

Table 3 Treatments in the last 48 h of life

Treatment	General wards (N=104)		Palliative care unit (N=201)		p value
	n	(%)	n	(%)	
Resuscitation	4	(3.8)	0	(0)	0.013*
Mechanical ventilation	5	(4.8)	0	(0)	0.004**
Intubation or use of airway ^a	4	(3.8)	1	(0.5)	0.048*
Tracheostomy ^a	5	(4.8)	1	(0.5)	0.019*
Oxygen inhalation	95	(91)	177	(88)	0.556
Intratracheal suction	43	(41)	74	(37)	0.460
Dialysis	1	(1.0)	0	(0)	0.342
Palliative sedation	5	(4.8)	48	(24)	<0.0001***
Urinary catheter ^a	63	(61)	100	(50)	0.090
Therapeutic drainage ^a					
Gastrointestinal fluids	7	(6.7)	15	(7.5)	1.000
Pleural fluids	8	(7.7)	3	(1.5)	0.009**
Percutaneous transhepatic cholangiole drainage	4	(3.8)	6	(3.0)	0.739
Ascites	0	(0)	2	(1.0)	0.549
Diagnostic testing					
Radiography	28	(27)	29	(14)	0.013*
CT scan	2	(1.9)	1	(0.5)	0.269
Laboratory examination	46	(44)	49	(24)	<0.0001***
Electrocardiogram	65	(63)	3	(1.5)	<0.0001***
Oral medication including rectal or transdermal	42	(40)	97	(48)	0.185
Parenteral medication	102	(98)	195	(97)	1.000
Route of administration ^b					
Central vein access	21	(21)	9	(4.6)	<0.0001***
Peripheral vein access	72	(71)	161	(83)	0.027*
Continuous subcutaneous infusion	45	(44)	161	(83)	<0.0001***
Vasopressor	22	(21)	1	(0.5)	<0.0001***
Antibiotic	50	(48)	63	(31)	0.006**
Blood transfusion					
Albumin transfusion	2	(1.9)	1	(0.5)	0.269
Red blood cell transfusion	5	(4.8)	5	(2.5)	0.317
Platelet transfusion	2	(1.9)	0	(0)	0.116
Chemotherapy	1	(1.0)	3	(1.5)	1.000
Artificial hydration (>50 ml/day)	92	(88)	174	(87)	0.720
Volume of infusion (the day before death) ^c					
<500 ml/day	9	(10)	73	(42)	<0.0001***
500–1,000 ml/day	21	(23)	84	(48)	
>1,000 ml/day	62	(67)	17	(10)	
Methods ^c					
Intermittent administration	16	(17)	165	(95)	<0.0001***
Continuous administration	76	(83)	9	(4.5)	
Intravenous hyperalimentation	10	(10)	3	(1.5)	0.002**
Tube feeding	2	(1.9)	3	(1.5)	1.000

CT Computed tomography

* $p < 0.05$

** $p < 0.01$

*** $p < 0.001$

^a Newly insert or continued placement of tubes

^b Percentages calculated from patients with parenteral medication

^c Percentages calculated from patients with fluid infusion

Discussion

We investigated DNR decisions and the treatments provided for dying cancer patients in the last 48 h of life in

general wards and PCU and the aggressiveness of end-of-life cancer care at a Japanese regional cancer center using QIs. This is the first study in Japan to examine the quality of end-of-life treatment for dying cancer patients

Table 4 Palliative care drugs in the last 48 h of life

Drug	General wards (N=104)		Palliative care unit (N=201)		p value
	n	(%)	n	(%)	
Strong opioids	71	(68)	185	(92)	<0.0001***
Morphine ^a	65	(92)	136	(74)	0.375
Fentanyl ^a	11	(15)	76	(41)	<0.0001***
Oxycodone ^a	3	(4.2)	9	(4.9)	0.757
Methods ^a					
Routine	70	(99)	184	(99)	0.479
As required (PRN)	41	(58)	140	(76)	0.006**
Route of administration ^a					
Oral, rectal, or transdermal	14	(20)	71	(38)	0.005**
Parenteral	60	(85)	165	(89)	0.294
Gastric protection	56	(54)	153	(76)	<0.0001***
Corticosteroids	51	(49)	140	(70)	<0.0001***
NSAIDs or acetaminophen	35	(34)	171	(85)	<0.0001***
Diuretics	28	(27)	43	(21)	0.318
Antiemetics	21	(20)	16	(8.0)	0.003**
Neuroleptics	18	(17)	105	(52)	<0.0001***
Sedatives/anxiolytics	16	(15)	95	(47)	<0.0001***
Laxatives	11	(11)	41	(20)	0.036*
Antidepressants	1	(1.0)	12	(6.0)	0.040*

