The Role of Chemotherapy at the End of Life: "When Is Enough, Enough?"

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Sarah Elizabeth Harrington, MD
Thomas J. Smith, MD

THE PATIENT’S STORY
Mr L was a 56-year-old previously healthy businessman. He presented with progressive back pain in April 2005. Vertebral biopsy showed poorly differentiated non–small cell (squamous cell) lung cancer. His vertebral metastases and multiple asymptomatic brain metastases were treated with dexamethasone and radiation therapy.

After discussing prognosis and options with his oncologist, Dr O, he received chemotherapy with weekly gemcitabine and carboplatin. He tolerated treatment well, and for 4 months during this period his cancer did not grow. When the disease progressed, he switched to erlotinib orally. This prevented further cancer growth for almost 6 months, during which time he was asymptomatic, except for a mild rash and diarrhea. For a few months, he was able to travel and lead a normal life. However, in January 2006, Mr L’s cancer again progressed. His chemotherapy was switched to pemetrexed but the tumor continued to grow.

Mr L developed diplopia in February 2006, and meningeal carcinomatosis was confirmed in March 2006 when magnetic resonance imaging of the brain showed enhancement of the fifth, seventh, and eighth cranial nerves. In the few days Mr L took to discuss his care with his medical student son, he progressed from manageable double vision to needing a wheelchair and becoming incontinent. An Ommaya reservoir was placed, and Dr O started the patient on twice weekly intrathecal methotrexate. He improved slightly, then remained stable for 2 months, enough to return to work part time and to travel a bit. Soon progression of the leptomeningeal disease resulted in additional cranial neuropathies. The intrathecal therapy was changed to liposomal cytarabine. Mr L continued to want active therapy; he attempted to enter a clinical trial for an investigational central nervous system chemotherapeutic treatment but was not accepted due to his general debility.

Over the month prior to hospital admission, Mr L had a rapid decline with less appetite and reduced ability to walk. After several falls, he required a wheelchair for mobility. In July 2006, he was admitted to the hospital for aspiration pneumonia and hypoxemia. At the time of admission, Mr L was a “full code” and had appointed his wife as durable power of attorney for health care decisions. The patient and family had been considering hospice, as suggested by the oncologist, and had been visited at home by a hospice intake worker. However, the patient wanted to continue fighting the disease instead of entering hospice.

Patients face difficult decisions about chemotherapy near the end of life. Such treatment might prolong survival or reduce symptoms but cause adverse effects, prevent the patient from engaging in meaningful life review and preparing for death, and preclude entry into hospice. Palliative care and oncology clinicians should be logical partners in caring for patients with serious cancers for which symptom control, medically appropriate goal setting, and communication are paramount, but some studies have shown limited cooperation. We illustrate how clinicians involved in palliative care and oncology can more effectively work together with the story of Mr L, a previously healthy 56-year-old man, who wanted to survive his lung cancer at all costs. He lived 14 months with 3 types of chemotherapy, received chemotherapy just 6 days before his death, and resisted entering hospice until his prognosis and options were explicitly communicated. Approaches to communication about prognosis and treatment options and questions that patients may want to ask are discussed.

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Author Affiliations: Department of Internal Medicine and the Thomas Palliative Care Program of the Massey Cancer Center of Virginia Commonwealth University, Richmond.

Corresponding Author: Thomas J. Smith, MD, Virginia Commonwealth University, Division of Hematology/Oncology and Palliative Care, MCV Box 980230, Richmond, VA 23298-0230 (tsmith@hsc.vcu.edu).

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On examination, Mr L was a chronically ill–appearing man whose breathing was aided by nasal oxygen and who sat on a bedside “neuro” chair. He had a fourth cranial nerve palsy and disconjugate gaze, facial droop, hoarse voice, absent gag reflex, and coarse breath sounds. Chest x-ray showed multiple pulmonary nodules and a new patchy left lower-lobe infiltrate.

The medical house staff called a palliative care specialist, Dr A, who noted that the patient was receiving a dose of intrathecal liposomal cytarabine during his initial visit. Dr A discussed the patient with Dr O, who now estimated that the patient had “only a month to live.” Dr A estimated a prognosis that could be as short as 2 weeks.

The palliative care team initially conferred with the patient’s son and sister, outlined the likely prognosis, advised them to proceed with hospice enrollment, and outlined the requirement for a do-not-attempt resuscitation and do not intubate order for this hospice. After this meeting, all acknowledged that this was the end of beneficial palliative chemotherapy, which his oncologist was no longer recommending. The family accepted these plans. Dr A then met Mr L and his wife, who agreed to these recommendations, and he met with the executor of the patient’s estate whom he urged to immediately complete a durable power of attorney for legal and financial transactions. Later, Dr A met with Mrs L and 2 sons to answer their questions (eg, likely time course, signs of impending death, eating for pleasure rather than nutrition, how to inform relatives at a distance), then talked with the hospice nurse to begin hospice enrollment. Finally, at Mrs L’s request, Dr A spoke with the patient’s mother and brother in England, who were displeased with the plan for hospice enrollment.

Mr L was transferred to his home with hospice care, where he remained alert and interactive for several days. On the sixth day at home, Mr L died peacefully with his wife and his children at his side and with his favorite music playing, some 14 months after the initial diagnosis. His mother and brother flew in from abroad but arrived only after Mr L had died.

Mrs L, Dr A, and Dr O were interviewed by a Perspectives editor in August and September 2006, 2 months after Mr L’s death.

PERSPECTIVES

Dr O (The Oncologist): We discussed with Mr L and his wife that this [leptomeningeal carcinomatosis] was a very ominous turn of events and that without intervention, his prognosis was clearly going to be weeks to a couple of months or so. His choices were to just focus on his comfort or to try to see if we could reverse that and . . . do additional systemic therapy. Without hesitation, Mr L did not want . . . hospice care or [to] just focus on palliative care. He absolutely wanted to try. . . .

Mrs L: I think our doctor in this case was amazing. . . . He obviously knew what the outcome was going to be, but you always pray for the miracle. I think the miracle we got was another year of his life. . . . you know my husband was extremely determined to remain positive, and he never was going to give in [to the fact] that this could eventually kill him. . . . It didn’t really dawn on my husband that he was going to die until he was in the hospital with pneumonia, which was 2 weeks before he passed away. . . . I think my husband lived very well at the end and he died well.

Dr A (The Palliative Care Consultant): I was called by the primary medicine team, who were taking care of him for an aspiration pneumonia. They wanted me to talk to the patient about future options and hospice, but he was still getting chemotherapy. Before I saw the patient, I called the oncologist. He said he would talk to the patient about his prognosis and about his chemotherapy. I went by later that day and the patient was seeing a speech therapist. Instead of talking to him first, I talked to his son, who was a medical student, and his sister, who was visiting from abroad, separately. They were shocked about the prognosis that I offered . . . of days to weeks. They were still expecting more chemotherapy. Here I was, walking into the room and basically saying, “Okay, folks, it’s time for hospice.”

Seeking Balance: The Goals and Use of Chemotherapy Near the End of Life

The appropriate role of chemotherapy near the end of life is a complex issue.1 As chemotherapy is increasingly available, and better tolerated, its use at life’s end involves sophisticated oncological assessment, a focus on the patient’s goals of care, and a balancing of perspectives of the patient and treating oncologist. Ultimately, it may involve judgments about the use or restraint of use of costly resources despite little chance of benefit.2

In some respects, Mr L’s care proceeded appropriately from a cancer diagnosis to hospice care. But were there missed opportunities to improve Mr L’s care? How can clinicians help patients and families determine when further chemotherapy is no longer beneficial and when they have had enough? Using the case of Mr L as an example, we discuss how clinicians can help patients identify the goals of therapy, the ways that oncology and palliative care clinicians can work together, and strategies to improve communication when chemotherapy is being considered at the end of life.

From the viewpoint of oncologist Dr O, Mr L presented with stage IV lung cancer, with brain and bone metastases. His cancer initially responded to brain and spinal radiation and first-line chemotherapy but then progressed. It stabilized for several months on a second-line agent, but a third-line agent did not halt its growth. He died of leptomeningeal metastases that progressed despite 2 types of intrathecal chemotherapy. He lived 14 months, fairly typical for non–small cell lung cancer, but spent only 6 days in home hospice before death. At the time of the first visit by Dr A, the palliative care physician, Mr L was still a full code and had not made any financial transition plans, although he did have a designated power of attorney for health care, which may
be more important, and Dr A believed that the family and patient were unprepared for the nearness of death. Dr A bore the brunt of some family anger when recommending hospice. He responded by stating that oncologists “need to be trained to involve palliative care folks earlier.” However, the oncologist had brought up hospice, and the patient initially declined it, only accepting palliative care involvement when death was imminent. The admitting house staff and palliative care consultant had a sense that this patient with brain metastases was not always making informed choices and had lost opportunities to do other important things with his remaining time while pursuing further chemotherapies and clinical trials. They had concerns about providing care (such as the final dose of intrathecal chemotherapy) that really could not help the patient.

Identifying the Appropriate Goals of Chemotherapy

Reasons for Late-Stage Chemotherapy. Patients may find it hard to get or accept truthful information about the benefits and harms of palliative chemotherapy. In the largest study of 95 consecutive patients receiving palliative chemotherapy, prognosis was discussed by only 39% of medical oncologists. In a longitudinal study of hospitalized patients for whom death was believed imminent, families reported that the attending physician never discussed the possibility of death 62% of the time and no one on the medical team discussed the possibility of death with cancer patients in 39% of cases. In other studies, at least one-third of patients and families reported they did not believe the information given them that treatment was not curative despite receiving such information. Another study showed that physicians may “collude” in this hopefulness by giving such a wide range of outcomes that people choose the most favorable.

It is critical to understand that people looking death in the eye have a different perspective. Studies from the United States, England, Canada, Japan, Norway, and Italy consistently show that patients with cancer generally were willing to undergo aggressive treatment with major adverse effects for very small chance of benefit, different from what their well physicians or nurses would choose. Some patients with previously treated non–small cell lung cancer would accept chemotherapy for a survival benefit as short as 1 week, while others would not, even for a benefit of 2 years (the actual expected benefit was 3 months). Highly educated and motivated patients enrolled in phase 1 studies at the National Cancer Institute said that they would be willing to take an experimental drug—with a 10% mortality rate—for an unknown small chance of benefit.

Box 1 lists some of the difficulties in giving and receiving information about prognosis in advanced cancer.

Multiple studies document that palliative chemotherapy is increasingly given near death. More than 20% of patients receiving Medicare who had metastatic cancer started a new chemotherapy treatment regimen in the 2 weeks before death. In Italy, 23% of patients with incurable cancer received chemotherapy within 30 days of death. In a US community practice, chemotherapy for patients with lung cancer was given within 30 days of death for 43% and 14 days for 20% of patients. In 2008, a medical director of a large insurance company reported that 16% of its cancer patients receive chemotherapy within 14 days of death. Patients are unlikely to benefit from chemotherapy when they have already been failed by the standard regimens, have poor performance status, and otherwise have a poor prognosis. The largest study of matched patients who received hospice and no chemotherapy vs those who did not receive hospice but had chemotherapy showed that survival was significantly longer for hospice patients with lung cancer and pancreatic cancer, marginally longer for colon cancer, but no different with breast or prostate cancer. The authors concluded that this was consistent with chemotherapy not prolonging and possibly shortening life for those eligible for hospice. Furthermore, chemotherapy produces adverse effects, precipitates hospitalization and emergency department visits, precludes entry into most hospices, and may require additional supportive care with erythropoietinlike drugs and colony-stimulating factors that are expensive and contribute little to the patient’s overall quality of life. For these reasons, the factors that go into patients’ decisions to undergo chemotherapy near the end of life bear examination.

Is Distinguishing Curative From Palliative Chemotherapy Important? Chemotherapy for metastatic solid tumors such as lung, breast, colon, or prostate cancer rarely if ever cures patients. The indication for such chemotherapy is to improve disease-free or overall survival, relieve symptoms, and improve quality of life. Palliative chemotherapy accounts for most of the work of everyday oncology given the rarity of curable disease. The American Society of Clinical Oncology could not decide on a minimal benefit for which chemotherapy was indicated, only that some benefit must be demonstrable.

Consensus panels that include cancer advocates make little distinction between curative treatment and palliative treatment that could extend life, since 6 months’ added survival could be as important as an increased rate of cure.

The increasing effectiveness and lessened toxicity of palliative chemotherapy is well supported by randomized trial data. First-line chemotherapy for patients with non–small cell lung cancer improves survival by 2 to 3 months, relieves symptoms, and improves quality of life compared with best supportive care. Second-line treatment of patients with non–small cell lung cancer with docetaxel vs best supportive care is associated with significantly longer survival (7.0 vs 4.6 months, or 10 weeks, and a difference in 1-year survival, 29% vs 19%); and improvements in pain and less deterioration in quality of life. Even third-line treatment may improve survival or symptoms, especially with novel, relatively nontoxic oral agents such as erlotinib, which, in
CHEMOTHERAPY AT THE END OF LIFE

Box 1. What Patients Know About Their Advanced Cancer and Its Prognosis

Patients Are Never Told or Are Not Told Well

Small Cell Lung Cancer
Thirty-five patients reported learning more about their prognosis from other patients in the waiting room than from their health care professionals. Physicians did not always want to pronounce a “death sentence,” and patients did not always want to hear it.12

High-Dose Chemotherapy (With Stem Cell Transplant)
Physicians prescribing high-dose chemotherapy overestimated survival, especially for patients with poor prognosis who might most need to balance toxicity with outcomes.13 The optimistic patients had no better survival than those who were more realistic.14

Terminally Ill With Cancer
Even if patients requested survival estimates, physicians said that they provided them only 37% of the time. Physicians reported that they would provide no estimate, conscious overestimates, or conscious underestimates 63% of the time.15

Solid Tumors
In Belgium, only 39% of oncologists reported ever reviewing prognosis with patients. Most of the interview was spent on active treatment, not alternatives.4 Nearly all patients could name their diagnosis, but only 23% knew their stage, which is critical to appropriate goal setting.16 Oncologists consistently overestimated prognosis by at least 30%.17 In our own study, physicians’ estimate of survival could be divided by 3.5 for actual survival.18

Patients Don’t Believe Information About Benefits and Risks of Treatment

Metastatic Lung Cancer
One-third of patients thought they were receiving therapy with curative intent despite being told prognosis and goals of care.6

Head and Neck Cancer
Thirty-five percent of patients believed their palliative radiation was supposed to be curative.7

Phase 1: Overoptimistic
If told that a treatment helps 20% of people like them, patients reported a 44% chance of it helping them personally.19

Patients Change Their Mind About Communication

Metastatic Breast Cancer
Between first and second lines of chemotherapy, 79% of patients with advanced cancer changed their preference about involvement in decision making; 37% wanted a less active role, and 22% wanted a more active role.20 Thirty-eight percent of women took an active role in decision making for first-line chemotherapy, and 43% for second-line chemotherapy. The reasons to take chemotherapy shifted from the possibility of controlling the tumor (50% for first chemotherapy, 38% for second) to providing hope (19% for first-line chemotherapy, 43% for second line); the proportion expecting to be cured fell from 10% to 0% with second-line chemotherapy.21

Phase 1 Participants
Of 163 patients participating in a phase 1 study, for which by definition, the goal is to assess toxicity, only 7% considered no treatment at all; 81% were aware of hospice, but only 6% had seriously considered hospice for themselves.22 “More than 90% of patients said they would still participate in the study even if the experimental drug caused serious adverse effects, including a 10% chance of dying.”

