

Nursing-care for family caregivers of terminally ill cancer patients to enhance preparedness for death

Akiko Unesoko¹, Naoki Ozawa², Ayumi Sugimura¹, Kazuki Sato¹
and Shoko Ando²

¹*Nursing for Advanced Practice, Department of Integrated Health Sciences, Nagoya University
Graduate School of Medicine, Nagoya, Japan*
²*Ichinomiya Kenshin College School of Nursing, Ichinomiya, Japan*

ABSTRACT

Family caregivers of terminally ill cancer patients prepare for a patient's death. Nursing-care for preparedness is effective for their psychological health. This study aims to structuralize nursing-care for preparedness and extract related factors while presenting the implications for improved quality of care. Data from a cross-sectional survey of general ward and palliative care unit nurses in designated cancer care hospitals (n=561) was analyzed with exploratory factor analysis and multiple regression analyses. The results of the analysis, the structure was classified into "Nurse-centered support" and "Support through inter-professional work." Both supports were practiced significantly more frequently in palliative care units than general wards. Related factors in general wards were; communication skills, cooperation with doctors, the existence of certified nurse/certified nurse specialists as consultants, attitudes toward care of the dying, frequency of death conferences, and cooperation with specialist cancer counselors. Therefore, the results can help improve the quality of family care in palliative care, especially in general wards.

Keywords: preparedness for death, bereavement, family caregiver, nurse, counselor

Abbreviations:

GW: general ward

PCU: palliative care unit

QoC: quality of care

CN/CNS: certified nurse/certified nurse specialist

PCT: palliative care team

This is an Open Access article distributed under the Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International License. To view the details of this license, please visit (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

INTRODUCTION

Family caregivers of terminally ill cancer patients are highly exposed to psychological distress,¹ mainly related to impending death. While many family caregivers have an opportunity to adjust to the impending death during the period of caregiving,² some of them suffer poor adjustment, causing

Received: April 17, 2023; accepted: July 12, 2023

Corresponding Author: Akiko Unesoko, RN, MS

Nursing for Advanced Practice, Department of Integrated Health Sciences, Nagoya University Graduate School of Medicine, 1-1-20 Daiko-minami, Higashi-ku, Nagoya 461-8673, Japan

Tel: +81-52-719-1109, E-mail: unesoko.akiko.a1@s.mail.nagoya-u.ac.jp

anticipatory grief and unpreparedness for death. Previous studies have reported that 25.9% of caregivers had high anticipatory grief,³ and 16–23% of bereaved were unprepared,^{4,5} which have been associated with psychological distress, such as major depressive disorder and complicated grief.^{2,6}

Anticipatory grief, proposed by Lindemann,⁷ refers to emotions of pre-loss grief. While it was considered a psychological outcome before bereavement and as an alleviator of caregivers' post-loss grief, because no positive effect of anticipatory grief has recently been found on bereavement, the concept has been questioned, and there are calls to rename it.² Therefore, fewer studies on anticipatory grief have been conducted, and it is more widely viewed as a predictor of caregivers' bereavement reactions regarding preparedness for death.

Preparedness for death (preparedness) is a relatively new concept that emerged in the 1980s, from studies on caregivers' experiences of caring for discharged or terminal patients.⁸ Subsequently, through increasing studies, the concept of preparedness encompasses cognitive, behavioral, and emotional dimensions of caregivers of terminally ill patients.² Previous studies have revealed that caregivers with high levels of preparedness were associated with good communication with medical staff, perception of time before death, and participation in care,^{5,9,10} suggesting that medical staff interventions could increase caregivers' preparedness. However, specific interventions have not been elucidated,² and no studies have been conducted on nurses' role in this process.

Such support comprises a large part of family nursing in palliative care units (PCUs); however, in general wards (GWs), where active treatment transitions to palliative care, this practice could be difficult. Therefore, it is important to clarify the degree of nurses' practice in both wards and derive implications for improving the quality of care (QoC). Consequently, the objectives of this study are 1) to identify a structure of nursing-care for family caregivers to enhance their preparedness for death and 2) to evaluate the current state of ward nurses' care and extract the related factors, especially regarding GW nurses.

METHODS

Design, participants, and procedures

Requests for research cooperation were sent to 100 facilities (50 each with/without a PCU) selected from 398 designated cancer care hospitals by stratified random sampling. Self-completed questionnaires were sent to GW and PCU nurses at the participating facilities and returned between January and March 2019. Respiratory wards were selected as GWs because lung cancer is the most common cause of cancer-related deaths in Japan. The ethics review committee of Nagoya University, School of Health Sciences, approved the ethical and scientific validity of the study.

Data collection

Nursing-care for family caregivers of terminally ill cancer patients. There are no questionnaires or scales that indicate nurses' support for families preparing for death. Therefore, we designed a questionnaire consisting of 35 items referring to relevant studies^{1,5,11–13} and had discussions with two experts in palliative care research and two certified nurse specialists in cancer nursing, who also checked the content validity. Each item was assessed using a Likert scale, ranging from 1 (never) to 5 (always).

