Growth in hospice care redefines its role in medicine

By Henry L. Davis
NEWS MEDICAL REPORTER
Sandra Thielke is at a turning point in her life when Dr. Christopher Kerr walks into her room at Hospice Buffalo. She has slept and eaten little, and is sitting exhausted in a big leather chair that envelops her frail body.

He tells her that she made the right decision to come to hospice, that he can help her sleep and ease the terrible pain related to the liver disease that is killing her.

Thielke, her cheeks sunken and hands folded on her lap, musters a faint smile. Joseph Len, her nephew and closest relative, nods in agreement.

“This is the right thing,” he says.

Their meeting on a recent morning resembles many others for Kerr and his colleagues. Nearly 3,900 patients in Erie County alone will receive hospice care this year — at home, in hospital or at Hospice Buffalo’s inpatient unit in Cheektowaga.

More patients are choosing hospice, yet the movement of hospice into the mainstream of medicine remains a work in progress.

The growth of hospice programs and greater spending on them have brought greater government scrutiny. In January, a federal commission recommended changing how hospices are paid amid demands for standards to ensure quality.

Despite the advantages in quality of life for terminally ill patients, most Americans still die in institutions. About 39 percent of patients die under hospice care, and they generally choose it only in the last few weeks of life.

In Buffalo, the trends have prompted new efforts to expand access to palliative care, including a push to attract more minorities.

“Most people say they want to die at home, but they don’t consider what is going to happen to them. The number one complaint we hear from people is that they were left alone with their disease and their families were left with the burden of dealing with it,” said Kerr, medical director at Hospice Buffalo.

The struggles that palliative care doctors face to comfort dying patients and their families are bittersweet. Hospice has become both an emerging success story and a striking symbol of the nation’s confused views about death.

It conflicts with a health system and culture absorbed with maintaining life at all costs, even if a treatment has little chance of success and leaves a patient in agony.

Physicians still fight a stigma about palliative care that what they do is not real doctoring.

This is so, despite advances in managing pain and other symptoms. It, moreover, often falls on hospice to break bad news to patients and families when their doctors don’t.

It’s not easy. Recently at the Cheektowaga site, Dr. Mary Alfano Torres and her team walked out emotionally shaken from a meeting with a family of a patient, a 65-year-old man with stomach cancer.

He had gone through multiple chemotherapy regimens and, after the last of his hospitalizations, was sent home attached to several tubes.

He kept gagging and was in pain. His wife, unsure of who to turn to, called hospice. Now, family members were in a room arguing among themselves and with Torres and her colleagues about what to do.

They had seen him perk up after past attempts at intravenous nutrition and couldn’t understand why it wasn’t working again. They debated whether he should return to the hospital. One of them told Torres that hospice equals death.

“They think he’s going to bounce back, but it’s false hope,” she said.

More than 1.4 million patients used hospice in 2007 at 4,700 programs, up from 215,088 patients in 1993. For-profit hospices make up the fastest-growing slice of the industry.

Medicare pays for hospice if a doctor certifies a patient has six months or less to live, though the time can be extended.

The cost is rising quickly. Medicare, which pays a predetermined amount per patient per day, spent $2.9 billion in 2000 and $10 billion in 2008. The median length of a patient’s stay is about two weeks, but a growing number of patients now stay longer.

Critics say the payment system encourages hospices—particularly for-profits in other states — to target patients who need longer periods of care. Others counter that the payment system, with its cap on total reimbursement for each patient, has not kept up with changes in the industry and limits expansion.

Cancer patients used to account for 95 percent of the patients but now represent 41 percent. More patients have heart failure and other diseases in which death is difficult to predict.

The Medicare Payment Advisory Commission, which advises Congress, wants to change the way hospices are paid to reflect higher costs at the start and end of care. Other proposals attempt to improve quality and financial accountability.

“We need to realign payments to reflect who we are taking care of,” said J. Donald Schumacher, a Buffalo native who heads the National Hospice and Palliative Care Organization.

The palliative care system taking shape provides services where patients need it. Mirroring national trends, two-thirds of Hospice Buffalo patients get their care at home from doctors, nurses and social workers.

Patients must give up curative procedures to receive hospice. But some hospices, including Buffalo’s, allow patients to get aggressive and palliative care at the same time. Insurers also are starting to recognize that palliative medicine can prevent seriously ill patients from going through a revolving door of hospitalizations.

Hospice Buffalo has attracted physicians. They include Dr. Megan Farrell, who gave up an endocrinology practice three years ago to join. She cares for patients in their homes, in Sisters Hospital and in Hospice House, a residence for the terminally ill opened last year in the inner city in collaboration with St. John Baptist Church.

Farrell sees herself making a difference at the most important moment in an individual’s life. “All I do is worry about the person in the bed,” she said on a recent day making the rounds.

At Sisters Hospital, Farrell’s patients included 99-year-old Inez Baumann, who had passed out while at the mall with her granddaughter, Lisa Naylon.

She had a do-not-resuscitate order, a request not to be revived if her heart stopped. But she wasn’t carrying it, so emergency personnel started cardiopulmonary resuscitation, an aggressive procedure that most seriously ill patients don’t survive.

At the hospital, Baumann was placed in restraints to control her agitation and had a urinary catheter inserted. When staff recommended a feeding tube, Naylon asked to see a palliative care doctor.

“This woman is very frail, not eating, confused and fighting for every breath,” said Farrell, who had Baumann moved to a bed devoted to hospice care. “She didn’t want to be revived.”

To Farrell, the case exemplifies how the hospital culture is focused on forestalling death, not on knowing when to stop.
She calmed the patient with medication, a small victory. Six days later Baumann died.

The collaboration with St. John Baptist Church — the first of its kind in the nation — represents a major undertaking to improve access.

Hospice is making progress educating patients about the residence, but the profile of individuals who use it remains mixed.

Thielke, for instance, was transferred there after Kerr saw her. In the next room, throngs of relatives and friends of a dying Hispanic man created an almost celebratory mood with music and conversation as they stopped by to say hello.

A few days after her arrival, her liver failing, the former nurse quietly died. She was 64.

hdavis@buffnews.com

Find this article at:
http://www.buffalonews.com/home/story/592871.html

Check the box to include the list of links referenced in the article.

© 2008 The Buffalo News.