patient questions and the contents of questions, however, there is no evidence that patients' recall is accurate.

In conclusion, for those advanced cancer patients who read the QPS it seemed to be a moderately useful tool. Compared with controls, patients rated the QPS more favourably in terms of enabling them to ask relevant questions and for future use. The QPS seemed to help patients to prepare questions and it may help patients to articulate and organize their information needs. However, the QPS did not seem to directly promote patient confidence to ask questions. In Asian countries, active endorsement of QPS by physicians and/or communication skills training for physicians might be effective for promoting question-asking behavior. In the future, research would be needed to examine the impact of the use of QPS over time and in other settings.

Acknowledgements

Appendix A

Question Prompt Sheet is given in Table A1.

Table A1. Question prompt sheet

Diagnosis	1	What is the diagnosis?
	2	What is the stage of my cancer?
Condition of a disease	3	What is wrong with me?
	4	Where is my cancer located?
	5	Which test showed that?
Symptom	6	What symptoms will the cancer cause?
	7	What kind of treatments for the symptoms do you have?
Test	8	Do I need any more tests before my treatment?
	9	If so, does it hurt?
	10	What do the tests show?
Treatment	11	What treatment options are available for me?
	12	What are my options aside from anticancer drugs?
	13	What is the best case scenario? What is the worst case scenario? What is the most likely case scenario? How about survival length and quality of life?
	14	What complications, short/long side effects and sequelae does each treatment have?
	15	What is your recommendation regarding the best treatment for me?
	16	Which treatment do other patients with the same condition as mine choose?
	17	What is involved in administering the treatment, for example, contents, timing, frequency, duration, schedule, location, costs of treatments?
	18	What is the purpose of the treatment?
	19	What physical limitations will I have during the treatment?
	20	What are the common side effects of the treatment?
	21	Does the treatment cause pain?
	22	What can be done about the side effects?
	23	When will I know whether the treatment is working?
	24	How will I know whether the treatment is working?
	25	What are my next options if the treatment fails?
	26	What costs will I incur throughout my treatment?
	27	What is the percentage of success of this treatment for the other patients?
	28	Can I get my treatment at my local doctor's office?
	29	If I am taking alternative medicine, can I still continue?
	30	Can I take folk medicine or complementary and alternative medicine during treatment?
Life	13	Will the treatment affect my ability to work or perform other activities?
	32	Is there anything I have to do before and during my treatment?
	33	Is there anything I should not do during my treatment, for example, diet, exercise, housekeeping, sexual life, childbirth?
	34	Is it OK for me to do... during the treatment?
	35	Is it OK for me to eat/ drink... during the treatment?
	36	Is it OK for me to go...during the treatment?
	37	Is there anything that I should prepare before my treatment?
	38	What symptoms should I be alert for?
	39	What should I do when some symptoms occur?
Family	40	Will my family be affected by my cancer/ treatment?
	41	Will my family members have higher risk of getting cancer?
	42	Who can my family members talk to if they they have concern and worry?

Table A1. (Continued)

Psychological issues	43 Can I talk about my concern and worry?
	44 How can I cope with sleeplessness caused by anxiety and depressed feeling?
	45 Can you give me any advice on how to cope with the disease?
	46 Is there someone I can talk to about my feeling?
Prognosis	47 How long am I likely to live? The reason why I want to know is...
	48 Is there any chance for cure?
	49 What can I expect in the future?
Other issues	50 What causes cancer?
	51 How much time do I have to think about this? Do you need my decision today?
	52 There are some changes about... (in my life, physical aspect, mental aspect) after the previous consultation.
	53 The things that I hope to take precedence or continue doing in my life are...

