On Caring For ‘Difficult’ Patients

Difficult patients and their frustrated doctors fail each other.

by Tony Miksanek

Let’s be blunt. It’s hard to care for difficult patients. It’s sometimes impossible to actually like them. This species of sick individuals tends to strain time, patience, and resources. They often generate a cascade of phone calls. They sometimes demand a heap of medically unnecessary tests. They occasionally refuse recommended treatment. Many have unreasonable expectations. Some whine and gripe incessantly. A few threaten to sue. Almost all of them need at least thirty minutes—and want sixty minutes—of face time with the doctor at every encounter instead of the usual fifteen minutes the schedule actually allows.

In more than twenty years of general practice in a very small town, I can claim only a tiny number of demanding patients who have made my life difficult—much less than 1 percent. Consider three patients all seen by me in the same week. In their own unique ways, they make my professional life tricky. Even in my private life, they invade my thoughts—with disappointment, irritation, and worry.

Willy: Refusing Recommendations And Calling The Shots

Willy is a great guy even though he’s a lousy patient. The thirty-seven-year-old salesman was diagnosed with type 1 diabetes fourteen years ago. He has been my patient for three years. I treat his father and mother; they asked me to accept their son as a patient. They said that he was looking for a “good doctor.” Little did I know that “good doctor” meant any physician unfamiliar with his history and naive enough to take him as a patient.

It turns out that Willy had burned his bridges with most of the other local physicians. He didn’t have many doctors left to choose from in our rural area; I might have been the only name left on the list. At his first office visit, he made his intentions quite clear.

“Look, Doc, I’m not going to waste your time. All I need is a prescription for my
insulin and syringes. I’m a decent patient. I’ll never bother you.”

What doctor wouldn’t be enamored by the promise of never being bothered? I never thought such a thing was possible.

After a thorough history and physical examination during that initial visit, the man had me convinced of his benign nature. His blood pressure was excellent. Pulses were strong. His feet were in good condition. There was no sign of any damage to his eyes from diabetes.

I began blabbering about diabetic care. I gave him a laundry list of lab tests to get done and insisted he call or fax one week’s worth of his blood sugar values—taken at least twice a day—to the office for my review. Willy was courteous and listened intently up to that point, but he couldn’t take any more.

“Whoa!” he interrupted me. “I’ve got it covered. No problem. All I need are some refills.”

Willy apprised me that he managed his blood sugars and adjusted the insulin dose on his own. He wasn’t asking for my assistance. He confessed he had no sliding-scale system or arithmetical formula to guide his insulin management. Instead he relied on intuition and personal experience.

“No offense to you, Doc” Willy apologized. “I know my body pretty well. I’ve got a good track record in fourteen years—no passing out from low blood sugars; no being put in the hospital because my sugar was way too high.”

And then he flashed a smile and patted me on the back. It was role reversal. His gesture was supposed to make everything all right—his need for absolute autonomy, his uncanny ability to control a serious disease, and my relegation to a pen and prescription pad.

At that moment all I could think was, “Damn, this guy’s a good salesman.”

What self-respecting physician would relinquish total control of a complex illness to a patient? None that I know. That answer was corroborated by the later knowledge that Willy had been “fired” by a few doctors in the area. I suggested a referral to an endocrinologist. There are only two of them within ninety miles of our town. Willy refused without offering any reason, even though he might have offered distance as an excuse. He also made it clear that he would come to the office only once a year. It was his way or no way.

I had a choice to make. If I refused to treat Willy, where else could he go? Perhaps I could change his behavior. Maybe I could succeed where my peers had failed. Willy was polite and funny and hard-working and smart. Most important, he seemed incapable of lying. He believed that he knew his body better than any doctor. He never alleged that he understood the physiology of diabetes and the intricacies of insulin.

“Role reversal. His gesture was supposed to make everything all right—his need for autonomy, his uncanny ability to control a serious disease, and my relegation to a pen and prescription pad.”

Narrative Matters

HEALTH AFFAIRS - Volume 27, Number 5
His glycohemoglobin Alc (a blood test that measures the average sugar for the past two to three months) at that first office visit was 7.5 percent—not ideal, but not too bad for a do-it-yourselfer (a normal value is less than 6 percent). I wrote him refill prescriptions for needles and syringes along with two types of insulin: NPH (an intermediate-acting form that he injects twice a day) and Regular (a short-acting form). He refused to consider changing his insulin to Lantus, a newer, long-acting one that he would need to inject only once a day. He promised that he would continue regularly monitoring his blood sugars at home. I shuddered to think what he considered “regularly.”

True to his word, Willy never bothers me. He faithfully comes to my office once a year but never more. At this week’s visit, I write refill prescriptions for him. I worry about Willy, but what can I do? If I cut him loose, how will he fend for himself? Will he find a friendly pharmacist to do his bidding? Or purchase insulin over the Internet?

