Improving prognosis communication for patients facing complex medical treatment: A user-centered design approach

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ABSTRACT

Background: The understanding and processing of numerical prognostic information can be challenging for patients who suffer from disease and the stress of a diagnosis.
Objective: This paper investigates how patients diagnosed with Leukemia respond to different graph representations of prognosis information.
Methods: We conducted a user-centered design process, for which three experimental prototypes (vertical, horizontal, and pie charts) with and without animation were developed. Twelve patients diagnosed with Leukemia were recruited to evaluate the prototypes using a think-aloud interview protocol.
Results: The results showed a preference for vertical bar charts over horizontal and pie charts. In addition, we found that animating the charts to "fill-up" generally conveyed a subtle sense of positivity even when diagnosis information was negative. The value of explicitly indicating numeric values and scale varied but the results suggest that what matters to participants is having control over when such details would be seen. The results also point out that making sense of prognostic information involves balancing the tension between information utility and patient judgments about authenticity and credibility of prognosis information.
Conclusion: Our findings are important for the design and implementation of representations of prognostic information. They suggest that an appropriate visual format can reduce potential negative effects in conveying prognosis information, as well as helping patients stay positive and motivated for cure in the delivery of prognosis information.

1. Introduction

The meaningful communication of numeric prognostic information is essential for establishing informed decision-making in clinical settings [10]. However, even for patients with high numeracy, the understanding and processing of numerical information can be challenged when suffering from disease and the stress of a diagnosis [1,28,40]. To facilitate the communication of numeric prognostic information electronic decision aids adopt a variety of visuals (e.g., icons, charts, pictograms) [9,14]. In particular, graphs are widely used in decision aids because they support human processing of quantitative information by reducing the amount of mental computation required to interpret information [41]. However, there is little empirical guidance regarding how to use different visual aids to better support patients' understanding of risk information, especially when such risks may be life-threatening or reduce life expectancy [45]. For distressed patients who face a complex medical treatment, it is as important to minimize

emotional stress and promote patients' optimism as to deliver realistic information for effective risk communication [13]. In the design of electronic decision aids, therefore, it is essential to understand how different types of visuals for presenting numeric information influence patients' comprehension of prognosis both informationally and emotionally [32] and subsequent psychological adjustment of decision-making [43]. The objective of this study, therefore, is to investigate how patients facing a complex medical treatment perceive and respond to different types of visual representations presenting numeric data of projected treatment outcomes.

Acute myeloid leukemia (AML) is a type of malignant blood cancer, characterized by the rapid growth of abnormal cells that build up in the bone marrow and blood and interfere with normal blood cells [39]. In AML, a major therapeutic challenge is deciding whether a patient should receive allogeneic hematopoietic stem cell transplant or proceed with chemotherapy. This treatment decision requires patients to understand projections of survivability and the likelihood of relapse after

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receiving a transplant. Using a knowledge bank approach for precision medicine, it is now possible to quantitatively predict patient outcomes from genomic and clinical variables [22]. Inevitably, however, these predictions are not always favorable, and such negative outcome likelihoods can be distressing to patients, which complicates physicians' responsibilities when informing patients about their treatment options.

In this paper, we report on the user-centered design of the Outcomes Projections and Experienced Narratives for patients with Acute Myelogenous Leukemia Treatment (OPEN:AML) tool, a decision aid for patients with AML to help better comprehend treatment options and prepare for possible outcomes. As the name indicates, OPEN:AML utilizes two types of information: clinical data of projected treatment outcomes and experience-narrative videos of patients who have already been treated for AML. This paper focuses on the visual representation of projected outcomes as a key element of the broader project.

2. Related work

2.1. Health risk communication

Researchers have documented patients' difficulty in understanding prognostic information and medical consultations [5,6]. Accordingly, efforts have been put to enhance health risk communication by identifying patient information preferences when communicating risks [32]. While studies have shown that the needs of patients are highly individualized [25,35], the findings revealed common preferences for the presentation of prognostic information to improve patients' understanding. Patients emphasize the importance of receiving realistic information with positively framed language, the ability to ask questions, a confident and supportive health-care professional, and using visual representations to improve comprehension or risk estimate [3,27,48]. This last component, the use of visual representations is particularly important to help patients comprehend numeric data which tend to pose the most significant challenges for patients [17,19]. However, the presentation of data, not just the results, can also unexpectedly undermine optimism and stimulate fear [34]. This study explores differing patient expectations and assessments of visual aids to represent numeric prognostic information by employing a user-centered approach to elicit patient perspectives about different representational strategies. The aim is to identify visual representations that patients find more accessible to help support patients' receptivity to and engagement with receiving prognosis information in complex emotional and informational conditions.

2.2. Visual aids for risk communication

Visual aids are simple graphical representations of numerical expressions intended to facilitate the communication of risk information [19]. Well-designed visuals can help comprehension of treatment risks and benefits [21], reduce errors induced by anecdotal narratives [12], and require less time to interpret than the same information presented

numerically [14]. Prior studies have investigated the design space of graphs to effectively visualize numerical information [15,38]. In the context of clinical settings, several recommendations have been made regarding how to present numeric risk information, including the use of estimates, conveying uncertainty, and presentation of time on the illness trajectory [12,31]. Extending this prior work, this study focuses on comparing different types of visual representations to determine how different representations are perceived differently by patients with the goal of improving informed medical treatment decision practices [42].

Animation has been studied as an important design feature of visual aids. Animation is a method in which part of the graphics is manipulated to appear as a moving image. Researchers have adopted animation in the presentation of health information for its effective delivery [24,17]. However, its effectiveness depends on its proper use [16]. Animation has been found to be useful when presenting trends or transformations of numeric information over time [29]. Through iterative design processes with patients, this study additionally explores the value of animated graph formats to visualize numeric prognostic information.

