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DESIGN FOR SENSEMAKING IN COMPLEX AND AMBIGUOUS MEDICAL  
SITUATIONS

By

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A dissertation submitted to the

School of Graduate Studies

Rutgers, The State University of New Jersey

In partial fulfillment of the requirements

For the degree of

Doctor of Philosophy

Graduate Program in Communication, Information, and Media

Written under the direction of

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New Brunswick, New Jersey

May, 2021

## **ABSTRACT OF THE DISSERTATION**

Design for Sensemaking in Complex and Ambiguous Medical Situations

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The tools designed to support patients facing complex and ambiguous medical situations often take an episodic and information-centric view emphasizing decision making. Such an approach neglects to consider a patient's evolving understanding of the illness experience and the effects of that understanding. A sensemaking perspective offers an alternative to the traditional view of a "decision" by examining the processes that people go through as they experience and interpret the world around them. This dissertation describes the development of a theory of design for sensemaking support in complicated, high-risk medical situations by adapting a participatory design (PD) approach. With the bone marrow transplant (BMT) unit at a large academic medical center as a case study, this research assesses the feasibility and utility of this theory to investigate and support sensemaking.

This process consisted of three studies. Studies 1 and 2 relied on the user-centered design (UCD) methods of need-finding and prototype development and testing to provide a point of comparison with Study 3 that utilized PD adapted for sensemaking. As participants responded to prototypes of a system designed to support expectation formation, it became clear that there was a significant gap between the rationale for the

design of the proposed support tool features and the lived experiences of stakeholders. When evaluating the system, patients, caregivers, and providers expressed confusion about its intended use and doubts about when (and if) it would be useful before or after transplant.

This gap led to a shift in perspective for the third and final study. Study 3 adopted a PD approach that aimed to investigate patient and caregiver sensemaking in the period of time leading up to transplant. This method asked participants to create a timeline that visually represented the memorable events in their pre-BMT experience and to creatively ideate around potential support solutions. This achieved a more holistic representation of their sensemaking practices. Participants described a progressive and gradual process of coming to understand and accept the possibility of BMT while also actively coping with the uncertainties of attempting to reach remission and find a donor – a process that was not well-served by the future-oriented solutions proposed in Study 2.

The comprehensive, longitudinal view of the period before transplant facilitated through the novel design approach used in Study 3 enabled refinement of the design problem to one of sensemaking rather than decision making. These findings will inform the continued development of the BMT support tool while also having clinical, methodological, and theoretical implications relevant to design for sensemaking in other complicated health contexts. Accordingly, guidance on the application of this sensemaking approach to design in both research and applied contexts is presented.

## **ACKNOWLEDGEMENTS**

I am extremely grateful to all those who supported me in my academic journey. I would first like to thank my advisor, Dr. Lisa Mikesell, for being a thoughtful and inspiring presence in my life. I cannot thank you enough for the amazing amount of time and effort you spent supporting me through this project.

I would also like to sincerely thank the members of my committee for offering their varied and valuable expertise. Dr. Mark Aakhus, for your appreciation of design and its application to communication research. Your work has been a tremendous inspiration for my own. Dr. Itzhak Yanovitzky, for teaching me the value of theorizing and for your belief in my capabilities as a communication scholar. Dr. Kaitlin Costello, for introducing me to the concept of sensemaking and guiding me in its application. Dr. Thomas Mackie, for offering direction on ways to ensure this work makes a meaningful difference in patient care. Thank you all for your time, guidance, and encouragement.

I am also very grateful to the people who shared their stories with me. Thank you for volunteering your time and perspectives.

The completion of this dissertation would not have been possible without the support of my friends and family. To my grandmother, the original Dr. Fadem, thank you for being such a brilliant role model and mentor. Thank you to my father, Dan Fadem, for teaching me how to connect with people, and my mother, Laura Gesin, for instilling me with creativity. Finally, Oscar Tews, thank you for your love and encouragement, and for always believing that I would get here.

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## **CHAPTER ONE: Introduction**

The shift towards patient-centered care has prioritized interventions that value patient participation as a means of improving care quality. Because this often manifests in the active involvement of patients in life-altering health decisions, shared decision making (SDM) is considered the epitome of patient-centered care (Barry & Edgman-Levitan, 2012). Patient participation in clinical situations plagued by complexity and ambiguity is especially valuable, as the ideal option must be based on more than medical evidence and must also consider patient preferences and values (Epstein & Gramling, 2013). Yet, patients may struggle to fully understand the nature of these complicated decisions and the implications of their choices. For instance, the complexity of risk/benefit tradeoffs and emotional factors can challenge how patients understand the consequences of their options (Paling, 2003). For decisions in which each option has significant and long-lasting implications, a patient's ability to contextualize health information and determine its relevance is critical for their meaningful participation in SDM. However, interventions to support SDM are often centered around information transfer (Elwyn, Frosch, Volandes, Edwards, & Montori, 2010; Wieringa et al., 2019). As a consequence, they often provide the necessary information, but do not always help people to meaningfully interpret it (Kunneman & Montori, 2017). Patients may receive more information than is typical, but information alone does not necessarily lead to patients feeling adequately informed or supported in deciding how they should proceed (Ruland, 2004). Although SDM interventions may improve patient knowledge about their options by offering more information relevant to the decision, they often lack adequate

support for patients as they attempt to make sense of the information in the context of their own lives (Hargraves, Leblanc, Shah, & Montori, 2016).

Decision aids (DAs) are one of the primary tools for supporting patients in participating in SDM. These tools present relevant and objective risk and benefit information about various options to patients making a decision. Yet, DAs are plagued by a fallacy in which a patient is viewed as “a passive and empty vessel” that becomes an informed and emboldened decision maker once filled with information (Charles, Redko, Whelan, Gafni, & Reyno, 1998, p. 88). In actuality, presenting information, especially risk probabilities, in ways that is easy for patients to understand remains a common usability issue in DA development (Ankolekar, Dekker, Fijten, & Berlanga, 2018). The information-centric view that underlies many DAs is problematic, and the episodic view of decision making that forms the roots of institutional practices like informed consent are not conducive to more complicated illness experiences such as those where both risk and uncertainty are high. Existing knowledge, past experiences, expectations, and other situational factors influence how patients interpret and use information, yet the empty vessel fallacy has left this influence relatively unexplored.

Sensemaking, or how people interpret and understand the world around them, is an alternative perspective that shifts the focus away from the individual level decision maker and looks at how situational and contextual factors intersect with individual action (Snook, 2002). A sensemaking perspective looks beyond information design and engages with the ways that people find and synthesize large amounts of information in order to develop a cohesive understanding (Blandford & Attfield, 2010). This dissertation extends the boundaries of designing for complex medical situations by 1) exploring and critiquing

information-centric practices of existing interventions targeting decision making and 2) proposing generalizable principles to design for sensemaking support. With the bone marrow transplant (BMT) unit at a cancer center connected to a large academic medical center in the northeastern United States serving as a case study to test the applicability of the theoretical and methodological concepts of sensemaking, the present study adopts a design approach to develop a sensemaking support tool for patients with acute leukemia facing the possibility of bone marrow transplant.

The scope of this work is in analyzing and refining the design process itself and not (yet) the resulting design outcome. This process uncovered shortcomings in the current methods for supporting patients in complicated medical situations, suggesting the need for an alternative method for confronting the challenges of these situations. Though a final artifact has not yet been developed, there are opportunities for future designers to take a sensemaking approach. This work is considered design research, like that described by Zimmerman, Forlizzi, and Evenson (2011) in that it applies an iterative and reflective process of artifact development that regularly reframes the problem in an “attempt to make the right thing.” (p. 493). The result of this design research is not only progress towards the future implementation of a finalized product, but also in identifying the limitations of conceptualizing support interventions as “decision aids” for complicated medical contexts. To illustrate this, I will address two aims throughout this dissertation: 1) to apply methods for uncovering sensemaking practices of relevant stakeholders using design methods and 2) to evaluate those methods to develop an approach to design that elicits and incorporates sensemaking practices in pursuit of more supportive interventions. These goals are related, and the exploratory application of these

methods in this case study will allow for reflections on both the findings concerning sensemaking practices in this context and how the methods to uncover these practices can be applied to other complex medical situations.

### **Dissertation Overview**

Chapter 1 details prevalent methods of attempting patient-centered care in complicated clinical spaces through shared decision making (SDM) and the use of decision aids (DAs). A critique is presented of the conceptualization of a “decision” that informs common patient support practices and the challenges of developing tools to support patients in these circumstances. This chapter also describes the difficulties of designing support for the particular clinical context being investigated as a case study, bone marrow transplant. Chapter 2 presents the theoretical basis for this work, including the similarities and differences between user-centered design (UCD) and participatory design (PD) methods. The theoretical and practical foundations of design for information, interaction, and communication are discussed, establishing the context and opportunity for design for sensemaking among those established design disciplines. Chapter 3 describes the methods used across three research studies, including participants, data collection, and data analysis. Chapter 4 presents the results from the first study, which included UCD need-finding interviews with patients and providers to investigate how they made sense of the challenges of BMT decision making. Findings from this study informed the development of prototypes for two proposed features: a risk calculator and an archive of patient experience videos. Chapter 5 presents the results of feedback sessions held with providers, patients and caregivers in which they offered their perceptions of the support tool. This study led to a dramatic shift in perspective as to the

problem this tool was intended to solve. Specifically, feedback from patients and caregivers suggested that the prototypes presented to them may not have been particularly useful before transplant, as their struggle had not been one of decision making but instead one of sensemaking. Consequently, the third and final study described in Chapter 6 adapted a PD approach to more effectively uncover stakeholder sensemaking. To do this, patients and caregivers were asked to create visualizations of their experience leading up to BMT, emphasizing the questions and concerns they had and the emotions they felt to uncover their sensemaking processes. Chapter 7 discusses the implications of these findings and reflects on the utility of design for sensemaking support. This dissertation concludes with recommendations intended for other researchers who seek to apply this method to develop sensemaking support for other complex clinical spaces.

### **Navigating Complicated Medical Situations with Shared Decision Making**

A commonly recommended method for implementing patient-centered care in complicated medical situations is shared decision making (SDM), a technique that promotes honoring patient perspectives and autonomy to achieve preference-sensitive decisions (Elwyn, Dehlendorf, et al., 2014). This process is believed to be most applicable in situations with no single medically defined right or wrong choice and that are characterized by high levels of uncertainty, possible negative outcomes, and time constraints (Charles, Gafni, & Whelan, 1997; Whitney, McGuire, & McCullough, 2003). When medical evidence alone does not indicate a clear choice, patient preferences are argued to be the deciding factor (Coulter, Entwistle, & Gilbert, 1999). Conceptually, SDM is a collaborative process in which a patient and provider work together to make treatment decisions that are appropriate for the patient's preferences and circumstances

(Whitney et al., 2008). Descriptions of SDM generally include a process that begins with recognition that there are several viable treatment alternatives and that a decision can be made. Such a decision requires knowledge exchange, the identification and expression of values/preferences, and deliberation (Stacey, Légaré, Pouliot, Kryworuchko, & Dunn, 2010). For SDM to take place, patients and providers progress towards an agreed upon treatment decision by exchanging information and sharing preferences for treatment (Gattellari, Butow, & Tattersall, 2001).

SDM's approach to the discussion of possible treatment options notably differs from other models of patient provider interaction for decision making. Unlike the traditional paternalistic model of decision making, whereby providers maintain decisional authority, and the model of informed decision making, in which the doctor provides information about options but does not offer recommendations, SDM views patients and providers as equal contributors to the decision making process with shared decisional responsibility (Krieger, 2013). Their status as equal partners is based on the premise that patients and providers come to the interaction with complementary epistemic expertise - the provider has expert knowledge about available treatment options along with their risks and benefits, while the patient has understanding of his/her values and preferences (Barry & Edgman-Levitan, 2012). Part of the motivation for the provider sharing medical expertise is to reduce the "information/competence gap" inherent to the patient-provider relationship (A. G. H. Thompson, 2007). Descriptions of SDM embed these two types of expertise in *information exchange* processes between patients and providers. Providers are encouraged to disclose unbiased information about the risks and benefits of the



various treatment options (Charles et al., 1997) and patients are expected to articulate their needs and preferences (Lown, Hanson, & Clark, 2009).

SDM is not only described as a process of information transfer, but must include deliberation, or the process of considering participants' perceived pros and cons of different options, assessing their implications, and considering possible futures (Elwyn et al., 2012). Deliberation in SDM often takes the form of values clarification, or the processes by which patients gain clarity on how they value treatment options and why (Pieterse, de Vries, Kunneman, Stiggelbout, & Feldman-Stewart, 2013). This element of SDM stems from the belief that the benefits and risks of treatment decisions should be evaluated by the people who have to live with them. As many have argued, for patients to meaningfully participate in decision making, they must have access to unbiased information about options, recognize and consider their values and goals and the likelihood of achieving these goals with each outcome, and have a conversation with their providers in which these goals are incorporated into the decision making process (Fowler, Levin, & Sepucha, 2011). The ideal deliberation process includes conversations between patients and providers about various options and initial preferences. Through this discussion, they may form informed preferences based on how the most relevant pros and cons reflect what they value most (Elwyn et al., 2012). The provider's role in these conversations is to help patients evaluate their options based on patient goals and expectations, and to ensure they have the information they need to comfortably make and carry out their decision (Kane, Halpern, Squiers, Treiman, & McCormack, 2014; Stiggelbout et al., 2012). Despite these ideals, in practice, providers' SDM strategies may be information-centric, with more emphasis on the information transfer component of

SDM than on the conversation for deliberation support (Elwyn, Frosch, Volandea, Edwards, & Montori, 2010).

Recently, the discourse around SDM has evolved to encompass ideas and proposed practices that go beyond providing information for patients to use on their own—as Kunneman and Montori (2017) put it, “there is nothing shared about choosing alone from a menu!” (p. 523). For example, Gullbrandsen et al.’s (2016) suggestions for SDM to incorporate the relational and emotional components of the illness experience, building the patient-provider relationship by recognizing the burden of navigating illness challenges riddled with uncertainty. Entwistle et al. (2018) exposed some of the understudied challenges of providing person-centered care, including the “paradox to be navigated when intervening to support someone’s autonomous agency” (p.1465). The authors emphasize the impact of potentially irresolvable uncertainties around what matters to people and what may be the limits on possible improvements in their lives. Such recognition of the complex nature of decision making in certain difficult clinical situations is a remarkable advance with potential to seriously impact the ways that patients are supported. Yet, the tools that have been developed to support SDM struggle to account for the complexity of illness experiences. There is no clearer evidence of this deficiency than in decision aids (DAs) designed to support SDM, which, despite their recognized intentions to foster collaboration and deliberation amongst stakeholders, tend to focus heavily on the design of information as the primary means of developing support for the deliberative requirements of SDM (Elwyn, Frosch, et al., 2010).

## **Putting SDM Into Practice: The Status (and Shortcomings) of Decision Aids**

There is a vast amount of literature describing SDM but there is limited guidance about how to practically implement this ideal (Elwyn et al., 2012). One of the primary means of attempting SDM comes in the form of decision aids (DAs). DAs are tools that intend to offer patients a balanced view of treatment options and relevant outcomes so that patients can make “informed judgments about the personal value of those options” (O’Connor et al., 2007, p. 717). DAs can be designed to be used within the patient-provider encounter, or more commonly, to be used by patients in preparation for the encounter (Elwyn, Frosh, et al., 2010). In theory, SDM is perceived to be supported by DAs because patients who come to the conversation more informed about treatment options are more likely to feel comfortable participating in the decision-making process. However, the effects of DAs on conversations between patients and providers are less clear. For example, a recent systematic review found that a modest percentage—9.5%—of DA studies measured effects on patient-provider communication (Stacey et al., 2017). One challenge of affecting patient-provider communication—the medium through which SDM and deliberation is more readily realized—may be that the act of providing patients with information alone does not necessarily result in increased feelings of confidence or improved capacity for one to contribute to the final decision (Hargraves et al., 2016; Joseph-Williams, Elwyn, & Edwards, 2014). The pervading narrative that patients and providers can engage in SDM if they share the same information provided the basis for early DAs. However, sharing information is not the same as sharing decision making power, improving patient understanding, or actually making a treatment decision. The most common and consistently measured effects of DAs are improving patient

knowledge about treatment options and outcomes and patients' perceptions of being better informed (O'Connor et al., 1999; Stacey et al., 2017). Though these outcomes are undeniably valuable, they prioritize information exchange as the primary mechanism for achieving SDM. As such, DAs tend to neglect how patients make sense of or interpret and effectively implement this information and thus often fail to genuinely support patient understanding.

### **Making Sense of DAs**

The lack of consideration for how patients are interpreting DAs during their development and evaluation promotes an inadequate conceptualization of patient needs. This deficit does not necessarily serve deliberative outcomes or patients' reflections on how this information relates to their specific circumstances. When encountering unfamiliar information, such as when patients face novel and complex medical situations, people draw on their past knowledge, experience, emotions, and other situational and contextual cues to make sense of it (Dervin, 1983). They aim to form an understanding that is plausible rather than one that is accurate (Weick, 1995). However, common methods for designing and evaluating DAs overemphasize information presentation and accuracy of recall while neglecting to support users in finding meaning in information that most effectively prepares and guides them through their illness trajectory (Munro, Stacey, Lewis, & Bansback, 2016; Stacey et al., 2017). Practical recommendations for DAs tend to focus on designing information materials that facilitate patients' retention of accurate outcomes information (like statistics or side effects) but generally refrain from designing to support patients in making meaningful sense of that information in the context of their lives so as to be able to effectively apply it. Such recommendations often

highlight design principles for information delivery such as using simple language (Goldberg & Musgrave, 1996; King & Hoppe, 2013; Skelton, Waterman, Davis, Peipert, & Fish, 2015), presenting only three pieces of information at a time (as in the Ask-Tell-Ask approach [Back et al., 2005]), or using visual representations of risk percentages (Trevena et al., 2013). Recommendations like these are useful in that they increase the likelihood of patients receiving the intended message. However, again, the emphasis on achieving information transfer neglects to provide support for patients as they develop an understanding of what this information means for their personal contexts.

When putting SDM ideals into practice, providers and DA designers perhaps naturally adopt an information-centric view, as it centers on the tangible representation of knowledge that can be most readily manipulated by intervention design. However, by focusing on designing for information, what gets backgrounded in DA development is the process that patients and providers go through as they navigate situations characterized by ambiguity. As noted earlier, one of the most common types of DAs are those meant to support SDM by educating patients prior to clinic encounters to better prepare them for interacting with providers (Elwyn et al., 2010). These DA designs emphasize one-way information transfer from the tool to the patient, and while they assume that such interventions will in turn improve deliberation, their designs do not directly address the interactive components of SDM or the shared meaning created through these DA-facilitated conversations. This assumption that addressing the information transfer element of SDM will improve deliberation rests on the belief that when parties have more balanced access to information prior to their interaction, they will also be more capable of participating as equals. However, patients' ability to make sense of the information given

to them is influenced by many factors, both individual and situational, that may change over time and affect their interpretation/use of the information provided. In reality, this information is only useful when it accounts for individual patient circumstances (Hargraves et al., 2016).

### **The Lack of Situational Considerations in Evolving Clinical Circumstances**

The episodic view of a decision that inspires institutionalized practices like informed consent forms is not conducive to developing adequate support for complex and preference-sensitive treatments. Rather, patient preferences are “often provisional, conditional, and evolving” in such a context, and thus the ideal treatment and outcomes may not become clear until the patient has begun their illness journey (Epstein & Gramling, 2013, p. 104S). Yet, research on SDM has largely focused on episodic decisions made at a single point in time, with analyses often relying on cross-sectional observations of clinic conversations (Elwyn et al., 2014). Elwyn, Edwards, and Kinnersley (1999) cautioned against evaluating SDM through observation of interactions, as this alone does not account for contextual elements such as participants’ cognitive/internal processing or information exchange that has occurred in previous encounters. The same criticism has continued to be raised when evaluating current measures for SDM (Bugge, Entwistle, & Watt, 2006). Barr and Elwyn (2016) suggest that the pitfalls of patient-reported SDM measurement tools lie in two assumptions: 1) that patients are aware of “decision points” and 2) that there is only one decision being made in a single interaction. It is notable that these assumptions persist despite evidence to the contrary. Beyond the longitudinal elements of doctor-patient relationships and of the decision making process that occurs outside of the clinic, the emphasis on “value

clarification” assumes that patients will have static values, that these values can be communicated, and that they are applicable to the current medical situation (Epstein & Street, 2011). As the SDM conversation unfolds, each party becomes aware of new information and incorporates that into their understanding of the current situation. In sum, the need for individualized patient context when analyzing and supporting interactions for SDM, including the longitudinal nature of both the process and the patient-provider relationship, is best suited for a sensemaking approach that considers the dynamic contexts of the patient experience. The primary contributions of this approach are its emphasis on continuous sensemaking and unmaking and attention to the situational factors that influence such processes. In contrast to the episodic evaluations described above, a sensemaking perspective aims to capture understanding and its implications over a period of time.

Relatedly, another episodic tendency of SDM in practice is seen when patients are asked to make decisions based on how they are feeling or how they presently imagine they might feel in response to certain outcomes in the future. This is problematic, as people are notoriously bad at predicting emotional reactions to future events, known as *affective forecasting* (Wilson & Gilbert, 2005). People may inaccurately predict their future emotions because of the emotions they are feeling in the present (Mellers & McGraw, 2001), because the perceived effect of a single aspect of life changing seems larger when focusing only on what will change (Schkade & Kahneman, 1998), or because they underestimate their ability to adapt to new circumstances (Ubel, Schwarz, Loewenstein, & Smith, 2005). They may make sense of unexpected events through largely unconscious processes, and consequently are unable to predict how their ability to

explain events may reduce the emotional impact (Wilson & Gilbert, 2005). This presents another opportunity for sensemaking to support patients in complex medical situations, as it is proposed to occur in response to differences between expectations and experiences. Sensemaking theory suggests that people anticipate and make predictions about certain events, either consciously or unconsciously, and when they experience an event that is discordant with their expectations, it triggers a need for explanation and starts a process for interpreting this discordance (Louis, 1980). As patients are being asked to make choices in the present based on predictions for the future, it is therefore useful to examine the sensemaking practices of patients as they are navigating these situations.

The temporal challenges of treatment decisions make it exceedingly difficult to design and evaluate a DA that can be used in a clinical encounter. A “decision” is conceptualized as an action that takes place at a single point in time (Jefford & Moore, 2008), a view epitomized by the signing of an informed consent form that may not have been thoroughly read or internalized (Cassileth, Zupkis, Sutton-Smith, & March, 1980). Patients consent to a treatment at a single point in time when they sign the form. However, the patient’s understanding of their illness and its trajectory changes as they come in contact with new information or have new experiences. A key theoretical premise of sensemaking is that information only has meaning in the context of what a person already knows. Thus information means different things to each person, and it may mean different things to the same person at different points in their life (Dervin, 1999). Sensemaking emphasizes that information’s meaning is dependent on the person interacting with it. Instead of the current information-centric, episodic methods for SDM support, a design approach that intends to study and support sensemaking has the



potential to create systems that can recognize and adapt to variations in individual context, thus ensuring that patients are able to meaningfully understand the information that they are given.

### **Existing Support Tool Development Processes**

Though this dissertation ultimately recommends and describes the development of a sensemaking support tool, DAs are a similar, existing intervention. Both have idealistic intentions, in that improved patient understanding is a desired outcome. As such, exploring current development practices for this already widely used intervention can be a starting point for developing sensemaking support tools. One of the most common frameworks used to guide the design of DAs is the International Patient Decision Aids Standards (IPDAS). The IPDAS includes criteria for 10 categories: information, probabilities, values, guidance, development, evidence, disclosure, plain language, evaluation, and test/screening (Joseph-Williams et al., 2014). In the IPDAS, there are two items categorized under “Values” that partially align with the goals of a sensemaking approach: 1) “The patient decision aid describes what it is like to experience the consequences of the options (e.g. physical, psychological, social)” and 2) “The patient decision aid asks patients to think about which positive and negative features of the options matter most to them (implicitly or explicitly).” Among the 42 other items, these two stand out because they suggest the importance of considering the real-life implications of treatments on patients’ everyday lives and of supporting patients in meaningfully interpreting their options. However, these two items maintain a focus on information itself rather than patient understanding of this information. The first recommends inclusion of experiential information and the second requires that patients

are asked to “think about” the risks and benefits and their personal importance. These recommendations neglect to consider either how patients might process and use experiential information (particularly in expectation development) or if patients are truly able to conceptualize what the positive and negatives of different options will mean to them specifically. Table 1 offers a direct comparison between the currently recommended methods for DA design and the sensemaking approach proposed here.

**Table 1**

*Design for Information Transfer vs. Design for Sensemaking*

|  | <b>Design for Information Transfer (IPDAS)</b>   | <b>Design for Sensemaking</b>   |
|--|--|---|
| <b>Theoretic Foundation</b>            | Information exchange   | Sensemaking   |
| <b>Focal area</b>                      | Content of decision aids; maximizing comprehension of risk information   | Accounting for individual situations and context; maximizing understanding of personal consequences   |
| <b>Intervention Development</b>        | Needs assessments with patients and providers (linear progression)   | Iterative design process  |
| <b>Role of End-user in Development</b> | Requires review of DA by patients and providers not included in the development process<br>Field testing with patients and providers who are facing the decision | Participation of patients and caregivers in creative design process<br>Usability testing with patients and providers<br>Field testing with patients and providers who are facing the decision |

Beyond the imperfect conceptualization of a “decision” as illustrated in the “Values” category of the IPDAS, the actual development processes used to create DAs are often vaguely and minimally described. These types of descriptions are unfortunately common in the reporting of healthcare intervention design (Chandler et al., 2016; Wight, Wimbush, Jepson, & Doi, 2016). Although the IPDAS includes a well-documented development process, a recent review of patient DAs revealed very little discussion of the actual design processes (Coulter et al., 2013). The authors found that only half of the DAs reviewed were actually field tested with patients. Although another IPDAS recommendation includes involvement of multiple stakeholders in the development process, providers were involved even less often than patients were. Thus, there is a notable lack of practical recommendations for how to best involve stakeholders (Witteman et al., 2015), which may account for the tendency of DA developers to neglect it.

Further, what field testing actually means and how and when it should be accomplished is not entirely made clear by IPDAS. Decision aid development processes often test DAs for acceptability and usability once finalized rather than incorporating user involvement early in development (Evans et al., 2007). There are some notable instances of field testing and user involvement that point to the value of a design orientation for DA development. Sawka et al. (1998) used needs assessments, focus groups, and multiple pilot studies, and found that incorporating user feedback early on allowed for necessary clarity on both the content and the presentation of the DA. Durand et al. (2012) performed multiple rounds of field testing with researchers, providers, and patients

actually facing the decision they were targeting. The field testing revealed that a portion of the content that was deemed acceptable and appropriate by some researchers and providers was not easily understood by patients. Garvelink et al. (2016) extensively documented their development process, including the involvement of caregivers, and were explicit in how this feedback led to changes in various iterations of the system. Hoffman et al (2020) adapted an iterative user-centered design approach to develop an elder care DA by presenting early paper prototypes to older adults and caregivers before field testing their DA website with older adults. While a valuable contribution in the feasibility of stakeholder involvement, the authors recognize that the field of DA development is still lacking in stakeholder engagement while best practices are still being determined. These studies, and others, adopt methods that look much like a human-centered design process including needs assessments, usability testing, and iterative prototyping. Among the benefits, a design approach offers practical methodologies that allow for engagement with end-users throughout the development process, not just for evaluation of final products, among other benefits. The present research adopts a user-centered and participatory design approach that specifically targets sensemaking and relies on end user involvement throughout the development process. The theoretical basis for this approach is described in greater detail in Chapter 2.

### **The Alternative: Design for Sensemaking**

In sum, the episodic, information-centric view of “decisions” is not conducive to developing support for patients who face complex and ambiguous health situations in which evolving or uncertain clinical information may lead to changes in patient interpretations, values, and goals. Not only does this view fail to address the evolving and

progressive elements of patient experience, but the tools designed for these situations are often created without the input of those who use them. In contrast, a design approach for sensemaking can address some of these shortcomings. Sensemaking theory looks towards individual circumstances and experiences as the best indicator of support needed and user-centered and participatory design processes involve stakeholders throughout development. Although such an approach can tease apart the complexities of ambiguous medical situations, the potential for sensemaking and design to be integrated and applied to healthcare remains underexplored.

This dissertation adopts a case study approach to explore the potential for design for sensemaking by investigating a complex medical situation. This situation involves patients with acute myeloid leukemia (AML) who are presented with bone marrow transplant (BMT) as a treatment option. BMT offers an ideal case study for expanding on design for sensemaking support in complex medical situations for a number of reasons. Patients facing BMT and their loved ones are required to continually make sense of unfamiliar, potentially threatening information in the face of uncertainty. Not only does it present an opportunity to look at how the situational factors of individual patients influence the ways that they interpret information, but also the role of providers and caregivers in patient sensemaking. Patients with AML who are offered BMT have frequent interactions with their providers, and thus the communicative elements of this illness journey and its implications for patient understanding are at the forefront.

The nature of BMT presents an opportune case for examining a complicated medical situation for at least two reasons: 1) BMT is the only potential cure for AML and 2) BMT comes with significant risk of morbidity and mortality. For these reasons, patient

values and preferences are critical in determining if the potential risks to quality of life are worth the chance for a cure. Thus, understanding the ways that patients and providers communicate about BMT has relevance for the development of tools that can support the conversations and help patients effectively understand and evaluate their options.

Because of the complexities in communicating the risks and benefits surrounding BMT, studying sensemaking in this patient population has the unexplored potential to improve support tools designed for other health contexts with similar challenges.

### **Current Case Study: Bone Marrow Transplant for Acute Myeloid Leukemia**

#### **Patient population**

As noted above, BMT for AML is a complex, high-risk medical situation that is ideal for studying and supporting sensemaking. AML is one of the most common types of leukemia diagnosed in adults, and the most common cause of death due to leukemia in the United States (O'Donnell et al., 2017). Treatment decisions for this population can be complex. The only possibility for a cure is an allogeneic BMT, in which patients receive stem cells from a closely matched donor, and the donor's immune cells can recognize and destroy remaining leukemia cells. Although it offers the possibility of a cure, BMT is a procedure with variable outcomes and a high-risk of morbidity and mortality (Mohty & Apperley, 2010). As such, the procedure can cause a number of potentially acute and chronic side effects and life-threatening complications that may have a significant impact on the patient's quality of life (Cook & Runaas, 2016; Forsyth, Scanlan, Carter, Jordens, & Kerridge, 2011). BMT involves a prolonged stay in the hospital with numerous invasive medical procedures and an almost total loss of independence. To further complicate the decision to undergo such a physically demanding treatment, the best time

for patients to undergo transplantation is when they are in remission and feeling well (Forsyth et al., 2011).

### **The Complicated Nature of BMT**

For this patient population, it is critical that treatment be based on more than just survival outcomes as patients must also consider the potential difficulties of surviving with transplant-related complications. The risk of life-altering complications, like organ dysfunction and chronic graft-versus-host disease (GVHD) persists for years after transplant. Complications also present heterogeneously, making it extremely difficult for providers to predict potential outcomes for individual patients (Büyüktür & Ackerman, 2017; Mohty & Apperley, 2010). Several studies have documented the challenges with patient comprehension of AML treatment options, which are complicated by the complex nature of the condition, and the available treatments, and their associated risks. First, patients may not fully understand their condition when they begin discussing treatment options (Stiff et al., 2006). For instance, hematological conditions lack a specific location in the body, which can be difficult for patients to grasp (Ernst et al., 2010). Second, the decision making process for BMT can be overwhelming, as it requires that patients be exposed to large amounts of unfamiliar, and potentially emotionally traumatic, information (Jacoby et al., 1999; Raj, Choi, Gurtekin, & Platt, 2018; Randall, Keven, Atli, & Ustun, 2016). Additionally, the decision to receive transplant is often time-sensitive and must be made urgently (Sekeres et al., 2004). Patients may also want to avoid this negative information (Koehler, Koenigsmann, & Frommer, 2009; Nissim et al., 2013) and may thus make the decision to receive BMT prior to going through the informed consent process (Pisu et al., 2014; Schenker & Meisel, 2011). Perhaps the

feature that most limits the possibility for a truly informed decision to occur is that BMT is the only chance for long term survival (Jacoby et al., 1999). Patients are quick to view BMT as a “life raft” and often do not fully understand the meaning of the high morbidity and mortality of the transplant process, or the significant threat to quality of life (Cook & Runaas, 2016, p. 2). They have difficulty making sense of how a potential cure can cause life-threatening dangers that may be worse than life with blood cancer or even death.

When patients are informed of such negative treatment outcomes and risks, they have yet to experience BMT and thus lack a reference point to understand the realities of life after transplant in a way that they recognize while actively experiencing. In particular, they do not fully understand how these physical complications can manifest and severely impact their everyday lives. This gap in understanding requires research exploring how patients are effectively interpreting risk and benefit information based on their current life circumstances and how they are considering those circumstances when imagining possible future outcomes. As described earlier, expectation management is something that patients often struggle to perform. This can be improved by incorporating a sensemaking approach that looks at how people both form and evaluate their expectations and experiences based on the information they interact with prior to the treatment experience. Thus far, pre-BMT information provision and consequent expectation development has been significantly lacking, and the challenges identified by past researchers suggest an opportunity to look directly at the sensemaking practices of patients when they interact with information.



## **Supporting Patients Considering BMT**

Past studies examining current support for patients as they navigate BMT have shown significant shortcomings in current communication practices. Little et al. (2008) measured patient satisfaction with pre-transplant education before and after transplant. They found that the majority of patients were satisfied with the information they received before transplant, but after transplant, patients felt they had been unprepared for the impact of side effects on their everyday lives. Patients struggled with uncertainty about whether their condition would ever improve, and some patients noted that they might not have gone through with transplant had they known what the experience would really be like. Poloméni et al. (2016) found that post-transplant experiences that did not match expectations had harmful effects on the individual well-being and relationships of patients and caregivers. Jacoby et al. (1999) investigated the value of the informed consent process in BMT and the effects of it being the only potential for a cure. They found that patients did not put much weight on understanding the information they received, but instead decided to receive transplant based on trust in their physician and how they made sense of BMT as a cure—that is, patients believed that BMT was their only chance at long-term survival. The authors concluded that, independent of the patient's interest and understanding of any relevant information provided, the nature of decision making for BMT is inherently coercive as there is no other viable/curative option.

Although these prior studies have implications for redesign of practices for informing BMT patients and suggest situational factors that influenced patients' sensemaking practices, these studies did not systematically examine how patients made

sense of this information. As these findings indicate, patients may have put little weight on the information they received before transplant, felt it had inadequately prepared them for transplant, or had expectations that differed from their experiences. However, uncovering the ways that patients made use of/meaningfully interpreted and evaluated information, used it to prepare for the BMT experience, or to form expectations is necessary to design interventions that address these problems. Knowing what information patients “need” to feel prepared for BMT consequences is important, but there must first be an understanding of how it is being interpreted by patients at that point in their illness trajectory. For example, in Little et al (2008), patient perceptions of the information they received changed before and after transplant. Before going through transplant, patients understood the information they received to be sufficient, but afterwards they reinterpreted it and perceived it to be inadequate in that they felt they had not been adequately prepared for the ordeals of transplant. This information may have been used to form expectations early in the illness trajectory that later did not align with their lived experiences, but it is not clear how or what was salient to patients as they attempted to imagine what their lives would be like after transplant. Even if the information they received prior to BMT was less important than trust or survival, the interaction between risk information, relationships, and beliefs about transplant may be better supported through a support tool that is designed to be sensitive to patients’ evolving sensemaking practices. The emphasis on preparation and expectations points to an unaddressed temporal component. Uncovering the impact of such situational factors on sensemaking is a key element of this research and designing for sensemaking support more broadly.

## Summary

Interventions to support patients in complex and ambiguous clinical contexts have often been information-centric, episodic, and developed without significant stakeholder participation. A sensemaking perspective has potential to improve the means by which we investigate and design tools to support patients in understanding the information they receive and in navigating their illness experiences. Design methods like user-centered (“designing for” users) and participatory design (“designing with” users) offer means for incorporating stakeholders into the design process and are well-suited to exploring abstract concepts like sensemaking. This dissertation has two aims: 1) to use the case study of bone marrow transplant to explore and refine a theory of design for sensemaking in healthcare, and in doing so, achieve aim 2) to make practical recommendations for designing sensemaking support using participatory design in other health contexts.

## Research Questions

In pursuit of investigating the application and utility of a theory of design for sensemaking support applicable to other contexts, the overarching question informing this study is:

*RQ: What processes can be used to investigate and design interventions to elicit and support sensemaking in complicated and ambiguous health contexts?*

This work adopts an iterative design approach towards intervention development that relies on user-centered and participatory design methods in three different studies. The three studies follow the pattern of the “virtuous circle” in which the design changes over time to reflect knowledge gained from research (Allen & Chudley, 2012). To begin the design process, the first stage is to understand the *design situation*, or the context that is

the catalyst for the design process (Löwgren & Stolterman, 2004). In the beginning of this project, the challenge was understood to be one of decision making rather than sensemaking. Thus, the questions guiding the needs assessment for Study 1 were as follows:

*RQ1: How do patients and providers currently understand and communicate about BMT decisions?*

*RQ 1.1: What are perceived challenges and successes around BMT decision making?*

Based on the answers to these questions, low-fidelity prototypes of potential support systems were developed and, following principles of UCD, presented to providers, patients, and caregivers for feedback to address the following question in Study 2:

*RQ2: What do providers, patients, and caregivers see as the purpose and potential utility of the proposed tool?*

The results of the UCD prototype testing in Study 2 suggested a shift in perspective on the design situation as it was being conceptualized. Instead of considering the issue as one of decision making and the tool as supporting stakeholders in choosing among options, a more appropriate framing, and one that would be more accurate to the experiences of patients and caregivers as they described them, would be to look at sensemaking. To explore this new framing, an adapted participatory design approach theoretically motivated by sensemaking and the following question guided Study 3:

*RQ3: What are the sensemaking processes that patients and caregivers go through leading up to transplant?*

The evolution of this understanding is illustrated across Chapters 4–6, as the studies shift from a user-centered design approach to decision making towards a participatory design approach to supporting sensemaking. In the following chapter, the theory of design for sensemaking support that informed and was inspired by this work is outlined.

## **CHAPTER 2: Theory of Design for Sensemaking Support**

This chapter presents a theory of design for sensemaking that offers principles to guide interactions with users by integrating tenets of user-centered (UCD) and participatory design (PD) with the premises of sensemaking. Despite significant efforts to developing support tools for patients facing complicated health situations and increased interest in applying design methods to healthcare, there is not yet a design theory to inform the development of tools that support sensemaking specifically. In this chapter, I propose a theory of design for sensemaking support in high risk medical contexts that can be used to inform both the design processes and the practical outputs of such processes. Human-centered design methods, like UCD and PD, rely heavily on interaction with users, yet the communication practices that occur in the design process and how they affect design outcomes have yet to be thoroughly explored. Though UCD and PD emphasize the importance of interactions with users in refining understanding of the design situation, they differ in their philosophy, goals, and the roles of the designer and the users. UCD takes a more constructivist approach, with the designer acting as a translator of user needs into potential solutions based on their observations and understanding of the design situation. PD instead adopts a constructionist philosophy, with the designer acting as a facilitator to enable non-designers to creatively participate in the design of possible solutions. Still, user involvement does not inherently lead to more successful design outcomes. Thus, the design result and the communication between designers and users are both subject to the design process.

In this dissertation, I apply UCD in Studies 1 and 2 and PD in Study 3 to examine the benefits and weaknesses of these methods as they relate to communication between

designers and users. This evaluation is intended to determine the effective applications and combinations of these methodologies to elicit existing sensemaking practices and develop potential solutions. I refer to literature from three related disciplines—design for information, interaction, and communication—to both situate design for sensemaking and to illustrate the progressive expansion of what might be considered “designable.” The ultimate goal of this dissertation is to use the case study of BMT to develop and assess the feasibility of a process for studying and supporting sensemaking and the utility and refinement of this theory of design for sensemaking support applicable to other contexts. The theory guiding this case study includes five principles intended to facilitate the use of design to investigate and support sensemaking practices: to be meaning-centered, temporal, inclusive, self-reflective, and action-oriented.

### **Design**

Design is the process of “turning existing situations into preferred” by developing artifacts that allow people to accomplish goals (Simon, 1996, p. 111), and a means of “making things right” (Caplan, 2004, p. 4). Design is a way of intentionally altering the world around us to achieve desirable outcomes. The methods that designers use to develop and test both their understanding of the design situation and their proposed solutions vary, though human-centered design (HCD) has become one of, if not the most dominant, force in design (Norman, 2005). HCD includes approaches such as user-centered design (UCD) and participatory design (PD), which prioritize end user involvement to collaborate on both problem definition and on solution development (Steen, 2012). Prioritization of end user involvement is based on the belief that involving future users early and often reveals potentially unexpected consequences and promotes

improvement in future iterations (Brown & Wyatt, 2010). Continuous interaction with potential users encourages mutual reflection on the problems in question, leading to discussions between designer and user on how to reconcile the “could be” of future designs with the normative “should be” of feasible designs (W. T. Thompson, Steier, & Ostrenko, 2014).

