https://www.theatlantic.com/health/archive/2014/10/when-doctors-dont-know-how-to-talk-about-death/381123/

HEALTH

Doctors Who Don't Know How to Talk About Death

When physicians avoid discussions of mortality and end-of-life care, their patients are the ones who suffer.

ATUL GAWANDE
OCTOBER 7, 2014

I learned about a lot of things in medical school, but mortality wasn't one of them. Although I was given a dry, leathery corpse to dissect in my first term, that was solely a way to learn about human anatomy. Our textbooks had almost nothing on aging or frailty or dying. How the process unfolds, how people experience the end of their lives, and how it affects those around them seemed beside the point. The way we saw it, and the way our professors saw it, the purpose of medical schooling was to teach how to save lives, not to tend to their demise.

The one time I remember discussing mortality was during an hour we spent on *The Death of Ivan Ilyich*, Tolstoy's classic novella. It was in a weekly seminar called Patient-Doctor—part of the school's effort to make us more rounded and humane physicians. Some weeks we would practice our physical examination etiquette; other weeks we'd learn about the effects of socioeconomics and race on health. And one afternoon we contemplated the suffering of Ivan Ilyich as he lay ill and worsening from some unnamed, treatable disease.

In the story, Ivan Ilyich is 45 years old, a mid-level St. Petersburg magistrate whose life revolves mostly around petty concerns of social status. One day, he falls off a stepladder and develops a pain in his side. Instead of abating, the pain gets worse, and he becomes unable to walk. Formerly an "intelligent, polished, lively, and agreeable man," he grows depressed and enfeebled. Colleagues and friends avoid him. His wife calls in a series of ever more expensive doctors. None of them can agree on a diagnosis, and the remedies they give him accomplish nothing. For Ilyich, it is all torture, and he simmers and rages at his situation.

- 

  Podcast: Long COVID Questions Answered

- 

  The Era of Mass Vaccinations Is Ending

  SARAH ZHANG

- 

  6 Questions for the Boss Who Wants You Back in Your Cubicle

  RACHEL GUTMAN

-

"What tortured Ivan Ilyich most," Tolstoy writes, "was the deception, the lie, which for some reason they all accepted, that he was not dying but was simply ill, and he only need keep quiet and undergo a treatment and then something very good would result." Ivan Ilyich has flashes of hope that maybe things will turn around, but as he grows weaker and more emaciated he knows what is happening. He lives in mounting anguish and fear of death. But death is not a subject that his doctors, friends, or family can countenance. That is what causes him his most profound pain.

"No one pitied him as he wished to be pitied," writes Tolstoy. "At certain moments after prolonged suffering he wished most of all (though he would have been ashamed to confess it) for someone to pity him as a sick child is pitied. He longed to be petted and comforted. He knew he was an important functionary, that he had a beard turning grey, and therefore what he longed for was impossible, but he still longed for it."

As we medical students saw it, the failure of those around Ivan Ilyich to offer comfort or to acknowledge what was happening to him was a failure of character and culture. The late-19th century Russia of Tolstoy's story seemed harsh and almost primitive to us. Just as we believed that modern medicine probably could

have cured Ivan Ilyich of any disease he had, so too we took for granted that honesty and kindness were basic responsibilities of a modern doctor. We were confident that in such a situation we would act compassionately.

What worried us was knowledge. While we knew how to sympathize, we weren't at all certain we would know how to properly diagnose and treat. We paid our medical tuition to learn about the inner process of the body, the intricate mechanisms of its pathologies, and the vast trove of discoveries and technologies that have accumulated to stop them. We didn't imagine we needed to think about much else. So we put Ivan Ilyich out of our heads.

Yet within a few years, when I came to experience surgical training and practice, I encountered patients forced to confront the realities of decline and mortality, and it did not take long to realize how unready I was to help them.

* * *

I began writing when I was a junior surgical resident, and in one of my very first essays, I told the story of a man whom I called Joseph Lazaroff. He was a city administrator who'd lost his wife to lung cancer a few years earlier. Now, he was in his 60s and suffering from an incurable cancer himself—a widely metastatic prostate cancer. He had lost more than 50 pounds. His abdomen, scrotum, and legs had filled with fluid. One day, he woke up unable to move his right leg or control his bowels. He was admitted to the hospital, where I met him as an intern on the neurosurgical team. We found that the cancer had spread to his thoracic spine, where it was compressing his spinal cord. The cancer couldn't be cured, but we hoped it could be treated. Emergency radiation, however, failed to shrink the cancer, and so the neurosurgeon offered him two options: comfort care or surgery to remove the growing tumor mass from his spine. Lazaroff chose surgery. My job, as the intern on the neurosurgery service, was to get his written confirmation that he understood the risks of the operation and wished to proceed.