NSAIDs Nonsteroidal anti-inflammatory drugs

* $p < 0.05$

** $p < 0.01$

*** $p < 0.001$

^aPercentages calculated from patients with strong opioids

in general wards and to compare general ward care to PCU care. We are also the first to use QIs.

In this study, DNR orders were documented for 94–98% of patients. This was comparable to previous reports in Japan [21] and a little higher than abroad where 77–88% of patients had DNR orders [3, 7, 8, 11, 27]. Questionnaire surveys indicated that the end-of-life decision making was more often entrusted to families rather than to patients in Japan [23–25]. We confirmed that family (97%) usually

consented to DNR. This family-centered decision making is a Japanese cultural feature that is seen less frequently in Western countries.

We found that life-sustaining treatments for dying cancer patients were generally withheld. In studies conducted abroad, 9–12% of patients who died of any disease in general wards received resuscitation, and 13–37% received mechanical ventilation in the last 48 h of life [4–7, 11]. In Japan, Masuda et al. [22] reported on patients in a geriatric

Table 5 Aggressiveness of cancer care near the end of life

Quality indicator of aggressive care	Total patients (N=305)		General wards (N=104)		Palliative care unit (N=201)	
	n	(%)	n	(%)	n	(%)
Proportion starting a new chemotherapy regimen within 30 days of death	9	(3.0)	6	(5.8)	3	(1.5)
Proportion receiving chemotherapy within 14 days of death	13	(4.3)	6	(5.8)	7	(3.5)
Proportion with >14 days in hospital in the last month of life ^a	221	(72)	75	(72)	146	(73)
Proportion admitted to the ICU in the last month of life	10	(3.3)	10	(9.6)	0	(0)
Proportion of palliative care unit patients with length of stay of 3 or fewer days	9	(4.5)	–	–	9	(4.5)

ICU Intensive care unit

^aThe denominator did not include 5 patients in general wards and 14 patients in PCU who hospitalized within 2 days because of the study criteria

ward; 42% had cancer, and among those patients, 11% received resuscitation, 11% had mechanical ventilation, and 16% were intubated. In our study, all patients died of cancer, and 3% were resuscitated, 5% placed on mechanical ventilation, and 4% were intubated in general wards; therefore, we conclude that there are less life-sustaining treatments provided for dying cancer patients. Concurrently, we note that families rather than patients usually do the DNR consent. Further study is needed to understand how much patients' preferences are reflected when families decide to forgo life-sustaining treatments.

Our results revealed contrasting styles of artificial hydration between settings. Although similar percentages of patients received artificial hydration, the methods of delivering fluids were completely different in terms of volume of hydration, continuous administration, route of administration, and hyperalimentation. Although the current evidence [28–33] is not in agreement regarding the palliative benefits of hydration, large volume hydration may not facilitate improvement in patients' outcomes in the final few days of life [29–30]. Therefore, the decision to hydrate should be personalized, based on careful assessment of symptoms, fluid administration, and patients' wishes [34]. Adjusting delivery of fluid (i.e., decreasing excess volume, using intermittent administration, or continuous subcutaneous infusion) may contribute to patients' comfort.

We also found that strong opioids were used sufficiently for end-of-life cancer patients, although use of palliative care drugs other than morphine may need to be improved in general wards. Strong opioids were used significantly less in general wards; however, usage was better than that reported in previous studies: Opioid usage in the last 48 h of life was 19–83% in general wards [4, 9, 21, 22] and 55–85% in PCU [10, 22, 26, 35]. However, fentanyl was far less used in general wards. This indicated an insufficient usage of opioid rotation. There was also significantly less usage of NSAIDs or other classes of palliative care drugs. Concomitant administration of opioids and NSAIDs or adjuvant analgesics and symptom management other than pain may be insufficient in general wards as compared to PCU. We suggest that physicians should be educated to increase use of palliative care drugs other than morphine to improve symptom management in general wards. Concurrently, more patients suffered from severe symptoms in PCU, thus requiring a variety of drugs to palliate intractable symptoms.

