

Language and Reality at the End of Life

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To find adequate answers to a changing reality heavily influenced by advances in technology, medical professionals have developed and adopted an array of terms that have brought new concepts into the profession. “Dignity,” “vegetative state,” “futility,” “double effect,” and “brain death” have become indispensable words in the medical setting. In the following discussion, the attention is on terminology. If we believe in phenomenology, the assumption is that we should closely reflect on the words we use in all spheres of life, especially in those that concern life and death. This article calls for a sincere discussion about these terms and concepts. The thesis put forward is that the language in the medical setting serves primarily the physicians, at times at the expense of the patients’ best interests. This language and the concepts it describes have generated an unhealthy atmosphere for patients, which might lead to undesirable actions at the end of patients’ lives.

Preliminaries

People are social beings. We communicate with one another, converse, exchange ideas and different points of view via language and signs. Language constructs, affects, and changes reality; facilitates communication; promotes understanding; and helps to erect bridges between cultures.

Every profession has its concepts, phrases, and keywords that are important to help categorize phenomena, save time, and provide a framework for working together. Medicine is no exception. Here, too, we find some important concepts and terms that deserve probing and analysis. In response to the changing reality—a reality that is heavily influenced by technological advances—medical profession-

als have adopted concepts like “dignity” and “double effect,” as well as new terminology, to handle new challenges to the profession. Terms like “futility,” “vegetative state,” and “brain death” have become indispensable in the medical setting. The question is whether these concepts and terms are designed chiefly to serve the physicians or the patients. My thesis is that they serve primarily the physicians, often at the expense of patients’ best interests. Indeed, such language can be offensive and degrading, even harmful, to patients.

In the field of medical ethics, some of the concepts and terms convey a clear meaning. Thus, when they are used by a speaker or writer, they convey that person’s point of view. For instance, if a person declares his association with the “pro-life” movement, it is clear that he is, generally speaking, against the practice of abortion. Conversely, if someone associates herself with the “pro-choice” movement, it is clear that this person is, generally speaking, in favor of a woman’s right to choose the fate of her pregnancy.

Similarly with the end-of-life debate, we find many phrases that have a clear meaning. “Life has intrinsic value,” “sanctity of life,” “doctors as hangmen,” “doctors playing God”: People who use these terms would surely be opposed to active euthanasia. Other terms often used are “persistent vegetative state” and “brain death.” Over time, these terms began to represent a particular point of view. People who use them would most probably argue that it is pointless (“futile”) to maintain life-sustaining treatment for such patients.

Some of the terms used by ethicists are not clear, however, and careful reading is needed before making up one’s mind as to the intentions of the speaker or writer. These terms might be used by advocates of opposite points of view, each justifying his or her position by resorting to the same language. For instance, one who speaks of “double effect” or “death with dignity” might be an advocate of

active euthanasia, mercy killings, and physician-assisted suicide, or might side with those who are against these practices.

Finally, some of the terms used by ethicists might be transient, i.e., once they had a dubious meaning, but increasingly became loaded, and today are associated with one school of thought. This is the case with “quality of life.” In the past, the term was used by ethicists holding viewpoints across the spectrum of ideas, but increasingly became associated with active euthanasia advocates,¹ and now contrasts with the notion of “sanctity of life.”²

Because phenomenology is important—language does play a critical role in the shaping and reshaping of our existence—we must reflect on the language people use to describe their experiences, especially those concerning life and death. Let me start by canvassing the concept of dignity.

“Death with dignity”

Death with dignity is one of the most complicated and fascinating subjects in medical ethics. The term “dignity” is derived from the Latin noun *dignitas*, which means: (a) worthiness, merit; (b) greatness, authority; and (c) value, excellence. The noun is cognate with the adjective *dignus* (worthy), from the Sanskrit root *dic* and the Greek root *deik*, which have the sense of “bringing to light,” “showing,” or “pointing out.”³

When using the phrase “death with dignity,” liberals refer to both (1) the timing of death (e.g., people should be allowed, whenever possible, to choose the time of their departure); and (2) the way people die (e.g., with the help of medical professionals, people should be able to control the process of dying—maintain autonomy until the end of life, not be humiliated, perceive themselves with honor). The concept of dignity refers to a worth or value that flows from an inner source. It does not come from the outside but rather is intrinsic to the bearer. As Ulrich notes, a painting may have value, but it does not have dignity. The value is placed upon it by members of the artistic community in light of the skill of the artist and the aesthetic priorities of the community. The value does not derive from the painting itself. Persons, on the other hand, can be said to possess dignity as an inner source of worth. If this were not the case, they would simply be the bearers of instrumental value like all other objects in the world. Instead, human beings are set apart and treated in special ways.⁴

Unlike Leon Kass, I do not conceive of dignity as an aristocratic term of distinction.⁵ We all have a right to dignity. Dignity must be accorded to every person from birth—some say from the moment of conception. We are both endowed with dignity and have the right to be treated with dignity. Furthermore, dignity involves not only *objective* but also *subjective* notions. It is the source from which human rights are derived. It refers also to one’s own feelings about oneself.⁶ To have dignity means to look at oneself

with self-respect, with some sort of satisfaction. It means to feel human, not degraded. By a subjective concept of the self, I mean how a person conceives of her life, her achievements, and her place in the world. The subjective evaluation is affected by the individual’s self-respect, relative to the abilities she believes she possesses, and relative to her peers and surroundings. For example, an independent, active, and energetic person with desires and ambitions, who becomes in her own eyes dependent on others, who reaches the conclusion that her life has become a burden to herself and the people she loves, might lose her sense of humanity as well as her self-respect. This might lead her to lose interest in life and to choose death.⁷

More specifically and with reference to the role of physicians, preserving dignity means helping patients to feel valuable. The physical move from the familiarity of the home to the estranged hospital entails the transformation of a “person” to a “patient.” Sometimes, the patient is even reduced to a mere “case,” stripped of personality, representing an interesting disease to be studied, a valuable tool for advancing physicians’ research.⁸ This shift from a person to a patient to a case betrays human dignity. The preservation of dignity involves listening to the patients’ complaints; helping patients cure their diseases, or at least assisting them in the control of their pain; responding to their distress and anxieties, making an effort to relieve them; demonstrating sensitivity to the physical indignities that occur with severe illnesses; making patients feel like human beings and not infants, case studies, or—worse—bodies that occupy beds and consume resources. Patients can feel that their self-respect is undermined by their deteriorating condition. Maintaining patients’ dignity requires physicians as well as patients’ families to reinforce the patients’ sense of self-respect. The aim is to secure dignified living under severe health conditions.

