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## Research and Applications

# Informatics opportunities to involve patients in hospital safety: a conceptual model

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Received 8 July 2019; Revised 22 August 2019; Editorial Decision 26 August 2019; Accepted 28 August 2019

### ABSTRACT

**Objective:** Inpatients could play an important role in identifying, preventing, and reporting problems in the quality and safety of their care. To support them effectively in that role, informatics solutions must align with their experiences. Thus, we set out to understand how inpatients experience undesirable events (UEs) and to surface opportunities for those informatics solutions.

**Materials and Methods:** We conducted a survey with 242 patients and caregivers during their hospital stay, asking open-ended questions about their experiences with UEs. Based on our qualitative analysis, we developed a conceptual model representing their experiences and identified informatics opportunities to support patients.

**Results:** Our 4-stage conceptual model illustrates inpatient experiences, from when they first encounter UEs, when they could intervene, when harms emerge, what types of harms they experience, and what they do in response to harms.

**Discussion:** Existing informatics solutions address the first stage of inpatients' experiences by increasing their awareness of potential UEs. However, future researchers can explore new opportunities to fill gaps in support that patients experience in subsequent stages, especially at critical decision points such as intervening in UEs and responding to harms that occur.

**Conclusions:** Our conceptual model reveals the complex inpatient experiences with UEs, and opportunities for new informatics solutions to support them at all stages of their experience. Investigating these new opportunities could promote inpatients' participation and engagement in the quality and safety of their care, help health-care systems learn from inpatients' experience, and reduce these harmful events.

**Key words:** patient safety, patient-facing technologies, patient engagement, personal health informatics

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## INTRODUCTION

For 2 decades, patient safety has been recognized as a critical problem in healthcare systems worldwide. In the United States alone, medical errors are the third leading cause of death, accounting for over 200 000 casualties every year.<sup>1</sup> As primary witnesses to the care they receive, patients have different perspectives from providers on problems that occur during their hospital stay, and could play a meaningful role in identifying, preventing, and reporting these problems.<sup>2–5</sup> Indeed, patients are often the first to detect lapses in their

safety, and have successfully intervened in problems.<sup>6–8</sup> Despite having important roles in improving hospital safety, patients' insights into the breadth of quality and safety problems—hereafter referred to as undesirable events (UEs)—are not well understood, as they are often unreported, unacknowledged, and inadequately supported by informatics systems.<sup>9,10</sup>

Researchers have called for solutions that encourage patient participation in safety.<sup>11</sup> However, most solutions implemented in hospitals are not designed to overcome barriers patients face when

speaking up,<sup>12,13</sup> nor do they address the breadth of UEs that patients experience.<sup>14,15</sup> Health informatics research has produced several inpatient-facing technologies—including information displays and patient portals—for patients to engage in their care.<sup>16</sup> Yet, few inpatient-facing technologies foreground patient participation in their safety. Therefore, a substantial gap exists between patients' potential to be actively involved in improving their safety, and the interventions that are currently available to them.

Understanding how patients experience quality and safety problems in the hospital is a critical step toward developing informatics solutions that patients can use to identify and prevent such problems. In this article, we present a conceptual model that represents patient experiences from when they first encounter UEs, to what actions they take in response to harms. Our model is based on findings from a survey study we conducted with 242 adult and pediatric patients, as well as their caregivers. This model reveals new opportunities for informatics solutions to support patient participation in improving the quality and safety of their hospital care.

## MATERIALS AND METHODS

We conducted a survey study to understand inpatients' and caregivers' experiences with UEs, which we define as satisfying the following 3 criteria: (1) a small or a big concern, (2) something that was unpleasant or caused harm, and (3) something that could have been avoided, from the patient and caregiver perspective. Our goal was to capture patient and caregiver perspectives, rather than provider perspectives. Therefore, we did not compare our data to medical records, formal reports, or provider accounts of events. Ethical approval was obtained from our institutional review boards.

### Survey instrument

Our web-based, anonymous survey instrument consisted of 30 closed- and open-ended questions about the participant's UE, general hospital experience, and demographics. We included 3 free-text questions asking participants about (1) the event in their own words, (2) what caused the event from their point of view, and (3) the outcome of the event. Our article focuses on responses to these open-ended questions to understand participants' perspectives. Participants could describe events that occurred during any previous hospital stay, not necessarily at the study site. The instrument was pilot tested to ensure readability for various ages and education levels.

### Recruitment and procedures

To capture diverse perspectives, we recruited participants at a pediatric and an adult hospital in an urban region of the United States. We obtained a convenience sample across medical and surgical services. Patients and caregivers were approached if they satisfied the following criteria: if they spent at least 1 night in the hospital during their current stay, were at least 7 years of age, could communicate in English, and were well enough to provide informed consent. We asked them if they experienced a UE based on our definition. For those who wanted clarification of this definition, we provided examples (eg, a disagreement with a provider, a wrong surgery site, or anything in between). Patients and caregivers who experienced a UE, accepted participation, and provided informed consent were administered the survey on an iPad. Research team members answered questions and helped the participant take the survey if needed.

