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Original Paper

Difficulties Felt by Nurses Providing End-of-Life Care in an Intensive Care Unit in Japan : A Nationwide Survey

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ICU 看護師の終末期ケアに関する困難感：全国調査の結果から

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Intensive care unit nurses often experience difficulties when providing end-of-life care in Japan. However, the areas of difficulties, how strongly the difficulties are felt, and their relationships to other factors are unclear. Thus, we aimed to clarify difficulties experienced by intensive care unit nurses who provide end-of-life care and to elucidate the associated factors. A cross-sectional nationwide survey was conducted at hospitals in Japan. A scale to measure the “difficulties felt by intensive care unit nurses providing end-of-life care” (DFINE), consisting of five domains, was used. Related factors were identified using simple and multiple regression analyses. One domain, “Difficulties are related to the end-of-life environment,” corresponded to the highest score (mean±standard deviation : 3.6±0.8/5). The results of the simple and multiple regression analyses showed that the item “Nurses are unable to become involved in the decision to either continue or discontinue life-prolonging treatment because physicians make that decision” was strongly related to all domains for “difficulties felt by intensive care unit nurses providing end-of-life care” (DFINE) (p<0.001). Overall, intensive care unit nurses need to be involved in decision-making related to life-prolonging treatment to improve end-of-life care.

1. Introduction

The intensive care unit (ICU) is designated for the recovery of critically ill patients. However, it has been reported that in Japan, anywhere from 10% to 30% of patients in ICUs are patients who eventually die there[1-4]. Since end-of-life care is not one of the ICUs’ original purposes, ICU nurses experience a variety of difficulties associated with treating end-of-life care. The results of a survey of ICU nurses in Japan indicated that approximately 70% of those surveyed responded that they thought “it is

more difficult to care for patients who eventually die and their families when the patients are in the ICU than when they are in a general care hospital ward[5,6]." The reasons for this were : 1) the end-of-care environment in ICUs ; 2) insufficient time to provide care ; 3) the experiencing of many types of deaths in the ICU, from sudden deaths to unexpected deaths ; 4) the difficulty family members' have with accepting the patient's death since they have a strong desire to see the patient recover ; and 5) the impossibility of knowing the patient's wishes and desires concerning their death[5,6]. Worldwide, there have been reports indicating the existence of obstacles and barriers to providing end-of-life care in the ICU for many years[7-14]. Furthermore, the decision-making process has been found to be more difficult in cases where treatment withdrawal or withholding at the end of the patient's life is being considered[15]. These complications, along with those that occur as a result of differing perceptions of physicians and nurses[16] and problems related to multidisciplinary cooperation, have been reported[17]. In addition, psychological effects in ICU nurses that are associated with their patients' death and end-of-life care have been discovered[18-25]. These issues are likely to lower the quality of end-of-life care.

Previous studies have shown that ICU nurses face difficulties ; however, it is unclear which areas the difficulties correspond to, how strongly they are experienced, and what they are related to in Japan. Therefore, the objective of this study was to clarify difficulties experienced by ICU nurses who provide end-of-life care and to elucidate the associated factors.

2. Methods

1) Sample and procedure

We conducted a cross-sectional nationwide questionnaire between September 2009 and March 2010. Participants were ICU nurses working for one year or more at 315 Japanese hospitals that had 500 or more beds. All hospitals included in the study had ICUs (general ICUs, high care units [HCUs], coronary care units [CCUs], or similar units, excluding neonatal ICUs). The protocol describing the study, including what was requested of the study participants and the study method, was sent to the directors of nursing at the 315 hospitals. Overall, 111 wards from 103 hospitals agreed to participate in the study. A total of 2,229 ICU nurses at these facilities expressed a desire to participate.

2) Measurement

(1) Instrument

A questionnaire was created to measure the "difficulty felt by ICU nurses providing end-of-life care" (DFINE)[26]. We defined DFINE as ICU nurses' feelings that end-of-life care is difficult and that their experience of patients' end-of-life illness or death is accompanied by negative emotions. In addition, nurses were asked if experiencing end of life in the ICU was a main source of the difficulty or obstacle in implementing end-of-life care. The DFINE questionnaire comprised five factors represented by 28 items. Study subjects responded using a 5-point Likert-type scale : 5 (absolutely agree), 4 (somewhat agree), 3 (unsure), 2 (somewhat disagree), and 1 (absolutely disagree).

