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Public Awareness, Knowledge of Availability, and Readiness for Cancer Palliative Care Services: A Population-Based Survey across Four Regions in Japan

Kei Hirai, Ph.D.,¹ Tadashi Kudo, M.A.,² Miki Akiyama, Ph.D.,³ Motohiro Matoba, M.D., Ph.D.,⁴
Mariko Shiozaki, Ph.D.,⁵ Teruko Yamaki, B.A.,⁶ Akemi Yamagishi, R.N., Ph.D.,⁷
Mitsunori Miyashita, R.N., Ph.D.,⁸ Tatsuya Morita, M.D.,⁹ and Kenji Eguchi, M.D., Ph.D.¹⁰

Abstract

Background: This study explores the distribution of public awareness, knowledge of availability, and readiness for palliative care services, and the perceived reliability of information resources as part of a nationwide palliative care implementation intervention in Japan (Outreach Palliative Care Trial of Integrated Regional Model [OPTIM]).

Methods: A cross-sectional anonymous questionnaire survey was conducted, and 3984 responses were used in the final analysis.

Results: A total of 63.1% of respondents admitted having no knowledge about palliative care, while 0.5% of respondents were using palliative care services. Respondents who knew about palliative care services, yet did not know about their availability were 18.6% of all respondents. Respondents who had cancer-related experiences were more likely to be aware of palliative care compared to the general population and availability of palliative care services. Only awareness of palliative care was significantly associated with two typical images, while cancer-related experiences were not.

Conclusion: Findings show that the public awareness of palliative care services and their availability is insufficient, and cancer-related experiences affect awareness of cancer palliative care but not directly related to typical images for palliative care such as care for patients close to death.

Introduction

PALLIATIVE CARE for patients with cancer in Japan has rapidly progressed in the past decade, but many critical issues still need to be resolved. To improve overall cancer care (including palliative care) throughout Japan, the Cancer Control Act was established in April 2007. To facilitate the dissemination of palliative health services, the Ministry of Health, Labour, and Welfare focuses on palliative care concerns, and has launched a multiple nationwide project for community-based intervention trials in four areas in Japan, as described via the Outreach Palliative Care Trial of Integrated

Regional Model (OPTIM) study.¹ The study includes creating community-based specialized palliative care teams, developing educational materials, educating community medical staff on palliative care, and campaigning to disseminate knowledge relevant to specialized palliative care programs to patients, families, and the general public.

The reason that this trial includes the campaign is that the general public does not have adequate knowledge about palliative care concepts.¹ For example, only 34% of the general population knows about palliative care units in Japan, whereas the rate of knowledge in the United Kingdom is 70%.^{2,3} Of note, although 32% of the Japanese general public

¹Center for the Study of Communication Design, ²Graduate School of Human Sciences, ⁶Graduate School of Human Sciences, Osaka University, Osaka, Japan.

³Faculty of Policy Management, Keio University, Japan.

⁴Department of Palliative Medicine and Psycho-Oncology, Palliative Care Team, National Cancer Hospital, Japan.

⁵Faculty of Applied Sociology, Kinki University, Japan.

⁷Department of Adult Nursing/Palliative Care Nursing, School of Health Sciences and Nursing, Graduate School of Medicine, The University of Tokyo, Tokyo, Japan.

⁸Department of Palliative Nursing, Health Sciences, Tohoku University Graduate School of Medicine, Japan.

⁹Department of Palliative and Supportive care, Palliative Care Team and Seirei Hospice, Seirei Mikatahara Hospital, Shizuoka, Japan.

¹⁰Department of Internal Medicine and Medical Oncology, Teikyo University School of Medicine, Japan.

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believes that palliative care units are places where patients simply wait for death, these misperceptions are significantly decreased after individuals actually use a specialized palliative care service.^{3,4} Thus, the lack of knowledge and general misperceptions regarding palliative care are considerable barriers to palliative care and appropriate pain control, and further education of the general public would be of great value.

This research has revealed prevalence and relationships among general knowledge and perceptions for barriers but has not clarified intentions, acceptance, and knowledge of the availability if the people use the services in a local region. To develop effective strategies to promote the enhanced utilization of palliative care services, we must explore the demographics (such as gender, age, or residential status) and barriers related to not only general public awareness of palliative care, but also intention for use, knowledge of the availability, and actual rate of service utilization. As the previous study revealed,^{3,4} it is also expected that opinions of palliative care, which are supposed to be formed from personal experiences, affected not only general awareness but intention or readiness. In particular, sources to form opinions of cancer palliative care are supposed to be cancer-related experiences as the patient themselves or as the patient's family members.⁵

This article, therefore, has the following aims: (1) to clarify the distribution of public awareness, knowledge of availability, and readiness for palliative care services, (2) to clarify the differences in awareness, knowledge, and readiness among demographic variables and between healthy individuals and those who have cancer-related experiences (either personally or via family), (3) to clarify the differences of typical opinions of palliative care in awareness, knowledge, and readiness, in relation to cancer-related experiences and other demographics.

Methods

Subjects

This study was a part of OPTIM, and the overall protocol has been provided in detail elsewhere.¹ Our investigation was a survey of the general population, including patients with cancer and their families in four regions from the OPTIM study. These consisted of a large urban area (Chiba), an urban area (Shizuoka), and two rural areas (Nagasaki and Yamagata). The first three areas are places in which palliative care services are available and the last one (Yamagata) is, in comparison, a location in which services are practically unavailable.

A cross-sectional anonymous questionnaire survey was conducted in a sample of the general population selected by stratified two-stage random sampling in each area (2,000 subjects in each of four regional areas). As a result, this sample included cancer patients (outpatients receiving or having received cancer treatment). We mailed a total of 8,000 questionnaires to these potential participants in June 2007 and on a later date sent a reminder postcard. On the questionnaire, we explained the aim of the study and regarded completion and return of the questionnaire as consent for participation in this study. The institutional review boards of Tokyo University confirmed the ethical and scientific validity.

Questionnaire

We developed our own questionnaire on the basis of the aims of OPTIM and through literature reviews, existing sur-

veys, and consensus among the authors as follows. On the cover page of the questionnaire, palliative care was defined as: attempts to make patients with cancer and their family less anxious or to experience less pain, to immediately start consultations about anxiousness and pain regardless of the state of cancer development, and in addition to treatment, to facilitate the teamwork of doctors and nurses in the practice of treating patients who are suffering from the physical and/or emotional effects of cancer.

