Table 2 Problems identified in 1,000 questionnaires

	Prevalence (%)[a]			Mean±SD (median)[b]
Physical problems				
MDASI items	Severe	Moderate	Total	
Fatigue	9.0	16	25	2.4±2.5 (2.0)
Appetite loss	8.8	11	20	1.9±2.6 (0.0)
Constipation	5.6	13	19	1.7±2.3 (1.0)
Somnolence	4.9	14	19	1.8±2.2 (1.0)
Pain	4.9	9.9	15	1.6±2.1 (1.0)
Numbness	6.0	7.5	14	1.4±2.3 (0.0)
Dyspnea	2.9	7.5	11	1.2±1.9 (0.0)
Nausea	3.4	6.9	10	1.1±2.0 (0.0)
Oral problems			20	
Fever			6.0	
Psychological problems				
Insomnia			20	
Distress thermometer			14	
Concern				
Information and help with decision-making			16	
Nutrition			6.8	
Daily activities			5.6	
Economic problems			2.9	

[a] The percentages of responses with moderate (4–6) and severe (7–10) symptom intensity for the MDASI items. The percentages of the score ≥6 for the distress thermometer. The percentages of problem presence for the other items.

[b] Mean values calculated for the MDASI items only.

recognized palliative care needs and referring them to the specialized palliative care service when patients wished for. Among the half of the patients who received chemotherapy and reported physical or psychological problems or concerns at the questionnaire level, 23% of all cancer patients were newly referred to the palliative care team with the primary aim of improving their quality-of-life. Despite clear limitation of the lack of control group, this finding strongly indicates that our intervention could provide specialized care for patients with profound symptoms irrespective of the disease extent.

The additional but third important finding was the clarification of the types of symptoms and concerns observed in heterogeneous cancer outpatients receiving chemotherapy. In this study, psychological issues (insomnia, distress), concern about information and decision-making, nutrition-related issues (oral problems and appetite loss), and fatigue were major concerns for patients. Consistent with the previous findings from Western countries, this finding indicates that developing systematic intervention strategies targeting psychosocial distress, decision-making, nutrition, and fatigue is of great importance and an emerging task for Japanese palliative care specialists [34–39].

In addition, this study revealed a considerable difference between the symptom patterns of the patients referred via the screening system and those from the treating physicians. While pain, dyspnea, and delirium were major reasons for the referral from the treating physicians, the screening system identified a broader range of patient distress, such as psychological distress, appetite loss, numbness, and fatigue. The result indicates that the screening system could be useful in identifying the patients with serious psychological distress, appetite loss, numbness, and fatigue, which are often overlooked by physicians.

This was a descriptive study of routine clinical experience and thus had considerable limitations. First, we did not formally measure the changes in the symptoms and concerns after consulting the palliative care team and we cannot conclude whether referral to the specialized palliative care service actually provided a benefit for the patients. Second, as the patients were a heterogeneous sample of their primary tumor sites, stages, and chemotherapy regimens, the results might not be automatically generalized to specific target populations. We believe this is not a fatal flaw of this study because we need to develop a useful system for heterogeneous outpatients receiving chemotherapy. Third, as this was a single institution study where the palliative care unit and palliative care team have been regarded as an essential function of the hospital [27, 28], the results could not be generalized to other institutions. Finally, because we had not decided to explore solid cutoff points, the most appropriate cutoff points for the screening and the definition of moderate and severe symptom intensities should be further studied.

In conclusion, the combined intervention of introducing the specialized palliative care service, using screening tools, and providing on-demand specialized palliative care service when starting chemotherapy as a part of routine clinical practice was feasible and could be useful in identifying patients with underrecognized palliative care needs and referring them to specialized palliative care service. To evaluate the accurate effects of this intervention, controlled trial is promising.

Appendix

Screening questionnaire

A. What is your greatest concern?

B. Physical symptoms. During the last week, how severe were your symptoms on the average?

	Not present ←									→ As bad as you can imagine
Pain	0	1	2	3	4	5	6	7	8	9	10
Shortness of breath	0	1	2	3	4	5	6	7	8	9	10
Nausea	0	1	2	3	4	5	6	7	8	9	10
Lack of appetite	0	1	2	3	4	5	6	7	8	9	10
Drowsy (sleepy)	0	1	2	3	4	5	6	7	8	9	10
Fatigue (tiredness)	0	1	2	3	4	5	6	7	8	9	10
Constipation/Diarrhea	0	1	2	3	4	5	6	7	8	9	10
Numbness or tingling	0	1	2	3	4	5	6	7	8	9	10

Oral problems YES NO Fever YES NO Sleep Difficulty YES NO

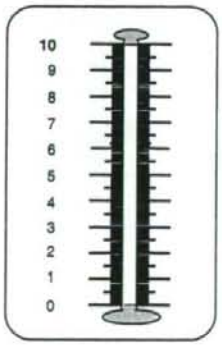
C. In the past week…

	Very poor ←						→ Excellent
1) Overall quality of life	0	1	2	3	4	5	6	7

2) Body Weight ( ) kg

3) How distressed are you?

Extreme distress



No distress

D. Do you need some help with…

- ☐ Information about the treatment and help with decision making
- ☐ Economic problems
- ☐ Nutrition
- ☐ Daily activities (house work, work, toilet…)

