The Heart of Health Care
Parents’ Perspectives on Patient Safety

Dale Ann Micalizzi, AASa,*, Marie M. Bismark, MBChB, LLB, MBHL, MPHb

AUTHORS’ BACKGROUND
Dale, a childhood educator in New York, is mother of Dan, Andrea, and Justin and grandmother to Isabella. When Justin was 11 years old he underwent minor surgery on his ankle. During the procedure, something went terribly wrong and Justin’s heart arrested. Justin was urgently transported from the surgical hospital to a pediatric intensive care unit where Dale and her husband experienced every parent’s worst nightmare: the preventable loss of their loving, healthy child. Error on error killed Dale’s son and her faith in a medical system that was meant to comfort and heal. Determined not to let this unbearable pain happen to another family, Dale has spent more than 10 years working with the health care sector, trying to reduce the fear and secrecy that surrounds adverse events. As part of this endeavor, Dale founded the Justin’s HOPE Project at the Task Force for Global Health.1

KEYWORDS
- Patient safety • HEART model • Service recovery • Medical error • Patient harm
- Healthcare quality

KEY POINTS
- Today there is no lack of discussion about health care delivery and quality.
- Quality from the parent’s perspective includes access to care, responsiveness and empathy, good communication and clear information, appropriate treatment, relief of symptoms, improvement in health status, and safety and freedom from medical injury.
- If a medical injury occurs it is important to listen to the parent, acknowledge the damage, give an honest and open explanation and an apology, acknowledge anxieties about future treatment, and provide practical and financial help quickly.
- Nursing shortages, overtime, financial obligations, and insurance company guidelines interfere with the quality of care.
- Work as a team, review all the information, establish a plan, communicate between specialists, remove arrogance and intimidation, and have a common goal to heal.

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with the Institute for Healthcare Improvement, provides yearly scholarships to health caregivers who are committed to patient safety and providing a safe health care environment for patients and their families.\(^2\)

Marie has three children (Finn, 12; Stella, 10; and Zoe, 8) who have experienced the usual spectrum of childhood bumps and illnesses while living in New Zealand, Australia, and the United States. For the last 10 years Marie has worked in the field of patients’ rights and complaints resolution, including 4 years as an advisor to the New Zealand Health and Disability Commissioner and a year as a Harkness Fellow at the Harvard School of Public Health. Marie currently works as a Senior Research Fellow at the University of Melbourne researching the influence of patients’ complaints on quality and safety of health care.

**INTRODUCTION**

Health care providers that encourage patients and parents to be "the eyes and ears" of patient safety gain many insights into opportunities for improvement and risk prevention.\(^3\) Yet, in the world of quality improvement the voices of patients and their families often go unheard. As mothers of children who have benefited from and been harmed by pediatric care we are grateful for this opportunity to share our perspectives on patient safety.

Our views are informed by our personal experiences, and enriched by conversations and written communications with hundreds of families. Many of the parents we have spoken with lost not only a child, but also their trust in medicine as a result of a senseless and preventable medical error.

*As they were administering the anesthetic to James he looked at the anaesthetist and said “don’t hurt me.” Those were James’ last words.*

Others recall extraordinary care and moments of compassion as doctors partnered with them to provide their child with the best possible care.

*It is the memory of one act that still brings tears to my eyes. In the junction between hospital buildings there is a join in the floor. This caring nurse stopped Chloe’s trolley and individually lifted each wheel over the join to prevent her broken neck from being jolted. Compassion is revealed in the smallest acts.*\(^4\)

There is no substitute for being present with these families as they recall their experiences of pediatric health care: the good and the bad. To communicate some of their sentiments and suggestions with the reader, we have woven their words within this article wherever possible. Through different yet connecting eyes we offer the parents’ view of patient safety and share our hopes for the future.

This article is arranged in five sections, which correspond to the five parts of the HEART model for service recovery: *Hear, Empathize, Apologize, Resolve, and Thank*. Variations of this model are used within\(^5,6\) and outside\(^7\) health care by front-line staff who seek to resolve problems by putting the needs of the affected person first.

