May I please see the prices on the menu?

By Corey A. Siegel, M.D., M.S.

I am embarrassed. As a specialist in inflammatory bowel diseases, including Crohn’s disease and ulcerative colitis, I see patients in the clinic, but I also have research funding to study the risks and benefits of treatment options for these conditions. More specifically, I try to translate the vast medical literature published on these topics into tools that will help patients (and their families) better understand the complicated tradeoffs involved in making decisions about treatments.

Why are these decisions so complicated? Well, a typical conversation during a far-too-short office visit entails explaining to a patient that my recommendation is to take a combination of medications to treat a given disease. If that patient does not take the medications, there is a significant risk that the disease will progress from causing symptoms such as diarrhea, rectal bleeding, and abdominal pain to a problem that could necessitate multiple intestinal surgeries and even an ostomy that would require a bag to be worn on the abdomen to collect stool. The decision seems simple enough: “I’ll take the meds!” But then I tell the patient that these medications, although effective, don’t work in everyone. Oh, and also they carry the risk of life-threatening side effects, including tuberculosis and cancer. So now I’ve scared the patient into thinking that the treatment could be worse than the disease.

But that isn’t why I’m embarrassed. I think I’ve become fairly adept at explaining the tradeoffs to patients, and I’ve even developed tools through my research to help them understand that these medications can be extremely beneficial and safely used. I believe that between my research and Dartmouth-Hitchcock’s dedication to shared decision-making I treat patients with respect and avoid taking a paternalistic approach.

Until recently, I thought all of this meant that I was doing a pretty good job. But I’ve realized that I’ve been ignoring a large component of a patient’s decision: cost.

I understand, of course, that patients pay to see me in the office, to undergo colonoscopies, lab tests, and scans, and to buy medications, but I have no idea how much all of that costs. Furthermore, what patients pay depends on their insurance company, their copayment plan, co-insurance, deductibles, and other variables. Some patients may completely agree with the treatment plan but be unable to pay, at least not without giving up things they would much rather spend their hard-earned money on.

I am embarrassed because I haven’t focused on this problem for patients, and even more so because when patients ask me how much my recommended plan will cost, I don’t have an answer. Dartmouth-Hitchcock does have a fairly slick website that can estimate how much a patient will owe based on a set of variables, but to be honest I have never suggested that a patient check this site. Even if I did, the tool isn’t refined enough to compare the cost of a specific treatment plan against another plan.

Imagine going to a restaurant, asking the waiter for a recommendation, and then finding out that there are no prices on the menu. You sheepishly ask how much an item costs, only to have the waiter respond, “I have no idea. It could be free; it could be $2,500. It depends.” But, the waiter adds, it will all be clear when the bill comes, in about three months. And don’t worry—it will be delicious. I’d walk out.

Shared decision-making helps patients understand the tradeoffs between decisions in which there is equipoise. Without question, this is a good starting point. But cost—the most practical, realistic, and tangible part of a decision after a patient leaves the office—is often ignored. When dealing with chronic diseases such as Crohn’s disease, ulcerative colitis, diabetes, or heart disease, it’s not just the cost of any immediate procedures, surgeries, or medications, but also the cost over the next months to years. Decision aids have provided evidence-based data to help patients make decisions about treatment options, regardless of cost. I believe we should work on techniques to incorporate the cost of care as a factor in future decision tools.

I suspect that I am not the only one ignoring short- and long-term costs in my discussions of treatment options with patients. I don’t know how to fix this problem, but I hope that we can start to address it. You wouldn’t buy a car, plan a vacation, or order a restaurant without knowing the price.

So why does cost have to be so obscure in health care? I’m not suggesting that care needs to be free—but the cost needs to be clear. A knowledgeable patient is engaged patient, and it is to no one’s benefit to have a patient walk out on their health.