

cancer and to identify quality indicators from reviews of administrative data and/or medical charts.

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

The author(s) indicated no potential conflicts of interest.

AUTHOR CONTRIBUTIONS

Conception and design: Mitsunori Miyashita, Tatsuya Morita, Kei Hirai
Administrative support: Tatsuya Morita
Manuscript writing: Mitsunori Miyashita
Final approval of manuscript: Mitsunori Miyashita, Tatsuya Morita, Kei Hirai

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Appendix

The Appendix is included in the full-text version of this article, available online at www.jco.org. It is not included in the PDF version (via Adobe® Reader®).

Quality of Life, Day Hospice Needs, and Satisfaction of Community-Dwelling Patients with Advanced Cancer and their Caregivers in Japan

Mitsunori Miyashita, R.N., Ph.D.,¹ Tomoyo Misawa, M.Hlth.Sci.,¹ Mayumi Abe, R.N.,² Yasuko Nakayama, R.N.,³ Koji Abe, Ph.D.,⁴ and Masako Kawa, R.N., Ph.D.¹

Abstract

Background: The aims of this study were to clarify (1) the quality of life (QOL) of community-dwelling patients with advanced cancer and their caregivers in home palliative care and day hospice settings, (2) the need for day hospice of home palliative care patients and caregivers, and (3) the satisfaction with day hospice by day hospice patients and caregivers.

Methods: A cross-sectional questionnaire was administered to patients with advanced cancer and their caregivers who were cared for at day hospice and home palliative care. We measured the health-related quality of life using the SF-8, the need for day hospice of home palliative care patients and caregivers, and the satisfaction with day hospice by day hospice patients and caregivers.

Results: A total of 57 pairs of patients and caregivers participated in the study (day hospice, $n = 23$; home palliative care, $n = 34$). The physical and mental aspects of the patient QOL were significantly lower than national standard value. However, although physical aspect of caregivers QOL was significantly lower than national standard value, mental aspect of caregiver's QOL was not lower than national standard value. Forty-four percent of home palliative care patients and 67% of home palliative care caregivers preferred day hospice. The needs of patients and caregivers were wide ranging including medical treatment, distraction, information provision, and respite. Overall, the Japanese day hospice was evaluated highly.

Conclusion: This is the first study of day hospice in Japan. Although there are several day hospices in Japan, the initiation of day hospice would probably be successful. The dissemination of day hospice is an important issue for patients with advanced cancer and their caregivers in Japan.

Introduction

IN JAPAN, the growth of home-based palliative care programs has been slow. Although several home palliative care services are available, almost all of those for patients with advanced cancer are provided by small-scale clinics and visiting nurses stations. Several day hospices exist for patients with advanced cancer in Japan, but their current status in Japan is unclear.

Although caring for patients with advanced cancer at home would enhance quality of life (QOL) for the patient, the QOL of patients with cancer and caregivers receiving home palliative care services has not been investigated in

Japan. In addition, to overcome barriers to home palliative care service, day hospices could play an important role for advanced cancer patients and their families, as in Western countries.¹⁻⁷ The need for day hospices has not been studied in our country. Moreover, although several day hospices for patients with advanced cancer are available, satisfaction with services provided by day hospices is unclear.⁸

The aims of this study were: (1) to clarify the QOL of community-dwelling patients with advanced cancer and caregivers in home palliative care and day hospice settings; (2) to shed light on the need for day hospices for home palliative care patients and caregivers; and (3) to examine satisfaction with day hospices by patients and caregivers.

¹Department of Adult Nursing/Palliative Care Nursing, School of Health Sciences and Nursing, Graduate School of Medicine, The University of Tokyo, Tokyo, Japan.

²Nagoya University, Aichi, Japan.

³Home Palliative Care Support Center "Rainbow," Miyagi, Japan.

⁴Gerontological Policy, National Center for Geriatrics and Gerontology, Aichi, Japan.

Methods

Participants and procedures

A cross-sectional questionnaire was administered to patients with advanced cancer and caregivers who were cared for at day hospices or by home palliative care services. Three day hospices and eight home palliative care service clinic/visiting nurse stations in the four areas participated. Inclusion criteria were as follows: (1) presence of advanced cancer in the patient; (2) patient age 20 years or more; and (3) use of these institutions by the patient 2 or more times.

Study physicians or nurses explained the study aims to participants who signed consent forms. A coupon book worth 1000 yen (US \$8.30) was provided to participants. The study was conducted from September 2006 to March 2007. The ethical and scientific validity of this study was approved by the Institutional Review Board of the University of Tokyo.

Measurements

Health-related QOL (SF-8). The MOS short-form 8 (SF-8) questionnaire was used as a health-related QOL measure-

TABLE 1. PARTICIPANT CHARACTERISTICS

	Day hospice (n = 23)		Home palliative care (n = 34)		p value ^a
	n	%	n	%	
<i>Patients</i>					
Age (years, mean ± SD)	69 ± 12		76 ± 11		0.08
Gender (male)	14	61	17	50	0.59
Length of service use (weeks, mean ± SD)	34 ± 36		22 ± 33		0.22
Opioid use	5	22	17	50	0.05
Chemotherapy	7	30	5	15	0.19
Intravenous hydration therapy	1	4	8	24	0.07
Oxygen therapy	3	13	8	24	0.50
Metastases	17	74	24	71	1.00
ECOG performance scale					
0	3	13	0	0	0.003
1	5	22	2	6	
2	7	30	8	24	
3	4	17	12	35	
4	4	17	14	41	
Symptoms (STAS-J)	0.6 ± 0.9		1.4 ± 1.0		
Pain	0.7 ± 0.8		1.4 ± 0.9		0.003
Fatigue	0.3 ± 0.5		0.5 ± 0.9		0.004
Dyspnea	0.2 ± 0.5		0.4 ± 0.8		0.34
Nausea	0.2 ± 0.5		0.4 ± 0.8		0.36
Vomiting	0.7 ± 0.8		1.2 ± 1.5		0.58
Appetite loss	0.4 ± 0.6		0.8 ± 0.9		0.34
Insomnia	0.3 ± 0.5		0.6 ± 0.7		0.05
Depression	0.0 ± 0.2		0.2 ± 0.6		0.26
Delirium	0.8 ± 0.7		1.1 ± 1.0		0.14
Anxiety					0.42
<i>Caregivers</i>					
Age (years, mean ± SD)	53 ± 13		60 ± 12		0.10
Gender (male)	8	35	4	17	0.74
Working status (present)	13	57	16	70	0.58
Hospital visit by caregiver's chronic illness	7	30	14	61	0.40
Relationship (spouse)	10	43	17	74	0.77
Duration of caregiving (months, mean ± SD)					0.41
Daily time spent on care (min, mean, SD)	20 ± 27		23 ± 44		0.09
Annual household income ^b	300 ± 272		540 ± 459		
<0.2 million yen	1	4	4	17	0.05
<0.4 million yen	3	13	11	48	
<0.6 million yen	5	22	3	13	
<0.8 million yen	4	17	5	22	
<1 million yen	4	17	1	4	
≥1 million yen	3	13	3	13	

^aStatistical tests were the Wilcoxon rank-sum test, Fisher's exact test and Cochran-Armitage exact trend test, as appropriate.

