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Balancing risks and rewards: How hematologists discuss uncertainty in allogeneic hematopoietic cell transplantation outcomes

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ABSTRACT

Objective: Allogeneic hematopoietic cell transplant (alloHCT) offers many patients with blood cancers a chance of cure but carries risks. We characterized how hematologists discuss the high-risk, high-reward concept of alloHCT.
Methods: Qualitative analysis of video-recorded virtual encounters of hematologists who routinely perform alloHCT with actors portraying an older man recently diagnosed with high-risk myelodysplastic syndrome.
Results: Hematologists (n = 37) were a median age of 44 years, 65% male, and 68% white. They frequently used "teeter-totter" language that juxtaposed alloHCT's risks and rewards in a dynamic, quickly alternating fashion and communicated uncertainty in transplant outcomes. This dialogue oscillated between encouragement about alloHCT's potential for cure and caution about its risks and occurred within single speech turns and in exchanges between hematologist and patient. Fewer hematologists outlined their big-picture stance on transplant's risks and benefits early in the conversation. Meanwhile, hematologists varied in how they counseled patients to manage transplant-related uncertainty and consider treatment decision making.
Conclusion: Hematologists use "teeter-totter" language to express hope and concern, confidence and uncertainty, and encouragement and caution about the high-risk, high-reward nature of alloHCT.
Practice implications: Teeter-totter language may help frame big-picture content about alloHCT's risks and benefits that is essential for patient education and decision making.

1. Introduction

Allogeneic hematopoietic cell transplantation (alloHCT) offers many patients with blood cancers a chance of cure but has significant risks. Patients and hematologists confront uncertainties related to prognosis and outcomes that variably impact patients' identity, relationships, and physical function and may cause premature mortality or long-term complications [1,2]. At initial consultation, uncertainty also exists regarding whether patients can safely undergo alloHCT, pending their response to initial chemotherapy, formal pretransplant evaluation, and donor search. Patients must decide between the high-risk, high-reward route of alloHCT versus an alternative option which may prolong their life with less toxicity but offers no chance for long-term survival [3,4].

Higher-risk myelodysplastic syndromes (MDS) are a representative blood cancer primarily affecting older adults that often necessitates this high-stakes decision making. This cancer is associated with poor overall survival, substantial risk of transformation to acute myeloid leukemia, and cytopenia-related complications [4,5]. AlloHCT is considered a standard of care and the only curative option, but is limited to patients with adequate baseline fitness [4, 6, 7]. Overall survival after transplant is estimated at less than 50%, due to relapse and complications including graft versus host disease (GVHD) [6, 7, 8].

Collaborative decision making requires that physicians discuss treatment options, relevant practical considerations, and uncertainties about each option's risks and benefits, thereby facilitating a shared understanding of complex issues [9]. Because many uncertainties persist

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over time (e.g. whether or not the patient's disease will recur), physicians are also tasked with helping patients tolerate and cope with often long-lasting uncertainties. In the setting of alloHCT, hematologists must communicate risks sufficiently to ensure informed consent while avoiding overwhelming the patient with too much information [10]. While shared decision making is considered beneficial [11], many patients report feeling that they have "no choice" but to pursue transplant given other options invariably result in cancer progression and death [12, 13, 14]. There is a need to evaluate how hematologists actually communicate the uncertainties of alloHCT's risks and benefits to patients; this knowledge could be used to identify best practices that encourage patient engagement and understanding in alloHCT. In this secondary analysis from a study assessing how transplant hematologists facilitate shared decision making, our aim was to characterize one technique hematologists use to discuss the high-risk, high-reward concept of alloHCT during decision making conversations.

2. Methods

2.1. General design

This qualitative study was comprised of video-recorded virtual encounters of a convenience 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 to conduct this study from the University of Wisconsin Minimal Risk Research Institutional Review Board. Encounters occurred between February 2022 and March 2023. Our team was led by a communication expert and dually practicing palliative care physician and oncologist (TC) and social psychologist with expertise in diversity science research (MB). Our team also included an experienced transplant hematologist (AH), physician experts in diversity (EW, CS), a palliative care physician in hematology-oncology fellowship (RR), and an internal medicine resident focused on hematology (TT).

