

Using Mobile Phones to Present Medical Information to Hospital Patients

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ABSTRACT

The awareness that hospital patients have of the people and events surrounding their care has a dramatic impact on satisfaction and clinical outcomes. However, patients are often under-informed about even basic aspects of their care. In this work, we hypothesize that mobile devices – which are increasingly available to patients – can be used as real-time information conduits to improve patient awareness and consequently improve patient care. To better understand the unique affordances that mobile devices offer in the hospital setting, we provided twenty-five patients with mobile phones that presented a dynamic, interactive report on their progress, care plan, and care team throughout their emergency department stay. Through interviews with these patients, their visitors, and hospital staff, we explore the benefits and challenges of using the mobile phone as an information display, finding overall that this is a promising approach to improving patient awareness. Furthermore, we demonstrate that only a small number of technology challenges remain before such a system could be deployed without researcher intervention.

Author Keywords

Patient awareness; mobile phone; health information

ACM Classification Keywords

J.3 [Life and Medical Sciences]: Health;

INTRODUCTION

Hospital visits are stressful experiences for patients and their loved ones [4]. Anxiety stems from the myriad uncertainties faced during a hospital stay: What is wrong with me? What will they do to fix it? When will I be able to leave? Simple answers to these questions are usually unavailable, but there is evidence that better information flow during a patient's stay can mitigate the impact of the uncertainty. A recent exploration by Wilcox et al. [22] suggests that patient comfort and satisfaction during an emergency department (ED) visit might be greatly improved if, in addition to verbal communication, patients are kept informed of their health status and treatment progress with a real-time,

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CHI '12, May 5–10, 2012, Austin, Texas, USA.

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in-room display. The use of dedicated in-room displays for improving patient awareness holds great promise, but also has limitations: privacy is difficult to preserve, patients arrive unfamiliar with the device, displayed information is not portable, and interaction is limited.

We hypothesize that mobile devices – increasingly entering the hospital with patients and caregivers – address these limitations and offer an alternative for information delivery in clinical environments. We further hypothesize that presenting medical information on a patient's mobile phone will promote a sense of *information ownership* as a consequence of physical possession of the device, which we anticipate will lead to increased patient engagement.

In order to explore these hypotheses, we present a design for an interactive, mobile-phone-based information display for emergency department patients. Through a field study with 25 patients and their families, we explore the benefits and challenges associated with handheld devices as medical information displays. Our study provides evidence of positive patient responses to personal information displays, and provides guidance for future work in this area.

The specific contributions of this paper are:

- (1) A design for a “patient-friendly” handheld information display, including a real-time stream of simplified, abstracted information.
- (2) A field study evaluating this design, focusing on the subjective response of patients, family members, and hospital staff.
- (3) An exploration into the feasibility of deploying such a display at scale and without researcher intervention, highlighting remaining challenges but demonstrating that this approach is feasible in the near-term future.

RELATED WORK

Patients in the emergency department (ED) are presented with a tremendous volume of information in a short time, much of it critical to medical decision-making and long-term health management. However, due to stress, medication, limited medical literacy, and other factors, patients are unable to absorb and remember information such as care plans and discharge instructions [7,9,11]. This failure to absorb information has immediate impacts on patient satisfaction: Krishel [10] and Boudreaux [3] both find that pa-

