SUPPORTIVE CARE INTERNATIONAL

Barriers to referral to inpatient palliative care units in Japan: a qualitative survey with content analysis

Mitsunori Miyashita · Kei Hirai · Tatsuya Morita · Makiko Sanjo · Yosuke Uchitomi

Abstract

Objectives We investigated the barriers to referral to inpatient palliative care units (PCUs) through a qualitative study across various sources of information, including terminal cancer patients, their families, physicians, and nurses.

Materials and methods There were 63 participants, including 13 advanced cancer patients, 10 family members, 20 physicians, and 20 nurses in palliative care and acute care cancer settings from five regional cancer institutes in Japan. Semi-structured interviews were conducted regarding barriers to referral to PCU, and data were analyzed by content analysis method.

Results A total of 21 barriers were identified by content analysis. The leading barriers were (1) a negative image of PCUs by patients and families ($n=39$), (2) delay of termination of anti-cancer treatment by physicians in the general wards ($n=24$), (3) unwillingness to end anti-cancer treatment and denial of the fatal nature of the disease by patients and families ($n=22$), (4) patient's wish to receive care from familiar physicians and nurses ($n=20$), and (5) insufficient knowledge of PCUs by medical staff in general wards ($n=17$).

Conclusions To correct these unfavorable images and misconceptions of PCUs, it is important to eliminate the negative image of PCUs from the general population, patients, families, and medical staffs. In addition, early introduction of palliative care options to patients and communication skills training regarding breaking bad news are relevant issues for a smooth transition from anti-cancer treatment to palliative care.

Keywords Palliative care · Hospice · Neoplasms · Referral and consultation · Qualitative research

M. Miyashita (✉) · M. Sanjo
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: miyasita-tky@umin.net

K. Hirai
Graduate School of Human Sciences, Osaka University,
Osaka, Japan

T. Morita
Department of Palliative and Supportive Care,
Palliative Care Team and Seirei Hospice,
Seirei Mikatahara Hospital,
Shizuoka, Japan

Y. Uchitomi
Psycho-Oncology Division,
Research Center for Innovative Oncology,
National Cancer Center Hospital East,
Chiba, Japan

Introduction

Palliative care specialists are faced with extensive barriers to providing effective end-of-life care [1, 14, 15, 30]. It is important to explore barriers to referral to hospice because late referral results in low family satisfaction with care [25]. Many studies have been done regarding obstacles to hospice referral [3–6, 10, 13, 19, 21, 23, 29], and various barriers have been identified. They include the difficulty of predicting prognosis [3, 29], lack of physician acceptance of terminal diagnosis and death [1, 6, 14], physician's unwillingness to refer to hospice service [1, 5], physician's unfamiliarity with hospice [5], physician's negative opinion of hospice service [5], insufficient knowledge of physician about hospice service [1], insufficient education for physi-

cians about palliative care [1, 6, 14], a medical system that does not include hospice as standard care [14, 30], patient's and family's unwillingness to use hospice [1, 19, 23], patient's and family's desire for life-prolonging treatment [29], lack of acceptance of a terminal diagnosis by the patient and family [23, 29, 30], insufficient knowledge by the general population and patients and families about hospice service [10, 13], and social attitudes toward death [30].

In Japan, the Ministry of Health, Labor, and Welfare has strongly supported the dissemination of specialized palliative care services. National Medical Insurance has covered inpatient palliative care units (PCUs) for terminal cancer patients since 1991, and the number of PCUs has dramatically increased from 5 in 1991 to 162 in 2006. On the other hand, the growth of home-based palliative care programs has been slow, and 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 [7, 9, 17]. Although western studies are focused on referral to home hospice, in Japan, referral is usually to the PCU. As there is a difference in medical systems and cultural background, Japanese barriers to referral to the PCU should be examined [27].

Morita explored reasons for late referral to the PCU in Japan and found misconceptions about palliative care among families, inadequate communication with physicians, and insufficient preparation of the family for the deterioration of the patient's condition [17]. However, Morita's study sample included only bereaved family members of PCU patients. He did not include the families of patients who were not referred or were denied admittance to the PCU. About 5% of cancer deaths occur in PCUs in Japan. Many patients who should have been referred to the PCU are assumed to have died in general wards. Nonetheless, in Japan, there has been no research exploring barriers to referral to the PCU. Therefore, we investigated the barriers to referral to inpatient PCUs using a qualitative study across various sources of information, including terminal cancer patients and their families, physicians, and nurses.

Materials and methods

Participants

Participants were advanced cancer patients, their family members, physicians, and nurses in palliative care and acute care cancer settings of five regional cancer institutes in Japan (Ibaraki, Gunma, Shizuoka, Hiroshima, and Yamaguchi prefectures). We predetermined that we needed to recruit 20 participants in each group as the sufficient number required for a qualitative study. Then 16 participants (four for each group) were allocated for each institution, and

the patients who met the following conditions were recruited: having incurable advanced cancer, knowing their diagnosis, having no cognitive impairment, and being aged 20 to 80 years. The physicians and the nurses in acute care settings were required to have had more than 2 years of clinical experience in cancer treatment. The physicians and nurses in palliative care settings were also required to have had more than 2 years of clinical experience in specialized palliative care service. We obtained written informed consent from all the participants.

Interview procedure

Semi-structured interviews were conducted by five interviewers, including the authors of this article (M. M. and K. H.), two graduate school students of psychology, and one research nurse. The interview followed guidelines developed by the authors through careful consideration of the purpose of this study. There were two sets of questions. One set contained predetermined, open-ended questions for patients and family members, such as the following: "If you were offered referral to the PCU, what would be the barriers to admittance to the PCU?" The other set included predetermined, open-ended questions for physicians and nurses, as follows: "What do you think are barriers to referral of patients to the PCU?" For both procedures, the participants were asked to respond freely to the questions.

Analysis

All the interviews were audiotaped and transcribed. Content analysis was performed on the transcribed data [11]. First, a research nurse (M. M.) and a psychologist (K. H.) extracted all statements from the transcripts related to the study topics, such as barriers to referral to inpatient palliative care units. Then, under the supervision of an experienced palliative care physician (T. M.), they carefully conceptualized and categorized the attributes from the transcripts based on similarities and differences in the content and created definitions for all the attributes. Finally, two coders among the research nurses independently determined whether each participant had made remarks that belonged to any of the attributes according to the definitions. When their coding was inconsistent, a third coder was the final judge. The concordance rate and Kappa coefficient by the two independent coders were 89% and 0.55, respectively.

In addition, we conducted descriptive analyses on the frequencies of the attributes. We summarized four groups into non-medical populations (patient and family) and medical staff (physician and nurse), and Fisher's exact test was used to test group differences in the responses for each attribute. Significance level was set 0.05, and a two-tailed test was conducted. All statistical analyses were performed

using statistical package SAS for Windows version 9.1 (SAS Institute, Cary, NC).

Results

Respondent characteristics

There were a total of 63 participants, including 13 patients, 10 family members, 20 physicians (10 PCU, 10 general ward), and 20 nurses (10 PCU, 10 general ward; Table 1). In several institutions, the enrollment of non-medical populations was insufficient because of the absence of suitable participants. Although several institutions did not recruit the required number due to the absence of suitable participants during the study periods, we did not recruit additional participants because the number of extracted attributes was satisfactorily saturated by the end of the planned study period. Fifty-seven percent of the participants were female, and the mean age was 45 years. The patients' primary sites of cancer were the lungs ($n=5$), pancreas ($n=5$), liver ($n=2$), and others ($n=2$). Patient expected survival time from interviews was 1–3 months ($n=6$), 3–6 months ($n=2$), 6 months–1 year ($n=3$), and unknown ($n=2$). Patient performance status (ECOG PS) was 0 ($n=2$), 1 ($n=3$), 2 ($n=4$), 3 ($n=3$), and 4 ($n=2$).

Barriers to referral to PCU in Japan

A total of 21 barriers were identified by content analysis. We classified these barriers into three categories: (1) patient- and family-related barriers, (2) medical staff-related barriers, and (3) PCU system-related barriers. Their frequency is shown in Table 2. The leading attribute was a negative image of the PCU by patients and families ($n=39$). Second was delaying the termination of anti-cancer treatment by general ward physicians ($n=24$). The third barrier was unwillingness to end anti-cancer treatment and denial of the fatal nature of the disease by patients and families ($n=22$). Fourth was the patient's wish to receive care by the accustomed physician and nurse ($n=20$). And the fifth barrier was insufficient knowledge of PCUs by medical staff in the general ward ($n=17$).

