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# HOSPICE NEWS NETWORK

*What the Media Said about End-of-Life Care This Week*

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## PATIENTS' UNDERSTANDING OF ILLNESS INFORMS THEIR CHOICES ABOUT TREATMENT

**“End-of-Life Care: The Last Chapter,” in *The Los Angeles Times*, says that informed choice on the part of patients can “help ease emotional and financial strains.”** Rosemary Gibson, who worked on improving healthcare quality at the Robert Wood Johnson Foundation, says, **“Generally speaking, when patients are given their treatment options and the risks and benefits of each, they tend to choose, the research has shown, less intensive and less costly approaches to care.”**

Dr. Holly Prigerson, one of the authors of an end-of-life care study published last year in the *Archives of Internal Medicine*, says, “People may not realize what their healthcare dollar buys them at the end of life. We found that as the costs of care increase dramatically as death approaches, so too does the patient’s emotional and physical suffering.” **Prigerson adds that people who die in hospice get less aggressive care, have a better quality of life, and there is no difference in survival. Additionally, the bereaved family members are better off emotionally six months after the death.**

**Prigerson also says that people may not understand the practical effects of their choices, unless those are explained to them.** They may not realize that a person on a ventilator cannot speak. **In her experience, once the details of some procedures are explained, many patients choose a different path.**

**CMS estimates that 5% of the Medicare beneficiaries who die each year use 30% of Medicare’s \$446 billion budget. Eighty percent of that is spent during the last month of life, “on mechanical ventilators, resuscitation and other aggressive life-sustaining care.” That aggressive care is often futile, the article says.** The author cites a 2009 study that found that only 18% of adults over 65 who got CPR in the hospital survived to discharge. In some cases, CPR only prolonged the patients’ suffering.

**Dr. Sean Morrison**, director of the National Palliative Care Research Center at New York’s Mt. Sinai School of Medicine, says, **“If you sit down with patients and families in the setting of serious illness, and talk to them about their goals of care, talk realistically about what modern medicine can achieve and what it can’t, and then match treatments to those goals, you save money.”** The article cites a 2008 study that found that palliative care saved about \$1,700 per patient for those discharged alive, and almost \$5,000 per patient for those who died in the hospital. Much of the savings occurred in reduced pharmacy, lab and ICU costs.

Morrison, as well as other experts, say, **“Focusing so intently on end-of-life costs won’t fix what ails our healthcare system.”** Morrison adds, “We don’t want to save on the backs of the dying. The larger issue is cost associated with people living with serious illness.”

**The healthcare reform bills now before Congress provide for demonstration projects to see if costs can be reduced and the quality of healthcare improved for terminally ill Medicare recipients.** One project would allow Medicare hospice patients to continue receiving all services they were eligible for before enrolling in hospice. Others are aimed at improving communication among clinicians and providers.

Peter Notarstefano, of the American Association of Homes and Services for the Aging, says, **“Congress is saying we have to break down the silos and the mind-set of ‘this provider does this and that provider does that.’ It’s losing the fee-for-service mentality and recognizing that we need to learn how to best treat people at the end of their life.”** (*The Los Angeles Times*, 1/25)

## **ARTICLE EXAMINES DECISIONS RELATED TO WITHHOLDING INFORMATION FROM PATIENTS**

**“Withholding Information From Patients: When Less is More,”** in the current *NEJM*, examines the circumstances in which physicians consciously or unconsciously hold back information from patients about **“their conditions, treatments, and outcomes.”**

Authors Ronald M. Epstein, MD, David N. Korones, M., and Timothy E. Quill, MD, say that the principle of autonomy suggests that **“patients should always be fully informed, not only so that they can make the best possible decisions, but also because information helps them to make sense of and cope with illness.”** That information, however, sometimes increases the **“cognitive and emotional burden”** on the patient, and leads to **“greater confusion rather than clarity.”** Therefore, they say, **“The right to autonomy must be balanced with the ethical obligations to do good for patients (beneficence) and not to harm them (nonmaleficence).”**

The article briefly cites that the clear cases for withholding information include when the patient is not competent so the information is given to a surrogate, medical treatment is so urgently needed there is not time to explain, or the patient chooses not to know, so again the surrogate is informed.

