Patient Strategies as Active Adaptation: Understanding Patient Behaviors During an Emergency Visit

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ABSTRACT

Although the ability of patients to access their health information during ongoing care is considered crucial for better health outcomes and increased satisfaction, the current care model places patients in a passive role. To investigate the patient experience in the hospital environment where information is lacking and in accessible, we conducted an ethnographic study with patients, caregivers, and healthcare providers in the emergency care setting. We report the three types of information breakdowns ED patients encountered during their emergency visits and the strategies they developed to cope. Our findings reveal a rich picture of the coping mechanisms ED patients use to proactively adapt to the nature of the ED care context. This work expands upon our understanding of the unique information challenges ED patients face, as well as the important adapting behaviors they engage in; it also uncovers design opportunities for supporting crucial, yet unmet, patient information needs.

Author Keywords

Health informatics; hospital; patient coping strategies; adaptation; information technology; HCI.

ACM Classification Keywords

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

INTRODUCTION

Although recent healthcare technologies, such as online patient portals and mobile health applications [1,4,41], have enabled patients to access, track, review, and manage their health-related information in domestic or general care settings [5,34], providing real-time care-related information to patients during their ongoing medical visits is not supported in current clinical settings. A previous study found that the information patients needed regarding their ongoing care processes was not readily available to them; instead, patients had to wait for information to be delivered, cope with complex terminology, and go through unfamiliar procedures[37]. Thus, the lack of information in the clinical environment often puts patients in a passive role; patients are unable to be engaged and empowered actors who can make informed decisions and contribute to their care process [37]. In contrast, encouraging patients to seek more information and actively ask questions during clinical visits has been shown to reduce anxiety [35], improve compliance with instructions [31], and improve patient satisfaction [30].

The lack of information access for patients is especially serious in urgent care environments, such as an Emergency Department (ED). A large number of prior studies has shown that patients experience various difficulties in the ED care context, including the lack of prior acquaintance with healthcare providers, the short duration of clinical encounters, frequent staff changes, feelings of uncertainty, and overcrowding in the environment [21,22]. These problems, in turn, may negatively affect the patients' medical experience, as well as care quality. The unique challenges of the ED call for an in-depth study of the types of information breakdowns that occur during patient visits, and the ways in which patients cope with a lack of information in such an interruptive and complex environment.

In the HCI and Health Informatics communities, many have studied different health technologies that enhance access to information for patients, and found that better information access leads to better patient empowerment and engagement [2,7,37]. Recently, researchers have illustrated the potential for technologies to support the information needs of patients and caregivers in hospital settings [3,19,37]. Researchers have also begun to study the behaviors and roles of hospitalized patients and their caregivers during their hospital stay [23,24,28] For instance, Mishra et al. have reported on five roles that patients and caregivers take on when interacting with their healthcare providers [24]. Yet, we still know little about what motivates or triggers patient engagement [13], how patients and caregivers become engaged in their behaviors and roles, and the detailed process of how they actually develop these behaviors, particularly during ED visits.

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Building on these prior works on patient behaviors and roles, in this paper, we report findings from an ethnographic study conducted with patients and their caregivers during emergency visits. Specifically, the findings of our study identify three types of information breakdowns ED patients face in the process of receiving their care, and the corresponding strategies they develop to cope with these breakdowns and to assist with their own care. We then look at the patients' creation of the coping strategies as a) a process of active patient engagement and b) as a proactive adaptation to the unique characteristics of the ED care context. Finally, we offer suggestions for the design of a sociotechnical care environment that can serve patient information needs and behaviors, promote patient engagement in their care, and improve the overall patient experience during their clinical stays.

RELATED WORK

The need for patients to access their health-related information has been widely studied in prior research. Many studies have investigated the information needs of health consumers and shown that patients desire more educational materials regarding their illnesses and more information about possible treatments and alternatives plans than they typically receive during clinical visits [32,34,36]. A variety of health IT systems have also been developed to address patient information needs, such as online patient portals, Personal Health Records (PHR), and mobile health apps [2,5,34,41] It is reported that these systems bring in many of the benefits of health information access, such as better patient satisfaction [1,4], reduced conflicts in decision-making [17], increased adherence to care [17], and increased patient empowerment [39]. Yet, these previous works have primarily focused on the information needs of chronically ill patients in the outpatient setting, rather than addressing the needs of patients in ongoing care during their hospital visits.

In HCI, CSCW, and Health Informatics communities, there has been an increased attention toward acknowledging the need to support patients and their caregivers during their ongoing care. Researchers have investigated the role of novel technologies, such as information wall displays, tablets, kiosks, and mobile apps [15,19,29,37,38] to provide care-related information to patients to enhance their engagement and improve their communication with healthcare providers. For instance, Bickmore et al. designed the virtual nurse agents system that guides patients through their discharge paperwork. They found that this system effectively improves patients' comprehension of discharge instructions and increases patient satisfaction [3]. Tablet computers, mobile applications, and kiosks have also been offered to facilitate patient access to information regarding medication, and other care-related and educational information during their hospital visits 15,29,37,39].

