

Communicating With Realism and Hope: Incurable Cancer Patients' Views on the Disclosure of Prognosis

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Submitted November 25, 2003; accepted November 16, 2004.

Supported by New South Wales Cancer Council, Australia.

Presented at the 15th International Symposium of the Multinational Association of Supportive Care in Cancer, Berlin, Germany, June 2003.

Authors' disclosures of potential conflicts of interest are found at the end of this article.

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0732-183X/05/2306-1278/\$20.00

DOI: 10.1200/JCO.2005.11.138

A B S T R A C T

Purpose

To identify preferences for the process of prognostic discussion among patients with incurable metastatic cancer and variables associated with those preferences.

Patients and Methods

One hundred twenty-six (58%) of 218 patients invited onto the study participated. Eligible patients were the consecutive metastatic cancer patients of 30 oncologists, who were diagnosed within 6 weeks to 6 months before recruitment, over 18 years of age, and without known mental illness. Patients completed a postal survey measuring patient preferences for the manner of delivery of prognostic information, including how doctors might instill hope.

Results

Ninety-eight percent of patients wanted their doctor to be realistic, provide an opportunity to ask questions, and acknowledge them as an individual when discussing prognosis. Doctor behaviors rated the most hope giving included offering the most up to date treatment (90%), appearing to know all there is to know about the patient's cancer (87%), and saying that pain will be controlled (87%). The majority of patients indicated that the doctor appearing to be nervous or uncomfortable (91%), giving the prognosis to the family first (87%), or using euphemisms (82%) would not facilitate hope. Factor analysis revealed six general styles and three hope factors; the most strongly endorsed styles were realism and individualized care and the expert/positive/collaborative approach. A range of demographic, psychological, and disease factors were associated with preferred general and hope-giving styles, including anxiety, information-seeking behavior, expected survival, and age.

Conclusion

The majority of patients preferred a realistic and individualized approach from the cancer specialist and detailed information when discussing prognosis.

J Clin Oncol 23:1278-1288. © 2005 by American Society of Clinical Oncology

INTRODUCTION

The communication of distressing news is demanding for both doctor and patient.¹⁻³ Disclosure of a short life expectancy has been specifically identified by both clinicians and patients as an important and contentious issue,^{4,5} with the debate having previously focused on whether to tell the patient the prognosis, but in more recent times, the debate has focused on what information to give and how to convey it.⁶⁻⁸

Prior research demonstrates that a clear majority of cancer patients in the Western world reports a preference for detailed information about their disease and expected outcome,⁹⁻¹³ although information needs can vary across different phases of the illness.¹⁴⁻¹⁶ Legal rulings have emphasized the responsibility of doctors to provide all necessary information in some jurisdictions.¹⁷ Nevertheless, patients often misunderstand the status of their disease and the aim of treatment¹³ and commonly overestimate their life

expectancy.¹⁸ This may impact on decision making, particularly concerning anticancer treatment that may have side effects and reduce quality of life.^{19,20}

Issues that concern clinicians about communicating life expectancy to patients include how much information to give, difficulties with prognostication, and disclosing prognostic uncertainty without increasing anxiety, reducing trust, and destroying hope.^{5,14,21-25} Others, however, believe expressing this prognostic ambiguity carefully to patients is one means of engendering hope^{4,19} and that providing information decreases anxiety associated with ignorance and uncertainty.^{14,26-28}

The need for optimism and hope to be sustained in the process of honestly delivering bad news and a limited life expectancy is an ideal expressed by both doctors and patients.^{4,5,12,15,29} However, there is a delicate balance between fostering realistic hope and unethically creating unrealistic expectations of longevity.^{5,19,21,29} Furthermore, hope is a broad concept that can hold different meanings for each individual. Similarly, prognosis, a term often thought of as synonymous with life expectancy, encompasses broader issues surrounding the future course of the disease and how this may impact on the quality of life of the patient.^{19,27,30,31} Despite the complex issues surrounding this topic, apart from one study on communicating hope in the diagnosis of early-stage cancer,³¹ research is lacking in determining how patients define hope and how health professionals communicate hope to patients.^{14,32}

Much of the communication literature has focused on how to break bad news.^{6,33,34} Few studies or guidelines have targeted the communication of prognosis specifically, and these few studies focus on either early-stage disease^{10,35} or palliative and end-of-life issues.^{12,13,29,36,37} There is a lack of evidence-based information on discussing a poor prognosis, a context that arguably demands more resources from both doctors and patients.^{5,38} Furthermore, although patient preferences for general information have been associated with demographic, psychological, and disease variables, for example, age,^{11,26,28,39} sex,^{11,16,39} religiosity,¹⁶ education level,²⁶ involvement preference scores,^{16,40} anxiety and depression levels,^{35,41} and disease status,^{16,28} it has not yet been clarified whether such variables specifically influence metastatic cancer patient preferences for prognostic information.

