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PROFESSION

Susan M. Block, MD, believes a checklist can ensure that patients get better end-of-life care, such as appropriate use of hospice. "The checklist systematizes an approach to individualizing patient care," she says. Photo by Bizuayehu Tesfaye / AP images for American Medical News

How to talk about hospice care

■ The discussions are trying for everyone involved. But there are concrete strategies to make these end-of-life care talks go more smoothly.

By KEVIN B. O'REILLY (HTTP://WWW.AMEDNEWS.COM/APPS/PBCS.DLL/PERSONALIA?ID=KOREILLY) amednews staff — Posted March 18, 2013

About once a year, a patient or family member will "jump up and just walk out of the room when I mention hospice," says David Casarett, MD, chief medical officer of the University of Pennsylvania Health System's hospice program.

"They will say: 'We came to Penn for the best possible treatment. You were supposed to save Dad's life, and now you're giving up on him. How dare you do that to my father!' "

Even though such harsh reactions may be the exception, Dr. Casarett says, they are enough to make many doctors uneasy about bringing up hospice — a program that offers at-home nursing care, pain and symptom relief, spiritual counseling and other services but typically requires patients to forgo disease-directed treatments that aim to extend survival time.

"Physicians don't want to cause that sort of distress," says Dr. Casarett, associate professor of medicine at the Perelman School of Medicine at the University of Pennsylvania. "We're basically nice people. We don't want to walk in and start a conversation that will make a person start crying."

Rising hospice use, shorter stays

More Americans than ever are dying under hospice care. The number exceeded 1 million in 2011, according to the National Hospice and Palliative Care Organization, which represents hospices. Even as more patients choose hospice, physicians who specialize in end-of-life care say enrollment often comes too late for dying patients and their families to get the most from the service.

Between 2000 and 2009, the share of Medicare patients dying in hospitals fell from 33% to 25%, while those in hospice at the time of their deaths rose from 22% to 43%, according to a Feb. 6 study in *The Journal of the American Medical Association*. That trend is belied by a rise in the level of burdensome care that patients receive in the three months before they die, the study found.

The average number of care transitions in the last three months of life rose from 2.1 to 3.1. Seventy percent of patients were hospitalized within 90 days of death, with 12% being hospitalized three times or more. Nearly a third of patients visited the intensive care unit in the 90 days before death, and 9% were ventilated sometime in their final month. All of these figures were increases from 2000 figures.

Meanwhile, the number of patients who spend three days or less under hospice care before death has more than doubled to 10% since 2000, the study said. The median length of time patients spend in hospice fell from 21.1 days in 2009 to 19.1 days in 2011, according to the NHPCO.

Many factors contribute to late hospice enrollment, experts say. These include prognostic uncertainty about the required terminal diagnosis of less than six months to live that is required under the Medicare hospice benefit and widespread misconceptions among patients and families about hospice care.

Too often, discussion about how hospice can help meet patients' and families' goals of care is delayed for too long. These are difficult talks to have, experts say, and it is important to start them early and to do them right.

A checklist for end-of-life care

One way to make sure these critical, emotionally charged end-of-life care talks happen may be to make them routine. That's the strategy of Susan M. Block, MD, and her colleagues at the Dana-Farber Cancer Institute in Boston. They are using the same kind of checklist approach that has cut surgical complications and central line-associated bloodstream infections dramatically.

Cancer remains the most common primary diagnosis for patients in hospice care, accounting for 38% of patients in the program nationwide, the NHPCO says. And while nearly 90% of patients with cancer have documented end-of-life care talks with doctors, most of the discussions happen while patients are hospitalized, less than five weeks before death, with physicians other than the patient's oncologist, according to a Feb. 7, 2012, *Annals of Internal Medicine* study.

DID YOU KNOW:
More Americans than ever before are dying under hospice care — more than a million in 2011.

“The average time of the first conversation about end-of-life is 33 days before death,” says Dr. Block, chair of the Dept. of Psychosocial Oncology and Palliative Care at Dana-Farber. “That's really late, when you think about how much people have to come to terms with emotionally, as well as the practical issues, the family issues, the transportation issues, all the issues about getting care set up, making decisions about next steps.

