

Lessons Learned From a Yearlong Deployment of Customizable Breast Cancer Tablet Computers

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ABSTRACT

Patient-centered technologies demonstrate great promise for users, however they often focus on solitary moments or singular tasks within a broader healthcare journey. We utilized a technology probe to investigate how patients managing long-term diseases use flexible health tools throughout their health journeys. Through a yearlong deployment, we provided 36 cancer patients with a suite of resources on customizable mobile tablets. The majority of our participants did engage with the technology throughout treatment and into survivorship. We analyzed participants' tablet adoption, usage patterns, and customization and describe how each of these influenced technology engagement and changes in use. Finally, we identified a set of lessons researchers can use to guide the design of future patient-centered technologies. Specifically, we discovered that customizable tools reveal insights into patients' goals and values, integrating health and non-health resources encourages participants to return to health resources when needed, and a need exists to expand our definition of health resources.

Categories and Subject Descriptors

H.5.3 Group and Organization Interfaces: computer supported cooperative work, Organizational design; J.3 Life and Medical Sciences: Health, Medical Information Systems

General Terms

Design

Keywords

Mobile health; Cancer; Patient-centered technology

1. INTRODUCTION

While mobile technology can help users with their health management in a variety of ways [8], existing resources typically focus on supporting singular tasks such as accessing health records or tracking a specific health goal or behavior. However the needs and goals of people going through complex healthcare

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journeys such as cancer can change over time, highlighting the need for more flexible, holistic tools. To explore the ability for technology to provide continued value to patients over time, we deployed a technology probe to examine how breast cancer patients utilize a suite of resources on a mobile platform as they progress through their extended healthcare journeys.

Over the course of a year we provided 36 newly diagnosed breast cancer patients in Rome, GA with tablet-based personal health management tools. The technology, named My Journey Compass, provides patients with a broad range of clinical and non-clinical applications, a customizable interface, and a suite of tools that are integrated into patients' existing healthcare system. We take an open-ended approach to the design and deployment of personal health technologies, allowing patients to customize the resources on their tablet and use the technology without restrictions.

To understand the potential for mobile technologies to support the needs of breast cancer patients' across their dynamic health journeys, we logged participants' use of their tablets and interviewed a subset of our participants about their experiences engaging with our mobile health tool. Our work contributes to the health and HCI literature in the following ways:

- We discuss motivating factors that led participants to integrate our technology into their daily lives.
- We describe participants' usage patterns and the insight these patterns provide into the various ways a flexible health tool may support patients' healthcare needs.
- We discuss the benefits of using a customizable platform for encouraging long-term engagement with a health technology.
- We identify lessons learned through this deployment to guide the design of future technologies aimed at supporting patients through their healthcare journeys.

Overall our work highlights potential benefits of designing flexible and customizable health management tools that afford easy adoption and appropriation to provide holistic support over the course of a breast cancer journey. This approach is in sharp contrast to the trend of siloed health tools that segregate managing disease from embracing life.

2. Related Work

Patient-centered health technologies demonstrate great promise for supporting patients' personal health management. For example, video blogs have helped chronically ill patients share and receive information about their health [9] and tablets have been used to improve patient satisfaction during hospital visits [16]. Supporting patients over time is particularly important when patients are grappling with chronic diseases such as diabetes, obesity and cancer.

2.1 Continuous Health Management in Cancer Care

Health management proves especially important for those diagnosed with cancer, when treatment adherence is critical to survivorship. Side effects, stress, and lack of knowledge can all hinder patients' treatment adherence [2]. Health management and the responsibilities placed on patients are further complicated by the number of providers, family members, and friends with whom patients must share health information [14].

Fortunately, both in-person and technological support is emerging to help cancer patients through these health management challenges. Cancer navigators provide in-person support to patients with the goal of reducing barriers to care [12]. These trained professionals provide personalized care to patients by helping patients acquire necessary resources (including health insurance and counseling), answering medical questions, and providing emotional support [4].

While navigators strive to provide a range of patient support, technology is beginning to offer complementary, ubiquitous aid. Mobile tools in particular have proven beneficial to patients, as they afford the ability to access resources anywhere at anytime. Such tools can be particularly useful for patients undergoing cancer treatment, as patients often need to record issues or questions that come up when they are away from home or their treatment facility [6]. Further, technology can help patients monitor their health over time [11,13], providing them with a valuable alternative to relying solely on their memory, which is particularly challenging during chemotherapy [13].

