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LEGAL ISSUES IN MEDICINE

INFORMED CONSENT, CANCER, AND TRUTH IN PROGNOSIS

GEORGE J. ANNAS, J.D., M.P.H.

BARBARA TUCHMAN records that during the Black Death epidemic in the early 14th century, "doctors were admired, lawyers universally hated and mistrusted."¹ The great plagues and wars of the Middle Ages produced a "cult of death," including a vast popular literature that had death as its theme. As the 20th century closes, our emphasis is on the denial of death, and the honest discussion of death remains rare both in popular literature and in conversations between physicians and patients. This is one reason why Shana Alexander shocked a national conference of bioethicists last year by saying, "I trust my lawyer more than I trust my doctor." What she meant, she explained, was that she trusted her lawyer to tell her the truth about her alternatives and to execute faithfully the one she chose; she did not have this confidence in her physician, at least not if she were critically ill.

To the extent that Alexander's attitude is shared by Americans, it is an indictment, because nowhere in medicine is trust so necessary as in physician-patient conversations near death. The national survey conducted by Louis Harris for a presidential commission on bioethics in 1982 supports her view. It found that 96 percent of Americans wanted to be told if they had cancer, and 85 percent wanted a "realistic estimate" of how long they had to live if their type of cancer "usually leads to death in less than a year."² On the other hand, fewer than half the physicians surveyed said they would either give a "straight statistical prognosis" (13 percent) or "say that you can't tell how long [the patient] might live, but stress that in most cases people live no longer than a year" (28 percent) if the patient had a "fully confirmed diagnosis of lung cancer in an advanced stage."²

The country's most recent important case involving informed consent, *Arato v. Avedon*,³ centers on whether the law should require physicians to report statistical life-expectancy data to their patients in cases of illness that is likely to be terminal.

THE CASE OF MIKLOS ARATO

On July 21, 1980, Miklos Arato, a 43-year-old electrical contractor, was operated on to remove a non-functioning kidney. During surgery a tumor was found in the tail of his pancreas, and the tumor, along with the surrounding tissue and lymph nodes, was removed. Several days later, the surgeon met with Mr. Arato and his wife. He told them that he thought he had removed all of the tumor and referred them to an oncologist. The surgeon did not tell them that only

about 5 percent of patients with pancreatic cancer survive for five years or give Mr. Arato either a prognosis or a reasonable estimate of his life expectancy. The oncologist told the Aratos that there was a substantial chance of a recurrence, and that a recurrence would mean that the disease was incurable. He recommended experimental chemotherapy and radiation treatment, acknowledging that this might produce no benefit. The oncologist was not asked for and did not volunteer a prognosis.

While the chemotherapy and radiation treatment were continuing, on April 22, 1981, a recurrence was detected. Even though the physicians believed Mr. Arato's life expectancy could then be measured in months, they did not tell him so. Mr. Arato died on July 25, 1981, approximately one year after his cancer had been diagnosed. After his death, his wife and two adult children brought suit against the surgeons and oncologists, alleging that they had had an obligation, under California's informed-consent doctrine, to tell Mr. Arato, before asking him to consent to chemotherapy, that approximately 95 percent of people with pancreatic cancer die within five years.

THE PROCEEDINGS IN THE LOWER COURT

At trial it was shown that at the first meeting with his oncologist, Mr. Arato had filled out an 18-page questionnaire in which he answered "yes" to the question, "If you are seriously ill now or in the future, do you want to be told the truth about it?"³ The physicians who treated Mr. Arato justified their nondisclosure of the statistical prognosis on a variety of grounds, most based on traditional medical paternalism. His surgeon, for example, thought Mr. Arato had shown such great anxiety about his cancer that it was "medically inappropriate" to disclose specific mortality rates. The chief oncologist said he understood that patients like Mr. Arato "wanted to be told, but did not want a cold shower." He thought that reporting extremely high mortality rates might "deprive a patient of any hope of a cure," and that this was medically inadvisable. His physicians also said that during his 70 visits with them over a one-year period, Mr. Arato had avoided ever specifically asking about his own life expectancy and that this indicated that he did not want to know the information. In addition, all the physicians testified that the statistical life expectancy of a group of patients had little predictive value when applied to a particular patient.^{3,4}

Mrs. Arato argued that the statistical prognosis should have been disclosed because it indicated that even with successful treatment (the physicians measured success in terms of added months of survival), Mr. Arato would probably live only a short time. If Mr. Arato had known the facts, she believed, he would not have undergone the rigors of the experimental treatment, but would instead have chosen to live out his final days at peace with his wife and family and

would have made final arrangements for his business affairs. Mr. Arato had failed to order his financial affairs properly before his death, which had resulted in the eventual failure of his contracting business and substantial tax losses after his death.

