

Continuing Research and Reflections on Better End-of-life Care

End-of-life issues continue to be in the news and in the literature. A new study that appeared in the online version of the *Journal of Clinical Oncology* on Nov. 12, 2012 reported that terminally ill cancer patients, when they have conversations with their physician early on regarding how they want to die, are less likely to receive aggressive end-of-life treatment in the last two weeks of life (<http://bit.ly/gPtMdm>).¹ The study's lead author was Dr. Jennifer Mack from the Dana Farber Cancer Institute in Boston. It involved 1,231 people with advanced lung or colon cancer who died over a 14-month period and who were part of a larger cancer study. Researchers interviewed either the patients themselves or their caregivers about whether and when the patients had discussions with their doctors about their wishes at end-of-life. They also reviewed medical records for documentation of those conversations and to determine whether there had been any treatments provided or hospitalizations during the last month of life.

What the researchers found was that 88 percent of patients had end-of-life discussions, but one third of those took place less than a month before the patient died, when their health was severely compromised. Two-thirds of the conversations occurred when the patient was in the hospital. Almost half of study participants received aggressive, life-

prolonging care. However, those who did have these conversations more than a month before dying were 50 to 60 percent less likely to receive aggressive treatment than patients who put off such conversations or did not have them. And patients who had them were almost seven times more likely to end up in hospice.

In speaking to Reuters Health, the lead researcher observed that “if we start these conversations early, then patients have time to process this information, to think about what’s important to them (and) to talk with their families about that. ... We should at least consider having these discussions soon after diagnosis if we know that a patient has incurable cancer.”²

In a NYTIMES.COM Opinionator Blog on January 3, 2013, Ezekiel J. Emanuel, M.D. challenges a prevailing assumption about end-of-life care and then proposes four ways to improve it. He challenges the conventional wisdom that “end-of-life care is an increasingly huge proportion of health care spending” and that “people spend more on health care in the year before they die than they do in the entire rest of their lives.”

Ezekiel believes that this is mistaken. The real numbers, he believes, are the following: “the roughly 6 percent of Medicare patients who die each year do make up a large proportion of Medicare costs: 27 to 30 percent. But this figure has not changed significantly in decades. And the total number of Americans, not just

older people, who die every year—less than one percent of the population—account for much less of total health care spending, just 10 to 12 percent.”

Futhermore, he contends, the fact that we spend quite a bit on end-of-life care does not mean that we can save quite a bit. No one can say what specific changes would significantly lower costs. Studies suggest that hospice may reduce costs for cancer patients by 10 to 20 percent, but they find no savings for patients who die from other causes.

Ezekiel believes, however, that even if nothing can be saved through better end-of-life care, we should try to do better. He outlines four things that the health care system can do to improve care for the dying, even if they don't save money.

First, doctors and nurses should be trained in how to talk to patients and families about end-of-life care. Second, physicians should be paid a one-time fee for doing so because even if physicians are well-trained, these conversations take time and are emotionally draining. Third, every hospital should be required to have palliative care services both in the hospital and in the homes of dying patients. And, finally, there needs to be a revision of eligibility requirements—less than six months to live and no “aggressive” therapy—for hospice care.

On Nov. 30, 2011, Dr. Ken Murray, clinical assistant professor at USC, published an article on Zocalo Public Square titled, “How Doctors Die:

It's Not Like the Rest of Us, But It Should Be

(<http://www.zocalopublicsquare.org/2011/11/30/how-doctors-die/ideas/nexus/>).³

“What's unusual about them [doctors],” he says, “is not how much treatment they get when compared to most Americans, but how little. For all the time they spend fending off the deaths of others, they tend to be fairly serene when faced with death themselves. They know exactly what is going to happen, they know the choices, and they generally have access to any sort of medical care they would want. But they go gently. . . . They know enough about modern medicine to know its limits. And they know enough about death to know what all people fear most: dying in pain, and dying alone. They've talked about this with their families. They want to be sure, when the time comes, that no heroic measures will happen. . . .”

Murray goes on to explain some of the causes of the disparity—unrealistic expectations on the part of patients; doctors who may not communicate as well as they could or should and who too often defer to patients out of fear of litigation; and a health care system that encourages excessive treatment.

Each of these pieces (and a good number more could have been surveyed) suggests that there is still much work to be done. Emanuel ended his blog post this way: “But doing nothing to try to help the dying when the rest of the health care system is improving care is not an option.”