

Table 2

Correlations between demographic data, alexithymia, depression, and complicated grief for the seriousness of complicated grief.

	1	2	3	4	5	6	7	8	9	Mean	SD
1 Age	1.000	-.054	-.014	-.049	-.012	.024	.046	-.069	-.029		
2 Sex	-.073	1.000	-.060	.175*	-.123	-.049	-.125	-.103	.106		
3 Primary caregiver	-.119**	-.191***	1.000	.185**	.098	.000	-.019	.149*	.002		
4 Expected death	.007	.055	.041	1.000	-.044	.051	-.014	.036	.150*		
<i>Alexithymia</i>											
5 Difficulty identifying feelings	.040	-.003	.059	-.009	1.000	.650***	.415***	.582***	.132*	16.24	5.63
6 Difficulty describing feelings	.005	-.063	.056	-.048	.618***	1.000	.473***	.447***	.143*	14.82	2.87
7 Externally oriented thinking	-.023	-.062	.039	.006	.340***	.360***	1.000	.301***	-.062	24.43	3.19
<i>Psychological distress</i>											
8 Depression	-.034	.040	.033	-.035	.529***	.416***	.200***	1.000	.211***	10.89	4.21
9 Complicated grief	.021	.053	-.118**	.122**	.187***	.121**	.043	.190***	1.000	3.01	2.17

Above = the high risk group of complicated grief (n = 243) and below = the low risk group of complicated grief (n = 705).

\* p &lt; .05.

\*\* p &lt; .01.

\*\*\* p &lt; .001.

addition, those who have a higher extent of alexithymia may not suffer from complicated grief when they experience bereavement with significant others, and those who suffer from complicated grief may not experience clinical increases in alexithymia. Because alexithymia had been found to influence patient's response to psychotherapy (McCallum et al., 2003; Taylor, 2000), this result was attention-provoking.

The difference between these mechanisms may be due to the lack of a correlation between complicated grief and alexithymia in the high risk group. Lipsanen et al. (2004) found that there is a very low distress level that accompanies the alexithymia factor based on the minimal correlation between alexithymia and GHQ (General Health Questionnaire) distress scores. The items of complicated grief described the daily distress following the experience of bereavement. This lack of a relationship with alexithymia may reflect the extent of emotional distress and that there are different mechanisms underlying the symptoms of alexithymia and complicated grief. Therefore, the extent of alexithymia may not significantly influence complicated grief. In regards to patients' characteristics that relate to complicated grief, previous research has

found a significant influence of attachment style, especially insecure attachment. Shear and Shair (2005) discussed complicated grief in relation to separation anxiety, attachment style and grief process. These other factors of attachment style may contribute to research that aims to understand and improve complicated grief. Further research is necessary concerning the factors that relate to or influence complicated grief.

The results that alexithymia was significantly related to general depressive symptom and the differing relationships of alexithymia with complicated grief and general depressive symptoms were supported by previous research (Lipsanen et al., 2004; Ogrodniczuk et al., 2005). The difference between the relationships suggests that improvements in alexithymia will influence improvements in general depressive symptom, but not complicated grief. However, Zygmunt et al. (1998) reported that improvements in complicated grief were correlated with improvements in depressive symptoms. Following the suggestion of Zygmunt et al. (1998), it is possible that improvements in alexithymia are indirectly related to improvements in complicated grief through improvements in general depressive symptoms. The observed correlation between depressive symptoms and complicated grief in the present results might indicate a similarity between the constructs. Therefore, although there are distinctions between these constructs in phenomenology, psychophysiology, and responses to treatment (Lichtenthal et al., 2004), the correlation between them and the relationship between alexithymia and depressive symptoms might be considered in the treatment of

Table 3

The fit indices and AIC of each model.

	$\chi^2$	df	p	RMR	GFI	AGFI	CFI	RMSEA	AIC
Model 0	31.031	8	.000	.328	.987	.952	.978	.055	75.031
Model 1	32.766	10	.000	.388	.987	.960	.978	.049	72.766
Model 2	33.790	9	.000	.365	.986	.953	.976	.054	75.790
Model 3	35.409	11	.000	.420	.985	.960	.976	.048	73.409
Model 4	33.520	11	.000	.467	.986	.963	.978	.047	71.520
Model 5	35.866	12	.000	.487	.985	.963	.977	.046	71.866

Model 0: all parameters are different between two groups.

Model 1: the path coefficients of the latent variable of alexithymia to observed variables are equal.

Model 2: the path coefficients of the latent variable of psychological distress to observed variables are equal.

Model 3: in addition to Model 1, the path coefficients of the latent variable of psychological distress to observed variables are equal.

Model 4: in addition to Model 1, the path coefficient of alexithymia to psychological distress is equal.

Model 5: in addition to Model 3, the path coefficient of alexithymia to psychological distress is equal.

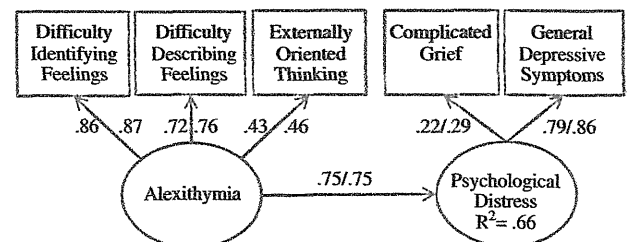


Fig. 2. The standardized path coefficients in model 4. Left coefficients: the low risk group of complicated grief (n = 705), Right coefficients: the high risk group of complicated grief (n = 243).

complicated grief. The current research was cross-sectional and, therefore, causality could not be determined and further research is necessary.

Limitations of the present study are as follows. First, the present study used a cross-sectional design. Therefore, alternative explanations are possible. In daily life, individuals who have a strong tendency to experience psychological distress may experience more alexithymic symptoms, resulting in greater psychological distress. These psychological aspects may exacerbate each other in a downward-spiral fashion. We cannot determine a causal relationship among these psychological variables. It is necessary to conduct further research with a longitudinal design to clarify causality. The second limitation is that the results cannot be generalized to a clinical population because the number of participants in the high risk of complicated grief group was insufficient and the data solely depended on the participants' self-report.

The current study has several limitations that must be considered; however, the study may have implications in the treatment of complicated grief. Further clinical and research attention will help researchers and clinicians better understand patients' complicated grief and, therefore, will help design and evaluate interventions for clinical patients with complicated grief.

#### Role of funding source

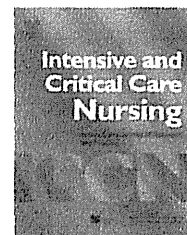
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#### Conflicts of interest

All authors declare that they have no conflicts of interest.

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ORIGINAL ARTICLE

# Development of a scale for ‘‘difficulties felt by ICU nurses providing end-of-life care’’ (DFINE): A survey study

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## KEYWORDS

Intensive care unit;  
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Scale development

## Summary

**Objectives:** To develop a scale for assessing ‘‘difficulties felt by intensive care unit (ICU) nurses providing end-of-life care’’ (DFINE).

**Design and setting:** A questionnaire survey of nurses in ICUs at general hospitals in the Kanto region, Japan.

**Main outcome measures:** The scale was evaluated by exploratory factor analysis, calculation of Cronbach’s  $\alpha$  and test–retest reliability. The Frommelt Attitudes Toward Care of the Dying Scale (FATCOD-B-J) and the Nursing Job Stressor Scale (NJSS) were used to investigate concurrent validity.

**Results:** Respondents were 224 ICU nurses (response rate, 78%) at 18 hospitals. Five factors comprising 28 items were identified, involving difficulties related to: ‘‘the purpose of the ICU is recovery and survival’’; ‘‘nursing system and model nurse for end-of-life care’’; ‘‘building confidence in end-of-life care’’; ‘‘caring for patients and families at end-of-life’’; and ‘‘converting from curative care to end-of-life care’’. Cronbach’s  $\alpha$  for each factor ranged from 0.61 to 0.8. In terms of test–retest reliability, intraclass correlations for each factor ranged from 0.62 to 0.72. ‘‘Building confidence in end-of-life care’’ in DFINE showed a negative correlation with ‘‘positive attitudes towards caring for dying patient’’ in the FATCOD-B-J ( $r = -0.4$ ). ‘‘Nursing system and model nurse for end-of-life care’’ in DFINE showed a positive correlation with ‘‘conflict with other nursing staffs’’ ( $r = 0.32$ ) and ‘‘conflict with physicians/autonomy’’ ( $r = 0.31$ ) in the NJSS.

