Ethical Issues in Palliative Care
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No Place Like the Hospital
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Abstract
The gold standard for end-of-life care is home hospice. A case is presented in which a patient dying of irreversible small bowel obstruction from metastatic cancer insisted on remaining in the acute care hospital for care when alternative sites of care, including a skilled nursing facility and residential hospice, were available to her and covered by her health insurance plan. The ethical issues raised by this case are discussed from the perspective of the patient, the clinical team, the hospital, and the insurance company. Over the past decade, hospital-based palliative care consultation and general inpatient hospice care have sought to improve the quality of dying in the hospital. To the extent that such efforts have been successful, they may result in increasing demand for the hospital as the site for terminal care in the future.

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Key Words
Hospital, hospice, end-of-life care

Introduction
The gold standard for care of the dying patient is home care. The landmark report of the Robert Wood Johnson Foundation, “Means to a Better End: A Report on Dying in America Today,” therefore used the proportion of a state’s deaths that occur at home as one of eight measures of the quality of end-of-life care. Surveys from disparate parts of the country have consistently shown that about 80% of Americans say that they would prefer to die at home. In addition, some patients enroll in hospice with the expectation that they will die at home and then change their minds: the rate of disenrollment from hospice is about 15%. Although the factors precipitating this decision are varied, they include the desire for around-the-clock, sophisticated nursing care generally available only in institutional settings. We present a case of a patient who preferred to die in the hospital, which engendered ethical conflicts about the site of care.

Case Report
Brenda Ingram (not her real name) was a 55-year-old woman with advanced ovarian acute care hospital. An interview study of older patients who had recently been hospitalized for congestive heart failure, chronic obstructive pulmonary disease, or pneumonia found that 48% believed that they would prefer terminal care in the hospital, 43% at home, and 9% were uncertain. In addition, some patients enroll in hospice with the expectation that they will die at home and then change their minds: the rate of disenrollment from hospice is about 15%. Although the factors precipitating this decision are varied, they include the desire for around-the-clock, sophisticated nursing care generally available only in institutional settings. We present a case of a patient who preferred to die in the hospital, which engendered ethical conflicts about the site of care.
cancer hospitalized repeatedly over a four-month period for recurrent small bowel obstruction caused by peritoneal carcinomatosis. Her disease had become refractory to chemotherapy and failed to respond to maximal medical management with metoclopramide, dexamethasone, and octreotide. She was seen in surgical consultation, but resection was not felt to be a viable option given the diffuse nature of her disease. In addition, the tumor had infiltrated the lining of her stomach, thus precluding placement of a percutaneous endoscopic gastrostomy tube. The patient was treated with total parenteral nutrition and advised to limit her oral intake to small amounts. She was discharged home with hospice care.

Within one day of enrollment in hospice, Mrs. Ingram again developed nausea, vomiting, and abdominal pain. Her husband called an ambulance, and she was hospitalized at a tertiary medical center and evaluated in palliative care consultation. Her symptoms rapidly resolved after placement of a nasogastric tube and treatment with a fentanyl patch and sublingual morphine concentrate for breakthrough pain. The medical staff concluded that home hospice was not a viable option for the Ingram family: the patient had a teenaged daughter at home and her husband was very uncomfortable providing the care the patient increasingly required. The hospital case manager explored inpatient options for end-of-life care for Mrs. Ingram and found that she met the medical criteria for residential hospice or care in a skilled nursing facility. Moreover, her insurance plan would pay for either option.

The case manager identified two institutions near the Ingrams’s home that had the capacity to provide continuous nasogastric suction and treatment with opioids. A bed was available in both facilities. When the options were presented to the patient and her husband, Mr. Ingram asserted forcefully that his wife regarded the hospital as her “home” and it was where she felt secure. He emphasized that both he and his wife trusted the hospital physicians to be responsive to changes in his wife’s condition over time and felt that the hospital nursing care was excellent. He indicated that his wife expected to stay in the hospital until her death.

The attending oncologist, the palliative care consultant, and the medical resident explained to Mr. and Mrs. Ingram that although the patient was terminally ill, her symptoms were readily controlled with her current treatment regimen. Her medical needs could be met by either of the two facilities specializing in end-of-life care that were identified by the case manager. Both options were homey and easily accessible from the Ingrams’s residence; the hospital, by contrast, had a very institutional character and was a 45-minute car ride from the town where the Ingrams lived. Mr. Ingram appeared to understand the information offered but explained that he wanted the best possible end-of-life care, care that he believed was available only in the tertiary care hospital.

**Patient/Family Perspective**

Respect for patients’ autonomy dictates that they have a say in their own medical care, weighing the benefits and burdens of any proposed medical intervention in light of their own values and preferences. From the perspective of the Ingrams, hospital care, nursing facility care, and home care were all forms of medical intervention, each with its own pros and cons. They clearly valued around-the-clock nursing care and immediate access to physician care far more highly than being in one’s own home. Mr. Ingram in particular believed that he and his wife had a choice of several alternative sites of care, just as they had been offered a choice between maximally aggressive medical treatment (the total parenteral nutrition and chemotherapy that Mrs. Ingram had until recently received) and treatment focusing on comfort (the hospice approach).

