Design Opportunities for Supporting Patient Information Needs during an Emergency Visit

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ABSTRACT

Recent technologies, such as online patient portals, mobile apps and various health-related information websites, provide information to patients. However, these systems often only provide pre-defined categories of information for patients to browse through, instead of providing information that can meet patients' situated information needs during their ongoing care process, particularly during an emergency visit when information is lacking the most. To understand what information is desired by patients during this time and why they need this information, we conducted an ethnographic study with patients during their ED visits. We report various phases of the patient care trajectory and describe the three types of information wanted by patients: medicine-related, ED care process-driven, and care plan-oriented. We then discuss how these different types of information needs are related to the overall patient care trajectory, highlighting the situational and temporal aspects of information needs. Finally, we identify key design opportunities for pervasive computing technology to support patients during a short-term hospital stay.

CCS Concepts

• Information systems→ Information System Application
• Human-Center Computing→ Ubiquitous and mobile computing

Keywords

Patient information needs, Hospitals, Information technology

1. INTRODUCTION

Recent technologies development has provided new opportunities for patients to access, review, and manage their health information [6,24]. These technologies, including online and pervasive computing systems, aim to offer easier information access and better ways to meet patients' information needs. For instance, many online and mobile health applications are designed for patients with certain diseases to track their health-related information [1, 5, 28]. In addition, online patient portals and Personal Health Records (PHR) are specifically designed to address patient information needs by allowing patients to view their medical history, review test results, and communicate with healthcare providers online [24].

Studies show that these online and pervasive health technologies can increase patient care quality, enhance patient awareness, and potentially improve patient relationships with healthcare providers through better information access [15, 18]. For example, when patients were invited to review electronic notes written by their primary care physicians, it was found to have several potential benefits, including improved patient understanding, shared decision-making, and ultimately better health outcomes [9].

Despite the rapid development and increased interest in meeting patients' health information needs, less has been studied about how to provide real-time information to patients during their medical visits. As patients not only go through various clinical procedures, and also interact with different healthcare providers, a medical visit or a hospital stay is the time period when patients desire information the most. However, the difficulties of accessing and acquiring the right kinds of information at the right moment introduce significant challenges and barriers for patients during their medical visits. In addition, previous studies on information needs have mostly focused on identifying the content of the information patients prefer to know through surveys or retrospective interviews, rather than investigating the reasons why patients need certain information during their ongoing care. Researchers have shown that patients having access to information, particularly information about what to expect next while receiving care, has a significant impact on their hospital experience [4]. Therefore, studying patient information needs, situated in ongoing hospital care during their visit, can potentially address this issue.

In order to gain an in-depth understanding of patient information needs in the care context *in situ*, we conduct an ethnographic study consisting of field observation and interviews with patients in ongoing care, in an Emergency Department (ED). We investigated what types of information patients desire during their ED visits, why such information is needed, and what information sources are available or can be designed to fulfill these information needs. The finding of this study identifies three distinct types of information that patients need during their ED visits – medicine-related, ED care process-driven, and care plan-oriented information.

We characterize patient information needs situated in the patient care trajectory, outlining its situational and temporal aspects. Finally, we suggest key opportunities for pervasive computing technology to support the information needs of patients during their hospital stay. Our study is significant because it offers new ways of designing technologies that truly address patient information needs that are time-sensitive and situated in the real care context.

2. RELATED WORK

Patient information needs in healthcare have been well documented in prior works in the HCI, CSCW, and Health Informatics communities. Prior studies have investigated health consumers' information needs, and shown that patients want more

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educational materials regarding their illnesses and more information about possible treatments and alternatives plans than they typically receive during clinical visits [19, 23, 25]. These studies report various benefits of accessing health information, such as better patient satisfaction [1, 5], reduced conflicts in decision-making [13], increased adherence to care [13], and increased patient empowerment [27]. However, researchers have also pointed out that patient needs are still unmet by not having sufficient information access; for instance, after an outpatient visit, the patients sought information from a variety of information sources, including friends, relatives, pharmacies, public libraries, and the World Wide Web [23, 25].

Recently, various health technologies have also been developed to address patient information needs, such as online websites, PHR, and mobile health apps [6, 24, 28]. Although a majority of these systems have focused on chronically ill patients in outpatient settings during regular clinical visits, there has been an increased attention to developing health information technologies (HIT) for patients during their ongoing care in hospitals. Researchers have investigated the role of novel technologies such as large displays, tablets, kiosks, and mobile apps [11, 16, 17, 26], in providing information access to patients for enhancing their healthcare engagement and improving their communication with healthcare providers. For instance, Bickmore et al. designed the Virtual Nurse Agents system that guides patients through their discharge paperwork. The results show that this system effectively improves patients' understanding of hospital discharge instructions and increases patient satisfaction [3]. Tablet computers, mobile phone applications, and kiosks have also been used to offer patients access to information regarding medication, and other care-related and educational information [11, 16, 17, 27].

However, technologies for patient information access offer mainly medical knowledge related information, such as the meaning of a particular diagnosis, test results, or discharge instructions; this information also focuses on the content of the information patients prefer, instead of why such information is wanted in specific care contexts. In addition, while these studies and technologies provide personalized and specific information for patients, they seldom offer the situational information that fits the dynamic nature of the ongoing care context patients actually experience.

