Table 2. (*continued*)

Item	Mean	SD	Strongly prefer %	Prefer %	No preference either way %	Do not prefer %	Strongly do not prefer %
Touching your hand or shoulder	2.31	0.85	0.8	5.9	34.6	41.2	17.6
Talking at physician's pace	2.20	1.02	1.1	13.2	17.2	41.8	26.6
A physician at the first meeting breaking bad news	2.18	0.97	1.3	8.5	24.0	39.5	26.7
Breaking bad news to your family first	2.15	0.91	1.5	6.0	22.7	45.7	24.0
Using technical words	2.13	0.81	1.7	9.8	15.4	45.4	27.5
Telling only bad news	2.01	0.91	0.8	8.3	12.5	48.2	30.1
Talking in a business-like manner	1.99	0.80	0.2	5.3	14.4	53.3	26.8
Breaking bad news by telephone	1.68	0.73	0.4	2.3	6.6	46.3	44.4
Dealing with your questions in an irritated manner	1.43	0.55	0.0	0.2	2.1	38.0	59.7
Breaking bad news in a vague manner	1.37	0.59	0.4	0.8	0.9	31.8	66.2

Bold: The items for which more than 20% of respondents chose both prefer or strongly prefer and do not prefer or do not.

Table 3. Variables associated with communication styles with interindividual variations ($N = 526$)

Independent variables	Beta	P	R	R^2	Adjusted R^2
Telling about your life expectancy.				0.034	0.028
Marital status (No/yes)[a]	0.132	0.003	0.131		
Helplessness/hopelessness	−0.097	0.027	−0.096		
Education (Year)	0.089	0.047	0.087		
Breaking bad news in a matter-of-fact manner				0.112	0.104
Age (Year)	0.163	<0.001	0.153		
Education (Year)	0.161	<0.001	0.158		
Fatalism	0.144	0.003	0.129		
Anxious preoccupation	−0.130	0.004	−0.125		
Recurrence or metastasis (No/yes)[a]	0.086	0.048	0.087		
Breaking bad news step-by-step				0.112	0.103
Fighting spirit	0.153	<0.001	0.153		
Education (Year)	−0.150	<0.001	−0.153		
Employment status (No/yes)[a]	−0.122	<0.001	−0.125		
Avoidance	0.121	0.006	0.121		
The number of received bad news (0–4)	0.097	0.020	0.102		
Breaking bad news before it is definite				0.030	0.024
Avoidance	0.119	0.007	0.118		
Education (Year)	0.098	0.026	0.097		
Breast cancer (No/yes)[a]	−0.086	0.048	−0.086		
Talking in a decisive tone of voice				0.050	0.044
Sex[b]	−0.169	<0.001	−0.168		
Fatalism	0.099	0.027	0.097		
Education (Year)	−0.091	0.042	−0.089		

[a] Coded as 0 = no, 1 = yes.
[b] Coded as 0 = male, 1 = female.

Communication styles preferred by most patients and communication style preferences with interindividual variations

Descriptive data of each item are shown in Table 2. The communication styles preferred by most patients were as follows: physicians should discuss their treatment with them and establish a rapport with them. On the other hand, some communication styles were not preferred by most patients. For example, physicians deal with patients' questions in an irritated manner and break bad news in a vague manner. Furthermore, the communication style preferences with interindividual variations were as follows: the desire for information regarding the patient's life expectancy, the desire to receive bad news in a matter-of-fact manner, the desire to receive bad news gradually, the desire to receive bad news in a decisive tone of voice, and the desire to receive bad news even before diagnosis is definite.

Variables associated with communication style preferences with interindividual variations

Table 3 lists the multiple regression models for each item which exhibited high interindividual variations (indicated in bold in Table 2). Three participants were excluded from this statistical analysis because of missing data. Married patients,

patients with less helplessness/hopelessness, and patients with more formal education preferred to talk about their life expectancy with their physicians. Older patients, patients with more formal education, patients with more fatalism and less anxious preoccupation, and patients with recurrence or metastasis preferred that their physicians break the bad news in a matter-of-fact manner. Patients with more fighting spirit, less formal education, employed patients, patients with more avoidance, and patients who received a more large number of bad news preferred that their physicians break the bad news in a step-by-step manner. Patients with more avoidance, patients with more formal education, and patients with breast cancer preferred that their physicians break the bad news before a definite diagnosis had been made. Female patients, patients with more fatalism, and patients with less formal education preferred that their physicians talk in a decisive tone of voice.

Components of the patients' preferences regarding the communication style of the physicians disclosing bad news about cancer

The results of the exploratory factor analysis yielded four components (Table 4). The correlation coefficients between each factor were weak to moderate ($r = -0.20-0.50$). Factor 1: Method of disclosure of bad news (21 items, variance explained = 9.81, alpha coefficient = 0.93). This factor pertained to how physicians delivered bad news to patients during consultations. Factor 2: Provision of emotional support (17 items, variance explained = 7.77, alpha coefficient = 0.88). This factor covered the supportive aspects of the communication and included offering comfort and support to the patient. Factor 3: Provision of additional information (15 items, variance explained = 5.17, alpha coefficient = 0.82). This factor dealt with the additional information delivered by physicians during consultations while breaking bad news. Factor 4: Setting (17 items, variance explained = 10.23, alpha coefficient = 0.77). This factor focused on the fundamental communication skills of the physicians while delivering bad news.

Discussion

The communication styles preferred by the majority of the patients might be recommended to physicians delivering bad news to patients; physicians should deliver both positive (e.g. treatment plan and what patient can hope for) and negative (e.g. risk and side effect of treatment) information pertaining to the disease and its treatment and should also adopt a supportive attitude. Continuing physician responsibility for patient care and

future treatment plans were the most preferred attitudes and vagueness was the least preferred attitudes from the patients' perspectives. These findings suggest that engagement between the patients and their physicians is important when bad news is being broken.

Not all but many of the items pertaining to the communication styles preferred by most patients were consistent with those published in previous general guidelines and recommendations, for example, discussion of the possible treatment options with the patient, provision of warning signals, and delivery of the diagnosis to the patient honestly and in simple language, but not bluntly [20,7]. However, some of the items preferred by most patients or with high interindividual variations were not consistent with previously published guidelines and recommendations. For example, only 6.7% of patients wanted their physician to touch their hands or shoulders when delivering bad news, although Ptacek and Eberhardt [20] reported the benefit of touch.

Consistent with the findings in the previous report [21], patients responded with a high inter-individual variation in preferences for discussing life expectancy. Furthermore, about half of the patients in the present study did not want physicians to deliver bad news step-by-step, a recommended communication style [5]. About one quarter of the patients in the present study preferred communication styles in which physicians delivered the bad news even before the content of the news was definite, a communication style that was not recommended in the previous report [6]. These results suggest the importance of communicating with patients on an individual basis.

Furthermore, while patients preferred to be clearly told of their diagnosis, half of them preferred that physicians use euphemisms and 33.5% of them preferred that physicians do not repeatedly use the word 'cancer'. As we checked on the accuracy of patients' understanding of each item in the pilot survey, we think there is little possibility of misunderstanding the item's meaning. These results do not support the guidelines recommended for using the word 'cancer' and avoiding euphemisms in order not to cause a misunderstanding [7,20]. Japanese physicians use more euphemisms when delivering bad news to patients than Western physicians [13,22], and the word, 'cancer' might have a psychologically invasive impact on patients with cancer in Japan. Therefore, the use of euphemisms may give patients the impression that their physician is supporting them emotionally; these items were included in the emotional support factor.

Interestingly, 84% of the patients preferred to have their physicians show the same concern for the feelings of their family as for themselves. This

Table 4. Components of the patients' preferences for communication when receiving bad news: a factor analysis ($N = 529$)

Factor1: Method of disclosure of bad news	Factor loading
Breaking bad news honestly	0.757
Breaking bad news in a way that is easy to understand	0.719
Explaining the progression of disease	0.704
Explaining the status of your illness	0.670
Telling all the bad news	0.666
Breaking bad news in precise terms	0.660
Explaining the symptoms	0.644
Communicating clearly the main points of bad news	0.612
Using actual images and test data	0.593
Telling the recommended treatment	0.584
Explaining until you are satisfied	0.563
Breaking bad news in detail	0.556
Answering your questions	0.547
Breaking bad news in a courteous manner	0.542
Giving papers that physician referred to	0.524
Being a trusting physician	0.454
Assuming responsibility for your care until the end	0.422
Writing on paper to explain	0.405
Telling the prospects of cancer cure	0.404
Looking at your eyes and face	0.380
Telling about your life expectancy	0.363
Factor 2: Provision of emotional support	
Saying words that soothe your feelings	0.675
Saying, 'You're OK'	0.673
Saying, 'Let's fight this together'	0.667
Telling in a way with hope	0.662
Talking gently	0.609
Speaking words of encouragement	0.599
Telling what you can hope for	0.560
Saying words to prepare mentally	0.542
Breaking bad news in using euphemisms	0.525
Breaking bad news in a sympathetic manner	0.473
Showing the same concern for your family as for you	0.455
Breaking bad news step-by-step	0.421
Telling with concern for your feelings	0.394
Accepting your expressing emotions	0.380
Checking questions	0.309
Breaking bad news in a setting with family	0.294
Not using the word 'cancer' repeatedly	0.263
Factor 3: Provision of additional information	
Telling the treatment plan	0.543
Telling about all treatment options available to you	0.532
Telling about the latest treatment	0.513
Explaining the risks and side effects of treatment	0.490
Explaining a second opinion	0.481
Giving specialized medical information	0.478
Taking sufficient time	0.472
Telling frequent questions	0.447
Telling how to obtain information (e.g., books or the Internet)	0.434
Checking to see that you understand	0.434
Talking about alternative medicine	0.431
Providing information on services and support	0.386
Breaking bad news in a private setting	0.385
Discussing your everyday life and work in the future	0.349
Asking how much you know about your illness before breaking bad news	0.297
Factor 4: Setting	
Breaking bad news by telephone.	0.639
Telling only bad news	0.573