Like “quality of life,” the term “death with dignity” was once used by ethicists with differing positions. But because of its extensive use by advocates of physician-assisted suicide and active euthanasia, this concept is more clearly associated today with the active euthanasia movement.

Patients in a “persistent vegetative state”

There are those who focus on the right to “die with dignity” and who would like living wills or advance directives to be options offered to and followed on behalf of all patients, including persistent vegetative state (PVS) patients.

The connotations of the term, “persistent vegetative state,” are demeaning. The term is used in reference to patients who are in the twilight zone between life and death. In referring to these individuals, I prefer the terms “prolonged unawareness” and “post-coma unawareness” (PCU). The logic for using these terms has both medical and ethical considerations. First, medically speaking, the term “pro-

longed unawareness” has replaced the term “prolonged coma” because “coma” (an acute sleeplike state of unarousability) is commonly defined today in terms of three elements: closed eyes, no utterance of meaningful sounds, and no adequate motor reaction to external stimuli. If any one of these elements is missing, the term “coma” should not be used and the term “unawareness” used instead. PCU patients, unlike patients in a coma, have sleep-wake cycles.⁹ Also, whereas a serious injury to the brainstem causes a deep, irreversible coma because the brainstem regulates the awareness mechanism, the damage in cases of PCU is in the cerebral hemisphere and the possibility for awakening remains.

Second, the use of “vegetative” to describe a state of prolonged unawareness is ethically suspect. The term “persistent vegetative state” was coined by Jennett and Plum to describe a set of clinical features associated with profound brain damage.¹⁰ They wanted to identify an irrecoverable and permanent state, but they named the syndrome “persistent” because they did not have the data to verify an *irreversible* state.¹¹ Upon introducing the term in 1972, they commented that it was a neutral term, with no derogatory connotations.

“To vegetate” is defined by the *Oxford English Dictionary* as “to live a merely physical life, devoid of intellectual activity or social intercourse”; “vegetative” is defined as “an organic body capable of growth and development but devoid of sensation and thought.” To the layperson, the term suggests a limited and primitive responsiveness to external stimuli; to the doctor, it means that there is relative preservation of autonomic regulation of the internal milieu.¹² To me, it dehumanizes patients and, therefore, is offensive to the dignity of patients and their family and other intimates—their beloved people. It implies that these patients are vegetable-like, inferior, subhuman beings and perhaps unworthy of treatment as humans. From “vegetative,” it is very easy to slip to “vegetables,” as doctors and even leading authorities in the field have done.¹³ No one would like to be treated as a carrot or a potato, nor would anyone like the idea that a loved one would be treated as such. Because language is—to a great extent—a reality-building instrument, a warning should be raised against the use of discriminatory and demeaning terms that could cause medical personnel to disrespect patients. We should strive to describe patients’ conditions without offending them or their loved ones; in our descriptions, we should not strip patients of their human and moral characteristics.

While “vegetative” is a biased, even degrading term, the terms “prolonged unawareness” and “post-coma unawareness” are more neutral. Obviously, there are costs involved in changing a medical term. But the major obstacle is to acknowledge that it was the wrong term to choose in the first place because it is unethical and offensive and because of the dire consequences that might result when us-

ing the term to describe patients. After all, there isn’t much point in spending scarce and costly resources on mere vegetables. On the other hand, the terms “prolonged unawareness” and “post-coma unawareness” describe without any bias a certain state of living. The terminology used by doctors in this matter is crucial. For if human life and the dignity of the patient are our first and foremost consideration, then we should use terms that describe the situation without bias, and without offending the people concerned.

Some specialists speak of “persistent” or “permanent vegetative state” as if it were a defined condition, without looking for any variations in the condition—without paying any attention to what caused the condition, the length of the condition, and other factors that are pertinent to the evaluation of the state of unawareness.¹⁴ Others hold that “Persistent vegetative state . . . should be considered a form of death.”¹⁵ This is not an illogical step to take after legitimizing the term “persistent vegetative state” and describing human beings as vegetables. These scholars suggest redefining death away from whole-brain death to post-coma unawareness. They speak of a trend through court decisions of slowly moving toward a reformulation of the definition of death. Financial costs play a crucial role in their considerations, a fact that is reflected in the reports of the Hastings Center and the Society of Critical Care Medicine. These reports concluded that providing intensive care to patients in persistent vegetative states is generally a misuse of resources. Consequently, treatment of such a patient could be withdrawn even without the patient’s advance directive or approval of the legally appointed surrogates.¹⁶ Indeed, research indicates that resuscitative treatment has been withheld from post-coma unawareness patients without prior directives from the patients or without the consent of their families.¹⁷

I find these developments alarming. There is room to suspect that the use of language was instrumental in generating a dismissive attitude towards this group of patients. The basic problem is that an economy of words has minimized or even eliminated the differences among patients. Post-coma unawareness may be the *general* condition of these patients, but there are clear differences that we must take into account when evaluating each and every patient. We cannot and we should not characterize all patients with a single term. We must be aware of the variations that led to their situation—their particular condition, age, the time involved, and other relevant criteria.¹⁸ We must resist the temptation of resorting to a single criterion, itself reduced to a stylized term—persistent vegetative state—which might lead to treating patients inappropriately.

