

My Journey Compass: A Preliminary Investigation of a Mobile Tool for Cancer Patients

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ABSTRACT

Health information management for cancer care is a challenging and personal process that changes over time based on one's needs, goals, and health status. While technologies supporting health information management appear promising, we do not fully understand how health information tools fit into patients' daily lives. To better understand the opportunities and usage barriers of these tools, we designed and deployed a mobile, tablet-based health management aid: My Journey Compass. After one month of use, we interviewed twelve breast cancer patients to investigate their initial patterns of adoption, adaptation, use and non-use. We found that developing a tool that was customizable, mobile, and integrated into the patients' healthcare system resulted in a set of surprising uses by breast cancer patients for a wide variety of tasks. Our study demonstrates the potential for health management tools to improve the cancer care experience and for HCI research to influence existing healthcare systems.

Author Keywords

Breast cancer; mobile health; cancer navigation;

ACM Classification Keywords

H.5.3 Group and Organization Interfaces: Organizational Design

INTRODUCTION

For the 230,000 people diagnosed with breast cancer last year [1], the diagnosis likely carried more than an emotional burden. Upon diagnosis, cancer patients are almost immediately required to manage information across a variety of complex tasks. These tasks include obtaining medical information regarding their diagnosis and treatment plan, sharing health information with family and friends, and coordinating treatments across multiple physicians

[15]. Health information management for cancer care is additionally challenging because it is a personal process that changes over time based on one's needs, goals, and health status [22]. Therefore, effective health management tools must adapt to meet patients' dynamic situations. By learning how health information tools fit into patients' daily lives, we will be able to develop better design requirements for such technologies and more fully understand the potential for these tools to directly impact health outcomes.

To better understand the opportunities and usage barriers associated with integrating health management tools in patients' lives, we provided breast cancer patients with a mobile, tablet-based health management aid, named My Journey Compass. The My Journey Compass project provides a new model for personal health technologies by incorporating health and non-health uses in a single tool, providing patients with the ability to customize the interface and applications on the tool, and utilizing a strong partnership with an existing healthcare system and local cancer navigation organization throughout the design and deployment.

After one month we interviewed participants about their usage patterns and motivations for adoption. We found that My Journey Compass met a variety of needs, and many participants used the tool regularly. These findings indicate that similar technologies may be able to successfully integrate into patients' lives and meet a broad range of breast cancer patients' needs as they go through the cancer journey. Through the results of this study, our paper offers three contributions to the CHI community:

1. We provide a model for, and discuss the benefits of, combining personal and health technologies.
2. We provide insight into four factors that motivated our participants to use the tablet, including customization, mobility, balance of information, and privacy.
3. We provide evidence for the importance of integrating new health management technologies into existing healthcare systems and discuss how such integration strengthened both our research project and the existing healthcare system.

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RELATED WORK

Breast Cancer Journey

Cancer journeys vary in many ways depending on the type, stage, and severity of the cancer. These factors influence patients' treatment plans and their associated side effects. However, Hayes, et al. found common phases which many journeys share: screening and diagnosis, initial information seeking, acute care and treatment, no evidence of disease, chronic disease and disease management [7]. As a patient moves through these phases, their needs change along with the challenges they face.

The first two phases occur during and immediately following the cancer diagnosis and include "rapid and aggressive searching for information [7]." In these early phases of the cancer journey many patients face increased stress and uncertainty [23]. These emotions can act as a barrier against the patients engaging in information seeking activities, as the amount of information can feel overwhelming and unmanageable, hindering overall information seeking effectiveness [25].

During acute care and treatment the need for health information management continues. Patients must balance appointments with multiple providers, cope with various side effects, receive little time to speak with oncologists [7] and struggle to obtain details about their health status [26].

Upon completing treatment, breast cancer patients will often either show no evidence of the disease or, when that is not possible, will move into chronic disease management. During this time, quality of life becomes the emphasis, with patients often focusing on health promotion and coping with lasting emotional challenges [2].

In examining the cancer journey, we can see that breast cancer patients have a range of fluctuating needs, a subset of which we discussed here. Since these needs can change and multiply in response to a patient's health situation, we wanted to develop a tool that patients could customize and extend throughout their journey.