In addition, few recent studies have examined the behaviors and roles patients and caregivers participate in, in the inpatient setting [18,23,24]. Similar to the work of Mishra et al.[24], Miller et al. [23] has described the five active roles of caregivers at hospitals by examining the interactions between patients and caregivers. These studies suggest that patients and caregivers can play an active role in their own care process.

During an emergency visit, patients suffer from an urgent and serious medical condition in an unfamiliar, stressful environment. They face difficulties getting basic information about their care, unable to find out about the expected duration of their wait time, when they will see their doctor, and what care procedures will be coming next [40]. Prior studies have also mentioned the communication challenges most ED patients face and their struggles with being acknowledged by providers and having their psychosocial and emotional needs met through quality interactions [12]. Despite the need, the ED has not been studied much [29,37]. Recently, studies have offered insight into the three types of information patients need [26] and the barriers and the barriers' causing factors in patient-provider communication in ED care [27]. These studies illustrate the need to understand how patients deal with the complexities of the ED care context.

In this study, we build on these prior works to identify the information breakdowns patients face in the ED and examine how they deal with the situations. We believe this ethnographic study can offer useful insights into when and how ED patients get actively involved in their own care, and show how information breakdowns can be turned into opportunities for active patient engagement.

METHODS

We conducted an ethnographic study in an ED affiliated with a large urban hospital in the US. The ED has nearly 50,000 patient visits each year, and approximately half of the patient population is covered by private insurance. The authors' institutional review board approved this study.

Our study included in-depth observations and interviews with ED patients and their caregivers over a five-month period between January 2015 and May 2015. Observation was used to understand the patients' experiences, and the interactions among the patient, their caregiver(s), and their healthcare providers in the ED. Our observations totaled 230 hours and each session lasted roughly two to six hours. All observation data was collected by two researchers. The researchers followed the entire journey of a patient visit from the waiting room to the discharge/admission, if possible. Our observational activities also involved following key 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 needed and any information they wished to have; any information sources they used, including artifacts and technology use in the patient rooms; and the behaviors patients, caregivers, and providers engaged in throughout the entire ED care process. In addition, we performed informal interviews with patient participants and their caregivers during, or after observations, to gain a better understanding of the perceptions, feelings, and questions they had during their ED stay.

Our site selection and sampling criteria allowed us to recruit patients with a wide variety of ages and medical conditions. We recruited a total of 35 patients to participate. In terms of the patient selection for our observation, we tried to maximize the diversity of patients. We selected patients based on age, gender, ethnicity, and disease complexity. Following the ED rules, we excluded trauma patients, patients with contagious diseases, and psychiatric patients from our study. Patient participants had diverse medical complaints that related to various levels of complexity and urgency, different lengths of hospital stay, and varied medical conditions (ranging from migraines to congenital cerebral palsy to cancer). The patients' ages[*] ranged from 4 months to 90, and the majority were accompanied by caregivers, including family and friends. Patients were ethnically diverse: 16 were Caucasian, 1 African-American, 8 Hispanic, 7 Asian, and 3 American Indian/Alaska Native. Half of the patients were male, and half were female. The patients' health or computer literacy was not measured in this study; however, we found that even when patients have a higher health and computer literacy (based on their medical history and occupation), they still engaged in the same information behaviors during actual care situations in the ED.

Data Analysis

While observations and informal interviews were being conducted, the research group met regularly to discuss preliminary findings and identify themes in the data. After the data collection was completed, three researchers coded the field notes from the observations and the informal interviews in an iterative coding process, using the open coding method from the grounded theory approach [11]. Each of the three researchers coded the same data to look for predominant concepts. Through several rounds of coding, the research team identified emerging themes, such as the various information breakdowns participants experienced while they were in the ED. The list of breakdowns was then used by two researchers to code all the data to explore what behaviors participants engaged in during their ED stay and what underlying factors and issues influenced their behaviors. During the analysis, the two researchers discussed the preliminary findings to determine how the various patient behaviors fit into coping strategies, and revised iteratively until agreement was reached among all researchers. Although we mainly focused on patients, we analyzed both patients and caregivers because their behaviors complemented each other.

OVERVIEW OF PATIENT CARE IN THE ED

Our observation showed that despite patients' desire to know and manage health information during care, most of the existing information technologies available at our field site did not offer information access to patients. First, the Electronic Health Records (EHR) system, the primary information infrastructure in the hospital, is mainly designed for healthcare providers and administrative staff as their working system. The EHR would appear to be an ideal resource for patients to access information as it contains all the patient information generated in the care process; yet, patients currently lack direct access to EHR data during their care.

In addition to the EHR, other information media in the patient room are a whiteboard (physical displays presenting basic patient care information, such as body temperatures, and tests orders) and a vital sign monitor (display for blood pressure and heart rate). Despite their physical accessibility, the patients we studied did not consider them to be beneficial or useful. The whiteboards were often found to be empty or to contain outdated information due to the busy bedside nurses who could not manually keep them updated, and the information on the vital sign monitor was not easy to read for ED patients who lacked medical knowledge. Thus, without proper system support, the current ED becomes an information-lacking environment for patients and makes the healthcare providers the only available information source for patients during their ED care stay.

