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PATIENT SAFETY & MEDICAL LIABILITY

Patients as Partners in Learning from Unexpected Events

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Importance. Patient safety experts believe that patients/family members should be involved in adverse event review. However, it is unclear how aware patients/family members are about the causes of adverse events they experienced.

Objective. To determine whether patients/family members interviewed could identify at least one contributing factor for the event they experienced. Secondary objectives included understanding the way patients/family members became aware of adverse events, the types of contributing factors patients/family members identified for different types of adverse events, and recommendations provided by patients/family members to address the contributing factors.

Design. We interviewed patients/family members using semistructured interviews to understand their perceptions about why these adverse events occurred. The adverse events occurred between 1991 and 2014.

Setting. Participants described adverse events that occurred in various types of health care organizations (i.e., hospitals, ambulatory facilities/clinics, and dental clinics).

Participants. We interviewed 72 patients and family members who each described a unique adverse event. Eligibility requirements were that patients/family members spoke English or Spanish and were aware of an adverse event that happened to them or a loved one.

Intervention(s) for Clinical Trials or Exposure(s) for Observational Studies. N/A.

Main Outcome(s) and Measure(s). The main outcome was determining whether patients/family members could identify at least one contributing factor they perceived as related to the adverse event they described.

Results. Each participant identified at least one contributing factor and on average identified 3.67 contributing factors for their event. The most frequently mentioned contributing factors were Staff Qualifications/Knowledge (79 percent), Safety Policies/Procedures (74 percent), and Communication (64 percent). Participants knew about the contributing factors from personal observation only (32 percent), personal reasoning (11 percent), personal research (7 percent), record review (either their own medical records or reports they received in their own investigation; 6 percent), and being told

by a physician (5 percent). Finally, patients/family members were able to provide recommendations that address each of the nine contributing factors we examined.
Conclusions and Relevance. Patients/family members identified contributing factors related to their adverse event. Given that these contributing factors might not be known to health care organizations because most participants stated that they were not involved in the analysis process, opportunities for organizational learning from patients are potentially being missed. Health care organizations should interview patients/family about the event that harmed them to help ensure a full understanding of the causes of the event.
Key Words. Learning, contributing factors, patients, family, events

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Health care organizations are beginning to recognize that information learned from the patient and family during the error disclosure process may be invaluable for event analysis and prevention of recurrences (Zimmerman and Amori 2007; Etchegaray et al. 2014; National Patient Safety Foundation, 2015). Patients and family members may possess valuable information for organizations seeking to understand the contributing factors of adverse events because (1) patients or family members might be key witnesses to the event and therefore could provide critical insights about what took place; (2) the patient might be the only person who knows about a communication breakdown between him/herself and a provider (e.g., patient told the nurse of an allergy to a specific medicine that was subsequently given; Millman et al. 2011); and/or (3) patients/family are often the single connecting thread of continuity between various providers and specialists. When an organization fails to ask patients and family members about factors contributing to their event, potentially valuable information from them is lost and not considered in the event analysis.

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Although research suggests that patients are oftentimes aware of many aspects of the events they experienced (Agoritsas, Bovier, and Perneger 2005; Surbonne, Rowe, and Gallagher 2007; Weissman et al. 2008; Zhu et al. 2011), there is much to learn about how to involve patient and family members in a manner that is meaningful and effective for all concerned parties (i.e., patient, family, provider, risk management, etc.). For example, we previously found that clinicians and administrators were supportive of involving patients/family members in the event analysis process but were unsure how to operationalize and implement this idea (Etchegaray et al. 2014). We also found skepticism from some clinicians and administrators about whether patients would provide useful information about their event because of unfamiliarity with hospital processes and/or technical jargon (Etchegaray et al. 2014). Such skepticism and lack of research motivated this study to determine what patients/families know about contributing factors for their events. By determining whether patients/family members can identify contributing factors, we aimed to address a research gap by querying patients about the adverse events they experienced *and* the contributing factors of those events (Van den Bemt et al. 1999; Weingart et al. 2005, 2007; Fowler et al. 2008; Friedman et al. 2008; Schwappach 2008; Weissman et al. 2008; Daniels et al. 2010, 2012; Hasegawa et al. 2011; Zhu et al. 2011; Saranto et al. 2012; Ward and Armitage 2012; The Patient Safety Organization Privacy Protection Center [PSOPPC] 2016).

