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

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

In our preceding analysis of the same survey, perceptions of PCUs as "alleviates pain" and "provides care for families" were significantly associated with preferences for PCUs as place of end-of-life care.[19] It is, therefore, particularly important to disseminate adequate information about empirical evidence for effective pain control and the palliative care concept, including treatment of the patient and their family as the unit of care. Future research is needed to clarify the most effective strategy to improve public awareness of palliative care.

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

Moreover, it is important that both perceptions were significantly associated with overall satisfaction with care and differed considerably among institutions. In Japan, there are significant differences in medical and nonmedical care performed in certified PCUs,[21] possibly due to each institution's economic and staffing pressures, and their staff's philosophy of what constitutes palliative care. Recent literature suggests that terminally ill cancer patients choose palliative chemotherapy as a means of maintaining a sense of hope,[22-24] and thus the fact that no anticancer treatments are available at PCUs can make patients and families feel abandoned.[14] This can become a barrier to providing palliative care. More discussion is needed about the most appropriate medical system for a certain group of patients who receive chemotherapy and have difficult symptoms requiring a specialized inpatient palliative care service. That is, because patients and families may have equal access to quality specialized palliative care whether or not they receive anticancer treatment, we believe that PCU administration criteria should change from focusing on disease incurability to degree of need for specialized palliative care, and functional classification of specialized palliative care services (i.e., primary, secondary, and tertiary PCUs) should be established.[25,26] In addition, further efforts to minimize the real differences in provided care among PCUs are essential. This would enable patients receiving anticancer therapy to temporarily receive quality symptom control in PCUs, reflecting a continuum of cancer care.

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

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

Acknowledgments

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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

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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.

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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 dis-

closure 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.

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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

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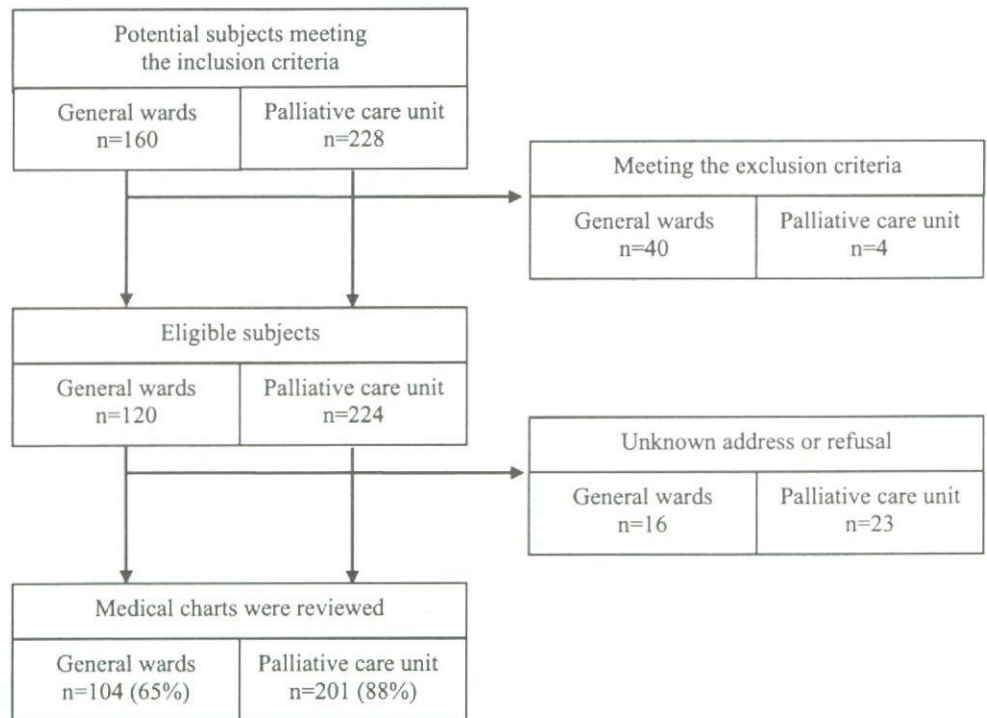
we separately calculated results from general wards and PCU and then compared the differences between the settings. For DNR decisions and treatments and palliative care drugs in the last 48 h of life, we also separately calculated results and then compared the differences to examine quality of end-of-life 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%, $p=0.739$).

