Systemic Therapy Decision Making in Advanced Cancer: A Qualitative Analysis of **Patient-Oncologist Encounters**

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QUESTION ASKED: How do patients with advanced cancer and their oncologists engage in decision making to continue or limit systemic therapy?

SUMMARY ANSWER: We found that (1) patients and oncologists framed continuing therapy as the default, (2) deficiencies in shared decision making contribute to this default, and (3) oncologists use persuasion rather than deliberation when broaching discontinuation.

WHAT WE DID: We performed a content analysis of outpatient oncology encounters audio recorded at two different academic medical centers between November 2010 and September 2014.

WHAT WE FOUND: Among 31 randomly sampled dyads with 3 encounters each, systemic therapy decision making was discussed in 90% (84 of 93) encounters, and 90% (76 of 84) discussed continuing systemic therapy. Thirty-four (40%) broached limiting therapy, which 27 (79%) framed as temporary, nine (26%) as completion of a standard regimen, and five (15%) as permanent discontinuation.

BIAS, CONFOUNDING FACTORS, DRAWBACKS AND REAL-LIFE IMPLICATIONS: This was a secondary analysis, and we could not directly interview participants about their decision-making process, analyze nonverbal communication, and include participants from the community setting. During the study time period, immunotherapy was not a prevalent systemic therapy option, and few encounters discussed it. The framing of continuing systemic therapy as the default likely contributes to the receipt of chemotherapy near death and delayed hospice enrollment, both of which are associated with lower patient quality of life.

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ASSOCIATED CONTENT

See accompanying article on page 543

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original contributions

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PURPOSE We sought to characterize patient-oncologist communication and decision making about continuing or limiting systemic therapy in encounters after an initial consultation, with a particular focus on whether and how oncologists foster shared decision making (SDM).

METHODS We performed content analysis of outpatient oncology encounters at two US National Cancer Institute—designated cancer centers audio recorded between November 2010 and September 2014. A multidisciplinary team used a hybrid approach of inductive and deductive coding and theme development. We used a combination of random and purposive sampling. We restricted quantitative frequency counts to the coded random sample but included all sampled encounters in qualitative thematic analysis.

RESULTS Among 31 randomly sampled dyads with three encounters each, systemic therapy decision making was discussed in 90% (84 of 93) encounters. Thirty-four (37%) broached limiting therapy, which 27 (79%) framed as temporary, nine (26%) as completion of a standard regimen, and five (15%) as permanent discontinuation. Thematic analysis of these 93 encounters, plus five encounters purposively sampled for permanent discontinuation, found that (1) patients and oncologists framed continuing therapy as the default, (2) deficiencies in the SDM process (facilitating choice awareness, discussing options, and incorporating patient preferences) contributed to this default, and (3) oncologists use persuasion rather than deliberation when broaching discontinuation.

CONCLUSION In this study of outpatient encounters between patients with advanced cancer and their oncologists, when discussing systemic therapy, there exists a default to continue systemic therapy, and deficiencies in SDM contribute to this default.

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INTRODUCTION

Many patients with incurable cancer receive treatments toward the end of life (EOL) that are more aggressive than their preferences would support. Decisions regarding systemic therapy (ie, chemotherapy and immunotherapy) are inextricably linked to EOL quality both directly and indirectly through hospice enrollment since the Medicare hospice benefit requires forgoing cancer-directed treatments. 4

Since the receipt of systemic therapy within the last two weeks of life is as an indicator of poor-quality EOL care, ^{5,6} previous work has focused on (1) predictors and outcomes on the receipt of systemic therapy and (2) evaluating communication and decision making between patients and oncologists. Factors such as patient

age, ⁷ previous treatments received, ⁸ race and ethnicity, ⁹ prognostic awareness, ¹⁰ pre-encounter preferences, ¹¹ and early integration of palliative care¹² are associated with limiting systemic therapy. Medical record review suggests that definitive (explicit) decisions to discontinue systemic therapy occur only approximately 20% of the time; other processes (eg, deferred decisions or breaks and disruption for radiation or hospitalization) constitute the majority of instances of systemic therapy limitation. ¹³ Although these studies helped identify both the scope and potential mediators of the problem, they often lacked granularity to identify specific communication behaviors contributing to the outcomes observed.