3. System design for visual aid

To achieve the goals of the tool, we followed a user-centered, iterative design process for its implementation. A user-centered design (UCD) is a broad term that describes design processes in which end-users influence how a design takes shape. Key principles of UCD include the iterative and incremental development process, the active involvement of end-users and multidisciplinary teams throughout the development process, and the system evaluation in a real-life context [25]. It is important to use the UCD approach in the design of online health tools because it helps take the needs and requirements of potential end-users into account during the development of innovative healthcare products and services [49]. To increase the success rate of the usability in a technology, it is of importance to understand the context of use and the user requirements [50].

Following the UCD approach, the tool was developed in two iterative stages. We first created a set of paper-based, low-fidelity prototype sketches to visually present treatment outcomes for rapid assessment of its fidelity (See Fig. 1). To ensure UCD from the outset, the research team gathered initial requirements from both clinicians and patients in the first stage. During this phase, there was a continuous interaction between the research team and the clinician team to facilitate the match between the patient's requirements and the clinical practices. With these prototypes, we conducted the first round of evaluation sessions (the full report is available at [34]), which key findings indicate a strong user preference for a pie chart that is simple, straightforward, and strategically ambiguous.

Based on the findings from the first iteration, we created three interactive prototypes for graph representations of outcome information to investigate how patients perceive and interpret different types of charts in presenting quantitative projected outcomes: a pie chart, a
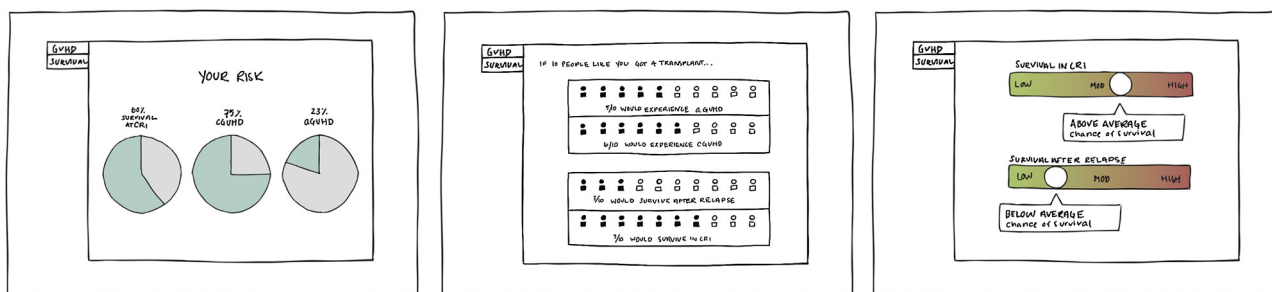

Fig. 1. Three graphical representations with a varying degree of abstraction to present predictive percentages of survivability including a plain pie chart (left), natural frequencies using a human icon (center), and abstract heatmap-colored bar (right). Patients from the first-round study rejected all graphical representations of survivability but a pie chart.
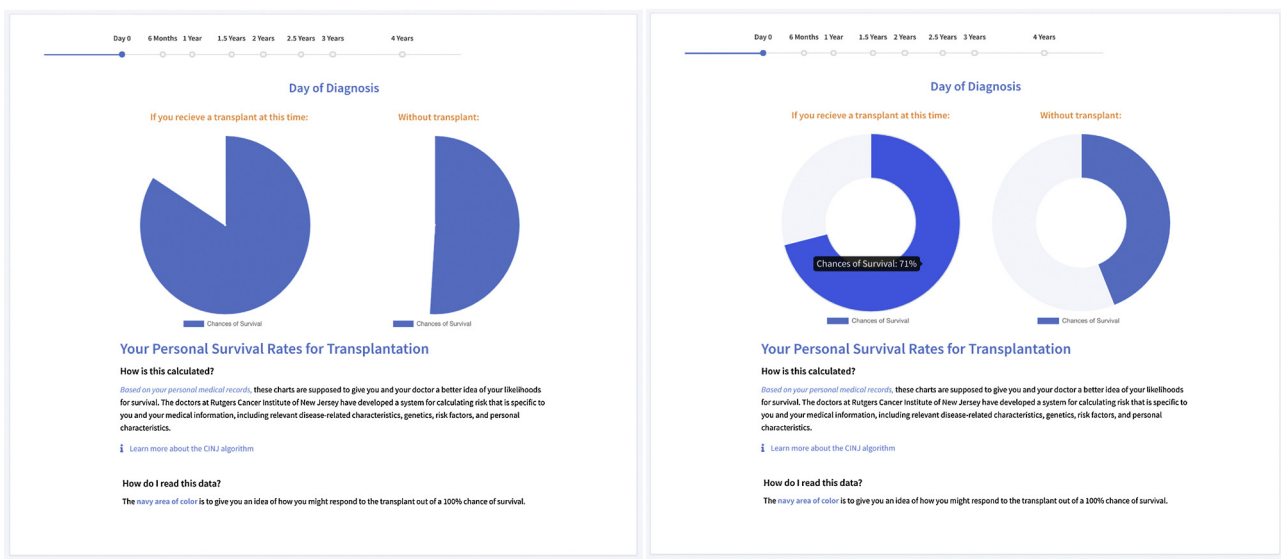
Fig. 2. A pie chart without a numeric label (left) and a donut with a numeric label predicted outcome when hovering a mouse over a graph (right).

vertical bar chart, and a horizontal bar chart. We chose these three types of charts because these are most popular and simple to graphically present numeric information [44]. The prototypes were created as working demos that run on a web server so that a user can have a real experience of interacting with the tool. Since one significant finding from the first-round study was the conflicting preferences among patients for accessing the numeric information of predictive outcomes, we created each prototype in two versions: one with a chart's scale and numeric labels of survivability data and one without them. A projected timeline since transplant (Day 0) up to 4 years was provided above the charts. Clicking each timeframe refreshes a chart with survivability data for the time frame selected. A variation of each prototype was also created that shows a numeric value of survivability when a mouse hovers over a chart. At the bottom of the chart, a short description of how the values are calculated and instructions about how to interpret the graph was provided.

