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The Palliative Care Knowledge Questionnaire for PEACE: Reliability and Validity of an Instrument To Measure Palliative Care Knowledge among Physicians

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Abstract

Background: In Japan, a nationwide palliative care education program for primary palliative care (the Palliative care Emphasis program on symptom management and Assessment for Continuous medical Education: PEACE) was established in 2008. Effective delivery of such programs relies on adequate evaluations of program efficacy; however, such an instrument does not exist.

Objective: This study aimed to develop and validate a measurement tool to quantify knowledge level of physicians about broader areas of palliative care, by which the effect of an education program could be measured.

Methods: We conducted a cross-sectional, anonymous, self-administered questionnaire survey with a group of 801 conveniently sampled physicians in October 2010. To examine the test-retest reliability of items and domains, the questionnaire was reissued two weeks after the first survey was completed. This study used psychometric methods, including item response theory, intraclass correlation coefficients, and known-group validity.

Results: The response rate was 54% ($n=434$). We included 33 items across the following 9 domains: (1) philosophy of palliative care, (2) cancer pain, (3) side effects of opioids, (4) dyspnea, (5) nausea and vomiting, (6) psychological distress, (7) delirium, (8) communication regarding palliative care, and (9) community-based palliative care. For these items, the intraclass correlation was 0.84 and the Kuder-Richardson Formula 20 (KR-20) test of internal consistency was 0.87. There was a significant difference in the scores between palliative care specialists and other physicians.

Conclusions: We successfully validated a newly developed palliative care knowledge questionnaire to evaluate PEACE effectiveness (PEACE-Q). The PEACE-Q could be useful for evaluating both palliative care knowledge among physicians and education programs in primary palliative care.

Introduction

Palliative medicine has become an essential part of cancer care in the past 30 years.[1] To achieve high-quality palliative care, education for physicians is crucial, but most physicians worldwide including in Japan agree that current undergraduate and postgraduate programs do not provide sufficient education on palliative care.[2]

Recently, several countries established nationwide palliative care education programs.[3,4] In the United States, the Education for Physicians in End-of-life Care (EPEC™) Project[3] aimed to increase physician knowledge about palliative care, with 62% of the participants attaining improved knowledge. In Japan, the Palliative care Emphasis program on symptom management and Assessment for Continuous medical Education (PEACE) was established in 2008,[2,5] with more than 1000 PEACE education opportunities and more than 20,000 participating physicians reported throughout Japan from 2008 to 2010.[6] To sustain the efficacy and significance of such programs, timely adjustment based on adequate

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and ongoing evaluations of the program is essential. Such evaluations should assess participant achievement and the effectiveness of the program among participants.

To date, the palliative care knowledge test (PCKT) was developed to measure the levels of knowledge about palliative care.[7] The PCKT consists of five domains: philosophy, pain, dyspnea, psychiatric symptoms, and gastrointestinal symptoms. However, the PCKT was originally designed to quantify knowledge about palliative care among general health care professionals, especially nurses; and consequently, the reliability and validity of PCKT was not formally investigated in physicians. In addition, existing measurement tools to measure the knowledge of physicians in palliative care literature focus on pain management, and no instruments have been established to measure knowledge level of physicians about broader areas of palliative care.[8–10]

The primary aim of this study was to develop and validate a measurement tool to quantify knowledge level of physicians about broader areas of palliative care, by which the effect of education programs could be measured.

Methods

We conducted a confidential and anonymous questionnaire survey among physicians, consisting of two phases: (1) instrument development and (2) psychometric analysis and selection of the 33 items for the final instrument. The ethical and scientific validity of this study was approved by the institutional review board of Saku Central Hospital. Consent to participate was indicated by the completion and return of the questionnaire.

Development phase

Initially, 12 palliative care specialists generated a total of 83 items for an item pool based on all modules of the PEACE program. Each such module includes nine domains and thus we designed our measurement instrument to include all these domains: (1) concept and philosophy of palliative care, (2) cancer pain, (3) side effects of opioids, (4) dyspnea, (5) nausea and vomiting, (6) psychological distress, (7) delirium, (8) communication, and (9) community-based palliative care.

To confirm the content validity, we adopted a modified Delphi method[11] with another group of 10 physicians (9 palliative care specialists and 1 psychiatrist). The experts evaluated the appropriateness of each item according to nine grades from 1 (inappropriate) to 9 (appropriate). If a participant rated the grade as less than 6, we asked him or her the reason. Items rated by eight or more members at 7 or more were selected; the remaining items were modified according to the members' opinions and then reevaluated. Following two such content-setting rounds we generated a provisional version of the instrument, the 79-item PEACE-Q (palliative care knowledge questionnaire for PEACE). Each question requires potential responses of right, wrong, and unsure.

Validation phase

The survey was carried out in October 2010 on 735 physicians from 15 conveniently sampled hospitals. The inclusion criterion was registered physicians whose specialty was not palliative medicine. In addition, to explore the known-group validity, 66 palliative care specialists were recruited. For this study, "palliative care specialist" was defined as a responsible physician in a certified palliative care unit belonging to Hospice Palliative Care Japan.

Procedures

The questionnaire with an accompanying cover letter was distributed to physicians by mail. Completed questionnaires were collected in a box specifically provided in each participating hospital. The survey for test-retest examination was conducted on the subjects who had consented to participate during the first survey in three institutions with two-week interval administrations. For the 79-item PEACE-Q, we then analyzed and compared physician backgrounds—i.e., age, gender, specialty, institutions, years of clinical experience, the number of terminally ill cancer patients seen in the past year, the number of cancer deaths per year, the number of patients they prescribed opioids to in the past year, and whether they participated in a PEACE program. No reminder or reward was used.

Statistical analysis and item selection

For analyses, 'unsure' responses were regarded as incorrect. First, to assess feasibility we calculated the percentage of missing data for each question; if the missing value accounted for more than 1% of all data, that item was regarded as inappropriate. Next, to assess sensitivity we calculated the percentage of correct answers for each question; if correct answers accounted for more than 90% of all data, that item was regarded as inappropriate. Third, to examine the test-retest reliability of each item, the kappa coefficients were calculated (cutoff: kappa coefficient of 0.3). Fourth, we estimated the difficulty and discrimination based on the two-parameter logistic Item Response Theory (IRT) model. IRT models are used for the statistical estimation of parameters that represent the magnitude of a latent trait attributable to the items. An advantage of IRT is that it potentially enables a researcher to improve the precision and reliability of an assessment.[12] We then determined the precision (cutoff: discrimination of 0.5). Finally, to confirm the content validity, the first 12 experts discussed the appropriateness of each item from both statistical and clinical viewpoints: (1) items in which sensitivity was likely to be higher and (2) items that could be viewed as providing lessons. Through this process, 33 items were selected to comprise the PEACE-Q.

Reliability and validity

Internal consistency was determined by calculating the Kuder-Richardson Formula 20 (KR-20) index. The test-retest reliability was explored by calculating intraclass correlation coefficients. To explore known-group validity, the unpaired t-test was used to determine a potential statistically significant difference in the total score of the PEACE-Q (33 items) and for each domain, between the palliative care specialists and the other physicians.

Statistical analysis was performed using statistical software SAS (SAS version 9.1; SAS Institute Inc., Cary, NC). The significance level was set at $P < 0.05$ (two-tailed).

Results

Among 801 physicians included in the validation study, 434 responses (54%) were obtained and analyzed. For the

test-retest investigation, 124 physicians agreed to participate and a total of 44 responses (35%) were obtained and analyzed.

The subject characteristics are summarized in Table 1. Approximately 70% were male, with an average of 16 years of clinical experience. Among them, 51% experienced more than 21 terminally ill cancer patients in the past year, while 17% cared for less than 5 cancer patients.

Item selection

Missing values totaled more than 1% in three items (1.2% each). However, we gave priority to content validity over psychometric properties based on the discussion among experts; thus, these three items were included in the PEACE-Q.

The percentage of correct answers ranged from 19% to 99% across the items, with the highest percentage of correct answers (99%) for, 'Oral care should not be offered to the patients with nausea and vomiting, because mouth stimulation causes vomiting.' Eighteen items showed a correct response rate of 90% or more, and these items were excluded. There were no items with 10% or less correct response rate.

The kappa coefficient in the test-retest reliability of each item ranged from −0.04 to 0.85, and was 0.3 or less for 14 items. However, we gave priority to content validity over psychometric properties based on the discussion among experts, and 6 out of these 14 items were included.

The results of the item analysis and IRT are shown in Table 2. The difficulty in all items ranged from −2.76 to 0.29, with a discrimination of 0.69 to 2.67. We determined that a subject who correctly answered an item with high discrimination would also have a high total score, whereas for an item with poor discrimination, the percentage of correct answers for that item would not relate to the total score.

