

When the Patient Says No

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Disclosures of potential conflicts of interest may be found at the end of this article.

I was recently consulted in the hospital about abnormal computed tomography (CT) scan findings showing concern for metastatic disease. I have learned that this doesn't always mean cancer, but findings must be very suspicious for a radiologist to say those words. Before seeing the patient, I reviewed the chart and looked at the images. I agreed—the scans did not look good; I called the radiologist, and he stated that it looked like it was coming from the kidney or the lung. Before entering the room, I first discussed with the nurse to check if I was the bearer of bad news, as I often am.

When I went into the patient's room, I saw a man who was relatively young and very healthy. He had multiple family members by his side, and as it turned out, he had already been briefed on the results of his CT report. I reviewed his history with him and what had brought him to the hospital. I reviewed his risk factors—he had never smoked. I reviewed the scans and then ordered a biopsy of the rib lesion. All that time, I was talking to him, trying to search for a clue as to where his tumor came from.

As all oncologists do, I hope for the best. I close my eyes every time I open a positron emission tomography (PET)/CT scan, as I hope to see a response to treatment. I am not ashamed to say that I wanted an easy path for him, the drug that gives the best response with the fewest number of side effects. In this case, after hearing he was a never-smoker, I was hoping radiology was right. If this was lung cancer, he was more likely to have EGFR- or ALK-mutated disease. These patients have three, even four lines of oral treatment available to them, even before being exposed to cytotoxic chemotherapy and the infusion center.

I felt like we connected as we talked. We shared a favorite sports team and discussed stories about the legends on that team. He told me about his kids, his career, and his life. He had amazing stories and a supportive family at his side. When I talked with him, he made it clear to me that he wasn't ready to die. I kept asking questions, and then I came to this one:

Me: "So you never have had any surgery? Nothing?"

Him: "Oh yeah, I did have a melanoma removed from my left arm about 12 years ago."

Me: "Oh."

There it was. It's melanoma, I kept repeating in my head. Still, I didn't want to lead the patient down that path, not without a pathology report. So I departed the room with a smile and a promise to see him tomorrow after the biopsy was performed.

I returned to his room the next day and we talked more. He was alone this time and showed some fear. I told him this was normal. A cancer diagnosis is a life-changing event, and I was going to be with him every step of the way. It was at this point that I told him there was a chance this was melanoma that had spread and become metastatic. I told him that there was hope and that cytotoxic chemotherapies were no longer the drugs of choice. I explained that immunotherapy has been around longer than I have been alive and that, nowadays, some of the best responses are being seen in melanoma.

I called the pathology department that afternoon—the pathologist suspected melanoma. I asked him to add BRAF, a marker for targeted therapy, to the sample so we could have a treatment plan in the next few days. The patient was discharged in stable condition, with a diagnosis pending and an appointment to see me in 2 days. I explained to him that we would plan what to do next when I saw him as an outpatient.

He came into the office like any other new patient. He was no longer at a hospital but in a cancer office. The diagnosis was looming. I didn't mince words or beat around the bush—I told him that it was metastatic malignant melanoma. He seemed stunned, as if he were hoping I was wrong. The truth is, I was hoping I was wrong, too. However, now was the time to start making decisions and moving forward. He told me he wanted to fight, so we discussed treatment options. I recommended immunotherapy, but his BRAF status was still pending so we had time to change our minds. I recommended further work-up to complete staging and then planned to start treatment in the coming week. I sat and answered questions, performed my physical exam, and asked again, "Do you have any questions or concerns?" The answer was no, and we planned his return to clinic next week. He was agreeable; we shook hands and he left.

That would be the last day I would see him.

He disappeared.

He called to cancel his PET/CT. When I heard that, I was concerned but knew he was claustrophobic. I spoke to him and told him we could start treatment without it, although it might make it slightly more difficult to follow his disease without the baseline. I suggested we reschedule it, but he was reluctant.

I learned later that he did not show up to his treatment teaching session. My office called a few times, and he would answer. Soon he stopped answering; his wife would answer and tell us, "He is not talking to anyone right now." Then she

stopped answering as well. We all called: my receptionist, medical assistants, nurses, and myself, hoping for an answer. I even sent text messages, hoping that a personal connection would let him tell me something, anything. I had hoped he was being treated somewhere else. After all, I told him I welcome second opinions, especially because I want to make sure I am not missing anything. I just wanted to know he was being treated. I was confident in telling him he had two (if not three) lines of therapy that would possibly be able to extend his life by years; without treatment, he would be dead within months. But I was greeted with silence. He just vanished. He never picked up the phone, he never came in to the office, he never got treated.

What happened? What had changed? Where was the man I met, who wanted so badly to live?

Weeks later, I received a call from a friend of his. Apparently, he had deteriorated rapidly. After hearing some of the story, the friend was finally able to get him on the phone. We talked, and I proceeded to ask him what he wanted. He knew that without treatment, he would die quickly, likely within a few months. His reply to me was simple:

“Well doc, I want more than 6 months.”

That was the answer to me; he needed treatment. I told him that. I said come in today or tomorrow and we will get started. I am here for you. I talked to his wife and friend before hanging up the phone. They were going to settle some things and make an appointment.

I hung up the phone and sank into my chair. I suspected that phone call was the last time I would talk to the patient.

He never called back. Nor did his wife or friend. I found out later that he went to hospice and died. He received no

treatment for his metastatic disease. This man walked into the hospital with vague abdominal pain and was dead less than 2 months later.

His metastatic disease wasn't treated not because he was in ill health or owing to a lack of treatment options, cost, or even lack of insurance. He received no treatment because he decided not to be treated, and to this day, I don't know why. He didn't tell me. He told me he wanted to live. He had grandkids, a family, and a life ahead of him. He never said no to the options I presented. But he walked away from them. He likely had years left, and that was changed to weeks.

To me, that is the hard part of what we face—not being able to get inside a patient's head and understand the why behind some of these decisions that don't make sense. Every day, I question the course he chose. Yes, we have some patients who undergo treatment using a novel agent, even though we know it is probably futile, hoping against reason it will work. And sometimes—sometimes—it does.

But this patient never gave treatment a chance. Was it a lack of education of his disease? Was it a lack of understanding as to what he was up against? Did I deliver the message wrong? Was he not ready for the message to be delivered? I will never know. I just know the patient told me he wanted to live, and died without any treatment. That's a tragedy in my eyes.

Hopefully, I can use this experience to help me care for the next patient I meet.

DISCLOSURES

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