

A Co-Design Study Developing an Early Prototype Intervention to Support Oral Anticancer Medication Use in Breast Cancer

Yejin Seo ¹, Karen Suchanek Hudmon ¹, Kellie Jones Weddle ¹, Yuehwern Yih ²,
Kathy D Miller ³, Ephrem Abebe ^{1,4}

¹College of Pharmacy, Purdue University, West Lafayette, IN, USA; ²Edwardson School of Industrial Engineering, Purdue University, West Lafayette, IN, USA; ³Indiana University Melvin and Bren Simon Comprehensive Cancer Center, Indianapolis, IN, USA; ⁴School of Medicine, Indiana University, Indianapolis, IN, USA

Correspondence: Yejin Seo, College of Pharmacy, Purdue University, Fifth Third Bank Building, 640 Eskenazi Ave, Indianapolis, IN, 46202, USA, Tel +1 317 880 5400, Email seo104@purdue.edu

Purpose: Breast cancer is the most commonly diagnosed cancer among women and a leading cause of cancer-related death. The increasing use of oral anticancer medications (OAMs) shifts responsibility for medication management to patients, often without adequate support. This study aimed to co-design an early-stage prototype intervention to support patients with breast cancer in managing OAMs, using a patient-centered, participatory design approach.

Patients and Methods: We conducted three rounds of participatory design (PD) sessions with five patients receiving OAMs at a federally qualified health center's outpatient breast cancer clinic, in central Indiana. Eligible participants were 18 years old or older, diagnosed with breast cancer, and currently taking OAMs. The PD process involved three stages: (1) Inspiration—patients identified key challenges in OAM management; (2) Ideation—patients co-developed potential solutions; and (3) Convergence—patients evaluated and selected preferred design concepts.

Results: Participants (median age: 66; range: 38–75) identified key challenges, including side-effect management, difficulty navigating resources, and lack of clear information. Ten solution ideas were generated and grouped into three categories: resource booklet, care navigation/support, and transportation assistance. Two priority prototypes emerged: (1) a physical breast cancer handbook, and (2) an interactive treatment navigation app. Participants favored the ease of use from the handbook while appreciated the mobile app's potential for bidirectional communication and peer support features.

Conclusion: This study highlights the value of engaging patients as co-designers in the early stages of intervention development. Both the physical handbook and interactive app show potential to support OAM adherence and management. While the two design concepts require further refinement before implementation and pilot testing, the findings offer valuable insight for potential interventions in the context of oral anticancer medications used for treating breast cancer.

Keywords: participatory design, patient centered outcomes, medication management, medication adherence, breast cancer

Introduction

Among women, breast cancer is the most commonly diagnosed cancer and is the second leading cause of cancer-related death.¹ The use of oral anticancer medications (OAMs) has risen significantly in recent years, with a 2024 publication reporting that they comprise 30% to 50% of the cancer drug development pipeline.² In breast cancer, OAMs are widely used across different stages of disease.³ OAMs for breast cancer include oral endocrine therapy, targeted therapies, and oral chemotherapeutic agents, which are used for adjuvant, metastatic and maintenance treatment. Oral endocrine therapy remains the primary adjuvant treatment for hormone receptor-positive breast cancer, which accounts for approximately 70% of newly diagnosed cases.⁴

Reflecting the growth in their therapeutic use, spending by Medicaid, a public insurance program for low income individuals in the US, has significantly increased in recent years.⁵ Many patients prefer oral therapy due to its convenience, lack of need for intravenous (IV) line access, and minimal disruption to daily life.⁶ However, despite their benefits and widespread availability, managing OAMs can be challenging for patients.

