

**Original Article****Meaninglessness in Terminally Ill Cancer Patients: A Randomized Controlled Study**

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**Abstract**

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

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willingness to help, positive appraisal, and helplessness subscales, in addition to the overall levels of burnout, emotional exhaustion, personal accomplishment, job satisfaction, and the FACIT-Sp. The change ratio of each parameter ranged from 5.6% (willingness to help) to 37% for the helplessness score and 51% on the Confidence Scale. The percentages of nurses who evaluated this program as "useful" or "very useful" were 85% (to understand the conceptual framework in caring for terminally ill patients with meaninglessness), 80% (to foster nurses' personal values), and 88% (to know how to provide care for patients with meaninglessness). This educational intervention had a significant beneficial effect on nurse-perceived confidence, practice, and attitudes in providing care for patients feeling meaninglessness, in addition to the levels of burnout and spiritual well-being of nurses. *J Pain Symptom Manage* 2009;37:649–658. © 2009 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

### Key Words

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

## Introduction

Recent empirical studies reveal that fostering patients' perceptions of meaning in their lives is an essential task for palliative care clinicians.<sup>1–4</sup> In Japan, multiple surveys have identified that terminally ill cancer patients experience considerable levels of meaninglessness.<sup>5,6</sup> Our group recently proposed a conceptual framework for psycho-existential care for Japanese patients.<sup>7</sup> We defined psycho-existential suffering as pain caused by extinction of the being and the meaning of the self. We assumed that psycho-existential suffering is caused by the loss of essential components of meaning for human beings: loss of relationships with others, loss of autonomy, and loss of future (temporality). In this model, sense of meaning is interpreted as a main outcome, as consistent with some psychometric instruments measuring sense of meaning as a core concept of the state of spiritual well-being.<sup>7</sup>

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

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

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

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

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

### Methods

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

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

### Subjects

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

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

### Interventions

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

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

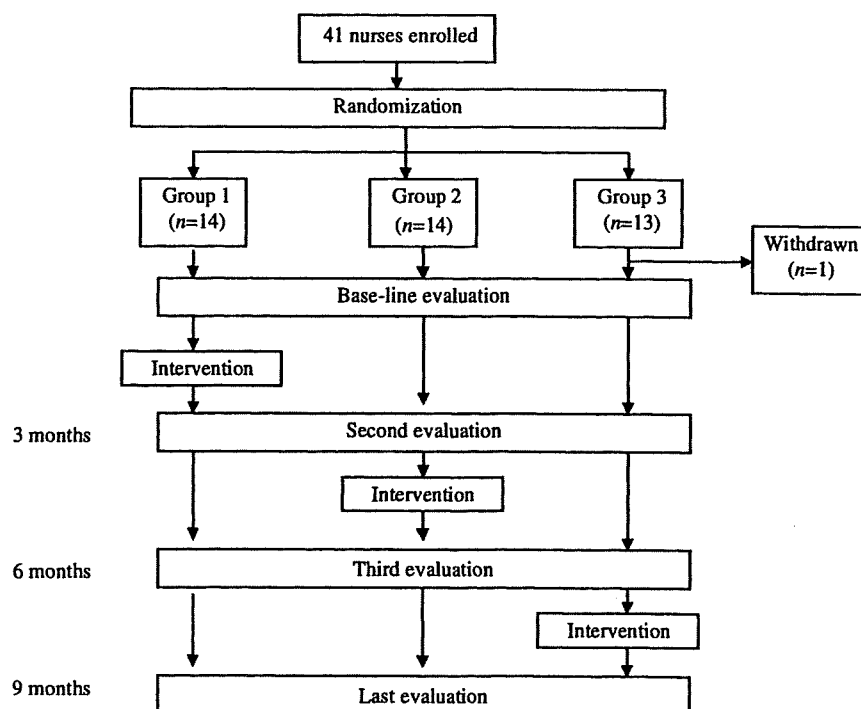


Fig. 1. Study protocol.

Table 1  
Participants' Backgrounds

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

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

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

Table 2  
Program Contents

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

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

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

#### Measurement Instruments

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

**Confidence.** Confidence in caring for terminally ill cancer patients with meaninglessness was evaluated on a single Likert-type scale from 1: "not confident at all" to 7: "very confident" for the question "With what degree of confidence can you communicate with terminally ill cancer patients saying, 'I can see no meaning in life?'"<sup>17</sup>