Although patients’ values should affect the choice of treatment, along with data about the efficacy of the various alternatives, patients do not have an unqualified right to dictate treatment if it conflicts with professional standards. The negative right to refuse proposed treatment is not equivalent to the positive right to receive treatment that is not medically effective. For example, patients do not have the right to undergo antibiotic treatment for a viral infection or futile interventions near the end of life. In this case, however, the treatment demanded was not ineffective. Conflict arose because it was possible to obtain comparable treatment in a less expensive facility, just as
analogous conflicts have arisen when patients prefer continued hospital treatment to care in a rehabilitation facility.

**Hospital Perspective**

The acute care hospital has an obligation to a patient who has been admitted to provide medical treatment in accordance with the standard of care and then to discharge the patient to a suitable environment for post-acute care, commonly home but often a skilled nursing facility or other institutional environment. Properly managing “transitions of care” is increasingly recognized as an important responsibility of the hospital staff. As part of the Affordable Care Act, for example, Medicare will start penalizing hospitals with high 30-day readmission rates on the assumption that a quick return to the hospital is symptomatic of an inadequate discharge plan. Patients and families participate in the transitions process and must support the plan proposed by the hospital for it to be a viable choice. In the case of the Ingrams, the recommended transfers were rejected on the grounds that no site of discharge was acceptable to the patient and her husband.

The hospital has a specific mission and must use its beds in ways that are consonant with that mission. In this instance, its beds were an expensive and scarce resource. Treating Mrs. Ingram in the acute setting could have limited access to a bed for a patient whose needs could be met only in the hospital. From the institutional perspective, providing medical and nursing care to Mrs. Ingram for 19 days when she could have been transferred to another facility capable of supplying that care was no more justifiable than admitting a patient to the Intensive Care Unit (ICU) who could be managed on the medical floor just because the patient preferred the 2:1 nursing ratio available in the ICU.

The hospital is providing a service in exchange for payment, in this case from the patient’s health insurance company. When the patient no longer meets established criteria for hospitalization, there is a substantial risk that the insurance company will cease paying for her care. From the hospital’s perspective, it has no obligation to provide hospital-level care as long as a suitable alternative site of care can be found. Hospital administrators could seek a negotiated solution, such as keeping Mrs. Ingram in the hospital but billing her directly, although this would not solve the problem of access for other patients needing the bed.

**Insurance Company Perspective**

The American health care system allows individuals to choose to buy health care insurance, usually from any of several plans offered through their employer or their spouse’s employer. Each of these insurers offers a “benefit package,” a detailed description of which is provided with enrollment in the plan. The insurer is then obligated to provide those services covered by the plan for which the patient is medically eligible. Medicare is required by law to provide services that are “reasonable and necessary,” although what exactly this phrase means has never been determined. State divisions of insurance may further specify that health plans provide particular benefits. Massachusetts, for instance, requires that private insurers cover infertility treatment and hospice care, among other services.

The health insurance company from which Brenda Ingram received benefits covered treatment in an acute hospital, a skilled nursing facility, and also a residential hospice. For the insurance company to provide payment, however, Mrs. Ingram needed to meet the medical eligibility requirements for care in these institutions. From the perspective of the payer, its obligation was met by providing coverage for home hospice (in which Mrs. Ingram enrolled briefly) and acute care in the hospital (multiple times over the months before her terminal hospitalization) and by offering to provide coverage in either the skilled nursing facility or residential hospice once her symptoms were stabilized during her final hospitalization. The insurance company could make a “benefit exception” on compassionate grounds and pay for Mrs. Ingram to remain in the hospital until her death, but this approach would be problematic if increasing numbers of patients requested such an exemption.

**Case Resolution**

The oncology attending discussed with the Ingram family the basis of their strong
preferences. Mr. Ingram was able to articulate that his mother had been discharged from an acute care hospital after being told that she was not sick enough to require hospitalization, only to die one day later. The oncologist tried to explain that although Mrs. Ingram was certainly very sick and was expected to die in the near future, because of her age and the vigor of her major organs, her prognosis was likely measured in weeks rather than hours or a few days. The primary nurse pointed out that Mrs. Ingram was eating and drinking and, despite the presence of the nasogastric tube, enough food passed into her gut for her to continue to have bowel movements. Mrs. Ingram reluctantly accepted the proposed transfer to a residential hospice facility, but her husband insisted that he would not allow such a move.

