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## Diagnosing Death: Communication in the Face of Uncertainty

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Prognostication is an uncertain art in most cases, but most experienced physicians are aware of the likelihood of poor outcome well before it becomes overtly evident. Expressing this impression to patients and families is frequently interpreted by them as giving up, may be met with a great deal of denial, and, therefore, be unsettling to the physician as well as to the patient and his/her family.

There are techniques that I have found very helpful in these conversations:

- Listen before speaking. Find out what the patient already knows or believes about the current state of affairs. You may be surprised by what the patient knows or thinks he knows.
- Include the poor outcome in a list of possible outcomes, describing the plan for each. It may be helpful to have data on the frequency of such outcomes if it exists, since that makes the assessment of possibility appear less arbitrary.
- Assure that acknowledging the possibility of death does not change the plans for the present, unless the patient or his/her surrogate wishes those plans to change. When faced with the possibility of poor outcome, many patients fear medical abandonment. Specific statements like “This doesn’t mean we will try any less hard,” may be very useful.

Deal with the question, “What would you do if this was your parent?” honestly. It is worth admitting that your goals and expectations may be different from those of the patient, and that your response for this question is more an expression of personal opinion than it is medical advice, and that your

ethical and religious framework may not be the same. It is also worth stating that they are free to disagree with your response without offending you, and that the direction that treatment actually takes is more determined by standards of care and medical evidence than by that opinion. It may be helpful if you are willing to tell them why you respond as you do.

### Tolerating Unpleasant Events

According to the authors of “Diagnosing and Discussing Imminent Death in the Hospital: a Secondary Analysis of Physician Interviews,” it is known that patients and families tolerate unpleasant events much better if they have been allowed to anticipate them. Very frightening events, such as exsanguinations, are tolerated well when families are prepared for them. These conversations are important to have. All patients and families will not necessarily respond as we would like, but that is their prerogative. We can deliver the possibilities without denying the patient hope, and we can show the patients and their families that we are prepared for all the contingencies in the process.

Waiting for certainty about prognosis may leave little opportunity for physicians to help dying hospitalized patients and their families prepare for death, conclude the authors of a report on physician communication, which was published in the Journal of Palliative Medicine.

Investigators from several major centers analyzed data collected from 1999 to 2001 on 196 attending physicians, residents, and interns caring for 70 patients (mean age, 65.7 years; range, 21 to 94 years) who died on the general medicine or intensive care unit at two hospitals.

## Key Findings

- 42.8% of physicians said they felt certain upon admission or first meeting that the patient would die during this hospitalization, with 38.3% reporting they were uncertain.
- 86.4% of physicians had become certain over the course of hospitalization that the patient's death was imminent.
- Only 11% of physicians reported having personally spoken with patients about the possibility of dying, while 33.3% reported believing that someone on the medical team had done so.

- No relationship was found between physician or patient variables and whether or when physicians recognized that death was imminent. However, patients whose physicians were certain of imminent death were three times more likely to have been told of this possibility than were patients whose physicians were not certain.

“Because certainty came only within days of death, however, and because more than two-thirds of patients were, by that point, unconscious or in and out of lucidity, waiting for certainty appeared to preclude meaningful communication with the majority of patients,” write the authors. “Given the inherent uncertainty

in predicting death, these findings point to a need for enhancing communication about end-of-life issues in the face of this prognostic uncertainty.”

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## Handling Requests for Nondisclosure: Experts Offer a Clinical Approach

A family's request that a clinician not reveal bad news to a patient raises legitimate ethical issues, and may cause considerable distress when the situation is viewed as an I win/you lose dilemma. Either the patient is told despite the family's wishes, or the patient is not told in violation of the physician's medical values.

“We think, however, there is a third way that often allows satisfaction of the patient, the family, and the physician's concerns,” write two experts in physician-patient communication in the *Journal of Clinical Oncology*. The authors propose a strategy using negotiation skills and an understanding of the cultural factors underlying each party's point of view, based on related communication techniques and their own experience.

