Title

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Journal

JCO Clinical Cancer Informatics, 9(9)

ISSN

2473-4276

Authors

Gresham, Gillian
Luu, Michael
Henry, N Lynn
et al.

Publication Date

2025-04-01

DOI

10.1200/cci.24.00109

Peer reviewed

Clinician and Patient Perspectives on a Patient-Facing Online Breast Cancer Symptom Visualization Tool

Gillian Gresham, PhD[1]; Michael Luu, MS[1]; N. Lynn Henry, MD, PhD[2]; Tyra Nguyen, BS[1]; Katherine Barnhill, BS[1]; Greg Yothers, PhD[3]; Sungjin Kim, MS[1]; Andre Rogatko, PhD[1]; Deanna J. Attai, MD[4]; Mourad Tighiouart, PhD[1]; Ron D. Hays, PhD[5]; and Patricia A. Ganz, MD[5,6]

DOI https://doi.org/10.1200/CCI.24.00109

ABSTRACT

PURPOSE Endocrine treatments for patients with hormone-sensitive breast cancer are associated with significant side effects that can negatively affect health-related quality of life and result in treatment discontinuation. The objective of this qualitative study was to obtain feedback from stakeholder clinicians and patients about an online interactive tool that was designed to provide information and visualizations of breast cancer symptoms.

METHODS The online Breast Cancer Symptom Explorer tool was developed to allow patients to visualize trajectories for common symptoms associated with tamoxifen and anastrozole using symptom data from the NSABP B35 breast cancer clinical trial. To refine the tool, virtual focus groups were conducted among oncology clinicians and women with a history of breast cancer who had received treatment with an aromatase inhibitor or tamoxifen, seeking feedback on the tool and its potential usefulness. Discussions took place using a secure web-conferencing platform following a semi-structured interview guide. Focus groups were audio-recorded, transcribed, and analyzed using reflexive thematic analysis.

RESULTS Nine focus groups were conducted (n = 21 participants: eight clinicians and 13 patients). Key benefits and barriers to tool use emerged from the discussions. Both patients and oncologists valued the ability to engage with the tool and visualize symptoms over time. They indicated that ideal settings for its use would be at home before treatment initiation. Combinations of graphical representations with text were perceived to be most effective in communicating symptoms. Key barriers identified included concerns about accessibility to the tool and digital literacy, with recommendations to simplify the text and provide health literacy support to enhance its clinical utility in the future.

CONCLUSION Clinician and patient involvement was critical for refinement of the breast cancer symptom explorer and provided insights into its future use and evaluation of the tool in clinical decision making.

ACCOMPANYING CONTENT

Data Supplement

Accepted February 14, 2025
Published April 4, 2025

JCO Clin Cancer Inform
9:e2400109

INTRODUCTION

Breast cancer is the most common cancer and the second leading cause of cancer-related death in women, with approximately 4.1 million breast cancer survivors living in the United States.[1] Treatments, such as endocrine therapies (eg, tamoxifen, aromatase inhibitors), have significantly prolonged survival and reduced the risk of recurrence in women with hormone receptor–positive breast cancer. However, they are associated with side effects that negatively affect a patient's health-related quality of life (HRQOL) and lead to treatment discontinuation or nonadherence, with over 50% of patients discontinuing endocrine therapy before 5 years.[2]

Common side effects, such as musculoskeletal symptoms (eg, joint pain, muscle pain) from aromatase inhibitors (eg, anastrozole, letrozole, exemestane) or hot flashes and vaginal symptoms from tamoxifen, are significant contributors to treatment nonadherence or discontinuation.[3,4] In some cases, side effects occur early during treatment and will improve over time, whereas other patients may experience worsening symptoms. Thus, educating patients about the common symptoms and their trajectories may improve

CONTEXT

Key Objective

To explore patient and clinician perspectives on an online interactive patient-facing tool developed to provide information and visualizations of breast cancer treatment symptom trajectories.

Knowledge Generated

Patient and clinician stakeholder feedback was critical for refinement of the breast cancer symptom explorer, focusing on tool usability and its potential role in cancer care.

Relevance *(F.P.-Y. Lin)*

This study demonstrates how structured qualitative research, using focus groups, can inform the refinement of patient-facing digital tools for breast cancer symptom monitoring by identifying key implementation factors and usability barriers. This stakeholder-driven approach is crucial for optimizing such tools to empower patients with relevant information, supporting medication adherence and enhancing communication in a shared decision-making environment.*

*Relevance section written by *JCO Clinical Cancer Informatics* Associate Editor Frank P.-Y. Lin, PhD, MBChB, FRACP, FAIDH.

symptom management and reduce the risk of early treatment discontinuation.