**SERVICE RECOVERY AND THE HEART MODEL**

As parents, we do not expect perfection. We understand that people make mistakes and we understand that no part of life is entirely free from error or harm. However, we do expect that systems are designed with safety in mind and that when things go wrong someone steps in quickly to fix the problem. Unfortunately, health care performs poorly on both counts compared with other industries with stronger cultures.
of safety, service, and learning. Day after day, children are harmed by care that was intended to heal.\textsuperscript{8,9} Frequently, parents seeking to understand what happened and why are faced with a wall of silence.\textsuperscript{11,12} Too often, injured families are treated as adversaries rather than allies in the search for safer care.

Much has been written about the negative impact of medical malpractice litigation on doctors’ reluctance to speak openly and honestly with families in the aftermath of adverse events. Certainly, the punitive, individualistic, adversarial approach of tort law runs counter to the nonpunitive, systems-oriented, cooperative strategies promoted by leaders of the patient-safety movement.\textsuperscript{12} Yet it is too simplistic to suggest that the fear of legal action is the only obstacle standing in the way of true partnership with patients and families who have been injured by the very care that was intended to heal. Medicine has a long tradition of exercising paternalistic sovereignty over patients’ information\textsuperscript{13} and “circling the wagons” in defense against accusations of patient harm. Even within such countries as New Zealand, where malpractice litigation is effectively barred and compensation is provided on a no-fault basis,\textsuperscript{14} fears of reputational damage, professional discomfort with uncertainty and failure, medicolegal myths regarding the risks of disclosure, and an entrenched culture of self-protection still impede the willingness of some doctors to talk openly about and learn from adverse events.\textsuperscript{15}

However, the news is not all bad. Many industries outside of health care have effectively designed safety features into the workflow (ie, limited hours for taxi drivers, checklists for pilots).\textsuperscript{16} In hospitals and clinics around the world, an increasing number of providers are finding the courage to “do the right thing” with or without the support of legislative or policy reform. Examples include the “3R’s program” implemented by COPIC in Colorado\textsuperscript{17} and the “seven pillars” process developed by the University of Illinois Medical Center at Chicago.\textsuperscript{18}

One simple, yet effective, model of service recovery that goes a long way toward meeting the needs of injured patients and their families is the HEART framework. Variations of the HEART model, including the Cleveland Clinic “Respond with HEART” program,\textsuperscript{6} are used by several health care providers in the United States and elsewhere.\textsuperscript{5} As explained by Brenda Radford, from Duke University Hospital,\textsuperscript{19} HEART has two aims: “The first goal is to prevent patient concerns from occurring ... If that fails, service recovery is simply making right what went wrong.”

By using the HEART model, providers can respond with compassion and learn from every mistake. The following sections break down each of the five steps and provide context for providers interested in applying the model to their own practices.

\textbf{Hear}

Parents have a critical role to play in the delivery of safe, high-quality pediatric care. We can assist with diagnosis, management, and administration of treatment. We can provide an extra set of “eyes and ears,” noticing subtle changes in our child’s condition and alerting providers to possible risks and errors in the delivery of care. However, we can only fulfill that role if our voices are heard and respected.

\textit{It had been extremely distressing that no one would believe Simone was seriously ill, when I – as her mother – was all too aware of her precarious state. Then, when it was almost too late, I was being treated as if I had not acted soon enough.}

Honest information, clear communication, and a participative approach should be the watchwords in promoting safety at all levels of pediatric health care. Some hospitals do this well.
Upon arrival we were shown around, introduced to the nurses, told all about the monitors, and everything was fully explained to us ... Nothing was ever too much bother, every question we asked was answered no matter how silly it sounded ... Whenever a doctor or nurse did anything to Oliver it was explained fully, what and why they were doing it ... Everything was parent and child oriented.

Yet many parents feel unsafe to speak up, worry about being labeled a “difficult parent” if they ask too many questions, or face exclusion from conversations about their child.

When I saw [the doctor] he was always accompanied by other people and seemed to be talking to them and at me as opposed to including me in the conversation and making sure I understood exactly what was going on.

Likewise, many children who are old enough to have a voice in their own care are treated with little respect for their dignity or independence.

No one even told me their name. They just started poking at me and talking amongst themselves like I wasn’t even in the room.

