Designing Patient-Centered Interventions for Emergency Care: Participatory Design Study with Patients

Woosuk Seo, Shruti Jain, Vivian Le, Ella Li, Zhan Zhang, Hardeep Singh, Kalyan Pasupathy, Prashant Mahajan, Sun Young Park

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Abstract

Background: Emergency departments (EDs) are high-pressure environments where a diagnosis is made in a resource-constrained context. These environments also require complicated interactions between patients, caregivers, and healthcare providers to make timely diagnoses. EDs, in consequence, predispose to suboptimal diagnostic outcomes, leading to potential errors and subsequent patient harm. Various interventions have been designed to improve the ED diagnostic process and patient safety. However, designing patient-centered interventions is challenging due to limited opportunities for engaging patients in intervention design processes.

Objective: This study aims to invite ED patients to participatory design sessions, identify their challenges and needs during ED visits, and present design guidelines for patient-centered interventions.

Methods: We conducted a participatory design study with ED patients to design patient-centered interventions to improve diagnostic safety. In total, 36 ED patients or caregivers participated in eight design sessions. We presented ten intervention ideas as storyboards to the participants. Through storyboards describing the use cases of each intervention idea, we assessed the participants' needs and challenges during the ED care process. We also facilitated co-design activities with them to improve the intervention designs. We audio- and video-recorded the design sessions. We then analyzed session transcripts, field notes, and design sketches.

Results: Based on ED patients' feedback and evaluation of our intervention designs, we found the three most preferred intervention ideas that address the common challenges that ED patients experience. We also identified four themes of ED patients' needs: feeling of inclusion in the ED care process, access to sources for patient comprehension of medical information, need to address patient anxiety related to information overload and privacy concerns, and ensuring continuity in care and information. We interpreted them as insights for designing technological interventions for ED patients. Hence, based on the findings, we present five considerations for designing better patient-centered interventions in the ED care process: 1) technology-based interventions should address patients' dynamic needs to promote continuity in care, 2) interventions should consider the amount and timing of information that patients receive, 3) interventions should empower patients to be more active for better patient safety and care quality, 4) interventions should optimize human resources, depending on patient's needs, and 5) interventions should be designed with the consideration of patients' perspectives on implementation.

Conclusions: This study provides unique insights for designing technological interventions to support ED diagnostic processes. By inviting ED patients into the design process, we present unique insights into the diagnostic process and design considerations for designing novel technological interventions to enhance patient safety.

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Keywords

emergency departments; participatory design; patients; technology; interventions

Introduction

In the high-pressure environment of Emergency Departments (EDs), diagnosing and managing patients is inherently complex. This complexity arises from extensive interactions among various stakeholders, including physicians (trainees and consultants), nurses, family caregivers, and patients. The dynamic and time-sensitive context of EDs forces stakeholders to make critical medical decisions promptly. The urgent nature of emergency care thus imposes substantial challenges to ED providers, compounding the difficulty of achieving timely and accurate diagnoses and raising concerns regarding patient safety. While exact rates of diagnostic errors remain elusive, a conservative estimate of 5 percent errors in adults out of the 131 million annual ED visits translates to about 7 million cases of ED-based diagnostic errors [1]. Notably, nearly half of these diagnostic errors have the potential to cause harm to patients.

Many technology interventions focus on supporting the diagnostic process and promoting patient safety in the ED. A mobile app, PIMPmyHospital, was designed for ED providers to support their collaborative management of patients. The app delivers real-time, relevant information about the patients under their care. It also offers a secure chat and messaging platform, enabling virtual connections between physicians and nurses involved with the same patients [2]. AI-based software [3] was developed to provide practical guidance to novice nurses or scan operators in the ED who have limited experience in echocardiography. In addition, AI-based systems [4,5] have been used to support documentation for the nursing team, indirectly promoting the efficiency of the care process. Such systems could support providers by easing the documentation burden (e.g., parsing long notes and automatically populating relevant text) so that they could focus more on patient care.

On the other hand, some technological interventions have been developed that focus more on ED patients. An indoor navigation system [6] was designed to assist patients unfamiliar with the ED environment, and a mobile display [7] presented an interactive report on patients’ progress, care plans, and care teams throughout their stay in the ED. To reduce patients’ anxiety, some prior studies showed opportunities to use music apps [8] or VR applications [9]. More recently, a study presented the opportunity for an AI-based application to provide medical triage to patients more efficiently [10]. Compared with human clinicians, the AI-based application made probable triage decisions. While these technological interventions improve providers' diagnosing work or patient safety, direct input from patients and providers working at the frontline is often overlooked when developing such solutions.

Participatory design (PD) [11] is a methodology that engages all stakeholders in the design process to create solutions that address their needs. PD has been widely used by researchers in prior research to co-design user-centered technologies with healthcare providers. For instance, Kusunoki et al. [12] conducted PD workshops with trauma team members to understand the different needs of awareness support among the various roles of team members and identify concrete design strategies to manage the differences in their awareness needs. Pollack et al. [13] organized a design session with 11 clinicians to develop a clinical information tool using PD techniques. Based on the session's findings, the authors identified benefits (e.g., a high level of domain knowledge can be used to anticipate how design ideas can be applied to clinical processes and workflow) and potential challenges (e.g., power dynamics between physicians) of leveraging PD techniques in designing a clinical information tool. The authors also outlined guiding principles for implementing these methods in healthcare organizations interested in advancing health information technology. These prior studies have presented how PD is helpful and practical for designing human-centered technology in healthcare settings.

Despite the benefits of PD in designing health technology, only limited work has adopted a user-centered PD approach to develop technology interventions for ED specifically to enhance patient safety. Østervang et al. [14] conducted PD workshops with healthcare providers and patients to design an ED information system. In the study, providers brainstormed initial design ideas for an ED information system in a workshop; then, patients provided feedback in separate workshops. The authors presented how the PD approach helps yield insights from ED providers and patients to create a more user-centered system. However, ED patients in the study had limited participation since the workshops were conducted one-on-one, and patients were only asked to provide feedback on intervention ideas developed by healthcare providers. Extending on these earlier works, we aimed to invite ED patients to validate their needs and co-design novel intervention ideas to promote patient safety and enhance the ED diagnostic process. We conducted eight participatory design sessions with 36 ED patients or their caregivers to accomplish our research goal. Based on the analysis of transcripts, design sketches, and field notes, we identified four themes representing patient needs, strategies to mitigate the challenges, and expectations for potential interventions.

METHODS

Design Idea Generation Phase for ED Care Interventions

This PD study is part of a larger research project that aims to study diagnostic errors during the ED care process that involves multiple stakeholders, including patients, informal caregivers, nurses, and physicians. Before our PD study with ED patients, the research team interviewed eight patients/caregivers to better understand their experiences and challenges during ED visits. From the interviews, we identified difficulties, emerging patterns of complaints, and general levels of satisfaction with different aspects of the care process (See Table 1). In addition to the known problems such as long wait times and insufficient or poor communication with providers, ED patients, and caregivers also faced difficulties due to the absence of caregivers, lack of ED process literacy, or inadequate understanding of discharge information. Based on the findings, the research team brainstormed numerous design ideas for each problem category, focusing on the stakeholders (e.g., patients, caregivers, and providers). We then merged the design ideas based on feasibility and usefulness. Finally, we narrowed the list and finalized the ten most effective intervention ideas (See Table 2). Each intervention idea aims to address at least one problem category.

