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Two Arms, Two Choices: If Only I'd Known Then What I Know Now

Disabled by faulty arm surgery and harmed by a hospital-acquired infection, a patient wishes he'd been better informed.

BY KERRY O'CONNELL

I sat in an orthopedic surgeon's office in Golden, Colorado, in 2004 as we discussed my left elbow. Just two days earlier, I'd fallen off a ladder in my driveway and dislocated the elbow. I'd also fractured the radius bone in my forearm nearest the elbow.

Repairing the elbow and the radius bone now would be complicated, the surgeon told me. He offered me a choice.

Option one was to forgo surgery. If I went that route, I'd have a very loose elbow, would be unable to fully straighten my arm, and would probably develop early arthritis.

Option two was surgery. The surgeon explained that he would try to screw the fractured pieces of my radius bone back together. But it might not be possible. In that case, he'd saw an inch off the end of the radius bone and install a cup-shaped piece of titanium in its place.

We discussed the possibility of a surgical complication: the chance of infection. It was also likely that the titanium implant would wear out and need to be replaced in about fifteen years.

Finally, the surgeon said that in lieu of a plaster cast, which wouldn't provide the flexibility my arm needed, he'd bolt a metal hinge device called an external fixator onto the outside of my arm. It would be held in place by three-inch bolts screwed through my arm and uninjured parts of my bones.

I had no idea what he was talking about. But he seemed knowledgeable and competent.

When he told me that if it were his arm he'd want the surgery done, I signed the consent form. I wanted a fully functioning left arm.

On my way out the door, I turned and asked my only relevant question of the day, "How many of these fixator things have you installed?" The surgeon gave a curious answer. They were fairly new, he said, but his practice group had installed three or four of them. I left without a second thought.

Surgery Number One

Two weeks later, I woke up from surgery with my left hand and lower forearm paralyzed.

I went to my physical therapy diligently, three days a week, for four months. Every two weeks I had follow-up appointments with my surgeon. He'd gaze off into the corners of the room and tell me that the paralysis was temporary, that my arm would fully heal.

I grew increasingly unsure of that, though, and my doubts often kept me awake at night. Finally, my physical therapist advised me that I should request a nerve-conduction test.

I sat in the specialist's office looking at the flat green line on an old-fashioned oscilloscope. I prayed for a blip. I stared intently, willing with all my might for an electrical signal from the nerve in my arm to set the green line jumping. The line stayed flat.

The specialist turned to me and asked, "Mr. O'Connell, what do you do for a living?" With that question he gave me the results of the test. The question also told me that at age forty-eight, I'd just joined the ranks of the disabled.

Illustration by Brett Ryder

I looked up sadly and told him. "I'm a construction guy who loved to work with his hands."

Surgery Number Two

Many surgeries cause temporary numbness; very few result in permanent paralysis, as mine had. Months later I learned that the damage had probably been caused while my first surgeon was placing the external fixator device on my arm. Most likely, about seven centimeters of my radial nerve had gotten wrapped around his drill bit, turning the nerve to mush.

Even without that knowledge, I'd already lost all trust in my surgeon. I began the search for a new orthopedic surgeon to repair the nerve damage from the surgery.

I talked to friends, family, physical therapists, my insurance company, and my family doctor, asking for referrals to a new surgeon. I studied the Colorado Physician Licensing website and found a few Internet sites that also rated physicians. RateMDs.com was great for finding out where your doctor went to school, how many years he or she had practiced, and how long patients have to sit in the waiting room. But what I needed was a list of surgeons who'd pulled off miraculous, come-from-behind arm repairs, and none of the websites showed that.

Eventually, I settled on a surgeon who'd done a lot of arm repairs on pitchers for the Colorado Rockies baseball team. I figured if the Rockies trust this doctor to fix the million-dollar arms of pitchers, he must be very good.

Arm surgery number two, performed by my new surgeon, took place in April 2005, four and a half months after the first one. It was expected to be a simple nerve repair. In a worst-case scenario—if it turned out the arm nerve was beyond repair—the surgeon would surgically remove the sural nerve from my left leg to use as a donor nerve graft.

This time, to understand what my surgeon was talking about, I spent $300 on a copy of Gray's *Anatomy of the Human Body*. There I found where the sural nerve was on the back of my left calf and the part of my foot that would become numb forever if the nerve were removed. I read about nerve grafts on

a number of Internet sites and learned that short nerve grafts of one to three centimeters usually bring back some motor function, while longer nerve grafts seldom work.