The first prototype is a pie chart. Two pie carts are juxtaposed horizontally to present a chance of survival with and without receiving a transplant (See Fig. 2). There are different perspectives regarding the usability of pie charts since they have been found to be useful in displaying multiple values in a single chart [46] yet have also been found to result in poor comprehension of risk information [28]. Nevertheless, we decided to include a pie chart in our prototype testing upon strong suggestion from our collaborating research team of clinicians who envisioned pie charts as useful for clinic practice. We created the prototype to be interactive by animating the colored portion of a pie chart to gradually fill up clockwise after the page loads.

A second prototype is a bar chart. Two vertical bar charts are juxtaposed horizontally to present a chance of survival with and without receiving a transplant (See Fig. 3). A vertical bar chart is known to be useful to compare groups side by side on the same measure [23]. We created the prototype to be interactive by animating the colored portion of a bar chart to gradually fill up from bottom to top after the page loads.

The third prototype is a horizontal bar chart. Two horizontal bar charts are juxtaposed vertically to present a chance of survival with and without receiving a transplant (See Fig. 4). Information presented in a horizontal bar chart is known to be more readable than the vertical layout and to be preferred by users [23]. We created the prototype to be interactive by animating the colored portion of a bar chart to gradually extend from left to right after the page loads.

4. Methods

We conducted semi-structured, think-aloud interviews with twelve leukemia survivors to understand their perspectives regarding the graph presentations of survivability likelihoods. Our study was conducted at an oncology clinic center at a large teaching hospital in a US metropolitan area. The study was reviewed and approved by the institutional IRB board.

4.1. Participants

Participants were recruited through the oncology clinic center. Our collaborative clinic team identified potential participants from a pool of AML patients, contacted each patient to ask if s/he was interested in the study, and sent us the contact information of those who agreed. We contacted each patient to confirm his or her participation. Finally, before doing an interview, the study was discussed, and a consent form was provided. Semi-structured interviews were conducted with twelve patients (7 females and 5 males, Mean age = 53.3 with SD = 14.7. See Table 1). All but one patient received allogeneic hematopoietic stem cell transplants.

4.2. Data collection

Interviews lasted between one and a half and two hours and sought patients' feedback on the prototypes highlighting their perspectives, experiences, and preferences. Participants were first asked to share their experiences when they were informed about possible outcomes. After we explained the purpose of the OPEN:AML tool, they were asked to freely interact with it and provide feedback reflecting on their experiences. While exploring each prototype, participants were asked to verbalize their thoughts through a think-aloud process. The think-aloud protocol can reveal any thinking process, insights into reasoning, and decision-making processes [11]. If they refrained from "thinking aloud", they were prompted by the interviewer. All interviews were conducted in a consultation room of the oncology center and were audio recorded and transcribed. Participants were compensated for participation. Interviews consisted of open-ended interview questions around four themes targeting patient perspectives of the graph visualizations of survivability data on the tool: 1) first impressions about the tool, 2) reactions to different graph representations of survivability data, and 3) reactions to the access (and no access) to numeric values of
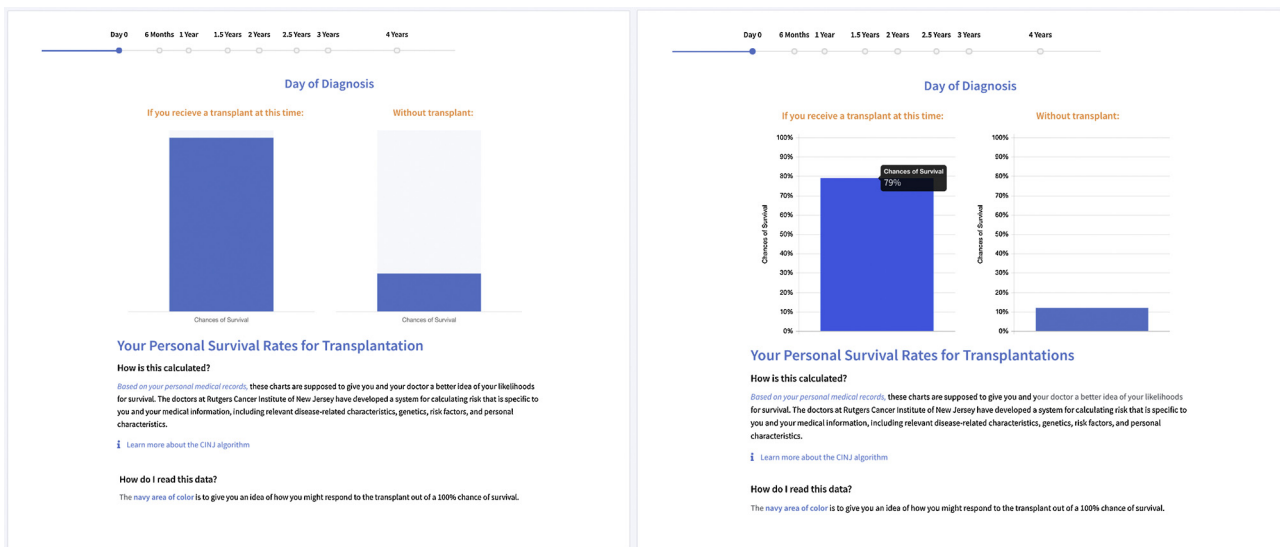
Fig. 3. A vertical bar graph without a scale and a numeric label (left) and with a scale and a numeric label when hovering a mouse over a graph (right).

survivability data. In addition, we collected participants' basic demographic information, including age, gender, type of diagnosis, and years since transplant if undergone.

