NARRATIVE MATTERS



DOI: 10.1377/HLTHAFF.2010.0407

'In Technology We Trust'

But for many patients, our intervention-oriented medical culture doesn't produce humane care.

BY MURIEL R. GILLICK

n Christmas Day, I was the doctor on call for the cluster of skilled nursing facilities my physician group works with. It was going to be busy—I had four facilities to visit-but traffic was light, and the winter sun was shining. My professional life is divided largely between seeing patients in palliative care consultation at a teaching hospital and doing research on issues that occur near the end of life. So I regard the occasional day devoted to practicing geriatrics, the field in which I originally trained, as refreshing.

In the morning I drove up to the first nursing facility on my list. With the lobby's plastic Christmas tree and faux fireplace, the place could have been mistaken for a budget motel. The floors where the patients lived, though, looked like scaled-down, quieter versions of the hospitals they were modeled after: long corridors radiating from a central nursing station, their linoleum floors opening into spartan patient rooms.

The nurse on duty greeted me warmly. She told me about my first patient, Mr. G, a ninety-year-old man who'd been transferred for rehab from the local community hospital, where he'd been admitted following a fall. "Very routine: no fractures, work-up negative. He supposedly gets agitated but so far he's been a real sweetie. He needs something for

his knee pain, though."

With that summary, the nurse handed me the information that had accompanied Mr. G from the community hospital. There was a one-page medical discharge sheet that showed he had a complex cardiac history, as well as diabetes; a report from a physical therapist that said Mr. G had trouble walking because of pain in his knee; and a note from a social worker expressing concern about safety at home, as both Mr. G and his wife had Alzheimer's disease. So we had a patient who'd had a fall and had heart problems, diabetes, knee pain, and Alzheimer's, whose daughter was his health care proxy.

The nurse also passed on a lab report that had just been faxed from the community hospital. The report showed bacteremia—bacteria growing in Mr. G's blood. If the test was accurate, this was very serious. Maybe this wasn't going to be a routine admission after all.

Most people with bacteria in their bloodstream look sick—pale, sweaty, drawn—and most ninety-year-old people with bacteria in their bloodstream look extremely sick. But Mr. G was sitting up in bed watching TV, engrossed in the morning soaps. He was a pixie of a man: Put a stocking cap over his bushy white hair and he could pass for one of Santa's elves. He broke into a broad smile when I walked in. After telling him who I was, I asked, "How are you feeling?"

"Fair."

"Does anything hurt you?"

"My knee."

I promised to look at his knee shortly. Then, trying to get a sense of just how demented he was, I asked, "Do you know where you are? Did they tell you the name of this place?"

"It's the hospital."

Good try, but not quite. I tried to put a positive spin on the fact that he didn't have a clue where he was. I acknowledged that until recently he'd been in a hospital. But now he was in a skilled nursing facility for rehabilitation to help him get back on his feet. The fall had taken a lot out of him.

Mr. G smiled again. He didn't seem to know what rehab meant, and he didn't remember having fallen, but he was pleased to have a visitor.

I put my stethoscope on his chest and listened to his heart, then his lungs. His skin temperature felt normal. I moved on to examining his knees. His left knee had a scar marking the site where the joint had been replaced; it was slightly warm, and I could feel fluid in the joint.

My mind began sifting through the diagnostic possibilities. He could have septic arthritis—bacteria in his replacement joint that had leaked into his bloodstream. Or he might have two separate issues: one, a chronically inflamed knee; the other, bacteria in his blood that was coming from some other part of his body. Or the bacteria might not have come from Mr. G at all. The bacteria could have contaminated the blood sample after it had been drawn.

I telephoned the physician who had cared for Mr. G at the community hospital to see what he thought of the swollen knee and the blood culture.

"The guy's had knee pain for years," he assured me. "Probably has a chronic effusion [excessive fluid inside his knee joint]. He's gone to a bunch of orthopedists. No one's been able to do much for him. I'm sure the culture is contaminated."

