

How Do Blood Cancer Doctors Discuss Prognosis? Findings from a National Survey of Hematologic Oncologists

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Abstract

Background: Although blood cancers are accompanied by a high level of prognostic uncertainty, little is known about when and how hematologic oncologists discuss prognosis.

Objectives: Characterize reported practices and predictors of prognostic discussions for a cohort of hematologic oncologists.

Design: Cross-sectional mailed survey in 2015.

Setting/Subjects: U.S.-based hematologic oncologists providing clinical care for adult patients with blood cancers.

Measurements: We conducted univariable and multivariable analyses assessing the association of clinician characteristics with reported frequency of initiation of prognostic discussions, type of terminology used, and whether prognosis is readdressed.

Results: We received 349 surveys (response rate=57.3%). The majority of respondents (60.3%) reported conducting prognostic discussions with “most” (>95%) of their patients. More than half (56.8%) preferred general/qualitative rather than specific/numeric terms when discussing prognosis. Although 91.3% reported that they typically first initiate prognostic discussions at diagnosis, 17.7% reported routinely never readdressing prognosis or waiting until death is imminent to revisit the topic. Hematologic oncologists with ≤15 years since medical school graduation (odds ratio [OR] 0.51; confidence interval (95% CI) 0.30–0.88) and those who considered prognostic uncertainty a barrier to quality end-of-life care (OR 0.57; 95% CI 0.35–0.90) had significantly lower odds of discussing prognosis with “most” patients.

Conclusions: Although the majority of hematologic oncologists reported discussing prognosis with their patients, most prefer general/qualitative terms. Moreover, even though prognosis evolves during the disease course, nearly one in five reported never readdressing prognosis or only doing so near death. These findings suggest the need for structured interventions to improve prognostic communication for patients with blood cancers.

Keywords: communication; hematologic neoplasms; prognosis; terminal care

Introduction

THERE IS GROWING EVIDENCE that individuals with cancer want their physicians to discuss prognosis early and often, and desire a numerical estimate of life expectancy.^{1–4} Additionally, although oncologists express concerns about

causing emotional distress, candid prognostic discussions do not seem to cause hopelessness, depression, or negatively affect the patient–physician relationship.^{5–8} Despite these studies, oncologists often exhibit reluctance in communicating prognosis.^{5,9} Delayed prognostic conversations contribute to misunderstanding between patients and oncologists

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regarding the severity of disease.¹⁰ This can hinder patients' wishes to play an active, informed role in choosing between disease-targeted or palliative treatment.^{11–13}

Given the longstanding challenge of prognostic uncertainty for blood cancers, hematologic oncology presents an instructive perspective on this discordance between evidence and practice. As early as the late 1980s, combination chemotherapy was found to cure even advanced cases of some lymphomas,¹⁴ and hematopoietic cell transplant (HCT) offers the potential for cure even for relapsed or refractory blood cancers.¹⁵ The continued possibility of long-term survival, including in those with advanced disease, consequently makes it difficult for hematologic oncologists to define the end-of-life (EOL) phase in patients with blood cancers.¹⁶ This difficulty in prognostication has been suggested to contribute to the higher rates of intensive, cancer-directed care at the EOL among patients with hematologic cancers compared to those with solid malignancies.^{17–19} Clear prognostic communication, even when uncertain, is arguably foundational for meaningful goals-of-care conversations.²⁰ Despite this, there are minimal data regarding when and how hematologic oncologists discuss prognosis.

Given that patients rely primarily on their oncologists to initiate prognostic conversations,²¹ we analyzed data from a national survey of hematologic oncologists to characterize physicians' self-reported approaches to prognostic discussions in terms of both timing and language preference. We hypothesized that overall, hematologic oncologists would prefer general/qualitative rather than specific/numeric terms, and that a sizable percentage would report either never addressing prognosis or not routinely readdressing it during the disease course.

