
Designing Personalized Technology to Augment Patient-Centered Care

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Abstract

As people live longer and medicine improves, health issues also become more long lasting. During lengthier health journeys, patients' needs, goals and priorities change with time. Despite the dynamic nature of these health journeys, research has yet to examine how patient-centered health tools may adapt over time with users. My dissertation research aims to explore the utility and need for adaptable technology through a longitudinal deployment of mobile tools that progress with patients through their individual cancer journeys. The study will result in novel patient-facing tools and will demonstrate the feasibility of developing technologies that provide personalized support to individuals over time.

Author Keywords

Mobile technology; Personalization; Cancer care

ACM Classification Keywords

H.5.2. Information interfaces and presentation – user interfaces

Introduction

My research explores the opportunities for personalized technology to enhance people's daily lives through an analysis of the real world benefits of personalized health tools for cancer patients- technology that reflects information about individual patients and provides customized support and resources to users.

For patients, a cancer diagnosis is an extremely overwhelming event. In addition, the medical system can feel impersonal and overburdened, making it difficult for patients to receive needed support. Through this research, I will explore how to design appealing and usable personalized user experiences that reverse this situation.

Developing personalized health tools presents significant challenges. The technology must possess the flexibility and robustness to cater to the full range of an individual patient's needs in order to make an overwhelming experience like being diagnosed with cancer manageable on a day-to-day basis. The technology must be able to adapt along with the patient, while maintaining an easy to use and engaging interface.

While challenging to develop dynamic and holistic health tools, work in this area will be critical as the rate of chronic disease and cancer diagnoses continues to increase. Such diseases necessitate patient engagement. Missed appointments and poor health management directly affect health outcomes. Further, patients must grapple with numerous barriers to care. For instance logistic barriers such as distance between home and the health system and the cost of gas money to get to treatment every day can impede on patients' ability to receive the necessary care. The challenges that become barriers to care can differ amongst patients; thus, targeted help in the home could make a significant difference in supporting patients' individual needs and ultimately impacting health outcomes.

For my dissertation, I am designing tablets that utilize personal interfaces to present customized support to

breast cancer patients. The tablets will highlight new resources and make recommendations to patients based on data from health system and patients themselves. Ultimately, I will examine through this research the opportunities for personalized and adaptive tools to improve the patient experience throughout the breast cancer journey and assist in the clinical care patients receive.

My research addresses four research questions:

1. What factors influence one's personal health journey?
2. How can tablets be designed to support personal health journeys?
3. What influence do personalized tablets have on health outcomes, supporting healthcare transitions and mitigating barriers to care?
4. How do personalized patient-centered tools influence the clinical care provided to patients?

I aim to provide a real world case study that will foreground future research making personalized health tools available to those managing complex health issues. This work provides fundamental contributions to the HCI research community through the design and evaluation and novel patient-facing tools. Further, the study will provide insight into how technologies may utilize heterogeneous user data to provide customized support. Such technology may prove especially important for those who experience greater burdens in accessing the traditional healthcare system, including those in rural areas, minorities, and people of a low socioeconomic status. This technology may provide one strategy for reducing the healthcare disparities that characterize the national healthcare system.

Related Work

Patient-Centered Care

Patient-centered care, highlighted in the Institute of Medicine's seminal report "Crossing the Quality Chasm: A New Health System for the 21st Century" [7], looks at providing individualized support that considers patients' personal needs [1]. Prior research shows that this healthcare approach can enhance patient satisfaction, engagement, and lead to better health outcomes [5,9].

While patient-centered care offers many benefits, challenges prevent its rapid adoption. For successful patient-centered care, health providers, who often are constrained by limited time and resources, must spend more time getting to know their patients. Thus, an opportunity exists to develop patient focused health tools that can provide this individualized support.

Recent studies have looked at developing personalized health tools outside of health centers. Personal health records, for example, provide users with their individual health information and healthcare records [10]. Tools have also been deployed that help patients better manage their personal health by supporting reflection and learning [6].

While these tools help patients receive more personalized care, they typically focus on a subset of patient needs, such as information organization or social support. One aim of my research is to develop technology that is more holistic, considering a broader range of patient issues, thus helping more patients overcome challenges in managing their health and mitigating barriers to effective care.

Mobile Health Technology for Cancer Care

Ubiquitous tools have proven particularly valuable for those battling cancer. One project used mobile phones to present patients in a hospital emergency department with up-to-date medical information regarding their health and treatments [8]. The study found that the increased awareness that the phones provided helped to reduce patient anxiety.