Best practice guidelines for oncology patient-clinician communication consider the principles of shared decision making (SDM) to be particularly important for

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systemic therapy decision making.¹⁴ SDM is a collaborative process with three key steps: creating choice awareness, discussing options, and then integrating patient preferences into the decision.¹⁵ Studies that include a focus on SDM when evaluating patient-oncologist communication on the initiation of chemotherapy for incurable cancer revealed deficiencies in all three steps.¹⁶⁻²⁰ However, few studies describe communication and decision making in outpatient oncology visits for advanced cancer after the initial decision to pursue systemic therapy. This study aimed to characterize patient-oncologist communication and decision making about continuing or limiting systemic therapy in encounters after an initial consultation, with a particular focus on whether and how oncologists foster SDM.

METHODS

Overview

We conducted a secondary analysis of outpatient oncology encounters from two US National Cancer Institute-designated cancer centers that were audio recorded between November 2010 and September 2014 as part of a randomized controlled trial comparing two web-based communication tools. The trial protocol is described at ClinicalTrials.gov (NCT00994578),²¹ and both communication tools are described in detail elsewhere. 22,23 These tools focused on recognizing and responding to emotion, not medical decision making. Eligible providers included medical, gynecological, and radiation oncologists. Eligible patients were those with stage IV malignancy, whom the oncologist would not be surprised if they were admitted to an intensive care unit or died within 1 year.²⁴ Three consecutive encounters between each patient-oncologist dyad were audio recorded: one before study intervention and two postintervention. The trial was approved by local institutional review boards.

Sample

We summarize the sample in Figure 1. From available encounters with oncology providers (n = 615), we restricted analysis to patient-oncologist dyads with three consecutive encounters involving the study oncologist to increase the likelihood of finding dyads engaged in systemic therapy decision making. From these encounters (n = 141 dyads, n = 423; full sample), we randomly sampled all three encounters from 7 to 8 dyads from each of the four trial arms (n = 31 dyads, 93 clinical encounters; random sample). We included all three encounters to account for the longitudinal nature of cancer care and decision making.

In a separate strategy to enrich for encounters discussing permanent discontinuation of systemic therapy, we reviewed the remaining audio from the full sample (110 dyads, n=330) for mentions of EOL topics, including treatment discontinuation. Details of the identification procedures are described elsewhere.²⁵ The final purposive

sample included all encounters discussing permanent discontinuation of systemic therapy. Audio files of included encounters were professionally transcribed for analysis.

Analysis

Our content analysis followed the model described by Elo and Kyngas, 26 where, after code development, we counted systemic therapy discussion at the encounter level and finally characterized the discussion. We used a hybrid approach of inductive and deductive coding and theme development to describe systemic therapy decision making, as outlined by Fereday and Muir-Cochrane. 27 The three talk model of SDM formed the basis of deductive coding. 15 A multidisciplinary research team with expertise in medical oncology, palliative medicine, public health, medical anthropology, and decision science was engaged in analysis. After careful review of 10 randomly selected encounters. four investigators (G.T.W., K.E.K., M.A.L., and A.E.B.) developed a preliminary codebook. The team reviewed a subset of 10 dyads from the random sample (30 encounters) using the preliminary codebook, and new codes were inductively added to capture emergent themes. Existing codes were also refined. Five investigators contributed to the development of the final codebook (G.T.W., K.E.K. G.F.M., O.C.B.-B., and A.E.B.; see the Data Supplement [online only] for codebook). One investigator (K.E.K.) independently reviewed the entire random sample (n = 93 encounters) while a second investigator (G.T.W.) reviewed 45% of the sample (n = 42 encounters). Both investigators reviewed all encounters discussing permanent discontinuation. Encounter-level counts of discussions regarding therapy continuation and limitation, and who initiated the limitation discussion, were affirmed by one investigator who is a practicing medical oncologist (G.T.W.). The study team iteratively discussed their findings to develop themes and refine interpretations.27 Any disagreement among team members was resolved through discussion; we did not calculate inter-rater reliability. We performed coding using Atlas.ti version 8.4.4 (ATLAS.ti Scientific Software Development GmbH) qualitative data analysis software, and we adhered to the Consolidated Criteria for Reporting Qualitative Research Checklist.²⁸

RESULTS

Table 1 describes the demographics and clinical characteristics of patients and oncologists. Of the 36 patients included in this analysis, 39% (12) were women and 89% (32) were White. Of the 25 oncologists, 12% (3) were women and 80% (20) were White, with a mean age of 58.0 years (standard deviation 10.0). The median duration of conversations was 33 minutes (interquartile range 20-44 min, 4-113 min range). All encounters included a physician, most (n = 59; 60%) included an additional clinician (eg, nurse practitioner, fellow, or medical student), and most (n = 63; 68%) also included a patient support person (eg, family member).

