

# To treat or not to treat, that is the question\*

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## Abstract

Following a diagnosis and surgical treatment for localized breast cancer, medical oncologists present patients with adjuvant systemic therapeutic options that have been shown to reduce the risk of subsequent cancer recurrence. In this commentary, I present the challenge that resulted from my discussions with a patient and family who asked that I not only discuss options and make recommendations but also decide the choice of therapy on her behalf.

## Keywords

cancer, communication, emotions, health psychology, patient satisfaction

Recently, the author of the *New York Times* book review of “The First Cell: And the Costs of Pursuing Cancer to the Last” (2019) suggested that if given a screwdriver, a medical oncologist would open the casket of their dead patient and resume treatment and the reviewer agreed with the book’s author that oncologists, such as myself, “don’t know when to stop.” Apparently the author and reviewer agreed that oncologists are making those profoundly important decisions not—as I believe it should be—their patients. But what if my patient asks me to decide and, like Hamlet, I am paralyzed with ambivalence? I threw the Sunday *New York Times* across the room, just missing our cat Cecil, who scurried off in fear.

That afternoon I decided to make a list of my responsibilities as part of the oncologist–patient relationship and ask myself whether making decisions for the patients—when asked to do so—is one of my duties.

Being thorough and honest and not overestimating or underestimating the risks and benefits of the therapies I offer topped my list of responsibilities. Then I considered the balance between being realistic and offering hope, often one of my most challenging responsibilities. Even though the outlook for patients with many cancer types is improving, the first reaction to a diagnosis of cancer is often fear. Emily Dickinson wrote “Hope is the thing with feathers—That perches in the soul—And sings the tune without words—And never stops at all.”

When it comes to cancer, we covet hope. Even when the prognosis is terribly grim, hope, as Emily Dickinson wrote, is still in our souls. Still, every few days I see patients who are from the old school: “you’re the doctor, just tell me what to do.”

I decided to investigate further. Decision making between doctors and their patients has been variously referred to as informed decision making, shared decision making and evidence-based patient choice as well as terms emphasizing the word “empowerment” as part of the process. In a recent article, “Empowerment from patient’s and caregiver’s perspective in cancer care,” Marzorati and colleagues (2018) noted that the World Health Organization definition of empowerment is “a process through which people gain greater control over decisions and actions affecting their health” and state that patients should have a “key role” in the process. The authors state that by being better informed patients will be more “compliant” in their cancer therapy and suggest that the less the patient is a passive participant, the more it ensures

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\*This story is essentially fiction.

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against treatment decisions being made that are influenced by biased caregivers. From their study of 510 participants (patients and caregivers from five different countries), they concluded that patients “can or want to manage their journey alone much more than what caregivers think,” and that by patients receiving high-quality information it better ensures meeting this goal, and cite three earlier studies showing similar findings (Marzorati et al., 2018).

Recently, I saw a 69-year-old woman who weeks earlier underwent a left-sided mastectomy and lymph node dissection. The pathology report described a 7.5 cm, high grade, hormone receptor positive invasive breast cancer along with one positive sentinel lymph node.

The immunohistochemistry was HER2 2+. Fluorescence in situ hybridization (FISH) testing demonstrated that HER2/SEP17 ratio was 2.57 and the number of HER2 signals/average cell was 3.6. Repeating the FISH tests gave essentially the same results. Per the National Comprehensive Cancer Network (NCCN) Guidelines, her tumor was classified as HER2 negative, Group 2. However, before mid-2018, with those same FISH results the classification would have been as HER2 positive.

When I joined the patient and her three devoted daughters in the exam room, she was sitting comfortably and pleasantly. I told her that given the large size of the cancer and the involved lymph node, I was very concerned that her cancer had already spread to distant places in her body, in spite of a recent computed tomographic (CT) scan showing no radiographic evidence of spread. I explained that now that she’s had surgery, treatment with drugs that would be called adjuvant therapy might “nip it in the bud” and prevent the cancer from coming back and taking her life.

The patient looked understandably worried and then said she wanted “to do everything she needed to do.” After all three daughters nodded and the youngest said, “Mom wants to do everything possible, even if it involves side effects like losing her hair or vomiting, to stop the cancer from coming back. That is the way she is, that’s her personality.” I could tell she was proud of her mother for her determination.

