






# Communication Strategies of Transplant Hematologists in High-Risk Decision-Making Conversations

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## ABSTRACT

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**PURPOSE** Shared decision making (SDM) is essential to empower patients with blood cancers to make goal-concordant decisions about allogeneic hematopoietic cell transplantation. This study characterizes communication strategies used by hematologists to discuss treatment options and facilitate SDM with patients in this high-risk, high-reward setting.

**METHODS AND MATERIALS** We recruited US hematologists who routinely perform allogeneic hematopoietic cell transplant through email. Participants conducted up to an hour-long video-recorded encounter with an actor portraying a 67-year-old man with recently diagnosed high-risk myelodysplastic syndrome. We transcribed and qualitatively analyzed video-recorded data.

**RESULTS** The mean age of participants (N = 37) was 44 years, 65% male, and 68% White. Many hematologists included similar key points in this initial consultation, although varied in how much detail they provided. Their discussion of treatment options included transplant and chemotherapy and less commonly supportive care or clinical trials. They often emphasized transplant's potential for cure, discussed transplant chronologically from pretransplant considerations through the post-transplant course, and outlined risks, complications, and major outcomes. Hematologists referred to several elements that formed the basis of treatment decision making. The strength of their treatment recommendations ranged from strong recommendations for transplant or chemotherapy to deferrals pending more information. Hematologists also varied in the extent to which they indicated the decision was physician-driven, patient-led, or shared.

**CONCLUSION** The transplant decision-making discussion is complex. Identification of similar content areas used by hematologists can be used as the basis for a communication tool to help hematologists discuss allogeneic hematopoietic cell transplant with patients.



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## INTRODUCTION

Patients diagnosed with blood cancers face serious physical and psychological burdens. Anticancer therapies including allogeneic hematopoietic cell transplantation (alloHCT) may provide a chance of cure but carry risks of life-altering complications, relapse, and even early mortality.<sup>1,2</sup> In this high-risk, high-reward setting, incorporating patients' values, goals, and preferences into decision making is imperative to helping patients make informed decisions and achieve effective shared decision making (SDM).<sup>3-8</sup>

Higher-risk myelodysplastic syndromes (MDS) are a representative blood cancer that involves this critical decision making. Particularly in older adults, higher-risk MDS is

associated with poor overall survival and significant risk of progressing to acute myeloid leukemia.<sup>9-12</sup> Although alloHCT is considered a standard-of-care option for fit patients up to age 75 years,<sup>13,14</sup> the substantial risks offset its curative advantage, even in those considered excellent transplant candidates.<sup>15-17</sup> Ultimately, patients must decide whether to pursue alloHCT versus an alternative pathway that may prolong their life and/or help with symptoms but offer no chance for cure.<sup>18-20</sup> Despite reported limitations of hematologists' communication,<sup>21-25</sup> we do not know how they discuss alloHCT and engage patients in decision making.

This study aimed to characterize the communication strategies used by hematologists to discuss treatment

## CONTEXT

### Key Objective

To characterize how hematologists discuss treatment options and facilitate decision making in patients referred for allogeneic hematopoietic cell transplantation (alloHCT).

### Knowledge Generated

Using virtual visits with actors portraying a patient with recently diagnosed high-risk myelodysplastic syndrome, we found that hematologists included similar key points in their discussion but varied in extent of detail. Although several factors informed decision making, often hematologists focused on the patient's fitness and transplant's chance for cure.

### Relevance

Recorded conversations of physicians talking with patients about urgent, complex medical decisions are rare and valuable. This study captures how hematologists begin a longitudinal discussion about alloHCT. Our findings will be used to develop a communication tool to optimize patient-centered communication about transplant.

options including alloHCT and to facilitate decision making in the challenging landscape of high-risk MDS.

## METHODS AND MATERIALS

### General Design

This observational study was composed of video-recorded virtual encounters of a nonrandom sample of hematologists with actors trained to portray an older patient with recently diagnosed high-risk MDS referred for discussion of treatment options including alloHCT. We obtained approval from the University of Wisconsin Minimal Risk Research Institutional Review Board. Encounters occurred between February 2022 and March 2023.

### Patient Case

Our team designed a patient case representing a clinical scenario in which alloHCT was a reasonable option. This simulated patient was a 67-year-old man referred for specialty hematology consultation. He had a few common medical comorbidities (well-controlled noninsulin-dependent diabetes, hypertension, and a remote peptic ulcer), an active lifestyle, and good family support, including from several healthy adult children. He valued being active and spending quality time with his family. The results of his recent bone marrow biopsy indicated he had high-risk MDS. We constructed the scenario to enable hematologists to spend most of their time discussing treatment options and issues surrounding decision making.

