PERSPECTIVE

Why I'm Opting out of Mammography

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At a routine appointment a few days after my 40th birthday, my gynecologist gave me a prescription for a mammogram. There was no discussion, no explanation. Just a slip of paper, handed to me without a word as I left the examination room. When I asked the doctor what she'd just given me, she told me it was an order for a mammogram. I could call the number to schedule an appointment.

"Wait—why should I get a mammogram?" I asked.

"Because it could save your life." Her voice conveyed a note of impatience.

I wanted to make an informed decision, but she'd given me none of the information I needed to do so. It suddenly occurred to me—she doesn't view this as a decision.

As a journalist who has written about cancer screening for more than a decade, I've learned that every screening has the potential to spur a cascade of further testing, and I wanted to consider the possible consequences before proceeding.

I had many questions. Why was my doctor recommending this screening for *me*? What did she expect the test to reveal? What's the best case scenario? Worst case? What are other possible outcomes? And what happens if I don't get a mammogram?

I left without answers that day, because she never gave me a chance to ask. The moment I questioned her orders, my doctor's defenses went up. I'd read the US Preventive Services Task Force recommendations, I told her, and they call for an individualized decision for someone my age. Shouldn't we discuss this?

Her tone became hostile. "I *am* discussing it. I'm telling you to get a mammogram."

This wasn't the conversation I was seeking. She wasn't listening to my questions; she was defending her authority. Here's how she described the visit in my medical chart: "I gave the patient a form to have a mammogram performed. She has some concerns about starting mammography, and we discussed the risks and benefits. She will decide if she wants to have mammography at this point."

Reading this entry later, as I looked over the copy of my medical records I was taking to the doctor I chose to replace her, I was outraged. No—we did not discuss the risks and benefits. She told me to get a mammogram, and when I asked about the risks, she brushed me off. I'd read the major mammography studies published in the past decade, and I knew that the test that she was framing as an imperative was actually a choice.

Given what I knew of the evidence, I was not inclined to start mammography, but my knowledge centered on the data. My doctor possessed clinical experience that I lack, and I wanted to include her expertise in my decision-making.

After she denied me that opportunity, I sought answers on my own. First, given my health status and family history, was there reason to think that a mammogram was critical for me? The answer, I decided, was no. I was healthy and had no first-degree relatives with breast cancer, nor did I have any apparent symptoms of the disease. The National Cancer Institute's Breast Cancer Risk Assessment Tool[1] estimated that my 5-year risk of developing breast cancer was 0.6%, "average" for a woman my age.

Possible Outcomes

A screening mammogram could result in 5 possible outcomes. Most likely, the scan would turn up nothing suspicious. I'd get some reassurance, but no certainty; 27% of the cancers in the mammography arm of the Canadian National Breast Screening Study[2] were interval cancers, and these cancers, which appear in between mammography screenings, are most common for women in their 40s.

A second possibility is that I'd be called back for further testing, perhaps even a biopsy, for something that was not cancer. In between the call-back and the results, I might have a few sleepless nights and perhaps some lingering worry afterward, but the relief I'd get from learning that it was nothing would probably overshadow this anxiety.

A third possibility is that the mammogram would find a cancer that would have remained innocuous if not detected. In contrast to the "relentless progression" narrative put forth by some advocacy groups, not every breast cancer is fated to become deadly. Longitudinal investigations and autopsy studies have shown that some breast cancers lie indolent in the breast without causing harm. If a mammogram found one of these cancers (and right now it's impossible to definitively differentiate them from the dangerous ones), I would be treated and "cured" for a cancer that was never destined to hurt me. If the mammogram found ductal carcinoma in situ, I'd face the difficult decision of whether and how to treat a condition that only rarely becomes invasive.

The fourth possibility is that the mammogram could find a very aggressive, incurable cancer—the kind responsible for most deaths. In this case, I might be diagnosed sooner, but I'd ultimately die anyway, and I'd spend more of the years I had left receiving cancer treatment. Any benefits I might receive from the earlier diagnosis would probably appear larger than they actually are because of "lead-time bias," an illusion that death is delayed, simply because the diagnosis is pushed forward. (With the diagnosis made sooner, the postdiagnosis survival period is extended, even if the date of death remains the same.)

Finally, the mammogram could find a dangerous cancer that's amenable to treatment, and my life would be saved. This is the potential outcome that spurred my doctor's order, and it's one that might compel me to comply.

Probabilities

With these possible outcomes laid out, I wanted to know their probabilities. An analysis published earlier this year calculated that having a yearly mammogram starting at age 40 years would give me about a 50/50 chance of a false

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alarm over the next 10 years.[3] I'd also have a 6% to 8% probability of getting a biopsy to learn that I didn't have cancer, and my risk of getting treated for an indolent cancer would be as high as 1.1%. The chance that a mammogram would prevent me from dying of breast cancer would be no greater than 0.16%.

The risk of developing breast cancer increases with age, but the probability that a mammogram would help me avert a breast cancer death remains less than one half of 1% throughout my 50s and 60s.

Once I'd put these numbers together, the decision felt easy—I'm opting out. But by the numbers, and my own values, the risks outweigh the benefits, by a mile.

Whenever I write about mammography, I receive letters from women who tell me that a mammogram saved their life. Some of them are correct, but the inconvenient truth is that most of them are actually victims of overdiagnosis. In every decade studied—40s, 50s, and 60s—a mammogram is more likely to "cure" me of a harmless cancer (by subjecting me to life-disrupting and potentially harmful treatments like chemotherapy and radiation) than it is to prevent me from dying of breast cancer. For me, that's a deal breaker.

As a self-employed, self-insured person who'd almost certainly be unable to work or earn income to pay my bills if I had to take time off for cancer treatment, the desire to avoid unnecessary medical treatment isn't just a quality of life decision, it's an economic one. The Affordable Care Act protects me from losing my insurance, but I could lose my livelihood and meager assets if I were unable to work for an extended period.

Looking at the numbers, it's clear that the risk of a mammogram leading to unnecessary diagnosis and treatment for breast cancer is tiny, but the chance of a mammogram saving my life is even more miniscule. Cancer treatments have improved tremendously over the past few decades, and this has made early detection less important than it once was. If I ever find a lump or develop some other symptom, there's no question that I'll get it checked out immediately.

But after much thought, I've decided to opt out of screening mammography. Not just in my 40s, but indefinitely. If new evidence shows that my risk of benefitting from a mammogram is greater than my likelihood of being harmed, I'll reconsider. Until then, I'm saying no.

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1. National Cancer Institute Breast Cancer Risk Assessment Tool. http://www.cancer.gov/bcrisktool/. Accessed October 13, 2014.

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