Chronic disease forces patients to continuously make decisions that affect all aspects of their daily lives. Patients diagnosed with hypertension or diabetes mellitus must decide on the appropriate therapy, their level of tolerance for adverse side effects, and the degree to which they are willing to commit to long-term therapy. A diagnosis of cancer or acquired immunodeficiency syndrome (AIDS) imposes similar decisions, but the process is further complicated by the more immediate fatal consequences of the disease. The patient/physician relationship begins in this stressful context, and as Donald Cohodes pointed out in the previous Commentary, this relationship is complex but crucial to the patient's future well-being.

The doctrine of informed consent recognizes that decisions should be based on patients’ needs, values, and wishes. The extent to which patients want to or can be actively involved in making decisions often is not clear. Physicians who are ambivalent about patient involvement often are criticized for being “paternalistic” and making decisions with limited patient participation.

Cohodes provided a view of patient/physician interaction as it affected him during the treatment of his cancer. He dismissed the paternalistic model of patient/physician interaction and agreed with the many healthcare providers who believe that, short of emergencies, a paternalistic relationship is not ideal. Rather, he advocated acceptance of the “informative” or “interpretive” patient interaction models. The physician’s primary role in these relationships is to provide the patient with all relevant information but to minimize dictating or guiding the patient’s treatment decisions.

I do not disagree with Cohodes’s basic premise that the physician must be the educator, but I believe that few patients want a doctor who is little more than an information resource and technician. Rather, patients want and deserve a relationship with their physician that encourages expression of their needs and preferences, allows them to maintain personal control, and provides unfaltering support. This type of interaction more closely mirrors the “deliberative” model. This model expects the physician not only to be a teacher and a friend, but also to outline and guide the patient on the best course of action. However, patients are inherently in a dependent position, and it is primarily the responsibility of the health care provider to encourage and require increased patient participation.

As a physician who has specialized in treating patients with cancer and AIDS, I can attest to the fact that the task of developing the optimal, individualized patient/physician partnership is not as straightforward or as easy as Cohodes suggested. These relationships do not develop instantaneously; rather, they are cultivated over time and are usually strengthened by shared experiences. Yet, for a physician to fail to achieve a successful partnership is a disservice to patients and their families. Here I describe, from a physician’s point of view, some of the issues patients and physicians face as they attempt to build a partnership and define an optimal course of therapy.

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Making informed decisions. Patients' beliefs are susceptible, as are those of physicians, to a variety of biases, and patients' preferences can appear irrational. However, the decision to seek help, comply with treatment, or alter one's present lifestyle can only be made by the patient.

Many factors can influence a patient's decisions. These include comprehensible, accurate information; a nonbiased presentation of the information; an understandable risk/benefit evaluation; previous decisions and their outcomes; and an understanding of the importance of emotion. Ideally, patients would have complete background information and unlimited time to calculate the costs and benefits of every feasible option. Unfortunately, patients facing catastrophic illnesses such as cancer and AIDS usually have limited time and often lack complete information, sufficient education, or cognitive resources to calculate and analyze all of the costs and benefits. Consequently, patients often reach judgments based on the rules of simplification, and they will search until an acceptable or comfortable solution or compromise is found. This process may not be ideal, but it is practical, is often effective, and usually leads to sensible decisions.

Patients' preferences for participating in medical decisions and for acquiring information vary widely and cannot be accurately predicted from their sociodemographic or health status characteristics. Younger, less severely ill patients are viewed as more active decisionmakers, but patients' preferences are dynamic and change as health status improves or deteriorates and as knowledge and experience increase.

Regardless of the degree to which patients wish to actively participate in making decisions, most have a strong desire to be kept informed about their medical condition, prognosis, treatment options, and the ways in which treatment can be expected to affect their lives. Charles Lidz and colleagues suggest that patients rarely want information to direct their therapy. Rather, patients want information as a sign of respect for themselves as a person, as justification for complying with recommended treatment, and so (admittedly rarely) that they might register a veto if the physician's choice seems ill-conceived.

Characteristics of information. Information is necessary, but alone it is usually insufficient. Choices require "good information," which must be usable and must relate to and meet an individual patient's needs. It also must be accessible and understandable. Accessible information requires time for the physician to present the appropriate background and options; a single explanation of the subject is rarely adequate. Repetition is critical to patients' understanding, so repeated discussions need to be planned.

Information also must be accurate. This concept is not as simple as one may assume. Most treatment options are of necessity a summation of the results of many studies, some of which may have reported conflicting conclusions. Medical research is a dynamic process, and thus the available information continuously changes. Good information also must be of a quantity that is "digestible." This requires that the physician and patient set limits on the quantity of information that is needed, based on the individual patient and the medical event.

Perception of risk and benefit. Patients process information in different ways, and interpretations are developed in the context of individualized factors such as perceived risk and benefit, risk aversion, and the influence of emotion. Part of human nature is to characterize an option as either "dangerous" or "safe." Patients vary in their ability and their willingness to grade and tolerate different levels of treatment-associated risk. Because a patient's risk profile cannot be accurately predicted in advance, a dynamic and individualized approach is needed.

Patients who face the possibility of death often find their perception of risk greatly altered. Impending death obscures one's vision of what the future may actually represent. Chronic or long-term treatment consequences, even when severe, become irrelevant, and immediate and short-term effects dominate the decision among options.

Research study populations and conditions are usually designed to be as homogeneous as possible; in contrast, patients are heterogeneous and respond in unique ways.
They must be taught that study probabilities are only helpful in providing comparisons of therapeutic alternatives, and that such probabilities poorly predict an individual patient’s response. Cohodes’s desire for basic outcome probabilities may have been reasonable for his individual case, but such raw information could be confusing and inappropriate for another patient with the same diagnosis, illness, or stage of disease.

