

CASE IN POINT

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QUALITY & SAFETY

An Unflinching Look at Medical Errors Promotes Patient-Centered Design

A personal tragedy fuels the author to improve the quality and safety of healthcare

BY DAN FORD

A tragic event occurring within the health-care system, involving an irremediable medical error and a spate of ensuing complications, inspired the author to seek out change, and to create a patient-centric structure of determining medical harm and improving the delivery of healthcare.

Over the past 10 years, I have waged a battle within healthcare. Mainly, I seek to create a patient-centered paradigm, whereby patients are involved in root cause analysis. My goal is to improve patient safety and prevent harmful – even deadly – medical errors from occurring in the first place.

My feeling is thus: If we truly believe in patient-centered care, reducing the way-too-large number of medical errors that cause death and injury, and seeking the input of the person with the most skin in the game – the patient – in the process of root cause analysis (RCA), including investigations and discussions, must involve the patient at the very core of its processes and procedures. Otherwise, we are being disingenuous. Leadership, driven by boards, CEOs, physicians and insurance carriers, is central to seeing this happen.

A HARROWING JOURNEY

My wife, Diane, experienced brain damage, including permanent short-term memory loss, following a hysterectomy and an emergency colostomy at a hospital in Illinois in

May 1991. Twelve hours after the surgery, laying in her hospital room, she suffered an overdose of morphine delivered through the IV. Thankfully, the code team from the ER responded right away. However, the damage was already done. It took more than 21 minutes to intubate my wife – which was too late for her brain to survive intact.

Two months later, Diane's colon was reconnected during a third surgery. She did not know how to clean or change the bag on her own, and, because of her memory lags, was reminded why she had it in the first place with a message on the white board in our bedroom. Weeks later, she returned to the hospital with a kinked colon. After five days of rest and no surgery, she was released from the hospital. She then discovered further complications from a fistula caused by a stray staple from her colon repair. This fistula did not heal on its own. It had to be repaired three months later during her fourth surgery and fourth hospitalization in seven months.

This was extremely traumatic for my wife. For me, it was no less harrowing. And my search for answers took me to an even darker place. When I started asking direct questions, I experienced a very difficult relationship with the hospital's senior risk manager. He was gruff and carried an air of condescension and arrogance, and loved to argue. His primary associate was his wife, a sweet, direct and empathetic nurse. A clear case of bad cop, good cop. The idea of hospital care revolving around the patient

seemed foreign to this man. He told me on several occasions that his was not a philanthropic organization, that his job was not to give away money. He had no empathy for the negative impact on Diane's quality of life, or that of her family.

I requested a copy of Diane's hospital medical record and got it (for \$94). I then asked for a copy of the report by the hospital committee that reviewed what happened to Diane. The request was denied. "That report is confidential," is the refrain I heard. At that point, a figurative wall went up: I was clearly trespassing where I was not invited or wanted. With no due cause to deny me the report, I was offended and angry.

ATTEMPTS AT RISK MANAGEMENT

Several months later, the deadline for the two-year statute of limitations was approaching. A meeting was arranged with risk management. His wife told us her husband was sick when she showed up and he did not. We had a short, polite discussion. We were offered a settlement of \$100,000. Fully aware of the costs in health, medical care, quality of life, and the passionate soul that was ripped away due to gross negligence, the trade-off was not equitable, and not acceptable. The nurse stated this was their estimated cost of legal fees in a lawsuit. The amount would be covering their risk, but took no regard for Diane or her brain damage.

We filed a lawsuit, which was settled nine years later, in 2002, when Diane quit

the lawsuit. The defense attorneys successfully delayed our case. It did not get to trial. Diane simply wanted a functioning brain, and had no accurate recollection or understanding of what had happened to her. We settled for a very small amount, for which there is a gag order. The defense attorneys, hospital, physicians, risk management and insurance company won. It was the legal outcome, the official outcome. But it was not right, nor did it fit the intended spirit of medicine.

FAULTY PRACTICES IN REVIEW

Diane has a master's degree in education and was working part time on a master's in divinity when her respiratory arrest happened. She loved to learn, and was interested in becoming a hospital chaplain. Yet today, her ability to analyze, reason and learn is gone.

I became a volunteer patient safety advocate in 2002, in addition to my day job as a recruiter of healthcare executives. The catalyst that launched my interest in patient advocacy was the denial of the committee's report based on the premise that it was a confidential document. That was nonsense. It was Diane's body that was permanently damaged. Rosemary Gibson, author of the Wall of Silence, describes the overall treatment of Diane and the Ford family, including her multiple surgeries, hospitalizations and complications, permanent brain damage, post-hospital interaction that was driven by the attitude of the hospital and doctors and risk management and insurance company to control the information exchange and to simply shut out the Ford family, as "cruel." I agree.

The Importance of Root Cause Analysis

I remain convinced that involving the patient and family in the RCA – participating in data gathering, discussion and analyses – is the right thing to do. It is also good business, and can contribute to healing by all involved. Yet the issue is not simple; the responsibility gets passed around like a hot potato. Many hospital attorneys advise against it. State laws impact peer review. Many CEOs and risk managers are reticent. The clinician power gradient and politics play a role.

