

## Cancer Patient Preferences for Communication of Prognosis in the Metastatic Setting

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### A B S T R A C T

#### Purpose

To identify preferences for and predictors of prognostic information among patients with incurable metastatic cancer.

#### Patients and Methods

One hundred twenty-six metastatic cancer patients seeing 30 oncologists at 12 outpatient clinics in New South Wales, Australia, participated in the study. Patients were diagnosed with incurable metastatic disease within 6 weeks to 6 months of recruitment. Patients completed a survey eliciting their preferences for prognostic information, including type, quantity, mode, and timing of presentation; anxiety and depression levels; and information and involvement preferences.

#### Results

More than 95% of patients wanted information about side effects, symptoms, and treatment options. The majority wanted to know longest survival time with treatment (85%), 5-year survival rates (80%), and average survival (81%). Words and numbers were preferred over pie charts or graphs. Fifty-nine percent (59%) wanted to discuss expected survival when first diagnosed with metastatic disease. Thirty-eight percent and 44% wanted to negotiate when expected survival and dying, respectively, were discussed. Patients with higher depression scores were more likely to want to know shortest time to live without treatment ( $P = .047$ ) and average survival ( $P = .049$ ). Lower depression levels were significantly associated with never wanting to discuss expected survival ( $P = .03$ ). Patients with an expected survival of years were more likely to want to discuss life expectancy when first diagnosed with metastases ( $P = .02$ ).

#### Conclusion

Most metastatic cancer patients want detailed prognostic information but prefer to negotiate the extent, format, and timing of the information they receive from their oncologists.

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### INTRODUCTION

Cancer patients in developed countries increasingly express a preference for more detailed information and involvement in decisions about their care.<sup>1</sup> Documentation of high levels of psychological morbidity in cancer patients has also highlighted the importance of doctor communication when delivering bad news, discussing prognosis and negotiating treatment decisions.<sup>2</sup>

Doctors commonly find these interactions challenging. Issues debated in the literature include how to determine what the patient wants to hear, whether to provide life expectancy (eg, median survival) or

make general comments (eg, "I think your chances are good"), whether to discuss outliers, and how to engender hope.<sup>3-8</sup> The best way of presenting prognostic information to optimize understanding, psychological adjustment, and decision-making is uncertain. To date, much of the communication literature has focused on how to break bad news, and there is little guidance available for clinicians in estimating or communicating prognosis, particularly in the context of newly diagnosed metastatic disease.

The literature suggests that cancer patients frequently misunderstand much of what they are told,<sup>9,10</sup> incorrectly state the extent of their disease and the goal of treat-

ment, and overestimate their prognosis.<sup>9,11-13</sup> Such misunderstanding may lead patients to make decisions contrary to their best interests—for example, choosing futile life-extending therapy at the expense of quality of life.<sup>14</sup>

The misunderstanding commonly reported in cancer patients may be attributed in part to poor communication by physicians. Most doctors in Western cultures now report that they tell their cancer patients the diagnosis;<sup>15,16</sup> however, fewer disclose prognosis, particularly when the prognosis is poor.<sup>11,17-19</sup> In an Australian study of initial consultations between oncologists and incurable cancer patients, most patients were informed of the aim of anticancer treatment (85%) and that the disease was incurable (75%). However, slightly more than half (58%) were told about life expectancy, only one third (35%) received a quantitative estimate, and fewer than 10% were given a time frame of life expectancy.<sup>20</sup>

Doctors face particular difficulties when discussing life expectancy with patients with a poor prognosis. Such information raises immediate issues for the patient, and the information required includes much shorter time frames than the long-range forecasting required in early stage disease. Considerable inaccuracy in doctors' predictions of the survival of individual patients with incurable disease has also been documented.<sup>21,22</sup> Kaplowitz et al<sup>4</sup> interviewed physicians about their communication of prognosis with metastatic cancer patients. Nearly all respondents stated that they routinely reveal when the cancer cannot be cured but experienced tension between providing hope and realism in these situations.

