

the number of bad news, and medical status were also associated with patients' preferences, while psychological distress and social support were not associated with them. However, all the independent variables in this study had small standardized partial regression coefficients in each regression model, and all the multiple regression models showed a low proportion of variance. Thus, communication preferences with interindividual variations are difficult to identify on the basis of the patients' medical and psychosocial data alone, so physicians should try to understand each patient's preferences and tailor their communication style to meet the needs of individual patients.

The exploratory factor analysis in the present study identified four separate, internally reliable factors related to the communication style of physicians disclosing bad news. These factors were fundamentally based on the results of our previous qualitative study [15]. Parker *et al.*, [9] reported a 3-factor structure; what and how much information, emotional support, and setting. Our present study supported the report by Parker *et al.* Furthermore, the factor structure of the present study also independently identified the provision of additional information factor, and this factor was not identified in the report by Parker *et al.* This difference can probably be attributed to the fact that the design of the two studies differed; we collected the survey items in the present study based on a previous analysis of several interviews [15], while Parker *et al.* [9] collected their survey items based on the opinions of experts, including oncologists and psychooncologists, and a literature review.

The result of the factor analysis provide a framework for devising interventions to enhance physicians' communication skills, that is, physicians may be taught how to disclose bad news in a manner that corresponds to an individual patient's preferences. As far as we know, no communication skills training programs based on patients' preferences have been reported. In the future, it would be desirable to design intervention programs based on the frameworks thus identified. Furthermore, future study to model the relationship between each factor of the patients' preferences and psychosocial and medical characteristics, based on the results of this exploratory factor analysis, is needed.

Two limitations of the present study should be noted. First, we conducted the study at a single teaching cancer center. Thus, the results of this study might not be representative of other cancer centers. Nonetheless, because the consecutive sample included patients with a variety of cancers, stages of disease, and from several age groups, of both genders, with several different psychosocial characteristics, we believe that our results reflect the preferences of a broad range of patients. The

second limitation is that our study examined the preferences of patients at only one point in time, and not over time. Thus, we cannot speculate on the stability of the measurements used in this study. The informational needs of patients have been reported to change over the course of their treatment. [11] Because of the cross-sectional nature of this study, we did not attempt to formally address this question. However, significant differences were partially found between patients without and those with tumor recurrence or metastasis.

In conclusion, while the preferences of patients in Japan are mostly similar to those of patients in Western countries, some communication, for example, the desire for the physician to show consideration for the patient's family, seems to be particularly important to patients in Japan. Although communication style preferences with interindividual variations are difficult to identify based on medical and psychosocial data alone, understanding an individual's communication preferences may be useful for promoting patient-physician communication.

Acknowledgements

This work was supported by a Grant-in-Aid for Cancer Research and Third-Term Comprehensive 10-Year Strategy for Cancer Control and Research, Japanese Ministry of Health, Labor and Welfare.

References

1. Buckman R. Breaking bad news: why is it still so difficult? *Br Med J* 1984;288:1597-1599.
2. Takayama T, Yamazaki Y, Katsumata N. Relationship between outpatients' perceptions of physicians' communication styles and patients' anxiety levels in a Japanese oncology setting. *Soc Sci Med* 2001;53:1335-1350.
3. Schofield PE, Butow PN, Thompson JF *et al.* Psychological responses of patients receiving a diagnosis of cancer. *Ann Oncol* 2003;14:48-56.
4. Morita T, Akechi T, Ikenaga Y *et al.* Communication about the ending of anticancer treatment and transition to palliative care. *Ann Oncol* 2004;15:1551-1557.
5. Baile WF, Buckman R, Lenzi R, Glober G, Beale EA, Kudelka AP. SPIKES-A six-step protocol for delivering bad news: application to the patient with cancer. *Oncologist* 2000;5:302-311.
6. Girgis A, Sanson-Fisher RW, Schofield MJ. Is there consensus between breast cancer patients and providers on guidelines for breaking bad news? *Behav Med* 1999;25:69-77.
7. Cegala DJ, Lenzmeier Broz S. Physician communication skills training: a review of theoretical backgrounds, objectives and skills. *Med Educ* 2002;36:1004-1016.
8. Butow PN, Kazemi JN, Beeney LJ, Griffin AM, Dunn SM, Tattersall MH. When the diagnosis is cancer: patient communication experiences and preferences. *Cancer* 1996;77:2630-2637.
9. Parker PA, Baile WF, de Moor C, Lenzi R, Kudelka AP, Cohen L. Breaking bad news about cancer: patients' preferences for communication. *J Clin Oncol* 2001;19:2049-2056.

10. Shilling V, Jenkins V, Fallowfield L. Factors affecting patient and clinician satisfaction with the clinical consultation: can communication skills training for clinicians improve satisfaction? *Psycho-Oncology* 2003; **12**:599–611.
11. Butow PN, Maclean M, Dunn SM, Tattersall MH, Boyer MJ. The dynamics of change: cancer patients' preferences for information, involvement and support. *Ann Oncol* 1997; **8**:857–863.
12. 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.
13. Baile WF, Lenzi R, Parker PA, Buckman R, Cohen L. Oncologists' attitudes toward and practices in giving bad news: an exploratory study. *J Clin Oncol* 2002; **20**: 2189–2196.
14. Sekimoto M, Asai A, Ohnishi M *et al*. Patients' preferences for involvement in treatment decision making in Japan. *BMC Fam Pract* 2004; **5**:1.
15. Fujimori M, Akechi T, Akizuki N *et al*. Good communication when receiving bad news about Cancer in Japan. *Psycho-Oncology* 2005; **14**:1043–1051.
16. Watson M, Greer S, Young J, Inayat Q, Burgess C, Robertson B. Development of a questionnaire measure of adjustment to cancer: the MAC scale. *Psychol Med* 1988; **18**:203–209.
17. Akechi T, Fukue-Saeki M, Kugaya A *et al*. Psychometric properties of the Japanese version of the Mental Adjustment to Cancer (MAC) scale. *Psycho-Oncology* 2000; **9**:395–401.
18. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. *Acta Psychiatr Scand* 1983; **67**: 361–370.
19. Kugaya A, Akechi T, Okuyama T, Okamura H, Uchitomi Y. Screening for psychological distress in Japanese cancer patients. *Jpn J Clin Oncol* 1998; **28**: 333–338.
20. Ptacek JT, Eberhardt TL. Breaking bad news. A review of the literature. *JAMA* 1996; **276**:496–502.
21. Hagerty RG, Butow PN, Ellis PA *et al*. Cancer patient preferences for communication of prognosis in the metastatic setting. *J Clin Oncol* 2004; **22**:1721–1730.
22. Holland JC, Geary N, Marchini A, Tross S. An international survey of physician attitudes and practice in regard to revealing the diagnosis of cancer. *Cancer Invest* 1987; **5**:151–154.
23. Resendes LA, McCorkle R. Spousal responses to prostate cancer: an integrative review. *Cancer Investigation* 2006; **24**:192–198.

Japanese cancer patients' communication style preferences when receiving bad news

Maiko Fujimori¹, Patricia A. Parker², Tatsuo Akechi^{1,3}, Yuji Sakano⁴, Walter F. Baile⁵ and Yosuke Uchitomi^{1*}

¹ Psycho-Oncology Division, Research Center for Innovative Oncology, National Cancer Center Hospital East, Kashiwanoha 6-5-1, Kashiwa, Chiba 277-8577, Japan

² Department of Behavioral Science, The University of Texas M.D. Anderson Cancer Center, 1515 Holcombe Blvd, Houston, TX 77030, USA

³ Department of Psychiatry, the Nagoya City University Medical School, Kawasumi 1, Mizuho-cho, Mizuho-ku, Nagoya, Aichi 467-8601, Japan

⁴ School of Psychological Science, the Health Sciences University of Hokkaido, Ainosato 2-5, Kita-ku, Sapporo, Hokkaido, 002-8072 Japan

⁵ Section of Psychiatry, Department of Neuro-oncology, The University of Texas M.D. Anderson Cancer Center, 1515 Holcombe Blvd, Houston, TX 77030, USA

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

Abstract

This study describes the communication style preferences of Japanese patients when receiving bad news, examines the factor structure of the measure for patients' preferences (MPP) in a Japanese population, and explores variables that may be associated with patients' communication style preferences. Five hundred twenty-nine cancer outpatients completed several psychosocial measures including the Japanese version of the MPP (MPP-J), the Mental Adjustment to Cancer Scale (MAC), and the Hospital Anxiety and Depression Scale (HADS). The patients desired detailed information and a supportive environment when receiving bad news. The MPP-J demonstrated a 5-factor structure: support, facilitation, medical information, clear explanation, and encouraging question-asking. Regression analyses indicated that a female gender, the fighting spirit and anxious preoccupation dimensions of the MAC were positively associated with all 5 MPP-J factors. In conclusion, Japanese cancer patients' preferences for communication when receiving bad news differ somewhat from those of American patients. Japanese physicians should encourage patients to ask questions and should consider the demographic (e.g. gender), medical (disease status) and psychosocial characteristics (fighting spirit and anxious preoccupation) of patients when delivering bad news.
Copyright © 2006 John Wiley & Sons, Ltd.

Received: 15 February 2006
Revised: 17 August 2006
Accepted: 18 August 2006

Keywords: cancer patients' preferences; bad news; communication; patient-physician relationship

Introduction

Medical specialists must be able to discuss complex medical information with patients. Oncologists, in particular, must be able to disclose bad news like a life-threatening diagnosis, recurrence, or the discontinuation of anticancer treatments. A physician's communication skills when disclosing bad news about cancer can reportedly influence a patient's anxiety levels and subsequent psychological adjustment [1–4]. Therefore, several guidelines and interventions have been developed to enhance physicians' skills when breaking bad news [5–8]. Communication skills training programs may also improve health care providers' behaviors, beliefs, and confidence in their ability to communicate with patients [9–11].