(2) Questionnaires

Nurses' individual background characteristics included sex, age, number of years of clinical experience as a nurse, number of years of experience in the ICU, number of deaths experienced in the ICU, number of patients they provided end-of-life care to in the ICU, number of patients they provided end-of-life care to in settings other than the ICU, and number of years of experience in settings other than the ICU. In addition to DFINE, there were questions regarding their perceptions of end-of-life care (10 items). The ICU nurses responded using the aforementioned 5-point Likert-type scale to describe how applicable the items were or how strongly they felt about each item.

We conducted a pilot test with 50 ICU nurses to assess the reliability, content, and face validity of the questionnaire. The phrasing of the end-of-life question items was examined, and the respondents' comprehension was confirmed. Cronbach's α for the five DFINE factors — "the end-of-life care environment," "nursing system and nurse model 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 to end-of-life care" — were 0.7, 0.8, 0.8, 0.7, and 0.5, respectively. The value for "converting from curative to end-of-life care" was low, but we included it considering the number of items and respondents in the pilot test was small. In addition, its reliability has been confirmed in existing research[26].

Additionally, the facility questionnaire collected information regarding hospital ward characteristics. The percentages of patients who were utilizing artificial respirators, dialysis, and percutaneous cardiopulmonary support (PCPS) were also calculated.

3) Data analysis

Higher scores on the DFINE questionnaire reflected more difficulty experienced in providing end-of-life care. Simple and multiple regression analyses were performed between respondent characteristics, and evaluations of end-of-life care in ICUs as the predictor variable and DFINE as the response variable were performed. For facilities with 15 or more respondents, the mean value of DFINE was calculated. Furthermore, simple and multiple regression analyses were also performed between each facility's characteristics as the predictor variable and the mean value of DFINE as the response variable. To avoid multicollinearity in our multiple regression analyses, we removed items that were strongly correlated. All analyses were performed using SPSS Statistics v20 (IBM, New York, USA) and Stata v13. The significance level was set at $p<.05$ (two-tailed).

4) Ethical approval

Written forms sent to individual participants explained the aims and methods of the study, participant anonymity, and that returning the survey form would indicate consent. The study protocol was approved by the research ethics committee of Kanagawa University of Human Services, Japan (approval number 21-006, 21-046).

3. Results

1) Respondents' background characteristics and perceptions of end-of-life care

A total of 102 wards returned the facility questionnaire. Overall, 35 indicated that they had at least 15 staff members per ward. These 35 wards were subject to a facility background analysis. The background characteristics of these facilities are shown in Table 1. Of these 35 wards, the majority (51%) had ICU wards, followed by 34% with ICU/CCU wards. A total of 86% of the wards indicated that at least 80% of the patients who died in the wards were on a ventilator; in 12% of the wards, least 80% of patients were on dialysis; and in 6% of the wards, at least 80% of patients were receiving PCPS.

Regarding individual nurses, those who never experienced the death of a patient under their care in the ICU, those who did not provide end-of-life care, and those who did not respond were excluded. This resulted in a total of 1,372 ICU nurses who were included in the analysis. The background characteristics of these individuals are shown in Table 2. The percentage of female respondents was 91%. The largest number of respondents (23%) had 5-8 years of clinical experience, and 42% had 2-5 years of clinical experience in the ICU. The highest response bereavement episodes and experience of end-of-life care in ICU were both 1-10, 45% and 51%. Of the respondents, 23% had no end-of-life care experience outside of the ICU.

