iCare:
Providing Patient Advocates with an Integrated Supportive Mobile System

By

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Abstract

The implementation of restorative design solutions in mobile healthcare is an emerging field in design practice. There is, however, a significant knowledge deficit in family/ patient-centric designs and systems. This paper describes the importance of implementing restorative and stress-reducing solutions for patient advocates and caregivers. This research investigates the potential of a mobile iOS application and the benefits it could have for families and friends caring for chronically ill patients. The application allows the patient advocate to input and recover patient health data and provides social support via an integrated networking platform. The design of the application enables a holistic experience that draws attention to the often-neglected emotional and social needs of the patient advocate. Its purpose is to improve health-related outcomes and communication between patients, caretakers, and care providers.

Empathic and User Experience (UX) design tools are triangulated with mHealth practices in the development of the platform. Designer John Maeda's Laws of Simplicity, Nathan Shedroff's Experience Design and Donald A. Norman's Human Centered Design processes are described in detail as they identify some of the fundamentals of usability, aesthetics, cognition and interaction with operating systems. Conclusions are drawn from the analysis of six co-design attendees, thirty semi-structured interviews and three user-testing focus groups.

Keywords

User Experience Design (UXD), User Centered Design (UCD), Empathic Design, iOS Application, Mobile eHealth, mHealth, Patient Advocates, Family/Patient Centric Healthcare Systems, Personal Health Records (PHR), Experience Healthcare Design

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to those who always believe in me

1.0 Framing the Design Opportunity

1.1 Inspiration

As an industrial designer, I have always been interested in the correlation between design and cognitive science. To date, I have dedicated much of my professional practice to emphasizing the interrelation within the clinical manifestations of design in healthcare. My original intention with this thesis was to transform existing standards of aesthetics in healthcare environments through ambient experience design. During my ethnographic research, which included semi-structured interviews with caregivers and families, however, I realized that there were other unmet psychosocial needs within these groups. I was empathetic to their situations, as I had just overcome the fear and anxiety of taking care of a loved one myself. When I heard a woman I met during the early phases of my research describe her experience as a patient advocate, I was inspired to make a detour in my practice and apply design to support patient advocacy.

> *"My husband was diagnosed with a life threatening disease. Devastated with the news, I had to be as positive as I could be. The doctor visits started; the treatments were very intense. A year after the initial diagnosis, the disease had spread and the treatments were going to be more intense and more frequent. Never mind that I had to watch the love of my life, the father of my children, deteriorate so fast and so hopelessly in front of me. Never mind that I had to deal with the fact that he would never walk our daughter down the aisle or watch our children graduate. I had to take care of my children, make a living, accompany my husband to treatments, regularly take him to the emergency room, remember to give him his medication at the right time, and make adjustments to my own schedule to arrange future doctor visits. I didn't have a moment to myself, even at the end of the day, because then I had to report to our family and friends on his health status.*
>
> *Approximately five months after his death, I woke up to see the bright white hospital ceiling and walls. The doctors were not sure when exactly, but they estimated that two years previously, I developed what had at that point become stage three breast cancer; it had already spread to my skin and lymph nodes. I had to save myself for my children. Losing one parent was enough for them. As a patient advocate, I had not had the support I required to care for everyone in my family, including myself. Because of the stress, I had forgotten about myself. Hypothetically speaking, if there were ten elements*

> *that contributed to my stress levels, if even one or two of those elements were taken away, then perhaps I would have spent more time on myself. Maybe instead of reminding myself to call his parents or his doctors, I would have been more mindful of myself and I would have felt that large lump."*
>
> — K. Collins, personal communication, September 13, 2011

I investigated the matter further by conducting more interviews and found that family members of patients and patient advocates were in dire need of a support system to cope with illnesses and deaths of their loved ones. The transposed interview below illustrates some of the common issues patient advocates face during their care-providing experience.

> *"… I was constantly in and out of the hospitals, accompanying my wife to treatments. I was mentally and emotionally beat. I was getting little sleep, and felt like I was constantly on stand-by mode in case of an emergency. I had to use several apps on my phone and iPad to organize myself: iCal for appointment reminders and medication alerts; the notepad app to write the allergies, previous medications and general doctors notes; Pixable to share and document photos I had taken of medicine bottles, forms etc.*
> *I don't know how, but I somehow managed to make sense of all of these portals.*
> *She was going through chemotherapy, which meant that her body was extra sensitive to food. I had to spend extensive time finding recipes that didn't conflict with the chemo.*
> *There were several chat-rooms, forums and online support groups that I would log in to, hoping I would find someone in the same shoes as me. They were all desktop websites to say the least. I was less than interested in going on these sites using my iPad while I was killing time in waiting rooms, and by the time I would get home to do this I was too exhausted to mine through forums."*
>
> —E. Kimmet, personal communication, November 28, 2011

These stories, along with my own experiences, highlighted a number of issues that patient advocates face, and persuaded me to consider a practical technical solution to ease their emotional and social needs, rather than my original concept, which sought to de-stress patient advocates through environmental psychology design. While work remains to be done on these hospital environments, the proposal I make in this thesis can help patient advocates with the pressing needs they describe above.

1.2 Hypothesis

This thesis project investigates and builds a theoretically informed and empirically grounded design paradigm for building a communication and care management platform to support patient advocates of chronically ill patients.

1.3 Research Questions

Can an integrated communication platform help support a patient advocate in providing patient care? Could it simultaneously improve the patient advocate’s care-providing experience? Can patient advocate stress be alleviated in the digital healthcare ecosystem through healthcare experience design and empathic design? How will making an integrated social support and patient health recording platform benefit the lives of patient advocates?

1.4 Overview

This thesis project includes an investigation of healthcare design support systems. There is a significant knowledge deficit in design studies on patient advocate-centric healthcare systems. An increasing number of studies emphasize the critical need to implement stress-reducing support solutions for patients, physicians, patient advocates and families. Many recent studies in the humanities and social sciences demonstrate that patient advocates, family and friends play a significant role in the overall recovery and well being of patients. The main caretaker, i.e. the patient advocate, needs to be supported within the overall healthcare system in order play their role holistically and efficiently. Despite these findings, however, academic and practical healthcare design studies have sidelined the needs of patient advocates. Little attempt has made taken to alleviate stress associated with logistical, organizational and emotional needs of patient advocates. This thesis project investigates these emotional and logistical needs, and provides a supportive design remedy for patient advocates.

Theoretical design practices, such as human-centered design, user experience design, and empathic design, are reviewed and summarized in this thesis project. This research was undertaken in order to better understand the factors that influence the experiences of a patient advocate. With greater understanding, this project aims to address patient advocate needs, while contributing academic and practical emphasis to a patient advocate-centric healthcare design paradigm. A synthesis of ethnographic fieldwork, semi-structured interviews, and co-creation activities, together with user-testing, quantitative, and qualitative methodologies, are conducted to validate and analyze the project.

This thesis project integrates user experience design (UXD) with mobile eHealth with the goal of creating a solution that will remedy stress experienced by patient advocates. The design of an iOS application, or app, using a mobile communication platform integrates an easy-to-access patient health record platform and encourages support networks among patient advocates. By providing these services through various design practices, the goal of alleviating stress associated with providing care to an ill loved one may be achieved.

1.5 Introduction

Advocacy is commonly understood as the act of speaking on someone else's behalf. This has become a growing terminology in healthcare used to describe the support and promotion of health provided by patient advocates and they may be individuals or organizations.

In this thesis, I refer to a patient advocate as the main person providing support to a patient outside of the medical system. This role is frequently filled by a spouse, an adult child, a parent, or a sibling. A patient advocate helps a loved one to be heard by medical practitioners, ensures their needs (organizational, emotional and physical) are met, and provides pre- and post-operative long-term care. Figure 1. depicts the communication role between a patient advocate and the surrounding networks.

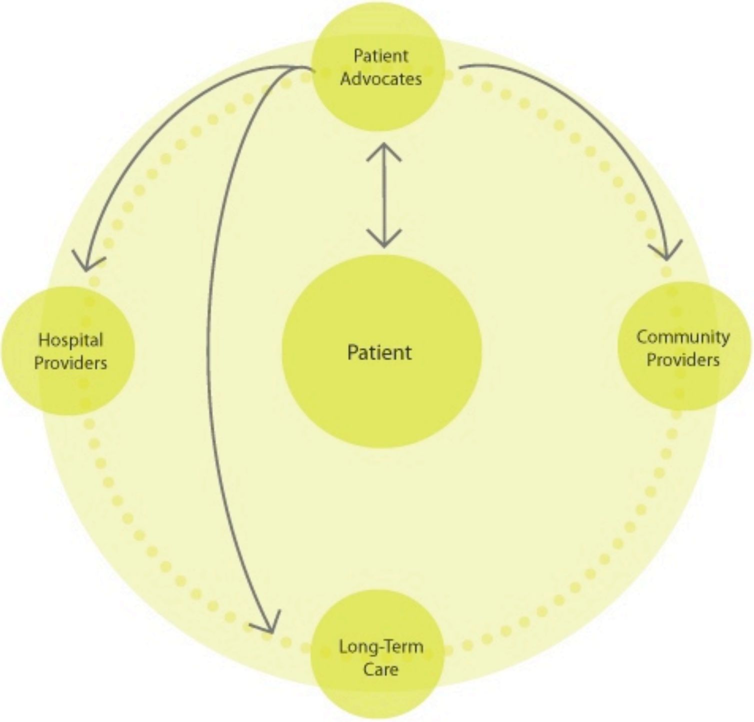


Figure 01. Communication pattern of a patient advocate, Sogol Assadbeigi

Some responsibilities that often arise for a patient advocate include gathering patient health information, organizing health data, making appointments with medical practitioners, and facilitating decision-making. An advocate may also play a major role in negotiating between a patient and care providers. The Institute for Family-Centered Health notes that those with chronic conditions; the individuals who are most dependent on hospital care and the broader health care system—are also those who are most dependent on families. They provide the major social support system… [and] the major tie of the patient to the community (Tanner, 2009). The research conducted for this thesis project demonstrates that patient advocates are frequently involved from the diagnosis and prognosis, to treatments and post-care.