^b1 Million yen is approximately equal to US \$8,333.

SD, standard deviation; ECOG, Eastern Cooperative Oncology Group.

TABLE 2. QUALITY OF LIFE (SF-8)

	Day hospice (n = 23)			Home palliative care (n = 34)		
	Mean	SD	p value	Mean	SD	p value
<i>Patient QOL</i>						
PCS	42.2	9.7	0.005	37.1	11.7	<0.001
MCS	45.3	7.7	0.001	44.5	9.9	<0.001
<i>Caregiver QOL</i>						
PCS	37.3	5.1	<0.001	35.2	6.2	<0.001
MCS	52.2	9.6	0.241	53.8	9.2	0.024

Figures represent standardized value in Japan (mean = 50, SD = 10). p values were calculated using the Wilcoxon signed-ranks test comparing national standard values in each mean age.
 PCS, physical component summary; MCS, mental component summary; SD, standard deviation; QOL, quality of life.

ment tool.⁹ We were able to calculate two summary scores, physical component summary (PCS) and mental component summary (MCS), in accordance with the scoring rules.

Need for day hospice for home palliative care patients and caregivers. First, we asked home palliative care service patients and caregivers, "Do you want to use a day hospice?" If they answered "Yes", we asked patients and caregivers

about various items regarding preference for specific day hospice services using a 4-point Likert scale (1, not at all; 2, a little; 3, some; 4, a lot).

Satisfaction with day hospice by day hospice-using patients and caregivers. We asked day hospice-using patients and caregivers about satisfaction with day hospices with questions showing similar content to the needs questions using a 4-point Likert scale (1, very dissatisfied; 2, dissatisfied; 3, satisfied; 4, very satisfied).

Participant characteristics. Background information about patient and caregiver characteristics was obtained.

Analysis

First, we summarized participant characteristics and examined differences between characteristics for home palliative care service and day hospice use. Second, we calculated patient and caregiver health-related QOL as a PCS and MCS. Third, we calculated the proportions preferring day hospices among home palliative care service patients. In addition, if participants preferred day hospices, we summarized the need for day hospices. Finally, we summarized satisfaction with day hospices. All statistical tests were two-tailed with values of p < 0.05 considered significant. All analyses were performed using SAS version 9.1 statistical software (SAS Institute, Cary, NC).

TABLE 3. NEED FOR DAY HOSPICE BY HOME PALLIATIVE CARE PATIENTS AND CAREGIVERS

	Patients (n = 34)		Caregivers (n = 33)	
	n	%	n	%
Do you want to use a day hospice?				
Yes	15	44	20	67
No	16	47	11	37
No answer	3	9	2	7
For those answering "Yes" to "Do you want to use a day hospice?" (Patients, n = 15; Caregivers, n = 20)				
<i>Patients</i>				
Relief of pain and other symptoms	12	80	13	65
Medical treatment	12	80	14	70
Information about living with disease	14	93	18	90
Presence of people to talk with the patient	14	93	18	90
Talking with other patients	10	67	16	80
Engaging in favorite activity such as hobby	14	93	17	85
Distraction	15	100	18	90
Staying in a calm and relaxing environment	15	100	16	80
Family respite	15	100	—	—
Bathing	13	87	16	80
Lunch	14	93	17	85
<i>Caregivers</i>				
Information about home care service	—	—	19	95
Information about methods of home care	—	—	19	95
Information about patient diet	—	—	18	90
Information about economic support	—	—	18	90
Family respite	—	—	19	95
Presence of people to talk with caregiver	—	—	20	100
Talking with other caregivers	—	—	18	90

Figures represent total number and percentage of "a lot" and "some."

Results

Participant characteristics

A total of 57 pairs of patients and caregivers participated in the study (day hospice, $n = 23$; home palliative care service, $n = 34$). Participant characteristics are shown in Table 1. Significant differences in patient and caregiver characteristics were seen between home palliative care service and day hospices users in some items.

Health-related QOL (SF-8)

Health-related QOL (SF-8) scores are shown in Table 2. Compared to national standard values, mean PCS for day hospice patients and MCS were significantly lower. For home palliative care service patients, mean PCS and MCS were significantly lower. For day hospice caregivers, mean PCS was significantly lower, and for home palliative care service caregivers, mean PCS and MCS were significantly lower.

Need for day hospices among home palliative care patients and caregivers

Table 3 shows the need for day hospices among home palliative care service patients and caregivers. Day hospices were preferred by 44% of patients and 67% of caregivers. Day hospices were preferred by 80% or more of home palliative care service patients for almost all questions.

Satisfaction with day hospices by day hospice-using patients and caregivers

Table 4 shows satisfaction with day hospices by day hospice-using patients and caregivers. For 8 of the 11 questions,

70% or more of patients were satisfied. Regarding satisfaction of caregivers, 80% or more were satisfied about patient-related items for 8 of the 10 questions. As for caregiver-related variables, 80% or more of caregivers were satisfied for 5 of the 7 questions.

Discussion

This is the first study of QOL, day hospice needs, and satisfaction of community-dwelling patients with advanced cancer and caregivers in Japan. We found that QOL for patients with advanced cancer and caregivers is significantly lower than the national standard. Many patients and caregivers using home palliative care services need access to day hospices. The needs of patients and caregivers were wide ranging, such as the need for medical treatment, distraction, information, family respite, and the presence of other people to talk with the caregiver. In addition, satisfaction with day hospices by day hospice-using patients and caregivers is quite high. Patients and caregivers were satisfied with most items involved with care provided in day hospices.

QOL among patients with advanced cancer and caregivers was lower than national standard values. In particular, PCS was significantly lower than MCS. However, in our study, PCS of caregivers was similar to that of patients. Given the burden on caregivers of advanced cancer patients, maintaining the health of both patients and caregivers is important.¹⁰⁻¹³

Day hospices were preferred by 44% of patients and 67% of caregivers using home palliative care services. Although several day hospices have been opened in Japan, we think this need is high. Advanced cancer patients and caregivers seek social support on medical issues and social aspects of care. Lohfeld et al.⁴ investigated the needs and potential roles

TABLE 4. SATISFACTION WITH DAY HOSPICE BY DAY HOSPICE PATIENTS AND CAREGIVERS

	Patients (n = 23)		Caregivers (n = 23)	
	n	%	n	%
Satisfaction for patient				
Relief of pain and other symptoms	23	100	21	91
Medical treatment	23	100	20	87
Information about living with disease	21	91	20	87
Presence of people to talk with the patient	22	96	20	87
Talking with other patients	14	61	13	57
Engaging in favorite activity such as hobby	14	61	17	74
Distraction	21	91	21	91
Staying in a calm and relaxing environment	21	91	21	91
Family respite	19	83	—	—
Bathing	14	61	15	65
Lunch	16	70	16	70
Satisfaction for caregiver				
Information about home care service	—	—	21	91
Information about methods of home care	—	—	20	87
Information about patient diet	—	—	18	78
Information about economic support	—	—	13	57
Family respite	—	—	17	74
Presence of people to talk with caregiver	—	—	19	83
Talking with other caregivers	—	—	11	48

Figures represent total number and percentage of "very satisfied" and "satisfied."

of day hospices in a qualitative study. The present results resemble the findings described by Lohfeld et al.⁴ in Canada. Day hospices allow patients to keep living at home while attending a specialist palliative care center on a regular basis.¹⁴ The dissemination of day hospices is an important issue for patients with advanced cancer and caregivers in Japan.