For health care providers the hospital environment is a second home: routines are familiar, everyone’s role is known and understood, and medical jargon is readily interpretable. However, for parents the hospital environment is a frighteningly unfamiliar place and explanations are often inadequate.

No one gave us any ideas on what to look for, to check if there was a change in her condition.

From clothing to meals, from visiting hours to pain relief, choices are repetitively taken away from parents. Little is posted, little is clear.

The worst aspect of her second operation was the “losing control.” There was nothing we could do. We had to rely entirely upon the “experts.”

Even the process of informed consent, which is intended to support choice and understanding, is frequently derailed through the use of vague and legalistic documents and forms. For a patient or family member who is already feeling frightened and vulnerable, quickly signing and pushing the form away may feel safer than struggling to work through language and concepts they are ill-equipped to understand.

From a parents’ perspective, three key elements in being heard are (1) trust, (2) openness, and (3) respect. Trust is present when we feel confident that a provider has our child’s best interests at heart, that he or she has the time to listen, and that he or she will take our concerns seriously. If we feel unable to trust our child’s doctor, we may turn to another member of the team (a nurse, a social worker, a health care assistant, or patient advocate) or we may simply remain silent and uneasy.

My concern at the time was that she was on a general nursing ward with a severe condition and no attempt of barrier nursing to help prevent her contracting further infections. I did not voice my concern at the time. It was difficult to criticize professionals.

Openness requires providers to share the information we need to participate in meaningful dialogue about our child’s care. How can we understand our child’s illness and medical needs when we do not have easy access to his or her test results and medical record? How can we explore our options when medical journals keep important research findings locked behind expensive pay walls? How can we choose the
safest care for our child when we do not know how many times the surgeon has performed this procedure or how the local hospital’s infection rate compares with the facility down the road? The health care system’s ongoing failure to provide parents’ with ready and timely access to information relevant to their children’s care is inexcusable.

We were not offered any part in the decision making. We were just told what would happen. The alternatives were not discussed with us … With hindsight we feel that it would have been helpful to have been confronted with the full facts, and to have been given an indication of the implications and the options open to us.

Finally, respect involves recognizing and valuing parents’ knowledge and perspectives. Many parents experience a powerful sense of intuition that something is wrong long before a doctor is able to put a name to the problem: a voice inside our heads warning us to be watchful and wary. Doctors disregard a parent’s inner voice at their peril.

My wife had always felt sure that there was something else wrong with Oliver. But the doctors brushed it aside. It would be another two years before anyone else would take my wife’s fears seriously.

Moms and dads should be reassured that their gut feelings matter and encouraged to speak up if they feel worried about their child’s care or clinical condition. A good clinician will ask: “Do you have anything inside that is bothering you because we would really like to hear it? Your thoughts can change the plan for the better.” For some children, having their parents’ voices heard in time can mean the difference between life and death.

**Empathy**

When an adverse event does occur, parents have different needs depending on the nature of the injury, relationship with the providers involved, previous health care experience, and cultural values and norms. Regardless of background, parents of an injured child always remember a compassionate moment from a child’s caregiver; a gentle touch or a shoulder to cry on:

Two nurses impressed us with their care in particular. They communicated empathy to us in our distress and demonstrated concern for our child.

Facing the raw emotions of a parent whose child has been injured is not easy. The providers involved often are dealing with their own shame and fear, and they may be ill-prepared and poorly supported in responding to the consequences of an adverse event. Yet, it is at that very moment when the injured patient and family need their care the most.

She seemed uneasy with us and the situation we were in. It was as if she was not sure what to say or was unsure how we would react. She remained detached from us. [It] was a deeply lonely experience.

The death of a child is a time of unparalleled grief and vulnerability. **Table 1** illustrates the scope and severity of symptoms reported by a group of 75 parents after the loss of a child. Many of these parents recall that being left alone at their lowest moment of despair was the most painful part of an already devastating experience. Parents need comfort when there is nothing else left to give.

Many health care providers could learn a lot about empathy and compassion from the end of life care provided in pediatric intensive care units and hospices. The doctors
and nurses in these units know all too well the devastation that follows the death of a child, they have heard the animal-like cries of loss from bereaved parents, and they have shared tears of sadness with the families they serve. They understand the importance of listening, rituals of care, support, and comfort while facing the reality that sometimes your best is not good enough.