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 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

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)
ICU Intensive care unit	Proportion receiving chemotherapy within 14 days of death	13	(4.3)	6	(5.8)	7	(3.5)
[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	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)

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

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

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

It is essential to discuss factors associated with the high use of opioids and palliative sedation and small volume hydration in PCU. Opioids and dehydration can cause delirium in terminally ill cancer patients [36], and thus, palliative sedation might be required to control delirium associated with frequent opioid use and small volume hydration in PCU. Some studies investigating the effectiveness of opioid rotation and hydration have found that hydration decreased myoclonus and sedation of dehydration [31], while hydration and opioid rotation decreased agitated delirium [37]. However, the latter finding was not confirmed by additional research [38], and beside, hydration did not improve delirium in the last few days of life [29]. The prevalence of hydration was similar, and opioid rotation was actively implemented in PCU. In addition, large-volume hydration may be unsustainable due to the presence of other fluid retention symptoms. As mentioned above, patients with severe symptoms can be easily transferred to PCU; therefore, the high use of opioids and sedation was considered to be reasonable.

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

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

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

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

Conclusion

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

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

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ELSEVIER

A study of disease management activities of hip osteoarthritis patients under conservative treatment

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KEYWORDS
Disease management;
Hip osteoarthritis;
Conservative treatment

Summary   The study aimed to determine the status of disease management activities that patients under conservative treatment actually performed and to examine the relevant factors in performing or not performing the activities. A survey was conducted with hip OA patients of the orthopaedic outpatient service of one university hospital in Japan. Results indicated that it is necessary to advise patients at an earlier stage of the disease to perform the management activities and to develop a program to link the advice to actual performance of the activities.
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Editor's comments
Mobility and mobilising patients are the essence of orthopaedics. This study provides a fascinating and much needed insight into the approach we should adopt when using conservative treatments for osteoarthritis of the hip even though many patients go on to have the almost inevitable surgery.
PD

Introduction

Hip osteoarthritis (OA) is a progressive chronic disease with pain and restricted range of motion, causing disorder in activities in daily life (ADL). In Japan, secondary disease of the hip joint resulting from dysplastic hip is common. In most cases, patients have symptoms such as pain or discomfort in their 1920s and 1930s and are diagnosed as having hip

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disease. Gradual degeneration over time is a characteristic of the disease, and in the slow progression of the symptoms, pain and restriction in the range of motion gradually increase over 10–30 years. If congruency in not acceptable, osteotomy is performed to prevent further development of OA (Honda et al., 1999). However, a limited number of patients can have surgery because of the indication required for arthroplasty, such as joint compatibility and the rate of progression. Typical surgery, total hip replacement (THR), is performed in Japan for OA patients aged 60 or over who have disorders in ADL due to unrelieved pain (Creamer et al., 1998; Anon., 2000; Dolin et al., 2003). Therefore, conservative treatment is the first line in treatment of OA. Patients are required to find a way of controlling their pain and managing the disease, by doing weight management and muscle training in daily life (Anon., 2000; Manek and Lane, 2000).

In conservative treatment, weight reduction and muscle training are firstly recommended. Weight reduction is important to reduce the load on the hip joint (Arokoski, 2005). The hip joint is subjected to a load three times that of the body weight (Davy et al., 1988) and patients are directed not to lift heavy objects or remain standing for long periods. A large randomized clinical trial (RCT) (van Baar et al., 1998) verified that weight reduction and muscle training lead to pain relief and improvement in the range of motion of the hip. The guideline suggests that exercises, including stretching and muscle training, have an effect of slowing the progress of the disease (Hochberg et al., 1995; Anon., 2000). Doctors explain this importance to patients and advise them to accept and practice the therapy in their daily lives.