Table 4. (continued)

Talking at physician's pace	0.549
Dealing with your questions in an irritated manner	0.545
Breaking bad news in a vague manner	0.524
A physician at the first meeting breaking bad news	0.488
Talking in a business-like manner	0.475
Using technical words	0.447
Breaking bad news in a matter-of-fact manner	0.420
Talking in a decisive tone of voice	0.416
Touching your hand or shoulder	0.391
Breaking bad news only to you	0.388
Breaking bad news your family first	0.361
Physician deciding on the method of treatment	0.322
Breaking bad news before it is definite	0.320
Providing information on services and support	0.301
Ensuring that the telephone does not ring	−0.232

finding might be related to the distress experienced by the families of cancer patients after diagnosis, treatment, or the appearance of adverse effects [23]. Another explanation for this finding might be related to Asian culture. In Japan, families and physicians have been accorded a larger role in clinical decision making, and a patient's family is usually informed of an incurable cancer diagnosis before the patients has been notified [12]. That is to say, the family might experience distress before the patient does. Therefore, patients might desire for their physicians to show concern for the feelings of their family.

In the present study, 78% of the patients preferred to be with their family when the bad news was being broken and 14% of the patients preferred to receive bad news at their physicians' pace. Although some previous studies in Western countries have recommended that bad news should be delivered at the patients' pace to increase the patients' sense of control, physicians should recognize that many Japanese cancer patients prefer to play a collaborative role in the decision making process, rather than assuming active and passive roles, and will respect the physician's opinion even if the physician's recommendation conflicts with their own wishes [14].

This study also showed that 85% of patients preferred not only to discuss the bad news but also to talk about the impact of their disease on their daily activities, the information of a second opinion (72.2%), and complementary and alternative medicine (64.7%), although previous studies have not adequately addressed whether other information should be given by physicians to patients during the consultation. Physicians might be encouraged to discuss such matters with their patients.

Previous studies [8,9,11] reported that age, sex, level of education, and medical condition are significantly associated with preferred communication styles. In the present study, marital status, employment status, psychological adjustment,

the number of bad news, and medical status were also associated with patients' preferences, while psychological distress and social support were not associated with them. However, all the independent variables in this study had small standardized partial regression coefficients in each regression model, and all the multiple regression models showed a low proportion of variance. Thus, communication preferences with interindividual variations are difficult to identify on the basis of the patients' medical and psychosocial data alone, so physicians should try to understand each patient's preferences and tailor their communication style to meet the needs of individual patients.

The exploratory factor analysis in the present study identified four separate, internally reliable factors related to the communication style of physicians disclosing bad news. These factors were fundamentally based on the results of our previous qualitative study [15]. Parker et al, [9] reported a 3-factor structure; what and how much information, emotional support, and setting. Our present study supported the report by Parker et al. Furthermore, the factor structure of the present study also independently identified the provision of additional information factor, and this factor was not identified in the report by Parker et al. This difference can probably be attributed to the fact that the design of the two studies differed; we collected the survey items in the present study based on a previous analysis of several interviews [15], while Parker et al. [9] collected their survey items based on the opinions of experts, including oncologists and psychooncologists, and a literature review.

The result of the factor analysis provide a framework for devising interventions to enhance physicians' communication skills, that is, physicians may be taught how to disclose bad news in a manner that corresponds to an individual patient's preferences. As far as we know, no communication skills training programs based on patients' preferences have been reported. In the future, it would be desirable to design intervention programs based on the frameworks thus identified. Furthermore, future study to model the relationship between each factor of the patients' preferences and psychosocial and medical characteristics, based on the results of this exploratory factor analysis, is needed.

Two limitations of the present study should be noted. First, we conducted the study at a single teaching cancer center. Thus, the results of this study might not be representative of other cancer centers. Nonetheless, because the consecutive sample included patients with a variety of cancers, stages of disease, and from several age groups, of both genders, with several different psychosocial characteristics, we believe that our results reflect the preferences of a broad range of patients. The

second limitation is that our study examined the preferences of patients at only one point in time, and not over time. Thus, we cannot speculate on the stability of the measurements used in this study. The informational needs of patients have been reported to change over the course of their treatment. [11] Because of the cross-sectional nature of this study, we did not attempt to formally address this question. However, significant differences were partially found between patients without and those with tumor recurrence or metastasis.

In conclusion, while the preferences of patients in Japan are mostly similar to those of patients in Western countries, some communication, for example, the desire for the physician to show consideration for the patient's family, seems to be particularly important to patients in Japan. Although communication style preferences with interindividual variations are difficult to identify based on medical and psychosocial data alone, understanding an individual's communication preferences may be useful for promoting patient–physician communication.

Acknowledgements

References

1. Buckman R. Breaking bad news: why is it still so difficult? Br Med J 1984;288:1597–1599.
2. Takayama T, Yamazaki Y, Katsumata N. Relationship between outpatients' perceptions of physicians' communication styles and patients' anxiety levels in a Japanese oncology setting. Soc Sci Med 2001;53:1335–1350.
3. Schofield PE, Butow PN, Thompson JF et al. Psychological responses of patients receiving a diagnosis of cancer. Ann Oncol 2003;14:48–56.
4. Morita T, Akechi T, Ikenaga Y et al. Communication about the ending of anticancer treatment and transition to palliative care. Ann Oncol 2004;15:1551–1557.
5. Baile WF, Buckman R, Lenzi R, Glober G, Beale EA, Kudelka AP. SPIKES-A six-step protocol for delivering bad news: application to the patient with cancer. Oncologist 2000;5:302–311.
6. Girgis A, Sanson-Fisher RW, Schofield MJ. Is there consensus between breast cancer patients and providers on guidelines for breaking bad news? Behav Med 1999;25:69–77.
7. Cegala DJ, Lenzmeier Broz S. Physician communication skills training: a review of theoretical backgrounds, objectives and skills. Med Educ 2002;36:1004–1016.
8. Butow PN, Kazemi JN, Beeney LJ, Griffin AM, Dunn SM, Tattersall MH. When the diagnosis is cancer: patient communication experiences and preferences. Cancer 1996;77:2630–2637.
9. Parker PA, Baile WF, de Moor C, Lenzi R, Kudelka AP, Cohen L. Breaking bad news about cancer: patients' preferences for communication. J Clin Oncol 2001;19: 2049–2056.

10. Shilling V, Jenkins V, Fallowfield L. Factors affecting patient and clinician satisfaction with the clinical consultation: can communication skills training for clinicians improve satisfaction? *Psycho-Oncology* 2003; **12**:599–611.

11. Butow PN, Maclean M, Dunn SM, Tattersall MH, Boyer MJ. The dynamics of change: cancer patients' preferences for information, involvement and support. *Ann Oncol* 1997;**8**:857–863.

12. Ruhnke GW, Wilson SR, Akamatsu T *et al.* Ethical decision making and patient autonomy: a comparison of physicians and patients in Japan and the United States. *Chest* 2000;**118**:1172–1182.

13. Baile WF, Lenzi R, Parker PA, Buckman R, Cohen L. Oncologists' attitudes toward and practices in giving bad news: an exploratory study. *J Clin Oncol* 2002;**20**: 2189–2196.

14. Sekimoto M, Asai A, Ohnishi M *et al.* Patients' preferences for involvement in treatment decision making in Japan. *BMC Fam Pract* 2004;**5**:1.

15. Fujimori M, Akechi T, Akizuki N *et al.* Good communication when receiving bad news about Cancer in Japan. *Psycho-Oncology* 2005;**14**:1043–1051.

16. Watson M, Greer S, Young J, Inayat Q, Burgess C, Robertson B. Development of a questionnaire measure of adjustment to cancer: the MAC scale. *Psychol Med* 1988;**18**:203–209.

17. Akechi T, Fukue-Saeki M, Kugaya A *et al.* Psychometric properties of the Japanese version of the Mental Adjustment to Cancer (MAC) scale. *Psycho-Oncology* 2000;**9**:395–401.

18. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. *Acta Psychiatr Scand* 1983;**67**: 361–370.

19. Kugaya A, Akechi T, Okuyama T, Okamura H, Uchitomi Y. Screening for psychological distress in Japanese cancer patients. *Jpn J Clin Oncol* 1998;**28**: 333–338.

20. Ptacek JT, Eberhardt TL. Breaking bad news. A review of the literature. *JAMA* 1996;**276**:496–502.

21. Hagerty RG, Butow PN, Ellis PA *et al.* Cancer patient preferences for communication of prognosis in the metastatic setting. *J Clin Oncol* 2004;**22**:1721–1730.

22. Holland JC, Geary N, Marchini A, Tross S. An international survey of physician attitudes and practice in regard to revealing the diagnosis of cancer. *Cancer Invest* 1987;**5**:151–154.

23. Resendes LA, McCorkle R. Spousal responses to prostate cancer: an integrative review. *Cancer Investigation* 2006;**24**:192–198.

Original Article

Meaninglessness in Terminally Ill Cancer Patients: A Validation Study and Nurse Education Intervention Trial

Tatsuya Morita, MD, Hisayuki Murata, MA, Kei Hirai, PhD, Keiko Tamura, RN, OCN, Jun Kataoka, RN, DNSc, Hideki Ohnishi, MD, PhD, Nobuya Akizuki, MD, PhD, Yukie Kurihara, CSW, Tatsuo Akechi, MD, PhD, and Yosuke Uchitomi, MD, PhD, on Behalf of the Japanese Spiritual Care Task Force[a]

Department of Palliative and Supportive Care, Palliative Care Team, and Seirei Hospice (T.M.), Seirei Mikatahara General Hospital, Shizuoka; School of Human Culture (H.M.), Kyoto Notre Dame University, Kyoto; Human Science (K.H.), Osaka University, Osaka; Hospice (K.T.), Yodogawa Christian Hospital, Osaka; Faculty of Nursing (J.K.), Hamamatsu University School of Medicine, Shizuoka; Department of Psychiatry (H.O.), Kanagawa Cancer Center, Yokohama; Psycho-Oncology Division, National Cancer Center Research Institute East (N.A., Y.U.), Chiba; Psychiatry Division (N.A., Y.U.), National Cancer Center Hospital East, Chiba; Department of Palliative Medicine (Y.K.), Shizuoka Cancer Center, Shizuoka; and Department of Psychiatry (T.A.), Nagoya City University Medical School, Nagoya, Japan

Abstract
Recent empirical studies revealed that fostering patients' perception of meaning in their life is an essential task for palliative care clinicians. However, few studies have reported the effects of training programs for nurses specifically aimed at improving skills to relieve the meaninglessness of terminally ill cancer patients, and we have had no specific measurement instruments. The primary aims of this study were 1) to validate measurement tools to quantify nurses' self-reported practice and attitudes toward caring for terminally ill cancer patients feeling meaninglessness and 2) to explore the effects of the five-hour educational workshop focusing on meaninglessness on nurses' self-reported practice, attitudes toward caring for such patients, confidence, burnout, death anxiety, and meaning of life. A quasi-experimental pre-post questionnaire survey was performed on 147 nurses. The questionnaire was distributed before the intervention workshop and one and six months after. The workshop consisted of lecture, role-play, and the exercise of assessment and care planning based on two vignette verbatim records. First, using the first questionnaire sample and an additional sample of 20 nurses for the test-retest examination, we validated a six-item Self-Reported Practice scale, and an eight-item Attitudes Toward Caring for Patients Feeling Meaninglessness scale with three subscales (Willingness to Help, Positive Appraisal, and Helplessness). The nurses also completed a scale to assess confidence in caring for terminally

ill patients with meaninglessness, the Maslach Burnout Inventory, the Death Attitude Inventory, the Frommelt Attitudes Toward Care of the Dying scale, the Self-Reported Practice Score in General Communication, and the three pain-related items from the Palliative Care Quiz for Nursing. For the Self-Reported Practice scale and the subscales of the Attitudes Toward Caring for Patients Feeling Meaninglessness scale, the Cronbach's alpha coefficients were 0.63—0.91, and the intra-class correlations were 0.89—0.94. The Self-Reported Practice scale significantly, but moderately, correlated with the Self-Reported Practice Score in General Communication (P = 0.41). The Willingness to Help and Helplessness subscales significantly but weakly correlated with the Frommelt scale (P = −0.27, 0.21). Both scales did not correlate or minimally correlated with the Palliative Care Quiz for Nursing (P < 0.20). The construct validity was confirmed using factor analysis. At the follow-up, of 147 nurses who participated in this workshop, 91 (62%) and 80 (54%) nurses responded. Self-reported practice and confidence significantly improved, whereas helplessness, emotional exhaustion, and death anxiety significantly decreased. The percentages of nurses who evaluated this program as "useful" or "very useful" were 79% (to understand the conceptual framework in caring for terminally ill patients with meaninglessness), 73% (to help in self-disclosing nurses' personal beliefs, values, and life goals), and 80% (to help in learning how to provide care for patients with meaninglessness). The Self-Reported Practice scale and the Attitudes Toward Caring for Patients Feeling Meaninglessness scale are reliable and valid tools to specifically quantify nurses' self-reported practice and attitudes toward caring for terminally ill cancer patients feeling meaninglessness of life. The five-hour workshop appeared to have a modest but significant beneficial effect on nurse-reported practice, attitudes, and confidence in providing care for terminally ill cancer patients feeling meaninglessness. Further educational intervention trials with control groups are promising. J Pain Symptom Manage 2007;34:160—170. © 2007 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Introduction

Recent empirical studies have revealed that fostering patients' perception of meaning in their lives is an essential task for palliative care clinicians.[1–4] In Japan, multiple surveys have identified that terminally ill cancer patients experience considerable levels of meaninglessness,[5,6] and our group recently proposed a conceptual framework for psycho-existential care for Japanese patients.[7] In that national project,[7] we used consensus-building methods with 26 panel members and 100 multidisciplinary peer reviewers. Through two days of face-to-face discussion, the group agreed to adopt a conceptual framework by combining the empirical model and a theoretical hypothesis. We defined psycho-existential suffering as pain caused by extinction of the being and the meaning of the self. We assumed that psycho-existential suffering is caused by the loss of

essential components that compose the meaning of human beings: loss of relationships with others, loss of autonomy, and loss of future. In this model, sense of meaning is interpreted as a main outcome, as consistent with some psychometric instruments measuring sense of meaning as a core concept of the state of spiritual well-being.[8]

In fostering a sense of meaning for terminally ill cancer patients, nurses play a major role, but, except for general training in communication skills,[9–12] few studies have reported the effects of training programs for nurses specifically aimed at improving skills to relieve the meaninglessness of terminally ill cancer patients,[13–16] and we have had no specific measurement instruments. The primary aims of this study were 1) to validate measurement tools to specifically quantify nurses' self-reported practice and attitudes toward caring for terminally ill cancer patients feeling

meaninglessness, and 2) to explore the effects of a five-hour educational workshop focusing on meaninglessness on nurses' self-reported practice, attitudes toward caring for such patients, confidence, burnout, death anxiety, and meaning of life.

Subjects and Methods

This study was designed as a quasi-experimental, anonymous, pre-post questionnaire survey. We used the first questionnaire sample for the scale validation. Nurses across the country voluntarily applied to the workshop via announcements in specialty journals and the Internet. No inclusion criteria for participation were required. After consent was obtained, the participants were asked to complete the questionnaire before, one month, and six months after the workshop. The initial questionnaire was collected at the place of the workshop. No reward or reminder was used.

Validation Study

Item Development

On the basis of literature reviews and discussion among the authors,[17–24] we had determined to develop instruments to specifically quantify nurses' self-reported practice and attitudes toward caring for terminally ill cancer patients, as potentially useful outcome measures in sequential intervention trials. A recent study suggested that measuring nurses' self-reported practice can be a sensitive outcome of educational interventions in palliative care settings.[21] Although nurses' attitudes about care in such difficult situations are associated with burnout and also are regarded as one of the endpoints of educational interventions,[18–20,22–24] there have been no specific measurement instruments to evaluate nurses' attitudes in caring for terminally ill patients with meaninglessness, in contrast to general end-of-life care.

Item generation was based on preliminary in-depth qualitative interviews with five palliative care nurses, a literature review, and discussion among the authors.[17–24] To achieve face validity, a multidisciplinary expert panel (two nurses, two psychiatrists, a psychologist, a social worker, and a palliative care physician) rated the appropriateness of each item using the

Delphi Method, and the items that achieved 8 or more on a 1–9 scale were selected.