E. Do you wish for specialized palliative care (see the reverse side for detailed information)

→ WISH NOT wish

References

1. Earle CC, Neville BA, Landrum MB, Ayanian JZ, Block SD, Weeks JC (2004) Trends in the aggressiveness of cancer care near the end of life. J Clin Oncol 22:315–321
2. Bang SM, Park SH, Kang HG et al (2005) Changes in quality of life during palliative chemotherapy for solid cancer. Support Care Cancer 13:515–521
3. Munkres A, Oberst MT, Hughes SH (1992) Appraisal of illness, symptom distress, self-care burden and mood states in patients receiving chemotherapy for initial and recurrent cancer. Oncol Nurs Forum 19:1201–1209
4. Matsuyama R, Reddy S, Smith TJ (2006) Why do patients choose chemotherapy near the end of life? A review of the perspective of those facing death from cancer. J Clin Oncol 24:3490–3496
5. Schonwetter RS, Roscoe LA, Nwosu M, Zilka B, Kim S (2006) Quality of life and symptom control in hospice patients with cancer receiving chemotherapy. J Palliat Med 9:638–645
6. Whitmer KM, Pruemer JM, Nahleh ZA, Jazieh AR (2006) Symptom management needs of oncology outpatients. J Palliat Med 9:628–630
7. Newell S, Sanson-Fisher RW, Girgis A, Ackland S (1999) The physical and psycho-social experiences of patients attending an outpatient medical oncology department: a cross-sectional study. Eur J Cancer Care 8:69–72
8. World Health Organization (2002) National cancer control programmes. Policies and managerial guidelines, 2nd edn. WHO, Geneva
9. Christakis NA, Escarce JJ (1996) Survival of medicare patients after enrollment in hospice programs. N Engl J Med 335:172–178
10. Costantini M, Toscani F, Gallucci M et al (1999) Terminal cancer patients and timing of referral to palliative care: a multicenter prospective cohort study. J Pain Symptom Manage 18:243–252
11. Morita T, Akechi T, Ikenaga M et al (2005) Late referrals to specialized palliative care service in Japan. J Clin Oncol 23:2637–2644
12. Bruera E (2006) Process and content of decision making by advanced cancer patients. J Clin Oncol 24:1029–1030
13. Hoekstra J, de Vos R, van Duijn NP, Schadé E, Bindels PJE (2006) Using the symptom monitor in a randomized controlled trial: the effect on symptom prevalence and severity. J Pain Symptom Manage 31:22–30
14. Detmar SB, Muller MJ, Schornagel JH, Wever LDV, Aaronson NK (2002) Health-related quality-of-life assessments and patient–physician communication. JAMA 288:3027–3034
15. Taenzer P, Bultz BD, Carlson LE et al (2000) Impact of computerized quality of life screening on physician behaviour and patient satisfaction in lung cancer outpatients. Psychooncology 9:203–213
16. Velikova G, Booth L, Smith AB et al (2004) Measuring quality of life in routine oncology practice improves communication and patient well-being: a randomized controlled trial. J Clin Oncol 22:714–724
17. McLachlan SA, Allenby A, Matthews J et al (2001) Randomized trial of coordinated psychosocial interventions based on patient self-assessments versus standard care to improve the psychosocial functioning of patients with cancer. J Clin Oncol 19:4117–4125
18. Allen SM, Shah AC, Nezu AM et al (2002) A problem-solving approach to stress reduction among younger women with breast carcinoma. A randomized controlled trial. Cancer 94:3089–3100
19. Sikorskii A, Given C, Given B, Jeon S, McCorkle R (2006) Testing the effects of treatment complications on a cognitive-behavioral intervention for reducing symptom severity. J Pain Symptom Manage 32:129–139
20. Miaskowski C, Dodd M, West C (2004) Randomized clinical trial of the effectiveness of a self-care intervention to improve cancer patient management. J Clin Oncol 22:1713–1720
21. Doorenbos A, Given B, Given C et al (2005) Reducing symptom limitations: effects of a cognitive behavioral intervention randomized trial. Psychooncology 14:574–584
22. Given C, Given B, Rahbar M et al (2004) Effect of a cognitive behavioral intervention on reducing symptom severity during chemotherapy. J Clin Oncol 22:507–516
23. Strasser F, Sweeney C, Willey J, Tolley SB, Palmer JL, Bruera E (2004) Impact of a half-day multidisciplinary symptom control and palliative care outpatient clinic in a comprehensive cancer center on recommendations, symptom intensity, and patient satisfaction: a retrospective descriptive study. J Pain Symptom Manage 27:481–491
24. Bruera E, Michaud M, Vigano A, Neumann CM, Watanabe S, Hanson J (2001) Multidisciplinary symptom control clinic in a cancer center: a retrospective study. Support Care Cancer 9:162–168
25. Rosenbaum E, Gautier H, Fobair P et al (2004) Cancer supportive care, improving the quality of life for cancer patients. A program evaluation report. Support Care Cancer 12:293–301
26. Rabow MW, Dibble SL, Pantilat SZ, McPhee SJ (2004) The comprehensive care team. A controlled trial of outpatient palliative medicine consultation. Arch Intern Med 164:83–91
27. Morita T, Yo T, Fujimoto M (2005) Palliative care team: the first year audit in Japan. J Pain Symptom Manage 29:458–465
28. Morita T, Imura C, Fujimoto K (2005) Trends toward earlier referrals to a palliative care team. J Pain Symptom Manage 30:204–205
29. Okuyama T, Wang XS, Akechi T et al (2003) Japanese version of the MD Anderson Symptom Inventory: a validation study. J Pain Symptom Manage 26:1093–1104
30. Groenvold M, Petersen MA, Aaronson NK et al (2006) The development of the EORTC QLQ-C15-PAL: a shortened questionnaire for cancer patients in palliative care. Eur J Cancer 42:55–64
31. Akizuki N, Yamawaki S, Akechi T, Nakano T, Uchitomi Y (2005) Development of an impact thermometer for use in combination with the distress thermometer as a brief screening tool for adjustment disorders and/or major depression in cancer patients. J Pain Symptom Manage 29:91–99
32. Akizuki N, Akechi T, Nakanishi T et al (2003) Development of a brief screening interview for adjustment disorders and major depression in patients with cancer. Cancer 97:2605–2613
33. Cossich T, Schofield P, McLachlan SA (2004) Validation of the cancer needs questionnaire (CNQ) short-form version in an ambulatory cancer setting. Qual Life Res 13:1225–1233
34. Koedoot CG, de Haan RJ, Stiggelbout AM et al (2003) Palliative chemotherapy or best supportive care? A prospective study explaining patients' treatment preference and choice. Br J Cancer 89:2219–2226
35. Grunfeld EA, Maher EJ, Browne S et al (2006) Advanced breast cancer patients' perceptions of decision making for palliative chemotherapy. J Clin Oncol 24:1090–1098
36. Barsevick AM, Dudley W, Beck S, Sweeney C, Whitmer K, Nail L (2004) A randomized clinical trial of energy conservation for patients with cancer-related fatigue. Cancer 100:1302–1310
37. Ream E, Richardson A, Dann CA (2006) Supportive intervention for fatigue in patients undergoing chemotherapy: a randomized controlled trial. J Pain Symptom Manage 31:148–161
38. Jatoi A, Rowland K, Loprinzi CL et al (2004) An eicosapentaenoic acid supplement versus megestrol acetate versus both for patients with cancer-associated wasting: a North Central Cancer Treatment Group and National Cancer Institute of Canada collaborative effort. J Clin Oncol 22:2469–2476
39. Ravasco P, Grillo IM, Vidal PM, Camilo ME (2005) Dietary counseling improves patients outcomes: a prospective, randomized, controlled trial in colorectal cancer patients undergoing radiotherapy. J Clin Oncol 23:1431–1438