Table 1 Participants' demographics

	Patient ($n=13$)	Family ($n=10$)	Physician ($n=20$)	Nurse ($n=20$)
Age, mean (SD), year	62.2 (11.7)	54.4 (11.5)	38.6 (6.5)	34.9 (7.6)
Male, n (%)	7 (53)	1 (10)	19 (95)	0 (0)
Professional career, mean (SD), year	NA	NA	13.3 (6.1)	12.8 (6.6)

Table 2 Barriers to referral to PCU in Japan ($n=63$)

	Number	Percent
Patient- and family-related barriers		
(1) Negative image of PCU among patients and family members	39	62
(2) Unwillingness to end anti-cancer treatment and denial of the fatal nature of the disease by patient and family	22	35
(3) Patient's wish to receive care by accustomed physician and nurse	20	32
(4) Family's request for patient not to be admitted to PCU	10	16
(5) Insufficient knowledge of the PCU among patients and family members	8	13
General ward medical staff-related barriers		
(6) Delaying the termination of anti-cancer treatment by the physician in the general ward	24	38
(7) Insufficient knowledge of PCU among medical staff in general ward	17	27
(8) Failing to communicate a bad prognosis by the medical staff in the general ward	15	24
(9) Insufficient explanation of PCU by medical staff to the patients and families in general ward	13	21
(10) Not proposing PCU as an alternative by medical staff in the general ward	11	17
(11) Negative image of PCU by medical staff in general ward	10	16
(12) Desire of medical staff in general ward to care for patient until death	10	16
(13) Insufficient communication skills of medical staff in general ward	6	10
(14) Uncertainty of limits of anti-cancer treatment by medical staff in general ward	5	8
PCU-related barriers		
(15) Poor access to PCUs (shortage of PCUs, inconvenient locations)	12	19
(16) Environment of PCU (private room, loneliness, and isolation from general ward)	10	16
(17) Poor communication between PCU staff and medical staff in general ward	9	14
(18) Discontinuation of anti-cancer treatment in PCU	7	11
(19) Economic problems (expensive private room fee, expensive hospital bill)	6	10
(20) Doctrinaire beliefs of PCU (emphasis on philosophy, stringent rules for admission)	5	8
(21) Prospective payment system of PCU	3	5

PCU Palliative care unit

Table 3 shows the differences in responses among groups. For patients, families, and nurses, a negative image of the PCU by patients and families was the leading barrier. For physicians, however, it was delaying the termination of anti-cancer treatment. The following barriers were significantly different among the studied groups: (1) negative image of PCU among patients and family members, (2) insufficient knowledge of the PCU among patients and

Table 3 Differences in responses among groups

Barriers	Patient (n=13)		Family (n=10)		Physician (n=20)		Nurse (n=20)		P value
	N	%	n	%	n	%	n	%	
Patient- and family-related barriers									
(1) Negative image of PCU among patients and family members	7	54	3	30	11	55	18	90	0.006
(2) Unwillingness to end anti-cancer treatment and denial of the fatal nature of the disease by patient and family	3	23	2	20	10	50	7	35	0.33
(3) Patient's wish to receive care by accustomed physician and nurse	2	15	1	10	9	45	8	40	0.12
(4) Family's request for patient not to be admitted to PCU	0	0	1	10	4	20	5	25	0.24
(5) Insufficient knowledge of the PCU among patients and family members	0	0	0	0	8	40	0	0	0.001
General ward medical staff-related barriers									
(6) Delaying the termination of anti-cancer treatment by the physician in the general ward	0	0	0	0	13	65	11	55	0.001
(7) Insufficient knowledge of PCU among medical staff in the general ward	0	0	1	10	8	40	8	40	0.013
(8) Failing to communicate a bad prognosis by the medical staff in the general ward	0	0	0	0	8	40	7	35	0.006
(9) Insufficient explanation of PCU by medical staff to the patients and families in general ward	0	0	0	0	4	20	9	45	0.003
(10) Not proposing PCU as an alternative by medical staff in the general ward	0	0	0	0	6	30	5	25	0.047
(11) Negative image of PCU by medical staff in general ward	0	0	0	0	4	20	6	30	0.051
(12) Desire of medical staff in general ward to care for patient until death	0	0	0	0	4	20	6	30	0.051
(13) Insufficient communication skills of medical staff in general ward	0	0	0	0	4	20	2	10	0.24
(14) Uncertainty of limits of anti-cancer treatment by medical staff in general ward	0	0	0	0	4	20	1	5	0.19
PCU-related barriers									
(15) Poor access to PCU (shortage of PCUs, inconvenient location)	2	15	1	10	6	30	3	15	0.59
(16) Environment of PCU (private room, loneliness, and isolation from general ward)	2	15	1	10	4	20	3	15	0.96
(17) Poor communication between PCU staff and medical staff in general ward	0	0	0	0	4	20	5	25	0.12
(18) Discontinuation of anti-cancer treatment in PCU	2	15	0	0	3	15	2	10	0.77
(19) Economic problems (expensive private room fee, expensive hospital bill)	0	0	1	10	1	5	4	20	0.27
(20) Doctrinaire beliefs of PCU (emphasis on philosophy, stringent rules of admission)	0	0	0	0	2	10	3	15	0.43
(21) Prospective payment system of PCU	0	0	0	0	2	10	1	5	0.77

PCU Palliative care unit

family members, (3) delaying the termination of anti-cancer treatment by the physician in the general ward, (4) insufficient knowledge of the PCU among medical staff in the general ward, (5) failing to communicate a bad prognosis by the medical staff in the general ward, (6) insufficient explanation of the PCU by medical staff to the patients and families in the general ward, and (7) not proposing PCU as an alternative by medical staff in the general ward. The comparison between PCU staff (PCU physicians and nurses) and general ward staff (general ward physicians and nurses) was not significantly different for any attributes (data not shown).

Discussion

This is the first study to investigate the barriers to referral to the inpatient PCU in Japan. A negative image of the PCU is recognized as the most important barrier by patients, families, and medical staffs. They described the PCU as a place of death in that once a patient was admitted to the PCU, he or she could not be discharged alive. They also believed that the PCU shortens the patient's life, isolates patients from the community, and does not offer medical treatment. The opinion that the PCU shortens the patient's life coincides with the findings of Morita's study of late referral [17]. Sanjo reported that the belief that the PCU isolates patients from the community contributes to avoidance of the PCU [24].

Although PCUs are recognized by the general Japanese population and bereaved family members as services that provide compassionate care, helping patients die peacefully and with dignity, providing care for families, and falleviating pain, they still view the PCU as a place that shortens patients' lives and isolates dying patients from the community and as an expensive place where people are

only waiting to die (Sanjo et al., submitted for publication). In addition, Shiozaki investigated dissatisfaction of bereaved family members in the PCU and reported a negative image of the PCU as one of the major reasons for dissatisfaction [26]. Of note, many medical staff reported that the dissemination of these unfavorable images was by patients to patients and families to families. Patients admitted to the general wards and their families were told that the PCU was a place of death by other patients and families. Although some of these images were true [26], Morita showed that the unfavorable opinions could be changed through the experience of being cared for in the PCU [17]. Therefore, of these negative images, several are misconceptions or misunderstandings. To correct these misconceptions, it is important to disseminate accurate information about PCUs to the general population, patients, and families [18].

Delay in ending anti-cancer treatment by physicians in the general ward could be due to the difficulty of predicting prognosis [3, 29]. In addition, it may be associated with the physician's lack of acceptance of the patient's terminal diagnosis and death [1, 6, 14]. Several study participants in the general wards said that even if a physician recognized that a patient might be in a terminal phase, the introduction of palliative care is postponed by the patient's desire for anti-cancer treatment and the uncertainty of the prognosis made the physician. In Japan, the palliative care option is seldom introduced to patients who are receiving anti-cancer treatment. Therefore, it is difficult for the physician to have the opportunity to communicate bad news, especially because physician education in this area is so poor. In addition, determining the time to stop anti-cancer treatment is difficult for the oncologist. Therefore, early introduction of the palliative care option to the patient [8] and communication skills training regarding breaking bad news are relevant issues [2, 20].

Unwillingness to end anti-cancer treatment and denial of the fatal nature of the disease by the patient and family are major problems. Some patients with terminal cancer seek out anti-cancer treatment even if the possibility of cure is low [12, 28]. In addition, a Japanese study revealed that a number of bereaved families experienced serious emotional burden with the ending of anti-cancer treatment and transition to palliative care [16]. Early introduction of the palliative care option and careful and sophisticated communication with the patient and family are important [16]. To that end, it is necessary for the medical staff in the general ward to have accurate information about the PCU and palliative care.

