

What Every Doctor Should Know About Hospice

KEY FACTORS TO CONSIDER WHEN WEIGHING ITS BENEFITS

BY CHARLOTTE HUFF

AS A TERMINALLY ILL PATIENT REACHES THE FINAL MONTHS OF LIFE, a cadre of specialists is often on hand to address many of the daily medical decisions. But it's the family doctor whose relationship with the patient has been developed over time, perhaps years, who is best situated to help sort through emotional end-of-life decisions, according to palliative medicine specialists.

A trusted family doctor might benefit from an intuitive sense of the patient's family dynamics, life goals, and spiritual influences. That physician might have witnessed firsthand how the patient handled prior treatment dilemmas. Thus, it might be easier for the patient's regular doctor to appreciate how sick the patient truly is, and that it's time to raise the possibility of a hospice referral, says David Casarett, a palliative medicine specialist, associate professor of medicine at the University of Pennsylvania, and the author of "Last Acts: Discovering Possibility and Opportunity at the End of Life."¹

"I would argue that primary-care doctors really have the largest role to play," says Casarett. "When you think about a specialist and the specialist's role, they get their blinders on, and they focus on a particular problem." An oncologist might be scrutinizing blood work and imaging scans, the cardiologist the

ejection fractions, and so on, he says. "Since primary-care providers are not in these ruts of treating one problem after another, but are trying to synthesize, they sometimes have a better perspective."

For these reasons, the primary-care physician can help facilitate a sometimes difficult decision-making process for terminally ill patients and their families. Don Schumacher, president of the National Hospice and Palliative Care Organization, describes a recent conversation with a friend, whose father has Alzheimer's disease and had just been referred to hospice care. "The primary-care doctor made the referral," Schumacher says. "She said that she thought that it was better that the primary-care doctor did so, because they had a long-standing relationship with him."

But that closer doctor-patient relationship also can become a double-edged sword, sometimes muddying the doctor's diagnostic assessment, says Holly G. Prigerson, who directs the Center for Psycho-oncology and Palliative Care Research at Dana-Farber Cancer Institute in Boston.²

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The logo for Crossroads Hospice features a stylized green figure with arms raised, resembling a person or a plant, above the word "Crossroads" in a cursive font and "HOSPICE" in a bold, sans-serif font below it.

Prigerson cites one study, published in 2000 in the *British Medical Journal*,³ which shows that the longer a doctor has treated a patient, the greater the likelihood of misjudging survival. “There may be some wishful thinking bias,” Prigerson says. “The closer they feel they identify with this person, the harder it is for them to be objective and to outline a grim prognosis.”

That bias may be one reason that the transfer of terminally ill patients to hospice by their primary-care physician is too often delayed, sometimes until the final days of life, according to data from National Hospice and Palliative Care Organization (NHPCO).

In 2010, nearly 1.6 million people received hospice care, with a median stay of fewer than three weeks (19.7 days), according to the latest NHPCO data. Slightly more than one-third of patients, 34.3 percent, were enrolled for a week or less before they died or were transferred to another program.⁴ Although it’s unclear precisely how many referrals to hospice are initiated by primary-care doctors, NHPCO president Don Schumacher estimates that roughly half involve one.

Among cancer patients, 64.9 percent spend at least part of their final month in the hospital, according to a study published in April in the journal *Health Affairs*. The average number of hospitalized days was 5.3, according to the analysis, which looked at data from 215,311 Medicare patients who died during the period 2003 to 2007.⁵ By comparison, 53.8 percent of patients received at least some hospice care during that last month.

“I think the paper showed that the default in this country is for aggressive care,” says family practitioner Nancy Morden, the study’s principal investigator and an assistant professor at the Audrey and Theodor Geisel School of Medicine at Dartmouth.⁶ “Sixty-four percent [hospitalized] is much higher than I would

deem is warranted clinically. That doesn’t likely reflect comfort care and palliation.”

Although public awareness of hospice’s role has increased substantially over the last decade, doctors still sometimes wrestle with misconceptions and hurdles in making the transition to hospice care, including with their own emotions, internist and palliative medicine specialist Dan Maison says.

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Dan Maison, internist and Palliative Medicine Specialist

“Some doctors equate calling hospice with giving up,” says Maison, medical director of the palliative care program at Spectrum Health, a non-profit health system in Grand Rapids, Michigan. “But they are not giving up at all. It’s just recognizing that people are at a certain place in their illness and need the extra help.”

