for outpatient chemotherapy. These instruments can clarify the patient's stage of readiness and describe current patient preferences and concerns regarding therapy.

This study has several limitations. The first is that it was cross-sectional in design. Although we could not definitely conclude causality in the relationship among variables, the SEM results have provided strong evidences and insights for future planning of longitudinal studies. Second, the sample of this study was comparatively small and limited to patients in one institution. Therefore, one important suggestion for future research is to use a longitudinal design and multi-center trial. Third, decision making for outpatient chemotherapy is a domestic problem based on the Japanese medical system. If the Japanese Ministry of Health decides to cover outpatient chemotherapy more fully with national health insurance, patients' willingness to transition may change. However, this study shows high applicability of TTM to specific domestic problems, such as outpatient chemotherapy in Japanese lung cancer patients, and that the psychological theory could provide a useful solution. This will encourage psychologists to adapt applied behavioral theory, such as TTM, to other specific behavioral problems in cancer care settings and other medical problems.

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9576   General Poster Session (Board #K13), Mon, 8:00 AM - 12:00 PM

Code status documentation in the outpatient electronic medical records of patients with metastatic cancer. *J. Greer, J. Temel, S. Admane, J. Solis, T. Lynch, W. Pirl; Massachusetts General Hospital, Boston, MA*

Background: Advanced care planning is an essential component of cancer care for patients with incurable malignancies. However, the extent to which clinicians clearly document end-of-life care discussions and code status preferences in ambulatory medical records is unknown. The goal of the study was to investigate the rate of code status documentation in the electronic longitudinal medical record (LMR) of patients with metastatic cancers. **Methods:** We conducted a retrospective review of outpatient medical records of 2498 patients with metastatic solid tumors seen at an academic cancer center from 10/1/06 through 2/29/08. An electronic database was used to gather information on patient demographics, cancer type, and visits to the cancer center. The sample consisted of patients with metastatic breast, colorectal, non-colorectal gastrointestinal (GI), bladder/kidney, ovarian, prostate, and lung cancers. For the study endpoints, we queried the LMR to determine completion and designation of code status, which could be documented as follows: full code, do not resuscitate (DNR)/do not intubate (DNI), or DNR/DNI with specific resuscitation requests. Multiple logistic regression was used to identify independent predictors of code status completion and resuscitation preference. **Results:** Among the 2498 patients, 508 (20.3%) had a documented code status. Code status was documented more frequently in patients with metastatic non-colorectal GI (193/609, 31.7%) and lung (179/583, 30.7%) cancers compared to patients with genitourinary malignancies (bladder/kidney [4/89, 4.5%], ovarian [4/93, 4.3%] and prostate [7/365, 1.9%] cancers). Independent predictors of having documented code status included cancer type and a greater number of visits to the cancer center. Younger patients and black patients were less likely to be designated as DNR/DNI. **Conclusions:** Despite the incurable nature of metastatic cancers, a minority of patients had a code status documented in the outpatient medical record. Given the importance of advanced care planning for those with terminal illness, interventions are needed to encourage discussion and documentation of end-of-life care preferences in patients with advanced cancer.

9577   General Poster Session (Board #K14), Mon, 8:00 AM - 12:00 PM

J-HOPE study: Evaluation of end-of-life cancer care in Japan from the perspective of bereaved family members. *M. Miyashita, T. Morita, K. Sato, S. Tsuneto, Y. Shima; The University of Tokyo, Tokyo, Japan; Seirei Mikatahara Hospital, Hamamatsu, Japan; Osaka University, Suita, Japan; Tsukuba Medical Center Hospital, Tsukuba, Japan*

Background: The Japan Hospice and Palliative Care Evaluation (J-HOPE) study was conducted in 2007 and 2008. The aim of the study was to evaluate the quality of end-of-life care at regional cancer centers (CCs), inpatient palliative care units (PCUs), and home hospices (HHs) in Japan from the perspective of bereaved family members. **Methods:** A nationwide cross-sectional mail survey was conducted in 2007 and 2008. The survey was sent to bereaved families 6–18 months after the death of a patient at 56 CCs, 100 PCUs, or 14 HHs. Outcome measures were the good death inventory, the care evaluation scale, and overall satisfaction with care. The protocol of this study was approved by the institutional review boards of each participating institution. **Results:** Of the 13,181 bereaved family members that received the survey, 8,163 (62%) participants returned their responses. Among bereaved family members, significantly fewer responded that patients were free from physical distress at CCs (50%) than PCUs (80%) and HHs (73%) (P<0.0001). Significantly fewer patients trusted the physicians at CCs (79%) when compared with PCUs (83%) and HHs (88%) (P<0.0001). Significantly fewer patients were valued as people at CCs (83%) than PCUs (93%) and HHs (95%) (P<0.0001). In addition, significantly fewer participants felt physicians should have worked to improve the patients' symptoms more quickly at CCs (55%) when compared with PCUs (78%) and HHs (77%) (P<0.0001). Significantly fewer participants felt nurse should improve their knowledge and skills regarding end-of-life care at CCs (51%) when compared with PCUs (76%) and HHs (78%) (P<0.0001). A total of 51% of participants reported that nurses should improve their knowledge and skills regarding end-of-life care. Finally, significantly fewer participants were satisfied with the end-of-life care provided by CCs (80%) when compared with PCUs (93%) and HHs (94%) (P<0.0001). **Conclusions:** Overall, the bereaved family members appreciated the end-of-life care provided by CCs, PCUs, and HHs in Japan. However, in some situations, the quality of end-of-life care provided by CCs was lower than that provided by PCUs and HHs.

9578   General Poster Session (Board #K15), Mon, 8:00 AM - 12:00 PM

Exploration of hereditary cancer and feasibility of genetic services at the end of life. *J. M. Quillin, J. N. Bodurtha, L. A. Siminoff, T. J. Smith; Virginia Commonwealth University, Richmond, VA*

Background: For families, optimal hereditary cancer assessment begins with an affected relative. End of life could be the last chance for testing or DNA banking. Many palliative care oncologists do not feel qualified to offer genetic services and are rarely doing so (NSGC, 2008). The genetic burden of cancer in palliative care is unknown. **Methods:** We investigated prevalence of hereditary cancer among dying cancer patients, previous genetic testing or DNA banking, and awareness and intentions regarding these services. In spring/summer 2008 we recruited and interviewed patients (or surrogate decision makers) from the VCUHS Palliative Care Unit. Genetic risk was characterized as "strong" using classification criteria developed by Scheuner et al. (1997) or other consensus diagnostic criteria. Statistics were assessed using SAS 9.1.3. **Results:** 43 (47%) patients (including 9 surrogates) agreed to participate. The most common diagnoses were leukemias/lymphomas (n=9), and cancers of the lung (n=8), colon (n=5), and breast (n=4). 8 of 43 (18.6%, 95% CI = 7.0% to 30.2%) patients had "strong" genetic risk. Currently available genetic tests could have addressed risk for several patients, especially for HNPCC and hereditary breast/ovarian cancer. None had previous testing or DNA banking. Of strong-risk patients (or surrogates), 7 (87.5%) had heard/read "almost nothing" or "relatively little" about testing. All had heard/read little or nothing about DNA banking. 83% would "probably get tested" if offered, and 72% would "probably" or "definitely" bank DNA. There were no significant differences by race/ethnicity, nor by genetic risk. **Conclusions:** The genetic burden of cancer may be at least as high in the palliative care population as in other clinical settings and is not being discovered upstream. Patient interest in genetic services is high, but awareness is low.

