Nearly all physicians believe this country should place a higher priority on providing palliative care to all patients who need and want it, and that it is more important to enhance terminally ill patients’ quality of life than to try to extend it by any means, a nationwide survey released by National Journal has found.

Results of the poll of 500 board-certified physicians were presented this past November at a Washington, DC, policy summit as the third and final part in the series entitled, “Living Well at the End of Life: A National Conversation.” The presenter was Brent McGoldrick, senior vice president and general manager of FTI Consulting, the firm that conducted the survey for National Journal.

Key findings include:

◆ 96 percent of physicians believe it is more important to enhance the quality of life for terminally ill patients than to attempt to extend life by any means.

◆ 96 percent think that patients and their families should be educated about palliative and end-of-life care and the options available to them.

◆ 94 percent agreed that palliative care should be made available to all seriously ill patients, should be offered alongside curative treatment, and should be fully covered by health insurance and Medicare.

◆ 79 percent think the nation’s health care system spends too much in an attempt to extend the lives of terminally ill patients.

However, the data revealed some noteworthy hesitations about palliative care and barriers to its full adoption, McGoldrick pointed out.

Similar to patient groups, many physicians (42 percent) are concerned that emphasizing palliative care could interfere with cure-directed treatment. This concern was found less frequently among those physicians most familiar with palliative care, showing that more education is needed to explain that palliative care is not an either/or choice.

A dramatic “generation gap” found in physicians’ early education and training in palliative and end-of-life care indicates encouraging progress in the last 15 to 20 years, said McGoldrick. Among physicians younger than 39 years, 73 percent reported having received at least some training in palliative care and end-of-life care counseling in medical school, compared with only 25 percent of respondents aged 40 years or older. Further, 60 percent of all respondents say they have pursued continuing medical education in this area.

Physicians are aware of the limitations of their training; while 49 percent feel somewhat prepared to discuss palliative care, only 35 percent say they feel very prepared. And only 30 percent feel very prepared to counsel patients on end-of-life care options.

Barriers to palliative care

Physicians identify the following as barriers to the implementation of palliative care:

◆ Patients are not adequately informed and don’t ask (91 percent).

◆ Patients are reluctant to accept palliative care because it means admitting they may not recover (84 percent).

◆ Health insurance companies and Medicare do not reimburse adequately for consultations (82 percent).

◆ There are insufficient palliative care physicians and services (78 percent).

◆ Patients lack the resources to afford the care (78 percent).

Physician communication and compensation

Two areas of crucial importance to physicians wishing to improve delivery of palliative care are training in the end-of-life conversation and compensation for such discussions, according to summit panelist Ezekiel J. Emanuel, MD, chair of the Department of Medical Ethics and Health Policy at the University of Pennsylvania.

See “Enhancing quality of life” on page 4
The bad news encounter: helping patients move forward

Most guidelines for delivering bad news that have been developed over the past 20 years focus effectively on diminishing patient distress. But physicians can provide more than protection from emotional pain as they relay the facts of terminal illness to a patient — physicians can help the patient to find “actionable hope” and move forward into a changed life.

That is according to an article published in the American Journal of Hospice & Palliative Medicine, in which the authors outline an approach physicians can use to support hope by assisting the patient in establishing realistic therapeutic and personal goals to match the values to be found in the patient’s new reality.

To illustrate the importance of changing the concept of “hope” from a state of mind to action, the authors use the example of a female acquaintance who has young children and is about to be newly diagnosed with metastatic disease.

“The best hope for this young mother of four is not a noun that sits with head in hands and wishes for a life that cannot be, but a verb that moves forward, seeking goals that will bring value into an altered world,” states lead author Alva Bowen Weir, MD, professor of medicine-hematology at the University of Tennessee Health Science Center in Memphis. “If I am to provide such hope for this patient... then movement toward realizable value must begin early, even with the first presentation of bad news.”

Preparing for a bad news encounter

To prepare for presentation of bad news, physicians can:

◆ Allow adequate time for discussion.
◆ If circumstances permit, review the latest literature on the disease, so as to have data available for decision making.
◆ Review the patient’s social history to understand which areas and issues of importance might need to be addressed.
◆ Have one’s own directional goals in mind. The physician should prepare his or her own best plan, which can then be merged with the patient’s best plan.
◆ Address one’s own personal fears and anxieties, particularly if the patient’s situation hits close to home.

Delivering information; building trust

In deciding how much information to impart, physicians can ask themselves beforehand how much this patient wants to know, and how much this patient needs to know. While some patients wish to have all available information, which is certainly their right, not all patients do, nor will all patients be capable of processing a great deal of information during a delivery of bad news.

Family and friends brought by the patient for the encounter should be deliberately included in the conversation and incorporated into the patient’s care team from the beginning, suggest the authors. This will not only enrich the physician’s understanding of the patient’s situation and build trust, but will also give the patient support for remembering and complying with therapeutic plans, and for constructing a new vision of hope and value.

GOALS FOR PRESENTING BAD NEWS

1. Provide information that leads to diagnostic, therapeutic, and social decision making.
2. Strengthen the relationship with the patient and family, so that movement toward health and well-being can proceed in an environment of trust.
3. Provide hope, and begin to help the patient reorder his or her life to maximize value in a changed world.

