

厚生労働科学研究費補助金
第3次対がん総合戦略研究事業

「緩和ケアプログラムによる地域介入研究」

*Outreach Palliative care Trial of Integrated regional Model
OPTIM*

III. 研究成果の刊行に関する一覧表
2012年

研究成果の刊行に関する一覧表

書籍（外国語）

著者氏名	論文タイトル名	書籍全体の編集者名	書籍名	出版社名	出版地	出版年	ページ
なし							

書籍（日本語）

著者氏名	論文タイトル名	書籍全体の編集者名	書籍名	出版社名	出版地	出版年	ページ
なし							

雑誌（外国語）

発表者氏名	論文タイトル名	発表誌名	巻号	ページ	出版年
Yamagishi A, Morita T, Miyashita M, Igarashi A, Akiyama M, Akizuki N, Shirahige Y, Eguchi K.	Pain intensity, quality of life, quality of palliative care, and satisfaction in outpatients with metastatic or recurrent cancer: a Japanese, nationwide, region-based, multicenter survey.	J Pain Symptom Manage	43(3)	503-514	2012 3
Igarashi A, Miyashita M, Morita T, Akizuki N, Akiyama M, Shirahige Y, Eguchi K.	A Scale for Measuring Feelings of Support and Security Regarding Cancer Care in a Region of Japan: A Potential New Endpoint of Cancer Care	J Pain Symptom Manage	43(2)	218-225	2012 2
Yamagishi A, Morita T, Miyashita M, Ichikawa T, Akizuki N, Shirahige Y, Akiyama M, Eguchi K.	Providing palliative care for cancer patients: the views and exposure of community general practitioners and district nurses in Japan.	J Pain Symptom Manage	43(1)	59-67	2012 1
Kei Hirai, Tadashi Kudo, Miki Akiyama, Motohiro Matoba, Mariko Shiozaki, Teruko Yamaki, Akemi Yamagishi, Mitsunori Miyashita, Tatsuya Morita, Kenji Eguchi	Public Awareness, Knowledge of Availability, and Readiness for Cancer Palliative Care Services: A Population-Based Survey across Four Regions in Japan.	Journal of Palliative Medicine	14(8)	918-922	2011 8
Akiyama M, Takebayashi T, Morita T, Miyashita M, Hirai K, Matoba M, Akizuki N, Shirahige Y, Yamagishi A, Eguchi K.	Knowledge, beliefs, and concerns about opioids, palliative care, and homecare of advanced cancer patients: a nationwide survey in Japan	Supportive Care Cancer (E-Pub)	20(5)	923-931	2011 6

雑誌（日本語）

発表者氏名	論文タイトル名	発表誌名	巻号	ページ	出版年
井村千鶴、鄭陽、白土明美、藤本亘史、佐々木一義、吉川陽子、鈴木留美、大岩早苗、井上聡、森田達也	患者・遺族調査の結果に基づいた緩和ケアセミナーの有用性	ペインクリニック	33(2)	241-250	2012 2
佐藤泉、小野宏志、細田修、青木茂、井村千鶴、佐藤文恵、前堀直美、小坂和宏、森田達也	在宅特化型診療所と連携する訪問看護ステーションの遺族評価	訪問看護と介護	17(2)	155-159	2012 2
森田達也、野末よし子、花田芙蓉子、宮下光令、鈴木聡、木下寛也、白髭豊、江口研二	地域対象の緩和ケアプログラムによる医療福祉従事者の自覚する変化：OPTIM-study	Palliative Care Research	7(1)	121-135	2012 2
古村和恵、山岸暁美、赤澤輝和、鈴木聡、和泉典子、的場元弘、森田達也、江口研二	市民の緩和ケアに対するイメージの変化	緩和ケア	22(1)	79-83	2012 1
山岸暁美、森田達也、古村和恵、末田千恵、白髭豊、木下寛也、秋月伸哉、鈴木聡、加藤雅志、江口研二	地域のがん緩和ケアの課題と解決策の抽出：OPTIM-studyによる複数地域・多職種による評価	がんと化学療法	38(11)	1889-1895	2011 11
小野宏志、細田修、井村千鶴、青木茂、佐藤文恵、前堀直美、小坂和宏、佐藤泉、森田達也	地域の多職種で作成した調査票を用いた在宅死亡がん患者の遺族による多機関多職種の評価	緩和ケア	21(6)	655-663	2011 11
森田達也	緩和ケアの地域関連OPTIMプロジェクト浜松 地域リソースの「オペティマイズ=最大活用」と網目のようなネットワークが緩和ケア普及の鍵	Medical Partnering	56	1-5	2011 11
古村和恵、宮下光令、木澤義之、川越正平、秋月伸哉、山岸暁美、的場元弘、鈴木聡、木下寛也、白髭豊、森田達也、江口研二	進行がん患者と遺族のがん治療と緩和ケアに対する要望—821名の自由記述からの示唆—	Palliative Care Research	6(2)	237-245	2011 11
川越正平、廣岡佳代、白髭豊	電話インタビュー調査に基づく在宅医療診療連携システムの類型化(OPTIM方式)	日本医事新報	No. 4565	87-92	2011 10
森田達也、井村千鶴、野末よし子、赤澤輝和、伊藤富士江	多施設との医療連携の現状：緩和ケア普及のための地域プロジェクト(OPTIM-study) 浜松地域のあゆみと今後の課題	最新精神医学	16(5)	563-572	2011 9
井村千鶴、青木茂、細田修、小野宏志、佐藤泉、佐藤文恵、前堀直美、小坂和宏、森田達也	在宅死亡したがん患者の遺族による退院前カンファレンス・退院前訪問の評価	緩和ケア	21(5)	533-541	2011 9
鈴木留美、山口崇、藤本亘史、安藤江美、加藤亜沙代、森田達也	「生活のしやすさ質問票 第3版」を用いた外来化学療法患者の症状頻度・ニードおよび専門サービス相	緩和ケア	21(5)	542-548	2011 9

	談希望の調査				
末田千恵、山岸暁美、鈴木聡、木下寛也、鄭陽、白髭豊、木澤義之、森田達也	どのような緩和ケアセミナーが求められているのか:4,188名が評価した緩和ケアセミナーの有用性に影響する要因	ペインクリニック	32(8)	1215-1222	2011 8
山岸暁美、赤澤輝和、瀬尾利佳子、末田千恵、古村和恵、森田達也	在宅緩和ケアに関する望ましいリソースデータベースとは何か-多地域多職種を対象とした質的研究	緩和ケア	21(4)	443-448	2011 7
森田達也	緩和ケア普及のための地域プロジェクト(OPTIM-study)の経過と今後の課題	ホスピス緩和ケア白書2011		24-36	2011 夏頃
清原恵美、井村千鶴、梨田えり子、福田かおり、森田達也、井上聡	地域における緩和ケア病棟の役割-緩和ケア病棟における地域の看護師を対象とした研修の評価-	死の臨床	34(1)	110-115	2011 6
井村千鶴、野末よし子、伊藤富士江、赤澤輝和、森田達也	病院と地域とで行う連携ノウハウ共有会とデスカンファレンスの参加者の体験	緩和ケア	21(3)	335-342	2011 5
森田達也	緩和ケア普及のための地域プロジェクト(OPTIM-study)の経過と今後の課題	大阪保険医雑誌	39(533)	10-17	2011 4