This study displays several limitations. First, the major limitation of this survey was that participants were not representative of all patients with cancer. The generalizability of these findings to all patients with cancer is thus limited. Second, patients with severe physical conditions were not recruited. QOL for patients using home palliative care services and day hospices would thus have been lower in the whole population than in this study. Finally, the characteristics and care offered by day hospices would differ among facilities, as several day hospices have opened in Japan. As the use of home palliative care services and day hospices grows, further studies are needed to confirm the present results.

Conclusions

In conclusion, we found that the QOL of patients with advanced cancer and caregivers was significantly lower than the national standard value, particularly with regard to physical aspects. Many patients and caregivers using home palliative care services needed access to a day hospices. The needs of patients and caregivers were wide-ranging, from medical treatment to social services. The dissemination of day hospices is an important issue for advanced cancer patients and caregivers in Japan. For most items, patients and caregivers were satisfied with the care. This study demonstrates that the introduction of day hospices in Japan would probably be successful. Day hospices have a potentially important role to play in home care for patients with advanced cancer in Japan.

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Author Disclosure Statement

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Address reprint requests to:
Mitsunori Miyashita, R.N.

Department of Adult Nursing/Palliative Care Nursing
School of Health Sciences and Nursing
Graduate School of Medicine
The University of Tokyo
7-3-1, Hongo, Bunkyo-ku
Tokyo 113-0033
Japan

E-mail: miyashita-tyk@umin.net

The Japan HOspice and Palliative Care Evaluation Study (J-HOPE Study): Study Design and Characteristics of Participating Institutions

Mitsunori Miyashita, RN, PhD, Tatsuya Morita, MD, Satoru Tsuneto, MD, PhD, Kazuki Sato, RN, MHLthSci, and Yasuo Shima, MD

This article describes the study design and background data of participating institutions in the Japan HOspice and Palliative care Evaluation (J-HOPE) study. The J-HOPE study is a large nationwide survey about the dying experience of cancer patients. The primary aim of this article is to describe the design of the J-HOPE study for the bereaved family members of Japanese inpatient palliative care units and home hospices. Secondly, the aim was to describe characteristics of participating institutions. The authors conducted a cross-sectional questionnaire survey in 2007. One hundred Japanese inpatient palliative care units and 14 home hospices

participated. The questionnaires were sent to 7955 bereaved family members of the Japanese inpatient palliative care units and 447 of the home hospices. The authors describe the structure of the Japanese inpatient palliative care units and home hospices, including type of staff, architectural structure, number of patients, and death. In addition, the authors describe available treatments at the Japanese inpatient palliative care units and home hospices.

Keywords: palliative care; bereavement; evaluation; hospice; J-HOPE study; Japan

In Japan, the Ministry of Health, Labor, and Welfare has strongly supported the dissemination of specialized palliative care services, with coverage of palliative care units (PCUs) by National Medical Insurance since 1990. The number of PCUs has dramatically increased from 5 in 1990 to 175 in 2007. In contrast, the growth of home hospice has been slow; inpatient palliative care teams were not

covered by National Medical Insurance until 2002. Therefore, the most common type of specialized palliative care service in Japan is the PCU.¹⁻³

It is important to ensure and improve the quality of palliative care in the specialized palliative care service.⁴⁻⁶ With this aim, we conducted 2 nationwide surveys on PCUs in collaboration with Hospice Palliative Care Japan as a part of a national quality-control project. First, in 1999, we developed the questionnaire "satisfaction scale for family members receiving inpatient palliative care" (Sat-Fam-IPC) and surveyed 37 PCUs in Japan.^{7,8} However, Sat-Fam-IPC was not a well-validated instrument and measured only satisfaction of bereaved family members. In addition, as a general satisfaction scale, Sat-Fam-IPC had a skewed distribution toward the satisfied direction, and the ceiling effect made it difficult to identify what factors should be improved. Therefore, from 2001 to 2003, we developed a new instrument to measure the structure and process of care from the viewpoint of bereaved family members, the Care Evaluation Scale (CES). At the same time, we conducted the second

From the Department of Adult Nursing/Palliative Care Nursing, School of Health Sciences and Nursing, Graduate School of Medicine, University of Tokyo, Tokyo (MM, KS), Department of Palliative and Supportive Care, Palliative Care Team and Seirei Hospice, Seirei Mikatahara Hospital, Shizuoka (TM), Department of Palliative Medicine, Osaka University Graduate School of Medicine, Osaka (ST), and Department of Palliative Medicine, Tsukuba Medical Center Hospital, Ibaraki (YS), Japan.

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Address correspondence to: Dr Mitsunori Miyashita, RN, PhD, Department of Adult Nursing/Palliative Care Nursing, School of Health Sciences and Nursing, Graduate School of Medicine, University of Tokyo, 7-3-1 Hongo, Bunkyo-ku, Tokyo 113-0033, Japan; e-mail: miyasita-tky@umin.net.

nationwide survey of 70 PCUs.⁹ This survey, with 1225 subjects, not only evaluated the level of palliative care at that time but also revealed several areas that needed improvement, such as lack of perceived support for maintaining hope, lack of perceived respect of individuality, perceived poor quality of care, inadequate staffing and equipment, unavailability of timely administration of the PCU, lack of accurate information about PCUs, and economic burden.¹⁰ The results of the 2 surveys were reported to the participant institutions, and these projects contributed to maintaining the quality of care in the PCUs in Japan.

In addition, one of the most important goals of palliative care is achieving a good death or a good dying process. In Western countries, elaborate efforts have been devoted to conceptualizing a good death¹¹⁻¹⁴ and quantitative research has been conducted by Steinhäuser et al.¹⁵ Teno et al conducted a nationwide mortality follow-up study to evaluate end-of-life care from the bereaved family member's view.¹⁶ In Japan, it is also important to conceptualize what constitutes a good death. Therefore, both qualitative and quantitative research have been done, and 18 important concepts of a good death were identified.^{17,18} For the next step, we developed a measure for evaluating a good death from the bereaved family member's perspective: the Good Death Inventory (GDI).¹⁹ We then completed the preparation for the evaluation of palliative care by the structure and process of care (CES) and outcome (GDI).