Achieving optimal levels of medication adherence and, in turn, improved health outcomes, partly depends on patients' ability to manage their medication regimens. Medication management is a comprehensive, patient-centered approach that respects and responds to individual patients' needs, knowledge, and self-efficacy for managing treatment.^{7,8} Effective medication management includes understanding how to properly take prescribed medications, navigate the medication use system (eg, filling prescriptions), and integrating medication administration routines into one's daily life. This requires patients to develop organizational skills and habits that support medication-taking behavior. Because adherence is key to oral chemotherapy outcomes, challenges with one or all of these factors can contribute to sub-optimal adherence, thereby diminishing the therapeutic benefits of the medications and increasing risk for cancer recurrence and mortality.⁹

Varying levels of adherence to hormonal therapy for cancer treatment are well-established in the literature with reported adherence across cancer therapies ranging from 16% to 100%,^{10,11} yet existing adherence interventions, such as those based on education/information delivery, digital tools, and reminder systems, have been shown to have limitations. Studies suggest that many existing interventions may not fully address patient-specific medication management challenges such as system navigation, organization, and problem-solving.^{12–14} Some interventions offer limited tailoring to patients' lived experiences and evolving needs, which may affect usability and sustained engagement.^{13–15} In addition, patient perspectives are not always incorporated in early development phases, which may reduce alignment with users' needs and preferences.^{12–14} Lastly, many tools focus primarily on adherence reminders rather than the broader set of skills and supports involved in everyday OAM management.^{16–19}

Participatory design (PD) actively engages end-users in developing solutions and therefore may overcome these limitations by ensuring interventions are directly grounded in patients' lived experiences, treatment contexts, and self-management challenges reflecting patients' specific needs and preferences.²⁰ Capturing the diverse perspectives and experiences can provide valuable insights regarding patient- and healthcare system-level barriers and facilitators of adherence; this information could then be leveraged in designing effective and scalable interventions to improve patient outcomes.²¹ Given the growing complexity of OAM management and the increased responsibility of the patient, PD provides a patient driven approach to co-create feasible strategies.²²

Our previous work identified specific unmet medication management needs among patients with breast cancer receiving OAMs, including difficulties related to medication organization, navigating health systems and side effect management.²³ These findings informed the present study, in which patient journey maps and personas were used to guide PD sessions focused on addressing these barriers from a patient's perspective. Building on these, the purpose of this study was to design an early prototype intervention intended to improve medication management for patients receiving OAMs for breast cancer treatment. These prototypes, which were developed through multiple rounds of PD sessions, have the potential to address key challenges to medication adherence for patients with breast cancer. This study reports the co-design and early-stage development of a prototype intervention, as a steppingstone for a future study that will evaluate the intervention's clinical effectiveness.

Materials and Methods

Overview

Building upon our prior work where we identified the need for OAMs management support,²³ we applied a PD approach to support rapid cycle design iteration and early stage prototype development consistent with ORBIT Phase 1a (Design)²⁴ and aligned with established co-design methodology in health research.^{20,22} This study utilized a three-phased, user-centered design process: inspiration, ideation, and convergence, with each PD session aimed at engaging patients in interactive activities.²⁵ A design panel consisting of five patients with breast cancer and two researchers trained in PD and user-centered design methods participated across sessions.

Study Participants, Settings, and Recruitment

Patients were eligible for inclusion in the study if they were 18 years of age or older, had been diagnosed with breast cancer, and were either currently receiving any OAM, including oral endocrine therapy, oral chemotherapy, targeted therapies, or had a recent history of using OAMs (last dose within 6 months) at the time of recruitment. Additional criteria included English-speaking/reading and willing and able to provide oral consent. Exclusion criteria included severe illness that precluded voluntary consent, hearing, vision, or cognitive impairment, or inability to provide consent without assistance. Participants were recruited from an outpatient breast cancer clinic in a federally qualified health center located in central Indiana serving a diverse patient population, including individuals from low socioeconomic backgrounds and ethnic and racial minorities.