Impressed that Mr. G looked well, and unsure whether the blood culture was a true positive, I ordered two more blood cultures and set off to see the rest of my patients.

Complications

A few days later I was at the same facility filling in for a vacationing colleague. When I arrived, my hands icy-cold from the brief walk to the front door from the parking lot, the head nurse handed me several lab reports. Mixed in with routine admission tests on new patients were the results of Mr. G's repeated blood tests. They again showed bacteria in his bloodstream. It wasn't a mistake then. Life was about to get complicated.

Mr. G was in his room, and I was relieved that he appeared much as I remembered him—looking chronically but not acutely ill.

"How are things?" I asked.

"My knee hurts," he told me.



He didn't have a fever, his blood pressure was normal, and his mental status had not changed, but his knee was slightly warmer and slightly more swollen. Just as I finished examining Mr. G, a middle-aged woman in polyester pants and a blue checked button-down shirt walked in. "Are you the daughter?" I asked. She nodded. "I was about to call you," I said. "There's a bit of a problem here." I explained about the blood cultures coming back positive and her father's swollen knee. I noted that her father had a serious infection. "Without antibiotics," I told her, "such an infection is often fatal."

I paused to let that sink in.

"You mean he could die?" she asked, eyes widening. I nodded, amazed, as I always am—despite years of working with older people and their families—that she could be shocked at the possibility that her ninety-year-old father, with his multiple medical problems, might not live forever. The best I could do was to explain the various ways to proceed and suggest, gently, that toward the end of life, doing less to a patient is sometimes doing more.

"We need to remove some fluid from your father's knee to see if that's where the infection is," I told her. "If it is, we'll have a choice. The usual treatment would be to hospitalize him and take out the artificial knee joint. But that's a major operation, one I'm not sure his heart could tolerate. If he did come through the procedure, he'd have to be given antibiotics intravenously for six weeks. That's a lot for anyone, and it's pretty overwhelming for a ninety-year-old with diabetes and coronary heart disease and dementia." I waited for my

words to register, then went on.

"But we don't need to do all that," I weighed in with my recommendation. "We could simply remove the fluid from your dad's knee and then treat him with antibiotics for several weeks. If he makes it—and there's a reasonable chance he would—great. If not..."

Mr. G's daughter looked alarmed. "Not making it" did not strike her as an acceptable possibility. It turned out that she assumed, as do so many of her peers, that there would always be a medicine or a procedure to keep an older person going-especially a parent. The idea that any medical treatment entailed risk, and that some risks might not be worth taking, was alien to her. That treatment options fell on a spectrum ranging from most aggressive medical care, to care using oral antibiotics and pain medications, to care focused exclusively on her father's comfort-was an equally foreign concept.

"Did you speak with my father's regular doctor?" she wanted to know. I hadn't. I got the contact information from her and hoped that hearing the same recommendation for less aggressive treatment from someone she knew and trusted would be useful.

I spoke with Mr. G's long-time primary care physician, but he, too, was skeptical about managing a serious infection outside of a hospital setting. "He's full code, you know," he told me. "A couple of years ago he said if he ever got sick he wanted 'everything done' to keep him alive."

"But that was a few years ago," I responded. "Now he's ninety. He has a dozen other medical problems, including dementia. He probably wouldn't survive a cardiac arrest."

At least Mr. G had actually had a conversation with his physician about his preferences for care in the event of serious illness. According to a recent national survey, only half of older Americans have discussed end-of-life care with anyone. But any advance care planning needs to be revisited when the patient's overall condition changes.

I wondered whether Mr. G had ever truly understood what wanting "everything done" meant. Did he have any idea what it would be like to be placed on a ventilator to breathe—that it would mean he would be unable to speak or

eat? Did he have any conception of the likely outcomes of various invasive procedures? TV medical dramas suggest that two-thirds of patients who undergo cardiopulmonary resuscitation survive and walk out of the hospital. In reality, fewer than 20 percent do, and for those who are over age eighty and have multiple chronic diseases, the percentage is considerably less.

