

Since weight loss and muscle training can relieve the pain of OA and improve the range of motion (van Baar et al., 1998) and exercises including stretching and muscle training are expected to slow the progression of OA (Hochberg et al., 1995; Anon., 2000), we consider it 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.

In terms of muscle training and weight management activities, a small number of patients performed half of its items. Also, stages of the disease did not affect motivation of patients' training performance. These two facts are considered to be the reasons why there were no related factors.

Caution is required when generalizing this result since the present study focused on the patients of an orthopaedic outpatient service specializing in hip joints at one university hospital. Also, we used the answers from the patients to determine whether they performed the disease management activities, and did not verify whether they actually did or did not. Since it is important to continue the management activities, we consider it necessary to study temporal change of the result in addition to the present cross-sectional survey at a specific point in time.

Conclusions

The present study clarified the status of the disease management activities of the patients who were having conservative treatment. We consider it 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.

References

- Anon, 2000. Recommendations for the medical management of osteoarthritis of the hip and knee. American College of Rheumatology Subcommittee on Osteoarthritis Guidelines. *Arthritis and Rheumatism* 43(9), 1905–1915.
- Arokoski, J.P.A., 2005. Physical therapy and rehabilitation programs in the management of hip osteoarthritis. *Europa Medicophysica* 41 (2), 155–161.
- Creamer, P., Flores, R., Hochberg, M.C., 1998. Management of osteoarthritis in older adults. *Clinics in Geriatric Medicine* 14 (3), 435–454.
- Davy, D.T., Kotzar, G.M., Brown, R.H., Heiple, K.G., Goldberg, V.M., Heiple Jr., K.G., et al., 1988. Telemetric force measurements across the hip after total arthroplasty. *Journal of Bone and Joint Surgery* 70 (1), 45–50.
- Dolin, S.J., Williams, A.C., Ashford, N., George, J., Pereira, L., Perello, A., 2003. Factors affecting medical decision-making in patients with osteoarthritis of the hip: allocation of surgical priority. *Disability and Rehabilitation* 25 (14), 771–777.
- Hochberg, M.C., Altman, R.D., Brandt, K.D., Clark, B.M., Dieppe, P.A., Griffin, M.R., et al., 1995. Guidelines for the medical management of osteoarthritis. Part I. Osteoarthritis of the hip. American College of Rheumatology. *Arthritis and Rheumatism* 38 (11), 1535–1540.
- Honda, M., Kitagawa, Y., Shishido, H., Namiki, S., Shiraishi, H., 1999. Our surgical indication for conservative surgery of the hip joint with coxarthrosis. *Hip Joint* 25, 73–77 (in Japanese).
- Manek, N.J., Lane, N.E., 2000. Osteoarthritis: current concepts in diagnosis and management. *American Family Physician* 61 (6), 1795–1804.
- Messier, S.P., Loeser, R.F., Miller, G.D., Morgan, T.M., Rejeski, W.J., Sevick, M.A., et al., 2004. Exercise and dietary weight loss in overweight and obese older adults with knee osteoarthritis: the arthritis, diet, and activity promotion trial. *Arthritis and Rheumatism* 50 (5), 1501–1510.
- Ravaud, P., Giraudeau, B., Logeart, I., Laruquier, J.S., Rolland, D., Treves, R., et al., 2004. Management of osteoarthritis (OA) with an unsupervised home based exercise programme and/or patient administered assessment tools. A cluster randomised controlled trial with a 2 × 2 factorial design. *Annals of the Rheumatic Diseases* 63 (6), 703–708.
- van Baar, M.E., Dekker, J., Oostendorp, R.A., Bijl, D., Voorn, T.B., Lemmens, J.A., et al., 1998. The effectiveness of exercise therapy in patients with osteoarthritis of the hip or knee: a randomized clinical trial. *Journal of Rheumatology* 25 (12), 2432–2439.

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Attitude of outpatients with neuromuscular diseases in Japan to pain and use of analgesics

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Abstract

The prevalence of pain and its impact on outpatients with neuromuscular disease, and their attitude towards the use of analgesics were studied. Seventy-eight outpatients at the university hospital, Tokyo, diagnosed with Parkinson's disease, spinocerebellar degeneration, amyotrophic lateral sclerosis, or multiple sclerosis were asked whether they had experienced pain in the preceding week. The Brief Pain Inventory, Japanese version was used to interview participants reporting pain, about its intensity and interference with activities, the way they dealt with it, attitudes to pain and use of analgesics, and desire for treatment. Forty-six participants experienced pain in the preceding week (59%). The mean pain intensity was 4.1 out of 10, and 20% of participants reported that the degree of interference with mobility was at least 6 out of 10. Most participants dealt with their pain without medication, by changing posture frequently or massage. Approximately 80% of participants regarded pain as something they should endure. Half of the participants wanted more information on methods for pain relief. Approximately 80% of participants were anxious about adverse reactions of analgesics. These findings suggest that medical staffs should provide appropriate information and educate their patients.

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1. Introduction

In Japan, the number of patients with Parkinson's disease (PD), spinocerebellar degeneration (SCD), amyotrophic lateral sclerosis (ALS) and multiple sclerosis (MS) was approximately 80,000, 15,000, 7000, and 10,000, respectively, in 2005 [1]. PD, SCD, and ALS are progressive neurodegenerative diseases, while MS is a demyelinating disease with a variable natural course [2]. Therapies for complete remission against these diseases have not yet been established. However, because of improvements in medical

treatment and the prevention of infectious complications, the prognosis of patients with these diseases has improved. Therefore, long-term disease and symptom management is needed.

Symptoms of neuromuscular diseases vary with the disease and the phase of disease. Pain is one of the common symptoms [3]. Pain is an unpleasant symptom and is a factor that reduces the patient's activity [3,4]. Although, the origin of pain varies with each disease, most previous studies have reported that analgesics and adjuvant analgesics such as antidepressants are effective to relieve pain in neuromuscular diseases. For pain that is not reduced by analgesics, physiotherapy or psychotherapy are effective [3,5]. Nevertheless, it has been reported that the prevalence of pain in neuromuscular diseases is approximately 10–60% in the

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USA and Europe, and many patients feel that pain interferes with their daily activities [6–14]. In Japan, there have been few studies on this subject.

From the clinical point of view, pain relief is an important goal of treatment and care, in order to maintain the patient's comfort and activities of daily living (ADL). Medical staffs need to know the prevalence and the impact of pain. Relief from pain depends not only on medical specialists' knowledge about methods of pain relief, but also on the patient's knowledge and cooperation with the medical staff [15]. Some previous studies suggest that the pain threshold depends on culture, education level, and the healthcare and health insurance systems [16]. From these findings, it seems that patients' attitudes to pain and relief from pain differ among different cultures. The United Nations points out that the consumption of opioids in Japan is less than that in Western countries [17]. The Pharmaceutical Society of Japan says that the consumption of analgesics such as nonsteroidal inflammatory drugs (NSAIDs) is also less [18]. Little is known about the reasons for the low consumption of analgesics in Japan; however, it is possible that patients do not desire to use analgesics and that physicians are reluctant to prescribe them, being afraid of overuse.

To achieve relief from pain, it is necessary to clarify the characteristics of pain in neurological diseases and patients' attitudes to pain and relief from pain. For the maintenance of pharmacotherapy, it is also helpful to know the patient's attitude to the use of analgesics. Therefore, the first aim of this study was to investigate the prevalence and characteristics of pain in several representative neurological diseases: PD, SCD, ALS, and MS. The second aim was to investigate patients' attitudes to pain in neurological diseases and to relief from this pain. The third aim was to compare attitudes to the use of analgesics in people with and without pain.

2. Methods

2.1. Participants

Participants were outpatients at the University of Tokyo Hospital. Patients were included if they were more than 20 years old, had been diagnosed with PD, SCD, ALS, or MS, and were able to communicate in Japanese. The exclusion criterion was cognitive impairment.

2.2. Procedure

Data were collected in face-to-face interviews with participants in a room where privacy was ensured. First, participants were asked to complete the Hasegawa Dementia Scale-Revised (HDS-R) [19] to confirm the absence of cognitive impairment. The HDS-R is widely used in Japan to assess cognitive function, with a cutoff point of 20 or 21 out of 30. The HDS-R score is reported to be positively correlated to the score on the Mini-Mental State Examination

(MMSE), which is popular in the USA and European countries [19]. When the HDS-R score was higher than 21, the participant was asked about their experience of pain in the preceding week. If the participant had experienced pain in the preceding week, they were further asked about the intensity and other characteristics of the pain. Data such as "time since disease diagnosis" were collected by reviewing the medical records.

This study was approved by the University of Tokyo institutional ethical review board and informed consent was obtained from each participant.

2.3. Measures

2.3.1. Prevalence of pain

All participants were asked about the presence or absence of pain in the preceding week.

2.3.2. Pain intensity and its interference with activities

Participants who had experienced pain in the preceding week were asked to assess the intensity of their pain and the extent to which it had interfered with their ADL, using the Japanese Brief Pain Inventory (BPI-J) [20]. The BPI was initially developed to assess pain severity and interference in persons with cancer in the USA [21,22] and has been validated for people with cancer and noncancer pain. BPI was translated into Japanese in 1998 and has been used to assess pain intensity and its interference with ADL in Japan. The BPI-J includes ratings for worst pain, weakest pain, and average pain in the preceding week, and current pain, on a 0–10 numerical rating scale (NRS), where 0 is no pain and 10 is pain as bad as can be imagined.