### Data analysis

We followed a multistage qualitative analysis of our open-ended survey questions.<sup>17</sup> Open coding was used to develop preliminary codebooks for types of UEs, harms, and other key aspects of the participant's experience. During recruitment, 2 coders met with the research team to discuss and iteratively edit the codebooks. This analysis continued until saturation was reached and recruitment concluded. Validity was tested by deductively assigning codes to a random sample of 20% of responses. After revisions to the codebooks, another 10 randomly selected responses were coded, interrater reliability was achieved (Cohen's kappa=0.815, percent agreement=96.3%), and the entire dataset was recoded with the revised codebooks. We then identified patterns of coappearing codes and developed a conceptual model characterizing the relationships between them.

### Participants

We approached 606 hospitalized patients and caregivers across our pediatric and adult study sites. Of those approached, 312 (51.5%) were considered eligible for participation, 70 of whom declined. The remaining 242 patients and caregivers agreed to participate and completed the survey (response rate 77.6%). We received a total of 246 responses, as some participants reported multiple distinct UEs. [Table 1](#) summarizes our participant demographics.

## RESULTS

Our analysis revealed 4 distinct stages that characterize patient and caregiver experiences with UEs and harms. Based on our findings, we developed a conceptual model that depicts the events, harms, interventions, and responses from patients, as well as the relationship between these elements ([Figure 1](#)). In the following sections, we describe each of these stages, and the types of UEs, harms, and responses involved. Quotes and examples are provided with the unique identifier S#.

### Stage 1: occurrence of UEs

In the first stage, patients and caregivers recognized that 1 or more UEs have occurred in their care. These UEs largely fell into 2 categories: clinical and nonclinical. Clinical UEs refer to problems in administering the patient's hospital care, and include the use of broken medical equipment, misdiagnoses, and unexpected deviation from agreed-upon treatment protocols. Nonclinical events, on the other hand, involve the quality of a patient's hospital stay that can negatively impact clinical care. Nonclinical events consisted of 3 subtypes that were present in our analysis: miscommunication, institutional barriers, and lack of respect. [Tables 2](#) and [3](#) provide summaries of the subtypes, definitions, and examples of both clinical and nonclinical UEs. Although the combinations of clinical and nonclinical events were unique, we found their subtypes to be interrelated and exacerbated each other's occurrence.

For example, one miscommunication event can lead to further miscommunication among patients, caregivers, and providers. Communication breakdowns between providers resulted in participants not receiving critical care information. Others thought that "poor bedside manner" led providers to convey inaccurate or misleading information about the patient's care. S78 was caring for her child when a doctor she had never seen before "discussed worse [sic] case scenario treatment options...without consulting the rest of the

**Table 1.** Summary of participant demographics

	Pediatric site	Adult site	Total
<b>Completed responses</b>	146 (59.3)	100 (40.7)	246 (100)
<b>Patients</b>	56 (22.8) <sup>a</sup>	79 (32.1)	135 (54.9)
<b>Caregivers</b>	90 (36.6)	21 (8.5)	111 (45.1)
<b>Sex</b>			
Female	108 (43.9)	53 (21.6)	161 (65.5)
Male	37 (15.0)	46 (18.7)	83 (33.7)
Other/no answer	1 (0.4)	1 (0.4)	2 (0.8)
<b>Age</b>			
7–18 y	48 (19.5)	0 (0.0)	48 (19.5)
19–24 y	12 (4.9)	2 (0.8)	14 (5.7)
25–44 y	67 (27.2)	17 (6.9)	84 (34.1)
45–64 y	16 (6.5)	45 (18.3)	61 (24.8)
65+ y	1 (0.4)	36 (14.6)	37 (15.0)
No answer	2 (0.8)	0 (0.0)	2 (0.8)
<b>Education</b>			
Grade 8	17 (6.9)	0 (0.0)	17 (6.9)
High school/GED	25 (10.2)	19 (7.7)	44 (17.9)
Some college	18 (7.3)	19 (7.7)	37 (15.0)
2- or 4-year degree	44 (17.9)	36 (14.6)	80 (32.5)
Graduate/professional	17 (6.9)	24 (9.8)	41 (16.7)
None/no answer	25 (10.2)	2 (0.8)	27 (11.0)
<b>Race/ethnicity<sup>b</sup></b>			
White/Caucasian	109 (44.3)	79 (32.1)	188 (76.4)
Black/African American	8 (3.3)	5 (2.0)	13 (5.3)
Hispanic/Latin American	16 (6.5)	5 (2.0)	21 (8.5)
Asian	17 (6.9)	6 (2.4)	23 (9.3)
Native American/Pacific Islander	12 (4.9)	4 (1.6)	16 (6.5)
Other/no answer	17 (6.9)	7 (2.9)	24 (9.8)
<b>Overnight hospital stays within the last 5 y<sup>c</sup></b>			
Less than 10 stays	84 (34.2)	69 (28.0)	153 (62.2)
More than 10 stays	58 (23.6)	30 (12.2)	88 (35.8)
No Answer	4 (1.6)	1 (0.4)	5 (2.0)
<b>Type of stay at the time of UE</b>			
Planned	45 (18.3)	39 (15.9)	84 (34.2)
Unplanned	101 (41.1)	61 (24.8)	162 (65.9)
<b>Length of stay at the time of UE</b>			
7 d or less	94 (38.2)	69 (28.1)	163 (66.3)
8 d or more	45 (18.3)	29 (11.8)	74 (30.1)
Unsure	7 (2.9)	2 (0.8)	9 (3.7)

