in each outcome measure between the intervention group and the control group were measured using independent sample t-tests. Proportions in the two groups were compared using Fisher's exact test or Chi-square test. Statistical analysis was conducted using SPSS for Windows version 15 (SPSS Inc., Chicago, IL, USA), with two-tailed statistical tests.

Results

Participant flow, assignment and follow-up

Eighty-seven eligible patients were identified and invited to participate in the study, and 63 consented (72.4%, Figure 2). Non-consent of patients was primarily due to their being too stressed mentally or being severely ill physically. Of the 63 patients [intervention group ($n = 32$); control ($n = 31$)], two (one in each group) had no consultation, one (control group) changed hospitals, and one (intervention

Eligible patients (n=87)

Excluded (n=24)
Refused to participate (n=16)
Not enough time to recruit patients (n=8)

Randomly assigned (n=63)   Participation rate 72.4%

Intervention group (n=32)

No consultation (n=1)
Refused (n=1)

Control group (n=31)

No consultation (n=1)
Changed hospitals (n=1)

Completed the study (n=30)

Completed the study (n=29)

Figure 2. CONSORT diagram

group) withdrew because of mental stress. Thus, a total of 59 patients were analyzed. Strict intention-to-treat analysis was conducted on all randomly assigned 63 patients using all available data from the patients. Dropout, partial absence of data, and failure to use the sheets were included in the analysis as score or number '0'. Patient demographics and clinical characteristics are shown in Table 1. Differences in these variables between groups were not significant.

Approximately 75% of the patients in both groups read their respective material(s) prior to consultation. Forty-four percent of the patients in the intervention group and 23% of the patients in the control group decided on their questions in advance ($p = 0.075$).

Usefulness of the material(s)

The mean usefulness rate (a numerical rating scale of 0 to 10) of the material(s) in helping the patients to ask questions was significantly higher in the intervention group than in the control group (4.4±3.6 and 2.7±2.8, respectively; $p = 0.033$). The mean score of usefulness of the material(s) in helping the patients to understand the treatment plan tended to be higher in the intervention group than in the control group (4.9±3.6 and 3.3±2.8, respectively; $p = 0.051$). The mean score of willingness to use the material(s) in the future was significantly higher in the intervention group than in the control group (5.3±3.8 and 2.8±2.8, respectively; $p = 0.006$; Table 2).

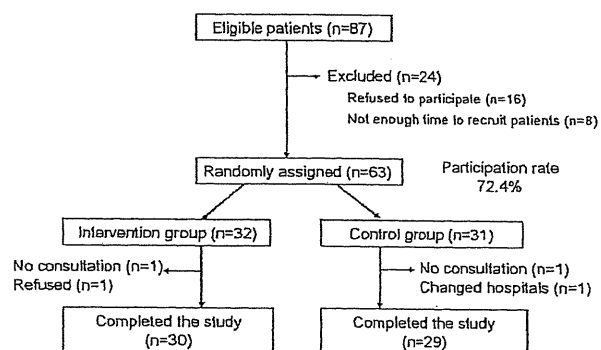For reference, we conducted treatment analysis including only patients who had read the material(s)

Table I. Demographics and clinical characteristics of patients ($n = 63$)

		Intervention ($n = 32$), n (%)	Control ($n = 31$), n (%)	Test result
Age, years	Median (range)	63.5 (52–82)	64.0 (28–82)	n.s.
Sex	Male	21 (65.6)	21 (67.7)	n.s.
Type of cancer	Lung	20 (62.5)	19 (61.3)	n.s.
	Gastric	4 (12.5)	3 (9.7)	
	Colorectal	3 (9.4)	4 (12.9)	
	Esophageal	5 (15.6)	5 (16.1)	
Stage	II (Esophageal cancer)	2 (6.3)	0 (0.0)	n.s.
	III	10 (31.3)	11 (35.5)	
	IV	19 (59.4)	18 (58.1)	
	Relapse	1 (3.1)	2 (6.5)	
Treatment	Chemotherapy	23 (71.9)	13 (41.9)	n.s.
	Chemotherapy+radiation	5 (15.6)	12 (38.7)	
	Other	4 (12.5)	6 (19.4)	
Use of the materials[a]				
Read the material(s) prior to the consultation		24 (75.0)	23 (74.2)	n.s.
Decided questions in advance		14 (43.8)	7 (22.6)	n.s.
Wrote down questions in advance		2 (6.3)	0 (0.0)	n.s.
Looked at the material(s) during the consultation		1 (3.1)	0 (0.0)	n.s.
Checked physician's explanation with the material(s)		1 (3.1)	0 (0.0)	n.s.
Asked questions included in the material(s)		6 (18.8)	1 (3.2)	n.s.

Proportions in the two groups were compared using Fisher's exact test or χ^2 test. Numerical scale was compared using the t-test.
[a]Based on intention-to-treat analysis, four drop outs (intervention ($n = 2$); control group ($n = 2$)) were included in the analysis as 'nonuser'.

prior to consultation. The mean usefulness rate of the material(s) in helping the patients to ask questions was significantly higher in the intervention group than in the control group (6.4±2.3 and 3.4±2.7, respectively; p<0.001; t=4.011). The mean usefulness of the material(s) in helping the patients to understand the treatment plan was significantly higher in the intervention group than in the control group (6.5±2.4 and 4.3±2.5, respectively; p=0.002; t=3.215). The mean score of willingness to use the material(s) in the future was significantly higher in the intervention group than in the control group (7.0±2.6 and 3.5±2.7, respectively; p<0.001; t=4.594).

Satisfaction with the consultation

The levels of satisfaction with (1) the ability of the physician to answer the patients' questions, (2) asking questions, (3) understanding the condition of the disease, and (4) comprehending the treatment plan, as well as the overall level of satisfaction with the consultation were high in both groups, although not significantly different (Table 3).

Number and contents of the questions

We determined the estimated number of patient questions from patients' interview. Sixty-three percent of the patients in the intervention group and 71% of the patients in the control group asked question(s) during the consultation (no significant difference). Patients in both groups asked a median of 1.0 question (interquartile range, 2.0) (no significant difference). The majority of questions were related to information about treatment. The analysis

of the number of questions asked in each question category by the two groups showed no significant difference in any category.

Discussion

To our knowledge, this is the first study of evaluation of a QPS for advanced cancer patients deciding on their initial treatment. In addition, this is the first QPS study in Asia. Nearly half of the patients in the intervention group prepared questions prior to consultation (23% of the patients in the control group; no significant difference). We found that, compared with supplying the HIS only, advanced cancer patients who received both the HIS and the QPS rated the materials significantly more favorably with regards to the materials usefulness in helping them to ask questions of the physician and for future consultations. The results show similar findings to the previous study [8].

Unexpectedly, the use of the QPS did not seem to promote question-asking behavior. The total number of questions asked by the patients in the intervention group (median: 1.0) in the current study was, surprisingly, smaller than that in the intervention group in previous studies of patients seeing an oncologist for the first time (mean/median: 8.5–14.0) [6,8,15], although nearly half of the patients in the intervention group had decided on their questions in advance. Although we could not reliably compare the number of questions asked in the present study with that in previous studies (we did not audiotape the consultation as in previous studies), it appears that the patients in the current study asked fewer questions than those in the previous studies.

Table 2. Mean scores of usefulness of the material(s) (n = 63)

	Intervention (n = 32) Mean (SD)	Control (n = 31) Mean (SD)	p-Value
Usefulness of the material(s) in helping to ask questions	4.4 (3.6)	2.7 (2.8)	0.033
Usefulness of the material(s) in helping to understand the treatment plan	4.9 (3.6)	3.3 (2.8)	0.051
Willingness to use the material(s) in the future	5.3 (3.8)	2.8 (2.8)	0.006

SD, standard deviation. All items were rated on a 0–10 scale (e.g. 0 = completely disagree, 10 = completely agree). Scores in the two groups were compared using the t-test. Based on intention-to-treat analysis, four dropouts (intervention (n = 2); control group (n = 2)), 10 nonusers of the materials (intervention (n = 6); control group (n = 4)) and four partially missing (intervention (n = 2); control group (n = 2)) were included in the analysis as score '0'.

Table 3. Mean scores according to satisfaction with the consultation (n = 63)

	Intervention (n = 32) Mean (SD)	Control (n = 31) Mean (SD)	p-Value
Satisfaction with the ability of the physician to answer the patients' questions	8.1 (3.0)	8.2 (2.8)	0.893
Satisfaction with asking questions	6.8 (2.9)	7.8 (2.5)	0.177
Satisfaction with understanding the condition of the disease	8.0 (2.6)	8.2 (2.7)	0.810
Satisfaction with comprehending the treatment plan	8.1 (2.5)	7.8 (2.8)	0.665
Overall level of satisfaction with the consultation	7.9 (2.6)	7.8 (2.8)	0.847

SD, standard deviation. All items were rated on a 0–10 scale (e.g. 0 = completely disagree, 10 = completely agree). Scores in the two groups were compared using the t-test. Based on intention-to-treat analysis, four dropouts (intervention (n = 2); control group (n = 2)) were included in the analysis as score '0'.