厚生労働科学研究費補助金
第3次対がん総合戦略研究事業

「緩和ケアプログラムによる地域介入研究」

*Outreach Palliative care Trial of Integrated regional Model
OPTIM*

IV. 研究成果の刊行物・別刷
2012年

Original Article

Pain Intensity, Quality of Life, Quality of Palliative Care, and Satisfaction in Outpatients With Metastatic or Recurrent Cancer: A Japanese, Nationwide, Region-Based, Multicenter Survey

Akemi Yamagishi, PhD, RN, Tatsuya Morita, MD, Mitsunori Miyashita, RN, PhD, Ayumi Igarashi, RN, PhD, Miki Akiyama, PhD, Nobuya Akizuki, MD, PhD, Yutaka Shirahige, MD, PhD, and Kenji Eguchi, MD, PhD

Department of Nursing (A.Y.), Seirei Christopher University, Hamamatsu, Shizuoka; Department of Palliative and Supportive Care, Palliative Care Team, and Seirei Hospice (T.M.), Seirei Mikatahara General Hospital, Hamamatsu, Shizuoka; Department of Palliative Nursing (M.M.), Health Sciences, Tohoku University Graduate School of Medicine, Sendai, Miyagi; The Dia Foundation for Research on Ageing Societies (A.I.), Tokyo; Faculty of Policy Management (M.A.), Keio University, Fujisawa; Psycho-Oncology Division (N.A.), Chiba Cancer Center, Chiba, Chiba; Shirahige Clinic (Y.S.), Nagasaki, Nagasaki and Department of Internal Medicine (K.E.), Teikyo University School of Medicine, Tokyo, Japan

Abstract

Context. Increasing numbers of patients with advanced cancer are receiving anticancer and/or palliative treatment in outpatient settings, and palliative care for outpatients with advanced cancer is being recognized as one of the most important areas for comprehensive cancer treatment.

Objectives. The aim of this study was to evaluate pain intensity, quality of life, quality of palliative care, and satisfaction reported by outpatients with advanced cancer.

Methods. Questionnaires were sent to 1493 consecutive outpatients with metastatic or recurrent cancer from four regions in Japan; 859 responses were analyzed (58%). Questionnaires included the Brief Pain Inventory, Good Death Inventory, Care Evaluation Scale, and a six-point satisfaction scale.

Results. Approximately 20% of the patients reported moderate to severe pain. Whereas more than 70% agreed or strongly agreed with “good relationship with medical staff” and “being respected as an individual,” less than 60% agreed or strongly agreed with “free from physical distress,” “free from emotional distress,” “maintaining hope,” and “fulfillment at life’s completion”; 54% reported some agreement with “feel a burden to others.” About 20% reported that improvement is necessary in physical care by physicians, physical care by nurses, psycho-existential care, help with decision making, and coordination/consistency of care; 13% reported some levels of dissatisfaction.

Address correspondence to: Akemi Yamagishi, PhD, RN, Department of Nursing, Seirei Christopher University, 3453 Mikatahara, Kita-ku, Hamamatsu,

Shizuoka 433-8558, Japan. E-mail: ayamagishi-tyk@umin.ac.jp

Accepted for publication: April 20, 2011.

Conclusion. A considerable number of outpatients with metastatic or recurrent cancer experienced pain, physical symptoms, emotional distress, and existential suffering, and advocated improvements in palliative care across multiple areas. *J Pain Symptom Manage* 2012;43:503–514. © 2012 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Key Words

Pain, quality of life, quality of care, satisfaction, outpatient, advanced cancer

Introduction

Palliative care is an essential part of integrated cancer treatment.¹ Increasing numbers of patients with advanced cancer are receiving anti-cancer and/or palliative treatment in outpatient settings,^{2–5} and palliative care for outpatients with advanced cancer is being recognized as one of the most important areas for comprehensive cancer treatment.^{6–15} Nonetheless, few studies investigating patient symptom burden have focused on outpatients with advanced cancer. For example, a recent review on pain prevalence in cancer patients identified 52 relevant studies.⁶ Of these, 22 studies specifically evaluated patients with advanced, metastatic or terminal illness, but only five specifically focused on outpatients. A recent research study from Ontario revealed that half of 45,118 ambulatory cancer patients experienced some level of pain or dyspnea.¹⁵ These studies revealed that many outpatients with cancer suffer from multiple physical and psychological symptoms.

Measuring not only symptom burden but quality of life and patient-reported quality of care can be of value for the comprehensive understanding patients' cancer experiences, and measuring these outcomes at a regional level would be useful for improving palliative care in particular areas. To our best knowledge, however, there are few region-based large surveys of outpatients with advanced cancer that identify symptom burden, quality of life, patient-perceived quality of care, and satisfaction with care.¹⁵ In addition, there have been no multicenter studies in Japan to assess the prevalence of pain as reported by cancer patients themselves, despite a large amount of empirical data from nationwide surveys of bereaved families.¹⁶

Thus, the primary aim of this region-based, multicenter study was to assess pain intensity, quality of life, quality of palliative care, and satisfaction with medical care in outpatients with

metastatic or recurrent cancer. Additional aims were 1) to explore the potential differences in pain intensity, quality of life, quality of palliative care, and satisfaction among regions, and 2) to explore the potential correlations among pain intensity, quality of life, quality of palliative care, and satisfaction.

Methods

A cross-sectional study was performed by sending questionnaires to consecutive outpatients with metastatic or recurrent cancer in four regions in Japan. This survey was part of the preintervention measurements collected for the regional intervention trial, the Outreach Palliative Care Trial of Integrated Regional Model (OPTIM) study, and the study's methodology is reported in detail elsewhere.¹⁷ The ethical and scientific validity of this study was confirmed by the institutional review board of the Japan Cancer Society, and by those of all participating hospitals.

Participating Hospitals

Four study regions were chosen for intervention studies to cover a variety of areas with different palliative care systems across Japan: Tsuruoka (population 170,000, Yamagata prefecture), Kashiwa (population 670,000, Chiba prefecture), Hamamatsu (population 820,000, Shizuoka prefecture), and Nagasaki (population 450,000, Nagasaki prefecture). Kashiwa and Hamamatsu have specialized hospital palliative care teams in a cancer center and general hospitals, respectively; Nagasaki has a coordinated palliative care system for home patients in addition to hospital palliative care teams; and Tsuruoka had no formal specialized palliative care service at the time of the survey.

Because of a lack of an established method to identify all cancer patients living in a specific

area in Japan, we identified all hospitals in the study areas by examining hospital lists from the Japan Hospital Association, the largest authorized organization of hospitals in Japan, and the local resource information. Of 54 hospitals identified, we excluded 20 hospitals primarily treating psychiatric, rehabilitation, and geriatric noncancer patients. We approached the remaining 34 hospitals (11,033 beds), and a total of 23 hospitals (8964 beds, 81%) participated in this survey: three hospitals in Tsuruoka, seven hospitals in Kashiwa, eight hospitals in Hamamatsu, and five hospitals in Nagasaki.

