

## Original Article

## Meaninglessness in Terminally Ill Cancer Patients: A Randomized Controlled Study

Tatsuya Morita, MD, Hisayuki Murata, MA, Emi Kishi, RN, Mitsunori Miyashita, RN, PhD, Takuhiro Yamaguchi, PhD, and Yosuke Uchitomi, MD, PhD

on behalf of the Japanese Spiritual Care Task Force<sup>a</sup>

Department of Palliative and Supportive Care, Palliative Care Team, and Seirei Hospice (T.M.), Seirei Mikatahara General Hospital, Hamamatsu, Shizuoka; School of Human Culture (H.M.), Kyoto Notre Dame University, Kyoto; Palliative Care Unit (E.K.), Takatsuki Red Cross Hospital, Osaka; Department of Adult Nursing/Palliative Care Nursing (M.M.), School of Health Sciences and Nursing, and Department of Clinical Trial Data Management (T.Y.), Graduate School of Medicine, University of Tokyo, Tokyo; and Psycho-Oncology Division (Y.U.), National Cancer Center Research Institute East, Tokyo; and Psychiatry Division (Y.U.), National Cancer Center Hospital East, Kashiwa City, Chiba, Japan

## Abstract

Although recent empirical studies reveal that fostering patients' perception of meaning in their life is an essential task for palliative care clinicians, few studies have reported the effects of training programs for nurses specifically aimed at improving these skills. The primary aim of this randomized controlled trial was to determine the effects of an educational workshop focusing on patients' feelings of meaninglessness on nurses' confidence, self-reported practice, and attitudes toward caring for such patients, in addition to burnout and meaning of life. The study was designed as a single-institution, randomized controlled trial using a waiting list control. The intervention consisted of eight 180-minute training sessions over four months, including lectures and exercises using structured assessment. A total of 41 nurses were randomly allocated to three groups, which were separately trained, and all were evaluated four times at three-month intervals (before intervention, between each intervention, and after the last intervention). Assessments included validated Confidence and Self-Reported Practice scales, the Attitudes Toward Caring for Patients Feeling Meaningless Scale (including willingness to help, positive appraisal, and helplessness items), the Maslach Burnout Scale, job satisfaction, and the Functional Assessment of Chronic Illness Therapy-Spiritual (FACIT-Sp). One participant withdrew from the study before the baseline evaluation, and the remaining 40 nurses completed the study. The nurses were all female and had a mean age of  $31 \pm 6.4$ , and mean clinical experience of  $8.9 \pm 5.5$  years. There were no significant differences in background among the groups. The intervention effects were statistically significant on the Confidence Scale, the Self-Reported Practice Scale, and the

Address correspondence to: Tatsuya Morita, MD, Department of Palliative and Supportive Care, Palliative Care Team, and Seirei Hospice, Seirei Mikatahara General Hospital, 3453 Mikatahara-cho, Hamamatsu, Shizuoka 433-8558, Japan. E-mail: tmorita@sis.seirei.or.jp

<sup>a</sup>See Appendix for list of members.

Accepted for publication: April 6, 2008.

willingness to help, positive appraisal, and helplessness subscales, in addition to the overall levels of burnout, emotional exhaustion, personal accomplishment, job satisfaction, and the FACIT-Sp. The change ratio of each parameter ranged from 5.6% (willingness to help) to 37% for the helplessness score and 51% on the Confidence Scale. The percentages of nurses who evaluated this program as "useful" or "very useful" were 85% (to understand the conceptual framework in caring for terminally ill patients with meaninglessness), 80% (to foster nurses' personal values), and 88% (to know how to provide care for patients with meaninglessness). This educational intervention had a significant beneficial effect on nurse-perceived confidence, practice, and attitudes in providing care for patients feeling meaninglessness, in addition to the levels of burnout and spiritual well being of nurses. *J Pain Symptom Manage* 2008;■:■-■. © 2008 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

### Key Words

Palliative care, neoplasms, education, spiritual care, suffering, meaning, nurse

## Introduction

Recent empirical studies reveal that fostering patients' perception of meaning in their life is an essential task for palliative care clinicians.<sup>1-4</sup> In Japan, multiple surveys have identified that terminally ill cancer patients experience considerable levels of meaninglessness.<sup>5,6</sup> Our group recently proposed a conceptual framework for psycho-existential care for Japanese patients.<sup>7</sup> 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 of meaning for human beings: loss of relationships with others, loss of autonomy, and loss of future (temporality). 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.<sup>7</sup>

In fostering a sense of meaning in terminally ill cancer patients, nurses play a major role. Nurses often experience difficulty and emotional stress when facing terminally ill cancer patients with unrelieved suffering.<sup>8-10</sup> One of the sources of nurses' stress is the lack of an adequate training system to improve the skills required to care for such patients.<sup>8-10</sup> General training in communication skills has been described and evaluated.<sup>11,12</sup> A few studies also have reported the effects of training programs for nurses, specifically aimed at improving skills to relieve meaninglessness in terminally

ill cancer patients.<sup>13-16</sup> These pioneer studies have major limitations, however, including no control groups, a nonstructured intervention, and the use of nonvalidated measurement tools.

In our previous work,<sup>17</sup> we validated measurement tools to quantify nurses' self-reported practice and attitudes toward caring for terminally ill cancer patients feeling meaninglessness, and explored 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. After the short-term educational session, the nurses' self-reported practice and confidence significantly improved, and helplessness, emotional exhaustion, and death anxiety significantly decreased. The percentage of nurses who evaluated this program as "useful" or "very useful" was about 80%. This result suggested that the five-hour workshop has a beneficial effect on nurse-reported practice, attitudes, and confidence in providing care for terminally ill cancer patients feeling meaninglessness. Lack of control group in the pilot study, however, limited the determination of the effects of the intervention as compared with conventional care.

The primary aim of this randomized controlled trial was thus to determine the effects of an educational workshop focusing on patient meaninglessness on nurses' confidence, self-reported practice, and attitudes toward



caring for such patients, in addition to nurses' burnout and meaning of life.

### Methods

This study was designed as a randomized controlled trial using a waiting list control (Fig. 1). The nurses were recruited from a single general hospital. A total of 41 nurses were randomly allocated to three groups using the envelope method. One participant (Group 3) withdrew from the study before the baseline evaluation, but we tried no supplementary recruitment because of adequate sample size. The remaining 40 nurses completed the study. We evaluated the nurses four times at three-month intervals (before intervention, between each intervention, and after the last intervention).

The Institutional Review Board approved the scientific and ethical validity of this study, and the nurses gave written consent.

### Subjects

The nurses were all female and had a mean age of  $31 \pm 6.4$  years (median, 29; range, 21–47), and mean clinical experience of

$8.9 \pm 5.5$  years (median, 8.0; range, 1 to 22). Eleven nurses worked in the palliative care unit. All nurses were general practice nurses, including those working in palliative care units (none of the nurses had formal certification in palliative care, such as clinical nurse specialists). There were no significant differences in the participants' backgrounds among the groups (Table 1).

### Interventions

The workshop was principally based on Murata and Morita's conceptual framework, and specifically focused on the care of terminally ill cancer patients feeling meaninglessness.<sup>7</sup> The intervention was the same throughout the study periods. The second author (H. M.) provided all lectures.

The workshop consisted of eight sessions over four months, and each session took 180 minutes. Table 2 summarizes the program contents. In the first three introductory sessions, participants were educated about basic communication skills through lectures and exercises. In the exercise section, each participant was requested to report short, typically 20 to 30 sentences, verbatim records of their actual

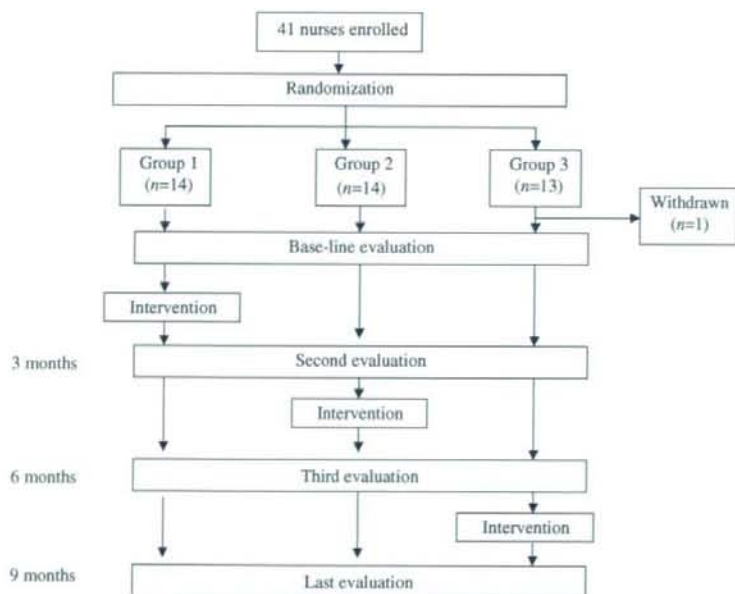


Fig. 1. Study protocol.