Problem Category	**Examples**
1. Waiting Room General Challenges	• Patients feel forgotten in the waiting room because providers do not check up on them • Patients are left in pain in the waiting room
2. Overcrowding Challenges	• There are patients with mild symptoms who make ED more crowded
3. Information Presentation and Overload Challenges	• Patients are not sufficiently informed of the ED process during the visit (lack of ED process literacy) • Test results can be confusing for patients to understand because of the use of medical terminology
4. Information Sharing Challenges	• Patients often feel that there are errors in the doctor's notes (e.g., it is different from what was discussed in the visit) • Providers at hospitals sometimes wait for information transfer from the patient's original hospital, which can take time
5. Communication Challenges	• Patients find it hard to recount all personal medical details in the ED because they are sick, stressed, or unaware • Patients sometimes have trouble communicating with providers because of challenges like being a non-native English speaker, etc.
6. Contagious Disease Transfer in ED	• Crowded waiting rooms can have many sick patients in close proximity, which makes patients concerned • Contact with surfaces can cause disease transfer
7. Discharge and Post-Visit Challenge	• Lack of post-visit resources for patients • Patients feel that they have been wrongly discharged

Table 1: A list of identified problem categories from the previous study's patient interview data

We also created storyboards for each intervention idea. The purpose of the storyboards was to help participants better understand the use cases and contexts where the proposed interventions could be used. A storyboard for each of these interventions consists of a 3-panel illustration. It describes an example of a patient facing one of the challenges mentioned above and using the intervention to mitigate or prevent the problem (See Figure 1 for sample storyboards). Details of the intervention's features and functionality were left vague. We wanted participants to focus on the need rather than specific features to encourage more discussion about improving the intervention concept. Each storyboard included a lead question to highlight the user's needs (i.e., patients) outlined in each intervention and to facilitate participant discussion about whether they had experienced the need (rather than directly referencing the intervention). Using storyboards allowed participants to have less biased and more open-ended discussions in the PD sessions. Table 2 describes each technology intervention and the patient need(s) it addresses, along with storyboard samples.

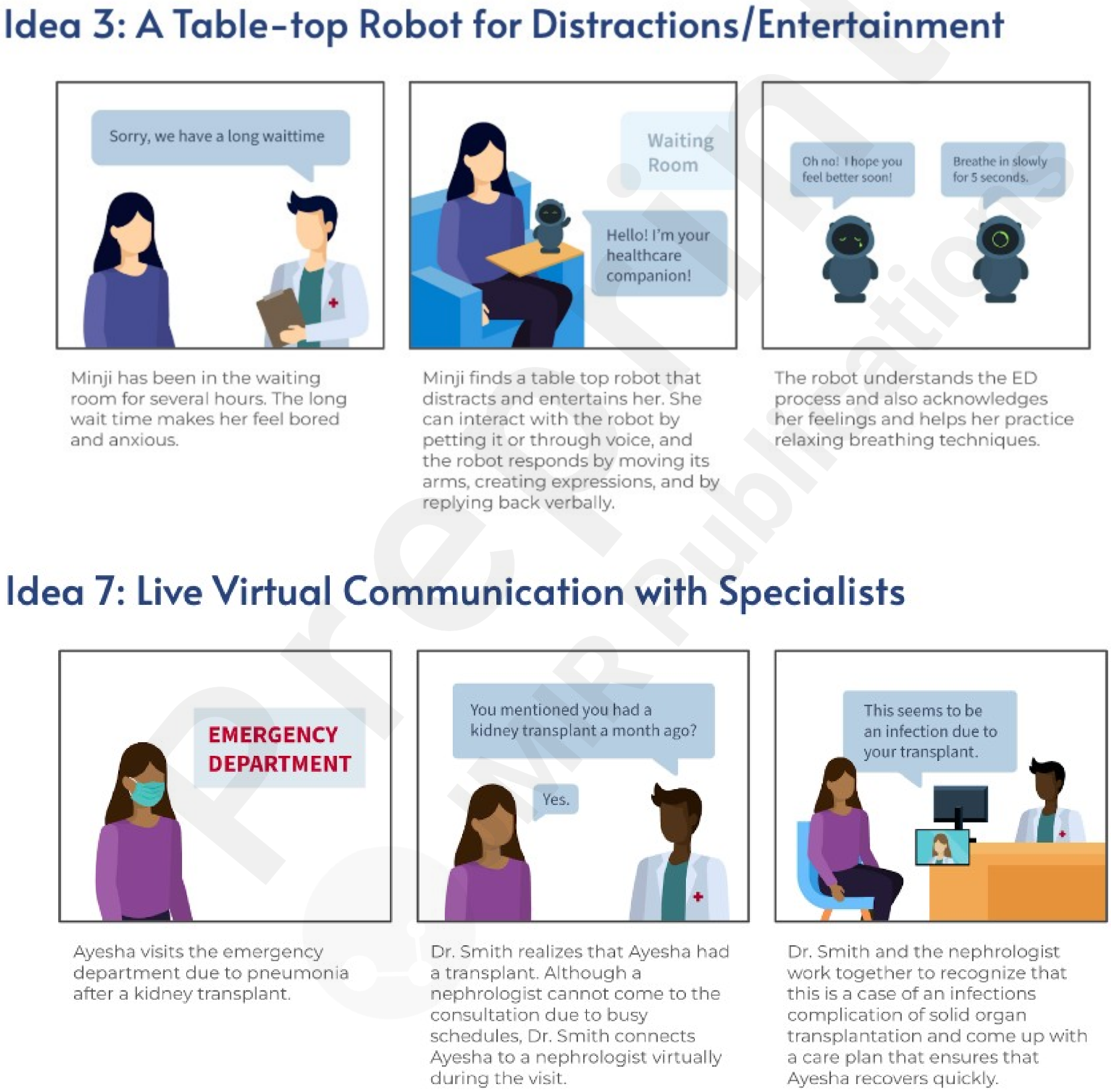

Figure 1: Sample storyboards of technology intervention ideas used to present to our participants during the sessions. (The top panels are the storyboards for Table-Top Robot, and the bottom panels depict Virtual Specialist)

#	Technology Intervention	Description	Sample of lead question used for the discussion of Patient Need
I-1	Virtual Presence of a Caregiver	A communication device for ED patients that enables a virtual presence of the caregiver for the patient and their ED provider when the caregiver cannot physically be with the patient.	Have you experienced any difficulty visiting the ED alone without a caregiver?
I-2	Transparent Interactive Display for ED-Related Guidance	An interactive display for ED patients in a waiting room that displays ED-related guidance and acts as a separator between patients for personal hygiene.	During your ED visit, have you worried that you might be coming in contact with contagious diseases while in the waiting room?
I-3	Table-Top Robot for Distraction/ Entertainment	A table-top robot for ED patients in the waiting room that provides distraction and entertainment as they wait.	Have you felt distraction/entertainment is helpful during a long wait in the ED?
I-4	Wearable Device for Monitoring Real-Time Condition	A wearable device for ED patients in the waiting room that tracks their real-time data (e.g., vitals such as heart rate and blood oxygen) and notifies providers if vitals indicate a patient needs immediate help.	Have you felt worried about worsening conditions during waiting and being unable to inform providers properly?
I-5	Assistant Robot in the Waiting Room	A mobile robot that assists and checks on ED patients in the waiting room.	Have you felt forgotten while waiting due to busy ED providers not checking up on your condition?
I-6	ED-Specific Chatbot for ED Practice Literacy	A mobile-device-compatible chatbot that can provide ED-specific information directly from the hospital to patients.	Have you ever felt confused about the meaning of the medical information you received during ED care?
I-7	Virtual Communication with a Specialist	A communication device for ED patients and providers that enables a virtual consultation with a specialist during ED care.	Have you needed to talk with a specialist during your ED visit?
I-8	Pain Expression Device	A tactile device that helps ED patients understand and describe	Have you had any difficulties in describing your pain verbally?

		pain through vibrations and haptic feedback.	
I-9	Patient-Facing Screen for Sharing Doctor's Notes	A screen display that presents care-related information for patients to view during consultation or follow-up with providers about diagnosis or test results.	Have you ever noticed errors or confusing details on doctor's notes (usually on discharge notes/ after-visit summaries)?
I-10	AI Caller for Providing After-Visit Support	A follow-up call powered by artificial intelligence (AI) to help answer patients' post-discharge questions regarding their ED visit.	Have you had any challenges or questions that needed to be properly addressed after your ED visit?

