

The Most Difficult of Conversations

EXPERTS OFFER GUIDANCE ON HOW TO COUNSEL PATIENTS ON HOSPICE, PALLIATIVE CARE OPTIONS

BY CHARLOTTE HUFF

Physicians talk to countless patients and their families about how to stay healthy and treat illness. But many physicians find themselves at a loss for words, or at least the right words at the right time, when faced with a patient who is terminally ill, studies show.

When treating a cancer patient with four to six months to live, for example, fewer than half (44 percent) of respondents in one survey of 4,074 physicians said they would immediately discuss the status of the patient's do-not-resuscitate (DNR) instructions, and just 26 percent would initiate a conversation about hospice. Moreover, 26 percent of physicians would delay a DNR conversation until all nonpalliative treatment options had been exhausted and 49 percent would accordingly delay a hospice discussion, according to the findings, published in 2010 in the journal *Cancer*.¹

"I think what a lot of these doctors do is they just wait until they have no more treatments to offer, or until the patient sort of backs down,"

says internist Nancy Keating, a study author and associate professor of medicine and healthcare policy at Harvard Medical School.

Numerous factors are likely to contribute to this delay, according to researchers, physicians, and palliative care experts. The ongoing development of drugs and other treatments for advanced illness, such as cancer, has expanded options, making the end of treatment a bit murkier. Meanwhile, the doctor and patient may have built an emotional bond, sometimes over years, united around a common goal: to defeat the illness. In that context, raising any end-of-life subject may feel like an admission of defeat.

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Myra Christopher, bioethicist

"My heart really goes out to healthcare professionals who are being asked to do their work in a new way, because historically their job has been to prolong life," says Myra Chris-

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Expect more from us. We do.

topher, president of the Center for Practical Bioethics in Kansas City, Mo. But many physicians haven't been adequately trained in end-of-life care, she says. "Most [people] avoid doing things that they don't do well. Most of our doctors in practice now have been socialized that death is a failure."

Recently, however, professional and nonprofit organizations have started taking steps to provide better support and training for physicians, and hospice care is becoming more common. In early 2011, for example, the American Society of Clinical Oncology issued a statement emphasizing that oncologists should strive harder to have realistic conversations with advanced cancer patients about prognosis, including their option to transition into comfort care rather than continuing with aggressive treatments.² According to a recent end-of-life care analysis by the Dartmouth Atlas Project, released in April 2011,³ the average number of days that patients spent in hospice increased nationally from 12.4 days in 2003 to 18.3 days in 2007.

Yet physicians continue to struggle with this most difficult of discussions. When is the right time to have a conversation with a patient on the subject of their end-of-life wishes? And how can physicians — trained as scientists and socialized, often, to view palliative care as a kind of surrender — manage the delicate implications of such conversations? In this white paper, experts, researchers, and physicians provide needed guidance. To date, physician training has been dominated by treating patients, Keating says. But how doctors handle this final stage of medical care represents just as important a calling, she says. "I think we for-

get that we could help patients have the death that they want to experience."

PHYSICIAN MINDSET

Doctors' own fears can sometimes inhibit their ability to initiate discussions about end-of-life planning, says Elizabeth Fine, an internist and assistant professor in the Center for Geriatrics at the University Hospitals Case Medical Center in Cleveland.

"I know there are physicians who feel that if they offer comfort as a priority, or palliative care or hospice, that they're giving up on the patient," Fine says. "And [that] they've failed in treating their disease. They won't say that, I think. What they'll say is, 'I'll be ruining their hope.'"

Another worry is misrepresenting a patient's survival odds, since prognosis is so intertwined with these types of conversations, and is difficult to predict, Keating

says. In this regard, physician optimism may give them reason to postpone a frank conversation. One frequently cited study, published in 2000 in the *British Medical Journal*, asked 343 doctors to predict how much longer 468 terminally ill patients would live, upon their referral to hospice care. Nearly two-thirds of the physicians, 63 percent, predicted survival times that proved too optimistic; only 20 percent made predictions that were close enough to be considered accurate under the study's parameters.⁴

Physicians who do broach palliative care and other end-of-life decisions tend to focus more on the medical detail, rather than emotional issues, according to research by Fine, published in the *Journal of Palliative Medicine* in 2010.⁵ Her article, which reviewed 20 studies involv-

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ing end-of-life conversations that had been directly observed, found several recurring themes. Among the findings:

- Doctors were more likely to talk about medical or technical issues, instead of the patient's emotional concerns. One of the studies, published in 2005, found that patients and families were 10 times more likely to raise psychosocial subjects than the physicians.
- As the conversation unfolds, doctors tend to dominate. Five studies found that doctors' verbiage comprised 60 percent to 70 percent of the spoken words during the exchange.
- Doctors tended to worry about the time investment involved.

