

The Washington Post

[Back to previous page](#)

Teaching doctors when to stop treatment

**By Diane E. Meier and Health Affairs,
Published: May 19**

The woman came into the office with her husband, looking totally out of place amid the frail geriatric patients at my palliative care clinic. Elegant, slender, with a gorgeous head of curly blond hair, she was nothing like what I expected when she had called a couple of weeks earlier, asking for a consultation.

Her cancer story, too, was atypical.

The woman, a 50-something practicing clinical psychologist, had been diagnosed with stage 4 non-small-cell lung cancer six years earlier, after experiencing a persistent cough. By the time her tumor was removed surgically, the disease had already spread outside the lung, so the patient received chemotherapy and radiation treatments. With each recurrence or progression of disease, the patient's oncologist thought of a new approach, and each one worked. The patient was able to maintain her busy practice and travel. She hoped she might turn this cancer into a chronic disease instead of a death sentence.

Given how well she appeared to be doing, I wondered why she was in my office. We typically see patients with pain, fatigue or shortness of breath. The woman had none of these symptoms.

What was going on? The patient described herself as a control freak. "Better to know and plan for the worst," she told me. "That way I don't have to worry about it."

The unknowns

Over the years she realized that her oncologist was unwilling — in her view, unable — to talk to her about the "what-ifs?" of her cancer. What if this next treatment doesn't work? What if my disease progresses and I can no longer function the way I want to? Will I be in pain? Will I suffocate? How will my family take care of me? Where and how will I die?

Healthy and happy as the patient appeared, the uncertainty and the unknown were consuming her.

Her oncologist's reaction to each setback was to redouble his efforts to get the cancer under control. The

patient's "what-ifs?" were met with comments along the lines of "We don't have to worry about that."

The patient reasoned that her oncologist was unable to face the possibility — indeed, the probability — that she would die of this disease. She came to me, hoping I could give her straight answers.

We talked about possibilities. Given the unusual course of her cancer, I admitted the real possibility that her oncologist could continue to find ways to keep it at bay. I explained that I could become a part of her treatment team to focus on her quality of life, provide the straight answers and participate in her desire to plan for the worst while continuing to hope for the best.

We talked about what she might expect as her lung cancer progressed, including increased fatigue and weakness, pain and shortness of breath, and exactly how we could manage these. She wanted to know what it was like to die. We talked about what the moment of death was like: slower and slower breathing, with pauses in between breaths, and during one of those pauses, she would die. She asked what would happen if she had pain and symptoms that couldn't be controlled. I explained that virtually all symptoms were manageable with palliative care. If necessary, there was the option of sedation, but it was quite unusual to need that.

We talked about hospice, which would include services such as a team available to come to her home 24-7, as well as equipment, medicine and training and support for her husband and daughter. If things ever got too difficult at home, she could go to an inpatient hospice setting with around-the-clock nursing and medical care.

Toward the end of our conversation, she said she was worried that her oncologist would feel upset that we had met and that he might not be comfortable teaming up with me on her care. I was worried about that, too. I offered to call him — and did. To my relief, he agreed to work with me.

The disease progresses

For the following 18 months, the patient received care from both her oncologist and me. Her oncologist and I remained in regular e-mail and telephone contact. When the patient learned, several months after we met, that her disease had progressed, the oncologist tried another experimental treatment; the patient responded well.

For another year, things remained stable, until the patient began to feel increasingly tired and started to have difficulty focusing her attention and memory. With her oncologist's agreement, I tried corticosteroids to reduce the swelling around the tumors in her brain and psychostimulants to improve energy and mood, which helped. She kept her psychotherapy practice but canceled a major trip and conserved her energy for home and work. She had no pain and experienced some shortness of breath but only when she ran for the bus or climbed a flight of stairs.

Several months after she first noticed the memory problems, the patient awoke with a headache and blurred vision. Brain imaging showed an enlarging mass that was progressing despite systemic chemotherapy and corticosteroids.

The patient came to see me to talk about this new reality. Her oncologist was recommending intrathecal chemotherapy, a treatment that involves placing a reservoir inside the brain in order to administer chemotherapy directly into the site where the tumor mass sits, in the hope of shrinking it. She wanted my opinion on whether she should accept this therapy. I was unfamiliar with the data on it and told her I would

ask her oncologist about it, and we'd get back to her.