Based on the item analysis, IRT, and expert discussions, we determined 33 items for inclusion in the final version of PEACE-Q across the following 9 domains: (1) philosophy of palliative care, (2) cancer pain, (3) side effects of opioids, (4) dyspnea, (5) nausea and vomiting, (6) psychological distress, (7) delirium, (8) communication, and (9) community-based palliative care.

Reliability and validity

The KR-20 index of internal consistency was 0.87, and the intraclass correlation in the test-retest examination was 0.84. Regarding the known-group validity, there was a significant difference in the score for each domain as well as in the total score between palliative care specialists and other physicians (see Figure 1).

Discussion

This study validated an instrument to measure the levels of knowledge about palliative care among physicians. This measurement tool enables us to evaluate the ongoing effectiveness of the PEACE program. The instrument showed good internal consistency, test-retest reliability, and known-group validity.

PEACE-Q would be useful for measuring the level of palliative care knowledge that all physicians engaged in cancer treatment should have. Furthermore, it could be used to measure the efficacy of undergraduate education programs about palliative care.

Previous measurement tools for quantifying the effect of palliative care education programs for physicians showed insufficient evaluation of reliability and validity,[13–16] and none other than the PCKT addresses a broad knowledge of palliative care.[7] However, the psychometric properties of the PCKT were formally evaluated only among nurses. The PEACE-Q is a specific measure for physicians in both patient care and symptom management.

This study has several limitations. The tool was developed only for physicians who attend a PEACE-based seminar. In addition, several questions (2, 3, 31, 32, 33) are specifically about the Japanese medical system, and thus are not suitable for physicians in other countries; this limits the instrument transferability.

TABLE 1. CHARACTERISTICS OF PARTICIPANTS (N=434)

	n	%[1]
Age, mean±SD	42±11	
Gender		
Male	306	70
Female	95	22
Specialty		
Internal Medicine	121	28
Surgery	75	17
Resident	50	12
Gynecology	12	2.8
Urology	12	2.8
Anesthesiology	12	2.8
Other	106	24
Institution		
University	37	8.5
Hospital over 400 beds	235	54
Hospital under 200 beds	47	11
Clinic	30	6.9
Other	43	9.9
Years of clinical experiences, mean±SD	16±10	
Number of terminally ill cancer patients in the past year		
None	20	4.6
1–5	54	12
6–10	37	8.5
11–15	33	7.6
16–20	18	4.2
21–	219	51
Number of patients prescribed opioids in the past year		
None	49	11
1–5	75	17
6–10	68	16
11–15	40	9.2
16–20	23	5.3
21–	125	29
Number of cancer deaths per year		
None	47	11
1–5	112	26
6–10	64	15
11–15	53	12
16–20	18	4.2
21–	89	21
Whether they participated in a PEACE program		
Yes	92	21
No	301	69

[1]The percentages do not add up to 100% due to missing values.

TABLE 2. (CONTINUED)

Questions			Correct answer (%)	k-coefficient (n=44)	IRT	
					Difficulty	Discrimination
Delirium						
25	Delirium occurs due to drugs or physical etiologies.	T	70	0.22	−1.28	0.73
26	Benzodiazepines should be used first for delirium.	F	52	0.26	−0.11	1.48
27	It is better to make the room pitch black for a patient with delirium, so that he or she can sleep well.	F	71	0.46	−1.05	1.03
Communication						
28	An open-ended question means that it cannot be answered with a simple 'yes' or 'no,' and requires an unrestricted answer based on the subject's own feelings.	T	82	0.08	−1.57	1.15
29	When physicians convey bad news, they should ask the patient's concern and understanding about the disease.	T	88	0.25	−1.80	1.37
30	It is better to repeatedly use the word 'cancer' when telling the patient about his or her malignancy.	F	75	0.77	−1.58	0.78
Community-based palliative care						
31	There is a consultation support center in all designated cancer centers.	T	56	0.38	−0.27	1.23
32	All terminally ill cancer patients 40 years of age can access long-term care insurance.	T	53	0.62	−0.17	1.16
33	All designated clinics with home hospice function have a 24-hour 7-day system.	T	73	0.37	−1.89	0.55

In conclusion, this study used psychometric methods to validate an instrument for evaluating palliative care knowledge among physicians who attend a PEACE-based seminar, which was developed as a nationwide education program in palliative care. This evaluation instrument was constructed to cover nine domains: philosophy of palliative care, cancer pain, side effects of opioids, dyspnea, nausea and vomiting, psychological distress, delirium, communication, and community-based palliative care. The PEACE-Q could be useful for evaluating both knowledge among physicians and education programs in primary palliative care.

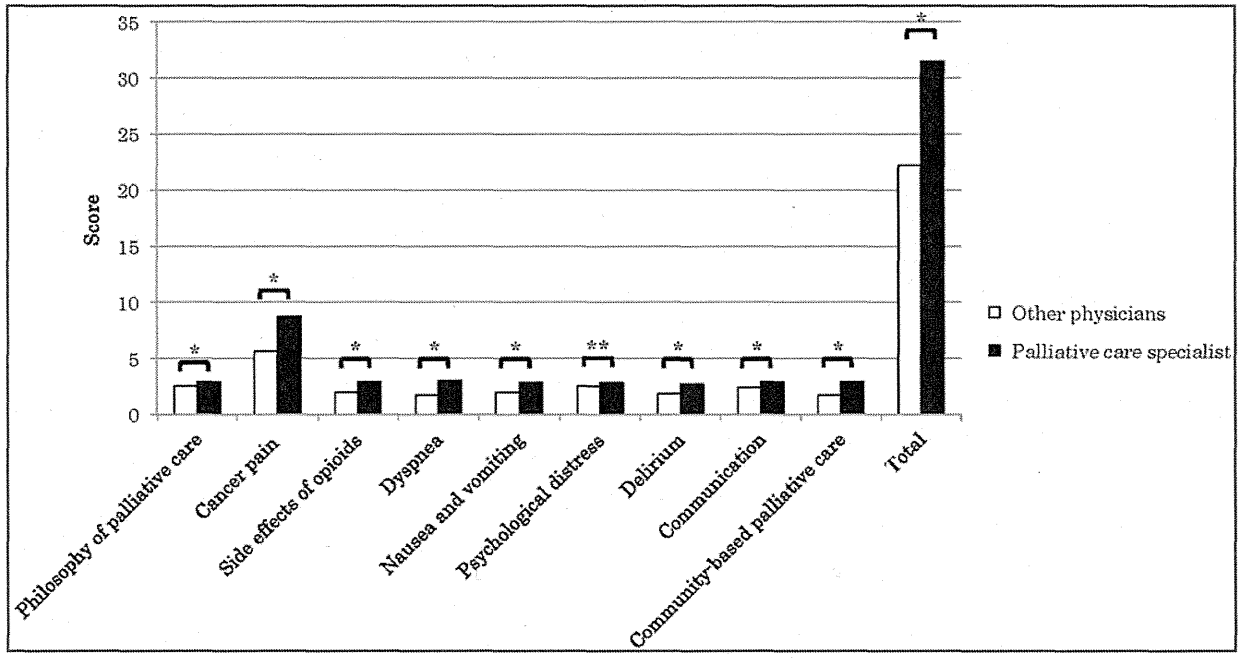

FIG. 1. PEACE, Palliative care emphasis program on symptom management and assessment for continuous medical education.

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Author Disclosure Statement

The authors declare no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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Prospective Clarification of the Utility of the Palliative Prognostic Index for Patients With Advanced Cancer in the Home Care Setting

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Abstract

Aims: This study aimed to prospectively clarify the accuracy of the Palliative Prognostic Index (PPI) for advanced cancer patients in home care settings. **Method:** The study included 66 advanced cancer patients who received home visiting services between April 2010 and June 2012, and who died at home or in the hospital. Using medical records from initial home visits, we prospectively calculated PPI scores along with sensitivity and specificity. **Results:** For 3- and 6-week survival, prognostic prediction showed respective sensitivities of 60% and 70.6%, and specificities of 87.0% and 71.9%. **Conclusion:** The sensitivity of the PPI for advanced cancer patients in home care settings was lower than that reported for patients in palliative care units. Development of prognostic tools suitable for home care settings is needed.

Keywords

palliative prognostic index, patients with advanced cancer, home care setting, prospective study, prognostic prediction, palliative care

Introduction

Making prognostic predictions is one of the core skills of physicians engaged in end-of-life care[1] and is a component of approaches to multidisciplinary palliative care.[2] In addition, patients with advanced cancer face difficult decisions regarding their treatment and choices related to end-of-life care.[3,4] Accurately predicting prognosis is therefore helpful not only for patients and their families but also for health care professionals who support their decision making,[5] especially those in the home care setting.

