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DEATH
FORETOLD

**PROPHECY AND
PROGNOSIS IN
MEDICAL CARE**

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PROGNOSIS IN MEDICINE

Predicting the outcome of life-threatening illness is never inconsequential or insignificant, for the patient or for the doctor. Will the outcome be survival or death? What kind of death? When will it occur? How might therapy affect the outcome? The difficulty physicians face in addressing such questions is only magnified when it is presumed that they are both able and willing to make such predictions. Prognostication elicits potent and troubling attitudes and behaviors in physicians. And these in turn ramify widely through many aspects of medical practice.

When physicians prognosticate, they confront some of the most serious, emotional, and meaningful aspects of their professional practice. Doctors often characterize their experience with prognosis quite vividly:

I had a patient who died of a progressive, degenerative neurological disease. And certain things started happening to this patient—like he couldn't speak, or he couldn't swallow, or he couldn't raise one eyelid, or he couldn't walk. Virtually every day something new would happen. Eventually, he stopped being able to see, he couldn't see his family, and then he got confused, and then he couldn't talk. And every time I went to see him throughout the course of his illness, he would ask: "Doctor, what is going to happen tomorrow? Will I wake up tomorrow and not be able to see? When is this going to end?" It was a horrible thing for me to see him go through this and not to be able to do anything.

I would say, "I'm sorry, I can't tell you what's going to happen tomorrow, and I can't make these things go away. If you're in pain, we can do something about that, and if you're feeling dry in your mouth, we can do something about that. But I'm sorry, I can't tell you when it's going to end, and it's not going to get better."

This patient has a serious, life-threatening illness, and he is being buffeted by serious symptoms that occur unexpectedly. He wants to know when it will end—when he will die. His lack of foreknowledge intensifies his suffering.

The doctor, like the patient, does not know what to expect, and he also finds this very disturbing. He is limited both therapeutically and prognostically, and these distinct limitations are both problematic.

The patient's clinical state and the patient himself demand a prognosis, yet the situation seems to defy prognosis. What the doctor does know—that the patient will die, that the therapy cannot “make these things go away”—provides little comfort to either patient or doctor. Indeed, the doctor avers, he cannot tell the patient “what's going to happen tomorrow”; the predictions he can make are both disagreeable and vague. Predicting the future for such a patient may engender feelings of ignorance, impotence, sadness, guilt, or fear. Yet, with patients in different circumstances—patients for whom the future is more certain or more favorable or more modifiable—predicting the future may engender feelings of competence, confidence, or joy. In no case of serious illness, however, is predicting the future straightforward or meaningless.

When physicians tell patients that they cannot predict the future, they are eliding an important distinction between *inability* to predict and *unwillingness* to predict. Physicians themselves are often not conscious of which is the greater obstacle in a given situation. But the distinction is important because inability and unwillingness have different origins and different implications. Part of the problem is that even formulating, much less communicating, a prediction about death is unpleasant, so physicians are inclined to refrain from it. But when they are able to formulate a prediction and fail to do so, the quality of medical care that patients receive may suffer. For example, the lack of a prognosis (or the presence of a needlessly inaccurate one) may mean that physicians give seriously ill patients unnecessary treatments or, conversely, deny them beneficial ones. And patients who themselves lack critical prognostic information may make bad choices near the end of their lives.

Prognostication is an essential part of medicine. Patients often seek prognostic information from physicians, and patients and physicians require it when choosing among alternative therapies. But despite its being essential, it is usually, and somewhat paradoxically, implicit. Explicit prognostication about unfavorable outcomes, or even about favorable ones, evokes anxiety and dread in physicians; hence, whenever possible, they avoid it. How can prognostication be both essential and implicit? What cognitive, emotional, professional, and social factors lead physicians to avoid or engage prognostication? How should a physician respond to a prediction? In short, what is the role of knowledge of the future, and of claims to such knowledge, in medical care?

These questions touch on issues that transcend the merely technical aspects of prediction or the merely individual aspects of clinical care. They are fraught with meaning, have overtones of morality, and suggest

lines of responsibility. As such, they cast the physician in the role of a prophet. To say that prognosis has prophetic elements is to say that it is often meaningful, mysterious, and influential. To say that physicians are like prophets is to say that, in rendering prognoses, they resemble the idealized image of prophets as selfless and reluctant sages engaged in a difficult, obscure, moral, and valuable activity.

The Neglect of Prognosis

There are three complementary ways in which physicians may understand and, in the broadest sense, control a patient's disease: they can identify it, eliminate it, or predict its course. All three—diagnosis, therapy, and prognosis—are means by which physicians come to terms, clinically and cognitively, with disease. These three means are clearly interconnected; nevertheless, physicians maintain rigid distinctions between them in their case presentations, notes, textbooks, and thinking. Of the three, diagnosis and therapy receive much more attention than prognosis—in patient care, medical research, and medical education. Prognosis is not merely neglected, however, it is avoided. Documenting the extent of this neglect and avoidance, and understanding the reasons for it, are two of my central concerns. When and why did prognosis come to be deemphasized in clinical practice? Is the ellipsis of prognosis uniform, or does it vary according to the clinical and social circumstances of the patient and physician?

The relative lack of explicit consideration of prognosis has been lamented by some physicians for a long time. In 1934, for example, one observed:

Of the three great branches of clinical science—diagnosis, prognosis, and treatment—prognosis is admittedly the most difficult. It is also that about which least has been written and of which our knowledge is least systematized.¹

In 1953, another wrote:

[Prognosis] still remains a stepchild in medical advance partly because it is a difficult subject and partly because, for some reason or other, it has rarely been studied scientifically. The few sentences devoted to it in the account of almost any disease or condition in almost all textbooks and papers are little more than a sop to the conscience.²

A review of the content of clinical research published between 1946 and 1976 revealed that in 1976 diagnosis and treatment were the subject

of 37 percent and 33 percent of published studies respectively, but prognosis was the subject of only 4 percent.³ Moreover, although interest in diagnosis increased during this period, there was no change in the low percentage of studies devoted to prognosis. In 1981, this state of affairs led other physicians to observe: "Neglect of prognosis in standard medical texts is nearly complete; often the term does not even appear in the index."⁴ A recent analysis of entries in contemporary textbooks confirms this. *Harrison's Principles of Internal Medicine*, a prestigious and widely used textbook, for example, has explicitly demarcated discussions of etiology, pathogenesis, clinical manifestations, diagnosis, and treatment for virtually all of the diseases it considers. However, only 27 percent of the entries contain discussions of prognosis, and such material, where it appears, is usually only one paragraph long.⁵ This organization of modern textbooks mirrors modern medical practice, in which physicians focus on diagnosis and therapy and avoid explicit consideration of prognosis.

The relative absence of explicit prognostication in modern textbooks is partly a consequence of the contemporary dominance of an ontological view of disease—a view in which disease is seen as generic and generally independent of its expression in an individual. Making a diagnosis has become the central concern of the clinical encounter—in large measure because the prognosis and the therapy are seen to follow from it necessarily and directly. This perspective is reinforced when there is an *effective* therapy for a disease, because effective therapy further narrows the range of possible outcomes. Once a diagnosis is made and effective therapy initiated, the clinical course of a disease is often presumed to be relatively fixed—the same for everyone. A favorable outcome is presumed, so it does not need to be explicitly predicted. The conflation of diagnosis and prognosis, and the reduction of prognostic variability through the application of effective therapy, are complex phenomena that imply an evasion of the individual and the idiosyncratic. Yet, in another sense, it is the idiosyncratic, the individual, and the atypical that define the prognosis.

The Progressive Omission of Prognosis

If it is true that physicians presume that diagnosis and therapy dictate prognosis, we would expect that when diagnosis is straightforward and many effective therapies are available, prognosis should be relatively less prominent. Conversely, when therapeutic options and diagnostic knowledge are limited, physicians should deem prognosis to be a more

central clinical task and should focus on it. An examination of entries in successive editions of *The Principles and Practice of Medicine*, another prestigious and widely used textbook, reveals that in the period from 1892 to 1988 there is just such a complementary, reciprocal relation between the clinical acts of prognostication and therapy—that as one increases in salience in the management of a disease, the other decreases.⁶ In entries for a variety of conditions written in the earlier part of the twentieth century, in contrast to those in more recent editions and to current practice, prognosis was an important part of the clinical formulation of patients' cases. That is, when effective treatment for a given condition was unavailable, prognosis played a key role in clinical management.⁷ However, with the advent of manifestly efficacious therapeutics, the ability to predict the "natural history" of a disease lost importance, if only because it was no longer observed.