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

<p>Patient: 76-year-old male Advanced prostate cancer, in bed nearly all day due to lower limb paralysis. Lost wife 5 years ago. No children.</p>	<p>Circumstances: I visited Mr. A during a round of the Palliative Care Team. According to a ward nurse, he had undergone painful and distressing tests the day before and was depressed, saying, "I'm finished. There is no sense in living." Mr. A was supine in the bed on the hall side of a 3-bed room. I sat on a chair beside his bed.</p>		
<p>Dimension</p>	<p>Patient dialog</p>	<p>Assessment</p>	<p>Care plan</p>
<p>Relationships</p>	<p>P4(underlined)  P5(underlined)</p>	<p>Mr. A reflected on his past and gave a positive meaning to his bitter experience, whereby his feelings changed from repentance to gratefulness and reconciliation.  Mr. A felt supported by someone listening to him.</p>	<p>Listen to Mr. A's reflections on his life and encourage him to talk to strengthen the meaning from his relationships with family and relatives. Continue to listen attentively to maintain a relationship with others.</p>
<p>Temporality</p>	<p>"I'm finished. There is no sense in living."</p>	<p>Mr. A sensed the ineffectiveness of treatment and felt that there was no hope of cure. This caused him to feel that he had no future and that his life was meaningless from temporality.</p>	<p>Encourage him to reflect on his past life, to regain the meaning supported by his past and relationships, not by the future.</p>
<p>Autonomy</p>		<p>He stays in bed all day due to paralysis of the bilateral lower limbs and dependence causes meaningless from autonomy.</p>	<p>Encourage reflections on life to divert their patients' value from dependency to the meaningful past.</p>
<p>Assessment and Planning</p>	<p>Mr. A feels his treatment to be ineffective and suffers from feelings of having no future, and physical dependence. No future and dependence cause meaningless from temporality and autonomy. However, he could reflect on his past of meaningful relationships. The care plan therefore would be to continue listening carefully to his reflections on life to increase the meaningfulness of his past experiences and relationships, rather than the future and physical autonomy.</p>		

Verbatim record N: nurse P: patient

N1: How are you, Mr. A?  
P1: ... at night. I get up in the middle of the night, and I can't help thinking of one thing after another.  
N2: You think of many things?  
P2: Yeah. (After being silent for a while) You visit other patients and listen to them, too?  
N3: Yes, there are others, too.  
P3: I guess it's pretty hard for a mother with small children. (Silent for a while)...  
N4: (Waiting)  
P4: I lost my mother, too, when I was 6. She was 36. Then, I was taken care of by a stepmother, but it was difficult to get used to her. We were never on good terms. (Weeps) I was raised by 3 mothers: My own mother, nurse, and stepmother. But, when my father died, I said at his funeral, "I was brought up by 3 mothers, and this was my greatest fortune," showing my thanks to relatives. That was good, because everyone thanked me for saying it. (Weeps)  
N5: At your father's funeral, you said you were very lucky to have been brought up by 3 mothers and thanked your relatives? And you felt good, because it made everybody grateful?  
P5: Yes. (Weeps) (Looking straight at me) I thank you for coming today. I really do. You are coming again to listen to me? It makes me feel relieved.  
N6: Yes, I am. I am looking forward to listening to you again. (Leaves the room)

Fig. 2. Spiritual Conference Summary Sheet.

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

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

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

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

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

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

#### *Statistical Analysis*

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

## **Results**

### *Primary End Points*

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

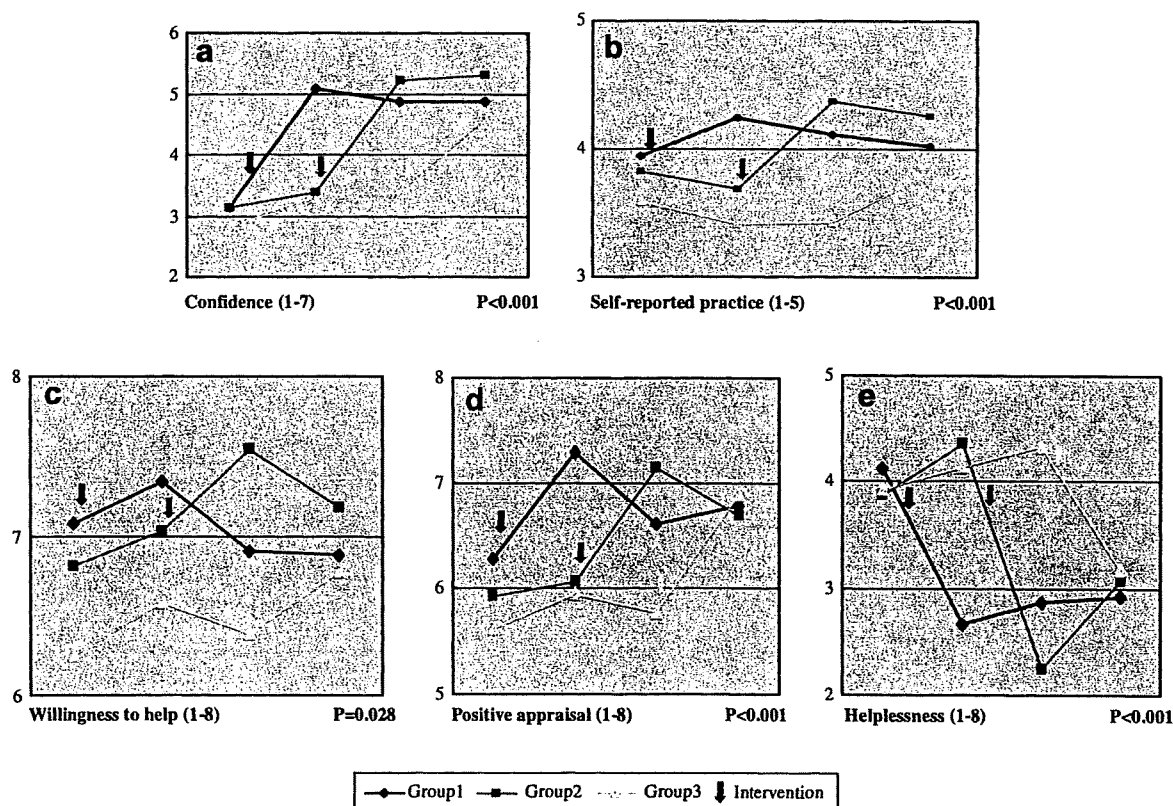


Fig. 3. Primary end points.

