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See me, hear me: When we lost trust in our surgical team



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INTRODUCTION

My husband hid his increasingly worrisome cardiac symptoms from me for a year, until one night in March when a trip to the grocery store left him breathless and with burning chest pain. Since he has type 1 diabetes, which was diagnosed at age 40, and because his brother had suffered and survived a massive heart attack 2 months earlier, I knew that he was in trouble.

A trip to the emergency room and a subsequent cardiac catheterization revealed that Erik had severe blockage of multiple coronary arteries. I had just parked in our community hospital's garage when the cardiologist called to say he had stopped the procedure because Erik would require open heart surgery and several—three, at least—bypasses. I asked him to give me a minute to cry.

Days earlier, Erik had been chopping wood and working on his motorcycle, so despite my understanding that diabetes is heart disease, I didn't realize its effects would be so dire for my hardy 58-year-old spouse of 25 years. I guess I had listened, but with the kind of denial that makes life more bearable. Erik saw an endocrinologist routinely and insisted on managing his disease without intervention from me.

"Well, I guess I'll take him home and wait till a surgeon can see him," I said.

"No, you don't understand," the cardiologist replied. "He can't leave the hospital, or a hospital of your choosing, until he has this surgery." This time, reality would have its way, and the doctor's words were clear.

We had the option of moving Erik to a renowned heart center in Washington, DC, but he wanted to stay put. We knew our local hospital, our children had been born there, it was where we turned to in emergencies. We trusted it to care for him as it had cared for everyone else in our family in the past.

Still, it would be a week before the surgery could occur, and another week before my husband could go home. I wondered if a transfer made more sense: the hospital staff seemed to struggle with managing his diabetes (even with his "good" A1C of 6.5) and had to move him to the intensive care unit (ICU) 36 h presurgery for an insulin drip. However, the cardiothoracic surgeon put him at ease with his credentials and bedside manner.

I was anxious. Erik would be Patient 20 in a brand-new open heart surgery program, where the first surgery had occurred fewer than 12 months ago, on Christmas Eve 2020. The surgeon assured me that the mortality rate for open heart surgery is low, less than 2%. In Erik's case, he said, the risk of dying within 30 days of surgery was less than 1%. In fact, he promised, Erik was likely to go home 3 or 4 days after his procedure. The surgery seemed so clear-cut, and the surgeon, so confident.

SIGNS OF TROUBLE

As a healthcare writer, I've often covered key challenges in our healthcare system, including what can go wrong when vulnerable patients, usually elders, don't have an advocate, or when communication breaks down, either among providers, systems, or families.¹ Medications get mixed up, problems and complaints go unheard, and, worse, people are injured. They die from errors. As I would learn during my husband's 2 weeks in the hospital, trust is easily fractured, and not handily reset.

As a person who lives with several chronic conditions, including a rare pain syndrome, nowhere is it harder to build trust than in ensuring that pain will be adequately managed. This is a persistent challenge for patients and clinicians in today's environment, where clinicians ride the pendulum between adequate pain control and fear of opioid addiction. I have heard and read too many stories about people who have undergone major surgeries—knee and hip replacements, for instance—only to be given extra-strength acetaminophen afterwards. Having been assured by the surgeon that my husband was not likely to die in surgery, I wanted to know that he would not suffer unduly afterwards.

The cardiac nurse educator told us that Erik would receive "multimodal pain management": intravenous (IV) acetaminophen and gabapentin.

"That won't be adequate for him, not after open heart surgery," I argued. "IV acetaminophen is an expensive drug and a big money-maker for the manufacturer, and the gabas are for neuropathic pain. He'll need opioids."

"Where did you get your degree in healthcare?" the nurse educator shot back.

Among the possible responses, this was not one I had anticipated, and, with that, I knew the struggle was on. I anxiously waited for the surgeon to make his rounds again. He was due back to detail the entire procedure for us once more, and to have Erik sign many consent forms. After the surgeon was finished, I raised my concerns about post-op pain management.

Behind his mask, he smiled.

"Oh no, your husband can't even have IV acetaminophen! That's only for patients who can't swallow pills. They'd never approve that. He'll have opioids, don't worry about that at all. His pain will be well-controlled. We won't send him home with a crazy amount of medicine, but in the days after surgery, his pain will be managed," the surgeon said.

With this assurance, my body relaxed. I felt that Erik was in good hands—except for the ongoing issue of glucose control, as the nursing staff inexplicably refused to believe that he was a type 1 diabetic—and that coming out of surgery his pain would be adequately managed.