The questionnaire included three parts. First, it included questions covering the demographic information of the subjects (age, gender, length of living in each area) and whether subjects are undergoing (or had undergone) cancer treatment or had family members who had experiences of undergoing cancer treatment. Second, it included an item originally designed to determine the extent of public awareness, knowledge of availability, and readiness and actual utilization of palliative care service. We asked the participants to choose only one option from six sequential options regarding palliative care and such services: (1) no knowledge (I have no knowledge regarding palliative care; I); (2) lack of knowledge of availability (I have heard of palliative care, but I do not know if there are any available facilities in my municipality; II); (3) no interest (I know about palliative care and its availability in my residential area, but I have no interest in the service; III); (4) no intention (I know about palliative care and its availability in my residential area, and have an interest, but I have no intention of using the service as a patient or for a family member; IV); (5) preparation (I am preparing to use palliative care services; V); (6) under utilization (I currently use palliative care services; VI; Fig. 1). We converted the subjects' responses for these responses (I to VI) into a numeric

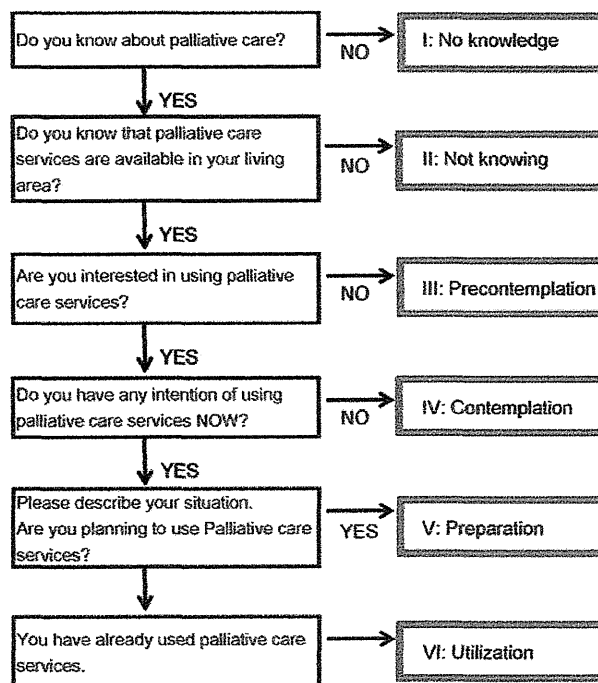


FIG. 1. Public awareness and readiness for palliative care services.

TABLE 1. DEMOGRAPHIC BACKGROUND OF THE RESPONDENTS

	Total		General population		Those who have experienced cancer	
	(n = 3190)		(n = 1330)		(n = 1860)	
	n	%	n	%	n	%
Age years						
40-49	705	22.1	302	22.7	403	21.7
50-59	1020	32.0	404	30.4	616	33.1
60-69	898	28.2	385	28.9	513	27.6
70-	567	17.8	239	18.0	328	17.6
Gender						
Male	1,426	44.7	666	50.1	760	40.9
Female	1,764	55.3	664	49.9	1100	59.1
Region (Prefecture)						
Chiba	945	29.6	413	31.1	532	28.6
Shizuoka	785	24.6	364	27.4	421	22.6
Nagasaki	733	23.0	274	20.6	459	24.7
Yamagata	727	22.8	279	21.0	448	24.1
Length of living in each area						
<1 year	38	1.2	22	1.7	16	0.9
1-5 year	131	4.1	60	4.5	71	3.8
>5 year	3,021	94.7	1,248	93.8	1,773	95.3

scale ranging from 1 to 6 points. Finally, three items related to palliative care beliefs/concepts ("Palliative care relieves pain and distress"; "Palliative care is used with chemotherapy and radiotherapy"; "Palliative care is for patients close to death.")^{3,5} were presented, and responses were measured on a five point Likert-type scale from 1) strongly disagree to 5) strongly agree.

Analysis

Descriptive analyses were carried out summarizing the subjects' backgrounds, awareness of palliative care and utilization of such services, and scores for reliable media source opinions for total and each sampled area. Then we explored

the distribution of knowledge and readiness of palliative care and utilization of the service associated with each sampled area and experiences of having cancer. These analyses were performed after dividing subjects into two groups (the general population and cancer patients/survivors) and we used the χ^2 test and Cramer's V to clarify relations between categorical variables and using coefficient correlation and relations between two categorical variables and ordered variables two-way analysis of variance (ANOVA). We conducted all statistical analyses using the Statistical Package for the Social Sciences (version 15.0.1.1J, SPSS Inc., Chicago, IL) software package. The significance level was set at $p < 0.05$ (two-tailed).

Results

Of the 8000 questionnaires delivered to the sampled subjects, 26 were returned as undeliverable and 3984 were returned (response rate, 49.8%). Of those returned, 3190 were considered valid for statistical analyses. The rest ($n = 794$) were invalid and were excluded from the analyses since major information was lacking. Thus, the final rate of valid replies was 39.9%.

A total of 1860 respondents (58.3% of all respondents) were identified as "those having experienced cancer" and the rest were identified as belonging to the "general population." Table 1 summarizes the background of respondents.

Public awareness, knowledge, and readiness for palliative care

A total of 63.1% of respondents admitting to having "no knowledge" of palliative care while 0.5% of respondents were actually using palliative care services. Respondents who knew about palliative care yet did not know about the availability of palliative care in their living area were 18.6% of all respondents. Female respondents were more likely to know about palliative care than male respondents ($\chi^2 = 55.09$, $df = 1$, $p < 0.001$, Cramer's V = 0.131), while age and length of living in each area were not significantly associated with

TABLE 2. PUBLIC AWARENESS AND READINESS FOR PALLIATIVE CARE SERVICES

	Total		General population		Those who have experienced cancer		Chiba		Shizuoka		Nagasaki		Yamagata	
	(n = 3190)		(n = 1330)		(n = 1860)		(n = 945)		(n = 785)		(n = 733)		(n = 727)	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%
I: No knowledge	2012	63.1	909	68.3	1,103	59.3	546	57.8	518	66.0	482	65.8	466	64.1
Having Knowledge	1178	36.9	421	31.7	757	40.7	399	42.2	267	34.0	251	34.2	261	36.0
II: Not knowing	593	18.6	230	17.3	363	19.5	201	21.3	96	12.2	115	15.7	181	24.9
III: Not interested	24	0.8	13	1.0	11	0.6	5	0.5	12	1.5	5	0.7	2	0.3
IV: No Intention	499	15.6	167	12.6	332	17.8	171	18.1	142	18.1	116	15.8	70	9.6
V: Preparation	46	1.4	10	0.8	36	1.9	18	1.9	14	1.8	10	1.4	4	0.6
VI: Under Utilization	16	0.5	1	0.1	15	0.8	4	0.4	3	0.4	5	0.7	4	0.6

Cancer experience \times Awareness (No knowledge vs. Having knowledge): $\chi^2 = 27.24$, $df = 1$, $p < 0.01$, Cramer's V = 0.092.

