

## Quality of Life, Day Hospice Needs, and Satisfaction of Community-Dwelling Patients with Advanced Cancer and their Caregivers in Japan

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### Abstract

**Background:** The aims of this study were to clarify (1) the quality of life (QOL) of community-dwelling patients with advanced cancer and their caregivers in home palliative care and day hospice settings, (2) the need for day hospice of home palliative care patients and caregivers, and (3) the satisfaction with day hospice by day hospice patients and caregivers.

**Methods:** A cross-sectional questionnaire was administered to patients with advanced cancer and their caregivers who were cared for at day hospice and home palliative care. We measured the health-related quality of life using the SF-8, the need for day hospice of home palliative care patients and caregivers, and the satisfaction with day hospice by day hospice patients and caregivers.

**Results:** A total of 57 pairs of patients and caregivers participated in the study (day hospice,  $n = 23$ ; home palliative care,  $n = 34$ ). The physical and mental aspects of the patient QOL were significantly lower than national standard value. However, although physical aspect of caregivers QOL was significantly lower than national standard value, mental aspect of caregiver's QOL was not lower than national standard value. Forty-four percent of home palliative care patients and 67% of home palliative care caregivers preferred day hospice. The needs of patients and caregivers were wide ranging including medical treatment, distraction, information provision, and respite. Overall, the Japanese day hospice was evaluated highly.

**Conclusion:** This is the first study of day hospice in Japan. Although there are several day hospices in Japan, the initiation of day hospice would probably be successful. The dissemination of day hospice is an important issue for patients with advanced cancer and their caregivers in Japan.

### Introduction

IN JAPAN, the growth of home-based palliative care programs has been slow. Although several home palliative care services are available, almost all of those for patients with advanced cancer are provided by small-scale clinics and visiting nurses stations. Several day hospices exist for patients with advanced cancer in Japan, but their current status in Japan is unclear.

Although caring for patients with advanced cancer at home would enhance quality of life (QOL) for the patient, the QOL of patients with cancer and caregivers receiving home palliative care services has not been investigated in

Japan. In addition, to overcome barriers to home palliative care service, day hospices could play an important role for advanced cancer patients and their families, as in Western countries.<sup>1-7</sup> The need for day hospices has not been studied in our country. Moreover, although several day hospices for patients with advanced cancer are available, satisfaction with services provided by day hospices is unclear.<sup>8</sup>

The aims of this study were: (1) to clarify the QOL of community-dwelling patients with advanced cancer and caregivers in home palliative care and day hospice settings; (2) to shed light on the need for day hospices for home palliative care patients and caregivers; and (3) to examine satisfaction with day hospices by patients and caregivers.

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## Methods

## Participants and procedures

A cross-sectional questionnaire was administered to patients with advanced cancer and caregivers who were cared for at day hospices or by home palliative care services. Three day hospices and eight home palliative care service clinic/visiting nurse stations in the four areas participated. Inclusion criteria were as follows: (1) presence of advanced cancer in the patient; (2) patient age 20 years or more; and (3) use of these institutions by the patient 2 or more times.

Study physicians or nurses explained the study aims to participants who signed consent forms. A coupon book worth 1000 yen (US \$8.30) was provided to participants. The study was conducted from September 2006 to March 2007. The ethical and scientific validity of this study was approved by the Institutional Review Board of the University of Tokyo.