Interference with ADL by pain was assessed in seven domains of life—general activities, mood, walking ability, normal work, relations with other people, sleep, and enjoyment of life—using a 0–10 NRS, with 0=does not interfere and 10=completely interferes.

2.3.3. How participants dealt with their own pain and its effect

Participants who had experienced pain in the preceding week were asked about the way they had dealt with their pain. Additionally, they were asked whether the means they had used to deal with their pain had any effect.

2.3.4. Attitude to their pain

Participants who had experienced pain in the preceding week were asked questions to discover if they thought they had to bear the pain and that whether they felt it was only they who had to face an unpleasant experience such as pain.

2.3.5. Desire for treatment

Participants who had experienced pain in the preceding week were asked three questions regarding the treatment for the pain relief: whether they were satisfied with the current treatment of pain, wished to be prescribed analgesics and

requested to be given more information about the methods of pain relief.

2.3.6. Use of analgesics

All participants were asked whether they used analgesics.

2.3.7. Attitude to use of analgesics

All participants were asked whether they would want to use opioids or analgesics other than opioids, or would not like to use any analgesics. Additionally, they were asked whether they had any anxiety for adverse reactions to analgesics and whether they thought that the effect of an analgesic decreased with continuous use.

2.3.8. Background

Background data on participants were collected by interview and medical record review, including age, gender, marital status, whether the participant was living with someone or had a caregiver, employment status, education level, use of health-care services, diagnosis, time since diagnosis, the worst symptoms, the number of medications, and activities of daily living (ADL). ADL was measured with the Barthel index (BI) [23], with a score ranging from 0 to 100. A BI score of 100 implies full functional independence.

2.4. Data analysis

Continuous data, such as age, other participant characteristics, and the BPI-J score, were expressed as mean and standard deviation (SD). Categorical data on the participant's characteristics, the way the patients dealt with their pain, attitudes to pain, etc., were expressed as frequency and percentage. The prevalence of pain in the preceding week was calculated. If the BPI-J score of pain intensity and interference with activities by pain was 6 or greater, this was categorized as "moderate to severe pain" and "moderate to severe interference."

Data on the use of analgesics and attitude to the use of analgesics were calculated as frequency and percentage and were analyzed with the chi-square test for the "with pain" and "without pain" groups. The worst symptom was analyzed with Fisher's exact test. Continuous data, such as age, time since diagnosis and the number of medications were analyzed with the *t*-test. All tests were two-tailed and considered significant at *p* level of 0.05. All statistical tests were undertaken using SAS version 9.1 (SAS Institute, Cary, NC).

3. Results

3.1. Response rate

Of the 81 patients invited to participate in the study, 80 accepted and one declined to participate in. One patient had a low HDS-R score and one patient was not eligible for other reasons, leaving 78 patients who completed the study (response rate was 96%).

3.2. Participant characteristics

The average age of participants was 61.2 ± 10.1 years, and 53% were male (Table 1). Approximately 80% of participants lived with their family and had one or more caregiver available when care was needed. The number of unemployed participants was 50 (64%). Eighteen participants were educated to at least college or graduate school level. The number of participants with diagnosis of PD, SCD, ALS, and MS was 46 (59%), 14 (18%), 7 (9%), and 11 (14%), respectively. The mean time since diagnosis was 9.6 ± 8.9 years. The worst symptoms were mobility disturbance (59%) and pain (24%). The mean number of medications that participants were prescribed was 5.1 ± 3.3 . The average BI score was 92.9/100.

Table 1
Characteristics of participants (N=78)

	n	(%)
Age [mean (SD)]	61.2 (10.1)	
Gender		
Male	41	(53)
Female	37	(47)
Marital status		
Married	50	(64)
Single/divorced/widowed	28	(36)
Live		
With family	62	(79)
Single/with friend	16	(21)
Caregivers, number of		
One or more	61	(78)
None	17	(22)
Employment status		
Employed	28	(36)
Unemployed	50	(64)
Education		
College graduate or beyond	18	(23)
Junior high school/high school graduate	60	(77)
Use of health-care services		
Used	20	(26)
Not used	58	(74)
Diagnosis		
PD	46	(59)
SCD	14	(18)
ALS	7	(9)
MS	11	(14)
Time since diagnosis, years [mean (SD)]	9.6 (8.9)	
Worst symptom		
Motility disturbance	46	(59)
Pain	19	(24)
Fatigue, weakness	13	(17)
Number of medications [mean (SD)]	5.1 (3.3)	
HDS-R [mean (SD)]	28.4 (1.6)	
BI [mean (SD)]	92.9 (17.0)	

PD, Parkinson's disease, SCD, spinocerebellar degeneration, ALS, amyotrophic lateral sclerosis, MS, multiple sclerosis, HDS-R, Hasegawa's Dementia Scale — Revised (a scale of cognitive function with scores 0–30; a score <20 indicates the presence of cognitive impairment), BI, Barthel index (BI score 100 implies full functional independence).

3.3. Prevalence of pain

Of 78 participants, 46 responded that they had experienced pain in the preceding week. The prevalence of pain was 59%. Thirty-one of 46 patients with PD, 4 of 7 patients with ALS, 5 of 14 patients with SCD and 6 of 11 patients with MS experienced pain.

3.4. Pain intensity and its interference with activities

The mean pain intensity of the worst pain in the preceding week was 5.6 (SD=2.2) and 17 participants (37%) responded that the worst pain was moderate to severe. The mean pain intensity in the preceding week was 4.1 (SD=1.9) and 8 participants (17%) responded that the average pain was moderate to severe (Table 2).

The mean level of interference of pain in walking ability, normal work, general activities, and enjoyment of life was 4.3 (SD=3.9), 3.2 (SD=3.4), 2.8 (SD=3.3) and 2.5 (SD=3.4), respectively. For these four domains, over 20% of participants responded that pain interference in the preceding week was moderate or severe.

3.5. How participants dealt with the pain and its effects

The ways patients dealt with the pain were, in percentage order, enduring the pain (78%), changing posture frequently (50%), and use of analgesics (33%). More than half of the participants reported that the following 5 ways of dealing with their pain were effective: use of analgesics (93%), massaging/having massage (90%), cooling (89%), changing posture frequently (83%), and warming up (67%). Enduring the pain was considered effective by 39% of participants (Table 3).

Table 2
Intensity of pain and its interference with activities (N=46)

	Mean (SD)	Moderate to severe ^a n (%)
Intensity of pain ^b		
Worst pain in the preceding week	5.6 (2.2)	17 (37)
Average pain in the preceding week	4.1 (1.9)	8 (17)
Interference of pain in activities ^c		
General activities	2.8 (3.3)	11 (24)
Mood	2.5 (2.6)	6 (13)
Walking ability	4.3 (3.9)	17 (37)
Normal work	3.2 (3.4)	12 (26)
Relations with other people	2.2 (3.2)	8 (17)
Sleep	1.6 (3.2)	6 (13)
Enjoyment of life	2.5 (3.4)	9 (20)

^a 6 or more on numerical rating scale.

^b 0–10 numerical rating scale, where 0 is no pain and 10 is pain as bad as can be imagined.

^c 0–10 numerical rating scale, where 0 is does not interfere and 10 is completely interferes.

Table 3
How patients dealt with their pain and its effect (N=46; multiple choice)

	n (%)	Effective n (%)
Enduring the pain	36 (78)	14 (39)
Changing posture frequently	23 (50)	19 (83)
Massaging or having massage	21 (46)	19 (90)
Warming up	18 (39)	12 (67)
Cooling	18 (39)	16 (89)
Use of analgesic	15 (33)	14 (93)
Others ^a	17 (37)	15 (88)

^a Moxibustion, exercising, drinking warm green tea, and magnetic treatment.

3.6. Participants' attitude to pain and desire for treatment

More than 80% of participants, who experienced pain in the preceding week, considered that they had to endure the pain within their tolerance and that they had to endure it as a symptom of the disease. Half of the participants who experienced pain questioned why only he or she had to face an unpleasant experience such as pain (Table 4).

Fifty-two percent of participants who experienced pain in the preceding week asked their physician or nurse to provide information on methods of relief from pain. Eleven percent of participants were satisfied with their present treatment, while 11% wanted their physician to prescribe analgesics, to increase the analgesics presently prescribed, or to change the analgesic prescribed.

3.7. Use of analgesics and attitude to analgesics use

The number of participants in the “with pain” group who took analgesics regularly or only when they experienced pain was 13 (18%; not significantly different from the “without pain” group statistically; $p=0.10$) (Table 5).

Thirty-six (78%) of participants in the “with pain” group thought that the effect of analgesics decreased with regular use and 78% feared adverse reactions of analgesics.

