Frank Talk About Care at Life’s End

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Legislators have begun to recognize the medical, humanitarian and economic value of helping terminally ill patients and their families navigate treatment options as they approach the end of life.

Last week, over the objections of New York State’s medical society, Gov. David A. Paterson signed into law a bill — the New York Palliative Care Information Act — requiring physicians who treat patients with a terminal illness or condition to offer them or their representatives information about prognosis and options for end-of-life care, including aggressive pain management and hospice care as well as the possibilities for further life-sustaining treatment.

The Medical Society of the State of New York objected, saying that the new law would intrude “unnecessarily upon the physician-patient relationship” and mandate “a legislatively designed standard of care.”

A similar provision in the original federal health care overhaul proposal, which would have reimbursed doctors for the time it takes to have such conversations, was withdrawn when it was erroneously labeled by conservatives as a “death panel” option.

Also last week, a study in The New England Journal of Medicine reported that among 151 patients with newly diagnosed metastatic lung cancer, those who received palliative care, which is care focused on symptoms, along with standard cancer therapy had a better quality of life, experienced less depression, were less likely to receive aggressive end-of-life care and lived nearly three months longer than those who received cancer treatment alone.

The New York law was sponsored by Assemblyman Richard N. Gottfried and Senator Thomas K. Duane, both Democrats of Manhattan, at the request of Compassion and Choices of New York, an organization that seeks to improve end-of-life comfort care and reduce the agony often associated with dying in this era of costly can-do medicine.

The organization said the law addresses “a major concern for terminally ill patients and their families, who often face the most important decision of their lives — how to live their final days — without being informed of their legal rights and medical options.” The law obligates health care providers to volunteer information on a complete menu of care options — if patients want to know about the options.

Tough Conversations

While some patients, especially those who are young or are the parents of young children, choose to pursue aggressive treatment for their diseases until their dying days, studies have shown that most terminally ill patients opt for comfort care after receiving honest information about their survival prospects and the benefits and risks of further disease-directed therapy.

For example, in a study published in the Journal of the American Medical Association in October 2008, Boston researchers found that patients who had end-of-life discussions with their physicians "were more likely to accept that their illness was terminal, prefer medical treatment focused on relieving pain and discomfort over life-extending therapies, and have completed a do-not-resuscitate order."

When compared with patients who had no such discussion, they were also more likely to be enrolled in outpatient hospice for more than a week and less likely to be placed on mechanical ventilators, or to be resuscitated if their hearts stopped, or to be admitted to intensive care units.

Contrary to fears that such discussions cause emotional harm to patients, the researchers reported that there was no increase in serious depression or worry and that the worst psychological distress occurred in patients and family members when end-of-life talks had not taken place. The poorest quality of life and worst bereavement adjustment resulted when patients received aggressive care during the last week of life, the researchers found.

The first author of the study, Dr. Alexi A. Wright, a medical oncologist at the Dana-Farber Cancer Institute, concluded that there was "a need to increase the frequency" of end-of-life conversations.The new law in New York, like a similar one in California, seeks to overcome physician resistance to talking frankly with terminally ill patients. Many studies have shown that such discussions can reduce costly aggressive yet futile treatments, improve the quality of remaining life for patients and their families and result in more dignified deaths unencumbered by medical technology.In a study published last year in the Archives of Internal Medicine, terminally ill patients who talked about hospice with their doctors were nearly three times as likely to take advantage of this service, which is covered by Medicare and is far less costly than aggressive hospital-based care.

More Yet to Be Done

Still, according to one palliative care expert, the law is not enough. Dr. Diane E. Meier, director of the Hertzberg Palliative Care Institute at Mount Sinai School of Medicine in New York, said in an interview that the law does not help doctors and nurses acquire the expertise they need to hold meaningful end-of-life discussions with their patients. To increase competency in palliative care, she said, courses in medical and nursing schools and a continuing-education requirement for practicing physicians are essential.

“Doctors need to know how to identify when patients are on the decline, be able to initiate conversations with patients and/or family members, discuss what to expect in the future and the pros and cons of alternative care options, and know how to provide support as a patient’s illness progresses,” Dr. Meier said.

Another problem is the admittedly poor ability of physicians to determine a patient’s remaining life expectancy, except perhaps when death is but a week or two away. Even with advanced cancer, when death may be most predictable, doctors are often wrong either because the disease follows an unexpected course or because doctors are reluctant to acknowledge their inability to delay death.

For any number of diseases that are considered terminal, like Alzheimer’s disease or emphysema, patients can survive many years. Dr. Meier maintains that all patients, regardless of how near or far death may be, should be told about and receive palliative care whether or not they are treated for their underlying disease.

In an editorial accompanying the new report in The New England Journal of Medicine, Dr. Meier and Dr. Amy S. Kelley wrote, “Physicians tend to perceive palliative care as the alternative to life-prolonging or curative care — what we do when there is nothing more that we can do — rather than as a simultaneously delivered adjunct to disease-focused treatment.”

Palliative care should not be limited to terminally ill patients, Dr. Meier insists. “Life-threatening illness, whether it can be cured or controlled, carries with it significant burdens of suffering for patients and their families and this suffering can be effectively addressed by modern palliative care teams. Perhaps unsurprisingly, reducing patients’ misery may help them live longer.”

This article has been revised to reflect the following correction:

Correction: August 25, 2010

The Personal Health column on Tuesday, about discussions between doctors and patients regarding end-of-life care, described incorrectly the professional credentials of Dr. Alexi A. Wright of the Dana-Farber Cancer Institute and misstated her role in a 2008 study on the subject. She is a medical oncologist, not a palliative care specialist, and she was the first author of the study, not the leader of the research team. (Holly G. Prigerson was the lead investigator.)