

Disclosure Through Our Eyes

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Abstract: When a system failure or human error leads to preventable patient harm, it offers care providers the challenge and the opportunity of disclosure: a challenge to step up and take the risk of treating patients and families in the way that we would wish to be treated and an opportunity to provide a healing experience both for patient families and caregivers involved in the event. When it is clear that our care has caused preventable harm and we allow a conspiracy of silence to betray those who have put their faith in us, we inflict the impact and pain that is nothing short of a “hit and run” accident. Four patient stories illustrate how the lives of family members would have been different if a new disclosure practice had been in place when they experienced the preventable loss of their loved ones. We view disclosure through their eyes. Their message is to hospital leaders. Historically, only the most courageous hospital leaders had the intestinal fortitude to insist that their organizations practice full disclosure. Now that the National Quality Forum disclosure safe practice has become a national standard, all will have to step up to be in compliance or explain to their communities why they will not.

Key Words: disclosure, safe practice no. 4, patient safety, communication, patient-centered care

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Is it possible that hospitals might be careening from 1 hit-and-run accident to another, leaving in their wake a trail of broken hearts, broken lives, and broken promises? The answer to this question is “yes.” However, most hospital leaders have become completely insulated from personal accountability and even sheltered from the facts regarding individual events. Yet, in the end, consumers believe that they are at the controls.

The obsession with capital asset protection, coupled with the obsolete assumption that disclosure will increase malpractice awards, has led to a pattern of suppression and compartmentalization of information.^{1,2}

Four stories of preventable adverse events leading to catastrophic losses illustrate how compliance with the recently endorsed National Quality Forum (NQF) disclosure practice would have made a significant impact on the families of those affected.³

This practice is 1 of 30 that have been synchronized and harmonized across major certifying, purchasing, and quality organizations, including the Centers for Medicare and Medicaid (CMS), the Joint Commission (JCAHO), The Leapfrog Group, the Institute for Healthcare Improvement (IHI), and the Agency for Healthcare Research and Quality.^{4,5}

In this paper, we hear the stories of 4 remarkable women who have lost loved ones to preventable system failures and human errors.

Sue Sheridan lost her husband when his cancer was not treated because of a lost surgical pathology report. Only a few years earlier, her newborn experienced preventable brain damage because a simple blood test was not run. In both cases, suppression of the information regarding the systems failures and errors occurred—disclosure did not occur.

Nancy Conrad lost her husband, an Apollo astronaut and national hero, when he had a motorcycle accident and experienced a systems failure of communication. To make it worse, she was coldly informed of his death with no explanation.

Jennifer Dingman’s mother went through agony because her medication was causing her organ systems to fail—and caregivers failed to listen to Jennifer as she tried to get appropriate care and focus on her mother’s medication issues... again, no disclosure.

Sorrel King lost her 18-month-old daughter because of communication and teamwork failures that led to misused narcotics and dehydration. In her case, full disclosure prevented a lawsuit and resulted in her teaming with the hospital to create a safety center that has saved lives and improved care performance.

Each story, although unique, is one of the patient and family trusting the medical system. In each case, their sacred trust was betrayed either by passive systems failures, or worse, by active suppression of the truth to avoid accountability and financial consequences.

They have all experienced a fall into a performance gap of lack of patient-centered care that exists at most hospitals. We see, through their eyes, the harsh reality of this gap. Yet they have each, in their own way, turned these experiences into opportunities to help us in health care.

SUE SHERIDAN’S STORY

Cal was born in March of 1995, and his birth was the most moving and touching experience that my husband and I ever experienced. Cal developed jaundice while in the hospital. They assessed him visually for jaundice. They never tested Cal, nor did they ever inform us that jaundice could hurt our baby. We were discharged with a “well baby.” We were told to put Cal in the sunlight maybe 15 minutes a day for the jaundice. They actually joked about his color and called him the “canary baby.” After approximately 2 days at home, Cal began to tire, and his behavior changed. Previously, he had

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been a very excited baby to feed, and suddenly, he was not that interested in breast-feeding. I called the hospital and reported the change. They asked me if I was a first-time mom. I said, "Yes, I was." They said, "Mom, you need to settle down. This is normal." They expressed that I was a first-time over-concerned mom.

Unsatisfied, we called the pediatrician who we then saw. I showed the pediatrician how he was not breast-feeding well anymore. He visually assessed Cal for his jaundice. Cal was so yellow, he was almost pumpkin colored! The physician never suggested testing Cal for bilirubin, and he sent us home. During the next 24 hours, Cal's condition started to worsen, so we kept calling the physician who told us to wait. However, finally we took him in to the hospital where they finally undertook a bilirubin test. The first test was so high that they did not believe the results, so they retested him. The reading was 34.6 mg/dL, which was the highest bilirubin level ever recorded in a newborn at that hospital. However, again, there was no concern. We were not told of any potential brain-damaging effect. They put him under phototherapy lights, but no more aggressive intervention was recommended.

After being in the hospital for 24 hours, Cal started arching his head and neck backwards...accompanied by a kind of a high-pitch scream, almost like a cat—obviously, a drastic change in his behavior. My husband and I reported that to the physician and the nursing staff. Again, there was no concern. Little did we know that we were witnessing the onset of brain damage of our newborn.