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

#### Secondary End Points

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

#### Overall Evaluation

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

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

#### Discussion

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

Table 3  
Changes in Primary and Secondary End Points

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

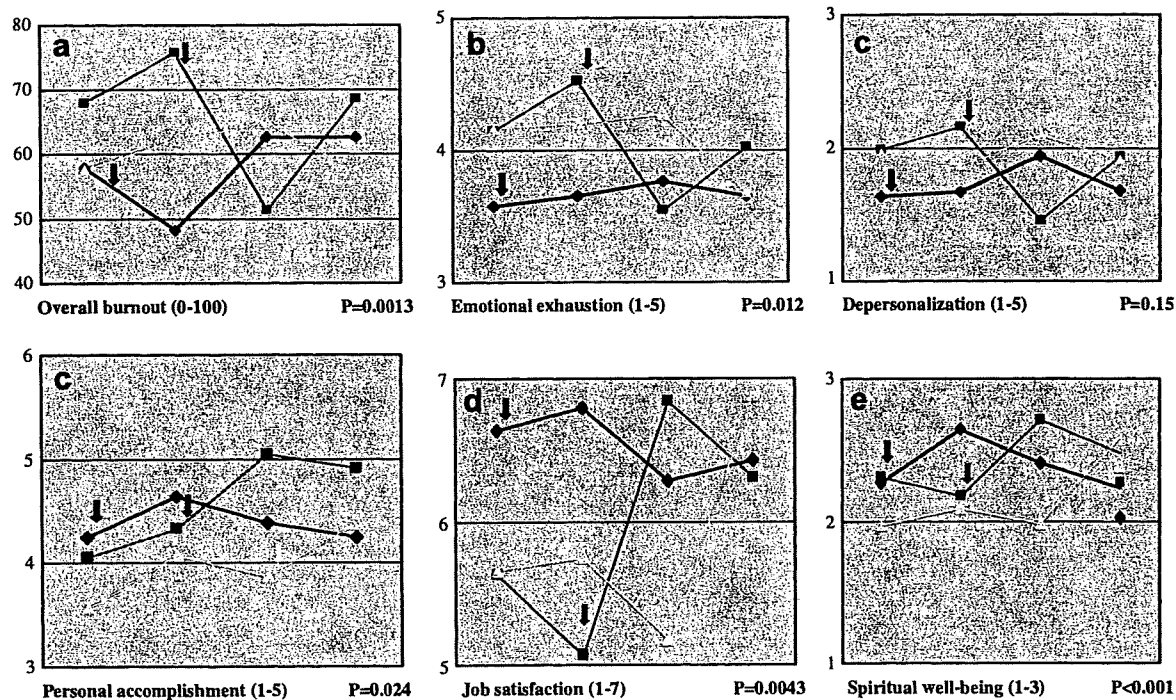


Fig. 4. Secondary end points.

meaninglessness on nurses' confidence, nurse-reported practice, and attitudes in providing care for such patients. This finding confirms our preliminary study that the intervention could provide considerable benefits for confidence, nurse-reported practice, and attitudes. Of note was the great change in nurses' confidence (51%) and helplessness (37%), in addition to the high evaluation of the overall usefulness of the workshop in learning how to provide care in clinical practice compared with a previous study (80% vs. 34%).<sup>15</sup> This result strongly suggests that this educational program can provide nurses with clinically useful specific strategies for caring for patients feeling meaninglessness.

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

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

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

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



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

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

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## Appendix

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Review Article

## Preferences of Cancer Patients Regarding Communication of Bad News: A Systematic Literature Review

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Most physicians regard the communication of bad news to be a difficult issue in clinical oncology practice. The optimal manner of communicating bad news to patients so that physicians can create maximal understanding in patients and facilitate their psychological adjustment is unknown. A systematic review of the literature was conducted to clarify available knowledge on patient preferences regarding the communication of bad news and associated factors. A comprehensive computer search of databases (MEDLINE and PsychINFO) and a manual search identified 24 studies. The above issue has been discussed mainly in Western countries. Most studies used different measures to obtain information on patient preferences and have provided mostly descriptive evidence. The findings in this review suggest that patient preferences with regard to the communication of bad news by physicians consist of four components: setting, manner of communicating bad news, what and how much information is provided and emotional support, and that patients' preferences are associated with demographic factors. Younger patients, female patients and more highly educated patients consistently expressed a desire to receive as much detailed information as possible and to receive emotional support. Asian patients were shown to prefer that relatives be present when receiving bad news more than Westerners do and to prefer to discuss their life expectancy less than Westerners. Physicians need to recognize these preferences to help patients understand.