My research also found that accompanying patients to surgical and non-surgical procedures, monitoring patient treatments, and anticipating health outcomes can be traumatizing and emotionally draining for patient advocates. Such intense care-providing experiences require a patient advocate's full attention and vitality. Patient advocates often find this time to be hectic and exhausting, as they attempt to balance their responsibilities toward the patient with being mindful of their own psychological and physiological health. As one patient advocate noted, "I can't take care of my family if I am not in a good state of health myself" (anonymous, personal communication, May 8, 2011). The patient advocate juggles many responsibilities between those of their own life and those of the patient's. They need to feel unflustered and in control in order to provide efficient support and care for their loved one. Patient advocates need a strong emotional and mental support system to carry them through their precarious, stressful, and exhausting experience. It is crucial to identify the type of supports that patient advocates require, in order to use design as a remedy. My research indicates that the most significant support patient advocates need is a networking and patient health record organizing system on a single consolidated platform.

Stress associated with illness is a documented, pervasive problem for patient advocates, patients, families, visitors and healthcare workers (Ulrich, 2000). Gabor Mate, a Vancouver medical practitioner and author of *When the Body Says No* states:

> *"The experience of stress has three components. The first is the event, physical or emotional, that the organism interprets as threatening. This is the stress stimulus, also called the stressor. The second element is the processing system that experiences and interprets the meaning of the stressor. In the case of human beings, this processing system is the nervous system, in particular the brain. The final constituent is the stress response, which consists of the various physiological and behavioral adjustments made as a reaction to perceived threat"* (Mate, 2004 p. 31)

Alleviating this type of stress is clinically significant in the healthcare industry, as it has negative health and behavioral outcomes, especially for the patient. The quality of care provided by medical personnel and patient advocates is also impacted by this type of stress. Finding a remedy to alleviate stress for patient advocates, therefore, would help with patient health outcomes and the overall well-being of the patient advocate. In reviewing research in various disciplines, however, it was evident that alleviating stress experienced by patient advocates has been sidelined in practical and academic studies. There is a clear design gap and an opportunity for designers to improve patient advocate experiences. This thesis project intends to close this gap, while highlighting its significance, using interaction and human-centered design.

There is growing emphasis among healthcare designers on developing systems that support patients and physicians. There are, however, very few designers or researchers focusing on design that emphasizes and addresses the needs of patient advocates. It is evident that insufficient supportive design for patient advocates is not due to bad design, but merely due to lack of awareness of the problem among designers. As the main caretakers and mediators for the patient and medical personnel, patient advocates are essential to a patient's psychological and physical health. Additionally, they are crucial advocates for quality and safety within the healthcare system (Nurse, Woodcock & Ormsby, 2003). Designers who are empathetic to patient advocates' experiences and emotional needs will be able to fill this much needed design gap, thereby improving the healthcare system as a whole.

2.0 Summary of Research

2.1 Supportive Design Paradigm for Patient Advocates

> *"…Technologies can make life easier, can let us touch people we might not otherwise. You may have a child with a birth defect and be able to get in touch with other parents and support groups, get medical information, the latest experimental drugs. These things can profoundly influence life."*
>
> — Steve Jobs (2003)

Stress is linked to both physiological and psychological complications. Roger Ulrich, a fellow at the Center for Health Systems and Design, Texas A & M University, argues, "alleviating patient stress is a significant clinical goal because stress is both an important negative health outcome in itself and has a variety of detrimental psychological, physical and behavioral effects that worsen other outcomes" (2000, p. 53). His argument can be extrapolated to patient advocates. His suggested design criteria can be implemented as guidelines in pursuit of lowering the stress levels of frequent hospital visitors.

Ulrich argues that healthcare design needs to focus on patients and families. In order to tackle this matter, he claims that multidisciplinary theoretical and scientific review needs to be held in behavioral science. Ulrich's suggested guidelines for manifesting supportive healthcare environments are: to foster emotional control; to promote social support; and to provide access to nature and positive distractions. Although these ideas are based on the physical environment, the conceptualization of supportive environments may also be employed in digital form.

Control refers to an individual's real or perceived ability to influence their situation and to determine what others do to them. Research indicates that people who feel they have control over their situation tend to cope better with stress, as opposed to people who lack this feeling of control (Evans and Cohen, 1987). Importantly, a provision of actual or perceived control over stressors tends to alleviate stress. Healthcare design criteria that enhance feelings of control, therefore, should also alleviate stress and improve overall well-being outcomes for patient advocates (Ulrich, 2000). In his book, *Flow: The Psychology of Optimal Experience* (2008), Mihaly Csikszentmihalyi, a renowned psychologist, demonstrates ways to achieve optimal experience and joy using emotional control and deep concentration. He claims "a sense of personal control over the situation or activity" will play a positive role in relaxation (p. 72). He goes further, claiming that life is full of stressors, and that by gaining control of our emotions and even our situation we can systematically shield ourselves from this stress.

Examples of goals that might enhance and enable feelings of control for patient advocates include: providing opportunities for empathy and information gathering via other patient advocates on a social networking platform; providing patient advocates with patient medical history data at the right place and at the right time; equipping patient advocates with interactive self- and patient-management tools; and creating supportive platforms or situations where patient advocates are able to achieve measurable decreased stress levels and to therefore provide better care.

The term social networks has been used to refer to the chain of social relationships that surround individuals (Glanz, Rimmer and Viswanat, 2008). The promotion of social support via networking is significant for an individual, since its function depends on healthy social relationships. The term social network refers to a bridge that bonds together people and communities with similar interests. In the case of patient advocates, this bridge is empathy. Numerous empirical and theoretical studies indicate that a wide variety of individuals who receive strong social support generally experience less stress and have better health than those who are more socially isolated (Glanz, Rimmer and Viswanat, 2008). Network members who provide the most emotional and concrete social support are spouses and family, with "several studies [finding] that social support from nurses, families and significant others reduces patient stress, improves patients' physiological outcomes, and has a positive influence on both patients and family members" (Tarkka et al., 2003, p. 20). Several studies have also shown that increased patient-family or patient advocate interaction as social support improves the overall recovery of patients (Kahn and Antonucci, 1980). Patient advocates themselves also need emotional support, in order to cope with the tragedy and strain of taking care of a loved one (Tarkka et al, 2003). Patient advocates often have a social support network of family, friends, and even coworkers.

Patient advocates, however, have limited access to their social support networks of peers when the patient they are accompanying is hospitalized. This makes it difficult for the patient advocate to obtain social support. There is an opportunity, however, for patient advocates to use electronic networks during times where the advocate is waiting for long hours in waiting rooms. As a result, online social networks are growing in a variety of ways in the healthcare industry. For example, fifty-nine percent of surveyed Americans receive health-related information online (Jane Sarasohn-Kahn, 2008). (Fig. 02)

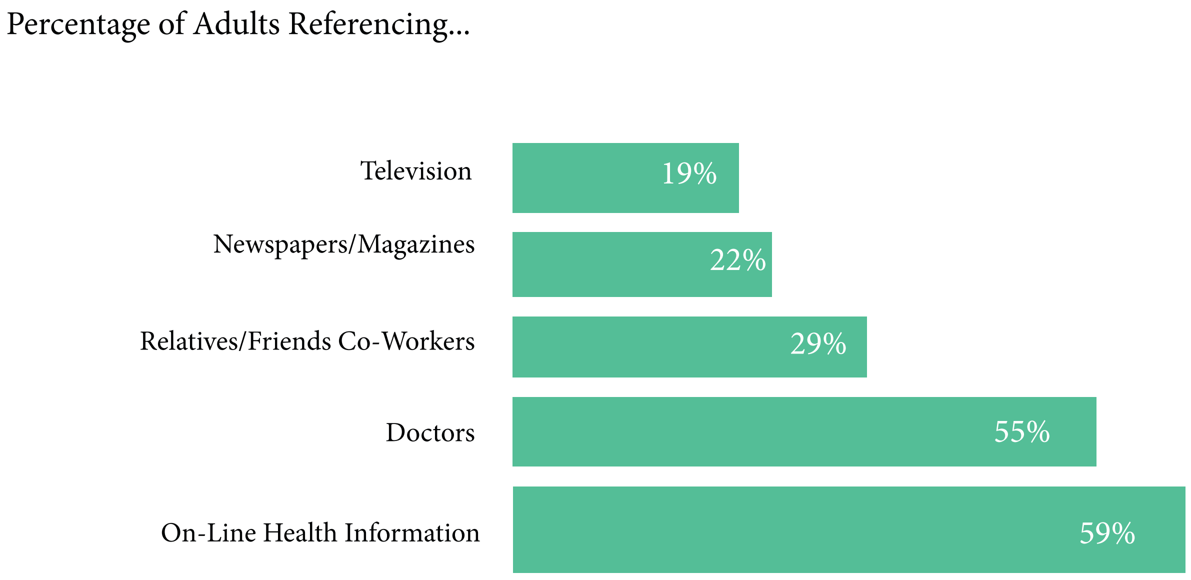


Figure 02: Sources used to find or access health- and wellness- related information in the past twelve months. iCrossing. January 2008. Re-illustrated by Sogol Assadbeigi

One reason for this growing trend is the notion that, when faced with a health related situation, individuals look online for information about a medication or treatment, descriptions of other people's experiences, and advice on how to manage the traumatizing situation (Jane Sarasohn-Kahn, 2008).

One such popular website is Patientslikeme.com, which provides consumers with a platform to access health-related information, track and document their own health data, and learn from the real-world experiences of other similar patients. This site is user friendly and popular among patients, as it enables them to compare their medical conditions using evidence-based data. Other consumer-generated websites include Medhelp.org, a social networking and tracking platform specifically for chronic conditions; and FacetoFace.org health, a social network site that utilizes proprietary algorithms to connect and match people with similar diagnoses. There are also sites that represent specific health communities such as those for the elderly, Alzheimer's, multiple sclerosis (Paul H. Keckley, 2010). Jane Sarasohn-Kahn (2008) explains the importance of these sites:

> “Social media on the Internet are empowering, engaging and educating consumers and providers in health care. This movement, known as Health 2.0, can be defined as: *the use of social software and its ability to promote collaboration between patients, their caregiver, medical professionals, and other stakeholders in health”* (authors emphasis) (p.2).

These online platforms are quite successful in providing emotional, instrumental, information and appraisal support to patients and patient advocates. They are usually geared specifically for certain demographic groups, addressing a specific disease such as cancer or mental illness. Most of the online social groups geared towards patient advocates are for those providing care to seniors or aging parents. Social media is indeed empowering and very beneficial in providing support to patients and patient advocates alike.