**Conclusion:** DFINE demonstrated acceptable reliability and validity. However, additional surveys need to be conducted with a larger sample to further characterise the scale.

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## Introduction

In recent years, one of the issues under debate in the Japanese Society of Intensive Care Medicine has been end-of-life care in the intensive care unit (ICU) (Gando and Marukawa, 2009). Within the Society, there has been an initiative to create "End-of-Life Care Guidelines" that incorporate criteria for suspension of treatment, but these have not yet been conclusively determined. In Japan, the law and the difficulty of knowing the will of the patient make it difficult to develop criteria for withholding or withdrawing treatment (Gando and Marukawa, 2009). At the same time, many nurses have doubts about excessive treatment to prolong life in ICU settings (Kinoshita, 2009).

Previous research outside Japan has demonstrated obstacles to undertaking end-of-life care, showing how nurses experience a sense of loss when faced with death in the ICU (Eastham, 1990; Isaak and Paterson, 1996) and how they experience feelings of conflict and distress at futile therapy (Badger, 2005; Meltzer and Huckabay, 2004; Palda et al., 2005; Sawatzky, 1996). Reports are being published related to the grief and burnout that may be experienced by nurses when patients die (Embriaco et al., 2007; Shorter and Stayt, 2010). At the same time, many recent reports have examined the importance of the nurses' role when treatment is withdrawn in the ICU (Hov et al., 2007; Latour et al., 2009) and the contribution of nurses to good care (Beckstrand et al., 2006; Bratcher, 2010; Kongsuwan and Locsin, 2009). Similarly, our own survey results have indicated ways in which some experienced ICU nurses realise the importance of cooperating and maintaining good relationships with doctors and intervening with them in order to establish a good environment for end-of-life care (Kinoshita et al., 2009). However, since nurses do not have the authority to make decisions about treatment, many nurses cannot express their opinions about treatment to doctors, yet are troubled by the implementation of end-of-life care (Kinoshita, 2009).

Within this context, assessments of the views of ICU nurses regarding difficulties in the practice of end-of-life care could contribute to improved care through the clarification of issues involving nurses themselves and end-of-life care in their establishments. However, research related to ICU end-of-life care and nurses remains very limited in Japan and no questionnaires are available to assess the difficulties felt in the implementation of end-of-life care. Outside of Japan, the 25 items identified by Kirchhoff and Beckstrand (2000) resembled the items included in the scale in this study, although some items were not relevant to Japan, so unmodified application was not feasible.

The aim of the present study was to develop a scale to measure the feelings and emotions of ICU nurses regarding the difficulties of implementing end-of-life care, as well as their understanding of the causes of difficulties felt in ICU end-of-life care.

## Methods

### Definition of terms

End-of-life: the period before death when it is thought that no effect can be expected from intensive or life-extending

Table 1 Preliminary domains for "difficulties felt by ICU nurses providing end-of-life care".

1. The purpose of ICU is recovery and survival.
2. Time and/or nursing staff for end-of-life care.
3. Education and nursing system for end-of-life care.
4. Model nurses in providing end-of-life care.
5. Building confidence in end-of-life care.
6. Caring for patients.
7. Caring for families.
8. Physicians' attitudes about end-of-life.
9. Converting from curative care to end-of-life care.

therapies in the ICU and that death cannot be avoided. The end-of-life period is not determined primarily by the physician, but includes the time when nurses themselves recognise that it is the final phase.

End-of-life care: care provided by nurses to the patient and family with the recognition that the patient is facing death.

Difficulties felt by ICU nurses providing end-of-life care (DFINE): the feeling that end-of-life care is difficult and the accompanying negative emotions during situations of death or end-of-life in the ICU. In addition, awareness with regard to end-of-life in the ICU is a cause of feelings of difficulty or obstacle by nurses in implementing end-of-life care.

### Process of developing items for the scale

Preliminary items were prepared based on a semi-structured interview survey of ICU nurses and the results of a self-completed questionnaire survey (Takano, 2003). These items were then referred to as obstacles that critical care nurses perceive in end-of-life care and compared with previous studies on perceptions of ICU nurses regarding end-of-life care (Bucher et al., 1997; Cartwright et al., 1997; McClement and Degner, 1995; Simpson, 1997). Furthermore, these items were compared with difficulties encountered by nurses providing care to terminal cancer patients in general wards in Japan (Sasahara et al., 2003) to verify that the content reflects specific characteristics of ICUs. Content validity was checked by three researchers.

Finally, 9 domains covering a total of 75 items were adopted for preliminary items. Table 1 shows the 9 domains, as difficulties related to "the purpose of the ICU is recovery and survival" (16 items), "time and/or nursing staff for end-of-life care" (5 items), "education and nursing system for end-of-life care" (8 items), "model nurses in providing end-of-life care" (4 items), "building confidence in end-of-life care" (14 items), "caring for patients" (8 items), "caring for families" (7 items), "physicians' attitudes about end-of-life" (6 items) and "converting from curative care to end-of-life care" (7 items). For each item, respondents were asked about the extent to which they experienced difficulty providing end-of-life care. Answers were given using a 5-point Likert-type scale.

## Setting

Fifty general hospitals that had both more than 300 beds and an ICU and were located in the Kanto region of Japan were selected using the Kanto Hospital information book (Ijinipou, 2005). The Kanto region is an area located in the centre of Japan. In the Kanto region, 50 general hospitals were randomly selected from the Tokyo metropolitan area (Tokyo, Kanagawa, Chiba and Saitama prefectures), which is located in the central part of Kanto where there are many general hospitals. Before conducting the present survey, hospitals that had conducted self-completed questionnaire surveys that included questions similar to those in the present study were excluded, in consideration of the burden of responding to surveys.

## Ethical approval

The survey was initiated only after obtaining written consent from a hospital representative. Written forms sent to individual subjects explained that participation in the survey was voluntary for each individual, that the survey forms were anonymous and privacy would be maintained, and that returning the survey form would be taken to indicate consent. The study protocols were approved by the research ethics committee of Kanagawa University of Human Services.

## Participants

Participants were ICU nurses working at general hospitals in the Kanto region of Japan. Self-rating survey questionnaires were sent to the participants by the director of nursing of each participating hospital.

## Data collection

A document describing the study, what was requested of participants and the study method was mailed to the directors of nursing at the 50 general hospitals. Also enclosed were a sample survey form, a consent form signed by a study representative, a sheet with the name of the contact person and the name of the person to whom the survey forms should be sent, a sheet giving the preferred survey period and number of survey forms needed and a return envelope.

Overall, 18 hospitals agreed to be involved in this study. The requested number of survey forms and corresponding number of letters of request for respondents were sent to these 18 hospitals. Consent for the repeat study was obtained from 17 of the 18 hospitals. A number was written on the cover of the first survey form so that the repeat survey could be compared with the first survey and a card was attached with the same number. The 17 hospitals that agreed to participate in the repeat survey were requested to keep this card until the second survey, so that they would not forget the number at the time of the repeat survey. Subjects were requested to use the survey form with the same number during the repeat survey and to return the form by post two weeks after the first survey.

## Measurements

To investigate concurrent validity of the scale for DFINE, the Japanese version of the Frommelt Attitudes Toward Care of the Dying Scale (FATCOD-B-J) (Nakai et al., 2006) and the Nursing Job Stressor Scale (NJSS) (Kitaoka-Higashiguchi and Nakagawa, 2003) were used, as similar items are included in these two scales, and some studies have indicated that the feelings of ICU nurses providing end-of-life care are related to stress (Crickmore, 1987; Foxall et al., 1990).

