Designing a Personalized Support Tool for Patients facing Bone Marrow Transplant

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ABSTRACT

It is crucial for patients facing complex medical treatment to understand possible treatment outcomes, but this is difficult to achieve in practice due to the nature of stressful situations. This study explores how Bone Marrow Transplant (BMT) patients and providers perceive graphical representations of outcome-related information as a first step toward developing a secure patient portal to support the information needs of patients facing BMT. To inform system design, we conducted interviews with 10 veteran BMT patients and a focus group with 7 providers about our prototypes. We found that patients perceived the proposed tool as sense-making support to better comprehend and prepare for the complexities and emotional challenges relating to treatment rather than decision support, whereas providers attended to the tool's functionality in supporting decision-making. Findings revealed insights for personalized sense-making support regarding representations of numeric data and the navigation of experience-videos of veteran patients describing outcomes. Drawing on these, we discuss implications and suggest directions for future work.

CCS CONCEPTS

• **Human-centered computing → Human computer interaction (HCI) → Interaction paradigms**

KEYWORDS

Sense-making, Patient support, Patient portal, BMT

1 INTRODUCTION

Available treatments for patients suffering from life threatening diseases can give a new lease on life. However, treatment options often come with additional, sometimes unexpected, outcomes that impact quality of life. While it is important for patients to understand the potential outcomes that treatment options might pose, this is hard to achieve in practice. Thus, our ultimate goal is to develop a personalized tool supporting patients facing complex medical treatment to be better informed about treatment outcomes. As a first step, this paper focuses on the perspectives of veteran patients who have had BMT to treat blood disorders and their providers, investigating effective design solutions to provide newly diagnosed patients with treatment outcome information. We studied BMT because it mimics many chronic conditions and medical treatments with an accelerated treatment trajectory.

BMT is a procedure to replace bone marrow that has been damaged or destroyed by disease, infection, or chemotherapy with healthy bone marrow stem cells. For patients with blood disorders and blood cell cancers, BMT may be the only treatment option for slowing disease progress or may accompany chemotherapy. However, BMT often involves adverse events that can emerge later and can be life threatening or lifelong. The potential severity of adverse treatment outcomes highlights the need to effectively inform patients about the spectrum of possible outcomes, which poses a significant design challenge for at least three reasons: (1) patients already experiencing the stress of life-threatening illness may have a reduced capacity to operationalize additional information about their health status; (2) patients can struggle to determine what outcomes are relevant to them; and (3) patients and providers are likely to hold different perspectives about the appropriate presentation of information. By consulting with the BMT clinic team as a preliminary step, we identified two types of information that patients might need: potential treatment outcomes and lived experiences of patients who had undergone BMT. Especially, providers considered it important for patient to make informed decision as they concerned about patients' inaccurate understandings of potential adverse treatment outcomes. Based on these, we created prototypes for *decision-making* support by presenting two types of personalized information: clinically validated numerical survivability and outcome-related videos narrated by veteran patients. This study investigates the perspectives about these prototypes from 10 patients and 7 providers. We aimed to address the following research and design questions:

- Research question: How do patients and providers perceive the purpose of a proposed tool?

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- Design questions: (1) How do patients and providers perceive the usefulness of different graphical representations of clinically validated numeric data of projected treatment outcomes? (2) How do they perceive the usefulness of different navigation features for viewing experience videos relating to treatment outcomes?

Key contributions of this work include: (1) demonstrating a tension between patients' informational needs and emotional needs, which can be balanced via a design approach of strategic ambiguity and (2) revealing an unmet need for specific design strategies for *sense-giving* to support risk communication for patients in complex health contexts.

2 RELATED WORK

The proliferation of personal computing technology has contributed to the shift from a disease-centered model of care in clinical settings to a patient-centered model in informal settings. Consequently, efforts to empower patients to play an active role in decisions about healthcare and quality of life have been made [8]. Two prevalent approaches enabling patient empowerment include supporting illness self-management and improving patient-provider communication.

2.1 Self-Management of Illness

Technology is increasingly being used to support self-management of care in non-clinical contexts to foster patients' health-related behaviors and clinical outcomes [5, 13]. The HCI community has paid particular attention to the utility of technology for chronic diseases, such as diabetes and cancer, as they require the ongoing and daily management of disease, thus posing significant burdens to patients themselves [22].

Key research was carried out by Mamykina et al. who examined the use of mobile tools to support people, newly diagnosed with diabetes, to reflect on and discuss their data with a diabetes educator [28]. Their work showed that well-designed tools could promote reflective thinking and help diabetic patients feel more in control of their disease. Chen demonstrated in a qualitative field study that diabetic patients better interpreted information when it was organized by illness trajectory [9]. Jacobs et al. found that their personalized mobile tool integrating health and non-health resources helped cancer patients feel more confident and prepared [19]. Similarly, Klasnja et al. found that a mobile tool providing cancer patients access to health resources at any time or location improved their confidence in ability to manage self-care [22]. Also, Pratt et al. have shown how patients organize information based on where they are in their treatment process [33], and Hayes et al. have argued that information needs in different phases of medical care could inform the design of technologies [17].