Table 2: A list of 10 intervention ideas with brief descriptions and discussion questions to validate patient needs

Participant Recruitment

We recruited patients and caregivers who had visited the ED within six weeks from the point of contact. Participants were mainly recruited from the adult and pediatric emergency departments (AED, CED) at a university-affiliated hospital in three ways: calling or emailing them after their most recent ED visit, posting fliers with the study's contact information in the AED and CED, and approaching patients during their ED visit. The inclusion criteria for participants were 1) 18 years old or older, 2) previously visited ED within six weeks from the point of contact, and 3) comfortable speaking English. During a patient's ED visit, researchers mainly focused on recruiting those having a triage level of 3-5, with 1 being critical and 5 being non-urgent, to avoid disrupting or risking their care. We contacted more than 150 potential participants via email and phone, as participant retention was challenging due to last-minute cancellations from patients. In total, 36 ED patients/caregivers participated in eight design sessions. All but one session had 4 or 5 participants, and one session had 3 participants. As compensation for participation, we provide each participant with a $100 gift card for the session. We recruited and obtained consent from participants as described in the institutional review board protocol approved by the University of Michigan (HUM00156261).

	Racial	**Sex**	**Patient or Caregiver**
Participant Demographics **n = 36**	White: 27 (75%)	Male: 12 (33%)	Patient: 23 (64%)
	Black: 7 (19%)	Female: 24 (67%)	Caregiver: 13 (36%)
	Asian: 1 (3%)		
	Unknown: 1 (3%)		

Table 2: Demographic information of study participants.

Participatory Design Session Procedure

We conducted a total of eight PD sessions. Each session was roughly divided into three parts: (1) session introduction, (2) storyboard critique, and (3) co-design as a group. Each session took approximately two hours.

In the session introduction, participants were each given a paper packet of the current ED care process timeline, the ten technology intervention storyboards for reference, and a sheet to rank the interventions based on their preferences. A presentation of the ED care process timeline (See Figure 2) was shown to prompt participants to recall their previous or most recent ED experience. We created this timeline based on our last interview study [15] and prior work on the ED care framework [16]. We first asked participants to write down one major challenge from this experience and expressly point out where this occurred in the current ED care process timeline in their packet. Each participant was then asked to discuss their experiences with the group, establishing the foundation for the main session activities. Allowing participants to reflect on their previous or most recent ED visit prefaced discussions about how their challenges might or might not be addressed with one or more of the ten technology interventions and the co-design activity.

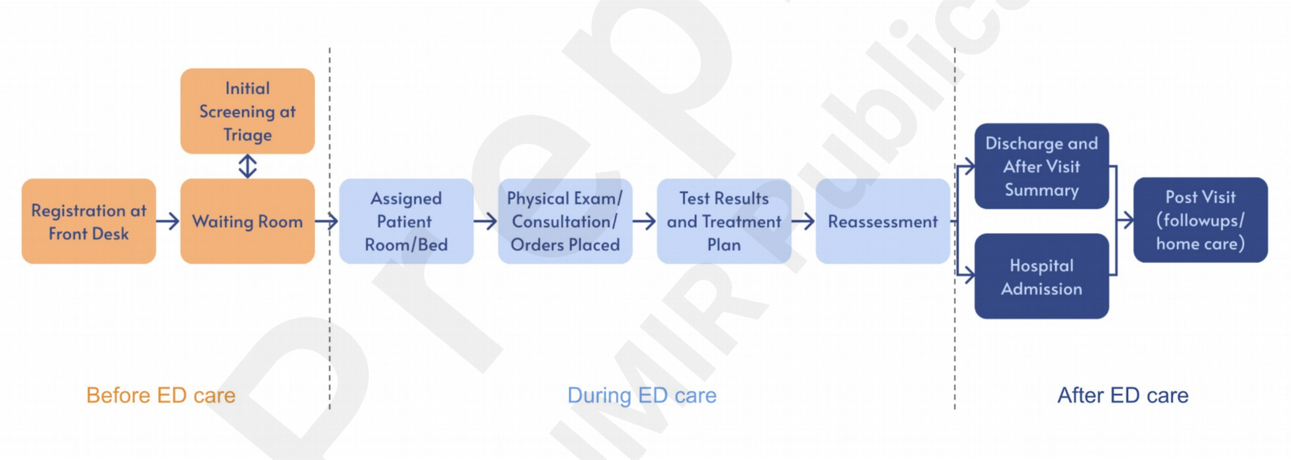

Figure 2: ED Care Process Timeline

For the storyboard critique activity, ten intervention design ideas were presented via storyboards to prompt participant discussion about each intervention's feasibility in the current ED care process. Researchers encouraged participants to initiate the conversation with lead questions, and additional follow-up questions related to each scenario were asked, as necessary, among the group to maintain the discussion. The discussion of the ten technology interventions validated patient needs during ED visits and formed the foundation for the co-design activity. After all the intervention storyboards were presented, participants ranked their top 3 preferred interventions based on preference and potential feasibility in ED care.

Each group of participants discussed the most preferred three interventions and then selected one for the co-design activity. Then, as a group, participants had approximately 25-30 minutes to augment their chosen technology intervention to improve the ED experience (See Figure 3). Participants were tasked with adding, changing, removing features, or modifying the context of the technology intervention to help it better align with their preferred, ideal future implementation. Researchers emphasized the importance of focusing on the roles and functionality of technology interventions rather than the aesthetic quality of the designs. The co-design activity helped us understand which features of the intervention technologies participants desired to address patient needs, along with other fundamental and feature-specific aspects that may have yet to be previously revealed in the storyboard critique. Through this, participants could also discuss their decisions in detail, out loud, and reach a consensus about the most critical design features to incorporate into an ideal intervention solution. Following the co-design activity, participants were asked to provide a summary presentation to the researchers and explain their reasoning behind the design decisions they made together.

