



FLORIDA HOSPICES AND PALLIATIVE CARE

THE HOSPICE E-NEWS

WEEK OF JULY 31, 2007

CHOOSING HOSPICE OFTEN MEANS “LETTING GO OF THE ROPE”

The current *NEJM's* “Letting Go of the Rope – Aggressive Treatment, Hospice Care, and Open Access” says, “More Americans are choosing hospice for end-of-life care, but ironically, hospice patients increasingly are forced to give up effective palliative treatments along with aggressive medical intervention.” The article uses the example of Joanne Doolin, who had to choose between hospice and continuing total parenteral nutritional support, because she could no longer eat but wanted to live until her daughter’s wedding.

Authors Doctors Alexi A. Wright and Ingrid T. Katz say that in Doolin’s case, and in many others, cost is the limiting factor. Small hospices “cannot negotiate pricing or spread the cost of expensive medications across many patients,” and the \$10,000 per month cost of many palliative therapies (such as oral chemotherapy, blood transfusions and radiation) are “too much for most hospice programs.”

Patients may also feel that hospice does not offer enough medical services. One cancer patient said, “It felt like I was trading in the Lamborghini of medical care for an old pick-up truck driving down a rutted road.” The authors write, “Optimal end-of-life support often necessitates careful titration of opioid, antipsychotic, and anxiolytic drugs, which can sometimes require a doctor's presence. But few patients ever meet a physician after enrolling for hospice care; there are no rules mandating the degree of physician involvement. Medicare does not even collect information on the number, frequency, or duration of visits or on which personnel provide which aspects of care. Each hospice program decides what services to offer, and family members often must fill in the gaps.”

Physicians also dislike the “disconnect between pre-hospice and hospice.” Dr. Thomas Smith, of Virginia Commonwealth University’s Massey Cancer Center, says the Medicare hospice benefit “is so restrictive that it requires divorcing yourself from your patient's care because you can't be their cancer doctor anymore. As soon as you enroll in hospice, there goes your Aranesp, your Zometa, and your Zofran. . . . I can't do anything but adjust pain meds and hold hands. These are wonderful things to do, but they won't keep my office running.” On the other side, however, the article says, “Many hospice directors counter that oncologists abandon their patients when they can no longer visit the office.”

The open-access programs offered by some large hospices and insurance companies try to address the problem of choosing either hospice or curative care. Washington’s Capital Hospice president and CEO, Malene Davis, says that the usual way of doing business is to offer two ropes. One “rope” is aggressive treatment, which patients are asked to hold onto with both hands until they’re willing to move to hospice. At that time, they grab the hospice rope. Open access, she says, “gives people the choice to let go of active treatment with one hand and grab on to the hospice rope until they feel comfortable letting the other hand go.” But only the large hospices can offer such

services, and CMS says that only 2.5% of the 4,100 hospices in this country have an average daily census large enough (over 400 patients) to support such services.

Some worry that offering open access “may be prohibitively expensive.” In fact, “The only randomized trial to date examining standard cancer care both with and without hospice support showed no significant difference in survival rates, but it did show significant improvements in quality of life when cancer care and hospice care were combined. Preliminary analysis revealed a 27% cost reduction in the combined-care group, which received less chemotherapy and diagnostic testing and required fewer hospitalizations.” But CMS expects hospice spending to rise 9% annually in the next 10 years, “which will outpace increases for hospitals, physicians, skilled nursing facilities, and home health services.”

A related article in *The Birmingham News* interviewed Dr. F. Amos Bailey, director of palliative care at Birmingham Medical Center. Bailey cites the cost of palliative chemotherapy and radiation as major barriers to hospices offering such services. Bailey says there’s no way hospices can routinely provide drugs that cost thousands of dollars a month above their average reimbursement costs of \$3,000 per month.

Bailey also spoke of the difficulty of adequately controlling pain in terminal cancer patients. He asserts that 95% of people could have adequate pain control with oral pain medications, but he says that there are systemic barriers to such control. One is the prescription process itself. Pain prescriptions can only be written for one month at a time and cannot be refilled, necessitating another visit to the doctor’s office. If the pain level changes and the patient uses more medication, then it runs out before the end of the month. Bailey says, “There are regulatory issues and education issues among physicians that make it such that we don’t usually reach that 95 percent of effective pain control.”

