

MyPath: Investigating Breast Cancer Patients' Use of Personalized Health Information

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Following a cancer diagnosis, patients must cope with numerous physical, emotional, and practical challenges. While health information exists to help patients learn how to manage these challenges, health information seeking often declines over time, recalling information is difficult, and limited time with healthcare providers can leave patients feeling uninformed about their illness. We designed MyPath to overcome these information access challenges. The mobile system offers personalized, dynamic, and trusted health information recommendations to help patients learn about and manage their cancer. Through a seven-month deployment study with breast cancer patients, we found that use of the application encouraged proactive health management behaviors, and identified factors that motivated technology adoption and abandonment. We discuss the implications of these results for facilitating use of mHealth tools by a rural patient population and the importance of scaling support to a large range of information needs. We use this work to demonstrate the value of personalized health information systems and to motivate future CSCW research developing personalized support systems for other health situations with complex information access models.

CCS Concepts: • **Applied computing** → **Life and medical sciences; Consumer health; Health care information systems; Human-centered computing** → *Ubiquitous and mobile computing; Tablet computers;*

Additional Key Words and Phrases: Mobile health; health information seeking; personalization; breast cancer; human-computer interaction

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1 INTRODUCTION

Following a cancer diagnosis, access to educational information plays an important role in helping patients learn how to manage the disease. Access and use of health information has been linked to reduced anxiety, improved adherence to treatment, and increased self-care [44]. However, several barriers currently limit a patient's ability to access and effectively use health information to inform their personal health management. For example, patients most often rely on their healthcare providers for trusted education material, but patients and providers can have different perspectives regarding health management goals and relevant health information [9]. Patients can also feel hesitant to share healthcare experiences or ask questions; particularly if they believe their healthcare

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providers are too busy or unable to help [27]. Finally, patients' information needs change as they progress through various treatments, requiring continuous support [46]; however, time and resource constraints limit the ability for health organizations to offer long-term support [26]. Thus researchers have called for health tools that can support patients' diverse needs as they change over time [36].

The ways in which patients typically interact with health information following a cancer diagnosis also limits the effectiveness of the material. Immediately following a cancer diagnosis, patients typically go through an aggressive information seeking phase [23]. During this time, which can continue for several weeks, patients often seek out a large quantity of information about the disease, treatments, and coping strategies. However, during this time patients also feel a great deal of stress, impeding their ability to learn [58]. As patients progress through cancer treatments, and their information collections grow, recalling or retrieving the needed information becomes increasingly difficult. This challenge is compounded by the fact that much of the information patients receive may not be applicable to individual diagnoses and treatment paths. [58]. Further, anxiety caused by information seeking can lead patients to actively avoid health information [11]. While these factors limit use of health information over time, patients information needs during and after treatment are numerous [46]. Thus, we see a gap between when patients are engaging with health information and when the information could be best put to use.

We developed MyPath, a mobile health application, to address these common challenges related to accessing and using health information following a cancer diagnosis, connecting patients with personalized and dynamic educational material. The application contains an aggregated set of health information vetted by healthcare professionals. MyPath indexes these materials and provides patients with personalized information recommendations based on their diagnosis and treatments, and uses a comprehensive survey to elicit patient information needs and update content accordingly. We ran a deployment study of MyPath over a seven-month period in a rural community in the Southeast region of the United States. We analyzed application usage logs and participant interviews to understand how participants used the technology to inform their health management during treatment. We found that the MyPath system was used consistently during the study period, and that participants' use of the application supported important health management behaviors. The results from this deployment offer insights into how personalized and dynamic health information can help patients take a proactive role in their own care. Our work offers the following contributions to the CSCW community:

- (1) We identify ways in which use of MyPath influenced participants' health management behaviors, including increased communication with their care networks, reducing fear, and proactively responding to changes in daily life.
- (2) We describe participants' motivations for using the MyPath system, as well as situations that led to technology abandonment.
- (3) We reflect on the benefits of personalized and dynamic health information, particularly within a rural healthcare context, while highlighting opportunities to improve support for illness trajectories.

2 RELATED WORK

2.1 Illness Trajectories and Patient Work

While cancer and chronic disease management are highly collaborative processes between patients and providers, an increasing amount of responsibility is being placed on the patient. Studies of illness trajectories highlight the immense patient work that individuals must take on following a cancer or other chronic illness diagnosis [13]. This work includes becoming his or her own health expert, developing new behaviors, and coping with new health experiences and problems [39].

Common tasks include managing symptoms, adhering to treatment regimens, sharing information with family and friends, and coping emotionally. These new responsibilities can significantly impact patients' quality of life, particularly if they do not feel they have the knowledge or skills to cope with health issues as they arise [4].

2.2 Health Information Seeking

After being diagnosed with cancer, patients' information needs are broad, including details about one's diagnosis, treatments, side effects, finances, and strategies for coping socially and emotionally [5, 16, 30]. Access to health information can have important benefits for patients, such as improved coping skills [31], less anxiety [50], and higher psychosocial wellbeing [4]. Despite these benefits, connecting patients to necessary health information is an ongoing challenge in many healthcare systems. Patients turn to health professionals for information and advice much more often than other sources, such as family members or printed material [17]. However, patients are often dissatisfied with the information they receive from their providers. In several studies the majority of patients have indicated a desire for more information [5, 30, 46].

An increased number of individuals are using the Internet to find health information, but finding the needed information is difficult for several reasons. First, patients require comprehensive support, as the diagnosis not only affects one's physical health, but also has lasting effects on one's psychosocial wellbeing [55]. Second, the information needs of patients are continuously changing as they progress through various treatments and into post-treatment survivorship [7]. Finally, cancer care experiences are diverse, with each patient experiencing different side effects and personal challenges [54]. These complexities make finding health information after a cancer diagnosis a burdensome process.

To address these challenges, research within public health has examined the potential benefits of tailored health information. Kreuter and Wray called for tailoring print materials within health interventions [38], positing that such tailoring would encourage greater attention and understanding of the information. An early randomized trial of computer-based information for cancer patients revealed several benefits of personalized summaries of one's medical record, including increased patient satisfaction and feeling less overwhelmed than with generalized or paper-based information [33]. More recently, researchers found that tailored computer-based information can increase knowledge of healthcare concepts, including breast cancer genetic counseling and diabetes self-care [2, 62].