Whereas, few studies have investigated self-management for other conditions including BMT treatment. One exception is longitudinal work done by a research team at University of Michigan, who has developed a personalized health portal to support the information needs and communication of BMT patients and caregivers in an inpatient setting [1,7,20,36]. Their work demonstrates the effectiveness of a personalized health IT tool to address various needs of BMT inpatients and their caregivers. Our work differs in that our proposed system is intended to support BMT patients' informational and emotional needs from the time of initial diagnosis throughout a patient's illness trajectory in the outpatient setting.

2.2 Patient-Provider Communication

Patients and providers often have different perspectives on illness. Providers tend to focus on clinical aspects of disease, which often results in deemphasizing non-clinical aspects, such as patients' lived experiences of illness [7]. Differences in the conceptualization of an illness trajectory also exist between patients and providers [2]. For example, Buyukter and Ackerman showed that patients and providers have contrasting expectations of care during different phases of the BMT treatment trajectory, which negatively influences patients' (and caregivers') experiences of care management [7]. As a solution, they suggested design guidelines for collaborative information systems to mitigate such misalignment of perspectives.

The emotional nature of disease discussions also makes it difficult for patients to fully understand much of the complex clinical terminology and concepts relating to diagnosis [23]. Patients must be provided not only with clinically relevant information but also with support to manage the emotional burden. For instance, Kaziunas et al. demonstrated the intensive needs for psychosocial and emotional support for patients during BMT treatment [21], and Maher et al. recommended displaying content on the social and emotional dimensions of care to support BMT patients [26].

Given the gap between patient and provider perspectives and the challenge it poses in delivering effective care, the HCI community has explored ways to facilitate technically mediated augmentation of patient-provider communication using technology (e.g., [10]). Patient portals, perhaps the most common technology, provide patients convenient access to their healthcare information and enable communication with providers [42]. Studies have shown that patients utilize portals to communicate not only about medical information but also to convey rich psychosocial experiences and emotional needs (e.g. [24,41]). Informed by these findings, we aim to investigate ways in which our proposed tool will present clinical data and psychosocial information to address participants' identified information needs to better support BMT patients.

3 SYSTEM DESIGN: PROTOTYPE SKETCHES

This study is part of a large project to develop a system that provides patients considering BMT with personalized, clinically validated information about possible outcomes of treatment. Based on our discussion with the BMT clinic team about patients' information needs, we created prototype sketches that present the two types of personal information in the form of a *Survival calculator* and *Experience videos* as part of a decision-making support tool.

3.1 Survival Calculator

Using patient-specific data, disease type, and donor characteristics, the algorithm developed for a survival calculator will generate predictive personalized likelihoods of the most clinically and personally relevant outcomes after BMT treatment: survival rates and outcomes relating to graft-versus-host disease (GVHD). Survival rate is a quantified prediction of a patient's chance of survival with and without transplant based on genomic, demographic, clinical, laboratory and disease-related features. GVHD-related outcomes are a projected degree to which GVHD will occur.

Because individuals often do not have a priori and stable opinions about risk magnitudes, their beliefs and feelings about risk are likely to be influenced by format [25]. Thus, formats used for conveying risk information are critical. We created three prototype sketches that present personalized likelihoods of these outcomes with graphical representations that varied in format and levels of abstraction.

3.1.1 Pie Chart. A pie chart can convey quantitative information to users in a simple and effective way. Thus, we created a prototype sketch that visualizes outcome and survival likelihoods using pie charts (Figure 1). This prototype presents personalized likelihoods numerically as the most direct representation.

3.1.2 Natural Frequency. Natural frequencies have been shown to be an effective way to improve the understanding of numeric information (e.g. "7 out of 10 patients" instead of "70% of patients") [14]. We therefore created an alternative prototype sketch that visualizes outcome and survival likelihoods using human icons to illustrate "how many out of 10 patients like you" would be affected by a particular outcome (Figure 2). This prototype presented personalized likelihoods using frequency as a semi-abstract representation.

3.1.3 Graphical Abstract. Graphical representations of data are known to enhance human cognition, increase perceptual inference, and improve understanding of numerical data [37]. We thus created a third alternative prototype sketch that graphically represents outcome and survival likelihoods by locating a dot on colored bar graphs showing a continuum of low to high risk (Figure 3). This prototype presented personalized likelihoods using "above/below" average as the most abstract representation.

3.2 Navigating Experience Videos

We created prototype sketches to show video clips in which experienced patients narrate their personal experiences of specific outcomes. The screen consists of a set of available videos, a timeline interface to navigate videos relevant to time lapsed since treatment, and different filtering options to display a subset of video clips that meet particular criteria (Figure 4). When creating prototypes, we focused on different ways that users might explore available video clips to locate ones perceived to be useful to them.