Cancer Navigation

To help address some of the challenges facing cancer patients, cancer navigation organizations have been developed in the United States with the goal of facilitating patients as they progress through their cancer journey. These organizations, which typically exist outside of the conventional healthcare system, consist of trained professionals who help patients obtain resources to address emotional, financial, and logistical challenges often overlooked by the traditional medical system [10]. These resources can include counseling, insurance and social security application assistance, and answers to medical questions. Navigators often provide patients with individualized support throughout their treatment [5], and thus develop close relations with patients providing them with extra social support. Our previous work with cancer

navigators details the benefits of working with cancer navigators when conducting technology deployments for cancer patients [10]. Cancer navigators are ideal partners for deploying technology into the field due to their expert knowledge of patient needs and their existing framework for meeting, working with, and developing relationships with cancer patients in their local community. We draw on this partnership throughout our study, leveraging navigators in the design of the technology, as well as employing them as conduits between the research project and the cancer patients.

Mobile Health Tools in Cancer Care

Several research projects have examined the utility of mobile tools in supporting breast cancer patients. One such project used mobile phones to present patients in a hospital with up-to-date information on their health and treatments [20]. The study found that the increased awareness helped to reduce feelings of anxiety while empowering patients to take a more active role in understanding their healthcare.

The Healthweaver Mobile project provides another example of the potential benefits of using mobile technology in cancer care [14]. Klasnja, et al. presented breast cancer patients with a website and smartphone application, and found that the mobile tool improved patients' confidence in their ability to manage their own health information, by allowing them to access necessary health resources at any time or location.

The ability for technology to successfully support the information management needs of cancer patients was a significant motivation for our study. Inspired by the Healthweaver Mobile project, we expanded on this work by providing patients with a suite of health applications, several of which support unanchored information work such as information capture and retrieval tools and information seeking tools. Further, we utilized a strong local healthcare partnership throughout the design and implementation of the technology. Finally, during our study we allowed for personal uses on the tablet outside of a health context.

Personal Health Records

One of the main technologies designed to help with health management activities are personal health records (PHRs). PHRs provide a single location for capturing and storing information about one's past care [24]. Several benefits are expected to be gained from the adoption of PHRs, including improved patient-provider communication and increased patient engagement in their own health. However, to date, PHRs have not been widely adopted by stakeholders in the US healthcare system. Studies of PHRs and industry reports indicate a rapid drop-off of PHR use after initial introduction [11]. The speculation is that the overly clinical PHRs are not considered relevant by patients in their daily health tasks [6,17]. Our study aims to provide a snapshot of a related tool early in its adoption / rejection phase.

HEALTH SYSTEM PARTNERSHIP

One goal of this study was to develop a tool that could be supported through the patients' health system. We worked with several types of health professionals throughout the design phase of the My Journey Compass tool, allowing us to utilize the expertise of professionals who work with cancer patients daily. The health professionals included oncologists, cancer navigators, breast cancer survivors, and the director and executive director of two local cancer care centers. This collaboration ensured that we selected useful and reputable resources for the tablets that were relevant to participants' local cancer care system. For instance, we provided participants with the names and contact information for their doctors and for the navigation organization directly on the tablet. Utilizing the healthcare partners in the tablet design, we developed a tool that could support the full range of expected breast cancer challenges, while also employing the strengths of the existing health system and local resources (such as the cancer navigation organization).

Collaboration with Cancer Navigators

In addition to using the healthcare partners in the design of the tablet, we also worked with them throughout the deployment of the technology. We believed introducing the project through representatives of the healthcare system would be important in demonstrating to participants that their healthcare teams supported this tool. We hoped that deploying My Journey Compass in this manner would encourage patient trust in the technology and its informational resources.

Cancer navigators became the key stakeholders responsible for introducing breast cancer patients to My Journey Compass. Using cancer navigators for this purpose was appropriate for several reasons. First, we were already working closely with the navigation organization and had developed close relationships with the navigators. Second, our previous work with the cancer navigators indicates that they could contribute to successful technology deployments due to their close relationships and expertise in working with cancer patients [10]. Finally, navigators meet with patients at the time of their diagnosis, so the introduction of the research fit easily into these existing meetings. Thus we determined that navigators would introduce the study to patients and present those who would like to participate with their My Journey Compass tablet.