The FATCOD-B-J is the Japanese version of a scale developed by Frommelt to measure the care attitudes of medical providers towards patients who are dying. This scale consists of subscales for "positive attitudes towards caring for dying persons" (16 items), "recognition of caring for the pivot dying persons and their families" (13 items) and "views about death" (1 item). Answers were presented on a 5-point Likert-type scale. The NJSS is a scale of job stressors in nurses that was developed by Kitaoka-Higashiguchi and Nakagawa (2003). This scale consists of "conflict with other nursing staffs" (7 items), "nursing role conflict" (5 items), "conflict with physicians/autonomy" (5 items), "dealing with death and dying" (4 items), "qualitative work load" (5 items), "quantitative work load" (5 items) and "conflict with patients" (2 items). Answers were presented on a 5-point Likert-type scale, with higher points indicating greater strain. All respondents were also asked to fill in a set of demographic characteristics (sex, age, number of years experience as a nurse, number of years working in an ICU, number of bereavements in the ICU, etc.).

## Data analysis

Analysis consisted of the following: (1) exploratory factor analysis (maximum likelihood method, promax rotation) to investigate item selection and factor validity after eliminating responses with a clear bias; (2) calculation of Cronbach's  $\alpha$  coefficient to investigate internal consistency; (3) a repeat survey and calculation of intraclass correlation coefficients (ICCs) for each factor score to investigate reliability; and (4) the assumption of combinations between factors predicted to be correlated with the FATCOD-B-J and NJSS, to investigate concurrent validity of the scale developed as a scale for DFINE. Pearson's correlation coefficient was calculated. However "views about death" in FATCOD-B-J were excluded because the subscale consists of only one item. Statistical significance was set at the  $p < 0.05$  level and SPSS version 12 software (SPSS Inc., USA) was used for statistical analyses.

## Results

### Study sample

Of the 288 survey questionnaires delivered, 224 were returned (response rate, 78%). Of the 249 repeat survey questionnaires delivered, 148 were returned (response rate, 59%). Characteristics of the respondents are summarised in Table 2.

Tables 3 and 4 show mean values and standard deviations for each domain in the FATCOD-B-J and NJSS.

Table 2 Subject characteristics (N=224).

	Number/mean $\pm$ SD	(%)
Age	29.7 $\pm$ 5.9	
Years of clinical experience	8.0 $\pm$ 5.7	
Years of clinical experience in ICU	3.8 $\pm$ 2.6	
Sex		
Male	12	(5.4)
Female	212	(94.6)
Number of bereavements in the ICU		
0	18	(8.0)
1–10	81	(36.2)
11–20	47	(21.0)
21–50	53	(23.7)
51–100	18	(8.0)
101–	3	(1.3)
No response provided	4	(1.8)
Number of people with experience of providing end-of-life care in the ICU		
0	9	(4.0)
1–10	93	(41.5)
11–20	56	(25.0)
21–50	41	(18.3)
51–100	17	(7.6)
101–	4	(1.8)
No response provided	4	(1.8)
Number of people with experience of providing end-of-life care in the wards excluding ICU		
0	79	(35.3)
1–10	24	(10.7)
11–20	22	(9.8)
21–50	39	(17.4)
51–100	36	(16.1)
101–	20	(8.9)
No response provided	4	(1.8)

Table 3 Frommelt Attitudes Toward Care of the Dying Scale (FATCOD-B-J).

	Mean $\pm$ SD	$\alpha$
Positive attitudes towards caring for dying persons (range 16–80)	57.0 $\pm$ 5.7	0.76
Recognition of caring for the pivot dying persons and their families (range 13–65)	50.5 $\pm$ 4.8	0.79

$\alpha$ : Cronbach's alpha coefficient.

Table 4 The Nursing Job Stressor Scale (NJSS).

	Mean $\pm$ SD	$\alpha$
Conflict with other nursing staffs (range 0–28)	19.5 $\pm$ 5.0	0.77
Nursing role conflict (range 0–20)	14.0 $\pm$ 2.9	0.79
Conflict with physicians/autonomy (range 0–20)	14.2 $\pm$ 3.6	0.77
Dealing with death and dying (range 0–16)	10.4 $\pm$ 2.7	0.53
Qualitative work load (range 0–20)	14.7 $\pm$ 3.1	0.73
Quantitative work load (range 0–20)	15.5 $\pm$ 3.2	0.81
Conflict with patients (range 0–8)	5.6 $\pm$ 1.4	0.67

$\alpha$ : Cronbach's alpha coefficient.

### Item selection and factor validity

Points were allotted so that there was a minimum of 1 point and a maximum of 5 points for the 75 questions of the scale for DFINE. To eliminate items with a clear bias, 2 items for which mean values were  $\leq 2$  and  $\geq 4$  were eliminated, along with 4 items showing an ICC  $\leq 0.3$ . Exploratory factor analysis was conducted with the remaining 69 items. The maximum likelihood method and promax rotation were used in factor extraction. Items with factor loading  $< 0.3$  and commonality  $< 0.2$  were eliminated, then factor analysis was repeated. The consistency of item content for the classified factors was confirmed, eliminated factors were re-included and changes in the number of factors were repeated. After confirming the consistency of item contents, 5 factors comprising 28 items were ultimately obtained (Table 5).

The final five factors were called: "the purpose of the ICU is recovery and survival"; "nursing system and model nurse for end-of-life care"; "building confidence in end-of-life care"; "caring for patients and families at end-of-life"; and "converting from curative care to end-of-life care". Mean values and standard deviations of the five factors are shown in Table 6. Table 7 shows a factor correlation matrix.

### Internal consistency

Means and standard deviations for each factor and results for internal consistency are shown in Table 6. Cronbach's  $\alpha$  coefficients for "the purpose of the ICU is recovery and survival", "nursing system and model nurse for end-of-life care", "building confidence in end-of-life care", "caring for patients and families at end-of-life" and "converting from curative care to end-of-life care" were 0.8, 0.74, 0.74, 0.79 and 0.61, respectively.

### Test-retest reliability

Intraclass correlation coefficients were calculated to confirm test-retest reliability. The ICC for each factor ranged from 0.62 to 0.72 (Table 6).

### Concurrent validity

Pearson's correlation coefficients were calculated between the FATCOD-B-J, NJSS and the scale for DFINE (Tables 8 and 9). A correlation was considered present if the correlation coefficient was  $\pm 0.2$  or more (Oshio, 2004).

"Positive attitudes towards caring for dying persons" in the FATCOD-B-J were assumed to have a negative relationship with each factor. Analysis revealed the most negative correlation with "building confidence in end-of-life care" ( $r = -0.4$ ). There was assumed to be no relationship, since no contents were similar to "recognition of caring for the pivot dying persons and their families" of the FATCOD-B-J and analysis showed no correlations with each factor (Table 8).

Some factors in the NJSS were assumed to be positively related to DFINE. Positive correlations were seen between some factors in the NJSS and "nursing system and model nurse for end-of-life care", as assumed, "conflict with

other nursing staff" ( $r = 0.32$ ) and "conflict with physicians/autonomy" ( $r = 0.31$ ) in the NJSS.

In "building confidence in end-of-life care", relationships were assumed with some factors in the NJSS, but a positive correlation was seen only with "qualitative work load" ( $r = 0.26$ ). In "converting from curative care to end-of-life care", relationships were assumed to exist with "conflict with physicians/autonomy" and "deal with death and dying". However, a positive correlation was seen with "conflict with other nursing staff" ( $r = 0.24$ ) and "conflict with physicians/autonomy" ( $r = 0.27$ ) (Table 9).

### Discussion

The most important result in this study was that we identified five factors to difficulties felt by ICU nurses providing end-of-life care. Moreover sufficient internal consistency was confirmed for four of these five factors, but Cronbach's  $\alpha$  coefficient for "converting from curative care to end-of-life care" was lower than that for the other four factors. Cronbach's  $\alpha$  coefficients  $\geq 0.7$  are considered desirable, but reconsideration is needed in cases showing coefficients  $\leq 0.5$  (Oshio, 2004). In this study, "converting from curative care to end-of-life care" was barely adopted. This was attributed to four items being too few. Other studies related to preparation of scales have also reported low Cronbach's  $\alpha$  coefficients when the number of items is small (Ito et al., 2002; Kim et al., 2006), which could be similar. However, in this study, Cronbach's  $\alpha$  coefficient for "the purpose of the ICU is recovery and survival" maintained good internal consistency with 0.8, so small numbers of items cannot necessarily be considered as the only cause. The issue of internal consistency for "converting from curative care to end-of-life care" remains. However, this factor was kept as an important factor that gives a semantic summation and is related to the withdrawal or withholding treatment and is thus inherent to the end-of-life period in the ICU.