While HCD has become the standard for design processes, the ways that users participate in design necessarily varies between projects, and oftentimes the effects of this participation on design outcomes are considered secondary and so remain unexplored. Neubauer, Bohemia, and Harman (2020) describe this issue as a potential symptom of the tendency to dichotomize the theory and practice of design; descriptions of *designerly ways of knowing* perpetuate an idea of designers having some sort of astute intuition to synthesize that cannot be articulated. Instead, the authors point to the social nature of design and the collaborations between humans and materials that generate products as the real object of interest. The communication practices that occur within the design process as well as those that are altered because of a design solution have yet to be thoroughly explored within HCD. As will be discussed further below, the iterative and reflective nature of the design process makes it difficult to truly separate the theoretical and practical, and their entanglement has salience for understanding and facilitating interactions that occur among designers and users. One can view design as a tool for developing communication theory and view interventions as tools for knowledge creation to both uncover current communication practices and develop ways to best support interactions in design processes (Aakhus, 2015). Particularly for design processes that rely heavily on relationships with potential users, like UCD and PD, communication



within the process is especially important. While UCD and PD both prioritize user involvement, their conceptualizations of that involvement, the role of the designer, and what they are meant to achieve are distinct, which I will explore in detail in this chapter.

This dissertation focuses on methods of participation and inclusion of various stakeholders in the design process. Although not often viewed as a relevant ‘stakeholder’ because of their third-party vantage point, the designer themselves plays a crucial role in shaping stakeholder involvement. Thus, I begin by describing how problems and solutions are designed in HCD with an emphasis on the role of the designer. The designer is often ultimately the one responsible for gathering and interpreting the current challenges facing stakeholders/users and leading prototype development to implementation. The design process described below is one in which a design expert is acting as the catalyst for the designing and redesigning of artifacts that address these issues. The designer may or may not be a member of the end user group, but their most important role is being responsible for the progress of artifact development. Following this description of the designer’s role within the HCD process will be a deeper investigation into differences in UCD and PD, particularly regarding the role of the users.

### **Defining a “Problem” and Designing a “Solution”**

In the context of social policy planning, Rittel and Webber (1973) criticized the idea that designers can solve problems the same way that other scientists do. Unlike the problems faced in the natural sciences, they describe the problems faced by designers as “wicked problems” (Rittel & Webber, 1973, p. 160). Wicked problems are not “solved,” as they have no single, definitive solution; rather, they are re-solved repeatedly. In other words, while problems in the natural sciences have solutions that can be determined to be

true or false, designers develop solutions that are only good or bad. A designer might choose a solution because it is “good enough,” or as Simon (1990) termed it, *satisficing*, but in reality there is no way to determine all of the consequences a solution might entail until it is implemented. Inevitably, the designer’s beliefs influence the judgment of the design as good or bad, and the nature of a wicked problem prevents the consequences of implementation from being fully or immediately assessed (Rittel & Weber, 1973). The definition of a design problem is a dynamic and critical element of achieving solutions that have positive impacts on design outcomes. Though it is impossible to define what constitutes “good” design outcomes, a design must be evaluated in relation to the situation (context-dependent), and with an adaptive and reflective definition of what “good” means (Löwgren & Stolterman, 2004).

One way to begin identifying potential areas for design is by looking for breakdowns or interruptions in the flow of action and to create interventions that manage or prevent those breakdowns (Flores, Graves, Hartfield, & Winograd, 1988). Tim Brown (2009), the CEO of well-known design firm IDEO, suggests designers should look at the ways that people adapt to systems and the seemingly inexplicable behaviors they participate in as a way to begin to empathize with potential users. Observing and investigating these behaviors allows designers to tap into the latent and difficult to articulate needs that are revealed in the adaptations that are used to cope with the complexity of the world around them. This can be accomplished through ethnography, interviews, or other methods of investigation frequently used by social science researchers. The designer’s interpretation of these needs can then be translated into prototypes for testing.

The *design situation* is both the reason that the design process has been initiated and the context in which that design work takes place (Löwgren & Stolterman, 2004). Schön (1992), in defining the concept, makes reference to John Dewey's use of the term "situation" to describe the process of determining what features of the world are present and relevant to the purpose and practice of the design. The designers are in a "transaction" with a design situation in that they "respond to the demands and possibilities of a design situation, which, in turn, they help to create" (Schön, 1992, p.4). Buchanan (1992) shares this sentiment in rejecting the idea of separate problem definition and problem solution phases and instead suggested that they are interdependent in the design process. Dzbor and Zdrahal (2002) empirically examined how designers frame the design situation by asking designers to describe their process for designing a way to turn wrinkled paper into smooth paper. They found that designers framed this "ill structured problem" using experiences of past design situations even if they could not articulate these conceptualizations (p. 5). How designers initially understand and define the problematic situation they encounter is influenced by their past experiences in a way that may not be entirely conscious.

As designers continue to investigate the problem and propose solutions, they then engage in *re-framing* in which their proposed solutions encourage them to re-interpret the problem space. Schön (1992) describes the re-framing process as a "reflective conversation with the situation." In this way, the designer's continuous interactions with the situation and the users within it are altering their view of the situation through the development of potential solutions and observation of their effects. Designers refine their understanding away from their past experiences as they reflect on the effects of proposed

solutions to reinterpret and reframe the problem. The ways that the design situation is constructed and refined differs in UCD and PD methodologies, particularly in the roles of the designers and users involved.

### **User-centered and Participatory Design**

As noted earlier, the HCD methods of UCD and PD incorporate users into the design process. However, in their theorized ideal states, the ways that users are involved differ, and consequently there are differences in how the designer's role is conceived as well. Particularly, UCD focuses more heavily on user-feedback, asking users to provide information such as their needs and current practices that can inform potential prototypes, while PD emphasizes much more active user participation in both the problem definition phase and in the actual design of the artifact. UCD is a more encompassing area of design than PD and the ways that UCD is practically applied are more highly variable. In contrast, PD centers on active involvement of potential end-users throughout the design process (Karat, 1997). While PD is arguably a subset of UCD, the designer's role, users' role, and methods of accomplishing design are distinct and serve different purposes, as illustrated in Table 2.

**Table 2***Comparison of User-centered and Participatory Design Methods*

|                         | <b>User-centered Design</b>   | <b>Participatory Design</b>   |
|-------------------------|---|---|
| <b>Goal</b>             | Create artifacts that are usable and understandable   | Create artifacts that improve the lives of users by involving those users in the design process                                       |
| <b>Philosophy</b>       | <i>Constructivist:</i> Users are sources of empirical evidence for designers to develop solutions that meet their needs     | <i>Constructionist:</i> Users and designers collaborate to create new artifacts based on shared meaning developed through interaction |
| <b>How/tools</b>        | Interviews, rapid ethnography, usability testing  | Utilizes UCD tools in addition to PD workshops, toolkits for creative expression to enhance participation                             |
| <b>Role of designer</b> | <i>Translate</i> user needs into prototypes for feedback  | <i>Facilitate</i> the creative participation of end users/non-designers   |
| <b>Role of users</b>    | Provide empirical evidence for what they do in current practice and their needs<br>Offer feedback on prototypical solutions | Co-interpret results<br>Actively participate in the shaping of the artifact<br>Implement into own life                                |

Table 2 illustrates the differences between UCD and PD in both conceptual and practical terms. While both fall under HCD, the reasons for human-centeredness and consequently the ways that it manifests in process have impact on design outcomes and how they are evaluated. The next section describes each component (goals/philosophy, tools, the role of the designer, and the role of users) of design to describe the differences between UCD and PD in more detail. Discussion of tools will be included in the section on the role of the designer, as the designer is responsible for determining/providing/using the tools through the process.

## Goals and Philosophy

User-centered design is based in the “needs and interests of the user, with an emphasis on making products usable and understandable,” meaning that a user must be able to determine what to do with an artifact and to evaluate the feedback it provides (Norman, 2002, p. 188). The core belief of UCD is that designers can create safe, efficient, effective, and enjoyable systems by understanding the people that will ultimately use them. This means investigating what activities they engage in/the practices they engage in their everyday lives, their motivations, when they are likely to do things, and how they make these choices (Ritter, Baxter, & Churchill, 2014). Thus, the UCD process adopts a constructivist epistemology in that the designer relies on data collected from users to develop mental models of the design situation (Talja, Tuominen, & Savolainen, 2005). Norman (2002) emphasizes the importance of mental models in UCD: the *design model* (the designer’s conceptualization), the *user’s model* (how the user develops to explain the system) and the *system image* (which the designer creates and the user interacts with to develop their mental model). In an ideal situation, Norman says, the designer’s and the user’s mental models are equivalent. Yet, the designer and the user only interact through the system, so the designer must do everything possible to ensure the system image communicates the “proper conceptual model” (p. 190) to the user. To accomplish this, user-centered designers focus heavily on collecting data from users throughout the three core stages of UCD: 1) user research, 2) creation and iterative refining of design, and 3) evaluation of design to ensure it is accomplishing what it intended (Hoeft & Ashmore, 2017). This process is known as the *virtuous circle* in which user research informs the design, which is then presented to users for feedback, which is

then used to inform the next design, in an iterative process aiming to develop progressively improved products based on users' input (Allen & Chudley, 2012). In UCD, user research and feedback are the driving forces for design decisions executed by the design team. UCD aligns with a constructivist perspective (Talji, Tuominen, & Salvolainen, 2004), as the designer observes and interacts with users to develop an understanding of their experiences and the challenges they face, ultimately creating solutions to the problems they observe.

Participatory design (PD), on the other hand, adopts a more constructionist approach (Talji, Tuominen, & Salvolainen, 2004), emphasizing the benefits of creating *with* users and the value of design as the result of collaboration between those with expertise in design and expertise in the lived experience of the design situation. The distinguishing feature of PD is that the people who will use the artifact play a critical role in designing it, not just informing the designer who ultimately designs it (Schuler & Namioka, 1993). In the 1970s and 1980s, a shift towards empowering workers began to take shape in Scandinavia, rejecting the belief that workers simply had to accept potentially disempowering or hard to use technologies. This movement instead made an effort to involve workers in developing the tools they would ultimately use (Spinuzzi, 2005). The methods of PD researchers were informed by action research, which, unlike traditional research, stipulates that the results are not just analyses and contributions to the discipline, but that they also contribute to practical improvement in the lives of those who are being studied. This is marked by alternating “between practical work in the field to support the desired changes, and systematic data collection and analysis of the practical work with the aim of improving the action” (Thoresen, 1992, p. 275). A PD

result should thus reflect the democratic ideals of empowering users that form the foundation of PD by giving users “a voice in matters they did not have before” (Bratteteig & Wagner, 2016, p. 141). Like in UCD, users are the central focus; however, PD takes this a step further by actively involving users in the design process itself, sharing decision making power and asking users to engage not just in clarifying problem definition but in imagining possible solutions.

### **Role of The Designer and Design Tools**

For those who practice UCD, the designer’s expertise lies in his/her creative ability, familiarity with product-oriented techniques, and knowledge of fabrication processes. Thus, the designer maintains the lead in translating findings from user research into prototypes. User research can be performed through methods like ethnography, interviews, or observations, with the explicit goal of better understanding the users (Hoeft & Ashmore, 2017). Prototypes in UCD are manifestations of designers’ interpretations about users’ needs which can be interrogated through testing (Lerouge, Ma, Sneha, & Tolle, 2011). Users are asked to give their feedback on these prototypes throughout the design process rather than once the product is finished (Mallin & Carvalho, 2015). The expectation during the design process is not that users will see no flaws in the prototype, but that they will be able to offer insight on what they like about it, how it could be improved, what it might look like once implemented in their daily lives, so that designers can use this information to improve the prototype.

In UCD, the designer is responsible for using the information and feedback gathered from users to make sure that the end product is usable and takes minimal effort to learn how to use (Abrams, Maloney-Krichmar, & Preece, 2004). Norman (2002)



described this particular design goal in terms of *execution*, *evaluation*, and *goals* in his *seven stages of action*. A user is interacting with a product in order to accomplish his/her goal, and to accomplish that goal, the user forms intentions on what actions are needed to reach it. These intentions take the form of execution once the user acts upon the world. To begin evaluation, the user perceives the world, interprets this perception according to his/her expectations, and evaluates this interpretation based on what was expected to happen and if it achieves the goal. The *gulf of execution* is the difference between the intentions and thoughts of the user and the actions afforded by the system. The *gulf of evaluation* is the amount of work it takes for a user to interpret the system's physical state and evaluate it against their expectations and intentions.

This theory of the seven stages illustrates Norman's overall mentality when he first defined UCD: when a user fails to accomplish his/her goals, "the problem is in the design" (p. 53). Thus, the user-centered designer's role is to limit these gaps between the user's psychological state (intentions, expectations, goals) and the designed product. This can be accomplished through designs that give user's feedback during use, offering clarity in how actions lead to results, providing users with a consistent and coherent mental model, and ensuring visibility so that users can easily determine the state of the system and what potential actions are available. The iterative quality of UCD allows designers to evaluate their understanding of user needs, goals, and expectations by presenting prototypes for testing. The designer's role in this sense is to facilitate opportunities for feedback from users via prototype testing. Early on in the process, these prototypes may be low-fidelity and be simple paper visuals shown to users, but as the

design process progresses, they may become more refined and introduced into actual use contexts for testing.

While UCD highly values user research and commentary, PD enlists users in doing more than just providing feedback or information on their needs. Users are invited to participate as “designers” while the professional designer instigates and facilitates this participation. To involve users in PD, the professional designer must develop accessible and understandable methods to facilitate users’ involvement (Sanders & Stappers, 2016). Doing this well means that users have the ability to make decisions about how they want the world around them to function. This is more likely to be accomplished if designers first identify the objectives of participation and the tools best suited to accomplish these goals (Sanoff, 2006). Participation in PD can take many forms, though a commonly used method comes in the form of PD workshops in which the designer brings together a group of users and facilitates a discussion about their experiences and their collaboration on potential design solutions. Oftentimes the designer has developed a toolkit with contents ambiguous enough for participants to provide their own interpretation based on their individual perspectives. This allows for a “creative act which involves construction and transformation of meaning” by those involved (Sanders & Stappers, 2014, p. 6). It is critical that tools are able to facilitate such participation and that designers can understand how participants are making sense of the toolkit and using that sense creatively. For the toolkits to resonate with users and actually include material that is relevant to their experiences and creative expression, designers will often first use UCD practices like interviews and field observations to get a sense of how users might prefer to involve themselves.

## **Role of Users**

In both UCD and PD, users are considered to have relevant knowledge that differs from the designers. Users are treated as experts in judging prototype usability and potential integration of proposed designs into their everyday lives (Ferraro & Ingaramo, 2015). Where the biggest difference in PD and UCD lies is that user involvement in UCD activities centers on providing information that improves the designer's understanding of the design situation, users' needs, and how the situation could be improved. Their contributions are manifested in prototypes by the designer, a process that perpetuates designerly ways of knowing in which a designer acts as a tool for synthesizing the various information provided by users. In these ways, the users' role is still largely passive (Bannon, 1995).

In contrast, PD significantly differs in the ways that users participate in the design process and how their contributions influence design outcomes. PD relies on the experiences and insights of end-users, considering their familiarity with the implementation context as an irreplaceable asset. Lee (2008) described design participation as existing in the intersection between the abstract space, or the experts' world where designers work, and the concrete space where people live. The designer develops and provides tools to facilitate user involvement, and the users' role is to offer their expertise on their own experiences and perspectives. In offering this expertise, users also participate in co-interpretation of the results, prototypes, or artifacts. This element of users' contributions to the PD process goes beyond simply aiding in understanding the design situation, but to "envision, shape, and transcend it" in ways that the end-users believe are positive (Spinuzzi, 2004, p. 164).

UCD is focused on understanding what people do and use, while PD is also concerned with what people make (Sanders & Stappers, 2008). Users engage in creative participation, with the designers creating tools that facilitate creative expression. Sanders (2005) described a spectrum of creativity that everyday people engage in. The first level of creativity, *doing*, requires minimal interest and experience, as the goal is to be productive. *Adapting*, or making something one's own, requires slightly more interest and experience. Someone participating in *making* must have genuine interest and experience, and the fourth level, *creating*, aims to express creativity and is accomplished with passion and expertise. Users participate in the design process at whatever creativity level they feel comfortable in, and if the professional designer is aware of the current creativity levels, ideally this creativity will be facilitated by the PD workshop activities. The principles for facilitating creativity, defined by Sanders and Stappers (2016), can be useful for guiding PD research: all people are creative, all people have dreams, people will fill in what is unseen and unsaid based on their own experiences and ideas, and people project their needs onto ambiguous stimuli because they are motivated to make meaning (Sanders and Stappers, 2016). While the professional designer creates environments for users to be creative, the user has the capacity, motivation, and responsibility to express themselves when given the opportunity and tools.

### **The Intersection Between Designers, Users, and the Design Process**

While user participation has potential to support more successful design solutions, participation does not guarantee successful design outcomes if not properly facilitated. In one example, Gallivan and Keil (2003) described a participatory design case study that frequently asked users to be involved but still failed, concluding that “an ineffective

communication process [between designers and users] can negate any benefits that might otherwise accrue from high levels of user participation” (p. 32). Particularly, this case study was plagued by focusing on concerns that were mentioned most frequently rather than those that were most salient. By targeting the most common complaints, which were mostly related to technical issues with the computer system, the designers were confident that they would be solving the most important barriers to use. However, they failed to recognize that the actual impact of “solving” these common problems would not actually address the underlying issues of motivation that were in the subtext of user comments.

Examples like this illustrate the importance of studying the interactions and communication environments in PD and the influence on the end product. Particularly for PD, collaboration between users and designers is directly related to the design result and its success. As Muller (2003) put it, you can’t just “add users and stir” (p. 3)—individuals have different needs and want to participate in different ways, and these needs must be accommodated through design of PD studies. In contrast to UCD, which is largely designer driven, decisions throughout a PD process account for user opinions and direction as well. For this reason, both the design result and the interactions between designers and users are subject to the design process.

### **Communication Throughout the Participatory Design Process**

In PD, the emphasis on including non-designers in the design process means that the communication that occurs among designers and stakeholders is exceptionally important for design outcomes. Interactions between professional designers and users is the main source of knowledge concerning current practices and potential use contexts, yet it is so rarely examined that it is “almost invisible” (Novick & Wynn, 1992, p. 2). As

noted, user participation alone does not necessarily lead to an improved design outcome; the hows, whens, and whys of participation need to be considered and tailored to the specific design situation, as the interactions between users and professional designers directly influence the development of the design process and its outcome. The professional participatory designer's role is to investigate how these specific user groups would like to participate and then create the tools that allow these particular involved non-designers to express their perspectives creatively (Standers & Stappers, 2008). For instance, a PD toolkit created for end users who are employed as chefs would likely not be transferable to another PD workshop held with a group of pilots. The professional designer in PD is responsible for giving users the tools they need to not only communicate their current practices but to also support users' expression of potential solutions that they might imagine during the workshop. Sometimes, participants can accomplish this with just a blank sheet of paper and some pencils, while other times they might need more direction, through techniques like design games (see: Brandt, 2006; Jessen, Mirkovic, & Ruland, 2018) or MakeTools, which include ambiguous and simple components for people to use to express their perspectives and ideas (Sanders, 2006). The importance of this responsibility of designers cannot be understated—the creation of *boundary objects*, or objects that allow for collaboration and communication between members of different groups/backgrounds (Star & Griesemer, 1989) by users is perhaps the greatest contribution and most notable feature of PD.

Boundary objects in PD are especially important because, unlike prototypes designed by professional designers based on user research, these objects come from the mind of the user—it is an external representation of that user's knowledge that can now

be commented on, questioned, refined, and possibly developed into a full-fledged implemented design solution. Further, the externalization of this knowledge leads to boundary objects that act as “links in the communication process” in which different perspectives can be negotiated to form “co-created meaning and consensus” (Islind, Snis, Pareto, & Rystedt, 2016, p. 4). Boundary objects also have use in UCD in the form of prototypes that are used to investigate the potential value of a proposed design that has been created by professional designers. In PD, the use/generation of boundary objects is bidirectional—users also have the autonomy and opportunity to make boundary objects that represent their needs and ideas rather than just commenting on those created by the designer.

Hendry (2004) described boundary objects as having five functions in design communication: *conscripting* (enlisting participation and gathering feedback), *coordinating* (sharing progress and possible solutions), *framing* (establishing/reaffirming common ground), *persuading* (convincing stakeholders of potential solutions’ utility), and *recording* (documenting so others can use the solution in the future). Though he identified these functions by studying UCD processes in relation to interdisciplinary design teams, they are also applicable to PD, where users and professional designers hold distinct but relevant expertise that they use to improve/create an effective design solution. To better understand the role of boundary objects in a PD setting, an additional communicative function potentially worth considering is *disclosing* to describe how non-designers/end users create objects that communicate their distinct perspectives, needs, and possible solutions. Recognizing this function of boundary objects in PD can be a useful step in creating and evaluating the goals of the PD workshop and the associated

toolkits. Expanding the exploration of boundary objects to include those created by users emphasizes the distinctions in users' roles in UCD and PD and how their processes might be designed to better support these goals.

### **Application of User-centered and Participatory Design Methods to Health Services Intervention Development**

Using UCD/PD to intervene and develop solutions for identified problems shares similarities with traditional health services intervention development processes, which have the more specific aim to inform health care systems and professionals on how best to improve the lives of patients (Agency for Healthcare Research and Quality, 2020). Yet, where UCD fits in implementing health services still remains unclear (Dopp, Parisi, Munson, & Lyon, 2019). A review of studies that employed design methods revealed significant variability, including almost a third of the studies reporting only literature reviews and expert consultations as need-finding steps (Altman, Huang, & Breland, 2018). Though the goal of improving people's lives may be the same, there are key ways in which UCD/PD design differs from traditional health services intervention development that are relevant to the study of communication. Some of the aspects of UCD/PD design processes that most differ include:

1. Design involves *specific contexts* and creating solutions for particular problems (Stolterman, 2008). Traditional health services interventions look to produce generalizable results that allow interventions to be adapted across contexts, often relying on the statistical analyses of large data sets from large samples (Altman et al., 2018). In contrast, design explicitly focuses on developing the best solution for a particular situation, often



relying on in-depth interactions with a small sample to truly empathize with and understand the design situation.

2. Design is concerned with a world that does not yet exist; it is a *future-oriented* mindset that requires imagination based on an understanding of the present. While any sort of intervention is looking to produce outcomes in the future, a design stance requires that designers engage in thought exercises prior to implementation in which potential negative effects are realized and designed out (Caplan, 2004). This can also be accomplished through the use of prototypes, as giving users an opportunity to test out how a product can reveal these unintended consequences while still in development, prior to large scale implementation.
3. There is a focus on *involving end users* and valuing their position as “experts of their own experiences.” Approaches like Community-based Participatory Research (CBPR) are well established in health intervention design and share similar core principles with PD in the democratization of research by involving the people who will ultimately be affected by a design. However, only recently has there been an effort to develop formalized recommendations for involving patients and other stakeholders in co-creating the interventions that serve their communities using UCD practices (see: Kaisler & Missbach, 2020).
4. The *iterative* nature of design means that problem definition and solution creation are not conceptualized as independent but are treated as interdependent (“reflexive practitioner”). In traditional health intervention,

reporting often focuses on the outcomes and efficacy rather than the process used for development (Chandler et al., 2016; De Vito Dabbs et al., 2009; Wight et al., 2016). It is possible that the design mentality that embraces experimentation to determine failures early is not well-received in healthcare, where failure can mean life or death. However, as Altman, Huang, and Breland (2018) point out, there are low stakes approaches to testing potential solutions using low-fidelity prototypes, like storyboarding.

5. Design uses *prototypes* to both refine the designer's understanding of the design situation and test potential interventions. Though there is little agreement on what a prototype is, generally it is considered to represent a product or experience before the actual artifact is complete (Sanders & Stappers, 2016). As noted earlier, the use of prototypes prior to intervention implementation is perhaps the most notable distinction between design and other methods. Both their use through the design process as boundary objects or as a means of testing the effectiveness of a proposed solution, prototypes offer a look into the future and a means of evaluating before implementation that could significantly benefit health interventions. Fixing a problem in the development stages is significantly easier and less costly than once implemented (Johnson, Johnson, & Zhang, 2005), and particularly for healthcare interventions where consequences can be more severe than poor consumer response, prototype testing can help avoid these issues.

These five premises offer a summary of design that is adapted in this dissertation. In what follows, I detail the foundations and practice of design for information, interaction, and communication, and then offer a theory of design for sensemaking support. The value of distinguishing these processes is two-fold: first, to place design for sensemaking among these three well-established areas of design and second, to illustrate a progressive expansion in what might be considered “designable.” Sensemaking plays an important part in these design disciplines and in their relationship to one another. The ways that people interpret and use information is dependent on the situation that they are in, including their past experiences, emotions, expectations, goals and other individually relevant factors. Thus, designing tools to support and investigate sensemaking has potential to affect and be informed by design for information, interaction, and communication, three domains/goals that require sensemaking to take place. A primary contribution of this work is in making sensemaking processes (both in the design process and the design situation) an explicit object of design. Sensemaking is often implicit in discussions of design for information, interaction, and communication rather than treating the sensemaking processes as a potential target of intervention, as the theory of design for sensemaking support proposes.

### **Design for Information**

Design for information is complicated by a lack of coherence in how to define “information” and, consequently, how to design information systems. Buckland (1991) described three uses of the word “information”: information-as-process (the action of telling or being told something), information-as-knowledge (intangible, personal, and conceptual information that exists in one’s mind), and information-as-thing (objects like

documents, data, etc.). Information systems can only interact with “information-as-thing” and thus information designers must explore how to represent internal knowledge so that it is useful for others. In the context of this dissertation, “information-as-thing” is the primary usage—defined as data (symbolic representations of observations of the world that lack meaning/value) that has been organized or processed to be useful (Rowley, 2007). *Information design* targets the organization and visualization of data to transform it into usable information (Shedroff, 1994).

Though effective knowledge representation is recognized as a key element of successful information systems (Baeza-Yates & Ribeiro-Neto, 2011), information designers have struggled to reconcile the differences between internal and external representations of knowledge. Knowledge, or a gap in knowledge, is thought to be the catalyst for information seeking, as is the anomalous state of knowledge, in which a person recognizes some anomaly in their knowledge that prevents them from solving a problem, though they cannot articulate what information they need to solve this problem (Oddy, Belkin, & Brooks, 1982). Consequently, the solutions proposed by information designers have been generally thought of as the presentation of the most “relevant” information to users, though the meaning of relevance is not without controversy (Saracevic, 2008). While there has been a movement to go beyond the content of a query to understand the context in which a person seeks or encounters information, what exactly “context” is has “the potential of being virtually anything that is not described as the phenomenon of interest” (Dervin, 2003, p. 112).

Oftentimes problems that appear to be due to uncertainty, particularly in complicated medical contexts, are “solved” with solutions that privilege information

exchange. Uncertainty, an overused term in defining patient challenges, is described by Weick (1995) as a sort of ignorance that prevents people from seeing the consequences of current actions. This state can be caused by a lack of information, but it can also be because of a lack of understanding of what that information means (Lipshitz & Strauss, 1997; Weick, 1995). This idea of solving uncertainty with increased information is particularly problematic and potent in issues of health communication, where patients frequently do not lack information but struggle to make sense of it in the context of their own lives (Kaziunas, Ackerman, & Veinot, 2013). This relates closely to challenges of ambiguity – a problem more akin to confusion than ignorance (Weick, 1995).

Overemphasis on information design is not unique to health communication; Dervin's (1976) initial critique of the communication and information science disciplines was motivated by this very imbalance. She described an overemphasis on getting “the right information to the right people at the right time” (p. 324). However, Dervin proposes that information only has meaning in the context of what a person already knows, and we know little about how external reality (“objective” information) is transformed into internal reality. This challenge is one element of information design that could especially benefit from design for sensemaking by looking at how people use their understanding of the world to act within it, including how they might try to represent their knowledge in a tangible form that can be accessed by others.

*Information design*, as its name would suggest, focuses more heavily on the design of the information itself rather than the ways that people interact with it and with each other. For instance, there is extensive work on determining the visual attributes that best represent specific types of information, but little on how to create the best possible

conceptual structure to support sensemaking (Blandford, Faisal, & Attfield, 2014) or the ways that people use information to accomplish their goals (Blandford & Attfield, 2010). Looking to interaction and communication design offers further insight into how to better develop systems that consider the user beyond their surface level information needs.

### **Design for Interaction**

Marchionini (2008) describes interaction as a “situation in which entities participate in several cycles of action that in turn cause changes in those entities” (p. 170). This illustrates one of the biggest differences in design for interaction and design for information: the former generates action while the latter creates or alters entities. One of the settings where design for information and for interaction overlap significantly is in the design of information systems. In user-centered approaches to information system design, there has been a shift from developing tools for effectively providing relevant data towards a focus on the user’s interaction with the system, as reflected in the term *interaction design*. As Mateosian and Hallnäs (2000) describe it, interaction design is “a shift of focus from what a thing does as we use it to what we do in the acts that define use” (p.15), or more concisely, it is the “design of acts that define intended use of things” (p. 23).

Barley (2015) describes an “interaction bias” (p. 1613) that focuses on knowledge representation objects (like graphs or drawings) as tools for sharing existing knowledge and neglects to consider how interaction with those objects might affect ongoing processes and knowledge creation. As in, understanding how the anticipation of future communication affects these representations might require a shift in focus to the practices of those who create rather than the object itself. Further, users are active agents and when

interacting with a system, they will try to make sense of its behavior (Bannon, 1995). The ways that people interpret such behavior from a designed machine and adapt their own behavior based on this understanding is part of interaction design that relies on understanding sensemaking processes to improve utility and usability of information systems.

The shift in perspective from system response to intended use is not a common view within the domain of interaction design, a field which largely focuses on improving user interfaces based on quantifiable task-oriented requirements (Löwgren, 2001). Instead, this alternative view presents interaction design as targeting user experiences that support people to work and interact with others in their everyday lives (Preece, 2006) and examines how humans act with each other and through artifacts (Waern & Back, 2017). In this framework, the *activity*, or a person's interaction with the world that is motivated by a particular outcome (Kaptelinin & Nardi, 2012) is the object of interest rather than the physical artifact. In this view, when a person interacts with a system, they are using that system as a tool to interact with the world (Kaptelinin, 1996), a perspective that mirrors the constructionist ideals of PD. This contrasts with the more common perspective within human-computer interaction by presenting the computer as a “mediating artifact” (Kaptelinin & Nardi, 2012, p. 6). Challenging the traditionally object-focused interaction design begins to highlight the importance of identifying the communicative impacts of these interactions.

The steps taken during an interaction, for example a doctor drawing a line graph of long-term survival or a patient questioning new medications, can be designed in specific ways to achieve larger communication goals. Thus, *interactions* are the actions

taken to achieve communication, and the affordances within an intervention can alter possible actions available to guide actors towards a specific communication goal.

### **Design for Communication**

Flores, Graves, Hartfield, and Winograd (1988) propose a theoretical orientation towards communication design that describes the relationship between interaction and communication. The authors emphasize the role of language as not just a means of representing information, but that through interactions, humans communicate to act together and create their world. Thus, *communication design* is supported by intentional design of information and interaction through interventions that alter the possibilities for achieving goals or creating shared meaning (Aakhus, 2015). Designers make some forms of communication more or less possible through the constraints and affordances they impart using interventions that guide interactions. Communication design is essentially a hypothesis about how communication works and how it should work, and this hypothesis can either be supported, rejected, or altered based on the outcomes of implementing such a design (Aakhus & Jackson, 2005).

For example, shared decision making (SDM) is a form of communication that many have attempted to design interventions to support. In SDM, doctors and patients work together to determine which treatment option best aligns with patient values and preferences. As described in Chapter 1, interventions to improve SDM often take the form of decision aids (DAs). However, DAs are more often designed to transfer information about options than to facilitate conversations around life circumstances or values as is recommended by the ideals of SDM (Serrano et al., 2016; Wieringa et al., 2019). This assumption that providing all of the information to patients will improve their



decision making is pervasive in healthcare, when in reality a conversation is required to truly understand what is best for an individual patient (Elwyn, Lloyd, et al., 2014). DAs are designed in such a way as to achieve goals of information, often looking to create informed patient populations. The ways this goal is achieved is by designing for particular interactions that center around information transfer and not necessarily for deliberation. While DAs may often be intended to design with the communicative goal of SDM in mind, they may instead be designed to facilitate interactions primarily to transfer information about risks and benefits (Wieringa et al., 2019). That is not to say that designing information to increase the likelihood of SDM as a collaborative, bilateral communicative event is not beneficial—ensuring that medical information is presented in layman's terms is one important way that information can improve patient understanding. Both information *and* interaction with that information and between all parties involved can also be intentionally designed to increase the likelihood of communication between doctor and patient that achieves SDM. A simple example of this is the Ask-Tell-Ask approach, which recommends providers engage in a series of three interactions: first ask the patient what they already know about the topic, then tell them in straightforward language what they need to know, then ask if they understand what they just heard (Back, Arnold, Baile, & Tulsky, 2005). This approach offers recommendations on both how the information should be presented to patients and how doctors should interact with them, all in the hopes of successful communication that achieves SDM.

## **The Intersection of Design for Information, Interaction, and Communication: Sensemaking**

Dervin (1976) defined the distinctions between *information systems*, which collect, store, and retrieve information, and *communication systems*, which help people inform themselves and establish their own understandings of the world (the latter of the two she claimed had not yet been invented). She promoted a de-emphasis on information for its own sake and a renewed effort to develop communication systems that account for the subjective reality within which people interact with and interpret information. Essentially, a communication system, to Dervin, is a system that aids in sensemaking. Sensemaking is concerned with the continuous flow of action and interaction in which humans are constantly engaging in internal and external processes towards developing an understanding of the world around them. Some of the largest contributors to sensemaking theory come from the communication discipline, examining the ways that people collectively construct reality and how sense informs behavior. It is through communication that people make sense of their roles and attempt to find mutual understanding with others (Churchman & Hanisch, 2005). Weick, Sutcliffe, and Obstfeld (2005) describe sensemaking as initiated by ambiguity, and as a communication issue because “situations, organizations, and environments are talked into existence” (Weick et al., 2005, p. 409). People make sense of the world and then enact that sense back in the creation of their environment.

This perspective differs from the traditional emphasis on information-exchange that has dominated much of health communication (Ruben, 2016), or the tendency to measure systems based on quantifiable usability as in interaction design (Gould & Lewis,

1985), to consider how individuals find meaning in the world around them. The transition from information to interaction, and from interaction to communication, is initiated and achieved through sensemaking. Thus, design for sensemaking is potentially applicable in designing artifacts that support people in achieving their goals through sensemaking. The distinctions in the goals, output, and what is considered designable across these four design domains is illustrated in Table 3.

**Table 3**

*The Design Domains*

|                                 | <b>Goal of Design</b>  | <b>Output</b>  | <b>Designable</b>  |
|---------------------------------|--|--|--|
| <b>Design for Information</b>   | Transfer knowledge   | Relevant information that attempts to address gap in knowledge                     | External knowledge representations   |
| <b>Design for Interaction</b>   | Enable actions that can create changes in participating entities | Facilitation of exchanges between information generator and information user       | Functional and visual qualities of systems that store and retrieve information |
| <b>Design for Communication</b> | Create shared meaning/achieving goals                            | Enable interactions within/between social systems/technologies in pursuit of goals | Affordances and constraints on types of communication are possible             |
| <b>Design for Sensemaking</b>   | Enable people to understand and act in the world around them     | Understanding; Ability to move forward; Resolve issues of ambiguity                | Information, interactions, and communication practices                         |

### **Design for Sensemaking**

Sensemaking is concerned with the processes people engage in to understand the world around them and how they are influenced by personal and situational contexts. A key theoretical premise of sensemaking is that information only has meaning in the context of what a person already knows, and thus it means different things to each person, and it may mean different things to the same person at different points in their life (Dervin, 1999). This view of information accounts for individual situations and context, which is particularly useful for maximizing a person's understanding of information in terms of its personal consequences. Design for sensemaking goes beyond focusing on what content to provide and emphasizes situational characteristics and the individual and collaborative processes that people engage in when they interact with information. The ways that people interpret these interactions, with systems or with other people, influences the actions they take. Sensemaking is of extreme importance in the ability for users to not only accomplish their goals but to understand how to take the actions necessary to do so.

The theory proposed here suggests that designing to target sensemaking specifically will improve the ability for patients who face complex medical encounters to resolve ambiguity and continue forward in their health journey. People who are otherwise cognitively capable often have difficulty processing ambiguity and complexity of information when faced with serious illness (Epstein & Street, 2011). Epstein and Gramling (2013) describe complex and ambiguous clinical situations as those that have insufficient clinical evidence, in which goals or options are not clearly defined, preferences are contextual, provisional, and evolving. Weick (1995) defines ambiguous

situations (of all kinds, not just medical) as occasions for sensemaking. Ambiguity is “an ongoing stream that supports several different interpretations at the same time” (p. 91). Ambiguous situations do not meet the requirements for rational decision making, as they are changing, paradoxical, or unclear. Information alone will not resolve the ambiguity of the situation; Weick concludes that in ambiguous situations, a greater quantity of information is not as helpful as a different quality of information. People are unsure of what questions to ask, what the problem is to solve or if there is even a problem at all. Weick suggests that navigating ambiguous situations requires that people have the opportunity to debate and discuss with others, gathering multiple subjective interpretations as “no one has the foggiest idea what objective data, if any, are relevant” (p. 99). Epstein and Street (2011), building in part on Weick’s sensemaking theory, proposed the concept of *shared mind* as a means of providing care to patients with serious illness. Shared mind is a dynamic interpersonal process “in which new ideas and perspectives can emerge through the sharing of thoughts, feelings, perceptions, meanings, and intentions among 2 or more people” (p. 454). Thus, the dynamic and evolving sense made in complex clinical contexts develops through communicative processes of interactions with information and with other people. The objects of design are these communicative processes/features of interactions with information in order to influence the internal sensemaking processes that allow patients to navigate ambiguity in a way that clarifies, adapts to, and approaches their health goals.

The theoretical framework presented below builds on existing sensemaking methodologies, primarily those of Dervin and Weick, by incorporating theories and practices of design for information, interaction, and communication. Much of the

sensemaking literature has been in organizational and information systems design; however, the actual *process* of designing of artifacts to support sensemaking and the associated processes to uncover existing sensemaking practices has yet to be well-documented. The present study uses a case study approach in pursuit of a larger theoretical goal: to develop and assess the feasibility of a sensemaking support system while also evaluating the usefulness of a theory of design for sensemaking support. By applying these principles of design for sensemaking to the current case study, in this dissertation I aim to explore their value in methodological application and how it affects communication both within the research study (i.e. designer-user interactions) and, in future work, in the final product (i.e. patient-provider interactions). The artifact can be treated as a prototype of this theory that is being refined through its application to the case of bone marrow transplant. Reflections on the utility of this theory are presented in the final chapter of this dissertation.

To illustrate the relationships between information, interaction, communication, and sensemaking, one might consider a hypothetical interaction based on a field observation between an oncologist and BMT patient that demonstrates the practical manifestation and relationships between these four domains. Following a description of the conversation are specific features that may be designable. The purpose of this is to show not only the boundaries and interdependence of information, interaction, communication, and sensemaking in practice, but also to illustrate the importance of context/the design situation in how one might intervene. To understand these relationships and the potential for designability, while reading this interaction, it is helpful to specifically attend to the artifacts used, information presented, and explicit

vocalizations of sensemaking (like asking questions) that occur in pursuit of the larger communication goal of achieving shared decision making.

In this interaction, a patient with AML (referred to as Matthew in the hypothetical scenario below) is meeting with the transplant doctor (referred to as Dr. B) to discuss transplant as a treatment option. Matthew is in his 70s and had a heart attack a few years ago but is otherwise healthy and has been vocal about his desire for transplant since his diagnosis. As discussed prior to the encounter, the doctor does not believe the patient is a good candidate for transplant, so he intends to present BMT so as to discourage the patient from going through with the transplant.

Dr. B begins the conversation by telling Matthew that based on his most recent labs, Matthew's average life expectancy without transplant would be 2.5 years. Dr. B then goes on to explain what Matthew's outcomes might be if he chose transplant by drawing a pie chart on a blank sheet of paper. These numbers in the pie chart come from an app on Dr. B's iPad that he uses to calculate transplant outcomes for individual patients. He inputs certain risk factors like age, mutations, and comorbidities, and receives outcome likelihoods. Dr. B begins to explain the pie chart: 30% percent of people who receive transplant experience relapse and their disease does not go away. Matthew asks if there is any remedy if the disease comes back. Dr. B tells him not really, and Matthew suggests that would be the same outcome as if he did not do anything at all.

Dr. B then explains 45% of people going through transplant have complications that are so severe they lead to death. Matthew, becoming less positive, points out that he's not completely healthy, referring to his heart attack,

but that it seems better to take some sort of action than to do nothing. To this, Dr. B responds that within those 25% that do survive, most will experience a potentially debilitating complication called graft-versus-host disease (GVHD). To offer an alternative, Dr. B says there will be a medication released this year for the specific mutation Matthew has.

Though Dr. B reminds Matthew that “the future is uncertain,” he summarizes the information he just presented: 50% of people like Matthew would be fine and do well without a transplant and survive on average 2.5 years, while 45% of people who do get a transplant die from complications of the procedure itself sooner than that. Matthew then, with a bit of frustration, says he “has no choice” and has to think positively about transplant. Dr. B responds by saying that by getting transplant, Matthew might be losing good time since he only has a 1 in 5 chance of disease-free, GVHD-free survival.