Pneumonia provides an illustrative example. Pneumonia was a leading cause of death throughout the period from 1892 to 1947. In 1900 it was the leading killer in the United States, and it remained one of the top five killers well beyond 1947.⁸ Indeed, during this period, many physicians regarded pneumonia as the prototypical condition they faced; in 1924, for example, a textbook referred to pneumonia as "one of the most widespread and fatal of all acute diseases" and "Captain of the Men of Death."⁹ After antibiotic therapy for pneumonia was discovered in the late 1930s, however, the prognosis improved substantially—so much so that it became assumed and, consequently, neglected. The natural history of the disease was replaced by a clinical course, and the "unnatural history of disease" became the standard in clinical encounters.¹⁰ Now the task of the physician was primarily to diagnose and treat the disease and only secondarily, if at all, to predict the future. Moreover, now the future was brought about not only by the disease itself but also by the beneficial or detrimental consequences of therapy.

Figure 1.1 shows the percentage of chapter length devoted to various aspects of the clinical management of pneumonia in various editions of *The Principles and Practice of Medicine*. The 1892 chapter gives more attention to the presentation of the disease than to anything else, but diagnosis, therapy, and prognosis receive roughly equal attention. By comparison, most of the chapter in 1988 is devoted to diagnosis, and there is no explicit discussion of prognosis at all. These proportions are relatively typical of modern textbook entries.¹¹ The 1947 entry is intermediate between those of 1892 and 1988; it shows increased attention to therapy, reflecting the emergence of effective antibiotic treatment in the late 1930s, and decreased attention to prognosis.

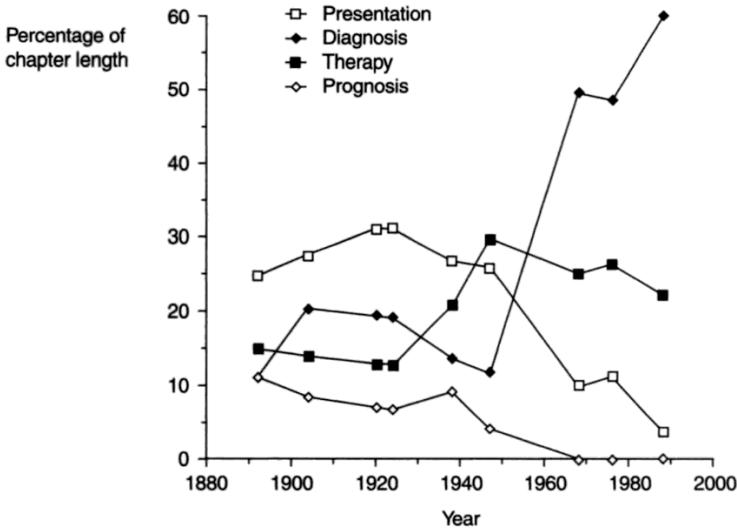


Figure 1.1. Percentage of chapter on pneumonia devoted to selected clinical tasks, *The Principles and Practice of Medicine*, 1892–1988. “Presentation” refers to symptoms and physical findings seen in the patient; aspects of the chapters that are not shown include etiology, pathology, and complications. Source: After N. A. Christakis, “The Ellipsis of Prognosis in Modern Medical Thought,” *Social Science and Medicine* 44 (1997): 301–15, used with permission from Elsevier Science.

Another force, in addition to the emergence of effective therapy, has led to the relative absence of prognosis from modern textbooks: a fundamental change in the cognitive basis of medicine with respect to diagnosis over the course of the twentieth century. In the late nineteenth century, the outcome and course of a disease were believed to be determined largely by the “constitution” of the patient. If two individuals were exposed to a contagious ailment, for example, the one with the “firmer” constitution would be expected to have the more favorable outcome. The two individuals were seen, in some sense, as having different diseases, and their prognoses were believed to differ because of individual factors distinct from the diagnosis itself.

Around the turn of the century, however, physicians began to believe that different patients might have—in a fundamental sense—the *same* disease. Beginning at that time, medicine moved from an individualistic notion of disease to one concerned with the centrality of diagnostic categories based on specific causative agents. This development in clinical thought—the belief that conditions have identities independent of their existence in given patients—was associated with a substantial increase in attention to diagnosis and a relative decrease

in attention to patient-specific factors, whether age, sex, occupation, or precise symptoms. A cognitive shift toward the notion that disease had a discrete existence that was not only ontological and etiological but also prognostic—that a disease had a “natural course” that was “typical”—had begun. Clinical thought progressively moved from an individual-based to a diagnosis-based conceptualization of disease, and prognosis increasingly was presumed to be intrinsic to the diagnosis.¹²

Effective therapy and nosologic systems thus both work to shift clinical attention from the individual patient. Attention is directed to what is deemed to be the essence of the patient’s problem, the diagnostic category and the corresponding therapy, and this leads to a clinical view that looks *through* rather than *upon* the individual case. The patient becomes not so much a sick person as an “endlessly reproducible pathologic fact.”¹³ Prognosis is viewed as a simple extension of diagnosis and therapy, an extension no longer dependent on individual traits and typically not requiring explicit consideration.¹⁴

The Complementarity of Prognosis and Therapy

The complementary relation between prognosis and therapy holds both in the construction of theoretical knowledge, as reflected in textbooks, and in the actual treatment of patients. Some physicians are old enough to recall the historical transition that has occurred in this relationship; as one seventy-year-old physician noted:

I think that fifty years ago, when their armamentarium was limited, physicians believed that the way one handled patients—the way one treated patients, the way one communicated with patients—was as important as whatever they had to do in the way of drugs or whatever. Indeed, often they had *nothing* they could do. Not only was communicating the prognosis important to the patient, but it also was important to the physician in that good communication with the patient meant that he became known as a good doctor.

Other physicians make this point about their current practice. When a patient is so sick that death seems certain, and when therapy is ineffective, they note a shift in their thinking and interactions toward predicting the course of the disease. That is, depending on the clinical circumstances of any given patient, prognosis may eclipse therapy as the focus of the clinical encounter.

This relation between prognosis and therapy is thus seen in several aspects of medical practice: at the level of epistemology, in the percep-

tion and representation of particular diseases, in the care of individual patients, and in the way particular specialties practice. Physicians rely on prognosis to “control” diseases for which they have no treatment—when a disease lacks effective treatment, prognosis occupies more space in textbooks and prognostication occupies more time in physicians’ ministrations. Indeed, the very term *incurable disease* evinces the transmutation of a strictly therapeutic assertion into a prognostic pronouncement. In the care of individual patients, physicians may focus more attention on prognosis if therapeutic options are absent or diminishing; the proverbial (and inappropriate) statement “There is nothing more we can do” often suggests the question “What will happen next?” On a broader scale, medical specialties with many options for therapy will tend to neglect prognosis, while those with few options will attend to prognosis. For example, there is, in general, greater attention to prognosis in neurology than in the specialty of infectious disease.¹⁵

Sometimes, patients’ actions too seem to reflect this complementary relation between therapy and prognosis. For instance, one physician contrasted two of his terminally ill patients as follows:

One patient wanted me to do very little therapeutically and wanted to know what the time frame for survival was. The other wanted me to do everything conceivable and didn’t want to know about timing. Although I think at some level both patients recognized and acknowledged that they had metastatic disease that would likely be the cause of their death, one recognized that it would do so in the short term, and the other one was not willing to accept that possibility.

Although both patients wanted their doctor to do something for them and to show mastery over the disease, they had different ideas about what this should be. Some patients strive for the elimination of their disease, others to know what will happen.¹⁶

The fact that prognosis and therapy are complementary, when coupled with the increasing prevalence of effective therapy, helps explain why modern clinical practice pays so little attention to prognosis. But there are many other reasons for the lack of attention. A close study of physicians’ attitudes and behavior reveals a *dread* of prognostication—whether favorable or unfavorable, accurate or inaccurate. Physicians would rather not formulate or discuss prognoses. As we shall see, especially in chapter 4, a number of powerful professional norms have evolved that limit the explicit consideration of prognosis in clinical practice.