Particularly for a short-term hospital stay, such as an emergency visit, situational factors, including a long wait, clinicians' availabilities, as well as that of many different healthcare providers, can significantly affect patient information needs. Since patients do not often know what to prepare for and what to expect for their visit, the information they need to know can be far beyond just care-related medical information. According to a survey conducted by the Center for Disease Control and Prevention [12], 1 in 5 Americans report visiting the ED at least once in the past year. Despite the high ED demand, many studies have pointed out that most patients are not satisfied with their ED care because of overcrowding, low quality of care, and lack of communication and information [7, 14]. These studies indicate the difficulty of enhancing patient comprehension, and emphasize the importance of providing appropriate and timely information, as well as engaging patients during their ED visits. Similar to the ED, a study conducted in an inpatient unit suggests that patients desire a greater awareness of what goes on in relation to their care and more transparent ways of communicating with their care team, families, and wider social network [20]. However, to our best knowledge, almost no study has been done to assess the situated information needs of ED patients throughout their entire medical visit. In this work, we investigate patient information needs situated in the real care contexts in situ, and examine the underlying reasons for these information needs, by following patients duri.ng their ED stay.

3. METHODS

To study patients' situated information needs during their medical visits, and investigate ways to design technologies that can support such needs, we conducted an ethnographic study in an ED affiliated with a large urban hospital in the US. The ED handles average 4,000 patients per month, and roughly half of these patients are insured through private insurance.

3.1 Data Collection

We conducted an observational study with informal interviews with patients in the ED. The observations took place for five months, from January to May 2015. Observation was used to understand patients' experiences and care process in the ED. At each patient observation session, one or two researchers shadowed the entire journey of a patient visit, from the waiting room to the discharge/admission. The observational activities also involved shadowing the care team members, asking clarifying questions, and taking field notes and photos. During the observations, we paid careful attention to discussions about the patient's care; any information exchanged among patients, caregivers, and providers; any information they required; any information they wished to have; and any information sources they used, including artifacts and technology use in the patient room or at the bedside. In addition, we performed informal interviews with participants during or after observations to gain a better understanding of the perceptions, feelings, and questions they had during their ED stay.

A total of 35 patients participated in our study. Our site and sampling criteria allowed us to observe ED patients with a wide diversity of illnesses and situations. For the patient selection for our observation, we tried to maximize the diversity of patients. We selected patients based on age, gender, ethnicity, and other specific attributes, such as the primary medical service, and disease complexity. We excluded trauma patients, patients with language barriers, patients with contagious diseases and psychiatric patients in this study, to be able to observe and inquire about questions during the study. We mainly focused on patients, though sometimes informal caregivers, such as family members or friends, were able to provide a more complete story by adding their perspectives.

Patient participants had diverse medical conditions that related to various levels of complexity, urgency, and lengths of stay. Patients' medical conditions were widely distributed, ranging from headaches, to broken toes, to congenital cerebral palsy to cancer. Ages of participants ranged from 4 months to 90. Half of the patients were male and half were female. Patients were ethnically diverse: 16 were White/Caucasian, 1 Black/African-American, 8 Hispanic, 7 Asian and 3 American Indian/Alaska Native.

3.2 Data Analysis

A team of three researchers began analyzing data by reviewing all the data collected in the study to understand patients' information needs during the entire ED visits, with special focus on the types of information needs patients have and the information sources they use or wish to use. We initially used various diagramming methods [2], including information flow diagrams, to understand different care phases in the ED patient care process. We then coded the field notes, using the open coding method from the grounded theory approach [10] to look for emerging themes in our data. Based on these emerging themes, we narrowed our analysis to focus on types of information needs with patients. After different information types were identified in the data, we then identified what information sources were available in the ED and where the unmet information needs occurred.

4. OVERVIEW OF ED PATIENT CARE

4.1 ED Patient Care

The main goal of ED care is to promptly stabilize patients' medical conditions and to make treatment and follow-up care decisions. The general ED care process consists of short patient care ranging from 1- 2 hours to 1-1.5 days. The ED deals with a wide variety of illnesses, ranging from simple care (e.g. for patients needing stitches or patients presenting with influenza) to more serious exams (e.g., patients requiring an MRI or CT scan requiring a specialist's diagnosis) to the treatment of life threatening injuries. After the medical conditions that brought patients to the ED are stabilized, patients may be discharged to see their primary care physicians, do home care with discharge instructions, or be admitted to an inpatient unit for continued monitoring and treatment. While receiving care in the ED, patients constantly want to access information related to their own care, and this often significantly impacts their medical experience.

4.2 Current Information Sources for Patients

Although patients want to know and be able to manage their health information, most of the existing information technologies available in the ED do not offer access to patients. The Electronic Health Record (EHR) system, a primary information repository in the hospital, is designed as a comprehensive information infrastructure that contains all patient information generated in the care process, such as past medical history, medication orders, and progress notes. Healthcare providers and administrative personnel use the EHR as their main tool to search, retrieve, document, and share patient medical information. This comprehensive information repository would seem to be an ideal resource for patients to access information regarding their own care during hospital stays, yet patients lack direct access to EHR data during their clinical encounters. This is partially because the current HIT systems, including the EHRs, are usually designed as working systems for healthcare providers, and not patients. In the current ED environment, patients do not have access to the EHR even when it is located at their bedsides. While the bedside computers are mounted on the wall to help providers with easy access during clinical encounters, patients are not provided login access to the system, and the EHR often faces the opposite direction of the patient's eyesight (Figure 1).

