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“Not Just a Receiver”: Understanding Patient Behavior in the Hospital Environment

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Abstract

Patient engagement leads to better health outcomes and experiences of health care. However, existing patient engagement systems in the hospital environment focus on the passive receipt of information by patients rather than the active contribution of the patient or caregiver as a partner in their care. Through interviews with hospitalized patients and their caregivers, we identify ways that patients and caregivers actively participate in their care. We describe the different roles patients and caregivers assume in interacting with their hospital care team. We then discuss how systems designed to support patient engagement in the hospital setting can promote active participation and help patients achieve better outcomes.

Keywords

Health informatics; interface design; patient engagement; hospital; HCI

ACM Classification Keywords

J.3 Life and Medical Sciences; Health; Medical Information Systems; H.5.m. Information interfaces and presentation

INTRODUCTION

More than 35 million US hospital admissions occurred in 2013 alone [2]. During these stays, patients are often viewed as passive recipients of care, rather than as active stakeholders who can make decisions and even prevent errors. However, engaged patients have not just a better

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experience of care [17], but also improved health outcomes on multiple indicators [16]. Improved access to health information has also been tied to patients' ability to take an active role in ensuring their safety [13]. In a survey, 91% of patients said that they themselves believed they have a role in patient safety [39]. Given that upwards of 400,000 deaths occur each year as a result of preventable harm to patients [21], finding ways to improve patient safety is an urgent problem.

Patient engagement has been conceptualized in a variety of ways. In biomedical research, for example, it is a way to manage one's own health, while in nursing it is the level of awareness the patient has about their own needs, and in mental health it is the collaboration between patient and clinician [4]. Measures of patient engagement like Graffigna and Barelo's Patient Health Engagement scale [15] and Hibbard's Patient Activation Measure [20] examine patients' attitude towards their role in their own care or confidence in carrying out the tasks necessary for them to manage their care moving forward. However, these measures do not tie these attitudes to the specific behaviors which patients perform within the hospital. Looking at patient engagement in the hospital setting, Maurer et al. [29] define it as "a set of behaviors by patients, family members, and health professionals and a set of organizational policies and procedures that foster both the inclusion of patients and family members as active members of the health care team and collaborative partnerships with providers and provider organizations." However, Maurer et al. also note that existing literature focuses more on what patients *should* do than on what they *actually* do in the hospital environment [29]; thus, exactly what behaviors constitute patient engagement is not well defined. To create systems that support patients in engaging in their care, we need to understand what behaviors patients and caregivers perform and what factors influence their performance.

For this project, we interviewed hospitalized patients (also referred to as inpatients) and their caregivers at two different hospital sites. In this paper, our goal is to understand what patient engagement means in terms of the behaviors patients and caregivers engage in with respect to their care. Our contribution consists of:

- A description of the behaviors which patients and their caregivers actually engage in while in the hospital, put in terms of the roles patients assume in interacting with their hospital care team
- An analysis of psychological and external factors that influence patients' behaviors
- A discussion of design techniques that could be used to motivate patients and their caregivers to participate actively in their care

RELATED WORK

Although HCI researchers have explored ways to promote health engagement outside the hospital, very little work has investigated the inpatient environment. Below we explain why patients in the inpatient environment need support. We look at existing work examining what behaviors comprise patient engagement in the hospital setting. We also discuss existing interventions to support patient engagement in the hospital.

Focus on the hospital environment

Within the HCI literature, much work reports on ways to promote everyday engagement with health. Behavior change applications like Ubifit [10] and Fish'n'Steps [26], for example, support users in maintaining physical activity, while applications like ShutEye help users adjust their behavior to achieve better sleep hygiene [5]. Researchers have also explored ways to support patients working with their clinicians. For example, Lee and Dey's embedded assessment tool provides patients with a way to effortlessly supply data to clinicians about their ability to perform everyday tasks [24]. Chung et al. examine how providers use patient-generated life-logging data in their practice [9].

However, existing work largely deals with the outpatient environment, rather than the hospital environment. In the inpatient setting, patients are removed from their home environments, frequently suffering from a serious condition, and often confined to their rooms or their bed. They encounter difficulty in getting basic information about their care, such as what the schedule for the day is or when they can expect to see the doctor next [22]. Perhaps because of these extreme conditions, Bickmore et al. called the experience of being hospitalized "one of the most dis-empowering situations one can experience in modern society" [6]. Because the hospital environment imposes such unique constraints on patients, work focusing on the outpatient environment cannot be directly extended without further examination of patient needs and behaviors in this inpatient context.

Patient behaviors in the inpatient setting

Although several studies examine what patients could or should do in the hospital setting, little research has yet been conducted on what they actually do [29]. The work that has been done thus far on patients' behaviors consists of surveys or informal discussions with patients, rather than in-depth qualitative investigations of patients currently in the hospital. Below we summarize work thus far that focuses on patient behaviors in the hospital setting.

The patient engagement framework that is most focused on patient behaviors is Gruman et al.'s [18] Engagement Behavior Framework (EBF). This framework includes a list of more than 40 specific behaviors that patients can perform to engage with their health at all stages, from choosing a clinician to making lifestyle changes and managing chronic illness. The EBF is a valuable tool for guiding the design of systems to support patient engagement. However, the EBF focuses on the possible tasks that patients *could* do rather than what patients *actually* do, and does not address psychological factors in patients' performance of these tasks.

Carman et al. [8]'s framework of patient and family engagement ties engagement to specific behaviors by giving examples of the tasks patients undertake at each end of the spectrum. Patients and their family members engaged at the lower end of the engagement spectrum receive information about their care, but do not proactively manage their care. Patients at the other end of the spectrum make decisions about their care, working proactively with clinicians to create a care plan that reflects their goals and values. These patients first understand their condition, and might also engage in outside research about their condition and treatment options, ask questions of their clinicians, participate in the construction of

their medical record, and volunteer information about themselves to physicians relevant to their care. As with Gruman's EBF, Carman et al.'s link between behavior and patient engagement is a valuable scaffolding for the design of systems to support patient engagement. However, Carman et al.'s task examples are not meant to be comprehensive, and while it was "developed in conjunction with patient and family representatives," the nature and extent of those representatives' involvement is not clear. Thus, this framework does not represent a full and clear picture of the behaviors hospitalized patients and their caregivers engage in with respect to their care.