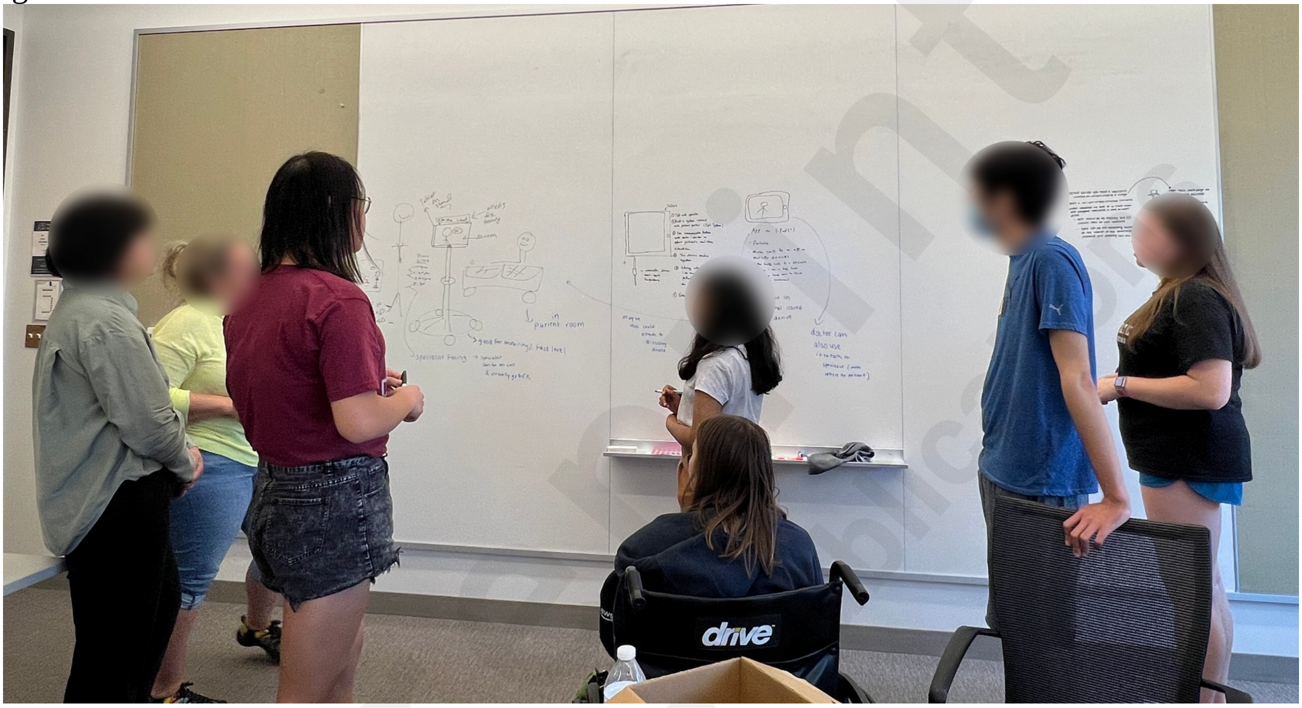

Figure 3: Co-Design Activity with participants in the middle of a discussion about improving Idea 7 (I-7 in Table 2). Participants collaboratively drew ideas on a whiteboard and wrote notes about imagined functionality.

Data Analysis

During the PD sessions, at least two researchers presented and took separate notes on points discussed among groups and overall interpretations of participant reactions to ideas. After every session, the researchers collaborated to reflect on session notes and compiled a document with notes on significant trends and sentiments toward each design idea. After each PD session, a researcher also took pictures of the sketches created during the design activity and on participant handouts (which contained participant notes, feedback, and intervention rankings). The entire session was also video recorded. The transcription from each recording was used as the primary data source, and all other collected data was used as a supplementary source. The above data collection was done with the participant's permission.

Then, the first three transcripts were individually analyzed by researchers to highlight preliminary findings and patterns. Using these notes and all other session data collected, researchers compiled a list of codes to develop a codebook. Duplicates were combined, and codes that failed to capture a more prominent theme or significant detail were removed. The codes were categorized into the interventions with which they corresponded, and some were put in a general category. The similarity in codes across interventions was noted in code descriptions. All eight transcripts were then coded using the codebook created. At least two researchers coded each transcript, and each coding was reviewed. If any new codes were found, they were either added to the codebook as a new code or incorporated into the definition of an existing similar code. Affinity diagramming [17] was used as the primary analysis method. The themes and subthemes were refined by referencing patient quotes and other collected data. Our analysis revealed emerging themes, such as ED patients' needs, benefits, and concerns regarding suggested interventions, suggestions for improvements, and existing interventions they use.

RESULTS

Based on the analysis of the collected data, we identified the top intervention ideas that participants preferred and four emerging themes that describe participants' needs in the ED care process. Across all sessions, participants collectively preferred I-4: Wearable Device, I-7: Virtual Specialist, and I-1: Virtual Presence of a Caregiver to address areas of improvement in the existing ED process that would help enhance the overall quality of care for patients. These interventions address the most common needs of patients in the ED care process. We also report four emerging themes of specific needs that the participants had during their ED visits: the feeling of inclusion in the ED care process, sources for patient comprehension of medical information, relief of patient anxiety over information overload and privacy concerns, and continuity in care and information. These themes describe broader perspectives of ED patients, including non-technology interventions beyond the intervention ideas we provided. While describing these needs, we explain how participants addressed or wanted to address those needs by utilizing the top intervention ideas they preferred.

The feeling of inclusion in the ED care process

Throughout all eight sessions, it is more than evident that participants wanted to be more included in the ED process. Participants often felt unheard, dismissed, and uninformed in their interactions with providers. *"[The nurses] almost like, didn't believe me or didn't care, until they saw like, I have to pass out in front of them before they're going to do anything. And the second I passed out, I got moved to an actual room in the ED when I've been sitting in the hallway for hours." (P13).* As described in the quote, participants sometimes felt that providers dismissed patient concerns unless they physically showed symptoms.

Their feeling of exclusion was caused mainly by the lack of timely and transparent communication with ED providers as they experienced providers not necessarily available to check on worsening patient conditions. Thus, it was challenging to inform providers of their health conditions: *"Because there's a lot of times if you're on a two-hour wait and you're in the process of having a stroke, you're not able to get up and go back to the waiting room or the front desk, but it'd be good if something flagged that your condition was deteriorating." (P24).* Because of the concern about potentially worsening conditions during the wait time, most participants favored I-4: Wearable Device to track their conditions in real-time and alert providers if necessary. In addition to the illustrated functionality, many participants suggested adding features like pain-tracking and fall detection to the intervention, borrowing functionalities from other less popular intervention ideas such as I-8: Pain Expression Device and I-5: Assistant Robot. Some participants also thought that real-time tracking devices could be used to update patient priority in the post-triage stage: *"If your condition is staying fine, or steady and stable and somebody else with a higher pain or priority could go first and you're still okay, you know something like that I could see being helpful." (P3)* Participants felt that by using real-time tracking data, patients in critical condition could get medical attention as soon as needed, ultimately improving the accuracy of the diagnosis.

Despite their general support for real-time tracking of symptoms, some participants expressed concerns about how providers could use such interventions. For instance, some participants were worried that providers would ignore tracking device emergency alerts in an already hectic environment. Others also expressed concern about providers becoming over-reliant on tracking devices and potentially disregarding verbal patient feedback about worsening conditions if the device's data did not corroborate with patient concerns. Regardless of these worries, some participants pointed out that capturing real-time health data alerts could increase provider accountability in cases where patients felt ignored or misdiagnosed: *"...if you're getting this information in real-time, then…people can be held to accountability. Because you go back and you look at their chart, you look at their record, 'Hey, this person was in distress, and you neglected them,' so I think in some ways, the AI could really assist in that because, again, there needs to be accountability to doctors and nurses and stuff that are just blowing you off." (P18)*

To feel inclusive in the part of the process, participants advocated the creation of more communication channels between patients and providers. A popular idea was incorporating a 'help' button that participants could use to get immediate medical attention from a provider, which participants suggested could be implemented into one or many interventions (I-2: Interactive Display, I-3: Table-Top Robot, I-4: Wearable Device, I-5: Assistant Robot). Figure 4 shows a sample drawing of an improved I-4: Wearable Device with a "Nurse Help" button on the side. Moreover, many participants indicated that the I-4: Wearable Device included a way to update their condition and pain levels as they changed during their visit, and some patients mentioned that concrete pain descriptors (tactile or word-based) could help them better describe their pain. Participants believed that having direct communication channels (such as a help button) with providers could lead to better care outcomes and higher trust in their care.

