

Virtual Mentor

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ETHICS CASES

Patient Self-Rationing, a Health System Problem

Commentary by Katherine J. Mathews, MD, MPH, MBA

Dr. Jansen is an internist in a small town. He makes it his priority to get to know his patients individually and takes great pride in caring for them as if they were family. One of his regular patients is Mr. Smith, a soft-spoken 55-year-old cashier who has hypertension, type 2 diabetes, and gastroesophageal reflux disease. Throughout the years, Mr. Smith has been punctual and kept his appointments. In just a few months, however, he has canceled two appointments without explanation. Finally, he makes an appointment and keeps it. When he enters the office, Dr. Jansen notices that Mr. Smith looks less healthy than ever before.

“Glad to see you this time, Mr. Smith. Why did you cancel your other appointments?” Dr. Jansen asks, with growing concern about his patient’s health.

Mr. Smith explains, “My health insurance has a very high deductible and copay, and I have been struggling so much to pay the bills recently that I just couldn’t afford to come in. I figure it’s not much use anyway, since I can’t afford to pay for my prescriptions either. Just that Nexium you want me to take would bankrupt me. The only reason I’m here today is because I haven’t been able to feel my feet since last week, and I’m really worried. But I still won’t be able to pay for tests to find out what’s wrong, expensive medications, or even a follow-up visit anytime soon. I just don’t know what to do.”

Commentary

The case of Dr. Jansen and Mr. Smith brings forth a jarring mix of emotions: a Norman Rockwell painting of the small-town doctor clashing with a call from a debt collection agency.

This story of patient self-rationing directs our attention on an interaction between two individuals and asks us to consider how shared decision making between patients and doctors can help improve the use of resources in our current health care environment.

At one level, the strategies are straightforward, falling within the increasingly popular domain of “health literacy.” The health literacy perspective assesses what patients do and do not know and focuses on solutions that improve their abilities to grasp complex technical concepts and navigate convoluted and confusing systems of care and health insurance coverage.

As a health care consumer, Mr. Smith is already fairly savvy. He knows about deductibles, copays, and the ever-looming threat of medical debt that can lead to bankruptcy. He understands that brand-name medications can cost an arm and a leg. He is also sensitive to how Dr. Jansen's office works—he cancels his appointments as opposed to just not coming and getting labeled as “noncompliant” and a “no-show.”

If we want to continue analyzing the case within the framework of individual decision making and invoke the tools of health literacy, we could advise Dr. Jansen to engage Mr. Smith in the following ways:

Review options, weighing both cost and effectiveness. Inform Mr. Smith of less expensive but equally effective options for diagnosing and treating his condition, if there are any. If there are none, talk with Mr. Smith about less-expensive options that are good enough if not the best. For example, he could take generic omeprazole rather than Nexium. He might even buy over-the-counter formulations, avoiding prescription drugs entirely.

Justify necessary work-up and eliminate unnecessary tests. Dr. Jansen should tell Mr. Smith which tests are necessary to diagnose the source of his loss of sensation in his feet. At the same time, Dr. Jansen must ask himself which test results would contribute to his decision making and which, though informative or confirmatory, would not alter his treatment plans. Is his reflux related to *H. pylori*? Could untreated *H. pylori* be worsening his insulin resistance? In other words, do we have the right mix of diagnoses and treatments?

Initiate conversations about payment plans. When Dr. Jansen has some idea of what testing must be done and what Mr. Smith's plan will cover, he can begin to collaborate with Mr. Smith about a payment schedule for the remainder of the charges. What amount does Mr. Smith think he can pay per month?

Negotiate the frequency and necessity of follow-up. Need for follow-up visits can only be determined after Mr. Smith's diagnosis is known and a treatment plan outlined. But, since Mr. Smith seems reliable and interested in his health, there may be a way to reduce the frequency of face-to-face visits in order to lower and spread out his overall out-of-pocket costs. What self-monitoring and measurements might he be able to track at home, e-mailing or calling in results to Dr. Jansen so as to minimize the number of visits he has to pay for?