However, in contrast to those who have surgery, patients having conservative treatment regimes usually visit the university hospital only about once a year and have few opportunities for medical guidance and information provision. If the disease becomes worse, and patients cannot relieve their pain even though muscle training is performed aggressively, doctors may suggest total hip replacement. Doctors give most patients the instruction of muscle training, mainly strengthening the adductors by lifting each leg in a recumbent position. Additionally, individual training can be provided whenever they request. Disease management is controlled by the patients themselves.

Methods

The survey was conducted with OA patients of the orthopaedic outpatient service of one university hospital who agreed in writing to participate in the study and satisfied the following conditions:

- Had not undergone a joint-preserving procedure or THA.
- Receiving conservative treatment using a cane and drugs such as NSAIDs and physical therapy — including exercises and stretch exercises.
- Were between the ages of 20 and 80 at the time of survey.
- Could communicate in Japanese.
- Had no dementia and could fill in the questionnaire sheet.

Patients were asked through doctors to cooperate in the research. Our staff explained the aim of the survey to the patients in a private room and received their letters of consent. Staff gave the patients the questionnaire to fill in by themselves in the room and collected the questionnaire directly from the patients. Their current Japanese Orthopaedics Association (JOA) score and number of years of being a patient were extracted from medical records, and the height and weight of the patients were measured. The survey was conducted from August 2003 to August 2004.

The questionnaire presented nine statements regarding disease management activity:

1. I try not to remain standing for long periods of time.
2. I do not choose shoes with high heels or hard soles.
3. I am careful about the walking distance and speed in daily life.
4. I use a cane or hold a handrail when necessary.
5. I try not to lift heavy objects.
6. I do muscle training.
7. I am careful with my diet to avoid weight gain.
8. I do stretching.
9. I do exercise to prevent weight gain.

The subjects answered Yes or No to these statements.

Other factors relevant to the disease management activity, such as age, number of years of being a patient, body mass index (BMI), JOA score, and discomfort in daily life were also studied. "Discomfort in daily life" was investigated by asking patients about what they felt was difficult in their daily life using answers graded from 1 to 5. The questions were:

1. There are no local medical specialists for disease management.
2. I find it difficult to maintain my body weight appropriately.

3. I have a hard time controlling pain in daily life.
4. I am reluctant to use a walking stick.
5. I have a hard time moving joints as I wish.
6. It is difficult to choose a treatment method.
7. I feel that I am putting burdens on my family or friends.
8. I have a hard time sleeping well due to pain.

These eight statements were created by researchers based on the result of preliminary interviews with 24 OA patients of the orthopaedic outpatient service and on earlier studies. Then necessary revision was made to the statements according to the examination of face validity based on the opinions of five medical specialists and five nurses who had more than 3 years experience in orthopedics. To examine the effectiveness of the survey sheets, a preliminary survey was conducted for eight patients, and necessary revision was made on the questions for the main survey.

Sex, age, disease stage, and number of years of being an OA patient were extracted from medical records. Occupation if any, financial status, and academic background were asked about on the survey sheet.

We analyzed the disease stage by dividing it into four stages: pre OA, primary stage, advanced stage, and end stage. If a patient had hip OA on both sides, the stage and JOA score on the more advanced side were used.

The ratio of the answers to the statements on the disease management activities was calculated for each disease stage. We used Mantel-Haenszel's chi-square test to examine any tendency in the fraction of the activities at each stage. A t-test was used for differences between one-side hip OA and two-side hip OA of disease management activities. We performed factor analysis on the nine statements of the disease management activities using the principal factor method with Promax Rotation, and calculated the coefficients of the correlation between the total score of the domain, derived from the factor analysis, and related factors. We performed a two-sided test with 5% significant level, using SAS Windows edition Version 9.1.

The Ethical Committee of the Faculty of Medicine, the University of Tokyo, approved the study. We explained the details of the study to the patients using a briefing document. They could stop participating in the study whenever they wished, as we thus tried not to force them to agree to the participation, and assured them that subsequent medical treatment would not be affected even if they refused or stopped the participation. We explained all of these factors to the patients and conducted the research for those patients who provided written consent to participate in the study.