Table 1  
Participants' Backgrounds

	Group 1	Group 2	Group 3	P
	(n = 14)	(n = 14)	(n = 13)	
Age, years (mean ± SD)	31 ± 5.2	32 ± 8.5	31 ± 5.3	0.94
Clinical experience, years (mean ± SD)	8.1 ± 3.7	9.8 ± 7.1	8.6 ± 5.3	0.73
Working in the palliative care unit, n (%)	3 (21)	4 (29)	4 (31)	0.77

experiences in their routine practice, and received face-to-face feedback based on group discussion about appropriate listening skills.

In the following two sessions, participants were educated about the conceptual framework of meaninglessness used in this practice, and how to use the Spiritual Conference Summary Sheet. In the last three sessions, participants were requested to complete the Spiritual Conference Summary Sheet for actual patients: to identify which of the patient's statements are expressions of meaninglessness from the verbatim record as the origin of the patient's meaninglessness (temporality, relationships, or autonomy), and to establish a care plan to alleviate the patient's sense of

Table 2  
Program Contents

Session	Contents
1	Lecture (overview and what is "helping others?") (90 minutes) Exercise: read and discuss three verbatim case records (90 minutes)
2	Lecture (sympathy and active listening) (90 minutes) Exercise: read and discuss three verbatim case records (90 minutes)
3	Lecture (communication) (90 minutes) Exercise: read and discuss three verbatim case records (90 minutes)
4	Lecture (conceptual framework of meaninglessness) (90 minutes) Exercise: read and discuss three verbatim case records (90 minutes)
5	Lecture (how to use the Spiritual Conference Summary Sheet) (90 minutes) Exercise: read and discuss three verbatim case records (90 minutes)
6	Exercise: case discussion based on four Spiritual Conference Summary Sheets (180 minutes)
7	Exercise: case discussion based on four Spiritual Conference Summary Sheets (180 minutes)
8	Exercise: case discussion based on four Spiritual Conference Summary Sheets (180 minutes)

meaninglessness in daily nursing practice by strengthening the factors supporting meaning and alleviating the factors causing meaninglessness. In these sessions, four Spiritual Conference Summary Sheets were discussed under supervision from the second author, and all participants received additional individual, written feedback.

Assessment and care planning based on the Spiritual Conference Summary Sheet is an essential part of this intervention. The Spiritual Conference Summary Sheet (Fig. 2) was designed to respectively assess the source of meaning for each patient (i.e., temporality, relationships, or autonomy) from patients' actual dialogue.

#### Measurement Instruments

We adopted the Confidence and Self-Reported Practice scales, and the Attitudes toward Caring for Patients Feeling Meaningless Scale (willingness to help, positive appraisal, and helplessness) as primary end points for this study. The rationale and scale development process were described in detail in our previous article.<sup>17</sup> In addition, we measured the levels of burnout (Maslach Burnout Scale<sup>18,19</sup>) and the nurses' own spiritual well being (Functional Assessment of Chronic Illness Therapy-Spiritual [FACIT-SP]<sup>20,21</sup>) as secondary end points.

**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?'".<sup>17</sup>

**Self-Reported Practice Scale.** The Self-Reported Practice Scale quantifies the level of self-reported adherence to recommended clinical practice in helping terminally ill patients to find meaning in their lives.<sup>17</sup> Self-reported practice was evaluated by the level of adherence to six recommended practice statements on a Likert-type scale from 1: "not do at all" to 5: "always": "I try to know what make the patient's life meaningful," "I try to know what strengthens or weakens the meaning of life for the patient," "I try to know how the



Patient: 75-year-old male Advanced prostate cancer, in bed nearly all day due to lower limb paralysis. Lost wife 5 years ago. No children.		Circumstances: I visited Mr. A during a round of the Palliative Care Team. According to a ward nurse, he had undergone painful and distressing tests the day before and was depressed, saying, "I'm finished. There is no sense in living." Mr. A was supine in the bed on the hall side of a 3-bed room. I sat on a chair beside his bed.	
Dimension	Patient dialog	Assessment	Care plan
Relationships	P4(underlined)  P5(underlined)	Mr. A reflected on his past and gave a positive meaning to his bitter experience, whereby his feelings changed from repentance to gratefulness and reconciliation.  Mr. A felt supported by someone listening to him.	Listen to Mr. A's reflections on his life and encourage him to talk to strengthen the meaning from his relationships with family and relatives. Continue to listen attentively to maintain a relationship with others.
Temporality	"I'm finished. There is no sense in living."	Mr. A sensed the ineffectiveness of treatment and felt that there was no hope of cure. This caused him to feel that he had no future and that his life was meaningless from temporality.	Encourage him to reflect on his past life, to regain the meaning supported by his past and relationships, not by the future.
Autonomy		He stays in bed all day due to paralysis of the bilateral lower limbs and dependence causes meaningless from autonomy.	Encourage reflections on life to divert their patients' value from dependency to the meaningful past.
Assessment and Planning		Mr. A feels his treatment to be ineffective and suffers from feelings of having no future, and physical dependence. No future and dependence causes meaningless from temporality and autonomy. However, he could reflect on his past of meaningful relationships. The care plan therefore would be to continue listening carefully to his reflections on life to increase the meaningfulness of his past experiences and relationships, rather than the future and physical autonomy.	

## Verbatim record N: nurse P: patient

N1: How are you, Mr. A?

P1: ... at night. I get up in the middle of the night, and I can't help thinking of one thing after another.

N2: You think of many things?

P2: Yeah. (After being silent for a while) You visit other patients and listen to them, too?

N3: Yes, there are others, too.

P3: I guess it's pretty hard for a mother with small children. (Silent for a while)...

N4: (Waiting)

P4: I lost my mother, too, when I was 6. She was 36. Then, I was taken care of by a stepmother, but it was difficult to get used to her. We were never on good terms, (Weeps) I was raised by 3 mothers: My own mother, nurse, and stepmother. But, when my father died, I said at his funeral, "I was brought up by 3 mothers, and this was my greatest fortune," showing my thanks to relatives. That was good, because everyone thanked me for saying it. (Weeps)

N5: At your father's funeral, you said you were very lucky to have been brought up by 3 mothers and thanked your relatives? And you felt good, because it made everybody grateful?

P5: Yes. (Weeps) (Looking straight at me) I thank you for coming today. I really do. You are coming again to listen to me? It makes me feel relieved.

N6: Yes, I am. I am looking forward to listening to you again. (Leaves the room)

Fig. 2. Spiritual conference summary sheet.

patient's life is supported," "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 scale score as the mean of the total score of the responses, and thus the score ranged from 1 to 5, with a higher score indicating a higher level of performance of recommended practices. Reliability was high, and convergent validity was examined by moderate correlation with self-reported practice about general communication.<sup>17</sup>

*Attitudes Toward Caring for Patients Feeling Meaningless: Willingness to Help, Positive Appraisal, and Helplessness.* Willingness to help, positive appraisal, and helplessness quantify the degree of willingness to make an effort to help patients feeling meaninglessness, nurses' positive appraisal of their experience of encountering patients feeling meaninglessness, and nurses' perception of helplessness when facing patients feeling meaninglessness, respectively. These were evaluated by levels of agreement with several statements on a Likert-type scale from 1: "never" to 7: "very much." The instructions specifically presented a situation in which the nurse faced a terminally ill cancer patient suffering from meaninglessness. The item questions were: "I feel willing to do something to relieve the patient's suffering," "I think how I can support the patient effectively," and "I wish to relieve the patient's suffering as much as possible" (willingness to help; three items, range = 1–3); "I feel grateful that the patient has told me," and "I feel that the patient trusts me" (positive appraisal; two items, range = 1–3); "I feel helplessness," "I feel like escaping," and "I feel willing to be involved (reversed item)" (helplessness; three items, range = 1–3), respectively. Higher scores indicated higher levels of nurses' willingness to help, positive appraisal of their experience, and perception of helplessness, respectively. Reliability was high, construct validity was confirmed using confirmatory factor analysis, and convergent validity was examined by moderate correlation with the Frommelt Scale.<sup>17,22,23</sup>