Bailey sees pain control as a major benefit of switching to hospice. “So one of the things that hospice does is it helps people work through those regulatory issues. So they’re less likely to have their pain medication run out, that they get their pain medication escalated when they need to,” he said. (*NEJM*, 2007; 357:324-327; *Forbes.com*, 7/25; *The Birmingham News*, 7/23)

HOSPICE “STILL MISUNDERSTOOD” DESPITE INCREASED USE

“Understanding Hospice – An Underutilized Option for Life’s Final Chapter,” by Dr. Gail Gazelle, appears as a “free full text” article in the current *NEJM*. Gazelle says that increasing patient enrollment and Medicare hospice expenses mean that hospice is now seen as part of mainstream medicine. In spite of this, “many aspects of hospice care are still misunderstood by both physicians and patients,” she writes.

One area of misunderstanding cited in the article is the fact that many do not consider non-cancer diagnoses eligible for hospice care. Actually, cancer accounts for just under half the admitting diagnoses and 40% of the others are for end-stage cardiac disease and dementia, debility, COPD and stroke.

A second cause for misunderstanding is that many patients and physicians do not realize that Medicare hospice home care is free for almost all care relating to the terminal diagnosis. Only care related to other conditions is still the responsibility of the patient or other insurance company.

In spite of surveys that show extremely high (98%) family satisfaction with hospice and of “the general understanding by clinicians that at least 6 months of care are provided,” one-third of patients are not referred until the last week of life, and the median length of stay is 26 days.

The main reason for this, Gazelle says, is physician attitudes. “In its first position paper on the topic of cancer and dying, the American Society of Clinical Oncology acknowledged that many oncologists and other physicians regard the death of a patient as a professional failure. Many also fear that they will destroy their patients’ hope, which physicians may believe lies only in efforts to increase the quantity rather than quality of life. Furthermore, physicians receive little training in the compassionate discussion of bad news. But perhaps the most critical factor is that physicians view hospice care as something reserved for the imminently dying instead of as a service designed to help people live as well as possible in the face of advanced incurable disease.”

Gazelle cites “one serious challenge” in hospice care: “Attending physicians typically receive little to no training in the use of medications for pain and symptom management and thus rely on a presumed level of expertise on the part of the hospice nurse. Given the current nursing shortage, however, such an assumption of competency may or may not be well founded. Attending physicians should routinely evaluate recommendations and should have a low threshold for reviewing cases with the hospice medical director.”

Gazelle concludes by saying, “With the growing number of baby boomers seeking more control over all aspects of their health care, the use of hospice care will probably continue to increase. It is especially important, therefore, that physicians become more familiar with what hospice care offers and work to overcome barriers in talking frankly with patients about what lies ahead.”

Sidebars to the article include data on the increase in the use of the Medicare Hospice Benefit between 2000-2004 and Medicare hospice eligibility guidelines for several of the most common diagnoses. Accompanying the article is an audio interview, also free, with Dr. Timothy Quill, in which he distinguishes between hospice as provided by the Medicare hospice benefit and open access hospice. He also discusses patient and physician attitudes toward hospice. See content.nejm.org for both items. (*NEJM*, 2007;357:4)

PUBLIC POLICY NOTES

* Under its new medical marijuana law, New Mexico has cleared six patients, out of 22 who have applied, to use the drug. Health Secretary Alfredo Vigil said, however, that the portion of the law regarding state supervision and licensing of marijuana production and distribution remains unresolved. Vigil's agency has asked the state attorney general "whether employees can legally license production and distribution of marijuana and remain in compliance with federal law, which outlaws the drug's possession and distribution." (*Albuquerque Journal*, 7/20; *AP*, 7/21)

