

Whose body is it anyway?

What doctors should do when patients make bad decisions

Atul Gawande

Joseph Lazaroff's cancer had spread throughout his body. Eight months earlier, he had seen his doctor about a backache. A scan revealed tumours in Lazaroff's liver, bowel, and up and down his spine. A biopsy showed an untreatable cancer. Lazaroff went on around-the-clock morphine to control his pain. ... his legs had become weak and he became incontinent. A scan showed a metastasis compressing his thoracic spinal cord. Radiation had no effect. Spinal surgery offered a last-ditch chance of restoring some strength to his legs and sphincters. The risks, however, were severe and his chance of surviving the procedure and getting back home was slim. The alternative was to do nothing. He'd go home with hospice care, which would keep him comfortable and help him maintain a measure of control over his life. It was his best chance of dying peacefully surrounded by his loved ones. The decision was Lazaroff's.

Only a decade ago, doctors made the decisions; patients did what they were told. People were put on machines, given drugs, and subjected to operations they would not have chosen. And they missed out on treatments that they might have preferred. Then in 1984 a book, *The Silent World of Doctor and Patient*, by a Yale doctor and ethicist named Jay Katz, dealt a devastating critique of traditional medical decision-making. Katz argued that medical decisions could and should be made by the patients involved. By the early '90s, we were taught to see patients as autonomous decision-makers.

In practice, patients make bad decisions too. But when you see your patients making a grave mistake, should you simply do what the patients' want? The current medical orthodoxy says yes. After all, whose body is it, anyway?

Lazaroff wanted surgery. The oncologist was dubious about the choice, but she called in a neurosurgeon who warned them about the risks. But Lazaroff wasn't to be dissuaded. Outside the room, David, his son, told me that his mother had spent a long time in intensive care on a ventilator before dying of emphysema, and since then his father had often said that he did not want anything like that to happen to him. But now he was adamant about doing 'everything'. Lazaroff had his surgery the next day. The operation was a technical success. Lazaroff's lungs wouldn't recover however, and we struggled to get him off the ventilator. It became apparent that our efforts were futile. It was exactly the way Lazaroff hadn't wanted to die — strapped down and sedated, tubes in every natural orifice and in several new ones, and on a ventilator.

Lazaroff chose badly because his choice ran against his deepest interests as he conceived them. It was clear that he wanted to live. He would take any risk — even death — to live. But life was not what we had to offer. We could offer

only a chance of preserving minimal lower-body function at cost of severe violence to him and extreme odds of a miserable death. But he did not hear us. Couldn't it have been a mistake, then, even to have told him about the surgical option? We are exquisitely attuned to the requirements of patient autonomy. But there are still times when a doctor has to steer patients to do what's right for themselves.

This is a controversial suggestion. People are rightly suspicious of those claiming to know better than they do what's best for them. But a good physician cannot simply stand aside when patients make bad or self-defeating decisions.

Suppose you are a doctor seeing a female patient in her 40s. She had a mammogram before seeing you, and now you review the radiologist's report, which reads, "There is a faint group of punctate clustered calcifications. Biopsy may be considered to exclude the possibility of malignancy." You suggest a biopsy. Three times in the past five years, her annual mammogram has revealed an area of suspicious calcifications. Three times a surgeon has taken her to the operating room and removed the tissue in question. And three times under the pathologist's microscope, it has proved to be benign. "I'm not getting another goddam biopsy," she says, and she stands up to get dressed. Do you let her go? It's not an unreasonable thing to do. She's an adult, after all. Still, these calcifications are not equivocal findings. They often do indicate cancer. Now people have to be permitted to make their own mistakes. But when the stakes are high, and the bad choice may be irreversible, doctors are reluctant to sit back. You could tell her she's making a big mistake. And in all likelihood you'll lose her. The aim isn't to show her how wrong she is. The aim is to win her over. Notice what good doctors do. They sit her down. And when you sit close by, on the same level as your patients, you're no longer the rushed, bossy doctor with no time for them; patients feel less imposed upon and more inclined to think you are both on the same side of the issue. Oddly enough, nine times out of ten this approach works. People feel as if they've been heard, and have had an opportunity to vent. At this point, they finally begin to ask questions, voice doubts, even work through the logic themselves. And they come around.