Most guidelines and interventions for breaking bad news have been developed for patients from western countries, and few studies have examined the preferences of Japanese cancer patients. Japanese patients are traditionally more passive and receptive to a 'paternalistic' approach in their

relationship with their oncologists [12,13]. Typically, the physician and the family decide how much information should be given to the patient [14]. Traditionally, Japanese physicians are less likely to disclose cancer diagnoses to patients than in the West. However, Japanese culture is changing, and patients now want more information and expect to participate more actively in their care [15]. Therefore, it is particularly important to consider and understand a patient's communication style preferences in light of the changing cultural values regarding medical care and the patient-physician relationship.

The importance of communicating with patients on an individual basis has also been recognized, and several associations between medical or psychosocial variables and patients' communication style preferences have been examined. Some evidence suggests that sex, age, education level, and physical status may be associated with a patient's communication style preferences [16–18]. As far as we know, only one validated measure has been developed to examine the communication style

preferences of cancer patients when receiving bad news: the measure of patients' preferences (MPP). In the US, Parker *et al.* [18] conducted a cross-sectional survey by administering the MPP to cancer patients. They found that patients placed the greatest importance on the physician's expertise and the delivery of information regarding their physical condition and treatment options. The patients' communication style preferences could be categorized into three dimensions: the content of the message, the setting, and supportive elements [18]. These results were reproduced in another study examining men with prostate cancer in Canada [19].

The purpose of the present study was to describe the communication style preferences of Japanese cancer patients when receiving bad news, to examine whether the factor structure of the MPP was similar to that found in a US population, and to explore the associations between the dimensions of patients' communication style preferences and demographic, medical and psychological adjustment variables.

Methods

Patients

The study participants were outpatients at the National Cancer Center Hospital East in Japan who had attended follow-up medical appointments with their oncologist. The eligibility criteria were as follows: an age of 20 years or older, physician approval regarding the capacity of the patient to complete the survey, the ability to speak and write in Japanese, and the delivery of bad news (i.e. cancer diagnosis, recurrence, treatment failure, or discontinuation of active anticancer treatment) at least 3 months prior to the start of the study. This time frame was chosen to allow patients time to adjust to the idea of their diagnosis and to reflect on their experience. The dates on which the patients were informed of bad news were obtained from the patients' medical charts, and the patients were also asked when they had received bad news.

Procedure

This study was a cross-sectional consecutive survey. The Institutional Review Board and the Ethics Committee of the National Cancer Center of Japan approved this study. Each participant signed a written informed consent.

All the patients who were being treated by oncologists in our outpatient clinic and who met the eligibility criteria were approached in person and invited to participate in the study. After giving their informed consent, the patients completed a series of questionnaires and were asked to return them by mail. A single attempt was made by

telephone or post to obtain any missing information.

Measures

Measure of patients' preferences, Japanese version

The original MPP is a 46-item self-rating scale developed to assess what items are important to American patients with cancer when receiving bad news [18]. All the items are worded as statements, and the responses are recorded using a five-point Likert scale. The response options for each item are as follows: (1) not at all important; (2) optional, can take it or leave it; (3) important; (4) very important; and (5) essential, every doctor should do it. Participants were asked to think about the time when they were first told they had cancer or that their cancer had recurred and to respond to the questions as they would have liked to have been told.

We collaborated with the original author of the MPP (P.P.) to create a Japanese version of the MPP (MPP-J). To do this, we first translated the instructions and items of the MPP into Japanese; the instructions and items were then back translated into English by a native English speaker who was also fluent in Japanese. To examine the readability of the MPP-J, the instrument was piloted among 42 cancer outpatients attending the NCCHE. None of the patients reported problems completing the questionnaire. The results of this pilot study suggested that the Japanese version was easily understood and appropriate for use with Japanese cancer patients.

Mental adjustment to cancer scale

The Japanese version [20] of the Mental Adjustment to Cancer (MAC) Scale [21] is a 40-item measure developed to evaluate cancer patients' mental adjustment to their cancer after diagnosis. The scale, which has been shown to have adequate validity and reliability, consists of five subscales: fighting spirit, anxious preoccupation, fatalism, helplessness/hopelessness, and avoidance.

Hospital anxiety and depression scale

The Japanese version of the Hospital Anxiety and Depression Scale (HADS; [22]) assesses anxiety and depressive symptoms and has been shown to be a reliable and valid measure. The scale consists of 14 items [23]. In the present study, the total HADS score was used to assess psychological distress.

Demographic and medical variables

Demographic information, including age, education level, occupation, and marital status, was collected in the survey. Medical information

regarding the type of cancer, disease stage, presence of recurrence or metastasis, and the time since the patients had received their initial diagnosis was obtained from the patients' medical charts.

Statistical analysis

To examine the Japanese cancer patients' communication style preferences, we examined the distribution of the patients' responses to the 46 items of the MPP-J. We then performed a factor analysis using the maximum-likelihood method with a varimax rotation to examine the reproducibility of the original three-factor structure of the MPP. Items with a communality of 0.25 or greater and factor loadings of 0.30 or greater have a high degree of correlation and are generally considered reliable. Thus, items meeting these criteria were retained. Because the factor structure of the MPP-J did not reproduce the original factor structure of the MPP, we performed an exploratory factor analysis using the maximum-likelihood method with a varimax rotation. We applied a number of factors based on the results of a scree plot (the 3-factor, 4-factor, 5-factor, 6-factor and 7-factor eigenvalues were 1.85, 1.79, 1.52, 1.11, and 1.08, respectively). We then selected the best rotation based on the goodness of fit index (GFI) and the comparative fit index (CFI) of each factor. The CFI and GFI can range from 0 to 1, and a value of 0.90 or more indicates a good model fit. Cronbach's alpha was calculated to evaluate the internal consistency reliability of each factor. We then performed a series of stepwise multiple regression analyses to examine the unique contribution of demographic (age, sex, marital status, employment status, and education level), medical (cancer site, presence of recurrence or metastasis, current treatment, and the time since the patients had received their initial diagnosis), and psychological status (each MAC subscale and the total HADS score) variables on each subscale of the MPP-J. Three participants were excluded from this statistical analysis because of missing data. The statistical analyses were performed using SPSS 12.0 statistical software. A *P*-value of less than 0.05 was considered significant.

Results

Patients

One thousand fifty-six consecutive outpatients who were being treated by 36 oncologists were screened for inclusion. Of the 656 patients who were eligible, 34 were not interested in learning about the study, and 47 could not be contacted. Of the remaining 575 patients who were approached in person, nine refused to participate. Thus, 566 outpatients were given questionnaires; 529 questionnaires (93.5%)

Table 1. Demographic characteristics of the subjects (*N* = 529)

		<i>N</i>	%	
Age (years; mean, SD range)		62, 11, 26–97		
Sex	Male	274	51.8	
Employment status	Employed	190	35.9	
Marital status	Married	452	85.4	
Household size	Living alone	19	3.6	
Education	9 or less years	98	18.5	
Cancer site	Digestive	185	34.7	
	Breast	125	23.5	
	Head and neck	112	21.2	
	Lung	107	20.2	
Recurrence or metastasis	Yes	299	56.5	
	Absence	229	43.3	
Treatment received	Surgery	426	80.5	
	Chemotherapy	221	41.8	
	Radiation therapy	153	28.9	
	Hormone therapy	45	8.5	
	Other	16	3.0	
Current anti-cancer treatment	Yes	134	25.5	
Bad news received regarding	Diagnosis	Yes	529	100
	Recurrence	Yes	164	31
	Disease progression	Yes	38	7
	Absence of active anticancer treatment	Yes	1	0.2

were returned. Overall, 80.6% (529/656) of the eligible patients participated in the study. The demographic characteristics of the participants are listed in Table 1. The mean time since the patients had received their initial diagnosis was 3.3 years (S.D. = 2.7 years; range, 0.3–11.9 years). Three patients had missing data regarding demographic or medical variables (education [2 patients] and recurrence or metastasis [1 patient]).

Ratings for important aspects of delivering bad news

The 46 MPP-J items are listed in descending order based on the perceived importance of the items, and the mean score and standard deviation of the original MPP items are shown in Table 2. The mean scores of the MPP-J items were generally about 0.5 points lower than the scores in the US study. The highest rated item was 'Being told in person rather than over the phone (item 1),' and the lowest rated item was 'The doctor holding my hand or touching my arm while telling me the news (item 7).'