Four areas \times Awareness (No knowledge vs. Having knowledge): $\chi^2 = 16.83$, $df = 3$, $p < 0.01$, Cramer's V = 0.073.

Within People who Knew Palliative Care:

Cancer experience \times Availability: $\chi^2 = 4.83$, $df = 1$, $p < 0.028$, Cramer's V = 0.064

Four areas \times Availability: $\chi^2 = 61.88$, $df = 3$, $p < 0.01$, Cramer's V = 0.229.

Availability: No awareness of availability vs. awareness of availability.

either awareness, knowledge or readiness. Respondents who had cancer-related experiences (either themselves or via family members) were more likely to be aware of palliative care compared to the general population ($\chi^2 = 27.24, df = 1, p < 0.001, \text{Cramer's } V = 0.092$). Also among people who knew palliative care, there was a significant association between cancer experience and knowledge for availability or readiness ($\chi^2 = 4.83, df = 1, p = 0.028, \text{Cramer's } V = 0.064$). Table 2 also shows that awareness and knowledge of and readiness for palliative care was significantly different among each area ($\chi^2 = 16.84, df = 3, p < 0.001, \text{Cramer's } V = 0.073$). Particularly, respondents in Chiba-city have more knowledge about palliative care than individuals from the other three areas.

Typical images of palliative care

Table 3 indicates the results of two-way ANOVA for responses on three typical images of palliative care using awareness and cancer experiences as dependent variables, when age, gender, and area were controlled. First, the analysis revealed the differences in perception for three common images of palliative care between individuals having no knowledge of palliative care and those who had knowledge. Significant differences were observed between them in terms of images of palliative care in the following dimensions: "Palliative care relieves pain and distress" (general population; $F(1, 3186) = 33.02, p < 0.001$, Those having experienced cancer; $F(1, 3186) = 60.85, p < 0.001$) and "Palliative care is for patients close to death" (general population; $F(1, 3186) = 13.62, p < 0.01$, Those having experienced cancer; $F(1, 3186) = 13.00, p < 0.01$). People who know about palliative care have an overall positive image of it, tend to think that palliative care brings symptom control to the patients, and is specialized for terminally ill patients. There were no significant differences between the general population and cancer-experienced individuals on the three typical opinions of palliative care, and there were no significant interactions between cancer experience and knowledge of palliative care.

Discussion

This study is the first attempt to understand the public awareness of palliative care and utilization of services based on a nationwide sample in Japan. A clarification of these findings will hopefully contribute to understanding general perception of cancer palliative care and its variations by experiences related to cancer.

The primary aim of this study was to clarify the distribution of public awareness, knowledge of availability, and readiness for palliative care services. Per the results of the survey, 63.1% of all the participants had no knowledge of palliative care services. These results demonstrate a low public awareness of the Japanese palliative care services compared with other countries.^{2,3} Moreover, among those who did possess knowledge about palliative care in general, 18% did not know about the specific availability of the service in their region. These results indicate that over 80% of people do not have sufficient knowledge of palliative care to take advantage of its services, and it is therefore important to promote a more comprehensive understanding of palliative care (including availability) to the general population.

Second, our data clarified that cancer experiences were related to a greater knowledge of and readiness for palliative

TABLE 3. MEAN SCORES OF IMAGES OF PALLIATIVE CARE BY AWARENESS AND EXPERIENCE OF CANCER

Awareness	General population						Those who have experienced cancer						Main effect						
	Total		No knowledge		Having knowledge		Total		No knowledge		Having knowledge		Exp. Cancer		Awareness		Interaction		
	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD	F	P	F	P	F	P	
Experience of Cancer	3.81	0.80	3.72	0.83	4.00	0.70	3.88	0.85	3.76	0.88	4.06	0.76	2.75	.07	74.73	.00	0.08	.78	
Palliative care relieves pain and distress	3.51	0.90	3.53	0.85	3.47	1.00	3.51	0.97	3.50	0.94	3.52	1.02	0.18	.68	0.04	.85	1.09	.30	
Palliative care is used with chemotherapy and radiotherapy	3.19	1.22	3.12	1.12	3.34	1.26	3.22	1.29	3.15	1.27	3.32	1.30	0.01	.91	15.30	.00	0.36	.55	
Palliative care is for patients close to death																			

The results by two-way analysis of variance (ANOVA) were shown when age, gender, and area were controlled as covariates.

care, but did not significantly relate to specific images commonly associated with palliative care. From our data it is difficult to strictly compare patients with cancer with the overall population since the sample surveyed in this study was from the general population, and therefore only a small number of patients with cancer were included. However, people who had experiences with cancer (either personally or via family members) recognized both the term and meaning of palliative care. Also, people who had knowledge of palliative care have an overall positive image of it, tend to think that palliative care brings symptom control to the cancer patients, and is specialized for terminally ill patients. Generally, as the images will be reinforced by actual experiences, those who experienced as patients with cancer or as family members might see or hear the care at late stage of the cancer process. This indicated current situation that palliative care for patients with cancer in general Japanese hospitals was mainly provided for late-stage cancer and that contributed to form the general opinions of palliative care. Also, the perception that palliative care is primarily for terminally ill patients care may cause late referrals to palliative care services.^{5,6} These suggest that images derived from actual experiences will have strong impact for actual decision making for choosing or readiness for the services when the patients need. Therefore, it is important to provide proper and detailed information about palliative care services, as well as information regarding the availability of services, within areas of residence. We still have very big challenges to modify the general perception of cancer palliative care, because there is no known effective method to achieve this. Educational approaches in community may become one of the solutions, and will especially be needed to help people recognize that palliative care services accept even patients with early-stage cancer.

This study has several limitations. First, this study did not include measurements for the effectiveness of each medium and we cannot discern which media sources and what kind of information directly led individuals to be more aware of palliative care and to use these services. Second, we did not explore the possible associations between the awareness of palliative care and amounts of actual cancer treatment undergone. A more detailed survey will need to be conducted in order to clarify the above items. Moreover, it would be useful to better explore the insights of specific populations. In future surveys, it should be possible to design more directed questionnaires to support hypothesis-based studies.

