St Louis Post: Is hospice a better way to die?

August 20, 2012 11:13AM ET

By Jim Doyle St. Louis Post-Dispatch

Aug. 19--Breathing has become increasingly difficult for Jeanne Lampe, who spends her days hooked to an oxygen tank.

Lampe, 79, has "end stage" emphysema, but still lives at home in a south St. Louis apartment. She's visited twice a week by a nurse from Hope Hospice Inc., which also provides a massage therapist, a social worker, a chaplain and workers to help with showers and chores -- all paid for by Medicare.

When the end comes, she's resolved to die at home, on her own terms.

"Death itself doesn't bother me, but emphysema is a crappy death. You're basically gasping for breath," she said. "When I'm ready to go, I want morphine and a margarita."

Lampe is among a fast-growing number of patients locally and nationally who are choosing hospice, which seeks to provide comfort rather than a cure. Advocates say the trend holds great potential to hold down runaway U.S. health costs by steering end-of-life patients away from more expensive and aggressive hospital care. But the industry's rapid growth also presents regulatory challenges to federal authorities concerned about unethical recruitment of patients and the cherry-picking of less complex but more profitable cases.

The number of hospice patients on Medicare doubled to 1.1 million between 1998 and 2008, according to the federal Centers for Medicare & Medicaid Services. Another estimate of hospice patients this year, from the National Hospice & Palliative Care Organization, put the number at 1.6 million.

"With the aging population and many people suffering from chronic illnesses, the number of people choosing hospice has exploded," said Melissa D.A. Carlson, an assistant professor at Mt. Sinai School of Medicine in New York. "As people understand hospice, they want more and more to stay at home with their family."

And more and more health care providers want to get into the burgeoning market. About 58 percent of Americans still die without hospice care, says the National Hospice & Palliative Care Organization, leaving ample room to grow the business.

A decade ago, hospice care was a niche dominated by nonprofit organizations. But now at least two-thirds of licensed hospices in the St. Louis area are run by for-profit companies, according to the state Department of Health and Senior Services. And about 80 percent of Medicare-certified hospice providers entering the market between 2000 and 2009 were for-profit firms, according to a study published in June by Health Affairs, a Bethesda, Md.-based policy journal.
"There's obviously money to be made," said Carlson, who co-authored the study.

In the big picture, advocates say, hospice offers more quality of life and dignity in death -- at much lower cost. In St. Louis County, for instance, providers receive a daily rate from Medicare of $144.91 for each patient in 'routine' hospice care. That typically includes the cost of drugs, medical equipment, supplies, and nursing care, but not room and board.

By contrast, hospitalization in an intensive care unit can cost upwards of $10,000 a day, including drugs, equipment and staff costs.

"It is a phenomenal benefit to the family members and the patient as well as the healthcare delivery system," said Judy Alexander-Weber, president and chief executive of the Visiting Nurse Association of Greater St. Louis, a non-profit whose hospice workers visit residences and nursing homes. "It's the most cost-effective way to manage end-of-life care."

MAINTAINING CONTROL

Costs aside, many hospice patients choose that option out of a more fundamental desire to control their destiny and manner of dying.

Benny Davenport, 84, a former flight engineer and auto mechanic, resides in St. Charles County with his wife Martha -- and wants to keep it that way until his death. SSM Hospice is helping his wife take care of him as his lung cancer spreads through his body.

"I want to clone my nurse," Davenport said. "I'm as happy as I can be."

In the St. Louis region, hospice care is growing and becoming more competitive. Smaller for-profit firms like Ballwin-based Hope Hospice and national chains such as Miami-based Vitas Hospice Services have entered the market, competing for patients against local non-profit heavyweights like BJC Healthcare, SSM Health Care, and Mercy Health.

Larger nonprofit health systems such as BJC Healthcare enroll many hospice patients at their own hospitals. Smaller and mid-size operators, who claim they offer more individualized care, compete to recruit hospice patients before admission to a hospital.

BJC Hospice leads the local market, with about 16 percent of hospice admissions. BJC's "Wings" program helps children who have had long-term hospital stays move to home care and supports the family after the child's death.

Locally, demand is driven in part by local demographics. St. Louis is ranked No. 5 in the nation in the number of adults per capita ages 65 and older, and No. 10 nationwide in the per capita number of adults 65 and older who live alone, according to the "2009 American community survey" by the U.S. Census Bureau.

The state of Missouri has more than 100 licensed hospice providers, and about 25 of those serve the St. Louis area. It also allows dozens of unlicensed hospice providers to do business, if
accredited by professional organizations. Typically, hospice care is delivered in homes, hospital rooms, nursing homes, and assisted living facilities.

In Missouri, the average length of stay for hospice patients is 79 days, according to the state's 2011 report on hospice providers. But about 28 percent of hospice patients statewide receive this care for less than seven days. At BJC Hospice, the median length of stay is 11 to 14 days.