Patient-facing tools and educational materials can improve patient engagement and knowledge, leading to more informed decisions.[5,6] A Patient-Centered Cancer Treatment Planning Workshop emphasized the importance of engaging patients and their families meaningfully and interactively to improve patient-centered treatment planning.[7] Technology and mobile health apps, which are increasingly being used in health care, may offer a feasible way to communicate treatment information with patients with cancer and allow them to share in the decision-making process with their care team.[8-12]

Emerging from our work within the U01 Tolerability National Cancer Institute Moonshot grant (U01 CA232859), we developed a Web-based, interactive, patient-facing tool to communicate treatment symptoms through visualizations and interactive displays of symptom trajectories.[13] To illustrate the tool, we used existing symptom data from a clinical trial in patients diagnosed with breast cancer randomly assigned to anastrozole or tamoxifen.[14,15] We conducted a qualitative focus group study to obtain stakeholder evaluation of the tool regarding the presentation format of information and its perceived usefulness in treatment discussions between patients and clinicians. The goal was to refine the tool for future evaluation and dissemination.

METHODS

Study Design

Virtual focus groups were conducted between November 2022 and August 2024 with oncology clinicians and women with a history of breast cancer. Focus group formats were used to allow for synergy among participants and allow them to react to one another's thoughts and feedback. Reflexive thematic analysis was used to analyze the data. All research procedures were approved by the local Institutional Research Ethics board. Before participation in the study, all participants were provided with the informed consent document. They were provided with sufficient time to review the document and ask questions before signing the consent form.

Online Symptom Visualization Tool

We developed the Breast Cancer Symptom Explorer to allow patients to view trajectories for common symptoms.[16] A description of the tool development has been described in detail elsewhere.[13] The tool uses symptom data from the NSABP B35 breast cancer clinical trial, in which 1,275 postmenopausal women with ductal carcinoma in situ were randomly assigned to tamoxifen or anastrozole. Patients completed a 42-item Breast Cancer Prevention Trial symptom checklist before treatment, and every 6 months over a period of 60 months, which were included in the online tool (Data Supplement, Table S1).[2] Figure 1 shows a screenshot of the tool interface using hot flashes of moderate severity level before anastrozole initiation (0 months) and 12 months, as a case example. Visualizations included a combination of graphical displays of symptoms at single time points (eg, bar graphs or waffle plots of proportion of trial participants experiencing hot flashes at varying levels of symptom severity grades), figures demonstrating symptom trajectories (eg, Sankey diagrams), and text summaries (Fig 2).

Participants and Recruitment

Separate focus groups were conducted with oncology clinicians and women with a history of breast cancer. Women