In the current study, we aimed to identify the context and the way in which patients with incurable metastatic cancer wanted to be informed about their prognosis and to explore what features in the delivery of prognostic information they would experience as more or less hopeful. We hypothesized that the majority of patients would want detailed prognostic information as well as communication that facilitated hope. We also expected some variation in preferences according to patient demographic, disease, and psychological characteristics.

PATIENTS AND METHODS

Sample

All oncologists in New South Wales (n = 106), Australia, were invited to participate. Patients of participating oncologists attending outpatient clinics who were diagnosed with metastatic cancer within the time frame of 6 weeks to 6 months previously, were over 18 years of age, were English speaking, and had no psychiatric illness were recruited onto the study. The oncologists were asked to identify consecutive patients who fulfilled the eligibility criteria, briefly inform them about the study, and gain consent for the researcher to contact them. The researcher then telephoned or spoke to patients face to face and gained verbal consent to participate. Patients were then mailed a copy of the survey, together with a written consent form and a stamped, addressed return envelope, or completed the survey immediately in the clinic. Timing of recruitment was chosen to ensure that patients had time to adjust to their diagnoses, be exposed to information about their own prognosis, and make any treatment decisions before being approached to participate, thus reducing the potential for causing distress while still ensuring survey completion at a time when the issues explored were salient. Institutional review boards at all participating centers reviewed and approved the conduct of the study.

Measures

Survey development. A written survey was used to elicit patient preferences for the content and format of prognostic discussion. To develop survey items, key themes were abstracted from the published literature, including an earlier qualitative study of breast cancer patients⁵ and analysis of audiotapes of initial oncology consultations.^{42,43} These themes included patient desire for information and involvement,^{9,16,26,40} honesty, and the provision of hope when prognosis is communicated.^{5,12,16,36,44} The instrument was reviewed by oncologists, health professionals, and members of a consumer advocacy group and piloted among 10 patients with metastatic cancer. Minor revisions were made in response to reviewers' and pilot participants' feedback.

Demographics and disease details. Participants were asked about the following: age, relationship status, occupation, highest educational level achieved, medical or allied health training, language spoken at home, parents' country of birth, whether or not they have children, and whether or not they have a religious denomination or spiritual belief. Oncologists provided patient disease information, including type of cancer, dates of diagnosis of primary and metastatic cancer, mode of treatment, and estimated survival.

Doctor style. Thirty-five doctor informational and supportive behaviors when discussing prognosis, which were derived from earlier studies of prognostic information preferences,^{10,31} were listed. Patients rated their response to each item on a 5-point Likert scale (agree completely, agree, neutral, disagree, and disagree completely). Examples of items included, "I would like my cancer specialist to: (a) check my understanding of what he/she has told me, (b) be realistic, (c) be optimistic, and (d) tell me about cancer support groups."

Definition of hope. Participants were provided with four exemplar hope definitions, using the words of patients from a previous study.⁴⁵ The definitions were as follows: a feeling or expectation (1) that things can go well; (2) that because one thing has gone wrong, it doesn't mean that other things will not go well; (3) that you have just as good chances (if not better) as the next person of having the best outcome; (4) that you can still enjoy a

good quality of life, even if life expectancy is uncertain; or (5) other. Participants were asked to indicate what hope means to them in their current situation; they could select more than one item and/or write their own definition under other. Participants were also asked a separate open question about what else (apart from doctor communication) helps them to be hopeful.

What patients find hopeful. Thirty doctor behaviors that might convey or discourage hope, such as “gave me survival statistics,” “appeared nervous or uncomfortable,” and “was occasionally humorous,” were listed. The items were derived from Sardell and Trierweiler³¹ and our earlier qualitative study exploring ideal prognostic communication in the metastatic setting.⁵ Participants were asked to indicate on a 5-point Likert scale how hopeful each of the behaviors would make them feel (ie, very hopeful, hopeful, neutral, not hopeful, and hopeless).

