When bioethicists from the United States call for recognition of the rights of patients, are they simply expressing their unique American adherence to individualism? The familiar charge of “ethical imperialism” is leveled against proposals that patients in other countries, where individualism is not a prominent value, should nevertheless be granted a similar right to informed consent. While it is true that the doctrine of informed consent focuses on the rights of individual patients, it is not rooted solely in the cultural value of individualism. Rather, it stems from a value many cultures recognize, especially those that aspire to democracy and a just social order: the notion that powerful agents, be they from governmental or nongovernmental organizations, may not invade the personal lives, and especially the bodies, of ordinary citizens.

The prominent American sociologist Renée Fox accurately describes the early focus of American bioethics: “From the outset, the conceptual framework of bioethics has accorded paramount status to the value-complex of individualism, underscoring the principles of individual rights, autonomy, self-determination, and their legal expression in the jurisprudential notion of privacy.” Critics of mainstream bioethics within the United States and abroad have complained about the narrow focus on autonomy and the concept of individual rights. Such critics argue that much – if not most – of the world embraces a value system that places the family, the community, or the society as a whole above that of the individual person. But we need to ask: What follows from value systems that accord the individual a lower priority than the group? It hardly follows that individual patients should not be granted a right to full participation in medical decisions. Nor does it follow that individual doctors need not be obligated to disclose information or obtain their patients’ voluntary, informed consent. It surely does not follow that the needs of society or the community for organs, bone marrow, or blood should permit those bodily parts or products to be taken from individuals without their permission. What might follow, however, is that patients’ families may be fuller participants in decision-making than the patient autonomy model ordinarily requires.

Perhaps we need to be reminded just why American bioethics began with such a vigorous defense of autonomy. It is because patients traditionally had few, if any, rights of self-determination: Doctors neither informed patients nor obtained their consent for treatment or for research. In a country founded on conceptions of liberty and freedom, it was at least odd that the self-determination Americans so highly prized in other areas of life was largely absent from the sphere of medical practice. An evolution took
place in the United States over a period of many years, from an early court ruling in 1914 that required surgeons to obtain the consent of patients through a series of informed consent cases in the 1950s and 1970s. By the time bioethics became an international field of study, paternalistic medicine had been largely transformed in the United States and patients’ rights had been solidly established. The same developments are occurring today in the many developing countries where bioethics has more recently become a topic of interest and study. Although most of these countries lack the tradition of individualism that marks North American culture, the legal guarantee of certain rights of the individual has in the past few decades been one of the goals of social and political reformers.

Cross-cultural misunderstandings can affect the way people in one country perceive a situation in another. Participating in a workshop in the Philippines, I encountered an example of a common cross-cultural misunderstanding about informed consent. The discussion focused on the ethical principle of respect for persons and its role in justifying the need to inform patients and obtain their permission to carry out therapeutic or research procedures. A Filipino physician in the audience objected that informed consent may be needed in the United States, where people do not trust their doctors, but, he said, in the Philippines patients place great trust in their physicians. Doctors do not need to protect themselves against lawsuits by having patients sign a consent form.

Throughout the world (and even at times in the United States), people confuse informed consent with the informed consent document. The Filipino physician misunderstood two things: first, the ethical basis for informed consent; and second, the difference between the process of informing and obtaining permission and the piece of paper (the documentation) attesting that the process took place. The ethical judgment that patients should be full participants in their treatment decisions is the ethical justification for the doctrine of informed consent. It is not the protection of the doctor, as the Filipino physician believed, that serves as an ethical basis for the practice. Although it is true that the number of medical malpractice lawsuits in the United States far exceeds that in other countries, especially in the developing world, that phenomenon bears little relation to whether patients lack trust in their doctors.

**“Physicians Treat Patients Badly”**

“Physicians treat patients badly” was a constant theme in virtually all of the developing countries I visited. Unfortunately, many of the shortcomings in the physician–patient relationship that are all too common in many countries continue to exist in the United States, as well. A major difference is that patients in this country are more aware of their legal and moral rights and are consequently more assertive. An Egyptian physician said that in Egypt there is no process by which consent is obtained in clinical practice. She complained that there is no physician–patient communication, in part because doctors do not have the time. Patients are not told about complications, about medical errors, or anything that transpires in the course of treatment. Patients can get no information whatsoever from doctors about their diagnosis, prognosis, or proposed treatment. Before surgical procedures, papers are signed. But those papers say nothing at all. Patients who ask questions are viewed by the doctors as “impolite,” and in any case doctors do not like to answer questions posed by patients.

