

a standardised tool, which includes information on symptoms such as pain and dyspnoea, through Web-based and interactive workshops. An example is a palliative care manual that describes symptom management.

To deliver quality educational programmes, it is necessary to conduct evaluations to determine whether an educational programme is effective. Such evaluations can assess individual achievement, clarify the effectiveness of the programme and provide information on whether the programme should be continued. Therefore, a valid instrument to evaluate educational programmes is needed. We considered the linkages among knowledge, skills and practice of palliative care, and we determined that a knowledge test with a wider assessment of symptomatology was necessary. Existing studies have generally focused on knowledge about pain management; broader areas of palliative care, however, have rarely been investigated.¹²⁻¹⁵ Furthermore, we found little information on the psychometric properties of the measures used. The most frequent measurement of palliative care knowledge is the Palliative Care Quiz for Nursing (PCQN) that was developed in 1996 to evaluate nurses' knowledge of palliative care.¹⁶ The validity and reliability of this instrument have been confirmed. However, there were some limitations in assessment of the PCQN, and we felt that the development of a new instrument would be useful for the following reasons: (1) many studies have shown that terminal patients experience a variety of symptoms.¹⁷⁻¹⁹ We wanted to evaluate a wider range of knowledge, including psychiatric problems such as delirium and gastrointestinal problems such as nutrition, that often arise in end-stage cancer patients. (2) We wanted to evaluate not only general nurses but also general physicians who were subjects of the educational programme. (3) We wanted to develop an instrument that is not limited to terminal care and is more in accord with the recent definition by WHO that palliative care is applicable early in the course of illness.¹ (4) Finally, the PCQN included medication that was not available in Japan, and we wanted to develop a tool suitable for Japanese culture.

The aims of this study are two-fold: (1) to develop and validate the Palliative Care Knowledge Test (PCKT) for general physicians and nurses and (2) to identify the factors associated with palliative care knowledge.

In this study, we defined 'patients with terminal cancer' as follows: 'Patients with cancer who are not likely to respond to treatment and whose life expectancy is less than 6 months'. We also defined 'mentor' as follows: 'A person (physician, nurse, family member or friend) with whom a health professional can talk about palliative care personally'.

Methods

Design

The questionnaire survey was designed as a cross-sectional, anonymous, self-administered questionnaire survey. To examine the test-retest reliability of items and domains, the questionnaire was re-issued 2 weeks after the first survey was completed.

Sample

The survey was carried out in August 2007 in two hospitals. The subjects were 940 nurses from a university hospital (661 beds) and a general hospital (634 beds) located in Yokohama city in Japan. Both the facilities had inpatient palliative care units (PCUs). The inclusion criterion for the subjects was that they were registered nurses. The retest was conducted on the subjects who had consented to participate during the first assessment ($n = 204$).

The questionnaire and cover letter were distributed to nurses in each ward. The cover letter explained that this survey was confidential and anonymous. Consent to participate was indicated by the completion and return of the questionnaire. The questionnaire for retests was distributed in each ward as well. Completed questionnaires were collected in a box that we put in the ward. The ethical and scientific validity of this study was approved by the Institutional Review Board in one hospital. Because there was no Institutional Review Board in the other hospital, the study was approved by the director of the hospital.

Procedure

Development of test

We developed an instrument to quantify health care professionals' general palliative care knowledge. Item generation was based on the literature reviews and discussion among nine experts.^{13,16,20-22} Content areas included philosophy, pain, dyspnoea, psychiatric problems, gastrointestinal problems and communication regarding palliative care. A pool of 148 items was generated. To achieve face validity, an expert panel (three palliative physicians, four oncology clinical nurse specialists and two home care nurses) rated the appropriateness of each item. First, experts evaluated the appropriateness of each item according to four grades. Next, the mean, minimum and maximum values were calculated, and the items with less than a mean of two and a minimum of zero were deleted. Then, the argument for the item selection was repeated including an evaluation of the way the concept was

expressed. As a result, a preliminary list of 40 items (Appendix 1) was selected from the original 148 items.

Questionnaire

- (1) The PCKT: preliminary 40 items
- (2) Total number of terminal cancer patients whom you have cared for and the number in the past year
- (3) Experience of working in hospice or PCU
- (4) Hours of palliative care education
- (5) The existence of a mentor regarding end-of-life issues
- (6) Demographic factors (gender, age, education, clinical area and years of clinical experience)

We included factors 2 through 5 as potentially related to palliative care knowledge among nurses. The original questionnaire was in Japanese.

Statistical analyses

Item selection: Participants who responded to 90% or more of the 40 items were included as subjects of the analysis. Responses were determined to be right or wrong for the 40 questions. 'Unsure' responses were regarded as incorrect.

First, item analysis was conducted. We considered the percentage of missing data to enhance feasibility (cut-offs: missing more than 1% of data) and ceiling effect to enhance sensitivity (cut-offs: correct answers are more than 90% or 10% or less). Second, to examine the test-retest reliability of each item, the kappa coefficients were calculated. We considered the reliability of each item (cut-offs: kappa coefficients 0.3 or less). Third, the difficulty and discrimination based on the 2-parameter logistic Item Response Theory (IRT) model were estimated. IRT models are used as a basis for statistical estimation of parameters that represent the magnitude of the latent trait attributable to the items. An advantage of IRT is that it potentially provides information that enables a researcher to improve the precision and reliability of an assessment.²³ We then determined the precision (cut-offs: discrimination 0.5 or less).

Then, to achieve content validity, we repeated the discussion with the experts. We chose particular items based on the analysis results and the following points: (1) items in which sensitivity seemed to be higher and (2) items that could be viewed as providing lessons in themselves. Eventually, 20 items were selected to comprise the PCKT.

Reliability and validity: The sample of the subjects who were surveyed with the 40-item questionnaire was analysed using the 20-selected items. The Kuder-Richardson formula 20 (KR-20) was used to assess the

internal consistency of the 20 items. The test-retest reliability was explored by calculating intraclass correlation coefficients with 2-week interval administrations.

To explore known-group validity, the unpaired *t*-test was used to determine differences between the group of nurses working in PCUs and the group of other nurses. The total overall score of the 20 items and of each domain were examined with the unpaired *t*-test.

Related factors: To identify the factors associated with palliative care knowledge among nurses, first, univariate analyses were conducted using the unpaired *t*-test, ANOVA and Pearson product-moment correlation coefficients, where appropriate. Thereafter, the associations of each hypothesised factor with the total overall score of the 20 items and of each domain were determined using multivariate linear regression. Standardised partial regression coefficients were calculated with models including all explanatory variables other than age. Dummy variables were created for clinical areas. Statistical analysis was performed using SAS version 9.1 (SAS Institute, Inc., Cary, NC, USA). The significance level was set at <0.05 (2-tailed).

Results

The response rates are shown in Figure 1. Finally, 773 responses (82%) in the first and 148 responses (73%) in the second round were used for analysis.

The characteristics of the respondents (first round) are summarised in Table 1. The characteristics of the respondents in the second round were as follows: approximately 97% were women. Job locations were the surgical ward for 38% of the nurses, internal medicine ward for 18% and PCU for 14%. The duration of clinical experience was less than 4 years for 35% of the nurses and from 5 to 9 years for 34%. The number of terminal cancer patients who have been cared for was as follows: 66% were less than 50 people, 17% were 50–99 and the remainders were more than 100 people. Approximately 70% had a mentor.

Validation study

The results of the item analysis and IRT are shown in Table 2.

Feasibility

Missing values were less than 1% in all items.

Ceiling effect

The percentage of correct answers was from 12 to 97%. The item with the highest percentage of correct answers

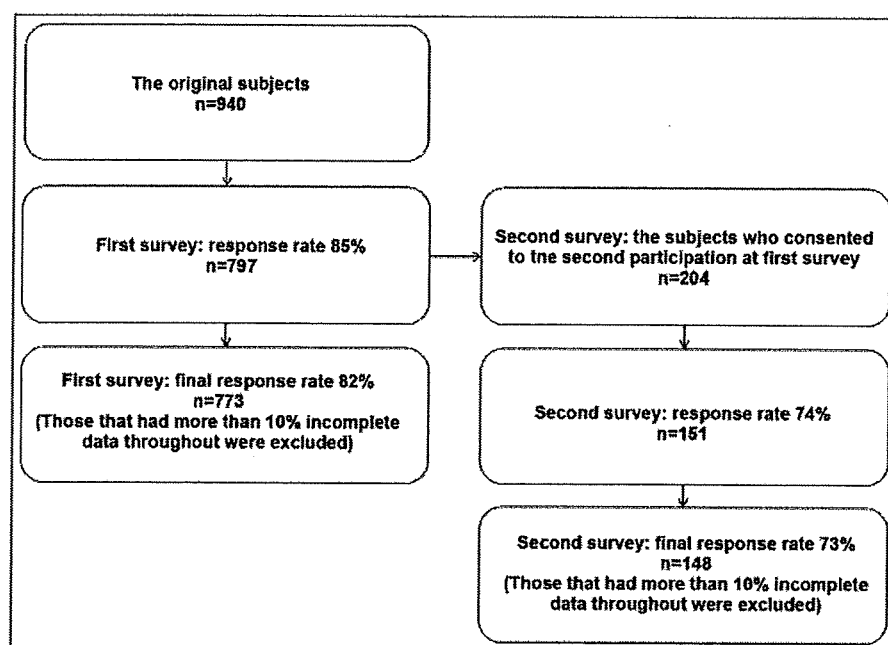


Figure 1. Response rate of the first and the second survey.

