actually received specialized inpatient palliative care at 12 palliative care units (PCUs) in Japan ($n = 513$). The respondents reported their awareness and perceptions of PCUs. Thirty-eight percent of the general population answered that they had "considerable" or "moderate" knowledge of PCUs, but 24% answered that they had "no" knowledge. Bereaved families who received PCU care (PCU-bereaved families) were likely to have better perceptions of PCUs than the general population: "alleviates pain" (68% of the general population and 87% of PCU-bereaved families agreed), "provides care for families" (67% and 86%, respectively), and "provides compassionate care" (67% and 87%, respectively). Both groups, however, expressed concerns about PCUs: "a place where people only wait to die" (30% and 40%, respectively) and "shortens the patient's life" (8% and

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17%, respectively). These perceptions were associated with overall satisfaction with received care, and differed among the 12 PCUs. In conclusion, public awareness of PCUs was insufficient in Japan. Although PCU-bereaved families were generally likely to have better perceptions of PCUs than the general population, both groups shared concerns that a PCU was a place where people only wait to die. To facilitate appropriate use of specialized palliative care services, more efforts to inform the general population about the actual palliative care system are needed. In addition, the role of PCUs might be reconsidered in terms of the continuum of cancer care. *J Pain Symptom Manage* 2008;35:275-282. © 2008 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Key Words

Palliative care, end-of-life care, neoplasm, health knowledge

Introduction

The numerous barriers to quality end-of-life care are related to patients, families, medical professionals, and the health care system itself.¹⁻³ One recognized impediment to palliative care is that the general population has insufficient knowledge about palliative care and hospices.³⁻⁸ Population-based surveys have revealed that although the majority of the general population had heard of specialized palliative care, many are relatively ill-informed about what it comprises.^{8,9} In Japan, the most common type of specialized palliative care service is inpatient care, that is, care provided in palliative care units (PCUs), because home-based specialized palliative care programs and palliative care teams are still being developed.¹⁰⁻¹² Although the number of PCUs has increased dramatically from only five in 1991 to 135 in 2004, no population surveys have been conducted to clarify the public awareness and perceptions of PCUs in Japan.

Moreover, patients are concerned about transition to palliative care services based on the perception that palliative care equates to imminent death,¹³ and families fear that palliative care shortens the patient's life before determining the use of PCUs.¹⁰ These concerns may impede appropriate referrals. Nonetheless, retrospective surveys of bereaved families who had actually chosen PCUs as a place of end-of-life care and received specialized inpatient palliative care showed that these negative perceptions of PCUs improved markedly after using the service.¹⁰ Given the necessity of providing sufficient and correct information about PCUs, it is important to understand

the differences in perceptions of PCUs between the general population and bereaved families who have actually received specialized palliative care (PCU-bereaved families). Although a recent qualitative study suggested that negative perceptions of PCUs, for example, "a place where one dies" and "somewhere from which you can never return," were associated with dissatisfaction with received care among PCU-bereaved families,¹⁴ this association has not yet been quantitatively investigated. Clarifying the association between the perception of PCUs and overall satisfaction with received care can provide valuable clues as to how health care providers should offer information about PCUs and issues that should be addressed when providing end-of-life care.

This survey, therefore, had the following aims: 1) to clarify the awareness and perceptions of PCUs among a representative sample of the Japanese general population and PCU-bereaved families, 2) to clarify the differences in perceptions of PCUs between these two groups, and 3) to explore the association between perceptions of PCUs and overall satisfaction with received care among PCU-bereaved families.

Methods

Subjects

This study was part of a nationwide survey, and the protocol has been described in detail previously.¹⁵ We initially identified four target areas to obtain a wide geographic distribution for the nationwide sample; these comprised an urban prefecture (Tokyo) and three mixed

urban-rural areas (Miyagi, Shizuoka, and Hiroshima). A cross-sectional questionnaire survey was performed in a sample of the general population selected by stratified two-stage random sampling and a sample of bereaved families who actually received specialized inpatient palliative care at one of 12 PCUs (PCU-bereaved families). We initially identified 5,000 subjects within the general population (that is, the nonbereaved general population and the bereaved general population) using stratified two-stage random sampling of residents in the four areas. We mailed questionnaires to potential participants in March 2004 and sent a reminder postcard two weeks later.

To identify bereaved family members, we initially identified all 37 PCUs in the four areas as potential participating institutions. We then approached the 18 PCUs with available collaborative researchers. Ultimately, 12 of the PCUs (two in Miyagi, five in Tokyo, two in Shizuoka, and three in Hiroshima) agreed to participate in the survey. Primary care physicians identified bereaved families in which the caregiver fulfilled the following inclusion criteria: 1) primary caregiver of an adult patient with cancer, 2) older than 20 years, 3) capable of replying to a self-reported questionnaire, 4) aware of the diagnosis of malignancy, and 5) without serious psychological distress as determined by the physician. We mailed self-report questionnaires to potential participants in August 2004, and resent them in October 2004 to those who did not respond; we requested that the primary caregiver filled in the questionnaire.

The protocol was approved by the institutional review board of each participating PCU, and met the requirements of the Helsinki Declaration.

Questionnaire (Available from the Authors)

The questionnaire was constructed through an extensive literature review,^{4-9,18} expert consensus among the authors, and on the basis of a previous study.¹⁰ We investigated three topics in this survey: 1) public awareness of PCUs, 2) perceptions of PCUs, and 3) overall satisfaction with received specialized inpatient palliative care. In addition, we investigated respondents' age and gender. The general population was asked whether they had been bereaved through cancer within the previous 10 years. PCU-bereaved families were asked about length of

hospital stay, time since the patient's death, and the level of the patient's physical distress on a five-point Likert-type scale (1: not distressed at all, 2: not too distressed, 3: unsure, 4: distressed, 5: very distressed). Despite the possibility of a recall bias, we selected 10 years as the limit of experience of bereavement through cancer in the general population, because a limit of five years yielded essentially the same conclusion in this survey.

We asked the general population to rate their level of awareness of PCUs on a four-point Likert-type scale (1: no knowledge, 2: some knowledge, 3: moderate knowledge, 4: considerable knowledge).

We asked participants who identified themselves as having at least some knowledge of PCUs to rate their levels of agreement with 10 statements regarding a PCU on a five-point Likert-type scale (1: strongly disagree, 2: disagree, 3: unsure, 4: agree, 5: strongly agree). The statements were "supports patients in living peacefully," "supports patients in living with dignity," "provides care for families," "provides compassionate care," "alleviates pain," "expensive," "provides no medical treatments," "a place where patients are isolated from the community," "a place where people only wait to die," and "shortens the patient's life."