A study conducted among nurses at Toronto Hospital on the question of whether they support organ donation from patients with post-coma unawareness revealed a major cause of concern with the lack of certainty in diagnosis and the varying degrees of PCU.¹⁹ Borthwick argues that

there are unquestionably hundreds of people in the United States who now are being treated *as if* they are in a persistent vegetative state when they are not.²⁰ In another essay, I suggested that we should adopt a two-year waiting policy with patients who are younger than 50 years old and whose situation was caused by traumatic incidents.²¹ This period of time is necessary to verify their medical condition and to allow them an opportunity to recover.²²

“Futility”

The Latin word *futilis* refers to actions or instruments that are inherently “leaky” and therefore ill-suited to achieving the desired end. The implication is that the use of leaky means would always be in vain as the leak would make failure inevitable.²³ According to the general definition of Schneiderman and Jecker, “medical futility” means any effort to provide to a patient a treatment that is highly likely to fail and whose rare exceptions cannot be systematically produced.²⁴

One could think of three sorts of futile treatment. First, it is futile to provide treatment that does not produce positive effects. For instance, using plaster to treat cancer or chemotherapy to treat a Parkinson patient would be futile. Similarly, tube feeding or intravenous fluids would be futile treatments—as well as possibly painful—for patients who are no longer able to assimilate nourishment or fluids. Consider a patient with severe congestive heart failure. Intravenous feeding cannot be tolerated by the patient because the fluid would be too much for the weakened heart. Or consider a patient with a severe clotting deficiency and a nearly total body burn. Gaining access to the central veins is likely to cause hemorrhage or infection; nasogastric tube placement may be quite painful; and there may be no skin to which to suture the stomach for the tube.²⁵

Second, it is futile to provide a radical treatment whose side effects outweigh the good emerging from the treatment. If the side effects are too severe, the patient is better off without the particular treatment.

Third, it is futile to treat a disease when the patient is suffering from a more pressing life-threatening disease. For instance, it is futile to treat the gangrene in the leg or to perform an amputation on a cancer patient if the patient is likely to die from the cancer in a few days.

Much of the debate about futility is taking place in the United States. The general context is the need to set limits on health-care expenditures. Concerns about costs often underlie the appeals in the clinical setting and public policy discussions that treatment under certain situations is futile. Doctors who generally argued that loyalty to their patients required that every potentially beneficial treatment be offered—that it was impossible to put a price on life, that even if the chance of success was only one in a million, they would still be ethically obligated to provide it—suddenly

changed their minds. Instead, they began to argue that it was “unethical” to provide such treatments. When reimbursement incentives changed so that doctors began to lose money instead of making money from providing certain treatments, doctors discovered an ancient ethical obligation to refrain from providing these treatments.²⁶

One study speaks of “futility” in the context of a medical condition in which the diagnosis is of a fatal and incurable disease, death is expected to occur within three months, and survival is not expected even if aggressive treatment is provided.²⁷ The problem is that doctors are quite often not able to ascertain that the above conditions are met. Moreover, a treatment, such as CPR, is futile when it offers no benefit to the patient because maximal therapy has failed and no physiologic improvement is possible. Under these circumstances, a unilateral decision by physicians to withhold therapy is argued to be in order. But the question arises: At what percentage chance of recovery should a treatment be considered futile? Are treatments futile at a 1 percent chance of success, a 2 percent chance of success, an 8 percent chance of success?²⁸

Schneiderman and colleagues have argued that a treatment should be considered futile when 100 consecutive patients do not respond to it or if the treatment fails to restore consciousness or alleviate total dependence on intensive care.²⁹ Truog and his colleagues wonder how similar these 100 patients must be. They press the question of whether, in assessing the efficacy of mechanical ventilation to treat pneumonia, it is sufficient simply to recall the 100 most recent patients who received artificial ventilation for pneumonia, or whether this group of 100 must be stratified according to age, etiologic organism, or coexisting illness. Clearly, they argue, many of these factors will make an important difference in determining if a particular treatment is futile.³⁰

On my part, I wonder at which point one could determine that a given treatment had failed to restore consciousness. It might be the case that short-term treatment will produce no positive results. The unqualified statement by Schneiderman and colleagues opens the door to stop treatment prematurely. What if the treatment alleviates significant dependence on intensive care, but not *total* dependence? Why such treatment would still be considered futile is unclear. After all, even according to the general definition of Schneiderman and Jecker, it is possible to discern a benefit to a patient whose condition progressed from total dependence to some independence, and there is no reason to think that such treatment would *necessarily* be likely to fail.

Futility is an elusive concept. As an evaluative instrument, it is used to say that a certain treatment would be ineffective because it would not yield any significant positive results or that the treatment would be inappropriate because its benefits are questionable. In public policy, the

concept of futility could be used to sanction restrictions in the allocation of health-care resources. After all, patients cannot demand futile therapy, and society and doctors are under no obligation to provide it. In terms of ethics and the law, a physician's opinion that treatment is futile lessens his or her obligation to the patient. A claim of futility is supposed to rest on reasonable medical judgment. The problem is that physicians disagree about the type of clinical evidence necessary to support this reasonable medical judgment. Doctors often disagree not only about the likelihood of treatment success, but also about the value of certain outcomes. Some physicians would consider a treatment futile if all it could provide was a chance to survive for a couple of weeks. Others would consider this a reasonable goal. Dying patients might consider this lengthening of their lives a supreme value.³¹

Recently, members of the Council on Ethical and Judicial Affairs concluded that they found great difficulty in assigning an absolute definition to the term "futility" since it was an inherently value-laden term. Thus, they recommended instead a fair process for determining and subsequently withholding or withdrawing from what was felt to be futile care. The process insists on giving priority to a patient's or proxy's assessment of worthwhile outcomes, accommodating community and institutional standards, and listening to the quantitative, functional, and interest perspectives offered by the parties involved.³²