“That's a lot to do in the last month of your life, if you haven't started to prepare psychologically beforehand — not to mention that you're wicked sick.”

Dr. Block is principal investigator of a trial of the serious illness communication checklist with 60 oncologists and 450 patients. The trial began in June 2012, and data on patient and family satisfaction and treatment choices, including rates of hospice use, will be collected for three years.

Oncologists taking part in the trial get a 2½-hour training session on how to use the checklist. Nurse practitioners can take the training and help conduct patient discussions, which last between 25 and 40 minutes. Health professionals are asked to use the checklist with patients who are estimated to have less than a year to live to discuss:

- Their understanding of the prognosis.
- How much information they want shared with loved ones.
- Their goals of care, should their health seriously worsen.
- Their biggest fears and what functional abilities they could not imagine living without.
- How much medical intervention they are willing to undergo to gain more time.
- How much they want family members to know about their priorities and wishes.

The discussions will be documented and periodically updated in the patient's electronic health record so that the treatment team is on the same page about what the patient's understanding, values and goals are. Making a routine of the care-planning process can accustom patients to the difficult choices they soon may be faced with, such as whether to transition to hospice care, says Dr. Block, professor of psychiatry and medicine at Harvard Medical School in Boston.

“Hospice is the gold standard for end-of-life care for most people,” she adds. “Yet for many patients, that first conversation about hospice is the first time anyone has told them that their disease wasn't going well. It's just too much to take that in. … We want people to be prepared with the first hospice conversation before it's a crisis.”

The primary care physician's role

Dr. Block and her team are expanding the checklist for use among dialysis patients. While it is under study, the complete checklist is not publicly available. In the meantime, experts offer advice for physicians to walk patients and families through difficult end-of-life care choices.

Most agree that the primary care physician should be the one to take the lead in having such talks, even when a specialist is taking on the bulk of the care in treating the life-threatening illness. But it is important for primary care doctors to have consulted with the treating specialist about their prognosis. Simply asking, “How long do you expect this patient to survive?” is a good way to get a handle on the situation, experts say.

“It's helpful to have had that conversation with the oncologist, or if it's end-stage heart disease with the cardiologist,” says Charles Cutler, MD, a general internist in Norristown, Pa. “If that conversation hasn't taken place, that can be really problematic, because then the patient will throw at me, 'Well, Dr. Jones told me he could do this treatment or procedure, so why aren't we doing that?' Then, I've lost any kind of credibility within the conversation.”

Not only should hospice care talks happen earlier in the course of the life-threatening illness, but they also should be given an adequate amount of time, Dr. Cutler says.

“These aren't quick conversations,” he says. “Don't expect fast decisions. Don't even try that, because if it hasn't been thought through by the patient and the family, then they'll have second thoughts and buyer's remorse and all of that. You want to have a thorough conversation spread out over a long enough period of time so they feel comfortable with it. If that family's not ready, or the patient's not ready, it doesn't help to try and convince them.”

Never: “Nothing more we can do”

Often, patients and their families have misconceptions about hospice care. They may believe that the patient must be bedridden, actively dying or only days away from death to qualify, or that their time in hospice will be marked by pain treatment to the point of near sedation.

All of these are myths, experts say. Earlier enrollment in hospice can mean enjoying a more active life freed from draining and burdensome disease-directed treatment. And pain treatment can be balanced with other patient goals, such as being more alert to enjoy time with loved ones.

The biggest objection, of course, is fear of death and that enrolling in hospice means “giving up.” Experts acknowledge that hospice care is not for everyone, and that patients who would like to pursue long-odds treatment should do so. It is true that some patients will die more quickly under hospice care than under disease-directed treatment, but many others live longer than they would undergoing aggressive interventions.

Patients — and relatives worried about losing their loved ones too soon — often say they do not want to stop "fighting" a life-limiting disease such as cancer. That language can be turned around in favor of comfort care, says R. Sean Morrison, MD, director of the Hertzberg Palliative Care Institute at Mount Sinai Hospital in New York.