4.3. Data analysis

We analyzed the interview data using thematic analysis based on grounded theory, which includes open coding, axial coding, and selective coding [47]. The first author led the data analysis. The emerged themes were continuously discussed with others in the research team until data were saturated with recurring themes and no new information was anticipated. In the first step, we conducted open coding to identify and code concepts that are significant in the data as abstract representations of events, objects, happenings, actions, etc. The example below explains how one participant perceive data in a vertically animated bar chart. This response is coded as "vertical animation".

"[vertical animation] If you're going to have numbers, I mean the bottom line is you want to get to the top rung of the ladder. So, I want to climb it. [/vertical animation]." (P5)

Next, we categorized the related concepts created by open coding into higher conceptual phenomena using axial coding. Phenomena in grounded theory refer to repeated patterns of events, happenings,

Table 1
Participant summary.

ID	Gender	Age	Diagnosis	Years since treatment
P1	F	54	Chronic Myelomonocytic Leukemia	4
P2	F	54	Acute Myeloblastic Leukemia	N/A
P3	M	57	Acute Myeloblastic Leukemia	7
P4	M	59	Acute Myeloid Leukemia with mylodysplesia	17
P5	M	60	Non-Hodgkins Lymphoma	6
P6	F	34	Human T-cell leukemia virus type 1	6
P7	F	66	Non-Hodgkins Lymphoma	6
P8	F	27	Acute Myeloid Leukemia	3
P9	F	67	Acute Myeloid Leukemia	2
P10	M	65	Follicular lymphoma	2
P11	F	30	Acute Myeloid Leukemia	5
P12	F	67	Acute Myeloid Leukemia	1

actions, and interactions that represent people's responses to the problems and situations. For instance, "encouragement" is a phenomenon that represents a patient's desired attitude when interpreting prognostic data. During axial coding, the open code "vertical animation" in the example above was categorized as "encouragement".

Lastly, we followed with the selective coding process to assemble
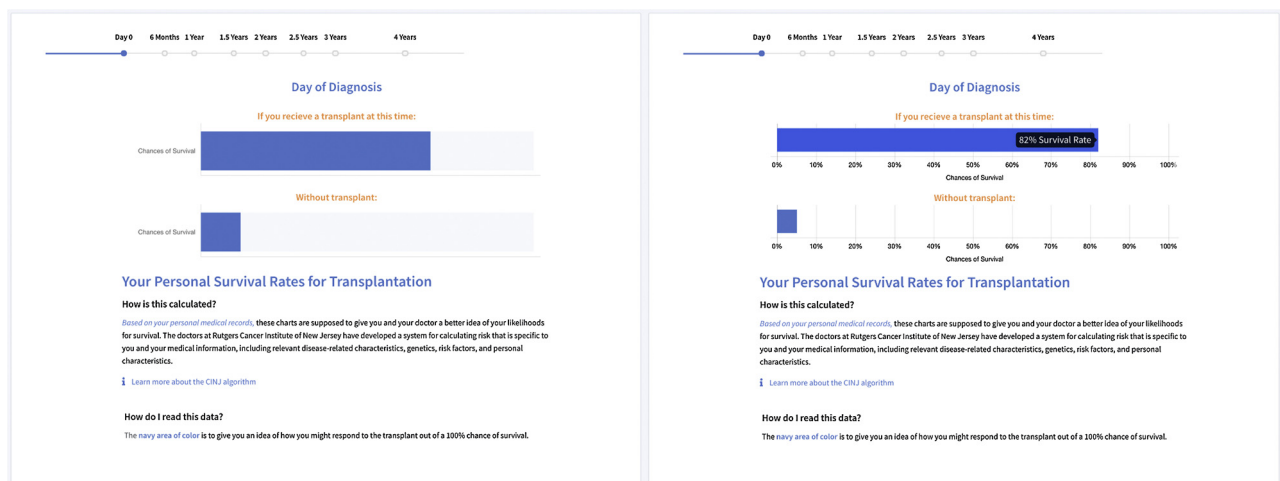

Fig. 4. A horizontal bar graph without a scale and numeric values (left) and with a scale and numeric values when hovering a mouse over a graph (right).

our conceptual phenomena extracted from axial coding into a coherent narrative. The goal of this step is to integrate all concepts into a single storyline throughout building relationships across phenomena.

5. Findings

5.1. Influence of a numeric value on user perceptions of visuals

Before discussing patient perspectives regarding the different types of visual aids that we prototyped, it is important to point out that the numeric value of the prognostic information – whether survivability was numerically low or high – had a significant influence on patients' preference for a particular graph format, that appeared independent of the visual format itself. That is, the presented value significantly influenced initial user feedback, which was negative when a prototype presented a low survivability data and it was positive when the value was high:

"This (a vertical bar graph) feels good because it (survivability) is higher. If I would not have it, my chances of survival were less. It looks like my chances of survival would get worse without transplant." (Participant P1)

"This (a pie chart) is definitely better because it shows that you're better without transplant." (Participant P10)

This finding suggests that the value of quantitative information influencing users' perspectives on its visualization may be inevitable. Thus, to capture authentic perspectives about graph visualizations of quantitative information in our evaluation, it was critical that users were presented graphical representations with different survivability values multiple times to shift their attention from the survivability value to the visual format. In order to minimize the influence of the value of the survivability data on users' perception of different visualizations, we created our prototype system to randomly select the numeric and feedback about each prototype was elicited multiple times by refreshing a screen to show a graph with different values to dilute the influence of the numeric values on the perception of a prototype. After allowing a participant to thoroughly explore one prototype, we refreshed the screen to change the numeric value and participants were asked if their perspectives remained the same. This strategy helped as, in most cases, after seeing the graph multiple times with different values, their feedback became more focused on the graph format, not the survival rate.

