should play a central role in educating general physicians.

Providing information on palliative care to patients and their families is also important. The most powerful barrier to providing effective palliative care is likely to be the physician in charge of the patient. Most physicians are reluctant to introduce palliative care options, particularly in early treatment phases. Development of a system that allows nursing staff to propose referral to palliative care is necessary, and nurses should be aware of their role.

It should be noted that establishment of a specialty for palliative care is hindered by these problems. In Japan, because of a lack of specific departments for palliative care and the lack of a systematic educational system for palliative care specialists, there may not be common opinions about the curriculum for palliative care education. A palliative care specialty should be established immediately. The low response rate (16%) to the questionnaire represents a major limitation of this study. Although there is some overlap in members between the Japanese Society of Palliative Medicine and Hospice Palliative Care Japan, the response rate was still disappointing. The low response rate can be explained by the fact that open-ended questions are tiresome and time consuming to answer, therefore, many potential respondents might have been reluctant to complete the questionnaire. Nevertheless, the 426 responses we did receive provided much worthwhile information, which could be equivalent to 426 interviews. Another limitation of the present study was that home care practitioners and hospital administrators were underrepresented because of the sampling procedure used. Home palliative care practitioners are a minority in Japan. Thus, the problems relating to home care and economic factors might be underestimated. Furthermore, medical social workers, psychotherapists, physiotherapists, and occupational therapists also participated at only very low levels. The opinions of these professionals would thus also have been underrepresented.

As mentioned above, a report detailing the barriers to palliative care as identified in the present study has been developed (the report can be obtained by contacting, in Japanese, the corresponding author of the present study). It is expected that the relevant organizations will use the report as a basis for cooperation to overcome the various barriers identified. In addition, the report details challenges for hospitals and individuals to overcome.

CONCLUSIONS

In conclusion, we identified 95 critical barriers to providing effective palliative care and 136 future actions necessary to advance palliative care. We found that there exist numerous barriers, including not only problems related to medical practitioners, but also those related to economic factors and the general population. These findings suggest that to overcome these barriers, we need to take action on many fronts, including increasing social awareness and effecting political change, as well as addressing problems relating to practitioners. In addition, we prioritized the future actions necessary to advance palliative care. The five most frequent urgent problems were identified. We hope that collaborative efforts by the relevant organizations will improve palliative care in Japan.

ACKNOWLEDGMENTS

REFERENCES

1. Meier DE, Morrison RS, Cassel CK: Improving palliative care. Ann Intern Med 1997;127:225–230.
2. Ahmed N, Bestall JC, Ahmedzai SH, Payne SA, Clark D, Noble B: Systematic review of the problems and issues of accessing specialist palliative care by patients, carers and health and social care professionals. Palliat Med 2004;18:525–542.
3. Yabroff KR, Mandelblatt JS, Ingham J: The quality of medical care at the end-of-life in the USA: existing

barriers and examples of process and outcome measures. Palliat Med 2004;18:202–216.

4. Cleeland CS, Cleeland LM, Dar R, Rinehardt LC: Factors influencing physician management of cancer pain. Cancer 1986;58:796–800.

5. Hiraga K, Mizuguchi T, Takeda F: The incidence of cancer pain and improvement of pain management in Japan. Postgrad Med J 1991;67(Suppl) 2:S14–25.

6. McCaffery M: Pain control. Barriers to the use of available information. World Health Organization Expert Committee on Cancer Pain Relief and Active Supportive Care. Cancer 1992;70(5 Suppl):1438–1449.

7. Cleeland CS, Gonin R, Hatfield AK, Edmonson JH, Blum RH, Stewart JA, Pandya KJ: Pain and its treatment in outpatients with metastatic cancer. N Engl J Med 1994;330:592–596.

8. Larue F, Colleau SM, Fontaine A, Brasseur L: Oncologists and primary care physicians' attitudes toward pain control and morphine prescribing in France. Cancer 1995;76:2375–2382.