Creation of the Education Navigator Position

In developing the process of introducing the research to patients, we discovered that certain aspects of the project would fall outside of the responsibility and abilities of the current navigators. When patients acquired their tablet, we needed to present them with formal training and a point of contact should problems or questions arise. Since this training would need to occur soon after a patient's diagnosis, both the researchers and navigators agreed that

someone within the navigation organization would best serve these responsibilities. This decision led our collaborators to create a new position for education navigation.

The education navigator was given the responsibility of providing a one to two hour training session for each new participant. In addition to providing an overview of the applications and functionalities on the tablet, the training was important in providing a level of customization not yet seen in mobile health tools. The education navigator was able to talk to patients about their questions, concerns and goals, and to show them how the tablet could be used to address those specific issues. The education navigator also provided participants with a single point of contact for any technology-specific questions that arose after training.

While this paper focuses on the patients' adoption of My Journey Compass, we also note the importance of the healthcare system changing to support the distribution and upkeep of the tablets. Given the scarce resources available to the navigation organization, we value their early adoption of this approach. Introducing participants into the project via the cancer navigators allowed us to be particularly sensitive to participants' needs. The weeks following a cancer diagnosis can be a difficult and emotional period. Navigators are experts at working with patients during these arduous times, building close relationships with patients, and providing constant support. By having navigators introduce the tablet and train patients, we were able to utilize the navigators' expertise, provide technology support to patients through an organization they already knew, and avoid overwhelming participants by asking them to speak with researchers so early in their cancer journey. As we will discuss later, the development of the education navigation position exemplifies the ability for HCI research to directly enhance healthcare practices.

METHOD

Our goal for this project was to develop a health management tool that patients could easily embed into their regular daily routines. The work leading to this deployment consisted of an assessment of patient needs, selecting features to be included in the tablet design, and recruiting patients to participate in interviews after one month of tablet usage.

Needs Assessment

To begin, we interviewed seven members of the local cancer navigation organization [10], as well as seven breast cancer survivors, five caregivers (family members or friends), and two oncologists in an effort to gain an understanding of patient needs. Interviews focused on current technology usage, points of communication in the medical treatment process, and the overall healthcare experiences of the patients from the time of diagnosis through the conclusion of treatment. Our informants discussed a large breadth of needs and priorities, which we

broadly classified as falling into one of three categories: access to essential resources (such as transportation, food, and health insurance), support for emotional and spiritual wellbeing, and guidance surrounding health information. This insight guided the My Journey Compass design, as we aimed to provide features on the tablet that would address these three overarching needs.

Tablet Description

Through the design process with the healthcare partners, we selected a suite of applications, PDF informational resources, and websites deemed useful for breast cancer patients (Table 1). We deployed a seven-inch Android tablet (the Nexus 7) for two reasons: the portability of the device allows patients to have it with them all the time, supporting health information management away from the home; and stock android tablets provided a clean user experience that gave patients the ability to easily customize and personalize their tablet experience. We encouraged patients to add or delete applications of their choosing.

Recruitment

Participants were recruited into the study through the cancer navigator's organization. Due to our partnership with the navigators, recruitment occurred immediately after patients' first treatment consultation with their oncologist, as navigators are typically present at this meeting. Patients received the tablet from their cancer navigators and were encouraged to use it any way they wished, with no restrictions. Upon receiving the tablet, participants set up a training session with the education navigator, which typically occurred one to two weeks following the initial consultation. After approximately one month of tablet usage, the research team conducted semi-structured

interviews with participants to explore their initial tablet usage. Upon completion of the interviews, we used an iterative inductive analysis to uncover themes around usage patterns and motivations for technology adoption. We transcribed the interviews and segments of the transcripts were clustered to further develop these findings. Members of the research team then reviewed the segment clusters and verified each of the themes.

Participants

We interviewed twelve breast cancer patients, eleven female, each of whom had possessed the tablet for at least one month. Four of the participants were in the middle of their treatment at the time of deployment; the remainder received the tablet upon diagnosis or as part of their first appointment with general surgery. Participant ages ranged from 39 to 80. Patient diagnoses and treatment plans varied. All participants were receiving care at one of the local cancer centers.

FINDINGS

In this section we describe the usage habits of the participants. First, we present the most common ways participants utilized the tablets. We then discuss factors that motivated participants to adopt the technology.