Because of unusual neurologic behavior while he was in the hospital, we requested a neurology consultation that led to a magnetic resonance imaging (MRI) of the brain. We were told by a jubilant team that his MRI was insignificant, and my son was discharged as a "well baby."

In the weeks that followed, Cal was a very difficult baby. He cried all the time. He could not breast-feed. He arched all the time. He had a real significant startle response—nothing that looked like normal baby behavior to us. He could not sleep. He went some 20 hours at a time without sleeping. He had terrible esophageal reflux. We reported all this to physicians. We became concerned that he was not developing normally. All the physicians in our town were reluctant to make any type of diagnosis. They just thought that he was just a little bit behind.

So finally, at 18 months, we took him to a well-regarded academic medical center, and a team of prominent physicians diagnosed him with classic kernicterus or brain damage from jaundice. When we collected all of the original hospital records, we learned that the original MRI report stated that Cal had classic findings consistent with brain damage from jaundice. This was never shared with us.

We, as parents, fell apart. We had learned that we had a very damaged son who would suffer for the rest of his life. He had hearing impairment and severe cerebral palsy. His eyes crossed. His teeth all needed to be capped. He was not able to speak or do anything as a toddler. The grief process that we went through was very profound and extremely challenging to our relationship.

However, what was more upsetting to us was the fact that our community, our physicians, chose not to disclose to us

what had happened to Cal. We could have started the healing process and the therapy process for our son a lot sooner. So the betrayal that we felt was significant. We also knew that Cal's future health care costs would be in the millions.

While we were dealing with our son's health issues, my husband, Pat, started having severe headaches. An MRI at our community hospital revealed a mass at the base of his skull. We went to a specialist in another state. Pat had a surgery of his neck and spine. We were told, by our surgeon, that it was a benign tumor and that it would not require any follow-up treatment.

Six months later, Pat developed pain in his neck again, and an MRI showed that the mass was back, and this time, the tumor was the size of a surgeon's fist. It was invading the spinal cord. A second surgery by the same surgeon revealed a malignant sarcoma. We were led to believe by the surgeon and his team that over those 6 months, this tumor became a malignant cancer.

During the postoperative period, a parade of physicians who were on the tumor board asked us the same question: "Why didn't Pat get treatment of his cancer after his first surgery?" I was confused; thus, I went on a mission to find out what the original pathology report revealed from the first surgery. When I got the final pathology report from the medical records and read "malignant synovial cell sarcoma," I had to lean against the wall to keep myself upright. The preliminary pathology report stated that the tissue was atypical, and the final report clearly confirmed cancer. A second error had occurred in our family. This time, the communication error had caused a life-threatening delay of treatment.

I went back to Pat's room, and I shared with him this pathology that no one had discussed with us. I tried to comfort Pat by reassuring him that this hospital was going to do the right thing. However, within a couple of hours, we were discharged without any explanation or without seeing our physicians.

We walked out of that hospital with no explanation of the error. After we were home, we called our surgeon. Basically, he denied ever telling us that the tumor was benign after the first surgery.

At first, the hospital administration acknowledged that the diagnosis of cancer had never been communicated to us. Initially, they were supportive and helpful; however, ultimately, they were instructed by their insurance company and legal advisors to cut off communication. Again, we were betrayed by caregivers we trusted.

Despite heroic measures at a major cancer center to keep Pat alive through a number of recurrences, he woke up 1 night paralyzed from his waist down. The disease was severing his spinal cord. He had 2 weeks to live!

Pat made the inspired choice to, within those 2 weeks, go to Disney World. He wanted to watch his kids have the time of their lives. So 53 of us went to Disney World, where he passed away.

Pat got to write his final chapter. During those 2 weeks that were probably the most precious 2 weeks of our relationship, we were able to talk about what I would do—go forward as a single mom. Pat asked me to never to give up on patient safety, and I do not think I ever can.

Had the New NQF Safe Practice Addressing Disclosure Been in Place, How Would This Have Changed My Life?

It is so hard to articulate the profound sense of betrayal and abandonment that my family felt. I can only describe it as a hit-and-run health care accident. My family was abandoned at the side of the road, injured and traumatized by a well-meaning motorist who fled because of legal and personal fears. We were left to seek out help on our own with our own resources. No one looked back. They pretended as if nothing had happened, including those eyewitnesses on the side of the road. A hit-and-run, in our world, is considered criminal. Why is it OK in medicine? The nondisclosure of medical error is the most destructive phenomenon in health care. Trust and confidence disappears in a heartbeat.

If this practice had been in place in both hospitals so that the administrators and caregivers would have behaved according to its specifications, the lives of my children and family would have been dramatically different. Healing would have begun at that time, and it would have been more complete. The calculated dishonesty to protect their money and pride is at the very core of the challenge I face to forgive. It is this forgiveness that we need to move on. Without it, our lives are unalterably changed.

What Is My Message to Hospital Trustees, CEOs, and Administrators?

