Original Article

Goals-of-Care Decisions by Hospitalized Patients With Advanced Cancer: Missed Clinician Opportunities for Facilitating Shared Decision-Making

Rashmi K. Sharma, MD, MHS, Kenzie A. Cameron, PhD, MPH, Jennifer M. Zech, MSc, Sasha F. Jones, BA, J. Randall Curtis, MD, MPH, and Ruth A. Engelberg, PhD

Division of General Internal Medicine (R.K.S., J.M.Z.), University of Washington, Seattle, Washington; Cambia Palliative Care Center of Excellence (R.K.S., J.R.C., R.A.E.), University of Washington, Seattle, Washington; Division of General Internal Medicine and Geriatrics (K.A.C.), Northwestern University, Chicago, Illinois; Division of Hospital Medicine (S.F.J.), Northwestern University, Chicago, Illinois; and Division of Pulmonary, Critical Care and Sleep Medicine (J.R.C., R.A.E.), University of Washington, Seattle, Washington, USA

Abstract

Context. Hospitalized patients with advanced cancer often face complex, preference-sensitive decisions. How clinicians and patients engage in shared decision-making during goals-of-care discussions is not well understood.

Objective. The objective of this study was to explore decision-making by patients and clinicians during inpatient goals-of-care discussions.

Methods. This is a qualitative study of audio-recorded goals-of-care discussions between hospitalized patients with advanced cancer and their clinicians. Grounded theory was used to analyze transcripts.

Results. Sixty-two patients participated in goals-of-care discussions with 51 unique clinicians. Nearly half of patients ($n = 30$) were female and their mean age was 60.1 years (SD = 12.7). A palliative care attending or fellow was present in 58 of the 62 discussions. Decisions centered on three topics: 1) disease-modifying treatments; 2) hospice; and 3) code status. Clinicians' approach to decision-making included the following stages: "information exchange," "deliberation," "making a patient-centered recommendation," and "wrap-up: decisional status." Successful completion of each stage varied by the type of decision. When discussing code status, clinicians missed opportunities to engage patients in information exchange and to wrap up decisional status. By contrast, clinicians discussing disease-modifying treatments and hospice failed to integrate patient preferences. Clinicians also missed opportunities to make patient-centered recommendations when discussing treatment decisions.

Conclusion. Clinicians missed opportunities to facilitate shared decision-making regarding goals of care, and these missed opportunities differed by type of decision being discussed. Opportunities for clinician communication training include engagement in collaborative deliberation with patients and making patient-centered recommendations in situations of high medical uncertainty. J Pain Symptom Manage 2019;58:216–223. © *2019 Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine.*

Key Words

Decision-making, cancer, palliative care, communication

Background

For patients with advanced cancer, most discussions about goals of care occur in the hospital and with physicians other than their oncologist.[1] Such discussions involve high-stakes preference-sensitive decisions in which the benefits of treatment depend on the patient's preferences about the associated outcomes.[2] Decision-making in this context can be especially challenging

Address correspondence to: Rashmi K. Sharma, MD, MHS, Division of General Internal Medicine, University of Washington, 1959 NE Pacific St. Campus Box #356526, Seattle, WA, USA. E-mail: rasharma@uw.edu

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for patients who may depend on their inpatient clinician to "diagnose" their preferences.[3] Shared decision-making provides a way for patients and clinicians to engage in a collaborative process where these informed preferences drive decision-making and facilitate receipt of goal-concordant care for the patient.[4]

Previously published models of shared decision-making have suggested that it is an iterative process that includes information exchange and collaborative deliberation between the patient and clinician.[5–9] Collaborative deliberation comprises the presentation and interpretation of treatment options, elicitation of patient values and goals and construction of preferences, and the integration of those preferences into a decision.[4,6] In addition to its role in promotion of patient-centered care, shared decision-making has been associated with increased patient satisfaction and decreased decisional conflict.[10]

Although clinician-patient engagement in shared decision-making may improve the quality of care and patient outcomes,[10] operationalization of the elements of shared decision-making has been challenging, particularly in areas of high medical complexity.[11] Few studies have examined clinician-patient engagement in shared decision-making regarding goals of care for patients with advanced cancer in real time and in the hospital.[1] Rather, research in the inpatient setting has focused on communication between clinicians and surrogate decision makers[12–15] who may have their own values, goals, and preferences. Studies in cancer have focused on treatment decision-making in the outpatient setting,[16–22] where the timeline for decision-making may be much longer. Our study aim was to examine the way in which clinicians and patients with advanced cancer approach decision-making during inpatient goals-of-care discussions.