PCU-bereaved families were asked to rate the levels of overall satisfaction with received specialized palliative care on a seven-point Likert-type scale (1: very dissatisfied, 2: dissatisfied, 3: somewhat dissatisfied, 4: unsure, 5: somewhat satisfied, 6: satisfied, 7: completely satisfied).

Analyses

Initially, we clarified public awareness of PCUs using descriptive statistics. Then, we confirmed similar distributions of variables between the four areas sampled, and explored factors associated with public awareness of PCUs using univariate and multivariate regression analyses. The independent variables were age, gender, and experience of bereavement through cancer. Next, perceptions were analyzed using descriptive statistics for the two study groups (the general population and PCU-bereaved families) and compared the mean between two groups using a *t*-test. We explored the factors that affect perceptions of PCUs using *t*-tests, linear regression, and

analysis of variance, as appropriate. The independent variables were age and gender (for both groups), levels of awareness of PCUs and experience of bereavement due to cancer (only for the general population), and length of PCU stay, time since the patient's death, institution (as data were collected regarding 12 PCUs), and level of patient's physical distress (only for PCU-

bereaved families). These analyses were conducted separately for the general population and PCU-bereaved families. Finally, we explored the correlation between perceptions of PCUs and overall satisfaction with received care using Spearman's rank correlation. As a large sample size may result in an excess of statistically significant results ($P < 0.05$), we have mainly described "clinically significant" results for which the effect size (ES) was over 0.5.¹⁶ This criterion indicates that the mean value difference as an absolute figure between two extreme categories was over half of the pooled standard deviation.

All analyses were performed using the SAS Statistical Package (version 9.1). Significance level was set at $P < 0.05$ (two-tailed).

Results

Of the 5,000 questionnaires sent to the general population, 26 were undeliverable and 2,670 were returned to the authors. Among these respondents, eight refused to participate, 14 were excluded due to missing data, and 2,548 responses were analyzed (effective response rate, 51%). Among the respondents from the general population, 25% ($n = 649$) had lost family members from cancer during the previous 10 years. There were no differences in gender and age between these respondents and the general population according to the vital statistics data for 2003.¹⁷

Among the 866 respondents from PCU-bereaved families considered as potential participants, 72 were excluded due to serious psychological distress ($n = 30$), lack of competent adult family members ($n = 17$), and other reasons. Of 794 questionnaires sent to the remaining bereaved families, 56 were undeliverable and 552 were returned to the authors. Within this group, 27 individuals refused to participate, 12 were excluded due to missing

data, and 513 responses were analyzed (effective response rate, 70%). Comparing the backgrounds of respondents and nonrespondents revealed no differences in gender, age, or time since patient's death, but a significant difference in the length of patient's hospital stay (mean = 44 vs. 36 days). Table 1 summarizes the backgrounds of the respondents.

Public Awareness of PCUs (Table 2)

Although 4.3% of respondents answered "very knowledgeable," 34% answered "moderate knowledge," 38% reported having "some knowledge," and 24% had "no knowledge" of PCUs. Female respondents were more likely to be knowledgeable about PCUs (standardized partial regression coefficient; $\beta = 0.18$, $P < 0.001$), while experience of bereavement due to cancer was not significantly associated with knowledge of PCUs ($\beta = 0.02$, $P = 0.15$).

Perceptions of PCUs (Table 3)

Overall, 67%–72% of the general population and 75%–87% of PCU-bereaved families agreed that a PCU "supports patients in living peacefully," "supports patients in living with dignity," "provides care for families," "provides compassionate care," and "alleviates pain." On the other hand, approximately 30% of the general population and 30%–45% of PCU-bereaved families agreed that a PCU "provides no medical treatments," "isolates patients from the community," and "is a place where people only wait to die." In addition, 61% of the general population and 41% of PCU-bereaved families agreed that PCUs were "expensive" and 8% of the general population and 17% of PCU-bereaved family thought that they "shorten the patient's life." PCU-bereaved families were clinically significantly more likely than the general population to agree that a PCU "provides care for families," "provides compassionate care," "alleviates pain," and "provides no medical treatments." However, they were less likely to agree that PCUs are "expensive."

Factors Associated with Perceptions of PCUs

Among the general population, better awareness of PCUs was clinically significantly associated with agreement that PCUs "provide care for families" (ES = 0.53, $P < 0.001$), while other factors (i.e., age, gender, and

Table 1
Demographic Backgrounds of the Respondents

	General Population (n = 2,548)		Bereaved Families from PCUs (n = 513)	
	%	n	%	n
Age (years)				
<49	25	613	21	104
50-59	30	758	29	144
60-69	28	710	29	146
>70	17	420	22	110
Gender				
Male	47	1,186	32	158
Female	53	1,326	68	343
Bereavement experience*	25	649	100	513
Length of hospital stay: days (mean ± SD/median)			44 ± 49/29	
Time since patient's death: months (mean ± SD/median)			28 ± 7/28	
Satisfaction with received care				
Very dissatisfied			1.4	7
Dissatisfied			1.6	8
Somewhat dissatisfied			2.8	14
Unsure			7.5	37
Somewhat satisfied			15	76
Satisfied			32	160
Very satisfied			27	134
Completely satisfied			12	60

SD = standard deviation; PCUs = palliative care units.

*Experience of losing a family member from cancer during the previous 10 years.

bereavement experience) were not significantly associated with perceptions (data not shown).

Among the PCU-bereaved families, the respondents who thought their patient had experienced less pain were clinically significantly likely to agree that a PCU "alleviates pain" (ES = 0.56, $P < 0.001$). There were also significant differences among institutions with regard to perceptions that a PCU was "a place where people only wait to die" (ES = 1.02, $P < 0.001$), was "expensive" (ES = 1.01, $P < 0.001$), "provides no medical treatments" (ES = 0.94, $P < 0.001$), "isolates patients from the community" (ES = 0.82, $P = 0.02$), "supports patients in living with dignity" (ES = 0.73, $P = 0.005$), "supports patients in living peacefully" (ES = 0.72, $P = 0.03$), and "shortens the patient's life" (ES = 0.70, $P = 0.01$). Other variables, such as age and gender, were not significantly associated with agreement with any statement (data not shown).