In test-retest, ICC was 0.62 for "nursing system and model nurse for end-of-life care," compared to  $\geq 0.7$  for the other four factors. An ICC of 0.61–0.8 is said to be "substantial," and that of  $\geq 0.81$  to be "almost perfect" (Landis and Koch, 1977). With the repeat survey method, the sample size in the second survey was assumed to be smaller because of the burden of responding to the study participants. However, sufficient reproducibility of the scale was confirmed.

As a result of factor analysis, the number of domains was reduced to 5 from the hypothesised 9. The hypothesised domains, "time and/or nursing staff for end-of-life care", "education and nursing system for end-of-life care" and "model nurses in providing end-of-life care" were integrated into "nursing system and model nurse for end-of-life care". The hypothesised domains "caring for patients" and "caring for families" became "caring for patients and families at end-of-life". "Physician attitudes about end-of-life" and "converting from curative care to end-of-life care" became "converting from curative care to end-of-life care". Factor loading was low and the number of items was drastically reduced from that predicted. However, the 28 items adopted comprised several items from each of the hypothesised domains. In this respect, the predicted con-

Table 5 Exploratory factor analysis of a scale for difficulties felt by ICU nurses providing end-of-life care.

	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5	Commonality
1. The purpose of ICU is recovery and survival:						
ICU is not an appropriate place to die.	0.77	0.00	-0.01	0.05	0.10	0.70
Patients cannot approach peaceful death in the ICU.	0.74	0.11	0.01	0.02	-0.10	0.59
Patients do not want to die in the ICU, I suppose.	0.56	-0.07	0.11	0.11	0.02	0.42
When death is unavoidable, the patient had better leave the ICU quickly.	0.48	0.02	-0.15	0.16	0.17	0.40
2. Nursing system and model nurse for end-of-life care:						
No time to care for dying patient.	-0.01	0.64	-0.04	0.12	-0.01	0.46
Nursing system for end-of-life care is not established.	0.12	0.62	-0.05	0.04	0.00	0.45
No time to discuss amongst nurses about end-of-life care.	-0.05	0.55	0.04	0.07	0.04	0.33
More nurses are needed for providing end-of-life care.	-0.03	0.46	0.10	0.05	0.26	0.36
There are no nurses to consult about end-of-life care.	-0.05	0.38	0.08	0.10	0.04	0.20
There are no model nurses in providing for end-of-life care.	0.28	0.37	0.02	-0.11	0.01	0.25
3. Building confidence in end-of-life care:						
I am frightened to tell the family that a patient's condition is worsening.	-0.04	0.02	0.60	-0.04	0.01	0.34
I often feel a pang of guilt when I face patient death.	0.02	0.05	0.59	-0.21	0.13	0.33
I want to avoid the family when a patient's condition is worsening.	-0.10	-0.01	0.58	0.09	0.09	0.33
I often feel that it is my responsibility when a patient's condition is worsening.	-0.07	-0.02	0.56	-0.05	0.21	0.29
No confidence to provide end-of-life care.	-0.04	0.10	0.54	0.20	-0.22	0.49
I would like to avoid care for dying patients, if possible.	0.23	-0.05	0.48	-0.11	0.03	0.28
No knowledge and skills to provide end-of-life care.	0.26	0.07	0.42	0.04	-0.30	0.42
4. Caring for patients and families at end-of-life:						
Not enough contact with families.	-0.10	0.27	-0.11	0.63	0.07	0.50
It is difficult to provide care for families in the ICU.	0.16	0.13	-0.05	0.58	0.15	0.61
It is difficult to fulfil patients' wishes of end-of-life.	0.24	-0.10	0.01	0.55	-0.10	0.43
No wish to develop a relationship with the family.	-0.12	0.34	0.06	0.50	-0.09	0.44
It is difficult to provide care for dying patients in the ICU.	0.25	0.04	-0.12	0.50	-0.17	0.38
Family has difficulty accepting death in the ICU.	0.24	-0.09	0.13	0.31	0.11	0.29
It is difficult to fulfil family's wishes.	0.29	-0.04	-0.04	0.30	0.20	0.33
5. Converting from curative care to end-of-life care:						
Doctors are too late in deciding that treatment is ineffective, I feel.	-0.02	0.22	0.06	-0.19	0.59	0.39
It is difficult to attend to the family when a patient is dying.	0.09	-0.20	0.09	0.30	0.58	0.51
Life-sustaining treatment is often given excessively.	0.16	0.23	-0.05	-0.21	0.45	0.33
Even in the end-of-life phase, limits on visiting hours and people are unavoidable.	-0.01	-0.08	0.10	0.21	0.39	0.22
Total contribution of factors			0.40			

tent can be considered to have been broadly reflected. In relation to existing research, broad consistency was seen with factors impeding ICU end-of-life care. However, compared to the obstacles felt by nurses to end-of-life care reported by Beckstrand and Kirchhoff (2005) and Kirchhoff and Beckstrand (2000), the scale created did not include items where care is continued due to threat of legal action, or unavailability of ethics boards, clergy to support the family, or organ donors. The item related to religious ministers

can be assumed to be absent due to cultural differences in religious views. The issue of having to continue treatment due to fear of legal repercussions has been noted in the Japanese literature by physicians (Gando and Marukawa, 2009). However, nurses in Japan see responsibility for treatment as lying with doctors (Kinoshita, 2009), and so may not go as far as to consider legal repercussions. As far as organ transplants are concerned, the history of organ transplant from brain-dead patients in Japan is still short, and this is



Table 6 Internal consistency and test-retest reliability.

	Mean $\pm$ SD	$\alpha$	ICC
The purpose of ICU is recovery and survival (range 4–20)	13.5 $\pm$ 2.9	0.8	0.71
Nursing system and model nurse for end-of-life care (range 6–30)	17.9 $\pm$ 3.6	0.74	0.62
Building confidence in end-of-life care (range 7–35)	21.0 $\pm$ 4.0	0.74	0.72
Caring for the patients and families in end-of-life (range 7–35)	23.0 $\pm$ 4.5	0.79	0.72
Converting from curative care to end-of-life care (range 4–20)	12.0 $\pm$ 2.6	0.61	0.71

$\alpha$ : Cronbach's alpha coefficient.

ICC: intraclass correlation coefficient.

Table 7 Factor correlation matrix.

	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5
The purpose of ICU is recovery and survival.					
Nursing system and model nurse for end-of-life care.	0.35				
Building confidence in end-of-life care.	0.29	0.29			
Caring for the patients and families in end-of-life.	0.51	0.36	0.31		
Converting from curative care to end-of-life care	0.31	0.16	–0.11	0.18	

Table 8 Concurrent validity of FATCOD-B-J.

	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5
Positive attitudes towards caring for dying persons	–0.16 <sup>*</sup>	–0.16 <sup>*</sup>	–0.4 <sup>***</sup>	0.14 <sup>*</sup>	0.15 <sup>*</sup>
<i>p</i> -Value	0.02	0.02	<0.001	0.04	0.03
Recognition of caring for the pivot dying persons and his families	0.04	–0.02	–0.09	0.06	–0.12
<i>p</i> -Value	0.59	0.73	0.19	0.34	0.08

Underline: an assumption of combinations between factors predicted to be correlated.

<sup>\*</sup>  $p < 0.05$  (Pearson's correlation coefficient).

<sup>\*\*\*</sup>  $p < 0.001$  (Pearson's correlation coefficient).

Table 9 Concurrent validity of NJSS.