(97%) was, 'What is important for quality of life varies among individuals'. This was the only item that had $\geq 90\%$ correct response rate. There were no items that had a 10% or less correct response rate.

Reliability of each item

The kappa coefficient in the test-retest reliability of each item was from 0.26 to 0.74. The kappa coefficient for the item, 'One of the goals of pain management is getting a good night's sleep' (Q3) was low. However, we gave priority to content validity over psychometric properties as a result of a discussion among experts, so it was included in the PCKT.

Item Response Theory

The difficulty in all items ranged from -2.9 to 3.09 . The discrimination was from 0.33 to 2.25 . The item with the highest difficulty and the lowest discrimination was, 'Uncertain information should not be given to patient or family because it may cause additional anxiety'. The item with the highest discrimination was, 'Steroids should improve appetite among patients with advanced cancer' (Q19). 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.

Reliability and validity

On the basis of the results of the item analysis, IRT and expert discussions, we determined that the PCKT would include 20 items in five domains: 1) philosophy, 2) pain, 3) dyspnoea, 4) psychiatric problems and 5) gastrointestinal problems. Table 3 summarises the internal consistency and test-retest reliability of the PCKT. The KR-20 index of internal consistency of the PCKT was 0.81 . The intraclass correlation in the test-retest examination was 0.88 overall and from 0.61 to 0.82 in each domain.

Also, to examine the known-group validity, nurses working in the PCU were compared with other nurses on the mean scores for each domain (Figure 2). There was a significant difference in the score for each domain (philosophy, $P < 0.01$; pain, $P < 0.001$; dyspnoea, $P < 0.001$; psychiatric problems, $P < 0.001$; gastrointestinal problems, $P < 0.001$) as well as for the overall score ($P < 0.001$) between the two groups.

Related factors

Univariate analyses: The relationship among the demographic factors and the factors potentially related to palliative care knowledge was examined with univariate analysis where appropriate, and the results are shown in Table 4. Many variables were identified with a significant difference in the score of each domain. Particularly, all variables other than sex and education

Table 1. Characteristics of participants ($n=773$)

	<i>n</i>	(%)
Sex		
Male	30	4
Female	740	96
Age, years		
≤ 29	465	60
30–39	229	30
40–49	60	8
50–59	15	2
≥ 60	1	0
Clinical area		
Surgical	185	24
Internal medicine	143	19
Palliative care unit	42	5
Others	394	51
Status		
Manager	23	3
Sub-manager	21	3
Staff	722	93
Duration of clinical experience, years		
≤ 4	295	38
5–9	260	34
10–14	128	17
15–19	44	6
≥ 20	43	6
Duration of experience in hospice or palliative care unit, years		
None	705	91
1–4	55	7
5–9	1	0
10–14	0	0
≥ 15	0	0
Number of terminal cancer patients who have been cared for		
None	132	17
1–9	223	29
10–49	250	32
50–99	90	12
≥ 100	71	9
Number of terminal cancer patients cared for in the past year		
None	278	36
1–9	299	39
10–49	134	17
50–99	31	4
≥ 100	19	2
Education		
Nursing school	482	62
Junior college	180	23
University or higher	102	13
Other	6	1
Palliative care education as an undergraduate, h		
None	190	25
≤ 1	64	8
2–5	270	35
> 5	225	29
Palliative care education as a postgraduate, h		
None	357	46
≤ 1	114	15
2–5	170	22
> 5	121	16
Participation frequency in palliative care seminars		
None	564	73
1	78	10
2–5	94	12
> 5	32	4
Presence of a mentor for palliative care issues		
Present	454	59
Absent	311	40

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

but including the number of terminal care patients the nurse had ever cared for ($r=0.52$, $P<0.001$), scored significantly higher in 'pain', 'psychiatric problems' and total score.

Multivariate linear regression analyses: The results of multivariate linear regression analyses are shown in Table 5. Multivariate linear regression identified a significant difference in many variables, as well. The number of terminal care patients the nurse had ever cared for was associated with a higher total score ($\beta=0.16$, $P<0.001$), as were the scores for the four domains including 'dyspnoea' ($\beta=0.17$, $P<0.001$). Greater participation in seminars was associated with a higher total score ($\beta=0.16$, $P<0.001$) and the three domain scores including 'philosophy' ($\beta=0.16$, $P<0.01$). Furthermore, the existence of a mentor for palliative care issues was associated with a higher total score ($\beta=0.07$, $P<0.05$) and scores for 'pain' ($\beta=0.1$, $P<0.001$) and 'dyspnoea' ($\beta=0.08$, $P<0.01$).

Discussion

This study validated an instrument to test the palliative care knowledge of general physicians and nurses. The instrument has good internal consistency, test-retest reliability, face validity and known-group validity. Also, the strength of this instrument is the higher precision compared to existing tools because the items were chosen based on IRT.

The strong points of this instrument are as follows: it is the first instrument concerned with palliative care that can be used for health professionals such as general physicians and nurses because it was developed and tested for content validity using a panel of nine experts in a variety of professions (palliative care physicians, oncology clinical nurse specialists and home care nurses). In addition, it is the first instrument that assesses a wide range of palliative care knowledge that includes 'philosophy', 'pain', 'dyspnoea', 'psychiatric problems' and 'gastrointestinal problems'. Also, the instrument consists of only 20 items with three responses of 'correct', 'incorrect' and 'unsure'.

The PCKT can be used not only to evaluate educational programmes but also to identify the knowledge level of the health care provider. In addition, it can be used to evaluate educational needs and priorities by identifying low-scoring domains and items. Results from the test can help develop strategies for improving the quality of palliative care. Alternatively, this test can be used for individuals to determine an objective measure of personal knowledge and methods for improvement.

Table 2. Item analysis and item response theory of the palliative care knowledge test (n = 773)

Questions			Correct answer (%)	κ -coefficient (n = 148)	IRT	
					Difficulty	Discrimination
Philosophy						
1	Palliative care should only be provided for patients who have no curative treatments available.	F	73	0.39	-1.83	0.55
2	Palliative care should not be provided along with anti-cancer treatments.	F	64	0.66	-1.29	0.47
Pain						
3	One of the goals of pain management is to get a good night's sleep.	T	62	0.26	-0.53	1.07
4	When cancer pain is mild, pentazocine should be used more often than an opioid.	F	42	0.49	0.30	1.40
5	When opioids are taken on a regular basis, non-steroidal anti-inflammatory drugs should not be used.	F	40	0.68	0.29	2.64
6	The effect of opioids should decrease when pentazocine or buprenorphine hydrochloride is used together after opioids are used.	T	34	0.74	0.59	1.59
7	Long-term use of opioids can often induce addiction.	F	34	0.73	0.50	2.03
8	Use of opioids does not influence survival time.	T	25	0.73	0.98	1.51
Dyspnoea						
9	Morphine should be used to relieve dyspnoea in cancer patients.	T	44	0.73	0.23	1.66
10	When opioids are taken on a regular basis, respiratory depression will be common.	F	12	0.62	1.47	2.01
11	Oxygen saturation levels are correlated with dyspnoea.	F	74	0.43	-1.01	1.20
12	Anticholinergic drugs or scopolamine hydrobromide are effective for alleviating bronchial secretions of dying patients.	T	17	0.7	1.19	1.92
Psychiatric problems						
13	During the last days of life, drowsiness associated with electrolyte imbalance should decrease patient discomfort.	T	19	0.55	1.29	1.42
14	Benzodiazepines should be effective for controlling delirium.	T	25	0.42	1.16	1.15
15	Some dying patients will require continuous sedation to alleviate suffering.	T	38	0.5	0.59	0.97
16	Morphine is often a cause of delirium in terminally ill cancer patients.	F	40	0.41	0.32	2.05
Gastrointestinal problems						
17	At terminal stages of cancer, higher calorie intake is needed compared to early stages.	F	38	0.53	0.47	1.49
18	There is no route except central venous for patients unable to maintain a peripheral intravenous route.	F	55	0.49	-0.22	0.98
19	Steroids should improve appetite among patients with advanced cancer.	T	35	0.72	0.42	2.59
20	Intravenous infusion will not be effective for alleviating dry mouth in dying patients.	T	40	0.39	0.57	0.81

IRT, item response theory (the numbers are analysis results for 20 items.); T, correct answer is 'right'; F, correct answer is 'wrong'. The analysis was based on participants who responded to 90% or more of the 40 items.