Preference for prognostic information, timing, and manner of presentation. Patients were asked to indicate their preference for specific prognostic facts, mode of presentation of statistics, and the timing of prognostic information and who should initiate the discussion. These results have been presented elsewhere.⁴⁶

Information and involvement preferences. Participants' preferences for information and involvement were elicited using the seven-item binary Information subscale of the Krantz Health Opinion Survey ($\alpha = .74$ in this sample).⁴⁷

Depression and anxiety. Levels of depression and anxiety were measured by the 14-item Hospital Anxiety and Depression Scale self-assessment tool devised by Zigmond and Snaith⁴⁸ ($\alpha = .84$ and $\alpha = .81$ in this sample).^{49,50}

Statistical Analyses

Open questions and patient preferences for the doctor's style and hope-giving items were analyzed using descriptive statistics. Doctor style and hope items were then entered separately into two factor analyses using varimax rotation with Kaiser normalization. Total scores for the identified factors were calculated by summing items with weights more than 0.3 on each factor. If an item loaded onto more than one factor, it was included in the factor on which it had the highest weight and excluded from the other factor(s). Associations between demographic, psychological, and disease variables (described earlier) and each factor (the dependent variable) were explored in univariate analyses (using linear regression, *t* tests, and ANOVA). Associated variables that were found to be significant at the 0.25 level in univariate analyses⁵¹ were entered into binary logistic regressions. Because anxiety and depression scores were highly correlated (Pearson's correlation, $r = 0.57$; $P < .01$), only one of these scores (the more significant on univariate analysis) was entered into multivariate analyses.

RESULTS

Patients were recruited from 12 clinics in New South Wales, Australia, by 30 participating oncologists, of whom 19 were medical oncologists and 11 were radiation oncologists. Eighteen of 106 invited oncologists actively refused to participate (primarily because of insufficient time or because they were no longer practicing in oncology), whereas 58 did not respond. Data were available on oncologists who refused and accepted. No differences were found in age, years in practice, specialty (medical or radiation oncology), and

number of total cancer and metastatic cancer patients seen per year between these groups. Nevertheless, it is possible that the resulting patient sample has some bias because they were accrued from a small (although apparently representative) group of oncologists.

Of the 218 patients approached to participate, 10 were ineligible, and 22 refused. Of the remainder, 126 patients completed the survey. The most common reason cited for not completing the survey was ill health. No significant differences were found between those who completed the survey and those who did not complete the survey on the variables of age ($F_{2,194} = 0.180$; $P = .672$), sex ($\chi^2 = 0.294$; $df = 1$; $P = .588$), clinic where recruited (metropolitan or nonmetropolitan; $\chi^2 = 2.540$; $df = 1$; $P = .111$), type of cancer ($\chi^2 = 4.341$; $df = 4$; $P = .362$), and time since diagnosis of metastatic disease ($F_{2,192} = 0.008$; $P = .930$).

Fifty-six percent of participants were male, whereas 25% had breast cancer, 18% had colorectal cancer, 16% had prostate cancer, 10% had lung cancer, and 31% had other cancer types. The mean time since diagnosis of metastases was 13 weeks (range, 1 to 39 weeks; standard deviation [SD], 8.7 months). The majority of patients had an expected survival estimated by their oncologist of months (42%), or years (42%) and were receiving either systemic anticancer therapy or radiotherapy (92%; Table 1).

Information and Involvement Preferences

The average score on the Krantz Health Opinion Survey: Information Preferences Subscale was 3.9 (SD, 2.15), which is in the medium score range, indicating that, overall, participants did not have either a particularly high or low desire to ask questions or to be informed about medical decisions.⁴⁶

Anxiety and Depression

Twenty-three percent and 19% of patients fell into the possible case range (scores, 8 to 10) for anxiety and depression respectively. Ten percent and 7% of patients fell into the probable case range (scores, 11 to 21) for anxiety or depression, respectively.⁴⁸

Preference for Doctor Style

Of the 35 doctor behaviors listed, the most preferred included for the doctor to be realistic, provide an opportunity to ask questions, and acknowledge the patient as an individual when discussing prognosis (all 98%; Table 2). Less-preferred items were for the oncologist to discuss the patient's financial situation (37% of patients), give the patient his or her prognosis with another medical person present (28% of patients), give the patient an audiotape of their discussion (19% of patients), and give the patient his or her prognosis over the telephone (14% of patients; Table 2).

Table 1. Demographic Characteristics

Demographic	No. of Patients*	%
Age, years		
Mean	62.6	
SD	11.7	
Range	34-82	
Sex		
Male	70	56
Female	56	44
Area		
Metropolitan	107	85
Nonmetropolitan	19	15
Relationship status		
Married/de facto	80	63
Other	46	37
Occupation		
Professionals	23	18
Nonprofessionals	103	82
Medical/allied health training	7	6
Education level		
University entrance level and above	67	53
Below university entrance level	59	47
Language spoken at home		
English	116	92
Other	10	8
Background		
Anglo-Saxon	104	85
Non-Anglo-Saxon	18	15
Children	106	84
Religious belief	111	88
Primary cancer		
Breast	31	25
Colorectal	23	18
Prostate	20	16
Lung	13	10
Melanoma	6	5
Ovarian	3	2
Other	30	24
Mean time since diagnosis of primary, months	36	
Mean time since diagnosis of metastases, weeks		
Mean	13	
Range	1-39	
Estimated survival		
Weeks	4	3
Months	50	42
Months to years	16	13
Years	50	42
Treatment		
Active anticancer (systemic or local)	110	92
Nonactive/supportive care	10	8

Abbreviation: SD, standard deviation.
 *Not all groups' totals equal total number because of missing data.