In our study, although most of the barriers to inpatient PCU care are similar to those reported by western countries, several issues unique to Japan were found. Ten participants

told of the family's request for the patient not to be admitted to the PCU. In Japan, it is traditional for the family to intervene in decision-making [22]. Twelve participants told of poor access to a PCU. Only 5% of cancer deaths occur in the PCU. Therefore, the number of PCUs is insufficient and many patients die in the general ward while awaiting admission to the PCU. In addition, some PCUs have stringent admission rules, such as compelling the patient to recognize the diagnosis or prognosis, restrictions on the patient's physical and cognitive condition, and a correct understanding of the purpose of the PCU by patients. The shortage of PCUs is an important barrier to providing specialized palliative care in Japan. An increase in the number of PCU beds and the development of home hospices are needed to deliver palliative care to all dying patients.

The barriers to PCU admission significantly differed according to the group. Patients and families were not aware of physicians' attitudes and were not familiar with their barriers. This indicates an asymmetry of information regarding medical systems among patients, families, and medical staffs.

Our study has several limitations. First, we surveyed a limited number of institutions, and all participating institutions were hospitals with PCUs. If patients, families, and medical staff in general wards with non-PCU hospitals had participated, there may have been more emphasis on access to PCUs. Therefore, generalizing the present results is difficult. Second, barriers identified by patients and families were of low frequency. It was difficult to elicit barriers from patients in terminal stages of cancer and their families. Therefore, a study targeting an earlier phase might be required. Third, although we predetermined that we needed to recruit 20 participants for each group, we could not achieve such number among patient and family member groups. However, we believe that the variety of participants would assure the content validity of this study. Finally, because the number of participants in the four groups were different, determining the importance of each barrier by summing up the answers of the four groups might be not conclusive.

Conclusions

In conclusion, we identified 21 barriers to referral to the PCU and determined the frequency of these barriers. The leading barriers were a negative image of the PCU by patients and families, delaying the termination of anti-cancer treatment by general ward physicians, unwillingness to end anti-cancer treatment and denial of the fatal nature of the disease by patients and families, the patient's wish to receive care by the accustomed physician and nurse, and

insufficient knowledge of PCUs by medical staff in the general ward.

To correct these unfavorable images and misconceptions of PCUs, it is important to eliminate the negative image that the general population, patients, families, and medical staff have of PCUs. In addition, early introduction of palliative care options to patients and communication skills training regarding breaking bad news are relevant issues for a smooth transition from anti-cancer treatment to palliative care.

References

1. Ahmed N, Bestall JC, Ahmedzai SH, Payne SA, Clark D, Noble B (2004) Systematic review of the problems and issues of accessing specialist palliative care by patients, carers and health and social care professionals. Palliat Med 18(6):525–542
2. Baile WF, Lenzi R, Parker PA, Buckman R, Cohen L (2002) Oncologists' attitudes toward and practices in giving bad news: an exploratory study. J Clin Oncol 20(8):2189–2196
3. Brickner L, Scannell K, Marquet S, Ackerson L (2004) Barriers to hospice care and referrals: survey of physicians' knowledge, attitudes, and perceptions in a health maintenance organization. J Palliat Med 7(3):411–418
4. Casarett DJ, Marenberg ME, Karlawish JH (2001) Predictors of withdrawal from hospice. J Palliat Med 4(4):491–497
5. Feeg VD, Elebiary H (2005) Exploratory study on end-of-life issues: barriers to palliative care and advance directives. Am J Hospice Palliat Care 22(2):119–124
6. Friedman BT, Harwood MK, Shields M (2002) Barriers and enablers to hospice referrals: an expert overview. J Palliat Med 5(1):73–84
7. Fukui S, Kawagoe H, Masako S, Noriko N, Hiroko N, Toshie M (2003) Determinants of the place of death among terminally ill cancer patients under home hospice care in Japan. Palliat Med 17(5):445–453
8. Gattellari M, Voigt KJ, Butow PN, Tattersall MHN (2002) When the treatment goal is not cure: are cancer patients equipped to make informed decisions? J Clin Oncol 20(2):503–513
9. Ida E, Miyachi M, Uemura M, Osakama M, Tajitsu T (2002) Current status of hospice cancer deaths both in-unit and at home (1995–2000), and prospects of home care services in Japan. Palliat Med 16(3):179–184
10. Johnson CB, Slaninka SC (1999) Barriers to accessing hospice services before a late terminal stage. Death Stud 23(3):225–238
11. Krippendorff K (1980) Content analysis: an introduction to its methodology. Sage, Beverly Hills
12. Matsuyama R, Reddy S, Smith TJ (2006) Why do patients choose chemotherapy near the end of life? A review of the perspective of those facing death from cancer. J Clin Oncol 24(21):3490–3496
13. McNeilly DP, Hillary K (1997) The hospice decision: psychosocial facilitators and barriers. Omega J Death Dying 35(2):193–217
14. Meier DE, Morrison RS, Cassel CK (1997) Improving palliative care. Ann Intern Med 127(3):225–230
15. Miyashita M, Sanjo M, Morita T et al (2007) Barriers to providing palliative care and priorities for future actions to advance palliative care in Japan. A nationwide expert opinion survey. J Palliat Med (in press)
16. Morita T, Akechi T, Ikenaga M et al (2004) Communication about the ending of anticancer treatment and transition to palliative care. Ann Oncol 15(10):1551–1557
17. Morita T, Akechi T, Ikenaga M et al (2005) Late referrals to specialized palliative care service in Japan. J Clin Oncol 23(12):2637–2644
18. Morita T, Miyashita M, Shibagaki M et al (2006) Knowledge and beliefs about end-of-life care and the effects of specialized palliative care: a population-based survey in Japan. J Pain Symptom Manage 31(4):306–316
19. Ogle KS, Mavis B, Wyatt GK (2002) Physicians and hospice care: attitudes, knowledge, and referrals. J Palliat Med 5(1):85–92
20. Parker PA, Baile WF, de Moor C, Lenzi R, Kudelka AP, Cohen L (2001) Breaking bad news about cancer: patients' preferences for communication. J Clin Oncol 19(7):2049–2056
21. Pugh EM (1996) An investigation of general practitioner referrals to palliative care services. Palliat Med 10(3):251–257
22. Ruhnke GW, Wilson SR, Akamatsu T et al (2000) Ethical decision making and patient autonomy: a comparison of physicians and patients in Japan and the United States. Chest 118(4):1172–1182
23. Sanders BS, Burkett TL, Dickinson GE, Tournier RE (2004) Hospice referral decisions: the role of physicians. Am J Hospice Palliat Care 21(3):196–202
24. Sanjo M, Miyashita M, Morita M, Kirai K, Akechi T, Uchitomi Y (2007) Preferences regarding end-of-life care and their association with concepts of good death: a population-based survey in Japan. Ann Oncol (in press)
25. Schockett ER, Teno JM, Miller SC, Stuart B (2005) Late referral to hospice and bereaved family member perception of quality of end-of-life care. J Pain Symptom Manage 30(5):400–407
26. Shiozaki M, Morita T, Hirai K, Sakaguchi Y, Tsuneto S, Shima Y (2005) Why are bereaved family members dissatisfied with specialised inpatient palliative care service? A nationwide qualitative study. Palliat Med 19(4):319–327
27. Voltz R, Akabayashi A, Reese C, Ohi G, Sass HM (1997) Organization and patients' perception of palliative care: a cross-cultural comparison. Palliat Med 11(5):351–357
28. Voogt E, van der Heide A, Rietjens JAC et al (2005) Attitudes of patients with incurable cancer toward medical treatment in the last phase of life. J Clin Oncol 23(9):2012–2019
29. Weggel JM (1999) Barriers to the physician decision to offer hospice as an option for terminal care. WMJ 98(3):49–53
30. Yabroff KR, Mandelblatt JS, Ingham J (2004) The quality of medical care at the end-of-life in the USA: existing barriers and examples of process and outcome measures. Palliat Med 18(3):202–216

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, MHlthSci, 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

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.[18] In Japan, Morita et al. developed a satisfaction scale for bereaved family members[19] 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 participants[24] 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.

Participant Characteristics. The patient's age, sex, hospital days, and care settings 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, living status with the patient, faith, education, and household income during the caregiving period.

