A patient-initiated voluntary online survey of adverse medical events: the perspective of 696 injured patients and families

Frederick S Southwick,[1] Nicole M Cranley,[2] Julia A Hallisy[3]

▸ Additional material is published online only. To view please visit the journal online (http://dx.doi.org/10.1136/bmjqs-2015-003980).

[1]Department of Medicine, University of Florida, Gainesville, Florida, USA
[2]Department of Behavioral Science and Community Health, College of Public Health and Health Professionals, University of Florida, Gainesville, Florida, USA
[3]Empowered Patient Coalition, San Francisco, California, USA

Correspondence to
Dr Frederick S Southwick, Department of Medicine, University of Florida, 1600 Archer Rd, Box 100277, Gainesville, FL 32610, USA; southf@epi.ufl.edu

Received 19 January 2015
Revised 20 May 2015
Accepted 30 May 2015
Published Online First 19 June 2015

▸ http://dx.doi.org/10.1136/bmjqs-2015-004573

To cite: Southwick FS, Cranley NM, Hallisy JA. *BMJ Qual Saf* 2015;**24**:620–629.

ABSTRACT

Background Preventable medical errors continue to be a major cause of death in the USA and throughout the world. Many patients have written about their experiences on websites and in published books.

Methods As patients and family members who have experienced medical harm, we have created a nationwide voluntary survey in order to more broadly and systematically capture the perspective of patients and patient families experiencing adverse medical events and have used quantitative and qualitative analysis to summarise the responses of 696 patients and their families.

Results Harm was most commonly associated with diagnostic and therapeutic errors, followed by surgical or procedural complications, hospital-associated infections and medication errors, and our quantitative results match those of previous provider-initiated patient surveys. Qualitative analysis of 450 narratives revealed a lack of perceived provider and system accountability, deficient and disrespectful communication and a failure of providers to listen as major themes. The consequences of adverse events included death, post-traumatic stress, financial hardship and permanent disability. These conditions and consequences led to a loss of patients' trust in both the health system and providers. Patients and family members offered suggestions for preventing future adverse events and emphasised the importance of shared decision-making.

Conclusions This large voluntary survey of medical harm highlights the potential efficacy of patient-initiated surveys for providing meaningful feedback and for guiding improvements in patient care.

Despite the efforts of many dedicated professionals, modern healthcare continues to endanger the lives and well-being of many patients. The incidence of avoidable medical harm remains high in healthcare settings.[1] The consequences of medical harm are profound, and many patients and family members have described their personal stories on websites[2–10] and in books.[11–20] Previous work comparing patient reports of medical errors to hospital records reveal that patients are able to accurately identify preventable adverse events, and many of the events they report are not captured by the hospital incident reporting system or recorded in the medical record.[21–23]

Systematic patient-initiated data collection on medical errors is rare. As patients[24] and family members[25 26] of patients who have been harmed by preventable adverse events, we wanted to more broadly and systematically capture the patient perspective on the issues surrounding adverse medical and surgical events, as well as document the perceived impact these events have on patients and their families. To this end we created and administered a voluntary online survey (see online supplementary file).

METHODS

Survey

This voluntary survey was posted on the Empowered Patient Coalition (EPC) website (see online supplementary file) and was administered from January 2010 to November of 2013 using a password secure version of Survey Monkey that included both quantitative and open-ended qualitative question formats. EPC volunteers created the quantitative survey based on the categorisation of adverse medical errors by the Office of Inspector General (OIG) in their March 2010

report.[27] Additional questions were added to assess the personal impact of adverse events on patients and their families. These questions were based on the EPC volunteers' personal experiences and those of fellow patients and families. The survey is available online https://www.surveymonkey.com/r/?sm=p7JEPTM4TYa%2bxOAO1GlLMQ%3d%3d

Participants

Participants were first recruited via email using the email contact list of the Safe Patient Project, a Consumers Union sponsored organisation that recruits patients and patient advocates to work to improve the safety of medical care. Subsequently recruits were obtained through the EPC website, an organisation founded in 2009 as a consumer and advocate-led effort to inform, engage and empower the public to assume a greater role in their own medical treatment, and to become a driving force for meaningful healthcare reform. The coalition is a 501(c) charitable organisation.[26]

Respondents were predominantly from the USA (681/696) and from every state except North Dakota. The number of respondents closely correlated with each states population (r=0.966, figure 1A) and encompassed patients ranging from age 2 to 90 years (mean age 54.9±20 SD) (figure 1B). Of those who filled in the male/female category, more females reported adverse events (n=394) than males (279). Patients (346) and relatives (332) primarily filled out the surveys, the remaining respondents being friends (10), healthcare professionals (6), a patient advocate and a pastor. The majority of reported events occurred within the 5-year intervals of 2001–2005 (n=169) and 2006–2010 (n=307), but extended from 1972 to 2013 (figure 1C).

