

patient), with delirium during the final two weeks of life (based on a retrospective chart review and using Diagnostic and Statistical Manual of Mental Disorders, 4 (DSM-IV) criteria¹⁵), 2) capable of replying to a self-reported questionnaire, 3) aware of the diagnosis of malignancy, and 4) no serious psychological distress recognized by the primary palliative care physicians. The last criterion was adopted in the same way as in our previous surveys,^{16,17} on the assumption that primary palliative care physicians could identify families who would suffer serious psychological distress from this survey, because they were closely involved in caring for their relative in an inpatient care setting with a mean admission period of 43 days. We excluded patients with preexisting symptomatic organic brain pathology (i.e., brain metastasis, infarction) or psychiatric disorders other than delirium (i.e., psychosis, dementia), because the psychiatric symptoms might influence the results. To minimize the possibility of sampling bias among institutions, we compared the percentages of patients diagnosed with delirium per all dead patients and the percentages of patients excluded from this study due to the last criterion among the institutions.

Each hospital was requested to consecutively enroll the families of 90 patients who developed delirium and died in 2005 (one institution with clinical activity of less than one year enrolled all patients treated there).

The completion and return of the questionnaire was regarded as consent to participate in this study. Ethical and scientific validity was confirmed by the institutional review board of each hospital.

Measurement Tools

Questionnaire. A questionnaire (available from the authors upon request) was developed for this study based on a systematic literature review,^{6-14,18-23} our previous qualitative study based on in-depth interviews with 20 bereaved family members,¹⁴ and discussions among the authors. Content validity was assessed by full agreement of the authors, and the face validity of the questionnaire was confirmed by a pilot test.

As background data, the families reported their ages, genders, relationships to the patient, and intervals from patient death to the study. In the first part of the questionnaire,

we asked the respondents whether they thought the patient was delirious or not, because in our previous interview study, 17 of 37 families denied delirium despite diagnostic confirmation based on chart review.¹⁴ Delirium was paraphrased in the questionnaire as "the rapid development of difficulty in concentration, forgetfulness, disorientation about time and place, hallucinations and delusions, incoherent speech, clouding of consciousness and difficulty in communicating, emotional instability, reversal of daytime and nighttime activities (drowsiness during the day and wakefulness during the night), and inconsistent behavior, with these conditions changing even within a day." We carefully developed this introduction section on the basis of the DSM-IV criteria through full agreement among the author liaison psychiatrists and palliative care specialists.

The primary endpoints of this study were family-perceived emotional distress related to terminal delirium and the necessity for improvement in professional care at that time. Due to the lack of validated instruments, these outcome parameters were developed for this study following previous surveys.^{16,17} The level of family-perceived distress was evaluated by the response to "How distressing was the patient's delirium for you?," rated on a 5-point scale from 1, "no distress at all" to 5, "very distressing." The necessity for improvement was evaluated by the answer to "How much improvement do you think is necessary in the care for delirium?," rated on a 4-point scale as 1, "no need for improvement," 2, "need for some improvement," 3, "need for considerable improvement," and 4, "need for much improvement." To explore the families' emotions, we asked the respondents to rate their degree of agreement with 16 statements to describe their feelings on a 5-point Likert-type scale of 1, "disagree," to 5, "strongly agree" (Table 2). In addition, we asked the respondents to rate their degree of agreement with eight potential meanings of delirium for the family member on a 5-point Likert-type scale of 1, "disagree," to 5, "strongly agree" (Table 4).

The families were further requested to report factors potentially contributing to these primary endpoints. They were conceptualized prior to the survey and classified into the

following categories: 1) family-reported patient behavior (rated on a 5-point Likert-type scale of 1: none, 2: occasionally, and 3: often) (Table 3); 2) families' interpretation of the causes of delirium (examined by the degree of agreement on a 5-point Likert-type scale of 1: disagree to 5: strongly agree) (Table 4); 3) family-reported professional care practice (examined using the yes-no format) (Table 5); and 4) the family care subscale of the Care Evaluation Scale.²⁴

The Care Evaluation Scale is an originally validated 28-item questionnaire to measure bereaved family-perceived necessity of improvement in end-of-life care;²⁴ its reliability and validity have been well established. The family care subscale was designed to quantify the family-perceived necessity of improvement in care to relieve the family care burden. A lower score indicated a greater care need for improvement (possible range, 0–10).

Chart Review Data. Primary palliative care physicians recorded the patient backgrounds (age, gender, primary tumor site, admission periods, and the type and severity of delirium on item 9 of the Memorial Delirium Assessment Scale—Japanese version²⁵).

Analyses

To describe the estimated frequency of the phenomenon observed, we calculated the 95% confidence intervals (CI) for each figure.

For comparisons, the respondents were classified into two groups: family members who rated their distress level as "very distressed" (high-level distress) and others (low-level distress); and family members who rated the necessity for improvement as "much," "considerable," or "some" (defined as a high level of perceived necessity for improvement) and others (low level). These cutoff points were determined on the basis of the actual data distribution to divide the whole sample into appropriate sizes of comparison groups.

To explore the underlying structure of the families' emotions (Table 2), we reported factor-loading values by exploratory factor analysis with promax rotation on emotion-related items, and calculated Cronbach's alpha. Two ambivalent items with different meanings within one sentence were excluded from this analysis.

To explore the determinants of the levels of family-perceived distress and necessity for improvement, we initially screened: 1) demographic variables (patient age, gender, admission periods, responding family member age, gender, relationship to the patient, interval from patient death to study, health status in the last week, availability of someone with whom they could consult about the patient, and someone who could care for the patient instead of them); 2) type and severity of delirium (measured using item 9 of the Memorial Delirium Assessment Scale by the primary physicians); 3) family-reported patient behavior (Table 3); 4) families' interpretation of the causes of delirium (Table 4); 5) family-reported professional care practice (Table 5); and 6) the family care subscale of the Care Evaluation Scale. Univariate analyses were performed using Student's *t*-test or the Chi-square test, where appropriate. Multiple logistic regression analyses were then performed in a forward-elimination fashion. All potential predictors with statistical significance by univariate analyses were entered in the equation as independent variables, and we reported the factors that achieved $P < 0.1$ because they had a clinically meaningful interpretation despite marginal statistical significance.

All analyses were performed using the Statistical Package for the Social Sciences (version 11.0).

Results

Of 984 patients who died during this study period, 672 patients (68%) were diagnosed with delirium during the final two weeks of life. Of them, 53 patients had preexisting symptomatic organic brain or psychiatric disorders, and 19 patients had no competent adult family members available. Of the remaining 600 patients, we excluded 40 bereaved family members (6.7%) due to serious psychological distress recognized by primary physicians. Among the institutions, the percentages of patients diagnosed with delirium per all deceased patients ranged from 47% to 87% (three institutions below 70%), and the percentages of patients excluded from this study due to psychological reasons ranged from 0% to 12% (all but one institution below 7.0%).

We thus sent questionnaires to 560 families, 10 of which were returned as undeliverable. Four hundred twenty-seven families returned questionnaires (response rate, 78%, 427/550). Of them, nine families refused to participate, and 16 responses were excluded due to missing data in primary endpoints. Thus, we obtained 402 effective responses (effective response rate, 73%, 402/550). As 160 families denied delirium episodes, further analyses were performed on 242 responses. Table 1 summarizes the backgrounds of patients and bereaved family members. The subtypes of delirium were hypoactive, 29% ($n = 70$); hyperactive, 48% ($n = 117$); and mixed, 20% ($n = 48$). Symptom severity was mild, 39% ($n = 95$); moderate, 47% ($n = 114$); and severe, 11% ($n = 26$) on item 9 of the Memorial Delirium Assessment Scale.