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1 study, improved survival compared with best supportive care from 4.7 to 6.7 months with improved results for pain, dyspnea, and physical functioning.37 Palliative chemotherapy has also increased survival and quality of life in metastatic colorectal38 and prostate cancer39 (TABLE 1). Mr L benefited from receiving 3 separate types of palliative non–small cell lung cancer chemotherapy: gemcitabine and carboplatin, oral erlotinib, and pemetrexed. Although he never had dramatic responses to treatment, his disease stabilized for months while he received the first 2 treatments, and his central nervous system disease was stable for weeks because of intrathecal methotrexate.

How Can Clinicians Help Patients With Decision Making? Mr L’s palliative care specialist noted that because patients are vulnerable to fastening on slim hopes, oncologists must improve their skills in helping patients think clearly about the appropriateness of chemotherapy.44,45 To help their patients make wise decisions, oncologists can start with a prompt list of questions, proven to enhance communication46-48 and similar to one in use in several oncology practices,49,50 including ours (BOX 2). This can be provided to the patient in the waiting room for discussion with his or her physician.

Another important communication is a straightforward discussion of the quality and quantity of life with or without chemotherapy. In most cases, there will not be a randomized trial of best supportive care vs best supportive care plus chemotherapy, but at least the important discussion points can be raised. There must be some definable benefit before chemotherapy can be recommended. TABLE 2 provides some examples of helpful communication strategies.

Studies consistently document that patients want and use such information. Of 126 terminally ill patients, 98% said they wanted their oncologists to be realistic52 and patients want oncologists to be truthful and compassionate and to continue caring for them during their illness.52 A comprehensive review found that randomized trials of decision aids in oncology yielded increased patient knowledge and more involvement in decision making.51 and a decision aid for adjuvant therapy of breast cancer (http://www.adjuvantonline.org) improved medical decision making and helped low-risk patients avoid unnecessary chemotherapy.54,55 A preliminary study showed that directly giving patients information about prognosis and treatment to share with their oncologist is desired and helpful.56 We use decision aids in our own practice that address prognosis with and without chemotherapy in a question-and-answer format, using simple terms (ie, “10 in 100 people” instead of “10%”) and figures.

What Should the Clinician Do When the Patient Wants to Continue Chemotherapy at the Very End of Life? Dr O: I couldn’t get him to stop thinking that he needed one more treatment. One more treatment was what he needed to spring him loose.

In the difficult situation faced by Dr O and Mr L, when the oncologist thinks further chemotherapy is not indicated, a number of strategies may be tried: holding family conferences to identify the decision makers in the family and getting the same information to all involved; informing people of and giving them access to the actual medical research studies and results; or writing the options down in concrete terms.57 Much of the time, patients and families may simply need more time to adjust to a difficult situation. Sometimes, they just have a different perspective that must be valued as much as the health care professional’s.

### TRANSITIONING TO PALLIATIVE OR HOSPICE CARE

#### When Should Patients Stop Chemotherapy and Transition to Palliative or Hospice Care?

Mrs L: I think that he felt he was in control until the last 2 weeks of his life, and that was important. The kids were very involved. We had a lot of closure.

Dr O: [Within weeks of his death,] Mr L was still in a “I’ve got to do something” mode, but I was telling him . . . . “We’ve got to get hospice going so that you can relax and everyone [in your family] can get what they need and they can move on.” He was not having any of it, though.

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**Table 1. Palliative Chemotherapy for Metastatic Disease for 4 Common Solid Tumors**

<table>
<thead>
<tr>
<th>Cancer Treatment</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non–small cell lung cancer</td>
<td>Improves survival by ≥3 mo with acceptable toxicity, better symptom control, manageable toxicity34</td>
</tr>
<tr>
<td>First-line chemotherapy with modern regimens</td>
<td>Improves survival by about 2 mo vs best supportive care, with better symptom control while taking treatment36</td>
</tr>
<tr>
<td>Second- or third-line (erlotinib)</td>
<td>Improves survival by about 2 mo vs placebo, with acceptable toxicity37</td>
</tr>
<tr>
<td>Third- or fourth-line</td>
<td>Response rate only 2% and 0% when patients have previously received docetaxel and platinum35</td>
</tr>
<tr>
<td>Breast cancer</td>
<td>Average survival has improved over the past decades with lessened adverse effects from chemotherapy, but there are no randomized clinical trials of treatment vs best supportive care41</td>
</tr>
<tr>
<td>Colon cancer</td>
<td>Average survival from diagnosis of metastatic disease has improved from 9 to 22 mo with the new drugs available, eg, oxaliplatin, irinotecan, cetuximab, bevacizumab40</td>
</tr>
<tr>
<td>Prostate cancer</td>
<td>Docetaxel every 3 wk improves survival by 2.4 mo, with no adverse effect on quality of life42</td>
</tr>
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CHEMOTHERAPY AT THE END OF LIFE

Box 2. Helpful Questions to Consider Asking About Palliative Chemotherapy

Treatment
What is my chance of cure?
What is the chance that this chemotherapy will make my cancer shrink? Stay stable? Grow?
If I cannot be cured, will I live longer with chemotherapy?
How much longer?
What are the side effects of the chemotherapy?
Will I feel better or worse?
Are there other options, such as hospice or palliative care?
How do other people make these decisions?
Are there clinical trials available?
What are the benefits?
Am I eligible?
What is needed to enroll?

Prognosis
What are the likely things that will happen to me?
How long will I live? (Ask for a range, and the most likely scenario for the period ahead, and when death might be expected.)
Are there other things I should be doing?
Will?
Advance directives?
Durable power of attorney for health care who can speak for me, if I am unable?
Financial or family legal issues?
Durable power of attorney for financial affairs?
Trust?
Family issues
Will you help me talk with my children?
Spiritual and psychological issues
Who is available to help me cope with this situation?
Legacy and life review
What do I want to pass on to my family to tell them about my life?
Other concerns?

Dr A: I was going in there to talk hospice, prognosis less than 6 months, and he was still full code. He had to be made no code. He was still expecting chemotherapy, [and] at least some of the members in his family were, and he was getting chemotherapy. When I went in on Saturday morning, it was a totally changed picture. The patient and his wife were now demanding to go home on hospice.

Making the transition to palliative care or hospice is difficult for both patients and oncologists. There are usually some treatment options, even for relapsed disease. The available lung cancer treatment data suggest that each 3.3% of response rate leads to better survival of 1 week and increases survival at 1 year by 1.6%, which might be important to some patients.58 The National Comprehensive Cancer Center Network guidelines recommend that after 2 chemotherapy regimens have failed to benefit the patient or if the patient’s performance status declines to 3 or more, such that chemotherapy will not be tolerated, a switch to palliative or hospice care be made (http://www.nccn.org/professionals/physician_gls/default.asp). The American Society of Clinical Oncology and other major professional societies have long recommended hospice as the best available care for dying patients.59

In our experience, many families and patients who choose, like Mr. L, to enroll in hospice wish they had done so sooner. The median length of stay on hospice has declined from 29 days in 1995 to 26 days in 2005, with one-third enrolling in the last week of life and 10% on the last day of life (http://www.nphco.org). Hospice care may help the family as well as the patient. One study showed that hospice care was associated with a 0.5% lower absolute risk of death for the Medicare-age surviving spouse.60 Families’ perception of late referral is associated with lower satisfaction with hospice care overall.61 In the most recent and largest study, among those with hospice stays of less than 30 days, 16% of families said they were referred too late.62 Of note, the perception of being referred too late, but not the actual length of stay, was associated with more unmet needs, lower satisfaction, and more concerns. One study found that patients would have liked palliative care consultation earlier in their course.63 It is unknown whether this view of “too-late” referrals to palliative care and hospice will change with the new relatively nontoxic chemotherapy treatments.

Improving Communication About Hospice and End of Life

Mrs L: He wanted to keep fighting. There was also a lot of animosity [from the overseas family members] toward Dr A, who is the most honest and incredible person on the planet. They felt that he had talked my husband into stopping treatment, and that was not the case at all. Dr A never really had anything to do with that. It was strictly between my husband and his oncologist.

Dr O suggested hospice enrollment to Mr L and he was even visited by a hospice intake worker, but he chose not to enroll until it was explicitly clarified that there were no further chemotherapy options. This is not unusual: Teno et al64 estimated that 23% to 61% of short-stay hospice patients could not have been referred earlier due to late diagnosis or patient refusal.

In our opinion, oncologists should note the availability of hospice from the beginning, as part of routine good care of the seriously ill patient. After all, in 2005 hospices enrolled more than 1.2 million patients, representing one-third of all deaths in the United States, with nearly half of...
the patients having cancer. Unfortunately, families often receive little information from physicians about hospice. In one study, physicians initiated the discussion about hospice about half the time, while patients or families initiated one-third of the discussions. Patients and families identified as important in deciding about hospice the frequency of visits, payment, and the practical help it provides. (A list of the resources that hospices can provide to patients is found in the online resources [http://www.getpalliativecare.org].) Barriers include physicians’ lack of knowledge of hospice philosophy, services, and patient eligibility requirements. Brickner et al found that 84% of physicians surveyed were unable to identify appropriate hospice diagnoses and that only 12% were aware of the National Hospice Organization Medical Guidelines for Determining Prognosis in Selected Non-Cancer Diagnoses. In a randomized trial of nursing home residents, a structured interview on admission—in essence, bypassing physician reluctance and making the hospice benefit known to families and patients—increased appropriate hospice enrollment from 1% to 20%.

In our opinion, patients and families should receive all of the necessary information about hospice and palliative care in order to permit the most informed decision about how to spend their last few weeks or months. We also recognize that even after the most earnest communication efforts, patients and families may continue to want chemotherapy. Communication about prognosis, what to expect with disease progression, and advanced directive and financial planning can all be done independently of a hospice decision and should remain a high priority for patients with advanced disease.

**WHY DON’T PATIENTS AND ONCOLOGISTS DISCUSS PROGNOSIS?**

Dr O: I thought that it would help everybody for Mr L to hear that he couldn’t get into a clinical trial because physically he wasn’t up to the standards of the trial. That, I thought, would have allowed Mr L to accept palliative care sooner than he did.

Mrs L: I never thought “too much” was too much. You always hope that he can come out of this by some miracle. The “too much” was when he became ill in the hospital.

When the prognosis is predictable, as with Mr L, why do most oncologists not directly address it? One paradoxical explanation is that patients do not want to discuss such terrible issues with their oncologist. Of 101 inpatients with cancer admitted without advanced directives, only 23 wished to discuss the issue with their oncologists; however, 56% of those without advanced directives (44 of 78) supported discussing it with the admitting physician and not the oncologist.

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**Table 2. Things to Do or Say (and Not to Do or Say) About Chemotherapy for Advanced Cancer**

<table>
<thead>
<tr>
<th>Do</th>
<th>Don’t</th>
<th>Comment</th>
</tr>
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<tbody>
<tr>
<td>Ask patients how much they want to know.</td>
<td>Don’t assume that people will or won’t want to know their diagnosis.</td>
<td>Although cultures vary, most patients want to know their prognosis and options. They may underestimate their odds, too, and forgo useful chemotherapy.</td>
</tr>
<tr>
<td>Define “response” and “cure.”</td>
<td>Patients can mistake a 20% chance of response with a 20% chance of cure.</td>
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<tr>
<td>Write down a list of benefits of and adverse effects from chemotherapy.</td>
<td>Don’t assume that patients will know their odds of being helped.</td>
<td>There must be some definable benefit before chemotherapy is justified.</td>
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<tr>
<td>Ask patients their goals.</td>
<td>Two months may be critical to some people, unimportant to others.</td>
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<tr>
<td>Begin a discussion about what to do if or when the cancer is resistant to chemotherapy.</td>
<td>This is a good place to say, “We hope to control the disease, but at some point it may grow so that it will end your life. We need to prepare for that, too.”</td>
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<tr>
<td>Say, “The cancer is shrinking, but is still there.”</td>
<td>Don’t say, “The cancer is responding.”</td>
<td>Important to emphasize what is likely to happen, so that people can make plans.</td>
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<tr>
<td>Be hopeful if there is reason to hope about the cancer.</td>
<td>Most people can be hopeful about something, even if their cancer is growing.</td>
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<tr>
<td>Begin a discussion about do-not-attempt-resuscitation orders.</td>
<td>This is a good place to say, “The cancer is growing, and may end your life. There are some important issues to discuss. Tell me how much you want to know.”</td>
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<tr>
<td>Bring up hospice when there are still some oncology options, not at the end of life.</td>
<td>Don’t ask hospice to just manage the acute deaths at home.</td>
<td>Make hospice an option that is part of usual medical care for someone with cancer.</td>
</tr>
<tr>
<td>Ask for your own hospice length of stay and the number of your patients who die within 7 days of enrollment.</td>
<td>Make this a performance improvement goal for the practice to meet or exceed the national length of stay in hospice.</td>
<td></td>
</tr>
<tr>
<td>Tell people you will not abandon them if they enroll in hospice.</td>
<td>Some physicians make appointments for every 2 weeks even for hospice patients. If they are too sick to attend, it is a good reminder to check in by telephone or visit.</td>
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2673
Another explanation is that such discussions are simply too difficult and painful. Even clinicians who are well trained and skilled at giving bad news can find it burdensome and emotionally difficult. Prior surveys documented “serious shortcomings in the training and current practices of oncologists” of palliative care and that only 25% of oncologists found end-of-life care highly satisfying. Given the incurability of some cancers, such as with Mr L, there is a need for these conversations and consideration of hospice care. At the very least, finding out how much a patient wants to know and then providing that information should be addressed by all clinicians.