## Measurements

**Health-related QOL (SF-8).** The MOS short-form 8 (SF-8) questionnaire was used as a health-related QOL measure-

TABLE 1. PARTICIPANT CHARACTERISTICS

	Day hospice (n = 23)		Home palliative care (n = 34)		p value <sup>a</sup>
	n	%	n	%	
<b>Patients</b>					
Age (years, mean ± SD)	69 ± 12		76 ± 11		0.08
Gender (male)	14	61	17	50	0.59
Length of service use (weeks, mean ± SD)	34 ± 36		22 ± 33		0.22
Opioid use	5	22	17	50	0.05
Chemotherapy	7	30	5	15	0.19
Intravenous hydration therapy	1	4	8	24	0.07
Oxygen therapy	3	13	8	24	0.50
Metastases	17	74	24	71	1.00
ECOG performance scale					
0	3	13	0	0	0.003
1	5	22	2	6	
2	7	30	8	24	
3	4	17	12	35	
4	4	17	14	41	
Symptoms (STAS-J)					
	0.6 ± 0.9		1.4 ± 1.0		
Pain	0.7 ± 0.8		1.4 ± 0.9		0.003
Fatigue	0.3 ± 0.5		0.5 ± 0.9		0.004
Dyspnea	0.2 ± 0.5		0.4 ± 0.8		0.34
Nausea	0.2 ± 0.5		0.4 ± 0.8		0.36
Vomiting	0.7 ± 0.8		1.2 ± 1.5		0.58
Appetite loss	0.4 ± 0.6		0.8 ± 0.9		0.34
Insomnia	0.3 ± 0.5		0.6 ± 0.7		0.05
Depression	0.0 ± 0.2		0.2 ± 0.6		0.26
Delirium	0.8 ± 0.7		1.1 ± 1.0		0.14
Anxiety					0.42
<b>Caregivers</b>					
Age (years, mean ± SD)	53 ± 13		60 ± 12		0.10
Gender (male)	8	35	4	17	0.74
Working status (present)	13	57	16	70	0.58
Hospital visit by caregiver's chronic illness	7	30	14	61	0.40
Relationship (spouse)	10	43	17	74	0.77
Duration of caregiving (months, mean ± SD)					0.41
Daily time spent on care (min, mean, SD)	20 ± 27		23 ± 44		0.09
Annual household income <sup>b</sup>					
	300 ± 272		540 ± 459		
<0.2 million yen	1	4	4	17	0.05
<0.4 million yen	3	13	11	48	
<0.6 million yen	5	22	3	13	
<0.8 million yen	4	17	5	22	
<1 million yen	4	17	1	4	
≥1 million yen	3	13	3	13	

<sup>a</sup>Statistical tests were the Wilcoxon rank-sum test, Fisher's exact test and Cochran-Armitage exact trend test, as appropriate.

<sup>b</sup>1 Million yen is approximately equal to US \$8,333.

SD, standard deviation; ECOG, Eastern Cooperative Oncology Group.



TABLE 2. QUALITY OF LIFE (SF-8)

	Day hospice (n = 23)			Home palliative care (n = 34)		
	Mean	SD	p value	Mean	SD	p value
<b>Patient QOL</b>						
PCS	42.2	9.7	0.005	37.1	11.7	<0.001
MCS	45.3	7.7	0.001	44.5	9.9	<0.001
<b>Caregiver QOL</b>						
PCS	37.3	5.1	<0.001	35.2	6.2	<0.001
MCS	52.2	9.6	0.241	53.8	9.2	0.024

Figures represent standardized value in Japan (mean = 50, SD = 10). p values were calculated using the Wilcoxon signed-ranks test comparing national standard values in each mean age.

PCS, physical component summary; MCS, mental component summary; SD, standard deviation; QOL, quality of life.

ment tool.<sup>9</sup> We were able to calculate two summary scores, physical component summary (PCS) and mental component summary (MCS), in accordance with the scoring rules.

**Need for day hospice for home palliative care patients and caregivers.** First, we asked home palliative care service patients and caregivers, "Do you want to use a day hospice?" If they answered "Yes", we asked patients and caregivers

about various items regarding preference for specific day hospice services using a 4-point Likert scale (1, not at all; 2, a little; 3, some; 4, a lot).

**Satisfaction with day hospice by day hospice-using patients and caregivers.** We asked day hospice-using patients and caregivers about satisfaction with day hospices with questions showing similar content to the needs questions using a 4-point Likert scale (1, very dissatisfied; 2, dissatisfied; 3, satisfied; 4, very satisfied).

**Participant characteristics.** Background information about patient and caregiver characteristics was obtained.

### Analysis

First, we summarized participant characteristics and examined differences between characteristics for home palliative care service and day hospice use. Second, we calculated patient and caregiver health-related QOL as a PCS and MCS. Third, we calculated the proportions preferring day hospices among home palliative care service patients. In addition, if participants preferred day hospices, we summarized the need for day hospices. Finally, we summarized satisfaction with day hospices. All statistical tests were two-tailed with values of  $p < 0.05$  considered significant. All analyses were performed using SAS version 9.1 statistical software (SAS Institute, Cary, NC).

TABLE 3. NEED FOR DAY HOSPICE BY HOME PALLIATIVE CARE PATIENTS AND CAREGIVERS

	Patients (n = 34)		Caregivers (n = 33)	
	n	%	n	%
Do you want to use a day hospice?				
Yes	15	44	20	67
No	16	47	11	37
No answer	3	9	2	7
For those answering "Yes" to "Do you want to use a day hospice?" (Patients, n = 15; Caregivers, n = 20)				
<b>Patients</b>				
Relief of pain and other symptoms	12	80	13	65
Medical treatment	12	80	14	70
Information about living with disease	14	93	18	90
Presence of people to talk with the patient	14	93	18	90
Talking with other patients	10	67	16	80
Engaging in favorite activity such as hobby	14	93	17	85
Distraction	15	100	18	90
Staying in a calm and relaxing environment	15	100	16	80
Family respite	15	100	—	—
Bathing	13	87	16	80
Lunch	14	93	17	85
<b>Caregivers</b>				
Information about home care service	—	—	19	95
Information about methods of home care	—	—	19	95
Information about patient diet	—	—	18	90
Information about economic support	—	—	18	90
Family respite	—	—	19	95
Presence of people to talk with caregiver	—	—	20	100
Talking with other caregivers	—	—	18	90

Figures represent total number and percentage of "a lot" and "some."

