A Heart of Healing
When things go wrong in care-The family perspective

By Dale Ann Micalizzi

We arrived at the emergency department in the evening of a snowy day in January - myself, my husband, and our 11 year old son Justin. There was orange construction fencing blocking the entry path to the hospital so the three of us squeezed through to the walkway to the Emergency Department entrance. I'm not sure why I remember that fencing but perhaps it was an internal warning or an intuition of danger. Malcolm Gladwell's book *Blink* asks:[1] "Why do some people follow their instincts and win, while others end up stumbling into error?" Could it be that we don't want to face what that instinct is telling us so we push it away hoping to forget about it; or are we afraid that we may be right?

As parents, we were apprehensive about bringing our child to this facility for emergent medical care. It wasn't a common occurrence for our family as our three children were, thankfully, healthy.

Justin looked afraid as we entered. His pediatrician had suggested that he might require an intravenous antibiotic following drainage of his infected ankle. Justin asked us not to leave him if he had to stay in the hospital overnight. I promised that one of us would always be with him at all times. "Even if they told you to leave?" he asked. "We will stay no matter what" was my reply. We assured him that everything would be fine, fully expecting that we would be on our merry way as soon as the staff had performed an incision and drainage of his septic ankle.

We trusted his caregivers even though we had never met them before and knew nothing about any of them. It's what patients have done for years: trust and respect medical professionals. We now know that this thinking is antiquated. Trust alone is not enough. In his recent book *Laugh, Sing, And Eat Like A Pig,*[2] Dave deBronkart ("e-patient Dave") reminds us that safe healthcare relies on patients and families becoming active participants in their own healthcare – seeking information, asking questions, keeping their own records, and raising concerns. We need to be partners with our physicians rather than passive recipients of care.

That night, back in 2001, my husband and I hadn't heard much about medical errors. We had heard some talk about anesthesia complications, so when we were told that Justin would need general anesthesia we asked for a local instead. The doctors denied our request, stating that he couldn't move during the procedure. We didn't ask how many years of experience the anesthesiologist had or whether he had ever completed this procedure before or whether he had ever been disciplined for poor care. If we had asked those simple questions, we would have known to demand a more experienced provider. But, we didn't know.

The Institute of Medicine's report estimating that up to 98, 000 Americans die each year due to medical error*[3]* had been released a few years before Justin's death. But, like most members of the public, we were unaware of the report. Many clinicians and medical students were also oblivious to the report's findings as patient safety was not yet a common component of medical school training.

Our confidence that everything would be fine was misplaced. Something went terribly wrong during Justin's surgery. We began to sense fear and secrecy as codes were called. Our anxiety increased as the wait time became increasingly long. The surgeon finally arrived and told us quietly that Justin had arrested during the procedure and was being transported to the area Pediatric Intensive Care Unit (PICU). We were in shock. We couldn't talk or move or ask questions. We just sat and stared. It was a parent's worst nightmare and we were paralyzed in the clenches of the trauma.

Broken Promises

The staff involved met us in the hospital corridor prior to transport. Papers were signed and a young nurse hugged us with tears in her eyes. Justin was on a stretcher in the hall being wheeled away by the trauma team to the ambulance. They wouldn't let us ride along. I had broken my promise not to leave him already. My husband's promise that he would be fine was also broken. That pain and guilt has eased only minimally over the ensuing years. I often wonder and worry about that nurse and resident who completed the surgery alone; it must have been so difficult for them to experience that adverse event.

The surgeon walked us to our car in silence. If he said anything, we have no idea what it was. Our world had crashed and listening wasn't one of our active senses yet. This may be why physicians often think that parents don't hear what they are saying: because they can't, not because they don't want to, they just are not physically able.

Our other children and family now joined us at the hospital upon advice from the chaplain, as moments of life were sparse. Two ministers held our hands and prayed with us in a tiny room. I was heaving over a garbage can, unable to control the turmoil in my stomach. The chaplain later wrote his thesis about Justin.

Religion and God are important for many families and they are often neglected in the medical setting following an adverse medical event or a hospital death. Even though they don't request a chaplain, many families still need one. God promised to take care of my children. That promise to me was now broken and the years of belief were shaken.

The pain of seeing my child in this condition was unfathomable. I left his room as the team attempted to revive him over and over again. His lungs were now in a white out state and we learned later that he had hemorrhaged through the endotracheal tube at the time of the initial arrest. I couldn't watch. I rocked back and forth while kneeling down outside his room. I remember a group of residents being briefed on the case and one of them wanting to comfort me but sadly turning away. I remember his dark hair and eyes looking down at me. Even nine years later, tears stream down my face as I write this like it was yesterday.

