Ethics Forum

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When Is the Best Time to Refer to Hospice?

Over the past several decades, hospice has been a valuable resource for patients with cancer who are no longer being treated actively but who require symptom management during the dying process.[1,2] Hospice can offer physical, emotional, and spiritual support in the last weeks of life.

Patients may be deprived of the full benefit of hospice, however, when their hospice referrals are delayed.[3–6] The two following cases illustrate the importance of timing in hospice referrals.

CASE ONE

A 55-year-old white man who had been diagnosed with metastatic non–small cell lung cancer presented to the oncology acute care unit of the Central Arkansas Veterans Healthcare System (CAVHS), Little Rock, AR for his second cycle of chemotherapy. When the patient was found to have anemia and dehydration with acute renal failure, his chemotherapy was put on hold. He was admitted to the hospital for transfusion and hydration, with the hope that he could receive his second chemotherapy cycle prior to discharge.

The patient became febrile shortly after his admission. A chest roentgenogram revealed multilobar pneumonia, for which he was treated with oxygen and antibiotics. Subtle changes in his mental status were noted. With worsening of his oxygen requirements, he was transferred to an intensive care unit and treatment with diuretics was initiated.

This treatment resulted in mild improvement, but the patient still required an oxygen mask when he was transferred back to the oncology unit. He was subsequently found to have bilateral, lower-extremity deep vein thrombosis, with probable pulmonary emboli. His renal function continued to deteriorate, and his altered mental status persisted. Within several days of his admission to the hospital, computed tomography scans were performed to evaluate the reasons for the changes in his condition. They revealed metastatic brain lesions, suggesting a terminal state.

Within days of this discovery, the patient was referred for the first time to the palliative care service. He was accepted to inpatient hospice, and arrangements were made for him to be transferred the following day. During an examination prior to transfer, a physician noted that the patient was lethargic. The physician attributed this lethargy to the patient's intake of morphine several minutes prior to examination, rather than to a change in clinical condition that indicated impending death. Accordingly, the patient was placed in an ambulance with oxygen and intravenous fluid treatment, with plans to arrive at the inpatient hospice within three hours. The patient died en route to the facility. The patient's family members communicated to nursing staff that they were distressed by the circumstances of his death.

CASE TWO

An 85-year-old man with advanced stage lung cancer was admitted to the oncology acute care unit of the CAVHS with multiple medical problems. These included congestive heart failure, acute deterioration of chronic renal failure, and possible sepsis. Medical treatment was initiated, but the patient's renal function and respiratory status continued to worsen, suggesting a terminal condition.

Over a period of three to five days, the patient and his family met several times with the palliative care experts on the unit's Hematology/Oncology, Palliation, and Education (HOPE) team and elected for inpatient hospice. Due to the patient's metabolic derangements, however, his physicians considered his death to be imminent. The physicians, in concert with the patient's family, decided that he should remain on the acute care unit to avoid interruption of care. The patient died, with his family present, the morning after this decision was made.

A COMMON PROBLEM

The mistake of referring a patient to hospice too late, which was made by physicians in the first case but avoided by physicians in the second case, is a common one. Although physicians consider a three-month hospice stay before death as ideal, the median stay is less than one month.[7] Various investigators have reported death rates of 10% to 20% in the first few hours or days after transfer to hospice.[7–9] In one study, patients who were depressed, were not well oriented, or did not have prostate cancer were more likely than other patients to die soon after transfer.[4] Whether these patients actually were referred too late or whether they were acutely ill and died as a result of the transfer is difficult to determine.

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Timing of hospice referrals is strongly related to characteristics of the physicians.[7,9–11] In one study, the single most important predictor of whether a physician would make an earlier hospice referral was whether he or she had done so previously.[7] In general, female physicians appear to make earlier hospice referrals than do male physicians,[9] and internists and geriatricians tend to make earlier referrals than do oncologists.[7] Patients referred late are more likely to be black and to have been treated in acute care hospitals,[10] but patients who were referred too late do not seem to differ in terms of insurance status.[11]

A common reason for late referral is difficulty in predicting the time of impending death. Sometimes, an emotionally stressful event can hasten death; in other cases, hope or the desire to live for a specific event can delay death.

EFFECTS OF LATE REFERRALS

Late referrals to hospice detract from the full benefit of hospice in multiple ways.

First, such referrals hinder the ability of hospice staff to support patients. Staff members need enough time to befriend the patient and learn about his or her background, values, and beliefs in order to help him or her die well.[8,10,11] When patients are referred to hospice late in the process, staff do not have time to gain an understanding of the patient's life journey or relationships with family members.[3,4,8,12,13] And without this understanding, staff are not as prepared as they could be to offer spiritual, psychological, and cultural knowledge and support. This situation can lead to a patient dying alongside strangers, rather than people with whom he or she has created a bond.

