WHAT DO MEDICAL MIRACLES AT END OF LIFE COST?

In the second of a five-part series, *Kaiser Health News* looks at the high cost of end-of-life care. The article, “What Price for Medical Miracles? High Costs at End of Life Still Part of National Health Debate,” concedes that heroic treatments sometimes work – “miracles” do seemingly occur. But, author David Ewing Duncan says, “Aiming for miracles … can lead to debilitating therapies that continue after there is no hope; to dying patients being hooked up to feeding tubes and to ventilators; and to agonizing surgeries that cannot save them.”

Advances in health care mean that more people are now employed in the health care industry than in manufacturing, and more than twice those employed in the computer, mathematics, and engineering fields. Health care in the US this year will cost $9,000 per person, for a total of $2.7 trillion. Medicare and Medicaid will soak up $763 billion, eight times more than federal education spending.

Duncan says that American civilization may be remembered for the “extraordinary effort and investment” that goes into keeping us “alive and well,” but two realities stand in the way. One is the inevitability of death, unless a few futurists are right and death can ultimately be defeated. The second is the “extraordinary cost” of an experiment that yields “increasingly marginal benefits in terms of outcomes and quality of life as death approaches.”

According to Duncan, some medical advances “saved millions of lives and transformed society,” such as the advent of penicillin. One of our latest advances, Avastin, cuts off the blood supply of some tumors and extends some cancer patients’ lifespans by two months, and costs $55,000 per year. The American “way” is to give Avastin to everyone who might be helped by it, but that philosophy has led us to spend two to three times as much on healthcare as most other industrialized countries.

That outlay has not drastically improved health in this country. US mortality rates for cancer and stroke are only slightly better than other industrialized nations, and are near bottom for diabetes and infant mortality. We’re 23rd out of 27 in life expectancy. Our large immigrant populations and groups who lack health insurance affect those numbers, but they “make it hard to argue, as some do, that by spending substantially more on health care the U.S. has achieved significantly better results.”

Duncan discusses the recent Dartmouth study that found that health care costs more where more health care is provided, and the more recent insistence by UCLA that its “high-intensive, and more costly” health care is affected by its large population of very poor and
very sick patients. An American Heart Association study of six California hospitals found the cost of care for heart failure to be less than suggested by the Dartmouth study.

Dartmouth’s Elliott Fisher, one of the lead investigators on the Dartmouth study, said, “Sometimes more medical care is better, but the question is when.” Fisher “admitted that the California study did a better job of identifying patients who would benefit from more intensive care.”

The article concludes by saying, “Finding the right balance between too much and too little care is excruciating and highly personal for physicians, patients and families—which is one reason that we don’t talk about this at a national level. This reluctance is mirrored by a political reluctance to have a meaningful debate among our elected leaders.” (Kaiser Health News, 3/9, www.kaiserhealthnews.org/Stories/2010/March/09/fiscal-times-end-of-life.aspx)

RESEARCH & RESOURCE NOTES


* The Texas Pain Advocacy and Information Network, in collaboration with the Nurse Oncology Education Program, is offering a free CNE resource where nurses in any state can take CNE programs online. Programs offered include “Nursing Principles of Pain Management,” and a four-part series, “Every Nurse’s Guide to Pain Management.” The four sections of the Nurse’s Guide are “Introduction to Pain Management & Nursing Assessment,” “Pharmacologic and Nonpharmacologic Management of Pain,” “Pain Management for Culturally Diverse, Elderly and Substance Abuse Populations,” and “Pain Management at the End of Life & Ethics.” (Nurse Oncology Education Program Website, www.noetexas.org)

* The Hospice Foundation of America’s Annual National Teleconference, on Cancer and End-of-Life Care, will be held on March 24. The conference will deal with care options related to cancer, loss and grief, psychosocial aspects of cancer, pain management, and ethical issues. Information is available at the HFA website. (Hospice Foundation of America Website, www.hospicefoundation.org)

* Researchers from Mt. Sinai School of Medicine have found that most hospices do not ask patients if they have a defibrillator implanted, and only 10% discussed deactivating the device. According to the article, NHPCO “recommends identifying every individual with a defibrillator who is seeking hospice care and discussing the option of deactivating the device.” (McKnight’s Long-Term Care News, 3/8, www.mcknights.com/defibrillator-implants-often-overlooked-in-hospice-end-of-life-care/article/165220/)