9579   General Poster Session (Board #K18), Mon, 8:00 AM - 12:00 PM

Correlates of hospice use in elders with cancer. *C. Owusu, S. Koroukian, E. Madigan; Case Western Reserve University, Cleveland, OH*

Background: Use of hospice has remained relatively low. We aim to identify correlates of hospice in elders with cancer, hypothesizing that the presence of functional limitations and geriatric syndromes are associated with hospice use, independently of age and comorbidities. **Methods:** The study population included Ohio residents age 65 years or older, diagnosed with breast (n=774), prostate (n=271), or colorectal cancer (n=1,011) during the period 07/1999–12/2001, receiving care through the Medicare fee-for-service system, and first receiving home health care (HHC) in the 30 days before or after cancer diagnosis. This strategy was aimed at obtaining clinical data at baseline, as documented in the HHC Outcome Assessment Information Set (OASIS). Our data source consisted of records from the Ohio Cancer Incidence Surveillance System (OCISS) linked with Medicare data, and the OASIS. In addition to descriptive analyses, multivariable logistic regression analysis was conducted to evaluate the association between hospice use, comorbidity, functional limitations, and geriatric syndromes, after adjusting for patient and tumor attributes. **Results:** Respectively across the anatomic cancer sites, hospice was used by 9.8%, 22.5%, and 25.1%, of patients. Hospice use increased significantly with age, and was higher among men than women. No differences in hospice use were observed by race, Medicaid status, or the presence of comorbidities. Conversely, hospice use was significantly higher (p < 0.001) among patients with functional limitations (24.0% vs. 16.5% in all others), and those with geriatric syndromes (23.8% vs. 15.3% in all others). Results from the multivariable logistic regression analysis indicated that comorbidities and functional limitations were not associated with hospice use, whereas patients with geriatric syndromes were 1.5 times as likely as those without geriatric syndromes to use hospice (adjusted odds ratio (AOR): 1.5, 95% confidence interval (1.2–1.9). **Conclusions:** The findings highlight the importance of clinical data that extend beyond comorbidities, when analyzing hospice use. Given marked differences in the disease trajectory across the anatomical cancer sites, future studies should analyze these associations separately in breast, prostate, and colorectal cancer patients.

Original Article

Symptom Prevalence and Longitudinal Follow-Up in Cancer Outpatients Receiving Chemotherapy

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Abstract

Palliative care for cancer patients receiving chemotherapy in the outpatient setting is important. The aims of this study were 1) to identify symptom prevalence and intensity in cancer patients receiving chemotherapy and 2) to describe longitudinal follow-up data obtained from repeated assessment using the distress thermometer (DT). Questionnaires were distributed to consecutive cancer outpatients newly starting chemotherapy at the first appointment and at every hospital visit. The questionnaire included the severity of 11 symptoms (M. D. Anderson Symptom Inventory [MDASI], Japanese version), the DT, and the need for help in four psychosocial areas (decision-making, economic problems, nutrition, and daily activities). In total, 4000 questionnaires were returned by 462 patients. The frequently identified problems were oral problems (21%), insomnia (19%), psychological distress (defined as a DT score of 6 or more; 15%), help with information and decision-making (14%), severe fatigue (8.2%), and severe appetite loss (6.3%). Cluster analysis identified four symptom clusters: 1) fatigue and somnolence; 2) pain, dyspnea, and numbness; 3) nausea, appetite loss, and constipation; and 4) psychological distress. Of 165 patients with a DT of score 6 or more, 115 patients (70%) demonstrated a DT score below 6 at a median of 17 days follow-up. In the remaining 50 patients who had a DT score of 6 or more at follow-up, 34 patients (68%) had one or more physical symptoms rated at 7 or more on an 11-point numeric rating scale. Compared with patients with a DT score below 6 at follow-up, patients with a DT score of 6 or more at follow-up had higher levels of all physical symptoms. Frequent symptoms experienced by cancer outpatients receiving chemotherapy may be categorized as: 1) psychosocial issues (insomnia, psychological distress, decision-making support); 2) nutrition-gastrointestinal issues (oral problems, appetite loss, nausea); 3) fatigue; and 4) pain, dyspnea, and numbness. Developing a systematic intervention program targeting these four areas is urgently required. The DT score may be highly influenced by coexisting physical symptoms, and future studies to develop an appropriate system to identify patients with

Key Words
Palliative care, neoplasms, chemotherapy, outpatient

Introduction

Increasing numbers of cancer patients receive chemotherapy in the outpatient setting,[1] and symptom palliation for these outpatients is urgently required. The recent literature suggests a broad range of palliative care needs, including physical symptoms, psychological distress, help with decision-making, and economic and practical support.[2-7]

Knowledge of symptom prevalence is important in clinical practice: 1) to anticipate problems and needs of patients; 2) to plan care for patients; and 3) to educate clinical staff to focus on particular symptoms.[8] To clarify symptom prevalence and understanding patient needs are the first steps to establish an effective palliative care system for patients.

Although many studies have addressed symptom prevalence in cancer patients, their findings may not generalize to cancer outpatients receiving chemotherapy because: 1) most studies include cancer patients receiving no anticancer treatments,[9-13] and few have specifically addressed cancer patients receiving chemotherapy; 2) sample sizes are usually small and nonrepresentative (i.e., limited to a certain specialty or patients consenting to a research intervention); and 3) no systematic survey has been performed in Japanese patients. In addition, cancer patients often have multiple concurrent symptoms,[14-18] and symptom management has shifted from individual symptoms to symptom clusters,[19-21] but few empirical studies have examined clustering symptoms in outpatient cancer patients receiving chemotherapy. To address these limitations, the first aims of this study were: 1) to clarify the prevalence of physical and psychological symptoms and concerns among a representative sample of cancer patients receiving chemotherapy in the outpatient setting and 2) to evaluate symptom clusters in this study population.

One of the most important symptoms is psychiatric comorbidity, including major depression and adjustment disorders. Despite the importance of early diagnosis and treatment, psychiatric comorbidity is difficult to identify and is often overlooked.[22,23] Recent empirical studies suggested that the Distress Thermometer (DT) can be an appropriate method to identify cancer patients with major depression and adjustment disorder.[24-27] The study populations in these studies, however, were limited to cancer patients referred to a psychiatric consultation service or a palliative care unit, or awaiting bone marrow transplantation, and only cross-sectional assessments were obtained. Longitudinal data from the outpatient chemotherapy setting, where the patient often experiences short-term deterioration and improvement of physical symptoms related to chemotherapy, are lacking. Clarifying longitudinal changes and the effects of physical symptoms on the DT can contribute to better understanding of the DT as a tool to identify psychiatric comorbidity in outpatient chemotherapy settings. The second aim of this study was thus to explore longitudinal change and the effects of physical symptoms on the DT.

