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'I'm not that sick!' Overcoming the barriers to hospice discussions

ABSTRACT

Hospice programs care for patients facing life-limiting illness. Although patients and family members report that they are satisfied once they are enrolled in a hospice service, many patients are referred late or not at all. Several barriers and misconceptions about hospice likely contribute to its underuse. We explore these issues and provide guidance to more effectively communicate with patients about hospice services.

KEY POINTS

Patients and their families benefit more from hospice care if they enroll early enough to develop relationships with the hospice team and can prepare for end-of-life needs.

Both patients and doctors sometimes avoid discussing hospice, but patients are better served if goals of care are realistic and targeted to their true needs.

Conversations with patients about goals of therapy should take place regularly over the course of illness and be modified as necessary over time, so that when the need for hospice arises it does not come as a surprise.

Choosing hospice care does not preclude a patient from keeping a physician, choosing treatments, or withdrawing from hospice care and reinstating hospice benefits at a later time.

Most hospice patients remain in their own homes.

HOSPICE CAN PROVIDE a valuable service to dying patients and their families. But doctors and patients are often reluctant to discuss using hospice until it is too late for them to derive many of the benefits the service offers.

In this article we describe the role and services of hospice, explore misconceptions about hospice care and barriers to discussing the issue, and suggest what to say to facilitate conversations with patients with terminal illness.

HISTORY AND PHILOSOPHY OF HOSPICE

People have provided care for the dying long before any formalized system for end-of-life care was conceived. Hospice as a model for providing palliative care began in the United Kingdom when Dame Cicely Saunders founded Saint Christopher's Hospice in 1967. The first hospice in the United States was founded in Branford, Connecticut, in 1974.

The philosophy of hospice is to provide the total care of patients who have a life-limiting illness, such as cancer, advanced heart disease, acquired immunodeficiency syndrome, amyotrophic lateral sclerosis, dementia, or advanced organ failure. Hospice provides an alternative to what many perceive as the overuse of technology and the lack of symptom control for dying patients, a perception confirmed by the landmark Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) in 1995.[1]

HOSPICE BENEFITS AND SERVICES

Hospice is interdisciplinary: the care team consists of nurse case managers, nursing aides, medical social workers, pastoral care workers, physicians, and volunteers, who address not only the physical, but also the psychological, social, and spiritual needs of patients.

For a patient to qualify for hospice benefits, Medicare requires that a referring physician certify that he or she is likely to live only 6 months or less if the disease follows its natural course.[2] Recognizing the difficulty in accurately predicting time of death, Medicare authorizes payment for hospice care in set periods: two 90-day periods are followed by an unlimited number of 60-day periods.[2] If a patient needs continued care, a hospice physician or medical director must recertify at these intervals that the patient continues to have a life-limiting illness and has goals consistent with hospice care.

Medicare pays the hospice program a capitated fee for medical services, medications, and durable medical equipment related to the hospice diagnosis. Most major insurance companies provide a similar benefit. Medical conditions unrelated to the hospice diagnoses continue to be reimbursed by the patient's insurance, and care for these conditions need not change.

Most patients are referred to hospice too late to fully benefit

DEMOGRAPHIC AND USAGE DATA

Data collected from the National Hospice and Palliative Care Organization's National Data Set help to characterize the population served by hospice.[3] In 2002, one third of patients were over 85 years old, and 56% were women. Most (82%) were white, 50% had a noncancer diagnosis, 58% were served in the home upon admission, and 81% of reimbursement was from Medicare.