Have the courage to be honest. Disclosure and transparency are simply a new kind of glitzy way to say the word *honesty*, and I know of no other industry where honesty is optional. Governance leaders must call for a return to values, honesty, and honor. One thing that profoundly affected Pat, as a patient, a father, and a husband was the intolerable lack of integrity.

It is poor leadership that leads to a departure from values in the face of fear, in the face of fear of litigation, in the face of not being accepted, in the face of challenging legal counsel and medical staffs, and in the face of bottom-line centered management and pressure to protect the public image. I have heard from leaders who say that, sometimes, they are too busy or that they simply pass problems on to someone else. I implore leaders to live, breathe, and eat your institution's mission. Put it right on your desk, and let it be your guide.

What Is My Message to Physicians, Nurses, and Direct Caregivers?

This practice is a call to action for everyone. This is an invitation and a challenge to do what is right. You now have the opportunity to treat patients and families as you would want to be treated. Religious or not, everyone understands "the golden rule."

The fear of liability and litigation is very real; however, in reality, such liability is becoming more fiction than fact.^{6,7}

You might be surprised to know that many experts have shared research findings that you have more risk of being sued for lack of disclosure than for an error itself; and many patients sue because they feel betrayed by not being told what happened when an adverse event occurs, and they have not

been assured that the hospital will try to correct the error.^{8,9} (See Appendix A for Sue Sheridan's mission and contributions for patient safety.)

NANCY CONRAD'S STORY

I had the unbelievable good fortune to be married to Pete Conrad. Pete was a test pilot and an astronaut. He was the main character in the first 4 chapters of *The Right Stuff* by Tom Wolfe.¹⁰ Pete really was the right stuff. He flew 4 flights in space. He flew Gemini V, Gemini XI, Apollo XII, and Skylab. He commanded the second landing on the moon, which was Apollo XII, and he was awarded the Congressional Space Medal of Honor for his rescue of Skylab. Pete's motto was "if you can't be good, be colorful." He was both.

He drew people to him to reflect aspects of his own personality. He loved people who follow their dreams, and above all, he loved people who had fire in their bellies. Pete always had a fire in his belly. He knew that growing up might be mandatory, but growing old was optional. Pete never stopped caring about space, and he was hard at work on the commercialization of space, working on new vehicles and expanding satellite technologies.

On July 8, 1999, I received a phone call that changed everything. Pete was involved in a motorcycle accident and was receiving care in a small emergency department, very similar to the emergency departments throughout this country. A call from a friend who was with Pete informed me that they had found some bleeding but that Pete was in surgery and going to be fine.

When I arrived at the small rural hospital, the receptionist could not seem to find Pete within the hospital system. I sat in a hospital room waiting to hear something and then later, a physician walked in and simply told me, "Your husband is very grave." I did not get any details. I have no idea what it was really about, and I was sort of whisked off to a hospital room with 2 beds where some of the folks from the motorcycle ride were waiting for me. We just sat there for hours on end, and no one spoke to us.

Finally, a physician came in, one whom I had never met. He did not introduce himself, and he said, "Which of you is Mrs Conrad?" I said, "I am." And he said "He's dead." The physician then just abruptly walked out of the room with no explanation. There was nothing else. No one ever came to tell me how my husband died or why he died.

When I later learned that Pete's death was preventable and that it was the result of a system failure and delay in appropriate treatment of internal bleeding in his chest, I felt totally victimized. I alternated from feelings of utter helplessness to despair and rage. The pain and the anger only intensified the longer I was left in the dark. Pete's caregivers could have done 3 things that could have helped me so much. First, they could have told me what happened. Second, they could have told me how their care could have been different. Third, they could have told me what they would do so that it would never happen again. It is very ironic that Pete spent his entire life in high-risk environments protected by high-performance safety systems, yet he died the preventable death of systems failure in a hospital.

Had the New Proposed NQF Safe Practice Addressing Disclosure Been in Place, How Would This Have Changed My Life?

Personally, I have an aversion to any situation that results in “victim,” and they victimized both Pete and me. Pete’s death was the result of a systems failure, and he had been victimized by that failure. Then I was victimized by the lack of disclosure. Because of the situation and the way it was handled, I was thrown into shock, anger, and fear on top of grief. I was immediately consumed with the angst of knowing that something had gone terribly wrong...how could someone die of broken ribs?...but there was no explanation, and I was left with no support.

On top of the death of my husband, because of the stonewalling, lack of empathy, and lack of information that would have been helpful, I had been victimized in a way that was emotionally and viscerally insulting to my intelligence and that had acutely intensified my grief.

If the physician had taken a disclosure approach and told me, “We are sorry this happened, and we are going to investigate exactly what happened and get back to you,” that would have made a huge difference in my emotional state at the time. It would have started the healing right away and would have shortened the 2 years of solitary confinement in a prison of inconsolable pain.

What Is My Message to Hospital Trustees, CEOs, and Administrators?

Stonewalling is abusive. It is not passive; it is an active assault to the spirit. It negates us as human beings. It is equivalent to being actively abused by an arrogant thug—like a rape. Just because you have a policy of keeping the facts from your leadership and governance people does not mean that you are not and should not be held accountable.