Self-Reported Practice Scale. We conceptualized self-reported practice as the level of self-reported adherence to recommended clinical practice in helping terminally ill patients to find meaning in their lives. Self-reported practice was thus evaluated by the level of adherence to each recommended practice statement on a Likert-type scale from 1: "not do at all" to 5: "always"—"I try to know what makes the patient's life meaningful," "I try to know what strengthens or weakens the meaning of life for the patient," "I try to know what supports the patient's life," "I try to know what meaning the disease has for the patient," " I try to understand the patient's wishes," and "I try to know what is important to the patient." We defined the score on the Self-Reported Practice scale as the mean of the total score of the responses, and thus practice subscores ranged from 1 to 5, with a higher score indicating a higher level of performance of recommended practices.

Attitudes Toward Caring for Patients Feeling Meaninglessness scale: Willingness to Help, Positive Appraisal, and Helplessness. We conceptualized attitudes toward caring for patients feeling meaninglessness as having three dimensions: Willingness to Help (the degree of willingness to make effort to help patients with meaninglessness), Positive Appraisal (nurses' positive attribution of the experience of encountering patients feeling meaninglessness), and Helplessness (nurses' perception of helplessness when facing patients feeling meaninglessness).

These were evaluated by the levels of agreement with several statements on a Likert-type scale from 1: "never" to 7: "very much." The instruction specifically clarified the situation when the nurse faced a terminally ill cancer patient suffering from meaninglessness of life. Item questions were the following: "I feel willing to do something to relieve the patient's suffering" (Item 1), "I think how I can support the patient effectively" (Item 2), and "I wish to relieve the patient's suffering as much as possible" (Item 3), (Willingness to Help); "I feel grateful that the patient has told it to me" (Item 4), and "I feel that the patient trusts me" (Item 5), (Positive Appraisal); and "I feel

helplessness" (Item 6), "I feel like escaping" (Item 7), and "I feel willing to be involved" (reversed item, item 8), (Helplessness). Because we theoretically hypothesized no single higher structure exists for the three dimensions, each subscale score was defined as the mean of the responses, and we did not calculate a total score. Higher scores indicated higher levels of nurses' willingness to help, positive appraisal of their experience, and perception of helplessness.

Reliability and Validation Testing

Reliability. To determine the internal consistency, the Cronbach's alpha coefficients were calculated. The test-retest reliability was explored in a convenience sample of 20 nurses by calculating intra-class correlation coefficients with two-week interval administrations.

Construct validity. The construct validity of the Self-Reported Practice scale was examined using an exploratory factor analysis, because a single factor structure had been hypothesized. The construct validity of the Attitudes Toward Caring for Patients Feeling Meaninglessness scale was tested using a confirmatory factor analysis. We had decided the cutoff points of 0.90 on the goodness-of-fit index (GFI), adjusted GFI, and the comparative fit index (CFI) as acceptable construct validity.

Convergent and discriminate validity. To examine convergent and discriminate validity, we calculated the Spearman's correlations of these scales with the Frommelt Attitudes Toward Care of the Dying scale,[17–20] the Self-Reported Practice Score in General Communication,[21] and the Palliative Care Quiz for Nursing.[25,26]

Frommelt Attitudes Toward Care of the Dying scale.[17–20] The Frommelt Attitudes Toward Care of the Dying scale (short version) is a six-item brief inventory to measure the degree of nurses' willingness to participate in general end-of-life care.[17–20] Internal consistency, test-retest reliability, and construct validity of the Japanese version have been established.[17] Scores range from 1 to 5, and a higher score indicates higher levels of nurses' willingness to participate in general end-of-life care.

The Self-Reported Practice Score in General Communication.[21] The Self-Reported Practice

Score in General Communication measures the degree of self-reported adherence to recommended general communication practice in caring for terminally ill cancer patients.[21] Item questions included "Talk with patient and family in a quiet and private place," "Make efforts to provide compassionate response to patients," and "Use open-ended questions." Good internal consistency and sensitivity after educational intervention have been reported.[21] The scores range from 1 to 5, with a higher score indicating a higher level of perceived performance of recommended practices.

The Palliative Care Quiz for Nursing.[25,26] The Palliative Care Quiz for Nursing measures the degree of correct knowledge about multiple fields in palliative care. Following an earlier study,[21] we selected three items about opioids to examine the degree of nurses' knowledge about medical aspects of palliative care: "morphine often induces addiction," "patients receiving morphine often require laxatives," and "pain threshold is lowered by anxiety or fatigue." We defined a Knowledge score as the total number of correct answers ("unsure" responses were regarded as incorrect answers); thus, the Knowledge score ranged from 0 to 3, and a higher score indicated a higher level of knowledge. We had hypothesized that low correlations with the nurses' knowledge about medical aspects of palliative care could support the discriminant validity of the new instruments.

Pre-Post Intervention Study

Interventions

The workshop was principally based on Murata's conceptual framework and specifically focused on care for terminally ill cancer patients with meaninglessness.[7] The second author (HM) provided all lectures. This workshop consisted of introduction and pre-test (30 minutes), a general lecture about Murata's conceptual framework using a visual presentation (60 minutes), role-play and discussion about communication skills when caring for patients feeling meaninglessness (60 minutes), real assessment and care planning based on one verbatim case record and feedback (90 minutes), and assessment and care planning in

another case (30 minutes). In addition, the participants were requested to send the assessment and care planning about the latter case to Prof. Murata by mail, and he gave written feedback individually within one month.

The assessment and care planning exercise is a main part of this workshop. In this session, each participant was provided with a brief verbatim record of one patient and was requested to analyze these statements following Murata's conceptual framework: to identify which part of the patient's statement is an expression of meaninglessness and define the origin of the patient's meaninglessness (loss of future, loss of relationships, or loss of autonomy). Then, the respondents were requested to establish a care plan to improve the patient's sense of meaninglessness in daily nursing practice by strengthening the factors supporting meaning and alleviating the factors causing meaninglessness. A structured assessment sheet is used for this process. This sheet was designed to make a comprehensive assessment to determine what represents meaninglessness to the patient (i.e., loss of future, loss of relationships, or loss of autonomy) from the patient's own statements.

Outcome Measures for Intervention Trials

In addition to newly validated measures, the nurses' Self-Reported Practice and the Attitudes Toward Caring for Patients Feeling Meaninglessness, we assessed confidence in caring for terminally ill patients with meaninglessness, burnout, death anxiety, and meaning of life as outcome measures. Time difference was tested using the Friedman test.

Confidence. Confidence in caring for terminally ill cancer patients with meaninglessness was evaluated on a single Likert-type scale from 1: "not confident at all" to 7: "very confident" for the question "With what degree of confidence can you communicate with terminally ill cancer patients saying 'I can see no meaning in life'"?

Burnout. Professional burnout was measured using the Maslach Burnout Inventory.[27,28] The Maslach Burnout Inventory measures three components of burnout syndrome: emotional exhaustion, depersonalization, and lack of personal accomplishment.[27] The

psychometric properties of the Japanese version have been confirmed.[28]

In addition, we used the same numeric rating scales (0, not at all to 10, very much) for job satisfaction, job stress, and compassion for dying persons for comparison with the previous study.[14]

Death anxiety and meaning of life. Similar to an earlier study,[14] we measured nurses' own death anxiety and meaning of life using the Death Attitude Inventory.[29] The Death Attitude Inventory is a self-reported questionnaire to measure the levels of death anxiety and meaning of life, in which subjects are requested to identify the degree of agreement with short statements on a 5-point Likert-type scale from "not agree (1)" to "agree (5)." The reliability of these subscales was established by high internal consistency and the stability of test-retest examination. Construct validity was ascertained by confirmatory factor analysis, and criterion validity was established by significant correlation with other psychometric measures including Temper's Death Anxiety Scale[30] and the General Health Questionnaire-28. Higher scores on death anxiety and meaning of life indicate higher levels of death anxiety and perception that life is meaningful for the respondent. Each scale ranges from 1 to 5.

Overall Evaluation

Finally, following the previous study,[15] we asked the respondents to rate their overall evaluation about the usefulness of this program in terms of helping 1) to understand the conceptual framework in caring for terminally ill patients with meaninglessness; 2) to self-disclose nurses' personal beliefs, values, and life goals; and 3) to learn how to provide care for patients feeling meaninglessness in clinical practice. The choices were "not useful," "slightly not useful," "slightly useful," "useful," and "very useful."

Results

Of 173 nurses who participated in this program, we obtained the consent from a total of 147 nurses (85%). Mean age was 39 ± 9.7 years old, and 146 were female. Working institutions were general hospital for 87 nurses,

specialized palliative care centers for 22, cancer centers or academic hospitals for 19, and outpatient clinic or home care setting for 10. The nurses had a mean clinical experience of 15 ± 9.1 years, and a median number of cancer deaths of 10 per year. At the postal follow-up, the response rate was 62% ($n = 91$) and 54% ($n = 80$) in the second and last surveys, respectively.

Validation Study

Feasibility and Demographic Values

Missing values were less than 5% in both scales. Mean scores of the Self-Reported Practice scale, Willingness to Help, Positive Appraisal, and Helplessness were 3.6 ± 0.73, 6.1 ± 0.83, 5.3 ± 0.92, and 3.7 ± 1.3, respectively (Table 1).