Matthew says that with transplant he does have a shot at a longer life, but it's like “rolling the dice versus a gradual decay.” Matthew says he wants to investigate his other options. With transplant he has a 25% shot of survival, and to him it's the best way to get some kind of shot. If he had a 50% chance, he would say probably.

As the conversation comes to a close, Matthew says that his focus will be on the new meds for his mutation and asks Dr. B what he thinks. Dr. B responds, “it's an uncertainty” to which Matthew replies “Well, transplant is an uncertainty as well.” Dr. B tells Matthew to think it over and call him in a few days.



In looking at this example, we see all four of these domains, information, interaction, communication, and sensemaking, and potential for designability.

*Information:* The risk calculations from Dr. B's iPad, the outcome percentages, details of Matthew's health status and of potential complications are some pieces of information seen in this scenario. Some information that stands out as designable here is the algorithm that calculates these outcome likelihoods, or the patient's medical records.

*Interaction:* There are multiple interactions occurring in this example that revolve around exchanging and interpreting information. The most obvious is the doctor-patient interaction as Dr. B and Matthew go back and forth discussing transplant risks and benefits. Another is Dr. B's interaction with the iPad risk calculator. A third is with the doctor, the patient, and the pie chart that the doctor drew. All of these interactions are potentially designable, but in the spirit of traditional interaction design, the interface of the iPad risk calculator and of the pie chart representation are most immediately designable and would influence the doctor-patient interaction as well. These interactions have potential designability to influence how the participants interpret/make sense of the information being discussed. For example, if the pie chart of outcome likelihoods, in the event that the Matthew did choose transplant, instead were presented as a comparison between outcomes with and without transplant, perhaps Matthew would not have understood declining transplant as "doing nothing." Instead, he may have been more receptive to a visual representation of the positives of this alternative option.

*Communication:* The larger communication goal for this encounter is for doctor and patient to come to a shared treatment decision. Though Dr. B approaches this conversation intending to discourage Matthew from choosing transplant, he treats this as

Matthew's choice, else he would not even present it as an option. He explains what he believes to be the most relevant facts, and also the reasons he is not explicitly recommending transplant, in the hopes that Matthew will see how dangerous the procedure is and decide against it. He offers alternatives, like not getting transplant or the possibility of novel medications, to again bring Matthew away from deciding to get transplant. By the end of this encounter, Matthew and Dr. B did not come to a shared decision on how to move forward.

One way this situation may be redesigned to make SDM more likely would be to facilitate a discussion of values, which was largely absent from this encounter. Discussing values has been established as a significant factor in achieving a shared decision (Barry & Edgman-Levitan, 2012; Hashim, 2017; Makoul & Clayman, 2006; Politi & Street, 2011; Sepucha et al., 2016). Facilitating a discussion not only around accurately comprehending the pie chart, but its relevance to Matthew and his current situation may have served this overall goal. If Dr. B knew Matthew valued survival more highly than quality of life, perhaps Dr. B would have changed the information he presented or would have interacted with Matthew differently when describing the pie chart. As Hargraves et al. (2016) described, "the challenge in shared decision making is using the dispassionate and objective evidence of medical science to inform care for a patient in his or her particular circumstances" (p. 628). It is possible to redesign the information and interaction that occurs in these encounters so that they better serve the overall communication goal of collaborating on treatment decisions.

*Sensemaking:* Instances of Matthew externalizing his sensemaking are prevalent throughout. For example, when he interprets experiencing a relapse after transplant as the

same as “if he doesn’t do anything at all” or when he describes not getting transplant as a “gradual decay,” this may suggest to Dr. B that Matthew views transplant as an active attempt to fight illness rather than accepting his inevitable death, regardless of the quantified outcomes he is being presented. These vocalizations of Matthew’s interpretation of the information being presented give Dr. B cues as to how the conversation is going, for instance when Matthew seems discouraged, Dr. B mentions the new medications that might be available soon. Though it is difficult to directly design individual sensemaking practices that occur inside one’s mind, designing interventions targeting the information, interaction, and communication practices occurring in this encounter could ultimately address sensemaking practices in such a way as to resolve ambiguity and better serve the larger goal of coming to a treatment decision. What this means depends on the patient – they may want to be able to determine what actions to take next, and/or they might want to find meaning in a seemingly reasonless and chaotic illness experience (Epstein & Gramling, 2013). In what follows, I describe the relevance of design for sensemaking to high risk medical encounters before introducing a novel theory of design for sensemaking support.

### **Design for Sensemaking in High-risk Medical Situations**

Before describing the current principles of this theory, it is useful to describe its relevance to the case study, a high-risk and complicated medical context. In describing the principles, I will start with a general description of how each is defined before relating it specifically to complex and ambiguous medical situations.

While there is a significant amount of literature on patient decision making, there has been little work to understand the sensemaking processes that influence patient

decision making (Goering & Krause, 2017). Few researchers have looked to sensemaking as a means to accomplish this in intervention design despite recognition that there is a need to adapt to individual patient circumstances (Mamykina, Smaldone, & Bakken, 2015). A focus on sensemaking can be particularly relevant in healthcare settings, as illness can uncover gaps in understanding that have serious implications for a person's wellbeing (Davidson, 2010). The shift from information-centricity to sensemaking resolves the challenges that cannot be solved by information design alone; however, a sensemaking approach would also look to how people interpret that information and use it to influence their actions.

Adopting a design approach for sensemaking is ideal for studying the ways that people engage in high-risk medical situations for a number of reasons. First, sensemaking looks towards individual situations as the best indicator of information needs and use rather than demographics or disease. This is important as patients vary in their preferences on information quantity (Dey, 2004), in information seeking behaviors, and in the specific topics about their disease that they want to know about (Ahamad, Wallner, Salenius, Ross, & Fernandez, 2019), all of which may vary within a single individual throughout their illness journey (A. T. Chen, 2012; Finneyruttena, Arorab, Bakosc, & Noreenazizb, 2005; McCaughan & McKenna, 2007). Second, sensemaking theory suggests that there is no such thing as objective information given that information only has meaning in the context of what a person already knows (Dervin, 1976). Third, it looks beyond what might be typically considered “information” and also aims to uncover anything else that people might have used to make sense of a situation such as experiences, feelings, and ideas and how these elements informed their ultimate

understanding of a situation or the actions they took (Dervin, 1999). Such a perspective adopts a more holistic view of the person encountering information by looking to the cognitive and affective influences on the interpretations they form (Kuhlthau, 1991). This is important because identifying ideal treatments according to patient values can manifest in decision aids based on the assumption that these values are static and they exist within the individual patient, perhaps neglecting the potential of social networks to contribute to a dynamic and evolving valuation (Epstein & Street, 2011). These alternative approaches offered by sensemaking that focuses on the situational and contextual characteristics of a person can address some of the challenges of presenting medical information and supporting deliberation in a way that is meaningful and helpful in addressing clinical complexity. Below, I will present five principles to enable practical application of sensemaking theory through a design approach and describe their potential application to complicated medical situations.

### **Theory of Design for Sensemaking Support**

#### **Meaning-centered**

*Examine how people make sense of their lived experiences and the influence of situation on what users attend to and how such extracted cues are provided meaning*

Sensemaking theory suggests that information is defined by existing knowledge and its meaning is dependent on the person who is interacting with it. “Information,” in this context, is expanded to include anything that a person uses to make sense of a situation and the ways they use this sense to bridge gaps in understanding. Weick, Sutcliffe, and Obstfeld (2005) propose that people do not need to have an ‘accurate’ view of a problem to solve it, but just need to make sense of the circumstances in a way that

allows them to move towards their goals. If the sense made allows for progress as determined by the sense maker, then it is sufficient; a person will try to make enough sense of information to determine how they might interact with it in a way that achieves their goals. The human experience does not pause, and the actions taken based on this newly made sense (even if unsuccessful) will produce new data for sensemaking. In this way, sensemaking places an emphasis on process rather than product (Dervin, 1999).

Sensemaking suggests that it is critical for designers to first understand the meaning making processes that users are engaged in before designing systems that account for these processes. Without first understanding the interpretations being formed as users encounter information, interact, and communicate, we cannot properly design objects to support these processes. This includes examining, for example, *extracted cues*, or what people may knowingly or unknowingly notice or observe to understand what is happening in the world (Weick, 1995). It may also include expectations and the disruptions that occur when expectations differ from what is actually experienced (Louis, 1980), and the ways that people bridge these gaps in understanding when they either consciously or unconsciously make sense of their experiences (Dervin, 2010). Attention to such aspects of experience go beyond those of information design, which looks more specifically on what information is missing and is most useful for solving problems of uncertainty. However, in situations like high-risk medical decisions, people face ambiguity and equivocality of options which can only be addressed by successfully forming an interpretation that is plausible and useful enough that they can move forward towards their goals (Weick, 1995). These elements of the sensemaking process must be examined and established prior to any attempt to design sensemaking support.

The idea of meaning-centered design is seen in *product semantics*, a term used to describe the study of what artifacts mean in their context of use and the application of this understanding to the design of future objects (Krippendorff & Butter, 1984). As Krippendorff (2006) writes, “design is making sense of things.” In doing so, he proposes that design engage in a “semantic turn” that focuses on the potential to create artifacts that have meaning to people. Designers create objects based on their own conceptualizations, and users interact with these objects using their own separate understanding. Designers must then attempt to understand the ways that users come to understand the object in their own personal contexts. Assuming that the use of the object is intentional and not arbitrary, it can be assumed that it has meaning for the people involved – but to understand the meaning that other people bring to a situation requires communicating with them (Krippendorff & Butter, 2008). Thus, product semantics suggests that design be based in the study of how people attribute meaning to artifacts and how this influences their interactions with the world around them.

In a similar sentiment to the accuracy vs. plausibility tension described by Weick (1995) in his theory of sensemaking, Krippendorff (2006) suggests that a user’s understanding of the artifact does not need to be “correct,” or as the designer intended, but rather it needs to enable the user to interact with the technology as effortlessly as possible. Observing people’s reactions to products can be used to uncover the difficult to articulate latent needs of users, as designers can attend to the emotional meaning of things as well as their function (Brown, 2008). Investigating how people interpret artifacts and their experiences, and how those interpretations inform their actions, is the most fundamental requirement of design for sensemaking.

## Temporal

*Recognize the dynamic internal and external processes that people engage in over time as they make and ‘unmake’ sense*

One of the biggest contributions of sensemaking is the addition of temporality and its influence on how a person interprets their situation. Temporality is seen in the patterns that define a process or activity that give it meaning and relevance (Ballard, 2017). Any instance of sensemaking originates in the past, exists in the present, and moves towards the future (Dervin, 1999). Sensemaking is concerned with the continuous internal and external processes that people engage in to develop an understanding of the world around them. Information designers have traditionally relied on a position that information can be transferred from one individual to another; however, the situation that a person is in when they encounter information differs from day to day, and one person may interpret the same piece of information differently today than they did yesterday (Dervin, 1998). This recognition of temporality is especially critical for patients facing complicated medical situations, as the provisional nature of patient preferences and understanding may continue to evolve as they experience their illness journey over time (Epstein & Gramling, 2013). Thus, design for sensemaking adopts a sensitivity to temporality and changes that occur in individuals, situations, and interactions over time.

Like sensemaking, design also considers temporality in its theoretical basis through its concern with possible futures and that which does not yet exist. Designers must adopt a future-oriented mindset that requires use of their imaginations to both predict and design out adverse effects (Caplan, 1995). Brown (2008) suggests that we “design with time” and view people as growing and evolving beings with autonomy over



how their lives unfold (p. 132). This approach enables design solutions to meet the unique needs of individuals as they evolve over time, as allowing people to determine how their stories unfold makes it more likely that they will be open to a design solution that will adapt to meet their unique needs. A person's understanding of an artifact will change as they interact with it, and subsequent actions will reflect this new understanding is a cyclical and never-ending process during that engagement.

Sensemaking similarly describes this process in that information, or an artifact, may mean something different to the same person at a different time. Designers should not consider a person's understanding of an artifact to be static but instead to change during use. Further, recommendations and requirements aimed at generalization are rarely sufficient for developing a successful design as design choices are often highly context-dependent (Gould & Lewis, 1985). Dervin (1983) recognizes the dynamic situation that a user exists in and its influence on that user's actions. The situation, which is ever-changing, is proposed to be a better predictor of sensemaking behaviors than demographics or other more stable factors. Thus, systems should be designed to be flexible and adapt to the constantly changing reality in which they exist.

As opposed to the episodic view of decision making processes, which tends to look at how people process relevant information as a means of achieving the discrete outcome of a "decision," sensemaking recognizes that people are constantly and repeatedly making and unmaking sense of their worlds as their situations and understandings change (Dervin, 1999). This approach is ideal for situations where patients are facing significant uncertainty, are forming and adjusting expectations, and are regularly presented with new, complicated challenges. As a patient's situation

changes over time, both their information needs and their understanding of their illness change as well (Chen, 2012). Further, treatment decision making requires that patients imagine possible futures and engage in affective forecasting, and they must use these imagined futures to make decisions about their present actions (Paton, 2019), a practice that designers, concerned with what does not yet exist, know well. In this way specifically, support for medical decision making can benefit from both sensemaking and design perspectives.

### **Inclusive**

*Examine the perspectives of multiple stakeholders; Encourage awareness of/engagement with others' sensemaking processes*

Taking a communicative stance towards design employs need-finding and design thinking to identify normative and empirical processes in the design situation, and challenges “traditional assumptions of roles, values, and whose needs are served by design” (Thomas, Steier, & Ostrenko, 2014, p. 215). Culturally shared assumptions and expectations may influence communication practices, but designers can challenge these assumptions and explore what kinds of communication are possible (Aakhus & Jackson, 2005; Jackson & Aakhus, 2014). Through manipulating different features of interactions, design can impose constraints that limit the ways people can plausibly make sense of what is said and done (Aakhus & Laureij, 2012). Still, people can change their communication practices to fit the affordances and constraints designed within the communicative environment, as the desire to communicate and develop mutual understanding encourages adaptation to the restrictions imposed by the system (Churchman & Hanisch, 2005). The malleability, as noted earlier in the discussion of

problem definition, presents an opportunity for designers to identify and intervene on potentially disruptive conditions.

Including various stakeholders throughout the design process, as is promoted in UCD and PD, can uncover these inequalities and adaptations from multiple perspectives. Just as the same person might have different interpretations of the same artifact at different points in time, stakeholder groups will likely vary in their perspectives on the same issue or proposed intervention, and they may differ from the designer's perspective as well. Thus, design prototypes can be considered hypotheses (Petroski, 1985), with prototype testing and user feedback providing opportunities to confirm or deny the designer's or other stakeholder groups' understandings of the problem and possible solutions. Ideally, this iterative process leads to a prototype that not only meets stakeholder perceived needs, but can be implemented more easily as the responses of those who would be impacted by its implementation are more readily observed (Sanders & Stappers, 2008).

When designing for multiple stakeholders, there is potential for the needs of one group to take priority, go unaddressed, or be designed for in a way that unintentionally harms. When there is not involvement from all stakeholder groups in the development process, implementation can face unforeseen problems, particularly if there is not buy-in from all parties. Not only is it important for designers to be aware of the various perspectives, but particularly in situations such as SDM where collaboration is required, it is important that the stakeholder groups are able to see the perspectives of other groups, i.e. for patients to know what providers are saying and for providers to hear from patients. Creating an environment in which these disparate groups can be exposed to each other's

beliefs allows them to comment on things that they may not otherwise be able to comment on. It may uncover needs that would have never been realized had the design team not created a space for that discussion.

### **Self-reflective**

*Recognize the privileges afforded by power differentials (including those for designers) and attempt to understand/limit their influence*

Sensemaking theory points to the potential influence of power differentials in sensemaking practices. To resolve such differences, it is important to be aware of how these differences impact the creation and use of information (Dervin, 1999). There is evidence that communication with providers influences patient interaction with health information (Costello, 2016) and that patient health information seeking may influence interactions with providers (Stone, Scott, Martin, & Brashers, 2013). Power differences may lead people towards certain sensemaking resources and thus encourage certain answers in spite of a person's own experiences (Dervin, 1998). To recognize this, designers should identify user perceptions of power differences and barriers to sensemaking.

Designers should also assess the potential influence of their own privileged position, perhaps limiting such inequality by engaging in PD practices (Spinuzzi, 2005). Though, as noted above, user participation alone does not automatically lead to adjustment of power differences, a self-reflective designer gives users the ability to influence not only the end products of PD processes, but the PD process itself. Schön (1983) described the *reflective practitioner*, a designer who is able to recognize his/her understanding of the problem and revise this understanding. This involves creating

potential interventions, implementing them, paying attention to what happens, and then adapting their understanding. This *conversation with the materials of a situation* is possibly one of the most useful means to facilitate successful PD. There is a gap between user and designer conception of a problematic situation, and this can be resolved through dialogue, collaboration, and the willingness of the designer to iterate based on user input.

This type of reflection depends on the willingness of the user to engage with designers and ultimately communicate their real needs. However, users are not always conscious of their “real” needs (Oddy, Belkin, & Brooks, 1982). This makes communicating those needs potentially difficult for users, and communicating them in a way that is practical and actionable to designers can be a significant struggle (Sleeswijk Visser, van der Lugt, & Stappers, 2005). While people may struggle to articulate their “real” needs in a way that is useful to designers, their success largely depends on the quality of needs elicitation tools provided by the designer. Involving users through PD creates a forum for this conversation, but for this to be achieved designers must embrace their role as facilitators for participation while also recognizing that tools created by the designer will be imbued with the designer’s perspective on what users need to express themselves. For this reason, the tools provided to users throughout the process should be presented as unfinished objects that need their feedback along with prototypes of potential solutions. For a truly participatory process, potential users should be involved in the development of needs elicitation tools as well.

### **Action-oriented**

*Observe actual, situated use of the system to identify the processes users engage in as they make sense of the system and its effects on their practices*

The ideal of sensemaking research to “observe rather than assume” connections between situations and information behavior (Dervin, 1983, p. 7) as well as the reality that a technology may be designed for one kind of use but in practice be applied very differently (Aakhus & DiDomenico, 2016) suggest that to truly understand the sensemaking practices of users, a designer must watch people actually use a prototype rather than just collecting perceptions and retrospective feedback (see: Mikesell, Marti, Guzmán, McCreary, & Zima, 2018). As people use a product their understanding of it changes, particularly if they are being faced with an actual problem rather than a simulation. As Harrison (2014) put it, “Designs in theory work differently than designs in action” (p. 9). Users form newfound understandings as they incorporate a novel design into their current practices, and an ideal sensemaking support tool would help them to determine their actions as they move forward. Thus, designers should observe actual use of the system to identify the internal and external sensemaking processes users engage in as they make sense of the system and its effect on their practices. They should solicit user reflection on the reasons behind their interactions with the prototype with particular attention to social and emotional reasoning.

Sensemaking is more obvious when the continuous flow of action is disrupted (Weick, 1995). The artifact created by the designer will likely “disrupt” the flow of action once it is implemented, a key consideration for the development process. These disruptions can act as both an inspiration for a potential design and as something that designers need to be aware of when thinking about implementation. Perhaps the most obvious reason that design is an appropriate method to investigate sensemaking is because of the value of prototypical artifacts. “Sense” is a difficult to capture

phenomenon; it exists largely in the minds of humans but can most readily be observed in the actions they take. As such, introducing prototypes into an environment where sensemaking is a critical process creates an opportunity to not only ask users how they are making sense of the prototype, but to also observe their interactions with the prototype. As opposed to other methods of uncovering sensemaking, such as interviews, prototype testing presents another means of examining “sense” through the observation of actions taken as a result of that sense.

Not only does prototype testing allow designers to examine the sense made of the artifact they produce, but design tangibly communicates the sense made by designers of the design situation, as described by Schön’s reflective practitioner. When a person presents new knowledge to others, this represents the transformation of information into meaning (Kuhlthau, 1991). The designer’s conceptualization of the current situation is transformed into boundary objects that can act as a mutual point of reference around which different groups can discuss and refine their understandings of each other’s perspectives (Muller, 2003). Acting as a reflective practitioner, the use of prototypes aids designers in better refining their understanding of the situation and potential solutions while also revealing potentially meaningful differences in the ways that various stakeholder groups conceptualize their problems.

Finally, success in design is measured “in location, in real use, and over time” (Stolterman, 2008, p. 59). This sentiment, that a design must be evaluated based on its real world impact, summarizes many of the principles described above. The success of a product must be based on both stakeholder input and the designer’s impression of his/her own work. It must be in real life circumstances, not just in a one shot focus group but as

users come to know the artifact and interact with it based on an evolving understanding. This final principle of action-orientation holds perhaps the greatest distinction and advantage from other sciences: design leads to artifacts that are meant to be used in the real world. The artifacts that actually make it into the world represent just a few of many possible solutions—the best possible solutions given the current understanding of the situation. In evaluating the effectiveness of a proposed design, a designer is also generating useful knowledge around how practices change and how people interact with the artifact that can be used in the development of alternative solutions.



## **CHAPTER 3: Methods**

### **Overview of the Design Process**

The current research examines design processes that elicit and support sensemaking in complicated medical situations by adopting an iterative design approach that relies on investigative and generative user-centered (UCD) and participatory design (PD) methods. Aligning with practices of UCD, this research draws on semi-structured need-finding interviews and observations of the clinic context that serves as the case study to gain an initial understanding of the design situation, and prototype feedback sessions utilizing focus groups with providers and interviews with patients and caregivers to assess the perceived utility of potential solutions. An assessment of the strengths and weaknesses of these UCD practices then led to the adoption of PD workshops with patients and caregivers in order to investigate the sensemaking processes that patients and caregivers go through leading up to transplant. Design theory stipulates that a designer's first aim is to understand the design situation by exploring the goals and problems of relevant stakeholders and their current strategies for coping (Brown, 2008). Part of this problem definition process is collecting views from all stakeholders and discovering their needs. These findings are then used to develop working hypotheses and subsequent prototypes for further exploration (Buchanan, 1992). Thus, this process began with what might be deemed standard process in UCD, with need-finding interviews with patients and providers and observations of the institutionalized procedures surrounding transplant including the education and informed consent procedures (Study 1) to identify unmet needs and areas participants believed should be improved (Patnaik & Becker, 2010).

From a design perspective, the goal of this early phase is to be able to “design the right thing before designing the thing right” (Martelaro & Ju, 2019, p. 52). While interviews allow access to participants’ rationalized and retrospective reflections of their experiences with transplant, observations, such as those used in design ethnography, are a tool for better empathizing with potential users and adopting their perspectives (Van Dijk, 2010). For a designer, empathy is a tool to “see the world through the eyes of others, understand the world through their experiences, and feel the world through their emotions” (Brown, 2008, p. 50). Accordingly, attending the transplant orientation class allowed a glimpse of the event as a patient or caregiver might experience it—though without the context of a life-threatening medical condition—and an opportunity to see this practice that the clinical team so often spoke about first-hand. Direct observations also allowed critical reflection on the solution that the clinic implemented to address providers’ perceived challenges. The findings from Study 1 were then used to inform the iterative development of low-fidelity prototypes of an interface designed to serve users’ identified needs. The prototype development process included regular meetings among the research team to evaluate and discuss the sketches and their revisions.

A second key element of UCD is that ideas must be tested early and often using hands-on methods that involve representative users in the process, as this reveals potentially unexpected consequences and promotes improvement in future iterations (Brown & Wyatt, 2010). The prototypes developed following Study 1 were presented to providers in a focus group in 2017 and to patients and caregivers in early 2018 for feedback (Study 2). Thus, the studies began with interviews and observations to capture stakeholders’ retrospective perceptions of the design problem, then shifted towards a

more hands-on approach by asking participants to imagine how they might use these proposed systems. The use of such low-fidelity prototypes for gathering early user feedback is critical to a successful design process, as a system appearing unfinished encourages participants to present their uncensored criticisms (Rudd, Stern, & Isensee, 1996). The method of showing early-stage prototypes to participants can be a means of not only gathering preferences for particular design elements, but also soliciting more experiential information as participants must project their own interpretations onto an unfinished design rather than one that has already been decided upon. Asking participants to actively reflect on their experiences when evaluating prototypes allows designers “to have [their] questions, ideas, prototypes and interfaces held up to the scrutiny of a diverse set of potential future customers so we can make better choices” (Dishman, 2003, p. 44). Prototype critiques solicited in Study 2 pointed to a reevaluation of the design situation, because the decision making perspective informing these prototypes did not resonate with stakeholder experiences and was not perceived to serve patient and caregiver needs. The prototypes were developed with the intention of supporting decision making by improving communication of risk/benefit tradeoffs and real-life consequences of transplant, but in reflecting on the prototypes, stakeholders questioned their utility. Most notably, the questionable utility for patients and caregivers seemed closely tied to the fact that they did not treat transplant as a genuine decision they had to make. This realization called for a re-assessment of the early design process, how this misunderstanding arose, and how such misunderstandings might be better addressed with a design approach. To correct for this misalignment, the final study (Study 3) included participatory design

workshops specifically investigating the sensemaking processes that patients and caregivers employed during the period leading up to BMT.

Study 3 combined PD and sensemaking methodologies to engage participants in a creative activity in which they drew on visual and temporal cues to represent their lived experiences leading up to transplant and thus ultimately contributed to the development of innovations to improve the design process. Visual methods of data collection can be useful for capturing more abstract phenomena, like sensemaking, by making them more concrete (Cox et al., 2014). While Study 2 included tangible artifacts as points of reflection in pursuit of a more action-oriented, constructivist perspective, Study 3 was unique in that participants were asked to create the visuals rather than respond to visuals created by the designer. The method used in Study 3 tapped into sensemaking practices by borrowing from Dervin's (1983) Micro-Moment Time-Line interview, which was developed to explore the key elements of sensemaking methodology: *situations* (the time-space contexts), *gaps* (the questions people have/information needs) and *uses* (how people employ this newly created sense). Instead of directly asking about what information people would hypothetically need, as is customary in traditional in-depth interviews and focus groups, the Micro-Moment Time-Line interview allows people to talk about situations they were actually in (Cheuk, 2008). This is especially useful for a design process that values contextually appropriate, practical outputs.

The Micro-Moment Time-Line interview intends to identify the ways that people find meaning in situations where they experience gaps in understanding that prevent them from moving forward. During Micro-Moment Time-Line interviews, participants are asked to describe a specific experience (like the period leading up to BMT) step by step,

and at each step they describe the questions they had and what they needed to make sense of. Once participants identify the steps in the process they perceive as meaningful, they are asked to answer a series of questions about each of these points to further explicate that specific situation. In Study 3, the Micro-Moment Time-Line interview approach was integrated with the *path of expression* described by Sanders and Stappers (2016). The path of expression is a tool to explore past, present, and future experience. To engage this path, participants first describe their current experiences and reflect on particularly salient memories. In sharing these experiences, they form the basis for ideating around their aspirations for future experiences. The objectification of something as abstract as the pre-BMT process enables participants to reflect on their experiences in a way that supports imagining desirable futures and encourages ideation about improved support processes. The resulting redesigns from this process and the associated visuals are reflections of patient values and also have the potential to become real-life prototypes to be implemented and assessed in actual clinical consultations. The combination of questions from the Micro-Moment Time-Line interview with the creative visualization of PD prompted participants to reflect on the points in time when they most needed support in making sense of their experiences. Ultimately, this led to the creation of an external boundary object that became the focus of the discussion of possible improvements. Participants created an artifact that was used as a mutual reference point and thus provided an opportunity for clarification among the patients, caregivers, and designer. The methods used in Study 3 to better extract the problems patients and caregivers face can also be used to inform development of support tools for sensemaking in BMT and other medical contexts.

Study 3 stood in contrast to the first two in that, rather than UCD methods to investigate and facilitate decision making, it used PD methods to investigate and invent tools to support users' sensemaking leading up to BMT. Though each of the three studies resulted in overlapping themes and served to validate some elements of the problem definition that was guiding the design of the prototypes, their unique findings presented different opportunities for intervention. As will be discussed in Chapter 7, while the UCD methods pointed to solutions that better prepared patients and caregivers for outcomes they might experience in the future, the PD methods offered a more holistic view of the experience leading up to BMT and provided insights regarding how these challenges occur prior to actual transplant. Although these challenges have been comparatively neglected in clinic, they are, in fact, crucial to how patients and caregivers understand and experience the entire BMT process. In short, the evolution of this methodological approach was developed to explore the proposed theory of design for sensemaking support, particularly as it may be applicable to high-risk medical procedures rife with uncertainty. Table 4 describes how UCD and PD methods were operationalized using interviews, observations, and focus groups and how they serve the overall design process.

**Table 4***Overview of Design Activities and Associated Goals, Methods of Inquiry, and Products*

| <b>Study: Design Activity</b>           | <b>Goal</b>   | <b>Method of Inquiry</b>   | <b>Products</b>  |
|---|---|--|--|
| Study 1: Need-finding                   | Identify challenges and successes of BMT decision making as perceived by patients and providers | Semi-structured interviews with patients (n=7) and providers (n=8)<br>Observations of clinic and orientation class   | Stakeholder needs<br>Design hypotheses and rationale<br>Prototypes of potential system features      |
| Study 2: Prototype feedback             | Solicit feedback from stakeholders on perceived utility of low-fidelity prototypes              | Focus group with providers (n=7)<br>Interviews with patients (n=10) and caregivers (n=10)  | Indication of shortcomings in problem framing<br>Recommendations for potential system features       |
| Study 3: Participatory design workshops | Investigate the sensemaking processes of patients and caregivers leading up to transplant       | Pre-workshop sensitization exercise (survey)<br>Remote focus groups with patients (n=10) and caregivers (n=5) utilizing Micro-Moment Time-Line interview approach and PD toolkit | Multi-phase sensemaking process leading up to BMT<br>Recommendations for sensemaking support systems |

## **Case Study Context**

This research was performed at the BMT unit associated with the cancer center of a large academic medical center in the northeastern United States. Patients with hematologic malignancies visit the unit to receive infusions or to meet with providers. A variety of providers work with patients in this unit, including hematologists/oncologists, advanced practice nurses, transplant coordinators, registered nurses, and social workers. The clinical space includes a waiting room, exam rooms, a conference room, clinician offices, and a room with an open floor plan for patients to receive infusions. In-person orientation classes are held in conferences rooms/auditoriums at the cancer center.

In 2014, providers from the BMT unit approached researchers in the School of Communication and Information at Rutgers University to propose development of a decision support tool for patients considering BMT. These providers described instances of patients returning after transplant and claiming they had not been prepared for the consequences they experienced. This led providers to conclude that patients needed to be more engaged in the decision making and the informed consent process (as is described in more detail in Study 1, Chapter 4). The initial design idea presented to the research team described the potential for improvement in decision support procedures, as defined by the providers. They proposed the solution as a tool for “personalized clinical decision support” that would use individualized patient-specific data to predict personalized outcome likelihoods with BMT or with other treatments such as chemotherapy.

## **Ethics**

All research protocols were approved by the Rutgers IRB.



## **Participants and Recruitment**

Across the three studies, a total of 11 providers, 18 patients, and 11 caregivers participated in various capacities, with some of these participants taking part in multiple studies (see Appendix A for characteristics of participants identified by pseudonyms and their associated contributions). Because information that patients/caregivers had considered sufficient before transplant may later be perceived as inadequate once the consequences of transplant are experienced (Little et al., 2008), only patients/caregivers who had already experienced BMT (“veterans”) were included in these studies.

### ***Study 1***

Patients (n=7) and providers (n=8) participated in need-finding interviews. The providers were part of the BMT clinical team and included medical oncologists who specialize in BMT (n=3), a medical resident (n=1), a licensed social worker (n=1), and transplant coordinators (n=3). Transplant coordinators are specialized registered nurses who organize transplants. This organization process includes finding/testing donors, scheduling the BMT procedure and organizing and delivering the orientation class. Both the physicians and the transplant coordinators counsel patients on transplant decisions. Providers identified patients who were healthy enough to participate. After the patients were identified, the research team then reached out to these patients to see if they would be interested in being interviewed. Those who agreed to participate were contacted and asked to participate in an interview discussing their experiences with transplant.

### ***Study 2***

After the low-fidelity prototypes were designed, providers (n=7) at the BMT clinic were asked to participate in a focus group to provide feedback. These providers

then identified and recruited patients (n=10) whom they believed to be reflective on their transplant experiences and motivated to help improve processes for future patients.

Patients who participated in Study 1 were also recruited to give feedback on the prototypes.

All patients who agreed to participate were asked if they would like to invite their caregivers (n=10) to provide feedback as well. Because caregivers have significant responsibilities in caring for a patient receiving BMT, their unique perspectives are especially relevant. Also, interviews with dyads such as patients and caregivers can be especially useful when exploring issues that are hard for people to articulate (Ireland, 2003). Participants met with the researcher either at the clinic, in a user-testing lab, or in their own homes.

### ***Study 3***

Ten patients and 5 caregivers participated in remote PD workshops. Patients and caregivers who had previously participated in Studies 1 and/or 2 were contacted to participate in a remote PD workshop to discuss their experience leading up to transplant. New participants for the workshop were also recruited through the veteran patient panels present at the orientation class. As before, patients who expressed interest in participating were asked if they would like to invite their caregivers or any other household members although they were also able to participate alone. Caregivers or other household member participation can provide a safe context to simulate the participatory and collaborative environment of a traditional PD session and was encouraged to help patients recall elements of the experience. As the results from Studies 1 and 2 offered insight into providers' perspective of the problem and the results of Study 3 suggested that providers'

perspective was guiding development of the prototypes, providers were not included in Study 3.

## **Data Collection Procedures**

### ***Study 1***

**Need-finding interviews.** The need-finding phase consisted of semi-structured interviews with providers and patients, as well as observations of the clinic. Interviews were performed in 2015-2016 by three members of the research team. During these interviews, which lasted approximately 1 hour, providers were asked questions about 1) values, 2) communication challenges, 3) decision making, and 4) transplant decisions based on patient profiles. Patients were asked about 1) communication and information needs, 2) decision making, 3) challenges in the BMT experience, 4) successes in the BMT experience, and 5) needs and values. Interviews were recorded and professionally transcribed.

**Observations of Clinical Practice.** The transplant orientation class for patients and caregivers is held approximately once a month, lasts 3-4 hours, and includes 4-20 patients and caregivers in attendance. In 2017, four of these classes were observed. During the class, descriptive field notes were taken in order to document the nature and organization of the content as well as participants' questions and requests for clarifications. In addition, clinical documents including consent forms and educational materials (e.g., PowerPoint slides) presented in the mandatory education class were collected.

## *Study 2*

Based on the findings of Study 1, prototypes were developed to represent two primary features of the proposed system: a risk calculator and an archive of patient experience videos (described in more detail at the end of Chapter 4). The prototypes were then presented to patients, caregivers, and providers for feedback (see Appendix B for interview guide). Gathering feedback on the prototypes for this feature was intended to gain a better understanding of how patients/caregivers wanted to interact with the content and navigate the system to find the most relevant information. Feedback was obtained on 1) the relevance and meaning of the experience video concept, 2) the filters used to view particular videos reflecting specific kinds of content, and 3) the timeline feature. Of particular interest was users' feedback on the filters and timeline because these features were hypothesized to facilitate interactions that would serve the need to form more accurate expectations and a better understanding of the unpredictability of transplant complications.

The providers participated in a focus group in the BMT clinic's conference room in November 2017. During this focus group, providers were first presented with a PowerPoint with images of the general interface design including low-fidelity prototypes and various filtering options and asked for their feedback. Focus group questions targeted their preferences among different options and how/if they saw this tool as having utility for their current practices. As is described in Chapter 5, using providers' feedback, additional filtering options were added and ultimately shown to patients and caregivers.

The patient/caregiver interviews were collected in 2018 and lasted 1-2 hours. The interviews began by asking participants about their experience with BMT up until that

point and what they perceived to be key issues and challenges. Then, participants were shown paper print outs of the interfaces, with one option being introduced at a time. These prototypes included four different risk presentation sketches, the video archive interface design, and three options for filtering the videos, described in detail in Chapter 4. Interviews and focus groups were recorded and professionally transcribed. Patients and caregivers were compensated \$50 for their participation.

### ***Study 3***

Participation in this study included two parts: 1) a sensitization exercise (Sanders & Stappers, 2016) in which participants were asked to complete an exercise before the workshop to aid them in recalling relevant experiences and 2) a virtual participatory design session/workshop. Due to COVID-19, these workshops took place virtually. Patients and caregivers who agreed to participate were asked if they had a phone that was video chat enabled. Video chats were performed using encrypted video chat software (i.e. WhatsApp, FaceTime) and recorded and transcribed.

**Sensitization Exercise.** Sensitization exercises are intended to engage participants with their relevant memories and provide an opportunity to collect their stories and experiences that they find most important (Sanders & Stappers, 2016). In the week prior to the scheduled session, participants were sent a sensitization exercise in the form of an online Qualtrics survey of open-ended questions. Questions asked about their transplant experiences as well as demographic questions (see Appendix C). Participants were asked to send their responses to the researcher at least a day ahead of the session.

**Participatory Design Workshops.** Participants were mailed a “participation package” prior to their scheduled session which included a phone tripod, art supplies

(colored pencils, markers, etc.), a return envelope with pre-paid postage, and a PD toolkit. A toolkit is a way to facilitate non-designers' participation in the design process by giving them means to imagine and express their ideas (Sanders & Stappers, 2014). The toolkit (Appendix D) was developed using Sanders and Stappers (2016) methodology for developing Make toolkits. Make tools aim to uncover tacit and latent knowledge, allowing participants to better imagine the future through a deeper analysis of the past (p.75). The words and images in the toolkit are intended to trigger associations in the participant experiences of interest to the study. Triggers are designed to be ambiguous so that participants can interpret the trigger through the perspective of their own experience. When participants use a particular trigger, they then are asked to explain their reasoning, thus revealing more about their perspective and how they understand a particular experience. The steps to developing a toolkit (Sanders & Stappers, 2016, p. 163) are:

1. Write the instructions
2. Brainstorm a list of words
3. Look for visual material (based on list of words)
4. Review the trigger items all together (at once)
5. Fill in holes in the trigger set by testing it on one's own experiences related to the topic
6. Review the final set which should consist of 150-200 words/images

The method of a PD workshop was integrated with Dervin's (1983) Micro-Moment Time-Line method for investigating sensemaking. Toolkit development began with the creation of instructions based on the Micro-Moment Time-Line guidelines. As

described earlier, this interview technique asks participants to describe what happened in a given situation and the steps that they went through, targeting the three core elements of sensemaking: situations, gaps, and uses. Participants are asked to describe each step by answering questions that extract elements of their sensemaking, as described by Dervin and Frenette, (2003): “What questions arose at this step? What thoughts? What feelings? What emotions?” These elements are then triangulated in terms of the situation, gap, bridge, and outcome metaphor through questions like “Did you get an answer? How? Any barriers in the way? Did the answer help? Hinder? How?” (p. 241). The goal is to understand how the participant experienced this situation. In doing so, the recollections of past experiences are intended to both give insight into how participants were making sense of their pre-BMT experience and to inspire designs around potential future solutions, as per the path of expression (Sanders & Stappers, 2016).

The content of the toolkit was crafted to facilitate expression of sensemaking and of experiences related to BMT. As Sanders and Stappers (2016) recommend for developing a toolkit, a list of words related to transplant was created. These words originated in the themes uncovered in the interviews conducted in Studies 1 and 2. This included information needs, resources/information sources used, BMT specific language, and emotions that patients and caregivers had described. The actual contents of the toolkit reflecting these words were chosen with Sanders and Stappers’ (2016) requirements in mind: varied in content, abstraction, levels of ambiguity, and visual style, with positive, negative, and neutral stimuli. This ambiguity requires that the participant explain their interpretation of the content and why they chose to include it on their timeline, thus facilitating verbal expression of their sensemaking.

Images were found using free stock photo image sites. Search terms for images were based on the list of words created for the toolkit, as well as Dervin's (1983) *situation movement states*, a categorization scheme that focuses on how the participant seems themselves "as stopped or moving at a particular point in time" and *utilities*, which are categories to "evaluate outcomes in terms of how they facilitated movement through time and space" (Dervin & Frenette, 2003, p. 242). The choice to represent these words via photos rather than as words was an attempt to capitalize on the ambiguity of photos. By keeping the content of the toolkit ambiguous, participants have the opportunity to interpret the content from the perspective of their unique experience and can begin by choosing the items that most resonate with them. As it was not yet clear how participants would describe their situations or how they used information, using images in place of language allows for ambiguity and promoted a more varied interpretation of the triggers.

BMT specific words (i.e. GVHD, Relapse, Chemo) were included as words in the toolkit. This was done to inspire participant reflection on what these words meant to them and if they were more meaningful at any particular point in time. It was important to include emotion-based triggers because emotions are an element of creativity. Root-Bernstein and Root-Bernstein (2003) describe this process: "once a person feels the existence of a problem or a possibility, he or she must then work with attendant emotions and sensations to translate them, in an explicitly secondary step, into forms that can be communicated." (p. 377). Emotions are also considered a means of bridging gaps in sensemaking (Dervin & Frenette, 2003). Emotions were represented as words, as more complex emotions like "regret" were believed to be important in the reflection and ambiguous enough to promote individual participant interpretation, but difficult to



represent visually. Importantly, the toolkit was designed to evolve and participants were encouraged to use the art supplies included in the package to add any additional elements of their experience that were not represented in the toolkit. Details of how the toolkit evolved based on participant feedback are described in Chapter 6.

