Evaluation of Data Visualizations for an Electronic Patient Preferences Tool for Older Adults Diagnosed with Hematologic Malignancies

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Abstract

Patients diagnosed with hematologic malignancies account for 10% of cancer related deaths. The growth of treatment options for hematologic malignancies has led to increased focus on treatment decision-making. However, little research has been done integrating patient-generated data and shared decision making to facilitate patient-clinician collaboration and understand patient preferences in cancer care. Our study aims to develop and evaluate data visualizations to support an electronic healthcare tool (EHT) to facilitate patient understanding of treatment outcomes using human-centered design methods. Data visualizations were developed and updated based on feedback from healthy volunteers, older adults with hematologic malignancies (patients), caregivers, and clinicians. We conducted a content analysis on the qualitative data gathered from participants. Our findings showed that users preferred easy to understand visualizations with simple, explanatory text compared to visualizations that were not immediately intuitive. Users also preferred visualizations that were more reflective of the individual's cancer treatment rather than a comparison to the patient population. Iterative improvements were made to the visualizations to reflect user feedback and will be used to inform the next iteration of visualizations for user testing in the clinic. This paper demonstrates the benefit of human- and user-centered design to iterate on data visualizations used to support a patient preference tool.

Keywords: data visualization, user-centered design, patient preference, patient-centered care, electronic healthcare tool, oncology

Index Terms: Human-centered computing—Visualization—Visualization design and evaluation methods; Human-centered computing—Human computer interaction (HCI)—HCI design and evaluation methods—Usability testing; Human-centered computing—Human computer interaction (HCI)—HCI theory, concepts and models

1 Introduction

Hematologic malignancies are cancers that affect the blood, bone marrow, and lymph nodes and impact approximately 186,400 new patients in the United States each year. New cases of hematologic malignancies, including leukemia, lymphoma, and myeloma, account for 10% of new cancer cases and 10% of all deaths from cancer overall [1]. Between 2011 and 2021, the Food and Drug Administration (FDA) approved 52 new drug registrations for use in the treatment of hematologic malignancies [2]. These new treatments have increased treatment options for patients but have also increased the complexity of treatment decision-making. Consequently, the growth of treatment options has led to an expanded interest in understanding patient preferences to personalize treatment recommendations [3]. Several studies have highlighted the challenges of incorporating patient preferences into treatment decisions for patients with hematologic malignancies. Such challenges include the lack of preference elicitation, steep learning curves for patients in communicating with clinicians about complex decisions, frequent mismatches between the information needs of patients compared to the information provided by clinicians, and patient-clinician discordance in the perception of risks and benefits of treatments [3]–[8].

Data visualizations have been increasingly used in healthcare settings to support decision making by clinicians [9], [10]. Data visualizations may effectively address some of the challenges of personalizing treatment decisions by making data more understandable and accessible and minimizing cognitive workload (CWL) [11], [12]. Visualizations have been increasingly used in healthcare settings, including electronic health record data, to support decision making by clinicians [9], [10]. Human- and user-centered design methods have been used to adapt data visualizations in the clinical setting, however, few studies have evaluated the use of human-centered design approaches to adapt data visualizations to improve personalized medicine for patients with cancer [13], [14]. Therefore, further research is needed to evaluate the application of human-centered design principles to improve data visualizations and support personalized medicine in oncology.

Our study aimed to develop and evaluate data visualizations of patient preferences for treatment outcomes within an electronic healthcare tool (EHT). We intend to use this EHT to facilitate personalized decision-making about chemotherapy. We previously developed the EHT prototype (an interactive, patient- and clinician-facing assessment taken on an iPad by the patient) using a preference elicitation instrument for older adults with hematologic malignancies that we created (see Appendix) [15]-[18]. Here, we describe how we used human-centered design methods to iteratively adapt data visualizations used in the EHT prototype to visualize patient preferences for treatment outcomes.

2 Methodology

Human-centered design methods and interpretative phenomenological analysis (IPA) [19] were used to elicit feedback from study participants on data visualizations from four different groups: 1) healthy volunteers (3 sequential cohorts), 2) older adults with hematologic malignancies, 3) caregivers, and 4) clinicians.