2.2 mHealth

Undoubtedly, technology has had a massive influence on the health industry. This influence continues to grow. Electronic health records, electronic medical records and personal health records (PHR) have received a face-lift, and are available on many new platforms. mHealth, also referred to as m-health or mobile health, is a term that is used for healthcare supported by mobile platforms such as smartphones and tablets. mHealth falls under the umbrella of electronic health (eHealth). Since the 1970s, PHRs have become more popular, as the information on these systems is owned and controlled by patients and caregivers. The PHRs available on the market today provide different benefits, with many including services that provide health documentation in a timely manner; reduce communication barriers between the patient, caretakers and care providers; provide patient access to personal health profiles; and promote self assessment which can lead to early intervention. The electronic PHR providers, however, struggle to conform to eHealth market needs.

Some fundamentals that may facilitate the success of an electronic health record platform are user privacy controls, comprehensible information architecture, multi-platform synchronization abilities, and a mobile friendly website design and user interface.

Google, one of the most innovative companies worldwide, discontinued their "Google Health" services in early 2012. They claimed that it was due to the limited usage in the daily routines of millions of people (Brown, 2011). Why was this program used so little in people's daily routines? I believe that this under use and consequent termination may have been due to Google missing some of the fundamentals mentioned earlier.

Privacy is always a major concern for PHRs. Google Health promised to put the users in control of their own health records. Among their policies is the promise never to sell data or make health information publicly accessible (Google Health privacy, 2008). Despite Google Health's long disclosure statements and privacy promises, people may have felt uneasy about inputting their health records on Google, the largest search engine in the world.

In terms of the comprehensiveness of the Google PHR information architecture, there were a few major user needs that were overlooked. From user stories, blog entries and focus groups, Google found that people were looking for tools that coached them through their wellness program. Google's bland iconography and taxonomy made it difficult for users to navigate the platform. Users were asking for easier data-tracking capabilities and more personalization. The official Google blog stated in early 2010 that Google realized the necessity of an "easier to use dashboard" that would meet these user needs. (Google, n.p.)

From a user experience and information architecture point of view, Google Health's improvement and refurbishment attempts, as shown in figures 03 and 04 were disappointing to say the least . The dashboard is filled with data, not information. For data to be useful information, it has to be organized and well expressed. Richard Saul Wurman describes this in his book, *Information Anxiety* (1989) as follows: "Data is fairly worthless to most of us; it is the product of research or creation (such as writing), but it is not an adequate product for communicating. To have informational value, it must be organized, transformed, and presented in a way that gives it meaning" (as cited in Shedroff, 1994, p. 2-3).

Patients and distressed patient advocates like to enter their data immediately as they receive it, with minimum delay. By carrying their health records with them to doctor's offices, hospitals and clinics, they are able to effectively exchange critical health information with their healthcare providers. Google Health, much like other online PHRs, was not primarily a mobile application or a mobile website. This platform asked users to fill in large amounts of health data on a desktop-optimized website.

The interface and information architecture of a website designed specifically for a mobile device attracts users due to its specific and simple navigation process. Yet while health related mobile apps continue to grow exponentially, as Jacob Nielsen's 2009 study on mobile usability demonstrates, users' success rates when using mobile devices to access non-mobile websites averaged only 64% compared to an 80% success rate for users accessing websites on a desktop computer. Nielson (2009) claims that "users lose interest upon entering a website on a mobile device that is made for personal computers and is therefore difficult for the user to navigate through." In hindsight, Google Health may have been more successful if it had not chosen to provide its PHR services only via a desktop web application.

As mentioned earlier mobility plays a significant role in a successful electronic health record system. The iPad offers a great opportunity for patients and patient advocates to carry their health records with them to the medical facilities. They are able to review them with their medical practitioners and make additional recordings. However, this opportunity can only be available if the device provides this platform effectively. Otherwise it will not be adopted by the consumers and is short lived. This communication and support system may be available in in two ways, a mobile website and an app. A native app is generally known to have better marketability than a mobile website. They generate revenue in several ways such as the subscriber model, the in-app purchase model, and the in App store purchase model to name a few. For these reasons stakeholders have geared more towards creating apps which has contributed to its growth. Although a mobile website has better usability versus a website; an app is yet a better choice if navigation, usability, and experience is a priority (Fig. 5). Furthermore an app that is mainly used for management purposes, once downloaded, is not limited to Internet connectivity.

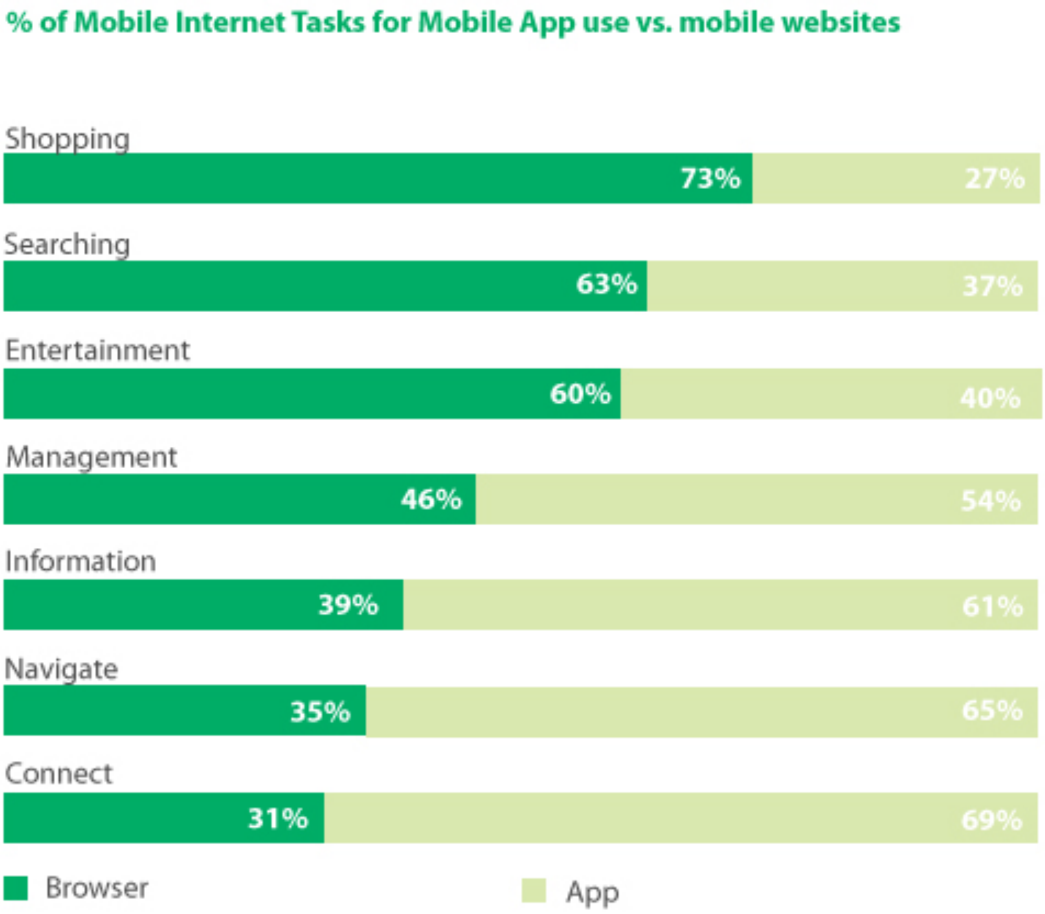


Figure 03: Percentage of Mobile Internet Tasks for Mobile Apps versus Mobile Websites

In 2011, PEW Research Center for the People and the Press, reported that 17% of mobile phone users were using their devices to look up health and medical information. Jupiter Research's study on health apps recently estimated that 44 million health apps were downloaded in 2011 (Empson, 2012). This popularity is due to the advent and increased use of portable smart digital devices, such as smartphones and tablets. Rip Empson (2012) notes this key connection between the new devices and new applications, asserting that "smartphones are connecting with these diagnostic apps and health-measuring devices to help you stay on top of your health and fitness-like basics like heart and health tracker, Lark, Fitbit and Jawbone's UP—to name a few" (Empson, 2012, para. 3). The software apps that are being downloaded perform functions that range from tracking diagnostics to social networking with care providers. Philips' Vital Signs Camera, which measures vital signs via an iPad camera, is a favorite app among patients (Philips, 2004). Mobile devices have also changed the way physicians communicate diagnosis and treatment procedures, with many using the iPad as a multimedia platform (Empson, 2012). These apps are, for the most part, designed for physicians, patients and medical staff.

There is currently one app, called Capzule PHR, on the online Apple store that claims to provide for the needs of patients, family, friends and caregivers. The app states that it offers a PHR platform for families and caregivers, while, it does not meet several clear criteria that my research has identified as key requirements specific to patient advocates, (January, 2012). Health and medical app developers and stakeholders neglect to include families and friends of the patient in their development and designing of these integrated platforms. When someone is sick, however, whether it is a simple flu or a chronic illness, there is almost always someone accompanying the patient. These advocates are evidently sidelined in the development and design of such integrated platforms.

Empson raises a good question: "Should the definition of 'mobile wellness spill over into how we define 'mHealth'? How should we differentiate between mHealth and "mMedicine"? The distinction between these two categories is rooted in who is the intended user of the app. An app that is designed, programmed and marketed specifically for a physician is, and should be, different from those designed for a patient or a patient advocate. Not all software applications made for medical personnel are appropriate for patients or their patient advocates. The same can be said for applications that are made for patients—they are not ideal apps for their caregivers or families. In the iOS Human Interface Guidelines, the authors and creators talk extensively about the importance of user experience design and user centered design: "A great user interface follows human interface design principles that are based on the way people—users—think and work, not on the capabilities of the device" (iOS HIG, Human Interface Principles Section, 2012, para. 1). If user experience designers are creating these apps with their users in mind, then these user boundaries should be clear. While a patient advocate may find an app designed for a medical professional or patient useful, for those apps to claim that they are designed for patient advocates, while neglecting the specific needs of those patient advocates, is dishonest.

The question still remains: if these apps aren't meeting patient advocate needs, why are they still being used by a wide variety of users? Is it because their specific needs are not fully met by the apps available to them on the market? With no app on the market specifically designed for patient advocates, other apps within the mHealth and mMediciene category are downloaded—apps that do not target the specific needs of patient advocates. A successful design will depend upon the ability to look deeper into the experiences and emotions of patient advocates in order to meet their needs. The efficient use of experience design and human centered design (HCD) practices will be discussed in further detail in the next section.