**Shifting Goals of Care to Palliation: Why Is It So Difficult for Physicians?**

Clinicians often struggle with initiating discussions about shifting treatment goals and in particular transitioning to palliative care. Patients may respond with denial, anger, or sadness. These are all normal responses to the associated loss of control, a fear of the immediate future, or an underlying fear of death. For the most part, patients and families will have their own unique timetable and method for processing this information. Clinicians should generally respond with patience, emphasizing support (non-abandonment) and assurance of aggressive symptom management (Table 2).

Not surprisingly, physicians may respond to their patients, particularly those with whom they share a long-term relationship, with powerful emotions of their own. These can include a personal and professional sense of failure and frustration, guilt, powerlessness against the illness, grief, a need to rescue the patient, or a desire to separate from and avoid patients to escape these feelings. Clinicians’ feelings of medical ineffectiveness can lead to failure to identify patient-specific and family-specific values influencing decisions, which may lead to a lack of clarity about care goals. Avoidance of the discussion altogether can lead to mistrust of the health care system and medical profession, inappropriate use of life-sustaining medical technologies, increased medical complications, and long hospital stays. Recognizing, accepting, and reflecting on the normalcy of such feelings allows the professional to make a conscious choice about how to proceed in the relationship with the patient. Finding a trusted colleague in whom to confide can be part of a plan to prevent isolation, improve objectivity, and avoid burnout.

**Doesn’t Honesty Take Away Hope?**

No data are available that show hope can be taken from patients, as was once thought, or that patients are harmed by carefully provided information. As the Education Physicians End of Life Care for Oncologists (EPEC-O) curriculum states, “Information carefully shared is a gift to the patient and the family who want it and minimizes the risk that patients will distrust the cancer care team.” In pediatric oncology, full prognostic disclosure supported hope, even when the prognosis was poor.

**Ways That Oncologists and Palliative Care Specialists Can Work Together**

Dr A: I think oncologists, in general, need to get more comfortable with palliative care. It’s not an “either, or” situation, it’s a “both, and.” I think physicians, in general, including people like this excellent oncologist, need to be bolder at offering more real prognoses.

Evidence, albeit far from conclusive, suggests that “concurrent” palliative or hospice care alongside routine oncology care improves health outcomes (Table 3). Project Safe Conduct was started to integrate hospice care into lung cancer care at the Ireland Cancer Center. Before the study, 13% of patients with advanced lung cancer were referred to hospice; afterward, 80% of such patients enrolled in hospices and the average length of stay in hospice increased from 10 days to 44 days. The one randomized trial of concurrent hospice care plus usual oncology care vs usual oncology care alone has been published only in abstract form. The group with concurrent care lived slightly longer (not statistically significant), had quality of life preserved longer, used less chemotherapy, and transitioned to hospice enrollment sooner. The clinical care differences were modestly in favor of the concurrent-care approach, but the hospice cost was substantial and much higher than the cost of hospitalizations avoided (oral communication, John Finn, MD, Ascension Health Systems, Detroit, Michigan, October 2004). Meyers and colleagues enrolled patients in a phase 1 and 2 cancer treatment study and into a simultaneous care program that emphasized symptom management and transition to hospice. The uptake of the program was excellent. Patients received as many cycles of chemotherapy as without simultaneous care and were referred to hospice more frequently and earlier. A study at the Dana Farber Cancer Institute showed that cancer patients will use a free palliative care service alongside their usual oncology care, but health outcomes are not yet available. The one large randomized controlled trial of usual care plus palliative care consultation, in which 27% to 34% of patients had cancer, showed no difference in symptoms or survival but did show a $4855-per-patient cost savings. Proof of symptom control or survival improvement at a cost society can afford will require rigorous testing, preferably in randomized clinical trials.

One of the largest barriers to hospice in the United States is the way it is defined in the Medicare Hospice Benefit. Patients must have a life expectancy of 6 months or less and must forego curative treatment. Funding for chemotherapy and radiation is limited; thus, being enrolled in hospice can significantly limit very useful palliative treatment. Several hospice programs have begun to respond to these eligibility barriers and are providing a broader range of services. Some have changed to palliative care programs under home health care services, integrating palliative che-
motherapy and radiation and related treatments (paid for by the patient’s insurance or Medicare drug benefit) with elements of traditional hospice care. Passik and colleagues at Hospice of the Bluegrass showed that patients who transition from acute care to palliative care then to the hospice benefit, compared with those who transition directly from acute care to the hospice benefit, may prove to be both financial and care burdens to the hospice. As noted above, a randomized trial showed palliative care consultation alongside usual medical care saved the insurer $4855 per patient with no decrement in survival or symptoms. Several larger insurance-sponsored trials are ongoing.

INTEGRATING OTHER CANCER CARE ISSUES INTO DECISION MAKING AT THE END OF LIFE

Experimental Chemotherapy

Dr O: We were continuing the current course of treatment because he wanted it, but it was quite appropriate to initiate palliative care. Then Mr L and his wife embarked on this idea that he needed to get into a clinical trial. . . . Dr A was able to help the family put aside their differences in order to allow Mr L to enter into palliative care and go home and stay home.

Patients on clinical trials have as good an understanding of the risks and benefits as we can give them—after all, they have read and signed informed consent documents—but this understanding is far from perfect. Despite written information, many will still overestimate their own particular chance of success. Mrs L expressed, as do many patients and families, that they hoped Mr L would survive long enough to receive a new treatment, or even a cure. And as we noted above, informed phase 1 patients are willing to undergo new treatments with a 10% mortality risk for an unknown but low chance of benefit.

Reimbursement and Economic Issues: Why Oncology is Different

Most palliative care is relatively inexpensive. However, palliative chemotherapy regimens have a huge price tag, at a cost of up to $100 000 a year per patient, and even insured patients can be burdened by a 20% co-payment requirement. The cost of palliative chemotherapy for colorectal cancer could easily be $50 000 a year, not counting supportive care drugs or imaging. Patients with cancer account for about 40% of all Medicare drug costs, totaling an estimated $5.3 billion in 2006, with $1.5 billion for erythropoietin-like drugs alone. Some drugs (oxaliplatin for metastatic colon cancer and docetaxol for metastatic prostate cancer) have acceptable cost-effectiveness ratios in which

### Table 3. Studies of Concurrent Palliative Care With Oncology Care

<table>
<thead>
<tr>
<th>Source</th>
<th>Results</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Finn et al, 2002</td>
<td>Randomized oncology patients to standard care with or without hospice or palliative care consultation. Intervention group had longer preserved quality of life, fewer symptoms, and (nonsignificantly) better survival. No difference in symptom control but quality of life declined less in the intervention group. Intervention cost &gt;$1.5 million, or &gt;$17 800 per patient, but was associated with cost savings &gt;$2500 per person by avoided hospitalizations. Final results are in process. (John Finn, MD, personal communication, January 2004).</td>
<td>Only shows some improvement in symptoms but no difference in survival at increased cost due to the high cost of interdisciplinary hospice services when used for palliative care (unpublished).</td>
</tr>
<tr>
<td>Pitorak et al, 2003</td>
<td>Project Safe Conduct gave modified hospice consultations for all patients with lung cancer starting treatment. After the program, 75% died in hospice care vs 13% before, with a median length of stay in hospice of 36 d after vs 10 d before. Program expanded to include advanced cancers, specifically lung, gastrointestinal, and head and neck cancers.</td>
<td>Project Safe Conduct has been sustained, is highly successful, and well received with demand for more teams at the Ireland Cancer Center. (Elizabeth Pitorak, RN, PhD, written communication, February 2, 2004).</td>
</tr>
<tr>
<td>Bakitas et al, 2002</td>
<td>Project ENABLE, a joint hospice–cancer center program. The program was well received at 2 of 3 sites, and the palliative care team experts were often called to help deliver bad news. No outcome data are available.</td>
<td>Demonstration project that showed the approach was feasible.</td>
</tr>
<tr>
<td>Elsayem et al, 2004</td>
<td>For patients at a comprehensive cancer center referred to palliative care, severe distress on admission and severe symptoms of distress significantly improved after palliative care consultation. Mean daily charges in the patient care information system were 30% lower than the mean daily charges for the rest of the hospital.</td>
<td>First published demonstration of better symptom control and lower costs for patients at a tertiary comprehensive cancer center; not really concurrent care.</td>
</tr>
<tr>
<td>Meyers et al, 2004</td>
<td>44 Patients in phase 3 trials “simultaneously enrolled into a defined home care program focused on supportive care needs of the patient and family, as well as assessment of the toxicities of investigational therapy” vs 20 usual-care patients. Quality of life improved but not significantly; 35 of 44 receiving supported care were referred to hospice vs 8 of 15 receiving usual care (P = .03) with longer mean but not median stay. Use of 2.5 cycles of chemotherapy did not differ and was well accepted.</td>
<td>Supportive care may enhance coordination of care and facilitate patients’ explicit transition from curative intent to palliative intent; a comparative randomized trial evaluating supportive care has yet to be completed.</td>
</tr>
<tr>
<td>Temel et al, 2007</td>
<td>51 of 53 Patients with lung cancer enrolled in a study during which they were seen concurrently by oncology and a palliative care team, which visited most several times and all who survived 6 mo, continued team visits in addition to oncologist visits. Only 2 (of 53 patients) refused to meet with the team. No outcome data.</td>
<td>Concurrent care is feasible, but whether it improves health outcomes (effectiveness) and cost-effectiveness vs usual care should be evaluated in a randomized trial.</td>
</tr>
</tbody>
</table>
CHEMOTHERAPY AT THE END OF LIFE

treated patients gain several weeks or months of life, at a cost less than $100,000 per additional year of life saved, but for Medicare, these are new costs to pay. For Mr L, his last dose of intrathecal cytarabine given 6 days before his death would cost $3400 at our institution.

The manner in which oncologists are reimbursed may play a role in chemotherapy use. Over the past 10 years, oncologists have become some of the highest paid medical specialists. Some of oncologists’ practice income comes from administering and selling chemotherapeutic agents and supportive care drugs (eg, bisphosphonates, erythropoietin-like drugs and colony stimulating factors). As is the case in other medical specialties, oncologists are reimbursed more for their specialized treatment of chemotherapy than for lengthy discussions about prognosis and palliative care options. This potential for conflict of interest has been the subject of controversy. The only published study was conducted before Medicare chemotherapy reimbursement was reduced in 2003 and found that reimbursement did not affect the decision to give palliative chemotherapy but that oncologists tended to choose chemotherapy that gave the highest profit to the practice. Although hospice care and inpatient palliative care may save money during the last month of life, total disease costs are unchanged or increased, so hospices cannot save enough money to allow more chemotherapy. It is critical to improve reimbursement incentives. For example, in 1 study, more than 25% of oncologists reported insufficient reimbursement for time spent in discussion with patients and families as “the most troublesome” reimbursement barrier to providing better end-of-life care.

If societal resources become limited, and maximizing health benefit becomes more difficult, there are only a few ways to reduce the cost of oncology care:

- Reduce the services provided (eg, “stopping rules,” in which no more than 3 lines of chemotherapy would be given for refractory metastatic breast cancer or no erythropoietin-like drug treatment for anemia would be given unless the hemoglobin is <10 g/dL);
- Reduce requested services by increasing patient co-payments;
- Reduce the amount that Medicare or insurers pay for chemotherapy and supportive care drugs, health care professional services, or hospitalizations;
- Prevent or delay new drugs from entering the market, or delay reimbursement for them;
- Reduce the payment to oncologists for administering chemotherapy and supportive care drugs, perhaps influencing the type of chemotherapy administered.

Ultimately, unless resources are unlimited, patients and families (or society at large) may be asked to balance individual patient needs against those of society.

CONCLUSION

Given understandable patient, family, clinician, and societal goals and concerns, how can all individuals be educated and informed as to the appropriate use of chemotherapy and the value of palliative care and hospice? First, as suggested by hospice experts and oncologists, other than the oncologist might give information about the hospice option and provide specific prognosis and palliative treatment information. Second, palliative care specialists should be aware of the difficult decision making that cancer patients face near death, and how different their perspective is about benefit and toxicity. Decision aids may be used. Finally, regarding palliative care options, completion of studies integrating hospice and palliative care into usual oncology care will permit evidence-based decision making.

The conundrum for today’s oncologist is that moving on to third- or fourth-line chemotherapy may be easier than discussing hospice care, the patient and family may be less upset, and they may prefer to not discuss the issue with the oncologist. Adverse effects of chemotherapy may be minimal, discussions take more time, and chemotherapy intervention is better compensated than are discussions. However, without a clear goals-of-care discussion, patients like Mr L and their families may be unprepared for what the final few months, weeks, or even days may bring. Through honest and respectful communication about the last stages of cancer, physicians can give patients a genuine choice about how to spend their last phase of life.

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CHEMOTHERAPY AT THE END OF LIFE

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Web Sites for End-of-Life Care Resources

AMERICAN CANCER SOCIETY
http://www.cancer.org
The American Cancer Society offers a complete listing of cancer services.

AMERICAN SOCIETY OF CLINICAL ONCOLOGY
http://www.cancer.net
Patient Information Web site has disease and symptom management information.

CENTER TO ADVANCE PALLIATIVE CARE
http://www.getpalliativecare.org
This Web site is geared toward patients, and tells them where to find palliative care.

NATIONAL CANCER INSTITUTE
http://www.cancer.gov
The National Cancer Institute has a complete listing of cancer treatment for the public and health care professionals. It also lists ongoing clinical trials. The Web site address for “Coping With Cancer” is http://www.cancer.gov/cancertopics/coping.
Titrating Guidance

A Model to Guide Physicians in Assisting Patients and Family Members Who Are Facing Complex Decisions

Nathan E. Goldstein, MD; Anthony L. Back, MD; R. Sean Morrison, MD

Over the last century, developments in new medical treatments have led to an exponential increase in longevity, but, as a consequence, patients may be left with chronic illness associated with long-term severe functional and cognitive disability. Patients and their families are often forced to make a difficult and complex choice between death and long-term debility, neither of which is an acceptable outcome. Traditional models of medical decision making, however, do not fully address how clinicians should best assist with these decisions. Herein, we present a new paradigm that demonstrates how the role of the physician changes over time in response to the curved relationship between the predictability of a patient’s outcome and the chance of returning to an acceptable quality of life. To translate this model into clinical practice, we propose a 5-step model for physicians with which they can (1) determine at which point the patient is on our model; (2) identify the cognitive factors and preferences for outcomes that affect the decision-making process of the patient and his or her family; (3) reflect on their own reaction to the decision at hand; (4) acknowledge how these factors can be addressed in conversation; and (5) guide the patient and his or her family in creating a plan of care. This model can help improve patient-physician communication and decision making so that complex and difficult decisions can be turned into ones that yield to medical expertise, good communication, and personal caring.