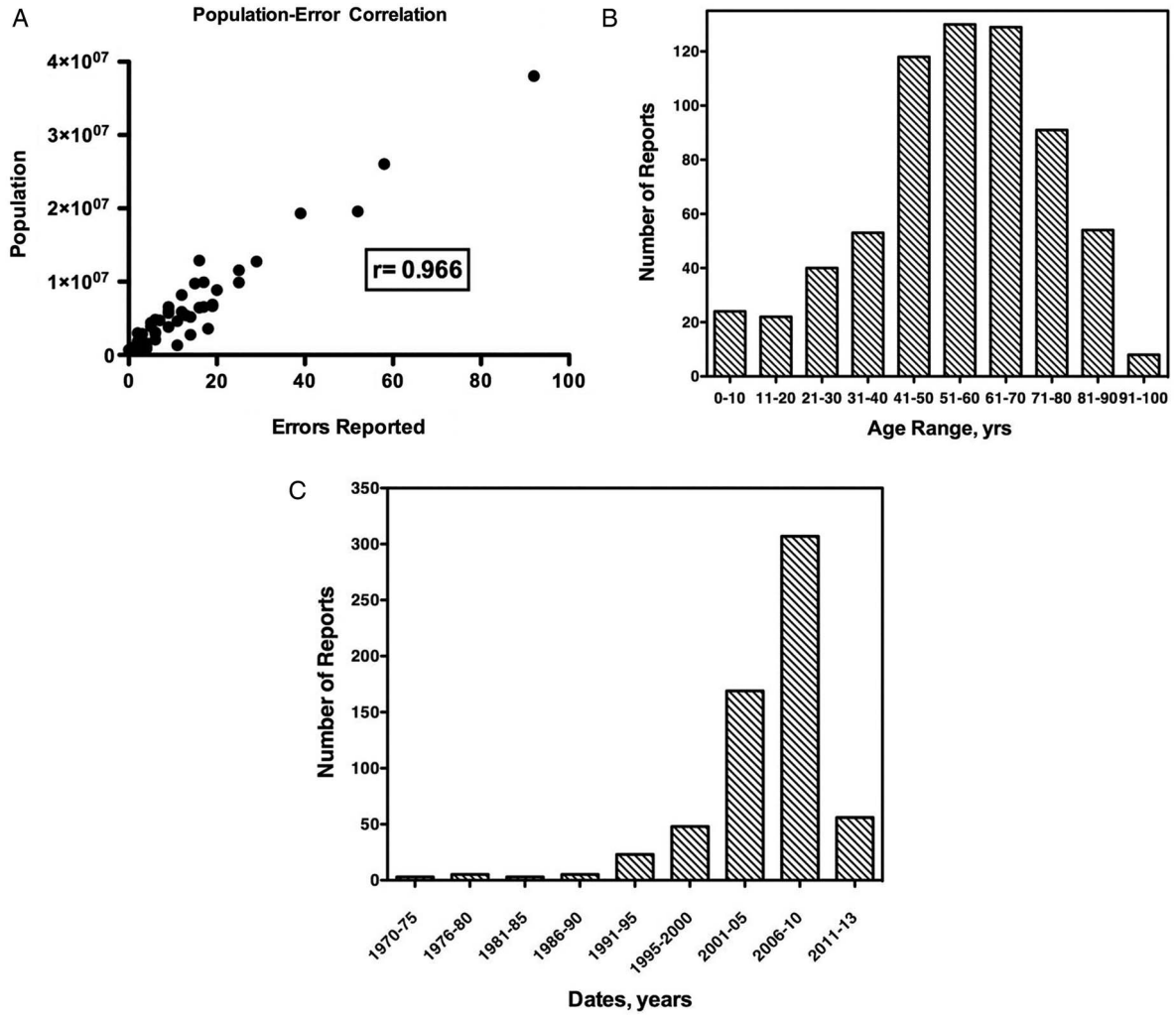

Figure 1 (A) Plot of state population versus number of errors reported per state. With one exception, North Dakota (one of the three least populated states), reports originated from every state in the USA, and the number of error reports closely correlated with the population of each state (r=0.966) (see table 1). (B) Bar graphs showing the age distribution of harmed patients. The ages of harmed patients ranged from under 2 to over 90 years with the peak number of cases being seen in the age ranges of 41–50 years (118), 51–60 years (130) and 61–70 years (129). (C) Bar graphs showing the distribution of reported cases over 5-year intervals. The dates ranged from 1972 to 2013, with the majority of cases being reported within the 5-year intervals of 2001–2005 (n=169) and 2006–2010 (n=307).

Table 1 Categorisation and distribution of adverse medical events

Category	Per cent	Number
Failure of diagnosis or treatment	30.0	541
Surgical-related or procedure-related complications	24.5	442
Healthcare-associated infections	22.5	406
Adverse medication event	17.7	320
Miscellaneous	5.3	96
Total	100	1805

Percentages were calculated using the total number of events as the denominator.

Measurement

The quantitative section of the survey allowed respondents to place their perceived adverse events into specific categories as defined by previous surveys.[27] Examples of quantitative survey questions are shown here:

Check all that apply:

1. adverse surgical procedures—unintentional cut, puncture or tear
2. infections—pneumonia, urinary tract infection, sepsis
3. adverse medication events—overdose, given medication that was not prescribed for him/her or was intended for another patient, medication prescribed to which the patient was known to be allergic.

Questions regarding infections were included in both the section related to 'surgical-related or procedure-related errors' and 'hospital-associated infections' to assure that respondents were given every opportunity to be as specific as possible in identifying and classifying healthcare-associated infections.

Respondents were also given the opportunity to provide a written narrative regarding the incident and any additional comments or suggestions for how the incident might have been prevented. This question provided participants an opportunity to share their experiences and make suggestions for improvement. All narratives were thoroughly screened for any identifying information prior to analysis.

The narrative transcripts were read and reviewed by all three authors. One author (NMC) performed the coding, applying open coding methods to identify emergent themes and creating a codebook that was repeatedly discussed among the authors. The narratives were closely read and coded line by line. All authors used 'memoing' techniques to create an ongoing audit trail to document study findings and to track methodological and substantive decisions made during the analysis.[28] The memos served to record the thought process during coding and analysis. The authors met regularly to discuss emerging themes and ideas. Any differences of opinion regarding the meaning of respondent narrative was discussed and resolved among the authors and additional outsider reviewers. All coding was conducted in QSR International's NVivo 10 qualitative data management software.[29] As more narratives were analysed, codes were grouped into new and refined thematic categories by applying constant comparative analysis.[30] This process continued until saturation had been reached.[28 30]

RESULTS

There were 696 participants who filled out the quantitative survey. Four hundred and fifty participants also provided written narratives that ranged from just a few words to several pages. Nearly half of the narratives were from patients and the remainder primarily from family members. The majority of family narratives indicated that their family member had died.

Our results begin with the quantitative findings followed by descriptions of the major themes identified in our qualitative analysis of open narratives. Each theme is accompanied by representative quotes.

Adverse event categories and relative frequency

As shown in table 1, the leading category of error reported by patients was failure in diagnosis and treatment. Further breakdown of this category revealed the leading event (subcategory) was a delay in diagnosis and treatment. Misdiagnosis was another frequent event, as was failure to rescue a patient whose clinical condition was worsening. The second most common category was surgical or procedural complications. Wrong site surgery was surprisingly common in our survey (4.3%), as were foreign objects left in the patient (3.6%). Hospital-associated infections were the third most common category, sepsis being the most frequently reported complication, followed by postoperative infections, *Clostridium difficile* intestinal infection and urinary tract infections. Medication errors were the fourth major category in our survey. It is of interest that a significant percentage (12.8%) reported receiving medications that they were known to have had an allergic reaction to in the past.

Deficient provider and system accountability

A high percentage of responses (90%) in the quantitative survey expressed concern over a lack of provider accountability. Patients and families indicated a belief that their health systems and providers often failed to respond appropriately to their suffering. As outlined in figure 2A, the responses included insistence by the provider that the care had been appropriate despite the family's assessment to the contrary (48%), denial of responsibility (47%), a secretive approach combined with an unwillingness to include the family in the investigation (40%). One-third of respondents reported that the healthcare providers who initially

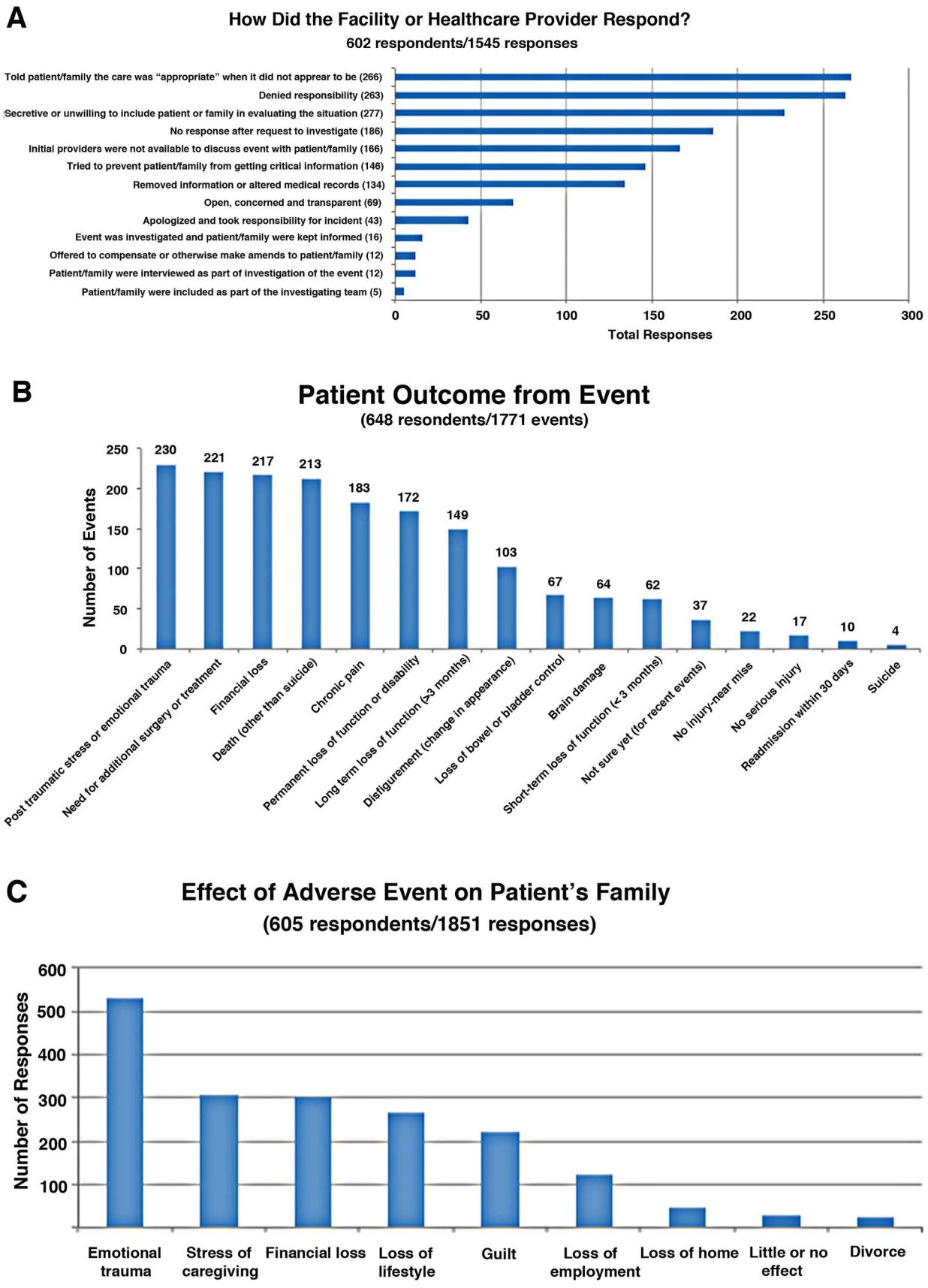

Figure 2 Bar graphs showing patient and family assessment of the impact of and responses by healthcare systems to adverse events. (A) Responses of the healthcare systems; (B) patient impact; (C) family impact.