Maurer et al.'s [29] environmental scan on patient and family engagement names a few studies on patient and family behavior within the hospital. One telephone survey found that while in the hospital, 85% of patients did ask hospital staff medical questions, but only 17% took a more active role by marking their surgical site themselves [41]. This finding could suggest that patients generally view themselves in a passive light, wanting to understand their care but not to interfere with or participate in it. Another telephone survey, investigating patients' willingness to perform AHRQ's "20 tips to help prevent medical errors" [1], found that most respondents were willing to question clinicians about procedures, unfamiliar drugs, or things they did not understand. Most respondents also said they were willing to seek a second opinion when making an important health decision. However, a minority of patients said they would confirm clinicians' identity before they performed a procedure, ask clinicians if they had washed their hands, bring a medication list to appointments, or refuse a procedure that they had not discussed with their clinicians in advance [28]. Hibbard et al. conducted a survey on a convenience sample to understand consumer attitudes about their role in patient safety and found that in general, consumers were less willing to engage in behaviors that involve questioning clinicians' practices or judgment [19]. None of the surveys were conducted while patients were in the hospital, although [41] was conducted with recently discharged patients. Walrath and Rose [40] did interview hospitalized patients about their behaviors; however, this exploration was focused on patient attitudes towards medication administration in the hospital.

Patient engagement interventions in the hospital

Researchers in health informatics have discussed design needs for patients in the hospital environment, and created several interventions to help patients understand and manage their care. However, most of these systems focus on information delivery to the patient rather than on encouraging the patient to perform any particular behaviors. Below we summarize existing design recommendations and interventions for patients in the hospital environment and discuss where there is room for more investigation.

In 2013, Prey et al. [33] conducted a literature review of existing patient engagement interventions and design recommendations for the inpatient environment. In this review, they discuss related literature that suggests that patients desire a record of their history [42], a tool for understanding medical jargon [42], and a way to assess their progress in the trajectory of their stay [35]. They also detailed several patient-specific systems aimed at encouraging engagement [6,37,38,14,43]. However, apart from [35], these systems all focused on allowing patients to *receive* information about their care, not act upon it.

Similarly, Caligtan et al. [7] conducted interviews to determine the information needs of patients in the hospital. In contrast, Skeels and Tan [35] offered patients a more active role, discussing their desire to send more information with a nurse call button to help the nurse prioritize which patients to see first.

Coulter and Ellins' [12] review evaluated the effectiveness of various interventions targeted at various aspects of patient engagement, including the role of the patient in improving patient safety. They state that most work up to that point focused on medication adherence and infection control [12], an extremely limited slice of patient behavior in the hospital environment. Thus much room remains for exploring interventions to support active patient involvement in their care in the hospital setting.

METHODS

We interviewed 14 pediatric and 14 adult inpatients, together with their caregivers, at a children's hospital (Site Y) and an adult tertiary care hospital (Site A). Both sites are located in Seattle, Washington, and support patients from a wide, diverse geographic area. Each semi-structured interview lasted between 40-60 minutes. When a caregiver was available to be interviewed, two interviewers were present and the two interviews took place simultaneously in the same room. We conducted 60-90 minute bedside observations with each patient to understand their interactions with hospital staff. These observations occurred at different points in the day—in some cases we observed high-intensity interactions like rounds, and in others low-intensity interactions like routine check-ins with nurses. These observations formed the basis for many of our insights regarding interactions between the patient or their caregiver and the hospital team. The authors' institutional review board and the hospital sites approved this project. Interviews included questions about how patients and caregivers sought, received, and managed information relating to their care. Bedside observation sessions were conducted by one of the interviewers and typically occurred directly after the interview, although we made exceptions to accommodate participants' scheduling constraints.

Forty-eight participants were recruited for our study, including 28 patients and 20 caregivers from the two hospital sites: 14 of the patients were from each site, and 16 of the caregivers were parents of patients from Site Y. Participants were recruited using a purposeful, maximally diverse sampling framework covering gender, age, ethnicity, medical service (medical or surgical), and complexity of medical condition. Adult participants ranged in age from 20 to 76, with a median age of 53. Pediatric participants ranged in age from 7 to 16, with a median age of 12.5. Because we interviewed only those who were in relatively stable condition, participants in our study tended to be close to the end of their stay.

While interviews were being conducted, the research group met regularly to discuss preliminary findings from the data and determine new avenues for exploration. After interviews were completed, five members of the research group coded the interview transcripts in an iterative coding process. Through several rounds of coding, the research team developed a list of tasks performed by interview participants during their stay. This list was then used by two members of the research team to code all the primary interview

transcripts to explore what behaviors participants engaged in while they were hospitalized and what factors influenced their behavior. During the analysis, these two members iteratively discussed the task schema to determine how the various activities fit together into roles. Because we focused on the role of information and the informal care manager with respect to the hospital team, we analyzed patients and caregivers together because either of them could fill that manager role.

FINDINGS: PATIENT AND CAREGIVER TEAM ROLES

We organized the care-related behaviors of patients and their caregivers into five distinct roles that patients and caregivers assume when interacting with their hospital care team. These roles included bedside monitor, apprentice, decision-maker, historian, and **team manager**. Within each role, we illustrate the range of activities, contrasting participants who took a more active role in their care with those who took a less active role. We also describe the attitudes patients and caregivers expressed about their participation in their care.

Bedside monitor

One way for patients and caregivers to engage with their care was to act as a bedside monitor by observing the patient's condition and reporting on it to clinicians. For most participants, clinicians coming by on rounds would ask them how they were feeling, or ask caregivers about the patient's physical symptoms like stool consistency and passing gas. Caregivers acting as a bedside monitor were able to report back. Sometimes clinicians asked caregivers and patients to keep track of particular things. For example, clinicians asked Y02's caregiver to let them know when the patient first passed gas. Y09 and his caregiver were asked to keep track of how often the patient walked around. Y13 and her caregiver had to keep track of how much water the patient was drinking to reach an ambitious goal of several liters a day. Y12's caregiver logged more than just what clinicians specifically asked for. She asserted her desire to maintain her own record of what was happening: "If I'm in a hospital...I wouldn't rely on somebody else to keep track of things." Instead, she wrote down everything she needed to stay on top of the patient's care plan and progress updates:

He gave us this pad when we came and I've been writing everything down - kept track of some of his vital signs, questions that I have, things that were provided to me, some lab results. So I write it down so I don't need to remember. — Y12, caregiver

In contrast, some participants either did not keep track of what was going on with their care or logged only what they had to. For instance, A11 said, "I can't even tell you what medicines I'm on, I just don't know." Y02's caregiver tracked only what had specifically been requested, and relied on hospital processes for the rest:

...they want to know if he passed gas so I wrote it on there at the time, the first time he did.... But if he goes to the bathroom, I don't tell them, because they just automatically know. So I haven't – I mean just the automatic things I haven't had to. But they're amazing. — Y02, caregiver

Apprentice

Behaviors that patients and caregivers must learn to understand the patient's condition and administer their care comprise the apprentice role. All the patients and caregivers we spoke to had at least some interest in understanding their condition and treatment. To perform this role, patients and caregivers listened attentively to clinicians during rounds and other face-to-face interactions, actively sought out information, and took notes to track their questions and new information as needed. Some patients and caregivers did research on their own to understand the care plan and learned how to administer care to themselves or the patient.