Support Care Cancer (2008) 16:113–122
DOI 10.1007/s00520-007-0332-x

SUPPORTIVE CARE IN CANCER

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

Kazuki Sato · Mitsunori Miyashita · Tatsuya Morita · Makiko Sanjo · Yasuo Shima · Yosuke Uchitomi

Received: 13 May 2007 / Accepted: 29 August 2007 / Published online: 5 October 2007

Abstract
Goals In Japan, most cancer patients die in the hospital. The aim of this study was to assess the quality of end-of-life treatment for dying cancer patients in general wards and palliative care unit (PCU).
Materials and methods A retrospective chart review study was conducted. The following data on cancer patients who died in general wards (N=104) and PCU (N=201) at a regional cancer center were collected: do-not-resuscitate (DNR) decisions, treatments in the last 48 h of life, and aggressiveness of cancer care for dying patients.
Main results DNR orders were documented for most patients (94% in general wards, 98% in PCU, p=0.067) and families usually consented (97%, 97%, p=0.307). Comparison of general wards with PCU showed that, in the last 48 h of life, significantly more patients in general wards received life-sustaining treatment (resuscitation, 3.8%, 0%, p=0.001; mechanical ventilation, 4.8%, 0%, p=0.004), large volume hydration (>1,000 ml/day, 67%, 10%, p<0.001) with continuous administration (83%, 5%, p=0.002) and fewer palliative care drugs (strong opioids, 68%, 92%, p< 0.001; corticosteroids, 49%, 70%, p<0.001; nonsteroidal anti-inflammatory drugs, 34%, 85%, p<0.001). Regarding aggressiveness of cancer care, patients received a new chemotherapy regimen within 30 days of death (3.0%), chemotherapy within 14 days of death (4.3%), and intensive care unit admission in the last month of life (3.3%).
Conclusion We found that families, not patients, consented to DNR, and life-sustaining treatments were appropriately withheld; however, patients on general wards received excessive hydration, and the use of palliative care drugs could be improved. Application of our findings can be used to improve clinical care in general wards.

Keywords Quality of health care · Palliative care · Terminal care · Decision making · Retrospective study · Neoplasm · Japan

K. Sato (✉) · M. Miyashita · M. Sanjo
Department of Adult Nursing/Palliative Care Nursing,
School of Health Sciences and Nursing,
Graduate School of Medicine, The University of Tokyo,
Faculty of Medicine Bldg. 5, 7-3-1 Hongo, Bunkyo,
Tokyo 113-0033, Japan
e-mail: kazukisato-tky@umin.ac.jp

M. Miyashita
e-mail: miyasita-tky@umin.ac.jp

M. Sanjo
e-mail: shibagaki-tky@umin.ac.jp

T. Morita
Department of Palliative and Supportive Care,
Palliative Care Team and Seirei Hospice,
Seirei Mikatahara General Hospital,
3453 Mikatabara-cho, Hamamatsu,
Shizuoka 433-8558, Japan
e-mail: tmorita@sis.seirei.or.jp

Y. Shima
Department of Palliative Medicine,
Tsukuba Medical Center Hospital,
1-3-1 Amakubo1-3-1, Tsukuba,
Ibaraki 305-8558, Japan
e-mail: shima@tmch.or.jp

Y. Uchitomi
Psycho-Oncology Division,
Research Center for Innovative Oncology,
National Cancer Center Hospital East,
6-5-1 Kashiwanoha, Kashiwa,
Chiba 277-8577, Japan
e-mail: yuchitom@east.ncc.go.jp

Introduction

For cancer patients in the last days of life, there are a wide variety of issues, including distressing physical symptoms, psychological concerns, decreased physical and communication abilities, and the ethical considerations of treatment [1, 2]. Providing appropriate care for these patients is very important.

Unfortunately, poor-quality end-of-life care occurs in hospital settings. The SUPPORT study revealed substantial shortcomings in the care of seriously ill hospitalized adults: patients' preferences regarding resuscitation were unknown to their physicians (47%), do-not-resuscitate (DNR) orders were written within 2 days of death (46%), patients received mechanical ventilation (46%), and patients suffered moderate-to-severe pain in the last 3 days of life (50%) [3]. After publication of the SUPPORT study, many studies reported inadequacy of end-of-life treatment in general wards. Especially in the last 48 h of life, many patients received inappropriate life-sustaining treatment [4–9] and inadequate pain and symptom management [4–6, 9–11]. The current status of end-of-life treatment should be investigated to improve the clinical care of dying hospitalized patients. Recently, quality indicators (QIs) of end-of-life cancer care have been identified: intensive use of chemotherapy, low rates of hospice use, and interventions resulting in emergency room visits, hospitalization, or intensive care unit (ICU) admissions [12]. These indicators were effectively utilized to assess the aggressiveness of cancer care using administrative data [13–15] and applied in a hospital setting [16].

In Japan, cancer is the leading cause of death (30% of all deaths), and 91% of cancer patients died in hospital in 2005 [17]. Palliative care developed from inpatient care for terminal cancer patients in Japan. In 1990, coverage for care in a palliative care unit (PCU) was included in National Health Insurance, and the number of PCUs has increased from 5 to 163 in 2007. Coverage for care provided by the palliative care team (PCT) began in 2002. These interdisciplinary teams cooperate with attending physicians to provide specialized care in general wards. Also in 2002, the Japanese Ministry of Health, Labor and Welfare designated a regional cancer center to provide standardized cancer diagnosis and treatment, which included palliative care. Only 5% of cancer patients died in PCU; therefore, a major task is to help staff on the general wards provide appropriate end-of-life care for dying cancer patients. This is also the case with Western countries. Previous studies investigated some aspects of quality of end-of-life care in Japan as follows: satisfaction of end-of-life care for cancer patients who died in PCUs [18], the efficacy of PCTs [19, 20], documentation of DNR orders in a teaching hospital [21], treatments and status of disclosure in the last 48 h of life in PCU and those provided in a geriatric hospital, where 42% of patients had cancer [22]. It is unclear who actually consents to DNR; however, in Japan, a cultural feature is that the family plays a greater role in this type of decision making [23–25]. There is also limited information about the comprehensive aspects of end-of-life treatment provided for dying cancer patients in general wards, and there are no data regarding QIs because of underdeveloped cancer registries in Japan. Improvements in the end-of-life treatment in general wards can be made by comparing practices that occur in PCU. In addition, understanding the aggressiveness of cancer care can be accomplished by using QIs.