At the conclusion of this week’s appointment with Willy, I perform a little self-analysis. Why do I picture him as a difficult patient? Obviously, he isn’t playing by the rules—at least not the rules I learned in medical school. He won’t allow me to do my job. If I can’t control his treatment, I’d at least appreciate a 50 percent stake in it. I aim for perfection. Willy’s goal is just getting along with his disease on friendly terms and avoiding hassles or complications. If his chart is ever reviewed by the insurance company for quality of care, I’m going to get dinged. At the same time, Willy’s self-reliance might offer a lesson about controlling health care costs and empowering patients. Still, I need to quit coddling Willy. What makes me an ineffective physician in my mind is exactly the quality that Willy deems vital in his primary care doctor. I’m easy.

**Mrs. Thomasina: Worried But Well And Demanding Lots Of Testing**

In contrast to Willy, I can never do enough for Mrs. Thomasina. The eighty-one-year-old widow is in good health except for high blood pressure and osteoarthritis. She is a lonely woman who likes to talk. She also has a bad case of “testophilia”—an unnatural affection for medical testing. I suspect that Mrs. Thomasina has never met a doctor she doesn’t doubt.

Mrs. Thomasina tests my accessibility day after day. She bypasses my office receptionist when she wants to talk to me. Instead, she phones me at home in the evening. If the line is busy or no one is home, she has the hospital operator page me. Such is the life of a small-town doctor. Her calls never involve an actual emergency. Rather, they are about matters that “can’t wait.” Examples include failing to have a bowel movement the day before, ringing in her ears, a muscle cramp, and unexplained itching.
Mrs. Thomasina has trouble coming to my office. She no longer drives. Her aging children live out of state. She has hired a part-time caregiver to assist her with grocery shopping and household chores. I make home visits every three months to check on Mrs. Thomasina. Her telephone calls bridge the span between house calls and occasional office visits. If a week went by without a call from her, I’d fear she might be dead.

Mrs. Thomasina is apprehensive that there’s something terribly wrong with her. In truth, she’s much healthier than she imagines. The only way to assuage her concern is to perform some kind of test. Often a urinalysis is enough to satisfy her. I have no inkling what it is about urine that so fascinates Mrs. Thomasina. It is a mystery that ranks up there with Stonehenge and the Bermuda Triangle.

Mrs. Thomasina’s lack of confidence in my diagnosis skills is beyond deflating. It’s an unintentional insult. As soon as she learns about any medical test (from television or the newspaper or a friend), she must have it. Lately she’s lobbying me to order a total-body computed tomography (CT) scan for her. I don’t know how much longer I can hold out. It’s not that I’m worried about the radiation exposure as much as I am about some of the incidental findings that will inevitably cause her additional anxiety and necessitate a further work-up.

Money is no object for Mrs. Thomasina when it comes to her health. When the topic of expense is broached, her response is always the same: “I think I’m worth it.”

She gladly signs all waivers in case Medicare doesn’t approve a diagnostic test. She would happily spend her last penny paying for a test. Her faith in technology and medical science approaches religious devotion.

Mrs. Thomasina keeps a notebook of all her medical test results and statistics. It’s as thick as an encyclopedia volume. At this week’s home visit, she asks me to page through it like a scrapbook. Although she isn’t single-handedly bankrupting the health care system, Mrs. Thomasina is definitely putting a small dent in it. I resist as best I can at being her accomplice. God knows I’ve told Mrs. Thomasina “No” on many occasions when she asks for tests that I deem medically unnecessary. Yet she has a way of wearing me down. I’ve suggested cognitive behavioral therapy to her, but she steadfastly refuses. Mrs. Thomasina prefers the life of a test addict.

“As soon as Mrs. Thomasina learns about any medical test (from television or the newspaper or a friend), she must have it.”
Max: Angry, Pessimistic, And Running Out Of Options

Unlike Mrs. Thomasina, Max doesn't worry night and day about staying well. Instead, the fifty-two-year-old laborer has pretty much given up on the likelihood of recovering his good health. Almost a year ago, Max injured his neck at work. He's mad at his employer. He's mad at the workers' compensation insurance company. He's mad at me. I understand his frustration, anger, and distrust. After eleven months of medical treatment, he feels his condition is unimproved. He senses that his boss no longer cares whether he ever returns to work. Max thinks the insurance company is spying on him because it believes he's well enough to resume working.

“Not a bit better,” Max announces at his follow-up visit this week. It’s the same greeting he has used in the past five office calls.

Without pausing to take a breath, he hands me four pieces of paper and says, “You have to fill these out.” They are insurance forms and temporary disability statements that need to be completed. Max sits on the exam table and seethes. His posture is stiff. He cannot (or will not) move his neck from side to side. He is capable of flexing his neck only about a few centimeters, and even this small change of verticality is accompanied by a grimace and a grunt.

Max is at a point of no return. He has convinced himself that his neck will never improve. Max sits on the exam table and seethes. His posture is stiff. He cannot (or will not) move his neck from side to side. He is capable of flexing his neck only about a few centimeters, and even this small change of verticality is accompanied by a grimace and a grunt.

