Advance care planning knowledge and documentation in a hospitalized cancer population

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To have a better understanding of our patients' knowledge of advance directive planning and execution, as well as communication with their oncologists regarding their wishes, we conducted a survey on our inpatient hematology-oncology services. A total of 68 unique hospitalized patients with a diagnosis of cancer completed surveys. Surveys were given to all oncology patients regardless of their reason for admission. Overall, 29% of the patients reported having had a discussion with their oncologist regarding their wishes if they became seriously ill or near death. Of those who did have this conversation, the majority said that they, rather than their physician, initiated it. Although the vast majority of patients (97%) knew what a living will was, only 54% had one in place. Twenty patients had a discussion with their oncologist, and 14 of them (70%) had a living will. This percentage was higher than in the group that did not have a conversation with their physician (48%; 23 of 48 patients), but the difference was not statistically significant. Most cancer patients admitted to an inpatient oncology unit either did not have or did not recall having a discussion with their oncologist regarding end-of-life issues. This study gives us a baseline of information in evaluating future interventions directed to improve the quality of patient-physician communication regarding end-of-life planning.

The diagnosis of cancer provides challenges to patients, their families, and their medical providers. Initially, the objective for medical oncologists is to find a cure or at least a treatment to reduce symptoms and prolong survival of their patients. Having a discussion about an advance directive (AD) or end-of-life (EOL) issues with patients at this time may seem counter-intuitive to physicians. More importantly, it may be seen by patients as a confirmation of their fear that they are going to die from this disease. Many times this conversation is avoided until the disease progresses or is refractory, or the conversation never occurs.

Ideally individuals should have sufficient time to think about and discuss these issues with health care providers and others long before they have a life-threatening disease. The 2005 Gallup Public Opinion Poll reported that 40% of Americans over age 18 had a living will (1). Various other public opinion polls report figures of 25% to 40%. In a survey of primary care physicians in Northeastern Ohio, 97.5% of physicians reported comfort with discussing advance care planning, yet reported having those discussions with

only 43% of appropriate patients (2). Thus, even though health care providers understand the benefit of EOL discussions with their patients, they initiate such discussions less than half the time.

Oncology patients have a relatively high chance of dying from their disease, yet a national survey of physicians caring for cancer patients concluded that most physicians did not discuss EOL options until symptoms were significant and/or there were no further treatment options (3). A recent study by Zhang et al of 603 patients with advanced cancer reported that only 31% of patients had EOL discussions with their physicians (4). In that study EOL discussions were associated with significantly lower health care costs in the final week of life. The majority of cancer patients surveyed in one German study wanted their physician to initiate a discussion about writing an AD only if their physician thought it appropriate (5). Almost 80% of physicians in that study thought that they should initiate the discussion if appropriate, but only 17% thought it should be a routine matter as compared to 27% of the patients and 46% of healthy controls.

Another study of patients admitted to a hematology-oncology inpatient service in Virginia provided information about their preferences and attitudes toward AD and which physicians they preferred to host the discussion (6). Of the 75 patients enrolled in the study, nearly all (95%) thought that discussing an AD was very or somewhat important, but only 41% had an existing AD. When asked which physician they would prefer to discuss AD with if it were necessary, 48% indicated their oncologist—but only 7% of the patients actually had this discussion with their oncologist. In a report by Mack et al in a study of over 2000 patients with stage IV lung or colorectal cancer, 73% had EOL discussions identified by at least one source; however, oncologists documented EOL discussion with only 27% of their patients (7).

We conducted a survey on the hematology-oncology inpatient service at Baylor University Medical Center at Dallas

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regarding AD and patient-physician communication. The purpose of the survey was to establish baseline information to use to evaluate the effectiveness of future interventions regarding AD and EOL planning.

METHODS

From September 2011 to May 2012, inpatients in the oncology and blood and marrow transplantation units at Baylor University Medical Center at Dallas were surveyed to determine the frequency and effectiveness of EOL discussions between patients and their oncologists. Surveys were given to all oncology patients regardless of the reason of their admission, excluding only those who were unable to speak English and those in any type of medical isolation.

A printed questionnaire with 26 questions was created and distributed (*Table 1*), along with a cover letter explaining the project. In addition, one of the research nurses verbally explained the project to each patient. After completing the survey, patients placed it in an envelope, sealed it, and returned it to a nurse. Completed surveys were collected on a weekly basis.