Methods

Study Design

We conducted a qualitative, observational study of hospitalized patients with advanced cancer at an urban, academic NCI-designated cancer center who had a goals-of-care discussion with a physician between October 2012 and November 2014. An eligible discussion was one in which a physician planned to discuss the patient's goals of care, prognosis, end-of-life decision-making, advance care planning, hospice, or bad news to inform preference-sensitive treatment decisions. This study was approved by the Northwestern University Institutional Review Board.

Participants

Participants were recruited from the inpatient palliative care consult, oncology teaching, and hospitalist-oncologist comanaged services. Eligible patients were English speaking, ≥ 18 years of age, had metastatic cancer which had progressed despite treatment, and were able to mentally and physically communicate about their care. Planned goals-of-care discussions were identified by a research assistant through weekday chart review and communication with medical teams. Eligible patients were approached by the research assistant for consent before participation in the planned discussion; all persons present at the discussion provided informed written consent.

Data Collection

Discussions were digitally audio-recorded, transcribed verbatim, and deidentified. Before the discussion, patients completed brief surveys that included demographics (e.g., race, age, sex), and their disease characteristics.

Data Analysis

Transcripts were analyzed using grounded theory methods.[23–25] Three coders used open coding (identifying major themes and component codes) to independently code the first five transcripts and then met to discuss codes and develop the initial codebook. Subsequently, transcripts were independently coded by two coders (from a team of six coders), who met to confirm, revise, and create codes using a constant comparison method.[25] We conducted axial coding (uncovering relationships among themes and codes) to identify consistencies between and within transcripts and develop conceptual themes. Ninety percent of coded transcripts were coreviewed. Trustworthiness of the coding was supported by reaching consensus among pairs of coders on 90% of codes. The coding process was managed using MaxQDA qualitative analysis software (Berlin, Germany). Quantitative data from participant surveys were analyzed in Stata version 14.0 (College Station, TX).

Results

Sample

Eighty-five patients were approached; 64 (75%) consented to participate. Two discussions were excluded (one in Spanish and one with a hearing-impaired patient) leaving 62 discussions for analysis. Mean patient age was 60.1 ± 12.7 years (Table 1). Participants were primarily white (56.5%) or black (38.7%), 48.4% were female. Forty-five discussions (72.6%) included at least one family member or friend (Table 2). Forty-seven unique physicians, three oncology nurse practitioners, and one palliative care nurse participated in the discussions; 56% of discussions included more than one clinician. Fifty-eight discussions (93.5%) included a palliative care attending or fellow (13 unique

Table 1
Characteristics of Hospitalized Patients With Advanced Cancer

Characteristics	Patients ($N = 62$)
Age, yrs, mean (SD)	60.1 (12.7)
Female sex, *n* (%)	30 (48.4)
Race/ethnicity, *n* (%)	
White	35 (56.5)
Black	24 (38.7)
Other (Asian, Hispanic)	3 (4.8)
Marital status, *n* (%)[a]	
Single	20 (32.3)
Married	26 (41.9)
Separated/divorced	7 (11.3)
Widowed	8 (12.9)
Education, *n* (%)[a]	
Less than high school	2 (3.2)
High school graduate or equivalent	21 (33.9)
Associate degree/junior or two-year college	7 (11.3)
College graduate or equivalent	12 (19.4)
Postgraduate degree	10 (16.1)
Cancer type, *n* (%)	
Lymphoma/leukemia	7 (11.3)
Breast	4 (6.5)
Colorectal	4 (6.5)
Lung	13 (21.0)
Noncolon gastrointestinal (e.g., pancreatic, liver)	19 (30.6)
Other (e.g., uterine, sarcoma)	15 (24.2)
Time since diagnosis, *n* (%)[a]	
<1 yr	9 (14.5)
1–2 yrs	8 (12.9)
2–3 yrs	11 (17.7)
>3 yrs	13 (21.0)

[a]Percentages may not add up to 100% because of missing values.