When the cases fall into a **“gray zone ... choices about providing or withholding information should be made in such a way as to maximize benefit and minimize psychological and cognitive and emotional burdens.”** The article suggests that physicians weigh instrumental benefits (help in decision-making, or in obtaining resources), and emotional and relational benefits.

Consideration of the burdens of information is **“more complex.”** When patients and family are under stress, too much information **“may impair rather than facilitate understanding and decision making.”** For instance, listing all possible, but improbable, side effects of a treatment can distract both patient and physician and **“obscure more relevant information.”** Discussion of a benign incidental finding, such as a cyst unrelated to the patient’s terminal illness, **“can derail exploration of the complexities of a serious illness and the relevant treatment options.”**

The authors add, **“Providing every detail of clinical information also takes time and may crowd out more important discussions.** Time taken to explain to a hospice patient that she now has five rather than three pulmonary metastases might be better used to discuss how to relieve her symptoms or how her family is coping.” **Clinicians should determine whether information will “enhance or reduce patients’ autonomy.”**

**“Patients’ ability to acquire and use information and fully participate in their care does not depend solely on how much information they receive — it also depends on the nature of their relationships with their clinicians, their families, and others. If patients distrust their physicians, they tend to seek more information. If patients are left alone to sort out complex information, they may feel abandoned and less able to exercise control.** The ideal goal may be ‘autonomy-in-relation,’ which entails collaboration among patients, their loved ones, and clinicians in seeking, interpreting, contextualizing, and acting on information.”

The authors caution physicians against bias, conscious or unconscious, in judging whether to withhold clinical information. Pressures of time and financial incentives may discourage conversations about treatments. If patients or families are potentially contentious, physicians may omit mentioning some “controversial aspects of care.” Clinician decisions about providing information require “self-awareness and honesty.”

In conclusion, the authors say, **“We propose some simple rules: If the patient asks, the clinician should tell. If the clinician is anxious about what would happen if a patient discovers that information has been withheld, then the decision to withhold should be reconsidered. Clinicians should scrutinize their tacit judgments** by routinely asking themselves questions such as ‘What would a trusted peer say?’ ‘Am I feeling uncomfortable?’ or ‘Am I assuming that the patient’s values are the same as mine?’ **Clinicians should overcome potential biases by getting to know each patient as an individual. And, when uncertain, clinicians should discuss the decision to withhold information with a trusted member of the patient’s inner circle, experienced colleagues, or both.”** (*NEJM*, 2010;362:380-381)

## RESEARCH & RESOURCE NOTES

\* A study from the University of Colorado has found that **“informal caregivers of hospice patients have support needs that are amenable to telephone-based counseling designed to be complementary to existing hospice services.”** A pilot program has been established to test a **“telephone-based cognitive-behavioral stress management program for informal caregivers.”** A “pervasive theme” of the study of 36 caregivers and 11 hospice staff members was that **“there can never be enough support for a caregiver.”** (*Journal of Palliative Medicine*, 2010;12(12):1101-1104)

\* **The free full text of “Willful Modulation of Brain Activity in Disorders of Consciousness” is online at [NEJM](#).** The results of the functional MRI study showed that **“a small proportion of patients in a vegetative or minimally conscious state have brain activation reflecting some awareness and cognition.”** The technique of using MRI to measure the brain location of specific visual imagery may ultimately result in reclassifying the state of consciousness of some patients, and perhaps lead to establishing basic communication with patients who appear unresponsive. The results of the study, from the abstract, say that **“a small proportion of patients in a vegetative or**

minimally conscious state have brain activation reflecting some awareness and cognition. Careful clinical examination will result in reclassification of the state of consciousness in some of these patients. This technique may be useful in establishing basic communication with patients who appear to be unresponsive.”