In addition to the EHR, another information delivery media for patients is a whiteboard and vital sign monitor installed in the patients' rooms. The vital sign monitors continuously display key information about a patient's condition, such as blood pressure and heart rate. The whiteboard is specifically designed for ED patients to receive their basic care information, including the names of nurses and physicians, room number, body temperature, care plan, and tests ordered/conducted. The bedside nurses were responsible for manually adding information on the whiteboard once the patients were assigned to their beds, and keeping them updated during the patients' entire stays.

Although the whiteboards and vital sign monitors were available at the bedsides, the patients we studied did not consider them to be beneficial or useful. Information on the vital sign monitors is still mainly designed for the clinicians' use, as it was not legible or easy to read for ED patients who lacked medical knowledge or who were not familiar with their own health conditions. Similarly, the whiteboards were often found to be empty or to contain outdated information. Not having sufficient time to update the whiteboards manually in the fast-paced ED environment was considered a key barrier among nurses.

As a result, the way in which patients received or gathered information during ongoing care was mainly through face-to-face interactions with their healthcare providers. Patients usually received verbal updates during the physician consultations. They sometimes paged their bedsides nurse by pressing the call button in their room for urgent matters, or they viewed computer screens together with providers and requested paper printouts. Face-to-face interactions, though effective, relied heavily on the healthcare providers' availabilities. When physicians and bedside nurses were unavailable to provide clinical information due to their mobile and heavy workloads, patients had to simply wait, or request the information they needed from any available provider who may not be part of their care team. Therefore, despite their needs, ED patients lacked receiving timely and updated information about their ongoing care. There is no information source that efficiently meets patients' needs currently.

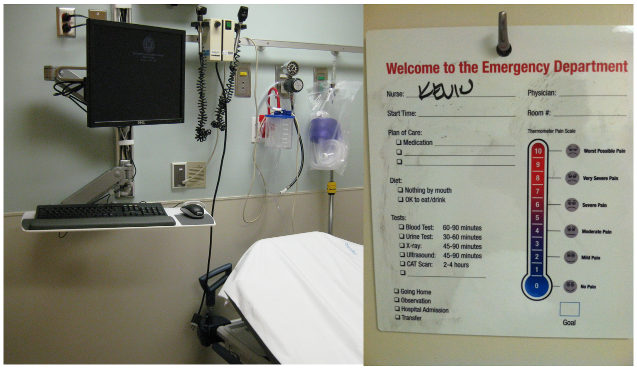
Welcome to the Emergency Department
Nurse: KEVIN
Physician:
Start Time:
Room #:
Plan of Care:
☐ Medication
☐
☐
Diet:
☐ Nothing by mouth
☐ OK to eat/drink
Tests:
☐ Blood Test: 60-90 minutes
☐ Urine Test: 30-60 minutes
☐ X-ray: 45-90 minutes
☐ Ultrasound: 45-90 minutes
☐ CAT Scan: 2-4 hours
☐
☐ Going Home
☐ Observation
☐ Hospital Admission
☐ Transfer

Figure 1. Patient room with a wall-mounted computer for EHR use (left) and a whiteboard (right). (note: whiteboard is on the other side of the room)

5. Situated Information Needs

Our study reveals that ED patients are in a great need of receiving care related information in real time. To unpack the situated nature of information needs, we detail an ED patient care trajectory in the ED. Note that although patient care in the ED varies a great extent depending on each patient's situation, in this work we summarize the common patient care phases in the ED based on key temporal events that occur in the care process. We then describe the three distinct types of information needs patients want to know: *medicine-related information*, *process-driven information*, and *care plan-oriented information*. Our study finding indicates the importance of recognizing these different types of patient information needs that are deeply situated in the ongoing care process, and supporting these needs by providing accessible and available information sources.

5.1 Patient Care Trajectory

Trajectory is one of the most important concepts drawn from medical sociology [22]. Strauss uses the term trajectory to describe the physiological unfolding of a disease process along with the entire organization of work done over the course of the process and the impact on the people doing this work. Over the course of a single trajectory, countless routines, artifacts, and rules are articulated in order to provide a course of treatment for a single patient. In this paper, we use the notion of trajectory to analyze the entirety of the coordination work that comes into play in service of the collective patient care work, as well as any information needs patients have at any given point of care.

The ED patient care trajectory consists of several distinct phases with different temporalities. These phases include the major "touch-points[1]" in the care process, where care activities and information delivery occur. A *touch-point* describes the interface between patients and any moment of decision-making through interacting with a product, service, provider, or any other stakeholder during their care process. Since information delivery mainly occurs during face-to-face-interactions, we use the touch-points as ways to phase the trajectory. This helps us to understand the questions and issues being asked by patients in each different care contexts.

