Walking the Dividing Line: The Challenges of Being a Doctor-Patient

Barbara W. Trautner

Author affiliations and support information (if applicable) appear at the end of this article.

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Corresponding author: Barbara W. Trautner, MD, PhD, IQuEST (152), 2002 Holcombe Blvd, Houston, TX 77030; e-mail: trautner@bcm.edu.

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Being both a doctor and a patient presents unique challenges. Unfortunately, most of us who deliver health care will also at some point be recipients of health care in a life-threatening situation. My experience with walking along the doctor-patient dividing line came when I was diagnosed with stage IIB breast cancer at age 47. In the months after I completed treatment, time and reflection have allowed me to organize the challenges faced by the doctor-patient along five main themes. Perhaps some of my experiences will be of use to others, regardless of which side of the line they are currently on.

CHALLENGE 1

Being a physician with a cancer diagnosis means that you simultaneously know too little and too much. On the side of knowing too much, you have a very clear picture of what death from cancer looks like, including death from breast cancer, even if you have been practicing infectious diseases at a Veterans Administration hospital for most of your career. One of my first patients during internship was a woman dying of breast cancer that had metastasized to her brain years after her initial treatment. Each adverse effect listed in the handy Guide to Chemotherapy that I received before my own chemotherapy treatment had the face and name of a former patient. For example, I had treated patients who developed heart failure and a patient who developed leukemia from the chemotherapy drugs I was about to receive.

Conversely, I knew enough to know what I did not know. Initially I turned to PubMed to read about breast cancer treatment, just as I would for a complicated infectious disease case, but I was confused by the cancer terminology. I also knew from following the evolution of HIV literature and resulting care over the past 17 years that no single trial can tell the entire story, and that even a trial published in a highly respected journal will have nuances in interpretation obvious only to breast cancer specialists. Therefore I abandoned my attempts to explore the breast cancer literature and instead followed the link to the National

Comprehensive Care Network guidelines for patients with early breast cancer. I pored over these backward and forward, in some ways with the intellectual curiosity and enthusiasm that I apply to learning about unusual infections. This juxtaposition of medical curiosity and personal experience reminded me of being pregnant, my other medically interesting experience. Yet when I was pregnant, at the end of treatment, I got to take home a baby. This time I got to take home my right breast and my life. It wasn't quite the same.

CHALLENGE 2

You walk a line between patient and health care provider. In casual health care encounters, it was hard to judge whether to reveal my profession or my specialty. For example, when the emergency room doctor realized I was an infectious diseases doctor (I was outed by my fleece jacket from my institution, which proudly proclaims my name, titles, and specialty), she offered me a role in choosing my antibiotics. At that moment, shaking with rigors, neutropenic, and unable to eat or drink because of mucositis, I emphatically did not want to participate in shared decision making. Conversely, when I did not tell the breast ultrasonographer up front that I was a doctor but then let slip a medical term during the examination, my subsequent unveiling clearly engendered a sense of distrust in her.

Respecting the normal physician-patient boundaries was paramount to me, because I did not want to demand special attention through my physician status. Yet I was in the unusual circumstance of having several friends among the physicians on my team, which raised the question of when to text the doctor directly versus following the usual triage channels. I learned the hard way that working within the system was the better approach. Shortly after my diagnosis, I attempted to transfer my records from my home institution to a cancer-specific institution. The records transfer was taking forever, so a pathologist friend at the cancer institution got involved personally. Her

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status resulted in a rapid release of records, including a preliminary pathology report that incorrectly identified my tumor as HER2-positive. Suddenly my lumpectomy planned for that week was cancelled, and my entire treatment plan changed—erroneously. To resolve the situation, I met with the pathologists at both institutions and reviewed my own slides with them. Given my love of all things microscopic, I thought that I would want to see my own tumor pathology, but I was very wrong. Seeing cancer cells invading the lymphatics of your own specimen is not a sight for someone newly diagnosed with breast cancer. After this experience, I moved myself firmly to the patient side of the doctor-patient line.

CHALLENGE 3

You empathize with the members of your health care team. I was constantly worrying about the well-being of the members of my health care team. For example, in my initial oncology visits, I was often wedged into an already packed clinic day. I could see the fatigue in the faces of my nurse, oncologist, and pharmacist, when they were wrapping up their morning clinic with me at 1:30 PM. I felt guilty about bringing out my list of questions at times such as these. My axillary dissection was scheduled during the peak of cold and flu season, and I lay awake at night worrying that my surgeon would get sick and not be able to operate on her scheduled days. I saw a couple in the radiation oncology waiting area giving the clerk and nurse an unnecessarily difficult time, and I worried about how they would treat my overworked doctor.

CHALLENGE 4

Pain hurts! As a medical professional, I somehow thought I would be mostly immune to pain. Probably all of us believe that we have above-average pain tolerance, just as we all provide above-average care to our patients. I first got an inkling of how bad the stereotactic biopsies were going to be when my nurse assured me she would stay in my line of vision during the procedures and offer me aromatherapy. For the record, I do not think I will ever want to smell lavender again. The presence of a single axillary drain was so painful that I had difficulty getting a spoon to my mouth, and the port was initially so tight under the skin of my chest that chewing hurt. The unpredictability of pain is frightening, because you do not know when or whether it will end. These simple, minor

procedures that caused me so much distress were essential for my treatment, and I would do the same to my patients. I just wish I didn't know how much so-called minor procedures will hurt them, too. On a happier note, applying an ice pack to my belly for 5 minutes renders my monthly Zoladex injections nearly painless. I refer to this event as my “belly piercing,” because that sounds much cooler than “hormone-suppressing shot.”

CHALLENGE 5

You want so badly to be on the other side of the line, in your normal role. I am fully aware that I owe my life to my health care providers, and I am now even more appreciative of the respect that patients hold for their physicians. But I would so gladly have traded my patient role to instead be one of them. For this reason, I fought against weakness and nausea to get to my own clinic. Feeling sorry for myself was paralyzing, but passing forward the excellent and personalized care I was receiving was empowering.

After I completed treatment (surgery, chemotherapy, and radiation), I felt calm and competent enough to read the American Society of Clinical Oncology guidelines about adjuvant endocrine therapy for premenopausal breast cancer. I was thirsting for more specific knowledge by this time, having heard various percentages banded about during the course of my treatment. I printed out the guidelines and sat at the table on our back patio, underlining the relevant sections. I noted with great satisfaction that my breast cancer oncologist friend was one of the coauthors. I circled the percentages of disease-free survival that applied to me, applying study habits developed as far back as medical school. Then as I was looking at the “77%” written in my own handwriting in sharp, black ink, the digits and words swam. This is not a test I could study for; this was my life and my future. I am one of the many who will contribute to these numbers for studies yet unpublished. Instead of wallowing in these emotions, I texted my breast oncology friend, congratulating her on contributing to such helpful guidelines, and asking her if the typical physician response to reading them involved tears? Our ensuing chat cheered me up, and I felt appreciative of being able to stand on both sides of the doctor-patient line at once.

AUTHOR'S DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

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Affiliation

Barbara W. Trautner, Michael E. DeBakey Veterans Affairs Medical Center and Baylor College of Medicine, Houston, TX.

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Barbara W. Trautner

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