### Actor Hiring and Training

We recruited and hired two professional actors. On the basis of a secondary aim looking at differences in communication with a Black versus White patient (results to be reported elsewhere), actors were of similar physical features except for race (one Black and one white). Over four virtual sessions lasting 8 hours,

we trained the two actors to portray the same character described above until their performances mirrored each other.

We emphasized improvisation over strict scripted responses, although we trained actors to have semisc scripted responses to anticipated common moments in the encounter. We also directed our actors to ask for a treatment recommendation by the end if the hematologist had not provided one. Our actors and study team discussed issues that arose about character portrayal to reach a consensus about appropriate patient representation.

As a quality assurance measure to ensure fidelity across encounters, team members provided written line-by-line feedback after each actor's first two study encounters.

### Hematologist Selection and Recruitment

Hematologists whose clinical practice included patients with MDS and who routinely performed alloHCT in the United States were eligible to participate.

We excluded physicians still in fellowship training. We recruited hematologists through email and personal connections. During the early stages, we asked known professional contacts to send introductory emails to colleagues at their home institutions, and we sent follow-up emails. Later we sent emails to hematologists at additional institutions whose contact information was available on the Internet. We contacted each hematologist up to three times, after which they were deemed not interested in participating. We offered all participants an honorarium of \$249 US dollars.

### Hematologist Informed Consent and Random Assignment

After hematologists responded with interest, study staff screened them for eligibility and obtained informed consent.

Hematologists knew the encounter would be with a simulated patient. We randomly assigned hematologists to an encounter with either the Black or the White patient actor, stratified by race (White/non-White) and sex at birth.

### Patient Encounter

We provided each participant with a document containing the patient's background clinical information immediately before the virtual encounter. The hematologist and the patient actor met over a videoconference set up by our study staff. We selected a virtual platform originally because of safety concerns amid the COVID-19 pandemic and maintained this modality for ease in recruitment of hematologists nationally. Each video-recorded encounter lasted up to 1 hour. After the encounter, a study member contacted each hematologist and solicited feedback. We stored all recorded data in a secure, encrypted, cloud-based file accessible only to study members.

### Sample Size Considerations

On the basis of consideration of our secondary aim looking at race differences, our target recruitment goal originally was 60 hematologists. On the basis of previous studies, we expected data saturation for the current qualitative analysis to occur between 20 and 30 hematologists.<sup>23,26</sup>

### Qualitative Analysis

We used NVivo Transcription to transcribe video-recorded encounters, and research assistants verified transcript fidelity and deidentified participant information. We also used NVivo for data organization. Team members (R.A.R., T.T., and T.C.C.) met regularly during and after data collection to view video encounters and transcripts. We used an inductive, iterative process of coding to develop a preliminary coding scheme, and revised and added to our coding scheme until no new codes emerged. We used constant comparative analysis to examine relationships within and across codes and transcripts. Once we were confident that no additional codes were needed, one team member (R.A.R.) coded the remaining transcripts independently and brought issues for review in ongoing team meetings. We shared our initial findings with study participants in May 2023.

## RESULTS

We personally contacted over 200 hematologists from 85 academic centers. Thirty-seven hematologists from 25 academic centers participated (Table 1). The average encounter duration was 41 minutes 54 seconds (standard deviation, 11 minutes 49 seconds).

### General Overview

Many hematologists included similar key points during this initial consultation (Fig 1; Table 2), although they varied

greatly in the amount of detail they presented within each content area. Some hematologists concentrated on contrasting the risks and benefits of each treatment option, while others focused more exclusively on transplant. Some hematologists discussed in detail many components of transplant beyond its risks and benefits.

### Introductory Talk

Hematologists started the conversation with a brief introductory phase. This nearly uniformly included an inquiry about the patient's perception, or understanding, of his condition.