Previous research has shown that patients benefit from mobile health technologies that combine multiple health focused applications, including calendars, notes, and personal health information. One evaluation found that many patients preferred using a mobile application over the equivalent functionality on the web and used additional features on the mobile tool, such as sending photos through email [11]. In addition, the Healthweaver mobile project demonstrated how a smartphone application that allowed patients to complete a variety of health related tasks increased cancer patients' confidence in managing their health [7].

Personal health records (PHRs) also aim to support patients' health management. While PHRs allow patients to continuously record and track important health information, we have yet to see large adoption of this technology into people's daily lives. The low adoption is thought to be due to the inability for PHRs to support many activities patients use to manage their healthcare, such as quickly capturing notes or questions, as well as the perception of the technology being overly complicated [10].

While technologies are instrumental in supporting patients through specific health challenges, research has yet to examine how patients use health technologies over an extended healthcare journey and how their usage changes over time. In this work, we provide participants with a suite of relevant applications in an effort to understand how technology use changes with patients' dynamic needs and healthcare experiences.

2.2 Breast Cancer Journeys

In an effort to explore technology use during a healthcare journey, we specifically examine technology use by breast cancer patients from the time of diagnosis through survivorship. Over the course of a breast cancer journey, patient needs change many times. The breast cancer journey typically comprises clinical events such as surgery, treatment (chemotherapy or radiation), and survivorship. While patients often focus on obtaining health information

initially after diagnosis and in the beginning of treatment [1], many patients will transition to focusing more on their personal lives as treatment schedules change their "normal" daily routines [3]. Thus we can see patients refocus their priorities during and after treatment to include coping with side effects and managing personal relationships. As patients move from receiving active treatment for their breast cancer into survivorship new challenges arise, such as how to reduce the chance of a disease recurrence.

Understanding patients' priorities at different phases of the cancer journey underscores the importance of providing patients with dynamic and flexible tools that adapt to patients' changing situations. We aim to gain insight into the opportunities for flexible patient-centered tools to engage patients throughout the various phases of their healthcare journeys.

3. Methods

3.1 Tablet Design

For this study, we used tablet computers as a probe to explore how breast cancer patients would use technology to support their health over time, and how their usage would change. The My Journey Compass tablet consists of a suite of useful applications and resources specifically selected to support breast cancer patients in the cancer journey. To assemble these resources, we collaborated with health professionals in the Rome, GA community, including oncologists, cancer navigators, breast cancer survivors, and directors from two local cancer care centers. With this team, we identified a suite of PDF informational resources, websites, and applications that we then preloaded on each participant's tablet. Table 1 shows a summary of the resources that comprise My Journey Compass.

3.2 Recruitment and Training

Every individual diagnosed with breast cancer in the Rome GA cancer care system during the study period was offered the opportunity to participate in our research efforts. Participants who chose to enroll in the study received a My Journey Compass tablet at the time of diagnosis. The local cancer navigation organization, a non-profit group consisting of 6 healthcare professionals with backgrounds in nursing and social work, played an integral role in the deployment of the My Journey Compass tablets. Specifically, newly diagnosed patients were introduced to the project through the navigators, as the navigators were typically already present at patients' clinical appointments. Navigators introduced participants to the My Journey Compass project at their first meeting with their oncologist. At this meeting, the cancer navigators provided patients who wished to participate with a tablet.

The cancer navigation organization employed an education navigator who was responsible for training participants on how to use the tablet and providing technical support for the patients. The education navigator held a 1-2 hour training session with each participant a week or two following their initial introduction to the program. Post-training, participants were able to use the tablet freely and were provided with the education navigators' contact information for technical issues or questions.

Once enrolled, patients were given the tablet computers to keep indefinitely and could add or delete applications and content to the tablets as desired. This freedom and flexibility for our participants allowed us to run a deployment that closely matched how patients would use resources on their own technology, giving us insight into how people's personal technologies could be used as health tools.

