If you were to ask any terminally ill cancer patient if there were worse things than death, he or she would answer with a resounding affirmative—indeed, in many instances the purported cure brings anguish and suffering that make death appear a welcome friend. As a cancer victim and a recipient of two separate rounds of biologic and chemotherapy, I have some sense of the dynamics and pressures facing individuals and physicians over the decision to pursue chemotherapy as the principal treatment for the disease. The pressure to pursue treatment is subtle as well as overt, and a decision is often reached without careful consideration of all of the factors involved. Both physicians and patients embrace chemotherapy as a logical and conventional tactic, given that the alternative is the presumed unrestricted progression of the disease. Failure to act is presumed by society to be a failure on the part of the treating physician and avoidance of reality on the part of the patient. What is unclear is whether the physician and the patient are making the right decision in choosing to proceed with chemotherapy. Will the patient’s quality of life or life expectancy be improved as a result? Any answer other than yes raises questions about the appropriateness and efficacy of chemotherapy. Obviously, every situation is unique. Still, there are some basic circumstances facing all cancer patients and their physicians that cross all cases and that deserve attention.

Physicians’ Instinct To Treat

Training. All of the training physicians receive is designed to convert them into proactive interventionists for their patients. Most physicians subscribe to the paternalistic belief that any action they take is in the patient’s best interest and thus, by definition, good. This classic form of physician/patient relationship whereby the patient vests his or her decision-making rights with the physician in trust is the historical model of...
the 1950s. It is somewhat shocking to recognize that this mode of unilateral decision making remains the preferred brand for many physicians today. Joint/shared decision making is the hallmark of modern medicine. For this to work, the physician and the patient have to shed certain traditional behavior patterns. Physicians have to yield authority and share more information, and patients have to act as their own advocates. Many physicians, particularly young physicians, are uncomfortable ceding decision-making authority when they themselves are uncertain about the most appropriate course of action. As a result of this uncertainty, along with time pressures and limited information, physicians often give their patients short shrift in explaining treatment options and their consequences. Physicians exert both subtle and overt pressures on their patients: “Don’t you trust me? Don’t you believe that I am acting in your interest? If you don’t accept treatment, you will most certainly die.” Few patients have the wherewithal or the desire to withstand such pressures. Consequently, treatment, without complete review of its merits, almost inevitably results.

Moral burden. The instinct developed in training to do something is compounded by the moral burden facing a physician if he or she does not act. Failure to act is for many physicians failure to carry out their life’s work. They believe that doing something is better than doing nothing. As a consequence, physicians have a tendency to overstate the potential value of a treatment and to understate the risk associated with it. In some quarters this would be labeled “being optimistic;” in others it would be deemed “raising false expectations.” It is a difficult line to walk. No patient would be happy with visiting his or her oncologist and hearing the words, “No matter what we do, you are going to die; although someone makes it once in awhile, we really don’t know why and can’t say with any confidence that you will be the one.” The truth is not always welcome.

Patients' Beliefs

About medicine. Most laypersons believe that medicine is an exact science—pure, clean, instructive, and unequivocal. The further one moves into the medical system as a patient, the clearer it becomes that medicine is as much an art as it is a science. In the area of cancer treatment, reliable data are scarce. Studies are limited, interrupted, and nonrandom; the sample sizes for most analyses are too small to generalize; and the applicability of a given research protocol to any one person is more accidental than intentional. Further, for ethical as well as institutional training reasons, there is an absence of research on the null hypothesis of nontreatment and its relationship to outcomes. The research literature provides little insight into treatment versus nontreatment with respect to quality of life or life
expectancy. Again, there is a presumption that treatment is superior; thus, studies tend to focus on the efficacy of various treatments rather than on a comparative analysis with the null hypothesis.