In general, it is difficult to predict the prognosis of patients with advanced cancer, especially those in the home care setting, because of limitations in the number of blood tests and radiological evaluations performed. Clinicians usually predict prognoses based on their own experience. A previous study revealed that prognostic prediction tools improved the accuracy of physicians' predictions.[6] Several prognostic prediction tools have been examined for patients with cancer, for example the Palliative Prognostic Index (PPI),[7] Cancer Prognostic Scale,[7] Palliative Performance Scale (PPS),[8] Palliative Prognostic Score (PaP score),[9] PaP Score with Delirium,[10] Japan Palliative Oncology Study-Prognostic Index,[11] and Prognosis in Palliative Care Study model,[12] and each was properly validated. These tools are intended for use in assessing inpatient and ambulatory patients, and the appropriateness of their application to patients with advanced cancer in the home care setting is uncertain.

The PPI, which resulted in significant improvement in prognostication,[6] was defined based on the performance status assessment using the PPS version 2 (PPSv2),[8] oral intake, and the presence or absence of dyspnea at rest, edema, and delirium. The PPI was developed and successfully validated for patients with cancer in palliative care units by Morita et al in Japan.[13]

The PPI does not require blood tests or radiological evaluation and would therefore be very useful for patients with cancer in the home care setting when compared to other validated

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prognostic prediction tools. Each PPI component is assigned an individual score, and these are added to derive the overall score. The final PPI score classifies patients into 1 of the 3 groups, those with survival predicted to be shorter than 3 weeks (PPI $\geq$ 6), shorter than 6 weeks (PPI $\geq$ 4), or longer than 6 weeks (PPI < 4).

Previous studies[14] were performed prospectively and did not clarify the usefulness of the PPI in the home care setting. The aims of this study were thus to prospectively determine the sensitivity and specificity of the PPI in the home care setting and to evaluate the association of each PPI component with 3 and 6 weeks' prognostic prediction.

Methods

Our study population included all patients with advanced cancer who received home visiting services regularly from Yamato Clinic between April 2010 and June 2012 and who died at home or in the hospital. Yamato Clinic provides ambulatory care and home visiting services for community residents, with 3 doctors (including 1 researcher: JH) specialized in family medicine and palliative care. The 3 doctors (including 1 researcher: JH) had trained to assess the PPI components and used the PPI in their usual practice. We recorded patients' background information and prospectively assessed the components of the PPI at the first home visit, PPS score, oral intake, and the presence or absence of dyspnea at rest, edema, and delirium. One researcher (JH) calculated the PPI score and actual survival time when each patient died. Subsequently, we calculated overall sensitivity, specificity, and area under the curve (AUC) of the PPI. Survival predictions were defined as mentioned earlier, less than 3 weeks for PPI $\geq$ 6 and less than 6 weeks for PPI $\geq$ 4. In addition, we conducted univariable analyses to assess significant differences between 3- and 6-week survival and each PPI component.

To determine the association of each PPI component with 3 and 6 weeks' prognostic prediction, we used Student *t* test for continuous variables and Pearson chi-square test or Fisher exact test for categorical variables. All analyses were conducted using SPSS-J, ver.21.0, IBM (Tokyo, Japan).

This study was not confirmed by the institutional review board, but our study was performed according to the ethical guidelines for Epidemiological Research by the Ministry of Health, Labour and Welfare of Japan, and written informed consent was not necessary.

This study was conducted in conformity with the Declaration of Helsinki and was carried out with special regard for the protection of individual data.

Results

A total of 66 (48 males) patients were included in this study. Table 1 shows the patient background information in detail. The mean patient age was 75.6 years, with 28 (42.4%) patients in their 70s and 15 (22.7%) patients in their 80s. The primary cancer site was lung in 17 (15.8%) patients, stomach/esophagus

Table 1. Patient Background (n = 66).

	All patients (n = 66), n (%)
Gender	
Male	48 (72.7)
Female	18 (27.3)
Mean age (year ± SD)	75.6 ± 11.3
Range, years	41–94
Age distribution	
35-49	3 (4.5)
50-59	1 (1.5)
60-69	12 (18.2)
70-79	28 (42.4)
80-89	15 (22.7)
90+	7 (10.6)
Primary cancer site	
Lung	17 (25.8)
Stomach/esophagus	12 (18.2)
Colon/rectum/anus	10 (15.2)
Kidney/bladder	6 (9.1)
Liver/biliary system	6 (9.1)
Pancreas	4 (6.1)
Prostate	3 (4.5)
Brain	3 (4.5)
Breast	1 (1.5)
Blood	1 (1.5)
Others	3 (4.5)

Abbreviation: SD, standard deviation.

Table 2. The PPI Scores and 3-Week Survival.

	<3 weeks' survival	≥3 weeks' survival	Total
PPI ≥ 6	12[a]	6	18
PPI < 6	8	40	48
Total	20	46	66

Abbreviation: PPI, Palliative Prognostic Index.
[a] Number of patients surviving <3 weeks with PPI scores >6.

Table 3. The PPI Scores and 6-Week Survival.

	<6 weeks' survival	≥6 weeks' survival	Total
PPI ≥ 4	24[a]	9	33
PPI < 4	10	23	33
Total	34	32	66

Abbreviation: PPI, Palliative Prognostic Index.
[a] Number of patients surviving <6 weeks with PPI scores >4.

Table 4. Accuracy of PPI for Patients With Advanced Cancer in Home Care Settings.

	<3 weeks, %	<6 weeks, %
Sensitivity	60.0	70.6
Specificity	87.0	71.9
Positive predictive value	66.7	72.7
Negative predictive value	83.3	69.7
Area under the curve	74	67

Abbreviation: PPI, Palliative Prognostic Index.

Table 5. Univariable Analyses for Patients Surviving <3 Weeks and 6 Weeks (n = 66).

Variable	<3 weeks' survival (n = 20), n (%)	≥3 weeks' survival (n = 46), n (%)	*P* value	<6 weeks' survival (n = 34), n (%)	≥6 weeks' survival (n = 32), n (%)	*P* value
Mean age (year ± SD)	73.1 ± 10.7	76.6 ± 11.5	.25[a]	72.4 ± 10.4	78.9 ± 11.4	.019[a]
Sex						
Male	15 (75.0)	33 (71.7)	.785[b]	26 (76.5)	22 (68.8)	.482[b]
Female	5 (25.0)	13 (28.3)		8 (23.5)	10 (31.3)	
Palliative Performance Scale version 2 (PPSv2)[8]						
10-20	3 (15.0)	0	.01[c]	3 (8.8)	0	.001[c]
30-50	16 (80.0)	36 (78.3)		30 (88.2)	22 (68.8)	
60+	1 (5.0)	10 (21.7)		1 (2.9)	10 (31.3)	
Oral intake						
Severely reduced	8 (40.0)	1 (2.2)	<.01[c]	8 (23.5)	1 (3.1)	.006[c]
Moderately reduced	12 (60.0)	31 (67.4)		23 (67.6)	20 (62.5)	
Normal	0	14 (30.4)		3 (8.8)	11 (34.4)	
Edema						
Present	11 (55.0)	16 (34.8)	.125[b]	17 (50.0)	10 (31.3)	.122[b]
Absent	9 (45.0)	30 (65.2)		17 (50.0)	22 (68.8)	
Dyspnea at rest						
Present	8 (40.0)	3 (6.5)	.002[b]	9 (26.5)	2 (6.3)	.028[b]
Absent	12 (60.0)	43 (93.5)		25 (73.5)	30 (93.8)	
Delirium						
Present	8 (40.0)	4 (8.7)	.005[c]	11 (32.4)	1 (3.1)	.002[b]
Absent	12 (60.0)	42 (91.3)		23 (67.6)	31 (96.9)	

Abbreviation: SD, standard deviation.
[a] Student *t* test.
[b] Pearson chi-square test.
[c] Fisher exact test.

in 12 (18.2%) patients, and colon/rectum/anus in 10 (15.2%) patients.

The mean survival time after the first home visit was 72.9 days. Survival time was shorter than 3 weeks in 20 (30.3%) patients and shorter than 6 weeks in 34 (51.5%) patients. Table 2 shows PPI scores and 3-week survival, and Table 3 shows PPI scores and 6-week survival. In all, 18 (27.3%) patients had PPI scores ≥6, while 33 (50%) had PPI scores ≥4. In all, 12 patients with PPI scores ≥6 survived for less than 3 weeks, while 24 patients with PPI scores ≥4 survived for less than 6 weeks.

