

the reality and difficulties involved in palliative care for cancer patients at the regional level.

Therefore, this region-based comprehensive survey aimed to clarify 1) clinical exposure of GPs and DNs to cancer patients dying at home, 2) availability of symptom control procedures, 3) willingness to participate in out-of-hours cooperation and palliative care consultation services, and 4) reasons for admission of terminally ill cancer patients. The hypotheses of this study are that 1) in GPs, clinical exposure to cancer patients dying at home is not so high and some symptom control procedures are often unavailable, 2) in DNs, clinical exposure is high and symptom control procedures are generally available, 3) both GPs and DNs are willing to participate in out-of-hours cooperation and palliative care consultation services, and 4) DNs list various reasons for admission beyond medical reasons.

Health Care System Related to GPs, DNs, and Palliative Care in Japan

In Japan, there is no formal "family practice" or "general practitioner" system. Many clinic physicians functioning as GPs in the community are actually specialists, and after working at hospitals as specialists, they open their clinics under two or more specialty names irrespective of their certifications (e.g., a gastroenterologist usually can open a clinic under the names of "internal medicine," "pediatrics," and "gastroenterology"). The total number of clinics was about 90,000 in 2010, and all patients can visit any clinic and hospital they choose; they are not confined to their city or prefecture of residence.

Home nursing in Japan is provided through district nursing services. The number of district nursing services was 5763 in 2010. No expert palliative care nursing service (e.g., Macmillan nursing service) exists.

Since 1990, specialized palliative care service has been provided through palliative care units and inpatient hospices. The number of palliative care units was 208 (4153 beds) in 2010. Hospital palliative care teams are increasingly disseminated through cancer centers and general hospitals functioning as local cancer centers. The number of palliative care teams was about 500 in 2010. No community palliative care teams exist. Many health care professionals have regarded palliative care as a part of cancer

care. Although the concept of palliative care is not limited to cancer patients, we decided that this study should focus on palliative care for cancer patients.

Methods

This study was a cross-sectional mail survey of GPs and DNs in Japan and was a part of a regional intervention trial, the Outreach Palliative Care Trial of Integrated Regional Model (OPTIM) study. It was performed at the initial phase of the OPTIM study to explore the intervention protocols likely to be effective in each region; an overview of the OPTIM study is reported elsewhere.²¹

Questionnaires were sent to all GPs and DNs who met the inclusion criteria. No reminder or incentive was used. The ethical and scientific validity of this study was confirmed by the institutional review board.

Subjects

The survey was performed in four regions where the OPTIM study was used. Four areas with different palliative care systems were selected from across Japan: Tsuruoka (population 170,000, Yamagata prefecture); Kashiwa (population 670,000, Chiba prefecture); Hamamatsu (population 820,000, Shizuoka prefecture); and Nagasaki (population 450,000, Nagasaki prefecture). Kashiwa and Hamamatsu have specialized hospital palliative care teams in a cancer center and general hospitals, respectively; Nagasaki has a coordinated palliative care system for home patients in addition to hospital palliative care teams; and Tsuruoka had no formal specialized palliative care service at the time of the survey.

For this survey, we identified two groups of study subjects; a group of GPs and a group of DNs. The GPs all had a specialty of internal medicine, surgery, respiratory medicine, gastroenterology, urology, or gynecology. As there is no formal "family practice" or "general practitioner" system in Japan, we decided to include all specialties usually treating cancer patients. One questionnaire was sent to each GP clinic because many GP clinics are solo practice in Japan. The DNs comprised those working full time in a district nursing service. We had investigated the number of nurses

working at each district nursing service. Furthermore, we asked one representative DN from each district nursing service to answer questions relating to the service.

Measurements and Questionnaire

Because of a lack of validated tools and the exploratory nature of this study, the questionnaire was developed for this survey through literature review and discussions among authors.⁷⁻¹⁸ The clinical exposure of GPs and DNs to cancer patients dying at home was measured by 1) the number of cancer patients dying at home per year seen by each service (GP clinic or district nursing service), and 2) the predicted number of cancer patients dying at home likely to be seen by each service if out-of-hours cooperation among community health care providers and palliative care consultation services were available. The selected choices were none; one to five patients; six to 10 patients; 11 to 20 patients; or more than 20 patients per year. Furthermore, we investigated whether each service was available 24 hours a day.

The availability of symptom control procedures was measured using the choices "unavailable," "available if expert advice available," and "available" for each procedure, including oral opioids, subcutaneous opioids, subcutaneous haloperidol, home parenteral nutrition, peripheral intravenous infusion, hypodermoclysis, drainage of ascites or pleural effusion, and transfusion. "Expert" was described as expert only in the questionnaire because some physicians may not know palliative care specialists.

Willingness to participate in new regional systems was measured using two potential systems: out-of-hours cooperation among community health care providers (positive, neutral, and not interested), and palliative care consultation service in the community (want regular outreach visits, want on-demand consultation, and not interested). At the time of this study, neither system (out-of-hours cooperation among community health care providers, palliative care consultation in the community) was available in any of the four regions.