To better understand patient and family member perceptions of adverse events, we had a primary and three secondary research questions. Our primary research question was as follows: (1) Can patients/family members identify at least one contributing factor they perceived as being a cause for their event? To more fully understand the value to postevent learning of information patients/families might be able to share with health care organizations after events, we also sought to determine (2) how they become aware of the contributing factors related to their event; (3) whether some contributing factors were perceived by patients/family members to occur more frequently for certain types of events; and (4) their recommendations to address these contributing factors.

METHODS

Participants

We conducted 72 interviews with patients and family members who reported that they or their loved one experienced an adverse event while in the

hospital. All of the events were unique from each other (i.e., each participant discussed a different event from all other participants). Participants were recruited through various methods. First, risk managers from participating institutions located in Texas (i.e., Houston and Austin metropolitan areas) either (1) provided us names, phone numbers, and email addresses of interested participants or (2) provided our contact information to potential participants and asked them to contact us directly for more information. Second, we sent letters to patients who had closed medical malpractice claims through one of The University of Texas (UT) System health institutions. Third, we used flyers, emails, and phone calls to recruit patients/families who were involved with Consumers Union, the Connecticut Center for Patient Safety, and ProPublica—all nonprofit organizations that provide a voice for patients/families who experienced medical errors and harmful events. Table 1 documents the number of participants from each type of referral source.

Eligibility Criteria

Patients/family members were eligible to participate if they spoke English or Spanish, experienced a harmful event during their hospitalization or clinic care, and were willing to talk about their story. Family members or significant others that were present during the event were also eligible to participate on behalf of the patient. For patients under 18 years of age, the parents were contacted for participation. We did not interview patients who were currently involved in litigation proceedings related to the event.

Procedure

We developed and used an interview guide to provide measurement consistency across interviews. The interview guide consisted of six sections. First, we established rapport with the participant by asking some icebreaking questions.

Table 1: Number of Participants throughout Recruitment Process

Participant Group	*Total Contacted*	*Expressed Interest in Participating*	*Agreed to Participate*	*Eligible and Interview Completed*
Texas hospitals	178	14	12	9
UT system	125	10	9	8
Patient advocacy groups	197	91	85	55

Second, we asked the participant to describe the event and the harm experienced from the event. Third, we asked the participant to describe what he or she thought contributed to the event in an unprompted way (Section Three). Fourth, we prompted the participants about nine specific contributing factors with definitions and asked them if these factors were related to the event (Section Four). Fifth, we asked participants how and when patients and families would like to participate in analyzing the event that impacted them. Sixth, we concluded the interview by asking participants to provide any additional details about the event and/or contributing factors that we had not discussed. The contributing factors used in Section Four were based on AHRQ's Common Format for reporting medical errors and other adverse event reporting tools referencing several characteristics of personnel and/or environments that facilitate unsafe conditions (Agency for Healthcare Research and Quality, 2016). Hospitals use these contributing factors when conducting a Root Cause Analysis after an adverse event. The nine factors, their definitions, and the examples we provided to participants for the prompted questions are included in Table 2.

We obtained IRB approval from UT Health prior to conducting the interviews. Participants provided informed verbal and/or written consent prior to the interviews. Each participant was assigned a unique identifier in order to maintain anonymity of the participant. The interviews were conducted via teleconference by two trained research assistants with each session lasting between 30 and 120 minutes. The interviews were audio recorded and uploaded to a secure password-protected site for transcription purposes. Thereafter, the researchers verified the transcript verbatim and removed all names and identifying information of the participant/families, clinicians, and hospital administrators from the transcript. The transcripts were then uploaded into the qualitative research software, *ATLAS.ti (v.7)*, for analysis.

Three researchers (A. A., E. S., M. O.) developed an initial codebook based upon the research questions and interview guide. They coded three interviews together to reach consensus about the meaning of each code. The next six interviews were coded by each researcher separately and discussed to identify additional codes and further refine the definitions. The codebook was reviewed with the first (J. E.) and last author (E. T.) to reach final consensus of the codes, definitions (e.g., event types), and instructions for usage. The remaining 63 interviews were coded individually with 10 percent of the interviews being double-coded to ensure reliability between coders. After all transcripts were coded, the research team met to discuss the results and resolve any discrepancies or questions about coding.