2.3 Emotion and User Experience

> *"... experiences should, ultimately, change and modify themselves to be more appropriate for users".*
>
> —Nathan Shedroff (2001, p. 116)

User experience design, also known as UXD, is the study of the interactions between people and products, and the way people feel while using those products—in other words, their experiences. Donald Norman, a cognitive science researcher and author of *The Design of Everyday Things* (1988), claims that the way the product is perceived, learned and used are all aspects of user experience design. UXD draws from multidisciplinary roots, and reaches into human-centered design. It plays a significant role in software development, especially for haptic device interfaces where information architecture and hand gestures are key to the experience of the user. Haptic, or touch screen, smartphones and tablets have immersive and interactive interfaces. Users of such devices are generally intrigued by them, due to their high stimulation and interactivity.

In his book, *The Psychology of Everyday Things* (1988), Norman provides a connection between product design and UXD. He triangulates the basics of experimental psychology and cognitive science with design. The usability of any product is reliant on design that is centered on human physical and cognitive capabilities—in other words, human-centered design.

Both human-centered design and user experience design depend on the consideration of the user's behavior and emotions during the design process. Experience designers depend heavily on cognitive models to better understand the users they design for. Three of those models are discussed below. They examine experience from different perspectives, including product-centered models, user-centered models, and interaction-centered models. The latter two models have become underlying processes in designing apps for complex mental models, such as those of patient advocates. User-centered models help developers and designers to better understand the users they are designing for. Marc Hassenzahl, for example, provides "a theoretical model to describe people's goals and actions when interacting with products. It broadens traditional goal- and task-based thinking to include fun and action-oriented models of behavior" (2003, p. 39). Interaction-centered models investigate ways a product connects designers and users. Here it is useful to define user behavior and the role of emotion in experience.

Designing a user experience for a distressed and fatigued patient advocate is complex. Experience design expert Nathan Shedroff (2001) talks about creating cognitive models in experiences: "The most important aspect of any design is how it is understood in the minds of the audience." No matter what the user's competence level and type of understanding, the experience they walk away with is always re-interpreted by the user. Shedroff (2001) suggests to designers that "whether or not you focus on creating a cognitive model for your experience, your participants will nonetheless".

During traumatizing times, when a loved one is chronically ill or is hospitalized, the patient advocate's stress, anxiety and fatigue levels tend to be high. To propose a type of PHR platform that helps patient advocates organize health information and gain social support solves only part of the problem. The experience of such distressed consumers in using an application can be a significant, pivotal point not only with regard to their experience in using the application, but also in their overall experience as a patient advocate.

A UX designer also needs to consider how the patient advocate's association with the system might change over time. Their initial interaction needs to enable easily obtained fluency, "to ensure that they will continue to use the product and not abandon it in frustration" (Forlizzi and Battarbee, 2004 p. 265). The user should need to invest little time in figuring out the functions, controls, tabs and gestures, and should be able instead to spend their time browsing through the benefits the app provides. The browsing and navigation experience should be seamless, last longer, and support the user. As John Maeda declares in his final and most important law of simplicity, "simplicity is about subtracting the obvious, and adding the meaningful" (p. 89). This simple process of elimination enables the users to walk away with valuable experiences.

2.4 Empathic Design

"Every journey to a great user experience starts when someone empathizes with a user in a way that is authentic, human, and compelling."

—Tim Kieschnick (2011, HxD Conference)

In order to create positive emotions in users, there is a need for designers to deeply understand the context in which users are situated (Hassenzahl, 2004). As a result of this awareness, new design approaches such as empathic design have gained much support in the design realm. Through a strategic empathic design approach, it is possible to promote positive cognitive experiences for patient advocates.

The empathic design approach is not a new concept. In fact, it has been evident in design thinking and design processes for years. Donald Norman's plenary analysis of *The Design and Psychology of Everyday Things* (1988) knits empathic design into the core of user-centered design approach. This approach has been adopted in several industries such as business, marketing, and especially in healthcare design.

Through observing and deep listening, healthcare designers in all disciplines can grasp a deeper level of the hurting, the caring, and the healing of those whose lives have been changed due to the illness of a loved one. What is the experience of someone taking care of a cancer patient? How many hours do patient advocates spend in oncology units? What do they do during this time? Where or who do they turn to in order to rejuvenate and gain strength? How do they cope with a loved one's health deteriorating? How about their own lives, their full-time jobs, their mental and physical wellbeing, their networks? Through the empathic design process, user stories are gathered, which yield product innovation and new design opportunities.

Leonard and Rayport (1997) have identified five underlying steps to facilitate the empathic design process. These steps provide designers with a lens through which to see the personal experiences and lives of the consumers they are designing for. The steps are: observation, capturing data, reflection and analysis, brainstorming for solutions, and developing prototypes of possible solutions (Leonard and Rayport, 1997).

Empathic design thinking is especially vital in enhancing social support systems in healthcare. Health education interventions have attempted to enhance the social support available to participants by linking them with professional helpers. Professional helpers, however, are rarely available to provide social support over long periods of time, especially online, and are costly. Additionally, professionals are not typically reciprocal and lack the empathic understanding that other patient advocates in similar situations may have. Hence, a supportive communication platform that brings similar patient advocates together could be one remedy possible for this design gap.

Healthcare, and in particular mHealth, has sidelined patient advocates as participants in a patient's recovery. The reason underpinning this neglect could be that design, business, cognitive science, and other disciplines are spending their energy on enhancing patient-centric healthcare systems. Disciplines that are passionate about providing care have the opportunity to widen the scope of what they consider factors in patients' lives and wellbeing, and could come to realize that the families who support patients during these times are a major keystone of the system.

3.0 Methodology

This thesis project has a bi-fold empathic design opportunity. First, my own experience as a patient advocate gives me insight into the experience of those I am designing for; second, as a designer and a Certified Aging in Place Specialist, I have been able to use therapeutic communication skills to connect with the patient advocates during interviews and focus groups.

In order to understand the precise needs of patient advocates and to implement the best design approaches, research using qualitative and quantitative methodologies was conducted. Co-creation activities, as well as other research tools, were designed to assess and understand patient advocates' social, emotional and behavioral needs. Ethnographic fieldwork, thirty semi-structured interviews and two focus groups were conducted. After the fieldwork, interviews and test period, the diaries and tapes were analyzed. Low fidelity mock-ups, along with working prototypes, were designed and tested during three user-testing sessions. Overall, empathic design criteria were built up through the extensive review of the research conducted.

3.1 Ethnography and Interviews

The foundation of empathic design is observation (Burns, 2010). Watching patient advocates provides a deeper understanding of their social, emotional and behavioral needs. The research methodology used for the purpose of this thesis project examined health and design in the context of family-centric healthcare; in particular, it examines how experience healthcare design can have a positive effect on communication and support patterns. Various healthcare institutions in Vancouver, British Columbia were visited, and ethnographic field research was conducted over the course of a month at Bogen Hospital in Bogen, Germany. Several weeks were spent at these various locations. The facilities were studied from a visitor's point of view.

Lions Gate

Lions Gate Hospital was the primary institution where ethnographic research was conducted in North Vancouver. The hospital was built in the 1970s and has a culturally diverse environment. Social interaction between families, patients and medical personnel within the lobby, waiting rooms and gathering spaces was observed. During the months of April and June of 2011, the traffic flow and use of social spaces was monitored. The observation was conducted by shadowing the volunteers, sitting in social spaces and closely observing the naturally occurring events. During this time, it was noted that the hospital visitors, friends and family of the patients were spending several hours in the social gathering spaces, such the cafeteria, coffee shop, waiting rooms and lobby. Forms of entertainment engaged in by these visitors were particularly noteworthy. The majority of the hospital visitors passed time reading a magazine, making phone calls, and working on their tablets and smartphones. Some visitors made notes on note pads and others mined through apps and websites on their tablets.

Semi-structured interviews and conversations with hospital volunteers and staff were held and later transcribed and analyzed. During these conversations, I was told that there were a significant number of patient advocates and families wandering the halls of hospitals aimlessly, even though they had very busy lives. Way-finder volunteers were typically asked if there was a computer that visitors could access, or where the nearest internet café was. Within the last few years, hospital volunteers had received more complaints regarding Wi-Fi connectivity and IT related issues from hospital visitors.

Bogen, Germany

After several months of observing social behavior of families accompanying patients in hospitals in Vancouver, unique circumstances enabled me to go to Bogen, Germany. My sister had been diagnosed with a collapsed spine, and artificial disk replacement surgery was recommended. Bogen Hospital had very friendly and accommodating nursing staff. I felt emotionally and mentally supported by them. Despite this, I was exhausted, nervous, and anxious. I had to keep these dramatically changing emotions under control, however, in order to maintain focus and to provide better care as a patient advocate for my sister.

My sister's operation day came, and so did an overwhelming number of phone calls and emails from our extended family and social networks. Repeating information by phone and email to each of our family members was one of the biggest challenges for me. It was not something that I could overlook, however, as reporting the status of my sister was a significant reason why I was accompanying her.

After speaking with other patient advocates in the hospital in several different wards, I concluded that this challenge was common among all twenty-three patient advocates that I spoke with. A mitigating solution suggested by some patient advocates was emailing or using a social network site such as Facebook or Twitter. The common consensus among patient advocates, however, was that these general social networking sites are too open to extended social networks and have a certain negative connotation to them regarding privacy.

This experience suggested new design opportunities. How could I provide heath status updates at once, in order to avoid the overwhelming phone calls and emails? Was there a communication system available, other than general social networking sites such as Facebook and Twitter?

After further investigation into the lives of the patient advocates at the hospital, I interviewed a pastor. I had observed him go from room to room, visiting the patients and family members every day for a week. In a brief interview, he stated that patients with social support recovered faster, because of their sense of affiliation and belonging.

While family members were supporting the patients, the pastor was supporting those family members. Families were calmer after speaking with the pastor. They declared that he provided emotional support and a sense of control by providing sympathetic communication skills. This therapeutic communication strategy reduced family members' stress, which led to fewer complaints to hospital staff and care providers. He also introduced families who shared rooms and were in the same ward together, creating temporary communities. Patient advocates and families felt more welcomed, supported and satisfied with their experience at the hospital because of this. On several occasions, I was invited to roundtable meetings held by the pastor in the hospital's common area specifically for the families of patients. My observation of the roles the pastor played in this hospital revealed further design opportunities, as it highlighted the importance of providing a social networking platform for patient advocates in similar situations to meet based on common interests and concerns. Such a platform would enable the exchange of experiences and health information among patient advocates.

