

HOW SHOULD DOCTORS SHARE IMPOSSIBLE DECISIONS WITH THEIR PATIENTS?

By Lisa Rosenbaum

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On a Friday evening a few months ago, my mom broke her arm. A doctor in the E.R. told her it was a simple fracture, and put her arm in a sling. The following Monday, though, she called me. She had consulted two surgeons who had a different assessment: the bone was broken in four places, surgery would be quite involved, and the rates of complications were high.

“How high?” I asked.

“Twenty-to-fifty-per-cent risk of avascular necrosis,” she said.

“And the alternative?”

“No surgery,” she said. “Good chance of immobility and arthritis for the rest of my life.”

And then, after a moment of thinking I might throw up, I said, “I don’t understand. What does avascular necrosis mean?”

Here’s the thing: I’m a doctor. Strictly speaking, I know what avascular necrosis means. It means the bone can die. It means the blood vessels can be compromised. Which means, again, dead bone. My mom, a cardiologist, knows

this too, as does my father, a rheumatologist.

But what I meant was: What did it really mean? How would it feel? How was she supposed to make such an impossible decision?

According to the Affordable Care Act, one answer is something called “shared decision-making,” or S.D.M. It’s an approach to medical care in which patients are encouraged to make decisions with their doctors. For some clinical scenarios, like having a heart attack, there is one best treatment, but for many others more than one reasonable option exists. For these less clear-cut decisions, like treatment of early-stage breast cancer, or whether to get prostate-cancer screening, S.D.M. aims to integrate patients’ preferences and values into the weighing of each choice.

Though S.D.M. has captured the attention of policy leaders, investors, and researchers over the years—leading to the creation and testing of support tools, known as “decision aids”—it is rarely used in clinical practice. The A.C.A. aims to change that; it requires Accountable Care Organizations to integrate S.D.M. into the daily rhythms of patient care. Patient-satisfaction surveys, which are being used to partially determine reimbursement, will ask patients whether or not their care honored the principles of S.D.M.

S.D.M. advocates have argued that heeding patient preferences will help improve quality and cut costs. That remains to be determined. For now, we can at least agree that physicians can never fully grasp, nor anticipate, the subjective nature of their patients’ experiences. But whether the answer lies in asking patients to share more in the decision-making process remains a matter for debate. Doctors know all about probabilities and trade-offs, but we don’t know much about how to engage patients in decision-making in a way that actually achieves the most desired long-term outcome.

Paul Slovic, a psychologist at the University of Oregon, studies judgment and

decision-making under conditions of uncertainty. He discovered the “affect heuristic,” which describes the role that emotions play in our perceptions of benefit and risk. When we feel good about something, we tend to behave with little conscious thought about its risk. The role of positive affect in influencing investment behavior has been well documented. For example, in the late nineties, when everyone was feeling good about Internet start-ups, businesses that simply added the phrase “dot-com” to their names found a much higher rate of investment in the five days following the change. When we feel bad about something, the converse is equally true. That is, when an activity elicits fear, disgust, or other preconceived negative associations, we are quick to assume it provides little benefit.

When affect guides our decisions, we are far more sensitive to possibility than to probability. In one experiment, some subjects were asked how much they were willing to pay to avoid a potential loss of twenty dollars; others were asked how much they would pay to avoid a potential electric shock. The people asked about the shock paid about the same amount of money, regardless of whether the probability of receiving it was one per cent or ninety-nine per cent. The responses of people asked about the monetary loss, however, tracked more closely to the associated probabilities. The mere possibility of risk, no matter how small, drives our behavior.

How might this tendency play out in medicine? Take, for instance, the increasing rate of women with breast cancer pursuing prophylactic double mastectomy—most famously, Angelina Jolie. For most women with breast cancer, the risk of later developing breast cancer in the other breast is low, meaning the risks of mastectomy outweigh the benefits. Indeed, a recent survey of women who had undergone prophylactic mastectomy found that some seventy per cent would derive little survival benefit. Nevertheless, ninety per cent of those women reported that they were “very worried” about breast-cancer recurrence. In other words, in the setting of fear, the possibility of recurrence, rather than its actual

probability, fuels decisions that, over all, likely cause more harm than good.