Analysis

For item reduction, we first deleted attributes with 20% or more of the data missing or highly skewed distribution of the ratings, defined as "absolutely disagree" or "absolutely agree" in 80% of responses. We then used explanatory factor analysis, using the principle method with a promax rotation, for the 10 core domains and eight optional domains separately. According to the results of the factor analysis, attributes with factor loadings less than 0.4 (standardized regression coefficient) were deleted. In addition, we discussed the final adoption of attributes so that each domain had three items with regard to exhaustibility and clinical viewpoint.

To examine the validity and reliability of the GDI, we first examined factor validity with explanatory factor analysis, using the principle method with a promax rotation, for the final 30 attributes with the 10 core domains and 24 attributes with the eight optional domains separately. Second, to examine concurrent validity, we calculated the Pearson's correlation coefficients between each domain of the GDI and each item of the CES and overall care satisfaction. Third, for internal consistency and test-retest reliability, we calculated Cronbach's alpha coefficients (Cronbach's alpha) and intraclass correlation coefficients (ICCs).

Finally, we developed the short version of the GDI. We selected items for each domain using the standard regression coefficient in the factor analysis, Pearson's correlation coefficient between each item and domain score, and content representativeness. We calculated Pearson's correlation coefficient between selected items and overall each domain score that the item belonged to. In addition, Cronbach's alpha coefficient and ICC of the short version of the GDI were calculated. The inverse items were transformed before all

analyses. All analyses were performed using the statistical package SAS version 9.1 (SAS Institute, Cary, NC).

Results

There were 388 potential participants. Subjects were excluded for the following reasons: recruitment in another questionnaire survey for bereaved family members ($n = 23$), serious psychological distress as determined by the primary physician ($n = 8$), cause of death was treatment related or due to injury ($n = 4$), no bereaved family members older than 20 ($n = 4$), and other ($n = 5$). Of 344 questionnaires sent to the remaining bereaved family members, 11 were undeliverable and 215 were returned (response rate, 65%). Among these, 23 individuals refused to participate and three responses were excluded due to missing data. Thus, 189 responses were analyzed (effective response rate, 57%). As for the retest, of 175 questionnaires sent to bereaved families who responded during the study period, nine individuals refused to participate, and two responses were excluded due to missing data. Finally, 112 responses were analyzed (effective response rate, 64%).

Participant Characteristics

Participant characteristics are shown in Table 1. Patient characteristics were as follows: the mean age ± standard deviation was $69 ± 12$ years, males made up 57% of the total, the mean number of hospital days was $41 ± 37$, and 71% of the patients died in the PCU. As for bereaved family members, the mean age was $57 ± 12$ years, 33% were males, 81% were in good or moderate health, spouses made up 46% of the total and children 34%, 69% claimed to be less religious (fair and none), 51% had a high school education or less, and the proportion with a household income of less than five million yen (US $41,700) was 55%.

Factor Validity

In accordance with the above-mentioned item reduction procedure, 30 attributes for core domains and 24 items for optional domains were selected. The results of the factor analysis for core domains is shown in Table 2.

Table 1
Characteristics of Participants (n=189)

	n	%
Patients		
Age, y (mean±SD)	69±12	
Sex		
Male	108	57
Female	91	43
Hospital days (mean±SD)	41±37	
Setting		
General ward	55	29
Palliative care unit	134	71
Bereaved family members		
Age, y (mean±SD)	57±12	
Sex		
Male	63	33
Female	122	65
Health status		
Good	48	25
Moderate	106	56
Fair	28	15
Poor	5	3
Relationship		
Spouse	87	46
Child	64	34
Child-in-law	20	11
Parent	1	1
Sibling	11	6
Other	3	2
Frequency of attending patient		
Every day	133	70
4–6 days/week	17	9
1–3 days/week	26	14
Less than 1 day/week	9	5
Presence of other caregivers		
Present	131	69
Absent	54	29
Living status		
Living together	157	83
Not living together	30	16
Religiousness		
Much	14	7
Moderate	34	18
Fair	46	24
None	85	45
Education		
Junior high school	34	18
High school	82	43
College	40	21
University	31	16
Household Income (thousand yen)		
−249	31	16
250–499	74	39
500–749	37	20
750–999	21	11
1000–	16	8

Several total percents do not equal 100% due to missing values.

The following 10 domains were identified: (1) environmental comfort, (2) life completion, (3) dying in a favorite place, (4) maintaining hope and pleasure, (5) independence, (6) physical and psychological comfort, (7) good relationship with medical staff, (8) not being a burden to others, (9) good relationship with family, and (10) being respected as an individual. The cumulative proportion was 83%. The results of factor analysis for optional domains are shown in Table 3. Eight domains were identified, as follows: (11) religious and spiritual comfort, (12) receiving enough treatment, (13) control over the future, (14) feeling that one's life is worth living, (15) unawareness of death, (16) pride and beauty, (17) natural death, and (18) preparation for death. The cumulative proportion was 81%. These 18 domains coincided with the 18 hypothesized domains. The mean value of each domain score ranged from 2.7 to 5.5 and each standard deviation ranged from 1.1 to 1.8. We classified these 18 domains into four categories by discussion of researchers: (1) physical and psychological comfort, (2) decision making and relation to medical staff, (3) family relationship, and (4) psycho-existential issues.

Concurrent and Discriminant Validity

Table 4 shows the concurrent and discriminant validity demonstrated by the correlation between each domain of the GDI and the item of the CES. The figures represented by bold face were presumed correlations as concurrent validity. As for *physical and psychological comfort*, "physical and psychological comfort" of the GDI correlated with "physical care by physician" ($r=0.44$) and "physical care by nurse" ($r=0.23$) of the CES. As for *place of care*, "environmental comfort" correlated with "environment" ($r=0.34$), and "dying in a favorite place" correlated with "environment" ($r=0.24$). As for *decision-making and relation to medical staff*, "good relationship with medical staff" correlated with "help with decision making for patient" ($r=0.36$), "help with decision making for family" ($r=0.34$), "physical care by physician" ($r=0.44$), "physical care by nurse" ($r=0.23$), "coordination of care" ($r=0.40$), and "family burden" ($r=0.42$). "Receiving enough treatment" correlated with "help with decision making for patient" ($r=0.32$),