### MDS Talk

The patient's answers to perception questions often led directly to a discussion about MDS. Hematologists frequently

**TABLE 1.** Demographic and Clinical Characteristics of Hematologists

Characteristic	N = 37
Age, years, median (IQR)	44 (38-50)
Sex, No. (%)	
Male	24 (65)
Race, No. (%)	
White	25 (68)
Asian	9 (24)
Other (Middle Eastern, North African)	3 (8)
Formal fellowship training, No. (%)	
Hematology and medical oncology	32 (86)
Clinical hematology	5 (14)
Medical oncology	5 (14)
Blood and bone marrow transplants	22 (59)
Palliative care	2 (5)
Formal communication training, No. (%)	
Workshop, didactics, and/or palliative care rotation	27 (73)
Estimated number of patients treated with alloHCT annually, No. (%)	
<25	5 (14)
25-50	19 (51)
51-75	6 (16)
76-100	3 (8)
>100	4 (11)
Estimated clinical time devoted to alloHCT annually, No. (%)	
<25%	3 (8)
25%-50%	14 (38)
51%-75%	13 (35)
76%-100%	7 (19)
Location of medical center/place of employment, No. (%)	
Large urban area	24 (65)
Moderate-size city that draws from a rural state	13 (35)

Abbreviation: alloHCT, allogeneic hematopoietic cell transplantation.

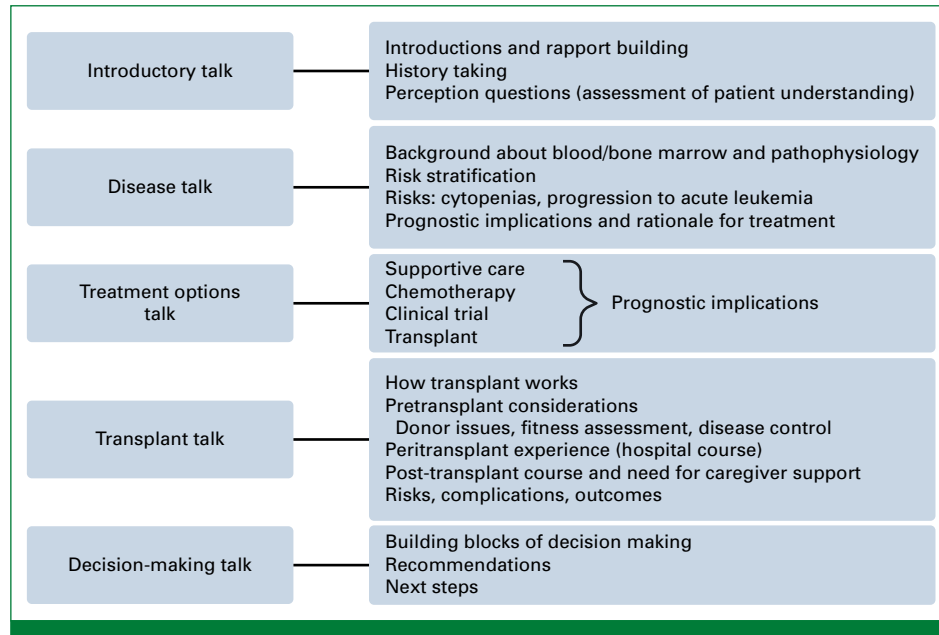


FIG 1. Structure of the transplant consultation.

talked about the pathophysiologic basis behind MDS; the severity of the patient's MDS and his risk for adverse outcomes including life-threatening cytopenias and transformation to acute leukemia; and prognostic estimates. These details provided a rationale for treatment. In particular, despite the patient's serious condition, transplant offered a chance of cure.

### Treatment Option Talk

Most hematologists made clear that multiple treatment options existed. Hematologists described chemotherapy and transplant most consistently, and less commonly brought up supportive care alone or a clinical trial. Many acknowledged the potential difficulty in deciding among options, given their different risk/benefit profiles. The prominent difference among options was their possibility of cure or not, with consequent prognostic implications. In particular, hematologists closely linked transplant with its potential for cure and referenced its high-risk, high-reward nature with language that juxtaposed hope and optimism about cure against warning about life-altering complications and even death.

Some hematologists described chemotherapy with hypomethylating agents nearly exclusively as an antecedent step before transplant. Many others discussed chemotherapy also as an alternative, standalone option, although with varying levels of endorsement. Some expressed caution that although chemotherapy could prolong life and allow decent quality of life in the short term, it did not offer a chance for cure. Others gave a more neutral deliberation on the risks and

benefits of chemotherapy and described how patients' preferences may lead them to choose chemotherapy alone.

Although less often hematologists named supportive care as an option at one end of the treatment spectrum, many alluded to it as an essential aspect of care throughout the patient's illness journey.

### Transplant Talk

In further discussion about transplant, hematologists described how it worked and often outlined steps before transplantation, including finding a donor, formally evaluating the patient's fitness, and sometimes addressing disease control with chemotherapy. The hematologist's determination of the patient's candidacy to undergo transplant tied closely to transplant's high-risk, high-reward nature. Some indicated that without these prerequisite components in place, transplant could not occur, while others explained that these steps yielded useful information they would incorporate into transplant planning.