We then examined the rank order of each item in the present study and those of the items in the original MPP study to identify the perceived importance to patients in Japan and the US. For example, item 43 ('Having the doctor inform my family members about my diagnosis') was ranked 19th in the present study and 39th in the US study. Meanwhile, item 5 ('Having my doctor give me his/her full attention') was ranked 27th in the present

Table 2. The rating scores of the Japanese cancer patients' preferences of communication

No. Item	The present study		Parker et al. [18]		
	Mean	SD	Mean	SD	Ranking
1 Being told in person	4.23	0.81	4.31	1.05	24
16 Telling me best treatment option	4.14	0.77	4.70	0.57	2
40 Telling me he/she will do everything to cure my cancer	4.14	0.81	4.42	0.82	19
24 Feeling confident about doctor's skill	4.03	0.70	4.59	0.55	5
12 Giving news in clear, simple language	4.02	0.77	4.56	0.70	7
15 Being given detailed information about test results	4.00	0.77	4.45	0.74	15
25 Being up to date on research on my type of cancer	3.99	0.82	4.72	0.49	1
22 Being honest about my condition	3.90	0.75	4.61	0.64	4
38 Doctor really listens to me	3.84	0.84	4.44	0.71	16
34 Making me feel comfortable to ask question	3.79	0.84	4.35	0.74	22
10 Telling news directly	3.77	0.73	4.56	0.62	8
23 Telling me how cancer may affect my daily functioning	3.75	0.83	4.39	0.76	20
26 Taking the time to answer my questions completely	3.74	0.89	4.66	0.56	3
4 Setting time aside	3.72	0.84	4.43	0.76	18
28 Being given enough time to ask my questions	3.67	0.89	4.57	0.63	6
39 Offering hope about my condition	3.64	0.87	4.11	0.97	28
27 Stopping to ask if I have questions	3.64	0.91	4.46	0.56	13
43 Informing family about my diagnosis	3.62	0.89	3.38	1.31	39
17 Describing treatment options in detail	3.62	0.97	4.48	0.72	12
21 Giving a lot of information about my cancer	3.60	0.91	4.22	0.89	26
14 Asking how much I want to know about my cancer	3.59	0.87	4.36	0.97	21
13 Asking how much I want to know about my treatment	3.57	0.83	4.43	0.97	17
44 Informing family about my prognosis	3.54	0.90	3.42	1.30	36
46 Giving written summary to take home	3.50	1.01	4.06	1.06	29
33 Doing things to show his/her concern for me	3.47	0.88	3.91	0.94	31
3 Being told in private setting	3.47	0.97	3.86	1.14	32
5 Giving me full attention	3.46	0.89	4.53	0.68	10
9 Waiting until all tests in before giving news	3.45	0.94	4.15	1.03	27
2 Being told by a doctor who knows me well	3.43	0.97	3.33	1.25	41
18 Letting me know all of the treatment options	3.43	1.04	4.55	0.65	9
6 Maintaining eye contact	3.40	0.91	4.05	0.95	30
20 Telling me the prognosis	3.40	0.96	4.46	0.87	14
32 Telling how to contact him/her	3.34	0.95	4.22	0.87	25
41 Making me feel ok to show emotional reactions	3.34	0.99	3.76	1.02	34
19 Telling me about new experimental therapies	3.33	0.99	4.33	0.77	23
37 Encouraging me to talk about feelings	3.29	0.92	3.42	1.14	37
31 Arranging for another meeting to discuss treatment	3.25	0.96	3.82	1.02	33
29 Telling me about support services available	3.22	0.92	3.60	1.03	35
36 Telling me it's ok if I become upset	3.11	0.94	3.40	1.14	38
8 Telling me as soon as possible	3.10	0.92	4.51	0.72	11
35 Comforting me if emotional	2.91	0.92	3.29	1.10	42
30 Telling me about resources in the community	2.80	0.94	3.35	1.04	40
11 Warning me there will be unfavorable news	2.74	1.01	3.01	1.32	44
45 Helping me figure out how to tell family about the cancer	2.73	1.05	2.62	1.25	45
42 Having another healthcare provider present	2.58	0.92	3.14	1.23	43
7 Holding hand/touching arm	1.68	0.76	2.23	1.17	46

study and 10th in the US study, and item 18 ('My doctor letting me know all of the different treatment options') was ranked 30th in the present study and 9th in the US study.

Factor structure of the MPP-J

Factor analysis was used to examine whether the three-factor structure found in the original MPP study could be replicated in our sample. We found that the MPP-J did not reproduce the original MPP 3-factor structure.

The results of an exploratory factor analysis yielded the following five factors from among the 42 items of the MPP-J (Table 3).

Factor 1: Emotional support. Nine items loaded on this factor, accounting for 14.5% of the total variance. These items covered supportive aspects of communication styles and included offering comfort and support to the patient, and helping to communicate information to family members and friends of the patients.

Factor 2: Medical information. Ten items loaded on this factor, accounting for 11.8% of the total variance. These items emphasized medical

Table 3. Factor structures of the original MPP and the MPP-J

Item No.	Factor	
	Revised 5-factor structure of the MPP-J	Parker et al. [18]
36	Emotional support	Support
37	Emotional support	Support
35	Emotional support	Support
41	Emotional support	Support
39	Emotional support	Support
45	Emotional support	Support
33	Emotional support	Support
42	Emotional support	Support
32	Emotional support	—
18	Medical information	Content
19	Medical information	Content
17	Medical information	Content
21	Medical information	Content
20	Medical information	Content
23	Medical information	Content
14	Medical information	—
13	Medical information	—
29	Medical information	Support
30	Medical information	Support
31	Medical information	—
10	Clear explanation	Facilitation
12	Clear explanation	—
22	Clear explanation	Content
15	Clear explanation	Content
16	Clear explanation	Content
43	Clear explanation	Support
44	Clear explanation	Support
24	Clear explanation	Content
1	Clear explanation	Facilitation
46	Clear explanation	—
28	Encouraging question-asking	Content
26	Encouraging question-asking	Content
34	Encouraging question-asking	—
40	Encouraging question-asking	—
27	Encouraging question-asking	—
38	Encouraging question-asking	—
25	Encouraging question-asking	Content
4	Setting	Facilitation
3	Setting	Facilitation
5	Setting	Facilitation
6	Setting	Facilitation
2	Setting	—
7	—	—
8	—	—
9	—	Facilitation
11	—	—

information and the expertise of the physician (e.g. discussion of treatment options and new experimental therapies).

Factor 3: Clear explanation. Eight items loaded on this factor, accounting for 11.5% of the total variance. These items focused on how the news was conveyed, such as delivering news directly and clearly in words that are easy to understand.

Factor 4: Encouraging question-asking. Nine items loaded on this factor, accounting for 9.9% of the total variance. These items involved question-asking, such as allowing the patient to ask questions and taking sufficient consultation time to answer the patient's questions completely.

Factor 5: Setting. Five items loaded on this factor, accounting for 6.8% of the total variance. These items dealt with where and when the information was conveyed and included privacy and having the physician's full attention.

The correlations among the five factors were significant and of moderate to high ($r = 0.58-0.79$) magnitude.

Fit and internal consistency of each MPP-J factor

A summary of the fit indices for each factor using the original MPP structure model and the revised MPP-J 5-structure model and the internal consistency of each factor are presented in Table 4. In the original 3-factor model, only the facilitation factor of the MPP-J had a GFI > 0.90 and a CFI > 0.90. In the revised 5-factor model, the emotional support factor and the setting factor had a GFI > 0.90. The emotional, encouraging question-asking, and setting factors had CFIs > 0.90. However, the other factors had GFIs < 0.90 and CFIs < 0.90. All of the factors had a good internal consistency (Cronbach's alpha coefficient > 0.80).

Associations between demographic, medical and psychosocial variables and patients' communication style preferences

A series of regression analyses were conducted to determine the unique contribution of the demographic, medical, and psychological status variables on each of the MPP-J subscales (Table 5). Three participants were excluded from this statistical analysis because of missing data. All the MPP-J factors received significantly higher ratings from the female patients than from the male patients. Furthermore, all the MPP-J factors except for emotional support received significantly higher ratings from patients with lower levels of education than from patients with higher levels of education. Medical information, clear explanations, and encouraging question-asking received significantly higher ratings from younger patients than from older patients. Encouraging question-asking received a significantly higher rating from patients without recurrence or metastasis than from patients with recurrence or metastasis. The fighting spirit and anxious preoccupation subscales of the MAC were positively correlated with all of the MPP-J factors. The total HADS score was positively associated with the emotional support factor.

Table 4. The internal consistency and the fit of the each factor the MPP-J

	Alpha ^a	GFI ^b	AGFI ^c	CFI ^d
Original MPP structure model by Parker et al. [18]				
Factor 1 (content)	0.93	0.818	0.745	0.840
Factor 2 (support)	0.91	0.794	0.702	0.769
Factor 3 (facilitation)	0.81	0.937	0.873	0.900
Revised MPP-J structure model				
Factor 1 (Emotional support)	0.90	0.913	0.855	0.924
Factor 2 (Medical information)	0.91	0.810	0.716	0.786
Factor 3 (Clear explanation)	0.89	0.855	0.772	0.818
Factor 4 (Encouraging to ask questions)	0.91	0.876	0.753	0.910
Factor 5 (setting)	0.83	0.963	0.889	0.952

^a Cronbach's alpha coefficient.^b The goodness of fit index.^c The adjusted goodness of fit index.^d The comparative fit index.**Table 5.** Variables associated with each factor of the MPP

Independent variables	Beta	p	r	R ²	Adjusted R ²
Factor 1 (emotional support)				0.138	0.132
Sex ^a	0.085	0.038	0.085		
MAC fighting spirit	0.235	<0.001	0.198		
MAC anxious preoccupation	0.170	0.001	0.107		
HADS total	0.136	0.009	0.085		
Factor 2 (medical information)				0.119	0.111
Age (year)	-0.118	0.009	-0.107		
Sex ^a	0.102	0.021	0.095		
Education (year)	0.171	<0.001	0.162		
MAC fighting spirit	0.113	0.009	0.108		
MAC anxious preoccupation	0.191	<0.001	0.183		
Factor 3 (clear explanation)				0.130	0.121
Age (year)	-0.148	0.001	-0.134		
Sex ^a	0.098	0.027	0.090		
Education (year)	0.201	<0.001	0.191		
MAC fighting spirit	0.161	<0.001	0.153		
MAC anxious preoccupation	0.113	0.008	0.108		
Factor 4 (encouraging to ask questions)				0.181	0.172
Age (year)	-0.172	<0.001	-0.156		
Sex ^a	0.158	<0.001	0.146		
Education (year)	0.193	<0.001	0.183		
Recurrence or metastasis	-0.085	0.040	-0.082		
MAC fighting spirit	0.147	<0.001	0.140		
MAC anxious preoccupation	0.197	<0.001	0.184		
Factor 5 (setting)				0.165	0.159
Sex ^a	0.235	<0.001	0.232		
Education (year)	0.200	<0.001	0.198		
MAC fighting spirit	0.182	<0.001	0.174		
MAC anxious preoccupation	0.177	<0.001	0.170		

^a Coded as 0 = male, 1 = female.

