

What Are Terminally Ill Cancer Patients Told About Their Expected Deaths? A Study of Cancer Physicians' Self-Reports of Prognosis Disclosure

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A B S T R A C T

Purpose

Little is known about how physicians discuss prognosis with terminally ill cancer patients. Thus, we sought to obtain cancer physicians' self-reports of their prognosis communication practices.

Methods

A survey seeking self-reports regarding prognosis communication with their terminally ill cancer patients was mailed to a systematic sample of medical oncologists in the United States.

Results

Of 1,137 physicians, 729 completed and returned surveys (64% response rate). Median age of respondents was 51 years (range, 33 to 80 years); 82% were men. Respondents had practiced cancer care for a median of 18 years (range, 1.5 to 50 years) and reported seeing a median of 60 patients per week (range, 0 to 250 patients per week). Although 98% said their usual practice is to tell terminally ill patients that they will die, 48% specifically described communicating terminal prognoses to patients only when specific preferences for prognosis information were expressed. Forty-three percent said they always or usually communicate a medical estimate of time as to when death is likely to occur, and 57% reported sometimes, rarely, or never giving a time frame. Seventy-three percent said prognosis communication education was either absent or inadequate during their training, and 96% believed it should be part of cancer care training.

Conclusion

Medical oncologists report routinely informing their terminally ill patients that they will die. However, they are divided in describing themselves as either always discussing a terminal prognosis or doing so if it is consistent with their patients' preferences for prognostic information. Most medical oncologists say they do not routinely communicate an estimated survival time to their patients.

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INTRODUCTION

For terminally ill patients, understanding of an eventually fatal prognosis is viewed as beneficial and allows them to make an informed health care decision.¹⁻³ Patient knowledge of prognosis is significantly associated with appropriate treatment choices.^{4,5} Acknowledgment of a terminal prognosis is also known to help many patients and physicians better manage the death process and has been associated with less emotional patient distress.^{6,7} In addition, withholding prognostic information to those who are terminally ill is deemed ethically unacceptable—even being viewed as a form of deception.^{8,9} Despite this information, problems persist regarding how prognosis information should be disclosed to terminally ill patients, and many physicians have been described as hesitant to communicate prognoses to the terminally ill.^{6,10}

Given that the majority of cancer-related deaths typically occur with some amount of anticipation, with median survival times of 9 to 12 months having been described for many advanced or terminally ill cancer patient populations,^{11,12} there would seem to be sufficient opportunities for meaningful physician disclosure of a terminal prognosis to take place with such patients. Despite these opportunities, many advanced cancer patients have been described as having an inadequate understanding of the likelihood of their deaths, generally overestimating the probability of their long-term survival and maintaining unrealistic therapeutic expectations.^{4,13-16}

Early research in cancer care communication documented great physician reluctance to disclose a cancer diagnosis and virtually no willingness to discuss prognosis.¹⁷⁻²² Although disclosure of cancer diagnoses to patients has been the well-recognized norm since the late 1970s,²³ more recent studies

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have described physicians as specifically withholding prognostic information.²⁴⁻²⁹ Physicians seem to be reluctant to disclose grim prognostic information for the same reasons they had traditionally withheld a diagnosis, fearing that such information would psychologically damage patients' hopes to survive.^{22,30-31} Physician inaccuracies in providing prognostic estimates to their terminally ill patients likely add to the significance of this reluctance.^{6,32-34} Despite these data, there remains insufficient research examining the broader community of cancer physicians and their practices and attitudes toward prognosis communication with terminally ill patients.

METHODS

Participants

University of Chicago Biological Science Division Institutional Review Board approval was obtained before initiation of this survey study. Participants were selected from the 2004 American Society of Clinical Oncology Membership Directory.³⁵ Given our interest in American medical oncologists' communication practices, only the 9,639 physician members who listed their specialty as including medical oncology and who had US mailing addresses were considered eligible participants. Seeking to create a representative sample (10% to 15%) of these oncologists, we started with a random entry within the alphabetical directory listings and systematically selected every eighth member who listed his or her specialty as including medical oncology. This identified 1,275 survey participants with sufficient addresses for survey mailings.

