

Navigating Cancer Patients' Final Turn

HELPING THEM MAKE THE TRANSITION TO HOSPICE

BY CHARLOTTE HUFF

For doctors and patients alike, the road from cancer diagnosis through treatment can be fraught with emotion and uncertainty. The results of aggressive interventions may be unclear for some time, making it difficult to know precisely how and when to explore a patient's end-of-life preferences.

One challenge for physicians is how to gain insight from the patient on end-of-life care without triggering fear of abandonment. When is the optimal time to raise these issues without undercutting the doctor-patient relationship? Meanwhile, patients have understandable reasons for not forcing the subject.

The result can be an inadvertent standoff, with the highest of stakes in play, says pediatric oncologist Jennifer Mack, an assistant professor in pediatrics at Harvard Medical School and an end-of-life researcher on a battery of recent studies.

"I think sometimes if we wait for them to ask, as physicians, and then the patients wait for us to offer the information, nobody talks about anything," she says. "It really happens. We all sort of avoid this subject because it's so hard."

Oncologists are particularly likely to confront these end-of-life decisions with patients, including when to back off from aggressive treatment, and ultimately, the preferred location of death. Patients with cancer diag-

noses comprised nearly 38 percent of hospice patients in 2011, making them hospice's largest patient group by a wide margin, according to the National Hospice and Palliative Care Organization (NHPCO) in Alexandria, Va.¹ Clinical guidelines, such as those released in 2011 by the American Society of Clinical Oncology (ASCO), are increasingly encouraging physicians to initiate these conversations sooner with patients who have an incurable cancer, in order to maximize quality of life.² Among ASCO's recommendations: Treatment should only be considered when it has a meaningful chance of providing some benefit, and patients should be provided details about both the potential side effects of the therapy, as well as the type and likelihood of clinical response.

But reality continues to diverge from recommendations. One 2012 study in the *Annals of Internal Medicine*, involving 2,155 U.S. adults with stage 4 cancer, found that most end-of-life conversations were long delayed, to a median time span of about one month before the patient died.³ One out of every four patients didn't report any end-of-life discussion.

Mack, who was involved in the *Annals of Internal Medicine* study, also coauthored a separate 2012

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study that illustrates poor communication between patients and their doctors. Published in *The New England Journal of Medicine*, the study involved 1,193 patients with stage 4 cancer who were receiving palliative chemotherapy with the goal of either extending their life by weeks or months, or easing their symptoms. Most patients — 69 percent of those with lung cancer and 81 percent of those with colorectal cancer — didn't realize that the chemotherapy couldn't cure their malignancy.⁴

Mack says she and her fellow researchers “were floored” by the findings, and worry that poorly informed patients are not well served as they weigh end-of-life matters. “If patients don't understand the intent of treatment, then it's really hard for them to make good decisions on the direction of care,” she says.

Rather than stalling, both doctors and patients should discuss sensitive subjects far earlier in the treatment process, says Don Schumacher, president of NHPCO. Even if the patient's prognosis appears relatively good, the doctor can also briefly acknowledge that the treatment may not ultimately work.

That acknowledgment provides an opening for the doctor to ask about the patient's cancer fears and how much he'd want to know if his condition took a turn for the worse, Schumacher says. Some patients won't want to discuss these issues, but they should be afforded the opportunity to do so, he stresses. “Patients should never be forced or withheld from,” he says. “It's always trying to figure out that dance and balance.”

While difficult, such conversations can help form the basis of a trusting doctor-patient relationship that can prove invaluable if the malignancy eventually spreads, Schumacher says. “I do think it helps the patient, at the very beginning, to have at least in the back of their minds some sense that their doctor is worried about their quality of life — that he or she is worried about their well-being,” he says.

DISCUSSION DELAYS

Hospice use has become more common in recent years, with usage rates increasing among Medicare patients, according to a recent *Journal of the American Medical Association* study. Overall, twice as many people were enrolled in hospice at their time of death in 2009 compared with 2000 — 42.2 percent versus 21.6 percent.⁵ The findings, published in February 2013, analyzed data from a random 20 percent sample of Medicare patients who died in 2000, 2005, and 2009.