Hope-Giving Behavior

Of the 30 listed doctor behaviors, those rated as being most hopeful included being offered the most up to date treatment (90%), the oncologist appearing to know all there is to know about the patient's cancer (87%), the occa-

sional use of humor (80%), being told that the pain will be controlled (87%), and being told all treatment options (83%; Table 3).

Behaviors that were rated as causing the patient to feel not hopeful or hopeless were the doctor appearing to be nervous or uncomfortable (91%), giving the prognosis to the family first (87%), the use of euphemisms (82%), avoiding talking about cancer and only discussing treatment (75%), and giving the good news first and then the bad news (72%); however, almost half of the patients rated this last item as neutral (46%).

Thirty percent of participants rated giving statistics about how long they will live as likely to make them feel hopeful; however, similar percentages of patients rated this item as not hopeful (32%) and neutral (38%). Similarly, participants rated expressing uncertainty about the course of the cancer (ie, said that the course of the cancer cannot be predicted) evenly across the options, with 35%, 30%, and 35% rating this as hopeful, not hopeful, and neutral, respectively (Table 3).

Patient Definition of Hope

Some participants ticked one or more of the four exemplars of hope; however, the majority (62%) wrote their own definition with or without ticking an exemplar. The most commonly endorsed definition was "that you can still enjoy a good quality of life even if life expectancy is uncertain" (19%) and "a feeling or expectation that things can go well" (14%). Fewer endorsed the items of "that you have just as much chance as the next person of having a good outcome" (3%) and "that because one thing has gone wrong, it doesn't mean that other things will go wrong" (3%).

Of the alternatives proposed, the most common themes were quality of life and fulfillment of goals (23%; for example, "To get on with life, make sure you make the most of it for as long as you can; set a distant goal and work like hell to get there"), receiving the best treatment that would provide the best cancer and symptom control (8%; for example, "Hope for me is a general expectation that everyone involved in my treatment is doing their best"), and the hope for cure or remission (8%; for example, "... hope that they may find a cure or extend my life").

General Factors Influencing Hopefulness

One hundred four (83%) of the 126 respondents completed the open question on general factors influencing hopefulness. The majority (87%) stated that family helped them to be hopeful. Other factors cited were religious beliefs or spirituality (28%), friends (24%), a positive attitude (13%), his or her children or grandchildren (12%) or partner (10%), and scientific advances in cancer care (9%).

Factor Analysis

Factor analysis of the 35 doctor style items revealed six factors that accounted for approximately 57% of the total

Table 2. General Doctor Behaviors When Discussing Prognosis

I Would Like My Cancer Specialist to:	% Agree	% Disagree or Unsure	% Responded
Be realistic about my likely future	98	2	98
Acknowledge me as an individual	98	2	98
Give me an opportunity to ask questions	98	2	99
Ensure he or she tells me personally what results are	96	4	100
Check that I understand what he or she has told me	94	6	98
Explain what he or she has told me	94	6	98
Explain what I should expect regarding the effect of symptoms on my daily life	94	6	99
Keep checking how I am feeling	93	7	99
Emphasize what can be done not what can't be done	92	8	99
Examine scans/test results in my presence	91	9	98
Summarize what he or she has told me	90	10	98
Tell me my prognosis first before anyone else	90	10	99
Discuss my ability to cope at home	89	11	98
Discuss what is offered by palliative care services	84	16	98
Tell me how to go about accessing palliative care services	84	16	98
Tell me about complementary therapies	82	18	99
Tell me about cancer support groups	80	20	98
Be optimistic about my likely future	76	24	99
Tell me where me and my family can get emotional support	76	24	98
Refer me to a social worker if required	75	25	99
Acknowledge my fears and concerns about dying	75	25	98
Discuss my family's fears and concerns	74	26	98
Advise me how to talk to my family about my cancer	65	35	97
Make sure I have someone with me	64	36	99
Give me published information about my situation	62	38	98
Ask me if I would like a second opinion	61	39	97
Write down what he or she has told me	59	41	97
Acknowledge my spiritual beliefs	49	51	99
Sit next to me rather than behind the desk	46	54	99
Share some personal information	44	56	98
Discuss my financial concerns	37	63	98
Give my prognosis with another medical person present (eg, nurse)	28	72	99
Give me an audiotape of our discussion	19	81	98
Give me my prognosis over the phone	14	86	100