We assume that one of the reasons behind the fewer questions in the current study was that the unique patient–physician relationship in Asian culture. The views in Asian countries on individuality and personal rights are distinctively different from those in North America and Western countries [16,17]. Watanabe et al. reported that Japanese cancer patients who felt that they were compelled to make a decision even though they had no sufficient information or understanding of their medical condition and treatment options were dissatisfied with the decision-making process [18]. Nomura et al. described the dominant category of patient–physician relationship in Japan as follows: 'the relationship between a Japanese physician and a patient is clearly asymmetrical, since the patient seeks help and care from a medical expert whose diagnostic evaluations have to be accepted by the patient without discussion' [19].

In Taiwan, the common practice of nondisclosure of prognosis and detailed disease-related information by healthcare professionals continues, although there is a need to disclose information on the medical condition of Taiwanese cancer patients [20]. Patient–physician relationships in Asian countries have traditionally been based on a paternalistic and hierarchical culture that discourages patients from questioning doctors. For this reason, cancer patients in Asian countries might need more intervention to make them feel comfortable to ask questions of their physicians. In the current study, we did not ask the physicians to refer to or endorse the QPS, however, considering the interactive nature of communication, a combination of QPS and active endorsement of QPS by physicians and/or communication skills training for physicians might be needed to promote question-asking behavior. Indeed, results from some previous studies suggest that physician endorsement of a QPS seems to enhance its effectiveness [3,7].

Overall ratings for the usefulness of the written materials were rather low. One possible reason is that a strict intention-to-treat analysis was conducted. The other possible reason is that we assigned a value of 0 for ratings of the usefulness of the written materials when they were not read by the participants. The rating of the QPS for those who read the materials were higher (range: 6.4–7.0).

In the current study, QPS was perceived by the patients as useful for helping them to ask relevant questions of their physician and for future use without an increase in the number of questions during the consultation. There are several possible explanations for this. First, Bruera et al. described that communication may be better when patients are able to ask their most meaningful questions rather than just more questions [8]. In the current study, patients in the intervention group might be able to consider the information they need to know in advance from QPS and thereby ask questions that better address their main concerns rather than

simply asking more questions. Second, QPS might be helpful in collecting and organizing information. Rainbird et al. reported that advanced cancer patients have high levels of unmet needs, particularly in the areas of psychological and medical communication/information [21,22]. Teno et al. reported that more than one-third of advanced cancer patients wanted more information about their test results at the time of diagnosis [23]. These previous studies indicate that advanced cancer patients experience difficulty in obtaining sufficient information during consultation. QPS may prove useful for advanced cancer patients in collecting and organizing information related to their medical condition. Finally, during the interview, some patients emphasized their expectations for the future use of QPS, since they had decided not to ask any questions in the first consultation because they believed that they must first listen to the physician's explanation.

The level of satisfaction with the consultation was very high and there was no significant difference between the intervention group and the control group. Brown et al. reported that cancer patients rated their levels of satisfaction with the consultation extremely highly, even though their expectations were not met at the stated level desired [24]. Previous QPS studies also reported that the level of satisfaction showed a poor correlation with the number or duration of questions asked [14,15]. It might be difficult to evaluate the effect of QPS based on patients' satisfaction levels with the consultation. Of note, although not a significant difference, the intervention group rated their satisfaction with asking questions (mean score of 6.8) less favourably than those in the control group (mean score of 7.8). Perhaps, the QPS raised patients' expectations for being able to ask questions, and if the QPS was not endorsed or referred to by the physician then this caused the patient to be less satisfied with this aspect of the consultation.

Our study has several limitations. First, we could not get the required sample size because of dropout and research period restriction. Insufficient statistical power might lead underestimation. Second, we performed the study in only one cancer center and focused mainly on the first consultation. Thus, we cannot apply the present results to other settings and situations. The impact of the use of QPS over time and in other settings needs to be further examined in the future. Third, we did not audiotape the consultations and therefore were unable to analyze the consultations in detail. In some cases (intervention group ($n = 14$); control group ($n = 8$)), we timed the consultation length. For reference, the average consultation length showed no significant difference between the groups (31.1 ± 14.0 and 26.0 ± 12.2, respectively; $p = 0.398$; $t = 0.864$). In addition, we interviewed patients and determined the estimated number of

patient questions and the contents of questions, however, there is no evidence that patients' recall is accurate.

In conclusion, for those advanced cancer patients who read the QPS it seemed to be a moderately useful tool. Compared with controls, patients rated the QPS more favourably in terms of enabling them to ask relevant questions and for future use. The QPS seemed to help patients to prepare questions and it may help patients to articulate and organize their information needs. However, the QPS did not seem to directly promote patient confidence to ask questions. In Asian countries, active endorsement of QPS by physicians and/or communication skills training for physicians might be effective for promoting question-asking behavior. In the future, research would be needed to examine the impact of the use of QPS over time and in other settings.

Acknowledgements

Appendix A

Question Prompt Sheet is given in Table A1.

Table A1. Question prompt sheet

Diagnosis	1	What is the diagnosis?
	2	What is the stage of my cancer?
Condition of a disease	3	What is wrong with me?
	4	Where is my cancer located?
	5	Which test showed that?
Symptom	6	What symptoms will the cancer cause?
	7	What kind of treatments for the symptoms do you have?
Test	8	Do I need any more tests before my treatment?
	9	If so, does it hurt?
	10	What do the tests show?
Treatment	11	What treatment options are available for me?
	12	What are my options aside from anticancer drugs?
	13	What is the best case scenario? What is the worst case scenario? What is the most likely case scenario? How about survival length and quality of life?
	14	What complications, short/long side effects and sequelae does each treatment have?
	15	What is your recommendation regarding the best treatment for me?
	16	Which treatment do other patients with the same condition as mine choose?
	17	What is involved in administering the treatment, for example, contents, timing, frequency, duration, schedule, location, costs of treatments?
	18	What is the purpose of the treatment?
	19	What physical limitations will I have during the treatment?
	20	What are the common side effects of the treatment?
	21	Does the treatment cause pain?
	22	What can be done about the side effects?
	23	When will I know whether the treatment is working?
	24	How will I know whether the treatment is working?
	25	What are my next options if the treatment fails?
	26	What costs will I incur throughout my treatment?
	27	What is the percentage of success of this treatment for the other patients?
	28	Can I get my treatment at my local doctor's office?
	29	If I am taking alternative medicine, can I still continue?
	30	Can I take folk medicine or complementary and alternative medicine during treatment?
Life	13	Will the treatment affect my ability to work or perform other activities?
	32	Is there anything I have to do before and during my treatment?
	33	Is there anything I should not do during my treatment, for example, diet, exercise, housekeeping, sexual life, childbirth?
	34	Is it OK for me to do... during the treatment?
	35	Is it OK for me to eat/ drink... during the treatment?
	36	Is it OK for me to go...during the treatment?
	37	Is there anything that I should prepare before my treatment?
	38	What symptoms should I be alert for?
	39	What should I do when some symptoms occur?
Family	40	Will my family be affected by my cancer/ treatment?
	41	Will my family members have higher risk of getting cancer?
	42	Who can my family members talk to if they they have concern and worry?

Table A1. (Continued)

Psychological issues	43	Can I talk about my concern and worry?
	44	How can I cope with sleeplessness caused by anxiety and depressed feeling?
	45	Can you give me any advice on how to cope with the disease?
	46	Is there someone I can talk to about my feeling?
Prognosis	47	How long am I likely to live? The reason why I want to know is...
	48	Is there any chance for cure?
	49	What can I expect in the future?
Other issues	50	What causes cancer?
	51	How much time do I have to think about this? Do you need my decision today?
	52	There are some changes about... (in my life, physical aspect, mental aspect) after the previous consultation.
	53	The things that I hope to take precedence or continue doing in my life are...

References

1. Street Jr RL, Voigt B, Geyer Jr C et al. Increasing patient involvement in choosing treatment for early breast cancer. *Cancer* 1995;76:2275–2285.
2. O'Cathain A, Thomas KJ. Evaluating decision aids—where next? *Health Expect* 2004;7:98–103.
3. Brown RF, Butow PN, Dunn SM et al. Promoting patient participation and shortening cancer consultations: a randomised trial. *Br J Cancer* 2001;85:1273–1279.
4. Parker PA, Davison BJ, Tishelman C et al. What do we know about facilitating patient communication in the cancer care setting? *Psycho-Oncology* 2005;14:848–858; discussion 859–860.
5. Tattersall MH, Butow PN. Consultation audio tapes: an underused cancer patient information aid and clinical research tool. *Lancet Oncol* 2002;3:431–437.
6. Butow P, Devine R, Boyer M et al. Cancer consultation preparation package: changing patients but not physicians is not enough. *J Clin Oncol* 2004;22:4401–4409.
7. Clayton JM, Butow PN, Tattersall MH et al. Randomized controlled trial of a prompt list to help advanced cancer patients and their caregivers to ask questions about prognosis and end-of-life care. *J Clin Oncol* 2007;25:715–723.
8. Bruera E, Sweeney C, Willey J et al. Breast cancer patient perception of the helpfulness of a prompt sheet versus a general information sheet during outpatient consultation: a randomized, controlled trial. *J Pain Symptom Manage* 2003;25:412–419.
9. Dimoska A, Tattersall MH, Butow PN et al. Can a 'prompt list' empower cancer patients to ask relevant questions? *Cancer* 2008;113:225–237.
10. Gattellari M, Voigt KJ, Butow PN et al. When the treatment goal is not cure: are cancer patients equipped to make informed decisions? *J Clin Oncol* 2002;20:503–513.
11. Tattersall MH, Thomas H. Recent advances: oncology. *Br Med J* 1999;318:445–448.
12. Fujimori M, Akechi T, Akizuki N et al. Good communication with patients receiving bad news about cancer in Japan. *Psycho-Oncology* 2005;14:1043–1051.

