

Sustaining Hope, Delivering Prognosis: An Approach to Exploring Patient Needs

Asking 'How Much Information Do You Want?' Is Not Enough

Addressing patients' simultaneous needs for physicians to both support their hope and to deliver explicit prognostic information about their life-threatening illness is challenging. Lack of physician understanding of patient needs in this type of communication can pose a serious barrier to end-of-life care discussions.

That is according to researchers at the University of Washington, Seattle, who have developed an approach that may help physicians understand how individual patients and their families incorporate the dual needs for hope and information, and thus how best to tailor delivery of prognostic information.

"Patients and families differ in their needs and desires for hope and explicit prognostic information," write the authors of a report in the *Journal of Palliative Medicine*. "We found that simply asking patients how much information they want, without exploring their emotions and concerns, did not adequately elicit informational needs."

The investigators analyzed responses gathered in multiple in-depth interviews with 147 participants in the Seattle-Tacoma area: physicians practicing in pulmonology, oncology, or internal medicine (n = 31); their patients with either advanced cancer or severe chronic obstructive pulmonary disease (COPD), about whom the physicians "would not be surprised if the patient died from any cause in the next year" (n = 55); family members (n = 36); and nurses identified by patients or physicians as involved in discussions of patient illness (n = 25).

Initially, when asked how much information they wanted about the patient's illness, all patients and family members declared that they would want "all" the information; but upon deeper

"This study suggests that there is important variability in the way that patients with life-limiting diseases, particularly COPD and cancer, approach the interaction of wanting support for hope and wanting explicit prognostic information from their clinicians."

--Curtis, Engelberg, et al,
Journal of Palliative Medicine

questioning, a substantial minority expressed reservations about knowing certain types of explicit information.

For the deeper exploration, patients and family members were invited to discuss each diagram in a four-diagram conceptual model depicting different methods of integrating hope and the need for information (e.g., alternating between hope and information; balancing both; integrating hope and information; redirecting hope).

Key Findings Include:

- Patients and families varied greatly in their desires for hope and explicit prognostic information.
- Simply asking, "How much information do you want?" was an unrevealing approach to understanding individual needs.
- The four-diagram approach enabled patients and families to explain their concerns and preferences for delivery of prognostic information.
- Based on the diagram chosen, respondents described their preferred prognosis communication approach, which resolved into one of two methods: direct and indirect.

Indirect Approach

The indirect approach to conveying prognostic information, as recommended

by participating patients and families, included such physician strategies as:

- Taking into account the fragility of the patient's and family's emotional states.
- Avoiding blunt or precipitous statements.
- Verbalizing a commitment to non-abandonment.
- Suggesting a clear and comprehensive care plan.
- Presenting outcomes for groups rather than for the individual patient.

Direct Approach

For the direct approach, respondents invited physicians to communicate fully and explicitly what could happen in the future. "These participants were able to manage the emotional impact of prognostic information, and were less dependent on the clinician to facilitate their emotional adjustment to the news," the authors comment.

"Physicians' inability to balance concerns about providing prognostic information with supporting patients' hope may be an important barrier to communication with patients and families about end-of-life care," the authors write.

They note that their four-diagram model may be a useful clinical tool for understanding individual patient and family needs and thus improving physician-patient/family communication, but recommend further research.

Source: "An Approach to Understanding the Interaction of Hope and Desire for Explicit Prognostic Information among Individuals with Severe Chronic Obstructive Pulmonary Disease or Advanced Cancer," Journal of Palliative Medicine; May 2008; 11(4):610-620. Curtis JR, Engelberg R, Young JP, Vig LK, Reinck LF, Wenrich MD, McGrath B, McCown E, Back AL; Department of Pulmonary and Critical Care Medicine, Department of Gerontology and Geriatric Medicine, Department of Biobehavioral Nursing and Health Systems, Department of Medicine, Department of Oncology, University of Washington, Seattle.



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Hospice Care Reduces Medicare Costs While Providing Quality Care

Increased Access to Hospice and Palliative Care Highly Recommended

When hospice services are used, the Medicare program realizes a savings of about \$2300 per enrollee — while patients with life-limiting illness and their families experience the benefits of quality care.

That is according to a team of researchers from Duke University, reporting on their landmark study, which used a methodology designed to improve upon earlier analyses of the effect of hospice care on Medicare expenditures.

“Given that hospice has been widely demonstrated to improve quality of life of patients and family members, the Medicare program appears to have a rare situation whereby something that improves quality of life also appears to reduce costs,” write the authors of the report published in the international professional journal *Social Science & Medicine*.

The team compared Medicare expenditures for 1819 hospice users and 3638 matched controls (all aged 67 years and older) who died between January 1993 and December 2003. To avoid design flaws of previous studies, the researchers accounted precisely for the actual length of hospice use — rather than analyzing an arbitrary time period — and controlled for selection bias.

KEY FINDINGS INCLUDE:

- Hospice use reduced Medicare expenditures by an average of \$2309 per hospice patient.
- Increasing the length of hospice use by four days for all hospice patients enrolled for fewer than 180 days would increase savings by 12.5%.
- Based on the current length of hospice stays, increasing the duration of hospice use for seven out of ten patients would reduce expenditures even further.
- Costs are lower among cancer patients enrolled in hospice for up to 233 days and among noncancer patients for up to 154 days, compared with controls.

Suggested Strategies for Increasing Length of Short Hospice Stays

- Educate physicians on the tendency to overestimate survival in cancer patients, which can lead to late referrals
- Improve physician communication skills to encourage discussion of hospice earlier in the course of treatment

Although Medicare expenditures for patients increased after these time periods, note the authors, only 7% to 8% of beneficiaries use hospice for longer than the presumptive eligibility period of six months, while 25% of patients currently use hospice for one week or less. Thus, they declare, **“we feel that more effort should be put into increasing short stays as opposed to focusing on shortening long ones.”**

“In the 24 years that hospice has been covered by Medicare, it has been a major innovator in the provision of palliative care at the end of life, and a growing body of research suggests that hospice provides high quality care when assessed from both the patient and family perspectives,” the authors conclude.

Source: “What Length of Hospice Use Maximizes Reduction in Medical Expenditures near Death in the U.S. Medicare Program?” Social Science & Medicine; October 2007; 65(7):1466-1478. Taylor DH, Ostermann J, Van Houtven CH, Tulskey JA, Steinhauer K; Terry Sanford Institute of Public Policy, Duke University; Center for Palliative Care and Department of Medicine, Duke University and VA Medical Centers; Durham Veterans Administration Medical Center, Durham, North Carolina.