Using a purposive sampling method, eligible participants were identified by the research team through the health facility's electronic medical record or were referred by an oncology care team member practicing in the breast cancer clinic. Three participants had participated in the prior study,²³ and two were newly recruited to capture additional perspectives related to varying OAM experiences. Verbal consent was obtained after which time participants were scheduled for the PD sessions, modeled after a focus group discussion format. A sociodemographic and health information survey was completed by the participants prior to the first session. Participants received a \$50 gift card for the first session and \$75 for each of the two subsequent sessions completed. Thus, each participant could receive up to \$200 in incentives. The PD sessions were conducted in person, and each session lasted approximately 90 minutes. The study was approved by the Institutional Review Boards of Indiana University and Purdue University.

Procedure

Six individuals consented prior to the first PD session; of these, two newly recruited participants dropped out prior to PD session 1. Four participants (two newly recruited and two from prior studies) completed the first PD session, and one additional participant joined the design panel for the second PD session. This participant was purposely recruited to capture their unique perspectives related to various oral anticancer medication use. One participant was unable to attend the final session, making the total number of participants completing PD session 3 to be four.

In PD session 1, termed "Inspiration", the discussion was used to verify the key challenges identified in our prior study and to identify additional challenges experienced by patients taking OAMs. In user-centered design methodology, this step is also referred to as defining "the problem space". Participants reviewed a consolidated journey map and personas developed from the prior study.²³ These documents provided a concise summary of key OAM-related challenges identified by participants, visually represented as medication related care gaps across a timeline of key milestones (initial prescription, initial medication fill, medication use at home, and first follow up clinic appointment), hence the term "journey map". Subsequently, participants were invited to reflect on the findings and share their own personal experiences. This exchange of insights allowed the researchers to update and refine the patient journey map, laying the foundation for subsequent ideation. Additionally, during this session, participants were prompted to generate a list of problems based on their individual experiences and discussion. The problem list was then shared among participants to foster further discussion and prioritize the identified issues.

PD session 2 was conducted with returning participants, two weeks after PD session 1, and focused on ideation, with the emphasis shifting to generating ideas and design concepts. A consolidated list of problems identified during PD session 1 was summarized and presented by the two researchers. Participants were then asked to generate potential solutions to the presented problems, by brainstorming ideas without constraints, to address identified gaps in the patient journey identified in the preceding PD session. The session concluded with a list of proposed solutions, setting the stage for refinement in PD session 3.

To prepare for PD session 3, the two researchers reviewed participants' ideas and proposed solutions generated during PD session 2. Ideas were consolidated into three conceptual categories by grouping ideas based on shared functions, goals, and content overlap. This process allowed researchers to identify key design concepts by organizing user generated solutions and supported the creation of two distinct actionable design prototypes. This decision emerged during the PD session to address patients' needs through separate approaches. The first prototype was a paper-based booklet designed to be a comprehensive,

easy-to-use resource to help patients navigate medication-related challenges. The process was supplemented by a literature search of currently available resources, including local resources available near the cancer clinic. The second prototype, taking a form of an interactive mobile app, was developed using Figma (<https://www.figma.com/>), an industry standard design tool used to create low- and high-fidelity interface designs and interactive prototypes that help users to visualize how the design will function.

PD session 3 aimed to converge on a few select design concepts. Participants were presented with mock-ups of the two intervention ideas generated (ie, paper-based and mobile-app-based prototypes). Each design idea was considered for its potential pros and cons. Additionally, participants provided further feedback with a goal of enhancing and iterating on the presented concepts. By engaging in open discussion and collaborative decision-making, participants worked towards reaching a consensus on promising design solutions that would be moved forward for further development, future implementation, and evaluation.