13. Fujimori M, Akechi T, Morita T et al. Preferences of cancer patients regarding the disclosure of bad news. *Psycho-Oncology* 2007;16:573–581.
14. Butow PN, Dunn SM, Tattersall MH et al. Patient participation in the cancer consultation: evaluation of a question prompt sheet. *Ann Oncol* 1994;5:199–204.
15. Brown R, Butow PN, Boyer MJ et al. Promoting patient participation in the cancer consultation: evaluation of a prompt sheet and coaching in question-asking. *Br J Cancer* 1999;80:242–248.
16. Blackhall LJ, Murphy ST, Frank G et al. Ethnicity and attitudes toward patient autonomy. *J Am Med Assoc* 1995;274:820–825.
17. Mitchell JL. Cross-cultural issues in the disclosure of cancer. *Cancer Pract* 1998;6:153–160.
18. Watanabe Y, Takahashi M, Kai I. Japanese cancer patient participation in and satisfaction with treatment-related decision-making: a qualitative study. *BMC Public Health* 2008;8:77.
19. Nomura K, Ohno M, Fujinuma Y et al. Patient autonomy preferences among hypertensive outpatients in a primary care setting in Japan. *Intern Med* 2007;46:1403–1408.
20. Tang ST, Lee SY. Cancer diagnosis and prognosis in Taiwan: patient preferences versus experiences. *Psycho-Oncology* 2004;13:1–13.
21. Rainbird KJ, Perkins JJ, Sanson-Fisher RW. The Needs Assessment for Advanced Cancer Patients (NA-ACP): a measure of the perceived needs of patients with advanced, incurable cancer. A study of validity, reliability and acceptability. *Psycho-Oncology* 2005;14:297–306.
22. Rainbird K J, Perkins J J, Sanson-Fisher R W et al. The needs of patients with advanced, incurable cancer. *Br J Cancer* 2009;101:759–764.
23. Teno JM, Lima JC, Lyons KD. Cancer patient assessment and reports of excellence: reliability and validity of advanced cancer patient perceptions of the quality of care. *J Clin Oncol* 2009;27:1621–1626.
24. Brown RF, Hill C, Burant CJ et al. Satisfaction of early breast cancer patients with discussions during initial oncology consultations with a medical oncologist. *Psycho-Oncology* 2009;18:42–49.

The Palliative Care Self-Reported Practices Scale and the Palliative Care Difficulties Scale: Reliability and Validity of Two Scales Evaluating Self-Reported Practices and Difficulties Experienced in Palliative Care by Health Professionals

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Abstract

Background: The development of palliative care educational programs is ongoing in Japan. To assess the effectiveness of educational programs for general nurses, it is necessary to develop scales for evaluating them.

Aims: The aims of this study were to develop two scales to measure the effectiveness of palliative care educational programs and confirm the validity and reliability of the scales.

Methods: A questionnaire survey was validated with a group of 940 nurses at two facilities. The response rate was 85% ($n = 797$). This study used psychometric methods such as factor analysis and intra-class correlation coefficients.

Main results: We selected 18 items in 6 domains, including "dying-phase care," "patient- and family-centered care," "pain," "delirium," "dyspnea," and "communication" for the Palliative Care Self-reported Practices Scale (PCPS). For this scale, the intra-class correlation was 0.64 to 0.74 in each domain. For the Palliative Care Difficulties Scale (PDCS), we selected 15 items in 5 domains, including "communication in multidisciplinary teams," "communication with the patient and family," "expert support," "alleviation of symptoms," and "community coordination." For the PCDS, the intraclass correlation was 0.61 to 0.69 in each domain.

Conclusions: The validity and reliability of these scales were established. Therefore, the clarification of actual practices used and difficulties experienced will be possible using these scales.

Introduction

PALLIATIVE CARE is an essential part of cancer care.[1] However, the lack of knowledge and skills in palliative care among health professionals is one of the most common barriers to quality care. Therefore, it is necessary to educate health professionals in palliative care.[2–5]

To date, studies of palliative care educational programs in foreign countries have shown that knowledge and skills can be improved.[6–9] The dissemination of palliative care for cancer patients is a national policy in Japan. Currently, the Outreach Palliative Care Trial of Integrated Regional Model (OPTIM) study, a nationwide demonstration project, is being conducted in order to improve palliative care throughout Japan.[10]

In order to deliver quality educational programs, it is necessary to conduct evaluations to determine whether an educational program is effective. Such evaluations can assess individual achievement, clarify the effectiveness of the program and provide information on whether the program

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should be continued. Therefore, a valid instrument is needed. One evaluation indicator for an educational program is knowledge. Other indicators of program quality are change in self-reported practices, attitudes and difficulties.[11–19] We considered that knowledge, practices, and difficulties with palliative care are interlinked; therefore, an assessment of palliative care would need to include a knowledge test, a self-reported practices scale, and a difficulties scale. In a previous manuscript, we reported on the Palliative Care Knowledge Test (PCKT) for health professionals.[20]

Published studies have generally focused on attitudes toward terminal care; however, practices in broader areas of palliative care have rarely been investigated.[9,19,21,22] Furthermore, we found little information on the psychometric properties of the measures used. The most frequent measurement for evaluating attitudes about palliative care among nurses is the Frommelt Attitude Toward Care of the Dying (FATCOD) scale.[23] The validity and reliability of this instrument have been confirmed. However, there are some limitations in the assessment of the FATCOD. Some reports have addressed the difficulties nurses experience when providing palliative care[11,14,24]; however, the scales used in these reports also had some limits. Consequently, we felt that the development of new instruments would be useful for the following reasons: (1) As many studies have shown that terminal patients experience a variety of symptoms,[25–27] we wanted to evaluate a wider range of practices, including care for patients with delirium and dyspnea, which often arise in end-stage cancer patients. (2) We wanted to develop instruments that are not limited to terminal care and are more in accord with the recent declaration by the World Health Organization (WHO) that palliative care is applicable even early in the course of illness.[1] (3) We wanted to evaluate the difficulties with community coordination for palliative care that were an aim of the OPTIM study. (4) We wanted to develop instruments to evaluate not only nurses but also other health professionals who participate in educational programs. (5) We wanted to briefly and easily evaluate practices and difficulties with palliative care.

The aims of this study were twofold: (1) to develop and validate the PCPS and the PCDS and (2) to identify factors associated with self-reported practices and difficulties with palliative care in order to improve the curricula of palliative care educational interventions.

Methods

Design

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

Sample

The survey was conducted in August 2007 in 2 hospitals. The subjects were 940 nurses from a university hospital (661 beds) and a general hospital (634 beds) located in Yokohama

TABLE 1. CHARACTERISTICS OF PARTICIPANTS (N = 773)

	n	%
Gender		
Male	30	4
Female	740	96
Age, y		
≤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
Submanager	21	3
Staff	722	93
Duration of clinical experience, y		
≤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, y		
None	705	91
1–4	55	7
5–9	1	0
≥10	0	
Number of terminal cancer patients ever 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/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.

TABLE 2. ITEM ANALYSIS AND FACTOR ANALYSIS OF THE PALLIATIVE CARE SELF-REPORTED PRACTICES SCALE $N = 739$

	Mean	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5	Factor 6	Communalities
		Standard regression coefficient						
Dying-phase care								
I routinely inquire about the family's concerns in the dying phase.	3.0	**0.92**	0.04	0.00	−0.02	0.00	0.01	0.87
I evaluate physical discomfort regularly in the dying phase.	2.9	**0.80**	−0.01	0.06	0.02	0.00	0.04	0.76
I evaluate the appropriateness of care given in the dying phase (e.g., positioning, suctioning, physical restriction, blood tests, measurement of urine, infusions).	2.9	**0.69**	−0.02	0.00	0.10	0.04	0.05	0.65
Patient- and family-centered care								
I try to find out what is important to the patient and family.	3.8	0.04	**0.92**	−0.02	0.04	0.02	−0.04	0.87
I try to understand the wishes of the patient and family.	3.9	0.02	**0.90**	0.05	0.04	−0.06	−0.01	0.84
I try to understand the suffering of the patient and family.	4.0	−0.06	**0.60**	0.05	−0.10	0.11	0.24	0.65
Pain								
I evaluate the effectiveness of rescue doses.	4.0	0.00	−0.01	**0.93**	0.03	−0.09	0.08	0.88
I understand the situation of the patient experiencing pain.	3.7	0.05	0.05	**0.81**	0.04	0.10	−0.06	0.85
To evaluate pain, I ask the patient directly regarding pain intensity or use the pain intensity scale when the patient cannot reply.	3.9	0.00	0.10	**0.56**	−0.02	0.26	0.01	0.68
Delirium								
I help patient's orientation with clock and calendar to prevent and improve delirium.	2.7	0.01	−0.02	0.02	**0.82**	0.04	−0.02	0.72
I evaluate discomfort from deteriorating delirium (e.g., urination, defecation, pain, anxiety).	2.9	0.08	0.00	0.03	**0.71**	0.04	0.07	0.73
I inquire about the family's concerns about delirium.	2.7	0.33	0.08	0.01	**0.48**	−0.02	−0.01	0.59
Dyspnea								
To evaluate dyspnea, I ask the patient directly about dyspnea intensity or use the dyspnea scale when the patient cannot reply.	3.5	−0.04	0.01	0.07	0.04	**0.79**	0.03	0.76
I understand the situation of the patient experiencing dyspnea.	3.5	0.14	−0.01	0.26	0.01	**0.62**	−0.02	0.79
I help the patient become comfortable to alleviate dyspnea.	3.7	0.02	0.10	0.02	0.12	**0.53**	0.20	0.73
Communication								
I confirm understanding of conditions by eliciting questions from the patient and family.	3.4	0.10	0.05	0.06	0.09	−0.01	**0.68**	0.75
I talk with the patient and family in a quiet and private place.	3.5	0.09	0.08	0.03	−0.04	0.07	**0.58**	0.54
I use open-ended questions for the patient and family.	3.2	0.09	0.10	−0.01	0.09	0.11	**0.43**	0.48

Participants who responded to 90% or more of the 40 items were the subjects of the analysis.