Max is at a point of no return. He has convinced himself that his neck will never improve. He has told me on multiple occasions that he’ll never be able to go back to his job. It wasn't that way in the beginning. Back then, he was optimistic and eager to return to work. I still wonder who or what changed his mind—the attorney he hired, the anger he feels at how he’s been treated, or his constant pain. Max sees himself as a victim. I used to feel sorry for Max. Now I feel just like him—pessimistic.

Our lack of success is not due to a shortage of effort. Many different kinds of medications have been prescribed and taken. Max is currently on Cymbalta, an antidepressant drug that also reduces the intensity of chronic pain. He doesn't think the medicine is doing him any good, but I see it differently. Whether it is helping his chronic pain or situational depression or both, Max appears a little less irritable even if he isn’t any more upbeat about his situation. He also takes pain pills two or three times a day.

It was a struggle getting workers’ comp to authorize the Cymbalta. The people there couldn’t understand why they should pay for an antidepressant medication. The insurance representative made it clear that the company was only on the hook for treatments related directly to Max’s neck injury. I was dumbfounded that they
could fail to see the big picture. After lots of phone calls and a little begging on my part, the comp people finally gave in when it became clear I wouldn't give up.

Max has had x-rays and an MRI scan of his neck, nerve conduction studies, an electromyogram (EMG), and even a cervical myelogram. He has seen a neurosurgeon, who advised him that any operation on his neck would be a last resort and not guaranteed to reduce his pain. Max has been through extensive physical therapy and does home cervical traction. He has received steroid injections for his neck. Acknowledging my failure, I referred Max to a pain management program.

“A waste of time,” was Max's verdict.

I realize that I'm going to sound like a terrible doctor when I say that I was beginning to think that Max isn't going to get any better. This week he's finally made me a believer; he's not going to get better. Faith works both ways. A patient has to believe in his doctor and vice versa. Max has given up on me and himself. Neither of us has any expectation now that I will fix his damaged neck. But what about his wounded psyche? Might there still be a chance at healing that?

Now the only thing that brings Max back to see me is the need to complete the workers' compensation forms and receive the pills that briefly and incompletely take away his pain. I remind him that neck problems are unpredictable. There's still a chance that his neck will get better even without surgery. Time might yet do the trick. Still, I am shamed by the lack of conviction in my pep talk. I hardly believe it myself. I recommend that Max keep taking the Cymbalta and continue physical therapy, including a specifically designed work-hardening program to enhance overall fitness and strengthen his muscles. I fill out Max's forms and hand them to him. We nod at one another without speaking a word. What more is there to say? We are both dreading a rerun of today's encounter in three weeks.

Realities

A know-it-all, a hypochondriac, and a pain in the neck—Willy, Mrs. Thomasina, and Max—seek only what we all need at one time or another: reassurance, comfort, compassion, and a helping hand. I desperately want to give them all these things and more. Yet despite my efforts, I am unable to deliver the goods. I can't give these patients everything they want. Maybe no one can. I am Don Quixote with an M.D. degree. I joust with windmills, but my windmills fight back.

How not to care for difficult patients is pretty obvious: Don't brush them off. Don't use “stress” as a diagnosis for unexplained symptoms unless you're 99 percent sure that anxiety is an accurate diagnosis and not just a cop-out. Don't be an-
gry. Don't be punitive. Don't propagate despair.

How to care for difficult patients? Inside my office, I know that it involves protocols and limits, truth (including knowing when to admit “I don’t know” to yourself and your patient), information and resources, and goals for reasonable results. In my heart, I know time is key. Time is a precious commodity subject to the laws of supply and demand. Difficult patients require more time. Busy doctors find that time is in short supply. Difficult patients are at risk of becoming casualties of the almighty schedule. A fifteen-minute time slot is hardly enough for complicated patients. No one would make a major decision—choose a spouse, buy a car or a house, select a college, pick a job—after only fifteen minutes of deliberation. Why then do we cram important decisions about personal health matters into fifteen- or twenty-minute appointments?

What exactly drives the office schedule of a doctor and dictates how much time is allotted each patient? Multiple considerations, but the big ones include patients’ needs, reimbursement, practice volume, hospital responsibilities, a doctor’s energy level, and the office staff’s desire to get a lunch break and still make it home by 6 p.m. When one is dealing with difficult patients, a good case can be made for longer but less frequent office visits.

Extended visits would likely improve patient and physician satisfaction, improve compliance, and upgrade the quality of care. Providing people with more face-to-face time with their doctors does more than merely help communication. Longer visits might actually be more cost-effective than brief ones by reducing the need for frequent follow-up appointments, curtailing the number of consultations and second opinions, decreasing excessive testing, cutting down on the cost of transportation and gas consumption necessitated by repeated short visits with the doctor, and minimizing the amount of missed work for numerous appointments. In this sense, lengthier visits are a bargain. Too bad insurance companies and other payers don’t see it that way.

To continue being blunt, it’s all about how doctors and patients relate to one another. And the problem with a difficult patient isn’t just the patient. It’s also the doctor. Difficult patients and their frustrated physicians fail each other. We flop together. We lose hope. And there is no more worthless doctor than one who has lost all hope. Same holds true for a patient.