Background factors affecting ward nurses' support. Data on the following demographic variables were collected: gender, age, educational background, years of nursing experience, years of recent ward experience, certified nurse/certified nurse specialist (CN/CNS) certification, training participation (palliative care, family nursing, and life and death), bereavement experience, and end-of-life care experience.

Communication skills. The patients–nurse communication skill scale was used,¹⁴ in which a Likert scale, from 1 (disagree) to 5 (agree), is used. The reliability and applicability were verified, and permission for use was granted.

Attitudes toward care based on views of life and death. A subscale (“positive attitudes toward caring for dying persons”) of the Japanese version of the Frommelt Attitudes Toward Care of the Dying Scale was used,^{15,16} comprising a Likert scale from 1 (disagree) to 5 (agree). The reliability and applicability were verified, and permission for use was granted.

Cooperation with doctors. The Japanese version of the Collaborative Practice Scale for nurses was used,^{17,18} comprising a Likert scale from 1 (never) to 6 (always). The reliability and applicability were verified, and permission for use was granted.

Cooperation with specialist cancer counselors. Specialist cancer counselors are staff of Cancer Information & Support Centers that, since 2006, are required to work at all designated cancer care hospitals. Most of the counselors are medical social workers or nurses who provide counseling and support for cancer patients and families. Cooperation with them was assessed on a Likert scale from 1 (never) to 5 (always).

The existence of consultants. The questionnaire enquired about the use of familiar palliative care consultants, including co-workers, superiors, palliative care team (PCT), and CN/CNS.

Holding frequency of death conference. A death conference is a unique Japanese meeting for discussing the care of the deceased patient.¹⁹ The frequency of death conferences was rated as follows: routinization, as needed, rarely, and not at all.

Statistical analyses

Structure of nursing-care for family caregivers of terminally ill cancer patients. Descriptive statistics were calculated and checked for ceiling and floor effects where, consequently, one item was deleted. Thereafter, the structure of nursing-care was analyzed by exploratory factor analysis in two stages. In the first stage, factor analysis (maximum likelihood method and Promax rotation) was performed using 34 items and finally 33 items. In the second stage, the average score for each factor obtained in the first stage was analyzed to identify the higher factor. In addition, internal consistency was confirmed by Cronbach’s alpha coefficient.

Comparison of practice and related factors of nursing-care. The differences between GW and PCU nurses in background factors were evaluated with unpaired t-tests and chi-square tests. In addition, the comparison of their practice was analyzed by regression analysis (with/without adjusted for years of nursing experience), and Cohen’s d was calculated as the effect size to evaluate the clinical significance.²⁰

The related factors were analyzed for each subgroup of GW and PCU. Univariate analyses were performed by multiple regression analysis. Multivariate analysis was performed using items that were $p < 0.10$ in univariate analyses. Variable selection was performed using backward stepwise method adjusted for years of nursing experience.

In all analyses, the significance level was set at $P < 0.05$. All statistical analyses were performed using JMP Pro15 software (SAS Institute Inc, Cary, NC, USA).

RESULTS

Of the 667 questionnaires sent to 51 hospitals, 561 valid questionnaires were returned, the response rate was 84.1% (Table 1). The valid respondents included 349 (62.2%) GW nurses and 212 (37.8%) PCU nurses. PCU nurses scored significantly higher than GW nurses in many background characteristics, except gender and education which were not different. More PCU

nurses consulted co-workers and CN/CNS, while more GW nurses consulted a PCT. Although there was no difference in cooperation with specialist cancer counselors, PCU nurses were significantly more cooperative with doctors and death conferences were more often held in PCUs.

Table 1 Background characteristics of the participants (n=561)

		General wards		Palliative care units		p
		n/Mean	%/SD	n/Mean	%/SD	
Gender	Male	28	8.0%	10	4.7%	.088
	Female	321	92.0%	202	95.3%	
Age		33.0	±9.3	40.0	±9.6	<.001
Education	Nursing school	106	30.4%	46	21.7%	.078
	Junior college/ University/ Graduate school	241	69.1%	165	77.8%	
Bereavement experience	Yes	226	64.8%	162	76.4%	.013
Nursing experience (years)		10.5	±8.7	16.8	±9.5	<.001
Current ward experience (years)		3.5	±2.7	4.5	±3.8	<.001
Cancer-related CN/CNS		3	0.9%	15	7.1%	<.001
Training participation	Palliative care	167	47.9%	190	89.6%	<.001
	Family nursing	107	30.7%	137	64.6%	<.001
	Life and death	48	13.8%	76	35.8%	<.001
End-of-life care experience	0–5 patients	56	16.1%	4	1.9%	<.001
	6–40 patients	186	53.6%	64	30.5%	
	More than 41 patients	105	30.3%	142	67.6%	
Communication skills ^a		3.4	±0.4	3.5	±0.4	.004
Attitudes toward care of the dying ^b		9.8	±1.8	11.2	±2.0	<.001
Existence of consultants	Co-worker	273	78.2%	191	90.1%	<.001
	Superiors	235	67.3%	156	73.6%	.130
	Palliative care team	188	53.9%	78	36.8%	<.001
	CN/CNS	129	37.0%	132	62.3%	<.001
Cooperation with specialist cancer counselors		3.2	±1.3	3.4	±1.4	0.128
Cooperation with doctors ^c		3.0	±0.9	3.2	±1.0	.009
Frequency of death conference in their ward	Routinization	95	27.2%	129	60.8%	<.001
	As needed	162	46.4%	64	30.2%	
	Rarely/Not at all	91	26.1%	18	8.5%	

SD: standard deviation

p: P-value obtained by unpaired t-test and chi-squared tests (general wards vs palliative care units)

CN: certified nurse

CNS: certified nurse specialist

^a The patients–nurse communication skill scale

^b The Japanese version of the Frommelt Attitudes Toward Care of the Dying Scale (FATCOD-B-J): Positive attitudes toward caring for dying persons (factor I).