I called him, and after an exchange of pleasantries, I got down to the matter at hand: "What are you hoping we can accomplish with this treatment?"

After a brief pause, he confessed what I suspected: that it wouldn't help her.

I struggled for a response. "Would you want me to encourage her to go ahead with it anyway?" I asked.

After another pause, this one longer and more awkward than the last, he told me that he didn't want her to think he was abandoning her.

A new perspective

His comment struck me. For years I had tried to understand why so many of my colleagues persisted in ordering tests, procedures and treatments that seemed to provide no benefit to patients and even risked harming them. I didn't buy the popular and cynical explanation: Physicians do this for the money. It fails to acknowledge the care and commitment that these same physicians demonstrate toward their patients. Besides, my patient's oncologist would make no money from the neurosurgery required for the intrathecal chemotherapy procedure.

It seemed that giving more treatment was the only way the oncologist knew to express his care and commitment. To him, stopping treatment was akin to abandoning his patient. And yet the only sense in which she felt abandoned was in her oncologist's unwillingness to talk with her about what would happen when treatment stopped working.

How did the patient and her oncologist come to see things so differently?

Patients and families often assume their doctors are trained and knowledgeable about end of life, and they assume that if the doctor recommends more tests and treatments, he or she thinks they will help in some way. Patients and families also assume that doctors will tell them when time is running out, what to expect and how best to navigate these unknown and frightening waters.

But many doctors don't do these things. Most, in fact, have no training in this. Medical school and residency have traditionally provided little or no instruction on how to continue to care for patients when treatments no longer work.

Physicians are trained to make diagnoses and to treat disease. Untrained in skills such as pain and symptom management, communication about what to expect in the future and achievable goals for care, physicians do what we have been trained to do: Order more tests, more procedures, more treatments, even when these things no longer help. Even when they no longer make sense.

So how do we fix this? Most policies to change physicians' behavior have focused on restructuring financial incentives. If we pay more (or less), the theory goes, for certain activities, physicians' behavior will change. The evidence correlating financial incentives and physicians' behavior change is mixed at best, however, and it is too early to judge their impact on patient-care quality and costs.

To change behavior, we must change the education and training of young physicians and the professional and clinical culture in which they practice. New doctors should learn about the management of symptoms such as

pain, shortness of breath, fatigue and depression, with intensive training on doctor-patient communication: how to relay bad news, how to stand with patients and their families until death and how to help patients and families make the best use of their remaining time together.

Things are, however, moving in the right direction: A 2010 report from the Medicare Payment Advisory Commission suggested linking federal support for graduate medical education to the achievement of specific medical competencies and standards, such as palliative care skills.

Moreover, today, virtually all medical school-affiliated teaching hospitals have palliative care teams. And recent data show that the younger the physician, the higher his or her familiarity and comfort with palliative care. Resources for teaching these skills are widely available and could be standardized and scaled to reach all trainees.

Saying goodbye

As we talked, my patient's oncologist had a change of mind about his treatment recommendation. He called the patient and told her that he didn't think intrathecal chemotherapy would help her and that he thought it was time to involve hospice. The patient gave up working, entered a hospice program and settled in at home. There, her husband and daughter, along with the hospice team and me, took care of her.

Toward the end of her life, the patient told me she wanted to thank her oncologist and say goodbye. Once she began receiving home hospice care, he had neither called nor visited. Her feelings of gratitude and connection to him had only grown as she prepared to die. With her permission, I called him and told him that his patient would love to see him.

But there isn't anything I can do for her now, he told me. Though he sounded slightly irritated, I thought about how many such losses he had experienced in his oncology practice and how painful and distressing the prospect of this patient's death might feel to him. I persisted.

"She feels very attached and grateful to you," I said. "She wants to thank you, and she wants to say goodbye. It would be great if you could stop by."

He had not visited a patient at home before, but he agreed to go. She thanked him for his amazing care and for giving her so many good years after her lung cancer was diagnosed. After that visit, she lived only a few more days.

This story is excerpted from the Narrative Matters section of the journal Health Affairs; it can be read in full at www.healthaffairs.com. Meier is the director of the Center to Advance Palliative Care and a professor in the Department of Geriatrics and Palliative Medicine at the Icahn School of Medicine at Mount Sinai in New York.