In addition, we asked all the DNs to consider the reason for admission of terminally ill cancer patients who they had cared for at home and rate the frequency of each of the following reasons, using a five-point Likert-type scale (1: none to 5: always): physical symptoms,

delirium, concern about out of hours, unexpected change in physical condition, family physician absent or inaccessible out of hours, unavailability of home care nurses, lack of informal caregivers, and family burden of caregiving.

Background data also were obtained from DNs concerning their age, clinical experience as a nurse, and their clinical experience as a DN. Data requested from GPs included their age, clinical experience, and whether their GP clinic was a certified home care clinic. Certified home care clinics are a recently developed medical system in Japan, whereby if the GP clinic has a 24-hour on-call system for patients at home, the clinic receives more payments from the national health care insurance.

Statistical Analyses

Data distributions, as well as 95% confidence intervals of the percentages, were calculated for all items. The difference among the regions was not statistically significant (data not shown) with the sample size small, and we determined to analyze all the data for this study.

Results

Of the 1106 GP clinics identified, a total of 235 (21%) responded. Responses were received from 22 of 88 clinics in Tsuruoka, 41 of 196 clinics in Kashiwa, 67 of 331 clinics in Hamamatsu, and 105 of 491 clinics in Nagasaki. Of the 70 district nursing services identified, a total of 56 services (80%) responded; a total of 115 responses were obtained from 270 DNs identified. Table 1 summarizes the background of the respondents.

Half of the GPs reported that they saw no cancer patients dying at home per year, and

Table 1
Background of Respondents

Characteristic	<i>n</i> ± SD
General practitioners (<i>n</i> = 235)	
Age (y)	57 ± 11
Clinical experience (y)	30 ± 11
Certified home care clinic, <i>n</i> (%)	30 (13)
District nurses (<i>n</i> = 115)	
Age (y)	42 ± 7.7
Clinical experience as a nurse (y)	18 ± 7.5
Clinical experience as a district nurse (y)	6.7 ± 4.5

Data are expressed as mean ± standard deviation unless otherwise noted.

Table 2
Number of Cancer Patients Dying at Home Seen by GP Clinics or District Nursing Services

Number of Cancer Patients Dying at Home (Per Year)	GP Clinics (n = 235)		District Nursing Services (n = 56)	
	n (%), 95% CI	If Out-of-Hours Cooperation Among Community Health Care Providers and Palliative Care Consultation Service Available, n (%), 95% CI	n (%), 95% CI	If Out-of-Hours Cooperation Among Community Health Care Providers and Palliative Care Consultation Service Available, n (%), 95% CI
None	125 (53, 47–60)	113 (48, 42–55)	4 (7, 3–17)	6 (11, 5–22)
1–5	80 (34, 28–40)	80 (34, 28–40)	19 (34, 23–47)	12 (21, 13–34)
6–10	15 (6, 4–10)	19 (8, 5–12)	14 (25, 15–38)	13 (23, 14–36)
11–20	7 (3, 1–6)	9 (4, 2–7)	10 (18, 10–30)	11 (20, 11–32)
20 or more	1 (0.4, 0–2)	6 (3, 1–5)	7 (13, 6–24)	13 (23, 14–36)

95% CI = 95% confidence interval.

40% cared for one to 10 cancer patients dying at home (Table 2). Of the district nursing services, 30% cared for 10 or more cancer patients dying at home per year, and 60% cared for one to 10 such patients. Although 96% of district nursing services ($n = 54$) were available 24 hours a day, only 38% of GP clinics ($n = 90$) were available 24 hours a day.

If out-of-hours cooperation among community health care providers and a palliative care consultation service became available, the number of GPs and district nursing services that reported they would not see any cancer patients dying at home did not change considerably (53% to 48% for GP clinics, and 7% to 11% for district nursing services (Table 2). However, the number of GPs and district nursing services that reported they would see 20 or more cancer patients dying at home per year increased considerably, from 0.4% to 2.3% for GP clinics and 13% to 23% for district nursing services.

Oral opioids, subcutaneous opioids, and subcutaneous haloperidol were available from more than 80% of district nursing services if expert advice was available, whereas 34% of GPs reported oral opioids were unavailable, and approximately 50% reported subcutaneous opioids or haloperidol were unavailable, even if expert advice was available (Table 3). Peripheral intravenous infusion was available from about 70% of GPs and about 90% of district nursing services, whereas hypodermoclysis was available from less than 60% of GP clinics and about 70% of district nursing services. Drainage of ascites or pleural effusion and transfusions were rated as unavailable by

more than 50% of GP clinics and district nursing services.

Concerning the out-of-hours cooperation among community health care providers, only 20% or fewer of GP clinics and district nursing services reported feeling “positive,” and 35% of GPs reported no interest (Table 4). However, palliative care consultation service in the community was regarded as more necessary, with about half the GP clinics and district nursing services wanting on-demand consultation, and an additional 24% of GPs and 41% of district nursing services reporting that they wanted regular outreach visits.