In October 2006, there were 162 institutions with PCUs. Quality assurance, evaluation, and improvement are important issues in Japan. Therefore, we planned a third nationwide project to evaluate hospice and palliative care, the J-HOPE study. For the J-HOPE study, we recruited home hospices. This multicenter survey of home hospice is the first of its kind in Japan. We used the same methodology and questionnaire for both PCUs and home hospices. In this article, we first describe the design of the J-HOPE study. Secondly, we depict participating institutions' characteristics, including structure of care, available treatment in these care settings, and bereavement care for family members.

Methods

Participating Institutions

All PCUs (n = 153) of Hospice Palliative Care, Japan, approved before September 2005 were recruited for

this study. Of these, 103 responded. Three institutions did not participate because of rejection by the institutional review board. Finally, 100 PCUs (65%) participated in the study. We asked 17 institutions to participate, and 14 institutions responded for home hospice. Finally, 14 home hospices (82%) participated in this study. We asked the institutions to describe their structure of care, available treatment, and bereavement care for family members.

Study Design

We conducted a cross-sectional questionnaire survey in June 2007. To find potential subjects, we asked each institution to identify bereaved family members of patients who died from November 2004 to October 2006, up to 80 subjects in each institution. The inclusion criteria were as follows: (a) patient died at PCU or home, (b) patient was aged 20 years or more, and (c) bereaved family member was aged 20 years or more. The exclusion criteria were as follows: (a) could not identify the bereaved family member's address, (b) participant would have suffered serious psychological distress as determined by the primary physician, and (c) participant was incapable of replying to a self-reported questionnaire. For the PCUs, 8508 potential study subjects were listed and 553 were excluded in accordance with the above criteria. Finally, we mailed questionnaires to 7955 subjects. For the home hospices, 467 potential study subjects were listed and 20 were similarly excluded. Finally, we mailed questionnaires to 447 subjects. The study's secretariat office prepared the complete set of questionnaires and sent them to the institutions. Each institution's collaborator then sent questionnaires to the individual subjects.

Questionnaires

Questionnaires were composed of 2 sections: the common questionnaires and additional questionnaires. The outline of the questionnaires is displayed in Figure 1.

Common Questionnaires

Care Evaluation Scale. The CES evaluates the structure and process of end-of-life care from the bereaved family's perspective by rating the need for improvement for each item on a 6-point Likert scale from 1: improvement is not necessary to 6: improvement is

Place of death

Questionnaires

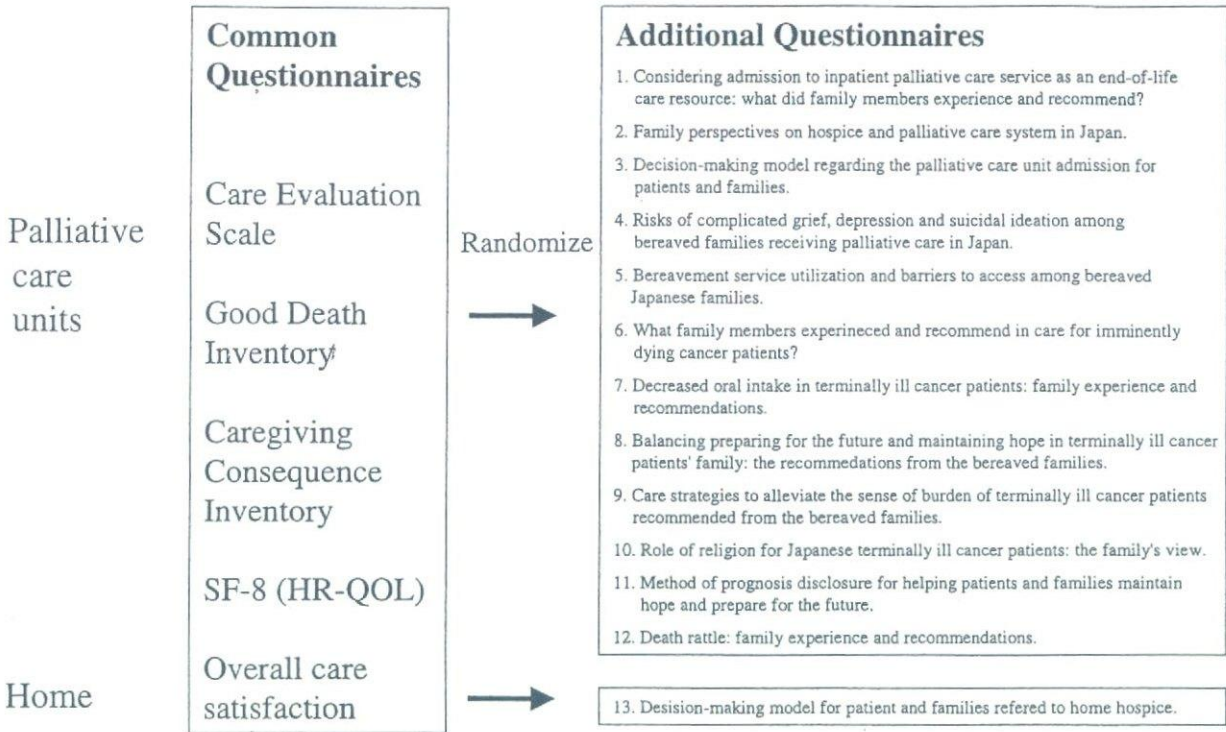


Figure 1. Contents of questionnaire of J-HOPE study.

highly necessary.⁹ The score was transformed to a 0 to 100 point scale, with a high score indicating excellent care. We used a short version of the CES in this study. The short version consisted of 10 items from each domain of the original CES, and validity and reliability were confirmed. The items are described in Appendix A.

Good Death Inventory. The GDI measures the outcome as evaluation of a good death from the bereaved family's perspective by rating the agreement for each item on a 7-point Likert scale from 1: strongly agree to 7: strongly disagree. A high score indicates achievement of a good death. We used the short version of the GDI in this study. The short version consisted of 18 items from each domain of the original GDI, and validity and reliability were confirmed.¹⁹ The items are described in Appendix B.

Caregiving Consequence Inventory. The CCI measures the caregiver's experience from both positive and negative aspects by rating the agreement for each item on a 7-point Likert scale from 1: strongly

agree to 7: strongly disagree. The CCI has 16 items in 5 domains: mastery, appreciation for others, meaning in life, reprioritization, and 1 perceived burden domain (Sanjo M, RN, MHLth Sci, et al, unpublished data, 2008). The validity and reliability of CCI were confirmed.