These studies motivate the need for personalized health information. However, few studies seek to address the specific information needs for underserved communities, including individuals living in rural areas. Many common information seeking challenges can be exacerbated within rural communities. Within the United States, the imbalanced availability of healthcare providers between rural and urban areas limits the availability of health resources in rural communities [64]. Patients in rural communities also must cope with increased barriers to care, such as transportation issues and feelings of isolation, but have access to fewer educational opportunities and peer support programs [8]. Further, older patients with a chronic disease and with low socioeconomic status are less likely to take advantage of online tools [14, 18, 19]. In this study, we explore how personalized health information and mobile health (mHealth) technology can help people in rural communities overcome these barriers to accessing health resources.

2.3 Mobile Health Interventions for Cancer Management

The CSCW and HCI communities have made several advances in understanding how technology can support patients' illness management and encourage engagement in their care. Studies have

demonstrated the ability for mobile devices and applications to support chronic disease management through self-monitoring and reflection of one's personal health data [40, 47, 57]. For cancer patients, studies have shown that mobile health tools can greatly benefit patients. For example, the HealthWeaver system supported a range of cancer management tasks, including tracking appointments, taking notes, monitoring symptoms - helping patients feel more confident in their disease management abilities [35]. A study of the ASyMS system, which used a mobile phone to track physical symptoms and connect patients to tailored self-care advice, revealed that the group that received the technology experienced less fatigue than the control group [34]. Research has also demonstrated how patients' use of health interventions, particularly self-monitoring systems, increases engagement in their care. Patient generated data captured through these health tools can serve as boundary objects that help patients share their health experiences with their providers while also reflecting on their own experiences and behaviors [1, 12, 48].

While there have been many advances in the ability for mHealth tools to support chronic disease management, there are still a number of gaps this research attempts to address. First, many of the tools described above help patients track and monitor their personal data, a critical component of health management. In addition to this data, managing cancer and other chronic illnesses requires access to a broader set of health information to learn how to cope following a diagnosis. Thus, while many CSCW and HCI studies focus on systems that allow for collecting and using personal health information, generated by the user, our work explores the ability for novel mHealth tools to connect patients with personalized educational health information. Second, we consider how mHealth tools may scale in order to support a broader range of patients' needs. Finally, we have seen few mHealth approaches that look at spacing out information over time, in order to overcome common information access challenges. Through this study we explore a possible approach to making information support more timely and actionable.

3 SYSTEM DESIGN

Our overarching goal with MyPath was to augment health information sharing within a rural cancer clinic. We have partnered with the cancer clinic over the past five years to identify opportunities to improve support for cancer patients. In this section, we review our formative work that guided the design of MyPath, our partnership with the existing healthcare system, and the features included in the MyPath application.

3.1 Formative Studies with Breast Cancer Patients

The design and content included in MyPath is based on a number of studies we ran to understand cancer patients' experiences and health management challenges. These studies included a journey mapping exercise in which survivors documented their illness trajectories [29], an evaluation of tablet use throughout the cancer trajectory [25], and an assessment of patients' and providers' health information sharing preferences [27].

Through this work we identified a number of challenges patients in the community encounter while learning about their diagnosis and managing their health. These challenges include feeling uncomfortable or unable to contact their healthcare providers when questions arose, finding inaccurate or conflicting health information online, and struggling to organize paper-based health information. We developed MyPath to address these challenges by connecting patients to dynamic health information recommendations tailored to each person's support needs. Table 1 outlines the specific features included in MyPath to address these health information access challenges.

Table 1. Existing Health Information Access Challenges Guiding the MyPath Design

Information Source	Limitation	MyPath Feature
Doctors	Limited time for patient-provider interaction	Continuously available health information recommended by patients' healthcare providers
Cancer navigators	Focus on patients who were recently diagnosed, patients must reach out when needed	System recommends patients reach out to cancer navigators (and provides contact information) when patients indicate high distress or issues that align with navigator expertise
Online content	Distrust Limited internet access in rural areas Difficult to identify most relevant information	Content vetted by healthcare professionals Most MyPath content is accessible offline Recommendations based on individual diagnosis and treatment
Paper-based material	Difficult to organize and recall	Dynamic recommendations to provide timely information based on current questions and challenges

3.2 Healthcare Partnership

Our research team collaborated with a cancer clinic the Southeast region of the United States to create and deploy the MyPath system. We worked with a team of oncologists, nurses, the director of operations at the clinic, and cancer navigators. The cancer navigators include nurses and social workers, employed by the cancer clinic, who provide a number of support services to patients. They answer patients' medical questions, meet patients at treatment to provide emotional support, offer counseling to patients and their families, and help patients acquire any necessary financial support, such as health insurance and transportation assistance.

We worked with this team of professionals throughout the MyPath development process. This collaboration allowed us to leverage their clinical expertise and helped to ensure that the healthcare team supported the final application. To begin this collaborative process, we ran a workshop with two oncologists, three cancer navigators, and the director of operations to develop our initial concept, followed by individual interviews to identify trusted content to include in the system. The research team then developed an application prototype and led a walkthrough of the initial design with the cancer navigators and the director of operations, in order to review the MyPath content and organization. Based on their feedback, the research team iterated on the design. The primary feedback from this phase was to include information about local resources, such as the contact information for the cancer navigators and the local breast cancer support group. We then developed the MyPath application, and ran usability tests with three oncologists, three cancer navigators, and four cancer survivors. Participants in the usability study generally found the application easy to use and indicated that they would recommend the application to future patients. Based on the usability evaluations, we finalized the MyPath design.