Keeping promises is essential. A provider who promises to stop by, bring a cup of coffee, or plan a family meeting must follow through. Broken promises are always remembered; forgiven usually but not forgotten.

After returning home I telephoned the hospital several times. On each occasion I was told that no one was available to speak to me, or alternatively, I was just put on hold and ignored.

Acknowledging the individuality of the child and the family is important too. Our children are important to us and should be important to providers, too. After an adverse event, providers should sit down, make eye contact with family members, and listen with an open mind and heart.

Hospital staff deal with countless patients and the individuality of the person may be lost amongst all the flesh and tissue.

When a child has been injured by medical care, the need for empathy and care extends long beyond the initial period of grief and well beyond the immediate family.

<table>
<thead>
<tr>
<th>Emotional and Psychological Symptoms</th>
<th>Percentage (n = 75)</th>
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<tbody>
<tr>
<td>Sleeplessness</td>
<td>82%</td>
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<tr>
<td>Depression</td>
<td>82%</td>
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<tr>
<td>Anxiety</td>
<td>73%</td>
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<tr>
<td>Lack of joy</td>
<td>68%</td>
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<tr>
<td>Fatigue</td>
<td>65%</td>
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<tr>
<td>Lack of concentration</td>
<td>60%</td>
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<tr>
<td>Alcohol or drug abuse</td>
<td>59%</td>
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<tr>
<td>Mood changes</td>
<td>58%</td>
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<tr>
<td>Lack of motivation</td>
<td>55%</td>
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<tr>
<td>Posttraumatic stress</td>
<td>53%</td>
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<tr>
<td>Uncontrollable crying</td>
<td>50%</td>
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<tr>
<td>Suicidal thoughts</td>
<td>45%</td>
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<tr>
<td>Irritability</td>
<td>40%</td>
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<tr>
<td>Morbid thoughts</td>
<td>33%</td>
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<tr>
<td>Lack of emotions</td>
<td>28%</td>
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<tr>
<td>Obsessive-compulsive tendencies</td>
<td>23%</td>
</tr>
<tr>
<td>Unable to return to work</td>
<td>22%</td>
</tr>
<tr>
<td>Unable to leave home</td>
<td>18%</td>
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<tr>
<td>Anger management concerns</td>
<td>18%</td>
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<tr>
<td>Uncontrollable laughing</td>
<td>3%</td>
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<tr>
<td>Bipolar diagnosis</td>
<td>2%</td>
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<tr>
<td>Delirium</td>
<td>2%</td>
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Table 1
Symptoms reported by 75 parents after the loss of a child
I remember walking up the steps out of the hospital feeling empty, leaving Daniel there and going home. The whole way home I was sobbing and then I had to tell people that he had died after an operation which was to give him life. There was no offer of counseling, though we were given a blue leaflet on how to cope with death.

Health professionals cannot always be there, but they can put parents in touch with groups and individuals who can help. Some support groups take advantage of the social media transformation that brings together parents from around the world to share support and guidance. Such Web sites as Caring Bridge, Patients Like Me, and many disease-specific sites are full of parents who want to offer a supportive shoulder to other families experiencing similar questions and concerns.

Others, such as those run by Family Voices and The Compassionate Friends International, meet in person. To witness a group of bereaved parents gathering in a support group is an extraordinary experience. Newly grieving parents arrive at their first meeting bent over with despair, and receive strength from other parents quietly listening, advising, holding, supporting, and knowing. At the next meeting they are there again, offering care and compassion to newer parents through their own grief. It is a circle of love and a true testimony of humanity.

I felt very alone so it felt good to be able to communicate with other parents, and share our concerns.

The impact of an adverse event on friends and the wider community should not be forgotten. When Dale returned to Justin’s school to clean out his locker, she witnessed one of his friends being scolded and punished for his bad behavior that day. The teacher said “I don’t know what’s wrong with you!” More than 10 years later Justin’s friends still visit his grave each year on his birthday.