	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5
Conflict with other nursing staff	0.11	0.32 <sup>***</sup>	0.21 <sup>**</sup>	0.11	0.24 <sup>***</sup>
<i>p</i> -Value	0.11	<0.001	0.001	0.11	<0.001
Nursing role conflict	0.09	0.2 <sup>**</sup>	0.16 <sup>*</sup>	0.08	0.04
<i>p</i> -Value	0.19	0.002	0.02	0.25	0.51
Conflict with physicians/autonomy	0.23 <sup>***</sup>	0.31 <sup>***</sup>	0.13	0.18 <sup>**</sup>	0.27 <sup>***</sup>
<i>p</i> -Value	<0.001	<0.001	0.05	0.01	<0.001
Dealing with death and dying	0.14 <sup>*</sup>	0.15 <sup>*</sup>	0.1	0.08	0.19 <sup>**</sup>
<i>p</i> -Value	0.04	0.02	0.15	0.26	0.004
Qualitative work load	0.05	0.12	0.26 <sup>***</sup>	0.03	0.08
<i>p</i> -Value	0.45	0.08	<0.001	0.65	0.26
Quantitative work load	0.08	0.19 <sup>**</sup>	0.18 <sup>**</sup>	–0.05	0.12
<i>p</i> -Value	0.21	0.005	0.01	0.48	0.08
Conflict with patients	0.03	0.11	0.19 <sup>**</sup>	–0.04	0.06
<i>p</i> -Value	0.69	0.1	0.004	0.51	0.41

Underline: an assumption of combinations between factors predicted to be correlated.

<sup>\*</sup>  $p < 0.05$  (Pearson's correlation coefficient).

<sup>\*\*</sup>  $p < 0.01$  (Pearson's correlation coefficient).

<sup>\*\*\*</sup>  $p < 0.001$  (Pearson's correlation coefficient).

not something that ICU nurses encounter frequently in daily work. Next, comparing this scale to a literature review of 22 studies related to barriers to ICU end-of-life care by Espinosa et al. (2008), content related to "inadequacy of pain relief" did not feature in the scale created in the present study. According to research results in Japan (Kinoshita, 2007), most patients who die in the ICU are already unconscious, so the understanding of pain management for terminal patients amongst ICU nurses may be low.

A link between scales was thus predicted and correlation coefficients were calculated for FATCOD-B-J and NJSS. However, the results showed that correlation coefficients were not as high as expected. This means that a different scale needs to be used.

As a result of factor analysis, the number of items in the present study was reduced substantially from that predicted. Accordingly, this scale cannot be claimed to measure all the difficulties felt by ICU nurses in end-of-life care. Unlike the barriers to end-of-life care in the ICU described by Nelson et al. (2006), predicted items related to the decision-making capacity of patients and the communication ability of doctors did not remain in the created scale. Measurement of whether nurses actually feel difficulties related to each factor using this scale is therefore possible, but further surveys related to more specific and detailed content are needed. Using this scale, however, quantitative demonstration of difficulties felt in end-of-life care and relationships with other factors should be possible. In the future, the present scale can be used not only to measure feelings of difficulties in end-of-life care, but also to identify primary factors and investigate strategies.

## Conclusion

A scale for DFINE was created and the reliability and validity of this scale were tested. Overall, the content created proved consistent with the obstacles and barriers suggested in the international literature on end-of-life care in the ICU, suggesting potential for use as a scale. However, limitations of this study include the small sample size. Therefore, as far as more specific and detailed content is concerned, additional surveys need to be conducted with a larger sample. In the future, the present scale needs to be used not only to measure feelings of difficulty in end-of-life care, but also to identify relationships involving DFINE and investigate strategies for difficulties faced in end-of-life care in the ICU.

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## Conflict of interest statement

All the authors declare no conflicting interests.

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# Public Awareness, Knowledge of Availability, and Readiness for Cancer Palliative Care Services: A Population-Based Survey across Four Regions in Japan

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## Abstract

**Background:** This study explores the distribution of public awareness, knowledge of availability, and readiness for palliative care services, and the perceived reliability of information resources as part of a nationwide palliative care implementation intervention in Japan (Outreach Palliative Care Trial of Integrated Regional Model [OPTIM]).

**Methods:** A cross-sectional anonymous questionnaire survey was conducted, and 3984 responses were used in the final analysis.

**Results:** A total of 63.1% of respondents admitted having no knowledge about palliative care, while 0.5% of respondents were using palliative care services. Respondents who knew about palliative care services, yet did not know about their availability were 18.6% of all respondents. Respondents who had cancer-related experiences were more likely to be aware of palliative care compared to the general population and availability of palliative care services. Only awareness of palliative care was significantly associated with two typical images, while cancer-related experiences were not.

**Conclusion:** Findings show that the public awareness of palliative care services and their availability is insufficient, and cancer-related experiences affect awareness of cancer palliative care but not directly related to typical images for palliative care such as care for patients close to death.

## Introduction

PALLIATIVE CARE for patients with cancer in Japan has rapidly progressed in the past decade, but many critical issues still need to be resolved. To improve overall cancer care (including palliative care) throughout Japan, the Cancer Control Act was established in April 2007. To facilitate the dissemination of palliative health services, the Ministry of Health, Labour, and Welfare focuses on palliative care concerns, and has launched a multiple nationwide project for community-based intervention trials in four areas in Japan, as described via the Outreach Palliative Care Trial of Integrated

Regional Model (OPTIM) study.<sup>1</sup> The study includes creating community-based specialized palliative care teams, developing educational materials, educating community medical staff on palliative care, and campaigning to disseminate knowledge relevant to specialized palliative care programs to patients, families, and the general public.

The reason that this trial includes the campaign is that the general public does not have adequate knowledge about palliative care concepts.<sup>1</sup> For example, only 34% of the general population knows about palliative care units in Japan, whereas the rate of knowledge in the United Kingdom is 70%.<sup>2,3</sup> Of note, although 32% of the Japanese general public

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believes that palliative care units are places where patients simply wait for death, these misperceptions are significantly decreased after individuals actually use a specialized palliative care service.<sup>3,4</sup> Thus, the lack of knowledge and general misperceptions regarding palliative care are considerable barriers to palliative care and appropriate pain control, and further education of the general public would be of great value.

This research has revealed prevalence and relationships among general knowledge and perceptions for barriers but has not clarified intentions, acceptance, and knowledge of the availability if the people use the services in a local region. To develop effective strategies to promote the enhanced utilization of palliative care services, we must explore the demographics (such as gender, age, or residential status) and barriers related to not only general public awareness of palliative care, but also intention for use, knowledge of the availability, and actual rate of service utilization. As the previous study revealed,<sup>3,4</sup> it is also expected that opinions of palliative care, which are supposed to be formed from personal experiences, affected not only general awareness but intention or readiness. In particular, sources to form opinions of cancer palliative care are supposed to be cancer-related experiences as the patient themselves or as the patient's family members.<sup>5</sup>

This article, therefore, has the following aims: (1) to clarify the distribution of public awareness, knowledge of availability, and readiness for palliative care services, (2) to clarify the differences in awareness, knowledge, and readiness among demographic variables and between healthy individuals and those who have cancer-related experiences (either personally or via family), (3) to clarify the differences of typical opinions of palliative care in awareness, knowledge, and readiness, in relation to cancer-related experiences and other demographics.

**Methods**

**Subjects**

This study was a part of OPTIM, and the overall protocol has been provided in detail elsewhere.<sup>1</sup> Our investigation was a survey of the general population, including patients with cancer and their families in four regions from the OPTIM study. These consisted of a large urban area (Chiba), an urban area (Shizuoka), and two rural areas (Nagasaki and Yamagata). The first three areas are places in which palliative care services are available and the last one (Yamagata) is, in comparison, a location in which services are practically unavailable.

A cross-sectional anonymous questionnaire survey was conducted in a sample of the general population selected by stratified two-stage random sampling in each area (2,000 subjects in each of four regional areas). As a result, this sample included cancer patients (outpatients receiving or having received cancer treatment). We mailed a total of 8,000 questionnaires to these potential participants in June 2007 and on a later date sent a reminder postcard. On the questionnaire, we explained the aim of the study and regarded completion and return of the questionnaire as consent for participation in this study. The institutional review boards of Tokyo University confirmed the ethical and scientific validity.

**Questionnaire**

We developed our own questionnaire on the basis of the aims of OPTIM and through literature reviews, existing sur-

veys, and consensus among the authors as follows. On the cover page of the questionnaire, palliative care was defined as: attempts to make patients with cancer and their family less anxious or to experience less pain, to immediately start consultations about anxiousness and pain regardless of the state of cancer development, and in addition to treatment, to facilitate the teamwork of doctors and nurses in the practice of treating patients who are suffering from the physical and/or emotional effects of cancer.