^c The Japanese version of the Collaborative Practice Scales

Structure of nursing-care for family caregivers of terminally ill cancer patients

In the first stage, seven factors were adapted as the factor structure, using a scree plot of the remaining 33 items which met the factor loading (less than 0.35) criteria (Table 2). From these seven lower factors, two higher factors were identified in the second stage (Table 3).

The higher factor I (nurse-centered support) comprised four lower factors: (i) support for family caregivers to prepare for bereavement by sharing time with the patient, (v) sufficient care for the patient to provide relief for family caregivers, (vii) support for family caregivers to express their grief, and (ii) support for the patient and family caregivers to enhance family ties.

The other higher factor II (support through inter-professional work) comprised three lower factors: (iv) support for family caregivers to cope with bereavement problems, (vi) support for patient and family caregivers to decide the place of end-of-life care, and (iii) support for family caregivers to understand the patient's prognosis.

Internal consistency was confirmed by a Cronbach's alpha coefficient of 0.85–0.95 (first stage), 0.83–0.91 (second stage).

Table 2 Structure of nursing-care for family caregivers of terminally ill cancer patients to enhance preparedness for death (the first stage)

No	Item	Mean	SD	i	ii	iii	iv	v	vi	vii
<i>(i) Support for family caregivers to prepare for bereavement by sharing time with the patient</i>		4.55	0.75							
31	Give the family a favorable environment for a satisfactory farewell.	4.13	0.76	.96	.03	.06	.00	.01	-.04	-.13
30	Explain the patient's physical changes to the family to accept the impending death.	4.06	0.83	.87	.02	.02	.01	-.04	.03	.00
33	Encourage the patient and family to spend time together and express emotions.	4.20	0.77	.84	-.05	-.01	-.04	.06	-.02	.03
32	Calm the family to avoid panic and fear of the patient's impending death.	4.07	0.78	.77	.03	.01	.05	.07	-.01	.01
26	Ensure the family can get appropriate rest to enable them to be by the patient's deathbed.	4.14	0.74	.61	.09	-.06	-.06	.11	.05	.17
35	Assist the family in preparing for the funeral.	4.12	0.88	.53	-.10	-.03	.16	.18	.03	.02
28	Listen to the wishes of the patient and family, such as going out or staying out, and assist them in planning for that.	3.89	0.84	.53	.20	.03	-.03	-.06	.14	.08
29	Consider the diversity of family relations and not compel the family to engage with the patient.	3.95	0.78	.52	.07	.13	-.04	.04	-.02	.26
25	Verify the impact of the patient's illness on the family life and support them to have time for themselves.	3.87	0.82	.40	.19	-.04	.00	.03	.02	.39

No	Item	Mean	SD	i	ii	iii	iv	v	vi	vii
(ii) Support for the patient and family caregivers to enhance family ties		3.55	0.79							
17	Provide an opportunity for the patient and family to look back on what they cherished in their lives.	3.53	0.94	.02	.84	-.08	.01	.07	.02	.01
18	Arrange an opportunity for the patient and family to discuss how to spend their remaining time.	3.45	0.97	.11	.80	.01	.07	-.08	.03	-.05
19	Create an atmosphere for the patient and family to talk about common hobbies, other family members, and so on.	3.63	0.93	.00	.70	.04	-.01	.13	.02	.05
20	Hear about changes in the family role due to illness and provide consultation.	3.41	0.94	.00	.66	.09	.12	.01	-.01	.05
15	Care for the patient together, considering the family's convenience.	3.74	0.90	-.01	.45	.03	-.01	.40	-.06	.06
(iii) Support for family caregivers to understand the patient's prognosis		3.74	0.71							
2	Make appointments for indicating the prognosis with more than one of the families so that they support each other.	3.68	0.95	-.07	.15	.71	-.06	.02	.04	-.05
3	Ask the family how they intend to tell the patient's prognosis to their children and provide consultation.	3.45	0.98	-.06	.09	.68	.09	-.04	.07	.04
1	Accompany the family at meetings about bad news such as prognosis by the doctor.	3.92	0.91	.12	-.05	.67	.00	.00	-.08	-.01
4	Evaluate the family's understanding of the end of aggressive therapy and the patient's prognosis. If insufficient, arrange a meeting with the doctor.	3.86	0.83	.20	-.14	.62	.06	.08	.03	.08
5	Provide tolerable information gradually to help the family to understand the future.	3.77	0.78	.11	.03	.47	.10	.10	.11	.07
(iv) Support for family caregivers to cope with bereavement problems		3.00	0.98							
10	Check whether the patient and family discussed after-death scenarios (bereaved families, property management, etc), and provide consultation or an introduction to a consultation desk if necessary.	2.91	1.08	.02	.03	-.03	.98	.02	-.08	-.05
9	Ask the family about practical preparedness (financial affairs, family care leave, funeral, etc) and provide consultation or an introduction to a consultation desk if necessary.	3.17	1.06	-.06	-.14	-.04	.72	.07	.20	.13
11	Inform the family about a place for post-mortem care such as a bereaved family association if their grief reaction to bereavement is expected to be high.	2.91	1.18	.06	.30	.09	.62	-.15	-.06	-.07