Apprentice participants like Y04's caregiver prepared for leaving the hospital by learning how to administer the patient's care herself. Y04's caregiver, who identified herself as the patient's "care provider" as well as parent, asked nurses to teach her how to administer medication to the patient herself and working with them to find a routine that worked for her: "Whoever the nurse [is] for him that day tells me their system and then helps me develop my own system." Y07's caregiver also considered herself "proactive in [her] kid's care" and felt that understanding the patient's care was "[her] responsibility." She involved herself in the process by doing outside research about the patient's condition:

...I have pretty easy access to articles, so that is mostly how I do it. I will just Google things sometimes. But I'm a big believer in reading peer review information.... — Y07, caregiver

Between her independent research and her understanding of the patient's treatment, Y01's caregiver became so much a part of the care team that the patient was released early:

They told us to anticipate 4-6 weeks being in the hospital, so being in the hospital for 17 days is the first time they'd ever released somebody so early, but it's because they knew we knew the signs of rejection, we knew how to take care of her. They felt confident that we knew what we were doing because we'd taken an active role. — Y01, caregiver

Y03's caregiver also described getting discharged earlier than was typical for patients in that situation because clinicians knew they could rely on her:

We will be discharged – a patient gets discharged because it is an option, because they know that I'm capable. Otherwise, if you didn't know about it we would be stuck here for two weeks and it's very depressing. — Y03, caregiver

Y12's caregiver contributed to the care team by leveraging her real-life medical training and sharing her diagnostic suspicions with clinicians:

You know, because he didn't respond to antibiotics and because my husband works in a hospital ... and I'm a nursing student working in the [hospital], we thought we brought MRSA home so we were very worried about it and we were proactive in asking our questions to the intern - the rounding. — Y12, caregiver

In contrast, some participants adopted a relatively passive approach to understanding their condition and treatment. A11, for example, was less interested in understanding his condition than in "get[ting] done with all this and mov[ing] on with my life." Although he

did want to understand what he needed to do for his care, “just what I have to do to get better,” he did not seek a deep understanding of what was happening:

I like to know how my health condition is coming along over time...I just like to know what's going on at all times, even if I don't understand it. I just like to know what's going on. — A11

A11 undertook relatively few information-seeking tasks himself, relying instead on his caregiver to seek out and track information for him:

When I don't know, she's like “Well, what can you eat? What can you do?” I'm like, I don't know, Mom. She'll be like “Well, all right, I'll be back then.” She'll go right out there, find a doctor or something, one of my nurses, and she'll ask them and see what's going on. — A11

Similarly, Y02's caregiver valued clinicians' explanations of the patient's surgery for the peace of mind it gave her rather than because it felt incumbent upon her as a stakeholder: “...it's important to understand because it takes away fear and concern.” Like A11, Y02's caregiver performed relatively few tasks related to understanding and participating in the patient's care. Although she demonstrated a stronger desire to understand what was happening than A11, she was content to leave administration of care to clinicians and not challenge it:

And I'm never going to question the medications per se. I trust the doctor, but I want to understand, because there's a difference. — Y02, caregiver

Decision maker

Patients and caregivers also played a decision maker role by shaping the plan of care itself. They carried out this role to varying degrees. Participants informed clinicians about the patient's needs and customized the care plan for their time inside the hospital and after discharge. Some participants also expressed a desire to be the final decision-makers, rather than ceding control to clinicians.

Decision-maker patients like Y11 (age 12) strongly preferred to be involved in decisions about their care. As Y11 said, “they're the doctors and stuff, but I am actually the one that's sick, so I want to have a role in it.” Other participants influenced decisions about their care by leveraging their own knowledge of the patient and working with clinicians to tailor the care plan to their needs. Y06 (age 13) and her caregiver, for instance, communicated with clinicians about how the patient's after school activities would affect the care plan, and A13 made arrangements with clinicians so that she could leave the hospital when a relative passed away. Some participants also performed outside research to inform themselves about treatment options. Y07's caregiver, for instance, read extensively about different treatment options before making a decision about her daughter's care:

...a lot of parents were saying well, this is what I think, this is what I think, and I just asked our surgeon and then I also read some of the research that was mostly on the National Institutes of Health site, the pros and cons and what the research is happening around different types of procedures. So if we really wanted to, we could have flown to [city], but I just trusted that what was happening here after I talked to

our surgeon was the right thing. I mean I just find what I can find online, but I try to look at things that are peer reviewed. — Y07, caregiver

A05, a physician himself, took a leading role in all aspects of his care:

A05: I looked at my CT scan before anyone else did and knew what was wrong with me before anyone else did, so kind of directed the way - I've never been not informed about what was going on. Like every time I get an X-ray, I look at it before the radiologist does.

I: How do you get access to that before they do?

A05: I just stand up after and I look on the screen. And I talk to the techs and tell the techs what I see, if they're interested too.

In contrast, A11, who took a less active approach to his care, stated his preference for leaving decisions about his medical care up to his physician, saying, "Just my doctor know me and my body, so hopefully they'll take care of it. [sic]" A02 seemed to view his admission to the hospital as a surrender in which he ceded control of his health temporarily over to others:

Coming in this time, I was just really ready to listen to what they were telling me because I knew there was something that was out of my control, something that I needed to let somebody else take care of and listen to what they were saying— A02

A06 also viewed his time in the hospital as a time to yield decisions about his health to physicians:

...after our discussion he determined that he'd like me to stick around for a while and be treated here, more closely monitored than leaving me to my own devices at home, which I felt was a really good decision on his part. I know what to do, but I don't always do what I'm told. — A06

Historian

Another way for patients and caregivers to interact with the hospital care team was to assume the role of historian and act as a backup information repository for clinicians. Historians would provide information to clinicians when their own knowledge base fell short.

Active historian participants contributed information about the patient's history proactively, as when Y02's caregiver informed nurses about the patient's pain medication preferences. Y02's caregiver stressed her trust in clinicians while recognizing that her own knowledge of the patient would sometimes be relevant for his plan of care:

I do trust what the doctors are deciding for him, but I need to understand and know what he's getting, because I also know previous history with him. — Y02, caregiver

Y11's caregiver expressed a much more wary attitude towards clinicians, which seemed to lead her into this active historian role. When explaining that the patient had an allergy to a particular medication, she described her vigilance to clinicians' awareness of this reaction:

So if we didn't hear like "oh, he has this going on," I try to keep them from giving him something we don't know why - maybe they just didn't communicate if something else is going on that needs treating that we don't know about. — Y11, caregiver

At this highly engaged end of the spectrum, Y11's caregiver proactively monitored clinicians to make sure they had all the information they needed when constructing a plan of care.

