

Investigating and Supporting Patient and Caregiver Sensemaking in Complex Medical Decisions Using Participatory Design

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Abstract

Background. Patients and caregivers facing complex health decisions must make sense of unfamiliar, emotionally challenging information and experiences. For patients with hematological malignancy, bone marrow transplant (BMT) may be the best chance for a cure but has significant risk of morbidity and mortality. This study aimed to investigate and support patient and caregiver sensemaking as they consider BMT. **Methods.** Ten BMT patients and 5 caregivers engaged in remote participatory design (PD) workshops. Participants drew timelines of their memorable experiences leading up to BMT. Then, they used transparency paper to annotate their timelines and design improvements to this process. **Results.** Thematic analysis of drawings and transcripts revealed a 3-phase sensemaking process. In phase 1, participants were introduced to BMT and understood it as a possibility, not an inevitability. In phase 2, they focused on meeting prerequisites including remission and donor identification. Participants came to believe they needed transplant, consequently describing BMT not as a decision between viable options, but that transplant was their “only chance” for survival. In phase 3, participants attended an orientation detailing the extensive risks of transplant, leading to anxiety and doubt. Participants designed solutions that provided reassurance to those grappling with the life-altering impacts of transplant. **Conclusions.** For patients and caregivers navigating complex health decisions, sensemaking is a dynamic, ongoing process that affects expectations and emotional well-being. Interventions targeting reassurance alongside risk information can alleviate emotional impact and facilitate expectation development. The integration of PD and sensemaking methodologies enables participants to create holistic, tangible representations of experiences while empowering stakeholder engagement in intervention design. This method could be applied to other complex medical contexts to understand lived experiences and develop effective support interventions.

Highlights

- Bone marrow transplant patients and caregivers experienced an evolving, emotionally challenging process of gradually understanding the transplant procedure and its risks.
- The solutions that participants designed centered on providing reassurance alongside risk information, suggesting future interventions could target emotional support as patients attempt to meet prerequisites and grapple with the risks of the potentially curative procedure.
- By viewing the challenges of complex medical decisions in terms of sensemaking and applying visual methods such as participatory design, researchers can facilitate expression of the dynamic, multifaceted, emotional components of experience and empower stakeholder involvement in intervention design.

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Keywords

patient experience, caregiver experience, design methods, visual methods, decision support

Date received: October 3, 2022; accepted: February 20, 2023

Complex and ambiguous medical situations in which uncertainty is irreducible, information incomplete, and outcomes poorly defined¹ create significant challenges to decision making and, relatedly, sensemaking, or how people interpret and act in the world around them. Sensemaking is a theory and methodology that looks beyond information design to examine how people find and synthesize large amounts of information to develop a cohesive understanding.² Illness causes breakdowns in sensemaking that can lead to emotional turmoil and confusion about how to move forward in treatment or recovery.^{3–5} Framing complex illness decisions in terms of sensemaking enables a longitudinal view of the experience and emphasizes the limitations imposed by situations characterized by an uncertain, ever-changing reality that can never fully be understood.⁶

Bone marrow transplant (BMT) for hematologic malignancy is one such situation. BMT is a complex, high-risk treatment with unpredictable outcomes. In making treatment decisions, the survival benefit of BMT must be balanced against the significant potential for morbidity and mortality.^{7,8} Measuring understanding of these outcomes is especially challenging, as patients may struggle to conceptualize their condition,⁹ be overwhelmed by the amount of information they receive,¹⁰ or be crippled by uncertainty.¹¹ Patients are likely to be unfamiliar with the procedure and may have an emotional response to the potentially permanent changes it brings to their daily lives.^{12–15}

Previous studies have identified significant challenges to decision making and sensemaking support for this population.^{16–22} The trauma of hematologic malignancy may lead patients to take a more passive role in treatment decisions.^{23,24} Differences in patient and clinician estimations of BMT outcomes, including likelihood of a cure and treatment-related morbidity, can also affect treatment decisions.²⁵ For some patients considering BMT, there may be no acceptable alternative, leading one group of researchers to suggest that “agreeing to a plan” may be a better way to frame the BMT decision.²⁶ In light of these challenges, the purpose of this study was 2-fold: 1) to investigate the sensemaking processes that patients and caregivers went through as they considered receiving BMT and 2) to facilitate patient and caregiver design of potential solutions. This work integrates sensemaking and participatory design (PD) methodologies to capture important sensemaking processes and engage stakeholders in intervention development.