Table 3. Reliability of the palliative care knowledge test ($n=773$)

Domains (range)	Mean	SD	ICC ($n=148$)	KR-20
Philosophy (0–2)	1.4	0.8	0.61	
Pain (0–6)	2.4	1.7	0.82	
Dyspnoea (0–4)	1.5	1	0.79	
Psychiatric problems (0–4)	1.2	1.1	0.62	
Gastrointestinal problems (0–4)	1.7	1.2	0.75	
Total (0–20)	8.2	4.3	0.88	0.81

ICC, intraclass correlation coefficients; KR-20, Kuder-Richardson formula-20; Mean, the mean of total scores in each domain.

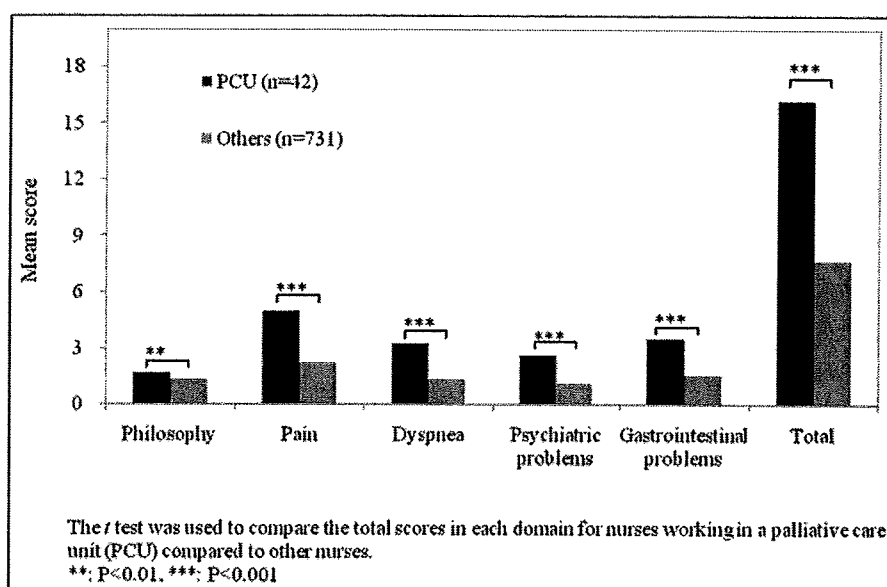


Figure 2. Known-group validity of the palliative care knowledge test. The *t*-test was used to compare the total scores in each domain for nurses working in a palliative care unit (PCU) compared to other nurses. ** $P < 0.01$; *** $P < 0.001$.

This study explored the factors related to palliative care knowledge of nurses. One of the important findings was that the number of terminal care patients the nurse had ever cared for and working in a PCU were associated with a higher total score and scores in four domains including pain, dyspnoea, psychiatric problems and gastrointestinal problems. Earlier research has reported that there is a relationship between pain management knowledge and years of nursing experience.²⁴ However, no significant relationship was found between the knowledge score and the length of nursing experience. These results suggest that education is necessary for nurses with less experience caring for terminal cancer patients even if the total nursing experience was long.

As for another associated factor, greater participation in seminars was only associated with scores for

'philosophy', 'pain' and 'dyspnoea'. In Japan, the contents of the curriculum for palliative care tend to focus on pain control; for example, there is certification for nurses who specialise in cancer pain management.²⁵ In the future, the curriculum should expand to include other areas such as psychiatric and gastrointestinal problems.

Furthermore, the existence of a mentor for palliative care issues was associated with scores for pain and dyspnoea. Earlier research has shown that the existence of a mentor decreased the difficulty that the nurses experienced.²⁶ Moreover, the palliative care team provides support for health care professionals and has been reported to positively affect patient symptoms, discharge planning and staff support.^{27,28} Therefore, the presence of a specialist and facilitator for consultation about palliative care is

Table 4. Factors related to nurses' knowledge according to univariate analyses ($n=773$)

	Domains of the palliative care knowledge test					
	Philosophy	Pain	Dyspnoea	Psychiatric problems	Gastrointestinal problems	Total
Sex						
Male	1.1	2.2	1.2	1.4	1.6	7.4
Female	1.4	2.4	1.5	1.2	1.7	8.1
Age, year						
≤29	1.4	2***	1.4	1.1*	1.5***	7.4***
30–39	1.4	2.9	1.6	1.4	1.9	9.1
40–49	1.4	2.9	1.6	1.5	2	9.4
50–59	1.5	3	1.3	1.2	2.1	9.2
>60	1	2	0	1	0	4
	$r=0.01$	$r=0.22$	$r=0.07$	$r=0.09$	$r=0.14$	$r=0.17$
Clinical area						
Surgical	1.3*	2.2***	1.2***	1.2***	1.5***	7.5***
Internal medicine	1.4	2.9	1.9	1.4	1.9	9.4
Palliative care unit	1.7	5	3.3	2.7	3.5	16.2
Others	1.4	2	1.2	1	1.5	7.1
Status						
Manager	1.5	3.5***	1.9	2***	2.4**	11.3***
Sub-manager	1.3	3.5	1.5	1.8	2.3	10.3
Staff	1.4	2.3	1.4	1.2	1.6	7.9
Duration of clinical experience, year						
≤4	1.4	1.8***	1.2***	0.9***	1.3***	6.5***
5–9	1.4	2.6	1.6	1.4	1.9	8.8
10–14	1.3	2.8	1.6	1.4	1.9	9
15–19	1.3	3.5	1.7	1.6	2.1	10.1
≥20	1.5	2.9	1.5	1.4	2.1	9.4
	$r=0.01$	$r=0.26$	$r=0.14$	$r=0.18$	$r=0.22$	$r=0.24$
Experience of working in hospice or palliative care unit, year						
None	1.4***	2.2***	1.3***	1.1***	1.6***	7.5***
≤4	1.7	4.8	3	2.5	3.3	15.3
5–9	2	6	4	4	3	19
	$r=0.1$	$r=0.39$	$r=0.44$	$r=0.33$	$r=0.37$	$r=0.47$
Number of terminal cancer patients who have been cared for						
None	1.4	1.2***	0.8***	0.6***	1***	4.9***
1–9	1.3	1.7	1.2	1	1.3	6.5
10–49	1.4	2.7	1.6	1.3	1.9	8.9
50–99	1.4	3.3	1.9	1.5	2.1	10.2
≥100	1.6	4.2	2.4	2.3	2.9	13.3
	$r=0.07$	$r=0.52$	$r=0.46$	$r=0.4$	$r=0.45$	$r=0.55$
Number of terminal cancer patients who were cared for in the past year						
None	1.3*	1.6***	1***	0.9***	1.3***	6.1***
1–9	1.4	2.3	1.5	1.2	1.6	8
10–49	1.3	3.3	2	1.6	2.2	10.4
50–99	1.5	4.4	2.6	2.2	2.6	13.4
≥100	1.9	5.2	2.9	2.5	3.5	15.4
	$r=0.09$	$r=0.48$	$r=0.46$	$r=0.34$	$r=0.39$	$r=0.51$

(continued)