Association Between Perceptions of PCUs and Overall Satisfaction with Received Care (Table 4)

Four statements of perception of PCUs had moderate correlations with overall satisfaction:

"provides compassionate care," "provides care for families," "supports patients in living peacefully," and "supports patients in living with dignity." Another four statements had weak correlations with overall satisfaction: "alleviates pain," "a place where patients are isolated from the community," "shortens the patient's life," and "a place where people only wait to die." Neither agreement with "expensive" nor with "provides no medical treatments" was significantly correlated with overall satisfaction.

Discussion

This study is, to our knowledge, the first large population-based survey to clarify the

Table 2
General Population Awareness
of PCUs (n = 2,548)

Awareness of PCUs	%	n
No knowledge	24	591
Some knowledge	58	936
Moderate knowledge	34	855
Considerable knowledge	4.3	106

PCUs = palliative care units.

Table 3
Perceptions of PCUs

	General Population				Bereaved Families from PCUs				PValue*	ES
	(n = 2,548)				(n = 513)					
	Agree (%)	Somewhat Agree (%)	Mean	SD	Agree (%)	Somewhat Agree (%)	Mean	SD		
Supports patients in living peacefully	37	35	4.05	1.06	45	30	4.12	1.23	0.067	0.09
Supports patients in living with dignity	32	38	3.94	0.93	38	38	4.12	0.84	<0.0001	0.19
Provides care for families	29	38	3.90	1.32	54	33	4.38	1.38	<0.0001	0.53
Provides compassionate care	28	39	3.88	1.18	56	30	4.36	1.21	<0.0001	0.52
Alleviates pain	32	36	3.87	1.03	57	30	4.40	0.85	<0.0001	0.52
Expensive	30	31	3.79	0.94	18	23	3.14	0.98	<0.0001	-0.58
Provides no medical treatments	12	20	3.00	1.03	29	25	3.59	1.32	<0.0001	0.49
Isolates patients from the community	7.5	21	2.80	0.90	8.4	21	2.75	0.81	0.40	-0.04
A place where people only wait to die	11	20	2.76	1.19	18	22	3.03	1.24	<0.0001	0.20
Shortens the patient's life	2.8	5.3	2.27	0.92	7.4	9.2	2.44	0.87	0.006	0.15

PCUs = palliative care units; SD = standard deviation; ES = effect size.

*t-test.

levels of awareness and perceptions of PCUs in Japan. Interpretation of the findings depends first on an understanding of the health care system and palliative care system in Japan.

In Japan, each person is obligated to enroll in a national health insurance system. The system is designed so that if a person moves, the insured person is expected to pay the same amount for the same amount of care. Medical fees are set and regulated by the government, and the maximum out-of-pocket cost for the patient is 30% of any such fee. In addition, to curb the expense of high-cost care, the government has instituted a monthly cap of 80,100 yen (670 US\$) co-payment. Meals and extra charges for private rooms are not

covered by the national health insurance system. The system provides the insured person with total freedom to choose any physician, hospital, or clinic.

Enhancement of palliative care for any Japanese citizen with cancer is a priority in Japan; thus, the Ministry of Health, Labor and Welfare supports dissemination of specialized palliative care services, with services provided by PCUs. PCUs have been covered by national medical insurance since 1991. To be approved as a PCU, institutions must fulfill the ministry's requirements regarding staff numbers, facilities, and equipment.

PCUs provide intensive symptom control and end-of-life care for patients with incurable cancer and their families, and the amount of money paid by national health insurance to medical institutions is fixed, irrespective of the treatment provided to patients. An approved PCU is reimbursed at the rate of 37,800 yen (315 US\$) per patient per day by the health insurance system. The maximum out-of-pocket cost for the patient is 30%, 11,340 yen (95 US\$). The majority of PCUs belong to general hospitals and have interdisciplinary teams, including attending physicians, nurses, and other specialists.¹⁸

Consistent with previous findings in Canada in 2004,⁹ public awareness of specialized palliative care services has remained insufficient in Japan. Moreover, experience of bereavement

Table 4
Association Between Overall Satisfaction with Received Care and Perceptions of PCUs

	n = 513	
	R*	P-value
Provides compassionate care	0.49	<0.0001
Provides care for families	0.49	<0.0001
Supports patients in living peacefully	0.43	<0.0001
Supports patients in living with dignity	0.40	<0.0001
Alleviates pain	0.30	<0.0001
Isolates patients from the community	-0.27	<0.0001
A place where people only wait to die	-0.27	<0.0001
Shortens the patient's life	-0.23	<0.0001
Expensive	-0.11	0.01
Provides no medical treatments	-0.06	0.19

*Spearman's rank correlation coefficient.

due to cancer was not significantly associated with awareness of PCUs, possibly suggesting that health care professionals do not adequately explain PCUs as an option for end-of-life care to patients with cancer and their families.

Of note, the PCU-bereaved families were likely to have better perceptions of PCUs as providers of comprehensive and human-focused care, that is, compassionate care, symptom control, and care for families. They were also less likely to perceive PCUs as being expensive than the general population. These findings highlight the need for a greater effort to inform the general population that the present palliative care system offers comprehensive and human-focused care, and that the cost of its services is covered by the national health insurance system.

In our preceding analysis of the same survey, perceptions of PCUs as "alleviates pain" and "provides care for families" were significantly associated with preferences for PCUs as place of end-of-life care.¹⁹ It is, therefore, particularly important to disseminate adequate information about empirical evidence for effective pain control and the palliative care concept, including treatment of the patient and their family as the unit of care. Future research is needed to clarify the most effective strategy to improve public awareness of palliative care.

On the other hand, the general population is concerned that the PCU is "a place where people only wait to die," and "shortens the patient's life." It is of note that PCU-bereaved families were more likely to agree with both statements than the general population, despite the fact that palliative care aims to help patients live as actively as possible until death and intends neither to hasten nor postpone death,²⁰ and the reality that patients receive their usual medical treatments in many PCUs.²¹

Moreover, it is important that both perceptions were significantly associated with overall satisfaction with care and differed considerably among institutions. In Japan, there are significant differences in medical and nonmedical care performed in certified PCUs,²¹ possibly due to each institution's economic and staffing pressures, and their staff's philosophy of what constitutes palliative care. Recent literature suggests that terminally ill cancer patients

choose palliative chemotherapy as a means of maintaining a sense of hope,²²⁻²⁴ and thus the fact that no anticancer treatments are available at PCUs can make patients and families feel abandoned.¹⁴ This can become a barrier to providing palliative care. More discussion is needed about the most appropriate medical system for a certain group of patients who receive chemotherapy and have difficult symptoms requiring a specialized inpatient palliative care service. That is, because patients and families may have equal access to quality specialized palliative care whether or not they receive anticancer treatment, we believe that PCU administration criteria should change from focusing on disease incurability to degree of need for specialized palliative care, and functional classification of specialized palliative care services (i.e., primary, secondary, and tertiary PCUs) should be established.^{25,26} In addition, further efforts to minimize the real differences in provided care among PCUs are essential. This would enable patients receiving anticancer therapy to temporarily receive quality symptom control in PCUs, reflecting a continuum of cancer care.