It is essential to discuss factors associated with the high use of opioids and palliative sedation and small volume hydration in PCU. Opioids and dehydration can cause delirium in terminally ill cancer patients [36], and thus, palliative sedation might be required to control delirium associated with frequent opioid use and small volume hydration in PCU. Some studies investigating the effectiveness of opioid

rotation and hydration have found that hydration decreased myoclonus and sedation of dehydration [31], while hydration and opioid rotation decreased agitated delirium [37]. However, the latter finding was not confirmed by additional research [38], and beside, hydration did not improve delirium in the last few days of life [29]. The prevalence of hydration was similar, and opioid rotation was actively implemented in PCU. In addition, large-volume hydration may be unsustainable due to the presence of other fluid retention symptoms. As mentioned above, patients with severe symptoms can be easily transferred to PCU; therefore, the high use of opioids and sedation was considered to be reasonable.

According to QIs, we suggest that cancer care at the regional cancer center in Japan should be less aggressive. Starting a new chemotherapy regimen within the last month was reported 5% in US [13] and in a Portuguese hospital [16], and chemotherapy within the last 2 weeks was 14–19% in US, 4% in Canada [14], and 11% in the Portuguese hospital. In this study, a new chemotherapy regimen within the last month was 3%, and chemotherapy within the last 2 weeks was 4%; moreover, the percentages were less if oral chemotherapy was excluded. We confirmed that chemotherapy was less frequently prescribed. In the USA, ICU use in the last month was reported about 12%, hospital stay longer than 14 days was 10–12%, and PCU stay shorter than 4 days was 14–17%. In this study, ICU use (3%) was less aggressive than in the USA. To our knowledge, these are the first data available to assess ICU use for dying cancer patients in Japan. Hospital stay or PCU use in this study is longer than in the USA. However, we cannot compare the aggressiveness of cancer care because the health care systems differ greatly between the USA and Japan.

This study has several limitations. First, all the data were collected at a single center. As palliative care resources may be adequate in this hospital, we cannot generalize our findings to the quality of end-of-life care in Japan. Second, our inclusion criteria allowed differences in primary cancer sites. In addition, patients with severe symptoms were more likely to be transferred to PCU. This indicated the possibility that different treatments were given to the different groups. Nevertheless, we identified 160 of 188 patients who died of a variety of cancers in general wards as potential participants for this study; therefore, we consider our findings reflected the care practices in general wards. Third, 24% of patients who died in general wards had received specialized palliative care. This means that the care practices in general wards were higher for these patients; thus, we may have underestimated the differences for the remaining patients. To further elucidate the quality of end-of-life care in Japan, additional information about the end-of-life care in general wards without palliative care

resources is required. Fourth, patients who died in PCU had a longer duration since cancer diagnosis and had received more cancer treatments. Therefore, they may have had increased opportunities to discuss treatment options. Finally, data may not be fully validated because this study was a retrospective medical chart review. We established a high inter-rater reliability, although the documentation itself may have been incorrect. In addition, we did not collect information about symptoms because the documentation in the medical and nursing records was insufficient [39, 40].

Future studies should include nationwide surveys to assess the quality of end-of-life treatment and establish achievable benchmarks for care in Japan. Information that highlights the quality differences among settings or rationale for differences is useful for planning interventions to improve the quality of end-of-life care.

Conclusion

We identified several features of end-of-life treatment in the last 48 h of life for cancer patients who died in general wards at a Japanese regional cancer center. Families, not patients, usually consented to DNR; life-sustaining treatments were appropriately withheld; in general wards, patients received more than 1,000 ml/day of continuous hydration; strong opioids were sufficiently used; however, palliative care drugs, other than morphine, were used less frequently. We suggest that end-of-life treatment can be improved, for example, artificial hydration could be decreased in volume and intermittently or subcutaneously administered for the comfort and convenience of the patient. Physicians should be educated about the use of palliative care drugs other than morphine in general wards.