Greater use of hospice by terminally-ill patients, advocates say, would improve quality of life and help save Medicare funds for future generations.

Hospice is "the best, well-rounded care because you have all the disciplines involved," said Jane Moore, executive director of the Jefferson City-based Missouri Hospice & Palliative Care Association.

Helen Cassidy, director of Mercy Hospice, said that as a nurse she grew tired of seeing people die in the hospital without the comfort of loved ones and familiar surroundings. "When it's your own home, you maintain control," she said. "For dying people, it's important to maintain control."

Walter Sanders, a cancer patient who will turn 80 on Wednesday, has been in hospice care with the Visiting Nurse Association since June 15. The retired Continental Can worker lives in south St. Louis with his disabled son, Gary, 55.

"At home, you have more freedom," he said. "If I want to go out in the yard and sit I can do that. I can look at my flowers."

**CHERRY PICKING**

The rush into the hospice marketplace, however, has raised concerns from regulators, investigators and academics about the potential for unethical operators.

Carlson questioned whether for-profit hospices may be "cherry picking" their mix of patients to increase their profits.

"A longer length of stay is more profitable for a hospice," Carlson said. "They tend to have patients with non-cancer diagnoses ... My guess is that they aggressively seek out patients with other diagnoses."

A study published last year in the Journal of the American Medical Association found that for-profit hospice providers were more likely to have patients who require less complex, less costly care -- but stay longer in hospice.

The study found, for instance, that for-profit firms have a higher proportion of patients residing in nursing homes. These patients are more likely to have dementia, which means they probably will live longer but have fewer needs than cancer patients.
Another study, published in 2010 by the Journal of Palliative Medicine, found that for-profit hospices often employ lower proportions of more highly qualified staff, such as nurses and medical social workers, than nonprofit hospices.

The national hospice association has proposed federal legislation that would require states to perform surveys, or periodic inspections, of hospice providers every three years. Faced with a budget crunch, Missouri regulators have cut back surveys from every three to every five years.

Lisa Coots, director of the bureau of homecare and hospice for the Missouri Department of Health and Senior Services, declined to comment.

Federal regulators have voiced concerns that some hospice providers are paying kickbacks or offering other financial inducements to entice nursing home directors or their staffs to refer patients to hospice care.

Last year, the federal Office of Inspector General began investigating hospice marketing practices and the business relationships between hospice providers and nursing homes.

The probe was prompted in part by a report to Congress in 2009 by the Medicare Payment Advisory Commission, which found that hospices were aggressively "trolling" for patients in nursing homes and using marketing materials that did not use terminal illness as a Medicare coverage requirement.

Some large hospice providers in the St. Louis area have offered free lunches, ice cream, and part-time nursing labor to lure nursing home directors and staff to refer patients for hospice care, said Laura Bilbrey, vice president and cofounder of Hope Hospice, whose employees visit patients in homes and nursing facilities.

Nationally, there have been at least four major prosecutions of hospice providers this year involving allegations that they submitted Medicare claims for patients who were not terminally ill.

Odyssey HealthCare Inc., a national chain owned by Atlanta-based Gentiva Health Services Inc., agreed in March to pay $25 million to settle allegations that it fraudulently billed Medicare for hospice services. Odyssey has local offices in Maryland Heights.

"Choose carefully. Do your homework," said Gail Barwick, patient coordinator for the nonprofit Fern and Russell F. de Greeff Hospice House, which is located on the campus of St. Anthony's Medical Center. "All the clients in hospice at some point become vulnerable. Not everyone appears to have the same code of ethics."

**SIX MONTHS TO LIVE**

A patient can qualify for hospice care if physicians certify that the person’s life expectancy is six months or less and the patient agrees not to pursue a cure.
But hospice patients can rescind that choice at any time, and a few decide to leave hospice and seek more aggressive treatment. Others leave hospice simply because they get better under the care they receive.

Medicare does not limit the number of hospice days. But hospice providers must periodically document that a patient is continuing to decline.

Though patients increasingly are turning to the hospice option, many doctors remain reluctant to refer patients to hospice care. To some, it represents giving up.

"Doctors are taught to save people, not to let them die. Putting someone on hospice is a failure to them," said Bilbrey, of Hope Hospice. "But what they don't realize is that all that time the patient spent in the hospital could have been spent with the patient's family, spending some quality time -- letting that person die with dignity."

Lampe, the retired nurse in hospice care, is taking the time to make end-of-life decisions and say goodbye to her two grown children and five grandchildren. In a pinch, she can press a button on her wristband to summon help from Hope Hospice, rather than calling '911' and be taken to an emergency room.

She has certainly seen better days. But given her current options, she can't think of a better way to go.

"I'm totally spoiled," she said. "I love it."

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