Patients

Inclusion criteria for patients in this study were 1) adult cancer patients with a primary tumor site in either the lung, esophagus, stomach, colon, rectum, pancreas, liver, biliary system, kidney, prostate, bladder, breast, ovary, or uterus; 2) presence of metastatic or recurrent cancer; 3) outpatient visits to the oncology or specialty division, such as respiratory medicine for lung cancer patients, between April and June 2008 (not the palliative care division only); and 4) informed of malignancy. We excluded malignancies of the brain, blood, central nervous system, neck, soft tissue, and other uncommon primary sites because of the infrequent prevalence and increased technical difficulties in patient recruitment. Only patients who had been informed of their diagnosis were recruited because we used the term "cancer" in the questionnaire. Exclusion criteria included 1) incapacity of the patient to complete the questionnaire (dementia, cognitive failure, or psychiatric illness); 2) severe emotional distress in the patient as determined by the principal treating physician; 3) poor physical condition leading to inability to complete the questionnaire; and 4) language difficulty or visual loss. Patients were recruited consecutively, with hospitals either sending each eligible patient a questionnaire by mail or delivering it directly by hand to the patient.

Measurements

Data were collected on 1) pain intensity, 2) quality of life, 3) patient-perceived quality of palliative care, and 4) satisfaction.

Pain Intensity. Pain intensity was measured using the Japanese adaptation of the Brief Pain Inventory (BPI), with a score given for the pain at its worst (0–10), at its least (0–10), and a score for the average pain felt (0–10) in the previous 24 hours.¹⁸ The reliability and validity of the BPI in Japanese populations has been established.¹⁸ We did not collect the data about other variables (e.g., current pain) or pain medication because of patient burden and cost.

Quality of Life. Quality of life was measured using the Good Death Inventory (GDI) (short version).^{19,20} The GDI was developed to specifically measure quality of life for Japanese patients with advanced cancer.^{19,20} We used the GDI, not common tools such as the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire or the Functional Assessment of Cancer Therapy scale, because we intended to investigate broader areas of quality of life that Japanese patients regard as important, especially psycho-existential components beyond physical or functional areas. The full version of the GDI scale consists of 10 domains (three items for eight domains and two items for two domains) with a seven-point Likert-type scale from "1: strongly disagree" to "7: strongly agree:" physical and psychological comfort, living in a favorite place, maintaining hope and pleasure, having a good relationship with medical staff, not feeling a burden to others, having a good relationship with family, having independence, having environmental comfort, being respected as an individual, and a feeling of fulfillment at life's completion. For this study, we adopted the shortened version, in which each domain had one item (i.e., a total of 10 domains with 10 items). The reliability and the validity of both versions have been established.^{19,20} The total score of the GDI was calculated as the total score of 10 items, potential ranges of 7–70, with higher scores indicating respondents who felt they had greater quality of life. In addition, we investigated the full three items for the "physical and psychological comfort" domain to allow detailed investigation of this attribute.

Patient-Perceived Quality of Palliative Care. Patient-perceived quality of palliative care was measured using the Care Evaluation Scale (CES). The CES

is a well-validated and commonly used measurement tool in Japan to quantify the level of patient- or family-perceived need for improvements in palliative care.^{16,21,22} The full version of the CES comprises eight subscales (three items for seven domains and two items for one domain), with a six-point Likert-type scale from “1: improvement is not necessary at all” to “6: highly necessary:” physical care provided by physicians, physical care provided by nurses, psycho-existential care, help with decision making, coordination/consistency of care, environment, availability, and cost. For this study purpose, we used the first five subscales (15 items), because the study aim focused on interpersonal areas, not social areas (i.e., environment, availability, and cost). The reliability of the validity of each subscale has been established.^{21,22} Each subscale score was calculated as an average of the items belonging to the subscale, and the total score was calculated as an average of subscale scores. All scores are proportionally adjusted to range from 0 to 100, following the original studies,^{21,22} and thus higher values indicate lower perception of necessity for improvement.

Satisfaction and Demographic Data. Satisfaction with medical care was measured using a single-item scale: “Are you satisfied with the medical care you currently receive?” As in a previous study,¹⁶ patient responses were selected from a six-point Likert-type scale varying from “1: very dissatisfied” to “6: very satisfied.”

Background data obtained from patients included age, gender, living status, marital status, working status, levels of daily activity, and whether they were receiving radiotherapy or chemotherapy. To measure levels of daily activity, patients evaluated their own Eastern Cooperative Oncology Group performance status: 0 (no symptoms, able to carry on all activities without restrictions), 1 (mild symptoms but ambulatory and able to carry out work of a light or sedentary nature), 2 (ambulatory and capable of self-care for more than 50% of their waking hours), 3 (lying in a bed or sitting in a chair for more than 50% of their waking hours), and 4 (lying in a bed or sitting in a chair for the entire day).²³ The primary sites of medical care for patients were obtained from their medical charts.

Statistical Analyses

As our primary aim was to understand the overall patient experience and no universal cut-off points exist, data distributions were analyzed for each item, not using the mean values or summary values. The difference among the regions of primary endpoints was not statistically significant, and we therefore report all the data.

For comparisons, pain intensity was classified into four groups following the previous systematic review: no pain, 0; mild, 1–4; moderate, 5–6; severe, 7 or more.⁶ In addition, the proportion of the patients with pain of 5 or more was calculated as “substantial pain” to compare the results with other studies.^{7,8}

Pain intensity, total score for the GDI, total score for the CES, and satisfaction were compared among groups of patients with different backgrounds and from different regions. Univariate analyses were performed using the Student’s *t*-test and using the analysis of variance with the Scheffé’s test, where appropriate. To explore the correlations among pain intensity, quality of life, quality of palliative care, and satisfaction, we calculated the Spearman’s correlation coefficients among these variables.

Results

Of 1880 patients who met the inclusion criteria, 182 patients were excluded because of 1) incapacity of the patient to complete the questionnaire as a result of dementia, cognitive failure, or psychiatric illness ($n = 87$), 2) severe emotional distress ($n = 48$), 3) poor physical condition ($n = 28$), 4) language difficulty or visual loss ($n = 5$), and 5) unspecified reasons ($n = 14$). During the study, 75 patients died, were admitted, or changed hospitals; and responsible physicians were unavailable for technical reasons for 30 patients. In addition, 100 patients refused to receive the questionnaire. Questionnaires were, therefore, sent to 1493 patients; five were returned because of an incorrect address. A total of 859 responses (58%) were obtained. Table 1 summarizes the patient backgrounds.