In conclusion, the public awareness of palliative care services and their availability is insufficient. Those with cancer experiences were more aware of palliative care and their availability than the general population. Only people who were aware of palliative care developed two typical images, while those with cancer-related experiences did not. Ap-

proaches to inform the general population (including those with cancer-related experiences) about palliative care have already been taken in Japan. However, more effective methods should be developed. We feel that it is possible to eliminate many existing barriers to the improvement of end-of-life quality, and the dissemination of knowledge related to such care and treatment in Japan should be a top priority.

Author Disclosure Statement

No competing financial interests exist.

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Address correspondence to:

Kei Hirai, Ph.D.

Center for the Study of Communication Design

Osaka University

1-2 Yamadaoka, Suita,

Osaka, 567-0871

Japan

E-mail: khirai@grappo.jp

Original Article

Experience with Prognostic Disclosure of Families of Japanese Patients with Cancer

Saran Yoshida, MEd, Kei Hirai, PhD, Tatsuya Morita, MD, Mariko Shiozaki, PhD, Mitsunori Miyashita, RN, PhD, Kazuki Sato, RN, PhD, Satoru Tsuneto, MD, PhD, and Yasuo Shima, MD

Department of Clinical Psychology (S.Y.), Graduate School of Education, University of Tokyo, Tokyo; Japan Society for the Promotion of Science (S.Y.), Tokyo; Center for the Study of Communication Design (K.H.), Graduate School of Human Sciences & Graduate School of Medicine, Osaka University, Osaka; Department of Palliative and Supportive Care, Palliative Care Team, and Seirei Hospice (T.M.), Seirei Mikatahara General Hospital, Shizuoka; International Center for Human Sciences (M.S.), Kinki University, Higashi-Osaka; Department of Palliative Nursing (M.M., K.S.), Health Sciences, Tohoku University Graduate School of Medicine, Sendai; Department of Palliative Medicine (S.T.), Graduate School of Medicine, Osaka University, Osaka; and Department of Palliative Medicine (Y.S.), Tsukuba Medical Center Hospital, Ibaraki, Japan

Abstract

Context. Prognosis is difficult to discuss with patients who have advanced cancer and their families.

Objectives. This study aimed to explore the experiences of families of patients with cancer in Japan in receiving prognostic disclosure, explore family perception of the way the prognosis was communicated, and investigate relevant factors of family-perceived need for improvement.

Methods. A multicenter questionnaire survey was conducted with 666 bereaved family members of patients with cancer who were admitted to palliative care units in Japan.

Results. In total, 86.3% of the families received prognostic disclosure. The overall evaluation revealed that 60.1% of the participants felt that the method of prognostic disclosure needed some, considerable, or much improvement. The parameter with the highest value explaining the necessity for improvement was the family perception that the amount of information provided by the physician was insufficient ($\beta = 0.39$, $P < 0.001$). Furthermore, the family perception that they had lost hope and that health care providers failed to facilitate preparation for the patient's death had significant direct effects on the necessity for improvement ($\beta = 0.21$, $P < 0.001$; and $\beta = 0.18$, $P < 0.001$, respectively). The feelings for the necessity for improvement also were affected significantly by seven communication strategies (i.e., not saying "I can do nothing for the patient any longer," pacing explanation with the state of the patient's and family's preparation, saying "We will respect the patient's wishes," making an effort to

Address correspondence to: Saran Yoshida, MEd, Department of Clinical Psychology, Graduate School of Education, University of Tokyo, 7-3-1 Hongo,

Bunkyo-ku, Tokyo 113-0033, Japan. E-mail: saran@p.u-tokyo.ac.jp

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understand the family's distress, being knowledgeable about the most advanced treatments, assuring continuing responsibility as the physician for medical care, and respecting the family's values).

Conclusion. This model suggests that strategies for care providers to improve family perception about prognostic disclosure should include 1) providing as much prognostic information as families want; 2) supporting families' hopes by keeping up with up-to-date treatments and by assuring the continuing responsibility for medical care; 3) facilitating the preparation for the patient's death by providing information in consideration of the family's preparations and values; 4) stressing what they can do instead of saying that nothing can be done for the patient; and 5) assuring the family that they will respect the patient's wishes. *J Pain Symptom Manage* 2011;41:594–603. © 2011 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Key Words

Prognostic disclosure, family, cancer, communication, Japan

Introduction

Prognosis is an issue that most physicians and patients describe as difficult to discuss,¹ and whether to tell patients with cancer about their diagnosis and prognosis is a matter of great debate.² Although it is said to be important to give patients prognostic information so that they can make important decisions in an informed manner,² the concern that prognostic information can cause distress^{3,4} and loss of hope^{5–7} can lead some physicians to avoid the topic^{8,9} or to disclose vague⁴ or overly optimistic information.¹⁰ Therefore, it is very important to consider better ways of prognosis communication.

To date, many studies have been carried out to clarify patients' preferences^{11–13} and experiences¹⁴ in receiving prognostic disclosure. At the same time, methods of prognosis communication also have been explored, and several suggestions have been made.^{12,15} As important factors for optimal ways of presenting a prognosis to a patient, several themes have been identified, as follows: communication within a caring, trusting, long-term relationship; open and repeated negotiations for patient preferences for information; clear, straightforward presentation of the prognosis where desired; incorporation of strategies to ensure patient understanding; encouragement of hope and a sense of control; consistency of communication within the multidisciplinary team; and communication with other members of the family.¹⁵ Through these communication strategies,

physicians hope to strike a balance between maintaining a patient's positive attitude and facilitating the preparation for possible death.^{9,16,17}

The description of these strategies has been accompanied by only a few empirical studies that have specifically addressed the preferences and experiences of the family in receiving information about the patient's prognosis,¹⁸ and familial views on optimal ways of presenting a prognosis have not been explored. In Japan, family members have a special role in communicating bad news, including prognoses.¹⁹ Although many studies recommend that physicians disclose the prognosis first to the patient,^{11,20,21} it is culturally approved that family members receive the information before the patient, and in Japan and other Asian countries, families are requested to decide how and to what degree the patient should be told.^{21–23} It is also noteworthy that many Japanese patients agree to follow a family member's decision.²⁴ Therefore, family members are typically the first to receive the full medical information, whereas patients receive the information gradually, and often partially, based on their own or on their family members' preferences. For this reason, improvement in the methods of prognostic disclosure for family members is a major task for Japanese medical professionals.