cared for them refused further communication following the adverse event. These quantitative findings were bolstered by patient and family narratives expressing a sense of abandonment by the physicians and the system that they had initially trusted. One family member's statement captured this common concern:

> The lack of concern for the victim's and their families was far worse for all of us than [if they] had admitted [a] mistake and apologized, which never happened since they would never admit fault.
>
> *This family member was a healthcare provider whose mother died of sepsis caused by a hospital-acquired vancomycin-resistant enterococcus central-venous line infection.*

Of those who pursued a legal solution only 27% (45/165) reached the settlement phase, and 17% (28/165) received compensation. Previous research has shown that patients would be less upset if the physician explained how the error occurred and apologised.[31] This sentiment was also reflected in several open narratives that expressed a desire for recognition of fault.

> There has to be a manner in how to hold doctors and medical staff accountable for their actions. I don't believe in lawsuits to correct such situations, but there is a great need for improvement.
>
> *This family member's loved one experienced a marked delay in the diagnosis of a brain tumor, an MRI identifying the tumor just prior to the patient's death.*

In addition, a significant number of open narratives (34/450) expressed a desperate need for answers that never came. Patients and families who did have a provider who acknowledged fault and apologised expressed a sense of closure that other respondents did not.

> She [physician] replied, "Of course it was my fault, it was entirely my fault. Who else's fault could it have been?" This made me think the world of her. I didn't take it as an apology, and I didn't think it indicated mistake or negligence. I took it as a statement that my doctor felt responsible for me.
>
> *This patient suffered perforation of her small bowel during elective upper gastrointestinal track endoscopy resulting in sepsis and necrotizing pancreatitis.*
>
> The doctor who treated me apologized and said he missed a blood clot. For that part I was grateful and told him I appreciated his follow-up and honesty and again was admitted to hospital.
>
> *This patient suffered pulmonary embolus that was missed on his first Emergency Room visit.*

Communication failures

Communication failures were characterised into several subthemes, abandonment, disrespect, intimidation and failure to listen. Overall, both patients and family members expressed a lack of communication with healthcare providers. Patients, families and informal caregivers felt that they were not being heard and that their concerns were often not addressed.

> I was complaining about fever and pain since I was at the hospital, and no one paid attention to my symptoms.
>
> *This patient suffered a severe postoperative infection that was not diagnosed for 5 days resulting in a large draining abdominal wall ulcer that persisted for over 2 months.*
>
> The bottom line is that I feel they wrote me off as a hysterical hypochondriac and I am quite certain that is written in his progress notes because the day I brought the little jar of yellow liquid in for my post-op appointment he wouldn't even look at me because he was so angry that I wasn't accepting that all was okay. To this day I have said to others and myself…if I can't get a surgeon to listen to ME, what does the lay-public do?
>
> *This physician underwent sinus surgery that failed to remove an obstructing lesion resulting in continued nasal drainage, and because of the first surgeon's refusal to acknowledge the problem, a second surgeon had to be recruited to perform corrective surgery.*
>
> Care providers need to listen to family members, parents and friends. We know our loved ones better than anyone else. If we tell them something isn't right they should stop and ask us questions. We see the little changes before they become apparent to others.
>
> *This parent watched her child clinically deteriorating on the hospital ward, and despite repeatedly expressing her concerns, rescue was delayed and her child died.*

Some respondents suggested potential physician-level barriers for why concerns were not addressed during their clinical encounters.

> Doctors need to stop thinking of themselves as 'know-it-alls' and listen to what the patient says… doctors need to look at patients as individuals without preconceived notions.
>
> *This patient claims to have received multiple unnecessary tests during her outpatient clinic visit, and did not receive care to relieve her symptoms.*

At times when respondents attempted to convey the nature or severity of their current health status they were disregarded.

> When I told her I felt my throat was closing she took the Red Robinson suctioning device, handed it to my daughter and said, 'suction your mother' and left the room.
>
> *This patient suffered a severe post-operative neck infection, and despite pus draining from her incision, operative intervention was delayed for over 8 hours.*

In some cases, patients said that they were met with hostility when they offered feedback and additional information, or asked questions:

> That's when he got offended. He then slammed his computer shut and sharply yelled, 'I'm done!' I tried to reason with him and explain that I was just trying to help him. Then he yells even louder, 'I don't like people telling me how to do my job!
>
> *This patient had experienced two weeks of severe cough and a severe sore throat interfering with sleep. She was asking if she should receive antibiotics.*

The profound impact of the adverse events

The self-reported, long-term effects of adverse events are summarised in figure 2B. Slightly over one-third reported suffering from serious postevent psychological stress, and for one-third of patients the perceived errors in care proved fatal. One-third suffered significant financial loss, and nearly one-third required follow-up surgery or therapy. Patients were also often left with chronic pain, and/or long-term or permanent loss of function. Respondents noted that family members often experienced emotional trauma (over two-thirds) (figure 2C), and approximately half reported that their family was stressed over caregiving, suffered financial loss and experienced significant loss of lifestyle. Box 1 lists quotes from respondents describing the negative impact of these events. Respondents felt traumatised by providers and no longer trusted them or the health system.

> I now ask for copies of all tests so that I can see the results of tests myself, and (I do) not have to trust that the doctor is telling me the truth.
>
> *This diabetic patient acquired an MRSA skin infection in the hospital and after her doctor told her the infection was cured developed severe MRSA osteomyelitis that resulted in a severe foot deformity.*
>
> I have no trust in the medical profession now. I suspect every Dr. not knowing if they are really being honest and have my best interests at heart.
>
> *This patient suffered avascular necrosis of both hips after her doctor treated her with corticosteroids for her migraine headaches (known to be ineffective therapy).*[32]

Box 1 Respondent descriptions of the impact of the adverse event

- "Trauma, financial loss, depression"
- "Tremendous emotional stress"
- "Chronic pain and total lifestyle change"
- "Very troubled. I can't describe the anxiety"
- "Financial, physical and emotional disaster"
- "Loss of insurance"
- "Horrible fear, upset, confused"
- "I have been made to feel like I wasn't of concern"
- "I tried my best to shield my loved ones from the trauma"
- "Tragic. It tore my family completely apart"
- "We will never be the same"
- "She had three small children at the time of her death"
- "It is difficult to capture the degree of emotional trauma"
- "Great emotional toll"
- "Extensive cost–loss of relationship and communication–isolation"
- "The pain and agony of seeing a wife/mother unable to care for her own needs"
- "It was devastating to watch him die a slow death"
- "It destroyed our lives"
- "Ended up my wife divorced me"
- "Devastation"

Patient suggestions for preventing adverse events

Part of the open narrative request was to offer suggestions for how the adverse event might have been prevented. The majority of respondents made suggestions that fell into three categories: use of protocols, coordination between providers and improved listening. Respondents pointed to systems-level changes that might have prevented the adverse event, especially for those who suffered from infection.

