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Burnout and psychiatric morbidity among physicians engaged in end-of-life care for cancer patients: A cross-sectional nationwide survey in Japan

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Abstract

Purpose: To determine the prevalence of burnout and psychiatric morbidity among physicians engaged in end-of-life care for cancer patients in Japan and to explore associated factors related to end-of-life care.

Methods: Questionnaires were mailed to 1436 Japanese clinical oncologists and palliative care physicians with a request to complete the Maslach Burnout Inventory (MBI), the General Health Questionnaire (GHQ-12), and to report on individual factors, including confidence in patient care. High levels of burnout and psychiatric morbidity were identified using cut-off scores of the MBI and GHQ-12.

Results: A total of 697 physicians returned the questionnaires (response rate, 49.6%). Twenty-two percent of the respondents had a high level of emotional exhaustion, 11% had a high level of depersonalization, 62% had a low level of personal accomplishment, and 20% had psychiatric morbidity. Clinical oncologists showed a significantly higher psychiatric morbidity than palliative care physicians. Confidence in having sufficient time to communicate with patients was significantly associated with all the burnout subscales.

Conclusions: A low level of personal accomplishment was relatively high among Japanese physicians compared with previous studies. Insufficient confidence in the psychological care of patients was associated with physician burnout rather than involvement in end-of-life care. Copyright © 2006 John Wiley & Sons, Ltd.

Keywords: burnout; psychiatric morbidity; physician; end-of-life care; Japan

Introduction

Burnout is a psychological state resulting from a prolonged period of high stress levels. Unlike a major depressive disorder, burnout is a distinct work-related stress syndrome and is often defined by the three components of emotional exhaustion, depersonalization, and diminished personal accomplishment [1,2]. Burnout occurs most frequently in those whose work requires an intensive involvement with people, including medical staff such as physicians.

Several studies have suggested that physicians engaged in end-of-life care are more likely to burnout because they may experience multiple stressors including a sense of failure or frustration when a patient's illness progresses [3,4], feelings of powerlessness against illness and its associated losses [3], role conflicts and ambiguity [5], and the failure to enable a good death [6]. According to the first report on burnout conducted via a random survey of 1000 American oncologists in 1991 [4], 56% of the 598 respondents reported having experienced burnout in their professional lives. To our knowledge, a few studies [7–13], including one nationwide study in the UK [12], have determined the prevalence of burnout among oncologists using the Maslach Burnout Inventory (MBI) [1], a standardized measure of burnout. According to these studies [7–13], oncologists or palliative care physicians were not at any greater risk of burnout, compared with other physicians, but approximately one third of them reported high levels of burnout and psychiatric morbidity. On the other hand, a nationwide study on the prevalence of burnout and psychiatric morbidity has never been conducted in Japan either among physicians or oncologists.

Physician burnout is a serious issue because of its crucial consequences for patient care: For example, depersonalization is associated with suboptimal patient care [14] and decision making in end-of-life care, such as physician-assisted suicide or euthanasia [15,16]. Moreover, oncologists with higher levels of emotional exhaustion were more likely to choose a deep-sedation treatment option in a hypothetical scenario presented to them than those with lower levels of emotional exhaustion [17]. In addition, oncologists have reported that patient care such as being involved in emotional distress or physical suffering is often a source of job stress [18,13]. Nevertheless, end-of-life care has a two-sided nature: it can be stressful if done badly, but rewarding if done well [19–21,13]. As described above, end-of-life patient care is estimated to be closely related with oncologist burnout and psychiatric morbidity, however, little is known about the association between them. Therefore, to develop strategies to alleviate physician burnout and psychiatric morbidity, we attempted in the present study to investigate physicians' involvement and confidence in patient care as factors associated with the prevalence of physician burnout and psychiatric morbidity.

The purpose of this study was to determine the prevalence of burnout and psychiatric morbidity among physicians engaged in end-of-life care for cancer patients in Japan and to explore associated factors related to end-of-life care.

Methods

Respondents and Procedure

This is a secondary analysis of our previous study [17] on the practices and attitudes of Japanese physicians concerning terminal sedation. We enrolled physicians who were clinical oncologists or palliative care physicians such as those who were engaged in end-of-life care for cancer patients in Japan. One source was a list of physicians from the Japanese Association of Clinical Cancer Centers, as a sample of clinical oncologists. The other source was a list of physicians from the Japanese Association of Hospice and Palliative Care Units, as a sample of palliative care physicians. Twenty-six institutions from a total of 27 hospitals that belonged to the Japanese Association of Clinical Cancer Centers and the Japanese Association of Hospice and Palliative Care Units approved the study. In February 2000, we mailed the questionnaire to 1436 eligible physicians. The inclusion criteria were: (1) being an attending physician whose specialty was primarily responsible for the care of terminally ill cancer patients, (2) having actual experience in oncology or palliative care, and (3) being unaffiliated with this study project.

Questionnaire

Burnout: The Maslach Burnout Inventory (MBI) [1] is a self-administered questionnaire consisting of 22 items using a 7-point Likert-type scale (possible range, 0–6) that measures the three subscales of burnout syndrome: emotional exhaustion (9 items), depersonalization (5 items), and personal accomplishment (8 items). A high levels of burnout was defined as a high level of emotional exhaustion (upper third, score of 27 or higher), a high level of depersonalization (upper third, score of 10 or higher), and a low level of personal accomplishment (lower third, score of 33 or lower) based on normative data from a sample of American health professionals (physicians and nurses) [1]. We used these cut-off scores to compare the prevalence of burnout in this study with that of previous studies in oncologists [7–13]. The psychometric properties of the Japanese version of the MBI are controversial [22] and because of this we performed reliability and validity testing on our study data ourselves. The reliability of the Japanese version of the MBI [23] was evaluated by calculating the Cronbach's alpha coefficients: emotional exhaustion, depersonalization, and personal accomplishment were 0.87, 0.68, and 0.88, respectively. Discriminant validity was evaluated by calculating the Pearson's correlations coefficients of the inter-subscales of the MBI: emotional exhaustion and depersonalization $(r = 0.50, \ p < 0.01)$, emotional exhaustion and personal accomplishment $(r = -0.04, p = 0.39)$, and depersonalization and personal accomplishment $(r = -0.17, \ p < 0.01)$. Convergent validity was evaluated by calculating the Pearson's correlations coefficients of the total score of GHQ-12 and emotional exhaustion $(r = 0.44, p < 0.01)$, depersonalization $(r = 0.28, p < 0.01)$, and personal accomplishment $(r = -0.18, p < 0.01)$. We considered these results were satisfactory and allowed the MBI results to be included in further analyses.

Psychiatric morbidity: The General Health Questionnaire 12-item version (GHQ-12) [24] is a self-administered questionnaire designed to screen for non-psychotic psychiatric morbidity, it is well validated including the Japanese version [25–27] and has been widely used in samples of healthcare professionals. It measures 12 symptoms of psychiatric morbidity (e.g. depression, loss of confidence, sleep disturbance). Each item is scored as 0 (less or no more than usual) or 1 (rather or much more than usual), giving a maximum total score of 12. Scores above a threshold of 4 or more are regarded as indicating psychiatric morbidity. This approach has been recommended by the developer of this scale [28] and has been shown to be applicable to the Japanese version [29]. We used it to compare the prevalence of psychiatric morbidity in this study with that reported in previous studies for oncologists [8–13].

Individual factors: We included physician characteristics and other individual factors in the questionnaire (available from the authors) that was developed for our previous study [17] to identify physicians' attitudes toward terminal sedation for cancer patients: the questionnaire was developed after a systematic literature review and discussions by an expert panel. Strength of religious belief was assessed by 3 items using a 5-point Likert-type scale (possible range, 1 to 5—with a higher score indicating greater strength). Involvement in end-of-life care during the past year was assessed by 3 items using a 4-point Likert-type scale (possible range, 1 to 4—with a higher score indicating greater involvement) Confidence in the physical or psychological care of patients were assessed by 5 items each using a 5-point Likert-type scale (possible range, 1 to 5—with a higher score indicating greater confidence).