After reviewing her history and examining her, I explained the concepts of adjuvant therapy, risk assessment, relative risk reduction, absolute benefit, and the likelihood of side effects associated with the drugs that she should consider.

“In your case, I suspect that if you were to do nothing more than the surgery you’ve had, your risk of recurrence might be 75%. But with chemotherapy followed by hormonal therapy, your risk of recurrence would be closer to 35%.” I was very confident that she could tolerate the chemotherapy and hormonal therapy. I highly recommended she take both.

I then explained that roughly 20 years ago and since, a number of studies have shown that if her tumor has excess copies of the HER2 gene, anti-HER2 drugs, in addition to the chemotherapy and hormonal therapy, will reduce the recurrence risk further.

If your cancer is classified as HER2 positive, by taking a fairly non-toxic anti-HER2 drug called trastuzumab intravenously every three weeks for one year, you will reduce your relative risk of recurrence of the cancer by another 40% and even further if you receive other F.D.A. approved anti-HER2 drugs as well. Your predicted risk of recurrence will be reduced to as low as 10% or so. That means that the cure rate would be closer to 90%, rather than 25% if you had chosen to do nothing besides the surgery you’ve already done.

“My head is spinning from all the statistics.” She turned to her youngest daughter. That youngest daughter anxiously asked “that’s good, but is mom’s cancer HER2 positive?”

Hearing this, I paused to consider carefully what to say next to the patient and her daughter. I then slowly said “It depends on who you ask. Before 2018, your tumor would unequivocally have been classified as HER2 positive. I would have said to you something like “I don’t think that you can find an oncologist in the country who wouldn’t practically tie you down for you to administer trastuzumab.” I’d have said “with receiving chemotherapy, hormonal therapy and anti-HER2 drugs, your chance of cure will be roughly 90%.”

I then launched into a lengthy discussion of the changing definitions of tumor HER2 status. I started by saying,

In 2018, a breast cancer expert panel assembled by the American Society of Clinical Oncologists or ASCO and the College of American Pathologists or CAP published their recommendations for defining HER2 status of breast cancers. Per their 2018 recommendations and NCCN guidelines changes that followed your cancer is now classified as HER2 negative or Group 2, as it says in your pathology report.

I showed them the list of NCCN breast cancer panel members and the esteemed institutions where they work. I further showed her the page titled “Principles of HER2 testing” that would have defined her cancer as clearly HER2 positive prior to 2018, but now classifies her cancer as HER2 negative.

I explained to them the basis for the controversial change.

Many experts would say that since you could have been enrolled on the key adjuvant studies, you should be told that study participants who received trastuzumab had a 40% reduction in recurrence risk compared to those receiving no trastuzumab. The study did not include enough patients to conclude that the average patient with your HER2 result did not benefit as did the group, as a whole, who received trastuzumab. On the other hand, the expert panel and NCCN guideline say there were not enough patients on the studies with your HER2 results to conclude that the average patient did benefit from trastuzumab therapy.

“Last week your case was presented at our weekly tumor board and three oncologists there all favored no anti-HER2 therapy.” “What do you think?” the youngest daughter asked.

I turned to her mother and said

I'm not really sure how to advise you. A few months ago, I spoke with an expert in breast cancer at a conference in Chicago. I asked him what he would recommend for a patient with your HER2 testing result and he said to me that he would "fight like hell" to get her anti-HER2 therapy.

In the end, my patient looked worn out and discouraged from our discussion. I excused myself in order to apologize to my other patients who were waiting and to give her and her daughters a chance to consider what I had said. Had I overwhelmed them with statistics that no patient could be expected to understand? Had I been balanced in my conversation with them regarding risks and benefits and hopeful but realistic at the same time? Was it fair to expect that if experts couldn't decide if her tumor should be classified as HER2 positive, she should?

The patient smiled, somehow sympathetically, and then looked me in the eyes and said "I trust you. You decide."

I offered to go over the information again. I offered to refer her for a second opinion. I told her that there was no right or wrong decision, only what felt right to her.