The questionnaire included three parts. First, it included questions covering the demographic information of the subjects (age, gender, length of living in each area) and whether subjects are undergoing (or had undergone) cancer treatment or had family members who had experiences of undergoing cancer treatment. Second, it included an item originally designed to determine the extent of public awareness, knowledge of availability, and readiness and actual utilization of palliative care service. We asked the participants to choose only one option from six sequential options regarding palliative care and such services: (1) no knowledge (I have no knowledge regarding palliative care; I); (2) lack of knowledge of availability (I have heard of palliative care, but I do not know if there are any available facilities in my municipality; II); (3) no interest (I know about palliative care and its availability in my residential area, but I have no interest in the service; III); (4) no intention (I know about palliative care and its availability in my residential area, and have an interest, but I have no intention of using the service as a patient or for a family member; IV); (5) preparation (I am preparing to use palliative care services; V); (6) under utilization (I currently use palliative care services; VI; Fig. 1). We converted the subjects' responses for these responses (I to VI) into a numeric

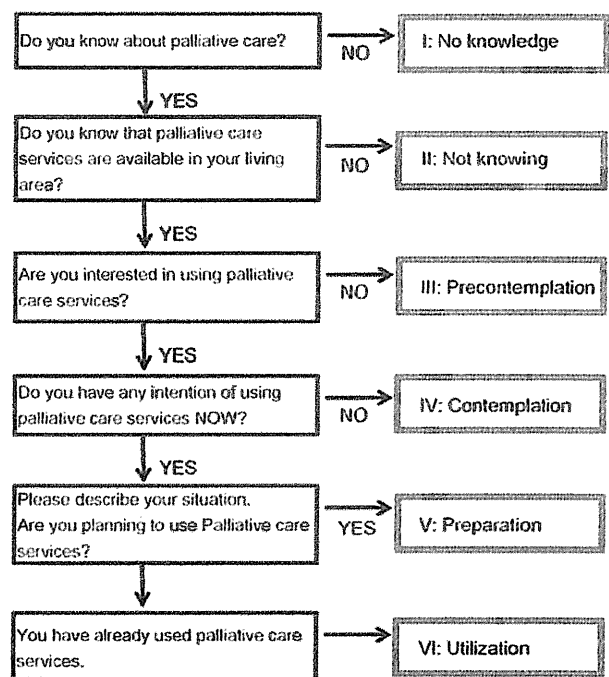


FIG. 1. Public awareness and readiness for palliative care services.

TABLE 1. DEMOGRAPHIC BACKGROUND OF THE RESPONDENTS

	Total		General population		Those who have experienced cancer	
	(n = 3190)		(n = 1330)		(n = 1860)	
	n	%	n	%	n	%
Age years						
40-49	705	22.1	302	22.7	403	21.7
50-59	1020	32.0	404	30.4	616	33.1
60-69	898	28.2	385	28.9	513	27.6
70-	567	17.8	239	18.0	328	17.6
Gender						
Male	1,426	44.7	666	50.1	760	40.9
Female	1,764	55.3	664	49.9	1100	59.1
Region (Prefecture)						
Chiba	945	29.6	413	31.1	532	28.6
Shizuoka	785	24.6	364	27.4	421	22.6
Nagasaki	733	23.0	274	20.6	459	24.7
Yamagata	727	22.8	279	21.0	448	24.1
Length of living in each area						
<1 year	38	1.2	22	1.7	16	0.9
1-5 year	131	4.1	60	4.5	71	3.8
>5 year	3,021	94.7	1,248	93.8	1,773	95.3

scale ranging from 1 to 6 points. Finally, three items related to palliative care beliefs/concepts ("Palliative care relieves pain and distress"; "Palliative care is used with chemotherapy and radiotherapy"; "Palliative care is for patients close to death.")<sup>3,5</sup> were presented, and responses were measured on a five point Likert-type scale from 1) strongly disagree to 5) strongly agree.

### Analysis

Descriptive analyses were carried out summarizing the subjects' backgrounds, awareness of palliative care and utilization of such services, and scores for reliable media source opinions for total and each sampled area. Then we explored

the distribution of knowledge and readiness of palliative care and utilization of the service associated with each sampled area and experiences of having cancer. These analyses were performed after dividing subjects into two groups (the general population and cancer patients/survivors) and we used the  $\chi^2$  test and Cramer's V to clarify relations between categorical variables and using coefficient correlation and relations between two categorical variables and ordered variables two-way analysis of variance (ANOVA). We conducted all statistical analyses using the Statistical Package for the Social Sciences (version 15.0.1.1J, SPSS Inc., Chicago, IL) software package. The significance level was set at  $p < 0.05$  (two-tailed).

### Results

Of the 8000 questionnaires delivered to the sampled subjects, 26 were returned as undeliverable and 3984 were returned (response rate, 49.8%). Of those returned, 3190 were considered valid for statistical analyses. The rest ( $n = 794$ ) were invalid and were excluded from the analyses since major information was lacking. Thus, the final rate of valid replies was 39.9%.

A total of 1860 respondents (58.3% of all respondents) were identified as "those having experienced cancer" and the rest were identified as belonging to the "general population." Table 1 summarizes the background of respondents.

### Public awareness, knowledge, and readiness for palliative care

A total of 63.1% of respondents admitting to having "no knowledge" of palliative care while 0.5% of respondents were actually using palliative care services. Respondents who knew about palliative care yet did not know about the availability of palliative care in their living area were 18.6% of all respondents. Female respondents were more likely to know about palliative care than male respondents ( $\chi^2 = 55.09$ ,  $df = 1$ ,  $p < 0.001$ , Cramer's V = 0.131), while age and length of living in each area were not significantly associated with

TABLE 2. PUBLIC AWARENESS AND READINESS FOR PALLIATIVE CARE SERVICES

	Total		General population		Those who have experienced cancer		Chiba		Shizuoka		Nagasaki		Yamagata	
	(n = 3190)		(n = 1330)		(n = 1860)		(n = 945)		(n = 785)		(n = 733)		(n = 727)	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%
I: No knowledge	2012	63.1	909	68.3	1,103	59.3	546	57.8	518	66.0	482	65.8	466	64.1
Having Knowledge	1178	36.9	421	31.7	757	40.7	399	42.2	267	34.0	251	34.2	261	36.0
II: Not knowing	593	18.6	230	17.3	363	19.5	201	21.3	96	12.2	115	15.7	181	24.9
III: Not interested	24	0.8	13	1.0	11	0.6	5	0.5	12	1.5	5	0.7	2	0.3
IV: No Intention	499	15.6	167	12.6	332	17.8	171	18.1	142	18.1	116	15.8	70	9.6
V: Preparation	46	1.4	10	0.8	36	1.9	18	1.9	14	1.8	10	1.4	4	0.6
VI: Under Utilization	16	0.5	1	0.1	15	0.8	4	0.4	3	0.4	5	0.7	4	0.6

Cancer experience  $\times$  Awareness (No knowledge vs. Having knowledge):  $\chi^2 = 27.24$ ,  $df = 1$ .

$p < 0.01$ , Cramer's V = 0.092.

Four areas  $\times$  Awareness (No knowledge vs. Having knowledge):  $\chi^2 = 16.83$ ,  $df = 3$ ,  $p < 0.01$ , Cramer's V = 0.073.

Within People who Knew Palliative Care:

Cancer experience  $\times$  Availability:  $\chi^2 = 4.83$ ,  $df = 1$ ,  $p < 0.028$ , Cramer's V = 0.064

Four areas  $\times$  Availability:  $\chi^2 = 61.88$ ,  $df = 3$ ,  $p < 0.01$ , Cramer's V = 0.229.

Availability: No awareness of availability vs. awareness of availability.

either awareness, knowledge or readiness. Respondents who had cancer-related experiences (either themselves or via family members) were more likely to be aware of palliative care compared to the general population ( $\chi^2=27.24, df=1, p < 0.001$ , Cramer's  $V=0.092$ ). Also among people who knew palliative care, there was a significant association between cancer experience and knowledge for availability or readiness ( $\chi^2=4.83, df=1, p=0.028$ , Cramer's  $V=0.064$ ). Table 2 also shows that awareness and knowledge of and readiness for palliative care was significantly different among each area ( $\chi^2=16.84, df=3, p < 0.001$ , Cramer's  $V=0.073$ ). Particularly, respondents in Chiba-city have more knowledge about palliative care than individuals from the other three areas.

