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Iterative Development of an Interactive Website to Support Shared Decision-Making in Metastatic Breast Cancer

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Abstract

Recent treatment advances have resulted in significantly increased survival times following metastatic breast cancer (MBC) diagnosis. Novel treatment approaches–and their related side effects–have changed the landscape of MBC treatment decision-making. We developed a prototype of an online educational tool to prepare patients with MBC for shared decision-making with their oncologists. We describe the five phases of tool development: (1) in-depth, semi-structured qualitative interviews and (2) feedback on storyboards of initial content with patients with MBC and oncology providers. This was followed by three phases of iterative feedback with patients in which they responded to (3) initial, non-navigable website content and (4) a beta version of the full website. In the final phase (5), patients newly diagnosed with MBC ($N=6$) used the website prototype for 1 week and completed surveys assessing acceptability, feasibility, treatment knowledge, preparation for decision-making, and self-efficacy for decision-making. Participants in Phase 1 characterized a cyclical process of MBC treatment decision-making and identified key information needs. Website content and structure was iteratively developed in Phases 2–4. Most participants in Phase 5 ($n=4$) accessed the website 2–5 times. All participants who accessed the website at least once ($n=5$) felt they learned new information from the website prototype and would recommend it to others newly-diagnosed with MBC. After using the website prototype, participants reported high preparation and self-efficacy for decision-making. This multiphase, iterative process resulted in a prototype intervention designed to support decision-making for MBC patients.

Keywords Metastatic breast cancer · Shared decision-making · Web-based interventions · Intervention development

Introduction

It is estimated that nearly 170,000 people in the US will be living with metastatic breast cancer (MBC) by 2025 [1]. People with MBC have significantly lower quality of life than the general population, report life-altering symptoms, and express the need for resources for managing symptoms and improving quality of life [2, 3]. Novel treatment approaches have changed the treatment landscape for MBC [4], with subsequent changes in patients' information needs [5]. Supporting patients in making complex, shared treatment decisions with their care team, incorporating clinical prognostic variables, treatment options, and patient preferences is key to improving clinical outcomes for patients with MBC [6].

A prior review identified seven tools developed for patients with MBC. They focused on either chemotherapy initiation or on all possible decisions during the MBC trajectory. All tools were patient-facing and designed to be used before the patient's appointment with their medical oncologist. No materials were provided to support communication and decision-making within the clinical encounter. Additional trials have been published since the review was completed [7, 8]. However, all existing tools were developed prior to the introduction of oral therapies and immunotherapies that have transformed the treatment of MBC in recent years [4]. These options have expanded the range of decisions faced by patients and their oncologists, but also increased the relevance of additional topics, such as financial toxicity [9], to the decision-making process.

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Given this new landscape, the objectives of this study were to: (1) determine information needs and preferences of patients with MBC; (2) develop a website that prepares patients for shared decision-making (SDM) with their oncologists; (3) refine this website through interviews with patients; and (4) assess the feasibility and acceptability of the website among newly-diagnosed patients with MBC.