9. Christakis NA, Iwashyna TJ: Attitude and self-reported practice regarding prognostication in a national sample of internists. Arch Intern Med 1998; 158:2389–2395.

10. Curtis JR, Patrick DL, Caldwell ES, Collier AC: Why don't patients and physicians talk about end-of-life care? Barriers to communication for patients with acquired immunodeficiency syndrome and their primary care clinicians. Arch Intern Med 2000;160:1690–1696.

11. Meisel A, Snyder L, Quill T, American College of Physicians—American Society of Internal Medicine End-of-Life Care Consensus P: Seven legal barriers to end-of-life care: myths, realities, and grains of truth. JAMA 2000;284:2495–2501.

12. Morrison RS, Morrison EW, Glickman DF: Physician reluctance to discuss advance directives. An empiric investigation of potential barriers. Arch Intern Med 1994;154:2311–2318.

13. Grande GE, Barclay SI, Todd CJ: Difficulty of symptom control and general practitioners' knowledge of patients' symptoms. Palliat Med 1997;11:399–406.

14. Levin ML, Berry JI, Leiter J: Management of pain in terminally ill patients: Physician reports of knowledge, attitudes, and behavior. J Pain Symptom Manage 1998;15:27–40.

15. Visentin M, Trentin L, de Marco R, Zanolin E: Knowledge and attitudes of Italian medical staff towards the approach and treatment of patients in pain. J Pain Symptom Manage Nov 2001;22:925–930.

16. McCaffery M, Ferrell BR: Nurses' knowledge of pain assessment and management: How much progress have we made? J Pain Symptom Manage 1997;14:175–188.

17. McNeilly DP, Hillary K: The hospice decision: Psychosocial facilitators and barriers. Omega 1997;35: 193–217.

18. Donner B, Raber M, Zenz M, Strumpf M, Dertwinkel R: Experiences with the prescription of opioids: A pa-

tient questionnaire. J Pain Symptom Manage 1998;15: 231–234.

19. Silveira MJ, DiPiero A, Gerrity MS, Feudtner C: Patients' knowledge of options at the end of life: Ignorance in the face of death. JAMA 2000;284: 2483–2488.

20. Tolle SW, Tilden VP, Rosenfeld AG, Hickman SE: Family reports of barriers to optimal care of the dying. Nurs Res 2000;49:310–317.

21. Eakin EG, Strycker LA: Awareness and barriers to use of cancer support and information resources by HMO patients with breast, prostate, or colon cancer: Patient and provider perspectives. Psychooncology 2001;10: 103–113.

22. Yates PM, Edwards HE, Nash RE, Walsh AM, Fentiman BJ, Skerman HM, Najman JM: Barriers to effective cancer pain management: A survey of hospitalized cancer patients in Australia. J Pain Symptom Manage 2002;23:393–405.

23. Morita T, Miyashita M, Shibagaki M, Hirai K, Ashiya T, Ishihara T, Matsubara T, Miyoshi I, Nakaho T, Nakashima N, Onishi H, Ozawa T, Suenaga K, Tajima T, Akechi T, Uchitomi Y: Knowledge and beliefs about end-of-life care and the effects of specialized palliative care: A population-based survey in Japan. J Pain Symptom Manage 2006;31:306–316.

24. Weggel JM: Barriers to the physician decision to offer hospice as an option for terminal care. WMJ 1999;98:49–53.

25. Brickner L, Scannell K, Marquet S, Ackerson L: Barriers to hospice care and referrals: survey of physicians' knowledge, attitudes, and perceptions in a health maintenance organization. J Palliat Med 2004; 7:411–418.

26. Friedman BT, Harwood MK, Shields M: Barriers and enablers to hospice referrals: an expert overview. J Palliat Med 2002;5:73–84.