To test the toolkit, I created narrative summaries of the period leading up to transplant as described in interviews in Studies 1 and 2. Then I attempted to use the toolkit to create a visual of these narratives, identifying missing elements and including them in the toolkit. Participants were instructed to use the toolkit along with the art supplies to visually represent the timeline of the significant moments leading up to BMT. First, they were asked to describe the series of significant 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 technique to capture sensemaking practices developed by Dervin, and Weick’s sensemaking theory as it relates to expectation development (see Appendix E for interview guide).

After completing the visual of what they actually experienced in the time leading up to the transplant “decision,” participants were then asked to overlay a sheet of transparency film over the timeline and instructed to identify areas that could have been improved, for example if they had had a question that went unanswered or had been frustrated with part of the process. The use of transparency paper is a method in PD for participants to add or modify ideas without destroying the original content (Walsh et al., 2011). Participants were prompted with questions to aid them in ideating around how they could have been better supported, for example “What did you not know that you

wish you had?” or “What might have helped you during this event?” To account for successes and not just shortcomings of the process, participants were also asked “What was especially helpful to you?” They were asked to expand on their proposed solutions and explain how they would be helpful. These sessions were recorded and professionally transcribed. Participants used the included envelope to mail back their timelines, transparencies, and anything else that they wrote on. Timeline drawings and any other returned content were scanned both with and without the transparency. Participants were compensated \$50 for their participation. Additionally, memos were recorded during the sessions documenting elements of the design process or participant comments on the process that were memorable or indicated a need for change in the process before the next workshop. Only 1-2 toolkits were mailed out at a time (depending on how soon the meeting was scheduled) so that the toolkit could be revised if needed before another participant received it.

## **Data Analysis**

### ***Study 1***

Transcripts of the interviews were imported into NVivo and segments were analyzed using thematic analysis, as this is a useful method for applied problems such as those in health research (Braun & Clarke, 2014). After reading through all transcripts, the research team engaged in “analysis on the wall,” a method in design research to handle “messy” data in preparation for more rigorous, computer-based coding processes (Sanders & Stappers, 2016, p. 212). This type of analysis involves the research team members writing memorable segments of data on small note cards or post its, placing them on a wall, and working together to iteratively maneuver the cards into meaningful

categories. Notes were taken during this first analysis before in-depth analysis in NVivo was started.

Provider transcripts were first coded inductively for themes related to the decision making process, then iteratively read to identify emergent themes regarding the type of challenges discussed. This led to coding categories concerning the challenges within the institutional processes of informing patients (particularly those related to informed consent and the education class like information overload and excessive negativity), the perceived difficulties of supporting patient decision making (e.g. complexity of risk information, unpredictability of outcomes, quantity of outcomes), and what providers perceive as successful patient support through this process (e.g. veteran patient panel, informing patients). Patient-related coding categories described their perceptions of their decision making processes, as well as reflections on how they were prepared/educated prior to transplant and their actual transplant experiences. While iteratively coding the transcripts, patterns seen in the data were coded by common themes with particular emphasis on challenges to collaboration in decision making. Examples of provider themes include *risk presentation*, *decision regret*, and *unpredictability*. Patient themes included *unknowns*, *timeline*, and *experiential information*. These codes were visualized in a mind map, a method for data analysis commonly used in design research to identify most salient themes and the relationships between them (J. Chen, 2008). Members of the research team produced analytic memos reflecting on the common themes observed in these data which were discussed amongst the team. From this analysis and these discussions, a set of unmet needs to be addressed in the system design were identified. In

addition, the research team regularly discussed and refined design requirements and early sketches of potential interface designs.

### ***Study 2***

Transcripts of the patient/caregiver prototype feedback sessions and the provider focus group were analyzed using applied thematic analysis (Guest, MacQueen, & Namey, 2014). Transcripts were first read and segments tagged according to the feature of the system being discussed (i.e. pie charts, filters). Then, the segments describing features were tagged for participant feedback. These feedback segments were coded for the *technological frame*, defined as the frames (guidelines that shape interpretation/meaning) that concern the assumptions and expectations that people use to understand technology, which also includes the “conditions, applications, and consequences of that technology in particular contexts of use” (Orlikowski & Gash, 1993, p. 178). Hence, segments were also tagged for instances of participants hypothesizing uses of these tools for decision making. These segments were then reread to identify emergent themes in perceived utility.

### ***Study 3***

Transcripts and participant timeline drawings were scanned and imported into NVivo. Handwritten notes on participant timelines were converted to text and images were labeled with descriptive words based on the content of the image (e.g., in Appendix D, the first image in Figure D4 was labeled “hospital room”). 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, conversations that occurred while receiving treatment, or the

orientation class). Within each event category, transcripts and timelines were tagged for descriptions of emotions, questions that participants had during a specific event, and the cues they extracted from the situation that led them to ask these questions, feel these emotions, or form expectations around transplant. Questions were first assessed in terms of the gaps specific to the context of BMT and so were coded using a descriptive focus (Dervin, 1983). The major categories of patient questions were: outcomes (including survival and quality of life), next steps, timing, donor, and the in vivo code “why would anybody go through this?” 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 class). These codes were then condensed into the broader categories of design for information, design for interaction, or design for communication. Solutions were then categorized using in vivo codes that described participants’ intended outcomes, or how they would feel if they had the proposed interventions (e.g., better prepared, more confident, put it in perspective). These codes were iteratively reviewed to combine similar codes and explore the participants’ values underlying the solutions proposed and potential for improved sensemaking support to reach these outcomes.

**Reflection on the Design Process**

Throughout this process, I recorded memos of what I perceived to be significant events in the evolution of the design process itself including instances of participants appropriating the materials in surprising or innovative ways. I also used memos to make suggestions for the research procedures. In line with the principles proposed by the theory of design for sensemaking support, following the completion of Study 3, the design process, its evolution, and the benefits and shortcomings of the different methods used were reflected on. These reflections and the implications for the refinement of the proposed theory are discussed in Chapter 7.

## CHAPTER 4: Need-finding Interviews

This chapter describes the rationale behind the first set of prototypes developed using user-centered design (UCD), which begins with user research as part of the definition of the problem and the design situation. Schön and Wiggins (1992) describe design as a reflective conversation with the situation. The designer *sees, moves, and sees again* (Schön, 1992) – first, they *see* what is present in the design site (i.e. the challenges of BMT “decision making”), constructing meaning in the patterns they identify, then *move* by attempting to solve this problem (i.e. the prototypes of the risk calculator and experience video archive) before *seeing again*, evaluating the results and consequences of the move. This process enables designers to manage complexity, as addressing all of the elements of a domain in the first attempt at a solution is not only impossible, but overwhelming. Design is thus a conversation in which “the second 'seeing' involves recognition of unintended as well as intended consequences, and where unintended consequences fall into domains other than those in which the problem and its prospective solution are initially formulated” (p. 143). Below, I present the results of a need-finding interview study intended to document the perceived challenges and successes of the current decision-making process for BMT, as patients and providers understand them – the first seeing. These needs informed the design of the first round of prototypes, which can be considered the *move*. The need-finding process described below was intended to create something that could then be refined, enabling this reflective conversation, or the second *seeing*. In Chapter 5, the consequences of this first move are then explored and the conceptualization of the design situation is revisited.

The design process being developed in this dissertation is intended to lead to a solution that meets the needs of multiple stakeholders. In the case of complicated medical situations such as BMT, patients and providers must collaborate to determine the best treatment based on clinical factors and patient preferences. For this reason, understanding BMT decision making from the perspective of both patient and provider needs was deemed critical in the early stages of the design process. The project was initially brought to the research team by the providers, who presented the problem as one of informed decision making and were looking for help in developing a decision support tool. In the results that follow, it will become clear that the needs of patients and providers are not only different, but each is independently complex. Ultimately, exploring these needs in greater depth through the prototype feedback sessions in Study 2 challenged this initial framing of “decision support.”

In these need-finding interviews, providers saw their goal as achieving/facilitating informed decision making. They described barriers related to communicating information about the risks of morbidity/mortality, and effectively communicating the reality of life after transplant. They face the difficult and seemingly unresolvable challenge of ensuring that patients receive all relevant information about possible complications they might experience to present a realistic image of transplant, while trying not to overwhelm patients or induce anxiety. Yet, when providers err on the side of caution and present an abundance of information about possible complications, they still report patients later returning to them after transplant, claiming they never knew the complications they experienced were a possibility. Patients confirmed this challenge, describing a similar problem of retrospectively recognizing that they had not adequately understood the



consequences of transplant. But instead of describing a need for all of the information necessary for decision making, patients instead emphasized the need to develop accurate expectations in pursuit of being prepared for the outcomes they ultimately experience. Patient perceived challenges centered on the difficulties of understanding the nonlinear timeline of recovery and adapting to the unpredictability of transplant complications, but did not express feelings of regret.

Importantly, the BMT clinic developed a solution to address provider perceived challenges of achieving informed decision making by implementing a mandatory education class for patients considering BMT. However, as this study demonstrates, such a complex problem cannot be and has not been sufficiently solved by designing a solution aiming to provide patients with more and better information alone. Rather, an adequate solution must consider how to present meaningful information in a format that supports patients in accurately assessing the risks that they face when choosing transplant. As will become clear in Studies 1 and 2, this particular challenge of BMT suggests that a modified design approach that incorporates sensemaking support is appropriate.

The perceived needs identified in Study 1 were then translated into prototypical design solutions that are described, along with the design rationale, at the end of this chapter. These prototypes were then presented to stakeholders in Study 2, as is typical of a UCD approach. The iterative nature of this process and the continued refinement of both the understanding of the design situation and the prototypes themselves will be described in Chapters 5 and 6. Below, I describe the needs uncovered in these early interviews and how patients and providers made sense of the problems and existing solutions. The discussion of this chapter offers reflection on the design process used, and

a more in-depth discussion on the utility of UCD methods for allowing sensemaking to emerge is presented in Chapter 7.

### **How Providers Define the Problem**

Providers initially approached the research team presenting the problem as one of “decisional regret.” They described a common experience of having patients return after receiving a transplant, claiming that they had not been informed of the complications that they experienced. This was frustrating for providers because they knew that patients *had* been given this information as part of the informed consent process and patient education procedures. In interviews, providers described a complex problem, communicating seemingly contradictory values: 1) they want to present risk information that is *thorough*, but at the same time do not want to present more information than is *manageable* and thus risk overwhelming patients, and 2) they want to present a *realistic* representation of possible transplant outcomes, but also want to remain *optimistic*. To avoid this perceived decisional regret, providers identified that the most appropriate solution was to provide thorough and realistic communication; however, this communicative solution to the problem of decisional regret came with consequences: If they attempted to avoid decision regret by being thorough and realistic, they risked overwhelming patients with too much negative information.

### **Perceived Decisional Regret**

Providers often referred to the current practices of decision support, including informed consent, when describing the challenges they face and the failures of the current system to support informed decision making. Informed consent is an ethical requirement and is intended to ensure that a patient understands and accepts the risks that come with

their decision. However, as the providers clearly expressed, signing consent forms does not necessarily mean that patients fully understand the risks that they are accepting.

Vivienne, a transplant coordinator, describes the consequences of this in her recollection of a memorable interaction with a patient:

Six months after [transplant, the patient] relapsed, and she started accusing me of not explaining anything about the transplant, that the possibility that the disease could come back, that I never told her any of that stuff. She said it was never in the consent forms that she could possibly relapse, none of that. And it took everything... all the power in my body not to go back and grab the consent form and show her you signed here on the dotted line. By you signing here means that you've read everything and that you've heard everything that was said in the class.

Here, Vivienne describes a sort of “buyer’s remorse” from a patient who claimed to have not received risk information that was communicated in the consent form and in the orientation class that all patients are required to attend before receiving transplant. Her stated desire to rely on the patient’s signature as evidence of their receipt of information highlights the perceived value of information-centric solutions often perpetuated by the informed consent process. At the same time, because providers report regularly experiencing patients claiming to not have been adequately informed after signing consents, they also recognize that the informed consent process as it currently exists is flawed. By focusing on the informed consent process as the origin of this failure and relying on informed consent and the education class as the primary tools to ensure patients fully understand the risks and benefits of transplant, providers are continuing to

apply an information-exchange framework despite their recognition that this framework is not actually leading to the intended outcomes of informed consent. This suggests a need for an approach to developing patient support that does not focus exclusively on information-exchange but instead aims to support patients in better understanding the consequences of their decisions.

Below, I present providers' views on transplant information that they perceive to be most difficult to communicate effectively: *mortality risk*, *morbidity risk*, and *the reality of life after transplant*. These communication concerns are marked by the seemingly irreconcilable challenges of presenting information that is both thorough and manageable and that is both realistic and positive.

### **Communicating Mortality Risk**

While transplant offers the only option for a potential cure for patients, it is especially important for patients to fully understand the risks that they are subjecting themselves to because this potential cure comes with a high risk of mortality. Providers emphasized the struggle to adequately communicate that transplant may offer a cure but might unexpectedly lead to deadly complications. Patients may die from transplant-related complications and they theoretically might have survived longer if they had not received transplant. For instance, David, a medical oncologist, called it a "bad bet:"

What's hard to relay is for some people, the chance that they will die as a consequence of transplant when they could've survived without a transplant—that they made a bad bet. And there's no way to say they would've survived. There's no way to say they would've survived. But they could've.

Tension exists between presenting the realistic possibility that the transplant might lead to death sooner than if the patient had opted out of transplant while still allowing patients to maintain hope at the possibility of a cure. Along with the challenges of unpredictability, discussions of mortality risk were a challenge recognized by the providers because, as transplant coordinator Danielle put it, “there's no soft way to say you can die.”

Second, because death could result from complications of a procedure that is offered to patients as a potential cure, there is an added level of responsibility for providers. In some cases, it is not the disease that kills the patients, but a procedure potentially advocated for and performed by the providers. Thus, providers find it critically important that patients have a realistic understanding of the possibly deadly outcomes of transplant. Providers recognized the inadequacy of current pre-transplant practices in communicating the potential for mortality, and without the patient being fully informed and being able to participate in the decision making, the responsibility falls solely on the provider. In the case that the decision leads to a patient's early death, the burden on providers is immense. Thus, providers feel it is especially important for patients to understand the potential for mortality that comes with such a high-risk treatment.

### **Communicating Morbidity Risk**

Although the potentially life-changing outcomes of transplant are unpredictable, they are still realistic possibilities that patients might experience. Accordingly, providers described a professional obligation to inform patients of all of the relevant risks that they might encounter. At the same time, providers recognized that if they cover *all* of the risks, the situation is likely to seem excessively negative and may incite anxiety in

patients during a time when patients require support and want optimism (Kim, Mikesell, Fadem, & Aakhus, 2019). Providers experience a tension when trying to ensure that patients have been adequately prepared for the outcomes they end up experiencing without presenting so much information that it becomes overwhelming. Frank, a medical oncologist, described this challenge:

I will say that there are patients who are almost accusatory when something happens, like, “How did this happen? I didn’t know this was going to happen.” Well, you know, I can’t tell you every possible complication otherwise that’s all we’d be talking about. There’s like a million things that can go wrong. How do we pick and choose?

Providers articulated the need to prioritize some risks over others because if they were to communicate all of the possible complications, knowing that patients will likely not experience every single one, they risk creating unnecessary anxiety. However, because they cannot know which outcomes are relevant for particular patients in advance, they risk under informing patients, potentially leaving these patients unprepared for the risks they ultimately experience. As John, a medical oncologist, describes, the possibility of inducing anxiety in patients threatened his ability to connect and develop trust with his patients:

[The risks are] the last thing you want to talk about, you know, for the patient and for the doctor, you know? It would reduce that sort of bond that you have with the patient, you know? Because you're coming to see a doctor to be better.

If providers communicate all of the possible complications, they risk inciting anxiety in patients and creating information overload, resulting in poor understanding and possibly

negatively impacting the patient-provider relationship. However, there is a concern among providers that if they do *not* provide all of the information about possible complications, patients are more likely to experience decisional regret because they made a high-risk decision without all the available outcome information. As detailed below, the organizational solution that was implemented into clinic practice reflected the clinic priority to avoid underinformed patients. Although this solution was information rich, patients still struggled to apply this information meaningfully, and providers continued to observe patients struggle to form accurate expectations about post-transplant experiences before they experienced it first-hand.

### **Communicating the lived reality of BMT**

Because patients likely have never had an experience like transplant before, providers described challenges regarding how to effectively communicate the risks of transplant to facilitate patients' understanding so that they can imagine how it might practically impact their lives. Particularly, a few providers described difficulties discussing graft-versus-host disease (GVHD), which is a common and potentially life-threatening complication that can manifest in almost any part of the body and presents unpredictably. It is critical that patients know the risk of GVHD because it is potentially disabling or deadly. It is also a complication that is unique to transplant, and thus is probably a new concept unlike anything patients have encountered before. The following quote from Frank explained what he believed to be behind the challenges of communicating the unfamiliar experiences of GVHD with patients:

I think that concept [GVHD] is difficult because it's so foreign compared to anything they can relate to... Nobody's ever experienced tight skin. [Patients] have

no idea what it means. And then all of a sudden, they'll come and say one day, "You know, I don't feel like I have enough skin for my body." And I'll say, "What do you mean?" "Well, I just, when I try to go like this, I can't do it anymore. I know I used to be able to turn in my chair and I can't do it. I can't raise my arm above my head." And so, there's one thing to say that you might develop tight skin, the patient shakes their head, they understand what you meant, but they had no idea what you meant until they developed it.

The current pre-BMT patient education practices describe the potential manifestations of GVHD, often using labels like “tight skin” that are unlikely to reflect patients’ actual GVHD experiences. A resulting and important challenge is that although patients may indicate and believe that they understand they might be at risk for developing a particular complication like “tight skin,” when they actually experience such a complication, they are often unable to recognize it as the GVHD they had been warned about. Part of the reason that GVHD complications are disconnected from patient experiences is that patients do not often frame their lived experiences in the language used in the clinic and informed consents, but instead perceive and describe the complications they face in terms of the impact on their lived experiences. This is especially important because patients are expected to notify providers of any physiological changes that could possibly be the beginnings of GVHD, a difficult task if they do not understand what they are experiencing to be a symptom they had been warned about. Further, and of relevance to the providers’ problem of perceived decision regret, if patients are unable to understand that what they are experiencing is what they were warned about, they may believe that they had not actually been warned at all.



Providers recognize that patients pre-transplant cannot fully understand what life might look like after transplant before they go through it, and the life-changing complications may not be properly conceptualized by patients before they actually experience it themselves. As Sharon, a licensed social worker, put it, “no matter what we say, there is this just lack of understanding until you go through it.” This manifests itself when patients experience what providers perceive as decision regret, when patients pre-transplant react to the information as excessively negative and discouraging, and post-transplant express surprise and unpreparedness at what they do ultimately experience. The providers have consequently attempted to develop solutions based on their understanding of the problem as being one of information delivery and thus, the main solution that they developed (the orientation class) takes the approach of designing for information. However, in looking at the challenges of communicating complex risks and in understanding the realities of life after transplant, it becomes clear that the problem is not necessarily the information delivery but the ability of patients to understand and apply the information that they receive. This need to present patients with information in a way that they would be better able to use it to imagine the outcomes of transplant was a key element of the design rationale for the prototypes, described in more detail at the end of this chapter.

The following section describes the patient perspective on the challenges of understanding transplant and offers some insight into how a support tool might serve their interests as well.

### **How Patients Define the Problem**

Reflecting providers' concerns, patients also expressed being inadequately informed about potential complications. However, they described the nature of this problem and its potential causes differently than providers. Whereas providers described the problem as one of informed decision making, patients perceived being inadequately informed in terms of their expectations for transplant and recovery. Accordingly, providers perceived the success or failure of the transplant decision making process in terms of a patient claiming they had not made an informed decision, while patients perceived success/failure in terms of how closely their transplant expectations aligned with their actual experiences. Importantly, patients did not describe experiencing regret about the decision to undergo transplant, but instead wanted better tools to manage their expectations and be better prepared for the ever-changing experiences.

### **Understanding Mortality Risk**

Although providers believed that communicating mortality risk was essential for patients to make an informed decision, patients rarely described mortality outcomes of transplant as part of their decision making process. The few patients who did discuss the possibility of dying from transplant complications notably did not emphasize this information as particularly valuable for decision making, because many understood transplant as a requirement for survival. For example, Edwin explained his experience when it came to mortality risk, saying "that thought never really crossed [my mind] because oh, I need to get the bone marrow transplant." Whether patients were in denial about the deadly outcomes of transplant or whether they viewed transplant as their only hope, transplant-related mortality was not often recalled as a significant factor in their

decision making. Thus, how patients valued mortality risks conflicts with providers' attempts to emphasize mortality risk as important to decision making.

### **Understanding Morbidity Risk**

Patients, like providers, recognized how difficult it was to communicate the unpredictability of transplant complications; however, patients did not find that providers ineffectively communicated the unpredictability of outcomes. Patients indicated that they were able to recognize the unpredictable nature of transplant outcomes. The challenge patients faced, nevertheless, stemmed from this uncertainty. For patients, the primary challenge was how to form expectations about what recovery might look like and how to navigate and evaluate their recovery amidst the nonlinear recovery timeline. Because patients might develop new complications years after transplant, they struggled to determine where they were in the recovery timeline and when they might return to normal. Patients expressed surprise at what Gail called the “roller coaster ride” of recovery, the surprises of when and how they experienced new complications in a nonlinear recovery timeline, and how that limited their ability to successfully adapt to their new circumstances. In the following quote, George recognizes that the providers did explain that they could not predetermine what complications each patient would experience, but how he continued to struggle with the nonlinear progression of recovery:

These [complications] are sort of surprising because you don't know when they're going to come up, and [the providers] tell you about, oh, you might have this, you might have that in the PowerPoint presentation, but I felt like, well, if I'm a year out then I'm probably fine, and then a year and six months later something comes up or whatever... We all think of it like a disease is you just get better or you don't

get better. But this is like you get better, but you're not ever really totally better, but hopefully you are better. And every day who knows what's going tomorrow's going to bring. It is a difficult thing to articulate to someone as opposed to sort of a regular type of a break a bone, the bone heals and you go back to normal. It's not like that.

This quote parallels two issues brought up by providers about the nonlinear nature of transplant recovery: the variety of possible complications and the unpredictability with which they can become problems. Yet, to patients, the problem is not about a lack of complete information about all of the possible risks and their unpredictability. Patients may be aware of the possible risks of transplant, but they expect to get better as time passes and instead must cope with the ups and downs of recovery.

### **Understanding Life After Transplant**

Patients recognized that it may be impossible for providers to realistically communicate the effects of transplant complications in a way that helps patients form accurate expectations. For example, one patient, Stephen, described his experience in coping with unexpected outcomes. After expressing that he had not expected to be as debilitated as he ultimately was post-transplant, he was asked if he could have been better prepared for the complications he experienced. In response, he remarked that having been told would likely not have made much of a difference:

I don't think I would've believed them. I don't think I would've thought that I'd take a shower and I didn't have the strength to dry myself off. I needed to go fall down in the bed. You're going to be weak after, you know (laughs)... They do the

‘you’re going to be tired and debilitated.’ That doesn’t say it... Masterfully understated.

As in the quote from provider Frank above, Stephen suggests that the way that transplant complications are being described does not effectively communicate the lived experience of these complications. This prevents patients from matching their experiences to the expectations developed during pre-BMT education.

Patients described the same phenomena as providers, similarly recognizing the inadequacy of patient expectations prior to transplant. However, patients are not understanding decision regret as the providers do, as no patient that was interviewed said that they actively regretted or had not consented to getting transplant. Instead, patients expressed feeling unprepared *in spite* of being informed about possible complications. This lack of preparedness is not attributed to a lack of information; if anything, patients feel as though they received an overwhelming amount of information prior to transplant. Rather, they perceive the challenge to be an inability to use this information to imagine the reality of BMT in a way that reflected their actual experience.

### **Organizational Solution**

To address the perceived challenges of communicating risk and improve informed decision making, providers designed and continually refined a solution to the problem as they understood it. They developed a mandatory orientation class required of all patients and a caregiver to learn about the process and risks of BMT. The orientation class lasts approximately three hours and includes a detailed explanation of the biomedical aspects of BMT, a description of the process and what patients and families need to do to prepare for it, and an overview of the immediate and long-term consequences of transplant.

Patients are required to bring at least one caregiver to the class with them, as some of the content focuses on preparing caregivers for their new responsibilities. Approximately two thirds of the class is didactic, consisting of prepared presentations from the providers, with the last third consisting of a panel of the veteran patients that is intended to provide real world experiences from people who have actually been through transplant. A significant portion of this time is spent describing the various manifestations of GVHD. The last portion of the orientation is the panel of veteran patients. Because every patient and their caregiver are required to attend this class, it offers a standardized representation of how patients and caregivers are educated prior to making the BMT decision. Despite this effort to standardize the information presented to patients/caregivers, even patients who take the class express surprise when they experience a complication, which points to the inadequacies of this information-centric solution. The following sections detail provider and patient perspectives of the class.

### **Provider Perceptions of the Class**

Although providers designed the orientation class to resolve the challenge of patients claiming to have been ill-prepared for their transplant experiences, they also recognized that even this hours-long course was not an adequate resolution. They described instances of patients who had attended the class to still claim to have been unprepared for the complications they ultimately experienced. Providers made sense of the class's shortcomings by describing both the quantity and content of information as potentially overwhelming and by describing patients as plagued by challenges of retention.

Because the class exposes patients to significant amount of novel information about numerous possible complications, ranging from mild inconveniences to life-threatening side effects, providers recognized the class to be potentially “paralyzing” and “overwhelming” for patients. In the following example, Sharon describes a specific interaction with a patient that represents the complexity of these issues well. She recognizes that the patient had received risk information that the patient perceived in the moment as excessively negative. Nevertheless, she reports how the patient was later unable to adequately draw on this information to make sense of their post-transplant challenges. Sharon recognizes that informing patients about negative outcomes is an ethical requirement but is also aware that patients may not be able to effectively use this information when it is needed:

I had a patient call me 20 minutes after she left the class... those were [the patient’s] words, “it was all negative.” So I said to her, “This is going to be harder than you can even really imagine, and we can’t in good conscience give someone a transplant and have them look back and say, ‘You didn’t tell me it was going to be this hard.’” And then, I kid you not, I went to visit this woman in the hospital while she was having her transplant, and she said, “Nobody told me it was going to be this bad.” So we have a struggle... the class probably is a little more on the negative, scary side, and sometimes that’s still not enough.

The orientation was designed to systematically inform all patients about the variety of risks that they might experience to avoid later claims from patients that they had not been uninformed. To providers, the risk of not providing all of the information to patients was greater than the potential for the orientation class to be a negative and possibly

discouraging experience. Even though providers recognized that this solution is not entirely effective at preventing patients' claims of having been uninformed, they struggle to recognize that its ineffectiveness stems from implementing a solution that prioritizes the provision of information rather than supporting patient understanding of that information.

### **Patient Perceptions of the Class**

Patients described concerns about the institutionalized practices of BMT education and decision making, the orientation class and the informed consent forms. While patients often saw the necessity of receiving this information, they also shared the providers' views of the information presented in the orientation class as excessively negative. They described the clinical information presented in the orientation class as overwhelming, referring to it as "dreadful," "a long day" and "a blur of horrible things that we could experience." The struggles that patients described reflected providers' concerns including the quantity of novel information and the lack of time to absorb it.

Patients appreciated hearing from the veteran patient panel as part of the class. They cited the ability to hear about the real-world impacts of transplant and the hope and optimism that came with seeing someone who was still alive post-transplant. Renee described her response to seeing veteran patients, saying "it gave me hope because if you're brave enough to do it, it can work out." While the clinical portion of the orientation exposed patients to the many possible negative outcomes, seeing other patients who had survived transplant despite so many potential negative outcomes instilled optimism for their own future. Still, this did not seem to prepare them effectively for the actual experience of the nonlinear recovery.



These need-finding interviews revealed significant shortcomings in the current patient support practices. The nature of transplant is extremely difficult for providers to translate into terms that effectively communicate the actual risk a patient is taking on and what everyday life might look like for an individual patient who decides to go through with the procedure. Patients only realize after they have been through transplant that their expectations were inaccurate, and they continuously struggle to evaluate their recovery progress. The current institutional solution, the orientation class, has proven insufficient as patients continue to return to providers and claim that they are unprepared despite having been exposed to a considerable amount of risk information. While informative, patients and providers perceive the orientation class to have too much information and be overly negative. This feedback seems to indicate that a solution designed for information delivery has not solved the issue of patients feeling unprepared. With this in mind, a design approach ensuring that the information provided is meaningful, memorable, and useful—that supports patients’ sensemaking—would be better suited to solving the problems patients and providers are facing.

### **Design Rationale**

The needs of patients and providers described above are summarized in Table 5. These needs inspired a number of potential design solutions, and through an iterative design process, design hypotheses were developed and are explored in Chapter 5. These hypotheses were tested by creating low fidelity prototypes of potential features of the system, which were then presented to providers, patients, and caregivers for feedback. These proposed solutions centered on two system features: a risk calculator and an archive of experience videos. The personalized risk calculator was designed to address

the providers' need to inform patients of possible outcomes before patients make the decision. To reflect the needs described by patients, which put less emphasis on accurate risk information and more on understanding and preparing for the real life impacts of transplant, the second proposed feature of the system was an archive of patient experience videos that patients could filter according to their perceived needs.

**Table 5**  
*Results of Need-Finding Interviews and Design Rationale*

| Need   | Design Hypothesis  | Feature in system  |
|--|--|--|
| <b>Optimistic:</b> Maintain hope for a cure  | Ambiguity in statistical output will allow patients to avoid negative statistics if desired  | Including various levels of abstraction for outputs (e.g. pie charts and scales)                               |
| <b>Realistic:</b> Communicating mortality; Make clear the risk of death from transplant vs. disease                | Including statistical likelihoods for survival with and without transplant will emphasize mortality of transplant  | Outcome statistics   |
| <b>Realistic:</b> Communicating morbidity; Present the many possible risks of BMT that could affect QoL            | Including variety of different experiences in patient videos will cover most common side effects   | Experience videos featuring patients speaking about practical consequences; filters for specific complications |
| <b>Holistic:</b> Communicating/Understanding the lived reality of BMT; Form expectations for life after transplant | Other patient/caregiver stories will help people making the decision to imagine their possible futures   | Videos of people who have been through transplant  |
| <b>Progressive:</b> Understand the nonlinear recovery timeline   | Being able to see other people's experiences at different points in transplant recovery will enable patients/caregivers to see the ups and downs of recovery | Timeline filter/nodes  |
| <b>Manageable:</b> Avoid overwhelming patients/caregivers  | Having access to this information after the orientation will allow participants to go at their own pace and review information                               | Access at home   |
| <b>Personal:</b> Determine what information is relevant  | Giving users the option to filter through videos will aid their navigation of the system and help determine most relevant content                            | Filters for disease/psychosocial characteristics   |

The development of two prototypes that serve distinct stakeholder interests can be used as a method to investigate the different, and potentially conflicting, needs described by the stakeholders. This is what Mogensen (1994) refers to as *provotypes* which are prototypes designed to provoke problems and “call forth and challenge what is usually taken for granted” (p. 113) to trigger discussions on current practices. Creating physical representations intended to serve the stakeholders’ independent needs (the risk calculator for providers and the experience videos for patients) serves the inclusivity principle of the theory of design for sensemaking support. This creates an opportunity to comment on the perceived needs of the other and for the groups to clarify the needs as understood by the designers.

### **Risk Calculator**

In an effort to provide the most complete and accurate information available, the providers developed an algorithm that offers patients more precise and personalized risk calculations for likelihoods of treatment outcomes. As such, patients would not be bombarded with risk information that is less likely to apply to them. However, how the algorithm outputs this information, how patients can interact with this content, and how patient-provider interactions scaffold the output were not yet determined. Thus, our first task was to design the algorithm output to present realistic, personalized, and understandable risk information, in an effort to support providers’ need to better communicate morbidity and mortality risk. We hypothesized that visualizing the potential for transplant-related mortality alongside the survival potential would provide patients a more accurate understanding of the potential for transplant to prematurely end their lives. To do this, we created low fidelity prototype sketches of potential visuals for representing

the statistical outputs of this algorithm with numbers presented with various levels of abstraction.

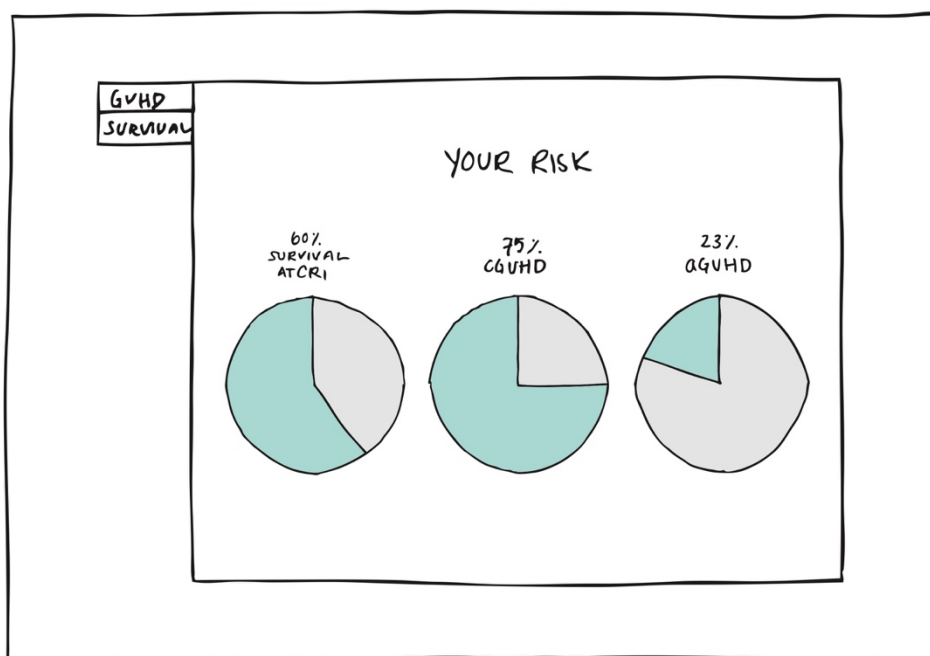
### ***Algorithm***

The algorithm uses data from various clinical resources including meta-analyses and government sponsored outcomes research. It presents four survival-based outcomes (non-relapse mortality, disease-free survival, death after relapse, survival after relapse) and two outcomes related to GVHD (severe acute GVHD and chronic GVHD that requires systemic therapy). This algorithm uses patient, disease, and donor characteristics to make these projections with and without transplant. Survival projections are presented as a percentage likelihood at 3 years. GVHD outcomes are presented as mean incidences of these outcomes along with the modifier “lesser, similar, or greater risk” based on the patient’s specific clinical data in relation to the population data.

### ***Format***

The risk calculator prototyping process began by exploring various options for presenting numerical risk information. Ultimately, we settled on four different options for displaying the outputs of the algorithm (Figures 1–4). We included 4 different options for risk presentation of various abstraction to explore how to best resolve the tension between being realistic and being overly negative. Two of these options, the pie charts and natural frequencies present *probability statements*, while the two scales present *possibility statements* (Zikmund-Fisher, 2013). The statistical outputs in the pie chart and natural frequencies are considered probability statements in that they include quantitative/numerical information, while the scales are possibility statements, communicating risk in a nonnumeric way. By presenting options with outcomes as either

probability or possibility, we hoped to allow those participants who valued optimism the opportunity to maintain it, even in the face of potentially upsetting numbers. We expected that patients who described a desire for hope and optimism would prefer the more abstract variations of the risk calculator that would leave more to interpretation rather than providing an explicit percentage.



*Figure 1.* Prototype of the risk calculator output using pie charts.

**Pie Charts** (Figure 1). Pie charts use area to represent probability (Spiegelhalter, Pearson, & Short, 2011). This type of visual is especially useful for understanding proportional relationships (Lipkus, 2007). Inclusion of this type of visual was largely based on the suggestion of the providers who developed the algorithm, as they believed this to be the simplest way to present these outcomes.

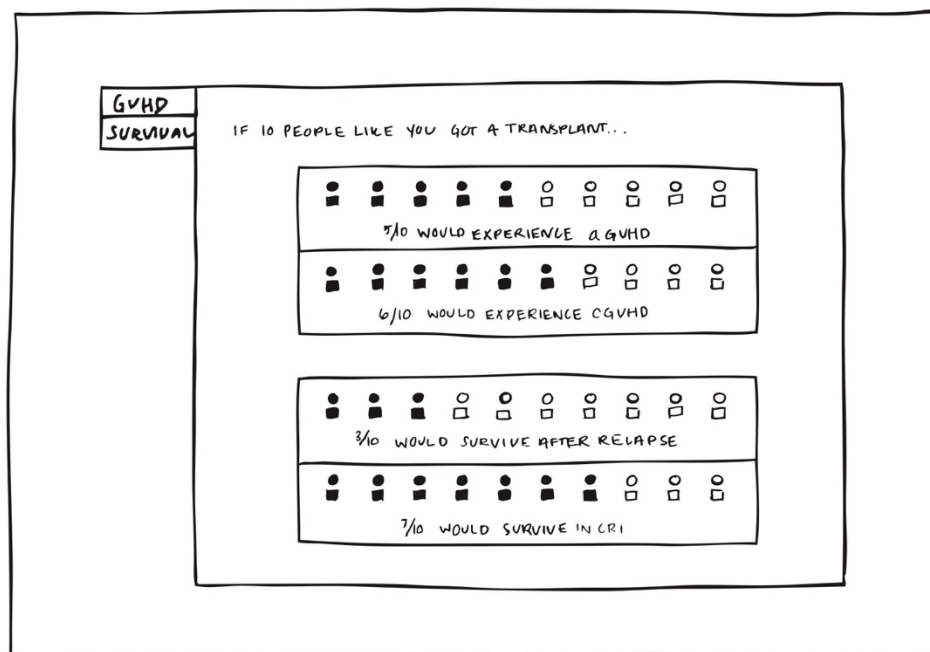
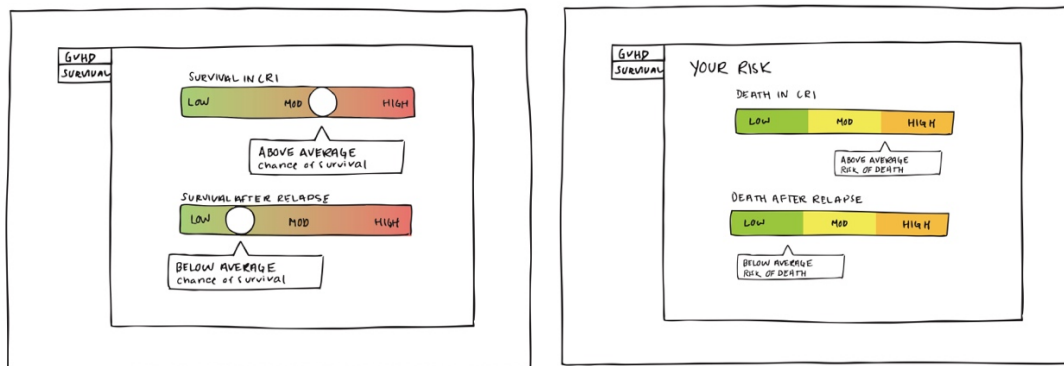


Figure 2. Prototype of the risk calculator output using natural frequencies.

**Natural frequencies** (Figure 2). The second option presented natural frequencies. There is evidence that people tend to have less difficulty interpreting this type of information in comparison to percentages (Gigerenzer & Edwards, 2003) and that this type of pictograph can produce adequate levels of knowledge around risk information for people with low numeracy (Hawley et al., 2008). Frequencies represented in pictographs are more quickly comprehended than other visual formats as pictographs show both the numerator (people affected) and the denominator (total population) (Fagerlin, Zikmund-Fisher, & Ubel, 2011). We presented this natural frequency using an icon array with the part-to-whole relationship emphasized to aid in participants understanding the proportion of transplant patients who would ultimately be at risk (Ancker, Senathirajah, Kukafka, & Starren, 2006).



*Figure 3.* Prototypes of the risk calculator output using scales. The one of the left shows the scale (low, medium, high) as a gradient, while the one on the right shows the risk levels in discrete sections.

**Scales** (Figure 3). The decision to include possibility scales without numerical risk was inspired by patients' desire to maintain optimism in the face of potentially devastating outcome probabilities. By withholding numbers and instead presenting risk as higher or lower than the average, users could avoid confrontation with potentially negative numerical percentages. We hypothesized that this would allow them to maintain the hope that they desired while still being exposed to the information that the providers found necessary for decision making. Relative possibility, used here, is effective at communicating the gist of the information and thus offer the “bottom-line meaning,” (Reyna, 2008, p. 850). People rely on gist representations of information for decision making, and so patients being able to understand the gist of risk information is essentially the purpose of informed consent (Wilhelms & Reyna, 2013).