Statistical Analysis

We first calculated the Cronbach's alpha coefficients for the subscales: strength of religious belief (0.89), involvement in end-of-life care (0.88), confidence in the physical care of patients (0.77), and confidence in the psychological care of patients (0.75). Because of its excellent internal consistency, we used these as a single subscale to compare physician characteristics between two practice settings (clinical oncologists versus palliative care physicians). To compare the prevalence of burnout and psychiatric morbidity between two practice settings, we performed chi-square tests. To examine the association between high levels of burnout and psychiatric morbidity, high levels of burnout were entered as independent variables into a multivariate logistic regression analysis. To explore the association with total scores of MBI and GHQ-12, all individual factors were entered as independent variables into a multivariate linear regression analysis using forced entry.

In all statistical evaluations, p values of 0.05 or less were considered significant; all reported p values were two-tailed. SPSS ver.12.0J statistical software for Windows (SPSS Japan Institute Inc, Tokyo, Japan) was used to perform all statistical analyses.

Results

Physician characteristics

Of the 1436 physicians to whom questionnaires were mailed, 550 physicians responded within 1 month and 179 responded after a reminder. Thirty-two responses did not meet the eligibility criteria, so 697 responses were finally analyzed (49.6% effective response rate, 697 of 1404). The responses were obtained from 560 (43%) of the 1306 physicians working at medical centers for cancer and adult disease and from 87 (67%) of the 130 physicians working at hospices or palliative care units. The data on 50 missing values indicated the data on physicians whose practice settings were unknown. The physician characteristics are summarized in Table 1. The respondents were 28–69 years of age (mean ± S.D., 45 ± 8.2), with 0.5–40 years of oncology experience (mean ± S.D., 16 ± 8.1). When the two practice settings were compared, the clinical oncologists had a higher proportion of male physicians (95% versus 87%, $p < 0.01$), more years of oncology experience (mean ± S.D., 16 ± 7.9 versus 12 ± 7.6, $p < 0.01$), less religious beliefs (mean ± S.D., 2.8 ± 0.9 versus 3.6 ± 1.0, $p < 0.01$), less involvement in end-of-life care (mean ± S.D., 1.4 ± 0.4 versus 3.3 ± 0.9, $p < 0.01$), less confidence in the physical care of patients (mean ± S.D., 3.0 ± 0.7 versus 3.5 ± 0.8, $p < 0.01$), and less confidence in the psychological care of patients (mean ± S.D., 2.8 ± 0.6 versus 3.3 ± 0.7, $p < 0.01$) than palliative care physicians.

Prevalence of burnout and psychiatric morbidity

The prevalence of burnout and psychiatric morbidity are shown in Table 2. Compared with American normative data, the proportions of physicians with high levels of emotional exhaustion (22 versus 33%) and depersonalization (11 versus 33%) were lower, while the proportion of physicians with a low level of personal accomplishment (62 versus 33%) was much higher. Psychiatric morbidity was 20% among all the physicians who responded. When we compared the data for the two practice settings, the clinical oncologists showed a significantly higher prevalence of psychiatric morbidity (21 versus 12%, $p = 0.05$), and a higher proportions of physicians with low levels of personal accomplishment (65 versus 53%, $p = 0.05$), compared with palliative care physicians.

We next examined the association between high levels of burnout and psychiatric morbidity, as shown in Table 3. A high level of emotional exhaustion ($p < 0.01$) and a low level of personal accomplishment ($p < 0.01$) were significantly associated with psychiatric morbidity. On the other hand, a high level of depersonalization ($p = 0.21$) was not significantly associated with psychiatric morbidity.

Factors associated with total scores of MBI and GHQ-12

The associations between individual factors and total scores of MBI and GHQ-12 , as determined using a multivariate linear regression analysis, are shown in Table 4. Among the items for physician confidence in the psychological care of patients, having sufficient time to communicate with patients

Table 1. Physician characteristics

	Total physicians (n = 697) n (%)	Clinical oncologists (n = 560) n (%)	Palliative care Physicians (n = 87) n (%)
Age (years)			
Mean ± S.D.	45 ± 8.2	45 ± 8.2	43 ± 8.1
Range	28–69	28–68	31–69
Gender			
Male	639 (92)	531 (95)	76 (87)
Female	43 (6)	27 (5)	11 (13)
Religion			
None	521 (75)	441 (80)	49 (56)
Buddhism	108 (16)	87 (16)	9 (10)
Christianity	47 (7)	18 (3)	24 (28)
Others	13 (2)	3 (1)	4 (5)
Oncology experience (years)			
Mean ± S.D.	16 ± 8.1	16 ± 7.9	12 ± 7.6
Range	0.5–40	0.5–40	1.0–30
Involvement in end-of-life care during the past year			
Percentage of time used for palliative care			
<25	502 (72)	452 (81)	13 (15)
25–50	103 (15)	91 (16)	9 (10)
51–75	14 (2)	7 (1)	7 (8)
>75	67 (10)	9 (2)	58 (67)
Percentage of patients with an estimated survival time of less than 6 months			
<25	466 (67)	423 (76)	11 (13)
25–50	116 (17)	105 (19)	6 (7)
51–75	31 (4)	21 (4)	8 (9)
>75	70 (10)	8 (1)	61 (71)
Number of patients who died			
<5	222 (32)	196 (35)	3 (4)
5–25	374 (54)	344 (62)	16 (19)
26–50	42 (6)	16 (3)	24 (28)
>50	47 (7)	3 (1)	43 (50)

Note: We included 50 missing values among total physicians whose practice settings were unknown. S.D.: standard deviation.

Table 2. Prevalence of burnout and psychiatric morbidity

	Total physicians (n = 697) (%)	Clinical oncologists (n = 560) (%)	Palliative care physicians (n = 87) (%)	χ2	P value
High level of Emotional Exhaustion	22	23	15	2.81	0.09
High level of Depersonalization	11	10	8	0.19	0.66
Low level of Personal Accomplishment	62	65	53	4.03	0.05
Psychiatric Morbidity	20	21	12	3.80	0.05

Note: We included 50 missing values among total physicians whose practice settings were unknown.

Table 3. Association between high levels of burnout and psychiatric morbidity: multivariate logistic regression analysis (n = 697)

	Psychiatric morbidity		
	OR	95%CI	P value
High level of Emotional Exhaustion	4.41	2.70–7.20	<0.01
High level of Depersonalization	1.49	0.79–2.79	0.21
Low level of Personal Accomplishment	2.32	1.43–3.78	<0.01

OR: odds ratio; CI: confidence interval.

had the lowest score (mean ± S.D., 2.7 ± 1.0) and was significantly associated with all the total scores of MBI and GHQ-12: emotional exhaustion

($p < 0.01$), depersonalization ($p < 0.01$), personal accomplishment ($p < 0.05$), and GHQ-12 ($p < 0.01$). Though all the total adjusted R^2 values presented in Table 4 were very low, the best performing model is that for personal accomplishment (total adjusted $R^2 = 0.18$). Being male ($p < 0.05$), being little involved in care for patients who died during the past year ($p < 0.05$), having greater confidence in having adequate resources in physical care ($p < 0.01$), having greater confidence in the assessment of patient anxiety and depression ($p < 0.01$) and assessment of patient ability to make decisions ($p < 0.05$) were significantly associated with higher personal accomplishment. Being a clinical oncologist was significantly associated with

Table 4. Factors associated with burnout and stress: multivariate linear regression analysis ($n = 697$)

	Emotional Exhaustion β	Depersonalization β	Personal Accomplishment β	GHQ-12 total scores β
Age (years)	−0.14	−0.11	−0.01	0.01
Gender[a]	0.05	0.00	−0.08[e]	0.04
Practice setting[b]	−0.13[e]	0.00	0.04	−0.13[e]
Strength of religious belief[c]	0.07	0.03	0.08	0.09[e]
Oncology experience (years)	0.08	0.03	0.07	−0.07
Involvement in End-of-life care during the past year[d]				
Percentage of time used for palliative care	0.01	−0.11	−0.02	−0.05
Percentage of patients with an estimated survival time of less than 6 months	0.02	−0.02	0.04	0.10
Number of patients who died	0.09	0.12	−0.13[e]	0.06
Confidence in the physical care of patients [c]				
Knowledge and skill (pain)	0.00	0.01	0.09	−0.04
Knowledge and skill (physical symptoms)	−0.03	−0.01	0.08	−0.01
Having trained (physical management)	0.03	−0.01	−0.03	−0.05
Having adequate resources	−0.03	0.09	0.16[f]	−0.03
Ability to make a prognosis	0.04	0.01	0.04	−0.04
Confidence in the psychological care of patients [c]				
Assessment (patient anxiety and depression)	−0.02	−0.02	0.17[f]	0.06
Knowledge and skill (psychotropics and psychotherapy)	0.06	−0.02	−0.06	−0.03
Having adequate resources	−0.06	−0.01	−0.10	0.01
Assessment (patient ability to make decisions)	−0.03	−0.05	0.13[e]	−0.09
Having sufficient time to communicate with patients	−0.16[f]	−0.23[f]	0.10[e]	−0.15[f]
Total R^2	0.07	0.09	0.21	0.09
Total adjusted R^2	0.04	0.07	0.18	0.06