27. Ogle KS, Mavis B, Wyatt GK: Physicians and hospice care: Attitudes, knowledge, and referrals. J Palliat Med 2002;5:85–92.

28. Emanuel EJ, Emanuel LL: The promise of a good death. Lancet 1998;351(Suppl 2):SII21–29.

29. Berger AM, Berry DL, Christopher KA, Greene AL, Maliski S, Swenson KK, Mallory G, Hoyt DR: Oncology Nursing Society year 2004 research priorities survey. Oncol Nurs Forum Online 2005;32: 281–290.

30. Lee E-H, Kim J-S, Chung BY, Bok MS, Song BE, Kong SW, Lee EO: Research priorities of Korean oncology nurses. Cancer Nurs 2003;26:387–391.

31. Lin CC, Ward SE: Patient-related barriers to cancer pain management in Taiwan. Cancer Nurs 1995;18: 16–22.

32. Chung TK, French P, Chan S: Patient-related barriers to cancer pain management in a palliative care setting in Hong Kong. Cancer Nurs 1999;22: 196–203.

33. Fujimori M, Akechi T, Akizuki N, Okamura M, Oba A, Sakano Y, Uchitomi Y: Good communication with

patients receiving bad news about cancer in Japan. Psychooncology 2005;14:1043–1051.

34. Fujimori M, Oba A, Koike M, Okamura M, Akizuki N, Kamiya M, Akechi T, Sakano Y, Uchitomi Y: Communication skills training for Japanese oncologists on how to break bad news. J Cancer Educ 2003;18:194–201.

35. Robinson K, Sutton S, von Gunten CF, Ferris FD, Molodyko N, Martinez J, Emanuel LL: Assessment of the Education for Physicians on End-of-Life Care (EPEC) Project. J Palliat Med 2004;7: 637–645.

36. Llamas KJ, Llamas M, Pickhaver AM, Piller NB: Provider perspectives on palliative care needs at a major teaching hospital. Palliat Med 2001;15:461–470.

Address reprint requests to:
Mitsunori Miyashita, R.N., Ph.D.
Department of Adult Nursing/
Palliative Care Nursing
School of Health Sciences and Nursing
Graduate School of Medicine
The University of Tokyo
7-3-1 Hongo, Bunkyo-ku
Tokyo, 113-0033
Japan

E-mail: miyasita-tky@umin.net

original article

Good death in cancer care: a nationwide quantitative study

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

[1]Department of Adult Nursing/Palliative Care Nursing, School of Health Sciences and Nursing, Graduate School of Medicine, The University of Tokyo, Tokyo; [2]Department of Palliative and Supportive Care, Palliative Care Team and Seirei Hospice, Seirei Mikatahara Hospital, Shizuoka; [3]Center of the Study for Communication Design, Psychology and Behavioral Sciences, Graduate School of Human Science, Department of Complementary and Alternative Medicine, Graduate School of Medicine, Osaka University, Osaka; [4]Psycho-Oncology Division, Research Center for Innovative Oncology, National Cancer Center Hospital East, Chiba, Japan

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

*Correspondence to: Dr M. Miyashita, Department of Adult Nursing/Palliative Care Nursing, School of Health Sciences and Nursing, Graduate School of Medicine, The University of Tokyo, 7-3-1 Hongo, Bunkyo-ku, Tokyo 113-0033, Japan. Tel: +81-3-5841-3507; Fax: +81-3-5841-3502; E-mail: miyasita-tky@umin.net

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

references

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

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

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

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

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

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

7. Grant E, Murray SA, Grant A, Brown J. A good death in rural Kenya? Listening to Meru patients and their families talk about care needs at the end of life. J Palliat Care 2003; 19(3): 159–167.

8. Spronk K. Good death and bad death in ancient Israel according to biblical lore. Soc Sci Med 2004; 58(5): 987–995.

9. van der Geest S. Environmental comfort/dying as one sleep: considering good death and bad death in Kwahu-Tafo, Ghana. Soc Sci Med 2004; 58(5): 899–911.