Reasons for admission of terminally ill cancer patients that DNs had cared for at home are shown in Table 5. Family burden of caregiving was the most frequent reason given by DNs, with about 60% reporting this as “often” or “always.” The next most frequent reason was unexpected change in physical condition (about 40%), followed by uncontrolled physical symptoms (about 30%), and delirium (about 30%). Concern about out of hours, the family physician absent or inaccessible out of hours, lack of home care nurses, or lack of informal caregivers was infrequently listed.

Discussion

We believe this survey provides useful insights into the development of community palliative care services in Japan and also helps us understand how to deliver more effective palliative care through existing community health care services around the world.

Table 3
Availability of Symptom Control Procedures for GPs and District Nursing Services

Procedure Variation	GP Clinics (n = 235)			District Nursing Services (n = 56)		
	Unavailable n (%), 95% CI)	Available if Expert Advice Available n (%), 95% CI)	Available n (%), 95% CI)	Unavailable n (%), 95% CI)	Available if Expert Advice Available n (%), 95% CI)	Available n (%), 95% CI)
Oral opioids	81 (34, 29-41)	85 (36, 30-43)	59 (25, 20-31)	1 (2, 0-10)	30 (54, 41-66)	24 (43, 31-56)
Subcutaneous opioids	121 (51, 45-58)	82 (35, 29-41)	23 (10, 7-14)	6 (11, 0-22)	42 (75, 62-85)	6 (11, 5-22)
Subcutaneous haloperidol	113 (48, 42-55)	90 (38, 32-45)	24 (10, 7-15)	6 (11, 0-22)	42 (75, 62-85)	5 (9, 4-19)
Home parenteral nutrition	116 (49, 43-56)	68 (29, 23-35)	43 (18, 14-24)	3 (5, 2-15)	21 (38, 26-51)	32 (57, 44-69)
Peripheral intravenous infusion	57 (24, 19-30)	63 (27, 22-33)	104 (44, 38-51)	2 (4, 1-12)	18 (32, 21-45)	35 (63, 49-74)
Hypodermoclysis	95 (40, 34-47)	100 (43, 36-49)	33 (14, 10-19)	15 (27, 17-40)	35 (63, 49-74)	5 (9, 4-19)
Drainage of ascites/pleural effusion	118 (50, 44-57)	56 (24, 19-30)	52 (22, 17-28)	31 (55, 42-68)	20 (36, 24-49)	5 (9, 4-19)
Transfusion	131 (56, 49-62)	49 (21, 16-27)	47 (20, 15-26)	28 (50, 37-63)	24 (43, 31-56)	4 (7, 3-17)

95% CI = 95% confidence interval.

One of the most important results of this study was the finding that Japanese GPs had little exposure to cancer patients dying at home. This figure is comparable to the largest survey conducted to date in Japan, which reported that 60% of all GPs had no experience in caring for cancer patients who died at home.¹⁹ This is different than results from studies in Canada, the U.K., and Australia, which showed that almost all GPs in those countries have some experience in caring for terminally ill cancer patients dying at home.¹¹ One possible interpretation of our results is that many GPs in Japan are former "specialists" who worked in hospitals, and a considerable number of physicians are unfamiliar with managing cancer patients (e.g., cardiology). In addition, Japanese GPs have no formal responsibility in the health care system for caring for patients in the community of their clinics, and cancer patients usually receive medical treatments in hospitals. Nonetheless, a third of Japanese GPs had experience in caring for one to five terminally ill cancer patients dying at home per year. This result is consistent with previous findings from the U.K. and Australia, where a GP sees about five terminally ill cancer patients per year.¹¹ Our results highlight the difficulties faced by Japanese GPs in learning up-to-date skills in palliative care when they only have minimal exposure to terminally ill cancer patients. This finding suggests that easily available on-demand consultation services from palliative care experts are necessary.

In this survey, hypothetical out-of-hours cooperation among community health care providers and the availability of palliative care consultation services in the region did not noticeably increase the number of GPs that intended to see terminally ill cancer patients at home. In addition, 30% of GPs reported no interest in participating in or developing such regional palliative care services. This figure is very close to the finding from an Australian survey, which identified lack of interest as one of the most frequent reasons for GPs not participating in palliative care.¹² Similarly, a U.K. survey reported that about 30% of London GPs believed "palliative care at home should be handed over to specialists."¹³ In contrast, the number of GP clinics and district nursing services that reported they would care for 20 or more cancer patients dying at home considerably increased in

Table 4
Willingness to Participate in Out-of-Hours Cooperation and Palliative Care Expert Consultation

Item	GPs (n = 235), n (%), 95% CI	District Nursing Services (n = 56), n (%), 95% CI
Out-of-hours cooperation among community health care providers		
Positive	33 (14, 10–19)	11 (20, 11–32)
Neutral	106 (45, 39–52)	40 (71, 58–82)
Not interested	82 (35, 29–41)	5 (9, 4–19)
Palliative care consultation service		
Want regular outreach visits	56 (24, 19–30)	23 (41, 29–54)
Want on-demand consultation	101 (43, 37–49)	29 (52, 39–64)
Not interested	63 (27, 22–33)	4 (7, 3–17)

CI = 95% confidence interval.

response to this question in our study. Taken together, these findings show that about 70% of GPs around the world believe that palliative care is one of their essential tasks, but the remaining 30% are unwilling to care for terminally ill cancer patients because of the balance between other occupational and personal responsibilities and/or lack of interest.^{12,13} Development of a regional system, therefore, should be intended to support those GPs who already care for terminally ill cancer patients at home or are interested in caring for such patients so that they see more patients with a minimum increase in their workload. To increase the total number of GPs in the community with interest in palliative care might require political or social intervention strategies.