Table 4 shows the accuracy of the PPI for patients with advanced cancer in the home care setting. Three-week survival was predicted with a sensitivity of 60% (95% confidence interval [CI], 39%-78%), a specificity of 86.9% (95% CI, 74%-94%), a positive predictive value of 66.7%, and a negative predictive value of 83.3%; the AUC was 74% (95% CI, 59%-88%). Six-week survival was predicted with a sensitivity of 70.6% (95% CI, 54%-83%), a specificity of 71.9% (95% CI, 55%-84%), a positive predictive value of 72.7%, and a negative predictive value of 69.7%; the AUC was 67% (95% CI, 54%-81%).

Table 5 shows the association of each PPI component with 3 and 6 weeks' prognostic prediction. We conducted univariable analyses concerning PPI components for patients who survived less than 3 weeks and less than 6 weeks. These analyses found that PPS, oral intake, dyspnea at rest, and delirium were statistically significant for patients who survived less than 3 weeks and less than 6 weeks.

Discussion

This study demonstrated 3 important findings. First, the sensitivity of the PPI for patients with advanced cancer in the home care setting was lower than for patients with advanced cancer in palliative care units. Morita et al[13] reported that the sensitivity of the PPI for patients with advanced cancer in the hospice setting who survived less than 3 weeks and less than 6 weeks was 83% and 79%, respectively. This finding is same as that of our previous retrospective study.[15] Maltoni et al[16] also reported a prospective comparison between several prognostic scores, including the PPI, in the hospice setting. They found that the sensitivity and specificity of PPI scores ≥5 in patients who survived for less than 3 weeks in the hospice setting were 73.7% and 67.1%, respectively. To the best of our knowledge, however, our study is the first to prospectively reveal the usefulness of the PPI for patients with advanced cancer in the home care setting while also pointing out the limitations of the utility of the PPI in this population and setting.

One possible reason for the discrepancy in PPI sensitivity between patients with advanced cancer in the hospice setting and those in the home care setting is the differential prevalence of PPS ≤20 and delirium, which are the most heavily weighted scores in the PPI scoring system. In our study, the prevalence of

PPS ≤20 in the home care setting was 4.5%, whereas Morita et al[13] and Maltoni et al[16] reported prevalence of 23% and 41.3%, respectively, in the hospice setting. This discrepancy suggests the possibility that home visiting services tend to be started at early stages for patients with advanced cancer, because whilethe median duration of survival was 40 days in our study, Morita et al[13] reported 27 days and Maltoni et al[16] reported 22 days in the hospice setting. Regarding the prevalence of delirium, our study revealed a prevalence of 18.2% in the home care setting, whereas Morita et al[13] and Maltoni et al[16] reported prevalence of 38% and 28.2%, respectively, in the hospice setting. This discrepancy may have 2 causes. First, we may have underdiagnosed delirium because we did not use routinely a specific assessment tool for its screening. Second, patients who have delirium may tend not to transfer from hospital to home care, because management of delirium is commonly difficult in the home care setting. The prevalence of other symptoms in our study, namely, oral intake, edema, and dyspnea at rest, also differed compared to the hospice setting. In our study, the prevalence of severely reduced oral intake, edema, and dyspnea at rest were 13.6%, 40.9%, and 16.7%, respectively, although Morita et al[13] reported prevalence of 38%, 35.4%, and 18% and Maltoni et al[16] reported prevalence of 27.7%, 33%, and 24.4%, respectively. These discrepancies may suggest that patient background differs intrinsically between the home care setting and the hospice setting. Therefore, the low sensitivity of the PPI means that this instrument may not be suitable for detecting poor prognosis in patients with relatively good performance status, especially in the home care setting. In addition to the results mentioned earlier, we found that the specificity of PPI for patients with advanced cancer in the home care setting was nearly 90% in our study for 3-week survival, the same as in our previous study.[15] These results support our previous suggestion that the PPI might not be useful as a screening tool for poor prognosis in the home care setting because of its low sensitivity but might be useful with PPI scores <6, predicting survival longer than 3 weeks.

The second important finding of this study was that PPS, oral intake, dyspnea at rest, and delirium had statistically significant associations with survival durations of less than 3 weeks and less than 6 weeks for patients with advanced cancer in the home care setting, while edema showed no significant correlation. This finding is in accordance with the European Association for Palliative Care recommendations regarding prognostic factors.[2] It is possible that no association was detected between edema and survival due to insufficient power resulting from the small sample size of this study. We must reevaluate this question using a larger sample size from this patient population before forming a definitive conclusion, because a previous study[11] showed that edema was significantly related to patient survival in the hospital setting.

The last important finding of this study was that all 14 patients with normal oral intake survived longer than 3 weeks. One possible reason may be that the nutritional status of the current study, patients with normal intake, was maintained better than that of patients in previous studies using inpatient settings. In the home care setting, patients can eat their favorite foods whenever they want, making it more likely that they can maintain a normal oral intake which may lead to prolonged survival. A corollary to this is that there may be several disadvantages to using oral intake as a factor in predicting prognosis in the inpatient setting; for example, patients may not be served meals they like, and they may not express their meal preferences as easily as in the home care setting. Therefore, we may mistakenly judge that patients in the inpatient setting may have decreased oral intake when in another setting they would in fact have normal oral intake.

This study has 3 limitations. First, our report may not be representative of patients with advanced cancer in the home care setting, because it was carried out only in 1 institution. Second, the population of this study was relatively small. These limitations restrict the generalizability of our results. Third, as we have already described, we may have underdiagnosed delirium because we did not screen using a standardized specific assessment tool such as Confusion Assessment Method.[17] This may affect the accuracy of the PPI in the current study. To overcome these limitations, we should carry out a large multicenter study for patients with advanced cancer using standard symptom assessment tools in the home care setting.

In conclusion, this study showed that the PPI had a lower sensitivity for patients with advanced cancer in the home care setting than for those in palliative care units, although the specificity of the PPI for patients with advanced cancer in the home care setting was nearly 90% for 3-week survival. Further research is needed to develop more accurate prognostic prediction tools for use in the home care setting.

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Declaration of Conflicting Interests

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Effects of a programme of interventions on regional comprehensive palliative care for patients with cancer: a mixed-methods study

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Summary

Background **Improvement of palliative care is an important public health issue, but knowledge about how to deliver palliative care throughout a region remains inadequate. We used surveys and in-depth interviews to assess changes in the quality of palliative care after regional interventions and to gain insights for improvement of palliative care at a regional level.**

Methods **In this mixed-methods study, a comprehensive programme of interventions for regional palliative care for patients with cancer was implemented from April 1, 2008, to March 31, 2011 in Tsuruoka, Kashiwa, Hamamatsu, and Nagasaki in Japan. Interventions included education, specialist support, and networking. We surveyed patients, bereaved family members, physicians, and nurses before and after the interventions were introduced. We also did qualitative interviews with health-care professionals after the interventions were introduced. Primary endpoints were numbers of home deaths, coverage of specialist services, and patient-reported and family-reported qualities of care. This trial is registered with UMIN Clinical Trial Registry, Japan (UMIN000001274).**

Findings **859 patients, 1110 bereaved family members, 911 physicians, and 2378 nurses provided analysable preintervention surveys; 857 patients, 1137 bereaved family members, 706 physicians, and 2236 nurses provided analysable postintervention surveys. Proportions of home deaths increased significantly, from 348 of 5147 (6·76%) before the intervention programme to 581 of 5546 (10·48%) after the intervention programme ($p<0·0001$). Furthermore, 194 of 221 (87·78%) family members of patients who died at home answered that these patients had wanted to die at home. The ratio of patients who received palliative care services to all patients who died of cancer increased significantly (from 0·31 to 0·50; $p<0·0001$). The patient-reported (effect size 0·14; adjusted p 0·0027) and family-reported (0·23; <0·0001) qualities of care were significantly better after interventions than before interventions. Physician-reported and nurse-reported difficulties decreased significantly after the introduction of the interventions. Qualitative interviews showed improved communication and cooperation between health-care professionals because of greater opportunities for interactions at various levels.**

Interpretation **A regional programme of interventions could improve the quality of palliative care. Improvement of communication between health-care professionals is key to improvement of services.**

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Introduction

Improvement of palliative care is an important health-care issue worldwide.[1] Several systematic reviews have shown the benefits of palliative care to patients and families.[2,3] Palliative care should thus be provided consistently throughout an entire region, and several studies have explored the effects of programmes of interventions in regional palliative care on place of death (ie, home death *vs* death in hospital, nursing home, or other location), use of palliative care services, patient-reported and family-reported outcomes, and health-care costs.[4–9] For example, a cluster-randomised controlled trial has shown that regional palliative care interventions helped to increase family satisfaction and the proportion of deaths occurring at home. However, whether such increases show patients' preferences, and how such changes occur, were not explored.[4–9]

In the past 10 years or so, the UK has implemented the Gold Standards Framework, which stresses communication and coordination in the community through development of a palliative care registry and regular meetings.[10] The results of a review[10] suggested that the most important perceived benefit of the Gold Standards Framework is enabling of communication between health-care professionals in the community—a finding consistent with those from studies in Australia,[11] Canada,[12] and the Netherlands.[13] These studies provide important insights into the potential benefits of regional palliative care programmes. However, clinical implications are few because the interventions often required structural or

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financial changes in the health-care system (and thus could not be applied when such changes were difficult or unfeasible), and multidimensional outcomes (especially patient-reported outcomes) were not measured or were explored in only some populations and provided few insights about the regional effects of the interventions. A mixed-methods approach has been proposed as a potentially useful strategy to examine the effects of complex interventions,[14,15] but, to the best of our knowledge, no large-scale mixed-methods studies of regional palliative care interventions have been done.