Table 2
Factor Validity of the Good Death Inventory, Core 10 Domains

	Standardized Regression Coefficients										
	F1	F2	F3	F4	F5	F6	F7	F8	F9	F10	Communality
1. Environmental comfort (Mean=5.4, SD=1.3)											
Living in quiet circumstances	**0.95**	−0.09	0.07	−0.09	−0.02	0.08	−0.04	0.00	0.05	0.05	0.92
Living in calm circumstances	**0.92**	0.00	0.13	−0.03	0.00	0.02	0.02	0.07	−0.03	−0.07	0.88
Patient was not troubled by other people	**0.84**	−0.01	0.10	−0.11	−0.02	0.04	0.07	−0.04	0.12	0.02	0.85
2. Life completion (Mean=4.2, SD=1.6)											
Having no regrets	−0.10	**0.90**	−0.07	−0.04	−0.13	0.06	0.03	−0.04	0.16	−0.05	0.78
Feeling that one's life was completed	−0.09	**0.88**	0.13	0.00	0.06	0.01	0.02	0.00	−0.07	0.05	0.86
Feeling that one's life was fulfilling	0.11	**0.87**	0.14	−0.05	0.08	−0.06	−0.10	0.01	−0.01	0.05	0.87
3. Dying in a favorite place (Mean=4.9, SD=1.7)											
Being able to stay at one's favorite place	0.15	−0.01	**0.80**	0.13	−0.02	0.01	0.02	−0.03	0.00	−0.03	0.90
Being able to die at one's favorite place	0.08	0.08	**0.80**	0.09	0.03	0.06	0.01	−0.02	−0.04	−0.01	0.89
Met the patient's preference of place to die	0.11	0.15	**0.73**	0.10	−0.01	−0.05	0.08	−0.01	0.01	0.01	0.85
4. Maintaining hope and pleasure (Mean=1.0, SD=1.6)											
Living positively	−0.07	−0.03	0.07	**0.91**	0.04	−0.04	0.03	0.00	0.09	0.00	0.91
Having some pleasure in daily life	−0.08	−0.11	0.12	**0.88**	−0.03	0.04	0.01	0.03	0.12	0.01	0.87
Living in hope	−0.06	0.10	0.15	**0.72**	−0.08	0.21	−0.04	−0.03	0.01	−0.07	0.79
5. Independence (Mean=3.7, SD=1.8)											
Being independent in moving or waking up	−0.04	−0.08	0.04	0.03	**0.93**	0.09	−0.09	−0.08	0.06	−0.01	0.80
Being independent in daily activities	−0.03	−0.06	0.05	0.09	**0.88**	−0.11	0.03	0.07	−0.03	−0.06	0.85
Not being troubled with excretion	0.03	0.15	−0.09	−0.18	**0.80**	0.08	0.08	0.01	0.01	0.03	0.69
6. Physical and psychological comfort (Mean=4.9, SD=1.5)											
Being free from pain	0.09	−0.03	−0.02	0.02	0.00	**0.93**	0.00	−0.01	0.00	−0.01	0.92
Being free from physical distress	0.01	0.03	0.00	0.04	0.05	**0.89**	0.05	−0.02	−0.04	0.04	0.92
Being free from emotional distress	0.08	0.13	0.19	0.28	0.01	**0.47**	0.01	0.09	−0.05	0.00	0.78
7. Good relationship with medical staff (Mean=5.5, SD=1.1)											
Trusting physician	0.05	0.13	−0.01	−0.05	0.00	−0.08	**0.90**	0.03	0.05	−0.12	0.80
Having a professional nurse with whom one feels comfortable	0.01	−0.17	0.00	0.10	0.01	0.04	**0.80**	−0.06	0.05	0.07	0.76
Having people who listen	−0.03	−0.01	0.15	−0.03	−0.01	0.19	**0.73**	0.01	−0.07	0.07	0.79
8. Not being a burden to others (Mean=4.0, SD=1.5)											
Not being a burden to others	0.20	−0.01	−0.20	0.07	−0.05	0.03	−0.06	**0.91**	−0.10	0.00	0.86
Not being a burden to family members	0.03	0.07	−0.09	0.05	0.04	−0.06	0.02	**0.87**	0.04	−0.02	0.80
Having no financial worries	−0.28	−0.12	0.35	−0.15	0.01	0.03	0.02	**0.79**	0.10	0.05	0.80
9. Good relationship with family (Mean=5.0, SD=1.2)											
Having family support	0.11	−0.06	0.14	−0.02	0.00	−0.18	−0.02	−0.05	**0.80**	0.08	0.67
Spending enough time with one's family	−0.02	0.05	−0.11	0.17	0.03	0.10	0.02	0.02	**0.72**	0.02	0.72
Having family to whom one can express one's feelings	0.05	0.19	−0.12	0.14	0.02	0.06	0.05	0.07	**0.72**	−0.06	0.80
10. Being respected as an individual (Mean=5.8, SD=1.1)											
Not being treated as an object or a child	−0.13	−0.03	0.06	−0.24	−0.09	0.11	−0.05	0.03	0.12	**0.96**	0.82
Being respected for one's values	0.14	0.15	−0.09	0.29	0.04	−0.17	0.14	0.03	−0.18	**0.66**	0.82
Being valued as a person	0.29	−0.02	−0.07	0.20	0.07	0.01	−0.05	−0.05	0.06	**0.65**	0.82

Cumulative proportion, 82.7%

F# = Factor 1 to Factor 10.
Boldfaced numbers indicate attributes belonging to each domain.

"help with decision making for family" (*r* = 0.30), "physical care by physician" (*r* = 0.37), and "physical care by nurse" (*r* = 0.16). "Unawareness of death" correlated with "help with decision making for patient" (*r* = 0.26), and "help with decision making for family" (*r* = 0.25). "Natural death" correlated with "help with decision making for

patient" (*r* = 0.38) and "help with decision making for family" (*r* = 0.32). As for *psycho-existential issues*, there were weak correlations between each domain and "psycho-existential care." Finally, "not being a burden on others" correlated with "cost" (*r* = 0.25).

Table 5 shows the correlation between each domain of the GDI and total score of the

Table 3
Factor Validity of the Good Death Inventory, Optional Eight Domains

	Standardized Regression Coefficients								
	F11	F12	F13	F14	F15	F16	F17	F18	Communality
11. Religious and spiritual comfort (Mean=2.7, SD=1.7)									
Supported by religion	**0.98**	−0.01	−0.02	0.02	−0.03	−0.02	−0.02	−0.01	0.94
Having faith	**0.97**	0.02	0.03	0.03	0.00	0.00	−0.03	−0.02	0.95
Feeling that one is protected by a higher power beyond oneself	**0.90**	−0.02	0.05	0.00	0.02	0.00	0.04	0.00	0.84
12. Receiving enough treatment (Mean=5.1, SD=1.5)									
Receiving enough treatment	−0.02	**0.90**	0.03	0.02	0.06	−0.01	0.02	−0.04	0.89
Believing that one used all available treatments	0.02	**0.86**	0.03	−0.06	0.13	−0.02	−0.01	0.05	0.85
Fighting against disease until one's last moment	0.00	**0.86**	0.10	0.08	−0.11	0.02	−0.02	0.04	0.80
13. Control over the future (Mean=4.0, SD=1.7)									
Knowing how long one will live	0.06	−0.01	**0.92**	−0.12	0.10	0.02	−0.03	0.06	0.84
Knowing what to expect about one's condition in the future	0.05	0.06	**0.89**	0.02	−0.07	0.01	0.01	0.04	0.90
Participating in decisions about treatment strategy	−0.06	0.18	**0.70**	0.15	−0.04	−0.04	0.05	−0.06	0.69
14. Feeling that one's life is worth living (Mean=5.2, SD=1.3)									
Feeling that one can contribute to others	−0.01	0.03	−0.01	**0.94**	−0.02	0.02	−0.12	0.04	0.87
Feeling that one's life is worth living	0.07	−0.04	0.02	**0.86**	0.11	−0.03	0.04	−0.05	0.79
Maintaining one's role in family or occupation	0.02	0.05	−0.03	**0.75**	−0.10	0.05	0.13	0.09	0.70
15. Unawareness of death (Mean=3.8, SD=1.5)									
Dying without awareness that one is dying	−0.05	−0.08	0.10	0.04	**0.96**	−0.02	−0.06	−0.07	0.83
Living as usual without thinking about death	−0.03	0.03	0.08	−0.01	**0.88**	0.00	−0.02	0.00	0.79
Not being informed of bad news	0.16	0.23	−0.35	−0.08	**0.62**	0.04	0.11	0.11	0.72
16. Pride and beauty (Mean=3.4, SD=1.4)									
Not having a change in one's appearance	0.06	0.07	−0.02	−0.08	−0.11	**0.88**	−0.05	0.03	0.83
Not receiving pity from others	−0.03	−0.01	0.05	0.10	0.15	**0.86**	−0.09	−0.02	0.75
Not exposing one's physical and mental weakness to family	−0.04	−0.07	−0.03	0.01	−0.04	**0.85**	0.12	−0.04	0.74
17. Natural death (Mean=5.4, SD=1.3)									
Not being connected to medical instruments or tubes	−0.01	−0.20	0.00	0.04	0.01	−0.03	**0.93**	0.09	0.82
Not receiving excessive treatment	0.02	0.21	−0.01	−0.08	−0.10	0.02	**0.87**	−0.10	0.81
Dying a natural death	−0.08	0.24	0.06	0.13	0.18	−0.02	**0.56**	0.00	0.73
18. Preparation for death (Mean=4.8, SD=1.4)									
Seeing people whom one wants to see	−0.03	0.13	0.06	−0.06	−0.06	−0.01	−0.01	**0.85**	0.64
Feeling thankful to people	−0.05	0.07	−0.11	0.16	−0.01	−0.05	−0.10	**0.79**	0.77
Saying what one wants to tell dear people	0.06	−0.18	0.21	−0.01	0.07	0.05	0.14	**0.74**	0.79

Cumulative proportion, 80.6%

F# indicates Factor 11 to Factor 18.
Boldfaced numbers indicate attributes belonging to each domain.

CES and overall care satisfaction. The correlation of each domain of the GDI and the total score of the CES ranged from $r = 0.07$ to $r = 0.42$. The correlation of each domain of the GDI and the overall care satisfaction ranged from $r = 0.11$ to $r = 0.55$. Most domains correlated with the CES and overall care satisfaction moderately. In addition, the GDI tended to more strongly correlate with overall care satisfaction than the CES. All 18 domains of the GDI correlated with the total score of the CES ($r = 0.26$) and overall care satisfaction ($r = 0.39$). The total of the 10 core domains of the GDI correlated with the total score of the CES ($r = 0.31$) and overall care satisfaction ($r = 0.41$). The total of the eight optional domains of the GDI were not correlated with the total score of the CES and overall care satisfaction.