The responses regarding nurses' evaluation of

Table 1. Characteristics of the facilities

		n	%	*n*	%
		n = 102		*n* = 35	
Number of bed in the Hospital	400 or 400>	2	2	3	9
	401-500	11	11	10	29
	501-600	37	36	6	17
	601-700	21	21	3	9
	701-800	6	6	6	17
	801-900	11	11	1	3
	901-1000	4	4	6	17
	1,001 or 1,001<	10	10		
Type of ICU	ICU	42	41	18	51
	ICU/CCU	35	34	12	34
	ICU/HCU	4	4	1	3
	HCU	7	7	1	3
	CCU	4	4	1	3
	EICU	1	1	2	6
	Others	9	9		
Number of bed in the ward	mean± SD	12.4±8.6		12.7±6.8	
Number of nursing staff	mean± SD	32±13.8		35.0±11.5	
Number of admission per year	400 or 400>	14	14	2	6
	401-500	13	13	6	17
	501-600	11	11	3	9
	601-700	16	16	8	23
	701-800	10	10	3	9
	801-900	1	1	0	0
	901-1,000	5	5	3	9
	1,001-1,100	1	1	1	3
	1,101-1,200	4	4	1	3
	1,201-1,300	3	3	2	6
	1,301-1,400	3	3	1	3
	1,401-1,500	2	2	1	3
	1,501-1,600	1	1	0	0
	1,601-1,700	1	1	1	3
	1,701-1,800	3	3	0	0
	1,801-1,900	1	1	1	3
	1,901-2,000	1	1	0	0
	2,001 or 2,001<	6	6	2	6
	none	4	4		
	no answer	2	2		
Episodes of bereavement per year	50 or 50>	64	63	24	69
	51-100	20	20	5	14
	101-150	4	4	2	6
	151-200	6	6	3	9
	201-250	1	1	0	0
	251-300	1	1	1	3
	none	5	5		
	no answer	1	1		
Use of ventilator before death in one year	0%	1	1	1	3
	10%	4	4	1	3
	20%	0	0	0	0
	30%	2	2	0	0
	40%	1	1	0	0
	50%	3	3	0	0
	60%	4	4	1	3
	70%	6	6	2	6
	80%	10	10	4	11
	90%	27	26	10	29
	100%	38	37	16	46
	no answer	6	6		
Use of dialysis before death in one year	0%	6	6	2	6
	10%	17	17	7	20
	20%	14	14	4	11
	30%	16	16	6	17
	40%	5	5	2	6
	50%	20	20	7	20
	60%	4	4	1	3
	70%	3	3	2	6
	80%	3	3	2	6
	90%	5	5	2	6
	100%	1	1	0	0
	no answer	8	8		
Use of PCPS before death in one year	0%	23	23	8	23
	10%	51	50	19	54
	20%	9	9	4	11
	30%	5	5	1	3
	40%	0	0	0	0
	50%	3	3	1	3
	60%	0	0	0	0
	70%	0	0	0	0
	80%	3	3	2	6
	90%	0	0	0	0
	100%	1	1	0	0
	no answer	7	7		
There is a consultation organization outside the ward with regard to end-of-life care	Yes	53	52	16	46
	No	47	46	18	51
	no answer	2	2	1	3
Bereaved family care	Yes	9	9	4	11
	No	92	90	31	89
	no answer	1	1		

**n*=102 : all facilities　　*n*=35 : analyzed facilities

Tabel 2. Participant Demographics $n=1,372$

Sex	Male	125	9
	Female	1,247	91
Age	≦25	206	15
	26-30	484	35
	31-35	342	25
	36-40	182	13
	41-45	94	7
	46-50	46	3
	51 or over	16	1
Years of clinical experience	<2	94	7
	2-5<	244	18
	5-8<	320	23
	8-11<	233	17
	11-14<	191	14
	≧14	284	21
Years of clinical experience in ICU	<2	318	23
	2-5<	575	42
	5-8<	289	21
	8-11<	116	8
	11-14<	51	4
	≧14	21	2
Number of bereavement episodes in the ICU	1-10	613	45
	11-20	315	23
	21-50	291	21
	51-100	119	9
	101-	34	2
Number of patients that I have provided the end-of-life care in the ICU	1-10	705	51
	11-20	278	20
	21-50	233	17
	51-100	108	8
	101-	48	3
Number of patients that I have provided the end-of-life care in the wards without the ICU	0	318	23
	1-10	321	23
	11-20	188	14
	21-50	280	20
	51-100	161	12
	101-	89	6

The sum of the proportions was not 100% due to missing values.
ICU : intensive care unit

end-of-life care are shown in Table 3.

Respondents indicated with whom end-of-life care is always or mostly discussed, corresponding to answers of “absolutely agree” and “somewhat agree,” as the following : patients with a physician (21%), family members with a physician (68%), respondent with other nurses (57%), respondent with physician (40%), among nurses after death (25%), and multidisciplinary discussions after death (6%). Regarding “utilize consultation organizations outside the ICU,” only 7% respondents answered “absolutely agree” or “somewhat agree.” Regarding difficulties related to end-of-life decision-making (responses of “absolutely agree” and “somewhat agree”), respondents felt difficulties with “complying with patients’ prior living will or advanced directives,” “complying with family members refusal of life-prolonging treatment,” and “nurse involvement in end-of-life decision-making,” corresponding to 29%, 25%, and 40% of respondents, respectively

2) Responses to DFINE

The responses for “Difficulties are related to the end-of-life care environment” showed the highest mean score (±standard deviation) at 3.6 (±0.8), while those for “Difficulties are related to building confidence in end-of-life care” had the lowest at 3.0 (±0.8). Results of the highest and lowest mean scores for DFINE from the 35 facilities included in this study for “Difficulties are related to the end-of-life care environment” were 4.1 (±0.5) and 2.7 (±0.8) ; “Difficulties are related to the nursing system and nurse model for end-of-life care” were 3.9 (±0.6) and 2.0 (±0.6) ; “Difficulties are related to building confidence in end-of-life care” were 3.4 (±1.0) and 2.5 (±0.8) ; “Difficulties are related to the care for the patient and families at end-of-life” were 3.7 (±0.7) and 2.1 (±0.5) ; and “Difficulties are related to converting from curative to end-of-life care” were 3.7 (±0.5) and 2.4 (±0.7), respectively.