Approval for the study was obtained from the Baylor University Medical Center at Dallas institutional review board. The surveys had no patient-identifying information; therefore, the results were anonymous.

Univariate analysis was performed using χ^2 tests, and multivariate analysis was done using logistic regression with Proc Logistic. The SAS statistical analysis system (SAS Institute Inc., Cary, NC) was used for data analysis. Statistical significance was defined as $P < 0.05$ with a two-tailed test. Categorical variables were expressed as percentages and continuous variables as mean $\pm$ SD, unless otherwise stated.

RESULTS

Surveys were distributed to 100 oncology patients, and 91 completed surveys were returned. Twenty-three patients submitted more than one survey over different hospital admissions, and only their original survey data were included in the primary analysis.

There was a balance of patients by gender: 46% were women and 54% were men (*Table 2a*). About 74% of the sample was in the age group of 50 to 69 years. Of the patients responding, 47 had a blood cancer diagnosis, while the others either had a solid tumor diagnosis or were unsure of their diagnosis. A further breakdown of tumor types is included in *Table 2a*; information on the stage of disease or treatment type was not collected.

One of the most important factors in designing this study was to assess the frequency with which our oncologists were having EOL discussions with their patients. Even though the patients were of variable ages and diagnoses, only 29% ($n = 20$) of the patients indicated that they had had a conversation with their oncologist regarding their EOL wishes. Women reported having this conversation slightly more often than men (35% vs 24%, $P = 0.42$), but the difference was not significant. Similarly, patients over the age of 60 reported having an EOL discussion more often than younger patients (36% vs 22%, $P = 0.29$), but again, the difference was not significant. Finally, the

Table 1. Survey items to determine factors associated with advance care planning in a hospitalized cancer population

1. Location/unit name
2. Have you completed this questionnaire before?
3. Cancer diagnosis
4. Date of diagnosis (month and year)
5. Gender
6. Current age
7. Have you ever had a discussion with your oncologist regarding your wishes when you become very ill or close to dying?
8. Did they initiate it, or did you?
9. My oncologist was comfortable having this discussion.
10. I was comfortable having this discussion with my oncologist.
11. I was satisfied with the amount of time my oncologist spent having this discussion with me.
12. Have you had a discussion with any other health care provider(s) regarding your wishes when you become very ill or dying?
13. How often do you visit your treating oncologist?
14. How often do you visit your primary care provider?
15. Describe your relationship with your treating oncologist.
16. Describe your relationship with your primary care provider.
17. I trust my treating oncologist.
18. I trust my primary care provider.
19. I am comfortable asking my treating oncologist questions regarding my care.
20. I am comfortable asking my primary care provider questions regarding my care.
21. My treating oncologist encourages me to ask questions related to my care.
22. My primary care provider encourages me to ask questions related to my care.
23. My treating oncologist explained why I was admitted to the hospital in a way I could understand.
24. Do you know what a living will is?
25. Do you have a living will or an advance directive?
26. Please enter today's date.

percentage of patients who reported having a conversation with their oncologist was not statistically different between those with a blood cancer versus a solid tumor (28% vs 33%).

Out of the 20 patients who had a discussion with their oncologist, 12 patients (60%) said they, not their doctor, initiated the discussion. As shown in *Table 2b*, 16 of the 20 patients (80%) agreed or strongly agreed that their treating oncologist was comfortable having a discussion on EOL issues; 3 (15%) responded neutral, and only one person strongly disagreed with this statement. None of the patients who had an EOL discussion with their oncologist felt uncomfortable having this discussion, and none were dissatisfied with the amount of time they spent having this discussion. Most patients who took the survey stated

Table 2. Key survey responses from oncology inpatients related to factors associated with advance care planning

2a. Demographic variables	Level	% (n)			
Gender	Male	54.4% (37)			
	Female	45.6% (31)			
Age	20–29	4.4% (3)			
	30–39	7.4% (5)			
	40–49	2.9% (2)			
	50–59	32.4% (22)			
	60–69	41.2% (28)			
	≥70	11.8% (8)			
Cancer diagnosis	Blood cancer	69.1% (47)*			
	Solid tumor	30.9% (21)†			
Frequency of visits with their treating oncologist	≥Weekly	52.5% (31)			
	Monthly	37.3% (22)			
	~Every 3 months	5.1% (3)			
	<Every 3 months	5.1% (3)			
	No response	(9)			
2b. Patient-physician relationship questions for the 20 patients who had a conversation with their oncologist regarding end-of-life wishes			Positive	Neutral	Negative
My oncologist was comfortable having this discussion.			80%	15%	5%
I was comfortable having this discussion with my oncologist.			90%	10%	0%
I was satisfied with the amount of time my oncologist spent having this discussion with me.			89%	11%	0%
I trust my treating oncologist.			98%	2%	0%
I trust my primary care provider.			83%	11%	6%
I am comfortable asking my treating oncologist questions regarding my care.			100%	0%	0%
I am comfortable asking my primary care provider questions regarding my care.			92%	5%	3%
My primary care physician encourages me to ask questions related to my care.			77%	16%	7%
My treating oncologist encourages me to ask questions related to my care.			97%	3%	0%
My treating oncologist explained why I was admitted to the hospital in a way I could understand.			98%	2%	0%