*Burnout.* Professional burnout was measured using the Maslach Burnout Inventory,<sup>18,19</sup> which measures three components of burnout syndrome: emotional exhaustion, depersonalization,

and lack of personal accomplishment, in addition to overall levels of burnout (visual analog scale, range = 0–100).<sup>18</sup> The psychometric properties of the Japanese version have been confirmed.<sup>19</sup> In addition, job satisfaction was measured on a 0–10 rating scale following the previous study.<sup>14</sup>

*Spiritual Well Being.* Nurses' own spiritual well being was measured using the FACIT-SP.<sup>20,21</sup> The psychometric property of the Japanese version has been confirmed.<sup>21</sup>

*Overall Evaluation.* Finally, we asked the respondents to rate their overall evaluation about the usefulness of this program in terms of: 1) understanding the conceptual framework in caring for terminally ill patients feeling meaninglessness; 2) helping in self-discussing nurses' personal beliefs, values, and life goals; and 3) helping in learning how to provide care for patients feeling meaninglessness in clinical practice.<sup>17</sup> We used the second question, given the possibility that nurses' own spirituality might change through this educational session about patient suffering,<sup>17</sup> although the intervention itself did not deal with nurses' own spirituality. The choices were "not useful," "slightly not useful," "slightly useful," "useful," and "very useful."

### Statistical Analysis

We first compared participants' backgrounds (age, clinical experience, and working setting) among groups by analysis of variance or Chi-square test, as appropriate. We then calculated the change ratio of each score from the mean value of each score at the baseline and just after intervention for all end points. Finally, we tested the statistical significance of treatment effect using the mixed effect model for all end points. In all analyses, the significance level was set at  $P < 0.05$  and a two-sided test was used. All analyses were conducted using statistical package SAS (SAS Institute, Cary, NC).

## Results

### Primary End Points

As shown in Fig. 3, the intervention effects were statistically significant for all primary end points: Confidence and Self-Reported Practice scales, and Attitudes toward Caring for Patients



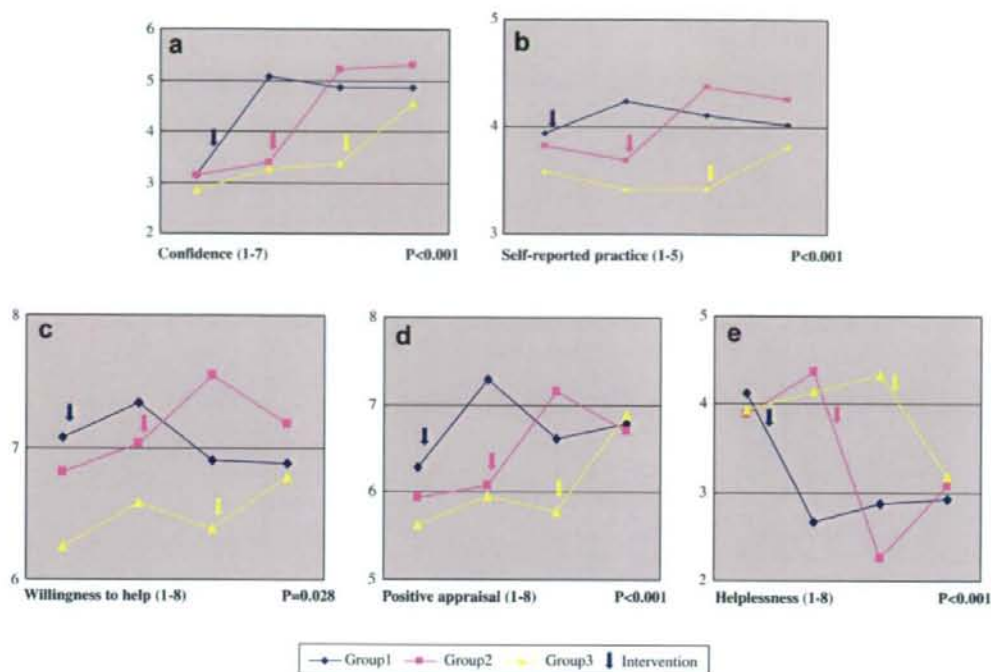


Fig. 3. Primary end points.

Feeling Meaningless (willingness to help, positive appraisal, and helplessness). The changes in these primary end points were: 5.6% (willingness to help), 12% (self-reported practice), 18% (positive appraisal), 37% (helplessness), and 51% (Confidence Scale) (Table 3).

#### Secondary End Points

As shown in Fig. 4, the intervention effects were statistically significant for the overall levels of burnout, emotional exhaustion, personal accomplishment, job satisfaction, and nurses' own spiritual well being. The changes in these parameters were: 12% (emotional exhaustion), 13% (personal accomplishment), 15% (depersonalization), 21% (overall burnout, job satisfaction), and 23% (spiritual well being) (Table 3).

#### Overall Evaluation

The percentages of nurses who evaluated this program as "useful" or "very useful" were 85% (to understand the conceptual framework in caring for terminally ill patients feeling meaninglessness), 80% (to help in self-discussing nurses' personal beliefs, values, and life goals),

and 88% (to help in learning how to provide care for patients feeling meaninglessness).

#### Discussion

The most important finding of this study is a significant and clear beneficial effect of an educational intervention focusing on patient

Table 3  
Changes in Primary and Secondary End Points

	Before	After	Change (%)
Confidence (1-7)	3.29	4.97	51
Self-Reported Practice score (1-5)	3.70	4.16	12
Attitudes toward caring for patients feeling meaningless			
Willingness to help (1-8)	6.85	7.24	5.6
Positive appraisal (1-8)	6.06	7.12	18
Helplessness (1-8)	4.27	2.68	-37
Maslach Burnout Inventory			
Overall burnout (0-100)	66.1	52.1	-21
Emotional exhaustion (1-7)	4.11	3.62	-12
Personal accomplishment (1-7)	4.16	4.70	13
Depersonalization (1-7)	1.96	1.67	-15
Job satisfaction (0-10)	5.65	6.84	21
Spiritual well being (FACTI-Sp. 0-4)	2.15	2.65	23

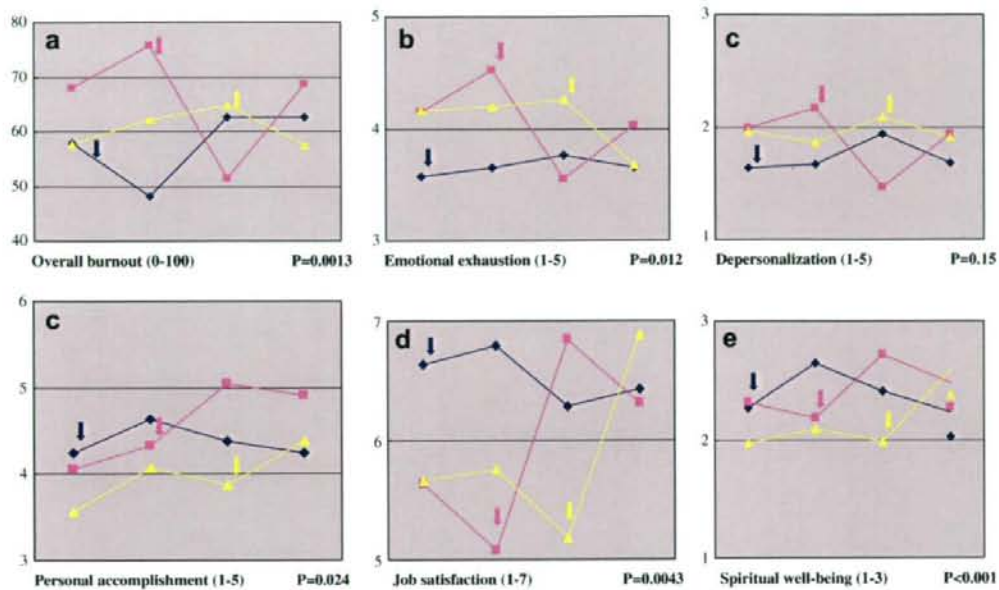


Fig. 4. Secondary end points.

meaninglessness on nurses' confidence, nurse-reported practice, and attitudes in providing care for such patients. This finding confirms our preliminary study that the intervention could provide considerable benefits for confidence, nurse-reported practice, and attitudes. Of note was the great change in nurses' confidence (51%) and helplessness (37%), in addition to 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%).<sup>15</sup> This result strongly suggests that this educational program can provide nurses with clinically useful specific strategies for caring for patients feeling meaninglessness.