This Egyptian physician did not seek to defend the customary practices of doctors in her country or to argue that they were reflections of cultural values in Egypt. On the contrary, she was attempting in her work to introduce reforms into medical practice in order to bring about better treatment of patients. When I asked what possible remedies there could be for all these ethical shortcomings, she replied by describing two broad strategies. The first is to document abuses — violations of patients’ rights, failures to obtain proper informed consent, and the like; the second is to mount a campaign by lobbying, bringing these issues before the public, and putting cases into court. I asked whether these steps are likely to be effective, and she replied that they can succeed in raising consciousness and awareness and further that people have received some compensation when their cases have reached the courts. Gathering cases and making them public can be used to mount campaigns. By this means reforms might be accomplished. The Egyptian physician’s criticism of practices in her own country and the specific reforms she sought to introduce show that, however different in other ways the culture of Egypt may be from that of Western nations, the ethical ideal that
requires physicians to treat their patients with respect is widely acknowledged, if not always honored.

A colleague in Mexico gave a similar account of the lack of recognition of patients’ rights in her country. One example was a story told to her by the doorman of her building. His wife was in labor and went to the public hospital. She remained in labor for 2 days, during which time neither the woman nor her husband were told anything about her condition. Eventually she gave birth and was discharged from the hospital while the baby had to remain there for a while longer. Still the couple was told nothing. My colleague expressed her outrage at this situation, blaming the doctors in public hospitals for their unwillingness to disclose information to patients, much less to obtain properly informed consent.

While I agreed that this was an outrage, I noted that things were not so very different years ago in the United States. It is a mere 40 years since the concept of informed consent to treatment was introduced into the legal domain and probably only about 25 years since the practice of obtaining informed consent took root. Still, my Mexican colleague insisted, there are cultural differences. As an example, she cited the pervasive corruption in Latin America as a difference between that region and the North. “What, no corruption in the United States or in Europe?” was my surprised reaction. Of course there is, but we have a much lower tolerance for official corruption, we make strenuous efforts to root it out, and we probably succeed more often in punishing instances that are discovered.

In India I heard more stories about how doctors treat patients badly. One physician described the efforts he and others have been making to inform and enlist the public in opposing unethical medical practices. He recounted a long list of horrors: incompetent doctors practicing poorly or negligently; untrained and unlicensed doctors practicing medicine; physicians overcharging patients; and more. The array of unethical behavior ranged from genuine malpractice to arrogance and indifference to patients. I asked about legal recourse, and here the situation is just as bleak. There exists a body called the Medical Council of India, which is supposed to be responsible for monitoring and dealing with the standard of care delivered by physicians. But this is a peer review system in which doctors protect other doctors. When cases of blatant malpractice are brought before this council, they fail to find the physician at fault. As a result, nothing is done to remedy instances of actual malpractice or the behavior of incompetent physicians. Patients can, in principle, bring suits against doctors. However, doctors win most of the cases brought to court in spite of their having committed actual malpractice, and judicial appeals take many years.

A different group of doctors repeated the same list of horror stories that I had heard from the first Indian physician, and more. When they mentioned the “kick-back” system, I naively though they were referring only to money paid to the referring doctor by the surgeon or specialist to whom the referral was made. But they meant much more by “kickbacks,” including demands by the referring doctor that the surgeon perform unnecessary procedures, charge the patient for them, and then give a percentage of the take to the referring doctor. Surgeons and other specialists who rely on referrals for their practice have to play the game or else they are not sent a single patient. Thus even doctors who begin by being ethical and idealistic end up getting caught up in a system in which they must play or fail to make a living.

All these accounts of bad behavior of physicians toward patients have little to do with cultural differences or with ethical relativism. They simply remind us that arrogance, corruption, greed, and indifference are universal character flaws that can be found in human beings throughout the world, wherever they live and whatever their profession. The chief difference between these countries and the United States lies not in a divergence in the cultural acceptance of such behavior by physicians but, rather, in the existence of laws and other forms of social control to root out and punish doctors who violate universally acknowledged ethical norms and standards of good clinical practice. The efforts of the Egyptian physician and the Indian doctors to bring about reforms in their countries are evidence of a widespread cross-cultural identification of the same ethical values that ought to govern the doctor–patient relationship everywhere. Respect for persons – in this case, individual patients – was the principle invoked implicitly or explicitly by people from Latin America, Asia, and North Africa in my visits to those regions.
Similarities and Differences

Even in those parts of the world where the cultural traditions differ radically from those in the West, certain values in the doctor–patient relationship are overarching. I participated in a meeting in Nigeria that included several non-English speaking tribal chiefs and native healers. One chief was asked for his views about helping a woman to have an abortion. (Abortion is illegal in Nigeria as in many other countries, but legal prohibitions have never succeeded anywhere in eliminating requests for or performance of the procedure.) Suppose a woman came to him, a traditional healer, asking for an abortion. What would he do? His reply was translated from his native tongue as follows: “If a client comes to me, as a professional, I will help the woman because I have the knowledge to do so.” He added, however, that “the community would not be happy.”