Patients and Methods

This study included all cancer patients newly starting chemotherapy, with primary tumor sites of the lung, stomach or intestine, pancreas, bile duct, breast, ovary, and uterus, from April 2006 to December 2007. At the appointment regarding chemotherapy, pharmacists handed out a self-report questionnaire, with coaching on how to complete it.[28] This intervention was part of general instruction for outpatient chemotherapy, and required 10 to 20 minutes for completion. All pharmacists received an hour of educational instruction by the second author. Questionnaires were thereafter distributed at every hospital visit. If the

patients refused to complete the questionnaire or recognized no need, they were not obliged to complete it.

Demographic and medical variables (age, sex, primary cancer site, and opioid consumption) were obtained from medical charts. Opioid consumption was calculated as the daily amounts (mg) of oral morphine using the standard calculation ratio (transdermal fentanyl 25 µg/hour = oral oxycodone 40 mg = oral morphine 60 mg).

The Institutional Review Board approved the ethical and scientific validity of a retrospective analysis of the questionnaire data obtained as part of routine clinical activity. Admitted patients gave written consent that their clinical information could be used for clinical research.

Questionnaire

The study group developed the questionnaire on the basis of existing validated instruments[24,29–32] (available in our previous report[28]). The questionnaire included: 1) an open-ended question about the patient's greatest concerns; 2) 0–10 numeric rating scales of eight physical symptoms (pain, dyspnea, nausea, appetite loss, somnolence, fatigue, constipation, numbness) adopted from the Japanese version of the M. D. Anderson Symptom Inventory (MDASI);[29] 3) presence or absence of oral problems, fever, and insomnia; 4) a 0–7 numeric rating scale of overall quality of life adopted from item 29 of the European Organization for Research and Treatment of Cancer (EORTC)-C30 questionnaire;[30] 5) the DT;[24,31] 6) presence or absence of a need for help in four areas, i.e., information about treatment and decision-making, economic problems, nutrition, and daily activities;[7,32] and 7) wish for help from the specialized palliative care service.

Analyses

The prevalence of problems was calculated for each questionnaire. Analyses of opioid consumption were performed only for patients receiving opioids. For calculations, we adopted the definition of moderate and severe symptom intensity for MDASI items as 4–6 and 7–10, respectively. We used cutoff points on the DT of 6 or more based on previous findings,[24,31] and follow-up data of the DT was defined as the score obtained at a visit closest to

two weeks after the initial assessment and within four weeks. We determined that a patient had problems if s/he had MDASI symptom scores of 7 or more, an oral problem, fever, insomnia, a DT score of 6 or more, or an expressed need for any help with information and decision-making, nutrition, economic problems, or daily activities.

For comparisons, age was classified into two groups (less than 60 years and 60 years or more), and primary tumor sites were classified into three groups (chest, breast, and gastrointestinal). Univariate analysis was performed by the Mann-Whitney test or Kruskal-Wallis test, where appropriate. The effect of age was estimated with adjustment for gender and primary tumor site, and the effect of gender was estimated with adjustment for age and primary tumor site.

We performed cluster analysis and displayed a dendrogram using average linkage. Clusters were formed based on the distance between symptom ratings, which were calculated using squared Euclidian distances.

To explore the longitudinal change and effects of physical symptom on the DT, we initially identified all patients who had a DT score of 6 or more at any time during the study period. We then classified them into two groups: those with a DT score that declined to less than 6 at the follow-up and those with a DT score of 6 or more at the follow-up. We compared their demographic factors and the intensity of all physical symptoms.

For statistical analysis, SPSS for Windows (version 11.0) was used.

Results

During this study period, 472 patients newly started chemotherapy, and 10 refused to complete the questionnaire. In total, we obtained 4000 questionnaires from 462 patients (compliance rate, 98%). Each patient completed a median of six questionnaires during the study period. The percentages of missing values ranged from 2.8% (appetite loss) to 4.8% (dyspnea). Table 1 summarizes the patient characteristics. Forty-seven patients received an opioid, with a mean of 36 mg oral morphine equivalent/day (range, 5.0–170;

Table 1
Patient Characteristics (n = 462)

	n (%)
Age (yr ± SD)	62 ± 11
Sex	
Male	209 (45)
Female	253 (55)
Primary sites	
Lung, chest	150 (33)
Breast	113 (25)
Colon, rectum	65 (14)
Stomach	74 (16)
Uterus, ovary	33 (7.1)
Pancreas, bile duct	19 (4.1)
Others	8 (1.7)
Chemotherapy regimens	
Carboplatin and taxanes	100 (21)
Oral tegafur, gimeracil, oteracil with/without taxanes	80 (17)
Taxanes	76 (16)
Doxorubicin and cyclophosphamide	75 (16)
Fluorouracil	47 (10)
Gemcitabin	20 (4.3)
Oxaliplatin and 5-fluorouracil/leucovorin	10 (2.1)
Irinotecan (with/without taxanes)	9 (1.9)
Transtumab (with/without taxanes)	8 (1.7)
Gefetinib	7 (1.5)
Low-dose cisplatin and 5-fluorouracil	3 (0.6)
Vinorelbine	2 (0.4)
Oral capecitabine	2 (0.4)
Others	23 (7.1)

Table 2
Problems Identified in 4000 Questionnaires

Physical problems MDASI items	Prevalence (%)[a]			Mean ± SD (median)[b]
	Severe	Moderate	Total	
Fatigue	8.2	15	23	2.2 ± 2.5 (1.0)
Appetite loss	6.3	11	17	1.6 ± 2.4 (0.0)
Constipation	4.9	11	16	1.5 ± 2.2 (0.0)
Somnolence	4.6	9.1	15	1.7 ± 2.2 (1.0)
Pain	3.6	11	14	1.5 ± 2.0 (1.0)
Dyspnea	3.5	9.0	13	1.2 ± 2.0 (0.0)
Numbness	5.3	6.9	12	1.2 ± 2.2 (0.0)
Nausea	2.4	6.2	9.0	0.9 ± 1.7 (0.0)
Oral problems		21		
Fever		6.8		
Psychological problems				
Insomnia		19		
DT		15		
Concern				
Information and help with decision-making		14		
Nutrition		5.6		
Daily activities		4.6		
Economic problems		2.4		

[a]The percentages of responses with moderate (4–6) and severe (7–10) symptom intensity for MDASI items; the percentages of score of 6 or more for the DT; the percentages of problem presence for other items.
[b]Mean values calculated for only MDASI items.

oral oxycodone, n = 25; transdermal fentanyl, n = 11; and oral morphine, n = 11).

Symptom Prevalence and Symptom Clusters

Frequently identified problems were oral problems (21%), insomnia (19%), psychological distress (defined as a DT score of 6 or more; 15%), needing help with information and decision-making (14%), severe fatigue (8.2%), and severe appetite loss (6.3%) (Table 2). As a whole, problems were identified in half of all questionnaires.

Table 3 summarizes the effects of age and gender on each symptom. Younger patients reported significantly higher intensity of pain and nausea, and male patients reported significantly higher intensity of fatigue, dyspnea, appetite loss, and somnolence, after adjustment for other demographic variables. Opioid consumption was significantly higher in male patients.