Please have the “right stuff,” and take a leadership role in creating the systems and environment that will lead caregivers to do the right thing for their patients. Now that disclosure is one of the safe practices designated as national standards, the hospitals will finally get to experience what we families of patients who have experienced severe medical errors know: when disclosure increases, the litigation will go down.

What Is My Message to Physicians, Nurses, and Direct Caregivers?

As an aerospace expert, Pete often advised people regarding accidents and would routinely explain how most accidents are a cascade of events and often begin when we are “behind the curve” trying to handle too much when we are in high-risk environments. He would say that you need systems solutions for these systems problems. I know that he would say that caregivers need to learn these lessons.

Instead of suppressing the information around a systems failure, you must have the courage to be transparent and learn from the failures to prevent harm to other patients and families. Without practicing disclosure and transparency, you are burying, with our family members, the very answers to some of the most important questions that will lead you to some of the answers for your most daunting problems.

(See Appendix A for Nancy Conrad’s mission and contributions for patient safety.)

SORREL KING’S STORY

Josie was 18 months old. She had brown eyes and light brown hair. She loved to dance and had just learned to bounce on the trampoline with her older siblings, Jack, Relly, and Eva. She had just learned to say “I love you.”

In January of 2001, Josie was admitted to Johns Hopkins after experiencing first- and second-degree burns from climbing into a hot bath. She healed well and, within weeks, was scheduled for release. Two days before she was to return home, she died of severe dehydration and misused narcotics.

What were the events that resulted in this needless tragedy? Josie spent 10 days in the pediatric intensive care unit. I was by her side every day and night. I paid attention to every minute detail of the physicians’ and nurses’ care, and I was quick to ask questions. I bonded with them and was in constant awe of the medical attention she received. Every time Josie moved or fussed, someone would be quick to push her pain medication button.

I tried rubbing her head and found that, often, this would settle her. Much to our relief, Josie was experiencing a quick recovery. Her burns were healing beautifully. She was sent down to the intermediate care floor with expectations of being sent home in a few days. Her 3 older siblings prepared for her welcome home celebration. We were told that no one had ever been sent back to the pediatric intensive care unit.

The following week, her central line had been taken out. I began noticing that every time she saw a drink, she would scream for it. I thought this was strange, but I was told not to let her drink.

While a nurse and I gave her a bath, she sucked furiously on a washcloth. As I put her to bed, I noticed that her eyes were rolling back in her head. Although I asked the nurse to call the physician, she reassured me that, oftentimes, children did this, and her vitals were fine.

I told her that Josie had never done this, and perhaps another nurse could look at her. After yet another reassurance from another nurse that everything was fine, I was told that it was OK for me to sleep at home. I called to check in 2 times during the night and returned to the hospital at 5:30 in the morning. I took one look at Josie and demanded that a physician come at once. She was not fine.

Josie’s medical team arrived and administered 2 shots of Narcan. I asked if she could have something to drink. The request was approved, and Josie gulped down nearly a liter of juice. Verbal orders were issued for there to be no narcotics given. As I sat with Josie, I noticed that the nurse on morning duty was acting very strangely. She seemed nervous, overly demonstrative, and in a hurry. Uneasy, I ask the other nurses about her, and they said that she had been a nurse for a long time. Still worried, I express my concern to one of the physicians, and he agreed that she was acting a bit odd. Meanwhile, Josie started perking up. She was more alert and had kept all the liquids down. I was still scared and asked for physicians to please stay close by. At 1:00 PM, the nurse walked over with a syringe of methadone. Alarmed, I told her that there had been an order for no narcotics. She said that the

orders had been changed and administered the drug. Josie's heart stopped as I was rubbing her feet. Her eyes were fixed, and I screamed for help. I stood helpless as a crowd of physicians and nurses came running into her room.

The last time I saw Josie, I looked into their faces and said to them, "You did this to her, now you must fix her." I was ushered into a small room with the chaplain. I was told to pray.

Two days later, Jack, Relly, and Eva were brought to the hospital to kiss their beloved Josie good-bye. Josie was taken off of life support. She died in our arms on a snowy night in what is considered to be one of the best hospitals in the world. Our lives were shattered and changed forever. Josie died of severe dehydration and misused narcotics—careless human errors.

Had the New Proposed NQF Safe Practice Addressing Disclosure Been in Place, How Would This Have Changed My Life?

In our case, the head of pediatrics came directly to my home and literally stated, "I am responsible, and this happened on my watch." Not only did he do so but he continued to maintain a relationship with us regardless of how upset we got. This was a pivotal act of courage. This and the transparent behavior of the organization saved the hospital a terrific lawsuit, as we would have done everything in our power to harm it.

Although the practice was not in place, the will and desire necessary to adopt such a practice was in place. Many of the behaviors described in it were exhibited. This led us to our ultimate agreement to work together to partner in certain activities now embodied by the Josie King Patient Safety Center that will prevent such an event from happening to another child.

What Is My Message to Hospital Trustees, CEOs, and Administrators?