Reliability and Validation Testing

Self-Reported Practice Scale. Cronbach's alpha coefficient was 0.91, and the intra-class correlation in the test-retest examination was 0.94. The Self-Reported Practice scale significantly correlated with the Self-Reported Practice Score in General Communication, but the correlation was moderate ($P = 0.41$, Table 1); the practice score did not significantly correlate with the Knowledge score (Table 1). The

Table 1
Correlation Coefficients Among Measurement Scales

	Frommelt Scale[a]	Self-Reported Practice Score in General Communication	Knowledge Score[b]
Self-Reported Practice score	0.13	0.41[c]	0.16
Attitudes Toward Caring for Patients Feeling Meaninglessness			
Willingness to Help	0.21[d]	0.26[c]	0.16
Positive Appraisal	0.14	0.28[c]	0.18[d]
Helplessness	−0.27[c]	−0.20[d]	−0.098

[a]Frommelt Attitudes Toward Care of the Dying scale (short version).
[b]Three items from the Palliative Care Quiz for Nursing.
[c]$P < 0.01$.
[d]$P < 0.05$.

exploratory factor analysis revealed a single structure.

Attitudes Toward Caring for Patients Feeling Meaninglessness Scale. Cronbach's alpha coefficients were 0.81 (Willingness to Help), 0.67 (Positive Appraisal), and 0.63 (Helplessness). The intra-class correlations were 0.94 (Willingness to Help), 0.91 (Positive Appraisal), and 0.89 (Helplessness).

Willingness to Help and Helplessness subscales significantly correlated with the Frommelt scale, but the correlation was weak ($P < 0.30$, Table 1). These subscales minimally correlated with the Knowledge score ($P < 0.20$, Table 1). The confirmatory factor analysis supported the underlying structure hypothesized: Chi-square (18) = 51.8, $P = 0.00$; GFI = 0.95; adjusted GFI = 0.89; CFI = 0.90; the root mean square error of approximation = 0.10 (Fig. 1).

Pre-Post Intervention Study (Table 2)

The Self-Reported Practice and confidence item significantly improved after the intervention, whereas Helplessness significantly decreased. These changes were maintained at the six-month follow-up (all $P < 0.01$).

Emotional exhaustion and death anxiety significantly decreased, but the statistical significance was moderate ($P = 0.048$, 0.021, respectively). In addition, there was statistically marginal improvement in Personal accomplishment. There were no significant changes in the Willingness to Help, Positive Appraisal, depersonalization, and meaning of life. In addition, the Frommelt scale, as well as three single measurements of job stress, job satisfaction, and compassion for patients, demonstrated no statistically significant changes.

Overall Evaluation

The percentages of nurses who evaluated this program as "useful" or "very useful" were 79% ($n = 72$, to understand the conceptual framework in caring for terminally ill patients with meaninglessness), 73% ($n = 67$, to help in self-disclosing nurses' personal beliefs, values, and life goals), and 80% ($n = 73$, to help in learning how to provide care for patients with meaninglessness). At the six-month follow-up, these figures were 81% ($n = 65$), 71% ($n = 80$), and 74% ($n = 80$), respectively.
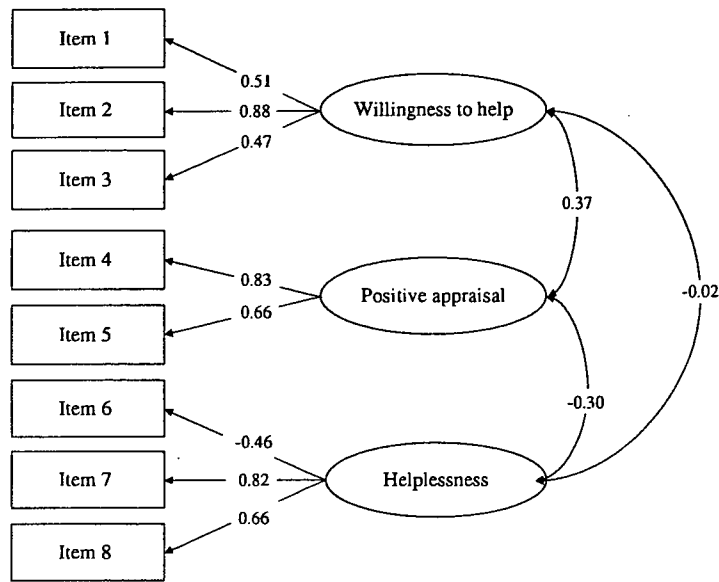
Fig. 1. Factor structure of attitudes toward caring for patients with meaninglessness.

Discussion

This study validated measurement tools to specifically quantify nurses' self-reported practice and attitudes toward caring for terminally ill cancer patients feeling meaninglessness and identified the potentially beneficial effects of a five-hour educational workshop focusing on meaninglessness and nurse-reported practice,

attitudes, and confidence in providing care for such patients.

The data provided psychometric evidence for these new instruments. That is, these scales have acceptable internal consistency, test-retest reliability, face validity, convergent and discriminate validity, and construct validity. The fact that the Self-Reported Practice scale

Table 2
Pre-Post Analyses

	Baseline	One Month After	Six Months After	P
Self-Reported Practice score (1—5)	3.6 ± 0.73	3.8 ± 0.71	3.9 ± 0.62	<0.001
Attitudes Toward Caring for Patients Feeling Meaninglessness				
Willingness to help (1—7)	6.1 ± 0.83	6.2 ± 0.72	6.2 ± 0.69	0.66
Positive appraisal (1—7)	5.3 ± 0.92	5.4 ± 0.98	5.4 ± 1.1	0.61
Helplessness (1—7)	3.7 ± 1.3	3.5 ± 1.3	3.3 ± 1.3	0.004
Confidence (1—7)	3.1 ± 1.3	3.6 ± 1.2	3.8 ± 1.1	<0.001
Burnout				
Maslach Burnout Inventory				
Emotional exhaustion	33 ± 11	31 ± 10	31 ± 10	0.048
Personal accomplishment	32 ± 10	34 ± 9.6	34 ± 9.3	0.076
Depersonalization	27 ± 8.1	28 ± 7.7	28 ± 7.3	0.44
Ad hoc measures for comparisons[14]				
Job stress (0—10)	7.5 ± 2.0	7.4 ± 1.8	7.3 ± 2.4	0.45
Job satisfaction (0—10)	6.3 ± 2.2	6.1 ± 2.1	6.3 ± 2.0	0.69
Compassion for patients (0—10)	7.2 ± 1.8	7.4 ± 1.8	7.5 ± 1.7	0.35
Death Attitude Inventory				
Death anxiety (1—7)	4.3 ± 1.7	4.1 ± 1.6	4.0 ± 1.5	0.021
Meaning of life (1—7)	4.3 ± 1.1	4.4 ± 1.2	4.3 ± 1.2	0.70
Frommelt scale (1—5)	3.9 ± 0.45	3.9 ± 0.48	3.9 ± 0.49	0.34

significantly but only moderately correlated with the Self-Reported Practice Score in General Communication indicates that this new tool measures the levels of adhesion to recommended practice specifically in caring for terminally ill cancer patients with meaninglessness, not general communication practice. Furthermore, the fact that the Attitudes Toward Caring for Patients Feeling Meaninglessness scale only weakly correlated, at best, with the Frommelt scale indicates that this new scale can specifically measure nurses' attitudes toward caring for terminally ill patients with meaninglessness, not general attitude toward end-of-life care. In addition, because both scales did not correlate or minimally correlated with medical knowledge about opioids, these scales have sufficient discriminate validity in measuring caring for patients with meaninglessness. A potential limitation of these scales is probable ceiling effects, especially with the Willingness to Help subscale, but this is reasonable, because the study participants voluntarily participated in this workshop, and if nonselected nurses are enrolled, we believe the ceiling effects would reduce.

The second important finding is the potentially beneficial effects of a five-hour workshop to improve nurses' skills in caring for terminally ill cancer patients feeling meaninglessness. Of note was the high evaluation of the overall usefulness of the workshop in learning how to provide care in clinical practice compared with a previous study (80% vs. 34%[15]). Also, inconsistent with the previous study,[14] this workshop demonstrated no, or small, influence on nurses' own death anxiety, meaning of life, and work-related stress, but appeared to influence more specifically practical aspects in caring for patients with meaninglessness, such as self-reported practice, confidence, and helplessness. These findings are reasonable, because this program was specifically designed to improve the clinical skills for each nurse, rather than focusing on their own work-related stress, death anxiety, or meaninglessness.

In addition, the fact that we observed significant changes after the intervention on the newly developed measurement tools (self-reported practice and helplessness), not on the Frommelt scale, indicates that they could have satisfactory sensitivity in future intervention trials.

