Palliative Care May Trump Heroic Measures in Life Expectancy

A new study finds palliative care doesn’t put patients out of their misery; it puts the misery out of the patients.

By Joanne Kenen

What if those “death panels” were actually good for your health?

The death panels, of course, don’t exist; they were the product of overheated political imaginations amid an overheated debate about health care reform. But palliative care does exist — and despite the distortions of last summer’s debate, it doesn’t mean “pulling the plug on Grandma.” (Or Grandpa for that matter, although he seems to have been neglected in the national brouhaha about death panels.)

A study published this week in the New England Journal of Medicine found that palliative care — which includes talking to patients and families about treatment goals and end-of-life wishes — doesn’t hasten death.

To the contrary, the study of terminally ill lung cancer patients found that early access to palliative care prolonged life — even though the patients opted for less aggressive care as they neared death.

Researchers compared two similar sets of patients at Massachusetts General Hospital with advanced metastatic non-small cell lung cancer — the lethal and fast-moving form of the disease. Both groups got standard cancer treatment, consisting of chemotherapy and/or radiation. But one group also got early and ongoing palliative care.

By several standard measures, the palliative care group had a better quality of life at 12 weeks and was less depressed. In other words, palliative care didn’t put the patients out of their misery. It took at least some of the misery out of the patients.

“Among patients with metastatic non-small-cell lung cancer, early palliative care led to significant improvement in both quality of life and mood,” the authors wrote. “As compared with patients receiving standard care, patients receiving early palliative care had less aggressive care at the end of life but longer survival.” More chemotherapy didn’t mean more life.

Patients in the palliative care group lived 11.6 months, compared to 8.9 months for the standard group. Two to three months is a long time for a patient with advanced lung cancer. Two months is about how long the state-of-the-art chemotherapy drugs extend life. And some of the chemo drugs carry risks that themselves can shorten lives.

The study was not designed to directly measure or compare costs, although it did look at utilization of health care. Patients who received ongoing palliative care spent less time in the hospital, made fewer trips to the emergency room and were less likely to have chemotherapy in the last two weeks of life. They were more likely to have their end-of-life wishes clearly documented in their medical records, and their median stay in hospice was 11 days, compared to four days for the nonpalliative group.
The researchers say that more analysis is needed to confirm that less intensive care was less expensive.

This research, funded in part by an American Society of Clinical Oncology Career Development Award, and with collaboration from researchers at Yale, Columbia and the State University of New York at Buffalo, has limitations. Mass General is a resource-rich setting with a well-known, well-developed palliative care program available to inpatients and outpatients. Most of the patients in the study were white. And it deals with only one disease, a particularly dire lung cancer. More outcome, quality and economic research will be needed to analyze the benefits of early palliative care on other cancers as well as other diseases.

Still, palliative care leaders expect the findings to resonate.

For most of the last 20 or 30 years, hospice has been the main focus of end-of-life care, providing both management of pain, nausea, delirium, shortness of breath and other distressing symptoms while also providing psychosocial and spiritual support for patients and families, usually at their home.

But hospice generally requires people to give up curative — what doctors call “disease-modifying” — care, which may mean hurling off an emotional cliff as this implies accepting the imminence of death. Hospice is available to patients expected to live six months or less, which may or may not be easy to predict, depending on the disease, and the individual. So people often put off seeking hospice care until they are quite close to death — or they never seek it at all, increasing the odds of dying in the hospital, quite possibly hooked up to invasive machines in an ICU.

Palliative care has grown over the last decade or so in an attempt to give people a similar multipronged approach to serious illness — without having to give up curative treatment or be on the brink of death. But it is not always available, and often misunderstood. Practitioners hope this study helps them clear up the myths and establish the benefits, enabling them to make the case for offering it to more patients earlier in the course of their disease.

Jennifer Temel, an oncologist at Massachusetts General and the lead author of the study, said fellow cancer doctors often regard palliative care as a last-resort discipline, a place to turn to when cancer treatment fails — not as a companion treatment.

“Patients can get expert cancer care and comprehensive palliative care at the same time,” she said in an interview summing up the study’s message. “And it has an impact on their symptoms and life expectancy.”

Palliative care teams offer more than a jolt of morphine at the death bed (although morphine and its pharmacological cousins are part of the palliative tool kit). It includes management of symptoms, guidance in decision-making and psychosocial support for both patients and families.

The new federal health reform law expands palliative care coverage for seriously ill children on Medicaid or the State Children’s Health Insurance Program (better known during Washington wrangling by its acronym, SCHIP). It also creates a three-year, 15-site program to test a “concurrent care model” that allows terminally ill patients to access hospice without having to surrender other treatment.

“It’s about matching treatment to patient goals,” said Diane Meier, who directs the Center to Advance Palliative Care based at New York’s Mount Sinai School of Medicine, which has helped train palliative care teams and helped them make the case to hospitals as to why it’s both good medicine and good business.

“It’s not about denying beneficial care,” added Meier, who co-authored an editorial that accompanied the New England Journal of Medicine study. “It’s about providing beneficial care in the safest, most appropriate setting.”

The study began with 151 patients; 27 of whom died within 12 weeks. One hundred and seven completed assessments. Additional data was collected from the patient’s electronic medical records. Palliative care patients had their first appointment within three weeks of enrollment, and at least one a month thereafter. Patients in the control group who requested a palliative care consult could also get it, and some did, but that didn’t dilute the study’s bottom line.

The palliative care patients were less depressed — even though the standard care patients were as likely to be taking antidepressants. It’s not that the pills don’t help the “standard” patients, said Vicki Jackson, a Mass General palliative care physician who collaborated with Temel. It’s that the palliative approach added a whole other component by addressing the person, not just the illness — the physical symptoms, the psychological stresses, the decision-making, the needs of the family.
“You are addressing what matters to them, the context of the disease,” agreed Ira Byock, a longtime leader in hospice and palliative medicine now at Dartmouth-Hitchcock Medical Center who was not involved in this study. “When someone has a life-threatening illness — involving their emotional, social, spiritual well-being — their personal life is inseparable from their physical health.”

“This is an incredibly important study,” he added. “It demonstrates the efficacy of palliative care in both improving quality of life and extending length of life.”

Jackson said palliative care can give patients a “safe space” to confront their condition and evaluate choices. “These patients are very sick and they are complicated. They are more likely to tell the palliative care doctor when they are feeling poorly than the physician holding the keys to the chemo cabinet.”

“We help educate them as to what’s possible — that it’s fine to ask the oncologist to postpone chemo for a week to go to the beach with the family. We found patients are more likely to talk to me about what it would mean if they stopped treatment. It doesn’t mean they don’t have a good relationship with Jennifer [the oncologist]. But they didn’t want to let Jennifer down. There’s a different relationship.”

To doctors in the trenches — or at least in the ICUs — the study resonates. “These conversations are hard. It’s not easy for the oncologist to change from cheerleader to, ‘This isn’t going the way you want it to go,’” said Christopher Hughes, critical care specialist at St. Clair Hospital in Pittsburgh, who has seen oncologists keep offering chemo rather than “deal with what’s at hand.”

When Hughes encourages goal-setting and end-of-life conversations, he said, he has found patients don’t really want “chemo while they are nailing your coffin. … Most people will choose a shorter, higher quality life.” But even before the empirical evidence of this study, his own observations had taught him, “It’s not always going to be shorter.”