This study had several limitations. First, because the respondents were not terminally ill cancer patients, results cannot be automatically applied to patients. We believe that this study is valuable, nonetheless, because PCU-bereaved families could provide worthwhile suggestions on the basis of their actual experience. Second, as the response rate among the general population was not high, response bias could exist. Third, we did not explore the possible associations between actual treatment received and perceptions of PCUs among PCU-bereaved families. A more detailed survey is necessary to clarify what kind of care had led to the difference in perceptions and overall satisfaction.

In conclusion, public awareness of PCU remains insufficient in Japan. PCU-bereaved families were generally likely to have better perceptions of PCUs than the general population, but both groups shared concerns that the PCU is a place where people only wait to die. More efforts to inform the general population about the actual palliative care system are needed, and it is necessary to reconsider the role of the PCU within the continuum of cancer care.

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Identification of Quality Indicators of End-of-Life Cancer Care From Medical Chart Review Using a Modified Delphi Method in Japan

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End-of-life care is one of the principle components of cancer care. Measurement of the quality of care provided for end-of-life cancer patients is an important issue. The aim of this study was to identify the quality indicators (QIs) for end-of-life cancer care for Japanese patients using a medical chart review. A modified Delphi method for the development of QIs was adopted. Seventeen multi-professional specialists participated by rating the appropriateness and feasibility of potential QIs. Thirty QIs for end-of-life cancer care were ultimately identified within 4 domains: (1) symptom

control, (2) decision-making and preference of care, (3) family care, and (4) psychosocial and spiritual concerns. These QIs will be useful for monitoring and evaluating end-of-life care for Japanese cancer patients. The QIs are feasible for use in any clinical setting and cover a comprehensive area in accordance with the World Health Organization's (WHO) definition of palliative care including physical, psychosocial, and spiritual concerns.

Keywords: palliative care; neoplasms; quality indicators; Delphi technique; terminal care; quality of life

Recently there has been an increased emphasis on measuring and monitoring the quality of cancer care for the purpose of improving clinical practice.¹⁻⁴ End-of-life care is one of the principle components of cancer care; therefore, measuring the quality of care that is provided for end-of-life cancer patients is an important issue.⁵⁻⁷

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In the United States, Earle et al identified quality indicators (QIs) of end-of-life cancer care from an administrative database using the Delphi method.⁸ Those indicators included aggressiveness of care, hospice use, ER (emergency room) visits, and ICU (intensive care unit) admissions. They also measured and validated reliability of data extraction from the cancer registry and the Medicare database.^{9,10} In Canada, Barbera et al measured Earle's QIs and identified factors related to poor quality end-of-life care.¹¹ Furthermore, Grunfeld et al investigated 14 QIs of end-of-life care from the cancer registry, medical claims, and palliative care databases based on Earle's QIs and additional expert panel interview.¹² Although QIs that are identified using administrative databases are timely and economic,⁸ it is difficult to use this method in Japan because of an insufficiency in the cancer registry, inaccessibility of medical claims, and immaturity of palliative care databases.

As an alternative method, Wenger et al developed QIs from medical chart reviews and interviews.¹³ In the ACOVE (Assessing Care of Vulnerable Elders)

project, they selected 22 conditions to develop QIs. The potential candidates for QIs were extracted from existing guidelines, systematic literature review, and expert opinions. The potential candidates were reviewed by experts, and final QIs were identified for each domain.¹⁴ As for end-of-life care, 14 indicators were identified which included issues of surrogate decision makers, advance directives, documentation of care preferences, life-sustaining treatment, and treatment of distress such as pain, dyspnea, and spiritual issues.¹⁵ Although these QIs were measured for vulnerable community-dwelling older patients in the United States, the results regarding measurement of end-of-life care were not sufficient in that sample.¹⁶ QIs from medical chart review cover a broader range of end-of-life care issues than those from an administrative database¹⁷; therefore, it is worthwhile to develop more appropriate QIs according to culturally specific end-of-life care models.

In Japan, the Ministry of Health, Labor, and Welfare has strongly supported the dissemination of specialized palliative care services. National Medical Insurance has covered inpatient palliative care units (PCUs) for terminal cancer patients since 1990, and the number of PCUs has dramatically increased from 5 in 1991 to 162 in 2006. On the other hand, the growth of home-based palliative care programs has been slow, and care provided by palliative care teams was not covered by National Medical Insurance until 2002.^{18,19} Although the number of PCUs has increased, they provide care for only 5% of cancer deaths. In 2004, only 6% of cancer deaths occurred at home, and over 80% of cancer deaths occurred in general wards. Therefore, QIs that are applicable to all clinical settings are desirable. In addition, the Japanese concept of a good death is slightly different from Western countries.^{20,21} The QIs that are adequate for Japanese end-of-life settings are required to evaluate quality end-of-life care. The aim of this study was to identify QIs for end-of-life cancer care using medical chart reviews in Japan.

Methods

We adopted the modified Delphi method as the consensus technique for development of the QIs.^{22,23} Participants included 17 multi-professional specialists: 5 palliative care physicians, 1 medical oncologist, 1 general medicine physician, 3 psycho-oncologists, 3 nurses, 2 sociologists, 1 medical ethicist, and 1 expert

on Delphi methodology. This study was conducted from October 2004 to September 2005.

First, we used the modified Delphi method to develop the QIs from a systematic literature review and the opinions from an expert panel (communication via Internet). Ninety-six potential candidates for QIs were listed. Second, participants rated each potential QI from medical chart review using a 9-point Likert scale for appropriateness of quality end-of-life cancer care (inappropriate 1-3, intermediate 4-6, appropriate 7-9) and feasibility for extraction (infeasible 1-3, intermediate 4-6, feasible 7-9). Third, we summarized those items with high ratings and deleted items that were equal to or less than 6 for appropriateness or feasibility. This left a total of 60 items. Fourth, the summary (median and difference between maximum and minimum) of the 60 items was returned to the participants, and the participants rated each of the 60 potential QIs using the same method. Finally, we summarized this second round of ratings, and the final QIs were identified. Throughout the above-mentioned steps, participants discussed via the Internet.