From the fact that the change rate of willingness to help was much smaller than other variables, it could be interpreted that the participating nurses had voluntarily participated in this program and had higher motivation to help such patients. As for nurse-reported burnout, job satisfaction, and spiritual well being, our preliminary study failed to demonstrate beneficial effects,<sup>17</sup> but the present study, in addition to Wasner et al.'s pioneer work, showed positive results.<sup>14</sup> This discrepancy could be explained by the intensity of

the intervention: our preliminary work was only a five-hour workshop, whereas the two positive studies consisted of at least three month continuing education. The greater difference in the scores in the present study vs. Wasner et al.'s study could indicate that our intervention has a stronger role in preventing nurses' burnout: 21% vs. 6.6% (overall burnout), 21% vs. 9.7% (job satisfaction), and 23% vs. 7.8% (spiritual well being on the FACIT-Sp) 14. From the fact that intervention effects on burnout items in Group 1 was relatively lower compared with Groups 2 and 3, it could be interpreted that the instructor became more skillful in preventing nurses' burnout through the study periods.

A concern about this intervention is the possibility that the intervention effect may not be maintained, because some variables returned to the baseline levels after six to nine months. The finding suggests that this intervention may require periodic exposure or "maintenance therapy," and this should be a main focus of future research.

This study has several limitations. First, as this study measured nurse-reported outcomes, a future study should examine patient outcomes and/or observer-rating behavior of nurses.



Second, as the intervention was performed by one facilitator (the second author) and at a single institution, the generalizability might be limited. This shortcoming should be overcome in the next study by using different instructors and a multicenter design. Third, the intervention effects might be nonspecific effects, such as the supportive environment of a group session. We believe, however, that this possibility is low because specific outcomes, not only general burnout, significantly changed.

In conclusion, this educational intervention had a significant and clear beneficial effect on nurse-perceived confidence, practice, and attitudes in providing care for patients feeling meaninglessness, in addition to their levels of burnout and spiritual well being. Further intervention trials with patient-oriented end points using trained instructors are promising.

## References

- Breitbart W, Gibson, Poppito SR, Berg A. Psychotherapeutic interventions at the end of life: a focus on meaning and spirituality. *Can J Psychiatry* 2004;49:366-372.
- Chochinov HM. Dignity-conserving care. A new model for palliative care: helping the patient feel valued. *JAMA* 2002;287:2253-2260.
- Borneman T, Brown-Saltzman K. Meaning in illness. In: Ferrell BR, Coyle N, eds. *Textbook of palliative nursing*. New York: Oxford University Press, 2001.
- Kissane DW, Clarke DM, Street AF. Demoralization syndrome—a relevant psychiatric diagnosis for palliative care. *J Palliat Care* 2001;17:12-21.
- 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.
- 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.
- Murata H, Morita T. The Japanese spiritual care task force. Conceptualization of psycho-existential suffering by the Japanese task force: the first step of a nationwide project. *Palliat Support Care* 2006;4:279-285.
- White K, Wilkes L, Cooper K, Barbato M. The impact of unrelieved patient suffering on palliative care nurses. *Int J Palliat Nurs* 2004;10:438-444.
- Wakefield A. Nurses' responses to death and dying: a need for relentless self-care. *Int J Palliat Nurs* 2000;6:245-251.
- Sinclair HA, Hamill C. Does vicarious traumatization affect oncology nurses? A literature review. *Eur J Oncol Nurs* 2007;11:348-356.
- 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.
- 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.
- Fillion L, Dupuis R, Tremblay I, de Grâce G, Breitbart W. Enhancing meaning in palliative care practice: a meaning-centered intervention to promote job satisfaction. *Palliat Support Care* 2006;4:333-344.
- Wasner M, Longaker C, Fegg MJ, Borasio GD. Effects of spiritual care training for palliative care professionals. *Palliat Med* 2005;19:99-104.
- 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.
- 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.
- Morita T, Murata H, Hirai K, et al. Meaninglessness in terminally ill cancer patients: a validation study and nurse education intervention trial. *J Pain Symptom Manage* 2007;34:160-170.
- Maslach C, Jackson SE. The measurement of experienced burnout. *J Occup Behav* 1981;2:99-113.
- 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.
- Peterman AH, Fitchett G, Brady MJ, Hernandez L, Cella D. Measuring spiritual well-being in people with cancer: the functional assessment of chronic illness therapy-Spiritual Well-Being Scale (FACIT-Sp). *Ann Behav Med* 2002;24:49-58.
- 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.
- Nakai Y, Miyashita M, Sasahara T, et al. Factor structure and reliability of the Japanese version of the Frommelt Attitude Toward Care of the Dying Scale (FATCOD-B-J). *Jpn J Cancer Nurs* 2006;11:723-729.
- Frommelt KH. Attitudes toward care of the terminally ill—an educational intervention. *Am J Hosp Palliat Care* 2003;20:13-19.

*Appendix**Members of the Japanese Spiritual Care Task Force*

Tatsuya Morita, MD, Palliative Care Physician, Seirei Mikatahara General Hospital, Hamamatsu, Shizuoka

Yosuke Uchitomi, MD, PhD, Psychiatrist, Research Center for Innovative Oncology, National Cancer Center Hospital East, Kashiwa City, Chiba

Terukazu Akazawa, Medical Social Worker, Seirei Mikatahara General Hospital, Hamamatsu, Shizuoka

Michiyo Ando, RN, PhD, Nursing Psychologist, St. Mary College, Kurume City, Fukuoka

Chizuru Imura, RN, Certified Nurse (palliative care nursing), Seirei Mikatahara General Hospital, Hamamatsu, Shizuoka

Takuya Okamoto, MD, Palliative Care Physician, Eikoh Hospital, Fukuoka

Masako Kawa, RN, PhD, Nurse, The University of Tokyo, Tokyo

Yukie Kurihara, LMSW, LMT, Clinical Social Worker, Shizuoka Cancer Center, Shizuoka

Hirobumi Takenouchi, PhD, Philosopher, Shizuoka University, Shizuoka

Shimon Tashiro, PhD, Sociologist, Tohoku University, Sendai City, Miyagi

Kei Hirai, PhD, Psychologist, Osaka University

Yasuhiro Hirako, Buddhist Priest, Soto Institute for Buddhist Studies, Osaka

Hisayuki Murata, MA, Philosopher, Kyoto Notre Dame University, Kyoto

Tatsuo Akechi, MD, PhD, Psychiatrist, Nagoya City University Medical School, Nagoya, Aichi

Nobuya Akizuki, MD, PhD, Psychiatrist, Research Center for Innovative Oncology, National Cancer Center Hospital East, Kashiwa City, Chiba

Eisuke Matsushima, MD, PhD, Psychiatrist, Graduate School of Tokyo Medical and Dental University, Tokyo

Kazunari Abe, Occupational Therapist, Chiba Cancer Center, Chiba

Masayuki Ikenaga, MD, Palliative Care Physician, Yodogawa Christian Hospital, Osaka

Taketoshi Ozawa, MD, Palliative Care Physician, Yokohama Kosei Hospital, Yokohama, Kanagawa

Jun Kataoka, RN, Nurse, Aichi Prefectural College of Nursing and Health, Aichi

Akihiko Suga, MD, Palliative Care Physician, Shizuoka General Hospital, Shizuoka

Chizuko Takigawa, MD, Palliative Care Physician, Keiyukai Sapporo Hospital, Sapporo, Hokkaido

Keiko Tamura, Certified Nurse (oncology), Yodogawa Christian Hospital, Osaka

Wataru Noguchi, MD, Psychiatrist, Graduate School of Tokyo Medical and Dental University, Tokyo

Etsuko Maeyama, RN, Department of Adult Nursing/Palliative Care Nursing, School of Health Sciences and Nursing, Graduate School of Medicine, The University of Tokyo, Tokyo



# Palliative Care in Japan: Current Status and a Nationwide Challenge to Improve Palliative Care by the Cancer Control Act and the Outreach Palliative Care Trial of Integrated Regional Model (OPTIM) Study

Akemi Yamagishi, RN, MN, Tatsuya Morita, MD, Mitsunori Miyashita, RN, PhD, Nobuya Akizuki, MD, PhD, Yoshiyuki Kizawa, MD, Yutaka Shirahige, MD, PhD, Miki Akiyama, PhD, Kei Hirai, PhD, Tadashi Kudo, MA, Takuhiro Yamaguchi, PhD, Asuka Fukushima, RN, and Kenji Eguchi, MD, PhD

Palliative care is an essential part of integrated cancer treatment. To improve palliative care throughout Japan, a nationwide demonstration project, the Outreach Palliative Care Trial of Integrated Regional Model (OPTIM) study, is ongoing. This article reviews the current status and the problems of palliative care in Japan and introduces the OPTIM study. Although the number of palliative care services is increasing, empirical evidence shows the quality of life of cancer patients is still inadequate. The OPTIM study is an intervention trial targeting 4 areas across Japan. Primary end points are

quality of care reported by patients as well as the bereaved family, number of patients who received specialized palliative care services, and place of death. The interventions are comprehensively designed to cover all areas identified by the national task force. The OPTIM study will contribute to improve patients' quality of life by proposing a regional palliative care model suitable for Japan.