In short, physicians are edgy about opening the proverbial Pandora's Box by venturing into this emotional and time-consuming territory, Fine says. "Either because they are not comfortable or they perceive that it's going to take more time," she says. "And it does take more time."

Among her recommendations for physicians: seek training to improve communication skills; speak less and listen more; and solicit help from other professionals, such as social workers, psychiatrists, or chaplains.

TIMING THE TALK

In its new policy statement, ASCO recommends that physicians start talking about quality-of-life goals upon a patient's diagnosis with an advanced malignancy, and then revisit those conversations as the disease progresses. That includes speaking candidly with patients about the impact of chemotherapy and other

treatments on their quality of life, they write. Palliative care that focuses on easing symptoms also should be offered.

With an expanding array of treatment options these days, the timing of when to discuss comfort care can sometimes be tricky, says Don Schumacher, president of the National Hospice

and Palliative Care Organization (NHPCO). "Cancer in many ways is becoming a chronic illness, which is wonderful. But I do think a really good oncologist understands when aggressive treatment is winding down."

Cancer patients aren't unique in facing end-of-life decisions. Cancer patients were most likely to enroll in hospice care in the 1970s, when it was first established, according to NHPCO. Now just four out of 10 hospice patients have cancer. Other leading diagnoses

include heart disease (11.5 percent), dementia (11.2 percent) and lung disease (8.2 percent).⁶

There's no single "right" time to discuss a patient's philosophy toward comfort measures, says oncologist Anthony Back, who directs the Program on Cancer Communication at the Seattle Cancer Care Alliance. Rather, what's important is that the subject is naturally incorporated into a patient visit, starting earlier in the disease process if possible, rather than being suddenly introduced.

As one example, Back describes how a doctor treating a congestive heart failure patient can explain how in some cases patients may suddenly deteriorate and be unable to speak for themselves. While explaining this, Back suggests, the doctor can say: "It's really important to have a backup plan in place, so if that happens, everyone knows what to do."

In hospice, caregivers "do everything to the role of comfort versus everything to the role of cure."

Elizabeth Fine, internist

Clearly, though, physicians are stalling. In 2009, about one-third of patients died within a week of entering hospice, according to data provided by NHPHO.⁷ “That’s way too high,” Schumacher says. In early 2011, ASCO released similar numbers, based on a preliminary analysis from that organization’s Quality Oncology Practice Initiative, involving 600 cancer practices nationally. Fewer than half — 45 percent — of cancer patients were enrolled in hospice care prior to their deaths. Of that group, one-third of patients were transferred to hospice during their final week of life.⁸

Delaying end-of-life decisions also can be costly. In one study, published 2009 in the *Archives of Internal Medicine*, the care of advanced cancer patients who had discussed end-of-life preferences totaled an average of \$1,876 in the last week of life. In comparison, the cost for those who hadn’t discussed their preferences averaged \$2,917. Plus, that latter group also reported a worse quality of life during their final week.⁹

INITIATING THE TALK

Fine recommends that physicians follow a standardized approach in discussing prognosis and related end-of-life decisions with severely ill patients and their families.

Sometimes the conversation can involve quite a few people, as family members may have traveled some distance to gather at the patient’s bedside. In such cases, it’s important to have a brief round of introductions, Fine says. Even before delving into end-of-life options, the physician should have gotten a quick window into what the patient or family understands about the medical prognosis and treat-

ment options. Most typically, she says: “They’ll either tell you spot on or they’ll give you something so far off.”

In situations where the severity of the prognosis hadn’t been grasped, the doctor should directly state that she has “some bad news” to convey. That gives patients and family mem-

bers an opportunity to speak up, if they want to be shielded from some of the specifics.

Once the patient’s medical prognosis has been updated and explained in more detail, it’s important to pause, allowing some of the information to be absorbed before outlining options moving forward. Sometimes, there are tears, Fine says. Less frequently, anger flares. In those cases it’s less likely to be directed at the clinician delivering the news

and more that the patient or the family felt like they hadn’t gotten the full prognosis picture previously, she says.

If a patient or family member cries, the doctor doesn’t have to say the perfect thing, but simply show that he cares, Fine advises. An empathetic look can help. “You have to avoid saying, ‘I understand,’” she says. “You can say, ‘I see you are very upset. Do you need more time to process?’”

Along with laying out the options, part of the doctor’s role is to provide some guidance, Fine says. Sometimes, she says, doctors “feel like their responsibility is to offer all of the options, like a menu, rather than guiding the patients and the family, based on the patient’s individual situation, to what’s best. But that’s our job.”

A doctor doesn’t necessarily have to lead the entire conversation, but it’s important that the doctor initiates it, Back says. Then the patient

Patients live an average of 29 days longer under hospice oversight compared with similar patients who didn’t opt for hospice care.