Values are n (%).

UE: undesirable event.

<sup>a</sup>Two caregivers at the pediatric site described their experiences as a patient.

<sup>b</sup>Participants could select more than 1 category.

<sup>c</sup>At the time of the study in 2016.

[care] team. He was not a doctor in charge of making treatment decisions but more of a consult however didn't identify himself that way." This interaction caused a great deal of unnecessary "stress and anxiety" for S78.

Miscommunication events are also interconnected with institutional barriers—UEs originating at the organizational level of the hospital, of which patients and caregiver experience downstream effects. These barriers consist of logistical or scheduling failures between hospital departments, poor use or design of electronic health records (EHRs), and burdensome policies for patients and caregivers. For example, S246 witnessed a planned upgrade to the hospital's EHR system that went poorly and caused communication breakdowns between her providers. She said, "[N]urses and docs were unable to chart patient info and their communication with each other and other departments was severely impaired. . . it was outrageous."

Miscommunication events and institutional barriers can lead to patients and caregivers not feeling respected by providers or the healthcare organization. Participants sometimes felt forced into making decisions that were incongruent with their values, thought their physical environment was disempowering, and experienced unwanted restrictions—or a lack of consideration for—their ability to engage in their care. S184's providers were not communicating with each other, and both called her to make a care decision during her intravenous (IV) placement. The event "*made the process confusing and frustrating during a time when I really wasn't in a position to make big decisions.*" S26, was caring for her child in the neonatal intensive care unit when her family was asked to relocate and make room for another patient in the middle of the night. S26 explained, "This transition would have been a lot more respectful and courteous with some warning. . . when we aren't sleeping and recovering from severe trauma."

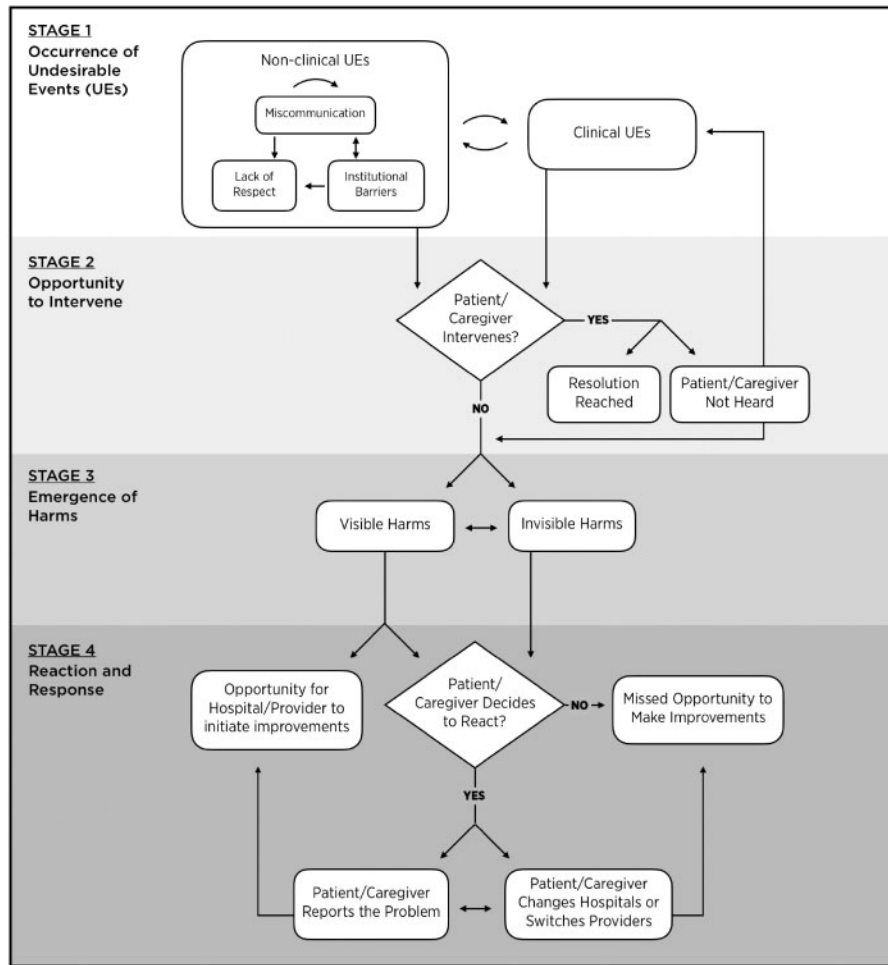


Figure 1. Our 4-stage conceptual model that describes patient experiences with undesirable events (UEs).