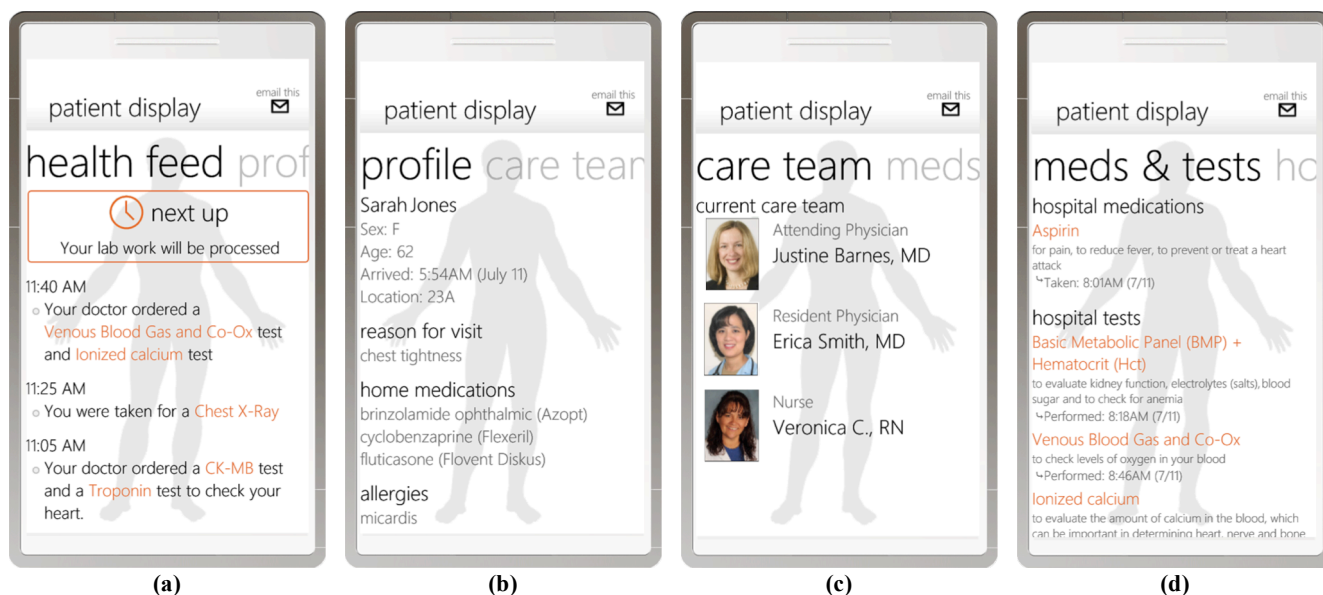


Figure 1: The main screens of our mobile patient interface. (a) The Health Feed provides a real-time list of pending and completed care events. (b) The Profile page provides general information about the patient’s visit. (c) The Care Team page provides a record of relevant staff. (d) The Meds & Tests page provides a list of medications and tests administered during the patient’s stay.

tients who are more informed about their ED process report higher satisfaction and better impressions of care quality.

Perhaps more important is the fact that limited understanding of care has clinical consequences. Patients’ access to and understanding of information is directly related to their anxiety levels [4,21]; high anxiety has been shown to correlate with negative clinical outcomes and in-hospital complications during emergency treatment [1,6,14]. Inadequately informed patients often incur repeat visits and fail to comply with discharge instructions [18].

In contrast, encouraging patients to seek more information and ask questions proactively during clinical visits has been shown to reduce anxiety [19], improve compliance with instructions [17], and improve patient satisfaction [8]. Accordingly, clinical facilities often provide patients with pamphlets or other literature to facilitate patient understanding. However, generic, non-interactive materials often contain information not applicable to a given recipient, or are presented at an inappropriate health literacy level, especially for a patient under stress [15,18]. In other words, generic pamphlets often contain an overwhelming amount of information, when patients and family members often want just a short, high-level summary of medical information [21,13]. Consequently, the clinical literature demonstrates significant deficiencies in the effectiveness of paper discharge materials [15,18].

Fortunately, there is early evidence that computer-based displays can provide information that is more patient-friendly and patient-specific than traditional paper materials. Wilcox et al. [22], for example, presented ED patients with paper-based, Wizard-of-Oz prototypes of in-room computer-based displays containing simplified medical information. Patient response to these displays was positive;

the displays were found to both calm patients and facilitate communication with family members and providers.

Bickmore et al. [2] take a different approach, presenting hospital patients with a computer-based conversational agent acting as a “virtual nurse” to assist in presenting discharge instructions. Patient response to this approach was positive as well, with most patients indicating that they preferred receiving information from the computer-based agent than from a doctor or nurse.

To our knowledge, almost no work has explored using a mobile device for in-clinic information display. Vawdrey et al. [20] have looked at tablet-based access to a Web portal, but present only early-stage, albeit promising, subjective responses. Other work has shown that the mobile phone is a promising form factor for outpatient, chronic care management [5,12], but did not explore potential in-clinic benefits.

In the present work, we explore the extension of patient-specific, patient-friendly information displays to the mobile phone, which we hypothesize has unique affordances – and ever-increasing availability – that make it a powerful clinical information delivery medium.

THE MOBILE PATIENT DISPLAY

Providing patients with health information on a mobile phone offers several advantages over other form factors. First, care in the ED is dynamic; new information is continually available and courses of treatment may change rapidly. With a mobile display, patients have private access to their current and historical information in near-real time. Additionally, the ED is an inherently mobile environment. Patients can be in testing locations, in the hallway, or inside their rooms. A mobile display gives patients access to their information regardless of their location.

In order to assess our hypothesis that the mobile phone is a promising platform for medical information delivery, we developed a prototype mobile patient display to serve as an experimental probe. The system presented here represents the endpoint of an iterative design process that included a lab-based pilot study in which we assessed the basic usability and intuitiveness of our design prior to conducting our in-hospital study. For brevity, we present only the final version of our design, but we will briefly discuss key lessons learned from our pilot study later in this section.

Guided by [22], we aimed to include as much information from a patient's medical record as possible. Save for a few data points (e.g., physician notes), the interface contained nearly all data recorded about a patient, data typically only available to the medical team.

Our final design was organized into four pages, shown in Figure 1 (a-d). The user can move from screen to screen with horizontal swiping gestures that we anticipated would be familiar to most smartphone users.

The *Health Feed* (Figure 1a) is a real-time view on key events occurring on a patient's behalf, including administrative events (e.g., being assigned to a room) and medical events (e.g., being administered a medication). When appropriate, each event is associated with a short explanation, such as "to check your heart". This information structure was intended to be familiar to users accustomed to social media feeds, and to be compatible with quickly glancing at the application when engaged in other tasks. The "next up" section of the *Health Feed* contains a dynamic, short description of a patient's next step in their care plan. The *Profile* page (Figure 1b) provides demographic information and general information about the patient's visit, which previous work [22] suggests is surprisingly important in confirming to patients that their medical identity is correctly represented in the system. The *Care Team* page (Figure 1c) provides the names, titles, and pictures of current or past assigned care staff. Finally, the *Meds & Tests* page (Figure 1d) provides a reverse-chronological list of medications and tests administered during the patient's stay, with a short (2 to 23 word) explanation of each.