Results

The questionnaire was distributed to 339 patients and the completed questionnaire was collected from 330 patients (response rate of 97%). Those who did not agree to cooperate gave their reasons for disagreement: 7 patients answered that they did not have enough time, 1 answered that he/she felt bad, and 1 answered that he/she did not understand the purpose of the research.

Table 1 shows the characteristics of all the patients and of the patients at each disease stage. The average age of the patients was 51 years (SD13). Females occupied 89% and the BMI was 23 (SD 3). The average period of being a patient was 7 years (SD 3), and the JOA score was 68 points (SD 20).

Table 2 shows the achievement ratio of the management activities. More than 85% of the patients answered yes to the statement "I try not to remain standing for long periods of time." and "I do not choose shoes with high heels or hard soles." Seventy-three percent of patients answered yes to the statements "I do muscle training." and "I am careful with my diet to avoid weight gain." The patients at the advanced stage tended to answer yes to these statements. To the statements "I do stretching." and "I do exercise to prevent weight gain," more than half of all the patients, and less than half of the patients answered no.

Differences between one-side hip OA and two-side hip OA of disease management activities are shown in Table 3. Results of a t-test showed no significant differences between two groups.

About 70% of the patients answered that they performed the disease management activities because "I do not want to let OA progress" or "I want to control pain." About 50% gave the reason that "I do not want to have surgery." About 20% answered that "I was told by doctors to do so" (Table 4).

We show in Table 5 the result of the factor analysis to examine the pattern of the nine disease management activities. As a consequence, we extracted ⟨muscle training and weight management activities⟩ as the first factor, ⟨Activities to prevent load on hip⟩ as the second, and ⟨Activities to aid careful walking⟩ as the third. The factor loading of "I am careful with my diet to avoid weight gain" was relatively low, 0.3, but we included it in the first factor ⟨Positive management activities⟩ from the clinical perspective. Cronbach's α coefficient of each factor was in the

Table 1   Background of the patients

		Total N = 330		Pre OA n = 56		Primary n = 49		Progressive n = 68		End n = 157	
Age (years)	Mean (SD)	51	(13)	38	(10)	44	(12)	50	(10)	59	(9)
Sex (Female)	%	89%		91%		90%		91%		88%	
Weight (kg)	Mean (SD)	55	(9)	54	(8)	55	(8)	57	(9)	54	(9)
BMI[a] (kg/m^2)	Mean (SD)	23	(3)	22	(3)	22	(3)	23	(3)	23	(3)
Duration of osteoarthritis (years)	Mean (SD)	7	(7)	6	(5)	7	(7)	6	(7)	9	(8)
Academic background (high school graduate or below)	%	44%		25%		24%		35%		60%	
Economic condition (the better)[a]	%	12%		13%		18%		7%		13%	
Job-having	%	48%		66%		47%		59%		37%	
JOA score[b]	Mean (SD)	68	(20)	88	(10)	81	(13)	71	(15)	56	(17)
Range of motion	Mean (SD)	13	(6)	19	(2)	18	(2)	15	(3)	9	(5)
Pain	Mean (SD)	26	(10)	31	(7)	28	(8)	25	(9)	23	(11)
Ability to walk	Mean (SD)	14	(5)	18	(3)	17	(3)	14	(4)	11	(5)
Activity of daily life	Mean (SD)	16	(4)	19	(2)	18	(3)	16	(3)	13	(3)
Difficulty in their daily life[c]											
There are no local medical specialists for disease management	%	20%		5%		22%		10%		29%	
I find it difficult to maintain my body weight appropriately	%	45%		41%		43%		46%		47%	
I have a hard time controlling pain in daily life	%	23%		16%		10%		24%		30%	
I am reluctant to use a walking stick	%	43%		36%		43%		44%		46%	
I have a hard time moving joints as I wish	%	49%		13%		31%		51%		68%	
It difficulty to choose a treatment method	%	41%		27%		39%		41%		46%	
I feel that I am putting burdens on my family or friends	%	42%		27%		31%		41%		52%	
I have a hard time sleeping well due to pain	%	19%		9%		8%		18%		27%	

[a] BMI: Body Mass Index.
[b] JOA score (In the bi-lateral hip OA group, the score of the more advanced hip joint was adopted).
[c] The numbers in the table show the rate of responses for "I live in fairly affluent circumstances." and "I live in very affluent circumstances".