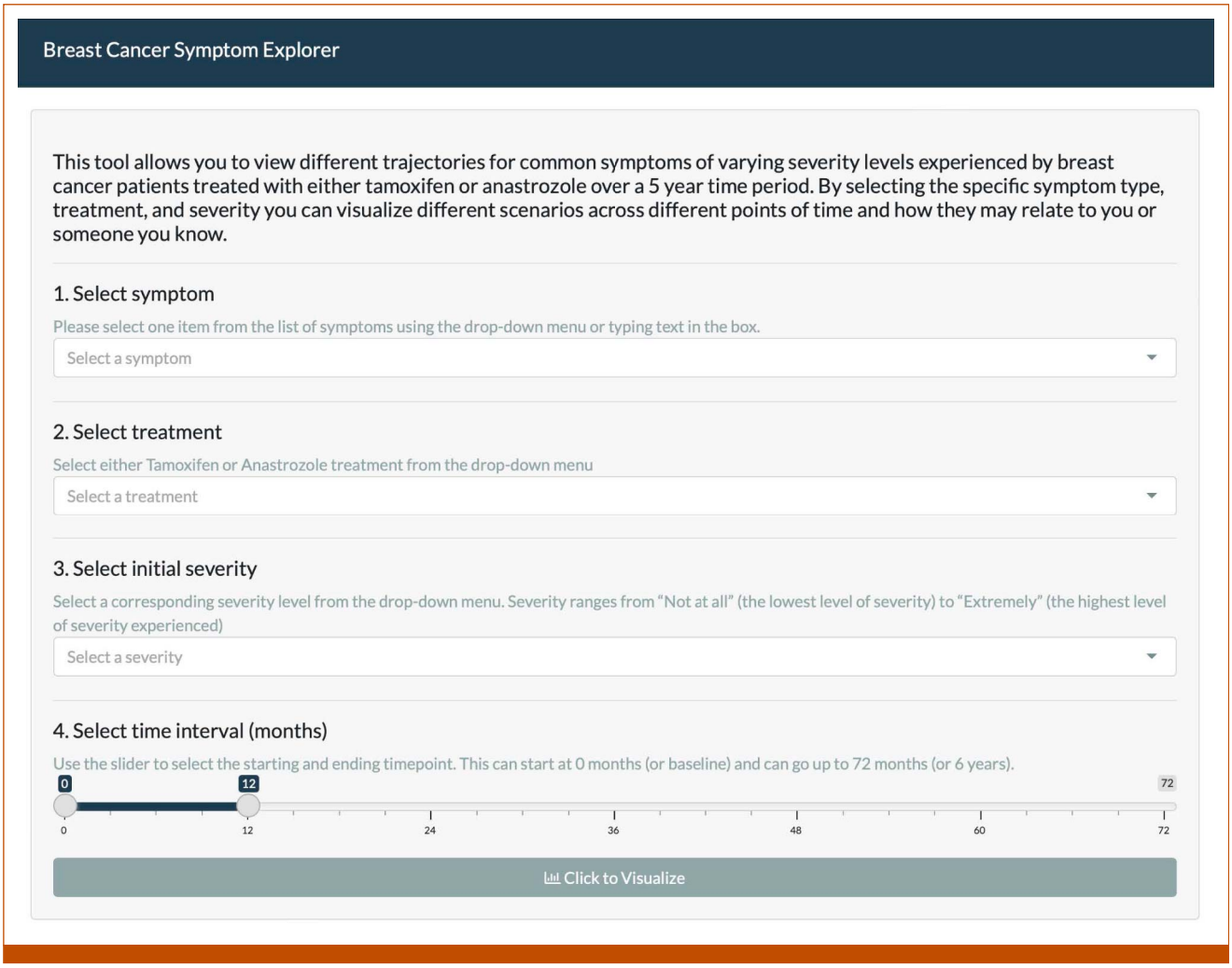

FIG 1. Symptom explorer interface.

(>18 years) were eligible if they reported a history of non-metastatic breast cancer and were diagnosed within the last 5 years and previously received or are currently being treated with an aromatase inhibitor (eg, anastrozole, letrozole, exemestane) or tamoxifen. Oncology clinicians were recruited by e-mail and/or referral from other oncology clinicians. Clinicians were provided with a link to the study information, a self-eligibility checklist, and a consent form. Oncology clinicians (physicians, nurse practitioners, or physician assistants) were eligible if their focus was the treatment of patients with breast cancer.

All participants (patients and clinicians) were required to speak and read English and have access to a computer, phone, or tablet with an Internet connection for the purpose of e-consent, connecting to the video conference, and viewing the online tool. Upon electronically signing consent, potential participants were contacted by the study coordinator via e-mail or by phone to schedule the focus group session and provided with a link to the virtual meeting as well as a link to the online tool to provide them with sufficient time to explore the tool before participating in the focus groups. All participants received a $20 in US dollars electronic Amazon gift card to thank them for their time. Recruitment was deemed complete when data saturation was reached, and no new themes or concepts emerged from the focus groups.

Procedure

Virtual focus group discussions took place via a secure Web-conferencing platform (Zoom). Participants were given the option to have their video on or keep it off and did not use any name identifiers to ensure confidentiality and privacy. An hour time was scheduled for each focus group. All focus groups were conducted by the same interviewer (G.G.). A live demonstration of the tool was provided by a second interviewer (M.L.). After demonstrating the tool, the first interviewer followed a semi-structured interview guide that covered topics including initial reactions and thoughts about the tool; what they liked and disliked about the tool, and feedback on the information and visual representations