In addition, we are the first in Japan to assess the aggressiveness of cancer care for dying patients by using QIs. We suggest that cancer care at the regional cancer center in Japan could be less aggressive and more in order with palliative care philosophies.

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Original Article

Screening for Discomfort as the Fifth Vital Sign Using an Electronic Medical Recording System: A Feasibility Study

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Abstract

Late referral to a specialized palliative care service hinders quality symptomatic management. The aim of this article is to describe the feasibility and clinical usefulness of screening for patient discomfort as the fifth vital sign using an electronic medical recording system to identify patients with undertreated physical symptoms. For the electronic medical recording system, all admitted patients received routine nurse assessment of discomfort (defined as any physical symptom) at every vital signs check using Item 2 of the Support Team Assessment Schedule Japanese version (STAS). All medically treated cancer patients admitted to seven oncology units were automatically screened at one-week intervals. Positive screening was defined as a STAS score of 2 or more at least two times during the previous week. For each patient identified by screening, a palliative care team reviewed the medical record and provided written recommendations when other treatments might improve the patient's physical symptoms. Of 629 patients screened, 87 (14%) initially met the positive screening criteria. Fifteen (17%) were false positive due to psychiatric symptoms without physical symptoms or due to misrecording. Of 72 cases with actual discomfort, 33 had already been referred to the palliative care team, 14 had received adequate palliative care as determined by the palliative care team, 14 had self-limiting transient discomfort, and one patient died before the screening day. In the remaining 10 cases (11% of symptomatic patients, 1.7% of all screened patients), the palliative care team recommended potentially useful interventions for symptom control; seven patients were referred to the palliative care team within one week. The time required for all screening processes was about 30 minutes per week. This experience demonstrates that screening for patient discomfort as the fifth vital sign using an electronic medical recording system can be successfully implemented and may be useful in facilitating early referral of distressing patients to the specialized

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Key Words

Palliative care team, neoplasms, screening, fifth vital sign, pain

Introduction

Multiple empirical studies suggest that health care professionals often underestimate the symptom distress of advanced cancer patients,¹⁻⁴ and the timing of referral to specialized palliative care services might be late.⁵⁻⁷ Screening methods to identify patients with considerable distress could be beneficial, encouraging earlier and more appropriate referral to specialized care from additional resources, such as specialized palliative care services. Several empirical studies have suggested the clinical efficacy of such a screening system,⁸⁻¹³ but these studies focus on psychological distress rather than physical discomfort and use patient-reported assessment scales. Using patient-rated assessment scales is essential to receive accurate information about patient distress, but in busy clinical practice, the screening procedure itself may be a burden to both patients and medical professionals.

The American Pain Society describes pain as the fifth vital sign and recommends that clinicians assess patients for pain every time they check the pulse, blood pressure, temperature, and respiration.¹⁴ If all patients receive such "screening" at every vital signs check, this would contribute to better symptom control by identifying patients with undertreated pain, with minimum burden to patients and clinicians. To our knowledge, however, empirical studies have not confirmed the clinical usefulness of such a screening system.^{15,16}

The aim of this report is to describe the feasibility and potential clinical usefulness of screening for patient discomfort as the fifth vital sign using an electronic medical recording system to identify patients with undertreated physical symptoms.

Patients and Methods

Selecting the Screening Tool

The primary aim of this study was to identify patients with considerable physical discomfort.

Patient discomfort was conceptualized as any physical symptom, such as pain, dyspnea, nausea, fatigue, and constipation. The rationale to target multiple symptoms, in addition to pain, was their high prevalence and considerable impact on patients' quality of life.¹⁷⁻²⁰ We decided not to include psychological symptoms, despite their well-acknowledged importance in patients' quality of life, because (1) routine assessment of multiple items would be a significant burden to nurses as the first step of our project, and (2) medical professionals cannot always provide proxy assessment of patients' psychological distress.¹⁻⁴