I'd stood outside his room, his chart in my damp hand, trying to figure out how to even broach the subject with him. The hope was that the operation would halt the progression of his spinal cord damage. It wouldn't cure him, or reverse his paralysis, or get him back to the life he had led. No matter what we did, he had at most a few months to live, and the procedure was inherently dangerous. It required opening his chest, removing a rib, and collapsing a lung to get at his spine. Blood loss would be high. Recovery would be difficult. In his weakened state, he faced considerable risks of debilitating complications afterward. The operation posed a threat of both worsening and shortening his life. But the neurosurgeon had gone over these dangers, and Lazaroff had been clear that he wanted the operation. All I had to do was go in and take care of the paperwork.

Lying in his bed, Lazaroff looked gray and emaciated. I said that I was an intern and that I'd come to get his consent for surgery, which required confirming that he

was aware of the risks. I said that the operation could remove the tumor but leave him with serious complications, such as paralysis or a stroke, and that it could even prove fatal. I tried to sound clear without being harsh, but my discussion put his back up. Likewise, when his son, who was in the room, questioned whether heroic measures were a good idea, Lazaroff didn't like that at all.

"Don't you give up on me," he said. "You give me every chance I've got." Outside the room, after he signed the form, the son took me aside. His mother had died on a ventilator in intensive care, and at the time his father had said he did not want anything like that to happen to him. But now he was adamant about doing "everything."

I believed then that Mr. Lazaroff had chosen badly, and I still believe this. He chose badly not because of all the dangers but because the operation didn't stand a chance of giving him what he really wanted: his continence, his strength, the life he had previously known. He was pursuing little more than a fantasy at the risk of a prolonged and terrible death—which was precisely what he got.

The operation was a technical success. Over eight and a half hours, the surgical team removed the mass invading his spine and rebuilt the vertebral body with acrylic cement. The pressure on his spinal cord was gone. But he never recovered from the procedure. In intensive care, he developed respiratory failure, a systemic infection, blood clots from his immobility, then bleeding from the blood thinners to treat them. Each day we fell further behind. We finally had to admit he was dying. On the 14th day, his son told the team that we should stop.

It fell to me to take Lazaroff off the artificial ventilator that was keeping him alive. I checked to make sure that his morphine drip was turned up high, so he wouldn't suffer from air hunger. I leaned close and, in case he could hear me, said I was going to take the breathing tube out of his mouth. He coughed a couple of times when I pulled it out, opened his eyes briefly, and closed them. His breathing grew labored, then stopped. I put my stethoscope on his chest and heard his heart fade away.

Now, more than a decade after I first told Mr. Lazaroff's story, what strikes me most is not how bad his decision was but how much we all avoided talking honestly about the choice before him. We had no difficulty explaining the specific dangers of various treatment options, but we never really touched on the reality of his disease. His oncologists, radiation therapists, surgeons, and other doctors had all seen him through months of treatments for a problem that they knew could not be cured. We could never bring ourselves to discuss the larger truth about his condition or the ultimate limits of our capabilities, let alone what might matter most to him as he neared the end of his life. If he was pursuing a delusion, so were we. Here he was in the hospital, partially paralyzed from a cancer that had spread throughout his body. The chances that he could return to anything like the life he had even a few weeks earlier were zero. But admitting this and helping him cope

with it seemed beyond us. We offered no acknowledgement or comfort or guidance. We just had another treatment he could undergo. Maybe something very good would result.

We did little better than Ivan Ilyich's primitive 19th-century doctors—worse, actually, given the new forms of physical torture we'd inflicted on our patient. It is enough to make you wonder, who are the primitive ones?

This article is excerpted from Atul Gawande's Being Mortal: Medicine and What Matters in the End.

ATUL GAWANDE *is a staff writer at* The New Yorker*, a surgeon at Brigham and Women's Hospital, and a professor at Harvard Medical School and the Harvard School of Public Health. He is based in Newton, Massachusetts.*