A large survey was undertaken to help understand the methods of disclosure and opportunities for improvement in Japan. The primary aims were to 1) explore the experiences of

families of patients with cancer in Japan in receiving prognostic disclosure, 2) explore family perception of the way the prognosis was communicated, and 3) investigate relevant factors of family-perceived need for improvement.

Methods

Procedure

This study was part of a large cross-sectional, anonymous nationwide survey named the J-HOPE Study (Japan Hospice and Palliative Care Evaluation Study). The detailed methodology of this survey was described in a previous article.²⁵ All 153 palliative care units (PCUs) of Hospice Palliative Care Japan approved before September 2005 were recruited for this study, and 100 PCUs participated. We asked each institution to identify the bereaved family members of patients who died from November 2004 to October 2006 consecutively (up to 80 subjects from each institution). A total of about 8000 subjects were randomly allocated to receive 10 different questionnaire surveys. We mailed questionnaires to bereaved families in June 2007, and then again in August 2007 only to nonresponding families.

Participants

Primary physicians identified potential participants based on the following inclusion criteria: 1) bereaved family member of an adult patient with cancer (one family member was selected for each patient), 2) at least 20 years of age, 3) capable of replying to a self-report questionnaire, 4) aware of the diagnosis of malignancy, and 5) no serious psychological distress recognized by the primary physician. The last criterion was adopted on the assumption that primary physicians could identify families who would suffer serious psychological burden by taking this survey. In total, 8402 subjects were assigned to the J-HOPE study, and 12 questionnaires including this study were randomly assigned to them.

Completion and return of the questionnaire were regarded as consent to participate in this study. The ethical and scientific validity were confirmed by the institutional review board of each hospital.

Questionnaire

The questionnaire was developed by the authors based on information from previous

studies^{15,17,26–28} and extensive discussions among the authors. Content validity was confirmed by unanimous agreement of the authors. The primary endpoint was the family-perceived evaluation of prognosis communication that was provided by the physician who was in charge of the patient's treatment. As a result of the lack of previously validated instruments, the outcome parameters were developed by the authors similar to previous surveys. As an overall evaluation, we assessed the necessity for improvement, based on the answer to the question "How much improvement do you think was needed in the prognosis communication?" rated on a 4-point scale as 1: no improvement, 2: some improvement, 3: considerable improvement, and 4: much improvement.

In addition, family perception on amount of information, loss of hope, and usefulness of prognostic disclosure in preparation for patient death were assessed. The amount of information was rated on a 5-point scale as "much less than expected," "less than expected," "appropriate," "should have been a little less," and "should have been much less." For the other two aspects, the following questions were asked: "Did you lose hope after the prognosis communication?" and "Was the prognosis communication useful in preparing for the patient's death?" These questions were rated on a 5-point scale from 1: strongly disagree to 5: strongly agree.

The family members also were requested to report the level of prognostic disclosure they received, from 1: no disclosure (they did not receive any disclosure at all), 2: no answer (physician said "I don't know" or "I cannot answer"), 3: specific survival periods with some ranges or probability (e.g., several weeks or months), or 4: definite survival periods without ranges or probability (e.g., "until May" or "for three months"). We also asked about the amount of prognostic disclosure the patients received relative to their family members, from 1: no disclosure, 2: the same level of disclosure as the family received, 3: less specific information than the family received, or 4: more specific information than the family received.

In addition, we investigated 24 communication strategies derived from prior empirical studies on the assumption that physicians' communication skills could influence families'

emotional distress.^{12,18} The family members were requested to rate their level of agreement with the listed physicians' communication behaviors on a 5-point Likert-type scale from 1: strongly disagree to 5: strongly agree, or with a yes-no format.

Analysis

Descriptive analyses were carried out summarizing the participants' backgrounds and scores following psychological measurements. To explore the determinants of the family perception of prognostic disclosure, we initially screened 11 background variables (patient's age and sex, number of hospital days, type of cancer, bereaved family member's age, sex, relationship with the patient, health status during the caregiving period, frequency of attending to the patient, presence of other caregivers, and financial expenditure during the last month), the type of disclosure, family perception on amount of information, loss of hope, and usefulness of prognostic disclosure in preparation for patient death, and 24 communication strategies by univariate analyses. Univariate analyses were carried out with Student's *t*-test or the Chi-square test, where appropriate. To assess the results of the 31 comparisons, the *P*-value necessary for statistical significance was set at 0.002 (0.05/39) using the Bonferroni correction. For the comparisons, the respondents were classified into two groups: family members who rated the necessity for improvement as "some," "much," or "considerable" vs. "none." This cut-off point was determined on the basis of the actual

data distribution to divide the whole sample into approximately equal-sized comparison groups.

Next, a path analysis was carried out to test the model. All potential predictors with statistical significance by univariate analyses were entered in the model as independent variables.

We conducted all statistical analyses using SPSS version 11.0 (SPSS Inc., Chicago, IL) and AMOS version 5.0 (SPSS Inc., Chicago, IL).

Results

Of the 427 questionnaires returned (response rate 64.4%), 409 were valid for statistical analyses. The rest ($n = 18$) were invalid because of missing data on the primary endpoint, such as the necessity for improvement. Thus, the rate of valid replies was 61.9%. Table 1 summarizes the main background information for the family members. Only the participant's age was observed to be a significant predictor of necessity for improvement in the univariate analysis.

Family Reported Practices of Prognosis Disclosure

The types of prognostic disclosure received were no disclosure (7.6%, $n = 31$), no answer (4.9%, $n = 20$), specific survival periods with some ranges or probability (52.1%, $n = 213$), and definite survival periods without ranges or probability (34.2%, $n = 140$). Meanwhile, the types of prognosis communication that patients received were no disclosure (46.5%, $n = 190$), same as family (29.6%, $n = 121$),

Table 1
Background of Participants

Characteristic	Total		No Improvement		Some or More Improvement		<i>P</i>
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	
Total	409		163		246		
Age (mean ± SD)	59 ± 12		61 ± 11		58 ± 12		0.004
Sex							
Male	114	27.9	46	28.2	68	27.6	0.345
Female	291	71.1	114	69.9	177	72.0	
Relationship to patient							
Spouse	203	49.6	83	50.9	120	48.8	0.176
Child	130	31.8	42	25.8	88	35.8	
Child-in-law	23	5.6	11	6.7	12	4.9	
Sibling	28	6.8	15	9.2	13	5.3	
Other	22	5.4	10	6.1	12	4.9	

SD = standard deviation.