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Original Article

Experience with Prognostic Disclosure of Families of Japanese Patients with Cancer

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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

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 vague[4] 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 experiences[14] 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		P
	n	%	*n*	%	*n*	%	
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 *n*	No Improvement *n*	No Improvement %	Some or More Improvement *n*	Some or More Improvement %	*P*
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 definitively 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/patient'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.
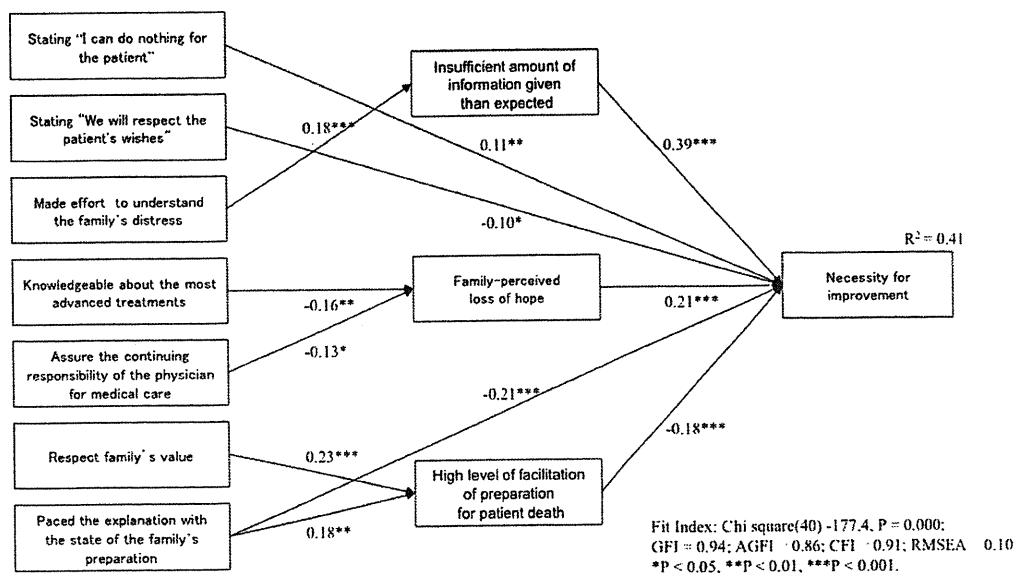

Fig. 1. Model for the relevant factors for family-perceived need for improvement.

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.

Disclosures and Acknowledgments

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Development of a Japanese Benefit Finding Scale (JBFS) for Patients With Cancer

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Abstract

The primary aim of this study was to develop a scale to evaluate benefits for patients with cancer under treatment in Japan (the Japan Benefit Finding scale [JBFS]). The participants were 98 patients with cancer who completed the JBFS, which has 26 items, the General Health Questionnaire short version (GHQ 12). Factor analysis, structural equation modeling (SEM), and correlation analysis were performed. Three key domains were identified: "Recognition of one's role in the family and priorities," "Appreciation for life," and "Faith." Validity was confirmed by SEM. There was a significant correlation between the JBFS and GHQ 12. The reliability and validity are adequate, and the JBFS shows that Japanese patients who found benefits in cancer were able to adjust to their disease.

Keywords

benefit finding, scale, cancer patient, Japanese

Introduction

Patients with cancer experience physical problems such as pain, fatigue, and nausea, and psychological problems such as anxiety, depression, distress,[1,2,3] and spiritual pain. A growing body of literature suggests that individuals coping with trauma seek to make sense of their experience and that some individuals derive benefits of personal growth from the experience.[4,5] Positive changes that result from this trauma are referred to as benefit finding.

A study shows that posttraumatic growth of disease-free women 5 to 15 years diagnosis showed slight association with mental quality of life (QOL) and happiness,[6] posttraumatic growth marginally related to lower perceived stress,[7] and meta-analysis of posttraumatic growth after cancer revealed that growth was related to increased positive mental health, reduced negative mental health, and better subjective physical health.[8] These studies show that some of patients with cancer find benefits after posttraumatic experiences, and benefit finding relate with QOL. To improve patients' QOL, examination of benefit finding is important.

As for details of benefit findings, Antoni et al found that most women diagnosed with early-stage breast cancer reported that their lives had changed in positive ways.[4] The reported common positive changes included becoming more accepting, focusing more on the importance of relationships with family and friends, and changing life priorities. Another study showed that women with breast cancer reported greater positive psychosocial adaptation, such as improved life outlook, enhanced interpersonal relationships, and deeper spiritual and religious satisfaction, in comparison with controls.[9]

The Benefit Finding scale was developed to evaluate this phenomenon, with domains of growth, personal priorities, daily activities, and family.[10,11] The studies referred to above are from Western countries, and relatively few studies of benefit finding have been performed in Japan. In our previous study about meaning of illness for terminally ill patients with cancer,[12] there were differences in attitude toward cancer; patients in Western countries tended to confront with illness or fight against illness, however, those in Japanese tended to live together with the illness. We predicted that there were some differences in construction of the benefit findings.