A clear majority of cancer patients report a preference for detailed information about their disease.<sup>23-29</sup> However, few studies have specifically explored preferences for information about prognosis. Lobb et al<sup>28</sup> surveyed 100 women with early stage breast cancer about this issue. More than 90% of the women wanted information about the probability of cure, staging details, and the chance that the treatment would work. Eighty-seven percent wanted 10-year survival figures, and 70% wanted average survival figures. The women emphasized that the way information is presented is as important as the actual content.

Kaplowitz et al<sup>30</sup> reported somewhat different results. A large majority of their sample of early and late stage cancer patients wanted a qualitative prognosis (eg, "Will I die from the disease?"); however, less than half wanted a quantitative estimate of their prognosis, and those with a poorer prognosis were less likely to request this information.

A recent qualitative study by Butow et al<sup>3</sup> documented the views of 17 metastatic breast cancer patients and 13 health professionals on optimal ways of communicating prognosis to metastatic cancer patients. The major issues raised were that patient preferences be elicited on an ongoing basis; that information be presented

clearly when desired; that doctors encourage hopefulness and a sense of control; and that strategies be used to ensure patient understanding.

The purpose of the current study was to determine the preferences of a sample of metastatic cancer patients for content and format of prognostic information and to explore predictors of these preferences.

## PATIENTS AND METHODS

### Sample

All oncologists in New South Wales ( $n = 106$ ), Australia, were invited to participate. Patients of participating oncologists attending outpatient clinics, diagnosed with metastatic cancer within the time frame of 6 weeks to 6 months, who were older than 18 years, were English speaking, and who 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, provided more detail about the study, 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 they completed the survey immediately in the clinic. Timing of recruitment was chosen to ensure that patients had time to adjust to their diagnosis, 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 the items in the survey, key themes were abstracted from the published literature, an earlier qualitative study in breast cancer patients<sup>3</sup> and analysis of audiotapes of initial oncology consultations.<sup>20,31</sup> Two sex-specific hypothetical scenarios (a woman with metastatic breast cancer and a man with metastatic prostate cancer) were developed to provide an objective focus for patients to answer questions on the presentation of statistical prognostic information. The instrument was reviewed by oncologists, health professionals, and members of a consumer advocacy group and was piloted among 10 patients with metastatic cancer, from one of the study centers. Minor revisions were made in response to reviewers' and pilot participants' feedback.

**Demographic details.** Patients were asked their ages, relationship status, occupations, highest educational level achieved, medical or allied health training, language spoken at home, parents' country of birth, and whether or not they had children and religious beliefs.

**Information and involvement preferences.** Participants' preferences for information and involvement were elicited by using the seven-item binary "Information" subscale of the Krantz Health Opinion Survey ( $\alpha = 0.74$  in this sample).<sup>32</sup>

**Depression and anxiety.** Levels of depression and anxiety were measured by the 14-item Hospital and Anxiety and Depression Scale (HADS) self-assessment tool devised by Zigmond and Snaitch ( $\alpha = 0.84$  and  $\alpha = 0.81$  in this sample).<sup>33-35</sup>

*Specific prognostic information desired.* Participants indicated their preferences for prognostic information from a list of 15 specific information items (eg, average survival, 5-year survival) by ticking yes or no and indicated in an open-question format why they would or would not like to know each item.

*Preferred presentation of survival statistics.* Participants were asked to read a short scenario of a patient who had recently developed metastases (from either prostate cancer or breast cancer) before considering six different formats of the same prognostic information that could be given to the patient by the cancer specialist. Participants indicated on a 5-point Likert scale how easy each was to understand and how much they liked each format. The six formats were (1) words, (2) percentage, (3) fraction, (4) 100-person diagram, (5) pie chart, and (6) survival graph. For example the "word" format for the patient with breast cancer was, "There is a good chance that Jane will be alive in 2 years time." The "percentage" format for the same scenario was, "There is a 50% chance that Jane will be alive in 2 years time." Patients also indicated their overall preference for "words," "numbers," "both," or "other," and the reason for that preference.