Mr G is an 86-year-old man with a history of coronary artery disease and atrial fibrillation. He works as a chemical engineer and has been widowed for 4 years. He lives independently and has close relationships with his 3 children. After a night of dancing, he is at dinner with his female companion, when he has the sudden onset of right-sided weakness and an expressive aphasia. At a large community hospital, he is diagnosed as having a left middle-cerebral artery thrombosis, and thrombolytic medications are administered. A week after the event, he continues to have a dense, right-sided hemiparesis, expressive and receptive aphasia, and difficulty swallowing. Although delirious, he can still interact with his family intermittently, and by their description, he is “in there.” Given Mr G’s difficulty swallowing and his high-risk for aspiration, his physician asks his family members if they want to have a gastric tube inserted for artificial hydration and nutrition or if they want to follow a comfort-based approach, without further life-sustaining treatments. The family members are conflicted: they feel that they are being forced to choose between 2 unacceptable outcomes—prolonged disability or death.

Over the last century, developments in public health and new medical therapies have led to an exponential increase in lon-
and there was an overall culture of paternalism,1 as it was believed that their inherent trust in authority figures. As medical care evolved, numerous problems with the paternalism model came to light. Input about desires for quality of life was not sought, and cultural and religious factors relating to health care were ignored. The model began to fall out of favor in the 1970s, partly as a result of an increasing distrust in medical authority figures and the increasing number and complexity of medical decisions.3 For all these reasons, the autonomy model was created.

EXISTING MODELS OF MEDICAL DECISION MAKING

Paternalism

The model of paternalism guided medical decision making from the time of Hippocrates until the 1970s. In that paradigm, patients were allowed to be passive and therefore exempted from their responsibilities in making their own health care decisions,1 as it was believed that their illnesses made them incompetent to make choices.2 Clinicians were charged with making all decisions for the patient,3 including establishing priorities for care. In a primarily male-dominated, nonpluralistic society, this model worked well, particularly because there were few treatment options available to patients. Also, most patients had long relationships with their physicians, and there was an overall culture of inherent trust in authority figures. As medical care evolved, numerous problems with the paternalism model came to light. Input about desires for quality of life was not sought, and cultural and religious factors relating to health care were ignored. The model began to fall out of favor in the 1970s, partly as a result of an increasing distrust in medical authority figures and the increasing number and complexity of medical decisions.3 For all these reasons, the autonomy model was created.

Autonomy

Under the autonomy model, clinicians are responsible for informing patients and their families regarding the salient issues in their care and the available treatment options, but the ultimate decision is made by patients5 and, after the landmark case of Karen Ann Quinlan in 1976,6 by families. The difficulty with the autonomy model is that it presumes the physicians’ role in decision making is matched to the patient’s likelihood of recovery. Unlike previous models that describe a static role for physicians, this paradigm demonstrates how the physicians’ role adapts over time in response to changes in patients’ states of health. As shown in the Figure, there is a curved relationship between the predictability of a patient’s outcome and the chance of returning to an acceptable quality of life. Our model is accompanied by a series of steps that can help clinicians translate theory into improving clinical care.

Shared Decision Making

In shared decision making, physicians work with patients and families to make health care decisions.4,5 This model assumes that clinicians and patients can evaluate the options together in a systematic way, consider the benefits and burdens of each treatment, and arrive at clear and logical decisions.5 Although seemingly combining the benefits of both paternalism and autonomy, the shared decision-making model is rooted in the assumption that patients and families make decisions in a rational way based solely on the clinical evidence. While physicians often make decisions by applying the latest evidence-based medicine to clinical scenarios and then assessing the likelihood of potential outcomes, patients and their families do not proceed in this fashion.9 The stress of illness, prior experiences with health care, and fears of future complications10 may lead patients and families to make decisions that lead health care providers to label patients and families as “having unrealistic hopes,” “acting in denial,” or “acting irrationally.”

A NEW MODEL: TITRATING GUIDANCE

We propose a new model whereby the physician’s role in decision making is matched to the patient’s likelihood of recovery. Unlike previous models that describe a static role for physicians, this paradigm demonstrates how the physicians’ role adapts over time in response to changes in patients’ states of health. As shown in the Figure, there is a curved relationship between the predictability of a patient’s outcome and the chance of returning to an acceptable quality of life. Our model is accompanied by a series of steps that can help clinicians translate theory into improving clinical care.
Left of the Curve
At the left of the curve, patients are healthy, so the outcome is easily predicted and there is a high probability of recovery. The role of physicians at this part of the curve is to provide information, as the choices are relatively straightforward, with low risks.

Top of the Curve
At the top of the curve, the outcome is difficult to predict and it is not possible to determine the patient’s probability of recovery. Patients and families need the most assistance from clinicians at this point on the curve because the most complicated decisions lie here. Each question creates a seemingly endless series of subsequent additional choices and conundrums. One way to guide patients and families at this point is to acknowledge that there are numerous factors that influence decision making. For example, uncontrolled physical symptoms,11 depression,12,13 functional status,14 anxiety,15 lack of feeling in control about one’s own health,15,16 and trust in physicians have all been shown to influence patients’ desires to engage in decision making. The family and the caregivers are particularly important because they can also suffer from emotional and physical strain,17-19 which may influence their decision making. Cultural, religious, and socioeconomic issues play a role and may even be in conflict.

In addition to these concerns, an understanding of the cognitive and psychological processes that influence decision making is key. One issue for patients and families at the peak of the curve is their concerns about future regret.10 It has been postulated that the potential regret of having failed to “do everything” (ie, refusing treatments or interventions) is so great that patients will choose treatments even if they are presented as having a small likelihood of benefit.20 After one path is chosen, the family may always wonder what would have happened had they chosen an alternate path, leading to a state of indecision.

“Sunk costs” are another factor that clinicians must understand in communicating with patients and families. Adapted from economics,22 this theory postulates that once patients have begun a certain treatment, they will continue with it (regardless of efficacy or future discomfort) to avoid the feeling that any resources (including time) used until this point were not wasted.20

In addition to these psychological factors, physicians must consider patients’ and families’ preferences and values for acceptable outcomes. Decisions about interventions are ultimately a comparison of the benefits of a particular treatment weighed against its burdens. Acceptable outcomes vary based on the benefit-burden analysis of the individual patient and family members. The balancing of this equation may be influenced by past experiences with the healthcare system (either for themselves or others), and physicians may need to inquire about these experiences to better understand how they shape the decision-making process.

Physicians must also examine the role their own emotions play in the guidance they provide. Concern for future regret also can affect physicians. When counseling families about stopping treatments, clinicians may wonder if there is just “one more thing” that can be done, a feeling that can influence the way they counsel individuals as well as turn into an enduring sense of guilt after the patient dies.22 Sunk costs may also affect physicians; clinicians may feel that terminating therapies invalidates their original rationale. In terms of personal values, it is important to remember that an acceptable outcome for the patient may differ dramatically from what clinicians would want for themselves.23

Finally, physicians’ reactions can have a concrete influence on the family. For example, unconscious emotions may alter the way that a physician frames a medical treatment or problem. Studies have shown that patients are more likely to choose treatments if the outcome is presented in terms of survival rather than mortality rates, even when the odds are the same.9,24

Right of the Curve
At the right of the curve, the outcome is easily predicted, but the chance of return to an acceptable quality of life is almost nil, because at this point the patients have advanced illness. There is little to no chance of recovery, and choices often relate to desire for symptom control, maximizing quality of life, and location and nature of death. Patients and families must deal with balancing treatment options with personal values and preferences, and the process of making these decisions is complex and distressing. Because there are ultimately few paths down which the treatment plan can proceed, the role of the physician changes from guiding decision making to reducing emotional and psychological stressors.

USING THE TITRATING GUIDANCE MODEL IN PRACTICE
As outlined in Table 2, applying the guide to practice can be accomplished through a 5-step process: (1) determine where the patient is on the curve; (2) identify the emotional and cognitive factors affecting patient/family decision making (which may be articulated as values, preferences, and past health care experiences) and determine which factors need further exploration; (3) reflect on the physician’s own reactions to the decision at hand, including personal preferences and values, acknowledging that they may differ from those of the patient; (4) determine how each of these factors can be addressed on the part of the patient/family as well as the physician; and (5) guide the patient/family in creating a plan of care. Steps 1 through 4 are done by the physician as preparation for step 5, which occurs as a conversation with patients and their families.
If she were faced with this decision herself but also acknowledges that Mr G may have a bias toward not intervening. Fourth, Dr R considers how she will address the issue of concern for future regret, and she decides to tell Mr G about her single bad outcome. Finally, Dr R has a conversation with Mr G during which she outlines the need for the treatment, as well as its benefits and burdens. Ultimately, Mr G needs little guidance in making the decision, and Dr R respects and supports his choice regardless of whether it is in conflict with her recommendation or the personal preferences she might have for her own care.

**Top of the Curve**

Dr R uses a similar process in her approach to communication with Mr G’s family members immediately after his stroke. First, she notes that the ultimate outcome cannot readily be predicted, and it is unclear what his future quality of life will be. The family members are being forced to make an extremely difficult decision: should they continue to support him in a comfort path is chosen and the family members immediately after his stroke. Fourth, Dr R considers how she will address the issue of concern for future regret, and she decides to tell Mr G about her single bad outcome. Finally, Dr R has a conversation with Mr G during which she outlines the need for the treatment, as well as its benefits and burdens. Ultimately, Mr G needs little guidance in making the decision, and Dr R respects and supports his choice regardless of whether it is in conflict with her recommendation or the personal preferences she might have for her own care.

**Left of the Curve**

Returning to the case of Mr G, consider the clinical scenario when he was first diagnosed as having atrial fibrillation. At that point, his physician wanted to add warfarin to his medication regimen. First, Dr R thinks about the titrating guidance curve and determines that because Mr G is relatively healthy and because data about the benefits and burdens of anticoagulation are robust, this conversation occurs at the left portion of the curve. (While Mr G is based on an actual patient, Dr R is a hypothetical physician used to illustrate how the titrating guidance model can be applied in clinical practice; Dr R is not based on an actual clinician.) For step 2, she determines that it is unlikely that Mr G will have a strong emotional reaction to the conversation, but he may have some concern for future regret—wondering about what the outcome might be if he chooses the other path. She remembers that she needs to inquire about any previous experience Mr G might have had with others who have made decisions about anticoagulation and how such an experience might influence his own benefit-burden analysis. In step 3, Dr R thinks about her own emotions. In her years of practice, she has had numerous patients who received anticoagulation, with only 1 case that she considers had a bad outcome. She acknowledges that her own personal bias would be to opt for anticoagulation stopped later if Mr G does not improve? For all of these reasons, Dr R determines that the current decisions that need to be made place Mr G and his family at the top of the curve.

In step 2, Dr R examines the emotional and cognitive factors that are affecting the family’s ability to make decisions. The family members have a range of reactions to Mr G’s sudden illness, so their sadness, shock, and denial all play a role in their decision making. In terms of cognitive factors, sunk costs should also be considered; the idea of not providing all life-sustaining treatments may leave the family members wondering if they should have ever chosen to provide previous treatments (eg, thrombolytic agents) in the first place. Concern for future regret is particularly high; if the comfort path is chosen and the family foregoes AHN, they may always wonder what would have happened if they had chosen an alternate path. Preferences for quality of life also affect their decision. Is living in a state where he is alive but not able to communicate acceptable to Mr G? Some patients would find a life of dependency on others unacceptable, whereas others would consider it in line with their religious and moral values.

A strategy that is often used to assist patients and families in these complicated decisions involves a time-limited trial of AHN. In this scenario, Dr R decides that she understands the

**Table 1. Examples of Communication Tools and Phrases to Aid Physicians in Discussions With Patients and Their Families at the Top of the Titrating Guidance Curve**

<table>
<thead>
<tr>
<th>Communication Tools</th>
<th>Definition</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>Articulating challenge for patient/family</td>
<td>Physician acknowledges difficulty of decision as well as importance of careful thought</td>
<td>“This is a tough decision and in this sort of situation I think it is helpful to do the following….”</td>
</tr>
<tr>
<td>Value-based proposal</td>
<td>Physician makes a proposal about care plan based on values elicited from patient and/or family</td>
<td>“I’m hearing a couple of important values as we talk, which are….” Tell me what you think about this proposal. What if we decided on a trial of a tube for AHN, because…”</td>
</tr>
<tr>
<td>“What if?” scenarios</td>
<td>Physician projects into the future based on hypothetical decisions</td>
<td>“Let’s think through what might happen if we put in a tube for AHN….” Now let’s think through what might happen if we do <em>not</em> put in a tube.”</td>
</tr>
<tr>
<td>Informed recommendation</td>
<td>Physician makes a medical recommendation informed by patient/family values and medical evidence related to efficacy of intervention</td>
<td>“Would it be helpful to hear a recommendation from me?…” Here’s how I put the situation together…”</td>
</tr>
<tr>
<td>Negotiate process for decision making</td>
<td>Physician helps family identify a process for thinking through the decision</td>
<td>“I can see there are many different perspectives here. Would it be helpful to talk about a process your family could use to think this through?”</td>
</tr>
</tbody>
</table>

Abbreviation: AHN, artificial hydration and nutrition.

*Which option is selected depends both on the physician’s assessment of the patient’s and/or the family’s dynamic and on the clinician’s comfort with using each style.*
family well enough to propose that a gastric tube be placed for a prespecified length of time (eg, 1 month). This option will allow the family a better sense of the potential benefits and burdens of this treatment modality, and it will provide more time to see if his neurologic status improves. Of note, while withholding and withdrawing medical treatments are considered to be both legally and ethically equivalent, patients and their families often may not see them as such. When the end of the allotted time frame arrives, Dr R plans another conversation about the outcomes observed by the family and the medical team.

In the third step, Dr R examines her own emotions. She has been Mr G’s physician for many years, so she must acknowledge her own feelings of loss and grief. If the family chooses to forgo further life-sustaining treatments, then Dr R may be left wondering if there is just “one more thing” that could be done. This consideration of hers is a variation of concern for future regret, and it can turn into an enduring source of guilt for Dr R if Mr G dies. Dr R must also acknowledge the personal preferences that she might have if one of her family members were in the same situation as Mr G, and she must be sure that her own preferences do not color her conversation with the family.