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Table I. Background of Patients

Item	Data (Number)
Gender	
Male	47
Female	51
Age mean ± SD	63 ± 12.5 years old
Stage	
1	14
2	4
3	21
4	59
ECOG-PS	
I	46
II	25
III	22
IV	5
Primary tumor site	
Breast	22
Uterus	12
Lung	16
Stomach	2
Pancreas	2
Uterine	1
Kidney	3
Leukemia	1
Rectal	2
Colon	1
Others	36

Note: ECOG-PS = eastern cooperative oncology group performance status.

Therefore, we developed the Japan Benefit Finding scale (JBFS) and compare the construction. It is important for us to find commonality or differences in the construction, because medical staffs can propose useful interventions or supports tailored to people in various countries based on the construction. Moreover, we focused on the patients under treatments, because they have to receive treatments like chemotherapy or radiation, which are sometimes accompanied with pain and sever symptoms, and they need psychological energy. For these patients, benefit findings in sever experience may be useful.

Methods

Participants

The participants were inpatients and outpatients who were receiving radiation treatment at a general hospital in Western Japan. The inclusion criteria were age >20 years old and under anti-cancer treatment. The exclusion criteria were severe pain or physical symptoms judged by the primary physician. A total of 98 patients (47 males, 51 females) with a mean age of 63.2 years participated in the study. The performance status of the patients measured by the Eastern Cooperative Oncology Group Performance Status (ECOG-PS) were I (n = 46), II (n = 25), III (n = 22), and IV (n = 5). The background of the patients is shown in Table 1.

Outcome Measures

We used 26 items based on the Benefit Finding scale,[10,11] which are unidimensional scale with a high internal consistency for survivors that has 4 domains: growth, personal priorities, daily activities, and family. We referred these scales because Tomici and Helgeson have demonstrated longitudinal studies and developed many versions. We also referred to the Caregiving Consequence Inventory (CCI),[13] which was developed to measure benefits found by caregivers such as family members through caring experiences. We referred the CCI because it demonstrates characteristics of benefit findings in traumatic experiences for Japanese people. The CCI has 5 domains, mastery, appreciation, meaning in life, reprioritization, and burden, which consist of 17 items measured on a 4-point Likert scale. Based on these scales, we prepared the following 26 items: "(1) Having cancer has brought my family close together," "(2) Having cancer has brought me feel family's love," "(3) Having cancer has made me grateful for my family," "(4) Having cancer has made me grateful for people around me," "(5) Having cancer has made me more grateful for each day," "(6) Having cancer has made me recognize the importance of health and life," "(7) Having cancer has made me think that illness proceeds as it will," (8) Having cancer has taught me to get along with illness well," "(9) Having cancer has taught me to be patient," "(10) Having cancer has led me to be more accepting of things," "(11) Having cancer has made me live along with illness well," "(12) Having cancer has made me more sensitive to my family issues," "(13) Having cancer has made me realize the importance of planning for my family's future," "(14) Having cancer has made me think about my life and work," "(15) Having cancer has made me think of priorities for what I will do in my life," "(16) Having cancer has helped me plan what I can do in my life," "(17) Having cancer has made me realize that life is limited and that time is precious," "(18) Having cancer has made me think that there is meaning or purpose in my life," "(19) Having cancer has made me appreciate life," "(20) Having cancer has made me religious," "(21) Having cancer has made me feel that there is a transcendent power exceeding human power," "(22) Having cancer has made me think that there is meaning in a difficult experience," "(23) Having cancer has given me a serious physical burden," "(24) Having cancer has given me a serious mental burden" "(25) Having cancer has caused me to sacrifice my time and schedule" and "(26) Having cancer has given me a serious economic burden."

We also prepared a General Health Questionnaire short version (GHQ 12).[14] The GHQ was used for measuring mental health or mental adjustment and to examine concurrent validity of the JBFS. The GHQ consisted of 12 items scoring from 1 to 4 on a Likert scale, where a high score indicates high mental distress.