The aim of this study was to assess quality of end-of-life treatment for dying cancer patients in general wards and the PCU at a regional cancer center in Japan. In particular, we focused on DNR decision making, treatments in the last 48 h of life, and aggressiveness of cancer care for dying patients.

Materials and methods

Patients and settings

Data were collected retrospectively on cancer patients who died in general wards and the PCU from September 2004 to February 2006 at Tsukuba Medical Center Hospital in Ibaraki Prefecture, Japan. The inclusion criteria were as follows: (1) died from cancer; (2) aged 20 years or older at the time of death; and (3) hospitalized for 3 days or more. The cancer sites could not be matched between settings because various clinical departments including respiratory medicine, general thoracic surgery, gastroenterology, gastroenterological surgery, general medicine, and palliative medicine participated in this study. These departments represented 88% of all cancer deaths in general wards and 100% in PCU during the study period. The exclusion criteria were as follows: (1) recruited by other study for bereaved family members; (2) bereaved family members would suffer serious psychological distress as determined by the attending physician; (3) cause of death was treatment or injury related; and (4) no bereaved family member aged 20 years or older.

Tsukuba Medical Center Hospital is a regional cancer center, in the suburbs of Tokyo. It has 409 beds (6 ICU beds and 20 PCU beds) and plays a central role in cancer treatment, community health care, and emergency medical care in Ibaraki Prefecture, Japan. PCU was certified in 2000 and provides specialized palliative care for patients in PCU and consultation, as requested, for general wards. During the study period, 188 patients died in general wards, and 242 patients died in PCU.

Procedure

We mailed a letter to identified bereaved families to inform them about the study. They were instructed to check and return the form in the enclosed envelope if they refused to participate in the chart review study in October 2006. The chart review was conducted between October and December 2006. Data were excluded for unknown addresses or if bereaved families declined to participate. A qualified research nurse (K.S.) reviewed all medical charts under the supervision of a PCU doctor. Initially, 20 medical charts were randomly selected and independently abstracted by two researchers (K.S. and M.M., also a licensed research nurse) to assure inter-rater reliability. The average rate of accordance was 93% between the reviewers; therefore, good inter-rater reliability was assured. The Ethics Committee of Tsukuba Medical Center Hospital approved this study.

Measures

Data were collected on five major categories: (1) patients' characteristics; (2) DNR decisions; (3) treatments in the last 48 h of life; (4) palliative care drugs in the last 48 h of life; and (5) QIs of end-of-life cancer care. Content validity was checked by two palliative care doctors and two research nurses before the medical chart review. A data collection sheet was utilized for documentation.

Patients' characteristics included information about sex, age, primary cancer site, cancer stage, and experience of cancer treatment (surgery, chemotherapy, and radiotherapy), length of time since cancer diagnosis, length of hospital stay, palliative care referral, length of time since palliative care referral, and length of PCU stay. Information concerning DNR decisions included: documentation of DNR order, patient or family consent to DNR, and length of time between documentation and death. Treatments in the last 48 h of life were comprehensively surveyed in reference to previous studies (see Table 4) [1, 4–6, 11]. We reviewed whether palliative care drugs were used in the last 48 h of life. They included ten classes of drugs which Nauck et al. [26] reported to be the most common in PCU (see Table 5). In addition, use of strong opioids, types of opioids in Japan (i.e., morphine, fentanyl, and oxycodone), methods [routine and as required (PRN)], and routes of administration were surveyed. We used QIs which Earle et al. [12] had identified and were available for our hospital setting to assess aggressiveness of cancer care near the end of life. QIs were identified during the chart review: new chemotherapy regimen within 30 days of death, chemotherapy within 14 days of death, more than 14 days hospital stay in the last month, admitted to the ICU in the last month, and 3 or fewer days PCU stay in the last month of life.

Data analysis

First, we calculated the relative frequency for categorical variables and the median, mean, and standard deviation (SD) for quantitative variables. For patients' characteristics,

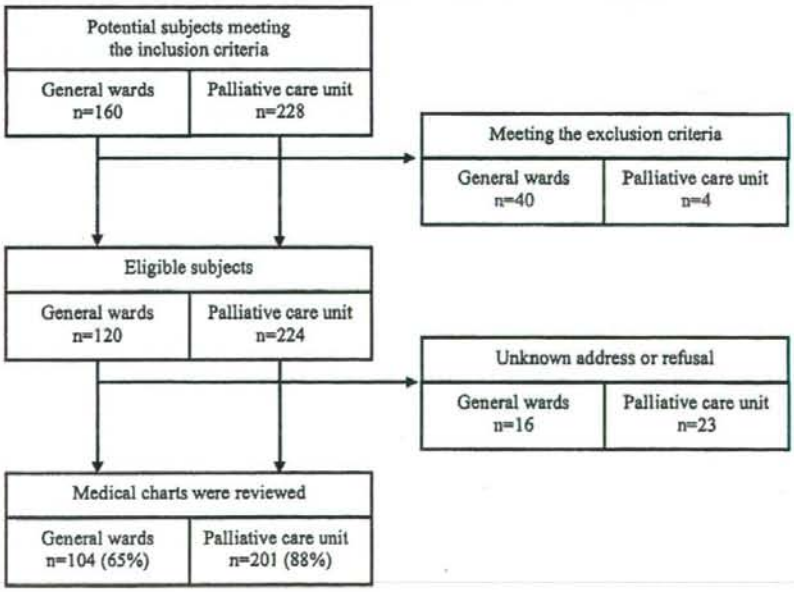


Fig. 1 Flow chart showing the patients' entry into the study

we separately calculated results from general wards and PCU and then compared the differences between the settings. For DNR decisions and treatments and palliative care drugs in the last 48 h of life, we also separately calculated results and then compared the differences to examine quality of end-of-life treatment for dying cancer patients in general wards. For aggressiveness of cancer care for dying patients, the calculated results combined for all settings were used to examine quality of end-of-life treatment throughout the hospital because these indicators were unsuited for comparing the aggressiveness between general wards and PCU. Statistical tests included Fisher's exact test, Cochran–Armitage exact trend test, or Wilcoxon test, as appropriate. A p value of less than 0.05 was considered statistically significant. All statistical analyses were performed with SAS version 9.1 for Windows (SAS Institute, Cary, NC).