*When to discuss prognosis and who should initiate the discussion?* Participants were asked to indicate when they would like to receive information on (1) "treatment goals and options," (2) "symptoms of the cancer and side effects of treatment," (3) "how long I would be likely to live", and (4) "issues about dying and palliative care services." Options given were (1) "when first told cancer has spread," (2) "next few consultations," (3) "later, on my request," (4) "never," or (5) "unsure." Patients also indicated for each information item whether they would like the (1) "specialist to just tell me," (2) "specialist to check first if I want to know," (3) "specialist to tell me only if I ask," (4) "not to discuss at all," or (5) "other."

*Statistical analyses.* Preferences were analyzed using descriptive statistics. Demographic, psychological, and disease predictors of patient preferences were explored, using  $\chi^2$ , analysis of variance, and logistic regression analyses. These predictors included age, sex, education level (up to 11 years or 12+ years), relationship status (partnered or not), children (0 or more), father's country of birth (Australia or not), whether English was spoken at home (yes or no), depression and anxiety scores, information preference style, type of cancer (breast, colorectal, prostate, or other), time since diagnosis of first cancer and of metastatic disease, expected survival (weeks to months, months to years, or years), and type of treatment (active or supportive care).

Only preferences for which fewer than 80% of the sample indicated a particular preference were included in predictive analyses (ie, where there was sufficient variability). These included: preference (yes or no) for information regarding average survival, chance of living 1 year, shortest time to live without treatment, and longest time to live without treatment; preferences for format of information (like, dislike, or neutral), including survival graph, 100-person diagram, pie chart, and words; and preferences for the manner of discussing expected survival and palliative care/dying, including when (immediately, later, or never) and how the discussion should be initiated (specialist to just tell or tell only if asked/check first). Predictors that were found to be significant at the 0.25 level in univariate analyses were entered into binary and multinomial logistic regressions as appropriate.<sup>36</sup> Because anxiety and depression scores were highly correlated (Pearson's correlation = 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 that they were no longer practicing in oncology), and 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, in that they were accrued from a small (though apparently representative) group of oncologists.

Of the 218 patients approached to participate, 10 were ineligible, and 22 refused. Of 186 patients who agreed to participate, 126 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 and those who did not complete the survey on the variables of age ( $F_{2,194} = 0.180$ ;  $P = .672$ ), sex ( $\chi^2 = 0.294$ ;  $P = .588$ ), clinic where recruited (metropolitan or nonmetropolitan;  $\chi^2 = 2.540$ ;  $P = .111$ ), type of cancer ( $\chi^2 = 4.429$ ;  $P = .362$ ), nor time since diagnosis of metastatic disease ( $F_{2,192} = 0.008$ ;  $P = .930$ ).

Of the 126 patients who completed the survey, 54% were male; 25% had breast cancer, 18% had colorectal cancer, 15% had prostate cancer, 10% had lung cancer, and 30% had other cancer types. The mean time since diagnosis of metastases was 13 weeks (range, 1 to 39 weeks; standard deviation [SD], 8.7 weeks). The majority had an expected survival estimated by their oncologist of months (42%), or years (42%) and were receiving anticancer treatment with either systemic 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.<sup>32</sup>

### Anxiety and Depression

Scores on the HADS show that the majority of participants fell into the "normal" or "noncase" range (scores 0-7) for both anxiety (67%) and depression (74%). Twenty-three percent and 19%, respectively, fell into the "possible case" range (scores 8-10) for anxiety and depression respectively. Ten percent and 7% of patients fell into the "probable case" range (scores 11-21) for anxiety or depression, respectively.<sup>33</sup>

**Table 1.** Patient Characteristics

Demographic	% of Patients
Age, years	
Mean	62.6
SD	11.7
Range	34-82
Sex	
Male	54
Female	46
Area	
Metropolitan	85
Non-metropolitan	15
Relationship status	
Married/de facto	64
Other	36
Occupation	
Professional	18
Non-professional	82
Medical/allied health training	6
Education level	
University entrance level and above	53
Less than university entrance level	47
Language spoken at home	
English	92
Other	8
Ethnicity	
Anglo-Saxon	86
Non-Anglo-Saxon	14
Children	84
Religious belief	88
Primary cancer	
Breast	25
Colorectal	18
Prostate	16
Lung	10
Melanoma	5
Unknown primary	4
Ovarian	2
Other	20
Time since diagnosis of primary, months	
Mean	36
Range	1-349
Time since diagnosis of metastases, weeks	
Mean	13
Range	1-39
Estimated survival	
Weeks	3
Months	42
Months to years	13
Years	42
Treatment	
Anti-cancer (systemic or local)	92
Non-anti-cancer/supportive care	8