Methods

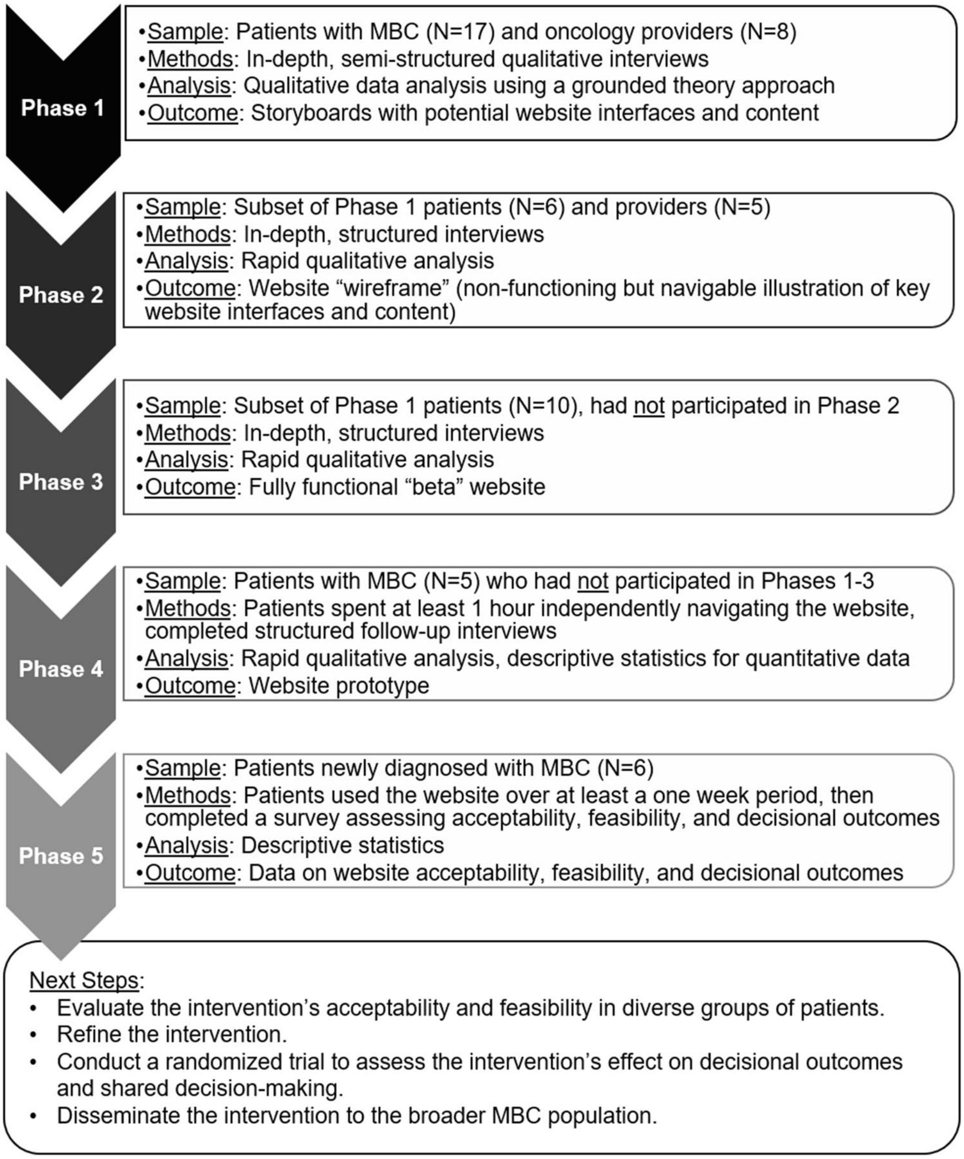
Study Design

Study procedures were reviewed and approved by the Georgetown University Institutional Review Board (Protocol #0003415). We used a multiphase mixed-methods approach (Fig. 1), wherein early qualitative results were used to develop and refine the intervention prototype used in the subsequent quantitative phase. Across all five phases, participants provided verbal or written informed consent prior to participating and received incentive gift cards upon completion. In Phases 1–4, interviews were conducted via telephone or video call, audio-recorded, and transcribed. At the conclusion of the interview, participants provided sociodemographic variables and permission to be contacted for subsequent phases.

Developmental Phases

Phase 1. We conducted in-depth, semi-structured qualitative interviews with patients with MBC (N = 17) and providers (N = 8; medical oncologists [N = 4] and oncology nurses

Fig. 1 Iterative intervention development process



Phase 1

- Sample: Patients with MBC (N=17) and oncology providers (N=8)
- Methods: In-depth, semi-structured qualitative interviews
- Analysis: Qualitative data analysis using a grounded theory approach
- Outcome: Storyboards with potential website interfaces and content

Phase 2

- Sample: Subset of Phase 1 patients (N=6) and providers (N=5)
- Methods: In-depth, structured interviews
- Analysis: Rapid qualitative analysis
- Outcome: Website “wireframe” (non-functioning but navigable illustration of key website interfaces and content)