While healthcare providers were expected to deliver care information to patients in the ED, we found that the patients in our study were not satisfied with the information they received, and often experienced information breakdowns. At our field site, especially during busy times, patients and caregivers often had to wait for providers to drop by and/or wait for tests results. These information breakdowns caused patients frustration. A few mentioned that the lengthy waits and information delays made them feel like they never got proper answers to their questions. These breakdowns more seriously led to unexpected care treatment changes, such as not getting a medication properly due to time delay, which can affect a patient's health and health care quality. To further understand this issue, we analyzed the information breakdowns experienced by ED patients, the causing factors, and how patients handled these breakdowns and the information-lacking environment of the ED.

INFORMATION BREAKDOWNS AND PATIENTS COPING STRATEGIES WITH THEM

While the work practices of ED providers are well-supported by health IT systems, such as the EHR, the current ED practice does not provide patients access to their care-related information nor consider their need to access such information during their hospital stays. In this section, we report on three types of information breakdowns resulting from the patients' lack of information access and information support in the ED. We chose these three breakdowns and their corresponding strategies as they

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[*] For the patients younger than 18, we followed their caregivers.

represent the common information behaviors that patients engage in to adapt to the challenges of the ED.

Information Delay and Unavailability

The first type of information breakdown patients commonly experienced in the ED was the delay in receiving their care-related information. Resonating with many ED studies [18,19,23], delayed information delivery was one of the prevalent information breakdowns in our field site. Delays in receiving information induced lengthy wait times, increased patients' anxiety, and even led to information failure or loss in the middle of delivery to patients.

Information delays were caused by multiple factors related to ED work processes. First, the nature of the ED providers' work is very impromptu and must respond to emergent situations, instead of being pre-organized. Unlike other typical care settings, the ED deals with patients whose conditions span different levels of severity and urgency. Dependent on the patient cases and the numbers of patients the providers are taking care of, care priorities can be altered at any minute. Even with patient updates available on the EHR or reminders from the bedside nurses, providers might be caught up caring for trauma cases, or patients with higher care priority, for hours before providing necessary information to other patients in person; such information would not be available to those patients till then.

Second, the other reason for information to be delayed was because of the fallout of the temporal dependency in the collaborative ED care process. The medical care activities are temporally dependent on the previous ones in the patient care trajectory, since information only becomes available after the execution of prior care activities. For instance, after the initial clinical consultation, physicians mainly provide clinical updates to patients. Only after all of the orders for a patient are executed and the results are successfully collected from the lab, the physicians properly decide on a next step. Bedside nurses are not allowed to quickly deliver information to patients, since they are required to wait until the physicians communicate the lab results to patients since such information often needs to be provided with detailed medical explanations. Thus, information get delayed meanwhile. In addition, at times, care activities, such as a consultation with an admitting resident or surgeon, may require orders or care tasks to be completed by other departments, which can cause further delays due to the workloads in other departments.

In our study, we often observed many cases where ED providers were stuck waiting in the treatment process for, among other things, a consultation from an admitting resident, a confirmation from a surgeon, a pharmacy approval, or a bed availability from an inpatient unit. In these cases, patients had to simply wait for hours, suffering with their pain without a proper information update. The lag and wait between care activities often induced a delay in notifying the patient about their care progress. This delay and unavailability of information eventually led to extra stress, frustration, and anxiety for patients and caregivers, and more seriously, potential effects to patient health and health care quality.

Strategy to cope with information delays

Most patients felt that their ED care providers were usually preoccupied with other care tasks, and proactively followed up for updates on their care to prevent further delays or unexplained waits. Specifically, the patient participants in our study approached their providers or any other available provider they could find for information. For instance, patients approached providers passing by to ask when they could expect to hear updates about the next procedure. Patients also reminded providers that they were waiting for information in order to make sure their providers were aware of their need to receive updates. Most participants started engaging in these strategies by observing situations (e.g., counting the number of sicker patients to find out their turn to see doctors), as well as the behaviors of other patients and caregivers in the hallways. By doing this, patients tried to figure out the reason why information was delayed and what they could do. At our fieldsite, we observed a patient with an eye infection reached out to her providers to remind them that she was waiting.

Yasmine, a female patient came in the ED for an eye infection. After having multiple clinical consultations and examinations with ED providers and an ophthalmologist, she was informed that she would be discharged once she took the prescribed medication. After that, Yasmine had to wait for the medication for a couple of hours in the eye-exam room. Then, she was asked to leave since another patient needed the exam room, and she was in the process of being discharged anyway. However, her lengthy wait for the medication continued even in the waiting room. After another two hours of waiting, Yasmine started worrying that her care team members might have forgotten her, as there were more trauma patients coming into the ED. So, she decided to approach an ED staff member who was passing in the hallway to remind her previous bedside nurse that she was still waiting for the medication. After some time, Yasmine finally received information that her medication had to be compounded by the pharmacy, which was more time-consuming than simply getting it from the shelf. It turned out that the bedside nurse, who was occupied with several incoming patients, did not receive this information from the resident, who was also busy with multiple trauma patients until Yasmine asked for it.