Table 3. Evaluation of regarding end-of-life care n=1,372

	absolutely agree		somewhat agree		unsure		somewhat disagree		absolutely disagree	
	n	%	*n*	%	*n*	%	*n*	%	*n*	%
Patients discuss their desires regarding end-of-life care with a physician	61	4	229	17	337	25	434	32	307	22
Family members discuss their desires regarding end-of-life care with a physician	267	19	673	49	288	21	119	9	23	2
I discuss with other nurses regarding end-of-life care	115	8	679	49	370	27	182	13	25	2
I discuss with a physician regarding end-of-life care	51	4	488	36	510	37	262	19	60	4
Nurses have discussions among themselves after a patient dies	46	3	301	22	456	33	405	30	161	12
There are multidisciplinary discussions after a patient dies	11	1	73	5	313	23	508	37	465	34
I utilize consultation organizations outside the ward in regards the end-of-life care	13	1	87	6	300	22	417	30	550	40
It is difficult to comply when patients have prior living wills or advanced directives indicating that they refuse life-prolonging care	69	5	327	24	563	41	314	23	91	7
It is difficult to comply when family members refuse life-prolonging treatment when the death of the patient is unavoidable	65	5	271	20	480	35	419	31	135	10
Since the physician determines whether to continue or discontinue life-prolonging treatment, nurses are not involved in that decision	176	13	364	27	482	35	273	20	76	6

The sum of the proportions was not 100% due to missing values.

3) Association between individual background characteristics and DFINE

The results of the simple and multiple regression analyses performed between the individual nurses' background characteristics and DFINE are shown in Table 5. The relationship between "Difficulties are related to the end-of-life care environment" was strongest for lower scores for "number of patients that I have provided end-of-life care in the ICU" (p=0.01), "discussion with another nurse" (p=0.03), and "discussions among nurses after death" (p<0.001), as well as for higher scores for "number of patients that I have provided end-of-life care in wards without the ICU" (p=0.01), "it is difficult to comply when patients have prior living wills or advanced directives refusing life-prolonging care" (p=0.003), and "nurses are unable to become involved in the decision to either continue or discontinue life-prolonging treatment" (p<0.001, R^2=0.13, R^2 adjusted for degrees of freedom=0.12).

Moreover, the relationship between "Difficulties are related to the nursing system and nurse model for end-of-life care" was strongest for lower scores for "family members discuss their desires with a physician" (p<0.001), "discussion with another nurse" (p<0.001), "discussions among nurses after death" (p=0.001), and "consultation with organizations outside the ward" (p=0.04), as well as for higher scores for "it is difficult to comply when family members refuse life-prolonging treatment when the death of the patient is unavoidable" (p=0.04) and "nurses are unable to become involved in the decision to either continue or discontinue life-prolonging treatment" (p<0.001, R^2=0.17, R^2 adjusted for degrees of freedom=0.16).

The relationship between "Difficulties are related to building confidence in end-of-life care" was strongest for lower scores for "years of clinical ex-

Table 4. Difficultes experienced by ICU nurses providing end-of-life care $n = 1{,}372$