Nine of the twelve participants used the tablet regularly, employing both preloaded resources as well as applications added to the tablet by the participants themselves. Three of the participants reported low usage of My Journey Compass. These participants described having an initial interest in the tablet upon first acquiring it, but described no subsequent use.

PDF Resources		Applications	
2011-2012 Breast Cancer Facts and Figures	Nutrition for the Person With Cancer During Treatment: A Guide for Patients and Families	After Diagnosis: A Guide for Patients and Families	Exercises After Breast Surgery
After Diagnosis: A Guide for Patients and Families	Sexuality for the Woman With Cancer	Breast Cancer Detailed Guide	Fatigue in People With Cancer
Breast Cancer Detailed Guide	Snapshot of Breast Cancer	Breast Cancer Dictionary	Keep (note taker)
Breast Cancer Dictionary	Surgery Choices for Women with Breast Cancer	Breast Cancer Overview	MyFitnessPal
Breast Cancer Overview	Survivorship Nutrition Guide	Breast Reconstruction After Mastectomy	Nutrition Facts
Breast Reconstruction After Mastectomy	Talking With Your Doctor	Calendar	Paced Breathing
Exercises After Breast Surgery	Understanding Chemotherapy: A Guide for Patients and Families	Cancer.net	Personal Email Inbox
Fatigue in People With Cancer	Understanding Radiation Therapy: A Guide for Patients and Families	Caring Bride	Power Grid
Inflammatory Breast Cancer	What You Need to Know About Breast Cancer	Contact Widgets (3-4)	Relieve Stress
Lymphedema: What Every Woman With Breast Cancer Should Know	Your Guide to the Pathology Report	Dictionary	Wifi Shortcut and Finder
NCCN Guidelines for Patients			
Bookmarks		Cancer Navigation Resources	
ACS: Breast Cancer	Facebook	Wikipedia	Cancer Navigators Brochure
National Breast Cancer Foundation	Pinterest	Camera Starter for Nexus 7	Caring For the Caregiver Flyer
BreastCancer.org	Youtube	Photo Gallery	Why You Should Visit Cancer Navigators
ChemoOrders.org	Pandora	My Library	Retreat Brochure 2012
Herceptin 2	Flipboard	What's this song? widget	Sustainable Wellness Brochure
My Journey Compass YouTube video	Angry birds	Google Play store	

Table 1: List of Features Preloaded on the My Journey Compass Tablet

Relaxation and Entertainment Tool

One of the most common, yet unexpected, uses of My Journey Compass was as a relaxation and escape tool. Patients used Pandora, online books, preloaded stress relief tools, and a variety of downloaded games to relax. Eight participants reported using the tool to help them alleviate anxiety:

"This is something you can just sit and do. And it takes away some of the anxiety. It keeps you from thinking What if? What could? Should I?" – P8

Although using the tablet to relax was a common theme, the times when participants would use the tool as a calming mechanism varied. Two participants discussed taking the tablet to chemo to help them pass the time:

"One of the best things about it was being able to take it to chemo and have it and plug in my earphones and if I wanted to listen to music or if I wanted to read a book or whatever it is. It just made the whole thing a lot more relaxed and easier." – P6

Using the tablet to relax during chemotherapy not only highlights the importance of providing patients with mobile tools, but also suggests that treatment may impact patterns of health technology use. In addition to chemotherapy, three patients discussed using the tablet while waiting in doctor's office in order to pass the time:

"In the doctor's office, instead of just waiting there with nothing to do I would get on there and check email or go on the Internet." – P3

Participants discussed various ways in which they could relax using the tablet. Many of the relaxation tools (such as the online books and games) did not come with the original tablet setup, but rather were applications participants downloaded for themselves. Support for relaxation is one of the most significant ways in which providing a flexible and customizable health tool for patients was useful for them. If patients were solely provided the applications included in the My Journey Compass suite, this usage pattern may have never emerged, and yet it was a pattern adopted by nearly all of the participants who used the tablet during treatment. Allowing patients to customize other health management tools may help researchers identify additional unforeseen benefits of such tools.

