Hospice

Dean Schuyler, MD, and Woodrow Coker, MD

EDITOR'S NOTE

Through this column, we hope that practitioners in general medical settings will gain a more complete knowledge of the many patients who are likely to benefit from brief psychotherapeutic interventions. A close working relationship between primary care and psychiatry can serve to enhance patient outcome.

Dr Schuyler is a member of a palliative care team in the Department of Medicine at the Ralph H. Johnson Veterans Administration Medical Center in Charleston, South Carolina. **Dr Coker** is a senior hematology/oncology fellow in his sixth year at the Medical University of South Carolina in Charleston, South Carolina.

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***Corresponding author:** Dean Schuyler, MD, Geriatrics/Extended Care, Ralph H. Johnson Veterans Administration Medical Center, Charleston, SC 29401 (deans915@comcast.net).*

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Hospice is one of those words that has become defined by the view that many people have of it. When a patient reaches the end of life, and when the health care focus is on comfort, hospice can make a major contribution to patient care. At times, the hospice worker may come to the patient's home. At times, the patient may be referred to an inpatient hospice. The medical meaning is clear: hospice aids the patient in obtaining comfort, and hospice supports the caregivers tending the patient.

If this is the case, why do so many veterans with serious medical illness that we care for react so negatively when a referral to hospice is suggested? "I guess you're giving up on treating me" is an all too common response. It seems to be one example of polarized thinking. Either the underlying disease is being treated or the medical team is "giving up and abandoning the patient" to hospice care.

The result is an alarming misreading of referral to hospice care. One consequence is that the patient and his or her caretakers are deprived of a potential source of critical end-of-life care. How can this misreading be dealt with so that more end-of-life patients get the benefits that hospice provides?

One focus of psychological work at the end of life is to deal with the cognitive errors frequently encountered in this period. Reaction to the suggestion of a referral to hospice is one situation in which the provision of someone to discuss mindset at the end of life can be beneficial. For the patient (or family) who has not confronted the issue of dying, this focus can provide a stimulus. For the patient or family whose views negate the value of hospice, this focus can provide a corrective.

Whether the patient's physician or nurse or a team psychiatrist confronts the issue of hospice, it is important that this cognitive distortion be addressed. The following case and comment will illustrate the benefit and explore some of the issues of a hospice referral to a patient at the end of life.

CASE PRESENTATION (DR COKER)

As a senior hematology/oncology fellow at the Medical University of South Carolina, Charleston, South Carolina, to supplement my learning and income, I have had the privilege of covering weekends at our local inpatient hospice facility for the past 2 years. This case is representative of many patients that I have seen who present for end-of-life care.

Mr A was a 90-year-old World War II Army captain with a history of prostatic hypertrophy, hypertension, chronic obstructive pulmonary disease, and vascular dementia who had fallen while walking with a walker at his assisted living facility. He received palliative pinning for a right femur fracture. His course, however, was complicated by aspiration pneumonia and delirium. Despite good postoperative care, he continued to decompensate. His advanced directive supported his daughter's decision for comfort care and to allow a natural death. Mr A was transferred to an inpatient hospice center for end-of-life care. They managed his subsequent respiratory failure and his uncontrolled agitation. Intravenous morphine and haloperidol addressed his symptoms, although he was not taking food or fluids. Mr A's son arrived on the second day after admission and insisted that his father be given tube feeding and intravenous fluids.

DISCUSSION (DR COKER)

My experience with dying patients is that they tend to complete the process at their own pace with minimal intervention. Rarely have I ever had a patient with symptoms that could not be managed within a few hours. Some typical scenarios are end-stage malignancy necessitating inpatient pain management and acute stroke patients with neurologic devastation. End-stage liver or renal failure is common in the debilitated patient as are sepsis and hip fractures. Pain, dyspnea, delirium, and nausea are each easily controlled in the inpatient setting. The challenges I have struggled with, rather, are educating family and friends on hospice philosophy. These can be very difficult concepts for lay persons to grasp. Among the most difficult concepts are withholding tube feedings and intravenous fluids.

I have consistently had some success with the following approach. First, it is critical to establish rapport. Never dismiss the importance of introductions. Regardless of the number of family members, identify the key decision makers and use their names in conversation. The health care professional must convey a genuine interest in the patient's comfort. It will serve as the foundation for all future interactions. Verify that the setting is appropriate by asking if it is okay to discuss the details in front of those present, even if the patient is obtunded.

It is important to acknowledge your gratitude and your commitment to providing comfort care. I tell the family that I am grateful to be chosen as the patient's last physician. This tends to be disarming, as the final decision to transfer from the hospital to an inpatient hospice facility is often not one in which the patient is directly involved. Those who made the decision may be dealing with guilt and second guessing. Since we are treating family as well as the patient, there is a duty to address this guilt. It is important to congratulate the family for making a brave decision (hospice), consistent with the patient's expressed wishes. This approach is typically effective for gaining family trust, reaffirming the decision for hospice care, and emphasizing your commitment to patient comfort.

Use casual conversation with the family to learn more about the patient by asking open-ended questions. The first few stories will often help you to formulate an accurate impression of the patient's character and values. When appropriate, contribute to the stories with your own. Inquire about the family's hopes for hospice care for their loved one. You may learn about their view of feeding tubes, family conflicts, or their need for a prediction for life expectancy. I never use the term *death* unless the family uses it first. There are numerous suitable alternatives. I tend to explain dying as a process that the patient does in his or her own time, at his or her own pace.

A dilemma may arise when there is an opposing viewpoint regarding patient care, tube feedings, or intravenous feeding. This may provide an opportunity to explain that among the first organs to fail are the kidneys and gut, which is fortunate because it allows products to build in the body that induce coma and result in a peaceful passing. If we provide intravenous feeding that failing kidneys cannot process, the fluid may accumulate in the lungs. If blood is being shunted away from the gut to support other vital organs, food will not digest well, and it will make the patient more uncomfortable, with an increased likelihood of aspiration. I tend to finish these discussions by restating my commitment to excellent end-of-life care. Then, I suggest that the family member have the health care power of attorney or next of kin repeat the reasoning for avoiding parenteral nutrition because they may be asked by other family members why such measures are not being taken.

I am often asked how much time is left in the patient's life. A direct answer is probably never correct. "I do not know and we should be thankful that I do not," is what I typically say. It is best to accompany this with a vague range of time: hours to days, days to weeks, weeks to months. It is important to add encouragement for the family to celebrate the patient's life while he or she is here.

Family members often spend all of their time with the patient and fail to take adequate care of themselves. Therefore, it is important to encourage the caregivers to hydrate, eat well, take walks, and look to other family members for support. They often are guilty if the loved one dies in their absence. I employ the analogy of the man who leaves for work each day but does not always wake his wife. This example represents a similar principle, and it has always been well received.

Interpersonal communication often does not come easily when speaking about death and dying. In order to cultivate these skills, hospice personnel should be guided by a genuine concern for the patient's interest. This stage of a patient's life can be meaningful and be dominated by care and concern. When caregivers understand the parameters of hospice care, this is often the result.