Methods

Study Design

This study integrated PD and sensemaking methodologies to produce a longitudinal, contextual, dynamic approach to studying experience. PD uses visual methods of data collection, which can be useful for capturing more abstract phenomena, like sensemaking, by making them more concrete.²⁷ Stakeholders actively engage in the design of interventions that may ultimately affect them or others in similar situations, allowing them to use their expertise in the lived experience.²⁸

The PD method of the Make toolkit²⁹ and the sensemaking method of the Micro-Moment Time-Line Interview³⁰ were used. A Make toolkit is a way for non-designers to participate in the design process by giving them tools to express their ideas.³¹ The toolkit helps participants design for possible futures through a deeper analysis of their past.²⁹ In this study, the toolkit supported participants in creating a timeline that visualized their experiences leading up to transplant.

Rutgers Robert Wood Johnson Medical School, Piscataway, NJ, USA (SF). The author declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article. The author disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: Financial support for this study was provided in part by a grant from the Rutgers University Community Design for Health and Wellness Interdisciplinary Research Group and the Health Resources and Services Administration (HRSA) of the US Department of Health and Human Services (HHS) as part of award No. 5 T32HP42017-02-00. The contents are those of the authors and do not necessarily represent the official views of, nor an endorsement, by HRSA, HHS, or the US government. The funding agreement ensured the authors' independence in designing the study, interpreting the data, writing, and publishing the report.

The Micro-Moment Time-Line Interview examines how people find meaning in situations where they experience gaps in understanding that prevent them from moving toward their goals. Interview questions explored the key elements of sensemaking: situations (the time-space contexts), gaps (the questions people have/information needs), and uses (how people employ this newly created sense).³² Instead of directly asking what information people think they would hypothetically need, the Micro-Moment Time-Line Interview allows people to talk about situations they were actually in.³³

Context

This research was performed at the BMT clinic of a large academic hospital in the Northeastern United States. This study is part of a larger project to develop a support tool for patients and families considering BMT.

Participants and Recruitment

Transplant clinicians recommended patients they believed would be willing and healthy enough to participate. Ten patients participated, and 5 of these patients were joined by their caregivers. Four of these caregivers were the patient's spouse, while 1 caregiver was a lifelong friend. Caregivers or other household member participation can provide a safe context to simulate the collaborative environment of a traditional PD session and was encouraged to help patients recall the experience. Of all patient and caregiver participants, 8 were female and 7 were male, with an average age of 55.4 y.

Data Collection

Participation in this study included 2 parts: 1) a sensitization exercise²⁹ and 2) a virtual workshop. Due to pandemic restrictions and the immunocompromised status of this population, workshops were held remotely. Workshops were held using encrypted video chat software (i.e., WhatsApp, FaceTime) and recorded and transcribed. All research procedures were approved by the Rutgers University Institutional Review Board (No. 14-495M). All participants provided informed consent prior to enrollment in the study.

Sensitization exercise. Sensitization exercises provide an opportunity for participants to collect the relevant stories and experiences they find most important before the workshop.²⁹ Prior to scheduled workshops, participants

were sent a Qualtrics survey about their transplant experiences.

Participatory design workshops. Participants were mailed a participation package including a phone tripod, art supplies, return envelope with postage, and the Make toolkit. This toolkit was crafted to facilitate creation of a visual timeline of the pre-BMT experience. Participants were given stickers featuring words and images informed by interviews with patients and caregivers performed in an earlier phase of this research. This included information needs and sources, BMT-specific language, and emotions. The final contents of the toolkit were chosen with Sanders and Stappers' requirements in mind: varied in content, abstraction, levels of ambiguity, and visual style, with positive, negative, and neutral stimuli.²⁹ Items included in the toolkit were intentionally ambiguous, intending to trigger participants' imaginations and interpretation through the perspective of their own experience. When participants use a particular toolkit item, they are asked to explain their reasoning, thus revealing more about their perspective and eliciting verbal expression of sensemaking.

Emotions were represented as words, as more complex emotions like "regret" were believed to be important in reflection but difficult to represent visually. Importantly, the toolkit was designed to evolve, and participants were encouraged to use the art supplies to add any additional elements of their experience that were not represented in the toolkit.

Participants were instructed to use the toolkit to visually represent significant moments leading up to BMT. First, they were asked to describe the series of memorable events leading to their decision to receive transplant or when they would have considered themselves committed to transplant. As they used the toolkit to make their timeline, they were also prompted with questions inspired by the Micro-Moment Time-Line Interview method and Weick's sensemaking theory³⁴ as it relates to expectation development.