In contrast, some participants adopted this role passively, contributing information only when explicitly asked. A11, for instance, received a heparin shot unnecessarily because he did not know what it was when it was administered, an error which could have been fatal. He reflected later that if he had known, he could have told the nurse that he did not need the shot:

Like the heparin shot, I wish I would have known I was going to get that this morning, I would have told her "I don't need it, I already have a drip, I don't need the shot," for what reason. ... Well, I already knew I had the drip, that's why it was in my head, I'm thinking like, why did I just get a heparin shot when I had the drip? I just didn't understand at all. I asked the lady and my mom went out there, like "why did he get the shot?" and they were like well, it was a mistake, he wasn't supposed to get it. — A11

Another caregiver described having to provide information about the patient's medication to a clinician within the hospital. The clinician did not know what medication the patient needed, even though they had seen the patient previously:

Yesterday one of therapists actually asked me how one of her inhaler medications worked which I thought was odd, we had him last year. — Y03, caregiver

Team manager

Patients and caregivers sometimes acted as team managers, both for clinicians and for their own party. Patients and caregivers acted as team managers when they helped operations run smoothly, communicated patient needs to clinicians to keep patients happy, and coordinated among clinicians. As discussed in other work [31], collaboration between patients and caregivers could be quite complex. Patients and caregivers had to find out each others' needs and limitations to form a functioning care team. Tasks related to improving life in the hospital comprised another aspect of this internal management. Patients and caregivers worked together to improve the patient's quality of life within the hospital, as when Y03's caregiver requested a day pass so that she and the patient, who was in isolation, could leave the "depressing" room for a time. In some cases, caregivers were more engaged with the care than the patients were, as in the case of A11, who relied on his caregivers to perform almost all the information management tasks for his care, saying, "it's always been better for me if somebody's always there with me....." Caregivers acted as team managers for almost

all juvenile patients. One exception to this was Y10, who declared that the responsibility of knowing about his care was “100 percent mine and 100 percent theirs [his parents’].”

On the adult side, participants like A01 saw it as his role to understand everything that happened, and was displeased when he felt that clinicians had not fully informed him of updates to his care plan:

If you know something that has to happen or if you know something’s happening, if you don’t tell me, I have a real problem with that. This is my healthcare, not yours that you’re talking about. — A01

A01 compared learning about his care to managing a team in the workforce:

Having people work for you who are not straightforward with you is not really good. You’ve got to manage your team. If you don’t manage your team, it can backfire real quickly. You can’t have a loose cannon out there. — A01

With this attitude, A01 did extensive research on his clinicians as well as his condition before coming to the hospital, looking up their histories to assess their qualifications:

I did a lot of research, which I think people should do. And he was surprised how much research I had done on him and the hospital. ... You need to know about your healthcare. Actually, when I explained about his life, he said, “Where did you get that from?” I was like, well, I got it. And how many surgeries being in the same hospital for 19 years shows he’s stable which is a good sign too that’s some things I take, I look at experience. — A01

A13, who also considered herself an active participant in her care, described her role as the nexus point between different clinicians who had to work with them all to put things together:

Well, I’ve got nephrologists and gastroenterologists and a hematologist now and all of them kind of have a slightly differing opinion about kind of where I ought to be, and I know where I usually am, but we had the thyroid out and that’s going to change things around a little bit. ... and I have to figure out sort of the best logical progression to do that, and that’s going to be kind of a team thing too, between all the specialists and hopefully a new primary doctor that I’ll be getting lined up too. So it’ll be getting back on the rails, it’s just doing it in the right way. — A13

A13 also saw it as her role to learn enough about hospital structures to help things run smoothly and efficiently. She made a point of learning to navigate hospital structures and identify the different expertise areas of different clinicians so that she could help the process along by better targeting her questions:

... because I know I’m not dealing with gods, they don’t know everything, and everybody has their specialty and that’s part of why they’re here. They can’t know everything. So if I can facilitate my care by knowing which question needs to land with who, that’s always helpful. — A13

At the low end of engagement, participants like Y02’s caregiver were content to let clinicians run the show as they saw fit:

I trust that they have systems and procedures and policies in place, that that's all taken care of. I don't need to know when that is. part of that is with me managing people in the business world, I don't micromanage so I just know people have their responsibilities and they do it. I think it would be time consumption for them to have to explain to me what each of their responsibilities are. — Y02, caregiver

FINDINGS: FACTORS THAT INFLUENCE ENGAGEMENT

Our study illuminated several factors that influence patients' and caregivers' willingness to engage with their care. Below we discuss how patients' and caregivers' attitudes towards partnership and their perceptions of their relationship with clinicians affected both their engagement and their understanding of medical terms. We also discuss barriers to that engagement, such as lack of access to outside resources and clinicians who ignored information from patients and caregivers.

Patient and caregiver characteristics that influence engagement

Patients' and caregivers' engagement in their care varied. Below we discuss how patient and caregiver attitudes towards partnership, their relationship with their clinicians, and their understanding of medical jargon influenced their engagement in their care.

Attitudes toward partnership—Participants who were very active in their care viewed themselves as partners in delivery of their care and took more ownership of decisions than less active participants. Y12's caregiver described her stance on patient involvement, saying, "...as a patient you're not just a receiver, you're part of the healthcare team, actively making a decision you're not receiving care, you're participating in it." Similarly, Y14's caregiver expressed her desire to make decisions about her child's care by stating: "I want to be able to take a pick and say this is what works for our lives and our family and her, what I feel she would do the best with, the best outcome." Y01's caregiver stated that patients and caregivers sometimes had more authority than clinicians:

Their [clinicians'] opinions are not always the most important. That our opinion as parents and knowing them out of the hospital setting is just as important as what their opinion is. On some matters. On some things, yes, they have the authority and we don't. —Y01, caregiver

As previously described, A13 was proactive in learning who she should direct her questions towards because she knew that her clinicians had human limitations. She felt it was her responsibility to help out where she could.

By contrast, participants who took a less active role saw themselves as ceding control. For instance, as mentioned earlier, A02 saw his admission to the hospital as a surrender, stating that he "felt it was time to, like they say, put the cotton in your mouth and open the ears.... I thought it was time to listen to others." A11 distinguished between his personal values and what was needed for his care, and saw the former as irrelevant:

See, to me it's a difference about what's most important to me and what I need. ... the doctors don't care about what's important to me, it's just what I need to go through, I need to do. ...what needs to happen is important instead of what I want or need. — A11

In some cases A11 preferred to not even to know the details of what might happen:

They didn't really give me a book, they just really told me everything, which I wish they wouldn't have. I feel like half the stuff they told me that was probably going to happen that I was so terrified about didn't happen, wasn't going to happen, probably. They told me my legs were going to swell up and stuff like that, and it never happened. So I'm just like whatever. I wish they just kept their mouth shut or be like "well, you're going to be sore," all right, I can deal with that. — A11

For some participants, this cessation of control was based in absolute trust. Y02's caregiver, for example, described her tolerance when clinicians rescheduled her son's surgery without notifying her:

...we thought we were going to go in and have surgery right away, but then we didn't - that's probably the only thing that communication wasn't really, we didn't know why we didn't have it but I trusted them I knew that they would never put him in harm. I truly felt that way. Otherwise I would have asked. — Y02, caregiver

Many of our pediatric participants seemed content to rely on their caregivers. However, some felt equally responsible for their care: as described before, Y10 felt that the responsibility of knowing what was needed for his care belonged equally to him and to his parents.