On the basis of standard California jury instructions on informed-consent requirements, the jury returned a verdict in favor of the physicians. The Aratos appealed. A California court of appeals reversed the decision in a two-to-one opinion, stating that physicians were under an obligation to disclose statistics concerning life expectancy to patients so that they might take timely action to plan for their deaths, including the financial aspects of their deaths.⁴ The physicians then appealed.

THE CALIFORNIA SUPREME COURT

The California Supreme Court unanimously upheld the appeals court's decision. The justices began their analysis by reviewing their own most important previous cases related to informed consent: *Cobbs v. Grant*,⁵ *Truman v. Thomas*,⁶ and *Moore v. Regents of the University of California*.⁷ The court noted, as it had in *Cobbs*, that the doctrine of informed consent is "anchored" in four postulates:

- patients are generally ignorant of medicine;
- patients have a right to control their own body and thus to decide about medical treatment;
- to be effective, consent to treatment must be informed;
- patients are dependent upon their physicians for truthful information and must trust them (making the doctor-patient relationship a "fiduciary" or trust relationship rather than an arms-length business relationship).⁵

In *Truman*, a case about the refusal of a patient to have a Pap smear, the court decided that information had to be disclosed even if the patient refused treatment "so that patients might meaningfully exercise their right to make decisions about their own bodies."⁶ And in *Moore*, a case about creating an immortal cell line from a diseased spleen, the court held that the physician must disclose "personal interests unrelated to the patient's health, whether research or economic, that may affect the physician's personal judgment."⁷ Instead of taking the opportunity to resolve what the California Supreme Court described as a "critical standoff" in the development of the doctrine of informed consent between the extremes of absolute patient sovereignty and medical paternalism, the court focused on one very narrow question: whether California's standard instructions to juries should be revised to require the specific disclosure of a patient's life expectancy as predicted by mortality statistics.³

Framing the question so narrowly made answering it relatively easy. The court described the physician-patient relationship as "an intimate and irreducibly judgment-laden one" that had to be judged within "the overall medical context."³ As for statistics on

life expectancy, the court found them of little use to individual patients. The court thought, for example, that "statistical morbidity values derived from the experience of population groups are inherently unreliable and offer little assurance regarding the fate of the individual patient."³

Perhaps most important, the court described this case as one that was "fairly litigated" and properly put in the hands of "the venerable American jury," which had rendered a reasonable verdict that it was not prepared to second-guess.³ The court concluded:

Rather than mandate the disclosure of specific information as a matter of law, the better rule is to instruct the jury that a physician is under a legal duty to disclose to the patient all material information — that is, information which would be regarded as significant by a reasonable person in the patient's position when deciding to accept or reject a recommended medical procedure — needed to make an informed decision regarding a proposed treatment.³

The patient's desire to be told the truth, as evidenced by his answer on the questionnaire, was found to be irrelevant, since the physician has an independent legal duty to tell the "truth" (although a patient can waive the right to information). The court also dealt with the issue of expert testimony, noting that in addition to the information required to be disclosed by *Cobbs*⁵ (the nature and benefits of the proposed treatment, its risks of death or serious harm, reasonable alternatives and their risks, and problems of recuperation), physicians must also disclose any other information that another skilled practitioner would disclose. The court ruled that specific data on life expectancy fell within this standard. Thus, the defendant physicians were properly permitted to call expert medical witnesses to testify that it was not standard practice in the medical community in 1980 to disclose specific life-expectancy data.