5.2. User feedback on different types of visuals

While participants had varied preferences of different prototypes, we found coherence in the reasoning underlying their preferences and concerns about the prototypes. Although generalization is challenged by the small sample size, overall, participants perceived a vertical bar graph to be most appropriate to present numeric survivability information, followed by a horizontal bar graph and a pie chart. Based on this finding, this study further explores patients' preference on different chart types with access to numeric data of survivability and graphical animation that gradually fills up the colored portion of a chart when the page loads.

5.2.1. Vertical bar chart

Participants counted a vertical layout of a bar chart as the most preferred prototype because of its familiarity, simplicity, and generality. This finding confirms prior research that demonstrated vertical bar graphs are user-friendlier than horizontal bar graphs for its familiarity [16]. In particular, many participants perceived the animation of this prototype that gradually fills up the graph from bottom to top to positively frame the interpretation of survivability information. They perceived that the animation of the value filling up from bottom to top was analogous to their effort of striving to achieve the goal and be

successful. Consequently, participants perceived a vertical bar graph that is animated to fill up to be encouraging and emotionally supportive in interpreting the projected survivability data regardless of whether the actual value of survivability was positive or negative.

"I think the bars make more sense for this kind of information than the pie. And, I just find it easier to read vertical than horizontal. So, I prefer the vertical bar. If you're going to have numbers, I mean the bottom line is you want to get to the top rung of the ladder. So, I want to climb it." (Participant P5)

"Vertical is more representative of direction and success but the circles don't necessarily do that here. That's how my brain is functioning right now. The circle suggests that this thing is just going to keep going and going. It's going to be nonstop. But when you have like an incline on a vertical column, it suggests strength. So, a vertical column to me is stronger in a subconscious kind of way, I guess." (Participant P6)

5.2.2. Horizontal bar chart

Participants declared the horizontal layout of a bar chart as the second preferred prototype thanks to its simplicity and familiarity of reading from left to right. This finding confirms prior research that demonstrated people in Western cultures would perceive it to be natural to process information horizontally since the left-right association is a default, at least in Western cultures, possibly reflecting reading habits.

"Horizontal is actually better than the bar chart since most people read from left to right, this is kind of better although it'd be even better with the numbers. Actually, yeah, I think that this is the best kind." (Participant P1)

Interestingly, many participants commented on the perceived ease of comparing survivability data with and without transplant through the two graphs juxtaposed vertically as a significant benefit of this prototype. While all prototypes juxtaposed two graphs either horizontally or vertically to present a projected survivability both with and without transplant, it was only for the horizontal bar charts in which participants commented about ease of comparing survivability data with and without transplant. We assume this might be due to two visual elements (1) the close proximity between the charts and (2) the horizontal-movement animation. First, two horizontal bar charts were placed adjacent to each other. While all prototypes juxtaposed two charts either horizontally or vertically, the distance between two charts were closest in the horizontal bar-chart prototype, which might have prompted participants to more easily perceive them to constitute a set of related data. Second, the horizontal-movement animation implemented on the horizontal bar-chart prototype might have drawn users' attention to the difference in the values of two charts. While these assumptions could be applied to the vertical bar-chart prototype too, we did not receive any feedback related to data comparison in the vertical bar-chart prototype from our participants.

"When I look at this (a horizonal bar graph), I can compare the two very easily, even these more easily than I can in a vertical because I can see how much longer that line extends." (Participant P8)

"I think it (horizontal) is easier to do a comparison of the information because I compare it down. I think it's easier to see comparing those two bars down." (Participant P10)

With regard to the animation, some participants perceived the animation that gradually extends from left to right to positively frame the interpretation of survivability information. They interpreted that the animation of the value expanding from left to right was analogous to effort of sprinting to a finish line or a goal and be successful. Consequently, participants perceived a horizontal bar graph with the horizontal-movement animation to be encouraging and emotionally supportive in interpreting the projected survivability whether the

actual value of survivability is positive or negative.

5.2.3. Pie chart

Participants described the pie chart as the least preferred of all the prototypes due to its seeming irrelevance to presenting a single piece of data. Several participants mentioned that a pie chart should be used to illustrate numerical proportions of multiple values in order to compare different sections in a given chart by dividing it into multiple slices, which confirms our prior study. While participants perceived the other two prototypes as a graph representation of a single value of survivability, they perceived a pie chart as consisting of two values, a colored proportion to present projected survivability and a non-colored proportion to present projected non-survivability. This, consequently, brought participants' attention to a negative aspect of survivability information: their chances of dying.

"I don't like it (a pie chart) because pie charts are supposed to have multiple things in it. You can't just have one thing for a pie chart. Usually, the pie chart works most effective when you have several different variables, and you have three, four, five different colors." (Participant P11)
"What would you name the other piece? Chance of you dying?" (Participant P12)

The animation of a pie chart also negatively influenced the interpretation of the information. The animation of gradually filling up the chart clockwise reminded some participants of an old video game, Pac-Man, which made them perceive the chart less professional and even non-clinical.

5.2.4. Access to numeric values of survivability

One consideration that we had in creating a prototype was whether or not to present the numeric value of projected survivability on a prototype, and how if so, because our previous study showed patients' conflicting opinions of seeing their survivability in precise numbers. Thus, we created each prototype in two versions, one with a chart's scale and numeric labels of survivability and one without them. Again, participants expressed mixed feelings about seeing numeric data of their survivability: some participants liked it for its accessibility and precision, while other participants strongly rejected the idea of seeing the numeric value of survivability because of its potential influence to elicit negative emotions around treatment and possible recovery. Regardless of their perspectives on whether to have access to numeric data of survivability, however, all participants expressed a strong preference to have access to a precise numeric value on the graph visualization once they had access to it. Even though our prototypes did not adopt abstract visualization components (e.g., icons, colors, pictogram), participants perceived the prototypes to be abstract, uncertain, or incomplete when a prototype did not have a chart's scale and numeric labels. This was because they still had to estimate the actual value of survivability when a graph did not present a numeric value and its scale.