The second important finding of this study is the clarification of the availability of symptom control procedures in Japan. District nursing services reported a variety of opioids available, but 35% of GPs reported that oral opioids were unavailable, even if expert advice was available, and 50% reported that

subcutaneous opioids or haloperidol were unavailable. In contrast, previous studies from Australia and the U.K. demonstrated that GPs were, in general, familiar with the use of opioids but less confident or experienced difficulties dealing with psychiatric symptoms and/or the use of home care technology.^{11,12,14} Possible interpretations of these findings are the strict regulation of opioids in the community in Japan, the lack of opportunity in medical education regarding opioid medications, and the lack of a coordinated system to support home care technology.²² Although peripheral intravenous infusion was available in many situations for medically assisted hydration at home, hypodermoclysis was less readily available despite existing evidence that hypodermoclysis is more convenient and safer than intravenous access.²³ In addition, the fact that drainage of ascites or pleural effusion and transfusions were unavailable in 50% of GP clinics and district nursing services could be partly because they are time-consuming procedures and not only the result of

Table 5
Reasons for Admission of Terminally Ill Cancer Patients After Care at Home From the District Nurse's Perspective (n = 115)

Reason for Admission	None n (%), 95% CI	Rarely n (%), 95% CI	Sometimes n (%), 95% CI	Often n (%), 95% CI	Always n (%), 95% CI
Physical symptoms	9 (8, 4–14)	28 (24, 17–33)	32 (28, 20–37)	32 (28, 20–37)	5 (4, 2–10)
Delirium	17 (15, 9–22)	38 (33, 25–42)	24 (21, 14–29)	27 (23, 17–32)	9 (8, 4–14)
Concern about out of hours	48 (42, 33–51)	17 (15, 9–22)	18 (16, 10–23)	18 (16, 10–23)	5 (4, 2–10)
Unexpected change in physical condition	6 (5, 2–11)	20 (17, 12–25)	32 (28, 20–37)	41 (36, 27–45)	8 (7, 4–13)
Family physician absent or inaccessible out of hours	46 (40, 31–49)	25 (22, 15–30)	19 (17, 11–24)	15 (13, 8–20)	4 (4, 1–9)
Lack of home care nurses	67 (58, 49–67)	21 (18, 12–26)	11 (10, 5–16)	7 (6, 3–12)	1 (1, 0–5)
Lack of informal caregivers	38 (33, 25–42)	32 (28, 20–37)	25 (22, 15–30)	8 (7, 4–13)	4 (4, 1–9)
Family burden of caregiving	5 (4, 2–10)	17 (15, 9–22)	24 (21, 14–29)	55 (48, 39–57)	10 (9, 5–15)

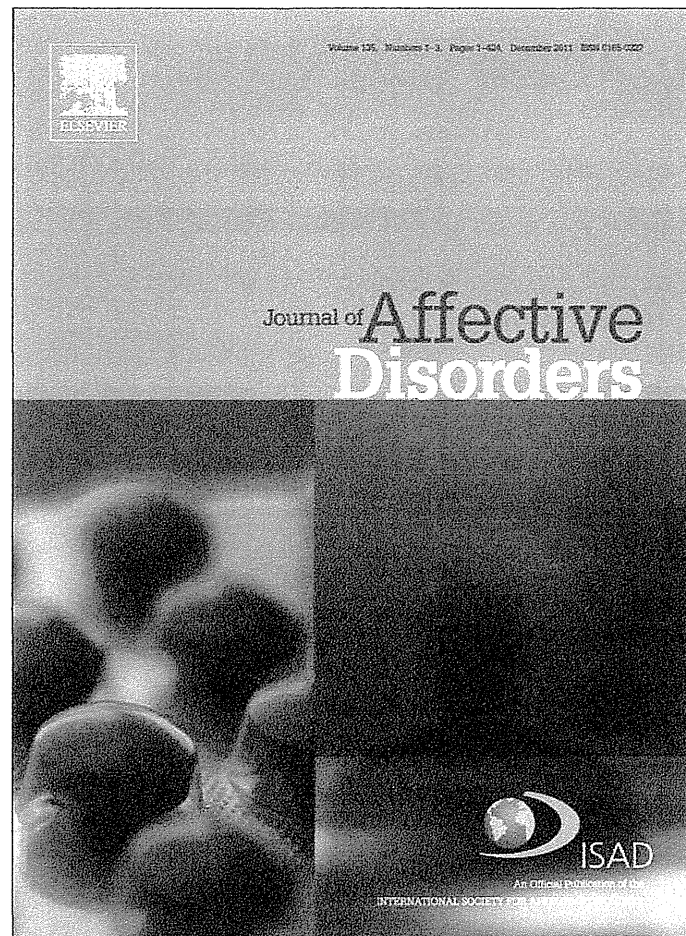
95% CI = 95% confidence interval.