	mean	SD	Absolutely agree		somewhat agree		Unsure		somewhat disagree		Absolutely disagree	
			n	%	*n*	%	*n*	%	*n*	%	*n*	%
1. The end-of-life care environment	3.6	0.8										
・ICU is not an appropriate place to die	3.7	1.0	337	25	500	36	376	27	103	8	56	4
・Patients cannot approach peaceful death in the ICU.	3.3	1.1	181	13	442	32	475	35	189	14	85	6
・Patients do not want to die in the ICU, I suppose.	3.6	1.0	284	21	463	34	476	35	107	8	42	3
・When death is unavoidable, the patient had better leave the ICU quickly.	3.9	1.0	430	31	462	34	374	27	75	5	30	2
2. Nursing system and model nurse for end-of-life care.	3.1	0.9										
・No time to care for dying patient.	3.2	1.1	159	12	429	31	404	29	287	21	93	7
・Nursing system for end-of-life care is not established.	3.4	1.1	225	16	457	33	367	27	249	18	74	5
・No time to discuss among nurses about end-of-life care.	3.0	1.1	119	9	368	27	367	27	399	29	117	9
・More nurses are needed for providing end-of-life care.	3.4	1.1	234	17	392	29	437	32	250	18	59	4
・There are no nurses to consult about end-of-life care.	2.9	1.1	126	9	305	22	436	32	377	27	128	9
・There are no model nurses in providing for end-of-life care.	2.9	1.1	121	9	306	22	456	33	360	26	129	9
3. Building confidence in end-of-life care.	3.0	0.8										
・I am frightened to tell the family that a patient's condition is worsening.	3.3	1.1	143	10	522	38	342	25	305	22	59	4
・I often feel a pang of guilt when I face patient death.	3.0	1.0	104	8	305	22	494	36	384	28	85	6
・I want to avoid the family when a patient's condition is worsening.	2.9	1.1	74	5	360	26	397	29	411	30	129	9
・I often feel that it is my responsibility when a patient's condition is worsening.	2.9	1.1	103	8	296	22	476	35	383	28	113	8
・No confidence to provide end-of-life care.	3.0	1.0	98	7	304	22	517	38	379	28	72	5
・I would like to avoid care for dying patients, If possible.	2.7	1.1	84	6	256	19	435	32	425	31	172	13
・No knowledge and skills to provide end-of-life care.	3.2	1.0	121	9	363	26	541	39	294	21	52	4
4. Caring for patients and families at end-of-life.	3.3	0.8										
・Not enough contact with families.	3.6	1.0	202	15	611	45	355	26	166	12	37	3
・It is difficult to provide care for families in the ICU.	3.4	1.1	179	13	497	36	403	29	226	16	67	5
・It is difficult to fulfill patients' wishes of end-of-life.	3.3	1.0	159	12	492	36	432	31	243	18	46	3
・No wish to develop a relationship with the family.	3.3	1.0	145	11	464	34	450	33	264	19	49	4
・It is difficult to provide care for dying patients in the ICU.	3.2	1.1	169	12	433	32	402	29	300	22	66	5
・Family has difficulty accepting death in the ICU.	3.0	1.0	94	7	314	23	559	41	346	25	58	4
・It is difficult to fulfill family's wishes.	3.1	1.0	79	6	375	27	523	38	328	24	64	5
5. Converting from curative care to end-of-life care.	3.1	0.7										
・Doctors are too late in deciding that treatment is ineffective, I feel.	3.3	1.0	166	12	341	25	632	46	188	14	45	3
・It is difficult to attend to the family when a patient is dying.	2.6	1.1	63	5	243	18	375	27	514	37	175	13
・Life-sustaining treatment is often given excessively.	3.5	1.0	238	17	459	33	477	35	171	12	27	2
・Even in the end-of-life phase, limits on visiting hours and people are unavoidable.	2.9	1.2	104	8	363	26	339	25	357	26	208	15

The sum of the proportions was not 100% due to missing values.
Absolutely agree 5 point, somewhat agree 4 point, Unsure 3 point, somewhat disagree 2 point, Absolutely disagree 1 point
SD=standard deviation

perience" ($p<0.001$), "number of patients that I have provided end-of-life care in the ICU" ($p<0.001$), "family members discuss their desires with a physician" ($p=0.006$), and "discussion with physician" ($p<0.001$), as well as for higher scores for "nurses are unable to become involved in the decision to either continue or discontinue life-prolonging treatment" ($p<0.001$, $R^2=0.18$, R^2 adjusted for degrees of freedom$=0.17$).

The relationship between "Difficulties are related to the care for the patient and families at end of life" was strongest for lower scores for "number of patients that I have provided end-of-life care in the ICU" ($p=0.02$), "family members discuss their de-