Table 2
Characteristics of Inpatient Goals-of-Care Discussions

Characteristics	Discussions ($N = 62$)
Family/friends present, *n* (%)	45 (72.6)
Spouse	19 (30.6)
Child(ren)	17 (27.4)
Parent(s)	6 (9.7)
Sibling(s)	8 (12.9)
Other (e.g., friend, brother-in-law)	11 (17.7)
Clinicians present, *n* (%)[a]	
Palliative care	
Attending physician ($N = 7$)[b]	50 (80.6)
Fellow ($N = 7$)[b]	20 (32.3)
Outpatient nurse ($N = 1$)	2 (3.2)
Oncology	
Oncologist ($N = 5$)	6 (9.7)
Oncology fellow ($N = 3$)	5 (8.1)
Nurse practitioner ($N = 3$)	3 (4.8)
Other physician (two hospitalists, one pulmonologist)	3 (4.8)
Medicine resident ($N = 21$)/other fellow ($N = 2$)	20 (32.3)
Other health care team member (e.g., social worker, chaplain)	48 (77.4)
Discussion content, *n* (%)	
Disease-modifying treatments	61 (98.4)
Hospice	44 (71.0)
Code status	20 (32.3)

[a]Number of discussions that included a clinician of that type.
[b]One palliative care fellow became a palliative care attending physician during the course of the study and is double-counted in the table.

physicians). A clinician from the patient's outpatient oncology care team (oncologist, nurse practitioner, or oncology fellow) was present in 11 discussions (Table 2).

Overview

Decisions addressed during these discussions comprised three types (Table 3): 1) disease-modifying treatments (61 discussions); 2) hospice (44 discussions); and 3) code status (20 discussions). We identified four decision-making stages: 1) "information exchange" during which clinicians and patients share information to achieve a shared understanding of the decision being considered; 2) "deliberation" during which clinicians present and interpret decision options and associated harms and benefits for the individual patient; elicit the patient's values, goals, and preferences; and assist the patient with integrating their preferences into decision-making; 3) "making a patient-centered recommendation" in which the clinician makes a recommendation that is grounded in the patient's values, goals, and preferences; and 4) "wrap-up: decisional status" in which the clinician explicitly assesses whether a decision has been made or where in the decision-making process the patient is, and outlines next steps to facilitate making of the decision. Clinicians and patients moved back and forth between individual stages iteratively (Fig. 1). Clinician participation in these stages differed by the type of decision being addressed (i.e., treatment, hospice, or code status), and missed opportunities for shared decision-making occurred across decision types.

Treatment Decisions

When discussing disease-modifying treatments, clinicians engaged in information exchange and wrap-up but often failed to facilitate deliberation and make patient-centered recommendations (Table 3).

Information exchange: Most clinicians ascertained patients' understanding of their illness including prognosis and clarified the clinical context for the decision. Several clinicians asked permission to provide information in a "direct" way before frankly discussing disease progression:

> *"I think I have a picture of what is important to you and I also think I have a picture of what you understand, but I am asking your permission to be as open and as direct as possible about some difficult things, okay?" (Discussion 107, Palliative Care Attending 204).*

Clinicians reinforced patients' knowledge that they had incurable disease and linked cancer progression to eventual death. Most clinicians elicited patients' questions, concerns, and fears about their illness and

Table 3
Clinician Missed Opportunities to Facilitate Shared Decision-Making by Type of Decision

Decision-Making Stage	Definition	Type of Decision		
		Treatment	Hospice	Code Status
Information exchange	Exchange of information between the patient and clinician to achieve a shared understanding of the medical and personal issues underlying the decision	+	+	−
Deliberation	Presentation and interpretation of options and associated harms/benefits	−	+	+
	Elicitation of patient preferences	+	+	+
	Clinician integration of patient preferences into decision making	−	−	+
Making a patient-centered recommendation	Clinician makes a recommendation regarding the decision that is grounded in the patient's values/goals	−	+	+
Wrap-up: decisional status	Explicit assessment of whether the patient has made a decision or where in the decision-making process the patient is	+	+	−

+ skill demonstrated.
− skill not demonstrated; missed opportunity.

addressed these concerns with treatment-related information.