3.2.1 Timeline. The unpredictable and often non-linear nature of post-BMT recovery was made clear to us in our preliminary work. The trajectory of transplant recovery is difficult for patients to predict because patients can go through periods of having no symptoms to periods of complete incapacitation. While the trajectory of transplant does not follow a linear path, there are a number of time-based milestones that patients and providers refer to that are used as a frame of reference when

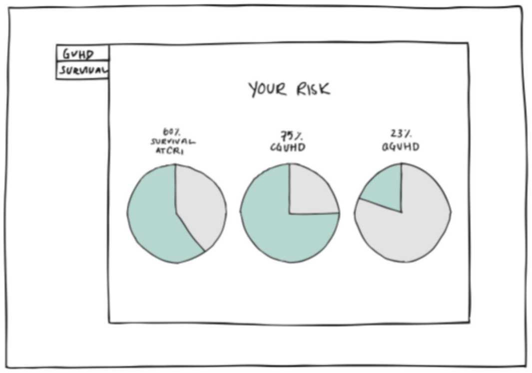

Figure 1: Pie charts show predictive percentages of survival after remission, getting chronic-GVHD, and getting acute-GVHD

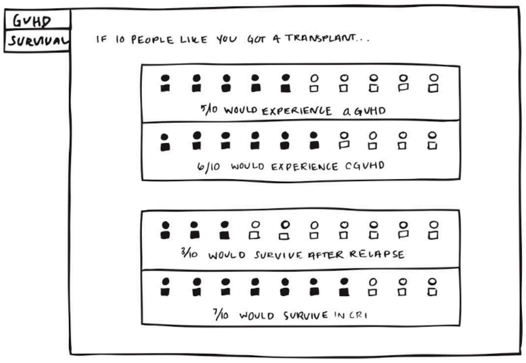

Figure 2: Natural frequencies use a human icon to present predictive percentages of getting GVHD, survival after relapse, and survival after clinical remission (e.g. "6/10 people like you experienced c-GVHD").

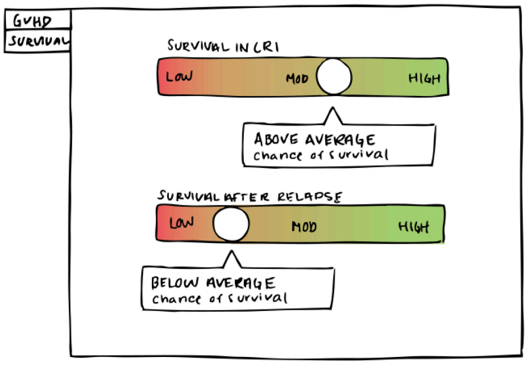

Figure 3: Graphical abstract presents survival rates after remission and relapse by locating a cursor on a color-coded bar with its description of "above/below average".

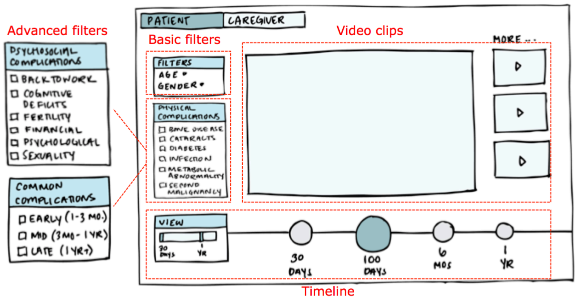

Figure 4: A screen with an experience video with basic filters, a timeline navigator, and 3 variations for advanced complications filters (physical, psychosocial, and common).

discussing recovery (e.g. 30 days, 100 days, 6 months, 1 year). Thus, one of the main features we incorporated into our design was a timeline-based interface for both information representation and navigation. The timeline allows users to explore available video clips chronologically since transplant [32]. By clicking a bubble on a timeline, users can see a list of available videos relevant to that time phase post-transplant.

3.2.2 Filters. Our prototype offers two basic filters: demographics (age, gender) and a zoomable time-span (Figure 4). In addition, we created three different advanced filter options as follows:

- Physical Complications: This filer allows users to explore available video clips based on the types of complications that are likely to occur. The options include bone disease, cataracts, diabetes, infection, and metabolic anomaly
- Psycho-social Complications: This filter allows users to explore available video clips relating to quality of life. The options include returning to work, cognitive deficits, fertility, financial, psychological, and sexuality.
- Common Complications: This filter allows users to explore available video clips by complications that they are likely to experience at different points in time after treatment, such as early (1-3m), mid (3m–1y), late (1y+).

4 METHODS

We conducted semi-structured interviews with patients and a focus group with providers to understand their perspectives regarding the presentations of the likelihoods of personalized outcomes and outcomes-specific videos. Our study was conducted at an oncology clinic center at a large teaching hospital in a US metropolitan area. The study was reviewed and approved by the institutional IRB board.

4.1 Focus Group with Providers

Seven clinical providers of the hospital's BMT program - three oncologists, three nurses and one coordinator - participated in a focus group (Table 1). The two chief medical oncologists are our co-researchers and are developing the algorithms to generate predictive data about survival rates and possible outcomes. They invited the rest team to the focus group, which elicited providers' perceived utility of different prototypes. Providers were shown each prototype sketch and asked for feedback. The focus group was lasted approximately 90 minutes and was audio recorded and transcribed.