Medical schools and postgraduate training programs play a critical role in equipping students with the self-awareness and skills they require to respond to adverse events in an open and empathetic manner. Some, such as the University of Illinois at Chicago Institute for Patient Safety Excellence, already emphasize the importance of sharing information with families and integrate disclosure practices into the course of their practice. Others continue to expose students and trainees to a culture of detachment and denial.

The trauma that parents experience as the result of an adverse event is bad enough. The trauma inflicted when the incident is managed poorly can be even worse. When things go wrong, more than ever before, parents need their child’s caregivers to be kind, dependable, and above all to be there.

They may not remember what you said or what you did but they will remember how you made them feel.

~ Maya Angelou

Apologize

In addition to empathy and compassion, parents dealing with the aftermath of an adverse event need to know that their child mattered to caregivers and that lessons will be learned to prevent another family suffering similar harm. Rapid open disclosure, a thorough investigation, appropriate accountability, and a sincere apology can save relationships and save lives.

All I kept thinking was ... why had this happened? The following day we asked to see [the doctor] for an explanation. I can remember him saying words to the effect “It’s one of those things that happens.” I did not feel at all happy with the explanations – or rather, lack of explanations. We were receiving no straight answers ...
When we suspect that information is being withheld or altered, when we face barriers to accessing our child’s medical record, when we wait and wait for telephone calls to be returned, when we hear whispers in the hallways—we become suspicious. Secrecy is damaging. Being open brings comfort and respect.

*We wanted to know why our daughter had died. We did not understand why the report should have been hidden from us.*

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. The thought that this catastrophe could have been prevented if we, the family, had done something differently may nag parents and siblings for years.

*It was our job to keep our child safe. If we don’t know what happened, we inevitably blame ourselves for having failed in our duty as parents.*

An apology from the doctors may provide important confirmation to the family that the health system had more responsibility for the injury than did the patient or the family. By truthfully acknowledging the extent to which the outcome was a result of their actions or of broader aspects of the health care system, health practitioners can lift the burden of uncertainly and guilt from the shoulders of the family and provide an understanding of how and why things went wrong.26

*At one point we noticed Laura had a burn on her leg caused by drugs which were leaking from her drip. When we brought this burn to the doctor’s attention, he said it was not a problem since “we can always do a skin graft.” He did not say “I’m sorry.”*

Kathryn Schulz notes in her book *Being Wrong*: “As a culture, we haven’t mastered the basic skill of saying ‘I was wrong.’ This is a startling deficiency, given the simplicity of the phrase, the ubiquity of error, and the tremendous public service that acknowledging it could provide.”27

*There was complete silence from the hospital. It made us feel that something had gone wrong and that the hospital staff were too embarrassed to face us.*

**Resolve**

What differentiates health care organizations—positively or negatively—is the way they respond in a crisis. Are they willing to work with patients and their families to resolve a problem in a positive and proactive manner, or do they run and hide?

Resolving the harm caused by an adverse event usually takes two forms: remedying the harm to the individual patient and family wherever possible (by way of treatment, rehabilitation, and compensation where appropriate28); and addressing the underlying problem to provide safer care in the future. Such restorative measures—combined with timely and compassionate communication—benefit patients and their families, may avert potential medicolegal action,17 support safer care, and strengthen trust in health care systems. Given the opportunity, the families of children injured by health care will give the best that they have to give to protect another child from suffering similar harm.

*I could not bear the thought of another parent going through what we went through.*

Parents’ efforts to develop and promote safer care have been arduous and the results slow at times. Yet, great strides have been made toward improving pediatric
health care for the better. Some of the many contributions offered by families of children harmed by health care are shown in Table 2.

During the course of a typical hospital admission, parents learn quickly about systems that work and those that do not. Look-alike medication bottles, miscommunication, poor hand hygiene, missing test results, short staffing, inconsistent advice from different doctors, no clear processes for reporting or learning from errors—the opportunities for improvement seem so clear to parents sitting for hours on hours watching the daily activities of care.

We see the difference between well-trained and rested staff and those who are exhausted or out of their depth.

At the shift changeover I remember than an agency nurse took over. He said he did not work on the unit very often and it was apparent that he was not at all used to the equipment ... I was a little worried at his lack of knowledge and experience.

We see what happens when a member of senior hospital leadership does a safety walk and what happens when his or her back is turned. We see which protocols are followed and which are ignored when the ward becomes busy.