Four symptom clusters emerged in this population (Fig. 1): 1) fatigue and somnolence; 2) pain, dyspnea, and numbness; 3) nausea, appetite loss, and constipation; and 4) psychological distress.

Longitudinal Change in the DT

Of 462 patients, 170 patients (37%) had a DT score of 6 or more at any time during the study period. Owing to a lack of follow-up data in five patients, we used 165 patients for follow-up analyses, and the median interval from the initial assessment was 17 days (range, 7–28 days).

Of 165 patients with a DT score of 6 or more, 115 patients (70%) had a score below 6 at follow-up (Fig. 2). In the remaining 50 patients who had a DT score of 6 or more at follow-up, 34 patients (68%) had one or more physical symptoms rated as 7 or more, and an additional 12 patients (24%) had one or more physical symptoms rated as 4 to 6.

Compared with patients with a DT score below 6 at follow-up, patients with a continuing DT score of 6 or more had higher levels of all physical symptoms at follow-up, including pain, dyspnea, nausea, appetite loss, somnolence, fatigue, constipation, and numbness (Table 4). The level of the DT and all physical symptoms in the initial assessment

Table 3
Association Between Symptom Intensity and Age, Gender, and Primary Tumor Site

	Age			Gender			Primary Tumor Sites			
	<60	>60	P	Male	Female	P	Abdominal	Chest	Breast	P
Fatigue	2.2 ± 2.3	2.2 ± 2.6	0.51	2.3 ± 2.6	2.1 ± 2.4	<0.001	2.5 ± 2.7	1.5 ± 2.1	2.3 ± 2.3	<0.001
Pain	1.7 ± 1.9	1.5 ± 2.0	0.003	1.5 ± 2.0	1.7 ± 2.1	0.70	1.6 ± 2.0	1.3 ± 2.0	1.9 ± 2.1	<0.001
Numbness	1.4 ± 2.2	1.1 ± 2.1	0.71	0.9 ± 1.8	1.5 ± 2.5	0.16	1.1 ± 1.8	0.7 ± 1.7	2.2 ± 3.0	<0.001
Dyspnea	1.2 ± 1.9	1.3 ± 2.0	0.41	1.3 ± 2.0	1.1 ± 1.9	<0.001	1.2 ± 1.8	1.3 ± 2.1	1.2 ± 2.0	0.15
Appetite loss	1.6 ± 2.3	1.7 ± 2.4	0.33	1.8 ± 2.5	1.5 ± 2.2	0.004	1.9 ± 2.5	1.4 ± 2.3	1.3 ± 2.1	<0.001
Nausea	1.1 ± 2.0	0.8 ± 1.6	<0.001	0.9 ± 1.8	0.9 ± 1.8	0.84	1.2 ± 1.8	0.6 ± 1.8	0.8 ± 1.7	<0.001
Somnolence	1.7 ± 2.0	1.8 ± 2.3	0.62	1.8 ± 2.3	1.7 ± 2.1	<0.001	2.0 ± 2.3	1.3 ± 2.0	1.8 ± 2.1	<0.001
Constipation	1.5 ± 2.1	1.6 ± 2.3	0.50	1.7 ± 2.4	1.4 ± 2.1	0.042	1.9 ± 2.3	1.2 ± 2.2	1.2 ± 2.0	<0.001
Psychological distress	3.2 ± 2.5	3.0 ± 2.8	0.066	2.9 ± 2.8	3.2 ± 2.6	0.32	3.2 ± 2.7	2.6 ± 2.7	3.5 ± 2.6	<0.001
Opioid consumption[a]	29 ± 27	28 ± 20	0.20	33 ± 25	18 ± 13	0.019	37 ± 28	23 ± 13	18 ± 15	<0.001

P-values for age were adjusted for gender and primary tumor sites. P-values for gender were adjusted for age and primary tumor sites.
[a]Oral morphine equivalent (mg/day).

demonstrated no significant difference between the groups.

Discussion

This is, to our knowledge, the first large study to identify symptom prevalence and intensity in cancer patients receiving chemotherapy, in addition to providing longitudinal follow-up data from the DT, in the outpatient setting of a general hospital, a typical regional cancer center in Japan.

The first important finding of this study was the clarification of the types of symptoms and concerns observed in cancer outpatients receiving chemotherapy. In this study, the predominant problems were psychosocial issues (insomnia, psychological distress, concern about information, and decision-making), nutrition-related issues (oral problems and appetite loss), and fatigue. Furthermore, four distinct symptom clusters were identified: 1) fatigue and somnolence; 2) pain, dyspnea, and numbness; 3) nausea, appetite loss, and

constipation; and 4) psychological distress. From these findings, the outpatient chemotherapy department should establish a palliative care program targeting: 1) psychosocial issues (insomnia, psychological distress, decision-making support); 2) nutrition-gastrointestinal issues (oral problems, appetite loss, nausea); 3) fatigue; and 4) pain, dyspnea, and numbness. Pharmacological treatments, collaboration with mental health professionals and dentists, and cognitive-behavioral nursing interventions are promising, and should be tested in future intervention trials of Japanese cancer patients.[33–38]

The second important finding of this study was longitudinal follow-up data from patients receiving outpatient chemotherapy who were repeatedly assessed using the DT. This is the first study to explore longitudinal changes in the DT in the outpatient chemotherapy setting. In this setting, 11% of all patients had a DT score of 6 or more at any time of treatment. The majority (70%), however, demonstrated a DT score below 6 within four weeks,
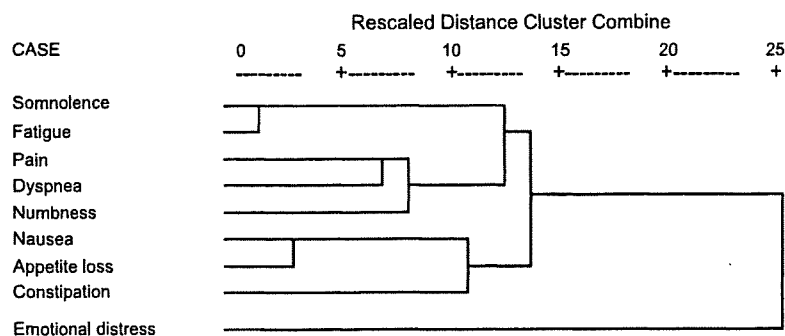
Rescaled Distance Cluster Combine

Fig. 1. Symptom cluster.