In the case of Yasmine, the information that the medication would take a longer time to be made because of a fallout of the temporal dependency of the care process, thus require a longer wait time should have been provided to her. This information should have been delivered from the pharmacy to the physician, to the bedside nurse, and finally, to the patient; however, the information had gotten lost in the middle due to the busy schedule of the physician, and then the bedside nurse almost forgot that Yasmine was waiting since she was busy with her other patients. As seen here, Yasmine's strategy of approaching and reminding her healthcare providers facilitated her receiving the update regarding her ongoing care process and helped relieve some of her anxiety about not getting the proper care from her providers. More importantly, she prevented further delays by reminding her providers of her incomplete care process (i.e., her medication) and helped to avoid the possibility of being forgotten or having a missed medication order.

We also found similar patient coping behaviors aimed at preventing further information delays and potential errors, such as proactively reporting their own condition changes while waiting. By frequently approaching their nurse to report their condition changes or any updates, patients and caregivers believed it would make their existence more visible in the face of the providers' busy workload, and eventually help them receive updates from their providers.

As seen in this section, strategies were created and utilized by patients and caregivers to facilitate their information access and awareness of their ongoing care situation when information was not timely delivered. These strategies emerged from the patients' active efforts to recognize breakdowns, cope with not getting their ongoing care information, and prevent further information delays. Ultimately, by employing these coping strategies, patients were able to prevent potential errors, such as forgotten or missed orders, and to improve their own care quality. Furthermore, these strategies helped to expedite the patient care processes by helping to maintain the providers' focus; without these strategies, it is possible that their care processes could have been further slowed down.

Information Overload

Most of the patients and caregivers in our study suffered from a lack of information most of times, as seen in the previous section. However, the amount of information delivered and the ways in which it was delivered frequently raised problems for patients. Our patient participants often received a great amount of information all at once within the short period of a physician consultation and were often unable to fully process, comprehend and remember the information they received. Having information delivered in a way they could process was important for ED patients who were experiencing high levels of stress and anxiety, yet needed to understand their medical condition in order to be involved in their own care. Although providers were usually very careful about the types of information they provided, taking care not to frighten patients or subject them to undue stress, providers did not necessarily deliver information in an appropriate manner. This was particularly true at busy times when providers had to see multiple patients in a row; then, they sometimes poured out a torrent of difficult terminologies at top speed, without taking the time to clarify or explain the information to patients at a more detailed level. Since it often took some time for many patients and caregivers to actually process, reflect, and understand the information in order to raise relevant questions, even when physicians tried to check up on patients' comprehension by asking, "*Do you have any questions?*" many patients and caregivers often sat there, looking blank, still processing the information, and not yet at the point of formulating thought.

This was common at the end of the initial consultation, in particular, when physicians usually communicated care plans by rapidly listing possible diagnoses and the tests or procedures they planned to perform. As a result, after the consultation, patients often felt overwhelmed; however, it was not easy to hold their physician back since the physician was so busy. It became even worse when more than one physician was involved in a consultation, such as when a specialist came with his resident and medical students. Thus, patients experienced long and silent bedside wait times followed by a period of intense information overload. This is demonstrated in the example that follows.

An 18 year old patient, Lee, was brought in by his parents after having black stools for two days. Lee is deaf and suffers from cerebral palsy, so his parents are in charge of his care, directly communicating with providers. A while after they waited for a doctor consultation at bedside, a resident finally came for the medical screening and asked questions about his last admission, medical history, and symptoms to Lee's mom. In the middle of the resident's consultation, an attending physician joined and asked more specific questions about Lee's current symptoms, while discussing the case with the resident simultaneously. After asking several questions, at the end of the consultation, the attending discussed a plan with the mother, speaking at a very fast pace: "he [Lee] may need a transfusion. We will do some IV and lab tests and then see the GI doc. He probably needs to be admitted again, but we will see. The blood might, probably have been from Tuesday and left out, or it may be new blood. Anyhow, we have to get rid of it. We will start with the rectal exam." Both physicians then ran out in the direction of the trauma room in response to an overhead page about two incoming trauma patients. The mother responded, "oh, okay..." and stood there with a puzzled expression. A minute later, Lee's dad came back from getting a snack.

In the case above, although the attending physician disclosed all the available information about Lee's care plan during the consultation, receiving all the information at once caused a sudden information overload for Lee's mother. She was not able to follow the information given by the physician, let alone comprehend its meaning and raise any questions that she may have. There were simply too many items on the care plan for a layperson to properly understand and remember in a few seconds. When her husband returned and asked what the doctor said, she was only able to briefly mention the chance of re-admission, but not the other items the physician had mentioned. After the consultation, we saw the mother persistently ask a bedside nurse about what kinds of tests they would do and what the next step would be. Even for Lee's parents, who have been exposed to and prepared for frequent medical visits, and who are somewhat knowledgeable about general healthcare information, it was still challenging to handle the overload of information during their ED visit.

Apart from some chronic illness patients, a majority of the ED patients had a relatively low health literacy and were not familiar with diagnostic terms and clinical procedures. During the interviews, we discovered that several patients did not even understand the roles or names of the medical professionals, such as ophthalmologist, and had to guess or make assumptions along the way regarding what roles these professionals might have and what medical diagnoses they could have based on these roles; half of the patients we spoke with could not even remember the names of their diagnosis and the procedures they had had in the ED.