Table 2: Contributing Factors and Definitions

Contributing Factor	*Definition*
Environmental	An identifiable element in the physical setting of a hospital or regulatory environment that affects the survival and operations of a hospital and/or health care facility (i.e., conditions of room, water spills, lighting, furniture placement, noise).
Staff qualifications/knowledge	Any factor related to lack of knowledge, skills, and/or qualifications pertaining to medications, patient diagnoses, training, competency, patient care, and level of experience among hospital staff.
Safety policies and procedures	Any factor related patient standard of care surrounding the clarity and/or lack of hospital policies, clinical protocols, and/or safety regulations/procedures.
Supervision/support	Any factor related to lack of and/or inadequate clinical or managerial supervision of hospital staff and other health care professionals (i.e., radiologist, infection disease specialist).
Equipment/device	Any factor related to the use, design, maintenance, availability, and/or function of medical equipment/devices used during patient treatment, patient care, and surgical and nonsurgical procedures/operation during hospitalization.
Documentation/charting	Any factor related to incorrect documentation and/charting medical information and diagnoses in terms accuracy, legibility, availability, completeness of medical documentation, and updated information from the patient medical history.
Communication	Any factor related to the exchange of verbal or written medical information among the staff, patient, family member, and/or other health care professional that have a direct effect on patient care and survival.
Human	Any factor related the inability of hospital staff to carry their work and/or assigned task such as being stressed, distracted, fatigue, inattentive, inability to think, or having other health issues that directly or indirectly affect patient care.
Staffing	Any factor related to staff availability which includes understaffing and right-type of staff for patient care in a hospital and/or health care facility.

Analysis

Using a mixed methods approach, we conducted a quantitative analysis of the numbers and types of factors identified by patients and families and a qualitative (thematic content) analysis of their recommendations for addressing contributing factors. For quantitative data, we examined frequencies of contributing factors, type of events, and how patients/families became aware

of contributing factors. Patient/family recommendations for addressing the contributing factors were analyzed using qualitative methods as described above.

RESULTS

Demographics

Participants included roughly half patients ($n = 37$) and family members ($n = 35$). More than half of the participants were female ($n = 56$) and 46 years or older ($n = 58$). Participants were primarily Caucasian ($n = 55$) or African American/black ($n = 8$) and most identified themselves as members of a consumer interest group ($n = 55$). Most participants ($n = 40$) had experienced their event in the last 5 years (between November 2008 and April 2014). About 22 participants experienced their events between 5 to 9 years ago with 10 participants experiencing their events more than 10 years ago.

Identification of Contributing Factors (Research Question # 1). All participants identified at least one contributing factor for the event they described based on the prompted questions in Section Four of the interview guide. The average number of contributing factors identified by participants was 3.67 with most participants identifying two or four factors. All contributing factors were identified by at least some of the participants (Table 3).

Participants who felt staff qualifications and knowledge ($n = 57$ (79.2 percent)) contributed to their event noted issues such as the staff's lack of training or experience with medications, procedures, or infection control practices. Many participants felt residents and young or new doctors or nurses did not have enough knowledge or experience, or that their providers were acting out of their scope of practice. Most participants learned about their providers' qualifications in multiple ways and through their own reasoning, but some participants directly observed instances where their providers' lack of knowledge led to a harmful event. For example, one participant's daughter had a bad reaction to a medication a doctor prescribed, but the nurses in charge had no knowledge or experience with the drug and accidentally overdosed her. When the patient had a severe reaction and the physician could not be reached, the nurses did not know why it occurred or how to fix the problem and had to reach out to the participant for her personal research about the medication.

Table 3: Contributing Factors by Type of Event

Contributing Factor	*All Patients (n = 72)*	*Infection (n = 20)*	*Medication Error (n = 13)*	*Diagnostic Error (n = 11)*	*Surgical Error (n = 9)*	*Procedure Error (n = 8)*	*Inappropriate Care (n = 8)*	*Equipment Error (n = 2)*	*Fall (n = 1)*
No. of patients identifying this contributing factor (% of group who identified this contributing factor)									
Communication	46 (64)	11 (55)	9 (69)	10 (91)	4 (44)	4 (50)	7 (88)	1 (50)	0 (0)
Documentation/charting	11 (15)	0 (0)	4 (31)	4 (36)	2 (22)	0 (0)	1 (13)	0 (0)	0 (0)
Environment	17 (24)	14 (70)	1 (8)	0 (0)	0 (0)	0 (0)	1 (13)	0 (0)	1 (100)
Equipment/device	14 (20)	8 (40)	0 (0)	0 (0)	2 (22)	1 (13)	1 (13)	2 (100)	0 (0)
Human factors	33 (46)	14 (70)	3 (23)	5 (45)	3 (33)	5 (63)	2 (25)	1 (50)	0 (0)
Safety policies/procedures	53 (74)	17 (85)	12 (92)	7 (64)	5 (56)	5 (63)	5 (63)	1 (50)	1 (100)
Staffing	17 (24)	10 (50)	2 (15)	1 (9)	1 (11)	1 (13)	2 (25)	0 (0)	0 (0)
Staff qualifications/knowledge	57 (79)	18 (90)	11 (85)	8 (73)	6 (67)	7 (88)	5 (63)	2 (100)	0 (0)
Supervision/support	14 (20)	3 (15)	2 (15)	2 (18)	2 (22)	1 (13)	4 (50)	0 (0)	0 (0)