Internal Consistency and Reliability
Table 6 shows the internal consistency (Cronbach's alpha) and test−retest reliability (ICC). Cronbach's alpha ranged from 0.74 to 0.95. The Cronbach's alpha coefficient of the total score was 0.94; of the 10 core domains, it was 0.92; and of the eight optional domains, it was 0.87. The ICC ranged from 0.44 to 0.72

Table 4
Concurrent and Discriminant Validity with Each Item of the Care Evaluation Scale

	Care Evaluation Scale									
	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	Family Burden
Physical and psychological comfort										
6. Physical and psychological comfort	0.40ᵃ	0.31ᵃ	**0.44ᵃ**	**0.23ᵇ**	0.25ᵃ	0.18ᶜ	0.06	0.07	0.29ᵃ	0.28ᵃ
Place of care										
1. Environmental comfort	0.35ᵃ	0.35ᵃ	0.40ᵃ	0.29ᵃ	0.37ᵃ	**0.34ᵃ**	0.22ᵇ	0.15ᶜ	0.27ᵃ	0.30ᵃ
3. Dying in a favorite place	0.37ᵃ	0.30ᵃ	0.40ᵃ	0.20ᵇ	0.30ᵃ	**0.24ᵇ**	0.10	0.06	0.23ᵇ	0.30ᵃ
Decision-making and relation to medical staff										
7. Good relationship with medical staff	**0.36ᵃ**	**0.34ᵃ**	**0.43ᵃ**	**0.33ᵃ**	0.36ᵃ	0.28ᵃ	0.19ᶜ	0.15	**0.40ᵃ**	**0.42ᵃ**
12. Receiving enough treatment	**0.32ᵃ**	**0.30ᵃ**	**0.37ᵃ**	0.16ᶜ	0.25ᵃ	0.17	0.10	0.11	0.22ᵇ	0.22ᵇ
15. Unawareness of death	**0.26ᵃ**	**0.25ᵃ**	0.26ᵇ	0.13	0.19ᵇ	0.11	0.13	0.14	0.15ᶜ	0.17
17. Natural death	**0.38ᵃ**	**0.32ᵃ**	0.37ᵃ	0.24ᵇ	0.35ᵃ	0.29ᵃ	0.13	0.07	0.28ᵃ	0.28ᵃ
Family relationship										
9. Good relationship with family	0.08	0.17ᶜ	0.11	0.02	0.07	0.12	-0.08	-0.03	0.04	0.06
Psycho-existential issues										
2. Life completion	0.24ᵇ	0.20ᵇ	0.22ᵇ	0.10	**0.16ᶜ**	0.07	0.02	-0.04	0.15ᶜ	0.13
4. Maintaining hope and pleasure	0.34ᵃ	0.29ᵃ	0.34ᵃ	0.21ᵇ	**0.23ᵃ**	0.18ᶜ	0.06	0.09	0.20ᵇ	0.25ᶜ
5. Independence	0.07	0.00	0.08	0.04	**0.05**	0.08	0.05	0.18ᶜ	0.07	-0.02
8. Not being a burden to others	0.14	0.18ᶜ	0.14	0.17	**0.20ᵇ**	0.14	**0.25ᵇ**	0.09	0.09	0.05
10. Being respected as an individual	0.22ᵇ	0.25ᶜ	0.25ᶜ	0.26ᵃ	**0.24ᵃ**	0.29ᵃ	0.18ᶜ	0.09	0.20ᵇ	0.17
11. Religious and spiritual comfort	0.04	0.09	0.04	0.04	**0.01**	0.03	0.06	0.02	-0.01	0.11
13. Control over the future	0.15	0.17ᶜ	0.17ᶜ	0.14	**0.14**	0.12	0.02	0.07	0.08	0.09
14. Feeling that one's life is worth living	0.14	0.18ᶜ	0.19ᶜ	0.16ᶜ	**0.24ᵇ**	0.19ᶜ	0.09	0.17ᶜ	0.16ᶜ	0.20ᵇ
16. Pride and beauty	0.11	0.06	0.12	0.09	**0.09**	0.05	0.15	0.09	-0.01	-0.05
18. Preparation for death	0.15ᶜ	0.18ᶜ	0.16ᶜ	0.16ᶜ	**0.18ᶜ**	0.13	0.04	0.03	0.13	0.12

Figures are Pearson's correlation coefficients.
Boldfaced numbers indicate attributes assumed to correlate with each item of the Care Evaluation Scale.
ᵃP<0.001.
ᵇP<0.01.
ᶜP<0.05.

Table 5
Concurrent and Discriminant Validity with Total Score of Care Evaluation Scale and Satisfaction

	Total score of CES	Overall care satisfaction
Physical and psychological comfort		
6. Physical and psychological comfort	0.32[a]	0.47[a]
Place of care		
1. Environmental comfort	0.39[a]	0.42[a]
3. Dying in a favorite place	0.32[a]	0.50[a]
Decision-making and relation to medical staff		
7. Good relationship with medical staff	0.42[a]	0.55[a]
12. Receiving enough treatment	0.28[a]	0.50[a]
15. Unawareness of death	0.23[b]	0.35[a]
17. Natural death	0.34[a]	0.45[a]
Family relationship		
9. Good relationship with family	0.07	0.18[c]
Psycho-existential issues		
2. Life completion	0.15[c]	0.33[a]
4. Maintaining hope and pleasure	0.27[a]	0.33[a]
5. Independence	0.08	0.11
8. Not being a burden to others	0.19[c]	0.14
10. Being respected as an individual	0.27[a]	0.28[a]
11. Religious and spiritual comfort	0.05	0.12
13. Control over the future	0.14	0.25[a]
14. Feeling that one's life is worth living	0.22[b]	0.28[a]
16. Pride and beauty	0.09	0.16[c]
18. Preparation for death	0.16[c]	0.27[a]
All 18 domains	0.26[a]	0.39[a]
Core 10 domains	0.31[a]	0.41[a]
Optional eight domains	−0.02	0.10

Figures are Pearson's correlation coefficients.
[a]*P*<0.001.
[b]*P*<0.01.
[c]*P*<0.05.

except for "not being a burden for others" (ICC = 0.38). The ICC of all 18 domains was 0.52; of the total of the 10 core domains, it was 0.59; and of the total of the eight optional domains, it was 0.50.

Development of Short Version of the GDI

In accordance with the process described in the Analysis section, we selected 18 attributes for each domain to create the short version of the GDI (Table 7). Pearson's correlation coefficient between each attribute and the final domains ranged from 0.80 to 0.97. The Cronbach's alpha coefficient of all 18 attributes

Table 6
Internal Consistency and Reliability

Domains	Alpha	ICC
Core 10 domains		
1. Environmental comfort	0.92	0.57
2. Life completion	0.87	0.63
3. Dying in a favorite place	0.94	0.68
4. Maintaining hope and pleasure	0.91	0.67
5. Independence	0.82	0.52
6. Physical and psychological comfort	0.92	0.44
7. Good relationship with medical staff	0.83	0.87
8. Not being a burden to others	0.83	0.38
9. Good relationship with family	0.79	0.44
10. Being respected as an individual	0.74	0.58
Optional eight domains		
11. Religious and spiritual comfort	0.95	0.58
12. Receiving enough treatment	0.90	0.59
13. Control over the future	0.87	0.72
14. Feeling that one's life is worth living	0.86	0.60
15. Unawareness of death	0.81	0.53
16. Pride and beauty	0.84	0.51
17. Natural death	0.74	0.50
18. Preparation for death	0.78	0.61
All 18 domains	0.94	0.52
Core 10 domains	0.92	0.59
Optional eight domains	0.87	0.50

Alpha = Cronbach's alpha coefficient; ICC = Intraclass correlation coefficient.

was 0.85; of the 10 core attributes, it was 0.78; and of the eight optional attributes, it was 0.69. The ICC of all 18 attributes was 0.71; of the 10 core attributes, it was 0.64; and of the eight optional attributes, it was 0.59.

Discussion

We validated the GDI in Japanese bereaved family members. This assessment will allow us to evaluate end-of-life care from the bereaved family's perspective. The most useful finding is in regard to concurrent validity. Some GDI domains measuring end-of-life care that focus on structure and process of care correlated with the CES. However, other domains did not correlate with the CES or overall care satisfaction. This means that the GDI might measure different aspects of end-of-life care and that the results are consistent with the hypothesis that the GDI explains a significant portion of the bereaved family member's overall satisfaction.