Deliberation: During the deliberation stage, clinicians frequently mentioned the importance of evaluating treatment harms and benefits as patients make decisions about treatment, but they rarely assessed the patient's perception of these harms and benefits. Other clinicians placed the onus of interpreting these tradeoffs on the patient:

> *"They're hoping it will work but as you discovered if you get in the middle of something and say 'Hey, the burden is really outweighing the benefit. I'm done.' Then you know, that's your choice." (Discussion 113, Palliative Care Attending 203).*

When clinicians, including oncologists, discussed harms and benefits, particularly with patients who were interested in pursuing additional disease-modifying treatments, few integrated patient values and goals into the discussion. However, when patients expressed a preference to forego disease-modifying treatments to spend time at home, for example, clinicians helped integrate patient values into the care plan by suggesting palliative care or hospice as a way to achieve patient goals:

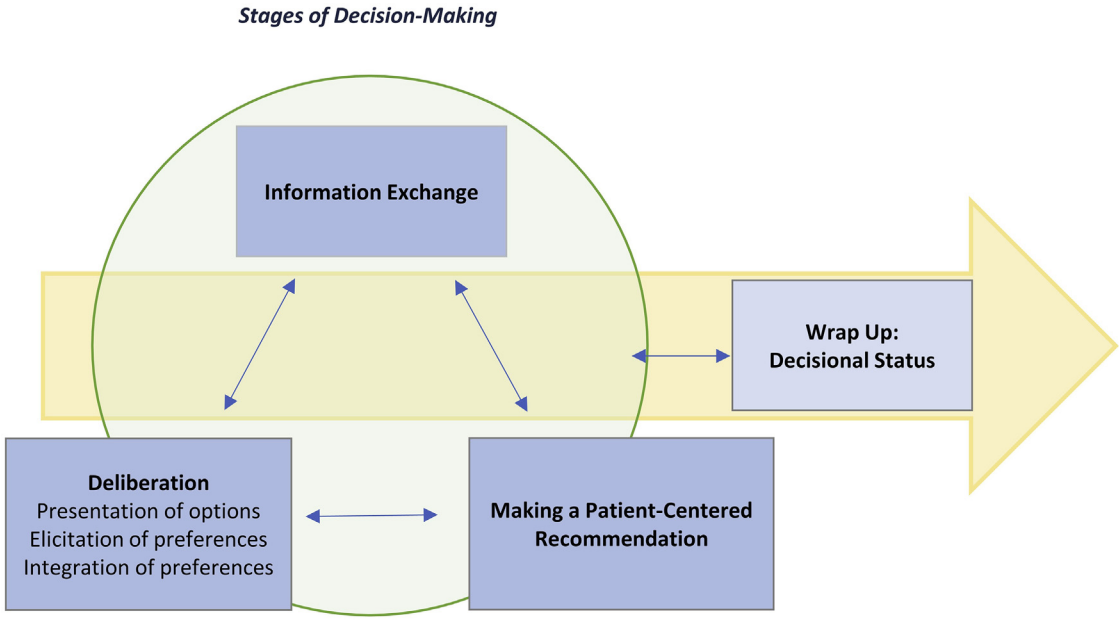

Fig. 1. Stages of shared decision making for goals-of-care decision.

"So I think, when thinking about you being cared for at home and how the medical system can support that, I think the best thing that we have is home hospice." (Discussion 122, Palliative Care Attending 210).

Making a patient-centered recommendation: Clinicians made treatment recommendations infrequently ($n = 7$). Six of the seven recommendations were for foregoing chemotherapy. Among these limited number of recommendations, patients' values and goals were not highlighted as the basis for the recommendation, in contrast to those provided for hospice or code status.

"We want you to feel as good as you can but at this point we wouldn't recommend more chemotherapy or radiation." (Discussion 148, Oncology Nurse Practitioner 233).

In the few instances where a patient or family member asked for a recommendation regarding treatment, clinicians avoided making a recommendation and focused on outlining the pros and cons of each decision option instead. In the following quote, the clinician avoids making a recommendation about whether to continue treatment in response to a family member's request and responds with information about tradeoffs instead:

"If it's prolonging things in a state that you're happy with, that may be a reason to continue. If you are in a state that you really feel is not consistent with a state that you would want to remain in for a long period of time, then Hydrea is probably not a good idea." (Discussion 110, Palliative Care Attending 200).

Wrap-up: decisional status: Most clinicians provided a clear wrap-up of the discussion, outlining next steps in the decision-making process and summarizing when a decision had been made. When decisions were not made, clinicians explicitly described an action plan for moving the decision-making process forward:

And the fellow will talk to you more but I think she already made sure that you have an appointment scheduled with Dr. P…So that's seeing her actually once you get home out of the hospital and coming back in and seeing her in clinic to really nail down a plan for cancer treatment. (Discussion 142, Medicine Resident 219).

Hospice

Similar to discussions about treatment, clinicians exchanged information and wrapped up discussions about hospice but missed opportunities to integrate patients' values and goals into decision-making. However, in contrast to treatment discussions, clinicians presented and interpreted harms and benefits related to the hospice decision for the patient and made patient-centered recommendations (Table 3).