Table 4. Continued

	Domains of the palliative care knowledge test					
	Philosophy	Pain	Dyspnoea	Psychiatric problems	Gastrointestinal problems	Total
Education						
Nursing school	1.3	2.4	1.5	1.3	1.7*	8.2
Junior college	1.4	2.4	1.6	1.3	1.7	8.4
University or higher	1.5	2	1.3	1	1.3	7.1
Other	1.2	2.2	1.2	1	1.8	7.3
Palliative care education as undergraduate, h						
None	1.4	2.8***	1.7***	1.4***	1.9***	9.2***
≤1	1.1	2.7	1.6	1.5	1.8	8.6
2-5	1.4	2.2	1.5	1.2	1.7	8
>5	1.4	2.1	1.2	1.1	1.5	7.2
	$r=0.05$	$r=-0.18$	$r=-0.17$	$r=-0.12$	$r=-0.14$	$r=-0.17$
Palliative care education as postgraduate, h						
None	1.3***	1.7***	1.1***	0.9***	1.3***	6.1***
≤1	1.3	2.1	1.3	1.2	1.4	7.4
2-5	1.4	2.8	1.8	1.5	2.1	9.5
>5	1.7	4.1	2.2	2	2.6	12.4
	$r=0.14$	$r=0.49$	$r=0.38$	$r=0.37$	$r=0.42$	$r=0.52$
Participation in palliative care seminars						
None	1.3***	1.9***	1.2***	1***	1.4***	6.8***
1	1.5	2.9	1.9	1.7	2.1	10
2-5	1.6	3.7	2.1	1.8	2.5	11.8
>5	1.7	4.7	2.8	2.3	3	14.4
	$r=0.17$	$r=0.45$	$r=0.41$	$r=0.34$	$r=0.38$	$r=0.5$
Existence of a mentor for palliative care issues						
Present	1.4	2.8***	1.7***	1.4***	1.9***	9.1***
Absent	1.3	1.7	1.2	1	1.4	6.6

Numbers in the table represent means or correlation coefficients.

* $P < 0.05$; ** $P < 0.01$; *** $P < 0.001$.

necessary for nurses who care for terminally ill cancer patients.

This study has several limitations. The tool developed by this research aimed at evaluating not only nurses but also physicians. Although physicians were included in the design of the questionnaire, the subjects of this survey were only nurses. To provide a more generalised test, this instrument needs to be evaluated psychometrically with other types of health care providers, including physicians, and in other cultures. Furthermore, we aimed to develop a PCKT with a wider range, but we had a specific focus within palliative care and were not able to cover other areas such as communication, care during the dying phase and family care and bereavement because we wanted to limit the length of the questionnaire. In other words, we sacrificed breadth for usability. Also, subjects were only recruited from two facilities in Japan. Therefore, this

sample is not sufficiently representative for relevant factors to be generalised.

Conclusion

This study used psychometric methods to validate an instrument for evaluating palliative care knowledge, and reliability and validity were determined. This instrument was constructed from five domains including 'philosophy', 'pain', 'dyspnoea', 'psychiatric problems' and 'gastrointestinal problems'. Therefore, research on palliative care knowledge of general physicians and nurses and the evaluation of educational programmes can be assessed using this test.

The number of terminal care patients the nurse had ever cared for was associated with the highest score. It is important to educate nurses who have had only limited experience with terminal cancer patients.

Table 5. Factors related to nurses' knowledge according to multiple regression analysis (n = 715)

	Domains of the palliative care knowledge test					
	Philosophy	Pain	Dyspnoea	Psychiatric problems	Gastrointestinal problems	Total
Sex (one, male; two, female)	0.06	-0.03	0	-0.07***	-0.01	-0.02
Clinical area						
Surgical ^a						
Internal medicine	-0.01	0.11***	0.18***	0.06	0.07*	0.12***
Palliative care unit	0.05	0.1*	0.21***	0.13*	0.15**	0.17***
Other	-0.04	0.03	-0.01	0.02	0.05	0.02
Status	0.03	0	-0.02	0.07	0.02	0.02
Years of clinical experience	-0.01	0.07	-0.06	-0.02	0.01	0.01
Experience of working in hospice or palliative care unit	0.01	0.07	0.11*	0.08	0.09	0.1*
Number of terminal care patients ever cared for	-0.07	0.12*	0.17***	0.16**	0.16**	0.16***
Number of terminal cancer patients cared for in the past year	0.01	0.15**	0.06	0.02	0.06	0.1*
Education	0.04	0	0.01	0.02	0.01	0.02
Hours of palliative care education as undergraduate	0.07	-0.04	-0.08*	-0.04	-0.03	-0.04
Hours of palliative care education as postgraduate	0.08	0.18***	0.06	0.14**	0.16***	0.18***
Participation frequency in palliative care seminars	0.16**	0.13***	0.14***	0.08	0.08	0.16***
Existence of a mentor for palliative care issues	0	0.1***	0.08**	0.04	0.01	0.07*
R ²	0.05	0.42	0.39	0.24	0.3	0.5
Adjusted R ²	0.04	0.41	0.38	0.23	0.29	0.49

R², coefficient of determination.

Numbers in the table represent standardised partial regression coefficients.

*p < 0.05; **p < 0.01; ***p < 0.001.

^aReference category.

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Appendix I. Potential 40 items of the PCKT and psychometric properties of each item (n = 773)

		Correct answer (%)	κ-coefficient (n = 148)	IRT	
				Difficulty	Discrimination
Philosophy					
Palliative care should only be provided for patients who have no curative treatments available ^a .	F	73	0.39	-1.95	0.53
Palliative care should not be provided along with anti-cancer treatments ^a .	F	64	0.67	-1.33	0.48
What is important for quality of life varies among individuals.	T	97	— ^b	-2.91	1.49
The patient provided palliative care must accept death.	F	65	0.55	-1.18	0.59
Pain					
When a patient with cancer has pain, opioids should be started first.	F	78	0.37	-1.36	1.11
One of the goals of pain management is to get a good night's sleep ^a .	T	62	0.26	-0.63	0.98
When cancer pain is mild, pentazocine should be used more often than an opioid ^a .	F	42	0.49	0.29	1.24
When opioids are taken on a regular basis, non-steroidal anti-inflammatory drugs should not be used ^a .	F	40	0.68	0.28	2.24
Regular use of an analgesic drug is effective for management of cancer pain.	T	68	0.32	-0.61	1.90
The effect of opioids should decrease when pentazocine or buprenorphine hydrochloride is used together after opioids are used ^a .	T	34	0.74	0.59	1.45
Some antidepressant and anticonvulsant medications help relieve cancer pain.	T	45	0.64	0.12	1.93
Even if breakthrough pain occurs when opioids are taken on a regular basis, the next dose should not be given earlier than scheduled.	F	76	0.39	-0.90	2.05
Long-term use of opioids can often induce addiction ^a .	F	34	0.70	0.51	1.79
Use of laxatives is effective for preventing opioid-induced constipation.	T	82	0.33	-1.16	2.02
Increase in opioid dosage should be limited because respiratory depression can occur as a side effect.	F	65	0.47	-0.50	1.86
Use of opioids does not influence survival time.	T	25	0.72	1.01	1.40
Dyspnea					
Morphine should be used to relieve dyspnea in cancer patients ^a .	T	44	0.70	0.22	1.42
When opioids are taken on a regular basis, respiratory depression will be common ^a .	F	12	0.58	1.66	1.63
Oxygen saturation levels are correlated with dyspnea ^a .	F	74	0.43	-1.10	1.19
Evaluation of dyspnea should be based on subjective report of patients.	T	33	0.56	0.73	1.17
Anti-cholinergic drugs or scopolamine hydrobromide are effective for alleviating bronchial secretions of dying patients ^a .	T	17	0.67	1.23	1.79
The only effective way to alleviate bronchial secretions in dying patients is by suctioning.	F	61	0.46	-0.54	1.06

(continued)

Appendix 1. Continued

		Correct answer (%)	κ -coefficient (n = 148)	IRT	
				Difficulty	Discrimination
Psychiatric problems					
During the last days of life, drowsiness associated with electrolyte imbalance should decrease patient discomfort ^a .	T	19	0.55	1.44	1.18
Benzodiazepines should be effective for controlling delirium ^a .	T	25	0.42	1.23	1.03
Some dying patients will require continuous sedation to alleviate suffering ^a .	T	38	0.50	0.57	0.92
Morphine is often a cause of delirium in terminally ill cancer patients ^a .	F	40	0.41	0.29	1.98
Delirium occurs frequently in patients who are prone to mental symptoms.	F	72	0.29	-1.19	0.94
Gastrointestinal problems					
A gastric tube must be inserted to relieve symptoms caused by digestive tract obstruction.	F	48	0.44	0.04	1.24
At terminal stages of cancer, higher caloric intake is needed compared to early stages ^a .	F	38	0.53	0.45	1.35
A decrease in oral intake associated with cancer can only be treated with infusion.	F	64	0.28	-0.63	1.17
Even if oral intake is not possible because of digestive tract obstruction, total parenteral nutrition often improves quality of life if performance status is good.	T	54	0.37	-0.26	0.82
There is no route except central venous for patients unable to maintain a peripheral intravenous route ^a .	F	55	0.49	-0.26	0.97
When patients receive an infusion of 1000 mL or more per day, pleural effusion and ascites tend to worsen.	T	46	0.52	0.17	0.89
Steroids should improve appetite among patients with advanced cancer ^a .	T	35	0.72	0.41	2.34
When patients with ileus use metoclopramide, stomach ache and vomiting may worsen.	T	29	0.43	1.02	1.02
Intravenous infusion will not be effective for alleviating dry mouth in dying patients ^a .	T	40	0.39	0.55	0.77
Communication					
More than 90% of Japanese want full disclosure of bad news including estimated prognosis.	F	41	0.42	0.63	0.59
Communication skill can be learned.	T	65	0.31	-0.97	0.72
Information that patients and families request and the degree to which patients and families take part in decision making may change according to the course of the illness and the condition.	T	84	0.39	-1.72	1.17
Uncertain information should not be given to patient or family because it may cause additional anxiety.	F	27	0.33	3.15	0.32

IRT, item response theory; T, correct answer is 'right'; F, correct answer is 'wrong'.