After multiple arrests and attempts to save our son by the caring physicians at the PICU, Justin couldn't be saved. We knew that they had tried their best. The doctors, nurses, ministers and our family cried together that morning as we left Justin alone for the final time.

Our thoughts often turn to the belief that we could have saved our son if we had done something differently. Perhaps, parents now, through patient advocacy, will learn that the caregiver is a guest in your life, not the host of it and it is ok – even vital - to get involved. My friend and mentor, Don Berwick, former President of the Institute for Healthcare Improvement and now Administrator for the Centers for Medicare and Medicaid Services writes about what Patient-Centered care should mean in a recent Health Affairs article:[4]

> "In the territory between the professionally dominant view of quality of health care and the consumerist view, my views are far from Freidson's definition. I think it wrong for the profession of medicine—or any other health care profession, for that matter—to "reserve to itself the authority to judge the quality of its work." I eschew compromise words like "partnership." For better or worse, I have come to believe that we—patients, families, clinicians, and the health care system as a whole—would all be far better off if we professionals recalibrated our work such that we behaved with patients and families not as hosts in the care system, but as guests in their lives. I suggest that we should without equivocation make patient-centeredness a primary quality dimension all its own, even when it does not contribute to the technical safety and effectiveness of care."

Compassionate Care

That caring team at the PICU softened my journey in a way that many other families never receive. I write about a special physician in a chapter entitled *Compassionate Care*

Personified in Putting the CARE in Health Care.[5] Some families carry anger around for years which becomes more intense with each broken promise or unreturned phone call. A gentle hug, listening ear, kind word, card, or visit can make a world of difference in the aftermath of an adverse event.

A call from the coroner's office later that morning informed us that something wasn't right in Justin's care and that we needed to agree to a complete autopsy. He also advised us to seek an attorney. Again, we didn't question. Knowing what I know now, I may have declined.

Seeking Support

Patients and families want honest answers from the physicians involved in their loved one's care. They want to know **what went wrong, why it happened and what's going to be done to prevent it from happening again**. Most want an unrehearsed, authentic apology but for many the apology isn't as important as the honest disclosure, which they **need**. The number one complaint of many of the families I meet is the difficulties they encountered in obtaining a copy of their child's hand written or electronic medical records. It often takes years for parents to piece together their child's care after meeting roadblocks and excuses every step of the way.

Families react differently to trauma, and may have different needs in the aftermath of an adverse event, depending upon their cultural background. One of my favorite books, *The Spirit Catches You and You Fall Down[6]* by Anne Fadiman, exemplifies the differences

unraveled by a warm, understanding physician. Lazare tells us in his book, *On Apology*: [7] "Thus, Japanese apologies are focused primarily on restoring the relationship with the offended party, rather than on relieving an internal state of mind, such as guilt, which is more characteristic of person-to-person American apologies." Or, as John Banja writes in *Medical Errors and Medical Narcissism:* [8] "Coming to accept the value of forgiveness in instances of harm-causing error will probably require nothing short of a "paradigm change" whereby the attitudes, values, beliefs, and the historically enculturated roles of health professionals and patients are overhauled."

My friend and colleague Marie Bismark writes in her paper *The Power of Apology*:[9] "For others, an apology may provide important confirmation that the health system, and not the patient or family, was responsible for the injury. Many patients and families (particularly the parents of children who have died or suffered permanent disability) wonder whether they are in some way to blame for the harm that occurred. By truthfully acknowledging the extent to which the injury was caused by healthcare, health practitioners can lift the burden of uncertainly and guilt from their shoulders, and provide an understanding of how and why things went wrong."

After turning to the caregivers for support and answers, the family often seeks counseling, medication or support groups for themselves and specifically for any children affected by the loss. The patient didn't really die alone; when they died they took a portion of each remaining family member along with them. I often refer to these as the

“second victims”: the memories and trauma will always remain a part of who they are and what they become.

The Adverse Childhood Experiences Kaiser Study[10] has established that traumatic childhood experiences are strong predictors of adult health risks and disease, including depression, teen pregnancy, alcoholism, drug abuse, liver disease, cancer, chronic lung disease, skeletal fractures, and impaired job function later in life. The death of a parent is scored in a category of defining moments, alongside other forms of trauma such as child abuse. In my experience, the death of a sibling can be just as traumatic as the loss of a parent and the death of a child outranks all others. Further research into the devastating effects of adverse medical events on children, adults, and providers might lead to stronger calls for effective trauma support.

