Advance Care Planning With Your Patients

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What would motivate you to initiate a conversation concerning end-of-life care with your terminally ill patient? Studies have clearly shown that patients want their doctor to talk to them about their advance care plans, and they want that discussion sooner rather than later.¹⁻² A recent randomized controlled trial found that patients with metastatic non-small-cell lung cancer who had a discussion about end-of-life care at the time of diagnosis lived longer than those who did not.³ In addition, ASCO's guidelines for care of patients with advanced cancer urges physicians to initiate candid discussions about the full range of curative and palliative options.⁴

Yet, despite evidence and professional guidelines, fewer than half of patients with advanced cancer had that important discussion. According to ASCO data collected in 2011 from more than 5,000 medical records as part of the Quality Oncology Practice Initiative, fewer than half of patients were enrolled in hospice more than 1 week, and a discussion about end-of-life plans had not occurred with 20% of patients by the last few months of life. We hope to provide some helpful guidelines and resources for talking to your patients about advance care planning.

Yes, It Is Hard To Do

In providing guidance about advance care planning, we in no way mean to minimize the challenge that such discussions present to you as physicians. To most of you, bringing up the subject of end-of-life plans represents the hardest part of your job.

Numerous hurdles exist. Many physicians interpret disease progression and death as therapeutic failure; having to talk about noncurative options flies in the face of the mantra of every oncologist: *beat the disease*. Oncologists do not want to take away hope, and they believe that patients don't want to talk about it. They worry that it will somehow adversely affect the patient and lead to a worse outcome. Most have not been taught how to do it. And finally, current reimbursement policies strongly favor intervention over prolonged discussion.

Start Early, Focus on Goals, and Have Ongoing Discussions

Experts advise discussing the patient's wishes about end-of-life care early in the treatment process. An essential first step is to identify the patient's surrogate decision maker, says David Casarett, MD, chief medical officer of Wissahickon Hospice, part of the University of Pennsylvania Health System. He suggests saying something like this at the very beginning of treatment for advanced cancer: "You will go through a lot of hard

treatment and have good days and bad days. If you can't make decisions for yourself, whom should I turn to?" He adds, "Other, more in-depth discussions about options such as hospice should not be front and center until later, and might be triggered by worsening symptoms or a decline in functional status."

Frame advance care planning within the patient's goals for care. "Identify what is most important to them currently and in the future," advises James A. Tulsky, MD, director of the Duke Center for Palliative Care in Durham, NC. Early on, overall survival and treating cancer aggressively will be clear goals. Says Tulsky, "Go full guns, but at the same time ask the patients what they would want to do if the chemotherapy is not successful." He finds the language "hope for the best but plan for the worst" to be a helpful approach with patients.

For those patients who say they don't want to think about end-of-life planning, Tulsky suggests asking them what they are most afraid of. "It might be dealing with relationships with loved ones, financial concerns, or having pain that is unremitting. Try to find out. If they still don't want to go there, fine; let it go for now."

Michael A. Kolodziej, MD, oncologist with New York Oncology Hematology in Albany, agrees that talking to the patient about his or her goals should guide one's treatment decisions. "What's important and not important to the patient? What are they willing to accept in terms of toxicity? Who is going to make decisions if they can't?" He suggests saying, "We don't want to have to guess what you want."

As care continues, regularly address the question of whether further anticancer therapy continues to be consistent with the patient's goals and current clinical picture. In the absence of these conversations, the "default care plan" is often further, and potentially futile, systemic therapy.

Empower the Patient

Recognize that patients also feel awkward broaching a discussion about the end of their life. They may even feel that talking about it is at some level a betrayal of your efforts or an expression of disappointment in you. Family members also may not want to bring it up because they believe they have to stay positive to support their loved one, or to ward off depression. Communicate to the patient and family that the advance care planning process is intended to give patients control of what happens; it is not ceding the management of their care to others. In all discussions about patients' care options, emphasize that the patients' goals and desires are paramount.

Patients need help understanding, both cognitively and emotionally, the diagnostic and therapeutic information and

options you lay out. They also need to have a clear understanding about noncurative options you present for their consideration. Many misunderstandings exist about the terms hospice and palliative care, for instance. Encourage patients to ask questions. Provide written information and encourage patients and families to consult patient-oriented information available online, such as that provided through Web sites of the National Cancer Institute and ASCO's cancer.net. Cancer.net offers a free booklet, *Advanced Cancer Care Planning*, that explains care options, palliative and hospice care, and advance directives.

Ask the patient specifically if he or she has an advance directive in place. A 2005 Pew Research Center survey found that only 29% of adults had a living will, though these numbers were higher for those age 65 and older, 54% of whom said they had a living will.⁵ Give patients referrals or resources to create a living will and a durable power of attorney for health care.