The analysis was based on participants who responded to 90% or more of the 40 items.

^aThe 20 items that were chosen as PCKT.

^bKappa coefficient was impossible to calculate because the first test sample had all correct answers.

Other modalities of care

Adjuvant analgesics: A wide range of adjuvant analgesics is available. Expensive agents such as pregabalin are available only after trials of less expensive options.

Radiotherapy: There is a great appreciation of the role of radiotherapy in cancer pain treatment. Patients generally have rapid access to high-quality services.

Invasive techniques: Israel has a very well-developed network of clinicians with expertise in invasive techniques. Radiofrequency with guided imaging is widely available. The application of approaches involving spinal infusions is limited by the availability of home care services skilled in the ongoing management of patients with spinal infusion devices.

Psychological services: In some centres, excellent psychological services are developed to assist in the care of patients with pain.

Patients with difficult pain problems

Reference centres with a high level of expertise exist in all regions of the country. Patients may be referred for expert evaluation and, if need be, inpatient stabilization.

In cases of truly refractory pain in patients at the end of life, there are no regulatory barriers to the use of palliative sedation. Hospitals and home care services are encouraged to develop procedural guidelines and some have already done so.

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Cancer pain – progress and ongoing issues in Japan

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Cancer has been a leading cause of death in Japan since 1981, accounting for 30.4% of total deaths in 2006 (1). A systematic approach for treatment of cancer pain and development of a health care system for specialized palliative care services has been progressing rapidly since 1990. The Cancer Control Act was established in 2006 to promote cancer prevention and early detection, disseminate quality palliative care, and promote cancer research (2).

Palliative care units (PCUs) provide care for 6% of all cancer deaths, whereas palliative care teams (PCTs) have been providing inpatient consultation services since 2002 in general wards, in which 91% of cancer deaths occur (3). Formerly, only patients in the terminal stage of cancer were approved for admission to PCUs; however, the criteria were revised in 2007 to include all patients with a cancer diagnosis with a considerable level of suffering. This was based on a nationwide survey, in which one-half of patients and families reported that referral to a PCU occurred too late. Eighty-five per cent of patients experienced distressing symptoms before admission to a PCU (4,5). Currently, all 353 regional cancer centres are obliged to establish PCTs, and

further administrative data will be reported within the next several years (6). PCTs typically consist of physicians, nurses certified in oncology, palliative care or pain, psychiatrists, medical or radiation oncologists, anesthesiologists and pharmacists; social workers are not mandatory. The first-year audit of PCTs in one of the acute care hospitals revealed marked effectiveness in management of severe pain within one week of intervention. The most common interventions implemented were nonsteroidal anti-inflammatory drugs, opioid agonists, corticosteroids and antiemetics. A small number of patients underwent nerve blocks performed by anesthesiologists (7).

There have been a number of specialized certificate courses for comprehensive nursing care, including oncology, palliative care and pain management; however, no established and accredited residency or fellowship training programs in palliative care are available yet. Undergraduate educational programs vary throughout the 80 medical schools.

CHARACTERISTIC FEATURES IN CANCER PAIN MANAGEMENT IN JAPAN

Strategic approach in cancer pain management – clinical practice guidelines

The approach for cancer pain control has been one of the priorities throughout the development of palliative care. A survey conducted in major cancer centres in 1986 revealed that only 38% of pain was controlled, which marginally improved to 57% in 1998 (8,9). Evidence-based guidelines for cancer pain management were established as a part of the Japanese Palliative Medicine project in 1999, which were further tested on 314 consecutive cancer patients admitted to 37 national hospitals. The postguidelines implementation group showed significantly more achievement of freedom from pain in two weeks compared with the preguidelines treatment group (14.7% versus 8.8%). Significantly fewer adverse reactions, especially constipation and drowsiness, were found in the postguidelines group (10). The guidelines are currently under revision to include new evidence and new pharmacological options, and will appear at the end of 2010.

Availability of opioids

As of March 2009, Japan limits the availability of types of opioid agonists in cancer pain control to morphine, fentanyl, codeine, dihydrocodone and oxycodone (which only became available in 2005). Hydromorphone and methadone (which may be advantageous due to its higher analgesic potency, especially in patients requiring higher doses of opioid agonists) are not available. Although opioid consumption per capita has been increasing dramatically since the 1990s, the average consumption per capita has not reached the world average. In 2006, compared with Canada, mean morphine consumption per capita was 3.5 mg versus 65 mg; mean oxycodone consumption per capita was 1.9 mg versus 115 mg. Canadian figures include opioid agonists prescribed for noncancer pain (11).

The role of neural blocks and adjuvant analgesics in difficult pain syndromes

A multicentre audit survey was performed and a total of 162 interventions in 136 consecutive patients (3.8% of all patients) were examined to clarify the frequency of neural blockade in certified PCUs and PCTs, determine the efficacy of

interventions, and explore the predictors of successful and unsuccessful intervention. A significantly higher frequency of neural blocks occurred when the leading physician's speciality was anesthesiology. Pain intensity and opioid consumption were significantly lower in the neural block group within one week of the procedures. No improvement was seen in the Communication Capacity Scale, occurrence of delirium or performance status. Epidural nerve block, neurolytic sympathetic nerve block and intrathecal nerve block with phenol were the three most common procedures (12). Active participation of anesthesiologists in palliative care and relatively limited availability of types of opioid agonists may have contributed to the relatively high frequency of neural blocks and use of adjuvant analgesics. An example of the latter is the use of ketamine for difficult pain syndromes – such as neuropathic pain, incident pain or rapidly developing opioid tolerance – that fail to respond to available opioid agonists.

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Cancer pain – progress and ongoing issues in New Zealand

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The health care system of New Zealand is predominantly a National Health Care system, funded by the government, with some elements of private health care. Total health care spending is 9.3% of the gross domestic product, of which the state funds 78%. The average life expectancy is 79.9 years (Organisation for Economic Co-operation and Development statistical data). Despite being a small country, it has significant diversity in the health care environment, with a geographical mix of metropolitan and rural areas, and is multiethnic, particularly in the metropolitan areas. New Zealand has a national Palliative Care Strategy, first released in 2001, that has clear goals of providing services for all people who are dying and could benefit from palliative care. It has nine strategies that it will implement over a five- to 10-year period to achieve this (1). These include education of health care professionals, as well as raising community awareness of palliative care services. New Zealand also has a Cancer Control Strategy, which has a Palliative Care Working Party subgroup.

In New Zealand, cancer pain in advanced cancer is mainly managed by palliative care services in hospitals and hospices. Hospital palliative care teams are dependent on general practice and hospices to continue care and review pain and symptoms at home. Hospices are community organizations, mainly based on the St Christopher's Hospice model (London, United Kingdom). St Christopher's Hospice was founded by Dame Cicely Saunders, who first described the concept of total pain, which is comprised of physical, psychological, social and spiritual dimensions (2). Despite the clear direction from the Crown, through both the Maori Health Strategy and the Palliative Care Strategy (1,3), the challenge remains to deliver a service that reflects the demography and actual needs of local communities. In Auckland, this is reflected in the variable uptake of hospice services by different ethnic groups.

