

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

Original Article

Symptom Prevalence and Longitudinal Follow-Up in Cancer Outpatients Receiving Chemotherapy

Akemi Yamagishi, RN, MNS, Tatsuya Morita, MD, Mitsunori Miyashita, RN, PhD, and Fukuko Kimura, MD, PhD

Japan Cancer Society (A.Y.), Tokyo; Department of Adult Nursing/Palliative Care Nursing (A.Y., M.M.), School of Health Sciences and Nursing, Graduate School of Medicine, The University of Tokyo, Tokyo; Department of Palliative and Supportive Care, Palliative Care Team and Seirei Hospice (T.M.), Seirei Mikatabara Hospital, Hamamatsu; and International University of Health and Welfare (A.Y., F.K.), Tokyo, Japan

Abstract

Palliative care for cancer patients receiving chemotherapy in the outpatient setting is important. The aims of this study were 1) to identify symptom prevalence and intensity in cancer patients receiving chemotherapy and 2) to describe longitudinal follow-up data obtained from repeated assessment using the distress thermometer (DT). Questionnaires were distributed to consecutive cancer outpatients newly starting chemotherapy at the first appointment and at every hospital visit. The questionnaire included the severity of 11 symptoms (M. D. Anderson Symptom Inventory [MDASI], Japanese version), the DT, and the need for help in four psychosocial areas (decision-making, economic problems, nutrition, and daily activities). In total, 4000 questionnaires were returned by 462 patients. The frequently identified problems were oral problems (21%), insomnia (19%), psychological distress (defined as the DT score of 6 or more; 15%), help with information and decision-making (14%), severe fatigue (8.2%), and severe appetite loss (6.3%). Cluster analysis identified four symptom clusters: 1) fatigue and somnolence; 2) pain, dyspnea, and numbness; 3) nausea, appetite loss, and constipation; and 4) psychological distress. Of 165 patients with a DT of score 6 or more, 115 patients (70%) demonstrated a DT score below 6 at a median of 17 days' follow-up. In the remaining 50 patients who had a DT score of 6 or more at follow-up, 34 patients (68%) had one or more physical symptoms rated at 7 or more on an 11-point numeric rating scale. Compared with patients with a DT score below 6 at follow-up, patients with a DT score of 6 or more at follow-up had higher levels of all physical symptoms. Frequent symptoms experienced by cancer outpatients receiving chemotherapy may be categorized as: 1) psychosocial issues (insomnia, psychological distress, decision-making support); 2) nutrition-gastrointestinal issues (oral problems, appetite loss, nausea); 3) fatigue; and 4) pain, dyspnea, and numbness. Developing a systematic intervention program targeting these four areas is urgently required. The DT score may be highly influenced by coexisting physical symptoms, and future studies to develop an appropriate

This study is supported by the Sasakawa Health Science Foundation.

Address correspondence to: Tatsuya Morita, MD, Palliative Care Team and Seirei Hospice, Seirei

Mikatabara Hospital, 3453 Mikatabara-cho, Hamamatsu, Shizuoka 433-8558, Japan E-mail: tmorita@sis.seirei.or.jp

Accepted for publication: April 6, 2008.

system to identify patients with psychiatric comorbidity are necessary. *J Pain Symptom Manage* 2008;■:■-■. © 2008 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Key Words

Palliative care, neoplasms, chemotherapy, outpatient

Introduction

Increasing numbers of cancer patients receive chemotherapy in the outpatient setting,¹ and symptom palliation for these outpatients is urgently required. The recent literature suggests a broad range of palliative care needs, including physical symptoms, psychological distress, help with decision-making, and economical and practical support.²⁻⁷

Knowledge of symptom prevalence is important in clinical practice: 1) to anticipate problems and needs of patients; 2) to plan care for patients; and 3) to educate clinical staff to focus on particular symptoms.⁸ To clarify symptom prevalence and understanding patient needs are the first steps to establish an effective palliative care system for patients.

Although many studies have addressed symptom prevalence in cancer patients, their findings may not generalize to cancer outpatients receiving chemotherapy, because: 1) most studies include cancer patients receiving no anticancer treatments,⁹⁻¹³ and few have specifically addressed cancer patients receiving chemotherapy; 2) sample sizes are usually small and nonrepresentative (i.e., limited to a certain specialty or patients consenting to a research intervention); and 3) no systematic survey has been performed in Japanese patients. In addition, cancer patients often have multiple concurrent symptoms,¹⁴⁻¹⁸ and symptom management has shifted from individual symptoms to symptom clusters,¹⁹⁻²¹ but a few empirical studies have examined clustering symptoms in outpatient cancer patients receiving chemotherapy. To address these limitations, the first aims of this study were 1) to clarify the prevalence of physical and psychological symptoms and concerns among a representative sample of cancer patients receiving chemotherapy in the outpatient setting and 2) to evaluate symptom clusters in this study population.

One of the most important symptoms is psychiatric comorbidity, including major depression and adjustment disorders. Despite the importance of early diagnosis and treatment, psychiatric comorbidity is difficult to identify and is often overlooked.^{22,23} Recent empirical studies suggested that the distress thermometer (DT) can be an appropriate method to identify cancer patients with major depression and adjustment disorder.²⁴⁻²⁷ The study populations in these studies, however, were limited to cancer patients referred to a psychiatric consultation service or a palliative care unit, or awaiting bone marrow transplantation, and only cross-sectional assessments were obtained. Longitudinal data from the outpatient chemotherapy setting, where the patient often experiences short-term deterioration and improvement of physical symptoms related to chemotherapy, are lacking. Clarifying longitudinal changes and the effects of physical symptoms on the DT can contribute to better understanding of the DT as a tool to identify psychiatric comorbidity in outpatient chemotherapy settings. The second aim of this study was thus to explore longitudinal change and the effects of physical symptoms on the DT.

Patients and Methods

This study included all cancer patients newly starting chemotherapy, with primary tumor sites of the lung, stomach or intestine, pancreas, bile duct, breast, ovary, and uterus from April 2006 to December 2007. At the appointment regarding chemotherapy, pharmacists handed out a self-report questionnaire, with coaching on how to complete it.²⁸ This intervention was part of general instruction for outpatient chemotherapy, and required 10 to 20 minutes for completion. All pharmacists received an hour of educational instruction by the second author. Questionnaires were

thereafter distributed at every hospital visit. If the patients refused to complete the questionnaire or recognized no need, they were not obliged to complete it.

Demographic and medical variables (age, sex, primary cancer site, and opioid consumption) were obtained from medical charts. Opioid consumption was calculated as the daily amounts (mg) of oral morphine using the standard calculation ratio (transdermal fentanyl, 25 µg/hour = oral oxycodone, 40 mg = oral morphine, 60 mg).

The Institutional Review Board approved the ethical and scientific validity of a retrospective analysis of the questionnaire data obtained as part of routine clinical activity. Admitted patients gave written consent that their clinical information could be used for clinical research.

Questionnaire

The study group developed the questionnaire on the basis of existing validated instruments^{24,29-32} (available in our previous report²⁸). The questionnaire included 1) an open-ended question about the patient's greatest concerns; 2) 0-10 numeric rating scales of eight physical symptoms (pain, dyspnea, nausea, appetite loss, somnolence, fatigue, constipation, numbness) adopted from the Japanese version of the M. D. Anderson Symptom Inventory (MDASI)²⁹; 3) presence or absence of oral problems, fever, and insomnia; 4) a 0-7 numeric rating scale of overall quality of life adopted from item 29 of the European Organization for Research and Treatment of Cancer (EORTC)-C30 questionnaire³⁰; 5) the DT^{24,31}; 6) presence or absence of a need for help in four areas, i.e., information about treatment and decision-making, economic problems, nutrition, and daily activities^{7,32}; wish for help from the specialized palliative care service.

Analyses

The prevalence of problems was calculated for each questionnaire. Analyses of opioid consumption were performed only for patients receiving opioids. For calculations, we adopted the definition of moderate and severe symptom intensity for MDASI items as 4-6 and 7-10, respectively. We used cutoff points on the DT of 6 or more based on previous findings,^{24,31} and follow-up data of the DT was

defined as the score obtained at a visit closest to two weeks after the initial assessment and within four weeks. We determined that a patient had problems if s/he had MDASI symptoms score as 7 or more, an oral problem, fever, insomnia, a DT score of 6 or more, or an expressed need for any help with information and decision-making, nutrition, economic problems, or daily activities.

For comparisons, age was classified into two groups (less than 60 and 60 or more years), and primary tumor sites were classified into three groups (chest, breast, and gastrointestinal). Univariate analysis was performed by the Mann-Whitney test or Kruskal-Wallis test, where appropriate. The effect of age was estimated with adjustment for gender and primary tumor site, and the effect of gender was estimated with adjustment for age and primary tumor site.

We performed cluster analysis and displayed a dendrogram using average linkage. Clusters were formed based on the distance between symptom ratings, which were calculated using squared Euclidian distances.

To explore the longitudinal change and effects of physical symptom on the DT, we initially identified all patients who had a DT score of 6 or more at any time during the study period. We then classified them into two groups: those with a DT score that declined to less than 6 at the follow-up and those with a DT score of 6 or more at the follow-up. We compared their demographic factors and the intensity of all physical symptoms.

For statistical analysis, SPSS for Windows (version 11.0) was used.