The Japanese medical system is characterised by free access, fully covered by national insurance, and has no system of primary-care physicians.[16,17] Patients can freely access all medical institutions, but the organisation of palliative care resources varies widely between regions. 7% of patients who die from cancer die at home, another 7% die in inpatient hospices or palliative care units, and the rest die in hospitals.[17] As in other countries, how to deliver palliative care throughout the region and how to increase the numbers of patients who die in their preferred location are important issues in Japan.

We did a mixed-methods study to assess changes in various outcomes in regional palliative care after the introduction of a programme of interventions and to explore how the changes occurred. Our ultimate purpose was to get insights into provision of high-quality palliative care at a regional level.

Methods

Study design and participants

The Japan Outreach Palliative Care Trial of Integrated Regional Model (OPTIM) study is a mixed-methods study of a regional palliative care intervention trial for patients with cancer[18,19] that was done in four regions of Japan—specifically, Tsuruoka (Yamagata Prefecture), Kashiwa (Chiba Prefecture), Hamamatsu (Shizuoka Prefecture), and Nagasaki (Nagasaki Prefecture). All cooperative hospitals, general practice clinics, district nurse services, and other health-care organisations in these regions participated into the study.

Methods have been previously described;[19] the rationale for the study design and each endpoint, psychometric properties, item examples of measurement instruments, interventions, sample size calculations, and details of statistical analyses are presented in an accessible short-form protocol. The ethical and scientific validity of this study was confirmed by the institutional review board of this study and the boards of all participating hospitals. Our study was done according to the ethical guidelines for Epidemiological Research by the Ministry of Health, Labor and Welfare, and written informed consent was not necessary.

For the **accessible short-form protocol** see http://gankanwa.umin.jp/optim_protocol.pdf

We surveyed participants, then introduced interventions to improve palliative care, and then surveyed participants again. Because of the absence of a registry system to identify all potential participants, we identified all hospitals, general practice clinics, and district nurse services in each area with reference to lists from the Japan Hospital Association and local information. Research coordinators at each institution identified and approached potential participants.

The aims of the surveys were to explore the perceived changes in quality of care and quality of life (patients and bereaved families) and the changes in perceived difficulties and knowledge (survey of doctors and nurses). Participants were administered identical questionnaires before and after the implementation of the programme of interventions.

We sent questionnaires by mail to all patients, bereaved family members, physicians, and nurses who met the inclusion criteria. We intended to obtain a sample that was as representative of each region as possible. Eligible patients were adults with metastatic or recurrent cancer of the lung, oesophagus, stomach, colon, rectum, pancreas, liver, biliary system, kidney, prostate, bladder, breast, ovary, or uterus, who had been informed of their malignancy and made outpatient visits to the oncology or relevant specialty department.

We identified bereaved family members in hospitals and at all general practice clinics with experience of caring for terminally ill patients with cancer. Inclusion criteria for bereaved family members were having an adult family member with cancer who had died in a health-care institution or at home (one family member listed as the main caregiver on the medical record was selected for each patient) who had had a primary tumour of the lung, oesophagus, stomach, colon, rectum, pancreas, liver, biliary system, kidney, prostate, bladder, breast, ovary, or uterus; received medical treatment from the institution on 3 days or more; and been informed of the malignancy. Bereaved family members of patients who died from treatment-associated complications or comorbidities or who died in intensive-care units were also excluded.

Physicians and nurses were recruited from hospitals, general practice clinics, and district nurse services. Hospital physicians and nurses working in cancer-related specialties, a representative physician of general practice clinics, and all district nurses with 3 years or more of clinical experience (ie, who had completed residency training) were eligible for inclusion. Health-care workers were excluded if they had not treated any cancer patients during the previous year.

We obtained preintervention data for outcomes before or in the early stage of the intervention period and postintervention data for outcomes after or in the late stage of the intervention period. The intervention programme was implemented from April 1, 2008, to March 31, 2011; these dates were prospectively defined. We got information about the location of death of patients with cancer from the national government registry and the number of patients who receive specialised palliative care services from each service for each year from 2007 to 2010. We consecutively recruited patients who were receiving

medical treatment for cancer in participating hospitals between March 1 and April 30, 2008 (preintervention), and between Nov 1 and Dec 31, 2010 (postintervention). We consecutively sampled bereaved families of patients who died between April 1, 2007, and March 31, 2008 (preintervention), and between April 1, 2010, and March 31, 2011 (postintervention), and questionnaires were sent in October, 2008 (preintervention), and October, 2011 (postintervention). Physicians and nurses were sampled in February, 2008 (preintervention), and January, 2011 (postintervention). Interviews with participating clinical staff were done from Jan 6, to March 31, 2011.

Interventions

Interventions were designed on the basis of a literature review, preliminary surveys, and discussion among the researchers and with health-care professionals in the study regions to resolve the identified major barriers to region-based palliative care.[18,19]

Four types of interventions were implemented—ie, those to improve the knowledge of, and skills in, palliative care (eg, dissemination of manuals and assessment instruments, interactive workshops), increase the availability of specialised palliative care services (eg, establishment of a new community palliative care team, outreach educational visits), coordinate community palliative care resources (eg, regional palliative care centres, whole-region interdisciplinary conferences, patient-held records, discharge-planning systems), and provide appropriate information about palliative care to the general public, patients, and families (panel 1).

To deliver the intervention, each region identified a team of local leaders, including a physician, a nurse, and a medical social worker who had already been working as a clinical specialist in the region, that was responsible for implementation. These leaders received a 2 day workshop from the research team before the interventions. To monitor and help with implentation of interventions, meetings between local leaders and the research group were held 25 times throughout the study, and a certified community nurse visited each region and followed up by telephone and email consistently.

We designed interventions so that structural or financial changes would not be needed in the health-care system, and aimed to optimise health-care resources within a region. With reference to the UK Medical Research Council recommendation[15] about complex interventions, we closely monitored the intensity of interventions, described the narrative intervention process in detail, and investigated the levels of exposure to interventions in the postintervention survey.

Procedures

Our study had four primary endpoints—namely, the proportion of patients with cancer who died at home, coverage of specialist services (ie, the ratio of patients who received specialised palliative care services to all patients who died of cancer), and patient-reported and family-reported qualities of palliative care on the care evaluation scale.[20,21] We obtained the proportion of patients who died at home from the national government registry. As reference data, the mean home-death rate of all patients with cancer in Japan was obtained. The number of patients who received specialised palliative care services was defined as the total number of patients listed by each specialised palliative care service. Duplicate counting was permitted (ie, if patients used more than one specialised palliative care service, they were counted each time). We used the total score of three subscales (physical care provided by physicians, physical care provided by nurses, and psychoexistential care, each of which had three items) of the care evaluation scale as a single scale. Each item was scored on a 6-point Likert-type scale (1=improvement is very necessary; 6=improvement is not necessary at all); high values suggest that patients perceive little need for improvement.