Dr R must also consider how her framing of the medical options will affect the decision the family makes. It is unlikely that the family members will agree to stopping treatments if she asks, “Do you agree to withdraw care?” But they might agree to the concept of reframing the goals of care, and Dr R could begin such a conversation by saying, “Let us focus now on assuring comfort and dignity in the time he has left instead of trying to prolong his life as long as we can.” In both cases, she is asking about moving from a life-sustaining treatment plan to a comfort-oriented approach to care, but the framing of the second scenario is more consistent with the values expressed by Mr G’s family.

In step 4, Dr R considers how she will handle these complex emotional and psychological issues when counseling the family. To address the degree to which the family is struggling with sunk costs, she will ask, “Are you concerned that stopping life-sustaining treatments now invalidates decisions that you have previously made?” To address concern for future regret, Dr R might say, “It is important to consider whether you will be comfortable with these choices when you look back on them 20 years from now.” In terms of her own reactions, she could discuss the plan to stop AHN with Mr G’s neurologist, or even ask for a second opinion, to lessen her own concerns for future regret.

In the final step, Dr R discusses the benefits and burdens of AHN with the family. For assistance with opening the conversation, Dr R chooses to use the informed recommendation tool described in Table 1. She begins the conversation with, “Given what you’ve told me about your father and his desire for both independence and quality of life, I don’t think it makes sense to put in a gastric tube. Tell me your reactions to my recommendation.” Dr R then moves on to address the family’s concerns about future regret and sunk costs. Ultimately, the family decides that a tube for AHN should not be placed.

### Right of the Curve

Several weeks later, it becomes clear that Mr G cannot eat enough to sustain himself. At this point, Dr R re-examines where Mr G is on the curve.

---

**Table 2. Elements to be Considered at 3 Points in Titrating Guidance Paradigm**

<table>
<thead>
<tr>
<th>Variable</th>
<th>Outcome Can Be Predicted, Chance of Recovery to Acceptable QOL Is High</th>
<th>Outcome Cannot Be Predicted, Chance of Recovery to Acceptable QOL Cannot Be Determined</th>
<th>Outcome Can Be Predicted, Chance of Recovery to Acceptable QOL Is Almost None</th>
</tr>
</thead>
<tbody>
<tr>
<td>Example of decision to be made</td>
<td>Should Mr G begin anticoagulation therapy?</td>
<td>Should Mr G’s family consent to having a tube inserted for AHN?</td>
<td>After AHN is discontinued, should Mr G’s family take him home or admit him to an inpatient hospice facility?</td>
</tr>
<tr>
<td>Step 1: Determine place on curve</td>
<td>Left</td>
<td>Top</td>
<td>Right</td>
</tr>
<tr>
<td>Step 2: Elicit patient’s and/or family’s emotional and cognitive reactions</td>
<td>No emotional response; no sunk costs, mild chance of concern for future regret</td>
<td>Strong emotional response; significant sunk costs and concern for future regret</td>
<td>Very strong emotional response, but to clinical situation, not to decisions themselves</td>
</tr>
<tr>
<td>Step 3: Reflect on physician emotional and cognitive reactions</td>
<td>Little</td>
<td>Strong emotional response; significant sunk costs and concern for future regret</td>
<td>Very strong emotional response, but to clinical situation, not to decisions themselves</td>
</tr>
<tr>
<td>Step 4: Acknowledge emotional/cognitive reactions, values, and goals that may shape decision preferences</td>
<td>Briefly address concern for future regret</td>
<td>Directly address emotional and cognitive issues; physician must consider own reaction as well as influence of framing</td>
<td>Attempt to relieve physical, emotional, psychological, spiritual, and existential suffering (and/or refer to experts in other disciplines)</td>
</tr>
<tr>
<td>Step 5: Titrate physician’s role in decision making based on previous 4 steps and location on curve</td>
<td>Inform patient of options and discuss risks/benefits</td>
<td>Guide patients/families in discussion about desired outcomes and then tailor treatments to those goals</td>
<td>Few decisions in care plan, so role moves to supportive</td>
</tr>
</tbody>
</table>

Abbreviation: AHN, artificial hydration and nutrition; QOL, quality of life.

The top row shows the point at which decision needs to be made, and the leftmost column outlines each of the 5 steps to guide families in decision making. The clinical questions take the case of Mr G and extrapolate it to decisions that he might have made in the past and that his family might have to make in the future.
She knows that recovery is unlikely, and so the decision now is whether the family will care for him at home or admit him to an inpatient hospice. The choices are well defined, and regardless of what is selected, the ultimate outcome—death—is known. Dr R therefore determines that the current decision is on the rightmost portion of the curve.

Next, Dr R determines both the emotional and the cognitive factors that influence the family’s decision making at this point. Sunk costs are not particularly applicable, and concern for future regret will come into play only if Mr G’s family is not provided with the resources (in terms of both guidance and medications) to ensure that his final days are comfortable. The family members may have preferences based on past experiences with the care of other family members or on their own personal beliefs about where Mr G should die. Likewise, although Dr R may have a strong emotional reaction to Mr G’s death, she realizes that because of the straightforward nature of the choices to be made, her emotions are unlikely to influence the way she guides the family (step 3). While she knows that if her father were in this situation she would want him to die at home, she will work to keep her personal preferences from influencing her counseling of the family.

In step 4, Dr R realizes that her role changes from guiding decisions to primarily supporting the family. In speaking with the family and creating a plan of care (step 5), she focuses on emotional counseling regarding the acceptance of imminent death rather than choosing biomedical interventions, and she assures the family members that treatments will be focused on sustaining life sometimes forces patients and their families to make choices that can seem difficult if not impossible. We have created a model for decision making that recognizes how a physician’s role ought to change with the uncertainty of the desired outcome and the chance of restoring an acceptable quality of life. While the model was applied to 3 scenarios in this discussion, it could theoretically be applied to aid decision making for any illness in any case. By using the titrating guidance paradigm, these difficult decisions can be turned into ones that yield to medical expertise, good communication, and personal caring.

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Correspondence: Nathan E. Goldstein, MD, Department of Geriatrics, Mount Sinai School of Medicine, One Gustave Levy Place, Box 1070, New York, NY 10029 (Nathan.Goldstein@mssm.edu).

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Cost Savings Associated With US Hospital Palliative Care Consultation Programs

R. Sean Morrison, MD; Joan D. Penrod, PhD; J. Brian Cassel, PhD; Melissa Caust-Ellenbogen, MS; Ann Litke, MFA; Lynn Spragens, MBA; Diane E. Meier, MD; for the Palliative Care Leadership Centers’ Outcomes Group

Background: Hospital palliative care consultation teams have been shown to improve care for adults with serious illness. This study examined the effect of palliative care teams on hospital costs.

Methods: We analyzed administrative data from 8 hospitals with established palliative care programs for the years 2002 through 2004. Patients receiving palliative care were matched by propensity score to patients receiving usual care. Generalized linear models were estimated for costs per admission and per hospital day.

Results: Of the 2966 palliative care patients who were discharged alive, 2630 palliative care patients (89%) were matched to 18,427 usual care patients, and of the 2388 palliative care patients who died, 2278 (95%) were matched to 2124 usual care patients. The palliative care patients who were discharged alive had an adjusted net savings of $1696 in direct costs per admission ($P = .004) and $279 in direct costs per day ($P < .001) including significant reductions in laboratory and intensive care unit costs compared with usual care patients. The palliative care patients who died had an adjusted net savings of $4908 in direct costs per admission ($P = .003) and $374 in direct costs per day ($P < .001) including significant reductions in pharmacy, laboratory, and intensive care unit costs compared with usual care patients. Two confirmatory analyses were performed. Including mean costs per day before palliative care and before a comparable reference day for usual care patients in the propensity score models resulted in similar results. Estimating costs for palliative care patients assuming that they did not receive palliative care resulted in projected costs that were not significantly different from usual care costs.

Conclusion: Hospital palliative care consultation teams are associated with significant hospital cost savings.

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Author Affiliations: Hertzberg Palliative Care Institute of the Brookdale Department of Geriatrics, Mount Sinai School of Medicine, New York, New York (Drs Morrison, Penrod, and Meier and Ms Litke); National Palliative Care Research Center, New York (Drs Morrison and Meier); Center to Advance Palliative Care, New York (Drs Morrison, Cassel, and Meier and Ms Caust-Ellenbogen and Spragens); Geriatric Research, Education, and Clinical Center, James J. Peters Veterans Affairs Medical Center, Bronx, New York (Drs Morrison and Penrod); Virginia Commonwealth University, Richmond (Dr Cassel); and Mount Carmel Health System, Columbus, Ohio (Ms Caust-Ellenbogen).

Group Information: The Palliative Care Leadership Centers’ Outcomes Group is listed at the end of this article.

Advances in Disease Prevention, Disease-Modifying Therapies, and Medical Technology in Combination with the Aging of the Population Have Resulted in a Dramatic Growth in the Number of Adults Living with Serious Illness. Despite enormous expenditures, patients with serious illness receive poor quality medical care, characterized by untreated symptoms, unmet personal care needs, high caregiver burden, and low patient and family satisfaction. Palliative care is the interdisciplinary specialty that focuses on improving quality of life for patients with advanced illness and for their families through pain and symptom management, communication and support for medical decisions concordant with goals of care, and assurance of safe transitions between care settings. Until a decade ago, palliative care in the United States was typically available only to patients living at home and enrolled in hospice. Now, palliative care programs targeting acutely ill patients are found increasingly in hospitals. As of 2005, 30% of US hospitals and 70% of hospitals with more than 250 beds reported the presence of a palliative care program—an increase of 96% from 2000. Unlike hospice, hospital palliative care is provided simultaneously with all other appropriate disease-directed treatments.

Hospital palliative care programs have been shown to improve physical and psychological symptom management, caregiver well-being, and family satisfaction, and small, single-site studies suggest that palliative care programs may reduce hospital and intensive care unit (ICU) expenditures by clarifying goals of care and assisting patients and families to select treatments that meet those goals. This study was undertaken to estimate the effect of palliative care consultation programs on hospital costs.

Methods

We used hospital administrative data to compare hospital costs of patients receiving palliative care consultation matched by propensity score with patients receiving usual care from 2002 through 2004.
Two crystal clear days in a row. The sun shining bright, the sky a canvas of blue. A gentle breeze whispers through the trees. The air is crisp and invigorating.

The rays of sunlight filter through the leaves, casting dappled shadows on the ground below. A cat lounges lazily on a nearby windowsill, basking in the warmth. A bird chirps from the tree, its song a melody of joy.

Around a corner, a family enjoys a picnic in the park. Children play tag, their laughter mixing with the rustling leaves. Parents chat, sipping coffee and enjoying the company of their loved ones.

The day is simply, beautifully perfect.}

---

**Table 1. Characteristics and Structures of Study Sites and Palliative Care Teams**

<table>
<thead>
<tr>
<th>Variable</th>
<th>A</th>
<th>B</th>
<th>C</th>
<th>D</th>
<th>E</th>
<th>F</th>
<th>G</th>
<th>H</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital type</td>
<td>Com</td>
<td>Com</td>
<td>Acd</td>
<td>Com</td>
<td>Com</td>
<td>Com</td>
<td>Acd</td>
<td>Acd</td>
</tr>
<tr>
<td>No. of hospital beds</td>
<td>348</td>
<td>807</td>
<td>434</td>
<td>330</td>
<td>220</td>
<td>336</td>
<td>574</td>
<td>976</td>
</tr>
<tr>
<td>No. of admissions, y</td>
<td>2002</td>
<td>13,342</td>
<td>27,379</td>
<td>19,921</td>
<td>17,645</td>
<td>14,916</td>
<td>22,463</td>
<td>20,302</td>
</tr>
<tr>
<td>No. of deaths, y</td>
<td>2002</td>
<td>474</td>
<td>438</td>
<td>557</td>
<td>613</td>
<td>313</td>
<td>682</td>
<td>549</td>
</tr>
<tr>
<td>No. of Medicare admissions, y</td>
<td>2002</td>
<td>7,871</td>
<td>6,078</td>
<td>6,693</td>
<td>5,927</td>
<td>2,958</td>
<td>6,593</td>
<td>7,308</td>
</tr>
</tbody>
</table>

**SAMPLE**

Eight geographically and structurally diverse hospitals representing low-, middle-, and high-cost markets served by 6 mature palliative care consultation teams (1 team served 3 hospitals) were included (Table 1). For the main analyses, the patient sample included all patients 18 years or older who had lengths of stay of 7 to 30 days. We excluded patients with short lengths of stay because these patients were unlikely to receive palliative care consultation. Patients with lengths of stay of more than 30 days were excluded because they represented outliers that were unlikely to be generalizable. Patients receiving palliative care were identified through the palliative care consultation teams’ administrative databases and billing records. The initial sample included 43,973 patients discharged alive and 4,726 patients who died in hospital.

**PATIENT FACTORS**

We used hospital databases to abstract patient characteristics. Medical comorbidities were determined using the Elixhauser algorithm that includes 30 categories of comorbid illnesses identified by secondary diagnosis codes and discharge diagnosis-related groups.

**COSTS**

Costs were abstracted from the hospitals’ cost accounting systems. Each hospital used the same system, TSI (Transitions Systems Inc, Boston, Massachusetts). TSI tracks all hospital resources and assigns cost (not charge) values to these resources. These estimates are based on direct acquisition costs for supplies and time-and-motion studies for labor costs. Various procedures are also used to determine the proportion of other costs, such as plant costs (eg, lighting and heating), that should be applied to each resource. This approach is generally considered the most accurate method to estimate costs. We abstracted direct and total costs for each subject for each hospital day and for the entire admission. Direct costs are costs that can be directly attributable to medications, procedures, or services. Indirect costs are the general costs of running a hospital that are not directly related to the test or service. Total costs are the sum of direct and indirect costs. We used Uniform Billing 92 codes to aggregate direct costs into specific categories that included the following: ICU, pharmacy and intravenous therapy, laboratory, and diagnostic imaging costs. All costs were converted into 2004 US dollars.

**ANALYSES**

Subjects were stratified by hospital site and then within each hospital into 2 strata comprising live discharges and hospital deaths. We computed propensity scores for each subject within each stratum. Propensity scores were determined by regressing whether patients received palliative care consultation on all patient characteristics present at hospital admission listed in the hospital databases. These variables included patient age, sex, marital status, medical insurance, primary diagnosis, attending physician specialty, and Elixhauser comorbidity score. Within each stratum we matched each patient receiving palliative care consultation with 1 or more usual care patients whose tending physician specialty, and Elixhauser comorbidity score. Within each stratum we matched each patient receiving palliative care consultation with 1 or more usual care patients whose logit of their propensity score was within ±0.05 standard deviations of the logit of the palliative care patient's score. Unmatched patients were excluded, and all subsequent analyses included matched live discharges and matched hospital deaths.