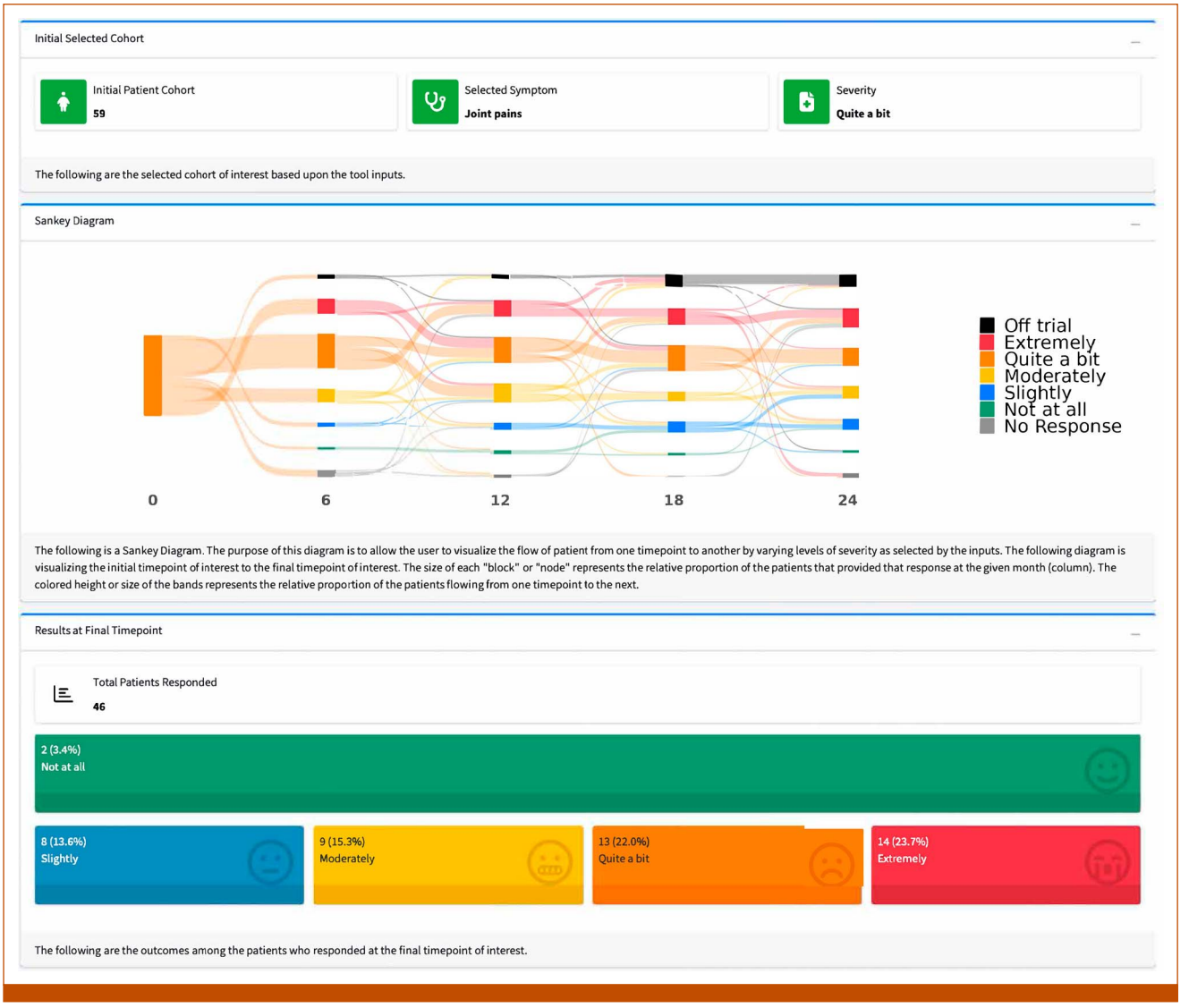

FIG 2. Example visualization output: joint pain in women being treated with anastrozole over 12 months.

provided in the tool; purpose and how they would envision using the tool; and missing features that participants would like to see, perceived barriers to using the tool, and any additional suggestions. The interview guide was developed by the study investigators and included questions that were open and broad in scope to encourage participants to describe their experience and provide feedback on the tool (Data Supplement, Table S2). All focus groups were audio-recorded for transcription purposes. After the focus group sessions, participants were provided with a link to an online survey to assess their knowledge and comprehension of the tool. The knowledge assessment included five multiple-choice questions and a question to rank their preference for visual displays of the symptom data (Data Supplement).

Theoretical Assumptions

For the current research, we sought users' perceptions and experiences with an online tool to understand its role in cancer care and survivorship, guided by multiple theoretical frameworks at the intersection of health technology, user-centered design, and patient-centered care. Within the context of the Technology Acceptance Model,[17] the research was grounded under the assumption that patients are more likely to adopt technology if they perceive it to be easy to use and beneficial for their care. Additionally, following a patient-centered framework, the underlying assumption is that patients are more likely to adopt health care technology tools that enhance shared decision making, foster trust, and address their individual goals and values.[18] Finally, the research methods were guided following a human-centered design framework, where this study represents the initial testing phase of the tool, where qualitative feedback from patients and providers was obtained to gain a deeper understanding of the tool's utility and acceptability.[19-21] The feedback was then used to refine the tool in an iterative process.