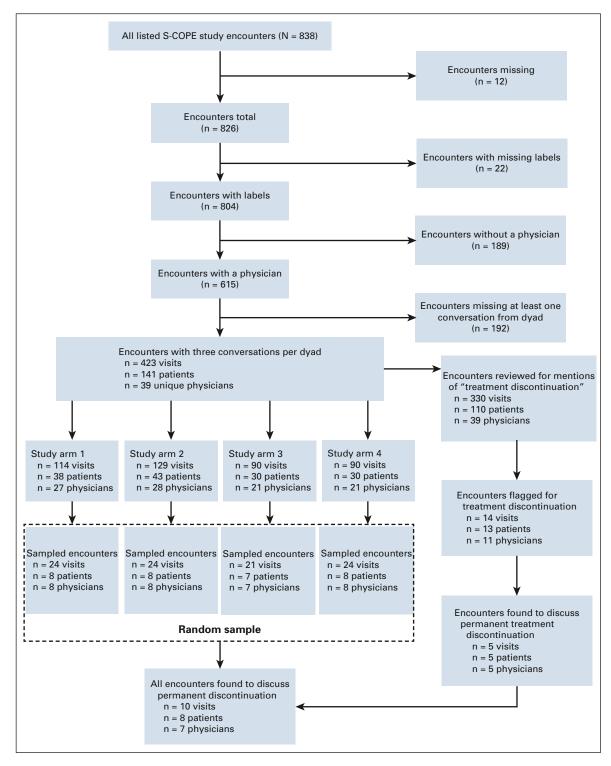


FIG 1. Flow diagram. Sampled encounters, encounter randomly selected from each study arm. Encounters found to discuss permanent treatment discontinuation are the additionally identified encounters for enrichment (aka purposive in the Methods).

Frequency of Systemic Therapy Talk

In the random sample, systemic therapy decision making was discussed in 90% (n = 84 of 93) of encounters (Table 2). Conversations about continuing systemic therapy (n = 76 of 93) were more frequent than limiting therapy

(n = 34 of 93), with both continuing and limiting being discussed in 28% (n = 26 of 93) encounters. Among encounters in which systemic therapy decision making was discussed (n = 84), discussing limiting exclusively occurred in only 10% (n = 8 of 84), whereas discussing

TABLE 1. Characteristics of the Patients and Oncologists in the Sample

Characteristic	Patients (n = 36), No. (%)	Oncologists (n = 25), No. $(\%)$
Age, years, mean (SD)	NA	58.0 (10.0)
Female sex	14 (39)	3 (12)
Race		
White	32 (89)	20 (80)
Black	2 (6)	0 (0)
Asian	1 (3)	3 (12)
Others	1 (3)	1 (4)
Missing	0 (0)	1 (4)
Cancer type ^a		
GI	9 (25)	6 (24)
Genitourinary	6 (17)	2 (8)
CNS	4 (11)	2 (8)
Thoracic	5 (14)	4 (16)
Hematologic	4 (11)	4 (16)
Gynecologic	3 (8)	3 (12)
Breast	1 (3)	1 (4)
Melanoma	1 (3)	1 (4)
Investigator could not identify	3 (8)	2 (8)

Abbreviations: NA, not available; SD, standard deviation.

^aDetermination inferred from transcript by explicit discussion of cancer, systemic therapy regimen, and imaging results.

continuation occurred exclusively in 60% (n = 50 of 84). When a new line of systemic therapy was discussed (n = 26 of 93 encounters), 50% (n = 13 of 26) of encounters exclusively discussed continuing therapy (Table 2).

When discussed, limiting therapy was framed as temporary in 79% (n = 27 of 34), completion of a standard regimen in 26% (n = 9 of 34), or permanent discontinuation in 15% (n = 5 of 34) of encounters. Discussions of permanent discontinuation often co-occurred with mentions of hospice 60% (n = 3 of 5) in the random sample and 60% (n = 6 of 10) in the random-plus-purposive sample (Table 2). Oncologists initiated discussions of limiting therapy more frequently than patients or their family members (Table 3).