Discussion

The present study population was relatively large and heterogeneous. It included patients with several types and stages of cancers, both genders, and a broad age range. The participants' characteristics in the present study were similar to those in the original MPP study [18] in that they were outpatients at a teaching cancer center and the

mean age and time since receiving the initial diagnosis were similar. The patient characteristics in this study differed from those in the original MPP study with regard to two primary variables, race and type of cancer (the participants in the original study had breast, gastrointestinal, gynecologic, and urologic cancers).

Overall, the mean scores of the majority of the items in the present study were lower than the

scores described in the original report. The rankings were partially similar to the results obtained in the US. For example, patients placed importance on receiving information about their cancer and its treatment, the physician speaking in a manner that is honest and easy to understand, and the physician offering support. However, the ranking of some items differed between the present study and the previous US study [18]. For example, compared with the US patients, Japanese cancer patients appeared to place more importance on having the physicians inform their family members about their diagnosis and prognosis (items 43 and 44 were ranked 18th and 23rd in the present study and 39th and 36th in the American study, respectively). This result is not surprising, given that a family-centered decision-making process [14] remains more dominant in Japan than in the US. Japanese cancer patients also appeared to place less importance on the physicians giving the patients their full attention (item 5 was ranked 27th in Japan, and 10th in the US) and on physicians telling the patients about all the available treatment options (item 18 was ranked 30th in Japan and 9th in the US). This may reflect the more 'paternalistic' physician-patient relationship, in which the patients are deferential to their physicians regarding the scope and specifics of their treatment, that has traditionally dominated Japanese medical care.

Most of the items that were rated as most important were consistent with the communication styles advocated by published guidelines and recommendations on how to deliver bad news, such as delivering the news in person, discussing possible treatment options with the patient, and delivering the diagnosis honestly and in simple language [5-8]. However, two communication skills that are relevant in Western cultures may not be as important in Japan. First, though studies and guidelines typically recommend that physicians sit close to patients to facilitate physical contact [7,24], the Japanese patients in the present study did not rate having their physician hold their hand or touch their arm while telling them bad news as being important. This finding may represent a Japanese cultural norm in which 'formality' is more important than 'familiarity' during encounters with others. Second, the patients in the present study placed less importance on whether another health care provider was present during the consultation to offer support and information, a factor that has been recommended by previous guidelines. This may reflect a preference for privacy when communicating with their physician and a sense that the patient's family will provide sufficient support. Future studies in Japanese populations are needed to explore these issues.

The factor analytic structure in this study did not replicate the original MPP factor structure. This differs from a study conducted in Canada, which confirmed the factor structure of the original MPP

[19]. The difference in the factor structures between North America and Japan may be due to cultural differences between these regions.

The exploratory factor analysis in our study showed a 5-factor structure, with the emotional support factor explaining most of the variance. The emotional support and setting factors were similar to the support and facilitation factors of the original MPP factor structure. Interestingly, the exploratory factor analysis included a new factor, the 'encouraging question-asking' factor; furthermore, the 'content' factor described in the original report was divided into two factors in our study, the 'medical information' factor and the 'clear explanation' factor. Items focusing on the encouragement of question-asking were rated highly by the patients (see items 40, 25, 38, 34, 26, 28, and 27 in Table 2). Patient-physician relationships in Japan have traditionally been based on a paternalistic and hierarchical culture that discourages patients from questioning doctors. For this reason, Japanese patients might need more time to ask questions, and to feel comfortable enough to ask any questions that they might have; they also like to be asked whether they have any questions. The new factor of encouraging question-asking might be related to the 'amae' culture described by Doi [25], which is a key concept for understanding typical interpersonal behaviors and interpersonal feelings among the Japanese. In Amae culture, people take it granted that they expect for another to behave and treat them guessing how they will feel and what they prefer. Our results suggest that it might be beneficial for physicians to encourage Japanese cancer patients to ask questions, to provide emotional support to their patients, and to understand their patients' communication style preferences regarding 'what information to receive' and 'how to receive it,' since patients might expect this information to be automatically provided by their physician.

Our findings indicated that female patients and patients with a fighting spirit or anxious preoccupation place greater importance on all aspects of physicians' communication styles when receiving bad news than male patients and those who scored lower on the fighting spirit scale. In addition, younger patients and patients with higher education levels rated medical information, clear explanations, and encouraging question-asking as being more important, compared with the ratings given to these items by older patients and those with less education. The setting variables were also given higher ratings by patients with higher education levels than by patients with lower education levels. These results were consistent with previous findings [16,18,26]. Furthermore, in the current study, patients who had higher levels of psychological distress indicated that they preferred having more emotional support from their

physicians, compared with the ratings given by less-distressed patients. Patients without recurrent or metastatic disease placed more importance on 'asking their physicians questions' than patients with recurrent or metastatic disease. Physicians should keep these results in mind when delivering bad news to Japanese cancer patients. Further study is needed to investigate other variables that were not considered in the present study and that may be associated with patients' communication style preferences. Some of these variables may include the estimated survival period and personality characteristics of the patients.

Three limitations of the present study should be noted. First, the cancer sites of the participants in the present study differed from those in the original study [18]. Therefore, the findings in the present study may have differed from those of the American study because the patients had different cancers. However, significant differences were not found between the types of cancer in the present study and the original study. The second limitation is that the study was conducted at a single teaching center specializing in cancer. Thus, the results of this study might not be representative of other cancer care settings. Nonetheless, because the consecutive sample included male and female patients with a variety of cancers, and disease stages, a wide range of ages, and different psychosocial characteristics, we believe that our results reflect the preferences of a broad range of patients. Another important limitation is that our study examined the preferences of patients at only one point in time. Thus, we cannot speculate on the stability of the measurements used in this study. Additionally, it is possible that a response shift occurred; that is, the patients' evaluations of their preferences may have changed as a result of a change in their personal standards or values or a reconceptualization of the construct [27]. Previous research has also found that patients' informational needs may change over the course of their illness and treatment [17]. Because of the cross-sectional nature of this study, we were not able to formally address this question. However, the amount of time that had elapsed since the patients received their initial diagnosis was not significantly associated with their preferences for communication.

Acknowledgements

We thank the physicians of the National Cancer Center Hospital East (Drs S. Imoto, K. Itou, K. Kubota, K. Matsuura, T. Nakagohri, A. Ohtsu, J. Yoshida), and the staffs at Psycho-Oncology Division, National Cancer Center Hospital East.

This work was supported by a Grant-in-Aid for Cancer Research and Third-Term Comprehensive 10-Year Strategy for Cancer Control and Research, Japanese Ministry of Health, Labor and Welfare. Maiko Fujimori is an awardee

of Research Resident Fellowships from the Foundation for the Promotion of Cancer Research in Japan.

References

1. Roberts CS, Cox CE, Reintgen DS, Baile WF, Gibertini M. Influence of physician communication on newly diagnosed breast patients' psychologic adjustment and decision-making. *Cancer* 1994;74:336-341.
2. Takayama T, Yamazaki Y, Katsumata N. Relationship between outpatients' perceptions of physicians' communication styles and patients' anxiety levels in a Japanese oncology setting. *Soc Sci Med*. 2001;53:1335-1350.
3. Mager WM, Andrykowski MA. Communication in the cancer 'bad news' consultation: patient perceptions and psychological adjustment. *Psycho-Oncology* 2002;11:35-46.
4. Morita T, Akechi T, Ikenaga M et al. Communication about the ending of anticancer treatment and transition to palliative care. *Ann Oncol* 2004;15:1551-1557.
5. Fallowfield L. Giving sad and bad news. *Lancet* 1993;341:476-478.
6. Girgis A, Sanson-Fisher RW. Breaking bad news: consensus guidelines for medical practitioners. *J Clin Oncol* 1995;13:2449-2456.
7. Ptacek JT, Eberhardt TL. Breaking bad news. A review of the literature. *JAMA* 1996;276:496-502.
8. Baile WF, Buckman R, Lenzi R, Glober G, Beale EA, Kudelka AP. SPIKES-A six-step protocol for delivering bad news: application to the patient with cancer. *Oncologist* 2000;5:302-311.
9. Jenkins V, Fallowfield L. Can communication skills training alter physicians' beliefs and behavior in clinics? *J Clin Oncol* 2002;20:765-769.
10. Fallowfield L, Jenkins V, Farewell V, Solis-Trapala I. Enduring impact of communication skills training: results of a 12-month follow-up. *Br J Cancer* 2003;89:1445-1449.
11. Fujimori M, Oba A, Koike M et al. Communication skills training for Japanese oncologists on how to break bad news—a preliminary report. *J Cancer Educ* 2003;18:194-201.
12. Sekimoto M, Asai A, Ohnishi M et al. Patients' preferences for involvement in treatment decision making in Japan. *BMC Fam Pract* 2004;5:1.
13. Fujimori M, Akechi T, Akizuki N et al. Good communication when receiving bad news about cancer in Japan. *Psycho-Oncology* 2005;14:1043-1051.
14. Akabayashi A, Fetters MD, Elwyn TS. Family consent, communication, and advance directives for cancer disclosure: a Japanese case and discussion. *J Med Ethics* 1999;25:296-301.
15. Miyata H, Takahashi M, Saito T, Tachimori H, Kai I. Disclosure preferences regarding cancer diagnosis and prognosis: to tell or not to tell? *J Med Ethics* 2005;31:447-451.
16. Butow PN, Kazemi JN, Beeney LJ, Griffin AM, Dunn SM, Tattersall MH. When the diagnosis is cancer: patient communication experiences and preferences. *Cancer* 1996;77:2630-2637.
17. Butow PN, Maclean M, Dunn SM, Tattersall MH, Boyer MJ. The dynamics of change: cancer patients' preferences for information, involvement and support. *Ann Oncol* 1997;8:857-863.
18. Parker PA, Baile WF, de Moor C, Lenzi R, Kudelka AP, Cohen L. Breaking bad news about cancer: patients' preferences for communication. *J Clin Oncol* 2001;19:2049-2056.

