

Triadic treatment decision-making in advanced cancer: a pilot study of the roles and perceptions of patients, caregivers, and oncologists

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Abstract

Purpose The research on cancer treatment decision-making focuses on dyads; the full “triad” of patients, oncologists, and caregivers remains largely unstudied. We investigated how all members of this triad perceive and experience decisions related to treatment for advanced cancer.

Methods At an academic cancer center, we enrolled adult patients with advanced gastrointestinal or hematological malignancies, their caregivers, and their oncologists. Triad members completed a semi-structured qualitative interview and a survey measuring decisional conflict and perceived influence of the other triad members on treatment decisions.

Results Seventeen patients, 14 caregivers, and 10 oncologists completed the study. Patients and caregivers reported little decisional regret and voiced high satisfaction with their decisions, but levels of decisional conflict were high. We found sizeable disagreement among triad members’ perceptions and preferences. For example, patients and oncologists disagreed

about the caregiver’s influence on the decision 56% of the time. In addition, many patients and caregivers preferred to defer to their oncologist about treatment decisions, felt like no true decision existed, and disagreed with their oncologist about how many treatment options had been presented.

Conclusions Patients, caregivers, and oncologists have discordant perceptions of the cancer treatment decision-making process, and bring different preferences about how they want to make decisions. These data suggest that oncologists should assess patients’ and caregivers’ decisional preferences, explicitly signal that a decision needs to be made whenever approaching an important crossroads in treatment and ensure that patients and caregivers understand the full range of presented options.

Keywords Advanced cancer · Treatment decisions · Triadic decision-making

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Introduction

Patients living with advanced cancer suffer significant distress, which is frequently compounded by treatment decision-making [1–6]. Clinical experience suggests that patients navigate these decisions by seeking input from their oncologists and caregivers. However, patients and their oncologists, the classic treatment “dyad,” often do not agree on goals of care [7] and may also disagree about each other’s roles in the decision-making process. For example, in two studies, patients agreed with their oncologists’ assessments of how decisions were made only 38 and 54% of the time [8, 9]. In general, oncologists tend to think their patients are more actively involved in the decision-making process than patients report actually feeling. Furthermore, oncologists are often largely unfamiliar with patients’ personal preferences, life priorities, and quality of life, and thus cannot take these factors into account when helping with decisions [10].

Patients and caregivers exhibit similar communication difficulties in the context of treatment decisions. Caregivers are present in at least three quarters of encounters between patients and oncologists [11] and actively participate in the decision-making process [12–15]. However, patients and caregivers often have differing perspectives. A meta-analysis of surrogate decision-making found that cancer caregiver surrogates correctly predicted patient preferences only 62% of the time [16]. Caregivers also experience their own significant distress about the disease and treatment decisions [17–20]. Poor disease-related communication between patients with cancer and caregivers results in both higher levels of psychological distress for both parties and increased complexity of treatment course [21–24].

These dyadic studies are informative, yet how decision-making operates within the full decision-making “triad” of patient, oncologist, and caregiver remains largely unstudied. For example, we know little about how caregivers influence treatment decisions. We also lack an understanding of variation or disagreement in triad members’ perspectives and perceptions of the decision-making process, or how those perspectives and perceptions impact patients’ and caregivers’ decisional satisfaction or conflict. Current models and guidelines for shared decision-making similarly omit caregivers, focusing instead on the patient-oncologist dyad [25, 26].

We sought to explore this triadic relationship by studying decision-making about treatment for advanced cancer. Specifically, we were interested in the following questions: (1) how much satisfaction, regret, and decisional conflict do patients and caregivers report after treatment decisions?; (2) how often do triad members’ perspectives differ about each other’s involvement in the decision-making process?; and (3) what are the sources, frequencies, and content of these differing perspectives? We hypothesized that patients, caregivers, and oncologists would have different perspectives about each

other’s influence and involvement in the decision-making process.

Methods

Study design

Using a mixed-method study design, we surveyed and interviewed patients, caregivers, and oncologists who had recently participated in a cancer treatment decision. Study recruitment took place between 9 August 2013 and 1 December 2013 at the Duke Cancer Institute. We screened outpatients with advanced gastrointestinal malignancies and inpatients with advanced hematological malignancies who had made a treatment decision within the preceding 3 months. We focused on these patients because their poor long-term prognosis often presents clearer choices between active therapy and palliation. The study was approved by the Duke University School of Medicine’s Institutional Review Board.