We noticed that some staff were more stringent in matters of hygiene than others. Some members of staff neglected to wear plastic gloves and masks [when undertaking procedures in the intensive care unit]. We found this worrying at the time and wonder, in retrospect whether such lapses in hygiene might have been responsible for Laura’s primary infection which led to her septicemia.

We see which doctors roll their eyes when required to complete a checklist and which ones understand their importance for safe, reliable care. We see the way that alarms are ignored like the boy who cried wolf, until one day there really is a wolf.

We observed that one of Michael’s monitors went haywire for a few seconds and we pointed this out to a nurse who dismissed this as a problem that happened quite frequently with that piece of equipment. We found that quite strange: how would they then know when there really was a problem?

We see the value of premixed medications and dedicated ward pharmacists. We see the opportunities to save money while still providing great care through the avoidance of duplicate tests and unnecessary delays.

Staff were unable to find her previous X-rays for comparison ... I was appalled at the lack of information technology systems available to the staff.

We see the care provided to our children across different shifts, different professions, different locations, and different times.

For those providers interested in improving patient safety, parents can provide an extraordinary resource. No one else has a greater insight into the day-to-day workings of the hospital, from the patient and family perspective, and no one else has a stronger incentive to ensure that the care provided is safe and effective.

As parents, we want to know that our child will be safe at any hospital and we are willing to help resolve any problems that might stand in the way of that goal. We are not looking for a tokenistic patient safety office but rather an embedded culture in which the safety of our child matters to each and every person caring for them. This is what we mean when we say “take care of my baby.” Is that naive? Or is it what our children deserve?
Table 2
Ways in which parents contribute to patient safety

<table>
<thead>
<tr>
<th>Examples</th>
<th>Case Study</th>
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<tbody>
<tr>
<td><strong>Education and information</strong></td>
<td>Dale Ann Micalizzi has presented her son Justin’s story to many medical students including students at Yale Medical School</td>
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<tr>
<td>Grand rounds</td>
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<td>Medical student teaching</td>
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<td>Curriculum design</td>
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<tr>
<td><strong>Advice and support</strong></td>
<td>Through a network of more than 600 chapters, The Compassionate Friends supports bereaved families after the death of a child</td>
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<td>Face-to-face support groups</td>
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<td>Online support groups</td>
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<td>Web sites</td>
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<tr>
<td><strong>Empowerment</strong></td>
<td>Cincinnati Children’s Hospital has developed and implemented a process that allows families to decide if they want to be part of attending-physician rounds</td>
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<td>Workshops</td>
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<td>Family rounds</td>
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<td>Advocacy</td>
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<td><strong>Medicolegal action</strong></td>
<td>Many parents gave evidence at the Inquiry into the management of care of children receiving complex heart surgery at the Bristol Royal Infirmary</td>
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<td>Complaints</td>
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<td>Lawsuits</td>
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<td>Inquiries</td>
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<tr>
<td><strong>Research and analysis</strong></td>
<td>The Young and Well CRC undertakes research in collaboration with young people and their families to reduce disengagement from health services</td>
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<td>Root cause analyses</td>
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<tr>
<td>Surveys</td>
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<td>Research collaborations</td>
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<tr>
<td><strong>Writing and presenting</strong></td>
<td>Time to Care was authored by Robin Youngson after his daughter’s spinal injury</td>
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<td>Editorials</td>
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<td>Conference presentations</td>
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<td>Articles and books</td>
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<tr>
<td><strong>Technology and design</strong></td>
<td>A charity founded by Parool Shah, the mother of a premature baby, has developed a smart phone application to help parents understand the medical speak they face in neonatal intensive care units</td>
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<td>Smart phone applications</td>
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<tr>
<td>Patient education tools</td>
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<tr>
<td><strong>Funding</strong></td>
<td>The Justin’s HOPE project awards scholarships to health care givers who are committed to improving patient safety for patients and families</td>
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<tr>
<td>Fundraising</td>
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<tr>
<td>Scholarships</td>
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<td>Foundations</td>
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<tr>
<td><strong>Policies and standards</strong></td>
<td>The IHI White Paper “When things go wrong: Responding to adverse events” represents the collaborative effort of a group of clinicians, risk managers, and patients</td>
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<td>White papers</td>
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<td>Accreditation standards</td>
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As Sheridan and Hatlie point out, when it comes to improving patient safety, parents “are not the enemy.” The focus of providers and parents should be on learning from adverse events to improve the quality of care and thus decrease the risk of similar events in future. Although parents do not expect to be thanked for raising concerns we do expect to be treated as partners in care. In the long run partnering with parents to redesign health care saves time, money, and lives.