When I awoke from surgery number two, I looked down and saw that my left arm and left leg were heavily bandaged. Worst-case surgery then; the sural nerve had been needed. A few minutes later my new surgeon walked in. My first question to him: "How long's my graft?" He stuttered a bit, looked down, and said, "The nerve [in your arm] was totally destroyed. Seven and a half centimeters."

I broke down. "This will never work!" I yelled at him between sobs. The surgeon tried to calm me, saying that sometimes, in younger patients who don't smoke, long grafts *do* work. A few days later, when the leg bandages came off, I found a long incision closed by forty staples, a line that ran from the back of my knee to outside my ankle bone. It looked like a giant zipper. My research had taught me that nerves grow back at glacial speed; a donated nerve is expected to take six to nine months to function once again.

My arm's radial nerve never fully recovered. I now had thirteen paralyzed left arm muscles and a permanently numb left foot.

Surgeries Numbers Three Through Seven

The internal scar tissue created by both surgeries had caused my arm to stiffen so much that I couldn't rotate my hand in either direction. My surgeon was confident that cleaning out all the scar tissue would return 100 percent range of motion to my arm.

Surgery number three took place in August 2005. Cleaning out the scar tissue worked. But now I learned what a hospital-acquired infection meant.

Because a surgical drain tube wasn't properly secured, I acquired a deep-muscle staph infection called MRSE or *Staph epi*. MRSE stands for methicillin-resistant *Staphylococcus epidermidis*. Like the better-known staph infection MRSA (methicillin-resistant *Staphylococcus aureus*), this bacterium customarily resides on everyone's skin.

But MRSE also loves to latch onto all things silicone and metal, such as drain tubes, breast implants, heart valves—and anything made of titanium. When it gets *under* the skin, it wreaks havoc. That's what happened to me.

It took four more surgeries—one every other day—to remove the staph bacteria busily trying to devour my arm. The surgeries consisted of opening up my arm and "debriding" (pronounced de-breeding) the area around the sawed off end of my radius bone, washing it out with sterile water and antibiotics.

These were surgeries number four, five, six, and seven. In surgery number five, they pulled out the titanium implant to save my arm. Doing so also meant that within eight years I'd need to have a new one put in.

For a week I lay alone in an isolation room, a procedure required for any patient with an infectious disease. I was assaulted in turn by fear and depression. I was certain that if the bacteria didn't kill me, the loneliness would. My cellphone and laptop were dead, and I didn't have the chargers. There was nothing to do except ponder my arm.

It had been eleven months since I'd fractured my left arm. Now I had a stiff, damaged elbow without its needed titanium implant, a paralyzed hand, and a forever numb foot. I also had an antibiotic drip that was slowly damaging my kidneys and liver.

I was seriously considering asking for my arm to be cut off when my surgeon walked in. He surprised me. "Kerry," he said, "I am so sorry for giving you this infection. I don't know how it happened. You're the last guy on earth who should have to endure this." He said it humbly, with sincerity.

It was an unforgettable act of courage on his part. It gave me the strength to not

give up hope and to consider yet another trip to the operating room.

Surgery Number Eight

My last hope to get back the use of my left arm was to have three working tendons from the underside of my left arm and hand relocated to the paralyzed top side. Replacing the titanium implant would need to wait.

This time I purchased three hand-and-forearm surgery textbooks and then used them to do what engineers like me do well. I built a spreadsheet, one with all of the possible combinations of tendon surgeries done in the past hundred years, analyzing the pros and cons of each. One Sunday afternoon my surgeon and I spent two hours on the phone reviewing it. Together we came up with our plan.

In December 2005 I mustered the courage to agree to surgery number eight: last-chance tendon transfers. As I lay in the preoperation waiting area, I was so scared that I couldn't speak.

The physician's assistant came in with the consent form and asked, "Now which tendons are we moving today?" I was stunned—*didn't they know?* I handed her a copy of my spreadsheet, and she copied down the three Latin names on it. I read the consent form, checked that the names were right, and signed it.

Then, across the top of the form, I wrote, "Please, Please, Don't Infect Me," in big bold letters. It was a desperate plea from my hospital gurney, the only way I felt that I could affect the outcome of my surgery.

An hour later my surgeon walked in to the same waiting area and said, "Kerry, we have to talk shop. We're moving the *pronator teres* today right?" I shook my head no. Once again I was speechless. I handed him my spreadsheet. "Oh, you're right, it's the FCR [*flexor carpi radialis*]." I nodded yes.

The last thing I remember as they were wheeling my gurney down the hall to the operating room was a physician's assistant shouting to the team, "Come on, guys, we have to get it right this time!"