Until recently, nondisclosure of medical bad news such as diagnosis of terminal illness or poor prognosis was the norm in this country, and is still traditional in most other countries, the authors point out. Thus, it is not uncommon to encounter families believing it their duty to protect a loved one from the burden of making difficult medical decisions.

### Responding to a Request for Nondisclosure

Do not overreact. Take a deep breath and acknowledge to yourself that this will be a difficult conversation. Arrange for an appropriate

place and enough time to address the request. Step back and try to understand the reason for the family's request before sharing your own concerns.”

Be flexible enough to reconsider the significance of patient autonomy if the patient had explicitly expressed the desire not to be told of a terminal illness. Offer to think through the implications with the family. “I wonder if you have thought about some of the practical issues associated with not telling your mother about her diagnosis. May I mention some of my concerns?”

Respond empathically to emotional distress. Fostering a connection can lower the emotional temperature and build a foundation for subsequent negotiation. “I appreciate and share your concern. None of us wants her to lose hope. We all want what is best for her.”

Talk to the family about what the patient would want. Even in cultures with a tradition of family decision making, an individual may want to decide for herself. If the family appears merely to assume patient agreement with nondisclosure, open the possibility that she might feel otherwise. “I wonder how we would know if your mother did want to know more about her illness.”

Negotiate your approach to talking with the patient. Make it clear that although you could

not lie if asked a direct question, your goal is not to talk the patient into anything. “I'm fine with your being the decision maker, if that is what your mother wants. I just want to confirm that, so we know we are doing what she wants.” Set up certain ground rules beforehand and discuss possible outcomes.

Begin your talk with the patient with an open-ended question. “What is your understanding of your medical condition?” Depending upon physician preference, the question about disclosure may be presented neutrally (“Some patients want to be told directly about their illnesses, and others would prefer for the family to be in charge. What do you want in this regard?”) or slanted in favor of nondisclosure (“Your daughters told me that in your family, details and decisions regarding your illness and care should be handled by them. This is fine with me, if this is what you wish.”) If the patient declares the desire to be told, this must be pursued.

Source: “A Request for Nondisclosure: Don't Tell Mother,” *Journal of Clinical Oncology*; November 1, 2007; 25(31):5030-5034. Hallenbeck J, Arnold R; Division of General Medicine, Stanford University, Stanford, California; Veterans Affairs Palo Alto Health Care System, Palo Alto, California; and University of Pittsburgh School of Medicine, Pittsburgh, Pennsylvania.

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# MedPAC Concludes Series on Hospice Medicare

By Mark M. Murray, President/CEO

The Medicare Payment Advisory

Commission (MedPAC) is an independent agency that advises the U.S. Congress on Medicare. In addition to making recommendations on payments and payment methodology to providers in Medicare's traditional fee-for-service programs, MedPAC is also tasked with analyzing access to care, quality of care, and other issues affecting Medicare. On April 10 I was pleased to see MedPAC in action by attending the last in a series of meetings designed to provide Commissioners with a wide-ranging synopsis and critical assessment of the current and key issues associated with the Hospice Medicare Benefit (HMB). For this final meeting, the topic was "Hospice Utilization and Quality." The conference room at the Ronald Reagan Building and International Trade Center in Washington, DC was standing room only.

Issues noted at this final meeting included observations that the HMB has grown considerably since its inception in 1983, most significantly in the last several years. Despite this growth, there has been no systematic analysis of the Medicare's payment system for hospice, which has remained virtually untouched since its initiation. Diversity in hospice diagnosis was also discussed. While initially hospices cared for primarily cancer patients, today non-cancer diagnoses, which often present longer lengths of stay, comprise the majority of hospice patients.