Japan. The authors made no other financial disclosures and declare no conflicts of interest.

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Research report

The relationships between complicated grief, depression, and alexithymia according to the seriousness of complicated grief in the Japanese general population

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ABSTRACT

Background: The present research investigated whether the relationship between alexithymia and complicated grief was different from the relationship between alexithymia and general depressive symptom according to the seriousness of complicated grief in the Japanese general population.

Methods: In the Japanese general population sample, 948 participants between 40 and 79 years old (effective response rate, 48.0%) completed a cross-sectional anonymous questionnaire about alexithymia, depression, and complicated grief. To compare the high risk ($n = 243$) and low risk ($n = 705$) of complicated grief groups, simultaneous analysis of two groups with standard maximum likelihood estimation was performed and six hypothesized models were verified.

Results: The model ($RMSEA = 0.047$, $AIC = 71.520$) that showed that the path coefficients of the latent variable of alexithymia to the observed variables were equal and that the path coefficient of alexithymia to psychological distress was equal was adopted. The contribution ratios from alexithymia to complicated grief were apparently smaller (2–4%) than those to depression (37–38%).

Conclusions: Our findings showed that alexithymia scarcely contributed to complicated grief compared to depression and that the contribution ratio in the high risk group was lower than that in the low risk group. The contribution of the latent variable of psychological distress to complicated grief and depression was lower in the high risk group than in the low risk group. The lack of a correlation between alexithymia and complicated grief might indicate that there are different mechanisms underlying the symptoms of alexithymia and complicated grief.

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1. Introduction

Maciejewski et al. (2007) empirically found that natural psychological responses to grief, such as disbelief, yearning,

anger, and depression, peak within 6 months following the death of significant others. Most people who experience bereavement overcome their natural emotional response to bereavement. However, integration of the loss does not occur and acute grief becomes more intensive and continuous in the form of complicated grief (Shear and Shair, 2005).

Individuals with complicated grief experience a constellation of symptoms that often include preoccupation with the lost person, anger about the death, and avoidance of reminders

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of the loss (Ogrodniczuk et al., 2005). Although it is widely recognized that symptoms of normal grief are similar to those of depression, there are distinctions between depression and complicated grief in phenomenology, psychophysiology, and responses to treatment (Lichtenthal et al., 2004). Previous research found that complicated grief does not respond well to proven efficacious treatments for depression (Reynolds et al., 1999; Zygmunt et al., 1998). The prevalence rates of complicated grief reported by epidemiological studies on the non-clinical population were 4.2% (Middleton et al., 1996), 24.6% (Chiu et al., 2009), and 2.4% (Fujisawa et al., 2010).

To improve the treatment of complicated grief, it is necessary to investigate the characteristics that effectively buffer complicated grief. Alexithymia, a patient characteristic that influences psychological distress in depression, has been found to influence a patient's response to psychotherapy (McCallum et al., 2003; Taylor, 2000). Ogrodniczuk et al. (2005) found that the negative influence of alexithymia on general symptoms, for example, anxiety, depression, and interpersonal distress, was buffered by psychotherapy. Taylor et al. (1997) found the following three core features of alexithymia: (1) difficulty in identifying feelings, (2) difficulty in communicating feelings, and (3) externally oriented thinking. This three-factor characterization of alexithymia has become the standard for describing the construct (Ogrodniczuk et al., 2005). Of note, alexithymia is not a psychiatric disorder, but rather a characterization of thinking, feeling, and relating processes among patients with a wide range of psychiatric diagnoses.

There has been a sizeable amount of theoretical and empirical work on the relationships between alexithymia and general depressive symptoms (Lipsanen et al., 2004; Ogrodniczuk et al., 2005). Statistically, Lipsanen et al. (2004) demonstrated that depression and alexithymia are highly correlated but distinct. Parker et al. (1991) have summarized the possible causes of overlap between alexithymia and depression as follows. First, the manifestation of alexithymic features might be a transitory reaction (secondary alexithymia) evoked by stressful situations and the accompanying depression and anxiety. Second, secondary alexithymia is a defensive response to the acute depression that typically accompanies stressful situations. Finally, it is a response to overall changes in the quality of life, and not depression per se, that is associated with the manifestation of secondary alexithymia. Furthermore, in some patients, secondary alexithymia may become permanent and indistinguishable from primary (i.e., trait) alexithymia (Parker et al., 1991).

However, few researches have been conducted on the relationship between complicated grief and alexithymia, and none have been conducted in Japan. For example, Ogrodniczuk et al. (2005) found that alexithymia (except for externally oriented thinking) did not correlate with complicated grief, for example, intrusion, pathological grief, and avoidance. A question related to the difference between complicated grief and general depression symptom is as follows: how different is the relationship between the extent of complicated grief and alexithymia from the relationship between depressive symptoms and alexithymia according to the seriousness of complicated grief? The investigation of complicated grief's relationship with alexithymia, which is related to feeling and expressing emotion, will be helpful in understanding and treating complicated grief. In addition, as there are both distinctions and similarities between complicated grief and

depressive symptom, it may be necessary to simultaneously and separately explore how extent complicated grief relates to general depressive symptoms.