Table 5. Relationship between DFINE and sbject characreristics

Single regression analysis	The end-of-life care environment		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		Converting from curative care to end-of-life care	
	β	*p*-value	β	*p*-value	β	*p*-value	β	*p*-value	β	*p*-value
Age	0.07	0.013*	0.01	0.81	−0.27	<0.001***	−0.03	0.22	0.09	0.001**
Years of clinical experience	0.09	<0.001***	0.02	0.50	−0.28	<0.001***	−0.02	0.39	0.12	<0.001***
Years of clinical experience in ICU	0.00	0.87	0.01	0.60	−0.17	<0.001***	−0.07	0.01*	0.01	0.59
Number of bereavement episodes in the ICU	−0.05	0.05	0.02	0.40	−0.20	<0.001***	−0.06	0.02*	0.00	0.91
Number of patients that I have provided the end-of-life care in the ICU	−0.07	0.01*	−0.02	0.42	−0.17	<0.001***	−0.11	<0.001***	−0.04	0.18
Number of patients that I have provided the end-of-life care in the wards without the ICU	0.08	0.002**	−0.01	0.64	−0.25	<0.001***	−0.01	0.64	0.11	<0.001***
Patients discuss their desires regarding end-of-life care with a physician	−0.12	<0.001***	−0.04	0.12	0.00	0.86	−0.11	<0.001***	−0.12	<0.001***
Family members discuss their desires regarding end-of-life care with a physician	−0.11	<0.001***	−0.18	<0.001***	−0.12	<0.001***	−0.15	<0.001***	−0.24	<0.001***
I discuss with other nurses regarding end-of-life care	−0.18	<0.001***	−0.33	<0.001***	−0.20	<0.001***	−0.25	<0.001***	−0.10	<0.001***
I discuss with a physician regarding end-of-life care	−0.18	<0.001***	−0.25	<0.001***	−0.26	<0.001***	−0.25	<0.001***	−0.13	<0.001***
Nurses have discussions among themselves after a patient dies	−0.22	<0.001***	−0.24	<0.001***	−0.10	<0.001***	−0.24	<0.001***	−0.15	<0.001***
There are multidisciplinary discussions after a patient dies	−0.16	<0.001***	−0.12	<0.001***	−0.08	0.005**	−0.17	<0.001***	−0.14	<0.001***
I utilize consultation organizations outside the ward with regards the end-of-life care	−0.11	<0.001***	−0.12	<0.001***	0.01	−0.07	−0.13	<0.001***	−0.05	0.07
It is difficult to comply when patients have prior living wills or advanced directives indicating that they refuse life-prolonging care	0.13	<0.001***	0.06	0.02*	0.04	0.10	0.12	<0.001***	0.27	<0.001***
It is difficult to comply when family members refuse life-prolonging treatment when the death of the patient is unavoidable	0.08	0.004**	0.13	<0.001***	0.09	0.0014**	0.15	<0.001***	0.25	<0.001***
Since the physician determines whether to continue or discontinue life-prolonging treatment, nurses are not involved in that decision	0.23	<0.001***	0.22	<0.001***	0.16	<0.001***	0.29	<0.001***	0.31	<0.001***
Multiple regression analysis										
Years of clinical experience	0.06	0.08	0.00	0.91	−0.17	<0.001***	−0.02	0.66	0.06	0.07
Years of clinical experience in ICU	−0.01	0.87	0.02	0.49	−0.05	0.12	−0.03	0.36	−0.03	0.35
Number of patients that I have provided the end-of-life care in the ICU	−0.08	0.01*	0.00	0.90	−0.04	0.17	−0.07	0.02*	−0.05	0.09
Number of patients that I have provided the end-of-life care in the wards without the ICU	0.08	0.01*	0.01	0.73	−0.14	<0.001***	0.02	0.46	0.07	0.03*
Patients discuss their desires regarding end-of-life care with a physician	-0.04	0.10	0.04	0.11	0.05	0.07	−0.03	0.31	−0.03	0.24
Family members discuss their desires regarding end-of-life care with a physician	−0.03	0.20	−0.10	<0.001***	−0.07	0.006**	−0.06	0.03*	−0.16	<0.001***
I discuss with other nurses regarding end-of-life care	−0.07	0.03*	−0.22	<0.001***	−0.06	0.08	−0.10	0.002**	0.00	0.97
I discuss with a physician regarding end-of-life care	−0.04	0.22	−0.03	0.39	−0.13	<0.001***	−0.06	0.09	−0.01	0.83
Nurses have discussions among themselves after a patient dies	−0.13	<0.001***	−0.11	0.001**	0.02	0.45	−0.12	<0.001***	−0.09	0.005**
There are multidisciplinary discussions after a patient dies	−0.01	0.80	0.04	0.29	−0.03	0.36	−0.01	0.81	−0.06	0.11
I utilize consultation organizations outside the ward with regards the end-of-life care	−0.03	0.33	−0.07	0.04*	−0.01	0.79	−0.04	0.18	0.01	0.71
It is difficult to comply when patients have prior living wills or advanced directives indicating that they refuse life-prolonging care	0.09	0.003**	−0.01	0.82	0.01	0.71	0.04	0.21	0.13	<0.001***
It is difficult to comply when family members refuse life-prolonging treatment when the death of the patient is unavoidable	−0.04	0.24	0.06	0.04*	0.06	0.05	0.06	0.07	0.09	0.003**
Since the physician determines whether to continue or discontinue life-prolonging treatment, nurses are not involved in that decision	0.17	<0.001***	0.16	<0.001***	0.13	<0.001***	0.21	<0.001***	0.20	<0.001***
Coefficient of determination	0.13		0.17		0.18		0.17		0.20	
Degree of freedom adjustment adjusted coefficient	0.12		0.16		0.17		0.16		0.19	