This study has several limitations. First, the effects of the workshop may be difficult to interpret due to the lack of control groups. Second, as the response rate at the follow-up survey was relatively low, nonresponders might feel the workshop was less useful. This limitation should be overcome in the next intervention study, which will have a control group and use face-to-face or telephone surveys, not postal follow-up. Third, small to modest changes in outcome measures suggest that intervention is not so strong, and whether these changes are clinically meaningful is uncertain. Fourth, as this study did not evaluate patient outcomes, we cannot determine the effects of the workshop on them.

In conclusion, the Self-Reported Practice scale and the Attitudes Toward Caring for Patients Feeling Meaninglessness scale are reliable and valid tools to specifically quantify nurses' self-reported practice and attitudes toward caring for terminally ill cancer patients feeling meaninglessness of life. Also, the five-hour workshop appeared to have a modest but significant beneficial effect on nurse-perceived practice, attitudes, and confidence in providing care for patients feeling meaninglessness. Intervention trials with control groups using these newly validated tools are promising, after modifying the program to include some stress management for nurses, such as personal counseling or group counseling led by a psychologist.

References

1. Breitbart W, Gibson C, Poppito SR, et al. Psychotherapeutic interventions at the end of life: a focus on meaning and spirituality. Can J Psychiatry 2004; 49:366–372.

2. Chochinov HM. Dignity-conserving care. A new model for palliative care: helping the patient feel valued. JAMA 2002;287:2253–2260.

3. Borneman T, Brown-Saltzman K. Meaning in illness. In: Ferrell BR, Coyle N, eds. Textbook of palliative nursing. New York: Oxford University Press, 2001.

4. Kissane DW, Clarke DM, Street AF. Demoralization syndrome—a relevant psychiatric diagnosis for palliative care. J Palliat Care 2001;17:12–21.

5. Morita T, Sakaguchi Y, Hirai K, et al. Desire for death and requests to hasten death of Japanese terminally ill cancer patients receiving specialized

inpatients palliative care. J Pain Symptom Manage 2004;27:44–52.

6. 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;12:137–140.

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

8. Noguchi W, Ohno T, Morita S, et al. Reliability and validity of the Functional Assessment of Chronic Illness Therapy-Spiritual (FACIT-Sp) for Japanese patients with cancer. Support Care Cancer 2004;12:240–245.

9. Wilkinson S, Roberts A, Aldridge J. Nurse-patient communication in palliative care: an evaluation of a communication skills programme. Palliat Med 1998;12:13–22.

10. Dalvaux N, Razavi D, Marchal S, et al. Effects of a 105 hours psychological training program on attitudes, communication skills and occupational stress in oncology: a randomized study. Br J Cancer 2004; 90:106–114.

11. Bowles N, Mackintosh C, Torn A. Nurses' communication skills: an evaluation of the impact of solution-focused communication training. J Adv Nurs 2001;36:347–354.

12. Arranz P, Ulla SM, Ramos JL, del Rincón C, López-Fando T. Evaluation of a counseling training program for nursing staff. Patient Educ Couns 2005; 56:233–239.

13. Razavi D, Delvaux N, Marchal S, et al. The effects of a 24-h psychological training program on attitudes, communication skills and occupational stress in oncology: a randomized study. Eur J Cancer 1993;29A:1858–1863.

14. Wasner M, Longaker C, Fegg MJ, Borasio GD. Effects of spiritual care training for palliative care professionals. Palliat Med 2005;19:99–104.

15. Shih FJ, Gau ML, Mao HC, Chen CH. Taiwanese nurses' appraisal of a lecture on spiritual care for patients in critical care units. Intensive Crit Care Nurs 1999;15:83–94.

16. Shih FJ, Gau ML, Mao HC, Chen CH, Lo CHK. Empirical validation of a teaching course on spiritual care in Taiwan. J Adv Nurs 2001;36:333–346.

17. Nakai Y, Miyashita M, Sasahara T, et al. Reliability and validity of the Japanese version of the Frommelt attitudes toward care of the dying scale (FATCOD-B-J). Jpn J Palliat Med, In press.

18. Rooda LA, Clements R, Jordan ML. Nurses' attitudes toward death and caring for dying patients. Oncol Nurs Forum 1999;26:1683–1687.

19. Frommelt KH. The effects of death education on nurses' attitudes toward caring for terminally ill persons and their families. Am J Hosp Palliat Care 1991;8:37–43.

20. Frommelt KH. Attitudes toward care of the terminally ill—an educational intervention. Am J Hosp Palliat Care 2003;20:13–19.

21. Morita T, Fujimoto K, Imura C, Fukumoto N, Itoh T. Self-reported practice, confidence, and knowledge about palliative care of nurses in a Japanese regional cancer center: longitudinal study after 1-year activity of palliative care team. Am J Hosp Palliat Care 2006;23:385–391.

22. Dagnan D, Trower P, Smith R. Care staff responses to people with learning disabilities and challenging behavior: a cognitive-emotional analysis. Br J Clin Psychol 1998;37:59–68.

23. Sharrock R, Day A, Qazi F, Brewin C. Explanations by professional care staff, optimism and helping behavior: an application of attribution theory. Psychol Med 1990;20:849–855.

24. Weiner B. A cognitive (attribution)-emotion-action model of helping behavior: an analysis of judgments of help giving. J Personal Soc Psychol 1980;39:1142–1162.

25. Proctor M, Grealish L, Coates M, Sears P. Nurses' knowledge of palliative care in the Australian capital territory. Int J Palliat Nurs 2000;6: 421–428.

26. Ross MM, McDonald B, McGuinness J. The palliative care quiz for nursing (PCQN): the development of an instrument to measure nurses' knowledge of palliative care. J Adv Nurs 1996;23: 126–137.

27. Maslach C, Jackson SE. The measurement of experienced burnout. J Occup Behav 1981;2: 99–113.

28. Higashiguchi K, Morikawa Y, Miura K, et al. The development of the Japanese version of the Maslach Burnout Inventory and the examination of the factor structure. Nippon Eiseigaku Zasshi 1998;53: 447–455.

29. Hirai K, Sakaguchi Y, Abe K, Morikawa Y, Kashiwagi T. The study of death attitude: construction and validation of the Death Attitude Inventory. [in Japanese]. Jap J Clin Res Death Dying 2000;23: 71–76.

30. Temper DA. The construction and validation of a Death Anxiety Scale. J Gen Psychol 1970;82: 165–177.

Appendix 1
Members of the Japanese Spiritual Care Task Force

Tatsuya Morita, MD, Seirei Mikatahara General Hospital
Yosuke Uchitomi, MD, PhD, Research Center for Innovative Oncology, National Cancer Center Hospital East
Terukazu Akazawa, Seirei Mikatahara General Hospital
Michiyo Ando, RN, PhD, St. Mary College
Chizuru Imura, RN, Japanese Nursing Association Center of Nursing Education and Research
Takuya Okamoto, MD, Eikoh Hospital
Masako Kawa, RN, PhD, The University of Tokyo
Yukie Kurihara, MSW, Shizuoka Cancer Center
Hirobumi Takenouchi, PhD, Shizuoka University
Shimon Tashiro, MA, Tohoku University
Kei Hirai, PhD, Osaka University
Yasuhiro Hirako, Soto Institute for Buddhist Studies
Hisayuki Murata, MA, Kyoto Notre Dame University
Tatsuo Akechi, MD, PhD, Nagoya City University Medical School
Nobuya Akizuki, MD, PhD, Research Center for Innovative Oncology, National Cancer Center Hospital East
Eisuke Matsushima, MD, PhD, Graduate School of Tokyo Medical and Dental University
Kazunari Abe, Chiba Cancer Center
Masayuki Ikenaga, MD, Yodogawa Christian Hospital
Taketoshi Ozawa, MD, Yokohama Kosei Hospital
Jun Kataoka, RN, Aichi Prefectural College of Nursing & Health
Akihiko Suga, MD, Sizuoka Prefectural Hospital
Chizuko Takigawa, MD, Keiyukai Sapporo Hospital
Keiko Tamura, Yodogawa Christian Hospital
Wataru Noguchi, MD, Graduate School of Tokyo Medical and Dental University
Etsuko Maeyama, RN, Department of Adult Nursing/Palliative Care Nursing, School of Health Sciences and Nursing, Graduate School of Medicine, The University of Tokyo
Eisho Yoshikawa, MD, PhD, Shizuoka Cancer Center

Appendix 2
Meaninglessness Intervention

I. Please answer the following questions concerning *your usual communication* with terminally ill cancer patients.

	Not at all	Rarely	Sometimes	Mostly	Always
I try to understand the patient's wishes.					
I try to know what is important to the patient.					
I try to know what makes the patient's life meaningful.					
I try to know what strengthens or weakens the meaning of life for the patient.					
I try to know what supports the patient's life from their words.					
I try to know what meaning the disease has for the patient.					

II. *To what degree of confidence can you communicate* with terminally ill cancer patients saying, "I can see no meaning in life"?