Results

During this study period, 472 patients newly started chemotherapy, and 10 refused to complete the questionnaire. In total, we obtained 4000 questionnaires from 462 patients (compliance rate, 98%). Each patient completed a median of six questionnaires during the study period. The percentages of missing values ranged from 2.8% (appetite loss) to 4.8% (dyspnea). Table 1 summarizes the patient characteristics. Forty-seven patients received opioid, with a mean of 36 mg oral morphine equivalent/day (range, 5.0-170;

Table 1
Patient Characteristics (n = 462)

	n (%)
Age (yr ± SD)	62 ± 11
Sex	
Male	209 (45)
Female	253 (55)
Primary sites	
Lung, chest	150 (33)
Breast	113 (25)
Colon, rectum	65 (14)
Stomach	74 (16)
Uterus, ovary	33 (7.1)
Pancreas, bile duct	19 (4.1)
Others	8 (1.7)
Chemotherapy regimens	
Carboplatin and taxanes	100 (21)
Oral tegafur, gimeracil, oteracil with/without taxanes	80 (17)
Taxanes	76 (16)
Doxorubicin and cyclophosphamide	75 (16)
Fluorouracil	47 (10)
Gemcitabine	20 (4.3)
Oxaliplatin and 5-fluorouracil/leucovorin	10 (2.1)
Irinotecan (with/without taxanes)	9 (1.9)
Trastuzumab (with/without taxanes)	8 (1.7)
Gefitinib	7 (1.5)
Low-dose cisplatin and 5-fluorouracil	3 (0.6)
Vinorelbine	2 (0.4)
Oral capecitabine	2 (0.4)
Others	23 (7.1)

oral oxycodone, n = 25; transdermal fentanyl, n = 11; and oral morphine, n = 11).

Symptom Prevalence and Symptom Clusters

Frequently identified problems were oral problems (21%), insomnia (19%), psychological distress (defined as the DT score of 6 or more; 15%), needing help with information and decision-making (14%), severe fatigue (8.2%), and severe appetite loss (6.3%) (Table 2). As a whole, problems were identified in half of all questionnaires.

Table 3 summarizes the effects of age and gender on each symptom. Younger patients reported significantly higher intensity of pain and nausea, and male patients reported significantly higher intensity of fatigue, dyspnea, appetite loss, and somnolence, after adjustment for other demographic variables. Opioid consumption was significantly higher in male patients.

Four symptom clusters emerged in this population (Fig. 1): 1) fatigue and somnolence; 2) pain, dyspnea, and numbness; 3) nausea, appetite loss, and constipation; and 4) psychological distress.

Table 2
Problems Identified in 4000 Questionnaires

	Prevalence (%) ^a	Mean ± SD (median) ^b		
Physical problems				
MDASI items	Severe	Moderate	Total	
Fatigue	8.2	15	23	2.2 ± 2.5 (1.0)
Appetite loss	6.3	11	17	1.6 ± 2.4 (0.0)
Constipation	4.9	11	16	1.5 ± 2.2 (0.0)
Somnolence	4.6	9.1	15	1.7 ± 2.2 (1.0)
Pain	3.6	11	14	1.5 ± 2.0 (1.0)
Dyspnea	3.5	9.0	13	1.2 ± 2.0 (0.0)
Numbness	5.3	6.9	12	1.2 ± 2.2 (0.0)
Nausea	2.4	6.2	9.0	0.9 ± 1.7 (0.0)
Oral problems			21	
Fever			6.8	
Psychological problems				
Insomnia			19	
DT			15	
Concern				
Information and help with decision-making			14	
Nutrition			5.6	
Daily activities			4.6	
Economic problems			2.4	

^aThe percentages of responses with moderate (4–6) and severe (7–10) symptom intensity for MDASI items; the percentages of score of 6 or more for the DT; the percentages of problem presence for other items.

^bMean values calculated for only MDASI items.

Longitudinal Change in the DT

Of 462 patients, 170 patients (37%) had a DT score of 6 or more at any time during the study period. Owing to a lack of follow-up data in five patients, we used 165 patients for follow-up analyses, and the median interval from the initial assessment was 17 days (range, 7–28 days).

Of 165 patients with a DT score of 6 or more, 115 patients (70%) had a score below 6 at follow-up (Fig. 2). In the remaining 50 patients who had a DT score of 6 or more at follow-up, 34 patients (68%) had one or more physical symptoms rated as 7 or more, and an additional 12 patients (24%) had one or more physical symptoms rated at 4 to 6.

Compared with patients with a DT score below 6 at follow-up, patients with a continuing DT score of 6 or more had higher levels of all physical symptoms at follow-up, including pain, dyspnea, nausea, appetite loss, somnolence, fatigue, constipation, and numbness (Table 4). The level of the DT and all physical symptoms in the initial assessment

Table 3
Association between Symptom Intensity and Age, Gender, and Primary Tumor Site

	Age			Gender			Primary Tumor Sites			
	<60	>60	P	Male	Female	P	Abdominal	Chest	Breast	P
Fatigue	2.2 ± 2.3	2.2 ± 2.6	0.51	2.3 ± 2.6	2.1 ± 2.4	<0.001	2.5 ± 2.7	1.5 ± 2.1	2.3 ± 2.3	<0.001
Pain	1.7 ± 1.9	1.5 ± 2.0	0.003	1.5 ± 2.0	1.7 ± 2.1	0.70	1.6 ± 2.0	1.3 ± 2.0	1.9 ± 2.1	<0.001
Numbness	1.4 ± 2.2	1.1 ± 2.1	0.71	0.9 ± 1.8	1.5 ± 2.5	0.16	1.1 ± 1.8	0.7 ± 1.7	2.2 ± 3.0	<0.001
Dyspnea	1.2 ± 1.9	1.3 ± 2.0	0.41	1.3 ± 2.0	1.1 ± 1.9	<0.001	1.2 ± 1.8	1.3 ± 2.1	1.2 ± 2.0	0.15
Appetite loss	1.6 ± 2.3	1.7 ± 2.4	0.33	1.8 ± 2.5	1.5 ± 2.2	0.004	1.9 ± 2.5	1.4 ± 2.3	1.3 ± 2.1	<0.001
Nausea	1.1 ± 2.0	0.8 ± 1.6	<0.001	0.9 ± 1.8	0.9 ± 1.8	0.84	1.2 ± 1.8	0.6 ± 1.8	0.8 ± 1.7	<0.001
Somnolence	1.7 ± 2.0	1.8 ± 2.3	0.62	1.8 ± 2.3	1.7 ± 2.1	<0.001	2.0 ± 2.3	1.3 ± 2.0	1.8 ± 2.1	<0.001
Constipation	1.5 ± 2.1	1.6 ± 2.3	0.50	1.7 ± 2.4	1.4 ± 2.1	0.042	1.9 ± 2.3	1.2 ± 2.2	1.2 ± 2.0	<0.001
Psychological distress	3.2 ± 2.5	3.0 ± 2.8	0.066	2.9 ± 2.8	3.2 ± 2.6	0.32	3.2 ± 2.7	2.6 ± 2.7	3.5 ± 2.6	<0.001
Opioid consumption ^a	29 ± 27	28 ± 20	0.20	33 ± 25	18 ± 13	0.019	37 ± 28	23 ± 13	18 ± 15	<0.001

P values for age were adjusted for gender and primary tumor sites. P values for gender were adjusted for age and primary tumor sites.

^aOral morphine equivalent (mg/day).

demonstrated no significant difference between the groups.

Discussion

This is, to our knowledge, the first large study to identify symptom prevalence and intensity in cancer patients receiving chemotherapy, in addition to providing longitudinal follow-up data from the DT, in the outpatient setting of a general hospital, a typical regional cancer center in Japan.

The first important finding of this study was the clarification of the types of symptoms and concerns observed in cancer outpatients receiving chemotherapy. In this study, the predominant problems were psychosocial issues (insomnia, psychological distress, concern about information, and decision-making), nutrition-related issues (oral problems and appetite loss), and fatigue. Furthermore, four distinct symptom clusters were identified: 1) fatigue and somnolence; 2) pain, dyspnea, and numbness; 3) nausea, appetite loss, and

constipation; and 4) psychological distress. From these findings, the outpatient chemotherapy department should establish a palliative care program targeting: 1) psychosocial issues (insomnia, psychological distress, decision-making support); 2) nutrition-gastrointestinal issues (oral problems, appetite loss, nausea); 3) fatigue; and 4) pain, dyspnea, and numbness. Pharmacological treatments, collaboration with mental health care professionals and dentists, and cognitive-behavioral nursing interventions are promising, and should be tested in future intervention trials of Japanese cancer patients.³³⁻³⁸

The second important finding of this study was longitudinal follow-up data from patients receiving outpatient chemotherapy who were repeatedly assessed using the DT. This is the first study to explore longitudinal changes in the DT in the outpatient chemotherapy setting. In this setting, 11% of all patients had a DT score of 6 or more at any time of treatment. The majority (70%), however, demonstrated the DT score below 6 within four

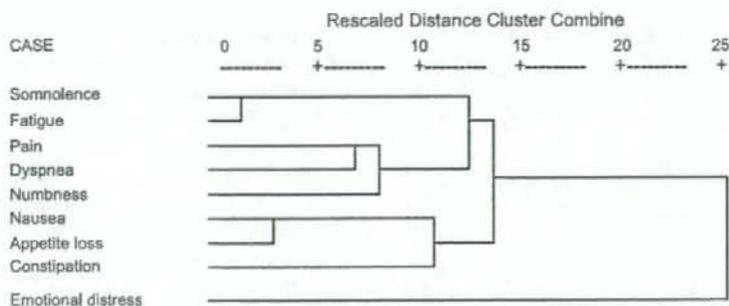


Fig. 1. Symptom cluster.