Prior to the MyPath deployment, we also worked with the director of operations to recruit and train an education navigator, akin to our past deployment studies with breast cancer patients [25], to serve as a point of contact for patients. In this project, the education navigator served several

roles. First, she was responsible for meeting newly diagnosed patients and enrolling them in the field deployment. As an employee of the cancer clinic, the education navigator had access to the clinic's electronic medical record and was able to configure each MyPath tablet based on diagnosis and treatment information. The education navigator also provided training, reviewing MyPath and tablet features with each participant. Finally, the education navigator provided all participants with her contact information in case questions or concerns about the technology or the research study arose. We opted to use an education navigator in the MyPath deployment in order to reduce the potential stress placed on newly diagnosed patients. Since the education navigator was an employee of the cancer clinic, she was more accessible to patients and was able offer continued in-person support.

3.3 MyPath Features

We deployed MyPath on Verizon Ellipsis 8 tablets, opting to use tablets because the devices provide a larger screen that can make reading materials more accessible for an older population and have been used in studies with similar populations [45, 52]. All participants received a tablet with the MyPath application installed when they enrolled in the study. Figure 1 shows an overview of the MyPath system and features, including the main page that presents categories in which patients can find sets of information, a sample list of resource links within the Day-to-Day Matters category, and the MyPath survey where participants can input their current health management challenges.

3.3.1 MyPath Interaction Scenario. We provide the following scenario of a typical MyPath interaction in order to describe the various MyPath features (which are then presented in more detail throughout this section):

Jane received her diagnosis of stage II breast cancer just last week. After her first visit with the oncologist she met the education navigator, who gave her an interactive, cancer-care tablet computer. After receiving some training on how to use the tablet and MyPath application, Jane unlocks her tablet for the first time. She is presented with an initial welcome message and then sees the main screen, with several categories listed, such as Treatments and Emotional Support, with an icon indicating there is unread information in these categories. Jane is nervous about her upcoming radiation treatment. She looks at the Treatment section and sees a list of informational resources tailored to her diagnosis and treatment. She selects a resource titled "Taking Care of Yourself During Radiation Therapy" which comes from the American Cancer Society. The information page includes expected side effects of radiation, and tips for how to address these issues at home to reduce their severity.

A month later Jane is progressing through her radiation treatment. Her side effects are manageable, but she is struggling with the financial burden of the cancer treatments. She picks up her tablet computer, opens MyPath, and selects the survey button on the main page. Within the survey she can indicate what issues she is dealing with and get new information added to the application. She selects the Insurance/finance option. Immediately after completing the survey she sees a new icon on the main page indicating that new informational resources have been added to the Day-to-Day Matters section. In this section she sees several new resources related to cancer and finance, such as "Managing the Costs of Cancer" from cancer.net, a forum on breastcancer.org titled "Employment, Insurance, and Other Financial Issues forum", and a link to her local cancer navigation organization, which can help people access financial aid.

3.3.2 Information Included in MyPath. To use MyPath, the education navigator first completes a user profile within the application with the participant's diagnosis and treatment information. Participants will then find personalized content when they open the application.

To create the information set, we asked our partnering oncologists and cancer navigators to identify resources they currently recommend to patients. Typically, patients would receive these

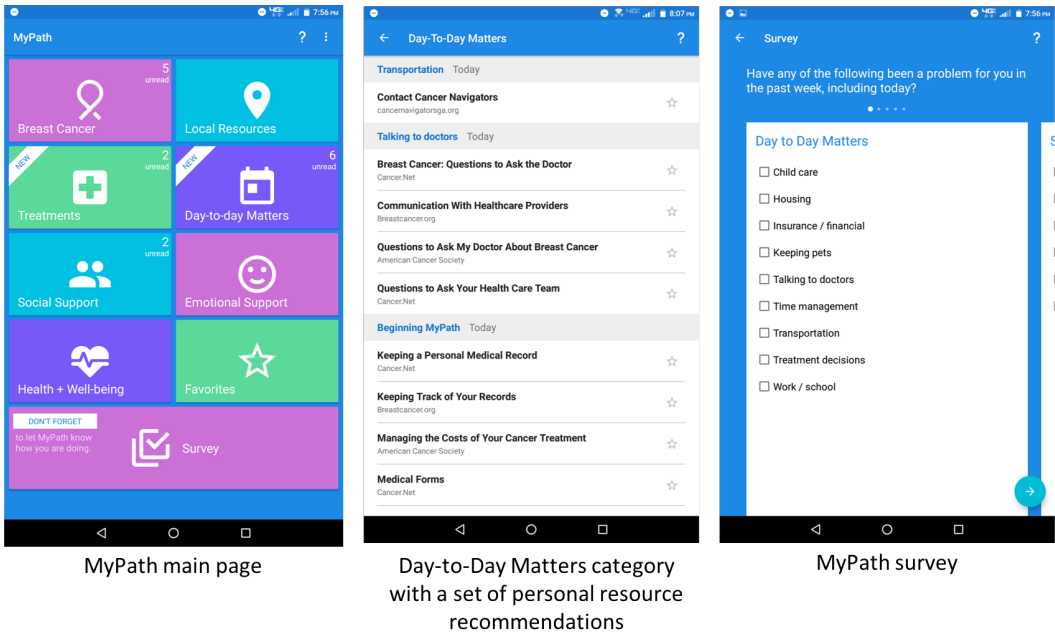


Fig. 1. MyPath features

recommendations through conversations with their care team if they requested information in addition to the booklet they receive upon diagnosis. We found that all of these healthcare professionals recommended patients use three trusted websites to find health information: American Cancer Society, Breastcancer.org, and Cancer.net.

Due to the healthcare professionals’ trust in these sources, as well as the comprehensive sets of information available through these sites, we opted to use them within MyPath. These three sources contain a breadth of information to help patients learn about and manage their health. We included all content related to breast cancer from these websites: 115 resources from American Cancer Society, 166 resources from Breastcancer.org, and 33 resources from Cancer.net. In addition, the healthcare providers recommended a small set of local resources, including the cancer navigation and cancer clinic websites. With this content MyPath can offer support on a range of issues, such as treatment side effects or topics such as fear, isolation, and transportation needs.

We use the term resource throughout the paper as a label for each unique page of information included in these websites. We made most resources accessible offline, though some content, such as online discussion boards and embedded hyperlinks, required an Internet connection.