Overall Levels of Family-Reported Distress and Necessity for Improvement

The degree of family-reported distress was very distressing (32% [95% CI: 26,38], $n = 77$), distressing (22% [95% CI: 17,28], $n = 53$), slightly distressing (31% [95% CI: 25,37], $n = 74$), not so distressing (10% [95% CI: 7.0,15], $n = 25$), and not distressing at all (5.4% [95% CI: 3.0-9.0], $n = 13$). The necessity of improvement in delirium care as rated by the family members was much improvement needed (0.8% [95% CI: 0,3.0], $n = 2$), considerable improvement needed (5.0% [95% CI: 3.0,9.0], $n = 12$), some improvement needed (31% [95% CI: 25,37], $n = 75$), and no improvement needed (59% [95% CI: 53,65], $n = 143$).

Family-Reported Emotions

Exploratory factor analysis categorized family-reported emotions into seven categories: ambivalent, guilt and self-blame, worry about staying with the patient, burden about proxy judgment, burden to others, acceptance, helplessness, and relief. 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 over proxy judgments, burden to others, acceptance, and helplessness. Less than 5% reported positive feelings such as relief (Table 2).

Table 1
Backgrounds

	% (n)
Patients	
Age (mean \pm SD)	69 \pm 12
Sex	
Male	64 (155)
Female	36 (87)
Primary sites	
Lung	26 (62)
Stomach	13 (31)
Colon, rectum	11 (27)
Pancreas, bile duct	12 (29)
Liver	5.3 (13)
Neck	6.2 (15)
Uterus, ovary	4.1 (10)
Bladder, kidney, prostate	7.9 (19)
Breast	3.3 (8)
Esophagus	2.5 (6)
Unknown	2.1 (5)
Others	7.0 (17)
Admission periods (d) (mean \pm SD)	43 \pm 48 (median, 28)
Bereaved families	
Age (mean \pm SD)	58 \pm 13
Sex	
Male	25 (60)
Female	74 (178)
Relationship	
Spouse	55 (132)
Child	30 (72)
Parents	1.7 (4)
Siblings	4.1 (10)
Others	9.1 (22)
Interval from patient death (mo) (mean \pm SD)	12 \pm 13 (median, 11)
In the last week	
Health status	
Good	74 (180)
Poor	24 (58)
Availability of person with whom the respondent consulted about the patient	91 (221)
Availability of person who cared for the patient instead of the respondent	71 (171)
Frequency of staying with the patient	
Every day	77 (186)
4-6 days/wk	12 (29)
1-3 days/wk	8.7 (21)

Some data do not add up to 100% due to missing values.

Family-Reported Patient Behavior

The bereaved family members reported various patient behaviors other than "psychiatric symptoms." More than half of the respondents reported that, during the delirium episodes, the patient expressed physiologic desires, seemed incoherent but talked about actual past events, and talked about uncompleted life tasks. In addition, about 30% said that the patient apologized

Table 2
Family-Reported Emotions

	Agree or Strongly Agree	95% CI	Factor Loadings	Alpha
	% (n)			
<i>Ambivalent</i>				N.C.
Simultaneously wanted the patient both to stay awake and to relieve the patient from suffering.	64 (155)	58,70	N.C.	
Simultaneously wanted the patient both to live longer and to die without suffering.	40 (97)	34,46	N.C.	
<i>Guilt and self-blame</i>				0.87
Could not understand what the patient wished for.	62 (149)	55,68	0.89	
Might not be able to realize the patient's unfulfilled wishes.	56 (135)	49,62	0.89	
Guilty, could not do enough for the patient.	52 (126)	46,58	0.88	
<i>Worry about staying with the patient</i>				0.77
Worried about caring the patient alone.	58 (140)	51,64	0.89	
Anxious about taking their eyes off the patient.	57 (139)	51,64	0.88	
<i>Burden about proxy judgment</i>				N.C.
Burden about having to make a decision on behalf of the patient.	39 (94)	33,45	0.86	
<i>Burden to others</i>				0.60
Distressed as the patient troubled others.	38 (91)	32,44	0.68	
Not wanting other members of the family to see the patient.	35 (84)	29,41	0.69	
Sad to see the patient having completely changed.	29 (71)	24,35	0.85	
<i>Acceptance</i>				N.C.
Just accepting the fact.	35 (84)	29,41	0.96	
<i>Helplessness</i>				0.78
Helplessness about what to do.	32 (78)	27,38	0.87	
Not sure about what was happening.	28 (68)	23,34	0.91	
<i>Relief</i>				0.81
Felt relieved.	3.3 (8)	2.0,6.0	0.89	
Felt happy.	2.5 (6)	1.0,5.0	0.91	

N.C. = not calculated.

for past events and was distressed as they noticed that they were talking strangely. About 20% of the family members reported a transcendent experience, that is, that the patient talked to or met people who had died (Table 3).

Family-Perceived Meaning of Delirium and Interpretation of the Causes of Delirium

About half of the respondents perceived delirium as a sign of approaching death, the patient trying to express what to say, or patient suffering. About one-fourth to one-third perceived delirium as a natural part of the dying process, dreaming, a transcendent phenomenon (entering the after-death world), or relief from actual suffering. Forty to 60% of the families interpreted the causes of delirium as pain/physical discomfort or medication effects (Table 4).

Family-Reported Professional Care Practice for Delirium

The families generally reported high adherence to the recommended care practice for

terminal delirium. Eighty percent or more families agreed that professionals treated patients the same as before, tried to understand what the patient wanted to say, were sufficiently compassionate to the family, explained the expected course along with daily changes, and respected the patient's subjective world (Table 5).

Determinants of Family-Perceived Emotional Distress and Necessity of Improvement

Compared with the family members with low-level distress, family members with high-level distress were more likely to experience agitated behavior, incoherent speech, the patient talking about uncompleted life tasks, the patient appearing incoherent but talking about actual past events, and being distressed by noticing that they were talking strangely; more likely to interpret the causes of delirium as pain/physical discomfort, medication effects, psychosis/"getting crazy," and mental weakness/death anxiety; less likely to report

Table 3
Family-Reported Patient Behavior in the Delirium Episodes

	Occasionally	95% CI	Often	95% CI
	% (n)		% (n)	
<i>"Psychiatric symptoms"</i>				
Incoherent speech	53 (128)	47, 59	25 (60)	20, 31
Mentally clear in some situations within the day	36 (88)	31, 43	37 (89)	31, 43
Hallucinations	34 (83)	29, 41	17 (40)	12, 22
Agitated behavior	31 (75)	25, 37	15 (36)	11, 20
<i>Other than "psychiatric symptoms"</i>				
Expressed physiologic desires (excretion, thirst)	31 (76)	26, 38	40 (96)	34, 46
Seemed incoherent but talked about actual past events	41 (100)	35, 48	26 (62)	20, 32
Talked about uncompleted life tasks	32 (78)	27, 38	24 (57)	19, 29
Good mood	33 (80)	27, 39	7.4 (18)	5.0, 11
Apologized for past events	22 (53)	17, 28	6.6 (16)	4.0, 11
Distressed as the patient noticed him/herself talking strangely	21 (51)	16, 27	6.6 (16)	4.0, 11
Said that the patient talked to or met people who had died	18 (44)	14, 24	4.1 (10)	2.0, 7.0

the medical professionals as present with the family; and more likely to report the patient being physically restrained (Table 6).

Compared with the family members who perceived a low-level necessity of improvement, family members who perceived a high-level necessity of improvement were more likely to be young and male; more likely to interpret the causes of delirium as pain/physical discomfort and medication effects; less likely to report that the medical professionals were present with the family, respected the patient's subjective world, explained the expected course along with daily changes, tried to understand what the patient wanted to say, were sufficiently compassionate to the family, had facilitated communication before it became

difficult, and had confirmed the patient's wishes before communication become difficult; and reported a lower score of the family care subscale of the Care Evaluation Scale.