Relationship with clinicians—Participants were also influenced by how they perceived their relationship with their clinician. This finding echoes other findings in the literature suggesting that patients are reluctant to perform tasks they see as challenging the clinician's judgment or behavior [19]. For example, A03 was concerned about appearing impolite to her clinicians when asking them questions:

I usually think about it. ...is it that important to bother them? Or something that worries me, then I want to ask them and try to be polite as possible. If they look like they're too busy, they're walking fast or they're behind, I don't ask. — A03

Another participant felt that she walked a narrow line in holding her ground with physicians without crossing social boundaries of good behavior, and rather than speaking up to her clinician, she switched physicians when she felt they were dismissing her:

Like the one hospitalist – well, I guess a creatinine of 3 is your new normal. See ya. Check out. And I mean, I was actively vomiting and stuff, the nurse there wanted to keep me, but I didn't want her to get in trouble for countering the doctor, and so I went ahead and left and I wound up up here in worse shape than I left [other hospital] in... —A13

At times the patients' faith in their own ability to take care of themselves or their child influenced their relationship with their clinicians. As discussed earlier, A02 ceded control of

decisions about his health over to physicians because he felt he had made bad decisions in the past. By contrast, Y14's caregiver described struggling with feeling less authoritative than clinicians, but decided that she needed to be involved nonetheless: "Sometimes I have to remember this is my child, I need to be an advocate for her and speak up, because I always feel like well, maybe they went to school for longer..." Y03's caregiver, on the other hand, felt confident in her ability to participate actively in creating a care plan:

... I want to agree and say what I think, and be listened to because I have read up, I do know a lot about what's going on with my family and the primary care person...
— Y03, caregiver

Understanding of medical jargon—Patients and caregivers struggled to understand their care when they could not understand medical jargon. Y13 commented that she wished she had "a sheet with all the words and their meanings at the very beginning so that you'd know what they're talking about." Y04's caregiver encountered difficulty learning about the patient's condition and treatment both from medical jargon and from her own feelings of being overwhelmed. In fact, Y04 burst out laughing at the idea of getting information only at a time when she could focus, explaining how clinicians over time developed the ability to tell if she could handle new information or not:

...we've been here for so long, they've gotten to the point where they could tell if I was having a good day or a bad day. So on days where they could tell I was having an okay day, they knew they could cram a lot of information in (laughs) and then they knew there were days where I was more emotional and they probably weren't going to get anything past me. — Y04, caregiver

Barriers to patient and caregiver engagement

Patients and caregivers' ability to engage with their care was limited by several external factors. Scheduling constraints limited patient and caregiver ability to be present for interactions with clinicians. Paywalls limited their access to research in outside resources. Patients and caregivers were also stymied when clinicians ignored or lost the information they offered, or did not inform patients and caregivers of new developments at all.

Being present—Simply being present for verbal interactions with clinicians was a challenge for some participants (see also [31]). Y06's caregiver, for example, described a time when they avoided leaving the room out of fear of missing an encounter with a clinician:

Well, I think one time we were in class and the nurses came looking for her, but then they were like "Go for a walk!" and I thought okay, I'll take her for a walk, and then I thought what if someone's looking for her? Like we don't know when people are coming. So we just stayed. — Y06, caregiver

Lack of access to outside resources—Patients and caregivers encountered obstacles in doing outside research about the patient's condition. In some cases, this was because they needed highly personalized information, as in the case of Y06, who did not do much outside research because "they said every diabetes is different for each person so you look it up, it's

more general.” Other participants encountered obstacles in accessing high-quality sources. Y13’s caregiver encountered difficulty trying to access information and was only able to get it with her clinician’s help:

It’s not easy, it’s almost like they’re hidden or something, or they want you to jump through a bunch of hoops to get them. There’s been a couple of articles where ... I want to read this article and I can’t get my hands on it. ... her urologist gave me a big paper on reflux So yeah, he gave me a big stack of like three different ones that I asked him for and I got those from him. — Y13, caregiver

Lost information—Even proactive patients and caregivers were stymied when clinicians ignored them. One caregiver described noticing that the patient’s temperature had risen and notifying the nurse that the patient had a fever. The nurse dismissed the caregiver’s concerns, and the next morning the patient’s temperature had risen by four degrees. Y08’s caregiver had learned through experience that clinicians had to cause the patient discomfort to draw blood because the patient was such a “hard stick”, but that the patient could tolerate the pain. She described trying to tell this to clinicians who ignored her, saying, “I don’t think people believe me when I say she can tolerate a lot of pain...”

Similarly, A13 described how clinicians ignored her medical concerns and treated her as a drug seeker:

At the risk of being a total cat here, it really didn’t seem like it was being taken very seriously in [place], to be perfectly honest. They were just kind of treating me like a pill chaser and sending me back out the door when I would show up at the emergency room... — A13

Providing information to clinicians was also complicated when information that had previously been communicated was lost at shift changes, placing an extra burden on patients and caregivers to inform clinicians of their needs all over again. For instance, Y02’s caregiver had specific requests for how to administer pain medication to her child, but a shift change occurred before it was time to give the patient his pain medication. Although the caregiver had made her request earlier, she did not remind the new clinician of her preferences, and the pain medication was administered contrary to her wishes.

Patients and caregivers also ran into difficulty when information was not passed on to them that they needed to respond to. As described earlier, A11 received an extra dose of a drug because of such a communication breakdown, an oversight that could have been fatal.

DESIGNING TO MOTIVATE AND SUPPORT PATIENT AND CAREGIVERS IN THE HOSPITAL

Our findings show that patients and caregivers possess a variety of attitudes towards participating in their care. Because patients and caregivers have different levels of interest, designers seeking to engage inpatients in their care should explore ways to motivate patients as well as to support them in performing care-related tasks. Below we discuss how patient-facing systems can support patients in each of the roles we have identified above.

Supporting the Bedside Monitor role

Patient-facing systems can support the bedside monitor role both by suggesting to patients what they can track and by facilitating the act of tracking. Previous outpatient research has suggested that setting actionable goals encourages behavior change [30]. Previous work has also found that goals assigned by a system can be as effective as goals chosen with the patient's input, as long as the goals' purpose is clearly conveyed [27]. Researchers have investigated the role of setting actionable goals in behavior change technologies for the wellness sphere (e.g. [11], [23], [32]). This technique could also be applied in the hospital context to motivate patients and caregivers to engage in the bedside monitor role. In the hospital, a system could prompt patients and caregivers to keep track of what medication the patient receives, the patient's vital signs, the consistency of the patient's stool, or other elements of the patient's condition or care. Suggestions should be customized to the patient's condition, so that patients and caregivers are only prompted to keep track of relevant symptoms.

