

When It's the Doctor Who Can't Let Go

By **Theresa Brown** September 6, 2014 2:30 pm

Bedside is a series about health care from a nurse's-eye view.

Sometimes it's the doctors, not the families, who can't let a patient go.

My elderly patient had lived much longer than seemed possible at the time of his cancer diagnosis. Ten years later, though, his relapsed lymphoma had become medically unstoppable.

The palliative care team was called in to manage his growing confusion and discomfort, and to discuss what we call "goals of care." That's what palliative care does: It focuses on keeping symptoms under control for the seriously ill and, for patients who can't be cured, addressing how they want to die, including the option of hospice care. Now that this patient's disease could not be restrained, what did he want? He could no longer answer, but his wife and son, sad but cleareyed, chose to stop all treatment aimed at curing his cancer.

Hearing this, his oncologist, standing beside me at the nurse's station, cried, heartbroken that her patient of so many years would not rally one more time.

That evening, though, the patient's primary care doctor came to the hospital, seeing himself, it seemed, as the cavalry. There was hope yet, he said: The patient needed rehab to make him strong enough for more chemotherapy,

not palliative care and hospice. So the patient — disoriented and unable to speak — went to an inpatient rehabilitation unit. He died there, a few weeks later.

I'm sure the primary care doctor meant well, but there's no question that his actions made the situation worse because he deprived the patient and his family of comfort at the man's life's end. And this was far from the first time I've seen something like this happen. Such situations arise in part because modern health care still embraces a false dichotomy between curative treatment and palliation, between making a patient healthy and relieving his or her pain.

Palliative care itself suffers from an identity problem, in that many people equate palliation with hospice — i.e., end of life. This mistaken association can make a palliative care consultation feel like a death sentence to even the most open-minded clinicians, patients and family members. Striving for a cure is historically seen as a unique pathway that restores health; easing suffering is a separate, non-curative path that ends with the patient dying.

And it's true that palliative care does offer symptom management to patients who are expected to die soon, as my lymphoma patient was. But it is more than that: It also helps patients with long-term illnesses like congestive heart failure and chronic obstructive pulmonary disease, people who are expected to live with their illness, but need careful managing of their symptoms. If it becomes clear that a patient receiving palliation along with curative treatment will not survive her illness, then the palliative care group works with the medical team to help her make the transition to hospice and help her decide how to spend the last of her time on earth.

Palliative care can extend life, too. A well-known 2010 *New England Journal of Medicine* paper co-written by Jennifer S. Temel, an oncologist at Massachusetts General Hospital, established that patients with a certain type of lung cancer who received early palliative care not only reported better

quality of life and reduced symptoms of depression, but also lived longer than patients who received only traditional oncology care — a result that has since been found with other forms of cancer.

Often, though, the palliative care team is consulted late in the illness, as was the case with my patient. One reason is money: To put it in the crass language of hospital accounting, palliative care is de-incentivized. It saves hospitals money by reducing costly and often futile care at the end of patients' lives, but earns little compared with the expensive drugs and scans used in curative treatment.

But another barrier is the attitude of physicians themselves. Many oncologists, focused on keeping patients alive for as long as possible and hoping, always, to beat the odds, find it hard to discuss what might happen if they don't.

It was the same with my patient's oncologist. Hearing about the move away from palliation to rehabilitation, she sounded relieved. "Well, if he goes to hospice he'll just die," she said — as if there were another alternative. She knew better than anyone that our bag of chemotherapy tricks was empty, but facing that reality proved too hard.

Had the palliative care team been consulted earlier, it could have worked with the primary care doctor, the nurses on the floor and the oncologist to understand and communicate the patient's wishes over a period of time, perhaps even when the patient could still speak for himself. Instead, the patient got lost in the back and forth, as did his family, caught between the rock of his imminent death and the hard place of arranging for rehabilitation that was presented as his salvation, but offered no real help or comfort.

Doctors face a difficult paradox: Their job is to keep patients alive, but part of that means keeping at bay the dark awareness that everyone dies. Because doctors are supposed to cure, efforts directed elsewhere, even palliative care, can feel like a surrender. But their job might actually be easier

if they found a way to better use what palliative care can achieve for patients, and not only at the end of life.

Physicians also need to recognize that there are occasions when the patient's fate is not, in the end, the doctor's work. Every patient deserves care on his own terms, for each patient's life, and death, is his own.

Theresa Brown is an oncology nurse and the author of "Critical Care: A New Nurse Faces Death, Life, and Everything in Between."

A version of this article appears in print on 09/07/2014, on page SR4 of the National edition with the headline: When It's the Doctor Who Can't Let Go.