After completing a timeline of what they had experienced, participants were asked to place a sheet of transparency film over their timelines and instructed to identify areas that could have been improved, for example, if they had a question that went unanswered or had been frustrated with part of the process. The use of transparency film is a method in PD for participants to add or modify ideas without destroying the original content.³⁵ Participants were prompted with questions such as, "What might have helped you?" and "What did you

not know that you wish you had?" These sessions were recorded and professionally transcribed.

Memos were recorded during the sessions documenting participant comments that indicated a need for change or instances of participants using the toolkit in innovative or unexpected ways. Only 1 to 2 toolkits were mailed out at a time to account for revisions.

Data Analysis

Participant timeline drawings were returned by mail, scanned, and imported into NVivo. Handwritten notes were converted to text, and images were labeled with descriptive words. Transcripts and timelines were initially segmented and categorized by the event being described or what would be considered a single step on the timeline (e.g., the first conversation in which a doctor mentioned transplant). Within each event category, transcripts and timelines were tagged for descriptions of emotions, questions, expectations that participants had during a specific event, and the cues they extracted from the situation. Questions were first assessed in terms of the gaps specific to the context of BMT and so were coded using a descriptive focus.³⁰ Cues were first categorized descriptively by topic and then thematically by the resulting sense made (e.g., a caregiver saying that the patient's "mutation was bad enough that I felt like without [transplant], it would just be a death sentence . . . so it was like, okay, then what do we have to do?" was coded for the cue topic of "mutation," the question category of "next steps," and the resulting expectation of transplant as "necessary for survival").

Solutions proposed by participants were first coded topically by the intended target of the proposed intervention (e.g., caregiver support, information access, orientation). Solutions were then categorized using in vivo codes that described intended outcomes of proposed interventions (e.g., better prepared, more confident, less frightened). These codes were iteratively reviewed to combine conceptually similar codes and explore the underlying values.

Funding Source

The funding source had no role in the design or execution of this research.

Results

Participant timelines revealed a multiphase sensemaking process in which patients and caregivers gradually came

to understand and accept the realities of BMT and its consequences. This process began when patients/caregivers first learned about BMT (phase 1), then began treatment in the hopes of achieving remission (phase 2), before participating in formalized educational procedures to learn about the risks/benefits of transplant (phase 3). Patients and caregivers saw transplant first as a possibility, then a necessity, and finally a cure with a cost. This evolution reflects how patients and caregivers perceive the decision to receive BMT as not being finalized at one particular moment. Participants largely described transplant as being their only option and not a true "decision" between viable treatment options. While creating their timelines, participants had an easier time indicating the moment when they would have considered themselves committed to getting transplant if offered rather than when they made the decision per se. As one patient put it, he considered himself having gone through a process of "accepting the fact that it's going to have to be done."

Twelve timelines were created by 15 participants, as 3 patient/caregiver pairs opted to represent their experiences on a shared timeline. Five timelines included photos from the toolkit. Five timelines included the emotion/BMT-specific stickers (see Figure 1), while the rest chose to write words, some inspired by the toolkit (see Figure 2). Across the entire process, the most common emotions participants experienced were anxious ($n = 11$ participants), afraid ($n = 11$), grateful ($n = 8$), and unsure ($n = 7$). The number and type of significant events that participants included in their timelines varied, although the processes described by participants followed a similar progression of understanding.

Phase 1: Transplant as a Possibility

Phase 1 began when participants first learned about BMT as a treatment option. BMT was introduced to participants by clinicians either at diagnosis or, more often, after other treatments failed to control their disease. During phase 1, transplant was not necessarily viewed as an inevitability. Participants perceived transplant as something that might be in their future if, for example, the disease remained uncontrolled. This belief was widely held by participants:

[BMT] was always something that was a possibility. It was never really, for me, something that I had never heard about before and then all of a sudden, oh, by the way, you might need a bone marrow transplant. (Patient)

The doctor [said] there's a possibility that eventually [the patient] will need a stem cell transplant. . . . Really thinking