The Healthweaver Mobile project helps to demonstrate the importance of mobile technology in cancer care [4]. In this study, providing patients with a smartphone application 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 provides a significant motivation for my research. Similar to Klasnja et al.'s work, I aim to develop technology that integrates into patient's lives, while providing a new level of customization within the technology.

Completed Work

Over the past three years, I have worked with the Rome, GA cancer community to understand patient needs and the existing healthcare practices [2]. Thus far, I have completed two research projects that have helped motivate my proposed work. In one project I addressed my first research question, developing a framework for understanding patients' personal cancer journeys. In addition, I examined the opportunities for tablets to support people's cancer experiences over time.

Over three years of research, I have conducted interviews and focus groups with cancer patients and survivors to understand how patients' needs change over time. These interactions have highlighted how cancer journeys are both unique to the patient and personal, revealing the broad range of factors that influence one's cancer experience. An analysis of this work led to the development of a cancer journey framework. The framework portrays the breadth of factors that comprise a cancer journey in order to aid designers in collecting a comprehensive set of information needed to personalize health tools appropriately [submission under review].

The second research project examined the ability for existing mobile technology to support breast cancer patients [3]. For this project I developed mobile tablets for breast cancer patients that included a suite of existing health, communication, and entertainment applications. The design was guided by initial interviews I held with breast cancer patients, and was finalized by a collaborative team that included cancer navigators and breast cancer survivors. Over the course of a year, the tablets were deployed to 72 newly diagnosed breast cancer patients and backend logs were used to record usage of the tablets.

This work revealed that patients with low levels of technology literacy experienced minimal barriers to adoption. Further, patients preferred the tablet to the more common cancer binders as the tablet provided greater privacy. Finally, while patients did use the informational resources provided on the tablet, they also added new applications to the tablet, such as games, which they would use to relax during stressful moments, such as during chemotherapy. Such

customization and flexibility helped to maintain engagement with the tool even when patients' health needs waned. This work contributes to my proposed research by providing design guidelines for future mobile health tools, specifically highlighting the importance of customization and personalization in patient-centric interventions.

Proposed Approach

My dissertation research examines how personalized mobile tools can be designed with an increased understanding of one's personal cancer journey. I am particularly interested in exploring what influence such tools will have on health outcomes and the health system.

For this research I propose running two real-world deployments in partnership with a Georgia cancer clinic. In the first deployment I specifically examine the role of personalized tablets designed for one's healthcare journey. The tablet's design and content will be based on up front information collected from the patients, as well as their providers. The information gathered will be guided by the cancer journey framework I previously developed as it includes the broad range of factors that can significantly influence, one's cancer experience. Thus, the tablet will provide each patient with a select set of resources and recommendations based on up front patient data.

In the fall of 2015 I will deploy approximately 100 personalized tablets to newly diagnosed breast cancer patients. I will evaluate the influence of the technology on the patient experience as well as the healthcare provided. Specifically, I will compare patient satisfaction, health locus of control, anticipated vs.

actual barriers to care, transition experiences, and health outcome metrics between patients utilizing and not utilizing the tablets.

While the first deployment will allow me to begin to understand how we can design personalized tablets for patients, an open question remains about how we can use information collected throughout the journey to support the dynamic nature of the breast cancer experience. Thus, for the second deployment I will deploy and evaluate an adaptive tablet system that captures information about patients' changing needs, behaviors, and health status. In addition to providing an initial, personalized set of resources, this system will aggregate patients' journey information along with behavioral data from the tablet to continuously update the tablet content.

For both deployments I will evaluate the influence of the technology on the patient experience as well as the healthcare provided. From a patient perspective, I will evaluate tablet usage alongside patient satisfaction, health locus of control, anticipated vs. actual barriers to care, and transition experiences. I will also capture clinical information such as ER visits, clinical transition challenges, and health outcome metrics. Such data will help to inform how deploying personalized tools can influence the broader health system. Ultimately, I will examine through this research the opportunities for personalized and adaptive tools to improve the patient experience throughout the breast cancer journey and assist in the clinical care patients receive.

Reasons for Attending the D.S.

I plan to propose my research this year, and I believe this doctoral school will provide valuable feedback as I

begin my final dissertation studies. I am particularly interested in discussing within the school my plans for analysis. With these longitudinal long-term deployments, I have the opportunity to collect and analyze a vast range of data. Through this school I hope to receive important insight regarding how to appropriately scope the data collection, as well as the most important and interesting aspects of this analysis, especially from the perspective of the mobile and ubiquitous computing community.

Biographical Sketch

I am a PhD student in the Human Centered Computing program at Georgia Institute of Technology, advised by Professor Elizabeth Mynatt. I began my PhD in the fall of 2012 and expect to complete my dissertation work in the spring of 2017.

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