Hematologists also reviewed the peritransplant and post-transplant course chronologically, including conditioning, the transplantation itself, close monitoring often in a hospital setting, and prolonged recovery necessitating dedicated caregiver support. Meanwhile, many hematologists discussed potential complications, including graft-versus-host disease (GVHD) and infection, and outlined major end outcomes of transplant. Outcomes included cure, relapse, or prohibitive morbidity or mortality resulting from transplant-related complications. Sometimes, in response

**TABLE 2. Representative Quotations of Major Components of the Transplant Consultation**

Component of the Transplant Consultation	Representative Quotations
Introductory talk	
Perception questions	<p>What has your doctor shared with you so far? (04)</p> <p>Tell me a little bit about what you hope to get out of today's visit and what you want to make sure we discuss. (33)</p>
Disease talk	
Risk stratification	<p>With some of the evaluation they did on your blood work and bone marrow, they were able to give you a risk score for your MDS. And so we categorize MDS into lower risk, middle of the road risk, and higher risk disease, particularly that risk for transforming to acute leukemia. And unfortunately, you're in the higher risk category, which means that with supportive care, we'd be looking at an average time to developing leukemia [of] one to two years. (28)</p>
Rationale for treatment	<p>What we'd like to do is treat people before that [acute leukemia] ever happens, because it's much easier to treat you now than it would be if the disease progressed. (32)</p>
Treatment options talk	
Treatment options differ in their risks and benefits, and choosing among them may be difficult	<p>There's many different treatment approaches to it. We're going to talk a little bit now about different approaches we could take to MDS, and some of this will depend on your goals and, and how you want to approach a major medical problem like MDS. (28)</p> <p>In one option, the risk is front-loaded. It's all within the first three or four months of the treatment for a better future. In the other option, the risk is pushed down the road favoring quality of life today in the now. Helping people be with their families and do the things that they want to do, but knowing that their time is limited in moving forward. (27)</p> <p>What I tell people is that transplant is a choice. It doesn't feel like a good choice when [ ] the other choice I'm telling you is that the disease is going to progress. [ ] It's not a great choice, but it's a choice. And it's something that you have to decide you're okay taking on that risk to move forward. (32)</p>
Supportive care	<p>This is an option, although most of our physicians who treat this disease would not recommend that option. (07)</p> <p>That [supportive care] comes along with anything that we do; we always try to help you feel as best you can. (35)</p>
Clinical trial	<p>We advance science by doing clinical trials. So, we always want to treat cancer patients on clinical trials because that's all we've got to find a cure. Other treatments that we have today are not good enough, especially in blood cancers. [ ] So, you could think about that; we'll provide you more information on that. And whatever you decided we'd go that way. (21)</p>
Chemotherapy	<p>The purpose[s] of these treatments are usually to try and improve quality of life, improve symptoms, decrease transfusions and, you know, give some good quality of life. But [ ] when I say it's not expected to last forever, it means it's not expected to cure the disease. (37)</p> <p>[Chemotherapy] may make you feel better, but it may not. Overall, we know that it on average makes people feel better and helps them live a bit longer. (25)</p>
Transplant	<p>Nothing is really going to cure the MDS at this point, except for a bone marrow transplant. [ ] Bone marrow transplant can be difficult. [ ] It's not the easiest procedure to go through, and there are a lot of people who do very well with it. And then there are complications too. (20)</p> <p>It's important to understand that myelodysplasia is not curable with anything other than a bone marrow transplant. So, every other treatment we have for myelodysplasia can make things better for a while. It may reduce the blasts, it may improve your blood, you may feel better, but in the long run, it will not make myelodysplasia go away. (16)</p>
Transplant talk	
Pretransplant considerations	<p>We just need to make sure it [MDS] stays stable, or if we did chemotherapy, to try to reduce the disease burden. So, you need to be in good shape, and you need to have a good donor. [If] any one of these three things doesn't happen, you won't be able to proceed with the transplant. (13)</p> <p>We need to go into a transplant [with] eyes wide open because it is a dangerous and it is a potentially hard treatment for someone like you. (23)</p>
The transplant experience	<p>Transplant changes your life. You know, it's, for at least the first year, you're living a very different life. (08)</p> <p>The overall process of the transplant, it is nobody's, I'm going to be very honest, it's no one's best year. It's no one's favorite year. It is, for no one is it the year that they feel the best they have. After that distress and the hospitalization, the [ ] process of getting your strength back, feeling better and [ ] getting back to the quality of life [ ] that you remember or a better quality of life than [ ] during the transplant certainly takes time and is very gradual and it is different for everyone. (09)</p> <p>This is obviously a diagnosis that you had no intention at this point in your life of having, and I'm sure, nobody signs up for a transplant and says, 'This is so great, I can't wait to do it.' [ ] It's</p> <p>(continued on following page)</p>