The Resurgent Relevance of Prognosis

Despite the reduced prominence, in recent decades, of explicit prognostication, several developments in contemporary medical practice, as well as broader cultural changes, are contributing to its renewed importance. These changes are occurring on three broad fronts: in the type of medical problems patients have, in the way health care is delivered, and in the philosophy and cultural outlook that guides health care delivery. We have seen increases, for example, in (1) the prevalence of chronic disease; (2) the bureaucratization of health care delivery; (3) the need to compare health care providers and rationalize expenditures; (4) the reliance on randomized, controlled trials to evaluate drugs and on health services research to evaluate other, nonpharmaceutical medical interventions; (5) the use of novel biomedical technologies; (6) the attention paid to patient self-determination and to other ethical issues in medical care, especially at the end of life; and (7) the expectations that patients express regarding access to information and respect for their “rights” (ranging from a “right to know” to a “right to die”).¹⁷

Changes in Types of Diseases

The number and percentage of patients with chronic disease—for whom the diagnosis is already known and therapy is often simply the continuation of previously initiated interventions—are increasing.¹⁸ In such cases, because curative therapy is limited and the course of the disease is long, prognostication can become especially prominent. The clinical encounter is focused on the anticipation, avoidance, and mitigation of complications of the underlying disease itself or of the treatment. Patients with long-standing diabetes, for example, do not need to be told their diagnosis (which is known to them) or their therapy (for example, insulin—also known to them). Rather, they and their physicians are concerned with such questions as “Will my kidneys fail, and if so, when?” “Will I become blind?” “How long will I be able to care for myself?” “How long do I have to live?” Moreover, in chronic conditions, there is more opportunity to revise previously rendered prognoses as, over time, the physician learns more about the patient.¹⁹

Changes in Health Care Delivery

Several developments in health care delivery and health care technology also support the increasing importance of prognosis in medicine. A

key factor is the increasingly bureaucratic structure of American medical practice. Physicians are increasingly becoming salaried employees beholden to bureaucratic management or are otherwise losing their economic independence and some of their professional autonomy.²⁰ External review of physicians' clinical behavior often focuses on actions that are at least implicitly based on their prognostic judgments. For example, administrative oversight plays an increasing role in therapy management. Physicians are being asked, in the context of cost-effectiveness, to predict outcomes among a variety of (more or less costly) treatment options or to estimate the length of the hospital stay necessary for an anticipated medical outcome. Better prognostication, in the sense of a superior ability to foresee the outcome of a patient's illness, can help to optimize the choice of treatment and the timing of hospital admission, thus reducing costs. Similarly, federal regulations dictate that physicians wishing to refer Medicare patients for hospice terminal care must certify that the patient has less than six months to live. Although physicians are expected to make this serious prognostic determination, which has significant administrative and clinical consequences, this characterization of the terminal state has no real clinical basis. It was adopted simply as a result of the original Medicare legislation.²¹ Prognosis is also evoked when physicians' performance is evaluated through the comparison of their patients' outcomes to "normal" standards, the latter being implicitly prognostic. Bureaucratic superiors, for example, may evaluate surgeons' success rates for certain types of procedures by comparison to expected success rates.²²

A greater focus on prognosis also results from the increasing need to compare the quality of health care providers, along with a more general societal interest in rationalizing health care expenditures by directing resources to those most likely to benefit. Accurate and reliable prognostic assessments are central to the identification, development, and implementation of optimal health care delivery systems in that they help patients and payers determine which systems lead to good or bad outcomes. Moreover, comparison across systems should optimally include a "risk adjustment" that takes into account the relative sickness of patients in the systems—that is, whether the patients in one were intrinsically sicker than those in another and thus might be expected to do worse.²³ Health care providers must demonstrate that the care they offer is effective and of good quality, after adjusting for their patients' "baseline" prognoses. Similarly, evaluating the cost-effectiveness of different medical therapies relies on access to accurate information about the probabilities of various outcomes, which are, in essence,

prognoses.²⁴ Some medical interventions may be cost-effective only in subpopulations where the patients are at particularly high or low risk of mortality, and payers may target interventions—conditional, again, on the patient's prognosis—to cases in which they feel the benefit justifies the cost. In each case, the ability to develop and analyze prognoses is essential to asking the right counterfactual questions and getting the right policy answers.

Another factor lending salience to prognosis is the increasing frequency of randomized, controlled clinical trials. The customary role of prognosis in clinical trials has been to ensure that patients of similar illness severity are compared, since groups of patients with an equivalent average prognosis (e.g., for death) are formed by the randomization process. However, prognosis is finding a new use: rather than waiting for uncommon or temporally distant outcomes to occur in long-term clinical trials, which can be difficult and expensive, investigators are increasingly making use of "intermediate endpoints," that is, findings that are taken to be *predictive* of long-term outcomes.²⁵ A decrease in a lab test value is taken to indicate a decreased risk of eventual death, making shorter and less expensive trials possible. The booming industry in clinical trials thus supports increasing interest in the development and use of various prognostic staging systems and clinical markers.²⁶

The emergence of certain medical technologies also increases the relevance of prognosis. On the one hand, the evaluation of their effectiveness generally relies on the availability of prognostic information.²⁷ But, in addition, these technologies—although often directed at improving diagnosis and therapy—also provide, directly or indirectly, more accurate and earlier prognostic information and therefore foster the rendering of prognoses. One example is obstetrical ultrasound, which may *incidentally* reveal information about the internal anatomy of a baby that would not otherwise be detected until well after the baby was born. Thus, parents and physicians are made aware of conditions long before the child is able to present with the illness. Such early findings, not yet corresponding to any observed symptom, demand explanation: patients wish to know what the findings *will* mean, what the future has in store. One pediatrician gives a typical example:

Nowadays, many kids come to our clinic when they're two weeks old because their kidneys were abnormal on *Mom's* prenatal ultrasound! In the old days when someone was diagnosed with polycystic kidney disease in the neonatal period, they died before they were one year old. But now there are so many much milder cases that only come to our attention because of an ultrasound that happens to have been

done for other [obstetrical] reasons. We have no idea what to tell the parents about what to expect. It used to be that the children came to our attention because they were failing to thrive or anemic or acidotic or any of the serious things that renal insufficiency causes, and all the information about prognosis used to be based on their features at that time. But now they're presenting much, much earlier and no one knows what to do with that.

The parents ask for predictions. They want to know when will the kid need dialysis, when will they have to start thinking about transplant, when will this kidney disease that we see on the ultrasound affect them. Because right now their kids are thriving, they're doing well. But at some point they're going to need erythropoietin shots and growth hormone and vitamin D and all these different things that we see with renal failure. We have no idea when that will be.

New technology makes it possible to detect bodily aberrancies with prognostic significance, even before they are symptomatic.²⁸

The advent of genetic testing technology provides yet another important new arena for prognostication. Analysis of a person's genes may reveal relevant medical outcomes years or decades in advance in what are generally termed "presymptomatic carriers." In contrast to other tests applied for diagnostic purposes, such genetic tests have specifically prognostic importance, which is made all the more apparent by the fact that, in most cases, no specific interventions are available to cure the condition so detected, or even to delay its onset. A prototypic example is Huntington's disease, a fatal, degenerative neurological disease that usually begins in the patient's forties. Tests can now reveal with certainty, decades before any symptoms are noted, whether asymptomatic individuals will or will not develop the disease.²⁹ Because no treatment is available for the condition, this is yet another example of the complementary relationship between therapy and prognosis, in that the prognostic significance of these tests eclipses their therapeutic utility. In other situations, genetic tests are used to develop prognostic information that does indeed have therapeutic implications. For example, some women, on the basis of the prognostic information provided by genetic tests to evaluate their risk for breast cancer, undergo prophylactic mastectomy—even though this prognosis is not certain.³⁰ As more studies reveal genetic bases for diseases as diverse as emphysema, diabetes, dementia, cognitive disability, and alcoholism, the prognostic use of genetic tests will certainly rise.³¹ The use of such tests is also likely to rise outside of medical arenas, for example, in law.