2.2. Patient case

Members of our team (TC, AH, TT) designed a patient case representing a clinical scenario in which alloHCT was a reasonable option. Remaining team members provided feedback. The patient portrayed by our actors was a 67-year-old man referred for specialty hematology consultation, who had no medical contraindications to transplant, a good performance status, and a supportive family. He valued being active and spending quality time with his family. Based on his bone marrow biopsy results, he had high-risk MDS (Revised International Prognostic Scoring System score 6). We constructed the scenario to minimize possible clinician "red flags" about proceeding to alloHCT and enable participating hematologists to spend most of their time discussing treatment options and issues surrounding decision making.

2.3. Actor hiring and training

We recruited and hired two professional actors. Based on a secondary aim of the study 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, one white). Over four virtual sessions lasting eight hours, we directed the two actors to mirror each other in portraying the same character described above. Multiple physicians not eligible to participate portrayed the transplant hematologist during training in order to expose the actors to different physician communication styles. Our team's practicing transplant hematologist (AH) served as the hematologist during actors' "dress rehearsal" session.

We emphasized improvisation over strict scripted responses, though we trained actors to have semi-scripted responses to anticipated common moments in the encounter. Our actors and study team discussed issues that arose about character portrayal to reach a consensus about appropriate and realistic patient representation.

As a quality assurance measure to ensure fidelity across encounters, team members (RR, TC, TT) provided written line by line feedback on transcripts after each actor's first two study encounters.

2.4. 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 early stages we asked known professional contacts to send introductory emails to transplant hematology 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 to be not interested in participating.

2.5. Hematologist informed consent and randomization

After hematologists responded with interest, study staff screened them for eligibility and obtained informed consent. Participants also completed a brief demographic survey. We told hematologists that the study's purpose was to understand how transplant hematologists approach the new patient consultation with different kinds of patients, including how they talk about diagnosis and treatment options, and that the encounter would be with a simulated patient. We randomly assigned hematologists to an encounter with either the Black or white patient actor. We stratified hematologists by race (white/nonwhite) and sex at birth, for a total of four hematologist subgroups.

2.6. Patient encounter

We provided each participant with a document containing the patient's background clinical information immediately before the virtual encounter (Appendix). The hematologist and patient actor met over a videoconference set up by our study staff. We selected a virtual platform originally due to 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 one hour.

2.7. Qualitative analysis

We used NVivo Transcription to transcribe video-recorded encounters, and research assistants verified transcript fidelity and de-identified participant information. We also used NVivo for data organization. Multiple team members (RR, TT, and TC) met regularly during and after data collection to view video encounters and code transcripts together. We used an inductive, iterative process of coding of four transcripts to develop a preliminary coding scheme and revised and added to our coding scheme until no new codes emerged based upon the data, indicating saturation [15,16]. We used constant comparative analysis to examine relationships within and across codes and transcripts [15]. We derived themes from the data through attention to patterns across transcripts and to outliers. Once we were confident that no additional codes were needed, one team member (RR) coded the remaining transcripts (n = 24) independently and brought content for review in ongoing team meetings. We shared initial qualitative analysis with study participants in May 2023.

3. Results

Thirty-seven hematologists from 25 academic centers participated (Table 1). The average encounter duration was 41 min 54 s (standard

Table 1
Demographic and clinical characteristics of participating hematologists.

Characteristic	No. (%)
Age	
Years (median, IQR)	44[38–50]
Sex	
Male	24 (65%)
Race	
White	25 (68%)
Asian	9 (24%)
Other (Middle Eastern, North African)	3 (8%)
Formal fellowship training	
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	
Workshop, didactics, and/or palliative care rotation	27 (73%)
Estimated number of patients treated with alloHCT annually	
<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	
Less than 25%	3 (8%)
25-50%	14 (38%)
51-75%	13 (35%)
76-100%	7 (19%)
Location of medical center/place of employment	
Large urban area	24 (65%)
Moderate size city that draws from a rural state	13 (35%)

deviation 11 min 49 s).