*Key words:* communication – patient preferences – bad news – review

### INTRODUCTION

Communication between physicians and patients is a fundamental aspect of cancer care, especially when bad news is being communicated. Bad news consists of any information likely to drastically alter a patients' view of their future (1) and includes information regarding diagnosis, recurrence and treatment failure in clinical oncology settings (2).

The manner in which physicians communicate bad news concerning cancer can affect the degree of the patient's

distress in response to the news (3–5). Significant associations have been founded between physician support and low levels of distress and helplessness/hopelessness and a high 'fighting spirit' level (6). On the other hand, the problems physicians face when communicating bad news to their patients include a lack of sufficient time, being honest without causing distress (7), dealing with the patients' families, responding to the patients' emotions (7,8) and discussing life expectancy (8).

Because of the above issues, communication between patients and their physicians needs to be facilitated further (9), but there is a lack of guidance for physicians with regard to the optimal way to approach the communication of bad news. Since patients' preferred manner of communication of

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bad news by physicians has recently been shown to be related to a lower level of psychological distress and a higher level of patient satisfaction (10), some recent studies have focused on preferences regarding communication style, such as what information to give and how to convey it. Our own in-depth interview-and-questionnaire survey in Japan showed that the cancer patients preferred that physicians spend sufficient time to discuss their illness with them, discuss the impact of their disease and treatment on their daily activities, facilitate their understanding, and encourage and allow expression of their emotions (11,12). In order to provide guidance to physicians when communicating bad news and to clarify this issue, we systematically reviewed the literature on cancer patients' preferences regarding communication of bad news by physicians, and associated factors.

## SEARCH STRATEGY AND SELECTION CRITERIA

A search of two relevant databases, MEDLINE and PsychINFO, was conducted up to and including November 2008 by using the following search terms: (Cancer OR Oncology OR Palliative care) AND (Communication OR Relationship) AND (Bad news OR Prognosis OR Unfavourable news OR Truth disclosure OR Truth telling) AND (Patients' preferences OR Patients' perspectives OR Patients' views). The search was restricted to papers published in English.

The two reviewers excluded non-original articles and duplicates from the resulting list, and then selected studies based on an eligibility checklist and agreement between the two reviewers. The eligibility criteria were: the aims of the study included identifying cancer patients' preferences regarding communication of bad news to them by physicians, the study method adopted was an interview or questionnaire survey and the results included data regarding the preferences of cancer patients. Studies involving participants with illnesses other than cancer but in which a substantial proportion of the participants were cancer patients were included. Studies that involved a non-clinical sample, e.g. surveys of the general population regarding a hypothetical cancer scenario, were excluded. Some studies included participants with different types of cancer and different stages of disease. A manual search of the references cited in the articles that met the criteria for inclusion in the review was also conducted.

The results of the studies were shown as summaries of patient preferences for communication of bad news and of factors associated with patient preferences for communication of bad news. These two aims guided the organization of the results.

## RESULTS

The initial search yielded 266 articles. After excluding articles on the basis of the above criteria (247 articles) and

adding articles retrieved in the manual search (5 articles), we identified 24 articles that met our selection criteria (11–34). Studies that addressed more than one of the two aims are listed in Table 1. Cassileth et al. (13) first reported in 1980 that patients prefer to be informed of bad news and to participate in medical decisions. The majority of the selected 24 articles was of studies conducted in Western countries (13–28,30,33,34), only 5 were conducted in Asian countries (11,12,29,31,32). As expected, given the exploratory nature of the patients' preferences regarding communication of bad news, the majority of the articles was qualitative or descriptive studies that used unvalidated measures. Four of the studies used a validated questionnaire, the Measurement of Patients' Preferences, developed by Parker et al. (21,25,31,32) in the United States. In 17 of the studies, the subjects had different types of cancer (11–19,21,23,24,29–32,34). The other studies surveyed patients with head and neck cancer (20), melanoma (22), prostate cancer (25), haematologic cancer (26), breast cancer (33) and unspecified cancer (27,28).

### PATIENT PREFERENCES FOR COMMUNICATION OF BAD NEWS

Nine studies examined the components of patient preferences for the communication of bad news (11–13,16,21,23, 25,26,31,32). Two of them were conducted by means of in-depth interviews, exploring this issue by content analysis (11,26), and the other seven studies were questionnaire surveys followed by factor analyses (12,16,21,22,25,31,32). These nine studies reported identifying from two to six different components of patient preferences. We have summarized these components in Table 2 and identified four main structural components: 'setting', 'manner of communicating bad news', 'what and how much information to be provided' and 'emotional support'.

Nineteen studies reported the most preferred manner of communication based on these components by using descriptive data such as proportions or mean scores (12–25,27–33).