Table 2. Clinical UEs, percentage of total responses in which they were mentioned, their definitions, and representative quotes

Clinical UEs	% of total responses	Definition	Representative quote
Medications	24.0	Mistakes in prescribing or administering medications to patients	<i>[Patient] was administered IV chemotherapy at over twice the prescribed rate. (S162)</i>
Medical equipment	17.9	When medical equipment used in patient care malfunctions or is mishandled	<i>High flow not working properly because of loose connections and faulty parts. (S33)</i>
Treatment protocol	10.2	Unexpected deviations in treatment protocols	<i>Nurse did not remember to put on gloves or sanitize hands prior to dispensing medication. (S198)</i>
Delayed or misdiagnosis	6.9	Uncertainty or incorrect judgement regarding the patient's diagnosis	<i>A [provider], unfamiliar with my child's complex medical history, made a misdiagnosis about my son's absolute low neutrophils. (S103)</i>
Natural cause	8.9	Natural, and sometimes unexpected reactions patients have to treatment	<i>Treatment caused unknown reactions and trip in night to ER. (S80)</i>
Hospital-acquired conditions	6.5	Additional medical conditions that the patient experiences due to their presence in the hospital (eg, falls, hospital-specific infections)	<i>Staph infection following surgery...required an additional surgery to patch a bursa sac on my shoulder. (R227)</i>
Inadequate diet or nutrition	3.3	Deficiencies in nutrition or hydration during patient or caregiver's hospital stay	<i>I bit into the [meal] and it was like eating pure salt...I'm on a salt restrictive and water restrictive diet. I didn't eat for the rest of the night. (S287)</i>

UE: undesirable event.

**Table 3.** Summary of nonclinical UEs, percentage of total responses in which they were mentioned, definitions, and representative quotes

Nonclinical UEs	Subtypes of UE	% of total responses	Definition	Representative quote
Miscommunication	Breakdowns between providers	19.5	Inadequate communication among individual members of the care team	<i>The hospital advertises the ‘team medicine’ concept but sometimes the team members are not following the same game plan. (S171)</i>
	Lack of information	14.2	Care-related information is not communicated to patients and caregivers	<i>No real information was provided about [my son’s] . . . Large lack of parent/provider communication. (S105)</i>
	Inaccurate information	7.7	Information is wrong or presented as more reliable than it actually is	<i>I thought I was coming in for a simple surgery. . . but really it was more complicated than they let on. (S141)</i>
	Lack of empathy	28.1	How a provider communicates is reflective of poor bedside manner or a lack of compassion	<i>The provider was mean and she tried to undermine my pain. She was rushing and wasn’t personal, not compassionate. (S219)</i>
Institutional barriers	Lack of care coordination	17.9	Conflicting or delayed schedules; logistical failures	<i>Scheduled test delayed from 9: 30am to 5pm but was delayed one hour at a time with no explanation. (S179)</i>
	Poor use of EHRs	4.1	EHR design, usability, access, and dependencies that negatively impact care	<i>Nursing staff did heavy time for electronic documentation and very little attention to the patient. (S175)</i>
	Burdensome policies	5.7	Organizational rules that negatively affect patients and caregivers	<i>I was denied service for 2 to 3 days before they start[ed] on me because of insurance. (S269)</i>
Lack of respect	Capacity to make decisions	2.4	Patients’ or caregivers’ ability to make critical care decisions is restricted or not considered by the care team	<i>I was given too much pain medication. I was not competent after the procedure to be reliable when asked, ‘is your pain still a 7?’ (S96)</i>
	Comfort of hospital environment	8.1	Physical surroundings of the hospital negatively affect patients’ and caregivers’ experience	<i>It was uncomfortable the whole time, bad blankets bad beds. (S18)</i>
	Personal privacy	2.4	Patients and caregivers struggle to establish personal boundaries with hospital staff	<i>[I] just don’t like people touching me without asking. . . they think because I’m a kid they don’t have to ask. . . (S37)</i>

EHR: electronic health record; UE: undesirable event.

In some cases, nonclinical events can trigger clinical events (eg, S30, a pediatric patient, reported miscommunication between his providers that he thought resulted in his misdiagnosis). When patients and caregivers experience both nonclinical and clinical events, they heighten each other’s perceived severity. For example, S21’s experience of feeling disrespected during a nonclinical UE when her request for a type of manual therapy that she had received at a different hospital was denied due to hospital policy. This negative experience worsened her impression of a series of later clinical events she experienced (“daily inhaled meds were missed,” “blood sugar was rarely checked”). As these problems accumulated, S21 felt her input was increasingly ignored by her care team.