Methods

Survey development

In 2015, we conducted a mailed survey of U.S.-based hematologic oncologists treating adult patients with blood cancers. The study team developed a 30-item survey instrument to elucidate perspectives and practices of hematologic oncologists with regard to EOL care for patients with blood cancers. The survey was developed based on review of existing literature, adaptation of previously published surveys,^{22–25} and data from focus groups of hematologic oncologists ($n = 20$).¹⁶ We conducted cognitive interviewing and testing of the survey with five hematologic oncologists. Specifically, we adapted questions regarding timing for prognostic discussions from a published survey.²³

Study population

To identify potentially eligible respondents, we employed the publicly available clinical directory of the American Society of Hematology (ASH). This web-based directory includes the names, practice addresses, and telephone numbers for physicians who treat patients with benign and/or malignant hematologic conditions and who are accepting new patients. We placed screening phone calls to the offices of all adult hematologic oncologists to confirm participant eligibility (e.g., "Does Doctor X take care of blood cancer patients?") and to verify the physician's mailing address. Concomitant care of patients with solid malignancies was not

an exclusion criterion. We confirmed mailing addresses for 1512 potentially eligible hematologic oncologists (Supplementary Fig. S1).

Sample size determination

We calculated the sample size based on the survey's primary outcome, which was the proportion of hematologic oncologists reporting an EOL quality measure to be acceptable. We estimated that we would need 400 returned surveys to report proportions within $\pm 5\%$ at a 95% confidence level. To account for a potential nonresponse rate of 40%, we thus administered the survey to 667 hematologic oncologists selected by simple random sampling. The findings from the survey's primary outcome have been previously reported.²⁶

Data collection

We administered our survey between September 2014 and January 2015 to a simple random sample of 667 eligible hematologic oncologists generated using SAS version 9.4 (Cary, NC). These physicians received an initial mailing through Federal Express containing a cover letter, the survey instrument, an opt-out card, a prepaid return envelope, and a preactivated \$25 American Express gift card. Participants could complete the survey online. We sent two postcard reminders at two and four weeks postmailing to those who had not responded, and a study team member (O.O.O.) contacted all remaining nonresponders by telephone at six weeks. The survey instrument and associated methods were approved by the Institutional Review Board at Dana-Farber/Harvard Cancer Center.

Survey instrument

Among the 30 questions included in the survey instrument, four focused on when and how hematologic oncologists typically conduct discussions of prognosis. First, we asked respondents with what percentage of their patients with hematologic cancers they discuss prognosis, with response options of "less than or equal to 25%," "26% to 50%," "51% to 75%," "76% to 95%," or "more than 95%." To examine timing of discussions, we asked: "When do you typically conduct the initial discussion addressing prognosis with your patients?" with response options of "upon presentation or diagnosis of hematologic cancer," "during a period of stability," "during an acute illness," or "when death is clearly imminent." Next, we assessed the terminology employed when communicating prognosis by asking: "What is your preferred terminology for discussing prognosis with patients?" with response options of "median survival (months or years)," "percent chance of survival (e.g., 5-year survival)," or "general discussion of whether patient has potentially curable disease." Finally, respondents were asked: "At what point during the course of disease do you readdress prognosis with your patients?" with response options of "during a period of stability," "during an acute illness," "when death is clearly imminent," or "in general, I do not readdress prognosis after the initial discussion." We collected demographic information including age, sex, and U.S. Census Bureau-designated geographic region. We additionally gathered information on practice setting (primarily tertiary vs. community), affiliation with an academic medical

center, the number of years since graduation from medical school, if the physician’s practice provided HCT care, whether the oncologist had received formal training in palliative care (by rotating on a palliative care team or hospice service), and whether the clinician personally felt prognostic uncertainty was a barrier to delivery of quality EOL care.

Statistical analyses

We first summarized responses for prognostic discussion practices with relative frequencies (%). We then employed chi-square tests to conduct univariable analyses of physician characteristics associated with three outcomes of interest: (1) proportion of patients with whom prognosis is typically discussed (dichotomized into “most,” defined as more than 95% of patients, vs. fewer than “most”), (2) preferred prognostic terminology (dichotomized into numeric estimates [median survival and/or percent chance of survival] vs. general terms), and (3) timing of readdressing prognosis, dichotomized into later (i.e., never or only when death is clearly imminent) vs. at earlier times (i.e., during a period of stability or acute illness).