City, Japan. Both facilities had inpatient palliative care units. The inclusion criterion for the subjects was that they were registered nurses. The retest was conducted for 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. For the retest, the questionnaire was distributed

TABLE 3. RELIABILITY OF THE PALLIATIVE CARE
SELF-REPORTED PRACTICES SCALE ($N = 739$)

Domain	Mean	SD	Cronbach α	ICC ($n = 144$)
Dying-phase care	8.8	3.3	0.90	0.71
Patient- and family-centered care	11.8	2.5	0.90	0.69
Pain	11.7	3.2	0.91	0.64
Delirium	8.3	3.0	0.85	0.74
Dyspnea	10.7	3.0	0.89	0.70
Communication	10.2	2.7	0.80	0.64

SD, standard deviation; ICC, intraclass correlation coefficients.

again in each ward. Completed questionnaires were collected in a box placed in the ward.

Procedure

Development of scales. We developed two instruments to quantify self-reported practices and difficulties experienced by general physicians and nurses in providing palliative care. Item generation was based on literature reviews and discussions among nine experts.[9,17,24,28,29] Content areas in the self-reported practices scale included pain, dyspnea, psychiatric problems, communication, and care of patients in the dying phase. Also, content areas for the difficulty scale included alleviating symptoms, expert support, communication, and community coordination. A pool of 141 items about self-reported practices and 121 items about difficulties were generated. To achieve face validity, a multidisciplinary expert panel (3 palliative physicians, 4 certified nurse specialists in oncology and 2 home care nurses) rated the appropriateness of each item. First, experts evaluated the appropriateness of each item (0 = inappropriate, 1 = somewhat inappropriate, 2 = somewhat appropriate, 3 = appropriate). Next, the mean, minimum and maximum were calculated, and items that had a mean of less than 2 and a minimum of 0 were deleted.

Subsequently, we repeated the discussion with the experts to achieve face validity for the item. As a result, a preliminary list of 40 items was selected from each pool of questions.

Questionnaire

1. PCPS: preliminary 40 items.
2. PCDS: preliminary 40 items.
3. Number of patients with terminal cancer cared for before and in the past year,
4. Experience of working at a hospice or palliative care unit,
5. Hours of palliative care education,
6. Existence of a mentor for end-of-life issues,
7. Demographic factors.

We included factors 3 through 6 as potentially related to palliative care practices and difficulties experienced by general nurses. The initial questionnaire was in Japanese.

Definitions

In this study, "patients with terminal cancer" was defined as follows: "patients with cancer who are not likely to respond to treatment and whose life expectancy is less than 6 months." Furthermore, "mentor" was defined as "a person (physician/nurse/family member/friend) with whom a health professional can talk about palliative care."

Statistical analyses

Item selection. Participants who responded to 90% or more of 40 items (each scale) were the subjects of the analysis. First, item analysis was conducted. We considered the percentage of missing data to enhance feasibility (cutoff: missing more than 1% of data) and ceiling effect to enhance sensitivity (cutoffs: more than 90% of responses are 1 or 5 on a 5-point Likert-type scale). Second, to examine the test-retest reliability of each item, the κ coefficients were calculated. We considered the reliability of each item (cutoffs: κ coefficients of 0.3 or less).
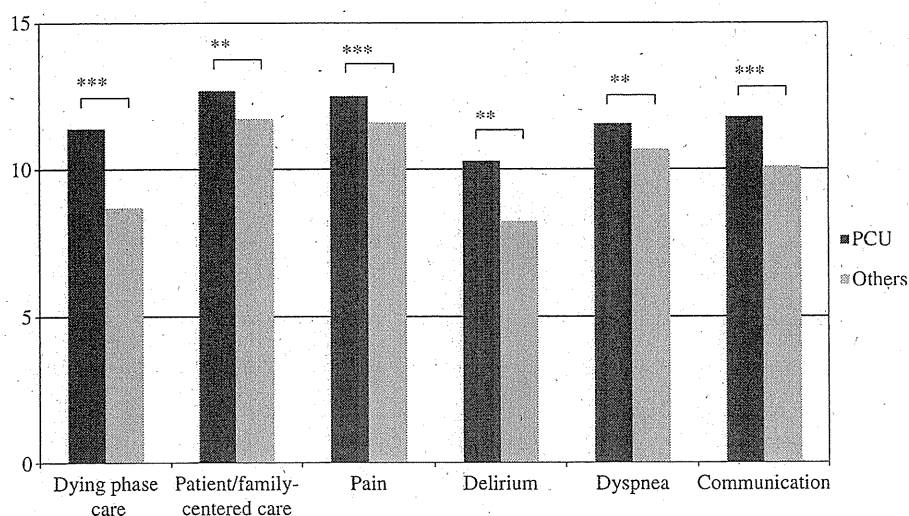

FIG. 1. Known-group validity of the Palliative Care Self-Reported Practices Scale. The t test was used to compare the total scores in each domain for nurses working in palliative care units (PCU) compared to other nurses. $*p < 0.05$; $**p < 0.01$; $***p < 0.001$.

TABLE 4. ITEM ANALYSIS AND FACTOR ANALYSIS OF THE PALLIATIVE CARE DIFFICULTIES SCALE $N = 689$

| | Mean | Standard regression coefficient | | | | | Communalities |
		Factor 1	Factor 2	Factor 3	Factor 4	Factor 5	
Communication in multidisciplinary teams							
The method of evaluating symptoms is not consistent in multiprofessional teams.	3.0	**0.95**	−0.04	−0.01	0.02	0.03	0.91
It is difficult to have a common goal toward alleviating symptoms in multiprofessional teams.	3.1	**0.93**	−0.02	0.00	0.03	−0.02	0.85
It is difficult to communicate about alleviating symptoms in multiprofessional teams.	3.0	**0.80**	0.07	0.03	−0.05	0.03	0.70
Communication with patient and family							
When a patient expresses anxiety, it is difficult to respond.	3.4	0.01	**0.94**	−0.01	−0.02	0.00	0.85
When a family expresses anxiety, it is difficult to respond.	3.5	0.01	**0.90**	0.03	0.01	−0.03	0.83
After a patient is informed of bad news, it is difficult to talk	3.6	−0.01	**0.74**	−0.02	0.13	0.03	0.66
Expert support							
It is difficult to get support from experts about alleviating symptoms.	2.8	0.02	−0.03	**0.99**	0.04	−0.04	0.97
There is no expert whom I can consult with about alleviating symptoms.	2.7	0.02	0.03	**0.93**	−0.01	−0.03	0.86
There are no facilities that can be consulted for alleviating the symptoms of home-care patients.	2.9	−0.03	0.01	**0.63**	−0.02	0.29	0.64
Alleviating symptoms							
There is a lack of knowledge about alleviating cancer pain.	3.8	−0.01	−0.04	−0.01	**0.95**	0.01	0.86
There is a lack of knowledge about alleviating dyspnea and digestive symptoms.	3.6	0.00	0.07	−0.05	**0.87**	0.03	0.82
Necessary training is not received about palliative care.	3.8	0.02	0.07	0.09	**0.67**	−0.05	0.53
Community coordination							
There is no meeting between facilities when the cancer patient moves from hospital to home care.	3.2	−0.02	−0.05	−0.01	0.00	**0.85**	0.68
It is difficult to get information about home care for cancer patients.	3.1	0.05	0.02	0.00	−0.01	**0.80**	0.68
It is difficult to share information between hospital and facilities that provide home care.	3.1	0.03	0.04	0.09	0.01	**0.70**	0.62

Participants who responded to 90% or more of 40 items were the subjects of the analysis.