Table 2
Family-Reported Practice in Prognosis Disclosure

No.	Item	n	%
1	The physician assured sufficient symptom control	315	77.0
2	The physician assured sufficient care at the patient's last hour	303	74.1
3	The physician said, "We will respect the patient's wishes"	276	67.5
4	The physician explained mainly in words	275	67.2
5	The physician made maximum efforts to understand my distress	262	64.1
6	The physician paced his/her explanation with the state of my/patient's preparation	243	59.4
7	The physician gave concrete advice for my actual concern	242	59.2
8	The physician was knowledgeable about the most advanced treatments	236	57.7
9	The physician respected my values	229	56.0
10	The physician assured the continuing responsibility of physician for medical care	226	55.3
11	The physician suggested what we should do because the patient's condition was relatively good	213	52.1
12	The prognosis is an "average," and it does not have to be suitable for the patient	199	48.7
13	The physician discussed how to achieve my wishes, such as home care	190	46.5
14	The physician clearly told me the disease is incurable	172	42.1
15	The physician showed the thought, "I don't want to give up"	147	35.9
16	The physician explained in terms of daily life perspectives	131	32.0
17	The physician said, "I can do nothing for the patient any longer"	117	28.6
18	The physician told the longest predicted prognosis	94	23.0
19	The physician told the shortest predicted prognosis	93	22.7
20	The physician said, "Treatment might be possible at some time in the future"	73	17.8
21	The physician told the average prognosis	65	15.9
22	The physician used graphs and tables	40	9.8
23	The physician told the one-year survival rate	24	5.9
24	The physician told the five-year survival rate	16	3.9

less specific than family (11.7%, $n = 48$), and more specific than family (4.6%, $n = 19$).

Table 2 shows the percentages of family members who agreed (agree or strongly agree/yes) with each statement. Over 70% of the respondents reported that the physician assured sufficient symptom control at the patient's last hour.

Family Perception of Prognostic Disclosure

In the overall evaluation of prognosis communication, more than half of the family members felt that the method of prognostic disclosure should be improved: no improvement (39.9%, $n = 163$), some improvement (40.8%, $n = 167$), considerable improvement (11.5%, $n = 47$), and much improvement (7.8%, $n = 32$).

About half of the bereaved family members stated that the amount of prognostic information provided by the physician was more or less than they expected: much less than expected (13.7%, $n = 56$), less than expected (19.8%, $n = 81$), more than expected (11.7%, $n = 48$), and much more than expected (3.2%, $n = 13$). The responses to "Did you lose hope after the prognosis communication?" were strongly agree 24.7% ($n = 101$), agree 25.9% ($n = 106$), and agree a little 25.7% ($n = 105$), and the responses to "Was the

prognosis communication useful in preparing for the patient's death?" were strongly agree 13.9% ($n = 57$), agree 43.3% ($n = 177$), and agree a little 26.4% ($n = 108$).

Factors Associated with the Family-Perceived Necessity for Improvement

Table 3 shows the results of the univariate analyses of the family perception on amount of information, loss of hope, and usefulness of prognostic disclosure in preparation for patient death, types of prognostic disclosure, and communication strategies obtained from family members at each level of necessity of improvement. There were significant differences across family perception on amount of information, loss of hope, and usefulness of prognostic disclosure in preparation for patient death and 12 communication strategies between families who rated a high necessity for improvement and families who rated a low necessity.

Path Analysis for Familial Evaluation

We carried out a path analysis by first selecting 12 communication strategies, family perception on amount of information, loss of hope, and usefulness of prognostic disclosure in preparation for patient death, and type of

Table 3
Determinants of Family-Reported Necessity for Improvement in the Prognostic Disclosure

Item	Total	No Improvement		Some or More Improvement		P
	n	n	%	n	%	
The physician assured sufficient symptom control	315	146	89.6	169	68.7	0.000
The physician explained mainly in words	275	109	66.9	166	67.5	0.324
The physician assured sufficient care at the patient's last hour	303	139	85.3	164	66.7	0.000
The physician said, "We will respect the patient's wishes"	276	127	77.9	149	60.6	0.000
I lost my hope after the prognostic disclosure	216	70	42.9	146	59.3	0.000
The physician made maximum efforts to understand my distress	262	129	79.1	133	54.1	0.000
The prognostic disclosure was useful in preparing for patient's death	243	114	69.9	129	52.4	0.000
The physician was knowledgeable about the most advanced treatments	236	111	68.1	125	50.8	0.000
The physician gave concrete advice for my actual concern	242	121	74.2	121	49.2	0.000
The prognosis is an "average," and it does not have to be suitable for the patient	199	80	49.1	119	48.4	0.484
The physician paced his/her explanation with the state of my/patient's preparation	243	126	77.3	117	47.6	0.000
The physician assured the continuing responsibility of the physician for medical care	226	111	68.1	115	46.7	0.000
The physician respected my values	229	115	70.6	114	46.3	0.000
The physician suggested what we should do because the patient's condition was relatively good	213	103	63.2	110	44.7	0.000
The physician told me clearly the disease is incurable	172	63	38.7	109	44.3	0.151
The physician discussed how to achieve my wishes, such as home care	190	93	57.1	97	39.4	0.000
The physician said, "I can do nothing for the patient any longer"	117	32	19.6	85	34.6	0.001
The physician explained in terms of daily life perspectives	131	54	33.1	77	31.3	0.389
I felt that the amount of information was insufficient	205	130	79.8	75	30.5	0.000
The physician showed the thought, "I don't want to give up"	147	73	44.8	74	30.1	0.002
The physician told the shortest predicted prognosis	93	38	23.3	55	22.4	0.526
The physician told the longest predicted prognosis	94	40	24.5	54	22.0	0.366
The physician said, "Treatment might be possible at some time in the future"	73	30	18.4	43	17.5	0.455
The physician told the average prognosis	65	26	16.0	39	15.9	0.520
The physician used graphs and tables	40	14	8.6	26	10.6	0.287
The physician told the five-year survival rate	24	12	7.4	12	4.9	0.222
The physician told the one-year survival rate	16	8	4.9	8	3.3	0.295

prognostic disclosure received as independent variables in the initial model, because they were observed to be significant predictors of necessity for improvement in the univariate analysis. Next, we drew all paths according to the results of the correlation analysis. We repeated the analysis and sequentially dropped paths that were not significant until all of the paths in the model became significant ($P < 0.05$). The variables "The prognosis represents an average, and it doesn't have to turn out that way for the patient," "The physician told me the disease is definitely incurable," "The physician said, "Treatment may be possible at

some time in the future," and "The physician explained daily life perspectives" were dropped from the model, because all of the paths from these variables did not reach significance. Fig. 1 represents the final model. The fit indices for this model were Chi-square (40) = 177.4, $P = 0.000$; goodness-of-fit index = 0.94; adjusted goodness-of-fit index = 0.86; comparative fit index = 0.91; and root mean-square error of approximation = 0.10. Correlations between independent variables were omitted to simplify the model. Overall, the final model accounted for 41% of the variance in the necessity for improvement.