19. Davison BJ, Parker PA, Goldenberg SL. Patients' preferences for communicating a prostate cancer diagnosis and participating in medical decision-making. *BJU Int* 2004;**93**:47–51.
20. Akechi T, Fukue-Saeki M, Kugaya A *et al.* Psychometric properties of the Japanese version of the Mental Adjustment to Cancer (MAC) scale. *Psycho-Oncology* 2000;**9**:395–401.
21. Watson M, Greer S, Young J, Inayat Q, Burgess C, Robertson B. Development of a questionnaire measure of adjustment to cancer: the MAC scale. *Psychol Med* 1988;**18**:203–209.
22. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. *Acta Psychiatr Scand* 1983;**67**:361–370.
23. Kugaya A, Akechi T, Okuyama T, Okamura H, Uchitomi Y. Screening for psychological distress in Japanese cancer patients. *Jpn J Clin Oncol* 1998;**28**:333–338.
24. Ptacek JT, Ptacek JJ. Patients' perceptions of receiving bad news about cancer. *J Clin Oncol* 2001;**19**:4160–4164.
25. Doi T. *The Anatomy of Dependence*. Kodansha International: Tokyo, 2001.
26. Cassileth BR, Zupkis RV, Sutton-Smith K, March V. Information and participation preferences among cancer patients. *Ann Intern Med* 1980;**92**:832–836.
27. Sprangers MAG, Schwartz CE. Integrating response shift into health-related quality of life research: a theoretical model. *Soc Sci Med*. 1999;**48**:1507–1515.

Associated and predictive factors of sleep disturbance in advanced cancer patients

Tatsuo Akechi^{1,2}, Toru Okuyama¹, Nobuya Akizuki², Ken Shimizu³, Masatoshi Inagaki², Maiko Fujimori², Yasuo Shima⁴, Toshiaki A. Furukawa¹ and Yosuke Uchitomi^{2*}

¹ Department of Psychiatry and Cognitive-Behavioral Medicine, Graduate School of Medical Sciences, Nagoya City University, Kawasumi, Mizuho-cho, Mizuho-ku, Nagoya 467-8601, Japan

² Psycho-Oncology Division, Research Center for Innovative Oncology, National Cancer Center Hospital East, 6-5-1 Kashiwanoha, Kashiwa, Chiba 277-8577, Japan

³ Psychiatry Division, National Cancer Center Hospital, 5-1-1 Tsukiji, Chuo-ku, Tokyo 104-0045, Japan

⁴ Department of Palliative Medicine, Tsukuba Medical Center Hospital, 1-3-1 Amakubo, Tsukuba, Ibaraki 305-8558, Japan

*Correspondence to: Psycho-Oncology Division, Research Center for Innovative Oncology, National Cancer Center Hospital East, 6-5-1 Kashiwanoha, Kashiwa 277-8577, Japan. E-mail: yuchitomi@east.ncc.go.jp

Abstract

Little attention has been paid to sleep disturbance experienced by advanced cancer patients. The purpose of the present study was to investigate longitudinal change in sleep disturbance and to identify factors that associated with and predicted sleep disturbance among 209 consecutive terminally ill cancer patients. Patients were assessed twice for sleep disturbance by one item of the structured clinical interview for assessing depression, once at the time of their registration with a palliative care unit (PCU) (baseline) and again at the time of their PCU admission (follow-up), and possible associated medical and psychosocial factors were evaluated. The proportions of patients with obvious sleep disturbance at baseline and follow-up were 15.3 and 25.9%, respectively. Sixty-seven percent of the subjects showed some sleep status changes, including both aggravation and improvement, between baseline and follow-up. Being younger, having diarrhea and living alone were significantly associated with sleep disturbance at baseline, and the increase of psychological distress was the only significant predictive factor for sleep disturbance at follow-up. These findings suggest that psychological distress is a possible key cause of sleep disturbance and management of psychological distress may be one promising strategy for prevention of sleep disturbance among advanced cancer patients.

Copyright © 2006 John Wiley & Sons, Ltd.

Keywords: cancer; oncology; sleep disturbance; psychological distress; prevention

Received: 25 April 2006
Revised: 13 September 2006
Accepted: 2 October 2006

Introduction

Sleep disturbance experienced by cancer patients is known as a prevalent but neglected issue in clinical oncology practice [1]. Previous reports have indicated that sleep disturbance is more frequent in cancer patients than in the general population and at least one-fourth of cancer patients experience sleep disturbance [1,2]. Because the potential consequences of sleep disturbance in cancer patients involve a broad range of problems, such as daytime fatigue and cognitive dysfunction, psychological distress and/or psychiatric disorders, physical symptoms (e.g. pain) and immunosuppression, appropriate management of sleep disturbance among cancer patients should receive more attention.

There are few studies which provide informative findings to understand and develop management strategies for sleep disturbance in cancer patients. For example, although several etiologic factors of sleep disturbance in cancer patients have been

proposed (e.g. gender, aging, physical symptoms, maladaptive sleep behaviors, psychologic distress, hospitalization, drugs, etc.) [1,2], very few empirical studies have supported these hypotheses. Several recent studies have focused on sleep disturbance in advanced cancer patients and they suggested that it is a prevalent and multi-factorial symptom caused by physical (e.g. pain, urinary frequency, dyspnea) and psychosocial distress (e.g. anxiety, depression, concerns about family and future, less social support) [3–6].

Little attention has thus been given to sleep disturbance experienced by cancer patients, and most studies on sleep in cancer patients have focused on patients with early stage disease. Study findings about sleep problems from the early stage cancer patients may not be generalizable because many eminent differences usually underlie early stage cancer patients and patients with terminal stage cancer, such as physical symptoms and psychological distress. Furthermore to the best of our knowledge, there are no findings regarding the

longitudinal course and predictors of sleep disturbance among terminally ill cancer patients in a prospective study. For patients suffering from advanced and/or terminal cancer in particular, the emphasis of treatment is on controlling symptoms and maintaining the patient's quality of life (QOL), and sleep is known as one independent item constituting the cancer patient's QOL [7,8]. Given the very limited amount and scope of research, there is an obvious need for further study on sleep disturbance among advanced cancer patients. In particular, findings on the associated and predictive factors of sleep disturbance are of obvious importance when considering the actual care of advanced cancer patients and developing appropriate management and/or preventive strategies. The purpose of the present study was to investigate longitudinal change of sleep disturbance and to identify factors that contribute to and predict sleep disturbance among advanced cancer patients.

Methods

Patients

The current study was conducted as part of the previously published studies investigating suicidality and psychological distress in terminally ill Japanese cancer patients and the detailed methodology of these studies has been described elsewhere [9,10]. Two hundred and nine consecutive patients were recruited upon registration with the palliative care unit (PCU) of the National Cancer Center Hospital East, Japan. The eligibility criteria for patient recruitment in the study were: (a) age 18 years or older, (b) being newly registered with the PCU, (c) not currently undergoing curative cancer therapy, such as surgery, chemotherapy, or radiotherapy (d) knowledge of the cancer diagnosis, (e) being not too ill, (f) not suffering from cognitive impairment, and (g) having no difficulty in verbal communication. While the 'not too ill' criterion was judged by palliative care physicians, the physicians and investigators frequently provided feedback to each other and discussed eligibility on a case-by-case basis to avoid biased judgment and selection bias. Each patient was screened for cognitive impairment by means of the Japanese version of the mini mental state examination (MMSE) [11,12] (a score of 24 or more was the criterion for eligibility).

This study was approved by the Institutional Review Board and the Ethics Committee of the National Cancer Center of Japan and was conducted in accordance with the Helsinki Declaration. Written informed consent was obtained from each subject before enrollment into this study.

Assessment of sleep disturbance

The subjects were assessed for the presence of sleep disturbance by a trained psychiatrist by using the sleep disturbance item (insomnia or hypersomnia nearly every day for at least for 2 weeks) of the major depressive episode module of the Structured Clinical Interview for DSM-III-R (SCID) [13] at the time they registered with the PCU (baseline) and again when they were admitted to the PCU (follow-up). Sleep disturbance was classified as absent, sub-threshold, or present. The reliability (kappa coefficient) of the interview ratings was investigated by having another trained psychiatrist attend the first 29 consecutive interviews as a second rater, and the kappa coefficient was 0.89.

Potentially associated and predictive factors of sleep disturbance

Socio-demographic and medical factors (brain metastasis, Karnofsky performance status [KPS]), and use of several kinds of drugs that potentially cause sleep disturbance, including opioids, corticosteroids, psychostimulants, anticonvulsants, bronchodilators, and antihypertensives were investigated [1,14,15]. The five frequent and distressing physical symptoms, pain, dyspnea, fatigue, diarrhea, and constipation, were assessed by asking the patient to describe the severity of each on a scale of 1, absent, to 5, extreme. Because there is no valid, brief, and appropriate method of assessing advanced cancer patients' physical symptoms at the time, this *ad hoc* method was used.