TABLE 5. RELIABILITY OF THE PALLIATIVE CARE DIFFICULTIES SCALE $(N = 689)$

Domain	Mean	SD	Cronbach α	ICC $(n = 142)$
Communication in multidisciplinary teams	9.1	3.3	0.93	0.63
Communication with the patient and family	10.5	3.0	0.91	0.69
Expert support	8.4	2.8	0.92	0.63
Alleviating symptoms	11.2	3.2	0.87	0.67
Community coordination	9.4	3.2	0.85	0.61

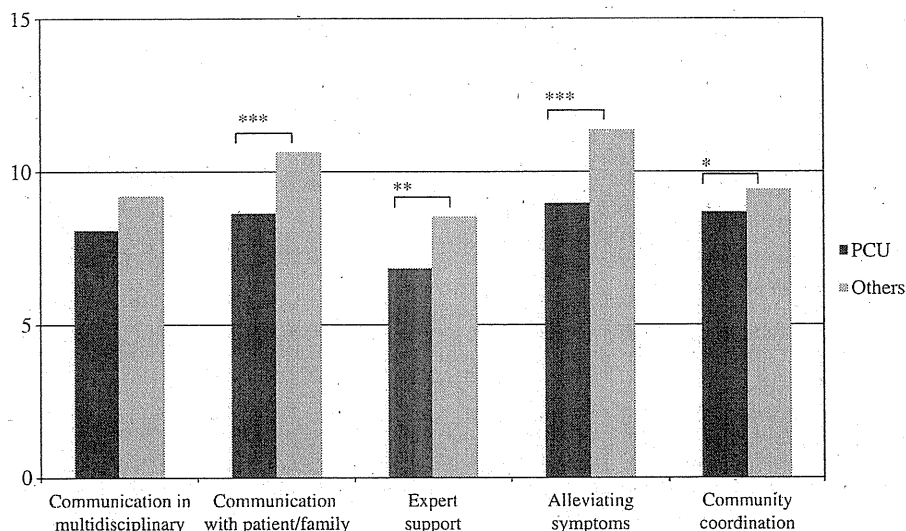SD, standard deviation; ICC, intraclass correlation coefficients.

FIG. 2. Known-group validity of the Palliative Care of Difficulties Scale. The t test was used to compare the total scores in each domain for nurses working in palliative care units (PCU) compared to other nurses. $*p < 0.05$; $**p < 0.01$; $***p < 0.001$.

Then, to achieve content validity, we repeated the discussion with the experts. Based on the results of the analysis, specific items were selected if they seemed to have high sensitivity.

PCPS

We defined self-reported practices as the level of self-reported adherence to recommended clinical practice guidelines in palliative care. Self-reported practices were evaluated using a Likert-type scale from 1 (not at all) to 5 (always). Because we hypothesized that no single higher structure exists for the 5 domains, we defined the score on the PCPS as the total score of the responses in each domain. Thus, practice subscores ranged from 3 to 15, with a higher score indicating a higher level of performance of recommended practices.

PCDS

We conceptualized difficulties about palliative care. These were evaluated by agreement with statements on a Likert-type scale from 1 (never) to 5 (very much). The instructions described situations when health professionals face difficulties providing palliative care. We defined the score on the PCDS as the total score of the responses in each domain, and thus difficulty subscores ranged from 3 to 15. Higher scores indicated a higher level of difficulties providing palliative care.

Reliability and validity

To determine internal consistency, Cronbach α coefficients were calculated. The test–retest reliability was determined by calculating intraclass correlation coefficients with 2-week interval administrations.

The construct validity of each scale was examined using exploratory factor analysis with promax rotation because a single factor structure had been hypothesized. Standard regression coefficients were taken as the minimum of 0.4. To

explore known-group validity, an unpaired t test was done to determine differences between a group of nurses working in palliative care units and a group of nurses working in other units. The total scores of each domain were examined with the unpaired t test.

Related factors

To identify factors associated with palliative care practices and difficulties experienced by general nurses, univariate analyses were conducted using the unpaired t test, analysis of variance (ANOVA), and Pearson product-moment correlation coefficients, where appropriate. Thereafter, the association of each hypothesized factor with the total score of each domain was confirmed using multivariate linear regression. Statistical analysis was performed using SAS version 9.1 (SAS Institute, Cary, NC). The significance level was set at <0.05 (two-tailed).

Results

Of 940 questionnaires delivered to nurses, 797 were returned (response rate, 85%). Of the 797 initial responses, 204 nurses agreed to take the retest and 151 questionnaires were returned (response rate, 74%). The characteristics of the respondents are summarized in Table 1.

Validation study: PCPS

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

Feasibility and ceiling effect

Missing values that indicate feasibility were less than 1.5% for each item. The ceiling effect was not confirmed.

Reliability of each item

The κ coefficient for the test–retest reliability of each item ranged from 0.34 to 0.58.

TABLE 6. FACTORS RELATED TO NURSES' SELF-REPORTED PRACTICES ACCORDING TO UNIVARIATE ANALYSES $N = 773$

	Domains of the Palliative Care Self-Reported Practices Scale					
	Dying-phase care	Patient- and family-centered care	Pain	Delirium	Dyspnea	Communication
Gender						
Male	9.2	11.0	11.8	9.2	11.2	10.5
Female	8.8	11.8	11.7	8.3	10.7	10.2
Clinical area						
Surgical	9.2^c	12.1^c	12.4^c	8.7^c	11.2^b	10.4^c
Internal medicine	9.4	12.0	12.2	8.6	10.8	10.3
Palliative care unit	11.4	12.7	12.5	10.3	11.5	11.8
Others	8.1	11.4	11	7.8	10.4	9.8
Status						
Manager	10.7^b	12.7	11.2	10.1^b	11.4	12.0^b
Submanager	10.1	12	12.1	9.9	11.6	11.3
Staff	8.7	11.7	11.7	8.2	10.7	10.1
Duration of clinical experience, y						
≤4	8.0^c	11.4^b	11.2	7.5^c	10.3^b	9.7^c
5–9	9.3	11.9	12.0	8.7	10.9	10.3
10–14	9.4	12.1	12.4	9.2	11.4	10.7
15–19	8.7	11.4	11.3	8.5	10.4	10.5
≥20	10.1	12.7	11.2	9.1	11.4	11.5
	$r = 0.17$	$r = 0.11$	$r = 0.05$	$r = 0.18$	$r = 0.1$	$r = 0.18$
Experience of working in hospice or palliative care unit, y						
None	8.6^c	11.7^b	11.6^a	8.1^c	10.7^a	10.1^c
≤4	11.5	12.6	12.7	10.3	11.7	11.8
5–9	9.0	13	11.0	9.0	10.0	12.0
	$r = 0.23$	$r = 0.1$	$r = 0.08$	$r = 0.19$	$r = 0.08$	$r = 0.18$
Total number of terminal cancer patients cared for						
None	5.7^c	9.9^c	9.0^c	6.2^c	8.8^c	8.4^c
1–9	8.1	11.8	11.6	8.1	10.7	10.1
10–49	9.7	12.0	12.3	8.8	11.1	10.4
50–99	10.4	12.5	12.5	9.1	11.6	11.0
≥100	10.8	12.7	12.8	10.0	11.8	11.6
	$r = 0.46$	$r = 0.29$	$r = 0.31$	$r = 0.33$	$r = 0.27$	$r = 0.31$
Number of terminal cancer patients cared for in the past year						
None	7.2^c	10.9^c	10.4^c	7.4^c	9.9^c	9.3^c
1–9	9.1	12.0	12.1	8.5	11.0	10.4
10–49	10.4	12.5	12.7	9.0	11.4	11.0
50–99	10.4	12.5	12.1	9.5	11.4	11.1
≥100	12.2	12.6	13.2	10.5	12.0	11.9
	$r = 0.39$	$r = 0.24$	$r = 0.25$	$r = 0.25$	$r = 0.19$	$r = 0.27$
Education						
Nursing school	9.1^b	11.9	11.8	8.6^a	11.0^a	10.3
Junior college	8.5	11.4	11.3	8.1	10.3	9.9
University/higher	8.0	11.7	11.3	7.6	10.3	10.0
Other	10.3	12.7	13.2	8.5	10.8	9.8
Undergraduate palliative care education, h						
None	9.3^b	11.8	11.7	8.5	10.8	10.4
≤1	8.9	11.7	11.8	8.3	11.2	10.2
2–5	8.8	11.7	11.7	8.5	10.6	10.1
>5	8.4	11.8	11.6	8.0	10.8	10.1
	$r = -0.11$	$r = -0.01$	$r = 0$	$r = -0.06$	$r = -0.02$	$r = -0.05$
Postgraduate palliative care education, h						
None	7.6^c	11.2^c	11.0^c	7.6^c	10.2^c	9.6^c
≤1	8.6	12.0	12.0	8.3	11.0	10.1
2–5	9.8	12.0	12.1	8.7	11.1	10.7
>5	10.8	12.7	12.7	9.8	11.6	11.3
	$r = 0.37$	$r = 0.21$	$r = 0.2$	$r = 0.27$	$r = 0.18$	$r = 0.26$
Participation in palliative care seminars						
None	8.3^c	11.5^c	11.4^c	8.0^c	10.5^c	9.8^c
1	9.6	12.0	12.4	8.7	11.1	10.7
2–5	10.4	12.6	12.3	9.5	11.3	11.3
>5	11.1	13.1	12.9	10.1	12.0	12.0
	$r = 0.27$	$r = 0.19$	$r = 0.14$	$r = 0.22$	$r = 0.13$	$r = 0.25$
Existence of a mentor for palliative care issues						
Present	9.5^c	12.1^c	12.1^c	8.7^c	11.1^c	10.6^c
Absent	7.8	11.1	11.0	7.7	10.2	9.6

$^a p < 0.05$.
$^b p < 0.01$.
$^c p < 0.001$.
Numbers in the table represent means or correlation coefficients.