My experience with hospital leaders is that they lack the knowledge of the severe pain that is inflicted on patients and families who do not receive the human right of disclosure and transparency when their institution harms a patient. When they harm us, it is typically a passive event. When they consciously withhold information, cover up what happened, or seek to discredit us in courts of law to preserve their precious financial resources, they are actively harming us. It is important that our leaders step up and do right by us because ultimately they are damaging their own characters when they do not.

What Is My Message to Physicians and Caregivers?

When I have spoken to medical students and residents in training, I am absolutely appalled at their lack of knowledge regarding patient safety issues and failures in care. They are just not getting this information in medical, nursing, and administrative training programs. However, they want it; they are hungry for it and want to do right by their patients. My message to physicians and caregivers is to step up and do not compromise. There is so much you can do to move the transparency ball forward. If they are in academic centers, they must innovate and put safety into the curriculum. Please take a

lesson from my experience. The clinical leader did not seek out legal guidance and hide behind others. He stepped up, took responsibility, and won our respect and support. (See Appendix A for Sorrel King's mission and contributions for patient safety.)

JENNIFER DINGMAN'S STORY

My mother passed away as a result of systems failures in information transfer, adverse drug events, and delays in diagnosis and treatment that led to fragmented health care.

In the fall of 1994, my mother's neurologist had her on prednisone for back pain, her orthopedic surgeon had her on muscle relaxants and pain pills, and her primary physician had her on several medications, including potassium for blood pressure and other medications for gout. A routine visit to her primary care provider in September of 1994 showed very high blood glucose, so diabetes medication was prescribed, although her physician was aware of the steroid medication prescribed by her neurologist.

Soon, her health began to deteriorate. She began to turn yellow and bruise easily; she showed petechiae, swollen ankles, swollen feet, and bloating, and her eyes were always glassy, with shortness of breath, trouble urinating, and other problems—all within 3 weeks after taking the new medication. Her primary care physician insisted that her health problems had nothing to do with medicine but were a result of the diabetes condition.

Our pharmacist told mother that he felt that it was the new medicine that was making her ill. She mentioned this to her primary care physician, who got angry and asked her if she wanted her pharmacist to be her physician. When she pleaded with him to not have to take the diabetes medication anymore, he told her to get a new physician. She subsequently saw another primary care physician who abruptly took off her steroids without weaning her at all. She became sicker, and her problems with urination worsened. This led to a series of events leading to her admission to the hospital. At this point, she had a gray shadow around her mouth, the whites of her eyes were yellow, and her tongue had a furry coating.

Numerous errors occurred in the documentation of her medical record during her admission and stay in the hospital. This led to misinterpretation of her clinical condition and the impact of multiple medications that had been administered. We, as family members, tried to communicate with the caregivers regarding her status as she deteriorated; however, they rarely listened. The heating of her hospital room was failing, and the temperature dropped to 60°F. Yet, she was not moved to another room, despite there being availability.

Whether the hospital was short staffed or there was a breakdown in coverage, my mother did not have consistent vital sign measurements, and there was confusion regarding potassium that had been administered to her. There were multiple handoffs of her care that clearly failed in their completeness, and she was inconsistently seen.

She continued to deteriorate, despite our family's attempt to get the physicians and nurses to listen to our concerns. Ultimately, she lost consciousness. A code was called, and she

was in a coma for 7 weeks before she died, never regaining consciousness.

I am one of the many lost souls who were not given any disclosure. I will probably never really know why my mother's care was so inconsistent and fragmented and what really led to her death. We do know that multiple systems failed. We do not know how or why, and most importantly, we do not believe that the circumstances around her death led to improved care delivered by her care team going forward.

My family and I carry with us the guilt that we could have done more to prevent her death. Perhaps there was some way that we could have gotten through to the care team regarding her deterioration and the incomplete medical records and documentation that might have helped my mother.

Had the New Proposed NQF Safe Practice Addressing Disclosure Been in Place, How Would This Have Changed My Life?

If full disclosure had been in practice, a good system would have been set in place to express apology, inform me about what happened, and examine how the error could have been prevented. My life would have totally changed had disclosure been practiced with me after my mother's death. If I had been told by the hospital management and staff that they were sorry and would conduct an investigation to find out what went wrong, I might have healed better and faster. Perhaps I would never have created Persons United Limiting Substandards and Errors in Healthcare, a support group for those who have experienced medical error and found it difficult to get answers. If they had told me that the nurses would have to attend relevant classes and the physician would have to get some training to act differently, I would have felt that some good could have come of this tragedy.

What Is My Message to Hospital Trustees, CEOs, and Administrators?

My message to hospital trustees, CEOs, and administrators is that they must understand that average folks are not vengeful and money hungry. They must be more honest with consumers and less concerned about the bottom line. If a mechanic fixes a car and the car does not work, most shops will often take the car back and fix it for free. Hospitals should think about this too. As a courtesy, instead of charging for their mistakes, they should fix the mistake for free. There are many people who lose their homes because they cannot pay medical bills. If medical error expenses cause additional harm to the patient and their family, this is not right! Consumers do not wish to put the hospitals out of business; they only want what is fair and right. Do not be afraid to tell the truth. If hospitals disclose what happens when there is a medical error, and work in partnership with the patient and/or family to improve the system, they will eliminate many lawsuits. They must learn to continuously improve the system so that the same errors do not repeat themselves.