*Lymphoma, 14; multiple myeloma, 6; acute myeloid leukemia, 11; acute lymphoblastic leukemia, 2; chronic lymphocytic leukemia, 4; leukemia not otherwise specified, 7; myelodysplastic syndrome, 3.

†Colon, 3; liver, 3; melanoma, 2; breast, 2; pancreas, 2; lung, renal cell, gastrointestinal stromal tumor, 1 each; unknown or unspecified, 6.

they had a good to a very good relationship with their treating physician, and over 90% of the patients felt comfortable asking their doctors questions regarding their treatment and care. Almost all the patients said they were encouraged by their oncologist to ask questions related to their care. Interestingly, although the majority of patients (96.9%) knew what a living will was, only 53.9% had one at the time of the survey.

Seventy-one percent of those who had a discussion with their oncologist also reported that they had a living will or other AD versus 48% among those who did not have a discussion with their oncologist ($P = 0.16$). Of those patients who had a discussion with either their oncologist or another provider, 70% stated that they had a living will, while 45% did not ($P = 0.73$).

We did find that older patients (over 60 years) were more likely to have a living will or other AD: 67% in the over-60 group vs 40% in the <60 age group ($P = 0.05$). There was not a difference in the percentage having a living will based on cancer type (solid vs blood) or gender. In a multivariate logistic model, age >60 years was the only patient characteristic that was significantly associated with having a living will or AD (odds ratio 2.98; 95% confidence interval [1.02, 8.67]). No additional variables listed in *Table 3* were significant in this model.

DISCUSSION

The results of our survey showed a slightly higher percentage of patients (54%) with an AD compared with other reports.

Table 3. Percentage of inpatient oncology patients with a living will based on various factors

Variable		Patients with a living will or advance directive*	P value
Had a discussion with their oncologist	Yes	71% (12/17)	0.16
	No	48% (23/48)	
How often visited oncologist	Weekly or more often	66% (19/29)	0.11
	Less than weekly	41% (11/27)	
Had a discussion with either their oncologist or another health care provider	Yes	70% (16/23)	0.07
	No	45% (19/42)	
Age	<60	40% (13/32)	0.05
	≥60	67% (22/33)	
Cancer type	Solid tumor	40% (8/20)	0.18
	Blood	60% (27/45)	
Gender	Male	58% (21/36)	0.46
	Female	48% (14/29)	
Relationship with oncologist	Very good	60% (27/45)	0.14
	<Very good	40% (8/20)	
Relationship with primary care physician	Very good	57% (17/30)	0.67
	<Very good	51% (18/35)	

*Numbers in parentheses show the number answering that they had a living will or advance directive over the total number answering the question. Three individuals who answered the variable question did not answer whether or not they had a living will or advance directive.

Various reports show that between 25% and 40% of the general population has living wills or other AD (1, 2, 4). In a study of oncology inpatients in a Virginia teaching hospital, 41% had an AD. In a study of cancer patients in a Veterans Administration Hospital, 47% had a documented AD, and 81% had some documentation in their chart that referred to their EOL preferences (8).

Our survey demonstrated a trend to a higher likelihood of having an AD for those patients who have had a discussion with their oncologist and/or other health care provider. Only a minority of our patients (29%) had an EOL discussion with their oncologist, and these results were similar to the 31% reported by Zhang et al (4). In addition, patients who had a discussion with their oncologist reported feeling comfortable with the discussion and the length of the conversation. In the report of the Virginia patients, only 7% reported having an AD discussion with their oncologist; moreover, only 23% said they would like to discuss AD with their oncologist (5). When Snyder and colleagues surveyed primary care physicians regarding their understanding of and experience with advance care planning (2), they found that only 43% reported having those discussions with the appropriate patients; 44% felt that the discussions took too much time, and most felt that the appropriate time to have the conversation was in the estimated last 6 months of life (6). The inclusion of other specialists and mid-level providers may help overcome the time constraints that some physicians face.