MOS Short Form 8 (SF-8). The SF-8 measures general quality of life of bereaved family members.²⁰ The SF-8 consists of the following items: physical functioning, role physical, bodily pain, general health perception, vitality, social functioning, role emotional, and mental health. We used the Japanese standardized version of the SF-8. We were able to calculate 2 summary scores: physical component summary and mental component summary in accordance with scoring rules.

Overall Care Satisfaction. We asked the participants about their overall care satisfaction to examine concurrent validity. The question was, "Overall, were you satisfied with the care in the PCU (home)?" The participant answered using a 6-point Likert scale from 1: absolutely dissatisfied to 6: absolutely satisfied.

Subject Characteristics

The age, sex, number of hospital days, and type of cancer of the patient were extracted from medical databases. We asked the bereaved family member's age, sex, health status during the caregiving period, relationship with the patient, frequency of attending the patient, presence of other caregivers, and financial expenditure during the last month.

Additional Questionnaires

As for the bereaved family members of the PCU patients, 12 additional questionnaires were randomly assigned. In particular, we sent No.10 additional questionnaires (role of religion) to all bereaved families of 4 selected PCUs with a full-time priest, and we sent 2 No.10 questionnaires to other PCUs. We considered these additional questions to be independent studies from the J-HOPE study. Twelve additional questionnaires were as follows:

1. Considering admission to inpatient palliative care service as an end-of-life care resource: what did family members experience and recommend?
2. Family perspectives on hospice and palliative care system in Japan.
3. Decision-making model regarding the PCU admission for patients and families.
4. Risks of complicated grief, depression, and suicidal ideation among bereaved families receiving palliative care in Japan.
5. Use of bereavement service and barriers to access among bereaved Japanese families.
6. What did family members experience and recommend for care of imminently dying cancer patients?
7. Decreased oral intake in terminally ill cancer patients: family experience and recommendations.
8. Balancing preparing for the future and maintaining hope in terminally ill cancer patient's family: the recommendations from the bereaved families.
9. Care strategies to alleviate the sense of burden of terminally ill cancer patients recommended from the bereaved families.
10. Role of religion for Japanese terminally ill cancer patients: the family's view.
11. Method of prognosis disclosure for helping patients and families maintain hope and prepare for the future.
12. Death rattle: family experience and recommendations.

As for the bereaved family members of the home hospice, the following additional questionnaires were assigned for all subjects.

13. Decision-making model for patient and families referred to home hospice.

Ethical Consideration

The ethical and scientific validity of this study was approved by the institutional ethical review of each participant institution and the University of Tokyo (Secretariat Office). We explained the aim of the study, sampling method, and anonymity to the subjects. In addition, we prepared 1 question regarding participation of this study on the cover of the questionnaire in consideration of the emotional burden of mourning.

Results

The structure of the PCUs, including type of staff, availability of staff, number of patients, number of deaths, and associated services are shown in Table 1. Similar items are displayed in Table 2 for home hospices. Available treatments, such as surgery, oral chemotherapy, intravenous chemotherapy, radiation therapy, intravenous hydration, intravenous hyperalimentation, pleurocentesis and paracentesis, nerve block, physiotherapy, and complementary and alternative medicine at the PCU or home hospices, are shown in Table 3. Intravenous hydration, intravenous hyperalimentation, pleurocentesis and paracentesis, physiotherapy, and complementary and alternative medicine were available at almost all PCUs. However, surgery and intravenous chemotherapy were available at only a few PCUs. As for home hospice, intravenous hydration, physiotherapy, and complementary and alternative medicine were available at almost all locations. Moreover, surgery, intravenous chemotherapy, and radiation therapy were not available at all home hospices. The availability of other treatments varied among PCUs and home hospices.

Most PCUs offered regular meetings for the bereaved, communicated with them after discharge by mail, and provided other bereavement services (Table 4). However, medical practitioners from home hospice were more likely to participate in funerals than those from PCUs.

Table 1. Structure of the PCUs (N = 100)

	Mean	Median	SD	Range
No. of physicians (full-time)	2.0	2.0	1.1	1-7
No. of physicians (part-time)	0.6	0.0	0.9	0-4
No. of patients per physician	9.5	9.0	3.7	2.5-25
No. of physicians per bed	0.1	0.1	0.1	0.04-0.4
Physician's system at night				
General doctor on duty in the hospital (n, %)	41	41		
Palliative care physician is doctor on duty every day (n, %)	3	3		
Palliative care physician is called by phone (n, %)	70	70		
No. of nurses (full-time)	16.0	16.0	4.3	9-41
No. of nurses (part-time)	0.3	0.0	0.7	0-4
No. of nurses per bed	0.9	0.2	0.9	0.4-1.8
No. of specialized trained nurses	0.8	1.0	0.8	0-4
No. of patients per nurse (weekday)	3.8	4.0	1.0	1.8-9
No. of patients per nurse (holiday)	4.6	4.5	1.2	1.8-10
No. of nurses in the midnight shift	2.2	2.0	0.4	2-3
No. of nurses in the twilight shift	2.2	2.0	0.4	2-3
No. of patients per nurse in the midnight shift	7.8	8.0	1.9	2-14
No. of patients per nurse in the twilight shift	7.6	7.8	1.9	2-12
Nursing shift				
2 shifts (n, %)	62	62		
3 shifts (n, %)	36	36		
Other (n, %)	2	2		
Psychiatrist				
Full-time for the PCU (n, %)	4	4		
Part-time for the PCU (n, %)	63	63		
None (n, %)	33	33		
Psychotherapist				
Full-time for the PCU (n, %)	5	5		
Part-time for the PCU (n, %)	32	32		
None (n, %)	63	63		
Medical social worker				
Full-time for the PCU (n, %)	16	16		
Part-time for the PCU (n, %)	76	76		
None (n, %)	6	6		
Religious staff				
Full-time for the PCU (n, %)	6	6		
Part-time for the PCU (n, %)	48	48		
None (n, %)	46	46		
No. of volunteers	2.6	2.0	3.5	0-29
No. of beds	18.9	20.0	5.5	6-50
No. of private rooms	16.0	16.0	5.5	6-38
Percentage of private rooms	86	100	21	45-100
No. of charge-free private rooms	8.6	10.0	5.6	0-27
Percentage of charge-free private rooms	47	50	30	0-100
Average extra charge of private room (\$: 1\$ = 120Yen)	74	60	69	0-475
No. of family rooms	1.8	2.0	0.9	1-8
Percentage of presence of family bath	86	86		
No. of admitted patients/year	142	133	56	27-392
No. of discharged patients/year	137	132	54	34-389
No. of deaths/year	117	114	41	28-277
Percentage of deaths discharge	87	89	9	44-100
Average number of patients/day	15.1	15.0	4.5	5.1-37.3
Bed availability rate (%)	80	82	11	44-100
Average hospitalized days	41.6	40.2	11.6	18.6-94.1
Years from initiation of hospice	8.3	7.3	5.3	1.2-25.6
Years from initiation of official PCU fee	7.0	6.5	3.8	1.2-16.5

(continued)

Table 1. (continued)

	Mean	Median	SD	Range
Type of the PCU				
Part of a ward in the hospital (n, %)	72	72		
Independent ward in the hospital (n, %)	25	25		
Fully independent hospital (n, %)	3	3		
Presence of palliative care clinic (n, %)	99	99		
Treatment at home (n, %)	45	45		
Home nursing care (n, %)	45	45		

Note: PCU; palliative care unit.