Multiple logistic regression analyses revealed that the independent determinants of high-level distress or high-level necessity of improvement were younger age; male gender; experience of agitation and incoherent speech; interpretation of the causes of delirium as pain/

Table 5
Family-Reported Professional Care Practice for Delirium

	Practiced	95% CI
	% (n)	
Treated patients the same as before	94 (227)	90, 96
Tried to understand what the patient wanted to say	88 (214)	84, 92
Was sufficiently compassionate to the family	86 (208)	81, 90
Explained the expected course along with daily changes	86 (207)	80, 89
Respected the patient's subjective world without denying "incoherent things"	83 (202)	78, 88
Discussed with the family about how to deal with the issue	75 (181)	69, 80
Explained the pathology of delirium (not dementia or psychosis)	72 (175)	66, 78
Was present with the family	71 (173)	65, 77
Facilitated with family members in communicating and being with the patient before it became difficult	68 (164)	62, 73
Explained the universality of delirium	66 (159)	59, 71
Confirmed the patient's wishes before communication became difficult	54 (131)	48, 60
Physical restraint		
Before admission to palliative care units	3.3 (8)	2.0, 6.0
In palliative care units	2.5 (6)	1.0, 5.0

Table 4
Family-Perceived Meaning of Delirium and Interpretations About the Causes of Delirium

	Agree, or Strongly Agree	95% CI
	% (n)	
<i>Meaning of delirium</i>		
Sign of approaching death	59 (143)	53, 65
Trying to express what the patient wanted to do or say	52 (125)	45, 58
Suffering	45 (108)	38, 51
A natural part of the dying process	31 (74)	25, 37
Dream	25 (61)	20, 31
Entering after-death world	22 (54)	17, 28
Relief from actual suffering	22 (53)	17, 28
Happy and welcome experience	7.0 (17)	4.0, 11
<i>Interpretation about the causes of delirium</i>		
Pain or physical discomfort	60 (144)	53, 66
Medication effects	41 (99)	35, 47
Psychosis or "becoming crazy"	19 (46)	15, 24
Mental weakness or death anxiety	15 (37)	11, 20

physical discomfort, medication effects, or mental weakness/death anxiety; and medical staff being present with the family, respecting the patient's subjective world, explaining the expected course along with daily changes, and relieving the family care burden.

Discussion

This is, to our knowledge, the first systemic survey to investigate the potential correlations of the distress levels of families and the perceived necessity of improvement in care related to terminal delirium with family-reported professional care practice, family-reported patient behavior, and perception of the causes of delirium.

This survey revealed that, although a relatively small number of families (5.8%) reported that considerable or much improvement was necessary in the professional care they had received in certified palliative care units, about half of the families reported being very distressed or distressed about the experience of terminal delirium. This figure is relatively low compared with the previous two surveys,^{6,7} but confirms that at least 50% of the families of patients with delirium experienced considerable emotional distress.

The most important finding of this study was the identification of factors associated with the distress levels of families and their perceived necessity of improvement. The chief factors included family experience of agitation, their interpretation of the causes of delirium, and their perception about the care they had received.

Consistent with previous surveys that identified agitation as a significant determinant of family distress,^{6,7} family-reported agitation was an important determinant of family distress in this study. The control of agitation symptoms, therefore, is an important task for palliative care clinicians. This study revealed, however, that ambivalent wishes between symptom control and maintaining communication were the most common emotions of the families. Together with qualitative studies stressing the importance of ambivalent wishes in this situation,^{12,14} clinicians should note that families want not only symptom palliation but also much broader elements of quality of life, such as maintaining cognitive control,

communicating with others, and living as long as possible.^{26,27} That is, clinically, pharmacologically sedative therapy should not be routinely applied to control agitation symptoms without careful individualized considerations, and the depth or duration of sedation should be closely adjusted for each situation.²⁸

Families often interpreted delirium as the consequences of pain/physical discomfort, medication effects, psychosis/"becoming crazy," or mental weakness/death anxiety, and these interpretations were significantly associated with both family distress and necessity of improvement. These findings confirm the great importance of information focusing on the cause and pathologies of delirium (i.e., terminal delirium is usually not an expression of pain, medication effects, "becoming crazy," or mental weakness), as stated in expert literature.^{10,14}

The major care practices related to a family's emotional distress and necessity of improvement included being present with the family, respecting the patient's subjective world, explaining the expected course with daily changes, and relieving the family care burden.

Of special note, as this study suggests, respecting the patient's subjective world can be an important care strategy in terminal delirium. This care strategy was associated with the overall necessity of improvement, and the family members experienced various patient behaviors other than "psychiatric symptoms": the patient expressed physiologic desires, seemed incoherent but talked about actual past events, talked about uncompleted life tasks, and apologized for past events. Consistent with the recommendations of palliative care textbooks,⁸⁻¹¹ these findings suggest that the care strategy for terminal delirium may include exploring and fulfilling unmet physiological needs behind delirium symptoms, and trying to understand the "strange" behavior of delirious patients as a potentially meaningful experience to find a clue for important landmark events and achieve uncompleted life tasks for patients and families.

Among care strategies investigated in this study, only being with the patient was associated with families' emotional distress. This result indicates, as nonempirical literature stresses the importance of "being" for palliative care clinicians,⁸⁻¹¹ being with the families of delirious patients is an essential element of care.

Table 6
Determinants of Family-Reported Emotional Distress and Necessity of Improvement

	Emotional Distress Level				Necessity of Improvement			
	Univariate Analyses		Multivariate Analysis ^a		Univariate Analyses		Multivariate Analysis ^b	
	High-Distress (n = 77)	Low-Distress (n = 165)	Odds Ratio [95% CI]	P	High Necessity (n = 89)	Low Necessity (n = 143)	Odds Ratio [95% CI]	P
<i>Background</i>								
Age (family)	0.85 ± 0.78	0.51 ± 0.69 ^c	1.5 [0.98–2.4]	0.063	55 ± 11	60 ± 14 ^c	0.96 [0.93–0.99]	0.016
Sex (family, female)	1.2 ± 0.72	0.97 ± 0.64 ^c	1.7 [1.0–2.9]	0.042	64% (n = 57)	79% (n = 113) ^c	0.22 [0.096–0.50]	0.001
Sex (patient, female)	1.0 ± 0.83	0.73 ± 0.77 ^c			45% (n = 40)	31% (n = 44) ^c		
<i>Family-reported patient behavior^d</i>								
Agitated behavior								
Incoherent speech								
Talked about uncompleted life tasks	1.2 ± 0.72	0.90 ± 0.76 ^c						
Seemed incoherent but talked about actual past events								
Distressed as the patient noticed	0.49 ± 0.73	0.30 ± 0.53 ^c						
<i>Interpretations of the causes^e</i>								
Pain or physical discomfort	3.0 ± 1.3	2.5 ± 1.2 ^f	1.3 [0.95–1.7]	0.099	2.9 ± 1.2	2.5 ± 1.2 ^c		
Medication effects	2.3 ± 1.2	2.0 ± 1.2 ^c						
Mental weakness or death anxiety	1.6 ± 1.3	1.3 ± 0.94 ^c	1.3 [0.97–1.8]	0.078	2.4 ± 1.1	1.9 ± 1.200 ^f	1.5 [1.1–2.1]	0.014
Psychosis or "getting crazy"	1.6 ± 1.3	1.3 ± 1.1 ^c						
<i>Family-reported professional care^b</i>								
Was present with the family	62% (n = 48)	76% (n = 125) ^c	0.49 [0.23–1.0]	0.068	58% (n = 52)	83% (n = 119) ^c	0.35 [0.12–1.0]	0.053
Respected the patient's subjective world					81% (n = 72)	88% (n = 126) ^c	0.16 [0.019–1.3]	0.088
Explained the expected course					79% (n = 70)	92% (n = 132) ^f	0.13 [0.028–0.64]	0.011
Tried to understand what the patient said					87% (n = 77)	93% (n = 133) ^c		
Was sufficiently compassionate to the family					76% (n = 68)	93% (n = 133) ^c		
Had confirmed the patient's wishes before communication became difficult					44% (n = 39)	64% (n = 91) ^c		