During the first step, we listed potential QIs that should be documented in the medical chart upon admission to the medical service or during the last 2 weeks before the patient died. When participants were rating each of the QIs, we made the following assumptions: (1) each QI should be used to measure the quality of end-of-life cancer care, (2) each QI should be extracted from the medical chart during the 2 weeks prior to the patients' death with meticulous reliability, and (3) each QI should apply in all clinical settings including general wards, PCUs, and home care.

The criteria of adoption of the final QIs included: (1) a median rating above or equal to 7 in both appropriateness and feasibility, and (2) the difference between maximum and minimum rating equal to or less than 4. All analyses were performed using the SAS statistical package, version 9.1 (SAS Institute, Cary, NC).

Results

Through the modified Delphi process we identified 30 QIs of end-of-life cancer care within the following 4 domains: (1) symptom control, (2) decision-making and preference of care, (3) family care, and (4) psychosocial and spiritual concerns. The final QIs and median, minimum, and maximum rating for

Table 1. Final QIs Identified Using the Modified Delphi Method^a

	Appropriateness ^b			Feasibility ^c		
	Median	Min	Max	Median	Min	Max
I. Symptom control						
1. Presence or absence of pain	9	9	9	9	9	9
2. Degree of pain	9	8	9	8	6	9
3. Physician's prescription order for pain management	9	9	9	9	8	9
4. Presence or absence of dyspnea	9	9	9	9	4	9
5. Physician's prescription order for dyspnea	9	7	9	9	7	9
6. Presence or absence of delirium or agitation	9	6	9	8	5	9
7. Physician's prescription order for delirium or agitation	9	6	9	8	5	9
8. Observation and care of mouth	9	7	9	7.5	4	9
II. Decision making and preference of care						
9. Patient's preference of place of care	9	8	9	8	6	9
10. Patient's insight of disease	9	7	9	8	4	9
11. Patient's preference of care or advance directives	9	5	9	7	6	9
12. Discussion of strategy of care among physicians and nurses	9	7	9	9	5	9
13. Time of patient's enrollment in palliative care program and documented medical history	9	5	9	9	5	9
III. Family care						
14. Configuration of family relationships	9	7	9	9	3	9
15. Key person involved in patient care	9	7	9	9	7	9
16. Family's preference of place of care	9	7	9	7	4	9
17. Family's preference of explanation of medical condition	9	7	9	8	7	9
18. Explanation of medical condition to patient or family	9	7	9	9	7	9
19. Family's preferences or expectations	9	5	9	7	3	9
20. Discussion with family about do-not-resuscitate order	9	7	9	9	5	9
21. Explanation to family about course of disease until death	8	6	9	7	3	9
22. Explanation to family of patient's impending death	9	6	9	8	6	9
23. Explanation to family 1 week prior to patient's death	9	6	9	7	6	9
24. Care strategy for family	8.5	5	9	7.5	2	9
IV. Psychosocial and spiritual concern						
25. Degree and content of patient's anxiety	9	8	9	7	6	9
26. Emotional reaction to explanation of medical condition	9	7	9	7	4	9
27. Patient's preference of daily living	9	7	9	7	5	9
28. Patient's religion	7.5	7	9	7	4	9
29. Patient's preference for bowel and bladder excretion	8	7	9	7	4	9
30. Coordination of social resources when patient had no family or friends	8.5	5	9	8	4	9

a. All QIs were documented in the medical chart at the admission of medical service or during the last 2 weeks before the patient's death.

b. Inappropriate 1-3, intermediate 4-6, appropriate 7-9.

c. Infeasible 1-3, intermediate 4-6, feasible 7-9.

both appropriateness and feasibility are shown in Table 1.

Symptom Control

Concerning symptom control, the following 8 QIs were identified: the presence or absence of pain, degree of pain, physician's prescription order for pain management, presence or absence of dyspnea, physician's prescription order for dyspnea, presence or absence of delirium or agitation, physician's

prescription order for delirium or agitation, and observation and care of mouth.

Decision Making and Preference of Care

As for decision making and preference of care, 5 QIs were identified: patient's preference of place of care, patient's insight of disease, patient's preference of care or advance directives, discussion of strategy of care among physicians and nurses, and time of

patient's enrollment in a palliative care program and documented medical history.

Family Care

For family care, 11 QIs were identified: configuration of family relationships, key person involved in patient care, family's preference of place of care, family's preference of explanation of medical condition, explanation of medical condition to patient or family, family's preferences or expectations, discussion with family about do-not-resuscitate order, explanation to family about the course of the disease until the patient's death, explanation to the family about impending death of the patient, explanation to the family about the care strategy for the family, and explanation to the family of impending death about 1 week prior to the patient's death.

Psychosocial and Spiritual Concern

Concerning psychosocial and spiritual concerns, 6 QIs were identified: degree and content of patient's anxiety, emotional reaction to explanation of medical condition, patient's preferences or desires related to daily living, patient's religion, patient's preference of bowel and bladder excretion, and the coordination of social resources when the patient had no family or friends.

Discussion

We identified 30 QIs for end-of-life cancer care by using the modified Delphi method and the expertise of a multi-professional review panel. Henceforth, we are now able to monitor and evaluate the quality of care using these QIs. First, they are feasible for use in any clinical setting. Second, the measurement is a relatively simple procedure, and there are no burdens for patients and families. Third, these QIs cover a comprehensive area in accordance with WHO's definition of palliative care including physical, psychosocial, and spiritual concerns.²⁴

As for symptom control, these QIs cover pain, dyspnea, and delirium. These are major symptoms for end-of-life cancer patients.²⁵ Pain and dyspnea are distressing for the patient. Documentation of these symptoms is essential for clinical practice among physicians and nurses, and treatment should

be ordered in anticipation of discomfort to prevent unnecessary suffering. In addition, delirium-related symptoms are distressing for family members.²⁶

As for decision making and preference of care, place of care is an important issue for Japanese cancer patients.²¹ The preference of care and advanced directives are more emphasized by ACOVE's end-of-life QIs.¹⁵ In addition, QIs identified in this study cover more comprehensive aspects of care including patient insight²⁷ and coordinated care.²⁸

Family care is an important aspect of Japanese end-of-life care. In the WHO's definition of palliative care, family care is emphasized.²⁴ Family consent and involvement in decision making for end-of-life care issues are unique characteristics in the Japanese people.²⁹⁻³¹ Therefore, identifying the configuration of family relationships and the key person involved in care is important. In Japan, the do-not-resuscitate order is usually obtained from the family.³²