## **Experience Video Archive**

Inspired by the perceived benefits of the veteran patient panel during the orientation class, the second feature of the system was an archive of videos featuring patients and caregivers describing their experiences with transplant and decision making (Figure 4). While patients and caregivers perceived the veteran patient panel as it currently exists to be useful, there is potential for a virtual tool to address some of its shortcomings. First, the panel is limited to the veteran patients who are available to attend the class that day. The class is typically held in the middle of a weekday, meaning that patients who have been able to return to work rarely participate in the panel. Second, there is a general belief among patients and caregivers that “everyone is different,” meaning there is significant opportunity for patients to dismiss the experiences of the few patients that participate on the panel as irrelevant if they do not relate to them in some meaningful way. Third, these veteran patients are all survivors and well enough to travel to the clinic, a characteristic which has the potential to misrepresent other, less positive, transplant outcomes. Essentially, the veteran patient panel offers a limited number of perspectives. We saw this as an opportunity for the DA to facilitate the sharing and curation of veteran patient experiences.

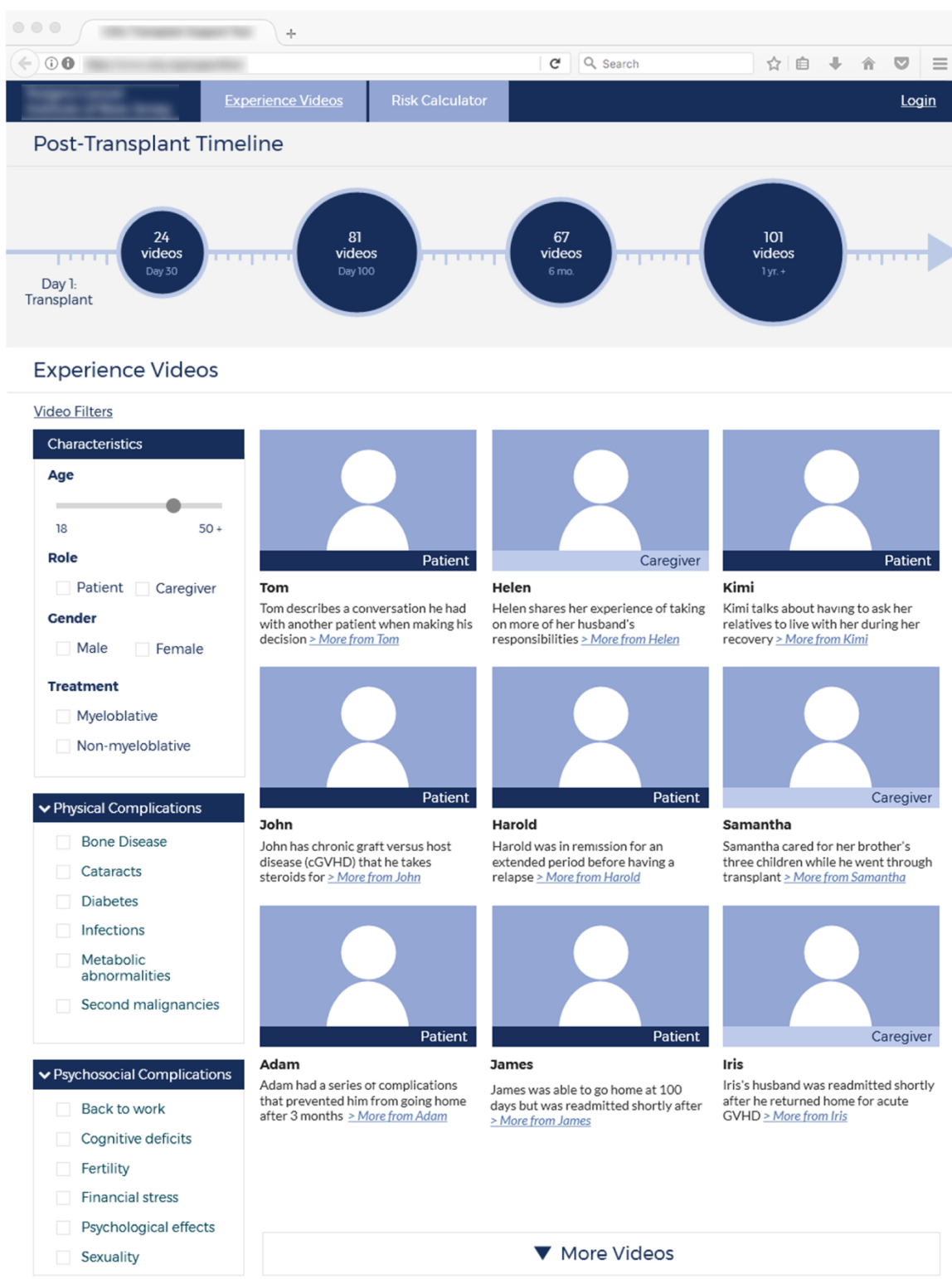


Figure 4. Experience video archive prototype. “Physical Complications” and “Psychosocial Complications” filters are expanded.

We hypothesized that including videos would support the important and difficult task of helping families form accurate expectations for the actual lived experience of life after transplant. Providers and patients recognized that it may be impossible for a provider to communicate the lived realities of experiencing certain complications in way that enables patients to effectively evaluate treatment options. Though narratives are a controversial feature in decision aids (Bekker et al., 2013; Winterbottom, Bekker, Conner, & Mooney, 2008), there is interest in their potential usefulness for enabling patients to imagine future outcomes. The narratives of other patients who have already experienced certain events can improve affective forecasting, or the ability to predict emotional responses to future events (Halpern & Arnold, 2008; Shaffer & Zikmund-Fisher, 2012) and aid patients in developing an accurate and vivid image of the consequences of different treatment options (Butow, Fowler, & Ziebland, 2005). Narratives can also help patients conceptualize the realities of life after treatment, which in turn influences their own treatment decisions (Morton, Tong, Howard, Snelling, & Webster, 2010). Hearing the experiences of other patients can aid patients in constructing preferences about treatments that they are unfamiliar with (Elwyn et al., 2010), and define alternative treatment options (Bruce, Lorig, Laurent, & Ritter, 2005). It is hypothesized that this is due to the transportation effects of narrative allowing the audience to more easily form mental simulations of certain experiences (Green, 2006). The potential for patient experience narratives to improve expectation development and treatment option evaluation inspired the inclusion of the experience video archive.

### ***Recovery Timeline***

To accommodate patients' struggles to understand the nonlinear recovery timeline, one of the primary features of this prototype was a timeline marked with different milestones (i.e. 30 days, 100 days, 1 year etc.) post-transplant. The nodes along the timeline representing each milestone vary in size based on how many videos were available discussing that point in time. A milestone node could be selected to filter for videos talking about this milestone as well. In this way, the timeline acted as both a source of information and a tool to interact with the video archive. The second feature of the interface tested was the filters participants might want to use to navigate the archive. To ensure that users were given a holistic view of BMT and its consequences, the filters included a list of specific psychosocial or physical complications that providers had offered as common side effects (i.e. Bone disease, Diabetes, Fertility, etc.). We included other filtering options that did not list specific complications after meeting with providers, who believed that the list identifying specific complications would not be particularly useful for patients.

### **Discussion**

This need-finding process uncovered important differences in the ways that patients and providers understand the challenges of BMT decision making and the reasons for those problems. Providers recognized the shortcomings of the current practices in the frustrating experience of having patients return after transplant, claiming to have not been properly warned of the complications they end up experiencing. They look to the informed consent process as the crux of this problem, a mindset that is both encouraged by and reinforces an information-centric view. Examining the orientation

class, a solution the providers developed to the problem as they perceived it, provides insight into the ways that providers are making sense of the challenges. Providers had attempted to design a solution that aims to effectively and efficiently inform patients and caregivers prior to transplant by giving them an abundance of information about complications they might experience. While patients described feeling unprepared for some of the outcomes they experienced, they did not consider this a problem of insufficient information. They recognized that transplant complications are varied and unpredictable, but nevertheless were frustrated by the difficulties in understanding the reality of this nonlinear recovery timeline. The length of time after transplant that they remain at risk of experiencing new complications, even when feeling well, was surprising. Further, both patients and providers described the inadequacies of current methods for describing the practical consequences of potential complications.

The results of this need-finding study were the basis for our initial conceptualization of the design solution. We designed prototypes to explore these needs in more depth. This included a risk calculator to aid providers in communicating the risk/benefit tradeoffs and an experience video archive with a timeline-based filtering system to support patients in understanding the nonlinear recovery timeline. These prototypes were not intended to be information-centric in the same way as the orientation class, in that the focus was not on transferring information to patients but on offering them tools to interact with this information in such a way as to facilitate improved decision making. This goal was hypothesized to be accomplished through design features like the visualization of risk/benefit tradeoffs, at-home access to a variety of the veteran patient stories they found so valuable, including filters to sort out the most relevant

information. Our intention was to present these prototypes to stakeholders to gather their perspectives about whether these features would be useful in supporting BMT decision making.

At this point in the design process, “decision making” was still the framework being used to define the design situation. However, the complex situation presented by BMT meets the requirements of being ambiguous as outlined by Weick (1995) and thus does not meet the requirements of rational decision making. The privilege given to the perspective introduced by providers, a common problem in health intervention design, contributed to us holding on to this view, as patients had not fully provided evidence to the contrary. Though there were some notable instances of patients describing something other than rational decision making, the prevailing mentality was that the design challenge was rooted in patients not properly understanding the consequences of transplant prior to opting in. What will become clear in Chapter 5 is that, when responding to the prototypes, patients and caregivers clearly articulated that they had not perceived themselves to have made a decision. Accordingly, this system, because it was designed to improve decision making, was not perceived by patients and caregivers to likely provide adequate support.

Though the prototypes ultimately did not serve the needs they were designed to, they did facilitate expression of relevant patient/caregiver experiences, how stakeholders made sense of them, and challenge the information and episodic view that had informed these initial prototypes – effectively “provoking” the decision making framing we had inherited from providers’ perspective (and the prevailing view of high-risk medical situations; see Epstein and Gramling (2013) for description of complex and ambiguous

medical situations akin to BMT that still maintains that these are “decisions”). In this way, the results of Study 1, pointing to the distinct needs as perceived by patients and providers, serves the larger purpose of designing interventions that need to serve multiple stakeholders. By capturing the perceptions of providers as being rooted in information delivery and informed consent, we could then create boundary objects (the prototypes) to be shown to other stakeholders, challenging that perception. The design rationale for the experience video archive, that narratives would help patients imagine their potential futures and that the timeline would help them to understand the nonlinear timeline, was also assessed. Thus, the value of UCD for design for sensemaking in these early stages is to have *something* to grasp, some tangible sense of the problem, to be iterated. Because this initial framing of the problem as one of decision making was manifested in physical artifacts and presented to stakeholders while still in low fidelity stages, it facilitated the reflection necessary of us as designers.

## CHAPTER 5: Prototype Feedback

Based on the initial understanding of the needs of patients and providers, the research team prototyped possible solutions in multiple variations of two main system features (as described in Chapter 4): 1) a risk calculator and 2) an experience video archive. As stipulated by a user-centered design (UCD) process, these prototypes were shown to stakeholders (patients, caregivers, and providers) for feedback. This reflective practice, as described by Schön (1992), can be viewed as a conversation between the prototype and the situation: Prototypes are “inherently ambiguous and are subject to multiple readings, each of which involves the construction of a different design world” (p. 13). As such, the purpose of this second study was to present the initial, low-fidelity prototypes to stakeholders and explore their interpretations. This process was intended to lead to a refinement of the system and the design situation. Despite this intention, the process of prototype testing did not straightforwardly lead to clear refinements of the system. Rather, it provided a renewed opportunity to reconsider the rationale that led to these prototypes in the first place. In what follows, stakeholders’ perspectives of these two features will be described. Then, how stakeholders’ feedback during prototype testing led to a reevaluation of the design situation and a reconceptualize of the problem in need of a solution as one of sensemaking rather than decision making.

Adopting a UCD approach for Study 2, stakeholders were asked to provide feedback on prototypes that were developed based on the designers’ understanding of their needs identified in Study 1. To recap, the need finding interviews had found that providers were challenged to communicate morbidity/mortality risk and the reality of life after transplant, while patients desired better expectations for transplant outcomes and an



improved understanding of the recovery timeline. However, as discussed below, there were problems with this initial understanding. Namely, feedback from patients, caregivers, and providers on the developed prototypes demonstrated that stakeholders were confused about the intended purpose of the system. Participants across stakeholder groups questioned when and how this tool might actually be used, pre-transplant to make a decision or post-transplant as they experienced new complications. Stakeholder skepticism showed how little was truly understood about the patient and caregiver experience and the support they needed, especially leading up to transplant.

In responding to these prototypes, providers framed their feedback in terms of evaluating the tool's effectiveness for supporting informed decision making. In contrast, patients' and caregivers' framing in their responses offered new insight into their experiences in ways that had not been clear from the need-finding interviews alone. For example, instead of indicating which of the four risk calculator options they felt was most useful, patients and caregivers often described having had little interest in this risk information because they did not perceive transplant as a decision they had made. This realization that patients/caregivers did not perceive transplant as an option they were actively choosing called into question where the proposed tool might fit into the process leading up to transplant and also highlighted how the system did not align with the patient and caregiver experiences as they understood them.

This chapter describes the findings that resulted from UCD methods and serves to illustrate a key turning point in the reflective design process and in our refinement of the design situation. To do this, the findings from the feedback sessions and how participants made sense of the prototypes will be described first. Then, what these findings revealed

about the flawed understanding of the design situation that inspired these prototypes will be clarified. Finally, the questions that remained about the functionality of this tool in the face of this refined understanding of the problem will be addressed. Ultimately, this revelation led to a third study (presented in Chapter 6). This third study took a vastly different approach by targeting sensemaking using participatory design methods.

### **Prototype Feedback Sessions Results**

Overall, patients, caregivers, and providers described situations in which there was potential for the prototypes to serve as a useful supplement to current practices, as well as concerns about the utility of the proposed system. Providers felt the prototypes served their need to communicate transplant-related mortality and morbidity through the ability to visually compare the differences in outcomes for receiving BMT or not receiving BMT. Providers also supported the inclusion of patient experience videos as a way to more realistically inform patients about the potential complications they might experience. Although they prioritized providing thorough risk information in Study 1, providers also worried that information about long term complications, like those represented in the filters, may not actually be used by patients for decision making. This concern is also notable because patients and caregivers evaluated prototypes through a very different framing: that the “decision” was not a genuine choice between two viable options. Consequently, patients and caregivers questioned the usefulness of the proposed risk calculator as they were unable to imagine how it would have impacted or improved their transplant experience. They described the patient experience videos as a potentially useful resource, though they often saw that feature as being more beneficial after

transplant rather than during the period before the procedure, as it had originally been intended.

### **Provider Feedback on Risk Calculators**

In Study 1, providers emphasized that the risk/benefit tradeoffs of transplant were both difficult to communicate and critical for patient decision making. So, for providers, the most important feature of the risk calculator was its ability to visually compare outcome likelihoods with and without transplant to, as medical oncologist David described, “highlight the actual decision that’s being made.” Among the four risk calculator prototypes presented, providers felt that the least abstract representation, the pie charts were the most clear and straightforward presentation of risk. This is not surprising, considering that the providers who developed the algorithm had recommended pie charts be used to represent the calculations. Providers noted that representing risk visually with pie charts would enable them to more effectively communicate some of the complexities of transplant’s potentially life-threatening risks and enable a comparison of the outcomes of transplant and outcomes if they opted not to receive transplant.

### ***Comparing Outcomes With and Without Transplant***

Provider feedback on the prototypes suggested that the pie charts especially would fulfill the need identified in Study 1 to clearly articulate the potential for transplant-related mortality or survival with life-altering complications. Nurse practitioner Rebecca suggested that patients frequently ask for “percentage of survival” and, as Frank put it, “it seems like it’s harsh but ... they sort of have to know.” Providers felt that including the likelihood of experiencing potentially debilitating complications (such as GVHD) along with the survival benefit might visually communicate to patients

the possible downsides of transplant relative to its benefits. In Study 1, the providers described the challenge of discussing transplant-related mortality, or the potentially deadly side effects of transplant. Consequently, they viewed this ability to visually compare the outcomes with transplant (and associated transplant-related mortality) and without transplant (in which mortality would most likely be a result of relapse) as especially useful.

### ***Visualizing Complexity of Risk/Benefit Trade-Offs With Transplant***

As noted above, providers felt that of all the risk calculator representations, the pie chart was the most clear representation of risk and would be the easiest for patients to understand. The pie charts were described by transplant coordinator Danielle as “a simple straightforward numeric,” by Rebecca as “an obvious quick glance,” with Vivienne suggesting that patients “would understand that probably a little better.” They suggested that the visualization through pie charts might aid patients as they assessed the trade-offs between the curative potential of transplant and the potential for transplant-related mortality, for reasons described by David:

[The pie charts show] dying of different causes. You can die because you relapse. You can die because you have a complication of treatment. Some people find that dying as a consequence of treatment is something they want to avoid because it fills up a lot of the difference in the efficacy of the therapy.

As David points out, there is a possibility that the benefits of transplant for controlling disease are essentially negated by the risk of dying or experiencing severe side effects. As he puts it, visually, the risk might “fill up” as much space in the pie chart as the benefit. The pie charts could give patients a visual representation of this complex distinction

between outcomes of treatment and outcomes of disease that the providers are actively struggling to communicate. However, providers still noted the complexity of this risk information. For example, there was concern about patients' ability to understand the differences between mild, moderate, and severe GVHD and its implications. As described by providers, patients need to understand the outcomes being represented to effectively assess the severity of risk, and was a challenge not resolved through this visualization alone.

### **Patient and Caregiver Feedback on Risk Calculators**

When providing feedback on the risk calculator prototypes, patients and caregivers often referred to their own experiences leading up to transplant. In response to the premise that these features were intended to support decision making, they did not describe having made a “decision” to receive transplant. They had not perceived a genuine choice between two viable options but instead saw transplant as the only choice for treatment or they saw the choice as between transplant and death. A similar sentiment was seen in Study 1 in patients who felt they needed to get transplant or believed the risk of not getting transplant was high enough to justify the risk. Accordingly, when asked if they would have wanted this personalized risk information prior to transplant, participants in Study 2 most often said no and expressed that access to survival rates would likely have not made a difference for them, or even led to negative emotional effects.

### ***Making a “Decision”***

When patients and caregivers were asked for *preferences* concerning the risk calculator prototypes, they usually indicated which of the four options they would prefer

if they had to choose. However, when talking about the potential *utility* of such information, they reflected on their own personal experience that transplant was something they needed and there was no real decision to be made. For the majority of patients, the “decision” to receive transplant did not include a conscious consideration of the pros and cons, because they perceived transplant to be their only option for survival. Accordingly, they felt they had to accept the risks that came with it, as Stacey, a patient, describes:

I had to decide if I wanted to do it or not, which I feel was a no-brainer. That or die from leukemia? Yeah. I'll do the bone marrow transplant. I understand the risks and that you can die from that, but you know, that's a chance.

The way that participants described making their “decision” differed from how providers perceived it. Participants echoed the patients in Study 1 who had expressed that they needed transplant and so did not put much emphasis on the potential risks. However, in being offered a prototype manifesting the providers’ perceptions of patient perceived needs (for informed decision making), participants had an opportunity to amend this understanding. While the providers had described the benefits of the risk calculator as emphasizing the comparison of the risks and benefits of transplant vs. not getting transplant, patients (and often their caregivers) essentially dismissed the survival calculator as likely to not have any impact on whether or not they received transplant. If anything, they suspected that it would have been irrelevant or even discouraging at a time when they were already dealing with significant emotional challenges.

### *Remaining Optimistic Before Transplant*

Seeing survival outcomes presented in the risk calculators was perceived by some as being potentially discouraging. Not surprisingly, the suggestion of not surviving was met with an emotional response. Instead of seeing survival rates as information that could be used as a potential tool for decision making, they were seen as possibly affecting emotional well-being, as reflected in the following quotes from patients Carol and Stephen:

I would not want to know what the chances are because then I'm thinking oh my god what if I went in there—what if I don't survive. (Carol)

[The survival outcome] is personalized. For me that strikes too hard. (Stephen)

Seeing the survival outcomes presented by the risk calculator had the potential to minimize the hope that patients in Study 1 had explained was so valuable. The statistics could diminish their ability to maintain this optimism if the numbers could be perceived as negative. Caregiver Cynthia articulated this well, saying “When you are already in a compromised state, it's hard to keep negative out.”

One particularly memorable interaction between a patient and caregiver during a feedback session illustrates a real-life example of the potential for the risk calculator visualization to evoke negative emotions. George and his wife (Marnie) were looking at the natural frequencies sketch. In the following exchange, Marnie attempts to explain why she dislikes the natural frequencies sketch, and in the process reveals the emotional response that she is experiencing during the workshop:

Marnie: I don't know that I would want to see it that obviously. I would rather see the percentages and the numbers and not say this many people don't make it.

George: Because that's your—you become one of those dots.

Marnie: Right. Right.

George: Whereas, that's [the pie charts] not connected to a person anyway. That's just almost like dry numbers.

Marnie: [The natural frequencies are] almost too... that makes my heart beat fast.

George: Too personal?

Marnie: Yeah. Yes.

Seeing the natural frequencies, in which “5 out of 10 people” were visually displayed using icons abstractly resembling humans evoked an emotional response, as Marnie was more easily able to imagine her husband as “one of those dots.” Her husband had received transplant five years prior and would likely have been considered a successful transplant at the time they were looking at the prototype sketches. Yet, her experience of having been the loved one of someone during the traumatic period leading up to transplant informed her feedback on this prototype. We had anticipated that participants would respond most positively to the natural frequencies, hypothesizing this to be the easiest to interpret. In actuality, nearly all participants either disliked or were neutral about the natural frequencies, and in the case described above the idea of seeing personalized statistics in this format provoked a negative reaction. Overall, there was a general sentiment across participants that focusing on the positive was essential during this time and being confronted with this risk information could challenge that.

### ***Determining Relevance of Outcomes Information Before Transplant***

Because patients and caregivers described BMT as not having been a real choice, they did not believe that personalized outcomes information would have been especially



useful before transplant. Instead, and in line with the goal of staying positive, they spoke about how their mindset was looking towards survival independent of the mortality risk, finding reasons to avoid exposure to risk information. Kelly, a patient, described this mindset:

I didn't really care about anything except making it through. I tried not to look at any numbers at that time, any survival rate. It's not something you want to think about, and everyone is individual so I don't want to put myself into any of them.

It is of interest that while these patients viewed transplant as being their only chance at survival, they did not put much emphasis on the possibility of transplant causing their death. Like Kelly, patients and caregivers were often able to find ways to dismiss risk information they received prior to transplant as not being relevant to them. This featured reasoning related to their own unique characteristics (e.g. “I am younger than most other patients used to calculate the percentages”) or to the nature and unpredictability of the treatment itself (e.g., “Everyone’s experience will be different”). For example, Stacey was diagnosed in her 40s and recalled being told by her doctor that the statistics available would not be an accurate reflection of their personal risk:

[My doctor] had said that [this disease is] mostly in older people so the numbers don't really—they're not as clear as they could be. They are skewed because when you're looking at somebody who is 70 years old with a five-year survival rate, that's going to be way different from somebody who's 40 years old, you know—I was 44. I didn't want to know the numbers.

For Stacey, the perception that the risk information did not apply to her led her to avoid information about risks before getting transplant. Stacey and others pointed out that

statistics reflect the outcomes of a certain population and do not guarantee their own individual outcomes. Between the perception of transplant as having not been a choice and the perception that risk calculations may not be relevant to one's particular circumstances, participants overall expressed that the survival calculator would not have made a difference or have been particularly helpful to them before transplant.

### ***Preparing for GVHD Before Transplant***

While the survival calculators were perceived to have minimal value to patients and caregivers, the risk calculators that represented the statistical likelihood of experiencing GVHD received a positive response. Like in Study 1, participants valued forming accurate expectations for life after transplant, consequently showing more interest in seeing the risk calculator prototypes that presented GVHD risk. Knowing the GVHD risk might have helped better prepare them for its effect on their everyday lives, as Renee suggested:

I'd appreciate this. Especially the graft-versus-host situation. 'Cause I'm already telling myself I want to survive. I just want to know what I'm going to have to deal with after.

Anticipating the potential problematic effects of transplant may have given patients and caregivers some insight into ways they would need to adjust in the future. Still, because participants largely described the BMT "decision" as not being a decision at all, they still did not see the GVHD risk calculators as having a significant impact on whether or not they received transplant. As Samuel, a patient, explained, the GVHD risk calculators might have been "more relevant" but "at the same time you think your back is up against the wall, so let's do it." Overall, even those participants who were potentially interested

in seeing the GVHD risk calculators thought it would be useful for preparation, not for decision making.

### **Provider Feedback on Patient Experience Videos**

Providers perceived the risk calculator to address one of their expressed needs in Study 1, namely helping patients to understand and weigh the risks and benefits of treatment options for decision making. Providers viewed the patient experience videos as attending to the second of their needs described in Study 1, communicating the realities of life after transplant. During prototype testing, providers confirmed that patients often ask them about when they might experience certain complications or when they can expect to return to their lives before transplant. However, providers also expressed hesitancy around the actual utility of the tool for patients considering transplant.

### ***Perceived Utility of Experience Video Filters***

The physical complications presented in the system filters are currently communicated to patients before transplant as part of the informed consent process. When providers gave feedback about the filters, however, they doubted that the list of complications would be relevant to someone who was facing such a life or death treatment decision. Once again, providers were evaluating the prototypes based on what their perceived end goal – informed decision making – a framework that was not shared by patients and caregivers. Providers noted that the physical complications in the filters might be unfamiliar and complex to patients and caregivers. Providers doubted that patients would actually use information about specific complications that might not be realized for years, whether psychosocial or physical, for decision making. This is especially interesting considering the Study 1 finding that providers struggled to

communicate, and patients struggled to understand the timing of transplant complications.

The following provider exchange between three medical oncologists (Frank, David, and Gregory) and a transplant coordinator (Vivienne) discussing the list of filters describing specific complications (e.g. metabolic abnormalities, cataracts, etc.) illustrates the differences in provider perspectives on the possible use of this feature. Notably, despite the differences in the perspectives portrayed, all of the providers frame their feedback in terms of the BMT decision.

Frank: Wait, so is this meant to tell everything about transplant or just [for the] decision because I think it's almost—it's kind of like too much for—

David: No, they don't have to click everything. They don't have to click on anything... But then if you don't at least mention it, it's like having a consent form that doesn't—

Frank: Yes. But every consent form, it's got to be self-limited or else it's no longer—then it becomes like a book.

Gregory: But this is something that's already filtered through us. Otherwise people are going to be on the Internet themselves just going through everything.

Vivienne: Is somebody really going to care whether they get cataracts in order to make their decision whether they need to be transplanted?

In this exchange, we see Frank and Vivienne questioning the usefulness of this information for decision making while David and Gregory attempt to describe the benefits of the system. Frank has questions about the experience video interface and if it functions as decision support or as providing all of the information about transplant,

noting the potential for there to be too much information. David and Gregory respond with what they perceive to be the benefits of the system. Still, Vivienne reiterates Frank's overall point and the underlying question that remains: is this information something that a patient will use for making their decision?

The providers circled back to this problem as the focus group continued. Despite the belief that this information was considered good information for patients to have, conflicting views on the perceived utility of the tool for decision making persisted, as epitomized in this comment from Frank:

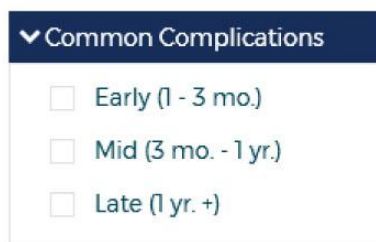
I think the psychosocial [filters] as you have there is very good. I think the physical stuff—because I think the back to work, am I gonna have chemo brain, fertility and the financial, all that stuff I think is fine although I don't know that it's going to make or break how somebody decides to have a transplant.

In these conversations where providers questioned the utility of this information for patient decision making, it is important to note that they were often referring to information that they are currently giving to patients as part of the informed consent process. As they view informed consent as critical, and achieving informed decision making as an ideal of their practice, to see their skepticism when this information was presented in the interface prototype was surprising. In Study 1, providers suggested that patients must know about all of the possible risks to make an informed decision. Yet, when this same, specific risk information was presented in the context of this interface, providers found it to be possibly irrelevant for someone making this decision. Unlike the patients and caregivers, who did not see transplant as having been a real decision, providers were concentrating on the decision when assessing the system's usefulness, and

the prototype inspired provider comments that challenged the focus on informed decision making.

### ***Adding More Filter Options for Patient and Caregiver Feedback***

The feedback from providers suggested that the specific complications filters might not actually be useful to patients who are making the decision. Therefore, two alternative filtering options were included in the prototypes that were shown to patients and caregivers. Whereas the first interface design shown to providers featured only a list of specific possible complications (i.e. diabetes, cataracts), we showed patients and caregivers two new potential filter options. The first was labeled “Common Complications” with the filtering options being “Early”, “Mid”, and “Late” to filter by the most likely complications during those time periods (Figure 5). This came from providers suggesting that there are complications that patients are more likely to experience at certain points in their recovery.



*Figure 5.* “Common Complications” filter option.

The second set of new filters generalized the type of complication rather than listing specific complications. The filter menu was labeled “Type of Complication” with the options “Physical”, “Psychosocial”, “Cognitive”, and “Daily Life” (Figure 6). This categorization was inspired by the providers suggestion that the medical terminology

(e.g. “Metabolic abnormalities”) might be confusing and unfamiliar to patients. When showing these filters to patients and caregivers, we first showed them the interface with no filtering options visible, then the list of specific complications (as we showed providers) followed by the two new filtering options. As described below, patients often suggested a *combination* of filters would be the ideal interface.



Figure 6. “Type of Complication” filter option.

### **Patient and Caregiver Feedback on Patient Experience Videos**

In viewing the proposed interface for patient experience videos, patients and caregivers responded largely positively and seemed eager to have access to a variety of stories from other people who had been through transplant. However, they saw the system as potentially being more useful during recovery rather than in the period leading up to transplant.

#### ***Perceived Utility of the Experience Video Archive***

When describing the utility of the video archive, participants again brought up their beliefs that every patient is different and will have a unique experience. Accordingly, the variety of experiences and possible outcomes that could be presented in the system was appealing to patients and caregivers, especially when compared to the

limitations of the veteran patient panel during the education class. For example, Renee described how she could not relate to the veteran patient who spoke at the end of the orientation class she attended because of their age difference and different backgrounds. In describing the benefits of having a variety of experiences, she also emphasized the importance of representing this variety as soon as users accessed the system:

As soon as anybody looks [at the interface], they should see somebody they can relate to. Just by looking. Even if it's age, gender, you know, race.

If patients and caregivers did not feel that they related to the patients selected to speak on the panel, there was no alternative. Being able to choose from a collection of transplant recovery experiences meant they would likely find someone that adequately reflected their own situation and whose experiences could be more like their own.

The inclusion of the timeline at the top of the page was considered useful in seeing potential variation in the individual experience over time. It was noted that the timeline could represent the ups and downs in even a single patient's experience as they progressed through transplant recovery. In Study 1, patients described the surprise of continuing to experience new complications despite getting further from transplant. The timeline was also perceived to aid in understanding this nonlinear progression of recovery. Participants also suggested additional timepoints going as far as five years post-transplant. Being able to see not only the variation between people's experiences but within the same person's experience was considered valuable, as Kelly explained:

[The timeline] is great... People heal different, you know? But also, timing is different. Like 100 days post-transplant is so different from a year after.



Participants reflected on their own experiences and how much they had changed over these various time points. In this way, the timeline nodes could help users to connect more abstract concepts to specific points in time.

### ***Using the Experience Video Archive***

Multiple participants said they would want to use this feature throughout the recovery process as they experienced new complications. They noted that the pairing of the timeline with the videos and the ability to see progression after transplant was considered a more useful resource during the recovery period rather than in the pre-BMT period. As Margaret, a patient put it, “it’s nice [information] to have before, but you don’t really get it until you’re actually living it.” Before transplant, this information might have seemed like too much and potentially irrelevant, as there was no way to know which of the videos and complication filters would ultimately be relevant. After transplant, as patients came to experience new and unfamiliar complications, hearing from others might have been a way to capture practical tips for coping or as a reminder of the information learned in the orientation.

These issues are similar to the ones brought up by providers—namely, would the proposed system be used primarily for decision making or primarily after transplant when patients may begin to experience complications? As Samuel put it:

I can’t imagine I would have seen anything here that would make me go oh, I should really consider this when I’ve been told if you don’t get the transplant, you don’t dance at your daughter’s wedding or you don’t see graduations, so we’ll make you comfortable. I can’t imagine seeing anything here that’s going to make me go well, gee, I should think twice about this.

Samuel, and participants who shared similar sentiments, perceived the tool as potentially useful after transplant as they came to experience these new complications. However, they considered it good information to have prior to transplant, but not something that would have made a meaningful difference. This response challenged the researchers' perception of the tool as supporting patients and caregivers in the period leading up to transplant, whether it was a true "decision" or not.

### ***Responding to Additional Filters***

The two additional filters included after the provider focus group were seen as useful for filtering information to only what would be immediately relevant. Participants largely favored the "Common Complications" filters ("Early, Mid, Late") because it gave them the ability to filter information that would be relevant for them immediately post-transplant rather than seeing the complications they might experience later:

Before transplant, I would really only be looking at that early stage. I didn't really care about the later stage yet. (Stacey)

I like that because then it's like it's not so overwhelming, because beforehand we could say oh, we're only going to look at the early and the mid. We're not going to spend more time on a year out, or we'll do that a quick look just to see but not so much. (Deborah)

The ability to limit the amount of information to just what would be relevant in the near future was considered useful in the period leading up to transplant and more manageable during an already stressful time. Interestingly, multiple participants (n=8) suggested a combination of the two new filtering options. One suggestion was that the top-level filter would be "Early" "Mid" and "Late" with sub-categories featuring the most common

specific complications for those time periods. For example, the top-level filter would be “Early” and the sub-category filters might be “Acute GVHD” or “Infections.” Another common suggestion was that the top-level filters be “Physical” “Psychosocial” “Cognitive” and “Daily Life” with the drop downs for each being “Early” “Mid” and “Late” or the specific complications in those categories. To see the list of all the specific complications that could happen over the years of recovery in the period before transplant may be potentially scary to see, as Marnie called it, a “list of all the things that can go wrong.” Breaking the complications down into those they are most likely to see at the beginning, versus mid-recovery and then long term made for a more digestible and less frightening exposure to potentially serious complications. Though the inclusion of these filters was not viewed as potentially impacting whether or not they received transplant, the ability to limit the information to a manageable amount, only viewing what would be relevant in the near future rather thoroughly covering the available information, could improve feelings of preparedness and expectation development without being overwhelming.

### **Discussion**

This study tested prototypes developed based on the needs of patients and providers identified in Study 1. To address providers’ expressed need to facilitate informed decision making by more effectively communicating morbidity/mortality and the realities of life after transplant risk calculator prototypes providing personalized outcomes information were developed. While patients in Study 1 had confirmed difficulties in understanding morbidity and mortality risk, they put less emphasis on making informed decisions and instead described challenges related to forming accurate

expectations for the practical impacts of transplant and understanding the variability and unpredictability regarding transplant complications. To address patients' expressed needs, prototypes of an experience video archive were developed and tested. In alignment with UCD principles, the rationale behind these designs was their hypothesized ability to improve patients' capacity to imagine the consequences of transplant through more accurate outcomes information and narrative accounts from other patients.

Patient, caregiver, and provider feedback on the prototypes had meaningful implications for our design process. In particular, the feedback revealed differences in stakeholder perceptions of the design situation. Weick's (1995) sensemaking theory suggests that people do not need an accurate view of a problem, they just need to make enough sense of it to keep moving forward. In the interviews described here, and especially in response to the proposed "Early, Mid, Late" complications filters, patients and caregivers described having a present-focused mindset in which they were much more concerned with the information that would be immediately relevant post-transplant. To receive transplant, they did not see the need to fully understand the long-term consequences of the treatment. Participants perceived the value of this tool was highest during recovery as they were trying to understand and cope with new complications after transplant. The stakeholder reflections on the prototypes made clear that 1) they are making sense of the process leading up to BMT differently and 2) they see the goals and functions of the process differently. The prototypes effectively provoked the design situation being viewed as a challenge of decision making and brought forth conflicts in the provider and patient/caregiver view of BMT and the support needed. This also

uncovered conflict between the designer view of the situation and the patient/caregiver experience.

### **The Design Process**

This study followed a more traditional UCD approach by presenting stakeholders with possible interface designs for their feedback. UCD as it was employed here is most appropriate for refining a proposed solution, but this requires that the designer have an accurate understanding of the design situation. In this case, the feedback from stakeholders emphasized how little the research team understood about the problem we were facing. This use of a boundary object can be very helpful, and in this case, it revealed inconsistencies in our understanding of the pre-BMT period, and conflicts in stakeholders' perspectives. For example, the providers questioned if patients would care about these potential long-term consequences while making a life or death decision. This was interesting in light of their emphasis in Study 1 on the importance of similar information in the current patient education practices. When seeing this information in a patient-facing interface, however, providers recognized that it might not be especially relevant for patient decision making. There is potential for the concreteness of a prototype to enable stakeholders to in some way adopt the perspectives of one another, as in the providers looking at the prototype and imagining themselves as a patient in that situation.

However, there are limitations to providing feedback on a prototype that already exists. Part of the limitations of UCD comes from the reduced capacity for participants to communicate the experiences they had; in the findings presented here, patients and caregivers largely offered feedback on these proposed designs by referring to their own

experiences but discussed them in the context of utility of the prototype. Because this prototype had been developed based on a decision making framework, participants were able to communicate that they did not understand the experience to have been a “decision.” Yet, they did not have the tools to articulate what process they *had* gone through leading up to BMT.

Participants in Study 1 expressed their needs in response to questions designed by the interviewers to examine the decision making process, and in Study 2 communicated their experiences by reflecting on the prototypes. Both studies were performed under the belief that this was an issue of decision making. Ultimately, it was clear that the design situation that informed the prototypes was inaccurate. The revelation that this was not perceived as a “decision” pointed to the necessity of an alternative approach.

### **Looking Ahead**

In Studies 1 and 2, patients’ choice of whether or not to have BMT was viewed as a problem of decision making. Since feedback from Study 2 indicated that BMT patients and caregivers did not perceive decision making to have even occurred, the idea that the goal was addressing “decision support” was challenged and led to a serious reevaluation of this approach. In particular, questions remained about how patients and caregivers *did* view the pre-BMT process and how this system could give them the support they required. To do this, a novel approach was needed.

When attempting to design novel interventions, “complexities, paradoxes, and ambiguities are to be fostered rather than eliminated” as “it is out of these “problems” or “situations” that new future possibilities emerge” (W. T. Thompson, Steier, & Ostrenko, 2014, p. 223). The feedback on the prototypes not only indicated that all stakeholders

doubted the relevance of long-term outcomes information on decision making, but, unlike providers, patients and caregivers did not perceive decision making to have even occurred. One thing that stakeholders did consistently articulate was that patient and caregiver expectations did not match the experiences of BMT recovery. As will be solidified in the results of Study 3, a tool for pre-BMT support might focus on making sense of illness experience rather than becoming informed enough to make a decision. This further supports an approach that emphasizes and aims to support sensemaking rather than decision making. Thus, the third and final study of this dissertation adopted a novel participatory design approach to better understanding of the sensemaking processes that patients and caregivers engage in leading up to transplant.

## CHAPTER 6: Participatory Design Workshops

The prototypes shown in Study 2 intended to aid patients pre-BMT in informed decision making; however, they were met with confusion and skepticism from stakeholders about their utility because they did not perceive decision making to be a problem in need of resolution. The purpose of Study 3 was to answer questions that were newly raised by the finding that patients and caregivers did not perceive decision support as beneficial prior to BMT. To investigate this finding, the present study adopted a participatory design (PD) approach specifically targeting the sensemaking practices of patients and caregivers in the period leading up to bone marrow transplant. The questions addressed included 1) what are the sensemaking processes that patients and caregivers engage in leading up to transplant and 2) how can we better support patients and caregivers during this time? By incorporating design elements to elicit stakeholder sensemaking practices, this final study offers a point of comparison to user-centered design (UCD) methods employed in Studies 1 and 2. This comparison offers insights on how sensemaking can be methodically elicited in design work. In this study, a visual timeline to represent the period leading up to transplant was used to encourage stakeholder reflection on the most memorable experiences. This timeline was intended to capture a more complete view of the illness experience and to be able to identify opportunities for a support tool to be most beneficial. The implications of a holistic understanding of the pre-BMT sensemaking process on potential support solutions, and the comparison between findings stemming from UCD processes in Studies 1 and 2 and those stemming from an adapted PD approach for sensemaking in Study 3 are discussed at the end of this chapter.



Results from this study show that patients and caregivers go through a multi-phase sensemaking process from the time they are introduced to BMT as a potential treatment to when they finally receive transplant. This process begins when patients/caregivers first learn about BMT (phase 1), then undergo treatments in the hopes of achieving remission (phase 2) and participate in formalized educational procedures to learn about the risks/benefits of transplant (phase 3). Each phase and the important events within it have distinct effects on patients' and caregivers' understanding of BMT. When BMT is first introduced in phase 1, patients and caregivers do not understand it as an option – an event they can simply choose to undergo – but rather as a “possibility.” Transplant is considered a possibility either because they perceive it as something that might be considered in the future after beginning other treatments, or because a series of preparatory activities must be successful for transplant to become a reality. Factors outside of patients' control, like finding a donor or achieving remission, determine if patients can actually undergo transplant. Accordingly, during phases 1 and 2 patients and caregivers described their heightened focus on meeting the prerequisites to transplant as compared to the decision itself, since at this point in time their “decision” has less impact on their experiences since transplant is contingent on these other factors.