### Stage 2: opportunity to intervene

After recognizing UEs, some patients were unable to intervene because they felt too vulnerable to speak up, they were not aware of their rights in the situation, or fast-paced care decisions meant the “damage was done” before they saw any chance to prevent it. Those who did have an opportunity to intervene did so by expressing their concerns directly and repeatedly to providers, asking for justifications of care decisions, or requesting involvement from high-level staff and third-party representatives (eg, patient-family representatives) to mediate conflicts. Caregivers also advocated on the patient’s behalf to relay concerns to providers.

The patient’s or caregiver’s intervention is sometimes recognized by providers, prompting each party to collaborate efficiently, and reach a resolution to avoid potential harm. In some cases, patients and caregivers may need to attempt intervention more than once to achieve resolution. S131 experienced this when he was in “agony” from a urinary retention problem and repeatedly asked for a bladder scan and catheter. A nurse finally acknowledged his persistence and took the steps necessary for catheterization within a few minutes, mitigating further unnecessary harm.

In other cases, however, the patient’s and caregiver’s attempt to intervene is not heard. Several participants raised a concern or questioned a provider’s decision that contradicted their own expertise in their health. Pediatric patients who were skilled in managing their care requested treatment modifications to prevent anticipated harms, but these concerns were often denied or unaddressed. S34 was a caregiver who spoke up about her son receiving the wrong medication: “Despite my concerns of no improvement. . . [providers] were dismissive to my own experience and history with my child, leaving enormous room for error.” For S50, her unaddressed concerns led to additional clinical UEs when she requested an alternative to her daughter’s IV line. The request was rejected, and the patient “suffered multiple failed attempts to place new IV lines.”

**Table 4.** Types of invisible and visible harms, percentage of total responses in which they were mentioned, definitions, and representative quotes

Harms	Subtypes of harm	% of total responses	Definition	Representative quote
Invisible	Negative emotions	26.8	Feelings that patients and caregivers experience after UEs (eg, fear, anxiety, loneliness, helplessness)	<i>I was in an extreme state of panic and [the event] has made me fear other surgical procedures.</i> (S129)
	Loss of trust	3.3	Patients' and caregivers' confidence in their providers and healthcare system is undermined	<i>I wasn't nervous until they put [on] the mask. . . I was rushed. All the doctors said different things. Who are you supposed to trust???</i> (S156)
	Additional life burdens	11.8	Work or responsibilities added to patients' or caregivers' lives because of the UE (eg, financial stress, finding child care for young siblings of patients during a longer hospital stay)	<i>"[Daughter's] drain "balloon" popped open. . . I've got bodily fluids on my shirt, sweater, pants &amp; even my parent badge. Once we got into the double room, we were told not to use that bathroom (or work it out with your neighbors). So now I've got to figure out where the bathroom down the hall is to clean up. . .</i> (S36)
Visible	Pain or discomfort	27.6	Poor pain management and physical discomfort that could have been avoided or reduced (eg, bruising, lack of sleep)	<i>I went to get my port placed and [the nurse] jammed it in and it hurt so bad. . . I was in pain and it left a bruise.</i> (S181)
	Decline in health condition	24.8	The general health or condition of the patient worsens	<i>My dad's condition worsened in my opinion due to a lack of nursing observation on the patient.</i> (S175)
	Delay in care or discharge	17.1	The delayed administration of time-sensitive, critical care; setbacks in the discharge process	<i>The pharmacy had difficulty obtaining my insulin. . . medication was finally administered but it took at least 24 hours.</i> (S223)
	Additional care or readmission	16.7	Patient requires more care than originally expected, or is readmitted for problems due to UEs	<i>Had infection in shunt fluid. . . they needed emergency surgery to help defeat my infection.</i> (S223)
	Affected diet or nutrition	3.7	Dietary consequences due to treatment or inadequate nutrition	<i>Patient was not given food until 1:30am. . . was hungry and distressed as a result.</i> (S218)

UE: undesirable event.

### Stage 3: emergence of harms

If patients' and caregivers' concerns are unheard, harms of varying severity emerge. For example, S285 tried to convince his providers of symptoms he unexpectedly experienced after gallbladder surgery. When his concerns were not heard, he visited the emergency room and discovered severe damage due to surgical mistakes that required months of reconstructive surgery.

The additional care that S285 needed is a type of visible harm—a tangible, clinical consequence. However, patients and caregivers can also experience invisible harms, which often are unnoticed or unreported to hospital staff. For example, many participants took issue with the “waste of time” caused by procedure delays and communication breakdowns, “additional billing” caused by the need to receive more hospital care after UEs, and the anxiety from not receiving adequate explanations for being placed under isolation protocols. Table 4 has additional examples of invisible and visible harms.