Psychosocial and spiritual concerns are also important. Anxiety and emotional issues contribute to the psychological distress that patients and families experience during end-of-life care. For the patient, loss of control related to preferences in daily living activities and bowel and bladder excretion are among the spiritual concerns for Japanese end-of-life cancer patients.³³

There are some limitations to this study. First, the feasibility of these QIs is not established by actual measurement. Second, the relationship between QIs and outcome measures is unclear. In future studies, the QIs should be measured, and feasibility, reliability, and validity should be confirmed using data that is extracted from actual medical charts. Furthermore, it would be desirable to verify appropriateness of QIs and correlate outcome measures such as in a study of family bereavement.³⁴

Conclusion

We identified Japanese QIs for end-of-life cancer care using a modified Delphi method and medical chart reviews. Thirty QIs with 4 domains were identified: symptom control, decision-making and preference of care, family care, and psychosocial and spiritual concerns. The confirmation of feasibility, reliability, and validity is a task for future studies.

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Effect of a population-based educational intervention focusing on end-of-life home care, life-prolonging treatment and knowledge about palliative care

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The effectiveness of population-based educational interventions in palliative care is unclear. We conducted an educational intervention study for the general public focusing on end-of-life home care, life-prolonging treatment and knowledge about palliative care and measured the change in perception about these issues. Participants were recruited from the 11 districts of Fukushima City, Japan. One-hour educational lectures were conducted in each district from April 2006 to March 2007. Meetings were held in a community centre or hall in each district. We asked participants to fill in a questionnaire before and after the educational lecture. Of 607 participants, 595 (98%) answered both pre- and post-intervention questionnaires. The feasibility of a home death changed from 9% before to 34% after the intervention ($P < 0.001$). In addition, preference for life-prolonging treatment and attitudes toward end-of-life care including symptom management at home, misconceptions about opioids, artificial hydration and communication issues between patient and medical practitioners were significantly improved after the intervention. Factors that were significantly associated with changing perceptions about the feasibility of a home death were male gender, change in beliefs regarding burden to family caregivers, anxiety regarding admission to the hospital with worsening physical condition and fear that pain would not be relieved at home. This population-based educational intervention was effective in changing beliefs regarding the feasibility of home care, preference for life-prolonging treatment and attitudes toward end-of-life care. *Palliative Medicine* (2008); 22: 376-382

Key words: barriers; education; home death; intervention studies; palliative care

Introduction

It is important for terminal cancer patients to be able to remain in their favourite place.¹ Over half of Japanese would like to be cared for at home.² However, in Japan, the growth of home-based palliative care programs has been slow.^{3,4} As a result, in 2004, only 6% of cancer deaths occurred in the home and over 90% occurred in hospitals.

There are many barriers to home care for end-of-life cancer patients.⁵⁻¹² For example, previous studies have suggested that sex,¹² age,^{8,12} burden to the family^{6,7,12} and the ability of the family to care for the patient^{11,13} were factors associated with home care of terminal patients.

There are also many barriers to receiving appropriate palliative care for end-of-life cancer patients.^{14,15} For

instance, misconceptions about analgesics,¹⁶⁻¹⁹ misperceptions about life-prolonging treatment²⁰⁻²² and lack of communication between patient and medical practitioner^{23,24} were reported to be potential barriers to palliative care.

In a large population-based survey of Japanese, we found many misconceptions about pain and opioids, communication with health care professionals, hydration and nutrition and legal issues about end-of-life options.²⁵ In addition, our previous study showed that misconceptions regarding opioid use and life-prolonging treatment prevented members of the general public from believing that they could live at home until death.²⁶

To overcome these barriers, it is important to provide appropriate education for the general public.¹⁵ Although education for cancer patients and their families has been conducted,²⁷⁻³³ educational interventions about palliative care for the general public have not been reported except for one regarding attitudes about cardiopulmonary resuscitation,³⁴ and a Canadian study using a trade show to educate the general public.³⁵ The effectiveness of population-based educational interventions is still

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unclear. Therefore, we conducted an educational intervention study for the general public focusing on end-of-life home care, life-prolonging treatment and knowledge about palliative care and measured the change in perception about these issues before and after the intervention.

Methods

Subjects

Potential participants were recruited from the 11 districts of Fukushima City, Fukushima Prefecture, Japan. Fukushima City has a population of 288,000 and is the most urban city in Fukushima Prefecture. However, Fukushima Prefecture is a relatively rural region. The lectures were held during a periodic regional community meeting. Before the meeting a simple pamphlet about the lecture was distributed. No special invitation was conducted. A total of 607 community-dwelling residents attended the lecture.

Intervention

One-hour educational lectures were held in each district from April 2006 to March 2007. Meetings were held in a community centre or hall in each district. The themes of the educational lectures were as follows: limitations of cancer treatment, life-prolonging treatment for end-of-life cancer patients, correct information about opioids, artificial hydration, communication between patient and physicians, feasibility of home care for end-of-life cancer patients and district health resources for terminally-ill cancer patients. The lecturer for all the sessions was one physician (M.S.).

Procedure

We asked participants to fill out the questionnaire before and after the lecture. We described the aim of the study, protection of privacy and voluntary nature of participation by written document and oral explanation.

Questionnaire

Feasibility of home death

We asked participants to consider the feasibility of home death by answering 'possible', 'impossible' or 'unsure' to the questions.

Barriers to home care at the end-of-life setting

We explored barriers to home care in the end-of-life setting by asking whether participants agreed that the following were attributes of home care: absence of visiting physician, absence of visiting nurse system, absence of 24-h consultation system, absence of family caring for me, burden of care on family, anxiety about worsening

physical condition, anxiety about admission to the hospital when physical condition worsens, concern that one's residence would be too small, economic burden and pain would not be relieved at home.

Preference for life-prolonging treatment

We asked about the preference for life-prolonging treatment using a 4-point Likert scale with the possible responses: 'want to receive', 'probably want to receive', 'probably do not want to receive' and 'do not want to receive'. Questions asked were regarding artificial hydration, artificial nutrition, vasopressors, mechanical ventilation and cardiopulmonary resuscitation.