"I respond by saying, 'There are many ways of fighting. What we know is that the treatments we have specifically directed at your tumor are no longer shrinking your tumor. I wish we had a treatment that could take this all away, but we don't. So we need to focus on other treatments that will enable you to have the best quality of life you can have for the longest period of time. That means focusing on pain, avoiding infections, spending more time with your family,' " Dr. Morrison says.

One phrase that everyone agrees doctors never should utter during the hospice care discussion: "There's nothing more we can do."

"Saying that strikes at patient fears about abandonment, and it says, 'I'm giving up on you,' or it is perceived that way," Dr. Morrison says.

Many patients simply do not care to dwell on dying. Enrolling in hospice should not necessarily mean a constant parade of death chat, says Eytan Szmuilowicz, MD, a palliative care specialist at Northwestern Memorial Hospital in Chicago.

"I don't think we have to focus on this idea of 'letting go' if it's difficult for people to do," he says. "Just because you're in hospice, you don't have to talk about dying all the time. Let's focus on your living for whatever time you have left, knowing there will be some limitations around this. Let's focus on how well you can live in whatever way we can control that."

Many hospice and palliative care specialists say that referrals to hospice care will continue to be delayed as long as the Medicare benefit requires patients to forgo disease-directed treatment. A provision of the Affordable Care Act calls on the Dept. of Health and Human Services secretary to conduct a three-year, budget-neutral demonstration project of "concurrent care" for Medicare patients at 15 hospice-care sites. Concurrent care is the simultaneous provision of curative and palliative treatments in a hospice care setting.

A Centers for Medicare & Medicaid Services spokeswoman confirms that no request for proposal has been issued related to the provision and notes that the ACA "did not provide funding for the program." She added that CMS is "working to identify ways to improve the hospice benefit in Medicare," but did not respond to requests for further details by this article's deadline.

Ultimately, there is no way to make discussions about hospice care painless, says Timothy E. Quill, MD, immediate past president of the American Academy of Hospice and Palliative Medicine. The organization represents about 5,000 doctors who specialize in treating patients with serious, life-limiting illnesses.

"I probably know more about this than anybody, but it's still a hard discussion," he says. "We have to tell people that things aren't going well, that they're more likely than not to die. Each of those things is a hard nut to swallow."

But, he adds, addressing hospice during earlier stages of treatment can make the talk a little easier.

"So, then, at least they've heard the word," Dr. Quill says. "It's not completely out of the blue."

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ADDITIONAL INFORMATION

15 steps in the hospice discussion

Talks about hospice should not come without context. Instead, experts say, they should emerge from a series of discussions about the patient's care, values and goals.

1 **Identify other decision-makers.** "Who in the family should be there with us when we discuss the results?"

2. **Assess understanding of prognosis.** “What have other doctors told you about your condition? … From what you know, do you think that over the next month your cancer will get better or worse, or stay the same?”

3. **Define the patient's goals for care.** “What do you hope for most in the next few months? … Is there anything you're afraid of?”

4. **Reframe goals.** “I wish we could guarantee that we could keep you alive until your daughter's graduation, but unfortunately we can't. Perhaps we can work together on a letter for her to read on that day, so she will know you are there in spirit in case you cannot be there.”

5. **Identify needs for care.** “It can be very difficult to care for a family member at home, and no one can do it alone. Have you thought about what kinds of help you might need?”

6. **Summarize and link goals with care needs.** “So I think I understand that your main goal is to stay at home and spend time with your family. To do that, we will need to help you in several ways, for instance, by sending a nurse out to your home and giving you both some help around the house. Is that right?”

7. **Introduce hospice.** “One of the best ways to give you the help that you will need to stay at home with your family is a program called hospice. Have you heard of hospice? … Hospice can provide more services and support at home than most other home-care programs, and the hospice team has a lot of experience caring for seriously ill patients at home.”

8. **Acknowledge emotional response.** “You seemed surprised to learn how sick you are. … I can see it's not easy for you to talk about hospice.”

9. **Legitimize reaction.** “Many people are understandably upset when they learn how ill their loved one is and that hospice is a possibility.”

10. **Empathize.** “I can imagine how hard this is for both of you; you care about each other so much.”

11. **Explore concerns.** “Tell me what's upsetting you the most.”

12. **Explain hospice goals.** “Hospice doesn't help people die more quickly; it helps people die naturally, in their own time.”