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

Table 1: List of resources included on the My Journey Compass tablets

3.3 Participants

We monitored tablet usage of 36 patients diagnosed with breast cancer (Stage 0 through 3) between August 2013 and March 2014 through the Rome health system. 35 participants were female and one male. Participant ages ranged from 24 to 80 years old (M=60). Participants on average had the tablet for 310 days, with a minimum of 170 days and maximum of 365 days. 36 patients declined to participate (50%), often because they felt overwhelmed by the diagnosis.

3.4 Analysis

Two researchers analyzed participants' use of the technology from the time they received the tablet until September 2014. Each tablet included an application tracker that logged the application name, the date and time the application was opened, and the duration of time for which the application was used. While we logged the launching and closing of individual applications, we did not track activity within applications, such as search terms or social media posts. Using an iterative thematic analysis, the researchers examined the data with a specific interest in understanding how participants used the tablet throughout treatment and into survivorship.

In order to gain additional context around the usage logs, we interviewed participants about their healthcare journeys and tablet usage. We interviewed 25 participants at various points in their breast cancer journeys, including one month after diagnosis, during treatment, and upon completion of treatment. These interviews help provide insight into how personal and clinical factors influence technology usage behaviors.

4. FINDINGS

Collectively, 36 participants used the tablet for 2,316 hours. On average, participants used the tablets for 2.6 hours/week. We captured 40,884 distinct instances of application use, across 239 unique applications. We found participants used the tablets for a wide variety of purposes including finding personally relevant health information, playing games, organizing schedules and appointments, communicating and sharing information with friends and family, recording questions for future doctor appointments, and finding health information for others [5]. 29 of the participants utilized the tablet regularly, often using the tablet daily and with gaps in use lasting less than two weeks. 14 participants continued to use My Journey Compass after completing active treatment. Through an analysis of usage logs and participant interviews, we examine participants' motivations for this lasting engagement with the technology. Our analysis of tablet adoption, usage patterns across treatments, and the role of customization demonstrates how the My Journey Compass tablets supported patients' needs throughout treatment.

4.1 Tablet Adoption

Early interviews with participants revealed three main motivations for initially adopting the technology into their daily routines: mobility, privacy, and the ability to compartmentalize information. Subsequent interviews revealed that these motivators also influenced continued use of the My Journey Compass tablets. Mobility provided one motivator for adoption that many participants discussed. Participants often shared that they would keep the tablet with them, taking it to doctor appointments, treatments, and everyday errands. One participant stated that she specifically enjoyed taking the tablet with her during long chemotherapy sessions: "In chemo I would play little games on it



Figure 1: Usage data for the four participants who used both the tablet (shown in grey) and health resources (highlighted in black) regularly

just to make the time go by. And that was good, because two and a half hours gets a little boring.”

The privacy provided by the technology also motivated participants to use the tablets in their daily lives. When breast cancer patients are diagnosed in the Rome health system, they typically receive a large binder of information about their disease and the health system. As one participant shared, she felt more comfortable looking up information on the tablet because people in the doctor’s office waiting room were able to identify cancer patients from their “big cancer folders.”

The ability to compartmentalize medical information provided another motivation for adoption that participants typically discussed during interviews. The vast amount of information on breast cancer often overwhelmed participants. As one participant shared, she looked up information about her treatment and medicine, and then purposefully avoided cancer resources because she did not wish to “agonize” over her health. Looking up information in the organized PDFs allowed participants to focus their searching on personally relevant details. One participant shared how the informational resources helped her find important medical details regarding both her medical history and her family’s: “What I really like about the tablet, because of the type of cancer that I had I really didn’t have a lot of knowledge in that area... so I went in to some of the information on different types of cancer and actually did some research on breast cancer and the kinds of cancers that my folks and my brother had. And that gave me some knowledge that made me feel a lot more comfortable about the decisions we were making about how we were going to handle my breast cancer.”

While the interviews with participants revealed several motivations for adopting technology, they also highlighted

barriers to adoption. Specifically, two participants who used computers regularly throughout the day for work shared that they preferred not to use the tablet regularly. Despite their comfort using technology in their daily lives, these participants indicated a desire to avoid using technology outside of work due to feeling overwhelmed by the amount of time they already spend “looking at a screen.”