Subjects

Eligible patients were adult, English-speaking, able to provide informed consent, and had one of the following conditions: metastatic pancreatic cancer, metastatic colorectal cancer, metastatic gastroesophageal cancer, metastatic cholangiocarcinoma, relapsed or refractory acute myeloid leukemia, relapsed or refractory non-Hodgkin’s lymphoma, or relapsed or refractory acute lymphoblastic leukemia. Oncologists were enrolled and consented first, and we then identified eligible patients from their clinic schedules and inpatient rosters. Each consenting patient was asked to also identify a primary caregiver who generally accompanied them to oncologist visits. Patients, caregivers, and oncologists completed an audio-recorded semi-structured interview and a series of survey questions.

Measures

Standard, validated instruments included an adapted *Decisional Conflict Scale*; [27] *Satisfaction with Decision* instrument; [28] and *Decision Regret Scale*. [29] The *Decisional Conflict Scale* quantifies the uncertainty and internal conflict experienced in making a health care choice. We used a shortened and modified version of this scale. The *Satisfaction with Decision* and *Decision Regret Scales* are 6- and 5-item scales, respectively, that measure participant attitudes about a decision after it has been made. We also created a series of survey questions assessing each triad member’s perception of their confidence in the decision, the strength of their preference about a particular choice, their influence on the decision, and their participation in the decision-making process. Each of

these questions used an ordinal numerical-rating scale, ranging from 0 to 10. We did not administer the *Decisional Conflict* and *Satisfaction with Decision* scales to clinicians, as these questions were not applicable to them. Each respondent also completed a separate semi-structured audio-recorded qualitative interview that focused on their patient's clinical scenario, decision, and decision-making process.

Statistical approach

We used descriptive statistics to characterize baseline participant variables. To assess the level of agreement within the triad, we analyzed data at the level of individual pairs of triad members (e.g., patient and caregiver, oncologist and patient, caregiver and oncologist). We considered “disagreement” as a difference in numerical rating on the Likert scale of more than 2 units, based on an a priori assertion that a > 25% difference is probably clinically meaningful. We created plots to help visualize levels of agreement, and numerical tables to facilitate quantification thereof. We calculated descriptive statistics for the demographic and satisfaction measures. Comparisons were made for variables that were present in at least 2 out of the 3 groups. For continuous variables, a Kruskal-Wallis test was implemented. For categorical variables, a Fisher's exact test was used. All three scales, *Decision Conflict*, *Satisfaction with Decision*, and *Decision Regret*, were transformed to a range of 0–100, using established scoring methods for each scale [27–29]. A score of 0 signifies no conflict, low satisfaction, or no regret with the decision, respectively, and a score of 100 signifies marked conflict, high satisfaction, or high regret with the decision, respectively.

Qualitative analysis

We used content analysis to explore the transcribed audio-recorded interviews. Each member of the research team individually reviewed the interview transcripts and made notes about possible latent and manifest codes and themes. We convened and reviewed common and recurrent themes, definitions and initial decision rules regarding codes and their relationship to larger themes. These were then discussed by the group, and representative quotes were identified for inclusion in this manuscript.

Results

We screened records for 396 patients, 343 were ineligible. Of the 53 eligible patients, we approached 41 patients. We ultimately enrolled 22 patients, 16 caregivers of these patients, and 12 oncologists, of whom 17, 14, and 10 completed the study, respectively. Some oncologists had more than one patient in the study. Oncologists were only asked

to participate in an interview if one of their patients was enrolled, hence the final analyzable sample of 10 oncologists. The mean age of oncologists was 47.4, with an average of 20.3 years in practice. Participants' baseline variables are reported in Table 1. The mean age of patients and caregivers was 61 and 60, respectively. Nine patients (53%) had a relapsed/refractory hematologic malignancy (5 with non-Hodgkin's lymphoma, and 4 with acute myeloid leukemia). Eight patients (47%) had a metastatic gastrointestinal tumor (4 colorectal, 2 gastric, and 2 pancreatic).