Bivariate comparisons of unadjusted per diem costs and patient demographics were examined using unpaired t tests and χ² tests as appropriate. Usual care patients’ data were weighted to account for the one-to-many propensity score matching algorithm. Generalized linear models (GLMs) using normalized weighted data were estimated for total and direct costs per hospital admission and hospital day. In addition, we estimated GLMs for pharmacy, diagnostic imaging, laboratory test, and ICU direct costs for all usual care patients admitted to an ICU and for...
patients receiving palliative care consultation prior to ICU discharge. The GLMs were specified as having a gamma distribution and log link. The dependent variable was cost, and the independent variables included patient age, principal diagnosis, comorbidity score, palliative care team, attending physician specialty, marital status, insurance type, hospital discharge site for live discharges, and the key independent variable, whether the patient received palliative care consultation. Each cost model was adjusted for clustering by hospital. The GLM was used to examine the effects of palliative care consultation on hospital length of stay in days controlling for the aforementioned covariates.

ADDITIONAL CONFIRMATORY ANALYSES

We performed 2 additional confirmatory analyses. We matched usual care and palliative care patients by intensity of medical services before palliative care consultation to confirm that the palliative care and usual care groups were well matched. This analysis was performed by developing propensity scores using mean direct daily costs before consultation (palliative care patients) and before a corresponding reference day (usual care) as a regressor in the propensity score models. The reference day for usual care patients was hospital day 6 for patients with lengths of stay of 10 days or less, day 10 for those with lengths of stay of 11 to 20 days, and day 18 for those with lengths of stay longer than 20 days. These reference days represented the average day of consultation for palliative care patients for lengths of stay within these 3 categories. The GLMs were used to estimate costs for the usual care and palliative care patients.

We also used the GLM to model costs up to the day before consultation for palliative care patients. We then used these models to predict hypothetical costs in the absence of a palliative care consultation for the remaining length of stay, assuming that the slope of the cost curves remained constant, as was actually observed for usual care patients. We compared these predicted costs to actual costs for palliative care patients.

All analyses were performed with Stata version 9.2 statistical software (StataCorp, College Station, Texas), and this study was approved by the institutional review boards of all sites.

RESULTS

Of the 2966 patients who received palliative care consultation and who were discharged alive, 2630 (89%) were matched to 18,427 usual care patients discharged alive, and of the 2388 palliative care patients who died in hospital, 2278 (95%) were matched to 21,24 usual care patients who died in hospital (Table 2 and Table 3). There were no statistically significant differences in length of stay between usual care and palliative care patients discharged alive (12.4 vs 13.1 days; P = .12) and those who died in hospital (13.9 vs 14.1 days; P = .40).

COSTS FOR PATIENTS DISCHARGED ALIVE

Patients receiving palliative care consultation had significantly lower costs than usual care patients. For patients discharged alive, palliative care consultation was associated with adjusted net savings in total costs of $2642 per admission (P = .02) and $279 per day (P < .001) compared with usual care. Adjusted net savings in direct costs associated with palliative care were $1696 per admission (P = .004) and $174 per day (P < .001). These savings included significant reductions in laboratory costs ($424 per admission; P < .001) and ICU costs ($5178 per ICU admission; P < .001) (Table 4). Including outlier patients—those with lengths of stay less than 7 days and longer than 30 days—resulted in reductions in direct costs per day of $275 and $246, respectively, favoring palliative care.

COSTS FOR PATIENTS WHO DIED IN HOSPITAL

For patients who died in hospital, palliative care consultation was associated with adjusted net savings in total costs of $6,896 per admission (P = .001) and $549 per day (P < .001). Adjusted net savings in direct costs were $4908 per admission (P = .003) and $374 per day (P < .001). These reductions in direct costs included significant reductions in pharmacy costs ($1,544 per admission; P = .04), laboratory tests ($926 per admission; P < .001), and ICU costs ($6,613 per ICU admission; P < .001) (Table 4). Including outlier patients—those with lengths of stay less than 7 days and longer than 30 days—resulted in reductions in direct costs per day of $559 and $370, respectively, favoring palliative care.

CONFIRMATORY ANALYSES

Including mean cost per day before palliative care consultation and before the reference day for usual care subjects in the propensity score models as a surrogate for intensity of medical services resulted in qualitatively similar results (ie, the parameter estimates were contained within the 95% confidence intervals of the estimates of the primary analyses) across all major cost categories albeit with fewer matched subjects (78% of palliative care patients discharged alive could be matched to a usual care patient and 92% of palliative care patients who died could be matched to a usual care patient).

Figure 1 displays mean daily direct costs for live discharges and hospital deaths. For palliative care patients, we plotted the 6 days before and after palliative care consultation (day 0). For usual care patients, day 0 was the reference day established for the confirmatory analyses previously described. There were no significant differences observed between the cost curves' slopes or the mean daily direct costs for palliative care and matched usual care groups before the day of consultation (palliative care patients) or the reference day (usual care patients). Whereas the slope of the usual care cost curve approached zero following the reference day, palliative care consultation was associated with a significant reduction in hospital costs 24 to 48 hours after consultation. For patients discharged alive (Figure 1A), mean direct costs per day decreased from $843 for the 48 hours before palliative care consultation to $605 for the 48 hours after consultation (P = .001) and from $1163 for the 48 hours before consultation to $589 for the 48 hours after consultation (P = .003) for patients who died (Figure 1B).

We projected what the adjusted direct costs per admission for palliative care patients would have been if they had not received palliative care consultation. Projected direct costs per admission were $11,787 for patients discharged alive and $22,301 for patients who died in hospital. These projected costs were not significantly
different from the costs actually observed in the usual care group ($11,140 [P = .26] for live discharges and $22,674 [P = .44] for deceased patients).

Finally, to explore the question of whether the recommendations of the palliative care consultation teams reduced hospital costs or were simply a marker of changes in treatment plans already implemented by the primary care team, we plotted mean direct costs for each day of admission for usual care patients and for patients receiving palliative care consultation on hospital days 7, 10, and 15 for patients who died (Figure 2). Costs for patients who received palliative care were no different from those in the usual care group until 24 to 48 hours after palliative care consultation at which time costs in the palliative care group started to decrease. A similar pattern was observed for patients discharged alive (data not shown).

Studies have consistently demonstrated that patients with life-threatening illness experience untreated pain and other symptoms; lengthy hospitalizations involving unwanted, often low-yield and costly medical treatments; and low overall family satisfaction.2,9,25-27 Hospital palliative care consultation programs have been associated with reductions in symptoms and higher family satisfaction with overall care, and greater emotional support as compared with usual care.2,6,28,29 Although others have postulated that palliative care programs could substantially reduce hospital costs,26,30 this study is the first, to our knowledge, to empirically evaluate the actual effect of palliative care on US hospitals. 

### Table 2. Demographics and Characteristics of Patients Discharged Alive From the Hospital

<table>
<thead>
<tr>
<th>Variable</th>
<th>Weighted Value</th>
<th>Matched Value</th>
<th>Nonweighted Value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Usual Care (n=18,427)</td>
<td>Matched Palliative Care (n=2,630)</td>
<td>Unmatched Palliative Care (n=306)</td>
</tr>
<tr>
<td>Age, mean (range), y</td>
<td>68.07 (18-106)</td>
<td>68.2 (18-104)</td>
<td>.78</td>
</tr>
<tr>
<td>Men, %</td>
<td>41.8</td>
<td>41.19</td>
<td>.90</td>
</tr>
<tr>
<td>Married, %</td>
<td>42.0</td>
<td>41.7</td>
<td>.52</td>
</tr>
<tr>
<td>Insurance, %</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medicare</td>
<td>69.4</td>
<td>69.4</td>
<td></td>
</tr>
<tr>
<td>Medicaid</td>
<td>9.7</td>
<td>11.2</td>
<td></td>
</tr>
<tr>
<td>Managed care</td>
<td>16.4</td>
<td>15.7</td>
<td>.21</td>
</tr>
<tr>
<td>Indemnity plan</td>
<td>3.2</td>
<td>2.4</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>1.4</td>
<td>1.3</td>
<td></td>
</tr>
<tr>
<td>Principal diagnosis, %</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cancer</td>
<td>28.4</td>
<td>28.9</td>
<td></td>
</tr>
<tr>
<td>Infection</td>
<td>4.4</td>
<td>4.3</td>
<td></td>
</tr>
<tr>
<td>Cardiovascular</td>
<td>18.9</td>
<td>18.6</td>
<td></td>
</tr>
<tr>
<td>Pulmonary</td>
<td>15.8</td>
<td>15.4</td>
<td>.90</td>
</tr>
<tr>
<td>Gastrointestinal</td>
<td>6.7</td>
<td>7.2</td>
<td></td>
</tr>
<tr>
<td>Genitourinary</td>
<td>4.4</td>
<td>3.8</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>21.4</td>
<td>21.9</td>
<td></td>
</tr>
<tr>
<td>Comorbidities, mean (range), No.</td>
<td>2.6 (0-10)</td>
<td>2.6 (0-11)</td>
<td>.86</td>
</tr>
<tr>
<td>Physician specialty, %</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Internal medicine</td>
<td>69.4</td>
<td>67.0</td>
<td></td>
</tr>
<tr>
<td>Oncology</td>
<td>12.7</td>
<td>14.9</td>
<td></td>
</tr>
<tr>
<td>Surgery</td>
<td>12.7</td>
<td>12.9</td>
<td>.96</td>
</tr>
<tr>
<td>Other</td>
<td>5.2</td>
<td>5.2</td>
<td></td>
</tr>
<tr>
<td>Admitted to ICU, %</td>
<td>38.6</td>
<td>37.5</td>
<td>.43</td>
</tr>
<tr>
<td>Discharge destination, %</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home</td>
<td>67.4</td>
<td>56.3</td>
<td></td>
</tr>
<tr>
<td>Nursing home</td>
<td>25.7</td>
<td>38.1</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Other</td>
<td>6.9</td>
<td>5.6</td>
<td></td>
</tr>
<tr>
<td>Hospital, %a</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospital A</td>
<td>12.6</td>
<td>12.6</td>
<td></td>
</tr>
<tr>
<td>Hospital B</td>
<td>6.8</td>
<td>6.8</td>
<td></td>
</tr>
<tr>
<td>Hospital C</td>
<td>13.0</td>
<td>13.0</td>
<td></td>
</tr>
<tr>
<td>Hospital D</td>
<td>14.3</td>
<td>14.3</td>
<td>.99</td>
</tr>
<tr>
<td>Hospital E</td>
<td>18.2</td>
<td>18.3</td>
<td></td>
</tr>
<tr>
<td>Hospital F</td>
<td>9.3</td>
<td>9.3</td>
<td></td>
</tr>
<tr>
<td>Hospital G</td>
<td>2.3</td>
<td>2.3</td>
<td></td>
</tr>
<tr>
<td>Hospital H</td>
<td>23.5</td>
<td>23.5</td>
<td></td>
</tr>
<tr>
<td>Days receiving palliative care, mean (range)</td>
<td>NA</td>
<td>6.5 (1-29)</td>
<td></td>
</tr>
</tbody>
</table>

Abbreviations: ICU, intensive care unit; NA, not applicable.

*For a description of hospitals, see Table 1 footnote.*
tal costs using a sample size sufficient to assure reliable results, using propensity score–matched control patients and enrolling patients from 8 diverse hospitals serving low-, medium-, and high-cost markets, thus enhancing the generalizability of our results. Our finding that palliative care consultation is associated with

Table 3. Demographics and Characteristics of Patients Who Died in the Hospital

<table>
<thead>
<tr>
<th>Variable</th>
<th>Usual Care Patients (n=2124)</th>
<th>Matched Palliative Care Patients (n=2278)</th>
<th>P Value</th>
<th>Nonweighted Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, mean (range), y</td>
<td>71.7 (16-103)</td>
<td>71.6 (19-104)</td>
<td>.82</td>
<td>68.8 (19-100)</td>
</tr>
<tr>
<td>Men, %</td>
<td>48.4</td>
<td>48.1</td>
<td>.79</td>
<td>47.1</td>
</tr>
<tr>
<td>Married, %</td>
<td>43.9</td>
<td>44.0</td>
<td>.97</td>
<td>50.0</td>
</tr>
<tr>
<td>Insurance, %</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medicare</td>
<td>74.9</td>
<td>75.6</td>
<td>69.0</td>
<td></td>
</tr>
<tr>
<td>Medicaid</td>
<td>8.6</td>
<td>8.4</td>
<td>7.3</td>
<td></td>
</tr>
<tr>
<td>Managed care</td>
<td>12.6</td>
<td>12.2</td>
<td>.99</td>
<td>7.3</td>
</tr>
<tr>
<td>Indemnity plan</td>
<td>2.8</td>
<td>2.8</td>
<td>4.4</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>1.0</td>
<td>1.0</td>
<td>11.8</td>
<td></td>
</tr>
<tr>
<td>Principal diagnosis</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cancer</td>
<td>19.3</td>
<td>19.0</td>
<td>23.5</td>
<td></td>
</tr>
<tr>
<td>Infection</td>
<td>11.5</td>
<td>11.3</td>
<td>2.0</td>
<td></td>
</tr>
<tr>
<td>Cardiovascular</td>
<td>24.8</td>
<td>24.3</td>
<td>27.9</td>
<td></td>
</tr>
<tr>
<td>Pulmonary</td>
<td>17.5</td>
<td>18.3</td>
<td>16.0</td>
<td></td>
</tr>
<tr>
<td>Gastrointestinal</td>
<td>9.0</td>
<td>9.0</td>
<td>8.8</td>
<td></td>
</tr>
<tr>
<td>Genitourinary</td>
<td>3.7</td>
<td>3.9</td>
<td>4.4</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>14.2</td>
<td>14.2</td>
<td>16.1</td>
<td></td>
</tr>
<tr>
<td>Comorbidities, mean (range), No.</td>
<td>2.9 (0-9)</td>
<td>2.9 (0-10)</td>
<td>.98</td>
<td>2.5 (0-7)</td>
</tr>
<tr>
<td>Physician specialty, %</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Internal medicine</td>
<td>74.8</td>
<td>74.8</td>
<td>32.0</td>
<td></td>
</tr>
<tr>
<td>Oncology</td>
<td>8.8</td>
<td>8.8</td>
<td>10.0</td>
<td></td>
</tr>
<tr>
<td>Surgery</td>
<td>13.2</td>
<td>13.0</td>
<td>.96</td>
<td>8.0</td>
</tr>
<tr>
<td>Other</td>
<td>3.2</td>
<td>3.4</td>
<td>50.0</td>
<td></td>
</tr>
<tr>
<td>Admitted to ICU, %</td>
<td>74.2</td>
<td>68.3</td>
<td>&lt;.001</td>
<td>60</td>
</tr>
<tr>
<td>Hospital, %a</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospital A</td>
<td>5.4</td>
<td>5.4</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Hospital B</td>
<td>3.0</td>
<td>3.0</td>
<td>4.4</td>
<td></td>
</tr>
<tr>
<td>Hospital C</td>
<td>11.4</td>
<td>11.4</td>
<td>11.8</td>
<td></td>
</tr>
<tr>
<td>Hospital D</td>
<td>19.7</td>
<td>19.7</td>
<td>39.7</td>
<td></td>
</tr>
<tr>
<td>Hospital E</td>
<td>18.0</td>
<td>18.0</td>
<td>20.6</td>
<td></td>
</tr>
<tr>
<td>Hospital F</td>
<td>11.1</td>
<td>11.1</td>
<td>5.9</td>
<td></td>
</tr>
<tr>
<td>Hospital G</td>
<td>10.0</td>
<td>10.0</td>
<td>5.9</td>
<td></td>
</tr>
<tr>
<td>Hospital H</td>
<td>21.3</td>
<td>21.3</td>
<td>11.8</td>
<td></td>
</tr>
<tr>
<td>Days receiving palliative care, mean (range)</td>
<td>NA</td>
<td>4.8 (1-28)</td>
<td>NA</td>
<td>3.9 (0-15)</td>
</tr>
</tbody>
</table>

Abbreviations: ICU, intensive care unit; NA, not applicable.

a For a description of hospitals, see Table 1 footnote.