Data Analysis

Focus groups were analyzed using reflexive thematic analysis following Braun and Clark's framework for thematic analysis (2006), which includes six steps (familiarization, coding, generating, reviewing, and defining themes, and summarization).[22] Audio recordings were transcribed verbatim and reviewed by the first author for accuracy and data familiarization. Codes were then generated and combined into themes followed by review and discussion with the research team. The qualitative analysis was completed by two independent researchers (K.B. and T.N.) and reviewed by a third investigator (G.G.). Final themes were then organized into results, reviewed, and interpreted by the research team.

RESULTS

Focus Group Participants

Nine focus group sessions of two to three participants per group were conducted: four oncology clinician groups and five patient groups (n = 21 total participants). All participants were active during the focus group interviews. By the final focus group, saturation was reached and no new information emerged.

Of the 11 consenting clinicians, eight attended the sessions (three clinicians canceled or did not show up due to other conflicts or last-minute schedule changes). Oncology clinicians varied in terms of geographic location, profession, years of experience, and practice (eg, private, academic, or community hospital settings; Table 1A).

Of the 16 patients who consented, 13 attended the sessions (three patients did not show up for reasons unspecified). Patient participants were recruited from across the United States (median, 65 years; range, 27-85 years; Table 1B). All patients reported receiving aromatase inhibitors, tamoxifen, or both. To maintain patient confidentiality and anonymity, additional details regarding racial and ethnic backgrounds and geographic locations are not provided.

Focus Group Themes

Findings from the focus group discussions are presented by themes. Quotes to support each theme are provided in Table 2. Similar themes were identified in both patient and clinician groups. On the basis of thematic analysis, the following overarching theme categories were identified: (1) key benefits and tool usability, (2) perceived barriers, and (3) user preferences. Results are described below for each theme.

Key Benefits and Tool Usability

Key benefits identified included the simplicity of the tool design, the ability to visualize common symptoms over time, the ability to compare their experience with what other patients have experienced on similar treatments, and its perceived utility for shared decision making (Table 2).

Participants expressed that they liked being able to visualize the symptom data and compare their own experience with the experience of other patients. The majority of patient participants (n = 9) expressed that they appreciated the simplicity of the design and ability to access information and visualize common symptoms over time.

> "I like how simple it is to be honest. It takes a minute to figure out the chart, but once you have the diagram in front of you, it's easy to understand."

Patients also liked that the tool validated their experiences and provided reassurance, as they were able to use the tool to understand how symptoms change over the course of treatment and what to expect based on other patients on similar treatments.

For both patients and clinicians, the combination of text with visualizations was perceived to be useful (Table 2). Moreover, they noted that the bar graph was most familiar and effective for presenting the information compared with other less-familiar graphical representations. Mixed responses were provided when discussing the Sankey diagram: patients expressed that the Sankey diagram was unfamiliar and confusing at first, but after time, they recognized the value and potential usefulness of this visual display, especially for viewing symptom trajectories over time, whereas all clinicians felt it was the most useful and interesting visualization in the tool.

Perceived Barriers to Using the Tool

Barriers identified through discussions with patient and oncology participants included concerns about digital literacy and accessibility, complex language, and initial understanding of the visualizations. Four patient participants raised concerns about digital literacy and accessibility, especially regarding older users or those who were less tech savvy: "you want every demographic to use this," whereas six oncology clinicians expressed their concern about health literacy: "I worry about the patients' ability to use this tool properly." Oncologists were also concerned about the context of the data and emphasized the importance of including disclaimers (eg, these data do not include information on what treatments the patients were receiving to manage their symptoms while on the trial).