Agreement between triad members

Sizeable disagreement (a difference of two or more on the 10-item scales) was noted in multiple domains (Table 2). For example, 54% of patients and oncologists disagreed about the caregiver's strength of treatment preference. Patients and oncologists disagreed about the caregiver's influence on the decision 56% of the time, and 47% of patients and oncologists disagreed about the strength of the oncologist's preferences about the decision.

Forty-six percent of caregivers and oncologists disagreed about the patient's confidence in the decision, and 46% disagreed on the extent of the oncologist's participation in the decision-making. Thirty-nine percent of caregivers and oncologists disagreed about the oncologist's degree of influence on the decision, and 46% of caregivers and oncologists disagreed about the caregiver's influence on the decision. In general, patients and caregivers rated oncologists as having more influence than the oncologists rated themselves as having; 46% of patients and 41% of caregivers said the oncologist “completely” influenced the decision, while only 17% of oncologists they influenced the decision “completely.”

Disagreement among patients and caregivers was also relatively common. Patients and caregivers disagreed on how strongly the caregiver felt about their treatment preference 38% of the time. They disagreed about the extent of the caregiver's influence on the decision 33% of the time, and the extent of the oncologist's participation in the decision 31% of the time.

Regret, satisfaction, and conflict

Patients and caregivers reported little decisional regret and voiced high satisfaction with their decisions, but levels of decisional conflict were high (patients' mean score was 67.6 [Range 40–85; SD 13.1], and caregivers' was 57.9 [Range 25–85; SD 17.4]) (see Table 3). There were no statistical differences in regret, satisfaction, or conflict between groups.

Table 1 Demographics

	Patient (N = 17)	Caregiver (N = 14)
Female (N, %)	3 (17.6%)	12 (85.7%)
DoB/age		
Mean (SD)	60.6 (13.6)	60.1 (12.8)
Range	(33.0–78.0)	(35.0–73.0)
Marital status		
Single, never married	1 (5.9%)	0 (0.0%)
Married/living as married	16 (94.1%)	13 (92.9%)
Divorced or separated	0 (0.0%)	1 (7.1%)
Employment		
Working full-time	6 (35.3%)	3 (21.4%)
Working part-time	2 (11.8%)	1 (7.1%)
Not currently working	0 (0.0%)	3 (21.4%)
Retired	8 (47.1%)	7 (50.0%)
On disability	1 (5.9%)	0 (0.0%)
Finances		
You are having difficulty paying the bills	2 (11.8%)	2 (14.3%)
You have cut back on things to pay	0 (0.0%)	1 (7.1%)
You pay bills, but have little to spare.	4 (23.5%)	5 (35.7%)
You have plenty of money for payments	10 (58.8%)	6 (42.9%)
Other	1 (5.9%)	0 (0.0%)
Education		
Some high school, but did not finish	0 (0.0%)	2 (14.3%)
Completed high school diploma or GED	1 (5.9%)	3 (21.4%)
Some college, but did not finish	7 (41.2%)	1 (7.1%)
Completed trade school	1 (5.9%)	0 (0.0%)
College—associates degree	1 (5.9%)	0 (0.0%)
College—bachelors degree	2 (11.8%)	3 (21.4%)
Some graduate or professional school	1 (5.9%)	1 (7.1%)
Graduate or professional degree	4 (23.5%)	4 (28.6%)
Race		
White	15 (88.2%)	11 (78.6%)
Black or African American	1 (5.9%)	2 (14.3%)
Asian	0 (0.0%)	0 (0.0%)
Non-Hispanic/Latino	17 (100.0%)	14 (100.0%)
Religion		
Christian	15 (88.2%)	11 (78.6%)
Not a member of any religion	2 (11.8%)	2 (14.3%)
Other	0 (0.0%)	1 (7.1%)
Faith		
Very important	11 (64.7%)	10 (76.9%)
Somewhat important	4 (23.5%)	3 (23.1%)
Not at all important	2 (11.8%)	0 (0.0%)

Qualitative themes

The qualitative content analysis revealed four themes that help explain our quantitative findings (Fig. 1).

No choice to make

We noted that many patients and caregivers felt that no true decision existed. They sometimes articulated this as a false choice, such as between more treatment “or nothing.” For example, one patient said:

“I didn’t have any others left.... my choice was the trial or nothing.”

This idea of a “false” choice between treatment and death helps to explain why patients could be confident in the decision and simultaneously experience significant decisional conflict about it.