**Keywords:** palliative care; regional trial; neoplasms

Palliative care is an essential part of integrated cancer treatment.<sup>1</sup> Although palliative care should be provided throughout a whole region, a regionalized palliative care model has not been established in Japan. The Outreach Palliative Care Trial of Integrated Regional Model (OPTIM) study was therefore launched in 2007 to demonstrate a model suitable for the dissemination of high-quality palliative care in the Japanese community.

The two primary aims of this action paper are to review the current status and the problems of palliative care in Japan and provide an overview of the OPTIM study.

## Current Status of Palliative Care in Japan

### Health Care System and Specialty Training in Palliative Care

The health care system for specialized palliative care services in Japan has been progressing rapidly in this decade. Japan has 3 types of specialized palliative care services: palliative care units, hospital palliative care teams, and specialized home-care clinics.

Palliative care units are called "palliative care units" or "hospices" depending on their religious

background, but their clinical roles are essentially the same: intensive symptom control, psychosocial support, and end-of-life care for incurable cancer patients and their families. The first palliative care unit was established in 1981 in a private Christian hospital (Seirei Hospice).

The next landmark in the national strategy of palliative care was in 1989, with the publication of the end-of-life care report by the Ministry of Health, Labour and Welfare. This report resulted in the first government-approved palliative care units eligible for national health insurance coverage in 1990. The number of palliative care units has since dramatically increased, from 5 in 1990 to more than 170 in 2006.<sup>2,3</sup> Most palliative care units belong to general hospitals and provide integrated palliative care by an interdisciplinary team. This is the most common type of specialized palliative care service in Japan.

Hospital palliative care teams were first covered by national medical insurance in 2002.<sup>4</sup> The expected role of palliative care teams is to provide specialized palliative care to all cancer patients, including those receiving active cancer treatment, not only those in the advanced stage. For a palliative care team to be approved for national health insurance coverage, it must fulfill the requirements of the Ministry of Health, Labour and Welfare: interdisciplinary team activity, including at least 1 attending palliative care physician, a psychiatrist, and certified advanced-practice nurse. In 2007 the number of certified palliative care teams was approximately 60, and many hospitals intend to establish palliative care team activity.

Specialized home-care support clinics were first defined in 2006. These clinics are expected to provide home care for a wide range of patients in the community by a multidisciplinary team with 24-hour service, although the specialty requirement is still poorly defined. The clinics can obtain additional remuneration for their practices for terminally ill patients at home, and 8600 clinics have been established.

As for specialty training in palliative care, the Japanese Society for Palliative Medicine was established in 1996 as an academic association to conduct research, education, and dissemination of palliative care. It had approximately 6000 members in 2006. The number of advanced practice nurses is furthermore rapidly increasing: 79 oncology-certified nurse specialists and 891 certified nurses, including 420 in palliative care, 267 in pain management, and 204 in chemotherapy.

### Evidence to Suggest Poor Quality of Life of Cancer Patients

To date, no nationwide representative survey has clarified how cancer patients and their family members evaluated the quality of palliative care they actually received, although multiple surveys to understand the experience of patients and families are now ongoing. Empirical evidence, nonetheless, suggests a poor quality of life for cancer patients in Japan.

First, in a multicenter questionnaire survey of 630 bereaved family members of cancer patients admitted to palliative care units, 85% of 318 responding families reported that their relative had had distressing physical symptoms before admission to the palliative unit, and 50% reported that considerable or much improvement was necessary in the care they had received.<sup>5</sup>

Second, less than 10% of Japanese cancer patients received specialized palliative care services: 6.6% from palliative care teams and 2.2% from palliative care units.<sup>3,6</sup> Multiple Western studies have suggested that specialized palliative care services contribute to improving patients' quality of life, and family satisfaction was extremely high for inpatient palliative care services in Japan.<sup>2,7,8</sup> In the United Kingdom and United States, more than half of all cancer patients receive specialized palliative care.<sup>9-11</sup>

From the Japan Cancer Society (AY, AF) and Japan Department of Adult Nursing/ Palliative Care Nursing, Graduate School of Medicine, The University of Tokyo, Tokyo (AY, MM); Department of Palliative and Supportive Care, Palliative Care Team, and Seirei Hospice, Seirei Mikatahara General Hospital, Shizuoka (TM); Psycho-Oncology Division, Research Center for Innovative Oncology, National Cancer Center Hospital East, Chiba (NA); Graduate School of Comprehensive Human Science, University of Tsukuba, Ibaraki (YK); Shirahige Clinic, Nagasaki (YS); Faculty of Policy Management, Keio University, Kanagawa (MA); Graduate School of Human Sciences (TK, KH), and Center for the Study of Communication-Design, Department of Complementary and Alternative Medicine, Graduate School of Medicine, The University of Osaka, Osaka (KH); Department of Clinical Trial Data Management, Graduate School of Medicine, The University of Tokyo Hospital, Tokyo (TY); and the Division of Medical Oncology, Teikyo University School of Medicine, Tokyo, Japan (AF, KE).

Address correspondence to: Tatsuya Morita, MD, Seirei Mikatahara General Hospital, 3453 Mikatahara-cho, Hamamatsu, Shizuoka 433-8558, Japan; e-mail: tmorita@sis.seirei.or.jp.



**Table 1.** Palliative care in Japan, the United Kingdom, and United States of America

Variable	Japan	UK	USA
Cancer deaths per year	326 000	138 000	550 000
Use of specialized palliative care services, % of all cancer deaths			
Inpatient service	6.6	26	
Hospital consultation service	2.2	74	
Home-based service		69	99
Place of death, % of all cancer deaths			
Home	5.7	22	39
Palliative care unit or inpatient hospice	5.3	16	
Hospital or nursing home	86	60	54

Abbreviations: UK, United Kingdom; USA, United States of America.

(Table 1). The low involvement of specialized palliative care services suggests a lower quality of life for cancer patients in Japan.

Third, a discrepancy exists between the place where the patient preferred to die and the actual place of death. Although 50% of the Japanese general public expresses a preference to spend their final days at home and 30% in a palliative care unit,<sup>12</sup> the actual rate of death at home and inpatient specialized palliative care service is 5.7% and 5.5%, respectively, and most cancer patients die in hospitals (Table 1).<sup>13-15</sup> Because the location of death is an important element of the quality of life,<sup>16</sup> this finding suggests a poor quality of life for Japanese cancer patients.

Finally, opioid consumption is one sixtieth of that in the United States and one seventh of that in the United Kingdom.<sup>17</sup> Despite the differences in legal and medical regulations, as well as racial differences, this finding suggests that pain palliation of cancer patients in Japan is still not achieved.

### Barriers for Quality Palliative Care

To explore effective strategies to disseminate quality palliative care throughout the country, a national task force was organized and identified the barriers to quality palliative care, which were

1. lack of standardized clinical tools,
2. lack of knowledge about palliative care by the general public,
3. lack of whole-region organization to coordinate community palliative care, and
4. specialized palliative care services less available in community.<sup>18</sup>

### Lack of Standardized Clinical Tools

Standardized tools are important to maintain the quality and continuity of community palliative care.<sup>19</sup> Despite the variety of frameworks, guidelines, and clinical pathways available in English-speaking countries, in Japan, standard materials have not been developed or are inadequately disseminated. We have completed or are now performing a validation study of several key instruments to modify the original tools suitable for Japanese culture, including the Support Team Assessment Schedule, M.D. Anderson Symptom Inventory, Distress Thermometer, and Liverpool Care Pathway.<sup>20-22</sup> These instruments are gradually being disseminated to palliative care clinicians, but more distribution efforts to general practice are greatly required.