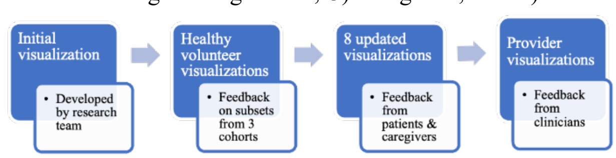


Figure 1: Study overview. Iterative improvement of data visualizations from initial visualization to clinician visualizations.

See Appendix for specific visualizations seen by each participant group.

Volunteers, caregivers, and clinicians were eligible if they were 21 years of age and older. Patients were eligible if they were 60 years of age and older and were receiving chemotherapy. See Appendix for additional demographic information. The study protocol was reviewed and approved by the Institution Review Board (IRB) at the University of North Carolina: 21-0228.

Participants first completed all tasks within the EHT prototype to elicit their preferences for outcomes. Then, we conducted semi-structured interviews to elicit feedback on visualizations. All interviews were conducted individually with one trained researcher. Healthy volunteers reviewed visualizations on an iPad; patients and caregivers reviewed colored, paper copies; and clinicians reviewed the visualizations via a shared screen on Zoom teleconference platform. An introductory prompt was read to the user noting that the visualizations represent a fictional representation of individualized results that would be presented to the patient in a clinic setting after the patient completed all of the tasks in the EHT.

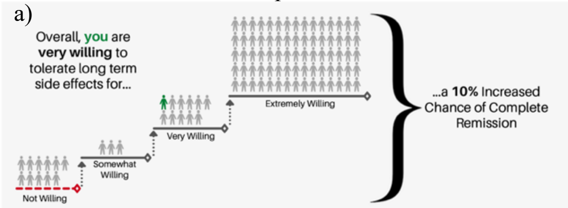
We used the Interpretative Phenomenological Analysis (IPA) framework and Guest's Qualitative Data Field Manual [20] in consultation with a qualitative research expert to formulate interview questions for exploring participants' perceptions, emotions, decision-making, and interpretation of the data visualizations (see interview guide in Appendix) [19], [21]. Interviews for healthy volunteers focused on eliciting general impressions of the visualizations and the clarity of the visualizations to display risk-benefit tradeoffs and change in preferences over time. Interviews of patients, caregivers, and clinicians focused on understandability and impressions about usefulness of the visualizations to improve personalized decision-making.

Using the IPA framework, we followed a real-time, participant-driven approach to analyze data with the cohort as the unit of analysis. Interviews were analyzed by categorizing responses into themes and visualization preferences by research team members. We revised the themes to ensure consistency with the transcribed interview recordings, then converted the themes into a narrative that supported the exact account from participants. This approach allowed us to develop themes based not only on repetitive occurrence, but also how well a participant articulated and summarized key aspects, which is consistent with other studies using IPA [19], [22].

2.1 Initial Visualization Development

All visualizations were developed using human-centered design methods and assessed for color and text size accessibility. We designed initial visualizations to reflect three aspects of patient preferences: 1) risk-benefit tradeoffs, 2) change in preferences over time, and 3) current strength of preferences for treatment outcomes. Example visualizations are shown in Figure 2. Figure 2a was developed to reflect risk-benefit tradeoffs using Segel and Heer's narrative visualization framework [23] to create a story that displayed how willing a patient was to tolerate certain levels of risk (compared to others with the same diagnosis) for a chance to increase their chance of complete remission.

a)



b) c)

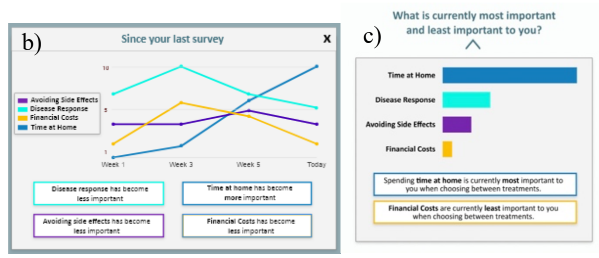


Figure 2: a) Initial visualization of risk-benefit tradeoffs, pictograph; b) line graph of change in preferences over time; c) bar graph of current strength of preferences for treatment outcomes. All visualizations and the order they were shown to stakeholders are displayed in the Appendix.

