Is there some kind of mystery that surrounds terms like “palliative care” and “advanced directives”? Are these new ways of caring for patients?

As a close observer of the bioethics movement, I have been curious to see how physicians react and respond to “outsiders” like ethicists who are trying to influence clinicians’ patient-management skills and techniques. Most of us physicians feel pretty good about how long and hard we have trained to have gained the respect and stature of “doctor.” It’s not surprising, then, that initial physician reaction to ethics committees and palliative-care task forces is often, “What do they know about taking care of patients? I’m well equipped, well trained, and can certainly do the job myself, thank you."

Well, there’s good news for the docs. Nothing in the bioethics movement diminishes physicians’ stature, importance, or authority. On the contrary, the principles of ethics and their application to everyday decision making will do nothing but make those very doctors better at providing care, whether it be curative or palliative.

Recently, a patient of mine who had a history of bladder tumors was admitted to the hospital after a protracted bout of severe hematuria.
Having just completed a visit overseas to see her family, Hetty presented in an extremely weakened and anemic state. After several transfusions and fluid replacement, she was taken to the operating room for an attempted removal of her bladder. Unfortunately, her tumor had metastasized and involved major pelvic vessels making its removal unfeasible. We closed her abdomen, knowing that her disease was incurable. The next day I told Hetty that she had an unresectable tumor. We talked some about other forms of treatment — although they wouldn’t cure — and about comfort care.

She needed some time, she said, to consider her options.

A week later, after having heard opinions from other cancer specialists, Hetty made her decision. She chose to go home with hospice care. We had a tearful farewell on the day she left the hospital. Both Hetty and I knew it was unlikely we’d see each other again. I told her I admired her tremendous courage and faith and that I would always remember her as a positive-minded, cheerful, brave individual. Her daughter, in tears, said, “Mom, you will always be my hero.”

Hetty’s eyes sharpened as she looked into her daughter’s face. In her dignified British accent, she said, “I’m not a hero, darling. I’m just your Mum.”

Hetty’s demonstration of fortitude gave me pause to think more deeply about things like heroes and strength and facing death.

How would I define a hero?

What constitutes a heroic act?

Where does the strength come from for people facing the Great Unknown?

And, finally, how do we as physicians honor such exemplary individuals?

After some reflection, I decided my definition of a hero was a loose one. But it would include qualities of selflessness, courage, faith, and strength. In school, we’re taught that heroes are either “god-like” in the classic sense or individuals who performed some miraculous deed, usually in war or a football game. Knowing and caring for Hetty had re-educated me. Although she did not consider herself a hero, her willingness to devote her life’s energies to her family had made her a modern-day hero in a skeptical and faithless world. Her “greatness” resulted, not from any single heroic feat, but from a lifetime of selflessness and devotion. In an effort to follow basic principles of respectful, compassionate palliative care, I had been given a life lesson by a courageous woman who was running out of options.

The longer I practice medicine, the more carefully I find myself listening to my patients. From them I “steal” the wisdom they bring to life and sometimes to death. We physicians have unique observation points as we educate and guide our patients through difficult and frightening experiences. By being tactful, empathetic partners to our patients, especially at times of intense human need, we can learn much about the human spirit while we care for the human body.

We physicians who wish to make the most difference to the most people will do it in small steps as we build relationships with our patients. By adhering to basic principles of respect, informed consent, honesty, and patient advocacy, we can make a significant difference. End-of-life decisions will then be a part of the continuum of care, instead of an uncomfortable interruption.

And, finally, if we view practicing palliative care as an opportunity for personal and professional growth as well as a benefit for our patients, we will have properly nourished a mutually beneficial partnership between physician and patient.

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