Next, we characterized which explanatory variables were independently associated with conducting prognostic discussions with “most” patients, preferred terminology of numeric estimates, and readdressing prognosis at earlier times using multivariable logistic regression analysis. Characteristics, which met the predetermined significance value of 0.05 in univariable analyses, were included in multivariable models. Given prior studies suggesting potential relationships between gender and years of clinical experience and propensity to engage in prognostic discussions,^{27,28} we controlled for these characteristics in our multivariable models regardless of significance level in univariable analyses. We report odds ratios (ORs) with associated confidence intervals (CI). All *p*-values are two-sided. Statistical analyses were conducted with SAS version 9.4 (Cary, NC).

Results

Characteristics of respondents

Among 667 hematologic oncologists surveyed, 58 were subsequently deemed ineligible either after returning an opt-out card indicating that they did not routinely care for patients with hematologic malignancies (*n*=29) or because they were not at the address listed in the ASH directory and alternate contact information was unavailable (*n*=29). Of the remaining 609 eligible hematologic oncologists, 349 completed surveys (response rate=57.3%). Nonrespondents did not differ significantly from respondents based on either sex (*p*=0.06) or region of practice (*p*=0.72).

Men constituted 75.4% of the cohort, and the median age was 52 years (interquartile range, 44–60 years). The median number of years of postgraduate clinical experience was 25 (interquartile range, 17–33 years). More than half (58.2%) considered prognostic uncertainty to, sometimes, often, or always, be a barrier to quality EOL care. Additional respondent characteristics are reported in Table 1.

Discussing prognosis with “Most” patients

Among the 345 individuals who answered the question about the proportion of patients with whom they discuss

TABLE 1. CHARACTERISTICS OF ANALYTIC COHORT (N=345)

Characteristic	Number (%)
Male	260 (75.4)
Age at survey completion ^a	
≤40	45 (13.4)
>40	291 (86.6)
Years since completing medical school ^a	
≤15	74 (21.9)
>15	264 (78.1)
Board certification ^b	
Certification in hematology	280 (81.2)
Certification in medical oncology	299 (86.7)
Practices in tertiary care center ^a	
Yes	148 (43.7)
No	191 (56.3)
Strongly affiliated with an academic center	214 (62.0)
Provides auto/allo transplant care	139 (40.3)
Region	
Midwest	82 (23.8)
Northeast	104 (30.1)
South	107 (31.0)
West	52 (15.1)
Method of learning how to provide EOL care ^b	
Trial and error in clinical practice	251 (72.8)
Through role models in clinical training	269 (78.0)
Through conferences and lectures	203 (58.8)
By formally rotating on a palliative/hospice service	66 (19.1)
Considers prognostic uncertainty to be barrier to quality EOL care ^a	
Sometimes/often/always	197 (58.2)
Rarely/never	141 (41.7)

^aItem nonresponse ranged from 1.7% for practice in tertiary center to 2.6% for age.

^bNot mutually exclusive. EOL, end-of-life.

prognosis, 60.3% reported that they conducted prognostic discussions with “most” (>95%) of their patients. An additional 28.4% stated they held such discussions with 76% to 95% of their patients, 7.5% with 51% to 75% of their patients, 2.0% with 26% to 50% of their patients, and 1.7% with ≤25% of their patients. Of those who engaged in prognostic conversations, 315 (91.3%) reported typically conducting an initial discussion at a patient’s diagnosis. In both univariable and multivariable analyses (Table 2), those with 15 or fewer years of postgraduate medical experience were significantly less likely to report discussing prognosis with “most” of their patients compared to those with greater years of experience (adjusted OR [AOR] 0.51; 95% CI 0.30–0.88). Similarly, respondents who considered prognostic uncertainty to be a barrier to quality EOL care had significantly lower odds of conveying prognostic information to “most” of their patients compared with hematologic oncologists who did not consider prognostic uncertainty to be a barrier to quality EOL care (AOR 0.57; 95% CI 0.35–0.90).