Strategy to cope with information overload

To address the information overload issue and to understand the unfamiliar terminologies, many patients and caregivers developed strategies during their ED stays. First, most patients tried to keep records of their care information by asking for printouts of images and lab results. Many patients and caregivers asked their bedside nurses to write down medication names or requested treatment procedure details right after consulting with physicians in order to fill in any blanks they may have had after their clinical consultation and to confirm the information they had received. Experienced chronic illness patients wanted to review the number values of test results and carry records with them, actively asking for paper copies of any test results they had. Through requesting, documenting, and keeping their own records, patients were not only able to capture missed information, but to gather and keep necessary information for themselves for later use. It also enabled them to remember the information, prepare appropriate questions, or discuss any concerns with their healthcare providers during the next consultation. This strategy was also beneficial for follow-up care because patients could provide better ED information to their family doctors or other specialists.

In addition, patients often engaged in looking up additional information, such as information related to their diagnosis or visuals of physical symptoms, to aid their own comprehension. They call their friends and family or browsed their smart phones. For instance, a patient who had come to the ER the night before because of an insect sting, came back again for the same, though not improved, symptom. To process all the information he heard from the physician consultation, he first tried to look for relevant images of the area on his arm stung by a bee. He then compared them with other images found on the web, based on potential diagnoses the physician mentioned so that he could ask the physician questions and make sure to receive the proper treatment this time.

To summarize, experiencing information overload at certain information peak times was another type of information breakdown for patients and caregivers at the ED, hindering their understanding, as well as their engagement in ED care. To deal with this breakdown, patients developed various strategies for documenting and keeping records based on the information they got from providers, and searching for relevant information in order to comprehend it. In the study, we found these strategies were not only beneficial for patients by helping them actively engage in their ED care, but also valuable for their own health as they were more able to understand and follow care instructions.

Inconsistent Information among Multiple Care Team Members

The last type of information breakdown identified in our study was the problem of inconsistent information, where different providers involved in a single patient case may not have the same level of information. In the ED, patients have to interact with multiple healthcare providers (up to 8-10), care team members who come and go during different phases of the care process.

When communicating information at the bedside, patients and caregivers sometimes found gaps in the information that different team members had. First, because of the number of team members, and the complexity of each member's tasks and expertise, it was challenging for every member to be on the same page all the time, as different members have different professional backgrounds and focus on different aspects of care. As a result, information inconsistencies often occurred. For example, when a patient who had a history of kidney failure came into the ED for a severe migraine as his chief complaint, the patient realized that not every care team member knew the medical history related to his kidney failure and was bothered by this fact.

Second, the urgent nature of the ED care work constrains the information shared among care members. With heavy and dynamic workflows, ED care team members did not have sufficient time to check the EHR or have a chance to update and verbally communicate with each other. For instance, in our study, many physicians could not have all the information up to date for every one of their patient cases because they had to watch out for critical patients or incoming trauma patients. As the physicians could not enter the patient data into the EHR in a timely manner, the EHR did not always contain the most up-to-date information, even though it was supposed to have a real-time information-feed for the other team members. Consequently, some (often physicians) might have the most updated information, while others, such as bedside nurses, float nurses, or technicians, might not get updated, or might only get partially updated, based on the frequency of their verbal interactions with physicians.

Inconsistent information among the providers sometimes introduced the possibility of potential errors to the medical care activities. This made the patients become more concerned about the quality of the care they received. In the example of the migraine patient who had previously had a history of kidney failure, one of the float nurses accidentally brought an IV fluid without properly knowing the patient's medical history. The patient recalls this moment:" *I do not think the first nurse communicated with the doctor because if she did, she wouldn't have been trying to give me IV fluids, knowing I'm a kidney patient."* In this case, the float nurse, who was working on four different patients, as she was assisting two other busy bedside nurses, did not have the right information due to her busy workload. Since there were two other new patients incoming at the same time, and fluids were often ordered early in the care process for new patients, the float nurse, who was in a hurry, brought fluids without properly checking the medical orders for each patients and without knowing each patient's medical history details.

Strategies to facilitate efficient information-sharing

While interacting with multiple care team members, patients were repeatedly asked questions about information they had already provided, and they also often received unclear answers from each team member when requesting same information. In these interactions, patient participants recognized inconsistencies in the information shared among the care team members. They then developed several coping strategies. First, the majority of the patients and caregivers we observed started carefully monitoring all of the medical activities providers performed at the bedside and requested detailed information. Before providers performed the tasks, patients verbally requested detailed information from the healthcare providers, such as what drug was being given, why they were getting an IV, what it would do to them, etc. The patients' close observations and information requests enabled the patients to become more attentive to the care process, and forced their providers be more aware of their tasks, reducing any potential medical errors, such as putting in the wrong IV fluids, overdosing, or doing unnecessary test preparation.