Table 4
Participants' attitude to pain and desire for treatment (N=46; multiple choice)

	n	(%)
Attitude to participants' own pain		
Must endure pain if it is tolerable	41	(89)
Must endure pain because it is a symptom of their disease	37	(80)
Questions why only the participant has to face such an unpleasant experience	23	(50)
Desire for treatment		
Desires to be given information on methods of pain relief by physician or nurse	24	(52)
Desires to have analgesics or more analgesics prescribed, or to have a different analgesic prescribed	5	(11)
Satisfied with present treatment	5	(11)

Table 5
Use of analgesics and attitude to use of analgesics (n=78)

	With pain (n=46)		Without pain (n=32)		p
	n	(%)	n	(%)	
Use of analgesics					
Regular use or single use	13	(28)	3	(9)	0.10
Not used	33	(72)	29	(78)	
Thinks the effect of analgesics decreases with regular use	36	(78)	25	(78)	1.00
Fears adverse reaction of analgesics	36	(78)	22	(69)	0.49
Desires to use analgesics only when external medicine or massage does not relieve pain	30	(65)	23	(72)	0.71
Desires to use analgesics other than opioids when pain is experienced	28	(61)	24	(75)	0.29
Desires to use opioids when pain is experienced	9	(20)	19	(59)	<0.01**
No desire to use analgesics	21	(46)	9	(28)	0.18

** $p < 0.01$.

Corresponding percentages in the “without pain” group were 78 and 69, respectively. There were no significant differences between the groups ($p = 1.00$ and $p = 0.49$ for the two variables, respectively). Thirty participants (65%) in the “with pain” group and 23 (72%) in “without pain” group responded that they desired to use analgesics only when external medicine or massage would not relieve pain ($p = 0.71$). Twenty-eight participants (61%) in the “with pain” group and 24 (75%) in the “without pain” group responded that they desired to use analgesics other than opioids ($p = 0.29$). The number of participants who responded that they desired to use opioids when they experienced pain was 9 (20%) in the “with pain” group and 19 (59%) in the “without pain” group ($p < 0.01$). Twenty-one participants (46%) in the “with pain” group and 9 (28%) in the “without pain” group reported that they did not wish to use any analgesic ($p = 0.18$).

4. Discussion

We investigated the prevalence of pain, its intensity, and interference with daily living in outpatients with neuromuscular disease, the ways in which patients dealt with their pain, and their attitude to the pain. Our findings on the use of analgesics show considerable variation in attitude to achieve relief from pain.

Fifty-nine percent of the participants had experienced pain in the preceding week and the prevalence of pain of PD, ALS, SCD, and MS was 67%, 57%, 36%, and 55% respectively. In Japan the prevalence of pain in neuromuscular disease is greater than that of chronic pain in the general population (13%) [24]. This suggests that pain is common in neuromuscular disease and is not relieved sufficiently.

The percentages of the pain intensity for the worst and average pain in preceding week were moderate to severe and similar to those reported in previous research [9]. However, in previous research, 58.5% of the participants took

analgesics or adjuvant analgesics such as steroids, anticonvulsants, antidepressants, and muscle relaxants. In contrast, in this study, only 28% (13 of the 46 participants with pain) of the participants with pain use analgesics. This suggests that the appropriate use of analgesics or adjuvant analgesics might relieve pain, although therapies other than pharmacotherapy might also reduce pain.

Interference with mobility (walking ability, normal work, general activities, and enjoyment of life) was moderate to severe in more than 20% of the participants. Interference in mood, relations with other people, and sleep was moderate to severe in more than 10%. This suggests that pain interferes in a wide range of aspects of daily life, and needs to be relieved. Some studies point out that a decline in daily activities leads to depression or low quality of life (QOL) [25]. Pain has been shown to prevent people from continuing physiotherapy [3]. Thus, maintenance of activities with the proper use of analgesics and physiotherapy may also prevent a decline in QOL.

Many participants dealt with pain without the use of analgesics, such as by changing their posture frequently and by massaging themselves or having a massage. This may not only be due to negative aspects of the image of analgesics, but also be due to the belief that an individual should accept pain as a companion in their life, and as something that they should endure [24]. However, most of the participants who used moxibustion, exercised, drank warm green tea and used magnetic treatment, did experience pain relief. More information needs to be obtained about the alternative methods of pain relief.

Many participants regarded their pain as something they should endure. A previous study on health-seeking behavior for acute pain suggested that Japanese people tend to delay health-seeking behavior because they think that the symptoms will go away and that the symptoms are not serious [26]. The participants in the present study might have thought that their own pain would go away or was not serious. In addition, patients might regard the reporting of pain to their physician or asking their physician to prescribe analgesics as complaining behavior in a negative sense.

While half of the participants who had experienced pain asked their physician or nurse to provide information about methods of pain relief, only 11% of participants requested to be prescribed analgesics. Participants want to relieve pain, but might not want to take analgesics for fear of their adverse reactions. It is important that the physician and nurse explain the necessity of relief from pain and give information about the methods for pain relief. They should additionally encourage the patients to deal with pain through physical therapy and other means. It is also important that medical specialists try to allay patients' anxiety about analgesics.

The shorter time after diagnosis for the patients who reported pain suggests that pain may occur at any time after diagnosis. Thus, physicians and nurses need to assess pain in their patients from an early phase of their disease [3]. While

72% of the participants with pain did not use any analgesics, 28% of the participants who took analgesics regularly or on a single occasion responded that they had experienced pain in the preceding week. This suggests that it may be difficult to relieve pain in these patients or that their analgesics may not have been appropriate for the relief of their pain [3,10]. The intention of using analgesics was not generally different in participants with or without pain. One possible reason is the negative image of analgesics and adverse reactions or the fear of a decrease in effect with regular use. A second reason may be that most of the participants wanted causal treatment rather than symptomatic treatment [24]. A third reason may be that the patients underestimate their own pain or regarded it as untreatable. To achieve relief from pain, the negative image of analgesics must be removed, and physicians and nurses must educate patients about appropriate methods for pain relief. It is also important to clarify the reasons why patients have a passive attitude to the use of analgesics and the attitudes of physicians and nurses to pain relief.

4.1. Study limitations

There are several limitations of this study. Because of the small number of participants, generalization of the results is difficult. The cause of the pain in these participants is not considered, so we cannot say whether the pain experienced by the participants was related to their neuromuscular disease. Finally, because the reliability and validity of the BPI-J for use in neuromuscular diseases have not yet been established, pain intensity and its interference in the participants' activities may have been under- or overestimated.

5. Conclusion

This study revealed that the prevalence of pain in outpatients with neuromuscular disease (PD, ALS, SCD, or MS) was 59%. The percentage of patients in whom the intensity of the worst and average pain in the preceding week was moderate to severe was 37% and 17%, respectively. Pain had moderate to severe interference with mobility in more than 20% of participants. Although analgesic use was the most effective means of relieving pain, only 33% of participants used analgesics and many participants dealt with pain by other means. Patients want more information about methods of relief from pain other than the use of analgesics. It is important for medical staffs to provide more information to patients actively. It is required in future to clarify the reason why patients are reluctant to use analgesics.

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References

- [1] Homepage of Japan Intractable Diseases Information Center. [updated 2007 Jan 12; cited] Available from: <http://www.nanbyou.or.jp/top.html>.
- [2] Hoffman A, Mayeux R. Investigating neurological disease. Cambridge: Cambridge University Press; 2001.
- [3] Voltz R, Bemat JL, Borasio GD, Maddocks I, Oliver D, Portenoy RK. Palliative Care in Neurology. New York: Oxford University Press; 2004.
- [4] Quitterbaum BH, Grahn B. Quality of life and pain in Parkinson's disease: a controlled cross-sectional study. *Parkinsonism Relat Disord* 2004;10:129–36.
- [5] Chou R, Peterson K, Helfand M. Comparative efficacy and safety of skeletal muscle relaxants for spasticity and musculoskeletal conditions: a systematic review. *J Pain Symp Manage* 2004;28(2):140–75.
- [6] Scherder E, Wolters E, Polman C, Sergeant J, Swaab D. Pain in Parkinson's disease and multiple sclerosis: its relation to the medial and lateral pain systems. *Neurosci Biobehav Rev* 2005;29:1047–56.
- [7] Lee MA, Walker RW, Hildreth TJ, Prentice WM. A survey of pain in idiopathic Parkinson's disease. *J Pain Symp Manage* 2006;32(5):462–9.
- [8] Etchepare F, Rozenberg S, Mirault T, Bonnet AM, Lecorre C, Agid Y, et al. Back Problem in Parkinson's disease; an underestimated problem. *Jt Bone Spine* 2006;73:298–302.
- [9] Jensen MP, Abresch RT, Carter GT, McDonald CM. Chronic pain in persons with neuromuscular disease. *Arch Phys Med Rehabil* 2005;86:1155–63.
- [10] Oesterberg A, Boivie J, Thuomas KA. Central pain in multiple sclerosis—prevalence and clinical characteristics. *Eur J Pain* 2005;9:531–42.
- [11] Solaro C, Lunardi GL, Mancardi GL. Pain and MS. *Int MS J* 2003;10:14–9.
- [12] Heckman-Stone C, Stone C. Pain management techniques used by patients with multiple sclerosis. *J Pain* 2001;2(4):205–8.
- [13] Terao A. Multiple sclerosis and headache, neuralgia. *Med Pract* 2003;20(6):1022–3 [in Japanese].
- [14] Taniguchi A, Narita Y, Naito Y, Kuzuhara S. Pain in initial phase of amyotrophic lateral sclerosis. *Neurol Ther(Shinkeichiryogaku)* 2000;17(4):361–5 [in Japanese].
- [15] Melzack R, Wall P. The Challenge of Pain. Chippenham: Penguin Books; 1982.
- [16] Guo Y, Kuroki T, Yamashiro S, Koizumi S. Illness behaviour and patient satisfaction as correlates of self-referral in Japan. *Family Pract* 2002;19(4):326–32.
- [17] United Nations Economic and Social Council. Commission on Narcotic Drugs Report for the forty-eighth session; 2005.
- [18] Homepage of The pharmaceutical Society of Japan. [updated 2007 Apr 1; cited] Available from: <http://www.pharm.or.jp>.
- [19] Kato S, Shimogaki H, Onodera A, Ueda H, Oikawa K, Hasegawa K, et al. The development of Hasegawa's dementia scale-revised (HDS-R). *Jpn J Geriatr Psychiatr (Nihon Ronenensei shishinagakuzasshi)* 1991;2:1339–47 [in Japanese].
- [20] Uki J, Mendoza T, Cleeland CS, Nakamura Y, Takeda F. A Brief Pain Assessment Tool in Japanese: the utility of the Japanese Brief Pain Inventory — BPI-J. *J Pain Symp Manage* 1998;16(6):364–73.
- [21] Daut RL, Cleeland CS, Flanery RC. Development of the Wisconsin Brief Pain Questionnaire to assess pain in cancer and other disease. *Pain* 1983;17:197–210.
- [22] Keller S, Bann CM, Dodd SL, Scherir J, Mendoza TR, Cleeland CS. Validity of the Brief Pain Inventory for use in documenting the outcomes of patient with noncancer pain. *Clin J Pain* 2004;20(5):309–18.
- [23] Mahoney FI, Barthel D. Functional evaluation: The Barthel Index. *Md State Med J* 1965;14(2):61.
- [24] Hattori S. Prevalence of chronic pain in Japan. *Folia Pharma Jpn (Nihon-Yakurigaku zasshi)* 2006;127:176–80 [in Japanese].
- [25] Schrag A. Quality of life and depression in Parkinson's disease. *Neurol Sci* 2006(248):151–7.
- [26] Liao L, Whellan DJ, Tabuchi K, Schulman KA. Differences in care-seeking behavior for acute chest pain in the United States and Japan. *Am Heart J* 2004;147(4):630–5.