In our observation, the care trajectory comprised nine phases, ranging from a patient's arrival in the ED until the moment of his or her departure. Specifically, *1)* upon arrival at the ED, a patient registers at the front desk with staff and checks in with a triage coordinator who classifies patients based on the severity of the chief complaints motivating the ED visit (*Checking-In*); *2)* the patient is then called in from triage for an initial assessment (*Triage Assessment*). In triage, the patient interacts with one to three nurses who ask questions, perform bloodwork, and conduct an EKG[2] exam; *3)* the patient is then sent back to the waiting room to wait until a bed is available (*Waiting for Bed*). *4)* At the bedside, the patient meets a bedside nurse who conducts a more thorough medical screening (*Bedside Screening*); *5)* he/she then meets with a resident and attending physician for a consultation (*Physician Consultations*). *6)* After ED physicians make a specific care plan, the patient undergoes different tests, such as a radiology test (*Test/Procedure*). *7)* Once the test results are back, the patient receives the results or any updated care plan from the physician or consults with specialists if applicable (*Result Updates*); *8)* then, he or she receives the necessary treatment, such as medication or a procedure (*Treatment Session*) and stays under observation until a proper recovery. *9)* Once all the final results are back, providers decide whether the patient is stable enough to be released or needs to be sent to another unit in the hospital (*Discharge/Admission*). Some of this process, such as from phase 5 through 8, can be repetitive; for instance, based on test results or symptom changes, the patient may need to undergo different or additional tests for further and more accurate clinical decision-making.

In our observation, we found that patients frequently had information needs at moments during a phase, or in-between phases throughout the ED care journey, when they had to wait for unknown periods of time, go through an unfamiliar test with unknown results, or undergo a treatment plan.

5.2 Types of Patient Information Needs

Although information needs vary based on patients' level of experience with and education of their diseases (for example, chronic disease patients may be more knowledgeable about their diseases and thus have less information needs during the ED visits), we identified three common information needs across diverse patient situations. Below we describe the three information types that ED patients are in need of and want to have during their hospital stay.

5.2.1 Medicine-related information

Medicine-related information is any clinical information (i.e., medical facts and knowledge) that helps patients understand their health conditions. This information is necessary for patients to understand their illnesses and the associated procedures, and to discuss treatment plans with their providers. In urgent care situations, diagnoses, tests, and test results may change dynamically in the process of ED care. As such, most ED patients, even including chronically ill patients who are familiar with their diseases, often do not have sufficient understandings about the ongoing problems that brought them to the ED. In the study, all of our participants expressed a need to acquire medicine-related information during their ongoing care processes.

Medicine-related information includes medical terminologies, meanings, explanations of symptoms, procedures, treatments, medications, and so on. For instance, after consulting with physicians, several patients in our study asked their bedside nurses to write down the specific names of their diagnosis or medications since they did not have a sufficient understanding of what they were exactly. Also, patients often requested printed information of their test results from the bedside nurses, after receiving the results from a physician. During their interactions with healthcare providers, we also saw some patients ask the meaning of various vital sign numbers displayed on the beside monitors in order to know more about their ongoing condition changes.

Patients wanted medicine-related information at different phases in ED care, often after having a consultation with physicians. Patients wished to obtain specific medical knowledge regarding their illnesses not only for understanding their symptoms and diagnosis, but also for communicating with healthcare providers properly. For instance, during the *Physician Consultation* and *Result Updates* phases, patients needed certain medical knowledge to apprehend the meaning of potential diagnoses or results and to ask necessary questions the next time they spoke to the physician, as illustrated in the following episode.

Adriana came to the ED with an eye infection. The ophthalmologist performed a detailed assessment of her right eye. While examining her eye, the ophthalmologist shared some potential diagnoses with Adriana. Since she has never heard of these serious terms, she became worried. During the wait time after the consultation, Adriana approached the bedside nurse to confirm the names of diagnoses; then she tried to look up visuals on her smart phone in order to compare them with her own symptoms. However, since there were many similar looking images, she saved some for further clarifying questions to the physician later on.

Like Adriana, obtaining medicine-related information was very challenging for most of our participants. Many patients in the study found it hard to understand the details of medical information due to a lack of information sources available to them. The physicians and bedside nurses were too pre-occupied with tasks to answer all the questions the patients had. Even using smart phones to search for information was not easy as patients had difficulty locating the right information and had a difficult time understanding the scientific information presented online. In our informal interviews with patients upon their discharge, we found that several participants surprisingly still did not know, or could not remember, the names of the procedures they had

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[1] The concept of touch-points is often used in the field of service design to describe a service-encounter, the point of contact between a service provider and customers.

[2] An electrocardiogram test that checks for problems with the electrical activity of the heart.

undergone or could not understand their diagnoses, both of which could lead to re-admission or to breakdowns in proper information delivery to their primary or home care.

Nonetheless, the medicine-related information needed is actually available and constantly updated in the EHR system, added along with each care phase; however, patients did not have access to the system, which was designed to primarily support the work of healthcare providers. Thus, patients often experienced a lack of necessary medical information and sufficient understanding of their own conditions.

5.2.2 ED care process-driven information

In addition to medicine-related information, we have also found that patients are in need of *care process-driven information* during their ED stays. Care process-driven information is information that is situated in the ongoing care and can constantly be altered by any factors related to the care contexts. This information contains the current care status, the next care procedure, where to find certain facilities/locations (e.g., the image room,) where one's healthcare providers are, the roles and names of providers, and so on. Nearly all patients in the study mentioned that they wanted to be aware of their current care situations and be able to decide what they should do or were supposed to do at that moment.