## Results

### Participant characteristics

A total of 57 pairs of patients and caregivers participated in the study (day hospice,  $n = 23$ ; home palliative care service,  $n = 34$ ). Participant characteristics are shown in Table 1. Significant differences in patient and caregiver characteristics were seen between home palliative care service and day hospices users in some items.

### Health-related QOL (SF-8)

Health-related QOL (SF-8) scores are shown in Table 2. Compared to national standard values, mean PCS for day hospice patients and MCS were significantly lower. For home palliative care service patients, mean PCS and MCS were significantly lower. For day hospice caregivers, mean PCS was significantly lower, and for home palliative care service caregivers, mean PCS and MCS were significantly lower.

### Need for day hospices among home palliative care patients and caregivers

Table 3 shows the need for day hospices among home palliative care service patients and caregivers. Day hospices were preferred by 44% of patients and 67% of caregivers. Day hospices were preferred by 80% or more of home palliative care service patients for almost all questions.

### Satisfaction with day hospices by day hospice-using patients and caregivers

Table 4 shows satisfaction with day hospices by day hospice-using patients and caregivers. For 8 of the 11 questions,

70% or more of patients were satisfied. Regarding satisfaction of caregivers, 80% or more were satisfied about patient-related items for 8 of the 10 questions. As for caregiver-related variables, 80% or more of caregivers were satisfied for 5 of the 7 questions.

## Discussion

This is the first study of QOL, day hospice needs, and satisfaction of community-dwelling patients with advanced cancer and caregivers in Japan. We found that QOL for patients with advanced cancer and caregivers is significantly lower than the national standard. Many patients and caregivers using home palliative care services need access to day hospices. The needs of patients and caregivers were wide ranging, such as the need for medical treatment, distraction, information, family respite, and the presence of other people to talk with the caregiver. In addition, satisfaction with day hospices by day hospice-using patients and caregivers is quite high. Patients and caregivers were satisfied with most items involved with care provided in day hospices.

QOL among patients with advanced cancer and caregivers was lower than national standard values. In particular, PCS was significantly lower than MCS. However, in our study, PCS of caregivers was similar to that of patients. Given the burden on caregivers of advanced cancer patients, maintaining the health of both patients and caregivers is important.<sup>10-13</sup>

Day hospices were preferred by 44% of patients and 67% of caregivers using home palliative care services. Although several day hospices have been opened in Japan, we think this need is high. Advanced cancer patients and caregivers seek social support on medical issues and social aspects of care. Lohfeld et al.<sup>4</sup> investigated the needs and potential roles

TABLE 4. SATISFACTION WITH DAY HOSPICE BY DAY HOSPICE PATIENTS AND CAREGIVERS

	Patients (n = 23)		Caregivers (n = 23)	
	n	%	n	%
<b>Satisfaction for patient</b>				
Relief of pain and other symptoms	23	100	21	91
Medical treatment	23	100	20	87
Information about living with disease	21	91	20	87
Presence of people to talk with the patient	22	96	20	87
Talking with other patients	14	61	13	57
Engaging in favorite activity such as hobby	14	61	17	74
Distraction	21	91	21	91
Staying in a calm and relaxing environment	21	91	21	91
Family respite	19	83	—	—
Bathing	14	61	15	65
Lunch	16	70	16	70
<b>Satisfaction for caregiver</b>				
Information about home care service	—	—	21	91
Information about methods of home care	—	—	20	87
Information about patient diet	—	—	18	78
Information about economic support	—	—	13	57
Family respite	—	—	17	74
Presence of people to talk with caregiver	—	—	19	83
Talking with other caregivers	—	—	11	48

Figures represent total number and percentage of "very satisfied" and "satisfied."



of day hospices in a qualitative study. The present results resemble the findings described by Lohfeld et al.<sup>4</sup> in Canada. Day hospices allow patients to keep living at home while attending a specialist palliative care center on a regular basis.<sup>14</sup> The dissemination of day hospices is an important issue for patients with advanced cancer and caregivers in Japan.