Patients and family members may not understand all of the language involved. Some will decline such involvement, and some may still choose to pursue a law-

suit. Doctors, other clinicians and hospital executives expect to find the discussion awkward and threatening. This is not a personal attack, but most are simply afraid of openness, candor, and their own emotions in having frank discussion with patients who have been harmed or the families of loved ones who died because of medical errors while under their care. They are frequently swayed or intimidated by resistant risk managers and attorneys. Needless to say, the process is not one size fits all.

PROMOTING PATIENT-CENTERED CARE

None of these are valid reasons for continuing to deny RCA involvement, though we have to take each aspect into account. It is a continuation of the partnering with the patient that started in the doctor's office. Maybe, just maybe, the patient and family will help providers overcome and deal directly and positively with this awkwardness. Useful information that will help prevent further deaths and serious injury can be uncovered.

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Helen Haskell, president of Mothers Against Medical Error, describes the relationship with providers:

"The patient and family are the one party whose sole interest is in finding out the truth. The patient and family are the only continuous thread in the patient's care. The patient and family are probably the most important source of information. I tell families that if the hospital doesn't interview them, the hospital is not really interested in finding out what happened. I feel sure that the lack of patient input is a major reason for our lack of progress in reducing medical harm."²

The involvement of patients/families in RCAs is a difficult subject for providers. Many nationally recognized provider patient safety advocates are philosophically in favor of total transparency between caregiver and patient – and recognize that it is very complicated. That should not stop us. We need to find the respect, courage, wisdom, trust and common sense to proceed.

A WAY FOR PROCESS IMPROVEMENT

In the widely respected 2010 IHI white paper on Respectful Management of Serious Clinical Adverse Events, Jim Conway and colleagues note that, given that the focus of RCAs is on learning and improvement, the patient and family should be included in the process. The extent of inclusion will be determined on a case-by-case, individual-by-individual basis. Staff, patients and families have all commented that, in addition to informing learning, inclusion supports healing. Routinely, no one was closer to the error, and what preceded the error, than the patient and those with them. A discussion provoked by Conway on the NPSF listserv in recent months pointed to both the perceived power and challenges of this inclusion.³

Says Becky Martins, volunteer patient advocate: "If the health system's goal/priority is to prevent future harm from occurring, how could they not include patient and family (P/F) in RCA? The patient (or surviving family) is the constant presence in the segmented

care. The docs/nurses and support staff are not present continuously, and there are shift changes, during the beginning to end of the care episode. The patient (sometimes family) is there the whole time. The P/F can help the health system identify exactly where the breakdowns occurred (where and when the patient became vulnerable)."⁴

Rick Boothman, an attorney and executive director for clinical safety and chief risk officer at the University of Michigan Health System, describes the UMHS approach:

"There are two main aspects of any valid root cause analysis: 1) The investigative phase and analysis phase; and 2) The phase in which action lists are compiled to address the findings of the first phase – action lists that are ideally meant to address each of the root causes in an effective, durable way that does not create deleterious unintended consequences. I would venture to say that, generally, root cause analyses that do not include the patient perspective in both phases is, by definition, incomplete at best.

You simply cannot understand the totality of an adverse event without understanding the patient's 'reality,' their experiences and observations. Compiling a response to an adverse event and its root causes cannot be responsive without patient input if we are truly striving to render patient-centered care. That is simple logic.

“Operationally, there are some challenges that require navigation, innovation and simple experience. There are multiple concerns and practical hurdles. Practically speaking, there is an urgency to understanding adverse events, and in the acute phase after an injury, patients harmed by medical error are often not in a position to participate because they or their families are struggling with the impact of the error. So, aside from the novelty and concern that we may introduce a chilling effect by having the patient physically present in any group setting, it is very difficult to arrange practically without unduly delaying the analysis. Therefore, here at the University of Michigan, investigation of adverse events must include the patient's and family's experience, but it is often captured and communicated via interview and shared with the investigative team. We believe, though, that no investigation can be complete without that input.”⁵

Kathryn Townsend, an attorney, consultant and risk management and patient

safety executive, provides sound advice: “Providers can no longer treat the patient as some sort of uninformed interloper. It's all about building respect and trust in each team member, through communications and teamwork development.” Kathryn was a Fellow in the 2001 Salzburg Seminar on “Patient Safety and Medical Error.”⁶

Says Gibson, author of Wall of Silence, which tells the human story behind the IOM report, *To Err Is Human*: “If a root cause analysis is conducted to find out why a sentinel event occurred, patients and families should be included in the investigation. They may have been the only constant presence and could provide crucial facts that no one else can.”⁷

CONCLUSION

I am in total agreement with Dr. Lucian Leape of the Harvard School of Public Health, whom many consider the father of the modern day patient safety movement, and his identification of respect as the primary cause of problems in healthcare. I was a participant in a 2011 Telluride Patient Safety Workshop where he stated this.⁸ We need to take this lack of respect seriously in all we do in healthcare and in life. Do we have so little respect for patients who have died or experienced serious injuries because of medical errors, and our healthcare industry with medical error factors that are left alone/unresolved,

that we deliberately leave patients and family members out of this process?

I would invite healthcare providers to review this attitude and policy, and to invite patients and family members to participate in RCAs. It's a partnership that could result in significant gains.

REFERENCES

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3. Personal conversation and email, Jim Conway, Nov 11, 2013.
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6. Personal communications, Kathryn Townsend, Patient Safety Presentation in Geneva, Switzerland, May 2006.
7. Personal communications, Rosemary Gibson, Nov. 11, 2013.
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