Develop a Systematic Approach You Use Consistently

Kolodziej believes that the dismal rate of end-of-life planning discussions with cancer patients could improve if oncologists developed and standardized the fundamental message and implemented it consistently with all patients. Kolodziej chairs the Pharmacy and Therapeutics Committee within US Oncology that has conducted several pilot projects with the goal of establishing and implementing such an advance care planning program. An objective of the committee is to develop a system that is beneficial for patients and reduces costs of end-of-life care; such a system could be used to negotiate reimbursement rates with payers. "But being rewarded by payers is not easy," Kolodziej acknowledges. "Insurance companies live in a world of the bottom line." Consequently, the committee has learned lessons and gained experience from the piloted approaches and is working toward finding a model that is applicable and efficient across different types of practices.

Casarett agrees that physicians should be "more organized in having not just end-of-life discussions but goal discussions." He clarifies that such discussions are not intended to be something that "can be packaged and dropped into a patient visit." Consider developing a systematic approach that works for you in helping patients with end-of-life planning. Identify numerous points at which you bring up the patient's desires and priorities. The time of diagnosis is one such point. Times of relapse or repeat hospitalizations are also appropriate times to revise goals with the patient.

Kolodziej points out that an important reason to develop a systematic approach is to counteract one's own biases. "When I'm treating a patient with advanced disease and trying to get them the best quality of life, my discussion is colored by my hopes of what could happen. Oncologists worry that talking to their patients about end-of-life goals and health care agents will make their patients depressed. But in truth this dialogue will not poison our relationship with patients—it will improve it. The solution may be in a very disciplined approach to this problem, such as what we have in the informed consent process regarding toxicity."

What the Evidence Shows

- Patients want to discuss end-of-life issues with their doctor.^{1,2}
- Patients do not have anxiety or distress as a result of hearing the truth about their illness.⁶
- Patients with metastatic non–small-cell lung cancer who had early palliative care and less aggressive care lived nearly 3 months longer than did patients receiving standard care.³
- Advance care planning reduces stress, anxiety, and depression in surviving relatives.⁷

Use a Team Approach

"The best model for doing this kind of care is through an interdisciplinary team," states Tulsky. "Involve different members of the team—the physician, the nurse, the chaplain." Tulsky's palliative care center provides consultation to inpatients at Duke University Hospital, and he acknowledges that a team approach is harder in a small community oncology practice. But even there, the patient's physician, nurse, midlevel provider, and office administrator can use a team approach in laying out options, working with loved ones, providing explanations and supportive material, completing an advanced directive if needed, and coordinating referrals for hospice care or specialized palliative care.

A team approach that has proven successful in community practice is to involve your nurse practitioner or other midlevel provider. For all patients with metastatic cancer, consider scheduling an extra appointment with the nurse practitioner to

Further Resources

- ASCO guidelines for end-of-life care.
- *Advanced Cancer Care Planning*. ASCO 24-page booklet for patients and families, in English or Spanish. PDF available at www.cancer.net. Quantities of print version can be ordered.
- *Talking about Treatment Options and Palliative Care: A Guide for Clinicians*. A two-page guide with suggested language for communicating with patients and caregivers. Available from the National Hospice and Palliative Care Organization at www.NHPCO.org.
- Back A, Arnold R, Tulsky J: *Mastering Communication With Seriously Ill Patients*. Cambridge, England, Cambridge University Press, 2009
- *Respecting Choices*. An advanced care planning program that provides training and consultation to individuals, communities, and practices: www.respectingchoices.com.
- Von Roenn JH, con Gunten CFI. Setting goals to maintain hope. *J Clin Oncol* 21:570-574, 2003

specifically discuss goals of treatment and advance care planning. This approach prompts the patient early on to think about their priorities and goals. At subsequent visits, the oncologist can inquire about questions or perspectives that the patient has regarding the discussion with the nurse practitioner.

Establish procedures with hospice resources in your community, and if possible use a palliative care physician for patient consultation in your office.⁶ Physicians certified in hospice and palliative medicine have training in eight domains, including psychological, social, spiritual, and cultural aspects of clinical palliative care.

Summary

Conversations about end-of-life care are tough—for the provider, the patient, and the family. But research shows, and patients agree, that advance care planning can improve quality and length of life. In order to make advance care discussions as painless as possible, incorporate resources and strategies from those who do it routinely. Develop and implement a systematic process, use a team approach, and direct the patient to resources already available, such as those at cancer.net. These conversa-

tions will never be easy, but every patient deserves an individualized assessment of needs, goals, and preferences throughout the continuum of care.

Accepted for publication on September 23, 2011.

Authors' Disclosures of Potential Conflicts of Interest

The authors indicated no potential conflicts of interest.

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DOI: 10.1200/JOP.2011.000442

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