Table 2   Disease management activities

	Total		Pre OA		Primary		Progressive		End		P-Value[a]	
	n	%	n	%	n	%	n	%	n	%		
	330	100	56	100	49	100	68	100	157	100		
I try not to remain standing for long periods of time	282	85%	37	66%	41	84%	61	90%	143	91%	<.001	***
I do not choose shoes with high heels or hard soles	281	85%	33	59%	42	86%	60	88%	146	93%	<.001	***
I am careful about the walking distance and speed in daily life	259	78%	37	66%	40	82%	57	84%	125	80%	0.10	
I use a cane or hold a handrail when necessary	257	78%	20	36%	35	71%	55	81%	147	94%	<.001	***
I try not to lift heavy objects	251	76%	26	46%	35	71%	49	72%	141	90%	<.001	***
I do muscle training	241	73%	35	63%	30	61%	52	76%	124	79%	0.00	**
I am careful with my diet to avoid weight gain	241	73%	35	63%	30	61%	52	76%	124	79%	0.00	**
I do stretching	148	45%	26	46%	23	47%	36	53%	63	40%	0.33	
I do exercise to prevent weight gain	146	44%	22	39%	28	57%	30	44%	66	42%	0.70	

[a] Mantel-Haenszel's chi-square test P-value $^{*}P < 0.05$, $^{**}P < 0.01$, and $^{***}P < 0.001$.

Table 3 Differences between uni-lateral hip OA and bi-lateral hip OA of disease management activities

	Uni-lateral		Bi-lateral		t-Score	P-Value[a]
	n = 127		n = 203			
	Mean	SD	Mean	SD		
I try not to remain standing for long periods of time	0.8	(0.4)	0.8	(0.4)	−0.49	0.63
I do not choose shoes with high heels or hard soles	0.8	(0.4)	0.9	(0.3)	0.91	0.36
I am careful about the walking distance and speed in daily life	0.9	(0.3)	0.8	(0.4)	0.36	0.72
I use a cane or hold a handrail when necessary	0.8	(0.4)	0.7	(0.4)	1.94	0.05
I try not to lift heavy objects	0.7	(0.5)	0.7	(0.4)	0.64	0.53
I do muscle training	0.4	(0.5)	0.4	(0.5)	−0.92	0.36
I am careful with my diet to avoid weight gain	0.8	(0.4)	0.7	(0.4)	−0.44	0.66
I do stretching	0.3	(0.5)	0.4	(0.5)	−1.13	0.26
I do exercise to prevent weight gain	0.4	(0.5)	0.5	(0.5)	0.18	0.85

[a] t-Test P-value $^{*}P < 0.05$, $^{**}P < 0.01$, and $^{***}P < 0.001$.

range of 0.63–0.69, indicating that the internal consistency remained at the acceptable level. Then we summed up the figures of each domain to obtain the personal management activity score of the domain.

Table 6 shows the correlation between the disease management activity score of domain 3 and each related factor. No factor was found significantly relevant in a statistical sense for ⟨Muscle training and weight management activities⟩. ⟨Activities to prevent load on hip⟩ had a statistically significant relevance to higher age ($r = 0.38$, $P < 0.001$), more advanced disease stage ($r = 0.51$, $P < 0.001$), larger BMI ($r = 0.13$, $P = 0.02$), lower total JOA score ($r = −0.33$, $P < 0.001$), lower score in each subscale of JOA score ($r = −0.32 - 0.49$, $P < 0.001$), more difficulty in finding medical specialists nearby ($r = 0.25$, $P < 0.001$), more difficulty in weight management ($r = 0.18$, $P = 0.00$), more difficulty in controlling pain ($r = 0.25$, $P < 0.001$), more difficulty in moving joints ($r = 0.41$, $P < 0.001$), more difficulty in choosing a therapy course ($r = 0.20$, $P = 0.00$), stronger feeling of placing burden on family or friends ($r = 0.30$, $P < 0.001$), and more difficulty in sleeping due to pain ($r = 0.16$, $P = 0.00$).