"I would completely take the entire page out, but if you asked my opinion, I think when you have a scale, especially for the older you get, I think it's better just to see the number." (Participant P2)
"With numbers is much better. You know, a bar chart is great. It's very visual but you like to have also a number because without it it's just an estimate. If you talk to somebody you could say yeah, the survival rate, you know, is 71 percent. Without the numbers you have to maybe kind of estimate based on what the bar graph is, you know? So, it is better with numbers." (Participant P12)

A particular consideration we had about presenting a numeric value of survivability was how to minimize a potentially negative impact of presenting it to patients who are already distressed and vulnerable. Thus, for prototype versions with a chart's scale and numeric labels, we made another variation so that a prototype randomly chooses between two modes when loading: a prototype that always displays the numeric label and one that only displays it when a user hovers their mouse over a chart. By refreshing each prototype page, we investigated how users would respond to a numeric value of survivability when it is displayed as a part of visualization or displayed only when a user requests to see it by hovering over it with a mouse. While some participants preferred having a numeric value displayed with a chart due to a concern of forgetting to hover over it, the majority of participants appreciated the idea that they can choose whether or not to further investigate the data. This finding implies that patients would feel empowered by having autonomy to decide the level of their engagement with the information for themselves.

"When you hover up and see the number then I get the best of both worlds. I don't have to confront with the number. I can see it only if I want to. That's what I would want it to do." (Participant P2)

However, participants recognized that it could be devastating to patients both physically and emotionally if they encountered an extremely negative value of survivability without any precursor information or accompanying explanations, and especially if they access this information by themselves. When the chance of survivability is very low, it is no more a system's usability issue to determine how to present such information, but an ethical and clinical issue to consider in which physicians and caregivers need to engage with the delivery of such information to a patient. In this case, the tool should not provide this information or at least add a screening procedure to confirm if a user really intends to access the information. Hence, we decided to implement the screening procedure in our tool so that a user should explicitly request access to the visualization of survivability information if the projected survivability is below 50 %. This threshold level needs further discussion with clinical stakeholders to meet clinical compliance requirements and other considerations.

"I think when it gets to here and you're just seeing this little barely 10 % bar, I get that. You don't need to tell me you have a 9% chance of survival. I get it. That's scary enough. I don't need to know that if the longer I wait… but when you're looking at one of these, is it 50 %? Or even this one, does that mean I have a 50 % of chance of surviving if I do have it? Maybe you do start getting into the specifics when you have to make that decision." (Participant P3)

5.3. Conscious effort to make sense of survivability

So far, we have described our findings about user feedback that are directly related to different types of visuals. In addition, our thematic analysis revealed two themes, "balancing tension between utility and fear" and "establishing authenticity and credibility", that are fundamental, and probably more nuanced regarding users' conscious efforts to make sense of the data that was presented to them.

5.3.1. Balancing tension between utility and fear

Initial overall reactions about the OPEN:AML tool were mixed. Several participants expressed enthusiasm about the general utility that the tool would offer, such as easy access to and precision of personalized medical information and the ability to pace the amount of information they would process at a particular point in time. One of the primary, and perhaps first, information sources for newly diagnosed AML patients is an education class that the clinic offers regularly (monthly in our collaborating clinic). The education class lasts about 3 hours, is required by all newly diagnosed patients and their caregiver providing them with general information about diagnosis and treatment options, introduces patients to the healthcare team, and answers any questions they have. All participants mentioned that attending the education class was an overwhelming and stressful experience because it delivers a large amount of information in a short amount of time, much of which is difficult for newly diagnosed patients to understand.

In addition, participants found it difficult to integrate the information in meaningful ways because the contents are not personalized and thus some information is not applicable to them. For patients who are already experiencing fear, anxiety, and stress about a disease, being exposed to irrelevant, and potentially terrifying, information can add extra burden [35]. Therefore, as an addition to or a substitute for existing education classes, having the ability to access personalized information about projected treatment outcomes at any time via the OPEN:AML tool was favored by participants for its utility.

> "This is laid out in a way that's practical but not overwhelming. And I can look at it as much at a time or as little at a time as I want. Whereas when I was staring at the big block of papers (received from the education class) and I was flipping through it, I felt like I got to take it all in… It was just overwhelming." (Participant P3)
>
> "This has a lot of good information. It's not overwhelming, and you could just select things that you want to that you'd be interested and not go through the whole thing if you don't want to." (Participant P7)

Independent access to personalized information of survivability data can, however, be a double-edged sword because one's survivability might be "bad news" - information that adversely and seriously affects a patient's view of his or her future [4]. Receiving unfavorable medical information might have a distressing impact on patients' lives [13]. Therefore, while some patients might desire accurate information to assist them in making important quality-of-life decisions, others might find it too threatening and may employ forms of denial, shunning or minimizing the significance of the information, while still participating in treatment [3]. Indeed, some participants strongly rejected the idea of having independent access to potentially distressing information without the support of their healthcare team especially when they may be in vulnerable stages of the disease process. They were concerned and even scared about being emotionally discouraged and distressed after seeing distressful information.