Process-driven information, in fact, was critical in enabling patients to develop expectations and to prepare their own schedules at each care phase. All of our patient participants wanted to know what they were waiting for and what the next step would be. One patient, Joe, with a complaint of high potassium, reported not getting informed about his upcoming procedure in advance, even when he asked his bedside nurse for the information a few times.

> *"It's better to ask what's coming up next because when the guy [transporter] come to take me downstairs I have no control. They are going to take me anyways, but you know when I was hospitalized before, they used to tell me within an hour, we are going downstairs. But I guess the [ED] doctor gave that order at the last minute before he went home, or maybe if they had known before that, may be they would tell me, but I don't know. I wasn't at all set. Plus, if I knew it's [the radiology room] downstairs, I would've gone to the bathroom beforehand and bring a blanket."*

This quote shows a need for obtaining care process-driven information in a timely manner. In this example, Joe wished that he had been told that the radiology test was the next care procedure, and knew when he was going to go, how long the test would take, and where the radiology room was located in the hospital. Since he was not informed and prepared physically and mentally, Joe was frustrated and ended up taking extra time in the cold radiology room looking for a bathroom during the procedure.

In addition, many patients in our study wondered about the roles of the ED staff. During each care phase, patients interacted with multiple healthcare providers, including core care team members (e.g., bedside nurse, resident, attending physician, and specialist) as well as auxiliary members of the ED care team who either directly interacted with the patients (e.g., a case manager or charge nurse) or only briefly interacted with them (e.g., a substitution of a care team member, transporter, interpreter, etc.). Our observations showed that many patients, especially ones new to the ED, were confused about the respective roles of many of the different providers and their changing roles, who to talk to, and where to find them.

The need for ED care process-driven information often arose during waiting periods in between clinical encounters. In this study, we found that obtaining real-time information about their care process was particularly difficult for patients in the ED for several reasons. First, healthcare providers in the ED were extremely preoccupied. Not only does a patient interact with multiple healthcare providers, but providers also interact with multiple patients simultaneously: a resident takes care of up to nine to ten patients; a bedside nurse can have one to five patients at a time, and float nurses or technicians may be in charge of the entire ED. Thus, it was burdensome or impossible for the busy health providers to keep patients updated with all the details of their care situations, and sometimes the nurses had to wait for doctors to update them. Second, certain information could only be delivered through ED physicians. For instance, during wait times at their bedsides, patients often relied heavily on their bedside nurses to seek such information, although nurses were not supposed to provide certain information, such as test results, that required detailed medical explanations. Lastly, the bedside whiteboards that supposedly provided care process updates for patients were rarely updated, as we discussed in the earlier section. While such information was available in the EHR system, there was no system access for patients. However, bedside nurses were too busy to update the whiteboard information consistently. Therefore, unless patients actively approached any available ED staff member to request it, the availability of this information was not efficiently supported by current practices. This often required patients to wait passively until their providers would visit their bedsides, leading to a severe shortage of information during their care.

5.2.3 Care plan-oriented information

Finally, *care plan-oriented information* is critical for patients to have an overall picture of their ED visits. Care plan-oriented information involves the anticipated length of the ED stay, the possibility of admission, and information about the department they may be admitted to or other possible follow-up care. Patients in the study indicated that knowing their care plans was helpful for them to figure out what to expect during their ED stay, as well as helping them facilitate plans after they left the hospital**.** While care process-driven information deals with information situated within the care process during the hospital stay, care plan information concerns the entity of the hospital stay, and the immediate care plans afterwards.

Unlike outpatient settings where patients are well aware of their specific care plans or the date of their next visit, ED patients cannot plan or prepare for their emergent medical conditions and have no idea what to expect during an emergency visit. Since most emergency visits occur unexpectedly, in such situations, it was important for patients to know their tentative care plans as early as possible – not just to relieve stress and tension during their emergency situation, but to better handle possible contingencies during their ED stay. In our study, we observed nearly all of the patients consistently want to figure out the bigger picture of their care plan at nearly every clinical consultation they had.

More importantly, knowing their care plan allowed patients to carefully arrange other plans and responsibilities in their life, such as family duties and professional tasks. This was particularly specific to ED patients, as many of the current ED patient population in our field site worked as day laborers or dealt with multiple daily responsibilities at home without assistance, often in single parent homes or as caregivers to other family members.

During our observation, one family caregiver, who came with a patient with abnormal chest pains, described needing to find out the tentative care plan as early as possible since she had to take care of other responsibilities at the same time.

"I had to ask for it [tentative care plan], because I [have] no time to stay. I have to go to my work. I leave my phone number to call me when my Mom will be moved [to an in-patient ward] and they will call me."

While important and much sought after, the care plan-oriented information was not easily given unless patients proactively asked for it during consultations, due to the disparate needs and expectations of the ED physicians and patients. As briefly mentioned earlier, the ED's goal is to immediately stabilize patients' medical problems and then make the decision to either discharge or admit them. In our observation, ED physicians mostly paid their attention to finding out details about the patients' symptoms and medical histories during the initial stage, while patients wanted to know whether they needed to be admitted to the hospital or not. We also observed that even when patients requested care plan related information, physicians often did not realize the underlying reason for this information need – that patients had to plan not just for the current ED stay but also for things outside of the ED or after the ED stay.