Surprisingly, low technology literacy did not prevent participants from engaging with My Journey Compass. One participant, for example, described herself as someone who is “not as technology oriented as I would like to be.” However, when asked to describe her tablet usage, the same participant listed a surprisingly wide range of tablet features she had utilized: “I can go online, and I can download books, and certainly go on Google, check my email and set the calendar. I can go in settings and get connected to Wi-Fi in different places. I’ve checked into my Healthvault some. And I’ve sent information to doctors... I’ve used the calculator a time or two. I’ve looked at the clock and the dictionary.” Another participant who rated her technology literacy as a 1 on a 5-point Likert scale has used the tablet thus far for a total of 179 hours, the fourth highest usage across all participants. These experiences help demonstrate how perceived low technical literacy does not always impede actual utilization of technology in daily life.

4.2 Utilization Throughout the Cancer Journey

In examining how each participant’s tablet usage changed over the course of their cancer journey, we found three common usage patterns emerge. Four participants used the tablet including the health resources regularly, with fewer than 2 weeks between uses (figure 1). Twelve participants used the tablets and health resources periodically, with frequent use for several weeks

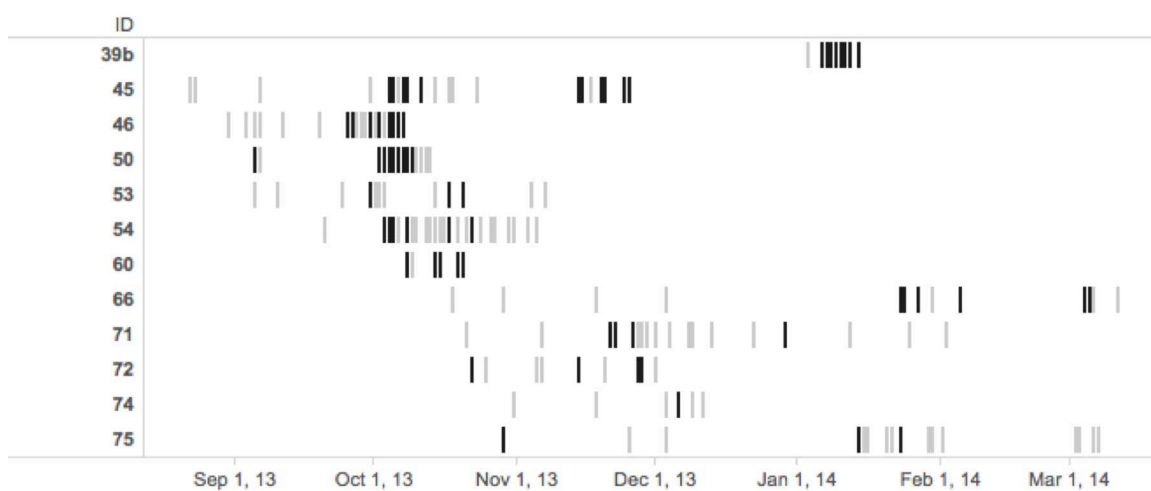


Figure 2: Usage data for the twelve participants who used both the tablet (shown in grey) and health resources (highlighted in black) infrequently