1. Totally unconfident	2. Unconfident	3. Moderately unconfident	4. Unsure	5. Moderately confident	6. Confident	7. Very confident

III. How do you feel if a terminally ill cancer patient tells you he/she "can see no meaning in life"?

I never do.	I do not.	I probably do not.	I am not sure.	I probably do.	I do.	I very much do.

I feel willing to do something to relieve the patient's suffering.
I think how I can support the patient effectively.
I wish to relieve the patient's suffering as much as possible.

I feel helplessness.
I feel like escaping.
I feel willing to be involved. (Reversed item)

I feel grateful that the patient has told it to me.
I feel that the patient trusts me.

original article

Preferences regarding end-of-life cancer care and associations with good-death concepts: a population-based survey in Japan

M. Sanjo[1]*, M. Miyashita[1], T. Morita[2], K. Hirai[3], M. Kawa[1], T. Akechi[4] & Y. Uchitomi[5]

[1]*Department of Adult Nursing/Palliative Care Nursing, Health Sciences and Nursing, Graduate School of Medicine, The University of Tokyo;* [2]*Department of Palliative and supportive care, Palliative Care Team and Seirei Hospice, Seirei Mikatahara General Hospital, Hamamatsu, Shizuoka;* [3]*Center of the Study for Communication Design, Osaka University, Osaka;* [4]*Department of Psychiatry and Cognitive-Behavioral Medicine, Nagoya City University Graduate School of Medical Sciences, Nagoya;* [5]*Psycho-Oncology Division, Research Center for Innovative Oncology, National Cancer Center Hospital East, Chiba, Japan*

Background: The aims of this study were to clarify end-of-life cancer care preferences and associations with good-death concepts.

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 ('PCU-bereaved families') were surveyed (*N* = 513; response rate = 70%). The respondents reported their end-of-life care preferences and good-death concepts.

Results: Regarding place of end-of-life care, approximately 50% of the general population preferred 'Home', while 73% of PCU-bereaved families preferred 'PCU'. The concepts of 'Maintaining hope and pleasure' and 'Dying in a favorite place' were associated with the preference for 'Home'. Regarding prognostic disclosure, approximately 50% of the participants preferred some level of negotiation with the physician. The concept of 'Control over the future' was associated with this preference. Regarding treatment of severe refractory physical distress, 75% of the general population and 85% of the PCU-bereaved families preferred palliative sedation therapy. The concepts of 'Physical and psychological comfort' and 'Unawareness of death' were associated with this preference.

Conclusions: End-of-life care preferences were associated with good-death concepts. It would be useful for health-care workers to discuss patients' good-death concepts to support subsequent treatment decisions.

Key words: attitude towards death, palliative care, neoplasm, cross-sectional studies

<div style="writing-mode: vertical">original article</div>

introduction

An important goal of end-of-life care is to honor patients' preferences based on their concepts of 'quality of dying' and 'good death' [1, 2]. To date, researchers have explored such preferences with respect to three key issues: place of end-of-life care and death [3–6], prognostic disclosure [7–9] and terminal sedation and euthanasia for refractory suffering [10–12]. However, studies on preferences for discussing prognoses and treating severe refractory suffering using representative samples in Japan are lacking.

Although recent studies have suggested that a good death is the primary end-point of end-of-life care [13–15], the associations between end-of-life care preferences and good-death concepts are poorly understood. Research has focused on the concept of 'burden' [3, 16] or general beliefs about suffering

Correspondence to: M. Sanjo, Department of Adult Nursing/Palliative Care Nursing, Graduate School of Medicine, The University of Tokyo, 7-3-1 Bunkyo-ku, Tokyo 113-0003, Japan. Tel: +81-3-5841-3508; Fax: +81-3-5841-3502; E-mail: shibagaki-tky@umin.ac.jp

[16] without comprehensively conceptualizing these notions. Vig and colleagues [17] examined end-of-life preferences among geriatric outpatients in a preliminary quantitative study; however, quantitative associations between end-of-life care preferences and good-death concepts could not be identified from their data. As preferences for end-of-life care change with experience [18], it is essential to explore associations in individuals who have encountered bereavement and specialized palliative care. Our survey explored the associations between preferences and comprehensively conceptualized a good death in a representative sample of the Japanese population.

palliative-care system in Japan

The Japanese Ministry of Health, Labor and Welfare supports specialized palliative-care services, which have been covered by National Medical Insurance since 1991. Accordingly, the number of palliative care units (PCUs) increased from 5 in 1991 to 135 in 2004. To be approved as a PCU, institutions must fulfill requirements regarding staff numbers, facilities and

equipment. PCUs with religious associations are sometimes called 'hospices', but both PCUs and hospices aim to provide intensive symptom control and end-of-life care for cancer patients and their families. Most PCUs belong to general hospitals, and have interdisciplinary teams including physicians, nurses and other specialists [19]. By comparison, the growth of home-based specialized palliative-care programs has been slow [20]. Palliative-care teams were not covered by National Medical Insurance until 2002, and remain in an early phase of development. The most common and best available palliative-care service in Japan remains the PCU, which is the subject of the present study.

materials and methods

study sample and procedures
This study was part of a nationwide survey, and the protocol has been described previously [21, 22]. We initially identified four target areas, in order to obtain a wide geographic distribution for the nationwide sample; these comprised an urban prefecture (Tokyo) and three mixed urban–rural areas (Miyagi, Shizuoka and Hiroshima).

A cross-sectional questionnaire was administered to nonbereaved members of the general population ('nonbereaved general population'), members of the general population who had been bereaved thorough cancer ('bereaved general population'), and bereaved family members of cancer patients who had died in 12 certified PCUs in Japan ('PCU-bereaved families').

We initially identified 5000 subjects within the general population (that is, the nonbereaved general population and the bereaved general population) using stratified two-stage random sampling of residents in the four areas. 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 with available collaborative researchers. Ultimately, 12 of the PCUs (two in Miyagi, five in Tokyo, two in Shizuoka, and three in Hiroshima) agreed to participate in the survey. Primary-care physicians identified bereaved families in which the caregiver fulfilled the following 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.

We mailed self-reporting questionnaires to potential participants in August 2004, and re-sent them in October 2004 to those who did not respond; we requested that the primary caregiver filled in the questionnaire.

The protocol was approved by the institutional review board of each PCU, and conformed to the requirements of the Helsinki Declaration in respect to fully explaining the aims of the study, protecting the confidentiality of participants, ethical considerations and voluntary participation.

questionnaire
The questionnaire was designed based on an extensive literature review [3, 5, 7, 11, 13, 17, 23–32] and expert consensus (copies are available from the authors on request). Its feasibility and face validity were confirmed by a pilot study of a convenient sample of 54 members of the general population.

end-of-life care preferences
Respondents stated their preferences for the following aspects of end-of-life care in a scenario where they had incurable cancer. The questionnaire that was finally adopted is described in the Appendix.

place of end-of-life care and death. Respondents chose 'Home', 'Acute hospital' or 'PCU' as their desired place of care and place of death assuming they had a 1–2 month life expectancy, no physical distress and needed care assistance in their daily activities.

prognostic disclosure. In two scenarios where respondents had a life expectancy of 6 or 1–2 months, respectively, they stated their preference for initiating a discussion of prognosis from the following: 'Not to discuss at all', 'Physician to inform me only if I ask', 'Physician to check with me first whether I want to know' or 'Physician to initiate a discussion and inform me in detail'.

treatment of severe refractory physical distress. Respondents rated their treatment preferences for severe refractory physical distress on a four-point Likert-type scale, ranging from 'Absolutely do not want' (1) to 'Strongly want' (4). The options were 'Treatment so that the patient keeps consciousness clear even if distress is not alleviated' (care without sedation), 'Administration of sleeping drugs so that the patient feels no distress because of a reduction in patient consciousness' (palliative sedation therapy) or 'Administration of lethal medications' (euthanasia).

factors associated with preferences
Prior to the survey, relevant factors were conceptualized and grouped into five categories based on a literature review [5, 13, 17, 23–25, 27–32]: 'Concepts of good death', 'Perception of PCUs' 'Cancer-related beliefs', 'Legal knowledge of end-of-life care options' and 'Demographic variables'.

good-death concepts [13, 17]. Respondents rated the importance of 58 components of a good death [13] on a seven-point Likert-type scale. Concepts were classified into 18 domains using an explanatory factor analysis [21]: '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', 'Life completion', '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'. Each domain score was defined as the mean of the item scores (range = 1–7).

perceptions of PCUs [28, 29]. Respondents rated their levels of agreement with 10 statements about the PCU on a five-point Likert-type scale on the basis of a previous study [28]: 'Alleviates pain', 'Supports patients in living with dignity', 'Provides no medical treatments', 'A place where people only wait to die', 'Shortens the patient's life', 'Expensive', 'Provides compassionate care', 'A place where patients are isolated from the community', 'Supports patients in living peacefully' and 'Provides care for families'. If the respondents did not know what PCUs were, they were instructed to choose 'Do not know'.