But it is misleading to view all this simply as the art of doctorly manipulation: when you see patients cede authority to the doctor, something else may be going on. The new orthodoxy about patient autonomy has a hard time acknowledging an awkward truth: patients frequently don't want the freedom that we have given them. That is, they are glad to have their autonomy respected, but the exercise of that autonomy means being able to relinquish it. It turns out that patients commonly prefer to have others

make their medical decisions. One study found that although sixty-four percent of the general public thought they'd want to select their own treatment if they develop cancer, only 12 percent of newly diagnosed cancer patients actually did want to do so.

Carl Schneider, a professor of law and medicine at the University of Michigan, recently published a book called *The Practice of Autonomy* in which he sorted through a welter of studies on medical decision-making. He found that ill patients were often in a poor position to make good choices. Schneider found that physicians, being less emotionally engaged, are able to reason through the uncertainties without the distortions of fear and attachment. They work in a scientific culture that disciplines the way they make decisions. They have the benefit of 'group rationality' – norms based on scholarly literature and refined practice and the relevant experience.

Just as there is an art to being a doctor, there is an art to being a patient. You must choose wisely when to submit and when to assert yourself. Even when patients decide not to decide, they should still question their physicians and insist on explanations. The doctor should not make all these decisions and neither should the patient. Something must be worked out between them.

Where many ethicists go wrong is in promoting patient autonomy as a kind of ultimate value in medicine rather than recognizing it as one value among others. Schneider found that what patients want most from doctors isn't autonomy per se; it's competence and kindness. Now, kindness will often be involved in respecting patients' autonomy, assuring that they have control over vital decisions. But it may also mean taking on burdensome decisions when patients don't want them, or guiding patients in the right direction when they do. Many ethicists find this disturbing, and medicine will continue to struggle with how patients and doctors ought to make decisions. But, as the field grows ever more complex and technological, the real task isn't to banish paternalism; the real task is to preserve kindness.

Mr. Howe was in his late 30s, in the hospital following an operation for a badly infected gallbladder. Three days after his surgery, he spiked a high fever and become short of breath. I found him sweating profusely, he had an oxygen mask on, his heart was racing and his blood pressure was much too low. I drew blood for tests and cultures, and went into the hall and paged S., one of the chief residents, for help. S. came right over and went over to him, put a hand on his shoulder, and asked how he was doing. She explained the situation: the sepsis, the likely pneumonia, and the probability that he would get worse before he got better. The antibiotics would fix the problem, but not instantly, she said, and he was tiring out quickly. To get him through it, she would need to place him on a breathing machine. "No," he gasped and sat straight up. "Don't... put me... on a... machine." It would not be for long, she said. Maybe a couple of days. We'd give him sedatives so he'd be as comfortable as possible the whole time. And – she wanted to be sure he understood — without the ventilator he would die. He shook his head. "No... machine!" He was, we believed,

making a bad decision. With antibiotics and some high-tech support, we had every reason to believe he'd recover fully. Could we be certain we were right? No, but if we were right, could we really just let him die? S, looked over at Howe's wife, who was stricken with fear and, in an effort to enlist her in the cause, asked what she thought her husband should do. She burst into tears and left the room. Soon Howe did tire out and he gradually fell into unconsciousness. That was when S. went into action. She slipped a breathing tube into his trachea. We wheeled Howe to the intensive care unit. Over the next twenty-four hours, his lungs improved markedly. He woke up and opened his eyes, the breathing tube sticking out of his mouth. "I'm going to take this tube out of your mouth now, OK?" I said. Then I pulled it out, and he coughed violently a few times. "You had a pneumonia," I told him, "but you're doing fine now." He swallowed hard, wincing from the soreness. Then he looked at me, and, in a horse but steady voice, he said, "Thank you."

Excerpted by Meenal and Bashir Mamdani from 'Whose body is it, anyway?' by Atul Gawande, *The New Yorker*, October 4, 1999 pp 84-91.