> Just maybe [infections would be reduced] if these health care professionals would not answer their cell phone while examining patients; maybe if they would change gloves consistently between patients and wash their hands completely; just maybe not wear the hospital uniforms out into the street then back into ICU or into the infectious disease unit.
>
> *Concerns of a mother who witnessed her son die of septic shock due Acinetobacter baumannii acquired soon after undergoing renal transplant surgery*

Additionally, some respondents commented on the responsibility of providers to adhere to system-level measures to reduce infections.

> The placement of containers for hand sanitizers, vinyl gloves, vinyl gowns, sinks, etc., are a start, but consistent and conscientious use by all staff is critical.
>
> *The recommendations of a husband whose wife was admitted with chronic venous stasis ulcers that became chronically infected with MRSA in the hospital.*

Patient and families expressed concern with regards to failure of health systems to properly supervise inexperienced physicians:

> No one that day had my medical history nor knew me, I was injured from neglect, inexperience and incompetency.
>
> *This patient was an R.N. who suffered a laceration of her bladder during her caesarian section performed by*

an inexperienced surgical resident who was not being supervised.

Recommendations for improvement were offered by a nurse who lost her prematurely born daughter to a fatal overdose of zinc mistakenly added to her child's hyperalimentation solution. Her comments capture the sentiments of nearly all respondents.

> Initial disclosure and an apology could have given me validation and the feeling of being more empowered, but we did not receive that. We felt abandoned by the hospital, who was 100% responsible for our daughter's death. Their desire to (cover up the error) exceeded their humanity; they treated us as if we had done something wrong and as if we were an inconvenience. The re-current theme I have read through countless articles on medical mistakes and medication errors is that patients and their families often feel powerless, abandoned and deceived by the institution. Families worry that the event that injured their loved one will happen again and that their loved ones death would be in vain. I felt all of this. It was going to the news and speaking out that made me feel empowered. What I encourage healthcare facilities to do is: develop an early disclosure policy. This can take the guesswork of what to do and when to do it. Don't be reactive; be proactive with disclosure.

When patients are injured or die, family members are deeply committed to correcting the problem that led to their loved one's injury or death. They strongly support transparency and open communication as critical conditions for improving patient safety.

Desire for shared decision-making

The final major theme related to patients' requests for shared decision-making and patient empowerment, conditions that they regarded as important for reducing medical errors. Patients and families felt that their opinions and concerns were not considered:

> There was no communication with the family whatsoever. We were there. We should have been included in any decisions.
>
> *This family member's father died following multiple surgical procedures to control a severe postoperative infection.*

Patients felt that they should be treated as experts with regards to their own experiences, but found that this approach was a rarity:

> I think I know my body a lot better than he [the doctor] does. He just didn't listen to me.
>
> *This patient was visiting her new primary care physician for the third time, and when she described her complaints during each visit, she felt he repeatedly ignored them.*

Families too often commented that providers dismissed patient's and family member's concerns:

> Nonetheless, the surgeon literally waved his hand in front of us to 'shush' us, saying he had performed hundreds of bypass surgeries and there was nothing we could offer that could possibly be of use to him.
>
> *This family member was trying to warn the surgeon that her father had suffered recurrent staphylococcal infections making him a high risk for surgery. The surgeon ignored her warning, operated, and her father died of a staphylococcal (MRSA) postoperative infection.*

Patients and their families wanted to partner with their providers and were asking providers to embrace a patient-centred approach to their care.

> I would like staff (mainly doctors, nurses seem to be much nicer) to realize that the patient is stressed. They need information, they need choices and they need the right to control their own treatment (if they are capable) or designate someone to take care of that.
>
> *This patient came to the Emergency Room with pancreatitis. She received insufficient pain medication, her IV infiltrated, and her friend who was trying to serve as her advocate was removed from her room.*

DISCUSSION

The purpose of our nationwide voluntary survey was to relay to healthcare providers and administrators a first-hand quantitative and qualitative view of the impact that adverse medical events has on patients and their families. Our patient-initiated survey confirms the quantitative findings of previous provider-initiated patient surveys suggesting that our survey is likely to be a representative sample of adverse events. In addition to categorising adverse events, we have qualitatively analysed the personal written narratives of 450 injured patients and their family members. Adverse events were often accompanied by a sense that providers and health systems did not feel responsible or accountable for the harm that patients and family experienced. Second, patients and families felt that providers failed to effectively communicate with them both before and after the adverse event, and too often when providers did communicate the interactions were disrespectful. Third, those who had suffered medical harm emphasised the profound emotional, physical and financial impact of these events. In the hopes of preventing similar adverse events from impacting future patients, they offered constructive suggestions for preventing future errors. They encouraged providers to follow infection control and other safety protocols, and to listen and respond when patients or family members express concerns about the patient's medical condition. Based on our

respondents' narratives, such concerns should be regarded as an early warning of a potential adverse event.

As discussed in the introduction, investigators have long recognised the importance of patient surveys and recently British healthcare providers have been attempting to design a valid patient measure of safety in hospitals based on 'think out loud' interviews with patients and short surveys. The key domains they identified were communication, individual factors (eg, provider attitudes and stress), team factors and dignity and respect.[33 34] It is of interest that our qualitative analysis of written narratives also identified communication, individual factors (particularly attitude), coordination of care and dignity and respect as key attributes for a safe and nurturing healthcare system environment. One condition that has not been emphasised in prior patient surveys is the importance patients attribute to shared decision-making. Our narratives reveal that patients and families would like to be part of the medical decision-making process. When a partnership exists between the provider and the patient there is greater understanding and a greater likelihood that management decisions will be tailored to the patient's needs.[35–37]

With regard to dignity, our open narratives revealed that a number of patients and family members regarded healthcare providers as curt and authoritarian, conditions that lead to loss of dignity.[38] Another important issue that relates to dignity and respect was the perceived responses of the healthcare professionals and health system when a patient was injured by an adverse event. When patients are harmed they are asking providers to take responsibility and help them to recover rather than 'deny and defend'.[39] Too often providers are constrained by the prevailing legal system and are instructed to avoid communication with injured patients. However, most patients and families do not understand these mitigating circumstances, and rightfully feel that providers and the system have abandoned them in their time of need. Our narratives reveal that patients and families view the system and the providers as one, and when the system is designed to hide fault the providers are seen as untrustworthy, fuelling the desire to take legal action.[31]

Reports of provider-initiated patient surveys of medical errors suggest that patient surveys can complement health professional incident reporting and chart reviews to identify adverse events, and investigators have recommended that health systems initiate patient surveys of adverse events to more accurately estimate the incidence of medical errors.[21–23 40] A concern that has recently been expressed in a review of patient reports of safety incidents is the fact that all studies to date have been clinician-led. Furthermore, these studies have actively 'solicited' reports from patients, by interview or written survey. None of the study designs to date have allowed patients to spontaneously report patient safety incidents. Finally, the study designs of previously published patient reports are likely to have missed insights from the families of patients who suffered fatal outcomes, thus underestimating the severity of the problem.[40]

We recommend an alternative approach. Why not encourage patients and patient advocates to administer their own surveys as we have done? Patient organisations could be created to initiate surveys both locally and nationally, and the results could serve as the basis for forums where patient suggestions for improvement could be generated. This strategy promises to increase patient belief that preventive measures can be effective,[41] and will increase the voice of the patient in our healthcare systems.

LIMITATIONS

Voluntary patient surveys are inherently biased because respondents represent a self-selected population and their descriptions are self-reported. These narratives and our qualitative analysis represent the patients' and families' perceptions, and given the complexity of care, it is not possible to prove whether or not medical harm was directly attributable to medical errors. Furthermore, we recognise that the many, or even most, providers communicate effectively and empathetically with their patients. Nonetheless these results represent a robust patient-initiated survey that documents the experiences and perceptions of the recipients of medical care, and can provide helpful feedback for providers and healthcare systems.