What Is My Message to Physicians, Nurses, and Direct Caregivers?

We consumers are grateful for the hard work and dedication of our physicians, nurses, and other direct

caregivers. We realize that they are human beings, and we do not feel that they should have to overperform. Mistakes will always happen, but the mistakes can be mitigated by systematic improvements. Systems can be greatly improved by learning from mistakes. We, as consumers, want to do everything that we can to help providers do their job—from better communication to giving them our perspective about how the error happened and how the system could be fixed. We will forgive errors if the direct caregivers can show us that they have learned from the errors so that they will not happen again. If the caregivers remain silent, for whatever reason, then we, the consumers, lose trust, and the ramifications of that lost trust are astronomical. (See Appendix A for Jennifer Dingman's mission and contributions for patient safety.)

NQF DISCLOSURE PRACTICE BACKGROUND

In 2003, the first group of Safe Practices was developed and taken through the NQF Consensus process.¹¹ Adoption of these practices was measured yearly by The Leapfrog Group, through which, more than 1300 hospitals publicly reported their adoption.

In 2005, the NQF convened a Safe Practices Maintenance Committee chaired by C. Denham and G. Meyer with representation from the Joint Commission (JCAHO), CMS, the Agency for Healthcare Research and Quality, The Leapfrog Group, and the IHI. Furthermore, the leaders of each of these organizations agreed to commit to harmonize a common set of practice standards that they would embrace, thereby providing a common roadmap for hospitals and health care organizations.

The committee sought input from leading subject matter experts in disclosure¹² and developed a harmonized disclosure practice presented in Appendix B. In the fall of 2006, after a national public review period and refinements to practice, the NQF board endorsed the disclosure practice along with 29 others.

In 2007, The Leapfrog Group, in collaboration with the survey developer, Texas Medical Institute of Technology, has been in the process of measuring adoption of the 30 Safe Practices, including the disclosure practice. This survey provides purchasers and consumers a transparent source of comparative performance information regarding adoption of the Safe Practices.

NQF DISCLOSURE RATIONALE

The new Safe Practice of disclosure was written to be undertaken when an unambiguous systems failure or human error causes death, disability, or harm requiring unanticipated treatment. Many patient family advocates were interviewed, and their experiences and requests resonated with the patient stories described above. Input from all 4 of the patient family stories was provided to the subject matter experts who crafted the Safe Practice. Detail of the practice is articulated in other articles, and adoption will be studied by Texas Medical Institute of Technology in collaboration with The Leapfrog Group's survey process and follow-up reviews.¹²

The rationale for the definition of events requiring disclosure was based on harmonization opportunities with the

major certifying, quality, and purchasing organizations; applicability to multiple care settings; and ultimately, reasonableness for implementation at the front line.

The critical need for leaders to be directly and completely informed was addressed by the requirement for governance to be briefed, and they ensure that disclosure information inform and contribute to performance improvement activities. Although all of our patient advocates articulated this, the Nancy Conrad Story and her message hammer this issue home.

The importance of including the practice in credentialing structures addresses the issue of physician involvement, underscored by Sorrel King's reference to training and knowledge development.

Clearly, the issues of communicating the facts, expression of regret and apology, and commitment to investigating the events for the purposes of future prevention of adverse events address major concerns described in the patient stories above and in the recent literature.¹³⁻¹⁵ Timeliness of disclosure and development and maintenance of relationships with families are addressed to develop a healing environment, both for patients' families and caregivers. The Jennifer Dingman, Nancy Conrad, and Sue Sheridan experiences would definitely have been different had this disclosure practice been in place at the hospitals where their loved ones were treated and died.

The development and administration of a disclosure support and improvement system were addressed to enable solid implementation and capability of an organization to sustain satisfactory disclosure.

CONCLUSIONS

To say that the failure to disclose is like perpetrating a "hit-and-run" accident at first seems harsh and overreaching. Seen through the eyes of patients and families who have made themselves vulnerable by trusting their caregivers and then violated by such betrayal makes it hard to argue to the contrary,¹⁶ especially when one understands how frequently hospitals stonewall or actively suppress truth, either by commission or omission to protect their financial assets.

Many organizations are aggressively stepping up. They are recognizing the importance of the newly harmonized NQF Safe Practices by JCAHO, CMS, The Leapfrog Group, and IHI. The fact that they have all endorsed the same disclosure practice provides a terrific opportunity for compliance. Many are joining the IHI 5 Million Lives Campaign collaborative, of which, disclosure is an element.¹⁷ Other organizations will be fast followers as a critical mass builds, driven by transparency and pay for performance. Still, others may try to look the other way and continue to aggressively institutionalize dishonesty until they have a burning platform.