They did get it right. After seven months, the surgeon declared my arm "functional" and pointed out that I'd learn new ways to do things. I was strong enough to win a left-handed arm wrestling match with my ten-year-old daughter. But looking back to that day in the first surgeon's office, the option of forgoing surgery and having a loose elbow wouldn't have been a bad choice.

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Instead, I left the medical system damaged but alive. I was also broke. In addition to the large amount my insurance covered, I'd spent more than $20,000 of my own money on my left arm.

And Then…

Fast forward to spring of 2008. One day at home, when I tried to lift a ninety-pound box with both arms, I couldn't rotate my left arm enough to get underneath it. So I tried to lift and slide the box using only my right arm.

Suddenly I felt my right biceps spasm, then tear. It was like I'd touched a live electrical wire. As the pain escalated, I realized that I'd just seriously injured my only good arm. After a week, the pain subsided, and I began to think that just maybe I'd escaped another operation.

Fear makes me stupid. For the next six months, I prayed—*please, please*—that my arm would heal itself. I'd tell myself, "Hey, it doesn't really hurt that much."

And there was the shame. It was extremely hard to admit to my friends and family that I'd messed up again. Then, one day in the shower, I noticed that my right biceps had changed. The muscle was bunched up, looking like Popeye's cartoon version of bulging biceps. I had to do something.

To ask a surgeon the right questions this time around, I wanted to fully understand my injury and my treatment options. I needed more than my copy of Gray's *Anatomy*.

I drove to the University of Colorado Medical Center Library, where I researched biceps tendon ruptures. I got an Internet access card so that I could read articles in the *Journal of Bone and Joint Surgery*. One article described a simple pinch test to determine if the biceps tendon has detached from the radius bone. I did the test on myself, and it confirmed my worst fears: the tendon was detached. Old memories of postoperative sleepless, morphine-distorted nights came rushing back.

My Internet research also uncovered an online forum with a database of information submitted by several hundred patients about their outcomes from this kind of biceps injury. I plotted a two-by-three-foot spreadsheet with detailed information on each of the reported cases. A few patients had elected not to have surgery. Of those who had surgery, about 15 percent had experienced a variety of complications, such as infections, nerve damage, bone fragments pulled off, and loss of hand rotation. Even so, most were happy with their outcomes.

No matter how scared I was, it was time to talk to an orthopedic surgeon. But which one?

The first doctor who'd wrapped my nerve around his drill bit?

The second doctor who'd been responsible for my life-threatening infection?

Or start over with someone brand-new?

I chose to go back to my second doctor. He'd had the courage to apologize for the infection, and he'd always answered my many questions.

When I went to see the surgeon, he immediately examined his work on my left arm from two years earlier. He was pleased and asked me how it functioned. I told him the truth. "It works pretty well except that four fingers go up and down together, and I still have constant pain in my index knuckle and forearm. And there's a great deal of pain in my shoulder." His response: "Sorry, I only do elbows and hands."

Then he started to examine my more recently injured right arm. He pinched the tendon, felt my biceps, and announced what I already knew, that my right biceps was torn. "How long ago did you tear it?" he asked. With great embarrassment I responded, "I don't remember the exact date, but it was more than six months ago."

That wasn't good, he told me. He explained that most doctors would say an injury ignored that long couldn't be re-

paired. Then he smiled and told me that he and a Mayo Clinic surgeon he knew were having great success in fixing old ruptures. He practically glowed as he told me that he performed thirty-nine of these biceps surgeries a year with zero complications.

I unrolled my spreadsheet, and we discussed in great detail all of the major complications that had been reported by patients on the website I'd found. Some of his comments were reassuring. Others made me very nervous.

He told me that I'd be in a full arm cast for six weeks, which would make eating difficult and typing or writing nearly impossible. I told him I needed time to think about whether to have the surgery. He said I should do it within the next two months or not at all.

I never did muster the courage to go under the knife again—a decision that some people can't understand. But they haven't gone through what I have. Most days I'm quite happy with my personal policy of surgical abstinence. There are days, though, when I'm lifting something heavy or trying to work on my car, when I'd give anything for even one full-strength arm.

Looking back, there are two arms and two different paths. The "just trust me" path I followed with my left arm resulted in two years of agony, moderate permanent disability, and what will be lifelong chronic pain. The path I followed with my right arm, the "I won't let them hurt me" path of no treatment, is resulting in occasional pain and a minor disability. Both are less-than-desirable outcomes.

The Crucial Link To Outcome Information

What happened to my left arm wasn't recorded anywhere. If you search the State of Colorado's ALISON (Automated Licensure Information System Online) database today, you'll find both of my surgeons listed, but nothing about any nerve injury or hospital-acquired infection that occurred on their watches.