3.1. Communication of transplant's rewards and risks

Hematologists referenced transplant's high-risk, high-reward nature early and throughout the conversation. While few used the term "high-risk, high-reward" explicitly, many described taking a substantial risk upfront in exchange for a chance of cure with transplant: "You're taking a lot of short-term risk in the hope that you get, you know, the long-term gain" (hematologist #10). Life-ending complications and short-term impaired quality of life was "a price that we pay for it" (hematologist #31).

3.1.1. Teeter-totter dialogue

Frequently hematologists juxtaposed the unpredictable risks and rewards of transplant in a dynamic, quickly alternating fashion that often repeated across conversations. This back-and-forth dialogue resembled a teeter-totter, a long board with a central pivot point on which two persons can sit on opposite ends and take turns propelling themselves up and down. While we did not identify a threshold for frequency of turns that defined teeter-totter language, it involved back-and-forth discussion of transplant's risks and benefits over relatively short periods. This "teeter-totter" language oscillated between hopeful encouragement about transplant's potential for cure and cautious hesitancy about its disadvantages and dangerous outcomes. Ultimately, it depicted the uncertainty in transplant outcomes that the hematologist and patient faced in decision making. We observed teeter-totter language in 86% (32 of 37) encounters.

Many hematologists used the conjunction "but" to compare transplant's risks and benefits and signal shifts from one side of potential transplant outcomes to another. On a high, optimistic end, the benefit of potential cure dominated the motivation behind transplant as a treatment consideration (Table 2 section A). However, from a grounded, concerned perspective, transplant had limitations.

Firstly, cure was not guaranteed. Overall survival estimates of around fifty percent "may be disappointing" (hematologist #05), but "without transplant the cure rates are zero percent" (hematologist #12). Further, falling short of cure might mean that the transplant could "do more harm than good" (hematologist #37) by negatively impacting quality of life and survival. Many also disclosed significant variability in "survivable toxicity" and how patients cope with these toxicities: "So outcome number one, we give you the transplant. Your MDS is cured. You get a little bit of GVHD, which we fix, and life goes on. That's the most practical outcome we'll be aiming to achieve" (hematologist #13) (Table 2 section B).

Secondly, hematologists emphasized downsides related to the patient's transplant experience: undergoing transplant would require considerable effort and perseverance over many months or longer. As one elaborated, "It's really the only thing going on in life. Everything else gets put on hold" (hematologist #28). Further, rather than occurring as a discrete event, setbacks could arise unpredictably over time: "Sometimes things do change as we go along, either for the better or for the worse" (hematologist #27) (Table 2 section C).

This teeter-totter language played out in both brief hematologist utterances and more prolonged dialogue. During teeter-totter exchanges, frequently the hematologist countered the patient's previous statement either to augment his perspective or to remind him of an alternative outcome. This frequently led to rapid up-down/down-up oscillations in their conversation about potential outcomes. At other

Table 2
Sides of teeter-totter dialogue: benefits and limitations of transplant.

Benefit/Limitation	Representative quotation
A. Transplant offers a chance of cure	What transplantation is, is a way potentially to cure the disease. So, when we think about diseases, the most important thing that we like to think about is, is there something we can do to cure the disease? Bone marrow transplantation has the potential to cure the disease.[27]
	I've got to tell you about the risks of this. I can't just tell you, come here, have a transplant, don't worry about it. [] But if it's the path we decide to take forward, our intent is to cure you.[24]
B. Transplant does not guarantee cure and risks complications	It's a big procedure with risk and not any assurance of success. As I said, it's the only potentially curative treatment, but it doesn't, doesn't always work. (05)
	And it is really the only thing out there, the only treatment out there that we think cures myelodysplasia. But you know, it has risks involved in it.[18]
	Transplant, what's important to understand about it is that it gives you a big benefit when it works. It gives you a cure. But it comes at a price for some people. So it's a dangerous thing to go through. It's a dangerous thing to get rid of your immune system, replace it with someone else, to be vulnerable during that period of time. There's, there's a lot of risks that are inherent to transplant.[32]
C. Transplant requires effort and adjustment over time	So, a transplant, although it's a potentially curative treatment for MDS, it's not an easy process to go through. And it's a bit of a marathon.[25]
	I don't want to, you know, paint it as a rosy picture all along. [] The chemotherapy is not that easy. The stem cell transplantation procedure before and after, you know, it requires a lot of support. It requires a lot of chemotherapy as well as medications after the stem cell transplant.[22]
	It's not like an operation where you just sort of, you know, go to the O.R. and somebody cut[s] you open and they say, 'OK, now you're sewed up and now you're fine.' This is really a process that takes months to go through.[18]