Among cancer patients, hospice use also increased, from 45.1 percent to 59.5 percent during the same nine-year span. But cancer patients were more likely to use the intensive care unit prior to death, with ICU use during the final 30 days of life increasing from 19.9 percent to 26.8 percent.

Sometimes hospice patients do need to be admitted to the hospital during their final days if they develop a complication that's scary for them or their loved ones, such as coughing up a lot of blood, says lung cancer specialist David Carbone, who directs The James Thoracic Center at The

Ohio State University Wexner Medical Center. Still, health professionals should attempt to keep such sudden transitions to a minimum, he says.

“If the family and the patient are prepared and understand the gravity of the situation,” he says, “then the pre-terminal conditions that arise are no surprise and are handled in a setting where they were planned for, such as a hospice setting or at home with well-prepared caretakers. So that mom is not rushed to the hospital in the last few days of life.”

Whether hospice is selected at all depends at least in part on the timing of end-of-life discussions, according to another analysis from the same group of stage 4 lung and colorectal cancer patients who were part of Mack's *NEJM* study. Of the 1,231 patients en-

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rolled in the Cancer Care Outcomes Research and Surveillance Consortium (CanCORS), nearly half received some type of aggressive care during their final month of life, according to the findings, published in December 2012 in the *Journal of Clinical Oncology*.⁶ But when clinicians raised end-of-life options a bit earlier in the disease course, more than 30 days prior to death, the result was more hospice care and less aggressive treatment, the researchers found.

“The problem is that by putting off having a discussion about what’s ahead, you end up taking away the opportunity that the patient has to make decisions about how they want to live their life,” says Mack, one of the study’s authors. “And I think that can be a really important opportunity that I think most of us would want, if we knew that we had limited time left.”

Frequently doctors will talk to patients about their prognosis, if they believe the cancer is likely incurable, says oncologist Thomas J. Smith, director of palliative medicine at Johns Hopkins Medical Institutions. “But we [discuss] that on the first visit, when they’re still reeling from the diagnosis,” he says. “And then typically we don’t revisit it at multiple opportunities later.”

Smith cited one 2010 study analyzing survey responses from 4,074 physicians, who were presented with the case of a patient newly diagnosed with metastatic cancer. The patient was feeling relatively well, but had an estimated life expectancy of four to six months. While two-thirds said they would discuss that prognosis with the patient right away, only 44 percent would ask about DNR preferences and 26 percent would discuss hospice, according to the findings, published in the journal *Cancer*.

In fact, most physicians preferred to wait until the patient developed symptoms or they’d exhausted

treatment options before discussing DNR status or the possibility of hospice.⁷ Noncancer physicians were more likely than oncologists to ask about end-of-life logistics, according to the *Cancer* findings.

It’s far easier, as the months spiral forward following diagnosis, to discuss the pros and cons of another chemotherapy regimen, rather than more open-ended questions about the patient’s preferences and worries, Smith says. Propping open that emotional door can

quickly devolve into a tissue box of tears and related unfinished business that can’t be addressed in a quick conversation, he says.

“It also exposes me, the oncologist, to a whole lot of difficult parts of this person’s life, which it’s easier, frankly, to avoid,” Smith says. “She may tell me, ‘Well, I’ve been mad at God, since he took my mom when I was 7. And I haven’t seen my brother in LA for 15 years. And what am I going to do with my kids — they are 11 and 13?’”

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Don Schumacher, President, National Hospice and Palliative Care Organization

MAKING THE TURN

By the time the patient is recommended for hospice, ideally he

has already been benefitting from emotional support for some time, starting from the very beginning of his diagnosis, palliative medicine specialists say.

Palliative care services can be provided at any time during chemotherapy and other aggressive interventions, even while the goal remains a cure, according to the American Academy of Hospice and Palliative Medicine.⁸ The palliative team might include a mix of health professionals, ranging from doctors and nurses to social workers and chaplains, to assist with pain relief, spiritual or mental health support, and other needs.