$^{*}p<0.05$ $^{**}p<0.01$ $^{***}p<0.001$

sires with a physician” ($p=0.03$), “discussion with another nurse” ($p=0.002$), and “discussions among nurses after death” ($p<0.001$), as well as for higher scores for “nurses are unable to become involved in the decision to either continue or discontinue life-prolonging treatment” ($p<0.001$, $R^2=0.17$, R^2 adjusted for degrees of freedom=0.16).

Furthermore, the relationship between “Difficulties are related to converting from curative to end-of-life care” was strongest for lower scores for “fam-

Table 6. Relationship between DFINE and hospitals characreristics

Single regression analysis	The end-of-life care environment		Nursing system and model nurse for endof-life care		Building confidence in end-of-life care		Caring for patients and families at endof-life		Converting from curative care to endof-life care	
	β	*p*-value	β	*p*-value	β	*p*-value	β	*p*-value	β	*p*-value
Number of beds in the hospital	−0.13	0.45	0.11	0.52	0.12	0.49	−0.09	0.59	−0.09	0.61
Number of beds in the ward	−0.01	0.96	0.57	<0.001***	0.05	0.76	0.37	0.03*	−0.01	0.96
Number of nursing staff	−0.07	0.68	0.26	0.13	−0.05	0.78	0.14	0.41	0.01	0.97
Number of admissions per year	0.19	0.29	0.37	0.03	0.07	0.68	0.39	0.02	0.21	0.23
Episodes of bereavement per year	−0.22	0.21	0.05	0.76	−0.06	0.71	−0.05	0.80	−0.15	0.38
Use of ventilator before death	0.11	0.53	−0.18	0.29	0.01	0.98	−0.13	0.46	0.17	0.34
Use of dialysis before death	−0.17	0.33	−0.27	0.07	−0.51	0.002**	−0.24	0.17	0.03	0.86
Use of PCPS before death	0.12	0.50	−0.14	0.43	0.02	0.92	−0.04	0.84	0.13	0.46
Multiple regression analysis										
Number of beds in the hospital	−0.04	0.85	−0.04	0.84	0.41	0.04*	−0.15	0.49	−0.06	0.82
Number of beds in the ward	−0.04	0.86	0.66	0.007**	−0.04	0.85	0.38	0.15	−0.09	0.75
Number of admissions per year	0.46	0.06	0.06	0.78	0.21	0.30	0.33	0.17	0.48	0.07
Episodes of bereavement per year	−0.48	0.02*	−0.13	0.43	−0.24	0.16	−0.30	0.11	−0.38	0.07
Use of ventilator before death	0.31	0.18	0.27	0.19	0.20	0.32	0.25	0.27	0.26	0.30
Use of dialysis before death	−0.31	0.12	−0.37	0.04*	−0.79	<0.001***	−0.29	0.14	−0.06	0.76
Use of PCPS before death	0.10	0.59	−0.05	0.79	0.23	0.17	0.00	1.00	0.08	0.68
Coefficient of determination	0.30		0.44		0.48		0.33		0.22	
Degree of freedom adjustment adjusted coefficient	0.11		0.30		0.35		0.15		0.01	

$^*p<0.05$ $^{**}p<0.01$ $^{***}p<0.001$

ily members discuss their desires with a physician" ($p<0.001$) and "discussions among nurses after death" ($p=0.005$), as well as for higher scores for "number of patients that I have provided end-of-life care in the wards without the ICU" ($p=0.03$), "it is difficult to comply when patients have prior living wills or advanced directives indicating refusal of life-prolonging care," "it is difficult to comply when family members refuse life-prolonging treatment when the death of the patient is unavoidable" ($p=0.003$), and "nurses are unable to become involved in the decision to either continue or discontinue life-prolonging treatment" ($p<0.001$, $R^2=0.2$, R^2 adjusted for degrees of freedom=0.19).