3.3.3 MyPath Organization. When first reviewing the three websites from which we drew MyPath content, we found that each of these sources had different organization schemes. We worked with the broader healthcare team to harmonize the three sets of resources. Through our conversations with the oncologists, we found that the cancer clinic regularly asks patients to complete the National Comprehensive Cancer Network (NCCN) distress survey to identify patients’ needs and challenges. The NCCN survey organizes common patient issues into five categories: practical problems, family problems, emotional problems, spiritual/religious concerns, and physical problems. Since patients at our partnering clinic were already using this questionnaire, we opted to use this categorization within the MyPath application.

We made adjustments to the categories to better fit the curated content. First, we added a breast cancer overview category that provides general information of the disease, and therefore did not fit any of the original NCCN categories. Second, we split resources related to physical problems into two categories: Treatments and Health + Wellbeing. We made this change to prevent one category from including too many resources, as this imbalance could hurt the system's usability. Third, we opted to remove the spiritual concerns category since our curated set of resources from our healthcare partners did not address this need. However, we noted that our participants often added spiritual content and applications to their tablets. Finally, we created a 'Local Resources' category with information from the cancer clinic and local navigation organization.

3.3.4 MyPath Survey and Dynamic Content. To help patients receive timely information as their needs change, the system includes a survey that patients may complete at any time in order to update the MyPath content. As previously mentioned, the questionnaire in MyPath uses the NCCN distress thermometer [24], which includes two questions. The first asks participants about their level of distress, scored from 1 to 10. If patients indicate a distress level greater or equal to 4, the application recommends that they contact one of their healthcare providers, and lists contact information for the cancer clinic and cancer navigators.

The second question in the survey asks patients to select what issues they have encountered. The survey includes 58 possible issues, including common side effects, as well as practical, family and emotional problems. Example responses include fatigue, insurance, transportation, and fear. In addition to the issues included in the distress thermometer, we added 21 other possible patient challenges. These topics emerged from work with cancer patients outlining the breadth of challenges experienced during and after treatment [29]. Examples of added survey options include Infections and Talking to Doctors.

Once the user completes a survey, the application immediately updates with new recommendations relevant to the issues selected in the survey. The survey questions ask participants to indicate which issues they have encountered during the past week. While participants could complete the survey at any time, the education navigator helped participants set a weekly reminder on their tablets, at a time that each participant thought would be useful.

3.3.5 Summary of MyPath Personalization. We designed MyPath to help patients find information that is personalized to each person's diagnosis, treatment path, and current support needs. When patients first open the application they see an initial, personalized set of information resources. This information includes details about the patients' diagnosis and upcoming treatments. For example, when a patient diagnosed with stage I breast cancer who will receive radiation treatment opens the tablet, they will see resources such as "How Radiation Works" and "Stage 1A and 1B treatment options" from breastcancer.org. In contrast, a patient diagnosed with stage II breast cancer and receiving chemotherapy will see resources such as "Chemotherapy for Breast Cancer" from American Cancer Society and "Stage IIA and IIB treatment options" from breastcancer.org.

Patients will also receive information tailored to their support needs when they complete the survey included in MyPath. For example, when a patient selects Pain, a small set of new resources will be added to her tablet, including "Treatments for Pain" and "Pain Discussion Board" from breastcancer.org. These resources may also be personalized to patients' diagnosis and treatment when appropriate. For example, when a patient currently receiving radiation therapy selects Pain, they will see the previously mentioned resources as well as "Armpit discomfort" and "Chest Pain". If a patient selects Pain after undergoing a mastectomy, they will see the resource "Post-Mastectomy Pain Syndrome" added to their MyPath application.

In both of these examples, MyPath is matching patient needs with tags associated with the curated resources. These metadata tags indicate if a resource's content pertains to a particular

diagnosis, treatment, and/or survey response. MyPath then offers the most relevant content based on these personalization criteria. One insight from our design experience is that MyPath includes a tractable number of resources for this “bag of words” matching approach to produce a usable experience.

4 METHODS

4.1 Participants

We recruited participants through the cancer clinic. The clinic is located in a town with a median household income of \$36,000 (which is below the national median of \$57,617 [20]) and a 26% poverty rate. The clinic’s patient population comes from a wide, predominantly rural, geographic area.

During the seven-month deployment study of MyPath, we invited all newly diagnosed breast cancer patients to participate. Participation was voluntary. To recruit patients, one of the cancer navigators would briefly introduce the research project to new patients at their first oncology appointment. This cancer navigator was already present at these initial meetings to offer emotional support to patients. Patients who were interested in enrolling could ask for the education navigator to contact them directly. Patients who asked for time to decide if they would like to join the study were given a short flier about the project that included the education navigator’s contact information. The education navigator then set up a meeting with each participant to give them their tablet and provide training on how to use the technology.

While patients did not receive remuneration for participating, they received a general purpose tablet computer with the MyPath application installed that they were able to keep. Twelve participants enrolled in the study, an acceptance rate of 57%. Four people declined to participate, and five people could not be reached by the education navigator. The patients who declined to participate typically stated that they felt too overwhelmed by their health situation. The twelve participants who enrolled in the study were all receiving treatment for breast cancer at our partnering cancer clinic. All participants were diagnosed with stage I or stage II breast cancer, though all stages were in our inclusion criteria. All participants had a lumpectomy, eight of the participants received radiation therapy during the study and four received chemotherapy. Participants’ ages ranged from 49 to 74 (mean = 66). We also asked participants at their meeting with the education navigator to score their technology comfort from 1 to 5 (1=very uncomfortable, 5=very comfortable). Participants’ responses ranged from 3 to 4 (mean = 3.6).

4.2 Data Collection and Analysis

Throughout the MyPath deployment we captured participants’ MyPath use. This data consisted of all interactions within the application, including the date and time a participant opened the application and moved between screens, all resources viewed, and all survey responses.