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**TABLE 2.** Representative Quotations of Major Components of the Transplant Consultation (continued)

Component of the Transplant Consultation	Representative Quotations
	long; it can be very arduous. It has a lot of potential side effects, but it is the one therapy that we know which is curative for MDS. (18)
	What I also guarantee for my patients is that we're here regardless of what happens. Right? So, we're your team to help get you through the unpredictable. We've got plans A, B, and C, and if we run out of A, B, and C, then we come up with D. And we, we always have those conversations together as a group and make sure that we're making things, making decisions together in your best interest, weighing all the risks and benefits. (35)
Complications and outcomes	Then there's much more severe forms of graft versus host where we are sometimes trading one disease for another and those more serious forms can cause a lot of problems and can sometimes be life-threatening. (05)
	Even if we cure you of the MDS, [there] might be things that we have to deal with sort of in exchange for the cure of the MDS. (24)
	Just because there's a risk of relapse doesn't mean you don't do the transplant. [] But I need to let you know that, you know, like I said, that there is a risk of relapse. [] Our goal is to cure, and we'll try our very best to do so. (13)
Decision-making talk	See <a href="#">Table 4</a>

to the patient, they subsequently provided more detailed estimates about potential outcomes and prognosis.

Hematologists conceded that although transplant was the only chance for cure, this was not guaranteed. Some also relayed the message that by going through the transplant experience, the patient's life would never be the same, and many acknowledged that the patient's post-transplant course would be long and emotionally and physically taxing. In particular, chronic GVHD could profoundly affect the patient's life but was part of the binding transaction of transplant. Many expressed the sentiment that despite the risks, transplant was worth it. Finally, hematologists emphasized that they and the transplant team would be committed to supporting the patient along his illness journey.

### Decision-Making Talk

Although decision-making talk often occurred throughout, it amplified as the conversation progressed. Hematologists discussed several elements that formed the basis of the patient's and hematologist's decision making ([Fig 2](#); [Table 3](#)), although they placed differing amounts of weight on each factor. Many concentrated on transplant as the only chance for long-term survival. Although several hematologists acknowledged on a general level the importance of patients' values and preferences in decision making, they less frequently inquired about the individual patient's specific goals. When our patient actor volunteered content about his preferences, hematologists incorporated this information into their subsequent discussion to varying extents, including how transplant may affect quality of life.

Alternatively, the patient's candidacy for transplant, including his medical fitness, disease state, and anticipated potential for complications, was prominent in several hematologists' discussion about whether the patient could and

should pursue this potentially curative option. Some hematologists indicated that they were responsible for finding a donor and that they did not expect this to be a problem. Meanwhile, some referred to the patient's risk tolerance and comfort with the unpredictability of transplant outcomes in considering treatment pathways.

Hematologists made a few types of recommendations distinguished by time frame ([Table 4](#)). Hematologists generally offered similar advice about the immediate future and emphasized that the patient did not need to decide about transplant at this initial visit, particularly given all the new, complex information. Instead, the patient should take time to absorb and discuss the material with loved ones. Some also recommended that the patient start chemotherapy regardless of his longer-term treatment pathway, as well as initiate the donor search.

Hematologists varied in the strength of their longer-term recommendations about transplant itself, which ranged from unequivocal recommendations for transplant or for chemotherapy, to conditional recommendations pending further information, to deferrals. Many explained the rationale behind their recommendation at varying lengths, citing any number of elements of decision making. Those who deferred making a recommendation specified either that the decision rested with the patient or that they did not yet have enough information to justify a recommendation.

These recommendations reflected a range of decision-making strategies, from a hematologist-led approach to a primarily patient-driven effort. In the middle, some hematologists described a joint effort, in which the patient and the hematologist would work together to reach a shared decision ([Table 4](#)). Within a single encounter, many hematologists expressed various statements suggesting that their approach to decision making fell along a continuum that evolved as the encounter and the patient's illness course proceeded.