times, hematologists expressed teeter-totter language within longer speech turns (Table 3). Several hematologists employed both brief and more gradual teeter-totter language throughout the visit as they introduced, added layers to, and reinforced transplant's high-risk, high-reward nature. Many used a "potential cure, but risks" frame that underscored transplant's downsides, while some used the reverse framing ("risks, but potential cure") that emphasized survival. One said, "There's more potential harm to you upfront from this treatment, and it may not work, but it also has a chance of long-term success that nothing else has" (hematologist #11). A handful of hematologists provided a clear outline of their big-picture stance on transplant's risks and benefits early in the conversation, which framed their subsequent discussion (Table 3, hematologist #39).

Meanwhile, other hematologists used relatively little or no teeter-totter dialogue in their discussion of transplant. This included some who strongly recommended transplant upfront. Although these hematologists acknowledged risks with transplant, they returned to the possibility for cure with transplant as the essential consideration without immediate qualification. One advised, "You got to just keep your eyes on the prize, right? The goal is to make this go away and not come back" (hematologist #16).

3.2. Transplant compared to other options

Many hematologists compared transplant's high-risk, high-reward profile to other treatment pathways, primarily chemotherapy or supportive care alone. Many acknowledged possible benefits of chemotherapy, including improving the patient's blood counts, decreasing his symptom burden, and delaying transformation to acute leukemia, ultimately helping him to have decent quality of life and live longer. However, hematologists consistently noted that chemotherapy did not provide a pathway to cure and would invariably result in disease progression and eventual death. One hematologist described this by saying, "Unfortunately, anybody who receives that treatment, they're not cured. So eventually the disease will raise its ugly side of its head and become a problem. And when that occurs, often people will die from the disease" (hematologist #27). In contrast to this certain longer-term outcome with chemotherapy, transplant at least offered a chance of cure. At the same time, many pointed out that although without transplant patients will generally die of MDS, they could also die because of transplant complications.

Meanwhile, hematologists also outlined risks and benefits of supportive care, which "could help support a person to live better with less symptoms from the disease" (hematologist #35). However, supportive care alone similarly would guarantee disease progression: "You will not get better … What happens is the longer you go, you're needing more and more blood transfusions and then you typically get weaker and weaker as your disease gets worse" (hematologist #12).

3.3. Teeter-totter language in relationship to uncertainty and decision making

On a broader level, hematologists' teeter-totter dialogue communicated uncertainty in transplant outcomes. Hematologists acknowledged that transplant's unpredictability and complexity made prognostication for individual patients challenging: "We still don't have the ability to have a crystal ball of what's going to happen with any individual patient" (hematologist #02).

Hematologists referenced several reasons for the uncertainty in predicting outcomes for individual patients. Firstly, there were substantial limitations in applying aggregate-level data to single patients, because for the patient, "There's no 55% or 60% []; it's either you're 100% or you're zero percent. [] Either you're a success or you're not" (hematologist #06). Secondly, there were innumerable potential scenarios along the transplant pathway: "Lots of unpredictable things come up, a hundred percent. I could talk to you and your family for hours

Table 3
Teeter-totter language within speech turns of hematologists and in exchanges between hematologist and patient.