### Prognostic Information Desired

Almost all patients wanted information that related to treatment, for example treatment options (98%), common side effects of treatment (99%), information relating to the goals of treatment such as the chance that the treatment will

improve symptoms (96%). Most patients also wanted to know about uncommon treatment side effects (91%), and both common (97%) and uncommon symptoms of the cancer (88%; Table 2).

More specifically, 91% of participants wanted to know about less common symptoms and treatment side effects (ie, those that could occur in 10 of 100 patients). More than one third (38%) wanted information about very rare symptoms or side effects (ie, those that could occur in 5 of 1,000 patients), and 36% wanted to know about those that occurred in 1 of 1,000 patients. The most common reason cited by patients for wanting to know details of uncommon side effects and symptoms was to enable them to make treatment decisions and prepare for the future.

The majority also desired information items about survival duration. Information that could be perceived as more positive—for example, “the chance of living 5 years” (80%), “the average length of time I would be likely to live” (81%) and “the *longest* survival without treatment” (76%) was desired by slightly more patients than less positive information—for example, 1-year survival rates (65%) and the shortest survival without treatment (72%).

The most common reason patients cited for preferring not to receive survival information was that this information would not be useful because it could not be accurately predicted.

### Preference for Format

Words and numbers were preferred over visual presentations such as pie charts or graphs and were deemed easier to understand (See Table 3). Ratings of preference and ease of understanding for each format were found to be significantly and positively correlated at the  $P = .01$  significance level (words:  $R = 0.6$ ; percentages:  $R = 0.6$ ; fractions:  $R = 0.5$ ; 100 person diagram:  $R = 0.5$ ; pie chart:  $R = 0.5$ ; survival graph:  $R = 0.6$ ).

Patients commented: “Words and numbers seem more optimistic and less clinical”; “I think words are not as harsh—even though you have to face up to the inevitable—words don’t seem to be so final; [they] give hope!”; “Charts and numbers are too dogmatic; they do not necessarily relate to my specific problem.”

### When to Discuss and Who Should Initiate the Discussion

The majority indicated that they wanted to discuss treatment goals and options (84%), and symptoms and side effects (81%) when “first diagnosed” with metastatic disease and also for the specialist to “just tell them” this information (83% and 81%, respectively). Fewer wanted to be told how long they had to live (59%) when first diagnosed, and for the specialist to “just tell them” this (53%). One third wanted to discuss issues about dying and palliative care when first diagnosed with metastatic disease, and one third wanted to discuss these issues later; 45% wanted the



**Table 2.** Specific Prognostic Information Desired

Type of Prognostic Information	Want, % of Patients	Do Not Want, % of Patients	% Responding
Common side effects of treatment	99	1	96
Treatment options	98	2	97
Common symptoms from the cancer	97	3	96
Chance that the treatment will improve symptoms	96	4	96
Uncommon symptoms from the cancer	88	12	94
Chances of treatment shrinking the cancer	95	5	98
Likely time you will be without symptoms	92	8	93
Factors which make my prognosis better or worse than average	92	8	94
Uncommon treatment side effects	91	9	94
The longest time you might live, if treatment worked as well as could be expected	85	15	94
Average length of time you would be likely to live	81	19	95
The chance of living 5 years	80	20	92
Chance of living 1 year	65	35	91
The longest time you might live without treatment	76	24	94
The shortest time you might live without treatment	72	28	94

specialist to raise these issues. A minority of patients (11%) preferred never to discuss dying and palliative care or were unsure (10%). However, many patients wanted the specialist to check first if they wanted to discuss expected survival (17%) and dying and palliative care (20%) or indicated that they only wanted the information if they asked (21% for survival and 24% for dying and palliative care, respectively; Table 4).