Survey Mailing(s)

A survey prenotification letter was mailed to the eligible participants. Through prenotification mailings, 138 physicians were eliminated as a result of incorrect mailing addresses or because physicians were no longer clinically active. This yielded a final sample of 1,137 survey participants. Two weeks after the prenotification letter, a self-addressed survey was mailed with a \$25 gift card (from Barnes and Noble Booksellers, New York, NY) as an honorarium to the participants. A second set of surveys was sent to nonresponders.

Survey Instrument

The survey instrument was developed by the investigators. The survey was based on published research regarding physician communication of terminal prognoses to cancer patients,^{19,23} and the investigators' prior qualitative work studying cancer physician-patient communication of terminal prognoses.²⁸ Survey participants were specifically asked to respond to questions within the context of clinical encounters with their own patients "where death is expected within 6 to 12 months." The survey included 10 questions, using both quantitative (closed-ended questions) and semiquantitative (open-ended questions asking for short, hand-written responses) items. (Please see *Journal of Clinical Oncology*—supplied appendix [online only] for the survey instrument.) The survey sought demographic information about participants' age, sex, religious affiliation, practice environment, years since completion of formal training, and estimated number of cancer patients seen per week in clinical practice. Quantitative survey items asked participants to select the single responses that best described their usual practices, frequencies, and format of communication with patients and/or family members regarding a terminal prognosis. Participants were also surveyed about their educational experiences in prognosis communication. Additionally, participants were queried about their own and their (perceived) patients' satisfaction with their prognosis communication practices. Although not reported here, participants were also asked to give semiquantitative (short answer) responses to three questions regarding clinical factors affecting their communication and their own emotional responses to communicating terminal prognoses.

Survey questions were printed on both sides of a sheet of cardstock and mailed with a cover letter explaining the purpose of the study and how to return the survey. The survey was designed to be folded in thirds, sealed with an adhesive strip, and mailed back to study investigators.

Statistical Analyses

All survey data were coded and entered into a database using standard statistical software (STATA, Release 9.0; STATA Corp, College Station, TX). Missing responses, responses that did not fit into one of the specific item responses, and items for which participants provided more than one response were all considered missing values. Descriptive statistics are reported as proportions. To test for an association between demographic variables (eg, sex) and continuous survey responses, two-sample *t* tests were performed. To test for an association between demographic variables and ordinal survey responses, Mann-Whitney *U* tests were performed. To test for an association between years since completing formal training and continuous variables, Pearson's correlation coefficient was calculated and tested for equivalence to zero. Spearman's correlation coefficient was calculated and tested for equivalence to zero to test for an association between years since completing formal training and the ordinal variables. Where noted, univariate and multivariate logistic regression modeling was performed.

RESULTS

The two survey mailings were completed between November 2004 and April 2005. Seven hundred twenty-nine completed surveys were returned, for a final survey response rate of 64%.

Demographic Data

Demographic characteristics of respondents are listed in Table 1. The median age of responding oncologists was 51 years. Eighty-two percent were male. Respondents had completed training a median of 18 years ago and saw a median of 60 patients per week in clinical practice.

Self-Described Prognosis Disclosure Practices

Respondents were asked about their usual practice of telling their terminally ill patients they have a life-ending disease that will eventually cause their death. Selecting from a dichotomous option, 98% of oncologists stated, "I tell them" they will die of their disease, and 2% responded, "I do not tell them."

Additionally, choosing from four possible responses, participants were asked to select which single item best summarized his or her communications with advanced cancer patients about a terminal prognosis. Results are listed in Table 2. Respondents were relatively evenly divided between saying they "always discuss their patients' prognosis because they need to know it" (42%) and either saying they "ask their patients if they want to know their prognosis and discuss it if they say yes" or "only discuss it if the patients ask about it" (total of 48% for these latter two responses).

Participants were asked how often they give their terminally ill patients a specific time frame, or medical estimate of the amount of time, as to when death is likely to occur. Results to this question are shown in Figure 1A. Overall, 43% reported "always" or "usually" providing a prognostic time frame or medical estimate of time until death, and 57% reported "sometimes," "rarely," or "never" giving a time frame.

Participants were queried about whether, in situations in which they do not communicate a prognosis to a patient, they tell the patient's spouse, relative, or close friend of the terminal prognosis. Results are shown in Figure 1B, with respondents reporting they tell a spouse/relative/close friend either "always" or "usually" approximately 60% of the time in such instances.