Here was a medical person – a traditional healer – referring to his “professional” obligation to his patient. He invoked precisely the same consideration most Western physicians would appeal to as a reason why they should help a woman to have an abortion despite the community’s disapproval of abortion. Although the cultures may differ in significant ways, the obligations of healers to those who come to them for help remain a cultural universal, one that exists in virtually all societies.

Not every customary practice is properly termed a tradition. Values inherent in a social institution such as medical practice may be a reflection of a value in the culture at large, or they may be specific to that particular institution. Lack of recognition and respect for the decision-making autonomy of patients has been a feature of Western medicine throughout most of history and even today remains prominent in other parts of the world. There is a difference, however, between the professional norm in which doctors decide for their patients and a cultural norm that gives family members complete control of another’s freedom of decision and action.

Similarly, not every set of norms deserves to be called a culture. Although phrases like “the culture of Western medicine” are tossed around, medicine is not a culture in the genuine sense of the term, as anthropologists define it. To refer to “the culture of medicine” is to speak metaphorically rather than anthropologically. As one commentator observes: “Used metaphorically, culture is everywhere these days. . . . Today the press is full of stories about the ‘culture’ of the Defense Department, the Central Intelligence Agency . . . , Congress . . . , and any large corporation that happens to be in the news. GQ even describes opera as being characterized by ‘the culture of booing.’”

Rural areas in many parts of the world still maintain many features of traditional culture in the true sense of the term. Women’s health advocates in Mexico reported that in some areas the husband or mother-in-law of a woman decides whether she may visit a physician or whether she may use a method of birth control. This behavior prevails today in rural areas and among indigenous groups and is sanctioned by certain beliefs and values regarding women. For example, women are believed incapable of making their own decisions; or, even if they are capable, they must remain subordinate to men; or the role of women is to reproduce and therefore they should not be permitted to choose to control their own fertility. Control by husbands and mothers-in-law of a woman’s fertility is based on the traditional culture and has little to do with the social institution of medicine. Although these sorts of beliefs and values have deep cultural roots they, too, may change over time, as women’s health advocates work at the grassroots level and expose women in rural and indigenous communities to the ideas of the global women’s movement. Defenders of traditional culture condemn these activists in Mexico and elsewhere as intrusive purveyors of Western feminism who seek to destroy traditional cultural values.

Interestingly, some women’s health advocates worry about the effect of introducing values such as autonomy and independence to the women they work with. One social scientist used the example of women with whom they work in a traditional Mexican setting. These women have to ask permission from their mothers-in-law to visit a physician. A mother-in-law may question that decision or refuse to grant permission. The woman then asks the researcher for help. This poses a problem for the researcher: Can the researcher provide some assistance without causing the research subject further psychological damage or harm to her interests? The woman might actually be expelled.
from her home if the mother-in-law finds out she has gone to a physician without her permission.

While it is no doubt true that some customary practices are rooted in cultural traditions, others may simply have been passed down from one generation to the next as ways of behaving that no one questioned or sought to change. The medical profession has a long history of customary practices, but few qualify as “cultural” traditions. The custom of physicians withholding information from patients and talking, instead, to family members is probably a good example. Everyone from Western anthropologists to physicians in non-Western cultures remark on the difference between the nature of communications between doctors and patients in North America and other parts of the world as if this represents a deep-seated difference in cultural traditions. These commentators probably do not realize, or may have forgotten, that it is only a few decades since physicians in the United States began disclosing diagnoses of fatal illnesses directly to patients. One may call these norms of truth-telling a “tradition,” but that would be to distort the more prevalent meaning of “tradition.” That meaning is related to the concerns of the ethical relativist – that different societies have distinct and possibly incommensurate ethical values stemming from their cultural diversity.