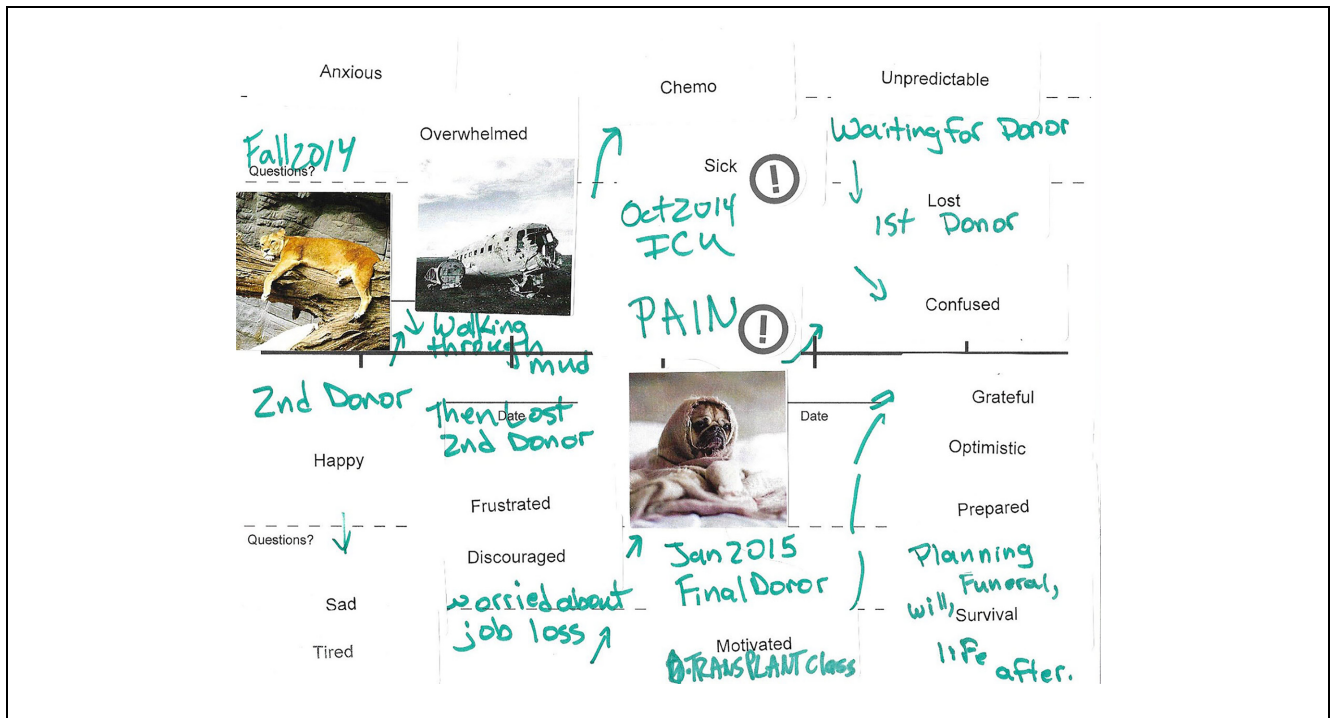


Figure 1 A patient's timeline drawing. The images and word stickers were provided as part of the toolkit.