Information exchange: Clinicians established a shared understanding with patients by assessing their understanding of their illness and clarifying whether disease-modifying treatments were still being offered or desired by the patient. Clinicians routinely asked patients and their families if they had any knowledge about hospice and asked permission to discuss further:

"Is that something you'd like to talk about or have you heard of hospice or do you know anything about it?" (Discussion 152, Palliative Care Fellow 222).

Deliberation: Clinicians consistently discussed specific options, interpreted harms and benefits for the patient, and elicited patient preferences but failed to integrate patients' values and goals into the decision. Deliberations about the hospice decision followed a consistent pattern, with clinicians first exploring if a patient's values and goals were aligned with the philosophy of hospice before discussing hospice itself. If the patient expressed a desire to focus on quality of life, maximizing time at home, or had concerns about continuing cancer treatments, clinicians introduced hospice as a way to achieve those goals. They then provided detailed information about the logistics of hospice care, discussing advantages and disadvantages of different options, and dispelling patient misconceptions about hospice being a place patients "go to die." Most patients, including those who indicated that decisions about hospice would be premature, expressed appreciation for this approach to discussing hospice:

"And you helped me to focus on what's important. If that's what hospice is about you're certainly helping me to realize that so many things aren't that important that I was emphasizing." (Discussion 118, Patient).

Despite this well-grounded approach to presenting options and eliciting preferences, clinicians often failed to complete the last stage of deliberation—integrating values into a shared decision. Instead, they framed the decision to enroll in hospice as one for the patient and/or family to decide alone:

"And, yeah, you'll make kind of a decision about what seems best for you." (Discussion 113, Palliative Care Attending 203).

Making a patient-centered recommendation: When clinicians did make recommendations regarding hospice ($n = 12$), they based the recommendation on patient's expressed values and goals:

"So based on everything you've told me about wanting to be at home and wanting to be comfortable and wanting to be with your family for the time that you have left, my recommendation and my thought is I think we focus on…

having you at home as comfortable as possible with hospice." (Discussion 151, Palliative Care Fellow 225).

Wrap-up: decisional status: Most clinicians used the end of the discussion to wrap up and assess how patients were processing information about hospice and where patients were in the decision-making process. Clinicians also frequently explained next steps:

But I know that your priority is being at home and sounds like your family is willing to support that going forward. So I can have our social worker come by and give you information about those hospice agencies and make referrals. (Discussion 135, Palliative Care Fellow 216).

Code Status

In contrast to discussions about treatment options or hospice, clinicians missed opportunities to exchange information and wrap up discussions about code status but facilitated deliberation and made patient-centered recommendations (Table 3).

Information exchange: Although many clinicians explained resuscitation, few assessed patients' understanding of these explanations. Clinicians limited their questions to how familiar a patient was with the term "resuscitation" or if they had previously discussed code status. Several clinicians brought up the concept of code status and then deferred further discussion without asking patients if they wanted more information:

"When people do healthcare power of attorney, sometimes people ask them things like, uh, resuscitation, you know? What happens when your heart stops? Should we ever consider putting in a breathing machine? Things like that. Right now at this moment, I don't think it's important to talk about that." (Discussion 141, Palliative Care Attending 204).

Deliberation: Among those clinicians who engaged in further discussion about code status ($n = 14$), clinicians engaged in all three steps of deliberation. After exploring patient values, goals, and their relevance to resuscitation preferences, clinicians discussed the harms and benefits associated with CPR and then helped to integrate the patient's values and goals into a decision:

"I think you're able to say that very directly and almost with a strength behind that and I can absolutely say to you that I agree. If something ever gets to the point where a finite event happens, the heart stops, the lungs stop… any attempts to try to restart a heart… would just be asking too much." (Discussion 119, Palliative Care Attending 208).

Making a patient-centered recommendation: Clinicians made recommendations in 10 of the 20 discussions; five of these were made by the same clinician and all were recommendations for foregoing a resuscitation attempt. When clinicians made recommendations, most placed them in the context of the patient's values and goals:

Clinician: "And one thing I would recommend for you if you're the type of person who really believes that you know, I want to take my chemo and fight as much as I can against the cancer, but when my time has come it's come, … I want to be peaceful about it.

Patient: I don't want to prolong it

Clinician: I would actually recommend that we think about what we call a "Do-Not-Resuscitate" order in your chart (Discussion 104, Palliative Care Attending 200).