Phase 3

- Sample: Subset of Phase 1 patients (N=10), had not participated in Phase 2
- Methods: In-depth, structured interviews
- Analysis: Rapid qualitative analysis
- Outcome: Fully functional “beta” website

Phase 4

- Sample: Patients with MBC (N=5) who had not participated in Phases 1-3
- Methods: Patients spent at least 1 hour independently navigating the website, completed structured follow-up interviews
- Analysis: Rapid qualitative analysis, descriptive statistics for quantitative data
- Outcome: Website prototype

Phase 5

- Sample: Patients newly diagnosed with MBC (N=6)
- Methods: Patients used the website over at least a one week period, then completed a survey assessing acceptability, feasibility, and decisional outcomes
- Analysis: Descriptive statistics
- Outcome: Data on website acceptability, feasibility, and decisional outcomes

Next Steps:

- Evaluate the intervention’s acceptability and feasibility in diverse groups of patients.
- Refine the intervention.
- Conduct a randomized trial to assess the intervention’s effect on decisional outcomes and shared decision-making.
- Disseminate the intervention to the broader MBC population.

[N = 4]) who care for patients with MBC. We considered including caregivers in this phase; however, our prior work demonstrated that few patients with MBC (36%) were able to identify a caregiver, and many described self-sufficiency in regards to their cancer care (i.e., "I am my own caregiver") [3]. Thus, we focused on the perspectives of patients and oncology providers. Patients were recruited via: (1) social media advertisements, or (2) direct outreach to individuals with upcoming oncology appointments. There were no inclusion or exclusion criteria based on time since MBC diagnosis. Providers were recruited via targeted email invitations from our clinical collaborator (CI).

Phase 1 interviews used an inductive, data-driven approach to determine the information needs and decision-making preferences of patients with MBC. We engaged in constant comparative analysis [10] and conducted interviews until theoretical saturation was reached [11].

For Phase 1, qualitative data were analyzed using a grounded theory approach, including open coding, axial coding, and selective coding [12]. Two members of the research team (CCC, SCO) independently reviewed a randomly selected subset of transcripts and collaboratively developed a detailed codebook consisting of data-driven codes. Two raters (CCC, SC) then independently coded two transcripts (8%). The remaining transcripts were coded by a single rater (SCO, SC), with a second rater (CCC) conducting additional review of a random subset of transcripts. Coding disagreements were resolved through discussion until consensus was reached. Coding was conducted using Dedoose.

Phase 2. We used Phase 1 results to create storyboards to visualize potential website interfaces and content. Proposed content incorporated in the storyboards included: (1) orienting to the treatment decision-making process for MBC; (2) information about breast cancer (e.g., staging, tumor characteristics); (3) values clarification; and (4) creating an action plan, including a customizable question prompt list.

A subset of Phase 1 patients (N = 6) and providers (N = 5) completed structured interviews designed to elicit feedback on the abovementioned content areas. Participants' responses were analyzed via rapid qualitative analysis [13]. Main topics ("domains") were drawn from the interview guide and a summary template was developed. Team members (SCO, JDR) used the template to summarize interview transcripts. Summary templates were compiled into a single matrix reflecting the depth and breadth of information for each domain [14].

Phase 3. We applied the results of Phase 2 to create a non-functioning, but navigable illustration of key website interfaces and content.

A subset of Phase 1 patients (N = 10) who had not participated in Phase 2 completed structured interviews designed to elicit feedback on website acceptability and utility. Phase 3 data were analyzed via rapid qualitative analysis, as described above.

Phase 4. We applied the results of Phase 3 to develop a fully functional version of the website, with the goal of testing and finding bugs before the final prototype.