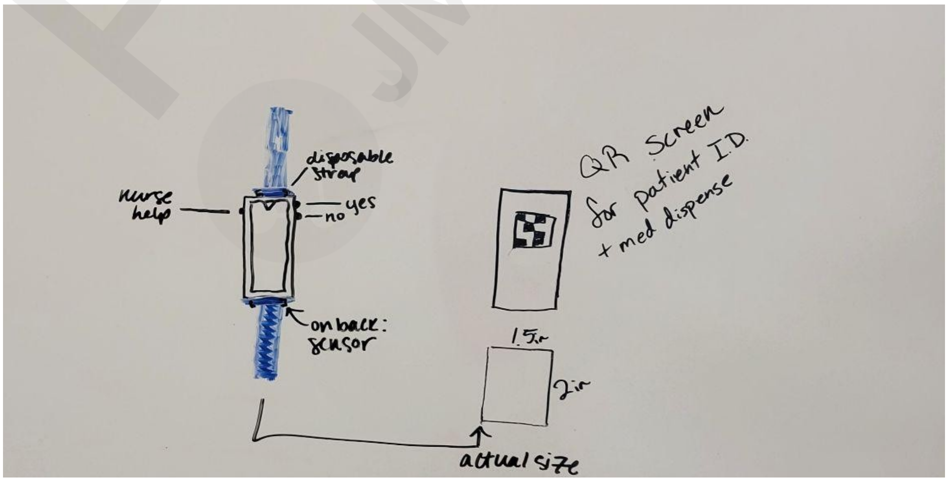

Figure 4: A sample drawing by participants during a co-design activity. The drawing shows how the I-4: Wearable Device could be improved with additional features such as the "Nurse Help" button.

As our participant pool included caregivers and patients, the role of the caregiver in patient-provider communication was also emphasized. Caregivers are especially crucial as patients advocate for children and older adults, as they can significantly help patients who cannot correctly remember or communicate their condition in the ED. Participants were receptive to the idea of incorporating I-1: Virtual Caregiver into the ED process when an in-person caregiver was unavailable, and some emphasized that a caregiver list could be incorporated into patient records for cases when the patient was too incoherent to call a caregiver.

Sources are needed to improve patient comprehension of medical information

Another theme we found was patients needing more information resources to improve their comprehension of care-related information. Participants expressed that their understanding of medical information required more alignment with their providers. Despite having access to their patient portal, most patients found it hard to familiarize themselves with the terminologies providers used in the ED when communicating about their condition or test results: *"When I see…I think it's [a] diagnosis or something or like conditions I have…in my chart or portal or whatever. Like it says Latin…something just saying that my knees are bad…So I wish in parentheses it could say in English […], the layman's term for that." (P25)*

A similar concern around patient health literacy arose when clarifying personal medical information. Participants said they often used Google and other online resources to help understand their condition or diagnosis better while waiting for a provider's consultation. One participant expressed that it could be more accessible to conduct a Google search because patients can have a baseline understanding to prepare follow-up questions for providers. However, participants also noted that when seeking medical information online in this way, they could be misled into thinking their condition had severe side effects or symptoms that were not identified or considered relevant to the provider's diagnosis.

To address the concern of potentially misleading diagnoses, participants frequently mentioned the necessity of incorporating personalized information into intervention technology to enhance patients' understanding of their medical history. Depending on the patient's level of health literacy, they might struggle with formulating questions or initiating conversations when communicating with their provider. In many design sessions, participants suggested that hospital-specific information can be curated based on the patient's medical history to provide relevant and reliable search results sourced directly from the ED that might otherwise be retrieved from a Google search. Participants specifically valued the features of the I-6: ED Chatbot and I-4: Wearable Device for providing personalized patient information and helping effectively facilitate conversations from patient to provider and with the patient themselves — such technology can break down complex medical terminology so that patients can follow up with providers in a more efficient way and aid in making informed decisions about their condition: *"I think that it [I-6: ED Chatbot] can be helpful to the emergency room staff or doctors because they could input the information that they want you [patients] to know [...] so they can control the information that's being given. Versus you [patients] googling it." (P3)*

Along with the difficulty in understanding medical information regarding their care, participants expressed the challenge of explaining their pain to providers. Issues with patient-provider communication arose when patients felt unable to properly convey pain levels, struggling with arbitrary scales from 1 to 10. Several participants mentioned that current pain scales do not provide adequate ways to express different types of pain (e.g., *"Whenever they say on a scale of one to 10, I don't feel pain like other people." (P15))*. Some participants who struggled with chronic pain also recalled that current pain scales do not take into account that people might consider different levels of pain to be "normal." In such cases, the lack of medical information comprehension hinders patients from accurately describing their medical conditions (e.g., pain) to providers. While many EDs ask about pain on a scale of 1-10, it is difficult to pinpoint or trace a patient's condition over time based on this abstract measurement: *"The description of the pain varies for me. [...] And, I do live with pain. [...] All the rest of the pain is still there." (P16)* Some participants found the intervention idea of an I-8: Pain Expression Device valuable in addressing this issue, especially for patients who cannot communicate verbally with a provider or have a language barrier. Participants particularly liked the device's tactile capabilities as this feature could help anchor patients to a basic description or visualization of their pain to communicate with providers effectively. At the same time, some participants were also concerned about the ability of a patient to understand how a complex device works when in pain, further delaying their time in the ED and getting a proper diagnosis from providers: *"If they[ED patients] are in pain already and we [the participants and researchers] have to stop and give an explanation of how to work it [a new intervention], I think it might present some difficulties, and there might actually end up being more of a barrier in terms of getting the information." (P20).*

Relief of patient anxiety over information overload and privacy concerns

Many of our participants mentioned patient anxiety during their ED visit as one of their top concerns. On top of being admitted to the ED, participants experienced anxiety due to various factors beyond diagnosis, including long wait times, fear of contagious diseases (especially during and after the pandemic), and uncertainty about the subsequent steps in the ED process. They also noted that being overwhelmed with information as a patient in the ED aggravated their anxiety. Whether from a Google search or looking at test results, patients might not be able to understand all the information presented to them. Participants thought it was essential to consider the types of information that would be accessible – such as vitals or pain levels – to patients, providers, or both: *"Do [patients] know how to read it? Do they know how to interpret the information that's given to them? Too much information for a patient can be bad. Then their mind wanders because they don't know." (P30).*

Potential anxiety induced by overwhelming information brought different perspectives regarding how much information should be displayed in the intervention ideas. Participants wanted to be informed but felt too much information could be unnecessary for patients who did not understand medical terminology: *"I think that's a hard one. Because some people — it doesn't stress them out to know, and they like to know, other people can like to say their heart rates [are] high, but it can make it worse because then they're anxious about it." (P13)* Participants across sessions discussed different scopes of information access available for each intervention idea. For example, patients might be presented with a fundamental view that only shows whether their vitals were in a normal range. At the same time, providers might have more detailed access to numeric values and other data that could help track patient conditions over time. Participants suggested this could be paired with alerts on the I-4: Wearable Device for the patient and provider, or providers only, to notify hospital staff in an emergency and better support care priority in the waiting room. Some participants even considered extending this idea for the entire duration of a patient's ED visit. Overall, participants suggested informing providers of a patient's condition would help mitigate patient anxiety in an ED setting.