At the end of the study period we invited all participants to partake in an interview, in order to share their thoughts about the technology. Three participants were unavailable for interviews. The nine participants we interviewed met one member of the research team at the cancer clinic. One participant also brought her primary caregiver (her daughter) to the interview, as they often used the tablet together. At the time of the interviews, participants were either in chemotherapy or radiation treatment or had recently completed treatment. All interviews were semi-structured, with questions focused on understanding when and why participants used the MyPath application. To analyze the data, the research team transcribed the interview recordings and used an iterative inductive analysis [53]. The primary researcher independently coded the transcripts, identifying themes related to motivations for using the technology, and impacts of use on health management

and daily life. The research team then reviewed the transcript segments and associated codes, and collaboratively refined the codes to identify emergent themes around tablet use.

5 RESULTS

Here we first report on the results from the analysis of MyPath usage logs. We used these results to drive the interview study. Through the interviews, we identified three themes related to how use of MyPath influenced our participants' health management behaviors, as well as motivations for using the technology. We also report on reasons that a subset of participants abandoned the technology, and highlight an unmet support need raised frequently by our participants.

5.1 General Tablet Use

Participants were able to add their own applications to the tablets and use the devices however they wished. While use of the broader tablet device was not our primary focus for this study, we found that participants used the tablets in similar ways discussed in prior work [25]. Many participants used the calendar to track appointments and the cancer clinic's patient portal to look up test results. Participants also added games, books, and movies to the tablets. Our prior work points to the importance of deploying mHealth applications on general purpose devices to sustain device use across intermittent health use [28].

5.2 Overview of MyPath Use

At the conclusion of this study, participants possessed the tablets for an average of five months, with a range of two to seven months. We reviewed the usage logs to identify any common patterns of use over time and types of resources viewed. We found that participants used the system consistently. Figure 2 shows the days each participant used the system and the session durations, and table 2 summarizes participants' MyPath use. On average per month, participants used the MyPath application three times, viewed 19 health resources, and completed two surveys. 65% of MyPath sessions included a survey submission. These sessions were frequent and short. MyPath sessions that included a survey submission lasted four minutes on average. Participants selected 55 distinct issues through the survey, across all categories. The most common health issues patients selected in the survey were fatigue, sleep, dry skin, fear, and memory. By comparison, 52% of MyPath sessions included viewing health information resources. Viewing health information was a less regular activity on MyPath, but participants spent more time on the tablet when reading health information. The average duration of sessions that included viewing health resources was 18 minutes. While the majority of participants consistently used the MyPath application over the study period, we found that four participants abandoned the technology after about 2 months of continuous use. We explore the reasons for this non-use in the interview study.

We were also interested in the types of information participants viewed. Participants viewed a total of 242 distinct resources. Each of these resources was viewed by an average of two participants. Resources related to cancer treatments were the most viewed resources (44% of all page views), followed by day-to-day matters and health and wellbeing. All categories were used by participants, with a minimum of 6 participants viewing resources in each category. Participants on average viewed resources from 5 of the categories included in MyPath. A review of resource use over time did not show any changes in the types of categories accessed as participants progressed through treatment. These results indicate that participants each viewed a broad set of resources, spanning several categories, though these resource sets differed greatly between participants.

The MyPath usage logs revealed several important behaviors. The majority of participants used the application consistently throughout the study. While using the application, participants viewed broad sets of information spread across several categories. In addition, participants routinely

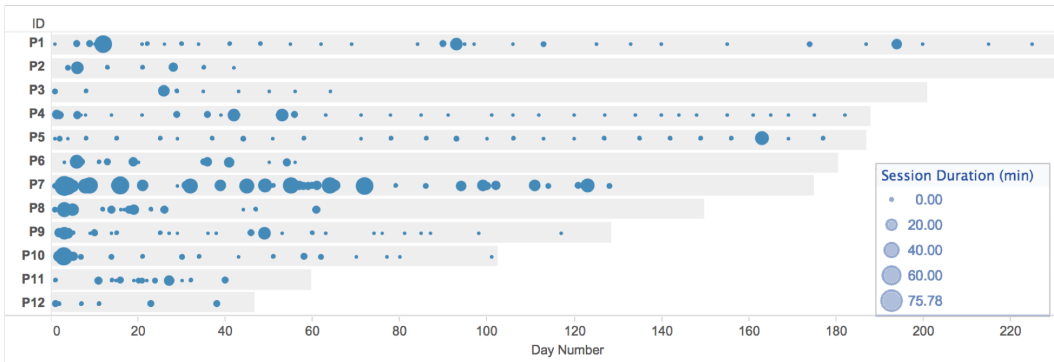


Fig. 2. Participants' Use of MyPath over Time
Grey boxes show the length of time participants had possessed MyPath at the time of data analysis.

completed the surveys, and included a wide variety of responses within the surveys. These behaviors suggest that participants experienced a wide range of information and support needs.

5.3 Influence of MyPath Use on Health Management

In reviewing the usage logs, we found that participants engaged with MyPath regularly. Therefore, our goal with the interview study was to understand if participants found the information useful and how they used the information in their daily life. In the interviews, participants shared that they would typically complete a survey, and then return later to read any recommended content that seemed relevant or interesting. Participants shared a number of ways in which the MyPath recommendations helped them to manage their health, including communicating with their care networks, reducing fear, and coping with the effects of the disease on daily life.

5.3.1 Communicating with their Care Network. Six participants provided examples in which the health information on MyPath encouraged them to communicate with their care team, including doctors and cancer navigators. Participants used the materials to figure out which side effects they should discuss with their doctors, such as one participant who shared:

“It got me thinking maybe I should tell them more about the little side effects because you never know what could be really important. We started talking about the neuropathy in my fingers and she told me don't let it go too far. Right now we are just going to watch it because it just started. But she told me not to let it go too far because if it does it may not be reversible and they have things they can prescribe to help with it. So that was important to tell them.” (P7)

In this case, the participant had read about other patients' experiences on the breastcancer.org forum, which was recommended on MyPath. Based on the stories shared in the forum, the participant decided she should tell her providers about the side effects she was experiencing. This discussion ended up leading to important conversations with her chemotherapy nurse about the importance of monitoring this treatment side effect. Other participants shared that by making sure that side effects were related to their cancer, they felt more confident bringing them up in conversations with their oncologists.