Table 1. Demographic Characteristics of Survey Respondents

| Characteristic | No. of Respondents* (N = 729) | % |
|--|-------------------------------|-----|
| Age, years | | |
| Median | 51 | |
| Mean | 50 | |
| Range | 33-80 | |
| Missing | 19 | |
| Sex | | |
| Male | 585 | 82 |
| Women | 129 | 18 |
| Missing | 15 | |
| Years since completion of formal training | | |
| Median | 18 | |
| Mean | 17.75 | |
| Range | 1.5-50 | |
| Missing | 20 | |
| Patients per week | | |
| Median | 60 | |
| Mean | 59 | |
| Range | 0-250 | |
| Missing | 29 | |
| Practice environment | | |
| Private group | 154 | 62 |
| Medical school | 94 | 38 |
| Private solo | 1 | 1 |
| Other | 3 | 0.5 |
| Missing | 32 | |
| Religion | | |
| Protestant | 183 | 26 |
| Catholic | 162 | 23 |
| Jewish | 159 | 22 |
| Hindu | 34 | 5 |
| Muslim | 23 | 3 |
| Other | 75 | 11 |
| Not applicable | 6 | 1 |
| Missing | 20 | |

Table 2. Responses to the Following Survey Question: Of the Following Examples, Choose Which One Best Summarizes Your Communications With Your Advanced Cancer Patients About Their Prognosis? (n = 710)

| Survey Item | No. of Respondents | % |
|---|--------------------|-----|
| I do not discuss prognosis with my patients | 3 | 0.4 |
| I discuss it if my patients ask about it | 115 | 16 |
| I ask my patients if they want to know their prognosis and discuss it if they say yes | 236 | 33 |
| I always discuss my patients' prognoses with them because they need to know it | 303 | 42 |
| Other | 65 | 9 |
| Missing | 7 | |

reported undergoing prior prognosis communication education, 56% indicated that this training occurred during residency, 27% reported being taught communication practices during subspecialty fellowship training, 23% had communications training as a part of a continuing medical education activity, and 8% indicated that such training occurred in medical school. An additional 10% said their education in prognosis communication occurred in some other unspecified setting. Of those who stated they had communication instruction, 27% described this prior teaching as inadequate. Overall, 96% reported believing that such education should be part of cancer care training.

Factors Associated With Cancer Physician Self-Reports of Prognosis Communication

Univariate models were developed for survey question responses using the following covariates: survey participants' age (per 10 years), number of years since completing medical training (per 10 years), self-reported number of patients cared for each week (dichotomized between those seeing ≥ 60 patients per week and those seeing less), female sex, whether they reported having prior training in prognosis communication, whether in solo private practice, and religion (Christian, Jewish, or other). Multivariate models were developed by including variables with $P \leq .10$ from these models. Variables were dropped from the final multivariate model if $P \geq .05$. Because of the strong (and expected) correlation between respondents' age and years since completing training, only data regarding associations with age are reported.

Univariate analysis reveals that physicians who reported not wanting to know their own prognosis (if faced with advanced cancer) were more likely to report not telling their patients that their disease will result in death (odds ratio [OR] = 0.76; 95% CI, 0.064 to 0.92; $P = .004$). Physicians in solo private practice were also more likely to report not telling their patients that they had life-ending disease (OR = 0.11; 95% CI, 0.037 to 0.30; $P < .001$).

As shown in Table 3, results from multivariate analysis reveal that older age (OR = 0.76; 95% CI, 0.64 to 0.92; $P = .004$) and being Jewish (OR = 0.59; 95% CI, 0.38 to 0.91; $P = .018$) were associated with being less likely to report communicating to patients a medical estimate, or time frame, as to when death would occur. Alternatively, physicians wanting to know their own prognostic time frame if faced with advanced cancer were much more likely to report "always" or "usually" communicating such a time frame to their patients (OR = 5.82; 95% CI, 3.65 to 9.27; $P < .001$).

Table 4 shows that younger age, number of patients per week, and wanting to know their own prognosis if they (the physicians) had advanced cancer were all associated with respondents' self-reports of

Physicians' Desire to Know Their Own Prognoses if Diagnosed With Terminal Cancer

One survey item queried oncologists' reported desires to know their own prognosis if they were diagnosed with advanced cancer, including a medical estimate of time until death. Results are shown in Figure 1C. Seventy-four percent responded "yes," they would wish to be told their prognosis—including a medical estimate or time frame as to when death would be expected.