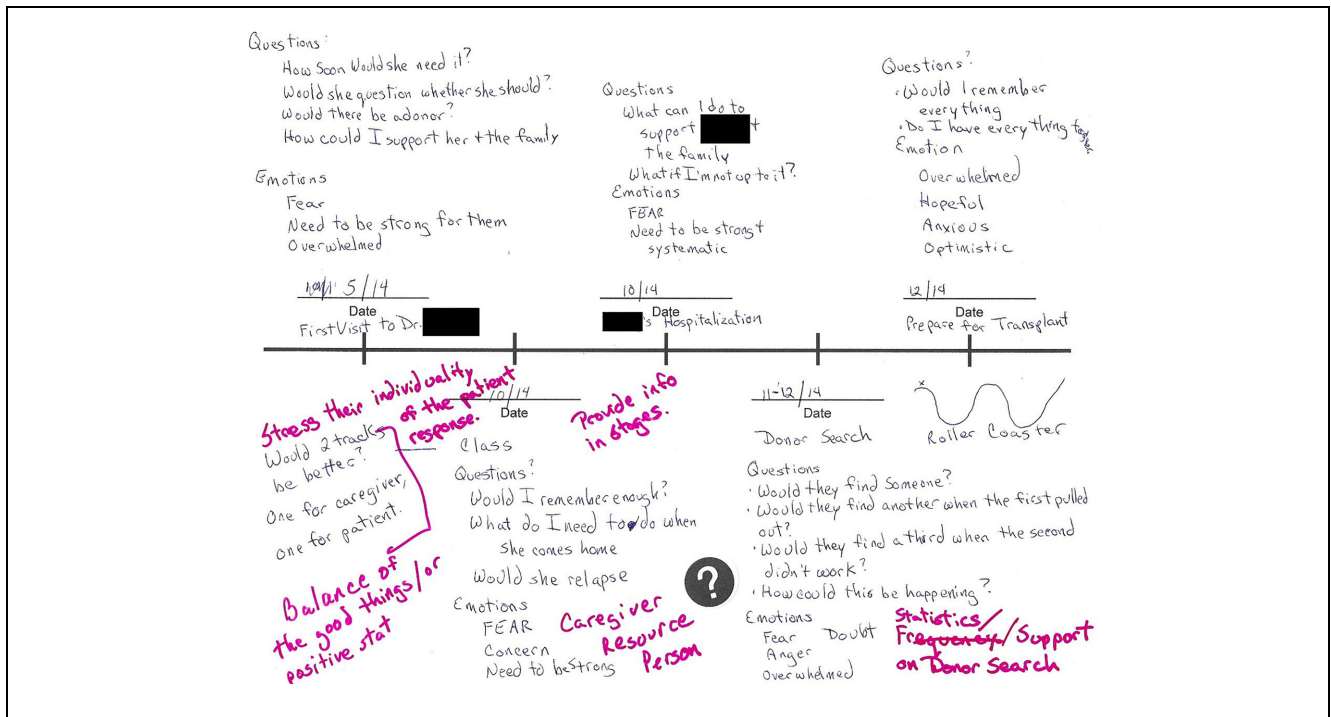


Figure 2 A caregiver's timeline drawing. Her experience is represented in the black ink, while her proposed solutions are in pink.

about eventually. He just put the possibility out there but I was kind of in denial and I was more thinking, okay, let's get through getting him in remission because he's really sick. (Caregiver)

Transplant was not seen as an option they could freely choose but as a possibility.

Phase 2: Transplant as a Necessity

Participants entered phase 2 once they began attempting to meet the prerequisites for transplant: 1) achieving remission, 2) finding a donor, and 3) proving physically able to tolerate transplant. In phase 2, patients began receiving intensive chemotherapy over several weeks, including an extended hospital stay, often concurrent with the donor search. The search usually began by testing family members, waiting for results and, should no family member match, tapping into the unrelated donor registry. The anxiety of waiting for a donor was particularly memorable during this period:

If I was gonna get a match or not, that was the biggest thing—that's always what kept me in suspense, was waiting on the match. (Patient)

I was anxious until they found a donor because it's nice to have a plan and then it relies on one thing. (Patient)

Even if patients want transplant, there are external factors that determine if this can actually happen. Because participants recognized that transplant would not be a reality without first meeting these requirements, they described how the consequences of transplant itself were not especially important at this time. Instead, participants adopted what one patient called a “one step at a time” mentality focused on meeting the prerequisites rather than what this might mean for their future:

Let's hope we get to the point where we can have the transplant, then let's talk about the transplant itself. (Patient)

Patients may already be committed to receiving transplant if offered, but they must cope with anxiety as they wait to find a donor, reach remission, and receive test results. By the end of phase 2, patients came to see transplant as a necessity. All patients described a moment, almost universally during a conversation with a clinician, when they realized they would “need” transplant:

The doctor said, “You have [a specific mutation]. If you have that, then with that abnormality, chemotherapy alone

won't—you won't stay in remission so you need a transplant.” She was very—she didn't mince words. She just said you need it. . . . Yeah, you have no choice. If you can get a donor, you need a transplant. (Patient)

I had no choice in the matter. I had to get the transplant [the doctor] said. There was no choice... I had no other options because of how severe the cancer was that the transplant was my last resort. (Patient)

This transition from understanding transplant as a possibility to a necessity was the result of conversations perceived to mean their disease could not be treated otherwise. For instance, 3 patients had a mutation that they recalled learning would not respond to chemotherapy alone, making transplant the only choice to remain disease free. As such, patients and caregivers came to see transplant as what many called the “only chance” for survival, making it a choice between life with transplant or death.

