

# Whose Cancer Is It Anyway?

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The oncology nurse and I played telephone tag Monday and Tuesday. She wouldn't sound so chipper if there were anything wrong, I told myself.

We finally connected on Wednesday, and that's when I learned I had breast cancer. The nurse reached me five minutes before a meeting at the agency where I am the ethics officer. I told the nurse I understood what she was telling me. I said I would call back in half an hour.

I assume that I walked down the hall to my meeting. I remember none of what happened once I got there, nor what happened that day, aside from telling my husband, telling my mother, telling my staff.

I soon learned that the surgeon had had the diagnosis in hand the previous Friday, but had left for a conference without sharing it with me. Inadvertently, he left me worried and wondering while the nurse and I missed connecting. Later, he said that he didn't call me on Friday because he "didn't want to ruin my weekend." I thought I deserved to hear the news immediately from the doctor who could answer my questions rather than later from the nurse who deflected them. That's why I fired my first surgeon.

Now, here's why I fired my first oncologist...

I spent the week between my diagnosis and my first meeting with the oncologist who was to oversee my treatment surfing the Internet, absorbing all that I could about "locally advanced breast cancer." I stayed desperately intellectual, focused on climbing the steepest learning curve of my life. When I met the doctor, I opened a single-spaced typed page, organized by subcategories: *further diagnosis*, *treatment*, and *beyond*. She calmly listened past my mispronunciations as I asked my first question. Her response overflowed with unfamiliar terms like "cytology" and "differentiation." I tried my second question. I scribbled down what she said: "FISH," "HER2Neu," "ER/PR."

I shook my head. "I don't understand these terms without definitions. I don't have a medical degree."

"That's why you just have to trust us," she said.

I disagreed. I moved from one award-winning breast cancer research center to the next in my semi-successful attempt to find medical personnel willing to guide me through this involuntary adventure in language I could understand.

Never have I felt so vulnerable. Worse than the cancer was feeling incapable of breaking the code that would let me understand the information about my condition. Every medical practitioner shared my goal of helping me survive. But there the shared agenda ended. The medical system was constructed in such a way that I was to be a passive object of care. I insisted on being an active partner.

From the beginning, I was at odds with medical conventions. I approached cancer as if I had been taking a tax issue to an accountant or a legal issue to a lawyer. I did my best to hire a team of fiduciaries for my cancer care. But few doctors were ready for my approach. And support staff's priority seemed to be protecting doctors from their patients rather than supporting the profes-

sional relationship between fiduciary and client. I found the medical world to be one of function and biology filled with strangers who called me sweetheart and who expected me to simply present my body to them for procedures and treatment.

I ultimately chose my treatment center based on its philosophy of a multidisciplinary approach and including the patients as part of the decision-making team. During my initial six-hour appointment, my slides and I had attention from physician-researchers, residents and fellows. In between, volunteers who were "living with cancer" stopped in with coffee and conversation. The social worker pronounced me "information-seeking" and "appropriately anxious." The medical oncologist who happened to be on duty for multi-team review was the one assigned to be my primary doctor, but their team approach meant that I would have the expertise of the whole group of researcher-clinicians. With my input, it was decided that I would have four months of chemotherapy prior to a double mastectomy, then radiation and hormonal therapy. Due to my prior professional commitments, treatment was scheduled to begin in three weeks. I left thinking that I had found cancer nirvana. I didn't know that this was the last day that I would be included in multidisciplinary team meetings or in any conversation at all.

The next day, I realized I had questions: Which chemo would I get? What about nausea control? Could I take Neulasta and Aranisip immediately or did I have to wait until my blood counts went to hell? My treatment center was more than an hour's drive from home. What should I do in an emergency?

I called the oncologist to whom I had been assigned. Voicemail instructed that if this was a life-threatening emergency, hang up and dial 911. Press 1 for doctor appointments, 2 for chemotherapy appointments, 3 for medical records and so on until option 8: record a message for my doctor. So I left a message. It was ignored.

I tried once each day, pushing random numbers until, Day 4, I reached a live human. The doctor was out of town, but Phone Person said she'd leave her a message.

I called again the next week, apologizing for being a pest, but hoping to talk to the doctor. The doctor is very busy as she is just back in town, Phone Person said, but she'd leave a message. I called daily, left messages, and waited for the phone to ring. By now, my anxiety was more than appropriate, but I couldn't get the social worker to call me back to confirm that fact.

Finally, three days before treatment was to begin, Phone Person said that the doctor would not speak to me until I came in for my treatment.

*The doctor would not speak to me.* I had to repeat that sentence before it sank in. I wasn't prepared for this. The doctor would not speak to me? I looked at the list of questions that I wanted answered before my first chemo. I tried not to panic, tried to be creative. I sent a fax: "Dear Doctor, I understand that you are not willing to speak to me prior to our appointment, when I will begin my chemotherapy. Unfortunately, I have questions that I think need to be addressed before I start treatment. I apologize for the intrusion." I reduced my list to the three most urgent questions. And I waited some more.