Patients who had not participated in any prior developmental phases (N = 5) were recruited from oncology clinics, completed an introductory phone call with a member of the research team, and were emailed a link to the website. As in earlier phases, there were no inclusion/exclusion criteria based on time since diagnosis. Participants were asked to spend at least one hour navigating the website independently. After one week, participants completed in-depth interviews including open-ended questions to elicit general feedback and closed-ended questions to capture participants' ratings of website satisfaction (1 item, 1 = "not at all" to 4 = "a lot") and credibility (1 item, 1 = "not at all" to 4 = "a lot"). Finally, participants indicated how likely they were to recommend the website to a person newly diagnosed with MBC (1 = "not at all" to 4 = "a lot"). Qualitative data were analyzed via rapid qualitative analysis, as described above. Descriptive statistics were used to summarize quantitative data.

Phase 5. Results from Phase 4 were used to finalize the website prototype. Although not ready for widespread dissemination, this prototype is fully functional with complete design and content elements.

We recruited newly-diagnosed patients with MBC (N = 6). Participants used the website over at least a one-week period, then completed a survey assessing acceptability (whether or not they would recommend the website to other people recently diagnosed with MBC), feasibility (whether and how frequently they accessed the website; whether they learned new information from the website), and two measures of decision-making. The Preparation for Decision-Making Scale [15] assessed patients' perceptions of how useful the tool is in preparing them to communicate with their provider about a health decision (10 items, 1 = "not at all" to 5 = "a great deal"; $\alpha = 0.957$). For the present study, we selected seven items most relevant to the process of MBC treatment decision-making. The Decision Self-Efficacy Scale [16] assessed self-confidence in decision-making ability (11 items, 0 = "not at all confident" to 4 = "very confident"; $\alpha = 0.993$). Items for these two scales were averaged and converted to a 0–100 scale, with higher scores indicating higher perceived levels of preparation and self-efficacy for decision-making. Descriptive statistics were used to characterize website acceptability and feasibility and decisional outcomes (preparation and self-efficacy for decision-making).

Results

Participant Characteristics

Across phases, a total of 28 patients with MBC participated (Table 1). On average, participants were 3.3 years post-MBC diagnosis ($SD = 2.6$, range: 0.1–7.7). The majority were non-Hispanic (89%), White (57%) or Black (36%), and women (96%) with a college degree or greater (64%). Oncology providers (N = 8) were primarily White (50%) and women (88%).

Phases 1

Participants described their experiences living with or treating MBC. Coding resulted in five categories of themes: (1) the cyclical process of MBC treatment decision-making; (2) unique information needs; (3) values and priorities driving decision-making; (4) actions taken to manage MBC; and (5) internet use behaviors. Sub-themes are described in detail below. Table 2 provides exemplar quotes for each theme and corresponding website sections developed to address each theme.

MBC treatment decision-making cycle

Although participants frequently noted that there is *only one option for first-line treatment of MBC*, *treatment complications* and/or *disease progression* require revisiting the treatment plan frequently. Thus, *decision-making is an ongoing process*; even if treatment decisions do not need to be made now, they will need to be made again in the future. Patients and providers described working together to make *shared treatment decisions*, leveraging the expertise of the providers and the preferences and values of the patient. They also