Table 1. Participant summary

Provider participants		Patient participants			
ID	Title	ID	Years since BMT	Gender	Age
C1	Medical Oncologist	P1	2	M	69
C2	Medical Oncologist	P2	2	M	45
C3	Medical Oncologist	P3	2	F	59
C4	BMT Coordinator	P4	3	M	69
C5	Practice Nurse	P5	4	F	59
C6	RN Nurse Clinician	P6	6	M	56
C7	BMT Coordinator	P7	16	M	59
		P8	2	F	30
		P9	5	F	32
		P10	5	M	59

4.2 Interviews with Patients

Patients were recruited through the oncology clinic center. The clinic team identified potential participants from a pool of BMT patients, contacted each patient to ask if s/he was interested in the study, and sent us the contact information of those who agreed. We contacted each patient to confirm his or her participation. Finally, before doing an interview, the study was discussed, and a consent form was provided. Semi-structured interviews were conducted with 10 patients lasting approximately one hour (Table 1). Interview questions focused on soliciting patients' feedback on our prototypes highlighting their pers pectives, experiences, and needs. In the interview, participants were first asked to share prior experiences of being informed about possible outcomes. Then, they were shown the prototypes and asked for feedback reflecting on their experiences. All interactions were audio recorded and transcribed. Participants were compensated for participation.

4.3 Data Analysis

We analyzed our interview data using a grounded theory method, which includes open coding, axial coding, and selective coding. [40]. The first author led the data analysis. The emerged themes were continuously discussed with others in the research team to identify less prominent themes, which were then dropped from further analysis.

4.3.1 Open Coding. In the first step, we conducted open coding to identify and code concepts that are significant in the data as abstract representations of events, objects, happenings, actions, etc. The example below explains how one participant interprets colors. This response is coded as "visual component". Throughout the open coding process, a total of 86 loosely connected concepts were created.

"The ***[visual component]*** *green is go, like you're good* ***[/visual component]****."* *(P5)*

4.3.2 Axial Coding. Next, we categorized the related concepts created by open coding into higher conceptual phenomena using axial coding. Phenomena in grounded theory refer to repeated patterns of events, happenings, actions, and interactions that represent people's responses to the problems and situations. For instance, "positivity" is a phenomenon that represents a patient's desired attitude when coping with treatment. During axial coding, the open code "Visual component" in the example above was categorized as "Positivity". Our axial coding resulted in a total of 7 categories.

4.3.3 Selective Coding. Lastly, we followed the selective coding process to assemble our conceptual phenomena extracted from axial coding into a single storyline. The goal of this step is to integrate all concepts into a single storyline throughout building relationships across phenomena.

5 FINDINGS

In this section we explain our findings starting with how participants learned about outcomes-related information when deciding to undergo BMT. We highlight their reported feelings and perceived needs. We then describe how patients and providers perceived the general utility of the proposed tool followed by their perspectives on the usefulness of the two focal tool features and preferences for different prototypes.

5.1 Limitations of Current Practices

Providers are patients' primary resource for learning about BMT and its possible outcomes. Thus, patients expressed the importance of strong trust in their providers and of receiving adequate information about treatment and possible outcomes from them. They also expressed that it is equally important to know what their lives after transplant would be like. However, both providers and patients recognized some limitations that providers face when offering information about lived experiences after transplant to patients.

"They [patients] want to know when they can get back to the way they were before or what a new normal is going to be like." (C2)

"A doctor can tell you what might happen. But there is no way you can describe it until you've gone through it. No matter how much they explain about what is going to be going through, it's nothing like hearing it actually from the people who went through it already." (P6)

Another information resource for patients is an education class that the clinic provides monthly to help patients and their families understand BMT, meet the healthcare team, and answer any questions patients have. All participants mentioned that this education session was overwhelming as it provided a large amount of information much of which neither patients could easily make sense of nor apply to their situation. Information from the education class proved not only to be difficult to integrate in meaningful ways but also daunting.

"We had a lengthy conversation with [a provider]. It was a flood of information. I was inundated. It was too much." (P9)

"During the presentation the words used were fairly overwhelming. There was a lot of technical information. Some of it was kind of alarming the way they describe, some of the side effects that you could possibly get. I sat there and I thought this is just overwhelming. They gave us booklets and pamphlets about the whole process. I looked up a few things but didn't get too caught up in it because it became overwhelming." (P1)

What we observed across the interviews parallels prior research findings about the limitations of common practices for effectively conveying meaningful information about treatment and patients' lived experiences [7]. The limits of the current practices to inform patients about BMT provides opportunities to design a tool to enhance patient experience by better helping them prepare for treatment and possible outcomes.