The increasingly technological, “postclinical” nature of medical practice fosters the availability of information that is presymptomatic in nature, and thus *inherently* prognostic.³² “Presymptomatic” illness is, indeed, the specifically prognostic analog of “asymptomatic” illness. The notion of asymptomatic or “occult” or “silent” illness is itself interesting in that it posits a phenomenological realm of disease of which the patient has no subjective experience. This realm requires the intercession of an expert, a physician, to be comprehended. Typically, the expert must use technology to approach this realm, as when the physician uses diagnostic tests to adduce the presence of disease even when the patient has no symptoms.³³ The implications of the term *presymptomatic*, however, extend even beyond those of *asymptomatic*. Rather than indications of an already present disease, the expert is said to have discovered indications of a disease that is not yet even present. Some physicians have even begun to call individuals whose genetic tests are positive for a worrisome gene “prepatients.”³⁴ The notion of presymptomatic illness thus represents an even further distancing of the patient’s subjective experience of disease from the everyday practice of medicine. Moreover, the term *presymptomatic* suggests an inexorable outcome: the patient *will*—eventually—develop symptoms.

The application of new technologies to patient care increases the importance of prognostication in one other way: it creates a whole new class of things about which to prognosticate, namely the complications of the technology.³⁵ Beneficial new technologies in medicine—from computed tomography to chemotherapy to open heart surgery—have not come without risk. Predicting their consequences is important, and doctors are frequently called upon to explain to patients a potentially confusing array of possible outcomes.

Changes in Ethical and Cultural Expectations

In addition to changes in the types of medical problems people face and in the ways physicians confront them, there have been changes in the way that patients and physicians think about the ethical duties of physicians to their patients. Prognosis is a fundamental, though implicit, basis for many theoretical and practical ethical decisions in medical care, and prognostic uncertainty may complicate such decisions considerably. Ethical decision making is increasingly finding its way to the bedside.³⁶ The elaborate informed consent process that patients undergo prior to having procedures or participating in research, for example, is predicated upon *predicting* risks and benefits.³⁷ Prognosis

also profoundly affects decisions to initiate, withhold, or terminate life support for critically ill newborns and adults, and it figures in the discussions about these decisions that doctors have with patients' families.³⁸ Prognostication is critical when one must allocate scarce medical resources to those patients for whom they can do the most good. Finally, it is central to the notion of "futility," a concept usually invoked in situations where death is predicted to be imminent and inevitable.³⁹ The relatively recent emergence of futility as a theme in bioethics reflects the moral desirability of acknowledging medical limitations and the practical necessity of allocating scarce resources.⁴⁰ Futility is based on a prognosis not only that the patient is unlikely to recover spontaneously, but also that any intervention will likely be ineffective. As the avoidance of futile treatment has assumed increasing prominence, for reasons of justice, beneficence, or economy, prognostication—which is, after all, the fundamental and essential basis for a determination of futility—has increased in importance.⁴¹

Broad changes in American society are influencing the doctor-patient relationship and fostering an increased interest in prognosis. In areas ranging from childbearing to terminal care, patients want information about expected outcomes that they can use to manage their care actively. This is especially true with respect to care at the end of life. Beginning in the 1960s, and consistent with then-contemporary societal trends toward "consciousness raising" and the questioning of authority, a death awareness movement emerged. The way was led by books such as Herman Feifel's *The Meaning of Death* in 1959 and Elisabeth Kübler-Ross's *On Death and Dying* in 1969.⁴² Kübler-Ross showed, among other things, that dying patients did not wish to be isolated, abandoned, or misled by their physicians. These books, both authored by psychiatrists, galvanized the public more than they changed the medical profession. Nevertheless, the sentiment that patients and physicians should discuss death more openly eventually gave way, in the 1970s and 1980s, to the obligation that they do so. Now, physicians have the *duty* to inform their patients about their illness, and patients have a *right* to know.

In recent years, the American public has become more focused on planning for death, a development reflected in the increasing interest in everything from living wills to physician-assisted suicide. There has been a profusion of books on caring for the terminally ill at home, which include vivid, nontechnical descriptions of what to expect and which document the impact of death on family members.⁴³ There have been best-selling how-to books on "self-deliverance."⁴⁴ And there have

been books describing the process of dying, often using detailed and intimate case histories.⁴⁵ These latter books typically reflect an attempt to help people find meaning in dying, and they suggest that death is increasingly viewed as a passage that can be actively anticipated and therefore managed. To enact these popular visions of death, however, patients must rely on reasonably accurate prognoses from professional physicians.

In sum, ongoing changes in the nature of illness in contemporary American society as well as in the way medical problems are being confronted are resulting in a substantial increase in the relevance of prognostication in clinical care. Although it has typically been a less obvious part of medicine, prognosis has never been easily avoided, and several trends are converging to make it still harder to avoid.

The Social Construction of Prognosis

The foregoing factors suggest an increasing relevance for prognosis in medicine. But they also suggest the extent to which prognosis depends on context. Indeed, prognosis, like other forms of medical knowledge, may be seen to be socially constructed: it is not merely a function of patients' biology, but is influenced by physicians' and patients' beliefs and attributes and by social structures and organizations.

To begin with, social attributes of patients may influence the prognosis, affecting the biological prognosis itself, influencing the doctor's actual formulation of the prognosis, and determining whether the doctor communicates it to the patient. The impact of poverty, race, religion, and social support on medical outcomes, even after taking into account the patient's diagnosis and treatment, is well documented.⁴⁶ For instance, the actual, biological course of coronary artery disease may depend on such variables as whether the patient lives alone or has social contacts or economic resources.⁴⁷ The patient's capacity to interact socially may transcend its impact on biological course and come to influence how physicians formulate a prognosis. Patients who are disconnected from the physician or from their family are, according to physicians, more likely to have unfavorable outcomes. As sociologist Renée Anspach observes in her study of neonatal intensive care, this particular aspect of prognosis is social in that the relevant information is gleaned through interaction with the patient and in that the relevant information is interpreted by reference to "appropriate" social standards.⁴⁸ Thus, when strictly biological criteria for prognostication are absent, doctors may turn to social criteria in order to formulate the prognosis.⁴⁹

Regardless of the true import of social factors, physicians *believe* that such factors can influence the prognosis. One physician characterized their role as follows:

In prognosis, you have got the combination of a disease process and "host resistance." Host resistance probably accounts for why so many people die within a short period of time after the death of their spouses. They've had these chronic diseases or problems which have been stable for years; then their husband dies, and six months later they are dead because their resistance has been compromised. Or, right at the age of sixty-five, at retirement, you see the same type of thing. You have got a disease with a reasonably well known prognosis, for example, exercise-related angina pectoris. The patient retires, and two weeks later they have died of an infarct. Explain it! You can't, except that prognosis in an individual patient is a combination of disease-related factors and host-related factors. That is why prognosis has more inherent variability than diagnosis. Diagnosis is fixed to a disease process, tagging a label, but what happens in an individual patient is not only a function of the disease but also a function of them.

Another elaborated:

Estimates of prognosis take into account a complicated set of factors, including the patient's own perceptions of what they have; the patient's social, economic, and support situation; their physical frailty; their emotional frailty; and the number of the problems and their severity levels. In an individual patient's situation, the set of variables that we use to estimate likely outcome is extremely complicated.

Physicians often characterize the use of such information as "knowing the patient and the patient's life situation," and they think that it is important for proper prognostication. However, physicians are much more likely to take certain types of social information into account than others when making predictions. For example, nearly all physicians believe that social support affects the course of illness, but smaller percentages believe that the patient's religion or income does.⁵⁰ Overall, however, physicians' acquisition of social information about patients meaningfully affects the survival predictions they make.⁵¹

Insofar as prognosis depends on patients' social attributes, physicians believe that prognosis may indeed be patient-specific. That is, although a patient's income or religion might not be so much a factor in the biological expression of a disease, they are likely to be a factor in the course of the disease. Although a diagnosis as an abstract concept

does have a prognosis attached to it, the prognosis in a specific patient might still depend on individual factors, including social ones. Making a prognosis thus requires the physician to be more familiar with the particular and social circumstances of the patient than diagnosis does.⁵²

Patients' social attributes can influence whether a prognosis is offered at all, and not just its content. For example, a study of routine prognostication revealed a broad pattern in which prognostic information was more likely to be shared with patients with privileged socioeconomic status, regardless of whether they asked for it; the physician, that is, was more likely to discuss prognosis with male, wealthy, college-educated, and white patients during routine clinical encounters.⁵³ Moreover, the patient's physical or emotional health was *not* associated with whether prognosis was discussed; that is, social attributes appear to be more important than clinical ones.

Not only may social attributes be used as *determinants* of prognosis (influencing the formulation and communication of the prognosis as described above), they may sometimes replace medical parameters as the *outcomes* of interest. For example, for a thirteen-year-old girl who is pregnant, the doctor might predict "social failure" despite an acceptable clinical outcome (i.e., the delivery of a healthy baby). Similarly, physicians may make prognoses about a patient's ability to fulfill professional obligations, such as returning to work.