Pain Intensity

Approximately, 60% of patients reported some level of pain, with approximately 20%

Table 1
Patient Characteristics (n = 859)

Characteristic	n	%
Gender (male, %)	471	55
Mean age (standard deviation [SD])	67 (11)	
Primary tumor sites		
Lung	221	26
Breast	148	17
Colon, rectum	131	15
Prostate	86	10
Stomach	75	8.7
Liver	39	4.5
Pancreas	30	3.5
Bladder	25	2.9
Uterus	24	2.8
Ovary	21	2.4
Esophagus	19	2.2
Bile duct	12	1.4
Kidney	11	1.3
Others	16	1.9
Living arrangement		
Not alone	784	91
Alone	66	7.7
Marital status		
Married	695	81
Divorced	100	12
Not married	49	5.7
Working		
Not working	657	77
Full time	120	14
Part time	65	7.6
Performance status		
0	243	28
1	371	43
2	181	21
3	37	4.3
4	14	1.6
Chemotherapy and/or radiotherapy		
Receiving	498	58
Not receiving	343	40

The percentages do not sum to 100% because of missing values.

reporting moderate to severe pain (Table 2). If the cut-off points are determined as 5, 17% of patients had a pain intensity of 5 or more for their worst pain in the previous 24 hours, and 11% of patients had this pain level as the average in the previous 24 hours.

Quality of Life

For the items of the GDI (Table 3), more than 70% of the patients “agreed” or “strongly

agreed” with living in a favorite place (74%), having a good relationship with medical staff (77%), having independence (77%), having environmental comfort (71%), and being respected as an individual (73%). More than half but less than 60% of patients “agreed” or “strongly agreed” with “free from physical distress” (58%), free from emotional distress (52%), maintaining hope and pleasure (53%), and feeling of fulfillment at life’s completion (51%). Furthermore, approximately 50% of the patients “slightly agreed,” “agreed,” or “strongly agreed” with the statement “I feel a burden to others.”

Quality of Palliative Care and Satisfaction

Approximately, 20% of patients reported that improvement is “necessary,” “substantially necessary,” or “highly necessary” in all five subscales: physical care by physicians, physical care by nurses, psycho-existential care, help with decision making, and coordination/consistency of care (Table 4).

Satisfaction levels were strongly dissatisfied in 1.0% (n = 9), dissatisfied in 2.2% (n = 19), slightly dissatisfied in 9.5% (n = 82), slightly satisfied in 27% (n = 229), satisfied in 49% (n = 417), and strongly satisfied in 10% (n = 88).

Comparisons Among Patients With Different Backgrounds and From Different Regions

Analysis of patient background data showed working status was significantly associated with intensity of pain, and total score from the GDI (Table 5). Patient-reported performance status was significantly associated with pain intensity, total score for the GDI, total score for the CES, and satisfaction levels. Intergroup difference existed in performance status 0 vs. 1–4, 1 vs. 2–4 (pain intensity); 0 vs. 1–4, 1 vs. 2–4, 2 vs. 3, 4 (GDI); 0 vs. 2, 3 (CES); and 0 vs. 1, 2, 4 (satisfaction). There were no statistically significant differences in these outcomes among the regions (Table 5).

Table 2
Pain Intensity Measured by the BPI

BPI Item	No Pain	Mild (1–4)	Moderate (5–6)	Severe (7–10)
Worst pain	43% (n = 373)	36% (n = 312)	8.5% (n = 73)	7.7% (n = 66)
Average pain	43% (n = 371)	42% (n = 363)	7.5% (n = 64)	2.7% (n = 23)
Least pain	51% (n = 435)	40% (n = 347)	2.9% (n = 25)	1.4% (n = 12)

The percentages do not sum to 100% because of missing values.

Table 3
Quality of Life Measured by the GDI

Items in the GDI	Strongly Agree	Agree	Slightly Agree	Unsure	Slightly Disagree	Disagree	Strongly Disagree
<i>Physical and psychological comfort</i>							
Free from pain	25% (n = 216)	43% (n = 370)	12% (n = 104)	6.2% (n = 53)	4.4% (n = 38)	3.4% (n = 26)	2.2% (n = 19)
Free from physical distress	18% (n = 158)	40% (n = 346)	16% (n = 139)	8.6% (n = 74)	5.6% (n = 48)	4.4% (n = 38)	2.6% (n = 22)
Free from emotional distress	17% (n = 145)	35% (n = 301)	20% (n = 172)	11% (n = 91)	6.8% (n = 58)	4.9% (n = 42)	1.7% (n = 15)
<i>Living in a favorite place</i>							
Able to stay at favorite place	29% (n = 251)	45% (n = 384)	9.4% (n = 81)	6.3% (n = 54)	2.0% (n = 17)	2.2% (n = 19)	1.2% (n = 10)
<i>Maintaining hope and pleasure</i>							
Have some pleasure in daily life	19% (n = 162)	34% (n = 291)	16% (n = 139)	11% (n = 92)	5.7% (n = 49)	5.5% (n = 47)	2.7% (n = 23)
<i>Good relationship with medical staff</i>							
Trust the physician	37% (n = 316)	40% (n = 347)	11% (n = 93)	4.3% (n = 37)	2.1% (n = 18)	0.8% (n = 7)	1.3% (n = 11)
<i>Not being a burden to others</i>							
Feeling a burden to others	11% (n = 97)	19% (n = 159)	24% (n = 202)	9.1% (n = 78)	8.4% (n = 72)	13% (n = 115)	9.7% (n = 83)
<i>Good relationship with family</i>							
Spend enough time with family	28% (n = 241)	38% (n = 328)	13% (n = 109)	8.7% (n = 75)	3.6% (n = 31)	2.6% (n = 22)	1.6% (n = 14)
<i>Independence</i>							
Independent in daily activities	39% (n = 336)	38% (n = 327)	9.4% (n = 81)	3.5% (n = 30)	2.3% (n = 20)	1.7% (n = 15)	2.3% (n = 20)
<i>Environmental comfort</i>							
Live in calm circumstances	30% (n = 253)	41% (n = 349)	14% (n = 122)	5.9% (n = 51)	1.9% (n = 16)	1.6% (n = 14)	2.1% (n = 18)
<i>Being respected as an individual</i>							
Being valued as a person	29% (n = 245)	44% (n = 379)	12% (n = 103)	7.1% (n = 61)	1.2% (n = 10)	1.0% (n = 9)	1.5% (n = 13)
<i>Life completion</i>							
Feels that his or her life is fulfilling	21% (n = 177)	30% (n = 260)	17% (n = 147)	15% (n = 129)	6.6% (n = 57)	3.3% (n = 28)	2.4% (n = 21)

The percentages do not sum to 100% because of missing values.
Domain names in italics.