(Continued)

Table 6 (Continued)

	Emotional Distress Level				Necessity of Improvement			
	Univariate Analyses		Multivariate Analysis ^a		Univariate Analyses		Multivariate Analysis ^b	
	High-Distress (n = 77)	Low-Distress (n = 165)	Odds Ratio [95% CI]	P	High Necessity (n = 89)	Low Necessity (n = 143)	Odds Ratio [95% CI]	P
Had facilitated communication before it became difficult					62% (n = 55)	73% (n = 105) ^f		
Relieved the family care burden ^g					6.4 ± 2.5	7.9 ± 2.5 ^e	0.84 [0.73–0.98]	0.025
Physical restraint	10% (n = 8)	3.6% (n = 6) ^c						

^aR² = 0.15.^bR² = 0.37.^cP < 0.05.^dRated as 0 (none), 1 (occasionally), and 2 (often).^eP < 0.001.^fP < 0.01.^gRated as 0 (strongly disagree) to 4 (strongly agree).^hRated as practiced or not.ⁱRated on the family care subscale of the Care Evaluation Questionnaire. Lower score indicates a family-perceived higher necessity of care to relieve the family care burden.

The family-perceived necessity of improvement in care to relieve the family care burden was a significant determinant in the overall family-perceived necessity of improvement. As the family is an important target in palliative care, clinicians should make maximum efforts to relieve the family care burden, through reassuring the families that they can leave the patients' care to the staff, making the hospital environment comfortable for the families, and coordinating support from other members of the family.

Of interest was that this study highlighted some specific emotions evoked by the experience of terminal delirium. In this study sample, the three major emotions were ambivalent wishes, guilt and self-blame, and worry about staying with the patient. As only a few qualitative studies proposed a care strategy to relieve such specific distress,¹⁴ more empirical studies are needed to understand in-depth family emotions related to terminal delirium and explore a specific care strategy.

Despite several strengths, including the success in obtaining a large sample with more than a 70% response rate, this study has some limitations. First, due to its retrospective nature, there might be a recall bias. Second, some families denied the episode of delirium despite a psychiatrically confirmed diagnosis, and might recall episodes other than delirium. Third, as all patients received specialized palliative care, adherence levels to recommended care practice were generally high and might result in low-sensitivity statistical analyses, and the findings could not be automatically generalized to other situations. Fourth, the cross-sectional design of this study cannot allow the causality of the associations identified. Fifth, we excluded 6.7% of the potential respondents with profound emotional distress due to ethical reasons. Finally, what is important for a good death, such as maintaining consciousness and dying during sleep, is different among cultural backgrounds,^{27,29} and the results might not be automatically applied to different cultural settings.

In conclusion, a considerable number of family members experienced high levels of emotional distress and felt some need for improvement of the care for terminal delirium. Control of agitation symptoms with careful consideration of ambivalent family wishes,

information about the pathophysiology of delirium, being present with the family, respecting the patient's subjective world, explaining the expected course with daily changes, and relieving the family care burden can be useful care strategies. Intervention trials to determine the efficacy of these care strategies are needed.

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Terminal delirium: families' experience

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Background: Although delirium is a common complication in terminally ill cancer patients and can cause considerable distress to family members, little is known about the actual experience of family members. The primary aims of this study were thus to explore: (1) what the family members of terminally ill cancer patients with delirium actually experienced, (2) how they felt, (3) how they perceived delirium and (4) what support they desired from medical staff. **Methods:** A single-center in-depth qualitative study on 20 bereaved family members of cancer patients who developed delirium during the last two weeks before death. Content analysis of transcribed text was performed. **Results:** Families experienced various events including other than psychiatric symptoms, such as 'patients talked about events that actually occurred in the past', 'patients were distressed as they noticed that they were talking strangely,' 'patients talked about uncompleted life tasks', and 'patients expressed physiologic desires such as excretion and thirst'. Family emotions were positive, neutral, or negative (eg, distress, guilt, anxiety and worry, difficulty coping with delirium, helplessness, exhaustion and feeling a burden on others). Families perceived the delirium to have different meanings, including positive meanings (eg, relief from real suffering), a part of the dying process, and misunderstanding of the causes of delirium (effects of drugs, mental weakness and pain). Families recommended several support measures specifically for delirium, in addition to information and general support: 'respect the patients' subjective world', 'treating patients as the same person as before', 'facilitating preparations for the patients' death', and 'relieving family's physical and psychological burden'. **Conclusions:** From the results of this study, we generated a potentially useful care strategy for terminal delirium: respect the patients' subjective world, treat patients as the same persons as before, explore unmet physiological needs behind delirium symptoms, consider ambivalent emotions when using psychotropics, coordinate care to achieve meaningful communication according to changes in consciousness levels during the day, facilitate preparations for the patients' death, alleviate the feelings of being a burden on others, relieve family's physical and psychological burden and information support. *Palliative Medicine* 2007; **21**: 587–594

Key words: palliative care; delirium; family; neoplasm; end-of-life care

Introduction

Delirium occurs in 85–90% of terminally ill cancer patients, and persists until death in 50–70%.^{1,2} Therefore, many families spend their last days with delirious patients, and recent studies have demonstrated that this can cause great emotional distress.^{3,4} Thus, understanding the experience of families of delirious terminally ill patients is important to explore effective care strategies.

To date, several empirical studies have explored the experience of delirious patients and their families in the intensive care unit setting and the transient delirium of elderly patients,^{5–10} but there have been few reports on delirium in the terminal stage.^{11–13} One qualitative study revealed various experiences of the families, such as their ambivalent feelings (ie, wish to relieve patient distress but hesitating to use sedative medication), wish for medical information concerning delirium and wish for respect and dignity in patient care.¹¹ Another preliminary study on the effectiveness of psycho-educational intervention for families of delirious terminal patients suggests that advance information could give family members confidence and a sense of security in their communication with patients.¹² However, these studies do not cover the full aspects of the family experience,

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especially the type of support they actually desire from nurses and physicians.

The primary aims of this study were thus to explore (1) what the family members of terminally ill cancer patients with delirium actually experienced, (2) how they felt, (3) how they perceived delirium and (4) what support they desired from medical staff. The ultimate purpose of this study was to obtain in-depth insights to generate a potentially useful care strategy for terminal delirium.

Subjects and methods

Methods

This was a qualitative interview study of the bereaved families of cancer patients who developed delirium during the last two weeks. Semi-structured interviews were performed between September, 2003 and March, 2004 once for each subject for an hour, and the contents were tape-recorded. The interviewers were nurses at Seirei Hospice who had not been involved in direct patient care. In the interviews, questions concerned the actual experience of delirium by the families, their feelings and perceptions of delirium, and family-recommended support provided by medical staff, when the patients had delirium.

Subjects

Primary physicians initially identified potential participants following these inclusion criteria: (1) bereaved family members of an adult cancer patient diagnosed with delirium during the last two weeks on retrospective chart review on the basis of DSM-IV criteria,¹⁴ (2) aged 20 or more and (3) no serious psychological distress recognized. Among 250 families of patients who died at Seirei Hospice between January, 1999 and December, 2000, 184 met the inclusion criteria and cooperation with the study was requested by mail. Of them, 37 families gave consent and were interviewed.

On initiation of the interview, the interviewers confirmed that family members acknowledged that patients had experienced delirium. Delirium was paraphrased as 'the rapid development of difficulty in concentration, forgetfulness, disorientation about time and place, hallucinations and delusions, incoherent speech, clouding of consciousness and difficulty communicating, emotional instability, reversal of daytime and nighttime activities (drowsy during the day and a wake during the night), and inconsistent behavior, with these conditions changing even within a day'. As 17 families denied that the patients had had delirium, 20 family members were finally interviewed. The final sample consisted of 9 men and 11 women who ranged in age from 42 to 75 years, with a mean of 55 years (SD = 9.4). The family relationship to the deceased consisted of 11 spouses, 8 children, and 1 sibling. The patients were 12 men and 8 women and the age

ranged from 58 to 78 years with a mean of 65 years (SD = 11). Primary tumor sites were: lung ($n = 7$), gastrointestinal ($n = 6$), genitourinary ($n = 4$) and others.