> "This is so scary. I wouldn't even want to know this, because I remember when I asked my doctor how much time I have to live if I won't do the transplant, and he told me two weeks. After I asked him, I thought why the hell I asked him this. I didn't need to know that. And, those two weeks still stick out, you know? Like, in a way, what if the number will be only 5? I think it's very, very scary." (Participant P5)
>
> "You go home, and you're still overwhelmed. Now you sit down and you're trying to navigate through this. I'm not sure if you can read this all properly. I don't know. I think it's a helpful resource, but I'm not sure exactly how to use it." (Participant P10)

As such, our participants expressed conflicting feelings about possible consequences of using our tool: they recognized the positive utility of information accessibility along with a fear of confronting distressful information about poor survivability outcomes that they did not perceive as beneficial. Throughout the interviews, participants shared their conscious efforts to stay both positive and well-informed. However, this finding illuminated moments when these two values could be in conflict, and when this happens, participants deliberately prioritize one of these goals over the other to secure a delicate balance between fear and utility. Therefore, the key design challenge is how to balance the tension between utility and fear of having individual access to prognostic information. While some of our findings in previous sections could be used to overcome this challenge, further investigation is needed to identify factors that can secure the utility, while reducing a fear, of using decision aids.

5.3.2. Establishing authenticity and credibility

Due to the necessity of information that the OPEN:AML tool provides, one's chance of survival, participants requested viable means to establish the authenticity and credibility of the information. For

authenticity, participants were seeking to understand how the data was processed. This means that it is important not only to present the information to patients but also to provide guided instructions to ensure the authenticity of the information. Without it, users would have no means to determine the validity of the information underlying their reported chance of survival. Among several methods, patients first asked for a clear and easy but thorough explanation about the algorithm that the tool uses to calculate projected survivability data. To support this, instructional guidance to easily interpret how the information is processed is vital to establishing the authenticity of the information. While our tool provides a short snippet underneath the graphs to describe how the data is calculated, most participants found it was not enough.

> "How do you determine what my survival rate will be? My own survival rates after getting a bone marrow transplant? I want to know how you would determine that." (Participant P7)

However, it is not a trivial task for distressed patients to read a lengthy and complex written instruction about the detailed algorithm to calculate one's survivability on their own. Especially when the information is not positive (e.g., low survivability rate), it would be very difficult for patients to remain calm and read the detailed explanation about how the data is calculated. All participants mentioned that patients, and those with high emotional stress in particular, would not have enough emotional capacity to process instructions about the tool's algorithm, which would be nothing but another way of overwhelming a patient.

To cope with this problem, participants requested a way to build a credibility of the information that the tool provides. For credibility, participants wanted reassurance that the information is verified and confirmed by their clinical team so that they do not need to question its authenticity. To ensure credibility, participants asked their doctors to engage in their initial interactions with the tool by providing them with a brief but thorough explanation about the tool to help patients understand, such as how the data is calculated and how to interpret it, as well as answering any questions relating to the information. Not only can this procedure fulfill patients' informational needs to better understand the data but also allows patients to build a sense of credibility about the tool. This implies that patient-provider communication is crucial for patients' adoption and use of electronic decision aids like the OPEN:AML tool. Since a doctor is the most reliable resource for patients, provider communication can play a vital role in building patients' credibility to new technology interventions. This finding is important because electronic tools designed for patients to have ongoing access to information may be perceived as methods for offloading some types of clinic communication, but in essence, patients were clear that they this tool would require new forms of communication with their providers.

> "I might freak out if it says I only have such a such percentage… So, I would want to know that the doctor is completely involved in this. As a non-medical professional, I would prefer to have my doctor's explanation about this tool as one of the first things at the top to tell me what I need to know and why I'm here. Without having a doctor explaining how to use this information, it could be a little bit confusing. As much as I'd love it, I want to know what my doctor thinks about this tool." (Participant P1)

6. Discussion

6.1. Methodological lessons for risk tool designers

One finding that deserves further discussion concerns participants' difficulty evaluating design formats of numerical prognostic information without considering the symbolic meaning and/or personal value of the numerical information presented. That is, when risk information

forecasted poor outcomes, participants tended to draw their interpretations of the design features from the meaning of negative risk and thus evaluate the design formats more negatively; contrastively, when risk information projected positive outcomes, they tended to evaluate the formats for presenting risk information more positively. This was a valuable finding and has methodological implications for user-centered design. To address this challenge, we rotated numerical values randomly and had participants view the formats with various values (i.e., projecting both negative and positive risk outcomes) to help focus participants' attention to the delivery formats rather than the value of the numbers themselves. Future design studies may work to develop methodological approaches in design to strategically scaffold participants' engagement with risk information, as we have done here, to bring their focus and facilitate their assessment of whatever design formats are being tested. However, this tension for participants also deserves more systematic inquiry as it may be that people are generally challenged to make these distinctions in real-world contexts. Assessing patients' evaluations of delivery formats divorced from how they make sense of the content being delivered compromises ecological validity since it is unlikely that patients facing high-risk decisions and receiving risk information will tease a part the content from its delivery. Indeed, there may be a nuanced and complex relationship between the delivery format and the content of the risk information such that positive risk information may be preferred in a particular format while negative risk information may be preferred in a different format. This is not a relationship we investigated and so warrants future investigation.

6.2. Influence of visual formats on data interpretation

This study provided useful insights about design considerations when delivering critical health information in a way that minimizes emotional stress. It shows the importance for accounting for the consequences of delivering sensitive medical information when a patient is in a vulnerable state. A critical issue in the communication of prognostic information, especially when the information is negative, is how to convey potentially distressing information to patients in a way that could still be framed positively and supportively. Since it is important to reduce emotional distress and promote patients to maintain optimistic for effective risk communication, providing information in a constructive and empathetic manner is a key to help patients better manage stressful information [30]. However, when the prognosis is very negative (e.g., short life expectancy), prognostic information itself could negatively impact healthcare outcomes, anxiety, and depression, regardless of delivery form. Therefore, following prior research that suggests bad news be communicated by a physician [2], we prevented a patient's direct access to the information online when the prognosis was poor in our design. This design choice should be further investigated, particularly an exploration of the potential values and tradeoffs associated with patients' accessibility, empowerment, and autonomy of managing health information in the design of online healthcare tools.