### Predictors of Patient Preferences

Several key variables emerged in multivariate analyses as predictors of preference for content, format, and when and how to initiate discussions of prognosis.

**Content.** Patients with higher depression scores were more likely to want to know average survival ( $P = .049$ ) and the shortest time to live without treatment ( $P = .047$ ). Those with an expected survival of weeks or months (as opposed to months to years or years;  $P = .047$ ) and those who had higher HADS anxiety scores ( $P = .02$ ) were less likely to want to know the chance of living 1 year. Those

with higher scores on the HADS anxiety and Krantz involvement preference scales were more likely to want to know the longest time to live without treatment ( $P = .009$  and  $P = .04$ , respectively; Table 5).

**Format.** In terms of preference for format, participants of Anglo-Saxon background were more likely to want words ( $P = .005$ ). Older patients were more likely to prefer the 100-person diagram ( $P = .03$ ). Those with higher scores on the Krantz involvement preference scale were more likely to dislike the pie chart ( $P = .005$ ), whereas those who had more than 12 years of school education were more likely to prefer this format ( $P = .02$ ; Table 6).

**When and how to initiate prognostic discussions.** Due to the occurrence of singularity in the Hessian matrix in the multinomial logistic regression of "when to discuss how long to live," two separate binary logistic regressions were executed with outcome variables coded as "immediately/never" and "immediately or later/never." Patients who were less depressed were more likely to want to never (as opposed to

**Table 3.** Format of Statistics: Rated Ease of Understanding and Preference

	% of Patients					
	Words	Percentages	Fraction	100-Person Diagram	Pie Chart	Graph
Ease of understanding						
Easy	67	65	69	56	60	40
Difficult	11	10	12	23	10	31
Neutral	14	14	11	8	18	13
Responded	92	89	89	87	88	83
Preference						
Like	47	42	40	25	28	21
Dislike	17	17	28	48	48	53
Neutral	17	18	11	8	4	8
Responded	81	77	79	81	80	82

**Table 4.** Negotiation of Prognostic Discussion

Type of Prognostic Information	% of Patients			
	Treatment Goals and Options	Symptoms and Treatment Side Effects	Likely Duration of Survival	Dying or Palliative Care Services
When to discuss				
When first told cancer has spread	84	81	59	33
Next few consultations	21	23	15	19
Later, upon my request	9	9	22	33
Never	1	1	12	11
Unsure	1	2	7	10
Responded	99	98	91	87
Who to initiate discussion				
Specialist just to tell	83	81	53	45
Specialist to check first if want to know	15	14	17	20
Specialist to tell only if I ask	3	6	21	24
Not to discuss at all	0	0	9	2
Other	1	1	1	2
Responded	97	97	87	85

NOTE. Respondents were given the option to select more than one item.

immediately or later) discuss how long they had to live ( $P = .03$ ). Patients who were expected to survive for years (as opposed to weeks to months or months to years) were more likely to want to discuss how long to live when first diagnosed with metastatic disease ( $P = .02$ ).

With regard to when to discuss palliative care and dying, a multinomial regression was undertaken. Patients who had children were more likely to want to discuss these issues in later consultations than when first diagnosed with metastases or never ( $P = .02$ ; Table 7).

Patients with colorectal cancer ( $P = .02$ ) or prostate cancer ( $P = .04$ ; as opposed to those with breast cancer or other type of cancer) were more likely to want to have prognostic discussions negotiated as opposed to the specialist "just telling," them, and among these patients, there was a strong trend for younger patients to prefer this ( $P = .057$ ). Colorectal cancer patients were also more likely to want to negotiate the discussion of issues

about dying and palliative care ( $P = .02$ ; Table 7). No other predictors were identified

## DISCUSSION

In this survey of cancer patients with metastatic cancer, we found that the majority want detailed prognostic information. These findings support earlier studies of general information needs in cancer patients,<sup>23,24,26-29</sup> our earlier qualitative study of the prognostic information needs of patients with metastatic breast cancer patients,<sup>3</sup> and our quantitative study of early stage breast cancer patients.<sup>28</sup> However, our findings contrast with those of Kaplowitz et al,<sup>30</sup> who found that, although a large majority of patients wanted prognostic estimates using verbal descriptors, less than half wanted a quantitative estimate of survival. Although more patients in our sample wanted the more positive information (that implied either a long time frame or pertained to