Prognosis is also socially constructed in that the valence and nature of a prognosis may themselves be defined socially. For example, sociologist Fred Davis, in his remarkable analysis of the medical experience of polio patients in the 1950s, demonstrates that the same clinical outcome can be presented and perceived in different lights; a prediction that the patient will be left partially paralyzed can be presented with varying degrees of optimism.⁵⁴ Physicians might note that although the patient will have to wear braces for the rest of his life, he will be able to use his legs. More generally, institutional and social systems structure prognostication. The treatment that patients undergo and the rhythm of their care, especially in hospital settings, reshape and redefine their expectations. A patient who at first expects to recover from a paralyzing injury, for example, eventually realizes (even if not told explicitly) that he should instead hope for different outcomes. The perception of any particular outcome is thus socially contingent. Moreover, differently situated individuals regard prognoses for severe incapacity differently. People who are more familiar with disability, for example, tend to regard being disabled as less problematic than those who are not.⁵⁵

Finally, prognosis is socially constructed in that the prognosis rendered depends on the social and occupational attributes of the physician and on structural and organizational factors of the physician's practice. One study found that the survival estimates given by physicians varied according to their specialty training.⁵⁶ Another noted that physicians' definitions of "terminal" illness varied with both their specialty and their clinical experience.⁵⁷ A study of the propensity to overestimate prognosis for survival, on the other hand, found that it tended to be associated not with the attributes of physicians but rather with the extent to which the physician was familiar with the patient.⁵⁸

A study of 125 routine clinical encounters found that the most important factor accounting for whether prognosis was discussed was the specialty of the physician—surgeons were much more likely than primary care physicians to offer predictions.⁵⁹ Other physician attributes that were associated with whether prognosis was mentioned included the number of years in practice and the number of hours per week devoted to patient care; physicians who had been in practice longer and those who spent fewer hours per week in clinical practice were less likely to mention prognosis. Less experienced physicians appear to have had fewer opportunities to be humbled by their errors; older physicians are more cautious about offering predictions. This is a general pattern. Older physicians feel that, when it comes to prognosis, "you're more likely to be wrong than right, so keep quiet."

The setting in which physicians practice may also affect prognostic decision making. For example, Anspach observes that in life-or-death decision making in the neonatal intensive care unit, even if there is agreement about what to do given a particular prognosis (for example, with respect to withdrawing life support), there may still be disagreement about the prognosis itself. Such disagreement, she argues, may arise from the different social and professional positions of the various actors.⁶⁰ Moreover, in patients from whom the withdrawal of life support is contemplated, the dissent of a single physician regarding the prognosis is often sufficient to introduce uncertainty and thus to mandate continued treatment. In this sense, the rendering of a prognosis is truly a group process: a definitive prognosis—upon which action may be based—can be rendered only by the group as a whole. The uncertainty as to prognosis here arises from the organization of decision making rather than from conflicting clinical facts.⁶¹ And the requirement for unanimity of opinion in part reflects the belief that the more people who agree with a prediction, the more likely it is to be correct and accurate.⁶²

The institutional practice of medicine has an impact on prognosis in other ways as well.⁶³ The nature of the statistics that are collected by bureaucracies may structure the prognoses that are communicated to patients and may be used to rationalize treatment decisions. For example, partly for reasons of administrative simplicity, follow-up studies conducted by neonatal ICUs often collect data taking as an endpoint "survival to discharge." These statistics are then used to justify a strongly interventionist stance, guiding decisions about therapy and the provision of life support, even though statistics about longer-term survival, quality of life, or longer-term cognitive or physical deficits might not show such a favorable prognosis for these infants.⁶⁴ Similarly, as we have seen, the frequency and type of visits, examinations, and procedures indicates to patients which outcomes they should be interested in and what "recovery" means; institutional perspectives on what expectations are legitimate can supplement, if not supplant, the expectations of the patient or physician.⁶⁵ Patients come to realize, for example, that daily visits from the speech therapist suggest an outcome to focus on. Finally, the way prognoses are made and communicated can vary according to institutional settings (such as HMOs), which structure how well and how long the doctor knows the patient and the patient's family.⁶⁶

In sum, social attributes of the patient and physician influence the actual and predicted course of illness. The importance of social factors in determining prognosis is another reason that physicians avoid prognosis, both because physicians consider social factors to be imponderable compared with the biological factors in a patient's illness (contributing to the greater uncertainty and complexity of prognostication compared to, say, diagnosis) and because the relevance of social factors is viewed as a threat to medicine's claims to scientific precision and legitimacy.

Attributes of Prognosis

Prognosis can have at least two meanings. First, prognosis can be what actually will happen—that is, the objective reality or "true prognosis," the actual prospect of recovery from a disease given the nature of the disease and the special features of the case in question. Second, prognosis can be a physician's impression of what will happen—that is, the subjective reality or "anticipated prognosis." The anticipated prognosis, which I will refer to as "prognostication," in turn includes the acts of both *foreseeing* and *foretelling* the course and outcome of a disease, which I also characterize as "inward" and "outward" prognostication.⁶⁷ Foreseeing the future and foretelling it are, however, distinct elements,

the first act being to formulate a prognosis, the second to communicate it. The true prognosis is thus what actually happens to a patient in the course of a disease and is the patient's experience of it. The anticipated prognosis, on the other hand, is the physician's mode of understanding the patient's course (albeit in advance of its occurrence); it is a *professional* perception of the patient's experience of the disease.⁶⁸

The notion of a "true prognosis" captures what is often termed the "natural history" or "clinical course" of a disease. The former is the typical course of an illness that is not treated (the "innate prognosis") and the latter is the typical course of a disease that is treated. Prognostication thus is equivalent to stating the natural history or clinical course of the given disease—in a sense, specifying its average prognosis in most patients—and then establishing its applicability to a particular patient, for whom particular treatment decisions have been made. In this light, prognostication is an intellectual process whereby the physician moves from knowledge about disease in patients in general to knowledge about its expression in an individual.

The true prognosis can never be known definitively in a specific patient. After the fact, a particular outcome may be observed, and we may speak of a "realized prognosis"—as when physicians say, "His prognosis was good, but he died anyway; the prognosis turned out to be bad."⁶⁹ Among other things, the outcome in any given patient can deviate from the true prognosis on the basis of the treatments that are (correctly or incorrectly) instituted; in other words, the realized prognosis is not necessarily the same as the true prognosis, though the two are empirically indistinguishable in a given patient.

"Natural history" is a problematic concept even without the implementation of an effective therapy that transmutes the natural history of a disease into a clinical course. Moving from the general to the specific and trying to sort out the likely course of an illness in a given individual is always fraught with uncertainty. Aside from the intrinsic variation in the expression of a disease, the trajectory of illness in a given person may depend upon a number of individual factors, as we have seen. In a sense, there is no such thing as a usual or natural illness trajectory because each patient's experience is unique and because each patient, in ways large and small, modifies the course of a disease both subjectively and objectively.⁷⁰ That is, there is a *personal*—and a *social*—course of a disease that fundamentally subverts, if not replaces, the natural—implicitly solely biological—course. When treatment is superimposed upon natural history, the task of prognostication can become even more difficult; doctors are then faced with the tasks of predicting not only

the impact upon the patient of the underlying disease and the patient's underlying traits, but also the impact of the treated disease and, finally, of the treatment itself. Moreover, the institution of therapy magnifies the doctor's sense of responsibility for the course. The extent to which the physician believes that the prognosis does or does not depend on individual factors (whether social, biological, or therapeutic) is one of the key problematic aspects of prognostication. Prognosis is at once about the generic and the individual, the typical and the atypical, and the treated and the untreated course of disease. It touches on the difference between knowing and communicating knowledge, between personal and professional domains, and between subjective and objective realities.

Favorable, Optimistic, Certain, and Competent Prognoses

To say that a prognosis is "good" or "ideal" masks several important distinctions about prognoses that are important to both patients and physicians.⁷¹ Certainly, a crucial attribute of an ideal prognosis is that its "valence" should be favorable, in the sense that the outcome will be salutary and the patient will recover. Patients with favorable prognoses reassure physicians that what they do is valuable and effective. Favorable prognoses are also pleasant to deliver and are generally unthreatening to the physician-patient relationship. For these reasons, they are desirable.