TABLE 2. UNIVARIABLE AND MULTIVARIABLE ANALYSES OF FACTORS ASSOCIATED WITH REPORT OF DISCUSSING PROGNOSIS WITH MOST PATIENTS

Characteristic	Univariable analysis			Multivariable analysis
	Proportion of patients with whom prognosis is discussed			Outcome modeled: discussions with >95% of patients
	≤95% of patients N=137	>95% of patients N=208	p	Adjusted OR (95% CI)
Sex, %			0.75	
Male	39.2	60.8		Ref.
Female	41.2	58.8		0.80 (0.48–1.36)
Years since medical school graduation, %			0.02	
>15	35.6	64.4		Ref.
≤15	50.0	50.0		0.51 (0.30–0.88)
Practices in tertiary care center, %			0.59	
Yes	40.5	59.5		—
No	37.7	62.3		
Provides auto/allo transplant care, %			0.86	
Yes	40.3	59.7		—
No	39.3	60.7		
EOL care training through rotation on palliative/hospice service, %			0.18	
Yes	47.0	53.0		—
No	38.0	62.0		
Considers prognostic uncertainty to be barrier to quality EOL care, %			0.04	
Rarely/never	33.3	66.7		Ref.
Sometimes/often/always	44.2	55.8		0.57 (0.35–0.90)
Region, %			0.48	
Midwest	35.4	64.6		—
Northeast	37.5	62.5		
South	41.1	58.9		
West	48.1	51.9		

Percentages are row percentages. For example, 60.8% of male hematologic oncologists discuss prognosis with “most” (>95%) of their patients, whereas 58.8% of female hematologic oncologists reported discussing prognosis with “most” of their patients.

Sex and number of years since medical school graduation were forced into the multivariable model regardless of statistical significance. All other covariates were included in the model if they reached the significance threshold of <0.05 in univariable analysis. ORs >1 represent higher odds of having prognostic discussions with most patients (>95% of patients).

CI, confidence interval; OR, odds ratio.

Preferred terminology for prognostic discussions

Among hematologic oncologists who responded to the question on preferred prognostic terminology ($n=333$), 56.8% opted for a general discussion of the potential curability of a patient’s disease, while 43.2% favored numerical estimates. None of the explanatory factors considered in univariable analyses were significant predictors of the choice of terminology (Table 3).

Readdressing prognosis later in the disease course

While most hematologic oncologists reported that they spoke with patients about prognosis early in the disease course either during a period of stability (29.3%) or during an

acute illness (53.0%), almost one-in-five respondents reported either never revisiting prognosis (2.1%) or only doing so when death is clearly imminent (15.6%). Female hematologic oncologists were significantly more likely to readdress prognosis before imminent death (AOR 2.42; 95% CI 1.09–5.39; Table 4). Hematologic oncologists who reported having prognostic discussions with “most” of their patients were also more likely to then readdress prognosis before a patient’s death was imminent (AOR 2.01; 95% CI 1.12–3.59).

Discussion

Although most hematologic oncologists in our national sample reported discussing prognosis with their patients, the majority reported using only general/qualitative terms.

TABLE 3. UNIVARIABLE ANALYSIS OF FACTORS ASSOCIATED WITH PREFERRED TERMINOLOGY FOR DISCUSSING PROGNOSIS

Characteristic	General terms N = 189	Numeric estimates N = 144	p
Sex, %			0.23
Male	54.9	45.1	
Female	62.5	37.5	
Years since completing medical school, %			0.82
≤15	55.6	44.4	
>15	57.1	42.9	
Practices in tertiary care center, %			0.26
Yes	53.1	46.9	
No	59.3	40.7	
Provides auto/allo transplant care, %			0.49
Yes	54.5	45.5	
No	58.3	41.7	
EOL care training through rotation on palliative/hospice service, %			0.56
Yes	60.0	40.0	
No	56.0	44.0	
Considers prognostic uncertainty to be barrier to quality EOL care, %			0.65
Sometimes/often/always	58.4	41.6	
Rarely/never	55.9	44.1	
Region, %			0.07
Midwest	48.2	51.8	
Northeast	67.0	33.0	
South	53.9	46.1	
West	56.0	44.0	

All percentages are row percentages. No characteristics were significant in univariable analysis; therefore, no multivariable model was created.