CONCLUSIONS

Our nationwide patient-initiated voluntary survey consisting of 696 respondents confirms previously published provider-initiated patient surveys with regard to the relative frequency of different categories of medical and surgical errors. Qualitative analysis of 450 written narratives highlights the concerns of patients and families who have experienced adverse events. They perceived a lack of accountability on the part of both caregivers and health systems, and repeatedly commented on poor and at times disrespectful communication both before and after the adverse event. Many described profound suffering, and as a consequence of how they were treated, a loss of trust in their health delivery system and providers. Respondents made a number of suggestions for improvement, and emphasised the importance of patients and families being actively involved in decisions about their care. When working to improve the quality and safety of patient care, patients and providers share common goals. And we recommend that patients be encouraged to become part of the solution by creating local surveys similar to our national survey with the goal of providing meaningful feedback to their community's providers and healthcare delivery systems.

Twitter Follow Frederick Southwick at @FS_Southwick

Acknowledgements We would like to thank the many patients and families who devoted their time to fill out our survey. This qualitative analysis is based on data collected from the survey developed by Helen Haskell and Julia Hallisy of the Empowered Patient Coalition. We acknowledge the support of the Consumers Union Safe Patient Project in the launch of the survey and in the initial public outreach efforts. We thank Mary Ellen Young, PhD, Department of Behavioral Science and Community Health, University of Florida, as well Martha Bojko, PhD and Julia Rosanova, PhD both from the Department of Psychiatry, Yale College of Medicine, for assistance with our qualitative analysis, and Frank Davidoff, MD, Steven Southwick, MD, and John James, for their editorial assistance. This project was approved as exempt by the University of Florida IRB-01, approval number IRB201300839.

Contributors FSS: wrote the manuscript and reviewed the applicable literature, and also assisted in analysing the data. NMC: performed the qualitative analysis of the open narratives using NVivo software under the supervision of Fred Southwick. JAH: designed and administered the survey and collated the survey responses. She also reviewed the manuscript and made suggestions for improvement.

Competing interests None declared.

Ethics approval Institutional review board.

Provenance and peer review Not commissioned; externally peer reviewed.

Data sharing statement The survey is ongoing, and following publication all data in the paper and all subsequent survey results will be shared online through the website http://empoweredpatientcoalition.org/

REFERENCES

1 Kohn LT, Corrigan J, Donaldson MS, *et al*. *To err is human: building a safer health system*. Washington DC: National Academy Press, 2000.
2 Southwick FS. Recovering from a medical error. http://recoveringfromamedicalerror.org/ (accessed 23 Feb 2015).
3 Consumer's, Union. Safe patient project. http://safepatientproject.org/ (accessed 10 Jun 2015).
4 Skolnik P. Citizens for patient safety. http://www.citizensforpatientsafety.org/ (accessed 23 Feb 2015).
5 Corina I. Pulse of New York. http://pulseofny.org/ (accessed 23 Feb 2015).
6 Kenney L. Medically induced trauma support services. http://www.mitss.org (accessed 23 Feb 2015).
7 Leah's Legacy. http://www.leahs-legacy.org/ (accessed 23 Feb 2015).
8 The Niles Project. http://www.nilesproject.com (accessed 23 Feb 2015).
9 Patient Safety ASAP. http://patientsafetyasap.org/ (accessed 23 Feb 2015).
10 The Peggy Foundation. http://peggyfoundation.org/ (accessed 23 Feb 2015).
11 Hallisy JA. *The empowered patient*. San Francisco, CA: Bold Spirit Press, 2008.
12 McIver S, Wyndham R. *After the error*. Toronto, Ontario, Canada: ECW Press, 2013.
13 Gibson R, Singh JP. *Wall of silence: the untold story of the medical mistakes that kill and injure millions of Americans*. Washington DC: Lifeline Press, 2003.
14 Gilbert SM. *Wrongful death*. New York, NY: W.W. Norton & Company Inc, 1997.
15 King S. *Josie's story*. New York, NY: Atlantic Monthly Press, 2009.
16 Mastors P. *Designed to survive: 9 ways an IKEA approach can fix health care and save lives*. New York, NY: Morgan James Publishing, 2013.
17 James JT. *A sea of broken hearts: patient rights in a dangerous, profit-driven health care system*. Bloomington, IN: AuthorHouse, 2007.
18 Torrey T. *You bet your life! The 10 mistakes every patient makes—how to fix them to get the healthcare you deserve*. Minneapolis, MN: Langdon Street Press, 2010.
19 Millenson ML. *Demanding medical excellence: doctors and accountability in the information age*. Chicago, IL: University of Chicago Press, 2000.
20 Southwick FS. *Critically ill: a 5-point plan to cure healthcare delivery*. Gainesville, FL: Southwick Press, 2014.
21 Weissman JS, Schneider EC, Weingart SN, *et al*. Comparing patient-reported hospital adverse events with medical record review: do patients know something that hospitals do not? *Ann Intern Med* 2008;149:100–8.
22 Weingart SN, Pagovich O, Sands DZ, *et al*. What can hospitalized patients tell us about adverse events? Learning from patient-reported incidents. *J Gen Intern Med* 2005;20:830–6.
23 Zhu J, Stuver SO, Epstein AM, *et al*. Can we rely on patients' reports of adverse events? *Med Care* 2011;49:948–55.
24 Southwick FS. Opinion/editorial: losing my leg to a medical error. *New York Times*, February 2013.
25 Southwick F. Who was caring for Mary? *Ann Intern Med* 1993;118:146–8.
26 Hallisy J. The empowered patient coalition. http://empoweredpatientcoalition.org/ (accessed 16 Mar 2015).
27 Department of Health and Human Services, Office of Inspector General. Adverse events in hospitals: national incidence among medicare beneficiaries. http://oig.hhs.gov/oei/reports/OEI-06-09-00090.pdf (accessed 16 Mar 2015).
28 Strauss AL. *Qualitative analysis for social scientists*. New York, NY: Cambridge University Press, 1987.
29 Giles EL, Sniehotta FF, McColl E, *et al*. Acceptability of financial incentives and penalties for encouraging uptake of healthy behaviours: focus groups. *BMC Public Health* 2015;15:58.
30 Strauss A, Corbin JM. *Basics of qualitative research: techniques and procedures for developing grounded theory*. 2nd edn. Thousand Oaks, CA: Sage Publications Inc, 1998.
31 Gallagher TH, Garbutt JM, Waterman AD, *et al*. Choosing your words carefully: how physicians would disclose harmful medical errors to patients. *Arch Intern Med* 2006;166:1585–93.
32 Fiesseler FW, Shih R, Szucs P, *et al*. Steroids for migraine headaches: a randomized double-blind, two-armed, placebo-controlled trial. *J Emerg Med* 2011;40:463–8.
33 Giles SJ, Lawton RJ, Din I, *et al*. Developing a patient measure of safety (PMOS). *BMJ Qual Saf* 2013;22:554–62.
34 McEachan RR, Lawton RJ, O'Hara JK, *et al*. Developing a reliable and valid patient measure of safety in hospitals (PMOS): a validation study. *BMJ Qual Saf* 2014;23:565–73.

35 Mitnick S, Leffler C, Hood VL, *et al*. Family caregivers, patients and physicians: ethical guidance to optimize relationships. *J Gen Intern Med* 2010;25:255–60.
36 Yin HS, Dreyer BP, Vivar KL, *et al*. Perceived barriers to care and attitudes towards shared decision-making among low socioeconomic status parents: role of health literacy. *Acad Pediatr* 2012;12:117–24.
37 Street RL Jr, Richardson MN, Cox V, *et al*. (Mis)understanding in patient-health care provider communication about total knee replacement. *Arthritis Rheum* 2009;61:100–7.
38 Baillie L. Patient dignity in an acute hospital setting: a case study. *Int J Nurs Stud* 2009;46:23–36.
39 Kachalia A, Kaufman SR, Boothman R, *et al*. Liability claims and costs before and after implementation of a medical error disclosure program. *Ann Intern Med* 2010;153:213–21.
40 Ward JK, Armitage G. Can patients report patient safety incidents in a hospital setting? A systematic review. *BMJ Qual Saf* 2012;21:685–99.
41 Schwappach DL. Review: engaging patients as vigilant partners in safety: a systematic review. *Med Care Res Rev* 2010;67:119–48.