> And I was like, "What's going on?" And [the nurse] says right to me, "I'm not sure. We're not familiar with—we don't normally use that drug on this floor. We don't have any information on it." I'm like, "What do you mean you don't know?" . . . And I was just like, "Somebody tell me what is going on now." And the nurse that was caring for her said, "I hate to do this. We don't have any information on the drug. Can we use your information that you photocopied?" . . . I said, "I don't even know what year that medical journal I pulled that from, I don't know any of that." And they're just like, "Well, that's the only information we have right now." (Interview 67)

Safety policies/procedures was the second most frequently mentioned contributing factor (n = 53 (73.6 percent)). Many participants either observed or used their own research or reasoning to deduce that (1) their caregivers did not follow hospital policies and protocols or 2) the health care facility lacked policies/protocols that would have prevented the event from occurring. Verifying or confirming these policies procedures was beyond the scope of this study, but some of the clearest and most universal examples that participants provided included (1) a lack of giving informed consent before beginning a treatment or procedure and (2) a lack of compliance with sanitation procedures such as handwashing. One participant witnessed several violations of the hospital's infection control policies, which he believes contributed to his postoperative MRSA infection.

> At one point [the physician] was examining me, and I noticed that he had walked over to the sink and he just sort of wiggled his fingers in front of the water and made this sort of perfunctory hand washing, but he didn't really. And so, then he started pushing his finger down into my open wound, and I said to him, you know, "Shouldn't you have washed your hands before your treating this wound?" And he said, you know, "My hands aren't any dirtier than your infection." (Interview 7)

In addition to staffing qualifications knowledge and safety policies/procedures, which were the two most frequently mentioned contributing factors, participants mentioned communication (n = 46 (64 percent)), human factors (n = 33 (46 percent)), environment (n = 17 (24 percent)), staffing (n = 17 (24 percent)), equipment/device (n = 14 (20 percent)), and supervision/support (n = 14 (20 percent)).

How Patients Learned about Contributing Factors for Their Adverse Event (Research Question # 2). Participants knew about the contributing factors primarily from personal observation only (32 percent). Other ways that participants learned about contributing factors were from deductive reasoning (11 percent),

personal research (7 percent), records (either their own medical records or reports they received in their own investigation; 6 percent), and being told by a physician (5 percent), nurse (2 percent), or other staff (1 percent). Many participants (23 percent) learned about contributing factors from more than one of the above-mentioned ways.

Communication and human factors were the two contributing factors that had the largest percentage of participants that identified these factors through personal observation. The observations patients could make in these categories were much more straightforward than the observations made for staff qualifications/knowledge and safety policies/procedures. For example, patients witnessed and experienced several types of communications issues: patients reported they were not listened to or ignored when voicing concerns or providing information that was contrary to a clinician's decisions, not given answers to their questions or given misinformation, or witnessed ineffective and inaccurate information exchanges between clinicians and health care teams. For example, one participant recalled a conversation with her physician when she attempted to ask questions and voice concerns about a medication the physician wanted to prescribe that was similar to others she was allergic to. The physician prescribed the medication anyway despite the patient's urgings and the patient took the medication which began a chain of adverse events that caused her permanent harm.

> He had decided what was wrong with me, without listening to me. When I was telling him that I can't take—we got into an argument over whether or not I was going to take it. I kept telling him that my body doesn't tolerate it . . . And he told me that he's the doctor . . . he knows how to be a doctor better than I do. (Interview 66)

Patients witnessed a variety of human factors issues, including greed, anger, and one upsmanship, which varied from our conceptualization of human factors. They also witnessed several human factors issues that might not necessarily be known by the hospital during an event investigation. Patients noticed that the staff was overworked, overburdened, and stressed—they noticed the high number of patients and tasks providers were expected to tend to and the little time they were able to spend with each patient—this caused them to seem hurried and take short cuts, rush through tasks, or do them minimally. Patients saw their care providers become interrupted, distracted by cell phones, or lose focus as they neared their shift's end time. Patients also saw providers working when they were sick, working long hours, and working on very little sleep. One participant witnessed several of these

issues which she believed inhibited her son's health care team's ability to recognize the developing complications from his surgery which ultimately led to his death.