### Lack of Knowledge About Palliative Care

Despite strong empirical evidence that opioids for cancer pain rarely cause addiction, 30% of the Japanese general public believes that they are addictive, and such misapprehension is a significant barrier for better pain management.<sup>23-25</sup> Also, 34% of the general public in Japan knows about palliative care units compared with 70% in the United Kingdom.<sup>12,26</sup> Of note is that although 32% of the Japanese general public believes that palliative care units are a place where patients just wait for death, these negative perceptions significantly decreased after they actually used a specialized palliative care service.<sup>5,12</sup> This lack of knowledge and misinformation about opioids and palliative care is a considerable barrier to palliative care and pain control at an appropriate time, and education of the general public is of great value.

### Lack of Whole-Region Organization to Coordinate Community Palliative Care

The resources potentially available for community cancer patients are becoming more complicated and involve more than a single institution. Although an increasing number of Japanese hospitals have support centers available for community patients, they provide the services principally to their own patients. Whole-region organizations to implement comprehensive coordination for community patients are therefore strongly required.

### Specialized Palliative Care Services Less Available

Specialized home-care clinics have just started and are quite primitive in Japan, but specialized palliative care services are currently available only for institutionalized patients. In Europe, community palliative care teams provide consultation services for all patients in the community.<sup>27</sup> It is necessary to establish a medical system to provide specialized palliative care that is easily available for community cancer patients.

## The OTIM Study

### Overview

From these findings, palliative care in Japan has rapidly progressed in this decade, but many issues still must be resolved. To improve cancer care including palliative care throughout Japan, the Cancer Control Act was established in April 2007. The aims of this law are to promote cancer prevention and early detection, disseminate quality palliative care, and promote cancer research. The Ministry of Health, Labour and Welfare especially focuses on palliative care and has launched multiple nationwide projects to facilitate the dissemination of palliative care. One of these is the OPTIM study, a 5-year project from 2006 to 2011 with a yearly budget of US\$2.5 million.

### Aim of the OPTIM Study

The primary aim of the OPTIM study is to evaluate whether a systematic, multi-intervention regional palliative care program can improve the quality of

life of cancer patients in the community. The ultimate purpose of this study is to develop a success model of regional palliative care suitable for Japan.

### Subjects and Methods

This is a regional intervention trial measuring the end point before and after intervention. This trial involves 4 intervention regions across Japan with different palliative care system development: Chiba (Kashiwa city, Abiko city, Nagareyama city), Shizuoka (Hamamatsu city), Nagasaki (Nagasaki city), and Yamagata (Tsuruoka, Mikawa-cho; Figure 1). Chiba, Shizuoka, and Nagasaki have a growing organized system to provide palliative care led by a national cancer center, a general hospital, and a regional general practitioner association, respectively. Yamagata has an unorganized system of palliative care.

The study subjects are all residents of the participating regions, including the general public, patients, their families, and health care providers. A total of 0.2 million people are potential participants in this study.

### Intervention

The interventions of the OPTIM study are comprehensive and designed to cover all areas identified by the national task force.<sup>18</sup> Each intervention was determined by discussion among clinical specialists and researchers, including palliative care physicians, psychiatrists, nurses, medical social workers, and home care practitioners. In addition, we performed a preliminary survey of 8000 members of the general public and all medical health care providers in the target regions before planning the interventions, and the results were reflected in the details of the interventions.

The interventions include (1) disseminating standardized clinical tools, (2) providing appropriate information about palliative care to the general public, patients and their family, (3) establishing whole-region organization to coordinate community palliative care, and (4) establishing specialized palliative care services available in the community (Table 2).

Clinical tools prepared for this study include (1) assessment tools (comprehensive patient-reported assessment tools consisting of the Japanese version of the M.D. Anderson Symptom Inventory, Distress Thermometer, observer-rating Japanese version of



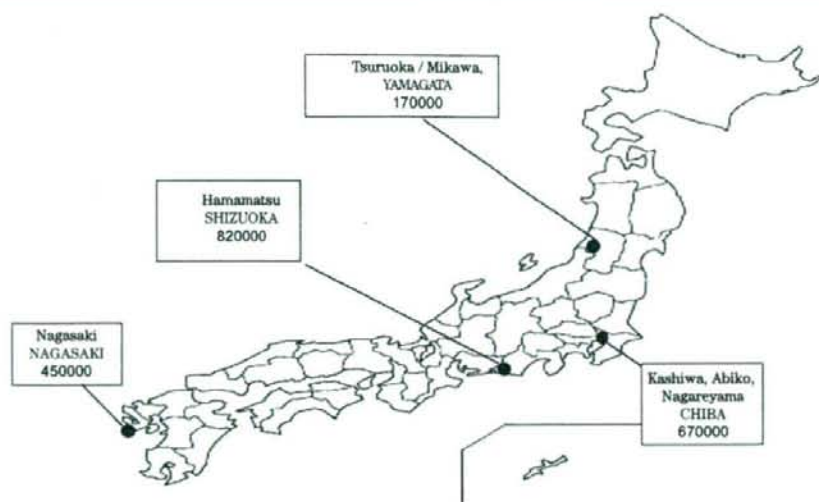


Figure 1. Participating areas of the Outreach Palliative Care Trial of Integrated Regional Model (OPTIM) study are shown with the resident population number.

Table 2. Interventions of the Outreach Palliative Care Trial of Integrated Regional Model Study

Target Area	Intervention	Main Contents
Lack of standardized clinical tools	To standardize and improve the knowledge, skills, and continuity of palliative care in the community	Dissemination of standardized clinical tools via printed and Web materials  Interactive workshop and on-demand Web lectures Contents Assessment tools Treatment algorithm Education materials for patients and family members Patient-held records Discharge planning program
Lack of knowledge about palliative care by the general public, patients and their family	To provide appropriate information about palliative care	Distribution of materials via hospitals, Web, visits, patient library, symposia, and local mass-media  Materials Leaflets and posters DVDs Books
Lack of whole-region organization to coordinate community palliative care	To establish regional palliative care centers to coordinate community palliative care	Coordination and information service about palliative care services for community residents  Regional conference to create local networks and identify local problems
Specialized palliative care services less available in community	To increase availability of specialized palliative care services for community patients	Community palliative care team Educational outreach

Abbreviation: DVD, digital video disc.

the Support Team Assessment Schedule), (2) 3-step ladder-based symptom control algorithm for 9 leading symptoms, (3) educational materials for patients and families, (4) patient-held records, and (5) discharge planning program with a discharge conference as an essential part.

### Outcome Measures

Primary end points are quality of palliative care as reported both by patients and the bereaved family, the number of patients who received specialized palliative care services, and place of death. The quality of palliative care is measured by the Care Evaluation Scale, a validated tool to quantify user-perceived quality of care.<sup>28</sup>

Secondary outcome measures include knowledge, competency, and difficulties of regional physicians and nurses, and quality indicators of regional palliative care, including opioid consumption and the number of nursing agencies providing around-the clock services.

### Conclusion

Palliative care in Japan is rapidly progressing through multiple nationwide actions with support from the Cancer Control Act. Palliative care specialists will overcome the challenges and grasp this unique opportunity in cooperation with other specialties to disseminate quality palliative care throughout Japan. The OPTIM study has received much attention and will contribute to improving patient quality of life by proposing a regional palliative care model suitable for Japan. The OPTIM study will be completed in March 2011, and initial results are expected in mid-2012.