Emotional/Physical Impact Following a Child’s Death-My research

I’ve personally heard hundreds, if not thousands, of testimonies from families following the deaths of their children via my involvement with a parent support group and through my patient safety work. My website for Justin’s HOPE at The Task Force for Global Health[11] invites those who have lost a child to complete a survey on the emotional and physical impacts of their child’s death.

Around half of the survey respondents reported that their child’s death involved some form of healthcare, with many of the deaths attributable to adverse medical events. Other causes of death ranged from auto accidents to suicide to drug overdose and drowning to

“bullycide” and homicide. Regardless of the cause of death, or the parents’ circumstances, the pain of losing a child is similarly devastating. However, those who had lost a child to an adverse medical event tended to have more symptoms of “complicated grief”, suffering from a loss of trust in future caregivers and the anguish of living with unanswered questions.

Most of the parents who responded to my survey reported physical ailments and all experienced emotional trauma following the death of their child. Half received medical treatment for one or both categories of symptoms and all experienced profound sadness. 75% experienced guilt for many years following the event. Many still remain in treatment, while others have found family or friend support and counseling helpful. Some did not return to work because of the lasting physical and emotional affects of the trauma. A few filed for bankruptcy. Some have turned to sports, exercise, reading, writing, music, art or adopting a pet for comfort.

The Compassionate Friends[12] Support group was helpful to many. Some parents became more religious and found comfort in a regained faith. Those who had tried to relocate after their child’s death usually found that moving didn’t help as they took their pain with them. However, some found short vacation breaks to be cleansing.

The greatest healing, for both adults and children, seems to come from finding a kind and caring person who is willing to go that extra mile.

What emotional symptoms did you develop following the death of a child?	Response percentage
Sleeplessness	81.7%
Depression	81.7%
Anxiety	73%
Mood changes	58.3%
Delirium	1.7%
Fatigue	65%
Post Traumatic Stress	53.3%
Alcohol/drug abuse	59%
Anger management concerns	18.3%
Uncontrollable crying	50%
Uncontrollable laughing	3%
Lack of emotions	28.3%
Lack of concentration	60%
Morbid thoughts	33.3%
Suicidal thoughts	45%
Obsessive compulsive tendencies	23.3%
Bipolar diagnosis	1.7%
Irritability	40%
Unable to leave home	18.3%
Unable to return to work	21.7%
Lack of motivation	55%
Lack of joy	68.3%

Additional consistent emotional complaints-Comments of interest:

Weight gain and loss, eating disorders, husband's loss of interest in sex, overprotective of other children, irrational decision making, frequent job changes, not the person that I was before, zest for life is gone.

Conclusion: Added financial burden on the healthcare system caring for the victims of adverse events seems staggering. Preventing harm seems to be the answer and the cure.

Common physical complaints-Comments of interest:

Chest pain and palpitations, arm numbness, insomnia, dizziness, hair loss, weight gain and loss, headache, several gynecological surgeries.

***All families had some healthcare contact even if their child was transported to hospital following a near death at home. Their need for support was significant and the lack there of was blatant.**

There were 75 participants completing this ongoing study. We would suggest further detailed research but this may give readers synapses of the affects of trauma.

Scientific advances

When one of the chief supervising anesthesiologists overseeing Justin's anesthesiologist told us that we may never know what happened to Justin as "medicine doesn't have all of the answers" we were shocked. At the time, we thought it to be a callous and disparaging remark. Yet, in reality it was probably the honest truth. They either didn't know or no one would be talking.

Being a board member for an Anesthesia Association, I am privy to cases discussed and have realized that physicians and scientists are often guessing when things go wrong. I have heard the fear in physician's voices when they're trying to save a patient that they're loosing. Yes, they review and scrutinize all of the data and research that is provided to them and try to decipher circumstances or common occurrences, but many unsolved medical cases remain.

How many life-altering errors could be prevented if we had accurate electronic medical records, mandatory reporting, a culture of transparency and learning, and improved research funding? How many deaths could be avoided if we enlisted parents and families as partners in understanding what went wrong and designing safer systems? Nobody knows a child better than his or her own family; nobody else witnesses the care that is delivered from quite the same perspective; nobody else has a greater interest in saving another child from tragedy.

Closure

When faced with silence following an adverse medical event, patients and families often jump to the conclusion that an error has occurred. And, sometimes they are not jumping to conclusions at all; an error may in fact have occurred. Renowned surgeon Atul Gawande writes that: [13] “The way that things go wrong in medicine is normally unseen and, consequently, often misunderstood. Mistakes do happen. We tend to think of them as aberrant. They are, however, anything but.”