However, a prognosis may also be "good" if the anticipated outcome is simply more favorable than might otherwise be expected—that is, relative to the patient's illness. For example, physicians may say a patient with a particular type of cancer has a good prognosis and mean that the patient has only a 30 percent chance of death over five years. A 30 percent chance of death would not be a good prognosis for an individual with a less serious condition, such as pneumonia. In such circumstances, when physicians say that the prognosis is good they mean not so much that the valence of the prognosis is favorable, but that it is favorable compared with expectations. Hence, it is possible to be "optimistic." Optimistic prognoses can be offered when favorable outcomes are possible, relative to the seriousness of the diagnosis and relative to similar patients. Optimism may also refer, however, to situations where the prognosis being offered is *unduly* and not merely *relatively* favorable. That is, an optimistic prognosis may mean that, relative to the true prognosis, the physician is biased and is overestimating the prospects for recovery despite evidence to the contrary.

A prognosis may also be good if it is certain. Just as unfavorable prognoses challenge physicians' feelings of efficacy, uncertain prog-

noses challenge physicians' feelings of knowledge. Paradoxically, as we shall see, physicians find prognostic uncertainty to be both threatening and felicitous. Uncertainty leads to unavoidably unexpected results and can compromise perceptions of professional standing. But uncertainty may also lead physicians to the conclusion that they cannot be held responsible for ensuring that any particular outcome will occur.

Finally, a prognosis may be good if it is possible to formulate it easily and accurately. Such a prognosis, for example, might not require complex interventions or evaluations. To make a "good" prediction is to make an accurate prediction. In other words, a prognosis is good if a physician can develop it competently.

"Routine" versus "Serious" Prognoses

A key attribute of a prognosis is its object: about what is a prediction being made, and in what clinical situation? In everyday clinical encounters examined in one study, the great majority of prognostically relevant remarks were short, tangential, and casual, typically reflecting optimistic reassurance by the doctor that the patient would respond to the proposed treatment. They were routine. Examples include the following actual remarks:

- A muscle relaxant should help. I bet by Monday you're recovered.
- Use one suppository a day for a week. Sometimes there is a little bit of irritation left after a week, and you can take a second week. There is a refill on there but I think one week should do it.
- The reason your knee is uneven and distorted like that is that we took a big chunk out of it. Then we pulled everything together. But that will smooth out just fine.
- If a new breast lump ever shows up, we should be able to find it.

In most cases, remarks such as these are the *only* prognostically relevant remarks made during a clinical encounter between a doctor and patient in an outpatient setting.⁷² Usually, such remarks are embedded in the routine business of the visit, not presented as a distinct part of the clinical encounter, and neither the patient nor the physician elaborates on them. Both doctor and patient seem to gloss over prognostic statements with little or no analysis, especially in comparison to diagnosis or therapy. Cases where patients inquire or doctors volunteer what would happen if things did not go as the doctor had predicted—for example, if a prescription did not work—are quite rare in routine settings.

Although a majority of the encounters in the study of outpatient practice from which these examples are drawn (58 percent) contain at least some prognostic information, only 14 percent contain a substantial or deliberate discussion of prognosis. Moreover, the median amount of time devoted to prognosis is only three seconds (out of an average encounter length of 14.6 minutes). The overriding impression from this study is that explicit prognostication is only a peripheral part of everyday outpatient medical practice.

When one thinks of prognosis, however, one tends to think of a more serious type of prediction, one involving more formality or higher stakes. Medical care often involves especially meaningful and serious concerns, such as reproduction, fetal development, physical incapacitation, cognitive impairment, and, especially, terminal illness. Predictions regarding these topics tend to be ritualized, somber, and anxiety-provoking. Although physicians realize that most clinical encounters do not involve serious prognostication, they nevertheless tend to associate prognosis with life-or-death issues. Other, less important criteria, including attributes of the patient and of the social situation, may also influence physicians' views regarding this distinction; predictions in young patients, in important persons, in those with dependents, or in those whose illness is iatrogenic may also be deemed "serious" rather than "routine."⁷³ In all of these situations, the stakes in the outcome are high, and bad outcomes are regarded as particularly meaningful, deplorable, or sad. Predictions that are particularly uncertain or in which dramatic reversals are possible can also be serious. Finally, predictions involving outcomes with moral overtones (e.g., about a fetus, about a person's genes, or about the likelihood of death after withdrawal of life support) are serious. It is in serious prognostication that the starkest examples of how physicians generate and use prognostic information are found, and in which the most prophetic aspects of prognosis are apparent.

Modern American Death

The most important objects of prognostication are generally whether a patient will die and, if so, when and how. Physicians have a substantial impact on such matters; therefore, prognostication about the results of their actions can play an important role in the management of death and dying in contemporary society. The impetus to foretell death is both fundamental and ancient (reflected, for example, in stylized depictions of deathbed scenes in which the dying person has time for confession or last

rites because the death is anticipated). However, the notion that death can and should be accurately predicted is especially consistent with broader contemporary beliefs about the possibility of *managing* death.

To understand the centrality of death in medical prognostication, it is helpful to begin with some features of dying in contemporary America: more than 80 percent of American adults die in health care institutions rather than at home;⁷⁴ 25 to 35 percent receive intensive care or other high-tech treatment prior to their deaths;⁷⁵ 70 to 75 percent die after a prolonged chronic illness, with the time from diagnosis to death usually exceeding two years;⁷⁶ 40 to 70 percent unnecessarily suffer significant pain;⁷⁷ 50 to 60 percent are short of breath;⁷⁸ 10 to 30 percent express preferences about end-of-life care that are disregarded by their health care providers;⁷⁹ and 25 to 35 percent impose significant personal and financial burdens on their families.⁸⁰ Over 75 percent of adults are hospitalized at some point during the year before they die, and almost 60 percent see a physician at least five times during the last year of their life.⁸¹ Thus, patients tend to be ill for quite a while before death, tend to have significant involvement with the medical profession and with medical technology in the period leading up to death, and yet tend to have dying experiences that are suboptimal in fundamental ways.⁸² That is, physicians have ample opportunity to make and act on prognoses regarding the timing and manner of death, and to optimize care at the end of life in accord with these prognoses, yet patients and their families complain of being neglected near death, of not being made as comfortable as possible, and of not being given enough information to make appropriate end-of-life arrangements.

As a result of both the proliferation of medical technology and the ever-greater contact of dying patients with physicians and hospitals, contemporary American physicians, more so than ever before, influence the timing, rapidity, and nature of patients' deaths. Life-threatening illness and death are routine parts of most physicians' professional life.⁸³ Physicians have control over the treatments instituted to forestall death; the degree of symptom relief;⁸⁴ the withholding or withdrawal of medical interventions;⁸⁵ the information patients have about their terminal illnesses;⁸⁶ the location where patients die; their state of consciousness at their death; and the policies regarding resuscitation. Indeed, in our society, one is not even legally dead until a physician so pronounces.

The role of medical technology and of physicians in the management of death suggest that death, like prognostication, is not only a physiological but also a social phenomenon. Attributes of death and how they are perceived are not fixed and immutable: they are socially constructed.

This proposition finds support in the substantially varied perceptions of death across time and place.⁸⁷ Sociologist David Sudnow's classic book *Passing On*, for example, shows that the recognition that someone is dying, the recognition of death itself, the specification of permissible causes of death, and, finally, the occupational rituals of the professionals who tend to the dying are all culturally constituted.⁸⁸ Patients are socialized to the dying role.⁸⁹ Indeed, the "trajectories" that patients experience while seriously ill—in the sense of their biological, psychological, and interpersonal experiences—are largely socially defined.⁹⁰ These trajectories in turn dictate the professional and personal responses by the patient, family, and medical staff.

The explosive growth in both the amount and sophistication of technology deployed by physicians to combat disease has given physicians unrealistic expectations about their own abilities. Indeed, physicians tend to regard death as a personal failure.⁹¹ Powerful emotional and intellectual (and not just fiduciary) elements of their professional culture cause physicians to feel this way: optimistic, activist, melioristic attitudes are endemic in American physicians. Indeed, when physicians speak of the death of their patients, they often use expressions that suggest either rectifiability ("we lost the patient") or a failing on the part of the patient ("that patient died on me"). Physicians' rituals (such as false reassurance of the dying or "heroic" efforts on their behalf) and institutional practices (such as rapid sequestration of dead bodies in hospitals) serve to protect physicians from being identified with a betrayal of confidence or a failure to fulfill their duty to eliminate disease.