The total score of the Japanese version of the Hospital Anxiety and Depression Scale (HADS) [16,17], a brief validated self-report questionnaire, was used to assess psychological distress.

Study procedures

After obtaining the consent, eligible patients participated in the interview and completed the questionnaires at the first outpatient visit after registration (baseline) and on admission to the PCU (follow-up). The follow-up investigations were conducted within 1 week of their admission.

Statistical analysis

To identify cross-sectional factors that were associated with sleep disturbance at baseline, the subjects were divided into two groups according to whether they had obvious sleep disturbance or not at baseline (present vs absent/sub-threshold), and all of the variables investigated were included in the preliminary univariate analysis, as appropriate. We have separated drugs used into two categories (i.e. opioids and anticonvulsants as positive impact agents on sleep and corticosteroids, and

psycho-stimulants, bronchodilators, and antihypertensives as negative impact agents on sleep) according to the previous papers [1,14,15]. To identify the final associated factors, variables having a *p*-value of less than 0.10 in the univariate analysis were entered into a logistic regression model as independent variables. Similarly, to identify baseline predictive factors for sleep disturbance at follow-up, subjects who had completed the follow-up assessment were divided into two groups according to the presence of sleep disturbance at follow-up, and the variables investigated were included in the univariate analysis. The analysis to identify baseline predictive factors was performed on the cases with no sleep disturbance at baseline. In addition, to identify longitudinal change between baseline and follow-up as predictive factors for sleep disturbance at follow-up, a similar analysis was performed. In this analysis, longitudinal change was calculated by subtracting the degree of the baseline factors from that of the follow-up factors, and drug use was divided into two groups according to presence or absence of new drug use at follow-up.

A *p*-value of less than 0.05 was adopted as the significance level in all of the statistical analyses, and all *p*-values reported are 2-tailed. All statistical procedures were conducted with the SPSS 12.0J version software for Windows (SPSS Inc., 2003).

Results

As previously reported, a total of 764 cancer patients registered with the PCU during the study entry period, but 507 of them were ineligible (too ill, *n* = 443; cognitive impairment, *n* = 50; other reasons = 14) [10]. Of the 257 eligible patients, 28 refused to participate and 20 could not be contacted (e.g. because of emergency admission to another hospital), and 209 patients participated in the baseline assessment. Subsequent to the baseline investigation, 37 patients were not admitted to the PCU (e.g. because of emergency admission to another hospital), and the other 172 were admitted to the PCU. However, six of them refused to cooperate further and 81 were judged to be ineligible (too ill, *n* = 57; cognitive impairment, *n* = 24). Thus, 85 patients completed the follow-up assessment.

As also reported, to assess longitudinal changes in performance status and physical symptoms among the 85 subjects who participated in the follow-up study, we investigated within-patient differences between the baseline and the follow-up. The results of the analysis indicated that performance status (*p* < 0.001), pain (*p* = 0.03), and fatigue (*p* < 0.001) were significantly worse in the follow-up investigation than in the baseline investigation, while dyspnea (*p* = 0.24) and

constipation (*p* = 0.1) did not change significantly. The median interval and mean (standard deviation) interval between the baseline and follow-up assessment were 58 days and 103 (119) days, respectively, and the intervals ranged from 7 to 622 days. The median/mean survival time estimated by the Kaplan–Meier method after the baseline assessment and follow-up assessment were 100/229 and 45/75 days, respectively.*

Prevalence of and longitudinal changes in sleep disturbance

At baseline (registration to PCU), 32 (15.3%) of 209 subjects had obvious sleep disturbance and 61 (29.2%) sub-threshold disturbance, while 116 (55.5%) subjects did not have sleep disturbance. At follow-up (on admission to PCU), 22 (25.9%) of the 85 subjects suffered from obvious sleep disturbance and 31 (36.5%) from sub-threshold disturbance while 32 (37.6%) subjects did not have sleep disturbance. The longitudinal changes that were calculated in the 85 participants who completed both baseline and follow-up assessment in sleep disturbance are shown in Figure 1. A total of 57 (67.1%) subjects showed some changes of their sleep status between baseline and follow-up. Thirty-nine (45.9%) subjects experienced worsening of sleep status while 18 (21.2%) improved.

Factors associated with sleep disturbance

The cross-sectional analyses based on the baseline data (*n* = 209) showed that younger age, higher psychological distress, pain, diarrhea, marital status (unmarried), and living alone were significant factors associated with sleep disturbance while performance status and constipation were borderline significant factors (Table 1). Because marital status and living alone seemed to be variables which were similar to each other, we decided to conduct two logistic regression analyses that included one of these two variables. The logistic regression analysis (retaining the variable of 'living alone') showed that younger age, diarrhea, and living alone were the final significant factors associated with the sleep disturbance at baseline, and performance status, psychological distress, and pain were of borderline significance (Table 2). The other logistic regression analysis (retaining variable of 'marital status') showed similar findings (data not shown).

Predictive factors for sleep disturbance

Tables 3 and 4 show the statistical results based on the cases with no sleep disturbance at baseline (*n* = 72). There were no significant factors at baseline that could predict the development of

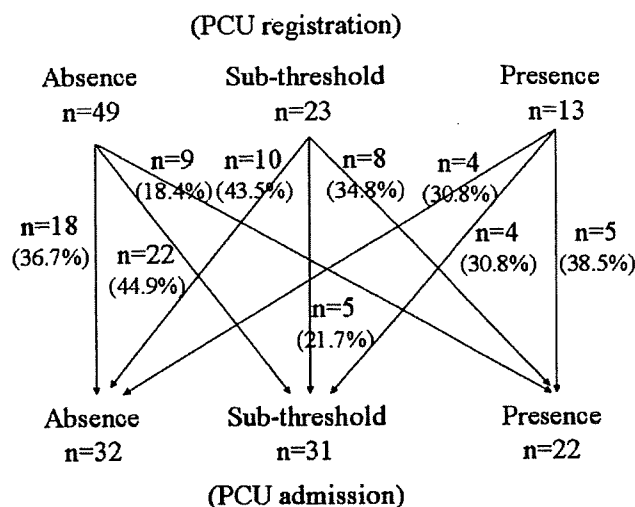


Figure 1. Longitudinal change of sleep disturbance in advanced cancer patients

Table 1. Associated factors for sleep disturbance in advanced cancer patients—univariate analysis

Associated factors	Sleep disturbance		Analysis		
	Present (n = 32)	Absent (n = 177)	t	df	p
Age	Mean (S.D.) 57.5 (9.8)	Mean (S.D.) 61.7 (10.2)	2.19	207	0.03
Performance status ^a	69 (14)	74 (15)	1.92	207	0.06
Psychological distress ^b	15.2 (6.8)	10.9 (6.5)	-3.41	205	0.001
	Mean (S.D.)	Mean (S.D.)	z	p	
Pain ^c	2.4 (1.0)	1.8 (0.9)	-3.19	0.001	
Dyspnea ^c	2.0 (0.9)	1.9 (1.0)	-1.20	0.23	
Fatigue ^c	2.4 (1.0)	2.1 (1.1)	-1.50	0.13	
Constipation ^c	2.2 (1.3)	1.7 (1.1)	-1.87	0.06	
Diarrhea ^c	1.5 (0.9)	1.1 (0.4)	-3.48	0.001	
	N (%)	N (%)	Chi-square	df	p
Sex (male)	19 (59)	118 (67)	0.64	1	0.43
Marital status (married)	24 (75)	157 (89)	4.38	1	0.04
Education (\geq 12 years)	22 (69)	125 (71)	0.05	1	0.83
Employment (full/part)	11 (34)	52 (29)	0.32	1	0.57
Living alone	5 (16)	7 (4)	6.82	1	0.009
Brain metastasis	1 (3)	22 (12)	— ^d	— ^d	0.22
Use of opioids or anticonvulsants	15 (47)	71 (40)	0.51	1	0.47
Use of corticosteroids psycho-stimulants, bronchodilators or antihypertensives	11 (34)	47 (27)	0.83	1	0.36

^a Defined by Karnofsky criteria.

^b Total score of the Hospital Anxiety and Depression Scale (HADS).

^c Coded as 1 = absent; 2 = mild; 3 = moderate; 4 = severe; 5 = extreme.

^d Chi-square values were not calculated, because Fisher's exact tests were performed.

sleep disturbance at follow-up (Table 3). On the other hand, investigation of the longitudinal changes between baseline and follow-up factors demonstrated that the increase in psychological distress was a significant predictive factor for the development of sleep disturbance at follow-up, while worsening of physical symptoms, declining physical functioning, and new use of drugs were not (Table 4). Very similar findings were obtained after adjustment for the interval between the baseline and follow-up investigation regarding these analyses (data not shown).

Discussion

This is a preliminary and, to the best of our knowledge, the first prospective investigation of associated and predictive factors for sleep disturbance among advanced cancer patients.

Factors associated with sleep disturbance

Several factors were shown as associated to sleep disturbance among advanced cancer patients. The finding that younger age is one of the significantly

associated factors for sleep disturbance is consistent with previous studies [18,19]. As suggested by these studies, possible explanation of this association may be younger cancer patients being with increased level of psychosocial burden.

Regarding physical symptoms, diarrhea was the only significant associated factor in the study. To the best of our knowledge, there have been no studies investigating the association of diarrhea with sleep disturbance among advanced cancer patients. This finding suggests the importance of appropriate management of bowel habits, and that diarrhea should not be neglected among patients with sleep disturbance. While pain was of borderline

significance in the current study, our finding regarding the possible association between pain and sleep disturbance would appear to be consistent with previous studies and appropriate pain management is essential for advanced cancer patients to maintain their QOL [3,4,6].