Interviews

Upon the completion of the observational field studies at Bogen hospital, I reached out to families with chronically ill loved ones. Some of the patients they were caring for were hospitalized, while others had regular weekly treatments. During various phone conversations and personal interviews, the patient advocates' journeys and compelling stories were collected. The stories had notable measures of emotional highs and lows. Below are some of the responses gathered when patients' family members were asked: "what was the biggest struggle in your care-providing experience?"

"I have been taking care of my sister all of my life. It has been a difficult journey. There are days that I juggle up to three events at one time. You can never get used to it."

(Anonymous, personal communication, September 22, 2011)

"What are my worries? There are a few, where do I start? I stay up some nights trying to remember if I gave my father the corresponding dosage of his prescriptions. I have saved all the pharmacy prescription papers in a handy file in case there is an incident and I need to be reminded of the side effects. "

(T. Schmolick, personal communication, September 12, 2011)

"I have an iphone, and the worst is when I need to make a quick emergency phone call to a doctor, I have to go through my entire contact list to find his name. It's not difficult to find the name, but when you are trembling and under severe stress, your mind plays tricks on you."

(Anonymous, personal communication, November 8, 2011)

"The emergency room doctors ask me what drug allergies she has. To this date I have a hard time remembering all of them as they change all the time. I always carry an updated list and carry it in my wallet."

(Anonymous, personal communication, November 8, 2011)

"After spending all day by your partner's side who is going through chemotherapy, the last thing you want to do when you get home is make endless phone calls to family and friends telling them how it went. Not answering the calls and text messages is not an option either, because that just multiplies the calls until you answer."

(P. Duck, personal communication, December 5, 2011)

These user stories were valuable for understanding the experiences and needs of patient advocates. Further qualitative and quantitative assessment, however, was necessary. Methods such as focus groups and co-creation activities were used to holistically investigate aspects of supportive design.

3.2 Understanding Users

Focus Groups: First Session

The user stories collected indicated a design direction for the thesis project. To explore this opportunity further, two focus groups consisting of three participants each were established. The participants were patient advocates and medical personnel who were invited to share their stories, experiences and to produce emotional maps. These maps were then shared and discussed in detail within the group.

The patient advocates had comparable, if not identical, support needs. These needs included a portable digital organizer that would help with the process of setting appointments, medication reminders, emergency contacts, history of episodes, allergy records, and image storage on a single platform.

Notably, the requirements included a communication platform where patient advocates could update the status of the patients' well being, which selected networks could access. This service would enable the families and other network members to be notified of a patient's well being without intensive patient advocate contact. With this capability, patient advocates would be relieved of the responsibility of answering numerous phone calls and emails.

Another finding from the focus groups was the need of patient advocates to connect with other patient advocates experiencing similar traumatic events. Strikingly, there were strong feelings of disappointment among patient advocates regarding the lack of online support platforms specifically for patient advocates. The participants claimed that existing support groups were not dynamic enough, and that finding a mobile-friendly social support group for patient advocates was very difficult.

A website named carebridge.com was well known and referred to within the group. This website connects people experiencing a significant health challenge to family and friends. In pursuit to making each care providing experience easier it offers personal and private space to communicate and show support, saving time and emotional energy when health matters most. It enables users to create a personalized website. Authors add health updates and photos to share their story while visitors leave messages of love, hope and compassion in the guestbook. (carebridge.org) The participants of my focus group explained, however, there is some time required to make the webpage, personalize it, add contacts, and finally learn the navigation. Patient advocates would have considered using the site's services while they were passing time in waiting rooms, but the site is not mobile friendly. By the time patient advocates arrive home or at their desktop computers, it is highly unlikely that they will use the site, as they are exhausted.

Focus Groups: Second Session

Upon the completion of the first experience, focus group meeting information architecture tools were implemented, including static and interactive wireframes, content maps, user decision trees and informational taxonomies. The tools were then consolidated into a single interactive low-fidelity mock-up of a tablet-based app. In the second focus group, meeting participants were presented with the mock-up, and were asked to provide feedback on the proposed services, which aimed to meet the needs of patient advocates (fig. 6 and 7).

Figure 04: Wireframe interface exploration: medication, allergies, immunization tool

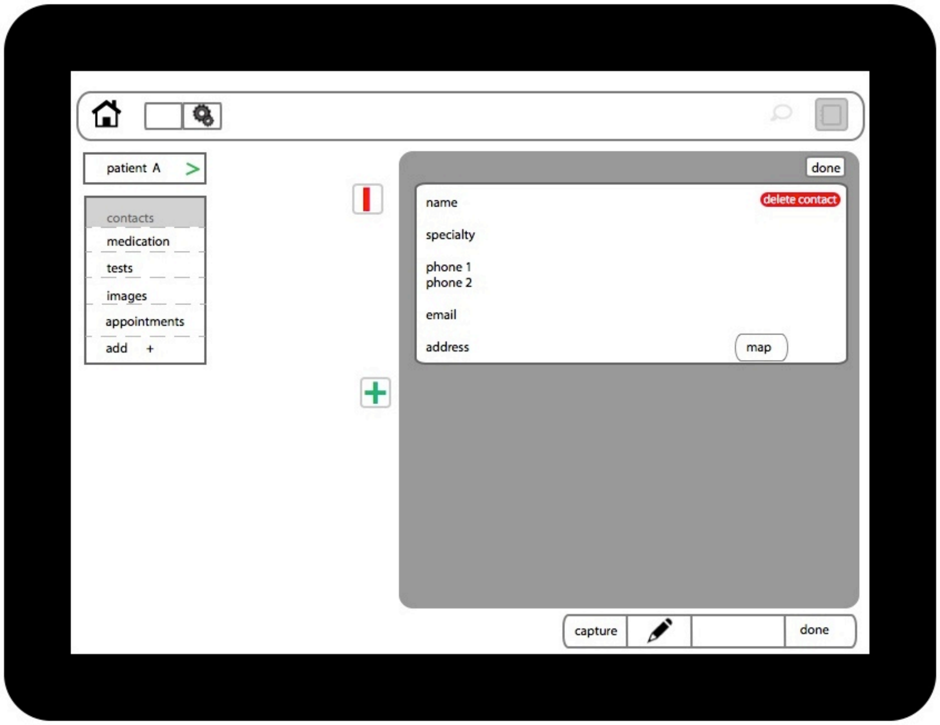


Figure 05: Wireframe interface exploration: emergency and medical contacts

By the end of the meeting, a hierarchy of services was identified, labeled, integrated and prioritized. The hierarchy of services and tools to be provided by the proposed app were: a patient status update platform for chosen network members, a connection opportunity with other patient advocates dealing with similar experiences, a designated emergency and medical practitioners contact information list, a health information collection system including a past and current medication list with side-effects, an appointment and medication notification system, image uploading capabilities, and an allergies list. These functions and tools may alleviate the stress that accompanies a mentally exhausting patient advocate experience.

4.0 Analysis

4.0 Analysis

This design research first started with ethnographic fieldwork. During this time, several conclusions were drawn. In the semi-structured interviews held at the chosen hospitals, it was found that healthcare providers' and authorities' assertions of the importance of leaving patients alone to rest is incorrect. This misconception is borne from the belief that visits from family and friends cause stress to patients. Patients were actually much more at ease knowing that their loved ones were nearby. Patient advocates were also more relaxed and reassured when they could keep an eye on patients at all times. It was found that the patient advocates provide patients with emotional support in an over-stimulating environment, and lend a sense of familiarity in unfamiliar surroundings. The same was concluded for patient advocates. Empirical data also shows that visits by family and friends do not usually increase patients' stress levels, as measured by blood pressure, heart rate and intracranial pressure, but may in fact lower them (Meredith, and Wood, 1996).

After interviewing patient advocates and professional staff, it was found that patient advocates serve as a helpful support structure facilitating communication between patients and clinicians. Furthermore, patient advocates were well informed about the wellbeing of patients, which enabled them to pass along this knowledge to patients' extended social networks. Patient advocates were often also able to provide feedback to nurses and physicians more effectively than the critically ill patient. The strict nursing hours and inflexibility of the healthcare institutions, however, created unnecessary stress for patient advocates. During interviews with nurses and volunteer staff, it was found that medical care providers were subconsciously dependent on patient advocates for mediation and communication with patients. Consciously, however, there was an evident lack of emphasis on the importance of patient advocates' role within the system as a whole, which has resulted in limited support for patient advocates.

Custom-tailored organizational and networking tools designed specifically for distressed patient advocates could create a meaningful experience that would counter the negative experiences patient advocates might experience due to their already distressing situation, or a lack of support and understanding for them and their roles within the medical system as a whole.

To provide supportive data for the ethnographic research, a set of focus group workshops were held. Both performance and qualitative feedback data was collected. During these workshops, interaction with the app was tested. The ease of use and learning opportunities was noticeably high during the usability testing. Patient advocates reported that it was easy to get to their desired destination when they had a task in mind. The number of tabs and pages they had to go through was irrelevant to them, as long as they knew where they were and where they were heading. The taxonomy was also tested in several decision tree activities. Users related faster to icons, and used the titles of functions as reassurance. This feedback provided opportunities for the design of the app to improve. A feedback loop held upmost importance, due to the haptic nature of the device. Functions that lit up and changed color were regarded higher than those with another popup prompt. The visual design was presented in the form of mood-boards and color swatches Patient advocates reacted positively toward nature scenes and organic forms of info-graphics.

The goal of the user tests and task flows was to observe the way participants interacted with the product. During this observation, however, distinct user experiences and emotions were noted as arising from use interaction with the product. Patient advocates walked away with an ease of mind that their logistical health recording needs were consolidated on a single mobile platform. It was concluded that the services this app provided could measurable reduce anxiety and stress experienced by flustered patient advocates.