variance (Table 4). These styles were as follows: factor 1, realism and individualized care (providing realistic and direct information tailored to the individual); factor 2, emotional support (providing information on support services and an openness to discuss patients' fears and concerns); factor 3, facilitation of coping with dying (displaying openness to discuss concerns about dying and providing information on palliative care services); factor 4, provision of information (ensuring patient understanding and providing information materials such as publications and audiotape of consultation); factor 5, emphasizing all options (providing information on complementary therapies, discussing optimistic future scenarios, and suggesting a second opinion); and factor 6, a personal approach (sitting next to the patient and sharing personal information; Table 4).

Three factors were identified among the 30 hope items, which accounted for approximately 54% of the variance (Table 5). These were as follows: factor 1, expert/positive/

collaborative (expertise, humor, and inclusion of patient as part of the team); factor 2, avoidant (avoiding or appearing uncomfortable about discussing the cancer, using euphemisms, and giving the prognosis to others first); and factor 3, empathic (expressing one's own feelings or asking the patient about his or her own reaction to the prognosis; Table 5). One item ("asked me if I would like a second opinion") did not weigh on any of the factors.

The strength of preference for these styles was determined by calculating the total scores for each factor. Because different factors included varying numbers of items, the totals were normalized to allow direct comparison. Thus, scores could range from 20 to 100. The most strongly endorsed doctor style was realism and individualized care (mean score, 88.9; SD, 9.6), and the least endorsed doctor style was personal approach (mean score, 59.9; SD, 14.1). The most strongly endorsed hope-giving style was the expert/positive/collaborative approach (mean score, 78.4; SD, 14.4).

Table 3. Hope-Giving Behaviors

If My Cancer Specialist . . . I Would Feel:	% Hopeful	% Not Hopeful	% Neutral	% Responded
Offered most up to date treatment available	90	6	4	96
Said my pain will be controlled	87	8	5	94
Appeared to know all there was to know about my cancer	87	6	7	97
Told me there are many treatments that slow cancer	83	8	9	95
Told me all treatment options	83	3	14	96
Was occasionally humorous	80	3	17	96
Offered to answer all my questions	78	12	10	96
Suggested we work together on this as a team	78	7	15	94
Said each day I survive new developments are possible	75	12	13	96
Said my will to live would affect outcome	74	17	9	95
Guided me to medical research about my type of cancer	67	10	23	96
Insisted he or she would not abandon me	65	22	13	96
Made all the decisions for treatment	60	12	28	96
Said that cancer affects individuals differently	60	4	36	95
Asked about my reaction to my prognosis	54	9	37	94
Said case will be discussed by the team	53	10	37	96
Said nutritional changes might help	49	24	28	95
Told me only positive aspects about my case	49	18	33	96
Offered to tell prognosis with a friend or family member present	46	32	22	95
Gave the bad news first, then the good news	45	20	35	94
Physically touched me to offer comfort	44	26	36	97
Expressed his or her own feelings	42	22	36	94
Said that the course of the cancer cannot be predicted	35	30	35	96
Asked me if I would like a second opinion	33	15	52	94
Gave statistics about how long I will live	30	38	32	95
Gave the good news first, then the bad news	28	26	46	95
Avoided talking about the cancer and only discussed treatment	25	39	36	95
Used euphemisms like growth and did not use the word cancer	18	38	44	96
Gave my prognosis to my family, then gradually told me	13	58	29	96
Appeared nervous or uncomfortable	9	74	17	94

Variables Significantly Associated With Preferences

Doctor style. Table 6 lists the means scores on the general doctor style factors by those variables found to be significant in multivariate analyses. Higher anxiety scores ($t_{102} = 2.463; P = .02$), having a partner ($t_{102} = 2.00; P = .048$), English speaking at home ($t_{102} = -2.363; P = .02$), expected survival of years as opposed to weeks or months ($t_{102} = 2.23; P = .03$), and longer time since diagnosis of metastatic disease ($t_{102} = 2.09; P = .04$) were found to significantly and independently predict preference for the oncologist to have a realistic and individualized approach (factor 1). Higher Krantz Information Subscale scores ($t_{102} = 2.88; P = .005$) were also significantly associated with this factor.