Thus, care plan-oriented information not only provides care plans based on patients' medical conditions in the face of uncertainty, but also allows for the facilitation of practical matters outside of the ED, particularly in making plans. What happens in the ED often has direct impact on other parts of patients' lives. Information related to care plans is critical to minimizing any of the potential impacts unexpected ED stays can have in the daily lives of ED patients.

6. DISCUSSION AND DESIGN OPPORTUNITIES

In this study, we found that patients experience a severe shortage of information during their emergency visits. We identified three types of information needs – medicine-related, care process-driven, and care plan-oriented – as patients went through different phases of the care trajectory in the ED. However, these needs were often unrecognized or unmet by the current health IT systems and healthcare providers, because the patients' needs in the ED were largely situational, transient, time-sensitive, and communication-oriented. In this section, we discuss the nature of information needs during patients' ED visits and how technologies can be designed to support their needs.

6.1 *Beyond* Medical Information

Prior technologies that support patient information needs during ongoing care, such as mobile applications, often provide medical related information, including diagnoses, medication lists, and test results [21,23,26,27]. Nevertheless, as our study shows, patients' needs for medically relevant information is dynamic and changes with their current situation, such as what they have been diagnosed with, and what will happen next. As ED visits are often unexpected, and the course of diseases differ in each patient case, these prior technologies cannot sufficiently meet patient needs during ongoing care. The patients in our study had to request medical information written on paper, check the meaning on their own. To that end, we first suggest pervasive technologies support information needs in patients' ongoing care to provide medicine-related information in an appropriate manner. This information should be offered to patients at the time when they need such information (e.g. when new diagnosis, test, medications are introduced) and done so in a way that it is comprehensible to them (e.g. containing sufficient explanations using languages fit to patients' background) [29]. This can be done through providing patients' partial access to the patient records system currently deployed in the ED. As we mentioned earlier, the EHR system is a comprehensive information system for healthcare providers to document their work progress for their patients. As such, information, including diagnoses and lab orders, is already entered into the system. If such information could be shared with patients through an inpatient portal, along with pointers to other information sources to explain the meaning of the given information, such as WebMD, patients could have access to the desired information in a timely manner, even though their needs for medically relevant information are dynamically changing during the care process.

In addition, our study discovers that patients want information that goes beyond medical knowledge. Patients in our study expressed needs for other types of information – namely, information regarding their *care process* (e.g., current status, logistics in the ED) and *care plans* (e.g., possibility of admission or discharge). These two types of information, though deemed critical, have not been incorporated into the current pervasive technologies for ongoing patient care. First of all, process-driven information is inherently situational and contextual. It is, from moment to moment, the current procedure, the current wait time, the current availability of providers, etc. Thus, the need for process-driven information is on a short-term basis, since this type of information changes along with the ongoing care status. The need for process-driven information has been reported in other studies, with a particular focus on providing information about key medical events [16], such as procedures that have already been conducted and upcoming tests or procedures. In our study, process-driven information is much broader, and closely relates to transitory activities, events, situations, and the provider's role and availability, all of which could cause changes in the patient's care process, and result in potential confusion and stress.

Compared to the situational process-driven information, care plan-oriented information is less about moment-to-moment details, and more about overall plans affecting one's stay during and after the ED visit. In our study, patients wanted to know their overall care plan even as early as at the beginning of their ED care, so they could begin communicating with family members, coworkers, their own specialists, or other individuals involved in the follow-up care plans. Since planning for follow-up care often involves other people, especially for elderly or chronically ill patients, and it takes time to arrange schedules based on plan changes, patients wanted to know the overall care plan sooner rather than later. Thus, care-plan-oriented information is desired in order to roughly sketch out and better prepare for his or her ED stay, as well as for his or her care after the ED stay.

However, as we have shown in the study, these two types of information – process-driven and care plan-oriented – are often neglected by the current care practices. First, currently deployed information systems do not offer process or plan-driven information to patients, and healthcare providers who have knowledge of the information are too busy to verbally update patients, especially on the moment-to-moment changes in process information. Second, other information sources accessible to patients, for instance, the whiteboards at the patients' bedsides, do not offer situational information, and often are not updated in a timely manner, as manual updates of such information by bedside nurses are unrealistic in the busy ED environment.

To address care-process and care plan-related information, it is essential to create one integrated, accessible information source for patients by integrating the hospital patient portal with the EHR, where most of the care status information (e.g., info on healthcare providers, order status, etc.) is already available for providers, and providing patients partial access to the patient records system. We suggest the system also offer ED specific information, with such information differing from ED to ED, so that patients can check specific locations, facility information, the ED care workflow, and find out details on how long a certain procedure takes. In addition, in this system design, care plan-oriented information can be shared with patients once the diagnosis is entered. Sharing information with patients can be done in a semi-automatic way, for instance, the system can provide patients with access to certain information recorded in the EHR system such as diagnosis but leaving out incomplete physician notes or documentations that are not appropriate for patients to view. Doing so would eliminate the extra documentation burden imposed on busy ED staff and also allow them to choose what information to share with their patients during ongoing care. This design can help patients turn to and use a single platform to receive and coordinate information and minimize the burden of looking for any available sources or tracking their healthcare providers, who were the only source to fulfill their information needs in our study, especially in light of the physical and mental stress faced by hospitalized patients. In this way, both the process-driven and the care plan-oriented information that was previously only available in providers' workflow and knowledge can be visible and transparent to patients. In addition, it is crucial to recognize and share the overlooked information needs of patients with healthcare providers, particularly with core care team members.