TABLE 1
Referrals to Mercy Hospice Auckland and ethnic mix of Auckland District Health Board (DHB) and New Zealand populations

	Hospice referral, %	Auckland DHB, %	New Zealand, %
European	74	66	80
Maori	4	8	15
Pacific peoples	9	13	7
Asian peoples	8	19	7
Other nations	3	2	0.5

Hospice services (and therefore specialist pain services) are not adequately reaching three major population groups, namely the Maori, Pacific and Asian peoples. Of these, the former two have attitudes and cultural expectations aligned to the traditional hospice model (holistic care, family focus, spiritual practice and desire to be cared for at home) whereas the Asian people have expectations of increasing intensity of care, often in an institutional setting. Attitudes toward use of opioids as analgesics vary among ethnic and cultural groups. Opioids tend to be less acceptable in traditional cultures, with

Care for Imminently Dying Cancer Patients: Family Members' Experiences and Recommendations

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ABSTRACT

Purpose

The aim of this study was to clarify the level of emotional distress experienced by bereaved family members and the perceived necessity for improvement in the care for imminently dying patients and to explore possible causes of distress and alleviating measures.

Methods

A cross-sectional nationwide survey was performed in 2007 of bereaved families of cancer patients at 95 palliative care units across Japan.

Results

Questionnaires were sent to 670 families, and 76% responded. Families reported their experiences as very distressing in 45% of cases. Regarding care, 1.2% of respondents believed that a lot of improvement was needed, compared with 58% who believed no improvement was needed. Determinants of high-level distress were a younger patient age, being a spouse, and overhearing conversations between the medical staff outside the room at the time of the patient's death; those reporting high-level necessity of improvement were less likely to have encountered attempts to ensure the patient's comfort, received less family coaching on how to care for the patient, and felt that insufficient time was allowed for the family to grieve after the patient's death.

Conclusion

A considerable number of families experienced severe emotional distress when their family member died. Thus, we propose that a desirable care concept for imminently dying cancer patients should include relief of patient suffering, family advisement on how to care for the patient, allowance of enough time for the family to grieve, and ensuring that family members cannot overhear medical staff conversations at the time of the patient's death.

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INTRODUCTION

A fundamental principle of palliative care is the support of patients and their families.¹ Care needs at the time of impending death increase because of the considerable physical and emotional burden on patients and their families.²⁻⁵ Patients and their families have identified comfort and adequate symptom control as essential components of end-of-life care.⁶⁻⁸ Little formal research has been performed to comprehensively define desirable end-of-life care,⁹⁻¹³ although the importance of symptom control has been emphasized.^{3-5,14} There is even less empirical research into the best care for imminently dying cancer patients.

Although many of the patients in the last stages of life are no longer conscious, most bereaved families have identified physician communication in end-of-life care as a major concern.^{7,15,16} Despite

widespread acceptance that communication between patients, families, and clinicians is an important component of high-quality care, few empirical or qualitative studies have examined the key elements of communication when caring for imminently dying cancer patients.^{17,18} Thus, the aims of the present study were to clarify bereaved families' perception of their emotional distress and the need for improvements in the care of imminently dying patients and to explore the factors contributing to their distress.

METHODS

Participants

This study was part of a cross-sectional nationwide survey of bereaved families of cancer patients, namely the Japan Hospice and Palliative Care Evaluation (J-HOPE) study.¹⁹ Details of the J-HOPE study are included in Appendix A (online only).

The inclusion criteria were as follows: the patient had died at a palliative care unit; the patient was ≥ 20 years of age; and the bereaved family member completing the survey was ≥ 20 years of age. The exclusion criteria included an inability to identify the bereaved family member's address, an inability on the part of the family member to respond to a self-administered questionnaire, and a decision that completing the questionnaire would cause serious psychological distress to the respondent, as determined by the primary physician.

The participants in this study comprised 670 bereaved families who had experienced the death of a family member during the period from November 2004 to October 2006 at one of 95 certified palliative care units. The questionnaire was first sent out to family members in June 2007, and again in August 2007 to nonresponding families. For each patient who had died, one family member was asked to complete the questionnaire. The ethical and scientific validity of the present study was approved by an ethics review board from each of the participating institutions.

Questionnaire

Because of the lack of an existing specific measurement tool to evaluate the family experience of the care for imminently dying cancer patients, we developed the questionnaire for this study. First, we adopted the following two primary end points for the study: the family member's level of perceived emotional distress when the patient died and family-perceived need for improvements in the care of imminently dying patients. We measured the level of family-perceived emotional distress when the patient died using a five-point scale. The family-perceived need for improvements in care was evaluated with a four-point scale, similar to a validated instrument used in our previous study.²⁰⁻²³ Details of the questionnaire are described in Appendix B (online only).

Second, families were asked to specify factors that potentially contributed to these primary end points. These factors were conceptualized before the survey and classified into three categories and, with these, a number of subcategories, as follows: family-reported information received (five subcategories), family-reported professional behavior (six subcategories), and family-reported circumstances of death (seven subcategories). Internal consistency of subcategorized factors was confirmed by explanatory factor analysis and calculation of Cronbach's α . Internal consistency was acceptable for all subcategories (Cronbach's $\alpha = .67$ to $.88$). Details of all contributing factors and the internal consistency and reliability of items are included in Appendix B. In addition, as background data, families reported the age and sex of the patient, their relationship to the patient, and the interval from patient death to questionnaire completion.

Chart Review

Primary palliative care physicians recorded patient background information (age, sex, primary tumor site, and admission period).

Statistical Analysis

We first calculated 95% CIs for the primary end points to broadly describe the data. For the purpose of comparisons, respondents to the two questions regarding distress and the need for improvement were divided into two groups, as follows: family members who rated their distress level as "very distressed" (high-level distress) and others (low-level distress); and family members who rated the need for improvement as "much," "considerable," or "some" (defined as a perceived high-level need for improvement) and others (low-level need for improvement). These cutoff points were determined on the basis of the distribution of the actual data to enable division of the entire sample into appropriately sized groups for comparisons. The relationships between the bereaved family member and the patient were represented by dummy variables, setting the spouse as a reference category in all analyses.

Univariate analyses were performed using logistic regression analysis for continuous and dummy variables, and χ^2 tests were used for other categorical variables. Multiple logistic regression analyses were then performed in a forward elimination. All potential predictors that were shown to be significant by univariate analyses were entered into the equation as independent variables, and any variables that achieved $P < .05$ are reported herein. Results of regression analyses are presented as point estimate odds ratios (ORs) with two-sided 95% CIs. All statistical analyses were performed using SPSS version 16.0 (SPSS, Chicago, IL).

RESULTS

Of the 670 questionnaires sent to bereaved family members, 20 were undeliverable because of a wrong address. Of the 650 questionnaires delivered, 492 were completed and returned (response rate = 76%). Of these, 40 family members declined to participate in the study, and 17 responses were excluded as a result of missing data for primary end

Table 1. Demographic and Clinical Characteristics of the Patients and Their Bereaved Family Members

Characteristic	No.	%
Patients		
Total No.	434	
Age, years		
Mean		71
SD		11
Sex		
Male	227	52
Female	207	48
Primary tumor sites		
Lung	118	27
Stomach	52	12
Colon, rectum	51	12
Liver	26	5.9
Bile duct, pancreas	45	10
Esophagus	17	3.7
Breast	24	5.5
Prostate, kidney, bladder	34	7.8
Head and neck	12	2.8
Uterus, ovary	25	5.8
Other	30	6.9
Time from first visit to death, days		
Mean		46
SD		61
Bereaved family members		
Total No.	434	
Age, years		
Mean		59
SD		13
Sex		
Male	150	35
Female	279	64
Relationship to patient		
Spouse	192	44
Child	140	32
In-law	44	10
Sibling	31	7.1
Other	22	5.1
Health status at last admission		
Good	103	24
Fair	220	51
Poor	86	20
Very poor	20	4.6
Availability of person who cared for the patient instead of the respondent		
Yes	312	72
No	118	27
Time from patient death to study, months		
Mean		12
SD		4

NOTE. Some data do not add up to 100% as a result of missing data. Abbreviation: SD, standard deviation.

points. Thus, 434 responses were finally analyzed (effective response rate = 67%). Table 1 lists background information for the patients and their families.

Overall Levels of Family-Reported Distress and Need for Improvement in Care

The degree of family-reported distress was very distressed in 45% of cases (95% CI, 41% to 50%; $n = 197$), distressed in 29% of cases (95% CI, 24% to 33%; $n = 124$), slightly distressed in 18% of cases (95% CI, 15% to 22%; $n = 80$), not so distressed in 6.5% of cases (95% CI, 4.5% to 9.2%; $n = 28$), and not distressed at all in 1.2% of cases (95% CI, 0.5% to 2.7%; $n = 5$). Of the responses received, 1.2% of family members (95% CI, 0.6% to 3.0%; $n = 6$) felt that much improvement was needed in the care of dying patients, 4.4% (95% CI, 2.8% to 6.8%; $n = 19$) felt that considerable improvement was needed, 37% (95% CI, 32% to 41%; $n = 159$) felt that some improvement was needed, and 58% (95% CI, 53% to 62%; $n = 250$) felt that no improvement was needed.