Procedure

A primary physician selected candidate individuals at the time patients received radiation therapy. The study was explained to

Table 2. Results of Factor Analysis Showing Items and Factor Loadings

Items in Each Factor	F 1	F 2	F 3	Commonality
Factor 1: Recognition of one's roles in the family and priorities				
(12) Having cancer has made me more sensitive to my family issues	0.87			0.69
(13) Having cancer has made me realize the importance of planning for my family's future	0.66			0.38
(1) Having cancer has brought my family closer together	0.53			0.30
(2) Having cancer has brought me feel family's love	0.50			0.42
(14) Having cancer has made me think about my life and work	0.47			0.45
(9) Having cancer has taught me to be patient	0.42			0.22
(10) Having cancer has led me to be more accepting of things	0.42			0.29
(16) Having cancer has helped me plan what I can do in my life	0.38			0.18
Factor 2: Appreciation for life				
(19) Having cancer has made me appreciate life		0.81		0.63
(17) Having cancer has made me realize that life is limited and that time is precious		0.67		0.46
(11) Having cancer has made me to live along with illness well		0.61		0.50
(5) Having cancer has made me more grateful for each day		0.47		0.28
Factor 3: Faith				
(20) Having cancer has made me religious			0.73	0.57
(18) Having cancer has made me think that there is meaning or purpose in my life			0.66	0.47
(22) Having cancer has made me think that there is meaning in a difficult experience			0.55	0.37
(21) Having cancer has made me feel that there is a transcendent power exceeding human power			0.49	0.24

the patient and the interviewer obtained informed consent after the patient agreed to participate. The patient then completed the JBFS and GHQ 12 questionnaires orally over about 30 minutes. This study was approved by the St Mary's Hospital Ethical Board.

Statistical Analysis

A mean score of each question item of the JBFS was calculated, and items which showed the ceiling effects or flour effects were deleted. Thus, 22 items of 26 items were used for factor analysis. The validity of the JBFS was confirmed by factor analysis. Seven-point Likert scores for each item were used for statistical analysis. A factor analysis by weighted least squares and promax rotation was performed on the 22 items of the JBFS. Factors with an eigenvalue ≥ 1 and items with a factor loading >0.4 were selected. The conceptual structure of the JBFS, including factors confirmed by factor analysis, was assessed by structural equation modeling (SEM) using Amos 16.0 SPSS 16.0.[15] Values of $P < .05$ were considered significant. A correlation analyses between JBFS and GHQ scores were also performed.

Results

Factor Analysis

Three domains validated by factor analysis are shown in Table 2. The first was interpreted as "recognition of one's roles in the family and priorities," and consisted of the following 8 items: "having cancer has made me more sensitive to family issues," "having cancer has made me realize the importance of planning for my family's future," "having cancer has brought my family close together," "having cancer has made me feel

my family's love," "having cancer has made me think about my life and work," "having cancer has taught me to be patient," "having cancer has led me to be more accepting of things," and "having cancer has helped me plan what I do in my life."

The second domain was interpreted as "appreciation for life," and consisted of the following 4 items: "having cancer has made me appreciate life," "having cancer has made me realize that life is limited and that time is precious," "having cancer has taught me to cope with my illness well," and "having cancer has made me more grateful for each day."

The third domain was interpreted as "Faith," and consisted of the following 4 items: "having cancer has made me religious," "having cancer has made me think that there is meaning or purpose in my life," "having cancer has made me think that there is meaning in a difficult experience," and "having cancer has made me feel that there is a transcendent power exceeding human power."

To assure the internal consistencies of this inventory, Cronbach α was calculated. Cronbach α values for the 3 subordinate domains were .80, .74, and .70, respectively.