Results

The patients' entry into the study is shown in Fig. 1. During the study period, patients who died in general wards (n=160) and PCU (n=228) were identified as potential subjects meeting the inclusion criteria. Among potential subjects, 44 were excluded due to participation in the other study (n=23 in general wards, n=0 in PCU), serious psychological distress as determined by the attending physician (n=8, n=0), treatment- or injury-related deaths (n=3, n=1), or no bereaved adult members (n=2, n=2). Subjects were also excluded if the bereaved family had no known address (n=3, n=8) or refused to participate (n=13, n=15). Finally, 104 (65%) medical charts from general wards and 201 (88%) from PCU were reviewed.

Patients' characteristics

Patients' characteristics are shown in Table 1. Among patients whose charts were reviewed, 71 and 55% were male and mean age was 71±9 and 68±12 years old in general wards and PCU, respectively. Primary cancer sites were lung (41% in general wards, 15% in PCU), hepatobiliary and pancreatic (28%, 17%), gastric (11%, 16%), and colorectal (6.7%, 17%).

In comparing patients' characteristics in general wards with those in PCU, significant findings include: more males

Table 1 Patients' characteristics

	General wards (N=104)		Palliative care unit (N=201)		p value
	n	(%)	n	(%)	
Sex, male	74	(71)	110	(55)	0.007**
Age, years (mean±SD)	71±9		68±12		0.100
Primary cancer site					
Lung	43	(41)	30	(15)	<0.0001***
Hepatobiliary and pancreatic	29	(28)	34	(17)	
Gastric	11	(11)	32	(16)	
Colorectal	7	(6.7)	35	(17)	
Head and neck	0	(0)	16	(8.0)	
Breast	1	(1.0)	15	(7.5)	
Other	13	(13)	39	(19)	
Cancer stage					
Local	7	(6.7)	2	(1.0)	0.002**
Regional	19	(18)	26	(13)	
Distant	74	(71)	171	(85)	
Experience of cancer treatment					
Surgery	26	(25)	118	(59)	<0.0001***
Chemotherapy	52	(50)	131	(65)	0.014*
Radiotherapy	45	(43)	93	(46)	0.630
Length of time since cancer diagnosis, months (median, mean±SD)	7, 14±27		18, 32±39		<0.0001***
Length of hospital stay, days (median, mean±SD)	27, 37±37		30, 45±65		0.296
Palliative care referral[a]	25	(24)	–		–
Length of time since palliative care referral, days (median, mean±SD)[b]	20, 31±27		61, 108±152		<0.0001***
Length of palliative care unit stay, days (median, mean±SD)	–		23, 37±60		–

Several total percentages are not 100% due to missing values.
SD Standard deviation
*p<0.05
**p<0.01
***p<0.001
[a] Palliative care referral to provide specialized care by PCT in general wards
[b] Median, mean, and SD calculated from patients with palliative care referral

(p=0.007), primary cancer sites were different (p<0.001), cancer stage was less advanced (p=0.002), fewer experienced surgical treatments (p<0.001) or chemotherapies (p=0.014), fewer with shorter length of time since cancer diagnosis (p<0.001), and shorter length of time since palliative care referral (p<0.001).

DNR decisions

Information about DNR decisions is shown in Table 2. DNR orders were documented for most patients (94% in general wards, 98% in PCU). Families (not patients) usually consented to DNR (97%, 97%). Median length of time between documentation of DNR and death was 8 days for general wards and 7 days for PCU. There was no significant difference between settings.

Treatments in the last 48 h

Treatments provided in the last 48 h of life are shown in Table 3. There were significant differences between general wards and PCU for the following: patients received life-sustaining treatment (resuscitation, 3.8% in general wards, 0% in PCU, p=0.001; mechanical ventilation, 4.8%, 0%, p=0.004; intubation, 3.8%, 0.5%, p=0.048); and had diagnostic testing (radiography, 27%, 14%, p=0.013; laboratory examination, 44%, 24%, p<0.001; electrocardiogram 63%, 1.5%, p<0.001). Meanwhile, significantly less palliative sedation (4.8%, 24%, p<0.001) was provided in general wards. Other treatments did not show significant differences between settings: oxygen inhalation (91%, 88%, p=0.556); intratracheal suction (41%, 37%, p=0.460); urinary catheter (61%, 50%, p=0.090); and therapeutic drainage (gastrointestinal fluids, 6.7%, 7.5%, p=1.000; percutaneous transhepatic cholangiole drainage, 3.8%, 3.0%, p=0.739).

Table 2 DNR decisions

	General wards (N=104)		Palliative care unit (N=201)		p value
	n	(%)	n	(%)	
Documentation of DNR order	98	(94)	197	(98)	0.067
Consent to DNR order[a]					
Patient	0	(0)	4	(2.0)	0.307
Family (not patient)	95	(97)	192	(97)	
Length of time between documentation and death, days (median, mean±SD)[a]	8, 17±29		7, 20±55		0.893

Several total percents are not 100% due to missing values
SD Standard deviation
[a] Percentage, median, mean, and SD calculated from patients with DNR orders

Approximately half of patients were given oral medicine (40% in general wards, 48% in PCU, p=0.185), and most received parenteral medication (98%, 97%, p=1.000); however, route of administration was significantly different. More patients had central venous access (21%, 4.6%, p<0.001), and fewer had peripheral venous access (71%, 81%, p=0.027) or continuous subcutaneous infusion (44%, 83%, p<0.001). Vasopressors (21%, 0.5%, p<0.001), antibiotics (48%, 31%, p=0.006), and intravenous hyperalimentation (10%, 1.5%, p=0.002) were used significantly more in general wards. In addition, 88% in general wards and 87% in PCU received artificial hydration, while significantly more patients received large volume hydration (>1,000 ml/day, 67%, 10%, p<0.001) with continuous administration (83%, 5%, p=0.002).

Palliative care drugs in the last 48 h of life

Use of palliative care drugs in the last 48 h of life is shown in Table 4. Significantly more patients took eight of ten drugs such as strong opioids (68% in general wards, 92% in PCU, p<0.001), gastric protections (54%, 76%, p<0.001), corticosteroids (49%, 70%, p<0.001), nonsteroidal anti-inflammatory drugs (NSAIDs, 34%, 85%, p<0.001), neuroleptics (17%, 52%, p<0.001), and sedative/anxiolytics (15%, 47%, p<0.001), while fewer took antiemetics (20%, 8.0%, p=0.003) in general wards than in PCU. Among those patients taking strong opioids, morphine (92%, 74%, p=0.375) was used most frequently, followed by fentanyl (15%, 42%, p<0.001) and oxycodone (4.2%, 4.9%, p=0.757). Strong opioids, PRN, were used significantly less in general wards (58%, 76%, p=0.006).