Age was the only variable significantly associated with preference for factor 2, with younger patients more likely to prefer an emotionally supportive approach ($t_{103} = -4.53; P < .001$). Higher anxiety scores ($t_{115} = 2.80; P = .006$) and female sex ($t_{115} = -2.68; P = .008$) predicted preference for the facilitation of the coping with dying approach (factor 3). Patients who scored higher on information seeking ($t_{108} = 3.10; P = .002$) were more likely to prefer the informative approach (factor 4). Younger pa-

tients ($t_{114} = -3.65; P < .001$) were more likely to prefer the emphasizing all options approach (factor 5). Patients who stated they had a religious belief ($t_{109} = 3.40; P = .001$) were more likely to prefer the personal approach (factor 6; Table 6).

Hope-giving style. Table 6 lists the mean scores on the hope-giving factors by those variables found to be significant in multivariate analyses. Older patients rated the expert/positive/collaborative (factor 1) and empathic (factor 3) approaches as significantly more hope giving than younger patients (factor 1: $t_{97} = 2.08; P = .04$; factor 3: $t_{102} = 3.18; P = .002$). Anxiety was also significantly associated with these factors (factor 1: $t_{97} = 2.20; P = .03$; factor 3: $t_{102} = 2.43; P = .02$; Table 6). None of the variables explored were found to be significantly associated with the avoidant approach (factor 2).

DISCUSSION

We surveyed patients with metastatic cancer regarding their preferences for the process of prognostic communication, including how hope is conveyed. A clear majority of patients in this sample found individualized and realistic

Table 4. General Doctor Behaviors When Discussing Prognosis

Physician Behavior	Factor Loading (eigen value)	% of Total Variance Explained
Realistic and individualized care		22
Acknowledge me as individual	.805	
Ensure he or she tells me personally what my results are	.766	
Explain what I should expect	.736	
Tell me my prognosis first before anyone else	.713	
Be realistic about my likely future	.686	
Give me an opportunity to ask questions	.657	
Keep checking how I am feeling	.644	
Emphasize what can be done, not what can't be done	.576	
Discuss my ability to cope at home	.533	
Examine scans/test results in my presence	.483	
Emotional support		12
Tell me where me and my family can get emotional support	.714	
Tell me about cancer support groups	.673	
Discuss my family's fears and concerns	.629	
Refer me to a social worker if required	.593	
Ask me if I would like a second opinion	.572	
Advise me how to talk to my family about my cancer	.548	
Discuss my financial concerns	.521	
Discuss my being able to continue working	.311	
Facilitation of coping with dying		7
Make sure I have someone with me	.713	
Acknowledge my fears and concerns about dying	.636	
Tell me how to go about accessing palliative care services	.614	
Discuss what is offered by palliative care services	.600	
Provision of information		5
Write down what he or she has told me	.790	
Explain what he or she has told me	.664	
Summarize what he or she has told me	.537	
Give me an audiotape of the consultation	.513	
Check with me that I understand what he or she has told me	.512	
Give me published information about my situation	.501	
Emphasizing all options		5
Tell me about complementary therapies	.684	
Be optimistic about my likely future	.668	
Give my prognosis with another medical person present (eg, nurse)	.349	
Personal		5
Sit next to me rather than behind the desk	.633	
Share some personal information	.629	
Acknowledge my spiritual beliefs	.421	
Give me my prognosis over the phone	.395	
Total		57

disclosure from a confident, collaborative, and supportive cancer specialist more hopeful than an avoidant approach. Detailed information about discussing prognosis, an opportunity to ask questions, and the clinician checking patient understanding were also favored. The results of this study provide a useful taxonomy of physician approaches and hope-giving approaches preferred by metastatic cancer patients, which may provide guidance to clinicians working in this setting.

There was some variability in preferences according to patient characteristics, which allows some insight into who may prefer which style. Overall, younger, anxious patients placed a stronger focus on emotional support for themselves

and their families. This is understandable given that these patients are more likely to have a dependent family whose support needs during their illness and after their death may be a primary concern for them. These patients seemed to have high needs and high expectations for medical care. This is in accordance with other studies that report that younger patients have a preference for more information and have high unmet needs.^{26,52}

Patients who had been diagnosed with metastatic disease for a longer period and those with longer expected survival were more likely to want realism (factor 1). Perhaps patients are better able to cope with realism over time. In