Regardless of the motivation, the single most important ingredient to catalyzing change is personal involvement of leaders, be they trustees, CEOs, officers, or physician leaders.¹⁸ This kind of responsibility cannot be delegated to legal advisors paid to preserve financial resources, to risk managers who manage claims, to officers paid to make the organization look good, or to frontline staff. This kind of responsibility is "trustee, CEO, and physician leader

responsibility." Leaders must be the conscience of the organization. If they are not, there is no conscience!¹⁹

First, they must be aware of the catastrophic psychological damage inflicted when a patient experiences preventable harm, and the organization actively avoids disclosure and transparency. Second, they must make themselves accountable for change. Third, they must invest in capacity and systems for change. Last and most important, they must act. Leapfrog will be measuring disclosure practice adoption through the 4 *As* of awareness, accountability, ability, and action in its pay-for-performance program.¹⁸

When the Conscience of an Organization Is Distributed Over Many, It Can Disappear

Trustees need to demand transparency, and now that an evidence-based practice has been harmonized by the leading certifying, quality, and purchasing organizations and has become a federal standard, there are no excuses. Trustees must provide the funds and support to their CEOs to step up and embrace this new requirement. Funds to support disclosure will not likely be part of a 3-year-old budget. This will require out-of-budget expenditures. That is why this is "job one" for trustees.

CEOs must have the intestinal fortitude to bring the issue up to the board, the honor to make sure this is done right, and the strength of character to back down legal advisors or those who would prioritize financial asset preservation over the healing of patient families and opportunity for performance improvement.

Officers of the C Suite must back the issue of disclosure and transparency. They typically talk themselves into a path of least resistance or short-term pain avoidance. It is time that our nation's health care officers get off the bench. They can no longer check the morals that they teach their children at the door when they come into the boardroom.

External and internal legal advisors need to move into the 21st century and find out that the prevailing wisdom and data support disclosure. It is 1980's thinking to stonewall and find corrupt "professional hired gun" expert witnesses to railroad the truth out of our relationships with patients. Early disclosure and compensation save huge sums of defense costs and awards. Early disclosure can also decelerate the retirement plans of the defense team that is billing "on the clock." Let them be warned. Clearly, a growing conflict of interest will need to be addressed by the CEO who is paying the bills.

Risk managers have a lot to gain by embracing the new NQF Safe Practice of disclosure, as it will help reduce workload, improve results, and revitalize their own self-esteem, knowing that they are helping heal patient family relationships and their own organization.

Physician leaders, whether they are employed by the organization or as independent physicians, have a great opportunity to encourage institutional honesty. They must help hospital leaders recognize the psychological damage that undisclosed adverse events cause to patients and to caregivers. However, all stakeholders and independent physicians must address coordination of malpractice carriers, as they are often different companies than those engaged by their hospital. This is still a daunting problem to all involved.

Mid-level managers are often pressured to look the other way and complement a practice of “don’t ask and don’t tell” with their leaders. They must step up and make sure that their leaders have the facts, even if the facts are not what those leaders will want to hear.

Finally, direct caregivers must be supported in the area of reporting so that we can learn from near misses and errors that harm patients that might go unnoticed. If the first victims are the patient and families who are harmed, and the second victims are the caregivers who unintentionally harm a patient, then the third victim is the collective social organism that is the hospital staff. The culture of this third victim can be mortally wounded when hospital staff cover up an error to save face and save money. This culture wound may never heal if it is infected with active institutionalized dishonesty by leaders.²⁰

“You Can Run But You Can’t Hide”

“You can run but you can’t hide” are the immortal words of the pilot combat instructor speaking to Tom Cruise when he was closing in on him in the motion picture “Top Gun.” These words capture the essence of the impact of transparency on hospital and clinic leaders. Transparency is no longer an option—it is a given.

In the book and motion picture *The Right Stuff*, mentioned above by Nancy Conrad, the concept of the idea of “the right stuff” is described as: “The idea was to prove at every foot of the way up that you were one of the elected and anointed ones who had the right stuff and could move higher and higher and even—ultimately, God willing, one day—that you might be able to join that special few at the very top, that elite who had the capacity to bring tears to men’s eyes, the very Brotherhood of the Right Stuff itself.”¹⁰

This paper was specifically written with a view through our eyes for you who are trustees, you who are CEOs, you who are officers, you who are physician leaders, you who are mid-level managers, and you who are servant leaders at the front line of care. We pray that you will have the “right stuff” regarding disclosure and return the “care” back to health care and the “trust” back to the public trust. We are counting on you.

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Appendix A: Consumer-led Missions

Sue Sheridan champions numerous international patient safety initiatives. A founder of Parents of Infants and Children with Kernicterus, she catalyzed development of the first consumer-driven sentinel event by the Joint Commission on Accreditation of Healthcare Organizations (now the Joint Commission), the issuance of public health alerts by the Centers for Disease Control, and establishment of a national standard by the National Quality Forum with designation of kernicterus as a “never event” on the list of reportable events. She is a cofounder and president of Consumers Advancing Patient Safety that envisions a partnership between consumers and providers to create global health care systems that are safe, compassionate, and just (www.patientsafety.org). She also chairs the Patients for Patient Safety program, which is 1 of 6 programs of the World Alliance for Patient Safety, established by World Health Organization in 2004 to advance patient safety practices and policies across the world.