All medication and test names in Figure 1 can be clicked for more information, revealing a page with additional detail – typically a short paragraph (Figure 2). These "more information" pages contain further links to in-depth online information, at sites approved by hospital staff (e.g., NIH MedlinePlus). Each page also contains an "email this" button, which allows a patient to quickly email information to herself or to family members.

Pilot Study

We recruited 12 people (8 male) from the general population of the Seattle, WA area who had recently (within the year) been a patient at a hospital. Participants had a range of technology expertise and education levels, were between 20 and 52 years old (median 34), and most (10) owned

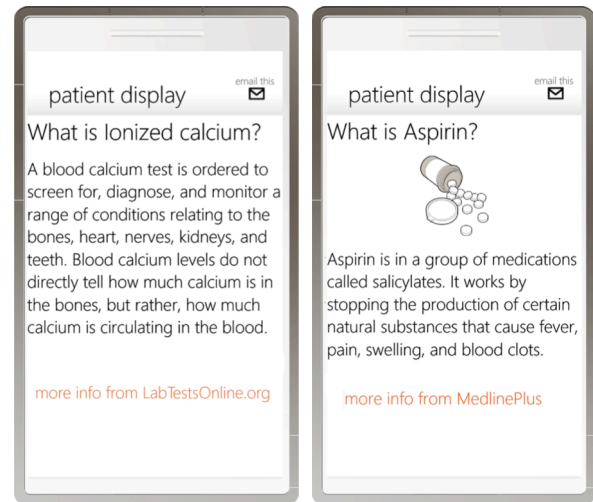


Figure 2: Clicking links on the main screens reveals more detail about tests or medications. Clicking links on these "details" pages opens an approved online resource in a browser.

smartphones. The evaluation consisted of two phases: an interview and a technology probe. We began by conducting a semi-structured interview about the hospital visit in general, focusing specifically on aspects relating to information access and communication during the stay. During the second half of the evaluation we directed the participant's attention to the mobile patient display, which we pre-populated with data for a fictional patient. Participants provided feedback using a think-aloud protocol and answered questions about perceived usability.

Overall, participants were highly receptive to the interface design and information contained in the display, but they did raise several consistent suggestions, which were incorporated into our final design. Our original prototype included a *Vital Signs* page, which was deemed to provide an unnecessary level of detail that was hard for patients to interpret. Our original mechanism for emailing content used a button labeled "share", which interestingly elicited strong negative responses by evoking notions of sharing via social media, such that even patients who *did* want to email content to loved ones expressed concern about this feature. Our original prototype incorporated information about medications and tests only into the *Health Feed*; patients requested more detail about these information categories relative to other items on the *Health Feed*, so they were eventually promoted to a dedicated page.

EMERGENCY DEPARTMENT STUDY

To understand the impact such a system might have on patients, visitors, and care staff, we deployed our final prototype and conducted a field study in an urban emergency department. All procedures were approved by the hospital's institutional review board.

Wizard-of-Oz Infrastructure

In this study, we used a semi-automated approach to populating mobile displays in real-time. Specifically, we pulled information from the electronic medical record (EMR) and

other sources into an application running inside the hospital network, from which study administrators could send information to patients' mobile phones. This was intended to simulate the fully-automated experience from the patient's perspective (the "wizard" was entirely invisible to participants), while satisfying the hospital's requirement for this study that a human screen all data presented to patients.

Due to logistic and security issues involved in connecting phones to the hospital's infrastructure, we provided Samsung Focus smartphones to participants for the duration of their stay, rather than allowing participants to use their own devices. Our study infrastructure was designed to safeguard data: each phone used a private key to secure an authenticated, encrypted connection to the administrative application, and the administrator could revoke a phone's credentials at any time. Medical data on the phone was stored in memory only, and was discarded when the application was exited or when the phone was locked (which occurred automatically after 5 minutes of non-use). To examine how patients used the prototype, we logged application launches, touch events, page transitions, and link clicks.

The administrative application is written in C#; it hosts a Web service for communicating with the phones, incorporates a SQL database client layer for extracting data from the EMR, and maintains a set of local database files for logging actions by both administrators and patients. The left side of the application's single-patient view (Figure 3) displays information currently visible to the patient's phone. The right side ("EMR Data") exposes non-editable patient data as it exists in the hospital database for the administrator to screen. Double-clicking an entry in this area creates a copy in the lower-right corner of the view that can (optionally) be edited prior to "submitting" to the phone. Entries in the lower-right can also be created from scratch for information derived from sources other than the EMR. Entries submitted to the phone can be edited or deleted at any time, giving the administrator full control over the patient's view.

Procedure and the Role of the Wizard

After a patient consented to participate in the study (see "Participants" for information about recruiting), she was given a 2-4 minute tutorial about the interface, encouraged to ask questions, and left to use the device.