The other factor that contributed to patient anxiety was related to patient privacy. Some participants felt that their health information was exposed to others in the waiting room when providers periodically checked in with them. Participants did not feel their privacy was protected during these discussions and thus felt their rights were being violated. Participants also attributed this feeling to more functional ED issues like the waiting room's size, layout, structure, and overall ED design. With a small waiting room and open, shared space for beds in the ED, participants felt uncomfortable about exchanging confidential health information between patients and providers in open environments and public areas: *"I heard everything that was going on. I could have told you what was going on. [...] Because of our health and our health being we have rights for nobody to know." (P16)* P20 also had a similar experience: *"I'm hearing people's whole names being called out in this huge waiting room. I felt like the confidentiality was being breached because I knew that person was there getting care." (P20)* To address this issue, many participants advocated for existing ED processes to be remediated at the structural level. This included the addition of more ED beds with closed walls or partitions, private spaces in the waiting room, and priority-based interventions. Overcrowded EDs induce long wait times and quickly fill up space in the waiting room where patient information is highly vulnerable to others. Some participants also suggested interventions, such as I-2: Interactive Display and I-5: Assistant Robot, should avoid displaying personal information to protect patient privacy, mainly since these interventions would be concentrated in the waiting room.

To alleviate anxiety induced in general by multiple factors during ED visits, many participants stressed the importance of having human providers as an aspect of emotional support for patients in the ED care process. When presented with ideas that limited patient-to-provider interactions (e.g., I-3: Table-Top Robot, I-10: AI Caller), participants expressed how technological interventions should support human providers rather than replace them. For this reason, interventions involving AI or robot technology were not popular with participants because they could have limitations in understanding patient requests or evaluating a patient's condition due to the lack of sophisticated technology in this space. Participants further highlighted empathy as another critical factor to consider since technology in the form of a robot would not convey as much sympathy and support as a human would in a stressful ED situation. Many participants thus preferred to have human support for alleviating the anxiety along with technological interventions because humans can communicate medical information and reassure patients in a manner that helps in coping with an anxiety-inducing environment: *"I don't think people would have a lot of confidence in [I-5: Assistant Robot] either. You know what I'm saying — it needs to be people who still like to interact." (P18).*

Continuity in care and information

During group discussions, many participants shared their experiences with discontinuity in care and information. Based on their experience, participants perceived that discontinuity might have occurred due to the handoff process within the care team. They noted that the involvement of multiple providers in their care team meant that information would often get lost during handoffs. Due to such missing information, some participants experienced discrepancies in provider-to-provider communication that caused patient confusion: *"Even a stay in the hospital, the doctors just rotate* *and roll over. [...] The first doctor said they wouldn't consider [discharging] until it [the protein level] goes below 10,000. Then the next doctor said, 'Oh no, I'm not going to even think about it unless it's below 500'. So, each time the shift changed — they told us something different." (P10)* Such discrepancies in care also occurred between hospitals. For instance, P27 shared her experience when she got a different diagnosis in the second hospital: *"So if he [P27's son] would have asked for a second opinion, at that point, you're leaving me in a lot of pain, and I still don't know what's going on. If he could have asked for that second opinion at that point, maybe he would have been diagnosed with a real issue five days earlier than he was." (P27)*

Reflecting on those situations where information discontinuity had occurred, most participants favored the I-7: Virtual Specialist to improve the breakdowns. They insisted that for interventions such as I-7: Virtual Specialist, an ED doctor should be present when the patient talked to the specialist so that the ED care team could have updated information. They envisioned that bringing specialists directly to the ED care process would improve diagnosis and documentation in patient-care records with the second opinion. Participants also expressed the need to allow for secure but easy information-sharing with providers outside the hospital when external providers were invited to the care. For instance, a global access healthcare platform could be used across hospitals for patient medical data transfer. Hence, they thought that I-7: Virtual Specialist could be expanded to include medical professionals beyond certain specialists: *"I think it depends on the context, the question, but for certain questions, it could be any nurse, it could be a PA [physician assistant], or someone who had familiarity with the patient. Based on the level of question, it may need to be a provider. Or a pharmacist." (P27)*

To promote continuity of care, participants commented that the technological interventions should be designed in an accessible way for different patient situations. For example, some patients wanted to use their existing wearable devices like smartwatches or fitness trackers instead of wearables provided by the ED to integrate live vitals tracking with historical data accurately. They also suggested that the I-6: ED Chatbot could be offered as an application for mobile devices that patients and caregivers could download when they arrived at the ED and utilize throughout their ED stay and after their ED care. These participants expected that utilizing interventions with patients' devices would ensure that patient-collected health data would be used to its fullest extent during care in the ED — and would allow providers to glimpse the patient's complete health profile over time rather than only view current condition. On the other hand, some other participants emphasized the need for care continuity for those who may not have the same access to technology (e.g., smartphones, smartwatches) or may have different amounts of previously collected health data (for instance, patients with chronic illnesses may have more personal health data tracked than those without). Thus, it is important that intervention use did not become a privilege reserved only for a subset of patients who had access to certain technological and data resources. *"I think that one, look at the person that comes in without any communications, no phone or no computer, you know, nothing… I often go into situations and emergencies without any kind of feature… I carry a phone — an old-fashioned flip phone with me. I can't access some of those things." (P20)*

Participants' desire for continuity of care was also shown during their co-design activity when they worked to improve the intervention designs. They envisioned an integrative, connected system where multiple intervention ideas were integrated with the current health portal or text notification system to flow health-related information continuously. For example, they imagined a tablet that could be used for I-7: Virtual Specialist, showing vitals synchronized with I-4: Wearable Device or the patient's health device (See Figure 4). Through such integration of features, participants envision inventions to enhance the continuity of care and information and to address their complex challenges in the ED care process. Although a few participants felt concerned that such an integrated intervention could delay ED stay time or contribute to patient information overload, many still thought our suggested interventions could be integrated with the existing patient portal and offered in an app format on various devices.

DISCUSSION

Design Implications for Patient-centered Interventions in ED

Based on the participatory design sessions, we identified ED patients' needs in the ED care process and expectations for future technological interventions. This section discusses how these findings may lead to design guidelines for more patient-centered interventions in ED.

First, technology-based **interventions should address patients' dynamic needs to promote continuity in care**. Our participants found that their needs could be met by more than one intervention idea (or multiple specific features) to address their complex needs since their needs may change depending on where they stand in the ED care process. For instance, many participants suggested integrating critical functions into one system in the co-design activity. Patients shared their desire for an integrated system, from arrival at the ED to post-visit follow-up. This desire was evident when some participants suggested integrating two different intervention ideas (I-7: Virtual Specialist and I-4: Wearable Device) so that an integrated system could track patients' status and share data with specialists. Those integrated interventions may be used to support issues in patient-provider communication. Our findings are related to how patients did not have sufficient information from or interaction with ED providers. Thus, our participants shared how integrated interventions may reduce such deficiency in information by providing various information. However, mere integration of systems may lead to additional challenges for patients. As some of our participants highlighted, myriad resources may cause information overload that can lead to patient anxiety. In another case, inviting outside providers would require extra documentation, potentially resulting in patient burdens. To design a better patient-centered integrated system in the ED, we suggest that the system consider patients' needs that may change throughout the ED care timeline. Existing technologies (e.g., a mobile app for an interactive report [7] to inform patients about their real-time progress and care plans) can be improved if integrated with other interventions, such as sensors or wearable devices, by collecting more accurate patient data and providing real-time information. Such an integrated system would provide timely, relevant information to patients depending on their status within the ED care process.