Table 1 Participant characteristics

	Phase 1	**Phase 2**[a]	**Phase 3**[a]	**Phase 4**	**Phase 5**
MBC Patients	**N = 17**	**N = 6**	**N = 10**	**N = 5**	**N = 6**
Age (*M*, range)	52 (34–68)	49 (34–63)	52 (36–68)	64 (46–76)	50 (33–76)
Gender (N, %)					
Woman	16 (94%)	6 (100%)	9 (90%)	5 (100%)	6 (100%)
Man	1 (6%)	0 (0%)	1 (10%)	0 (0%)	0 (0%)
Race (N, %)					
Black	3 (18%)	2 (33%)	1 (10%)	2 (40%)	5 (83%)
White	12 (71%)	4 (67%)	7 (70%)	3 (60%)	1 (17%)
Other	2 (12%)	0 (0%)	2 (20%)	0 (0%)	0 (0%)
Ethnicity (N, %)					
Hispanic/Latino	3 (18%)	1 (17%)	2 (20%)	0 (0%)	0 (0%)
Not Hispanic/Latino	14 (82%)	5 (83%)	8 (80%)	5 (100%)	6 (100%)
Education (N, %)					
< College degree	2 (12%)	1 (17%)	1 (10%)	0 (0%)	1 (17%)
≥ College degree	13 (76%)	5 (83%)	8 (80%)	0 (0%)	5 (83%)
Missing	2 (12%)	0 (0%)	1 (10%)	5 (100%)	0 (0%)
Time since diagnosis (years; *M*, range)	4.2 (0.2–7.7)	4.1 (0.5–5.7)	4.9 (1.1–7.7)	3.9 (0.4–6.9)	0.3 (0.1–0.4)
Oncology Providers	**N = 8**	**N = 5**	**N/A**	**N/A**	**N/A**
Age (*M*, range)	45 (28–60)	46 (37–53)	—	—	—
Gender (N, %)					
Woman	7 (88%)	5 (100%)	—	—	—
Man	1 (12%)	0 (0%)	—	—	—
Race (N, %)					
Asian	2 (25%)	2 (40%)	—	—	—
Black	2 (25%)	0 (0%)	—	—	—
White	4 (50%)	3 (60%)	—	—	—
Discipline (N, %)					
Medicine	4 (50%)	3 (60%)	—	—	—
Nursing	4 (50%)	2 (40%)	—	—	—

[a] Participants in Phases 2 and 3 are unique subsets of Phase 1 participants

Table 2 Themes identified in Phase 1 qualitative interviews, representative quotes, and how they were incorporated into the website

Theme	Representative Quotes	Website Component(s)
Decision-Making Cycle		
Only one option for first-line treatment	“My provider only presented one treatment option. She basically said that this is what she wanted to do, and so that's what we did.” (Patient #20) “Sometimes there's no choice. They only have one best option or maybe two. First, second, third line, is pretty set in every cancer subtype.” (Provider #2)	Where You Are Now: Interactive graphical representation of the decision-making cycle described by study participants. The cycle includes four stages: (1) gather information, (2) decide with your care team, (3) treatment and outcomes, and (4) (re) assess and (re)align. Users are instructed to select the stage that best represents their current needs, and are provided with recommendations for corresponding resources within the website
Treatment complications	“My neutrophils were so low that they [reduced my dose]. They were really vigilant about scans to make sure we were still getting efficacy.” (Patient #15) “Maybe they respond to the treatment, but have terrible side effects. You're not sure they're going to be able to continue it, and they're going to have to move to a different treatment, and you don't know if it's going to work.” (Provider #3)	
Disease progression	“I’m currently at five years with no progression. At some point it’s going to happen, and when it does I’ll have some decisions to make.” (Patient #14) “Typically, we do scans every three to six months. If the cancer's growing, you change to a different treatment.” (Provider #8)	
Decision making is an ongoing process	“When I was first diagnosed, there was no conversation about preferences or values in regards to treatment. But as we progressed further into treatment conversations around goals definitely happened.” (Patient #16) “In most cases, treatment [for MBC] is lifelong. You cross one bridge, and if something's not working, you have to take another bridge. It's more of a marathon, not a sprint like it was in earlier-stage disease.” (Provider #3)	
Shared decision-making	“We collaborated… I was part of the team making the decision.” (Patient #14) “Shared decision-making is absolutely critical and essential, and we try to offer that to every patient.” (Provider #7)	
Importance of quality of life	“This is a long-term process, and you have many treatment options to choose from, and it's all really dependent on your quality of life.” (Patient #21) “When they have a few different [treatment] options to consider, quality of life is a big factor.” (Provider #5)	
Variety of treatment experiences	“I tell patients that every breast cancer is different. It's really important that they understand that the disease trajectory is very different, depending on those unique characteristics. It's not just all one Stage IV. The care is different, the treatments are different, the outcomes are very different.” (Provider #2)	
Information Needs		
Breast cancer subtypes	“Why would I choose that [treatment] combination based on my subtype and my particular cancer? That's a difficult question to answer.” (Patient #16) “The type of cancer matters because triple-negative is treated very differently than someone with HR-positive or HER2-positive breast cancer.” (Provider #4)	Breast Cancer Subtypes: Defines hormone receptor status and HER2 status