cancer-related beliefs [5, 23–25, 27, 31, 32]. Respondents rated their levels of agreement about nine cancer-related belief statements on a five-point Likert-type scale. These comprised three pain-related statements ('Cancer pain is sufficiently relieved if adequately treated', 'Opioids shorten life' and 'Consciousness is clear until death if pain medication is not used'), three communication-related statements ('Physicians are generally poor at communicating bad news', 'Physicians are uncomfortable discussing death' and 'I could not cope if I was told my cancer was incurable'), two hydration-related statements ('Artificial hydration and nutrition should be continued as the minimum standard until death' and 'Artificial hydration and nutrition relieve patient symptoms'), and one home care-related statement ('It would be difficult for me to receive care in my home environment').

legal knowledge of end-of-life care options [30]. Respondents stated whether they thought the following medical acts, if requested by a terminally ill patient, were legal or illegal in Japan: 'Administration of medication for symptom relief when it might shorten life' (the 'double-effect' act) and

'Administration of lethal medications' (euthanasia). At the time of the survey, no laws in Japan governed these practices. After discussion with a legal expert, we reached a consensus opinion that the double-effect act would be regarded as legal and euthanasia as illegal for the purpose of our study.

demographic variables. The respondents reported their age and gender. The general population also reported whether they had a chronic disease (defined as the presence of a regular hospital visit over the previous year) and a bereavement experience caused by cancer within 10 years, and, if so, where the deceased had died.

Despite the possibility of a recall bias, we selected 10 years as the limit of experience of bereavement through cancer in the general population because it yielded similar conclusions to a limit of 5 years.

statistical analyses

End-of-life care preferences were analyzed using descriptive statistics for the three study groups (nonbereaved general population, bereaved general population and PCU bereaved families). We confirmed similar distributions of variables between the four areas sampled, and evaluated the significance of differences in preferences among the three groups using a chi-square test.

To explore the factors associated with preferences, we performed multivariate (for 'Treatment for severe refractory physical distress') logistic regression analysis using all potentially significant predictors identified by the univariate analysis ($P < 0.2$) as independent variables via backward elimination.

We created a multinomial variable capturing the three possible categories of preferred place of care and the four possible categories of preferred prognostic disclosure. To model the multivariate effect of potentially significant predictors on the categorical variables, we performed multinomial regression [33, 34], which has been used in recent palliative-care research [26].

We combined the general population and PCU-bereaved families as subjects, so subject group was always included in the model.

The independent variables were age, gender, time since patient's death, concept of a good death, and cancer-related beliefs potentially associated with preferences. We tested the following hypotheses: preferences for end-of-life-care setting were influenced by all cancer-related beliefs [5, 29, 32]; preferences for prognostic disclosure were influenced by communication-related beliefs [24, 32]; and preferences for treatment for severe refractory physical distress were influenced by pain-related [31, 32], communication-related [25] and hydration-related beliefs [23, 27]. We also included 'Perceptions of PCUs' in the analysis of 'Place of care' [28, 29], and 'Legal knowledge of end-of-life care options' in the analysis of 'Treatment for severe refractory physical distress' [30], as independent variables.

To facilitate interpretation, we collapsed the five response categories for 'Perceptions of PCUs' into two: 'Strongly agree or agree' and 'Neither agree nor disagree, disagree, strongly disagree or do not know'. In the multivariate logistic regression analysis for 'Treatment of refractory severe physical distress', we collapsed the four response categories into two: 'Absolutely do not want or probably do not want' and 'Probably want or strongly want'.

All analyses were performed using SAS (version 9.1; SAS Institute Inc., Cary, NC, USA). The significance level was set at $P < 0.05$ (two-tailed).

results

Of the 5000 questionnaires sent to the general population, 26 were undeliverable and 2670 were returned to the authors.

Among these respondents, eight refused to participate, 14 were excluded due to missing data, and 2548 responses were analyzed (effective response rate = 51%). Among the respondents from the general population, 25% ($N = 649$) had lost family members from cancer during the previous 10 years. There were no differences in gender and age between these respondents and the general population according to the vital statistics data for 2003 [35].

Among the 866 respondents from PCU-bereaved families considered as potential participants, 72 were excluded due to serious psychological distress ($N = 30$), lack of competent adult family members ($N = 17$) or for other reasons. Of the 794 questionnaires sent to the remaining bereaved families, 56 were undeliverable and 552 were returned to the authors. Within this group, 27 individuals refused to participate, 12 were excluded due to missing data and 513 responses were analyzed (effective response rate = 70%). Comparing the backgrounds of respondents and nonrespondents revealed no differences in gender, age or time since patient's death, but a significant difference in the length of patient's hospital stay (mean = 44 days versus 36 days). Table 1 summarizes the backgrounds of the respondents.

end-of-life care preferences

Summarized in Table 2.

Table 1. Demographic backgrounds of respondents

	General population (N = 2548)		PCU-bereaved families (N = 513)	
	%	n	%	n
Age (years)				
<49	25	613	21	104
50–59	30	758	29	144
60–69	28	710	29	146
>70	17	420	22	110
Gender				
Male	47	1186	32	158
Female	53	1326	68	343
Having chronic disease	40	1023		
Bereavement experience[a]	25	649	100	513
Place of patient's death	100	649	100	513
Home	13	86	0	
Acute hospital	77	502	0	
PCU	5.4	35	100	513
Nursing homes	1.8	12	0	
Other places	2.2	14	0	
Length of hospital stay (mean ± SD/median)			44.4 ± 49.3/29 (days)	
Time since patient's death (years)				
<1	13	207	0	
−3	26	411	71	416
−5	18	280	19	97
−10	43	680	0	
(mean ± SD/median)			28.4 ± 7/28.1 (months)	

SD, standard deviation; PCUs, palliative care units.
[a]Experience of losing a family member from cancer in the previous 10 years.

Table 2. Preferences for end-of-life care

	Nonbereaved general population (N = 1899)		Bereaved general population (N = 649)		PCU-bereaved families (N = 513)		P value[b]
	%	n	%	n	%	n	
Place of end-of-life care and death[a]							
Place of end-of-life care							
Home	46	845	44	279	21	105	<0.0001
Acute hospital	18	334	22	142	6	30	
PCU	36	668	33	212	73	367	
Place of death							
Home	55	1024	50	315	30	150	<0.0001
Acute hospital	15	280	21	131	5	23	
PCU	29	545	29	185	65	325	
Communicating estimated prognosis							
6 month life expectancy							
Not to discuss at all	11	200	11	70	8	38	0.20
Physician to inform me only if I ask	27	498	29	183	28	144	
Physician to check me first whether I want to know	21	398	22	142	25	124	
Physician to initiate discussion and inform me in detail	41	763	38	240	40	200	
1–2 month life expectancy							
Not to discuss at all	17	309	17	106	13	66	0.23
Physician to inform me only if I ask	25	457	26	162	28	140	
Physician to check me first whether I want to know	16	300	19	118	18	91	
Physician to initiate discussion and inform me in detail	43	788	39	249	41	210	
Treatment for severe refractory physical distress							
Care without sedation							
Absolutely do not want	12	215	13	76	12	59	0.04
Probably do not want	36	613	41	243	40	191	
Probably want	42	723	35	212	35	167	
Strongly want	10	175	11	68	12	56	
Palliative sedation							
Absolutely do not want	6	99	5	33	3	16	0.0007
Probably do not want	20	345	18	113	13	62	
Probably want	54	949	52	319	57	277	
Strongly want	21	370	24	149	28	135	
Euthanasia							
Absolutely do not want	19	333	18	110	23	113	0.09
Probably do not want	35	616	32	195	36	175	
Probably want	31	538	32	194	28	137	
Strongly want	15	267	18	106	13	62	

PCU, palliative care unit.

[a]Respondents were asked to choose their desired setting if they had a life expectancy of 1–2 months and no physical distress, but needed assistance in their daily activities.

[b]Determined using chi-square test among the three groups.

place of end-of-life care and death. Approximately 50% of the general population (nonbereaved and bereaved groups) preferred 'Home' as the place of end-of-life care and death, while approximately 70% of the PCU-bereaved families preferred 'PCU' (P < 0.0001). In all groups, at least 70% of the respondents preferred either 'Home' or 'PCU' as place of end-of-life care and death, while no more than 20% preferred 'Acute hospital' (P < 0.0001).

prognostic disclosure. Across all groups, approximately 10–20% of respondents preferred 'Not to discuss at all', 40% preferred 'Physician to initiate a discussion and inform me in detail', and 50% preferred a negotiated approach (either

'Physician to inform me only if I ask' or 'Physician to check with me first whether I want to know'). The distributions of responses were similar for the scenarios with life expectancies of 6 and 1–2 months.

treatment for severe refractory physical distress. While there was a significant difference in the preference for care without sedation between the groups (P = 0.04), approximately 50% of all respondents preferred this option.

Regarding palliative sedation therapy, 75% of the general population preferred this treatment compared with 85% of the PCU-bereaved families (P = 0.0007).