Second, **interventions should consider the amount and timing of information that patients receive**. Our participants shared their challenges with accessing information during their ED visits. They felt excluded from the ED care process if they did not have enough information. In contrast, they felt more anxious when they got overwhelming information. Thus, participants suggested patients be allowed to choose the timing of when they can receive different tiers of information access to applicable interventions, such as partial, complete, or none. One of the examples of such suggestions was utilizing a chatbot that could provide personalized care information. Based on participants' ideas, the I-6: ED Chatbot could be further developed to offer relevant information depending on which step patients undergo in the care process and their current health condition. This approach would also give patients more autonomy and flexibility in what information they can or cannot access during their ED visit. The need for timely and appropriate information resonates with the findings of a prior study [18], which describes how temporal dependency can delay the information that ED patients need. As ED medical activities often depend on previous activities, the information patients need or want is usually delayed. Without having relevant information during the ED process, patients may experience communication challenges with ED providers, such as different perceptions of what information is critical to ED care [19]. Hence, as our participants suggested, interventions should provide ED patients with optimized information relevant to the current step of the care process or options to control the amount and timing of information they expect to receive.

Third, **interventions should empower patients to be more active for better patient safety and care quality.** Our findings showed participants' need for patient autonomy in ED care. Unlike other patient care settings, the ED context is particularly intimidating for patients since ED visits are unexpected and urgent. Each visit may be different from the previous one. However, we found that participants in our study were eager to take a more active role in the ED care process. In the PD sessions, the need for empowerment was evident when most participants suggested features that allowed them to communicate assertively with providers about their symptoms. For instance, though the I-4: Wearable Device was initially designed to track patients' condition so they would not feel forgotten while waiting, many participants wanted to have another function, like a ‘help’ button, to more actively request support from providers when their conditions worsened or changed. This suggestion indicates how ED patients want to be more active stakeholders in the ED care process rather than be considered passive stakeholders who are just being assessed for their symptoms. Patient-empowering interventions are implemented based on prior studies’ insights from existing interventions, such as an inpatient portal [20] and a smartphone app [21]. For instance, a smartphone app called MySurgery [21] was developed to provide information about surgery risks and practical step-by-step advice for each risk. The app demonstrated a significant ability to enable patients to engage actively in discussions regarding their care and adopt behaviors related to their safety. Likewise, ED patients can be empowered with relevant information and advice, such as explaining medical terms or notices about the next step in the ED care process. This need for patient empowerment resonates with previous studies on shared decision-making (SDM) in the ED [22,23]. These studies identified that ED patients want some degree of involvement in medical decision-making. Extending this line of study, we found contextual nuances and more concrete examples of ED interventions to promote patient involvement. For instance, a review study showed the opportunities for wearable devices to monitor patient vital signs and provide the collected data to providers to improve decision-making [24]. Our findings suggest how ED patients perceive such wearable devices as an opportunity to be more actively involved in the care process rather than letting the devices passively collect data. Hence, we suggest that future ED interventions be designed to empower patients to be included in shared decision-making.

Fourth, **interventions should optimize human resources, depending on patients’ needs**. We identified that some issues cannot be addressed through technical interventions alone. These issues may be related to the distress or emotional needs of ED patients. For instance, our participants preferred human support rather than interactions with technical tools in alleviating their anxiety during ED visits. This preference implies that ED patients can manage their stress through human interactions, even though the suggested interventions, such as I-5: Assistant Robot, can still provide medical information. Moreover, human resources for ED patients include those not ED providers. Many participants expressed their need to connect with informal caregivers (e.g., family members), specialists, or other providers during their ED visit. Their needs were particularly evident when patients visited the ED once since they did not know about the ED care process. Based on their previous visits, patients learned that some external resources (e.g., family members and specialists) could provide more information to help assess their conditions or, in the case of family members, provide emotional support during the ED visit. This finding indicates that ED patients leverage resources they are more familiar with in intimidating and unfamiliar ED settings. Prior studies in the medical literature have shown the opportunities and challenges of telehealth for patients [25,26,27]. However, those identified challenges (e.g., unsteady or poorly framed video [27]) and strategies to overcome them may not be implemented in the fast-paced ED care process. Depending on the patient's current conditions, the right timing (e.g., when a specialist can be contacted) and method (e.g., simple video call or additional camera to show the patient's status) for providing external resources to patients should be determined. Thus, designing patient-centered interventions should optimize human resources to address ED-specific challenges, as we identified in our study. It will be critical to identify when and how interventions should provide external resources to patients. For instance, some of our participants wanted to be connected with specialists when they met ED providers after examinations so that they could have second opinions on their symptoms.

Lastly, **interventions should be designed considering patients' perspectives on implementation**. Through co-design activities, we identified how our participants expected intervention ideas to be implemented to address their needs better. However, their expectations could differ from actual implementations, potentially conflicting with what providers or the hospital expect. In such cases, it is critical to mitigate those expectations to implement patient-centered interventions. For instance, one of the potential reasons for our participants' preference for I-7: Virtual Specialist, was the assumption that specialists are available to have on-demand consultations. In contrast, in actual implementations, it would require other resources (e.g., cost, time, and human resources) to implement a system to get connected with specialists. As the prior work shows, ED providers must modify their work practices to adopt the new interventions [28]. Moreover, some of our participants pointed out the accessibility of devices that ED patients may not have. While mobile device ownership is high among ED patients [29], our suggested intervention ideas involved devices that patients may not have, such as wearable trackers. Thus, it is essential to consider how ED patients perceive the implementation of technical interventions in the ED.

Limitation

This study has some limitations. Given their qualitative nature, the findings are specific to the context we examined. Providers and patients from other EDs may face different challenges. However, our findings will contribute to identifying potential interventions that address such challenges through a participatory design approach. Also, we recruited participants with varying backgrounds from two ED units (pediatric vs. adult ED), which could help with the study's generalizability. Another limitation is that we did not distinguish participants' previous experiences as ED patients or caregivers. While the ED experiences of patients and caregivers do not have noticeable differences, future work can explore caregiver-specific perspectives on interventions designed to address their challenges in the ED care process. Lastly, we only presented concepts, not interactive system prototypes. Therefore, participants may not be quite familiar with some intervention ideas. They could only imagine how an intervention might work but could not see the real system/product. Yet, storyboards are a common HCI methodology for eliciting user needs in the early system design stage. They are useful for validating user needs and expectations before implementing a system in a complex environment like an ED.

Conclusion

In this participatory design study, we invited ED patients to design sessions to assess their needs in the ED care process and co-design technical interventions. Based on the analysis of collected data, we identified four themes of ED patients' needs: the feeling of exclusion from the ED care process, limited resources for patient comprehension of medical information, anxiety about overwhelming information and privacy, discontinuity in care and information, and concerns about diagnosis accuracy. The findings also informed us to develop guidance for designing future technology-based patient-centered interventions to improve the diagnostic process in the ED.