Physician Satisfaction With Communication Practices

Oncologists were queried about how often they were satisfied with their own communication practices in discussing prognoses with their terminally ill patients. They were also queried about how often they believe their patients are satisfied with these communications. Results to these two questions are shown in Figure 1D. Respondents were "always" or "usually" satisfied with their own communication practices more than 90% of the time and believed their patients were "always/usually" satisfied in equal amounts.

Prior Education in Prognosis Communication

Fifty-eight percent of participants reported that they had no formal education in prognosis communication. Of the 42% who

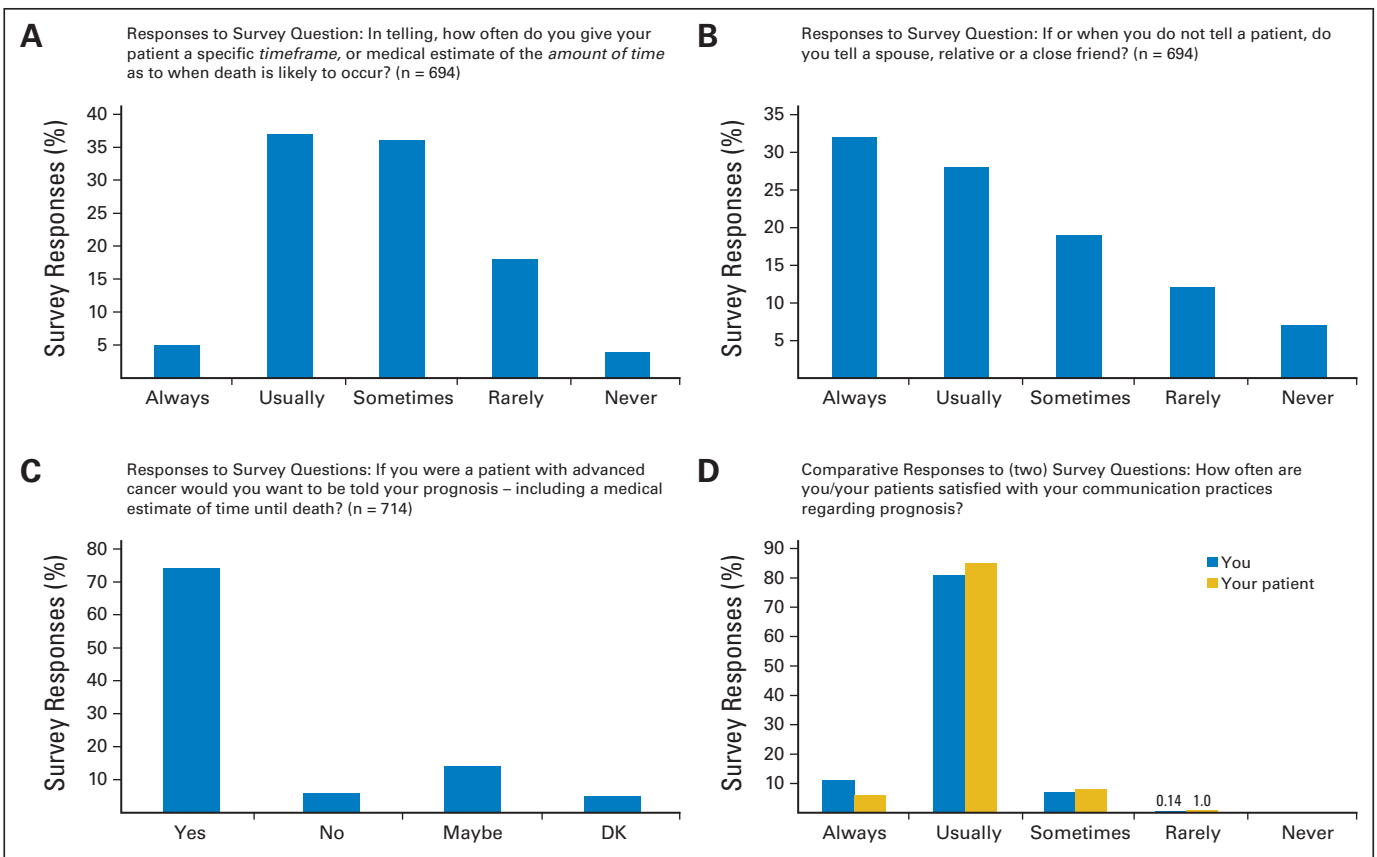


Fig 1. (A) Responses to the following survey question: “In telling, how often do you give your patient a specific *timeframe*, or medical estimate of the *amount of time* as to when death is likely to occur?” (n = 694). (B) Responses to the following survey question: “If or when you do not tell a patient, do you tell a spouse, relative or a close friend?” (n = 694). (C) Responses to the following survey question: “If you were a patient with advanced cancer, would you want to be told your prognosis – including a medical estimate of time until death?” (n = 714). (D) Comparative responses to two survey questions: “How often are you/your patients satisfied with your communication practices regarding prognosis?”

“I always discuss my patients’ prognoses with them because they need to know it.” Multivariate analysis data in Table 5 reveal that younger age and seeing more than 60 patients per week were associated with being more likely to report disclosing prognostic information to family or friends when it is not disclosed to the patient.

Additional multivariate analysis revealed that older age was associated with physicians being more likely to report being always or usually satisfied with their communications (OR = 1.5; 95% CI, 1.09 to 2.21; *P* = .015). Being Jewish was associated with being less likely to report being always or usually satisfied with their own communication

practices (OR = 0.38; 95% CI, 0.20 to 0.74; *P* = .004). There was a significant association between respondents’ satisfaction with their own communication practices and their views of their patients’ satisfaction (*P* < .001).

DISCUSSION

We believe that one of the most significant findings of this study are the data of cancer physicians describing themselves as routinely telling

Table 3. Multivariate Models: ORs of Physician Always/Usually Communicating Medical Estimate of Time Until Death (n = 673)

| Variable | OR | 95% CI | <i>P</i> |
|----------------------------------|-----------|--------------|----------|
| Age, per 10 years | 0.76 | 0.64 to 0.92 | .004 |
| Would want to know own prognosis | 5.82 | 3.65 to 9.27 | < .001 |
| Religion | | | |
| Christian | Reference | | |
| Jewish | 0.59 | 0.38 to 0.91 | .018 |