## Hospice Costs and Payments

In past meetings about the HMB, MedPAC outlined its history; eligibility, payment system, and costs compared to conventional end-of-life care. The MedPAC meeting on March 6 focused on "Hospice Costs and Payments." It was noted that Hospice spending tripled from 2000 – 2007, from \$2.9 billion to \$10 billion. During that period there was significant growth in the number of hospice providers. Most of the growth was in the for-profit sector. In 2000, there were 1,200 non-profit hospices and about 700 for-profit. Seven years later there were 1,200 non-profit

providers and more than 1,600 for-profit hospices. It was also stated that little is known about the content or quality of care provided under the HMB and despite a new requirement for hospices to report visit data beginning this summer, it may be years before appropriate analysis of this data yields any reliable conclusions. One MedPAC commissioner stated that some type of "blunt instrument" may be needed to slow the growth of hospice use in the meantime. Other commissioners relayed that the definition of hospice seems to have changed from its original intent.

## Increasing Length of Stay

MedPAC has been concerned with increasing lengths of stay (LOS), increased costs to Medicare, and the relationship of these facts with the profitability of some hospice providers. They reported the mean LOS for HMB patients increased by over 30% from 2000 – 2005, noting that costs of hospice care are non-linear, meaning there is variation in costs across the LOS. Thus, short LOSs are less profitable, and profitability is boosted with the increase in LOS. MedPAC observed the increase in the LOS coincided with the growth in the number of for-profit hospice providers. It was suggested that incentives in the payment system, which appear to reward providers for more profitable long stays over less profitable short stays, may have actually influenced the shift in case mix over time – cancer vs. non-cancer diagnosis. MedPAC has previously stated that hospice reimbursement methodology is "ripe for overhaul."

MedPAC analyzed hospice claims standard analytical files and Medicare hospice cost reports from CMS (2005 data is the latest available) and examined the profit margins over time by type and tax status of hospice programs. I have listed two of those in the chart below.

Category	2001 Margin	2005 Margin
For-profit Hospice	2.0% Profit	11.8% Profit
Not-for-profit Hospice	-4.4 Loss	-2.8% Loss

MedPAC reported that hospices certified after January 1, 2000 -- which are mostly for-profit -- had margins more than five times higher than older, established hospices and that the margins increased with longer LOSs. MedPAC concluded that the current reimbursement incentive drives longer LOSs. Some commissioners stated that the payment system needs to be refined to establish appropriate care and right kinds of incentives.

MedPAC meets publicly to discuss policy issues and formulate its recommendations to Congress. In the course of these meetings, Commissioners consider the results of staff research, presentations by policy experts, and comments from interested parties, including national associations like the National Hospice and Palliative Care Organization. Two reports -- issued in March and June of each year -- are the primary outlets for Commission recommendations. MedPAC will include a chapter on hospice issues in its June 2008 report to Congress but will not be making any recommendations for changes to the HMB at that time. It was hinted at the April 10 meeting that perhaps HMB reimbursement should be at its highest at admission and then taper off over time as a patient's LOS increases, presumably to create disincentives for long LOSs.

Currently, the June 2008 draft chapter on hospice synthesizes analytic material presented to the Commission in the fall of 2007 and the spring of 2008. This material covers changes in the hospice user population, changes in utilization and associated spending, issues related to the hospice cap, and an analysis of hospice payments and costs. The chapter also includes new material on the content of hospice episodes, and measurement of the quality of hospice care.

Transcripts from all meetings along with the slide presentations can be found at the MedPAC website: [www.medpac.gov](http://www.medpac.gov) and may be downloaded in .the .pdf format.



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## Medical Staff Update

Kubley photo coming

Effective June 1, 2008, Jon Kubley, MD, will serve as a full time medical director for CHAPC. Dr. Kubley has been the part time medical director of our Plymouth office since it opened in 1995. With our patient census continuing to rise, Dr. Kubley will also assume additional responsibilities in our South Bend office. Dr. Kubley will be CHAPC's second full time medical director.

- David Tribble, MD, ABHPM, FAAFP, CHAPC's Chief Medical Officer, became full time in 2005 following 13 years of part time duties.
- Tom Kolakovich, MD, serves as the part time medical director in our Elkhart office.

To reach our medical staff, please call 574-243-3100 or 800-413-9083.



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