Reliability and validity of the PCPS

On the basis of the results of the item analysis and expert discussions, we selected 18 items in 6 domains for the PCPS: (1) dying-phase care, (2) patient- and family-centered care, (3) pain, (4) delirium, (5) dyspnea, and (6) communication. The construct validity is shown in Table 2. The exploratory factor analysis revealed a single structure, which consisted of 6 factors. Table 3 summarizes the internal consistency and test-retest reliability of the PCPS. Cronbach α coefficients were from 0.80 to 0.91 in each domain. The intraclass correlation in the test–retest examination was from 0.64 to 0.74 in each domain. Also, to examine the known-group validity, we compared the scores in each domain for nurses working in palliative care units and other nurses (Fig. 1).

PCDS

The results of the item analysis are shown in Table 4.

Feasibility and ceiling effect

Missing values that indicate feasibility were less than 1.5% in 40 items. The ceiling effect was not confirmed.

Reliability of item

The κ coefficient in the test–retest reliability of each item was from 0.3 to 0.53.

Reliability and validity of the PCDS

On the basis of the results of the item analysis and expert discussions, we selected 15 items in 5 domains for the PCDS: (1) communication in multidisciplinary teams, (2) communication with the patient and family, (3) expert support, (4) alleviation of symptoms and (5) community coordination. The construct validity is shown in Table 4. The exploratory factor analysis revealed a single structure, which consisted of 5 factors. Cronbach α coefficients ranged from 0.85 to 0.93 in each domain. The intraclass correlation in test-retest examination was from 0.61 to 0.69 in each domain (Table 5). Also, the known-group validity was examined in the same way as for the PCPS (Fig. 2).

Related factors

Factors associated with self-reported practices. Univariate analyses of self-reported practices scores identified significant differences for many variables (Table 6). The number of terminal care patients the nurse had ever cared for was associated with a higher score for every domain including "dying-phase care" ($r = 0.46$, $p < 0.001$), "patient- and family-centered care" ($r = 0.29$, $p < 0.001$), "pain" ($r = 0.31$, $p < 0.001$), "delirium" ($r = 0.33$, $p < 0.001$), "dyspnea" ($r = 0.27$, $p < 0.001$) and "communication" ($r = 0.31$, $p < 0.001$). These results were confirmed by multivariate linear regression analysis. Furthermore, the presence of a mentor for palliative care issues was associated with a higher score for every domain. By multivariate linear regression analysis, an association was reported for the presence of a mentor and higher practice level only for "dying-phase care" ($\beta = 0.09$, $p < 0.05$) and "patient- and family-centered care" ($\beta = 0.12$, $p < 0.01$).

Factors associated with difficulties

Univariate analyses of the difficulties score identified a significant difference for many variables (Table 7). The number of terminal care patients the nurse had ever cared for was associated with lower scores for the domains "communication with the patient and family" ($r = -0.27$, $p < 0.001$), "expert support" ($r = -0.09$, $p < 0.05$), and "alleviating symptoms" ($r = -0.31$, $p < 0.001$). Many of the nurses who participated in seminars and who had mentors for palliative care had lower scores for "communication with the patient and family," "expert support," and "alleviating symptoms." Furthermore, results of multivariate linear regression confirmed that clinical experience and terminal patient care experience were associated with a lower score for "alleviating symptoms." Also, multivariable linear regression confirmed the association between frequency of participation in palliative care seminars and lower score for "communication with the patient and family" ($\beta = -0.15$, $p < 0.01$).

Discussion

This study validated two scales that evaluate self-reported practices and difficulties experienced by general nurses in providing palliative care. Both these scales have good internal consistency, test-retest reliability, face validity and construct validity.

They add the following to already existing instruments: (1) they provide the ability to evaluate a wider range of palliative care practices; (2) they can be used not only for terminal care but also for palliative care that is given early in the course of illness; (3) they could be used in research to evaluate health professionals other than general nurses; and (4) the scales are concise and easy to administer.

Consequently, these scales can be used to identify practices and difficulties in providing palliative care, assess problems and evaluate educational programs. Results from the evaluations can help improve the quality of education received by health professionals and ultimately the quality of palliative care received by patients and their families. Moreover, these scales can be used as an objective measure for individuals for determining areas in need of improvement. The PCDS can be used to identify difficulties experienced by nurses and to help them develop strategies.

This study explored the factors related to nurses' practices and difficulties in palliative care. One of the most important findings was that the number of terminal cancer patients the nurse had ever cared for was associated with a higher score in 6 domains of the PCPS. Some research has shown that there is a relationship between positive attitudes toward caring for dying patients and nurses' experiences of caring for dying patients, discussion of hospice with patients and the number of terminal care patients a nurse had ever cared for.[22,28,30] These results are consistent with our findings. The number of terminal cancer patients the nurse had ever cared for was also associated with a lower score in three domains including "communication with the patient and family," "expert support," and "alleviating symptoms" on the PCDS. These results support the view that education is necessary for nurses with less experience who care for patients with terminal cancer.

Furthermore, the existence of a mentor for palliative care was associated with higher scores for every domain on the

TABLE 7. FACTORS RELATED TO NURSES' DIFFICULTIES ACCORDING TO UNIVARIATE ANALYSES $N = 773$

	Domains of the Palliative Care Difficulties Scale				
	Communication in multidisciplinary teams	Communication with patient and family	Expert support	Alleviating symptoms	Community coordination
Gender					
Male	10.2	10.8	8.9	10.7	10.8[b]
Female	9.0	10.5	8.3	11.3	9.3
Clinical area					
Surgical	9.4[b]	10.9[c]	8.5[a]	11.6[c]	9.7
Internal medicine	9.5	10.6	8.0	11.5	9.4
Palliative care unit	8.1	8.6	6.8	9.0	8.5
Others	8.9	10.5	8.6	11.3	9.3
Status					
Manager	8.8	7.5[c]	5.9[b]	9.4[b]	9.2
Submanager	10.0	9.3	6.9	10.2	9.6
Staff	9.0	10.6	8.4	11.3	9.3
Duration of clinical experience, y					
≤4	8.7	11.4[c]	8.6[a]	12.2[c]	9.4
5–9	9.4	10.5	8.4	11.1	9.3
10–4	9.1	9.6	8.3	10.4	9.3
15–19	9.6	9.0	7.5	9.9	9.2
≥20	9.1	9.0	7.2	10.4	9.6
	$r = 0.05$	$r = -0.26$	$r = -0.09$	$r = -0.25$	$r = 0$
Experience of working in hospice or palliative care unit, y					
None	9.1	10.7[c]	8.4[a]	11.5[c]	9.4
≤4	9.1	8.4	7.4	8.8	8.9
5–9	10.0	6.0	7.0	6.0	8.0
	$r = 0.01$	$r = -0.22$	$r = -0.08$	$r = -0.26$	$r = -0.04$
Total number of terminal cancer patients cared for					
None	8.3[a]	10.9[c]	8.4[a]	11.8[c]	8.5
1–9	9.0	11.5	8.7	12.3	9.6
10–49	9.5	10.5	8.4	11.1	9.5
50–99	8.9	9.4	8.0	10.4	9.3
≥100	9.4	8.4	7.2	9.0	9.4
	$r = 0.08$	$r = -0.27$	$r = -0.09$	$r = -0.31$	$r = 0.04$
Number of terminal cancer patients cared for in the past year					
None	8.4[a]	10.7[c]	8.4	11.6[c]	8.8
1–9	9.4	11.0	8.4	11.6	9.7
10–49	9.6	10.0	8.6	10.7	9.4
50–99	8.7	8.4	7.0	9.5	9.0
≥100	8.8	8.1	6.9	8.8	10.0
	$r = 0.09$	$r = -0.19$	$r = -0.06$	$r = -0.21$	$r = 0.07$
Education					
Nursing school	9.2	10.3[a]	8.4	11.1	9.2
Junior college	8.8	10.7	7.9	11.4	9.3
University/higher	8.9	11.1	8.7	11.8	10.0
Other	9.5	12.3	8.3	11.3	11.3
Undergraduate palliative care education, h					
None	9.5[a]	9.8[c]	7.8[b]	10.7[b]	9.5
≤1	9.3	10.1	7.8	11.3	8.5
2–5	9.0	10.8	8.6	11.6	9.5
>5	8.7	10.9	8.7	11.4	9.4
	$r = -0.08$	$r = 0.15$	$r = 0.1$	$r = 0.1$	$r = 0.01$
Postgraduate palliative care education, h					
None	8.7[a]	11.0[c]	8.6[a]	11.8[c]	9.1
≤1	9.4	11.4	8.7	12.2	9.9
2–5	9.1	10.1	8.2	10.9	9.4
>5	9.7	8.9	7.6	9.4	9.5
	$r = 0.09$	$r = -0.25$	$r = -0.09$	$r = -0.3$	$r = 0.04$
Participation in palliative care seminars					
None	9.0	11.0[c]	8.6[c]	11.7[c]	9.4
1	9.2	10.1	8.1	10.9	9.6
2–5	9.2	9.1	7.5	10.2	9.0
>5	10.0	8.0	7.0	8.2	9.2
	$r = 0.05$	$r = -0.28$	$r = -0.14$	$r = -0.28$	$r = -0.03$
Existence of a mentor for palliative care issues					
Present	9.0	10.2[b]	7.8[c]	10.9[c]	9.3
Absent	9.1	11.0	9.0	11.8	9.4

[a]$p < 0.05$.
[b]$p < 0.01$.
[c]$p < 0.001$.
Numbers in the table represent means or correlation coefficients.

practices scale. This factor was also correlated with lower scores in three domains including "communication with the patient and family," "expert support," and "alleviating symptoms" on the difficulties scale. Previous research has shown that the existence of a mentor decreased the difficulty nurses experienced.[24] We believe that results of the present study further emphasize the need for a palliative care team. The palliative care team provides support for health care professionals and has been reported to have a positive impact on the management of patient symptoms, discharge planning and staff support.[31,32] Therefore, the presence of an expert to consult about palliative care, such as a palliative care team or clinical nurse specialist, can help improve care for patients with cancer.