Transcript Number	Representative quotation*	Comments
04	Patient: That's amazing. And this works, this can cure? Doctor: [] This has been shown to be a curative therapy for patients with MDS and an effective therapy and has been shown to be superior to treating patients with medicines like azacitidine or a sister drug alone. Patient: Yes. Wow. OK. Doctor: *But certainly we are manipulating your immune system so that there can be some significant side effects of the treatment as well.*	Patient expresses optimism about transplant. Doctor initially reinforces this. Patient expresses further optimism. Doctor then shifts and brings up risks.
21	Doctor: But in higher-risk disease, other treatment options are, the only curative therapy is an allogenic transplant. Patient: So, it is curable. Doctor: It is. There is, *although the odds are against us, the chances are, of long-term cure are maybe 30, 40%.* But yes, there is a possibility of cure and that can be achieved with a bone marrow transplant. Patient: Wow. Doctor: *Well, but bone marrow transplant is not a simple thing. It has its own complications, own set of complications.*	Doctor introduces transplant as the curative option. Patient and then doctor reinforce this. Doctor then teeters ("the odds are against us") before again quickly reinforcing the possibility of cure. Patient expresses optimism, and doctor counters this by introducing complications.
06	Doctor: *There is a risk of transplant [] that sort of negates the benefit of transplant in the early period.* However, if you can survive the early period of transplant in either three to five years, you're going to reap the benefit of the transplant. [] *We really have to acknowledge the early risks*. We acknowledge this is a potential curative approach, *but it's not for everyone.*	Doctor acknowledges risks of transplant and then pivots to note the potential to "reap the benefit" of transplant. Doctor turns back to sequentially note both risks and potential cure again, and then shifts to acknowledge "it's not for everyone."
07	Doctor: *The transplant approach is the riskiest in the short term*, but is the only treatment that could potentially cure the MDS. *And so the short-term risks* could be offset by the potential of a lifespan that could measure in the decades yet. *But there are substantial short-term risks that we just talked about.* The long-term risks are improving with our newer technology. [] *But even with the transplant, I should be transparent that there's a risk of the MDS coming back despite a transplant as well. That risk is about 30%. So, what does that look like? With the transplant, and recognizing that it's a bumpy road. And recognizing that we can have complications of infection, graft* versus *host disease, and relapse.* With our current approach, our long-term survival is looking to be about 40%. If you look in the literature and if you're looking at some older studies, you'll	Doctor alternates in rapid succession between risks and potential cure (and improving technology) three times. Doctor shifts back to downsides of MDS recurrence and other complications. Doctor finishes by shifting back to long-term survival better than historical measures.

(*continued on next page*)

Table 3 (*continued*)

Transcript Number	Representative quotation*	Comments
	note that the survival was not as good.	
39	The other pathway, and that's what I want to discuss with you more about today, is … a bone marrow transplant. And the reason I bring up that is because as far as we know today, in 2023, a bone marrow transplant remains the most likely way to potentially cure you of the MDS, meaning not only improve the way you're feeling and functioning, but potentially make the MDS go away forever. And that's why I would recommend that we at least talk about a bone marrow transplant, to consider it. It's really appealing to think about something that can make this go away for good. *But as we spend more time talking about a bone marrow transplant today, I do want you to know that it's pretty complicated, requires a lot of time and investment on your end, and it's not without its risks.*	Doctor introduces transplant and its big-picture considerations early in the encounter. Doctor introduces transplant as a potential for cure, and later shifts to acknowledging multiple downsides of transplant.

* Font style reflects the direction of the teeter-language: regular font indicates language about the positives and benefits of transplant, while italics signals dialogue about downsides to transplant.

about the risks of transplant, and I guarantee something will come up that we didn't talk about" (hematologist #35). Finally, some hematologists noted that the patient's outcome would depend on additional information that was not yet available. As one noted, "There's a lot of, sort of 'if's' in here" (hematologist #18). However, some unpredictability would always remain: "We can be more precise the more information we have. But I still caution that even with that information, there's a lot of heterogeneity. People are different" (hematologist #07).

Hematologists varied in how they counseled patients to consider treatment decision making and manage transplant-related uncertainty (Table 4). On one side, hematologists relayed a stance of clinical equipoise, in which there was not a clearly right or wrong decision and instead the patient's decision would depend upon his tolerance of risk. These hematologists indicated that their role was to educate patients about different possible transplant outcomes, as sharing an understanding of risks and benefits was an essential step in patient decision making.