Palliative services also can provide a quality-of-life bridge until the patient’s enrollment in hospice. To enroll, Medicare requires the patient’s physician and the

hospice medical director to certify an anticipated life expectancy of six or fewer months.⁹ But given the uncertainties of some illnesses such as cancer, a patient can be recertified. In 2011, patients spent a median of 19.1 days in hospice, but 11.4 percent were enrolled more than six months, according to NHPCO.¹⁰

In a 2012 *NEJM* commentary, Smith recommended that physicians initiate end-of-life discussions once it becomes clear that the patient's cancer will never be eradicated.¹¹

Thus, exploring DNR or site-of-death preferences wouldn't be appropriate if a patient has early-stage breast cancer, for example, Smith says. But these conversations should be attempted with anyone who has metastatic disease, such as a breast malignancy that has spread to the liver or the brain, he says. "I might be able to keep them alive for a year or two, but not much beyond that."

Physicians should watch for natural trigger points to start delving into illness progression and coping strategies, Smith says. The imaging scans might show that the first- or second-line chemotherapy didn't work, he says. Or the patient's functioning may be negatively affected, and now she requires support to walk into the clinic.

"That's the time to pull up a chair," Smith says, "sit down and say, 'How much do you want to know about what's going on with you? ... Would you like to talk about prognosis and what might happen in the future?'"

In his own practice, once Smith believes that a patient's life expectancy is fewer than six months, he talks to that individual about scheduling an informational session about hospice. Typically, a local hospice group can meet the patient in her own home.

Taking that step satisfies two goals — it introduces the patient to the concept of hospice and the people who will be involved, Smith says. And, the earlier timing lightens some of the emotional baggage for both the doctor and the patient, he says.

"It moves all of the angst about the H-word way upstream," Smith says. "Because you're bringing up the fact again that the person has a terminal illness, and will eventually die from the illness. But they are still pretty well. And they are in much better shape to process and use the information and take advantage of the hospice's services."

ADDRESSING CONCERNS

In the 2012 *NEJM* study about palliative chemotherapy, the researchers didn't know what information the doctors had shared with the stage 4 patients about the treatment's pros and cons. But there was a high rate of acceptance. In all, 1,274 patients were offered the option of palliative chemotherapy; of those, 93.6 percent agreed to treatment.

Mack attributes that high response rate in part to the patient-oncologist relationship — patients expect oncologists to prescribe chemotherapy. But to prevent any misunderstanding as the disease advances, doctors should avoid using vague or difficult-to-understand words, such as palliative, Mack says.

"I find that it's often helpful to be specific about what I think chemotherapy might do or not do for someone," Mack says. "Rather than terming it palliative, maybe I'll say, 'The goal of this treatment is to improve your symptoms, or is to help you live longer, but without a hope of cure.'"

For physicians, it's an ongoing balancing act between being honest and not snuffing out hope, Carbone says. Even patients with advanced lung cancer can become five-year survivors, although the odds are slim, he says.

"I often tell them [patients] at the very first visit that their cancer is not curable, but I tell them that it's treatable," he says. "And I don't know how well the treatments will work, and how long they will last. We'll just go day by day and decision by decision."

With subsequent visits, Carbone tries to "maintain a little bit of hope," while still being upfront about treatment success. "So I've had very little trouble with my patients being surprised about dying or surprised about the intent of therapy, or surprised when I start talking about hospice," he says.

As physicians navigate the end-of-life transition, it's also become increasingly apparent that they should make an effort to acknowledge a patient's religious or spiritual perspective, says Holly Prigerson, PhD, a psychiatry professor at Harvard Medical School and end-of-life researcher. Prigerson was involved in one study with 339 advanced cancer patients, which looked at hospice usage in the final weeks of life among patients reporting low spiritual support from their medical team compared with patients who rated spiritual support as high.