### SETTING

Seven articles identified setting (11,12,21,25,26,31,32) as component, which included face-to-face consultation (15,19,24,29–31), sufficient consultation time (11,21,22,25, 26,32) and privacy (11,15,22). There was high inter-individual variation in patients' responses regarding their preferences as to whether relatives should be present: 40–78% wanted to be told the bad news while their relatives were present, but 10–81% wanted to be alone (12,14,18,20,22,27,28). Very few patients (0–17.5%) desired the presence of other health professionals (12,18,22,28). Physicians should be trusted by and familiar to their patients (11,12,21,25,31,32), should turn off their beepers to avoid interruptions (11,32) and should greet the patient and family members politely before beginning the consultation (11,32).

Table 1. Patient preferences with regard to communication of bad news

Author	Year	Journal	Country	Sample	N	Cancer sites	Method	Results	Components of patient preferences	Items of patient preferences	Factors associated with patient preferences
Cassileth et al. <sup>13</sup>	1980	Ann Intern Med	USA		256	Lung 12% Breast 24% Gynaecologic 6% Head and neck 4% Haematologic 22% Gastrointestinal 9% Other 22%	Questionnaire (Information Styles Questionnaire: 12-item)			Want to know: what all possible side-effects: 98% Want to know what the treatment will accomplish: 98% Want to know whether or not the disease is cancer: 98% Want to know the chances of a cure: 96% Want to know whether all parts of the body are involved: 95% Want to know what the treatment will do inside their body: 95% Want to know what their day-to-day progress is: 93% Want to know whether the disease is inherited or contagious: 91% Want to know how effective the treatment has been for other patients: 93% Want to know examples of cases in which the treatment has been effective: 91% Want to know examples of cases in which the treatment has not been effective: 77%	Wanting detailed information: Age (younger > older) Race (white > black) Education (higher > lower) Wanting to participate in treatment decisions: Age (younger > older) Education (higher > lower) Wanting as much information as possible: Age (younger > older)
Lind et al. <sup>14</sup>	1989	J Clin Oncol	USA		55	Breast 35% Lung 15% Colorectal 11% Prostate 9% Other 29%	Semi-structured interview			Want to be told honestly: 2/3 Want to be told everything: 4/5 Want to be told as much as is necessary: 1/5 Want to know the effect of the physician: <1/2 Want to be told gently, without excessive negativism: 1/3 Want to be told with others: <1/10 Want the sense of personal tragedy that many feel taken seriously and not trivialized: many patients	
Petecet et al. <sup>15</sup>	1991	J Fam Pract	USA		32	Breast 16% Lung 16% Haematologic 28% Gastrointestinal 16% Testicular/ovarian 13%	Semi-structured interview			Want to be given information: 47% Want to be told to sustain hope: 19% Want to be told with compassion and caring: 16% Want to be told with a supportive person present: 13% Want to be told without additional information: 6% Want to be told not to sustain hope: 6% Want to be told without privacy: 3% Want to be told without support available: 6%	

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Table 1. Continued

Author	Year	Journal	Country	Sample N	Cancer sites	Method	Results	Items of patient preferences	Factors associated with patient preferences
Sardell and Trierweil <sup>16</sup>	1993	Cancer	USA	56	Breast 25% Colorectal 21% Lung 4% Other 50%	Questionnaire (57-item)	Components of patient preferences 1. Physician behaviors reflecting positive emotional support 2. Communications that deflect the impact of the diagnosis 3. Physician communication is limited or delayed 4. Communication of medical information relevant to the treatment	Highest rating Want to be told patient will receive the most up-to-date treatment: 98% Want to be told patient's pain will be controlled: 95% Want physician to insist that he/she will not abandon patient: 93% Want to be told all medical information: 91% Want to be told there are many treatments that slow/stop cancer: 91% Want to be told that other physicians will be called in: 89% Want offer to be patient's resource for all questions: 89% Want to be guided to medical research about the cancer: 89% Want to be told all treatment options: 88% Want it to be stated that physician needs patient help to help patient: 86%	
Fallowfield et al. <sup>17</sup>	1995	Psychooncology	UK	101	Gestational trophoblastic disease 29% Testis 20% Breast 11% Colorectal 7% Ovary 6% Lung 5% Bladder 5% Other 17%	Questionnaire (Cassileth's Information Needs: 12-item, by Cassileth et al. 1980)		Want to be told everything: 95% Want to know specific medical name of illness: 99% Want to know all possible treatments: 99% Want to know all possible side-effects of treatments: 99% Want to know exactly how treatment works to treat illness: 99% Want to know whether or not the disease is cancer: 98% Want to know what week by week progress is: 98% Want to know the chances of a cure: 97%	
Butow et al. <sup>18</sup>	1996	Cancer	Australia	144	Breast 39% Melanoma 61%	Questionnaire		Want to be told face-to-face: 77% Want to be told with family member: 57% Want to be told with other health professional: 13% Want to be alone to hear diagnosis: 38% Want to be given all information: 78% Want to discuss life expectancy: 57% Want to talk about influences on daily functioning: 63%	