Late hospice referrals also tend to have a negative impact on patients' family members.[12] When a patient dies soon after transfer to hospice, family members often are unable to process their loved one's end of life, to say goodbye, or to be with their loved one in his or her dying moments. Such missed opportunities can disrupt the family's grieving process. Families of patients who died soon after admission to hospice have expressed lower overall satisfaction, more unmet needs, and less confidence with hospice than families of patients who spent more time in hospice.[12] One study showed that family members of patients who died within seven days of hospice admission had positive responses to the hospice initially but negative responses when interviewed one month later.[3]

In the two cases described earlier, neither of the patients were able to receive the full benefits of hospice care because the decision to transfer to hospice was not made until death was imminent. An important difference, especially in terms of the family's grieving process, however, is that the second patient's physicians recognized that it likely was too late for a hospice referral and recommended that the patient remain on the acute care unit. This allowed the second patient to die with his family members around him. In contrast, the first patient's death during transfer to hospice distressed his family members, who were not able to prepare for his death or to commune with him in his final moments.

AVOIDING THE PROBLEM

What is the optimal time for oncologists to refer patients to palliative care experts or hospice? The answer to this question must be individualized according to the patient's own preferences and the community's resources.

Sometimes, though, clear physical changes can signal that death is coming soon and that transfer to another facility is not advisable. Mandibular movements with respiration, excessive somnolence, and withdrawal may be signs of an imminent death. If these signs occur, the patient should not be transferred to another service.

Unfortunately, the signs are not always so clear. For instance, in the first case described here, it is difficult to judge whether the physician who examined the patient prior to transfer was correct in attributing the patient's lethargy to morphine and not interpreting it as a sign of impending death. In the second case, physicians based their correct belief that the patient's death was imminent on his metabolic derangements.

In general, palliative care experts should be involved early in the care of patients with cancer. Although this specialty was introduced initially to provide help to patients with terminal illness until their death, its function has expanded to include symptom management early in the course of disease and throughout survivorship.[14–17] As such, it is now both appropriate and beneficial to involve palliative care professionals in care planning and provision long before the patient's last hours of life.

In addition, it is important for oncologists to remain involved with their patients' care even after they have been transferred to a hospice or palliative care environment. This is crucial both to ensure overlapping and seamless care and to avoid any ethical concern about patient abandonment.

THE LEGAL PERSPECTIVE

Today, it is relatively clear that a clinician can be found negligent for delaying a patient's referral to a hospice or palliative care specialist, even if such a referral is made eventually.[18] In general, a clinician is not legally required to consult with a specialist or an outpatient care center for every conceivable complication that may arise. When a clinician discovers that a patient needs more extensive treatment than the clinician can provide, however, he or she

has a duty to refer the patient to a specialist or specialized care center.

The seminal case regarding this duty is *Buck v. United States*, a 1977 case tried in Florida.[18] There, the court held that clinicians were negligent because they did not refer a patient to an outside specialist until 14 hours after the patient's admission to a hospital. The *Buck* case has been cited approvingly in several cases since 1977.[19,20]

Physicians can protect themselves from liability by erring on the side of caution in regard to referrals and consultation. In short, they should consult with specialists early and often. Institutional programs designed to facilitate consultations also can offer protection from liability.

IMPROVING REFERRAL TIMING

Several demonstration projects to bridge the divide between hematology/oncology and palliative care have been reported in medical literature. For example, Rosenfeld and colleagues have started the three-year program "Pathways of Caring," in which patients are referred to palliative care experts early and advance planning, hospice enrollment, and advance care planning are administered through "clinical pathways" as soon as patients with lung cancer relapse.[21]

At the CAVHS we have developed a demonstration project called the HOPE program.[22] (The palliative care experts consulted in the second case described earlier were participants in this program.) The HOPE program incorporates hematology/oncology, palliation, and education into the care of all patients from the time that any type of cancer is diagnosed. A treatment plan with stated goals is established for every patient and managed jointly by palliative care and oncology specialists. As treatment emphasis changes from cure to care, palliative care experts take on increasing responsibility for joint management. The program includes joint rounds, Grand Rounds speaker programs, monthly psychosocial ethics rounds, educational programs, and a hospice and comfort care unit within a dedicated, single-focus oncology unit. The expansion of this program will allow patients to be cared for by a single team in a single location when appropriate for the patient. ●

Author disclosures

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