There is no doubt that experienced pediatric patients and their families can teach health care a thing or two. To get their attention, providers need to know “Why is this important to me?” Having heard Dale Ann Micalizzi quietly but forcefully speak of her experience, a provider recounted to me that “everyone in the room was in tears.” After that kind of experience, each time a provider undertakes their daily duties, that family and their adversity and tragedy will be in the back of the provider’s mind. Identifying with the patient’s experience can change behaviors for the better.

Yet, many hospitals continue to exclude families from care improvement processes, and treat parents’ suggestions for improvement as a threat or a distraction from their “real” work. The risks of this adversarial approach are significant, and include losing trust, impairing healing, preventing learning, increasing regulatory action and lawsuits, attracting adverse media comment, and contributing to staff burnout.

For hospitals who chose to see every error as an opportunity to learn and improve, and who want to acknowledge the valuable contribution of parents to improving pediatric care there are many ways to do so. The most effective way of thanking parents for their contribution to patient safety is by implementing meaningful changes in response to their suggestions.

The father of a child receiving radiation treatment emphasized that his child was at increased risk of infection because of the cancer treatments and should not be exposed to many people for no reason. This led to streamlining and improvements in the process of patient admission and discharge for radiation treatment.

### Table 2 (continued)

<table>
<thead>
<tr>
<th>Examples</th>
<th>Case Study</th>
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<tbody>
<tr>
<td>Governance</td>
<td>Advisory councils Directorships All hospitals in Massachusetts are required to have a Patient and Family Advisory Council to advise the hospital on patient and provider relationships, quality improvement initiatives, and patient education</td>
</tr>
<tr>
<td>Legislation and regulation</td>
<td>Lobbying Drafting bills The Michael Skolnik Medical Transparency Act 2007 requires physicians in Colorado to disclose specific information that can be accessed by the public</td>
</tr>
<tr>
<td>Art and culture</td>
<td>Music Gardens Art Regina Holliday paints the stories of dozens of patients (including children and their families) on the backs of jackets to form a “Walking Gallery”</td>
</tr>
</tbody>
</table>
What steps are being taken in your hospital to recognize and respect the role of parents in improving patient safety? Are expressions of concern and suggestions for change viewed as a burden or as a gift?

SUMMARY

Today there is no lack of discussion about health care delivery and quality. We hear leaders in the field professing that improving quality is the industry’s first priority. Quality from the parent’s perspective includes access to care, responsiveness and empathy, good communication and clear information, appropriate treatment, relief of symptoms, improvement in health status, and safety and freedom from medical injury. When we who have experienced the trauma of errors see more providers engaging parents and patients, we believe we will see true quality improvement.

If a medical injury occurs it is important to listen to the parent, acknowledge the damage, give an honest and open explanation and an apology, acknowledge anxieties about future treatment, and provide practical and financial help quickly. By following the HEART model (or another patient-centered framework of service recovery), providers and parents can become allies rather than adversaries in the quest for safer care.

We know about the nursing shortages, the overtime, the financial obligations, and the insurance company guidelines that interfere with the quality of care. We also know, when it comes time for a child’s care, providers must find a way to remove the chaos. Work as a team, review all the information, establish a plan, communicate between specialists, remove arrogance and intimidation, and have a common goal to heal. Complete checklists, double check medications and dosages, and treat every case as a possible emergency with our child as your only focus for as long as it takes. Because if the child in that hospital bed was your child, that is what you would want too.

_The highest courage is to dare to be yourself in the face of adversity. Choosing right over wrong, ethics over convenience, and truth over popularity...these are the choices that measure your life. Travel the path of integrity without looking back, for there is never a wrong time to do the right thing._

~unknown

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