Despite a substantial delay between patient death and the interview, we decided to choose this population, because the institutional review board recommended this time-interval to avoid unnecessary emotional burden on the bereaved family. The institutional review board approved the ethical and scientific validity of this study and each participant gave written consent.

Analyses

Content analysis was performed using the transcribed data obtained. First, the parts containing the experience, feelings, perceptions and family-recommended support related to delirium were extracted from the transcriptions using the phenomenological method. Then, two of the authors carefully conceptualized and categorized the contents of the transcription based on similarities and differences. Another two investigators then independently coded whether each transcription included remarks that belonged to any of the attributes according to their definitions. The initial Cohen's kappa coefficients were greater than 0.40 for 26 categories and lower than 0.40 for 7 categories. Finally, the authors jointly reviewed and discussed each coded data set under the supervision of an experienced palliative care specialist (TM) until all discrepancies were resolved.

Results

As shown in Table 1, the data were classified as experience, emotions, perception and support.

Experience of delirium

Family-reported experiences were classified into: Symptoms of delirium as described in the DSM-IV criteria of delirium,¹⁴ and Experiences other than symptoms of delirium.

Symptoms of delirium. Families reported that the patients had decreased consciousness levels ($n = 10$, 50%), communication difficulty ($n = 9$, 45%), inappropriate/agitated behavior ($n = 9$, 45%), hallucination/delusion ($n = 8$, 40%), and unstable mood ($n = 6$, 30%).

Experiences other than symptoms. Besides 'psychiatric symptoms', the families reported various experiences.

Patients talked about events that actually occurred in the past or that they used to do. Five families (25%) noticed that,

Table 1 Categories identified in the interview with bereaved family members

Experience of delirium
Symptoms of delirium
Experiences other than symptoms
Patients talked about events that actually occurred in the past or that they used to do
Patients were distressed as they noticed that they were talking strangely
Patients talked about uncompleted life tasks
Patients expressed physiologic desires such as excretion and thirst
Mental activity was normal in some situations
Emotion
Positive or neutral emotion
Negative emotion
Distress
Guilt
Anxiety and worry
Difficulty in coping with delirium, helplessness and exhaustion
Burden on others
Ambivalent emotion
Perception of delirium
Positive or neutral meanings
Relief from real suffering
Same as usual and dreaming
Part of the dying process
Misunderstanding the causes
Recommended support
Recommended support specifically for delirium
Respect the patients' subjective world
Treating patients the same as before
Facilitating preparations for the patients' death
Relieving families' physical and psychological burden
Information support
Non-specific general recommended support

although what the patients talked about in the episodes of delirium appeared 'strange' to nurses and doctors, it actually related to past real events or the work that the patients used to do.

'Since (the patient) said, "... on the wheelchair ... , on the wheelchair ... , in fact, he was talking about his trip to Korea.' (Bereaved 3)

(The patient) moved her hands like she would do when binding flowers. That was her work. She grew flowers.' (Bereaved 17)

Patients were distressed as they noticed that they were talking strangely. Two families (10%) reported that the patients felt distress as they at times noticed that they were delirious.

'When the patient talked about strange things, he noticed that he was out of his mind and seemed distressed. So, he stopped talking.' (Bereaved 8)

Patients talked about uncompleted life tasks. Six families (30%) experienced patients expressing uncompleted life tasks in the episodes of delirium, such as confessing and apologizing for past events, or aftermath concerns.

'(The patient) was saying, "I am sorry. That was my fault," although I am not sure whom she was saying that to.' (Bereaved 3)

'(The patient) said to his daughter that he was sorry for not having been a good husband and asked her to apologize to his wife for him.' (Bereaved 1)

'(The patient) talked a lot about how to make preparations for the funeral.' (Bereaved 17)

Patients expressed physiologic desires such as excretion and thirst. Three families (15%) saw the patients behaving 'inappropriately' to fulfill their physiologic desires.

'(The patient) suddenly woke up even at night and removed the diapers by himself. I could not initially understand what he wanted, but after he went to the toilet, every time he settled down.' (Bereaved 9) '(The patient) became agitated at night, often saying, "Give me water."' (Bereaved 3)

Mental activity was normal in some situations. Six families (30%) noted that there were changes in the patients' mental activity during the day, and thus the patients could achieve normal mental activity for some periods of the day or with some people.

'(The patient) was not like that all day. When he was sound, he was clear-minded.' (Bereaved 2)

Emotion

Family emotion evoked by the experience of delirium varied from positive or neutral, negative and ambivalent.

Positive or neutral emotion. Seven families (35%) reported positive emotions with the episodes of delirium, such as 'happy', 'relieved', 'not distressing at all', 'feeling bound to the patient', or 'feeling meaningful by staying at the patient's side'. One bereaved person said, 'I was happy to hear such wandering talk, rather than pain or suffering.' (Bereaved 4)

In addition, five families (25%) reported that they just accepted the delirium. One bereaved person said, 'I knew such a condition would occur as the disease advanced, so I accepted it as it was.' (Bereaved 5). Three families (15%) stated that the delirium was just 'mysterious.'

Negative emotion Distress. Fourteen families (70%) expressed some level of distress on seeing delirious patients. They felt distress to see the patient changed from what he was before, being physically restrained, and therefore did not want to have other families see the patient. A bereaved family member said, 'Everything was distressing.' (Bereaved 3)

'My father was once a distinguished person who would always look sharp in a well-tailored suit and be on the stage with a flower in his lapel. So, it was miserable, or rather painful to see him this way.' (Bereaved 3)

'I thought I should never let my daughters see their father behaving like that.' (Bereaved 11)

Guilt. Six families (30%) expressed guilt concerning 'not taking good care of the patient', 'not facing the patient,' 'having driven the patient into a corner' or 'having made the patient fall.'

'I could not be of sufficient help to the patient. I might have been able to maintain a more relaxed relationship with the patient. I blamed myself later.' (Bereaved 3)

Anxiety and worry. Nine families (45%) expressed anxiety and worry that 'they could not leave the patient alone so that s/he might do something unexpected,' 'staying with the patient alone at night,' and 'the soul of the patient was splitting.'

Difficulty in coping with delirium, helplessness and exhaustion. Ten families (50%) expressed difficulty in coping with delirium, helplessness and exhaustion, such as 'difficult to accept,' 'I made an effort to persuade myself it was real,' 'not sure what was happening,' 'at a loss how to deal with it,' 'I wanted to escape from reality,' and 'so exhausted both physically and mentally.'

'I had no idea what was happening. That was my honest feeling.' (Bereaved 16)

'I was at a loss what to do. I thought the situation was out of control.' (Bereaved 3)

'Honestly, I wished to kill (the patient) by choking her and kill myself. Just hearing those cries wore me out.' (Bereaved 16)

Burden to others. Five families (25%) expressed their emotional burden, because they felt the patient had become a burden on others.

'The nurses told the patient that, if he stayed in a large room, the roommates would be disturbed if he had those attacks. It must have been disturbing to others.' (Bereaved 1)

'The patient made a lot of noise at night. The person in the next bed was also very sick, and I felt sorry for him.' (Bereaved 12)

Ambivalent emotion. One family referred to ambivalent wishes that the patient would remain conscious but at the same time sleep or die in peace, saying that 'I certainly wanted the patient to live longer, but it was also true that I felt the patient should be quickly relieved of this horrible situation.' (Bereaved 16)

Perception of delirium

Families perceived the delirium as having different meanings, including positive or neutral meanings, a part of the dying process and misunderstanding of the causes.

Positive or neutral meanings.