Second, once patients received information from their caregivers, patient participants proactively passed along such information to each incoming provider, thereby hoping to avoid any information inconsistency among team members. The information they passed along ranged from the names of medications, the names of the tests were being ordered, results of tests and labs, documents they received, updates on their care plan, and even care activities they observed at the bedside. By doing this, patients and caregivers serve as gatekeepers, maintaining information quality among the different care team members interacting at the bedsides.

Later on, some of the patients even purposely asked the same questions to each incoming provider as a way of proactively finding out whether each provider carried the same understanding of the care plan. They often asked questions, such as "*what is next after this [procedure]?*" or "*what [medication] are you giving me?*" When patients found discrepancies, like omitted details on the kidney failure, they actively reported them, and repeated the necessary information to the other providers. The strategy of asking repeated questions was perceived to be very useful because it allowed patients to discover the inconsistent or missing information, if there was any, as well as to make sure the multiple providers remained on the same page. The following vignette from our observations illustrates one caregiver proactively checking and providing information updates of a change in his father-in-law's care plan to incoming care team members in order to eliminate any information gaps.

A 68 year-old male patient who had an issue with high potassium for the hyperkalemia came in to the ED with his son-in-law, Paul, as a caregiver. Over the time patient went through tests and waited for the results, Paul had interacted with several different care team members – bedside nurse, two float nurses, two technicians, a resident and an attending physician. After more than a two hour wait, a resident came to the room to inform Paul that they would keep the patient in the hospital overnight and consider admission since his potassium level was still too high for unknown reasons, and left the room. After 10 min, two float nurses came in to the room with medications and fluids.

Paul: *(scanning what nurses were bringing with) Are you giving him [a med name]?*
Float nurse*: Yes, we are going to give him [the med name] that will make him want to poop. He will mostly have to go alone if none of us are around. [Speaking to the patient] You have to drink it...*
Paul*: What about after that?*
Float nurse*: I am not sure... I will have to speak to the doctor about it.*
Paul*: I think they're admitting him. I just spoke to the doctor. He will be admitted. Could you check?*
Float nurse*: Oh, really? Alright.*

The float nurse left to check with the bedside nurse and the EHR to see if there's any new order based on the decision made for his admission, and the other float nurse carried on the task in the patient room.

As seen above, the caregiver, Paul, actively monitored the incoming providers' activities and requested information about what providers would be doing to the patient and what the next step would be. Doing so, he could make sure that not only was he receiving information updates from providers, but also ensuring each provider had the same information update regarding the care procedure and plan. In this case, the admitting decision was made, but not all the care team members had been notified. When Paul asked the float nurse about the next step ("*what about after that?*"), this information was already given to him by two other providers, but he wanted to keep the float nurse updated if needed, and prevent any potential mistakes, such as not getting properly informed about an admitting procedure.

In responding to information discrepancies among multiple ED care team members, patients and caregivers gradually developed and refined their information strategies, such as deliberately checking up on all incoming care members by asking them the same questions to maintain the shared information amongst providers. These strategies enabled patients and caregivers to monitor their own care and ensure its quality. They were able to address potential concerns arising from the information inconsistency and help facilitate care team members' information-sharing and overall level of awareness. Of course, not all the patients and caregivers were as active as Paul, and there were patients we observed who did not engage with these proactive strategies nor even notice the information inconsistencies. In such cases, without the patients' active involvement, the risk of having breakdowns was higher and the patients may not have felt as satisfied or safe as when they were more engaged with their own care.

DISCUSSION

The findings of our study indicate that while patients developed strategies in order to accommodate their basic information needs during breakdowns, these strategies later improved the overall care process of the ED by expediting information delivery during patient care, aiding providers' information sharing, and potentially enhancing patient safety. In this section, we first present the coping mechanisms that ED patients developed to deal with information breakdowns as an active engagement process. We then look at the design needs for the patients' adaptations to the ED care context.

Patients' Coping Strategies as Active Engagement

In the ED, the time-critical and heavy workloads of the current ED work practice often places patients in a passive role and imposes challenges to receiving proper information, by forcing ED providers primarily focus on performing care tasks and limiting information support for patients. Our study has shown that nonetheless, many ED patients and caregivers are, in fact, active actors who have developed various strategies to cope with the information breakdowns they experience during their care. The coping strategies the patients created can be seen as an active engagement process of realizing problems, altering expectations and behaviors, and devising new ways of accessing and managing information.

Coping has been one of the key concepts for theory and research on engagement and health. Coping strategies are cognitive and behavioral efforts an individual takes to reduce stress caused by environmental change [20]. In the theory of coping as a process by Lazarus [20], coping changes over time and in accordance with the situational contexts in which it occurs. Coping strategies are looked at through two approaches – *emotion-focused* and *problem-focused*. Emotion-focused coping looks at an individual's emotion regulation as a means of adapting to environmental change. Problem-focused coping strategies tend to be action-based and externally focused on trying to find ways to change the environment to suit the individual's needs. Therefore, coping strategies are essentially a means of negotiating a balance between the individual and the environment as a way to reduce stress.

