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## A trip to healthcare

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### Abstract

This narrative shares how my experience with two colonoscopies and three surgeries in one year taught me that I am not so good at engaging in treatment decisions. I thought I was. This essay sets out where I made my mistakes, why I believe I made those mistakes, and how the hospitals, intentionally or not, made good decision-making harder. I offer two suggestions for enhancing the role of the patient in decision-making including 1) Every doctor in a diagnostic-decision-making interview should use the sentence “You have some choices here.” The doctor will have preferences, of course, but the patient needs to hear that there is more than one way to take the next step and 2) For diagnostic-decision-making moments, all doctors (and hospitals) should provide patients with support personnel to help the patients use decision-aids, prepare for discussions with doctors, and make the decisions. I conclude with why this is critical in healthcare today.

### Keywords

Patient engagement, patient involvement, healthcare decision-making, patient experience

### Me Vs. The Hospitals

A gastroenterologist told me I needed “fairly serious surgery.” In my self-image, I seek control of my life as much as my limits and luck will allow. And perhaps a bit beyond. This essay is about how that self-image engaged with two hospitals, two colonoscopies, and three surgeries, and about how those hospitals responded. I finish with some thoughts about how the hospitals and I might do things differently.

### A Narrative of Failure and Success

I am in my seventies. Polyps began developing in my colon, and my gastroenterologist at Hospital A removed them during colonoscopy. In March of 2015 he told me that one polyp had grown into the colon wall and wouldn't come out using the technique he had used for years. I needed a second colonoscopy, this time to be done by his colleague down the hall using a different procedure. I was troubled.

Why did I need two colonoscopies? How come the first doctor didn't know the procedure used by the second doctor? Why didn't my PCP send me to the second doctor in the first place? Why was it so important to take out the polyp? The doctor explained that the shape of the polyp increased the likelihood that there could be cancer cells underneath it. But I had heard that cancer cells in the colon are very slow growing. I was 76. Might it make sense to do nothing? No, he explained, there are different kinds of cancer cells in the colon, and some are not so slow growing. I had doubts, did not press to learn about other

choices, and made the appointment for a second colonoscopy in June.

The second gastroenterologist's procedure (endoscopic mucosal resection) couldn't get the polyp out either; he was the one who said I needed surgery. This time I knew enough to ask: are there alternatives? Hesitation. Staring at the floor. “Yes. They do something in China (endoscopic submucosal dissection, ESD). They don't cut through the stomach; they use colonoscopy and cut from inside the colon. It can result in a torn colon and emergency surgery.” “How often does that happen?” “About a third of the time.” “Are there people in the States who do this?” “Yes.” “Would they give the same statistics?” Pause. “Probably not.” Pause again. “But there is a guest in our department this year from China who uses this procedure.”

I called a few other hospitals and it proved difficult to find a doctor who does the ESD procedure. But I didn't have a crisp vocabulary, my questions were blurry, and I never got to someone beyond the frontline clerical level. I felt discouraged, and that undermined my accustomed attitude to push my way through a bureaucracy.

So I went to a colorectal surgeon at Hospital A. She said the standard surgery was straightforward and drew a picture. “Take about an inch on each side of the polyp.” The surgeon answered all my questions, though she and the support staff were clearly in a hurry.

I sought a second surgical opinion at Hospital B. This took a month to set up. The second surgeon said the same thing

except that he also wanted to take out another polyp that was “nearby.” “Why?” “I wouldn’t go in just for this second one, but the polyp is dysplastic so it is better to get it now rather than wait for the next colonoscopy.” This surgeon had a very engaging manner: humorous, open, patient, even chatty. No rushing, I decided to go with him. He had no opening for five weeks. I made the appointment.

I had read a number of articles that described the pressure on doctors to increase the number of patients, procedures, tests, and meds. I have seen doctors running down the hall to their next patient. I have seen billboards and websites zealously selling hospital services. Competition among hospitals is common knowledge.