Structural Equation Modeling of the JBFS

Structural equation modeling was performed to examine the conceptual structure of the JBFS, based on the 3 subordinate domains obtained in factor analysis. The fit indices of this model were as follows: Goodness of Fit Index (GFI) = 0.826, Adjusted Goodness of Fit Index (AGFI) = 0.766, Comparative Fit Index (CFI) = 0.83. The more than 0.9 score shows the best fitness of the mode. The Root-Mean-Square Error of Approximation (RMSEA) = 0.087 and the score under 1.0 shows the best fitness. All of the standardized coefficients were significant $(P < .05)$. "Recognition of one's role in the family"

Table 3. Correlation Coefficients Among the JBFS, GHQ, and Burden

	JBFS Total	Recognition of One's Role	Appreciation for Life	Faith	GHQ
JBFS total	1				
Recognition of one's role	–	1			
Appreciation for life	–	0.40 (P = .00)	1		
Faith	–	0.43 (P = .00)	0.39 (P = .00)	1	
GHQ	−0.17 (P = .047)	−0.05 (P = .63)	−0.27 (P = .008)	−0.14 (P = .16)	1

Note: JBFS = Japanese benefit finding scale; GHQ = general health questionnaire.

influenced "Appreciation for life" and "Faith," with coefficients of .50 (P = .003) and .60 (P = .001), respectively, and "Appreciation for life" influenced "Faith" with a coefficient of .44 (P = .003).

Relationship Among the JBFS and GHQ 12

Correlation coefficients among the scales are shown in Table 3. The JBFS was significantly correlated with the GHQ ($r = -.17, P = 0.047$) and was not correlated with Burden ($r = .1, P = .17$).

Discussion

The JBFS consists of 3 domains: "Recognition of one's role in the family and priorities," "Appreciation for life," and "Faith." The Cronbach α values of these 3 domains were .80, .74, and .70, respectively, which indicates close to adequate reliability of the JBFS. The results of SEM analysis (GFI = 0.826, AGFI = 0.776, CFI = 0.83, RMSEA = 0.087) also indicate reasonable reliability, since a score over 0.90 is normally taken to indicate high reliability. The correlation coefficient for the JBFS with the GHQ was significant ($r = -.17, P < .047$), and this provides a concurrent validation. Therefore, these results support the validity of the 3 domains of the JBFS.

The correlation between the JBFS and the GHQ shows that patients with a high JBFS score have little mental distress and have adjusted well to their disease. This result supports those found in previous studies in Western patients.[16,17,18] For example, benefit finding shows a moderate positive correlation with posttraumatic growth.[18]

The first domain of the JBFS, recognition of one's role in the family, reflects the strong feelings of Japanese people regarding their relationship with family, as also found in previous studies.[19,20] The second domain of appreciation for life reflects the recognition among patients that life is limited, and that they should have respect for their lives. The third domain of faith had a slightly lower mean score compared to the other 2 domains, which may indicate that some patients found meaning or purpose of life and felt a transcendent power, whereas some did not do so. Therefore, individual differences may affect this domain.

We note that Tomich and Helgerson found a fourth domain in benefit finding based on "daily activities,"[21] whereas we did not identify daily activities (patients change their daily life or habit) as an important factor in the JBFS. This may reflect cultural differences, since patients in Western countries tend to fight against their illness positively through their own efforts, whereas Japanese patients tend to depend on physicians and do not change their daily activities.

Moreover, since effects of cognitive behavior therapy on QOL through benefit finding have been shown,[22] some kind of intervention including a variable of benefit finding may have possibility of new intervention. Finally, we note that the current study is limited by the small number of participants and data collection in only 1 hospital. A study with more participants in many hospitals is required to validate our findings.

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ORIGINAL ARTICLE

A qualitative study of mindfulness-based meditation therapy in Japanese cancer patients

Michiyo Ando · Tatsuya Morita · Tatsuo Akechi · Yuka Ifuku

Abstract

Purpose The primary objective of the study was to examine mindfulness-based meditation therapy qualitatively. A secondary goal was to examine the differences in themes selected by Japanese and Western patients receiving this therapy.

Methods The subjects were 28 patients who were undergoing anti-cancer treatment. The subjects participated in two sessions of mindfulness-based meditation therapy, including breathing, yoga movement, and meditation. Each patient was taught the program in the first session, then exercised at home with a CD, and subsequently met the interviewer in a second session after 2 weeks. Primary physicians recruited the patients and interviews were conducted individually by nurses or psychologists with training in the program. Patients provided answers to pre- and post-intervention interviews about the meaning of their illness.

