

Doubt

A father writes about the death of his daughter, offering his perspective on the system that broke down and efforts to reduce medical errors. He has requested that his name be withheld from the published version of this narrative

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My daughter Julia died unexpectedly after gallbladder surgery. She was 15 years old, and she received care in a great hospital. The immediate cause of death was disseminated intravascular coagulation. In the weeks after her death, I learned how disseminated intravascular coagulation kills people. I've described it to family and friends as a train wreck—the terminal event in a cascade that causes the circulatory system to seize up. An internal alarm tells the blood to clot throughout the body, preventing flow to vital organs and causing the blood to seep through perforating vessels. In my mind, this description leaves no doubt why Julia—4 hours after surgery and having been discharged from recovery, returned to her room far from the intensive care unit, and left in the care of her mother and a floor nurse—didn't have a chance.

Julia had been admitted to the hospital after several weeks of confusing symptoms. Her pediatrician thought she had a kidney infection. It didn't respond to the first-line antibiotic, so another was tried. We were considering a delay to our long-planned car trip to Yellowstone National Park, but the day before our departure, Julia said she was feeling better. Just to make sure she was okay to travel, we took her back to the clinic for a final check-up.

Julia's temperature was normal and she looked better, but her lower back was still tender. Her doctor thought that a computed tomographic scan was called for, and so began a series of tests with "weird" results. That's the word we heard more than once over the next 5 days as a parade of specialists weighed in on Julia's condition. The first conclusion—the result of the CT scan—was that her kidneys were fine but she had an inflamed gallbladder. We were assured that, although unusual, a gallbladder problem was not unheard of in a teenager. The gallbladder, a dispensable organ, could be removed. The surgery would be laparoscopic and recovery swift.

Julia was admitted late Thursday evening. The admitting physician told us that in spite of the inflammation, there didn't appear to be any gallstones. The next morning, the

chief surgeon explained that there were indeed stones ("little ones") and that surgery would be scheduled as soon as Julia's platelets—which had dropped unexpectedly—returned to a safe range.

One test led to another—repeated blood work, ultrasounds, an x-ray when she complained of upper respiratory congestion—while Julia's care was directed in anticipation of surgery. So for days, she was either receiving only clear liquids or nothing by mouth. Her platelets were increasing, but she was weak and increasingly jaundiced.

Julia's mother, Debra, and I think of ourselves as experienced health care consumers. We've had our own operations, we've been caretakers for elderly parents with chronic illnesses, and we have doctors among our family and friends. Debra had worked in the medical device division of a large corporation, and she was operating room certified. We asked good questions, and we were respected by the medical team. Maybe that's why they were so candid about the puzzling results. Did they give us more credit than we deserved? Should we have asked more questions? How much uncertainty is enough when the symptoms are "weird"?

Surgery was finally scheduled for Wednesday morning. But there was one more test—an ERCP (endoscopic retrograde cholangiopancreatogram), which was ordered late Tuesday afternoon. The procedure as described to the three of us was not for the faint of heart. But Julia was a trusting and brave soul and expressed no hesitation. Her goal was to do what needed to be done so she could still compete in the fall swim season at school.

When the gastroenterologist met with us after the test, he was puzzled. He sketched out the procedure and explained that it had been difficult to access the bile duct. He had performed a sphincterotomy. He found no obstruction of the duct, and he questioned whether the surgery should proceed. We agreed that he should confer with the surgeon and decide on a course of action in the morning. We said good night to Julia and went home to spend the night juggling doubt and fear with our trust in a system that strives mightily to dispel doubt and fear.

We were at the hospital by 6:30 on Wednesday morning. The charge nurse said surgery was on, but she didn't know about the promised consultation between the surgeon and the gastroenterologist. By midmorning, the surgeon arrived

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to tell us that they had talked and agreed that the gallbladder should come out. They would perform a liver biopsy at the same time, hoping that the results might help explain some of the still-mysterious symptoms.

Julia was nervous and light-headed when we escorted her to surgery. We met with the anesthesiologist and again with the surgeon and reviewed the procedure. I asked questions. Her platelets were now within the “safe” range. Despite this, I asked about the supply of blood. Reassurances were offered.

We kissed our daughter and promised her she would be fine. We didn’t doubt that she was in good hands.

The surgeon met with us after the procedure. They had successfully completed the laparoscopic cholecystectomy. The removal was clean, and there was no significant bleeding. When the surgical resident provided a further update, we began to relax. Julia’s hemoglobin had dropped, but the resident was reassuring. After about 90 minutes in the PACU, Julia was the only patient left, so I was allowed in for a visit. She was talking with the nurse about the movie she’d watched the night before. Everything looked good. I helped transport her from the basement surgical suite to her sixth-floor room, breathing easily in my belief that she was on the road to recovery.

Once she was settled back in her room, Debra stayed with her while I left the hospital to pick up our younger daughter, Hannah, for a visit. Then we planned to have dinner and let Julia rest.