As for the factor validity, we identified 18 possible domains. We conducted a nationwide opinion survey on this topic preceding the present study. The results of the present study

Table 7
Short Version of the Good Death Inventory

Attributes	Pearson's r[a]
Core 10	
Living in calm circumstances	0.93
Feeling that one's life was completed	0.92
Having some pleasure in daily life	0.94
Being able to stay at one's favorite place	0.96
Being independent in daily activities	0.87
Being free from physical distress	0.96
Trusting physician	0.87
Not being a burden to others	0.89
Spending enough time with one's family	0.89
Being valued as a person	0.83
Optional eight	
Supported by religion	0.97
Receiving enough treatment	0.92
Knowing what to expect about one's condition in the future	0.95
Feeling that one's life is worth living	0.88
Dying without awareness that one is dying	0.87
Not exposing one's physical and mental weakness to family	0.87
Dying a natural death	0.80
Saying what one wants to dear people	0.87
Internal consistency	Alpha
All 18 attributes	0.85
Core 10 attributes	0.78
Optional eight attributes	0.69
Test-retest reliability	ICC
All 18 attributes	0.71
Core 10 attributes	0.64
Optional eight attributes	0.59

Alpha = Cronbach's alpha coefficient; ICC = Intraclass correlation coefficient.
[a]Pearson's correlation coefficient with each domain total score.

confirm the findings of the preceding study and confirm that a good death concept in the Japanese population is constituted by these 18 domains.[25]

As for the concurrent and discriminant validity, physical and psychological comfort, environmental comfort, dying in a favorite place, good relationship with medical staff, receiving enough treatment, unawareness of death, and natural death were correlated with presumed items of the CES. However, good family relationship, life completion, maintaining hope and pleasure, independence, not being a burden to others, being respected as an individual, religious and spiritual comfort, control over the future, feeling that one's life is worth living, pride and beauty, and preparation for death either were not correlated or were weakly correlated with the items of the CES. These domains cover psycho-existential and

spiritual concerns in the Japanese population.[26,27] As the CES measures the structure and process of care, these results are considered reasonable. The GDI might be able to measure outcomes of care based on individualized important issues in the dying process. In addition, as a whole, the domains of the GDI were more correlated with overall care satisfaction than with the CES. This means that the GDI might cover more comprehensive aspects of end-of-life care outcomes than the CES. The concept of satisfaction of bereaved family members is still unclear and using satisfaction as a measure of quality of care contains unresolved problems.[28] The results of our study would provide more information of the understanding of care satisfaction from bereaved family members' perspectives.

Some might consider it odd that domains XIV (control over the future) and XV (unawareness of death) would coexist in the Japanese concept of a good death. However, our previous study found that the Japanese population emphasized both concepts. Actually, these two domains are part of the eight optional domains. These optional domains are thought to be concepts with lesser importance to the individual. In contrast to Steinhauser et al.'s[7] good death study, the Japanese population does not consider control over the future as important as the US population. The less autonomous attitude in the dying process might be unique to Japanese culture.[7,25]

Although the domains of the GDI demonstrated sufficient internal consistency, reliability measured by ICC was of moderate value.[29] We think the reasons for moderate reliability would be as follows: (1) the period of test—retest was over one month; (2) we recruited participants until two years after death, so memory might be vague; (3) although we asked the primary caregiver to answer the questionnaire, we could not be sure that the identical person filled out the two questionnaires; and (4) the family member's assessment of the GDI might change over time. However, the moderate reliability of the study of bereaved family members is consistent with previous work.[20,30] Therefore, these moderate ICCs would not be crucial drawbacks of the GDI. The relatively low ICC of "not being a burden to others" is reasonable because it is difficult for family members to infer the patient's viewpoint. Instead, we might appreciate

the sufficient internal consistency as a measure of reliability for a cross-sectional study.

In addition, we developed a short version of the GDI. Depending on the study objective, an investigator might be reluctant to use the full version. In that situation, the investigator would be able to use the short version. The psychometric properties of the short version of the GDI have been shown. This short version of the GDI could be used in any study setting.

Limitations and Future Perspectives

The limitations of this study are as follows: First, the response rate was 57%. We believe, however, this is not a fatal flaw because the objective of this study was to validate a scale, not to survey actual conditions. Second, this study was conducted at one regional cancer center. The results of this study might not be generalizable to other settings. Third, this study did not examine criterion validity. It is difficult to examine criterion validity, however, because the gold standard for measuring a good death has not yet been established.

In future studies, we would like to conduct a nationwide survey of the achievement of a good death using this scale. In addition, we should investigate the national level of a benchmark of the achievement of a good death and differences in the achievement of a good death among institutions or care settings. Furthermore, we should identify barriers to achieving a good death and develop methods for eliminating these barriers in all Japanese end-of-life care settings.

Conclusions

In conclusion, we validated the GDI as a measure for evaluating a good death from the bereaved family's perspective. The GDI has sufficient factor validity, concurrent validity, internal consistency, and acceptable test—retest reliability. The GDI is a valid scale for measuring comprehensive end-of-life care outcomes from the bereaved family members' perspective in Japan. In future studies, we would like to conduct a nationwide survey of the achievement of a good death using this scale. In addition, we should identify and eliminate barriers to achieving a good death in all Japanese end-of-life care settings.

References

1. Payne SA, Langley-Evans A, Hillier R. Perceptions of a 'good' death: a comparative study of the views of hospice staff and patients. Palliat Med 1996;10(4):307—312.

2. Emanuel EJ, Emanuel LL. The promise of a good death. Lancet 1998;351(Suppl 2): SII21—SII29.

3. Singer PA, Martin DK, Kelner M. Quality end-of-life care: patients' perspectives. JAMA 1999; 281(2):163—168.

4. Steinhauser KE, Clipp EC, McNeilly M, et al. In search of a good death: observations of patients, families, and providers. Ann Intern Med 2000; 132(10):825—832.

5. Patrick DL, Engelberg RA, Curtis JR. Evaluating the quality of dying and death. J Pain Symptom Manage 2001;22(3):717—726.

6. Teno JM, Casey VA, Welch LC, Edgman-Levitan S. Patient-focused, family-centered end-of-life medical care: views of the guidelines and bereaved family members. J Pain Symptom Manage 2001;22(3):738—751.

7. Steinhauser KE, Christakis NA, Clipp EC, et al. Factors considered important at the end of life by patients, family, physicians, and other care providers. JAMA 2000;284(19):2476—2482.

8. Steinhauser KE, Christakis NA, Clipp EC, et al. Preparing for the end of life: preferences of patients, families, physicians, and other care providers. J Pain Symptom Manage 2001;22(3):727—737.

9. Steinhauser KE, Bosworth HB, Clipp EC, et al. Initial assessment of a new instrument to measure quality of life at the end of life. J Palliat Med 2002; 5(6):829—841.

10. Steinhauser KE, Clipp EC, Bosworth HB, et al. Measuring quality of life at the end of life: validation of the QUAL-E. Palliat Support Care 2004;2(1): 3—14.

11. Fakhoury W, McCarthy M, Addington-Hall J. Determinants of informal caregivers' satisfaction with services for dying cancer patients. Soc Sci Med 1996;42(5):721—731.

12. Morita T, Chihara S, Kashiwagi T. Quality Audit Committee of the Japanese Association of Hospice and Palliative Care Units. Family satisfaction with inpatient palliative care in Japan. Palliat Med 2002; 16(3):185—193.

13. Teno JM, Clarridge BR, Casey V, et al. Family perspectives on end-of-life care at the last place of care. JAMA 2004;291(1):88—93.

14. Shiozaki M, Morita T, Hirai K, et al. Why are bereaved family members dissatisfied with specialised inpatient palliative care service? A nationwide qualitative study. Palliat Med 2005;19(4):319—327.

15. Mularski RA, Heine CE, Osborne ML, Ganzini L, Curtis JR. Quality of dying in the ICU: ratings by family members. Chest 2005;128(1): 280–287.

16. Levy CR, Ely EW, Payne K, et al. Quality of dying and death in two medical ICUs: perceptions of family and clinicians. Chest 2005;127(5):1775–1783.

17. Teno JM, Clarridge B, Casey V, Edgman-Levitan S, Fowler J. Validation of toolkit after-death bereaved family member interview. J Pain Symptom Manage 2001;22(3):752–758.

18. Curtis JR, Patrick DL, Engelberg RA, et al. A measure of the quality of dying and death. Initial validation using after-death interviews with family members. J Pain Symptom Manage 2002;24(1): 17–31.