One commentator suggests that cross-cultural differences in the physician-patient relationship are attributable to different systems of biomedical ethics. Diego Gracia, a professor of public health and history of science in Spain, distinguishes between Mediterranean biomedical ethics and the Anglo-American variety. Gracia notes that patients in Southern European nations are generally less concerned with matters related to informed consent and respect for autonomy than with trust in their physician. Mediterranean bioethics emphasizes virtues rather than rights. Accordingly, the virtue of trustworthiness is more crucial to patients than the right to information.7

But Gracia also points to a recent trend in Mediterranean countries, a trend that once again shows the evolution of the physician-patient relationship and the introduction of new ethical values. Gracia notes that, in all Mediterranean countries, respect for patients’ autonomy and the right of patients to participate in medical decisions have grown extensively in the last decades. Coming some decades after the patients’ rights movement began in the United States, this new trend in the Mediterranean countries also includes complaints about health care workers’ failure to provide information and for nonconsensual touching.

This phenomenon is one of historical evolution of the doctor-patient relationship rather than a cross-cultural difference between individualistic American culture and the more communitarian or virtue-based value systems in other countries. If the “culture” of medicine has evolved in this way first in the United States and shortly thereafter in some European countries, it is reasonable to suppose that the wider culture – society as a whole – may undergo other changes. No country today is so isolated from the rest of the world that it can remain aloof from and immune to cross-cultural influences.

Conceptions of Autonomy: East and West

A Japanese physician, Noritoshi Tanida, describes sharp differences between features of Japanese and Western culture related to the role of the individual.8 Tanida says that tradition has left little room for the individual or for individualism in Japan; yet he acknowledges that, since the opening of Japan to the West about 130 years ago, Western individualism was introduced into the country. Nevertheless, most Japanese are much less individualistic than are Westerners, a feature that is evident in the decision-making process. In general, Tanida notes, there is no open discussion or clear responsibility, but rather a process of mutual dependency. As a result, the person most affected by a decision may not be informed of what is happening and is not always a part of the decision-making process. The clearest example of this, Tanida holds, is concealing the truth from cancer patients in the practice of clinical medicine.

Another East Asian, Ruiping Fan, puts forth an even stronger view of the difference between East and West with regard to the individual’s role in medical decision-making.9 Fan argues that the Western concept of autonomy, which demands self-determination on the part of the individual, is incommensurable with the East Asian principle of autonomy, which requires family determination. In contending that
these two notions of autonomy are incommensurable, Fan insists that there is no shared abstract content between the Western and Eastern principles of autonomy; the two are separate and distinct.

One conclusion that can be drawn from the contrast between East and West is that there simply is no universal ethic regarding disclosure of information, informed consent, and decision-making in medical practice. Not only do these practices differ as a matter of fact in different societies, but they are incompatible. This conclusion is obviously true for the descriptive thesis of ethical relativism: Truth-telling, informed consent, and decision-making about medical treatment vary in different cultures. Furthermore, if we accept Fan’s account, a conceptual variation exists as well; autonomy means something different in East Asia from what it signifies in the West.

The East Asian principle of autonomy holds that “Every agent should be able to make his or her decisions and actions harmoniously in cooperation with other relevant persons.” Thus, when patients and family are in harmony, they decide together. That situation probably prevails most of the time in Western medical practice as well. However, it is the family who has the final authority to make clinical decisions in accordance with the East Asian principle. According to Ruiping Fan, if a patient requests or refuses a treatment while a relevant family member disagrees with that decision, the doctor should not simply follow the patient’s wish but should urge the patient and the family to negotiate and come to an agreement before the physician will act. It is the family that constitutes the autonomous social unit, and the physician may not act contrary to their decision.

This example of cultural diversity raises the enduring question of normative ethical relativism: Has Western bioethics arrived at the ethically right position with regard to respecting the individual autonomy of the patient? Is the practice in other cultures of deferring to the patient’s family, or leaving the decision in the hands of the physician, right in those cultures although it would be wrong in the United States?

The emphasis on autonomy, at least in the early days of bioethics in the United States, was never intended to cut patients off from their families by insisting on an obsessive focus on the patient. Rather, it was intended to counteract the predominant mode of paternalism on the part of the medical profession. In fact, there was little discussion of where the family entered in and no presumption that a family-centered approach to sick patients was somehow a violation of the patient’s autonomy. Most patients want and need the support of their families whether or not they seek to be autonomous agents regarding their own care. Respect for autonomy is perfectly consistent with recognition of the important role that families play when a loved one is ill. Autonomy has fallen into such disfavor among some ethicists in the United States that the pendulum has begun to swing in the direction of families, with urgings to “take families seriously” and even to consider the interests of family members equal to those of the competent patient.

Fan says that some people may deny that what he refers to as the “East Asian principle of autonomy” can even be characterized as a principle of autonomy. He nevertheless defends his use of the term, noting that the word for autonomy in the Chinese language is never used not only for individuals, but also for units like a family or a community. The same is true in the English language: In its political sense, autonomy means “self-rule” and can therefore apply to communities, countries, and, as in Mexico, universities.