In coping theory, coping mechanisms are created through two assessment stages: *primary appraisal* and *secondary appraisal* [20]. When a change occurs, an individual performs a primary appraisal of the situation, by asking himself or herself, "*How does this change affect me?*" If the result of the assessment is stressful and not positive, the next secondary appraisal is performed with the individual asking, "*What can I do about this change?*" Then, based on the level of perceived control that the individual has in a specific situation, i.e., whether they possess the necessary resources to address a change in the environment or not, they take the appropriate approach (either emotion or problem-focused) to develop a coping mechanism.

Soon after entering the ED, most of the patient participants and their caregivers realized that both the ED providers and the ED environment did not properly support their information needs. Patients and caregivers experienced frequent information delays, overloads, and inconsistency rather than timely updates. To cope with the problem, patients began wondering how these breakdowns would affect their care process (*primary appraisal*). In the specific case of Yasmine, the patient with the eye infection, when she did not get any updates on her medication and had to wait hours, she started worrying, not just about the lengthy wait, but the possibility that her physician or nurse had forgotten about her, or that her medication order had gotten lost. Her medication's information delay frustrated her and had a potentially negative impact on her health. As a result, she tried to figure out what to do to better handle the problem (*secondary appraisal*). Yasmine began to actively watch how other patients requested updates in the hallways and started approaching any ED staff passing by, to figure out what was going on and what she should do next. Since she had to wait in the waiting room, outside of the bedside area, Yasmine had to think about how to effectively reach out to the bedside nurse who had taken care of her two hours prior and remind her about the medication order. After a few attempts, she learned what resources were available and what worked (i.e., who to turn to and who to ask), and she approached the appropriate personnel to contact her care team and remind them of her ongoing wait for the medication (*problem-focused*).

The process of identifying the problem, assessing the current situation, and iteratively finding the best workable solution until the goal is achieved can be considered the patients' active engagement in their own care. Since the information breakdowns they identified had immediate impacts on their care process and the quality of their care, the patients had to change their passive behaviors and actively seek information.

Patient engagement has been studied extensively in medical literature, and many frameworks have been suggested [8,13]. Carman et al.'s framework [8] presents the forms patient engagement can take, with passive consultation at the lower end of the spectrum to shared partnership, including decision-making, at the other end. Positioning what this study discovered about the adaptive behaviors of ED patients and caregivers within this framework, patient and caregiver engagement in the ED begins at the passive consultation end, where patients reply to ED providers during short consultations. However, with the active efforts of creating coping mechanisms, the level of engagement eventually moves to the partnership end of the spectrum, where patients share information with their providers, and through gathering and managing information, eventually take responsibility for their own care. A systematic review study on patient engagement [13] indicates that despite a large body of studies on patient engagement, it is difficult to identify where and how patient engagement can be introduced into routine clinical settings, and what methods would be best for doing so. Our study indicates that patients' active involvement with creating various coping mechanisms is active engagement, and shows the detailed process of how patients become actively engaged in their care as active partners in the information-lacking environment of the ED.

We suggest that the information breakdowns in the ED care process be utilized as an opportunity for engaging patients and caregivers. As discussed in our study, when developing strategies to cope with the breakdowns, patients began to actively engage in, and become responsible for, their care. The previous literature [13] has pointed out how essential introducing patient engagement into clinical routines is, but how difficult it is to actually do. In our study, we have found that patient engagement can be triggered, not only by motivating patients or encouraging healthcare providers to invite patients to engage in their care, but though the introduction of potential problems that can impact patients' perceptions and satisfaction, and the quality of care. We believe that designing health IT systems, such as a patient-facing system, to improve the ED care experience should go beyond the conventional approach of simply providing information access. Providing patients access to their care-related information at bedsides could solve some of the breakdowns identified in this study, but would not engage patients to actively be involved in the problem-solving process. Also, information breakdowns are contextual and *in situ,* and the nature of breakdowns might vary in different care situations and inevitable in reality. Thus, finding and suggesting ways to facilitate patients to become active problem solvers would be a better approach.

Utilizing the information breakdowns identified in the study, we suggest having design sessions and inviting patients to cope with various breakdown issues in order to come up with a system based on actual care situations and actual patient needs and goals [42]. For instance, through a speed-dating technique [9], the multiple stakeholders can experience the set of situated breakdowns we identified in our study and explore and discuss design solutions together. We think that this participatory design session can help guide designers to the preferred state [33] at which patients can actively engage in their ongoing care without being burdened, and to provide effective ways for patients to approach complex, real world care situations.

We argue that the kinds of coping strategies that the patients develop in the sessions, how the strategies are developed, what resources or tools are needed for the strategies, and what specific situations the strategies are used in, should be used to inform the design practices of future systems or policies for emergency care or other similar care environments.

Adapting to the Nature of the ED Care Context and Healthcare Practice

The coping strategies the patients in our study developed have two distinct goals – one is to *address immediate information breakdowns* and meet information needs, and the other is to *proactively prevent potential breakdowns* by addressing safety and efficiency concerns specific to ED care practice. The former goal is the direct motivation for developing coping strategies, wherein patients and caregivers attempt to deal with the problems that occur when receiving care-related information. As discussed in the previous section, patients and caregivers are forced to cope with the breakdowns (e.g., information delays) because they have direct impact on their care process, causing lengthy waits, forgotten or incomplete orders, and can potentially damage their health.