* *Modern Healthcare* notes that the IRS released an interim report on a 2006 survey of how tax-exempt hospitals provide and report community benefits found they "are all over the map with no uniform definition of what constitutes 'uncompensated care,' among other things." Senator Chuck Grassley (R-Iowa) also released a "discussion draft of possible reforms to ensure that hospitals provide an adequate level of charitable care and community benefit to justify their tax-free status." The draft "suggests a threshold test requiring a hospital to dedicate at least 5% of its annual net patient revenue to charity care to guarantee its tax-exempt status." (*Modern Healthcare*, 7/23; *Philanthropy News Digest*, 7/23)

HOSPICE NOTES

* Phoenix Rising, a summer camp offered by the Hospice of the Chesapeake, helps teenagers deal with the grief of losing a loved one. Instead of the typical camp activities, the campers focus on trust-building exercises, learning about grief, and sharing their feelings about death with others who've had the same experience. Camp director Karen Frank says that teens have difficulty dealing with grief. "Everything with teenagers is about trying to fit in with their peers, and then something like this happens and it makes them feel so different," Frank says. For the article, search for "bond of bereavement," with the quotes, at www.washingtonpost.com. (*The Washington Post*, 7/28)

* Oscar, a cat owned by Steere House Nursing and Rehabilitation Center in Providence, Rhode Island, is very good at predicting patients' deaths. A *NEJM* article says, "His mere presence at the bedside is viewed by physicians and nursing home staff as an almost absolute indicator of impending death, allowing staff members to adequately notify families." Oscar ignores almost everyone except the dying, but when he curls up next to a patient, the staff realizes that person's end is near. For his service, a plaque on the wall from a local hospice reads: "For his compassionate hospice care, this plaque is awarded to Oscar the Cat." *The Washington Post* has posted the transcript of an online conversation with Dr. David M. Dosa, who suggests that Oscar may be responding to odors emitted by the dying patients that humans can't smell. (*NEJM*, 2007;357:328-329; *The Washington Post*, 7/27)

OTHER NOTES

* An article on the importance of advance care planning in *EastBayRI.com* notes that the Heart Failure Society of America (HFSA) has assembled a booklet to guide families through the process. HFSA has produced a number of resources, all available to be ordered from www.abouthf.org. (*EastBayRI.com*, 7/25)

* “Cancer Patients, Lost in a Maze of Uneven Care,” and “Doing Battle With the Insurance Company in a Fight to Stay Alive,” in *The New York Times*, illustrate many of the problems faced by patients when they are diagnosed with cancer. The articles are in a series on the six leading causes of illness and death in the US today – heart disease, cancer, stroke, COPD, diabetes and Alzheimer’s disease. Links to the already-published articles in the series can be found by searching for “six killers” at www.nytimes.com. (*The New York Times*, 7/29)

* Dr. Jonathan Fine, a retired Boston physician, realized, “Communication between doctor and patient is often the first casualty of a major illness.” He founded Bedside Advocates, which uses volunteers to guide patients through “the confusing terrain of the healthcare system.” Accountability for how well physicians communicate with patients is on the way. CMS will post the results of its patient satisfaction survey (Hospital Consumer Assessment of Health Providers and Systems) next year and hospitals must begin collecting data this summer or lose CMS funding. (*USA Today*, 7/25)

* The new Sheri & Les Biller Patient and Family Resource Center, at California’s City of Hope, focuses on helping patients “benefit from treatment psychologically, socially, and spiritually.” Patient navigators are personal guides for patients and families and make sure they are informed about and guided through the resources and social supports the Center offers. Administrative Director Matthew Loscalzo says, “One of the most common problems with cancer patients is how to make wise and informed decisions about medical care. We help them get information.” (*San Gabriel Valley Tribune*, 7/22)

Correction: Last week’s note about the fines and community service sentences of three top Purdue Pharma executives failed to report that the company and the executives were fined \$634.5 million “for misleading the public about the painkiller’s [OxyContin] risk of addiction.” (*AP*, 7/21)

Thanks to Don Pendley and Kathy McMahon for contributions.

Glatfelter Insurance Group is the national sponsor of Hospice News Network for 2007. Glatfelter Insurance Group provides property and liability insurance for hospices and home healthcare agencies through their Hospice and Community Care Insurance Services division. Ask your insurance agent to visit their website at www.bccis.com.