The parameter with the highest value explaining the necessity for improvement was the family perceived evaluation that the amount of prognosis information was insufficient (beta = 0.39, $P < 0.001$). Furthermore, family perception of loss of hope and usefulness of the prognosis in the preparation for patient death had significant direct effects on the necessity for improvement (beta = 0.21, $P < 0.001$ and beta = -0.18, $P < 0.001$, respectively). There were also three communication strategies that explained the necessity for improvement, as follows: "The physician said, 'I can do nothing for the patient any longer'" (beta = 0.11, $P = 0.005$), "The physician paced his/her explanation with the state of my/family's preparation" (beta = -0.21, $P < 0.001$), and "The physician said, 'We will respect the patient's wishes'" (beta = -0.10, $P = 0.013$).

Discussion

In Japan, family members have a special role in communicating bad news, including predicted prognosis.¹⁹ However, only a few empirical studies have specifically addressed the preferences and experiences of family members in receiving information about the patient's prognosis,¹⁸ and familial views on optimal ways of presenting the prognosis have not

been explored. This is, to our knowledge, the first large, multicenter survey to investigate family reported experiences in receiving prognostic disclosure.

Our survey revealed the experience of families of patients with cancer in Japan in receiving prognostic disclosure. Over 80% of the families received prognostic disclosure. This agrees closely with results of a previous Japanese study.¹⁹ The proportions of subjects who received each type of disclosure were told specific periods with some ranges or probability (40% in the previous survey vs. 52% in our survey) and told definite periods without ranges or probability (38% vs. 34%, respectively). In contrast, over 45% of the subjects answered that the patients were not told specific periods about their prognosis. These data support the view that Japanese family members have a special role in communicating prognosis, and it seems to be important for physicians to consider methods of communicating a patient's prognosis to family members. This study also demonstrated that 60% of family members reported that some, considerable, or much improvement was necessary in the methods of prognostic disclosure. This result suggests that methods in prognosis disclosure would need more improvement in general.

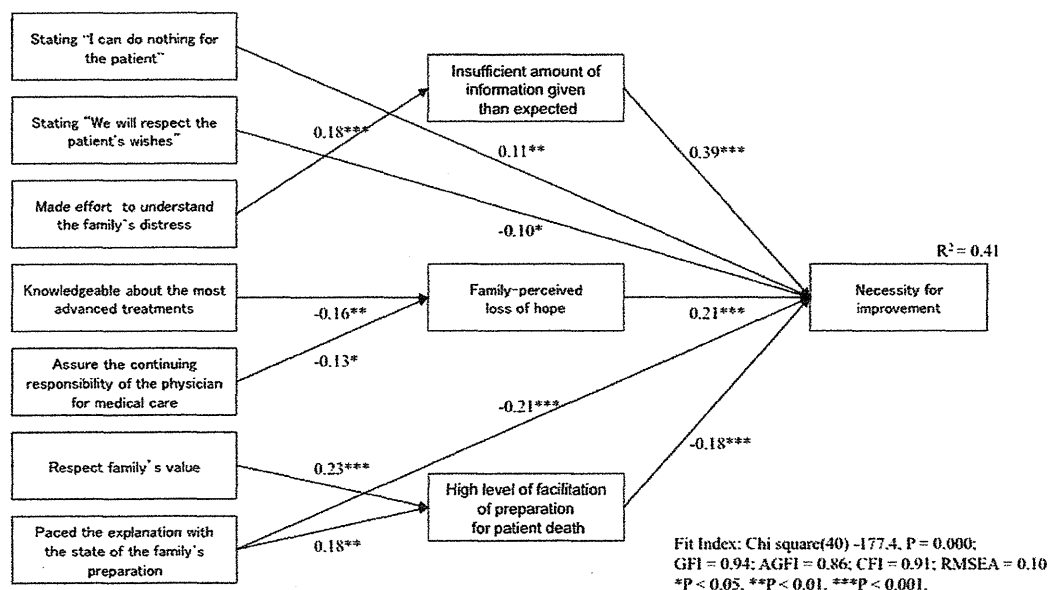


Fig. 1. Model for the relevant factors for family-perceived need for improvement.

The most important finding in the present study was the clarification of the determinants of the necessity for improvement in prognostic disclosure. Using path analysis, we determined that 41% of the variance for increased perceptions for the necessity for improvement was related mainly to the five variables: 1) insufficient amount of information given than expected; 2) loss of hope and failure in facilitation of preparation for patient death; 3) not providing information carefully in consideration of the family's preparation; 4) stating "Nothing can be done;" and 5) not stating "We will respect the patient's wishes."

First, the disclosure of an insufficient amount of information than expected had the largest effect on the necessity for improvement. In a previous study of parents of pediatric patients with cancer, almost all participants wanted as much information as possible about the prognosis, although they found the prognostic information very upsetting.⁸ It also is said that 69.6% of caregivers of Korean cancer patients want to know their own terminal condition.²⁹ The results of the present study show that this may be similar in the case of Japanese adult patients. Physicians, therefore, should comprehend family members' needs and communicate as much information as the family members want.

Second, the results of this study suggested that maintaining the family's hope and facilitating their preparation for a patient's death have a significant and moderate effect on the family member's evaluation of the prognosis communication. In previous studies of patients with cancer, both maintaining patients' hope and helping them prepare for death were of great importance for patients.⁵ The present study confirmed that these two factors are equally important in terms of the patient's family also. Maintaining hope while simultaneously preparing for a patient's death seems contradictory, and thus, it may represent a difficult issue for physicians. For patients, a useful way of accomplishing this task is to acknowledge all of the possible outcomes and to expand their planning goals to include both recovery and death.^{5,20} In this study, loss of hope was significantly accounted for by the two descriptions: "The physician was knowledgeable about the most advanced treatments" and "The physician assured continuing responsibility as the

physician for medical care." One possible interpretation of this result is that hope for family members means receiving assurance of continuing responsibility for medical care by a physician who is knowledgeable about up-to-date treatments. In addition, the type of disclosure they received affected the facilitation of preparation for patient death: "The physician paced his/her explanation with the state of my/patient's preparation" and "The physician respected my values." This finding means that although detailed prognostic information helps families in preparing for a patient's death, it is important to provide information with careful consideration for families' preferences and values. These results confirm that maintaining hope and preparing for death need not be mutually exclusive.⁵

Third, about 30% of the family members reported that the physician said she/he could do nothing for the patient, and this experience had a strong influence on the family-perceived necessity for improvement. This result was consistent with a finding from a previous study that indicated that both patients and families received the phrase from physician "I can do nothing for the patient any longer" with serious negative emotions when they were informed of the ending of cancer treatment.^{19,30} From this finding, physicians are advised to emphasize what they can do, such as providing symptom control, instead of stating "nothing can be done" in the prognostic disclosure.