In her powerful critique of the concept of futility, Rubin argues that futility is an insufficient ground on which a physician can engage in unilateral decision-making. That is, physicians should not be justified in refusing unilaterally to provide treatment based on their opinion that the treatment would be futile. According to Rubin, the concept of futility distracts us from addressing ethical questions about the role of medicine and the relationship between physicians and their patients. Rubin is disturbed by the simplistic terms with which clinicians are encouraged to make judgments regarding futility, and she is skeptical of attempts to separate these judgments into factual and evaluative statements. She rightly suggests that, *at a minimum*, patients must always be given an opportunity to participate in the decision-making process and that this opportunity must be genuine and meaningful for the patients.³³

Likewise, in a postscript written after publishing several essays on futility, Childress argues for restricting the term more narrowly than he intended at first, in part because appeals to futility have become a way to restore a kind of medical paternalism, to reinstate medical authority over patient and familial decision-making, to mask value-laden judgments as value-free and objective, to disguise rationing decisions, and so forth. Childress maintains that appeals to medical futility serve to stop conversation rather than to invite open discourse about the values involved in treatment and nontreatment decisions, whether in caring

for particular patients or in rationing care.³⁴

Some maintain that the situation of PCU patients is futile. By resorting to the term "futility," physicians project a certain attitude to the patients and their families. The Santa Monica Hospital Medical Center's Futile Care Guidelines address situations where the attending physician deems further treatment to be futile, but the patient or her loved ones insist on continuing treatment. It was the *hospital's* best interests that evoked the need for such guidelines, not the patients' best interests. The policy defines futile care as "any clinical circumstance in which the doctor and his consultants, consistent with the available medical literature, conclude that further treatment (except comfort care) cannot, within a reasonable possibility, cure, ameliorate, improve or restore a quality of life that would be satisfactory to the patient." One such clinical condition that was given is "persistent vegetative state."³⁵ I contest this unqualified statement. Studies show that physicians must have some data about the prolonged unawareness—the causes for this condition, the age of the patient, and the time since the onset of the unawareness—before concluding that treating post-coma unawareness is "futile."³⁶

Let me reiterate: Physicians are not prophets. They may carefully predict certain events according to the available data. They can say, to the best of their knowledge, that some diseases lead to certain death and that current medicine cannot reverse the trend. But they cannot determine with absolute certainty how long a person will live, and they should not formulate guidelines without making proper qualifications. Great Britain's highest court has recognized the lack of medical knowledge in this sphere. In the *Bland* case, the court ruled that cases concerning patients in prolonged unawareness should continue to be brought before the court for review "at least for the time being and until a body of experience and practice has been built up."³⁷

"Double effect"

The ethical concept of double effect is used to justify medical treatment designed to relieve suffering where death is an unintended, though foreseeable, consequence. It comes from the double effect doctrine developed by Roman Catholic theologians during the Middle Ages. These theologians developed the doctrine as a response to situations where it was impossible to avoid all harmful consequences of a required action. The doctrine makes intention in the mind of the actor a crucial factor in judging the moral correctness of the action. According to Roman Catholic teaching, it is never permissible to intend the death of an innocent person—that is, one who has not forfeited the right to life by the way he or she has behaved, e.g., by threatening or taking the lives of others.³⁸

The double effect doctrine, as applied to medicine, is based on two basic presuppositions: the doctor's motiva-

tion is to alleviate suffering; *and* the treatment must be proportional to the illness.³⁹ The doctrine applies if 1) the desired outcome is judged to be “good” (e.g., relief of suffering); 2) the “bad” outcome (e.g., death of patient) is not intended; 3) the “good” outcome is not achieved by means of the “bad,” and 4) the “good” outcome outweighs the “bad.”

I am not opposed in principle to the double effect doctrine, although my lack of opposition stems from practical, rather than ethical, considerations.⁴⁰ I think the doctrine offers a different terminology and also a practical—albeit not altogether sincere—way to deal with a pressing problem. Religious authorities speak of double effect and doctors use it in their practice. This doctrine serves both spiritual leaders and careful healers as a way out of dealing directly and sincerely with the question of mercy killings and physician-assisted suicide. Undoubtedly, the doctrine provides a better solution than letting people die slowly in terrible agony. Using the doctrine, doctors prescribe large doses of medication knowing that, as a result, suffering will be lessened and life shortened. They feel comfortable with what they are doing: They are not breaking the law; they are acting in accordance with their medical understanding and providing solace to suffering patients.

There are patients who do not want to play the doctor’s game and speak of “double effects” that would allow the doctor to prescribe to them a lethal dose of drugs (which would shorten their lives while safeguarding the doctor’s legal position). They seek a way out from a troubling existence. Why should their fate be worse than those who are able to commit suicide without assistance? Is it right that their inability to terminate their own lives forces them to continue to live under conditions they see as humiliating and pointless?

In 1990, the magistrate court of Tel Aviv received an appeal made by a patient named Benjamin Eyal. Mr. Eyal suffered from amyotrophic lateral sclerosis (ALS), a disease that causes progressive paralysis of the muscles of the face, tongue, throat, respiratory system, shoulders, hands, and legs. In its final stages the patient cannot swallow, speak, cough, or breathe unaided.⁴¹ One specialist described this situation as “a living hell.”⁴² Mr. Eyal, aware of the expected process, asked not to be attached to a respiratory machine when he could no longer breathe spontaneously, but to be allowed to die. He expressed this wish in an affidavit, in a video, and verbally. The medical specialist who testified before the court said that his commitment to care for Mr. Eyal “does not include a duty to prolong life of unimaginable suffering by committing an intrusive act that could be avoided by following the will of the patient.”⁴³ Judge Uri Goren decided to accept the appeal. He emphasized that such a decision concerning life and death should be made by a senior hospital administrator, either by the director of the hospital or by the head of the particular

department. This was because the decision involved considerations of medical expertise, moral values, religion, and ethics.⁴⁴

Benjamin Eyal died of complications before the disease had reached its final stage and before a respirator was necessary. Thus, the physicians at his nursing home did not have to act upon the court’s decision. For the sake of argument, however, let us suppose that the final stage had been reached, and the physicians refrained from connecting Benjamin Eyal to the respirator machine. Would it have been humane to witness Mr. Eyal suffocating to death? I asked one of Mr. Eyal’s senior doctors if it would have been possible for him to stand idly by while his patient was choking to death. The doctor’s replied: “Of course not. I would give Eyal something to shorten his suffering.”