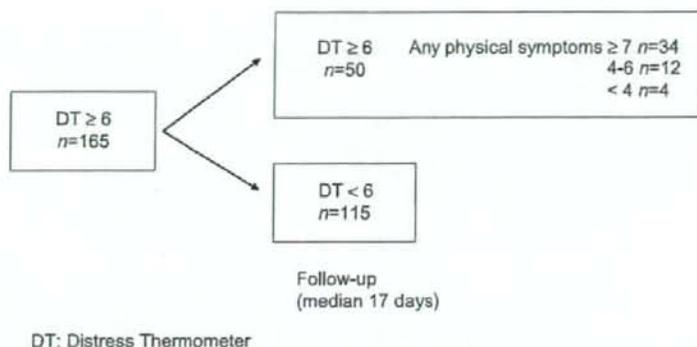


Fig. 2. Changes in the DT.

weeks, and the change in a DT was strongly associated with changes in physical symptoms. This result suggests that chemotherapy-related physical symptoms may highly influence the DT and result in rapid changes within several weeks in the outpatient chemotherapy setting. Future study is required to assess the usefulness of the DT as a clinical tool to identify patients with psychiatric comorbidity. Modifying the procedure, such as two-point follow-up, or encouraging symptom control to be

Table 4
Comparison of Patients with a DT of 6 or More and Below 6 at Follow-up

	Patients with DT of 6 or More at Follow-up (n = 50)	Patients with DT below 6 at Follow-up (n = 115)	P Value
Age	63 ± 9.6	63 ± 11	0.26
Sex (male)	56% (n = 28)	44% (n = 51)	0.17
At initial assessment			
Pain	3.2 ± 2.6	2.8 ± 2.8	0.63
Dyspnea	2.3 ± 2.6	1.8 ± 2.5	0.49
Nausea	2.1 ± 2.8	2.2 ± 3.0	0.11
Appetite loss	3.4 ± 3.1	3.4 ± 3.3	0.38
Somnolence	3.0 ± 2.5	2.5 ± 2.4	0.89
Fatigue	4.6 ± 3.0	3.5 ± 2.8	0.56
Constipation	2.4 ± 2.6	2.9 ± 3.2	0.027
Numbness	2.8 ± 3.0	1.8 ± 2.7	0.16
DT	7.4 ± 1.2	7.6 ± 1.3	0.15
At the follow-up			
Pain	3.5 ± 2.7	1.5 ± 1.8	0.001
Dyspnea	3.1 ± 2.8	1.1 ± 1.8	<0.001
Nausea	2.2 ± 2.7	0.48 ± 1.0	<0.001
Appetite loss	3.7 ± 3.0	1.1 ± 1.8	<0.001
Somnolence	3.9 ± 2.7	1.3 ± 1.6	<0.001
Fatigue	5.0 ± 3.0	1.9 ± 2.3	0.005
Constipation	3.1 ± 2.9	1.4 ± 2.3	<0.001
Numbness	3.0 ± 3.1	1.0 ± 1.7	<0.001

Analyses were performed on patients who had a DT score of 6 or more at any time in this study period (n = 165).

maximized before rating the DT, may be necessary. In the meantime, clinicians should note that a high score in the DT is not simply the indicator of psychiatric comorbidity. DT often indicates the need of palliating co-existing physical symptoms.

Age and gender differences in the symptoms of cancer patients are a focus of some researches.³⁹⁻⁴⁵ Consistent with previous findings from a systematic review of symptom prevalence,⁴⁴ higher pain intensity was significantly associated with younger age. This result indicates that younger patients need special attention in terms of pain management and active monitoring of pain. We also observed gender differences in some symptoms: male patients reported a higher intensity of fatigue, dyspnea, appetite loss, and somnolence, in addition to a higher dose of opioids, after adjustment for age and primary tumor sites. This result is not consistent with a large-scale study of patients receiving no anticancer treatments that revealed a gender difference in the prevalence of nausea.^{44,45} Potential interpretations of these differences include: 1) different measurement methods (i.e., symptom intensity vs. frequency); 2) different treatment settings (receiving chemotherapy in the outpatient setting vs. palliative phase); and 3) analyses with or without adjustment for other factors. To determine the effects of age and gender on symptom intensity in this population, more pooled data from this setting is necessary.

This was a descriptive study of clinical experience and thus had considerable limitations. First, as the patients were a heterogeneous sample of primary tumor sites, stages, and

chemotherapy regimens, the results cannot be automatically generalized to specific target populations. We believe that this is not a fatal flaw of this study, but rather can be a strength, because we need to develop a useful system for heterogeneous outpatients receiving chemotherapy. Second, this was a single-institution study. We believe, however, that the results are generalizable to other institutions, as our hospital is a typical general hospital functioning as a regional cancer center. Third, we adopted the single-item DT to increase patients' compliance. The combined use of the DT and impact thermometer (i.e., the degree of interference to daily activity) might decrease the influence of physical symptoms. Finally, we did not analyze the effects of chemotherapy cycle of each regimen on symptom intensity, and this should be explored in a future study.

In conclusion, frequent symptoms of cancer outpatients receiving chemotherapy are categorized as: 1) psychosocial issues (insomnia, psychological distress, decision-making support); 2) nutrition-gastrointestinal issues (oral problems, appetite loss, nausea); 3) fatigue; and 4) pain, dyspnea, and numbness. Developing a systematic intervention program targeting these four areas is urgently required. The DT might be an effective tool to monitor psychological distress but can be highly influenced by coexisting physical symptoms. Future studies are required to determine the intervention effects in the above four areas and to develop more appropriate procedure to identify patients with psychiatric comorbidity.

References

1. Earle CC, Neville BA, Landrum MB, et al. Trends in the aggressiveness of cancer care near the end of life. *J Clin Oncol* 2004;22:315-321.
2. Bang SM, Park SH, Kang HG, et al. Changes in quality of life during palliative chemotherapy for solid cancer. *Support Care Cancer* 2005;13:515-521.
3. Munkres A, Oberst MT, Hughes SH. Appraisal of illness, symptom distress, self-care burden and mood states in patients receiving chemotherapy for initial and recurrent cancer. *Oncol Nurs Forum* 1992;19:1201-1209.
4. Matsuyama R, Reddy S, Smith TJ. Why do patients choose chemotherapy near the end of life? A review of the perspective of those facing death from cancer. *J Clin Oncol* 2006;24:3490-3496.
5. Schonwetter RS, Roscoe LA, Nwosu M, Zilka B, Kim S. Quality of life and symptom control in hospice patients with cancer receiving chemotherapy. *J Palliat Med* 2006;9:638-645.
6. Whitmer KM, Pruemer JM, Nahleh ZA, Jazieh AR. Symptom management needs of oncology outpatients. *J Palliat Med* 2006;9:628-630.
7. Newell S, Sanson-Fisher RW, Girgis A, Ackland S. The physical and psychosocial experiences of patients attending an outpatient medical oncology department: a cross-sectional study. *Eur J Cancer Care* 1999;8:69-72.
8. Higginson IJ, Addington-Hall JM. The epidemiology of death and symptoms. In: Doyle D, Hanks G, Cherny N, Calman K, eds. *Oxford textbook of palliative medicine*, 3rd ed. Oxford: Oxford University Press, 2005: 14-24.
9. Conill C, Verger E, Henriquez I, et al. Symptom prevalence in the last week of life. *J Pain Symptom Manage* 1997;14:328-331.
10. Mercadante S, Fulfaro F, Casuccio A. The impact of home palliative care on symptoms in advanced cancer patients. *Support Care Cancer* 2000;8:307-310.
11. Mercadante S, Casuccio A, Fulfaro F. The course of symptom frequency and intensity in advanced cancer patients following at home. *J Pain Symptom Manage* 2000;20:104-112.
12. Meuser S, Pietruck C, Radbruch L, et al. Symptom during cancer pain treatment following WHO guidelines: a longitudinal follow-up study of symptom prevalence, severity and etiology. *Pain* 2001;93:247-257.
13. Wachtel T, Allen-Masterson S, Reuben D, Goldberg R, Mor V. The end stage cancer patient: terminal common pathway. *Hosp J* 1988;4:43-80.
14. Chang VT, Hwang SS, Deurman M, Kasmnis BS. Symptom and quality of life survey of medical oncology patients at a veteran affairs medical center: a role for symptom assessment. *Cancer* 2000;88:1175-1183.
15. Chen ML, Chang HK. Physical symptom profiles of depressed and non-depressed patients with cancer. *Palliat Med* 2004;18:712-718.
16. Given B, Given CW, McCorkle R, et al. Pain and fatigue management: results of a nursing randomized clinical trial. *Oncol Nurs Forum* 2002;29:949-956.
17. Armstrong TS, Cohen MZ, Eriksen LR, Hickey JV. Symptom clusters in oncology patients and implications for symptom research in people with primary brain tumors. *J Nurs Scholarsh* 2004;36:197-206.