DT ≥ 6   Any physical symptoms ≥ 7 n=34
n=50   4-6 n=12
                                         < 4 n=4

DT ≥ 6
n=165

DT < 6
n=115
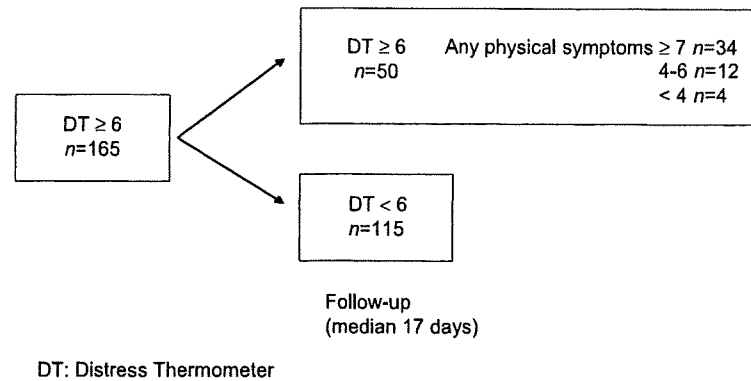
Follow-up
(median 17 days)

DT: Distress Thermometer

Fig. 2. Changes in the DT.

and the change in the DT was strongly associated with changes in physical symptoms. This result suggests that chemotherapy-related physical symptoms may highly influence the DT and result in rapid changes within several weeks in the outpatient chemotherapy setting. Future study is required to assess the usefulness of the DT as a clinical tool to identify patients with psychiatric comorbidity. Modifying the procedure, such as two-point follow-up, or encouraging symptom control to be

maximized before rating the DT, may be necessary. In the meantime, clinicians should note that a high score in the DT is not simply the indicator of psychiatric comorbidity. DT often indicates the need for palliating co-existing physical symptoms.

Age and gender differences in the symptoms of cancer patients are a focus of some researchers.[39–45] Consistent with previous findings from a systematic review of symptom prevalence,[44] higher pain intensity was significantly associated with younger age. This result indicates that younger patients need special attention in terms of pain management and active monitoring of pain. We also observed gender differences in some symptoms: male patients reported a higher intensity of fatigue, dyspnea, appetite loss, and somnolence, in addition to a higher dose of opioids, after adjustment for age and primary tumor sites. This result is not consistent with a large-scale study of patients receiving no anticancer treatments that revealed a gender difference in the prevalence of nausea.[44,45] Potential interpretations of these differences include: 1) different measurement methods (i.e., symptom intensity vs. frequency); 2) different treatment settings (receiving chemotherapy in the outpatient setting vs. palliative phase); and 3) analyses with or without adjustment for other factors. To determine the effects of age and gender on symptom intensity in this population, more pooled data from this setting is necessary.

This was a descriptive study of clinical experience and thus had considerable limitations. First, as the patients were a heterogeneous sample of primary tumor sites, stages, and

Table 4
Comparison of Patients with a DT of 6 or More
and Below 6 at Follow-up

	Patients with DT of 6 or More at Follow-up (n = 50)	Patients with DT Below 6 at Follow-up (n = 115)	P- value
Age	63 ± 9.6	63 ± 11	0.26
Sex (male)	56% (n = 28)	44% (n = 51)	0.17
At initial assessment			
Pain	3.2 ± 2.6	2.8 ± 2.8	0.63
Dyspnea	2.3 ± 2.6	1.8 ± 2.5	0.49
Nausea	2.1 ± 2.8	2.2 ± 3.0	0.11
Appetite loss	3.4 ± 3.1	3.4 ± 3.3	0.38
Somnolence	3.0 ± 2.5	2.5 ± 2.4	0.89
Fatigue	4.6 ± 3.0	3.5 ± 2.8	0.56
Constipation	2.4 ± 2.6	2.9 ± 3.2	0.027
Numbness	2.8 ± 3.0	1.8 ± 2.7	0.16
DT	7.4 ± 1.2	7.6 ± 1.3	0.15
At follow-up			
Pain	3.5 ± 2.7	1.5 ± 1.8	0.001
Dyspnea	3.1 ± 2.8	1.1 ± 1.8	<0.001
Nausea	2.2 ± 2.7	0.48 ± 1.0	<0.001
Appetite loss	3.7 ± 3.0	1.1 ± 1.8	<0.001
Somnolence	3.9 ± 2.7	1.3 ± 1.6	<0.001
Fatigue	5.0 ± 3.0	1.9 ± 2.3	0.005
Constipation	3.1 ± 2.9	1.4 ± 2.3	<0.001
Numbness	3.0 ± 3.1	1.0 ± 1.7	<0.001

Analyses were performed on patients who had a DT score of 6 or more at any time in this study period (n = 165).

chemotherapy regimens, the results cannot be automatically generalized to specific target populations. We believe that this is not a fatal flaw of this study, but rather can be a strength, because we need to develop a useful system for heterogeneous outpatients receiving chemotherapy. Second, this was a single-institution study. We believe, however, that the results are generalizable to other institutions, as our hospital is a typical general hospital functioning as a regional cancer center. Third, we adopted the single-item DT to increase patients' compliance. The combined use of the DT and impact thermometer (i.e., the degree of interference with daily activity) might decrease the influence of physical symptoms. Finally, we did not analyze the effects of chemotherapy cycle of each regimen on symptom intensity, and this should be explored in a future study.

In conclusion, frequent symptoms of cancer outpatients receiving chemotherapy are categorized as: 1) psychosocial issues (insomnia, psychological distress, decision-making support); 2) nutrition-gastrointestinal issues (oral problems, appetite loss, nausea); 3) fatigue; and 4) pain, dyspnea, and numbness. Developing a systematic intervention program targeting these four areas is urgently required. The DT might be an effective tool to monitor psychological distress but can be highly influenced by coexisting physical symptoms. Future studies are required to determine the intervention effects in the above four areas and to develop more appropriate procedures to identify patients with psychiatric comorbidity.

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Original Article

Quality Indicators of End-of-Life Cancer Care from the Bereaved Family Members' Perspective in Japan

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Abstract
Although several studies about quality indicators (QIs) in end-of-life (EOL) cancer care have been conducted, the bereaved family members' perspective of QIs has not been investigated in Japan. The primary aim of this study was to rate QIs for EOL cancer care from the bereaved family members' perspective in Japan. A cross-sectional anonymous questionnaire was administered to bereaved family members of cancer patients who had died in an inpatient palliative care unit. We mailed questionnaires to potential respondents in March 2007. Of 160 questionnaires sent, 109 responses were analyzed (effective response rate, 76%). Eighty-eight percent of participants rated the medical examination by the palliative care team or specialist positively, 80% rated the availability of emergency room (ER) services or after-hour examinations positively, and 77% agreed that medical orders to alleviate pain or suffering were documented in the chart. Only 15% of the respondents agreed that it was preferable to die at home. Additionally, 59% and 46% of participants agreed that the occurrence of a fall or pressure ulcer and death by an adverse event from surgery or chemotherapy were poor QIs, respectively. Moreover, only 17% and 14% rated the short interval from chemotherapy to dying and frequent visits to the ER or after-hour examination as poor QIs, respectively. In Japan, it would be appropriate to extract QIs from medical charts. However, many items suggested as QIs in a previous study were found to be different from the opinions expressed by bereaved family members in this study. J Pain Symptom Manage 2009;37:1019–1026. © 2009 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Introduction

It is important to measure the quality of cancer care.[1-5] End-of-life (EOL) care is one of the principal components of cancer care. Therefore, measuring the quality of care for EOL cancer patients is a critical issue.[6-8]