Those who expressed dissatisfaction were less likely to spend at least a week in hospice during their final days — 53.1 percent compared with 73.4 percent among patients reporting high levels of spiritual support. The findings were published 2011 in the journal *Cancer*.¹²

Ongoing research is attempting to unravel the precise reasons for that dichotomy, Prigerson says. But she encourages health professionals to attempt to relate to their patient's underlying religious belief system, whether that means involving the hospital chaplain or contacting the patient's spiritual adviser. "If you are treating patients who have religious beliefs and you are ignoring that, you're doing them a disservice."

For deeply religious individuals, stopping aggressive treatment can sometimes be perceived as a sin, whether that's because it's thought to be giving up on the possibility of a medical miracle or dismissing the faith of those praying on their behalf, Prigerson says. "I think they are suffering with the ethics and morality of giving up on life," she says. "And that's what needs to be addressed."

Patients also don't need to sever their emotional connection to their doctor when they move into hospice care, Schumacher says. Their cancer physician can remain as the hospice doctor on record and, regardless, can remain in close contact with the patient. Ohio State's Carbone says he provides this option to his patients.

And patients should be reassured that moving into hospice care will not shorten their life span, and might even extend it, Smith says. In one study involving 4,493 patients, the group getting hospice care lived an average of 29 days longer than those patients who were not. For patients with cancer — five out of the six diagnoses in the study — the average survival difference was greatest for lung cancer (279 days vs. 240) and pancreatic cancer (210 days vs. 189), according to the findings, published in 2007 in the *Journal of Pain and Symptom Management*.¹³

If doctors made just a few end-of-life modifications in their practice, such as scheduling a hospice informational visit before the need becomes imminent, they would be amazed at the payoff for the patient and the doctor-patient relationship, Smith says. This year's *JAMA* hospice data, despite an enrollment increase reaching 59.5 percent for cancer patients, reflects that there's still significant room for improvement, he says.

"Cancer is not sudden death," Smith says. "Cancer for the most part runs a very predictable course. If people aren't getting into hospice, it's because we aren't bringing it up soon enough or in a convincing enough way to let people know what the benefits are."

Charlotte Huff, a freelance writer in Fort Worth, Texas, specializes in health reporting, including end-of-life concerns and the compassionate delivery of bad news.

¹ National Hospice and Palliative Care Organization. NHPCO Facts and Figures: Hospice Care in America. 2012 edition

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² American Society of Clinical Oncology Statement: Toward Individualized Care for Patients with Advanced Cancer. *Journal of Clinical Oncology*. 2011; 29: 755-760.

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³ End-of-Life Care Discussions Between Patients With Advanced Cancer and Doctors. *Annals of Internal Medicine*. 2012; 156(3): 1-34.

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⁴ Patients' Expectations about Effects of Chemotherapy for Advanced Cancer. *New England Journal of Medicine*. 2012; 367: 1616-25.

⁵ Change in End-of-Life Care for Medicare Beneficiaries: Site of Death, Place of Care, and Health Care Transitions in 2000, 2005, and 2009. *Journal of the American Medical Association*. 2013; 309(5): 470-477.

⁶ Associations Between End-of-Life Discussion Characteristics and Care Received Near Death: A Prospective Cohort Study. *Journal of Clinical Oncology*. 2012; 30(35): 4387-95.

⁷ Physician factors associated with discussions about end-of-life care. *Cancer*. 2010; 116: 998-1006.

⁸ American Academy of Hospice and Palliative Medicine. Definition of Palliative Care. *Cancer*. 2010; 116: 998-1006.

<http://www.aahpm.org/positions/default/definition.html>

⁹ National Hospice and Palliative Care Organization. Caring Connections. Paying for Hospice.

<http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3358>

¹⁰ National Hospice and Palliative Care Organization. NHPCO Facts and Figures: Hospice Care in America. 2012 edition

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¹¹ Talking with Patients About Dying. *New England Journal of Medicine*. 2012; 367: 1651-1652.

¹² Support of Cancer Patients' Spiritual Needs and Associations With Medical Care Costs at the End of Life. *Cancer*. 2011; 117(23): 5383-91.

¹³ Comparing Hospice and Nonhospice Patient Survival Among Patients Who Die Within a Three-Year Window. *Journal of Pain and Symptom Management*. 2007; 33(3): 238-46.