A Year of Hope and Heartache: On the Road with Hospice

By Lisa Yarkony
Early this year John-William Frye embarked on an 8,000-mile trek across the country. Equipped with a bicycle, a cell phone, and 115 pounds of equipment, the 28-year-old set out from Florida to Alaska on a mission to make people talk about hospice. “No one wants to talk about hospice and the myth of the isolated, afraid, alone, out-of-your-home end of life gets perpetuated,” he said during a stop in Pennsylvania. “People think hospice is a place where you go to die, and it really isn’t. It’s more of a way to ‘get the most out of life,’” Frye learned when his mother was diagnosed with brain cancer and cared for by hospice. As his mother lay dying, he saw that hospice is not only for the patient. “Hospice didn’t just take care of my mother as she died,” he said. “They nursed a whole family back to life.”

Frye is convinced that others would share his vision if they explored the benefits of hospice. “Six months is the diagnosis that you come into hospice with,” he said. “That’s what Medicare would pay for, six months of end-of-life care. And I want to show how much life can be lived, how many people you can affect, and what an amazing journey you can have by living one day at a time for six months.”

This might seem like a romantic view of hospice, but a spate of recent studies has documented its value. And more people are choosing hospice, as we’ll see in looking at end-of-life care since about this time last year. Data that came out this January showed that the number of hospice patients in the United States has more than doubled — from about 700,000 patients in 2000 to over 1.5 million in 2009. That year nearly 42 percent of all deaths in the country were under care of a hospice program, and most of those deaths took place at home. Hospice has gained traction because it gives people more control over their final days and it is almost always a less costly way of caring for someone who’s terminally ill.

“What happens is, because the disease process is so acute, the patient makes a lot of trips to the emergency room and a lot of trips to the hospital,” said Kathleen Pacurar, president and CEO of San Diego Hospice and the Institute for Palliative Medicine. “With hospice, because we are managing their symptoms and pain and we’re available 24/7, patients call us rather than the medics when they are in pain or distress. That means fewer trips to the hospital and a lot fewer medical procedures.” It has also meant a growth in oversight and new questions about the ethics of hospice care.

As hospice has moved into the mainstream, concerns about costs and misuses have mounted. In August, the Office of the Inspector General of the U.S. Department of Health & Human Services advised looking more closely at billing for hospice care. “Some hospices may be seeking out beneficiaries with particular characteristics, including those with conditions associated with longer but less complex care,” the OIG reported. “Such beneficiaries are often found in nursing facilities. By serving these beneficiaries for longer periods, the hospices receive more Medicare payments per beneficiary, which can contribute to higher profits,” an accusation that has been flung most often at for-profit hospice programs.

“Do for-profit programs serve the interests of shareholders or those of dying patients and their families?” a survey asked in June. The responses indicate that for-profit programs tend to be more cost-effective their counterparts in the nonprofit world. But it does not affect the quality of care they provide according to a Family Evaluation of Hospice Care conducted earlier this year. Families involved in the evaluation said they were equally satisfied with for-profit and not-for-profit hospice programs. Whatever their financial status, the vast majority of hospices improve, and even prolong, their patients’ lives, as several recent studies have observed.

Last October, researchers urged earlier hospice care for men with terminal prostate cancer. “It’s important that we maximize quality of life when quantity of life cannot be changed,” said lead author, Dr. Mark Litwin, a professor of urology and public health at UCLA’s top-ranking Jonsson Cancer Center. “Most men are being referred to hospice too late and the timing hasn’t changed in the last 20 years, which is unfortunate. As cancer specialists, we should offer these patients the best quality of life that we can, and that means offering the best quality of death that we can give them.”

The best way to die is with hospice, families of dementia patients agreed in a survey this July. People whose loved ones received hospice care said that the quality of dying was improved, according to lead author Dr. Joan Teno, a gerontologist and Brown Medical School professor. Family members of hospice recipients were 51 percent less likely to report unmet needs and concerns with quality of care, the survey showed. It also revealed that those whose loved ones received hospice care “too late” typically had stronger concerns about care. “These are people who get slammed around the health care system in the last days of life,” Teno said. “These are people who go from an acute-care hospital to a nursing home in the last 24 hours. They are reacting to a set of circumstances that shouldn’t have occurred,” especially since we now know that hospice can actually extend life.
In August 2010, the New England Journal of Medicine published a study showing that patients with terminal lung cancer who began receiving palliative care immediately after diagnosis not only were happier, more active, and more comfortable as the end approached — they also lived nearly three months longer. The study confirmed what hospice care experts had long suspected and cast doubt on the decision to strike end-of-life provisions from health care reform. “It shows that palliative care is the opposite of all that rhetoric about ‘death panels,’” said Dr. Diane E. Meier, director of the Center to Advance Palliative Care at Mount Sinai School of Medicine in New York. “It’s not about killing Granny; it’s about keeping Granny alive as long as possible — with the best quality of life.”

Too bad that patients in some parts of the U.S. are less likely to receive hospice care in accordance with their wishes, said a report released this April by researchers at Dartmouth College. Many patients with advanced cancer get aggressive medical therapies they may not want and that may have no benefit, the study noted. “In addition to its effects on patients’ quality of life, unnecessarily aggressive care carries a high financial cost. About one fourth of all Medicare spending goes to pay for the care of beneficiaries in their last year of life, and much of the growth in Medicare spending in recent decades is the result of the high cost of treating chronic disease. It may be possible to reduce spending while improving the quality of end-of-life care by ensuring that patient preferences are followed more closely.”