**Table 5.** Results of Multivariate Analysis: Preference for Content of Prognostic Information

Outcome	Significant Variables	OR	P	95% CI
Average survival*	Depression	1.118	.049	1.001 to 1.382
Chance of living 1 year†	Expected survival (weeks/months)	0.115	.047	0.014 to 0.973
	Anxiety	1.170	.02	1.023 to 1.337
Shortest time to live without treatment‡	Depression	1.207	.047	1.014 to 1.437
Longest time to live without treatment§	Anxiety	1.224	.009	1.012 to 1.590
	Involvement preferences	1.268	.04	1.053 to 1.423

NOTE. Variables entered were those found to be significant at the 0.25 level in univariate analyses. Only outcomes found to have significant results in multivariate analyses are presented.

Abbreviation: OR, odds ratio.

\*Variables entered: expected survival, depression, involvement preferences.

†Variables entered: age, expected survival, time since first cancer diagnosis, cancer, anxiety.

‡Variables entered: children, language, depression, involvement preferences, cancer, time since diagnosis of metastases, expected survival.

§Variables entered: age, children, relationship status, time since first diagnosis, cancer, involvement preferences, anxiety.

**Table 6.** Results of Multivariate Analysis: Preference for Format of Prognostic Statistics

Format	Significant Variables	OR	P	95% CI
Words*	Parent's ethnicity (Anglo-Saxon)	0.167	.005	0.048 to 0.584
100-person diagram†	Age	1.04	.03	1.003 to 1.074
Pie chart‡	Involvement preferences	1.431	.005	0.108 to 0.853
	Education level (> 12 years)	1.431	.02	1.114 to 1.840

NOTE. Variables entered were those found to be significant at the 0.25 level in univariate analyses. Only outcomes found to have significant results in multivariate analyses are presented.

Abbreviation: OR, odds ratio.

\*Variables entered: age, parent's country of birth, treatment.

†Variables entered: age, education level.

‡Variables entered: age, relationship status, education level, parent's country of birth, cancer, involvement preferences.

positive outliers), more than 65% also wanted the less positive information (shortest survival without treatment and 1-year survival rates). The most common reasons cited for wanting the latter were that it would allow patients to prepare themselves and their families for the future and would assist with decision making and life planning, which reflect the findings of our previous qualitative study.<sup>3</sup> These results should reassure those Australian oncologists and members of the healthcare team who fear conveying poor prognostic information to their patients.

Although patients clearly want prognostic information, it is not always easy for doctors to accurately estimate prognosis. MacKillop and Quirt<sup>21</sup> determined the accuracy of oncologists' predictions of survival time of cancer patients. Although these oncologists' estimates of the probability of cure were accurate, and their predictions of the overall expected survival of incurable patients were well calibrated, their predictions for individual patients were imprecise. If the oncology community is to adequately respond to patient information needs, we will need to devise ways of improving both the accuracy of prognostic estimates and ways to communicate medical uncertainty to patients. The latter may be achieved by devising creative

ways to depict a range of values, such as pie and survival graphs with shaded areas around the line to indicate 95% CIs. Simply discussing the methods by which prognoses are formulated and acknowledging the uncertainty inherent in that process may be sufficient. However, there is a paucity of evidence regarding the impact of acknowledging medical uncertainty on patient outcomes; two studies outside oncology have produced conflicting results. (One found such acknowledgment led to a reduction in patient confidence, the other an increase in patient satisfaction, although there was considerable variability in responses.)<sup>37,38</sup>

However, although prognosis is often equated with survival time, patients in this study indicated a desire for broader information about their likely futures, including how the illness may affect their daily lives, with less emphasis placed on survival estimates. More than one third of patients in this survey wanted information about symptoms and side effects occurring in fewer than 5 of 1,000 patients, suggesting that these quality-of-life issues are very important to patients.