Systems should also support patients and caregivers in performing these tracking activities. For example, systems could provide instructions on how to track an important clinical sign or symptom, such as stool consistency using the Bristol stool scale [25]. Such a system would teach patients what to look for and give them language to describe the patient's output to clinicians [34]. Systems should also physically facilitate logging. Data should be easy to enter and retrieve; the process should also be readily interruptible, because patients and caregivers could be distracted at any moment.

Supporting the Apprentice role

Patient-facing systems should assist patients and caregivers in learning about the patient's condition and care, including general information about different procedures and statistics. For example, a system could show both lab results and explanations as to what is within a normal range, what would be expected for the patient based on their current condition, what the patient's levels mean, etc. The system could also help patients learn medical jargon, for example by offering a glossary like what Y13 requested.

As with the bedside monitor role, suggesting actionable goals to patients and caregivers could motivate them to perform specific tasks, in this case learning new behaviors. Although Y04's caregiver took it upon herself to learn how to administer the patient's medications, not all patients and caregivers were so proactive, as discussed above. A system that suggests specific goals like learning to administer medications or understanding particular procedures could motivate patients and caregivers to further their understanding of the patient's care. Such a system could also educate patients and caregivers about the potential benefits of increased patient engagement, such as better medical outcomes or early discharge date, to motivate them to learn more about their care.

To accommodate patients and caregivers with different levels of medical knowledge, systems should also offer graduated levels of information, or links to outside resources for users interested in gaining more in-depth knowledge. Although some resources still require

payment for access, a curated list of reliable resources would help patients determine which resources are worth expending effort or money to reach.

Supporting the Decision-maker role

Recommendations to support the apprentice role would also apply for the decision-maker role, because a certain level of knowledge of the patient's condition and care is necessary for helping to make decisions. The decision-maker role builds on this knowledge to proactively work with clinicians in shaping the care plan. In order to support this role, systems need to encourage patients to think of themselves as active partners rather than passive recipients of care. Patient-facing systems can cultivate this attitude in a variety of ways, for example by reminding patients at key decision points that they ultimately have the final say in what happens to them. Systems should also remind patients that their own knowledge of their habits and environments outside the hospital could be important for shaping the care plan or recovery plan, and that discussing these topics with their hospital care team could improve their ability to adhere to the plan both inside and outside the hospital.

As discussed earlier, anxiety about offending clinicians can inhibit patients and caregivers from speaking up. Because of this possibility, clinicians should be involved in the design process. Their support for patient engagement in shaping the care plan could both encourage patients and caregivers to participate actively and reduce the potential for clinicians to ignore patient and caregiver input. One way to cultivate a sense of partnership in patients and caregivers is to place them on an equal footing with clinicians in their meetings. A shared space where patients and caregivers could set a shared agenda for their meeting times would indicate to patients that they too have control of the conversation, as suggested in Unruh et. al [36]. Designers could also enable patients and caregivers to notify clinicians about blocks of time when they intend to be out of the room, giving them more control over when meetings happen and saving fruitless trips to empty rooms for clinicians.

Designing to allow for asynchronous communication and remote participation, suggested in other work as a solution to overreliance on verbal information transfer [31], could also help patients and caregivers feel less concerned about bothering their clinicians. A13 used email for this purpose:

They have the [patient portal] with the email and stuff? And I love that, because I can hit them up with a question and they can kind of take their time getting back to me if they have ... something they need to deal with so I have a vehicle that I can do that with, with the email and things like that, and that's really helpful. —
A13

Supporting the Historian role

Cultivating an attitude of partnership would also support the historian role, because it would remind patients and caregivers that they too have valuable information to contribute. However, designers could specifically support patients and caregivers in this role by educating them about how their contribution of information about the patient could help prevent medical errors. As with the decision-maker role, explicit clinician support could be

invaluable in supporting active participation from patients and caregivers because anxiety about annoying clinicians can inhibit patients and caregivers from speaking up.

Designers should also consider ways to support patients and caregivers in proactively communicating with physicians about things pertinent to their care. For example, designers could provide templates for checklists of information that patients and caregivers would want to communicate to clinicians. These lists could be accompanied by notifications of clinician discontinuity to inform patients and caregivers when they need to be on the alert for potential information loss.

Supporting the Team Manager role

Designers can support patients and caregivers in coordinating their care between clinicians by helping them understand the hospital structure. Patient-facing systems should include the names and roles of members of the hospital care team, together with enough information about the organizational structure to help patients understand how the team members interact. Systems could support patients even more by helping them identify which team members are best suited to answer their questions. In general the more patients and caregivers understand about how information flows between team members at the hospital and how decisions about care are made, the more able they will be to coordinate care between clinicians, be on the lookout for things that might go wrong, and identify the right person to ask their questions of.

LIMITATIONS AND FUTURE WORK

Communication and collaboration with clinicians is the heart of patient engagement, and no system can be complete without clinician involvement. Future work should explore the role of clinicians in supporting patient and caregiver engagement in the hospital. Because inpatients are heavily reliant on clinicians for even the most basic needs, clinician support for any patient engagement system is essential. Future work should also explore the limits of patient engagement. Relinquishing control can at times be beneficial for patients, comprising an important part of coming to terms with and managing illness [3]. Additional work is necessary to understand how best to support the full range of strategies patients and caregivers use to manage their health.

Although we sampled as broadly as possible with our interviews, we were limited to participants who agreed to speak with us. These participants could have been more engaged than average with their care. Additional research could uncover the motivations and behaviors associated with low patient engagement. This selection bias could have been especially pronounced at the children's hospital site because we only interviewed patients whose caregivers were there to give consent and participate in the interview.

CONCLUSION

In this paper, we describe patient engagement in terms of the behaviors patients and caregivers perform in the hospital environment. We describe factors that influence engagement such as information loss and patients' and caregivers' attitude towards

partnership. We offer design recommendations to encourage patients and caregivers to take an active role in their care. Our description of patient and caregiver roles on the care team and suggestions for ways to support patient engagement help patients help themselves to improve health care.