Results Narrative data from the semi-structured interview were analyzed qualitatively. Pre-intervention, themes such as "*Effort to cope,*" "*Looking back,*" "*Spirituality,*" "*Personal growth,*" and "*Suffering*" were often chosen. Post-intervention, themes such as "*Adapted coping,*" "*Personal growth,*" "*Positive meaning,*" "*Spirituality,*" and "*Negative recognition*" were more commonly chosen.

Conclusions Mindfulness-based meditation therapy may be effective for producing adapted coping, including positive recognition and changes for an adapted lifestyle. There were some common aspects and some differences in the themes selected by patients in this study and Western patients received mindfulness therapy in other studies.

Keywords Meditation therapy · Cancer patients · Adapted coping style

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Introduction

Patients receiving anti-cancer treatment experience physical problems such as pain, fatigue, and nausea and psychological problems such as anxiety, depression, distress [1–3], and spiritual pain. A mindfulness approach is an effective intervention from a psychological perspective. The Mindfulness-Based Stress Reduction (MBSR) program was modeled on the work of Kabat-Zinn [4] and colleagues at the Center for Mindfulness-Massachusetts Medical Center. The program is based on the principal of mindfulness, defined as moment-to-moment, present-centered, purposive non-judgmental awareness. The goal of the MBSR program is to guide participants to achieve greater awareness of themselves, their thoughts, and their bodies through class discussion, meditation, and yoga exercises.

For cancer patients, Speca et al. [5] showed effects of the MBSR on mood disturbance and stress symptoms and Carson et al. [2] showed an effect on QOL and the immune profile. Monti et al. [6] showed that Mindfulness-Based Art-

Therapy, which includes mindfulness and art therapy, also produces a significant decrease in symptoms of distress and improvements in key aspects of health-related QOL. Garland et al. [7] examined the effects on spirituality, stress symptoms, and mood of a Healing Art program compared with MBSR Post-Trauma Growth (PTG). Improved growth, a relationship of PTG in MBSR with spirituality, and increased spirituality with related decreases in stress and mood disturbance were found in participants in both groups.

In contrast to these quantitative studies, there have been very few qualitative studies on the experience of participants in MBSR. Mackenzie et al. [8] evaluated nine cancer patients who received a semi-structured interview after an 8-week MBSR program, and five major themes emerged from the data: (1) open to change, (2) self-control, (3) shared experience, (4) personal growth, and (5) spirituality. This study showed that changes could be achieved through MBSR, but it is not clear if the same effects would be observed for Japanese patients. Since Mackenzie et al. performed the study in Western patients, it is also unclear if the same themes will present in Japan. We have previously examined the efficacy of mindfulness-based meditation therapy [9]. In the current study, our primary objective was to evaluate this therapy qualitatively, with a secondary goal of examining possible differences in themes as outcomes of the therapy in Japanese and Western patients.

Patients and methods

Participants

The participants were outpatients who were receiving anti-cancer chemotherapy, radiation, or medication at a general hospital in Western Japan. The patients were >20 years old and were able to undergo an interview for about 60 min in a session. Patients were excluded if they had cognitive impairment or mental disease. These conditions were rated using a numeric rating scale (0–10 points) and patients with a score of above 8 were excluded from the study. Thirty-two patients were registered, but four subsequently dropped out because of a decrease in physical strength. Therefore, a total of 28 patients (four males, 24 females) with a mean age of 60.0± 9.2 years old participated in the study. The primary tumor sites were the breast ($n=21$), colon ($n=2$), stomach ($n=2$), and bladder ($n=2$). The performance status ranged from 0 to 2 and all patients were able to visit the hospital.

Outcome measures, interventions, and procedure

We used a modified version of the Mindfulness-Based Stress Reduction Program [4, 10], in which we refer to cyclic meditation as that including both breathing and

meditation. During meditation, patients move their hands or legs to focus their attention (Fig. 1) [9]. The cyclic meditation program takes about 30 to 60 min per session and was conducted by nurses or a clinical psychologist who received training for at least 3 h. The training included basic communication skills and Yoga skills learned directly from a Yoga specialist or using a CD. A primary physician recruited the patients and a clerk obtained informed consent and asked the patients to complete questionnaires pre- and post-intervention. In the pre-therapy session, the patient learned the cyclic meditation program and it was recommended that they perform the therapy at home once a day. After 2 weeks, the patients met the interviewers in a second session to talk about their impressions in a semi-structured interview to establish the patient's "perception of the meaning of the illness". The study was approved by the appropriate institutional ethics committees and was performed in accordance with the ethical standards laid down in the Declaration of Helsinki.