Table 4
Patient-Reported Quality of Palliative Care as Measured by the CES

Items in the CES	Improvement Is:					
	Not Necessary	Rarely Necessary	Somewhat Necessary	Necessary	Considerably Necessary	Highly Necessary
<i>Physical care by physicians</i>						
Tried to relieve physical discomfort	17% (n = 149)	38% (n = 325)	17% (n = 149)	16% (n = 135)	5.7% (n = 49)	1.6% (n = 14)
Dealt promptly with symptoms	19% (n = 164)	36% (n = 308)	17% (n = 144)	16% (n = 133)	5.2% (n = 45)	2.4% (n = 21)
Had adequate knowledge and skills	21% (n = 182)	34% (n = 290)	15% (n = 126)	15% (n = 131)	5.4% (n = 46)	2.7% (n = 23)
<i>Physical care by nurses</i>						
Responded promptly to needs	18% (n = 151)	35% (n = 296)	20% (n = 174)	14% (n = 122)	4.2% (n = 36)	1.5% (n = 13)
Had adequate knowledge and skills	14% (n = 122)	35% (n = 297)	23% (n = 193)	14% (n = 123)	4.4% (n = 38)	1.2% (n = 10)
Helped the patient to enjoy daily life	16% (n = 134)	35% (n = 297)	21% (n = 185)	16% (n = 134)	3.4% (n = 29)	0.9% (n = 8)
<i>Psycho-existential care</i>						
Helping to relieve concerns	17% (n = 148)	35% (n = 302)	22% (n = 185)	15% (n = 126)	4.7% (n = 40)	0.6% (n = 5)
Appropriate when depressed	16% (n = 134)	37% (n = 316)	21% (n = 182)	14% (n = 116)	5.1% (n = 44)	1.0% (n = 9)
Tried to keep the patient hopeful	18% (n = 158)	36% (n = 306)	20% (n = 168)	14% (n = 116)	5.5% (n = 47)	1.0% (n = 9)
<i>Help with decision making</i>						
Sufficient explanation about the current condition	23% (n = 197)	30% (n = 257)	20% (n = 175)	13% (n = 109)	7.1% (n = 61)	3.3% (n = 28)
Sufficient explanation about the expected outcome	15% (n = 130)	33% (n = 284)	25% (n = 211)	12% (n = 104)	7.2% (n = 62)	2.3% (n = 20)
Patient could participate in the selection of treatment	21% (n = 178)	35% (n = 296)	19% (n = 164)	13% (n = 113)	4.3% (n = 37)	2.1% (n = 18)
<i>Coordination/consistency of care</i>						
Cooperation among staff members	17% (n = 148)	36% (n = 305)	18% (n = 153)	15% (n = 125)	4.7% (n = 40)	1.6% (n = 14)
Same doctors and nurses provided care	23% (n = 201)	33% (n = 281)	15% (n = 131)	16% (n = 136)	4.1% (n = 35)	1.7% (n = 15)
Planned with consideration for the previous course of the disease	20% (n = 171)	33% (n = 287)	18% (n = 155)	12% (n = 104)	4.5% (n = 39)	1.6% (n = 14)

The percentages do not sum to 100% because of missing values.
Domain names in italics.

Table 5
Comparisons of Patient Backgrounds and Patient-Reported Pain Intensity, Quality of Life, Quality of Palliative Care, and Satisfaction

Patient Backgrounds	Pain Intensity (Worst Pain in Previous 24 hours)		GDI		CES		Satisfaction	
	Mean ± SD	<i>P</i>	Mean ± SD	<i>P</i>	Mean ± SD	<i>P</i>	Mean ± SD	<i>P</i>
Gender								
Male (<i>n</i> = 471)	1.8 ± 2.4	0.35	55 ± 9.5	0.84	68 ± 21	0.27	4.6 ± .97	0.48
Female (<i>n</i> = 374)	2.0 ± 2.5		55 ± 9.2		70 ± 20		4.5 ± .95	
Age								
Patient 75 years or older (<i>n</i> = 246)	2.0 ± 2.5	0.48	54 ± 10	0.18	69 ± 21	0.76	4.7 ± .90	0.004
Patient <75 years (<i>n</i> = 601)	1.8 ± 2.5		55 ± 9.0		69 ± 20		4.5 ± .98	
Primary tumor site								
Lung (<i>n</i> = 221)	1.9 ± 2.6	0.47	54 ± 9.5	0.79	69 ± 21	1.00	4.5 ± .9	0.93
Breast (<i>n</i> = 148)	1.9 ± 2.4		56 ± 9.1		69 ± 19		4.6 ± .9	
Colon, rectum (<i>n</i> = 131)	1.6 ± 2.3		55 ± 9.0		69 ± 21		4.6 ± 1.0	
Stomach (<i>n</i> = 75)	2.1 ± 2.7		55 ± 9.2		69 ± 20		4.5 ± 1.0	
Liver, pancreas, bile duct (<i>n</i> = 81)	2.1 ± 2.7		54 ± 8.3		69 ± 23		4.5 ± 1.1	
Prostate (<i>n</i> = 86)	1.4 ± 2.0		56 ± 11		68 ± 21		4.5 ± .9	
Urogenital (<i>n</i> = 81)	2.0 ± 2.6		54 ± 8.9		70 ± 21		4.4 ± 1.0	
Living								
Not alone (<i>n</i> = 784)	1.9 ± 2.5	0.80	55 ± 9.2	0.20	69 ± 20	0.029	4.5 ± .95	0.77
Alone (<i>n</i> = 66)	1.9 ± 2.6		53 ± 9.5		63 ± 23		4.5 ± 1.0	
Marriage status								
Married (<i>n</i> = 695)	1.8 ± 2.5	0.35	55 ± 9.3	0.24	70 ± 20	0.23	4.5 ± .95	0.15
Divorced (<i>n</i> = 100)	2.0 ± 2.4		53 ± 10		66 ± 23		4.6 ± .89	
Not married (<i>n</i> = 49)	2.3 ± 2.7		55 ± 8.0		67 ± 22		4.3 ± 1.2	
Working								
Not working (<i>n</i> = 657)	2.0 ± 2.6	0.001	54 ± 9.7	0.002	69 ± 21	0.74	4.5 ± .98	0.67
Full time (<i>n</i> = 120)	1.4 ± 2.1		57 ± 8.0		70 ± 19		4.5 ± .85	
Part time (<i>n</i> = 65)	1.1 ± 1.9		57 ± 7.7		67 ± 19		4.4 ± 1.0	
Performance status								
0 (<i>n</i> = 243)	0.48 ± 1.2	<0.001	60 ± 7.8	<0.001	74 ± 19	<0.001	4.7 ± .89	<0.001
1 (<i>n</i> = 371)	2.0 ± 2.3		55 ± 8.5		69 ± 20		4.5 ± .98	
2 (<i>n</i> = 181)	2.8 ± 2.8		51 ± 9.0		65 ± 21		4.5 ± .92	
3 (<i>n</i> = 37)	3.9 ± 3.3		44 ± 10		61 ± 20		4.3 ± 1.0	
4 (<i>n</i> = 14)	4.8 ± 3.4		43 ± 6.6		56 ± 27		3.8 ± 1.3	
Chemotherapy and/or radiotherapy								
Receiving (<i>n</i> = 498)	1.9 ± 2.4	0.38	55 ± 9.0	0.43	69 ± 20	0.52	4.5 ± .93	0.83
Not receiving (<i>n</i> = 343)	1.8 ± 2.5		55 ± 9.8		68 ± 21		4.5 ± 1.0	
Region								
Tsuruoka (<i>n</i> = 84)	1.6 ± 2.3	0.080	55 ± 8.6	0.27	66 ± 21	0.21	4.5 ± .91	0.41
Kashiwa (<i>n</i> = 147)	1.5 ± 2.4		56 ± 8.2		71 ± 19		4.6 ± .97	
Hamamatsu (<i>n</i> = 320)	2.0 ± 2.4		55 ± 10		70 ± 20		4.5 ± .87	
Nagasaki (<i>n</i> = 275)	2.1 ± 2.7		54 ± 9.3		66 ± 22		4.5 ± 1.0	

Correlations Among Patient-Reported Pain Intensity, Quality of Life, Quality of Palliative Care, and Satisfaction

There were significant but mild to moderate correlations among the pain intensity, total score for the GDI, total score for the CES, and satisfaction levels (all $P < 0.001$, Fig. 1), except for the relatively high correlation between the total score for the CES and satisfaction levels. The correlation coefficients between satisfaction and

subscales of the CES were physical care by physicians ($\rho = 0.63$), physical care by nurses ($\rho = 0.59$), psycho-existential care ($\rho = 0.63$), help with decision making ($\rho = 0.66$), and coordination/consistency of care ($\rho = 0.62$).