Four days before the scheduled surgery I visited Hospital B for a preparatory session. The surgeon explained with a drawing that the second polyp he wanted to take out was located in the lower left-hand corner of my colon. I was taken aback. “That’s a lot of colon to take out.” “About 30% of the colon.” “Why do you have to take out so much?” “If I take out the polyp in the transverse colon, then I need to make sure no cancer has spread, so I need to take out the blood supply that serves it. That blood supply also serves the left side of the colon, so I have to take out the left side also.” “Is there no way to avoid taking out so much?” “No. More of the cancer-prone polyps tend to grow on the left side, so taking it out will cut down on the number of polyps in your future.” “I didn’t know anything about this before.” “And, the reconnection if I do a left colectomy is more reliable.” He told me that the three most serious “complications” of this surgery are bleeding, infection, and the reconnection coming apart. He mentioned the “reconnect reliability” of his preferred approach three times. I asked if there is any long-term significance to my losing that much colon, and he said there is none. I asked if all surgeons at his level of experience would do the surgery this way. He said yes. I of course knew of at least one surgeon at Hospital A who would take out only 4” inches. I decided to go forward with the affable surgeon sitting in front of me.

There was a pattern. Doctors presented me with a path, I had doubts, I did little to act on the doubts, and I did as the doctor prescribed. Why? The certainty of the gastroenterologist and his dismissive manner about the Chinese alternative played a role. I felt rude and presumptuous going beyond his judgment. Though nothing in my self-image is consistent with that attitude, it felt simpler and smoother to go with the voice of authority.

With the surgeon, I felt that refusing his recommendation to go with the much larger surgery would be costly. I felt the pressure of being told of the full scale of the surgery so late in the decision-making process (four days before

scheduled surgery). If I canceled the scheduled appointment, what could I do to make my decision a better one? I now had two views about the right way to do this surgery. What could I do with that? It had taken two months to get this all set up. Under that polyp might be cancer looking for a way into the rest of me. Should I tell the surgeon who in four days was going to put a knife in my belly that he was wrong, that another reputable surgeon disagreed with him? Was I implying that he was ignorant of the views of other surgeons or that he was lying to me? (I had been advised by a doctor-friend: “Not smart to piss off your surgeon.”) Should I halt the process and seek a third opinion, or go back to that first surgeon? Again, the easiest path was to go with the doctor sitting amiably in front of me.

The surgery took place in September of 2015. In recovery, the surgeon explained that all had gone very well, though the offending polyp turned out to be somewhat further to the right than expected. (Puzzling: the colonoscopy had marked the polyp with dye, and I assumed they would have measured exactly where in my large intestine it sat.) So, instead of doing a left colectomy, he did a right colectomy. Again, I now have 30% less colon than before, though it is a different 30%. And that other polyp which he had identified initially as the reason to do a more extensive surgery is still in there.

In the hospital one night I discussed with a nurse whether giving me more water via an IV was a good idea. “I will ask the surgeon on call.” A half hour later I wandered to the nurses’ desk and found the on-call and the nurse. The surgeon said to me, “I understand that you are refusing water in the IV.” The nurse, in a blessed Annie Hall moment, said “No. That’s not what I said. I said he asked a question.”

In my various hospital visits more than one doctor was moved to say: “I have already explained to you that...”

My body recovered very well from the surgery, until:

On Thursday morning, November 12, I mailed much of what is written above to the Hospital B Patient Relations. That night, while teaching class, I had a violent stomach attack. This was later identified as a blocked small intestine. Big trouble. At Hospital B, they performed surgery at midnight. They took out the strangled part of my small intestine and another chunk of my colon, and fitted me with a colostomy bag.

I was told that the colostomy was temporary. Once some healing had gone on in my gut, I could have a third surgery to restore everything to its original design. With some qualms, I scheduled the surgeon who had done the emergency surgery to do the third surgery, the “take down” of the colostomy.

But a second opinion still seemed called for on the question. An internist-friend practicing in a nearby city recommended the chief of colorectal surgery there. I made an appointment.

The second-opinion volunteered, early in the conversation, that all the colorectal surgeons in the area know each other well, and that the surgeon scheduled for my third surgery had been his classmate in their residency. He spoke well of her. He said that everything done in the first two surgeries was done exactly as it should be. He justified the larger (13") surgery in the first operation with the same rationale that the operating surgeon had used.

I left with reassurance and the obvious worry. I had no energy for a third opinion, no real evidence that I needed one, and no idea what to do about the independence of my second opinion.