**Typical images of palliative care**

Table 3 indicates the results of two-way ANOVA for responses on three typical images of palliative care using awareness and cancer experiences as dependent variables, when age, gender, and area were controlled. First, the analysis revealed the differences in perception for three common images of palliative care between individuals having no knowledge of palliative care and those who had knowledge. Significant differences were observed between them in terms of images of palliative care in the following dimensions: "Palliative care relieves pain and distress" (general population;  $F(1, 3186)=33.02, p < 0.001$ , Those having experienced cancer;  $F(1, 3186)=60.85, p < 0.001$ ) and "Palliative care is for patients close to death" (general population;  $F(1, 3186)=13.62, p < 0.01$ , Those having experienced cancer;  $F(1, 3186)=13.00, p < 0.01$ ). People who know about palliative care have an overall positive image of it, tend to think that palliative care brings symptom control to the patients, and is specialized for terminally ill patients. There were no significant differences between the general population and cancer-experienced individuals on the three typical opinions of palliative care, and there were no significant interactions between cancer experience and knowledge of palliative care.

**Discussion**

This study is the first attempt to understand the public awareness of palliative care and utilization of services based on a nationwide sample in Japan. A clarification of these findings will hopefully contribute to understanding general perception of cancer palliative care and its variations by experiences related to cancer.

The primary aim of this study was to clarify the distribution of public awareness, knowledge of availability, and readiness for palliative care services. Per the results of the survey, 63.1% of all the participants had no knowledge of palliative care services. These results demonstrate a low public awareness of the Japanese palliative care services compared with other countries.<sup>2,3</sup> Moreover, among those who did possess knowledge about palliative care in general, 18% did not know about the specific availability of the service in their region. These results indicate that over 80% of people do not have sufficient knowledge of palliative care to take advantage of its services, and it is therefore important to promote a more comprehensive understanding of palliative care (including availability) to the general population.

Second, our data clarified that cancer experiences were related to a greater knowledge of and readiness for palliative

TABLE 3. MEAN SCORES OF IMAGES OF PALLIATIVE CARE BY AWARENESS AND EXPERIENCE OF CANCER

Experience of Cancer	Awareness						Main effect									
	General population			Those who have experienced cancer			Exp. Cancer		Awareness		Interaction					
	Total	Having knowledge		Total	Having knowledge		F	P	F	P	F	P				
	M	SD	M	SD	M	SD										
Palliative care relieves pain and distress	3.81	0.80	3.72	0.83	4.00	0.70	0.88	0.76	4.06	0.76	2.75	.07	74.73	.00	0.08	.78
Palliative care is used with chemotherapy and radiotherapy	3.51	0.90	3.53	0.85	3.47	1.00	0.94	1.02	3.52	1.02	0.18	.68	0.04	.85	1.09	.30
Palliative care is for patients close to death	3.19	1.22	3.12	1.12	3.34	1.26	1.27	1.30	3.32	1.30	0.01	.91	15.30	.00	0.36	.55

The results by two-way analysis of variance (ANOVA) were shown when age, gender, and area were controlled as covariates.

care, but did not significantly relate to specific images commonly associated with palliative care. From our data it is difficult to strictly compare patients with cancer with the overall population since the sample surveyed in this study was from the general population, and therefore only a small number of patients with cancer were included. However, people who had experiences with cancer (either personally or via family members) recognized both the term and meaning of palliative care. Also, people who had knowledge of palliative care have an overall positive image of it, tend to think that palliative care brings symptom control to the cancer patients, and is specialized for terminally ill patients. Generally, as the images will be reinforced by actual experiences, those who experienced as patients with cancer or as family members might see or hear the care at late stage of the cancer process. This indicated current situation that palliative care for patients with cancer in general Japanese hospitals was mainly provided for late-stage cancer and that contributed to form the general opinions of palliative care. Also, the perception that palliative care is primarily for terminally ill patients care may cause late referrals to palliative care services.<sup>5,6</sup> These suggest that images derived from actual experiences will have strong impact for actual decision making for choosing or readiness for the services when the patients need. Therefore, it is important to provide proper and detailed information about palliative care services, as well as information regarding the availability of services, within areas of residence. We still have very big challenges to modify the general perception of cancer palliative care, because there is no known effective method to achieve this. Educational approaches in community may become one of the solutions, and will especially be needed to help people recognize that palliative care services accept even patients with early-stage cancer.

This study has several limitations. First, this study did not include measurements for the effectiveness of each medium and we cannot discern which media sources and what kind of information directly led individuals to be more aware of palliative care and to use these services. Second, we did not explore the possible associations between the awareness of palliative care and amounts of actual cancer treatment undergone. A more detailed survey will need to be conducted in order to clarify the above items. Moreover, it would be useful to better explore the insights of specific populations. In future surveys, it should be possible to design more directed questionnaires to support hypothesis-based studies.

In conclusion, the public awareness of palliative care services and their availability is insufficient. Those with cancer experiences were more aware of palliative care and their availability than the general population. Only people who were aware of palliative care developed two typical images, while those with cancer-related experiences did not. Ap-

proaches to inform the general population (including those with cancer-related experiences) about palliative care have already been taken in Japan. However, more effective methods should be developed. We feel that it is possible to eliminate many existing barriers to the improvement of end-of-life quality, and the dissemination of knowledge related to such care and treatment in Japan should be a top priority.

#### Author Disclosure Statement

No competing financial interests exist.

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*Original Article*

## Experience with Prognostic Disclosure of Families of Japanese Patients with Cancer

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### **Abstract**

**Context.** Prognosis is difficult to discuss with patients who have advanced cancer and their families.

**Objectives.** This study aimed to explore the experiences of families of patients with cancer in Japan in receiving prognostic disclosure, explore family perception of the way the prognosis was communicated, and investigate relevant factors of family-perceived need for improvement.

**Methods.** A multicenter questionnaire survey was conducted with 666 bereaved family members of patients with cancer who were admitted to palliative care units in Japan.

**Results.** In total, 86.3% of the families received prognostic disclosure. The overall evaluation revealed that 60.1% of the participants felt that the method of prognostic disclosure needed some, considerable, or much improvement. The parameter with the highest value explaining the necessity for improvement was the family perception that the amount of information provided by the physician was insufficient ( $\beta = 0.39, P < 0.001$ ). Furthermore, the family perception that they had lost hope and that health care providers failed to facilitate preparation for the patient's death had significant direct effects on the necessity for improvement ( $\beta = 0.21, P < 0.001$ ; and  $\beta = 0.18, P < 0.001$ , respectively). The feelings for the necessity for improvement also were affected significantly by seven communication strategies (i.e., not saying "I can do nothing for the patient any longer," pacing explanation with the state of the patient's and family's preparation, saying "We will respect the patient's wishes," making an effort to

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understand the family's distress, being knowledgeable about the most advanced treatments, assuring continuing responsibility as the physician for medical care, and respecting the family's values).

**Conclusion.** This model suggests that strategies for care providers to improve family perception about prognostic disclosure should include 1) providing as much prognostic information as families want; 2) supporting families' hopes by keeping up with up-to-date treatments and by assuring the continuing responsibility for medical care; 3) facilitating the preparation for the patient's death by providing information in consideration of the family's preparations and values; 4) stressing what they can do instead of saying that nothing can be done for the patient; and 5) assuring the family that they will respect the patient's wishes. *J Pain Symptom Manage* 2011;41:594–603. © 2011 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

#### Key Words

Prognostic disclosure, family, cancer, communication, Japan

### Introduction

Prognosis is an issue that most physicians and patients describe as difficult to discuss,<sup>1</sup> and whether to tell patients with cancer about their diagnosis and prognosis is a matter of great debate.<sup>2</sup> Although it is said to be important to give patients prognostic information so that they can make important decisions in an informed manner,<sup>2</sup> the concern that prognostic information can cause distress<sup>3,4</sup> and loss of hope<sup>5–7</sup> can lead some physicians to avoid the topic<sup>8,9</sup> or to disclose vague<sup>4</sup> or overly optimistic information.<sup>10</sup> Therefore, it is very important to consider better ways of prognosis communication.