Table 2. Structure of the Home Hospices (N = 14)

	Mean	Median	SD	Range
No. of physicians (full-time)	1.9	2	1.1	0-4
No. of physicians (part-time)	0.9	0	1.4	0-5
No. of nurses (full-time)	5.7	4	4.8	2-17
No. of nurses (part-time)	1.9	1	2.1	0-7
No. of caregivers (full-time)	1.9	0	4.0	0-14
No. of caregivers (part-time)	0.8	0	1.4	0-5
No. of home care patients	118.2	72	141.0	12-507
No. of home care cancer patients	69.0	29.5	83.8	9-281
No. of deaths at home	28.3	13	48.8	4-193
No. of cancer deaths at home	23.1	10.1	40.0	2-157
Presence of beds in the clinic (n, %)	6	43		
No. of beds in the clinic (N = 6)	19.7	19.0	4.1	16-27
Registered home care assist clinic (n, %)	11	79		
Allied facility with the clinic				
Visiting nursing station (n, %)	4	29		
Home care support station (n, %)	5	36		
Helper station (n, %)	3	21		
Others	2	14		
Around-the-clock care				
Physician and/or nurse (n, %)	13	93		
Nurse only (n, %)	1	7		
Cooperation with inpatient unit (general wards)				
Possible and easy (n, %)	10	71		
Possible and not easy (n, %)	4	29		
None (n, %)	0	0		
Cooperation with inpatient palliative care unit				
Possible and easy (n, %)	10	71		
Possible and not easy (n, %)	3	21		
None (n, %)	1	7		
Cooperation with visiting nursing station				
Possible and easy (n, %)	12	86		
Possible and not easy (n, %)	1	7		
None (n, %)	1	7		

Discussion

In this article, we describe the design of the J-HOPE study. We obtained valuable information on the characteristics of the participant institutions regarding

structure of care, available treatment for patients, and bereavement care for family members. For the PCUs, the participation rate in this study was 65%, and the data are probably representative for the Japanese specialized inpatient PCUs. However, in

Table 3. Available Medical Treatment at the PCU or Home Hospice

	PCU			Home Hospice	
	n	%		n	%
Surgery					
Available at the PCU	8	8	Available at the home	2	14
Available on another ward	67	67	Refer to the hospital	9	64
Not available at the hospital	25	25	Not available	3	21
Chemotherapy by mouth					
Available at the PCU	44	44	Available at the home	10	71
Available on another ward	44	44	Refer to the hospital	2	14
Not available at the hospital	12	12	Not available	2	14
Chemotherapy by transvenous					
Available at the PCU	9	9	Available at the home	2	14
Available on another ward	68	68	Refer to the hospital	9	64
Not available at the hospital	23	23	Not available	3	21
Radiation therapy					
Available at the PCU	31	31	Available at the home	0	0
Available on another ward	8	8	Refer to the hospital	11	79
Not available at the hospital	61	61	Not available	3	21
Intravenous hydration					
Available at the PCU	100	100	Available at the home	13	93
Available on another ward	0	0	Refer to the hospital	1	7
Not available at the hospital	0	0	Not available	0	0
Intravenous hyperalimentation					
Available at the PCU	97	97	Available at the home	11	79
Available on another ward	2	2	Refer to the hospital	3	21
Not available at the hospital	1	1	Not available	0	0
Pleurocentesis/abdominocentesis					
Available at the PCU	99	99	Available at the home	9	64
Available on another ward	1	1	Refer to the hospital	5	36
Not available at the hospital	0	0	Not available	0	0
Nerve block					
Available at the PCU	68	68	Available at the home	4	29
Available on another ward	10	10	Refer to the hospital	10	71
Not available at the hospital	22	22	Not available	0	0
Physiotherapy					
Available at the PCU	91	91	Available at the home	10	71
Available on another ward	3	3	Refer to the hospital	2	14
Not available at the hospital	6	6	Not available	2	14
Complementary and alternative medicine					
Available at the PCU	93	93	Available at the home	12	86
Available on another ward	1	1	Refer to the hospital	1	7
Not available at the hospital	6	6	Not available	1	7

Note: PCU; palliative care unit.

Japan, progress of home hospice is very slow. The information obtained from this study is only preliminary for home hospices in Japan.

Regarding the structure of the PCUs, nursing care-related variables were similar to those obtained in a previous study in 1999.⁸ The information regarding physicians and allied medical workers was new. The percentage of private rooms increased from 72% in 1999 to 86% in 2005. Moreover, the mean number

of patients per year increased from 112 in 1999 to 142 in 2005, and the average number of hospital days decreased from 51 in 1999 to 42 in 2005. We believe that end-of-life care shifted from acute care facilities to some PCUs, and more individualized care was provided in the PCU during these 6 years. However, the percentage of deaths discharge varied from 44% to 100%. The institutional characteristics differed among Japanese PCUs. As for other structure

Table 4. Bereavement Care for the Family Members

	PCU		Home Hospice	
	n	%	n	%
Regular meetings for the bereaved				
For all bereaved	65	65	5	36
For a portion of bereaved	13	13	3	21
None	22	22	6	43
Communication after death by mail				
For all bereaved	78	78	4	29
For a portion of bereaved	15	15	7	50
None	7	7	3	21
Communication after death by phone				
For all bereaved	9	9	3	21
For a portion of bereaved	59	59	8	57
None	32	32	3	21
Participation in funerals				
For all bereaved	2	2	9	64
For a portion of bereaved	61	61	5	36
None	37	37	0	0
Other				
For all bereaved	91	91	10	71
For a portion of bereaved	9	9	4	29
None	0	0	0	0

Note: PCU; palliative care unit.

variables, such as number of physicians and nurses, comedicals, percentage of private rooms, percentage of charge-free private room, number of admitted patients per year, number of deaths per year, and average hospitalized days, there were different features in the Japanese PCUs.

The information obtained from this study comprises initial data on home hospice care in Japan. Of note, the number of cancer deaths at home varied from 4 to 193 among institutions. We know that there are several large-scale home hospices in Japan. One of them participated in this study. We also know that they have different features compared with PCUs. In addition, 93% of them provided around-the-clock care by physicians and/or nurses. Around-the-clock care is necessary for cancer patients and is one of the barriers to dissemination of home hospice in Japan.²¹ Moreover, the home death rate is 6% for cancer patients in Japan. Therefore, cooperation with general inpatient wards and inpatient PCUs is important for relieving the family caregiver's burden.