Relief from real suffering. Six families (30%) believed that delirium alleviated physical and psycho-existential

suffering of the patient, and interpreted the state as a comfort to the patient.

'The patient said he had been out having fun or met such and such people. Maybe, he forgot his pain and suffering while he was talking. He was relaxed, being able to talk like that.' (Bereaved 4)

Same as usual and dreaming. Four families (20%) thought that the patients were the same as usual even when they were delirious, saying '(the patient) had always had a bad temper, so I felt nothing about it.' (Bereaved 3)

Three families (15%) interpreted the symptoms of delirium as dreaming.

Part of the dying process. Fourteen (70%) families referred to delirium as part of the dying process; families recognized delirium as a sign that death was approaching, a natural part of the dying process, or a transcendence experience (ie, the patient visiting the next world).

'We had been told about the signs that many patients show before death. So, we felt it was about time.' (Bereaved 19)

'The patient died naturally as she was drowning. So did my brother. I understand it as a natural thing.' (Bereaved 13) 'I felt that the patient would be able to go to the next world, because he had someone to guide him.' (Bereaved 9)

Misunderstanding of the causes. Nine (45%) families attributed the causes of delirium to the effects of drugs, mental weakness and death anxiety, or pain and physical distress, without physicians' confirmation.

'Was it morphine? I thought it was a symptom caused by such drugs.' (Bereaved 20)

'I wondered if the patient became more and more like that, because of fear of death as a human being.' (Bereaved 16)

'I wondered if it was because the patient was in pain.' (Bereaved 12)

Recommended support

We identified four family-recommended support activities specifically for delirium and information support and four few general support.

Recommended support specifically for delirium.

Respect the patients' subjective world. Six families (30%) wanted the staff not to correct or deny the patients' 'unrealistic' remarks, but to try to understand what they wanted to say and respect what they experienced.

'When, for example, the patient says, "I have just been on an airplane. It was a pleasant flight," and if a nurse responds, "Weren't you cold? Be careful not to catch cold," it's good to give positive responses. But if a nurse

says, "No, this is a hospital," it ruins everything.' (Bereaved 4)

Treating patients the same as before. Four families (20%) wished the patients, even when they had delirium, to be treated with respect for their past lives and uniqueness, and to be treated as individuals, not as a 'delirious patient,' 'child,' or 'object.' A bereaved person additionally referred to the loss of dignity in using physical restraints.

'The staff treated the patients according to what kind of people they were: for a person in a high position, with the right attitude to ward such a person, and for a craftsman, with the right attitude to ward such a person.' (Bereaved 3)

Facilitating preparations for the patients' death. Three families (15%) reported they were supported by the in-advance advice from medical professionals to prepare for the patients' death, such as confirming the patients' preference about end-of-life care or to complete unfinished tasks before delirium.

'They advised us that the patient's consciousness would begin to decrease at such and such a time, so please be prepared. It was very important for us that we had enough time to say what we had to say to the patient.' (Bereaved 2)

Relieving family's physical and psychological burden. Seven families (35%) listed care strategies to relieve the family's physical burden as helpful, such as 'leave the physical care to hospital staff,' 'facilitating support from other family members,' 'good environment for the family to stay,' and 'encouraging families to maintain their normal daily activities.'

Five families (25%) reported they obtained comfort from medical professionals who reassured the families that they were doing their best and the right things.

'Since the staff did so well, we left everything to them with great trust.' (Bereaved 10)

'(On the general ward), nurses told us that they could not take care of the patient if she got excited, and insisted that we look after the patient.' (Bereaved 1)

'Since we were more worried about what would become of us after my father's death, we had to maintain our daily routine. They understood our situation, and even told us we would not have to look after him everyday.' (Bereaved 3)

'I felt reassured when I was told, "You are not wrong," "You will feel better that way," or "That is the best way."' (Bereaved 4)

Information support. Twelve families (60%) reported that good information was very helpful. The helpful information included the causes, pathologies (consciousness disturbance), possible treatments, expected course (eg, imminent death), how to treat the patients and the universality of delirium.

'Without understanding the cause of hallucination, we wondered if the patient had lost her soul, and we simply stopped talking, not being able to talk any longer.' (Bereaved 8)

'Whatever the outcome may be, the most worrying thing is the uncertainty of what will happen. So, I think we can feel more assured if we are informed in advance what drugs will be used if symptoms worsen.' (Bereaved 2)

'We had been told in advance that death was close. It was hard at that time, but I appreciated being informed.' (Bereaved 19)

'I was not sure how I should talk to the patient, but the nurses showed me how loud we should talk into the patient's ears. That was helpful.' (Bereaved 2)

'The phrase, "Everybody is like this toward the end," made me feel a lot better.' (Bereaved 16)

Concerning the helpful timing of information, they wished for information at appropriate points depending on changes in the patients' condition by medical staff before asking, easily understood information, an atmosphere they could feel easy to ask questions, and being reassured to be able to discuss mental or spiritual issues.

'It was helpful that, now and then, they explained the latest condition very well.' (Bereaved 14)

'We can talk to the doctor about pain, but we cannot consult with him about matters like hallucinations or the soul.' (Bereaved 8)

Non-specific general recommended support. Non-specific general recommended support by the families included: symptom control ($n = 7, 35\%$), human attitude of the medical staff, such as friendliness, sincerity, cheerfulness, warmth, professional pride and genuine regard ($n = 7, 35\%$), high-quality professional care ($n = 6, 30\%$; 'professional psychiatric and palliative care', 'do everything they could do'), prompt response and excellent teamwork ($n = 6, 30\%$), and good environment ($n = 2, 10\%$; private and comfortable room). A bereaved family stated, 'nurses were always close to the patient and talked to us, and the doctor would also come quickly whenever wanted. That was the best.' (Bereaved 5)

Discussion

This is, to our best knowledge, the first systematic study to explore the actual experiences of the family members of cancer patients with terminal delirium, what they felt, how they perceived delirium and what support they desired. This study suggests large variations in the experience of families concerning terminal delirium, their emotions, perceptions and support they desired. Therefore, in the care of terminal delirium, it could be of great importance to provide care tailored to the individual needs of each patient and family. From the results of this study, we generated a care strategy for

terminal delirium: respect the patients' subjective world, treat patients the same as before, explore unmet physiological needs behind delirium symptoms, consider ambivalent emotions when using psychotropics, coordinate care to achieve meaningful communication according to changes in consciousness levels during the day, facilitate preparations for the patients' death, alleviate the feelings of being a burden on others, relieve the family's physical and psychological burden and information support.

Respect the patients' subjective world

This recommendation is important because (1) the families noticed that, during episodes of delirium, the patients talked about events that actually occurred in the past, talked about uncompleted life tasks, and were distressed when they noticed that they were talking strangely, (2) some families and patients experienced delirium with positive emotions and meanings and (3) the families directly recommended respect for the patients' subjective world. These results indicate that, if medical professionals aim to understand the 'strange' behavior of delirious patients as a potentially meaningful experience of patients and families, they may find a cue to share important landmark events with patients and family members, and achieve uncompleted life tasks. In addition, although intentional correction of patient orientation is often recommended in psychiatric literature,^{15,16} this study suggests that repeated correction of patients' 'misconceptions' might ignore patient dignity, because terminal delirium is intrinsically untreatable and patients are often distressed to notice their 'symptoms' of delirium. Rather, efforts to allow the patients to stay in their subjective world, for example, not asking the time or place, might be appropriate for at least some patients.

Treat patients the same as before

This recommendation is based on the families' suggestion that, even when patients have delirium, they should be treated with respect for their past lives and uniqueness as individuals. This finding is consistent with a study on bereaved family members of sedated patients that identified 'to treat unconscious patients with dignity' is an essential care.^{17,18} Treating a patient as a unique individual is a basic principle in palliative care, and it should be more stressed in the care of delirium, because families see the 'same' individual through 'delirious' patients.