Shortly after I left, things began to go wrong. Julia’s pain spiked, and she had a series of bloody stools. Debra struggled to comfort her daughter and at the same time raise an alarm. To her, the situation seemed to be spinning out of control even as the bedside nurse calmly cleaned Julia, distracting attention from the monitors. Alerted by a phone call from Debra that there were problems, I battled rush hour traffic back to the hospital. My call to Debra’s cell phone in route was answered by hysteria and panic. Within minutes of Debra’s first call, Julia’s heart had stopped.

We have no doubt that the efforts to revive her were heroic, and we don’t underestimate the depth of sorrow, grief, and dismay experienced by her doctors, the hospital, and the broader medical community as Julia’s story spread quickly in the days that followed.

The hospital administration was forthright and compassionate. The CEO and chief medical officer expressed their profound regret and sympathy for our loss. They explained the hospital’s policies and procedures after an unexpected death. They helped us understand what had happened—the results of their internal investigation. They acknowledged that the system had failed and explained the steps that had been taken immediately to avoid, to the extent humanly possible, a similar tragedy from happening again.

Julia’s surgeon, on whose shoulders fell the task of telling us after 90 minutes of effort that Julia could not be saved, had offered to meet with us whenever we were ready. Two months after Julia died, we asked for the meeting with the surgeon; 6 additional physicians who were involved in Julia’s case were also there. Ours were

not the only tears shed at this meeting. Julia’s case was reviewed. Missteps and missed opportunities were cited. Questions were asked. Although the hospital’s procedures had been changed, policies reviewed, and protocols updated, the doctors all had their own questions reflecting on their own performance and their own decisions—and how Julia’s death would change their practices forever.

Upon hearing of Julia’s death, a friend who is the medical examiner in another county called her local counterpart to make sure that Julia was examined by the best pathologist available. The autopsy arrived several weeks later. The cause of death: “Complications of Disseminated Intravascular Coagulation and Liver Failure Due to Fulminant Epstein-Barr Virus Infection.” Other significant conditions were noted: “Recent sphincterotomy; cholecystectomy.”

The additional details of the final diagnosis were beyond me. I took for granted that the hospital, the infectious disease people, the clinicians, and the practice groups would parse the facts in reconstructing the case, determining which signals were missed, which decisions were in error.

To me, the narrative of the autopsy was shocking only in its lack of drama. The examination of Julia’s head, neck, respiratory system, etc, etc, revealed little that was unusual. Apart from her infection, the consequences of surgery, and the subsequent efforts to revive her, Julia was nothing if not normal.

These are the words of the man who held my daughter’s heart in his hands: “The walls of the left and right ventricles are 1 and 0.3 cm thick, respectively. The endocardium is smooth and glistening. The aorta gives rise to three intact and patent arch vessels. The renal and mesenteric vessels are unremarkable.”

Unremarkable. Absolutely normal. How could my daughter have slipped away? I ask this not from the throes of grief but in a deep and genuine desire to help us understand what happened and learn how we can diminish the chances that it will ever happen again.

I’ve read the popular books: Jerome Groopman’s *How Doctors Think*, Atul Gawande’s *Better* and his earlier *Complications*. I’ve read countless articles on the topic. I’m clearly not alone in this pursuit, and better minds than mine have wrestled with the same questions.

For what it’s worth, as a layman and as a father who has replayed countless times the 6 days before his daughter’s death, here’s what I find to be the common denominator: *Everyone involved in Julia’s care gave someone else the benefit of the doubt.* The gastroenterologist ceded to the surgeon; our pediatrician to the specialists; the surgeon to the anesthesiologist; the PACU nurse to the sixth floor—and we, Julia’s parents, to the whole system.

But isn’t trust the fundamental building block of collaborative care? How can the system function without an interdependent web of expertise? Don’t you strive for and ultimately depend on a team of qualified experts—the doctors, technicians, and nurses—as well as the families who know their children best?

The team attending Julia was experienced and well qualified. But in this case, with its confusing indicators, there

was, perhaps, too much trust. Where was the empowered skeptic, or the culture that rewards those who question, question, and question again?

There is so much knowledge, so much capacity, so much data. And yet with all of these assets, the chances for confusion, miscommunication, and conflicting analysis remain, and may even be enhanced. In medicine, a field like no other in its capacity to intervene between life and death, maybe it's time to reexamine the value of doubt in the diagnostic equation.

At the hospital, just after Julia died, I asked about organ donation. I was told that because of the way she had died, her organs couldn't be used; her corneas, perhaps,

but nothing else. I was connected by phone with the eye bank, and I provided the necessary information and consent. Two months later, the eye bank letter arrived thanking us for our generosity and explaining that, unfortunately, the corneas also could not be used.

In the months and now years after her death, Debra and I have come to believe that Julia would approve of our activism around the issues of patient safety and adolescent mental health (Julia experienced depression and was open about it). Perhaps our willingness to share these aspects of her story will serve others as her organs could not.

In the end, we hope that Julia's story might give pause on those occasions when data conflict, test results are weird, and doubt demands a voice.