Discussion

This was a region-based, multicenter survey comprehensively evaluating pain intensity,

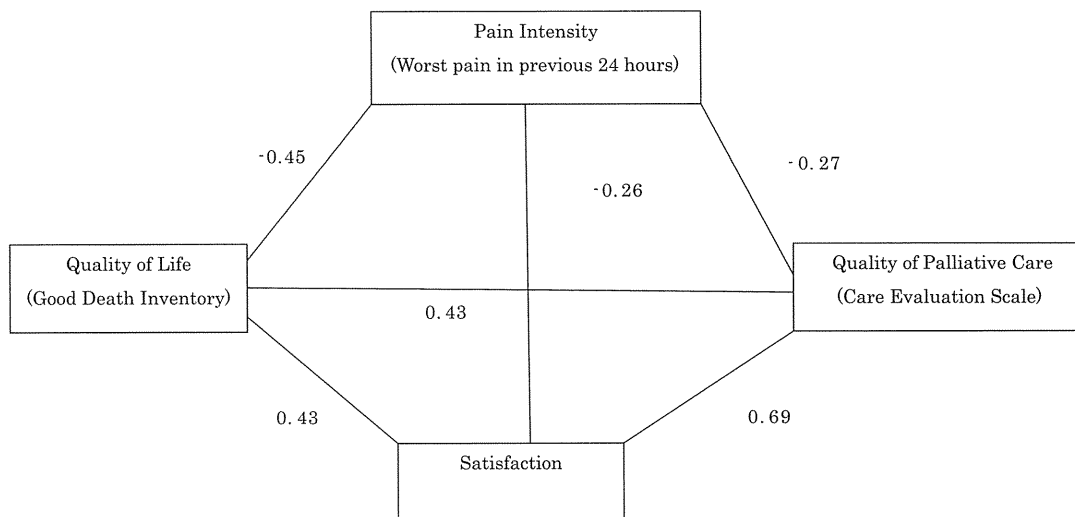


Fig. 1. Correlations among patient-reported pain intensity, quality of life, quality of palliative care, and satisfaction.

quality of life, quality of palliative care, and satisfaction as reported by outpatients with metastatic or recurrent cancer. In addition, this was the first nationwide multicenter survey about the pain experience of cancer patients in Japan. Significant but modest correlations among these variables indicated that they are overlapped but different concepts, and measuring them at the same time could be useful for understanding patients' overall experience. The strengths of this study include the relatively large number of patient responses analyzed, the high participating institution rates in each study region (which included 81% of the relevant inpatient beds), and the use of well-validated measurement tools of quality of life and quality of palliative care specifically developed for Japanese patients with advanced cancer. These measures enabled us to capture the broader areas of patient quality of life beyond symptom burden and functional status, especially psycho-existential components, and patient-perceived quality of care.

Approximately 60% of the patients in this study had some level of pain, which is similar to figures of 59%–74% reported in comparable Western populations.⁶ Approximately 20% of the population in this study had moderate to severe pain, with corresponding Western figures varying between 20% and 49%.⁶ Likewise, the population in this study with "substantial" pain, defined as pain intensity of 5 or more, was approximately 20%, compared with 20%

in a survey from The Netherlands.⁸ These findings confirm that at least 20% of advanced cancer patients in outpatient settings experience moderate to severe pain, and pain management is still one of the most important areas for outpatient cancer care.

Quality of life reported by the patients was generally high in this survey, particularly living in a favorite place, having a good relationship with medical staff, having independence, having environmental comfort, and being respected as an individual. These findings reflect that the ambulatory patients that were being undertreated had relatively good performance status. Conversely, patients reported relatively lower quality-of-life scores in three domains: 1) physical distress other than pain, 2) emotional distress, and 3) existential components such as maintaining hope, feeling of life completion, and feeling a burden to others. These findings are consistent with previous study findings in which frequent concerns for outpatient cancer patients included physical distress other than pain (i.e., fatigue and gastrointestinal symptoms such as appetite loss, nausea, and taste changes); psychological distress (i.e., anxiety, fear, and depression); and existential components (i.e., uncertainty, fears about their cancer spreading, concerns about their future, the unpredictability of their existence, their dependence on others, and feeling a burden to others).^{10–14} This study and others thus provide strong support for the urgent need for research to develop

appropriate assessment tools and effective interventions to palliate physical distress other than pain (e.g., fatigue, appetite loss), emotional distress including depression, and existential suffering specifically targeted to maintaining hope, life completion, and alleviating patient-perceived burden to others.^{24–26}

Of special note was the very high prevalence (approximately 50%) of Japanese outpatients with advanced cancer who perceived themselves to be a burden to others. This was despite the fact that more than 90% of the patients were independent in their daily lives. This is in line with a large survey performed in Japan on terminally ill cancer patients that also indicated that one of the most common facets of existential suffering was perceived burden to others, and that this was not always associated with objective evidence of any impairment in the patients' activities.²⁷ Several studies from Western countries also have revealed that being a burden to others is one of the biggest concerns for cancer outpatients.^{13,14} Recent studies on Japanese patients have identified potentially useful care strategies to palliate patient perception of being a burden, including practical, cognitive, and emotional approaches.^{27,28} Further studies should be encouraged to explore better interventions for relieving patient-perceived burden to others in physically independent outpatients with advanced cancer.

Regarding the patient-perceived quality of care, 20% of patients in this study reported there was some need for improvements in all five subscales assessing the quality of palliative care; however, less than 5% of patients rated the need as "highly necessary." This is similar to the findings of another study using the same questionnaire for bereaved family members of cancer patients who died in certified palliative care units; in that study, less than 5% of respondents reported that improvements in palliative care were "highly necessary." In contrast, the percentage of respondents who reported that "no improvement was necessary" ranged from 23% to 38% in the palliative care unit survey vs. 20% or less in this survey.¹⁶ This suggests that outpatients in the present study evaluated the quality of the palliative care they received as generally acceptable (i.e., not completely satisfied), and some improvement was desired in all areas, including physical care by physicians, physical care by nurses, psycho-

existential care, help with decision making, and coordination/consistency of care.