β: standardized coefficient.
[a]Coded as: 0 = Male; 1 = Female.
[b]Coded as: 0 = Clinical Oncologists; 1 = Palliative Care Physicians.
[c]Possible range 1–5. Higher scores indicate greater strength or confidence.
[d]Possible range 1–4. Higher scores indicate greater involvement.
[e]Statistically significant variables ($p < 0.05$).
[f]Statistically significant variables ($p < 0.01$).

emotional exhaustion ($p < 0.05$) and total scores of GHQ-12 ($p < 0.05$).

Discussion

This is the first cross-sectional nationwide survey to determine the prevalence of burnout and psychiatric morbidity among physicians engaged in end-of-life care for cancer patients in Japan. Based on the results of present study, several findings emerged. First, 22% of the respondents had a high level of emotional exhaustion, 11% had a high level of depersonalization, 62% had a low level of personal accomplishment, and 20% had psychiatric morbidity. Second, clinical oncologists showed a significantly higher prevalence of psychiatric morbidity than palliative care physicians (21% versus 12%). Third, physician confidence in having sufficient time to communicate with patients was the factor most strongly associated with burnout.

Before proceeding any further with this Discussion section, we would like to present several critical limitations of this study to help the readers' understanding of our interpretation of the results. First, there was a sample bias. The response rate

was relatively low (49.6%), so our prevalence may not be truly representative. Because the response rate of the clinical oncologists (43%) was lower than that of the palliative care physicians (67%) and the clinical oncologists showed a higher prevalence, physicians with high levels of burnout may not have responded to our study. Second, this study was a secondary analysis, so the number of factors included as independent variables was limited and neither the variance in burnout nor the relations among burnout, psychiatric morbidity and individual factors could be fully explained. Third, this was a cross-sectional study, so any causality between the prevalence and associated factors could not be determined.

In previous studies examining burnout in oncologists [7–13] and general physicians [30,31,14], high levels of emotional exhaustion (23–53% and 19–53%, respectively), high levels of depersonalization (13–31% and 22–64%, respectively), and low levels of personal accomplishment (21–48% and 13–31%, respectively) were observed. The present study showed a lower prevalence of depersonalization and a higher prevalence of diminished personal accomplishment, compared with the results of previous studies.

Depersonalization is associated with suboptimal patient care [14,16]; therefore, its lower level among the physicians in this study may not have a strong impact on end-of-life care.

On the other hand, the prevalence of a low level of personal accomplishment was relatively high and was significantly associated with psychiatric morbidity in the present study. Our results showing that personal accomplishment reduces the risk of psychiatric morbidity were consistent with a previous nationwide cross-sectional study [13,32]. The role of personal accomplishment is complicated: it is believed to prevent emotional exhaustion and depersonalization [1,33], whereas at a high level, it predicted higher levels of stress in a longitudinal study [34]. According to our results, improving physician confidence in assessing the mental state of patients (anxiety, depression, decision making ability) and having adequate resources for the physical care of patients may prevent a diminished sense of personal accomplishment. However, assessing a patient's mental state is difficult for oncologists because they receive little training on assessing psychological distress [35,36], so further education is needed. In addition, clarifying the physician role has been suggested as improving a diminished sense of personal accomplishment [5]. Therefore, we recommend that mental health professionals be consulted to provide education on psychological distress and to clarify the roles of physicians. In Japan, consultation teams for palliative care that include a palliative care specialist and a psychiatrist as essential members have started to receive expanded coverage under healthcare insurance since 2002; further studies are required to see whether this system will improve the confidence of physicians and prevent diminished personal accomplishment in Japan.

The overall psychiatric morbidity in this study was 20%. Since the prevalence of psychiatric morbidity in the general population of Japan is 16.5% [37], physicians engaged in end-of-life care for cancer patients were not considered to have a particularly high prevalence of psychiatric morbidity. Furthermore, psychiatric morbidity in this study was lower than that in previous studies on burnout in oncologists (25–32%) [9–13] and was nearly equal to recent data on UK doctors who were not oncologists (17–18%) [34] using the same GHQ-12 cut-off score. On the other hand, considering that the non-responders showed a higher psychiatric morbidity in a previous study [38], we might have underestimated the prevalence in the present study owing to our low response rate.

The palliative care physicians showed much lower levels of burnout and psychiatric morbidity than the clinical oncologists, and this result was similar to those of previous studies in which physicians and nurses working in hospices had lower stress levels than those working in oncology settings [39–41]. On the other hand, a previous study in the UK [12] showed nearly the same level of psychiatric morbidity in these two practice settings. As indicated in the limitations of this study, we could not investigate the job stress factors. Clinical oncologists reported feeling more overloaded and being involved with treatment toxicity, which factors were significantly associated with psychiatric morbidity [12]. Furthermore, situational factors such as workload, control, reward, community, fairness, and values have been said to be more importantly correlated with burnout than individual factors [2,42,43]. These job stress and situational factors may be more associated with the prevalence of burnout than involvement in end-of-life care, and these factors might be related to the Japanese palliative care system in 2000. In Japan, healthcare insurance has supported dissemination of specialized palliative care services since 1991, the number of palliative care units having dramatically increased from only 5 in 1991, to 123 in 2004 [44].

Burnout was associated with physician confidence, especially confidence in the psychological care of patients, rather than involvement in end-of-life care. Among the factors, confidence in having sufficient time to communicate with patients was the most strongly associated factor. To relieve physician burnout, ensuring sufficient time to communicate with patients or the development of clinical aids to help communication within a brief time are promising strategies. Communication skills training would not help physicians to have sufficient time but may help them acquire good communication skills, minimizing the need for more time. Physicians who felt insufficiently trained or who were not confident of their communication skills were more likely to have a low sense of personal accomplishment [7,12,13]. Despite the effectiveness of communication skills training in Western countries [45,46], our preliminary study showed that while oncologists became more confident of their communication skills, their level of emotional exhaustion also increased after training [47]; further studies on communication skills training are needed in Japan.

In conclusion, a low level of personal accomplishment was relatively high among Japanese physicians compared with previous studies. Insufficient confidence in the psychological care of patients was associated with physician burnout rather than involvement in end-of-life care.

Acknowledgements

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original article

Good death in cancer care: a nationwide quantitative study

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Background: The aims of this study were to (i) conceptualize dimensions of a good death in Japanese cancer care, (ii) clarify the relative importance of each component of a good death and (iii) explore factors related to an individual's perception of the domains of a good death.
Methods: The general population was sampled using a stratified random sampling method (*n* = 2548; response rate, 51%) and bereaved families from 12 certified palliative care units were surveyed as well (*n* = 513; 70%). We asked the subjects about the relative importance of 57 components of a good death.
Results: Explanatory factor analysis demonstrated 18 domains contributing to a good death. Ten domains were classified as 'consistently important domains', including 'physical and psychological comfort', 'dying in a favorite place', 'good relationship with medical staff', 'maintaining hope and pleasure', 'not being a burden to others', 'good relationship with family', 'physical and cognitive control', 'environmental comfort', 'being respected as an individual' and 'life completion'.
Conclusions: We quantitatively identified 18 important domains that contribute to a good death in Japanese cancer care. The next step of our work should be to conduct a national survey to identify what is required to achieve a good death.
Key words: attitude to death, good death, hospice, neoplasms, palliative care, public opinion

introduction

One of the most important goals of palliative care is achieving a 'good death' or a 'good dying process'. In many countries, elaborate efforts have been devoted to conceptualizing a good death using qualitative research [1–9]. Quantitatively, Steinhauser et al. [10, 11] have elucidated important factors that influence the end of life. Steinhauser et al. [10] reported that 27 items including pain and symptom management, preparation for death, achieving a sense of completion, decisions about treatment preferences and being treated as a 'whole person' are consistently important among patients, bereaved family members, physicians and other health care providers in the United States. In addition, several other surveys have been conducted that explore the attitudes of patients and bereaved family members [12, 13].