Family-Reported Information Received

More than 80% of respondents received information about the predicted course of the patient's disease; 60% and 76% of respondents received information assuring them that the patient could hear and would die painlessly, respectively. Conversely, one-third of respondents reported that they received warning of a sudden change without detailed information about the course of the patient's disease (Table 2).

Family-Reported Professional Behavior

Although more than 70% of respondents reported that physicians and nurses ensured the patient's comfort, provided advice for the family on how to care for the patient, and treated the patient in the same manner as when the patient was conscious, 10% to 20% of respondents reported rushed explanations about the patient's death, a burdening of the family with needless restrictions because of the possibility of a sudden change in the patient's condition, and discussions with the medical staff about what should not be heard by the patient in the patient's room (Table 3).

Information	No. of Respondents Informed	%
Ensuring painlessness		
The eyes remaining open is not an indication of pain	131	30
A sound when breathing is not an indication of pain	128	30
Jaw movement when breathing is not an indication of pain	156	36
Predicted course		
Estimates of life expectancy	379	87
Possibility of sudden death	378	87
Individual differences in the predicted medical condition	380	88
Assurance that the patient can hear	328	76
Assurance that the patient will die painlessly	262	60
Warning of sudden change without detailed information about the course of patient's disease	156	36

Behavior	Applicable and Partly Applicable	
	No. of Respondents	%
Ensuring the patient's comfort		
Maintaining a comfortable environment (eg, temperature and brightness)	409	94
Keeping the patient in a comfortable position	415	96
Maintaining the patient's appearance (eg, clothing, hair, and mouth)	404	93
Examining whether the patient is in pain	411	95
Coaching the family on how to care for the patient		
Advice on how to behave with the patient	371	85
Ensuring that the family is actually helpful for the patient	392	90
Discussing who wants to be present at the patient's death and when the family should call them	341	79
Arrangement of an opportunity to reminisce	325	75
No coaching on what to do with or how to talk to the patient*	160	37
Treating the patient in the same manner as when the patient was conscious	393	91
Giving rushed explanations about the patient's death	60	14
Burdening the family with needless restrictions because of the possibility of a sudden change in the patient's condition		
Burdening the family with needless restrictions because of the possibility of a sudden change in the patient's condition	55	13
Discussing with the medical staff what should not be heard by the patient in the patient's room	53	12

*This behavior was inverted.

Family-Reported Circumstances of Death

More than 70% of respondents reported sufficient consideration of patients' postdeath care, allowance of sufficient time for the family to grieve, confirmation of the patient's death after all family members had arrived, and sharing of words of encouragement with the family. Conversely, less than 10% of families reported that they were not allowed to be close to the patient at the time of death and that they could overhear conversations between the medical staff outside the patient's room at the time of death (Table 4).

Determinants of Family-Perceived Emotional Distress and Need for Improvement in Care: Univariate Analyses

Compared with family members who reported low-level distress, the factors contributing to high levels of distress in family members were a younger patient age ($P < .001$), the overhearing of conversations between the medical staff outside the room at the time of the patient's death ($P = .008$), reduced likelihood of perceiving treatment of the patient to be in the same manner as when the patient was conscious ($P = .019$), a poor health status of the bereaved family member at the time of patient admission ($P = .025$), and the relationship between the bereaved family member and patient ($P = .044$). Of all the reported relationships, there were significant differences between spouses, children, in-laws, and siblings.

In contrast with family members suggesting a low-level need for improvement in care, factors contributing to family members reporting a high-level need for improved care included a lower likelihood of being informed that the patient could hear ($P < .001$), not being

Care for Imminently Dying Cancer Patients

Table 4. Family-Reported Circumstances of Death

Circumstance	Applicable and Partly Applicable	
	No. of Respondents	%
Allowing the family to be close to the patient		
Not able to be close to the patient as a result of medical equipment or the absence of a place to sit	28	6.5
Not able to be close to the patient because of the presence of the medical staff near the patient	15	3.5
Giving sufficient consideration to the patient's postdeath care		
Makeup and clothes to make the patient appear his or her usual self	384	88
Treating the deceased with respect while being cleaned	366	84
Overhearing conversations between the medical staff outside the room at the time of the patient's death	17	3.9
Performing the desired religious ritual	122	28
Sharing words of encouragement with the family	340	78
Confirming the patient's death only after all family members have arrived	302	70
Allowing enough time for the family to grieve	360	83

assured that the patient would die painlessly ($P < .001$), not ensuring the patient's comfort ($P < .001$), not being coached on how to care for the patient ($P < .001$), not treating the patient in the same manner as when the patient was conscious ($P < .001$), receiving rushed explanations about the patient's death ($P < .001$), not seeing consideration given to the patient's postdeath care ($P < .001$), not receiving words of encouragement ($P < .001$), not allowing enough time for the family to grieve ($P < .001$), not receiving information about the patient's predicted course ($P = .003$), not waiting for all family members to arrive before confirming the patient's death ($P = .035$), a poor health status

of the bereaved family member at the time of patient admission ($P = .009$), not allowing the family to stay close to the patient ($P = .023$), and a younger patient age ($P = .049$; Tables 5 and 6).

Multivariate Analyses

Multiple logistic regression analyses revealed that the independent determinants of high-level distress were patient age and overhearing conversations between the medical staff outside the room at the time of the patient's death. Of the relationships between the bereaved family member and the patient, a spouse was most likely to

Table 5. Determinants of Family-Reported Emotional Distress and Perceived Need for Improved Care According to Demographic Characteristics

Variable	Emotional Distress Level					Necessity of Improvement										
	Univariate Analyses					Univariate Analyses										
	High Distress		Low Distress		P	Multivariate Analysis*			High Necessity		Low Necessity		Multivariate Analysis†			
	No. of Respondents (n = 197)	%	No. of Respondents (n = 237)	%		Odds Ratio	95% CI	P	No. of Respondents (n = 184)	%	No. of Respondents (n = 250)	%	P	Odds Ratio	95% CI	P
Patient age, years					< .001	0.96	0.94 to 0.98	0.001								.049
Mean	68		74						70		72					
SD	11		11						11		11					
Bereaved family																
Age, years					.87											.86
Mean	59		59						59		59					
SD	13		12						13		12					
Relationship to patient					.044											.34
Spouse	110	56	82	35	Reference	Reference			90	49	102	41	Reference			
Child	50	26	90	38	< .001	0.53	0.32 to 0.89	0.016	59	32	81	32	.94			
In-law	13	6.5	31	13	.001	0.40	0.18 to 0.89	0.025	16	8.7	28	11	.39			
Sibling	11	5.5	20	8.4	.027	0.28	0.11 to 0.71	0.007	10	5.4	21	8.4	.23			
Other	10	5.1	12	5.1	.29	0.64	0.24 to 1.72	0.38	7	3.8	15	6.0	.30			
Health status at the last admission					.025											.009
Good	34	17	69	29					29	16	74	30				
Fair	108	55	112	47					104	57	116	46				
Poor	40	20	46	19					39	21	47	19				
Very poor	12	6.1	8	3.4					20	11	10	4.0				

NOTE. Some data do not add up to 100% as a result of missing data.
Abbreviation: SD, standard deviation.
* $R^2 = 0.16$.
† $R^2 = 0.24$.