Personal Uses

Even though participants received the tablet from the health system as a health tool, they were encouraged to use the device in any way that they wished, without restrictions. This flexibility led seven of the participants to engage with the device for personal reasons above and beyond their use of the tablet as a health tool. They discussed numerous ways in which they used the tablet in daily life:

"I used it at church one time, to take notes from the pastor, and it picked up his voice." – P1

"I've done YouTube, I have Flipboard, I use that a great bit. Oh I have to show you [a picture of] my grandson!" – P8

While participants already used the tablet in a wide variety of personal ways, some discussed new ways they would want to use the tablet in the future. For example, one of the participants is a music teacher, and thought the tablet could be used to record her student choir once classes resumed in the fall. With such a wide range of personal uses and potential future applications, the role the tool plays in participants' lives can vary over time. Personal uses may help alleviate the novelty effect of the technology and keep participants engaged.

Tool for Supporting Others

Although less common, two participants shared stories in which they accessed the tablet to help others with their health needs. While this did not come up in conversations frequently, these powerful stories show the importance of making mobile health technologies available to those with chronic diseases. The first participant who mentioned helping others through the tablet used the nutrition application to support family members with diabetes:

"Diabetes is strong in my family... [The nutrition application] has a list of food with no sugar, low carbs, you know. I have a niece that's diabetic. And I said 'look sweetie, when you go to the store look at what you can get, what you can't get.' She said, 'I didn't know that information was out there aunty.'" – P1

In the second occurrence, our participant talked about her best friend, who was diagnosed with breast cancer two weeks before the participant received her own diagnosis. The participant was able to use share the resources on the tablet with her friend:

"I have a best friend diagnosed two weeks before I was, my best friend... she'll have questions and I'll say 'well let me check that.'" – P8

These uses begin to show a new way in which health tools can enhance empowerment and strengthen a social support network. By being informed and having easy access to resources, participants were able not only to use the tools for their own health, but also use the tool to help guide others through their own health challenges.

Organization and Memory Aid

In talking with participants, we found several uses similar to those presented in other studies examining patients' use of mobile health tools. For instance, seven of the participants used the tablet as an organization and memory aid, primarily by calendaring and note taking. Other studies working with breast cancer patients also noted participants' desires to be able to quickly and easily capture notes, appointments, and other important information with mobile tools [13], especially since forgetting important medical

information is a significant problem for cancer patients [21]. Our participants discussed being more on time to, and informed during, doctor appointments. This result helps demonstrate that mobile health technologies may be able to directly impact the quality of care provided to cancer patients by providing important reminders for patients that can increase attendance at medical appointments, treatment adherence, and other health behaviors [16].

Communication Support with Doctors

Another benefit of the tablet discussed by six of our participants was supporting patient-doctor communication both during and after appointments. Other studies providing cancer patients with the ability to electronically share health information with clinicians found improvements with patient-clinician communication, with patients sharing more information with the clinicians [3,4]. The Healthweaver project also found improvements in patient-doctor communication as the mobile technology allowed participants to answer clinical calls while away from home and provide more accurate health information during clinical visits [15,19].

In our own study, participants specifically discussed feeling prepared and confident when speaking with their health providers, demonstrating the empowering impact a health tool can have for patients. Many participants also discussed feeling less worried after an appointment because they were able to review parts of discussion they had recorded that they were unable to process or understand during the actual conversation.

Enhancing Support System Communication

Our formative interviews with patients, as well as prior studies [8,16], found the importance of social support for cancer patients. Seven participants discussed using My Journey Compass to communicate with their family and friends. Several participants mentioned that being asked questions they could not answer triggered them to use the PDF resources. In addition, participants discussed recording doctor appointments and sharing the audio with caregivers who could not attend the appointment. Using the tablet in this manner indicates that the technology may have lasting impact on users. Facilitating social support can play a significant role in healthy behavior change [12] and can lead to improved health measures, such as lower hospital readmission rates [16].

FACTORS INFLUENCING ADOPTION

Nine out of twelve of the participants actively engaged with My Journey Compass. To fully understand whether this technology could improve the cancer care experience for breast cancer patients, we examined participants' motivations for adoption and found that certain system design features significantly influenced usability and utility of the tablet.

Customization

In order to make the technology customizable, we provided features, Google Play being one, which would allow for exploration and discovery of new applications. Patients were not specifically trained on using this application, but they were told that they could use the tablet however they liked. Device customization enabled new and unexpected uses of My Journey Compass to emerge. We found that when participants customized the tablet, it was entirely for personal reasons i.e. several participants' downloaded games, books, and photos to be used as relaxation aides. This type of unexpected outcome reinforces the importance of allowing patients to modify their health management tools.