> The intern just always looked exhausted and when I, you know, looked through the chart I realized that she had been on duty for well over 24 hours. The nurses were—yes, they were distracted trying to get ready for inspection and so were very focused on that rather than on patient care. And everyone else who came through. The pain management team, I would say were—they were focused on each other. They were a bunch of young kids flirting with each other. There was just a lot of—and the team, the team of students and residents, you know they were sort of barreling in and out. I didn't even realize who they were at that point. They were not paying much attention to anything because they were just trying to get through it as fast as they could. (Interview 13)

Frequency of Contributing Factors by Event Type (Research Question # 3). The most frequently identified contributing factor varied depending on the type of event. Communication was the most frequently identified factor for participants discussing diagnostic errors and inappropriate care; safety policies/procedures was the most frequently identified factor for medication errors; staff qualifications/knowledge was the most frequently identified factor for infections, procedural errors, and surgical errors (Table 3).

Patient/Family Recommendations for Addressing Contributing Factors (Research Question # 4). Patients and family members were able to provide recommendations that address each of the nine contributing factors we examined. Some contributing factors had a small number of recommendations for improvement—such as environmental factors, equipment/device, and staffing, had one recommendation each—while others, such as communication and safety policies/procedures, had many recommendations.

DISCUSSION

Every patient/family member we interviewed was able to identify at least one contributing factor that they perceived as contributing to the event they experienced. All but two interviewees identified at least two contributing factors, and on average participants identified more than three contributing factors that they perceived as contributing to their event. These findings suggest that rather than anchoring on one specific cause for their event, patients/families

are able to consider and identify multiple contributing factors. In total, participants identified all nine of the contributing factors we included in the interview script. Importantly, almost one-third of interviewees were aware of the perceived contributing factors based on their own personal observation. Therefore, a sizable proportion of patients/families have information they can share based on direct experiences with their care, and this information is potentially lost if the hospital does not try to understand the patient/family perspective about the event. Furthermore, our results show that patients/family members are motivated to understand the causes of their events, with many using multiple sources of information, deductive reasoning, and personal research to understand what happened.

We also discovered that patients and families attributed certain contributing factors more frequently to certain types of events. For example, events related to diagnostic errors and inappropriate care were most often linked with communication as a contributing factor, while medication errors were linked with the contributing factor of safety policies/procedures. This finding refutes previous skepticism about whether patients/families can provide valuable information about hospital processes. Additionally, we found that participants identified contributing factors that logically made sense for events. For example, no participants claimed that the documentation/charting factor was responsible for causing their infection. To proactively partner with patients in the future to prevent errors, these findings suggest that patients should be empowered to speak up about these contributing factors so that they can notify providers if they see these factors impacting the care they or their loved one receives.

The fact that patients and families witnessed specific instances of factors contributing to their harmful events should solidify their place at the table in the analysis of these harmful events. They are important stakeholders who might be able to provide guidance as hospitals prioritize their quality improvement efforts. Furthermore, inviting patients and families as key stakeholders is a sign of respect to them and demonstrates institutional commitment to transparency and partnership.

Additionally, our results show that patients and family members are able to provide substantive recommendations for different contributing factors. For example, they recommended better handwashing, sterilization, and handoffs for addressing the contributing factor of safety policies and procedures. We were intrigued that patients and families interpreted the phrase "human factors" more broadly than is traditionally used in safety science because they mentioned provider characteristics such as greed, anger, and one-upsmanship

as human factors contributing to their events. Should health care organizations involve patients/families in the analysis of their events, it is important that these organizations establish clear and consistent definitions for contributing factors.

Generalizability of our findings may be limited because most of our participants were affiliated with a consumer interest group, which might mean that they are more aware of safety science principles and contributing factors. Furthermore, we do not know from other sources (i.e., risk management or providers involved in the event) if the contributing factors identified by the patients were in fact important contributors to their adverse event and whether these were the same contributing factors identified by clinicians or novel ones. Future studies comparing patient-identified contributing factors with health care organization identified factors will help better delineate what kinds of information patients can uniquely contribute. Future research needs to examine whether patients and families not affiliated with consumer interest groups are as aware of contributing factors as our participants, and whether including patient perspectives about the causes of their events can better inform efforts to improve safety for future patients. Additionally, future research is needed to determine how patient/family perceptions align with the results from root cause analyses and other standard hospital-based safety procedures.

Taken together, our results show that patients/families are willing to share their perceptions about what contributed to the event that harmed them and frequently are aware of these factors through personal observation. Given these results and the compelling and growing movement toward more patient engagement and transparency (Mazor et al. 2012), patient/family input about the events that harmed them should be solicited, and organizations should determine if it can be used to improve patient safety.

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of this article:

Appendix SA1: Author Matrix.