Fan demonstrates that the East Asian principle of autonomy has significant implications for truth-telling, informed consent, and advance directives in the East Asian clinical setting. If a physician directly informs a patient about a diagnosis of a terminal disease instead of first telling a member of the family, that would be extremely rude and inappropriate. Interestingly, however, while East Asian custom allows the family to choose a treatment on behalf of a competent patient, the family may not readily refuse a treatment on behalf of a competent patient. This is evidently because of the underlying assumption that a treatment recommended by a physician will be beneficial to the patient, whereas it is at least questionable whether a withholding or withdrawing of treatment is in the interests of a competent patient.

So when it comes to actually making medical decisions, who should decide? Should it be patients themselves in the West, in accordance with the principle of autonomy as “self-determination,” and families of patients in the East, in accordance with the “family-determination-oriented” principle? There is little
doubt at this point that in the United States the patient with decisional capacity holds the moral and legal right to decide, with very rare exceptions. Those exceptions include some cases in which a pregnant woman’s refusal of an intervention is deemed harmful to the life or health of the fetus (forced cesarean sections are the clearest example of this) and the situation in which physicians judge a treatment to be “medically futile” and take the decision-making out of the patient’s hands. But these exceptions are contested by those who contend that pregnant women should have all the rights of other competent patients and that a physician’s assessment that a treatment is “medically futile” should not replace the patient’s wish for the treatment, which may have psychological value.

So we are left with ethical relativism. As Ruiping Fan puts it: “Which principle is more true: the Western principle of autonomy or the East Asian principle of autonomy? Who should give up their own principle and turn to the principle held by the other side?” Fan’s own solution is to adopt the procedural principle of freedom, allowing both Western and East Asian people to follow their respective and incommensurable principles of autonomy. Interestingly, Fan’s solution appeals to a higher principle, that of freedom or liberty. He acknowledges as much and articulates the principle of freedom commonly associated with Western philosophical and political thought: “Every group of people as well as every single individual has freedom to act as they see appropriate, insofar as their action does not harm other people.” That sounds remarkably like something John Stuart Mill might have written.

Application of this principle appears to grant to an individual patient the right to reject the cultural custom of family autonomy in favor of individual decision-making. But would it really? If East Asian patients insisted on their freedom to act as they deem appropriate, doing so might damage family harmony, so perhaps other people would be harmed after all. Ruiping Fan does not raise the explicit question of what individual patients or physicians might do, but refers only to “Western and East Asian people” being free to follow their respective principles of autonomy. It leaves ambiguous the status of the individual patient in East Asia and possibly also the role of a family in the West that seeks to follow the family-determination notion of autonomy.

Is this a relativist solution? Fan says no, it is not to surrender to ethical relativism, “but to secure the most reasonable in a peaceful way in this pluralist world.” This reply embraces tolerance and is a practical accommodation to cross-cultural diversity. If not a surrender to relativism, how can we characterize Fan’s position? Fan himself describes this type of thought as a “transcendental argument for a contentless principle that ought to be employed in a secular pluralist society.” This merely replaces the puzzling with the obscure. Philosophy should seek to explain and clarify, not to obfuscate and muddy. We have to do better.

Truth-Telling

In the Western world the custom of withholding information from patients goes back at least as far as Hippocrates. Hippocrates admonished physicians to perform their duties

 calibratedly and adroitly, concealing most things from the patient while you are attending to him. Give necessary orders with cheerfulness and sincerity, turning his attention away from what is being done to him; sometimes reprove sharply and emphatically, and sometimes comfort with solicitude and attention, revealing nothing of the patient’s future or present condition.”

Does this ancient practice represent a tradition of some cultural group? If so, which one? Ancient Greek tradition, carried down through the Greco-Roman empire? That would not have been a likely influence on Asian medical practice. If it is part of any “culture” at all, it is that of the medical profession (speaking metaphorically), renowned throughout the ages for its paternalism. Medical paternalism remains the rule rather than the exception in Asia and Latin America, and it persists to a somewhat lesser extent in some parts of Western Europe, as well.

The shift in attitude toward disclosing the diagnosis to cancer patients began to occur in the United States in the late 1960s, a millennial moment since the time of Hippocrates. Although often portrayed as a cultural tradition, one in which many countries diverge from the preeminence accorded to the individual in the United States, nondisclosure by physicians to patients
Doctor–Patient Relationship in Different Cultures

appears rather to have been a nearly universal customary practice dictated by medical professionals throughout the world.

