Let’s talk to our patients about hospice

Too many who could benefit from it are learning about the option too late.

BY BARRY BAINES, MD, AND JANELLE SHEARER, RN, BSN, MA

Hospice care can provide patients who have life-limiting illnesses with relief from pain and other physical symptoms; help with the emotional, spiritual and psychosocial issues associated with the end of life; and a better quality of life during the time they have left. It is also cost-effective. A Duke University study showed that hospice use reduced Medicare expenditures during the last year of life by an average of $2,309 per patient, as it can ward off problems that can lead to hospitalization.

Many Minnesotans who could benefit from hospice care, however, are not receiving it in a timely manner. All too often, the hospice option is mentioned too late by physicians and others involved in the patient's care. In addition, many people have misconceptions about hospice.

Although coverage for hospice services is available through Medicare, it is underutilized because Medicare beneficiaries often do not understand how the benefit works. As a result, many people don't know they are eligible for hospice care. Also, they may believe they can get hospice care only if they have a short time to live. The national average length of stay in hospice is 70 days. In 2011, Minnesota Medicare patients were in hospice an average of only 56 days.

In addition, a number of patients and their families believe hospice care ends after six months—and that they will be “kicked out” if they still need care. That is not the case. After six months, patients can be recertified for the hospice benefit. Typically, the hospice medical director or a nurse practitioner conducts a face-to-face evaluation to determine if the patient still meets the hospice criteria (ie, if the patient's illness were to follow its expected course, their prognosis would be six months or less).

Patients aren't the only ones who are misinformed about hospice. Some physicians don't understand what it means to care for a patient who is in hospice. At one hospice, a man who was dying from cancer and suffering from frequent urinary tract infections (UTIs) was not given IV antibiotics. When asked about treating the UTI, the patient's doctor responded, “I thought he was in hospice.” This physician did not understand that aggressive treatment for the UTI was still appropriate care for someone in hospice, given that the goal of the treatment is comfort.

Misconceptions on the part of both physicians and patients have contributed...
to low hospice use across the nation. Also contributing to low use is the fact that on average physicians overestimate patients’ prognosis by 500 percent (they think a patient has five months to live, but the patient actually has only one).¹² That optimism may lead physicians to a later hospice referral—or none at all.

**Identifying barriers to hospice**

In 2013, Stratis Health launched a one-year project called Targeting Resource Use Effectively (TRUE) to explore ways to increase use of hospice services. The project, funded by the Centers for Medicare and Medicaid Services’ Quality Improvement Program, focused on three Minnesota communities—Alexandria, Mora and Waconia. We chose those communities because we recognized there was a significant opportunity to improve the use of hospice services in them.

We then worked to identify barriers to hospice care in all three. To do that, representatives from each of the communities had conversations with members of the general public, health care providers, patients who were currently in hospice or had used hospice in the past and their families. We asked them how they would describe hospice, whether they would consider it if they were facing a life-threatening illness and if they had concerns about hospice.

We learned from those conversations that the patients nearly all agreed that if they knew they had a life-limiting illness, they’d want to know about hospice. We also identified the following barriers that stood between them and hospice care.

**Patients don’t understand their illness.**

When we spoke with physicians, many said the biggest barrier to referring patients to hospice care was patients being in denial about their illness and/or not accepting that they have a serious condition. Patients may not fully understand their condition. Without this fundamental knowledge, they can’t even begin to ask questions about options for their care.

Their lack of questioning could be construed as denial or lack of acceptance.⁶

**Patients don’t understand differences in treatment goals.**

Hospice program staff said that in their conversations with patients who have a serious illness, many don’t understand what their illness means relative to their prognosis. They may not understand that their treatment will only slow down the course of the disease rather than cure it.

Other research has yielded similar findings. A study at Dana-Farber Cancer Institute, for example, found that 70 percent of patients with advanced lung cancer and 81 percent of patients with advanced colon cancer believed the chemotherapy they were receiving would cure them (the actual cure rates for these advanced cancers is near zero; the five-year survival rate for advanced lung cancer is approximately 1 percent and for advanced colon cancer 11 percent).⁷

**Patients wait for physicians to talk about their illness and hospice and physicians wait for patients to bring it up.**

We found many doctors are willing to have a conversation about serious illnesses with patients and their families, assuming the patient initiates the conversation. At the same time, we found patients were waiting for their doctors to start the conversation and bring up hospice.

**There is lack of clarity about who should conduct end-of-life discussions.**

Another problem we discovered was physicians not knowing which clinician should initiate end-of-life discussions. A specialty physician caring for a seriously ill patient may believe that the primary care physician will talk to the patient about hospice. The primary physician, on the other hand, may believe the specialist should have that talk because the patient’s allegiance as well as responsibility for care management may have been transferred to the specialist. As a result, no discussion occurs, misconceptions about hospice aren’t corrected, and patients and families lose out on hospice benefits.

**Finding solutions**

As part of the TRUE project, we sought to find ways to help qualified patients get timely hospice care. To encourage patients to ask their physicians questions so that they might better understand their condition and prognosis, the first thing we did was create brochures and wallet cards that list the following questions:

- Do I have a serious or life-limiting illness?
- Can my illness be cured?
- If my illness can’t be cured, are there treatments that can slow down my illness?
- What kind of care is available that focuses on making me comfortable?

The brochures and cards were placed in local gathering places in the three communities: churches, beauty salons, restaurants, libraries, senior centers and clinics.

Second, we wrote sample scripts physicians can use to initiate the dialogue with patients who have serious illnesses about various treatment options—curative, remissive and palliative—early on in the course of their illness. The scripts help them have those discussions at a level patients and families can understand. In addition, because we knew primary care physicians tend to share information about expectations and survival prognosis soon after a patient’s diagnosis, we encouraged them to give patients the opportunity to ask questions about where they are with their illness at all visits.

Third, to get physicians to think differently about when hospice is appropriate for a certain patient and to help them identify patients who might benefit from hospice earlier in the course of their illness, we asked them to ask themselves the following question: Would you be surprised if you saw a certain patient’s name in the local newspaper’s obituary column in the next year? If the answer was no, they knew that this was a patient for whom a hospice conversation would be of value.
Early results from our research show that both hospice use and the average length of time in hospice had increased in all three communities. For 2013, the mean length of stay was 33.3 days; for 2014, it was 36 days. If the number of referrals continues at the current rate, the 2014 count was expected to be 916, as compared with 804 actual referrals in 2013.

**Let’s start talking**

In today’s health care environment, it is rare to meet a physician who doesn’t believe in the value of hospice. Both primary care physicians and specialists are responsible for starting the conversation about hopes and goals for care when they see a patient with a serious illness. That conversation should include a discussion about hospice, and patients should be referred for evaluation when appropriate. Patients need to be assured that a referral does not indicate that the physician has given up on them; rather, it will help them better understand their options. The physician might compare it to meeting with a financial planner to discuss hopes and goals for retirement.

The TRUE project has shown that when patients and their care providers talk about hospice with their physicians, appropriate hospice use increases. We hope others can learn from this project and make use of the materials we created for it. We encourage all physicians to start hospice conversations soon after a patient is diagnosed with a life-limiting illness. That way, patients can receive the many benefits of hospice sooner rather than later and live their last days more fully.

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The materials created as part of the TRUE project are available at [www.stratishealth.org/providers/hospice.html](http://www.stratishealth.org/providers/hospice.html).

**REFERENCES**


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