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

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

12. Tsai JS, Wu CH, Chiu TY et al. Fear of death and good death among the young and elderly with terminal cancers in Taiwan. J Pain Symptom Manage 2005; 29(4): 344–351.

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

14. Yoshida M. Nurses perceptions of death and dying in a hospice setting: "Yoi-Mitori". J Jpn Acad Nursing Sci 1999; 19(1): 49–59.

15. Hamada Y, Sato R. Hope of end-stage cancer patients. J Jpn Soc Cancer Nursing (in Japanese) for Yoshida's paper 2002; 16(2): 15–25.

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

17. Hirai K, Miyashita M, Morita T et al. Good death in Japanese cancer care: a qualitative study. J Pain Symptom Manage 2006; 31: 140–147.

18. Voltz R, Akabayashi A, Reese C et al. End-of-life decisions and advance directives in palliative care: a cross-cultural survey of patients and health-care professionals. J Pain Symptom Manage 1998; 16(3): 153–162.

19. Kawa M, Kayama M, Maeyama E et al. Distress of inpatients with terminal cancer in Japanese palliative care units: from the viewpoint of spirituality. Support Care Cancer 2003; 11: 481–490.

20. 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.

21. Matsumura S, Fukuhara S, Bito S et al. Nihon jin no gan kokuchi ni kansuru kibou to sore ni eikyou wo ataeru syoyouin no kentou, toku ni jiritu sei ni tyuumoku site—1995 nen zenkoku tyousa yori. Nihon iji shinpo (in Japanese) 1997; 3830: 37–42.

22. Blackhall LJ, Murphy ST, Frank G et al. Ethnicity and attitudes toward patient autonomy. JAMA 1995; 274(10): 820–825.

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

24. Teno JM, Clarridge B, Casey V et al. Validation of toolkit after-death bereaved family member interview. J Pain Symptom Manage 2001; 22: 752–758.

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

26. Yabroff KR, Mandelblatt JS, Ingham J. The quality of medical care at the end-of-life in the USA: existing barriers and examples of process and outcome measures. Palliat Med 2004; 18: 202–216.

27. Ahmed N, Bestall JC, Ahmedzai SH et al. Systematic review of the problems and issues of accessing specialist palliative care by patients, carers and health and social care professionals. Palliat Med 2004; 18(6): 525–542.

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.
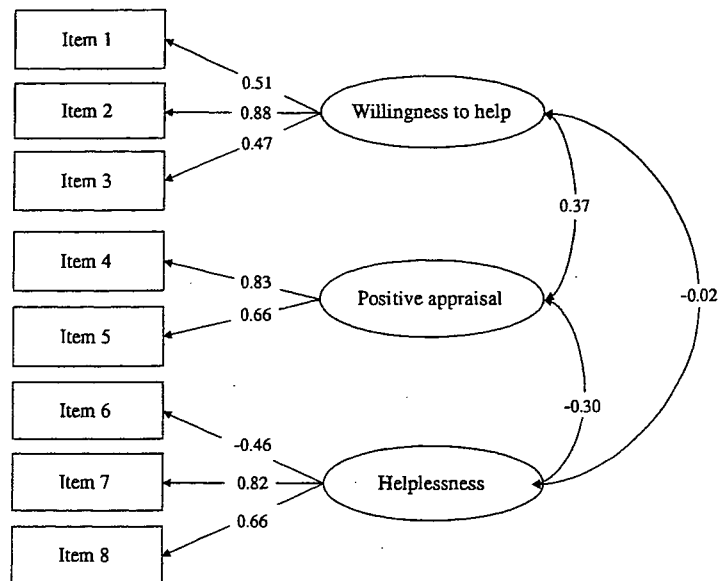
Fig. 1. Factor structure of attitudes toward caring for patients with meaninglessness.

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.