Palliative Care in Japan: Current Status and a Nationwide Challenge to Improve Palliative Care by the Cancer Control Act and the Outreach Palliative Care Trial of Integrated Regional Model (OPTIM) Study

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Palliative care is an essential part of integrated cancer treatment. To improve palliative care throughout Japan, a nationwide demonstration project, the Outreach Palliative Care Trial of Integrated Regional Model (OPTIM) study, is ongoing. This article reviews the current status and the problems of palliative care in Japan and introduces the OPTIM study. Although the number of palliative care services is increasing, empirical evidence shows the quality of life of cancer patients is still inadequate. The OPTIM study is an intervention trial targeting 4 areas across Japan. Primary end points are

quality of care reported by patients as well as the bereaved family, number of patients who received specialized palliative care services, and place of death. The interventions are comprehensively designed to cover all areas identified by the national task force. The OPTIM study will contribute to improve patients' quality of life by proposing a regional palliative care model suitable for Japan.

Keywords: palliative care; regional trial; neoplasms

Palliative care is an essential part of integrated cancer treatment.¹ Although palliative care should be provided throughout a whole region, a regionalized palliative care model has not been established in Japan. The Outreach Palliative Care Trial of Integrated Regional Model (OPTIM) study was therefore launched in 2007 to demonstrate a model suitable for the dissemination of high-quality palliative care in the Japanese community.

The two primary aims of this action paper are to review the current status and the problems of palliative care in Japan and provide an overview of the OPTIM study.

Current Status of Palliative Care in Japan

Health Care System and Specialty Training in Palliative Care

The health care system for specialized palliative care services in Japan has been progressing rapidly in this decade. Japan has 3 types of specialized palliative care services: palliative care units, hospital palliative care teams, and specialized home-care clinics.

Palliative care units are called "palliative care units" or "hospices" depending on their religious

background, but their clinical roles are essentially the same: intensive symptom control, psychosocial support, and end-of-life care for incurable cancer patients and their families. The first palliative care unit was established in 1981 in a private Christian hospital (Seirei Hospice).

The next landmark in the national strategy of palliative care was in 1989, with the publication of the end-of-life care report by the Ministry of Health, Labour and Welfare. This report resulted in the first government-approved palliative care units eligible for national health insurance coverage in 1990. The number of palliative care units has since dramatically increased, from 5 in 1990 to more than 170 in 2006.^{2,3} Most palliative care units belong to general hospitals and provide integrated palliative care by an interdisciplinary team. This is the most common type of specialized palliative care service in Japan.

Hospital palliative care teams were first covered by national medical insurance in 2002.⁴ The expected role of palliative care teams is to provide specialized palliative care to all cancer patients, including those receiving active cancer treatment, not only those in the advanced stage. For a palliative care team to be approved for national health insurance coverage, it must fulfill the requirements of the Ministry of Health, Labour and Welfare: interdisciplinary team activity, including at least 1 attending palliative care physician, a psychiatrist, and certified advanced-practice nurse. In 2007 the number of certified palliative care teams was approximately 60, and many hospitals intend to establish palliative care team activity.

Specialized home-care support clinics were first defined in 2006. These clinics are expected to provide home care for a wide range of patients in the community by a multidisciplinary team with 24-hour service, although the specialty requirement is still poorly defined. The clinics can obtain additional remuneration for their practices for terminally ill patients at home, and 8600 clinics have been established.

As for specialty training in palliative care, the Japanese Society for Palliative Medicine was established in 1996 as an academic association to conduct research, education, and dissemination of palliative care. It had approximately 6000 members in 2006. The number of advanced practice nurses is furthermore rapidly increasing: 79 oncology-certified nurse specialists and 891 certified nurses, including 420 in palliative care, 267 in pain management, and 204 in chemotherapy.

Evidence to Suggest Poor Quality of Life of Cancer Patients

To date, no nationwide representative survey has clarified how cancer patients and their family members evaluated the quality of palliative care they actually received, although multiple surveys to understand the experience of patients and families are now ongoing. Empirical evidence, nonetheless, suggests a poor quality of life for cancer patients in Japan.

First, in a multicenter questionnaire survey of 630 bereaved family members of cancer patients admitted to palliative care units, 85% of 318 responding families reported that their relative had had distressing physical symptoms before admission to the palliative unit, and 50% reported that considerable or much improvement was necessary in the care they had received.⁵

Second, less than 10% of Japanese cancer patients received specialized palliative care services: 6.6% from palliative care teams and 2.2% from palliative care units.^{3,6} Multiple Western studies have suggested that specialized palliative care services contribute to improving patients' quality of life, and family satisfaction was extremely high for inpatient palliative care services in Japan.^{2,7,8} In the United Kingdom and United States, more than half of all cancer patients receive specialized palliative care⁹⁻¹¹

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Table 1. Palliative care in Japan, the United Kingdom, and United States of America

Variable	Japan	UK	USA
Cancer deaths per year	326 000	138 000	550 000
Use of specialized palliative care services, % of all cancer deaths			
Inpatient service	6.6	26	
Hospital consultation service	2.2	74	
Home-based service		69	99
Place of death, % of all cancer deaths			
Home	5.7	22	39
Palliative care unit or inpatient hospice	5.3	16	
Hospital or nursing home	86	60	54

Abbreviations: UK, United Kingdom; USA, United States of America.

(Table 1). The low involvement of specialized palliative care services suggests a lower quality of life for cancer patients in Japan.

Third, a discrepancy exists between the place where the patient preferred to die and the actual place of death. Although 50% of the Japanese general public expresses a preference to spend their final days at home and 30% in a palliative care unit,¹² the actual rate of death at home and inpatient specialized palliative care service is 5.7% and 5.5%, respectively, and most cancer patients die in hospitals (Table 1).¹³⁻¹⁵ Because the location of death is an important element of the quality of life,¹⁶ this finding suggests a poor quality of life for Japanese cancer patients.

Finally, opioid consumption is one sixtieth of that in the United States and one seventh of that in the United Kingdom.¹⁷ Despite the differences in legal and medical regulations, as well as racial differences, this finding suggests that pain palliation of cancer patients in Japan is still not achieved.

Barriers for Quality Palliative Care

To explore effective strategies to disseminate quality palliative care throughout the country, a national task force was organized and identified the barriers to quality palliative care, which were

1. lack of standardized clinical tools,
2. lack of knowledge about palliative care by the general public,
3. lack of whole-region organization to coordinate community palliative care, and
4. specialized palliative care services less available in community.¹⁸

Lack of Standardized Clinical Tools

Standardized tools are important to maintain the quality and continuity of community palliative care.¹⁹ Despite the variety of frameworks, guidelines, and clinical pathways available in English-speaking countries, in Japan, standard materials have not been developed or are inadequately disseminated. We have completed or are now performing a validation study of several key instruments to modify the original tools suitable for Japanese culture, including the Support Team Assessment Schedule, M.D. Anderson Symptom Inventory, Distress Thermometer, and Liverpool Care Pathway.²⁰⁻²² These instruments are gradually being disseminated to palliative care clinicians, but more distribution efforts to general practice are greatly required.