We obtained information on available treatments in the PCUs and home hospices. Some variability exists among the PCUs. However, other treatments, such as oral chemotherapy, radiation

therapy, and nerve block, also varied among hospices. Although availability of treatments might depend on the institution's equipment, it is important to understand the Japanese health insurance system. In 1990, PCUs were institutionalized by the medical system. However, the payment system for PCUs was the Prospective Payment System (PPS). In 2005, the medical service fee for 1 patient per day was 37 800 Yen (\$315) regardless of actual medical treatment. Therefore, in some PCUs, cost of treatment was higher than on the general wards. In addition, the philosophy of PCUs might have affected the available treatment. In some PCUs, cure-oriented treatment may have been withheld. Detailed descriptions of medical treatment in the PCUs, including analgesia, surgical procedures, and alternative therapies, have been described in another article.²²

The majority of home hospices provided intravenous hydration (93%), intravenous hyperalimentation (79%), oral chemotherapy (71%), and pleurocentesis and paracentesis (64%). In addition, surgery (78%), intravenous chemotherapy (85%), radiation therapy (79%), nerve block (99%), and physiotherapy (71%) were available in hospice or the patients were referred to hospitals. In other words, these treatments were considered necessary components of home hospice.

Matsushima surveyed bereavement services provided by 50 PCUs in 1999.²³ Matsushima reported that 84% of PCUs sent memorial cards, 59% conducted memorial services, 35% held social group meetings, and 32% contacted the bereaved by telephone.²³ In our study, 93% communicated by mail with the bereaved after discharge and 78% held regular meetings. During 6 years, bereavement care services have progressed in Japan. As for home hospice, our survey was the first study in this field. It is interesting to note that 64% of them participated in funerals for all deceased patients, and the remaining 36% participated for some of the deceased patients. In addition, more hospices communicated after death by phone; 78% of the PCUs communicated by mail. These results suggest that home hospice builds closer relationships with family members than do PCUs.

The major outcomes and additional results will be presented in subsequent articles. In addition, we now plan further research on bereaved family members from Japanese nationwide regional cancer centers. We would like to compare the quality of end-of-life care among PCUs, home hospices, and regional cancer centers in the near future.

Conclusions

We described the design of the J-HOPE study for bereaved family members of Japanese PCU and home hospice patients. One hundred PCUs and 14 home hospices participated in this survey; 7955 questionnaires were sent to bereaved family members of PCU patients and 447 families of home hospices patients. In addition, we acquired valuable information on the participant institutions' characteristics regarding structure of care, available treatments, and bereavement care for family members. The information obtained by this study is the first data of its kind on home hospices in Japan.

Appendix A Short Version of the Care Evaluation Scale

1. Doctors dealt promptly with discomforting symptoms of the patient.
2. Nurses had adequate knowledge and skills.
3. The staff tried to bolster the patient's hope.
4. The doctors gave sufficient explanation to the patient about the expected outcome.
5. The doctors gave sufficient explanation to the family about the expected outcome.
6. The patient's room/home environment was convenient and comfortable.
7. Consideration was given to the health of the family.
8. The total cost was reasonable.
9. Admission (use) was possible when necessary without waiting.
10. There was good cooperation among staff members, such as doctors and nurses.

Appendix B Short Version of the Good Death Inventory

1. Patient was free from physical distress.
2. Patient was able to stay at his or her favorite place.
3. Patient had some pleasure in daily life.
4. Patient trusted the physician.
5. Patient was not being a burden to others.
6. Patient spent enough time with his or her family.
7. Patient was independent in daily activities.
8. Patient lived in calm circumstances.
9. Patient was valued as a person.
10. Patient felt that his or her life was completed.
11. Patient received enough treatment.
12. Patient died a natural death.

(continued)

Appendix B (continued)

13. Patient was able to say what he or she wanted to dear people.
14. Patient knew what to expect about his or her condition in the future.
15. Patient lived as usual without thinking about death.
16. Patient felt burden of exposing his or her physical and mental weakness to family.
17. Patient felt that his or her life is worth living.
18. Patient was supported by religion.

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Original Article

Good Death Inventory: A Measure for Evaluating Good Death from the Bereaved Family Member's Perspective

Mitsunori Miyashita, RN, PhD, Tatsuya Morita, MD, Kazuki Sato, RN, MHIthSci, Kei Hirai, PhD, Yasuo Shima, MD, and Yosuke Uchitomi, MD, PhD

Department of Adult Nursing/Palliative Care Nursing (M.M., K.S.), School of Health Sciences and Nursing, Graduate School of Medicine, University of Tokyo, Tokyo; Department of Palliative and Supportive Care, Palliative Care Team and Seirei Hospice (T.M.), Seirei Mikatahara Hospital, Shizuoka; Center of the Study for Communication Design, Psychology and Behavioral Sciences (K.H.), Graduate School of Human Sciences, and Department of Complementary and Alternative Medicine (K.H.), Graduate School of Medicine, Osaka University, Osaka; Department of Palliative Medicine (Y.S.), Tsukuba Medical Center Hospital, Ibaraki; and Psycho-Oncology Division (Y.U.), Research Center for Innovative Oncology, National Cancer Center Hospital East, Chiba, Japan

Abstract

The aim of this study was to develop a measure for evaluating good death from the bereaved family member's perspective, and to examine the validity and reliability of the assessment. A cross-sectional anonymous questionnaire was administered to bereaved family members of cancer patients who had died in a regional cancer center from September 2004 to February 2006. We measured the Good Death Inventory (GDI), Care Evaluation Scale, and an overall care satisfaction scale. A retest was conducted one month after sending the questionnaire. Of the 344 questionnaires sent to bereaved family members, 189 responses were analyzed (57%). A factor analysis of the responses to the GDI identified 10 core domains: "environmental comfort," "life completion," "dying in a favorite place," "maintaining hope and pleasure," "independence," "physical and psychological comfort," "good relationship with medical staff," "not being a burden to others," "good relationship with family," and "being respected as an individual." Eight optional domains also were identified: "religious and spiritual comfort," "receiving enough treatment," "control over the future," "feeling that one's life is worth living," "unawareness of death," "pride and beauty," "natural death," and "preparation for death." The GDI had sufficient concurrent validity with the Care Evaluation Scale and overall care satisfaction, sufficient internal consistency ($\alpha = 0.74-0.95$), and acceptable test-retest reliability ($ICC = 0.38-0.72$). Finally, we developed a short version of the GDI. The GDI is a valid scale to measure end-of-life care comprehensive outcomes from the bereaved family member's perspective in Japan. J Pain Symptom Manage

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Address correspondence to: Mitsunori Miyashita, RN, PhD, Department of Adult Nursing/Palliative Care Nursing, School of Health Sciences and Nursing,

Graduate School of Medicine, University of Tokyo, 7-3-1 Hongo, Bunkyo-ku, Tokyo 113-0033, Japan. E-mail: miyashita-ky@umin.net