On another side, some hematologists promoted transplant more strongly. Although education about transplant and potential risks was important, ultimately the goal for cure remained central to decision making and transplant was likely the best pathway forward. These hematologists spoke of taking the transplant journey one step at a time without worrying too far ahead about future uncertainty. Although transplant would be a leap of faith and require acceptance of its unpredictability, the hematologist and patient would deal with potential complications together.

Table 4
Views on decision making and management of transplant-related uncertainty.

	Tend towards clinical equipoise	Tend towards transplant
View on the transplant decision	*There is no clear right or wrong decision.* Finding the right approach for any individual patient with this disease is tricky on a number of levels. [] I don't think that there's a right and a wrong answer to what we should do here. This is not a black and white issue… But what I want to do is give you the best information I can to help think about that and then think about coming up with [a plan].[24]	*Despite the risks, transplant is likely the best path forward.* Is this a perfect therapy? I wish it was. I wish I could sit here and say, there's no way this isn't going to, you know, you aren't going to have problems or potentially even die because of a complication from this. But I think in a situation where we have limited interventions, I think this is a good one.[18]
Risk management	*The patient must decide based in part on his and tolerance of risk.* It's important to talk about that because sometimes people think or talk about transplant like it's, you know, you do the transplant and everything's golden, but it's not. That's, that's not necessarily the case. I just want to make sure you have all the information before going into a decision. (08)	*The patient and hematologist must focus on one step at a time and accept the possibility of unpredictable risks.* With transplant, you take it a day at a time, a milestone at a time. So, you know, if we decide that this is a path that we want to pursue, you just kind of focus on what's ahead of you. You get through that first hospital stay. That's a, that's a big victory. You get through day one hundred and no complications. That's even better.[32]
	I think the decision to proceed with transplant has to be balanced against, you know, 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)	People who are used to being in control of things, who have a set schedule, you know, you kind of have to throw that out the window because there's, there tend to be a lot of unknowns going forward. And so, we kind of have to roll with things a little bit with, with what, what comes.[37]

4. Discussion and conclusion

4.1. Discussion

Allogeneic hematopoietic cell transplantation is a high-risk, high-reward undertaking requiring patient hope, commitment, and awareness of unpredictable complications and impacts on daily life. Many hematologists relay transplant's high-risk, high-reward nature to patients through what we have described as teeter-totter language. This dynamic dialogue involved quick oscillations between hope for cure and caution about serious risks of alloHCT occurring over short periods. While a basic risk/benefit discussion may involve a sequential presentation of treatment options, potential benefits, and possible adverse effects, instead we observed that hematologists often put alloHCT's risks and benefits in immediate opposition. In this setting, subtleties such as word order were the only potential clue to preference. This type of language repeated during conversations and communicated uncertainty within this unique high-stakes clinical situation. In our study, hematologists' teeter-totter dialogue created an intricate balance of opposing information and conveyed a mix of hope and realism that is important to many patients with cancer and is promoted in the greater cancer and palliative care communities [17,18].

Prior research has shown that clinicians' positive versus negative framing of probabilistic information influences patients' perception of risk and treatment choice [19,20]. Thus, the structure hematologists use to discuss alloHCT's risks and benefits may affect patients' interpretation of the message and their decision about whether or not to proceed with transplant [13]. Framing teeter-totter language in the direction of the uncertainty that they want to promote may facilitate this (e.g. possible cure but *risks*, or risks but possible *cure*). In future work we need to ascertain hematologists' intention in how they frame alloHCT's high-risk, high-reward nature. However, it is possible that their dialogue may either provide a balanced overview of transplant's uncertain outcomes or influence patients' choice. For instance, a focus on the

possibility of living longer and viewing transplant's uncertainties as a positive opportunity for cure can encourage patient hope and inclination towards alloHCT [13,21]. Meanwhile, thought leaders have recognized that discussions framed around transplant's chance for cure can overwhelm other considerations including quality of life and eliminate patients' perception of treatment choice [13]. Notably, not all hematologists in our study used teeter-totter language, and many provided reassurance that transplant was a risk worth taking, which ultimately framed the discussion in a positive light.