But things change. Attitudes and practices of physicians in the United States have undergone a striking reversal in the past three decades. A study conducted in 1961 revealed that 90% of physicians did not inform their patients of the diagnosis of cancer.\(^\text{18}\) When that study was redone in 1977, it revealed that 98% of doctors usually informed patients of the diagnosis of cancer.\(^\text{19}\) It is entirely possible that such changes will begin to occur in other countries as well. Evidence suggests that this has already begun to happen.

These changes do not require us to impugn the motives of physicians who have thought it best not to tell patients they have cancer, nor is it to condemn the benevolence that undergirds medical paternalism in general. Now, as in the past, most justifications for withholding information from patients have rested implicitly or explicitly on an appeal to the principle of beneficence. If the behavior of doctors in the United States has changed in the past three decades or so, it is not because the principle of beneficence no longer serves as a justification or that physicians no longer act from benevolent motives. It is simply that the competing ethical principle of respect for autonomy has taken priority over the principle of beneficence in motivating and justifying physicians’ behavior. Once it became evident that patients wished to know their diagnoses (or already knew they had cancer in spite of families and physicians conspiring to keep the news from them), and once physicians came to realize that disclosing a diagnosis of cancer did not typically cast the patient into a deep depression and very rarely, if ever, led to documented cases of patients committing suicide, then benevolent paternalism could no longer be sustained on ethical grounds.

From the earliest moments of modern bioethics, some people worried about the alleged requirement always to “tell the truth.” In response to the claim that patients have “a right to know” their diagnosis and prognosis, challengers replied: what about “the right not to know?” Of course, there is no inconsistency here. People have a right to receive information, if they want it, and also the right to refuse to receive that information. That is precisely what “respect for persons” supports: respect for the wishes and values of the individual patient.

This is the point at which the philosophical distinction between ultimate moral principles and specific rules of conduct becomes critical. “Respect for persons” is a fundamental, or ultimate, ethical principle. The imperative “tell patients the truth about their condition” is a specific rule of conduct. Moreover, respecting a particular patient’s wish not to know is perfectly consistent with the general obligation to disclose to patients their diagnosis. This also demonstrates the distinction between ethical universals and moral absolutes. “Always tell patients the truth about their condition” would be the moral absolute in this case, clearly a different imperative from one that mandates respect for the wishes of patients.

On this analysis, the answer to the question of how the case of truth telling to patients fits into the debates over ethical relativism is simple (relatively speaking). No universal ethical mandate exists to tell patients the truth about their terminal illness. Nor is it the case that telling the patients the truth is right in some countries or cultures and wrong in others. Moreover, to contend that the principle of autonomy mandates disclosure misinterprets how that ethical principle should be applied. Respect for autonomy means, among other things, acting in a way that respects the values of individuals. Individuals’ values often mirror the predominant values of their country or culture, but they do not always do so. When they do, we must be sensitive to those values and respectful of the people who hold them.

A lingering problem, however, is that doctors often do not know or do not take the time or trouble to find out the patient’s values. They take the family’s word for whether the patient “can handle” the information. Or they simply honor the family’s wish not to tell the patient. Here is where the practice in the United States is most likely to diverge from that in other countries. Because respect for the patient’s autonomy has become entrenched in American medical practice, most physicians will probably not automatically comply with the family’s wish not to reveal a diagnosis of cancer or other fatal or terminal illness.

It is clear from published reports in the medical and bioethical literature that doctors in other countries do readily honor a family’s request not to tell the patient a diagnosis of cancer or other terminal illness. I believe that behavior is as much a reflection of the still dominant...
paternalism of physicians as it is an expression of a cultural value. When respect for autonomy is not recognized as an ethical principle in medical practice, physicians see no need to find out whether a patient wants to know the diagnosis of cancer or terminal illness. Medicine has always been paternalistic and hierarchical. In some ways, the culture of medicine remains paternalistic in the United States, as anyone can attest who has heard physicians urge the omission of “scary” items from consent forms.

A medical oncologist from Italy, who had practiced for a while in the United States, reported what she had learned in medical school. The Italian Deontology Code, written by the Italian Medical Association, included the following statement: “A serious or lethal prognosis can be hidden from the patient, but not from the family.” That was in the late 1970s. The Deontology Code was revised in 1989, with this statement: “The physician has the duty to provide the patient – according to his cultural level and abilities to understand – the most serene information about the diagnosis, the prognosis and the therapeutic perspectives and their consequences....Each question asked by the patient has to be accepted and answered clearly.” The code goes on to grant to physicians the well-known “therapeutic privilege” of withholding information if disclosure would be harmful to the patient, and in that case the information must be communicated to the family. But the revised code still represents a sharp reversal from the presumption of nondisclosure in the code of a mere decade earlier.