The study administrators worked "behind the scenes" to collate data from multiple sources and submit data updates to the patient's phone. Each time administrators pushed new data to the phone, an audible alert signaled the patient. Updates were generated by administrators based on three sources: 1) EMR orders and results (e.g., "*The lab is processing your blood work*"); 2) physical observations of staff visits (e.g., "*You had a surgery consultation*"); and 3) discussions with the care team about the patient's care plan (e.g., "*You will be admitted to the hospital*"). The descriptions for all entries were pulled from a list of medication, test, and feed entry templates. To provide personalized content, more specific templates were occasionally created

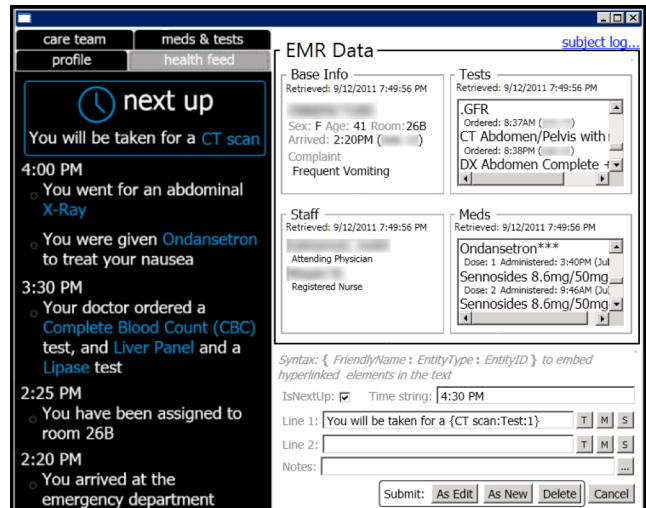


Figure 3: The application used to manage the transfer of data from the EMR to patients' phones. Here, the administrator is editing a "next up" entry for the Health Feed.

from existing ones (e.g., a chest x-ray "to check your heart and lungs" might be altered to "to check your heart"). All such edits and additions were logged. As we will discuss later, examining the precise role that the wizard played allows us to explore the potential for full automation.

Each patient participated in a final semi-structured interview. The interview lasted 10-20 minutes, was audio-recorded, and was conducted by the consenting administrator while another administrator took notes. The interviews covered a broad range of patient reactions to the phone, including: what they liked or did not like; how they interacted with the phone; how the phone impacted their visit; and how they shared the information with visitors or family members (if at all). Upon completion of the interview, each patient received a paper-based representation of their personalized information display that they could take home.

Participants

We conducted our study in the Emergency Department (ED) of a large urban hospital in Washington, DC, over a two-week period in July 2011. We teamed with attending physicians to screen candidates using the following criteria: patients needed to be English-speaking, over 18, feeling well enough to converse, mentally stable, not contagious, and expected to be in the ED for at least an hour. There was no payment or incentive for participation.

We recruited and consented a total of 27 patients. However, two were released prematurely: one was suspected to be contagious and was moved to confinement, and the other was admitted to the hospital quickly to undergo surgery. Of the 25 remaining participants who completed the study, 17 (68%) were female and 23 (92%) were African-American, with an average age of 46 years. Our study population demographics were similar to those of the 1162 patients who entered the ED during the study period (60% female, 80% African-American, with an average age of 47.8 years). Education levels among participants ranged from middle

school (16%), to high school (48%), to college (36%). Twenty-three participants (92%) owned a cell phone and 12 (48%) owned a smartphone.

Family members present with enrolled patients were also invited to participate in interviews subsequent to an IRB-approved consent process. A total of 8 family members or visitors participated in our study.

Finally, we conducted semi-structured interviews with consented hospital staff members. We interviewed 11 hospital staff members, bringing the total number of participants in our study to 44.

RESULTS AND IMPLICATIONS

Our analysis included researcher notes, patient interview audio recordings, and phone usage logs. All notes, augmented by audio recordings, were transcribed and iteratively coded for themes using a grounded theory approach.

We first provide a high-level overview of the patients' phone usage patterns, and then we present the themes gleaned from our data analysis. We describe how patients expressed the alleviation of anxiety and empowerment created by their access to information, as well as the ways in which the medical explanations were perceived as useful. We then transition to findings that are more specific to the use of mobile devices, describing the effect that physical possession of a portable, real-time hospital visit record has on patient memory, information ownership, sharing tendencies, and privacy perceptions. We end this section with observations about the ergonomics of using a mobile device in the hospital, the pragmatics of ensuring content appropriateness at the individual level, and the reactions of healthcare providers – all of which are crucial to consider if we seek to deploy an automated system in the wild.

Phone Usage

Patients had access to the phone for an average of 150 minutes ($sd=33.6$). During this time, patients were presented with an average of 14.4 items, spanning the *Health Feed*, *Meds & Tests*, and *Care Team* pages, including items that were available when patients first received their devices.

Log data revealed that three participants had particularly low usage of the mobile phone display – less than two minutes of total browsing time of the information content: P17, who clearly did not interact with the phone at all after our tutorial, commented that she found the device “too complicated”; P6 only had the phone in his possession for 13 minutes before we were notified of his discharge; and P25 experienced data server connectivity issues that discouraged her use of the phone.