— Adapted from Weir and Brint, American Journal of Hospice & Palliative Medicine

Making plans that foster hope and value

“From the initial visit where we deliver bad news, doctors should begin to navigate patients towards hope and value,” write the authors. Patients describing their hopes most often relate them to quality of life and goal fulfillment. “Such hope leads to value. Value is the perception that life is worth living.”

Physicians can help patients detach value from the life they will no longer have and reattach value to their life as it has become by redirecting such questions as “How long will I live?” and “How broken are my dreams?” to “How can I find value in each day of life?” and “What goals can I still accomplish?” Then physicians can help patients to make plans, which means moving toward realistic life and true hope. “I do my best to never tell a patient what I can’t do without laying out a plan for what I can do,” states Weir.

Because patients appreciate conversations that move them forward toward therapeutic goals, physicians would do well to remember that they are the experts concerning the circumstances of their patients’ health, and that “patients prefer to partner with their doctors in the decision making, rather than being left on their own.” Physicians are encouraged to recommend a care plan, confirm the next steps, and “end with commitment and hope.”

Source: “Hope Is a Verb: A Course Correction in Delivering Bad News,” American Journal of Hospice & Palliative Medicine; December 2011; 28(8):525-527. Weir AB and Brint JM. University of Tennessee Health Science Center of Memphis and Veterans Affairs Medical Center, Memphis, Tennessee.

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AHA offers online resource to help clinicians communicate with patients about treatment options and palliative care

The physician’s task of understanding a patient’s priorities and goals begins at diagnosis of a life-limiting illness, when questions regarding the patient’s hopes and fears can prepare the way for future discussions of palliative and hospice care. These questions will become necessary as the disease progresses and the patient feels ready, according to a publication newly available online from the American Hospital Association (AHA).

Originally created by the National Hospice and Palliative Care Organization (NHPCO), the two-page brochure, entitled, “Talking about Treatment Options and Palliative Care: A Guide for Clinicians,” offers suggestions for incorporating discussion of palliative care early on in clinical encounters with seriously ill patients.

“Introducing the concept of palliative care — as care focused on alleviating symptoms even as you work to cure the illness — will allow you to continue referencing palliation of symptoms, optimization of functional capacities, and the importance of psychosocial support for the patient and the family,” states the guide.

Finding the most effective way to communicate treatment options to patients with potentially life-limiting illnesses can be challenging, and sometimes the traditional phrasings are not necessarily the best. The guide offers new and alternative approaches for introducing and explaining palliative and hospice care options. [See sidebar, below.]

During these discussions, it helps to focus on these goals:

◆ Make sure you are heard.
◆ Make sure you listen to the patient and family.
◆ Provide information that helps them to understand their options and to make choices based on their individual needs.

Also included in the guide is a list of suggested questions for opening/continuing the topics of palliative and hospice care preferences and options, as well as a “translation” of what patients might really be thinking or want to know when they ask general or traditional questions.

The guide is available on the AHA’s Community Connections via the “Partner Tools” link at www.caringforcommunities.org. It is also available in brochure form on the NHPCO’s Caring Connections site through the “Resources” link at www.caringinfo.org.

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NEW APPROACHES TO EXPLAINING TREATMENT OPTIONS

◆ Instead of saying: “XYZ treatment has a 5 percent success rate,” try: This treatment works for one in 20 people. The people it works for live an average of X number of years or months. Or: In my experience, this treatment works for very few people. Those people may gain a few extra months, but many of them have told me that the side effects are not worth it.

◆ Instead of saying: “Some patients experience XYZ side effects as a result of the treatment protocol,” try: You can expect the following side effects. I will work with you to manage these side effects as best as I can. But, if the side effects become too troublesome, we can talk about other options, including stopping or changing the treatment.

◆ Instead of saying: “This is what I recommend,” try: I can explore options with you, but decisions about how to care for you are yours. Or: I want to be completely honest with you. Even with treatment, I think it is very unlikely you will live more than X months.

◆ Instead of saying: “Do you have any questions?” try: I’ve presented you with a lot of information. What questions do you have?

◆ Instead of saying: “At some point, we may have to look at hospice as an option,” try: With the disease you have, it is very likely that hospice care will be the best option for you at some time in the future. We can discuss this over time, so you can make decisions that best suit your needs.

— NHPCO, “Talking about Treatment Options and Palliative Care: A Guide for Clinicians”
Enhancing quality of life from page 1

of Medical Ethics and Health Policy, University of Pennsylvania, Philadelphia. Patients don’t want to ask about end-of-life care, he noted, but neither do physicians want to initiate these discussions.

“You resist that conversation as long as possible,” he said. “It’s emotionally draining, it takes time, it’s difficult, you have no way of knowing how the patient and family are going to react. That is enormously difficult.

“Figuring out how to start that conversation is the most important thing we can do to try to transform this. That requires education in better communication skills specific for end-of-life care.” Also needed, said Emanuel, is improved training in addressing and managing specific symptoms, as well as better research and the development of more effective interventions.

Emanuel feels strongly that physicians must be compensated for the time needed for end-of-life conversations, just as they are compensated for taking a patient’s history.

Results of the survey and a video of the November 2011 policy summit are available at: http://nationaljournal.com/events/event/74.