I think that this is a humane answer, in harmony with the morals of a humane practice of medicine. Any other answer, opposed in principle to active intervention, would be inhumane and cruel. Under such circumstances, when the patient is suffering and expresses his or her will to die, and the doctors admit that they are unable to cure the illness and all that they can do is ease suffering, there are strong reasons to consider active termination of life.

The double effect doctrine provides a better solution than letting people like Benjamin Eyal and Sue Rodriguez⁴⁵ die slowly in agony. In their everyday medical practice in hospitals, there are many instances in which doctors apply the doctrine. Although the result of their actions may be the death of the patient, their intention was to alleviate pain and suffering, not to kill. However, I suspect that there are many cases in which the intention *is* to kill the patient simply because no hope for recovery exists, the doctor thinks that there is no point in prolonging life, and the patient wishes to die, as in the Eyal case. It is time to be honest about this and describe what the doctor really intends in a sincere manner. Doctors terminate life under the guise of double effect because most countries do not allow physician-assisted suicide or other forms of mercy killing.

In their critique of the double effect doctrine, Timothy Quill, Rebecca Dresser, and Dan Brock argue that the doctrine’s complexities and ambiguities have limited its value as a guide to clinical practice and have impaired patient care. They conclude that the rule is not a necessary means to adequate pain relief because informed consent, the degree of suffering, and the absence of less harmful alternatives exist.⁴⁶

“Brain death”

More than 30 years ago, an *ad hoc* committee at Harvard Medical School promulgated criteria for the transplantation of vital organs from a donor.⁴⁷ Although the committee described the condition that any permissible donor should be in a state of “irreversible coma,” this condition

came to be known as “brain death” in the years that followed. The committee was explicit that one of the important purposes of the document it produced was to enable the nascent field of organ transplantation.

Although the diagnosis of brain death is among the most straightforward in the practice of medicine, there is evidence that clinicians are frequently confused by the concept. One study of physicians and nurses frequently involved with questions of brain death and organ donation found that only 35 percent were able to correctly identify the legal and medical criteria for determining brain death. Most of the respondents reported using inconsistent concepts of death. Moreover, most did not believe that the brain dead patients were really dead, although they nevertheless felt comfortable with the process of organ procurement on the basis that the patients were permanently unconscious and/or would soon be dead.⁴⁸ Rather than conclude that these clinicians were either unsophisticated or poorly trained, an accompanying editorial expressed the view that the confusion about brain death was actually *appropriate*, given the concept’s inherent inconsistencies.⁴⁹

In a recent essay, Bob Truog explores why the concept of brain death may be seen as an inappropriate—or at least outdated—means of determining death in today’s patients. Truog reviews the work of the 1968 *ad hoc* committee and proposes four questions that the committee sought to address with the notion of brain death:

1. When should life support be withdrawn for the benefit of the patient?
2. When should life support be withdrawn for the benefit of society?
3. When is a patient ready to be cremated or buried?
4. When is it permissible to remove organs from a patient for transplantation?

Truog argues that in 1968, the first question was very important because removal of a ventilator from a living patient was legally viewed as a homicide. Now, however, the situation is entirely different. In most intensive care units (ICUs), more than half of the patients who die have had some form of life-sustaining therapy discontinued. The relevant question before removal of a ventilator is not, “Is the patient dead?” but rather, “Do the burdens of mechanical ventilation exceed the benefits?” The notion of using brain death to address the question of when to withdraw life support for the benefit of the patient—so central to the reasoning of the Harvard committee in 1968—has become virtually irrelevant over the last three decades.

In contrast, the second question about allocation of resources is perhaps even more important today than it was

in 1968. However, the problem is not that ICUs are going to be overrun by brain dead patients on ventilators and that their beds are actually needed by others. Now the question is whether we can continue to provide expensive treatment that will have marginal benefit to individuals who are at the extremes of their lifespan or who have profoundly diminished capacities. Whatever the answer, Truog argues that this difficult question cannot be solved with the concept of brain death.

The third question differs from the first two in that it is essentially uncontroversial. We have always buried or cremated people after their pulse and breathing ceased. Even when a person has been diagnosed dead by neurological criteria and the ventilator removed, clinicians still must wait until the patient is pulseless and without breath before removing the body to the morgue. Consequently, as Truog argues, the concept of brain death is again irrelevant to answering one of the questions the concept was originally designed to answer.

Finally, we are left with the question of when it is permissible to remove vital organs from one patient for transplantation into another. From this discussion, it should be clear that the sole purpose of the term is to categorize persons from whom transplantation is possible. No wonder clinicians have been confused by this description of death—it isn’t about making a diagnosis of death, but about facilitating the procurement of organs for transplantation.⁵⁰ Truog maintains that at the very least this type of rationalization should prompt us to reevaluate whether the linkage between brain death and organ transplantation still makes sense and whether there might be better ways to address the need for transplantable organs.⁵¹

According to Truog, the concept may also be an inaccurate description of death. He notes that clinicians have observed that patients who satisfied the tests for brain death have frequently responded to surgical incision at the time of organ procurement with a significant rise in both heart rate and blood pressure. This suggests that integrated neurological function at a supraspinal level may be present in at least some brain dead patients. This may indicate a significant disparity between the standard tests used to make the diagnosis of brain death and the physiological conditions these tests are purported to measure. Faced with these troublesome facts, we need to acknowledge that the criterion for *whole* brain death is only an approximation of when death occurs.⁵²

Conclusion

The current health-care environment presents many dilemmas and challenges concerning possible conflicts of interest among the medical staff, patients, and other elements of the economic structure within which they operate. Ethics entails taking responsibility for one’s actions and speech;

being sensitive to the people with whom one is dealing; not offending them without justifiable grounds.