Data Analysis

Given the study's goal of supporting rapid-cycle prototype development, data analysis followed a rapid qualitative synthesis approach consistent with participatory design and ORBIT Phase 1a intervention development. The data analysis process for the three PD sessions began with a comprehensive review of session materials, encompassing patient journey maps, personas, and discussion notes. To enhance validity and reduce the risk of confirmation bias, we triangulated insights across multiple data sources, and participants and researchers served as equal partners in reviewing and refining design prototypes. In the "Inspiration" session, thematic analysis of discussions and persona refinement were completed to capture common themes and ensure that personas accurately represented user groups. Additionally, participants' individual problem lists were consolidated by category, laying the groundwork for the subsequent session. Transitioning to the "Ideation" session, the focus shifted towards synthesizing generated ideas and selecting promising concepts aligned with project goals. Proposed solutions and themes were collected and analyzed by concept, leading to the creation of two mock-ups for each proposed solution by the research team. Finally, during the "Convergence" session, mock-ups were evaluated through group discussion, with participants freely expressing their thoughts while researchers noted participants' feedback for each design concept. Participants' and researchers' notes were summarized, providing valuable input for the refinement and selection of design concepts moving forward. All PD sessions were audio-recorded, and the research team used session notes, written participant materials (problem lists) and prototype feedback as primary data sources to guide iterative design decisions. Two researchers reviewed session materials after each PD session, identifying recurring challenges, insights relevant to design requirements, and actionable ideas for prototype refinement. Findings were synthesized between sessions to allow timely integration into subsequent design activities. This rapid-cycle method is widely used in PD to ensure participant feedback drives ongoing decision-making rather than serving as stand-alone qualitative results.²⁵

Results

Participant Demographic Information

The study included 5 participants with breast cancer (4 females and 1 male), with a median age of 66 years (range, 38 to 75). Three identified as Black or African American, one identified as White, one identified as being of two or more races, and none identified as Hispanic, Latino, or of Spanish origin. All participants had attained some college education or higher. Three participants reported owning a personal vehicle, and two relied on alternative modes of transportation such as taxis, public transit, assistance from family or friends, or walking. One participant did not provide information on insurance coverage, but the remaining participants were covered by government-funded health insurance plans (Medicare and/or Medicaid). Regarding income, two participants reported finding it very difficult to manage on their current income, one reported getting by, and one reported living comfortably. One participant did not respond to this question. Three participants were taking traditional medications (anastrozole or exemestane), and two were taking specialty medications (ribociclib or palbociclib). The participants who were taking specialty medications obtained their prescriptions from two different

pharmacies, whereas those on traditional medications utilized a single pharmacy. On average, participants were seen by 2.4 doctors, including oncologists and other specialists for comorbid conditions.

PD Session 1: Inspiration

PD session 1 consisted of 4 patients and 2 researchers. During the session, participants reviewed the consolidated journey map from the prior study and confirmed that previously identified challenges remained relevant while also identifying additional medication management difficulties.

Insurance Navigation

Participants confirmed the challenges related to medication access due to insurance coverage or cost. These insights highlighted the need for additional support on insurance navigation and financial assistance.

B103: “None of the insurance companies would cover it, and they told me it would be thousands of dollars out-of-pocket...When you don’t have insurance or fall into the gap, the stress make everything worse. I eventually received help, but it took time to figure it out”.

The participant also shared her experience with a manufacturer program and admitted that she was hesitant to start it due to concerns about consistency. She described the whole process as an “adventure”.

Socioeconomic Factors

Another participant highlighted financial strain, unreliable transportation, and their direct impact on medication adherence.

B104: “I have gone without my medication on more than one occasion”.

She also noted that insurance-provided transportation was often unreliable, emphasizing the need for practical planning tools and resource navigation support. B104 expressed her frustration by stating, “Why can’t we have the help we need?” Other participants B101 and B103 commented, “They want you to advocate for yourself to get the help you need”. At the end of the discussion, individual participants were asked to list their prioritized list of concerns/problems (Table 1). Additional problems were identified during the discussion. These included: needing to advocate for myself, side effects, and uncertainty.