⟨Activities to aid careful walking⟩ had a statistically significant relevance to higher age ($r = 0.17$, $P = 0.00$), more advanced disease stage ($r = 0.18$, $P = 0.00$), lower JOA pain score ($r = −0.14$, $P = 0.01$), lower JOA ability to walk score ($r = −0.22$, $P < 0.001$), lower JOA ADL score ($r = −0.24$, $P < 0.001$), more difficulty in finding medical specialists nearby ($r = 0.14$, $P = 0.01$), more difficulty in weight management ($r = 0.12$, $P = 0.03$), more difficulty in moving joints ($r = 0.22$, $P < 0.001$), more difficulty in choosing a therapy course ($r = 0.11$, $P = 0.05$), stronger feeling of placing burden on family or friends ($r = 0.20$, $P = 0.00$).

Discussion

The present study clarified the current status of the disease management activities of the patients who were in conservative treatment courses, the relevant factors, and the reasons why they performed the activities.

Current status of disease management activities

Seventy-three percent of all the patients, and more than 60% of those in each disease stage, answered yes to the statement "I do muscle training." This percentage was higher among the patients who were at the more advanced stage than the pre OA of OA with few symptoms. Muscle training is the foundation of the conservative therapies and is sometimes difficult for patients to continue; however, the present study showed that many patients actually did the muscle training. It is important to strengthen the gluteus medius muscle to enhance the bearing ability of the hip joint, and muscle training was proved by a large RCT to be effective (Messier et al., 2004). A previous study indicated that, since the difference in instructional methods had no difference in their effects (Ravaud et al., 2004), making appropriate efforts for the individual patient, such as personal guidance, group exercise, or home exercise, was necessary for continuing muscle training. In particular, since only a limited number of exercises can prevent putting a burden on joints, information to individual patients about suitable exercise should be received from specialists.

Only less than half of the patients were performing "stretching" or "exercise to prevent weight gain". This may indicate that the ease of the

Table 4   Reason for the disease management activities

	Total		Pre OA		Primary		Progressive		End		P-Value[a]
	N 330	% 100	n 56	% 100	n 49	% 100	n 68	% 100	n 157	% 100	
I do not want to let OA progress	245	74%	42	75%	37	76%	56	82%	110	70%	0.38
I want to control pain	224	68%	29	52%	36	73%	46	68%	113	72%	0.03 *
I do not want to have surgery	173	52%	24	43%	26	53%	39	57%	84	54%	0.25
I cannot walk	135	41%	13	23%	14	29%	23	34%	85	54%	<.001 ***
I cannot move joint	129	39%	12	21%	12	24%	18	26%	87	55%	<.001 ***
I was told by doctors to do so	75	23%	11	20%	18	37%	15	22%	31	20%	0.36
I am anxious about the way of walking	61	18%	2	4%	11	22%	13	19%	35	22%	0.01 *
Because it is the condition that it can't operate at present	36	11%	4	7%	6	12%	12	18%	14	9%	1.00

As for the reasons of the disease control behavior, it asked in several answers.
[a] Mantel-Haenszel's chi-square test P-value $^*P < 0.05$, $^{**}P < 0.01$, and $^{***}P < 0.001$.

activities made a difference in actual performance. According to the guideline, exercises including stretching and muscle training are expected to have the effect of suppressing the progress of OA. Future progression of OA could be slowed by performing and continuing the disease management activities in the primary stage of the disease. It may be necessary to develop a program to improve the management activities that are not easy for patients to perform.

There were no significant differences between one-side hip OA and two-side hip OA of disease management activities. It may be because there were more than half of patients who performed disease management activities.

Reasons for disease management activities

The top reason for performing the management activities was "I do not want to let OA progress", to which 74% of the patients answered yes. Sixty-eight percent chose the reason "I want to control pain" and about half of the patients selected the reason "I do not want to have surgery". The reason "I was told by the doctor to do so" was chosen by only 23% of the patients. The patients performed the management activities to prevent progression of OA, and the information provision and suggestion from doctors did not largely enhance their motivation. Doctor's advice of performing the management activities did not always lead to actual performance of the activities. Personal guidance in accordance with individual understanding or interest may also be necessary.