Relatedly, during phase 2, patients and caregivers indicated that they focused on the curative potential of transplant rather than the side effects. As they described it, this mindset led them to form expectations that transplant was necessary for survival. Thus, in phase 3, when they were exposed to all the possible (and sometimes deadly) complications, their developed expectations of transplant as a life-saving procedure were significantly challenged, which led to doubts about transplant. Patient and caregiver

interpretation of the information received from doctors – that without transplant, they were likely to die – was difficult to reconcile with the potential risks later emphasized in phase 3.

The prototypes developed for Study 2 did not account for these phases or the progressive understanding of BMT that patients and caregivers developed, which limited the perceived benefit of the prototypes. These initial prototypes were hyper focused on helping patients understand what their futures might look like, neglecting to consider the significant sensemaking work that was going on in the period before BMT. The solutions that participants designed during the PD workshops were intended to improve their expectations and preparedness for transplant outcomes, a need made clear in Study 1 and 2. However, in taking an approach that looked specifically at sensemaking during this critical pre-BMT period, it was possible to see how these expectations were being formed and what cues patients and caregivers were using in understanding BMT. The use of a timeline portraying the experience and evolving in understanding allowed a lens to see into some of these dynamic sensemaking processes from a longitudinal vantage point. Providing participants with tools to visually communicate their experiences led to recognition of a more gradual process of acceptance and expectation development rather than a single point of decision making. The Study 2 prototypes had clearly demarcated the period before and after transplant, intending to inform patients about what happens after and neglecting to consider the period before.

In the pre-BMT period, patients and caregivers not only need support in forming expectations for the future but in understanding the new and distressing aspects of the illness experienced in the present. The prototypes did not resonate with patients and

caregivers in Study 2 because, before BMT, they struggled to imagine a future while they were actively facing so much adversity that might prevent them from getting transplant, independent of their “decision.” The primary challenge that patients and caregivers faced in the pre-BMT period was not making the right decision or having accurate knowledge of what the future would look like, but about productively making sense of the illness experience to more comfortably navigate the complexity of BMT.

In line with the principle of inclusivity and self-reflectivity outlined in the principles of design for sensemaking, participant feedback was solicited and incorporated into data collection procedures but done so in ways that are notably distinct from the processes of engaging participants utilized in Studies 1 and 2. While both Studies 2 and 3 asked participants to reflect on visuals, in this study, participants in Study 3 were asked to create visuals rather than respond to what the designers had created. Participants were given the opportunity to dictate what was most memorable and useful during the pre-BMT period. Participant feedback was also used to revise the toolkit and research procedures, aligning with the PD ideal of not only including potential end users in designing outcomes but in designing their participation as well. Notable examples of how participants altered the design process itself include the development of a timeline template in the toolkit, their appropriation of the emotion words sheet, and in their engagement in the creative ideation exercise.

### **The Pre-BMT Sensemaking Process**

Twelve timelines were created by 15 participants, as 3 patient/caregiver pairs opted to represent their experiences on a single, shared timeline. Five of these timelines used photos from the toolkit. Five timelines used the emotion/BMT-specific stickers (see:

Figure 7), while the rest chose to write words (see Figure 8). The latter choice was made either to save space or because they experienced that emotion at more than one point in time.

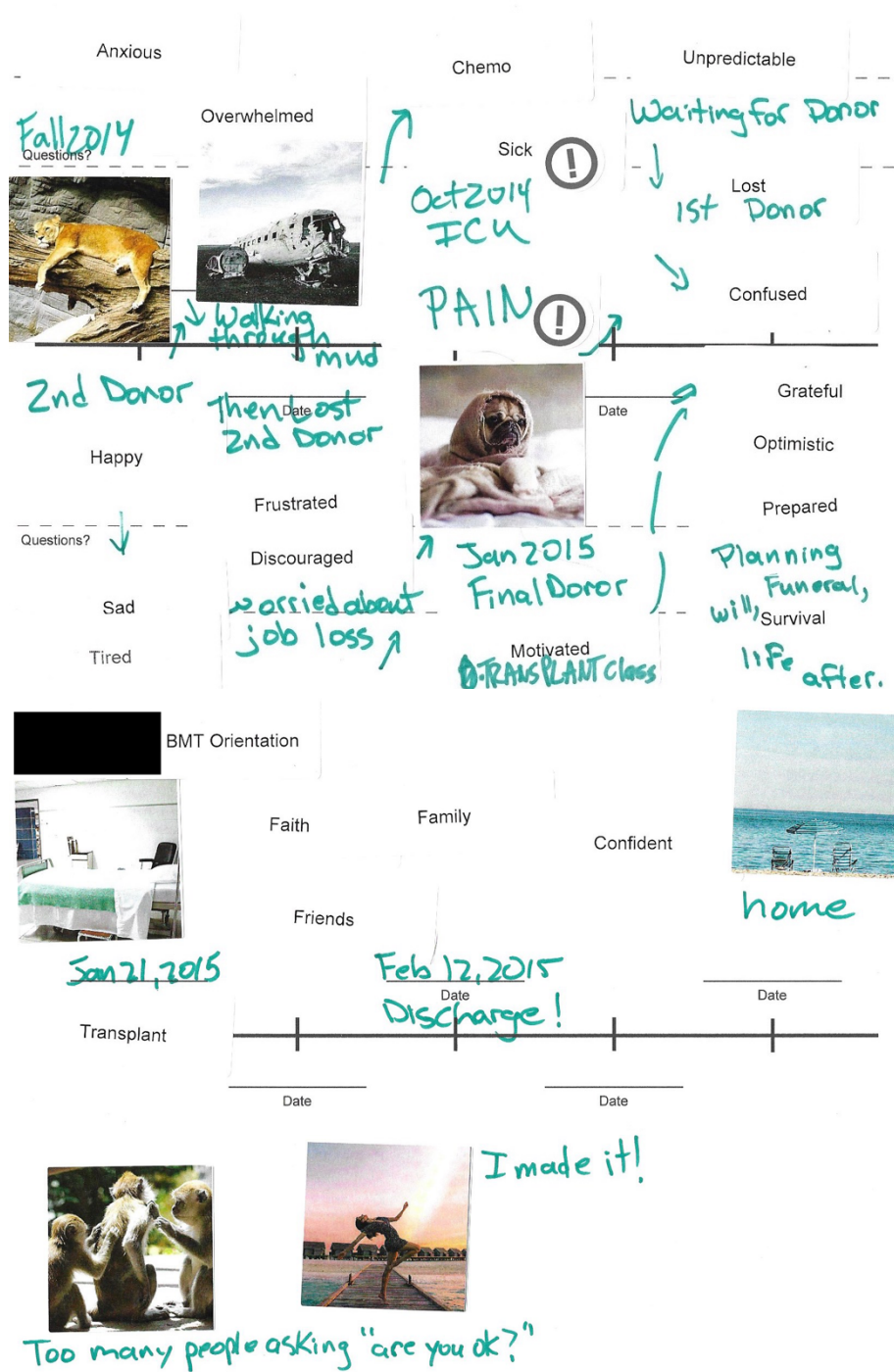


Figure 7. Margaret's timeline drawings (2 pages)

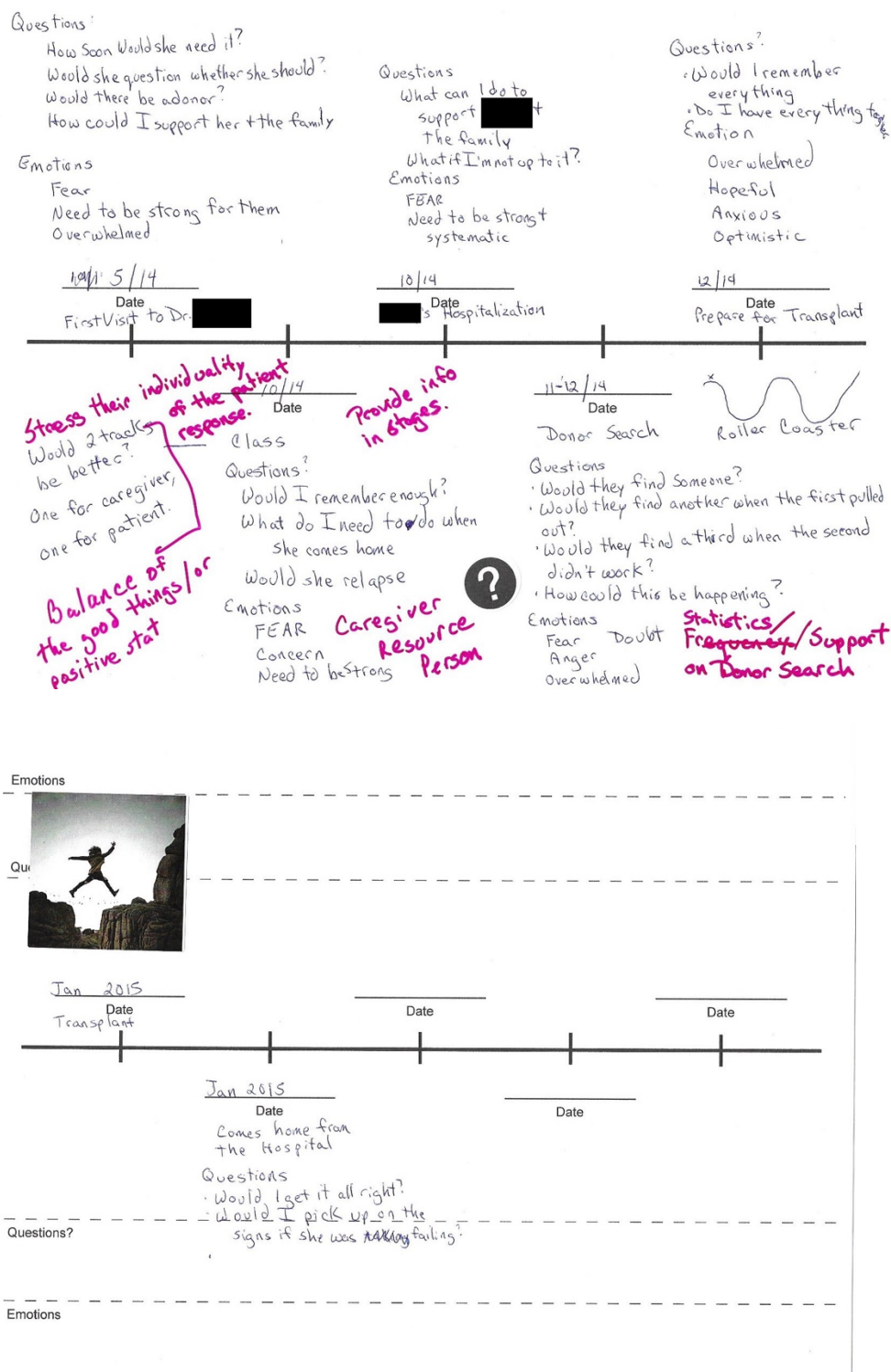


Figure 8. Harriet's timeline drawings (2 pages).

The number and type of significant events that participants included in their timelines varied. However, the processes that were described by participants generally followed a similar pattern of progression that included three phases that were meaningful for patients/caregivers before receiving transplant:

**Table 6**

*The Phases of Pre-BMT Sensemaking*

| Phase | Description                            | Examples of events on timelines   |
|-------|--|---|
| 1     | Introduction to BMT                    | Receiving diagnosis; Conversations with doctors about treatment options |
| 2     | Initial treatment to achieve remission | Induction chemotherapy; Extended hospital stay; Remission; Donor search |
| 3     | Formal education                       | Orientation class   |

The sensemaking process begins with patients and caregivers being introduced to BMT during a conversation with a provider (phase 1). Then, patients begin treatment for their disease in the hopes of achieving remission (phase 2). Finally, they attend a formal patient education class to receive information about BMT and its risks (phase 3). Each phase is marked by certain events with memorable cues extracted to inform sensemaking, though not every participant experienced every event, as outlined below. Additionally, these phases are not always sequential, as the treatment to achieve remission often overlaps with introduction to BMT and/or with the formal education proceedings. Across the entire process, the most common emotions experienced by participants were anxious (n=11 [participants]) and afraid (n=11 [participants]), grateful (n=8), and unsure (n=7). The emotions most commonly identified as things participants believed they had *not* felt

during this process were normal (n=8), regretful (n=7), and angry (n=5). The lack of regret experienced by participants is notable considering the perceptions of providers in Study 1 that patients were experiencing decisional regret.

The next section begins with descriptions of the three phases of the pre-BMT sensemaking process, the experiences that define them, and the memorable sensemaking activities associated with each. Then, the themes that emerged across phases, how the research procedures facilitated that understanding, and what this means for a potential support tool are discussed.

### **Phase 1: Introduction to BMT**

In Phase 1, participants heard for the first time that transplant is a treatment option. BMT was introduced to participants in concurrence with one of two different events:

1. When first learning of illness/diagnosis of disease
2. After other treatments had failed

Seven of the patients in this study first learned about BMT at the same time that they learned about their diagnosis, while 3 patients discussed BMT with their providers only after chemo had failed to control their disease. Five of the 7 patients who learned of BMT at the same time as they learned of their illness initially perceived BMT as something that might be a consideration in the future but at this point it was not necessarily viewed as an inevitability. As George described, after learning transplant might be in his future, transplant was “in the back of our minds,” not as a decision he needed to make but “just that it existed.” For the remaining 2 patients, they perceived transplant to be their only option for survival immediately upon learning about transplant, though they understood that receiving transplant heavily depends on finding a donor. The 3 patients who did not

learn about BMT until after their initial chemotherapy failed described being immediately interested in receiving transplant, although they first had to prove themselves able to tolerate the physical toll of transplant.

During phase 1, transplant was not necessarily viewed as an inevitability. This is true even the patients who wanted transplant as soon as they learned about it and considered it the only treatment option. Instead, transplant was perceived as a “possibility” dependent on the outcomes of phase 2. While patients were thinking about treatment outcomes in phase 1, they emphasize transplant success, not side effects. At this point, they were focusing heavily on the curative potential of transplant.

Phase 1 had the most questions, with nearly every participant reporting having had questions when first introduced to transplant. The most common questions were about outcomes, particularly the likelihood of transplant success (i.e. “What were my chances of recovery or getting better” [Kerry]), what the next steps were (i.e. “What do I need to do to beat this?” [Bob]), and the timing of transplant and recovery (i.e. “How long will treatment take?” [Stacey]). The emotions most commonly associated with phase 1 were afraid (n=6) anxious (n=5) and unsure (n=4).

### **Phase 2: Initial Treatment to Achieve Remission.**

Phase 2 is the longest of the phases and may overlap with phases 1 and 3. During this phase, patients were aware of their disease and that transplant might be in their future. Patients were actively receiving treatment in order to reach remission. This usually involved intensive chemotherapy that took place over several weeks and may involve a hospital stay. This period was marked by significant patient/caregiver-provider interactions in which patients and caregivers develop relationships with providers as they



tried to better understand the disease and treatment. Relationship building and familiarity with the clinic team occurs during the frequent time spent in the hospital and often increases patient and caregiver confidence in the providers' abilities.

### ***Milestones to Getting Transplant***

There are many prerequisites that must be achieved for patients to actually receive a transplant—despite patient's desire to receive transplant—that are out of the patient's control. These include achieving remission, finding a donor, and being physically strong enough to tolerate transplant. Even if patients *want* transplant, there are other external factors that determine if this can *actually* happen, depending on if they can meet the prerequisites during phase 2. If these requirements are not met, patients cannot receive transplant. 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, the focus was on achieving remission and potentially becoming a candidate for transplant rather than what would happen should they be met.

**Remission.** It is during this phase that all patients and caregivers were concerned with reaching remission. A patient's leukemia needs to be controlled in order to actually transplant the stem cells, and thus the first prerequisite for transplant is to reach remission. This is accomplished using high doses of chemotherapy, though not all patients in this study reached remission after the first round of chemotherapy and required continued chemotherapy to control their disease. Participants described focusing on reaching this first treatment milestone of actually achieving remission before

beginning to think about transplant. This focus on the present was common while attempting to control the disease.

**Donor.** Another prerequisite for transplant is finding a matched donor. This process might involve testing siblings or other family members, and if that proves unsuccessful, checking the donor registry for an unrelated donor. The donor must be matched to the patient's human leukocyte antigen (HLA), which is measured based on 10 markers. Within matched donors, there are also variations in the quality of the match. The more markers that are matched, the more likely that transplant outcomes will be successful. Ideally, a patient will have a 10/10 match, but doctors will also sometimes perform transplant with an 8/10 match. The process of waiting to find a donor was anxiety-inducing for participants, as without a donor, patients could not receive transplant no matter how much they wanted to.

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... I was gonna get the transplant. I made my decision right there and then when the doctor told me about it. So then from there it was just a matter of waiting on the results from my brothers. (Bob)

During the donor search, they must wait for results, which increased anxiety. As noted by Bob, patients may already be committed to receiving transplant but then have to wait to find a donor. In this period, patients may also be experiencing physically demanding treatments to achieve or maintain remission. Thus, the stress of waiting for a donor is immense—and they can do nothing but wait for a donor to be found.

**“Proof of concept.”** The last of the prerequisites for transplant is to demonstrate that the patient will survive the trauma of transplant. This involves a series of tests

intended to show that the patient is physically able to survive transplant, which includes tests on their lungs, eyes, and heart, among others. For some, this evidence came from their ability to survive the intensive chemotherapy regimen in order to gain, as Samuel put it, “proof of concept:”

We had to do the second round [of chemo] so that [my oncologist] could have some like proof of concept that I was a candidate for a bone marrow transplant, that I could safely be covered, as he used to put it, while undergoing the wrath of chemo.

Obviously, because this sample of patients was able to receive transplant and survived, they successfully proved that they could survive transplant. Yet, in the time between chemotherapy and confirmation that they met these requirements—proving themselves strong enough while staying in remission and having a donor secured—they experienced a great deal of anxiety. During this phase, questions most commonly asked about next steps (“Do I still keep on taking chemo to keep it away from me?” [Jacob]) and survival outcomes (“Will this work?” [Stacey]). Other than feeling anxious (n=5), participants did not often distinctly associate emotions with phase 2, possibly because Phases 1 and 3 are triggered by singular events (a conversation with a provider and an orientation) which they can more readily recall emotions experienced during.

### **Phase 3: Formal Education.**

In this last phase of the pre-transplant period, patients and caregivers participate in formalized educational procedures in which providers present the various risks and benefits of transplant. As described in Study 1, this includes the orientation class run by the transplant coordinators. The majority of participants described themselves as having

been mostly if not completely committed to receiving transplant before attending the orientation class. Notably, no participant mentioned the informed consent process as part of their decision making.

As in Study 1, participants described the orientation class as presenting a lot of information and being overwhelming. Afraid was the most common emotion indicated (n=7), along with anxious (n=4) and hope[ful] (n=3). Participants increasingly reported having questions about side effects (“Will I get graft-versus-host?” [Stacey]). More common were questions about whether transplant was worth it (“Why would anybody go through this?” [Charles]) especially if they are actively in remission (“If I’m already better now, why would I wanna risk it?” [Jacob]). Such questions were indicative of another common experience during formal education: doubt.

### **Doubt**

At the point they attend the class, they are candidates for transplant and have usually achieved remission. They are then exposed to the many painful and possibly deadly side effects of transplant. Patients (n=5) and one caregiver described personally experiencing or witnessing others experiencing doubt during or after attending the orientation class. During the orientation class, the most common questions were variations of “is BMT worth it?” The doubt appeared to stem from the realization that patients are putting themselves at significant risk with transplant despite currently being disease-free. Ultimately, they find answers to this question. Most often, they reason that it is likely that their cancer will return if they do not receive transplant. Up until this point, patients and caregivers have understood BMT to be a potential cure. Now, they see that it has the potential to kill them. This expectation of a cure that is formed in phase 1 is thus

challenged in phase 3, causing a reevaluation of the value of the procedure. The doubt that arises from the many possible risks is often described as leading patients to rationalize that the risks of not getting transplant must be greater. This rationalization justifies willingly taking on the many serious complications of BMT.

### **How Patients and Caregivers Make Sense of BMT During This Period**

These three phases, as described by patients/caregivers, illustrate the specific points through the journey where they extract cues and form expectations. This illustration is useful for understanding the overall progression of sensemaking and unmaking. Anticipatory thinking, a form of sensemaking, “is the process of recognizing and preparing for difficult challenges, many of which may not be clearly understood until they are encountered” (Klein & Snowden, 2007, p. 1). It differs from prediction, which is about guessing future states of the world, and includes preparing to respond. This type of thinking leads people to attend to certain cues and to downplay others. The anticipatory thinking that patients and caregivers describe engaging in during phases 1 and 2 can thus prevent patients and caregivers from attending to the consequences of actually getting transplant, which leads to emotional turmoil, namely anxiety and doubt, in phase 3.

Table 7 presents the novel information, interactions, and communicative outcomes for each phase along with the cues extracted and resulting sense made.

**Table 7**

*The Information, Interactions, Communication, and Sense Made in the Pre-BMT Period*

|                              | <b>Phase 1</b>  | <b>Phase 2</b>   | <b>Phase 3</b>                   |
|------------------------------|---|--|----------------------------------|
| <b>Information</b>           | Diagnosis<br>BMT as a treatment option                          | New findings about disease (i.e. mutations, response to treatment)<br>Next steps | BMT risks and process            |
| <b>Interaction</b>           | First conversation with provider around BMT                     | Conversations with providers during chemotherapy/hospital visits<br>Donor search | Unilateral orientation class     |
| <b>Communicative outcome</b> | Potential pursuit of BMT as treatment                           | Relationship development with providers  | Doubts about the value of BMT    |
| <b>Extracted Cues</b>        | Curative potential of transplant<br>Prerequisites to transplant | Disease information<br>Donor search<br>Doctor's suggestions                      | Mortality and morbidity risk     |
| <b>Sense made</b>            | Transplant as a possibility                                     | Transplant as a necessity  | Transplant as a cure with a cost |

Below, I describe in more detail the cues that patients and caregivers are attending to and making sense of, how the research procedures elicited this sensemaking, and what this means for the design of sensemaking support tools.

### **Transplant as “a Possibility, Not an Option”**

Patients in phase 1 understood transplant as a “possibility” for one of two reasons. For the group of patients and caregivers who immediately considered transplant as their only chance for survival, transplant was viewed as a possibility that would only become

an option *when* they met the prerequisites in phase 2. Consequently, they initially focused most heavily on how to meet the requirements for transplant. For those in phase 1 who had understood transplant as something that might be a consideration in the future, the possibility of transplant only became an option *if* they were not successfully treated with other means. These participants understood transplant as a treatment that might be needed if their disease was not well controlled with chemotherapy, if they found out they had certain mutations that would be better treated with transplant, or if their disease presentation changes suddenly. The consequences of transplant complications were not initially a consideration for participants who conceptualized the possibility in this way either.

Regardless of how participants had conceptualized transplant as a possibility, the progressive nature of understanding across the phases reflects how patients and caregivers perceive the transplant “decision,” as not necessarily being finalized at one particular moment. As seen in Study 2, patients and caregivers largely described transplant as ultimately being their only option, and not a true “decision” between treatment options. While creating their timeline, participants had an easier time indicating the moment when they would have considered themselves committed to getting transplant rather than when they made the decision *per se*. George said that he considered himself having gone through a process of “accepting the fact that it's going to have to be done.”

The methods and results of this study, particularly the use of the timeline to outline the sequence of events, helped to show why it is not considered a decision and how they come to understand it as such. They see achieving remission and the option to

get transplant as the goal in phase 2, and because it is not yet a reality for them, they adopt what Marnie called a “one step at a time” mentality. This mentality is focused on reaching the prerequisites rather than what reaching this goal might mean for their future.

A support tool accounting for this understanding of transplant as a possibility might put less emphasis on future outcomes and more on the immediate consequences of reaching the next step. For instance, during the donor search, emphasis may be put on the consequences of not finding a related donor and needing to look at the unrelated donor registry. The closeness of the donor match (which impacts the risk of experiencing complications like GVHD) may be more of a concern when actually evaluating potential matches. Essentially, “one step at a time” may instead be “one and a half steps at a time” – looking slightly towards the future without overwhelming patients with possibilities.

### **Transplant as a Necessity**

All patients described a moment, almost universally during a conversation with a provider, when they realized they would “need” transplant. The perception that they needed transplant to survive was clear in Studies 1 and 2, but in this adapted PD approach they were afforded the opportunity to describe *how* they came to perceive transplant as necessary. Whether they remembered transplant being presented by their providers as an eventual consideration (i.e. “He said that transplant might be something that they need to do” [Charles]) or immediately necessary (i.e. “He said you need it, I said okay.” [Bob]) all participants described having a conversation in phase 1 or 2 in which a provider said they needed or might need a transplant. This transition from viewing transplant as a possibility to a necessity came along with receiving information that they perceived to mean their disease could not be treated otherwise. For instance, 3 patients recalled



receiving results after their initial diagnosis that suggested they had a mutation that would not respond well to chemotherapy alone, making transplant the only choice to remain disease free.

Participants reported multiple memorable conversations with providers before transplant and described how their views of transplant evolved alongside these conversations. As Andrew remarked, he had three particularly memorable conversations with three different doctors during phase 2. In the first conversation, which occurred during his consolidation chemotherapy, he recalled his first doctor saying that he “shouldn’t think about” the risk of having a transplant, but “should also think about what are the risks if you don’t have a transplant.” Soon after this conversation, Andrew went to get a second opinion from another provider, who he recounts was much more explicit in telling him that he needed transplant. Andrew recalled this doctor telling him that because of his particular mutation, “you need it... you have no choice. If you can get a donor, you need a transplant.”

It was after this second conversation that Andrew said he was committed to getting transplant, as this doctor “confirmed what we already suspected,” that he needed transplant. However, he soon had a conversation with a third provider, the doctor who ultimately performed his transplant. Andrew described how this conversation reframed this seemingly decided issue as one still to be determined:

The feeling I got [during this conversation] was I had to decide whether I wanted to go through it or not knowing that there's risks involved with having a transplant both you might not survive the transplant and then, you know, you might have all

kinds of problems later... he was presenting it more as a decision and I was looking for more of do you need to do it or not.

Throughout this time, Andrew's understanding of what the best treatment option was and why was in flux. The first conversation led him to emphasize the threat of death from his disease. The second conversation emphasized the role of his mutation and how it necessitated transplant. Finally, Andrew interpreted the last conversation as the doctor attempting to facilitate decision making, but Andrew had already considered himself committed to getting transplant and wanted someone to tell him if he needed to do it or not.

In Studies 1 and 2, the providers believed they were presenting BMT as a decision that patients can contribute and consent to. Regardless of whether patients' recollections are accurate accounts of how providers presented this information, the fact that patients and caregivers interpret conversations with their providers as saying that BMT as a necessity to live is contributing to their perception that this is not a decision. This experience of transplant never being finalized or confirmed helps explain why it was extremely difficult for participants to identify when they had made the "decision" about transplant. Further, the potential for patients to feel like they have already committed to transplant before the risks are really emphasized is problematic.

Conversations between providers and patients/caregivers were explicitly described in Study 3 because participants were asked to detail what they considered most meaningful events leading up to transplant in their timeline. While similar discussions of important conversations may have occurred in Studies 1 and 2, the use of the timeline contextualized these meaningful conversations with providers and how they influenced

their understanding of BMT as a necessity. Whereas in Study 2, participants could say they did not perceive BMT as a decision simply because they needed transplant to live, in this study they were able to explain why they believed this to be true. Here, they were also able to express how they interpreted interactions with providers to indicate that they needed transplant. The focus on resulting interpretations rather than the informative content of the interactions explains why patients and caregivers perceived that having BMT had not been a decision.

The timeline in which patients are coming to understand transplant seems problematic. For example, Andrew interpreted early conversations with two providers as suggesting he needed transplant or he would die. It was only after he was committed to transplant that he started to learn about the complications, which did not serve his needs at that point. A support tool could be designed to gauge where patients are in their commitment to receiving transplant and simultaneously assess how aware they are of the consequences of this commitment. This is not to suggest a list of pros and cons for decision making. Rather, as will be discussed in the next section, patients and caregivers may just need to understand and accept that transplant means their lives will be different.

### **Transplant as a “Cure” With a Cost**

Patients and caregivers attended to cues that focused on the curative potential of transplant. In the sensitization exercise administered prior to the interview, when asked “What was the most important reason you/your loved one decided to receive transplant?” nearly all participants responded with answers referring to survival or longevity. This demonstrated the strong belief among participants that transplant was what caregiver Rachel called the “only chance” for survival. When it came to making sense of transplant,

participants 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). This is not surprising given the findings from Study 1 and 2 in which patients and caregivers described the experience as being a choice between transplant and death. However, in looking at the entirety of the sensemaking processes of participants in this study, it became clear that participants were not completely ignoring the potential negative effects of transplant. Instead, patients and caregivers were trying to reconcile transplant risks with its benefits. They were learning to accept that, if successful, transplant would irreversibly change (and potentially threaten) their lives.

Charles recreated a graph that he recalled his doctor drawing during a conversation they had after he had attended the orientation class that he left feeling “terrified” (Figure 9).

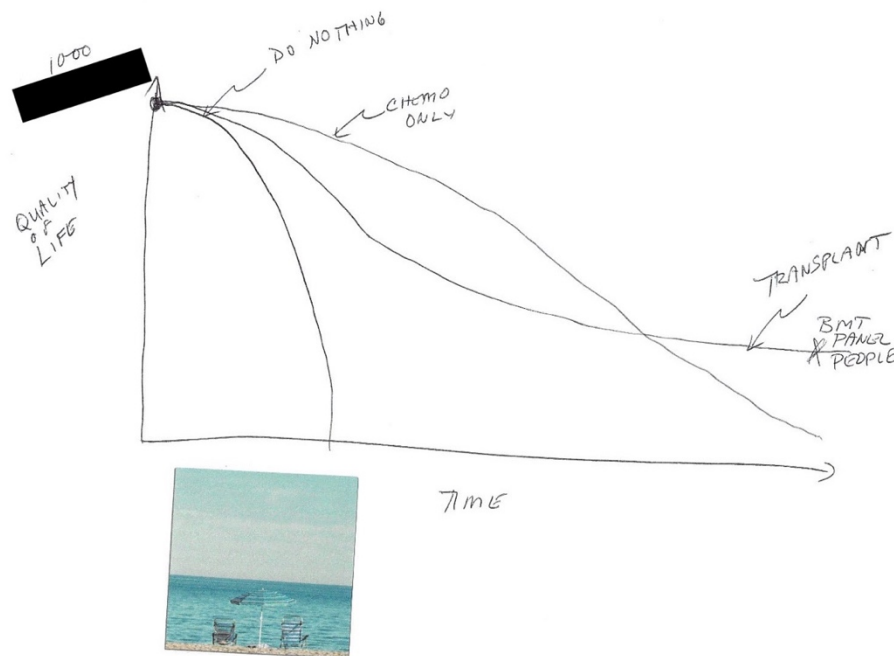


Figure 9. Graph drawn by Charles.

Charles had yet to make a decision about transplant at that point. While he recreated the graph, he described the doctor's chart as the "main factor" in his decision to receive transplant. Still, he experienced a significant emotional response in trying to understand what this graph meant for him:

Disheartening is too gentle of a word. Discouraged. Probably discouraged, off your list [the emotion words sheet], is probably the best word that would describe it at the time... I was 66 years old, but I was in, I thought, pretty good health... I had a lot of living to do. And when I see something like this, oh geez. Wow. I am speechless. Really, I'm not gonna have my quality of life back? I'm not gonna be doing some of the stuff I always did before?... Even with this chart, what does that [the difference in quality of life between transplant and chemo] mean? What's this—very scary. How degraded am I gonna be? And that's undetermined. That's an uncertainty there.

Charles struggled to come to terms with the potential for his life to be completely upended by transplant, but without transplant he would not be alive. Patients and caregivers are not neglecting to consider negative side effects. Nevertheless, they still struggle to reconcile the conflicting potential outcomes. When they are faced with the possibility of death or disability from transplant, they describe needing support to both maintain hope for a potential cure and also anticipate, prepare for, and accept a dramatic change in their quality of life.

Asking participants to describe the steps leading up to transplant illustrates why the orientation class was described by patients and providers in Study 1 as overwhelming and potentially discouraging. One reason for this can be seen in the steps leading up to

the orientation on the participant timelines. By the time they attend the orientation, they are relieved that they have achieved or seem likely to achieve the prerequisites to be a candidate for transplant. It is not just because there is so much information being presented in the orientation, but because, until the orientation, patients and caregivers have made sense of transplant as a necessity for survival. Then, they experience distress in phase 3 they are exposed to these negative outcomes of transplant. As George put it:

I was totally focused on ‘can we knock this out so I can get the transplant’ versus all the things about the transplant 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.

The visual timelines illustrated the progression of understanding of transplant from a possibility (if they meet the requirements), to a necessity (if they want to survive) to having a potentially devastating or deadly impact.

When patients and caregivers face a potentially life-changing procedure, they need to be informed of the potential negative outcomes. Yet, the current format can be fear-inducing and lead to doubts about transplant. Instead, a sensemaking support tool can center on fostering acceptance that their lives will be different. The concept that “cure” does not necessarily mean a return to life as it was before illness can focus on techniques for adapting to this new life. Similarly, participants proposed solutions (see below) in which information about the future would lead to a feeling of reassurance in the period leading up to transplant.

## Participants' Recommended Solutions

Of the solutions that participants came up with, nearly all were primarily concerned with either the design of information (e.g. “it would be helpful if you had even a caregiver... like an instructional. Like, listen you need as a caregiver to be prepared to do x, y, and z. Like just little helpful tips so that they know what they’re gonna be doing” [Rachel]) or interactions with information (e.g. “let us absorb [the risk information] more gradually, bit by bit, so we can better process it” [George]). Rarely were solutions described purely in terms of communicative outcomes (e.g. trust in the clinical team), as patients often described changes to the information or interaction in order to achieve these larger communicative goals.

Similar to the findings in Studies 1 and 2, the solutions that patients and caregivers most commonly proposed related to improving expectations and preparation for transplant outcomes. Another common theme among solutions was personalization of pre-BMT support. Additionally, when participants described solutions, they made it evident how important it was to offer support that provides reassurance and/or reduces fear in the pre-BMT period. Participant solutions appeared to be an attempt to reconcile the need to have accurate expectations for life after transplant with the need to make sense of the distressing experiences before transplant. What their solutions did that the prototypes in Study 2 did not was support the significant sensemaking work that patients and caregivers must do in the period leading up to transplant as they attempt to navigate their new illness experiences while also attempting to form expectations for the future.

### *Improving Expectations and Preparation by Providing Reassurance*

The majority of the solutions that participants proposed were designed to have better prepared them for the outcomes they experienced after transplant. While this need was clear from previous studies, having participants invent ways that their expectations could have been improved gave further insight into how they are forming these expectations and what they are referring to when they imagine the future. For instance, Margaret described how she worked to formulate clearer expectations by answering a question that arose during the orientation class about the hospital stay, using this experience to suggest improvements for future classes:

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 they 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 they took a picture if you can't bring the patient there. I just felt like it's one less unknown.

Margaret's suggestion aims to reduce the amount of uncertainty concerning the actual experience of getting transplant. Preparing for a long hospital stay (that is sometimes repeated when donors fall through) is one of the few things she could control. For many patients, the uncertainty is so great that any opportunity to develop a concrete sense of what to expect and how they could prepare is welcomed. Another example of this came



from Charles, who suggested that patients pre-BMT be told of the available treatments for GVHD while they are learning about potential side effects (like in the orientation class). He remembered being devastated when he learned of the complications of GVHD, but pointed out that he had not been told of the remedies available when he ultimately did experience GVHD. As such, the need for preparations and expectations, established in Studies 1 and 2, can be expanded to include *reassurance*—by not only presenting potential problems, but also providing potential solutions. Later in the interview, Charles went on to suggest that there be a way to “have the patient get confidence in the medical team.” Although he admitted that he was not sure how to systematically develop this relationship, he relayed his own experience. He recalled how valuable he found the team taking the time to talk to him and to explain BMT in terms that he could understand. In his case, the doctor “explained [BMT] to me in terms that I as an engineer can really relate to, and that helped a lot.” By the number of interactions with providers that participants included on their timelines, it is clear that the patient-provider relationship was a critically important element of pre-BMT sensemaking.

These proposed solutions illustrate at least two 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 misinterpreted as false hope. While providers should avoid making guarantees of a cure, they can guarantee that they will do whatever possible to support patients in their recovery. This solution is similar to that proposed by Little et al.

(2008), who concluded 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, providers offer “commitment to provide the support that patients and their carers needed during the ordeal” (p. 663). Thus, Little et al.’s suggestion focuses on support during the treatment/recovery experience. In contrast, the solutions developed by participants in this study emphasized the potential for reassurance in the pre-BMT period to have an impact on patient and caregiver experiences later in transplant. As Han (2011) describes, the “ultimate challenge” of clinical practice is “managing uncertainty arising from irreducible ignorance... It requires helping patients—and health professionals—cope with the consciousness of ignorance that cannot be remediated” (p. 836). The solutions developed by participants to help others pre-BMT to feel reassured in a time of irreducible uncertainty may inform other attempts to overcome this challenge.

### ***Personalizing Information***

In Studies 1 and 2, stakeholders discussed the difficulties of personalizing risk information for such an unpredictable treatment. Some of the solutions proposed by participants in Study 3 centered around having more personalized risk likelihoods concerning side effects. This echoes the patient and caregiver interest in Study 2 in the GVHD risk calculator rather than the survival statistics. However, in reflecting on their experiences in the pre-BMT period, patients and caregivers described the challenge of determining information relevance in a single class designed for multiple patients to learn about side effects. One suggestion from a patient/caregiver pair, George and his wife Marnie, offers more insight into how this might be accomplished. In the following

exchange, they collaboratively build on the idea of a scheduled follow-up as an opportunity to ask questions after processing the class. They suggest that this follow-up would help to contextualize the large amounts of new and scary information they had just received:

George: I think having almost like a structure where it says, okay, in about two weeks [after the orientation], we're going to have some of you come back or whatever, let's schedule a follow-up. To each of you, we'll give you like 45 minutes or whatever, to talk with one of us about what you learned and talk about what kind of thing—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 and get some more answers.

Marnie: And the follow-up would be on your specific situation, not someone else's with non-Hodgkin's or something else.

George: Right. So it's more targeted. It's targeted for us, not for everyone.

Marnie: 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.

George: So yeah, that would have been really nice to know that we have a finite, scheduled thing here, where we're going to follow up with you directly.

At least 4 needs are explicitly present in this exchange: 1) to ask questions privately, 2) to contextualize information for a patient's individual situation, 3) to determine which outcomes are most relevant to the patient specifically, and 4) to have a time organized as

part of clinic practice so that patients or caregivers do not need to request it. George and Marnie described having left the orientation feeling “terrified,” while also believing that there was no option but to receive a transplant. In essence, they were told “all the terrible things that are going to happen to you” without a scheduled opportunity to talk to the doctor and better understand/contextualize what they had just heard about this high-risk treatment that they believed was necessary for survival.

Patients attending the class are all candidates for transplant, but the similarities may end there. They might have different diagnoses, ages, and likelihoods for potential outcomes of transplant. After the class, there is not always a one-on-one conversation with providers when participants can express doubts or ask questions (only Charles described having a conversation like this after the class). Patients and caregivers also do not want to have the responsibility to follow-up with the providers. George said that he knew he could reach out to the providers and ask any questions but said he didn’t “want to burden him with my individual problems.” As he describes it, having dedicated time to follow-up would have alleviated some of the “freak out” after leaving the class. Again, this points to a need for reassurance and emotional support when patients face risk information.

The solution that George and Marnie came up with would both serve patients and caregivers in forming expectations that are more accurate to their circumstances. This solution could also aid in relieving the doubt that many experienced in phase 3 after learning of the risks associated with transplant. In this way, the solution supports patients and caregivers in their pre-transplant sensemaking and in their post-transplant illness experience. Table 8 presents three examples of participant solutions just described and

categorizes them as a design for information, interaction, or communication. For each solution, the proposed outcome is also presented along with a possible feature that could be included in a sensemaking support tool to help achieve these outcomes.