Phase 3: Transplant as a Cure with a Cost

In this last phase, requirements had largely been met, and transplant was looking more realistic. Patients and caregivers then participated in formalized educational procedures, including a required 3- to 4-h orientation class alongside other patients who may be receiving transplant and their caregivers. During this orientation, clinicians presented the various risks and benefits of transplant. Most participants described themselves as having been mostly if not completely committed to receiving transplant before attending the orientation. Participants described orientation as informative while also being overwhelming. Much of the information in the orientation was new, and some of the descriptions of side effects were confusing or upsetting.

Six participants described personally experiencing or witnessing others experiencing doubt during or after attending the orientation class. During the orientation class, participants commonly recalled asking variations of “is BMT worth it?” Ultimately, they often reasoned that, although currently disease free, their cancer would likely return without transplant.

By the time they attended orientation, participants were relieved to have met the requirements to become candidates for transplant. In earlier phases, patients and caregivers had made sense of transplant as necessary for survival and consequently focused on reaching transplant requirements. Then, they experienced distress in phase 3 when exposed to the negative outcomes of transplant:

I was totally focused on “can we knock this out so I can get the transplant” versus all the things about the transplant

Table 1 Examples of Solutions Proposed by Participants

	Expectations	Prioritization/Relevance
Content	<p>Estimated recovery timeline</p> <p>Caregiver: <i>Maybe just a little bit more [about what to expect after BMT], and maybe, without details, here's what some other people have. So, like kind of a generic, you probably won't work for 2 to 3 y. You'll be on 25 medications, and slowly, some of those won't wean off.</i></p>	<p>Caregiver orientation</p> <p>Patient: <i>Looking back, [I] wish [my husband] hadn't gone to [the orientation]. I just think he needed a condensed, less thorough meeting, you know? Basically, tell him what he needs to know, like not every little thing that could happen. It was too much for him.</i></p> <p>Caregiver: <i>I almost wonder if there could be almost 2 tracks within it. A caregiver track and a patient track and if it's up to the patient as to whether or not they want somebody with them . . . especially when there are family members who want to understand what she's going to face but don't necessarily need to know every aspect of what could happen, a second track might be a good idea.</i></p>
Process	<p>Connection with BMT survivor</p> <p>Patient: <i>Having a patient be able to reach out to other people who are going through, or been through it, is a big help in building the confidence to go through the decision.</i></p>	<p>Gradual presentation of information</p> <p>Patient: <i>During those final visits before transplant, give them a packet of information on diet, give 1 visit, let them chew that over, give them a packet on staying infection free, let them mull that over.</i></p>

that could happen or could not happen. Once it became apparent that I could get the transplant and we went to the class, then it was like, okay, holy crap. I didn't realize all these things were possible following the transplant. (Patient)

I did not take notes [during orientation] because I cried through the class. I tried really hard not to but, yes, I cried through the class. Especially when it was a woman . . . when she had said that she used to run all the time and she never got back into running, it broke my heart because we used to bike ride all the time and my thought was, well, if she never got back into running, like, am I going to get back into biking? (Patient)

In making sense of transplant in phases 1 and 2, participants had put more emphasis on the threats to their lives in the immediate future (from disease) than the threats to long-term quality of life (from transplant). In the orientation, they were confronted with the reality that BMT could lead to death or severely impact quality of life. This caused anxiety and occasionally raised questions about the value of the procedure.

Proposed Solutions

Nearly all of the solutions suggested by participants were designed for use in phase 3, when they were confronted with the risks of transplant and often experienced emotional distress as a result. Participants designed a variety of alternatives or enhancements to the current orientation class, revealing unmet needs. The solutions that

participants proposed targeted primarily the content of information they received pre-BMT or the process that they engaged in during decision making. Although many participants presented unique solutions, common underlying themes reveal several needs that were unmet or not sufficiently addressed. Needs included support in forming expectations for BMT outcomes and prioritization of information and/or determination of relevance. Table 1 includes examples of solutions that participants designed to address these needs.

Expectations. Often, solutions were designed to reconcile the need for accurate expectations for life after transplant with the need to make sense of emotionally distressing information and experiences. For instance, one patient recalled asking a question about her hospital stay during the orientation. The answer gave her clearer expectations and some emotional relief, and she referred to this experience when suggesting improvements for future orientations:

After the class, I wanted to go see the [hospital] room . . . I wanted to see where I was going to spend the next few weeks or whenever I got the transplant. So [the clinicians] walked me over and I could see a room . . . so I could see, okay, I can set up my computer here, I can bring a blanket, I have a closet, you know, it just feels more comfortable in my mind to see what I'm heading into. The less unknown, because you don't have control over a lot of it, but at least I had—I felt much better after I saw my room even though it was the

hospital room, you know, like any other hospital room. You know, even if [the orientation instructors] took a picture if you can't bring the patient there. I just felt like it's one less unknown. (Patient)

This suggestion aims to reduce uncertainty and increase feelings of preparedness, as packing for a long hospital stay was one of the few things this patient felt she could control. For many patients and caregivers, the uncertainty was so great that any opportunity to develop a concrete sense of what to expect and prepare for was welcomed.