18. Chen ML, Tseng HC. Symptom clusters in cancer patients. *Support Care Cancer* 2006;14:825-830.
19. Dodd MJ, Miaskowski C, Lee KA. Occurrence of symptom clusters. *J Natl Cancer Inst Monogr* 2004;76-78.
20. Dodd MJ, Miaskowski C, Paul SM. Symptom clusters and their effect on the functional status of patients with cancer. *Oncol Nurs Forum* 2001;28:465-470.
21. Miaskowski C, Dodd MJ, Lee KA. Symptom cluster: the new frontier in symptom management. *J Natl Cancer Inst Monogr* 2004;17-21.
22. McDonald MV, Passik SD, Dugan W, et al. Nurses' recognition of depression in their patients with cancer. *Oncol Nurs Forum* 1999;26:593-599.
23. Passik SD, Dugan W, McDonald MV, et al. Oncologists' recognition of depression in their patients with cancer. *J Clin Oncol* 1998;16:1594-1600.
24. Akizuki N, Akechi T, Nakanishi T, et al. Development of a brief screening interview for adjustment disorders and major depression in patients with cancer. *Cancer* 2003;97:2605-2613.
25. Gessler S, Low J, Daniells E, et al. Screening for distress in cancer patients: is the distress thermometer a valid measure in the UK and does it measure change over time? A prospective validation study. *Psychooncology* 2007;17(6):538-547.
26. Hegel MT, Collins ED, Kearing S, et al. Sensitivity and specificity of the Distress Thermometer for depression in newly diagnosed breast cancer patients. *Psychooncology* 2007;17(6):556-560.
27. Graves KD, Arnold SM, Love CL, et al. Distress screening in a multidisciplinary lung cancer clinic: prevalence and predictors of clinically significant distress. *Lung Cancer* 2007;55:215-224.
28. Morita T, Fujimoto K, Namba M, et al. Palliative care needs of cancer outpatients receiving chemotherapy: an audit of a clinical screening project. *Support Care Cancer* 2008;16:101-107.
29. Okuyama T, Wang XS, Akechi T, et al. Japanese version of the M.D. Anderson Symptom Inventory: a validation study. *J Pain Symptom Manage* 2003;26:1093-1104.
30. Groenvold M, Petersen MA, Aaronson NK, et al. The development of the EORTC QLQ-C15-PAL: a shortened questionnaire for cancer patients in palliative care. *Eur J Cancer* 2006;42:55-64.
31. Akizuki N, Yamawaki S, Akechi T, Nakano T, Uchitomi Y. Development of an Impact Thermometer for use in combination with the Distress Thermometer as a brief screening tool for adjustment disorders and/or major depression in cancer patients. *J Pain Symptom Manage* 2005;29:91-99.
32. Cossich T, Schofield P, McLachlan SA. Validation of the cancer needs questionnaire (CNQ) short-form version in an ambulatory cancer setting. *Qual Life Res* 2004;13:1225-1233.
33. Koedoot CG, de Haan RJ, Stiggelbout AM, et al. Palliative chemotherapy or best supportive care? A prospective study explaining patients' treatment preference and choice. *Br J Cancer* 2003;89:2219-2226.
34. Grunfeld EA, Maher EJ, Browne S, et al. Advanced breast cancer patients' perceptions of decision-making for palliative chemotherapy. *J Clin Oncol* 2006;24:1090-1098.
35. Barsevick AM, Dudley W, Beck S, et al. A randomized clinical trial of energy conservation for patients with cancer-related fatigue. *Cancer* 2004;100:1302-1310.
36. Ream E, Richardson A, Dann CA. Supportive intervention for fatigue in patients undergoing chemotherapy: a randomized controlled trial. *J Pain Symptom Manage* 2006;31:148-161.
37. Jatoi A, Rowland K, Loprinzi CL, et al. An eicosapentaenoic acid supplement versus megestrol acetate versus both for patients with cancer-associated wasting: a north central cancer treatment group and national cancer institute of Canada collaborative effort. *J Clin Oncol* 2004;22:2469-2476.
38. Ravasco P, Grillo IM, Vidal PM, Camilo ME. Dietary counseling improves patients outcomes: a prospective, randomized, controlled trial in colorectal cancer patients undergoing radiotherapy. *J Clin Oncol* 2005;23:1431-1438.
39. Grond S, Zech D, Diefenbach C, Bischoff A. Prevalence and pattern of symptoms in patients with cancer pain: a prospective evaluation of 1635 cancer patients referred to a pain clinic. *J Pain Symptom Manage* 1994;9:372-382.
40. Lidstone V, Butters E, Seed PT, et al. Symptoms and concerns amongst cancer outpatients: identifying the need for specialist palliative care. *Palliat Med* 2003;17:588-595.
41. Lo RS, Ding A, Chung TK, Woo J. Prospective study of symptom control in 133 cases of palliative care in patients in Shatin Hospital. *Palliat Med* 1999;13:335-340.
42. Krech RL, Davis J, Walsh D, Curtis EB. Symptoms of lung cancer. *Palliat Med* 1992;6:309-315.
43. Dunlop GM. A study of the relative frequency and importance of gastrointestinal symptoms, and weakness in patients with far advanced cancer: student paper. *Palliat Med* 1989;4:31-41.
44. Teunissen SC, Wesker W, Kruiwagen C, et al. Symptom prevalence in patients with incurable cancer: a systematic review. *J Pain Symptom Manage* 2007;34:94-104.
45. Walsh D, Donnelly S, Rybicki L. The symptom of advanced cancer: relationship to age, gender, and performance status in 1000 patients. *Support Care Cancer* 2000;8:175-179.

Caregiving Consequences Inventory: a measure for evaluating caregiving consequences from the bereaved family member's perspective

Makiko Sanjo^{1*}, Tatsuya Morita², Mitsunori Miyashita¹, Mariko Shiozaki³, Kazuki Sato¹, Kei Hirai^{4,5}, Yasuo Shima⁶ and Yosuke Uchitomi⁷

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

²Department of Palliative and Supportive care, Palliative Care Team and Seirei Hospice, Seirei Mikatahara Hospital, Shizuoka, Japan

³Research Fellow of the Japan Society for the Promotion of Sciences and Public Health, Graduate School of Medicine, Osaka University, Osaka, Japan

⁴Center of the Study for Communication Design, Psychology and Behavioral Sciences, Graduate School of Human Sciences, Osaka University, Osaka, Japan

⁵Department of Complementary and Alternative Medicine, Graduate School of Medicine, Osaka University, Osaka, Japan

⁶Department of Palliative Medicine, Tsukuba Medical Center Hospital, Ibaraki, Japan

⁷Psycho-Oncology Division, Research Center for Innovative Oncology, National Cancer Center Hospital East, Chiba, Japan

*Correspondence to:
Department of Adult
Nursing/Palliative Care
Nursing, School of Health
Sciences and Nursing,
Graduate School of Medicine,
The University of Tokyo, 7-3-
1 Hongo, Bunkyo-ku, Tokyo
113-0033, Japan. E-mail:
shibagaki-ky@umin.ac.jp

Abstract

Objective: The aims of this study were to validate an instrument for measuring bereaved family members' perceptions of caregiving consequences and to examine the association between caregiving consequences and psychological distress.

Methods: Cross-sectional questionnaires were administered to family members of patients who had died in regional cancer centers. We measured the Caregiving Consequences Inventory (CCI), respondent's optimism, overall reward scale, and psychological distress and collected background data. A retest was conducted.

Results: Bereaved families from two regional cancer centers were surveyed ($N = 189$ and 109 ; effective response rate, 57 and 80%). By exploratory and confirmatory factor analyses, we identified four perceived reward domains: 'mastery', 'appreciation for others', 'meaning in life', and 'reprioritization', and one perceived burden domain. Although the four reward domains were highly correlated with each other ($0.47 < r < 0.69$), the 4-domain model was superior. The respondents with less education, strong faith, and less optimism reported fewer perceived rewards, thus demonstrating known group validity. In addition, perceived reward had little or no correlation with psychological distress. The psychometric properties of this scale were good ($\alpha = 0.78-0.93$, ICC = 0.60-0.73) and construct validity was supported (GFI = 0.929; AGFI = 0.819; CFI = 0.749; RMSEA = 0.097).

Conclusions: The CCI is valid for measuring caregiving consequences from the bereaved family member's perspective in Japan. Furthermore, it is important to use perceived rewards and burdens as a measure of caregiving consequences for improving the quality of the caregiving and bereavement experience.

Copyright © 2008 John Wiley & Sons, Ltd.

Keywords: caregiver; palliative care; neoplasms; measures; reward; burden

Received: 15 December 2007
Revised: 30 July 2008
Accepted: 3 August 2008

Introduction

The World Health Organization concept of palliative care includes attention to the health and well-being of the family members caring for a patient, and it proposes a support system to help caregivers cope during the patient's illness and their own bereavement [1]. Research has shown that caring for severely ill patients can have a negative impact on the mental, physical, and financial well-being of the caregivers [2-5]. In addition, the caregiver's

burden is associated with family dissatisfaction and regret in received care [6], depression in family members [7,8], and caregiver mortality [9,10] in the course of caregiving and bereavement. Thus, palliative care specialists and researchers have tried to help reduce the caregiver's burden [11-15].

While past research has clearly documented the negative emotions experienced during caregiving and bereavement, recent research has investigated positive consequences of caregiving [16]. Approximately 60-70% of caregivers have reported

that they could recognize positive aspects of the experience [17–19], and psycho-educational interventions have had long-term positive effects on caregiving consequences [20,21]. Although several positive outcomes of caregiving such as appreciation, gratification, mastery, finding meaning and purpose in life, reprioritization, personal growth, and satisfaction [22–26] have been explored, the operational definitions of words used by researchers vary [16] and there is no consensus on what constitutes positive caregiving outcomes.

In Japan, cancer is the leading cause of death. Although enhancement of palliative care for Japanese cancer patients and family caregivers is a priority in Japan, we found only a few studies that investigated in detail caregiving for severely ill cancer patients. To deliver appropriate support for family caregivers, it is important to evaluate both positive and negative caregiving outcomes. There are a few scales that evaluate both positive and negative caregiving outcomes [27,28]. However, in these scales, various positive aspects are measured in 1 domain only, and it is difficult to understand the positive aspects of caregiving in detail. Moreover, surveys of families of patients at the end of life are not culturally appropriate in Japan. Thus, for considering how to provide care to the families, it is necessary to assess caregiving consequences, that is, the positive and negative experiences of the caregivers from the bereaved family's viewpoint. It is difficult to use the scale with many items (more than 20 items) for vulnerable bereaved families in Japan. Today, however, there are a few brief scales.