Participants also stated that they decided to go meet with the cancer navigators after seeing information about the organization in the tablet:

Table 2. Summary of Participants' Use of the MyPath System

Total Participants	12
Average Time in Study (months)	5
Average Sessions/Month	3
Average Resources Viewed/Month	19
Average Surveys Completed/Month	2
Average Session Duration (minutes)	10
Distinct Resources Viewed	242
Distinct Survey Responses Submitted	55

"They mentioned [cancer navigators] when I first got diagnosed, but then it came up on the tablet again. So then I went over there and talked to them about what they have to offer." (P5)

Experiences such as this one demonstrate that participants decided to meet with cancer navigators after learning about, or being reminded of, their services through the tablet. MyPath provided participants with information about cancer navigation services that related to their existing support needs. For example, if participants indicated that they were struggling financially, one of the informational resources would be a link to the cancer navigation website, as they are able to help cancer patients obtain financial resources. While the cancer navigators work within the cancer clinic, they rely on patients to initiate the relationship [26]. Connecting patients with reminders of these services helped to encourage participants to take advantage of this support system. Thus, participants provided a number of examples in which the information recommendations encouraged them to talk about their health experiences with members of their healthcare team.

5.3.2 Reducing Fear. Six participants shared that they used the information on MyPath to manage their emotional wellbeing by reducing fear during treatment. One way participants were able to reduce fear was by using the information to help them better understand what to expect in the future:

"It takes less fear if you know beforehand what's going to happen. Anticipation can make you nervous and upset." (P5)

"You know what to expect coming up... I just feel like now I know a little bit more about [cancer], and that makes me feel more comfortable about it usually." (P8)

In both of these situation, the participants described how they would use MyPath to learn about upcoming treatments and possible side effects. Participants stated that by feeling informed about next steps they felt less anxious about future treatments.

In addition to reducing fear of the future, participants used the information to reduce fear of their current situation. Participants commented that the information helped them determine if the side effects they were experiencing were typical for cancer patients, and make sure the side effects were normal:

"I was suddenly getting pimples, and it was answering questions about how radiation affects those things." (P1)

"I haven't signed up myself [on the forums] but I have gone in there a lot and just gone through to see how people are dealing with different issues and side effects. I can look at side effects and figure out what's normal, what's not normal." (P7)

As shown through these examples, when participants experienced treatment side effects, such as pimples, skin irritation, and nausea, they were unsure if the side effects were an expected part of their cancer treatment, a complication of the disease, or a new health issue. Medical complications and new health issues can be a significant cause of distress for cancer patients, as visits to a doctor's office or emergency room can be detrimental to a patient's already weakened immune system. Thus, identifying existing side effects as 'normal' became a common use of the MyPath system. Participants said that once they knew a health issue was a common side effect of their treatment they felt less worried about the health change. Participants' use of recommended forums also shows that MyPath was able to facilitate access to online health communities.

These examples show that participants found MyPath's targeted suggestions for educational materials useful for setting realistic expectations about their current and future health status. By understanding that their side effects were typical and feeling knowledgeable of their future treatments, participants said they felt calmer and less fearful of their health situation.

5.3.3 Managing Changes to Everyday Life. Seven participants described specific ways that the information they read helped them immediately respond to changes in their daily life. Most often participants described using the information to figure out how to handle new treatment side effects. For example, one participant described getting lotion to help with the effects of radiation:

"I have very sensitive skin anyways, and I was getting very dry skin. I had like a sunburn effect. It was telling you different lotions and things you could use." (P1)

As in this example, participants described situations in which the information immediately led them to actively respond to treatment side effects. In addition to addressing the physical implications of the disease, participants also described how they used MyPath to cope with non-physical life changes. Most commonly these included financial and social issues. For example, several participants talked about using MyPath to learn more about how to deal with the cost of cancer treatments:

"I read about medicare, because I am concerned about finances. After insurance I still have several thousand dollars to pay." (P6)

In the United States, the financial burden of cancer treatments can be an extremely distressing facet of the disease [3]. In addition to reading about medicare and medicaid, participants said they also decided to go talk with the cancer navigators about their financial concerns, due to the complexity of the issue.

Social support issues with spouses and close friends were also raised by participants. For example, one participant described feeling upset about how her friends were responding to her cancer diagnosis:

"People sometimes don't know what to say or do. It was good, it gave me advice about talking to friends or family about it." (P8)

A cancer diagnosis can often have negative social consequences. As demonstrated through this example, participants would use information in the social support section to figure out how to address communication issues with family and friends. Collectively, these discussions demonstrate how participants used the information to quickly learn how to cope with treatment side effects and develop new healthy behaviors. As we will discuss, this proactive health management can help improve patients' quality of life throughout the cancer trajectory.

5.4 Reasons for Technology Use and Disuse

5.4.1 Motivations for Routine Use. In our review of MyPath usage logs, we found that participants consistently engaged with the MyPath application. The MyPath logs showed that participants' average weekly survey completion rate was 82%. We asked participants to describe why they used

the technology. Participants consistently mentioned the role of altruism in motivating their routine survey completion. Participants often expressed to the researchers in the interviews that they hoped their data was helpful, similar to one participant who stated:

“I feel like if this is going to help, why wouldn’t I do my part to help the next person?”
(P12)

Motivating participant use through the desire to help others was an unexpected outcome of this work, and was not a part of the application design. However, in order to maintain open and ethical research practices, participants were informed that the research team would collect their survey responses. Further, upon enrollment, the education navigator explained to participants that they may not benefit from participation, but the tablet may be useful for treatment management, and that a goal of the research was to identify ways to create better support systems for future cancer patients. Participant interviews suggest that this information played an important role in motivating use of the MyPath survey.

Other affordances of the design were also mentioned as lowering barriers to effective use. The ease of the survey completion task was mentioned by all of our participants, and usage logs showed that participants typically completed a survey within a minute of opening the survey. We expect the low impact of the task influenced participants’ willingness to regularly engage with the technology, and helps to demonstrate why we saw a higher completion rate compared to studies involving more complex health tasks [21, 62]. Including recognizable categories and not overwhelming participants with too much information were also mentioned by participants as useful aspects of the design, which helped to motivate use of the information recommendations.