In the United States, Earle et al. identified quality indicators (QIs) of EOL cancer care from an administrative database using the Delphi method.[9] These indicators included aggressiveness of care, hospice use, emergency room (ER) visits, and intensive care unit (ICU) admissions; they measured and validated the reliability of data extraction from the cancer registry and Medicare database.[10,11] In Canada, Barbera et al. measured Earle et al.'s QIs and identified factors related to poor-quality EOL care.[12] Furthermore, Grunfeld et al. investigated 14 QIs of EOL care from cancer registry, medical claims, and palliative care databases based on Earle et al.'s QIs, and performed an additional expert panel interview.[13] In other efforts to maintain quality of EOL care, the National Quality Forum presented their performance measures[14] and the American Society of Clinical Oncology proposed Consensus Care Standards for Palliative Care to improve delivery of palliative care in the United States.[15]

As an alternative method, Wenger and Shekelle developed QIs from medical chart reviews and interviews.[16] In the Assessing Care of Vulnerable Elders (ACOVE) project, they selected 22 conditions to develop QIs. The potential QIs were extracted from existing guidelines, systematic literature reviews, and expert opinions. For EOL care, 14 indicators were identified, including surrogate decision makers, advance directives, documentation of care preferences, life-sustaining treatment, and treatment of distress, such as pain, dyspnea, and spiritual issues.[17]

However, these proposed QIs were mainly based on expert opinion from health professionals. The perspectives of patients and families have rarely been taken into account. Factors considered important in EOL care

might differ among patients, families, and health professionals.[18] Therefore, it is important to ask patients and families to identify QIs that are important to them. The bereaved family members are generally strong surrogates for cancer patients. Because they experience the disease trajectory from diagnosis to dying, they could provide rich information about the quality of EOL cancer care. In addition, identification of QIs should consider cultural characteristics, such as those that may apply in Japan.

The Japanese Ministry of Health, Labour, and Welfare has strongly supported dissemination of specialized palliative care services, with coverage of palliative care units (PCUs) by National Medical Insurance since 1990. The number of PCUs has dramatically increased from five in 1990 to 174 in August 2007. In contrast, the growth of home-based palliative care programs has been slow, as inpatient palliative care teams were not covered by National Medical Insurance until 2002. The most common type of specialized palliative care service in Japan is the PCU. Therefore, we sampled bereaved family members in the PCU.

We surveyed bereaved family members of patients who died in the PCU on the appropriateness of QIs. The aims of this study were: 1) to rate QIs of EOL cancer care; and 2) to explore factors related to the evaluation of QIs by bereaved family members of patients who died in a PCU in Japan.

Methods

Sample, Setting, and Procedure

A cross-sectional anonymous questionnaire was administered to bereaved family members of cancer patients who had died in an inpatient PCU in Shizuoka Prefecture, Japan. To find potential participants, we identified bereaved family members of patients who had died from April 2005 to April 2006. The inclusion criteria were as follows: 1) the patient died in a PCU because of cancer; 2) the patient was aged 20 years or more; and 3) the patient

was in the hospital (not just the PCU) for at least three days. The family member who cared for the patient the longest regardless of blood relationship to the patient completed the questionnaire. The exclusion criteria were: 1) the participant was recruited for another questionnaire survey for bereaved family members; 2) the participant would have suffered serious psychological distress as determined by the primary physician (e.g., family member was treated for psychological distress after death of the patient or who was depressed at the bereaved family's meeting); 3) the cause of death was treatment-related or caused by injury; 4) there was no bereaved family member who was aged 20 years or more; 5) the participant was incapable of replying to a self-reported questionnaire; and 6) the participant was not aware of the diagnosis of malignancy.

We mailed questionnaires to potential respondents in March 2007, and a reminder was sent in April 2007 to those who did not respond. We asked the primary caregiver to complete the questionnaire. If the respondents did not want to participate in the survey, they were asked to return the questionnaire with "no participation" indicated and a reminder was not mailed to them. The ethical and scientific validity of this study was approved by the institutional review boards of Seirei Mikatahara Hospital.

Measurements

We asked the bereaved family members to rate the appropriateness of QIs of EOL cancer care (in the last month) using a 5-point Likert scale (1: absolutely disagree; 2: disagree; 3: unsure; 4: agree; 5: absolutely agree). The attributes were generated based on a previous literature review[9–11,13,17] and selected based on items suggested from previous Western studies and discussion among the authors. We asked about these items to rate their appropriateness as QIs in accordance with the experience of the bereaved families. The question was as follows: "We are investigating measurements to evaluate the quality of medical treatment. How much do you think the following attributes are important for measuring the appropriateness of good (or poor) medical treatment?"

To evaluate good QIs of EOL cancer care, we asked about 22 items from seven domains (italicized) as follows:

> *Documentation of physical and emotional status in medical chart.* "Medical orders by physician for pain or suffering," "presence and level of pain and suffering," "patient's anxiety or concerns," "patient's use of the bathroom," and "family's anxiety or concerns."[19]
> *Documentation of disease explanation in medical chart.* "Explanation of medical condition to family," "explanation of medical condition to patient," and "prognosis disclosure to the patient from the physician."
> *Documentation of discussion about resuscitation in medical chart.* "Discussion about resuscitation (for example, cardiac massage) with the family" and "discussion about resuscitation (for example, cardiac massage) with the patient."
> *Documentation of religion in medical chart.* "Patient's religion."
> *Sufficient medical treatment.* "Medical examination by palliative care team or palliative care specialist," "availability of emergency room or after-hours examination according to patient's wishes," "medical examination by interdisciplinary team including physician, nurse, and pharmacologist," "medical examination by psycho-oncologist or psychologist (specialist in mental health care for cancer patients)," "appropriate opioid use for the treatment of pain," "frequent medical examination by physician," and "medical treatment in accordance with guidelines."
> *Use of low-cost treatment.* "Use of lower cost treatment in case of equal effectiveness."
> *Dying situation.* "Patient died with family present," "patient died at place of his or her choosing," and "patient died at home."

As for poor QIs of EOL cancer care, we asked about 11 items within four domains (italicized) as follows:

> *Trouble with medical treatment.* "Occurrence of fall or pressure ulcer," "died by adverse event due to surgery or

chemotherapy," and "frequent change of physician-in-charge or hospital."

ER visits and hospital stays. "Frequent visits to ER or after-hours examinations," "long stay in the hospital," and "use of intensive care unit."

Short interval from treatment to dying. "Short interval from chemotherapy to dying" and "short interval from surgery to dying."

Medical treatment during last phase. "Short interval from admission to hospice to dying," "dying at hospital," and "cardiopulmonary resuscitation was performed."

In addition, the patient's age, sex, and number of hospital days were extracted from medical databases. We asked the bereaved family member's age, sex, relationship to the patient, and frequency of attending the patient.

Analysis

Before the analysis, we conducted an explanatory factor analysis with an unweighted least square method to classify the items for good QIs and poor QIs. We identified six domains of good QIs and four domains of poor QIs, as mentioned earlier.

To simplify the analysis, we first calculated the total percentage of "absolutely agree" and "agree" for each item in both good QIs and poor QIs. Second, we tested related factors of good QIs and poor QIs with the Wilcoxon rank sum test with significance level of 0.05 and two-tailed tests, because several domains had a skewed distribution. All analyses were performed using the statistical package SAS version 9.1 (SAS Institute, Cary, NC, USA).