The response "Nurses are unable to become involved in the decision to either continue or discontinue life-prolonging treatment because physicians make that decision" had a significant relationship to all DFINE items ($p<0.001$).

4) Association between facility characteristics and DFINE

The results of the simple and multiple regression analyses performed between the hospital ward background characteristics and DFINE are shown in Table 6. The relationship between "Difficulties are related to the end-of-life care environment" was strongest for subjects with fewer "number of bereavement episodes a year" ($p=0.02$, $R^2=0.3$, R^2 adjusted for degrees of freedom=0.11). For "Difficulties are related to the nursing system and nurse model for end-of-life care," the relationship was stronger when there was a higher score for "number of beds in the ward" ($p=0.007$) and when there were few patients who "underwent dialysis several

days prior to death" (p=0.04, R^2=0.44, R^2 adjusted for degrees of freedom=0.3). For "Difficulties are related to building confidence in end-of-life care," the relationship was stronger when there was a higher "number of beds in the facility" (p=0.04) and when there were fewer patients who "use of dialysis before death" (p<0.001, R^2=0.48, R^2 adjusted for degrees of freedom=0.35).

4. Discussion

This study is the first nationwide survey of the difficulties experienced by ICU nurses in end-of-life care in Japan. We found that difficulties related to the end-of-life care environment were experienced by many nurses. A review of the literature related to end-of-life care in an ICU setting published in the United States indicated that an ICU environment is a barrier to the provision of end-of-life care[26]. Fridh et al.[27] reported that ICU nurses felt that an insufficient number of private rooms in ICUs was a major obstacle to providing care to patients facing death and that efforts should be made to create environments that were more protective of the privacy of family members. Conversely, it has been reported that it is not necessary to discharge patients who are facing death in the ICU and that many nurses think that care should be continued in the ICU[28]. From the current study's results, it can be assumed that nurses in Japan strongly feel that the ICU is not a place where patients should face death.

The response "Nurses are unable to become involved in the decision to either continue or discontinue life-prolonging treatment because physicians make that decision" was strongly related to all DFINE items. Difficulties can be alleviated by discussing issues related to end-of-life care with other nurses and by considering that nurses should be involved in determining whether or not to continue life-prolonging treatment. Reports indicate that nurses play an important role in decisions made by family members regarding end-of-life care in ICUs[28,29], which emphasizes the fact that one of the needs of families faced with this situation is the involvement of nurses in the decision-making process[30]. In addition, the participation of nurses in the decision-making process has been reported to alleviate the ethical distress involved in such decisions[25]. However, it has been reported that there is little involvement of ICU nurses in the decision-making process at the end of life[32-34]. Taken together, these suggest that the issue of whether or not nurses are involved in the decision-making process related to end-of-life care is an important issue[35].

Furthermore, the responses "Family members discuss their desires regarding end-of-life care with a physician" and "Nurses have discussions among themselves after a patient dies" were strongly related to most DFINE items. Higher ratings of physician-family communication by nurses were uniformly associated with higher quality of dying[36]. Increasing communication between physicians, nurses, and families can not only reduce difficulties but also improve quality of end-of-life care.

Investigation of the relationship between facility background characteristics and DFINE items indicated that there was a tendency for "Difficulties are related to the nursing system and nurse model for end-of-life care" to be more strongly related to wards with higher numbers of beds. This indicates that facilities with larger ICUs may find it difficult to establish a satisfactory end-of-life care system. Further, "Difficulties are related to building confidence in end-of-life care" was less strongly related to higher percentages of patients on dialysis at the time of their deaths. Findings regarding the relationship between confidence in the ability to provide end-of-life care and individual background characteristics indicated that the number of years of clinical experience as a nurse was an influential factor. This may therefore indicate that a high level of nursing skill is required to perform nursing tasks for patients who utilize medical devices. Although we

elucidated the fact that the degree to which difficulties related to end-of-life care are experienced differ between facilities, factors related to this may include other factors than those investigated in this study. Thus, future study of different end-of-life care measures taken at different facilities is required as a continuation of this study. Moreover, in our country, the development of guidelines for end-of-life care in the ICU are underway.

5. Conclusion

ICU nurses experienced many difficulties related to the end-of-life care environment. The results of this study suggest that the active involvement of nurses in the decision-making process related to end-of-life care may alleviate the difficulties they feel toward end-of-life care. Although this study elucidated the fact that there were different degrees in the difficulties related to end-of-life care at each facility, there is still a need to conduct further study of factors related to this phenomenon.

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