5.2 Perceived Utility: Sense-Making Support

By current standards, every patient has the right to decide whether or not to receive treatment, as do patients considering BMT. Because various complications, which may be lifelong or life threatening, can arise following BMT, providers mentioned that it is important for patients to have enough information about possible outcomes so that patients can make a well-informed decision, as one medical oncologist said:

"It is important for people to integrate that [possible outcomes] into their decision making. Probably no one is going to say, "If I need a cataract operation eight years from now, I am not going to do a transplant." But it is still part of the information they need to know when making a decision." (C2)

Most patients, however, mentioned that they felt they had no other options but to go through with transplant if they wanted to live. They viewed the decision as already made rather than a choice. It is thus noteworthy that patients did not consider the proposed tool as a device for helping them make the decision but instead viewed it as "good information to have" for them to be prepared for and make sense of what they are likely to experience after receiving transplant.

"At that point, I knew that pretty much this was my only chance to beat the lymphoma." (P1)

"The tool wouldn't have changed our decision to get transplant or not. It just would have been good information to have." (P7)

"You basically do not have any choice. You are going to need to have the transplant. A lot of things are probably going to happen. So, be prepared. That was pretty much it." (P6)

These findings are consistent with the empirically based criticisms that extant decision aids are nearly exclusively focused on the transplant decision with insufficient attention to the need for deliberation and collaboration between patients and providers [12]. Patients made apparent that their desires for support were not for making a single future decision about BMT to facilitate decision-making [3], but for support to help them give meaning to their experiences and integrate their experiences in coherent ways that reduce ambiguity – support of "sense-making" throughout the illness trajectory as a variety of disruptions are experienced [46].

Sense-making is fundamentally about the "continued redrafting of an emerging story so that it becomes more comprehensive, incorporates more of the observed data, and is resilient in the face of criticism." [46]. Patients perceived the value of the proposed tool as "sense-making", enhancing their ability to make sense of their challenging real-world situations and help them update that sense throughout a nonlinear illness trajectory; this was more fundamental than the act of decision-making itself. To that end, we reposition our proposed tool from a decision-making tool to a sense-making support to help patients make sense of the treatment, possible outcomes, and strategies to cope with complications by providing them with enhanced access to personalized and experiential information.

5.3 Quantitative Data: A Survival Calculator

The survival calculator will show predictive likelihoods of personally relevant outcomes of two types: survival rates after relapse/remission and GVHD-related outcomes. In our provider focus group, the majority of the discussion centered around the perceived utility and appropriate presentation of these data through a survival calculator visualization. Providers discussed advantages and drawbacks of different data representations, while also offering their varying perspectives about what patients would want.

"Patients would want to have the survival stuff and GVHD all in one slide because people want to know the competing rates." (C1)

"I would separate out GVHD in a separate slide [from survival rates] so that it is not overwhelming to them [patients]." (C2)

Contrarily, patient participants' reactions to a survival calculator were not as enthusiastic as providers. They recalled the time when they were facing transplant as a time riddled with fear, anxiety, and stress. Because, for most patients, BMT was not perceived to be a choice but as a necessity for survival, many of them described efforts to strategically avoid predictive outcomes so that they could instead focus on what they were currently facing and get through it successfully.

"I tried not to look at numbers at that time. I was just focused on what's next and how to get better." (P8)

"I didn't want to talk about anything. I said, "God will provide. I'll be fine." I had no interest in knowing what I had. I just went to the doctor and did what he told me to do." (P6)

These observations are consistent with research showing that patients and providers may consider the same set of concerns but differ in how they attend to and prioritize them [7]. The challenge then is how to accommodate these differences so that patients are better prepared for clinical encounters both physically and mentally, as a clinician said:

"In so many respects it [survival rates] seems like harsh but on the other hand they sort of have to know. They have to." (C2)

To get a better sense of how providers and patients understood the trade-offs of being presented with survival rates and GVHD outcomes, we further explored perspectives on three visual representations of these quantitative data.

5.3.1 Numeric vs. Abstract Visualizations. In our early discussion with the BMT clinic team, providers suggested a pie chart (Figure 1) to present outcome likelihoods, perceiving it to be good for judging proportions [38]. While it was thus not surprising that in the focus group all providers preferred a pie chart presentation, we found it interesting that patients also preferred the pie chart due to its simplicity and clarity.

"The traditional pie chart is very precise with the specific percentages presented to them. I think a pie chart is the most kind of obvious quick glance." (C4)

"I like that [a pie chart] much better. It is much more intuitive and clearer. That is easier to read because it's simple." (P5)

We had anticipated that patients would prefer graphically abstracted versions (Figures 2 and 3) to a pie chart because of the known benefits that graphical representations have been shown to have, such as improving understanding of numeric information and enhancing perceptual inference [37,39]. We anticipated that graphically abstracted visualizations would help patients better understand underlying meanings of quantitative values because these have additional visual components, such as description captions, icons, and colors, to help interpret its meanings. Contrary to our expectations, however, all patient participants found those to be inferior. They particularly disliked the natural frequency visualization (Figure 2) that used human icons to present outcome likelihoods as "N out of 10 patients like you would experience certain complications." Most participants perceived this iconized visualization as too personified or as rendering negative cases too tangible. Their dislike stemmed from two visual components: the expression "like you" in the description and the human icon. These visual cues made participants imagine themselves as one of these iconized humans and think about themselves as an adverse case.