Lack of Knowledge About Palliative Care

Despite strong empirical evidence that opioids for cancer pain rarely cause addiction, 30% of the Japanese general public believes that they are addictive, and such misapprehension is a significant barrier for better pain management.²³⁻²⁵ Also, 34% of the general public in Japan knows about palliative care units compared with 70% in the United Kingdom.^{12,26} Of note is that although 32% of the Japanese general public believes that palliative care units are a place where patients just wait for death, these negative perceptions significantly decreased after they actually used a specialized palliative care service.^{5,12} This lack of knowledge and misinformation about opioids and palliative care is a considerable barrier to palliative care and pain control at an appropriate time, and education of the general public is of great value.

Lack of Whole-Region Organization to Coordinate Community Palliative Care

The resources potentially available for community cancer patients are becoming more complicated and involve more than a single institution. Although an increasing number of Japanese hospitals have support centers available for community patients, they provide the services principally to their own patients. Whole-region organizations to implement comprehensive coordination for community patients are therefore strongly required.

Specialized Palliative Care Services Less Available

Specialized home-care clinics have just started and are quite primitive in Japan, but specialized palliative care services are currently available only for institutionalized patients. In Europe, community palliative care teams provide consultation services for all patients in the community.²⁷ It is necessary to establish a medical system to provide specialized palliative care that is easily available for community cancer patients.

The OPTIM Study

Overview

From these findings, palliative care in Japan has rapidly progressed in this decade, but many issues still must be resolved. To improve cancer care including palliative care throughout Japan, the Cancer Control Act was established in April 2007. The aims of this law are to promote cancer prevention and early detection, disseminate quality palliative care, and promote cancer research. The Ministry of Health, Labour and Welfare especially focuses on palliative care and has launched multiple nationwide projects to facilitate the dissemination of palliative care. One of these is the OPTIM study, a 5-year project from 2006 to 2011 with a yearly budget of US\$2.5 million.

Aim of the OPTIM Study

The primary aim of the OPTIM study is to evaluate whether a systematic, multi-intervention regional palliative care program can improve the quality of

life of cancer patients in the community. The ultimate purpose of this study is to develop a success model of regional palliative care suitable for Japan.

Subjects and Methods

This is a regional intervention trial measuring the end point before and after intervention. This trial involves 4 intervention regions across Japan with different palliative care system development: Chiba (Kashiwa city, Abiko city, Nagareyama city), Shizuoka (Hamamatsu city), Nagasaki (Nagasaki city), and Yamagata (Tsuruoka, Mikawa-cho; Figure 1). Chiba, Shizuoka, and Nagasaki have a growing organized system to provide palliative care led by a national cancer center, a general hospital, and a regional general practitioner association, respectively. Yamagata has an unorganized system of palliative care.

The study subjects are all residents of the participating regions, including the general public, patients, their families, and health care providers. A total of 0.2 million people are potential participants in this study.

Intervention

The interventions of the OPTIM study are comprehensive and designed to cover all areas identified by the national task force.¹⁸ Each intervention was determined by discussion among clinical specialists and researchers, including palliative care physicians, psychiatrists, nurses, medical social workers, and home care practitioners. In addition, we performed a preliminary survey of 8000 members of the general public and all medical health care providers in the target regions before planning the interventions, and the results were reflected in the details of the interventions.

The interventions include (1) disseminating standardized clinical tools, (2) providing appropriate information about palliative care to the general public, patients and their family, (3) establishing whole-region organization to coordinate community palliative care, and (4) establishing specialized palliative care services available in the community (Table 2).

Clinical tools prepared for this study include (1) assessment tools (comprehensive patient-reported assessment tools consisting of the Japanese version of the M.D. Anderson Symptom Inventory, Distress Thermometer, observer-rating Japanese version of

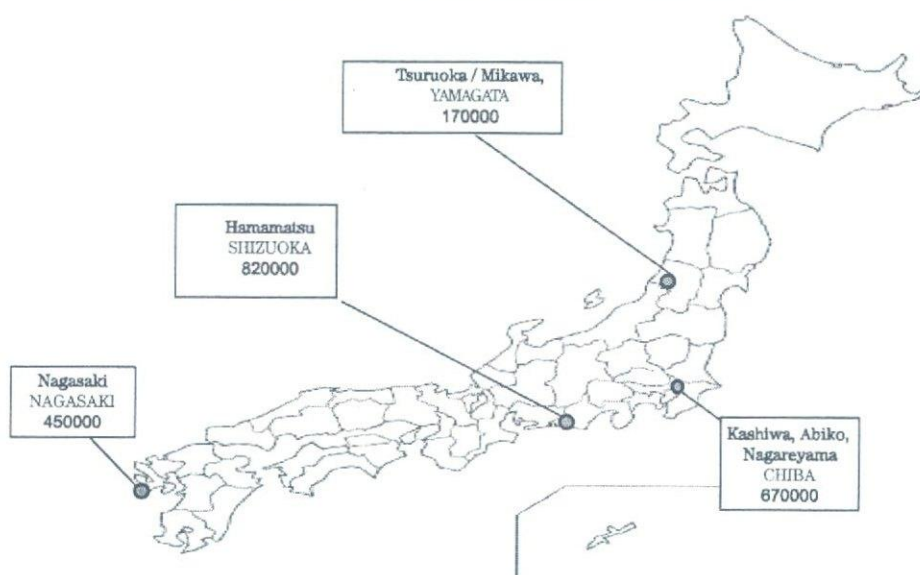


Figure 1. Participating areas of the Outreach Palliative Care Trial of Integrated Regional Model (OPTIM) study are shown with the resident population number.

Table 2. Interventions of the Outreach Palliative Care Trial of Integrated Regional Model Study

Target Area	Intervention	Main Contents
Lack of standardized clinical tools	To standardize and improve the knowledge, skills, and continuity of palliative care in the community	Dissemination of standardized clinical tools via printed and Web materials Interactive workshop and on-demand Web lectures Contents Assessment tools Treatment algorithm Education materials for patients and family members Patient-held records Discharge planning program
Lack of knowledge about palliative care by the general public, patients and their family	To provide appropriate information about palliative care	Distribution of materials via hospitals, Web, visits, patient library, symposia, and local mass-media Materials Leaflets and posters DVDs Books
Lack of whole-region organization to coordinate community palliative care	To establish regional palliative care centers to coordinate community palliative care	Coordination and information service about palliative care services for community residents Regional conference to create local networks and identify local problems
Specialized palliative care services less available in community	To increase availability of specialized palliative care services for community patients	Community palliative care team Educational outreach

Abbreviation: DVD, digital video disc.

the Support Team Assessment Schedule), (2) 3-step ladder-based symptom control algorithm for 9 leading symptoms, (3) educational materials for patients and families, (4) patient-held records, and (5) discharge planning program with a discharge conference as an essential part.

Outcome Measures

Primary end points are quality of palliative care as reported both by patients and the bereaved family, the number of patients who received specialized palliative care services, and place of death. The quality of palliative care is measured by the Care Evaluation Scale, a validated tool to quantify user-perceived quality of care.²⁸

Secondary outcome measures include knowledge, competency, and difficulties of regional physicians and nurses, and quality indicators of regional palliative care, including opioid consumption and the number of nursing agencies providing around-the clock services.

Conclusion

Palliative care in Japan is rapidly progressing through multiple nationwide actions with support from the Cancer Control Act. Palliative care specialists will overcome the challenges and grasp this unique opportunity in cooperation with other specialties to disseminate quality palliative care throughout Japan. The OPTIM study has received much attention and will contribute to improving patient quality of life by proposing a regional palliative care model suitable for Japan. The OPTIM study will be completed in March 2011, and initial results are expected in mid-2012.