Visible and invisible harms sometimes co-occur and influence each other. For example, pain or discomfort led to negative emotions (eg, fear, helplessness). S267 experienced delays in receiving her medications and felt “a huge amount of both physical and emotional pain, and loss of confidence and trust in my care team.” S18's communication breakdown with providers yielded an invisible harm, in which he felt his providers “gave up” on him. This negative relationship led to a difficult recovery and delayed discharge for “a month and a half.”

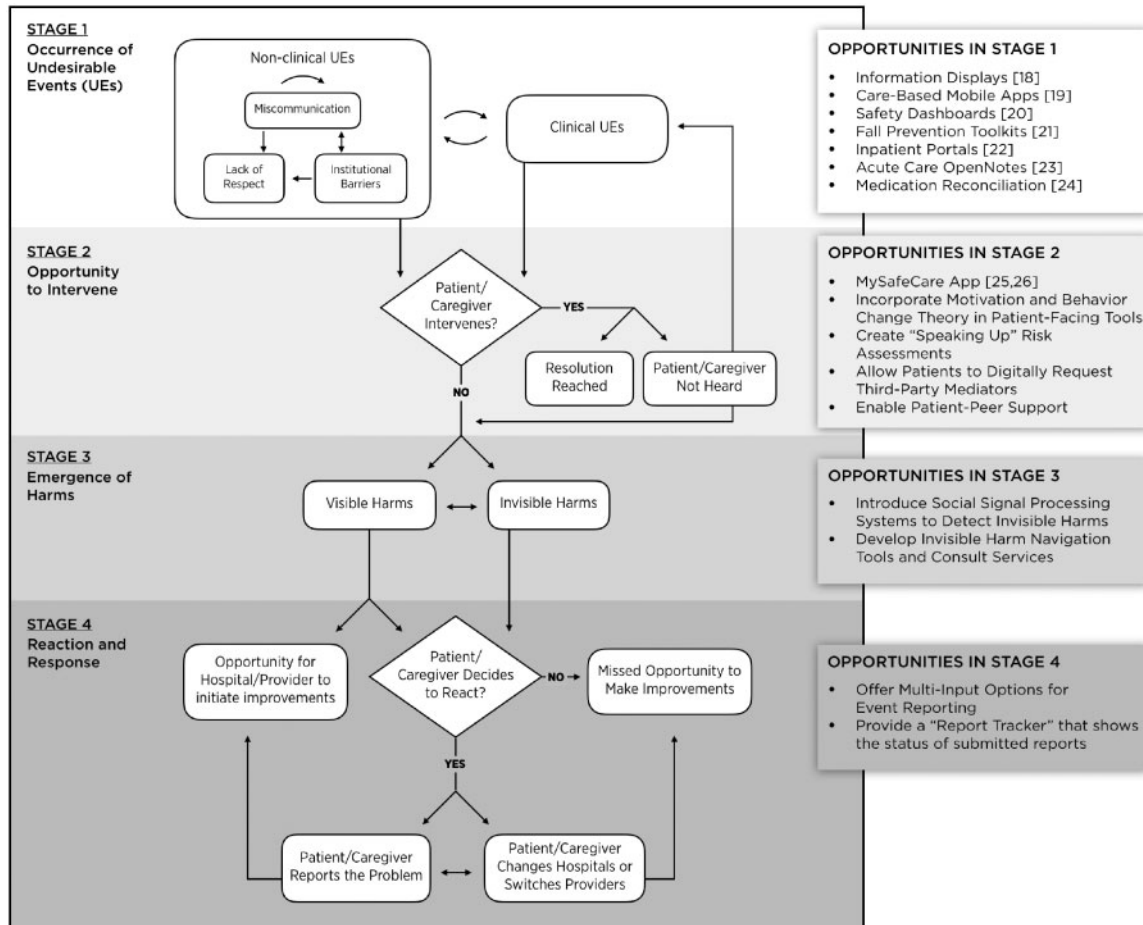
### Stage 4: reaction and response

After harms emerged, participants sometimes needed time to process or reconcile the experience they endured, and thus did not describe any actions they took in response. Others mentioned waiting for a dependency—such as a test result, or a second opinion—before deciding to take action.

Participants who decide to react take 2 types of approaches. The first is that they transfer hospitals or request new providers to be involved in their care. S201 was frustrated with the “large highly matrixed organization with busy people” and this impression “reduced patients [sic] confidence in patient care model. Patient switched to another hospital system with better communication to patients.” In some cases, however, this decision to change hospitals was forced upon the participant, rather than it being their choice. For example, S243 was denied additional care when her providers thought she was “faking pain. And literally kicked me out of the [hospital].”

The second action is that patients and caregivers alert providers to harms they experience, or report them to the hospital. Although some participants were encouraged by hospital staff to submit formal complaints, they encountered barriers in doing so. S19 experienced a lack of empathy from a nurse who ignored her child's cries for help. She was told her doctor would help her file a report about the UE, but “it never happened.”