Mr. G's primary care physician pointed out that the treatment approach outside of a hospital setting that I was advocating would be complicated to orchestrate. A specialist would need to "tap" (take a sample of the excess fluid from) Mr. G's knee. Mr. G would need to go to the specialist's office to have it done, so as to be sure that the necessary equipment was available both to do the procedure and to examine the fluid under a special microscope. If the knee proved to be the site of the infection, Mr. G would then need to return to the skilled nursing facility and begin taking antibiotics. The primary care doctor advised that Mr. G be hospitalized.

It was after 5:00 p.m. I'd spent an hour examining the patient, speaking with his daughter, and calling the primary care doctor. It would be much easier to simply send Mr. G to the hospital emergency department.

I returned to Mr. G's room and told him and his daughter that their family physician advised that Mr. G be admitted to the hospital to have the fluid removed from his knee and to start intravenous antibiotics. Mr. G seemed resigned to his fate; his daughter seemed relieved. But she didn't want her father to go back to the community hospital from which he'd recently been discharged. Instead she wanted him to go to the teaching hospital across town, the hospital where Mr. G had had both his knee surgery and open-heart surgery. I wrote a note in the medical record, asked the nurse to arrange for an ambulance, and called the emergency department at the teaching hospital to tell the staff members there the essential medical information about Mr. G.

A Cascade Of Actions And Reactions

The next day I conducted my palliative care rounds at the teaching hospital—

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adjusting the pain medication for a cancer patient and meeting with a family struggling with whether it was time to start hospice care. Then I checked in on Mr. G. He wasn't in his room. He was in the operating room. Tests had shown that the artificial knee joint was the site of the infection. An orthopedic team was cleaning out the artificial joint and removing part of the lining.

A bit later I ran into the medical intern who was caring for Mr. G, an earnest young woman who wore her stethoscope as un-self-consciously as other women wore a necklace. I asked how the surgery had gone. Speaking rapidly, she explained that while Mr. G was being operated on, he'd started to bleed. He had needed a transfusion of three units of blood. Then, in the recovery room, his blood pressure had suddenly plummeted, and he'd been put on a powerful intravenous medication to raise it to normal levels. An electrocardiogram showed inadequate oxygen going to his heart; blood tests indicated he'd had a mild heart attack.

I asked the intern what the plan was. "He's stable cardiac-wise," she told me. "The attending physician wants an infectious disease consultation."

I was dismayed. "Why?" I wondered out loud. "Of course, he could have an infected heart valve as well as an infected knee. But what would you do then? Open-heart surgery to replace the artificial valve?" I thought for a moment. "In a guy this age, bacteremia can be the first sign of colon cancer. Are you going to do a colonoscopy, too? If he does have a malignancy, what then? Take out his colon?"

The intern shrugged her shoulders. "Yeah, I'm not sure where all this is headed," she said. But she wasn't about to question her attending physician—and I no longer had any official involvement in the case.

Seeming to take the approach of leaving no stone unturned, both the attend-

ing physician and the infectious disease consultant thought it would be useful to have all the facts on hand, then figure out what to do with them later. Mr. G had an echocardiogram (hospital charge \$1,601) looking for bacterial growths on his artificial heart valve. He didn't have any. He had an abdominal computed tomography (CT) scan (hospital charge \$3,000) and a pelvic CT scan (hospital charge \$2,592), looking for a tumor. He didn't have one. But the dye used in administering the scans put him into acute kidney failure for a few days.

Mr. G spent six days in the hospital, for which Medicare was billed \$94,295—excluding physician fees.