Source: *Journal of Pain and Symptom Management*, 2007

can be referred to a social worker or nurse for a more extensive discussion. If family members want to be involved, so much the better, he says. Sometimes patients are reluctant to raise these subjects with family members.

Keep in mind that even the most sensitive and astute physicians may encounter some awkwardness or emotional sensitivity, Back says. “Don’t let a little bit of awkwardness derail you from the whole conversation.”

ADDRESSING MISUNDERSTANDINGS

In 2009, nearly 42 percent of all U.S. deaths occurred under the care of a hospice program, according to the NHPKO. Yet, there are still significant misunderstandings about the role of hospice and palliative care, says Schumacher. “A lot of people feel like when they get referred to hospice that they are going to die immediately,” he says.

In fact, patients live an average of 29 days longer under hospice oversight compared with similar patients who didn’t opt for hospice care, according to a 2007 study published in the *Journal of Pain and Symptom Management*. The survival difference in the study, which was sponsored by NHPKO, was the greatest for congestive heart failure, lung cancer, and pancreatic cancer. Heart failure patients experienced the greatest benefit, living an average of 402 days versus 321 days for those who didn’t choose hospice.¹⁰

Patients sometimes worry that palliative or hospice care means no treatment whatsoever, says Schumacher, who describes the two approaches to medical care as existing along a continuum. A palliative care patient may still receive some aggressive treatment, but also intensive management of pain, nausea, and other quality-of-life symptoms. Doctors must emphasize that patients will still be cared for, but with a different focus, says Fine: “Do everything to the role of comfort versus everything to the role of cure.”

Researchers in Boston have published a few studies looking at whether watching a video helps terminally ill patients better understand the differences between aggressive interventions and comfort care, compared with just getting a verbal description of those options. One study involving 50 brain cancer patients, published 2009 in the *Journal of Clinical Oncology*,¹¹ revealed that of the 23 patients who watched a six-minute video depicting different clinical scenarios, ranging from aggressive interventions to comfort care, 21 chose comfort care. None chose life-prolonging care, which would have included CPR and mechanical ventilation.

A second group of 27 patients heard a verbal description of the end-of-life options; six chose comfort care. Seven patients chose life-prolonging care. The remaining patients in both groups opted for what study authors described as basic hospital care, in which antibiotics and intravenous fluids would be provided, but not more aggressive interventions, such as CPR.

When Back raises the possibility of hospice, he doesn’t necessarily use the word itself with the patient right away. Instead he talks about how a shift in treatment might improve their quality of life. He described a recent patient, a woman with a terminal diagnosis whose husband was struggling with all of her medications. Back told the woman that he could schedule nurses to visit her home and assist with adjusting her pain medication. The best way to do that, he told her, was to enroll her in hospice care.

A RECURRING CONVERSATION

Talking honestly upfront about patients’ end-of-life goals and desires will not only help them, but possibly also their loved ones, Keating says. She cited a study published in 2008 in the *Journal of the American Medical Association* which assessed quality of life for pa-

tients and caregivers. It found that patients who were counseled about end-of-life decisions were not only referred earlier to hospice, but also reported less emotional distress, as did their caregivers.¹²

As treatment progresses, a doctor can always provide a variety of scenarios, honestly discussing the best case scenario and the worst case scenario, Christopher says. Given that nothing is set in stone in medical care, the doctor should be prepared to revisit that conversation, should medical circumstances change, Christopher says. “I don’t think you smack people in the face with this all at one time—I think it is a process.”

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.

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RESOURCES

For more information about hospice and end-of-life care, check out these organizations:

Advanced Care Planning Decisions: This nonprofit organization emerged from some of the work done by Boston researchers, using videos to help educate patients about comfort care and other treatment options: <http://www.acpdecisions.org/home.html>

American Society of Clinical Oncology: The professional group has recently developed a booklet for patients and families, discussing palliative care, hospice, advanced directives, and other end-of-life decisions: http://www.cancer.net/patient/Coping/Advanced%20Cancer%20Care%20Planning/Advanced_Cancer_Care_Planning.pdf

Coalition to Transform Advance Care Planning: The Center for Practical Bioethics has launched an initiative to improve the transition from aggressive treatment to palliative or hospice care, as well as to improve related clinician and patient education: <http://practicalbioethics.org/aging-and-end-of-life-care/coalition-to-transform-advance-care-planning/>

Education in Palliative and End-of-Life Care: An educational initiative, which provides conferences and online learning opportunities: <http://www.epec.net/>

National Hospice and Palliative Care Organization: The non-profit organization includes resources about hospice care, as well as links to other professional groups: <http://www.nhpco.org>

Oncotalk: Provides training and an expanding series of online modules, videos, and other resources to assist oncologists with discussing prognosis, end-of-life care, and other difficult topics: <http://depts.washington.edu/oncotalk/>