Attitudes toward end-of-life care

We asked about the attitudes toward end-of-life care using a 5-point Likert scale: 'strongly agree', 'agree', 'unsure', 'disagree' and 'strongly disagree'. Questions were identical to our previous study, as follows:²⁵ 'absence of sufficient medical system for treatment or care at home', 'in my circumstance, it is difficult to be cared for at home', 'cancer pain is sufficiently relieved if treatment is adequate', 'opioids shorten life', 'opioids cause addiction', 'consciousness is clear if pain medication is not used', 'artificial hydration and nutrition should be continued as the minimum standard until death', 'artificial hydration and nutrition relieve symptoms', 'physicians are generally poor at communicating bad news', 'physicians are uncomfortable discussing death', 'it would be intolerable if I was told I had incurable cancer', 'cancer treatment has only limited effectiveness', 'I want to receive cancer treatment as long as possible', 'death at home indicates to relatives that the family cannot provide sufficient medical care for the patient', 'death at home indicates to neighbors that the family cannot provide sufficient medical care for the patient' and 'large hospitals provide better quality medical treatment than clinics'.

Satisfaction with lecture

We asked about satisfaction with the lecture using the following responses: 'lecture was interesting', 'lecture was easy to understand', 'lecture would be of help in the future' and 'lecture gave me the chance to consider end-of-life medical treatment'.

Participant characteristics

We asked participant's age, gender, education, health status, experience of hospital admission, number of family members living together, ability to talk about end-of-life concerns with family and experience of bereavement over the past 10 years.

Analyses

Regarding feasibility of home death, we compared the proportion of 'possible' responses between the pre- and

post-intervention questionnaires with the Wilcoxon's signed rank test. We used the same test for comparing pre- and post-intervention barriers to home care at the end-of-life setting, preference for life-prolonging treatment and attitudes toward end-of-life care. In addition, we explored factors associated with changing perceptions regarding the feasibility of home death by logistic regression analysis among participants answering 'impossible' or 'unsure' in the pre-intervention questionnaire. The dependent variable was the answer to the feasibility of home death in the post-intervention questionnaire. The explanatory variables were: participant characteristics and changing perceptions regarding barriers to home care in the end-of-life setting, reference to life-prolonging treatment and attitudes toward end-of-life care from pre-intervention to post-intervention. The backward variable selection method with $P > 0.05$ criterion was used. In all analyses, the significance level was set at $P < 0.05$, and a 2-sided test was used. All analyses were conducted using statistical package SAS (SAS Institute, Cary, North Carolina, USA).

Ethical consideration

This study was approved by the institutional review board of the Fukushima Medical University and was conducted in accordance with the Helsinki Declaration.

Results

Of 607 participants, 595 (98%) answered both the pre- and post-intervention questionnaires. Participant characteristics are shown in Table 1. Mean age \pm SD was 66 ± 11 years; 67% were female; 24% had a college or university education; 84% reported excellent or good health status; 58% had a hospital admission; 87% were living with someone; 81% talked about end-of-life concerns with family members and 66% experienced bereavement during the previous 10 years.

Table 2 shows responses regarding the feasibility of home death. In the pre-intervention questionnaire, only 9% of respondents answered 'possible' to this question, whereas in the post-intervention survey 34% answered 'possible' ($P < 0.001$). Barriers to home care at the end of life are shown in Table 3. The following responses showed significant improvement as a result of the intervention: 'absence of visiting physician', 'absence of visiting nurse system', 'burden of care on family', 'anxiety about worsening physical condition', 'anxiety about admission to the hospital when physical condition worsens', 'economic burden' and 'pain would not be relieved at home'.

Table 4 shows preferences for life-prolonging treatment. The proportion that preferred artificial hydration, artificial nutrition and vasopressors was significantly

Table 1 Participant characteristics ($n = 595$)

	<i>n</i>	%
Age, years (mean \pm SD)	66 \pm 11	
Gender		
Male	191	32
Female	396	67
Education		
Junior high school	141	24
High school	304	51
College	77	13
University	63	11
Health status		
Excellent	249	42
Good	253	43
Fair	78	13
Poor	4	1
Experience of hospital admission		
Yes	343	58
No	240	40
Number of family members living together		
None	74	12
1	179	30
2 or 3	176	30
4 or more	158	27
Discuss end-of-life concerns with family		
Frequently	81	14
Sometimes	400	67
Rarely	92	15
Never	7	1
Experience of bereavement over 10 years		
Yes	395	66
No	187	31

Percentages do not add up to 100% because of missing values.

decreased after the intervention. Attitudes toward end-of-life care are presented in Table 5. There was a significant change in agreement with the following items: 'absence of sufficient medical system for treatment or care at home', 'in my circumstance, it is difficult to be cared for at home', 'opioids shorten life', 'opioids cause addiction', 'consciousness is clear if pain medication is not used', 'artificial hydration and nutrition should be continued as the minimum standard until death', 'artificial hydration and nutrition relieve symptoms', 'physicians are generally poor at communicating bad news', 'physicians are uncomfortable discussing death', 'it would be intolerable if I was told I had incurable cancer', 'death at home indicates to relatives that the family cannot provide sufficient medical care for the patient', 'death at home indicates to neighbors that the family cannot pro-

Table 2 Feasibility of home death pre- and post-intervention

	Pre		Post		<i>P</i> value
	<i>n</i>	%	<i>n</i>	%	
Possible	54	9	203	34	0.001
Impossible	314	53	163	27	
Unsure	199	33	191	32	

Table 3 Barriers to home care in the end-of-life setting pre- and post-intervention

	Pre (%)	Post (%)	P value
Absence of visiting physician	34	28	0.001
Absence of visiting nurse system	24	19	0.004
Absence of 24-h consultation system	21	23	0.484
Absence of family caring for me	19	21	0.402
Burden on family of care	78	66	0.001
Anxiety about worsening physical condition	62	52	0.001
Anxiety about admission to hospital if worsening physical condition	43	34	0.001
Insufficient resources at home	18	17	0.320
Economic burden	43	24	0.001
Pain would not be relieved at home	42	20	0.001

vide sufficient medical care for the patient' and 'large hospitals provide better quality medical treatment than clinics before death'. However, there was no significant change in agreement with 'cancer pain is sufficiently relieved if treatment is adequate'.

We show factors associated with the change of feasibility of home death by logistic regression in Table 6. The significant independently-associated factors with change in the feasibility of home death were: male gender, burden of care on family (changed from yes to no), anxiety about admission to the hospital with worsening physical condition (changed from yes to no) and concern that pain would not be relieved at home (changed from yes to no).

As for satisfaction with the lecture, participants answered that the lecture was interesting (95%), easy to understand (96%), would be of help for the future (95%) and provided the opportunity to consider end-of-life medical treatment (94%).