Living alone was also shown to be an independent associated factor for sleep disturbance. Several factors can be identified as underlying the 'living alone' status, such as loneliness, lack of social support, concerns about the future, and so on. On the other hand, living alone was not predictive for subsequent sleep disturbance. The latter finding may be due to the small sample size. Nevertheless, these findings suggest that there is a complicated mechanism connecting living alone and sleep disturbance. More studies are needed to clarify the actual influence of living alone on sleep disturbance and the underlying mechanism.

Table 2. Associated factors for sleep disturbance in advanced cancer patients—multivariate logistic regression analysis

	Beta	SE	Odds	95% CI ^a	p
Age	-0.05	0.02	0.95	0.91-0.999	0.046
Performance status ^b	-0.03	0.02	0.97	0.94-1.004	0.08
Psychological distress ^c	0.07	0.04	1.07	0.998-1.15	0.06
Pain ^d	0.46	0.23	1.58	0.998-2.49	0.051
Constipation ^d	0.05	0.19	1.05	0.73-1.51	0.80
Diarrhea ^d	0.97	0.35	2.65	1.33-5.26	0.006
Living alone	2.20	0.77	9.03	1.99-40.92	0.004

^a Confidence interval.

^b Defined by Karnofsky criteria.

^c Total HADS score.

^d Coded as 1 = absent; 2 = mild; 3 = moderate; 4 = severe; 5 = extreme.

Longitudinal changes in sleep disturbance

The clinical course of the sleep disturbance seems to have been variable. In fact, more than two-thirds of the patients showed some change in their sleep status, suggesting that the occurrence of sleep disturbance is state dependent and continuous monitoring of sleep disturbance is required in advanced cancer patients to maintain their QOL.

Table 3. Baseline predictive factors for sleep disturbance at admission to the palliative care unit in advanced cancer patients—univariate analysis

Associated factors	Sleep disturbance		Analysis		
	Present (n = 17)	Absent (n = 55)	t	df	p
	Mean (S.D.)	Mean (S.D.)			
Age	59.7 (9.5)	61.0 (9.8)	0.50	70	0.62
Performance status ^a	72 (16)	75 (14)	0.85	70	0.40
Psychological distress ^b	13.0 (5.8)	11.5 (6.3)	-0.90	70	0.37
	Mean (S.D.)	Mean (S.D.)	z	df	p
Pain ^c	1.6 (0.8)	1.9 (0.9)	-1.26		0.21
Dyspnea ^c	2.0 (1.3)	1.8 (0.8)	-0.07		0.94
Fatigue ^c	2.2 (0.9)	2.2 (1.1)	-0.38		0.70
Constipation ^c	1.8 (1.2)	1.8 (1.2)	-0.33		0.74
Diarrhea ^c	1.0 (0.0)	1.2 (0.5)	-1.49		0.14
	N (%)	N (%)	Chi-square	df	p
Sex (male)	8 (47)	32 (58)	0.65	1	0.42
Marital status (married)	17 (100)	49 (89)	— ^d	— ^d	0.33
Education (\geq 12 years)	13 (77)	37 (67)	— ^d	— ^d	0.56
Employment (full/part)	6 (35)	15 (27)	0.40	1	0.53
Living alone	0 (0)	1 (2)	— ^d	— ^d	1.00
Brain metastasis	1 (6)	8 (15)	— ^d	— ^d	0.68
Use of opioids or anticonvulsants	4 (24)	25 (46)	— ^d	— ^d	0.16
Use of corticosteroids, psycho-stimulants, bronchodilators or antihypertensives	3 (18)	14 (26)	— ^d	— ^d	0.38

^a Defined by Karnofsky criteria.

^b Total HADS score.

^c Coded as 1 = absent; 2 = mild; 3 = moderate; 4 = severe; 5 = extreme.

^d Chi-square values were not calculated, because Fisher's exact tests were performed.

Table 4. Longitudinal change between baseline and follow-up as predictive factors for sleep disturbance at admission to the palliative care unit in advanced cancer patients—univariate analysis

Associated factors	Sleep disturbance		Analysis		
	Present (n = 17)	Absent (n = 55)	t	df	p
	Mean (S.D.)	Mean (S.D.)			
Performance status ^a	-27.1 (16)	-21.8 (18)	1.08	70	0.29
Psychological distress ^b	6.5 (6.9)	1.3 (5.7)	-2.98	65	0.004
	Mean (S.D.)	Mean (S.D.)	z	p	
Pain ^c	0.5 (1.0)	0.2 (1.2)			-1.06
Dyspnea ^c	0.3 (1.6)	0.1 (1.0)	-0.39	0.70	
Fatigue ^c	0.7 (1.2)	0.4 (1.0)	-0.61	0.54	
Constipation ^c	0.4 (1.6)	0.3 (1.8)	-0.74	0.46	
Diarrhea ^c	0.1 (0.3)	0.4 (1.0)	-0.85	0.40	
New use of drugs	N (%)	N (%)	Chi-square	df	p
Use of opioids or anticonvulsants	3 (18)	5 (9)	— ^d	— ^d	0.38
Use of corticosteroids psycho-stimulants, bronchodilators or antihypertensives	7 (41)	27 (49)	0.33	1	0.57

^a Defined by Karnofsky criteria.

^b Total HADS score. There were some missing values.

^c Coded as 1 = absent; 2 = mild; 3 = moderate; 4 = severe; 5 = extreme.

^d Chi-square values were not calculated, because Fisher's exact tests were performed.

On the other hand, because the intervals between the baseline and follow-up investigation were not short (median 58 days) and variable (ranging from 7 to 622 days) and there the possibility exists of the occurrence of many events and changes regarding physical and psychosocial aspects, these factors may partly explain the variable clinical course of the sleep disturbance.

Predictive factors for sleep disturbance

Our findings suggest that an increase in psychological distress was the only predictive factor for development of sleep disturbance among advanced cancer patients. This finding is consistent with previous studies indicating that many forms of psychological distress, including anxiety, depression, and concerns, are significantly associated with sleep disturbance among cancer patients [3–6,18]. In addition, many studies investigating sleep disturbance experienced by the general population have demonstrated the significant association between sleep disturbance and psychological distress such as depression and anxiety [19–22]. These findings support a consistent association between sleep disturbance and psychological distress even in different populations.

There are discrepancies in the results obtained in the cross-sectional and longitudinal analyses regarding psychological distress. Because it is obvious that the findings obtained from a longitudinal analysis are more relevant than those from a cross-sectional analysis, psychological distress is one of the possible causes of sleep disturbance among advanced cancer patients.

In addition, the disappearance of any significant association between psychological distress and sleep disturbance in the cross-sectional multivariate analysis may be due to a statistical phenomenon resulting from over-adjustment for other variables. Actually, we conducted a similar multivariate analysis excluding age and living alone from independent variables, and psychological distress was found to be a significant associated factor (beta = 0.09, SE = 0.03, odds = 1.09 [95% CI = 1.02–1.16], $p = 0.01$).

Thus these findings indicate an even greater necessity for the management of psychological distress in the palliative care setting, and this approach may be one of the promising strategies for the prevention of sleep disturbance among advanced cancer patients.

Conclusion

The present finding indicated that the course of sleep disturbance in the palliative care setting is variable. Younger patients and those living alone may be at risk for sleep disturbance, and appropriate bowel symptom management may be important to manage sleep disturbance among advanced cancer patients. In addition, the management of psychological distress may be one promising strategy for prevention of sleep disturbance among advanced cancer patients.

Study limitations

The present study has several limitations. First, although sleep disturbance is a heterogeneous

complaint that may involve several different types of sleep problems (e.g. difficulties falling asleep, a complaint of nonrestorative sleep, insomnia, hypersomnia, etc.), in this study the interview assessing sleep disturbance may be nonspecific. We could not identify the exact types of sleep disturbance, nor did we use any diagnostic criteria of sleep disturbance [1]. In particular, two different types of sleep disturbance, namely insomnia and hypersomnia, were not analyzed separately. This may be one of the limitations of the present study because these two types of sleeping difficulty may vary in terms of etiological factors. Second, since only 27.4% (209/764) of the subjects at baseline and 11.1% (85/764) of the subjects at follow-up could be included in the analysis, generalizing the results may be impossible, and the sample size of the follow-up group was too small. These limitations may have resulted in underestimation of the sleep disturbance and distortion of the associated and predictive factors. Third, the fact that the baseline investigation was cross-sectional in design precludes drawing any conclusions about causality. Fourth, because the assessment of the physical symptoms and patients' concerns was conducted by an *ad hoc* method and the validity and reliability of the measures were not well established, this may have resulted in measurement errors. Fifth, the timing of the follow-up assessment (admission) may also have produced distortions, because the reasons for admission may have differed. Sixth, there may be other factors, such as the hyperarousability trait, cognitive impairment (e.g. delirium), and maladaptive sleep behaviors that can be associated with or predict sleep disturbance [1]. These factors should be addressed in the future studies. Finally, because this study focused on advanced cancer patients receiving palliative care, the results may not be applicable to patients with cancer at various stages or in other settings.

Acknowledgements

The authors wish to thank Yurie Sugihara for her research assistance. This study was supported in part by a Grant-in-Aid for Cancer Research (13-2) from the Japanese Ministry of Labour, Health and Welfare. All of the authors declare that they have no financial and proprietary interest in the subject matter or materials.