Although randomized controlled trials comparing hospice care with usual care are difficult to perform, several large outcome studies are under way.[3,4] Retrospective data suggest that family members of patients who receive hospice services are consistently satisfied with their care.[3,5,6] Unanticipated benefits to patients and families, such as education about the dying process, 24-hour support by telephone, spiritual support, and assistance after the death, were felt to be very helpful aspects of hospice that they wished they had understood better before choosing to enroll.[7]

Despite the positive aspects, only about 25% of patients who die in the United States receive hospice services.[8] The median length of enrollment in hospice in 2004 was 22 days, and 35% of patients received services for 7 days or less.[9] Difficulty in accurately predicting time of death is at least partially responsible for late referral patterns.[10–12] Although few patients or families felt they enrolled too late,[13] those with longer periods of hospice care felt they received more benefit.[14]

BARRIERS AND MISCONCEPTIONS

Numerous barriers and misconceptions about hospice persist. Both patients and physicians may be reluctant to discuss issues surrounding death,[15,16] resulting in unsatisfactory discussions about care and services that may be of value.[17]

A focus group at Cleveland Clinic, consisting of staff and fellows from the palliative medicine and medical oncology departments, identified several barriers and misconceptions related to hospice care, which we will explore.

'I'm not sick enough for hospice'

One of the most common barriers to hospice enrollment is the belief that it is needed only when a patient is in the final stages of dying. Common reactions from patients are "I am not that sick," or "I don't need hospice yet." Physicians may defer hospice referral because a patient "still has a good performance status."

But hospice care is optimal when relationships between the hospice team and the patient and family have time to develop. Experienced hospice workers help prepare patients and families for what they can expect throughout the stages of illness and dying, what to do when common symptoms arise, and how to react when unforeseen events occur. When patients are already too ill or time is too short, adequate preparation is left unrealized.

Suggested discussions. When a patient who could benefit from hospice care objects that it is too early to make use of it, helpful responses are:

- "That is why I wish to refer you now; the time to enroll in hospice is before you are really too ill to receive the full benefits of the service."
- "It is best to have the support system in place before the need arises."
- "This way you can get to know the team that will be there for you."

Another useful approach is to focus on goals of care:

- "I like to involve my patients in hospice whenever our goals of care change. We focused mostly on treating your disease before, but now we are trying to help you live as well as possible by responding to and treating your symptoms. Hospice has particular expertise in doing this."

'Hospice is a place'

Many hospitalized patients envision hospice as a place where they will go after discharge, such as a nursing home or rest home, involving separation from their loved ones. Occasionally, physicians share this misconception. In fact, most patients receive hospice services in their home, with most direct care provided by family members, in deference to a patient's desire to stay and ultimately to die there. If a patient wishes to remain at home, every effort should be made to honor this.

Occasionally, a stay in a nursing home or hospice facility is needed to better manage symptoms, to provide laborious caregiving, or for other reasons. Every Medicare-certified hospice must offer the option of inpatient care for symptom management in either a hospital or an inpatient hospice unit. Most hospices also provide care in nursing homes.

Respite care, involving a brief stay at a nursing facility or inpatient hospice, is also available to provide a break for the family in the event of caregiver fatigue, illness, or necessary travel. Although respite care is typically limited to 5 days at a time, no limit is generally placed on the number of times it can be invoked over the course of the hospice benefit.

'Hospice is only for when it's time to give up'

One of the thornier issues in modern hospice care is what level of intervention is appropriate in the care of a dying patient. The types of interventions can vary widely between hospice agencies, and cost may become a factor in deciding the extent of care. Hospice does not require a patient to stop seeing his or her primary physician.

The philosophy of hospice is to neither hasten nor postpone death. Surveys of Americans show that they prefer to have the dying process occur naturally.[1] However, this does not preclude treating common complications that may occur, such as symptomatic deep venous thromboses, urinary tract infections, respiratory infections, and painful bone metastases.

Electing the type and timing of treatment should always involve a discussion of the goals of care, taking into account the patient's condition, prognosis, personal preferences, symptom distress, and even psychosocial influences.

Many advanced treatments are available to treat chronic and life-limiting disease, such as growth factor injections, transfusions, low-molecular-weight heparin, intravenous antibiotics, targeted chemotherapy agents, and parenteral nutrition. If such treatments are considered, it is important that they be discussed with the patient and family in the context of the goals of care. Reimbursement for treatments is limited, so expensive treatments should especially be appropriate for a patient's situation and condition.