References

- World Health Organization. *National Cancer Control Programmes. Policies and Managerial Guidelines*. 2nd ed. Geneva, Switzerland: World Health Organization; 2002.
- Morita T, Chihara S, Kashiwagi T. Family satisfaction with inpatient palliative care in Japan. *Palliat Med*. 2002;16:185-193.
- Japan Hospice Palliative Care Foundation. *Hospice Kanwakea Hakusho* [in Japanese]. 3rd ed. Tokyo, Japan: Seikaisha; 2006.
- Morita T, Fujimoto K, Tei Y. Palliative care team: the first year audit in Japan. *J Pain Symptom Manage*. 2005;29:458-465.
- Morita T, Akechi T, Ikenaga M, et al. Late referrals to specialized palliative care service in Japan. *J Clin Oncol*. 2005;23:2637-2644.
- Health and Welfare Statistics Association. *Kokuminei-seinodoukou 53* [in Japanese]. Tokyo, Japan: Health and Welfare Statistics Association; 2006.
- Higginson IJ, Finlay I, Goodwin DM, et al. Do hospital-based palliative teams improve care for patients or families at the end of life? *J Pain Symptom Manage*. 2002;23:96-106.
- Higginson IJ, Finlay IG, Goodwin DM, et al. Is there evidence that palliative care teams alter end-of-life experiences of patients and their caregivers? *J Pain Symptom Manage*. 2003;25:150-168.
- The National Council for Palliative Care. *National Survey for Patient Activity Data for Specialist Palliative Care Services MDS Full Report for the Year 2004-2005*. Available from http://www.aswcs.nhs.uk/Informatics/PalliativeCareMinimumDataset/MDS_Full_Report_2005.pdf. Accessed February 10, 2007.
- National Center for Health Statistics. *Health, United States, 2005*. Table 31. Leading causes of death and numbers of deaths, according to sex, race, and Hispanic origin: United States, 1980 and 2003. Available from <http://www.cdc.gov/nchs/data/hs/hs05.pdf>. Accessed February 10, 2007.
- National Hospice and Palliative Care Organization. *NHPCO's Facts and Figures-2005 Findings*. Available from <http://www.alfa.org/files/public/NHPCO2005-facts-and-figures.pdf>. Accessed February 10, 2007.
- Sanjo M, Miyashita M, Morita T, et al. Preferences regarding end-of-life cancer care and associations with good-death concepts: a population-based survey in Japan. *Ann Oncol*. 2007;18:1539-1547.
- Ministry of Health, Labour and Welfare. *Population Survey Report 2005*. Available from http://www.dbtk.mhlw.go.jp/toukei/data/010/2005/toukeihyou/0005626/t0124446/MC210000_001.html. Accessed February 10, 2007.
- National Center for Health Statistics. *Worktable 307*. Deaths from 39 selected causes by place of death, status of decedent when death occurred in hospital or medical center, and age: United States, 2003. Available from http://www.cdc.gov/nchs/data/dvs/MortFinal2003_WorkTable307.pdf. Accessed February 10, 2007.
- National Statistics. *Series DH1 no. 37 Mortality Statistics*. Table 17. Deaths: place of occurrence and sex by underlying cause and age-group, 2004. Available from http://www.statistics.gov.uk/downloads/theme_health/Dh1_37_2004/DH1_no_37.pdf. Accessed February 10, 2007.
- Miyashita M, Sanjo M, Morita T, et al. Good death in cancer care: a nationwide quantitative study. *Ann Oncol*. 2007;18:1090-1097.
- The International Narcotics Control Board (INCB). *Tables of Reported Statistics*. Available from http://www.incb.org/pdf/e/tr/nar/2004/narcotics_part4_tables.pdf. Accessed February 10, 2007.

18. Miyashita M, Sanjo M, Morita, et al. Barriers to providing palliative care and priorities for future actions to advance palliative care in Japan: a nationwide expert opinion survey. *J Palliat Med.* 2007;10:390-399.
19. Bruera E, Neumann CM, Gagnon B, et al. Edmonton regional palliative care program: impact on patterns of terminal cancer care. *CMAJ.* 1999;161:290-293.
20. Miyashita M, Matoba K, Sasahara T, et al. Reliability and validity of the Japanese version of the Support Team Assessment Schedule (STAS-J). *Palliat Support Care.* 2004;2:379-385.
21. Okuyama T, Wang XS, Akechi T, et al. Japanese version of the MD Anderson Symptom Inventory: a validation study. *J Pain Symptom Manage.* 2003;26:1093-1104.
22. Shimizu K, Akechi T, Okamura M, et al. Usefulness of the nurse-assisted screening and psychiatric referral program. *Cancer.* 2005;103:1949-1956.
23. Morita T, Miyashita M, Shibagaki M, et al. Knowledge and beliefs about end-of-life care and the effects of specialized palliative care: a population-based survey in Japan. *J Pain Symptom Manage.* 2006;31:306-316.
24. Hojsted J, Sjogren P. Addiction to opioids in chronic pain patients: a literature review. *Eur J Pain.* 2007;11:490-518.
25. Ward SE, Goldberg N, Miller-McCauley V, et al. Patient-related barriers to management of cancer pain. *Pain.* 1993;52:319-324.
26. Koffman J, Burke G, Dias A, et al. Demographic factors and awareness of palliative care and related services. *Palliat Med.* 2007;21:145-153.
27. Kuin A, Courtens AM, Deliens L, et al. Palliative care consultation in the Netherlands: a nationwide evaluation study. *J Pain Symptom Manage.* 2004;27: 53-60.
28. Morita T, Hirai K, Sakaguchi Y, Maeyama E, Tsuneto S, Shima Y. Measuring the quality of structure and process in end-of-life care from the bereaved family perspective. *J Pain Symptom Manage.* 2004;27: 492-501.

Measuring the regret of bereaved family members regarding the decision to admit cancer patients to palliative care units

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Abstract

Objective: The purposes of this study were to develop a bereaved family regret scale measuring decision-related regret of family members about the admission of cancer patients to palliative care units (PCUs) and to examine the validity and reliability of this scale.

Method: Bereaved families of cancer patients who had died in one regional cancer center from September 2004 to February 2006 received a cross-sectional questionnaire by mail. The questionnaire contained seven items pertaining to decision-related regret about the patient's admission to the PCU, the Care Evaluation Scale (CES), an overall care satisfaction scale, and a health-related quality-of-life (QOL) scale (SF-8). One month after receiving a completed questionnaire, we conducted a retest with the respondent.

Results: Of the 216 questionnaires successfully mailed to the bereaved families, we received 137 questionnaires and were able to analyze the responses for 127 of them, as the other 10 had missing data. By exploratory factor analysis and confirmatory factor analysis, we identified two key factors: intrusive thoughts of regret and decisional regret. This scale had sufficient convergent validity with CES, overall care satisfaction, SF-8, sufficient internal consistency, and acceptable test–retest reliability.

Conclusion: We have developed and validated a new regret scale for bereaved family members, which can measure their intensity of regret and their self-evaluation about their decision to admit their loved ones to PCUs.

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Keywords: regret; the bereaved family; decision-making; cancer; oncology

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Introduction

Researchers into end-of-life issues have recognized the value of what they have called a 'good death'. Critical to achieving a 'good death' is the 'completion of life,' which entails one's being prepared for dying, a feeling that one's life has been completed, no regrets about one's death, and family members who also have no regrets about one's death. Thus, minimizing the regret of cancer patients and their families is an important issue for achieving a 'good death' [1, 2]. However, bereaved

family members who have lost a loved one may find themselves experiencing self-blame feelings of regret along the lines of, 'I may have had to do it for my loved one' or 'I may not have had to do it for my loved one' [3].

Such feelings are a component of regret, the painful sensation that can result from recognizing that 'what is' compares unfavorably with 'what might have been' [4]. Early regret studies have found that a bad outcome resulting from action seemed more regrettable than the same bad outcome resulting from inaction [5] and that regretta-

ble feelings may exhibit a temporal reversal, with action evoking more regret in the short term and inaction evoking more regret in the longer term [6]. Subsequent research has categorized regrets in the daily decision context into three types according to their target: outcome regret, option regret, and process regret [7]. For each of these regret types, researchers have examined the effects of anticipated regret on decision-making as well as the effect of decision-making on experienced regret. Investigators have explored various theories and models to try to explain decision-related regret. Connolly and Zeelenberg, for instance, have recently proposed a new model called decision justification theory (DJT) [8]. DJT postulates two core components of decision-related regret: evaluation of the outcome and the feeling of self-blame for having made a poor choice. The overall feeling of regret at the decision is the combination of these two components. Thus DJT might offer a new explanation as to how people still feel regret even when they experience a situation in which the actual outcome is good. In contrast, most regret studies to date have evaluated regret by examining either the past decision or the self-blame feeling.

With respect to cancer patients, regret studies have typically focused on fatal decisions regarding what course of treatment to follow, e.g. [9] or whether to undergo a screening test [10]. Several studies of prostate cancer patients have established that patients can feel substantial regret following their cancer-related fatal decisions [11–13] and that such treatment-related regret is associated with worse current health-related quality of life (QOL) [11] and with worse quality of life and emotional well-being [12]. Future research should further explore how aspects of the fatal decision process affect later regret in cancer patients and their families.

Family members will face various decisions as well as the cancer patients themselves during the course of illness. However, no reports are available regarding decision-related irretrievable regret among family members within bereaved families. Cohesiveness and control are much greater within Japanese than within western families [14]. Also, the opinions of family members tend to exert greater influence on clinical decision-making in Japan than in the United States [15, 16]. The assessment of current irretrievable regret can retrospectively color past decision-making processes. Current irretrievable regret also can strongly affect future psychological status. Developing a vigilant decision-making model focused on the regret of bereaved family could help provide useful information for improving decision-making by cancer patients and their families. One important area of decision-making for cancer patients and their families involves the decision process by which physicians

initially refer patients to palliative care units (PCUs) [17]. This study thus endeavored to develop a bereaved family regret scale measuring irretrievable regret regarding the decision to admit cancer patients into PCUs and to examine the validity and reliability of this scale.

Methods

Participants and procedure

Our initial set of potential study participants comprised family members of patients who had died from September 2004 to February 2006 in Ibaraki prefecture, Japan. Inclusion criteria were as follows: the patient had died in a PCU; the patient was 20 years of age or older; and the patient had been admitted to the PCU at least three days prior to death. Exclusion criteria were as follows: the family member participant had already been recruited for another questionnaire survey for bereaved family members; the family member's primary physician determined that the participant would suffer serious psychological distress from participation in the study; the patient's cause of death was either directly treatment related or secondary to a treatment-related injury; or no member of the bereaved family was 20 years of age or older, capable of replying to a self-reported questionnaire, or aware of the patient's diagnosis of malignancy.