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REFERENCES

1. Agency for Healthcare Research and Quality. 20 Tips to Help Prevent Medical Errors. Agency for Healthcare Research and Quality; Rockville, MD: 2014. <http://www.ahrq.gov/patients-consumers/care-planning/errors/20tips/index.html>
2. American Hospital Association. [Accessed Sept 24, 2015] Fast Facts on US Hospitals. 2015. <http://www.aha.org/research/rc/stat-studies/fast-facts.shtml>
3. Aujoulat, Isabelle, Marcolongo, Renzo, Bonadiman, Leopoldo, Deccache, Alain. Reconsidering patient empowerment in chronic illness: A critique of models of self-efficacy and bodily control. *Social Science & Medicine*. 2008; 66:1228–1239. <http://doi.org/10.1016/j.socscimed.2007.11.034>. [PubMed: 18155338]
4. Barelo, Serena, Graffigna, Guendalina, Vegni, Elena, Bosio, a Claudio. The Challenges of Conceptualizing Patient Engagement in Health Care: A Lexicographic Literature Review. *Journal of Participatory Medicine*. 2014; 6:1–19.
5. Bauer JS, Consolvo S, Greenstein B, et al. ShutEye: Encouraging awareness of healthy sleep recommendations with a mobile, peripheral display. *Human Factors in Computing Systems (CHI '12)*. 2012:1401–1410. <http://doi.org/10.1145/2207676.2208600>.
6. Bickmore, Timothy W., Pfeifer, Laura M., Jack, Brian W. Taking the time to care: empowering low health literacy hospital patients with virtual nurse agents. *Proceedings of the 27th international conference on Human factors in computing systems (CHI '09)*. 2009:1265–1274. <http://doi.org/10.1145/1518701.1518891>.
7. Caligtan, Christine A., Carroll, Diane L., Hurley, Ann C., Gersh-Zaremski, Ronna, Dykes, Patricia C. Bedside information technology to support patient-centered care. *International Journal of Medical Informatics*. 2012; 81(7):442–451. <http://doi.org/10.1016/j.ijmedinf.2011.12.005>. [PubMed: 22285034]
8. Carman, Kristin L., Dardess, Pam, Maurer, Maureen, et al. Patient and Family Engagement: a framework for understanding the elements and developing interventions and policies. *Health Affairs*. 2013; 32(2):223–231. <http://doi.org/10.1377/hlthaff.2012.1133>. [PubMed: 23381514]
9. Chung, Chia-Fang, Cook, Jonathan, Bales, Elizabeth, Zia, Jasmine, Munson, Sean A. More Than Telemonitoring: Health Provider Use and Nonuse of Life-Log Data in Irritable Bowel Syndrome and Weight Management. *Journal of Medical Internet Research*. 2015; 17(8):e203. <http://doi.org/10.2196/jmir.4364>. [PubMed: 26297627]
10. Consolvo, Sunny, Klasnja, Predrag, McDonald, David W., et al. Flowers or a robot army?: Encouraging awareness & activity with personal, mobile displays; *Proceedings of the 10th international conference on Ubiquitous computing (UbiComp '08)*; 2008; p. 54-63. <http://doi.org/10.1145/1409635.1409644>
11. Consolvo, Sunny, McDonald, David W., Landay, James A. Theory-Driven Design Strategies for Technologies that Support Behavior Change in Everyday Life; *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '09)*; ACM, New York, NY, USA. 2009; p. 405-414. <http://doi.org/10.1145/1518701.1518766>

12. Angela Coulter and Jo Ellins. Effectiveness of strategies for informing, educating, and involving patients. *BMJ: British Medical Journal*. Jul.2007 335:24–27. <http://doi.org/10.1136/bmj.39246.581169.80>. [PubMed: 17615222]
13. Carole Doherty and Charitini Stavropoulou. Patients' willingness and ability to participate actively in the reduction of clinical errors: A systematic literature review. *Social Science and Medicine*. 2012; 75(2):257–263. <http://doi.org/10.1016/j.socscimed.2012.02.056>. [PubMed: 22541799]
14. Dykes, Patricia C., Carroll, Diane L., Hurley, Ann C., Benoit, Angela, Chang, Frank, Pozzar, Rachel, Caligian, Christine A. Building and Testing a Patient-Centric Electronic Bedside Communication Center. *Journal of Gerontological Nursing*. 2013; 39(1):15–19. <http://doi.org/10.3928/00989134-20121204-03>.
15. Graffigna, Guendalina, Barelo, Serena, Bonanomi, Andrea, Lozza, Edoardo. Measuring patient engagement: development and psychometric properties of the Patient Health Engagement (PHE) Scale. *Frontiers in Psychology*. Mar.2015 6:1–10. <http://doi.org/10.3389/fpsyg.2015.00274>. [PubMed: 25688217]
16. Greene, Jessica, Hibbard, Judith H., Sacks, Rebecca, Overton, Valerie, Parrotta, Carmen D. When Patient Activation Levels Change, Health Outcomes And Costs Change, Too. *Health Affairs*. 2015; 34:431–437. <http://doi.org/10.1377/hlthaff.2014.0452>. [PubMed: 25732493]
17. Greene, Jessica, Hibbard, Judith H., Sacks, Rebecca, Overton, Valerie. When seeing the same physician, highly activated patients have better care experiences than less activated patients. *Health Affairs*. 2013; 32:1299–1305. <http://doi.org/10.1377/hlthaff.2012.1409>. [PubMed: 23836747]
18. Gruman, Jessie, Rovner, Margaret Holmes, French, Molly E., et al. From patient education to patient engagement: Implications for the field of patient education. *Patient Education and Counseling*. 2010; 78(3):350–356. <http://doi.org/10.1016/j.pec.2010.02.002>. [PubMed: 20202780]
19. Hibbard, Judith H., Peters, Ellen, Slovic, Paul, Tusler, Martin. Can patients be part of the solution? Views on their role in preventing medical errors. *Medical care research and review: MCRR*. 2005; 62(1):601–616. <http://doi.org/10.1177/1077558705279313>. [PubMed: 16177460]
20. Hibbard, Judith H., Stockard, Jean, Mahoney, Eldon R., Tusler, Martin. Development of the Patient Activation Measure (PAM): conceptualizing and measuring activation in patients and consumers. *Health services research*. 2004; 39:1005–1026. <http://doi.org/10.1111/j.1475-6773.2004.00269.x>. [PubMed: 15230939]
21. James, John T. A new, evidence-based estimate of patient harms associated with hospital care. *Journal of patient safety*. 2013; 9(3):122–8. <http://doi.org/10.1097/PTS.0b013e3182948a69>. [PubMed: 23860193]
22. Kendall, Logan, Mishra, Sonali R., Pollack, Ari, Aaronson, Barry, Pratt, Wandab. Making background work visible: opportunities to address patient information needs in the hospital; *AMIA 2015: Annual Symposium of the American Medical Informatics Association*; 2015;
23. Lau, Patrick W. C., Lau, Erica Y., Wong, Del P., Ransdell, Lynda. A Systematic Review of Information and Communication Technology–Based Interventions for Promoting Physical Activity Behavior Change in Children and Adolescents. *Journal of Medical Internet Research*. 2011; 13(3):e48. <http://doi.org/10.2196/jmir.1533>. [PubMed: 21749967]
24. Lee, Matthew L., Dey, Anind K. Embedded assessment of aging adults: A concept validation with stakeholders; *Pervasive Computing Technologies for Healthcare (PervasiveHealth)*, 2010 4th International Conference; 2010; p. 1-8.<http://doi.org/10.4108/ICST.PERVASIVEHEALTH2010.8849>
25. Lewis SJ, Heaton KW. Stool Form Scale as a Useful Guide to Intestinal Transit Time. *Scandinavian Journal of Gastroenterology*. 1997; 32(9):920–924. <http://doi.org/10.3109/00365529709011203>. [PubMed: 9299672]
26. Lin, James J., Mamykina, Lena, Lindtner, Silvia, Delajoux, Gregory, Strub, Henry B. Fish'n'Steps: encouraging physical activity with an interactive computer game; *Proceedings of the 8th international conference on Ubiquitous Computing (UbiComp'06)*; Springer-Verlag, Berlin, Heidelberg. 2006; p. 261-278.http://dx.doi.org/10.1007/11853565_16
27. Locke, Edwin A., Latham, Gary P. Building a practically useful theory of goal setting and task motivation. A 35-year odyssey. *The American psychologist*. 2002; 57(9):705–717. <http://doi.org/10.1037/0003-066X.57.9.705>. [PubMed: 12237980]