"You could have dots instead of people's heads. With these people [icons], you are going to look at it and think oh my God those people aren't going to make it." (P5)

"I would rather see the percentages and the numbers and not say this many people don't make it because you could become one of those people. That [the natural frequency visualization] makes my heart beat fast." (P6)

Our intention was to enhance the quantitative interpretation of different likelihood outcomes using different visual cues, but these instead drew patients' attention to adverse cases, germinating a negative or pessimistic interpretation. While not as disliked as the natural frequency visualization, participants also did not favor the graphical abstract (Figure 3) due to its use of the term "average", which we discuss in the next section.

5.3.2 Positivity and Clarity are Crucial. We found that patients were as sensitive to the tone and look of the tool as to its contents. They expressed their effort to remain positive regardless of outcome probabilities, and thus preferred visual components to help them remain optimistic. For example, participants indicated a preference for replacing negative expressions (e.g. risk) with more positively skewed ones and for replacing colors that may evoke strong negative emotions (e.g. red color) with more encouraging ones. Following on this, we named this feature as a "survival" calculator.

"Survival is much softer and positive than risk. Just be on the optimistic side." (P8)

"It should be framed as survival [not risk]. Positivity please." (P9)

"The red is the negative and the green is go, like you're good. I would do green. Green for survival!" (P5)

The biggest concern that both patients and providers pointed out was the term "average" used in the graphical abstract (Figure 3). In this prototype, we replaced the numeric data presentation (e.g. "70% chances of survival") with a color-coded bar in which a cursor is located between low and high so that people would easily recognize the relative likelihoods of different outcomes (e.g. "above average chance of survival" with a cursor on a bar's 70% location). We anticipated that presenting survival-related data indirectly through abstraction would pose less anxiety to patients and help better contextualize the meanings underlying the numeric values than presenting a numeric value as is, especially when the expected outcomes are not promising. Contrary to our expectation, patients noted that the abstract visualization was difficult to meaningfully interpret the contents and that it increased confusion and anxiety, especially when they saw the term "below average".

"I think this would scare me more than having a number. Below average chance of survival, what does that mean? If you give me a specific number, I can work with it." (P9)

"It is hard to define what an average is. I think average works when you give some connotation of what the average actually means." (C4)

Overall, our findings demonstrate that data presentation should be simple, straightforward, and strategically ambiguous. By strategically ambiguous we mean that patients did not want to engage in interpretive work to make sense of the objective meaning of numerical data (unambiguous preferences), while simultaneously preferring presentations that facilitated the meaningful integration of the data into optimistic narratives, regardless of its objective truth. Prior research has found that the format for presenting information can influence perceived risk magnitudes [25]. Here we specified how some visual representations could interfere with patients' desires for more positive sense-making around outcomes.

5.4 Qualitative Data: Experience Videos

Experience videos of our tool can provide long-term support throughout a patient's illness trajectory. Patient participants appreciated having access to video clips of veteran patients sharing personal stories about the experiences with BMT. All patients also reported beliefs that new patients would greatly benefit from these videos, highlighting how veteran patients' experiences presented in understandable, real-world terms would facilitate learning about complex outcomes and medical and psychological features. They perceived that access to experiential information could also scaffold better dialogue with providers regarding long-term effects and quality of life after treatment. They were particularly drawn to the potential of the videos to instill optimism from seeing other patients who had successfully managed them. Participants remarked that simply seeing patients like them who are still alive after treatment, regardless of what they say about their experiences, could potentially provide patients with strong emotional support and encouragement.

"The fact that they are alive, and they all made it through alone is positive. Even if they say some issues, "hey, I am still alive" that's enough. Even if I think things are terrible now, it seems like I've looked at this and think 'there are people who are actually doing okay later.'" (P6)

"Just the fact that there are people who made it through tells me a lot. I don't need to believe everything is perfect and they are perfectly healthy. Just to know that somebody is there who got that far gives me hope. For me to see this and just to know that all these people are down the road and made it is very encouraging." (P7)

Whereas, providers did not engage in much detailed discussion about the experience videos in the focus group but expressed general support for them. They offered one recommendation to include introductory videos presented by clinicians to provide relevant clinical background.

"It'd be good to have maybe one or two healthcare provider videos as an introductory. In the videos clinicians will talk about the chronology with transplant as an introduction to graft versus host disease and to occur within the first three months." (C3)

The strong general support for the use of videos raised questions about how to make them most useful for patients. We tested two key features for navigating the videos: a timeline and filters.

5.4.1 Timeline Helps Reflect on Treatment Milestones. To help patients find relevant videos, we proposed a timeline-based navigator where clicking a bubble on the timeline displays a list of videos associated with the selected time phase (Figure 4). Patients perceived the timeline to be useful to both functionally navigate through videos based on a time phase and reflect on milestones for progress, which in turn can support hope.