2.2 Visualization Testing with Healthy Volunteers

A co-design approach was used to engage healthy volunteers in evaluating the visualizations; feedback was used to iterate on existing visualizations and develop new visualizations to be reviewed by subsequent cohorts. This approach allowed the research team to rapidly develop additional prototype visualizations to be evaluated by the target population (patients and clinicians). In total, 8 visualizations were developed, of which a subset was reviewed by each cohort (see Appendix).

Cohort 1 reviewed and provided feedback for the initial patient visualization pictograph (Figure 2a), along with a line graph, bar graph, and aggressiveness gauge (Appendix Figure 1).

Cohort 2 reviewed and provided feedback on two visualizations of risk-benefit tradeoffs (a pros and cons weight scale and an aggressiveness of therapy scale), an updated iteration of the line graph (Figure 2b), an updated iteration of the bar graph, and the aggressiveness gauge (Appendix Figure 2).

Cohort 3 reviewed and provided feedback on four visualizations: a line graph, a bar graph, a benefit-risk summary, and an aggressiveness of therapy summary (Appendix Figure 3).

2.3 Visualization Testing with Patients and Caregivers

Data visualizations were iterated between the three cohorts of healthy volunteers and updated before being presented to patients and caregivers to reflect feedback. In total, eight visualizations (Figure 3, Appendix Figure 4) were used to elicit additional feedback from older adults with hematologic malignancies and their caregivers.

a) b) c)

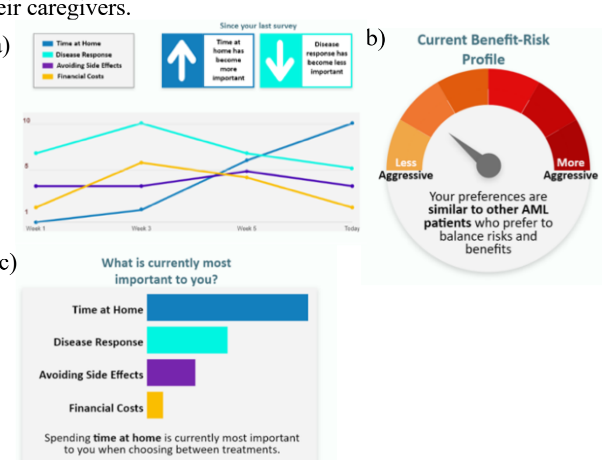


Figure 3: Example data visualizations (3 of 8) used to elicit feedback from patients and caregivers; a) bar graph; b) aggressiveness gauge; and c) line graph. All visualizations are displayed in the Appendix.

2.4 Visualization Testing with Clinicians

Three updated visualizations were shown to clinicians (Figure 4). Clinicians were asked for unstructured feedback on the visualizations, whether other clinicians would understand them, and whether they would recommend the EHT in general.

Figure 4: Clinician visualizations. Data visualizations used to elicit feedback from clinicians; a) line graph; b) histogram; and c) willingness to take a new drug summary. Visualizations are also displayed in the Appendix.

3 Results

3.1 General Feedback from Participants

In total, 29 participants provided feedback: healthy volunteers (n=15), patients (n=5), caregivers (n=4), and clinicians (n=5).

General feedback from healthy volunteers prompted simplification of graphs and the addition of text to supplement the graphs. Visualizations were also modified to provide clarity by simplifying the quantity and quality of text on certain visualizations and purposeful use of color (e.g., green for benefit and red for risk) before usability testing with patients and caregivers.

Patients and caregivers stated that the visualizations overall were easy to understand. Patients and caregivers overall liked the line graph (e.g Figure 3a), aggressiveness gauge (e.g. Figure 3b), and the bar graph (e.g. Figure 3c).

Clinicians preferred visualizations that required less CWL and were intuitive. One clinician recommended pie charts could be a helpful way to visualize patient preferences easily.

