MAURIE MARKMAN, MD
Chairman, Department of Hematology/Medical Oncology, Cleveland Clinic; director, Cleveland Clinic Cancer Center; associate editor, *Cleveland Clinic Journal of Medicine.*

The high cost of terminal care: Balancing conflicting goals

ABSTRACT

If the medical establishment fails to develop rational, realistic strategies for managing patients with advanced cancer, then non-physicians will make the decisions.

WHAT IS THE RIGHT WAY to medically handle the dying process? In caring for patients at the end of life, physicians are often torn by conflicting goals: optimizing quality of life, doing everything reasonable to extend life, exploring new treatment strategies, and providing cost-effective care. At present, we lack clear, objective strategies for balancing these goals—and we need to develop such strategies.

The following discussion focuses on terminal care for cancer patients, but is relevant to all physicians who care for patients at the end of life.

REGIONAL DIFFERENCES IN TERMINAL CARE

A recent, highly publicized news report suggested that the type of care that patients receive at the end of life may depend in part on where they live.[1] Major regional differences noted in the report include the following:

- In Miami, 46% of Medicare beneficiaries spend time in a medical intensive care unit in the last 6 months before death, compared to only 9% in Sun City, Arizona.
- Even after adjusting for local differences in the cost of care, Medicare spends approximately $16,500 per patient for hospital bills in Manhattan during the final 6 months of life, compared to $6,000 in certain areas of Oregon.
- In Newark, New Jersey, more than 50% of Medicare deaths occur in the hospital, compared to only 22% in Portland, Oregon.

Why these variations? A number of explanations can be offered, including the availability of hospitals and specialists, methods of physician and hospital reimbursement, and patient-family choice. However, no single reason can explain all or even most of the variations observed.

Do higher costs reflect unnecessary care?

With the heightened focus on controlling the cost of medical care in the United States, and with recent allegations of medical fraud, many members of the public assume the higher expenditures in some regions of the country reflect unnecessary care. However, based on the limited available data, such a conclusion may not be appropriate in all situations. In fact, although added costs do not necessarily lead to prolonged survival, they may help to optimize the quality of life for many patients during their final months.

Medicine must find a rational but humane way to allocate care at the end of life

DECIDING WHO GETS CANCER CARE

Cancer is the second most common cause of death in the United States and, if current trends continue, will surpass cardiac disease as number one during the next decade. The major explanation for the rise in cancer deaths is that people are living longer than before and are not succumbing to other potential causes of death as in the past. Therefore, a considerable amount of future discussion about the cost of terminal medical care will have to focus on cancer patients.[2,3]

TABLE 1

Important considerations in determining the care provided to cancer patients

Type of cancer

Availability of effective anticancer therapy
- Curative potential
- Prolongation of life
- Major symptomatic improvement

Ability of patient to tolerate the toxicity of available therapy

Patient choice

A number of factors contribute to decisions about cancer care (TABLE 1). Few would argue about the appropriateness of treatments with a high likelihood of either curing the disease (eg, surgical resection of localized colon cancer) or significantly prolonging survival (eg, initial chemotherapy for advanced ovarian cancer). However, when an initial treatment known to be effective has failed, or when available therapies are of only limited or marginal utility, then decisions become more difficult.[2,3]

New treatments can improve outcomes, but increase the cost of cancer care

For example, suppose a patient has a type of cancer for which a certain treatment produces a response in 30% of patients, and the response lasts approximately 9 to 12 months. Should the patient try the treatment? And should the insurance company, health maintenance organization, or Medicare pay for it?

If one third of patients will presumably benefit from the treatment with an improvement in symptoms and perhaps a year of prolonged survival, most patients (but certainly not all) would probably want to try it. However, two thirds of those treated will not respond, yet will experience the side effects of treatment. In addition, the costs of therapy will need to be covered for all patients receiving it, not just those responding to it.

Now suppose that the anticipated response rate is only 10%, with a response duration of only 3 to 5 months. Patients may still wish to try the treatment, as it provides them some opportunity for improvement. However, in this situation, only 1 in 10 patients will benefit, and even in these lucky few the benefit will last for less than 6 months.

Should patients continue to have the right to decide to receive such treatment? If not, who will decide, and on the basis of what criteria?

ADVANCES RAISE THE COST OF CARE

The complexity of this situation is heightened by rapid changes in our understanding of the biology of cancer, by the increasing availability of new classes of anticancer agents, and by our improved ability to safely apply new technologies in cancer patients.