5.0 Design Brief

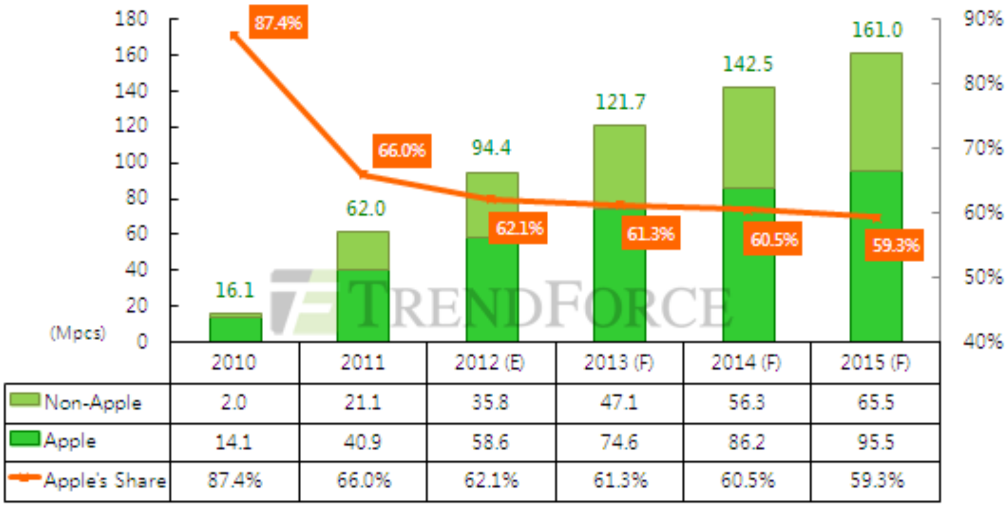
5.1 Tablets and Gestures

> *"Experts are rarely insulted by something that is clear enough for beginners. Everybody appreciates clarity."*
>
> —Steve Krug (2000)

Through the observation of patient advocates in healthcare facilities, it was noted that many used iPads and were more comfortable with the Apple operating system (iOS) versus others on the market. Apple products have become a key player in healthcare. The iPod touch for example, has greatly benefited patients with down syndrome, autism, stroke and other speech-impairing conditions via its speech software. The iPad has continued to provide these benefits amongst others on a larger and more dynamic platform. The iPhone has revolutionized mobile phones with it's effective human centered design. It has allowed many who have been reluctant to use iOS devices to reconsider. The iPad has done the same for tablets ever since its launch and consumers have had a sense of familiarity with the iOS therefore, adapting to the iPad requires minimum efforts.

Focus group members were very attracted to the idea of a tablet because of its size. The tablet is much more convenient to carry around than a laptop. It is also simple to use while serving multiple purposes, and is excellent for both entertainment and business purposes. Along with the portability and simplicity, what appeals to even the non-tech crowd is the intuitiveness of a tablet's natural user touch-interface and simplicity of iOS.

While there is a surfeit of options in the market, the tablet world is predominantly divided between the Apple iPad and Android hemispheres. The iPad, however, is the leading tablet on the market by 87% in 2010. (http://press.trendforce.com, 2012). Figure 8 shows that despite the growth of non-Apple products in the market the iPad will still be the leading tablet by 2015. While the iPad has the same operating system as the iPhone and offers many of the same services, the iPad focuses on business and leisure. The iPad's large screen has more information real estate, resulting in a superior experience for watching and recording information.



	2010	2011	2012 (E)	2013 (F)	2014 (F)	2015 (F)
Non-Apple	2.0	21.1	35.8	47.1	56.3	65.5
Apple	14.1	40.9	58.6	74.6	86.2	95.5
Apple's Share	87.4%	66.0%	62.1%	61.3%	60.5%	59.3%

Figure 06: TrendForce: 2012 Tablet Sales to Hit 100 Million; iPad to Take Up 60% Market Share Retrieved from http://press.trendforce.com/en/node/3218.

The direct manipulation capabilities of the iPad allow users to directly interact with an object in the digital world through touch. Users relate to this notion because it is exactly how they would react to an object in the physical world. The key to direct manipulation is the notion that the result of the interaction with an object is so closely associated with the user's input that they perceive no barrier between the virtual and the real.

It is a designer's responsibility to provide mental cues and indicators to the users of the product. Immediate feedback in the case of a digital application is necessary to guide the user through the functions. This is especially significant in a haptic device, where the sense of touch has been minimized and the user has been reduced to pressing a virtual button as opposed to an actual one. When using a touch screen device, it is a necessity to look directly at the screen to obtain visual confirmation as feedback. In every web application, a continual feedback loop assists with engaging the user. This is very significant to the tablet experience.

5.2 Clutter Reduction & Simplicity

One reason for technology's advancement today is a constant human need to make life easier. Often, however, technology defeats its intended purpose of making life easier due to its confusing software systems and information architecture. Norman (1988) indicates that with the creation of each new technology, a new benefit is offered to the user; with new benefits, technologies become more complex, which may lead to a paradox in design.

Due to faulty mental models, the patient advocate may feel frustrated, confused and incompetent, concluding that they are not technologically savvy. The real blame should rest on the design of the overly-complicated application. As Norman (1988) suggests, "the principles of good design can make complexity manageable." To avoid the paradox of technology, it is important to give voice to UXD and HCD. This is particularly significant in designing an operating system that specifically targets distressed patient advocates. By carefully deploying HCD practices in a software application, it is viable to alleviate stress and anxiety of patient advocates without adding to it with technological complexities.

One way to alleviate stress through design is to emphasize simplicity and organization of functions. John Maeda, in his book *The Laws of Simplicity* (2006), addresses the importance of simplicity in design using ten different laws. One clutter-reducing law that can be applied to help enhance the experience of app users is *The Law of Organization*. Maeda states: organization makes a system of many appear fewer (p. 11). He goes further to say that the organization of items has to be grouped together in order for them to make sense as a whole entity. He introduces SLIP, which stands for "Sort, Label, Integrate and Prioritize," as a means to organize a design process. An app should not consist of too many controls and complex functions, or the complexity of the design will defeat the purpose of alleviating patient advocate stress. Edward Tufte on information design states (1990) "Clutter and confusion is a failure of design, not an attribute of information." By employing SLIP and adding the "meaningful" in the design process, it may result in the elimination of unnecessary interface layers within the application. This provides users a meaningful and seamless experience with the app.

For a better usability and user experience, the application has also been designed using Normans' seven principles of "transforming difficult tasks into simple ones" (p. 188). One of the principles that has been taken into particular consideration for the design of this app is simplify the structure of tasks. Norman stresses that designers need to pay particular attention to the user's limitations of long-term and short-term memory: "tasks should be simple in structure, minimizing the amount of planning or problem solving they require. Unnecessarily complex tasks can be restructured, usually by using technological innovations" (p. 191). He goes on to state that "the system should provide technological assistance for any temporary memory requirements" (p. 192). This application in particular should not frustrate the users by requiring them to remember more than five unrelated items at a time. One key to the success of this application is to provide mental aids that keep the tasks simple. Simplifying the information architecture of an app ensures that the use of such a potentially complex interface is understandable and enjoyable by even distressed users. Another critical part of the design is the visual aesthetics of the app.

5.3 Visual Design

> *"Like all forms of design, visual design is about problem solving, not about personal preference or unsupported opinion."*
>
> —Bob Baxley (2003, p. 363)

During the focus groups and user tests, the participating patient advocates were presented with various themed mood-boards and color swatches. Among them were business, nature, cheerful and Zen-inspired themes. Participants responded positively towards the nature scenes and found them calming and pleasant to look at. The nature graphics were highly regarded, even by those who did not spend much time outside with the natural environment. Group members found that these scenes were "reminders and inspiration" to make the time for outdoor activity (anonymous, personal).

It has been theorized that nature and other positive distractions have therapeutic components that effectively improve mood and behavior while alleviating human stress. When someone experiences stress and anxiety, looking at particular kinds of nature scenes may elicit beneficial psychological changes such as lowering blood pressure (Ulrich et al., 1991). The deliberate attempt to translate an understanding of the inherent human ability to affiliate with natural systems and processes is known as biophilia (Wilson, 1984; Kellert and Wilson, 1993). It may be beneficial to incorporate holistic design process such as biophilic design into the digital environment. As was confirmed in the focus groups and user tests, one way to use nature is as a metaphoric visual language.

However, the app should not be decorated with green graphic leaves and wooden backgrounds. Micheal Mehaffy and Nikos Salingaros argue that fake wood patterns, cultured stones and laminated floors are a fake aesthetic costume and do not offer any biophilic nourishments (Salingaros and Mehaffy, 2006). As a case in point, the singer Bjork has collaborated with artists, designers and programmers to create an app that is named after her album Biophillia. Her app is an exploration platform where music meets nature and technology. The app uses nature as metaphor to playfully navigate through the tracks and the lyrics. Similar to how Bjork's app uses biophiliac techniques to enhance music experiences, the patient advocate app uses biophiliac techniques to enhance the user experience, and navigation design process to create a space that stimulates and engages the patient advocates in ways that alleviate stress and allows them to momentarily escape their reality.

The cheerful and colorful info-graphics were also highly regarded. They proclaimed that spending energy thinking about illness or death requires a boost in spirit and mood. While sitting in institutional waiting rooms it helps to interact with an app that is uplifting and even humorous (fig. 07).