To date, many studies have been carried out to clarify patients' preferences<sup>11–13</sup> and experiences<sup>14</sup> in receiving prognostic disclosure. At the same time, methods of prognosis communication also have been explored, and several suggestions have been made.<sup>12,15</sup> As important factors for optimal ways of presenting a prognosis to a patient, several themes have been identified, as follows: communication within a caring, trusting, long-term relationship; open and repeated negotiations for patient preferences for information; clear, straightforward presentation of the prognosis where desired; incorporation of strategies to ensure patient understanding; encouragement of hope and a sense of control; consistency of communication within the multidisciplinary team; and communication with other members of the family.<sup>15</sup> Through these communication strategies,

physicians hope to strike a balance between maintaining a patient's positive attitude and facilitating the preparation for possible death.<sup>9,16,17</sup>

The description of these strategies has been accompanied by only a few empirical studies that have specifically addressed the preferences and experiences of the family in receiving information about the patient's prognosis,<sup>18</sup> and familial views on optimal ways of presenting a prognosis have not been explored. In Japan, family members have a special role in communicating bad news, including prognoses.<sup>19</sup> Although many studies recommend that physicians disclose the prognosis first to the patient,<sup>11,20,21</sup> it is culturally approved that family members receive the information before the patient, and in Japan and other Asian countries, families are requested to decide how and to what degree the patient should be told.<sup>21–23</sup> It is also noteworthy that many Japanese patients agree to follow a family member's decision.<sup>24</sup> Therefore, family members are typically the first to receive the full medical information, whereas patients receive the information gradually, and often partially, based on their own or on their family members' preferences. For this reason, improvement in the methods of prognostic disclosure for family members is a major task for Japanese medical professionals.

A large survey was undertaken to help understand the methods of disclosure and opportunities for improvement in Japan. The primary aims were to 1) explore the experiences of

families of patients with cancer in Japan in receiving prognostic disclosure, 2) explore family perception of the way the prognosis was communicated, and 3) investigate relevant factors of family-perceived need for improvement.

## Methods

### Procedure

This study was part of a large cross-sectional, anonymous nationwide survey named the J-HOPE Study (Japan Hospice and Palliative Care Evaluation Study). The detailed methodology of this survey was described in a previous article.<sup>25</sup> All 153 palliative care units (PCUs) of Hospice Palliative Care Japan approved before September 2005 were recruited for this study, and 100 PCUs participated. We asked each institution to identify the bereaved family members of patients who died from November 2004 to October 2006 consecutively (up to 80 subjects from each institution). A total of about 8000 subjects were randomly allocated to receive 10 different questionnaire surveys. We mailed questionnaires to bereaved families in June 2007, and then again in August 2007 only to nonresponding families.

### Participants

Primary physicians identified potential participants based on the following inclusion criteria: 1) bereaved family member of an adult patient with cancer (one family member was selected for each patient), 2) at least 20 years of age, 3) capable of replying to a self-report questionnaire, 4) aware of the diagnosis of malignancy, and 5) no serious psychological distress recognized by the primary physician. The last criterion was adopted on the assumption that primary physicians could identify families who would suffer serious psychological burden by taking this survey. In total, 8402 subjects were assigned to the J-HOPE study, and 12 questionnaires including this study were randomly assigned to them.

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

### Questionnaire

The questionnaire was developed by the authors based on information from previous

studies<sup>15,17,26–28</sup> and extensive discussions among the authors. Content validity was confirmed by unanimous agreement of the authors. The primary endpoint was the family-perceived evaluation of prognosis communication that was provided by the physician who was in charge of the patient's treatment. As a result of the lack of previously validated instruments, the outcome parameters were developed by the authors similar to previous surveys. As an overall evaluation, we assessed the necessity for improvement, based on the answer to the question "How much improvement do you think was needed in the prognosis communication?" rated on a 4-point scale as 1: no improvement, 2: some improvement, 3: considerable improvement, and 4: much improvement.

In addition, family perception on amount of information, loss of hope, and usefulness of prognostic disclosure in preparation for patient death were assessed. The amount of information was rated on a 5-point scale as "much less than expected," "less than expected," "appropriate," "should have been a little less," and "should have been much less." For the other two aspects, the following questions were asked: "Did you lose hope after the prognosis communication?" and "Was the prognosis communication useful in preparing for the patient's death?" These questions were rated on a 5-point scale from 1: strongly disagree to 5: strongly agree.

The family members also were requested to report the level of prognostic disclosure they received, from 1: no disclosure (they did not receive any disclosure at all), 2: no answer (physician said "I don't know" or "I cannot answer"), 3: specific survival periods with some ranges or probability (e.g., several weeks or months), or 4: definite survival periods without ranges or probability (e.g., "until May" or "for three months"). We also asked about the amount of prognostic disclosure the patients received relative to their family members, from 1: no disclosure, 2: the same level of disclosure as the family received, 3: less specific information than the family received, or 4: more specific information than the family received.

In addition, we investigated 24 communication strategies derived from prior empirical studies on the assumption that physicians' communication skills could influence families'

emotional distress.<sup>12,18</sup> The family members were requested to rate their level of agreement with the listed physicians' communication behaviors on a 5-point Likert-type scale from 1: strongly disagree to 5: strongly agree, or with a yes-no format.

### Analysis

Descriptive analyses were carried out summarizing the participants' backgrounds and scores following psychological measurements. To explore the determinants of the family perception of prognostic disclosure, we initially screened 11 background variables (patient's age and sex, number of hospital days, type of cancer, bereaved family member's age, sex, relationship with the patient, health status during the caregiving period, frequency of attending to the patient, presence of other caregivers, and financial expenditure during the last month), the type of disclosure, family perception on amount of information, loss of hope, and usefulness of prognostic disclosure in preparation for patient death, and 24 communication strategies by univariate analyses. Univariate analyses were carried out with Student's *t*-test or the Chi-square test, where appropriate. To assess the results of the 31 comparisons, the *P*-value necessary for statistical significance was set at 0.002 (0.05/39) using the Bonferroni correction. For the comparisons, the respondents were classified into two groups: family members who rated the necessity for improvement as "some," "much," or "considerable" vs. "none." This cut-off point was determined on the basis of the actual

data distribution to divide the whole sample into approximately equal-sized comparison groups.

Next, a path analysis was carried out to test the model. All potential predictors with statistical significance by univariate analyses were entered in the model as independent variables.

We conducted all statistical analyses using SPSS version 11.0 (SPSS Inc., Chicago, IL) and AMOS version 5.0 (SPSS Inc., Chicago, IL).

### Results

Of the 427 questionnaires returned (response rate 64.4%), 409 were valid for statistical analyses. The rest ( $n = 18$ ) were invalid because of missing data on the primary endpoint, such as the necessity for improvement. Thus, the rate of valid replies was 61.9%. Table 1 summarizes the main background information for the family members. Only the participant's age was observed to be a significant predictor of necessity for improvement in the univariate analysis.

#### Family Reported Practices of Prognosis Disclosure

The types of prognostic disclosure received were no disclosure (7.6%,  $n = 31$ ), no answer (4.9%,  $n = 20$ ), specific survival periods with some ranges or probability (52.1%,  $n = 213$ ), and definite survival periods without ranges or probability (34.2%,  $n = 140$ ). Meanwhile, the types of prognosis communication that patients received were no disclosure (46.5%,  $n = 190$ ), same as family (29.6%,  $n = 121$ ),

Table 1  
Background of Participants

Characteristic	Total		No Improvement		Some or More Improvement		<i>P</i>
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	
Total	409		163		246		
Age (mean ± SD)	59 ± 12		61 ± 11		58 ± 12		0.004
Sex							
Male	114	27.9	46	28.2	68	27.6	0.345
Female	291	71.1	114	69.9	177	72.0	
Relationship to patient							
Spouse	203	49.6	83	50.9	120	48.8	0.176
Child	130	31.8	42	25.8	88	35.8	
Child-in-law	23	5.6	11	6.7	12	4.9	
Sibling	28	6.8	15	9.2	13	5.3	
Other	22	5.4	10	6.1	12	4.9	

SD = standard deviation.