**About physicians.** Some patients believe that one of the reasons physicians are so willing to prescribe chemotherapy is that most of them have never undergone chemotherapy themselves. Had many physicians enjoyed the charming consequences of toxic chemotherapy, they might be less enthusiastic about recommending it to their patients. To put it bluntly, chemotherapy is the equivalent of self-administered rat poison. One willingly undergoes such treatment only when one believes that there is no alternative. A good chemotherapy experience is one in which the patient can still function, even if every action requires effort and will. While a physician can empathize with the patient and relate what he or she has observed, the experience itself is necessary to know what the patient is being asked to go through. Of course, it is unrealistic to expect every oncologist to be a cancer survivor. It would be helpful, though, if before recommending a treatment course, the physician arranged a meeting with others who had undergone the treatment or even a viewing of a videotape relaying actual experiences with the treatment. These events would enable patients to make better-informed decisions regarding treatment.

**Physicians’ Challenges**

**Communicating the risks.** One of the challenges facing physicians today is to accurately and effectively communicate the risks and the potential payoffs of treatment. This is not as easy as it may sound. With how much detail, what kind of language, and how much advocacy should the physician make the case? While no one answer exists, it is the obligation of every physician to try to ensure that his or her patient can make an informed decision if treatment is recommended.

**Managing care.** Another challenge for the treating physician is how to manage a patient’s care when all treatment options promise little benefit. Generally, three choices remain. The first option is the experimental track. Here, the patient has the privilege of being one of the first persons to ingest certain poisons and toxins as part of a Phase I drug trial. The patient usually is guaranteed a severe negative physical reaction with only a small chance of improvement. However, when the alternative is death, even a long shot can be appealing to a treating physician and his or her patient.

The second option is more conventional but low-yield chemotherapy. Here, the physician presents the patient with choices that can inhibit tumor growth or, in rare instances, trigger a remission. But chemotherapy benefits only a small percentage of those who receive it and, like the Phase
I trial option, carries side effects that compromise quality of life. Pursuing this option means that both the physician and the patient agree that the treatment strategy has changed from the goal of achieving a complete remission to the goal of extending life.

The final option is to do nothing and allow the disease to progress while managing the pain and the consequences it generates. This choice underscores the futility of further treatment and instead relies on the natural progression of the disease as the guide to managing care.

Physicians and patients face a Hobson’s choice. Every option carries with it second guessing and uncertainty. There is not a right choice; all options are second best. The most a physician can do is to lay out the choices clearly, respond to questions, and allow the patient to decide his or her own fate. It is here, at the end, that a physician’s role changes from one of pathfinder to one of follower. Patients’ preferences are never more meaningful and binding than when expressed in life-threatening situations.

The Dynamics Of End-Of-Life Decision Making

Informed consent. The issue of informed consent has many tiers. It is influenced by many factors: the availability of information, the mode of communication, the patient’s ability to understand what has been communicated, risk aversion, and the stage of the disease that the patient is experiencing.

One of the barriers to informed consent is lack of information. For many treatments, particularly experimental ones, there is limited information on how the treatment is supposed to work, experience to date with the treatment, expected side effects, and potential benefits. Both the patient and the physician are working with many unknowns and uncertainties. Yet, to make an informed decision, the patient must understand as much as possible about the treatment and its risks.

How information is communicated is just as vital to decision making as what information is communicated. There is no one best approach, but sharing research literature with the patient, explaining at length what the research studies say, using videos, and simply spending time with the patient can do much to ensure that the message is conveyed. It is also critical that the patient understand what is being said. It is the physician’s responsibility to make certain that the patient understands his or her options. This generally means an investment of time. It may be necessary to go over the same ground in a number of different ways. Patients may have difficulty knowing where they stand, or they may resist accepting the ugly truth. Spending time explaining treatment options is the absolute minimum necessary to ensure patients’ understanding.
Finally, two other related elements influence informed consent: disease stage and risk aversion. Patients’ behavior is influenced by how close patients believe they are to death and how much risk they are willing to incur to avoid death. Much depends on whether a patient believes that he or she can cheat death and buy time by choosing a certain treatment. All that most patients want is another day and another chance at life.