Secondary endpoints were care burden, length of hospital admission, quality of life, difficulty of delivering palliative care, and knowledge of palliative care. We measured care burden on the basis of the care burden section of the caregiving consequences inventory,[22] which comprises four items about physical, emotional, practical, and economic burden scored from 1 ("strongly disagree") to 7 ("strongly agree"); high values suggest a high perceived care burden. Bereaved family members reported the length of inpatient hospital admission of "2 weeks or longer" in the last month of life. Quality of life of patients, as judged by both patients and bereaved

Panel 1: Interventions to improve regional palliative care

Interventions introduced comprised four components. To improve the knowledge and skills of palliative care providers, pocket-size manuals of palliative care (a book and videos) and 13 assessment instruments (12 educational pamphlets for patients and families for each symptom, such as pain, and one comprehensive assessment instrument) were disseminated via printed materials and a web site, and used in educational workshops. To increase the availability of specialised palliative care services for community patients, each region established a community palliative care team through optimisiation of resources; the team provided outreach educational visits for community institutions. To coordinate community palliative care resources, each region established a regional palliative care centre and held a multidisciplinary conference to develop collaborative relationships between health-care workers in the region. Use of patient-held records to maintain continuity of care and introduction of a discharge planning system was encouraged. To provide information about palliative care, hand-sized leaflets, note-sized leaflets, posters, and DVDs were disseminated. Public libraries provided a set of 100 books about palliative care, and workshops were held for the general public.

families (as a proxy for terminally ill patients), was measured with the good death inventory.[23,24] Each item was scored from 1 ("strongly disagree") to 7 ("strongly agree"); high values suggest a high perceived quality of life. Additionally, we asked bereaved family members about whether they believed that patients had died in their preferred place.[23]

Physician-reported and nurse-reported difficulty of delivering palliative care were measured with the palliative care difficulty scale,[25] which consists of five subscales (communication in multidisciplinary teams, community coordination, expert support, alleviation of symptoms, and communication with patients and families) that assess the frequency of problems in daily practice with a Likert-type scale scored from 1 ("never") to 5 ("very much"); high values suggest a high perceived difficulty. We measured physician-reported and nurse-reported knowledge about palliative care with the palliative care knowledge test.[26] Responses were scored as correct or incorrect; high test scores suggest a high level of knowledge about palliative care.

Qualitative assessment

In addition to the surveys, all health-care professionals who had roles in the implementation of the interventions underwent semistructured face-to-face interviews with two trained research nurses in the late stages of, or after, the interventions—specifically between Jan 6 and March 31, 2011. Questions focused on the perceived changes and experiences during the study and perceived reasons for the changes. All interviews were audiotaped, transcribed verbatim, and subjected to thematic analysis on the basis of the grounded theory tradition.[27,28] Two nurse researchers (distinct from the research nurses who did the interviews) used a consistent comparison method to independently code interviews for major themes. Coding frameworks and assignments were discussed under the supervision of an experienced palliative care specialist (TM). Discussions between researchers resulted in full agreement about the codes and themes that emerged.

Statistical analysis

We used logistic regression to compare changes in home death rates and ratios of patients who received specialised palliative care services before and after the interventions. The significance of interventions was assessed by time interaction terms (ie, time trend). For comparison with the national reference data for home deaths, we did repeated measures analysis with robust variances (ie, a generalised estimating equation approach) to account for the longitudinal nature of the data. Scores on the care evaluation scale, caregiving consequences inventory, palliative care difficulty scale, and palliative care knowledge test before and after the interventions were compared with the Student's *t*-test. We calculated Hedges' *g* to estimate effect size.[29] For duration of hospital admission, we used the χ^2 test for trend. For interpretation, we deemed effect sizes of 0·2 small, 0·5 moderate, and 0·8 large.[30] We did regressional analyses for all primary endpoints to adjust for participants' background characteristics, such as age, sex, and region.

To adjust for difference in the proportions of places of death of the patients sampled, the weighted means of death location according to census data of four regions

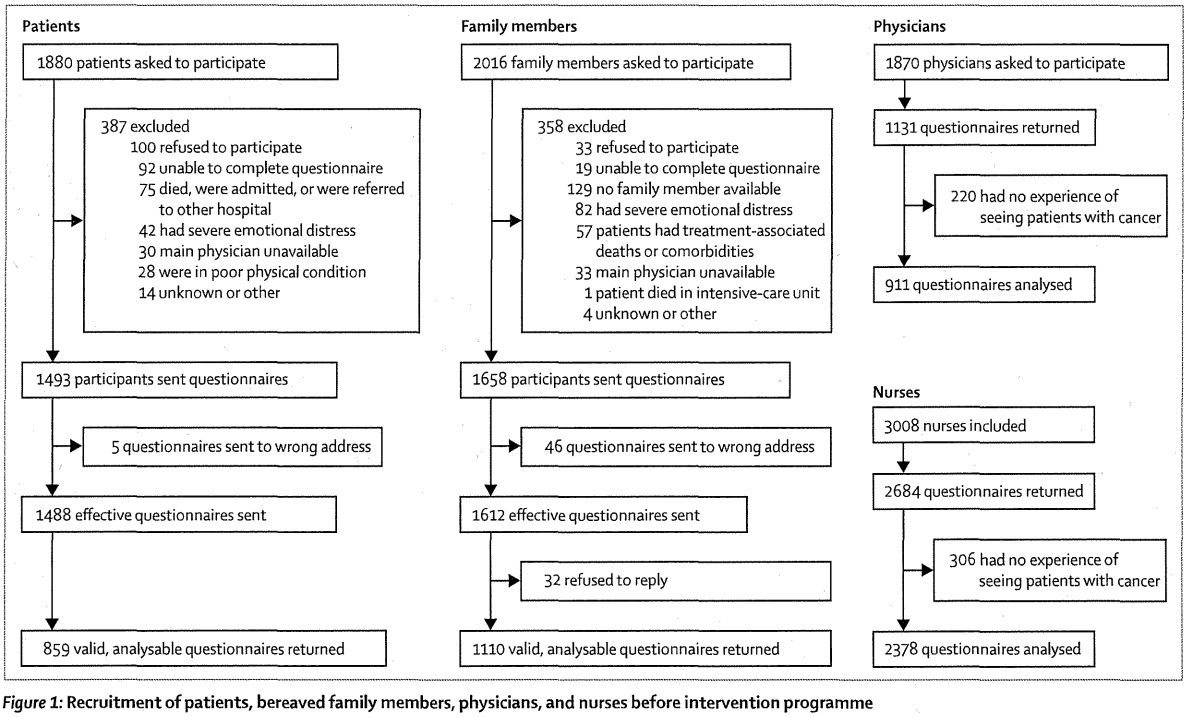

Figure 1: **Recruitment of patients, bereaved family members, physicians, and nurses before intervention programme**

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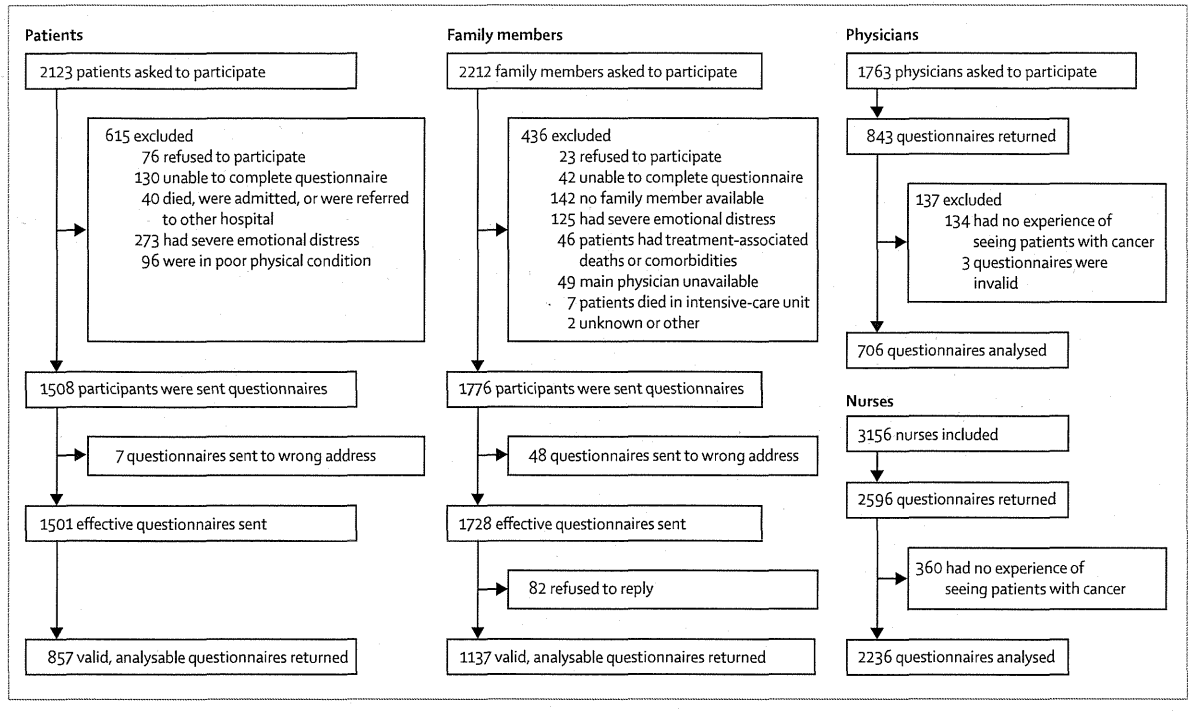

Figure 2: **Recruitment of patients, bereaved family members, physicians, and nurses after intervention programme**

were used for bereaved family outcomes. We did not calculate inter-reliability statistics for the results of qualitative interviews with health-care professionals. We calculated sample sizes for four primary endpoints. We used SAS (version 9.3) for all analyses. We deemed two-sided p values of 0·0125 or less to be significant (we used the Bonferroni correction for multiple comparisons). This trial is registered with UMIN Clinical Trial Registry, Japan (UMIN000001274).