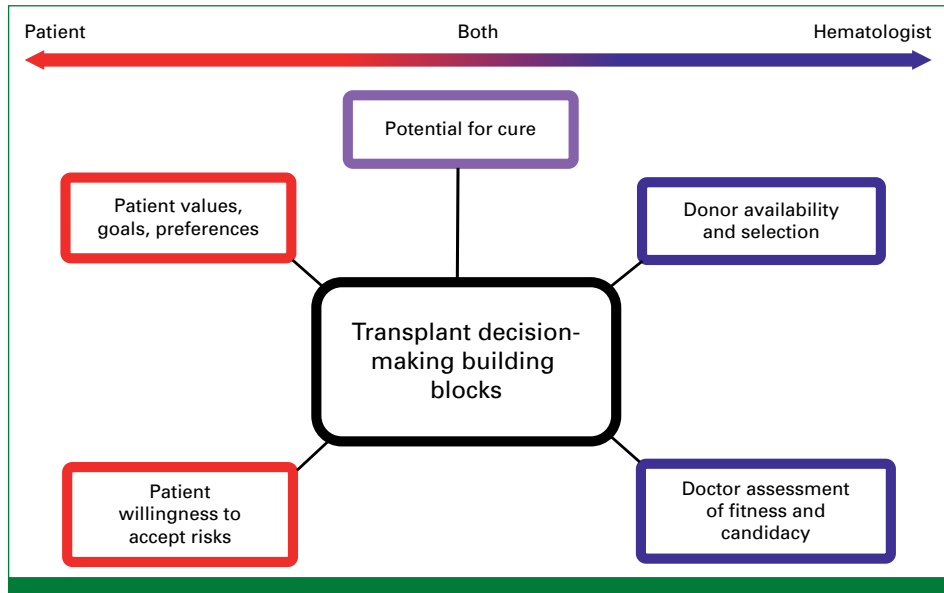


FIG 2. Building blocks of transplant decision making.

Hematologists offered their recommendations at different time points in the conversation. Those who gave a treatment recommendation early on generally strongly recommended that the patient pursue transplant.

## DISCUSSION

Regardless of its outcome, alloHCT is a complicated procedure that transforms patients' lives. Our results highlight the complex information that hematologists discuss with patients to help them make decisions and guide them through their transplant experience.

Many hematologists followed a similar structure and discussed the same major content areas. Although conversations varied in amount of granularity, much of hematologists' dialogue appeared directed toward educating the patient about the transplant experience and facilitating informed decision making. Additionally, many hematologists acknowledged the prolonged biopsychosocial toll of transplant, highlighted the commitment and sacrifice required, and indicated that no matter what bumps the patient encountered, his life would never be the same.<sup>27-30</sup> Big-picture statements, such as "Transplant changes your life" (08), framed this content clearly.<sup>31</sup>

Despite the detailed information hematologists often provide,<sup>23</sup> many studies have indicated patients perceive that their information needs are not met.<sup>32-41</sup> In particular, many patients express surprise and unpreparedness for the impact of transplant side effects and complications on their daily lives and identity.<sup>28,30,32,35,36,42,43</sup> In combination with observations from our hematologist-focused study, these findings highlight a delicate balance for patients considering

transplant among education, information processing, and actual experience.<sup>28,32,44,45</sup> The hematologist's ability to communicate information that helps patients make informed decisions and manages their expectations about the transplant experience is counterbalanced by patients' ability to withstand information overload and anticipate their transplant journey.

Our study does not elucidate hematologists' intent or patients' perception of hematologists' communication. Obtaining additional feedback from patients and hematologists will be essential in identifying what and how much content patients need.<sup>30</sup> Ultimately, our team plans on developing a communication tool that can be incorporated into clinician educational sessions and used to facilitate effective, patient-centered communication about transplant. In future work, we will evaluate hematologists' communication on the basis of patient race and the impact of this communication tool on patient outcomes.

Meanwhile, there are several important factors that hematologists and patients weigh in their decision making about alloHCT. We observed that hematologists' focus on cure sometimes hindered a more thorough inquiry into the individual patient's specific preferences and goals, which is similar to previous studies across oncology.<sup>46,47</sup> Furthermore, consciousness of possible cure seemed to affect the ways in which hematologists engaged the patient and shared the role of treatment decision making. Consistent with previous studies in malignant hematology,<sup>47,48</sup> we observed some hematologists make fitness-based recommendations in place of value-based recommendations. Such recommendations based primarily on the patient's candidacy neglect awareness that particularly older patients have