The generalizability of this study and the two instruments is significantly limited by the fact that only nurses were surveyed. The scales developed in this research were also intended for use with health professionals other than nurses who are directly involved with palliative care; however, the subjects of this survey were only nurses, although physicians were included in the design of the questionnaire. Therefore, to provide more generalized scales, these instruments must be evaluated psychometrically with other types of health care providers. Furthermore, subjects were only recruited from two facilities in one country. This sample is not sufficiently representative to allow for the generalization of this study to other populations. Additionally, future research should demonstrate improvement in provider behavior and patient outcomes.

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Author Disclosure Statement

References

1. Palliative Care, Cancer Control: Knowledge into Action: WHO Guide for Effective Programs. World Health Organization, Geneva, Switzerland, 2007.
2. Ahmed N, Bestall JC, Ahmedzai SH, Payne SA, Clark D, Noble B: Systematic review of the problems and issues of accessing specialist palliative care by patients, carers and health and social care professionals. Palliat Med 2004; 18:525–542.
3. Miyashita M, Sanjo M, Morita T, Hirai K, Kizawa Y, Shima Y, Shimoyama N, Tsuneto S, Hiraga K, Sato K, Uchitomi Y: Barriers to providing palliative care and priorities for future actions to advance palliative care in Japan: A nationwide expert opinion survey. J Palliat Med 2007;10:390–399.
4. Proctor M, Grealish L, Coates M, Sears P: Nurses' knowledge of palliative care in the Australian Capital Territory. Int J Palliat Nurs 2000;6:421–428.
5. Sato K, Miyashita M, Morita T, Sanjo M, Shima Y, Uchitomi Y: Quality of end-of-life treatment for cancer patients in general wards and the palliative care unit at a regional cancer center in Japan: A retrospective chart review. Support Care Cancer. 2008;16:113–122.
6. Ferrell BR, Dahlin C, Campbell ML, Paice JA, Malloy P, Virani R: End-of-life Nursing Education Consortium (ELNEC) Training Program: Improving palliative care in critical care. Crit Care Nurs Q 2007;30:206–212.
7. Ferrell BR, Virani R, Grant M, Rhome A, Malloy P, Bednash G, Grimm M: Evaluation of the End-of-Life Nursing Education Consortium undergraduate faculty training program. J Palliat Med 2005;8:107–114.
8. Robinson K, Sutton S, von Gunten CF, Ferris FD, Molodyko N, Martinez J, Emanuel LL: Assessment of the Education for Physicians on End-of-Life Care (EPEC) Project. J Palliat Med 2004;7:637–645.
9. VanGeest JB: Process evaluation of an educational intervention to improve end-of-life care: The Education for Physicians on End-of-Life Care (EPEC) program. Am J Hosp Palliat Care 2001;18:233–238.
10. Yamagishi A, Morita T, Miyashita M, Akizuki N, Kizawa Y, Shirahige Y, Akiyama M, Kei Hirai, Kudo T, Yamaguchi T, Fukushima A, Eguchi K: Palliative care in Japan: current status and a nationwide challenge to improve palliative care by the Cancer Control Act and the Outreach Palliative Care Trial of Integrated Regional Model (OPTIM) study. Am J Hosp Palliat Care 2008;25:412–418.
11. Blomberg K, Sahlberg-Blom E: Closeness and distance: A way of handling difficult situations in daily care. J Clin Nurs. 2007;16:244–254.
12. Bradley EH, Cramer LD, Bogardus ST Jr, Kasl SV, Johnson-Hurzeler R, Horwitz SM: Physicians' ratings of their knowledge, attitudes, and end-of-life-care practices. Acad Med 2002; 77:305–311.
13. Cherny NI, Catane R: Attitudes of medical oncologists toward palliative care for patients with advanced and incurable cancer: Report on a survey by the European Society of Medical Oncology Taskforce on Palliative and Supportive Care. Cancer. 2003;98:2502–2510.
14. Opp G, Dunn V: Frequent and difficult problems perceived by nurses caring for the dying in community, hospice and acute care settings. Palliat Med 1993;7:19–25.
15. de Rond M, de Wit R, van Dam F: The implementation of a Pain Monitoring Programme for nurses in daily clinical practice: Results of a follow-up study in five hospitals. J Adv Nurs. 2001;35:590–598.
16. Kwekkeboom KL, Vahl C, Eland J: Impact of a volunteer companion program on nursing students' knowledge and concerns related to palliative care. J Palliat Med 2006;9: 90–99.
17. Morita T, Fujimoto K, Imura C, Nanba M, Fukumoto N, Itoh T: Self-reported practice, confidence, and knowledge about palliative care of nurses in a Japanese Regional Cancer Center: Longitudinal study after 1-year activity of palliative care team. Am J Hosp Palliat Care 2006;23:385–391.
18. Silverdale N, Katz J: The impact of a distance learning death and dying course: An analysis of student self-reported changes. Nurse Educ Today 2005;25:509–518.
19. Steginga SK, Dunn J, Dewar AM, McCarthy A, Yates P, Beadle G: Impact of an intensive nursing education course on nurses' knowledge, confidence, attitudes, and perceived skills in the care of patients with cancer. Oncol Nurs Forum 2005;32:375–381.
20. Nakazawa Y, Miyashita M, Morita T, Umeda M, Oyagi Y, Ogasawara T: The palliative care knowledge test: Reliability and validity of an instrument to measure palliative care

knowledge among health professionals. Palliat Med (in press).

21. Bradley EH, Cicchetti DV, Fried TR, Rousseau DM, Johnson-Hurzeler R, Kasl SV, Horwitz SM.: Attitudes about care at the end of life among clinicians: A quick, reliable, and valid assessment instrument. J Palliat Care 2000;16:6–14.

22. Cramer LD, McCorkle R, Cherlin E, Johnson-Hurzeler R, Bradley EH: Nurses' attitudes and practice related to hospice care. J Nurs Scholarsh 2003;35:249–255.

23. Frommelt KH: The effects of death education on nurses' attitudes toward caring for terminally ill persons and their families. Am J Hosp Palliat Care 1991;8:37–43.

24. Sasahara T, Miyashita M, Kawa M, Kazuma K: Difficulties encountered by nurses in the care of terminally ill cancer patients in general hospitals in Japan. Palliat Med 2003;17:520–526.

25. Potter J, Hami F, Bryan T, Quigley C: Symptoms in 400 patients referred to palliative care services: Prevalence and patterns. Palliat Med 2003;17:310–314.

26. Weiss SC, Emanuel LL, Fairclough DL, Emanuel EJ: Understanding the experience of pain in terminally ill patients. Lancet 2001;357:1311–1315.

27. Ellershaw J, Ward C: Care of the dying patient: The last hours or days of life. BMJ 2003;326:30–34.

28. Miyashita M, Nakai Y, Sasahara T, Koyama Y, Shimizu Y, Tsukamoto N, Kawa M: Nursing autonomy plays an important role in nurses' attitudes toward caring for dying patients. Am J Hosp Palliat Care 2007;24:202–210.

29. Morita T, Akechi T, Sugawara Y, Chihara S, Uchitomi Y: Practices and attitudes of Japanese oncologists and palliative care physicians concerning terminal sedation: a nationwide survey. J Clin Oncol 2002;20:758–764.

30. Rooda LA, Clements R, Jordan ML: Nurses' attitudes toward death and caring for dying patients. Oncol Nurs Forum 1999;26:1683–1687.

31. Carter H, McKinlay E, Scott I, Wise D, MacLeod R: Impact of a hospital palliative care service: Perspective of the hospital staff. J Palliat Care 2002;18:160–167.

32. Higginson IJ, Finlay I, Goodwin DM, Cook AM, Hood K, Edwards AG, Douglas HR, Norman CE: Do hospital-based palliative teams improve care for patients or families at the end of life? J Pain Symptom Manage 2002;23:96–106.

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Multiple evaluation of a hospital-based palliative care consultation team in a university hospital: Activities, patient outcome, and referring staff's view

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ABSTRACT

Objective: Although the number of hospital-based palliative care consultation teams (PCCTs) is rapidly increasing in Japan, there is limited information available concerning the activities and usefulness of PCCT in the country. The aim of this study is to clarify the activities, patient outcome, and referring staff's view of an established PCCT in Japan.

Method: This was a prospective study to follow patients referred to a PCCT for 28 days over a 1-year period. Patients were assessed by the Support Team Assessment Schedule–Japanese version (STAS-J) and EORTC QLQ C-30 at the time of referral and on days 7, 14, and 28. A staff survey was implemented using a questionnaire after each observation period.