Exit this survey

The Empowered Patient Coalition

Report a Medical Event

WELCOME

Most reporting systems for adverse medical events are concerned with collecting information for use by health care providers. The Empowered Patient Coalition survey is designed to answer questions that are important to patients. What procedures are associated with harm? What are the common factors patients see as leading to harm, and how do health care providers respond? This survey is a way for patients to report their experiences as they have lived it, and to know that their report will be counted and added to the voices of other people.

The survey is divided into sections covering various categories of medical adverse events. Answers in the categories can be as brief or as lengthy as you wish. Boxes simply can be checked but we encourage you to use the narrative boxes to share vital details, observations and suggestions. Those who prefer not to fill out a survey can click through and leave a full narrative in the space provided at the end.

If you have had more than one unrelated adverse event or hospitalization, we would appreciate it if you would fill out a separate survey for each event. Adverse events do not have to be recent - events can be reported from any time period.

Unless you explicitly give it to us, we do not collect your computer IP address, contact information, or location. Reports are tallied by state or province where that information is available, and data will be aggregated nationally. With the understanding that this is a voluntary survey with subjective information, we make our findings available at www.EmpoweredPatientCoalition.org.

Please click below to begin the survey and thank you for sharing your experiences.

1. Personal Information

Name:	
City/Town:	
State/Province:	
Country:	
Email Address:	
Phone Number:	

2. May we contact you regarding your survey? (Please be sure to provide contact information)

- Yes
- No

3. State, province, or country where incident occurred

Unspecified location	Maryland	Tennessee
Alabama	Michigan	Utah
Alaska	Minnesota	Vermont
Arizona	Mississippi	Virginia
Arkansas	Missouri	Washington
California	Montana	West Virginia
Colorado	Nebraska	Wisconsin
Connecticut	Nevada	Wyoming
Delaware	New Hampshire	Alberta
District of Columbia	New Jersey	British Columbia
Florida	New Mexico	Manitoba
Georgia	New York	New Brunswick
Hawaii	North Carolina	Newfoundland
Idaho	North Dakota	Nova Scotia
Illinois	Ohio	Ontario
Indiana	Oklahoma	Prince Edward Island
Iowa	Oregon	Quebec
Kansas	Pennsylvania	Saskatchewan
Kentucky	Rhode Island	Northwest Territories
Louisiana	South Carolina	Nunavut
Maine	South Dakota	Yukon

Country or territory outside the United States or Canada (please specify)

4. Year incident occurred

5. Age of patient at time of incident

6. Sex of patient

- M
- F

7. In what size community did the incident occur?

- Very large city (greater than 1,000,000 population)
- Large city (500,000-1,000,000 population)
- Small to mid-sized city (100,000-500,000 population)
- Very small city (50,000-100,000 population)
- Small town or rural setting

(OPTIONAL) Name of city or community

8. What type of medical insurance did the patient have at the time of the event?

- Traditional indemnity- "fee for service"
- PPO (preferred provider organization)
- HMO (health maintenance organization)
- Medicare
- Medicare with a supplemental policy
- Medicaid
- State sponsored insurance
- State "high risk" policy
- County insurance plan
- No insurance/self pay

Other insurance (please specify)

9. Who is making this report?

- Patient
- Relative
- Friend
- Healthcare professional
- Other (please specify below)

(OPTIONAL) If relative or "other," what is your relationship to the patient?

10. If you are reporting an incident that affects you or a loved one as a patient, but you (or the patient) are also a practicing or retired healthcare professional, please specify your occupation.

- Physician
- Registered nurse
- Allied health professional
- Healthcare administrator
- Other

Additional comments

GENERAL MEDICAL INFORMATION

11. For what condition was the patient seeking treatment when the adverse event occurred?

12. (OPTIONAL) what if any chronic or underlying disease did the patient have at the time of the incident? (Examples: cancer, heart disease, asthma or lung disease)

13. Please list the procedure, treatment or surgery associated with the original adverse event.

TYPE OF EVENT

The following sections include questions about different types of adverse events. Several but probably not all categories will be relevant to your event. Please click through the survey and check as many boxes as apply under those questions that pertain to your event.

Narrative comment is always welcome; every question has a comment box for further explanation if you

should so desire. if you would like to leave narrative only, please scroll through to the narrative box at the end of the survey.

PLEASE NOTE: Any events that are criminal in nature, including abductions, assaults, or homicides are NOT to be reported on this form and should be reported to your local police department.

SURGICAL OR PROCEDURE-RELATED ERRORS OR COMPLICATIONS

14. Surgical or procedure-related errors or complications (Check all that apply)

- Blood loss from surgery or other procedure
- Unintentional cut, puncture, or tear of a blood vessel, organ, nerve, or other body part
- Foreign object left in patient after surgery or procedure
- Complications from an implanted medical device (please specify type of device below)
- Complications from organ transplant
- Anesthesia awareness (patient was awake or felt pain while under anesthesia)
- Other anesthesia-related complication
- Burns from a fire on the patient in the operating room (surgical fire)
- Burn during surgery- not associated with a fire
- Surgery performed by resident or other doctor without the patient's knowledge
- Wrong-site surgery or procedure
- Procedure or surgery performed on wrong patient
- Wrong procedure
- Post-operative infection
- Other post-operative complication or problem during recovery (please list below)
- Nerve damage from positioning the patient during surgery (positioning injury)

Other complications/Additional comments

HEALTHCARE-ASSOCIATED INFECTION OR PNEUMONIA

15. Did the patient get an infection or pneumonia while under medical treatment or in a healthcare-related facility? If not, please skip to Question 19.

- Yes (Please answer Questions 16 and 17)
- No (Please skip to Question 18)

16. Healthcare-associated infection or pneumonia (Check all that apply)

- Infection at the site of surgery
- Urinary tract infection associated with a urinary

Other infection following surgery

Sepsis or bloodstream infection

Infected pressure sore or ulcer (bed sore or decubitus ulcer)

Diarrhea caused by intestinal infection (ex: C-diff)

Necrotizing fasciitis (flesh-eating bacteria)

Other Infection or Pneumonia/Additional comments

Infection at site of IV catheter

Infection at site of central line, PICC line or port

Pneumonia that developed while on a ventilator (breathing machine)

Other pneumonia

17. If patient got an infection, please name the bacteria, virus, or fungus involved, if known. (Check all that apply)

Don't know

Achromobacter

MRSA (antibiotic-resistant Staph aureus)

MRSE (antibiotic-resistant Staph epidermis)

VRSA (vancomycin-resistant Staph)

Staph infection (antibiotic resistant)

Staph infection (not antibiotic resistant)

Streptococcus (Strep)

Clostridium difficile (C-diff)

Carbapenem-resistant Enterobacteriaceae (CRE)

VRE (vancomycin-resistant Enterococcus)

E.coli

Enterococcus not specified as antibiotic-resistant

Acinetobacter baumannii

Pseudomonas aeruginosa

Enterobacter

Unspecified gram negative bacteria

Serratia marcescens

Aspergillus or other fungus

Candida or other yeast infection

Klebsiella

Legionella

Other pathogen not listed above (please list below)

Other pathogen/Comments

PROBLEMS WITH MEDICATIONS

18. If patient had a bloodstream infection or sepsis, please specify the origin of the

infection, if known (Check all that apply)

- Don't know
- Nick or perforation during surgery or other procedure
- Infection at the site of surgery
- Pressure sore or ulcer (bed sore)
- IV line
- Central line, PICC line or port
- Urinary catheter
- Back, hip, knee or other joint surgery with implanted hardware
- Back, hip, knee or other joint surgery without implanted hardware
- Perforated ulcer or damage to bowel from medication

Other origin/Additional information

19. Adverse medication events (Check all that apply)

- Overdose
- Epidural or spinal anesthesia error
- Overdose or underdose related to patient-controlled analgesia (PCA pump)
- Medication prescribed to which patient was known to be allergic
- Medication was improperly administered
- Medication prescribed for incorrect purpose or at incorrect dosage
- Drug interaction (medications that should not be used together were given)
- Patient was not given medication that he or she needed to have
- Patient not given adequate medication to control pain
- Patient was prescribed or given medication that should not be given to a person with the patient's condition
- Patient was given medication that was not prescribed for him/her or was intended for another patient
- Pharmacist filled prescription incorrectly
- Patient was prescribed a generic medication that did not work as well as brand-name drug
- Healthcare providers did not recognize that the patient was suffering from medication side-effects
- Patient became addicted to pain medication
- Patient had reaction to medication according to accepted use

Other medication events/Additional comments

20. If patient experienced an adverse medication event, please give the medication(s) involved and briefly describe what happened to the patient.