Role of the funding source

The funding source had no role in study design; data collection, analysis, or interpretation; or the writing of the report. The corresponding author had full access to all data and final responsibility for the decision to submit for publication.

Results

859 patients, 1110 bereaved family members, 911 physicians, and 2378 nurses were analysed in the preintervention survey, and 857 patients, 1137 bereaved family members, 706 physicians, and 2236 nurses in the postintervention survey (figures 1, 2). Characteristics of patients are summarised in the appendix. Qualitative interviews, lasting a mean of 135 min (SD 39), were completed with 101 of 103 health-care professionals, resulting in 101 transcriptions (roughly 40 000 words each). 23 of 34 hospitals in the study regions agreed to participate (8964 of 11033 [81·2%] beds).

2016 of the 5147 (39·2%) patients surveyed who died of cancer in the study regions in the preintervention period died at participating institutions, and 2212 of 5546 (39·9%) patients surveyed during the post-intervention period died at participating institutions.

Table 1 summarises the coverage of interventions during the study. 355 of 706 (50·3%) physicians and 994 of 2236 (44·5%) nurses participated at least once in an interactive workshop or a whole-region interdisciplinary conference, or both, and 517 of 706 (73·2%) physicians and 1512 of 2236 (67·6%) nurses used or

	n
To improve knowledge of, and skills in, palliative care	
Manuals disseminated	24353
Assessment instruments disseminated	174891
Participants of interactive workshops	22189
To increase the availability of community-specialised palliative care services	
Patients referred to a community palliative care team	429
Outreach educational visits	38
To coordinate community palliative care resources	
Consultations at regional palliative care centres	6775
Participants in whole-region interdisciplinary conferences	5902
Patient-held records disseminated	13574
Hospitals introducing a discharge-planning system	23*
To provide appropriate information about palliative care	
Leaflets, posters, and DVDs disseminated	202340
Participants in public workshops	10226

Data are n, and are from four study regions (Hamamatsu, Kashiwa, Nagasaki, and Tsuruoka) between April 1, 2008, and March 31, 2011. *Of 27 hospitals.

Table 1: **Number of interventions delivered to improve palliative care**

See Online for appendix

acknowledged the manual or assessment instruments, or both.

In 2007, four palliative care units, ten hospital or community palliative care teams, five outpatient palliative care services, and no home palliative care teams were available. In 2010, after the interventions, five palliative care units, 11 hospital or community palliative care teams, 11 outpatient palliative care services, and two home palliative care teams were available. All services were maintained after the study.

The proportion of patients that died at home was significantly higher after than before the interventions (p<0·0001; table 2), and this increase was significantly greater than that noted in the national reference data (p<0·0001; figure 3). The ratio of patients who received palliative care services to patients who died of cancer (p<0·0001), and patient-reported (adjusted p=0·0027) and family-reported (p<0·0001) qualities of palliative care increased significantly from before the interventions to after the interventions.

In the postintervention surveys, of 581 patients who died at home, 311 family members were identified and sent questionnaires, and 221 returned completed questionnaires. 194 (87·78%) of the responding family members agreed or strongly agreed that the patient had died in his or her preferred place, and an additional nine (4·07%) slightly agreed. Furthermore, the care burden did not change significantly during the study period (for either all families or families of patients who died at home; table 2). Significantly fewer patients spent more than 2 weeks of the last month of their lives in hospital

	Before interventions	After interventions	Effect size	p	Adjusted p
Primary endpoints					
Home deaths	348/5147 (6·76%)	581/5546 (10·48%)	..	<0·0001	..
Ratios of patients who received specialised palliative care services to patients who died from cancer*	0·31	0·50	..	<0·0001	..
Quality of palliative care†					
Patient-reported	4·43 (1·08)	4·57 (0·97)	0·14	0·0055	0·0027
Family-reported	4·31 (1·12)	4·56 (1·08)	0·23	<0·0001	<0·0001
Secondary endpoints					
Care burden‡					
Total	3·97 (1·50)	4·03 (1·50)	0·04	0·3546	..
Families of patients who died at home	3·76 (1·57)	3·87 (1·54)	0·07	0·5874	..
2 weeks or more in hospital in the last month of life	744/1039 (71·61%)	677/1061 (63·81%)	..	<0·0001	..
Quality of life§					
Patient-reported	5·45 (0·98)	5·52 (0·92)	0·08	0·1024	0·1680
Family-reported	4·41 (0·97)	4·63 (0·96)	0·22	<0·0001	<0·0001
Physician-reported difficulty¶					
Total	2·69 (0·80)	2·28 (0·75)	0·52	<0·0001	<0·0001
Communication in multidisciplinary teams	2·47 (1·05)	2·10 (0·97)	0·37	<0·0001	<0·0001
Community coordination	2·96 (1·15)	2·25 (1·08)	0·63	<0·0001	<0·0001
Expert support	2·40 (1·25)	1·83 (1·06)	0·49	<0·0001	<0·0001
Alleviation of symptoms	2·94 (0·98)	2·76 (0·98)	0·18	<0·0001	<0·0001
Communication with patients	2·66 (0·94)	2·45 (0·92)	0·22	<0·0001	<0·0001
Physician-reported knowledge‖	72·00 (22·86)	78·46 (20·35)	0·30	<0·0001	<0·0001
Nurse-reported difficulty¶					
Total	3·15 (0·75)	2·72 (0·73)	0·59	<0·0001	<0·0001
Communication in multidisciplinary teams	3·09 (1·03)	2·65 (1·05)	0·42	<0·0001	<0·0001
Community coordination	3·03 (1·16)	2·37 (1·05)	0·60	<0·0001	<0·0001
Expert support	2·90 (1·30)	2·19 (1·14)	0·58	<0·0001	<0·0001
Alleviation of symptoms	3·49 (0·84)	3·28 (0·88)	0·24	<0·0001	<0·0001
Communication with patients	3·25 (0.91)	3·07 (0·97)	0·19	<0·0001	<0·0001
Nurse-reported knowledge‖	50·72 (20·16)	60·43 (21·89)	0·46	<0·0001	<0·0001

Data are n/N (%) or mean score (SD) unless otherwise specified. *N=1606 before the intervention and 2783 after the intervention. †Measured with the care evaluation scale, which ranges from 1 to 6 (high score suggests low perception of necessity for improvement). ‡Measured with the caregiving consequences inventory, which ranges from 1 to 7 (high score suggests low perceived care burden). §Measured with the good death inventory, which ranges from 1 to 7 (high score suggests a high perceived quality of life). ¶Measured with the palliative care difficulty scale, which ranges from 1 to 5 (high score suggests a high level of perceived difficulties). ‖Measured with the palliative care knowledge test, which ranges from 0 to 100 (high score suggests high level of accurate knowledge).

Table 2: **Summary of endpoints before and after programme of interventions**

after the interventions than before the interventions (p<0·0001; table 2).

Family-reported quality of life of terminally ill patients was significantly higher after than before the interventions (adjusted p<0·0001), whereas patient-reported quality of life did not significantly change (p=0·1680; table 2). Physician-reported and nurse-reported difficulties in delivering palliative care decreased significantly after the interventions (p<0·0001), with overall effect sizes of more than 0·5 (table 2). Physician-reported and nurse-reported knowledge increased significantly after the interventions (table 2). Greater improvements were noted in the subscales of community coordination, expert support, and communication in multidisciplinary teams (table 2).

Through analysis of the qualitative data, we identified seven themes, typical data for three of which are included in the appendix. The health-care professionals who had roles in the implementation of the interventions greatly emphasised improved communication and cooperation between regional health-care professionals (data not shown) and described various ways in which communication and cooperation improved daily palliative care practices—eg, many meetings were held at which specialists and responsible persons were more easily contactable than they had been previously. The main perceived reasons for changes were whole-region interdisciplinary conferences and informal interactions at various meetings (data not shown).

Implementing health-care professionals also perceived increased confidence in the system to care for patients with cancer at home (data not shown). Changes were identified both in hospitals and the community, and the implementing health-care professionals stated that these changes resulted in timely discharge to home or a longer stay at home, or both (data not shown). Perceived reasons for these changes included collaboration with various specialties, easier exchange of information, increased availability of specialists and inpatient resources, development of discharge-planning divisions, and improved hospital clinicians' knowledge about what care was provided at home and community clinicians' general improved knowledge (data not shown).

