

Pediatric Focus

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The Governance Institute

The Power of Patients and Families

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“What did Ethan’s parents think of the root-cause analysis?”

In my previous role at a pediatric hospital, I was standing at the podium in front of the quality, safety, and experience committee (QSEC) of our board of directors, when one of our parent representative committee members asked me this question, and it rendered me speechless. I had just finished sharing the results of a root-cause analysis (RCA) that we had completed in the aftermath of a missed diagnosis of a brain abscess that resulted in the tragic death of a young boy named Ethan. I thought we had done an excellent job with the review. The action items we were planning were robust, and I felt confident we would be able to advance our work to improve diagnostic safety through these efforts. I had not anticipated this question and paused before responding.

We had not shared the RCA with Ethan’s parents and did not have any plan to do so. Among the reasons for not doing so are that the findings of RCAs are considered “protected” under the 2005 Patient Safety and Quality Improvement Act (PSQIA). The PSQIA was enacted to foster transparency and the reporting of safety events, and to strengthen continuous learning and harm reduction in our healthcare systems. The findings of RCAs can create risks for hospitals in defending allegations in malpractice litigation that might follow an adverse safety event. Thus, they are not typically shared. Additionally, families might not want to relive the events that resulted in harm to their loved one. As I stood at the podium in our boardroom that morning, these were the first thoughts that ran through my brain.

We had two parent representatives serving as community (non-director) members of our board QSEC at that time, as we had done for more than five years. Both were parents of children with special healthcare needs, and one was the chair of our Patient Family Advisory Council. Over my years working with these two particular mothers, as well as many other extraordinary parents who have been partners in my safety and quality work since 2006, I had learned that, given the opportunity, parents will ask questions that we would not necessarily ask ourselves. In doing so, they can change the conversation, and that is precisely what happened on that day in our discussions about Ethan.

What followed that morning was a thoughtful and poignant discussion about our ethical obligations to our patients and families, about the risks and benefits of sharing the results of the RCA with Ethan’s parents, and potential strategies for doing so that would be sensitive to their wishes and responsible from a hospital risk perspective. Our senior management team, including our Chief Legal Counsel, participated in the discussion, along with the other members of our board committee. We left the meeting having made a commitment to offer to Ethan’s parents the opportunity to speak with us about what we had learned from our review of his care, and what we planned to do to improve. They would of course be under no obligation to do so, but the offer would remain open until such time as they were ready, and we would meet with them at a time and place of their choosing.

Several weeks later, my associate CMO and I met with Ethan’s parents at a café near their home. We heard their perspectives and feelings and shared with them what we had learned. It was emotional, and difficult, but in many ways one of the most impactful moments of my career in health system leadership. As a result of our meeting, Ethan’s parents became involved in our hospital’s diagnostic safety work. Ethan’s story has been told and countless trainees and staff have learned from his story and the experience of his family. Ultimately, Ethan’s story would be published in pediatric literature in an article co-authored by his parents.¹ But I am sure that none of this would have happened had we not had parents on our QSEC.

The idea of including patients and families in improvement work dates to the early 2000s and the advocacy of the Institute for Healthcare Improvement (IHI) and the Institute for Patient and Family-Centered Care. Cincinnati Children’s Hospital was among the earliest adopters, engaging parents of children with cystic fibrosis in the improvement work they embarked on, as described in Atul Gawande’s classic article, “The Bell Curve.”²

Examples of parent partners working in children’s hospitals on improvement teams and subsequently on hospital quality committees and board quality committees have expanded over the past 20 years. In my personal experience at three different institutions

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- 1 David Wyner et al., “A Family and Hospital’s Journey and Commitment to Improving Diagnostic Safety,” *Pediatrics*, December 2021.
 - 2 Atul Gawande, “The Bell Curve,” *The New Yorker*, November 28, 2004.

in New York, Colorado, and Pennsylvania, I have been regularly humbled, impressed, and motivated by the perspectives of families when they participate in the ongoing work of healthcare safety and quality improvement.

Resources for Boards and Senior Leadership

There are a number of resources available to boards and hospital leadership teams interested in identifying, recruiting, and incorporating the parent or family voice into their governance work. IHI's National Steering Committee for Patient Safety released their landmark report, *Safer Together: A National Action Plan to Advance Patient Safety* in 2020. In it, they recommend not only engaging "patients, families, and care partners in the co-production of care," but also including "patients, families, and care partners in leadership, governance, and safety and improvement efforts."³ Another helpful resource is IHI's white paper, *Framework for Effective Board Governance of Health System Quality*.⁴

The Joint Commission, Institute for Patient and Family-Centered Care, the Sala Institute, and the Agency for Healthcare Research and Quality are among other organizations with resources geared towards promoting patient and family engagement in care improvement generally.

Key Board Takeaways

Questions to consider include:

- Is the voice of patients and families heard directly in your board or committee meetings?
- How are patients and families included in the review of adverse occurrences in your organization?
- How are patients and families included in the improvement initiatives ongoing in your organization?

Discussing these opportunities with your teams that lead safety and improvement efforts, your patient and family advisory councils/patient family experience teams, and your fellow board members will likely identify opportunities to strengthen the voice of the patient and family at the level of the board.

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- 3 See National Steering Committee for Patient Safety, *Safer Together: A National Action Plan to Advance Patient Safety*, Institute for Healthcare Improvement, 2020.
 - 4 See Elizabeth Daley Ullem, et al., *Framework for Effective Board Governance of Health System Quality*, Institute for Healthcare Improvement, 2018.

Conclusion

While many hospital boards and their quality committees include directors who receive care in their hospital, or whose children do, the benefit of having non-director parents (patients) on board quality committees cannot be overstated. In my personal experience being asked what a family thought of an RCA led to a cascade of events that improved our care, helped a family find a way to turn their personal tragedy into something beneficial to other families, and reinforced for me the critical role parents can play in accelerating and strengthening our work, if we only give them the chance to do so.

The Governance Institute thanks Daniel Hyman, M.D., M.M.M., Chief Safety and Quality Officer, Children's Hospital of Philadelphia, for contributing this article. The events shared in this article took place in his prior role at a pediatric hospital. He can be reached at danhyman2@gmail.com.