5.4.2 Technology Abandonment. While participants shared many ways in which the MyPath application was useful in their health management, not all participants considered the application valuable. Three participants commented that they had not found the information useful and read few of the suggested resources. These three participants’ usage logs showed that they stopped using the application 40-60 days after enrollment. In our conversations with these three participants, we found that they all provided similar feedback into why they were not using MyPath. First, all participants made comments about having low illness severity, indicating that they experienced few side effects, and possessed the tools to cope with the illness:

“I had no ill effects from the radiation. No radiation burns. I had one little tiny pimple or blister, it was really nothing. No fatigue, I feel fine.” (P6)

When participants did not have significant physical health effects from the cancer or cancer treatments, they found MyPath to be less helpful. These participants also shared personal issues and priorities that overshadowed the cancer diagnosis, causing a gap between their personal needs or goals and the informational support available to them:

“I really haven’t found any practical application for it. Probably because the problems that I’ve had were not things that could be addressed with that. I was going through my mother dying.” (P3)

As in this case, MyPath was considered less useful when participants’ priorities were unrelated to their cancer, such as deaths in the family or other illnesses that required more of the participants’ attention. These participants highlighted important gaps in the types of resources and support available to cancer patients. As we discuss later, future mobile health tools ought to more closely align with patients’ personal values and provide a way for patients to articulate support gaps to their care networks.

5.5 Ideas for Improved Personalization

The previous results demonstrate benefits of the MyPath system. We also found that providing participants with personalized content helped to stimulate conversation and ideas about how future tools could be better designed to fit their individual needs. The most common idea that arose in conversations was personalized information for managing multiple chronic conditions. Six participants described other health issues that they were managing alongside cancer. These conditions included underactive thyroid, chronic kidney disease, and fibromyalgia. Several participants expressed the need for information to help them understand how to manage these conditions in parallel, particularly when they received contrasting advice from multiple clinicians:

“[The oncologist] was saying drink this much water a day, but the kidney doctor was saying no, do not drink more than 50 ounces because your kidneys just can’t handle that.” (P2)

Addressing inconsistent recommendations from healthcare providers was an ongoing challenge for many of our participants who were coping with multiple health conditions. Typically, these opportunities for enhanced personalization did not derail use of the MyPath application. However, when MyPath’s content failed to support the primary health focus of the participant, as was the case with the participant with chronic kidney disease, use of the application declined.

6 DISCUSSION

We developed MyPath to assess the ability for mHealth tools to provide personalized, dynamic, and trusted health information to help patients learn about cancer and to manage their cancer journey. The combination of MyPath features supported regular use of a diverse information set. Here we discuss the implications of these results for facilitating use by a rural patient population and the importance of scaling support to a large range of needs. Key design features, such as pacing recommended resources, appear successful in motivating sustained use and catalyzing participant actions throughout their cancer journeys. However, factors such as altruism also played an unanticipated role in participants completing regular surveys.

Going forward, these results also point to new, more complex challenges to providing comprehensive, personalized support for cancer patients that also struggle with other chronic conditions. These challenges indicate the need for more sophisticated information access models as the answers to questions surrounding comorbidities are difficult to discern from the existing cancer care information sources. Creating new ways to surface these issues to healthcare providers is likely needed. Finally there are limitations to the overall generalizability of our research results. More work is needed in diverse patient populations as well as in different healthcare systems.

6.1 Supporting Patients in Rural Areas

Many studies have identified the benefits that patients experience when using online support groups [32], patient portals [63], and mHealth tools [43, 48] to learn how to cope with cancer. However, these studies are not representative of our target population. Our participants’ demographics (including age, income and living in a rural area) are indicative of less health information seeking [14], lower adoption of health tools [19], and poorer health outcomes [61]. Therefore, a promising result from this study was that the majority of participants engaged with MyPath consistently over the seven-month study. This deployment study demonstrates the feasibility for mHealth tools to engage patients in rural areas, who are disproportionately offline and face increased barriers to care.

Participants’ descriptions of how they used MyPath also indicate that the system can help rural patients overcome health resource access issues. A lack of time with healthcare professionals and

inability to recall health-related events can impede on patient-provider communication [51]. CSCW research has therefore called for tools that help patients determine what information is important to share with providers [12, 27]. Our work suggests that personalized, timely health information can play a role in this process. Participants consistently shared examples in which the information on MyPath helped them prioritize which experiences and side effects to share with their healthcare providers. Further the information helped encourage participants to seek out additional support resources, such as the cancer navigators, when needed.

6.2 Using Comprehensive, Timely Information to Stimulate Action

While searching out health information can help patients feel more informed, the information does not always directly influence health behaviors. The transformation from information to self-care is a difficult process due to the many challenges patients face organizing and recalling large information sets [49]. These challenges persist across many types of patient education systems, including paper-based information [58] and online health communities [42]. Therefore, another promising result from this study is that participants shared many examples in which MyPath's targeted recommendations stimulated important coping behaviors, helping patients address various healthcare experiences and support needs. Such proactive behaviors, including telling clinicians about health issues, reducing fear, and managing the impact of the disease on daily life, are important aspects of health management and have all been shown to improve patients' overall quality of life [6, 65]. Thus, personalized and dynamic content can help transform health information into a usable resource, rather than something to be organized and recalled later.

Recent evaluations of novel mHealth tools have also demonstrated the ability for technology to help patients cope with cancer. For instance, ASyMS helped patients to manage chemotherapy-related toxicity, and participants stated that the technology helped them communicate with healthcare professionals [43]. Similarly, HealthWeaver Mobile allowed patients to actively use their health information in their everyday lives [35]. However, as we previously mentioned, there is an opportunity to explore how we may scale such mHealth support to accommodate a more comprehensive range of patients' support needs. Our participants' support needs were broad and diverse, indicated by the wide-ranging and distinct sets of resources they each viewed. Participants viewed resources from an average of five different categories, with resources in every category being viewed by at least one participant. Through the evaluation of MyPath, we demonstrate the ability for mHealth tools to support patient engagement with a broader set of information. This comprehensive information helped participants to cope with a range of cancer-related issues in their daily life, including physical, social and financial challenges. Thus, while cancer patients' healthcare experiences are highly variable, personalized health information tools can encourage patients to proactively address their individual health management challenges.