We mailed questionnaires to potential respondents in October 2006 and mailed reminders in November 2006 to those who had not responded. We asked respondents who did not wish to participate in the survey to indicate that they did not wish to participate and to return the questionnaire. To examine test-retest reliability, we sent a follow-up questionnaire one month after we received a completed questionnaire. The institutional review boards of Tsukuba Medical Center Hospital approved the ethical and scientific validity of this study.

Of the 224 questionnaires sent to eligible bereaved families, eight were undeliverable. We received 137 of the remaining 216 questionnaires, among which we had to exclude 10 due to missing data. Thus, we analyzed 127 responses (effective response rate, 59%). Among these 127 respondents who submitted analyzable test questionnaires, we sent retest questionnaires to the 121 bereaved families who responded during the study period; the other six families submitted their test responses too late to be included in the retest program. We received 82 retest questionnaires, among which we excluded 11 due to missing data. In total, we analyzed 71 retest questionnaires (effective response rate, 59%).

Measures

Decision-related regret about admission to PCUs

The questionnaires asked participants to rate on a 5-point self-reported Likert scale (strongly disagree–strongly agree) their level of agreement with each of seven possible regrets that they may have experienced regarding their decision-making in the past about admitting their loved ones to a PCU. Most previous studies have evaluated regret only for single statements, such as ‘how do you feel regret concerning XX’. In addition, we collected from prior studies three statements measuring the evaluation of decisions in the past [11, 18] and three other statements measuring severity and intensity of regret [19]. The evaluation-of-decision statements included, ‘I made the right decision’ and ‘I would make the same decision if I had to do it again’. The severity and intensity of regret statements included, ‘Once I start thinking about possible outcomes had I made a different decision, I find it difficult to think about other matters’ and ‘I had difficulty concentrating on daily activities because thoughts about regret kept entering my mind’. We constructed the wording of these statements based upon the palliative physicians’ and psychologists’ comments regarding understandability and wording.

Care evaluation scale, short version

We used the Care Evaluation Scale (CES), short version, to examine concurrent validity [20]. The questionnaire design has the respondent evaluating the necessity of improvement for each item on a 6-point Likert scale (improvement is not necessary–highly necessary). The short version of CES used in this study comprises 10 items covering the following 10 domains: help with decision-making for patient, help with decision-making for family, physical care by physician, physical care by nurse, psycho-existential care, environment, cost, availability, coordination of care, and family burden.

Overall care satisfaction

We assessed overall care satisfaction as part of our examination of concurrent validity by asking the following question, developed in a previous study [21]: ‘Overall, were you satisfied with the care provided in the hospital?’ The participant again responded on a 6-point Likert scale.

Health-related QOL

We used the SF-8 Japanese version [22], the short form, which is derived from the health-related QOL scale called the MOS 36-Item Short Form Health survey (SF-36). The eight items cover the eight concepts measured by the SF-36 (one item per concept), using a 5- or 6-point Likert scale. The

SF-8 provides two summary scores for physical and mental health: a Physical Component Scale and a Mental Component Scale. Scores for each item and summary measurements range from 0 to 100, with higher scores indicating better health. This scale includes questions such as the following: ‘Overall, how would you rate your health during the past 4 weeks?’; ‘During the past 4 weeks, how much did physical health problems limit your usual physical activities (such as walking or climbing stairs)’; and ‘During the past 4 weeks, how much difficulty did you have doing your daily work, both at home and away from home, because of your physical health?’

Participant characteristics

We extracted information concerning the patient’s age, sex, and hospital days from a medical database. We asked the respondent bereaved family members to provide the following personal information about themselves: age, sex, health status during caregiving period, relationship with patient, frequency of attending the patient, presence of other caregivers, living status with patient, faith, education, and household income during the caregiving period.

Analysis

We utilized the Statistical Package for SPSS for Windows (Version 14.0) for all data analyses. To examine validity of our regret scale, we conducted an exploratory and a confirmatory factor analysis along with correlation analyses of our regret scale vs CES, overall satisfaction, and QOL. To examine the reliability of the regret scale, we assessed the internal reliability of its two subscales with Cronbach’s α coefficients. We used correlation coefficients to assess test–retest reliability.

Results

Characteristics of participants

Table 1 shows the demographic characteristics of the 127 participants included in the development analysis. We compared the demographic characteristics of these 127 participants with those of the 71 participants included in the validation analysis. We identified no significant differences between the two groups with respect to all demographic characteristics. Table 1 also shows descriptive statistics of decision-related regret, CES, overall satisfaction, and health-related QOL.

Validity

All of the seven items had a moderate degree of variance, and no item evidenced bias. Using these

Table 1. Characteristics of the bereaved family and patient

	N = 127 Patient numbers or mean ± SD	%
<i>Bereaved family</i>		
Age	55.85 ± 12.11	
Sex, male	44	34.6
<i>Health status during caregiving period</i>		
Good	33	26
Somewhat good	71	55.9
Bad	20	15.7
Strongly bad	2	1.6
<i>Relationship to patient</i>		
Spouse	61	48
Parent	42	33.1
Parent-in-law	13	10.2
Others	10	7.9
<i>Frequency of attending patient</i>		
Everyday	96	75.6
4–6 days/week	11	8.7
1–3 days/week	15	11.8
None	3	2.4
<i>Presence of other caregivers</i>		
Living with patient	106	83.5
<i>Education</i>		
Less than high school	17	13.4
High school	56	44.1
Some college	28	22
Postgraduate	25	19.7
<i>Household income during caregiving period</i>		
Less than 250	13	10.2
250–500	58	45.7
500–750	25	19.7
750–1000	14	11
More than 1000	14	11
Care Evaluation Scale	75.49 ± 17.63	
Overall satisfaction	4.76 ± 0.96	
SF8; Physical Component Scale	48.78 ± 7.81	
SF8; Mental Component Scale	48.52 ± 6.37	
<i>Patient</i>		
Age	68.12 ± 12.28	
Sex, male	68	53.5
Hospital days	41.63 ± 33.90	

seven items, we conducted an exploratory factor analysis with promax rotation and the maximum-likelihood method. A minimal eigenvalue > 1 yielded a 2-factor solution (Table 2), in which these two factors explained 74% of the variance. The correlation coefficient between the two factors was 0.32 ($p < 0.01$). Factor 1, which measured the degree of focus on regret, we named 'intrusive thoughts of regret'; factor 2, which measured evaluation of decision-making in the past, we named 'decisional regret.'

Then, to confirm the adequacy of the scale structures, we conducted a confirmatory factor analysis with these seven items. The results

indicated that item 3 was the item with highest factor loadings for both factors 1 and 2. We then constructed two models, shown in Figure 1, and compared the fit indexes of the two models. We adopted model 2 because its fit index was higher than that of model 1.

Table 3 contains the Pearson correlation coefficients showing the correlation between the scores of regret subscales and scores for CES, overall care satisfaction, and health-related QOL. As expected, the scores for CES and overall care satisfaction negatively correlated with each regret subscale. Physical QOL and mental QOL correlated with only the intrusive thoughts subscale.

Reliability

We assessed the internal reliability of the two subscales with Cronbach's α coefficients. Internal consistency was high for both 'intrusive thoughts of regret' ($\alpha = 0.85$) and 'decisional regret' ($\alpha = 0.79$) subscales. We then defined the sums for each sub-factor as the intrusive thoughts of regret score and the decisional regret feeling score, respectively. Using these scores, we assessed test-retest reliability using correlation coefficients. Among the 71 participants who responded in both surveys, correlation coefficients among subscales were moderately high for factor 1 ($r = 0.69$, $p < 0.01$) and factor 2 ($r = 0.70$, $p < 0.01$).

Discussion

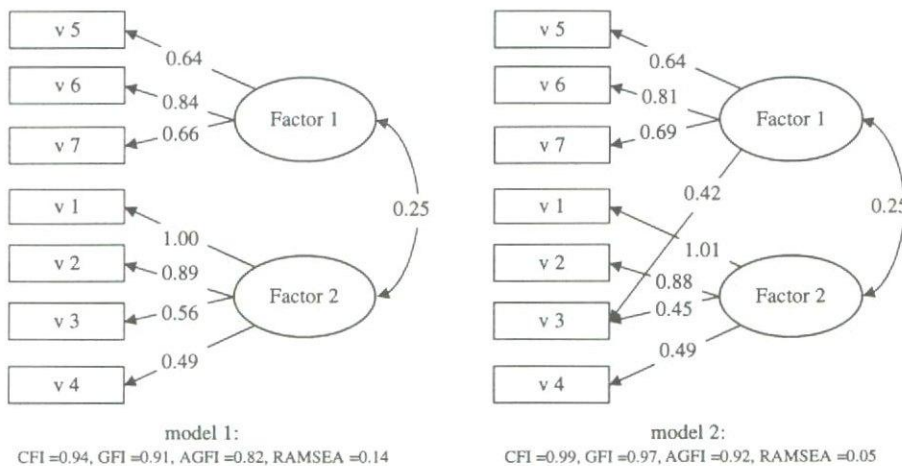
The purpose of this study was to develop a PCU's admission-related regret scale for the bereaved family and to identify its validity and reliability. Among the bereaved families, decisional-related regret was irretrievable. Furthermore, most families had thought that their past decision was fatal for the patients. By exploratory factor analysis and confirmatory factor analysis, we identified two key factors: intrusive thoughts of regret and decisional regret. This study provided good evidence of the reliability and validity of these two factors within this Japanese population. Using these two factors, we developed a new regret scale for bereaved family members, which was able to measure their intensity of regret and their self-evaluation about their decision to admit their loved ones to PCUs. Since this regret scale contains a small number of items and a simple structure, the scale is open to broad use.