Both patients and oncologists expressed the need to clarify and refine tool language to be at grade 8 reading level, to be consistent with readability recommendations for consent forms.[23] This was endorsed mostly by the participating clinicians (n = 4). Participants also requested clearer instructions on the time interval selection and the definition of off trial (eg, due to side effects, trial completion, or

TABLE 1. Participant Characteristics

Provider Characteristic	No. (%)
Female	6 (75)
Male	2 (25)
Profession	
Medical oncologist	4 (50)
Cancer rehabilitation doctor	1 (12.5)
Nurse practitioner	1 (12.5)
Oncology clinician (other)	2 (25)
Academic rank	
Assistant professor	3 (37.5)
Associate professor	2 (25)
Professor	2 (25)
NA	1 (12.5)
Practice	
Academic	4 (50)
Private	2 (25)
Community	2 (25)
Location	
California	4 (50)
Michigan	2 (25)
Ohio	1 (12.5)
Utah	1 (12.5)

Patient Characteristic[a]	No. (%)
Total	13 (100)
Age, years, median (range)	65 (27-85)
Female	13 (100)

Abbreviation: NA, not applicable.
[a]For the protection of patient privacy, no additional demographic data were tabulated.

withdrawal). Participants (n = 2) also noted some missing symptoms (eg, depression, hair loss) from the list.

User Preferences

Regarding tool usability, patients shared their thoughts about optimal timing and frequency of use, the context and environment (eg, at home or in the clinic), and reasons for using the tool.

Discussions with patients revealed the importance of using the tools when first starting treatment (Table 2A). Most patients believed it would be valuable for discussions with their oncologist and care team, expressing that they wished the tool had been available when they were first diagnosed or started treatment:

> "I wish I had this 4 years ago when I started my tamoxifen journey. I love it. It would be so helpful. It will be a huge tool for everyone."

Patients noted they would prefer to use the tool at home before seeing their oncologist.

Clinicians also felt there was value in using the tool (Table 2B), indicating that key benefits of the tool included its ability to visually communicate symptom trajectories to patients and its potential or integration into clinical decision making, especially for patients who may be hesitant about treatment. They expressed that the tool could aid in their discussion with patients about potential side effects on the different treatments and when answering patients' questions about side effects and be used at home.

Although not included in the initial interview guide, comments about the patients' symptom experiences and the impact that these treatments have had on their well-being and overall HRQOL emerged in the discussions. For instance, patients and clinicians discussed the impact of treatments on discontinuation or nonadherence. Patient participants remarked about how difficult their symptoms had been and how this led to their own treatment discontinuation or change (n = 6), despite understanding the importance of staying on treatment (Table 2). Some new suggestions also emerged from the patient discussions, where four different patients asked whether the tool could be used to track their own symptoms.

Tool Comprehension and Preference Rankings

All patients (n = 13) completed the comprehension survey. Nine patients responded correctly to all multiple-choice questions, whereas four patients missed at least one question (Data Supplement). The Sankey plot was ranked as being the most useful visualization in seven patients, followed by the bar graph in five patients. The waffle plot was ranked as least useful in all respondents; thus, it was decided to be removed from the refined version of the tool. Only four clinicians completed the comprehension evaluation, for which 100% completed all questions correctly. Oncology clinicians ranked Sankey as most useful.

DISCUSSION

Focus groups were conducted to gain a deeper understanding of the potential clinical utility and acceptability of an online interactive tool developed to communicate symptoms for patients with breast cancer. Patients and oncology clinicians found the tool to be generally acceptable and helpful for communicating common treatment side effects and symptoms to patients. Although focus groups were conducted separately for patients and oncology clinicians, both groups shared similar perceptions. Overall, findings from this research supported the theoretical assumptions of the research, highlighting the usability and perceived value of the tool as well as the importance of a patient-centered design in this first phase of refining the tool. We plan to further refine the tool and expand it to add symptoms from other available clinical trials.

Key benefits identified from the focus groups included the user-friendly and interactive design of the tool as well as the