Relevant factors in disease management activities

We found that higher age, more advanced disease stage, and lower score in each subscale of the JOA score were relevant to ⟨Activities to prevent load on hip⟩ and ⟨Activities to aid careful walking⟩. Patients at a higher age tended to be in a more advanced disease stage and present a lower JOA score, and hence the patients at a higher age had severe symptoms in the advanced stage and had to decide whether to perform the management activities. Also, a statistically significant relevance was found in difficulty in finding medical specialists nearby, difficulty in weight management, difficulty in controlling pain, difficulty in moving joints, difficulty in choosing a therapy course, feeling of placing a burden on family or friends, and difficulty in sleeping due to pain. In consideration of the result that the difficulty in their daily lives was

Table 5 The results of factor analysis of the disease management activities: factor loadings after Promax rotation and Cronbach's alpha coefficients ($N = 330$)

	Factor 1	Factor 2	Factor 3
Muscle training and weight management activities $\alpha = 0.69$			
I do muscle training	0.70	−0.01	0.01
I do stretching	0.67	0.02	−0.06
I do exercise to prevent weight gain	0.63	−0.05	0.03
I am careful with my diet to avoid weight gain	0.31	0.25	0.07
Activities to prevent load on hip $\alpha = 0.63$			
I use a cane or hold a handrail when necessary	−0.04	0.59	0.01
I do not choose shoes with high heels or hard soles	−0.04	0.55	−0.03
I try not to lift heavy objects	0.07	0.48	0.18
Activities to aid careful walking $\alpha = 0.66$			
I am careful about the walking distance and speed in daily life	0.00	0.09	0.53
I try not to remain standing for long periods of time	−0.03	0.18	0.54
Total contribution 38%			

Table 6 Related factors of the disease management activities

$N = 330$	Muscle training and weight management activities		Activities to prevent load on hip			Activities to aid careful walking		
	r^a	P-Value	r^a	P-Value		r^a	P-Value	
Age	0.07	0.22	0.38	<.001	***	0.17	0.00	***
Duration of osteoarthritis	−0.02	0.78	0.00	0.98		−0.04	0.46	
Disease stage	0.02	0.76	0.51	<.001	***	0.18	0.00	***
BMI	−0.05	0.34	0.13	0.02	*	0.07	0.22	
JOA score								
Range of motion	0.08	0.15	−0.33	<.001	***	−0.09	0.11	
Pain	0.03	0.60	−0.32	<.001	***	−0.14	0.01	**
Walk	−0.04	0.45	−0.46	<.001	***	−0.22	<.001	***
ADL	0.04	0.48	−0.49	<.001	***	−0.24	<.001	***
Difficulty in their daily life[b]								
There are no local medical specialists for disease management	0.03	0.60	0.25	<.001	***	0.14	0.01	**
I find it difficult to maintain my body weight appropriately	−0.07	0.18	0.18	0.00	***	0.12	0.03	*
I have a hard time controlling pain in daily life	0.01	0.91	0.25	<.001	***	0.08	0.16	
I am reluctant to use a walking stick	−0.07	0.18	0.02	0.76		0.08	0.13	
I have a hard time moving joints as I wish	−0.02	0.68	0.41	<.001	***	0.22	<.001	***
It difficulty to choose a treatment method	−0.01	0.85	0.20	0.00	***	0.11	0.05	*
I feel that I am putting burdens on my family or friends	0.04	0.47	0.30	<.001	***	0.20	0.00	***
I have a hard the sleeping well due to pain	0.03	0.64	0.16	0.00	***	0.07	0.19	

[a] r are expressed as Spearman's coefficients. P-value *$P < 0.05$, **$P < 0.01$, and ***$P < 0.001$.
[b] Difficulty in their daily life using answers graded from 1 to 5 which ranged from ''I feel exactly the same'' to ''I do not feel any at all''.

statistically significant, it is likely that the patients performed the management activities out of neces-sity because they had problems caused by OA symptoms.