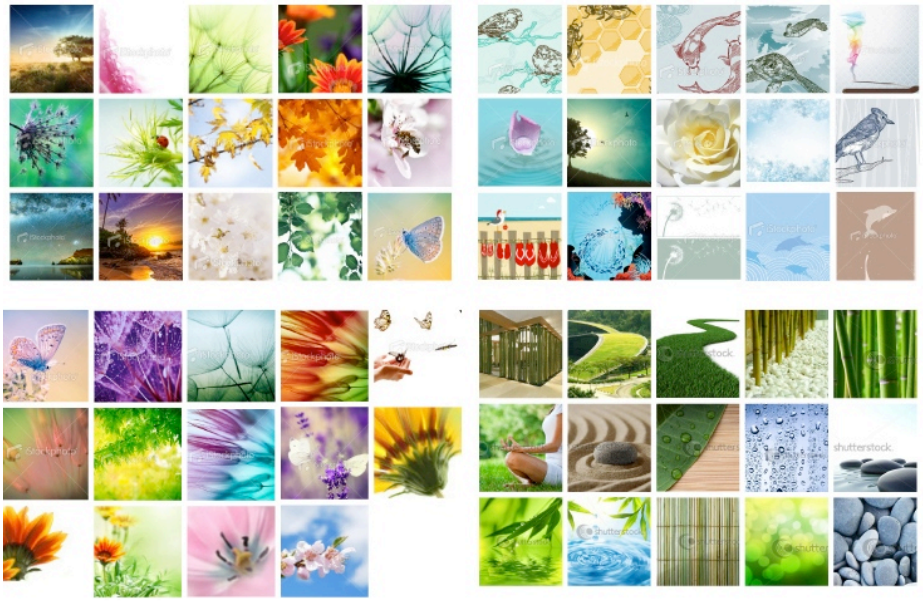
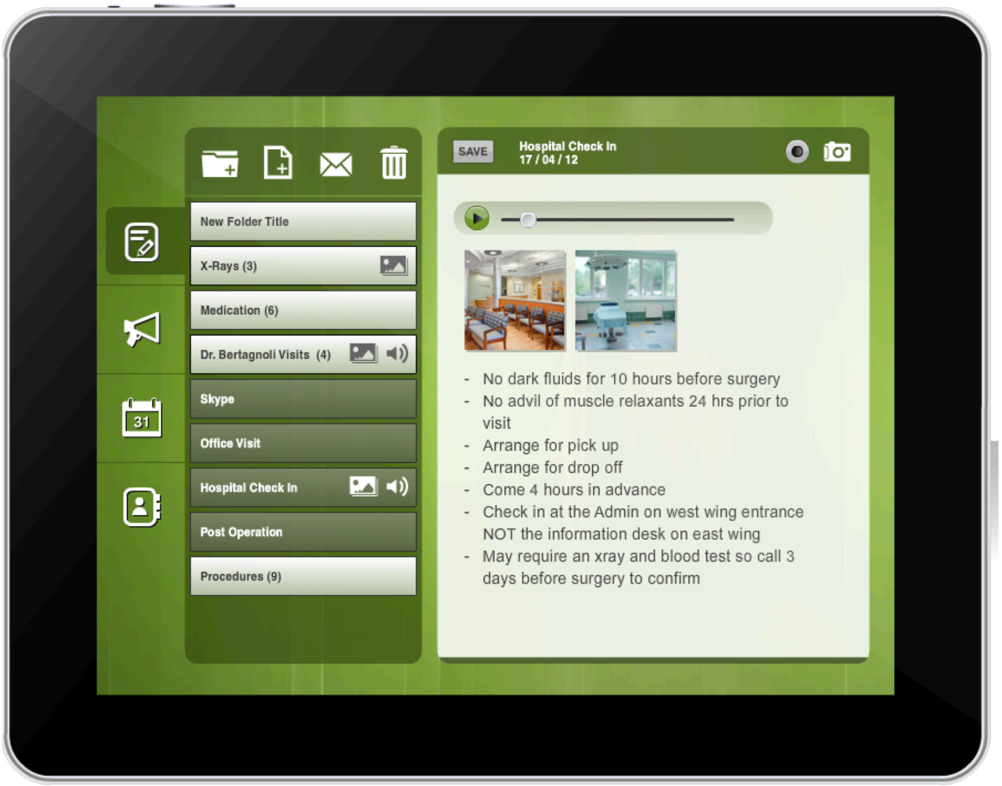


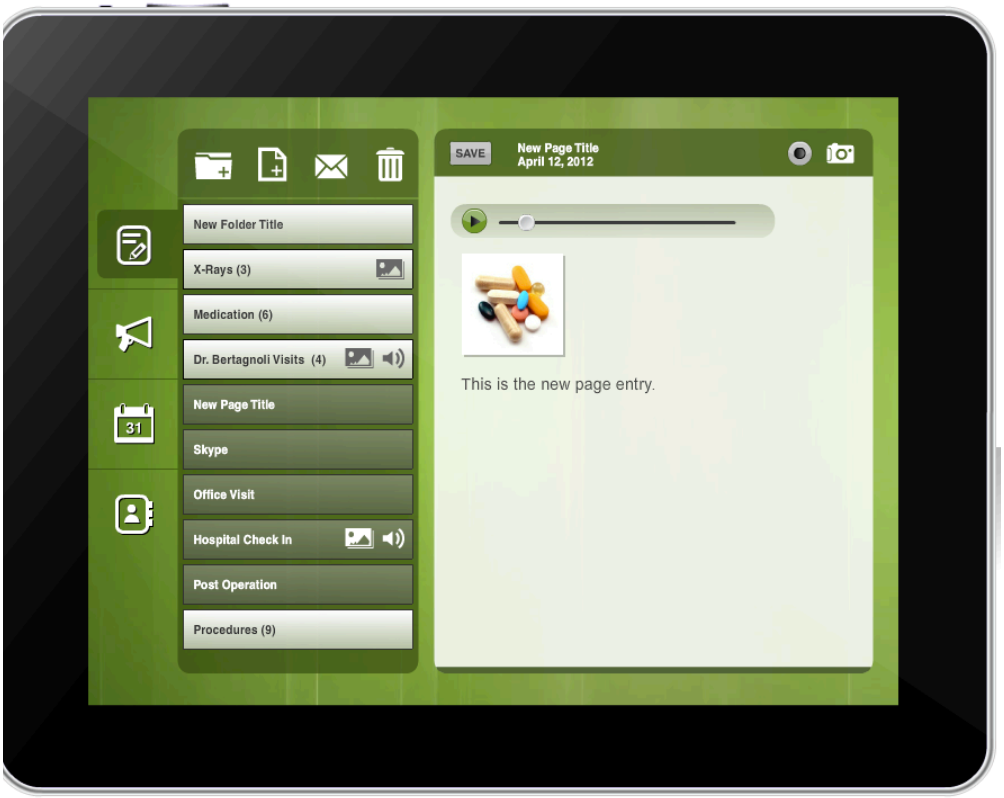
Figure 07: Mood-boards used to explore visual design during focus group session two.

Figure08: Note feature allows patient advocates to capture conversations and file them.



- No dark fluids for 10 hours before surgery
- No advil of muscle relaxants 24 hrs prior to visit
- Arrange for pick up
- Arrange for drop off
- Come 4 hours in advance
- Check in at the Admin on west wing entrance NOT the information desk on east wing
- May require an xray and blood test so call 3 days before surgery to confirm

Figure09: Additional note taking features include voice recording and image capturing.



This is the new page entry.

Figure10: File View mode.

Today 12:24 pm
Just spoke with Dr. B. Everything...

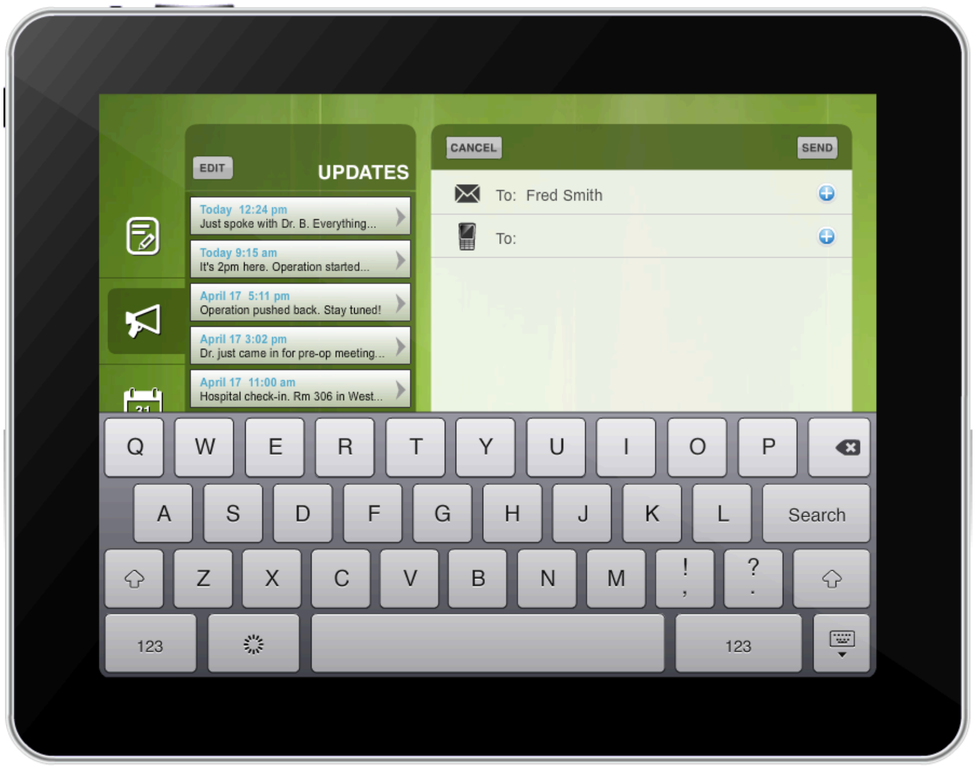
Today 9:15 am
It's 2pm here. Operation started...

April 17 5:11 pm
Operation pushed back. Stay tuned!

April 17 3:02 pm
Dr. just came in for pre-op meeting...

April 17 11:00 am
Hospital check-in. Rm 306 in West...

Figure11: Push Notification function allows users to send patient status updates at once.



Today 12:24 pm
Just spoke with Dr. B. Everything...

Today 9:15 am
It's 2pm here. Operation started...

April 17 5:11 pm
Operation pushed back. Stay tuned!

April 17 3:02 pm
Dr. just came in for pre-op meeting...

April 17 11:00 am
Hospital check-in. Rm 306 in West...

To: Fred Smith

To:

Figure12: Push Notification function

6.0 Conclusion

6.0 Conclusion

This paper identifies a significant knowledge deficit in patient advocate-centric healthcare design. The research investigates several different design processes that can be used to remedy the emotional, mental, and logistical needs of patient advocates. As a result, human-centered-design, empathic design, and healthcare experience design is utilized to remedy the needs of patient advocates.

First, the critical role of patient advocates within the healthcare system has been identified. They tend to be the main communication backbone between the patients and care providers, and patient and extended family. Their bedside companionship and mere presence reduces the patient's stress levels who often feel vulnerable in an over stimulated environment. This research has found that supporting patient advocates is unquestionably vital to the overall healthcare system as they play a significant role in it. Most patient advocates juggle many responsibilities being that of their chronically ill loved ones and that of their own. Some of these responsibilities include accompanying procedures and treatments, gathering patient health related information, making appointments, and facilitating decision-making. As a result of these responsibilities, patient advocates are stressed, and mentally exhausted. By reducing these strains, patient advocates are better able to cope with their stress, and provide better care and support for themselves and for the patient they are caring for.

Second, the emotional and logistical needs of patient advocates were investigated through several design research methodologies. Ethnographic field work offered a closer insight into a typical day of a patient advocate. By observing behaviors and social interactions, it was found that patient advocates and frequent hospital goers own iPads which they carry with them during hospital visits. This led to the realization of the significant role mHealth plays in providing organizational and emotional support to patient advocates. To explore these needs, patient advocates were invited to participate in focus groups and user testing sessions. As a result, palliative design recommendations were made. Strategic user-experience-design, human-centered-design and mhealth have been triangulated to create an iOS app for an iPad.