Patients often defer decision-making

Many patients and caregivers cited their confidence in the oncologist’s expertise, and thus preferred to defer to their oncologist about treatment decisions. For example, one patient said:

“I kind of leave the decision-making up to the doctor. I don’t even want to know the names of the stuff they’re giving me. I just want them to do what they know is right.”

Patients gave particular preference to this more paternalistic approach to shared decision-making when they faced a complex set of treatment options (e.g., multiple kinds of chemotherapy). When patients did take the lead in decision-making, patients and caregivers often seemed more sure about the decisions than oncologists did. For example, one doctor said:

“I think I have a little bit of hesitation – I still do – around whether or not it could [achieve the] goal ... [of] maintaining [the patient’s] quality of life. It’s a relatively toxic regimen and I’d be concerned about, uh, whether or not it’s the right choice in terms of symptom management.”

Understandably, oncologists seemed more attuned to the complexities and uncertainty involved in treatments. Conversely, patients and caregivers often seemed relieved to simply have a treatment option to choose, especially when they saw the choice as a “false” one between treatment and nothing, as above. Despite oncologists’ uncertainty, no oncologist ever

Table 2 Decisional disagreement* by pairs of triad participants

Question	Patient vs. MD	Patient vs. caregiver	Caregiver vs. MD
Patient's confidence in the decision	35%	23%	46%
How strongly the caregiver felt about their decision preference	54%	38%	22%
Extent of caregiver's influence on decision	56%	33%	46%
How strongly the MD felt about their decision preference	47%	27%	27%
Extent of MD participation in the decision-making	35%	30%	46%
Extent of MD's influence on the decision	29%	0%	39%

*here “disagreement” means that subjects' responses differed by more than 2 units on the 11-point Likert scale

mentioned assessing patients' and caregivers' preferences for how they wanted to make decisions.

So those were the four options. I mean, aggressive treatment vs. symptom management with no chemotherapy.”

Disagreement about choice set

In contrast, oncologists often recalled considering and discussing many different options in the same situations where patients felt they had none. One patient said:

“Well, I guess the decision would have been that I had a choice either to enter into the chemo treatment program or not do it at all,”

Whereas his oncologist stated:

“We talked about several different chemotherapy options. We talked about FOLFIRINOX vs. gem/abraxane vs. Gemcitabine monotherapy vs. hospice.

Discordant perceptions about preferences

Lastly, there was often a sizeable disconnect in the perceptions of the patient, caregiver, and oncologist, and this disconnect even occurred between patients and caregivers. For example, one patient said:

“I think that [the doctor's] decision was the correct one and I think that he ...encouraged us in the direction of hospice, and I think the decision was ultimately a triple decision between my wife, [the doctor] and myself.”

But this patient's caregiver said,

Table 3 Decisional scales

	Patient (N = 17)	Caregiver (N = 14)	MD (N = 10)	Total (N = 48)	
Decision conflict					$p = 0.1143^1$
Mean (SD)	67.6 (13.1)	57.9 (17.4)		63.2 (15.7)	
Range	(40.0–85.0)	(25.0–85.0)		(25.0–85.0)	
Satisfaction with decision					$p = 0.8020^1$
Mean (SD)	88.9 (10.7)	85.7 (16.2)		87.5 (13.3)	
Range	(70.8–100.0)	(50.0–100.0)		(50.0–100.0)	
Decision regret					$p = 0.6690^1$
Mean (SD)	12.9 (10.8)	15.2 (13.7)	15.0 (16.7)	14.3 (13.7)	
Range	(0.0–30.0)	(0.0–50.0)	(0.0–50.0)	(0.0–50.0)	
Satisfied					$p = 0.7079^2$
Missing	1 (.%)	0 (.%)		1	
3	1 (6.3%)	1 (7.1%)		2 (6.7%)	
4	4 (25.0%)	6 (42.9%)		10 (33.3%)	
5	11 (68.8%)	7 (50.0%)		18 (60.0%)	

¹ Kruskal-Wallis test

² Fisher's exact test

1. No Choice to Make?

EXAMPLE 1: “CHOOSING” BETWEEN A CLINICAL TRIAL AND NOTHING

Patient: “I didn’t have any others left.... my choice was the trial or nothing.”