"It gives you something to look forward to and say, "okay I can celebrate this milestone and now I can move to the next one. Without this, it's just never-ending. It's like whew, I made it to the hundred day mark. This gives you a hope of progression." (P5)

5.4.2 Filtering Facilitates Personalization. Basic and advanced filters allowing users to narrow down to a particular set of videos based on patient characteristics or types of complications were also tested. Since all patient participants reported feeling overwhelmed by the amount of information in the education class and the process of determining its relevance, our expectation was that users would find value in having some control in sorting and finding relevant content. Indeed, they indicated that patients would find such filters to be useful to easily identify personally relevant videos based on illness status and complications (physical, psychosocial, and common) and how far along they were in the trajectory.

Whereas, we observed differences in which filters patients and providers perceived to be useful. Providers focused on physical filters, highlighting which complications to include.

"People know about cataracts. They know about diabetes. They want to read about what their chances are. I would tuck that way away but the graft versus host disease has got to be front and center [of the physical complications filter]." (C2)

"The metabolic abnormality is important. I think patients want to know about when their white blood cell counts will come up from

their platelets. They think that their counts are going to recover but it doesn't always happen that way." (C5)

Many patient participants, however, opposed having a physical complications filter. They explained that just seeing a list of possible complications would overwhelm and scare patients, as they could become overly concerned about getting all these complications, especially given the fact that the tool aims to provide patients with individually relevant information. Another concern with the physical filter was that the terminology used in the filter might be difficult for a layperson to understand, highlighting potential challenges with routine medical knowledge [29,33]. The following responses provide insights about what may trigger patients' overwhelming responses to the physical filter.

"It [the physical filter] is going to scare me. I would think, 'Oh my gosh, I can have all these things?'. So, it is really not a good thing to show all these." (P6)

"I'm pretty up on technical terms. I know in general what a metabolic abnormality can be, but don't know what it really means here." (P1)

"Oh gee, I didn't know that I could get diabetes." (P7)

Instead, patients favored a common complications filter that allows users to refine videos based on a different time lapse after transplant (early, mid, late). Patients were pleased to have a way to filter out videos that are not immediately relevant but still have access to them if they became relevant later on. In addition, participants suggested combining psychosocial and common complications filters so that they could identify videos based on the time lapsed after transplant and personal experiences relating to quality of life.

"I like that [the common filter] because it is not so overwhelming. We are only going to look at the early and the mid. We are not going to spend more time on a year out, or we will do that a quick look just to see but not so much." (P7)

"You are told that there will be complications. Maybe we all understand that but to have it broken by early vs. late, I get that there is a progression of hopefully things getting better." (P6)

One important consideration that emerged about offering filters was to make sure that the tool would have at least one video available no matter how the filter is set. Given that patients perceived a major advantage of the tool is to be able to find other "people like me" who survived, patients noted that not receiving any results would be frustrating.

"What if you filter and no one shows up? When you filter and no one comes up, that would be really frustrating." (P6)

6 DISCUSSION

This study yielded important, albeit preliminary, findings that contribute to prior research in the design of patient-centered systems. In particular, patients' reactions to our proposed tool revealed a strong need for making sense of challenging situations and emotional support, which echoes prior work [26,28], while providers attended to its utility for informational support specifically to facilitate informed decision making. We take up these findings to discuss implications.

6.1 Adopt a Sense-making Framework

The relevance of "sense-making" over "decision-making" as a framework emerged as a consequence of testing our design prototypes with patients. Patient responses to our proposed tool emphasize that *sense-making* is an important way forward for design strategies that realize deeper support for managing new circumstances after complex treatments like BMT. Sense-making is about the "interplay of action and interpretation" [45] and constitutes the "primary site where meanings materialize that inform and constrain identity and action" [46, p. 409]. Much prior work adopting a sense-making perspective examines the processes by which actors construct meaning as well as deliberate efforts to shape the sense that is constructed [39]. In particular, the sense-making framework has been widely used in the design of technological interventions to elicit sustained behavior changes for chronic care in order to achieve managerial goals (e.g., [4,27,28]). By contrast, we aim to support patients' sense-making not by persuading patients to change behavior but by supporting patients' own construction of *situational meaning* of their circumstances [31]. We aim to help patients prepare mentally and emotionally for upcoming events along the illness trajectory, many of which are unanticipated or hard to appraise in advance. This need is most acutely expressed by patients' strong interest in hearing what people like them have gone through, as well as maintaining optimism as part of how they make sense of their changing circumstances and in the face of hardship.