3.2 Theme 1: Personalized Information Rather Than Comparison to the Patient Population

Although the patient visualization pictograph (Figure 2a) was developed using Segel and Heer's narrative visualization framework, all participant groups, including healthy volunteers who may not have the background nor experience of what a cancer patient might be going through, preferred a more individual, personalized visualization. Participants did not value the comparison with the entire population, stating they did not want the visualization to compare them to other people or against other people, citing it was *"[their] cancer treatment."* One healthy volunteer stated about Figure 1a:

"Showing [one's] own personal preferences are most important. [The patient] wouldn't care how they compare to others. Personal reactions to drugs, processing things is different. It's my journey. What matters is what currently is most important to me." (Healthy Volunteer 4004)

Similar sentiments were also expressed by some clinicians, who indicated they did not see the value of comparative preferences:

"If this is meant to be individualized, and as a tool to use in the clinic, I don't know that I care what everybody else thinks. I think it's an interesting thing to look at on the back end for research, but maybe not in the clinic." (Clinician 3005)

3.3 Theme 2: Simple and Easy to Understand, but Not Oversimplified

Participants preferred visualizations that were simple and intuitive, as anticipated. Visualizations that were more complex or required incorporation of several types of information received the most negative feedback. However, oversimplification of patient preferences in the visualizations was not favored by patients in particular, given the complex nature of treatment decision-making.

Healthy volunteers preferred a small amount of text in the visualizations to explain the graphics. Participants felt the bar graph followed by the line graph most addressed this:

"I like the bar graph because it's simple. I do not have to think, it just makes sense." (Healthy Volunteer 4001)

On the other hand, the pictograph (Figure 2a) and the aggressiveness gauge (Figure 3b) were difficult to understand, complex, and not immediately intuitive to some participants:

"I think this [aggressiveness gauge] graphic is a little confusing, as to the scales, is it saying I prefer less aggressive treatment? Is it just a treatment or talking about balancing risks and benefits? I think I'm a little confused there." (Healthy Volunteer 4005)

Patients and caregivers expressed mixed opinions about gauge visualizations in general – some liked them and felt they were easy to understand, while others felt they oversimplified patient preferences:

"For [the gauge visualization showing what is currently most important to you], I hate having to be that *definitive about any one thing."* (Patient 1009)

The line graph was preferred by both patients and caregivers for its ability to explain patient preferences over time. Patients recognized that their preferences might change over time and appreciated seeing those preferences longitudinally. Patients also noted that the line graph was similar to what is currently used for routine patient care, which made it easier to understand:

"[I like the] line graph, it can change over time because life is not static. I like that it gives you a big picture view." (Patient 1009)

"[I like the line graph] because I use that already. I get a monthly statement, and what it does is it averages me out and shows me where I'm at with my ups and downs, and I can go back to the present and what happened three months ago or whatever, so it gives me a better scale of where I like things to be." (Patient 1010)

Clinicians found the histogram (Figure 4b) to be challenging to quickly comprehend and required greater CWL:

"This [histogram] doesn't help me out quite as much…I'm needing to integrate a lot of information at the same time. Like I might have had no clue what the overall population felt about this. So number one, calibrating to that, and then doing this second order of 'how does my patient fit within that' is sort of a complex cognitive exercise." (Clinician 3001)

"As a provider, if I'm trying to, like look at this quickly between patients to kind of figure out how to stimulate conversations, this

would take me the most amount of time to actually fully comprehend what I was looking at." (Clinician 3003)

3.4 Theme 3: Importance of Human-Centered Design and Usability Testing

In addition to being used to iteratively improve visualizations, usability testing with different users and stakeholders was helpful for understanding the patient's motivation, beliefs, attitudes, and comprehension of the information provided via data visualizations. One participant stated about the shared decision-making EHT and visualizations:

"When you do paperwork or surveys, your doctor just gets the report, and it's the last time you hear of it, so it's cool to have some feedback and proof that not only are they seeing what you are telling them, it gives you a chance to challenge it. It gives you a proof of sanity." (Healthy Volunteer 4009)

Several visualizations prompted mixed responses from participants. For example, some clinicians felt the line graph (Figure 4a) was easy to understand and appreciated the visualization of the changes in patient preferences over time because it was realistic to what they have observed with their patients, while others felt it was too much information throughout the graphic to understand.

Figure 4c, demonstrating patient willingness to take a new drug to obtain specific benefits for known risks, also prompted mixed responses. One clinician described the visualization as *"a little categorical"* as the information provided such as time in the hospital *"can mean different things depending on what goes down"* (Clinician 3002). Other clinicians stated the visualization was easy to understand.