The palliative care team social worker spent many hours with the patient’s husband and daughters to provide support and further explore the basis of the desire to remain in the acute care hospital. Mr. Ingram stated that his wife had “never been able to get good care anywhere else:” he mentioned a brief hospitalization at a community hospital for small bowel obstruction where he became incensed that the attending physician advocated hospice care (although the patient and her husband accepted hospice care one week later) and he pointed to their experience with home hospice, which had lasted only one day. He also relayed that he had understood from his wife’s primary oncologist at the time of her final hospitalization that she was expected to die soon and would remain in the hospital until she did so.

On the 12th hospital day, the patient was evaluated by the hospice with which the hospital contracted for inpatient hospice care. The hospice coordinator felt she did not medically qualify for hospice general inpatient care. Mrs. Ingram remained on the acute medical service. On the 16th hospital day, she became less responsive and was felt to be actively dying. At that point, she was deemed eligible for general inpatient hospice level of care and was admitted to the hospice service, which entailed a virtual rather than a physical transfer. Mrs. Ingram became progressively less responsive and died peacefully on the 19th hospital day, with her husband at her side.

Mrs. Ingram’s health insurance company is reviewing the charges submitted by the hospital and physicians for her final hospitalization.

**Discussion**

Death in the hospital, as depicted in The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments, shows a patient intubated in an ICU, attached to a ventilator, and in pain. But today’s reality may be different: a commonplace scenario is that a patient with advanced illness is vigorously treated in the ICU, but when therapy fails to produce the desired outcome, care is redirected toward comfort. The patient remains in the ICU, his final hours or days spent in a private room, with 24-hour care provided by some of the most talented, knowledgeable, and compassionate nurses in the world. His pain is exquisitely managed by a pain and palliative care service, with intravenous dosing of analgesics and anxiolytics carefully titrated to his needs. A chaplain and social worker help support the family.

Patients have been reported to overwhelmingly favor dying at home. Although most surveys address what prospective patients think they would want in the event they develop a condition they do not currently have, polls of patients with advanced illness have found similar results. When cancer patients with a poor prognosis were asked about their preferred site of death, 90% of respondents said that they hoped to die at home. But even this study focused on patients’ preferences before they were faced with imminent death. Once the question of where to receive terminal care moves beyond the theoretical to the actual, patients and their families may feel differently.

Many surveys of patient preferences for site of death were conducted before the introduction of palliative care consultation and inpatient palliative care units into hospitals. They reflect earlier research findings demonstrating that end-of-life care in hospitals is frequently burdensome, with patients experiencing attempted cardiopulmonary resuscitation, ventilatory support, and unremitting pain in their final week of life. As of 2008, the proportion of hospitals with palliative care programs reached 58.5%, up from 24.5% in 2000. Awareness of
palliative care as an option has grown with the recognition of Hospice and Palliative Medicine as an accredited subspecialty in 2008. The publication in prominent medical journals of several seminal studies demonstrating the benefits of palliative care, research that was widely publicized in the general media, may have had a trickle-down effect on medical practice, even in hospitals without an inpatient palliative care program.

A potential unintended and unanticipated consequence of the improvement in the quality of hospital care of the dying may be a shift in patient preferences for the site of death away from the home and toward the hospital. The insistence by Mr. Ingram that his wife receive end-of-life care in the hospital does not, of course, demonstrate a new trend in the direction of more patients preferring the hospital as the site of death. There always have been patients who prefer to die in the hospital, but this preference typically reflects either a desire for continued maximally aggressive care or inadequate socioeconomic resources to provide optimal home care. The Ingrams’s end-of-life decision making, by contrast, was not influenced by ethnic, religious, or socioeconomic factors. Nor does the Ingrams’s desire for end-of-life care in the hospital setting prove that hospitals actually provide top-quality end-of life care. However, there is reason to believe that hospital-based care has improved over the last decade. A small retrospective telephone survey of family members of patients who had recently died found that, among the 45% of those who received inpatient care, the quality of care was viewed by the family as superior to what was reported among the 15% who died at home with hospice. The hospital where Mrs. Ingram received care had a well-established consultative palliative care team and had recently developed an inpatient palliative care service with the capacity to deliver hospital inpatient level hospice care.

As hospital care for the dying patient improves, more patients may request terminal care in the hospital. Several strategies are suggested by this case to avoid conflict between patients, clinicians, hospitals, and third-party payers. First, the clinical team should prepare the way for possible discharge by being clear from the beginning of a hospitalization what the role of the hospital will be. Involvement of a physician whom the family knows and trusts can facilitate this process. Second, all members of the team should be consistent in what they communicate to the patient and family. This applies to clinical data, prognostic information, and expectations about the course of the hospitalization. Finally, clinicians should not have to bear the burden of enforcing the rules laid down by the hospital or the insurer; ideally, the attending physician would have contacted hospital administration and the benefits department of the insurer to jointly determine a compassionate course of action.

Palliative care as a field can be proud that the quality of death in the hospital is improving. But success presents new challenges: in addition to controlling the demand for terminal care in the hospital to assure optimal allocation of resources, palliative care clinicians will need to further improve care at home.

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