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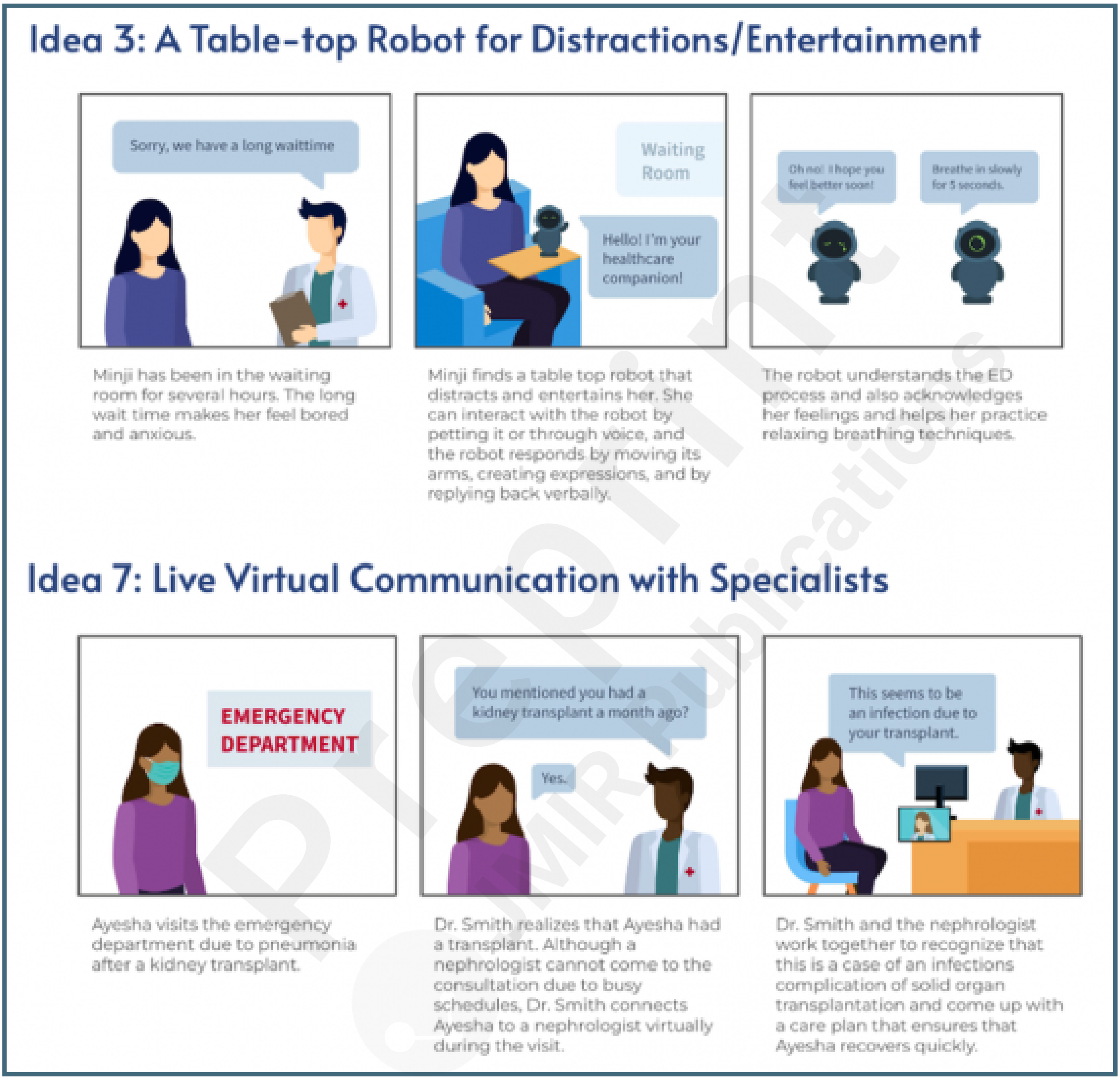
Supplementary Files

Figures

Sample storyboards of technology intervention ideas used to present to our participants during the sessions. (The top panels are the storyboards for Table-Top Robot, and the bottom panels depict Virtual Specialist).



Idea 3: A Table-top Robot for Distractions/Entertainment

Minji has been in the waiting room for several hours. The long wait time makes her feel bored and anxious.

Minji finds a table top robot that distracts and entertains her. She can interact with the robot by petting it or through voice, and the robot responds by moving its arms, creating expressions, and by replying back verbally.

The robot understands the ED process and also acknowledges her feelings and helps her practice relaxing breathing techniques.

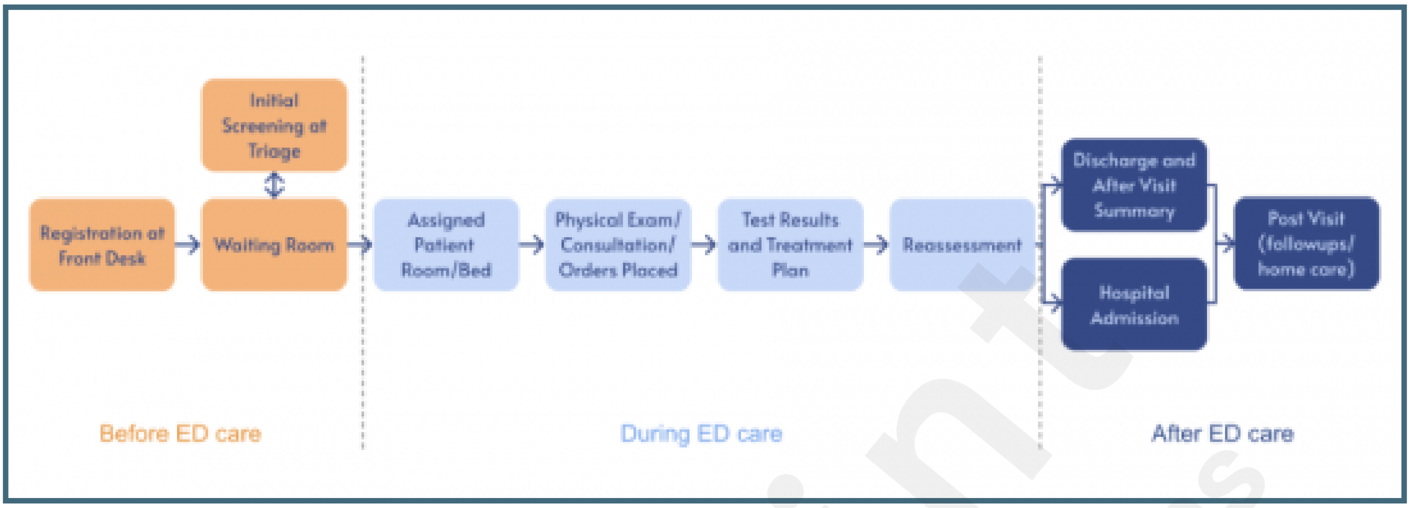
Idea 7: Live Virtual Communication with Specialists

Ayesha visits the emergency department due to pneumonia after a kidney transplant.

Dr. Smith realizes that Ayesha had a transplant. Although a nephrologist cannot come to the consultation due to busy schedules, Dr. Smith connects Ayesha to a nephrologist virtually during the visit.

Dr. Smith and the nephrologist work together to recognize that this is a case of an infections complication of solid organ transplantation and come up with a care plan that ensures that Ayesha recovers quickly.

An ED care process timeline that illustrates the steps before, during, and after ED care. We created this timeline based on prior studies. ED: emergency department.



Co-Design Activity with participants in the middle of a discussion about improving Idea 7 (I-7 in Table 2). Participants collaboratively drew ideas on a whiteboard and wrote notes about imagined functionality.

A sample drawing by participants during a co-design activity. The drawing shows how the I-4: Wearable Device could be improved with additional features such as the “Nurse Help” button.