Nonetheless, the material and psychological costs of this technology have also gradually come to light; patients and physicians are addressing the suffering and waste that the unblinking application of technology to prolong life may entail, as well as the dehumanizing transformation that dying has undergone. Describing physicians' attitudes toward death in America and the change they are undergoing, sociologist Renée Fox has observed that

the Judeo-Christian tradition emphasizes that, because human life is divinely given, it is inherently sacred and important, has absolute, inestimable worth and meaning, and should be protected and sustained. . . . [But] in recent years, the unqualified commandment to support and sustain life has become increasingly problematic in American society, particularly in the medical sector. The sanctity of life ethic has helped to push physicians, nurses, and other medical professionals into a pugilistic tendency to combat death at any cost, and to define its occurrence as a personal and professional defeat.

This heroically aggressive, “courage to fail” stance has been reinforced by the development of more powerfully effective forms of medical technology that increase the medical team’s ability to save and maintain life. However, some of the consequences of doing everything possible to keep all chronically afflicted and terminally ill patients alive have come to be questioned.⁹²

Patients have expressed deep sadness, frustration, and anger with modern medical care of the dying, especially in ICUs. A fundamental shift seems to be occurring in our society with respect to perceptions of medical technology; modern medical care at the end of life, especially that involving high technology, is often equated with “excruciating pain,” “imprisonment,” and “torture.”⁹³ In a sense, greater technology, which initially led to greater control over death, now leads to less control. Such technical and invasive therapy is viewed as causing meaningless suffering. Dying in modern American society has been characterized as highly professionalized, institutionalized, mechanized, secularized, and dehumanized. Americans appear to be so dissatisfied with these developments that they are even expressing interest in euthanasia as an alternative.⁹⁴

Professional and public attitudes have thus been shifting to a notion that death should be better managed if it cannot be averted. This shift is reflected in numerous developments. The newfound tolerance for voluntary euthanasia, the examination and limitation of life-support technology, the assertion of a “right to die” (as if death itself were optional and volitional), the increasing interest in hospice care and palliative medicine, and the proliferation of advance instructions by patients about how to care for them when they are terminally ill, along with the ongoing public discussion of the limits of medical technology and even the definition of death itself (with a confusing array of possibilities including “brain death,” “whole body death,” “irreversible death,” and the like): these are all ways in which patients and physicians seek to specify the timing and circumstances of death—as if, in so doing, they can specify whether death will occur at all. Paradoxically, within the context of modern medical practice, control over life is seemingly achieved only through control over death.

There is thus a prevalent idea, if not ideology, in contemporary medicine and society that death can and should be managed. This management is often achieved through the withdrawal or withholding of medical treatment and sometimes even the administration of lethal drugs—acts that represent the highest possible degree of control over the timing of death and thus the greatest foreknowledge.⁹⁵ An unavoidable

part of such decisions is making predictions about what would happen if life support were not withheld or withdrawn, what would happen if it were, and when death would occur in either case.

In contemporary American society, despite the actual way that most deaths transpire, death is ideally seen as a private, individual, and personal event.⁹⁶ Moreover, dying in modern contexts engenders fear of a loss of control, a loss that is antithetical to a core American value. There has been a change lately in a key element in the perception of what constitutes a good death, from a sudden and unconscious death (typified by dying in one's sleep) to an aware death that is individual-specific, that is subject to individual control, and that allows the patient to finish business (dying "my way"). The idealized perception of a good death is one that is painless, at home, and surrounded by loved ones, and also one that is in some ways anticipated. Such a death is managed, and thus must be predicted. Indeed, nowadays, death can often be anticipated long before it happens. This is partly a result of the fact that people are ill and interacting with medical professionals for longer periods before their deaths, but also partly a result of medical technology that can provide sophisticated diagnostic information.

Prognostication and Death

Prognostication is therefore another way for both physicians and patients to try to exercise some control over death. Predicting death is a way to counterbalance the sense of failure that arises when, despite the deployment of powerful technology in the care of the seriously ill, death cannot be prevented. If one cannot control whether death occurs, one can at least control, and thus anticipate, how and when it occurs. Patients and physicians alike believe that patients should have some general—albeit carefully circumscribed—awareness of death and its impending occurrence.

It is therefore not surprising that the technological forces arrayed to treat serious illness, in an effort to control death by postponing it, have in recent years come to be focused on controlling death by managing and predicting it. This development finds expression in the increasing technicalization of euthanasia (with attention, for example, to the pharmacology of inducing death as well as to protocols for the withdrawal of life support). It also finds expression in recent efforts to develop prognostic models of considerable sophistication, models themselves requiring technologies such as computers, statistical algorithms, and complex data acquisition system.⁹⁷ In other words, technological developments

in therapy are beginning to be mimicked by technological developments in prognostication, in part to justify the therapeutic technology that is being used in the first place.

Physicians use prognosis to manage death in another sense as well: they use it as a means to avoid being held responsible for the patient's death. Unanticipated or sudden death has always been problematic for those responsible for attending to the dying.⁹⁸ By configuring the patient's situation as one that leads inexorably to death—whether it is called a “terminal illness” or “dying state” or “fatal process”—the physician can avoid being held responsible for the death and can, simultaneously, get credit for having discerned the nature of the situation. As David Sudnow has observed:

The least comfortable circumstance of death, from the doctor's perspective, is when it occurs where there has been no predictive statement of its possibility in advance. Here the physician is in the situation of having possibly to confront accusations of his own incompetence. These accusations, in turn, may establish the conditions under which he, rather than a disease's inevitable, natural operation, can potentially be considered as material in the occurrence of the death.⁹⁹

Death must be made to be a consequence of *dying* (which itself is seen as an inevitably transitory status).¹⁰⁰ Without such an orderly transition and trajectory, death might be seen as unnatural or wrongly caused. From a professional point of view, sudden death is abhorred even if, from the patient's point of view, it has both advantages and disadvantages.¹⁰¹ Sudden death is deplored so much that unexpected deaths sometimes evoke historicizing by physicians, as when they are at pains to note that the patient “must have been ill for some time” or that “their body was too weak to fight this new disease”; histories may be retrospectively constructed to cast the death as more anticipated (or anticipatable) than it really was.

To predict death is a way to control it. Yet to engage in the business of predicting death is to further associate with it (and, as we shall see, possibly to be held responsible for causing it)—and this runs against several powerful forces within medical culture. Although the impetus to predict death is strong, equally strong are numerous reasons *not* to predict it, or to predict it in only the vaguest or most general ways. Nevertheless, death and prognosis are intertwined: each often involves the other.

A clinical situation involving prognostication about death is apt to be filled with unpleasant and intense emotions. These emotions arise as a result of both the obligation to prognosticate and the underlying

situation itself. Such a situation, moreover, highlights the limitations of medical knowledge in general and, perhaps worse, the limitations in the physician's knowledge and ability in particular. Physicians ideally would like to employ techniques to decrease the uncertainty of the future and the anxiety that it engenders. But paradoxically, as we shall see, foretelling the future is not necessarily more certain or reassuring than the future itself.

The act of foretelling the future represents in medicine—as it does elsewhere—an attempt to grasp an elusive future. In general terms, prognostication—whether implicit (usually) or explicit (rarely), and whether routine or serious—permits clinical work to take place. It motivates action because it obviates an epistemological and therapeutic paralysis that might arise from the great variability in a patient's expected subjective and objective experience of a disease. It forms the basis for the clinician to treat and for the patient to respond. It frames the illness episode by specifying its severity and its ordinary, permissible course. And, for the patient as well as the physician, prognostication is often a way to express (and partially to fulfill) fervent wishes for a favorable outcome and for a victory over death.

MAKING USE OF PROGNOSIS

A man came in to see me after having been fired from his job as a stockbroker. He had been working in that job—and had quite a brilliant career—for about twenty years at the same place. He was in his early 70s but he had been doing fine until about five months before, when his decisions became erratic and he began to lose a lot of money. But beyond just losing money, the people who worked with him saw immediately that there was a major change in his analytic ability. And they just fired him. They gave him a going-away party and they gave him a watch, and he was gone. So he came in to me kind of depressed. But I suspected that underlying the depression was a serious cognitive disorder, like Alzheimer’s disease, that had actually not yet manifested itself with his family or his day-to-day interactions. I ordered some cognitive testing by our neuropsychologists, and they agreed.