The Italian oncologist who wrote about this shift stated her belief that ethics is connected to cultural values and varies in different societies. She rejected a belief in “absolute values” in favor of respecting the pluralism of different cultures. This was by way of background to her contention that “the Italian society is not prepared for the American way.” She explained further, saying that even today Italians believe that patients will never acquire enough knowledge to enable them to understand what physicians tell them and therefore to participate in their own care. Italians still believe that protecting an ill family member from painful information prevents the sick person from suffering alone, from isolation, and is essential for keeping the family together.

Is it reasonable to expect that these attitudes will gradually be transformed, just as similar attitudes were in the United States several decades ago? The Italian oncologist waffled a bit on this point. On the one hand, she stated her belief that “Italians should not borrow the American way.” On the other hand, she urged Italians to learn from Americans and “try to find a better Italian way.” As examples of changes taking place within the medical profession, she noted courses in bioethics in universities and medical meetings on truth-telling and communicating with patients. In the end, she reached the conclusion that “the only way to respect both Italian ethical principles and the patient’s autonomy and dignity is to let the patient know that there are no barriers to communication and to the truth.” What is most peculiar is the reference to “Italian ethical principles.” Withholding information from patients is not a function of ethnic traditions but rather of how the medical profession has historically conducted its practice in most places in the world. It is also a class phenomenon, since doctors are typically better educated than most of their patients and question the ability of patients to fully understand what they have been told.

A mere 5 years after its 1989 revision, the Italian code of medical ethics was revised once again. The revision reflected the “constantly changing relationship between the medical profession and society, and between physicians and patients.” In the newly revised code, the “Italian way” has come very close to the “American way.” Article three of the new code adds to the physician’s obligation expressed in the 1989 code “to respect the dignity of the human being” the additional obligation to respect the patient’s freedom of choice. Article four of the new code adds the physician’s obligation to respect the rights of the individual, and extensive revisions of the doctrine of informed consent are in conformity with other modern codes of ethics. The code mandates respect for the decisional autonomy of the patient, even in cases in which the life of the patient is threatened.

Equally striking are revisions on the topic of confidentiality. Whereas the earlier Italian code permitted doctors to conceal the truth from the patient and disclose it to the next of kin, the new code essentially prohibits nondisclosure to the patient and disclosure to a third party. Two exceptions to this rule are, first,
when the patient specifically authorizes disclosure to others and, second, when there is potential for harm to a third party. It would be absurd to conclude that “Italian ethical principles” have changed in this brief interlude between the 1989 code and the more recent revisions. Instead, as the authors of an article describing the new code observe, “from a paternalistic attitude in which the physician, for the good of the patient, felt authorised and justified to set aside the personal requests of the patient and even to violate his wishes, a therapeutic alliance has evolved, in which the two partners together try to decide on the clinical choices that best promote the patient’s wellbeing.”

Changes are also occurring in Asia, a region of the world often cited as adhering to family and group values almost to the exclusion of recognizing the importance of the individual. A Japanese physician observes that the concept of informed consent has recently been recognized in his country, yet he acknowledges that most Japanese physicians withhold information about diagnosis and prognosis from their patients who have cancer. It is reasonable to wonder whether “informed consent” means the same thing in Japan as it does in the West. One report notes that the Bioethics Council of the Japanese Medical Association introduced the idea of “Japanese informed consent,” which was to be carried out in accordance with the prevailing medical paternalism in that country. A survey in Japan showed that 67% of physicians would disclose the diagnosis to patients with early cancer, but only 16% would tell those with advanced cancer. Studies from other countries show that many patients do want to be informed of a diagnosis of cancer, but a discrepancy exists between patients’ preferences and physicians’ attitudes.

A physician speaking at an international conference about truth-telling in Japanese medicine described a number of cultural features that help to explain physicians’ reluctance to disclose a bad prognosis. That reluctance stems from patients’ unwillingness to receive such information, which in turn is based on deeper cultural roots. Patients want to have an “edited” version of the truth. They enter a tacit conspiracy with their family and the physician to avoid a difficult subject. This results in the family taking over all responsibility and decisions for the patient’s illness. Although many patients will guess and come to know the truth eventually, they still will not ask directly. This behavior is rooted in the Japanese ethos in which silent endurance is a virtue. The aim is to make dying easier, not to invoke a dogma of telling patients the truth. Patients want to die as calmly and peacefully as possible, and that goal is more readily achieved if they remain ignorant of their prognosis. Relatives assume the burden of making an intuitive judgment of whether the patient wants to know the diagnosis and can handle it. Not to accept one’s death gallantly is worse than death itself. Physicians, patients, and families all want to avoid a “disgraceful upset” that conveying bad news could produce. The physician who explained all this echoed what others discussing medicine in Japan have said: Despite powerful influences from Western countries, Japan is not totally Westernized, yet the Japanese do not want to stick to their old traditions completely. The physician ended by saying that the Japanese people must achieve a new type of death education, with more ethical emphasis, closer to the Western style of dealing with death.