Explore unmet physiological needs behind delirium symptoms

This recommendation is based on the families' observation that patients behaved 'inappropriately' to fulfill their physiologic desires. Palliative care textbooks stress the importance of urinary retention and fecal impaction as aggravating

factors of agitated delirium.¹⁹⁻²¹ This study confirms these experts' recommendations, and suggests that general physiologic unmet needs, such as the wish to drink, eat, to be cleaned and take a bath may be remediable elements of terminal delirium.

Consider ambivalent emotions when using psychotropics

Some families reported ambivalent emotions as to whether the patients should remain conscious but at the same time sleep or die in peace. This finding is consistent with a preliminary finding.¹¹ Clinicians should note that patients and families want not only symptom palliation but also much broader elements of quality of life, such as maintaining cognitive control, communicating with others and living as long as possible.²²⁻²⁴ Clinically, if symptomatic sedation is applied, the depth and duration of sedation should be closely adjusted for each situation.

Coordinate care to achieve meaningful communication according to changes in consciousness levels during the day

This is recommended on the basis of the families' observation that mental activity was normal in some situations. This indicates daily changes in symptoms of delirium, as well-described in psychiatric literature.¹⁹ In palliative clinical care situations, this phenomenon encourages clinicians to carefully monitor the patterns of changes in the patients' consciousness levels and allow the families to communicate with patients in a relatively good state of consciousness.

Facilitating preparations for the patients' death

This recommendation is based on the families' suggestion that advance advice from medical professionals to prepare for the patients' death, such as confirming the patients' wishes or completing unfinished tasks before delirium, was useful, and actually many families perceived delirium as a part of the dying process. Previous studies about palliative sedation therapy revealed that the family burden in participating in decision making instead of patients, and insufficient consideration to provide an opportunity to say important things to patients before sedation was a source of great distress.^{17,18} These findings indicate that coordinating opportunities for families to communicate sufficiently with patients before they develop delirium, confirm the patients' preference in end-of-life care, and ensure a chance to give thanks and say good-bye, is important for palliative care clinicians.²²⁻²⁴

Alleviate the feelings of being a burden on others

Some families reported that feeling a burden on others was a distressing aspect of agitated delirium. Therefore,

clinicians should alleviate the family feelings of being a burden on others by modifying the environment (eg, transfer to a private room), not directly saying 'the patient can disturb other patients,' and stressing the universality of delirium.

Relieving families' physical and psychological burden

This recommendation is important because (1) many families reported negative feelings such as distress, guilt, anxiety, difficulty in coping with delirium, helplessness and exhaustion, and (2) families themselves listed this as a useful care strategy. The family is an important target in palliative care, and, in terminal delirium, clinicians should give intensive care to family members, not only patients. Care strategies can include: reassuring the families that they could leave the patients' care to the staff, making the hospital environment comfortable for the families, and coordinating support from other members of the family, reassuring them that they did their best and the right things, and allowing them to share information with other families undergoing a similar experience.

Information support

Information needs are a well-established concept, and a significant indicator of patient and family satisfaction with palliative care.²⁵ This study especially highlights misunderstandings about the causes of delirium, as well-documented in non-empirical literature.²⁰ Many family believed the patients developed delirium due to opioids, mental weakness and death anxiety or physical pain. These findings therefore stress the importance of information focusing on the cause, pathologies and the universality of delirium.

Limitations and conclusion

This study has several limitations. First, the subjects were recruited from a single institution. Second, the interviews were held a considerably long time after the actual experience, and some families denied the episodes of delirium. This suggests the possibility of recall bias, but we believe the use of DSM-diagnosis of delirium, ie, inclusion of hypoactive delirium, could lead to under-recognition of delirium by lay persons, and recall bias had minimal influence on the conclusion of this study. Finally, this is a qualitative study on a small number of subjects, and the generalizability of the findings should be explored in a future study.

In conclusion, this study revealed the experience of families concerning terminal delirium, their emotions and perceptions, and the support they desired. The clinical efficacy of potentially useful interventions generated from this study should be tested in future.

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Burnout and psychiatric morbidity among physicians engaged in end-of-life care for cancer patients: A cross-sectional nationwide survey in Japan

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Abstract

Purpose: To determine the prevalence of burnout and psychiatric morbidity among physicians engaged in end-of-life care for cancer patients in Japan and to explore associated factors related to end-of-life care.

Methods: Questionnaires were mailed to 1436 Japanese clinical oncologists and palliative care physicians with a request to complete the Maslach Burnout Inventory (MBI), the General Health Questionnaire (GHQ-12), and to report on individual factors, including confidence in patient care. High levels of burnout and psychiatric morbidity were identified using cut-off scores of the MBI and GHQ-12.

Results: A total of 697 physicians returned the questionnaires (response rate, 49.6%). Twenty-two percent of the respondents had a high level of emotional exhaustion, 11% had a high level of depersonalization, 62% had a low level of personal accomplishment, and 20% had psychiatric morbidity. Clinical oncologists showed a significantly higher psychiatric morbidity than palliative care physicians. Confidence in having sufficient time to communicate with patients was significantly associated with all the burnout subscales.

Conclusions: A low level of personal accomplishment was relatively high among Japanese physicians compared with previous studies. Insufficient confidence in the psychological care of patients was associated with physician burnout rather than involvement in end-of-life care. Copyright © 2006 John Wiley & Sons, Ltd.

Keywords: burnout; psychiatric morbidity; physician; end-of-life care; Japan

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Introduction

Burnout is a psychological state resulting from a prolonged period of high stress levels. Unlike a major depressive disorder, burnout is a distinct work-related stress syndrome and is often defined by the three components of emotional exhaustion, depersonalization, and diminished personal accomplishment [1,2]. Burnout occurs most frequently in those whose work requires an intensive involvement with people, including medical staff such as physicians.

Several studies have suggested that physicians engaged in end-of-life care are more likely to burnout because they may experience multiple stressors including a sense of failure or frustration when a patient's illness progresses [3,4], feelings of powerlessness against illness and its associated losses [3], role conflicts and ambiguity [5], and the

failure to enable a good death [6]. According to the first report on burnout conducted via a random survey of 1000 American oncologists in 1991 [4], 56% of the 598 respondents reported having experienced burnout in their professional lives. To our knowledge, a few studies [7–13], including one nationwide study in the UK [12], have determined the prevalence of burnout among oncologists using the Maslach Burnout Inventory (MBI) [1], a standardized measure of burnout. According to these studies [7–13], oncologists or palliative care physicians were not at any greater risk of burnout, compared with other physicians, but approximately one third of them reported high levels of burnout and psychiatric morbidity. On the other hand, a nationwide study on the prevalence of burnout and psychiatric morbidity has never been conducted in Japan either among physicians or oncologists.

Physician burnout is a serious issue because of its crucial consequences for patient care: For example, depersonalization is associated with suboptimal patient care [14] and decision making in end-of-life care, such as physician-assisted suicide or euthanasia [15,16]. Moreover, oncologists with higher levels of emotional exhaustion were more likely to choose a deep-sedation treatment option in a hypothetical scenario presented to them than those with lower levels of emotional exhaustion [17]. In addition, oncologists have reported that patient care such as being involved in emotional distress or physical suffering is often a source of job stress [18,13]. Nevertheless, end-of-life care has a two-sided nature: it can be stressful if done badly, but rewarding if done well [19–21,13]. As described above, end-of-life patient care is estimated to be closely related with oncologist burnout and psychiatric morbidity, however, little is known about the association between them. Therefore, to develop strategies to alleviate physician burnout and psychiatric morbidity, we attempted in the present study to investigate physicians' involvement and confidence in patient care as factors associated with the prevalence of physician burnout and psychiatric morbidity.

The purpose of this study was to determine the prevalence of burnout and psychiatric morbidity among physicians engaged in end-of-life care for cancer patients in Japan and to explore associated factors related to end-of-life care.