- Blood thinners (Heparin, Warfarin, Coumadin, Plavix, Lovenox, etc.)
- Narcotic pain medications (Morphine, Dilaudid, Oxycontin, etc.)
- Insulin
- Other diabetes medications
- NSAID pain medications (Toradol, Vioxx, Motrin, Advil, etc.)
- Benzodiazepenes (Ativan, Valium, etc.)
- Sleep medications (Ambien, Halcion, triazolam, etc.)
- Antibiotics
- Steroids
- Chemotherapy medications
- Psychiatric medications including antidepressants, anticonvulsants, ADD drugs
- Acetaminophen (Tylenol)
- Drugs used in anesthesia
- Heart (cardiac) medications
- Diuretics (Lasix, Diuril, etc.)

Please specify other medication and briefly describe what happened to the patient

21. Did the patient have a complication associated with childbirth? If not, please skip to Question 25.

- Yes (Please answer Questions 22, 23 and 24)
- No (Please skip to Question 25)

COMPLICATIONS OF CHILDBIRTH OR COMPLICATIONS IN A NEWBORN

22. Complications in infant at birth (Check all that apply)

- Death of baby at birth or baby born dead
- Brain damage in baby at birth
- Shoulder injury to baby during birth (shoulder dystocia or Erb's Palsy)
- Complication from inadequate monitoring of baby's heart rate
- Delay in performing Caesarean section
- Baby was dropped and suffered injury
- Infection in newborn
- Complication from untreated jaundice in a newborn (kernicterus)
- Complication related to circumcision
- Complication related to immunization (Hep B vaccine)

Respiratory distress or pneumonia in baby

Other complications/Additional comments

23. Childbirth-related complications in a mother (Check all that apply)

Death of mother in childbirth or associated with childbirth

Complication associated with labor-inducing drugs

Complication associated with epidural or other regional anesthesia

Complication of episiotomy

Injury to mother associated with forceps delivery

Severe bleeding during labor or delivery, or following birth

Retained placenta

Deep vein thrombosis or other blood clots requiring treatment

Infection in mother following childbirth or Caesarean section

Postpartum depression or psychosis (depression or severe mental changes following birth)

Other complicationa/Additional comments

24. If the patient experienced a childbirth-related complication, please describe the conditions of the birth and interventions used (Check all that apply)

Unmedicated childbirth with natural-onset labor

VBAC (vaginal birth after Caesarean)

Twins or other multiple birth

Other high-risk pregnancy

Vacuum extractor

Forceps

Episiotomy

Repair of a tear

Labor induced by Pitocin drip or other drugs

Labor induced by artificial rupture of membranes (i.e. breaking the bag of waters)

Epidural or spinal anesthesia

General anesthesia

Scheduled Caesarean section

Unplanned or emergency Caesarean section

Home birth

Other complications /Additional comments

OTHER COMPLICATIONS OF MEDICAL TREATMENT

25. Other complications or errors in diagnosis or treatment (Check all that apply)

- Misdiagnosis
- Laboratory or pathology error
- Delay in diagnosis or treatment
- Proper tests not ordered
- Test results were lost, misplaced or disregarded
- Delay in providing treatment to a patient who was getting worse (failure to rescue)
- Pulmonary embolism, blood clot or DVT (deep vein thrombosis)
- Pressure ulcer or bedsore
- Complications from not controlling blood sugar levels
- Blood transfusion error or reaction
- Problem with IV or central line (excluding infections listed above)
- Ventilator (breathing device) injury or death (excluding infections listed above)
- Medical equipment problem

Other complications or errors/Additional comments

ACCIDENTS OR FAILURE TO PROPERLY SUPERVISE THE PATIENT

26. Accidents or failure to properly supervise the patient (Check all that apply)

- Patient fall or injury while walking or trying to walk
- Patient fall or injury while trying to climb over bedrails
- Patient injury or death while in restraints
- Burn not associated with surgery
- Patient slipped away from a facility without a planned discharge
- Suicide while a patient in a medical facility
- Unexpected death or suicide while under outpatient medical or psychiatric treatment

Other accidents/Additional comments

27. PATIENT OUTCOME FROM EVENT (Check all that apply) (Please briefly provide details in the box at the end of the question)

- Death (other than suicide)
- Suicide
- Brain damage
- Chronic pain
- Need for additional surgery
- Readmission to the hospital within 30 days
- Loss of bowel or bladder control
- Disfigurement (change in appearance)
- Short-term loss of function (less than 3 months)
- Long-term loss of function (more than 3 months)
- Permanent loss of function or disability
- Post-traumatic stress or emotional trauma
- Financial loss
- No injury - near miss
- No serious injury
- Not sure yet (for recent events)

Other outcome/Additional comments

28. What was the effect of the event on the patient's family and significant others? (Check all that apply)

- Little or no effect
- Emotional trauma or Post-traumatic stress (PTSD)
- Guilt
- Financial loss
- Loss of employment
- Loss of lifestyle
- Loss of home
- Stress of caregiving
- Divorce

Other effect/Additional comments

29. If the patient experienced financial loss or had to utilize additional resources, please categorize the type of expenditure. (Check all that apply)

- Personal expense (out-of-pocket or use of savings)
- Personal expense (private loan or bank loan)
- Home care expense
- Employer benefits (use of sick or vacation time)
- Medicaid coverage
- Food stamps
- Unemployment benefits
- Catastrophic illness funds
- Bankruptcy filed due to medical bills
- Community/state funding (please list below)

- Employer benefits (short-term disability)
- Employer benefits (long-term disability)
- SSI disability income
- Other medical expense source (please list below)

List community/state funding or other medical expense source

GENERAL INFORMATION ABOUT THE EVENT

30. WHERE DID THE EVENT HAPPEN?

- General hospital
- Teaching hospital
- Psychiatric or behavioral health facility
- Emergency department
- Nursing home
- Assisted living facility
- Rehab unit or long-term acute care facility
- Dialysis unit
- Freestanding birthing center
- Outpatient surgery center
- Other outpatient clinic or health center
- Home
- Clinical laboratory (for lab or pathology error)
- Doctor's office or other healthcare provider's office
- Pharmacy or drugstore

Other location/Additional comments

31. PERSONNEL INVOLVED (Check all that apply)

- Pimary care physician
- Surgeon
- Board-certified obstetrician (for birth)
- Lay midwife
- Other physician (please list specialty below)
- Resident physician or intern
- Pathologist
- Nurse practitioner
- Nurse's Aide
- Hospital administration
- Pharmacist
- Chiropractor
- Other professional health worker (Examples: radiation tech, respiratory therapist)
- Chiropractor
- Medical assistant, patient care assistant or other assistive personnel

Bedside nurse

Other registered nurse

Emergency Medical Responders (EMS)

Social worker

Other personnel/Additional comments

32. CONTRIBUTING FACTORS TO THE ADVERSE EVENT (Choose as many as apply)

	Did not occur or not applicable	Occurred, but not a serious problem	Serious problem in patient's care	Major factor affecting patient outcome
Patient was not given the information needed to make an informed decision				
Healthcare personnel did not listen to patient or family				
Patient was not properly monitored				
Nurse did not respond quickly to the call button				
Doctor was slow to arrive				
Healthcare personnel did not communicate well with each other				
Healthcare personnel seemed untrained or lacking in knowledge				
Healthcare personnel seemed over-confident				