Family bereavement preparation support

No	Item	Mean	SD	i	ii	iii	iv	v	vi	vii
(v) Sufficient care for the patient to provide relief for family caregivers		4.11	0.64							
14	Care for the patient to become comfortable to relieve the family and earn the trust of the family.	4.11	0.72	.17	.06	-.08	.02	.70	.04	.08
13	Appreciate the effort of family participation in patient care, even if it was at a low level.	4.15	0.73	.20	.05	.02	-.04	.67	.05	.00
12	Inform the family about the patient's condition during their absence to maintain the family relations.	4.15	0.73	.29	.01	.13	-.02	.64	-.04	-.18
16	Consider the family's wishes for adequate nursing for the patient and inform them of the patient's condition and comfort changes.	4.04	0.72	.22	.14	.03	.01	.51	-.01	.08
(vi) Support for patient and family caregivers to decide the place of end-of-life care		3.71	0.83							
7	Provide information about end-of-life care such as a palliative care unit and home care.	3.72	0.93	.07	.03	.05	-.03	-.03	.95	.06
8	Provide information about home support services such as home-visit medical care and home-visit nursing.	3.62	0.94	-.02	.02	.08	.13	.05	.73	.06
6	Provide consultation about the place at the moment and at the end of life.	3.79	0.84	.08	-.01	.32	-.01	.00	.48	.06
(vii) Support for family caregivers to express their grief		3.05	0.60							
24	Consider the family's difficulty in expressing their feeling at different times and in different places and watch them carefully.	3.88	0.84	.20	.03	.06	.01	-.06	-.04	.76
22	Consider that the anger and hostility expressed by the family is a sign of grief and accommodate them.	3.78	0.83	.11	.20	.01	.03	.02	-.01	.60
23	Tell the family that crying and being upset are natural reactions and encourage them to express their feelings.	3.96	0.82	.26	.08	-.02	-.01	.01	.02	.59
21	Consider that a sense of guilt, love, and hate is a normal phenomenon, and watch over the family for these reactions.	3.65	0.90	.10	.28	.08	-.02	.02	-.05	.48
Eigenvalue				16.96	2.56	1.87	1.06	1.03	0.89	0.71

SD: standard deviation

Extraction method: Maximum likelihood; Rotation method: Promax rotation.

5-point Likert scale: 1 = never; 2 = rarely; 3 = sometimes; 4 = often; 5 = always.

Table 3 Final structure and practice of nursing-care for family caregivers of terminally ill cancer patients to enhance preparedness for death

Item	Factor I	Factor II	Cronbach's α	General wards		Palliative care units		ES	Adj P
				Mean	SD	Mean	SD		
Factor I: Nurse-centered support			.91	3.74	0.63	4.18	0.54	0.76	<.001
(i) Support for family caregivers to prepare for bereavement by sharing time with the patient	.88	.05	.95	4.35	0.75	4.89	0.62	0.79	<.001
(v) Sufficient care for the patient to provide relief for family caregivers	.84	.01	.90	3.95	0.64	4.37	0.55	0.69	<.001
(vii) Support for family caregivers to express their grief	.80	.09	.91	2.93	0.61	3.26	0.52	0.59	<.001
(ii) Support for the patient and family caregivers to enhance family ties	.59	.24	.90	3.39	0.79	3.81	0.73	0.54	<.001
Factor II: Support through inter-professional work			.82	3.39	0.73	3.76	0.62	0.55	<.001
(iv) Support for family caregivers to cope with bereavement problems	-.03	.75	.85	2.82	0.98	3.29	0.90	0.50	<.001
(vi) Support for patient and family caregivers to decide the place of end-of-life care	.15	.72	.90	3.60	0.85	3.89	0.75	0.36	.001
(iii) Support for family caregivers to understand the patient's prognosis	.23	.68	.86	3.60	0.73	3.96	0.63	0.53	<.001
Cronbach's α of all 7 first stage factors = .91									
Eigenvalue 4.68 0.81									

SD: standard deviation

ES: effect size (Effect sizes of 0.2, 0.5, and 0.8 were regarded as small, moderate, and large effects, respectively.)

Adj P: P-value after adjusting for nursing experience obtained by unpaired t-test (general wards vs palliative care units)

Extraction method: Maximum likelihood; Rotation method: Promax rotation.

Roman numerals indicate factor numbers; lowercase letters refer to the first stage, and uppercase letters refer to the second stage.