Meredith et al. <sup>19</sup>	1996	Br Med J	UK	250	Stomach or oesophagus 9% Colorectal 14% Lung 34% Breast 23% Cervix 4% Ovary 4% Bladder 7% Prostate 6%	Semi-structured interview	Want to be given all information: 79% Want to know whether illness is cancer: 96% Want to know specific medical name of illness: 76% Want to know what week by week progress is: 90% Want to know chances of cure: 91% Want to know all possible treatments: 86% Want to know all possible side-effects of treatment: 94% Want to know how treatment works to treat illness: 79%	Wanting as much information as possible: Income (average > deprived)
Kim and Alvi <sup>20</sup>	1999	Laryngoscope	USA	16	Head and neck 100%	Questionnaire (41-item)	Want physician to tell bad news without touch or hug: 75% Want to be alone to hear diagnosis: 81% Want to have a warning sign: 56%	
Parker et al. <sup>21</sup>	2001	J Clin Oncol	USA	351	Breast 30% Gastrointestinal 31% Gynaecologic 17% Urologic 22%	Questionnaire (The Measure of Patients' Preferences: 47-item)	Highest rating [Mean(SD), range; 1-5] Want physician to be up to date on research: 4.72(0.49) Want to be told best treatment option: 4.70(0.57) Want physician to take time to answer all patient's questions completely: 4.66(0.56) Want physician to be honest about severity of patient's condition: 4.61(0.64) Want to feel confident about physician's competence and skill: 4.59(0.55) Want to be given enough time to ask all of patient's questions: 4.57(0.63) Want to be given news in a clear, simple language: 4.56(0.70) Want physician to tell patient the news directly: 4.56(0.62) Want physician to inform patient of all treatment options: 4.55(0.65) Want physician to give patient full attention: 4.53(0.68)	1. Content: Gender (female > male), Education (higher > lower) 2. Emotional support: Gender (female > male) 3. Facilitation: Age (younger > older) Education (higher > lower)
							1. Content: what and how much information is told, 13 items, total variance = 33.4%, alpha coefficient = 0.92 2. Support: emotional support during the interaction, 12 items, total variance = 10.7%, alpha coefficient = 0.90 3. Facilitation: setting and context variables, 7 items, total variance = 6.3%, alpha coefficient = 0.70	

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Table 1. Continued

Author	Year	Journal	Country	Sample N	Cancer sites	Method	Results	Components of patient preferences	Items of patient preferences	Factors associated with patient preferences
Schofield et al. <sup>22</sup>	2001	Ann Oncol	Australia	131	Melanoma 100%	Questionnaire (32-item, by Butow et al. 1996)	<p>1. Information</p> <p>2. Social support</p>	<p>Want to be given all information about diagnosis: 69%</p> <p>Want to be given information about life expectancy: 61%</p> <p>Want to be given information about influence on daily functioning: 62%</p> <p>Want to be given all information about treatment: 81%</p> <p>Want to talk about treatment decision immediately after diagnosis: 63%</p> <p>Want to be told with someone patient would have liked to be present to hear diagnosis</p> <p>Spouse/partner: 44%</p> <p>Other relative: 9%</p> <p>Nurse: 0%</p> <p>Social worker: 0%</p> <p>No one: 47%</p> <p>Most important communication feature</p> <p>Want physician to prepare patient for possibility of diagnosis of cancer: 12%</p> <p>Want physician to use the word 'cancer': 32%</p> <p>Want a familiar physician to convey the bad news: 32%</p> <p>Want physician to inform of diagnosis without delay: 41%</p> <p>Want to be told face-to-face: 62%</p> <p>Want to be told in private: 39%</p> <p>Want to be told the diagnosis with someone wanted by the patient to be present: 25%</p> <p>Want to be given all information: 26%</p> <p>Want physician to offer to help tell others of diagnosis: 5%</p> <p>Want to be given opportunities for questions after diagnosis: 28%</p> <p>Want to be given extra written information: 14%</p> <p>Want to be given information about life expectancy: 15%</p> <p>Want to be given all information about treatment: 15%</p> <p>Want to be given all treatment options: 25%</p> <p>Want to participate in decisions regarding treatment: 19%</p> <p>Want to be told about cancer support services: 4%</p> <p>Want physician to be supportive: 26%</p> <p>Want to be given hope/reassurance: 22%</p>	<p>Want to be given all information about diagnosis: 69%</p> <p>Want to be given information about life expectancy: 61%</p> <p>Want to be given information about influence on daily functioning: 62%</p> <p>Want to be given all information about treatment: 81%</p> <p>Want to talk about treatment decision immediately after diagnosis: 63%</p> <p>Want to be told with someone patient would have liked to be present to hear diagnosis</p> <p>Spouse/partner: 44%</p> <p>Other relative: 9%</p> <p>Nurse: 0%</p> <p>Social worker: 0%</p> <p>No one: 47%</p> <p>Most important communication feature</p> <p>Want physician to prepare patient for possibility of diagnosis of cancer: 12%</p> <p>Want physician to use the word 'cancer': 32%</p> <p>Want a familiar physician to convey the bad news: 32%</p> <p>Want physician to inform of diagnosis without delay: 41%</p> <p>Want to be told face-to-face: 62%</p> <p>Want to be told in private: 39%</p> <p>Want to be told the diagnosis with someone wanted by the patient to be present: 25%</p> <p>Want to be given all information: 26%</p> <p>Want physician to offer to help tell others of diagnosis: 5%</p> <p>Want to be given opportunities for questions after diagnosis: 28%</p> <p>Want to be given extra written information: 14%</p> <p>Want to be given information about life expectancy: 15%</p> <p>Want to be given all information about treatment: 15%</p> <p>Want to be given all treatment options: 25%</p> <p>Want to participate in decisions regarding treatment: 19%</p> <p>Want to be told about cancer support services: 4%</p> <p>Want physician to be supportive: 26%</p> <p>Want to be given hope/reassurance: 22%</p>	