REFRAMING HOPE

Certainly the conversation about initiating hospice care, particularly if it’s been too long delayed, can be a difficult one for both doctor and patient, Maison says. Many of today’s doctors received little to no training on end-of-life care during medical school, and thus have had to learn the best ways to initiate these conversations through trial and error. “I think if somebody has had a bad experience early in their career,” Maison says, “it could absolutely color how they approach this in the future.”

On the extreme end, doctors involved with palliative care have been accused of hastening a patient’s death, according to a study published in March in the *Journal of Palliative Medicine*.⁷

Overall, 57 percent of the 663 palliative medicine specialists surveyed reported at least one experience during the prior five years in which a fellow clinician had characterized palliative care as euthanasia, murder, or killing. A similar number, 59 percent, said that a patient’s loved one had made a similar accusation to them. An allegation of euthanasia was most likely if the

doctors used either palliative sedation or stopped artificial hydration/nutrition, according to the respondents.

But psychiatrist Lewis M. Cohen believes that primary-care doctors are less vulnerable to these sorts of tensions.⁸ “They have the connection with the patients and the family that goes back over a period of years,” says Cohen, an author on the study, which was funded by The Greenwall Foundation in New York. “They will accordingly know their beliefs and be aware of them.”

One way to raise the option of hospice is by first exploring the patient’s goals for his or her remaining time, says Casarett, who provides some strategies for hospice discussions in a 2007 *Annals of Internal Medicine* article.⁹ When the patient describes a specific goal, such as maximizing time at home with the grandchildren, then the physician can outline the type of services that would make that possible, such as medication delivery and caregiving assistance for the spouse. Only then, Casarett suggests, should the physician pause and say, “Have you heard of hospice?”

Understandably, doctors worry about upsetting someone who is very ill, notes Maison. “They will say, ‘I don’t want to hurt the patient’s feelings. I don’t want to scare the patient. I don’t want to take away hope,’” he says.

But doctors can reframe hope in powerful ways for patients and their loved ones, Maison stresses. “Hope that you’re going to be as comfortable as possible. Hope that you’re going to be able to live your life every day as best you can. And that you’re going to be able to spend your last days, weeks, and months at home with your family.

“What’s been amazing to me, and I’ve been doing this now for about 14 years, is I’ve seen people grow amazing amounts in just days or weeks.”

BEYOND NURSING CARE

While some hospice services are well known, such as nursing care and pain control, there are other types of assistance that can be equally beneficial, Maison says. Medicare not only pays for vital equipment for the patient’s home, such as oxygen and a hospital bed, but also makes available a long list of home health aides, social workers, chaplains, and hospice volunteers to ease some

of the logistical and emotional challenges of caring for a terminally ill patient in his own home, he says.

“You take a family who on a good day has a hard time coping, and then you throw in the stress of losing somebody’s mom or the patriarch of the family, [and] you can imagine how much support that family needs to get through that,” he says.

Neither does the hospice relationship cease once the patient dies. Hospice can provide bereavement support for up to 13 months afterward, Schumacher says. For every patient who dies, two family members on average take advantage of the bereavement counseling, according to NHPCO data.¹⁰ “That’s a very big thing, because oftentimes families are really lost after that death occurs,” he says.

A 2010 study, published in the *Journal of Clinical Oncology*, illustrates how a network of hospice support can assist not just the patient but also their loved ones.¹¹ The study, which followed 333 patients with advanced cancer, found that those who died in the hospital experienced a worse quality of life, including more physical and emotional distress at the end of life, compared with those who died at home under hospice care. In addition, their caregivers were more likely to suffer from mental health issues, including post-traumatic stress disorder or prolonged grief disorder, according to the same study.

EXTENDING LIFE?

Beyond the quality of a patient’s life is hospice’s impact on the length of life. Contrary to notions that hospice is tantamount to euthanasia, some studies have indicated that patients can live longer within a hospice program than in traditional care. One analysis of nearly 4,500 Medicare patients, including those with congestive heart failure and cancer, calculated that survival among hospice patients averaged 29 days longer than non-hospice patients.

The survival difference was statistically significant for three of the six diseases studied, including congestive heart failure, lung cancer, and pancreatic cancer, according to the findings, published in 2007 in the *Journal of Pain and Symptom Management*.¹² It was marginally significant for colon cancer; no significant

survival difference was identified with breast or prostate malignancies.