Another illustrative solution came from a patient who suggested that clinicians should emphasize available treatments alongside information about potential complications like graft-versus-host disease (GVHD). He remembered being devastated when he learned about GVHD and “all these terrible things that are gonna happen to me” in the orientation but pointed out that he had not been told about the treatments that were offered to him when he ultimately did experience GVHD. He said that he wished he knew “whether [GVHD] is gonna be a real problem or not” because, although he still would have gotten transplant, “that would have made the decision a lot easier.”

Prioritization. Although patients and caregivers need to be aware of the many potentially negative outcomes of transplant, they received so much information about what could go wrong that it became overwhelming. Their suggestions revealed challenges to processing risk information in such large quantities, with solutions aiming to prioritize the most relevant information rather than all of the information at once. For example, 2 patient-caregiver pairs suggested that information be given gradually over the treatment period rather than all at once in the orientation class.

Another design for prioritization was proposed jointly by a husband (the patient) and wife, who suggested there be a scheduled 1-on-1 follow-up appointment with a clinician to discuss the orientation. The couple described their actual experience of leaving the orientation feeling “terrified,” while also believing that there was no option but to receive a transplant. They described being told “all the terrible things that are going to happen to you” without a scheduled opportunity to talk to the doctor and better understand and contextualize what they had just heard. They collaborated on the idea of a scheduled postorientation conversation as an opportunity to ask

questions and personalize the risk after processing the large amounts of new and scary information:

Patient: I think having almost like a structure where it says, okay, in about 2 wk [after the orientation], we're going to have some of you come back or whatever, let's schedule a follow-up. . . . It wasn't like we knew we couldn't do that, but there was no structured thing where it was set up to make that happen. And I think maybe that would be a really helpful thing . . . even if we're really freaked out, we could ask some questions and not be embarrassed that we're asking in front of other people. . . . It's targeted for us, not for everyone.

Caregiver: So the follow-up would be like, okay, this is your situation. Let's look at these things that might happen and how likely they are in your situation.

By talking with the clinicians to learn which risks of BMT were most likely to occur for this particular patient, they could prioritize what information really mattered for them specifically rather than trying to process the more general information presented in the class. The patient described how this meeting could be used to address the anxiety created by the orientation and reassert the clinicians' commitment to providing care:

If [the clinicians] said like, “Okay, we know you probably got really freaked out by all this that you've heard [in the orientation]. But let's put it in perspective a little bit. Let's talk about the things that really most concerned you, and let's not get away from the fact that as bad as this sounds, we're presenting this information because we want to save your life. We want to help you.”

As such, the need for preparation and expectations can be expanded to include reassurance—by presenting not only potential problems but also potential solutions and a commitment to the patient's care. When faced with the possibility of death or disability from transplant, participants described needing support to both maintain hope for a potential cure and also anticipate, prepare for, and accept a dramatic change in their daily lives.

Discussion

This study explored how patients and caregivers conceptualize BMT as they consider receiving transplant. The revelation that BMT was first understood as a “possibility” rather than an option highlights how factors outside of a patient's control (e.g., finding a donor) are decisive

in whether patients receive BMT. These factors may be more important than a patient's decision to receive transplant, leading to a focus on meeting prerequisites and the curative potential of transplant rather than the possible consequences. This concentration led to anxiety in phase 3 when patients and caregivers were confronted with potential risks. Accordingly, participants designed solutions aimed at improving expectations and providing reassurance pre-BMT.

Notably, patients and caregivers recalled conversations with their clinicians that they interpreted to mean BMT was necessary for survival. This perception led participants to believe that getting transplant was not a "decision" for them to make. Until they met the requirements for transplant, they did not put much emphasis on understanding the risks associated with the procedure. They felt committed to the procedure before they were able to form expectations, which created gaps in understanding that led to anxiety when finally faced with the various risks of transplant in phase 3. Participants suggested interventions that aided in forming expectations and in prioritizing the information that was most relevant to them at any one time. BMT is unique in the quantity, severity, and unpredictability of risks associated with the procedure. Future interventions may benefit from adopting a more longitudinal and personalized approach to supporting informed decision making. The underlying emotional need behind many of the proposed solutions was for reassurance, illustrating at least 2 important considerations when developing support for patients and caregivers pre-BMT: 1) there is significant potential for risk information to be framed in such a way that it does not induce fear and may even alleviate negative emotions and 2) one of the markers of "successful" sensemaking in this period may be reduced fear, not just improved expectations.