Although patients develop strategies for their own care concerns, these strategies are, at the same time, adapted as a way to meet and sustain the specific care goals of the ED. This latter underlying goal for patient coping strategies is about proactively anticipating and preventing any possible breakdowns during their care. For example, in the case of having multiple healthcare providers involved in the same patient's care, patients recognized that different care team members did not always have consistent information updates because of their busy, complicated workflows and multiple patient care demands (e.g., a float nurse did not have updates on a care plan that a physician had already updated a patient on). When patients realized the information inconsistency among the team members, they could gain a sense of how ED care work is performed, which includes having multiple providers with different roles. After acquiring the basic knowledge of team-based work, patients proactively began creating ways to bridge the information gap among the different providers, since not having consistent information could affect the providers' clinical collaboration, possibly jeopardizing the care they were receiving. To maintain information consistency among care team members, as well as to address safety concerns, patients strived to proactively anticipate any potential problems by monitoring and updating every piece of information between providers. They also asked providers probing questions to check up on their information updated. Patients developed these strategies as a way to address the unique nature of the ED care context, ultimately preventing potential breakdowns that put care quality at risk. We argue that the process of proactively foreseeing and preparing for potential breakdowns, as well as seeking the most appropriate method that would work for the particular care context and its particular needs, goals, and work efficiency can be considered *patient adaptation*.

This adaptation was developed by patients through learning that patient care is done by multiple care team members who are required to work collaboratively and efficiently. However, it is challenging to have everyone updated in *actual* practice, and patients and caregivers had to modify their own expectations and behaviors accordingly – i.e. bridge the information gap by reporting and checking up on each provider about the most updated information, at the patient's bedside. This proactive adaptation behavior further facilitated not only providers' information work but also expedited the next ED care process by picking up what the providers might have left out and helping them fill the gap among the team. Therefore, this second goal of addressing the specific needs of the ED care practice is devised on a higher level and within a broader perspective than the first, adapting to a complex sociotechnical healthcare environment [16,25]; it reflects a concern for maintaining care quality, care goals, and the needs of the healthcare practice, deploying the patients and caregivers' own strategies to ensure care safety, as well as to make the healthcare practice more reliable and efficient.

We suggest that system design utilize the patient adaptations of the clinical workflow and the patient care environment. We argue that these patient adaptations are driven by design thinking efforts in the complex ED care context. To adjust to the complexity of ED care, patients engaged in design thinking [6] – the activity of learning and understanding the current situation, identifying the best solution, and iteratively looking for alternative solutions until the goal is achieved. Design thinking enables patients to proactively adapt to their sociotechnical care environment, because they are forced to create their own coping strategies and eventually redesign their own care environment through creating their own tools and learning to understand the resources and the physical space within their situated contexts. We argue that this adaptation process, driven by design thinking, can offer a valuable insight to the design community to improve or redesign the patient care environment, or even compatible patient clinical workflows, since the ways that patients reconfigure and redesign their care environment can complement design insights in a way that designers cannot predict [10].

As shown in the study, the active adaptation of patients relies heavily on the recognition of the sociotechnical context that is often new or unfamiliar to them. Even under the same ED care context, figuring out and understanding local factors, such as the team-based or mobile workflow, the roles of care team members, the accessibility of resources, and the physical layout of the ED unit, can appear differently, dependent on an individual's ability to do design-thinking. In the study, we notice that not all the patients have the ability to engage in design-thinking and adapt to their care, due to the lack of proper knowledge, experience, and/or skills. Thus, we suggest providing mediatory support to foster better adaptation, offering necessary knowledge about the care environment (e.g., how the ED functions, the ED work structure, physical layouts, or the overall characteristics of ED care). Currently, this role is supported by the bedside nurses who are always occupied with numerous tasks; thus, we see this as an appropriate function for a new supportive intermediary system support.

The mediatory support could, for instance, provide patients with guidelines to help identify any breakdowns and/or assess current care situations, provide cues for where to find necessary information, and share proactive patient-safety behavior suggestions that are tailored to each patient case. This knowledge would help patients to proactively address potential, unexpected problems by offering appropriate information access and information delivery to patients. Furthermore, this will provide ED care team members with a common information channel that can improve their limited interactions with patients. We think that having this mediatory support is important because while it may not provide a perfect solution to every breakdown, it can give better, or more appropriate, workaround/solutions, given the existing care circumstances. Without this knowledge, it may take longer, or may even be impossible, for some patients to come up with adaptation strategies, particularly those without proper medical support or insurance, but make up a good part of the ED population currently.

CONCLUSION

We have described the experiences of patients and caregivers in ED care through the identification of three types of information breakdowns and their coping mechanisms. Our study indicates that the development of these strategies is an adaptive behavior that patients use to proactively adjust to the ED, a place where there is limited information support to address their needs. Our findings suggest that the design of a patient-facing system in a sociotechnical environment should consider patient adaptation as an active engagement process driven by design-thinking. Design support for patient adaptation behaviors should enhance patient engagement, potentially improving clinical outcomes and contributing to the quality control of care in the healthcare practice.

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