The aim of the current study was to investigate whether the relationship between alexithymia and complicated grief differs from the relationship between alexithymia and general depressive symptom according to the seriousness of complicated grief. The hypothesis model of the relationships between alexithymia, depression symptom, and complicated grief is shown in Fig. 1.

2. Methods

2.1. Procedures

A cross-sectional anonymous questionnaire was administered to a sample of the general Japanese population. Four target areas (Tokyo, Miyagi, Shizuoka and Hiroshima prefectures) were identified to obtain a wide geographic distribution for the nationwide sample. The four areas included an urban prefecture (Tokyo) and mixed urban–rural areas (Miyagi, Shizuoka and Hiroshima).

Initially, 5000 subjects aged 40–79 years were identified by a stratified two-stage random sampling method of residents of the four areas. Fifty census tracts were randomly selected for each area and then 25 individuals were selected within each census tract, thus identifying 1250 individuals for each area. Questionnaires were mailed to potential participants in June 2009, and reminder postcards were sent 2 weeks later. The ethical and scientific validity of this study was confirmed by the institutional review boards of graduate medicine in Tokyo University.

2.2. Measures

Alexithymia was assessed by the Japanese version of the Toronto Alexithymia Scale-20 (TAS-20) (Bagby et al., 1994; Komaki et al., 2003). This scale is a self-report questionnaire that is constructed by the following three factors: “difficulty identifying feelings”, “difficulty describing feelings”, and “externally oriented thinking.” Twenty items are asked, using a five-point Likert scale (1: absolutely disagree, 2: somewhat disagree, 3: neutral, 4: somewhat agree, and 5: absolutely agree). Content and concurrent validity and reliability of this scale were confirmed.

Complicated grief was assessed by the Brief Grief Questionnaire (BGQ) (Shear et al., 2006). The BGQ is a five-item, self-report questionnaire that inquires about difficulty accepting death, interference of grief in their life, difficulty of

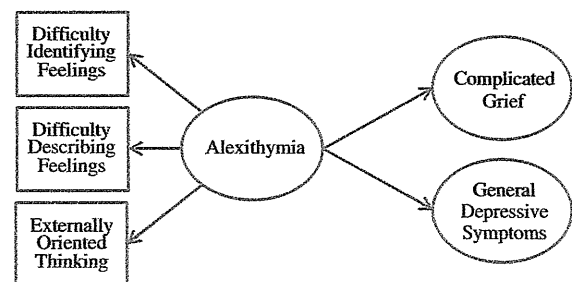


Fig. 1. Hypothesis model for the relationship between alexithymia and complicated grief.

images or thoughts of death, avoidance of things related to the deceased, and feeling cut off or distant from other people. The answers are rated as 0, not at all; 1, somewhat; or 2, a lot. A past report suggests that a total score on the BGQ of 8 or higher is indicative of complicated grief; between 5 and 7 of probable complicated grief; and less than 5 of no complicated grief (Shear et al., 2006). A diagnosis of complicated grief should not be given within six months after bereavement (Prigerson et al., 2009); therefore, those who had experienced bereavement within the past six months were excluded. In addition, those who had experienced bereavement with their children were also excluded because grief over children's death has been consistently reported to be prolonged, and the diagnostic reliability of complicated grief among this population has been questioned (Dyregrov et al., 2003; Stroebe et al., 2007).

General depressive symptom was assessed by K6 (Furukawa et al., 2003; Kessler et al., 2002). K6 is a six-item self-assessment scale that measures the extent of decreasing self-esteem and feelings of depression and hopelessness. The answers are rated on a five-point Likert scale. Content and concurrent validity and reliability of this scale were confirmed.

Demographic data were obtained including age, gender, time of recent bereavement, relationship with the deceased, cause and place of death of the deceased, and days spent with the deceased during the last week of the end-of-life period, whether the bereavement was expected or not, and whether the participant had been a caregiver of the deceased or not.

2.3. Participants

Of the 5000 questionnaires that were distributed, 44 were undeliverable and 1975 were returned (Response rate: 39.9%). Of these, 117 were excluded due to missing data. Of the remaining questionnaires, 792 were excluded because the respondents had not experienced bereavement within the past ten years, 114 because of bereavement within the past six months, and 4 because of bereavement with their children. Thus, 948 responses were analyzed (effective response rate, 48.0%).

2.4. Statistical analysis

The presence of complicated grief was defined using the abovementioned cutoff score, according to previous research (Shear et al., 2006). Using PASW version 18 (Polar Engineering and Consulting, 2009), ANOVA was conducted to investigate differences in complicated grief by demographic variables and factors related to bereavement.