The aim of this study was to develop a brief measure for evaluating caregiving consequences from the bereaved family member's perspective and to measure the validity and reliability of this new measure in Japan.

Methods

This survey was made up of two cross-sectional anonymous mailed surveys of the bereaved family members of cancer patients in two regional cancer centers in Ibaraki Prefecture (Part 1) and Shizuoka Prefecture (Part 2). Both centers have general wards and inpatient palliative care units (PCU).

Measurements

Caregiving Consequences Inventory (CCI)

To evaluate the consequences of caring for incurable cancer patients from the bereaved family's perspective, we pooled items found through a systematic literature review of studies that described the positive aspects of caregiving [22–25,29–31], caregiver burden [2–5], caregiving-related concepts [16,26,32–38], stress-related growth [39–41], and discussions about the similar-

ity of the concepts. Reviewers were a research nurse specializing in palliative care, a palliative care specialist, and a researcher specializing in clinical psychology. Then, we hypothesized a factor structure prior to psychometric testing of 5 domains of perceived rewards: personal growth, mastery, appreciation for others, meaning in life, and reprioritization, and 1 domain of perceived burden. In Japan and overseas, both a Caregiving Burden Scale with a clear domain structure [42,43] and one without a clear structure [44,45] are used. However, we used 1 domain for the caregiving burden in this survey for the following reasons: (1) the size of the contribution of the first factor is very large compared with the second factor (2) the caregiving burden in Japan can be assumed to be included in 1 domain [46,47]. We also discussed the content validity for the items using the following selection criteria: (1) easily understood and completed, (2) potentially applicable to both caregiving and bereavement, (3) comprising hypothesized dimensions, and (4) comprising three or more items for each domain. We then selected 19 items as perceived reward domains and 5 items as perceived burden domains. All of the authors were in agreement on these items and factors. This process ensured the content validity of the initial 24-item version of the CCI (available from the authors). These items were rated using a 7-point Likert scale (1: absolutely disagree, 2: disagree, 3: somewhat disagree, 4: unsure, 5: somewhat agree, 6: agree, 7: absolutely agree). We used the initial 24-item version in Part 1 of the survey and the 16-item shortened version in Part 2.

Overall perceived rewards

We asked about overall perceived rewards with the statement: 'It was a good experience for me to care for my family member' using a 7-point Likert scale (1: absolutely disagree, 2: disagree, 3: somewhat disagree, 4: unsure, 5: somewhat agree, 6: agree, 7: absolutely agree). We used this scale to examine the concurrent validity of the CCI in Part 2 of the survey. We did not have scales to examine details of positive aspects of caregiving consequences when the survey was conducted. We therefore used a single item to measure concurrent validity, the best method in such a situation [48].

The Life Orientation Test—Revised (LOT-R)

Research has shown that optimism is associated with positive aspects of difficult situations [18,49]. We hypothesized that the perceived reward domain score is positively correlated with optimism of the respondents. The LOT-R is a 10-item (six target items and four fillers) self-report scale measuring expectations about positive outcomes in general, using a 5-point scale from 0 (strongly disagree) to 4 (strongly agree) [49]. The validity and reliability of

the Japanese version have been confirmed, and Sakamoto proposed a two-factor model consisting of optimism and pessimism [50]. Responses are scored from 0–12 with higher scores on the three optimism items representing greater dispositional optimism, while higher scores on the three pessimism items represent greater dispositional pessimism. We used this scale to examine the known group validity of the CCI in Part 1 of the survey.

The General Health Questionnaire-12-item version (GHQ-12)

The GHQ-12 is a screening instrument covering a range of psychiatric symptoms (e.g. anxiety and depression) as well as somatic symptoms and social dysfunction [51]. We used the GHQ-12 to measure the degree of psychological distress of the respondents and to examine the discriminative validity of the CCI in Part 2 of the survey.

Background data of caregivers and patients

The patient's age, sex, and number of hospital days, time since patient's death, and care settings were extracted from medical databases. The caregiver's background data included the bereaved family member's age, sex, relationship with the patient, and frequency of attending the patient.

In Part 1, we also asked the respondents about health status during the caregiving period, presence of other caregivers, whether the caregiver lived with the patient, and caregiver's faith, education, and household income during the caregiving period. Research has shown that caregivers with less education and strong faith reported fewer perceived rewards [52,53]. Thus, we used these data to examine the known group validity of the CCI.

Participants and procedures

To find potential participants for Part 1 of the survey, we identified from medical records bereaved family members of patients who died from lung or gastrointestinal cancer from September 2004–February 2006 on the general ward in a regional health center in Ibaraki Prefecture and patients who died from all forms of cancer in PCUs in the same regional health center during the same period. We mailed questionnaires to potential respondents in October 2006 and a reminder was sent in November 2006 to those who did not respond. The respondents were asked to report the level of agreement on the initial 24-item CCI and LOT-R and to supply background data. To examine test–retest reliability, we sent the same questionnaire one month later.

For Part 2 of the survey, we identified from medical records bereaved family members of patients who died from April 2005–April 2006 in PCUs of regional cancer centers in Shizuoka

Prefecture. We mailed questionnaires to potential respondents in March 2007 and a reminder was sent in April 2007 to those who did not respond. The respondents were asked to report their level of agreement with the final 16 items of the shortened version of the CCI, their overall perceived rewards, responses to the GHQ-12, and background data.

The inclusion criteria were the same in both surveys and were as follows: (1) patient was aged 20 years or more and (2) patient was hospitalized at least 3 days. The exclusion criteria were the same in both surveys: (1) participant was recruited for another survey for bereaved family members, (2) participant would have suffered serious psychological distress as determined by the primary physician, (3) cause of death was treatment related or due to injury, (4) there was no bereaved family member who was aged 20 years or more, (4) participant was incapable of replying to a self-reported questionnaire, and (5) participant was not aware of the diagnosis of malignancy.

Ethical consideration

The protocols were approved by the institutional review board of each institute. In both Part 1 and Part 2, if the respondents did not want to participate in the survey they were asked to return the questionnaire with 'no participation' indicated, and a reminder was not mailed to them.

Statistical analyses

Scale development

For item reduction, we first deleted items with data missing for 20% or more of the respondents, or highly skewed distributions of the ratings defined as 'mean \pm standard deviation' beyond the scope of the variable. We then used exploratory factor analysis using the maximum likelihood method [54] with a promax rotation for perceived reward domains and perceived burden domains, separately. According to the results of the exploratory factor analysis, attributes with factor loadings less than 0.3 (standardized regression coefficient) were deleted. Among several models tested, we adopted the model that showed sufficient fitness to the factor structure based on the hypothesized concepts and clinical validity based on full agreement of the authors. The items that were finally adopted for the CCI are described in the appendix. The domain score was calculated by summing the items in each domain. The total reward score was calculated by summing the 12 items in all perceived reward domains, although we did not provide the CCI total score, which was calculated by summing the 16 items, including 12 perceived reward items and four burden items.

Scale validation

Validity: To examine concurrent validity, we calculated the Pearson's correlation coefficients between each domain of the CCI and one item overall for perceived rewards using data from Part 2. In addition, to examine construct validity of the final 16 items of the CCI, we calculated the Pearson's correlation coefficients between each domain score of the CCI using data from Part 1, and conducted a confirmatory factor analysis using data from Parts 1 and 2, separately. Known group validity was examined using a *t* test to compare the reward domain scores of respondents who had more faith compared with those with less faith, scores of respondents who had more education compared with those with less education, and scores of respondents who were more optimistic compared with those who were less optimistic.

Faith responses were grouped into a group with less faith (1: none at all and 2: slightly strong) and a group with more faith (3: moderately strong and 4: very strong). In addition, responses about education level were grouped into a group with less education (1: finished junior high school and 2: finished high school) and a group with more education (3: junior college graduate and 4: college graduate). As for optimism and set the threshold value for optimism was established at 6/7.

In addition, to examine discriminate validity, we calculated the Pearson's correlation coefficients between each domain score of the CCI and psychological distress. We used GHQ scoring (0-0-1-1), and set the threshold for psychological distress at 2/3 [55]. We divided the score into binary variables whether the score exceeded a cutoff value or not, and used it as a dependent variable.

Reliability: To examine the reliability of the CCI, we calculated Cronbach's α coefficients (Cronbach's α) and intra-class correlation coefficients (ICC) for test-retest reliability using data for Part 1 of the survey.

All analyses were performed using the statistical package SAS version 9.1 (SAS Institute) and AMOS version 7.0 (SPSS institute). The significance level was set at $P < 0.05$ (two-tailed).

Results

Of 344 and 160 questionnaires sent to bereaved family members in Part 1 and Part 2, respectively, 11 and 23 were undeliverable, and 215 and 121 were returned. Among these, 23 and 12 individuals refused to participate, and 3 and 0 were excluded due to missing data. Thus, 189 and 109 responses were analyzed (effective response rates, 57 and 80%, respectively).

As for follow-up of Part 1, of 175 questionnaires sent to bereaved families who responded during the study period, nine individuals refused to partici-

pate, and two responses were excluded due to missing data. Finally, 112 responses were analyzed (effective response rate, 64%). Table 1 summarizes the background of the respondents.