	Did not occur or not applicable	Occurred, but not a serious problem	Serious problem in patient's care	Major factor affecting patient outcome
Healthcare personnel seemed overtired or fatigued				
Healthcare personnel seemed overworked, rushed, or behind schedule				
Healthcare personnel did not seem familiar with the patient's case				
Healthcare personnel did not communicate important information to patient				
Healthcare personnel did not seem concerned about the patient				
Patient's room not cleaned properly, environment not sanitary				
Healthcare personnel did not follow sanitary procedure				
Medical procedures or treatments were not performed carefully				
Premature discharge				
Lack of follow-up after discharge				
Other (please describe below)				

Other contributing factors/Comments

HEALTHCARE PROVIDER/FACILITY RESPONSE TO THE EVENT

33. HOW DID YOU LEARN WHAT HAD HAPPENED? (Check all that apply)

- I am still trying to find out what happened
- Institution or healthcare provider disclosed error
- From the patient (or you are the patient)
- Witnessed the event personally
- Staff member warned you privately that something had gone wrong
- From a witness (not healthcare provider or staff)
- From a doctor or staff member at another hospital or office
- Reading the medical record
- Through a complaint process
- Through my own research or investigation
- Autopsy

Other means/Additional comments

34. HOW DID THE FACILITY OR HEALTHCARE PROVIDER RESPOND? (Check all that apply)

- Open, concerned, transparent
- Apologized and took responsibility for incident
- Offered to compensate or otherwise make amends to patient/family
- Event was investigated and patient/family were kept informed
- Patient/family were interviewed as part of investigation of the event
- Patient/family were included as part of the investigating team
- Secretive or unwilling to include patient or family in evaluating the event
- No response after request to investigate
- Denied responsibility
- Told patient/family that care was "appropriate" when it did not seem to be
- Individual providers who were involved were not available to discuss the event with patient/family
- Tried to prevent patient/family from getting crucial information
- Removed information or altered medical records

Other response/Comments

35. Do you feel that the patient or patient's family members later had a difficult time getting medical care because of the adverse event?

Yes

No

Comments

LEGAL AND REGULATORY CONSEQUENCES OF THE ADVERSE EVENT (OPTIONAL)

36. Did the patient or family consider suing over the adverse event?

Yes (please answer Questions 38 - 45)

No (please answer question 37 and then skip to Question 46)

37. If the patient or family DID NOT want to sue, what were the reasons? (Check all that apply)

Patient/family did not want to sue because provider or facility seemed remorseful and open

Patient/family did not feel a need to sue because provider or facility provided compensation without a lawsuit

Patient/family received an apology

The event was not serious enough for a lawsuit

Patient/family felt there was no point in suing because a lawsuit would not change the past

Patient/family did not want to be subjected to the ordeal of litigation

Patient/family were concerned about the expense of litigation

Other reason/Comment

38. If the patient or family DID want to sue, what were the reasons? (Check all that

apply)

- Patient/family wanted to hold the responsible parties accountable
- Patient/family wanted to find out what had happened
- Patient/family wanted to sue because of the financial losses they had suffered
- Patient/family were angry at the way they had been treated by the provider or facility
- Patient/family wanted to be sure that the same thing did not happen to someone else

Other reason/Additional comment

39. Did the patient or family consult a lawyer concerning the adverse event?

- Yes (Please answer Questions 40-45)
- No (Please skip to Question 46)

40. If the patient or family consulted a lawyer, what was the outcome of the interaction with the attorney? (Check all that apply)

- Family told they did not have legal standing to sue under state/provincial law
- After consulting a lawyer, patient/family decided not to file lawsuit
- Patient/family did not sue because no suitable lawyer wanted to take the case
- Patient/family acted as their own attorney
- Lawyer told patient/family that caps on medical malpractice payments made the case too expensive to bring
- Lawyer asked family to pay legal expenses up front
- Lawyer took the case on contingency basis
- Lawyer took the case, but dropped it before filing a lawsuit
- Lawsuit was filed and later dismissed

Other outcome (please specify)

41. If the patient or family pursued legal action, what was the outcome of the case? (Check all that apply)

Lawsuit was dismissed

Case settled out of court without a lawsuit being filed

Case settled out of court after filing a lawsuit

Case settled for attorney's expenses only

Case went to trial with verdict in favor of plaintiffs

Case went to trial with verdict in favor of defendants

Verdict was appealed

Case was settled according to pre-arranged agreement for less than the jury's verdict

Insurance company, Medicare or Medicaid placed a lien on settlement or jury award

Lawsuit is still ongoing

Other outcome/Additional comments

42. If the patient or family settled a case, did they sign a confidentiality clause agreeing not to discuss any of the following? (Check all that apply)

The amount of the settlement

The existence of the settlement

The details of the adverse event

The names of the parties to the lawsuit

The existence of the confidentiality agreement

Other agreements/Additional comments

43. If the patient or family signed a confidentiality agreement, what was the reason for signing?

Patient/family felt compelled to sign because they were told the defense would not settle without a confidentiality agreement

Patient/family signed the agreement voluntarily because they wanted to keep the details of the settlement confidential

Other/Additional comments

44. If the patient or family pursued legal action (with or without success), how long did the legal process last?

45. If the patient or family received a legal settlement or other financial compensation, how much did they receive after medical liens, subrogation of medical expenses, and legal expenses?

- The lawsuit cost us more than we received
- 0
- Less than $30,000
- $31,000 - $100,000
- $101,000 - $250,000
- $251,000 - $500,000
- $501,000 - $1,000,000
- More than $1 million

Other /Additional comments

REGULATORY FOLLOW-UP TO THE ADVERSE EVENT

PLEASE NOTE that the scope of problems in medical care can only be assessed if problems are reported to the appropriate authorities. Links to regulatory and accrediting agencies can be found at www.empoweredpatientcoalition.org/report-a-medical-event. If you have not yet reported your event, we urge you to do so, even if the event is not recent.

46. To what agencies and institutions, if any, did the patient, family, or other individuals report the adverse event?

- Not reported
- Reported to administration of facility or office where incident occurred
- Reported to state health department
- Reported to state medical, nursing, or other licensing board
- Reported to the Joint Commission
- Reported to the Accreditation Council for Graduate Medical Education (ACGME)
- Reported to the Food and Drug Administration (FDA)
- Medicare or Medicaid (CMS)
- Reported to the Institute for Safe Medication Practices (ISMP) or ConsumerMedSafety
- Ombudsman or Patient Relations
- Insurance Company
- Canadian Health Authority

Filed HIPAA complaint for privacy violation

Canada - Provincial Minister of Health (FIPAA in Canada)

Other agencies/Additional comments

47. Were you satisfied with the response of the institutions or agencies to which you reported the adverse event?

Yes

No

Please briefly describe the response to your reports, if any

OPTIONAL NARRATIVE OR COMMENT

48. NARRATIVE (Please give a brief description of the incident and any additional comments or suggestions you have for how the incident might have been prevented.)

NARRATIVE:

Comments

49. CONSUMERS UNION

This survey was created in a joint collaboration between The Empowered Patient Coalition and the Consumers Union Safe Patient Project (www.safepatientproject.org), which welcomes input from those who would like to share their stories of medical harm. The Consumers Union Safe Patient Project seeks to eliminate medical harm through public disclosure of patient safety events such as hospital-acquired infections and medical errors, as well as information about health care providers, the safety of prescription drugs and problems with medical devices.

May we share your story with Consumers Union?

- Yes
- No

50. Are you interested in sharing your story with members of the media reporting on health care issues? If so, please be sure that you have entered your contact information above or enter it in the box below.

51. Patient Harm Questionnaire from Propublica.

Please consider filling out an additional survey sponsored by Propublica at http://www.propublica.org/article/patient-harm-questionnaire

52. Thank you for completing our survey. Please tell us if you have suggestions for improving our reporting process and please alert others who may have experienced adverse events to complete the survey. For more information or to see survey results, please visit www.EmpoweredPatientCoalition.org.

Next