Discussion

We showed that a 1-h educational intervention regarding palliative care could change beliefs regarding the feasibility of home care, preference for life-prolonging treatment and attitudes toward end-of-life care, including symptom management at home, misconceptions about opioids and

Table 4 Preference for life-prolonging treatment pre- and post-intervention

	Pre (%)	Post (%)	P value
Artificial hydration	62	52	0.001
Artificial nutrition	49	38	0.001
Vasopressor	38	32	0.004
Mechanical ventilation	23	21	0.428
Cardiopulmonary resuscitation	25	22	0.098

Figures are total percentage of 'desired' and 'probably desired'.

artificial hydration and communication between patients and medical practitioners. Regarding the feasibility of home care, the percentage answering 'possible' was increased nearly 4 times compared with pre-intervention. Most Japanese believe that it is difficult to be cared for at home at the end of life. However, the provision of appropriate information would make it more likely that people will choose this option.

This intervention study was conducted during regular regional community meetings. Participants did not have a special interest in this topic. However, the educational intervention had a significant effect on the participants. The results of this study might be applied to the other regions in Japan.

In the multivariate analysis exploring factors associated with the change of feasibility of home death, we found that four independent factors contributed to a change in such beliefs. In the bivariate analyses, many factors including preference for life-prolonging treatment and attitudes toward end-of-life care were associated with change regarding the feasibility of home death. However, multivariate analysis showed four determinant factors. Men generally less concern about home care. Therefore, they might view the lecture more positively. However, we might consider a different strategy for addressing concerns of women. The change of opinion regarding the burden to the family was significantly associated with the change in feasibility of home care. The burden of caregiving on the family is the most relevant barrier in the pre-intervention survey, as seen in Table 3. The alleviation of the burden on the family and the ability of family members to provide care are important issues concerning home death.^{6,7,11-13} Change in degree of anxiety about admission to the hospital for worsening physical condition is another independent factor. We believe that this has two important implications. One is that it is important for hospitals to hold beds open for these patients. Patients and families would feel easier about staying at home knowing that hospital beds would be available when needed. Another implication is that Japanese home hospice services would develop. Sufficient home hospice care and information provision would relieve the patient's and family's anxiety about home care. This should be confirmed because the change in attitude about inadequate pain relief at home was the most influential factor associated with the feasibility of home care.

As for life-prolonging treatment, although the desire for artificial hydration and artificial nutrition decreased after the intervention, 38-52% of participants still expressed a preference for receiving such treatment. Because many Japanese patients and families hope to receive artificial hydration,³ it is important to discuss this in the clinical setting. However, the preference for mechanical ventilation and cardiopulmonary

Table 5 Attitudes toward end-of-life care pre- and post-intervention

	Pre (%)	Post (%)	P value
Home care system			
Absence of sufficient medical system for treatment or care at home	61	32	0.001
In my circumstance, it is difficult to be cared for at home	61	32	0.001
Pain and opioid use			
Cancer pain is sufficiently relieved, if treatment adequate	68	81	0.001
Opioids shorten life	31	7	0.001
Opioids cause addiction	23	5	0.001
Consciousness is clear if pain medication is not used	31	29	0.004
Artificial hydration			
Artificial hydration and nutrition should be continued as the minimum standard until death	50	31	0.001
Artificial hydration and nutrition relieve symptoms	35	24	0.001
Communication			
Physicians are generally poor at communicating bad news	31	23	0.001
Physicians are uncomfortable discussing death	18	12	0.001
It would be intolerable if told I had incurable cancer	42	27	0.001
Cancer treatment			
At present, there are limits to cancer treatment	65	63	0.062
I want to receive cancer treatment as long as possible	47	48	0.241
Attitude toward home care			
Death at home indicates to relatives that family cannot provide sufficient medical care for patient	16	10	0.001
Death at home indicates to neighbours that family cannot provide sufficient medical care for patient	17	13	0.001
Large hospital provides better quality medical treatment than clinic before death	51	15	0.001

Figures are total percentage of 'strongly agree' and 'agree'.

resuscitation did not change. If the effectiveness of mechanical ventilation and cardiopulmonary resuscitation were more widely known; however, the answer would probably be different.³⁴

The beliefs that opioids shorten life and cause addiction were significantly decreased from 31% to 7% and 23% to 5%, respectively. Although misconceptions about analgesics are a great barrier to palliative care,¹⁶⁻¹⁹ educational interventions could overcome these barriers. In addition, the beliefs that the absence of an adequate medical system for treatment or care at home and 'in my circumstance, it is difficult to be cared for at home' were both significantly decreased from 61% to 32%. Interventions such as this help educate the general public that pain can be relieved at home. The belief that 'large hospitals provide better quality medical treatment than clinics before death' decreased significantly from 51% to 15%. In Japan, the general public tends to think that large hospitals are necessary to adequately care for patients, espe-

cially at the end of life. Two reasons for this are that home hospice care has not been developed and the general public is not informed. Moreover, the educational intervention changed the belief that 'it would be intolerable if I was told I had incurable cancer'. This intervention could not only correct this misconception and increase the feasibility of home care but also bolster the sense of security for people who get incurable cancer.

Although many attitudes toward end-of-life care did change as a result of this intervention, two beliefs, 'at present, cancer treatment has limited effectiveness' and 'I want to receive cancer treatment until death' did not change. Although the limitations of cancer treatment were covered in the lecture, the general public still desires such treatment to prolong life. Fighting against cancer and receiving sufficient treatment are important issues in the Japanese concept of a good death.¹

This intervention survey has some limitations. First, the intervention was shown to have only a short-term

Table 6 Factors associated with the change in feasibility of home death

	Odds ratio	95% CI*	P value
Gender (male)	1.82	1.08-3.09	0.026
Burden on family to care (changed from yes to no)	1.72	1.03-2.87	0.039
Anxiety about admission to hospital when physical condition worsens (changed from yes to no)	2.03	1.25-3.30	0.004
Pain would not be relieved at home (changed from yes to no)	2.28	1.42-3.66	0.001

Logistic regression analysis with backward variable selection method ($P < 0.05$).

Among the participants who answered 'impossible' or 'unsure' before lecture, we explored the associated factors with the change of answer to 'possible'.

*95% confidence interval.

effect. Therefore, the sustainability of change of beliefs is unknown. We plan to study the long-term effects of this intervention. The planned follow-up study will occur at least 6 months after the educational intervention. If possible, we want to follow-up over several years. Second, this study was conducted in Fukushima City, Fukushima Prefecture, in a rural area in Japan. It might be difficult to extrapolate to urban areas in Japan.

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