* Larry Beresford, author of The Hospice Handbook, writes an occasional blog on hospice topics at growthhouse.typepad.com. Growth House advertises itself as “the Internet’s leading portal for information about end-of-life care.” The website, at www.growthhouse.org, “gives you free access to over 4,000 pages of high-quality education materials about end-of-life care,
palliative medicine, and hospice care, including the full text of several books,” and provides
education both for healthcare professionals and the general public. Several of his recent posts
discuss whether hospice enrollments are declining, palliative care grand rounds, AIDS and end-of-
life care, hospice and health reform, and others. (Larry Beresford Blog, growthhouse.typepad.com/larry_beresford/)

* “Difficult Questions for Pediatric Palliative Care Providers,” in a recent Journal of Palliative Medicine, explores the reluctance of both parents and healthcare providers to recognize when the time has come for aggressive treatment of children to stop, and for the child to be allowed to die in peace. Author Amy L. Getter, of the Hospice of Kitsap County, acknowledges the impossibility of imagining signing a DNR order for your child. She asks, however, “Shouldn’t it be more impossible to shove a tube down their throat, continue the thousands of needle pricks, and inject multiple doses of toxic chemicals in the hope that those final days can be prolonged?” (Journal of Palliative Medicine, 2010;13(3):239:240, dx.doi.org/10.1089/jpm.2009.0332)

PUBLIC POLICY NOTES

* The Idaho House State Affairs Committee recently passed the Health Freedom of Conscience bill, which allows “all Idaho health care professionals to ignore end of life care and treatment at any time they feel it violates their ‘conscience.’” The press release says, “The bill’s vague language will mean any end of life service could be denied, irregardless of the patient’s living will and advance directives, which provide instructions for exactly how to address end of life care issues.” The bill has already passed the Senate, and now goes to the full House for a vote. (PR Newswire, 3/11)

* A Missouri state representative, Cynthia Davis (R), has sponsored a bill requiring mandatory feeding tubes for terminally ill patients who have said that they don’t want them. The tubes would remain in place for 60 days. Nurses would have to put food and water in the patient’s mouth three times a day, and if the patient swallowed, reflexively or on purpose, the tube would remain in place indefinitely. Davis’s position is in contrast to her statement last summer that federally funded programs that feed poor children are an excuse “to create an expansion of a government program.” (St. Louis Post-Dispatch, 3/7, http://www.stltoday.com/stltoday/news/stories.nsf/editorialcommentary/story/073BB7E6E3CCDEC3862576DE0003EAD6?OpenDocument)

* Sheldon Smith isn’t afraid of dying, and after being diagnosed with Stage 4 abdominal cancer, he and his wife threw a backyard picnic that Smith considered “an alternative to a funeral.” But he does worry about pain, and he wants a lethal prescription that he can use to end his own life. Smith said, “I don’t think of it as suicide because I’m dying anyway.” There is now a case before the Connecticut Superior Court in which two doctors “have asked the court to interpret a statute that outlawed helping another person commit suicide.” The court has been asked “to declare that the law would not apply to a doctor who provides ‘aid in dying’ to a mentally competent, terminally ill patient facing a dying process that the patient finds unbearable, because it is not suicide.” (Hartford Courant, 3/7, www.courant.com/health/hc-doctor-assisted-suicide-0306.artmar07,0,5694973.story)
END-OF-LIFE NOTES

* An article by Barbara Coombs Lee, of Compassion and Choices, encourages readers to find doctors who “put the ‘care’ in healthcare.” She, and Compassion and Choices, suggest interviewing your doctor about what he or she would do if you wanted to forego heroic treatment for a terminal disease, how the doctor would handle a situation such as the family squabbling over Terri Schiavo, and whether enough pain medication would be prescribed to keep you comfortable even if it shortened your life. (The Huffington Post, 3/11, www.huffingtonpost.com/barbara-coombs-lee/find-yourself-a-good-doctor_b_495783.html)

* In West Virginia, The Journal recently published an article by Kathie Campbell of Hospice of the Panhandle and the West Virginia Center for End-of-Life Care. Campbell says that she used to blame doctors when patients were kept alive for months with aggressive care that was obviously futile, but has come to see that each person has the responsibility to determine what kind of care he or she would want at the end of life. The article suggests a number of questions for patients and families to discuss with doctors, and recommends that the discussion take place before a crisis occurs, if at all possible. (The Journal, 3/8, www.journal-news.net/page/content.detail/id/532920.html)

