



When a misdiagnosis becomes clinical blindness

By Leila Sinclair | November 16, 2016

I was idly browsing books when I got the call.

"Ruby has been in an accident," my mother said. "She's on her way to the hospital."

I learned that a solid piece of granite, a fancy outdoor fireplace, had crumbled spontaneously, pinning my 3-year-old daughter Ruby beneath it. It took five adults to lift the boulder-sized rock off her body.

It would also take a Herculean effort to overcome an initial mistake on the part of hospital staff and get Ruby a correct diagnosis and treatment. Navigating that process gave me a glimpse at how deeply entrenched a hospital's systems can be – and how unresponsive those systems can be to a patient's urgent needs.

When I found Ruby at the hospital, she had been given an X-ray and was sitting in a small exam room. We sat in silence together, staring at walls. Someone came over to say that we needed to wait, as though we had been playing too boisterously or pushing in line. After an obscene amount of waiting, someone more senior popped into view and said, "Kids' bodies are so pliable! She has no breaks or fractures!"

We took Ruby home and she slept soundly. When she awoke, she was surly and crying. She wouldn't attempt to walk or even sit up. She had finally learned to use the toilet a few weeks earlier; now she wouldn't even let us carry her to it. My husband ran to the store to buy diapers, defeated. Things didn't improve the next day, or the next.

I called the hospital. This became my new job. I spent hours on hold listening to Muzak, attended appointments with a grumpy preschooler in four departments – emergency care, pediatrics, orthopedics, kinesthesiology – waited whole days in waiting rooms and exam rooms. Everyone had the same refrain: Ruby's mind was likely a bit traumatized, but her body was fine.

A week after the accident, a family friend who is a renowned neonatologist put in a call to one of the hospital's higher-ups. An MRI was ordered. The scan confirmed that Ruby's left ankle was fractured, badly, "through-and-through."

Why had the hospital missed the fracture initially? We were told this kind of injury is rare, difficult to see in a standard series of X-rays. Why hadn't any of the medicals professionals I spoke with on the phone and in person believed me? Why couldn't I steer them away from their gut instincts towards mine?

I wasn't there when Ruby and her father checked in at the hospital, and perhaps as a type-A mother I would have given a more comprehensive health history. I would have reported that Ruby was a robust, happy-go-lucky child, and maybe they would have seen the discrepancy with the tentative, pain-ridden child we brought home from the hospital. Or maybe not. Throughout the process, I was treated as a hysterical sideshow rather than as a knowledgeable participant with valuable input.

It boggles my mind how much time and effort it took to get the correct diagnosis and care for my daughter. What if we did not have command of the English language? What if we did not feel comfortable questioning authority? What if we didn't have a family friend who was a big-wig doctor? What if we didn't have health insurance? Or a car?

How does anyone get what they need from the hospital without all the privilege and supports my family has? We were naïve enough to think American hospitals, or at least this one, were democratic. As in so much of life, it was all about who we knew, our connections.

My doctor friends assured me that Ruby's story was not universal that it was a human, not systems, problem. The neonatologist who helped us score an MRI reminded me that though we "endow doctors with superlative qualities," they remain human beings, and humans make mistakes.

"People — even doctors — aren't always great at making decisions," my friendly neighborhood anesthesiologist said. "People rely too heavily on one piece of information and then have a difficult time shifting frames of reference if their first assumption is wrong."

In other words, Ruby's initial X-rays didn't show a fracture, thus there wasn't a fracture, no matter how pathetically I pleaded with hospital representatives.

What can be done? How can parents more effectively advocate for their children to get the tests and care they need? My neonatologist friend recommends that we familiarize ourselves with the psychology of decision-making by reading books on the subject, such as the best-seller "Thinking, Fast and Slow"

by Daniel Kahneman. We must learn how to respectfully ask medical professionals to slow down so that they arrive more wholly informed at their initial conclusions about our loved ones, suppressing their certainty biases.

And medical professionals must learn a new way of viewing the patient relationship — not as a top-down transfer of information, but a cooperative arrangement. As payment models shift, patients and their families will be asked to play a more active role in their own care. That means their voices will have to be heard and trusted.

Ruby is good as new. She cannot even remember which leg had a fluorescent pink cast from her toes to her thigh for 10 weeks.

The healthcare system, on the other hand, is still broken.

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