We developed the following screening methodology: Nurses recorded the intensity of discomfort of all patients at every vital signs check (routinely three times per day) using Item 2 of the Support Team Assessment Schedule Japanese version (STAS).²¹⁻²⁴ The STAS is a well-established comprehensive outcome measurement tool rated by medical professionals, and Item 2 rates the intensity of patients' physical symptoms as 0 (none), 1 (mild), 2 (moderate), 3 (severe), or 4 (extreme). The rationale for selecting the STAS was as follows: (1) the STAS has established reliability and validity for the Japanese population;²⁴ (2) the STAS requires no active participation from and causes no additional burden to patients; (3) the STAS is applicable for all patients including the physically very ill and cognitively impaired who could not complete self-reported questionnaires; (4) rating using Item 2 requires only several seconds and would cause minimum burden to nurses; and (5) the STAS was adopted as a standardized assessment scale for clinical use throughout the hospital, not only for the present study.

We applied the electronic medical recording system so that all admitted patients received routine nurse assessment of patient discomfort. Figure 1 demonstrates that the levels of patient discomfort are visualized on the electronic medical recording system along with the vital sign data. Furthermore, we developed

from ward nurses, to determine (1) whether the patient actually suffered physical discomfort and (2) whether the patient had already received maximum palliative care medical intervention. If the palliative care team determined that additional treatments might improve the patient's physical symptoms, written recommendations were made in the medical record. This process required about 3 minutes for each patient.

For patients whose palliative care physicians provided written recommendations, primary physicians' adherence to recommendations was followed up one week later.

Palliative Care System in the Seirei Mikatahara General Hospital

The palliative care team that provided specialist input for this study is well established. The Seirei Mikatahara General Hospital is a local cancer center with about 700 beds. The resources of the palliative care division include an inpatient hospice (palliative care unit, 27 beds; four attending physicians and 27 nurses) and a specialized palliative care consultation service (150–200 consultation activities per year; one attending physician and two certified nurses) and receives regular support from liaison psychiatry, a pain service, rehabilitation, oral care, nutrition, social work division, and home-care groups. Symptom control manuals are available via the hospital home page. The clinical activity of the palliative care team has been generally recognized, and thus the

existing human network could have played a screening role before the beginning of this study (e.g., if a pharmacist notices a patient with unrelieved pain, he/she could freely call the palliative care specialist by phone and receive advice within 24 hours).

Results

In this nine-week study period, nurses completed 8,713 assessments of the 11,697 opportunities to apply the STAS (overall compliance rate, 74%). Of the 629 case records screened, 87 cases (14%) initially met the positive screening criteria, that is, a STAS score of 2 or more at least two times during the previous week (Fig. 3). The time required for screening was estimated to be about 30 minutes per week (87 cases/9 sessions, 3 minutes/patient).

Of 87 cases initially screened as positive, 15 (17%) were false positive due to psychiatric symptoms without physical symptoms ($n=13$) and misrecording ($n=2$). Thus, 72 of the 87 cases (83% of positive-screened patients, 11% of all screened patients) had actual physical symptoms.

Of 72 cases with actual discomfort, 33 had already been referred to the palliative care team, 14 had self-limiting transient discomfort, 14 received adequate palliative care as determined by the palliative care team, and one patient died before the screening day. Transient discomfort was related to (1) invasive procedures

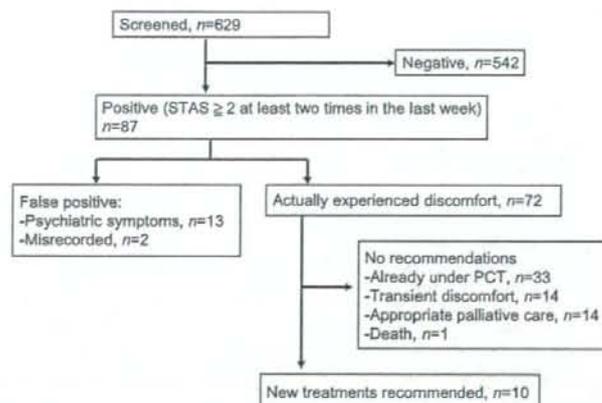


Fig. 3. Results.