OTHER NOTES

* In “Shock Me, Tube Me, Line Me,” ER physician Bruce Veysman tells the story of resuscitating an elderly patient brought into the ER, only to find that the patient is in the last stages of cancer and has both DNR and DNI (do not intubate) orders. Veysman argues against DNR and DNI orders, saying, “Even severe incurable illness can often be temporarily fixed, moderated, or controlled, and most discomfort can be made tolerable or even pleasant with simple drugs. … It’s so easy to let someone die, but it takes effort, determination, and stamina to help someone stay and feel alive. Only after you made every effort to let me be happy and human, ask me again if my life is worth living. Then, listen, and comply.” (Health Affairs, 2/2010, content.healthaffairs.org/cgi/reprint/29/2/324)

* Country music singers Randy Travis and Collin Raye will headline an April 11 concert in Indianapolis commemorating the 5th anniversary of Terri Schiavo’s death. The goal of the concert, sponsored by the Terri Schindler Schiavo Foundation, is to encourage families going through similar situations as the Schindlers, Schiavo’s brother Bobby said. (CNS News, 3/9, www.cnsnews.com/news/article/62460)

* There for a while, Sandy McBride thought it was going to cost her an extra $179 to die. That's the early termination fee that Verizon was going to charge her to cancel her phone, cable and Internet service. Even when she explained that she was dying and going into hospice, two different customer service representatives insisted that the company would stick by its policy. Fortunately, a friend reached Verizon’s customer care czar, who said that when the bill is sent, a credit will cover the fee. The czar suggested that customers facing similar situations “escalate” their issues to be sure they get the proper handling. (The Oregonian, 3/7, blog.oregonlive.com/complaintdesk/2010/03/orregon_case_adds_to_debate_ove.html)

* An article in the Estes Park Trail Gazette profiles the work of Rebecca Hazlitt, music thanatologist. Hazlitt is a graduate of the Chalice of Repose Project School of Music Thanatology
in Missoula, Montana. According to the article, there are two kinds of visits from music thanatologists – processing ones, where a patient has just received a terminal diagnosis and is assisted in processing their feelings, and imminent vigils, where the patient is actively dying. *(Estes Park Trail Gazette, 3/9, www.eptrail.com/ci_14641088)*

* **The Seattle Times** recently looked at the terminally-ill patients who wanted to use Washington’s Death With Dignity law, but were unable to for various reasons. Some did not realize that the process took time, and got started too late. Others mistook an assurance from their doctor that their pain would be managed for agreement to prescribe lethal medication, when the doctor did not agree to that. Others had difficulty finding two physicians who could agree that they were terminal and on the amount of time they had left. **Compassion and Choices of Washington estimates that half the patients who came to them for help came too late.** *(The Seattle Times, 3/6, seattletimes.nwsource.com/html/localnews/2011277544_deathdignity07m.html)*

* Susie Mann was determined to live life to the fullest after a diagnosis of cancer. In the process, she became known as “the daredevil granny.” With children, grandchildren and friends in tow, she planned a big event every four to six weeks, including hang gliding, sky diving, swimming with dolphins, a helicopter ride over the Grand Canyon, and several others. After her death, her daughter wrote on Susie’s website, “So, at 6:15 p.m. 2/15/10; without fanfare and with so much grace ... Sewall Boardman Weeks Weadock Mann set out on a new adventure taking her last leap without a kite or a parachute.” *(The Baltimore Sun, 2/28, www.baltimoresun.com/news/maryland/baltimore-county/bal-md.ob.co.mann28feb28.0,4757891.story)*

* **The Muskegon News** recently featured the work of Parents with Angels, a grief support group for parents who have lost children. Bill and Pam Montambo began the group when their 19-year-old son, Keith, died of a drug overdose, and others gradually came to join with them. One of the members, Pat Bray, lost her only son in 1999, and in 2008, her grandson. She and her daughter share an unusual understanding – both have lost only sons, both have two remaining daughters. Bray’s daughter, Jennifer Porter, says, “I’ll start to say, you wouldn’t understand ... you wouldn’t believe how I feel, what I thought, what I did ... but, she does. My mom does.” *(Muskegon News, 3/7, www.mlive.com/news/muskegon/index.ssf/2010/03/a_grief_like_no_other_is_sooth.html)*

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