TABLE 2. Themes and Selected Patient and Provider Perspectives

Theme Category	Patient Perspective	Provider Perspective
Key benefits and tool usability	"I like how simple it is to be honest. It takes a minute to figure out the chart, but once you have the diagram in front of you, it's easy to understand." "I like seeing the data. I like seeing how people experience this at different levels." "It is nice for patients, particularly those who are just starting to get an appropriate anticipation of what they might expect over time with this." "This would have been helpful to have from the beginning and I would really encourage you to have people keep track of their symptoms when they start them rather than 5 years after they had them." "I personally like the bar graphs. I am kind of use to those in a work setting. The Sankey graph is interesting, but I am not exposed to something like that often. It is still interesting to see. If I continued seeing it, I would probably appreciate it more. They're all good. It's nice to see the different variations." "You know, after seeing it a few more times now, I like this plot, the Sankey plot… after seeing it and kind of getting used to it, because then you really see the flow and who changes their mind and how"	"I think you definitely could use it for patients. I think this is really wonderful for patients because I think patients ask this all the time, how long am I going to have hot flashes or what do you expect? We kind of have our usual answers, but to really see what people say and when the symptoms subside or change is useful for clinicians as well." "I think it's helpful for patients to see how symptoms may change over time, and a lot of these symptoms are initially worse in the first couple of months." "If this is used prior to starting treatment, then it would be really helpful if you're kind of giving an overview of potential side effects and that sort of thing… where it would be important as well that the patient understands this is how you were before you started any treatment." "I like the Sankey plot… I think this is a really great graphic and tool to kind of, I think it's helpful for patients to see how symptoms may change over time, and a lot of these symptoms are initially worse in the first couple of months."
Perceived barriers	"Some older women might have difficulty seeing this. You want every demographic to use this." "Depression is not on the symptom list, and that's the main reason I discontinued treatment both times." "Just don't use the word cohort… maybe more common language used would be helpful." "This doesn't actually have any ability for us to track our own symptoms for the doctor, does it?… That's how I would have used it."	"I worry about patients' ability to use this tool properly and understand it." "You have to use seventh grade understanding. You have everyone at different levels. I would change that language." "Think of language that patients would understand." "Maybe even add a disclaimer that we don't have access or know whether or not patients were receiving treatment of their symptoms on trial."
User experience	"I would use at home for personal use to track and would be fine sharing that with my medical team if a problem arises. Initially for me, then if I saw a pattern of something wrong, I would share it with the oncologist." "It [the tool] reassures me that what I'm feeling is normal and others have gone through it too." "It [the tool] definitely would have been something that I could've played with to look at and see what could I expect in terms of these things and after the experience with tamoxifen to say, hey, I had these experiences, what if I switched to Arimidex? What could I expect or anticipate?" "Seeing how symptoms change could help me decide whether to continue treatment."	"This is a really interesting way of thinking about a very common and complex problem that we see in clinic." "I think patients really do struggle with their symptoms. This is a huge problem. And I think that some information about trajectory, about being able to say 'It'll get better' or you'll recover or won't recover—I think that's really helpful." "To see the point where a decision was made on quality of life versus treatment" "The tool is valuable for guiding discussions on symptom expectations and personalized care."

ability to visualize symptoms over time. Both groups recognized the clinical value of integrating the tool into cancer care. The use of visualizations for communicating patient symptom data was an important feature of the tool that improved user understanding of the flow of symptoms over time and what to expect. The combination of text with graphical displays was viewed to be effective in illustrating different aspects of the treatment experience. For instance, the Sankey diagram was found to offer unique insight into visualizing symptom trajectories. Sankey diagrams are increasingly being used for the visualization of patient tolerability data and can be effective tools to graphically display the changing status of patient symptoms over time.[24-26]

Research supports that providing patients with accurate information about their potential symptoms and treatment outcomes can improve patient satisfaction and ability to engage in shared decision making.[27,28] This has been demonstrated in the literature, where online tools that communicate patient-reported outcomes can be used to supplement discussions and improve clinician-patient communication.[7,8,11,12,29,30] Such patient-facing tools have been shown to be effective in improving patient knowledge, psychosocial well-being, communication, and decision making in other conditions and settings.[8-11] Research studies involving patients with breast cancer have also demonstrated improved communication and engagement when using patient-facing tools and graphical summaries,[25,26] and improved patient knowledge and satisfaction.[12] However, although there is a range of existing online patient-facing tools for breast cancer[11] (eg, Predict Breast!, Cancer and Aging Research Group-Breast Cancer Tool), these have focused more on prediction models for comorbidity and life expectancy, or included other geriatric assessment tools that require data entry instead of using existing trial data to provide information on symptom trajectories, as demonstrated in the Symptom Explorer.

Our findings further advance our understanding of patient engagement with technology, highlighting the important interplay between the usability of digital tools and their

potential to enhance care for cancer survivors. Although some participants found the tool to be empowering and appreciated its ability to facilitate self-monitoring and communication with their health care team, concerns were raised about the accessibility of the tool and digital literacy. Without considering important ethical considerations when using digital health technology, especially among older adults and individuals who may not have equitable access to technology, the potential benefit of such tools can be reduced and the potential gap or digital divide can widen.[31] Therefore, when refining and implementing the tool, it is important to ensure that the tool is designed for use among people with varying levels of technological literacy and in a manner that maximizes its perceived value while minimizing complexity, as noted in our focus group discussions. However, participants noted that the clear benefits of the tool and intuitive design often outweighed initial concerns about the usability of the tool.