Individual problems were consolidated into one list (Box 1). Navigating resources, including obtaining information about diagnosis, treatments, and other available resources, emerged as common concerns for all participants. Participants expressed limited access to case workers, limiting their ability to receive additional support. Transportation was also identified as a barrier to healthcare and medication access. Navigating insurance was a challenge, particularly issues related to coverage, renewal, and medication access. Additionally, concerns related to treatment included little information about treatment programs, alternative treatments, potential side effects, as well as navigating and living with uncertainty related to cancer treatment. These consolidated challenges formed the problem space for ideation in PD session 2.

Table 1 Individual Problem List, by Participant Number

B101	B102
<ul style="list-style-type: none"> ● Wish to receive information about alternative treatment earlier ● Lack of social worker presence ● Ease of getting a timely appointment 	<ul style="list-style-type: none"> ● Confusion regarding renewing insurance ● Transportation ● Care navigation ● Side effect management
B103	B104
<ul style="list-style-type: none"> ● Wish that they had asked more questions ● Uncertainty about duration of treatment ● Seeking additional information ● Additional support from caseworkers ● Side effects 	<ul style="list-style-type: none"> ● Navigating cancer and medication resources ● Help with getting prescriptions. ● Insurance coverage ● Emotional support ● Clarity on medication

Note: A summary of participant-reported challenges related to oral anticancer medication use.

Box 1 Consolidated Problem List

- 1 Navigating resources
 - a. Information
 - b. Social worker / caseworkers
 - c. Transportation
- 2 Navigating insurance
 - a. Insurance coverage
 - b. Renewal
- 3 Treatment
 - a. Alternative treatment
 - b. More information about the treatment
 - c. Side effect management
- 4 Emotional support
 - a. Counseling
- 5 Managing uncertainty about treatment and overall care

Note: Grouped priority challenges derived from participant input during PD session 1.

PD Session 2: Ideation

Five individuals (four from PD session 1 and one newly recruited participant) participated in PD session 2 along with 2 researchers. Participants collaborated to generate potential solutions, which were documented in real time and reflected on problems identified during PD session 1. Participants proposed solutions related to: resource navigation, side-effect and symptom management, transportation support, shared decision-making, and emotional and practical support. [Box 2](#) provides the list of potential solutions that emerged from these discussions.

Participants expressed a desire to receive better information about the treatment and the medication(s) they had been prescribed. One of the participants expressed a desire to be actively involved in the treatment decision-making process, making informed choices rather than simply following instructions to take specific medication.

B101: “Take the time to tell me: ‘I am prescribing this for you, and these are the possible side effects. But we also have another one—these are the side effects—and I can choose between the two.’ Give me something to say about it.”

The lists of ideas were consolidated into three categories ([Figure 1](#)).

PD Session 3: Convergence

Four participants and two researchers participated in PD session 3. The consolidated solution list was presented to the participants, and participants provided feedback. This structure guided the development of early prototypes presented in PD session 3. To enhance communication and underscore the significance of building strong relationships between providers and patients, participants emphasized the importance of having a physical presence to complement the provided resources. They expressed that verbal communication is equally vital as written information, and they desired to establish a positive rapport with their providers or care navigators to facilitate their cancer journey.

B101: “I don’t want to be just a number. I want to matter. The person next to me matters too, but you are here with me, so make me feel like I am the only one in this world”.

Participants reported difficulty retaining information provided during clinical visits and described written resources as valuable tools for reference after appointments. Two potential solutions were presented for feedback: a paper-based Breast Cancer Treatment Handbook and a mobile app-based prototype. The handbook contained comprehensive written information about treatment, medications, side effects, and resource navigation ([Appendix 1](#)). The mobile app included all core content from the handbook but offered additional interactive features, including side-effect monitoring and automated prompts for contacting providers, which participants described as particularly useful.