To investigate whether the relationship between alexithymia and complicated grief differs from the relationship between alexithymia and depressive symptom according to the seriousness of complicated grief, a simultaneous analysis of two groups was performed with AMOS version 18 (Arbuckle, 1983–2009), with standard maximum likelihood estimation. Six hypothesized models were compared. The models were as follows: 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; and model 5: in addition to model 3, the path coefficient of alexithymia to psychological distress is equal.

Indices of fit of the model to the data were evaluated with several statistics: goodness of fit index (GFI) of .95 or greater, adjusted goodness of fit index (AGFI) of .90 or greater, the comparative fit index (CFI) of .95 or greater, the root mean square error of approximation (RMSEA) less than or equal to .05, a chi-squared that was not significant ($p > .05$), and Akaike's Information Criterion (AIC).

3. Results

According to previous research, the participants were divided to three groups: high risk of complicated grief ($n = 25$), probable complicated grief ($n = 218$), and low risk of complicated grief ($n = 705$). It might be appropriate to compare three groups; however, the high risk group of complicated grief with the group of probable complicated grief were combined and regarded as the high risk group (a score of 5–10) because the number of participants in the high risk group of complicated grief was insufficient for conducting simultaneous analysis. In the present results, we compared two groups: the high risk of complicated grief ($n = 243$) and low risk of complicated grief ($n = 705$).

The results of the ANOVA that investigated differences by demographic variables and factors related to bereavement are shown in Table 1. Females experienced higher complicated grief than males ($t(918) = -2.675, p < .01$). Of the factors related with bereavement, the relationship with the deceased ($F(4, 943) = 22.300, p < .001$), primary caregiver ($t(929) = 6.229, p < .001$), cause of death ($F(3, 941) = 13.072, p < .001$), place of death ($F(4, 943) = 3.653, p < .01$), expected death ($t(866) = -3.369, p < .001$), and days spent with the deceased during the end-of-life period ($F(3, 864) = 13.001, p < .001$) were significant. Age and time since bereavement were not statistically significant. As for the relationship with the deceased, spouses of the deceased experienced the highest complicated grief compared to the other groups. Parents and siblings of the deceased experienced higher complicated grief than parents-in-law and others. There were no significant differences between parents and siblings or between parent-in-laws and others. Primary caregivers scored higher on complicated grief than those who were not primary caregivers. Cancer and cardiac disease caused more serious complicated grief than other causes of death. As for the place of death, those who lost their significant person in a care facility experienced higher complicated grief than others. In addition, the group of unexpected death experienced a higher complicated grief score than expected death. Among the groups of days spent with the deceased, the groups of everyday and 4–6 days per week scored higher on complicated grief than the groups of 1–3 days per week and none.

Pearson's correlation coefficients between variables are shown in Table 2. The results showed that the correlation coefficients between complicated grief and general depressive symptoms were significant (the high risk group; $r = 0.211$, the low risk group; $r = 0.190$, the same order shall apply hereinafter). To avoid modeling the subscales of complicated grief and

Table 1

The relationships of demographic variables/factors related to bereavement and complicated grief (n=948).

	n	Mean	SD	F or t
<i>Gender</i>				
Male	387	2.76	2.05	$t(918) = -2.675^{**}$
Female	533	3.14	2.19	
<i>Age</i>				
40–49	215	2.90	2.24	$F(3, 926) = 0.676$
50–59	340	2.98	2.07	
60–69	363	3.04	2.18	
70–79	12	3.74	2.39	
<i>Relationship with the deceased</i>				
Spouse	62	4.85	1.76	$F(4, 943) = 22.300^{***}$
Parent(s)	458	3.11	2.19	
Parent(s)-in-law	245	2.41	1.86	
Sibling(s)	88	3.65	2.15	
Others	95	2.32	2.14	
<i>Primary caregiver</i>				
Yes	457	3.46	2.18	$t(929) = 6.229^{***}$
No	487	2.59	2.07	
<i>Time since bereavement</i>				
6–12 months	110	3.04	2.11	$F(9, 938) = 0.864$
1–2 years	140	3.26	2.31	
2–3 years	135	2.83	2.13	
3–4 years	117	2.80	2.17	
4–5 years	87	2.98	2.20	
5–6 years	84	2.89	2.13	
6–7 years	96	3.12	2.10	
7–8 years	60	2.88	2.31	
8–9 years	48	2.90	2.04	
9–10 years	71	3.45	2.08	
<i>Cause of death</i>				
Cancer	350	3.42	2.20	$F(3, 941) = 13.072^{***}$
Stroke	94	2.99	2.22	
Cardiac disease	110	3.46	2.08	
Others	391	2.52	2.04	
<i>Place of death</i>				
Home	173	2.88	2.13	$F(4, 943) = 3.653^{**}$
General hospital	645	3.06	2.15	
Hospice/PCU	32	3.41	2.34	
Care facility	62	2.27	2.09	
Others	36	3.84	2.31	
<i>Expected death</i>				
Expected	564	2.84	2.13	$t(866) = -3.369^{***}$
Unexpected	304	3.36	2.20	
<i>Days spent with the deceased during the end-of-life period</i>				
Everyday	215	3.62	2.25	$F(3, 864) = 13.001^{***}$
4–6 days/week	93	3.61	2.12	
1–3 days/week	221	2.80	2.00	
None	339	2.62	2.13	

** $p < .01$, *** $p < .001$.

general depressive symptoms as factors of alexithymia, an underlying latent variable labeled “psychological distress” was assumed. Also, we assumed that “alexithymia” was the underlying construct between difficulty identifying feelings, difficulty describing feelings, and externally oriented thinking because of the high correlation coefficients between them ($r = 0.340$ – 0.618 and $r = 0.415$ – 0.650 , respectively).