Furthermore, approximately 60% of the patients surveyed wanted information about expected survival when first informed of their metastatic diagnosis, with one half

**Table 7.** Results of Multivariate Analysis: Preference for When and How to Initiate Prognostic Discussions

Outcome	Significant variables	OR	P	95% CI
When to discuss how long to live (immediately v later or never)*	Expected survival (years)	6.656	.02	1.311 to 33.781
When to discuss how long to live (immediately/late v never)†	Depression	0.771	.03	0.612 to 0.971
How to initiate: how long to live (Specialist to just tell v check first)‡	Cancer (colorectal)	7.303	.02	1.384 to 38.543
	Cancer (prostate)	6.394	.04	1.142 to 35.814
When to discuss dying and palliative care (immediately v later v never)§	Children (yes)	0.124	.02	2.147E-02 to 0.712
How to initiate discussion of dying or palliative care (Specialist to just tell v check first)	Cancer (colorectal)	5.353	.02	1.459 to 23.560

NOTE. Variables entered were those found to be significant at the 0.25 level in univariate analyses. Only outcomes found to have significant results in multivariate analyses are presented.

Abbreviation: OR, odds ratio.

\*Variables entered: gender, expected survival, treatment.

†Variables entered: expected survival, involvement preferences, depression, time since diagnosis of metastatic disease, treatment.

‡Variables entered: age, gender, education level, expected survival, cancer, involvement preferences.

§Variables entered: expected survival, cancer, children, time since first diagnosis and depression.

||Variables entered: age, gender, children, education level, expected survival, cancer, depression, involvement preferences.

preferring either that the doctor “just to tell” him or her, rather than waiting for the patient to ask or negotiating what and when to tell. However, given that approximately 40% of patients indicated they wanted both information about life expectancy and dying and palliative care issues only if they asked for it or after negotiation, there remains a considerable challenge for the oncologist in knowing how to tailor information to the individual patient. Many doctors rely on their intuition to guide them in this; however, several studies have shown that doctors are not accurate in guessing patients’ preferences for information and involvement.<sup>39,40</sup> Open negotiation seems the preferred course. Given that the majority in our study wanted prognostic information as soon as metastatic disease was diagnosed, it may be helpful to begin negotiating what prognostic information to disclose and the preferred way to do so from the first consultation. Interestingly, patients indicated that they might prefer prognostic information discussed over several consultations, suggesting (understandably) that it may take some time for them to ready themselves to hear, understand, and adjust to this information—particularly for patients with shorter expected survival.

With regard to presenting statistical information, patients generally preferred words and numerical descriptors to graphical representations. Unlike the findings of Kaplowitz et al,<sup>30</sup> patients did not report a clear preference for either the perceived qualitative softness of words or the greater precision of numbers. Both were equally endorsed, with the majority of patients reporting a preference for both. One subgroup (participants of non-Anglo Saxon background), however, was significantly more likely to prefer numbers to words. Perhaps these patients were struggling with English-language deficiencies and found numbers more accessible. In this group particularly, it would be important to back up words with numbers or graphic representations where possible. Ratings for preference and ease of understanding of each format were found to be significantly associated; however, these correlations were not very high, suggesting that factors other than ease of understanding are influencing patients’ overall preferences for format of statistics.

The general dislike of graphic representations is concerning, given their growing inclusion in decision aids designed to improve patient understanding and involvement in treatment decisions. However, many patients in this study reported that they found the graphical representations the most difficult to understand, as well as cold, clinical, and confrontational. That many patients chose not to complete these questions could also be indicative of this. Are we doing harm in showing these to patients, or will they help patients over the long term to understand and come to terms with the information they represent? Further research is needed to clarify these issues.

Depression and anxiety were the strongest predictors overall for preferences for prognostic information. Patients

with higher depression or anxiety scores were more likely to want to discuss expected survival and wanted to know more prognostic information, particularly about more negative outcomes, such as death. Perhaps these patients feel more vulnerable to and worried about death. Notably, the difference in depression and anxiety scores between those who wanted prognostic facts and those who did not was small, so it would be difficult (and inappropriate) to use this as the deciding factor in determining whether or not to disclose prognosis. However, these results at least highlight the need for an awareness of and ability to address patients’ cognitions and emotions when discussing prognosis.