PROGNOSIS AND SUCCESS

If the only issue is whether the law should require physicians always to disclose statistical life-expectancy data to critically ill patients as part of the informed-consent process, the conclusion of the court is defensible. But this is much too narrow a basis for the decision. Although by itself the statistical probability of survival for an individual patient may not be material, it is material if it indicates whether the patient is likely to survive and the probable quality of life with and without treatment. In other words, the issue of informed consent in this instance centers on the disclosure of the success rate of the proposed treatment in terms of both the prospects for long-term survival and the patient's quality of life. This is what patients need to know, and this is the type of material information patients have a right to — not only because it is the patient's body, but, more important, because it is the patient's life.⁸

It is unfortunate that the plaintiff did not argue the case on the grounds of the necessity to explain success rates, because the results could have (and

should have) been different. In *Cobbs*, which *Arato* affirms, the California Supreme Court had said:

A medical doctor, being the expert, appreciates the risks inherent in the procedure he is prescribing, the risks of a decision not to undergo the treatment, and the probability of a successful outcome of the treatment. . . . The weighing of these risks against the individual subjective fears and hopes of the patient is not an expert skill. Such evaluation and decision is a nonmedical judgment reserved to the patient alone.⁵

This language explicitly requires physicians to explain the probability that a proposed treatment will be successful and implicitly requires the physician to tell the patient what the physician means by "success."⁹ In this case, for example, the court seems correct in concluding that a statistical life-expectancy profile of all patients with pancreatic cancer, by itself, might not have been required to inform Mr. Arato of his prognosis properly. But such information is very valuable when coupled with an explanation of why the physician thinks the patient's case is or is not typical. Group data are the basis for predictions in individual cases—including both treatment recommendations and statements about probable risks and benefits. The physicians relied on group data, for example, to tell Mr. Arato that if his cancer recurred it would be "incurable." The court should have made it clearer that it is always material to a reasonable person to know both the probability of success of a proposed treatment and the meaning of success. Without this information, it is the physician, not the patient, who is making the treatment decision, and that is precisely what the doctrine of informed consent is designed to prevent.

CULTURE AND DEATH

A culture's general attitude toward death strongly influences what information about their prognosis will be provided to terminally ill patients. In the Middle Ages, for example, "when death was to be met any day around the corner, it might have been expected to become banal; instead it exerted a ghoulish fascination."¹ There was an emphasis on "worms and putrefaction and gruesome physical details"; instead of emphasizing a spiritual journey, the culture concentrated on the rotting of the body.¹ In our culture, with its unprecedented life expectancy, we tend to deny death altogether and celebrate new forms of medical technology designed to forestall death. In this context, it is not surprising that physicians often conceal prognostic information from their patients, just as most physicians once refused to use the word "cancer."⁹ But concealment of prognosis from patients near death makes them feel abandoned and makes physicians feel estranged.^{10,11} Candor toward the dying is an old problem, which Tolstoy described so well in "The Death of Ivan Ilych":

What tormented Ivan Ilych most was the deception, the lie . . . that he was not dying but was simply ill, and that he only need keep quiet and undergo treatment and then something very good would result.¹²

Ilych, a former prosecutor, also recognized that his physician's manner, which implied "if only you put yourself in our hands we will arrange everything—we know indubitably how it has to be done, always the same way for everybody alike," was "just the same air towards him as he himself put on towards an accused person."¹² Of course, the doctrine of informed consent is based on the recognition that people are not all the same and that physicians must let patients decide about treatment options so that they do not treat them "always the same way for everybody alike." In the treatment of cancer, the problem is especially acute because it is complicated by the financial conflicts of interest of oncologists. The chief beneficiaries of unproved cancer treatments are often the "appointment book of the oncologist" and "the pharmaceutical companies and their stockholders."¹³ It is also likely that there would be far less aggressive treatment at the end of life if patients were honestly informed of the "sheer futility" of such experimental interventions.¹³

After more than two decades of legal and ethical debate, neither the idea nor the ideal of informed consent governs the doctor-patient relationship.^{9-11,13} Jay Katz has properly noted that for conditions in which

prognosis is dire and fatal outcome a likely prospect . . . physicians should be guided by the strongest presumption in favor of disclosure and consent which can be modified only by clear and carefully documented evidence that patients do not wish to be fully informed.¹⁴

In affirming *Cobbs*, the court's decision in *Arato*, although very narrow, is consistent with Katz's vision and should be understood as an affirmation of information sharing and patient-centered decision making in the context of a physician-patient relationship based on trust.

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