Following an adverse event, silence instills distrust. When parents perceive that health professionals are indifferent to their suffering, a previously trusted physician may become a villain. When calls go unanswered, anger among family members may heighten. “They owe us answers”, many enraged parents share with me, adding “He/she was our child, not theirs!” The lack of response and lack of support implies that their family member was a number, rather than a deeply loved child.

If only physicians and legal counsel realized the potential for healing in the one simple powerful sentence those parents want to hear from providers after an adverse event: “I have no idea what happened but I will try everything in my power to find out for you.”

David Svahn, co-editor of *Let Me Listen To Your Heart[14]* a book containing writings by medical students, wrote to me: “Many students beginning their clinical medical training are possessed of the sensitivity and compassion that we all seek in our caregivers...The science of medicine is still uncertain; there are not always answers. But

the importance of compassion and empathy and the personal touch are not in doubt. I hope the book offers you reassurance that the profession recognizes that humanism must be given emphasis in a technological age."

From tragedy to advocacy

As the public gain awareness of medical error, the number of families taking action against poor and unacceptable treatment is steadily increasing. It is a heartening trend. With data and networking becoming more available to patients, partnerships are developing and progress is occurring. Jean DerGurahian, health writer for Modern Healthcare magazine writes:[15] "A determined breed of patient-safety advocates have forged their personal pain into a dedication to improving medical safety."

Courage is rising among patients and families ready to stand up for compassion and safety. Regina Holliday, an artist who paints about her husband's death and the pain her family has suffered because of adverse medical events and lack of compassion in his care, offers this advice: "It is amazing how much better life can be if we just listen to each other."

The art of listening and the act of caring are proven remedies to medical harm.

Dale Ann Micalizzi is the founder and director of Justin's HOPE Project at The Task Force for Global Health. http://www.taskforce.org/our-work/projects/justins-hope
She is a consultant and national speaker on patient safety and transparency in medicine and awards yearly scholarships to the Institute for Healthcare Improvements forum to those caregivers with a passion for pediatric patient safety. http://www.ihi.org/ihi

Portions of this manuscript can be found in my Modern Healthcare Commentary, "The aftermath of a never-event" Mar. 2008 and Pediatric Anesthesia, "What happens when things go wrong" by Barbara W. Brandom, Patrick Callahan and Dale Ann Micalizzi 2010.

*My gratitude goes to Jean DerGurahian and Marie Bismark for their editing assistance and friendship. To all of the families who have endured this unspeakable loss and have had the courage to share their pain with us in order to help others, we thank you immensely.

Resources:

1. Gladwell, M., *Blink*. 2007: Back Bay Books.
2. deBronkart, D., *Laugh, Sing, and Eat Like a Pig: How an Empowered Patient Beat Stage IV Cancer (And What Healthcare Can Learn from It)*. 2010: Changing Outlook LLC.
3. IOM, *To Err Is Human: Building a Safer Health System*. 2000, National Academy Press: Washington DC.
4. Berwick, D.M., *What 'Patient-Centered' Should Mean: Confessions Of An Extremist.* Health Affairs, 2009. **28**(4): p. w555-w565.
5. Shapiro, E., *Putting the CARE in health care*. 2009, Oakbrook, Illinois: JCAHO.
6. Fadiman, A., *The spirit catches you and you fall down: a Hmong child, her American doctors, and the collision of two cultures*. 1998: Farrar, Straus and Giroux.
7. Lazare, A., *On Apology*. 2004: Oxford University Press.
8. Banja, J.D., *Medical errors and medical narcissism*. 2005: Jones & Bartlett Learning.
9. Bismark, M., *The Power of Apology.* New Zealand Medical Journal, 2009. **122**(1304).
10. Dube, S., et al., *The impact of adverse childhood experiences on health problems: evidence from four birth cohorts dating back to 1900.* Preventive Medicine, 2003. **37**(3): p. 268-77.
11. Micalizzi, D. *Justin's HOPE.* Available from: http://www.taskforce.org/justinhope.asp.
12. Stephens, S. *The Compassionate Friends: Supporting family after a child dies*. [cited 2010; Available from: http://www.compassionatefriends.org/home.aspx.

13. Gawande, A., *Complications: A Surgeon's Notes on an Imperfect Science*. 2003, Picador.
14. Kozak, A., *Let me listen to your heart*. 2002: Bassett Healthcare.
15. DerGurahian, J., *From tragedy to advocacy: A determined breed of patient-safety advocates have forged their personal pain into a dedication to improving medical safety* Modern Healthcare, 2009. **7** September.