This study displays several limitations. First, the major limitation of this survey was that participants were not representative of all patients with cancer. The generalizability of these findings to all patients with cancer is thus limited. Second, patients with severe physical conditions were not recruited. QOL for patients using home palliative care services and day hospices would thus have been lower in the whole population than in this study. Finally, the characteristics and care offered by day hospices would differ among facilities, as several day hospices have opened in Japan. As the use of home palliative care services and day hospices grows, further studies are needed to confirm the present results.

### Conclusions

In conclusion, we found that the QOL of patients with advanced cancer and caregivers was significantly lower than the national standard value, particularly with regard to physical aspects. Many patients and caregivers using home palliative care services needed access to a day hospices. The needs of patients and caregivers were wide-ranging, from medical treatment to social services. The dissemination of day hospices is an important issue for advanced cancer patients and caregivers in Japan. For most items, patients and caregivers were satisfied with the care. This study demonstrates that the introduction of day hospices in Japan would probably be successful. Day hospices have a potentially important role to play in home care for patients with advanced cancer in Japan.

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### Author Disclosure Statement

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# Nurse Views of the Adequacy of Decision Making and Nurse Distress Regarding Artificial Hydration for Terminally Ill Cancer Patients: A Nationwide Survey

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We evaluated nurse views on the adequacy of decision-making discussion among nurses and physicians regarding artificial hydration for terminally ill cancer patients and nurse distress arising from artificial hydration issues, as well as factors related to this distress. A self-administered questionnaire consisting of 4 questions about nurse views of discussions regarding artificial hydration and 6 questions about nurse distress arising from artificial hydration issues was distributed in participating institutions in October 2002 and returned by mail. A total of 3328 responses (79%) were analyzed. Almost half of the nurses felt that discussion of terminal hydration issues was insufficient. Among responses, 39% of oncology nurses and 78% of palliative care unit (PCU) nurses agreed that patients and medical practitioners discuss the issue of artificial hydration adequately, and 49% and 79%, respectively, agreed that medical practitioners discuss the issue of artificial hydration with other physicians adequately.

As for distress on behalf of patients and families who refuse artificial hydration, 44% of oncology nurses and 57% of PCU nurses experienced such distress for patients, and 19% and 28% did so for families, respectively. Furthermore, 48% of oncology nurses and 47% of PCU nurses experienced distress arising from disagreements among medical practitioners about withholding artificial hydration, whereas 44% and 43% experienced distress about medical practitioners refusing artificial hydration, respectively. Discussion among care providers regarding artificial hydration is insufficient, particularly in general wards. Medical practitioners caring for terminally ill cancer patients should engage in greater discussion among patient-centered teams and facilitate individualized decision making.

**Keywords:** palliative care; attitude; fluid therapy; nurses; decision making; questionnaires

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Nurses encounter many difficulties in the care of terminally ill patients.<sup>1-4</sup> In Japan, Sasahara et al reported that 92% of nurses were distressed by insufficient opportunities to discuss care with physicians. Morita et al investigated the emotional burden faced by nurses in palliative sedation therapy and emphasized the importance of a team approach to resolving conflicting opinions, especially between physicians and nurses.<sup>5</sup> Regarding the team approach to care, Maeyama et al reported that perceptions of the practice of team care differ between physicians and nurses and that nurses regarded team care as insufficient in Japan.<sup>6</sup> Together, these



findings indicate that although team care is important in the care of terminally ill patients, its actual practice in Japan may be insufficient.

Artificial hydration is a common practice for terminally ill cancer patients. Guidelines developed by an expert committee sponsored by the European Association for Palliative Care for artificial nutrition versus hydration in terminal cancer patients defined the psychological attitudes of patients and families as one of 8 key elements to be considered in decision making on hydration.<sup>7</sup> Other researchers have also argued the relevance of considering the wishes of patients and families and of respecting these wishes.<sup>8-11</sup> Family members and loved ones play an important role in the care of terminal patients. For them, feeding is often one of their greatest concerns, and the need for ongoing hydration<sup>12</sup> or a lack of food intake often increases their anxiety.<sup>7</sup> Moreover, some patients and families may feel that the patient has been abandoned if hydration is withheld.<sup>13</sup>

In addition, attitudes toward hydration therapy differ between physicians and nurses.<sup>14-16</sup> Despite the importance of discussion by medical practitioners among patient-centered teams caring for terminally ill cancer patients and the conduct of decision making according to the individual patient's preference,<sup>10,16,17</sup> the decision-making process in artificial hydration remains unclear.