Most hospice patients are cared for in their homes, in deference to their wishes

The benefit of treatment must be carefully weighed against the burden of treatment and the prognosis. For example, interventions such as treatment of hypercalcemia, treatment of anemia with intermittent transfusions or growth factor injections, or treatment of recurrent infections with antibiotics have a substantially different benefit-to-burden ratio in a patient who has not been out of bed for weeks than in a patient who is still ambulatory and functional.

If a patient desires an intervention that hospice does not provide or that the hospice staff believes is not appropriate, the patient always can withdraw from hospice and revert to regular insurance coverage. The hospice benefit may be subsequently reinstated with-out penalty. In the past, a patient who opted out of a hospice benefit might have permanently lost future benefits, but this is no longer the case.

Suggested discussion. For a patient who fears that hospice implies that the medical care system is ready to give up on him or her, one can respond:

- "Choosing to be involved with hospice does not necessarily limit our treatment of problems that may arise in the future—we will look at how you are feeling overall, what the new problem is, and then decide the best approach to treating it."

'I want to get stronger so I can undergo more therapy'

Patients are often told that further therapy might be possible if they can first get stronger. Oncologists sometimes tell this to patients to maintain hope, but it may set unrealistic goals that actually prevent a patient from making the necessary preparations for death. Certainly, some people make considerable gains when in hospice care, usually because of effective symptom management or resolution of the toxic effects of prior treatments.

Suggested discussions. For patients who feel they should not have hospice because they want to recover and get more treatment, helpful responses are:

- "Let's hope for the best and prepare for the worst."
- "Hospice can be the best way to get additional support for your family."

Patients can be reassured that they can withdraw from hospice if they improve and still want additional therapy.

For patients who improve and feel they want more therapy, additional treatment should be considered within the context of their goals of care. A frank and realistic discussion of the potential benefits of further therapy is critical, particularly if their improvement results from resolution of prior toxic effects. A good starting question is:

- "What are you hoping this therapy will do for you?"

Patients who leave hospice and pursue active therapy can always resume hospice should the therapy prove ineffective, intolerable, or inconsistent with their goals.

Sometimes we have to change what we hope for

'I do not want to give up hope'

Hope is believed to be essential for most patients, and conversations about hospice should not detract from that. Physicians often worry that a patient will lose hope if they discuss the possibility of palliative as opposed to curative treatment. But respecting a patient's desire to maintain hope should be balanced with the obligation to provide accurate information and a realistic prognosis.

Hope at the end of life often manifests as an expectation that something will happen to change the current situation. This is natural, and not necessarily unhealthy. But hope should not interfere with the planning and providing of realistic care for present needs.

At times, hope overlaps with religious faith, and patients hope for a miracle from a higher power. It is usually helpful to acknowledge faith; contending it rarely wins trust. It is best to confirm that it is healthy to keep faith while at the same time planning for realistic care goals.

As the benefits of life-prolonging therapy diminish, hope can be refocused on different goals, such as spending quality time with loved ones and finding closure to strained relationships or unfinished business. Discussions are more effective when goals of care are considered frequently over time. Realistic goals can help patients to focus on important life issues, and the burden of providing futile care with finite health resources is reduced.

Suggested discussion. Hope may be refocused on more realistic goals by saying:

- "Sometimes we have to change what we hope for: perhaps hope that pain and suffering can be reduced, hope to spend good quality time with family, or hope to attend an upcoming family event."

■ COMMUNICATION IS KEY

Discussions about palliative care are best approached throughout the course of chronic illness or disease treatment. A discussion of goals of care is appropriate at every step and with every new therapy proposed. The transition to hospice care occurs best when it comes as no surprise to any of those involved.

Communication is the key to understanding needs and feelings of patients and families.

Listening to and understanding concerns, discovering goals and desires, conveying accurate and appropriate information, and proposing a reasonable and mutually agreeable plan of care are the skills that all clinicians should strive to master throughout their patients' course of chronic disease or incurable illness. Such skills ultimately ease the apprehensions and reservations that often limit discussions about hospice.

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