Comparison of nursing-care practices to enhance preparedness for death

In comparing nursing-care practices between GW and PCU nurses (Table 3), PCU nurses scored significantly higher than GW nurses in all forms of support ($p < .001$). Both higher factors had moderate effect sizes, but the difference was greater in "nurse-centered support" (Factor I: $d = 0.76$, Factor II: $d = 0.55$).

Comparison of related factors of nursing-care to enhance preparedness for death

Table 4 shows the results of univariate analyses on the relationship between the two higher factors of nursing-care to enhance preparedness for death and nurses' background factors in each subgroup of GWs and PCUs.

Table 4 Related factors of nursing-care for family caregivers of terminally ill cancer patients to enhance preparedness for death by univariate analyses

Item (reference)	I. Nurse-centered support				II. Support through inter-professional work				
	General wards		Palliative care units		General wards		Palliative care units		
	Std. beta	P	Std. beta	P	Std. beta	P	Std. beta	P	
Gender	Female (Male)	0.02	.752	0.04	.579	-0.03	.529	0.06	.384
Age		0.10	.517	-0.09	.541	0.10	.505	-0.12	.397
Education	Junior college/University/ Graduate school (Nursing school)	-0.01	.829	0.00	.991	-0.14	.013	-0.02	.771
Bereavement experience	Yes (No)	0.12	.026	-0.06	.421	-0.02	.696	0.03	.682
Current ward experience (years)		-0.03	.643	0.38	<.001	-0.06	.269	0.25	.001
CN/CNS	Yes (No)	0.09	.101	0.18	.012	0.12	.031	0.08	.228
Training participation									
Palliative care	Yes (No)	0.18	.001	0.12	.102	0.17	.002	0.02	.775
Family nursing	Yes (No)	0.16	.004	0.35	<.001	0.16	.003	0.33	<.001
Life and death	Yes (No)	0.19	<.001	0.25	<.001	0.20	<.001	0.22	.002
End-of-life care experience (patients)	6-40 (0-5) ≥41 (0-5)	0.21 0.26	.006 .002	-0.06 0.23	.749 .238	0.18 0.15	.017 .073	-0.29 0.01	.126 .970
Communication skills ^a		0.52	<.001	0.59	<.001	0.43	<.001	0.54	<.001
Attitudes toward care of the dying ^b		0.31	<.001	0.40	<.001	0.21	<.001	0.30	<.001
Existence of consultants									
Co-worker	Yes (No)	0.09	.085	0.00	.976	0.10	.054	0.01	.915
Superiors	Yes (No)	0.04	.420	0.09	.198	0.02	.688	0.12	.075
PCT	Yes (No)	0.07	.179	0.11	.121	0.10	.072	0.13	.064
CN/CNS	Yes (No)	0.22	<.001	0.04	.600	0.27	<.001	0.00	.977
Cooperation with specialist cancer counselors		0.20	<.001	0.14	.042	0.22	<.001	0.22	.002
Cooperation with doctors ^c		0.41	<.001	0.41	<.001	0.46	<.001	0.44	<.001
Frequency of death conference	As needed (None) Routinization (None)	0.18 0.11	.005 .091	0.22 0.41	.066 .001	0.20 0.16	.002 .015	0.21 0.38	.077 .001

Std. beta: standardized partial regression coefficient

PCT: palliative care team

CN: certified nurse

CNS: certified nurse specialist

Univariate analyses were performed after adjusting for nursing experience.

^a The patients–nurse communication skill scale

^b The Japanese version of the Frommelt Attitudes Toward Care of the Dying Scale (FATCOD-B-J): Positive attitudes toward caring for dying persons (factor I).

^c The Japanese version of the Collaborative Practice Scales

We conducted multivariate analyses based on the results of univariate analyses to identify related factors of nursing-care to enhance preparedness for death (Table 5). Each mean score of two higher factors was used as the dependent variable, and background factors that showed $p < 0.10$ in univariate analyses were used as independent variables. The variance inflation factor values were less than 10.0, indicating no multicollinearity.

Table 5 Related factors of nursing-care for family caregivers of terminally ill cancer patients to enhance preparedness for death by multivariate analyses

Item (reference)	I. Nurse-centered support				II. Support through inter-professional work				
	General wards		Palliative care units		General wards		Palliative care units		
	Std. beta	P	Std. beta	P	Std. beta	P	Std. beta	P	
Education	Junior college/ University/ Graduate school (Nursing school)		—	—	—	—	-0.12	.008	—
Training participation									
Palliative care	Yes (No)	—	—	—	—	—	—	—	—
Family nursing	Yes (No)	—	0.18	.002	—	—	—	—	—
Life and death	Yes (No)	—	—	—	—	—	—	—	—
Communication skills ^a		0.38	<.001	0.49	<.001	0.25	<.001	0.40	<.001
Attitudes toward care of the dying ^b		0.18	<.001	0.24	<.001	—	—	0.15	.008
Existence of consultants									
Co-worker	Yes (No)	—	—	—	—	0.12	.009	—	—
Superiors	Yes (No)	—	—	—	—	—	—	—	—
PCT	Yes (No)	—	—	—	—	—	—	—	—
CN/CNS	Yes (No)	0.12	.009	—	—	0.20	<.001	—	—
Cooperation with specialist cancer counselors		—	—	—	—	0.15	.001	0.15	.006
Cooperation with doctors ^c		0.19	<.001	—	—	0.29	<.001	0.22	.001
Frequency of death conference	As needed (None)	0.11	.016	—	—	—	—	—	—
	Routinization (None)	—	—	—	—	—	—	—	—
	R ²	0.36		0.44		0.35		0.40	
	Adjusted R ²	0.35		0.43		0.33		0.38	

Std.beta: standardized partial regression coefficient

PCT: palliative care team

CN: certified nurse

CNS: certified nurse specialist

Multiple regression analyses were performed using items that were set at $p < 0.10$ in univariate analyses (backward stepwise method adjusted for years of nursing experience).