Our knowledge of how cancers develop at the molecular level has led to new hypotheses of how it should be treated and even possibly prevented. New classes of drugs with novel mechanisms of action, such as antimetastatic and antiangiogenic agents, have recently begun to undergo clinical trials.

In addition, the US Food and Drug Administration has stated it will decrease the time it takes to approve agents for commercial use for serious illnesses and will lessen the regulatory requirements for drug approval. Innovative treatments, such as high-dose chemotherapy with peripheral progenitor cell rescue, have made it possible to safely intensify the delivery of cytotoxic chemotherapy in patients with specific tumor types, such as lymphoma and breast cancer.

While these trends promise to improve the outcome for patients with malignant disease, they also have the potential to dramatically increase the costs of cancer care, particularly in regions of the country where major cancer treatment centers are located. In fact, if patients with advanced cancers receive these new drugs and strategies, and they are not cured or their survival is not significantly prolonged, it is likely we will continue to observe high costs associated with terminal illness.

Is this necessarily bad? Does the public intend that the treatment of cancer should remain where it is currently, or do we want and need to expend the resources necessary to improve the ultimate outcome for this difficult group of diseases? Further, does the pub-

lic want new treatments to be rationed, and decisions regarding their use to be made solely by those who pay the bills—ie, insurers, health maintenance organizations, and Medicare?

INCOMPATIBLE CANCER CARE GOALS

Our multiple societal goals for cancer care are becoming increasingly incompatible. Court cases involving cancer patients who demand a treatment denied by a third party carrier (eg, insurance company, health maintenance organization), and attempts to legislate coverage for specific therapeutic strategies (ie, bone marrow transplantation) provide striking evidence of this inherent conflict.

If we hope to control the rising costs of medical care, provide cancer patients with treatment that maximizes chances for survival and optimizes quality of life, and at the same time improve the overall results of treating malignant disease through clinical investigation of innovative therapeutic strategies, then we must develop a different model for providing cancer care.

A MODEL FOR CANCER CARE

As with other groups of diseases, cancer care in the United States is fragmented among multiple medical specialists. As suggested by the report cited above,[1] the decision to use a specific therapeutic strategy may be based less on an objective assessment of the goals of therapy and more on which specialist the patient consults.

For example, a patient with advanced cancer who has failed known effective therapy for the malignancy might be offered "standard" second-line chemotherapy; local radiation therapy for pain control; a variety of experimental treatments; symptomatic management only, which can be provided either by the oncologist or primary care physician or both; or referral to a hospice program.

How is this decision made? Are the recommendations discussed and agreed upon by a *team* of health care professionals with expertise in cancer management? Has any thought been given to the optimal strategy in this particular individual for maximizing the quality of life, and in determining the most humane and cost-effective approach for all patients presenting in this clinical setting?

It is recognized by most physicians and the public that optimal initial management of cancer patients requires the input of multiple physicians with expertise in a particular tumor type (eg, a breast cancer team requiring a breast surgeon, radiation oncologist, medical oncologist, pathologist, and radiologist).

Similarly, it is increasingly understood that providing optimal care of advanced cancer patients entering into the terminal phase of their illness requires the presence of a dedicated health care team with knowledge of available treatment options in a particular clinical setting, and the relative benefits, toxicities, and costs associated with each approach. As with the primary therapy of cancer, individuals involved in the terminal phases of cancer patient management should include experts in the tumor type (eg, breast cancer), specialists in symptom management (eg, pain clinic, hospice physicians), and, in major cancer programs, oncologists involved with experimental clinical trials. In addition, discussions should include a physician familiar with the patient and family who can help demystify the alternatives proposed, so that the decisions are truly informed ones.

If the medical establishment fails to develop rational, realistic strategies for managing patients with advanced cancer, strategies that optimize the quality of life as well as consider the cost-effectiveness of the care provided, then bureaucrats and accountants will make these decisions. We all know what that will mean for the welfare of our patients.

A doctor who knows the patient can demystify the treatment options

REFERENCES

1. **Anders G.** Zip code is a key to course of terminal care. Wall Street Journal 1997 Oct 15; Section B:1.
2. **Markman M.** Beyond palliative chemotherapy: providing hope in an era of unrealistic expectations and medical-care rationing. J Cancer Res Clin Oncol 1992; 119:74–75.
3. **Markman M.** Patient choice, cost, and survival of critically ill cancer patients: a societal dilemma. J Cancer Res Clin Oncol 1993; 120:3–4.

ADDRESS: *Maurie Markman, MD, Department of Hematology/Medical Oncology, T40, The Cleveland Clinic Foundation, 9500 Euclid Avenue, Cleveland, OH 44195.*