4 Discussion

In this human-centered design study, we elicited feedback on visualizations of patient preferences for treatment outcomes to improve the design of an EHT to foster shared decision-making among patients with hematologic malignancies and their clinician. Patient preferences for treatment outcomes are personal, multi-dimensional, and change over time. This complexity makes developing intuitive, simple visualizations challenging. Little prior work has been completed using theory-driven processes to improve visualization of patient preferences. Here, we were able to identify several key themes that improved our initial attempts at visualizing patient preferences.

Patient participants preferred visualizations that were reflective only of their own individual treatment preferences and did not value visualizations of how their preferences compared to others. Likewise, clinicians also did not see the value in comparison of individual to population-level preferences. This was surprising and ran against our initial conceptions.

This has important implications on the use of preference elicitation tools clinically. Some have proposed using methods to derive individual patient preferences from population-based preferences (priors) [24]. Using these methods is appealing because patient preferences can be visualized compared to the population. We found that this was not valued and was even distracting to patients and clinicians. Therefore, further work should explore the use of methods that do not require population-based priors.

Further, we found that participants appreciated the opportunity to review their preferences and to discuss them with their clinician. This suggests that attempts to implement EHTs with patient preferences into clinical workflows should incorporate an opportunity for patients and clinicians to review results together, rather than providing visualizations for clinicians only. This also suggests that the process of eliciting patient preferences helped to clarify what mattered most to patients, though these elicited preferences were not considered "final" by patients.

Additional findings suggest that user preference for data visualizations across all participant groups were for simple and easy to understand visualizations, but not oversimplified in a way that might detract from the patient's nuanced preferences. Of note, researchers provided no detail on to how to interpret the visualizations for participants, so participants preferred visualizations with enough text to summarize the information in the visualization. Text from unpopular visualizations included terminology such as "complete remission" or "aggressive[ness]", which users might not fully understand, thus contributing to the perceived complexity of the visualization, even if the graphic itself was "simple".

This feedback for more personalized visualizations and need for simplicity to improve data comprehension and minimize CWL influenced the following core changes to the data visualizations:

1. Update risk-benefit tradeoffs from a narrative visualization (Figure 2a) to a visual bar graph (Figure 3a).
2. Remove the gauge visualization demonstrating aggressiveness.
3. Remove the comparison of patient preferences to the patient population.

We developed the aggressiveness gauge as a hypothetical "global" visualization of patient willingness to tolerate treatment risks for benefits. That is, we consolidated patient willingness to trade off risks for benefits across several domains (e.g. side effects v. length of life) to generate this score. In general, the gauge visualization was confusing to the majority of users, despite some patients and caregivers valuing the gauge over other visualizations. Some feedback suggests that participants did not value the entire idea of developing a global score (too "definitive" or absolute) while other feedback suggests that the visualization itself may be the cause for dislike. Many participants preferred visualizations like the line graph because they were similar to what they use for routine patient care, making them more familiar and interpretable. This finding supports data from other studies suggesting increasing acceptability among stakeholders with health-system integrated implementation solutions of patient-generated data visualizations [25], [26].

Limitations to the study include limited sample diversity. All participants were recruited from one tertiary care center. Feedback on all 8 visualizations rather than a subset from healthy volunteer cohorts could have provided more qualitative data. Although our sample size was small per visualization, this was adequate for achieving thematic saturation, the point at which no new concepts emerge from subsequent interviews [27]. A systematic review assessing saturation in qualitative research suggested a range of 9-17 were adequate to reach saturation [28]. Thematic saturation in our study was achieved following completion of 15 interviews, comparable to other qualitative research studies [29], [30].

5 Conclusion and Future Work

Here, we used human-centered design methods to elicit feedback and refine visualizations of an EHT to display personalized patient preferences to inform shared decision-making. Effective EHTs to support shared decision-making must be easily understandable, accurate, and intuitive for all users. Developing simple, intuitive data visualizations of patient preferences is a critical step in EHT development. This iterative human-centered design process allowed for rapid refinement of visualizations and will facilitate the routine elicitation and visualization of patient preferences. Future work will include further revisions of the EHT and a randomized trial evaluating the effectiveness of the tool to improve shared decision-making among patients with hematologic malignancies.

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