I should also mention something that did not happen. In the course of getting my "consent" signature, the surgeons in surgeries #1 and #3 were explicit about three risks: bleeding, infection, and the re-attachment of my innards coming loose. No one mentioned adhesions. According to several websites, these occur 93% of the time, and in fact were responsible for the emergency that led to my second surgery.

Two other events, which did happen, illuminate my feelings as a patient. An anesthesiologist friend promised me in advance of surgery #1 that he would try to be sure that I had the service of "the best anesthesiologist in the city." On the day of surgery my friend's friend came around, introduced herself, and chatted for about three minutes. I was greatly comforted. I thought to myself: "someone here is on my side." Later, while recuperating in the hospital, I found myself delighted with the professionalism and care of the nursing staff. As each shift changed the new nurse managed the bonding process with tact and talent. So it was jolt when, one day as the shift changed, I wandered into the hall to find the nurse who three minutes before had been my closest support, now walk up to me, look right at me, and continue walking. Rejection.

Shortly after sending my note to Patient Relations on November 12, I received a letter telling me they would investigate. On January 7, I received the result of their investigation: it carefully answered questions I did not ask, and ignored those I did.

The primary issue I had raised was the discrepancy between the narrow (2"-4") surgery proposed by the surgeon at Hospital A, and the 13" surgery done by the Hospital B surgeon. The letter from Patient Relations said nothing about this and instead explained (a) why their surgeon

did a left side surgery and not a right side, an issue I never raised, and (b) that "it was determined" that the risk of surgery is less than the risk that a cancer would not be detected, again an issue I never raised.

I noted in passing that I had a difficult time finding a doctor who does the "Chinese procedure". The hospital letter gave me reasons for not using that procedure; again, a question I did not raise.

I complained that it took four days beyond the promised five to get a return phone call from the hospital telling me the result of the biopsy. The Patient Relations letter explained that the doctor's staff was "continually looking for updates for your final pathology." No mention of why there had been no updating phone call.

The reverse colostomy surgery occurred on Feb 19 and everything was put back inside. I no longer had a bag. I recovered well.

But in summary of my experience, the first colonoscopy led to the second which led to the first surgery which required the second which led to the third. Not a bad business plan.

### **Reflections and Recommendations: Improving the Role of the Patient in Medical Decision Making**

In retrospect, I am critical of my failings and of the hospital's behavior when diagnostic decisions had to be made. There is more than enough literature proving that doctors live with incentives pulling their diagnostic judgment away from a patient's welfare.

Not one doctor along the path I describe above suggested I had a choice. Not one doctor suggested that my view had any role in diagnostic decision-making. A number of doctor decisions seemed implausible: they didn't fit what I thought I knew of medicine, they didn't fit what the doctor had said earlier (or was it just the labels that changed), they didn't fit what another doctor had said. And, of course, as with any organization, it felt as if the hospitals' priority was self-protection.

*Recommendation: Every doctor in a diagnostic-decision-making interview should use the sentence "You have some choices here." The doctor will have preferences, of course, but the patient needs to hear that there is more than one way to take the next step.*

I ought to have been the perfect patient to push back effectively. I wasn't. So, now my work focuses on improving the patient's role in diagnostic decision-making.

There already exists a small industry intended to help this. There are second opinions and a process called shared decision-making. The first has some major holes in it, the second is not used widely. Thus, I am working on a project to provide staff support for patients when facing diagnostic choices. The support could help a patient consider some key steps as they proceed including:

1. Do research on the medical nature of the problem.
2. Learn of alternative strategies for coping with the problem.
3. Plan for a meeting with the doctor.
4. Elucidate which values the patient feels are at stake.
5. Present those values in a dialog with the doctor.
6. Remember what the doctor has said, and sort out what to do in the face of conflicting medical opinions.

*Recommendation: For diagnostic-decision-making moments, all doctors (and hospitals) should provide patients with support personnel to help the patients use decision-aids, prepare for discussions with doctors, and make the decisions.*

## **In Closing**

There is a growing movement that links patient involvement in medical decision making with better medical outcomes, decreased health care costs, and increased patient satisfaction. We should all join that movement.

Uncertainty in medicine is inevitable; our bodies are enormously complex and variable, our collective ignorance about how they work is huge, and the best run systems are still run by humans. In that world, how far can we go to give patients confidence that the health care system is working in the interest of the patient's health?