Discussion

Our study was one of the largest and most comprehensive mixed-methods studies to explore the effects of a region-wide programme of interventions to improve palliative care for patients with cancer (panel 2). We measured interpretable multidimensional outcomes from a large population (that was nearly representative of the regions involved), and introduced interventions that could be adopted in other regions. The qualitative study, furthermore, suggests a framework for how this change occurred, and this framework can guide researchers and policy makers designing interventions to improve region-based palliative care.

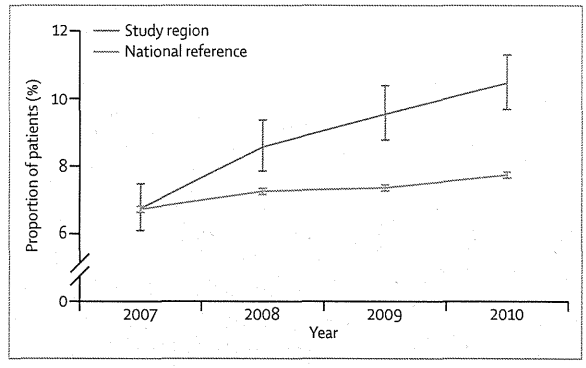

Figure 3: **Proportion of patients with cancer who died at home after the programme of interventions compared with national standards**
Bars are 95% CIs. In study regions, 348 of the 5147 (6·8%) total cancer deaths in 2007, 463 of the 5394 (8·6%) total cancer deaths in 2008, 507 of the 5302 (9·6%) total cancer deaths in 2009, and 581 of the 5546 (10·5%) total cancer deaths in 2010 were home deaths. In national reference data, 22 623 of the 336 468 (6·7%) total cancer deaths in 2007, 24 941 of the 342 963 (7·3%) total cancer deaths in 2008, 25 433 of the 344 105 (7·4%) total cancer deaths in 2009, and 27 508 of the 353 499 (7·8%) total cancer deaths in 2010 were home deaths.

Introduction of the interventions increased the proportion of deaths occurring at home—a result consistent with the findings of a previous randomised study,[4] which did not, however, assess whether the increase in the rate of home deaths was associated with the patients' preferences or those of their families. A strength of our study was that most family members of patients who died at home confirmed that the patient wanted to die at home. Furthermore, we noted no evidence of increases in the care burden of families of patients who died at home. The absolute number of home deaths was, nonetheless, still low after the interventions, suggesting that some structural or financial changes are needed in the health-care system before a further increase in the proportion of home deaths will occur.

Significant improvements in patient-reported and family-reported qualities of care and family-reported quality of life were noted, but changes in patients' outcomes were generally small, probably because the high scores of outpatients in the preintervention survey caused ceiling effects and interventions were mainly targeted to patients with more advanced cancer.

Importantly, the intervention programme significantly decreased difficulties associated with delivering palliative care reported by physicians and nurses at a regional level, especially those related to communication, coordination, and expert support. This finding was strongly supported by the qualitative findings, which showed that communication and cooperation were particularly improved, suggesting that one of the most powerful perceived effects is improved communication between health-care professionals.[10–13]

An additional strength of the qualitative study was that many ways in which good communication and cooperation can positively affect daily practice and patients' outcomes were clearly described. The key

Panel 2: Research in context

Systematic review

We searched PubMed and palliative care journals (*Journal of Pain and Symptom Management*, *Palliative Medicine*, *Journal of Palliative Medicine*, and *Supportive Care in Cancer*) with the terms ((“palliative care” [MeSH Terms] OR “palliative care”[All Fields]) OR “end-of-life” [All Fields]) AND (“region” [All Fields] OR “population-based” [All Fields] OR “community” [All Fields]) for articles published between Jan 1, 1990, and Jan 31, 2013. We identified four series of studies assessing regional palliative care programmes. The earliest work was about the development of a regional palliative care programme in Edmonton (AB, Canada).[7] Later, a cluster-randomised controlled trial[4,5] was done in Norway. We also identified quality-improvement projects with no control groups in Spain[6,9] and Ontario, Canada.[8] The results of these studies suggested that a programme of interventions has positive effects on some outcomes for regional palliative care delivery, including place of death. However, the comprehensive effects of such a programme on an entire region are poorly understood, because no studies have comprehensively assessed a representative sample of patients, bereaved family members, and health-care professionals throughout a region. Furthermore, no studies were based on a mixed-methods design to explore how these changes occurred.

Interpretation

Our study clarified the effects of a programme of regional palliative care interventions on a range of outcomes, including place of death, use of specialised palliative care services, patient-perceived and family-perceived quality of care, patients’ quality of life, family care burden, and physician-perceived and nurse-perceived difficulties and knowledge. Although the programme of interventions had an overall benefit, the largest effect in both quantitative and qualitative studies was improved communication between health-care professionals. Our study adds important insights about the comprehensive effect of regional palliative care programmes and the crucial value of communication between health-care professionals to improve palliative care at a regional level.

interventions cited were whole-region interdisciplinary conferences and informal interactions at various types of meeting. These findings provide insight into why improved communication is important for high-quality palliative care at a regional level and strongly imply that easing communication between health-care professionals is essential for improvement of regional palliative care.

Our study had some substantial limitations, the most important of which was the absence of a control group (excepting people who died at home and were included in national data). Second, the outcomes measured with questionnaire surveys might have been affected by selection, response, and recall biases. Although we statistically adjusted for all noted differences in participants’ backgrounds, the intervention effects might have been overestimated, especially in the samples of patients and bereaved families, because of an unexplained increase in excluded participants as a result of severe emotional distress and an increase in sampling from home settings. These methodological limitations can be overcome in future studies through use of, when feasible, data from complete patients’ registries or a mortality follow-back survey, or both. Third, our data might not be a fully representative regional sample, although most hospital beds and roughly 40% of deceased patients were included. Fourth, we did not measure objective metrics of health-service use (eg, number of admissions). Fifth, patients who received medical care from an institution within 2 days or who were not informed of malignancy (and their families) did not have input. Finally, we excluded patients who did not have cancer.

As a policy implication, establishment of a structure to improve communication between health-care professionals is an extremely important element of regional palliative care programmes. We recommend the use of combined methods to understand the overall effects of region-wide multicomponent interventions.

Contributors

TM drafted the paper and had roles in data collection and study conception and design. MM and TY contributed to data analysis and interpretation and study conception and design. AY, NA, YS, and MA contributed to study conception and design, data collection, and critical revision of the article for important intellectual content. YK and KH contributed to study conception and design and critical revision of the article for important intellectual content. CI contributed to study conception and design and data analyses of the qualitative study. MK and KE contributed to study conception and design, critical revision of the article for important intellectual content, and organisation of the research team.

Conflicts of interest

We declare that we have no conflicts of interest.

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Original Article

Troubles and Hardships Faced by Psychologists in Cancer Care

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Objective: The aim of this study was to identify problems experienced by psychologists involved in cancer and palliative care and consider an education system for psychologists.
Methods: We conducted a questionnaire survey of psychologists involved in cancer care and palliative care. At the 403 facilities, 419 psychologists who received the questionnaire were asked to fill it out anonymously. A total of 294 people (61 male, 233 female, average age $\pm$ SD $= 36.3 \pm 9.4$) responded about troubles and hardships actually faced by psychologists working in cancer care. We performed qualitative content analysis of free responses.
Results: We obtained the following five categories: 'Hospital system', 'Psychologist role and specialization (ambiguity of the role expected of psychologists and problems arising because psychologists are not nationally licensed)', 'Collaboration with other medical professionals (problems with the method of requesting psychologist cooperation and problems of consultation and liaison work within the hospital)', 'Specialized support provided by psychologists (difficulty of interaction with patients and their families, inadequate provision of psychological support in cancer care, problems related to death care and lack of psychiatric knowledge)', 'Stress faced by psychologists (psychologist's isolation and anxiety, psychologist's internal conflicts, psychologist burnout and helplessness and psychologist self-improvement)'.
Conclusions: Psychologists must acquire at least a minimal level of medical knowledge and understanding of cancer treatment. Furthermore, they require training through specific case studies in order to facilitate collaboration with other medical professionals and concrete training in aspects of psychological support that are specifically tailored to cancer treatment through case studies.

Key words: psychologist – cancer care – trouble – hardship – education

INTRODUCTION

The Basic Plan for Cancer Control Measures of 2009 emphasizes the alleviation of physical symptoms and provision of support for psychological problems from the early stages of treatment. In addition, providing appropriate support, including emotional care, to both cancer patients and their families is also highly valued. Thus, in the future, psychologists, along with psycho-oncologists are expected to increasingly contribute to cancer care and palliative care. Iwamitsu et al. (1) conducted focus group interviews of physicians and nurses about the roles of psychologists in palliative medicine; in particular, the roles demanded by the palliative care