To be eligible for hospice under Medicare, the patient's physician and the hospice medical director must certify that the patient is anticipated to live fewer than six months, if the disease follows its normal trajectory.¹³

The survival prognosis for some diagnoses, such as an aggressive malignancy, might be easier to predict, Schumacher says. But just one-third of hospice patients have a diagnosis of cancer, according to NHPCO data. The other leading diagnoses are: heart disease (14.3 percent); unspecified debility (13 percent); and dementia (13 percent).¹⁴

But doctors aren't being called upon to play fortune teller, an occasional misconception, Schumacher says. "I think that they believe that if the patient doesn't die within six months, that they [the patients] are going to get kicked off the program," he says. "And in fact, that's not the case."

A patient can be recertified for hospice as long as he is still believed to be within six months of death, Schumacher says. Nearly one in eight patients, 11.8 percent, are enrolled in hospice care for six months or longer, according to NHPCO data.¹⁵

Moreover, hospice is a two-way door: Patients can be discharged if their illness takes a turn for the better, or if they decide they want to try a new chemotherapy regimen, or another form of treatment, Schumacher says.

But patients who do leave hospice also are more likely to return to the hospital, according to a 2010 *Journal of Clinical Oncology* study.¹⁶ The study, based on data from 90,826 cancer patients who died between 1998 and 2002, found that 10.9 percent left hospice care prior to their death. Of those, 39.8 percent were subsequently hospitalized compared with 1.6 percent of patients who remained with hospice. They also were more likely to die in the hospital; 9.6 percent compared with 0.2 percent of hospice patients.¹⁷

FINANCIAL-QUALITY EQUATION

Those patients who disenrolled from hospice also incurred higher Medicare costs, according to the 2010 study's findings. The average bill totaled \$30,848 — 39 percent of which paid for hospice

care. Patients who remained with hospice until they died averaged \$6,537 in medical costs, 89 percent of which paid for hospice services.

The cost of more aggressive care also can reverberate beyond the price tag itself, says Prigerson. She authored another end-of-life cost analysis involving end-of-life discussions, published 2009 in the *Archives of Internal Medicine*.¹⁸

That study, which focused on costs in the final week of life among 603 patients with advanced cancer, found that 31.2 percent had talked to their doctor about their end-of-life preferences. The care for those patients cost \$1,876 during the final week of life, compared with \$2,917 for those patients who had not discussed their wishes. If the frequency of those conversations increased to half of all terminal cancer patients in the U.S., the national cost savings would exceed \$76 million annually, according to the researchers' projections.

"This is a rare instance of a win-win," Prigerson says. "We called it the multi-million dollar conversation."

But dollars and cents only paint part of the picture, says Prigerson, who is also an associate professor of psychiatry at Harvard Medical School. Those higher medical costs were also associated with a worse overall quality of death, including more physical stress in the final week, as reported by the caregiver, the study found.

In short, there's a higher cost to misery, Prigerson says. "The more you spend, because all of those procedures are so expensive, you are buying a worse quality of life, not a better quality of life."

STAYING CONNECTED

Even after the patient is transferred to hospice, the family doctor can and is encouraged to stay closely involved. Physicians can reassure patients directly by emphasizing that "they haven't given up on them, and that they'll still be there for the patient," Prigerson says. "That's usually important. No one likes to say goodbye."

Also, primary-care doctors can share stories and insights that can prove highly valuable to the hospice caregivers, Maison says. "Since they've gotten to know the patient over a long, long time, they've

gotten a really good sense of who they are as people beyond what illness has landed them in the hospital," he says.

Ideally, the family doctor also can set the stage a bit earlier for these end-of-life decisions, so the transition to hospice doesn't feel abrupt, Maison says. One such opportunity might occur after a patient with a terminal and worsening illness, such as heart failure, lands in the hospital for a stretch.

During that first follow-up visit, after the patient has returned home, the family doctor can use that episode to explore the patient's feelings about aggressive care, should their condition suddenly worsen, Maison says. "You can say, 'That was a pretty big medical event,'" Maison says. "We should probably talk about what your choices are. I want to make sure that I know what you want, should this happen again."

In many respects, no one is better suited to this role than the family doctor, Dartmouth's Morden says. "A long-term trusting relationship helps these conversations happen," she says. "People are far more afraid of care rationing than they are of being tortured at the end of life."

In the *Health Affairs* study, Morden notes, 9.3 percent of patients got a feeding tube, ventilator support or cardiopulmonary resuscitation during the final month of life. "Those are painful procedures," she says.¹⁹

Some people will always opt for more aggressive care, Morden and others point out. But when a doctor takes the time to walk a patient through the relevant factors in considering hospice, it is more likely that the patient's desires will be fulfilled. ▀

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