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What If Hospice Services Weren’t Just for the Dying?

A pilot program allowed people with cancer, AIDS and other illnesses to receive hospice care without ending treatments for their conditions.

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Gloria Foster wasn’t ready for hospice, even though, with a prognosis of less than six months to live, she qualified for it. She was debilitated by diabetes and congestive heart failure and was living with both a pacemaker and a device to help pump blood from her heart to the rest of her body. She also was tethered to an oxygen tank.

But Foster didn’t want to enter hospice, if, as is normally required by Medicare, she would have had to forgo treatments that might, against all odds, reverse the course of her disease.

“Why did I need hospice?” Foster, 73, asked in a phone interview recently from the home she shares with a grandson in Asbury Park, New Jersey. “Hospice is more or less when you’re ready to die. I just wanted to work my way back to doing as much as I could.”

But under a Medicare pilot program that began in 2016, Foster was able, for a time, to receive home care generally available only to hospice patients. Unlike hospice rules that normally govern Medicare, the public health plan for seniors, she wasn’t required to give up treatments for her terminal health conditions.

Still alive long beyond her prognosis, Foster credits the program, which ended for her in December 2019, with stopping her frequent hospitalizations, improving her mobility and greatly boosting her spirits.

“When it came to an end, I was very upset,” she said of the at-home services. “I cried, as a matter of fact.” She said she’s been hospitalized six times since then.

An independent evaluation of the five-year pilot—the Medicare Care Choices Model—recently provided its most robust data so far: The results found that participants were able to stay out of the hospital and live longer at home than a comparison group while also saving Medicare money.

The results were so encouraging that many who work in palliative and hospice care think the study’s conclusions will lead to some of the most important policy changes ever undertaken in the field—and not just for those in Medicare but also for patients with Medicaid, the state-federal health plan for low-income Americans, and for patients with private insurance as well.

Many who work in the field of hospice or palliative care hope the pilot project’s results will be the catalyst for bureaucratic changes that could deliver a raft of traditional hospice and palliative care services to millions more Americans struggling with debilitating chronic disease, whether imminently terminal or not.

The changes they would like to see include permanent removal of the requirement that patients give up curative treatments to access hospice-style benefits. Many also hope Medicare, Medicaid and private insurers will reexamine the requirement that home-based comprehensive palliative care services be provided only to those with a prognosis of six months or less to live. That denies many with serious chronic health conditions services they say would be beneficial and might also cost less, in part by keeping patients out of hospitals.

“This is a huge deal,” said Edo Banach, president of the National Hospital and Palliative Care Organization, which represents hospice and palliative care providers, and was among those who lobbied the U.S. Centers on Medicare and Medicaid Services, known as CMS, to undertake the pilot.

Hospice Has Evolved

When Congress created a Medicare hospice benefit in 1982, lawmakers and advocates mainly were focused on cancer. At that time, when treatments for cancer patients proved ineffective, the trajectory toward death often seemed clear. Hospice care was seen as an alternative to heroic but also, for patients, often agonizing measures to keep people alive at all costs.

Hospice switched the health care emphasis to symptom relief while enabling dying patients to use their remaining time in as fulfilling a way as possible by, for instance, spending time with family or simply sitting outside on a pleasant day.

But since 1982, cancer treatments have dramatically improved, extending lives, while higher percentages of Americans are dying of diseases other than cancer, particularly of illnesses related to dementia and respiratory illnesses such as chronic obstructive pulmonary disease, known as COPD.

And, as with many cancers today, the timetables of those diseases are less predictable.

“Six months for a patient with COPD isn’t realistic, because the trajectory of the disease isn’t the same as cancer,” said Susan Lloyd, CEO of Delaware Hospice, which participated in the pilot. “Even cancer is more chronic because of better treatments available. There needs to be a change in viewing the time frame to meet where patients actually are today.”

Many advocates and providers think other patients with serious but not necessarily terminal conditions also would benefit from a full array of palliative care services delivered in the home. The goals of both palliative and hospice care are to relieve symptoms and align medical care with the patient’s wishes and values. The main difference is the terminal prognosis in hospice.

CMS said it plans to issue a final report on the pilot early next year that will include data from the most recent report as well as qualitative results from interviews with participants, their families and providers.

Advocates hope that the latest data ultimately will result in changes that would enable many more Americans to receive full palliative care services at home, including those unwilling to give up on their disease treatments.

The pilot “opened up an avenue for so many more people to enter the program without having to admit, ‘My God, this is the end of my life,’” said Dr. Marianne Holler, chief medical officer at the VNA Health Group, which participated in the Medicare pilot and provides hospice services in Ohio and New Jersey. Foster was one of the group’s patients.

“Patients should not have to pick Column A or Column B at the end of their lives,” Holler said.

Holler and other providers said the pilot’s results demonstrate the cost-effectiveness of hospice care and argue for rules changes on eligibility and reimbursement.

Fewer Hospitalizations

The pilot followed 4,574 participants from January 2016 through September 2020. They were entitled to services identical to—with some exceptions—those typically available with the Medicare hospice benefit. The project sought to answer whether participation would improve patients’ quality of life, increase election of the full hospice benefit and lower overall Medicare expenditures.

Among the findings:

- Compared with a control group not enrolled in the pilot, participants required less intensive medical interventions. For example, they had 26% fewer inpatient hospital admissions and 14% fewer outpatient emergency department visits and observation stays. They also spent 38% fewer days in an inpatient intensive care unit and 30% fewer days in other inpatient hospital units.

- A large majority of participants—83%—made the transition to the traditional Medicare hospice benefit. Participants were nearly 30% more likely than nonparticipants to elect the Medicare hospice benefit before death.

- Participants were less likely to receive aggressive life-prolonging treatments in the last 30 days of life than their counterparts. They also were able to spend about six more days at home than those in the comparison group.

- As a result of all the findings above, Medicare expenditures for participants were 17% lower than for nonparticipants. The savings were even greater for those who lived less than six months after entering the pilot.

“When you give people more choice and greater freedom to make choices in their best interests, they make decisions that are better for them in terms of quality of care but better for the country in terms of costs,” Banach said. “The demo worked.”

The pilot waived a key requirement of Medicare’s hospice benefit: Patients weren’t forced to forgo treatments of their terminal conditions, such as chemotherapy, immunotherapy and radiation, intended to promote recovery or even a cure.

The pilot was open only to those with one of four diagnoses: cancer, chronic obstructive pulmonary disease, congestive heart failure or HIV/AIDS. To be eligible, people still needed to have received a prognosis of six months or less.

Once deemed eligible, patients could receive traditional hospice services in their homes, delivered by a multidisciplinary team of doctors, nurses, counselors, social workers and chaplains.

The services they received were similar to those provided under the Medicare hospice benefit: case management and care coordination, around-the-clock access to their hospice team, counseling services and symptom management.

The pilot did not cover some services that are part of the traditional Medicare hospice benefit, such as in-patient respite care, a care aide in the home and coverage for durable medical equipment, such as hospital beds.

Before she joined the pilot in 2017, Shirley Klionsky, 91, of Marlboro, New Jersey, recalled, “It was hard. Something was always going wrong, and I was always going to the hospital.”

That ended during the pilot, thanks to the hospice team’s weekly visits and monitoring of her advanced lung and heart disease. “It was the best thing I could have done,” she said.

Klionsky wouldn’t have entered the program if it had meant giving up the treatments for her disease. Hospice wasn’t for her.

“That would have meant dying,” she insisted, “and I said no to that.”

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