**Table 8**

*Participant Proposed Solutions and Potential Sensemaking Support Tools as Design for Information, Interaction, or Communication*

|                      | <b>Potential Solution</b>                                       | <b>Proposed Outcome</b>                               | <b>Sensemaking Tool</b>  |
|----------------------|---|---|--|
| <b>Information</b>   | Photos of hospital room (Margaret)                              | Less uncertainty; “more comfortable”                  | Visuals/narrative of transplant treatment experience in the hospital   |
| <b>Interaction</b>   | One-on-one meeting with provider after the orientation (George) | Put risks into perspective; alleviate “the freak out” | Option to privately ask specific questions as they arise               |
| <b>Communication</b> | Trust in clinical team (Charles)                                | “Increased confidence”                                | Assessing user understanding and adapting language to meet their needs |

### **The Design Process**

As discussed in Chapter 2, the ways that users participate and the interactions between users and professional designers are considered objects of study within the design process. The PD workshop is the means by which designers and users interact, as the toolkit is designed to enable participants to engage in creative activities. This is essentially an act of designing communication between/among the designer and the participant(s). As such, the materials in the toolkit have certain affordances that lead to particular kinds of interactions. In PD, participants should be engaged in developing the processes that facilitate their participation, not just the design outcomes. As participants

in Study 3 offered feedback on the process, either explicitly or in their interactions with the toolkit, practices around facilitating interaction with the toolkit were altered for future workshops. After all workshop sessions for Study 3, participants were asked to briefly reflect on their experiences participating in these design workshop and to provide comments on the usability of the toolkit. When comments included ways that participants felt the toolkit could have better enabled them to express themselves, changes to the process were made. There are three salient examples of how the toolkit and research procedures evolved based on suggestions or observations of use from participants: the addition of the timeline template, interactions with the emotion words sheet, and the ideation exercise.

### **The Timeline Template**

The toolkit was originally designed to include blank sheets of paper for participants to draw their timelines. The first patient-caregiver pair (George and Marnie) were asked to participate using such minimal tools. At the end of the session, the participants were asked about the experience of creating a timeline and how the toolkit helped or hindered their ability to express themselves. While this first pair was able to create a timeline, at the end of the workshop, they commented on the difficulties of having to start with a blank sheet. The following exchange between the participants and the designer ideate around how this process might be improved:

George: I think [the toolkit] needs some refinement and some structure before—because I'm not good at drawing and [my wife] kind of is, but sometimes it's like the blank piece of paper fear then like I got to create something here and there's

nothing here and I've got to come up with something. It becomes a pressure situation for some people.

Interviewer: What about even just like a line to show the timeline? Would that be helpful?

George: Maybe a blank line with chunks on the line where you could point to things, say here's where we go. I think a blank sheet is difficult. I think giving some structure to fill in is definitely going to be helpful versus like, okay, let's start with that kind of thing.

Marnie: And we can even work something up like that for you... just to help someone start to plot their thoughts.

George and Marnie later emailed a mockup of what they thought the timeline template should look like along with their feedback on the entire process. This contribution was unsolicited – they volunteered to create this timeline template and offer a written critique of the experience. Because they were the first participants to use the toolkit, their feedback was incorporated before the next interview. Instead of sending participants blank sheets of paper, they were given two timeline templates, one with spaces allotted for questions and emotions and one with just a timeline and spaces to fill in dates.

The second patient-caregiver pair (Margaret and Harriet) received the two templates along with blank sheets of paper and were told they could use whichever seemed more appropriate to their experiences. They ultimately used both timeline template sheets, as their timelines extended beyond a single page. The inclusion of the templates seemed to make a significant difference, as Margaret offered that she “did like some guidance.”

The value of the template (and the challenges of a blank piece of paper) is likely related to the levels of creativity participants have at the beginning of the workshop. As described in Chapter 2, people exist at different levels of creativity and the designer's job is to provide tools that enable participants to engage at all levels. Sanders and Stappers (2016) offer recommendations for how to support people at the various levels, with those at the *creating level* doing best with a "clean slate" to create things from scratch (p.40). However, for these participants the blankness of the paper did not facilitate creative expression and was instead considered daunting. In this case, participants might be best described at the *adapting level*, which is best supported with some guidance, or the *making level*, which benefits from scaffolds to support creative expression. The path of expression is intended to guide people through the levels of creativity by helping them to recall past experiences that inform ideation around future solutions. The addition of the timeline template offered guidance in expressing past experiences and led participants through the path of expression to more readily engage in creative ideation.

### **Emotions Page**

As described in Chapter 3, emotions are tools for creative thinking, and thus the inclusion of the emotions sheet was intended to capture the potential for emotional experiences to inform possible solutions. Though participants did not necessarily use many of the included stickers on their timelines, they referred to it frequently in the sessions or wrote words included on it directly rather than using the stickers. Some emotions were associated with particular phases of the pre-BMT process, while others were described as more of a general feeling throughout the process. This description of emotions as not being associated with particular points in time was unexpected, though



the size of the emotion word stickers may have contributed to this. The inclusion of just one copy of each emotion word sticker (which were designed to emphasize discrete points in the pre-BMT process) may have also contributed to participants instead verbalizing their emotions.

Participants appropriated the emotion word sheet in ways that it was not originally designed to be used. For instance, George and Marnie decided to include the emotions they had *not* felt, as they believed they had felt most of the ones on the list. To show this, they placed the emotions they had not felt on their timeline and crossed them out (Figure 10) This inspired a question asked in later workshops: “Are there any emotions on the page that do *not* resonate with you or that you did not feel during this process?” Another unexpected behavior was that three participants sent back the emotion words sheet with comments on individual stickers, as in the detailed reflection on each emotion from Charles (Figure 11). The unexpected use of the emotion word sheet supports its value in inspiring creativity and reflection on the emotional experiences informing sensemaking.

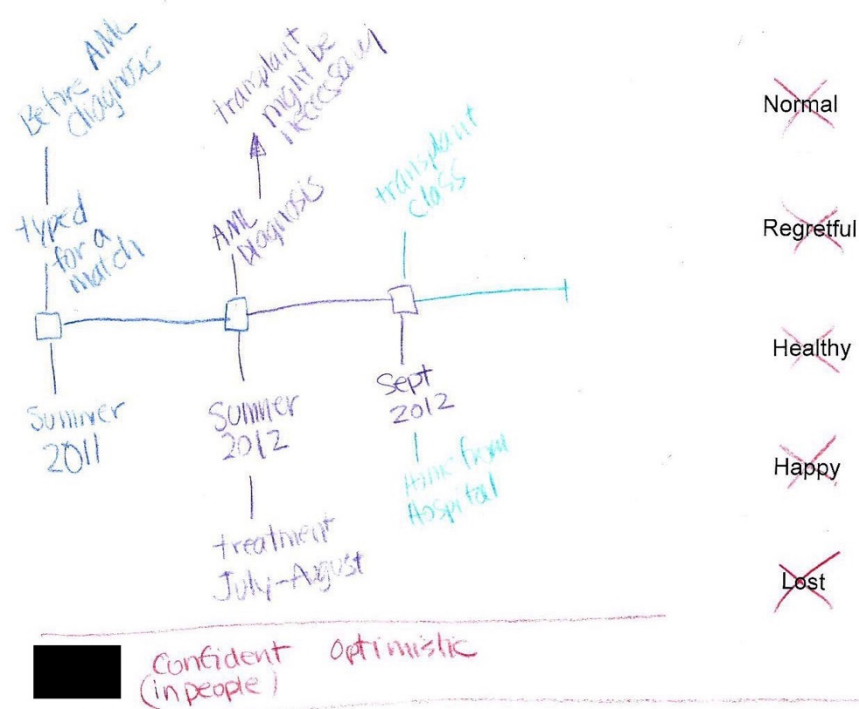


Figure 10. George and Marnie's timeline drawing.

|   |  |  |
|---|--|--|
| <p><b>Afraid</b> ✓<br/>GOT BETTER AFTER<br/>RELEASE FROM BMTU</p>                                 | <p><b>Angry</b> ✓<br/>IN THE BEGINNING,<br/>BUT I GOT OVER IT QUICKLY</p>                    | <p><b>Anxious</b> ✓<br/>CONTINUOUS IN THE<br/>BEGINNING, SOMETIMES STILL</p>                         |
| <p>NOT IN THE BEGINNING<br/><b>Comfortable?</b><br/>WAS MORE AFTER<br/>I MADE CHOICE FOR BMTU</p> | <p><b>Confident</b> ✓<br/>THAT I WOULD GIVE<br/>IT A GOOD FIGHT!</p>                         | <p><b>OFTEN</b><br/><b>Confused</b><br/>UNTIL I UNDERSTOOD<br/>THE PROCESS</p>                       |
| <p><b>CONSTANT</b><br/>Coping</p>   | <p>RARELY<br/>Discouraged</p>  | <p>AT TIMES<br/><b>Frustrated</b><br/>THAT I HAD TO<br/>GO THRU THIS</p>                             |
| <p><b>Grateful</b><br/><b>FOR DR.</b> [REDACTED]</p>  | <p>I TRIED TO STAY<br/><b>Happy</b> ✓<br/>KEEPS UP ENERGY,<br/>MOTIVATION, STRENGTH</p>      | <p>VERY MUCH BEFORE "L"<br/><b>Healthy</b><br/>GOOD NOW: NEVER<br/>LIKE BEFORE "L"</p>               |
| <p>MOSTLY YES.<br/><b>Informed</b><br/>EXCEPT FOR HOW MANY<br/>CYCLES OF CHEMO NEEDED</p>         | <p>NOT<br/>REALLY <b>Lost</b> ✗</p>  | <p>VERY<br/><b>Motivated</b><br/>TO GET THRU IT</p>  |
| <p><b>NEVER</b><br/>Normal!<br/><b>AGAIN</b>!</p>   | <p>I TRIED TO BE<br/><b>Optimistic</b><br/>AND USUALLY AM</p>                                | <p><b>ALWAYS</b><br/><b>Overwhelmed</b><br/><b>THEN</b> NOT SO<br/>MUCH NOW</p>                      |
| <p>NOT VERY<br/><b>? Prepared ?</b></p>   | <p><b>NEVER</b><br/><b>Regretful</b><br/>NOT LOOKING BACK!<br/>NOTHING I COULD HAVE DONE</p> | <p>IT HELPED ONCE I<br/><b>Relaxed</b><br/>DECIDED WHAT I<br/>WAS DOING - BMT</p>                    |
| <p>YEAH, ONCE IN A<br/><b>Sad</b><br/>WHILE MISSING MY<br/>OLD LIFE &amp; HEALTH</p>              | <p><b>NOT VERY</b><br/><b>Sick</b></p>   | <p>EVERY DAY!<br/><b>Surprised ?</b><br/>USUALLY IN A GOOD WAY</p>                                   |
| <p><b>OFTEN</b><br/><b>Tired</b><br/>PHYSICALLY &amp;<br/>MENTALLY</p>                            | <p><b>I'm VERY</b><br/><b>Tough</b><br/>BMT/"L" ISN'T GOING<br/>TO STOP ME</p>               | <p><b>YES</b><br/><b>Unsure</b><br/>OFTEN</p>  |
|   | <p><b>TERRIFIED</b> —<br/>AFTER BMT CLASS!!</p>  | <p>ON DAY OF TRANSPLANT<br/>- VERY EMOTIONAL<br/>- GETTING SOMEONE<br/>ELSE'S MARROW &amp; BLOOD</p> |

Figure 11. Annotated emotion words sheet from Charles.

### **Creative Ideation – Tools for Facilitating Creativity and Communication in PD**

Like the prototypes in Study 2, the toolkit acted as a boundary object in this study. However, unlike the prototypes, the participants were asked to personalize their timelines to reflect their unique experiences. In Chapter 2, the addition of a function for boundary objects specifically – *disclosing* – was proposed. The methods of Study 3 allow an assessment of this function and whether it is a useful way to view boundary objects within PD. Disclosing was described as “how non-designers/end users create objects that communicate their distinct perspectives, needs, and possible solutions.” The timeline toolkit fulfilled this function by creating a context for participants to express perspectives and needs that led to results regarding sensemaking in participants’ pre-BMT experiences. However, the design exercise to facilitate creative ideation by disclosing user-driven solutions did not always produce results as expected.

The ideation exercise may have been less successful than anticipated for the following reasons. First, the limitations imposed by the remote nature of the study prevented multiple participants from meeting in one group. The participants who were in pairs (i.e. a patient and caregiver together) contributed significantly more potential solutions than individual participants. Participants who were in pairs presented an average of 2.4 ideas (ranging from 1–8 ideas per person), while those who were alone averaged 1.4 ideas (with a range of 0–3). Though it is not useful to make quantitative claims with such a small sample size, interactions between patients and caregivers around their proposed ideas suggest that having someone with shared knowledge to collaborate with aided in idea development.

There was a noticeable difference in the ways that the proposed solutions evolved when two participants had a conversation with each other rather than with the researcher. This can be seen in the conversation excerpted above between George and Marnie in which they co-construct the solution by building on each other's proposals. Such collaborative brainstorming allowed participants to create a new understanding of their needs and possible solutions, and recording these conversations provided the researcher an opportunity to see in real time how participants were creating these new solutions. This co-creation can be seen in the conversation between George and Marnie excerpted above. That conversation began with Marnie asking George if a one-on-one class with a provider would have made a difference, and ultimately led to a mutually developed design of an individual follow up plan.

The toolkit appears to be more useful in facilitating creative ideation in pairs than in individual participants. It is unclear if this was because paired participants were intimately familiar with each other's BMT experiences. Future work would benefit from testing these design processes of groups of people who differ in their shared experiences (either strangers or patients/caregivers) as compared one-on-one sessions between designer and participant. Alternatively, for those who could only meet individually, perhaps they would benefit from seeing the solutions proposed by other participants and providing feedback. Future work will focus on developing the disclosure functionality of boundary objects in PD specifically in ideating solutions.

## **Discussion**

This study addressed similar questions to those asked in Studies 1 and 2. However, the emphasis on sensemaking and participation here offered a deeper look into

the perspective that BMT was not viewed as a choice between two options. Study 3 explored how patients and caregivers conceptualize transplant in the period of time leading up to treatment. The revelation that BMT was understood as a “possibility” rather than an option highlights how the 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 desire or commitment (i.e. ‘decision’) to receive transplant. The focus on meeting prerequisites and the curative potential of transplant in phases 1 and 2 rather than the possible consequences of transplant means that patients and caregivers felt ill-prepared for their formal education in phase 3. Participants subsequently experienced fear and doubt about transplant.

Accordingly, participants designed solutions that were intended to improve their expectations for transplant outcomes and help them understand what transplant would mean for their futures. While Studies 1 and 2 similarly showed that patients and caregivers need to know what to expect after transplant, the solutions proposed by participants also indicated a related need for reassurance. The PD method for sensemaking used here showed how patient/caregiver expectations are currently formed and how these expectations are informing patient and caregiver conceptualizations of BMT. By taking an approach that looks at how patients and caregivers are making sense of transplant during this important period, we can better design tools that support them in forming the most appropriate and useful understanding of what they will experience.

### **Refining the Design Situation**

In the first stages of this design process, the ultimate goal was perceived to be enabling informed decision making by aiding patients and caregivers in imagining

possible futures with or without transplant. There was recognition that the stakeholder groups differed in their required qualities of prediction; providers were looking to increase accuracy for patients to better understand both the consequences and probabilities of different complications (with calculated risk information) while patients and caregivers were more concerned about their ability to expect and prepare for possible outcomes/practical implications (supported with experienced patient narratives). The solutions that were developed using UCD methods focused on giving patients a better idea of what they could expect from transplant to more accurately imagine their futures. However, when presented to stakeholders, the utility of the proposed system was called into question. While all stakeholder groups could recognize that patient and caregiver expectations going into transplant were often retrospectively viewed as inaccurate, it was unclear where these expectations were coming from or why patients and caregivers did not see transplant as having been a decision.

The results of this study demonstrate that an episodic view of decision-making is not conducive to development of decision support for BMT. Instead, support for the multi-phase sensemaking process during this period might more effectively be designed to adapt to this gradual development of understanding. This was not something that came through in the interviews or in the feedback on the prototypes. Only when participants were given the opportunity to visually express their experiences did it become clear that there was consistency in the events they found meaningful and in the progression from first learning about transplant to actually receiving it. While the system developed and tested in Study 2 did feature a timeline, the first node on that timeline began with transplant. This prototype reflects a flawed understanding of the problem as one of

improving expectations by more accurately representing the future. The risk calculator and the patient experience video archive were both future-oriented support tools, but patients and caregivers must also make sense of the challenges they actively face during the pre-BMT period. The prototypes in Study 2 were designed around getting to a single point in time—the “decision”—and forming accurate expectations for the consequences of a procedure. However, patients and caregivers are so concerned with getting to remission, finding a donor, etc. that it is impossible for them to use information about what they might experience in the future while they are still uncertain if they will even get a transplant or that it will be successful.

Based on the findings of the present study, it is clear that patients and caregivers require support in the period leading up to transplant. The support they receive in that period can simultaneously aid in their pre-BMT sensemaking and improve their expectations for life post-BMT. The risk calculator and experiential prototype features as they currently exist may improve expectation accuracy, but they were not designed to meet the needs of patients and caregivers as they try to navigate the pre-BMT period.

### **A Comparison of Design Approaches: UCD vs. PD**

As in Studies 1 and 2, the need to have accurate expectations and be prepared for possible outcomes is critically important and difficult to achieve with the current institutional pre-BMT processes. The participation strategies used here gave patients and caregivers the opportunity to share their experiences and how they formed expectations visually. These strategies led to an external representation that was used for reflection, for clarification, and to record the process of reaching BMT. Eliciting visual representations can help participants to express abstract concepts in a more concrete way (Cox et al.,



2014). A concept like sensemaking, which is inherently abstract, is well-suited for a visual format. Whereas in Study 2, participants referred to their own experiences when providing feedback on low-fidelity, yet conceptually concrete, prototypes, the present study enabled patients to more clearly express these experiences in a holistic and tangible way. Findings expanded on the need to be more prepared to also include support in making sense of a complicated situation and being reassured during this period. Further, participants in this study were able to prioritize the experiences they found most memorable rather than just those that are triggered by the prototypes. As noted, these initial prototypes were based on an incomplete understanding of the design situation. The processes used in Study 3 allowed participants to guide the creation of the boundary objects used for discussion and gave clarity on the patient and caregiver perspectives.

Development of this study was guided by the five principles of design for sensemaking outlined in Chapter 2. This study took a *meaning-centered* approach by asking participants to describe the ways that they made sense of BMT in the period leading up to the procedure, emphasizing their questions, emotions, and expectations. *Temporality* was emphasized in the creation of timelines to capture changes in sensemaking over this period. Patients and caregivers were *included* in the design of potential solutions as well as the toolkit they used to participate. The process was *self-reflective* as participants were encouraged to act as designers of both the design outcome and the participation process, a concept that challenged the privileged position of the designer. This study was also initiated in response to the realization that the prototypes had foregrounded provider and designer perspectives that this was a “decision.” *Action* took center stage through the participants’ use of the toolkit and in the practice of

participants imagining potential real-life solutions as they would fit in the pre-BMT process.

The design processes used here were altered based on participant input and recommendations were incorporated into future workshops. This suggests a sixth principle for design for sensemaking support – *adaptability*. The frequent reflections on methods for participation and suggestions from participants led to a toolkit that better enabled expression of past experiences. Appropriation of the toolkit led to clarity in its potential utility outside of how it was intended in surprising ways. There is still work to be done, particularly in facilitating ideation on potential solutions. However, the benefits of participant involvement in the design of the methods as well as design outcomes in this study is encouraging.

Compared to the findings of Studies 1 and 2, this study offered a more realistic and holistic view of the BMT experience by giving participants the chance to share the entirety of their experience leading up to transplant rather than just sharing their unmet needs, which are often constrained by the interview questions framed by the designer's/researcher's understanding. The PD approach enabled participants to determine what events were most important to their decision making as they were encouraged to talk about the things they did not know and the ways they felt. This identification led to the realization that the multistage pre-BMT process that patients and caregivers go through is something they need more support for. They do not just need to be better prepared for the outcomes they experience, but they need to be supported throughout the entire process, as there is no guarantee that they will even reach the point of considering long term consequences. The support offered, and the PD tools used in

facilitating sensemaking in pursuit of designing support, need to be present, adaptive, and conducive to the ever-changing understanding of the illness experience.

## **CHAPTER 7: Discussion**

### **Summary of Findings**

This research adopted an iterative design approach that began with user-centered design (UCD) methods in Studies 1 and 2, followed by participatory design (PD) methods targeting sensemaking in Study 3. The outputs of this work are both a better understanding of the case study of bone marrow transplant (BMT) and the development of a methodology to investigate the challenges of sensemaking in ways that promote improved design of support tools for those facing complex medical situations.

### **BMT Specific Findings and Clinical Implications**

The results of this work revealed multiple points pre- and post-transplant where patients need support, and where it is inadequate to target information transfer as the primary supportive solution. Study 1 used the UCD method of need-finding interviews to gain an initial understanding of the design situation. Results showed that providers perceived decision regret in patients who had consented to transplant and later claimed that they did not fully understand what they were agreeing to. Providers understood their job as facilitating informed decision making and understood their challenges to be about communicating complicated information about transplant risks and benefits.

Patients confirmed their struggles in using information received prior to transplant to accurately imagine life after transplant. Yet, patients did not consider this failure of informed decision making but as a failure to develop accurate expectations and prepare for transplant outcomes. Providers had attempted to solve this problem based on their understanding of the challenge through the creation of an orientation class. Still, the class maintained some of the shortcomings in existing pre-BMT patient support practices.

While providers could recognize where the orientation fell short, they did not appear to recognize that these failures were partly because the class had been designed for information transfer rather than supporting patients in using this information to inform their expectations.

As is typical of a UCD process, prototypes of two features were developed based on the needs identified in Study 1: a risk calculator, that used patient-specific characteristics to calculate personalized outcome likelihoods, and an experience video archive, that would present users with videos of other patients and caregivers describing their experiences with transplant. Variations of low-fidelity prototypes of these features were shown to providers, patients, and caregivers for feedback on the perceived utility of these tools in Study 2. Stakeholders raised questions about where the proposed tool might fit into the process leading up to transplant. More importantly, their comments challenged the problem framing that had informed the development of these prototypes.

While we had expected that the risk calculator would meet the need of providers in Study 1 to articulate the complex risk/benefit tradeoffs, patients and caregivers in Study 2 did not seem to think this information would have made a meaningful difference for them. Patients and caregivers reflected on the prototypes using their own experiences, and much of their feedback was influenced by the perception that they had not actually made a “decision” between treatment options. Therefore, they saw potential for the risk calculator to have a neutral or even negative effect if the numbers were discouraging. This led them to question the utility of the risk calculator as they had not compared the pros and cons of transplant vs chemo as they saw transplant as their only choice. In reflecting on the experience video archive, providers saw value in the potential to inform

patient expectations but questioned the utility of this feature for someone who is facing a life or death choice. Patients and caregivers saw the variety of experiences and the inclusion of a timeline in the interface as useful for understanding transplant outcomes. Yet, when patients and caregivers imagined using the system, they believed it would be most useful *after* getting transplant rather than in the period leading up to transplant as it had been intended. The UCD methods in Studies 1 and 2 had allowed for an initial understanding of the challenges of BMT decision making. Designing and collecting feedback on prototypes, which acted as boundary objects between the users and designers, uncovered a gap in the design situation being framed as one of decision making.

The need for patients and caregivers to be better prepared for the outcomes of transplant still required a better understanding of the process that patients and caregivers went through leading up to transplant and how they were forming expectations. This process was not perceived by patients and caregivers to be one of decision making, so questions remained as to how patients *were* making sense of this experience. Thus, rather than continuing the refinement of existing prototypes, Study 3 took a step back by adopting an alternative approach to exploring how patients/caregivers understood their pre-BMT experience and its challenges.

Study 3 investigated this question using a PD approach, asking patients and caregivers to create visual representations of the time leading up to transplant. This presented a holistic view of their experiences in the period before transplant and how they were forming expectations. They described a multi-phase sensemaking process consisting of three phases: 1) introduction to transplant, 2) pre-BMT treatment, and 3) formal

education. Patients and caregivers attended to the curative potential of transplant rather than its consequences in phases 1 and 2. The lack of attention to transplant complications during the early phases was partly due to the series of requirements that patients must fulfill in phase 2 before they can qualify for transplant. The uncertainty before patients achieve these milestones is immense and painful, which contributes to their lack of attention during phases 1 and 2 to what might occur down the road. Consequently, transplant is first considered a possibility, not an option that requires conscious selection; uncovering this conceptualization of transplant helped to see how little a patient's "decision" actually influences whether or not they receive transplant. Patients' focus on achieving transplant prerequisites in phase 2 means that when they finally are exposed to transplant complications and risks in phase 3, they experience doubts around the value of transplant and begin to reconceptualize their understanding of BMT. Early on, they develop an understanding that transplant is necessary for survival and thus attend heavily to achieving prerequisites in pursuit of what they believed to be a life-saving treatment. When they learn in phase 3 that this treatment comes with significant and deadly potential side effects, their expectation of transplant as a cure is challenged and the emotional impact is significant.

These findings provide insight into why the solutions proposed in Study 2 were viewed as inadequate – they were designed to help patients and caregivers better understand life after transplant, but they face many challenges in the pre-BMT period that make transplant seem uncertain. The realization in Study 3 that patients and caregivers are experiencing a gradual development of understanding and acceptance of BMT contrasts with the episodic, information-centric view that informed the initial prototypes

and the informed consent procedures. It is a perspective in which the decision is marked as a transition of sorts, in which patients can conceptualize “before” and “after” making a decision, which was not what these participants experienced.

While improving expectations is critical to informed consent, the issue was that these prototypes were designed to help patients pre-BMT to more accurately imagine what the future might look like. However, sensemaking theory proposes that accuracy is not necessary for people to navigate complexity. Instead, sensemaking is about “continued redrafting of an emerging story so that it becomes more comprehensive, incorporates more of the observed data, and is more resilient in the face of criticism” (Weick, Sutcliffe, & Obstfeld, 2005, p. 415). This need for sensemaking support was seen in the patient and caregiver feedback in Study 2, as they rejected the proposed features as unnecessary and potentially harmful. Instead of looking towards improving accuracy of expectations, the goal of a sensemaking support tool may be to aid patients and caregivers in seeing the relevance of this information. The result would be a better understanding of what this information means for their specific circumstances and why this information is important. This could be achieved through the intentional design of patient-provider interactions, as in the suggestion of a follow-up meeting after the orientation proposed by George and Marnie in Study 3.

The finding that BMT was not perceived by patients and caregivers as a decision is similar to the finding of Jacoby et al. (2014) who concluded that the nature of decision making and informed consent was inherently coercive as patients perceived transplant as their only chance at survival. They also suggested that patients do not value understanding the risk information provided to them and that there may be more value in



the emotional benefits of informed consent (like building trust). Study 3 offered more insight into *why* patients are coming to see transplant as their only option and how that informs their expectations, as well as the emotional components of the pre-BMT process. Further, there is a need for reassurance underlying how patients form expectations. Providers may benefit from presenting information gradually, as it becomes relevant and perhaps letting patients know ahead of time that the information on particular complications or treatments is available to them if they need it. This potential solution has implications for patient-provider communication practices as well as the system being developed.

Patients' and caregivers' need to have emotional support may benefit from Epstein and Gramling's (2013) proposal that providers "check in" periodically with patients facing complex medical decisions as the clinical situation changes. This check in could facilitate decisions that are based on preferences that are conditional and provisional. This check in could be facilitated by the support system. Rather than simply presenting users with risk information, as in the original prototypes, users could be asked to record their current preferences/emotions towards transplant. These potentially changing preferences could be recorded over time, as patients and caregivers go through the prerequisites and the orientation class. This could not only be used as a piece of information for providers to capture and assess evolving understanding in this period, but also for patients to reflect on how their understanding of BMT and their expectations change over time.

Another meaningful change could be the inclusion of an easily accessible "Ask a Question" button on every page. As users navigate the system, they may have questions

about the content or its personal relevance. Being able to record questions in response to particular pieces of content would also give providers insight into what is triggering these questions and thus illustrate some part of user sensemaking. These are just some of the many possible solutions, as the BMT-specific findings presented here will be used in the continued development of this particular support tool.

### **Implications for Shared Decision Making**

This work has potential to alter the way SDM is put into practice. An approach that incorporates design for sensemaking could conceivably support collaboration between patients and providers by looking at the ways that each party's situation, past experience, emotions, expectations, etc. influence their interpretations of the information deemed critical in SDM. As stated in Chapter 1, the ideals of SDM suggest that providers should aid patients in evaluating their options based on their goals and expectations as part of the deliberation process. This is one element of SDM where practical implementation has been lacking, and where design for sensemaking can be especially beneficial. Particularly in situations/conversations where a decision is a possible outcome, like a patient experiencing side effects and considering a change in medication, sensemaking support could aid patients in articulating their evolving preferences and experiences. The benefits of design for sensemaking in these types of situation stem from the longitudinal view of "decisions" as events and experiences that do not happen at single points in time but may need to be reevaluated and discussed on multiple occasions, or may lead to further conversations among the patient's family or other providers. Lahtiranta, Koskinen, Knaapi-Junnila, and Nurminen (2015) present a similar conceptual argument in describing the value of *health navigators*, or artifacts that support personal

health decision making. These navigators are described as essentially facilitating health information organization to “help citizens to help themselves, and support in achieving health-related goals of relevance and personal commitment” (p. 802). As SDM has conceptually adopted a more holistic view of patients that accounts for the impact of the social systems they are part of, DAs have struggled to account for such complexities. Reconceptualizing the challenges of deliberation to include the ongoing, dynamic sensemaking processes that occur in evolving situational contexts could ultimately affect communication between patients and providers.

Further, this work illustrates the benefit and feasibility of involving stakeholders in the early design phases of support tools, a practice that is being increasingly recognized as critical to patient-centered care (Patient-Centered Outcomes Research Institute [PCORI], 2019). In this study, the tools that were produced based on methods common to DA development (interviews, focus groups, and low-fidelity prototype testing) were not considered to be especially useful for pre-BMT support. Asking patients and caregivers to participate in the creation of potential solutions and the visual expression of their experiences opened up new opportunities for sensemaking support beyond what was considered from the typical DA development processes. Similar methods could be applied to DA development in future work.

### **The Design Process**

Buchanan (1992) defines design processes for wicked problems as being based in the difference between determinacy and indeterminacy – the linear model of design is based on determinate problems that have definite conditions, so the designer must identify those conditions and calculate a solution. Indeterminate, or wicked, problems

have no definitive conditions or limits to the problem. Designers must “invent a particular subject out of the problems and issues of specific circumstances” (p. 16). Thus, the solution is dependent on the designer’s framing of the problem, and the designer must work to shape the design situation and develop a “working hypothesis suited to special circumstances” (p. 18). As Rittel and Webber (1984) put it, “the formulation of a wicked problem is the problem!” (p. 137). The way a problem is framed and the way that it is solved are simultaneous and inseparable.

As described in Chapter 2, the International Patient Decision Aid Standards (IPDAS) development process follows a linear modeling of development in which the problem is defined, prototypes developed and refined, and then implemented. The process used in this research essentially began by following the IPDAS recommendations, which suggest needs assessments with patients and providers and subsequently gathering feedback on prototypes. Although it pointed towards inaccuracies in the problem framing, this linear progression was not adequate for capturing the perceived experiences of patients and caregivers. Recognition of this inadequacy led to the shift towards sensemaking instead of decision making and the incorporation of PD methods.

UCD was most useful in creating an initial understanding of the design situation that could then be refined. Developing and gathering feedback on prototypes led to the identification of a gap in the current methods for patient support and in the design situation that was modeled. The PD methods employed in Study 3 facilitated communication between patients, caregivers and the designer to address that gap. This was accomplished through the use of the toolkit and inclusion of participants in designing

the ways in which they would participate. While the use of UCD and PD allows a point of comparison between the two methods, the goal of this work is not to determine if UCD or PD was a more valuable methodology. Instead, the aim is to draw from both of these mindsets to design most effectively for sensemaking in complex medical situations.

### **The Value of UCD**

Studies 1 and 2 made use of UCD methods via need-finding interviews and soliciting feedback on low-fidelity prototypes. While these studies did not ultimately lead to a complete picture of pre-BMT sensemaking, their role in the design process cannot be understated. Concerning findings, the need-finding interviews formed the initial design situation and the challenges of BMT. In these early interviews, it is notable that providers described their challenges in part based on what they believed patients' needs were – to be sufficiently informed to make a decision. While patients certainly need to be informed about what they are consenting to and the risks they are agreeing to, it was the perception that patients needed this information to make a choice that contributed to the flawed understanding of the design situation. The differences in perspective can partly be attributed to differences in stakeholder goals—a hallmark of wicked problems. This dichotomy was in some part clear from the results of Study 1, and ultimately these distinct needs informed the individual prototype features. Providers' needs were intended to be served by the risk calculator, while patients' needs informed the experience video archive. The value of these constructivist UCD methods lies in the ability to gain some sense of the design domain so designers can then create tangible representations of their interpretations of stakeholder needs to be used as boundary objects.

### *The Use of Prototypes*

In wicked problems such as this, where stakeholders may have conflicting needs, the development of prototypes that serve unique stakeholder needs can be a tool for understanding the differences and pulling out further opportunities for innovation. Presenting these prototypes in Study 2 did raise problems that had previously been underappreciated. Particularly, patients and caregivers did not actually perceive themselves as participating in decision making as providers had described. A design approach, like the one used here, can lead to prototypes representing the needs of multiple stakeholders, creating a unique opportunity for different groups to comment on one another's perspectives. One of the primary benefits of design is that findings are transformed into boundary objects that can act as a mutual point of reference around which disparate groups can discuss and refine their understandings of each other's perspectives (Muller, 2003).

The nature of boundary objects within UCD is also valuable. UCD promotes the practice of gathering feedback repeatedly before a finalized design is settled on. The use of low-fidelity prototypes in gathering early user feedback is critical to a successful design process. A system appearing unfinished encourages participants to present their uncensored criticisms (Rudd et al., 1996). This method of showing early-stage prototypes to participants can be a means of not only gathering preferences for particular design elements, but also in soliciting more experiential information as participants must project much more onto an unfinished design rather than one that has already been decided upon. In Study 2, patients and caregivers were essentially shown an artifact that represented what providers thought was important (personalized risk calculations) and were able to

reflect on the interface designs in terms of their own experiences and needs. This is how they made clear the distinction between their experiences as they understood them and how providers perceived them.

Another outcome of using such provotypes (Mogensen, 1994) can be a transformation by participants to gain “new contexts of plausible use” (p. 123). Though patients and caregivers did not see much value in the patient experience videos before transplant, their interest in using the system during recovery expanded the context of use to include the period after transplant when patients begin to experience complications. Participants created a new opportunity for this tool to act as support for patients in understanding their lived experiences of complications and/or how they might be remedied.

### ***How UCD Informs Toolkit Development***

For the PD toolkits to be effective and useful, they needed to be informed by some understanding of the design situation. This is how UCD methods are critical to the success of PD methods. As detailed in Chapter 3, data collected in Studies 1 and 2 was used to develop the toolkit in Study 3. The effectiveness of this toolkit was dependent on its ability to be used by patients and caregivers to articulate their experiences and imagine possible solutions. Without first having interviewed patients and caregivers to gain clarity on the challenges they face, it would be extremely difficult, if not impossible, to create a toolkit that facilitated their expression. To form a toolkit, the designer must first learn about current and past experiences to create trigger items that relate to the topic (Sanders & Stappers, 2016). Patient and caregiver reflections on relevant aspects of their pre-BMT

sensemaking experience during need-finding interviews and prototype feedback sessions were then used to develop the toolkit used in the PD workshops.

### **The Value of PD**

PD aims to generate shared knowledge between users and designers that accounts for their distinct experiences and expertise through an iterative process of joint problem exploration and creative collaboration (Sanders & Stappers, 2008; Steen, 2013). PD conceptualizes design as a social process and blurs the lines between designer and user (Luck, 2003). As described in Chapter 2, both UCD and PD involve users, but PD emphasizes the importance of users doing more than clarifying problem definition but also being involved in imagining potential solutions. End users do more than just provide feedback and also actively participate in the design process. Their participation is dependent on the designer's ability to facilitate this involvement. Thus, the ability for a PD approach to elicit sensemaking is dependent on communication between designers and users. In this research, end user involvement was largely facilitated by the use of a toolkit, developed using the UCD methods as described above. The PD process has value in the facilitation of communication between designers and users as it relates to understanding end user experiences/perspectives and incorporating user input in the design of their participation.

### ***Facilitating Communication Between Designers and Users***

Including end users does not guarantee a more valuable design outcome. There is always a gap between the designer's understanding and the users', and this gap is to be revealed through a dialogue aimed at understanding users' real needs and goals (Lie, 2011). This gap emphasizes the importance of design for sensemaking being inclusive.



Van den Hove (2006) suggests that participatory communication exists on a continuum between consensus-oriented processes towards a common interest and compromise-oriented negotiation processes that seek to adjust particular interests. Exposing conflicts in participatory processes can be beneficial if the participatory processes are designed so that addressing the conflict encourages the development of creative solutions rather than halting the process. Buur and Larsen (2010) propose a similarly constructionist view that innovation often emerges through the creation of new meaning in the face of conflict, or *crossing intentions* among stakeholders. In this case, Study 2 exposed conflicting intentions between the design situation and patient/caregiver experiences. This revelation gave some insight into why the prototypes were not ideal but did not enable the development of a better solution. Hence, Study 3 attempted to facilitate conversations that would clarify patient/caregiver intentions and uncover potential opportunities for innovation—elements of quality conversations suggested by Buur and Larsen (2010). Patients and caregivers were given the opportunity to reflect on and share what *they* found to be most important to their sensemaking as it evolved over time. While the application of these findings to an actual intervention is at the discretion of the professional designer, the only way to keep unearthing and confronting crossing intentions is to regularly communicate with end users.

Interactions between the designer and the users are considered the object of design, particularly in the toolkit. The toolkit was designed specifically for facilitating interactions that would enable discussions around patient and caregiver sensemaking. The toolkit borrowed from participatory design methods and Dervin's (1984) Multi-Moment Time-Line interview to study sensemaking. This combination enabled patients and

caregivers to communicate a more holistic view of their illness experiences. The timelines acted as a boundary object that could be used to clarify the abstract concepts related to sensemaking. As discussed at the end of Chapter 6, the toolkit was useful for enabling patients and caregivers to visually represent their experiences. However, the toolkit was less successful in facilitating creative ideation of potential solutions, particularly for those patients who used the toolkit by themselves. Though there is still work to be done in refining the toolkit, it did prove to be extremely useful in studying sensemaking processes during this period. A PD toolkit incorporating sensemaking methods such as the Multi-Moment Time-Line interview should be a technique useful in future efforts to design for sensemaking support.

### ***Involving End Users in Designing Participation***

A critical aspect of PD is that participants are involved in designing how they participate (Ehn, 2008). The risk of participants being considered “informants” is especially high in medical design due to the paternalistic nature of the healthcare system, and thus it is critical that there is genuine participation (Clemensen, Rothmann, Smith, Caffery, & Danbjorg, 2017). Winschiers-Theophilus, Bidwell, and Blake (2012) define *truthful participation* as that in which participation is negotiated within the context of the project instead of being dictated by designers. Participant suggestions were incorporated into the research procedures while data collection was still going on in Study 3. These suggestions were extremely valuable and improved the toolkit. Allowing participants to contribute to the research procedures in which they are involved is not only a means of being inclusive, but in this study, it was necessary to refine the toolkit to better enable meaning-centered discussions.

### Integration of Design Methods

The integration of UCD and PD methods surfaced a number of consistencies across the data as well as important variations in perspectives. Most notably, *BMT is not perceived by patients and caregivers as a “decision.”* Across all three studies, patients in some way described not having made a choice to receive BMT. In Study 1, this arose from participant discussions about avoiding information about mortality or believing they would die without transplant. In Study 2, patients/caregivers showed minimal interest in the risk calculator prototypes and even suggested that outcome statistics might affect them negatively. In Study 3, this finding was investigated further. Participants made clear that they believed that they needed transplant to live. Their desire to receive transplant or ability to comprehend the consequences was irrelevant. Meeting the requirements (finding a donor, reaching remission, etc.) was perceived as having more impact on the outcome than any “decision” they made.

*Patients and caregivers need support in the period leading up to transplant and not just for forming expectations for the future.* Providing this support is difficult with current institutionalized practices. Across the studies, patients and caregivers shared experiences of having expectations for transplant recovery that were not met. In Study 1, patients said they wished they had been better prepared before transplant and providers understood this to mean a lack of information. In Study 2, patients and caregivers questioned the utility of the prototypical support tools in aiding in expectation formation, and in the necessity for decision support at all. What came through only in Study 3 was the process in which these expectations are formed in the pre-BMT period. Study 3 showed that more than just specific elements of the informed consent process (like the

class) influence sensemaking but considered what patients and caregivers thought to be especially memorable. In other words, while Study 1 asked participants to reflect on events that the researchers perceived to be most relevant and Study 2 asked participants to reflect specifically on particular aspects of the prototypes, the PD process of Study 3 presented them with the opportunity to volunteer the events they found most important during this period.

Pairing UCD and PD allowed for these themes to be substantiated and for different aspects to be uncovered. It is in a methodical combination of design methods that there is maximum value at capturing sensemaking. Complex and ambiguous medical situations may be classified as a *dilemma*. A dilemma has no solution hidden in the details of the situation, so it can only be solved by a “creative leap, by transcending the limitations of the present” (Löwgren & Stolterman, 2004, p. 17). Exploiting the unique benefits of UCD and PD maximizes the potential for creativity to come forth.

### **The Theory of Design for Sensemaking Support**

From applying the five principles outlined in Chapter 2 to this design process, their value as guidelines for the application of UCD and PD to sensemaking can be more readily assessed. The goal in developing this theory is not to be prescriptive, but to enable others to apply this theory to other medical contexts.

