

HEALTH CARE REFORM

Ascertaining Costs and Benefits of Colonoscopy More Difficult Than the Procedure Itself

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My grandfather died of colorectal cancer when my mother was 13 years old, a catastrophic event that tore his family apart.¹ When I was a child and even a young adult, his death seemed to me more an abstraction than a tragedy that unfolded slowly, devastating people I love.

Things change. In my 20s, I saw up close what this illness does to its middle-aged victims and their families. In my 30s, I watched my father-in-law suffer in much the same way before saying good-bye to his daughters and grandchildren. And after decades of watching young faces turn slowly into old ones, I started to see, in my mother, a girl who lost the most important man in her life just as she was about to enter high school, a girl who was then uprooted and sent to live 200 miles from home.

Now in my 40s, I am the most important man in another girl's life. If I want to be around for father-daughter dances, graduations, and grandkids, I need to be smart about this inheritable disease. My wife—a girl who lost her father before his time—insists.

Being smart is harder than it needs to be.

The US Preventive Services Task Force (USPSTF) recommends that adults receive periodic colorectal cancer screening beginning at age 50 years.² If you are still in your 40s but have a family history of colon cancer, well, good luck finding expert guidance. The USPSTF says, in essence, that it sure would be nice to have more data. The American College of Physicians (ACP) likewise counsels, "Clinicians should not screen for colorectal cancer in average-risk adults younger than 50 years."^{3(p721)} Sounds reasonable enough. Screening carries risks that could swamp the potential benefits for average- or low-risk patients. But what about people younger than 50 years whose family history leaves them with an above-average risk? The ACP recommends "individualized risk assessment."³ Translation: they don't know either.

How can it be that no one has measured this? The *N* is more than adequate. Why isn't the *n*?

Daunted, I take what might be the next logical step: I meet with a gastroenterologist. He considers colonoscopy a reasonable option. We set a date that leaves me several weeks to complete the second-most-unpleasant part of colonoscopy preparation: ascertaining how much I will pay for it.

The Affordable Care Act requires health insurers to cover all preventive services that receive an "A" or "B" rating from the USPSTF—but again, the agency has issued recommendations only for patients older than 50 years. My health insurer's web site and (thick) benefits book stop being helpful right where the official recommen-

dations do: where the recommendations are unclear, so is my coverage.

I consult human resources. I call my health plan. My human resources department calls and emails our health insurance company. Coverage depends, we discover, on the codes the gastroenterologist submits for reimbursement. A clerk at the gastroenterology group snail-mails me several billing codes they like to use, with instructions to run them by my health insurer. On the phone with my health insurer again, I rattle off numbers, hoping one of them will crack the safe.

Eventually, I learn that my plan will cover my colonoscopy at 100%—not because the government mandates it, nor because it is medically necessary or recommended care, but because my family will have hit our (high) deductible by then.

Of course, "covered at 100%" does not really mean covered at 100%. I now must ascertain whether everyone in the supply chain will accept what my health insurer pays as payment in full. The gastroenterology group and endoscopy clinic are in-network, so there should not be any surprises there. The anesthesiology group is not. My insurer will pay them the in-network rate. Will they accept that or come after me for more? Multiple calls and messages generate no reply.

The day of reckoning comes. I arrive at the endoscopy clinic, feeling as colonoscopy patients do. I complete and sign the forms I already completed and signed at least once before. I ask to speak to the anesthesiologist. She is very busy, but I will have a chance to speak to her before the procedure.

Eventually, they summon me. I undress. Then comes the gown. The socks. I climb on the table. Then the cuff. The nasal cannula. The intravenous (IV) port. The IV, take 2. The oximeter. I am cold. Finally, the anesthesiologist enters. She greets me with a warm smile, a brief explanation of what to expect, and more forms. One final form asks me to attest that "I have received answers to all my questions." Actually...

I ask the anesthesiologist whether her group, like everyone else in the room, will accept my plan's in-network rate. I note how strange it is that my first opportunity even to pose the question comes only once I am in a gown, on a table, with a cuff on my arm, an oximeter on my finger, tubes in my nostrils, a tube in my vein—and a room full of people who now are staring at me, waiting for me to sign that last form.

The anesthesiologist's eyes widen. She shakes her head. Whether or what her group will bill me, she has no idea. Our eyes lock for what seems like an eternity.

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The gastroenterologist breaks the silence. I have 2 choices, he explains. I can sign the form, or we can do this thing without anesthesia. He urges me to choose quickly. He has a plane to catch.

I take stock of the faces standing over me, then I do something that surprises none of them. I sign the form, attesting to something we all know is untrue.

As I turn on my side, I marvel. The information I want about the benefits and costs of this procedure is out there, somewhere. It exists. Yet here I go, flying almost completely blind.

General anesthesia makes me anxious. I self-soothe by focusing on the reasons I am there—my mother, my daughter—until I am asleep.

When I am lucid again, the gastroenterologist briefs me. One sessile polyp, 3 mm, removed. (Billable, I think to myself.) Biopsy results soon. (I forgot about the laboratory—is it in-network?) See you in 5 years, he says. I guess he made his flight.

I consider myself a savvy patient. Yet I still don't know what my colonoscopy will cost me, and I still cannot find out what it means.

Further research revealed things I wish I had known. Anesthesia correlates with an increased risk of perforation during polypectomy, and two-thirds of colonoscopy patients aged 40 to 64 years undergo the procedure without it (the rate is below 5% in some states), although most of those do receive conscious sedation.⁴ One survey of gastroenterologists and endoscopy nurses⁵ found that respective respondents preferred no sedation by 13% and 4%; moderate sedation by 34% and 26%; and propofol by 53% and 70%. Yet

most of those who preferred propofol (70% and 63%, respectively) believed that the marginal benefit it provides over moderate sedation would be worth no more than \$100 to them.⁵

Still, no one has collected the information I consider most important. The literature review underlying the USPSTF's updated recommendations concludes "there is no accepted risk-assessment tool to help tailor colorectal screening"⁶ to patients with above-average risk; we still do not know the significance of small polyps; and, most stunning, "no [colorectal cancer] screening modality has been shown to reduce all-cause mortality."⁶

Did I, out of fear and ignorance, submit to a procedure that was not only costly and uncomfortable, but unnecessary?⁷ Had I waited until age 50 years—or never had a colonoscopy—what is the likelihood that those 3 millimeters would have denied me a father-daughter dance? What about a graduation? What about grandkids? What is the probability that I am now safe, or that I would have been sorry?

All I know for sure is that no one is competing to accumulate, condense, and present to me—the presumed beneficiary of all this education and technology—the information I need to make an informed choice. Quite the contrary: it is as though some force is actively trying to hide that information behind fragmentation, bureaucracy, and other barriers that prevent anyone from trying to capture my business by answering my questions.⁸

Is this a health care system, or a fog machine designed to ensure we do not see what is really happening?

Published Online: June 21, 2016.
doi:10.1001/jamainternmed.2016.3292.

Conflict of Interest Disclosures: None reported.

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