The remaining 22 participants interacted with the phone across an average of 10.8 distinct sessions, where a session was considered ended if the application was explicitly closed or the participant did not interact with the phone for more than 5 minutes. Interestingly, patients only received “alerts” an average of 2.1 times, since in many cases multi-

ple new items were batched into a single “alert”. We interpret the fact that the number of interaction sessions far exceed the number of update notifications pushed to participants' phones as evidence that the information content itself held participant interest over the course of their visit.

Awareness Reduced Anxiety

The most consistent theme that emerged across our participants, mentioned by 21 patients and 5 visitors, was the positive influence that “knowing” or “being in the loop” had on their experiences. Some patients explicitly made the connection between *knowing* and *calming*.

“To know, like they say – knowing is half the battle. I mean knowing – this is crazy, but – knowing sort of makes you feel better. Is that crazy?...I think it sort of strips the fear of ‘what’s next’. It really does.” –P11

“[The display] is like the best thing I’ve seen in a hospital, period ... it calms the person down, because they get a sense of what’s going on, what they just went through, what this was for, what it’s about, what this test is. That thing is amazing.” –Daughter of P9

“...you can actually go to what they're thinking about or what they plan on doing to you and you can see it on the phone. I really loved that... I'm not sitting here guessing and being nervous. What are they looking for? What do they want? What do they see? What do I got to do next? So, this pretty much tells me.” –P12

Patient appreciation for being kept up-to-date was corroborated in interaction logs, where the *Health Feed* page showed the highest mean interaction time of any content page. Patient thirst for information was also evident from the responses we received to questions about the chime-based notification of the system, which we initially thought might be disruptive or annoying. On the contrary, none of the 15 the patients we questioned found the chime annoying and 11 assured us that they wanted updates every time there was something new to be shared with them. (3 other patients had no preference about the timing of notifications, and 1 said it depended on the time of day.)

These findings have several implications. First, patients showed that they indeed *want* access to their medical information in real time. Providing this data is not standard practice during a patient's hospital stay, and patients' desire for real-time access has not been previously shown. Patients enrolled in our study had many reasons not to use the mobile display: they were sick, in pain, tired, had family present, and had access to their own phones. Despite this, they not only used the display, but reported the value it added to their experience, particularly in reducing anxiety. Given that patient anxiety is tied to poorer health outcomes [6], this system has the potential to not only calm patients, but to improve their outcomes overall.

Being “In the Know” Promoted Empowerment

Hospital patients are vulnerable to experiencing a loss of control and dignity, and the resulting disempowerment is a well-known threat to effective medicine and successful outcomes [16]. Patients in our study repeatedly echoed the fact that the phone display allowed them to regain some semblance of participation in their own care:

“I didn’t know that I needed an X-Ray until I saw it on the phone. So when she came in, I was like ‘We’re going for an X-Ray.’ And she looked at me like ‘How’d you know that?’ [laughs]. So I really liked that.” –P12

Six patients expressed tension and frustration around doctors being the gatekeepers of information, and expressed relief that phone removed some of their dependence on doctors and nurses for information. As P20 said:

“We know they are busy dealing with a lot of patients but sometimes when they come to tell you something, it’s like ‘Why didn’t you tell me this 30 minutes ago?’”

Family members also echoed that they appreciated having instant access to the most up-to-date information and expressed that the phone display eased the patient’s burden of having to bring new visitors up-to-speed with the status of their care. One visitor imagined that the information in the display could enable her to ask more specific questions of the doctor. The aunt of P20 stated: *“And if you have further questions, you know how to go about the questions, instead of just ‘well, I wanna know what’s wrong,’ [you can say] ‘this is what came up and I want to know about this.’”*

Somewhat surprising to us was that two patients suggested they perceived the data in the phone to be more authoritative than the staff. P21 stated: *“With someone [...] saying ‘oh, we’re giving you Zofran and that’s for nausea’ you have to take their word for it. With this information here, you can click on it and see what that is.”*

Patients also expressed pride in being entrusted with the device and having access to the information it contained. P19 was particularly struck by the *Profile* page because he was amazed that it was personalized (*“It’s got my name!”*), and he showed the device to his X-Ray nurse and his discharge nurse. P8 invited a volunteer into the room to show her the device, and P16 showed it to her radiologist.

These findings suggest that giving patients real-time updates on their medical care could increase the amount of participatory behavior by patients. As increased participation by patients is shown to improve satisfaction [17] and also improve outcomes [8], these findings are encouraging.

Medical Explanations Were Useful to Patients

One of our design goals was to provide patients information to deepen their understanding of what was being done to diagnose their illness. We were inspired by prior work pointing to the utility of providing short explanations of medications and tests [21,22], as well as our pilot study which surfaced examples where patient “information star-

vation” had negative consequences. For example, three of our pilot participants recounted situations in which they did not have access to key information to make appropriate decisions about their care plan or to provide truly informed consent. In addition to providing a short, 2-23 word explanation for each medication and test, we included, on demand, an additional 1-6 sentence explanation and a hyperlink to an authoritative website. While we were unable to quantify knowledge transfer or retention, we did look for evidence of whether patients valued this extra information.

Interaction logs revealed that 24 participants navigated to the *Meds & Tests* page. Furthermore, 9 participants explicitly mentioned exploring the more detailed descriptions of medications and tests in our interviews. Interaction logs found that 13 participants clicked through to the details pages of 20 unique tests and medications (an average of 3 unique pages per participant). Nine participants spent more time reviewing medications, tests and related details than in any other part of the interface.