I felt frustrated. Had I let down this nice patient by not agreeing to her seemingly simple request for me to decide? One moment I worried that if I recommended anti-HER2 therapy and she developed heart disease (a possible side effect) I would wonder if I had pushed her into the anti-HER2 therapy, but then I worried that if I recommended no anti-HER2 therapy, I would feel responsible should her cancer recur.

I had hoped that with my lengthy explanation she would decide; after all, wasn't that her responsibility, her role in our oncologist-patient relationship, not mine?

She repeatedly asked that I not only make a recommendation, but that I decide for her. "You're the doctor, you decide." I had to admit to myself that maybe sometimes my role had to be more than just explaining the mechanisms of drug action, concepts of adjuvant therapy, relative reductions versus absolute benefits, side effects, complicated statistics, pivotal studies, uncertainties and the reasons for the Food and Drug Administration (FDA) or NCCN endorsements of therapies and controversies among experts. But I still struggled with making the decision for her, as she requested, repeatedly. I just did not feel right about accepting that responsibility as part of our physician-patient relationship. Feeling somewhat defeated, I suggested we meet again in a week, saying that in the meantime I would speak with still a few more colleagues for their opinions.

In reviewing key elements of shared decision making in oncology, Politi and colleagues (2012) concluded that more than half of all medical interventions involve complex trade-offs between benefits and harms and that most

clinicians underestimate their patients' desire to be involved in the decision. Minkoff and Lysterly (2009) underscored the importance of presenting accurate information and that physicians should "eschew" the question of "What would you do?" Similarly, Gafni and others (1998) wrote that physicians should not be "surrogate" decision makers.

That evening it was gently snowing as I walked out of the massive clinic to the parking structure and thought that maybe I was making it too complicated for her and possibly overwhelming her with all the scientific details. I recalled what William Osler had said. "It is more important to know the person who has the disease than the disease the patient has." Was it realistic to think I could know her well enough to make this decision for her? If I really knew her, her nature, the basis for other critical decisions in her life it would have been easier for me to choose for her or maybe knowing her well would have made me less objective in presenting her options to her.

Maybe I should have never mentioned the HER2 issue. After all, the NCCN Guideline classifies her cancer as HER2 negative. If I had simply said, "your cancer is HER2 negative" would I have fallen short in being thorough in discussing her options?

Later that night the snow had oddly turned into rain. I listened to the steady drizzle on my rooftop and against my window panes. I imagined the three grown daughters years ago. Probably they were three loving, clinging little girls, who must have believed that their mother was always strong and certain and always knew exactly what to do; in their minds, she was indestructible and would live forever. It was touching and sad to me that now they were the parent to their mother.

I remain disappointed in the *New York Times* book reviewer and the book's author who characterized oncologists as "not knowing when to stop." I remain confident that patients, not their oncologists not only should but are making these tough treatment decisions. I believe in my patients and their ability to understand controversies like changing classifications schemes of HER2 positive and HER2 negative disease and I am inspired by their capacity to make informed decisions that are consistent with the ways they have led their lives, their goals, and their inherent natures and values.

In the short story "The Devil and Daniel Webster" by Stephen Vincent Benet, the attorney and larger-than-life statesman Daniel Webster convinces a jury of miscreants that the Devil has no right to the soul of Jabez Stone, who had signed away the rights to his soul to the Devil years earlier in exchange for material success. Furious with the jury's decision and spitefully, the Devil offers to tell Daniel Webster his future, as the Devil is able to do. He tells him that he will never realize his dream of becoming President of the Union and that he will die before he knows that the Union will be saved. He tells Daniel Webster that he will

make many great speeches “But the last great speech will turn many of your own against you.” Daniel Webster replies “So it is an honest speech, it does not matter what they say.”

I had thought that my responsibility was to be honest, thorough, and hopeful. I believed that to be the best I could do for her. But that night I pressed the pause button on the television remote control, looked Cecil in the eyes, and said “Maybe I should have just given her what she wanted and decided for her.”

As illustrated in this case story, after discussing with a patient and her family the risks and benefits of potential adjuvant systemic therapeutic options, a patient will still occasionally insist that her medical oncologist make the decision as to which therapy she undergoes. When faced with such a challenge, I believe that it remains unclear as to whether the medical oncologist has not only the responsibilities of presenting options and making recommendations but also added responsibility of making the therapeutic decision on behalf of the patient.

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