^a The patients–nurse communication skill scale

^b The Japanese version of the Frommelt Attitudes Toward Care of the Dying Scale (FATCOD-B-J): Positive attitudes toward caring for dying persons (factor I).

^c The Japanese version of the Collaborative Practice Scales

Common related factors in GWs to two higher factors were communication skills, cooperation with doctors, and the existence of CN/CNS as consultants. In nurse-centered support, the most influential factor was “communication skills” ($\beta=0.38$; $p<.001$), and the characteristic related factors were “attitudes toward care of the dying” ($\beta=0.18$; $p<.001$) and “frequency of death conference (as needed)” ($\beta=0.11$; $p=.016$). In support through inter-professional work, the most influential factor was “cooperation with doctors” ($\beta=0.29$; $p<.001$), and the characteristic related factor was “cooperation with specialist cancer counselors” ($\beta=0.15$; $p=.001$).

In contrast, the common related factors in PCUs were attitudes toward care of the dying and communication skills, the latter having the most impact on both factors (Factor I: $\beta=0.49$; $p<.001$, Factor II: $\beta=0.40$; $p<.001$). The characteristic related factors in nurse-centered support and support through inter-professional work were: “training participation about family nursing” ($\beta=0.18$; $p=.002$), and “cooperation with doctors” ($\beta=0.22$; $p=.001$) and “cooperation with specialist cancer counselors” ($\beta=0.15$; $p=.006$), respectively.

DISCUSSION

This study is the first nationwide survey of nurses on preparedness for death and elucidates the structure of nursing-care for family caregivers of terminally ill cancer patients to enhance preparedness for death. The nursing-care structure consists of seven factors classified into two upper factors: “nurse-centered support” and “support through inter-professional work.” This categorization is consistent with several studies that demonstrated the requirement for multidisciplinary approaches to support caregivers’ preparation.^{12,21} Thus, because preparedness for death is multidimensional,⁴ it needs to be worked closely with a multidisciplinary team, not just nurses.

“Nurse-centered support” consisted of four forms of support, including support for end-of-life care provided by nurses as palliative care. Even when family caregivers undertake practical preparations for the patient’s bereavement, such as a funeral, their emotional preparedness is often insufficient.⁶ Therefore, nurses must provide the caregiver necessary support after considering their psychosomatic fatigue⁶ and specific history. These supports contribute toward achieving a “good death” in Japan.²² Improving the quality of death can facilitate their adjustment to the bereavement,²³ as supported by the results of this study.

Contrastingly, “support through inter-professional work” consisted of three forms of support that are only possible because of collaboration with multiple professionals, such as prognosis awareness and choice of place of end-of-life care. Unfortunately, previous studies have reported that half of the bereaved fail to talk about death,²⁴ while 64% do not discuss patients’ preferences regarding a place of death.²⁵ This may lead to inadequate preparedness for death. The importance of these supports increases with the increase in nuclear families and weakening blood relationships.

Regarding nursing-care practices, GW nurses practiced support less than PCU nurses, especially in “nurse-centered support;” this is not surprising as PCU nurses specialize in palliative care. However, today, many people become terminally ill outside PCUs, and GW nurses need to increase their emphasis on terminal care in the coming super-aging society. Therefore, it is beneficial to inspect the related factors for GW nurses. These factors are “communication skills,” “cooperation with doctors,” and “existence of CN/CNS as consultants.” The results of this study support Hebert et al’s⁹ report that good communication between all parties involved in the end-of-life period is the primary way to prepare for death, by showing that communication skills are essential, especially in “nurse-centered support.” In addition, one of the distinctive aspects of “nurse-centered support” is that neither “nursing experience” nor “end-of-life care experience”

were related factors, however, “attitudes toward care of the dying” was. This suggests that the mere accumulation of experience does not improve the QoC and highlights the importance of enhancing positive attitudes toward caring for dying persons through these experiences, that is, fostering one’s views of life and death. Results regarding the frequency of death conferences show that participation in DCs affects the QoC, as also shown in Harding et al.¹⁹ Interestingly, the related factor identified was not regular death conferences but holding them as needed which is valuable information for facilities that do not or rarely hold death conferences. These findings suggest that improving communication skills and fostering a view of life and death could improve GW nurses’ practical skills of “nurse-centered support.”