**TABLE 3.** Essential Considerations in Transplant Decision Making

Factor	Representative Quotations
The potential for cure	<p>A transplant can be curative. So that's why we recommend it. [] You're a young guy; you take good care of yourself. [] This is something, you know, we want to give you the next twenty five years that you should have, and transplant is a really important consideration. (16)</p> <p>The important part right now is making the best decision for you and, and choosing a treatment that's going to give you the best shot at living as long as possible after this diagnosis, and I think transplant is likely the right choice here. (25)</p>
The patient's values, goals, and preferences	<p>I never tell people, anyone, you need a transplant, you have to have a transplant. I, in some cases, will say I recommend a transplant with the major caveat that I would recommend a transplant if it is within your goals, your preferences, and your family's preferences, which is absolutely the most important thing. (09)</p> <p>It does come down to [] a lot of what you think and sort of what you're planning and what your goals and hopes might be. (23)</p>
The patient's willingness to accept risks	<p>The decision to proceed with, with transplant has to be balanced against [] each person's preferences as to what level of complications they're kind of willing [] to accept and what potential complications they're willing to accept. (09)</p> <p>What I would recommend is considering the time that's immediately in front of you, the value of that time versus the time that might be in your future. Because in one option, you're really taking a risk for a better future. And the other option, you're making the best of the days that you have today. (27)</p>
The hematologist's assessment of the patient's fitness and candidacy	<p>This is the youngest you're going to be. This is the healthiest you're going to be. This is the weakest your MDS is going to be. So if we're going to go for a home run, we should go for it now, not later. (14)</p> <p>You don't look like you're overweight; you look like you're pretty fit. [] I have your history here that all sounds very encouraging. [] So I think you are a very reasonable candidate for this. (18)</p> <p>Based on what I know about you so far, I think that you're likely to be an excellent candidate, should this be something that you wish to do. (39)</p>
The identification of a donor	<p>If this is a path we decide to go down, that would be my responsibility to figure out how we get a donor. (32)</p> <p>Today, over 99 percent of people who need a transplant will have a donor. [] Technology has improved to the point where we can use these different donor sources and still get good outcomes. (07)</p>

different lived experiences that may affect how they view treatment decisions.<sup>47</sup> Instead, exploration and incorporation of the individual patient's goals into treatment recommendations, as demonstrated by some hematologists in our study, offers the opportunity to build trust, clarify misunderstandings, and promote SDM.<sup>8,23,47,49</sup>

We observed that hematologists' dialogue about decision making fell at different places along a physician- versus patient-led decision-making spectrum and often evolved over the encounter. Ultimately, decision making about alloHCT likely unfolds over time as a shared decision.<sup>50-52</sup> At this early stage, much of the conversation is hypothetical: transplant may be an option, if the patient has a suitable donor, is fit enough, and maintains adequate disease control. Meanwhile, patients themselves may need time to weigh and articulate their values in the midst of their new, overwhelming situation.<sup>51-55</sup> In fact, given alloHCT's high stakes and patients' frequent perception of having no alternative treatment options,<sup>56,57</sup> it has been proposed that true informed consent is not possible.<sup>34,56,58</sup> Instead, a trusting relationship ultimately may help to facilitate SDM.<sup>25,34,51,59,60</sup>

On the basis of the observations from our study, much of hematologists' early talk necessary for decision making centers on education, comparison of options, and supportive language, including broad recognition of the importance of patients' preferences. This initial consultation starts a

collaborative decision-making process that occurs over time as hematologists and patients gather more information from each other, share their expertise, and deepen their relationship.<sup>25,34,51,61</sup> Our study captures how hematologists initiate this longitudinal discussion, although many questions remain pertaining to how the conversation progresses and to what extent hematologists readdress patients' goals at each step of patients' transplant journey. Our findings also need to be verified in real-world practice.

This study has limitations. First, encounters were simulated conversations with patient actors and may not reflect how hematologists communicate with real-life patients. Additionally, questions asked by our patient actors when invited may have obscured some of the hematologists' natural script and contributed to variability in the amount of detail they provided. However, patient-initiated questions reflect real-life circumstances in which some patients pose questions, especially when physicians encourage them. Finally, although having a single patient script ignores the diversity of real-life patient phenotypes, we deliberately chose patient actors to have a consistent performance delivered across encounters and to isolate hematologists' general communication practices.