There is a need to introduce more ethics into the medical school curriculum, to improve knowledge and understanding of ethical principles while also equipping medical students with communication skills to convey and exemplify these principles. Research shows a positive correlation between medical schools' teaching higher-level moral reasoning and medical students' developing moral reasoning and, in turn, good clinical performance.⁵³ Progressively sophisticated ethics education should be integrated into the medical school curriculum.

Teaching medical ethics successfully requires medical schools to commit significant material and moral support.⁵⁴ This teaching can take the form of lectures that include pertinent films and video clips⁵⁵ as well as recent fictional and autobiographical literature about doctors and medicine.⁵⁶ The lectures should be accompanied by small-group tutorials and clinical visits that discuss potential ethical dilemmas as well as real situations and patients in the wards.⁵⁷ The traditional model of ethics teaching—case-based and issue-oriented, emphasizing the knowledge and cognitive skills necessary for ethical decision-making—should be maintained.⁵⁸ In addition, workshops and ethics rounds in hospitals in which a medical ethicist discusses with residents their ethical dilemmas are solid ways to provide practical ethics education.⁵⁹ Several studies evaluating the effect of medical ethics education have shown that both lectures and discussion of cases have improved the moral reasoning scores of medical students and that the small-group, case-study format promotes the development of moral reasoning even more than the lecture format.⁶⁰ In controlled trials, Sulmasy and colleagues found that lectures and discussions of ethics increased medical residents' knowledge and confidence in addressing ethical issues.⁶¹ Similarly, Wenger and colleagues have argued that a medical ethics curriculum can increase residents' knowledge and awareness of ethics, particularly in the areas of informed consent and physician-patient relationships.⁶²

One of the main problems in patient-doctor relationships arises from the fact that doctors are often oblivious to the feelings of their patients, unaware that their behavior and wording cause their patients anguish. This is not to say that doctors are intentionally unethical. Instead, they are *aethical*, not appreciating the power of words and the consequences that words have on their patients. Because doctors lack time, they adopt short and concise terms that *they* understand well and that serve *their* interests. These terms do not necessarily serve the patients' best interests.

The lack of time is a crucial factor. As Wear notes, not only does it usually preclude the growth of an in-depth relationship between physician and patient, but it has other detrimental effects. All communication or counseling between the parties, including informed consent, must be sand-

wiched in between many other diagnostic and therapeutic agendas. This means that communication will not occur in an unfolding process of mutual exploration, feedback, and understanding—the sort of communication that we would expect to produce true patient understanding.⁶³

Studies consistently show that effective communication between clinicians and patients is a critical determinant of patient satisfaction.⁶⁴ Many health organizations are aware of the need to promote communication skills and, consequently, they provide condensed training programs (e.g., “Thriving in a Busy Practice: Physician-Patient Communication”) in which tens of thousands of clinicians have taken part.⁶⁵ However, this is not enough. Communication skills programs need to be longer and more intensive, teach a broader range of skills, and provide ongoing performance feedback.⁶⁶ There is a need for doctors to invest more time talking with patients and their beloved people. Honesty, promise keeping, confidentiality, caring, and empathy are essential for effective communication, which, in turn, is the building block for an effective physician-patient relationship.⁶⁷

In his landmark work, *The Silent World of Doctor and Patient*, Jay Katz spoke of the silence that used to surround patients, arguing that historically the doctor-patient relationship was based on a one-way trust. Physicians conversed with patients about all kinds of things, but they did not, except inadvertently, employ words to invite patients' participation in any decision-making.⁶⁸ Katz criticized doctors for encouraging patients to relinquish their autonomy, and he demonstrated the detrimental effect their silence had on good patient care. Katz acknowledged the growing need in this age of medical technology for more sincere communication and a new, informed dialogue that would respect the rights and needs of both physicians and patients.

The new ethos of patient autonomy and the emerging doctrine of informed consent have contributed in recent years to creating more avenues of communication between doctors and patients. In the United States, the federal Patient Self-Determination Act and managed care have heightened our awareness of communication and what it can accomplish. The Act, which went into effect on December 1, 1991, promotes the principles of informed consent. It lays the foundation for the exercise of the patient's decision-making authority, which affects the course of treatment for all patients whether or not they possess decision-making capacity.⁶⁹ In turn, managed care has demonstrated the direct links among doctor-patient communication, treatment outcomes, and malpractice liability.⁷⁰

As the silence at the bedside is replaced by mutual exploration and discussion, patients' concerns and fears should become more apparent to clinicians and can be formally anticipated, rather than be allowed to fester unnoted and cause trouble later.⁷¹ A strong connection exists between the soul and the body; consequently, doctors who are edu-

cated to fight for the life of their patients should not resort to using terms that might weaken their patients' will to live. Doctors must strive to use not only simple, non-technical language to insure that patients and their loved ones not only understand the information disclosed but also are not offended by it. Dehumanizing terms like "persistent vegetative state" should be excluded from medical discussions for ethical reasons. Thoughtful and sensitive explanations should replace the concise and brutal terms that fall like an axe on patients and their beloved people. Terms like "double effect" and "futility" should be explained in detail and with sincerity. The motivation for using these terms and others, like "brain death," needs to be clarified. Doctors and patients, public leaders and religious figures, ethicists and intellectuals of social and philosophical backgrounds, psychologists, social workers, and others who care about patients should all take part in these discussions.