In Japan, however, we have had only a few studies investigating this topic: a qualitative study of hospice nurses [14], a small investigation of advanced cancer patients [15] and an observational study of participants [16]. To set up a goal

of palliative care in Japan, it is important to conceptualize what constitutes a good death in Japan.

In Japan, cancer is the leading cause of death. Patients with cancer suffer many physical and psychological problems in their dying process. Enhancement of palliative care for Japanese cancer patient is a priority in Japan. Therefore, we conducted a nationwide qualitative study to explore components of a good death in Japanese cancer care [17]. In the current investigation, we have conducted a quantitative study to determine what components were considered necessary for a good death, using a large nationwide sample of the general population and bereaved family members in Japan.

The primary aims of this study were to (i) conceptualize the dimensions of a good death in Japanese cancer care, (ii) clarify the relative importance of each component of a good death and (iii) explore factors related to an individual's perception of the domains of a good death.

methods

participants and procedures

A cross-sectional anonymous questionnaire was administered to a sample of the general Japanese population and to bereaved family members of cancer patients who had died in a certified palliative care unit (PCU). We

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Table 1. Participant characteristics

	General population (n = 2548)		Bereaved family (n = 513)	
Age, years				
≤49	24%	n = 613	20%	n = 105
50–59	30%	n = 758	28%	n = 144
60–69	28%	n = 710	28%	n = 146
70≥	16%	n = 420	23%	n = 120
Sex, female	52%	n = 1326	67%	n = 343
Having chronic disease	40%	n = 1023	NA	NA
Bereavement experience by cancer within 10 years	25%	n = 649	100%	n = 513
Place of patient's death				
Home	13%	n = 86		
Acute care hospital	77%	n = 502		
Palliative care unit	5.4%	n = 35	100%	n = 513
Nursing home	1.8%	n = 12		
Other	2.2%	n = 14		
Patient characteristics				
Age, years (mean ± SD)	NA	NA	68 ± 13	
Sex, female	NA	NA	42%	n = 216
Relationship to the deceased				
Spouse	NA	NA	56%	n = 288
Parent/parent-in-law	NA	NA	33%	n = 171
Child	NA	NA	2.7%	n = 14
Other	NA	NA	5.1%	n = 26
Hospital length of stay, days (mean ± SD/median)	NA	NA	44 ± 49/29	
Interval from patient's death, months (mean ± SD/median)	NA	NA	28 ± 7.0/28	

Percentages do not add up to 100% due to missing values.
SD, standard deviation; NA, not available.

identified four areas (Miyagi, Tokyo, Shizuoka and Hiroshima prefectures) as target areas for this study to obtain a wide geographic distribution for the nationwide sample. The main reason we selected these four areas was the feasibility of random sampling for the general population. The four areas included an urban prefecture (Tokyo) and mixed urban–rural areas (Miyagi, Shizuoka and Hiroshima). The survey was conducted in the general population in order to determine prevailing views. In addition, we surveyed bereaved family members who received specialized palliative care (best available practice in Japan) and who acted as proxies for deceased patients.

In Japan, the Ministry of Health, Labor and Welfare has strongly supported dissemination of specialized palliative care services, with coverage of PCUs by National Medical Insurance since 1991. The number of PCUs has dramatically increased from five in 1991 to 135 in 2004. On the other hand, the growth of home-based palliative care programs has been slow; 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, and we chose the bereaved family members of patients in PCUs as study targets for this investigation.

We initially identified 5000 subjects in the general population by a stratified two-stage random sampling method of residents of the four areas. We selected 50 census tracts for each area and then selected 25 individuals, aged 40–79 years, within each census tract, thus identifying 1250 individuals for each area. The census tracts usually cover 200 families to conduct national census survey in Japan. We randomly sampled 50 census tracts in each prefecture, and then we sampled 25 individuals in each census tract according to national census method in Japan. We mailed questionnaires to potential participants in March 2004, and sent a reminder postcard 2 weeks later.

To identify bereaved family members, we initially identified all 37 PCUs in the four areas as potential participating institutions. We then approached

the 18 PCUs (three in Miyagi, nine in Tokyo, three in Shizuoka and three in Hiroshima) that had collaborative researchers available, and ultimately 12 PCUs (two in Miyagi, five in Tokyo, two in Shizuoka and three in Hiroshima) agreed to participate in this survey. Primary care physicians identified bereaved families that fulfilled the inclusion criteria: (i) primary caregiver of an adult cancer patient, (ii) aged 20 years or more, (iii) capable of replying to a self-reported questionnaire, (iv) aware of the diagnosis of malignancy and (v) without serious psychological distress as determined by the physician. Each PCU was requested to enroll 50 (Tokyo) or 80 (Miyagi, Shizuoka and Hiroshima) consecutive families. We mailed questionnaires to potential respondents in August 2004, and again in October 2004, to those who did not respond, and we asked that the primary caregiver fill in the questionnaire. If the respondents did not want to participate in the survey, they were asked to return a questionnaire with 'no participation' indicated, and a reminder was not mailed to them. The ethical and scientific validity of this study was confirmed by the institutional review boards of all participating hospitals.

measurements

Our questionnaire asked about the relative importance of 57 components that might contribute to a good death in Japanese cancer care. We asked that participants answer for their experience of dying from cancer. The questions for the general population and bereaved family members were identical. We show details of the 57 components in Table 2. These components were based on a previous qualitative study [17] and literature review [1–6, 10, 11, 14–16]. The participants of the qualitative study were 13 advanced cancer patients, 13 family members of such patients and 20 physicians and 20 nurses caring for dying cancer patients. The participants were asked what was important in the experience of dying from cancer and we conducted a content analysis [17]. Then, we conducted pilot studies

Table 2. Conceptualization of a good death by factor analysis in Japan

Domain	Component	Standardized regression coefficient	General population, mean (SD)	Bereaved family, mean (SD)	Cronbach's alpha
1. Physical and psychological comfort	Being free from pain and physical distress	0.88	5.99 (0.79)	6.21 (0.63)	0.65
	Being free from psychological distress	0.58			
2. Dying in a favorite place	Being able to stay at one's favorite place	0.80	6.03 (0.91)	6.13 (0.81)	NA
3. Good relationship with medical staff	Having a professional nurse with whom one feels comfortable	0.82	5.94 (0.74)	6.17 (0.65)	0.84
	Receiving consistent care from the same physician and nurse	0.80			
	Trusting physician	0.78			
	Discussing one's treatment with one's physician	0.73			
	Having a physician or nurse with whom one can discuss fears of death	0.65			
	Having people who listen to me	0.54			
4. Maintaining hope and pleasure	Having some pleasure in daily life	0.92	5.73 (0.82)	5.78 (0.77)	0.83
	Living in hope	0.84			
	Living positively	0.82			
5. Not being a burden to others	Not being a burden to family members	0.90	5.82 (0.83)	5.74 (0.87)	0.79
	Not making trouble for others	0.86			
	Having no financial worries	0.67			
6. Good relationship with family	Spending enough time with one's family	0.82	5.84 (0.81)	5.92 (0.84)	0.88
	Family is prepared for one's death	0.79			
	Having family to whom one can express one's feelings	0.73			
	Having family by one's side when one is going to die	0.72			
	Believing that one's family will do well after one's death	0.71			
	Having family support	0.68			
7. Physical and cognitive control	Being able to eat	0.88	5.66 (0.78)	5.58 (0.79)	0.79
	Being mentally clear	0.78			
	Being independent in daily activities	0.73			
8. Environmental comfort	Living in calm circumstances	0.84	5.54 (0.90)	5.74 (0.82)	0.73
	Living like being at home	0.78			
9. Being respected as an individual	Not being treated as an object or a child	0.85	5.77 (0.89)	5.91 (0.83)	0.67
	Being free from trivial routines	0.67			
	Being respected for one's values	0.58			
10. Life completion	Having no regrets	0.82	5.64 (1.00)	5.81 (0.92)	0.80
	Feeling that one's life was completed	0.77			
	Family has no regrets for one's death	0.76			
11. Natural death	Not being connected to medical instruments or tubes	0.85	5.52 (1.06)	5.57 (1.04)	0.49
	Dying a natural death	0.62			
12. Preparation for death	Saying good-bye to dear people	0.85	4.91 (1.07)	4.97 (1.03)	0.80
	Seeing people whom one wants to see	0.83			
	Being reconciled with people	0.65			
	Feeling thankful to people	0.46			
	Being prepared for dying	0.38			
13. Role accomplishment and contributing to others	Maintaining one's role in family or occupational circumstances	0.82	5.25 (1.05)	5.24 (0.98)	0.84
	Feeling that one can contribute to others	0.77			
	Feeling that one's life is worth living	0.71			
14. Unawareness of death	Dying without awareness that one is dying	0.87	4.92 (1.02)	4.94 (1.01)	0.70
	Not being informed of bad news	0.81			
	Living as usual without thinking about death	0.51			
15. Fighting against cancer	Fighting against disease until one's last moment	0.80	5.10 (1.15)	5.08 (1.13)	0.78
	Believing that one used all available treatments	0.80			
	Living as long as possible	0.77			