28. Marella, William M., Finley, Edward, Thomas, Auden D., Clarke, John R. Health Care Consumers' Inclination to Engage in Selected Patient Safety Practices. *Journal of Patient Safety*. 2007; 3(4): 184–189. <http://doi.org/10.1097/pts.0b013e31815a6121>.
29. Maurer, Maureen, Dardess, Pam, Carman, Kristin L., Frazier, Karen, Smeeding, Lauren. Guide to Patient and Family Engagement: Environmental Scan Report. 2012 12 Retrieved from <http://www.ahrq.gov/research/findings/final-reports/ptfamilyscan/ptfamilyscan.pdf>.
30. Medynskiy, Yevgeniy, Yarosh, Svetlana, Mynatt, Elizabeth. In CHI '11 Extended Abstracts on Human Factors in Computing Systems (CHI EA '11). ACM; New York, NY, USA: 2011. Five strategies for supporting healthy behavior change; p. 1333-1338. <http://doi.org/10.1145/1979742.1979770>
31. Miller, Andrew D., Mishra, Sonali R., Kendall, Logan, Haldar, Shefali, Pollack, Ari H., Pratt, Wanda. Partners in care: design considerations for caregivers and patients during a hospital stay; To appear in Proceedings of the 19th ACM conference on Computer supported cooperative work & social computing (CSCW '16); ACM, New York, NY, USA. 2016; forthcoming <http://doi.acm.org/10.1145/2531602.2531634>
32. Munson, Sean, Consolvo, Sunny. Exploring Goal-setting, Rewards, Self-monitoring, and Sharing to Motivate Physical Activity; International Conference on Pervasive Computing Technologies for Healthcare; 2012; p. 25-32. <http://doi.org/10.4108/icst.pervasivehealth.2012.248691>
33. Prey, Jennifer E., Woollen, Janet, Wilcox, Lauren, et al. Patient engagement in the inpatient setting: a systematic review. *J Am Med Inform Assoc*. 2014; 21:742–750. <http://doi.org/10.1136/amiajnl-2013-002141>. [PubMed: 24272163]
34. Riegler, Gabriele, Esposito, I. Bristol scale stool form. A still valid help in medical practice and clinical research. *Techniques in Coloproctology*. 2001; 5:163–164. <http://doi.org/10.1007/s101510100019>. [PubMed: 11875684]
35. Skeels, Meredith, Tan, Desney S. Identifying opportunities for inpatient-centric technology; Proceedings of the 1st ACM International Health Informatics Symposium (IHI '10); ACM, New York, NY, USA. 2010; p. 580-589. <http://doi.org/10.1145/1882992.1883087>
36. Unruh, Kenton T., Skeels, Meredith, Civan-Hartzler, Andrea, Pratt, Wanda. Transforming Clinic Environments into Information Workspaces for Patients; Conference on Human Factors in Computing Systems; 2010; p. 183-192. <http://doi.org/10.1145/1753326.1753354>
37. Vardoulakis, Laura Pfeifer, Karlson, Amy, Morris, Dan, Smith, Greg, Gatewood, Justin, Tan, Desney. Using mobile phones to present medical information to hospital patients; Proceedings of the 2012 ACM annual conference on Human Factors in Computing Systems (CHI '12); 2012; p. 1411 <http://doi.org/10.1145/2207676.2208601>
38. Vawdrey, David K., Wilcox, Lauren G., Collins, Sarah a, et al. A tablet computer application for patients to participate in their hospital care; AMIA Annual Symposium proceedings / AMIA Symposium. AMIA Symposium 2011; 2011; p. 1428-35. Retrieved from <http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=3243172&tool=pmcentrez&rendertype=abstract>
39. Charles A, Vincent and Angela Coulter. Patient safety: what about the patient? *Quality & safety in health care*. 2002; 11:76–80. <http://doi.org/10.1136/qhc.11.1.76>. [PubMed: 12078376]
40. Walrath, Jo M., Rose, Linda E. The Medication Administration Process. *Journal of Nursing Care Quality*. 2008; 23(4):345–352. <http://doi.org/10.1097/01.NCQ.0000323287.64020.01>. [PubMed: 18521044]
41. Waterman, Amy D., Gallagher, Thomas H., Garbutt, Jane, Waterman, Brian M., Fraser, Victoria, Burroughs, Thomas E. Brief report: Hospitalized patients' attitudes about and participation in error prevention. *Journal of General Internal Medicine*. 2006; 21:367–370. <http://doi.org/10.1111/j.1525-1497.2005.00385.x>. [PubMed: 16686815]
42. Wilcox, Lauren, Feiner, Steven, Liu, Andy, Restaino, Susan, Collins, Sarah, Vawdrey, David. Designing inpatient technology to meet the medication information needs of cardiology patients. Proceedings of the 2nd ACM SIGHIT symposium on International health informatics (IHI '12. 2012:831. <http://doi.org/10.1145/2110363.2110466>.
43. Wilcox, Lauren, Morris, Dan, Tan, Desney, Gatewood, Justin. Designing patient-centric information displays for hospitals. Proceedings of the 28th international conference on Human factors in computing systems (CHI '10). 2010:2123. <http://doi.org/10.1145/1753326.1753650>.

44. Yin, Langxuan, Ring, Lazlo, Bickmore, Timothy. Using an interactive visual novel to promote patient empowerment through engagement. Proceedings of the International Conference on the Foundations of Digital Games (FDG '12). 2012:41. <http://doi.org/10.1145/2282338.2282351>.

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