6.2 Temporality in Information Needs

As our study shows, patient information needs are not static, but situated within the care trajectory. As the patient goes through the various phases of the ED care trajectory, the need for different types of information shifts accordingly. For example, a patient might have specific needs for medical-related information *right after* consulting with an ED resident, and want to know when she will receive test results *during the wait time*. As, such, there is a hidden temporal cycle as to when each type of information is desired during each phase of the trajectory.

Temporality has been found to play a crucial role in patients' information management [19]. For instance, one study found that cancer patients have different information needs as their illness progresses: in earlier stages, they want to gain knowledge about the disease, whereas in the later stages, cancer patients prefer to learn coping strategies and regiments. One study examining chronic patients' information use revealed that health information is organized and used based on the cycles of a routine medical visit with the subsequent homecare periods [8]. Though these studies addressed temporality issue in patients' information needs, they tend to focus on longitudinal care management, instead of the temporal structure of information needs within one medical visit.

Based on the nine phases in the care trajectory identified in the study, we argue that information needs change based on when activities occur, such as before, during, or after each touch-point. First, medicine-related information is usually required "*after*" interactions/care activities with healthcare providers, particularly after physician consultations. For example, after a patient and/or caregiver had a conversation with a physician for an initial assessment, a diagnosis consultation, or a results update, they wanted to fully understand and process what they were told. As shown in the finding section, they tended to look up information on their phones or ask their bedside nurses for additional information, to confirm their knowledge, or to fill-in what they didn't know. Next, care process-driven information is often requested "*before*" touch-points or "*in-between*" them. As we described previously, care process-driven information is any situational information related to the current status, as well as the upcoming activity/interaction/location; it is typically wanted before activities occur or during the wait time between activities to gain situational awareness. For instance, patients may wish to know information about a long wait, or what medications are to be given. Lastly, care plan-oriented information is often necessary "*during*" consultations with clinicians. The formal consultations with clinicians usually happen at the bedside with physicians. Physician interactions are an ideal time for patients to inquiry about the chance of being admitted to the hospital or the estimated length of the ED stay. Thus, phases of the care trajectory are found to be the decisive triggers for the different information needs of patients.

As describe earlier, addressing ED patients' information needs is challenging due to the highly-situated, detailed-oriented and dynamically changing patient situations in the emergency care process. Current technologies fall short in supporting the types of information needs desired by patients. Nonetheless, the inherent temporal structure embedded in the care trajectory provides a great opportunity for designing pervasive technologies that can provide in real-time and the right type of information to ED patients. A system should be designed to provide appropriate information at the right time when patients need or wish to have it. For instance, medical knowledge regarding a recent consultation, in the format of a summary and additional informational materials, can be automatically provided after a physician consultation – a time when such information is needed the most. Similarly, the system can start notifying patients of the reason for the long wait time or provide useful information on how ED care works, e.g., how long a MRI test may last, how many patients are waiting in a queue, where the radiology department is, and how to prepare for the test, both mentally and physically. Such process-driven information can eliminate much of the worries, uncertainty and anxiety of ED visits.

7. CONCLUSION

The findings of our observational study show that ED patients reveal three critical types of information needs during their ED visit: medicine-related information, care process-driven information, and care plan-oriented information. Our study results uncover that these patient information needs not only dynamically change over time, but are also deeply situated in different care phases of the patient care trajectory. We outline design opportunities for new systems to support these situational and time-sensitive patient information needs. These design considerations will enable healthcare providers to acknowledge and share patient information needs and provide patients with various learning opportunities to encourage active participation and empowerment. We would like to note that the findings of the study only represent the patients from a single emergency department in an urban area. The findings of our study contribute to the design of pervasive health technologies that can provide the right information at the right time when it is needed most. This has not been done in the past research, and we plan to bring our design prototypes to the ED in our next phase of the study.