Jenkins et al. <sup>23</sup>	2001	Br J Cancer	UK	2331	<p>Questionnaire (Cassileth's Information Needs: 12-item, by Cassileth et al. 1980)</p> <p>Breast 25% Gastrointestinal/colorectal 18% Haematological 8% Lung 7% Gynaecological 6% Urological 6% Skin 3% CNS 3% Head and neck 2% Unknown primary 7% Other 14%</p>	<p>Want to be given all information: 87% Want to know the specific medical name of the cancer: 88.7% Want to know whether or not the disease is cancer: 98.1% Want to know what the week-to-week progress is during treatment: 90.8% Want to know the chances of cure: 95.4% Want to know all possible side-effects of treatment: 97.1% Want to know how the treatment works to treat the illness: 91.9%</p>	<p>Wanting to leave details up to the doctor: Age (older &gt; younger) Wanting to know the name of the illness: Gender (younger female &gt; younger male) Wanting to know all the possible available treatments Gender (younger female &gt; younger male)</p>
Tang and Lee <sup>24</sup>	2004	Psychooncology	USA	364 (Taiwane)	<p>Haematological 19% Breast 16% Nasopharyngeal 10% Hepatoma 10% Colorectal 9% Lung 8% Gastric 7% Head and neck 6% Cervical 3% Primary unknown 3% Others 9%</p> <p>Semi-structured interview</p>	<p>Diagnosis Want to know medical name of the cancer: 54% Want to know degree of malignancy: 33% Want to know extent of metastasis 35% Prognosis Want to know chance of survival: 27% Want to know expected length of survival: 30% Diagnosis [Mean(SD), range; 1-5] Want physician to inform patient: 4.13(0.85) Want physician to inform family: 3.71(0.99) (<math>t = 7.15, P &lt; 0.0001</math>) Want physician to inform patient prior to informing family: 3.72(0.96) Want physician to inform family prior to informing patient: 3.08(0.96) (<math>t = 7.98, P &lt; 0.0001</math>) Prognosis [Mean(SD), range; 1-5] Want physician to inform patient: 3.97(0.90) Want physician to inform family: 3.69(0.97) (<math>t = 4.45, P &lt; 0.0001</math>) Want physician to inform patient prior to informing family: 3.74(0.98) Want physician to inform family prior to informing patient: 2.97(0.94) (<math>t = 8.07, P &lt; 0.0001</math>)</p>	<p>Continued</p>

Table 1. Continued

Author	Year	Journal	Country	Sample	Cancer sites	Method	Results	Items of patient preferences	Factors associated with patient preferences
Davison et al. <sup>25</sup>	2004	BJU Int	Canada	87	Prostate 100%	Questionnaire (The Measure of Patients' Preferences, by Parker et al. 2001)	<p>Components of patient preferences</p> <ol style="list-style-type: none"> <li>Content: what and how much information is told, 17 items, total variance = 34.4%</li> <li>Support: emotional support during the interaction, 10 items, total variance = 14.0%</li> <li>Facilitation: setting and context variables, 5 items, total variance = 6.5%</li> </ol>	<p>Highest rating [Mean(SD), range; 1-5]</p> <p>Want physician to be honest about severity of my condition: 4.70(0.57)</p> <p>Want physician to tell patient best treatment option: 4.67(0.68)</p> <p>Want physician to be up to date on research: 4.55(0.62)</p> <p>Want physician to disclose all treatment options: 4.54(0.68)</p> <p>Want physician to tell patient the prognosis: 4.54(0.70)</p> <p>Want physician to tell patient how the patient's condition may affect the patient's daily functioning: 4.52(0.82)</p> <p>Want physician to describe all treatment options in detail: 4.47(0.86)</p> <p>Want physician to take time to answer all questions completely: 4.45(0.66)</p> <p>Want physician to set aside enough time to ask all questions about cancer and treatments: 4.43(0.77)</p> <p>Want to feel confident about physician's technical competence and skill: 4.41(0.62)</p> <p>Want physician to tell news directly: 4.41(0.76)</p> <p>Want physician to wait until all test results are in before giving news: 4.34(0.93)</p> <p>Want to be given detailed information about results of medical tests: 4.20(0.90)</p> <p>Want physician to give patient full attention: 4.17(1.04)</p> <p>Want physician to give a lot of information about patient's cancer: 4.14(0.89)</p> <p>Want to be given information about experimental therapies: 4.08(0.92)</p>	<p>Factors associated with patient preferences</p>
Randal and Wearn <sup>26</sup>	2005	Palliat Med	UK	15	Leukemia 40% Lymphoma 60%	Semi-structured interview	<ol style="list-style-type: none"> <li>Characteristics of the person giving the bad news</li> <li>Amount of time available to the patient</li> <li>Type of information given and the language used</li> <li>Ongoing process of having a serious illness</li> <li>Support: when the news is received and throughout the illness</li> <li>Physical setting in which the news is given</li> </ol>		