Table 2 (continued)

Theme	Representative Quotes	Website Component(s)
Types of treatments	"Present different categories of treatment and how they work. Acknowledge that it's overwhelming, and your doctor will help determine the best treatment for your situation. And that there's generally a lot of options." (Patient #11) "Patients need information on their treatment options. It's our job as providers to give them that information realistically and also to describe the intent, side effects, and course of those treatments." (Provider #1)	MBC Treatments: Clarifies the goal of treatment for MBC and describes different categories of treatment (e.g., hormone therapy, chemotherapy, targeted therapy, immunotherapy, etc.)
Treatment side effects	"Include [information about] some of the side effects. Maybe you could type in, like, neuropathy, and then [find out] what to do about it." (Patient #12) "I think side effects are tricky because the information about side effects for a therapy often include some side effects that are rare, but it could very much influence a patient's decision to get treatment." (Provider #1)	Treatment Side Effects: Describes common side effects of treatments for MBC
Randomized controlled trials	"I also believed the myth that clinical trials are a last resort, which is just simply not true. Knowing what I know now, I really believe clinical trials need to be [introduced] earlier in the process." (Patient #16)	Clinical Trials: Describes the risks and benefits of clinical trials, phases of clinical trials, and the process of randomization
Credible sources	"The problem is that the correct information is mixed with the incorrect information. And as a patient, you don't know what is what." (Patient #10) "Sometimes they'll come in with something from an unreliable source, and we point them to sources that are peer-reviewed and balanced. (Provider #3)	Using Online Resources: Tips for evaluating the reliability of online information Outside Resources: List of helpful websites providing more information about MBC
Values-Based Decisions		
Side effect profiles	"Why pick one [medication] over another? It's based on your goals. If you want fatigue, take Ibrance. If you want diarrhea, take Verzenio." (Patient #16) "The first decision they make is if they want to continue treatment. And if they continue treatment, what side effects are they willing to tolerate?" (Provider #7)	Values Clarification Exercise: Interactive list of factors that patients may consider when making decisions about treatment for MBC. Users are instructed to rate each in terms of how important it is to them right now. They are also provided with the option to print a list of priorities to share with their family and friends and/or cancer care team
Care coordination	"My opinions and my priorities have shaped my treatment schedules and appointment times." (Patient #18) "The length and frequency of infusion visits. Does it need to be weekly? Or monthly? Is it going to be quick? Are you here a long time?" (Provider #7)	
Identity outside of cancer	"For some people, cancer becomes their whole life. I'm not that kind of person. I want to live my life, and I want cancer to take up like 10% of it." (Patient #15) "We try to be accommodating around things that they have going on in their life. We just don't want to interfere too much if we can help it." (Provider #5)	
Taking Action		
Communicating with the treatment team	"When I learn about different types of treatment, I take that back to the doctor, and we talk about them." (Patient #18) "When you're told that you've got an incurable cancer, your brain can't function in those moments. Unless somebody had handed me a list of questions to ask, there was no way I was going to come up with those on my own." (Patient #16)	Communicating with Your Care Team: Patient-directed tips for improving patient-provider communication Questions to Ask Your Care Team: MBC-specific, customizable, printable list of questions that users can select from

Table 2 (continued)