With each of these strategies, some costs might be whittled away, enabling Mr. Smith to manage his cash flow a little better. Let's hope Dr. Jansen's office staff are as willing to help Mr. Smith as he is. Dr. Jansen might consider hiring a social worker to provide case management as a way to tackle this mix of medical and financial issues that are probably widespread in their small town.

To summarize this part of the discussion, if we wanted to stay in the framework of individual decision making, we could. But the question is, do we want to work only within this framework? Is the individual level of analysis the correct ethical framing for these issues?

I would argue that it is not and that to do so is risky and potentially harmful to Mr. Smith. Here's the point: if we believe that these problems can all be solved by Mr. Smith's individual decisions and actions, we set up a situation where he's considered solely at fault when things don't work. It's challenging for physicians to face situations that they cannot resolve easily or in which they may be helpless, and there's the horrible temptation to blame the patient by labeling him or her noncompliant or uneducated. But to blame is to cause harm. In the face of large and systemic issues that limit what individual doctors and patients can do, the ethical and therapeutic stance is compassion. Even if Mr. Smith has challenges that Dr. Jansen can't solve, at least he can be aware of everything that Mr. Smith is up against and support him in his efforts.

The major forces at work in this case come not from an interaction between two men but from the financial structure of our current health care system. How so? First, as much as we lament rising health care costs, every dollar spent is somebody else's dollar of revenue. When it comes to large for-profit sectors like the pharmaceutical industry or outpatient dialysis, our national spending translates into highly coveted profit margins.

Second, as many have observed, we don't run a health care system, we run a sick care system. We pay providers when people are sick and can get a medical diagnosis, and the sicker and more complicated the medical case, the higher the reimbursement, especially when a few procedures are included as part of the work-up.

Consider, by contrast—what might have happened to Dr. Jansen and Mr. Smith 10 or 20 years ago if economic incentives had focused on risk reduction? Would Mr. Smith even have type 2 diabetes now? Or perhaps if we more systematically integrated behavioral health into medical care, might we have realized that Mr. Smith suffered from chronic low-grade depression resulting from a series of traumatic events in his childhood? Might we have known that he uses food and alcohol to manage stress, and might we have planned a very different and much more comprehensive wellness plan for him years ago?

Finally, there is one more challenge in illustrating these macro issues with a story about two individuals. As much as stories help us connect to the human side of events, they can also distance us from those human costs if they allow us to think that the story is about other people. Perhaps many readers will identify with Dr. Jansen and the pressures on physicians to manage costs in this complicated health care environment. How many readers will identify with Mr. Smith?

A few years ago, it would not have occurred to me to identify personally with Mr. Smith, as much as I might have known patients in similar situations. Now it does. Because I work in a small, charitably focused not-for-profit clinic, I don't get benefits. I purchase health insurance for my family through a broker and pay rates based on our individual underwriting. I opted for a plan with a relatively low deductible (given my choices) of \$5,000 per individual and \$10,000 for the family—as long as we stay within network. Because my son has a number of medical conditions, I chose fixed copays for ambulatory care including specialty visits. But his physical therapy and unexpected hospitalization last summer hit against the deductible. I have negotiated the frequency of visits with the physical therapist, and, with the hospitalization, I was quick to invoke my right to a payment plan that spread costs out over 12 months. You might imagine that I'm as health literate as they come, but it has not done much to lower my costs.

In my own 1960s, small-town childhood, our country doctor, Dr. Hobbs, lived around the corner and saw patients in his home. His dark-paneled waiting room included a collection of children's magazines on a bookshelf in an alcove beneath the stairs. As is true of Dr. Jansen, Dr. Hobbs knew everyone in town personally and even made house calls. What is absent from those memories is strife over financial arrangements, the issue at the heart of the story about Dr. Jansen and Mr. Smith. But without understanding the financial arrangements at the macro and micro levels, who benefits and who does not from each cost, we will not have a clear picture of how to create a more effective and sustainable health care system. From an ethical point of view, we will have abandoned our social justice responsibilities.

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