Thus, this work contributes to extending prior work by highlighting the challenges and opportunities in designing for *sense-giving* [39]. Ambiguous events that are interruptive are often the catalyst for sense-making efforts aiming to restore order, which involves providing "salient cues of an unfolding situation and developing them into a plausible narrative for what is going on" [37, p. S9]. Accordingly, sense-giving efforts may strategically identify which cues should be made salient and present them to facilitate the development of plausible narratives and bring coherence to the ambiguous, disruptive event. (Sense-giving is thus ultimately a design task.) We draw on the sense-making perspective to reflect that patients' lives have been disrupted by the discovery of disease and its treatment that introduces a range of ambiguous events. This includes BMT, which patients often do not experience as a choice but as an event inevitable for survival. Sense-giving support can be further developed by examining domain specific ways that patients and providers give meaning to treatment, its outcomes, and management skills.

6.2 Provide Positivity and Emotional Support

Patients emphasized the importance of incorporating positivity in their sense-making efforts. Patients expressed determination in reaching a new, livable normal after treatment and did not want the tool to undermine their effort in successfully achieving this. Specific design features were perceived to enable positivity (e.g. timelines, accomplishments, simple numeric abstractions), while others appeared to undermine optimism (e.g. overly interpretive graphic abstractions, physical complications filter, conditions without video experience). This finding corroborates prior work demonstrating the significance of optimism for physical and mental well-being [17]. It also raises key design challenges for preparing patients in a vulnerable state for likely treatment outcomes in ways that foster patient optimism and accurately convey clinical information that may not be optimistic. As such, design strategies to support sense-making need to carefully attend to any unexpected, or even detrimental, consequences of meeting patients' perceived need for positivity (e.g. if positivity introduces bias in interpreting information).

Like other complex treatments, BMT is physically and mentally taxing and thus draws out emotional issues. Our findings suggest a strong need for emotional support, which echoes prior work asserting that feelings of safety and anxiety reduction, are crucial components [11]. While there has been increasing interest in the HCI community to design systems that support the emotional dimensions of managing health concerns [15,16], such efforts have been complicated by the relative inseparability of informational needs and emotional support in complex treatments [21]. Thus, it is crucial for designers to reflect on the emotional and ethical consequences of designing for sensitive types of health information interactions that may impact sense-making, especially when information is encountered in a vulnerable state.

6.3 Carefully Present Clinical Data

The graphical display of health information has the potential to improve patient understanding and has been shown to influence treatment decision-making [6,30]. Various visual formats have been shown to differentially affect risk perception and treatment decisions among patients [43,44]. Perceptions of our proposed tool, particularly those of patients, revealed novel insights and starting points for developing design strategies for *sense-giving*.

First, our findings demonstrate ways in which a straightforward model of information transfer breaks down in light of the emotional weight of the data (e.g. life/death) for patients. This means that design decisions, even those with good intentions, can cause emotional harm to users. We expected, based on prior theory and research, that providing particular interpretative aids (e.g. icons and averages) would help, but found that these aids confuse patients more than using a simple representation that had been suggested by the providers. This was most dramatically illustrated in discussions of the survival calculator and the use of human icons to statistically and graphically represent chances of life or death. This finding points to the value of engaging vulnerable patient populations with designing patient-centric systems for developing representations of sensitive clinical data. Such design processes can lead to practical discoveries that facilitate sense-making processes important for patients and satisfy clinicians' desires to adequately educate patients.

Second, the findings highlight patient preference for timeliness of information, which was mostly about relevance and patients' ability to interpret information so as to coherently make sense of their immediate challenge or context. Similarly, their desire for information to be presented so as to contribute to their sense of accomplishment was evident in the patients' reactions to navigating experience videos to engage with particular types of information. These preferences for timeliness and accomplishment should not be perceived as incompatible with presenting accurate clinical information about treatment. Rather, patient perspectives merely differ from providers about when exposure to particular types of clinical information is crucial along unfolding illness trajectory [7]. These findings point to further potential for navigation design strategies that may support a wider range of health contexts (e.g. [19]). One implication is to support temporality [35] in collaborative sense-making that enables other stakeholders to engage with a patient's timeline presentation via commenting and annotating it where relevant [32].

Lastly, the filters developed for helping users sort the videos need to effectively mediate vernacular and technical terminology regarding treatment and its outcomes. More work is needed to understand the vocabulary that laypeople use to better align these with the terms and concepts providers use. Reconciling these different terminologies ought to be done within the tool to lower the burden of interpretation by all involved. Indeed, the language and clinical conceptualization of a survival calculator is worthy of deeper analysis.

7 CONCLUSION

This study examined how patients and providers perceive graphical representations of outcome-related information regarding BMT, including predictive quantitative risk assessment data for clinically important outcomes and related qualitative information narrated by experienced patients. We found that patients perceive the tool as *sense-making* support to better comprehend and prepare for the complexities and emotional challenges, whereas providers attended to the tool's functionality in supporting *decision-making*. We also identified enabling and detracting design features for interpreting numeric information and navigating experience videos. These findings contribute to our broader project developing a secure patient portal that helps patients to be better informed about and prepared for possible treatment options. While we have necessarily limited ourselves to BMT in this study, we believe that our findings could be applicable across a range of chronic illnesses, especially ones that pose significant emotional burdens and information overload to patients.

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