But let us assume that a cultural gap does exist between North American practices of disclosing bad news to patients and different customs in other parts of the world. What should we conclude about whether one cultural practice is “right” and the other “wrong”? How does this example fit into the debates over ethical relativism?

The answer depends entirely on how the question is framed and how the situation is described. Consider the following alternative descriptions.

1 Doctors and patients in the United States believe that patients should be told the truth about a diagnosis of terminal illness. Doctors and patients in other countries believe that doctors should tell the family but not the patient. The ethical principle of “respect for autonomy” mandates that doctors treat patients as autonomous individuals and so must inform them about their illness. The truth-telling practice in the United States conforms to this principle and is ethically right, whereas the nondisclosure practice in other countries violates this practice and is ethically wrong.

2 Autonomy is the predominant value in North American culture. Doctors and patients in the United States adhere to an autonomy model of disclosure in medical practice. Family-centered values
are more prominent than individual autonomy in other cultures. Doctors and patients in these cultures adhere to a family-centered practice of disclosure of terminal illness. Therefore, it is right to disclose to a patient a diagnosis of terminal cancer in the United States and wrong to make that same disclosure in the other countries.

3 Autonomy is the predominant value in North American culture, but disclosure of terminal illness by doctors to patients is nevertheless a fairly recent practice. The US population comprises many recent immigrants, and some cultural groups adhere to family-centered values from their country of origin, especially in specific matters such as disclosure of terminal illness. Family-centered values predominate in other countries, but practices such as disclosure of a diagnosis of terminal illness have begun to change in those places. “Respect for persons” requires that in any country or culture, doctors should discuss with their patients whether they want to receive information and make decisions about their medical care or whether they want the physician to discuss these matters only with the family.

The third description is obviously the “right” answer. What is wrong with the other two descriptions shows what is frequently amiss in debates over ethical relativism. Description 1 has two main flaws. The first is the common failing of distorting or misusing the principle of respect for autonomy. The principle does not require inflicting unwanted information on people; rather, it requires first finding out how much and what kind of information they want to know and then respecting that expressed wish. When the principle of autonomy is interpreted in that way, nothing automatically follows regarding whether patients should be told the truth about their diagnosis. The second flaw is the assumption that all people in a country or culture have the same attitudes and beliefs toward the values that predominate in that culture. In a Los Angeles study of senior citizens’ attitudes toward disclosure of terminal illness, in no ethnic group did 100% of its members favor disclosure or nondisclosure to the patient. Forty-seven percent of Korean-Americans believed that a patient with metastatic cancer should be told the truth about the diagnosis, 65% of Mexican-Americans held that belief, 87% of European-Americans believed patients should be told the truth, and 89% of African-Americans held that belief. If physicians automatically withheld the diagnosis from Korean-Americans because the majority of people in that ethnic group did not want to be told, they would be making a mistake almost 50% of the time.

Description 2 is flawed for one of the same reasons that description 1 is flawed: It presupposes that all people in a country or culture have the same attitudes and beliefs toward the values that predominate in that culture. That assumption is clearly false, as the Los Angeles study just cited demonstrates. In a multicultural society such as the United States, ethical relativism poses an array of problems not likely to arise in countries that enjoy a common cultural heritage (if any such countries still remain). “Multiculturalism is good,” its proponents contend. Whether or not that is true, it surely causes difficulties for doctors and patients.

Notes

2 The workshop, part of my Ford Foundation project, took place in Davao, Mindanao, in December 1995.
3 This interview took place in February 1996 during my second Ford Foundation project.
4 This interview took place in April 1994 in Bombay.
6 This meeting took place during my Ford Foundation visit to Mexico in February 1993.
10 Fan, p. 316.


13 Fan, p. 322.

14 Fan, p. 322.


21 Surbone, p. 1661.

22 Surbone, p. 1662.


26 Fineschi, Turillazzi, and Cateni, p. 241.


28 Tanida, p. 208.

29 Asai, p. 36.