Before my first arm surgery, had I known it existed, I could have tried searching the National Practitioner Data Bank. From 1990 to 2010, it showed that 249 of Colorado's 14,000 doctors accounted for one-half of all Colorado medical malpractice payments, a tragic $330,000,000 in payouts. But neither then nor now would the database allow me to determine whether either of the two surgeons I used was among those 249 doctors, because all of the names in the database are hidden.

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If you search the Food and Drug Administration's MAUDE (Manufacturer and User Facility Device Experience) database for fixator devices, you'll find a handful of issues relating to minor damage during shipping—and my case. My case is there only because I personally reported it. The full truth about elbow fixator devices is difficult to come by. But a Mayo Clinic study in 2008 determined that 25 percent of all elbow fixator installations have a variety of complications; 10 percent of the installations have serious complications, like mine.

Patients need accurate, easily available, up-to-date outcome information to make good decisions when selecting physicians and medical procedures. But sometimes only a world-famous hospital or an experienced medical detective can uncover it.

Back in the 1990s I was a project manager involved in building portions of Sprint's high-speed fiber-optic network across the United States. The company found that the ultimate limitation to great high-speed communication was the last hundred feet of little copper wires going into each home.

Information about doctors and medical devices and full-disclosure doctor-patient pretreatment conversations are health care's last hundred feet to success—the knowledge link that patients need to make sound medical decisions. As the federal government invests billions of dollars in comparative effectiveness research, recording and analyzing medical outcomes, it's that last hundred feet that we all need to stay focused on. Then patients would have the right information to answer the really tough question: "Is my condition so bad that even the worst outcome is worth the risk?"

Think about it this way. If you're considering buying a $30,000 new car, you can consult the government-required manufacturer's sticker that contains important information about such things as the price, gas mileage, crash tests, and the car's rollover rating. But if you're considering a $30,000 medical procedure, you make a choice based solely on what your doctor does—and doesn't—tell you.

I realize that the United States is unlikely to ever legislate full disclosure in pretreatment medical conversations, yet it's been proven that we're a country that knows how to legislate good disclosure and real shared decision making when it's needed. After all, many might consider my treatment decisions as "shared." In surgery one, the doctor and I both agreed on surgery, but without accurate information on the complication rate for fixators, the decision wasn't a wise one. Certainly the decision to perform surgery number eight, with three hours of debate, was "shared." But is it realistic to expect patients to do a month of intensive research, as I did, before making such an important health care decision?

Shared decision making must include accurate, detailed outcome information and physician outcome history to be successful. Last month the Food and Drug Administration took a step in that direction, announcing that the agency's Unique Device Identification System is being launched. Eventually, many orthopedic devices will have unique numbers, and a database will be established (called GUDID) that will show outcome results for each.

Fixators, like the one I got, are class II devices that will start to be tracked five years after this rule is finalized. Many experts think we will need five years of data to make sound conclusions. Thus, in 2022 patients should be able to look up fixators in the GUDID database, study relevant outcome data, and weigh the safety risk of various manufacturers' devices. A major shortcoming (in addition to its being a decade away), however, is that doctors and patients will not be able to directly report outcomes to

GUDID; all information will come through the manufacturers.

Other databases, such as California's Joint Replacement Registry, hold great promise for the next generation of knee and hip implant patients. The registry will track these operations performed by surgeons in the state to assess the effectiveness of various devices and implants, treatment protocols, surgical approaches, and patient factors that influence the results of the operations.

The Agency for Healthcare Research and Quality is now compiling a catalog of all such registries around the country, to provide a common source of information about them. I would argue that all of the registries funded by the government should be searchable by the public, so patients would have access to much of the best available information about medical interventions, devices, and their outcomes.

I often wonder why, in a country that spends nearly $3 trillion a year on health care, there aren't even more systematic efforts like this to track what works best for patients and what doesn't, and to inform everybody so that patients can make better choices and the health system itself can improve.

Someone once chastised me, saying that if I was stupid enough to fall off a ladder, I deserved what happened to me. In some ways he was right. It took a lot to pound ladder safety into my thick head, just as it seems to take a lot to pound the need for patient safety into the heads of doctors, other health care providers, researchers, and policy makers. But we shouldn't all have to learn everything the painful way, through tragic individual experiences. Wise systems learn systematically from the collective experience of millions of good and bad outcomes.

Patient safety and protections should be a given. I believe that if I'd been given all the information I needed, including some solid physician-specific outcome data and better information on the risks and benefits of the medical devices my doctors were proposing, even I could have made health care decisions that wouldn't have resulted in my having to type this essay with one hand. ■

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