This study has a few limitations that must be acknowledged. As with all surveys, the findings are self-reported, and a convenience sample of patients willing to participate was used. Information on stage or current treatment was not requested. Keating et al reported that many physicians delayed EOL discussions until there was symptomatic progression and/or limited options (3). We do not have sufficient data to judge if that occurred with our patients. Our population included patients undergoing blood and marrow transplants for hematologic malignancy, patients with complications of chemotherapy, as well as patients with advanced-stage disease. In addition, our inpatient population may be quite different from that of a usual cancer outpatient population or many inpatient populations. We see a high percentage of patients with malignancies of the hematologic system, and many undergo autologous and allogeneic blood stem cell transplantation with curative intent. A smaller percentage of the patients surveyed had solid malignancies. Although no significant differences were seen between patients with hematologic versus solid tumor malignancies, we did find that a higher percentage of patients with blood malignancies had an AD.

Due to the small sample size, there is a lack of statistical power for subgroup analysis for many of the comparisons presented. However, the counts and percentages are shown so readers can conclude for themselves the clinical relevance of the differences seen in this study.

Although we do not have the information, it is likely some patients in our study were admitted with end-stage disease. In the report by Mack et al, all patients had advanced solid tumor malignancies. In that study, oncologists documented EOL discussion with only 27% of their patients, but over 70% had EOL care discussions identified by at least one source (7). The percentage reporting discussions with their oncologist was similar to our findings; in contrast, in our population few of the patients reported having such a conversation with another health care provider. This may reflect differences in involvement of palliative care teams or other providers. The one factor in our population that reached statistical significance was age, with a higher percentage of those over 60 having had an EOL discussion compared to the younger patients. This is consistent with trends in the general population, with the likelihood of having a living will increasing with age (1).

Unfortunately, there is little formal training available for physicians regarding EOL discussions. A study done at Duke University Medical Center involved having medical residents take part in a short intensive course to improve communication with patients at the end of their life. The group of residents who participated in the course demonstrated significant

increases in their overall skill ratings in the delivery of bad news as compared to a control group of residents, and the patients of the residents involved in the course reported greater trust in their oncologists than did the patients of control oncologists (9). Others have reported similar benefits following interventions to improve physician communication. Fallowfield et al showed that British oncologists attending a 3-day intensive communications skills seminar demonstrated significant improvement (10); similar interventions with oncology nurses also yielded positive results (11). Through interventions based on our survey findings, we hope to improve the frequency and quality of EOL discussions. Twelve domains of physicians' skills were defined by focus groups of patients, family members of those who died with a chronic disease, and health care workers. The domains may provide a framework to focus on physicians' skill at providing high quality EOL care (12). Such a framework presents essential skills for oncologists—both those in training and those in practice—to attain to better serve their patients.

It has been shown that in the last week of life, advanced cancer patients who reported having an EOL discussion with physicians had significantly lower health care costs. Higher costs were associated with worse quality of death (4). A recent report documented that EOL care for Medicare beneficiaries varies widely and is highly intensive, and these findings are exhibited over a wide spectrum of hospital classifications (13). Our findings indicate that more needs to be done to ensure that patients with cancer have timely discussions regarding EOL discussions and that they have understood the information provided. This will involve efforts of their oncologists as well as other members of the health care team, to include palliative care practitioners and oncology mid-level providers. Temel et al has reported that non-small cell lung cancer patients who had early palliative care consultation had a more accurate assessment of their prognosis (14). Utilizing the information gathered in this study as a baseline, further quality improvement endeavors will be developed and implemented. Specifically, we will use the information obtained in this patient survey to evaluate future efforts to improve EOL discussions and AD planning. Efforts will include implementation of programs designed to improve physicians' communication skills around EOL discussions and greater incorporation of palliative care and other providers, including mid-level providers, to complement the oncologist's role in providing information to patients. Even though patients who had discussions with the oncologist reported comfort on their part and that of the oncologist, this represented only 30% of the patients surveyed. The survey did not address the physician perspective, but by providing increased awareness, better tools,

and additional resources, it is hoped that more oncologists will address these issues with their patients. Our philosophy is to bring all available measures to bear in order to further advance the necessary and appropriate components of advance care planning in the oncology setting.

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