Theme	Representative Quotes	Website Component(s)
Communication with family and friends	"My family doesn't completely understand, no matter how many times I explain it." (Patient #21) "People with cancer get a million people telling them what they should do, and it's not helpful." (Patient #9) "One patient was close to the end of her life, and wasn't talking to her husband about it. She couldn't have that conversation with her husband." (Provider #6)	Communicating with Family and Friends: Tips for talking to about MBC with family and friends, including recommendations for setting boundaries about discussing diagnosis and treatment
Getting a second opinion	"If you're uncomfortable or have any doubt about what your options are, absolutely, get a second opinion. And I've been told that doctors aren't mad at you that you do that. In fact, they encourage it. So, I think that you shouldn't be embarrassed if you want a second opinion." (Patient #9)	Getting a Second Opinion: Normalizes the process of seeking a second opinion, describes times when one might consider a second opinion, and provides tips for how to find a doctor for a second opinion
Complementary medicine	"My palliative care doctor does acupuncture to help my pain." (Patient #21) "I think a lot of people have this misconception that they can't talk to us about complementary therapies because we're going to automatically discount it. But integrative medicine is actually very important to most of us. I wish more patients knew that they can have that discussion with us, too." (Provider #1)	Complementary Care: Defines complementary care and provides an overview of common modalities and their evidence base
Mental health care	"The ability to learn how to cope with your diagnosis is as important as the actual diagnosis." (Patient #20) "At no point in this journey has my oncologist ever recommended a therapist or a psychologist. I think that needs to be worked in." (Patient #18) "I would like [my metastatic patients] to meet with a psychologist. I think that would let them know the support is there." (Provider #4)	Managing Mental Health: Describes treatment approaches for managing stress, anxiety, and depression. Includes a list of resources for psychological and emotional support
Internet Use		
Frequency of use	"It's rare that a day goes by that I don't look for health information online." (Patient #14) "I think the internet has some clear downsides in terms of people being exploited and bad things happening, but this [MBC] is one of the things where it can truly do some good for something that is psychologically a lot to deal with, and also very complex." (Patient #15)	Format: Elected to develop a web-based tool

wemphasized that *quality of life* is an important consideration in treatment decision-making. Finally, oncology providers emphasized the wide *variety of treatment experiences* for patients with MBC. Thus, “one-size-fits-all” educational materials are not appropriate for MBC.

Information needs

Patients and providers reported that understanding *breast cancer subtypes*, *types of treatments*, and *treatment side effects* is crucial for MBC treatment decision-making. Patients also noted that information about *randomized controlled trials (RCTs)* would be helpful, specifically that RCTs are not always a “last resort”. Both patients and providers emphasized the importance of getting information from *credible sources*.

Values-based decisions

Patients described choosing their treatment based on the *side effect profiles* and intentional efforts to *coordinate their care* to reduce treatment burden. While less frequent, some patients described the importance of maintaining their *identity outside of cancer* (i.e., professional identity, social identity). These patients made treatment decisions that allowed them to preserve these important life roles.

Taking action

Patients and providers described several actions taken by patients to manage life with MBC. Communication about MBC was emphasized as particularly important – both *communication with the treatment team* and *communication with family and friends*. Patients also emphasized the importance of *getting a second opinion* about treatment options. Finally, patients and providers noted the role of supportive care in treatment for MBC, including *complementary medicine* approaches and *mental health care*.

Internet use

Patient participants also described their internet use behaviors. All participants stated that they use a phone or computer to browse the internet “every day”. They felt that a website could be a useful resource for patients with MBC.

Phase 2

Phase 2 results pointed to content changes. Participants suggested removing information about tumor grade and adding information about cancer staging, typical sites of metastases, genetics and genomics, and palliative care. Suggested changes included emphasizing the team-based nature of cancer care and clarifying lymph node involvement in MBC (i.e., explaining when positive lymph nodes are/are not considered MBC). They also noted that the use of graphics (to supplement text) may be preferable for many users.

Phase 3

Phase 3 results highlighted strategies to increase website acceptability and utility. Participants suggested changes to the overall “look and feel” of the website that would increase engagement. These included changing the color palette (e.g., minimizing use of pink), ensuring gender-neutral content, increasing the text size, and enhancing the “human element” (e.g., images of real people). Participants also suggested components that would increase usability (e.g., search function and dictionary).