13. **Reassure.** “Hospice's goal is to improve your quality of life as much as possible, and to help you and your family make the most of the time you have left.”

14. **Reinforce commitment to care.** “Let's think this over for a day or two; you know I will continue to care for you whatever decision you make.”

15. **Recommend hospice.** “Hospice could be very helpful to you in the ways that we've talked about, but I realize it's a big decision. I'd like to arrange for a hospice nurse to visit you so you can decide for yourself whether hospice is right for you.”

Source: “ 'I'm Not Ready for Hospice': Strategies for Timely and Effective Hospice Discussions,” *Annals of Internal Medicine*, March 20, 2007 (link)

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7 prevalent myths about hospice care

Terminally ill patients and their loved ones sometimes react negatively when physicians bring up hospice. Part of that reaction may be due to widespread misconceptions.

Myth: Hospice means that the patient will die soon.
Reality: Receiving hospice care does not mean that death is imminent. The earlier an individual receives hospice care, the more opportunity there is to stabilize the patient's medical condition and address other needs.

Myth: Hospice means giving up hope.
Reality: When faced with a terminal illness, many patients and relatives tend to dwell on the imminent loss of life rather than on making the most of the life that remains. Hospice can help them understand that even though death can lead to sadness, anger and pain, it also can lead to opportunities for reminiscence, laughter, reunion and hope.

Myth: Patients can receive hospice care for only a limited amount of time.
Reality: The Medicare benefit and most private insurance pay for hospice care as long as the patient continues to meet the necessary criteria. However, if the patient lives beyond the initial six months, he or she can continue receiving hospice care as long as the attending physician recertifies that the patient is terminally ill.

Myth: To be eligible for hospice care, a patient must be bedridden.
Reality: Hospice care is appropriate at the time of the terminal prognosis, regardless of the patient's physical condition. Many of the patients served through hospice continue to lead productive and rewarding lives. Together, the patient, family and physician determine when hospice services should begin.

Myth: Hospice is a place.
Reality: Hospice care usually takes place in the comfort of an individual's home, but can be provided in any environment where a person lives, including a nursing home, assisted-living facility or residential care facility.

Myth: When a patient elects hospice, he or she no longer can receive care from the primary care physician.
Reality: Hospice reinforces the patient-primary physician relationship by advocating either office or home visits, according to the physician's preference. Hospices work closely with the primary physician and consider the continuation of the patient-physician relationship to be of the highest priority.

Myth: When a patient elects hospice care, he or she cannot return to traditional medical treatment.
Reality: Patients always have the right to reinstate traditional care at any time, for any reason. If a patient's condition improves or the disease goes into remission, he or she can be discharged from a hospice and return to aggressive, curative measures, if so desired. If a discharged patient wants to return to hospice care, Medicare, Medicaid and most private insurance companies and HMOs will allow readmission.

Source: Hospice Foundation of America's HospiceDirectory.org (link)

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EXTERNAL LINKS

"NHPCO Facts and Figures: Hospice Care in America, 2012 Edition," National Hospice and Palliative Care Organization, November 2012 (**link: http://www.nhpco.org/sites/default/files/public/Statistics_Research/2012_Facts_Figures.pdf**)

"Change in End-of-Life Care for Medicare Beneficiaries: Site of Death, Place of Care, and Health Care Transitions in 2000, 2005, and 2009," *The Journal of the American Medical Association*, Feb. 6 (**link: http://jama.jamanetwork.com/article.aspx?doi=10.1001/jama.2012.207624**)

"End-of-Life Care Discussions Among Patients With Advanced Cancer: A Cohort Study," *Annals of Internal Medicine*, Feb. 7, 2012 (**link: http://www.ncbi.nlm.nih.gov/pubmed/22312140/**)

" 'I'm not ready for hospice': strategies for timely and effective hospice discussions," *Annals of Internal Medicine*, March 20, 2007 (**link: http://www.ncbi.nlm.nih.gov/pubmed/17371889**)

Hospice Foundation of America's HospiceDirectory.org on hospice myths and realities (**link: http://www.hospicedirectory.org/cm/about/choosing/myths_facts**)

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