Aggressiveness of cancer care near the end of life

Table 5 shows the QIs used to assess aggressiveness of cancer care near the end of life: new chemotherapy regimen within 30 days of death (3.0%, n=9), chemotherapy within 14 days of death (4.3%, n=13), more than 14 days in hospital in the last month of life (72%, n=221), admitted to the ICU in the last month of life (3.3%, n=10), and length of stay of 3 or fewer days in PCU (4.5%, n=9).

Among those patients who received chemotherapy near death and died in PCU, all new chemotherapy regimens were started before admission to PCU, and five of seven chemotherapy treatments were actually done in PCU. All were oral chemotherapy: three hormonal and two molecular targeted. Regarding proportion, for those with more than 14 days in hospital, 19 patients who died within 2 days of hospitalization were not included in the denominator because of the study criteria. Among those patients who were admitted to the ICU, five of ten patients died in ICU.

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
[a] Percentages 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
[a] The 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.

Acknowledgment This research was supported by a grant from Health and Labor Science Research Grants, Third Term Comprehensive Control Research for Cancer. We would like to express our gratitude to the hospital staff for their cooperation in this study. The author would also like to thank Keiko Kazuma, RN, PhD (Department of Adult Nursing/Palliative Care Nursing, University of Tokyo) for contributing time and expertise to this study.

References

1. Ellershaw J, Ward C (2003) Care of the dying patient: the last hours or days of life. BMJ 326(7379):30–34
2. Plonk WM Jr, Arnold RM (2005) Terminal care: the last weeks of life. J Palliat Med 8(5):1042–1054
3. The SUPPORT Principal Investigators (1995) A controlled trial to improve care for seriously ill hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). JAMA 274(20):1591–1598
4. Toscani F, Di Giulio P, Brunelli C, Miccinesi G, Laquintana D (2005) How people die in hospital general wards: a descriptive study. J Pain Symptom Manage 30(1):33–40
5. Solloway M, LaFrance S, Bakitas M, Gerken M (2005) A chart review of seven hundred eighty-two deaths in hospitals, nursing homes, and hospice/home care. J Palliat Med 8(4):789–796
6. Paice JA, Muir JC, Shott S (2004) Palliative care at the end of life: comparing quality in diverse settings. Am J Hosp Palliat Care 21 (1):19–27
7. Fins JJ, Miller FG, Acres CA, Bacchetta MD, Huzzard LL, Rapkin BD (1999) End-of-life decision-making in the hospital: current practice and future prospects. J Pain Symptom Manage 17 (1):6–15
8. Oh DY, Kim JH, Kim DW et al (2006) CPR or DNR? End-of-life decision in Korean cancer patients: a single center's experience. Support Care Cancer 14(2):103–108
9. Bailey FA, Burgio KL, Woodby LL et al (2005) Improving processes of hospital care during the last hours of life. Arch Intern Med 165(15):1722–1727
10. Aldasoro E, Alonso AP, Ribacoba L et al (2005) Assessing quality of end-of-life hospital care in a southern European regional health service. Int J Technol Assess Health Care 21(4):464–470
11. Goodlin SJ, Winzelberg GS, Teno JM, Whedon M, Lynn J (1998) Death in the hospital. Arch Intern Med 158(14):1570–1572
12. Earle CC, Park ER, Lai B, Weeks JC, Ayanian JZ, Block S (2003) Identifying potential indicators of the quality of end-of-life cancer care from administrative data. J Clin Oncol 21(6):1133–1138
13. Earle CC, Neville BA, Landrum MB, Ayanian JZ, Block SD, Weeks JC (2004) Trends in the aggressiveness of cancer care near the end of life. J Clin Oncol 22(2):315–321
14. Barbera L, Paszat L, Chartier C (2006) Indicators of poor quality end-of-life cancer care in Ontario. J Palliat Care 22(1):12–17
15. Grunfeld E, Lethbridge L, Dewar R et al (2006) Towards using administrative databases to measure population-based indicators of quality of end-of-life care: testing the methodology. Palliat Med 20(8):769–777
16. Braga S, Miranda A, Fonseca R et al (2007) The aggressiveness of cancer care in the last three months of life: a retrospective single centre analysis. Psychooncology 16(9):863–868
17. Statistics and Information Dept., Minister's Secretariat, Ministry of Health, Labour and Welfare (2006) Vital statistics of Japan 2005 (in Japanese). Ministry of Health, Labour and Welfare, Tokyo
18. Morita T, Hirai K, Sakaguchi Y et al (2004) Measuring the quality of structure and process in end-of-life care from the bereaved family perspective. J Pain Symptom Manage 27(6):492–501
19. Morita T, Imura C, Fujimoto K, Shishido H, Tei Y, Inoue S (2005) Changes in medical and nursing care in cancer patients transferred from a palliative care team to a palliative care unit. J Pain Symptom Manage 29(6):595–602
20. Morita T, Fujimoto K, Tei Y, Morita T, Fujimoto K, Tei Y (2005) Palliative care team: the first year audit in Japan. J Pain Symptom Manage 29(5):458–465
21. Tokuda Y, Nakazato N, Tamaki K, Tokuda Y, Nakazato N, Tamaki K (2004) Evaluation of end of life care in cancer patients at a teaching hospital in Japan. J Med Ethics 30(3):264–267
22. Masuda Y, Noguchi H, Kuzuya M et al (2006) Comparison of medical treatments for the dying in a hospice and a geriatric hospital in Japan. J Palliat Med 9(1):152–160
23. Voltz R, Akabayashi A, Reese C et al (1998) End-of-life decisions and advance directives in palliative care: a cross-cultural survey of patients and health-care professionals. J Pain Symptom Manage 16(3):153–162