Subjectively, patients often mentioned the significance of the *Meds & Tests* page of the interface. For example, P3 appreciated *“... the educational component, because it describes what the tests are. So, I wasn’t laying here wondering, ‘what does PTT mean?’ I liked that piece of it.”* P8 also referred to the interface as “educational”, commenting that *“I learned something. It kind of teaches you.”* During the interview, she used the phone to bring up an explanation of a test, and said, *“See, I didn’t know these things!”* P21 found the test information useful *“because I didn’t necessarily know what – hold on – [bringing up the Meds & Tests page] what a lipase test did and what it was. It was to check for inflammation of the pancreas. So when you don’t know something, you know. It’s good and it gave you enough information to be, you know, to be sure of what it is.”* She also made the point that it was useful even if she could not fully grasp what it meant: *“Even though medically you may not know what it is they’re doing, it kinda gives you a sense of security that, you know, these are tests that they’ve taken... You don’t have to be a medical doctor.”*

Many family members also stated that they appreciated the medical explanations, not only to deepen their own understanding, but also to help their loved one grasp what was happening with regards to their care. The daughter of P9 stated that she spent the most time looking at the *Meds & Tests* page, *“Because it tells you exactly what it means and what it’s for. So that’s the part that I was on the most. So I can tell her – instead of just saying that it’s ‘blood work’ – I want her to understand exactly what blood work it is, so she’ll know from now on.”*

These data show that many patients read the optional, more in-depth medical information, and provide additional evidence that patients are interested in the details of their care.

The Persistent History Helped Memory

We found several examples of patients using the phone display as a memory aid throughout their ED visits. Five patients stated that remembering their care team's names was particularly difficult, and appreciated having the names and photos right on their phone. P2 stated: *"Sometimes doctors and nurses come in and you don't remember their names. It's very important to have them."*

Another piece of information that patients valued was simply the timestamp of their arrival time to the ED. Many patients are under high levels of pain and stress upon arrival, and stated that it was often difficult to have a sense of when they arrived, and thus how long they had been in the ED. This small piece of data was surprisingly valuable in re-orienting patients within their visit.

Physical Possession and Information Ownership

We recognized that handing patients unfamiliar phones might discourage patient perceptions of "ownership": our device lacked the customization, familiarity, and rich personal context that make mobile phones prized by their owners. So we were particularly surprised to observe that patients were willing and caring guardians of the phones, treating them as personal possessions.

An example of the care that patients took in managing the phone was their physical proximity to the device; for the most part, patients kept the device very close by – either on their chest/stomach or by their side – and the phone accompanied patients to test rooms. Otherwise, patients entrusted the device to family members in the same room. Although it could be argued that patients had few other options for storing the device, interview data suggests that this behavior is better explained by a personal connection that the patients felt toward the device and the data within it.

One simple way that patients implied a sense of ownership was by using possessive syntax, referring to *"my data"* (P5), *"my phone [pointing to the study phone]"* (P12), and *"my property"* (P9). We noted that two participants physically held the phone to their chests during the interview.

Another way that patients demonstrated ownership was by validating the data in the display, in effect taking responsibility for the information presented. Seven participants spoke of verifying their information on the *Profile* page, including their names (P21), reason for visit (P10), home medications (P13, P14), and allergies (daughter of P3, P13, P20); P20 even looked for a way to correct the information the display. Despite the fact that the *Profile* page contained entirely self-reported information, four participants cited the *Profile* page as their favorite page overall.

Finally, ownership was asserted in a more literal sense by the 11 participants that emailed themselves a copy of the phone's content. When asked why they emailed information to themselves, participants offered four primary reasons: 1) to archive it in their own personal records (9 participants); 2) to show to others outside of the hospital (5 participants);

3) to take the time to re-read it at home, allowing them to process it in a calmer state and to go over the information in greater detail (3 participants); and 4) to print the information and bring it with them to their primary care follow-up appointments (3 participants).

In fact, 10 patients expressed a desire to use the phone in order to personally transfer data from their ED visit to their primary care physician or other providers.

"For example, I know my doctor should get this information, but by chance if I got to the doctor and they haven't received it, I'll have that information. I keep one of these devices with me at all times, so I can just pull it up on that device and let them see what took place. ... A lot of times, the information doesn't get to the other place as quickly as it should. So I could just pull my device out and give 'em it." –P22

While it is impossible to determine causality from these observations, these observations suggest that the physicality of the mobile phones created a bond between patients and the information contained within.

Sharing Data with Visitors and Loved Ones

Of the 11 patients who had family members present in the ED, 10 chose to share the phone display with their family members. For two patients, the family member was the primary user of the display. In one of these cases, the patient did not have her glasses, so her daughter used the phone and read the information aloud. In the other case, the patient was feeling weak and had her great-granddaughter use the phone. The other eight patients would co-use the display, and would often pass the phone back and forth between their family member(s) and themselves in order to read the latest information.

Fifteen patients thought that the phone could assist in keeping loved ones *outside* the hospital up-to-date. Many expressed that it might keep their family members from worrying and rushing to the ED.

