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After the Medical Error

Miranda E Worthen, *San Jose State University*

A PIECE OF MY MIND

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Miranda Worthen, MPhil, PhD
San Jose State University, Health Science & Recreation, San Jose State University, San Jose, California.

I grew up knowing that my father had saved my mother's life. This wasn't some romantic drama. During her first cone-down radiation treatment for invasive breast cancer, she convinced the radiologist to let my father, an internist practicing in the same hospital, watch. As the machine was lowered, he realized that the cone was aimed at a 10-year-old fibroadenoma scar instead of her cancerous tumor. My dad stopped the treatment and my mom had new tattoos drawn, only to realize that these were also incorrectly placed. They drove to the surgeon's office, where the surgeon consulted his handwritten note and drew the location of the recent tumor with permanent marker.

Although this was in 1988, before the landmark Institute of Medicine (now the National Academy of Medicine) report *To Err Is Human*,[1] my mom's radiation oncologist did what is now recommended that a clinician do when he or she realizes an error has occurred. He called her at home that evening and made an appointment for the next day. He took full responsibility for the error his fellow had made and assured my mom that they would conduct a full system review to ensure that errors of that nature would never happen again. He asked what more he could do to reassure her that her care would be faultless. This physician is legend in my family, and he's cared for my mom through two other breast cancers. Unfortunately, his exemplary behavior is anomalous in our experience of medical errors.

My life began with a medical error. I was diagnosed at 4 hours old with Beckwith-Wiedeman syndrome, and while the diagnosis was correct, the prognosis—that I would likely die, and if I survived, I would be mentally disabled—was not.

Since then, I've had my arm accidentally set on fire in the emergency department, had my spinal fluid lost, been told I had a solid ovarian mass when I didn't, and, despite multiple clinicians noting that I bled excessively from straightforward procedures, I was not diagnosed with Von Willebrand syndrome until my 30s. As an epidemiologist, I consider these personal run-ins with medical errors in light of the recent findings that medical errors may be the third leading cause of death in the United States[2] and think, I'm glad I haven't been killed! … Yet.

While medical errors are scary, they are not just adverse events that disappear into the realm of story. These past experiences also influence the present. They impact my health care behaviors and interactions with health professionals who have nothing to do with the prior medical errors.

The Institute of Medicine guidelines are clear on how a clinician or institution responsible for a medical error should behave in order to reestablish trust with the patient who experienced the error, and physicians have written candidly about their experiences disclosing errors.[3] There are even recommendations for how a nonerring physician should disclose another clinician's error.[4] But how should a physician who is not responsible for the medical error deal with a wary patient who has experienced an error in the past?

In a study of patients with cancer, those who had experienced medical errors became more proactive in their care, seeking second opinions, researching their symptoms, and generally being more assertive with their clinicians. Some began bringing companions to appointments.[5] I do all of these things with every physician I visit.

When choosing a new clinician, I look for people who are curious about my symptoms and who don't immediately offer an explanation or suggest a treatment plan before listening fully. I seek clinicians who share their thought process so I can understand how they arrived at a diagnosis, recommendation, or prognosis. I seek clinicians who express compassion, even if it is only in one sentence. Nothing makes me more skeptical of a physician than an assertion of blanket expertise: "Trust me, I have a credential in … " is guaranteed to make me seek a second opinion—for myself and now for my children.

"It's a cephalohematoma and will be gone by the time she is 2 months old," the pediatric neurosurgeon announced from across the room as I held my 4-month-old daughter. "Actually, it didn't even appear until she was 9 weeks old," I told him. "Oh, then it'll be gone soon," he said dismissively. I returned to my daughter's referring pediatrician who listened to my account of the experience with the neurosurgeon, took a full history, carefully examined my baby again, and then reviewed the literature before arriving at a diagnosis of a delayed subaponeurotic fluid collection. Having now researched the experiences of other families seeking a diagnosis for their infants with this benign scalp mass, I feel lucky our experience wasn't worse.[6]

I've started to imagine a time when each new physician encounter begins not just with questions about my family medical history, but also my history with medical errors. Wouldn't it be amazing if physicians asked, "Have you or a family member ever experienced a medical error?" and if the answer was yes, followed up with, "How was the error handled?" and "What do you need to feel comfortable with a clinician now?"

I actually attained this ideal after a bad experience with a breast care center led me to change health care systems. During my first visit with my new clinician, she asked me why I was switching my care. She listened carefully as I described a series of delays and missed breast lumps. Expressing sympathy, she asked me how the breast care center had responded and what

Corresponding Author: Miranda Worthen, MPhil, PhD (miranda.worthen@sjsu.edu).

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I needed from her to feel well cared for now. After our frank conversation, she sent me down the hall for a repeat mammogram. Meeting again a few minutes later, she told me that the chip left during my previous biopsy was in the wrong place, the lesion had grown slightly, and I would need to have the biopsy repeated. While I was frustrated to learn about yet another medical error, I felt safe having her team redo the biopsy. I've stayed with her for several years (and several lumps). Now my mom is in her practice too.

Conflict of Interest Disclosures: The author has completed and submitted the ICMJE Form for the Disclosure of Potential Conflicts of Interest and none were reported.

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Without ethics, everything happens as if we were all five billion passengers on a big machinery and nobody is driving the machinery. And it's going faster and faster, but we don't know where.

Jacques Cousteau (1910-1997)