Results

Participant Characteristics

Of 183 questionnaires sent to bereaved family members, 23 were undeliverable and 121 were returned (response rate, 76%). Of those returned, 12 individuals refused to participate. Thus, 109 responses were analyzed (effective response rate, 68%).

Participant characteristics are shown in Table 1. Patient characteristics were as follows: The mean age ± standard deviation (SD) was 72 ± 13 years; males made up 43% of the total; and the mean number of hospital days ± SD

Table 1
Participant Characteristics (n = 109)

Patient demographics	
Age (mean ± SD, years)	72 ± 13
Gender (male), n (%)	47 (43)
Hospital days (mean ± SD)	56 ± 74
Bereaved family member demographics	
Age (mean ± SD, years)	61 ± 12
Gender (male), n (%)	42 (39)
Relationship	
Spouse, n (%)	47 (44)
Children, n (%)	42 (39)
Children-in-law, n (%)	8 (7)
Sibling, n (%)	4 (4)
Others, n (%)	6 (6)
Frequency of attending patient	
Every day, n (%)	80 (74)
4—6 days/week, n (%)	15 (14)
1—3 days/week, n (%)	11 (10)

Several totals do not equal 100% because of missing values.

was 56 ± 74. The length of hospitalization was longer than the national standard (about 40 days). This is because this unit is free of charge for private rooms. Japanese PCUs usually have longer hospital stays compared with Western countries. As for bereaved family members, the mean age was 61 ± 12 years; 39% were males; spouses made up 44% of the total, and 39% were children; and 88% attended the patient every day or four to six days a week.

Good Quality Indicators of End-of-Life Cancer Care

We show the evaluation of good QIs of EOL cancer care in Table 2. Agreement (absolutely agree and agree) of bereaved family members with good QI items for documentation in the medical chart were as follows: *documentation of medical condition,* 64%—78%; *documentation of disease explanation,* 42%—77%; *documentation of discussion of resuscitation,* 33—44%; and *documentation of religion,* 13%. As for *sufficient medical treatment,* 36%—83% agreed with each item. The items that received the most agreement were "medical examination by palliative care team or palliative care specialist" (83%) and "availability of emergency room or after-hours examination according to patient's wishes" (80%). Sixty-one percent agreed with the item *use of low-cost treatment.* As for the *dying situation,* 15%—65% agreed with each item, although only 15% agreed that dying at home was a good QI.

Table 2
Appropriateness of Good QIs in EOL Cancer Care Rated by the Bereaved Family Members

	n	%
Documentation of physical and emotional status in medical chart		
Medical orders by physician for pain or suffering	85	78
Patient's pain and suffering	80	73
Patient's anxiety or concerns	78	72
Patient's use of the bathroom	74	68
Family's anxiety or concerns	70	64
Documentation of disease explanation in medical chart		
Explanation of medical condition to family	84	77
Explanation of medical condition to patient	73	67
Prognosis disclosure to the patient from physician	46	42
Documentation of discussion of resuscitation in medical chart		
Discussion about resuscitation with family	45	41
Discussion about resuscitation with patient	36	33
Documentation of religion in medical chart		
Patient's religion	14	13
Sufficient medical treatment		
Medical examination by palliative care team or palliative care specialist	90	83
Availability of ER or after-hour examination according to patient's wishes	87	80
Medical examination by interdisciplinary team including physician, nurse, and pharmacologist	84	77
Medical examination by psycho-oncologist or psychologist	77	71
Appropriate opioid use for the treatment of pain	65	60
Frequent medical examination by physician	56	51
Medical treatment in accordance with guidelines	39	36
Use of low-cost treatment		
Use of low-cost treatment in case of equal effectiveness	66	61
Dying situation		
Patient died with family present	71	65
Patient died at place of choosing	53	49
Patient died at home	16	15

Figures are total number and percentage of "absolutely agree" and "agree."

Poor Quality Indicators of End-of-Life Cancer Care

We show the evaluation of poor QIs of EOL cancer care in Table 3. As for the occurrence of *adverse events*, 47%—59% agreed with each item. Agreement (absolutely agree and agree) with the following items was considerably less: *ER visits and hospital stays*, 2%—14%; *short*

Table 3
Appropriateness of Poor QIs in EOL Cancer Care Rated by the Bereaved Family Members

	n	%
Adverse events		
Occurrence of fall or pressure ulcer	64	59
Died by adverse event from surgery or chemotherapy	50	46
Frequent change of physician-in-charge or hospital	51	47
ER visits and hospital stays		
Frequent visits to ER or after-hour examinations	15	14
Long stay in the hospital	3	3
Use of ICU	2	2
Short interval from treatment to dying		
Short interval from chemotherapy to dying	18	17
Short interval rom surgery to dying	12	11
Medical treatment of last phase		
Short interval from admission to hospice to dying	6	6
Dying at hospital	0	0
Cardiopulmonary resuscitation was performed	0	0

Figures are total number and percentage of "absolutely agree" and "agree."

interval from treatment to dying, 11%—17%; and *medical treatment of last phase*, 0%—6%.

Factors Related to Evaluation of Good and Poor Quality Indicators

Table 4 shows factors that were significantly different between good QIs and poor QIs. Bereaved family members of patients with a long hospital stay were more likely to rate documentation of the medical condition in the chart positively. Older bereaved family members (≥65 years) were also more likely to agree that disease explanation was documented in the chart. In addition, women rated the sufficiency of medical care and the dying situation more positively. Bereaved family members of patients who had long hospital stays and younger family members were more likely to indicate the occurrence of adverse events (a poor QI).

Discussion

Most participants did not consider ER visits or ICU use, a short interval from treatment to dying, or medical treatment in the last phase of life to be poor QIs. In addition,

most bereaved family members rated death at a hospital positively in this sample.

In previous studies, aggressive treatment in EOL settings was regarded as a poor QI.[9,10,13] However, in our study, only 17% rated a short interval from chemotherapy to dying as a poor QI. In a Japanese good death study, fighting against cancer was an important issue for achieving a good death for some people.[20] In addition, Japanese bereaved families of patients in PCUs were distressed by the cessation of anticancer treatment and transition to palliative care.[21] Usually, family members were not able to abandon disease-modifying therapy and wished to prolong the loved one's life. Therefore, treatment availability is an important issue for family members. Similarly, ER visits or use of the ICU was not rated as a poor QI, in contrast to previous studies.[9,12,13] From the bereaved family member's perspective, it is important to be able to use the ER or ICU. These results do not conflict with previous studies in Western countries. The negative attitude toward aggressive treatment would include reaction to the high cost and distress of life-prolonging treatment, including chemotherapy, in the last phase of life.

Although the patient dying in a PCU did not usually experience aggressive treatments, the families desired life-prolonging medical treatment for the patient and were afraid that care would be insufficient. The availability of medical treatment is an important issue from the Japanese bereaved family members' perspective. Therefore, aggressive treatment and ER/ICU visits are not included as poor QIs for all cancer patients in Japan. We need to conduct further research to explore the relationship between aggressive treatment, ER/ICU visits, and the achievement of a good death in Japan.