Thematic Analysis

We found that (1) patients and oncologists framed continuing therapy as the default, (2) deficiencies in the SDM process (creating choice awareness, discussing options, and then integrating patient preferences into the decision) contributed to this default, and (3) oncologists used persuasion rather than deliberation in all three types of limiting systemic therapy discussions (temporary discontinuation, completion of standard regimen, and permanent discontinuation).

Continuing Therapy as the Default

Generally, continuing systemic therapy was framed as the default. Criteria for decisions on systemic therapy could be

general—"nothing's convincingly worse, and you are doing well with it"—or specific—"we'll have to see how your neuropathy does in time because that is the one thing that frequently leads to dose changes."

Deficiencies in SDM

Fostering choice awareness was uncommon. Oncologists infrequently offered anticipatory guidance regarding therapy

TABLE 2. Frequency of Select Patient-Oncologist Discussion Codes at Encounter Level

Discussion Code	Encounters, No. (%)
Random sample (n = 93)	
Systemic therapy	84 (90)
Continue	76 (82)
Same	58 (62)
Modify (dose or schedule)	31 (33)
New	26 (28)
FDA-approved	23 (25)
Clinical trial	14 (15)
Switch	10 (11)
Limiting	34 (37)
Temporary discontinue	27 (29)
Completion of standard regimen	9 (10)
Permanent discontinue	5 (5)
Hospice	4 (4)
Co-occurrence of continue/discontinue (n = 84)	
Continuing without any discontinuing	50 (60)
Both continuing and discontinuing	26 (31)
Discontinuing without any continuing	8 (10)
Co-occurrence of new with limiting therapy types $(n = 26)$	
New with temporary discontinue	10 (38)
New with completion standard regimen	2 (8)
New with permanent discontinue	3 (12)
New without any limiting therapy	13 (50)
Co-occurrence of permanent discontinue with hospice (n = 5)	
Both hospice and permanent discontinue	3 (60)
No mention of hospice	2 (40)
Combined samples permanent discontinue encounters (n = 10)	
Discuss new therapy	7 (70)
Discuss same	2 (20)
No mention of continuing therapy	1 (10)
Postpone final decision making	7 (70)
Hospice	6 (60)

Abbreviation: FDA, US Food and Drug Administration.

TABLE 3. Who Initiated First Mention of Key Limiting Therapy Discussion at Encounter Level

Discussion Code	Oncologist % (No.)	Patient % (No.)	Family % (No.)
Temporary (n = 27)	78 (21)	15 (4)	7 (2)
Completion of standard regimen (n = 9)	89 (8)	0 (0)	11 (1)
Permanent (n = 10)	90 (9)	10 (1)	0 (0)
Hospice $(n = 7)$	43 (3)	57 (4)	0 (0)

discontinuation (ie, discussion of a future time when the patient may choose to permanently discontinue therapy).

Oncologist: We'll keep an eye on you. We'll keep watching you—any issues, any symptoms—obviously, this is not like a contract. You know it depends on our tolerance—our quality of life.

Patient: Sure.

Oncologist: So as long as we're tolerating, we'll continue. If we need to take a break, we'll take a break. If we need to change plans, we'll change plans.

Generally, decisions about systemic treatment were not framed as involving choices:

Patient: What is next? Is this the permanent protocol? Oncologist: Generally, for our newly diagnosed Avastin protocol, we've been recommending a second year of what we call Avastin maintenance. It's not on the study, but it's just common sense that if we're significantly improving the number of people who are progression free at a year, continue the Avastin.

Discussing systemic therapy treatment options occurred as a monologue. Oncologists seldom invited patients to participate in deliberation about next steps; instead, they offered think aloud discussions of therapy alternatives, often invoking complex information from published and ongoing clinical trials. They typically concluded these narratives with a statement regarding their treatment recommendation, without referencing patient treatment preferences:

Oncologist: So this [clinical trial drug] could help with the rest of you. Other types of chemo could help with the rest of you. Other clinical trials that you may qualify for in the future, but not yet. Um, radio-pharmaceuticals, so kinda liquid radiation called Samarium or Quadramet can be given IV. And then that kind of goes into your bones and radiates lots of different spots. I usually do that—do that if there's lots of spots that are painful.