Table 4. Adjusted Costs for Live Discharges and Hospital Deaths

<table>
<thead>
<tr>
<th>Cost</th>
<th>Live Discharges</th>
<th>Hospital Deaths</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cost</td>
<td>Usual Care (95% CI), $</td>
<td>Palliative Care (95% CI), $</td>
</tr>
<tr>
<td>Total costs admission</td>
<td>19 379 (18 984-19 773)</td>
<td>16 737 (15 546-17 972)</td>
</tr>
<tr>
<td>Total costs per day</td>
<td>1450 (1430-1470)</td>
<td>1171 (1082-1260)</td>
</tr>
<tr>
<td>Direct costs per admission</td>
<td>11 140 (10 884-11 395)</td>
<td>9 445 (8761-10 128)</td>
</tr>
<tr>
<td>Direct costs per day</td>
<td>830 (815-846)</td>
<td>656 (588-723)</td>
</tr>
<tr>
<td>Laboratory costs</td>
<td>1227 (1185-1268)</td>
<td>803 (712-893)</td>
</tr>
<tr>
<td>ICU costs</td>
<td>7096 (5801-8390)</td>
<td>1917 (1646-2187)</td>
</tr>
<tr>
<td>Pharmacy costs</td>
<td>2190 (2116-2265)</td>
<td>2001 (1822-2180)</td>
</tr>
<tr>
<td>Imaging costs</td>
<td>890 (868-913)</td>
<td>949 (884-1014)</td>
</tr>
</tbody>
</table>

Abbreviations: CI, confidence interval; ICU, intensive care unit.
significant reductions in hospital costs has important implications for hospitals and policy makers.

OTHER FACTORS THAT COULD ACCOUNT FOR THE OBSERVED SAVINGS

It is possible that the cost saving observed might have occurred spontaneously without the palliative care consultation team's intervention due to unmeasured confounding variables that we were unable to obtain from administrative data. Specifically, it is possible that before the palliative care consultation, physicians recommended and patients agreed to forego some therapies and that the palliative care team enacted a previously decided-on care plan. Data suggest that this is unlikely. Although this study was a retrospective analysis, 3 of the participating palliative care teams have reported that most palliative care consultations are requested to help address goals of care and to discuss with patients all treatment options, including that of foregoing treatments that will not meet their goals or prolong life in a meaningful fashion.25 Other studies lend credence to this argument. The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT), which included more than 9000 seriously ill adults, demonstrated that patient preferences and physicians' knowledge of patients' preferences and prognoses did not have a measurable effect on hospital costs and treatments.25

Our data suggest that it was the actions of the palliative care teams that resulted in cost reductions. First, we found no significant differences in the palliative care and usual care groups across all observable patient characteristics, suggesting that the 2 groups were well matched. Second, as shown in Figure 1 and Figure 2, the decrease in costs consistently occurred 48 hours after consultation—no matter when the consultation occurred—and no corresponding decline was observed in the usual care group at any point in their hospital stay. If palliative care was only a marker for change, we would have expected the cost curves to drop before or at the time of consultation rather than be delayed for 48 hours, as was observed. Finally, our confirmatory analyses replicated our main findings. Specifically, including mean cost per day before palliative care consultation or the equivalent reference day for usual care patients as a surrogate for intensity of medical services in the propensity score analyses resulted in almost identical results. A comparison of the actual costs for palliative care patients after palliative care consultation with estimated costs in the case that palliative care consultation had hypothetically not occurred also resulted in almost identical savings.

WHAT ACCOUNTS FOR THE COST SAVINGS?

While it may appear self-evident that discontinuing costly nonbeneficial interventions among seriously ill patients reduces hospital costs, such a fundamental shift in the usual hospital care pathway is neither a simple nor straightforward process, given the highly patterned treatment culture of the US hospital, which is structured to prolong life and avert death at all costs. In this context, the fact that palliative care consultation appeared to consistently influence this process is an important finding. Indeed, prior studies have definitively demonstrated that even when seriously ill patients' preferences for treatments focused solely on comfort are documented and known by their physicians, these patients continue to receive low-yield, burdensome, and high-cost tests and treatments including prolonged ICU stays—a probable result of highly ingrained physician and hospital practice patterns and prevailing hospital culture.25 Our data suggest that palliative care consultation fundamentally shifts the course of care off the usual hospital pathway and in doing so, sig-

![Figure 1](image1.png)

![Figure 2](image2.png)
nificantly reduces costs. This shift is likely accomplished by establishing clear treatment goals, reviewing current treatments to establish their concordance with these goals, and recommending and legitimizing discontinuation of treatments or tests that do not meet established goals.

RELATIONSHIP TO OTHER STUDIES

Our data confirm and extend previously published small single-site studies. Two studies performed at Department of Veterans Affairs (VA) medical centers reported reduced health care utilization and costs associated with palliative care programs. Outside the VA, Cowan reported reduced charges associated with a palliative care consultation team in a community hospital; Elsayem and colleagues reported reduced charges associated with a palliative care inpatient unit in a cancer hospital; and Campbell and Frank and Norton and colleagues demonstrated reductions in ICU resource utilization associated with an ICU-based palliative care team. Two single site studies have looked at non-VA overall hospital costs. Smith and colleagues found significantly lower costs for patients who died in an inpatient palliative care unit compared with matched controls who died in other hospital units, and Ciemins and colleagues observed similar findings associated with a palliative care consultation service.

Our study has several strengths compared with these studies. We included data from 8 geographically and structurally diverse hospitals but with similarly structured palliative care consultation teams—now the standard of palliative care practice in US hospitals—thus enhancing the generalizability of our results. Prior studies used highly variable models of care and interventions that are neither comparable nor replicable. We used hospital costs rather than charges and thus our results reflect true rather than estimated savings. Finally, our estimates of savings per day may be conservative because the main analyses did not include patients with a length of stay longer than 30 days. The inclusion of outliers resulted in even greater savings.

IMPLICATIONS

Our results provide strong fiscal incentives for hospitals and policy makers to develop or expand palliative care consultation programs—programs that have already been demonstrated to improve quality and patient and family satisfaction. The most medically complex patients, such as the patients enrolled in this study, account for a growing proportion of admissions, bed days, and use of hospital resources. The median operating margin for a hospital is 2% ($27-$40 per day), thus the $174-per-day savings in direct costs for live discharges associated with palliative care consultation in this study could have a significant impact on hospital performance, particularly as the proportion of older, complex, and chronically ill admissions increases over the coming years. Whether a hospital is paid on a diagnosis-related group or a per diem basis, they benefit from the lower costs. As the proportion of discounted fee for service patients continues to dwindle, this is of increasing importance.

Hospital palliative care programs are also likely to help reduce Medicare expenditures. Five percent of Medicare enrollees with the most serious illness account for over 43% of Medicare expenditures, with the top 25% of enrollees accounting for 85% of the costs. Three-quarters of these 25% of "highest cost" enrollees have at least 1 hospital admission per year, and approximately 60% of total Medicare health care expenditures are for hospital care. Expansion of palliative care consultation programs to adequately serve the complex patient base of hospitals reduces cost pressures between hospitals and Medicare. Discharge orders and care plans resulting from palliative care consultations may also reduce ongoing care costs in the outpatient arena.

LIMITATIONS

This was not a randomized trial, and it is possible that the cost differences resulted from unmeasured differences between the 2 groups. We used several design and analytic measures to limit bias and confounding. First, we included subjects with a defined length of stay to eliminate the effects of outliers. Second, we stratified our sample both by site and by vital status prior to propensity score matching to minimize unobserved confounders. Third, we used propensity score methods to match patients based on patient characteristics to balance observed covariates and cannot draw conclusions about unmatched patients. However, the numbers of unmatched palliative care patients were relatively small (11% of patients discharged alive and 5% of patients who died). Finally, we used appropriate multivariable techniques to control for non–patient-based characteristics. Thus, although possible, we believe that it is unlikely that the magnitude of the effects noted here could be due to persistent unobserved confounders such as patient or physician preferences. Specifically, if patient preferences or another unmeasured variable were confounding our results, the parameter estimate would need to be several orders of magnitude larger than that observed in SUPPORT for us to have obtained these results, given the effects sizes observed in our models.

CONCLUSIONS

This study found that palliative care consultation was associated with a reduction in direct hospital costs of almost $1700 per admission ($174 per day) for live discharges and of almost $5000 per admission ($374 per day) for patients who died. For an average 400-bed hospital containing an interdisciplinary palliative care team seeing 500 patients a year (300 live discharges and 200 hospital deaths), these figures translate into a net savings of $1.3 million per year after adding physician revenues ($240 000) and subtracting personnel costs ($418 000). This study adds to the growing literature on the benefits of palliative care consultation by demonstrating that in addition to improved clinical care and patient, family, and physician satisfaction, these programs are associated with considerable reductions in hospital costs. The growth of the number of adults living with advanced and complex chronic illnesses, the documented inadequacies in care quality, and the increases in expenditures highlight the need for efficient models such as palliative care consultation teams that deliver quality services to complex patient populations.
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Correspondence: R. Sean Morrison, MD, Hertzberg Palliative Care Institute of the Brookdale Department of Geriatrics, Mount Sinai School of Medicine, Box 1070, One Gustave L. Levy Place, New York, NY 10029 (sean.morrison@mssm.edu).

Author Contributions: Dr Morrison had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis. Study concept and design: Morrison, Penrod, Cassel, Caust-Ellenbogen, Spragens, and Meier. Acquisition of data: Morrison, Caust-Ellenbogen, Litke, and Spragens. Analysis and interpretation of data: Morrison, Penrod, Cassel, Caust-Ellenbogen, Litke, and Spragens. Drafting of the manuscript: Morrison, Penrod, Cassel, Spragens, and Meier. Critical revision of the manuscript for important intellectual content: Morrison, Penrod, Cassel, Caust-Ellenbogen, Litke, and Meier. Statistical analysis: Morrison, Penrod, Cassel, and Litke. Obtained funding: Morrison and Meier. Administrative, technical, and material support: Litke, Spragens, and Meier. Study supervision: Morrison and Meier.

The Palliative Care Leadership Centers’ Outcomes Group: Center to Advance Palliative Care, New York, New York: Jessica Dietrich, MPH, Bradley Griffith, MBA, Amber Jones, MEd, Catherine Manorey, MPH, and Carol Sieger, JD; Hospice and Palliative Care of the Bluegrass, Lexington, Kentucky: Janet Braun, RN, MSN, and Terence Gutgsell, MD; Medical College of Wisconsin, Milwaukee: David Weissman, MD; Fairview Health Services, Minneapolis, Minnesota: Andrea Brandt, BA, Carolyn Ceronksy, MS, APRN, and Mark Leenay, MD; Mount Carmel Health System, Columbus, Ohio: Philip Santa-Emma, MD, and Mary Ann Gill, MA, RN; and University of California, San Francisco: Kathleen Kerr, BA, and Steven Z. Pantilat, MD.

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REFERENCES

Case Reviews in Pain

Physical Pain and Emotional Suffering: The Case for Palliative Sedation

Tara Sanft, Joshua Hauser, Drew Rosielle, David Weissman, Ahmed Elsayem, Donna S. Zhukovsky, and Nessa Coyle

Case Study

A 46-year-old woman with metastatic ovarian cancer was admitted to the palliative care service for pain control. The patient had been diagnosed 5 years earlier during a work-up of an adnexal mass that was found to be a papillary serous adenocarcinoma of the ovary, stage IIIA. She underwent chemotherapy with carboplatin and paclitaxel with good response until 2 years later, when the CA-125 (cancer antigen 125, an antigen used as a marker for ovarian cancer) levels rose from 11 to 55 U/mL. Initial computerized tomography (CT) scans did not show radiographic evidence of recurrent disease and chemotherapy was restarted. Over the next 2 months, the CA-125 rose to 125 U/mL, and CT scans of her abdomen and pelvis showed metastatic disease in the right pelvis and liver. Her disease continued to progress despite multiple therapies, including paclitaxel, topotecan, carboplatin, cisplatin, doxorubicin, altretamine, and capecitabine as well as radiation to metastatic sites in the chest and lower pelvis. Pain was managed with transdermal fentanyl patch 200 mg every 48 hours and oral oxycodone immediate release 30 mg or 60 mg every 2 or 3 hours for breakthrough pain. She expressed distress at her current situation and the uncertainty about her future as well as that of her husband and 2 teenage children.