Another trend we found across all nine of the participants who used the technology during treatment was that health was always a gateway into personal use and customization. No participant adopted the tablet as a personal device before using it as a health tool. This finding could be important for keeping users engaged with health tools once the novelty of the health device fades. By providing a tool that shifts between a health and personal device, participants may be, over the long term, more likely to return to using the tool for health purposes should the need arise. We expect this behavior might occur as a result of participants continuing to use the tool and thus would still have the technology readily available and integrated into their daily lives.

Designing for customization in health management tools allows patients to modify the tool freely as new challenges arise in their lives and in their treatment. It also affords researchers the ability to gain a deeper understanding of the needs of breast cancer patients by monitoring usage of customizable tools. The ability to modify technology allows My Journey Compass to remain relevant and useful to patients as new healthcare applications and resources become available to patients over the course of their treatment. Further, the personalized nature of the tool may allow it to be useful upon completion of treatment, affording patients the ability to revert to using it as a health tool should the need arise.

Mobility

Participants used My Journey Compass in a large variety of locations. Being able to take the technology to chemotherapy helped the participants relax during treatment. The tablet provided a mechanism for participants to easily capture and retrieve questions for their doctors, thus enhancing the quality of their discussions and improving both the participants and providers satisfaction with the experience. Several participants who used the tablet during travel felt more confident by simply having their doctors' information readily available. These particular uses begin to show a relation between tablet usage and treatment. Through a better understanding of how treatments impact health management technology

usage, tools may be designed to support patients through specific care plans.

Coming into this project we knew from our formative work and related studies that mobility would be an important element for helping breast cancer patients. We were surprised to find the broad range of ways mobility initiated increased usage. The portability of the tablet proved important for helping participants ease their mind during treatments and empowering participants to travel.

Balance of Information

All of the participants who used the tablet at some point used it to investigate health information. The tablet allowed for efficient information retrieval for patients who engaged with the preloaded resources. Because cancer affects people in different ways, one of the most common information seeking activities was looking up side effects and impacts of treatment, especially for chemotherapy and radiation. When discussing with participants their preferred resources for information seeking, we found they most frequently used the PDF resources that came preloaded on the tablet. Participants discussed trusting these resources more than information they could find online because the PDFs came directly from their health providers.

When speaking with participants about why they first began to use the tablet, the desire for as much information as possible without feeling overwhelmed, motivated participants to use the tablet. Typical resources for breast cancer patients come in the form of loose papers and pamphlets or large binders. Many participants described sorting through the vast amount of paper-based information as an overwhelming and negative experience:

"When you first hear that diagnosis you are overwhelmed... [The doctors] are great but they are all the time just handing you, especially for your first couple appointments, just handing you all kinds of paper and information. You go home with this bag of stuff and you're like 'I don't even want to look at this right now.'" – P6

"I had to compartmentalize everything because I could see I was going to be overload. And when you do that I think your whole positive attitude just crumbles." – P9

While many participants agreed that receiving such a large amount of information was overwhelming, many of these same patients also discussed a need for more information to help them cope with their diagnosis:

"When you first get diagnosed you want to find as much information as you can, or I did... the more information you get, it helps you through it." – P2

"I was thrown quite a few resources... but at the same time there's no impact particularly. You get so much that the knowledge is hard to assimilate... I felt a little on my own." – P12

The tablet improved the presentation of information by sorting informational resources into labeled PDF files. This organizational strategy helped participants easily find information when they wanted it, but the resources were also easy to ignore when they were not needed. One patient compared the tablet to the paper resources and described how the tablet helped her find specific health information:

"In the beginning you get all this information. Every doctor gives you information. To go through it and read all that is exhausting... but for some reason when you pull it up here it's not... You find what it is you really want to know and you pull that up, so you don't have to weed through a lot of other stuff. It's quick, and that's very helpful for me." – P8

By providing participants with information that was easy to find, organize, and manage, the tablet successfully engaged participants. This initial use often led to further exploration of the tablet features and adoption of the technology. Researchers and designers of future health technologies are faced with the challenge of providing patients with a robust set of resources that are beneficial but not overwhelming.