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9. REFERENCES

1. Jakob E. Bardram, Mads Frost, Károly Szántó, Maria Faurholt-Jepsen, Maj Vinberg, and Lars Vedel Kessing. 2013. Designing mobile health technology for bipolar disorder: a field trial of the monarca system. *Proceedings of CHI*, ACM, 2627–2636.
2. Hugh Beyer and Karen Holtzblatt. 1997. *Contextual design: defining customer-centered systems*. Elsevier.
3. Timothy W. Bickmore, Laura M. Pfeifer, and Brian W. Jack. 2009. Taking the time to care: empowering low health literacy hospital patients with virtual nurse agents. *Proceedings of CHI*, ACM, 1265–1274.
4. Hjordis Björvell and J. Stieg. 1991. Patients' perceptions of the health care received in an emergency department. *Annals of emergency medicine* 20, 7: 734–738.
5. Katherine Blondon, Msc1 Predrag Klasnja, and M. H. A. Logan Kendall. 2013. Long–term engagement with health–management technology: a dynamic process in diabetes1. *Katherine S Blondon*: 37.
6. Bernard S. Bloom. 2002. Crossing the quality chasm: a new health system for the 21st century. *JAMA: The Journal of the American Medical Association* 287, 5: 646–647.
7. Edwin D. Boudreaux and Erin L. O'Hea. 2004. Patient satisfaction in the Emergency Department: a review of the literature and implications for practice. *The Journal of Emergency Medicine* 26, 1: 13–26.
8. Yunan Chen. 2011. Health information use in chronic care cycles. *Proceedings of CSCW*, ACM, 485–488.
9. Tom Delbanco, Jan Walker, Jonathan D. Darer, et al. 2010. Open notes: doctors and patients signing on. *Annals of internal medicine* 153, 2: 121–125.
10. Barney Glaser and Anselm Strauss. 1967. The discovery grounded theory: strategies for qualitative inquiry. *Aldin, Chicago*.
11. S. Ryan Greysen, Raman R. Khanna, Ronald Jacolbia, Herman M. Lee, and Andrew D. Auerbach. 2014. Tablet computers for hospitalized patients: A pilot study to improve inpatient engagement. *Journal of Hospital Medicine* 9, 6: 396–399.
12. Eric Jamoom and others. 2012. *Physician adoption of electronic health record systems: United States, 2011*. US Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Health Statistics.
13. Sherrie H. Kaplan, Barbara Gandek, Sheldon Greenfield, William Rogers, and John E. Ware. 1995. Patient and Visit Characteristics Related to Physicians' Participatory Decision-Making Style: Results from the Medical Outcomes Study. *Medical Care* 33, 12: 1176–1187.
14. Scott Krishel and Larry J Baraff. 1993. Effect of emergency department information on patient satisfaction. *Annals of Emergency Medicine* 22, 3: 568–572.
15. Yves Longtin, Hugo Sax, Lucian L. Leape, Susan E. Sheridan, Liam Donaldson, and Didier Pittet. 2010. Patient Participation: Current Knowledge and Applicability to Patient Safety. *Mayo Clinic Proceedings* 85, 1: 53–62.
16. Laura Pfeifer Vardoulakis, Amy Karlson, Dan Morris, Greg Smith, Justin Gatewood, and Desney Tan. 2012. Using mobile phones to present medical information to hospital patients. *Proceedings of CHI*, ACM, 1411–1420.
17. S. C. Porter. 2004. The Asthma Kiosk: A Patient-centered Technology for Collaborative Decision Support in the Emergency Department. *Journal of the American Medical Informatics Association* 11, 6: 458–467.
18. Jennifer E. Prey, Janet Woollen, Lauren Wilcox, et al. 2014. Patient engagement in the inpatient setting: a systematic review. *Journal of the American Medical Informatics Association* 21, 4: 742–750.
19. Lila J. Finney Rutten, Neeraj K. Arora, Alexis D. Bakos, Noreen Aziz, and Julia Rowland. 2005. Information needs and sources of information among cancer patients: a systematic review of research (1980–2003). *Patient education and counseling* 57, 3: 250–261.
20. Meredith Skeels and Desney S. Tan. 2010. Identifying opportunities for inpatient-centric technology. *Proceedings of the 1st ACM International Health Informatics Symposium*, ACM, 580–589.
21. Diana Stade, Anuj Dalal, George Getty, et al. Participatory Design and Development of a Patient-centered Toolkit to Engage Hospitalized Patients and Care Partners in their Plan of Care.
22. A. L Strauss and S. Fagerhaugh. 1997. *Social organization of medical work*. Transaction Pub.
23. Paul C. Tang and Carol Newcomb. 1998. Informing patients A guide for providing patient health information. *Journal of the American Medical Informatics Association* 5, 6: 563–570.
24. P. C Tang, J. S Ash, D. W Bates, J M. Overhage, and D. Z Sands. 2006. Personal Health Records: Definitions, Benefits, and Strategies for Overcoming Barriers to Adoption. *Journal of the American Medical Informatics Association* 13, 2: 121–126.
25. Kenton T. Unruh, Meredith Skeels, Andrea Civan-Hartzler, and Wanda Pratt. 2010. Transforming clinic environments into information workspaces for patients. *Proceedings of CHI*, ACM, 183–192.
26. David K. Vawdrey, Lauren G. Wilcox, Sarah A. Collins, et al. 2011. A Tablet Computer Application for Patients to Participate in Their Hospital Care. *AMIA Annual Symposium Proceedings* 2011: 1428–1435.
27. Lauren Wilcox, Steven Feiner, Andy Liu, Susan Restaino, Sarah Collins, and David Vawdrey. 2012. Designing inpatient technology to meet the medication information needs of cardiology patients. *Proceedings of the 2nd ACM SIGHIT International Health Informatics Symposium*, ACM, 831–836.
28. Tae-Jung Yun, Hee Young Jeong, Tanisha D. Hill, et al. 2012. Using SMS to provide continuous assessment and improve health outcomes for children with asthma. *Proceedings of the 2nd ACM SIGHIT International Health Informatics Symposium*, ACM, 621–630.
29. Qing T. Zeng and Tony Tse. 2006. Exploring and developing consumer health vocabularies. *Journal of the American Medical Informatics Association* 13, 1: 24–29.