Only a few studies have investigated the decision-making process from the perspective of patients and families. Musgrave et al surveyed decision making for the administration of artificial hydration in Israel and reported that the majority of conscious patients (95%), family members (81%), and nurses (64%) played no role.<sup>18</sup> Scientific uncertainty regarding the effectiveness of terminal hydration,<sup>19,20</sup> as well as patient and family requirements<sup>9,11,21</sup> and their lack of involvement in medical decisions regarding terminal hydration,<sup>18</sup> might produce emotional distress in nurses in their dealing with this practice. To our knowledge, however, distress regarding artificial hydration among nurses has not been investigated.

The aims of the present paper were (1) to clarify nurses' views of discussions among nurses and physicians regarding artificial hydration for terminally ill cancer patients, and (2) to clarify nurses' distress arising from artificial hydration issues and to explore factors related to this distress.

## Methods

### Participants and Procedure

This is the second part of a survey on nurse attitudes toward terminal dehydration, which was started in October 2002.<sup>16</sup> Participants were recruited from 2 nationwide organizations, the Japanese Association of Clinical Cancer Centers and the Japanese Association of Hospice and Palliative Care Units. The former consists of 28 medical centers for cancer and adult disease that play leading roles in clinical oncology, and the latter of 80 hospitals with a variety of palliative care units or inpatient hospices. Sixteen cancer centers and 73 hospitals agreed to participate in the study, and an additional 4 general hospitals and a palliative care clinic from the Japan Palliative Oncology Study Group (J-POS), organized to investigate the effectiveness of artificial hydration in Japan,<sup>15,22</sup> were added. Representatives of each institution then identified potential participants working as nurses in units responsible for the care of terminally ill cancer patients. A total of 4210 nurses were recruited as a heterogeneous sample of nurses working at cancer centers, general hospitals, and palliative care units.

In Japan, the Ministry of Health, Labor, and Welfare has strongly supported the development of specialized palliative care services. With coverage of palliative care units provided under the National Medical Insurance system since 1991, the number of palliative care units has dramatically increased, from 5 in 1991 to 135 in 2004. In contrast, the growth of home-based palliative care programs has been slow, and palliative care teams were not covered by National Medical Insurance until 2002. The most common type of specialized palliative care service in Japan is therefore the palliative care unit (PCU). Here, we chose nurses belonging to general wards of cancer centers, general hospitals, and PCUs as study targets for this investigation.

### Questionnaire

The questionnaire (available from the authors) was developed by the J-POS group. Face validity of the questionnaire was confirmed by a pilot test using 15 nurses from oncology and palliative care settings.

*Nurse views of discussions regarding artificial hydration for terminally ill cancer patients.* Nurses responded



to 4 statements on the adequacy of discussion among physicians and nurses regarding artificial hydration using a 6-point Likert scale (from "strongly disagree" to "strongly agree"), as follows: "Patients and medical practitioners discuss the issue of artificial hydration adequately," "Medical practitioners discuss the issue of artificial hydration adequately," "Physicians respect the patient's/family's desires regarding artificial hydration," and "Physicians respect nurses' opinions regarding artificial hydration."

*Nurse distress arising from artificial hydration for terminally ill cancer patients.* Nurse distress arising from artificial hydration issues was evaluated from responses to 6 statements using a 4-point response scale of "none," "rare," "sometimes," and "frequently." Two categories each were evaluated for distress on behalf of patients/families who complained about the withholding of artificial hydration, and for distress for patients/families who refused artificial hydration, namely, "patient" and "family." Two further categories were evaluated for distress arising from disagreements among medical practitioners, namely, "withholding of artificial hydration by medical practitioners" and "refusing artificial hydration by patient and family."

*Attitudes of nurses toward artificial hydration for terminally ill cancer patients.* Fifteen further questions were asked regarding nurse attitudes toward artificial hydration, particularly symptom control and ethical issues. The descriptive statistics and 7 domains generated by the 15 questions have been detailed elsewhere.<sup>16</sup> Briefly, the 7 domains identified by explanatory analyses were as follows: "belief that artificial hydration palliates physical symptoms"; "belief that withholding artificial hydration palliates physical symptoms"; "perception of loss of trust by withholding artificial hydration"; "perception of guilt from withholding artificial hydration"; "belief that artificial hydration is a component of minimum care"; "perception of difficulty concerning decision making for artificial hydration"; and "belief that maintaining a venous route is a burden." The respondents were asked to evaluate each statement using a 6-point Likert scale (strongly agree to strongly disagree). Scores for each domain were summed and used for analysis.

*Demographics.* The respondents were first asked to describe their background, including number of years of clinical practice, clinical setting, and number

of cancer deaths that occurred in their unit during the preceding year.