"I could email this to my daughter. Because a lot of times when I'm in the hospital she'll run up here and she's so worried. I could email it to her and let her know that I'm alright – you don't have to come, stay with the kids, and she would be more relaxed." –P13

However, P24 pointed out that there are nuances to sharing information with family members outside of the hospital. This patient thought about emailing his information to his mom, but because the doctors had not yet made an official diagnosis, he worried that the lack of information would make his mother more concerned than she already was.

We explored various options for information sharing – asking patients if they preferred finer control over who sees what data. Overwhelmingly, patients expressed that they wanted family members to see everything about their visit. They would either share all of their data with someone, or share none of it. Many patients conveyed that they are often

in pain or drowsy, and it is a challenge to remember important details of the visit. Patients found it comforting to know that a family member was aware of their health status and care plan and could better serve as their advocate.

“I think most people, when they come to the ER, if they bring somebody with them, they’re bringing them because they want that person, you know, you don’t want to rely on just your own memory. You want someone who knows everything that happened to you.”

–Daughter of P3

One form of sharing that we expected to observe, but did not, was sharing between patients and the ED staff. While several patients showed the phone to their care team because they were excited about the technology, none of the patients stated that they co-used the phone with staff in order to ask questions or discuss medical information. Face-to-face interactions between patients and physicians in the ED are often brief, focused, and highly anticipated, which most likely dissuaded patients from introducing conversation outside of the topics at hand.

Nevertheless, we found that the small and familiar form factor of the phone allowed for sharing in a natural way: physical sharing among present family members and virtual sharing via email. As many patients expressed a desire to share their data with remote family members, subscription-based sharing could be a valuable feature to explore.

The Phone Helps Preserve Privacy

Overwhelmingly, patients were not concerned with having information from their medical record on the phone. Patients appreciated their ability to guard the information and have control over who sees their data. Eleven patients specifically stated that the phone’s small form factor, and knowing that passersby and roommates would not be able to see their health information, provided a sense of privacy.

“Yeah, like I said, no one has it here but me and it doesn’t stay on all the time so that’s good too. So if you leave it sitting here, it’s not like somebody’s peering at what’s going on.” –P17

One patient pointed out that even though she wasn’t concerned with having her data on the phone, she would feel more comfortable having the phone password-protected, in case it was misplaced. Ideally, with patients using such an application on their own device, they would be able to personally choose their desired level of security.

Ergonomics Issues Exist, But Are Not Overwhelming

With almost all patients being hooked to vitals monitors and IVs, we expected that patients might face ergonomic challenges trying to use a touch-based phone during their visits. However, we discovered that these impairments generally did not pose a problem. Most patients found a comfortable position from which use the phone, even if it was using their non-dominant hand. The interface required only simple, one-finger gestures, allowing patients to navigate

through the various screens, even if only with their thumb.

Surprisingly, the most common impairment faced by patients was poor eyesight, often as a result of not having access to their glasses. Six patients faced this issue. For some, the phone form factor worked well, because they could hold it close-up and read the information well. Others utilized family members to help them with the phone.

We explicitly asked 23 participants whether a different form factor might have worked better for them. Only 5 stated a preference for a different device type, citing needs for larger text (4) and reduced physical handling of the device (1). Noting that a large-text mode could easily be incorporated into the display design, we find that overall the phone appears to be ergonomically well-suited to the in-clinic medical information display task.

Automating the Mobile Patient Display

In this section, we reflect on the role of the study administrators in supporting the prototype, to gain insight into the technology that would be required to completely automate this system. We will demonstrate that although administrator screening of information was required in order to comply with IRB requirements, automation of a patient-friendly mobile display is feasible in the near-term future.

While the study hospital used a mix of paper and electronic medical records, the vast majority of display content was pulled directly from the hospital’s EMR. Data that required no human intervention included the patient name, arrival time in the ED, home medications, allergies, patient room number, names and timestamps for medication orders and administrations, test orders and results, and care team assignments. Other data that was drawn from the EMR required a small amount of manipulation. The chief complaint field of the EMR was entered free-hand and often included short-hand notation, which we expanded into patient-friendly terms to populate the “reason for visit” field on the *Profile* page. In addition, medications and tests were often recorded in the paper chart before they were entered into the EMR; if time permitted, the administrator updated the patient display to indicate that medications and tests had been ordered before this data was available via the EMR.

Prior to our field deployment, we worked with physicians to create a database of metadata for medications, tests and staff. The database included a short explanation, a long explanation, and an external resource (URL) for each of 47 tests and 106 medications, as well as staff photos drawn from an electronic staff directory. Administrators were responsible for matching medication and test names in the EMR to the database entries, and making any necessary adjustments to the short explanation. Over the course of study, a total of 106 tests (24 unique) and 17 medications (11 unique) were administered, which required the addition of 3 tests and 4 medications to the database. The only modifications that administrators made to explanations were for “Chest X-ray” and “X-ray”, which the administrator customized to the body part being analyzed (e.g., “to check

your lungs” vs. “to check your heart”). The low involvement by the administrator in customizing the medication and test content pushed to patients’ phones suggests that this is a highly automatable aspect of the user experience.