19. Morita T, Chihara S, Kashiwagi T. Quality Audit Committee of the Japanese Association of Hospice and Palliative Care Units. A scale to measure satisfaction of bereaved family receiving inpatient palliative care. Palliat Med 2002;16(2):141–150.

20. Morita T, Hirai K, Sakaguchi Y, et al. Measuring the quality of structure and process in end-of-life care from the bereaved family perspective. J Pain Symptom Manage 2004;27(6):492–501.

21. Yoshida M. Nurses perceptions of death and dying in a hospice setting: "Yoi-Mitori" [Japanese]. J Jpn Acd Nurs Sci 1999;19(1):49–59.

22. Hamada Y, Sato R. Hope of end-stage cancer patients [Japanese]. J Japan Soc Cancer Nurs 2002; 16(2):15–25.

23. Long SO. Cultural scripts for a good death in Japan and the United States: similarities and differences. Soc Sci Med 2004;58(5):913–928.

24. Hirai K, Miyashita M, Morita T, Sanjo M, Uchitomi Y. Good death in Japanese cancer care: a qualitative study. J Pain Symptom Manage 2006; 31(2):140–147.

25. Miyashita M, Sanjo M, Morita T, Hirai K, Uchitomi Y. Good death in cancer care: a nationwide quantitative study. Ann Oncol 2007;18:1090–1097.

26. Morita T, Kawa M, Honke Y, et al. Existential concerns of terminally ill cancer patients receiving specialized palliative care in Japan. Support Care Cancer 2004;12(2):137–140.

27. Murata H, Morita T. Japanese Task Force. Conceptualization of psycho-existential suffering by the Japanese Task Force: the first step of a nationwide project. Palliat Support Care 2006;4(3):279–285.

28. Aspinal F, Addington-Hall J, Hughes R, Higginson IJ. Using satisfaction to measure the quality of palliative care: a review of the literature. J Adv Nurs 2003;42(4):324–339.

29. Landis JR, Koch GG. The measurement of observer agreement for categorical data. Biometrics 1977;33(1):159–174.

30. Mularski R, Curtis JR, Osborne M, Engelberg RA, Ganzini L. Agreement among family members in their assessment of the Quality of Dying and Death. J Pain Symptom Manage 2004;28(4): 306–315.

Appendix

Good Death Inventory (GDI)

How do you think the patient felt during the end-of-life period? Please place the appropriate number next to each statement: 1: absolutely disagree, 2: disagree, 3: somewhat disagree, 4: unsure, 5: somewhat agree, 6: agree, 7: absolutely agree.

I. Physical and psychological comfort
> Patient was free from pain.
> Patient was free from physical distress.
> Patient was free from emotional distress.

II. Dying in a favorite place
> Patient was able to stay at his or her favorite place.
> Patient was able to die at his or her favorite place.
> The place of death met the preference of the patient.

III. Maintaining hope and pleasure
> Patient lived positively.
> Patient had some pleasure in daily life.
> Patient lived in hope.

IV. Good relationship with medical staff
> Patient trusted the physician.
> Patient had a professional nurse with whom he or she felt comfortable.
> Patient had people who listened.

V. Not being a burden to others
> Patient was not being a burden to others (*).
> Patient was not being a burden to family members (*).
> Patient had no financial worries (*).

VI. Good relationship with family
> Patient had family support.
> Patient spent enough time with his or her family.
> Patient had family to whom he or she could express feelings.

VII. Independence
> Patient was independent in moving or waking up.
> Patient was independent in daily activities.
> Patient was not troubled with excretion.

VIII. Environmental comfort
> Patient lived in quiet circumstances.
> Patient lived in calm circumstances.
> Patient was not troubled by other people.

IX. Being respected as an individual
> Patient was not treated as an object or a child.
> Patient was respected for his or her values.
> Patient was valued as a person.

X. Life completion
> Patient had no regrets.
> Patient felt that his or her life was completed.
> Patient felt that his or her life was fulfilling.

XI. Receiving enough treatment
> Patient received enough treatment.
> Patient believed that all available treatments were used.
> Patient fought against disease until the last moment.

XII. Natural death
> Patient was not connected to medical instruments or tubes.
> Patient did not receive excessive treatment.
> Patient died a natural death.

XIII. Preparation for death
> Patient met people whom he or she wanted to see.
> Patient felt thankful to people.
> Patient was able to say what he or she wanted to dear people.

XIV. Control over the future
> Patient knew how long he or she was expected to live.
> Patient knew what to expect about his or her condition in the future.
> Patient participated in decisions about treatment strategy.

XV. Unawareness of death
> Patient died without awareness that he or she was dying.
> Patient lived as usual without thinking about death.
> Patient was not informed of bad news.

XVI. Pride and beauty
> Patient felt burden of a change in his or her appearance (*).
> Patient felt burden of receiving pity from others (*).
> Patient felt burden of exposing his or her physical and mental weakness to family (*).

XVII. Feeling that one's life is worth living
> Patient felt that he or she could contribute to others.
> Patient felt that his or her life is worth living.
> Patient maintained his or her role in family or occupation.

XVIII. Religious and spiritual comfort
> Patient was supported by religion.
> Patient had faith.
> Patient felt that he or she was protected by a higher power.

(*) Inverse items.

Factors contributing to evaluation of a good death from the bereaved family member's perspective

Mitsunori Miyashita[1]*, Tatsuya Morita[2], Kazuki Sato[1], Kei Hirai[3,4], Yasuo Shima[5] and Yosuke Uchitomi[6]

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

[2] *Department of Palliative and Supportive Care, Palliative Care Team and Seirei Hospice, Seirei Mikatahara Hospital, Shizuoka, Japan*

[3] *Center of the Study for Communication Design, Psychology and Behavioral Sciences, Graduate School of Human Sciences, Osaka University, Osaka, Japan*

[4] *Department of Complementary and Alternative Medicine, Graduate School of Medicine, Osaka University, Osaka, Japan*

[5] *Department of Palliative Medicine, Tsukuba Medical Center Hospital, Ibaraki, Japan*

[6] *Psycho-Oncology Division, Research Center for Innovative Oncology, National Cancer Center Hospital East, Chiba, Japan*

*Correspondence to:
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*

Abstract

Background: Although it is important to achieve a good death in Japan, there have been no studies to explore factors associated with a good death. The aim of this study was to explore factors contributing to a good death from the bereaved family members' perspectives, including patient and family demographics and medical variables.

Methods: A cross-sectional anonymous questionnaire survey for bereaved family members of cancer patients who had died in a regional cancer center and a medical chart review was conducted. We measured the results from the Good Death Inventory and family demographics. In addition, we extracted patient demographics, medical variables, and medical interventions in the last 48 h before death from a medical chart review.

Results: Of the 344 questionnaires sent to bereaved family members, 165 responses were analyzed (48%). We found, first, that death in the palliative care unit was more likely to be described as a good death compared with death on a general ward. Some significant characteristics were 'environmental comfort,' 'physical and psychological comfort,' 'being respected as an individual,' and 'natural death.' Second, we found that a patient's and family member's age and other demographic factors significantly correlated with an evaluation of a good death. In addition, life prolongation treatment and aggressive treatment such as chemotherapy in the last 2 weeks of life were barriers to attainment of a good death. Moreover, appropriate opioid medication contributed to a good death.

Conclusion: Withholding aggressive treatment and life-prolonging treatment for dying patients and appropriate opioid use may be associated with achievement of a good death in Japan.

Copyright © 2007 John Wiley & Sons, Ltd.

Keywords: palliative care; end-of-life care; cancer; hospice; 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 [1–4] and quantitative research [5, 6]. In addition, Steinhauser et al. have measured the achievement of a good death by terminally ill patients [7, 8]. Moreover, Yun et al. have assessed patient-reported quality of end-of-life care and explored correlations of quality-of-life measures in Korea [9].

However, interviewing or administering a questionnaire to vulnerable terminally ill patients is burdensome, and may result in biased conclusions

due to nonresponse because of physical status. Therefore, many studies to evaluate end-of-life care have been conducted with bereaved family members [10–14]. To accomplish this, measures for bereaved family members were developed in Western countries [13, 15, 16].

In Japan, although Morita et al. developed the Care Evaluation Scale focusing on structure and process of end-of-life care [17], only a few studies have investigated a good death [18, 19]. In order to establish a goal of palliative care in Japan, it is important to conceptualize what constitutes a good death in Japan. Therefore, for the first step, we conducted a nationwide qualitative study to explore attributes of a good death in Japan for a total of 63 participants including advanced cancer