References

- Savard J, Morin CM. Insomnia in the context of cancer: a review of a neglected problem. *J Clin Oncol* 2001;19:895-908.
- Graci G. Pathogenesis and management of cancer-related insomnia. *J Support Oncol* 2005;3:349-359.
- Koopman C, Nouriani B, Erickson V et al. Sleep disturbance in women with metastatic breast cancer. *Breast J* 2002;8:362-370.
- Hugel H, Ellershaw JE, Cook L et al. The prevalence, key causes and management of insomnia in palliative care patients. *J Pain Symptom Manage* 2004;27:316-321.
- Mercadante S, Girelli D, Casuccio A. Sleep disorders in advanced cancer patients: prevalence and factors associated. *Support Care Cancer* 2004;12:355-359.
- Sela RA, Watanabe S, Nekolaichuk CL. Sleep disturbances in palliative cancer patients attending a pain and symptom control clinic. *Palliative Support Care* 2005;3:23-31.
- Aaronson NK, Ahmedzai S, Bergman B et al. The European Organization for Research and Treatment of Cancer QLQ-C30: a quality-of-life instrument for use in international clinical trials in oncology. *J Natl Cancer Inst* 1993;85:365-376.
- Cella DF, Tulsky DS, Gray G et al. The Functional Assessment of Cancer Therapy scale: development and validation of the general measure. *J Clin Oncol* 1993;11:570-579.
- Akechi T, Okuyama T, Sugawara Y et al. Suicidality in terminally ill Japanese patients with cancer. *Cancer* 2004;100:183-191.
- Akechi T, Okuyama T, Sugawara Y et al. Major depression, adjustment disorders, and post-traumatic stress disorder in terminally ill cancer patients: associated and predictive factors. *J Clin Oncol* 2004;22:1957-1965.
- Folstein MF, Folstein SE, McHugh PR. 'Mini-mental state'. A practical method for grading the cognitive state of patients for the clinician. *J Psychiatr Res* 1975;12:189-198.
- Mori E, Mitani Y, Yamadori A. Usefulness of a Japanese version of the Mini-Mental State Test in neurological patients. *Jpn J Neuropsychol* 1985;1:82-90.
- Spitzer RL, Williams JBW, Gibbon M et al. *Structured Clinical Interview for DSM III-R*. American Psychiatric Press: Washington, DC, 1990.
- Sateia M, Santulli R. Sleep in palliative care. In *Oxford Textbook of Palliative Medicine*, Doyle D, Hanks G, Cherny N, Calman K (eds). Oxford University Press: New York, 2004; 731-746.
- Vena C, Parker K, Cunningham M et al. Sleep-wake disturbances in people with cancer part I: an overview of sleep, sleep regulation, and effects of disease and treatment. *Oncol Nurs Forum* 2004;31:735-746.
- Zigmond AS, Snaith RP. The hospital anxiety and depression scale. *Acta Psychiatr Scand* 1983;67:361-370.
- Kugaya A, Akechi T, Okuyama T et al. Screening for psychological distress in Japanese cancer patients. *Jpn J Clin Oncol* 1998;28:333-338.
- Davidson JR, MacLean AW, Brundage MD et al. Sleep disturbance in cancer patients. *Soc Sci Med* 2002;54:1309-1321.
- Savard J, Simard S, Hervouet S et al. Insomnia in men treated with radical prostatectomy for prostate cancer. *Psycho-oncology* 2005;14:147-156.
- Foley DJ, Monjan AA, Brown SL et al. Sleep complaints among elderly persons: an epidemiologic study of three communities. *Sleep* 1995;18:425-432.
- Kim K, Uchiyama M, Liu X et al. Somatic and psychological complaints and their correlates with insomnia in the Japanese general population. *Psycho-som Med* 2001;63:441-446.
- Kaneita Y, Ohida T, Uchiyama M et al. The relationship between depression and sleep disturbances: a Japanese nationwide general population survey. *J Clin Psychiatry* 2006;67:196-203.

Original Article**Terminal Delirium: Recommendations from Bereaved Families' Experiences**

Tatsuya Morita, MD, Tatsuo Akechi, MD, PhD, Masayuki Ikenaga, MD, Shinichi Inoue, MD, Hiroyuki Kohara, MD, PhD, Tatsuhiro Matsubara, MD, Naoki Matsuo, MD, Miki Namba, RN, MA, Takuya Shinjo, MD, Kazuhiko Tani, MD, and Yosuke Uchitomi, MD, PhD

Department of Palliative and Supportive Care (T.M.), Palliative Care Team (T.M., M.N.), and Seirei Hospice (T.M.), Seirei Mikatahara General Hospital, Shizuoka; Department of Psychiatry and Cognitive-Behavioral Medicine (T.A.), Nagoya City University Graduate School of Medical Sciences, Nagoya; Hospice (M.I.), Yodogawa Christian Hospital, Osaka; Palliative Care Unit (S.I.), Aki City Hospital, Hiroshima; Palliative Care Unit (H.K.), National Sanyo Hospital, Yamaguchi; Palliative Care Unit (T.M.), Kawasaki Social Insurance Hospital, Kanagawa; Department of Palliative Medicine (N.M.), Saitama Cancer Center, Saitama; Palliative Care Unit (T.S.), Shakaihoken Kobe Central Hospital, Kobe; Department of Palliative Care (K.T.), Fukuiken Saiseikai Hospital, Fukui; Psycho-Oncology Division (Y.U.), National Cancer Center Research Institute East, Chiba; and Psychiatry Division (Y.U.), National Cancer Center Hospital East, Chiba, Japan

Abstract

Although delirium is a common complication in terminally ill cancer patients and can cause considerable distress for family members, little is known about effective care strategies for terminal delirium. The primary aims of this study were 1) to clarify the distress levels of bereaved families and their perceived necessity of care; and 2) to explore the association between these levels and family-reported professional care practice, family-reported patient behavior, and their interpretation of the causes of delirium. A multicenter questionnaire survey was conducted on 560 bereaved family members of cancer patients who developed delirium during their final two weeks in eight certified palliative care units across Japan. We obtained 402 effective responses (response rate, 72%) and, as 160 families denied delirium episodes, 242 responses were analyzed. The bereaved family members reported that they were very distressed (32%) and distressed (22%) about the experience of terminal delirium. On the other hand, 5.8% reported that considerable or much improvement was necessary, and 31% reported some improvement was necessary in the professional care they had received. More than half of the respondents had ambivalent wishes, guilt and self-blame, and worries about staying with the patient. One-fourth to one-third reported that they felt a burden concerning proxy judgments, burden to others, acceptance, and helplessness. High-level emotional distress and family-perceived necessity of improvement were associated with a younger family age; male gender; their experience of agitation and incoherent speech; their interpretation of the causes of delirium as pain/physical discomfort, medication effects, or

This study was supported by a grant from the Comprehensive 10-Year Strategy for Cancer Control Program of the Ministry of Health, Welfare, and Labour of Japan.

Address reprint requests to: Tatsuya Morita, MD, Department of Palliative and Supportive Care,

Palliative Care Team and Seirei Hospice, Seirei Mikatahara General Hospital, Shizuoka, 3453 Mikatahara-cho, Hamamatsu, Shizuoka 433-8558, Japan. E-mail: tmorita@sis.seirei.or.jp

Accepted for publication: January 19, 2007.

mental weakness/death anxiety, and their perception that medical staff were not present with the family, not respecting the patient's subjective world, not explaining the expected course with daily changes, and not relieving family care burden. In terminal delirium, a considerable number of families experienced high levels of emotional distress and felt some need for improvement of the specialized palliative care service. Control of agitation symptoms with careful consideration of ambivalent family wishes, providing information about the pathology of delirium, being present with the family, respecting the patient's subjective world, explaining the expected course with daily changes, and relieving family care burden can be useful care strategies. *J Pain Symptom Manage* 2007;34:579–589. © 2007 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Key Words

Palliative care, delirium, family, neoplasms, end-of-life care

Introduction

Delirium or cognitive disorder occurs in 68%–90% of terminally ill cancer patients just before death.^{1–5} Although cognitive impairment can sometimes be labeled as part of the “natural” dying process, delirium-related symptoms can cause great distress to both patients and family members.^{6,7} According to one prospective observation study of 75 family members of delirious cancer patients, 76% of family members showed high levels of psychological distress as a result of the delirium symptoms.⁶ A questionnaire survey involving 300 bereaved Japanese families revealed that more than two-thirds perceived all delirium-related symptoms other than somnolence as distressing or very distressing.⁷ These results indicate that, given that one of the primary goals of integrated palliative care is to alleviate family suffering, active support for the family members of delirious terminal patients is of great importance.

Understanding the experience of families of delirious terminally ill patients is vital to explore effective care strategies. To our knowledge, however, despite many experience-based recommendations by palliative care specialists,^{8–11} only a few studies have explored the actual experiences of families in the terminal stage.^{12–14} Our previous qualitative study revealed that the families experienced various phenomena other than psychiatric symptoms, had a range of emotions, interpreted the delirium variously, and listed some specific useful support strategies in caring terminal delirium.¹⁴ Although this study provides a potentially useful insight, generalizability is limited due to a lack of quantitative data.

The primary aim of the current study was thus to: 1) clarify the distress levels of bereaved families and their perceived necessity of care related to terminal delirium; and 2) explore the association between these levels and family-reported professional care practice, family-reported patient behavior, and their interpretation of the causes of delirium.

Methods

This was a cross-sectional, anonymous, multicenter survey of the bereaved families of cancer patients who had been admitted to eight palliative care units in Japan. We mailed questionnaires to bereaved families in February 2006, and again in March 2006 to nonresponding families. If the families did not want to participate in the survey, they were requested to return the questionnaire with “no participation” indicated, and the second questionnaire was not mailed. The participating institutions were conveniently selected from 150 certified palliative care units. We acknowledged the potential sampling bias, but decided to use convenient institutions due to the practical difficulties of obtaining participants from all palliative care units, and because a relatively large number of patients can minimize the risk of sampling bias.

Subjects

Primary palliative care responsible physicians identified potential participants following these inclusion criteria: 1) bereaved adult family members of an adult cancer patient (one family member was selected for each