EXAMPLE 2: “CHOOSING” HOSPICE AND NOTHING

Patient: “I think that [the doctor’s] decision was the correct one and I think that he ...encouraged us in the direction of hospice, and I think the decision was ultimately a triple decision between my wife, [the doctor] and myself.”

Caregiver: “I don’t think that we really had any other options [than hospice], because the cancer that he has does not die. Um, it does not respond [to treatment].”

2. Patients Often Defer

EXAMPLE 1: LEAVING THE CHOICE UP TO THE (UNSURE) ONCOLOGIST

Patient: “Basically, my attitude toward this is, um, the first one did not work. The doctor is the one with all the brains and knows about all of this stuff. He told me what he was using next, I said ‘very good,’ and we started it, and we were very fortunate that it actually worked. I kind of leave the decision-making up to the doctor. I don’t even want to know the names of the stuff they’re giving me. I just want them to do what they know is right.”

Caregiver: “I think it was Dr. X’s decision. Um, you know, he threw it out there and said ‘this is what I think is going to happen’ and we trust him.”

MD for Patient: “I think I have a little bit of hesitation – I still do – around whether or not it could [the] goal ... [of] maintaining his quality of life. It’s a relatively toxic regimen and I’d be concerned about, uh, whether or not it’s the right choice in terms of symptom management.”

EXAMPLE 2: LETTING THE ONCOLOGIST DETERMINE THE SPECIFICS

Patient: “I’ll use an analogy... If you go to a car mechanic, and he starts telling you about your compressor or if something’s not doing right, you don’t know enough to really challenge him on it, so you just hope you trust your, your mechanic. You better make sure you have a good, trustworthy mechanic. I’ve got a good, trustworthy doctor, so I don’t worry.”

Patient: “I don’t make decisions about which chemical he’s going to use. That’s out of my league, I’m sorry.”

3. Disagreement About Choice Set

EXAMPLE 1: DISAGREEMENT IN OPTION SET WHEN CHOOSING CHEMO

Patient: “They really didn’t give me no other treatment options. They just came out and told me that I need chemotherapy, that it would help, so I decided to take chemo.”

Fig. 1 Emerging themes and illustrative quotations

“I don’t think that we really had any other options [than hospice], because the cancer that he has does not die. Um, it does not respond [to treatment].”

Other times, patients and caregivers agreed, but both disagreed with the oncologist. One patient said,

“Well, this was the final option. There were two other ones the doctor wanted me to do, but I didn’t qualify for them.”

Similarly, the caregiver said,

[The doctor wanted] “him to do the clinical trial.” And also, “...the doctor said that he really wasn’t ready for palliat... how do you say that? Palliat care (sic)? He was

stronger, and he was doing pretty well for all he’s gone through.”

Yet this doctor expressed uncertainty about the right choice, and seemed to think that hospice probably would have been a better path (Fig. 1).

Discussion

In this pilot study, we found that patients, caregivers, and oncologists have significantly different preferences and perspectives about both treatment decisions and the decision-making process, despite high decisional satisfaction and low decisional regret. Furthermore, many patients and caregivers wanted to defer to the oncologist about treatment choices and

Caregiver: “...They just told us about the chemo, that was it.”

MD for Patient: “So, the options discussed there was standard of care chemotherapy versus a clinical trial we have in first-line colorectal cancer, and she wanted to pursue more of standard of care, and from a standard of care chemotherapy for colorectal cancer, the question then becomes from a cytotoxic chemotherapy based regimen, oxaliplatin base or irinotecan base. So, those were the options we discussed with her, ah, and we decided to go with oxaliplatin based therapy.”

EXAMPLE 2: REMEMBERING FEWER CHOICES THAN WERE PRESENTED

Patient: “Well, I guess the decision would have been that I had a choice either to enter into the chemo treatment program or not do it at all.”

MD for Patient: “So, we talked about several different chemotherapy options. We talked about Folfirinox vs. gem/abraxane vs. Gemcitabine monotherapy vs. hospice. So those were the four options. I mean, aggressive treatment vs. symptom management with no chemotherapy”

4. Discordant Perceptions About Preferences

Note: It was rare for all 3 members of the triad to be in agreement about the available options, the “correct choice,” and each individual’s preference about it

EXAMPLE: CHOOSING BETWEEN STANDARD CHEMO, CLINICAL TRIAL, AND HOSPICE

Patient: “Well, this was the final option. There were two other ones the doctor wanted me to do, but I didn’t qualify for them.”