Item reduction

In accordance with the above-mentioned item reduction procedure, we initially excluded one item

Table 1. Backgrounds of respondents

	Part 1 (N = 189)		Part 2 (N = 109)	
	n	%	n	%
Patients				
Age, y (mean \pm SD)	69 \pm 12		73 \pm 11	
Sex				
Male	108	57	47	43
Female	81	43	62	57
Hospital days (mean \pm SD)	41 \pm 37		56 \pm 74	
Care setting				
General ward	55	29	0	0
Palliative care unit	134	71	109	100
Bereaved family members				
Age, y (mean \pm SD)	57 \pm 12		60 \pm 12	
Sex				
Male	63	33	42	39
Female	122	65	64	59
Time since patient's death: months (mean \pm SD/range)	15 \pm 5 (7-25)		17 \pm 4 (11-24)	
Relationship				
Spouse	87	46	47	43
Child	64	34	42	39
Child-in-law	20	11	8	7
Other	15	9	10	10
Health status				
Good	48	25	—	—
Moderate	106	56	—	—
Fair	28	15	—	—
Poor	5	3	—	—
Presence of other caregivers				
Present	131	69	—	—
Absent	54	29	—	—
Living status				
Living together	157	83	—	—
Not living together	30	16	—	—
Religiousness				
Much	14	7	—	—
Moderate	34	18	—	—
Fair	46	24	—	—
None	85	45	—	—
Education				
Junior high school	34	18	—	—
High school	82	43	—	—
College	40	21	—	—
University	31	16	—	—
Household income (thousand yen)				
000-249 (-2500\$)	31	16	—	—
250-499 (2500-4990\$)	74	39	—	—
500-749 (5000-7490\$)	37	20	—	—
750-999 (7500-9990\$)	21	11	—	—
1000- (10000\$-)	16	8	-	-

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

Caregiving consequence inventory

Table 2. Exploratory factor analysis of Caregiving Consequence Inventory

		Standardized regression coefficients				Communality
		F1	F2	F3	F4	
<i>Perceived reward domain</i>						
1 Mastery (mean = 4.9, SD = 1.2)						
Q1	I feel confident enough to manage future life changes	0.91	0.05	-0.06	0.04	0.86
Q2	I have learned to cope better with my life	0.83	-0.10	0.05	0.18	0.85
Q3	I came to accept some of the changes in my life	0.75	0.11	0.14	-0.18	0.64
2 Appreciation for others (mean = 5.5, SD = 1.0)						
Q4	I came to have more appreciation for others	-0.04	0.96	-0.03	0.04	0.90
Q5	I became more aware of love from other people	0.06	0.84	-0.01	0.07	0.81
Q6	I came to place greater value on relationships	0.06	0.71	0.10	-0.06	0.58
3 Meaning in life (mean = 4.9, SD = 1.2)						
Q7	I came to find purpose and sense of meaning in my life	-0.04	0.04	1.00	-0.06	0.94
Q8	I have a better outlook on my life	0.19	0.00	0.64	0.07	0.66
Q9	I came to believe that there was a meaning in life no matter what happened	0.19	-0.05	0.63	0.15	0.69
4 Reprioritization (mean = 5.6, SD = 1.0)						
Q10	I came to understand of the brevity of life and appreciate each day	-0.02	-0.01	0.01	0.99	0.96
Q11	I came to notice what is really important in my life	0.21	0.17	0.09	0.50	0.66
Q12	I have learned the importance of being alive	-0.09	0.14	0.42	0.43	0.61
<i>Perceived burden domain</i>						
Burden (mean = 3.7, SD = 1.6)						
Q13	I felt a physical burden			0.96		0.58
Q14	I sacrificed my own time and schedule			0.76		0.92
Q15	I felt a mental burden			0.67		0.44
Q16	I felt a financial burden			0.33		0.11

Table 3. Concurrent validity of Caregiving Consequence Inventory

	Overall perceived
<i>Perceived reward domains</i>	
Mastery	0.37***
Appreciation for others	0.30***
Meaning in life	0.39***
Reprioritization	0.43***
Total reward score	0.44***

Figures are Pearson's correlation coefficients. * $P < 0.05$, ** $P < 0.01$, *** $P < 0.001$.

due to skewed responses from the initial CCI. According to the results of the exploratory factor analysis, 12 items for perceived rewards and 4 items for perceived burden were selected. The following 4 domains were extracted as perceived rewards: (1) mastery, (2) appreciation for others, (3) meaning in life, and (4) reprioritization. The result of the exploratory factor analysis of the CCI is shown in Table 2.

Scale validation

Validity

Table 3 shows the concurrent validity. The correlation of each reward domain of the

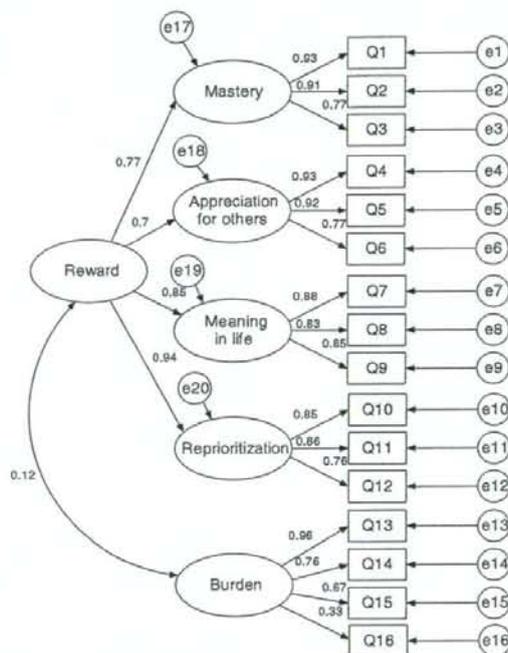
CCI and the one-item overall perceived reward was moderate and ranged from $r = 0.30$ to 0.43.

Table 4 shows the known group validity and demonstrates significant differences in each reward domain of the CCI according to the hypothesized respondent's characteristics (i.e. the respondent's faith, education, and optimism).

Figure 1 shows the result of confirmatory factor analysis using data from Part 1 of the survey. This solution has the most interpretable factors and showed sufficient fitness to the factor structure, consistency with the hypothesized concepts, and clinical validity. Although we hypothesized a model with five perceived rewards including a personal growth domain at first, exploratory factor analysis revealed that the three items we hypothesized as personal growth were due to an improper solution and no convergence could be attained. Therefore, we adopted 12 items for four perceived reward domains and 4 items for the burden domain. The fit indices for this final model were acceptable (χ^2 262.333 [df = 99], $P < 0.001$; GFI = 0.919; AGFI = 0.848; CFI = 0.792; RMSEA = 0.094) (see Figure 1). The confirmatory factor analysis using Part 2 data reproduced acceptable fit indices with one correlated error term (χ^2 191.6 [df = 98], $P < 0.001$; GFI = 0.929; AGFI = 0.819; CFI = 0.749; RMSEA = 0.097) (see Figure 2).

Table 4. Known-group validity of Caregiving Consequence Inventory

	Faith				P-value	Education				P-value	Optimism				P-value
	Less faith		More faith			Less educated		More educated			Less optimistic		More optimistic		
	Means	SD	Means	SD	Means	SD	Means	SD	Means	SD	Means	SD			
Perceived reward domains															
Mastery	4.8	1.2	5.2	1.0	0.02*	5.1	1.1	4.6	1.3	0.01*	4.8	1.1	5.2	1.2	0.03*
Appreciation for others	5.5	1.1	5.6	1.0	0.63	5.6	1.0	5.4	1.2	0.32	5.5	1.0	5.7	1.1	0.15
Meaning in life	4.8	1.2	5.4	0.9	<0.001***	5.2	1.0	4.6	1.3	0.001**	4.9	1.1	5.1	1.3	0.13
Reprioritization	5.4	1.1	5.8	0.8	0.03*	5.7	0.9	5.4	1.2	0.06	5.4	1.0	5.9	1.1	0.003**
Total reward score	5.1	1.0	5.5	0.7	0.01*	5.4	0.8	5.0	1.0	0.01*	5.1	0.9	5.5	1.0	0.03*

* $P < 0.05$, ** $P < 0.01$, *** $P < 0.001$.Figure 1. Confirmatory factor analysis of Caregiving Consequence Inventory (Part 1). $\chi^2 262.333$ (DF = 99), $P < 0.001$; GFI = 0.919; AGFI = 0.848; CFI = 0.792; RMSEA = 0.094

The four reward domain scores were highly correlated with each other ($0.47 < r < 0.69$) (Table 5). We tested the factor structure of reward further by conducting confirmatory factor analyses, comparing the 4-reward domain and 1-reward domain approaches. The analysis revealed that the 4-reward domain model fit the data significantly better than the 1-reward domain model ($\chi^2 699.4$ [df = 103], $P < 0.001$; GFI = 0.692; AGFI = 0.652; CFI = 0.541; RMSEA = 0.186).

Table 6 shows the known group validity and shows that no significant correlation exists between each domain score and psychological distress,

except for a slight correlation with mastery ($r = -0.19$, $P = 0.05$) and burden ($r = 0.24$, $P = 0.01$).

Reliability

Table 7 shows the internal consistency and test-retest reliability. Cronbach's α ranged from 0.78 to 0.93. The Cronbach's α coefficient of the total reward domain was 0.93 and of the burden domain was 0.78. The ICC ranged from 0.60 to 0.73. The ICC of the total reward domain was 0.73 and of the burden domain was 0.60.