Oncologists elicited and incorporated patient perceptions about symptoms from cancer and therapy into conversations about systemic therapy; however, discussions of broader patient values and preferences (eg, goals, abilities that are critical to their function, what brings them joy, etc) were much less frequent. Outside of permanent discontinuation of therapy, discussions of how patients perceived

trade-offs between the potential for more time and quality-of-life costs to being on therapy were absent. In the context of permanent therapy discontinuation, trade-offs were used as a rhetorical device to convince patients that discontinuation would allow a focus on quality-of-life goals. Additional strategies oncologists used to address actual or anticipated patient resistance to therapy discontinuation included offering hope for future therapies, emphasizing either uncertainty or low benefit from continuing therapy, and reassuring that the patient received standard of care.

Persuasion Over Deliberation

Oncologists used persuasion rather than SDM deliberation in all three patterns for how limiting systemic therapy was discussed: (1) temporary discontinuation, (2) completion of standard regimen, and (3) permanent discontinuation.

Temporary discontinuation. Discontinuation with the possibility of resumption was described with word choices such as vacation, break, or holiday, signaling both the temporary nature and positive valence of these stops. Whether the temporary stop was introduced by the oncologist or the patient, the basic structure was to (1) suggest some amount of time to wait, (2) outline a criterion to inform decision (eg, tumor marker, imaging, and cancer-related symptoms), and (3) establish consensus to re-evaluate at that point in the future. To help ease the anxiety some patients expressed about discontinuing therapy, some providers referenced future clinical therapy opportunities. For one patient who was hesitant to stop therapy, the oncologist framed the discontinuation of therapy as a pathway for opening new therapy possibilities: "I think that if we took a couple months off, we'd get a better feel for how the cancer's behaving ... We have other options like clinical trials, phase one trials, other trials. That may be an option, but you can't really go on any of those with a CT scan that's not showing anything." Through this lens, discontinuing therapy does not appear as a resignation to stop treating the patient's current cancer but may allow the patient to access therapy options that would otherwise remain inaccessible. Reasons patients initiated temporary discontinuation discussions included schedule conflicts (eg, "we're going on vacation") or concerns about treatment side effects (eg, "afraid [neuropathy] was gonna be permanent").

Completion of a standard therapy regimen. When framing limiting therapy around completion of a standard regimen, oncologists discussed a desire to avoid therapy harms: "But now that because of the weight issues, you know, and the

poor appetite, and the blood level, I think it's okay to stop here." The framing of completing a standard regimen also offered further reassurance: "I usually give additional chemotherapy for two to three cycles. So I shoot for two ... we've gotten what the majority of patients get."

Permanent discontinuation. When discussing permanent therapy discontinuation, emphasizing harm and/or limited benefit was universal. One clinical rationale was to explain systemic therapy was no longer safe by referencing either patient tolerability or therapy toxicity. The second was to acknowledge that although more systemic therapy was possible, the oncologist believed it was of low benefit and more likely to be harmful. In some encounters, the oncologist explicitly provided this assessment: "if we're giving him chemotherapy—and this happens a lot—and it's not working, what we're doing is getting the side effects without any benefit." In other encounters, oncologists pursued strategies to have the patient verbalize how he or she might evaluate these trade-offs in light of inherent uncertainties. In one instance, an oncologist used a normalization of extremes by describing hypothetical patients: Someone who would "do anything ... [to] eke out a few more months...[and] pursue further therapy at all cost" compared with another who would "say the best way of treating me is to leave me off therapy." Both strategies involved naming that continuing therapy was of limited or no benefit.

DISCUSSION

In this analysis of communication between outpatients with advanced cancer and oncologists around decisions to continue or limit systemic therapy, we had two main findings. The first was continuing systemic therapy as the default was pervasive and that deficiencies in SDM process—inadequate fostering of choice awareness and integration of patient preferences—contributed to this default. This finding is inconsistent with best practice guidelines for discussing systemic therapy in advanced cancer. 14,29 Previous studies restricted to a smaller number of cancer diagnoses also confirm this finding. 30,31 Second, we found that discussion of permanently discontinuing systemic therapy was infrequent and oncologist often emphasize both avoidance of harm and marginal benefit in these conversations. Uniquely, our study was able to provide a relative measure of its infrequency versus other systemic therapy decision-making talk (random sample), as well as review a sufficient number of encounters to better characterize these infrequently studied encounters (purposive sample).