So there I was with this man who was depressed, who knew he had been fired, and who was feeling ashamed. And I said to him: “I don’t know how much time you’ve got, whether it’s six months or a year or two years, but in the time that’s left that your brain is working reasonably well, I want you to stop brooding over getting fired. That’s behind you. I want you now to apply yourself to your family, to your hobbies (he liked to dance), to all the things you enjoy doing—because I don’t know how much longer you’ve got to function.”

That was an instance where I used prognostication. I thought that was, in retrospect, the right thing to do. He actually had a little under a year of reasonably good functioning before his dementia became rapidly progressive. At this point he’s still living at home with his wife, but he requires caretakers around the clock and it’s not clear whether there’s much communication or how much longer he’ll live. That was a time when I used an estimate of the progression of the disease to influence my care of a patient.

— EXPERIENCED GENERAL INTERNIST

Effective prognostication serves many functions, but perhaps the most poignant is to empower patients to manage their lives more effectively. “How much longer do I have to live, doctor?” has become a cliché

in popular depictions of doctor-patient relations precisely because the question reflects such a central concern of patients. Having some sense of what to expect allows patients to make the most effective use of their emotional, fiscal, and temporal resources and to regain some sense of control over lives thrown into disarray by serious illness. The desire for accurate information on which to base personal decisions is pronounced in people who suffer from terminal illness. Indeed, one of the central attributes of a good death in contemporary society is a death in which the patient has had a chance to put his affairs in order and otherwise organize aspects of his terminal care.¹ Patients need prognostic information.

Physicians do as well. Most of the time, physicians' use of prognosis is latent and incidental. Sometimes, however, it is manifest and deliberate. Indeed, even though prognosis tends to be neglected and inexplicit, it is still a critical part of clinical care. Prognosis can inform a great deal of physicians' behavior, from therapeutic and diagnostic decision making to communication with patients. In general, physicians too like to have some sense of where they are heading.

Patients' Need for Prognostic Information

Circumstances where patients require prognostic information are common. Patients with Alzheimer's disease and their families want to know the likely course of cognitive decline and when to expect that specialized services might be needed; patients with rheumatoid arthritis want to know whether and when they might become severely disabled; patients with hypertension want to know their risk of having a stroke or a heart attack and whether treatment might be expected to modify that risk; patients with prostate cancer want to know what they might expect with watchful waiting as compared with surgery; patients about to undergo hip replacement want to know their likely postoperative course; patients with colon cancer want to know their chances of survival to a certain point in time; patients with diabetes want to know the likely interval of time until they go blind or require renal dialysis; patients with a genetic test suggestive of an increased risk of breast cancer want to know what to expect; and patients with terminal illness want to know when they should be referred for hospice care.

Getting prognostic information is often the highest priority for seriously ill patients, out of a desire both to know what is in store (to decrease uncertainty and its attendant anxiety) and to make practical decisions better. Indeed, getting prognostic information can eclipse interest in treatment options or diagnostic details, and it is the principal motivation

of patients undergoing testing for numerous conditions.² Prognostic information, moreover, is a key determinant of patient decision making, especially with respect to end-of-life care,³ and the inadequacy of this information is often the greatest complaint patients and their families have about the terminal care they receive.⁴ Physicians are aware that patients usually want prognostic information, and the great majority have experience with situations that are likely to require formulation, if not communication, of a serious prognosis—making decisions, for example, about withdrawing life support, admitting patients to intensive care units, or referring patients for hospice care. In an average year, general internists address the question “How long do I have to live?” a median of six times, intensive-care specialists twenty-five times, and oncologists one hundred times.⁵

Physicians identify a number of reasons that patients want prognostic information. One pediatrician noted:

Parents always want to know what the prognosis is. They obviously want you to tell them something good, but I think that they just want to know what to be prepared for. Is the mother going to need to quit her job and stay home and take care of the child full-time? Because that’s going to affect their income. That’s going to impact their life profoundly. I think that they want to see these things coming. I can’t think of any families that *don’t* want to know.

Another physician explained why he makes predictions in his practice:

If you deal with diabetes—which I do a lot—you see that for people who have the disease when it is newly diagnosed, prognosis is an extraordinarily important area to discuss. And I often will discuss this before I even do a physical examination! They want to know, for example, what’s the potential outlook for their vision, their circulation, or their kidneys, because they know based on public knowledge that diabetes has a dramatic impact in terms of all these issues. So the future and its predictability is a thing that comes up very early and in considerable “density” in the care of a patient.

Still another remarked:

I think that is one of the things that patients like to hear and know: something about the outcome of their disease processes. But I don’t think that doctors communicate prognostic information to their patients. I think a large majority of physicians do not—in part because I don’t think they communicate well with patients in general. I think a great number of them just go ahead and treat patients, and don’t discuss what the future will bring or don’t, for example, try to allay

their fears by assuring them that this is going to be a short-term incident in their life as opposed to a long-term incident in their life.

These physicians express many of the commonsensical reasons that patients want prognostic information, including their desire to plan their practical and financial affairs and their desire to know what will happen to them physically. They also imply, but do not explicitly state, that knowing the future is a way for patients to understand the meaning of their condition, a way to decrease their uncertainty, their anxiety, and their fear about the impact of the illness on their lives and their families. Patients usually want their condition to be given a name and a cause, want to know what can be done to ameliorate it, and want to know its outcome. They want to know the past, present, and future, and they want to know that they are scrutable to the doctor. Not surprisingly, when physicians give prognostic information to patients, patients are more satisfied with their care.⁶

Uses of Prognosis in Patient Care

Physicians use prognostication in their practice in a number of ways beyond answering patients' questions. Physicians use prognosis to serve clinical objectives (to affect their therapeutic or diagnostic management of the patient's condition), interactional objectives (to affect their relationship with the patient), and symbolic objectives (to imbue certain actions or events with meaning).

Clinical Uses of Prognosis

Prognosis is instrumental to decisions about whether and how to treat patients. Decisions about treatment depend upon (typically implicit) prognostic assessments regarding the likely outcome of the condition if it is left untreated or the outcome of the condition if it is treated with various alternative means. When a physician chooses to treat a patient at all, the physician implicitly presumes that the prognosis for the treated condition is more favorable than that for the untreated condition.

Similarly, a major determinant in choosing one form of therapy over another is the likelihood of its resulting in a preferable outcome. Implicitly, if not explicitly, a physician uses prognosis in making such decisions. This can occur at several levels. The most straightforward is when one treatment is predicted to yield a better outcome than another. However, prognosis can also inform therapeutic choice when a prediction serves to clarify what therapy a patient can actually receive.

Doctor: They do everything they can to make it as safe as possible.

Patient: Well, but that is almost like heart surgery.

Doctor: Yeah, it puts a big stress on you. I just wanted to make sure you had all the information you needed. Right now, you seem to be suggesting that you are not interested in having an operation.

Patient: No.

Doctor: If a doctor were to come to you and say that we think it is very, very important that it be operated on, would you reconsider that?

Patient: [Pause.] If you convinced me it was dangerous the way it is, I might.

Doctor: Yes.

Patient: But, I don't know. That is a pretty tough decision. There is a woman who lives near me, she has a heart aneurysm. They give her a 10 percent chance.

Doctor: Of living or dying?

Patient: Of pulling through the operation, of making it through.

Doctor: Yeah.

Patient: 10 percent—that is pretty low.

Doctor: 90 percent chance of dying.

Patient: Yeah, she turned them down.

Doctor: What if they told you there was a 20 percent chance of dying from the operation?

Patient: [Laughs.] Twenty percent chance, I don't know. It is pretty hard. There is always a chance every time they put you under for the operation, always a chance of not coming out of it, right?

Doctor: Oh, sure. All surgeries have risks. Anytime you go for surgery, the ideal situation should be that we are saying that your chances of dying from that aneurysm are greater than your chances of dying from the operation.

Patient: Yeah.

Doctor: Otherwise only a fool would go ahead.

Patient: Yeah.

This case again illustrates the use of prognosis to guide the decision to treat the condition or not. This patient is in a "gray area," diagnostically, therapeutically, and prognostically. How big is the aneurysm? Will it rupture? If they operate, what are the patient's chances of survival? At what level of probability would an operation be indicated? It all seems very unclear, yet prognosis is central to the therapeutic and diagnostic management of this patient's condition. The physician proposes to use a diagnostic test (ultrasound) to help guide the decision-making process

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