Disgust is another powerful decision driver, highlighted in a clever experiment by Peter Ubel, an internist and behavioral scientist at Duke. He created a hypothetical scenario about two treatments for colon cancer, and asked subjects to choose between them. Both surgeries offered an eighty-per-cent chance of cure. With the first surgery, the risk of death was a flat twenty per cent, while in the second the risk of death was sixteen per cent. However, in the surgery with the lower risk of death, there was a one-per-cent risk of each of four complications: chronic diarrhea, wound infection, colostomy bag, and intermittent bowel obstruction.

Death is clearly a worse outcome than chronic diarrhea, so you would expect people to prefer the second surgery. The majority, however, including doctors, chose the first one. When Ubel asked people after about their choice, most people articulated “knowing” that the second surgery is better than the first, but “feeling” that they should still choose surgery No. 1. The finding is consistent with the affect heuristic’s predictions: for many people, the disgust of imagining life carrying around a bag of stool renders a lower absolute risk of death less resonant.

We know that emotions influence the understanding of benefit and risk. But doctors haven’t spent enough time trying to figure out the implications of this tendency for the actual decisions patients make. Consider a patient of mine, a young man with a cardiomyopathy, a disease which leaves his heart pumping about one sixth as well as everyone else’s. Research has shown that, for patients like him, an implantable cardiac defibrillator (I.C.D.) saves lives.

But are there risks to an I.C.D.? Of course. And as I began explaining those risks, my patient’s wife interrupted.

“What if it shocks him?” she asked.

“It might,” I said. “In fact, were he to experience a rhythm that might otherwise kill him, that’s exactly what it’s supposed to do.”

“But what if it shocks him when it’s not supposed to?”

That’s when a voice inside my head started screaming, “affect heuristic, affect heuristic!” I am certain that if I had first asked my patient, “Would you rather die or experience an inappropriate shock?” he would have chosen life. But watching their faces imagine this brutal possibility of accidental shocks, I knew that it would be better to save my recommendation for this procedure for another day.

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So we increasingly ask our patients: Which do you prefer?

Do you want chemo and three months of life, or six weeks of life without the nausea and vomiting that the chemo causes? Do you want high-risk open-heart surgery, with a fifteen-per-cent risk of dying during the operation, or would you rather continue as you are, with a fifty-per-cent chance you will be dead in two years? Do you want a prostatectomy, which has a five-per-cent chance of impotence and incontinence, or radiation, with a three-per-cent chance of leaving a hole in your rectum, or would you rather “watch and wait,” with the chance that your cancer will never grow at all?

Since my mother broke her arm, my sister graduated medical school. We’re now a family of four physicians. We could not be better informed or better connected to a health system that leaves many waiting months to see a specialist. Within two days, my mother had consulted three. Her values? She wanted to return to work as quickly as possible, and, like anyone, she wanted not to be in pain. But knowing her values did not make the decision any easier. In the end, we were desperate for someone we trusted, a doctor, to tell us what to do.

My mom went with the surgeon who insisted she should not have surgery. After

two months of conservative treatment and physical therapy, he announced last week that her bones had properly healed. He told her that she was “dismissed” from his care. Only when she stood to leave—a colleague again rather than a patient—did the burden of his own uncertainty slip. “Thank heavens,” he said. “I’m so glad we did not operate.”

For my mother, this admission revealed as much about his uncertainty as his humanity. But even though S.D.M. is, above all, an attempt to make medicine more humane, for some patients there is a fine line between gestures of humanity and abdications of responsibility.

One of my wisest, most medically complicated patients put it to me straight the other day. He has a weak heart muscle, but for him—unlike my other patient—the decision to put in an I.C.D. is far from clear. So in an attempt to engage him in this difficult choice, I tried to explain, in layman’s terms, the various factors to consider. His risk of infection, were he to receive an I.C.D., was higher than most. But his risk of a dangerous rhythm was high, too. Predicting the benefit was tough because people like him were not enrolled in the trials of I.C.D.s.

So on I went, laying it all out for him, pausing occasionally to ask him how he felt as we weighed these various risks. Each time, he urged me to continue, so I did, until I finally finished. Then I asked, “Do you understand?”

He looked at me kindly, as if he had done me a favor. “Doc,” he said, “you’re my quarterback. Do you understand?”

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