Phase 4

Participants reported moderate-to-high satisfaction with the website ($M = 3.4$). They felt that the information from it was very credible ($M = 4.0$) and were very likely to recommend it to someone newly-diagnosed with MBC ($M = 4.0$). Overall, participants felt the length of the website and amount of information was appropriate, and the material was easy to understand. They did not find the website upsetting to use. Participants made specific suggestions for improving the organization and navigation of the website. They also identified bugs and typos to be fixed before the website’s launch

Phase 5

The majority of Phase 5 participants (n = 4, 67%) reported accessing the website 2–5 times. One participant did not access the website and one participant accessed the website once. All participants who accessed the website at least once felt they learned new information and would recommend it to others newly-diagnosed with MBC. After using the website prototype, participants reported high preparation for decision-making (M = 73.6) and self-efficacy for decision-making (M = 85.9).

Discussion

This multiphase process resulted in a prototype decision support intervention for MBC patients. Our iterative methods engaged patients, oncologists, and oncology nurses throughout the design process and resulted in a tool that was highly-rated by patients newly-diagnosed with MBC.

To date, tools to support SDM in MBC only engage the patient [17]. Additional tools are needed to support oncologists in eliciting patient preferences [18]. Our results suggest that eliciting patient preferences is more nuanced than overall treatment preferences, for which patients might not be fully informed; these preferences are significantly informed by treatment features such as opportunity to extend survival v. maximizing quality of life, timing and methods of regimens, and cost of care. Correspondingly, we incorporated a values clarification component in our tool (see Supplementary Materials); participants reported that this component was particularly impactful.

Treatment decision-making for metastatic disease is an ongoing process [19]; thus, longitudinal research on this topic is crucial. Recent research has highlighted that SDM can have adverse outcomes for patients with advanced cancer [20], as the overall uncertainty can result in negative emotions. Carhuapoma and colleagues recently published on their tool, which was structured to address these ongoing decisions for those with advanced cancer [21]. Specifically, the tool first introduces less threatening decisions, and then over time incorporates the more complex decisions that the patient will confront in later stages of the disease. Carhuapoma et al.'s tool, like our own, allows a return to values clarification and decision preference, as these could change over time, partially as a consequence of the experience of advanced disease and its treatment. While our tool was developed for those with MBC, this model is translatable to other types of advanced and metastatic cancers, as well as non-cancer diseases. While treatment trajectories and modalities may differ by disease, the underlying process of decision-making is similar.

Study limitations include small sample sizes and, while our sample was relatively diverse with regard to race, it was less so regarding ethnicity. Likewise, all patients were English-speaking and highly educated. While lower-income patients may have unique needs, we did not assess patient socioeconomic status; thus, the generalizability of these findings across income levels is unclear. Furthermore, lower-income and older populations, who are less likely to have home internet, may face barriers to accessing the intervention [22]. The value of our tool among more diverse populations – particularly those with low digital literacy – would need to be assessed before formal efficacy testing and widespread dissemination. Future research is needed to: (1) evaluate the intervention's acceptability and feasibility in diverse groups of patients; (2) refine the intervention; (3) assess the intervention's effect on decisional outcomes and shared decision-making [23]; and (4) disseminate the intervention. Ongoing, iterative assessment and refinement of the intervention will be critical to ensure that it continues to meet the needs of MBC patients over time as treatments and technology continue to evolve [24].

Supplementary Information The online version contains supplementary material available at https://doi.org/10.1007/s13187-024-02451-8.

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Data availability The qualitative datasets analyzed during the current study will not be made available, given the conditions under which participants provided informed consent and the fact that qualitative interview data cannot be completely anonymized, even when aliases are used to replace names. Quantitative datasets will be made available upon on reasonable request to the corresponding author.

Declarations

Ethics approval All procedures were approved by the Georgetown University Institutional Review Board (IRB #00003415). This study confirms to the standards outlined in the Declaration of Helsinki and US Federal Policy for the Protection of Human Subjects.

Consent to participate All persons gave their informed consent prior to study participation.

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