The most significant role that the administrators played was in updating the *Health Feed* with information about the progress of the patient’s care. While in practice the feed entries were generated based on human observation, we were guided by a list of standard phrases, the majority of which were triggered by events documented in the paper chart or EMR (e.g., when the patient arrived at the ED, when vitals were taken, when tests and medications were ordered, when results had returned); we expect automation of this process to be straightforward. Other feed entries relied on an administrator having observed a doctor or nurse visiting the patient’s room; these events are not as easily automated today, but could be in the future through staff tracking, e.g., by RFID systems, which are increasingly common in hospitals. The “next up” aspect of the *Health Feed* presents the most significant challenge to automation. While the majority of the entries pushed to patients were based on loose rule sets that could reasonably be automated (e.g., if blood tests were ordered, then “next up” might be “your blood work will be processed”), some would require patient tracking, (e.g., if patient returned to her room from a CT Scan, then “next up” might be “the radiologist is reviewing your CT Scan”). Moreover, some feed entries depended entirely on discussions with staff members who provided context about the patient’s visit that was not reflected in the EMR (e.g., “the patient will be admitted to the hospital, we’re just waiting for a bed to become available”). Accurately capturing this knowledge might best be accomplished in collaboration with care staff, who might be willing to enter a one-line update in cases when observable events don’t readily predict a patient’s care plan. Indeed, if the benefits to patients of making this information readily available can be proven, hospital staff will likely be more willing to submit edits or update their EMR infrastructure to further support such a system.

Content Appropriateness

The content of our prototype was by nature an incomplete representation of a patient’s care progress; for example, we could not observe most interactions that the patient had with care staff, so patients’ *Health Feed* pages were often missing those interactions (e.g., “your doctor discussed your test results with you”). Furthermore, about half of the *Health Feed* entries captured events that the patient knew about personally (e.g., “you arrived at the ED”) so were not necessarily adding to the patient’s overall awareness.

So when we asked patients whether data was missing from the phone and whether they felt the information was appropriate to their situation, we were surprised that the vast majority of patients felt that the phone content was not missing any information or events, did not contain extraneous information, and applied to the patient’s current situation. Two patients noticed that their allergies were not in the

system, one noticed that her “reason for visit” did not match what she had told the intake nurse, and one noticed that an in-room exam was not reflected in the *Health Feed*. We consider this feedback encouraging, because it suggests that our approach can be scaled-up and still feel personal.

Provider Feedback and Response

A critical factor for the success of any hospital technology is the support of physicians and nurses. We interviewed 11 members of the hospital staff – including attending physicians, resident physicians, and nurses – in order to gain their insights and opinions of the patient phone display. Ten out of the eleven care team members reacted positively to the phone display. Physicians were keenly aware that they have little time with each patient, so they liked the phone’s ability to keep patients aware of their care status – especially letting the patients know what is next in their care plan. Six of the seven physicians did not want patients to automatically receive test results and diagnoses on the phone, but were supportive of all other information categories.

While physicians focused on the phone’s content, nurses were more focused on the phone’s impact on their workflow. The four nurses interviewed expressed positive reactions toward the phone, but were concerned that they would be burdened with providing technical assistance. However, they did suggest that a phone-based display could ease tensions between staff and patients by answering common questions. Our patient interviews supported this view, with 6 patients specifically mentioning how busy the staff was or not wanting to bother them with questions.

LIMITATIONS AND FUTURE WORK

Although the present study provides preliminary evidence that the mobile phone is suitable as an information display medium in the ED, and that our proposed design reflects a promising organization and level of simplification, limitations in this study suggest that follow-up work is necessary. The relatively small size of the study prevented us from exploring quantitative, controlled measures of satisfaction, comprehension, and particularly retention and post-visit compliance. A larger follow-up study should explore these variables, and most importantly explore the relationship between mobile information delivery and clinical outcomes.

Furthermore, we hypothesize that the use of a patient’s *own* mobile phone for information delivery in the hospital will increase access to information on the same device after a clinical visit. Our current methodology did not allow us to explore this: future work, pending the development of a sufficiently cross-platform infrastructure, will explore the consequences of using a patient’s own phone on post-visit use. Using a familiar device is also expected to increase the feelings of ownership and the propensity for sharing that were suggested during the present study, but future work is required to verify this. Using patients’ own devices comes with challenges, however: design iteration may be required to find a balance between surfacing salient medical infor-

mation and allowing patients to use their phones for communication and “passing the time”.

Similarly, our work was focused on the ED; different medical domains come with different pacing and different patient information needs. Therefore, future work will be required to see whether our design and lessons learned generalize to other medical domains.

Finally, as suggested in the previous section, some amount of work is still required to automate our mobile information display before it can be deployed at scale. This is an exciting area for future work, as it spans HCI, clinical informatics, and natural language processing.

CONCLUSIONS

In this study, 25 emergency department patients and 8 family members utilized a dynamic mobile phone interface presenting near-real-time data surrounding their medical status, care plan, and care team during their visit. Feedback and observations suggest that this approach is an extremely positive direction for reducing patient anxiety, improving awareness, promoting patient empowerment, and enhancing ownership of medical information in hospitals.

ACKNOWLEDGEMENTS

We thank Asta Roseway for visual design contributions.

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