Table 5. Hope-Giving Behaviors

Physician Behavior	Factor Loading (eigen value)	% of Total Variance Explained
Expert/positive/collaborative		28
Appeared to know all there was to know about my cancer	.835	
Told me there are many treatments that slow cancer	.818	
Offered most up to date treatment available	.801	
Told me all treatment options	.779	
Said my pain will be controlled	.779	
Was occasionally humorous	.768	
Suggested we work together on this as a team	.734	
Said each day I survive new developments are possible	.705	
Said that cancer affects individuals differently	.677	
Said case will be discussed by the team	.661	
Guided me to medical research about my type of cancer	.652	
Insisted he or she would not abandon me	.596	
Said my will to live would affect outcome	.582	
Made all the decisions for treatment	.450	
Physically touched me to offer comfort	.449	
Avoidant		14
Avoided talking about the cancer and only discussed treatment	.808	
Used euphemisms like growth and did not use the word cancer	.805	
Gave my prognosis to my family, then gradually told me	.678	
Appeared nervous or uncomfortable	.663	
Said nutritional changes might help	.548	
Gave the good news first, then the bad news	.476	
Offered to tell prognosis with a friend or family member present	.354	
Told me only positive aspects of my case	.338	
Empathic		12
Expressed his or her own feelings	.738	
Asked about my reaction to my prognosis	.631	
Offered to answer all my questions	.625	
Gave the bad news first, then the good news	.560	
Said that the course of the cancer cannot be predicted	.503	
Gave statistics about how long I would live	.422	
Total		54

earlier work, we found that patients who are in routine follow-up, without relapse, develop stronger preferences for involvement in decision making over time.¹⁶ A longer expected survival would be understandably easier to discuss frankly. Interestingly, because these data were derived from oncologists' prognostic estimates, it would seem that these patients had some awareness of their own prognosis.

English speakers were also more likely to prefer realism. Those who speak another language at home are possibly influenced by a culture where avoidance and paternalism is more common. It is well documented that, in some cultures, communication of prognosis is viewed as harmful and brutal.⁵³⁻⁵⁷ Overall, however, the majority of patients in all groups preferred a realistic approach. Generalizations concerning a group linked by cultural factors can lead to stereotyping. Thus, information about beliefs and practices within particular cultures and groups never obviates the need for exploring individual preferences and needs. Notably, patients who did have a religious belief wanted this to be

acknowledged by the cancer specialist in the context of discussing prognosis.

Only two variables were associated with preferences for hope-giving behaviors. Older patients were more likely to rate both the expert and empathic approaches as more hope giving. However, older patients were less likely to prefer the emotionally supportive approach as a general doctor style. It seems that older patients want direct emotional support from their doctor as opposed to more formal organized support. This supports previous findings in the literature.^{58,59} Anxiety was also associated with these factors, although, on examination of the means, it seems that the relationship may be curvilinear, with patients scoring high or low showing less interest in these approaches. This is difficult to interpret, and further research may clarify these relationships.

Some of the results are not consistent with current practice guidelines.^{37,60} For example having another medical person present during prognostic discussion and

Table 6. Mean Scores for Patient Preferences for Doctor Style and Hope Factors by Associated Variables

	General Doctor Style Factors (mean scores)						Hope-Giving Factors (mean scores)		
	Factor 1: Realistic and Individualized Care	Factor 2: Emotional Support	Factor 3: Facilitation of Coping With Dying	Factor 4: Provision of Information	Factor 5: Emphasizing All Options	Factor 6: Personal	Factor 1: Expert/ Positive/ Collaborative	Factor 2: Avoidant	Factor 3: Empathic
Score									
Range	19-50	12-40	4-20	10-30	5-15	8-25	18-75	8-40	8-30
SD	4.8	5.8	3.1	4.1	2.2	3.2	10.8	5.8	4.0
Overall mean	44.4	29.9	15.7	22.8	10.8	15.8	58.8	22.8	20.1
Associated variable									
Sex									
Female	44.7	30.9	16.5*	22.6	10.9	15.6	57.4	30.4	19.3
Male	44.3	29.1	15.1	23.0	10.8	15.9	59.8	30.7	20.8
Relationship status									
Partnered	44.9†	30.0	15.9	22.6	10.9	15.8	59.6	30.3	20.2
Not partnered	43.6	29.8	15.4	23.3	10.8	15.8	57.4	31.2	20.1
Religiosity									
No religious belief	44.1	29.8	15.2	23.6	10.7	13.7‡	58.6	20.1	18.8
Religious belief	44.5	30.0	15.8	22.7	10.9	16.1	58.8	23.2	20.3
Age									
30-45 years	46.7	33.9*	15.8	24.7	12.1*	15.1	57.0†	22.0	18.3*
46-60 years	44.7	31.1	16.0	23.1	11.6	15.5	55.7	21.8	19.2
61-75 years	44.5	29.7	15.9	23.0	10.3	16.0	61.2	23.3	20.9
76-85 years	42.6	23.8	14.5	20.8	10.1	16.2	60.2	24.3	21.1
Language spoken at home									
English	44.6†	30.1	15.8	23.0	10.8	16.0	58.8	30.3	20.2
Non-English	42.5	28.5	15.1	21.6	11.4	14.6	59.0	32.9	20.0
Anxiety									
Noncase	43.9†	29.0	15.0*	22.5	10.5	15.5	58.8†	22.5	19.8†
Possible case	45.0	31.1	16.8	23.7	11.4	16.2	61.9	23.6	21.2
Probable case	46.8	34.5	17.8	24.1	11.8	15.8	57.1	22.9	19.8
Expected survival									
Weeks/months	43.5†	29.8	15.5	22.7	10.7	15.9	58.4	29.3	20.4
Months to years	44.7	29.8	15.4	22.5	11.3	15.1	59.2	31.8	19.8
Years	45.5	30.9	17.1	23.1	10.1	17.2	56.1	29.0	20.1
Time since metastatic diagnosis									
< 2 months	43.4†	29.8	16.0	21.2†	11.1	16.0	63.4	23.6	21.0
2-6 months	44.3	29.9	15.4	23.1	10.8	16.7	58.1	22.8	20.1
> 6 months	46.4	29.9	16.4	23.1	10.3	16.0	57.0	21.8	19.4
Krantz involvement preferences									
Low	41.9*	28.6	15.3	20.9*	10.6	16.1	58.7	22.7	20.4
Medium	46.0	30.0	15.6	23.4	11.1	15.8	61.1	23.5	30.0
High	44.4	30.9	16.3	24.0	10.7	15.4	54.5	21.9	18.7