Participants responded positively to the handbook, noting that they would have benefited from receiving such a resource during their treatment. Preferences varied regarding the timing of the resource’s delivery among participants. Some preferred to receive these resources early, right after diagnosis, while others preferred to receive them after surgery

Box 2 Proposed Solutions

1. Booklet/handbook of resource
 - a. Location specific
 - b. Online website, treatment information, providers
 - c. Second opinion
- 2 Transportation system
- 3 Case navigation (concierge service) / social worker
 - a. At first appointment, additional support to answer questions and to provide encouragement
 - b. To help navigate resources
 - c. Personal advocate
- 4 Better explanation of post-surgery treatment
 - a. What to expect
 - b. What medications to take (including non-cancer medications, eg pain), and for how long
 - c. Side effects of medications
- 5 Personalized support
 - a. Reminders and motivation to attend clinic appointments
 - b. Assist hospital/clinic visits
- 6 Breast cancer Medication information
 - a. What to expect from OAMs throughout the treatment process
 - b. Overview of available treatment options
 - c. Treatment expectations: side effects, duration, potential drug-drug interactions
 - d. Prognosis-related information: addressing questions like “Is there a cure?” and long-term treatment outcomes
- 7 Convenient/free counseling
 - a. Call, appointment and refill reminders, encouragement
 - b. Reminder for appointment
 - c. Emotional support/company
- 8 Information about alternative treatment options
- 9 Information about cancer
 - a. Stage, what it means
- 10 Use of marijuana / whether it has any medicinal benefits

Note: A list of proposed solutions developed during PD session 2.

and radiation therapy. All participants agreed that a structured, bound resource was more useful than loose papers and that such a resource should be available to patients throughout treatment. One participant commented that providing this type of resource could benefit other cancer patients.

B104: “...I don’t think it should just be for breast cancer. I think it’s something they should do for every cancer. When you know if someone has been diagnosed, you have a copy of this, whether it is a book, heavy pamphlet, or folder, it should be there for you. They should be able to put this book in your hand and explain it to you. This is your book now...it is really good. This is something useful for everyone who has breast cancer to navigate and get information when needed”.

Participants also reviewed the mobile app prototype and expressed appreciation for its functionality and flexibility. They viewed the app as a helpful companion to the paper handbook, particularly for accessing information on the go. Screenshot of the prototype app is shown in [Figure 2](#). They expressed positive feedback regarding this type of solution and appreciated the various functions it provides, such as side effects management and insurance navigation. They also suggested to have more comprehensive information on disease progression signs and contact details for local resources, including financial assistance.

B101: “I do like the concept, in addition to hard copy. It depends on your setting—if you are on the go, (or) if you have time to read through it. I would like to have both options”.

B104: “This would be useful for anybody, at any point of their breast cancer treatment”.

Booklet / Handbook of resource	Care navigation / Advocacy / Emotional support	Transportation system
<ul style="list-style-type: none"> • Location-specific resources • Diagnosis <ul style="list-style-type: none"> - Stage: understanding what it means - Information about potential cures • Treatment <ul style="list-style-type: none"> - Expectation - Medication details: duration, dosages, and types of medications - Treatment options / alternative treatment - Side effects - Interactions 	<ul style="list-style-type: none"> • At first appointment <ul style="list-style-type: none"> - Someone to answer questions and to provide encouragement - Assistance in navigating resource • Personalized support <ul style="list-style-type: none"> - Personal advocate - Appointment reminders and motivation • Convenient / free counseling <ul style="list-style-type: none"> - Call, reminder, encouragement - Emotional support / company - Peer support group 	<ul style="list-style-type: none"> • To pharmacy <ul style="list-style-type: none"> - Pick up medication - Delivery • To clinic <ul style="list-style-type: none"> - Appointment

Figure 1 Consolidated solution. Overview of the three conceptual categories used to guide prototype development.