**Treatment refusal.** Many patients fear that they will alienate their physician if they refuse treatment. Somehow, saying no to the doctor is viewed as both impolite and a challenge to the physician’s expertise and judgment. It also has powerful psychological and social implications. Saying no is a formal declaration that the decision-making authority over future treatment belongs to the patient. The balance of power is irrevocably changed.

Patients who refuse treatment also fear that their action will be viewed by family and friends as a sign of cowardice or unwillingness to face reality. There is enormous family pressure to do something. Many families hold an almost mystical belief in the power of medicine. For them, there must be a cure, and if you refuse or fail to pursue treatment you are punishing those who love you. The problem is, of course, that cancer frequently does not respond to treatment. So refusing relatively futile treatment can be quite rational. Thus, the prisoner’s dilemma: Damned if you do, and damned if you don’t.

**Living wills and power of attorney.** For many patients, even executing a living will or durable power of attorney does not change the basic decision-making process. It may reduce the uncertainty surrounding end-of-life decisions, but having these documents does nothing to guide the patient in his or her end-of-life choices. Patients have to weigh considerations of family, work, financial security, and insurance coverage against the pain and suffering of treatment.

**Pain management.** Pain management is a serious issue in reaching a treatment decision and one that is difficult for many patients. Finding a balance between pain control and cognitive function is often not easy. There is a real fear of becoming a prisoner of the narcotics prescribed to manage pain or the side effects of treatment, and the narcotics themselves carry a series of unpleasant consequences. Patients frequently find themselves choosing among the degrees of pain and the amounts of narcotic relief they will accept. Constipation, sluggishness, and inhibited judgment are the prices one pays for the relief of pain. Deciding whether it is worth it is a daily choice, one that often depends on what needs to be accomplished and whether the patient wants to retreat from reality. The desire to be whole and functional as long as possible is one of the motivations for seeking treatment. Yet, curiously, treatment may result in the opposite
situation—one in which functional status is lost, not gained. In fact, treatment can shorten life or reduce quality of life or both. It is only one of many dilemmas facing cancer patients who are trying to decide on a course of action.

The placebo effect. There is one benefit of treatment that is real and meaningful even if the treatment itself is useless—namely, the placebo effect. Being in treatment bestows on the patient a certain psychological comfort. You are doing something. You are fighting the fight and refusing to go quietly into the night. All of this has benefit. Even your suffering is more meaningful and admired (by family and friends) because you are being proactive. It matters not if the cause is futile. In our culture, doing something is better than doing nothing.

The “watchful waiting” option. Ultimately, patients find that they have little choice if there is a treatment option that has any substantive probability of slowing the disease’s progression. It would take extraordinary willpower and self-control to resist the powerful professional and personal incentives to seek treatment. Until and unless physicians present “watchful waiting” as a legitimate treatment option, patients presented with chemotherapy choices will embrace them or some alternative intervention. To reach the point of accepting “watchful waiting” as a legitimate option, physicians would have to acknowledge that certain outcomes are beyond their influence. Doing nothing then may be more productive and meaningful than pursuing treatment. Yet, for many physicians, doing nothing is psychologically, emotionally, and even morally difficult. The urge to act is so strong that holding back and engaging in “watchful waiting,” even when future treatment is deemed futile, is an option seldom taken.

Postscript

I have been one of the lucky ones. My experience with my oncologist, Gersh Locker, represents, for the most part, the ideal relationship between doctor and patient suggested in the preceding pages. If Gersh is anything, it is that he is absolutely honest and direct. Every time I was faced with a decision, Gersh laid out the facts, shared the research literature, conducted computer searches on my behalf, and made certain that I sought appropriate outside expertise when necessary. It was painful at times, both for me and for him. The result is that I feel and believe that I am a full partner in any and all treatment decisions. At each step of the way we have discussed both the mechanical and philosophical aspects of treatment or even nontreatment. I deeply appreciate being treated as a full partner and an adult in determining how I will manage my care for the balance of my life. As I said, I have been one of the lucky ones.