Many studies have documented that patients with blood cancers and undergoing alloHCT have substantial prognostic misunderstandings in relation to their hematologists' predictions [22, 23, 24, 25], which persist even after patients report discussing prognosis with their hematologists [26,27]. We suspect that patients may have different prognostic interpretations and treatment preferences depending on how and to what extent hematologists emphasize the potential positive versus negative aspects of the transplant experience. However, we need to evaluate the impact of this teeter-totter language and framing of transplant risks on patients' prognostic perceptions and decision making in future work. As we observed a handful of hematologists do, offering an early and repeated big-picture message about alloHCT's risks and benefits may be helpful for highlighting key points, framing the discussion, facilitating prognostic awareness, and managing patients' expectations.

Hematologists also varied in how they appeared to manage transplant's uncertainties and engage the patient in decision making. While some kinds of uncertainty (e.g. whether or not the patient is a candidate for alloHCT) resolves with time, many uncertainties (e.g. risks of complications and relapse) are irreducible and necessitate that hematologists work towards minimizing their aversive effects [28]. Some hematologists in our study focused primarily on educating the patient on treatment risks and benefits, and others strongly encouraged the patient to consider the curative transplant option despite risks. This reflects different approaches to decision making and the physician-patient relationship [29], which we describe in greater detail elsewhere [30].

Ultimately, patients must live their lives despite potentially distressing prognostic uncertainties along their transplant journey [10, 31, 32, 33]. It is critical that patients' teams promote effective coping strategies amid irreducible uncertainties [1, 9, 21]. Our findings reflect that a first step towards promoting patient coping occurs at this initial visit by making patients aware of transplant's risks and rewards [9] and encouraging their participation in the conversation. Our results also support informed consent in alloHCT as a dynamic process involving provision and repetition of information ideally over multiple interactions [2,34].

The surprise, psychological distress, and unpreparedness many patients feel when complications arise has been well documented [10, 35, 36]. However, we do not know how hematologists' management of uncertainty and relative focus on risks versus benefits affects this. The ways in which hematologists can best incorporate and discuss the high-risk, high-reward nature of transplant longitudinally and help patients to cope with uncertainty requires additional input from hematologists, patients, and their families. Ultimately, our team aims to develop and test a communication tool for transplant hematologists that can facilitate effective, patient-centered communication surrounding the high-risk, high-reward decision making of alloHCT.

We note several limitations. Firstly, these simulated encounters were with patient actors, not real patients, though this allowed us to better isolate hematologists' general communication practices. Additionally, although our patient actors gave mostly consistent performances over time, we did not do refresher training sessions after their initial participant encounters nor have anyone blinded to study objectives assess the videos for consistency. Similarly, we did not systematically collect data from hematologists about their perception of the scenario's realism nor have anyone external to our research team check our simulated scenario for credibility. However, the five hematologists with whom we conducted post-study interviews reported the scenario was realistic and their conversation representative of encounters with real patients. Meanwhile, in order to characterize the "teeter-totter" phenomenon more broadly, we did not attend to differences in communication based on patient race; additional analyses evaluating race differences are forthcoming. Additionally, participating hematologists were a convenience sample likely not representative of the full range of communication strategies used by hematologists at the initial transplant consultation. However, given our larger goal of identifying best practice strategies that hematologists use in discussing transplant with patients, we expect that we obtained an adequate sample of hematologists who prioritize patient communication and have tried to polish their own skills over time. Finally, our study contained a limited number of hematologists from racially and ethnically diverse backgrounds.

4.2. Conclusions

In this study we have described how hematologists explain the high-risk, high-reward nature of allogeneic hematopoietic cell transplantation and situate this in the context of treatment decision making. There is unlikely to be a single "best" approach to communicating uncertainty in transplant [37,38], particularly given that patients' information needs and desire for decisional involvement vary widely depending upon many disease-related and personal characteristics [36, 38, 39]. However, the teeter-totter communication approach we observed in this study appeared to allow hematologists to downplay or amplify different sides of transplant [20]. Ultimately, the need to provide adequate anticipatory guidance about the unpredictability of transplant without emotionally harming the patient [10,40] creates a tough tension along patients' illness journeys – which, as findings from our study support, are manifest from the very beginning.