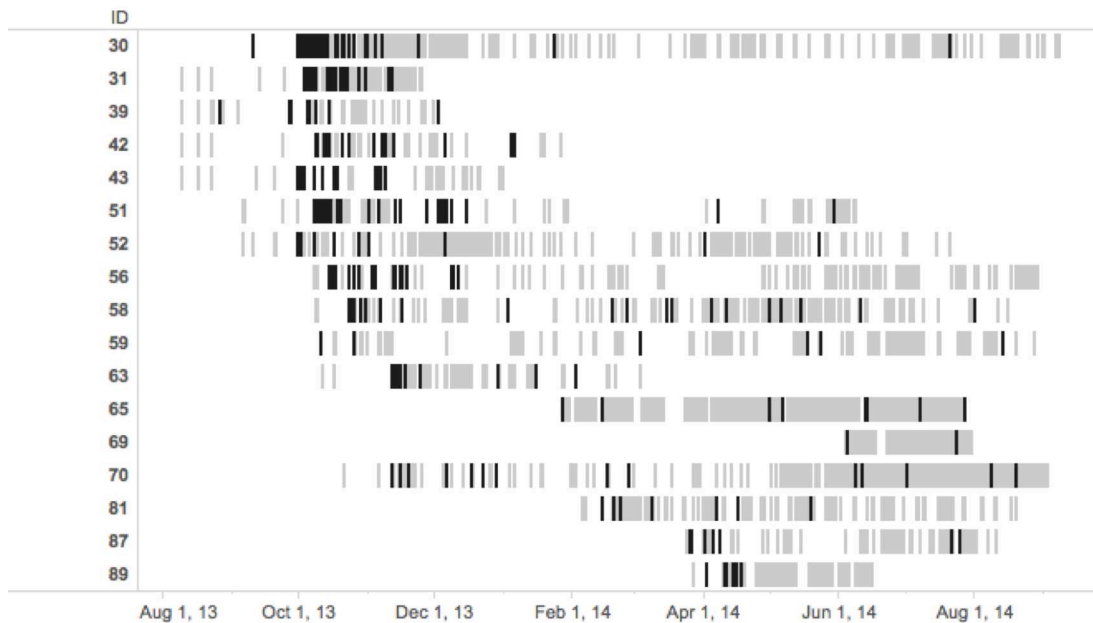


Figure 3: Usage data for the 17 participants who used the tablet (shown in grey) regularly and the health resources (highlighted in black) sporadically

followed by several weeks of no use (figure 2). The most common pattern, seen across 17 participants, consisted of regular use of the tablet with sporadic usage of the health resources (figure 3). The figures below show each of these usage patterns, helping to differentiate the types of tablet use we saw across participants. To better understand what led to these different patterns, we asked participants once they completed treatment to reflect on their tablet usage.

The post-treatment interviews, paired with the tablet usage logs, validate our initial hypothesis that integrating health and non-health resources would encourage participants to utilize and return to the health resources when needed. One participant described how she continued to use the tablet for personal reasons once her treatment was complete, but returned to use the health resources on multiple occasions to look up information for others. She used the tablet to look up information about her friend’s Melanoma diagnosis and to help her husband prior to his open-heart surgery. Another participant shared that once her treatment finished she stopped using cancer specific applications, as she wanted to focus on her future and more positive aspects of her life. However, she also stated that she would expect to use the tablet’s health resources if her clinical treatment plan changed: “I’m going to use [the tablet] more for other things than research on cancer stuff. Unless they say ‘you have to do a new treatment’, then I’ll go and research that.”

This trend in which participants utilized health resources when needed because of their engagement with the device points to the ability for the combination of health and non-health resources to encourage greater use of the health tools. The experiences of our participants highlight the need to consider how health resources may be better personalized and seamlessly integrated into people’s daily lives through tools that encourage daily use for health and non-health purposes.

4.3 Role of Customization

A unique aspect of this study was the use of an open platform that patients could personalize. Thirty-five participants added

applications to their tablets, on average adding nine applications (ranging from 0 to 32). In total, 178 unique applications were added to the tablets. Entertainment applications including Candy Crush and Amazon Kindle, as well as the Bible were the most commonly added applications, added by 10, 9, and 7 participants respectively.

The ability to add applications proved valuable to many participants as they could add personally meaningful resources. For example, several participants shared that they added photographs of family members onto the tablet. Religious applications were also frequently added. 13 participants added 16 different religious applications, such as the Bible and Gospel Library.

The addition of religious and other personal applications begins to demonstrate how technologies such as the My Journey Compass tablet may assist patients not only through their clinical treatments, but also by supporting their personal well-being. Existing literature highlights the number of psychosocial challenges cancer patients face and call for research to focus on improving patients’ psychological wellbeing [15]. The use of customizable platforms provides one way in which technological interventions may support patients’ clinical and emotional needs. Further, researchers may learn a great deal about participants’ values and needs by employing the use of customizable tools.

Interestingly, while patients added entertainment and religious applications, no participant added cancer specific applications to the tablets. However, our interviews revealed that entertainment and other non-health applications served underlying and unexpected health purposes. Several participants discussed using games, books, and music as a way to stay calm during the stress of receiving chemotherapy treatments and to improve their emotional wellbeing during particularly stressful moments. In addition, one participant revealed that she used the tablet to support her transition to an all vegan diet, often relying on YouTube videos for recipe ideas. Social media became an additional health platform, with one participant sharing: “I used [Facebook] as a teaching tool. What I found I would share with

other people and refer them to the websites I would use.” These examples demonstrate the ability for non-health resources, such as online games, YouTube, and Facebook, to serve underlying health purposes, demonstrating the importance of expanding our view of what constitutes a health resource.