Performance status was the strongest predictor of patient-reported severe pain intensity, poor quality of life, low quality of care, and low satisfaction. This suggests that disease progression causes the development of multiple symptoms and a variety of needs. As the full assessment of the palliative care needs of all patients is not practical in many outpatient settings because of the limited availability of time and resources, an easily applicable screening tool for outpatients targeted to those with considerable decreases in performance status could identify patients who should be candidates for intensive palliative care interventions.^{9,29} Feasible and effective strategies to identify the outpatients with lower performance status and unmet needs should be tested.

Of note, there was no statistically significant difference in pain intensity, quality of life, quality of palliative care, and satisfaction among the different regions with different palliative care systems. Potential interpretations include 1) presence or type of palliative care system had no influence on overall patient experience at a regional level, 2) measurement instruments have inadequate sensitivity (e.g., the CES is influenced by the patient-perceived quality of general care, not only quality of palliative care), and 3) many of the patients surveyed in this study were in generally good condition and may not require specialized palliative care. The effects of the palliative care system on patient outcomes should be investigated in further well-designed studies.

This study had several limitations. First, the response rate was moderate at 58%, and no analysis comparing respondents with nonrespondents was possible because of a lack of patient consent for using nonrespondent data. We cannot conclude, therefore, that response bias might make either over- or underestimation of the results possible. Second, we used a mail survey for this study instead of face-to-face or telephone interviews because of cost reasons, and the possibility that a different approach might obtain different results cannot be denied. One study performed in a similar setting in The Netherlands, however, demonstrated no statistically significant difference in the prevalence of pain when comparing data

collected using either an interview or a mail survey.⁸ Therefore, we believe the method of questionnaire distribution was unlikely to alter the overall conclusions. Third, although the patients in this study came from a variety of locations and hospitals within the regions studied (more than 80% of inpatient beds are covered in each area), not all hospitals participated in the survey, particularly small hospitals. We believe, however, the number of patients receiving cancer treatment in such hospitals is small, and this bias does not influence the conclusions. Finally, as we did not obtain the data about medical treatments the patients actually received, we cannot conclude the appropriateness of care they received.

In conclusion, at least 20% of outpatients with metastatic or recurrent cancer experience moderate to severe pain, physical symptoms other than pain, emotional distress, and existential suffering such as maintaining hope, life completion, and feeling a burden to others; and reported that improvement in the quality of palliative care is necessary in multiple areas. Palliative care for Japanese outpatients with recurrent or metastatic cancer should be further improved.

Disclosures and Acknowledgments

This study was funded by the Third Term Comprehensive Control Research for Cancer Health and Labor Sciences Research Grants in Japan. The authors have no other financial disclosures or conflicts of interest.

References

1. World Health Organization. National cancer control programmes. Policies and managerial guidelines, 2nd ed. Geneva: World Health Organization, 2001.
2. Bakitas M, Lyons KD, Hegel MT, et al. Effects of a palliative care intervention on clinical outcomes in patients with advanced cancer. *JAMA* 2009;302:741–749.
3. Follwell M, Burman D, Le LW, et al. Phase 2 study of an outpatient palliative care intervention in patients with metastatic cancer. *J Clin Oncol* 2009;27:206–213.
4. Rabow MW, Dibble SL, Pantilat SZ, McPhee SJ. The comprehensive care team. A controlled trial of outpatient palliative medicine consultation. *Arch Intern Med* 2004;164:83–91.
5. von Plessen C, Aslaksen A. Improving the quality of palliative care for ambulatory patients with lung cancer. *BMJ* 2005;330:1309–1313.
6. van den Beuken-van Everdingen MH, de Rijke JM, Kessels AG, et al. Prevalence of pain in patients with cancer: a systematic review of the past 40 years. *Ann Oncol* 2007;18:1437–1449.
7. Cleeland CS, Gonin R, Hatfield AK, et al. Pain and its treatment in outpatients with metastatic cancer. *N Engl J Med* 1994;330:592–596.
8. Schuit KW, Sleijfer DT, Meijler WJ, et al. Symptoms and functional status of patients with disseminated cancer visiting outpatient departments. *J Pain Symptom Manage* 1998;16:290–297.
9. Yamagishi A, Morita T, Miyashita M, Kimura F. Symptom prevalence and longitudinal follow-up in cancer outpatients receiving chemotherapy. *J Pain Symptom Manage* 2009;37:823–830.
10. Arnes J, Crowe M, Colbourne L, et al. Patients' supportive care needs beyond the end of cancer treatment: a prospective, longitudinal survey. *J Clin Oncol* 2008;27:6172–6179.
11. Lidstone V, Butters E, Seed PT, et al. Symptoms and concerns amongst cancer outpatients: identifying the need for specialist palliative care. *Palliat Med* 2003;17:585–595.
12. Tishelman C, Lövgren M, Broberger E, Hamberg K, Sprangers MAG. Are the most distressing concerns of patients with inoperable lung cancer adequately assessed? A mixed-methods analysis. *J Clin Oncol* 2010;28:1942–1949.
13. Dudgeon DJ, Raubertas RF, Doerner K, et al. When does palliative care begin? A needs assessment of cancer patients with recurrent disease. *J Palliat Care* 1995;11:5–9.
14. Osse BH, Vernooij-Dassen MJFJ, Schadé E, Grol RPTM. The problems experienced by patients with cancer and their needs for palliative care. *Support Care Cancer* 2005;13:722–732.
15. Barbera L, Seow H, Howell D, et al. Symptom burden and performance status in a population-based cohort of ambulatory cancer patients. *Cancer* 2010;116:5767–5776.
16. Miyashita M, Morita T, Hirai K. Evaluation of end-of-life cancer care from the perspective of bereaved family members: the Japanese experience. *J Clin Oncol* 2008;26:3845–3852.
17. Yamagishi A, Morita T, Miyashita M, et al. 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. *Am J Hosp Palliat Care* 2008;25:412–418.
18. Uki J, Mendoza T, Cleeland CS, Nakamura Y, Takeda F. A brief cancer pain assessment tool in

- Japanese: the utility of the Japanese Brief Pain Inventory—BPI-J. *J Pain Symptom Manage* 1998;16:364–373.
19. Miyashita M, Morita T, Sato K, et al. Good Death Inventory: a measure for evaluating good death from the bereaved family member's perspective. *J Pain Symptom Manage* 2008;35:486–498.
20. Miyashita M. Validation of the Good Death Inventory patient version 2008. Ministry of Health, Labor, and Welfare, 2008. Available from <http://mhlw-grants.niph.go.jp/niph/search/NIDD00.do>. Accessed June 4, 2010.
21. Morita T, Hirai K, Sakaguchi Y, et al. 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.
22. Miyashita M. Validation of the Care Evaluation Scale patient version 2008. Ministry of Health, Labor, and Welfare, 2008. Available from <http://mhlw-grants.niph.go.jp/niph/search/NIDD00.do>. Accessed June 4, 2010.
23. Oken MM, Creech RH, Tormey DC, et al. Toxicity and response criteria of the Eastern Cooperative Oncology Group. *Am J Clin Oncol* 1982;5:649–655.
24. Armes J, Chalder T, Addington-Hall J, Richardson A, Hotopf M. A randomized controlled trial to evaluate the effectiveness of a brief, behaviorally oriented intervention for cancer-related fatigue. *Cancer* 2007;110:1385–1395.
25. Lundholm K, Gunnebo L, Körner U, et al. Effects by daily long term provision of ghrelin to unselected weight-losing cancer patients: a randomized double-blind study. *Cancer* 2010;116:2044–2052.
26. Strong V, Waters R, Hibberd C, et al. Management of depression for people with cancer (SMaRT oncology 1): a randomised trial. *Lancet* 2008;372:40–48.
27. Akazawa T, Akechi T, Morita T, et al. Self-perceived burden in terminally ill cancer patients: a categorization of care strategies based on bereaved family members' perspectives. *J Pain Symptom Manage* 2010;40:224–234.
28. Ando M, Morita T, Akechi T, Okamoto T, Japanese Task Force for Spiritual Care. Efficacy of short-term life-review interviews on the spiritual well-being of terminally ill cancer patients. *J Pain Symptom Manage* 2010;39:993–1002.
29. Morita T, Fujimoto K, Namba M, et al. Screening for discomfort as the fifth vital sign using an electronic medical recording system: a feasibility study. *J Pain Symptom Manage* 2008;35:430–436.