4.3. Practice implications

Teeter-totter language reflects the uncertainties that exist during patients' transplant experience and manifests as dynamic, rapid oscillations between encouragement and caution which often occur repeatedly. Deliberate presentation of transplant's risks and benefits early in the alloHCT conversation may help hematologists to frame a big-picture dialogue that outlines information essential for patient education and decision making. Attending carefully and longitudinally to both sides of alloHCT – its overarching goal of long-term survival and its risks of failure, complications, and personal and communal sacrifice – may foster prognostic awareness and manage patients' expectations. However, given reported prognostic misunderstandings [23, 24, 25, 41], patients may still focus on the potential for cure; additional support to both patients and hematologists may be necessary. Further, finding a balance in discussing both desired and negative transplant outcomes may be challenging, as what hematologists say and how they say it can affect patients' perceptions of risks and impact decision making [20, 42, 43]. One must be mindful not to dissuade those who would otherwise be excellent candidates to proceed with alloHCT through inciting untamed fears of complications, and also to avoid pressuring those whose goals are not in line with alloHCT into proceeding with transplant.

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We confirm all personal identifiers have been removed or disguised so the person(s) described are not identifiable and cannot be identified through the details of the story.

CRediT authorship contribution statement

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analysis, Conceptualization. **Brauer Markus:** Writing – review & editing, Supervision, Resources, Methodology, Funding acquisition, Formal analysis, Conceptualization. **Thordardottir Thorunn:** Writing – review & editing, Methodology, Investigation, Formal analysis, Conceptualization. **Rodenbach Rachel A.:** Writing – review & editing, Writing – original draft, Methodology, Investigation, Formal analysis, Conceptualization. **Campbell Toby C.:** Writing – review & editing, Supervision, Resources, Methodology, Investigation, Formal analysis, Conceptualization. **Smith Cardinale B.:** Writing – review & editing, Methodology, Formal analysis, Conceptualization. **Ward Earlise:** Writing – review & editing, Methodology, Formal analysis, Conceptualization.

Declaration of Competing Interest

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Appendix

Simulated patient case.

Information for the physician:

Your patient, Mr. Aaron Johnson, is a 67 year old man with a past medical history of type 2 diabetes, hypertension and peptic ulcer, who was recently diagnosed with Myelodysplastic Syndrome. The disease was diagnosed after routine follow-up for diabetes revealed worsening cytopenias. He has had one visit with a local oncologist who informed him of the basics of the diagnosis. He has not started any treatment for the disease. He is referred to you for consideration for a transplant.

Mr. Johnson has high-risk MDS: IPSS-R score of 6 based on severe neutropenia with absolute neutrophil count of 360/μl, Hb 8.5 g/dl, platelets 75×109/L; bone marrow biopsy showing 7.4% blasts and intermediate cytogenetics (+8).

Mr. Johnson was diagnosed with type 2 diabetes 10 years ago. He made changes to his lifestyle in addition to being on metformin. He has mild diabetic retinopathy but otherwise he has no complications from the disease. His last HbA1c was 6.0% one month ago (in the setting of anemia). His hypertension has been well-controlled on lisinopril-hydrochlorothiazide. He developed a peptic ulcer diagnosed via upper endoscopy 7 years ago. He takes no other medications. Hematopoietic Cell Transplantation-specific Comorbidity Index (HCT-CI) score is 3 or high risk per hctci.org.

Mr. Johnson is presenting to see you in hematology clinic for the first time and for his first encounter with a hematologic oncologist. He was told about this new diagnosis by a local heme/onc physician who informed him he needed to see a specialist to consider treatment including, possibly, a hematopoietic stem cell transplant. The referring oncologist indicated the conversation was otherwise relatively brief.

Presume you are working with an advanced practice provider who has obtained the relevant history and demographics and reviewed this with you prior to the visit. You should be able to focus on discussing the clinical situation with the patient including his treatment options.

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