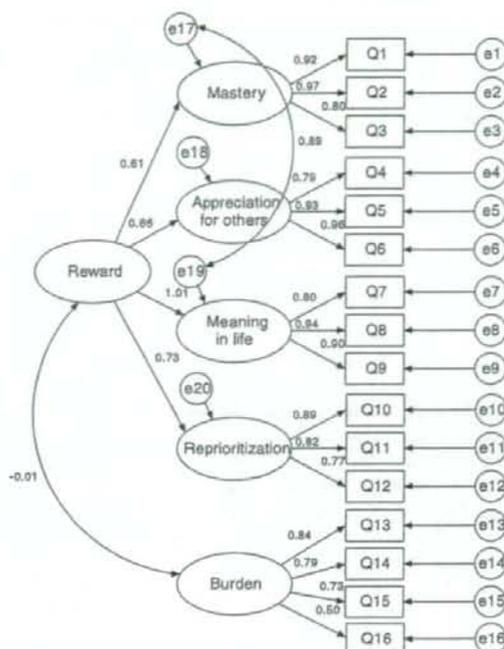


Figure 2. Confirmatory factor analysis of Caregiving Consequence Inventory (Part 2). $\chi^2 191.6$ (DF = 98), $P < 0.001$; GFI = 0.929; AGFI = 0.819; CFI = 0.749; RMSEA = 0.097

Table 5. The association with each other domain score of CCI

	Mastery	Appreciation for others	Meaning in life	Reprioritization
Mastery	1.00			
Appreciation for others	0.47***	1.00		
Meaning in life	0.63***	0.49***	1.00	
Reprioritization	0.60***	0.60***	0.69***	1.00
Burden	0.07	0.06	0.12	0.07

Figures are Pearson's correlation coefficients. * $P < 0.05$, ** $P < 0.01$, *** $P < 0.001$.

Table 6. The association between caregiving consequence and psychological distress

	Psychological distress
<i>Perceived reward domains</i>	
Mastery	-0.19*
Appreciation for others	0.11
Meaning in life	-0.13
Reprioritization	-0.01
Total reward score	-0.07
<i>Perceived burden domain</i>	
Burden	0.24*

Figures are Pearson's correlation coefficients. * $P < 0.05$, ** $P < 0.01$, *** $P < 0.001$.

Discussion

The most important result of this study was the development of an instrument to measure the bereaved family's perceptions about the caregiving experience in Japan. The instrument showed good

internal consistency and test-retest reliability, and known group validity was also consistent with a previous study [52,53]. The CCI is 16 items and takes less than 10 min to complete. Plain terms are used for these items, so the deficit rate is low 2% or less. Thus, we believe that this scale can assess caregiving consequences with few demands placed on the bereaved family.

Exploratory factor analysis and confirmatory factor analysis revealed 5 domains consisting of 4 sub-domains of perceived rewards and 1 domain of perceived burden: mastery, appreciation for others, meaning in life, reprioritization, and burden. The themes of the domains are consistent with our prior hypothesized concepts.

Items selected for the 'mastery' domain represented the extent to which the respondent felt in control over his or her life [35,36,56]. Although the operationalization of 'meaning' varied widely across studies and sometimes represented overall

Table 7. Reliability of Caregiving Consequence Inventory

	α	ICC
<i>Perceived reward domains</i>		
Mastery	0.90	0.73
Appreciation for others	0.90	0.60
Meaning in life	0.89	0.62
Reprioritization	0.86	0.67
Total reward score	0.93	0.73
<i>Perceived burden domain</i>		
Burden	0.78	0.60

α , Cronbach's alpha coefficient; ICC, intra-class correlation coefficient.

positive aspects of caregiving [34,57], items selected for 'meaning' in life domains assessed the sense of purpose in life and task [57]. The 'appreciation for others' domain included items about gratitude for relationships and compassion [52], and the 're-prioritization' domain assessed changes in values and attitudes about living life to the fullest [23,52]. These 4 reward domains are similar to those identified in other studies of post-traumatic growth [39,40], and the burden domain included the items identified important for assessing caregiver burden [2,3,12,14]. Thus, content validity is assured.

It was not surprising that the 4 reward domain scores were highly correlated with each other because a sense of mastery may occur through the development of new capabilities and finding a sense of meaning or purpose [32]. In addition, caregivers described their deeper appreciation for relationships for one of the changes in values [31]. On examining concurrent validity, each reward domain of the CCI and overall perceived rewards were only moderately correlated, and the comparisons between the 4-domain and 1-domain models of perceived rewards revealed the superiority of the 4-domain model. We thus believe that a comprehensive assessment of rewards by one overall item is difficult and evaluation of every domain is recommended.

As for discriminate validity, almost none of the reward domains correlated with psychological distress. Only mastery and burden showed slight correlation with psychological distress, however these correlations were very weak. Therefore, we believe that mastery and burden were not clinically correlated with psychological distress.

This means that the caregiver considered reward to be an entity distinct from psychological distress, and it is important to use perceived reward as a measure for evaluation of caregiving consequences, as well as the caregiving burden, for improving the quality of the caregiving and bereavement experience.

Although the domains of the CCI demonstrated sufficient internal consistency, reliability measured by ICC was of moderate value [58]. Possible reasons for the moderate reliability are (1) the test-retest period was longer than 1 month and (2)

the family member's assessment of the CCI may have changed over time. However, the sufficient internal consistency as a measure of reliability for a cross-sectional study is appreciated; therefore, these moderate ICCs are not considered critical limitations of the CCI.

Limitations and future perspectives

The limitations of this study are as follows: first, the response rate in Part 1 of the survey was 57%. We think that this was low because the response rate of the bereaved families receiving care on the general wards was low (47% on general wards vs 62% in PCU). We believe, however, that the effect on this study was not crucial because (1) the objective was to validate a scale, not to survey actual conditions and (2) comparing the backgrounds of respondents and non-respondents revealed no differences in age, gender, the length of patient's hospital stay, or time since patient's death. Second, we identified the bereaved family members of patients who died from lung or gastrointestinal cancer on the general wards in Part 1 of the survey. We believe, however, that the effect on this study was not crucial because (1) the proportion of deceased patients on the general wards who died from other types of cancers was only 12% (23/188) in Part 1 and (2) we identified the bereaved family members of patients who died of all types of cancer on the PCU in Parts 1 and 2 of the survey. Third, we were unable to examine concurrent validity sufficiently in this study because we did not have scales to examine the details of positive aspects of caregiving consequences when this survey was conducted. Fourth, we set only one correlation between errors in the confirmatory factor analysis in Part 2 because of insufficient sample size. However, we believe this is not a fatal flaw because the fit indices for this final model in Part 1 were acceptable. We are going to perform further confirmation with a larger sample size in the next step. Fifth, this validation was executed in Japan, a culturally and ethnically homogeneous country. It is necessary to examine whether the structure of CCI can be reproduced in different cultures.

In the future, we would like to conduct a national survey on the actual positive and negative aspects of caregiving consequences in Japan. To decide the focus of the intervention, it is necessary to clarify factors related to positive and negative experience, and to explore the mechanisms that maintain and increase positive experiences, as well as those that decrease negative experiences. This CCI provides a good base for further exploration of these mechanisms. We also would like to conduct a prospective survey to clarify factors related to the change of perceived rewards using this tool, and hope that this effort will lead to the

Caregiving consequence inventory

development of intervention programs that focus on specific aims and examine the effects on caregiver outcomes.

Conclusions

We validated the CCI in Japanese bereaved family members. The CCI was a valid scale having sufficient factor validity, internal consistency, test-retest reliability, and acceptable construct validity. The CCI comprises four perceived reward domains: 'mastery', 'appreciation for others', 'meaning in life', and 'reprioritization', and one perceived burden domain, evaluating both positive and negative aspects of caregiving consequences from the bereaved family member's perspective. As for discriminant validity, reward has little or no correlation with psychological distress. Thus, it is important to use perceived rewards as a measure for evaluation of caregiving consequences, as well as the caregiving burden, for improving the quality of the caregiving and bereavement experience.

Acknowledgements

This research was supported by a Health and Labor Sciences Research Grant for a third term comprehensive control research for cancer.

Appendix

Caregiving Consequences Inventory

How do you feel about your caregiving experience with your family member? Please check the appropriate number. 1: absolutely disagree, 2: disagree, 3: somewhat disagree, 4: unsure, 5: somewhat agree, 6: agree, 7: absolutely agree. Through caring for your family member,

Mastery

I feel confident enough to manage future life changes.
I have learned to cope better with my life.
I came to accept some of the changes in my life.

Appreciation for others

I came to have more appreciation for others.
I became more aware of love from other people.
I came to place greater value on relationships.

Meaning in life

I came to find purpose and sense of meaning in my life.
I have a better outlook on my life.
I came to believe that there was meaning in life no matter what happened.

Reprioritization

I came to understand the brevity of life and appreciate each day.

I came to notice what is really important in my life.
I have learned the importance of being alive.

Burden

I felt a physical burden.
I sacrificed my own time and schedule.
I felt a mental burden.
I felt a financial burden.