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References

1. H. Kuhse, *The Sanctity of Life Doctrine in Medicine: A Critique* (Oxford: Clarendon Press, 1987); H. Kuhse, "Quality of Life and the Death of 'Baby M,'" *Bioethics*, 6, no. 3 (1992): 233-250; H. Kuhse and P. Singer, *Should the Baby Live? The Problem of Handicapped Infants* (Oxford: Oxford University Press, 1985); P. Singer, *Practical Ethics*, 2nd ed. (Cambridge: Cambridge University Press, 1993); L. Chelluri, A. Grenvik, and M. Silverman, "Intensive Care For Critically Ill Elderly: Mortality, Costs, and Quality of Life," *Archives of Internal Medicine*, 155 (1995): 1013-1022. See also J.C. Joerden, "Peter Singer's Theories and Their Reception in Germany," in R. Cohen-Almagor, ed., *Medical Ethics at the Dawn of the 21st Century* (New York: New York Academy of Sciences, 2000): 150-156.
2. Compare E.W. Keyserlingk, *Sanctity of Life or Quality of Life* (Ottawa: Law Reform Commission in Canada, 1980): at 18; J.F. Keenan, "The Concept of Sanctity of Life and Its Use in Contemporary Bioethical Discussion," in Kurt Bayertz, ed., *Sanctity of Life and Human Dignity* (Dordrecht: Kluwer, 1996): 1-18; M.P. Previn, "Assisted Suicide and Religion: Conflicting Conceptions of the Sanctity of Human Life," *Georgetown Law Journal*, 84 (February 1996): 589-616; D.J. Bleich, "Life as an Intrinsic Rather Than Instrumental Good: The 'Spiritual' Case Against Euthanasia," *Issues in Law & Medicine*, 9, no. 2 (Fall 1993): 139-149; N. Rotenstreich, "On the Sanctity of Life," in Yeshayahu Gafni and Aviezer Ravitzki, eds., *The Sanctity of Life and the Defying of the Spirit* (in Hebrew) (Jerusalem: The Zalman Shazar

Center for the Study of Jewish History, 1993): 27-34.

3. Compare U. Lowenthal, "Euthanasia: A Serene Voyage to Death," in Amnon Carmi, ed., *Euthanasia* (Berlin: Springer-Verlag, 1984): 180-184. For discussion on the origin and rationale of the concept of dignity, see K. Bayertz, "Human Dignity: Philosophical Origin and Scientific Erosion of an Idea," in K. Bayertz, ed., *Sanctity of Life and Human Dignity* (Dordrecht: Kluwer, 1996): 73-90; D.J. Velleman, "A Right of Self-Termination," *Ethics*, 109, no. 3 (April 1999): 611-617.
4. L.P. Ulrich, *The Patient Self-Determination Act* (Washington D.C.: Georgetown University Press, 1999): at 88.
5. L.R. Kass, "Death with Dignity and the Sanctity of Life," in B.S. Kogan, ed., *A Time to Be Born and a Time to Die* (New York: Aldine DeGruyter, 1991): at 133. Kass argues that one has no more right to dignity than to beauty, courage, or wisdom. While it is puzzling to speak of a right to beauty, courage, or wisdom, I think all people have a right to dignity. It is part of a fundamental principle of respect for others that underlies liberal democracies.
6. Haim Cohn holds that human dignity is the source from which human rights are derived, and along with human rights, it is the foundation of freedom, justice, and peace. Cf. H.H. Cohn, "On the Meaning of Human Dignity," *Israel Yearbook of Human Rights*, 13 (1983): 226-251, at 226.
7. R. Cohen-Almagor, "Reflections on the Intriguing Issue of the Right to Die in Dignity," *Israel Law Review*, 29, no. 4 (1995): 677-701; R. Cohen-Almagor and M. Shmueli, "Can Life Be Evaluated? The Jewish Halachic Approach vs. the Quality of Life Approach in Medical Ethics: A Critical View," *Theoretical Medicine and Bioethics*, 21, no. 2 (2000): 117-137.
8. An eloquent characterization of this transformation is presented in Margaret Edson's 1999 Pulitzer-winning play, *Wit*.
9. Compare Z. Groswasser and L. Sazbon, "Outcome in 134 Patients with Prolonged Posttraumatic Unawareness," *Journal of Neurosurgery*, 72 (1990): at 81; C. Tommasino, "Coma and Vegetative State Are Not Interchangeable Terms," *Anesthesiology*, 83, no. 4 (October 1995): at 888.
10. B. Jennet and F. Plum, "Persistent Vegetative State after Brain Damage: A Syndrome in Search of a Name," *The Lancet*, 1 (1972): 734-737.
11. *Id.*, at 735.
12. B. Jennett, "Clinical and Pathological Features of Vegetative Survival," in H.S. Levin and A.L. Benton, eds., *Catastrophic Brain Injury* (New York: Oxford University Press, 1996): at 5.
13. Ronald Dworkin has no qualms referring to some patients as vegetables. See, for instance, *Life's Dominion* (New York: Knopf, 1993): at 180, 230-232. See also C. Borthwick, "The Proof of the Vegetable: A Commentary on Medical Futility," *Journal of Medical Ethics*, 21 (1995): 206-208.
14. S.A.M. McLean, "Legal and Ethical Aspects of the Vegetative State," *Journal of Clinical Pathology*, 52 (1999): 490-493. Sandra Horton writes that "The difference between coma and vegetative state is that coma appears to have gradations, whereas PVS is a 'permanent' state of unawareness." See Horton, "Persistent Vegetative State: What Decides the Cut-off Point?" *Intensive and Critical Care Nursing*, 12 (February 1996): at 41.
15. Compare statements of Safar and Meisel in "Philosophical, Ethical and Legal Aspects of Resuscitation Medicine. III. Discussion," *Critical Care Medicine*, 16, no. 10 (1988): 1069-1076, at 1069, 1074.
16. Compare The Hastings Center, *Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying* (Bloomington, Indiana: Indiana University Press, 1987): at 112; Task Force on Ethics of the Society of Critical Care Medicine, "Consensus Report on the Ethics of Foregoing Life-Sustaining

Treatments in the Critically Ill," *Critical Care Medicine*, 18 (1990): 1435-1439; R.D. Truog, A.S. Brett, and J. Frader, "The Problem with Futility," *N. Engl. J. of Med.*, 326, no. 23 (1992): 1560-1564, at 1563. For a critical review of this approach, see S.J. Youngner, "Futility in Context," *JAMA*, 264, no. 10 (1990): 1295-1296.