NOTE. Only means for associated variables found to be significant in multivariate analyses are included in this table.

Abbreviation: SD, standard deviation.

* $P < .01$ in multivariate analyses.

† $P < .05$ in multivariate analyses.

‡ $P = .01$ in multivariate analyses.

offering an audiotape of the discussion were not endorsed by participants in this study. A personal approach that involved sitting next to the patient or sharing some personal information was also less valued. These results are similar to those of Schofield et al⁶¹ who reported that patient preferences do not always reflect published consensus guidelines, which may need to be modified in light of this feedback.

There were several limitations to the study. Cultural factors have not been well considered because non-English

speakers were excluded from the sample. It is known that cancer patients from other cultures have different views and information needs.⁵³⁻⁵⁷ It is also not certain, although probable, that these results would be relevant to the cancer populations of Britain and North America. Furthermore, some subgroups in the sample (eg, particular cancers) are quite small, and therefore, this study did not allow detection of differences between these groups. A larger sample may have produced more significant and reliable results.

Only 30 of 106 oncologists invited to participate in this study took part. Although no demographic or practice differences were observed between those who accepted and those who actively refused to participate, more subtle differences (such as interest in communication) that we did not measure may have differentiated these groups and, therefore, influenced the results. Furthermore, no data were available on oncologists who did not respond at all.

Not all oncologists may have complied with the instruction to recruit consecutive eligible patients. They may have invited patients who felt more comfortable with their diagnosis or who were less symptomatic; few patients were receiving symptomatic care only. Although this is characteristic of outpatient oncology patients with a recent diagnosis of metastases,^{42,62-65} the potential for bias in the study sample remains significant.

It is possible that participants were more comfortable with addressing prognostic issues than nonparticipants. There was a low prevalence of probable cases of anxiety and depression in the sample; however, the levels were similar to levels of anxiety and depression reported in a sample of 159 patients with advanced disease recruited in a large English study,⁴⁹ which suggests that we did not have a particularly psychologically resilient sample.

The exemplar hope items and predictor variables included in this study were chosen on primarily empirical grounds (for example, those variables that had been found to be associated with general information preferences previously) rather than on theoretical grounds. Relevant theory (apart from the work on monitoring and blunting of Miller⁶⁶) is lacking. There is a need for further development of appropriate theory to underpin future work in this field.

Nevertheless, this study provides the first data of its kind in this area, and it is hoped that the data will prove useful for clinicians struggling to communicate effectively with their patients with incurable cancer. Future research could use a more qualitative, in-depth approach to better explore some of the issues raised by these data.

Acknowledgment

We are grateful for the contribution of M. Boyer, F. Boyle, S. Clarke, J. Clayton, S. Crossing, D. Goldstein, F. Kirsten, M. Stockler, A. Sullivan, S. Crossing, and S.K. Lo, and we thank all participating oncologists and their patients.

Authors' Disclosures of Potential Conflicts of Interest

The authors indicated no potential conflicts of interest.

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