This article appeared in a journal published by Elsevier. The attached copy is furnished to the author for internal non-commercial research and education use, including for instruction at the authors institution and sharing with colleagues.

Other uses, including reproduction and distribution, or selling or licensing copies, or posting to personal, institutional or third party websites are prohibited.

In most cases authors are permitted to post their version of the article (e.g. in Word or Tex form) to their personal website or institutional repository. Authors requiring further information regarding Elsevier's archiving and manuscript policies are encouraged to visit:

<http://www.elsevier.com/copyright>

Original Article

A Scale for Measuring Feelings of Support and Security Regarding Cancer Care in a Region of Japan: A Potential New Endpoint of Cancer Care

Ayumi Igarashi, RN, PhD, Mitsunori Miyashita, RN, PhD, Tatsuya Morita, MD, Nobuya Akizuki, MD, PhD, Miki Akiyama, PhD, Yutaka Shirahige, MD, PhD, and Kenji Eguchi, MD, PhD

Department of Gerontological Nursing (A.I.), Graduate School of Health Care Sciences, Tokyo Medical and Dental University, Tokyo; Department of Palliative Nursing (M.M.), Health Sciences, Graduate School of Tohoku University, Miyagi; Department of Palliative and Supportive Care (T.M.), Seirei Mikatahara General Hospital, Shizuoka; Psycho-Oncology Division (N.A.), Chiba Cancer Center, Chiba; Faculty of Policy Management (M.A.), Keio University, Kanagawa; Shirahige Clinic (Y.S.), Nagasaki; and Department of Internal Medicine and Medical Oncology (K.E.), Teikyo University School of Medicine, Tokyo, Japan

Abstract

Context. Having a sense of security about the availability of care is important for cancer patients and their families.

Objectives. To develop a scale for the general population to evaluate feelings of support and security regarding cancer care, and to identify factors associated with a sense of security.

Methods. A cross-sectional anonymous questionnaire was administered to 8000 subjects in four areas of Japan. Sense of security was measured using five statements and using a seven-point Likert scale: "If I get cancer 1) I would feel secure in receiving cancer treatment, 2) my pain would be well relieved, 3) medical staff will adequately respond to my concerns and pain, 4) I would feel secure as a variety of medical care services are available, and 5) I would feel secure in receiving care at home." We performed an exploratory factor analysis as well as uni- and multivariate analyses to examine factors associated with such a sense of security.

Results. The five items regarding sense of security were aggregated into one factor, and Cronbach's α was 0.91. In the Yamagata area where palliative care services were not available, the sense of security was significantly lower than in the other three regions. Female gender ($P=0.035$), older age ($P<0.001$), and having cancer ($P<0.001$) were significantly associated with a strong sense of security.

Address correspondence to: Ayumi Igarashi, RN, PhD, Department of Gerontological Nursing, Graduate School of Health Care Sciences, Tokyo Medical and

Dental University, 1-5-45 Yushima, Bunkyo-ku, Tokyo 113-8510, Japan. E-mail: igarashi.gh@tmd.ac.jp

Accepted for publication: April 12, 2011.

Conclusion. A new scale that evaluates sense of security with regard to cancer care was developed. Future studies should examine whether establishing a regional health care system that provides quality palliative care could improve the sense of security of the general population. *J Pain Symptom Manage* 2012;43:218–225. © 2012 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Key Words

Sense of security, palliative care, region, quality of care, general population

Introduction

Cancer is a serious disease affecting the lives of many people. In Japan, cancer affects half of the population (55% of males and 41% of females) throughout their lifetime¹ and is the cause of about 30% of all deaths.² It is essential that quality care is available for cancer patients. Outcomes of care for cancer patients have been measured using various indicators such as symptoms,^{3,4} prognosis, quality of life,^{5,6} quality of care,^{7,8} patient satisfaction,^{9,10} and family satisfaction;¹¹ however, there are no indicators that assess the overall availability of care, which could be used, for example, to compare regions.

Having a sense of security about the availability of high-quality care is very important for cancer patients and their families.¹² A sense of security should be evaluated from the perspective of the general population living in a region, in addition to cancer patients and their families. These perspectives reflect the quality of the regional system for providing health care services, and the awareness among the population of the services provided by the system. As part of quality assurance of regional cancer care, a sense of security among the general population is important.

Regarding the concept of a sense of security, Funk et al.¹² indicated that a feeling of security among family caregivers of cancer patients consisted of trust in competent professionals; timely access to needed care, services, and information; and a sense of their own identity and self-worth as caregivers and individuals. The domain of “access to care” encompasses a sense of feeling supported and the perceived access to care.¹² Milberg et al.^{13,14} also suggested that having competent staff with a good attitude, access to care 24 hours a day, and being at home contributed to

a feeling of security among family caregivers. According to these proposed concepts, security is not only just trust in an individual health care professional but also a generalized sense of institutional trust in the health care system that makes people feel supported.¹² However, the concept of a sense of security has not been explicitly validated.

The aims of this study were 1) to develop a scale for the general population in regions of Japan that evaluates the sense of feelings of support and security regarding cancer care, and 2) to identify factors associated with a sense of security in those regions. This study is new in that the scale to assess the sense of security is measured from the perspective of the general population in a region and includes both trust in competent health care professionals and in the regional health care system, as proposed by Funk et al.¹²

Methods

This study was conducted as a part of the Outreach Palliative Care Trial of Integrated Regional Model (OPTIM) study, launched by the Ministry of Health, Labor, and Welfare in Japan.^{15,16} The OPTIM study is a regional intervention trial with the aim of establishing a regional palliative care model in four areas of Japan: a large urban area (Chiba: Kashiwa, Nagareyama, and Abiko City), a smaller urban area (Shizuoka: Hamamatsu City), and two rural areas (Nagasaki: Nagasaki City, and Yamagata: Tsuruoka and Mikawa City). In Chiba, Shizuoka, and Nagasaki, palliative care services are available; in Yamagata, such services are sparse.

We administered a cross-sectional anonymous questionnaire. In the questionnaire, we explained the aim of the study and regarded