In conclusion, the alloHCT experience is long, intense, and unpredictable. In this study, we outlined how expert hematologists begin the transplant conversation, construct a



**TABLE 4. Types of Recommendations and Decision-Making Strategies**

Type of Recommendation	Representative Quotations
Recommendations for the immediate future	
Do not make a decision about transplant today	You do not have to make this decision today or even this month. [] I would actually encourage you not to make this decision today because I think it is [] so much information to process, especially, you know, having just received this diagnosis. (09) One of the rules that I have is I never ask anybody to have all of this information dumped on them and then just tell me what they want to do. [] This is the kind of thing that I think you need to have the opportunity to think about, [] talk about with friends, family, loved ones. And we're always here to discuss further and come up with a plan. (24)
Start chemotherapy regardless of transplant decision	I would start treatment if I were you because treatment improves the quality of life; it can prolong survival. Even if you don't have a transplant, [it] gives you more time at home. It's not usually a treatment that requires being in the hospital. And if you respond to it, it will improve the chances and the advisability of transplant. (19)
Consider initiating the donor search	But if you think that this is something that you may want to consider, that you might want to do, I would suggest that we go ahead and start the process and get some bloodwork and type your immune system. And start looking for donors so that if in two or three months we have a donor and you're doing well and you want to move forward, we can go ahead and we don't need to, you know, then wait another two or three months. We don't, I don't want the process of finding a donor to be the rate-limiting step here. (25)
Recommendations for the longer term	
(1) Recommendation for chemotherapy	Based on just our conversation today and what you've shared with me, the Vidaza [chemotherapy], I think, is a good option. It means that you still would, we'd still be trying to prevent the transformation to leukemia, trying to improve your blood counts. It would probably allow you to travel. It would certainly allow you to be at home and spend time with your family and do your thing at home and go hiking and the things that you enjoy. Being active for the most part. (08)
(2) Recommendation for transplant, on the basis of patient's fitness	You're 67 years old. You've got well-controlled diabetes. You are otherwise in good shape. You've got a good support system. I would say you should, knowing the risk, you should proceed with transplant. (13)
(2) Recommendation for transplant, on the basis of potential for cure	I feel very strongly that that's the right thing to do. [] You're a 67-year-old guy. You have a lot of life ahead of you. The transplant, you know, can be life-saving. (16)
(2) Recommendation for transplant, on the basis of patient's goals	I really do think that it's quite reasonable for you to consider this as a treatment option to go forward because of your goals. It fits with wanting some long-term disease control to go and do things, travel with your wife, and so forth. (36)
(3) Conditional recommendation for transplant, depending upon assessment of patient's fitness	Generally, for people who have high-risk MDS, we recommend to do a bone marrow transplant if you're healthy enough to undergo the process. (20)
(3) Conditional recommendation for transplant, depending upon patient's values and understanding of risks	That's my recommendation, is that it's worth considering with all the numbers we've talked about. If this fits with, with your goals and including [] that upfront risk versus the potential long-term benefit here, if this makes sense for you and your and your family. (28)
(4) Recommendation deferred; decision ultimately rests with the patient	I think for you in particular, I think it's something I would strongly consider. I can't say, I can't sort of make that decision for you. It's a very personal decision. And so whether you think it's worth the risk for you or not, it's something that you, I think, have to weigh yourself. (34)
(4) Recommendation deferred; not enough information to make a recommendation	I'd like to do the lung test, the heart test, the liver test, the social worker evaluation, the donor search. So, I put off the decision until we have all the pieces of information. [] I'm not in a position to make a recommendation until we have all the pieces together. (30)
Decision-making strategies	
Physician-directed	I think we should definitely aim for cure in your case, and the only cure for myelodysplastic syndrome is a bone marrow transplant. (22)
Patient-driven	I think then you may just have to do a little more thinking on your end about whether this is, this is what you want to do. (18) My hope is to give you information and to help you minimize risks, to do what you want to do. But, ultimately, the decisions are up to you. (37)
Shared	Whatever treatments we decide - and it's we. It's not me; it's us. We have to [] be together on it and you have to be informed as much as possible so we can move forward with this. (03) It's important that whatever we decide to do, ultimately, I want you to know that you're in the driver's seat. That, that I can make recommendations for you and I will make recommendations based on my medical knowledge. But at the end of the day, I want you to know that the decisions that you can make are ... they're yours. And I'm here to support you in whatever decisions that you choose to make for management of your health. (39)

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scaffold of essential elements in decision making, and set the stage for a longitudinal relationship.

The best practices for SDM in transplant hematology are still not well defined. Although there is unlikely to be a one-size-fits-all approach to SDM or to communication more broadly in transplant,<sup>6,37,38,62</sup> the content hematologists select to share and the ways they engage patients can

affect decision making.<sup>6,51,54,56,63,64</sup> Patients need information about transplant that is practical, contextual, and structured around their values and lived experience.<sup>30,32,36</sup> Hematologists can facilitate SDM by encouraging patients to participate in the conversation, inviting them to reflect on content and weigh their current feelings against previously held values, and facilitating ongoing dialogue.

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## AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

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## AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

### Communication Strategies of Transplant Hematologists in High-Risk Decision-Making Conversations

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