Fujimori et al. <sup>1,11</sup>	2005 Psychooncology Japan	49	Lung 31% Gastrointestinal 31% Breast 14% Head and neck 12% Malignant lymphoma 10% Leukemia 1% Oncologists 14%	In-depth interview	<ol style="list-style-type: none"> <li>1. Setting: providing a comfortable environment and sufficient time</li> <li>2. Information given: discussing treatment and impact on daily activities</li> <li>3. Method of disclosure: facilitating patient understanding</li> <li>4. Emotional support: encouragement and allowing expression of emotions</li> </ol>	<p>Want to be told full details of patient's condition: 80%</p> <p>Want to be given any bad news: 57%</p> <p>Want to be told with family member: 40%</p> <p>Want to be told by family member: 2%</p>
Keating et al. <sup>27</sup>	2005 Chest Ireland	207	Cancer or Alzheimer's disease	Interview	<p>Who communicates the diagnosis</p> <p>Want family physician to tell the diagnosis: 50%</p> <p>Want hospital physician to tell the diagnosis: 29%</p> <p>Want any physician to tell the diagnosis: 9%</p> <p>Want psychologist to tell the diagnosis: 3%</p> <p>Want nurse to tell the diagnosis: 0%</p> <p>Want social worker to tell the diagnosis: 0%</p> <p>Want family member to tell the diagnosis: 0%</p> <p>Want other person to tell the diagnosis: 9%</p> <p>Who present</p> <p>Want to be told with family member: 61%</p> <p>Want to be told with friend: 0%</p> <p>Want to be told alone: 10%</p> <p>Want to be told with other professionals: 3%</p> <p>Want to be told with other patients: 3%</p> <p>Indifferent: 23%</p> <p>Who participate in decisions regarding treatment</p> <p>Want to decide for oneself: 68%</p> <p>Want family member to decide: 49%</p> <p>Want only physician to decide: 21%</p>	
Goncalves et al. <sup>28</sup>	2005 Palliat Med Portugal	47	Unspecified cancer	Questionnaire		

Continued

Table 1. Continued

Author	Year	Journal	Country	Sample	Method	Results	Components of patient preferences	Items of patient preferences	Factors associated with patient preferences
Tang et al. <sup>29</sup>	2006	Cancer Invest	Taiwan	617	In-person interview	Cancer sites Lung 30% Colorectal 10% Haematological malignancies 9% Hepatoma 8% Head and neck 7%		Diagnosis [Mean(SD), range; 1-5] Want physician to inform patient: 3.20(1.50) Want physician to inform family: 3.05(1.49) Want physician to inform patient prior to informing family: 3.61(1.01) Want physician to inform family prior to informing patient: 3.41(1.00) Prognosis [Mean(SD), range; 1-5] Want physician to inform patient: 3.11(1.48) Want physician to inform family: 2.99(1.47) Want physician to inform patient prior to informing family: 3.58(1.03) Want physician to inform family prior to informing patient: 3.41(1.00)	
Cox et al. <sup>30</sup>	2006	Eur J Oncol Nurs	UK	394	Questionnaire	Breast 49% Colorectal 34% Gynaecological 17%		Want to be given all information: 87% Decision-making Want to decide for self: 2% Want to listen to physician and decide for self: 20% Want to decide collaboratively: 39% Want physician to listen to patient and decide: 24% Want physician to make all decisions: 15%	Information needs: none Preferences for physician: none Decision-making (decision for self): Age [younger > older(60 or over)]
Chiu et al. <sup>31</sup>	2006	Support Care Cancer	Singapore	200	Questionnaire (The Measure of Patients' Preferences, by Parker et al. 2001)	Breast 27% Gastrointestinal 24% Gynaecologic 4% Head and neck 14% Urologic 3% Lung 17% Liver 6% Others 6%	1. Content and facilitation: what and how much information is told, and setting and context variables, 26 items 2. Support: emotional support during the interaction, 7 items	Highest rating [Mean(SD) range; 1-5] Want to be given detailed information about test results: 4.27(0.87) Want to be told in person: 4.26(0.79) Want to feel confident about physician's skill: 4.26(0.79) Want physician to tell best treatment option: 4.24(0.88) Want physician to describe treatment options in detail: 4.19(0.88) Want physician to tell news directly: 4.16(0.92) Want physician to give patient full attention: 4.11(0.89) Want physician to be honest about severity of patient's condition: 4.11(0.98) Want physician to tell how the condition may affect daily functioning: 4.11(0.96) Want physician to tell the prognosis: 4.10(0.95)	Content and facilitation: none Support: gender (female > male)