### Statistical Analysis

Nurse views of discussions regarding artificial hydration were analyzed by calculating the overall percentage of "strongly agree," "agree," and "slightly agree" answers and comparing between clinical settings using the chi-square test.

Nurse distress arising from artificial hydration issues was analyzed by calculating the overall percentage of "frequently" and "sometimes" answers and comparing between clinical settings using the chi-square test. In addition, we performed an explanatory factor analysis using the principle component method and promax rotation for the following analysis. The data are shown in Table 1, presented according to the results of factor analysis and calculation of Cronbach alpha coefficient for each domain.

To explore factors related to these distresses, we performed multivariate analysis using a multiple linear regression model. Objective variables were "distress on behalf of patients/families who complain about withholding artificial hydration," "distress on behalf of patients/families who refuse artificial hydration," and "distress arising from disagreements among medical practitioners." These 3 variables were generated by summing the domain scores in Table 1. Explanatory variables were characteristics of respondents such as sex (1, female; 0, male), number of years of clinical practice, number of cancer deaths occurring in the unit during the preceding year and clinical setting (1, PCU; 0, oncology ward), 7 domain scores of attitudes toward artificial hydration, and nurse views of discussion on artificial hydration (summed scores of 4 statements in Table 2).

Two-sided *p* values were calculated for all statistical tests, and a *P* value < .05 was considered statistically significant. All analyses were performed using the Statistical Analysis System (SAS) statistical package (version 9.1, 2005, SAS Institute, Cary, NC).

## Results

### Subject Characteristics

A total of 3515 of 4210 nurses returned completed questionnaires. Since 187 responses contained missing values and were excluded from further analysis,



Table 1. Nurse Distress Arising from Artificial Hydration for Terminally Ill Cancer Patients

	Oncology Nurse (n = 2735)	PCU (n = 593)	P Value
Distress on behalf of patients/families who complain about withholding artificial hydration (alpha = 0.82)			
For patients	20	24	.049
For families	24	36	< .001
Distress on behalf of patients/families who refuse artificial hydration (alpha = 0.72)			
For patients	44	57	< .001
For families	19	28	< .001
Distress arising from disagreements among medical practitioners (alpha = 0.83)			
About withholding artificial hydration	48	47	.57
About refusal of artificial hydration by patient or family	44	43	.56

NOTE: The numbers denote the percentage of summed "sometimes" and "frequently" responses. Alpha indicates Cronbach alpha coefficient; PCU = palliative care unit.

Table 2. Nurse Views of the Adequacy of Discussions Regarding Artificial Hydration for Terminally Ill Cancer Patients

	Oncology Nurse (n = 2735)	PCU (n = 593)	P Value
Patients and medical practitioners discuss the issue of artificial hydration adequately.	39	78	< .001
Medical practitioners discuss the issue of artificial hydration adequately.	49	79	< .001
Physicians respect the patient's/family's desires regarding artificial hydration.	42	84	< .001
Physicians respect nurse opinions regarding artificial hydration.	36	68	< .001

NOTE: Values represent the percentage of summed "strongly agree," "agree," and "slightly agree" responses. PCU = palliative care unit.

3328 responses were finally analyzed (validated response rate, 79%). Background characteristics of the participants are shown in Table 3.

*Nurse views of discussions regarding artificial hydration for terminally ill cancer patients.* Nurse views of the adequacy of discussion regarding artificial hydration for terminally ill cancer patients are presented in Table 2. Regarding whether patients and medical practitioners discuss the issue of artificial hydration adequately, 39% of oncology nurses and 78% of PCU nurses agreed with the statement ( $P < .001$ ). Among other statements, 49% and 79% agreed that medical practitioners discuss the issue of artificial hydration adequately ( $P < .001$ ); 42% and 84% agreed that physicians respect the patient's/family's desires regarding artificial hydration ( $P < .001$ ); and 36% and 68% stated that physicians respect nurses' opinions regarding artificial hydration ( $P < .001$ ), respectively.

*Nurse distress arising from artificial hydration for terminally ill cancer patients.* Nurse distress arising from artificial hydration for terminally ill cancer patients is shown in Table 1. Explanatory factor analysis clearly identified 3 domains (detailed data not shown). Regarding distress on behalf of patients/families who complain about withholding artificial hydration (alpha = 0.82), 20% of oncology nurses and 24% of PCU nurses experienced such distress for patients ( $P = .049$ ), and 24% and 36% did so for families ( $P < .001$ ), respectively. Among other statements, 44% and 57% experienced distress on behalf of patients who refuse artificial hydration (alpha = 0.72) ( $P < .001$ ), and 19% and 28% did so for families ( $P = .001$ ); 48% and 47% experienced ( $P = .568$ ) distress arising from disagreement among medical practitioners (alpha = 0.83) about withholding artificial hydration; and 44% and 43% did so ( $P = .556$ ) about patients or families refusing artificial hydration.