The gap between patient wishes and care received was least in Utah and most pronounced in New York, where people with chronic disease get the most aggressive treatment in the country. Some of the disparity might be driven by financial incentives for keeping patients in hospitals while neglecting their wishes, said Dr. Elliot S. Fisher, a coauthor of the study. “Surveys show quite clearly that Americans don’t want to spend their last days in intensive care units,” Fisher said. “What they want to do is to avoid suffering, to be with their families, to be mentally aware.” Lead author David Goodman added, “The biggest problem we have with end-of-life care for cancer patients is not over treatment, it’s under treatment when it comes to quality of life. Patients want to live long, but they also want to live well.”

But some of them may not have access to hospice if they live in less prosperous areas of the country. The availability of hospice care in the United States strongly reflects a local area’s average household income, said a study that came out this May in the Journal of Pain and Symptom Management. The researchers noted that charity is the main source of funding for local community hospices, which is one explanation for the findings of the study. “Wealthy communities can afford large amounts of charitable giving and thus have the resources to build local hospices,” explained lead author Dr. Maria Silveira, “whereas poorer communities may not be able to donate in the amounts necessary to do the same.”

But money is not the only barrier to hospice care across the country. Many doctors choose to wait in facing end-of-life talks with patients, as they admit. “The hardest part of my job, bar none, is telling patients — most of whom I have been working with for months, even years — that I have nothing else to offer them,” said Dr. George Sledge, who is co-director of the breast cancer program at Indiana University. “These conversations are time consuming and difficult,” agreed Dr. Nancy Keating, an associate professor of medicine and public policy at Harvard. “Some doctors may feel patients will lose hope. It’s easier to say, ‘Let’s try another round of chemotherapy,’ instead of having a heart-to-heart discussion.”

In addition, these important conversations are not billable and they do not conveniently fit into the typical 15 to 20 minute appointments that patients have with doctors. Nine out of 10 patients would like to discuss end-of-life care with their physicians. Yet more than 60 percent of dying patients did not recall having had such discussions, according to data that appeared this April in USA Today. As a result, many patients who want to die at home wind up dying in the hospital. So doctors should level with their patients, Dr. Keating said. “When you know someone’s going to die of their disease, it’s only fair to the patients to help them understand that. But these conversations are very challenging. Figuring out how to do it well — it’s so tricky. It’s definitely not something everybody believes in,” including many politicians.

Hence the specter of “death panels” was raised again this year, prompting the Obama administration to back off yet again in its efforts to encourage end-of-life planning. On January 3, 2011, the administration revised a Medicare regulation to delete references to end-of-life planning as part of the annual physical examinations covered under the new health care law. After debates on the rule last year, Democrats dropped a similar proposal to encourage end-of-life planning when it inspired grumblings of “government-encouraged euthanasia.”
This year politics also trumped patients’ wishes in renewed talk of the rule, though the administration toned down its guidelines for end-of-life talks. The earlier proposal would have given specific directions to doctors on what they should tell patients, including discussion of hospice. The more recent rule simply listed “advance care planning” as one of the services that could be offered in the “annual wellness visit” for Medicare beneficiaries. Yet it, too, threatened to stir up a political storm and become a distraction to administration officials who were gearing up to defend the health law against attack by the new Republican majority in the House.

Hospice, too, came under siege this January when Medicare responded to longer hospice stays by adopting a new restriction. Hospice patients now need to have a “face-to-face” encounter with a physician or nurse practitioner to keep receiving care under Medicare. The regulation is meant to prevent abuse and ensure that a patient’s condition is still terminal, a good rationale in theory. But it ignores the increasing number of patients with diseases, like dementia, that can follow an unpredictable course. “Initiatives focusing on reducing long hospice stays could disproportionately and adversely affect the timing of hospice referral for persons with dementia,” warned gerontologist Susan Miller in the December 2010 issue of the American Journal of Alzheimer’s Disease & Other Dementias.

Miller is one of many who have come out against the new regulation. Hospice administrators say it is too costly to send a doctor or nurse practitioner out at the six-month mark to every patient, doctors worry about discharging the wrong patients, and advocates of the aged foresee major disruptions in hospice service that will force more patients to die in hospital beds engulfed by tubes. “Ensuring the right of the aged to be cared for in their homes is America’s last great civil rights battle,” said NAHC President Val J. Halamandaris. “Medicare should not jeopardize this with its overly hasty implementation of the face-to-face rule without testing it first and without sufficient time for everyone involved to understand what is required of them.”

Medicare, and other policy makers, should also look at what hospice has meant to the patients and families it served in recent months. Among them was Alexander Horvath, an 85-year-old Maryland man with dementia. His wife said she had chosen hospice for him because “I want him to be as happy and comfortable as long as he possibly can be.” Each moment of life is precious, 67-year-old Fern Kravets showed after being
diagnosed with cancer. The Illinois grandmother used her time in hospice to finally prepare for her bat mitzvah, the Jewish service that marks the passage from youth to adulthood. After the ceremony with family and friends, she marveled at “the feeling I have in my soul, the warmth, security, love, and spirit that God is with all of us and will always be with us and keep us always together.”

Hospice keeps families together, John-William Frye agreed as he recalled the hospice workers who helped him care for his mom. “She got to do everything she wanted to do, go where she wanted to go, and live at home every single day. Does that mean I was any less there for my mother, does that mean I was any less loving, close, intimate part of the family? No, I don’t think so.” Hospice just let him to do more for his mother than he could have done on his own. “If you truly care for your loved one, why wouldn’t you want to give them the best of care?” That’s what he asked everyone he met in his months on the open road. “Hospice needs to get its message out there,” he said, “because the story of hospice is a beautiful one.” And with all the new findings that are coming out, it is a story that has just begun to unfold.

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