Also, our findings demonstrate that different visual formats could variably influence users, determining which part of the data they are likely to pay attention to and how they interpret the meaning of the data both informationally and emotionally. Therefore, using an appropriate visual format can reduce potential negative effects and help patients remain positive and motivated when receiving risk information about a complex medical treatment. By doing so, we can support patients to make sense of distressing information in a positive and constructive manner. Design implications that the findings suggest for help patients keep positive without denying clinical realities include building reliability of decision aids, providing patient autonomy in the access to medical information, reconciling patients' conflicting needs between obtaining precise and detailed information and avoiding the encounter of distressful information, and promoting patient-provider communication. For instance, the way the animation of the visualization elegantly incorporates potentially distressing information within a positive frame to manage a narrative no matter what the facts are. Also, providing a control to the users to decide how and whether the precise estimates can assure patients' sense of autonomy.

Lastly, pie charts were the least preferred format of our prototypes, but in our prior study patients showed a preference for pie charts' simplicity and straightforwardness when compared to more abstract representations of communicating survivability such as icons of people or heatmaps with varying colors [34]. This points out that preferences are relative and depend on the options provided to participants for comparison [35]. Also, it is worth noting that physicians and patients showed different preferences regarding the graphical formats for prognosis visualization: a pie chart was originally chosen based on a clinic team's suggestion, but patients preferred a vertical bar chart and the pie chart was their least preferred option. These findings suggest a need for further studies comparing patient preferences across different studies as well as across different stakeholders, with a consideration of what such differences mean for design decisions.

6.3. Sense-making in clinical workflow

The findings about authenticity and credibility point to the importance of how the OPEN:AML system fits into the flow of activities among patients and clinicians. The graphical information stimulated questions by the participants about what the prognostic data means including how it is calculated. It is possible those questions could be treated with more information, but the findings here appear consistent with prior work [3,48] about patient preferences to ask questions rather than just hearing about mortality likelihood. This suggests that patients need guidance and conversation with clinicians about their plausible trajectories with AML with and without treatment. In this regard, the OPEN:AML may afford more than information provision by stimulating conversations between patients and clinicians – conversations with a better grounding for sensemaking. If the OPEN:AML were implemented without some further conversational context it may actually exacerbate patient concerns and comprehension by exposing questions about authenticity and credibility. This raises two further lines of investigation about fitting the OPEN:AML into the clinical workflow. First, practical implementation questions about how the OPEN:AML relates to the patient education activity of the clinic. Second, the OPEN:AML role in conversations between doctors and patients. There is a need to understand how the implementation of OPEN:AML will call for reconsideration of the design of the clinical service.

7. Limitations

Our findings must be evaluated within the context of several limitations. First, our sample size of patients was small and thus our participant pool may not be representative of a general population. Second, we used convenience sampling for recruitment, which also runs the risk of compromising generalizability. Selection bias or unmeasured factors (e.g., having an experience in the same hospital with a same doctor) could have influenced the responses during the sessions. In addition, all participants but one had survived after transplant. Thus, it is possible that patients currently facing these high-risk decisions and trying to interpret personalized risk information are under different stressors and have different reactions to seeing this information. Lastly, we did not explicitly test for whether participants accurately comprehended the risk information but focused on examining patient assessments of different approaches to representing numeric prognostic information. These findings, therefore, may not generalize to the larger population of participants with critical health concerns.

8. Conclusion

It is challenging in health risk communication to deliver critical prognostic information to patients in an easily comprehensible and less

intimidating form. This study aims to investigate how patients with leukemia would perceive different graph representations of projected treatment outcomes to support patients' understanding and interpretation of potentially critical prognostic information through a user-centered method. Our results indicate that in order for the visualization to be an effective means to communicate critical prognostic information, the graph visualizations need to be carefully chosen to assure the clarity and plainness of the data. Additionally, due to the criticality of the information, physicians' support for the introduction and interpretation of data on the tool is essential to aid the patients' comprehension of their risk information as well as to establish authenticity and credibility to the tool. These findings led to the implementation of the OPEN:AML tool. Based on the findings of this study, we are currently developing a working system of the OPEN:AML with a vertical-bar prototype as a presentation format of risk information. As a next step, we plan to deploy the system in the real world to investigate the effects of this tool on patients' understanding of prognostic information. We hope our work motivates future research to engage patients in the design process for the successful design of online healthcare tools.

9. Summary points

What was already known on the topic?

- Patients seek to stay positive and encouraging in their illness journey.
- Patients prefer detailed information about their diagnosis and expected outcomes, although information needs can vary by demographic, psychological and disease variables.
- Effective graph visualization of numeric prognosis information can help patients comprehend treatment risks and benefits, reduce errors induced by anecdotal narratives, and require less time to interpret than the same information presented numerically.

What this study adds to our knowledge?

- The results showed a preference for vertical bar charts over horizontal and pie charts; the charts with "fill-up" animation conveying a subtle sense of positivity even when prognosis was negative; and the importance of providing patients with control over when to access what information.
- The results point out that making sense of prognostic information involves balancing the tension between information utility and patient judgments about authenticity and credibility of prognosis information.
- The results suggest that an appropriate visual format can reduce potential negative effects in conveying prognosis information while helping patients stay positive and motivated for cure in the delivery of prognosis information.

Authors' contributions

All authors were involved in the conception of the work and the design of the study. Kim provided methodological expertise. Trinidad undertook the data collection. Kim and Trinidad performed the analysis and interpretation. Kim drafted the article. Mikesell and Aakhus did critical revision of the article. Kim, Trinidad, Mikesell, and Aakhus agreed on the final version to be submitted.

Declaration of conflicting interests

There are no known conflicts of interest associated with this work and there has been no significant financial support for this work that could have influenced its outcome.

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