Methods

Respondents and Procedure

This is a secondary analysis of our previous study [17] on the practices and attitudes of Japanese physicians concerning terminal sedation. We enrolled physicians who were clinical oncologists or palliative care physicians such as those who were engaged in end-of-life care for cancer patients in Japan. One source was a list of physicians from the Japanese Association of Clinical Cancer Centers, as a sample of clinical oncologists. The other source was a list of physicians from the Japanese Association of Hospice and Palliative Care Units, as a sample of palliative care physicians. Twenty-six institutions from a total of 27 hospitals that belonged to the Japanese Association of Clinical Cancer Centers and the Japanese Association of Hospice and Palliative Care Units approved the study. In February 2000, we mailed the questionnaire to 1436 eligible physicians. The inclusion criteria were: (1) being an attending physician whose specialty was primarily responsible for the care of terminally ill cancer patients, (2) having actual experience in oncology or palliative care, and (3) being unaffiliated with this study project.

Questionnaire

Burnout: The Maslach Burnout Inventory (MBI) [1] is a self-administered questionnaire consisting of 22 items using a 7-point Likert-type scale (possible range, 0–6) that measures the three subscales of burnout syndrome: emotional exhaustion (9 items), depersonalization (5 items), and personal accomplishment (8 items). A high level of burnout was defined as a high level of emotional exhaustion (upper third, score of 27 or higher), a high level of depersonalization (upper third, score of 10 or higher), and a low level of personal accomplishment (lower third, score of 33 or lower) based on normative data from a sample of American health professionals (physicians and nurses) [1]. We used these cut-off scores to compare the prevalence of burnout in this study with that of previous studies in oncologists [7–13]. The psychometric properties of the Japanese version of the MBI are controversial [22] and because of this we performed reliability and validity testing on our study data ourselves. The reliability of the Japanese version of the MBI [23] was evaluated by calculating the Cronbach's alpha coefficients: emotional exhaustion, depersonalization, and personal accomplishment were 0.87, 0.68, and 0.88, respectively. Discriminant validity was evaluated by calculating the Pearson's correlations coefficients of the inter-subcales of the MBI: emotional exhaustion and depersonalization ($r=0.50$, $p<0.01$), emotional exhaustion and personal accomplishment ($r=-0.04$, $p=0.39$), and depersonalization and personal accomplishment ($r=-0.17$, $p<0.01$). Convergent validity was evaluated by calculating the Pearson's correlations coefficients of the total score of GHQ-12 and emotional exhaustion ($r=0.44$, $p<0.01$), depersonalization ($r=0.28$, $p<0.01$), and personal accomplishment ($r=-0.18$, $p<0.01$). We considered these results were satisfactory and allowed the MBI results to be included in further analyses.

Psychiatric morbidity: The General Health Questionnaire 12-item version (GHQ-12) [24] is a self-administered questionnaire designed to screen for non-psychotic psychiatric morbidity, it is well validated including the Japanese version [25–27] and has been widely used in samples of healthcare professionals. It measures 12 symptoms of psychiatric morbidity (e.g. depression, loss of confidence, sleep disturbance). Each item is scored as 0 (less or no more than usual) or 1 (rather or much more than usual), giving a maximum total score of 12. Scores above a threshold of 4 or more are regarded as indicating psychiatric morbidity. This approach has been recommended by the developer of this scale [28] and has been shown to be applicable to the Japanese version [29]. We used it to compare the prevalence of psychiatric morbidity in this study with that reported in previous studies for oncologists [8–13].

Individual factors: We included physician characteristics and other individual factors in the questionnaire (available from the authors) that was developed for our previous study [17] to identify physicians' attitudes toward terminal sedation for cancer patients: the questionnaire was developed after a systematic literature review and discussions by an expert panel. Strength of religious belief was assessed by 3 items using a 5-point Likert-type scale (possible range, 1 to 5—with a higher score indicating greater strength). Involvement in end-of-life care during the past year was assessed by 3 items using a 4-point Likert-type scale (possible range, 1 to 4—with a higher score indicating greater involvement) Confidence in the physical or psychological care of patients were assessed by 5 items each using a 5-point Likert-type scale (possible range, 1 to 5—with a higher score indicating greater confidence).

Statistical Analysis

We first calculated the Cronbach's alpha coefficients for the subscales: strength of religious belief (0.89), involvement in end-of-life care (0.88), confidence in the physical care of patients (0.77), and confidence in the psychological care of patients (0.75). Because of its excellent internal consistency, we used these as a single subscale to compare physician characteristics between two practice settings (clinical oncologists versus palliative care physicians). To compare the prevalence of burnout and psychiatric morbidity between two practice settings, we performed chi-square tests. To examine the association between high levels of burnout and psychiatric morbidity, high levels of burnout were entered as independent variables into a multivariate logistic regression analysis. To explore the association with total scores of MBI and GHQ-12, all individual factors were entered as independent variables into a multivariate linear regression analysis using forced entry.

In all statistical evaluations, *p* values of 0.05 or less were considered significant; all reported *p* values were two-tailed. SPSS ver.12.0J statistical software for Windows (SPSS Japan Institute Inc, Tokyo, Japan) was used to perform all statistical analyses.

Results

Physician characteristics

Of the 1436 physicians to whom questionnaires were mailed, 550 physicians responded within 1 month and 179 responded after a reminder. Thirty-two responses did not meet the eligibility criteria, so 697 responses were finally analyzed (49.6% effective response rate, 697 of 1404). The responses were obtained from 560 (43%) of the 1306

physicians working at medical centers for cancer and adult disease and from 87 (67%) of the 130 physicians working at hospices or palliative care units. The data on 50 missing values indicated the data on physicians whose practice settings were unknown. The physician characteristics are summarized in Table 1. The respondents were 28–69 years of age (mean \pm S.D., 45 ± 8.2), with 0.5–40 years of oncology experience (mean \pm S.D., 16 ± 8.1). When the two practice settings were compared, the clinical oncologists had a higher proportion of male physicians (95% versus 87%, $p < 0.01$), more years of oncology experience (mean \pm S.D., 16 ± 7.9 versus 12 ± 7.6 , $p < 0.01$), less religious beliefs (mean \pm S.D., 2.8 ± 0.9 versus 3.6 ± 1.0 , $p < 0.01$), less involvement in end-of-life care (mean \pm S.D., 1.4 ± 0.4 versus 3.3 ± 0.9 , $p < 0.01$), less confidence in the physical care of patients (mean \pm S.D., 3.0 ± 0.7 versus 3.5 ± 0.8 , $p < 0.01$), and less confidence in the psychological care of patients (mean \pm S.D., 2.8 ± 0.6 versus 3.3 ± 0.7 , $p < 0.01$) than palliative care physicians.

Prevalence of burnout and psychiatric morbidity

The prevalence of burnout and psychiatric morbidity are shown in Table 2. Compared with American normative data, the proportions of physicians with high levels of emotional exhaustion (22 versus 33%) and depersonalization (11 versus 33%) were lower, while the proportion of physicians with a low level of personal accomplishment (62 versus 33%) was much higher. Psychiatric morbidity was 20% among all the physicians who responded. When we compared the data for the two practice settings, the clinical oncologists showed a significantly higher prevalence of psychiatric morbidity (21 versus 12%, $p = 0.05$), and a higher proportions of physicians with low levels of personal accomplishment (65 versus 53%, $p = 0.05$), compared with palliative care physicians.

We next examined the association between high levels of burnout and psychiatric morbidity, as shown in Table 3. A high level of emotional exhaustion ($p < 0.01$) and a low level of personal accomplishment ($p < 0.01$) were significantly associated with psychiatric morbidity. On the other hand, a high level of depersonalization ($p = 0.21$) was not significantly associated with psychiatric morbidity.

Factors associated with total scores of MBI and GHQ-12

The associations between individual factors and total scores of MBI and GHQ-12, as determined using a multivariate linear regression analysis, are shown in Table 4. Among the items for physician confidence in the psychological care of patients, having sufficient time to communicate with patients