(*NEJM*, 2010)

## PUBLIC POLICY NOTES

\* In an editorial, [The New York Times](#) says the failure of the legislature to pass the Family Health Care Decisions Act, which would allow family members to make decisions for loved ones who are incapacitated, is “a concrete measure of how New Yorkers are hurt by Albany’s chronic dysfunction.” The law was “first proposed 18 years and three governors ago by a nonpartisan commission,” and was intended to rectify situations that typically prevent family members from even reviewing medical records or enrolling their loved ones in hospice. The Assembly has passed the bill, which is now before the Senate Codes Committee, which is expected to approve it this week. (*The New York Times*, 2/4)

\* **The Arizona legislature has cut some care options for some patients with terminal illnesses, and hospices may have to repay the state for service already provided.** The issue stems from a one-year appropriation in 2007 that matched federal funds for hospice that was not renewed in 2008. A spokesman for the Arizona Health Care Cost Containment System said that the end of the legislative session was a “confusing time” because of the state budget crisis, and that AHCCCS was not able to provide notification “as soon as we would have like to.” ([Arizona Daily Star](#), 2/1)

## HOSPICE & PALLIATIVE CARE NOTES

\* **CMS has issued CR6791, requiring hospice providers to “report separate line items for the level of care each time the level of care changes.”** Under the current system, if a hospice patient has different levels of a care in a particular month, the claim is not always clear about which calls and visits are associated with which level of care. Information about [MM6440](#) and [CR6791](#) can be downloaded from the CMS website. (*NHPCO NewsAlert*, 2/3; *CMS Medicare Learning Network Website*)

\* **As the Institute for Palliative Medicine at San Diego Hospice marked its 20<sup>th</sup> anniversary recently, one of its physicians, Jeff Stoneberg, received the first ever Hastings Center Cunniff-Dixon Physician Award.** Stoneberg was recognized “for bringing some fundamentals of hospice care ... to a hospital that seeks to cure people.” (*KPBS Website*, 2/1)

\* **Nurses who work with Florida’s Partners in Care: Together for Kids (PIC:TFK) pediatric palliative care program, as well as those who do not, referred children for needed palliative care services, but those who worked with PIC:TFK were far more likely to refer children before the end of life than nurses who did not work with the program.** The authors suggest that expanding nurse training “will be essential for equitable and appropriate referrals across a diverse set of illnesses.” (*Journal of Palliative Medicine*, 2009;12(12):1131-1136; [The Institute for Child Health Policy Website](#))

\* **The founder of one of the first children's palliative care programs in the US, Dr. Burton Grebin, has died.** [\*The Wall Street Journal\*](#) article says Dr. Grebin “transformed a 40-bed children's hospital in Queens, N.Y., into one of the largest providers of care for special-needs pediatric patients, including those with AIDS, head traumas and eating disorders.” St. Mary's Healthcare System for Children, which included a children's hospice, served more than 4,000 children daily, and “became a model for integrated pediatric programs that include treatment for a wide variety of chronic or terminal illnesses.” (*The Wall Street Journal*, 2/4)

## OTHER NOTES

\* **The FDA has approved morphine sulfate for oral administration for the relief of acute and chronic pain. The drug is available in a 20 mg/ml concentration.** The press release says that, although this medication has commonly been used orally for pain, this concentration and form of morphine sulfate has only now been approved by the FDA. (*FDA Press Announcement*, 1/26)

\* ***Making Rounds With Oscar: The Extraordinary Gift of an Ordinary Cat*, by Dr. David Dosa, has been released.** Oscar (see *HNN*, 7/31/2007), whose ability to identify dying nursing home patients was chronicled in a *NEJM* article, is “important to family members and caregivers who have been with him at the end of a life,” Dosa said. Dosa adds that he never meant to make Oscar “sound creepy,” and hopes the book “will put the cat in a more favorable light as well as providing a book to help people whose loved ones are terminally ill.” (*Yahoo! News*, 2/2)

\* **Colorado coroners say the burgeoning green movement may mean that more people will be buried at home. They want the state to start tracking where people are buried. They're trying to forestall future problems, when new owners of a residential property dig up a body in the back yard, necessitating an investigation into whether foul play occurred.** The Colorado Coroners Association says it isn't trying to discourage such burials, only that they “want to know where you are if you aren't in a graveyard.” (*Vail Daily*, 2/3)

\* **“The Year Ahead,” in [\*The Hospitalist\*](#), cites Nancy Berlinger, deputy director of The Hastings Center, as saying that end-of-life issues will be prominent for hospitalists this year.** Berlinger says, “Hospitalists are increasingly associated with the care of patients on Medicare” who are likely nearing the ends of their lives, and notes that clinicians in her group often invoke the services of hospitalists. (*The Hospitalist*, 2/2010)

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