24. Asai A, Miura Y, Tanabe N, Kurihara M, Fukuhara S (1998) Advance directives and other medical decisions concerning the end of life in cancer patients in Japan. Eur J Cancer 34(10):1582–1586
25. Ruhnke GW, Wilson SR, Akamatsu T et al (2000) Ethical decision making and patient autonomy: a comparison of physicians and patients in Japan and the United States. Chest 118(4):1172–1182
26. Nauck F, Ostgathe C, Klaschik E et al (2004) Drugs in palliative care: results from a representative survey in Germany. Palliat Med 18(2):100–107
27. Tschann JM, Kaufman SR, Micco GP (2003) Family involvement in end-of-life hospital care. J Am Geriatr Soc 51(6):835–840
28. Bozzetti F, Cozzaglio L, Biganzoli E et al (2002) Quality of life and length of survival in advanced cancer patients on home parenteral nutrition. Clin Nutr 21(4):281–288
29. Cerchietti L, Navigante A, Sauri A, Palazzo F (2000) Hypodermoclysis for control of dehydration in terminal-stage cancer. Int J Palliat Nurs 6(8):370–374
30. Morita T, Hyodo I, Yoshimi T et al (2005) Association between hydration volume and symptoms in terminally ill cancer patients with abdominal malignancies. Ann Oncol 16(4):640–647
31. Bruera E, Sala R, Rico MA et al (2005) Effects of parenteral hydration in terminally ill cancer patients: a preliminary study. J Clin Oncol 23(10):2366–2371
32. Lawlor PG, Gagnon B, Mancini IL et al (2000) Occurrence, causes, and outcome of delirium in patients with advanced cancer: a prospective study. Arch Intern Med 160(6):786–794
33. Morita T, Tei Y, Tsunoda J, Inoue S, Chihara S (2001) Underlying pathologies and their associations with clinical features in terminal delirium of cancer patients. J Pain Symptom Manage 22(6):997–1006
34. Dalal S, Bruera E (2004) Dehydration in cancer patients: to treat or not to treat. J Support Oncol 2(6):467–479, 483
35. Goncalves JF, Alvarenga M, Silva A (2003) The last forty-eight hours of life in a Portuguese palliative care unit: does it differ from elsewhere? J Palliat Med 6(6):895–900
36. Centeno C, Sanz A, Bruera E (2004) Delirium in advanced cancer patients. Palliat Med 18(3):184–194
37. Bruera E, Franco JJ, Maltoni M, Watanabe S, Suarez-Almazor M (1995) Changing pattern of agitated impaired mental status in patients with advanced cancer: association with cognitive monitoring, hydration, and opioid rotation. J Pain Symptom Manage 10 (4):287–291
38. Morita T, Tei Y, Inoue S (2003) Agitated terminal delirium and association with partial opioid substitution and hydration. J Palliat Med 6(4):557–563
39. Stromgren AS, Groenvold M, Sorensen A, Andersen L (2001) Symptom recognition in advanced cancer. A comparison of nursing records against patient self-rating. Acta Anaesthesiol Scand 45(9):1080–1085
40. Stromgren AS, Groenvold M, Pedersen L, Olsen AK, Spile M, Sjogren P (2001) Does the medical record cover the symptoms experienced by cancer patients receiving palliative care? A comparison of the record and patient self-rating. J Pain Symptom Manage 21(3):189–196

Original Article

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

Tatsuya Morita, MD, Koji Fujimoto, RN, Miki Namba, RN, Emi Kiyohara, RN, Satoshi Takada, BBA, Ritsuko Yamazaki, RN, and Kimiyo Taguchi, RN
Department of Palliative and Supportive Care (T.M.), Palliative Care Team (T.M., K.F., M.N.), and Seirei Hospice (T.M., E.K.), Department of Medical Informatics (S.T.), and Nursing Department (R.Y., K.T.), Seirei Mikatahara Hospital, Shizuoka, Japan

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

Address correspondence to: Tatsuya Morita, MD, Department of Palliative and Supportive Care, Palliative Care Team and Seirei Hospice, Seirei Mikatahara Hospital, 3453 Mikatahara-cho, Hamamatsu, Shizuoka 433-8558, Japan. E-mail: tmorita@sis.seirei.or.jp

Accepted for publication: May 8, 2007.

0885-3924/08/$—see front matter
doi:10.1016/j.jpainsymman.2007.05.013

palliative care service. J Pain Symptom Manage 2008;35:430–436.

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

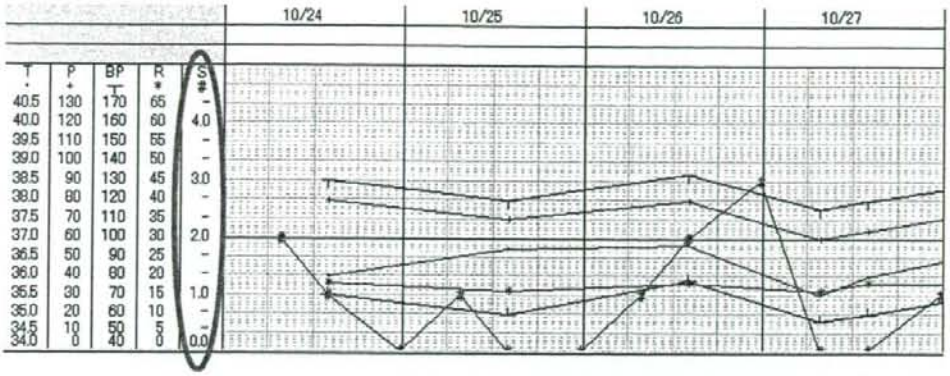


Fig. 1. Patient discomfort visualized as the fifth vital sign.

a computer-based program to automatically screen the scores of the STAS of all admitted patients and list the patients censored (Fig. 2). This procedure required only a few minutes. This system development required only minimum in-house modifications, and no additional costs were incurred.

For the clinical implementation of this system, we conducted multiple educational sessions for all nurses over six months, and distributed the rating instructions via the Web and written portable materials for each nurse.

Screening and Palliative Care Team Intervention

Just after ending the educational sessions, during August to October 2006, all cancer patients admitted to seven oncology units were automatically screened with the electronic medical recording system at one-week intervals. Each automatic screening required only a few minutes. Patients who had undergone surgery during the previous two weeks were excluded.

We defined positive screening as patients with a STAS score of 2 or more at least two times in the previous one week. We determined this ad hoc cutoff point after several explorative testing phases whereby stricter criteria (i.e., STAS score of 3 or more) detected only a small number of patients.