Patients with colorectal or prostate cancer were more likely to prefer their specialist tell them their expected survival and issues regarding dying and palliative care only after negotiation. It is possible that this group is less politicized than patients with other cancers. Breast cancer lobby groups are now very active in Australia, and individual patients with this condition may be more likely to be informed and to have an expectation that prognostic information is provided to allow informed decision-making.

### **Limitations of the Study and Summary**

An important issue in surveys of this nature that attempt to describe the prevalence of views is the potential bias in the sample. Although 30 oncologists took part in this study, 106 were invited to participate. It is possible that the participating oncologists were biased by their interest in communication issues. This interest may influence their interaction with their patients, which may have subsequently biased the patient responses in this study. When we compared those oncologists who actively refused to participate with those who accepted, no demographic or practice differences were observed. However, no data were available on oncologists who did not respond at all. Furthermore, more subtle differences (such as interest in communication) that we did not measure may have differentiated participants from nonparticipants, so this remains a concern.

Oncologists were asked to invite consecutive patients who fulfilled the eligibility criteria; however, not all oncologists may have complied with this instruction. They may have invited patients who felt more comfortable with their diagnosis or who were less symptomatic, although the oncologists did not report using these criteria to determine participation. The majority of patients in this sample were on “anticancer” therapy. However, this is characteristic of outpatient oncology patients with a recent diagnosis of metastases.<sup>20,21,41-43</sup> In Australia, there is no obstacle to patients’ receiving palliative or hospice care while receiving anticancer treatment, unlike the situation in the United States. We were unable to gather data on nonparticipants regarding expected survival or treatment received, because of concerns expressed by the ethical review boards to which



the protocol was submitted. Therefore, we were unable to assess bias in the sample on these variables.

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, these were similar to levels of anxiety and depression reported in a sample of 159 patients with advanced disease recruited in a large English study with only a 4% refusal rate,<sup>34</sup> which suggests that we did not have a particularly psychologically resilient sample.

Patients were invited to participate between 6 weeks and 6 months since their diagnosis of metastatic cancer. As stated earlier, this timing was chosen on ethical grounds to avoid distress in newly diagnosed patients and to allow patients time to reflect on the whole experience when providing responses. However, it is possible that participants' responses were influenced by the discussions they had with their oncologists about prognosis during this time period and that these responses would have been different had the patients been surveyed when they were first diagnosed. We have no data on participants' actual prognostic discussions. Time since diagnosis was not significantly associated with any of the preferences elicited in the current study, suggesting that preferences are stable at least after 6 weeks. Furthermore, nearly 50% in our sample stated that they preferred expected survival to be discussed some time after their diagnosis of metastases, suggesting that the survey timing was appropriate. We are following up with patients 6 months later to determine whether their situation and preferences have changed; however, these data are not yet complete. Future research might usefully explore differences between immediate and later preferences.

Participants were predominantly (85%) of Anglo-Saxon background, and most (91%) spoke English at home; they are, therefore, not representative of Australia's cultur-

ally diverse population. Many cultures have been found to have particular communication preferences and needs,<sup>44-48</sup> and future studies could usefully explore their specific preferences for prognostic information.

It still remains uncertain who the patients are who want particular information at particular times. Although some predictors of preferences in multivariate models were identified, none were found to explain a large amount of the variance, suggesting that there are factors other than those examined here that influence patient prognostic information preferences. A larger sample size would have perhaps allowed for detection of more predictors.

Nonetheless, this study has provided an important step toward improving the discussion of prognosis with metastatic cancer patients, which is a difficult and sensitive process for both clinicians and patients. We have specifically identified what these patients want to be told and how and when they want to hear it.

It seems from these and other data that prognostic communication is highly complex and that interventions are needed to facilitate this process. One possible intervention is a question-prompt list; these have been found by our group to significantly increase patient question-asking about prognosis while significantly decreasing anxiety levels if endorsed by the clinician.<sup>49-51</sup>

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## Authors' Disclosures of Potential Conflicts of Interest

The authors indicated no potential conflicts of interest.

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