Statistical analysis

The sentences in the patients' replies in the interviews were analyzed line by line and the content was extracted. This content was classified into codes and those with a common meaning were grouped together. Categories and sub-categories were then formed and integrated. Several meetings of investigators were held for this purpose. Strategies for increasing the reliability of the data and analysis included interviews conducted by each
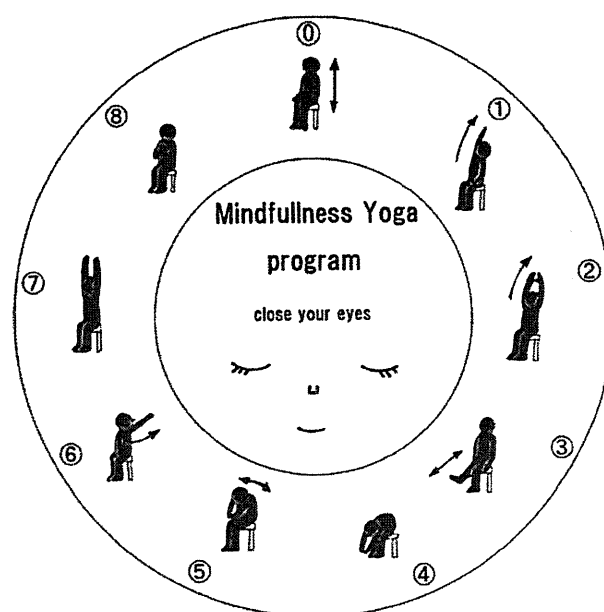

Fig. 1 The cyclic meditation program [9]

investigator, and concurrent data collection and analysis until the data were confirmed. Two researchers coded and categorized the data and the investigator obtained feedback and validation regarding the methods from experts in nursing and qualitative methodology.

Results

The main themes chosen from the data are shown in Tables 1 and 2. Pre-intervention, themes such as "*Effort to cope,*" "*Looking back,*" "*Spirituality,*" "*Personal growth,*" and "*Suffering*" were mostly chosen. Post-intervention,

themes such as "*Adapted coping,*" "*Personal growth,*" "*Positive meaning,*" "*Spirituality,*" and "*Negative recognition*" were commonly chosen.

Discussion

"*Personal growth*" and "*Spirituality*" were common themes that were chosen pre- and post-intervention. Some of the patients receiving anti-cancer treatment recognized the importance of health, paid attention to this after diagnosis, and appreciated their families and others (*Personal growth*). They also recognized the importance of limited

Table 1 Themes in replies of patients to interviews conducted before mindfulness-based meditation therapy

Small category	Sub-category	Large category
I believe that I will be cured	Effort for positive thinking	Effort to cope
Illness is my destiny		
I want to recover as soon as possible		
I have accepted my feeling of disbelief		
I feel the limitation of my life		
I try to think positively		
I try not to think deeply		
I want to devote myself to my anti-cancer treatment	Effort for concrete coping	
I am suffering at the moment		
I have to be energetic by myself		
I make my children look after themselves		
I try to enjoy my daily life and spend time fully		
I take care of my physical strength and health in daily life		
Illness is one of my life experiences	Looking back	Looking back
I have reviewed my life until now		
I have thought about my life		
I have lived somehow		
My view of my life has changed		
Illness is a good chance for me to look back at my health and my family		
I have recognized the importance of others	Recognition of importance of limited life or time	Spirituality
I feel the importance of family and people around me		
I recognize the importance of my life		
I value time		
I have begun to have a strong interest in my health and medicine	Paying attention to health	Personal Growth
Illness has been a wake		
A medical check		
I appreciate every day	Appreciation for other people	
I appreciate my family and others		
Why me?	Negative feeling	Suffering
I cannot believe that I have my illness		
I feel fear and anxiety		
I hate my life	Burden and suffering	
I have lost my job		
I worry about the future of my family		
I cannot die leaving my children		