For all patients identified by automatic screening, the palliative care team reviewed each patient's medical records, with help

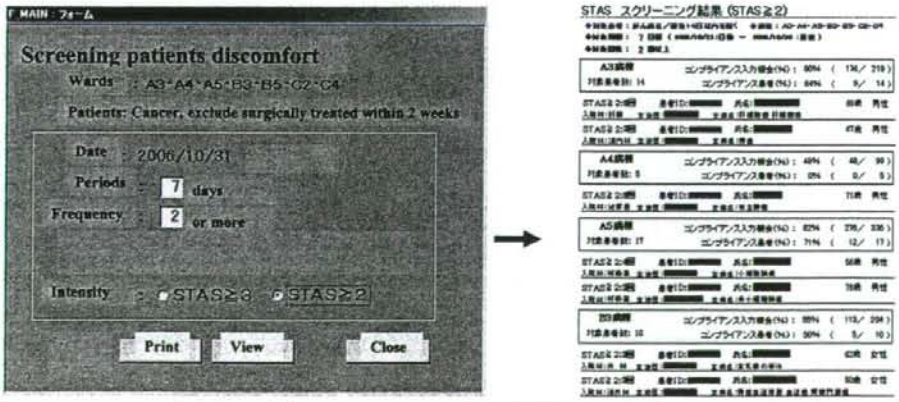


Fig. 2. Computer-based screening system.

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

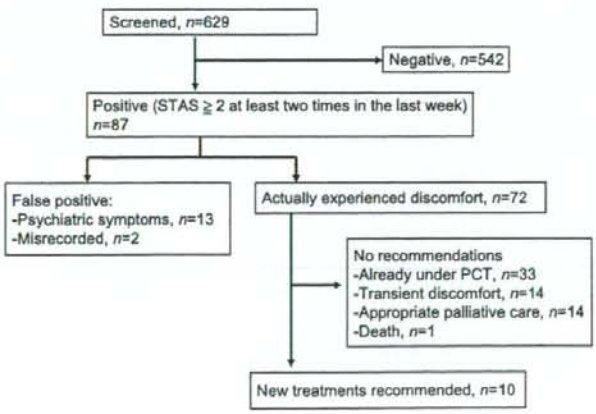


Fig. 3. Results.

(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.

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.

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

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.

References

1. Sprangers MAG, Aaronson NK. The role of health care providers and significant others in evaluating the quality of life of patients with chronic disease: a review. J Clin Epidemiol 1992;45:743–760.

2. Heaven CM, Maguire P. Disclosure of concerns by hospice patients and their identification by nurses. Palliat Med 1997;11:283–290.

3. Nekolaichuk CL, Maguire TO, Almazor MS, Rogers WT, Bruera E. Assessing the reliability of patient, nurse, and family caregiver symptom ratings in hospitalized advanced cancer patients. J Clin Oncol 1999;17:3621–3630.

4. Horton R. Differences in assessment of symptoms and quality of life between patients with advanced cancer and their specialist palliative care nurses in a home care setting. Palliat Med 2002; 16:488–494.

5. Christakis NA, Escarce JJ. Survival of Medicare patients after enrollment in hospice programs. N Engl J Med 1996;335:172–178.

6. Costantini M, Toscani F, Gallucci M, et al. Terminal cancer patients and timing of referral to palliative care: a multicenter prospective cohort study. J Pain Symptom Manage 1999;18:243–252.

7. Morita T, Akechi T, Ikenaga M, et al. Late referrals to specialized palliative care service in Japan. J Clin Oncol 2005;23:2637–2644.

8. Carlson LE, Speca M, Hagen N, Taenzer P. Computerized quality-of-life screening in a cancer pain clinic. J Palliat Care 2001;17:46–52.

9. Lloyd-Williams M, Friedman T, Rudd N. An analysis of the validity of the Hospital Anxiety and Depression scale as a screening tool in patients with advanced metastatic cancer. J Pain Symptom Manage 2001;22:990–996.

10. Barg FK, Cooley M, Pasacreta J, Senay B, McCorkle R. Development of a self-administered psychosocial cancer screening tool. Cancer Pract 1994;2:288–296.

11. Shimizu K, Akechi T, Okamura M, et al. Usefulness of the nurse-assisted screening and psychiatric referral program. Cancer 2005;103:1949–1956.

12. Jacobsen PB, Donovan KA, Trask PC, et al. Screening for psychologic distress in ambulatory cancer patients. Cancer 2005;103:1494–1502.

13. Akizuki N, Akechi T, Nakanishi T, et al. Development of a brief screening interview for adjustment disorders and major depression in patients with cancer. Cancer 2003;97:2605–2613.

14. Available at http://www.ampainsoc.org. Accessed on December 2, 2006.

15. Merboth MK, Barnason S. Managing pain: the fifth vital sign. Nurs Clin North Am 2000;35: 375–383.

16. Lynch M. Pain as the fifth vital sign. J Intraven Nurs 2001;24:85–94.

17. Morita T, Tsunoda J, Inoue S, Chihara S. Contributing factors to physical symptoms in terminally-ill cancer patients. J Pain Symptom Manage 1999;18:338–346.

18. Mercadante S, Casuccio A, Fulfaro F. The course of symptom frequency and intensity in advanced cancer patients followed at home. J Pain Symptom Manage 2000;20:104–112.

19. Walsh D, Donnelly S, Rybicki L. The symptoms of advanced cancer: relationship to age, gender, and performance status in 1000 patients. Support Care Cancer 2000;8:175–179.

20. Skaug K, Eide GE, Gulsvik A. Prevalence and predictors of symptoms in the terminal stage of lung cancer: a community study. Chest 2007;131: 389–394.

21. Carson MG, Fitch MI, Vachon ML. Measuring patient outcomes in palliative care: a reliability and validity study of the Support Team Assessment Schedule. Palliat Med 2000;14:25–36.

22. Hodgson C, Higginson I, McDonnell M, Butters E. Family anxiety in advanced cancer:

a multicentre prospective study in Ireland. Br J Cancer 1997;76:1211–1214.

23. Edmonds PM, Stuttaford JM, Penny J, Lynch AM, Chamberlain J. Do hospital palliative care teams improve symptom control? Use of a modified STAS as an evaluation tool. Palliat Med 1998; 12:345–351.

24. Miyashita M, Matoba K, Sasahara T, et al. Reliability and validity of the Japanese version of the support team assessment schedule (STAS-J). Palliat Support Care 2004;2:379–385.

25. Morita T, Yo T, Fujimoto M. Palliative care team: the first year audit in Japan. J Pain Symptom Manage 2005;29:458–465.

26. Morita T, Imura C, Fujimoto K. Trends toward earlier referrals to a palliative care team. J Pain Symptom Manage 2005;30:204–205.