Why was this so important to me? Because from my healthcare writing, I knew that inadequately managed or untreated pain can create problems of its own.² It stresses the body: blood pressure and heart rate increase. It impairs mobility, which is problematic post-surgery, when a goal is to have patients moving as soon as possible to prevent clots, enhance breathing, and more. Given these consequences, pain should never be poorly managed.³

"NOT GOOD FOR ACHES AND PAINS"

To our relief, the surgeon delivered on his promise of saving Erik's life. However, his promise of pain management was something else, as I discovered when I arrived in the cardiac ICU on post-op Day 1. Erik was upright in a bed that had been adjusted to approximate the angle of a chair, his face ghost-white, his lips a small line. I had only ever seen that face on him once before, when he had fallen on the stairs in our house and shattered his elbow. I immediately asked what he was being given for pain. As my confidence in the clinicians frayed, so did my nerves.

According to a 2017 study in the *Journal of Pain Management*, "postoperative pain is not adequately managed in greater than 80% of patients in the US," with caveats according to geography and type of surgery.⁴ The study notes, "Poorly controlled acute postoperative pain is associated with increased morbidity, functional and quality-of-life impairment, delayed recovery time, prolonged duration of opioid use, and higher health-care costs."

Of course, this was not running through my head when I saw my husband; I only knew that he was suffering. The nurse replied that he had been taken off IV fentanyl and was receiving IV gabapentin (an antiseizure drug) and oral extra-strength acetaminophen. I asked her what had happened to the surgeon's orders for opioids, and she replied that she had seen the two drugs Erik was on "work wonders" for open-heart surgery. I replied that they were *not* working. I began to

doubt if anything in the entire recovery process was going to work. I'd managed to stay fairly stoic around Erik for the sake of our five adult children, but this strained my confidence in what would happen to him. In fact, as a precaution, I began to stay with him at the hospital for 6 or 8 h a day.

I asked the nurse why he was sitting in a bed and not a chair, which is what the patient education booklet had indicated came next. She said that he'd been unable to move because of his pain, which Erik described as the worst pain of his entire life.

"You need to give him what the surgeon ordered," I insisted.

"Opioids don't help with aches and pains," the nurse replied.

A surgical cardiac physician assistant whom I'd met before was nearby and asked what the problem was. After I explained the situation, she instructed the nurse to administer the opioids as ordered, every 4 h. A few hours later, the physical therapists returned and moved Erik to a chair. Later he managed a short walk around the unit. This was the progress I'd been told to expect, and it was a relief to see him standing.

And yet later in the day the same scenario over the opioids played out again, this time with a different physician assistant from the cardiac team, who insisted that the IV gabapentin and acetaminophen would cover Erik's pain, and the oxycodone was causing him to be sleepy and light-headed.

In the meantime, I had found a 2020 article in the journal *Anesthesiology*, a meta-analysis of 281 trials ($n = 24,682$) that found that pregabalin and gabapentin are ineffective for postoperative pain management and, in fact, can lead to harmful problems, such as visual disturbances, somnolence, and dizziness.⁵ I took the review to the surgical team and asked that they halt the IV gabapentin and continue the opioids, just to see how Erik did. They agreed to try this, noting, however, that it would be my fault if he experienced more pain. His dizziness vanished. This, I thought to myself, was not to my credit.

The next day, two things happened: yet another cardiac physician's assistant (the team must have included four or five of them) told me that thanks to me, Erik was receiving "more narcotics than anyone else in the ICU" and that had "put him behind the eight-ball for his recovery." This was post-op Day 2. He was sitting in a chair, color had returned to his face, his vital signs were normal, and he could walk, with lots of assistance, around the unit. I held my tongue and did not suggest that perhaps her other patients' pain was undertreated.

A while later, two professionally dressed women appeared: the hospital's director of nursing and the patient advocacy manager. They had heard about my complaints—the ruckus I had raised the previous day when I had placed calls to the CEO of the hospital, the chief of surgery, and the head of quality assurance (did I mention that I am a healthcare journalist?)—and wanted to know how they could help. Although I appreciated their offers, by this time I had little confidence in the hospital staff.

I told them that I did not want to discuss my complaints at my husband's bedside, so we stood in an empty hallway full of beds while they took notes. They were appalled, they said, by news of the

nondiabetic diet, the problems in pain management, and the failure to listen to my husband and me.

From that day forward, the patient advocacy manager, a kind and knowledgeable woman, visited us every single day. Her attempts to ensure that Erik's care was appropriate and adequate were significant. Yet despite this, problems persisted. When Erik finally came home he told me about the one night he actually rang for the nurse and requested a pain pill. The nurse replied, "You don't need that stuff," and left the room.

Months after my husband's surgery, I too would undergo surgery, but with a team that truly listened and communicated with me. Perhaps that's the critical element of trust: to feel strengthened, informed, and comforted. With those three elements in place, I rested easy (in my mind, at least) while the surgical team did its job. And I did mine: I healed.

The people who work in healthcare are usually there from an earnest and profound desire to help and heal other human beings. But for that to happen, the people they are hoping to help must feel confident and safe in their care. They also must be able to trust that care. And that trust begins, as it does in any relationship, with feeling heard and respected.

CONFLICT OF INTEREST

The author declares that there is no conflict of interest.

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