| Other | 0.96 | 0.62 to 1.46 | .83 |
| Not applicable | 1.11 | 0.62 to 2.00 | .72 |

Abbreviation: OR, odds ratio from logistic regression model.

Table 4. Multivariate Models: ORs of Physician Always Discussing Prognosis or Discussing Prognosis After Asking Patient if They Want to Know Prognosis (n = 671)

| Variable | OR | 95% CI | <i>P</i> |
|----------------------------------|-----------|--------------|----------|
| Age, per 10 years | 0.75 | 0.61 to 0.92 | .007 |
| No. of patients seen (≥ 60) | 1.53 | 1.05 to 2.21 | .026 |
| Would want to know own prognosis | 3.04 | 2.06 to 4.51 | < .001 |
| Religion | | | |
| Christian | Reference | | |
| Jewish | 0.59 | 0.37 to 0.92 | .020 |
| Other | 0.86 | 0.52 to 1.43 | .57 |
| Not applicable | 1.07 | 0.53 to 2.14 | .85 |

Abbreviation: OR, odds ratio from logistic regression model.

Table 5. Multivariate Models: ORs of Physician Always/Usually Communicating Prognosis to Spouse, Relative, or Close Friend When Prognosis Was Not Communicated to Patient (n = 658)

| Variable | OR | 95% CI | P |
|-----------------------------------|------|--------------|--------|
| Age, per 10 years | 1.57 | 1.30 to 1.90 | < .001 |
| No. of patients seen (\geq 60) | 1.51 | 1.10 to 2.08 | .011 |

Abbreviation: OR, odds ratio from logistic regression model.

their terminally ill patients they will eventually die of their disease (even when a patient's prognosis involves as much as 1 year of estimated time left to live). However, although relatively uniform in respect to their self-reports of disclosing eventual death, physicians were relatively divided in their reports as to whether they provide a specific estimate about the amount of time they believe their patients may have to live. Also of note was the fact that, although a substantial number of physicians described themselves as eliciting and respecting a patient's preferences for prognostic information, many physicians (approximately 40%) reported that patients should always know their prognoses, presumably even if it goes against patients' preferences for this information. Perhaps crucial to understanding why physicians believe they should disclose a terminal prognosis, potentially even in the face of a patient's expressed preferences to not know his or her prognosis, are data analyses revealing that medical oncologists' own preferences for an estimate of time left to live if they had terminal cancer were strongly associated with self-reports of providing prognostic estimates or time frames to patients. Thus, physicians' own personal preferences for prognostic information may influence prognosis communication even to patients who may not want to know their prognosis. Specific demographic characteristics (eg, older age, being Jewish) may also influence communication practices. In addition, clinical factors seem to potentially influence communication practices because busier physicians were more likely to report more direct (if not forceful) prognosis communication with their terminally ill patients.