It is notable that family members who were told the physician will respect the patient's wishes reported a lower level of necessity for improvement. It is also noted that the disclosure of prognostic information as it corresponds to patient's values is essential for patients to make decisions about the terminal phase.³¹ At the same time, over 70% of physicians in Japan have experience of not telling patients their prognosis according to the request of family members.²² The results of the present study indicate the possibility that many family members have a conflict between their wish to respect the patient's wishes and their hesitancy about communicating the prognosis to the patient. Thus, in prognosis disclosure, physicians should assure the family of the intent to respect the patient's wishes while also conferring with the family on how to achieve this.

This study had several limitations. First, as the response rate was not very high (64%), the study subjects might not be representative of the population. Second, the study subjects were limited to the families of patients who had been admitted to PCUs, and the findings might not be applicable to families in other settings. Moreover, prognostic disclosure is sometimes required for admission to a PCU; thus, the amount of disclosure might be higher than in a general ward. The future survey of families of patients who had not been admitted to PCUs will be expected as the next step. Third, due to a lack of validated instruments, primary endpoints were measured without formal reliability and validity testing. Fourth, some factors that might be relevant, such as symptom distress and experience of anticancer therapy, were not analyzed as to whether they might influence the perception of prognostic communication. Fifth, this study depended on the retrospective evaluation of bereaved family members, and recall bias could exist. Confirmation of the findings will require prospective observational or interventional studies. Finally, due to the lack of comparable studies, we compared our results mainly with those of patient surveys, but preferences might be different between patients and families.

Conclusion

When receiving communication about a patient's prognosis, 60% of bereaved family members reported that some, considerable, or much improvement in the communication methods was necessary. Strategies for care providers to improve family perception include 1) providing as much prognostic information as families want; 2) supporting families' hopes by keeping up with up-to-date treatments and by assuring continuing responsibility as the physician for medical care; 3) facilitating the preparation for death by providing information in consideration of the family's preparations and values; 4) stressing what they can do instead of saying that nothing can be done for the patient; and 5) assuring the family that they will respect the patient's wishes. These suggested communication strategies should be tested in future prospective observational or interventional studies.

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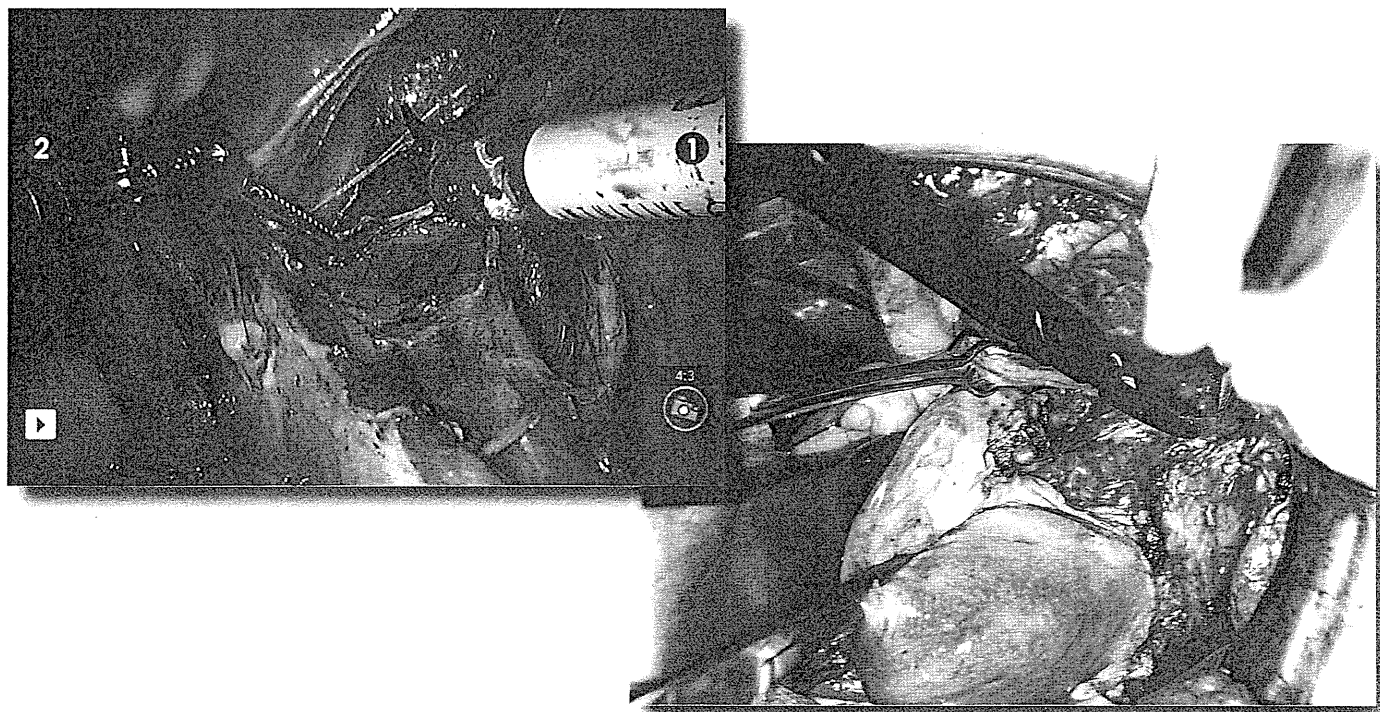
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動画で学ぶエキスパートのテクニック

婦人科がん 低侵襲手術

監修 落合和徳／青木大輔

編著 寒河江 悟／佐々木 寛／井坂恵一／岡本愛光／進 伸幸



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婦人科腫瘍外科医 必携!

重要 **10** 手術の動画



DVDつき

動画で学ぶエキスパートのテクニック
婦人科がん 低侵襲手術

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