(e.g., chest tube, percutaneous biliary drainage, and intubation), (2) radiation or chemotherapy-induced nausea, diarrhea, and fatigue, or (3) benign complications (e.g., pneumonia, gastric ulcer, and cholangitis).

In the remaining 10 cases (11% of symptomatic patients, 1.7% of all screened patients), the palliative care team recommended potentially useful interventions for symptom control, and seven patients were ultimately referred to the palliative care team within one week (Table 1). The majority of cases had complicated and/or multiple physical symptoms, such as neuropathic pain, a combination of pain and delirium, and pain and nausea. All three patients for whom the palliative care team recommended potentially useful interventions but did not refer them to the palliative care team received the recommended treatments by primary physicians.

Discussion

This study suggests that a screening system for patient discomfort as the fifth vital sign using an electronic medical recording system is feasible and may be useful to identify patients with undertreated physical symptoms. The greatest advantage of such a system is its high feasibility. The system development required no additional cost, and this method caused no patient burden and only a minimal burden to nurses. It is, therefore, applicable in busy

clinical practice settings. Thanks to advanced technology, the computer-based program screened the discomfort levels of all admitted patients within a few minutes. In addition, palliative care specialists could review each patient's records with positive screening results on an average of three minutes (30 minutes per week), as they could see all patient records via a single computer terminal in the office.

The assessment completion ratio was not high (i.e., 74%). We believe this figure is reasonable, however, because this observation was performed just after completing the six-month educational sessions. We have now achieved a greater than 85% completion ratio four months after this initial study period (unpublished data).

Overall, 11% of all screened patients actually experienced physical symptoms, and 11% of them, that is, 1.7% of all screened patients, received potentially useful treatments following written recommendations from palliative care specialists. Ultimately, 70% of the identified patients were referred to the palliative care team within one week. The relatively low percentages of patients with physical symptoms (11% of all patients: 72/629) and the patients with physical symptoms who were not referred to the specialized palliative care service (18% of patients with not-transient physical symptoms: 10/57) are unexpected but welcome findings in this study. The possible interpretations are (1) nurses underestimated patient symptoms and/or (2) the specialized palliative care system had been fully established in our hospital and patients with complicated symptomatology had already been referred to our team. We believe the latter is the most likely because previous studies suggested the increased awareness of the role of the palliative care team in our hospital.^{25,26}

Although we cannot demonstrate empirical data beyond the study aim, potential advantages of this system include (1) checking patient discomfort along with vital signs for all patients in *itself* could increase clinician attention to patient discomfort and contribute to improving patients' quality of life, (2) using the standardized tool STAS throughout the hospital could contribute to improving patient assessment, (3) informing doctors of the activity of the specialized palliative care team via the screening could promote physicians

Table 1
Recommended Interventions by Palliative Care Specialists

Case	Symptoms	Interventions
1	Hiccups	Clonazepam, herbal medicine
2	Neuropathic pain	Oxycodone
3	Neuropathic pain	Neck MRI, radiation, baclofen, oxycodone
4	Nausea, bone pain	Serum calcium, brain MRI, bone CT, epidural block, OR
5	Nausea, delirium	Hydration reduction, antihistamine, somatostatin
6	Abdominal pain	Epidural block, fentanyl
7	Nausea, headache	Brain CT, steroids, OR, antihistamine
8	Nausea, bone pain	Serum calcium, brain CT, antihistamine
9	Bone pain, delirium	Bisphosphonate
10	Abdominal swelling	Steroids, OR

OR = Opioid rotation.

unfamiliar with palliative care to consult our team, and (4) patients very reluctant to disclose their physical discomfort to their physicians may receive some benefits.

A major limitation of this study was the lack of a direct assessment of patient symptoms after screening, and this study, therefore, cannot conclude whether this screening system changed the patient outcome. Second, we excluded psychological and psychiatric symptoms in our initial project, and so the next step is to identify overlooked patient psychological modalities. Also, we did not measure formal psychometric properties as a screening instrument (sensitivity, specificity) due to the study design.

In conclusion, screening for patient discomfort as the fifth vital sign using an electronic medical recording system is feasible and may be useful for facilitating earlier and more appropriate referral of distressed patients to the specialized palliative care service. We believe that the low percentage of identified patients is mainly due to the widespread use of the specialized palliative care service in our hospital, and thus, we strongly encourage further studies to clarify the clinical effectiveness of this system in hospitals in which palliative care team activity has not been sufficiently introduced.