The fit indices of these models are shown in Table 3. As shown in Table 3, model 4 (with RMSEA = 0.047, AIC = 71.520)

yielded values smaller than the values of the other models, and thus was the correct result. Model 4 showed that the path coefficients of the latent variable of alexithymia to observed variables were equal and that the path coefficient of alexithymia to psychological distress was equal. The standardized path coefficients are shown in Fig. 2. The standardized indirect effect coefficients (contribution ratio) from alexithymia to complicated grief were 0.200 (4%) in the low risk group of complicated grief and 0.137 (2%) in the high risk of complicated grief group. The standardized indirect effect coefficients (contribution ratio) from alexithymia to general depressive symptom were 0.608 (37%) in the low risk of complicated grief group and 0.616 (38%) in the high risk of complicated grief group. Overall, the final model accounted for 66% of the variance in the latent variable of psychological distress.

4. Discussion

The results of the current study have advanced our understanding of the relationship between alexithymia, complicated grief, and general depressive symptom in the Japanese general population. The findings showed that the relationship between alexithymia and complicated grief differed according to the seriousness of complicated grief. In other words, alexithymia scarcely contributed to complicated grief, especially in the high risk of complicated grief group, and the contribution ratio in the high risk group was lower than in the low risk group. In addition, the relationship of complicated grief and general depressive symptom with alexithymia differed in both groups, as previous research has shown (Ogrodniczuk et al., 2005). The contribution of the latent variable of psychological distress to complicated grief and general depressive symptoms was lower in the high risk group than in the low risk group.

As for demographic variables and factors related to bereavement, the present results supported previous research. First, the complicated grief score was significantly related to gender, which is consistent with previous research (Boelen et al., 2006). However, because some research did not find a gender difference (Boelen and van den Bout, 2003), further investigation is necessary. Second, the relationship with the deceased was an important factor of complicated grief, which supported the previous research that indicated the important role played by close kinship in complicated grief (Gana and K'Delant, 2011; Johnson et al., 2007). The present result suggested that spouses of the deceased experienced the highest complicated grief, whereas, there was no significant difference between parents-in-law and others. Therefore, the impact of the death of significant others was likely influenced by the degree of kinship or direct blood relationships. Finally, as for primary caregivers and days spent with the deceased, these variables might be related to each other. All of these variables were quantity (not quality) aspects of the relationship with the deceased. Thus, primary caregivers might be those who were close relatives and might have spent more time with the deceased.

Interestingly, alexithymia, which had been found to influence patients' response to psychotherapy (Ogrodniczuk et al., 2005), showed different relations to complicated grief according to the seriousness of complicated grief. It suggests that, in the high risk group of complicated grief, alexithymia may not directly influence the improvement of complicated grief. In

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.

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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;
End-of-life care;
Difficulties felt by
ICU nurses;
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 α 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 α 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 α 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	α
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

α : Cronbach's alpha coefficient.

Table 4 The Nursing Job Stressor Scale (NJSS).

	Mean \pm SD	α
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

α : 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 ≤ 2 and ≥ 4 were eliminated, along with 4 items showing an ICC ≤ 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 α 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 ± 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 α coefficient for "converting from curative care to end-of-life care" was lower than that for the other four factors. Cronbach's α coefficients ≥ 0.7 are considered desirable, but reconsideration is needed in cases showing coefficients ≤ 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 α 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 α 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 ≥ 0.7 for the other four factors. An ICC of 0.61–0.8 is said to be "substantial," and that of ≥ 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	α	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

α : 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*	-0.16*	-0.4**	0.14*	0.15*
<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.

* $p < 0.05$ (Pearson's correlation coefficient).

** $p < 0.001$ (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***	0.21**	0.11	0.24***
<i>p</i> -Value	0.11	<0.001	0.001	0.11	<0.001
Nursing role conflict	0.09	0.2**	0.16*	0.08	0.04
<i>p</i> -Value	0.19	0.002	0.02	0.25	0.51
Conflict with physicians/autonomy	0.23***	0.31***	0.13	0.18**	0.27***
<i>p</i> -Value	<0.001	<0.001	0.05	0.01	<0.001
Dealing with death and dying	0.14*	0.15*	0.1	0.08	0.19**
<i>p</i> -Value	0.04	0.02	0.15	0.26	0.004
Qualitative work load	0.05	0.12	0.26***	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**	0.18**	-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**	-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.

* $p < 0.05$ (Pearson's correlation coefficient).

** $p < 0.01$ (Pearson's correlation coefficient).

*** $p < 0.001$ (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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