Table 6. Determinants of Family-Reported Emotional Distress and Perceived Need for Improved Care According to Family-Reported Experiences

Family-Reported Experience	Emotional Distress Level									Necessity of Improvement								
	Univariate Analyses						Multivariate Analysis*			Univariate Analyses						Multivariate Analysis†		
	High (n = 197)		Low (n = 237)		P	High (n = 184)				Low (n = 250)		P	High (n = 184)		Low (n = 250)			
	Mean Score	SD	Mean Score	SD		Mean Score	SD	Mean Score	SD	Mean Score	SD		Mean Score	SD	Odds Ratio	95% CI	P	
Received information																		
Ensuring painlessness‡	4.0	1.3	4.1	1.3	.2						3.8	1.2	4.3	1.4	.001			
Predicted course‡	5.6	0.9	5.8	0.6	.054						5.5	0.9	5.8	0.6	.003			
Ensuring that the patient can hear§	0.7	0.4	0.8	0.4	.065						0.7	0.5	0.9	0.4	< .001			
Ensuring that the patient will die peacefully	0.6	0.5	0.7	0.5	.27						0.5	0.5	0.7	0.4	< .001			
Warning of sudden change without detailed information about the course of patient's disease§	0.4	0.5	0.4	0.5	.12						0.5	0.5	0.3	0.5	.015			
Professional behavior																		
Ensuring the patient's comfort¶	10.6	1.9	11.9	1.5	.34						10.0	1.9	11.4	1.2	< .001	0.72	0.59 to 0.88	.001
Coaching the family on how to care for the patient¶	11.9	2.6	12.3	2.1	.054						11.0	2.3	12.9	2.1	< .001	0.84	0.73 to 0.97	.019
Treating the patient in the same manner as when the patient was conscious¶	2.6	0.6	2.8	0.5	.019						1.3	0.5	1.1	0.4	< .001			
Giving rushed explanations about the patient's death¶	1.2	0.5	1.2	0.5	.53						1.3	0.5	1.1	0.4	< .001			
Burdening the family with needless restrictions because of the possibility of a sudden change in the patient's condition¶	1.2	0.5	1.2	0.5	.97						1.3	0.6	1.1	0.5	.053			
Discussing with the medical staff what should not be heard by the patient in the patient's room¶	1.2	0.5	1.2	0.5	.98						1.2	0.5	1.2	0.5	.076			
Circumstances of death																		
Allowing the family to be close to the patient¶	2.2	0.6	2.1	0.3	.18						2.2	0.6	2.1	0.4	.023			
Giving sufficient consideration to the patient's postdeath care¶	5.4	1.1	5.5	0.9	.14						5.2	1.1	5.6	0.9	< .001			
Overhearing conversations between the medical staff outside the room at the time of the patient's death¶	1.1	0.4	1.0	0.1	.008	3.90	1.50 to 10.2	.005			1.1	0.3	1.0	0.2	0.059			
Performing desired religious rituals¶	1.6	0.8	1.6	0.9	.95						1.6	0.9	1.6	0.9	.93			
Sharing words of encouragement with the family¶	2.4	0.8	2.5	0.7	.53						2.3	0.8	2.6	0.7	< .001			
Confirming the patient's death after all family members have arrived¶	2.3	0.9	2.3	0.9	.98						2.2	0.9	2.4	0.8	.035			
Allowing enough time for the family to grieve¶	2.6	0.7	2.6	0.7	.75						2.4	0.8	2.7	0.6	< .001	0.67	0.46 to 0.98	.039

Abbreviation: SD, standard deviation.

* $R^2 = 0.16$.† $R^2 = 0.24$.

‡Sum of factors included (1 = informed; 0 = not informed).

§Score: 1 = informed; 0 = not informed.

¶Sum of factors included (1 = not applicable; 2 = partly applicable; 3 = applicable).

||Score: 1 = not applicable; 2 = partly applicable; 3 = applicable.

experience high-level distress at the time of patient death. Independent determinants of a perceived high need for improved care were reduced perception of measures ensuring the patient's comfort, lack of family coaching on how to care for the patient, and insufficient allowance of time for the family to grieve (Tables 5 and 6).

DISCUSSION

This study had two major findings associated with the level of distress experienced by families of terminally ill patients and their perceived need for improvements in care; these were relief of suffering and communication with patients and their families. This study identified

professional behavior to ensure a patient's comfort as a strong determinant of the perceived need for improved care, with increasing levels of professional behavior being associated with reductions in perceived need for improvements. Additionally, and similarly, receiving confirmation from professional health care staff that the patient was not in any pain and would die painlessly was identified as a significant factor in reducing a family's perceived need for improvements in care. Relief of suffering has been identified as a key component of comprehensive palliative care.^{3,17,24-26} The present study reconfirms that the management of pain and other forms of physical distress is a top priority.

This study highlighted the importance of physician communication in the care of imminently dying patients. In the present

study, the communication between medical staff and the patients and their families can be classified into the following three components: coaching of the family on how to care for the patient; allowing the family enough time to grieve; and ensuring that family members cannot overhear conversations between the medical staff outside the room at the time of the patient's death.

Receiving advice on how to care for the patient was an independent determinant of the need for improvements in patient care. Multiple empirical studies have found that the families of terminally ill patients are afraid of how to manage care at the time of death^{13,27,28} and require advice as to how best to provide care.^{14,15} The provision of this sort of advice by medical professionals can facilitate a new relationship between the family and the dying patient, whose condition is changing rapidly.⁶ Thus, medical professionals need to provide information to and support the family so that they may provide appropriate care for the patient.

Allowing enough time for the family to grieve after the death of the patient was also an independent determinant of the perceived need for improvements in care. In addition, the present study found that allowing the family to be close to the patient, providing words of encouragement, and waiting to confirm a patient's death until all family members had arrived were factors significantly correlated with the level of perceived need for improvements in care at the time of the patient's death. Some families require notification of a patient's impending death to prepare for that death and to call other family members who may wish to be present.²⁹ If death occurs suddenly when the family is not present, the family members may experience guilt, anger, or regret.⁶ According to the findings of the present study, allowing enough time for the family to grieve after a patient has died, allowing the family to be close to the patient, providing words of encouragement to the family, and waiting to confirm a patient's death until all family members have arrived are important aspects contributing to desirable end-of-life care.

In the present study, overhearing conversations between the medical staff outside the room at the time of the patient's death was significantly correlated with the distress level reported by the bereaved family member. Furthermore, assuring family members that the patient can hear and giving due consideration to the patient's postdeath care were negatively correlated with the perceived need for improved care. Our interpretation of these findings is that medical professionals should behave as if the patient is conscious. When patients become nonverbal or unresponsive, many family members grieve the loss of verbal communication. Traditionally, palliative care experts have stressed that patients continue to hear and feel and that a family's loving words and touch may comfort the dying patient, encouraging a continuing relationship.⁶ This study supports the notion that assuring the family that the patient can hear is a possible mode of care that can empower family members psychologically in the face of a patient's death.

In addition, receiving information regarding the patient's predicted course was significantly negatively correlated with the perceived need for improved care. This indicates that medical professionals should provide adequate information to the family about the predicted dying process. Several studies have stressed the importance of advising family members about the common signs that indicate that death is imminent (eg, deterioration in consciousness, terminal delirium, retained respiratory secretions, audible respirations with mandibular movement, cyanosis of the extremities, and no palpable

pulse).^{6,10,16,27,30} If medical professionals have not provided detailed information about the prognostic signs of dying, the likelihood of having to give sudden warnings about changes in the patient's condition, without detailed information about the course of the patient's disease, and providing rushed explanations about the patient's death may increase, and this was a factor found to contribute to a perceived need for improved care in the present study.

Of note, although the present survey revealed that only 1.2% of bereaved family members reported that much improvement was needed in end-of-life care, 45% of bereaved family members reported that they were very distressed at the time of the patient's death. These results might indicate that despite the severe distress experienced by family members after a patient's death, the end-of-life care provided in Japanese palliative care units is basically appropriate.

Despite several strengths, including success in obtaining a large sample with a response rate of more than 70%, this study has some limitations. First, because of its retrospective nature, there may be a recall bias. We chose the interval from patient death to questionnaire completion to be within 9 to 26 months (average, 12 months) so that family members would be past the immediate stages of grief, yet the death would not be so distant, thereby minimizing the risk of introducing a recall bias. Similar time periods were used in previous studies.²¹⁻²⁴ Second, because all patients received specialized palliative care, adherence levels to recommended care practice were generally high, and this may result in statistical analyses with low sensitivity. Thus, the findings of the present study cannot be automatically generalized to other situations. Third, the cross-sectional design of the study does not allow for the causality of the associations to be identified. Finally, the measurement instruments for primary outcomes had not received formal testing for reliability or validity. However, we believe that this was not a serious shortcoming of this study because the distress question was easily interpreted, and the structure of the need for improvements question was consistent with a well-validated instrument (the Care Evaluation Scale²⁰; see Appendix B). This research methodology was consistent with previous studies²¹⁻²³; factor validity and internal consistency were ascertained with factor analyses, and acceptable Cronbach's α values were obtained from this data set; and the results that emerged in the current study were clinically interpretable.

In conclusion, we propose that a desirable care concept for imminently dying patients and their families should include relief of suffering, advising the family on how to care for the patient, allowing enough time for the family to grieve, and ensuring that family members cannot overhear conversations between the medical staff outside the room at the time of patient death. Future studies should address the benefits to patients and their families of educational interventions for health care providers.

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

The author(s) indicated no potential conflicts of interest.

AUTHOR CONTRIBUTIONS

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