Nancy Conrad has been a national speaker, writer, and contributor for the national patient safety movement since her husband’s death. She is cofounder of the Community Emergency Healthcare Initiative through the Texas Medical Institute of Technology, focused on driving performance improvement in small and rural hospital emergency services. She contributes to the establishment of national performance improvement standards, including the disclosure practice included in the NQF Safe Practices for Better Healthcare—2006 Update. She is establishing national performance awards for hospitals and health care leaders who bring robust solutions into frontline use, including the Pete Conrad Performance Excellence Award in Patient Safety.

Sorrel King is a parent- and family-centered care advocate. She has established the Josie King Foundation which provides funding to a variety of patient safety activities and operates a Web site where health care professionals and the general public can learn more about preventing medical errors. At the Institute for Healthcare Improvement's 2004 National Forum, Sorrel suggested to an audience of 5000 health care providers that parents be allowed to call in emergency medical teams when they feel their child is in danger in a hospital. Thanks to her idea, a program called Condition H (H for help) was created in 2 hospitals in Pittsburgh. "This program creates a team including a doctor, nurse, patient safety person and a respiratory therapist. If, for example, a parent is concerned because they sense their child is not doing well, the parent can call the entire team in and explain their concern before a tragedy occurs. If I had been able to activate a Condition H team, I believe Josie would still be alive. I know a lot of families whose children have died of medical errors and I believe the same for them," she said. She has allowed the Josie King Story on video to be used by hospital teams for educational purposes to improve patient safety on 3 continents in multiple languages. She speaks frequently at national meetings, medical schools, and quality organizations, charging them to address the epidemic of patient safety failures causing harm.

Jennifer Dingman founded Persons United Limiting Substandards and Errors in Healthcare (PULSE), Colorado Division. She cofounded the American Division. The focus of PULSE is to comfort people who have experienced medical errors or unexpected adverse outcomes and help them become proactive in fixing the system, finding resources for coping and finding out the truth, and also helping the hospitals pinpoint where they may improve their systems so that the error will not happen again. The PULSE provides additional help with social services and children's needs and also provides referrals when necessary. She coproduced, with other patient advocates, LISTENING, a video and learning management system targeting caregivers, administrators, and families, teaching them about the art and science of active listening and how it can impact patient safety and prevention of systems failures and human error. Jennifer is a "Champion" with Patients for Patient Safety and participates with World Alliance for Patient Safety and Pan American Health Organization/World Health Organization.

Appendix B: NQF Safe Practice No. 4: Disclosure

After serious unanticipated outcomes, including those that are clearly caused by systems failures, the patient and, as appropriate, the family should receive timely, transparent, and clear communication concerning what is known about the event.³

Applicable Clinical Care Settings: All care settings. Additional Specifications:

- The types of serious unanticipated outcomes addressed by this practice include, at a minimum, a) sentinel events; b) serious reportable events; and c) any other unanticipated outcomes involving harm that require the provision of substantial additional care (such as diagnostic tests/therapeutic interventions or increased length of stay) or that cause the loss of limb or function lasting seven days or longer.

- Organizations must have formal processes in place for disclosing unanticipated outcomes and for reporting events to those responsible for patient safety, including external organizations where applicable, and for identifying and mitigating risks and hazards.
- The governance and administrative leadership should ensure that such information is systematically used for performance improvement by the organization. Policies and procedures should incorporate continuous quality improvement techniques and provide for annual reviews and updates.
- Adherence to the practice and participation with the support system is expected and may be considered as part of credentialing.
- Patient communication should include or be characterized by the following:
 1. the "facts"—an explicit statement about what happened that includes an explanation of the implications of the unanticipated outcome for the patient's future health, an explanation of why the event occurred, and information about measures taken for its preventability;
 2. empathic communication of the "facts," a skill that should be developed and practiced in healthcare organizations;
 3. an explicit and empathic expression of regret that the outcome was not as expected (e.g., "I am sorry that this has happened.");
 4. a commitment to investigate and as possible prevent future occurrences by collecting the facts about the event and providing them to the organization's patient safety leaders, including those in governance positions;
 5. feedback of the results of the investigation, including whether or not it resulted from an error or systems failure, provided in sufficient detail to support informed decision making by the patient;
 6. "timeliness"—the initial conversation with the patient and/or family occurs within 24 hours, whenever possible. Early and subsequent follow-up conversations occur, both to maintain the relationship and to provide information as it becomes available;
 7. an apology from the patient's licensed independent practitioner and/or an administrative leader if the investigation reveals that the adverse outcome clearly was caused by unambiguous errors or systems failures;
 8. emotional support for patients and their families provided by trained caregivers; and
 9. the establishment and maintenance of a disclosure and improvement support system to provide the following to caregivers and staff:
 - emotional support for caregivers and administrators involved in such events by trained caregivers in the immediate postevent period that may extend for weeks afterward,
 - education and skill building regarding the concepts, tools, and resources that produce optimal results from this practice, centered on systems improvement rather than blame and with a special emphasis on creating a just culture, and
 - the 24-hour availability of advisory support to caregivers and staff to facilitate rapid responses to serious unanticipated outcomes, including the provision of "just-in-time" coaching and emotional support.



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