Regarding the practice of “support through inter-professional work,” the clinical significance was not as great as the difference between wards in “nurse-centered support.” This support is more important in GWs because patients and families tend to place their hope on anticancer treatments as long as possible²⁶; therefore, GW nurses need to support the shift from aggressive cancer therapy to palliative care while considering “cooperation with doctors,” which had the largest impact on nursing practice. The second largest impact factor was “existent of CN/CNS as consultants.” In this study, CN/CNSs were found to demonstrate a supportive role for GW nurses. To improve QoC, the medical facilities to which CN/CNS belong should establish their consultation systems, especially in GWs. Additionally, a distinctive aspect of inter-professional work support was “collaboration with cancer counselors,” which is a novel result revealed by this study. Counselors approach the patient and their family in need, provide information and consideration about the treatment and daily life from an early stage and assist in decision-making and choosing a treatment plan.²⁷ Compared to ward nurses, who begin providing care after a patient’s admission, counselors often establish better trust. Additionally, continuous support is helpful in palliative care,⁶ suggesting that counselors are well-suited for this role. Remarkably, although GW nurses consulted the PCT more often than PCU nurses, PCT was not extracted as a related factor of both supports in this study. The role of this multidisciplinary team is to collaborate with physicians and nurses to provide adequate palliative care to patients and their families. However, it seemed to be dysfunctional at the clinical site, and approaches to ensure the effectiveness of the PCT are currently under discussion.²⁸ These findings suggested that cooperation with various specialists is essential in nursing-care for family caregivers to enhance preparedness for death.

While these results are significant, this study has certain limitations. First, self-reported data may not adequately reflect the nurses’ support. Second, the questionnaire was not retested; considering the psychological and temporal burden of busy ward nurses, the reliability of the questionnaire could have been improved had it been retested. Third, we surveyed only a limited number of facilities in Japan, and GWs were restricted to respiratory wards; thus, the results might not be generalizable. Fourth, because multiple nurses from the same hospital were sampled, a mixed model is needed to account for clustering which could not be implemented due to an insufficient sample size.

CONCLUSIONS

This study is the first to identify the structure, practice degree, and related factors of nurses’ support for the preparedness for death of families with a terminal cancer patient. The results demonstrate that nurses’ support can be divided into two forms— “nurse-centered support” and “support through inter-professional work”— and GW nurses’ practice degree was lower than PCU nurses. For improving the QoC, it is essential to reinforce communication skills and foster nurses’

views of life and death. Additionally, in GWs especially, it is useful to establish a system that facilitates good cooperation with doctors, cancer specialist counselors, and CN/CNS.

ACKNOWLEDGMENTS

We thank the nurses who helped perform the investigation and the researchers who advised us during the research.

CONFLICTS OF INTEREST

The authors declare no conflicts of interest.

FUNDING

This work was supported by JSPS KAKENHI [grant number 19K10849].

REFERENCES

- 1 Fasse L, Sultan S, Flahault C, MacKinnon CJ, Dolbeault S, Brédart A. How do researchers conceive of spousal grief after cancer? A systematic review of models used by researchers to study spousal grief in the cancer context. *Psychooncology*. 2014;23(2):131–142. doi:10.1002/pon.3412.
- 2 Nielsen MK, Neergaard MA, Jensen AB, Bro F, Guldin MB. Do we need to change our understanding of anticipatory grief in caregivers: a systematic review of caregiver studies during end-of-life caregiving and bereavement. *Clin Psychol Rev*. 2016;44:75–93. doi:10.1016/j.cpr.2016.01.002.
- 3 Areia NP, Fonseca G, Major S, Relvas AP. Psychological morbidity in family caregivers of people living with terminal cancer: prevalence and predictors. *Palliat Support Care*. 2019;17(3):286–293. doi:10.1017/S1478951518000044.
- 4 Hebert RS, Dang Q, Schulz R. Preparedness for the death of a loved one and mental health in bereaved caregivers of patients with dementia: findings from the REACH study. *J Palliat Med*. 2006;9(3):683–693. doi:10.1089/jpm.2006.9.683.
- 5 Hauksdóttir A, Valdimarsdóttir U, Fürst CJ, Onelöv E, Steineck G. Health care-related predictors of husbands' preparedness for the death of a wife to cancer: a population-based follow-up. *Ann Oncol*. 2010;21(2):354–361. doi:10.1093/annonc/mdp313.
- 6 Breen LJ, Aoun SM, O'Connor M, Howting D, Halkett GKB. Family caregivers' preparations for death: a qualitative analysis. *J Pain Symptom Manage*. 2018;55(6):1473–1479. doi:10.1016/j.jpainsymman.2018.02.018.
- 7 Lindemann E. Symptomatology and management of acute grief. *Am J Psychiatry*. 1994;151(6 Suppl):155–160. doi:10.1176/ajp.151.6.155.
- 8 Archbold PG, Stewart BJ, Greenlick MR, Harvath T. Mutuality and preparedness as predictors of caregiver role strain. *Res Nurs Health*. 1990;13(6):375–384. doi:10.1002/nur.4770130605.
- 9 Hebert RS, Schulz R, Copeland VC, Arnold RM. Preparing family caregivers for death and bereavement: insights from caregivers of terminally ill patients. *J Pain Symptom Manage*. 2009;37(1):3–12. doi:10.1016/j.jpainsymman.2007.12.010.
- 10 Wen FH, Chou WC, Hou MM, et al. Associations of death-preparedness states with bereavement outcomes for family caregivers of terminally ill cancer patients. *Psychooncology*. 2022;31(3):450–459. doi:10.1002/pon.5827.
- 11 Hudson P, Remedios C, Zordan R, et al. Guidelines for the psychosocial and bereavement support of family caregivers of palliative care patients. *J Palliat Med*. 2012;15(6):696–702. doi:10.1089/jpm.2011.0466.
- 12 Shore JC, Gelber MW, Koch LM, Sower E. Anticipatory grief: an evidence-based approach. *J Hosp Palliat Nurs*. 2016;18(1):15–19. doi:10.1097/NJH.0000000000000208.
- 13 Sindo S, Sugimura A, Mitsuyuki T, Sugita T, Ando S. The structure of nursing practices for anticipatory