Table 2. *(Continued)*

Domain	Component	Standardized regression coefficient	General population, mean (SD)	Bereaved family, mean (SD)	Cronbach's alpha
16. Pride and beauty	Not having a change in one's appearance	0.69	4.95 (0.95)	4.89 (0.97)	0.61
	Not receiving pity from others	0.59			
	Not exposing one's physical and mental weakness to family	0.47			
17. Control over the future	Knowing how long one will live	0.81	5.39 (0.93)	5.49 (0.85)	0.73
	Knowing what to expect about one's condition in the future	0.79			
	Controlling time of death, like euthanasia	0.72			
	Having planned arrangements for one's grave, funeral and last will	0.61			
18. Religious and spiritual comfort	Having faith	0.95	4.31 (1.44)	4.46 (1.46)	0.82
	Feeling that one is protected by higher power beyond oneself	0.88			

Standardized regression coefficients were calculated by explanatory factor analysis (principal method with promax rotation).
SD, standard deviation; NA, not available.

on 54 participants from the general population and 183 nurses by a similar method as in this study. We assumed there were 18 hypothetical domains before the study according to the results of these pilot studies by factor analysis and calculation of Cronbach's alpha coefficients.

We asked participants to rate the relative importance of each component for a good death on a seven-point Likert scale (1: absolutely unnecessary, 2: unnecessary, 3: somewhat unnecessary, 4: unsure, 5: somewhat necessary, 6: necessary and 7: absolutely necessary). In addition, we asked about the relative importance of three components of a good death: 'dying as one sleeps' [17], 'pokkuri' [16] (sudden death) and 'omakase' [18] (leaving the decision to a medical expert).

We also asked age and sex for all participants. For the general population, we asked whether they had a chronic disease (defined as the presence of a regular hospital visit during the previous year) or a bereavement experience caused by cancer within the past 10 years.

analysis

First, to conceptualize a good death, we used explanatory factor analysis (principal method with promax rotation) and Cronbach's alpha coefficients. We included all participants in the factor analysis because separate analyses showed essentially the same factor structure from the general population and bereaved family members, as well as from the general population with or without chronic disease. Secondly, to easily interpret the relative importance of each component of a good death, we summed up the proportion of 'somewhat necessary', 'necessary' and 'absolutely necessary' responses. We then classified each component into three groups: 'consistently important domains' (all summed proportions of components that were >80%), mixed important domains (some summed proportions of components that were >80% and others that were not) and relatively less important domains (all summed proportions of components that were <80%). We adopted 80% as the threshold level from a clinical point of view. Thirdly, we explored the factors that affect an individual's good-death domain score using bivariate analysis.

After calculation of the individual's domain score, defined as the mean value of all components belonging to each domain, we compared the mean value between the general population and bereaved family members using the student's *t*-test. Next, we explored the association between the mean value and age, sex, presence of a chronic disease, bereavement experience by cancer and interval from patient's death using the Student's *t*-test, linear

regression and analysis of variance, where appropriate. These comparisons were conducted for the general population sample and bereaved family members separately. Finally, we explored the association between each good-death domain score and the relative importance of dying as one sleeps, pokkuri and omakase by Spearman's rank correlation coefficient.

As a large sample size may result in an excess of statistically significant results ($P < 0.05$), we described only 'clinically significant' results if the effect size (ES) was >0.5. This criterion indicates that the mean value difference as an absolute figure between two extreme categories was more than half the standard deviation (SD) for each domain. All analyses were carried out using the statistical package SAS version 9.1.

results

participant characteristics

Of 5000 questionnaires sent to a sample of the general population, 26 were undeliverable and 2670 were returned (Table 1). Of these, eight subjects refused to participate and 114 were excluded due to missing data. Thus, 2548 responses were analyzed (effective response rate, 51%).

Of 866 bereaved families initially considered as potential participants, 72 were excluded due to serious psychological distress recognized by primary physicians ($n = 30$), lack of available adult family members ($n = 17$) and other reasons ($n = 25$). Of 794 questionnaires sent to the remaining bereaved families, 56 were undeliverable and 552 were returned. Among these, 27 individuals refused to participate, and 12 responses were excluded due to missing data. Thus, in this group, 513 responses were analyzed (effective response rate, 70%).

conceptualization of a good death by factor analysis

By factor analysis, we identified 18 domains of a good death in Japan: (1) 'physical and psychological comfort', (2) 'dying in a favorite place', (3) 'good relationship with medical staff', (4) maintaining 'hope and pleasure', (5) 'not being a burden

to others', (6) 'good relationship with family', (7) 'physical and cognitive control', (8) 'environmental comfort', (9) 'being respected as an individual', (10) life completion, (11) natural death, (12) preparation for death, (13) role accomplishment and contributing to others, (14) unawareness of death, (15) fighting against cancer, (16) pride and beauty, (17) control over the future and (18) religious and spiritual comfort (Table 2). The mean values of each domain score ranged from 4.3 to 6.2 and the SDs were 0.63–1.46. Cronbach's alpha coefficients ranged from 0.61 to 0.88, except for 'natural death'.

relative importance of each component of a good death

Table 3 lists the domains and the components classified as consistently important domains: (1) physical and psychological comfort, (2) dying in a favorite place, (3) good relationship with medical staff, (4) maintaining hope and pleasure, (5) not being a burden to others, (6) good relationship with family, (7) physical and cognitive control, (8) environmental comfort, (9) being respected as an individual and (10) life completion.

Table 4 lists the domains and components classified as mixed important domains: (11) natural death, (12) preparation for death, (13) role accomplishment and contributing to others and (14) unawareness of death.

Table 5 lists the domains and components classified as relatively less important domains: (15) fighting against cancer, (16) pride and beauty, (17) control over the future and (18) religious and spiritual comfort.

The five most frequently stated components for a good death were the following: (1) being free from psychological distress (general population sample, 97%; bereaved family members, 98%), (2) trusting physician (96%; 98%), (3) discussing one's treatment with one's physician (95%; 96%), (4) having people who listen (94%; 97%) and (5) having a professional nurse with whom one feels comfortable (94%; 97%). On the other hand, the five least frequent responses were the following: (58) religious and spiritual comfort (38%; 37%), (57) living as long as possible (42%; 39%), (56) not being informed of bad news (44%; 42%), (55) feeling that one is protected by a higher power beyond oneself (47%; 52%) and (54) being reconciled with people (51%; 53%).

factors influencing an individual's good-death domain score

No clinically significant difference was found in any domain scores of a good death between the general population sample and bereaved family members. In the general population, older participants were significantly more likely to perceive 'unawareness of death' as important for a good death (ES = 0.66, $P < 0.001$). Among bereaved family members, older participants tended to emphasize unawareness of death (ES = 1.00, $P < 0.001$), 'religious and spiritual comfort' (ES = 0.58, $P < 0.001$) and physical and cognitive control (ES = 0.53, $P < 0.001$); women emphasized good relationship with medical staff (ES = 0.63, $P < 0.001$) and other factors were not

clinically significantly associated with the good-death domain scores (data not shown).

association between good-death domain score and dying as one sleeps, pokkuri and omakase

Dying as one sleeps broadly correlated with nine good-death domain scores; unawareness of death correlated with dying as one sleeps, pokkuri and omakase (Table 6).

discussion

The most important results of this study were that we identified 18 domains contributing to a good death for Japanese subjects, and quantified the relative importance of each good-death component in Japanese cancer care. As a whole, the important domains that emerged in this study are similar to those in Western surveys [10, 11]. That is, most Japanese emphasized physical and psychological comfort, environmental comfort and dying in a favorite place, good relationship with family and medical staff, maintaining hope and pleasure, not being a burden to others, life completion, physical and cognitive control and being respected as an individual. This finding indicates that these concepts are core elements of a good death, despite ethnic and cultural differences.