References

1. World Health Organization National cancer control programmes. *Policies and Managerial Guidelines*. (2nd edn), 2002.
2. Wolff JL, Dy SM, Frick KD, Kasper JD. End-of-life care: findings from a national survey of informal caregivers. *Arch Intern Med* 2007;167(1):40-46.
3. Tilden VP, Tolle SW, Drach LL, Perrin NA. Out-of-hospital death: advance care planning, decedent symptoms, and caregiver burden. *J Am Geriatr Soc* 2004;52(4):532-539.
4. Giorgi Rossi P, Beccaro M, Miccinesi G et al. Dying of cancer in Italy: impact on family and caregiver. The Italian survey of dying of cancer. *J Epidemiol Community Health* 2007;61(6):547-554.
5. Emanuel EJ, Fairclough DL, Slutsman J, Emanuel LL. Understanding economic and other burdens of terminal illness: the experience of patients and their caregivers. *Ann Intern Med* 2000;132(6):451-459.
6. Shiozaki M, Morita T, Hirai K, Sakaguchi Y, Tsuneto S, Shima Y. Why are bereaved family members dissatisfied with specialised inpatient palliative care service? A nationwide qualitative study. *Palliat Med* 2005;19(4):319-327.
7. Kris AE, Cherlin EJ, Prigerson H et al. Length of hospice enrollment and subsequent depression in family caregivers: 13-month follow-up study. *Am J Geriatr Psychiatry* 2006;14(3):264-269.
8. Beach SR, Schulz R, Williamson GM, Miller LS, Weiner MF, Lance CE. Risk factors for potentially harmful informal caregiver behavior. *J Am Geriatr Soc* 2005;53(2):255-261.
9. Lichtenstein P, Gatz M, Berg S. A twin study of mortality after spousal bereavement. *Psychol Med* 1998;28(3):635-643.
10. Schulz R, Beach SR. Caregiving as a risk factor for mortality: the Caregiver Health Effects Study. *J Am Assoc* 1999;282(23):2215-2219.
11. Grov EK, Fossa SD, Sorebo O, Dahl AA. Primary caregivers of cancer patients in the palliative phase: a path analysis of variables influencing their burden. *Soc Sci Med* 2006;63(9):2429-2439.
12. Grunfeld E, Coyle D, Whelan T et al. Family caregiver burden: results of a longitudinal study of breast cancer patients and their principal caregivers. *Can Med Assoc J* 2004;170(12):1795-1801.
13. Goldstein NE, Concato J, Fried TR et al. Factors associated with caregiver burden among caregivers of terminally ill patients with cancer. *J Palliat Care* 2004;20(1):38-43.
14. Yun YH, Rhee YS, Kang IO et al. Economic burdens and quality of life of family caregivers of cancer patients. *Oncology* 2005;68(2-3):107-114.
15. McMillan SC, Small BJ, Weitzner M et al. Impact of coping skills intervention with family caregivers of hospice patients with cancer: a randomized clinical trial. *Cancer* 2006;106(1):214-222.

16. Kramer BJ. Gain in the caregiving experience: where are we? What next? *Gerontologist* 1997;37(2):218-232.
17. Hudson P. Positive aspects and challenges associated with caring for a dying relative at home. *Int J Palliat Nurs* 2004;10(2):58-65; discussion 65.
18. Davis CG, Nolen-Hoeksema S, Larson J. Making sense of loss and benefiting from the experience: two construals of meaning. *J Pers Soc Psychol* 1998;75(2):561-574.
19. Cohen CA, Colantonio A, Vernich L. Positive aspects of caregiving: rounding out the caregiver experience. *Int J Geriatr Psychiatry* 2002;17(2):184-188.
20. Hudson PL, Aranda S, Hayman-White K. A psycho-educational intervention for family caregivers of patients receiving palliative care: a randomized controlled trial. *J Pain Symptom Manage* 2005;30(4):329-341.
21. Manne S, Babb J, Pinover W, Horwitz E, Ebbert J. Psychoeducational group intervention for wives of men with prostate cancer. *Psycho-Oncology* 2004;13(1):37-46.
22. Farran CJ, Miller BH, Kaufman JE, Donner E, Fogg L. Finding meaning through caregiving: development of an instrument for family caregivers of persons with Alzheimer's disease. *J Clin Psychol* 1999;55(9):1107-1125.
23. Rodgers LS. Meaning of bereavement among older African American widows. *Geriatr Nurs* 2004;25(1):10-16.
24. Langner SR. Finding meaning in caring for elderly relatives: loss and personal growth. *Holist Nurs Pract* 1995;9(3):75-84.
25. Mehrotra S, Sukumar P. Sources of strength perceived by females caring for relatives diagnosed with cancer: an exploratory study from India. *Support Care Cancer* 2007.
26. Hunt CK. Concepts in caregiver research. *J Nurs Scholarsh* 2003;35(1):27-32.
27. Grov EK, Fossa SD, Tonnessen A et al. The caregiver reaction assessment: psychometrics, and temporal stability in primary caregivers of Norwegian cancer patients in late palliative phase. *Psycho-Oncology* 2006;15(6):517-527.
28. Cooper B, Kinsella GJ, Picton C, Cooper B, Kinsella GJ, Picton C. Development and initial validation of a family appraisal of caregiving questionnaire for palliative care. *Psycho-Oncology* 2006;15(7):613-622.
29. Koop PM, Strang VR, Koop PM, Strang VR. The bereavement experience following home-based family caregiving for persons with advanced cancer. *Clin Nurs Res* 2003;12(2):127-144.
30. Hogan NS, Greenfield DB, Schmidt LA. Development and validation of the Hogan Grief Reaction Checklist. *Death Stud* 2001;25(1):1-32.
31. Mok E, Chan F, Chan V et al. Family experience caring for terminally ill patients with cancer in Hong Kong. *Cancer Nurs* 2003;26(4):267-275.
32. Hudson P. A conceptual model and key variables for guiding supportive interventions for family caregivers of people receiving palliative care. *Palliat Support Care* 2003;1(4):353-365.
33. Lawton MP, Kleban MH, Moss M, Rovine M, Glicksman A. Measuring caregiving appraisal. *J Gerontol* 1989;44(3):P61-P71.
34. Noonan AE, Tennstedt SL. Meaning in caregiving and its contribution to caregiver well-being. *Gerontologist* 1997;37(6):785-794.
35. Pearlin LI, Mullan JT, Semple SJ, Skaff MM. Caregiving and the stress process: an overview of concepts and their measures. *Gerontologist* 1990;30(5):583-594.
36. Pearlin LI, Schooler C. The structure of coping. *J Health Soc Behav* 1978;19(1):2-21.
37. Park CL, Cohen LH, Murch RL. Assessment and prediction of stress-related growth. *J Pers* 1996;64(1):71-105.
38. Schumacher KL, Stewart BJ, Archbold PG. Conceptualization and measurement of doing family caregiving well. *Image J Nurs Sch* 1998;30(1):63-69.
39. McMillen JC, Fisher R. The Perceived Benefit Scales: measuring perceived positive life changes after negative events. *Soc Work Res* 1998;22:173-187.
40. Siegel K, Schrimshaw EW. Perceiving benefits in adversity: stress-related growth in women living with HIV/AIDS. *Soc Sci Med* 2000;51(10):1543-1554.
41. Tedeschi RG, Calhoun LG. The Posttraumatic Growth Inventory: measuring the positive legacy of trauma. *J Trauma Stress* 1996;9(3):455-471.
42. Chou KR, Jiann-Chyun L, Chu H. The reliability and validity of the Chinese version of the Caregiver Burden Inventory. *Nurs Res* 2002;51(5):324-331.
43. Miyashita M, Yamaguchi A, Kayama M et al. Validation of the Burden Index of Caregivers (BIC), a multidimensional short care burden scale from Japan. *Health Qual Life Outcomes* 2006;4:52.
44. Robinson BC. Validation of a Caregiver Strain Index. *J Gerontol* 1983;38(3):344-348.
45. Zarit SH, Reever KE, Bach-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. *Gerontologist* 1980;20(6):649-655.
46. Arai Y, Hosokawa T. Caregiving burden for elderly patient at home. *Health Cult Res (in Japanese)* 1997:1-6.
47. Ogata Y, Hashimoto M, Otsuka K. Subjective caregiving burden for patient who require nursing care at home. *Jpn J Public Health* 2000;47(4):303-319.
48. Cohen R, Leis AM, Kuhl D, Charbonneau C, Ritvo P, Ashbury FD. QOLTI-F: measuring family carer quality of life. *Palliat Med* 2006;20(8):755-767.
49. Scheier MF, Carver CS, Bridges MW. Distinguishing optimism from neuroticism (and trait anxiety, self-mastery, and self-esteem): a reevaluation of the Life Orientation Test. *J Pers Soc Psychol* 1994;67(6):1063-1078.
50. Sakamoto S. A study of the Japanese version of Revised Life Orientation Test. *Jpn J Health Psychol* 2002;15(1):59-63.
51. Goldberg DWP. *A User's Guide to the General Health Questionnaire*. NFER-Nelson Publishing: Windsor, Berkshire, 1988.
52. Kim Y, Schulz R, Carver CS. Benefit-finding in the cancer caregiving experience. *Psychosom Med* 2007;69(3):283-291.
53. Picot SJ, Youngblut J, Zeller R. Development and testing of a measure of perceived caregiver rewards in adults. *J Nurs Meas* 1997;5(1):33-52.
54. Fayers PM, Machin D. Factor analysis. In *Quality of Life: Assessment, Analysis and Interpretation*, Fayers PM, Machin D (eds). Wiley: Chichester, 2000; 91.
55. Goldberg DP, Oldehinkel T, Ormel J. Why GHQ threshold varies from one place to another. *Psychol Med* 1998;28(4):915-921.
56. Aneshensel C. The containment of care-related stressors. In: *Profiles in Caregiving*, Aneshensel C (ed.). Academic Press: California, 1995; 154-157.
57. Park CL, Folkman S. Meaning in the context of stress and coping. *Gen Rev Psychol* 1997;1(2):115-144.
58. Streiner DL, Norman GR. *Health Measurement Scales: A Practical Guide to Their Development and Use* (3rd edn). Oxford University Press: Oxford, 2003.