Table 3. Participant Characteristics (N = 3328)

Age	
Mean $\pm$ SD	33 $\pm$ 8.7
Median	31
Sex	
Female (%)	99
Number of years of clinical practice	
Mean $\pm$ SD	11 $\pm$ 8.6
Median	9
Clinical setting (%)	
General hospital	35
Cancer center	47
Perception of guilt from withholding artificial hydration	18
Number of cancer deaths that occurred in the unit during the preceding year	
Mean $\pm$ SD	40 $\pm$ 42
Median	22

Factors related to nurse distress arising from artificial hydration for terminally ill cancer patients. Results of the exploration of factors related to nurse distress arising from artificial hydration for terminally ill cancer patients are shown in Table 4. With regard to distress on behalf of patients/families who complain about withholding artificial hydration, associations were seen for the number of cancer deaths occurring in the unit during the preceding year ( $P < .001$ ) and perception of a loss of trust by withholding artificial hydration ( $P < .001$ ). For distress on behalf of patients/families who refuse artificial hydration, associations were seen for clinical setting ( $P < .001$ ), perception of a loss of trust by withholding artificial hydration ( $P = .045$ ), belief that artificial hydration is a component of minimum care ( $P = .022$ ), and belief that maintaining a venous route is a burden ( $P = .001$ ). For distress arising from disagreements among medical practitioners, associations were seen for a belief that artificial hydration palliates physical symptoms ( $P = .002$ ), belief that withholding artificial hydration palliates physical symptoms ( $P < .001$ ), belief that artificial hydration is a component of minimum care ( $P = .001$ ), perception of difficulty concerning decision making for artificial hydration ( $P < .001$ ), and nurses' views of discussion of artificial hydration ( $P < .001$ ).

## Discussion

This is the first nationwide survey on nurse attitudes toward terminal hydration in Japan. The most

notable finding was that almost half of the oncology nurses surveyed considered discussion regarding artificial hydration in general wards to be insufficient. In contrast, most PCU nurses evaluated discussion in the PCU positively. Although the importance of discussion by medical practitioners among patient-centered teams caring for terminally ill cancer patients and of individualized decision making is known,<sup>10,16,17</sup> our findings show that practice in general hospitals and cancer centers is poor and that there is room for improvement. Overall, although PCU nurses evaluated these factors positively, only 68% agreed that physicians respect nurse opinions regarding artificial hydration. Even in the PCU, nurses view nurse participation in the decision-making process as insufficient. Physicians should recognize that nurses seek to be more closely involved in the decision-making process than is the case now.

The second notable finding of this survey was that many nurses felt distress concerning artificial hydration for terminally ill cancer patients. Some 20% to 36% of nurses were distressed by patients/families who complain about withholding artificial hydration, whereas 19% to 57% were distressed by patients/families who refuse artificial hydration. PCU nurses were more distressed by patients who refuse artificial hydration because PCU inpatients tend to refuse medical treatment, placing nurses who are ordered by physicians to provide artificial hydration for symptom alleviation in an uncomfortable conflict. Generally, families request hydration therapy,<sup>11,12,21</sup> whereas patients sometimes refuse it, representing a source of nurse distress. Surprisingly, with regard to distress arising from disagreements among medical practitioners, no significant difference between the 2 settings was seen. Although PCU nurses evaluated discussion in the PCU positively, almost half were distressed by disagreements among medical practitioners. Sixty-eight percent were dissatisfied with respect for nurse opinions regarding hydration evidenced during communication with physicians, and disagreement might also occur among nurses in the PCU (Table 2). Even in the PCU, therefore, discussion and patient-centered decision making remain issues.