Hematologic oncologists with fewer years of clinical experience were less likely to engage in prognostic discussions. Moreover, even though prognosis evolves throughout the disease course, nearly one-in-five hematologic oncologists reported that they routinely either do not readdress prognosis or only do so when a patient’s death is clearly imminent.

Prognostication involves both “foreseeing” (formulation of a prognostic estimate) and “foretelling” (communicating that prognosis to patients), both of which can be difficult endeavors.²⁹ Although the majority of hematologic oncologists reported discussing prognosis with over three-quarters of their patients, most reported a preference for communicating prognosis using primarily qualitative terms. These findings are consistent with a study of audiorecorded, first-time consultations by hematologic oncologists at two U.S. cancer centers, where discussions about curative potential were not conducted quantitatively or at all in 49% of consultations.³⁰ This hesitancy to offer explicit prognostic estimates is provocative as the published literature suggests that patients with cancer often desire detailed information regarding prognosis, including an estimated life expectancy.^{2,4,31} For example, in one study, 80%

of patients with metastatic cancer wanted to know the relevant 5-year survival rates, and 81% requested disclosure of average survival.³ The preference of hematologic oncologists to use qualitative terms may reflect worry that explicit numbers may induce patient anxiety or take away hope, particularly when prognosis is poor.²¹ On the other hand, the increased propensity for using qualitative terms may be due to concerns that patients may misinterpret numeric prognostic estimates.⁹

The finding that hematologic oncologists with fewer years of clinical practice were less likely to engage in prognostic discussions contrasts with a national survey in which younger physicians caring for patients with lung or colorectal cancer were significantly more likely to discuss prognosis than older colleagues.²⁷ In the context of prognostication challenges for hematologic malignancies, these findings may reflect higher levels of “informational uncertainty”—difficulty in applying abstract criteria to specific situations—and ostensibly less confidence among younger respondents in their prognostication abilities.³² Physicians with fewer years of medical experience have reported higher stress from clinical uncertainty.³³ Given this heightened stress from uncertainty and physicians’ hesitance to admit such uncertainty to patients, avoidance of prognostic discussions is possibly one way that hematologic oncologists cope with prognostic uncertainty.³⁴

Our finding that hematologic oncologists who felt prognostic uncertainty is a barrier to quality EOL care had significantly lower odds of discussing prognosis with “most” patients suggests that how one *perceives* prognostic uncertainty may influence prognostic communication practices. With the boon of targeted therapies and immunotherapies, prognostic uncertainty is likely to become a growing challenge not only for blood cancers but also for solid malignancies. Further research that includes specific measures of prognostic uncertainty is thus needed to understand how oncologists can effectively manage such uncertainty and openly communicate prognosis (what is known of it) to patients.

Given that prognosis often changes during the disease course, it was striking that almost one-in-five hematologic oncologists reported either never revisiting the topic or doing so very late in a patient’s life. Patients’ perceptions of their prognosis influence their decisions regarding treatment and their likelihood of engaging in advance care planning³¹; hence, waiting until death is clearly imminent to readdress prognosis may deprive patients of the opportunity to meaningfully plan for their future.³⁵ It thus stands to reason that more optimal times for revisiting prognostic discussions would be earlier in the disease course and at times of significant changes in disease severity (e.g., relapse or progression). Moreover, readdressing prognosis is vital for several reasons. First, while discussing prognosis at diagnosis seems reasonable, the emotional and psychological stress that accompanies a cancer diagnosis may diminish patients’ abilities to process this information.^{36,37} Second, patients and their families express a desire for their oncologists, to discuss prognosis frequently, and patients’ informational preferences may change over time.^{1,38} Being attuned to these changes would allow hematologic oncologists to tailor prognostic discussions based on patients’ readiness.³⁶ Finally, readdressing prognosis when a patient’s disease progresses/relapses can also serve as an opportunity to clarify preferences regarding EOL care.³¹ This is particularly important given