6.3 Motivating mHealth Adoption through Altruism

Participants identified a number of design affordances that encouraged their use of the MyPath system, such as the ease of navigation and survey completion tasks. Participants also shared that a personal motivation for engaging with the MyPath system, and their initial motivation for completing the MyPath surveys, was their desire to help future patients. Subsequently, regular survey responses influenced consistent engagement with the informational resources in MyPath, leading to benefits surrounding timely information and subsequent patient action.

Altruism has often been identified as a motivation for using online health communities [56, 59, 60]. In these communities there is the exchange of social support. Even when the communication is asynchronous, participants will often be able to witness the positive effect of helping others. In MyPath, this social exchange is not present and yet participants expressed a similar motivation

to help other patients. This result suggests that altruism can motivate use of health interventions even in the absence of a social exchange. Researchers and healthcare professionals may therefore be able to encourage adoption of health interventions by sharing with participants how such behaviors may not only be personally beneficial, but how their behaviors and data can have broader implications. Health tools could support this sharing by allowing patients to track how their data is being used by research or clinical teams. For example, data maps could provide a visualization of the important results, future research questions, or new health tools that one's data directly or indirectly will influence. Such systems could help increase patients' interest in the technology, and therefore benefit the individual patient while also accelerating the ability for health systems to capture important patient data about their illness trajectory and health experiences.

6.4 Opportunity for Future Work: Helping Patients Voice Information Gaps

Participants abandoned the MyPath application when the application's content did not address their most pressing information needs. Participants most often identified the need for information about managing multiple chronic conditions. Currently, about 1 in 3 adults with breast cancer in the United States are living with multiple chronic illnesses [15]. Developing systems that can help people manage multiple illnesses could have important benefits for a large population. These situations involve navigating a particularly complex information space, with different, and at time contrasting, information coming from multiple providers. Tools which help patients successfully navigate these situation could be particularly important within underserved communities, including those living in rural areas, where comorbidities are more common [61].

Such information gaps may be best addressed through in-person support systems, such as case managers or cancer navigators. However, prior research has shown that patients can be hesitant to share health experiences and challenges, particularly if they are not related to their physical health [27]. Our ability to capture health experiences that patients have hesitated to share directly with their health providers suggest that mHealth tools can serve as a mediator in the patient-provider relationship, providing a platform where patients feel comfortable providing a comprehensive set of experiences. The ability for mHealth tools to facilitate patient communication and sharing of experiences is an important benefit of these systems, and could be used to further empower patients to articulate to their healthcare system when their support needs are not being met. We are currently exploring ways for patients to provide input when information recommendations do not address their personal needs. Such data could be aggregated across the cancer clinic's patient population and shared with healthcare providers. This data could be particularly useful for cancer navigators, who hold public classes for cancer patients and their family members to address common topics, such as coping with fear and the financial burden of cancer treatment. Information from patients about unmet information support needs could inform future course topics, helping to ensure that patients' support needs are met and that in-person support services are tailoring their support efforts to the needs of their patient population.

6.5 Generalizability

We developed MyPath to address three important health management challenges. First, patients' health information needs change over time. Second, patients experience a number of medical and personal challenges in parallel. Finally, patients often struggle with limited access to, and ability to recall, trusted health information. These challenges are not unique to cancer patients. Research has demonstrated that these health management issues are pervasive across many chronic illness trajectories [13, 37, 39, 41]. Therefore, we believe a promising research agenda is developing mHealth tools with personalized and dynamic health information that may be used across health contexts and by a more heterogeneous patient population. While this study revealed initial benefits

of such tailored information, our work also points to open challenges that ought to be addressed to create broader health tools and help patients voice unmet support needs.

7 LIMITATIONS

This study includes limitations that must be addressed. First, by working in a rural community, we had a limited sample size. This study size is not uncommon in HCI literature [10], but future work is needed to explore how results differ across a more diverse patient population. Our study also did not include any patients diagnosed with stage III or IV breast cancer. This omission was not due to any exclusion criteria, rather no patients with more severe diagnoses opted to enroll in the study. We found that our participants were generally interested in learning about their health and comfortable using technology. More research is needed about the extent to which self-selection influences mHealth field studies and possible strategies to reduce this bias.

Another important limitation of this study is that we focused only on patients' experiences using MyPath. Yet we expect that patient-facing technologies will have effects on the broader healthcare sociotechnical system [22]. Our initial results from this study reflect that such changes are likely, as participants have suggested that the application influenced their conversations with healthcare providers. Thus, more work is needed to explore the influence of personalized health information tools on the healthcare team. In our future work, we are deploying MyPath as part of a randomized controlled trial to assess how use of the application influences psychosocial metrics. As we scale the deployment to a larger patient population, we also plan to assess the broader effects of the technology on the healthcare system.

8 CONCLUSION

As care for longitudinal health trajectories moves outside of the traditional clinical setting, continuous support for patients becomes increasingly necessary yet challenging. This study demonstrates the ability for personalized health tools to facilitate patients' proactive health management; therefore changing the role patients play in the healthcare system, facilitating patients' engagement in their care. We found that the personalized and dynamic content, recommended through the MyPath application, served as a catalyst for health management behaviors. These behaviors included communicating with one's care network, reducing fear, and proactively responding to changes in daily life. Our study contributes to our understanding of how mHealth tools may facilitate use by a rural patient population and the importance of scaling support to a diverse and dynamic range of patient support needs. We present this work in order to motivate the need for, and guide the design of, personalized health information systems in other health contexts. We expect such systems will be valuable to patients coping with other chronic illnesses, as they require similar patient engagement and personal health management. Systems such as MyPath may be particularly useful for patients who experience greater burdens in accessing the traditional healthcare system.

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