In a subset of cases, providers involved in UEs would leverage the participant's report as an opportunity to initiate improvements.



**Figure 2.** Our 4-stage conceptual model with annotations for each stage on the right-hand side. Annotations summarize past research, and future opportunities, for informatics solutions to involve patients in their safety. UE: undesirable event.

For example, a lack of attention and communication resulted in S124 child's heart stopping. After this event, there was "improved communication among doctors and the teams were told to listen to the parent." For other participants, improvements were made as a direct result of their written complaint. S135 was an adolescent patient who reported her experience to her local health department and news channels, prompting an investigation and retraining of hospital staff. However, not everyone who submitted a complaint was told how their feedback was addressed, if at all. S63 was a caregiver who successfully stopped her care team from administering treatment to the wrong patient in their shared hospital room. Although she submitted a complaint, she was disappointed in the lack of update: "I don't know at this point if [the] team has been talk[ed] to. It would be nice to know that the follow-up continued that far."

## DISCUSSION

Our conceptual model illustrates how patients experience UEs and resulting harms, as well as highlights the specific actions they take and their consequences. This nuanced view helps us to understand how informatics systems might enable patient involvement in safety. In the following sections, we discuss how current and future patient-facing informatics systems could be integrated at each stage of their experience (Figure 2).

### Increasing awareness of UEs in stage 1

Many existing patient-facing technologies address stage 1 of the model. Specifically, these technologies make information contained within EHRs available to patients and their caregivers. These technologies provide transparency by offering patients a digital reference to monitor their care and recognize problems that could result in UEs and harms. For example, information displays and mobile applications helped patients in emergency departments alleviate concerns about discussing allergies and medications with providers.<sup>18,19</sup> Fall prevention toolkits and safety screensavers presented patients with customized safety plans that heightened their perception of risk factors that could lead to mistakes in their care.<sup>20,21</sup> Through using patient portals,<sup>22</sup> OpenNotes,<sup>23</sup> and medication reconciliation tools,<sup>24</sup> patients were able to monitor and identify mistakes in their records.

Despite extensive research demonstrating the safety-related benefits of such technologies, recognizing UEs is just one aspect of the patient experience. Given the inevitability of human error and the challenges that healthcare systems face in understanding the complex nature of hospital safety, there exist additional underexplored opportunities for patient-facing technologies to accommodate subsequent stages of the model.

### Encouraging intervention and resolution in stage 2

When patients experience stage 2 of the model, they require tools that both encourage their ability to intervene in UEs, and ensure a resolution

can be reached with their care team. Although patient-facing technologies that pull information from the patients' EHR can be helpful in alerting providers to mistakes in their record, patients also need tools when their concerns are not heard by the care team. One example of such a tool is MySafeCare, which allows patients to intervene in UEs in a real-time, low-burden way that does not require direct interaction with providers.<sup>25,26</sup> This nonconfrontational format helps patients speak up about concerns as they occur.

Future researchers can build on this work by exploring how theories of motivation and behavior can be leveraged in patient-facing technologies to help patients overcome the barriers they face to speaking up.<sup>27,28</sup> These technologies could present patients with information about the risk severity of not intervening in UEs. Inpatient portals could offer features for patients to request third-party mediators (eg, patient-family relations teams) to resolve conflicts. Systems might use skill-building exercises to teach patients and providers to have difficult safety discussions,<sup>29,30</sup> or might act as a neutral platform to moderate UE-related conversations.<sup>31</sup> Patient-peers have also been known to help patients intervene in UEs,<sup>32</sup> and have a need to share safety-related information with each other.<sup>33–35</sup> Systems could connect patients with each other during their hospital stay to exchange advice about—and normalize the behavior of—speaking up.

Making such technologies available to patients during their hospital stay can encourage their decision to intervene and avoid ensuing harms. Furthermore, technologies that support patients' abilities to intervene in stage 2 can lead to hospitals discovering upstream areas for improvement and UE prevention.

### Detecting and managing invisible harms in stage 3

Stage 3 of the model reveals invisible harms as encompassing both "emotional harms" and life burdens that—in contrast to visible harms—are nonphysical and difficult for providers to detect or challenging for patients to convey to their providers.<sup>36</sup> Thus, opportunities exist for future informatics solutions to support providers' detection of these invisible harms so they can be acknowledged and addressed. For example, researchers have studied social signal processing as a way for patients and providers in clinic to receive real-time feedback about the tone and empathy conveyed throughout their conversations.<sup>37,38</sup> Similar social signal processing solutions could be adapted for the inpatient setting to surface negative emotions or reduced trust that patients might express after handling a UE. Doing so could increase the visibility of such harms so providers can initiate an appropriate response.