5. DISCUSSION

Through the My Journey Compass project, we provided participants with a mobile, customizable tool that was integrated into their existing health system. Our goal was to understand how patients would use such flexible technology throughout their cancer journey. We found that utilizing existing resources sufficiently supported a variety of patient needs. Combining multiple resources on a flexible tablet interface not only engaged participants during treatment, but also continued to be used by participants as they transitioned into survivorship. Our analysis of tablet adoption, usage patterns across treatment, and the role of customization demonstrates the ability of the My Journey Compass tablet computers to successfully engage participants throughout their breast cancer journey. Through our findings we have identified a set of lessons learned to improve the design and implementation of future patient-centered technologies.

5.1 Lessons Learned

1. Integrating health and non-health resources encourage participants to return to health resources when needed.

As demonstrated through the My Journey Compass usage patterns, participants typically used the tablets for a variety of purposes, returning to health resources when needed. Changes in treatments, new health issues, and the goal of answering others’ health questions all motivated this return to using health-specific applications. We found that by providing a tool that supported participant’s holistic needs and interests, participants opted to use the technology regularly, affording an easy return to health resources when necessary.

2. Customizable tools reveal insight into patients’ goals and values.

Another finding from the My Journey Compass deployment is that customizable tools can provide significant insight into patients’ goals and values. In our project, patients’ use of games during chemotherapy and the addition of religious applications highlight the importance participants placed on emotional wellbeing throughout their cancer treatments. This customization can help reveal unintended benefits of health tools, and provide strategies for improving patient engagement. These insights regarding patient’s personal goals and values may prove particularly valuable for researchers and providers who wish to develop holistic healthcare innovations.

3. We must expand our definition of health resources.

Our interviews with participants revealed surprising ways in which applications that are not typically considered health-related in actuality supported participants’ health and wellbeing. The use of games to reduce stress, YouTube to find recipes, and Facebook to share health information with friends and families all exemplify this finding. These examples suggest that valuable health uses may be found in a broader array of tools and resources than typically examined. While many tools such as PHRs focus specifically on medical care, to fully understand the opportunities for technologies to support and empower patients we need to broaden our scope and examine how patients utilize technology

more generally to support their health and wellbeing. By doing so, we may gain a deeper understanding of how society integrates health into their daily lives and how such technological integration may be improved in the future.

6. Limitations

Our study was constrained by several limitations. We specifically focused on breast cancer for this study, and expect that a focus on other cancers and chronic diseases would reveal different results based on the obstacles patients face in their specific healthcare journeys. Patient self-selection into the study also influenced our results, as several patients opted not to participate at the time of diagnosis, often due to the emotional burden of the diagnosis. Further analytical, randomized interventions could be useful to better understand how user and environmental characteristics influence usage of mobile health systems.

7. Conclusion

The My Journey Compass project consisted of a deployment of tablet computers preloaded with a suite of health, communication, and entertainment applications for breast cancer patients to use from diagnosis throughout treatment and into survivorship. The results of this technology probe suggest that customizable, mobile tools that integrate both health and non-health resources may contribute to users’ adoption and continued engagement with personal health management technologies. Such technology affords levels of privacy and personalization not often found with existing cancer resources, such as the large cancer binders our participants typically receive. Future research should continue to examine the ability for these factors to promote engagement with health technology.

Through an analysis of participants’ usage logs and interviews, we highlight three lessons that could benefit future research and technology development efforts, including the benefits of making tools customizable, integrating health and non-health applications into a single tool, and utilizing a broader definition for what constitutes a health resource.

Our work highlights a number of challenges for future patient-centered HIT. Future research may want to further investigate and consider ways to mitigate feelings of technology burnout as participants whose work required constant technology usage indicated that they did not wish to include additional technology routines into their day. In addition, we did not examine how the clinical aspects of one’s cancer journey influences technology usage. Future research could examine how patients change their daily use of technology, and HIT in particular, as they transition through different phases of the breast cancer journey.

Many of our participants articulated sentiments similar to one participant who stated, “I do not define myself as a cancer patient.” We believe an important reason for the success of the tablet adoption and use was that the flexibility of the technology and the deployment allowed participants to customize and use the tablet to reflect who they were as people, not solely as patients.

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