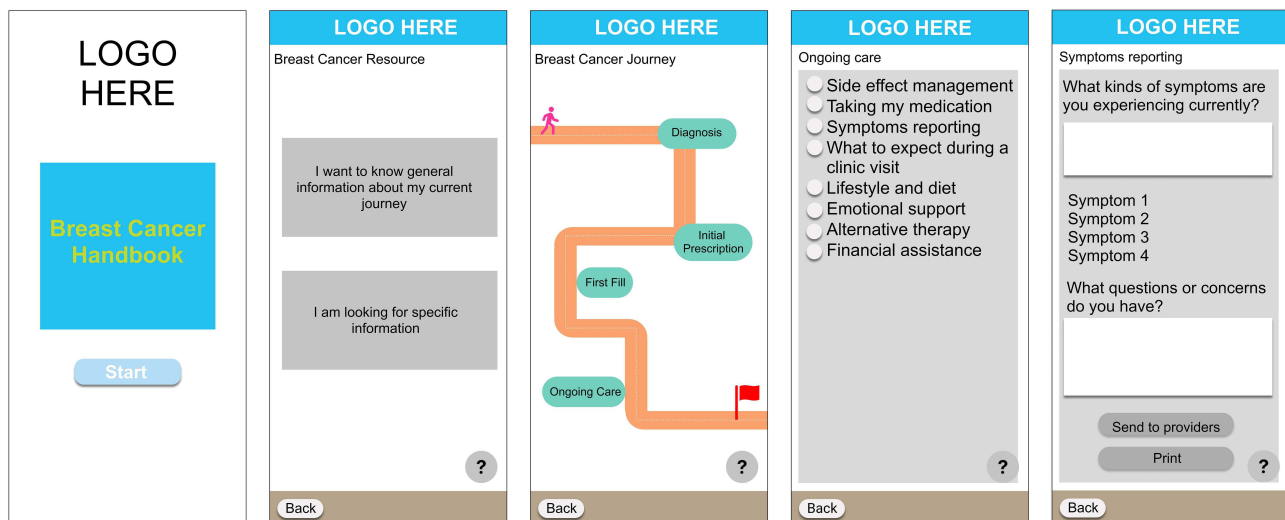


Figure 2 Example app screens. Early app design concepts demonstrate symptom tracking and resource navigation functions.

Participants further highlighted the app’s potential to facilitate bidirectional communication with healthcare providers. They expressed enthusiasm for the idea of messaging providers about symptoms between visits, noting that such a feature would help them act on concerns in real time rather than waiting until the next appointment.

B101: “It [having bidirectional communication] helps when you think about it. To be able to take an action on it rather than wait and ‘let me make a note so when I go in for my visit, I will ask about it’”.

Several additional functions were identified for future improvement of both prototypes. Participants recommended incorporating personalized tools for organizing medical information, appointments and medication reminders. Participants also expressed strong interest in a peer support function including an online community for individuals with breast cancer, along with a chat feature or information about survivor support groups. They expressed openness to communicating with other patients with breast cancer and showed interest in mentoring those recently diagnosed. Peer support was not included in the initial prototypes but emerged as a recommended addition during PD session 3.

Discussion

This study aimed to develop an early prototype intervention to support patients with managing OAM use for their breast cancer treatment and to address a gap in the literature by engaging patients with breast cancer in the early phases of intervention development. While many app-based interventions exist, few detail how patients are involved in intervention development, especially during the early-design phases. By using a PD approach, the interventions were created specifically to address the needs of end users, ie, the patients.

Participant feedback from PD session 3 provided early insight into potential value of both the handbook and mobile app prototypes. Participants highlighted the need for comprehensive and easy to understand information and viewed the early prototype concepts as potentially useful resources for navigating treatment. Additionally, the mobile app prototype was perceived as complementary to the handbook by offering interactive features including (a) serving as a communication tool with providers, and (b) providing connections with other patients diagnosed with breast cancer, acknowledging that such features cannot be delivered through a written handbook. Participants also identified additional features for future development, including appointment and medication reminders and personalized tools for organization. These suggestions provide initial proof of concept for the current proposed intervention and highlight opportunities for refinement in subsequent studies.