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Original Article

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

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Abstract

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

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

Key Words

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

Introduction

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

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

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

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

Methods

Subjects

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

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

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

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

Questionnaire (Available from the Authors)

The questionnaire was constructed through an extensive literature review,^{4-9,13} expert consensus among the authors, and on the basis of a previous study.¹⁰ We investigated three topics in this survey: 1) public awareness of PCUs, 2) perceptions of PCUs, and 3) overall satisfaction with received specialized inpatient palliative care. In addition, we investigated respondents' age and gender. The general population was asked whether they had been bereaved through cancer within the previous 10 years. PCU-bereaved families were asked about length of

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

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

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

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

Analyses

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

analysis of variance, as appropriate. The independent variables were age and gender (for both groups), levels of awareness of PCUs and experience of bereavement due to cancer (only for the general population), and length of PCU stay, time since the patient's death, institution (as data were collected regarding 12 PCUs), and level of patient's physical distress (only for PCU-bereaved families). These analyses were conducted separately for the general population and PCU-bereaved families. Finally, we explored the correlation between perceptions of PCUs and overall satisfaction with received care using Spearman's rank correlation. As a large sample size may result in an excess of statistically significant results ($P < 0.05$), we have mainly described "clinically significant" results for which the effect size (ES) was over 0.5.¹⁶ This criterion indicates that the mean value difference as an absolute figure between two extreme categories was over half of the pooled standard deviation.

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

Results

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

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

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

Public Awareness of PCUs (Table 2)

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

Perceptions of PCUs (Table 3)

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

Factors Associated with Perceptions of PCUs

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

Table 1
Demographic Backgrounds of the Respondents

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

SD = standard deviation; PCUs = palliative care units.

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

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

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

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

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

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

Discussion

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

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

Awareness of PCUs	%	n
No knowledge	24	591
Some knowledge	38	936
Moderate knowledge	34	855
Considerable knowledge	4.3	106

PCUs = palliative care units.

Table 3
Perceptions of PCUs

	General Population				Bereaved Families from PCUs				PValue*	ES
	(n = 2,548)				(n = 513)					
	Agree (%)	Somewhat Agree (%)	Mean	SD	Agree (%)	Somewhat Agree (%)	Mean	SD		
Supports patients in living peacefully	37	35	4.03	1.06	45	30	4.12	1.23	0.067	0.09
Supports patients in living with dignity	32	38	3.94	0.93	38	38	4.12	0.84	<0.0001	0.19
Provides care for families	29	38	3.90	1.32	54	33	4.38	1.38	<0.0001	0.53
Provides compassionate care	28	39	3.88	1.18	56	30	4.36	1.21	<0.0001	0.52
Alleviates pain	32	36	3.87	1.03	57	30	4.40	0.85	<0.0001	0.52
Expensive	30	31	3.79	0.94	18	23	3.14	0.98	<0.0001	-0.58
Provides no medical treatments	12	20	3.00	1.03	29	25	3.59	1.32	<0.0001	0.49
Isolates patients from the community	7.5	21	2.80	0.90	8.4	21	2.75	0.81	0.40	-0.04
A place where people only wait to die	11	20	2.76	1.19	18	22	3.03	1.24	<0.0001	0.20
Shortens the patient's life	2.8	5.3	2.27	0.92	7.4	9.2	2.44	0.87	0.006	0.15

PCUs = palliative care units; SD = standard deviation; ES = effect size.
*t-test.

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

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

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

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

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

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

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

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

*Spearman's rank correlation coefficient.

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

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

In our preceding analysis of the same survey, perceptions of PCUs as "alleviates pain" and "provides care for families" were significantly associated with preferences for PCUs as place of end-of-life care.¹⁰ It is, therefore, particularly important to disseminate adequate information about empirical evidence for effective pain control and the palliative care concept, including treatment of the patient and their family as the unit of care. Future research is needed to clarify the most effective strategy to improve public awareness of palliative care.

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

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

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

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

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

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