We were able to delineate the structure of our two factors, intrusive thoughts of regret and decisional regret. These two factors appear to correspond to the two core components of DJT (intensity of regret and their self-evaluation) [8]: Intrusive thoughts of regret correspond to intensity of self-blame feelings, and decisional regret corre-

Table 2. Results of exploratory factor analysis

Items	Mean \pm SD	Factor loadings		Communality
		F1	F2	
Once I start thinking about possible outcomes had I made a different decision, I find it difficult to think about other matters (v6)	1.88 \pm 1.15	0.90	0.22	0.67
I had difficulty concentrating on daily activities because thoughts about regret kept entering my mind (v7)	1.72 \pm 1.10	0.83	0.18	0.62
I could not stop thinking that the situation might have changed if I had made a different decision (v5)	2.03 \pm 1.16	0.81	0.33	0.59
It was the right decision (v1*)	1.63 \pm 0.75	0.30	0.99	0.82
I would make the same decision if I had to do it again (v2*)	1.73 \pm 0.90	0.25	0.89	0.79
I regret the decision that was made (v3)	1.69 \pm 0.08	0.56	0.57	0.48
I am satisfied with the decision (v4*)	2.06 \pm 1.04	0.12	0.49	0.26

*Reversed item.

**Figure 1.** The results of confirmatory factor analysis and fit indices**Table 3.** Criterion validity as measured by Pearson correlations

Scales	CES	Overall care satisfaction	Physical QOL	Mental QOL
F1: intrusive thoughts about regret	-0.33**	-0.33**	-0.22*	-0.37**
F2: decisional regret	-0.27**	-0.46**	-0.08	-0.09

* $p < 0.05$, ** $p < 0.01$.

sponds to evaluation of decision-making and subsequent outcome. Each of the two factors contained four of the seven statements; one statement overlapped both factors. The overlapping statement, 'I regret the decision that was made', directly represented the overall regret of bereaved family members about their decision-making. Our regret scale could thereby measure three aspects of the bereaved families' regret: overall degree of regret, evaluation of decisional regret, and severity of intrusive thoughts about regret. Evaluation of the details of regret assists greatly in formulating an appropriate plan of regret management and therapy. Several recent studies have examined regret management and therapy for cancer patients [23,24]. However, to develop better evidence-based regret management or regret therapy, future research should explore the effects of

the decision-making process or options on subsequent irretrievable regrets. We believe that psychosocial theories such as reference comparisons theory or justifications theory can provide a basis for utilizing our new scale to establish effective regret management and therapy.

We found good evidence for the reliability and validity of our regret scale. Examination of the convergent validity of this scale determined that the score of CES and overall satisfaction negatively correlated with each regret subscale, indicating that this regret scale could adequately measure regrets regarding decision-making about admission to PCUs. On the other hand, both physical and mental QOL scores did not correlate with decisional regret but correlated only with intrusive thoughts of regret. This pair of findings indicates that the bereaved family's QOL is not influenced by

how much they regret their decision but rather by how often their regretful thoughts come to mind. The finding that intrusive thoughts of regret were associated with health-related QOL is in accord with the results of previous studies among adults [25]. We believe that decisional regret and intrusive thoughts of regret comprise different concepts and thus should be measured separately. Our findings suggest that intrusive thoughts of regret have the potential to affect the health-related QOL of bereaved family members.

One limitation of our study is the somewhat small sample size of our study, especially for the retest survey. We sent out retest questionnaires one month after we received a completed questionnaire. Although our study design assumed that the regret of the bereaved family did not change during this one-month period, empirical confirmation of this assumption is lacking. Our analysis of test-retest reliability yielded correlation coefficients among subscales that were moderately high.

Utilizing this new scale to assess the regret of the bereaved family should help clinicians evaluate decision-making about the admission of cancer patients into PCUs retrospectively. Use of this scale in multi-institutional outcome surveys should assist evaluation of quality differences between institutions in the decision-making process. Developing a vigilant decision-making model of cancer patients and their families and examining the association of this model with irretrievable regret will require future studies in order to provide useful information about decision-making aids. Our new scale thus represents the first step for these future studies.

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References

- Hirai K, Miyashita M, Morita T, Sanjo M, Uchitomi Y. Good death in Japanese cancer care: a qualitative study. *J Pain Symptom Manage* 2006;**31**:140–147.
- Miyashita M, Sanjo M, Morita T, Hirai K, Uchitomi Y. Good death in cancer care: a nationwide quantitative study. *Ann Oncol* 2007;**18**:1090–1097.
- Shiozaki M, Morita T, Hirai K, Sakaguchi Y, Tsuneto S, Shima Y. Why are bereaved family members dissatisfied with specialized inpatient palliative care service? A nationwide qualitative study. *Palliat Med* 2005;**19**:319–327.
- Sugden R. Regret, recrimination and rationality. *Theory Decis* 1985;**19**:77–99.
- Kahneman D, Tversky A. The psychology preferences. *Sci Am* 1982;**246**:160–173.
- Gilovich T, Medvec VH. The experience of regret: what, when, and why. *Psychol Rev* 1995;**102**:379–395.
- Connolly T, Reb J. Regret in cancer-related decisions. *Health Psychol* 2005;**24**:29–34.
- Connolly T, Zeelenberg M. Regret in decision making. *Curr Dir Psychol Sci* 2002;**11**:212–216.
- Kaplan RM, Ganiats TG, Frosch DL. Diagnosis and treatment decisions in U.S. healthcare. *J Health Psychol* 2004;**9**:29–40.
- Briss P, Rimer B, Reilley B *et al.* Promoting informed decisions about cancer screening in communities and healthcare systems. *Am J Prev Med* 2004;**26**:67–80.
- Hu JC, Kwan L, Saigal CS, Litwin MS. Regret in men treated for localized prostate cancer. *J Urol* 2003;**169**:2279–2283.
- Clark JA, Inui TS, Silliman RA *et al.* Patients' perceptions of quality of life after treatment for early prostate cancer. *J Clin Oncol* 2003;**21**:3777–3784.
- Clark JA, Wray NP, Ashton CM. Living with treatment decisions: regrets and quality of life among men treated for metastatic prostate cancer. *J Clin Oncol* 2001;**19**:72–80.
- Morita T, Akechi T, Ikenaga M *et al.* Late referrals to specialized palliative care service in Japan. *J Clin Oncol* 2005;**23**:2588–2589.
- Saito S, Nomura N, Noguchi Y, Tezuka I. Translatability of family concepts into the Japanese culture: using the Family Environment Scale. *Fam Process* 1996;**35**:239–257.
- Voltz R, Akabayashi A, Reese C, Ohi G, Sass HM. End-of-life decisions and advance directives in palliative care: a cross-cultural survey of patients and health-care professionals. *J Pain Symptom Manage* 1998;**16**:153–162.
- Ruhnke GW, Wilson SR, Akamatsu T *et al.* Ethical decision making and patient autonomy: a comparison of physicians and patients in Japan and the United States. *Chest* 2000;**118**:1172–1182.
- Davison BJ, Goldenberg SL. Decisional regret and quality of life after participating in medical decision-making for early-stage prostate cancer. *BJU Int* 2003;**91**:14–17.
- Wrosch C, Heckhausen J. Perceived control of life regrets: good for young and bad for old adults. *Psychol Aging* 2002;**17**:340–350.
- Morita T, Hirai K, Sakaguchi Y, Maeyama E, Tsuneto S, Shima Y. Measuring the quality of structure and process in end-of-life care from the bereaved family perspective. *J Pain Symptom Manage* 2004;**27**:492–501.
- Morita T, Chihara S, Kashiwagi K. Family satisfaction with inpatient palliative care in Japan. *Palliat Med* 2002;**16**:185–193.
- Fukuhara S, Suzukamo Y. *Manual of the SF-8 Japanese Version*. Institute for Health Outcomes & Process Evaluation Research: Kyoto, 2004.
- Bonadona V, Saltel P, Desseigne F *et al.* Cancer patients who experienced diagnostic genetic testing for cancer susceptibility: reactions and behavior after the disclosure of a positive test result. *Cancer Epidemiol Biomarkers Prev* 2002;**11**:97–104.
- Di Prospero LS, Seminsky M, Honeyford J *et al.* Psychosocial issues following a positive result of genetic testing for BRCA1 and BRCA2 mutations: findings from a focus group and a needs-assessment survey. *Can Med Assoc J* 2001;**164**:1005–1009.
- Wrosch C, Bauer I, Scheier MF. Regret and quality of life across the adult life span: the influence of disengagement and available future goals. *Psych Aging* 2005;**20**:657–670.