Existing app-based interventions for cancer care often focus on symptom tracking, survivorship education, and treatment-related support.^{14,26} However, breast cancer specific apps vary widely in quality and scope, and fully integrated tools that combine comprehensive information, navigation support, and communication/coordination features are not consistently available or well-evidenced.^{27,28} Our findings extend this work by identifying patients' needs specific to OAM management and translating these needs into potential design concepts. Participants' needs for peer support align with prior studies highlighting the importance of social support in intervention design.²⁹

Prior mobile health interventions have demonstrated positive perceptions toward app-based reporting and communication with providers.¹⁵ Although our intervention was not specifically focused on daily symptom reporting, it aims to provide a convenient way to report and contact healthcare professionals when needed. This early concept will be further refined and evaluated during future studies. Involving end users throughout the intervention development process is important.³⁰ Despite the large number of app-based interventions reported in the literature, few published studies discuss details characterizing the development of interventions or extent of patient engagement early in the development process.¹⁴ This study suggests the value of involving patients as stakeholders in the early stages of intervention development to better understand their needs and co-create early concepts for further development in future studies. The findings provide valuable insights for shaping clinical practice as well as potential interventions in the context of OAMs for breast cancer treatment.

The study has some limitations worth acknowledging. First, due to logistical challenges, we were unable to include participants who speak languages other than English. This may have prevented us from learning about challenges unique to non-English speaking population. A future plan includes expanding this study to include Spanish-speaking participants. Second, this study represents ORBIT Phase 1a early intervention development study with a small number of participants, and its generalizability is limited. It is also important to note that our participants were primarily older adults with limited resources and had greater educational attainment than the overall clinic population. Therefore, the identified needs might not be applicable to younger patient populations or those with more resources or lower levels of education. To strengthen the intervention before feasibility testing, our team plans to conduct a subsequent PD session with both patient and healthcare providers to refine the intervention and evaluate its acceptability and usability. Future studies will also consider using stratified sampling to improve representations across different age groups and socio-economic status.

Conclusion

This study highlights results of a user-centered participatory design approach for developing early intervention prototype: a mobile app and a handbook to support patients with breast cancer in managing their OAMs. Challenges identified in our prior work were confirmed and reflect the persistent challenges experienced by patients and highlight the importance

of addressing these needs through a PD approach. By actively involving patients, this study translated challenges into actionable design intervention reflecting patients' priorities, including the need for comprehensive resources, health system navigation support, communication tools, and opportunities for peer connections. Although the prototypes were not tested in practice during this phase, the insights gained provide important direction for refining the intervention. Future work will involve additional participatory design sessions and evaluation of the prototypes' acceptability, usability, and feasibility.

Abbreviations

OAMs, oral anticancer medications; PD, participatory design.

Data Sharing Statement

Given the qualitative nature of the study and small sample, confidentiality of subjects cannot be guaranteed, and thus, data will not be shared with other researchers. A summary of findings is available upon request from the corresponding author, seo104@purdue.edu (Yejin Seo).

Ethics Approval and Informed Consent

This study was conducted in accordance with the Declaration of Helsinki. The study protocol was approved by the Scientific Review Committee at the Indiana University Melvin and Bren Simon Comprehensive Cancer Center and the Institutional Review Boards of Indiana University (IRB: #18075) and Purdue University (IRB-2023-543). It also received review and approval from the research department of the study site hospital. All study participants provided verbal informed consent prior to participation in the study procedures, including consent for publication of anonymized quotations. Participants were provided with a copy of the study information sheet that included all elements of informed consent. Verbal consent was used instead of written consent to reduce participant burden and encourage participation, as the research was deemed minimal risk by the IRB and electronic health records were not obtained. Consent was obtained after participants, and a researcher reviewed an IRB approved study information sheet and all questions were answered. Documentation of verbal consent was recorded by the research staff in internal study records and a web-based clinical trial management system, noting the participant's confirmation of consent, the date, and the staff member who obtained it.

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Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception study design, execution and acquisition of data, analysis, and interpretation. All authors took part in drafting, revising, or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

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