The clinical implication of this finding is that all practitioners caring for terminally ill patients should recognize broader good-death concepts beyond symptom control: not only symptom management (e.g. physical and psychological comfort) and improving the health care system (e.g. dying in a favorite place) but also challenging psycho-existential issues (e.g. hope and pleasure, not being a burden to others and 'completion of life') [19, 20] as an essential part of quality palliative care.

On the other hand, we identified some domain responses that varied significantly from individual to individual, including experiencing a natural death, preparation for death, role accomplishment and contributing to others, unawareness of death, fighting against cancer, pride and beauty, control over the future and religious and spiritual comfort. This finding indicates that beside the 'core elements' of a good death, there are no uniform styles of a good death. The clinical implication of this finding is that clinicians should explore the relative importance of these domains for each patient and each situation, and tailor the circumstances for each patient.

We found two major differences in quantitative results from Western surveys. One is about religious belief. Whereas Steinhauser et al. [10] showed that 89% and 85% of USA patients emphasized 'being at peace with God' and 'prayer', respectively, the corresponding figures were 37% and 52% in this Japanese study. The potential interpretation is that many Japanese have no specific religion and expression of religious belief tends to be ambiguous.

Another noteworthy difference was in 'control over the future' and unawareness of death. While 96% of USA patients emphasized 'know what to expect about one's physical condition' to achieve a good death, the proportion in this Japanese survey was 50%–69%, and the control over the future domain appeared in the relatively less important category. In addition, we identified unawareness of death as one of the

Table 3. Consistently important domains

Domain	Component	General population, %	Bereaved family, %
1. Physical and psychological comfort	Being free from psychological distress	97	98
	Being free from pain and physical distress	90	96
2. Dying in a favorite place	Being able to stay at one's favorite place	93	94
3. Good relationship with medical staff	Trusting physician	96	98
	Discussing one's treatment with one's physician	95	96
	Having a professional nurse with whom one feels comfortable	94	97
	Having people who listen to me	94	97
	Receiving consistent care from the same physician and nurse	83	88
	Having a physician or nurse with whom one can discuss fears of death	78	80
4. Maintaining hope and pleasure	Having some pleasure in daily life	91	93
	Living positively	91	92
	Living in hope	88	88
5. Not being a burden to others	Having no financial worries	92	92
	Not being a burden to family members	89	86
	Not making trouble for others	88	83
6. Good relationship with family	Spending enough time with one's family	84	83
	Having family to whom one can express one's feelings	92	94
	Believing that one's family will do well after one's death	92	91
	Family is prepared for one's death	91	91
	Having family support	90	94
	Having family by one's side when one is going to die	85	85
7. Physical and cognitive control	Being mentally clear	90	88
	Being able to eat	89	88
	Being independent in daily activities	88	85
8. Environmental comfort	Living in calm circumstances	87	91
	Living like being at home	83	88
9. Being respected as an individual	Not being treated as an object or a child	89	91
	Being respected for one's values	88	91
	Being free from trivial routines	81	84
10. Life completion	Family has no regrets for one's death	84	88
	Having no regrets	83	85
	Feeling that one's life was completed	81	86

Consistently important domains were defined as all summed proportions of components that were >80%.

Figures indicate percentage of somewhat necessary, necessary or absolutely necessary.

Table 4. Mixed important domains

Domain	Component	General population, %	Bereaved family, %
11. Natural death	Dying a natural death	89	90
	Not being connected to medical instruments or tubes	66	68
12. Preparation for death	Feeling thankful to people	92	95
	Being prepared for dying	86	89
	Seeing people whom one wants to see	76	79
	Saying good-bye to dear people	75	76
	Being reconciled with people	51	52
13. Role accomplishment and contributing to others	Feeling that one's life is worth living	81	83
	Maintaining one's role in family or occupational circumstances	62	61
	Feeling that one can contribute to others	75	73
14. Unawareness of death	Living as usual without thinking about death	85	88
	Dying without awareness that one is dying	53	53
	Not being informed of bad news	44	42

Mixed important domains were defined as some summed proportions of components that were >80% and others were not.

Figures indicate percentage of somewhat necessary, necessary or absolutely necessary.

Table 5. Relatively less important domains

Domain	Component	General population, %	Bereaved family, %
15. Fighting against cancer	Believing that one used all available treatments	78	79
	Fighting against disease until one's last moment	73	68
	Living as long as possible	42	39
16. Pride and beauty	Not receiving pity from others	69	69
	Not having a change in one's appearance	65	60
	Not exposing one's physical and mental weakness to family	57	52
17. Control over the future	Knowing how long one will live	67	68
	Having planned arrangements for one's grave, funeral and last will	66	69
	Knowing what to expect about one's condition in the future	58	64
	Controlling time of death, like euthanasia	57	50
18. Religious and spiritual comfort	Feeling that one is protected by a higher power beyond oneself	47	52
	Having faith	38	37

Relatively less important domains were defined as all summed proportions of components that were <80%.
Figures indicate percentage of somewhat necessary, necessary or absolutely necessary.

Table 6. Association between good-death domains and dying as one sleeps, pokkuri and omakase

	Dying as one sleeps	Pokkuri	Omakase
Percentage of somewhat necessary, necessary or absolutely necessary			
General population, %	93	77	59
Bereaved family, %	94	75	63
Correlation with good-death domain[a]			
1. Physical and psychological comfort	0.36	_[b]	_[b]
3. Good relationship with medical staff	0.40	_[b]	_[b]
4. Maintaining hope and pleasure	0.34	_[b]	_[b]
5. Not being a burden to others	0.35	0.30	_[b]
6. Good relationship with family	0.32	_[b]	_[b]
8. Environmental comfort	0.48	0.30	_[b]
11. Natural death	0.31	_[b]	_[b]
14. Unawareness of death	0.39	0.33	0.36
16. Pride and beauty	0.31	_[b]	_[b]

[a]Figures indicate Spearman's rank correlation coefficient.
[b]Spearman's rank correlation was under 0.3.

major contributors to a good death in Japan, and unawareness of death significantly correlated with the traditional Japanese style of death (dying as one sleeps, pokkuri and omakase). These Japanese traditional concepts of death indicate that unawareness of death is more important in Japan compared with Western countries. These findings, consistent with the previous finding that many Japanese do not want to know the seriousness of their condition [21], indicate that living as usual without the feeling of facing impending death can be a core factor for a Japanese good death. Thus, Japanese clinicians are challenged to help their patients achieve life completion through facing mortality and respecting their value of unawareness of death. This becomes a difficult task in such situations.

To achieve a Japanese good death, more in-depth studies are apparently required to explore how we can clinically achieve the maximized balance between life completion and unawareness of death. In addition, this study reveals several unique characteristics of a good death that are uncommonly described in Western culture. The Japanese general population might

tend to emphasize the relationship with others rather than autonomy; familial cohesiveness is a common attribute of Japanese and Asian cultures [18, 22]. This would result in a higher perception of a good death as including not being a burden to 'others' (e.g. not being a burden to 'family members', not making trouble for 'others'), 'feeling thankful to people' (rather than 'I' say good-bye) and 'not exposing one's weakness to family'.

Of note was that dying as one sleeps significantly correlated with nonspecific multiple good-death domains, including physical and psychological comfort, environmental comfort, good relationship with medical staff, unawareness of death and not being a burden to others. In other words, 'dying as one sleeps' would be an expression describing an overall good death in Japan, and not that they literally want to 'die in their sleep'.

limitations

The limitations of this study are as follows: First, the response rate was 51% in the general population and response bias could

exist. We believe this is not a fatal flaw of this study because this is the average response rate for public surveys in Japan.