As patients attempt to apply clinical study findings to their own situation, they frequently perceive findings that are “gray” in more understandable “black and white” terms. It is inaccurate and unreasonable for a patient to assume that because study results are reported as probabilities, he or she will experience “a certain fraction of an outcome.” In reality, the likelihood of an outcome for the individual patient who sustains that outcome will be 100 percent, and for the patient who fails to experience such an effect, the response will be zero. This makes the discussion of risk difficult, and it also makes the presentation of probabilities susceptible to patient or physician bias. Options presented by a physician to a patient will represent the integration of results gleaned from many sources. It is the physician’s task to take these pieces of information and configure them into an understandable, individualized course of action for the patient.

**Presentation of information.** Patients interpret events and options differently depending on the manner in which they are presented or framed. Consider how differently information pertaining to the outcome of 100 middle-age men undergoing surgery for lung cancer can be interpreted. Data could be described in one of two ways: (1) Ninety patients live through the surgery, and thirty-four will still be alive at the end of a five-year follow-up; or (2) ten patients died during the surgical period, and sixty-six will have died by the end of five years. Clearly, these two approaches engender a different level of concern and by emphasizing death or survival may influence a patient’s decisions in directly opposite ways.

This framing effect also affects physicians. Certain presentations may cause a physician to dismiss an option that, if framed in the opposite manner, would be viewed as an approach worthy of consideration for their patients. Framing effects are difficult to avoid, because there is no standard method for presenting options or result probabilities. The framing effect may be one reason why many physicians seem driven to treat rather than to “wait and see” what happens in the natural course of a patient’s illness.

Science also has a strong tendency to neglect variables that cannot be easily and accurately measured. Mortality and survival are inherently easier to quantify than are improvements in a patient’s quality of life. Research efforts have neglected approaches that may truly improve quality of life but may not have a discernible survival advantage. These types of interventions are easily dismissed if anticipated responses are not dramatic or do not occur rapidly, but their value should not be diminished. Patients seek medical care not only for cures but also for relief of symptoms, sympathy, reassurance, and validation. These needs are important and must be recognized.

**Hindsight bias.** Patients with chronic diseases make decisions in relation to where they are in their disease process; they often base new decisions on previous clinical experiences. Thus, retrospective judgments of previous decisions can distort future decisions. People are more likely to classify a previous decision as a mistake if an adverse effect occurred and the final result was not optimal. Yet, the same adverse effect may be viewed more favorably if the outcome was successful. Physicians must try to lessen these distortions by emphasizing that decisions must be made prospectively, evaluations are always retrospective, treatment outcomes are individual, and group statistics only give one an educated hunch about what may happen.

**Emotions, feelings, and decisions.** Part of the loss of control that comes with chronic illness is a reluctance to relinquish familiar routines. This may lead a patient to make decisions from a reference point that is no longer realistic. Patients often compare results of interventions based on the memory of maximum normalcy. Patients may use
their previous perceived state of good health as the reference point and not appreciate that cancer, AIDS, or other chronic diseases are associated with an inevitable and progressive loss of functioning. So, when therapy fails to maintain or reestablish the perceived reference performance level, the decision to be treated is judged to be a mistake. The physician can help patients to understand and define their current condition and to redefine a realistic reference point. These efforts must be accurate and honest, but they also should contain a goal for which the patient can continue to strive. This small nidus of hope can be the foundation for patients to continue, despite a progressive decline in functional status.

Some patients make treatment choices by trying to imagine what it will feel like to experience the available options. Such approaches are prone to error when deciding about long-term consequences, because patients fail to anticipate that their own preferences may change over time. Cohodes indicated that physicians arrange for patients to meet other patients who have experienced similar life changes. Although this is sometimes helpful, one must remember that such interviews are highly biased and can give false hope or may imply guarantees that cannot be met.

Concluding comments. Chronic diseases, especially those that can be acutely fatal, pose a major challenge for the patient, the physician, and the relationship between the two. There are no prescriptions or guidelines for the ideal patient/physician partnership. Not all patients will want the kind of relationship with a physician that Cohodes described, and these relationships should not be based on preordained policies. Yet a universal goal is to accommodate each patient's preferences and needs and to develop a unique relationship over time.

Patients may not always want to exercise their decision-making rights and may temporarily prefer to transfer decision-making power to their physicians. In doing so, patients are not abrogating their right to information, but rather are granting limited permission to the physician to take charge. This "paternalism with permission" is common as a patient's illness becomes more severe or as he or she feels an increasing sense of helplessness. This transfer of responsibility does not alter a patient's wish for dignity, need for information, or right to participate in his or her own care.

The relationship based on mutual advocacy that Cohodes described having had with his own physician is one reason that I have continued to practice medicine. Cohodes appears to have been a patient who, like many of my own, shared with his physician his need for comfort, his wish for dignity, and his desire for survival. Such a partnership is a privilege and not a responsibility that physicians can reject or assume lightly. It is a process that demands mutual respect, equality, support, and participation and that requires constant nurturing.

The more the patient/physician partnership mirrors the characteristics of the "deliberative" model, the more difficult it becomes to develop and sustain such an interaction when the number and duration of visits are prescribed by external forces. While physicians and patients must redefine their expectations in the changing health care market, it would be unfortunate if the patient/physician relationship were diminished and relegated to being an artifact of history. Physicians and patients must recognize that Cohodes's real message is that medical care must continue to be centered around a partnership of mutual advocacy.

NOTES

2. Ibid.
6. Redelmeier et al., "Understanding Patients' Decisions."