There are several potential reasons why patients and oncologists frame continuing systemic therapy as the default. Our study included SDM as a focus, and our results align well with others, and specifically, we found that (1) patients were infrequently invited to deliberate about therapy decisions, ^{17,32} (2) inadequate rates (0%-50%) of discussing no therapy as an option, ^{18,20} and (3) patient values were not frequently

assessed when making systemic therapy decisions. 20,30 We infer that these behaviors contribute to continuing systemic therapy as the default, yet they are not the only explanations. Brom et al³⁰ identified four patterns of daily oncology practice as potential contributors to this default: (1) Presenting the full therapy sets the standard, (2) focus on standard evaluation moments hampers evaluation of care goals, (3) opening question guides toward focus on symptoms, and (4) treatment is perceived as the only option. There are also potential benefits that support maintaining the possibility of future therapy (eg, arrival of a better therapy, maintaining hope, time for clinical improvement, and decision postponement). Our observation that oncologists attempted to either amplify positive emotions (eg, hope) or mitigate negative ones (eg, worry) when discussing limiting therapy lends support to the role that actual or perceived patient emotion has in these discussions. Given the theorized benefits of using defaults in therapy decision making,33 we speculate that both patients and oncologists might use this by default to simplify a set of complex and emotionally challenging decisions. Regardless of why it occurs, the unintended consequences of this default to continue systemic therapy are more hospital admissions in the later stages of cancer and delays in hospice enrollment, which are both linked to lower EOL quality.34,35

Our second finding that discussing permanent discontinuation was infrequent and oncologists tend to emphasize both harm avoidance and marginal benefit also finds support in the literature. Since our study was the first to quantify permanent discontinuation talk in this context, we needed to look at studies using documentation or specialty palliative care to assess our finding. Pirl et al¹³ found only a minority of patients with advanced cancer (16 of 81, 20%) had any oncology encounter where a definitive decision to permanently discontinue chemotherapy was documented. Looking at the intervention arm of a specialty palliative care trial for patients with advanced cancer, only 6% (31 of 497) of these encounters included discussion on either permanent discontinuation of systemic therapy or hospice enrollment.³⁶ Given that palliative care clinicians discuss EOL issues more frequently than oncologists, 37 the true estimate of discussing permanent discontinuation in oncology encounters is likely lower than 6%. By using a purposive sample to increase our number of permanent discontinuation encounters under review, we feel confident that oncologists tend to discuss both harm avoidance and marginal benefit in these conversations. This is significant because in their analysis of medical documentation, Pirl et al concluded, "in weighing the potential benefits and risks of additional chemotherapy, a decision may be guided more by the potential for harm."13 Although our findings support harm avoidance as an important rationale for permanently discontinuing treatment, we could not conclude that it was more important than perceived marginal benefit since both were mentioned. More work is needed to identify the salience of harm avoidance v perceived marginal benefit surrounding decision making for systemic therapy.

There were limitations in the study design. As a secondary analysis, we did not have the ability target which visits were recorded or interview participants to further probe potential influences on decision making. We could not independently verify the cancer and EOL care patients received outside of what was discussed in encounters beyond the available data. We cannot comment on communication differences between chemotherapy and immunotherapy discussion since the latter became a major therapeutic option after our study period. We speculate that emergence of more therapeutic options would only exacerbate the tendency to continue systemic therapy as the default as published literature in this area suggests that oncologists find immunotherapy presents additional challenges to discussing prognosis and treatment uncertainties with their patients.³⁸ Three sequential encounters are likely insufficient to fully evaluate the longitudinal nature of the patientoncologist relationship or changes in communication over time. Since participants knew they were being recorded, the potential that they may behave differently exists (Hawthorne effect). However, since encounters were recorded using personal recording devices and not a separate human observer, we infer this influence was negible.³⁹ We could not analyze nonverbal communication. Our study participants were selected from two large National Cancer Institute—designated cancer centers, although upward of 80% of patients who die with advanced cancer in the United States receive their cancer care at community hospitals.⁴⁰ Furthermore, since some protected health information was removed from the data because of participant confidentiality, our approach of inferring cancer type from transcripts opens up the possibility of misattribution for cancer diagnosis and treating clinician subspecialty.

The default decision to continue systemic therapy and infrequent discussion of permanent discussion likely contribute to the receipt of systemic therapy and hospitalizations closer to death and delayed hospice enrollment. Communication guidelines are useful practices to implement, ¹⁴ and a growing literature suggests outpatient interventions targeting patients and clinicians can improve communication in this context. ⁴¹⁻⁴⁴ Future work should focus on continuing to improve the effectiveness of patient-clinician communication and understanding the processes outside the oncology visit that contribute to patients receiving goal-aligned care throughout their continuum of cancer care.

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AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

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