Privacy

In the interviews, several participants discussed their desire to keep their diagnosis private, mainly to avoid the added attention a cancer diagnosis brings. Two participants specifically discussed how people's reactions impacted them negatively:

"I became known as the woman with four children and a husband with brain cancer. I worked a long time to get that behind me and just be me. And then we had this [breast cancer diagnosis]." – P18

"To be real honest with you there are not a whole ton of people that have shared the fact that I even have cancer... Most people's response is 'oh my god' but I'm not one of those 'oh my god' people. That just makes me feel strange when they do that, so I just won't tell them." – P7

Although we had not focused on the issue of privacy during the design of the tablet, we found the technology helped the participants maintain greater discretion than was initially feasible without the tablet:

"You're sitting in an office and people know why you're there. Even if it's the general surgeon they know why you're there because you have the big cancer folder. So this is great because it's discreet." – P9

We found that privacy greatly contributed to tablet adoption. Participants were motivated to carry the tablet because the technology allowed them to bring their medical resources to public areas while maintaining discretion.

Factors Influencing Low Adoption and Usage

Three of our participants in this study reported low tablet usage. We define low usage as essentially ignoring or forgetting about the tablet with the exception of some initial

browsing upon first acquiring the device. Through our discussions with these three participants, we found each individual had a unique attribute that lessened their need for a mobile health tool. One of the participants had already battled breast cancer once and felt she understood much of the health information. The second participant worked full time as a nurse and felt she also had less of a need for the medical resources on the tablet. Since the information resources served as one of the key initial motivators for adopting the system, we would expect a participant with a lower need for information to become less engaged in the technology.

For the final participant, many factors may have contributed to the low usage. The participant already owned and carried many portable technologies, including an iPad, a Nook, and a smartphone, so the My Journey Compass suite offered few additional portability features that the patient found attractive. In addition, this participant was the sole man in the study and he discussed how the health information resources were less relevant to his situation:

"[Being a man] made finding information specific for me more challenging. There's plenty of information out there about breast cancer, but for men it's more limited. Examples of men who have had breast cancer would have been helpful." – P12

Thus, each for the three participants who did not adopt the technology reported that the technology, as an informational tool, was less relevant to their particular needs. Future research could explore how to better support patients with recurrent diagnoses, high levels of medical knowledge, and unique populations such as men in the case of breast cancer.

Frequent Computer Users

One unexpected outcome came from participants who already used computers in their daily work schedule. Although many of them did utilize the tool, participants also revealed one significant reason they did not use the tool more often:

"I sit in front of a computer all day and when I get home that's probably the last thing I want to do is turn on another computer." – P2

"I use a laptop all day at work, so I don't really want to be back on it. I get overdone with electronics." – P3

We were surprised to find that lower adoption of the technology occurred amongst workers who have already adopted technology into their lives and have high digital literacy. This finding presents a new set of challenges for those developing mobile health tools. How do we design health tools that do not feel like just another screen to stare at as our world continues to become filled with technology? Our system attempts to provide one potential solution, by combining health with a personal tool, but even this may not be enough.

Low Technical Literacy

Surprisingly, we found that self-perceived low technological literacy did not constrain technology usage or adoption. Many people described themselves as low-tech users and yet used the tablet frequently.

"I'm old, sometimes you have to run me through it two or three times." – P1

This same participant was one of the most frequent users of My Journey Compass. She discussed using the tablet in a variety of ways including calendaring, looking up nutrition facts, and shopping online. This may be in part due to the assistance of the navigators, who provided training tailored to participants' needs and interests and served as technology support.

DISCUSSION

My Journey Compass afforded participants the ability to engage with their health, their health providers, and their support networks by supporting a wide a variety of uses. This work extends existing studies of technology for cancer patients by exploring how patients adopt and utilize a customizable mobile tool for health and non-health purposes that is integrated into their existing health care system. Our study contributes a set of findings that enhance our knowledge of how breast cancer patients may be supported by technology and that are generalizable to the broader healthcare community. As we will describe, this work has directly impacted the existing healthcare system.

Generalizability of Findings

Our work specifically focuses on the needs of breast cancer patients in a rural Georgia community. Our findings, which examine common tablet uses, as well as the significant system design elements that increased the tablet's utility, build on knowledge of how breast cancer patients may use technology during treatment. Some original findings that contribute to the body of knowledge in this area include using the technology for personal reasons and for relaxing during treatment. We also found common uses that confirmed findings in other studies, such as the ability for technology to enhance patient-provider communication and help patients organize logistics and health information during treatment.