Caregiver: [The doctor wanted] “him to do the clinical trial.” And also, “The doctor did say – and this is his regular oncologist – the doctor said that he really wasn’t ready for palliat... how do you say that? Palliat care? He was stronger, and he was doing pretty well for all he’s gone through.”

MD for Patient: “if I were in his shoes...I think I would have chosen just aggressive symptom management, perhaps hospice, but trying to grappling with it from his and his wife’s perspective, they’ve really been very hopeful that further chemotherapy will continue to control their disease and maybe even improve, or at least stabilize, his symptoms. They’ve wanted to continue to be very aggressive, um, he is very young and I know that from their side, I think that they really wanted to do further therapy.”

Fig. 1 (continued)

recalled different numbers and types of treatment options than their oncologist reported were being considered. In addition, triad members often disagreed about the “correct” choice in the decision-making process. These findings have important implications for communication about treatment decisions and the implementation of shared decision-making models in clinical practice.

We found disagreement among all triad members about the preferences and influence of other triad members, but especially about the roles of oncologists and caregivers. Moreover, oncologists did not mention ever asking patients or caregivers how they prefer to make decisions. If, indeed, patients and caregivers often prefer a paternalistic approach to decision-making, oncologists may have more influence over treatment decision-making than they realize. This imbalance can be mitigated by oncologists attending more closely to patient and caregiver preferences about decision-making, including

making a conscious effort to formally assess their preferred decisional roles.

Oncologists were concerned about accurately informing patients, and always discussed the presentation of multiple treatment options. However, many patients and caregivers did not feel like there was a true decision to make, or felt that their decisions involved only binary “treat or not” options. Patients and caregivers felt this way despite having been enrolled in this study only because their oncologists had identified a recent, significant treatment decision. For example, in one case of a patient with pancreatic cancer, the oncologist described an explicit decision about three different chemotherapy regimens commonly used in this setting, with varying intensities and tradeoffs; the patient and caregiver only recalled a decision about whether or not to receive chemotherapy. This finding suggests that patients and caregivers could benefit from more explicit “signposting” that an important

decision needs to be made, and that it is a nuanced one, rather than a binary “yes/no” choice. Health literacy challenges may also contribute to the lack of understanding about options. Therefore, using plain language or teach-back methods may also be helpful. Further study in this area is needed.

Finally, triad members frequently disagreed about the “correct” treatment choice. Patients and caregivers may select more aggressive treatment options when they are unclear about their oncologists’ preferences or confidence in specific treatment options. For example, one patient and caregiver decided to continue aggressive chemotherapy, despite the patient’s oncologist expressing a preference for a more palliative approach in his interview. Further study is needed in these areas, to better characterize triadic disagreement, identify its predictors, assess how disagreement relates to decisional outcomes, and to identify targets for interventions that will both improve alignment of triad members’ perceptions, and reduce decisional conflict.

Limitations

This study is limited by the single investigative site and small sample. The small sample particularly limits our abilities to make inferences about decision-making processes across different kinds of treatment decisions (e.g., aggressive vs. palliative treatments). It relied on triad members’ retrospective accounts and evaluations of the decision-making process, which may be subject to biased recollection. We did not adjust for potential confounders in our quantitative analysis and kept our metrics descriptive. We also did not examine any potential predictors of disagreement, as our small sample size precludes this. Finally, the study encompassed a wide range of treatment decisions across many kinds of cancer. Yet, the observations ring true clinically and deserve exploration in further research. Based on lessons learned from this pilot study, a larger study of triadic decision-making is now underway.

Conclusion

Members of the cancer treatment decision-making triad often feel conflicted, have discordant perceptions of other triad members’ roles in the decision-making process, and bring different preferences about how they want to make decisions. Our results suggest that oncologists should better assess patients’ and caregivers’ decisional preferences, explicitly signal that a decision needs to be made whenever approaching an important crossroads in treatment, and ensure that patients and caregivers understand the full range of options being presented. More research is needed to understand the predictors of and contributors to disagreement and decisional conflict in the cancer treatment decision-making triad, and to more closely

examine how shared decision-making operates within the full triad of patient, caregiver, and oncologist, amid the sizeable limitations we have identified here.

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