Secondly, as the study subjects were not terminally ill patients, results could not be automatically applied to patients. The patient's perspective is important, but we did not survey cancer patients because questions regarding dying are too burdensome to such patients in Japan. We believe, however, that this study provides a unique and valuable perspective because the study population included bereaved family members of patients who received specialized palliative care (best available practice in Japan), and the generalizability is supported by the fact that 40% of the participants in the general population had a chronic disease. Thirdly, since this was a cross-sectional study, we cannot rule out the possible instability of the findings. Finally, although we examined the questionnaire for factor validity by factor analysis and for reliability by calculating Cronbach's alpha coefficient, concurrent validity and test–retest validity were not examined.

conclusions

In conclusion, the good-death concept for Japanese cancer care consists of 18 domains, led by physical and psychological comfort, dying in a favorite place, good relationship with medical staff, maintaining hope and pleasure, not being a burden to others, good relationship with family, physical and cognitive control, environmental comfort, being respected as an individual and life completion. The next step of our work should be to focus on developing an instrument to measure achievement of a good death [23–25], and conducting a national survey to identify what is required to achieve a good death [26, 27].

acknowledgements

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16

Preferences of cancer patients regarding the disclosure of bad news

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Abstract

To understand patients' preferences regarding the disclosure of bad news is important in the clinical oncology setting. The aim of this study was to clarify descriptively the preferences of cancer patients. Five hundred and twenty-nine Japanese cancer outpatients were surveyed regarding their preferences regarding the disclosure of bad news, and several psychosocial and medical demographic variables were analyzed. In a descriptive analysis, more than 90% of the patients strongly preferred to discuss their current medical condition and treatment options with their physician and to have their physicians take the feelings of their family into consideration as well. While half of the patients preferred to receive information regarding their life expectancy, 30% preferred not to receive it. Multiple regression analyses indicated the preferences showing interindividual variations were associated with the level of education and the mental adjustment to cancer scores. A factor analysis revealed four preferences factors: method of disclosure of the bad news, provision of emotional support, provision of additional information, and setting. These four factors had good internal consistency reliability (Cronbach's alpha = 0.93–0.77). Providing emotional support, including the desire for the physician to show consideration for the patient's family, and understanding an individual's communication preferences may be useful for promoting patient–physician communication. Copyright © 2006 John Wiley & Sons, Ltd.

Keywords: patients' preference; bad news; communication; cancer; patient–physician relationship

Introduction

Bad news consists of any information likely to alter drastically a patient's view of his/her future [1] and includes information regarding diagnosis, recurrence, and treatment failure in clinical oncology settings. The communication skills of physicians delivering bad news about cancer can affect the degree of a patient's distress [2–4]. However, the majority of physicians do not have a standard strategy for delivering bad news to patients [5]. Furthermore, the majority of guidelines and interventions designed to enhance physicians' communication skills when delivering bad news, are based only on experts' opinions and do not have a strong theoretical basis [6,7], nor do they necessarily reflect the preferences of patients [8,9]. Consequently, enhanced communication skills do not always improve patients' experience [10]. Meanwhile, patients preferred communication features were linked with lower psychological distress and higher satisfaction levels [3]. Thus, future development of interventions in enhancing communication should include the patients' preferences and the theoretical framework of them [3,7]. However, information on the communication preferences of patients is insufficient, and present communication styles are restrictive and based on the opinions of experts.

Since the importance of providing individualized communication to patients has been recognized, medical and psychosocial predictive variables have been examined to determine their associations with patients' preferences [8,9,11]. In the US, [9] had surveyed cancer patients' preference when receiving their cancer diagnosis and suggested that patients'

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preferences consisted of three factors, the content, support, and facilitation, which were associated with sex, age, and education. For physicians to tailor their communication style to individual patients, predictive variables for individual item of, rather than just factors of communication preferences, must be examined. Little attention, however, has been paid to this approach.

Cultural as well as social variables pertaining to both the patient and the physician determine the physicians' communication style. Many cultural aspects concerning the patient–physician relationship in oncology settings differ between Western and Asian countries [12,13]; for example, family-centered decision-making processes, the use of euphemisms, and physician paternalism are more common in Japan [14,15].

The accumulation of further study results on the cancer patients' preferences may help to refine current guidelines and establish patient-preference-based recommendations for dealing with this challenging task. Thus, the purpose of this study was to clarify patients' preferences regarding the disclosure of bad news concerning their cancer. To achieve this purpose, the present study assessed descriptive data, to explore the components of patients' preferences, and to identify the variables associated with communication style preferences. A self-reported questionnaire was utilized to identify patients' desires regarding their physicians' communication style when delivering bad news; this questionnaire was based on previously conducted in-depth interviews with patients and their physicians [15].

Materials and methods

Patients

All the subjects were cancer outpatients who were attending follow-up medical appointments at the National Cancer Center (NCC) Hospital East in Japan, which treat mainly breast, digestive, head and neck, and lung cancer. The eligibility criteria were: patients who were deemed by their physician and their medical chart to have received bad news regarding cancer three or more months earlier, including news of diagnosis, recurrence, disease progression, or the absence of an active anticancer treatment; patients who were 20 years old or older; patients who were judged by their physician to be capable of completing the survey; and patients who were capable of understanding spoken and written Japanese.

Procedure

The Institutional Review Board and the Ethics Committee of the NCC, Japan approved this study, and each patient provided an informed written consent.

All eligible outpatients were consecutively invited to participate in the study after their follow-up medical visit. The patients completed a series of questionnaires, and mailed them back. If the questionnaires contained any blanks, a single attempt was made to obtain the missing information by telephone or post.

Measurements

Patients' preferences regarding the communication style of physicians delivering bad news about cancer. The preference questionnaire consisted of 70 communication styles of physicians disclosing bad news about cancer. The survey items were generated on the basis of previously conducted in-depth interviews with patients and their physicians [15], a systematic literature review, and discussions among authors, and included a broad range of communication styles. The instrument was piloted among 12 cancer patients. These patients responded to each item and provided feedback on the content, clarification, and format of the items. Minor revisions were made in response to their feedback.

The participants were asked to choose the responses that best reflected how they would like to be told if they were to receive bad news, such as the diagnosis of cancer, recurrence, or progression of cancer (scored on a five-point Likert scale; 1: strongly do not prefer–5: strongly prefer).

Demographic and medical characteristics. The questionnaire included demographic data, including age, sex, employment status, education, marital status, and social support. Medical data, such as the type of cancer, recurrence or metastasis, current anticancer treatment, received bad news, and the period after the latest bad news, were obtained from the patients' medical records.

Mental Adjustment to Cancer (MAC) scale [16]. The Japanese version of the MAC scale [17] is a standardized instrument for evaluating the adjustment of patients to their cancer. The MAC scale consists of 40 items in 5 subscales: fighting-spirit (16 items), anxious-preoccupation (nine items), helplessness-hopelessness (six items), fatalism (eight items), and avoidance (one item). Each item is rated on a 4-point Likert scale (1–4).

Hospital Anxiety and Depression Scale (HADS) [18]. The Japanese version of the HADS [19] is a standardized instrument for evaluating anxiety and depression. The HADS consists of 14 items in 2 subscales: anxiety and depression. Each item is rated on a 4-point Likert scale (0–3).

Data analysis

First, we assessed the distribution of the patients' responses for all the 70 items in the questionnaire. Second, we grouped the five response categories into three categories: 'prefer', 'do not prefer', and 'no preference either way'. The items for which more than 20% of the respondents chose both 'prefer' and 'do not prefer' were arbitrarily defined as communication style preferences with high interindividual variations. We performed multiple regression analyses configured using the stepwise method to investigate associations with demographic characteristics, medical characteristics, and psychological status as independent variables, and communication styles with interindividual variations as dependent variables. Third, we performed an explanatory factor analysis using the maximum-likelihood method with promax rotation to identify potential components of the patients' preferences, because we did not have any hypothesis. Four factors were adopted on the basis of a screeplot (the eigenvalues of 3-, 4-, 5-, 6-and 7-factor were 4.68, 2.67, 1.98, 1.70,

and 1.45, respectively) and interpretable, and the Cronbach's alpha value was calculated to evaluate the internal consistent reliability of each factor. Significance was defined as $p < 0.05$. SPSS software, version 12.0, was used to perform the statistical analysis.