Many studies have focused on how patients use single healthcare applications. Our project addresses the need for patient-centered technologies to become more general-purpose tools. Considering both health and personal uses when designing technologies will allow patients to more easily access the benefits of health technologies while also supporting the natural transition between focusing on health and daily life. We expect such technologies to enhance the care provided to cancer patients as well as those managing chronic diseases, where holistic and integrative care plays a critical role in the overall healthcare journey [9,18]. Just as our participants incorporated their new healthcare practices

into their daily routines, so must health technologies fit within more ubiquitous technologies developed for daily use. Such fluid and dynamic health technologies could encourage patients to engage continuously in their healthcare.

Through this study, we provide one model for combining health and personal technologies that may be replicated for other healthcare domains. As technologies such as PHRs become more pervasive and supported by more healthcare clinics, integrating these new health tools into existing technologies will bolster the utility of such tools. Future work may examine the success of this model for other healthcare areas, as well as how PHR technologies may better incorporate design elements such as mobility and customization.

Obstacles encountered in our work also point to possible future research directions. Designing health technologies without causing “technology burnout,” a sentiment expressed by several of our patients, is one challenge. We also struggled with designing a tool that benefited our male participant, calling attention to the more general challenge of designing tools for minority populations in the broader healthcare area. These challenges indicate areas where future research contributions are needed.

Impacts to the Existing Healthcare System

This project demonstrates the ability for HCI research to directly change an existing healthcare system. In planning the research with the navigation organization, we decided that the recruitment and technology support would be best handled by a cancer navigator, in order to respect the emotional burden placed on newly diagnosed cancer patients. In order to accommodate the new responsibilities, the navigation organization developed the new education navigator position, thus, changing the institutional structure of the navigation system. The education navigator provided participants with technological support early in the study from an organization they already knew and trusted.

Utilizing navigation provides a new strategy for recruiting in oncology, a challenge for many researchers as little infrastructure exists to support recruitment for HCI studies. Working with organizations like the cancer navigation group allows researchers to respect the emotional challenges faced by a vulnerable population at a challenging time while at the same time gaining the trust of their participants.

In reflection, this change to the organization was largely possible due to our collaboration with the navigation organization from the onset of the research project. The early partnership allowed the navigation organization to feel a sense of ownership of the research and allowed us to create a solution that would benefit both the organization and the research. We have found that the additional navigator provides benefits to the healthcare system extending beyond our immediate study. Specifically, the

education navigator, who was hired due to her technical literacy, will allow the navigation organization to expand its own technology fluency. Such fluency will allow the organization to better support patients as patients incorporate technology in their healthcare, an outcome we expect to occur irrespective of this study’s implementation.

While this organizational change addresses a need specific to the healthcare system in which we were working, it also addresses the more general need for greater navigational support across the nation. Our work hopefully can act as a case study demonstrating the importance for researchers and healthcare practitioners to collaborate in an effort to enhance both the research and the healthcare systems.

CONCLUSION AND FUTURE WORK

To better understand the needs of breast cancer patients we deployed a health management tablet. Based on the high variety of uses and clearly defined motivations for use exhibited by participants, we feel many of the tablet features could be used to enhance future health management tools. Finding new methods for enhancing the support of breast cancer patients remains a critical area for the CHI community. Past studies suggest that patient engagement will be critical for improving future health outcomes, and that mobile health tools may provide the gateway necessary to directly impact chronic disease management and long-term health results.

Several of our findings were surprising; helping us better understand the opportunities for health management tools, and pointing to future research directions. For instance, the importance of privacy and the insignificance of technology literacy on tablet usage provided two unexpected findings. We also found that health usage served as a gateway to personal usage, which could be key to developing long-term adoption of technology, as patients may remain engaged with the device even during periods when they are less involved with their health management.

This study was designed to occur early in the My Journey Compass deployment as a means to understand initial patterns in adoption, adaptation, use and non-use. We will continue to work with these participants and additional recipients of My Journey Compass to understand their usage patterns throughout the various stages of their cancer journeys. Ultimately, we plan to work directly with the clinical teams to evaluate the influence My Journey Compass has on health outcomes.

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