Results: Of 180 patients referred, 53 patients were eligible for the study. Although the median of the number of the reasons for referral was 1, the PCCT provided several kinds of support: pain management, 94%; emotional support for the patient, 49%; and emotional support for the family, 36%. On day 7 after referral, of the items of STAS-J and the EORTC QLQ C-30 subscales, only insomnia improved significant whereas "other physical symptoms" and constipation were significantly exacerbated. In the staff survey, of the 98 respondents, more than 90% considered the effect of the PCCT as "excellent" or "good" and were satisfied with the support provided.

Significance of results: This study showed that the PCCT performed comprehensive assessments on referred patients and provided extra support. No patient's QOL 1 week after referral was improved with the exception of insomnia. Referring staff highly evaluated the activities of the PCCT. In the evaluation of PCCTs, further research about the variation of clinical activities of PCCTs, their applicability, and benefit is needed.

KEYWORDS: Palliative care, Palliative care consultation team, Consultation, Evaluation, University hospital

INTRODUCTION

Specialized palliative care consultation teams (PCCTs) play an important role in acute care hospitals in terms of enabling the adoption of palliative care early in disease trajectories, as is stated in the WHO definition of the term (Sepulveda et al., 2002). In many Western countries, palliative care consultation services were established in the 1990s (Palliative Care Australia, 1999; Pan et al., 2001; Kuin et al., 2004; National Council for Palliative Care, 2007), and their usefulness has been investigated by systematic

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review (Higginson et al., 2002), randomized control- led trials (Hanks et al., 2002; Rabow et al., 2004), comparative study of different consultation types (Schrijinemaekers et al., 2003), before-and-after studies of intervention by PCCTs (Ellershaw et al., 1995; Abrahm et al., 1996; Jack et al., 2003, 2004), de- scriptive studies of PCCT recommendations (Man- fredi et al., 2000; Homsi et al., 2002; Kuin et al., 2004), examinations of newly identified problems by PCCTs (Braiteh et al., 2007; Vernooij-Dassen et al., 2007), satisfaction surveys of referring staff (Carter et al., 2002; Virik & Glare, 2002), and cost-effective- ness analyses (Axelsson & Christensen, 1998; Han- son et al., 2008).

In Japan, the number of hospitals with a PCCT has drastically increased to 351 over the past few years because the government cancer policy has strongly supported the dissemination of specialized palliative care. However, there is limited information available concerning the activities and usefulness of PCCTs in Japan. Morita et al. (2005*b*) implemented a prospective study of 111 referred patients and collec- ted data regarding the reasons for referral, patients' characteristics, symptom severity at the time of referral, improvement of symptoms during the first week, and types of therapeutic interventions performed after PCCT consultation. Yoshimoto et al. (2005) conducted a prospective study of 149 referred patients and reported that pain and dyspnea were improved after PCCT consultation. Nevertheless, these results were obtained at a gen- eral hospital, and data concerning PCCT activities were not collected.

In exploring the usefulness of PCCTs, the refer- ring staff's views are also important (Fischberg & Meier, 2004). PCCTs can only take action to help patients and families upon receiving a referral from ward staff. Thus, to ensure consistent referrals, it is important to investigate how referring staff view the usefulness of PCCTs and whether they are satis- fied with their activities and patient outcomes.

Showa University Hospital is a 1,100-bed acute care hospital without a palliative care unit (PCU). A PCCT based at this hospital has been playing a pio- neering role in Japan. In 1992, three physicians developed the PCCT to provide direct care for termin- ally ill patients, and, in 1999, a certified nurse specialist in oncology joined the PCCT, and the team's focus changed to consultation. The full-time members of the PCCT are a palliative care physician and a nurse. The physician was trained as a pain clin- ician and has worked in the PCCT for two and a half years (in Japan, there is no certification system for palliative medicine). The nurse has officially quali- fied as a "certified nurse specialist in oncology" and has 10 years of clinical experience. In addition, the

PCCT has a psychiatrist as a part-time member, available in the same hospital. (These three types of professionals are required for coverage by the National Medical Insurance.) After referral, the in- itial assessment of patients is undertaken by the palliative care physician or the nurse, either alone or together, and detailed advice about any identified problems is communicated to the ward staff directly and written in the patient's case notes. A follow-up is then carried out by the palliative care physician and/or the nurse on the basis of the patient's and ward staff's needs. Ward rounds by all PCCT members are undertaken for all referred patients once a week. Multidisciplinary care conferences including pharmacists, a medical social worker, and link-nurses are performed once a week, and all patients are reviewed.

The aims of this study are to clarify the activities, patient outcome, and referring staff's views of an established PCCT in a university hospital in Japan.

METHODS

This was a prospective study to follow the activities of a PCCT and the patients referred to it for 28 days over a 1-year period.

Subjects

The subjects were patients referred to the PCCT between February 2004 and March 2005. As a cer- tain number of patients were expected to decline due to their condition deteriorating (Hanks et al., 2002; Stromgren et al., 2005), we adopted a health professional-assessed tool (STAS-J) to cover a greater number of patients and asked for a self-assessment questionnaire (EORTC QLQ-C30) to be filled out by those patients who were able to do so. Inclusion criteria were (a) presence of a malignant disease and (b) an age of 20 years or older. Exclusion criteria were (a) previous referral to the PCCT, (b) not having been of informed of their diagnosis, (c) family refusal, (d) no direct PCCT involvement with the patient, and (e) refusal of the attending physician to allow the patient to participate. In the ward staff evaluation, primary nurses of all patients referred to the PCCT during the study period were asked to fill out a questionnaire.

Measurements

PCCT Activities

Providing support. From the literature (Manfredi et al., 2000; Zhukovsky, 2000; Blackford & Street,

2001; Homsi et al., 2002; Virik & Glare, 2002), 10 categories of support provided by PCCTs were identified: pain management, other physical symptom management, psychiatric symptom management, emotional support for the patient, emotional support for the family, informing the patient, informing the family; transition to home, transition to PCU, and end-of-life care.

The number of visits to patient/ward staff. The number of times the PCCT visited patient/ward staff was recorded on a daily basis.

Patient Outcome

Support Team Assessment Schedule–Japanese version (STAS-J). This is a health professional-assessed tool for palliative care including 9 items: pain, other physical symptoms, patient anxiety, family anxiety, patient insight, family insight, communication between patient and family, communication among staff, and communication between patient and staff. Each item is rated from 0 to 4, and a higher score represents worse symptoms or more serious problems. The reliability and validity of the Japanese version of STAS has been confirmed (Miyashita et al., 2004).

EORTC QLQ-C30 (version 3.0). This is a patient-assessed questionnaire including a total of 30 items and is composed of six functioning scales: physical (5 items), emotional (4 items), role (2 items), cognitive (2 items), and social functioning (2 items), as well as global health status (2 items). This questionnaire also comprises three symptom scales: vomiting (2 items), fatigue (3 items), and pain (2 items), and 6 single items: dyspnea, insomnia, appetite loss, constipation, diarrhea, and financial difficulties. The items of global health status are rated from 1 (very poor) to 7 (excellent), and the remaining items are rated 1 (not at all) to 4 (very much). The responses were converted to 0–100 scales according to the scoring manual. Higher mean scores represent better functioning or more severe symptoms. The reliability and validity of the Japanese version of the EORTC QLQ-C30 has been confirmed (Kobayashi et al., 1998).

Patient Characteristics

Demographic data regarding the patient's age, sex, primary cancer site, presence or absence of metastasis, specialty of referring physician, ECOG PS, whether or not the patient was receiving anticancer treatment, patient outcome when the observation period ended, reason(s) for referral, date of admission, and date of death were collected.

Referring Staff's View

We asked primary nurses of the referred patients three *ad hoc* items by questionnaire: (a) How did the PCCT affect the referred patient, (b) to what extent are you satisfied with the support provided by the PCCT for the referred patient, and (c) do you think that the PCCT needs to be improved? In cases where a need for improvement was indicated, we asked subjects to write their views. Prior to the study, a pilot test was conducted to confirm the face and content validity of the questionnaire, using two ward nurses who had previously referred patients to the PCCT as subjects.

Data Collection

After initial assessment by the PCCT, the researcher (T.S.) was introduced to the patient by a member of the PCCT and obtained written informed consent. PCCT members checked all provided support when the observational period had finished, which was either at the time of the patient's death, the patient's discharge, or 28 days after referral. Data concerning the number of visits to patient/ward staff were collected on a daily basis by the researcher, and STAS-J and EORTC QLQ-C30 were assessed at the time of referral and on days 7, 14, and 28. STAS-J was assessed by the ward nurse charged with the patient on the assessment day. As ward nurses were not familiar with STAS-J, simple instructions were attached to the sheet and the researcher gave directions when needed. EORTC QLQ-C30 was completed by the patient on the assessment day. Patient demographic data were collected through the patient case note or the PCCT chart. A staff questionnaire was given to the primary nurse of the patient referred to the PCCT when the observational period had finished. To reduce response bias, the questionnaire could be returned anonymously to the researcher by mail, and it was clearly stated that no PCCT members would have access to individual responses.

This study was approved by the Institutional Review Board of Showa University Hospital.

Analysis

Activities of the PCCT were analyzed using descriptive statistics. The number of visits to patients/ward staff per day was calculated by dividing the total number of visits to patients/ward staff by the total number of working days during the observation period.

The items of STAS-J were analyzed after collapsing them into dichotomous variables: "none/a little" (0, 1) and "over moderate" (2–4). To investigate the change in referred patients, each item of the