Results

Patients

One thousand and fifty-six consecutive outpatients were screened for inclusion. Of the 656 patients who were eligible, 34 refused the approach, 15 could not be contacted, and 32 were lost to contact. Of the remaining 575 patients who were approached, 9 refused to participate and 529 (93.5%) returned the questionnaire. Overall, 80.6% (529/656) of the eligible patients participated in the present study. The demographic characteristics of the participants are listed in Table 1.

Table 1. Demographic characteristics of the subjects $(N = 529)$

		N	%
Age (years; mean, S.D. range)		62, 11, 26–97	
Sex	Male	274	51.8
	Female	255	48.2
Employmental status	Employed	190	35.9
	Unemployed	339	64.1
Marital status	Married	452	85.4
	Unmarried	77	14.6
Household size	Living alone	19	3.6
	2 or more	510	96.4
Education	9 or less years	98	18.6
	10 or more years	430	81.4
Cancer site	Digestive	185	34.7
	Breast	125	23.5
	Head and neck	112	21.2
	Lung	107	20.2
Recurrence or metastasis	Presence	299	56.6
	Absence	229	43.4
Treatment received	Surgery	426	80.5
	Chemotherapy	221	41.8
	Radiation therapy	153	28.9
	Hormone therapy	45	8.5
	Other	16	3.0
Current anticancer treatment	Presence	134	25.5
	Absence	395	74.5
Bad news received regarding			
Diagnosis	Yes	529	100
	No	0	0
Recurrence	Yes	164	31.0
	No	365	69.0
Disease progression	Yes	38	7.0
	No	491	93.0
Absence of active anticancer treatment	Yes	1	0.2
	No	528	99.8

Table 2. Descriptive data on patinets' preferences for communication when receiving bad news ($N = 529$)

Item	Mean	SD	Strongly prefer %	Prefer %	No preference either way %	Do not prefer %	Strongly do not prefer %
Telling the treatment plan	4.53	0.58	56.5	40.8	2.1	0.4	0.2
Assuming responsibility for your care until the end	4.51	0.59	55.6	41.0	2.6	0.8	0.0
Answering your questions	4.49	0.52	49.5	49.7	0.8	0.0	0.0
Telling about the latest treatment	4.49	0.63	54.4	41.4	3.0	0.8	0.4
Breaking bad news in a way that is easy to understand	4.43	0.54	45.6	52.4	2.1	0.0	0.0
Telling about all treatment options available to you	4.42	0.69	51.0	42.2	4.7	1.9	0.2
Explaining the status of your illness	4.40	0.56	42.9	54.4	2.1	0.6	0.0
Breaking bad news honestly	4.35	0.58	38.9	57.7	2.6	0.6	0.2
Telling what you can hope for	4.35	0.64	43.3	49.1	7.0	0.4	0.2
Explaining until you are satisfied	4.34	0.63	41.4	52.2	5.3	1.1	0.0
Telling the recommended treatment	4.33	0.61	39.1	56.0	3.8	1.1	0.0
Explaining the risks and side effects of treatment	4.33	0.75	44.8	48.4	2.5	4.0	0.4
Explaining the progression of disease	4.31	0.61	37.4	58.0	2.8	1.7	0.0
Using actual images and test data	4.30	0.70	41.0	51.0	5.1	2.6	0.2
Communicating clearly the main points of bad news	4.28	0.62	34.8	60.9	2.5	1.5	0.4
Telling the prospects of cancer cure	4.28	0.65	37.1	55.0	6.8	0.9	0.2
Explaining the symptoms	4.27	0.59	32.7	62.8	3.2	1.1	0.2
Checking to see that you understand	4.24	0.74	36.3	55.6	4.9	1.9	1.3
Taking sufficient time	4.23	0.74	38.4	48.6	10.8	2.1	0.2
Breaking bad news in detail	4.22	0.79	39.1	49.0	7.0	4.5	0.4
Breaking bad news in precise terms	4.17	0.72	30.2	60.9	7	4.5	0.4
Telling in a way with hope	4.17	0.74	33.1	54.4	10.2	1.3	0.9
Talking gently.	4.16	0.76	33.8	52.0	11.3	2.1	0.8
Being a trusting physician	4.14	0.77	33.3	50.7	13.2	2.3	0.6
Breaking bad news in a sympathetic manner	4.11	0.76	31.2	52.7	12.7	3.0	0.4
Discussing your everyday life and work in the future	4.11	0.71	28.2	56.7	12.7	2.5	0.0
Giving papers that physician referred to	4.10	0.79	30.6	54.1	10.6	4.0	0.8
Showing the same concern for your family as for you	4.10	0.73	29.1	55.0	13.2	2.3	0.4
Breaking bad news in a courteous manner	4.09	0.75	29.3	53.7	13.6	3.4	0.0
Breaking bad news in a private setting	4.09	0.78	31.0	50.1	16.4	1.5	0.9
Telling with concern for your feelings	4.04	0.89	31.0	50.9	11.2	5.1	1.9
Breaking bad news in a setting with family	4.02	0.82	28.9	49.1	17.4	4.0	0.6
Telling all the bad news	3.99	0.85	27.4	51.8	13.6	6.6	0.6
Writing on paper to explain	3.98	0.88	27.6	51.8	13.4	5.7	1.5
Saying, 'Let's fight this together'	3.96	0.78	24.2	51.2	21.6	2.5	0.6
Speaking words of encouragement	3.96	0.82	25.3	50.7	19.5	3.6	0.9
Providing information on services and support	3.96	0.73	21.4	56.9	19.1	2.1	0.6
Looking at your eyes and face	3.94	0.84	23.0	55.4	15.7	4.1	1.7
Explaining a second opinion	3.93	0.85	26.5	45.7	23.3	3.8	0.8
Checking questions	3.91	0.83	22.1	54.3	17.4	5.3	0.9
Accepting your expressing emotions	3.89	0.77	20.2	53.1	21.9	4.7	0.0
Saying, 'You're OK'	3.86	0.86	22.7	47.3	23.8	5.5	0.8
Saying words that soothe your feelings	3.79	0.80	16.3	53.1	25.5	4.0	1.1
Saying words to prepare mentally	3.78	0.79	15.5	53.5	25.5	4.7	0.8
Giving specialized medical information	3.74	0.85	16.1	50.1	27.2	4.9	1.7
Physician deciding on the method of treatment	3.68	0.97	16.8	52.4	13.6	16.3	0.9
Answering your questions about alternative medicine	3.66	0.94	15.7	49.0	24.4	7.9	3.0
Ensuring that the telephone does not ring	3.62	0.92	16.8	39.5	35.5	5.5	2.6
Telling frequent questions	3.44	0.92	10.6	39.5	35.7	11.7	2.5
Asking how much you know about your illness before breaking bad news	3.44	0.84	7.4	43.5	36.3	11.3	1.5
Breaking bad news using euphemisms	3.42	0.98	11.3	39.5	32.3	13.0	3.8
Telling about your life expectancy	**3.28**	**1.18**	**14.7**	**35.7**	**19.7**	**22.7**	**7.2**
Not using the word 'cancer' repeatedly	3.23	0.86	7.4	26.1	51.6	12.1	2.8
Telling how to obtain information (e.g. books or the Internet)	3.22	0.94	8.1	28.9	44.0	14.6	4.3
Breaking bad news in a matter-of-fact manner	**2.90**	**1.09**	**5.3**	**29.7**	**23.3**	**33.1**	**8.7**
Breaking bad news step-by-step	**2.84**	**1.12**	**7.2**	**24.6**	**21.9**	**37.2**	**9.1**
Other caregivers attending (e.g. other physicians, or nurses)	2.79	0.90	2.8	14.7	50.1	23.6	8.7
Talking in a decisive tone of voice	**2.65**	**0.97**	**3.2**	**17.4**	**28.9**	**42.0**	**8.5**
Breaking bad news before it is definite	**2.60**	**1.06**	**2.8**	**24.0**	**14.7**	**46.9**	**11.5**
Breaking bad news only to you	2.33	0.97	2.3	10.8	23.4	45.2	18.3