This study is limited by its small and homogeneous sample in terms of cancer type, treatment history, and racial and ethnic backgrounds, thus limiting the generalizability of the results. This research was not a definitive assessment of how the tool should be used, and more qualitative research needs to be done to probe scenarios for utilization. Finally, the symptom data used to demonstrate the tool were limited to the available data collected from the trial and thus may not reflect the symptom experience for all women with breast cancer treated with endocrine therapy.

Despite these limitations, this research has potential implications for future clinical practice and research. For instance, the tool can help patients anticipate what to expect when initiating treatment and what symptoms may improve or resolve over time, thus reducing early treatment discontinuation. Furthermore, it can also be used to facilitate discussion with their care team and identify points of intervention, where strategies can subsequently be developed and delivered for symptom control.

This tool also demonstrates, in alignment with PROTEUS recommendations, how researchers can optimize the use of patient reported outcome data that have already been collected in clinical trials to engage patients, clinicians, and researchers.[32] Future research will involve conducting a feasibility study of the tool followed by a larger randomized trial to determine whether it is a useful adjunct to clinical care.

AFFILIATIONS

[1]Department of Computational Biomedicine, Cedars-Sinai Medical Center, Los Angeles, CA
[2]Department of Internal Medicine, University of Michigan Medical School, Ann Arbor, MI
[3]Department of Biostatistics, University of Pittsburgh, Pittsburgh, PA
[4]Department of Surgery, University of California Los Angeles, Los Angeles, CA
[5]Department of Medicine, University of California Los Angeles, Los Angeles, CA
[6]UCLA-Jonsson Comprehensive Cancer Center, Los Angeles, CA

CORRESPONDING AUTHOR

Gillian Gresham, PhD; e-mail: Gillian.Gresham@cshs.org.

SUPPORT

Supported in part by the National Cancer Institute (NCI) of the National Institutes of Health (NIH) 3U01CA232859-05S1, 1U01CA232859-01; the NIH National Center for Advancing Translational Sciences UCLA CTSI (UL1 TR001881-01); and NCI grants P01CA233452-02, U10CA180868, UG1CA189867, and U10CA180822.

AUTHOR CONTRIBUTIONS

Conception and design: Gillian Gresham, Andre Rogatko, Deanna J. Attai, Mourad Tighiouart, Patricia A. Ganz
Financial support: Andre Rogatko, Patricia A. Ganz
Administrative support: Greg Yothers, Patricia A. Ganz
Collection and assembly of data: Gillian Gresham, Michael Luu, Tyra Nguyen, Katherine Barnhill, Greg Yothers, Deanna J. Attai
Data analysis and interpretation: Gillian Gresham, Michael Luu, N. Lynn Henry, Sungjin Kim, Andre Rogatko, Deanna J. Attai, Mourad Tighiouart, Ron D. Hays, Patricia A. Ganz
Manuscript writing: All authors
Final approval of manuscript: All authors
Accountable for all aspects of the work: All authors

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

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N. Lynn Henry
Consulting or Advisory Role: Myovant Sciences, AstraZeneca
Patents, Royalties, Other Intellectual Property: Royalty from Up-to-Date
Open Payments Link: https://openpaymentsdata.cms.gov/physician/27894/summary

Greg Yothers
Employment: Mountainview Pediatrics (I)

Consulting or Advisory Role: Orbus Therapeutics

Mourad Tighiouart
Leadership: Da Zen Theranostics Inc
Stock and Other Ownership Interests: Da Zen Theranostics
Consulting or Advisory Role: Za Zen Theranostics Inc

Ron D. Hays
Employment: University of California Los Angeles
Research Funding: University of California Los Angeles (Inst)

Patricia A. Ganz
Leadership: Intrinsic LifeSciences (I)
Stock and Other Ownership Interests: Xenon Pharma (I), Intrinsic LifeSciences (I), Teva, Novartis, Merck, Johnson & Johnson, Pfizer, Abbott Laboratories, Disc Medicine (I)
Consulting or Advisory Role: InformedDNA, Ionis Pharmaceuticals (I), Disc Medicine (I), Silence Therapeutics (I), Dexcel Pharma (I), Chugai Pharma (I), Astellas Pharma
Patents, Royalties, Other Intellectual Property: Related to iron metabolism and the anemia of chronic disease (I), Up-to-Date royalties for section editor on survivorship

No other potential conflicts of interest were reported.

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