

When to Refer to Hospice

Advice to Physicians

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When to refer to hospice seems like such an easy question. Maybe, like most physicians, you know the Hospice Medicare Benefit pretty well and the answer would come quickly: “when a patient has a life expectancy of probably less than six months.” And that is a good answer, but it really doesn’t get to the heart of the issue. After all, according to the National Hospice & Palliative Care Organization (NHPCO) in Alexandria Virginia, almost one-third of hospice patients die within a week of admission. We all know that timely hospice referrals give patients and their families needed support as they work on the tasks of dying. Why the disconnect?

The studies are very clear. The comprehensive holistic care of hospice, which addresses suffering in all of the dimensions of living (physical, social, psychological, spiritual), greatly improves the quality of life of the dying patient and their family. Hospice improves pain and symptom scores, enhances closure, addresses spiritual needs, and reduces the risk for complicated grief. The interdisciplinary team model which drives all of hospice has begun to be emulated in other fields of medicine as a model for what healthcare is suppose to accomplish. Although all of this is well-known among most physicians and the general public, patients continue to come to hospice too late to reap the full benefits of hospice.

Although extensive treatises have been written detailing hospice eligibility criteria for various diseases, I think referral guidelines can be divided into three main categories: the lack of efficacy of treatment, changed goals of care, and an acute medical event.

The Lack of Efficacy of Treatment

Physicians should consider referring patients to hospice when a patient is no longer responding to current treatments. I am going to use chronic obstructive pulmonary disease (COPD) as an example for two reasons. First of all, I am a pulmonologist, and second of all, COPD is a physician’s nightmare when it comes to prognostication – especially when compared to other diseases like cancer. At first blush, one wonders how anyone could even dare to predict a COPD patient’s life expectancy? Patients sometimes go from moribund on ventilators to playing miniature golf three weeks later. And if you can’t prognosticate, how can a physician even think about making a hospice referral?

When I started to ponder this, it became fairly clear to me that physicians were concentrating too hard on precise prognostication rather than focusing on the lack of efficacious therapy. In other words, when does chronic long disease become end-stage

lung disease? I would suggest the best answer is this: when he or she is no longer responding to current treatments. For example, despite a week in the hospital (with IV steroids and antibiotics), patients with COPD would report to me that they didn't really feel that much better - that is when chronic lung disease becomes end-stage lung disease. That is when a hospice referral should be considered. Here are some other signposts:

- Persistent breathlessness despite optimal medical therapy
- Inability to get out of the house despite rehabilitation
- Increasing number of hospital admissions
- Limited improvement after admissions
- Unexplained weight loss
- Increasing fatigue and daytime sleeping

I chose COPD as an example because most physicians agree it is one of the hardest diseases to prognosticate and, consequently, referrals to hospice are sadly lacking. In other words, if I can establish simple referral guidelines for COPD, I feel that similar logic will translate to your other patients. All it takes is a little bit of thought.

Think hospice when treatments that may have been effective no longer have the same beneficial effect: the patient with cancer who is continuing to decline despite the new chemotherapy regimen, the patient with CHF who continues to be weaker and more short of breath despite an increase in medications, the patient with dementia who now has a stage III decubitus despite excellent care. When patients say things like, "Nothing seems to be working" or "I don't think the medications are doing anything," physicians and families should start thinking about hospice.

A Change in the Goals of Care

The second category for hospice referrals centers on goals of care. There comes a point in almost every chronic patient's disease process when they start saying things that suggest they are changing their goals. There was a time when my brother, who had leukemia, decided jointly with my parents that he didn't want to go back to the hospital anymore. "Just do the best you can for me at home," he said. The burden of a stay at the hospital simply outweighed the benefits. Physicians need to be alert for signs that their patients are changing their goals. This may be occurring when patients start declining new therapeutic options, call or visit the office more often with increasing anxiety, or start expressing fear and concerns about dying.

Some patients and families, not realizing how much can be done at home, continue to get hospitalized while resenting it. One patient recently told me, "I felt like I was spending all of my remaining days in the hospital - away from my family and friends." Now at home, with hospice, his final days have meaning, value, and purpose as he shares with family and friends. He has worked on end-of-life tasks like giving and receiving forgiveness and love. New goals will often naturally spring up when a patient acknowledges that their disease is fatal, while others may need help setting new goals.

I remember a patient with brain cancer who, when first diagnosed, wanted to do anything and everything to get better. Unlimited resources allowed him to seek treatments at the best hospitals. But his brain tumor grew despite everyone's best efforts. His symptoms and his care became increasingly complex; as he put it, "one thing led to another." And through it all, he grew sicker and sicker. At one point, against the advice of his physicians who were seeking more exotic treatments that they thought provided hope; he decided to enter hospice care. No longer hoping for a cure, his hopes became more realistic and he focused on the hopes that he would be able to live well until he died, that he would die a peaceful death, and that he would see his God and Savior in heaven. He made a will, said goodbye to friends and colleagues, and even started writing a book. With the help of hospice, he stayed home and lived a life full of meaning and growth until his death.

An Acute Event

Sometimes it is an acute medical event, despite optimal therapy and good compliance, which should precipitate a referral to hospice. This might be a stroke in a cardiac patient, or another MI in a CAD patient, or an aspiration pneumonia in a dementia patient, or a stage III decubitus in a Parkinson's patient. Such events can signal the need for a hospice discussion. Patients may indicate they are also thinking along these lines when they comment, "I can't believe this happened," "I wish it was over," or start declining options for additional treatments. These remarks and decisions can be a patient's way of opening up a discussion about end of life. Honestly responding to patient's efforts to communicate about their prognosis and discussing hospice can actually lessen their fears.

The Hospice Discussion

I don't feel that the "hospice discussion" should be a "big deal" and heart-wrenching time for physicians, patients, and families. The first lesson for physicians, in my view, is to introduce hospice as a part of what simply constitutes good medical care when "the time comes." I think patients should hear something along the following lines from their doctor: "I always try to provide the best possible care to my patients and when certain needs arise, I naturally call in a specialist. So it is a part of my routine practice to call hospice when my patients reach 'that time' in their illness. The expertise and help that hospice brings will benefit you and your family in so many ways. I always strive to treat my patients just as I would want my family to be treated." A discussion of hospice in this manner can facilitate conversations that explore a patient's fears and help develop a care plan that focuses on the patient's goals and tasks.

When a trusted professional explains hospice to patients and families in a personal and kind way, it is likely to be well received. It is interesting that many patients and families tell me, "I wish I had been admitted to hospice earlier – I don't know why I was so reluctant."