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Key Words

Palliative care, end-of-life care, neoplasms, hospice, questionnaires, measures, good death

Introduction

One of the most important goals of palliative care is achieving a “good death” or a “good dying process.” In Western countries, elaborate efforts have been devoted to conceptualizing a good death, using qualitative research.^{1–6} Quantitatively, Steinhauser et al. have elucidated important factors that influence the end of life.^{7,8} In addition, Steinhauser et al. have measured the achievement of a good death by terminally ill patients.^{9,10}

However, interviewing or administering a questionnaire to vulnerable terminally ill patients is burdensome, and nonresponse because of severe illness might result in biased conclusions. Therefore, many studies to evaluate end-of-life care have been conducted with bereaved family members.^{11–16} The evaluation of end-of-life care from the bereaved family member’s perspective requires valid and reliable measures. Some instruments have been developed for this purpose, such as the Toolkit for After Death Interview,¹⁷ Quality of Death and Dying questionnaire for end-of-life care settings,¹⁸ and the modified Quality of Death and Dying questionnaire for intensive care units.¹⁵ In Japan, Morita et al. developed a satisfaction scale for bereaved family members¹⁹ and the Care Evaluation Scale (CES) focusing on structure and process of end-of-life care.²⁰

In Japan, however, only a few studies have investigated the elements that constitute a good death: a qualitative study of hospice nurses,²¹ a small investigation of advanced cancer patients,²² and an observational study of patients.²³ To fulfill the goals of palliative care in Japan, it is important to conceptualize what constitutes a good death in Japan. Therefore, as a first step, we conducted a nationwide qualitative study to explore attributes of a good death in Japan; this included a total of 63 participants, including advanced cancer patients and their families, physicians, and nurses.²⁴ For the next step, we conducted a quantitative

study to determine what attributes were considered necessary for a good death, using a large nationwide sample of the general population and bereaved family members in Japan.²⁵ In this study, we identified 18 domains contributing to a good death for Japanese subjects, including 10 core domains that most Japanese consistently rated as important and eight optional domains that were not as consistently rated as important by individuals.²⁵

As a third step, the aim of this study was to develop a measure for evaluating good death from the bereaved family member’s perspective based on our previous investigations, and to examine the validity and reliability of this new measure in Japan.

Methods

Participants and Procedures

A cross-sectional anonymous questionnaire was administered to bereaved family members of cancer patients who had died in a regional cancer center’s general wards and inpatient palliative care unit (PCU) in Ibaraki prefecture, Japan. The Japanese Ministry of Health, Labor, and Welfare has strongly supported dissemination of specialized palliative care services, with coverage of PCUs by National Medical Insurance since 1990. The number of PCUs has dramatically increased from five in 1990 to 163 in 2006. In contrast, the growth of home-based palliative care programs has been slow, as inpatient palliative care teams were not covered by National Medical Insurance until 2002. Therefore, the most common type of specialized palliative care service in Japan is the PCU. Although the number of PCUs has increased, they cover only 5% of all cancer deaths. In 2004, only 6% of cancer deaths occurred in the home and over 80% of cancer deaths occurred on general wards. Therefore, death on general wards is an important issue in Japan.

To find potential participants, we identified bereaved family members of patients who died from September 2004 to February 2006. The inclusion criteria were as follows: (1) patient died in PCU or died on the general ward from lung cancer or gastrointestinal cancer, (2) patient was aged 20 years or more, and (3) patient was hospitalized at least three days. The exclusion criteria were as follows: (1) participant was recruited for another questionnaire survey for bereaved family members, (2) participant would have suffered serious psychological distress as determined by the primary physician, (3) cause of death was treatment-related or due to injury, (4) there was no bereaved family member who was aged 20 years or more, (5) participant was incapable of replying to a self-reported questionnaire, and (6) participant was not aware of the diagnosis of malignancy.

We mailed questionnaires to potential respondents in October 2006 and a reminder was sent in November 2006 to those who did not respond. We asked that the primary caregiver complete the questionnaire. If the respondents did not want to participate in the survey, they were asked to return the questionnaire with "no participation" indicated, and a reminder was not mailed to them. To examine test-retest reliability, we sent the same questionnaire one month after sending the original questionnaire. The ethical and scientific validity of this study was approved by the institutional review boards of Tsukuba Medical Center Hospital.

Measurements

Good Death Inventory. The Good Death Inventory (GDI) evaluates end-of-life care from the bereaved family member's perspective. Seventy potential attributes of a good death were asked, using a seven-point Likert scale (1: absolutely disagree, 2: disagree, 3: somewhat disagree, 4: unsure, 5: somewhat agree, 6: agree, 7: absolutely agree). The attributes were generated based on a previous qualitative study,²⁴ quantitative study,²⁵ and literature review.^{7,8,13,15,17-20} In the qualitative study, we found 58 attributes of a good death in Japan.²⁴ In the following quantitative study, we asked 57 questions based on the previous qualitative study and literature review. Finally, we concluded, using factor analysis and Cronbach's alpha coefficients, that the

Japanese concept of a good death was constituted by 18 domains.²⁵ We then composed three or more questions for each of the 18 domains. Therefore, we assumed there were 18 hypothetical domains based on the results of previous studies. We calculated the domain score by summing up attributes. A high score indicated the achievement of a good death in each domain. Total scores were calculated in three ways: a total of all attributes, a total of 10 core domain attributes, and a total of eight optional domain attributes. The questionnaire that was finally adopted is described in the Appendix.

The face validity was evaluated by two physicians, two nurses, and two lay persons. The GDI was generated based on the previous qualitative study with 63 participants²⁴ and a nationwide quantitative study with 3,061 participants.²⁵ In addition, we conducted a literature review and fully discussed the content validity among co-researchers. This process ensured the content validity of our questionnaire.

CES, Short Version. We used the CES, short version, to examine concurrent validity. The CES was developed to measure end-of-life care from the bereaved family member's perspective especially focusing on structure and process of care.²⁰ The original version of the CES was 10 domains (help with decision making for patient, help with decision making for family, physical care by physician, physical care by nurse, psycho-existential care, environment, cost, availability, coordination of care, and family burden), with 28 attributes. The validity and reliability of this scale have been tested.²⁰ The questionnaire was designed so that the respondent evaluated the structure and process of end-of-life care by rating the necessity of improvement for each item on a six-point Likert scale from 1: improvement is not necessary to 6: improvement is highly necessary. The score was transformed to a 0-100 point scale, with a high score indicating excellent care. The short version of the CES consisted of 10 items from each domain and validity and reliability were confirmed.

Overall Care Satisfaction. We asked the participants about their overall care satisfaction in order to examine concurrent validity. The question was, "Overall, were you satisfied with the care in the hospital?" The participant was asked to answer using a six-point Likert scale from 1: absolutely dissatisfied to 6: absolutely satisfied.