An office assistant called me back a day before my treatment was to begin. The doctor said, she informed me, "We'll discuss all of this when I see you."

When I saw her, the doctor was warm, caring and responsive. She seemed unperturbed when I told her about my frustrating attempts to get information that would help me prepare for this journey. But I was indeed frustrated. In fact, whenever I walked into that office for a doctor's appointment, a chemo infusion, or a shot of Neulasta, I waited at least 30 minutes—even when I called ahead to confirm that I would be seen on time. I couldn't help but

feel that I waited simply because someone decided that I would wait.

And the waiting wasn't the only thing that was frustrating. As someone with expertise in research ethics, I thought I understood all about informed consent. Theoretically, patients have the right and the responsibility to choose their clinical options. Ideally, they review the risks and benefits and alternatives and then make their treatment choices. But there was not one time in my cancer treatment year that giving consent approached this ideal. I found that when I was asked to give "consent," I was actually signing forms to protect the doctors and hospitals from liability and allowing information to be released to my insurance company. The forms called "consent" asked me to agree to go to arbitration rather than jury trial in case something went wrong. The consent forms let me know that whatever I was about to have done included some rare but unfortunate side effects including death. It's been the same with all the consent forms since then. Rarely has one included a description of the actual procedure. Never have they included alternatives.

Toward the end of the year, my doctor scheduled me for a bone scan. When I reviewed the consent form the day of the procedure, I noticed that I was consenting to be photographed for scientific or educational purposes, consenting to pay the bill, and consenting to a generic list of medical and surgical procedures that were generally unrelated to this procedure. I asked the receptionist what would happen if I didn't sign.

"Then we don't do it," she said.

"I've never had a bone scan," I said. "Is there something that explains what I'm agreeing to have done?"

The receptionist chewed her gum thoughtfully. "No. But you can ask Bobby when he gives you your shot."

"Oh, I'm going to get a shot," I said. "Can you tell me why?"

“Nope. Bobby can tell you.”

I signed the form and waited for Bobby.

When Bobby came to inject me with radionuclide, he had no explanation of the procedure, nor could he explain what he was injecting me with aside from saying, “It’s just some dye. I keep telling them that they should have brochures for the patients.”

The most ludicrous instance of my giving consent was when I was least competent to do so. I lay in the recovery room after the mastectomy and reconstructive surgery, hazily realizing that it was over. Suddenly, activity. “Her blood pressure is 70,” said one voice. “Crit’s at 15,” said another. “Get some blood in here NOW!” said a third.

“This isn’t good,” I thought.

Then my plastic surgeon stood over me. “You’ve developed some internal bleeding and we’re taking you back to surgery.”

It occurred to me that this might be serious when my mother and husband were ushered into the recovery room. Just then, someone waved a clipboard in front of me and said, “Hurry up. You need to sign the consent form.”

*Consent?* I couldn’t remember my name at that point or locate my hand to pick up a pen.

“My husband,” I mumbled, I think. Though he remembers signing something, he certainly doesn’t know what he signed.

This is not consent. It is waiver of liability. It is fine for patients to sign waivers, but shouldn’t the documents be labeled correctly? I was amazed to find that the American Medical Association provides a description of informed consent close to what I thought it was before my cancer year. “Informed consent,” the AMA says, “is more than simply getting a patient to sign a written consent form. It is a process of communication between a patient and physician that results in the patient’s authorization or agreement

to undergo a specific medical intervention.” The goal of that communication, which includes solicitation of patient questions, is for the patient to be able to make an “informed decision to proceed or to refuse a particular course of medical intervention.” There clearly is a divide between theory and practice.

Medical professionals create obstacles to optimum care when they fail to empower their patients by including them in the process. In this day of rapidly evolving research data, cancer treatment is a series of best guesses learned from some patients who have come before. But, each presenting individual has her own needs and own risk tolerance, along with her own unique set of errant cells. Failure to empower the patient eliminates the primary decision-maker from the choices that need to be made in her own care.

I had to empower myself. I became determined to be my own advocate. Because of that, my treatment was different from what it otherwise would have been: I had chemotherapy before surgery, with the result that I have the troubling, but important, knowledge that the drugs achieved only a partial remission. I had a double mastectomy, because I didn't want to risk the “slightly” abnormal cells in my left breast becoming cancerous as well.

I had immediate reconstruction because I was determined that my body image not be collateral damage in the “war” on my cancer.

I got more aggressive radiation therapy than the radiation oncologist had planned because I was educated by researchers about what counted as “optimal therapy.” I have argued successfully to be treated as though I've had a recurrence with the hope that such aggressive treatment will prevent one.

No one can predict if I will die from cancer, or die with it, or one day be called “cancer free.” But, if I do face recurrence, it is with certainty that everything that could have been done to prevent it was done. My treatment reflects last week's research findings, not “standard of care.”

There is more than one answer to each of the questions that arise with diagnosis. While medical personnel should present all alternatives, they rarely do. Fiduciaries, consent, and empowerment are essential elements of being engaged with one's own treatment, but are largely absent from the current medical model.

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