Several attitudes toward artificial hydration associated with distress were identified in 3 domains. Most of the associations identified in Table 1 appear clinically reasonable. For example, nurses who perceive a loss of trust by withholding artificial hydration



Table 4. Factors Related to Nurse Distress Arising from Artificial Hydration for Terminally Ill Cancer Patients

Explanatory variables	Distress on Behalf of Patients/Families who Complain about Withholding Artificial Hydration			Distress on Behalf of Patients/Families who Refuse Artificial Hydration			Distress Arising from Disagreements among Medical Practitioners		
	$\beta$	SE	P Value	$\beta$	SE	P Value	$\beta$	SE	P Value
Intercept	2.73	0.52	< .001	3.51	0.53	< .001	4.31	0.52	< .001
Characteristics of respondents									
Sex (1, female; 0, male)	.28	0.23	.22	.13	0.24	.60	.42	0.23	.07
Number of years of clinical practice	.00	0.00	.16	.00	0.00	.31	.01	0.00	.07
Number of cancer deaths that occurred in the unit during the preceding year	.00	0.00	< .001	.00	0.00	.58	.00	0.00	.99
Clinical setting (1, PCU; 0, oncology ward)	.11	0.10	.25	.39	0.10	< .0001	.18	0.10	.07
Attitudes toward artificial hydration									
Belief that artificial hydration alleviates physical symptoms	-.01	0.01	.50	.00	0.01	0.83	-.04	0.01	.002
Belief that withholding artificial hydration alleviates physical symptoms	.00	0.01	.81	.00	0.01	0.76	.06	0.01	< .001
Perception of loss of trust by withholding artificial hydration	.08	0.02	< .001	-.03	0.02	0.045	.00	0.02	.77
Perception of guilt from withholding artificial hydration	.01	0.02	.34	.01	0.02	0.36	.01	0.02	.55
Belief that artificial hydration is a component of minimum care	-.05	0.02	.040	-.06	0.02	0.022	-.09	0.02	.001
Perception of difficulty concerning decision making for artificial hydration	.03	0.02	.05	.04	0.02	0.018	.10	0.02	< .001
Belief that maintaining a venous route is a burden	.04	0.02	.12	.08	0.02	0.001	.02	0.02	.30
Nurse views of discussion of artificial hydration*	-.01	0.01	.10	.01	0.01	0.16	-.11	0.01	< .001

\*Summed score of 4 statements in Table 2. PCU = palliative care unit.

would be embarrassed by patient/family complaints about such withholding. Alleviation of distress related to beliefs over the palliative value of providing or withholding artificial hydration requires evidence for the effectiveness of hydration therapy and its dissemination.<sup>16</sup> Furthermore, to alleviate distress over the belief that maintaining a venous route is a burden, nurses should contrive methods of hydration that minimize the burden on patients, such as intermittent hydration and subcutaneous transfusion. Morita et al developed a satisfaction scale regarding rehydration therapy and explored related factors, and found that "the presence of a nurse with primary responsibility in charge" was associated with patient satisfaction for hydration therapy.<sup>22</sup> Thus, nursing

care would contribute not only to patient care but also to alleviating the burden on nurses.

Belief that artificial hydration is a component of minimum care and the perception of difficulty concerning decision making for artificial hydration were associated with the domain of distress arising from disagreements among medical practitioners. Nurse views of discussion of artificial hydration were also associated with this domain. These findings suggest that discussion regarding artificial hydration in the ward is an important factor in nurses' distress, and furthermore, they also suggest the need for more active discussion and patient-centered decision making.

The present study has several limitations. First, questions concerning attitudes toward artificial

hydration may obscure answers that depend on individual scenarios, for example, complications such as bowel obstruction, ascites, or pleural effusion. Second, data were gathered on nurses' retrospective views only, which might have been subject to recall error. Discussion about artificial hydration may require a prospective survey.

## Conclusion

Discussion among physicians and nurses regarding artificial hydration is insufficient, particularly in general wards. Medical practitioners caring for terminally ill cancer patients should engage in greater discussion among patient-centered teams and facilitate individualized decision making. Many nurses experience distress concerning artificial hydration for terminally ill cancer patients. Discussion with and active participation by nurses in decisions regarding hydration therapy might not only contribute to patient care but also alleviate the burden on nurses.

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## 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 is 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 (SD 13). 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  $\alpha$  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 (8)	54 (8)	55 (8)	57 (9)	54 (9)
BMI <sup>a</sup> (kg/m <sup>2</sup> )	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) <sup>a</sup>	% 12%	13%	18%	7%	13%
Job-having	% 48%	66%	47%	59%	37%
JOA score <sup>b</sup>	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 <sup>c</sup>					
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 is difficult 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%

<sup>a</sup> BMI: Body Mass Index.

<sup>b</sup> JOA score (in the bi-lateral hip OA group, the score of the more advanced hip joint was adopted).

<sup>c</sup> 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 <sup>a</sup>
	n	%	n	%	n	%	n	%	n	%	
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

<sup>a</sup> 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 <sup>a</sup>
	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

<sup>a</sup> 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 <sup>a</sup>
	N	%	n	%	n	%	n	%	n	%	
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.

<sup>a</sup> 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