After repeated admissions for pain and other complications of cancer and its treatment, the patient developed nausea and vomiting, as well as abdominal and back pain. Imaging at that time showed a colonic obstruction caused by tumor invasion. She was admitted to the palliative care unit and was treated with patient-controlled analgesia (PCA). As the PCA was increased to 15 mg per hour basal rate with 15 mg bolus every 15 minutes as needed, the patient developed myoclonic jerking that disturbed her sleep. The PCA rate was decreased and oral methadone at a dose of 30 mg twice daily was added, as was oral clonazepam 250 mg 3 times daily as needed. After resolving for approximately 24 hours, the myoclonus returned with greater severity, creating increased pain with each movement. The opioid was rotated to morphine without relief of myoclonus. Intravenous midazolam was begun as an infusion of 0.5 mg/h and titrated upward with the goal of managing the myoclonic jerking. When it became clear that the dose necessary to relieve myoclonus also caused significant sedation, the palliative care team discussed the use of palliative sedation with the patient and her family. All were in agreement that this approach was reasonable. The patient spent time with her family and met with her rabbi. She indicated that she was ready to have the dose increased. At 5 mg/hour she became sedated. Because she did not appear to be in pain, as demonstrated by facial grimacing or guarding, the opioid dose was reduced. After several hours, the myoclonus gradually diminished. She died 72 hours later in apparent comfort.

Tara Sanft, MD
Division of Hematology-Oncology
Northwestern University: Feinberg School of Medicine
Chicago, Illinois

Opioid-Related Myoclonus

This case presents the challenging syndrome of opioid-related myoclonus (ORM). Myoclonus describes involuntary, sudden, shock or jerk-like muscular contractions, usually of the extremities and head. Despite this, much of what we know about opioid-related myoclonus is based on anecdote and case reports; there are no widely accepted definitions of or measurement tool for ORM, nor have there been studies performed to specifically investigate its incidence, risk factors, or therapy. ORM’s presentation varies from mild, rare muscle twitching, barely noticed by a patient, to diffuse and...
persistent jerking that can be painful and significantly impair quality of life.\textsuperscript{31} It is believed to lie on a spectrum of neuroexcitatory toxicities of opioids including akathisia, hyperalgesia, and seizures, although it can present as an isolated symptom.\textsuperscript{24} A recent study that prospectively evaluated cancer patients taking morphine for dose-limiting toxicities found that 3.5\% reported any myoclonus and <1\% reported moderate or severe symptoms.\textsuperscript{27} ORM's incidence with other opioids is unknown.

**Pathophysiology**

Multiple pathophysiologic mechanisms have been proposed to explain ORM, mostly implicating the neuroexcitatory effects of opioid metabolites such as the 3-glucuronides of morphine and hydromorphone. A disinhibitory spinal antiglycinergic effect of these metabolites, as well as activation of the NMDA receptor, have both been proposed.\textsuperscript{20,32} Per this model, patients receiving long-term, high-dose opioids with neurotoxic metabolites such as morphine and hydromorphone are most likely to accumulate sufficient metabolites within the CNS to develop ORM. Patients with renal insufficiency should be particularly at risk, given that the 3-glucuronides are renally excreted. Along these lines, fentanyl and methadone have been proposed as opioids less likely to cause ORM, as they lack active metabolites. Methadone has been particularly recommended because it also directly antagonizes the NMDA receptor.\textsuperscript{32} At best, however, this model is incomplete and is belied by the following observations. First, both fentanyl and methadone cause myoclonus and hyperalgesia.\textsuperscript{2,23,31} Second, myoclonus has been reported with low-dose opioids\textsuperscript{19,24} and with short-term dosing.\textsuperscript{24} Third, renal insufficiency has not been a prominent comorbidity in the case reporting of ORM. It is possible that myoclonus results from different mechanisms in different patients and with different opioids and that the “neurotoxic metabolite” hypothesis explains most but not all myoclonus that is encountered clinically. Until ORM is studied systematically, the contribution of various risk factors, such as opioid type, dose, duration of therapy, and patient characteristics, will not be clear.

**Treatment of ORM**

ORM should be suspected in any patient receiving an opioid who has myoclonus, although typically the diagnosis is confirmed only after the myoclonus resolves with cessation of the offending drug. Attention should be given to other causes of myoclonus including electrolyte disturbances, ß-lactam antibiotics, and both tricyclic and newer antidepressants.\textsuperscript{6} Mild myoclonus can be watched without intervention.\textsuperscript{20} Benzodiazepine therapy and opioid dose reduction/rotation are the most common strategies used for moderate to severe myoclonus. Benzodiazepines nonspecifically suppress myoclonus from a variety of causes and are particularly helpful for mild to moderate symptoms.\textsuperscript{20} Dantrolene and baclofen are other suppressive agents that have been reported to be successful.\textsuperscript{19,20} Severe myoclonus, not responsive to opioid dose reduction or rotation, may require sedating doses of benzodiazepines. This may be acceptable for moribund patients but creates a therapeutic conundrum for healthier patients. A multidisciplinary approach, using the full complement of nonopioid analgesic modalities, is the best strategy.

Besides pharmacological suppressive therapy, reducing exposure to the offending opioid, either by dose reduction or rotation to another opioid, is often attempted. Opioid rotation is a well-accepted approach for any patient with inadequate analgesia or dose-limiting opioid toxicities.\textsuperscript{21} It has been studied both retrospectively and prospectively and has been reported to be successful overall 50\% to 80\% of the time; however, rates of success specifically for myoclonus have not been reported.\textsuperscript{27} If rotation is successful, the myoclonus usually attenuates within 48 hours.\textsuperscript{2,20}

In this case of far advanced cancer, myoclonus developed after the patient was given high-dose hydromorphone, improving only briefly with dose reduction and the addition of methadone and clonazepam. An alternative initial strategy would have been to completely discontinue the hydromorphone, as continuing even reduced doses of hydromorphone may have been sufficient to perpetuate the myoclonus and instead use intravenous fentanyl or methadone as the sole opioid. In our experience, some cases can be resolved with this approach while maintaining normal mentation. However, in other cases, when trying to balance the risks and benefits of further opioid drug/dose manipulations against the degree of current and expected future patient suffering, and a very limited prognosis, the decision to provide sedation is very appropriate. Cases such as this require the full involvement from interdisciplinary pain and palliative care professionals.

Drew Rosielle, MD
David Weissman, MD
Division of Neoplastic Diseases and Related Disorders
Medical College of Wisconsin
Milwaukee, Wisconsin

**When Is Enough, Enough? A Case for Palliative Sedation**

When performed in accordance with clinical practice guidelines,\textsuperscript{10,22} there is general consensus that palliative sedation (PS) is an ethical treatment intervention for patients at the end of life. Key to this determination are specific definitions and an ethical framework for decision-making.

**Definitions**

Palliative sedation is defined as “the use of sedative medications, at least in part, to reduce patient awareness of distressing and intractable symptoms that are insufficiently controlled by symptom-specific therapies.”\textsuperscript{7} A refractory symptom is one for which all possible treatments have failed, or it is estimated that no methods are available for palliation within the time frame and risk-benefit ratio that the patient can tolerate. Given the subjective nature of intolerable suffering expressed by the patient,
most clinical practice guidelines recommend that the
determination of refractoriness be made after skilled
multidisciplinary management by a palliative care
specialist.8,10

An Ethical Framework

PS is an ethically and legally well-accepted interven-
tion.25,28 Typically limited to terminally ill patients with
a prognosis of hours to days, the intention of PS is provi-
sion of patient comfort, consistent with the cardinal doc-
trine of beneficence. Because the desired outcome of
comfort is contingent on lowering of patient conscious-
ness, the principle of double effect is integral to PS.
Namely, the “good” intention, symptom palliation, may
result in the “bad,” or unintended, consequence of ear-
ier death. The principle of proportionality argues that
the choice for PS should be proportionate to the degree
of patient distress, available treatment options, expected
benefits, and expected harms.22 Another guiding prin-
iple is that of patient autonomy; as for other treatment
interventions, informed consent is required. If the pa-
tient lacks decision-making capacity, a surrogate should
participate in the decision-making process with the inter-
disciplinary medical team.10,22

Symptoms Requiring PS

For this patient, refractory myoclonus is 1 of many
symptoms that may be treated with PS at the end of
life. However, the most common indication for PS is agi-
tated delirium. Other common indications include dys-
nea, bleeding, seizure, and pain.12 Symptom-specific
interventions should always be attempted first; only for
refractory symptoms is PS a treatment option. For this pa-
tient, attempted interventions included opioid rotation,
hydration, treatment of infection, and addition of ben-
zodiazepines, all without durable benefit. This patient
was clearly at the end of her life, and controlling her
symptoms was of utmost importance to the patient and
her family. Despite labeling myoclonus as refractory, ini-
tiating PS should not prevent her clinician from reevalu-
ating its need, with downward titration of midazolam,
should her symptoms improve.

Drug Therapy

When establishing PS, midazolam is the drug of choice
due to its rapid onset of action, short half-life, dose-de-
pendent sedative effect, and an available antidote, flu-
mazenil.17 The American Academy of Hospice and
Palliative Medicine (AAHPM) differentiates 2 types of
PS, based on the level of consciousness preserved.1 In
the milder form, alertness is preserved to some degree
and communication may be possible. If ineffective, a
deeper degree of sedation to unconsciousness is in-
duced. The doses of midazolam used in this patient,
0.5 mg/h and 5 mg/h, are consistent with this approach.
The degree of sedation, mild versus deep, is proportion-
ate to the level of the patient’s distress; thus, the princi-
ple of proportionality, with the intention of sedation to
palliate suffering, rather than hastening death, holds
ture.10 In many US hospitals, midazolam use is restricted
to intensive care units or as conscious sedation, limiting
applicability for PS. These policies may be very restrictive,
leading providers away from using midazolam and from
following recommended clinical practice guidelines de-
veloped to support the ethical conduct of effective PS.
Palliative care providers in these hospitals are required
to establish policies for the use PS.

Controversial Issues in PS

Particularly controversial in the literature is the use of
PS for control of refractory psychological or existential
distress. Proponents argue that existential suffering
might cause more distress and suffering to the patient
than physical suffering, without well-established treat-
ments. Opponents argue that it is difficult to label exis-
tential distress as refractory and that these patients
may be earlier in the disease trajectory, thereby increas-
ing risks of PS and making it difficult to differentiate
from euthanasia.29,30 Clearly, PS should be differenti-
ated from euthanasia and physician-assisted suicide.28 Inten-
tion is the distinguishing factor. For euthanasia and phy-
sician-assisted suicide, the actual goal is to induce death
as the means of controlling suffering, whereas for PS, the
primary intention is symptom palliation for the remain-
der of the individual’s life.

Ahmed Elsayem, MD
Donna S. Zhukovsky, MD, FACP
Department of Palliative Care and Rehabilitation
Medicine
The University of Texas M.D. Anderson Cancer Center
Houston, Texas

Hurting Both Inside and Out

Suffering is central to the cancer experience for the pa-
tient and family—from diagnosis to treatment through
survivorship or as life draws to a close. Meaning, fear,
pain, fatigue, other symptoms, as well as uncertainty,
loss, grief, and mourning are part of this suffering.5,9 Ev-
ery domain of the individual is affected—physical, psy-
chological, social, and spiritual, with each interacting
with the other.13 Various conceptualizations of suffering
try to capture this uniquely human experience. Eric Cas-
sell describes this as “fragmentation of person-hood”4;
Howard Brody speaks of “broken stories”5; Victor Frankl
explores “challenge of meaning”6; and Cicely Saunders
talks of “total pain.”26

As many patients move through their illness, grief be-
comes a constant companion and people live in a state of
sorrow.11 Significant loss and grief will change a person,
yet there is great individuality to this change. Some peo-
ple are diminished by loss; others grow and transcend
the experience. At the end of life, questions that have
challenged us throughout life now become even more
important: How do I live as an ill person? How do I con-
duct myself? Do I have a new mission? Who am I now?
How can I matter?26

Changes in the trajectory of dying over the past several
decades contribute to suffering as life draws to a close.15
There may be a relatively long period of progressive
debilitation and decline, as suggested by the patient described in this case study. In addition, technology is available to prolong life (or prolong dying) and the possibility of “1 more chemotherapy sometime in the future if I eat more and get stronger” makes choices seem endless when, in reality, for most these goals can never be achieved.

The Relief of Suffering

The elements that contribute to the patient’s suffering and that of their loved ones must be assessed. The team can then organize a system of care to address this suffering. Palliative care, a model that strives to improve quality of life for patients and families facing life threatening illness, uses an interdisciplinary approach to attend to the needs of the whole person, including physical, psychological, social, and spiritual domains. The goal is to prevent unnecessary suffering and to relieve suffering should it occur. The patient described was appropriate for palliative care from the time of diagnosis and alongside life prolonging therapy (Fig 1).14 Yet, the relief of suffering remains elusive for many patients with cancer and their families. We have perhaps become too technical, resource rich but time poor, our histories too “boxed in” and truncated, the “person” somehow lost in the process.

Drawing on the work of others as well as their own, Kearney and Mount18 describe a general approach to suffering that is clinically useful, self-evident but sometimes forgotten: (1) Value the therapeutic relationship: The simple presence of one who is concerned, one who is willing to be a companion and to remain steadfast when there are no easy answers, is itself a form of powerful communication that goes beyond words. (2) Establish contact through active listening. (3) Control symptoms effectively: Pay attention to whatever meaning such symptoms hold for the patient. In parallel to controlling physical symptoms, all other aspects of the patient’s suffering whether in the area of communication, relationships, religious issues, activities of daily living, or financial or other practical issues must be identified and addressed using the varied skill of the interdisciplinary team. (4) Obtain a “clinical biography”: This is a narrative that provides a “who” as well as a “what,” knowledge of a real person, not simply their disease. We all have a uniqueness, a past, a family, a cultural background, roles and relationships, a perceived future, and a spiritual belief (even though this may not be recognized). Each of these domains shapes the individual’s identity and their experience of illness and each is affected by the illness. (5) Determine the meaning of the illness for the patient. (6) Determine the meaning of the illness for the family. (7) Explore sources of meaning in the patient’s life: The spark must come from the patient but the caregiver can be a catalyst in this process. This is achieved primarily by sitting down and taking time to ask and to listen. (8) Assist in redefining hope. Hope can be fostered by establishing realistic, concrete, short-term goals. (9) Examine fears, particularly concerning the unknown (10) Explore the patient’s need for reconciliation.18

Although it would not have been possible to remove all suffering in the woman described in the case study and of her family, it was possible to prevent and relieve unnecessary suffering, such as pain and other symptoms, and to bear witness to her grief at the prospect of leaving 2 teenage children behind without a mother. She appeared to have reached some resolution at the time of her death and was given a choice to be sedated in her dying.

Nessa Coyle, RN, PhD, FAAN
Supportive Care Program
Pain and Palliative Care Service
Memorial Sloan Kettering Cancer Center
New York, New York

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