On his sixth day in the teaching hospital, Mr. G returned to the skilled nursing facility where I'd first met him. He stayed there for eight weeks—until late February—receiving intravenous antibiotics and undergoing physical therapy for the knee surgery. Eventually he was able to "transfer," meaning that he could, with assistance, get from his bed to a chair and from a chair to a wheelchair, much as he had before this saga began. After his wife and daughter promised to hire twenty-four-hour personal care attendants to help him bathe, dress, and eat, as well as prepare meals and do light housekeeping, he was dis-

Two days later, when a visiting nurse went to the house to check on Mr. G, she found him confused and unsteady on his feet. She promptly sent him by ambulance to the local community hospital. Once again he was subjected to x-rays and blood tests, which didn't reveal anything. Then he was dispatched for unspecified "rehab" at the same skilled nursing facility (charge \$500 a day).

Mr. G's care during this three-month period included three hospitalizations (two at the local community hospital, one at the teaching hospital) and three stays in the skilled nursing facility. The total cost charged to Medicare approached \$200,000.

What Happened Here?

In the midst of this, the treatment that Mr. G received in one of America's distinguished teaching hospitals nearly killed him. Several of the tests he underwent contributed nothing to his medical

treatment and, in fact, caused complications. His care was also extraordinarily expensive. According to the *Dartmouth Atlas of Health Care*, the teaching hospital to which he was admitted spends an average of \$87,721 on a Medicare patient in the final two years of life—more than any other hospital in the state. During this same time period, it also ranks number two in the state for spending both on procedures and on imaging studies. Patients cared for at this hospital spend 33 percent more time in the hospital and 50 percent more time in an intensive care unit than the national average.

The approach that I had proposed for Mr. G—an office procedure to drain and wash out his knee, followed by intravenous antibiotics at the skilled nursing facility—wasn't seriously considered by the family, the patient's primary care doctor, or the admitting hospital, for that matter. The all-too-common reality of substituting expensive and invasive treatment when a cheaper, simpler strategy would have been at least as effective is classic overtreating. It's usually attributed to the economic incentives shaping physician practice and hospital care.

But financial factors weren't the driving force behind Mr. G's treatment. Not one of the doctors who provided his medical care had any economic incentive to order the many tests he received. The attending physician at the teaching hospital was a salaried member of a multispecialty group practice. His income was totally independent of how long Mr. G stayed in the hospital or how many tests he had—or of how well he did clinically.

However, the attending physician did

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work in a hospital where the culture dictated that patients were to be diagnosed and treated. That also meant doing whatever it took to achieve those ends. The hospital was particularly proud of its record of solving the most challenging diagnostic dilemmas and attempting to treat the highest-risk patients. And the cost of those interventions was irrelevant, in terms of both the suffering the patient would endure and the financial burden to society.

Driving Mr. G's care wasn't just this one hospital's culture to succeed and its definition of *success*. There is also a broader medical culture that values diagnostic certainty and technological solutions to problems. It's fueled by an economic system that rewards physicians for the process rather than the outcomes of the care they provide. That medical culture, in turn, is embedded within a society that believes fervently in the power of medicine and denies that life is finite, which creates unrealistic expectations on the part of patients and their families.

Preventing future patients from shuttling back and forth between hospitals and skilled nursing facilities will require attacking each component of what, in effect, is a complex ecosystem of economics, ideology, and medical culture. They all reinforce each other to maintain the status quo. Only by reforming medical education, increasing consumers' understanding of the roles of both medical treatment and palliative care, *and* altering how physician practices are organized and financed can we hope to bring about change.

Coda

On a brisk, windy New England day, with spring finally in the air, Mr. G was discharged from the skilled nursing facility. It was three months to the day since I'd determined he had an infection. He went home to hospice care (charge \$143 a day) to spend whatever time he had left with his family. He was still confused, but when he woke in the morning, he saw his wife in bed along-side him. He knew where he was.

Mr. G was home at last, with, as it turned out, six weeks left to live. During those last six weeks, he was surrounded by his family, and his knee continued to hurt. But with the strong pain medication he received, it hurt much less than it had before.

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