The Effects of the Profit Motive on the Hospice Movement

Will quality of care be compromised?

Hospice has long been regarded as one of the last outposts of altruism in health care. Greed simply seemed incompatible with the work of attending to the gravely ill up to the last moments of their lives. With its roots in mid-20th-century London, the modern hospice movement began in the United States in the 1970s when nurse Florence S. Wald established the first home-care hospice in Connecticut. Early U.S. hospices were run largely as not-for-profits serving patients with cancer. The 1983 enactment of the Medicare hospice benefit meant that Medicare would cover all end-of-life care, at a per-diem rate, for beneficiaries expected to live six months or less if the illness “runs its normal course.”

Now, with about 45% of deaths involving hospice care, most of it covered by Medicare, it’s becoming an increasingly for-profit enterprise. In 2012, 63% of Medicare-certified hospices were for-profit and 32% were not-for-profit (5% were government owned), according to the National Hospice and Palliative Care Organization (NHPCO). And while hospice represents only about 2% of Medicare spending, expenses have risen sharply—Medicare spent $2.9 billion for hospice services in 2000 and $13.8 billion in 2011.

Recent studies and investigative reports have looked into how these shifts toward profit making in the last 10 years have affected the hospice industry.

- A survey of nearly 600 hospices by Aldridge and colleagues, published in the April issue of JAMA Internal Medicine, found that for-profit hospices are less likely than nonprofits to offer training to care providers, to publish research, or to provide charity care, although they are more likely to target low-income and minority communities.
- The profits hospices reaped quintupled between 2002 and 2012, to nearly $2,000 per patient, reported Peter Whoriskey and Dan Keating in a December 26, 2013, Washington Post analysis of over 1 million California patients’ records. Also seen was a 50% increase in patients discharged alive from hospice.
- In 2012, the average lengths of stay were 105 days for for-profit hospices and 69 days for nonprofits, according to a June 19 Huffington Post analysis by Ben Hallman. Also, in 2009, for-profit hospices’ per-patient charges were 29% higher than nonprofits.
- In a study of California data from 2002 through 2004, patients in the two types of hospices received a comparable mean number of nursing visits. But in for-profits only 40% of nursing visits were made by RNs (rather than LPNs or aides), compared with 58% of visits in nonprofits. The study, conducted by Sabina Ohri Gandhi and published in the June 2012 issue of the International Journal of Health Care Finance and Economics,
also found that for-profits were significantly more likely than nonprofits to have “more patients with longer lengths of stay.”

The greatest expenses in hospice care occur at the time of admission and at the very end of life. And because roughly a third of hospice patients die within a week of admission, according to the NHPCO, all hospices must strike a balance among patients served.

Still, these reports raise several questions. Are for-profit hospices cherry-picking from among “low-cost” patients—such as those with dementia who’s most likely to live six months or longer? Also, even though studies have shown that most people are satisfied with the services they receive from hospice, how is the profit motive affecting care quality? And can nurses receive from their employers the training they need to work competently in hospice?

INITIAL TRAINING, ONGOING NURTURING
Melissa D. Aldridge, lead author of the *JAMA Internal Medicine* study and an associate professor in geriatrics and palliative medicine at the Icahn School of Medicine at Mount Sinai in New York City, acknowledged that more data are needed on the differences in outcomes—for providers, patients, and family members—between the two types of hospices. One important finding affecting nurses, she pointed out, is “the substantial difference” in hospices that offer on-site training.

“If only half of for-profit hospices are training sites and more than 80% of nonprofits are, that’s a big difference,” Aldridge said. “For hospice workers, training in the clinical setting is critical. If you have an area with only for-profit hospices, how will the nurses in that area be trained?”

Ruth McCorkle, one of Aldridge’s coauthors, the Florence Schonske Wald professor at the Yale School of Nursing, and a longtime researcher in oncology and palliative care, concurs that a deficiency in training could have serious consequences. If nurses and others on a hospice care team are inadequately prepared, not only does the patient suffer, but the staff suffers, as well, she said. And what “training” consists of may be a more complex issue than it appears.

“Even for those with training, the caseloads can be so heavy they don’t have time to debrief about their experiences. Just think about the intimacy they experience with a patient. You need to tell somebody about that. It affects you. It’s not just the initial training but the ongoing nurturing that helps you to learn from your experiences,” McCorkle said.

PREDICTING DEATH IS NOT AN EXACT SCIENCE
Health care is no stranger to controversies over runaway costs and exorbitant profits. Home care, for example, transitioned from a largely charitable, government-sponsored effort to a vast, profit-making venture when changes to Medicare and Medicaid payment systems in the 1980s led to earlier hospital discharges and more patients receiving treatment at home. This made home care more widely available but also boosted profits and intensified fraud. The Balanced Budget Act of 1997 sought to rein in the excesses, limiting the costs of home care provided to each patient and at each visit.

Linda M. Gorman, a palliative care clinical nurse specialist in Los Angeles and a blogger for The Onc, an online community for oncology nurses, said in a recent interview that while it may appear that some hospices seek to profit by admitting patients who don’t meet criteria, determining eligibility is not an exact science.

“In the old model, cancer patients made up the majority of the hospice population, and if you had stage IV cancer, you would die in six months,” Gorman said. “Now, the majority of hospice patients have dementia, frailty, heart failure, and that’s much less predictable. Someone with one of these conditions who gets a [urinary tract infection] can deteriorate really quickly if it’s not treated, or they can come back and live two years. It’s harder now to select appropriate patients, and that accounts for some of the growth in hospice.”

Nor is it clear-cut how profit seeking affects quality. LPNs and nurses’ aides can provide “outstanding” care in hospice, Gorman said, but a patient’s clinical condition can change rapidly, requiring sharp clinical assessment and independent action—expertise RNs can provide.

“People might think you don’t need a lot of skills to work in hospice, but you do,” Gorman said, emphasizing that in end-of-life care many situations can’t be anticipated. “How aggressive will you be if there’s an infection? You’re in the home and the family panics and wants you to do something different from what was agreed on. It can be very intense.” Gorman advises any nurse considering work at a particular hospice, regardless of whether it’s for-profit or nonprofit, to ask about staffing ratios, quality data, charity care, and team-based planning.

Florence S. Wald, who died in 2008, wrote in *AJN* in October 1979 about the challenges in providing hospice care. In words that might have been written today, Wald acknowledged the drawbacks to the overwhelming interest in end-of-life care. “The hospice movement began at a reasonable pace but may have grown too rapidly,” she wrote. “Yet reform needs time to take root and flourish. Any institution needs independence and careful thought to establish its goals.”—Joy Jacobson ▼