### References

- World Health Organization. *National Cancer Control Programmes. Policies and Managerial Guidelines*. 2nd ed. Geneva, Switzerland: World Health Organization; 2002.
- Morita T, Chihara S, Kashiwagi T. Family satisfaction with inpatient palliative care in Japan. *Palliat Med*. 2002;16:185-193.
- Japan Hospice Palliative Care Foundation. *Hospice Kanwakea Hakusho* [in Japanese]. 3rd ed. Tokyo, Japan: Seikaisha; 2006.
- Morita T, Fujimoto K, Tei Y. Palliative care team: the first year audit in Japan. *J Pain Symptom Manage*. 2005; 29:458-465.
- Morita T, Akechi T, Ikenaga M, et al. Late referrals to specialized palliative care service in Japan. *J Clin Oncol*. 2005;23:2637-2644.
- Health and Welfare Statistics Association. *Kokumiseinodoukou 53* [in Japanese]. Tokyo, Japan: Health and Welfare Statistics Association; 2006.
- Higginson IJ, Finlay I, Goodwin DM, et al. Do hospital-based palliative teams improve care for patients or families at the end of life? *J Pain Symptom Manage*. 2002; 23:96-106.
- Higginson IJ, Finlay IG, Goodwin DM, et al. Is there evidence that palliative care teams alter end-of-life experiences of patients and their caregivers? *J Pain Symptom Manage*. 2003;25:150-168.
- The National Council for Palliative Care. *National Survey for Patient Activity Data for Specialist Palliative Care Services MDS Full Report for the Year 2004-2005*. Available from [http://www.aswcs.nhs.uk/Informatics/PalliativeCareMinimumDataset/MDS\\_Full\\_Report\\_2005.pdf](http://www.aswcs.nhs.uk/Informatics/PalliativeCareMinimumDataset/MDS_Full_Report_2005.pdf). Accessed February 10, 2007.
- National Center for Health Statistics. *Health, United States, 2005*. Table 31. Leading causes of death and numbers of deaths, according to sex, race, and Hispanic origin: United States, 1980 and 2003. Available from <http://www.cdc.gov/nchs/data/hs/hs05.pdf>. Accessed February 10, 2007.
- National Hospice and Palliative Care Organization. *NHPCO's Facts and Figures-2005 Findings*. Available from <http://www.alfa.org/files/public/NHPCO2005-facts-and-figures.pdf>. Accessed February 10, 2007.
- Sanjo M, Miyashita M, Morita T, et al. Preferences regarding end-of-life cancer care and associations with good-death concepts: a population-based survey in Japan. *Ann Oncol*. 2007;18:1539-1547.
- Ministry of Health, Labour and Welfare. *Population Survey Report 2005*. Available from [http://www.dbtk.mhlw.go.jp/toukei/data/010/2005/toukeihyou/0005626/t0124446/MC210000\\_001.html](http://www.dbtk.mhlw.go.jp/toukei/data/010/2005/toukeihyou/0005626/t0124446/MC210000_001.html). Accessed February 10, 2007.
- National Center for Health Statistics. *Worktable 307*. Deaths from 39 selected causes by place of death, status of decedent when death occurred in hospital or medical center, and age: United States, 2003. Available from [http://www.cdc.gov/nchs/data/dvs/MortFinal2003\\_WorkTable307.pdf](http://www.cdc.gov/nchs/data/dvs/MortFinal2003_WorkTable307.pdf). Accessed February 10, 2007.
- National Statistics. *Series DH1 no. 37 Mortality Statistics*. Table 17. Deaths: place of occurrence and sex by underlying cause and age-group, 2004. Available from [http://www.statistics.gov.uk/downloads/theme\\_health/Dh1\\_37\\_2004/DH1\\_no\\_37.pdf](http://www.statistics.gov.uk/downloads/theme_health/Dh1_37_2004/DH1_no_37.pdf). Accessed February 10, 2007.
- Miyashita M, Sanjo M, Morita T, et al. Good death in cancer care: a nationwide quantitative study. *Ann Oncol*. 2007;18:1090-1097.
- The International Narcotics Control Board (INCB). *Tables of Reported Statistics*. Available from [http://www.incb.org/pdf/e/tr/nar/2004/narcotics\\_part4\\_tables.pdf](http://www.incb.org/pdf/e/tr/nar/2004/narcotics_part4_tables.pdf). Accessed February 10, 2007.



18. Miyashita M, Sanjo M, Morita, et al. Barriers to providing palliative care and priorities for future actions to advance palliative care in Japan: a nationwide expert opinion survey. *J Palliat Med.* 2007;10:390-399.
19. Bruera E, Neumann CM, Gagnon B, et al. Edmonton regional palliative care program: impact on patterns of terminal cancer care. *CMAJ.* 1999;161:290-293.
20. Miyashita M, Matoba K, Sasahara T, et al. Reliability and validity of the Japanese version of the Support Team Assessment Schedule (STAS-J). *Palliat Support Care.* 2004;2:379-385.
21. Okuyama T, Wang XS, Akechi T, et al. Japanese version of the MD Anderson Symptom Inventory: a validation study. *J Pain Symptom Manage.* 2003;26:1093-1104.
22. Shimizu K, Akechi T, Okamura M, et al. Usefulness of the nurse-assisted screening and psychiatric referral program. *Cancer.* 2005;103:1949-1956.
23. Morita T, Miyashita M, Shibagaki M, et al. 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. Hojsted J, Sjogren P. Addiction to opioids in chronic pain patients: a literature review. *Eur J Pain.* 2007;11:490-518.
25. Ward SE, Goldberg N, Miller-McCauley V, et al. Patient-related barriers to management of cancer pain. *Pain.* 1993;52:319-324.
26. Koffman J, Burke G, Dias A, et al. Demographic factors and awareness of palliative care and related services. *Palliat Med.* 2007;21:145-153.
27. Kuin A, Courtens AM, Deliens L, et al. Palliative care consultation in the Netherlands: a nationwide evaluation study. *J Pain Symptom Manage.* 2004;27: 53-60.
28. Morita T, Hirai K, Sakaguchi Y, Maeyama E, Tsuneto S, Shima Y. Measuring the quality of structure and process in end-of-life care from the bereaved family perspective. *J Pain Symptom Manage.* 2004;27: 492-501.

## Cancer patients' reluctance to disclose their emotional distress to their physicians: a study of Japanese patients with lung cancer

Toru Okuyama<sup>1,2\*</sup>, Chiharu Endo<sup>1,2</sup>, Takashi Seto<sup>3</sup>, Masashi Kato<sup>2</sup>, Nobuhiko Seki<sup>3</sup>, Tatsuo Akechi<sup>1</sup>, Toshiaki A. Furukawa<sup>1</sup>, Kenji Eguchi<sup>4</sup> and Takashi Hosaka<sup>2</sup>

<sup>1</sup>Department of Psychiatry and Cognitive-behavioral Medicine, Nagoya City University Graduate School of Medical Sciences, Nagoya, Japan

<sup>2</sup>Course of Specialized Clinical Care, Psychiatry, Tokai University School of Medicine, Isehara, Kanagawa, Japan

<sup>3</sup>Course of Internal Medicine, Medical Oncology, Tokai University School of Medicine, Isehara, Kanagawa, Japan

<sup>4</sup>Oncology Center, Tokai University School of Medicine, Isehara, Kanagawa, Japan

\*Correspondence to:

Department of Psychiatry and  
Cognitive-behavioral Medicine,  
Nagoya City University  
Graduate School of Medical  
Sciences, Mizuho-cho, Mizuho-  
ku, Nagoya 467-8601, Japan.  
E-mail: okuyama@med.  
nagoya-cu.ac.jp

### Abstract

**Purpose:** To explore cancer patients' concerns about emotional disclosure (ED) to their physicians, and to investigate the factors associated with them.

**Subjects and Methods:** Randomly selected ambulatory patients with lung cancer participated in this study. An 18-item questionnaire to assess patients' beliefs regarding ED to their physicians was developed for this study. Factor analysis was used to extract the underlying factors of this scale. Patients were asked to answer this questionnaire along with other self-administered questionnaires.

**Results:** Complete data were available from 104 patients. Four factors were extracted by factor analysis: 'Hesitation to disturb the physicians by ED', 'No perceived need for ED', 'Negative attitude towards ED', and 'Fear of a negative impact of ED'. All factors reached standards of internal consistency. The prevalence of the above concerns, in that order, among the patients was 68, 67, 46, and 20%. Patients with high distress levels were significantly more likely to endorse 'Negative impact' ( $p = 0.02$ ). Older patients were more likely to report 'Negative attitude' ( $p = 0.06$ ), whereas male patients were more likely than females to report 'Hesitation' ( $p = 0.05$ ).

**Conclusion:** Knowledge of such patient-related barriers should better prepare physicians to build good communication channels with their cancer patients.

Copyright © 2007 John Wiley & Sons, Ltd.

**Keywords:** cancer; oncology; communication; psycho-oncology; depression

Received: 12 March 2007  
Revised: 1 July 2007  
Accepted: 7 July 2007

### Introduction

Cancer patients frequently have psychological distress. The prevalence of major depression and adjustment disorder among these patients have been reported to range from 5 to 35% [1]. Since depression is not only distressing and disturbs the patients' quality of life, but also kindles the desire for death, affects usage of health care and poses a burden for the family; intensive treatment of depression in these patients is essential [2].

Delivery of supportive and palliative care, including psychological support, is one of the primary tasks of oncologists. A global Core Curriculum in Medical Oncology, released by the American Society of Clinical Oncology (ASCO) and European Society for Medical Oncology (ESMO), includes 'Psychosocial aspects of cancer' as one of the topics [3]. The Japanese Society of Medical Oncology has also implemented this curriculum.