- grief of cancer family caregivers at the palliative care units in Japan [in Japanese]. *Jpn J Clin Res Death Dying*. 2018;41(1):152–160.
- 14 Ueno E. Development of the patients-nurse communication skill scale [in Japanese]. *J Jpn Acad Nurs Sci*. 2005;25(2):47–55. doi:10.5630/jans1981.25.2_47.
 - 15 Frommelt KH. Attitudes toward care of the terminally ill: an educational intervention. *Am J Hosp Palliat Care*. 2003;20(1):13–22. doi:10.1177/104990910302000108.
 - 16 Nakai Y, Miyashita M, Sasahara T, Koyama Y, Shimizu Y, Kawa M. Factor structure and reliability of the Japanese version of the Frommelt attitudes toward care of the dying scale (FATCOD-B-J) [in Japanese]. *Jpn J Cancer Care*. 2006;11(6):723–729. doi:10.15106/J03022.2007018347.
 - 17 Weiss SJ, Davis HP. Validity and reliability of the Collaborative Practice Scales. *Nurs Res*. 1985;34(5):299–305. doi:10.1097/00006199-198509000-00010.
 - 18 Komi K, Onishi M, Kanda K. Measuring the physician-nurse collaboration: reliability and validity of the Japanese version of collaborative practice scales [in Japanese]. *J Jpn Acad Nurs Admin Policies*. 2010;14(2):15–21. doi:10.19012/janap.14.2_15.
 - 19 Harding Y, Ishibashi Y, Mori M, Yano M, Ando M. Relationship between death conference experiences and nurses' terminal care. *Open J Nurs*. 2020;10(4):381–395. doi:10.4236/ojn.2020.104026.
 - 20 Cohen J. *Statistical power analysis for the behavioral sciences*. 2nd ed. Hillsdale, N.J.: Lawrence Erlbaum Associates;1998. <http://utstat.toronto.edu/~brunner/oldclass/378f16/readings/CohenPower.pdf>. Accessed March 1, 2023.
 - 21 Kehl KA. How hospice staff members prepare family caregivers for the patient's final days of life: an exploratory study. *Palliat Med*. 2015;29(2):128–137. doi:10.1177/0269216314551320.
 - 22 Miyashita M, Morita T, Sato K, Hirai K, Shima Y, Uchitomi Y. Good death inventory: a measure for evaluating good death from the bereaved family member's perspective. *J Pain Symptom Manage*. 2008;35(5):486–498. doi:10.1016/j.jpainsymman.2007.07.009.
 - 23 Garrido MM, Prigerson HG. The end-of-life experience: modifiable predictors of caregivers' bereavement adjustment. *Cancer*. 2014;120(6):918–925. doi:10.1002/cncr.28495.
 - 24 Mori M, Yoshida S, Shiozaki M, et al. "What I did for my loved one is more important than whether we talked about death": a nationwide survey of bereaved family members. *J Palliat Med*. 2018;21(3):335–341. doi:10.1089/jpm.2017.0267.
 - 25 Witkamp FE, van Zuylen L, Borsboom G, van der Rijt CC, van der Heide A. Dying in the hospital: what happens and what matters, according to bereaved relatives. *J Pain Symptom Manage*. 2015;49(2):203–213. doi:10.1016/j.jpainsymman.2014.06.013.
 - 26 Hirvonen OM, Leskelä RL, Grönholm L, et al. The impact of the duration of the palliative care period on cancer patients with regard to the use of hospital services and the place of death: a retrospective cohort study. *BMC Palliat Care*. 2020;19(1):37. doi:10.1186/s12904-020-00547-8.
 - 27 National Cancer Center Institute for Cancer Control. Learning guide for specialist cancer counselors: practical essence [in Japanese]. 3rd ed. https://ganjoho.jp/med_pro/training/consultation/pdf/gakushu_guide03.pdf. Published February 2020. Accessed April 14, 2023.
 - 28 Ministry of Health, Labour and Welfare. Palliative Care Promotion Study Group Report. Ministry of Health, Labour and Welfare [in Japanese]. <https://www.mhlw.go.jp/file/05-Shingikai-10901000-Kenkoukyoku-Soumuka/0000120736.pdf>. Published April 2016. Accessed April 14, 2023.