Beyond using tools to detect invisible harms, healthcare organizations can provide resources that help patients manage invisible harms. In particular, additional life burdens that patients take on after UEs consist of invisible effort, in addition to their responsibilities of managing their health.<sup>39</sup> Prior work has revealed how patient-facing informatics solutions—including digital cancer navigation resources and patient-engagement consult services—could assist patients with the emotional, social, financial, and logistical challenges that they face while receiving treatment.<sup>40,41</sup> Future researchers could investigate how these solutions might help patients contextualize UEs, process the harms that have occurred, and support their ability to react to these harms in stage 4 in a way that drives positive change in the healthcare system.

### Reducing barriers to reporting in stage 4

After experiencing harms, participants in our study decided to react in stage 4 by reporting their experience to ensure the UE did not

happen again, or by switching healthcare institutions after losing trust in the hospital. However, when patients choose not to report their experiences, hospitals miss the opportunity to learn from the UE and prevent similar problems. Thus, hospitals must promote transparency and resilience, as well as reduce reporting barriers. Although communication and resolution programs (eg, the Communication and Optimal Resolution framework)<sup>42</sup> are intended to promote a culture of transparent error disclosure, they traditionally enable the reporting of events detected by providers or hospitals, rather than those detected by patients. Hospitals should have systems in place that allow patients to self-report events and harms, as well as make them known and readily accessible to patients. For example, systems can support multimodal reporting in the form of phone calls, text messaging, email, forms that can be submitted through patient portals, or voice-based technologies—such as Amazon Alexa or Google Assistant—which have been increasingly used in inpatient settings.<sup>43</sup> Offering multiple reporting methods would allow patients with situational impairments—cognitive or physical difficulties due to illness or treatment—to submit reports with minimal effort.<sup>44</sup>

After patients submit their reports, they have a strong interest in knowing how the hospital handles their report and what changes are made as a result.<sup>45</sup> Yet, participants like S63 were never informed of these changes, and failing to provide such updates can exacerbate the harms patients experience.<sup>46,47</sup> To address this problem, hospitals could provide patients with tools that track the status of their report from start to finish. Prior research has suggested tracking features within inpatient portals to keep patients updated about dynamic care information.<sup>48</sup> In the event reporting context, a tracking tool could include (1) a summary of the process and steps a reported UE takes within the organization; (2) the current status of the reported UE; (3) a list of who is responsible for processing and reviewing the UE at each step, including their role, name, and contact information; and (4) any system-based changes that were made as a result of the review process. Because the report review process can extend well beyond a patient's discharge, such a tracking tool must be available to the patient during and after their hospital stay.

### Limitations and future work

Our conceptual model uncovers opportunities for health informatics systems to help patients through each stage of their experiences with UEs, but we acknowledge the limitations of our study. Selection bias is possible, as participation was voluntary and uncompensated. Participants who submitted multiple responses introduced some demographic redundancies into our data. Because our study was conducted at one pediatric and one adult hospital site in an urban area of the United States, our findings might not generalize to broader geographic or demographic populations.

In addition to investigating the opportunities for patient-facing informatics solutions described previously, our findings point to several avenues for future work. Because our model represents patient perspectives, more work is needed to account for factors that influence these perspectives—such as the disclosure of UEs, ambiguity in how UEs and harms are defined, and varying thresholds for patients tolerating UEs—and refine the model accordingly. This work could unearth additional opportunities for effective informatics solutions.

## CONCLUSION

In this article, we describe a conceptual model based on survey results about patient experiences with UEs. Our findings from 242



participants demonstrate the complexity of their experiences, and present a stage-based approach toward understanding hospital safety from their perspective. Our model reveals the need for informatics solutions to support patients at all stages of their experience by increasing awareness of UEs, encouraging intervention and resolution, detecting and managing invisible harms, and reducing barriers and sharing report updates. Such informatics solutions represent new learning opportunities for healthcare systems to reduce harmful events and recognize patients as equal partners in improving hospital safety.

## FUNDING

This study was supported by the Agency for Healthcare Research and Quality 1R01HS022894 awarded to Dr. Wanda Pratt, PhD, and the National Library of Medicine Biomedical and Health Informatics Training Grant T15LM007442.

## AUTHOR CONTRIBUTIONS

SH led the study conceptualization, design, data collection, analysis, and authored the article. SRM participated in data collection, analysis, authored a portion of the article, and provided feedback and edits on the drafts. AHP and WP were involved in study conceptualization, provided feedback on design, wrote a portion of the article, and provided their feedback and edits.

## ACKNOWLEDGMENTS

We would like to thank all of our participants for their contributions to this study. We also acknowledge the efforts and support of the following research team members: Barry Aaronson, Christine Chan, Kate Nickel, Alex Filipkowski, Cory Brown, Kelsey Aiello, Rashmi Elera, Calvin Apodaca, Maher Khelifi, and Yoojung Kim.

## CONFLICT OF INTEREST STATEMENT

None declared.

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