Wrap-up: decisional status: While clinicians used explicit language when making recommendations, few summarized whether a code status decision had been made or what the decision was. Clinicians also missed opportunities to clarify whether patient statements indicated a code status preference:

Clinician: So it would be my recommendation for you to put in a DNR order.

Patient: Mm-hmm.

Clinician: Also I think it would be helpful for whomever you've designated so they won't be put in a situation where they have to think about things like …" (Discussion 103, Palliative Care Fellow 202).

In addition, whether a decision was made, few clinicians outlined next steps. In the following example, the clinician makes a recommendation but then defers actual decision-making to some unspecified future time:

"I think it's not something we would recommend that you have done, but it's not a decision that we can make for you. So my medical recommendation would be that you decide not to, but we'll talk about it some more some other time." (Discussion 148, Palliative Care Attending 210).

Discussion

Although the theoretical elements of shared decision-making are well described,[9] the operationalization of these elements for clinical practice, particularly in situations of high medical complexity and uncertainty, has been limited. Our study provides important data on the ways in which clinicians engage patients in the decision-making process in real time and navigate highly complex, preference-sensitive decisions regarding goals of care in the setting of advanced cancer. These are decisions that are especially suited to the process of shared decision-

making.[26] We found that clinicians frequently missed opportunities to facilitate the progression of the decision-making process from information exchange to deliberation, making a patient-centered recommendation, and wrapping up the discussion, and that these missed opportunities differed by the type of decision being discussed.

Some researchers have suggested that clinicians are more likely to place the responsibility of decision-making on the patient's shoulders when the clinician is ambivalent about the "right" choice and when greater uncertainty surrounds the options.[27] These are situations when clinicians may be reluctant to undertake the more challenging task of synthesizing information relevant to the decision in the context of the patient's values and goals. This hypothesis could help explain why clinicians were more likely to make recommendations about code status than about treatment options in which there may be greater uncertainty about outcome. It is also possible that clinicians conceptualize decisions about treatment, hospice, and code status differently. Clinician framing of decisions about hospice as one for the patient and family to make, for example, may reflect a perception that these decisions depend more on the patient/family's values and emotional acceptance of a terminal diagnosis than on cognitive understanding of the patient's condition. Yet, in discussing code status, which similarly forces patients to have to face their own mortality, clinicians were much more likely to be directive, perhaps because they had a strong opinion about what decision they thought was in the patient's best interest. Alternately, clinicians may believe that decisions about disease-modifying treatments and hospice, more so than code status, should be more directly preference-sensitive based on the patient's perception of quality of life and are thus hesitant to put forth an opinion.

An important contextual factor for interpretation of our study findings is that the majority of discussions we identified included a palliative care physician. As might be expected from the presence of palliative care clinicians with specialized training in serious illness communication,[28–30] almost all our discussions included clinician assessment of disease understanding, exploration of patient values and goals, and elicitation of patient preferences, regardless of the type of decision being discussed. It is hard to know if the other clinicians present would have completed these tasks in the absence of the palliative care clinician. In addition, some of the missed opportunities we identified in decisions focused on disease-modifying treatments may be due, in part, to the small number of oncologists present at these discussions who may have been needed to discuss treatment choices and harms and benefits. However, studies of outpatient discussions between patients and oncologists have identified similar deficits in shared decision-making.[16,20–22,31]

Several limitations are worth noting. First, this was a cross-sectional study. We recognize that patients may have had multiple discussions about goals of care over time, and we may have missed clinician engagement in shared decision-making that occurred in other discussions. Second, our data were from a single academic institution with a limited number of palliative care clinicians who participated in the majority of discussions, which may limit the generalizability of our findings. However, more than half of discussions also included clinicians from other specialties. Finally, our discussions included trainees (residents and fellows) who may have been less skilled at integrating patients' preferences into a decision and making a recommendation. However, of the 10 discussions that did not include an attending physician, eight were led by palliative care fellows who would have had more experience with these skills.

In conclusion, our data highlight how even clinicians who may have been trained to be more skilled communicators, such as palliative care specialists, often miss important opportunities to translate patient values, goals, and preferences into specific decisions and help guide patients and families. These findings suggest additional opportunities for clinician training regarding engagement in collaborative deliberation, helping patients to construct their preferences and translate those preferences into specific decision options, and making patient-centered recommendations in situations of high uncertainty.

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