The entirety of the sensemaking approach is built on the foundation of *meaning-centeredness*. The emphasis on the ways meaning is formed, however, differs between UCD and PD. As noted in Chapter 2, UCD adopts a constructivist approach, in which the designer interprets observations, interviews, etc. with users to identify their needs and translate these into prototypes. This is epitomized in Norman’s (2002) description of

conceptual models: the *design model* is how the designer has conceptualized the product, the *user's model* is the mental model that is created through interaction with the system, and the *system image* is the way that the designer communicates their model to the user. Thus, when the designer's model and the user's model are different, the goal is to create a system image that enables users to interpret the meaning/concept and use intended by the designer. As in, the designer's goal is to embed meaning in the system image that the user can successfully interpret and use the system. In Study 2, the designer's models were based around enabling expectation formation to improve decision making, while the patient and caregiver model interpreted the situation as having not been a decision at all. In this example, the difference between the designer's model and the users' models was revealed in the prototype feedback sessions. Participants ultimately suggested that the value of the system as it was designed may lie in its use after transplant to enable sensemaking around new illness experiences.

In contrast, PD adopts the constructionist view that sees meaning as being created with users rather than embedded in systems for their interpretation. Study 3 was designed to delve into the differences in meaning between designers and users to ultimately utilize both the designer's expertise in system development and user's expertise in the pre-BMT experience. This process led to findings that offered clarity in the sensemaking processes of patients and caregivers considering BMT and in potential tools designed to support them. Joint creation of meaning in the design process is critical to developing systems that target sensemaking support as it enables users to not only express their perspectives through use of a system preconceived by designers, but to contribute to the system image itself *and* to the creative processes used in development.

*Temporality*, introduced as one of the largest contributions of sensemaking, is relevant in both the design situation itself (BMT) and in the design processes (UCD and PD). In this study, temporality was noted as important in the design for sensemaking support in complex and ambiguous medical situations because of the evolving nature of the clinical situation. This emphasis on process and evolution was counter to the episodic approach of traditional decision support interventions. The iterative nature of these processes implies a necessary temporal perspective in following the evolution of the design situation over time. It is in the progressive development and refinement of understanding that the design perspective has value. Over time, the interactions between stakeholders and designers contributed to the development of a more useful problem framing and in design outcomes.

This work attempted *inclusivity* by incorporating perspectives from multiple stakeholder groups in the design process. By involving patients, caregivers, and providers, it became clear that these groups made sense of the pre-BMT period differently and consequently had different ideas about how it could be improved. This inclusion of multiple viewpoints enabled reflection of alternative perspectives via the UCD methods of the prototype feedback sessions. The PD methods further enhanced inclusivity by engaging patients and caregivers in actually designing potential solutions. In PD, users are included as designers. Their perspectives were not only considered, but they contributed to the development of artifacts and the design processes that facilitated their participation. The inclusion of providers in PD processes remains to be explored in future work. Overall, inclusion of multiple stakeholder groups enables underlying

conflicts or discrepancies in goals to be exposed, inspected, and applied to develop creative solutions in problematic situations.

*Self-reflectivity* was a necessary part of this research, as it was in this reflection that issues with the original problem framing became clear. The recognition that the design situation in Study 2 was flawed pointed to the power differentials that were leading to an insufficient solution. Priority was being given to the providers' perspective that informed decision making was the goal, and this was the framework in which the initial prototypes were designed. However, in Study 2, reflections on the patient and caregiver responses made clear that there was a need for more refinement of this design situation. In seeing that patients and caregivers did not perceive a decision to have even been made, the realization that the perspective of providers had been dominant was solidified. The designer's privileged position in UCD to dictate the forms of prototypes had enabled this prioritization of the decision making perspective. This imbalance of power was limited by facilitating design of potential solutions by patients and caregivers in Study 3.

The *action-orientation* promoted by design for sensemaking was manifested across the studies. In the UCD approaches of Studies 1 and 2, this was seen in clinic observations and in asking stakeholders to respond to prototypes based on their perceived utility. UCD promotes observations of users in the design context, particularly in their engagement with prototyped solutions. PD emphasizes thoughtful development of activities that facilitate user involvement in design. The ways that participants interacted with the toolkit to visualize their experiences was an object of study and of design. While the present research has not reached a point where users could test a prototype in actual

use scenarios, that is undeniably a critical part of any design process pre-implementation. As this project continues, observation of actual use of any product in real-life contexts, as the actual impact on communicative outcomes may be dramatically different than what is intended.

In Chapter 6, I suggested a sixth principle for design for sensemaking: to be *adaptive*. This relates to the principles of inclusivity and self-reflectivity, as it is through the inclusion of multiple stakeholders and in the ability to reflect on their contributions that adaptation is most effective. The iterative nature of UCD processes could arguably be considered adaptive to users' evolving needs as they are uncovered. It is in the willingness to adapt design processes, as in a PD process which asks end users to design their participation, that the adaptivity is both in the designed artifact and in the design process.

The principles of the theory are presented as ideals to act as a guide rather than a set of requirements. The goal is to inspire others to begin approaching design problems with the mindset of sensemaking as both a valuable element of human experience and as a potential object of design. Table 9 presents these principles and how each can be applied to the design process to both elicit sensemaking processes and to develop systems that support sensemaking.



**Table 9***Principles of Design for Sensemaking Support*

| <b>Principle</b>        | <b>Elicit Sensemaking</b>  | <b>Support Sensemaking</b>  |
|-------------------------|--|---|
| <b>Meaning-centered</b> | Emphasize participants sharing interpretations, expectations, questions, emotions, and other key elements of their sensemaking processes | Develop systems that assess and adjust to varying interpretations to aid in navigation of complicated illness experiences |
| <b>Temporal</b>         | Examine the progressive development of understanding over time   | Develop systems that are meant to be used over an extended period of time   |
| <b>Inclusive</b>        | Involve multiple stakeholder groups in design process, using boundary objects to encourage reflection on one another's perspectives      | Facilitate collaboration and discussion among relevant parties (patients, caregivers, providers, etc.)                    |
| <b>Self-reflective</b>  | Regularly assess and attempt to correct power differentials in the design process and in clinical practice                               | Include features that enable users to express their sensemaking and reflect on its utility, benefit, and evolution        |
| <b>Action-oriented</b>  | Observe current practices and engage stakeholders in design  | Test potential systems in real life settings  |
| <b>Adaptive</b>         | Solicit involvement from end users in designing methods for participation  | Create systems that can assess and adapt to changes in user's sensemaking and situation                                   |

### **Contribution to Communication Research and Practice**

The work presented here can be classified as *design inquiry* as described by Jackson and Aakhus (2014) as this research considers both the design product and improving design processes for designing future communication interventions. As such, reflections throughout this process on the utility of design methods used and associated communication between/among designers and users has led to the six principles identified above. These principles are the result of theorizing around the ways that communication can more effectively target sensemaking within the design process, ultimately attempting to serve sensemaking support interventions.

The methods of inquiry used at each step of the design process contributed to findings in unique ways. In Study 1, interview questions were framed around decision making, as this was the problem initially introduced to and adopted by the design team when approached by the providers. Consequently, the results of Study 1 were framed as challenges to decision making, even if patients in Study 2 ultimately shared that they had not perceived themselves as having made a genuine decision. This contradiction could be attributed to what Potter and Hepburn (2005) describe as interviews being embedded with the social science agenda motivating the interviewer. Because the findings of these interviews were guided by the decision-centered framing, the resulting prototypes were designed to support expectation formation in pursuit of better decisions.

The nature of wicked problems is that the definition of the problem is informed by ideas about the solution. Though the prototypes were designed with decision making in mind, their position as boundary objects in the focus group with providers enabled these

participants to take on the perspective of patients and recognize that information about long-term complications presented in the prototyped system may not be particularly useful for decision making. Similarly, patients and caregivers could actually imagine themselves using the prototypes to more explicitly make clear that they did not view their challenge as one of decision making. The concreteness of the prototypes enabled participants to imagine actual use rather than reflecting on what information would have hypothetically been helpful to them before transplant.

Study 3 adopted the most novel design method by integrating PD and sensemaking methodologies. Communication researchers might benefit from the adoption of this method to overcome limitations of interviews and focus groups like those used in Studies 1 and 2. While the Micro-Moment Time-Line Interview used in Study 3 has been used previously in studies attempting to understand illness experiences (e.g. Berends, 2011; A. T. Chen, 2018), this study incorporated PD methodology in two important ways. The first is the PD toolkit, a central element of facilitating creativity and ideation in non-designers, which was introduced as a means of enabling expression of experience. The second is inclusion of a transparency sheet to allow participants to annotate their actual experiences and ideate around potential solutions. This is a way of both identifying areas for improvement and giving participants an opportunity to develop their own ideas and create solutions that were contextualized to specific sensemaking needs. In the creation of the visual timeline, participants determined what events were most memorable and meaningful rather than being guided purely by research questions, as in the interviews in Study 1 or prototypes in Study 2. Patients and caregivers in Study 3 were also given the space to show the evolution of their sensemaking over an extended

period of time and *how* they were forming expectations rather than simply communicating that their expectations had not been met. Giving people the opportunity to visually share their experiences as they temporally unfolded over time, to provide commentary on this experience, and ultimately to imagine ways this experience might be improved for future patients, is believed to be a novel means of eliciting sensemaking and understand participant experiences.

Further, the toolkit in Study 3 was modified as needed as participants provided feedback on its utility or elements that they felt were missing. While it is not abnormal for researchers to adapt their methods based on pilot studies, this sort of reflective practice is unique to PD in that participants were given new means to potentially express themselves in a visual manner and the inclusion of their recommendations is an important part of their participation overall. The method of investigating sensemaking through PD used in Study 3 can offer communication researchers another tool for gaining an in-depth understanding the experiences and ideas of the people that are ultimately served by an intervention.

There have been previous efforts to engage in patient sensemaking methodologically and in clinical practice that have relevance to the proposed framework for design for sensemaking used here. What this particular study does differently is the integration of both sensemaking and design methods with the ultimate goal of applying findings towards development of an artifact intended to address problems uncovered through this process. Chen (2018) utilized a novel timeline drawing activity to elicit fibromyalgia patients' temporal representations of their illness journeys. She prompted participants to think about their fibromyalgia journey and to draw something that

represented it, finding that this method allowed participants to tap into a more holistic representation of their illness from their perspective. In contrast to this method, which gave participants a blank sheet and asked them to draw their journey, the current study used the PD technique of providing participants with a toolkit. The method used here, in which the toolkit is developed based on previous interviews with patients and providers and adapted based on participant feedback, was designed to facilitate participants' ability to more readily express themselves visually (Sanders & Stappers, 2008). Chen found that some participants felt uncomfortable having minimal instruction and required further prompting from the researcher. The PD toolkit avoided some of the pitfalls of a completely blank canvas while still capturing the benefit of encouraging people to use visuals to express themselves in a way that is in tune with the emotional aspects of their experiences. Visuals also give people an artifact to reference when communicating, thus facilitating collaboration (Sanders, 2000). Using the toolkit allows for a more directed design practice and thus a clearer direction for subsequent data analysis of the visuals (Sanders, 2013). The methodology developed here builds on past work looking at the temporal elements of illness experience while also advancing PD methods.

Along with aiding patients in interpreting their experiences, design for sensemaking needs to support reflection in patients and caregivers to lead to understanding. *Facilitated sensemaking*, a concept proposed by Davidson (2010) was conceptualized as a tool for nurses to help the families of patients facing significant health challenges in the ICU. Interventions for facilitated sensemaking aim to help families to interpret the situation by *decoding*, or having nurses explain which cues are most important and then engaging in "reflective inquiry" to clarify any misconceptions

about what has happened (Davidson, Agan, & Higgins, 2010, p. 180). These interventions also aim to give meaning to the caregiver role by counseling families on activities they can do to possibly help the patient heal. By including multiple stakeholders and involving them not only in patient care but in developing an understanding of the current situation, facilitated sensemaking is a practice that can be expanded on in the BMT setting, where both patients and caregivers must frequently make sense of large amounts of complex information.

These examples represent initial efforts to incorporate sensemaking into healthcare interventions in various ways; however, they do not capture the full benefits of integrating design and sensemaking. There have been past efforts to use sensemaking theory for healthcare interventions, but what the research presented here does differently is its explicitly design-based approach to both investigation of current sensemaking practices and development of tools to facilitate sensemaking support through communication within the design process and in the artifacts ultimately produced and implemented in the BMT clinic. Design approaches like UCD and PD largely assume that sensemaking occurs rather than directly investigating its role in how users interact with prototypes, with design toolkits, with designers, etc. This research, and its ultimate theoretical outputs, extend existing sensemaking models to develop a practical and theoretical framework for design for sensemaking support to be applied by communication researchers in other contexts.

### **Limitations and Future Work**

Reflecting on the design process overall, there are limitations in the current work that can be addressed in future research endeavors. Most notably, the small sample size

and biased sample creates challenges for generalizability. First, including only patients who received transplant likely resulted in findings that do not apply to all patients facing BMT. Enrolling only patients who had received transplant and survived was a conscious choice, as described in Chapter 3, because patients may find information to be adequate before transplant, but later reevaluate this information as inadequate as they experience complications (Little et al., 2008). Similarly, relying on retrospective accounts of patients who successfully received transplant and caregivers may have contributed to the finding that they did not see themselves as having made a choice between viable options. It is possible that when reflecting on transplant after having survived it, they retrospectively make sense of it as a ‘forced choice’ because the outcomes were positive, alleviating any negative feelings about the consequences of putting themselves at risk. Pre-transplant patients may have different perspectives while they are actively making sense of transplant. Future work should explore this gap. The present study relied on retrospective accounts of the entire process, which was useful in contextualizing memorable sensemaking events and had the benefit of patients knowing their BMT outcomes. Still, observing actual clinical consultations in the period before transplant and collecting post-consult interview data will create a more complete picture of the sensemaking process in the period leading up to transplant because it will illuminate the many interactions patients and caregivers experience and how information is made sense of in the moment.

As noted above, the lack of providers in the PD workshops is notable considering the importance of inclusivity. The choice to focus on patients and caregivers in the PD workshops was based on the findings in Study 2 that pointed to a misalignment in the design solutions and the patient and caregiver experience. At that point, it was necessary

to investigate this discrepancy further. Patients' emphasis on how conversations with providers influenced sensemaking, as seen in Study 3, suggests that provider perspectives on the pre-BMT sensemaking process would be useful. Providers in Studies 1 and 2 believed that they posed BMT as a decision, though patients and caregivers did not understand it as such. Further exploration of providers' understanding of the pre-BMT period is thus warranted. Follow-up studies might include presenting an idealized general framework of interactions (i.e. what is the typical process that you and a patient go through leading up to transplant?) and a specific example of this process (i.e. Recalling the last patient you transplanted, what are the conversations you have with patients leading up to the procedure?) along with observing interactions between patients and providers as they consider BMT.

Relatedly, the implications of this new sensemaking framework could extend to the patient provider relationship. As described in Study 1, current methods for pre-BMT patient support can lead to unnecessary anxiety and put a strain on the patient-provider relationship. Providers in Study 1 described an added responsibility to communication that the transplant might kill a patient sooner than if they had opted for chemotherapy alone. This might be why they so strongly feel the need to conceptualize transplant as a decision – as something that the patient opted to do rather than something the provider encouraged them to do. It may be for this same reason that patients do not see it as a decision, because choosing transplant that results in negative outcomes might be hard to decision to justify. These conflicts both within an individual and between stakeholder groups are why addressing sensemaking is likely to have benefit in this sort of clinical context. Further exploration about why providers believe that statistical risk information



is so useful may also be fruitful as it might reveal if such a belief is related to providers' need to facilitate a decision where patients see none.

Caregivers were included in this work, but only participated alongside patients. It was difficult to distinguish their individual perspectives at times, as they were only ever interviewed with patients. Though two caregivers in Study 3 opted to create their own individual timelines, future work may ask to see how caregivers might represent their experiences independent of the patients' reflections. To capture the unique caregiver perspective, it may be helpful to gather multiple caregivers rather than caregivers and patients in future PD workshops.

Participants in this research often contributed to multiple elements of the study. Because some of the patients and providers who participated in the need-finding interviews also provided feedback on the prototype design, it is possible that the positive responses to the prototypes could have been a result of the designs being based on their own needs. However, there were participants in the prototype feedback sessions who were not involved in the need-finding interviews. Presenting the prototypes back to the participants who expressed the original needs offered a type of validation test, in that their acceptance or rejection could be interpreted as supporting or refuting our design hypotheses. Ultimately, these hypotheses were not entirely supported and indicated that the initial interpretation of needs was not complete. Future iterations of the support tool may benefit from gathering feedback from participants outside of those who have previously engaged.

Issues of diversity in this patient population were reflected in the samples, as the challenges for non-white patients in finding a donor and receiving BMT are unique and

potentially devastating. The significant racial disparities in bone marrow transplantation are not only a result of the inequalities that exist in healthcare access, but because of the significantly limited availability of marrow donors from diverse populations. It is much more likely that an unrelated donor will be a match if the donor is of the same race as the patient because the markers that indicate a match are inherited. The largest donor registry in the world, Be The Match, reports that white patients have a 77% chance of finding a matched adult donor, while African American or Black patients have a 23% chance. Barker et al. (2019) found that people of European ancestry were significantly more likely to receive transplants from perfectly matched donors than non-Europeans (67% vs 33%). The disparities that exist in BMT are significant, and the challenges of finding a donor will likely differ depending on the patient's background.

The limitations imposed by pandemic restrictions prevented in-person meetings with participants. While the virtual workshop did generally progress as expected in an in-person setting on an individual basis, the difficulties of coordinating groups of patients/caregivers from different families remotely led to one on one interviews with either a patient or a patient and their caregiver. Despite these challenges, one of the benefits was participants having access to things they kept in their homes. For instance, multiple participants got up mid-conversation to get notes they had kept from this period. They would refer to these notes to get more accurate dates for the timeline or reminders of what happened during this traumatic period. In the future, this PD process may be better served by facilitating remote gatherings of groups of patients/caregivers who had different experiences to meet in person and brainstorm ideas together.

## Conclusion

This dissertation outlined a design method intended to examine and support the sensemaking processes of people facing complicated and ambiguous medical situations. Ultimately, the UCD approaches used in early studies proved insufficient and were supplemented with a PD approach to gain a more holistic understanding of patient and caregiver experiences. In applying these two human-centered design methods, it is possible to see where each has strengths and weaknesses, and how they can be best applied to solve problems in similar medical contexts.

Zimmerman and Forlizzi (2011), in an attempt to better incorporate design into human-computer interaction research, offered four criteria to assess the quality of design research contributions: *process*, *invention*, *relevance*, and *extensibility* (p. 499–500). *Process* is defined as “the rigor applied to the methods and the rationale for the selection of specific methods” such that they could be reproduced. In this dissertation, the process used was not only detailed explicitly but was thoroughly reflected upon as per the self-reflective principle of design for sensemaking. While details of the study like the specific elements of the toolkit would likely not be useful in another context, the approach (i.e. beginning with UCD methods to inform the facilitation of PD workshop targeting sensemaking) could be reproduced in other medical contexts with similar challenges of ambiguity.

*Invention* is judged by the demonstration of a “novel integration of various subject matters to address a specific situation” including details of the identified opportunities and guidance for future design work. While there has been some effort to incorporate design methods into healthcare intervention development, this is limited. Additionally,

the use of a PD approach that specifically examines sensemaking in ambiguous medical contexts is novel. This becomes especially clear when compared to the current methods for developing patient decision aids. Opportunities for advancement specific to the case study and to designers attempting to incorporate sensemaking into their work were presented.

*Relevance* is seen in the articulation of “the preferred state their design attempts to achieve” as well as “support for why the community should consider this state to be preferred.” The recommendations for the clinical context to apply these findings can be found at the beginning of this chapter. Support for these recommendations is evidence in the preceding data analysis chapters. Further, the preferred state of the design processes (in the principles of design for sensemaking proposed here) is detailed as well. Although future work will investigate the continued design process through implementation, there is value in the current findings as they relate to applying design methods to investigate sensemaking.

*Extensibility* is evident when the design research “has been described and documented in a way that the community can leverage the knowledge derived from the work.” This work is proposed as an alternative approach to developing support for patients in complex and ambiguous medical situations and differs from the dominant processes advocated for in decision aid development. Opportunities are presented for other designers to address these issues in similarly complex situations. Summarizing findings related to the design process in principles creates an accessible tool for applying this method.

This research was intended to develop a novel approach applying design methods to investigate and support sensemaking processes in complicated medical situations. The outputs of this work include the progressive development of a support tool for the particular clinical context of BMT and in evaluation and refinement of the design method used. The shift from design for decision making to design for sensemaking is a transformation that can be replicated in clinical situations that are inadequately supported by decision aids. The principles laid out as part of the theory of design for sensemaking support can be applied to similarly challenging health contexts in which patients, caregivers, and providers must work together to navigate complicated medical situations.

## APPENDIX A: Participant Characteristics

**Table A1**

*Provider Characteristics*

| <b>Provider<br/>(pseudonym)</b> | <b>Role</b>            | <b>Data Collection</b>             |
|---------------------------------|------------------------|------------------------------------|
| Frank                           | Medical Oncologist     | Need-finding<br>Prototype feedback |
| David                           | Medical Oncologist     | Need-finding<br>Prototype feedback |
| John                            | Medical Oncologist     | Need-finding                       |
| Gregory                         | Medical Oncologist     | Prototype feedback                 |
| Caroline                        | Medical Resident       | Need-finding                       |
| Sharon                          | Licensed Social Worker | Need-finding                       |
| Danielle                        | Transplant coordinator | Need-finding<br>Prototype feedback |
| Vivienne                        | Transplant coordinator | Need-finding<br>Prototype feedback |
| Jessica                         | Transplant coordinator | Need-finding                       |
| Rebecca                         | Nurse practitioner     | Prototype feedback                 |
| Samantha                        | Nurse clinician        | Prototype feedback                 |

**Table A2***Patient Characteristics*

| <b>Patient<br/>(pseudonym)</b> | <b>Years since<br/>BMT at first<br/>meeting</b> | <b>Age at first<br/>meeting</b> | <b>Sex</b> | <b>Data Collection</b>                                     |
|--------------------------------|---|---------------------------------|------------|--|
| Renee                          | 5   | 32                              | F          | Need-finding<br>Prototype feedback                         |
| George                         | 5   | 56                              | M          | Need-finding<br>Prototype feedback<br>Participatory design |
| Margaret                       | 3   | 59                              | F          | Need-finding<br>Prototype feedback<br>Participatory design |
| Samuel                         | 16  | 59                              | M          | Need-finding<br>Prototype feedback<br>Participatory design |
| Stephen                        | 5   | 59                              | M          | Need-finding<br>Prototype feedback                         |
| Edwin                          | 10  | N/A                             | M          | Need-finding interview                                     |
| Gail                           | 4   | N/A                             | F          | Need-finding interview                                     |
| Stacey                         | 1   | 45                              | F          | Prototype feedback<br>Participatory design                 |
| Kenneth                        | 1   | 69                              | M          | Prototype feedback   |
| James                          | 2   | 69                              | M          | Prototype feedback   |
| Carol                          | 1   | 59                              | F          | Prototype feedback   |
| Kelly                          | 2   | 30                              | F          | Prototype feedback   |
| Charles                        | 4   | 70                              | M          | Participatory design                                       |
| Jacob                          | 2   | 49                              | M          | Participatory design                                       |
| Amanda                         | 4   | 38                              | F          | Participatory design                                       |

| <b>Patient<br/>(pseudonym)</b> | <b>Years since<br/>BMT at first<br/>meeting</b> | <b>Age at first<br/>meeting</b> | <b>Sex</b> | <b>Data Collection</b> |
|--------------------------------|---|---------------------------------|------------|------------------------|
| Andrew                         | 6   | 65                              | M          | Participatory design   |
| Kerry                          | 7   | 68                              | F          | Participatory design   |
| Bob                            | 8   | 50                              | M          | Participatory design   |



**Table A3***Caregiver Characteristics*

| <b>Caregiver<br/>(pseudonym)</b> | <b>Patient<br/>(relationship)</b> | <b>Age at first<br/>meeting</b> | <b>Sex</b> | <b>Data Collection</b>                     |
|----------------------------------|-----------------------------------|---------------------------------|------------|--|
| Scott                            | PT8 (spouse)                      | 46                              | M          | Prototype feedback<br>Participatory design |
| Darla                            | PT10 (spouse)                     | 71                              | F          | Prototype feedback                         |
| Harriet                          | PT3 (friend)                      | 53                              | F          | Prototype feedback<br>Participatory design |
| Marnie                           | PT2 (spouse)                      | 53                              | F          | Prototype feedback<br>Participatory design |
| Deborah                          | PT4 (spouse)                      | 66                              | F          | Prototype feedback<br>Participatory design |
| Lauren                           | PT9 (spouse)                      | N/A                             | F          | Prototype feedback                         |
| Tina                             | PT11 (sister)                     | 48                              | F          | Prototype feedback                         |
| Cathy                            | PT11 (friend)                     | 53                              | F          | Prototype feedback                         |
| Cynthia                          | PT11(cousin)                      | 48                              | F          | Prototype feedback                         |
| Janet                            | PT11 (aunt)                       | 78                              | F          | Prototype feedback                         |
| Rachel                           | PT14 (spouse)                     | 49                              | F          | Participatory design                       |

## **APPENDIX B: Interview Guide for Prototype Feedback**

### **Risk Calculator:**

Drawing 1: Pie charts

1. What do you think?
2. What information do you want to see more of?
3. How would you feel if you were given risk calculator data in this way?

Natural Frequencies:

1. What do you think?
2. How about compared to drawing 1?
3. How would you feel if you were given risk calculator data in this way?

Scales:

1. What do you think?
2. What do you think about this compared to the first two with numbers?
3. How do you feel about the amount of information presented in these sketches?
4. Can you think of another way you might like to see this information that wasn't shown here?

### **Experience Videos**

1. Would you use these filters?
2. Do the filters make sense to you?
3. Would you want more information about each video before choosing it? What kinds of information?
4. Is there anything that you would like to see in the interface that you did not today?

Psychosocial/Physical Complications Filters:

1. What do you think? Why?
2. Are the filters something you find useful? Are there other filters you wish were included?
3. What do you think about the presentation of psychosocial issues?

Common Complications:

1. Would you prefer this to the first one?

Type of Complication:

1. How do you feel about this one compared to the other two?
2. Would you prefer the specifics?

### APPENDIX C: Sensitization Exercise

1. What is your age? \_\_\_\_\_
2. What is your sex? \_\_\_\_\_
3. What is the highest level of school you have completed or the highest degree you have received?

|   |  |
|---|--|
| <input type="checkbox"/> Less than high school degree   | <input type="checkbox"/> Bachelor's degree in college (4-year) |
| <input type="checkbox"/> High school graduate (high school diploma or equivalent including GED) | <input type="checkbox"/> Master's degree                       |
| <input type="checkbox"/> Some college but no degree   | <input type="checkbox"/> Doctoral degree                       |
| <input type="checkbox"/> Associate degree in college (2-year)                                   | <input type="checkbox"/> Professional degree (JD, MD)          |

4. Choose one or more races that you consider yourself to be:

|   |  |
|---|--|
| <input type="checkbox"/> White                            | <input type="checkbox"/> Asian                               |
| <input type="checkbox"/> Black or African American        | <input type="checkbox"/> Native Hawaiian or Pacific Islander |
| <input type="checkbox"/> American Indian or Alaska Native | <input type="checkbox"/> Other _____                         |
| <input type="checkbox"/> Latino or Hispanic               | <input type="checkbox"/> Prefer not to say                   |

5. Are you now married, widowed, divorced, separated or never married?

|                                   |  |
|-----------------------------------|--|
| <input type="checkbox"/> Married  | <input type="checkbox"/> Separated     |
| <input type="checkbox"/> Widowed  | <input type="checkbox"/> Cohabiting    |
| <input type="checkbox"/> Divorced | <input type="checkbox"/> Never married |

6. Which statement best describes your current employment status?

|  |   |
|--|---|
| <input type="checkbox"/> Working (paid employee) | <input type="checkbox"/> Not working (looking for work) |
| <input type="checkbox"/> Working (self-employed) | <input type="checkbox"/> Not working (retired)          |

|  |   |
|--|---|
| <input type="checkbox"/> Not working (temporary layoff from a job) | <input type="checkbox"/> Not working (disabled) |
| <input type="checkbox"/> Not working (other) _____                 | <input type="checkbox"/> Prefer not to answer   |

The workshop you will be participating in will ask that you reflect on the period after you learned bone marrow transplant was a potential treatment option and how that treatment decision was made. The next few questions are meant to help you to reflect on this in preparation for the workshop. These questions are meant to be very open-ended so answer to the best of your ability.

1. When and how did you first learn about bone marrow transplant as a potential treatment option for you/your loved one?
2. Did you attend the transplant orientation class? What did you think?
3. When did you/your loved one receive transplant?
4. What was the most important reason that you/your loved one decided to receive transplant?
5. If you were giving advice to someone making a decision about bone marrow transplant, what would you say is the most important thing they should know or resolve before making their decision?
6. Is there anything else you would like us to know before we talk?

APPENDIX D: Toolkit Contents

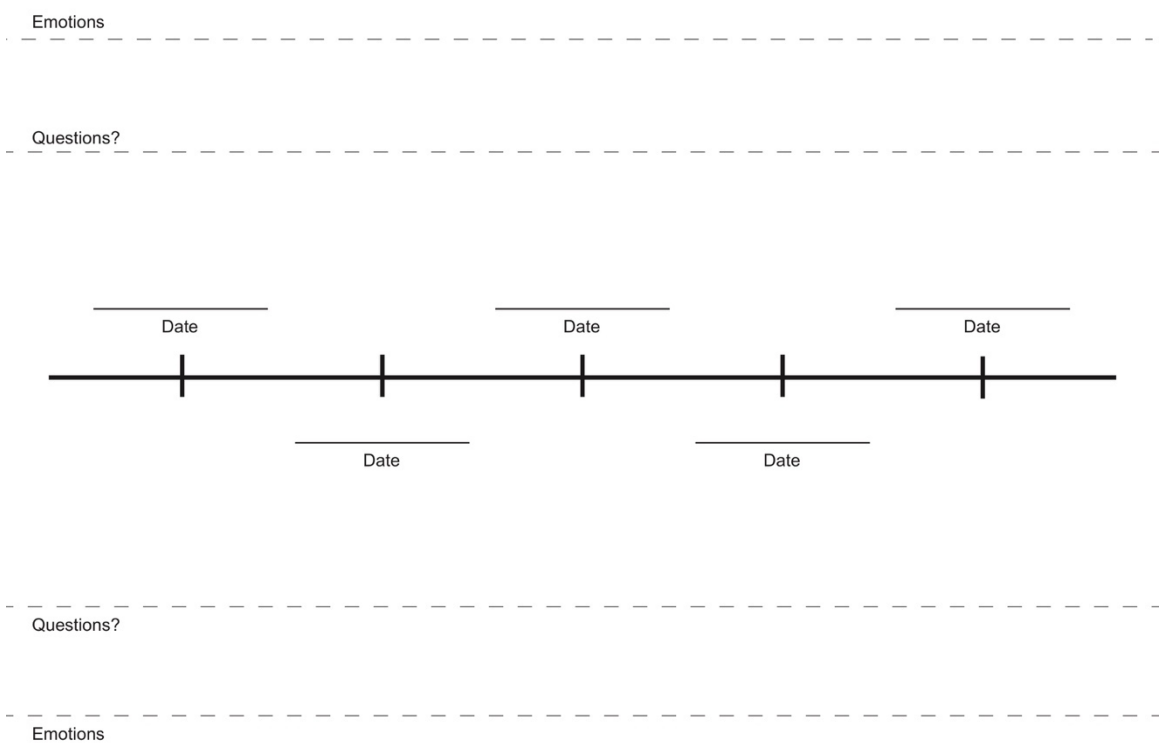


Figure D1. Timeline template.

|             |             |             |
|-------------|-------------|-------------|
| Afraid      | Angry       | Anxious     |
| Comfortable | Confident   | Confused    |
| Coping      | Discouraged | Frustrated  |
| Grateful    | Happy       | Healthy     |
| Informed    | Lost        | Motivated   |
| Normal      | Optimistic  | Overwhelmed |
| Prepared    | Regretful   | Relaxed     |
| Sad         | Sick        | Surprised   |
| Tired       | Tough       | Unsure      |
|             |             |             |

*Figure D2.* Emotion words.

|                                  |                  |               |
|----------------------------------|------------------|---------------|
| Chemo                            | BMT Orientation  | Cure          |
| Donor                            | Expectations     | Faith         |
| Family                           | Fertility        | Friends       |
| Graft-versus-host disease (GVHD) | Informed consent | Pain          |
| Personalized                     | Relapse          | Remission     |
| Risk                             | Side effects     | Support       |
| Survival                         | Transplant       | Unpredictable |
|                                  |                  |               |
|                                  |                  |               |
|                                  |                  |               |

*Figure D3.* BMT-specific terminology.

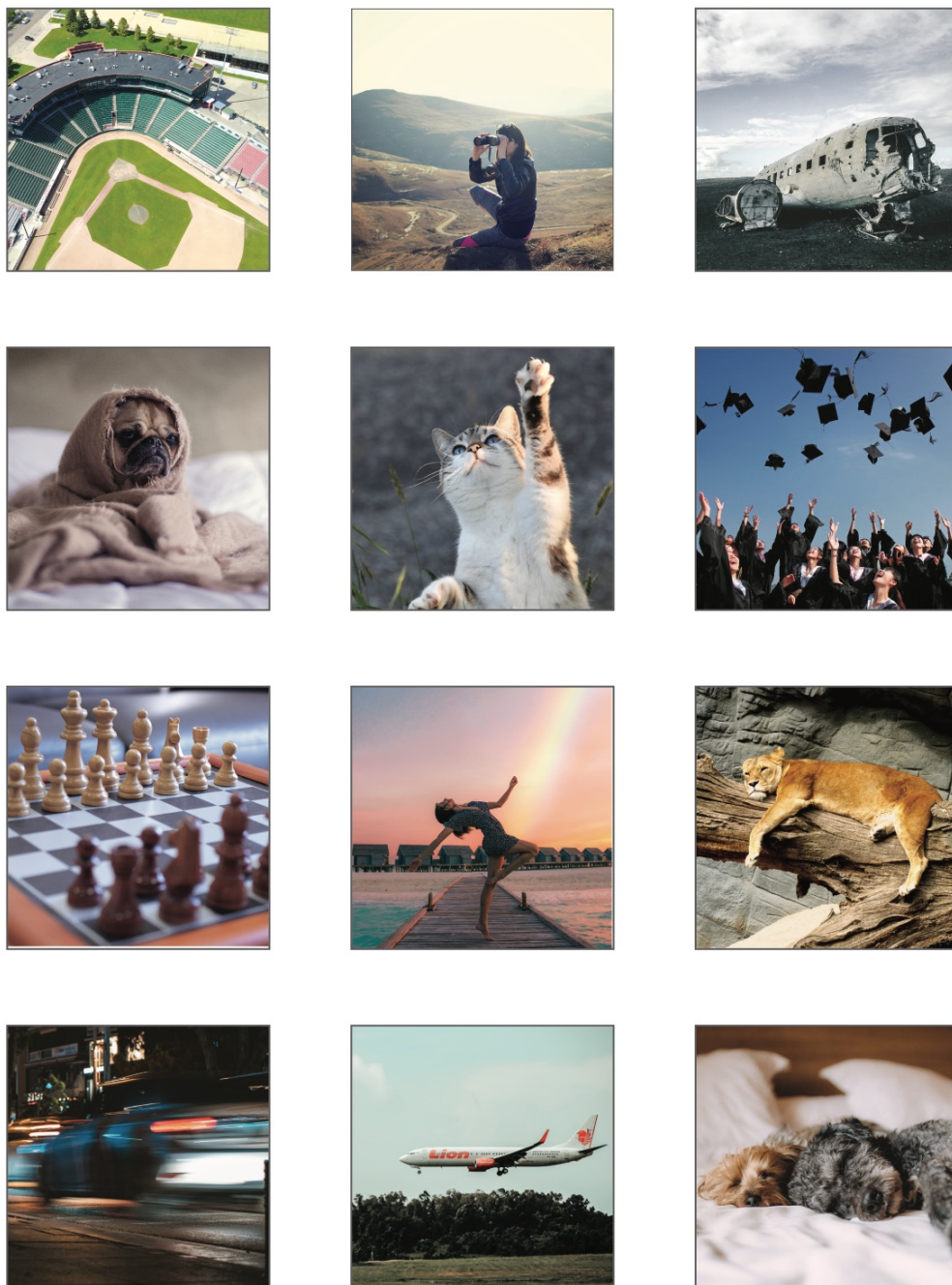


Figure D4. Toolkit photos (1).



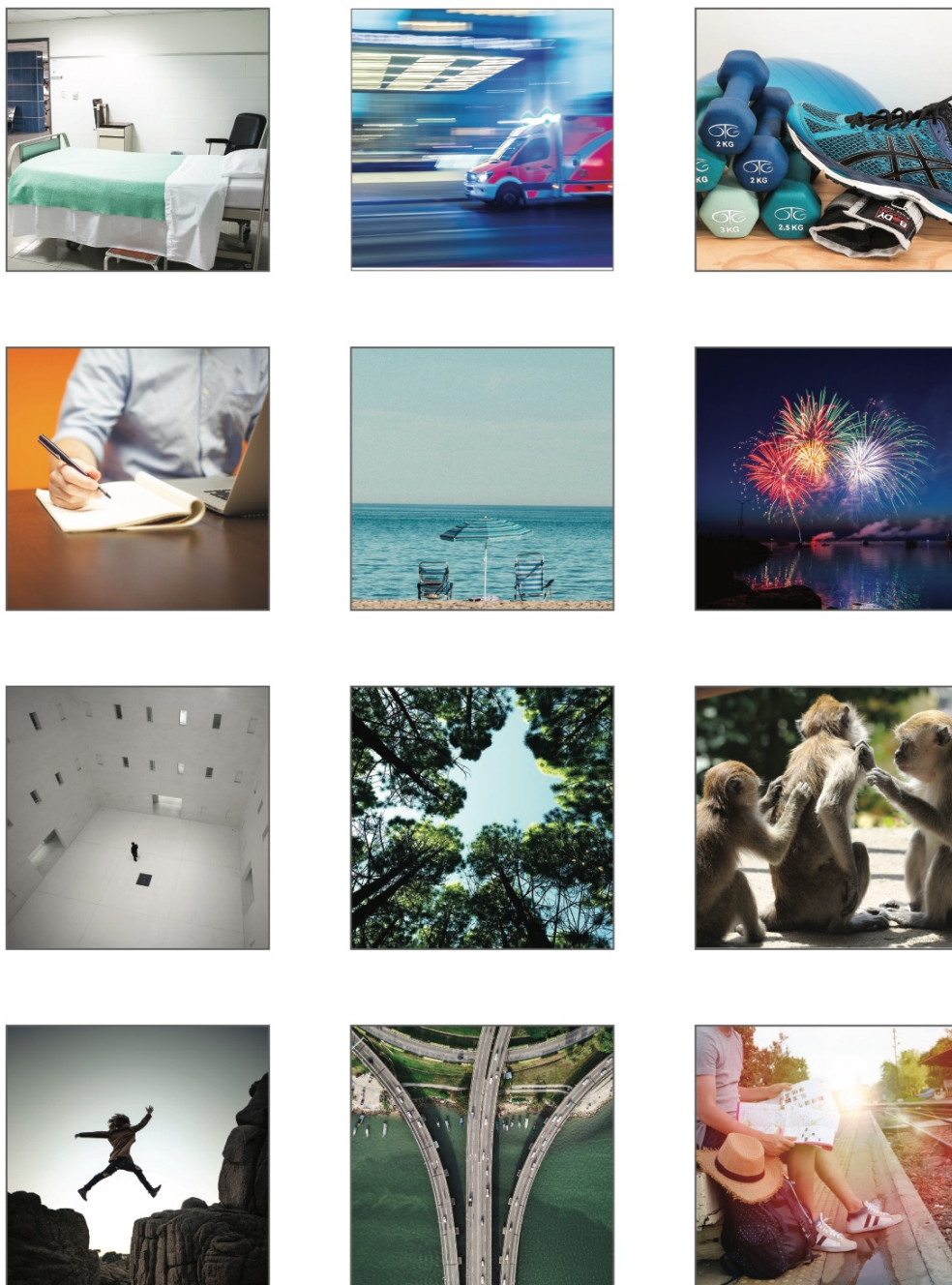


Figure D5. Toolkit photos (2).

## APPENDIX E: Participatory Design Workshop Guide

1. When did you first learn transplant was a treatment option for you?
2. What happened next?
3. For each step:
  - a. What were you thinking?
  - b. What questions did you have/ask?
    - i. What were you trying to do when you asked this question? Or what would the answer have done?
    - ii. Did you get an answer to your question? Were you satisfied with the answer?
  - c. What was helpful to you?
  - d. What got in your way?
  - e. How were you feeling?
  - f. What expectations did you have? Did your experience match these expectations?

Questions about overall experience:

1. What was the most important step for each of you?
2. What was the most surprising part of your experience?

Now we would like to imagine what the ideal decision making process might have been like, how it could be improved. Put the transparency sheet over your timeline and you can use the stickers, sharpies, or whatever you would like to draw over your actual experience and mark where it could have been improved.

1. What might have helped you [during this event]?
2. What did you not know that you wish you had?
3. What would you have changed about the decision making process?

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