Limited data suggest that most advanced cancer patients desire at least some information about their prognoses,³⁶ and our data describe oncologists as disclosing to the majority of their terminally ill patients that they will die. This would seem to contradict the wealth of data that describe many advanced cancer patients as not understanding their prognoses. This apparent contradiction may be better understood by recognizing the potential differences between what physicians believe they are disclosing and how patients actually understand this information. In addition, it should be noted that there is considerable variability in described patient preferences regarding the extent, format, and timing of this information,³⁶ and at least one study has suggested that, as patients get closer to the end of their lives, their preference for prognostic information declines.³⁷ In the end, further research is needed to examine how closely matched individual physician practices regarding prognosis communication are to actual patient preferences.

Peretti-Watel et al³⁸ have similarly attempted to examine issues of prognosis communication in the setting of terminal illness, reporting the self-described prognosis communication patterns of more than 900 French physicians (including general practitioners, neurologists, and oncologists). However, this study only included 217 oncologists.

Interestingly, the vast majority of these French physicians did not describe themselves as routinely communicating terminal prognoses to their patients, and nearly 70% said they would only do so if the patient explicitly asked for such information (compared with 16% in our study). In the United States, other research by Christakis and Iwashyna³⁹ specifically examined prognosis formulation practices of physicians but only examined the self-reports of general internists and did not provide data regarding what information was communicated to patients. A study by Lamont and Christakis²⁹ also sought physicians' self-reports of prognosis disclosure. However, in contrast to our study, their study only included 75 cancer subspecialists and only queried physicians about prognosis disclosure to a specific subgroup of the terminally ill (those already enrolled in hospice care).

Our data may have direct relevance to decisions for end-of-life care in the United States. For example, Christakis⁶ and Christakis and Escarce⁴⁰ have described physicians' inability to accurately formulate and communicate a prognostic time frame as an obstacle to hospice care referral. Our data describe cancer physicians as believing that they are communicating to their terminally ill patients at least the terminal nature of their patients' disease, even if the group as a whole is divided as to whether they communicate an actual prognostic time frame. Given that terminally ill cancer patients are referred to hospice care relatively late in their disease course (or not at all),⁴⁰⁻⁴² it may be reasonable to consider policies directed at making palliative care services, such as hospice, available to patients at a time when physicians first recognize that death is inevitable, rather than waiting for such services to only be provided to a subset of patients for whom a specific medical estimate of time left to live (eg, 6 months as currently required by the Medicare hospice benefit) has been communicated to patients and/or formulated by their physicians.

Several limitations to this study exist. First, the results describe physicians' self-reports of prognosis communication practices and cannot be relied on to represent what occurs within actual clinical encounters. Also, the data cannot be relied on to reflect what prognosis information terminally ill cancer patients themselves hear or understand within such encounters. In addition, the participant population studied was exclusively medical oncologists with US mailing addresses from a subspecialty professional directory. Thus, these data cannot be relied on to reflect communication practices of other physicians (eg, palliative care or primary care physicians) who care for terminally ill cancer patients both in the United States and elsewhere.

In conclusion, virtually all medical oncologists report telling their advanced cancer patients they will die of their disease. When cancer physicians do not tell their patients of their terminal prognoses, they frequently tell family or friends. Although most medical oncologists report not providing specific prognostic time frames or medical estimates of time left to live to their patients, most report wanting such a time frame communicated if they were faced with life-ending disease themselves. The vast majority of medical oncologists report that they are satisfied with their communication practices and believe their patients are satisfied as well. They also report either no prior training in prognosis communication or that their prior training was inadequate. Ultimately, US medical oncologists describe their communication practices as divided between either respecting their terminally ill patients' (perceived or elicited) preferences for prognostic information

or providing such information because they believe their patients need to know their prognoses.

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