Solutions promoting reassurance should not be mistaken for false hope. While clinicians should avoid making guarantees of a cure, they can guarantee that they will do whatever possible to support patients in their recovery. This is similar to the conclusion of Little et al.,³⁶ who found that informed consent for BMT was inherently flawed due to the impossibility of communicating the experience of such an extreme treatment. The authors suggest that instead of informed consent, clinicians offer their commitment to providing the support that patients and caregivers need during throughout the transplant process. Similarly, Scanlan et al.³⁷ proposed that informed consent for BMT is more about building a trusting relationship than about education. As the participants' solutions in this study emphasized, there is

potential for ongoing interaction with the clinical team, particularly in the pre-BMT period, to have an impact on patient and caregiver experiences later in transplant. Looking at this period through the lens of sensemaking presents new opportunities for decision support that focus less on efficient information provision and more on the relational and emotional needs of patients and families during this stressful time.

The results of this study reinforce the longitudinal, contextual perspective required to understand the experiences of BMT patients and their families.¹³ This understanding has implications for the development of support tools. The solutions developed by participants to help others pre-BMT to feel reassured in a time of irreducible uncertainty may enable useful and accurate expectations without creating unnecessary anxiety. The PD method of using a timeline and transparency facilitated expression of tacit needs and allowed participants the opportunity to apply their expertise in lived experience and come up with novel interventions.

The limited involvement of end users as partners in decision aid development³⁸ could be addressed through the use of PD and its many established methods for engaging nondesigners in the development process. This method facilitated participants' ability to visually represent their experiences, identify areas for improvement, and develop solutions that were contextualized to specific and evolving needs. In creating their timelines, participants determined what events were most meaningful rather than being guided purely by interview questions. They created artifacts used as mutual reference points, allowing for clarification among patients, caregivers, and researchers.

This study offered a realistic and holistic view of the BMT experience by giving participants the chance to share the evolution of their experience leading up to transplant and to imagine ways to improve the experience for future patients. This PD exercise is believed to be a novel means of eliciting participant experiences and has significant potential application in other medical decisions characterized by complexity.

Limitations

The small and purposeful sample used here creates challenges for generalizability. Including only patients who ultimately received transplant likely led to findings that are not applicable to all patients considering transplant. Including only patients who had been through BMT was a conscious choice, as patients may consider information to be adequate pre-BMT and later reevaluate this

information as inadequate after they experience complications.³⁶ Similarly, although all patients in this study experienced significant complications as a result of transplant, they all survived. It is possible that they retrospectively understood BMT to not be something they chose to put themselves through but as a forced choice for their survival.

Although participants described conversations with clinicians as having significant impact on their perception that they needed BMT to survive, there is no way to know how the decision was actually presented by clinicians. The ways that clinicians frame risk information can affect decision making,³⁹ and follow-up studies may benefit from including clinicians in the PD process.

Conclusion

Based on the findings of the present study, it is clear that patients and caregivers require support in making sense of their experiences in this uncertain period as they consider transplant. Patients and caregivers are asked to make sense of complex, distressing information about the future while also experiencing significant stress and uncertainty in the present. They hope to meet prerequisites that would enable them to receive a treatment that could save or end their lives. The support they receive can simultaneously address their emotional and sense-making needs pre-BMT and improve expectations for life post-BMT. Promotion of the mindset that “cure” does not necessarily mean a return to life as it was before illness can focus on techniques to prepare for and adapt to this new life.

The method used here could be applied to other contexts in which patients and caregivers face complex medical decisions. The support offered to these patients and families, and the PD tools used to design solutions, need to be adaptive, personalized, and conducive to the ever-changing understanding of the illness experience.


Authors' Note

Preliminary results of this work were presented as a poster at the 2021 International Conference on Communication in Healthcare.

Acknowledgments

Thank you to all of the people who participated in this work, including the patients, caregivers, and clinicians who graciously shared their time and experiences, and to Lisa Mikesell for her thoughtful guidance on this work.

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