An accurate evaluation of the symptom severity is crucial to the provision of optimal symptom management. Emotional disclosure (ED) by patients themselves is a primal source of assessing the degree of psychological distress in the patients. However, patients often hesitate to share their emotional distress and/or concerns with their physicians [4,5], even though most consider their attending oncologist as an invaluable person with whom to discuss their emotional distress [6]. A survey of cancer patients' preferences for discussing their psychological problems showed that 67% of cancer patients were willing to discuss their problems with the physicians, but 26% were willing to do so only at the initiative of their doctor [4]. Furthermore, one study indicated that patients with higher degrees of distress were less likely to disclose their concerns [5].

Why are they reluctant to do so? To the best of our knowledge, few studies have been conducted to explore the concerns for patients who do not



discuss their emotional problems with their physicians in the cancer care setting. A study in the general practice setting in UK investigated the reasons for patients not discussing their emotional problems with their physicians [7], and identified the top two reasons as 'doctors do not have enough time' (48%), and 'there is nothing that the doctor can do' (39%). Another study conducted in the general practice setting in New Zealand revealed that patients believed that 'their general practitioner was not the best person to talk to' (34%), and 'mental problems should not be discussed at all' (28%) [8]. These may also be applicable in the cancer care setting [9,10].

The purpose of this study was to explore the cancer patients' concerns about ED to their physicians, and to investigate the factors associated with them.

## Subjects

The study subjects were ambulatory patients with lung cancer attending the outpatient clinic of the Respiratory Medicine Division of Tokai University Hospital, located in a suburban residential area, about 50 km from Tokyo, Japan. We chose this population as subjects since provision of better supportive care for them is urgently and highly required. In a study examining psychological distress and its relation to the site of cancer, Dugan *et al.* reported that primary lung cancer was strongly associated with psychological distress in cancer patients [11]. In addition, Zabora *et al.* and Carlson *et al.* have demonstrated that the highest prevalence of psychological distress was observed among patients with lung cancer [12,13]. The incidence of lung cancer in Japan is increasing, and it is the commonest cause for all cancer mortality in Japan and accounts for 18% of all cancer deaths. Furthermore, the prognosis of patients with lung cancer has been poor.

The eligibility criteria were (a) 18 years of age or older, (b) informed of the cancer diagnosis, (c) well enough to complete the questionnaire and participate in a brief interview, and (d) not suffering from severe mental or cognitive disorders. We selected participants at random using a visiting list and random number table only for logistic reasons (to control the number of patient enrolled per day).

This study was approved by the Institutional Review Board and Ethics Committee of Tokai University, Japan. Written consent was obtained from each patient after a thorough explanation of the purpose and method of the study.

## Methods

Patients were randomly sampled using a planned visiting list and a table of random numbers. After

informed consent had been obtained, the patients were asked to complete the self-administered questionnaires described below at home and mail them the next day. In the case of inadequate answers, clarifications were sought over the telephone.

### Reluctance for emotional disclosure

The Reluctance for Emotional Disclosure Questionnaire (REDQ) was developed for this study to investigate the patients' beliefs which might affect their ED to physicians, as there was no appropriate instrument available previously for this purpose. First, we conducted a systematic review to collect and create items that could be useful. Papers focusing on stigma, under-recognition, under-treatment of depression [14,15] or other symptoms such as pain [16] and fatigue [17] in cancer and non-cancer populations, or medical staff-patient communication [7,9,10] were investigated. Then, we developed a draft of this scale based on the review, and asked 10 inpatients with lung cancer to complete them. In-depth discussions about the issue were also conducted with them. The items with small between-patient variability were deleted. Finally, an 18-item questionnaire was developed. Each item was to be rated on a 5-point Likert scale (1[not at all] to 5[very much agree]).

### Psychological distress

The Hospital Anxiety and Depression Scale (HADS) was used to evaluate the psychological distress level of the cancer patients. This questionnaire, developed by Zigmond *et al.* [18], is composed of a 7-item anxiety subscale and a 7-item depression subscale to assess the patients' condition over the preceding week. The characteristic of this scale was that questions about physical symptoms were not included in this scale. We have established the reliability and validity of the Japanese version of this questionnaire in cancer patients [19]. The optimal cutoff point for screening high distress (adjustment disorder or major depressive disorder) was  $\frac{10}{11}$ .

### Sociodemographic and biomedical factors

An *ad hoc* self-administered questionnaire was used to obtain information on the sociodemographic status, including marital status, level of education, and employment status. Performance status, as defined by the Eastern Cooperative Oncology Group (ECOG), was evaluated by the attending physicians. All other medical information (clinical stage and anti-cancer treatment) was obtained from the patients' charts.



### Statistical analysis

Factor analysis followed by Varimax rotation was conducted to extract the underlying factors of REDQ. The number of items was identified by Keiser's criterion (eigenvalue of 1.0 or greater). Items having factor loading scores of less than 0.50 on all factors were deleted from each subscale to clarify the meaning of each factor. We calculated the average of the constituent items for each subscale. The reliability of the scale was evaluated by calculating Cronbach's alpha coefficient, a measure of the internal consistency of the responses to a group of items.

To determine the correlated factors, univariate analyses between each factor and the independent variables were performed using unpaired Student's *t*-tests. A *p* value of less than 0.05 was adopted as the significance level in all of the statistical analyses, and all *p* values reported are two-tailed. All statistical procedures were conducted with the SPSS 13.0J version software for Windows.

### Results

#### Patient characteristics (Table 1)

Data were available for 104 cancer patients. A pool of 123 potential lung cancer patients was identified for the study. Nineteen patients (16%) were excluded, including 5 (4%) who refused to participate, 5 with cognitive disturbances, 4 (3%) with serious illness, and 5 for other reasons. The patient characteristics are summarized in Table 1; of the total, 77% had advanced cancer (stage IIIb, IV, or recurrence). The mean HADS total score was  $12.6 \pm 7.4$ , and 58% scored above the validated cutoff of HADS for adjustment disorder and major depressive disorder (a score of 11 or more on a HADS total scale). Two physicians were enrolled in the study. Patients had been followed by the same physician and one physician had followed the majority of patients (87%).

#### Reasons for reluctance for ED; extracted from REDQ (Table 2)

Four factors were identified by Keiser's criterion. The results of the factor analysis are shown in Table 2. The first four variables comprising 'No perceived need for ED' showed significant loading on Factor 1. Two items, including items related to 'Fear of negative impact of ED' loaded on Factor 2. Four items related to 'Negative attitude to ED' loaded on Factor 3, and three items representing 'Hesitation to disturb physicians with ED', showed high loading on Factor 4. After deleting six items having item loading  $<0.50$  on any factors, we repeated factor analysis and found the same factor loading pattern. Factor 1 accounted for 21%, Factor 2 for 13%, Factor 3 for 14%, Factor 4 for 13% of the total variance in the data. Cronbach's alpha coefficients showing internal consistency reliability ranged from 0.72 to 0.86, indicating substantial consistency (Table 3). When we used a cutoff to determine reluctance in an expedient manner, the most frequently endorsed reason was 'Hesitation' (68%), followed by 'No perceived need' (67%). About 90% of the patients had one or more reasons. Even if we excluded 'No perceived need' from the analysis, 77% of the patients had at least one reason and 44% had two or more reasons.

#### Factors correlated with each subscale of the REDQ (Table 4)

The results of univariate analyses are shown in Table 4. Patients with high distress levels were significantly more likely to endorse 'Negative impact' ( $p = 0.02$ ), whereas patients with low distress levels were significantly more likely to endorse 'No perceived need'. 'Negative attitude' and 'Hesitation' were not correlated with the level of distress. With regard to demographic factors, older patients were more likely to report 'Negative attitude' ( $p = 0.06$ ), whereas male patients were

Table 1. Demographical and clinical characteristics of patients ( $N = 104$ )

Sample characteristic		N	(%)
Age (year)	Mean: 65 (SD=10); median: 65 (range: 43-84)		
Sex	Male	82	78
Spouse	Married	81	22
Job	Employed (full-time/part-time)	27	26
Clinical stage	Advanced (IIIb, IV, or recurrence)	80	77
ECOG performance status <sup>a</sup>	0	21	20
	1	77	74
	2 or worse	6	6
History of anticancer treatment	Operation	15	14
	Chemotherapy	95	91
	Radiation therapy	97	93
Days after diagnosis	Mean: 358 (SD=502); median: 159 (range: 24-2413)		
HADS total score	Mean: 12.6 (SD=7.4); median: 12 (range: 0-30)		

<sup>a</sup>ECOG: Eastern Cooperative Oncology Group.