The second finding of our study is the positive attitude toward dying in a hospital. Although 49% rated dying at a favorite place as preferable, only 15% rated dying at home as the preferred place. In addition, only 3% rated a long stay in the hospital and none considered dying at a hospital to be a poor QI. However, we should be careful in interpreting these results. The participants are the bereaved family members who lost a loved one in a PCU. In Japan, only 6% of cancer patients died at

home in 2004. These results suggest that it is currently difficult to die at home in our country because of the lack of home palliative care specialists and the care burden on the family. Therefore, the role of inpatient facilities is important if the patient or family desire inpatient care. Most Japanese prefer "not being a burden to others" as an important component of a good death.[20] Therefore, although a nationwide Japanese study revealed that almost half the general public wanted to die at home,[22] dying at a hospital is not considered a poor QI of EOL cancer care. Although some patients prefer to die at home, the medical system in Japan may not make it practical. In addition, 65% of participants considered the patient dying in the presence of family members to be a positive QI. This shows that the place of death is not as important as the environment of care at the time of death. The medical practitioner should support an intimate relationship between the patient and family in EOL cancer care.

The documentation of medical conditions and disease explanation was rated as a good QI by bereaved family members. This is in agreement with the results of previous Western studies.[16,17] These results would suggest that documentation and communication among physician, patient, and family were recognized as important from the bereaved family members' view. However, only 42% of participants agreed that prognosis disclosure to the patient from the physician was documented in the chart. In Japan, not all patients want to know their prognosis. Careful communication between physician and patient about prognosis is necessary.[22] In addition, the occurrence of adverse events, which could be determined from a medical chart review, was rated as a poor QI. An audit of the documentation of QIs would be appropriate and feasible in Japan.

Most participants agreed that there was medical treatment, including medical examination by the palliative care team or palliative care specialist; medical examination by an interdisciplinary team including a physician, a nurse, and a pharmacologist; and medical examination by a psycho-oncologist or psychologist. Although care by an interdisciplinary team is necessary for EOL care, it is inadequate in Japan.[23] In addition, the number of palliative care professionals is insufficient.

Table 4
Factors Related to Good QIs and Poor QIs

	n	Mean ± SD	P-value[a]
Domains of good QIs and variables			
Documentation of physical and emotional status in medical chart			
Hospital days			
<30	54	3.8 ± 0.6	0.016
≥30	48	4.1 ± 0.7	
Documentation of disease explanation in medical chart			
Age (years)			
<65	67	3.7 ± 0.6	0.007
≥65	35	4.1 ± 0.7	
Sufficient medical treatment			
Gender			
Male	41	3.7 ± 0.5	0.030
Female	62	3.9 ± 0.6	
Dying situation			
Gender			
Male	41	3.4 ± 0.7	0.023
Female	62	3.7 ± 0.6	
Domains of poor QIs and variables			
Adverse events			
Hospital days			
<30	52	3.3 ± 0.9	0.002
≥30	49	3.7 ± 0.9	
Age (years)			
<65	66	3.7 ± 0.7	0.002
≥65	35	3.1 ± 1.0	

[a]Wilcoxon rank sum test.

The education and development of specialized palliative care providers is an urgent need.[24]

In Japan, also, most patients favor dying at home. We think that patients receiving home hospice care would not object to treatment in the ER or ICU. The sense of "safety" is important for EOL cancer patients. Family caregiver's time off and equipment at home vary among individuals. Overall, Japanese home hospice is less advanced than in the United States and United Kingdom. The status of home palliative care patients and caregivers is still unclear.

Limitations and Future Perspectives

This study has some limitations. First, the study was conducted at a PCU. The Japanese PCU usually does not provide aggressive treatment in the last phase of life.[25] If bereaved family members had experienced aggressive treatment in the EOL stage, their evaluation might have changed. In addition, the patient and family expressed a desire to be admitted to a PCU. Moreover, most Japanese bereaved families are satisfied with the care in the

PCU.[26] Therefore, participants rated inpatient care positively. For these reasons, the results of this study might not be generalizable to other settings. Second, in Japan, the progress of home hospice care is slower than in the United States and United Kingdom, and therefore, hospital stays are longer than in Western countries. This study might not be generalizable to Western countries. Third, the participants were surveyed one to two years after their family member's death; hence, there is a potential for recall bias. Finally, we investigated the evaluation of ACOVE's attributes from bereaved family members. However, the ACOVE project is aimed at the ambulatory elderly, not cancer patients. Although we believe that the concept of the ACOVE project is applicable to measuring the quality of cancer care in Japan, it might become a worldwide standard. It is necessary to evaluate QIs from medical charts targeting EOL cancer care.

In future studies, we should examine a broader range of bereaved families, including those with loved ones dying on general hospital wards and at home. Most of our results differed from previous studies in Western countries. It is still unclear whether these results are unique to Asian countries, including Japan. Further research comparing the Japanese experience with Western countries is needed. In addition, we need to clarify the relationship between the QIs examined and consequences of care, such as a good death.

Conclusions

In conclusion, we asked bereaved family members to evaluate QIs in EOL cancer care. Most participants did not consider ER visits or ICU use, a short interval from treatment to dying, and medical treatment in the last phase to be poor QIs. In addition, most bereaved family members rated death at a hospital positively. The documentation of medical conditions and disease explanation was rated as a good QI, and the occurrence of adverse events was rated as a poor QI. An audit of documentation would be appropriate. However, many QIs suggested in the previous study were different from those of the bereaved family members in this survey. We need further research regarding development of QIs in Japan.

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Original Article

Late Referrals to Palliative Care Units in Japan: Nationwide Follow-Up Survey and Effects of Palliative Care Team Involvement After the Cancer Control Act

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Abstract
*Referral to palliative care units tends to be delayed. In Japan, the Cancer Control Act was
established in 2006 to improve the quality of life of cancer patients by facilitating greater
access to specialized palliative care services. The primary aims of this study were to clarify the
family-perceived appropriateness of the timing of referral to palliative care units after the
Cancer Control Act, and to determine the effects of the involvement of the palliative care team
on the family-perceived referral timing. An additional aim of this study was to clarify the
family-perceived usefulness of the palliative care team. A multicenter questionnaire survey
was conducted on a sample of 661 bereaved family members of cancer patents who were
admitted to palliative care units in Japan. A total of 451 responses were analyzed (response
rate: 68%). Half of the bereaved family members regarded the timing of referrals to palliative
care units as late or too late: too late (25%, n = 114), late (22%, n = 97), appropriate
(47%, n = 212), early (2.4%, n = 11), and very early (1.8%, n = 8). Among 228
families who reported that patients had commented on the timing of referrals, about half
reported that the patients said the timing of referral was late or too late: too late (23%,
n = 52), late (21%, n = 49), appropriate (48%, n = 110), early (4.4%, n = 10), and
very early (3.1%, n = 7). The families of patients with a palliative care team (n = 191)
tended to report less frequently that they believed the referral timing to be late or too late (43%
vs. 51%, P = 0.073); they also reported significantly less frequently that the patients said
that the referral timing was late or too late (36% vs. 52%, P = 0.037). The percentages of
families who evaluated the palliative care team as useful or very useful were: 93% (symptom
control), 90% (emotional support), 92% (family support), and 87% (care coordination).*