The app is specifically designed for patient advocates. It offers an integrated platform made of organizational and communication tools. The research conducted suggests that patient advocates are in dire need to communicate with others who are experiencing similar traumatic events. The social networking aspect of the platform enables users to exchange health related information and sympathy by digitally connecting with other patient advocates ‘alike’.

The research also suggests that patient advocates need a consolidated platform to update the patient’s health status they are caring for. This alleviates the stress of receiving and making multiple phone calls, sms messages, and emails to extended family members and friends. The organizational tool acts as a mobile patient health data system that enables users to set appointment alerts, medication details, and health history. The content of these services tackles patient advocates’ logistical needs by creating an ease of mind and psychosocial support. The information architecture focuses on the necessity of keeping design simple with an emphasis on ease of function and usability heuristics.

As the mobile health industry grows exponentially with the number of health and medical related apps being downloaded, so will the interest of stakeholders and designers. The question remains: will designers and stakeholders realize the significance of patient advocates and caretakers? By using the mentioned design processes in this thesis, it is hoped the roles of patient advocacy be emphasized in future healthcare experience design directions.

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Appendices

Appendix
A. Letter of Invitation and Consent Form

Project Title: Support System for Patient Advocates

Dear medical professional and patient advocate,

You are invited to participate in a study that involves research. The purpose of this study is to investigate ways to alleviate unnecessary stress experienced by patient advocates through design tools in a hospital setting. Interviews with professional hospital personnel along with co-creation workshops aim to foster a better understanding and appreciation of the needs of patient advocates. Results will inform the development of a web, mobile app, and way-finding support system that aims to support the patient advocate in caring for their patient with the hospital system.

WHAT'S INVOLVED

The research study will consist of two parts, one personal interview, and a three phased co-creation design workshop.

The interview session, conducted by Sogol Assadbeigi, will take no longer than 20 minutes in a location most convenient for you. You will then be invited to join a small group of individuals for a co-creation workshop at Emily Carr University of Art and Design on Granville Island, Vancouver BC. The researcher, (Sogol Assadbeigi), will encourage an open discussion on how design can facilitate the needs of patient advocates in a hospital setting. You will be provided with appropriate stationary and are asked to take part in the design solution. In a second phase you will be asked to provide your comments on sketch models and mock-ups of the possible design solution. In the final phase you will asked to test and comment on the usability of the final prototype. Each co-creation workshop will take approximately 1.5 hours of your time.

POTENTIAL BENEFITS AND RISKS

Possible benefits of participation include a better understanding of the issues revolving way-finding and environmental psychology design, and potentially improve the role of the patient advocate which may result in better care. The research project is aimed at benefit the healthcare system attempting to improve the experience of patient advocates in a hospital setting.

There also may be risks associated with participation as participants may experience some stress in answering questions. The researcher will check in frequently with the participants to ensure that they are prepared to continue with the interview questions or probe activities. Participants will be advised of their right to withdraw, without penalty at any point in time.

CONFIDENTIALITY

Participants' contact information and identifiers (name, addresses, occupation) will be handled confidentially by the researcher (Sogol Assadbeigi). All information that you provide will be handled as confidentially as possible and grouped with responses from other participants. Given the format of the workshops, we ask you to respect your fellow participants by keeping all information that identifies or could potentially identify a participant and/of his/her comments confidential.

Data collected during this study will be secured via password protection on the primary computer used for the research and backed up on a secondary password-protected computer in a secondary location. All other research will be stored in a locked filing cabinet in a secured location. A complete set of all original research will be retained by the principal investigators for a period of five (5 years) from the date of publication results based on the data as per policy ECUAD Policy 5.1.1 p. 3 after which time it will be disposed.

VOLUNTARY PARTICIPATION

Participation in this study is voluntary. If you wish, you may decline to answer any questions or participate in any component of the study. Further, you may decide to withdraw from this study at any time and you may do so without any penalty or loss of benefits to which you are entitled.

PUBLICATION OF RESULTS

Results of this study may be published in reports, professional and scholarly journals, students theses, and/or presentations to conferences and colloquia. In any publication, data will be presented in aggregate forms. Quotations from interviews will not be attributed to you without your permission. Images of you will not be published without your permission.

Feedback about this study will be available upon your request. All participants will be invited to the graduate exhibition and the thesis defense. In addition, a package of the results will be complied and digitally given to each participant at their request. Each participant will be made aware that they will have access to said digital package. You may contact me directly to obtain further information on the results of the study.

CONTACT INFORMATION AND ETHICS CLEARANCE

If you have any questions about this study or require further information, please contact the Principal Investigator or the Faculty Supervisor (where applicable) using the contact information provided above. This study has been reviewed and received ethics clearance through the Research Ethics Board at the Emily Carr University of Art and Design ECU-REB File #2011051203. If you have any comments or concerns, please contact REB Assistant, Lois Klassen at ethics@ecuad.ca

CONSENT FORM

I agree to participate in this study described above. I have made this decision based on the information I have read in the Information-Consent Letter. I have had the opportunity to receive any additional details I wanted about the study and understand that I may ask questions in the future. I understand that I may withdraw this consent at any time.

Name: ____

Signature: ____________________________Date: ______________

Thank you for your assistance in this project. Please keep a copy of this form for your records.

Research Ethics Board Approval # 2011051203
Sogol Assadbeigi
Emily Carr University of Art + Design
Contact Information
sassadbeigi@ecuad.ca**Appendix**

B. Digital Image and Audio Release Agreement

Date: November 1, 2011

Can an integrated communication platform help prepare and support a patient advocate for a better care providing experience?

The purpose of this study is to investigate ways to alleviate unnecessary stress experienced by patient advocates through design tools in a hospital setting. Interviews with professional hospital personnel along with co-creation workshops aim to foster a better understanding and appreciation of the needs of patient advocates. Results will inform the development of a web, mobile app, and way-finding support system that aims to support the patient advocate in caring for their patient with the hospital system.

In signing this release it is my understanding that the material is to be used solely for educational purposes and that the major outcome will be public critique of the final project. The critique will involve members of the University community. I understand the risks and contributions of my participation in this project and agree to participate. I agree to allow use of images, clips of video footage and/or audio clips for documentation and display of the project results as identified below. I understand that the material may be used in the Emily Carr University of Art and Design Website, future academic papers, thesis report, case study reports, and thesis presentations. Furthermore, I understand that the images and video footage will be identified by the workshop phase, and location, and that the names of participants, including mine, may be used in the documentation of the interviews and workshops.

Please check all that apply:

ANONYMITY -
0 Yes, I consent to the inclusion of my identity (name) in all documentation and publications
0 No, I do not consent to the inclusion of my identity (name) in all documentation and publications. I choose to remain anonymous.

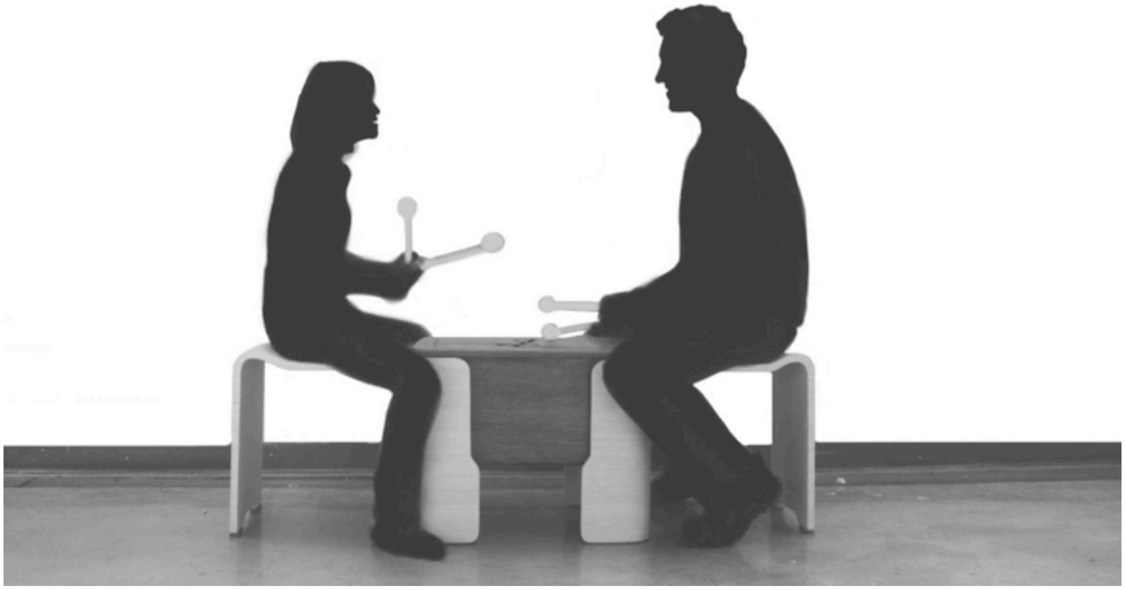
DIRECT QUOTATIONS -
0 Yes, I consent to being quoted in all documentation and publications
0 No, I do not consent to being quoted in the documentation and publications

IMAGES AND RECORDINGS OF ME OR OF MY PROPERTY -
0 Yes, I consent to the use of digital images (photos or video) or audio recordings taken during the

research user trials to be used for research and publication purposes.
0 No, I do not consent to the digital images (photos or videos) or audio recordings taken during the research user trials to be used for research and publication purposes.

0 Yes, I consent to my photo being published in any of the final publications
0 No, I do not consent to my photo being published in any of the final publications

0 Yes, I consent to my photo being converted to a line drawing, with all personal identifiers removed, as seen in the example provided below.
0 No, I do not consent to my photo being converted to a line drawing, with all personal identifiers removed, as seen in the example provided below.



I will indemnify and hold the student, and the University, and its employees safe and harmless against any legal prosecution or suit arising from or prompted by the use of all or any portion of the material in which I am quoted or appear.
I am signing this release freely and voluntarily and in executing this release do not rely on any inducements, promises or representations made by said student or Emily Carr University of Art and Design.
Name:______________________________ Date:____________________
Signature:____
Witness Name:_________________________ Date:____________________
Signature:____

Thank you for your participation.
Research Ethics Board Approval # 2011051203