TABLE 4. UNIVARIABLE AND MULTIVARIABLE ANALYSIS OF FACTORS ASSOCIATED WITH REPORTED TIMING OF READDRESSING PROGNOSIS

Characteristic	Timing of readdressing prognosis			
	Univariable analysis			Multivariable analysis Outcome modeled: earlier in the disease course
	Late or never N=59	Earlier in the disease course N=275	p	Adjusted OR (95% CI)
Sex, %			0.03	
Male	20.2	79.8		Ref.
Female	9.8	90.2		2.42 (1.09–5.39)
Years since completing medical school, %			0.67	
≤15	19.4	80.6		Ref.
>15	17.2	82.8		1.10 (0.55–2.18)
Practices in tertiary care center, %			0.26	
Yes	20.7	79.3		—
No	15.8	84.2		
Provides auto/allo transplant care, %			0.70	
Yes	18.7	81.3		—
No	17.0	83.0		
EOL care training through rotation on palliative/hospice service, %			0.40	
Yes	14.1	85.9		—
No	18.5	81.5		
Considers prognostic uncertainty to be barrier to quality EOL care, %			0.79	
Sometimes/Often/Always	17.9	82.1		—
Rarely/Never	16.8	83.2		
Has prognostic discussions with most patients, %			0.02	
No	23.5	76.5		Ref.
Yes	13.6	86.4		2.01 (1.12–3.59)
Region, %			0.38	
Midwest	19.8	80.2		—
Northeast	12.1	87.9		
South	20.6	79.4		
West	19.2	80.8		

All percentages are row percentages.

Sex and number of years since medical school graduation were forced into the multivariable model regardless of statistical significance. All other covariates were included in the model if they reached the significance threshold of <0.05 in univariable analysis. ORs >1 represent higher odds of readdressing prognosis earlier in the disease course (i.e., before death is clearly imminent).

that patients with hematologic malignancies are more likely to be hospitalized and to receive chemotherapy in the last 30 days of life, and are also less likely to enroll in hospice compared with solid tumor patients.^{18,19}

Our study has limitations. Although our response rate of 57.3% is considered acceptable for a physician survey and even though respondents and nonrespondents did not significantly differ by sex or geographic region, we may have had nonresponse and participation bias.³⁹ Second, our findings are based on physician self-report. Given that there is likely an implicit expectation that prognostic discussions should occur, hematologic oncologists may have overstated their frequency of prognostic discussions due to social desirability bias. While audiorecorded conversations might provide richer insights into the actual content of prognostic

discussions, such methods are logistically challenging across multiple institutions limiting their generalizability and may themselves suffer from biases, including the Hawthorne effect. Third, although prognosis can be viewed in different ways (e.g., life expectancy, quality of life, future course of illness), our study focused primarily on prognosis in terms of curability and estimation of life expectancy. Finally, our question about preferred terminology did not allow for respondents to indicate if their preferred terminology changes over time. It may be that initial discussions involve general terms while subsequent discussions involve numerical estimates.

In summary, our analysis suggests that the majority of hematologic oncologists discuss prognosis with their patients; however, most prefer qualitative terms, and one in five

either never readdress prognosis after an initial discussion or only do so near death. Delays in revisiting prognosis may contribute to discrepancies between physicians' and patients' expectations of prognosis, and importantly may compromise patients' abilities to make informed, preference-aligned treatment decisions as their disease evolves. Physician-targeted interventions to promote clear and compassionate prognostic discussions not only at diagnosis but also at key transition points—such as relapse, disease progression, and refractory disease—may have substantial benefits on prognostic understanding and quality of care for patients with blood cancers.⁴⁰

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Author Disclosure Statement

No competing financial interests exist.

Supplementary Material

Supplementary Figure S1

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