17. See, especially, J.C. Hackler and F.C. Hiller, "Family Consent to Orders Not to Resuscitate, Reconsidering Hospital Policy," *JAMA*, 264 (1990): 1281-1283; G.F. Molinari, "Persistent Vegetative State, Do Not Resuscitate . . . and Still More Words Doctors Use," *Journal of the Neurological Sciences*, 102 (1991): 125-127; T. Tomlinson and H. Brody, "Futility and the Ethics of Resuscitation," *JAMA*, 261 (1990): 1276-1280.

18. G.G. Celesia, "Persistent Vegetative State: Clinical and Ethical Issues," *Theoretical Medicine*, 18 (1997): 222-233.

19. M. Keatings, "The Biology of the Persistent Vegetative State, Legal and Ethical Implications for Transplantation: Viewpoints from Nursing," *Transplantation Proceedings*, 2, no. 3 (1990): 997-999, at 998.

20. C. Borthwick, "The Permanent Vegetative State: Ethical Crux, Medical Fiction?" *Issues in Law & Medicine*, 12, no. 2 (1996): 167-185, at 178.

21. R. Cohen-Almagor, "Some Observations on Post-Coma Unawareness Patients and on Other Forms of Unconscious Patients: Policy Proposals," *Medicine and Law*, 16, no. 3 (1997): 451-471. Consider, for instance, the following documented case: a 43-year-old man who was in prolonged unawareness for 17 months following anoxic brain damage before showing the first signs of awareness. He progressed to being able to tell stories and jokes, though was unable to recognize complex collections of objects in pictures and was unable to read. See G.A. Rosenberg, S.F. Johnson, and R.P. Brenner, "Recovery of Cognition after Prolonged Vegetative State," *Annals of Neurology*, 2 (1977): 167-168. In another case, a 44-year-old man who was in prolonged unawareness showed signs of recovery one year following a subarachnoid hemorrhage and eventually regained nearly normal physical and mental capabilities. See P.G. May and R. Kaelbling, "Coma of a Year's Duration with Favourable Outcome," *Diseases of the Nervous System* (December 1968): 837-840. Childs and Mercer reported the case of an 18-year-old woman who suffered a traumatic brain injury in a motor vehicle accident. After 15 months, the medical staff reported some responses on her part. Seventeen months after the injury, she became able to follow simple commands and could complete simple arithmetic problems and multiple-choice questions using eye blinks. She wrote: "Mom, I love you." N.L. Childs and W.N. Mercer, "Brief Report: Late Improvement in Consciousness after Post-Traumatic Vegetative State," *N. Engl. J. Med.*, 334 (1996): 24-25. See also the correspondence on "Late Improvement After Post-Traumatic Vegetative State," *N. Engl. J. Med.*, 334 (1996): 1201-1202.

22. It is beyond the scope of this essay to provide a comprehensive account on the rehabilitation of post-coma unawareness patients. However, let me provide some data. The Multi-Society Task Force, comprised of representatives of the American Academy of Neurology, the Child Neurology Society, the American Neurological Association, the American Association of Neurological Surgeons, and the American Academy of Pediatrics, considered data on 434 head injury patients. The task force noted that of those patients who had not died or recovered by the end of the first year 52 percent of the patients had recovered consciousness, 33 percent had died, 15 percent were still in post-coma unawareness, and 10.6 percent (7 out of 65) recovered after 12 months. See The Multi-Society Task Force on PVS, "Medical Aspects of the Persistent Vegetative State," *N. Eng. J. Med.*

(1994): at 1572; C. Borthwick, "The Permanent Vegetative State: Ethical Crux, Medical Fiction?" *Issues in Law & Medicine*, 12, no. 2 (1996): at 179. Heindl and Laub studied two groups of children: 82 patients with traumatic brain injury (TBI), and 45 patients with hypoxic brain injury (HBI). They found significant differences between the two groups. The TBI patients progressed better than the HBI patients. Of the patients in the TBI group, 34 percent (compared with 13 percent of the HBI group) regained consciousness after three months. One year after the trauma, 80 percent of the patients in this group had left post-coma unawareness. See U.T. Heindl and M.C. Laub, "Outcome of Persistent Vegetative State Following Hypoxic or Traumatic Brain Injury in Children and Adolescents," *Neuropediatrics*, 27 (1996): 94-100. Information from the Traumatic Data Bank Study of 84 post-coma unawareness patients who were followed up long term found that 41 percent became conscious by six months, a further 11 percent between six months and a year, and an additional 6 percent between one and two-and-half years. See H.S. Levin et al., "Vegetative State after Closed Head Injury: A Traumatic Data Bank," *Archives of Neurology*, 48 (1991): 580-585.

23. S.B. Rubin, *When Doctors Say No: The Battleground of Medical Futility* (Bloomington, Indiana: Indiana University Press, 1998): 42; L.K. Stell, "Real Futility: Historical Beginnings and Continuing Debate About Futile Treatment," *North Carolina Medical Journal*, 56, no. 9 (1995): at 434.

24. L.J. Schneiderman and N.S. Jecker, *Wrong Medicine* (Baltimore: Johns Hopkins University Press, 1995): at 11; L.J. Schneiderman and N.S. Jecker, "Is the Treatment Beneficial, Experimental, or Futile?" *Cambridge Quarterly of Healthcare Ethics*, 5, no. 2 (Spring 1996): at 249.

25. See J. Lynn and J.F. Childress, "Must Patients Always be Given Food and Water?" in J. Lynn, ed., *By No Extraordinary Means* (Bloomington, Indiana: Indiana University Press, 1986): at 51.

26. J.D. Lantos, "Futility Assessments and the Doctor-Patient Relationship," *Journal of the American Geriatrics Society*, 42 (August 1994): at 869.

27. M. Sonnenblick, Y. Friedlander, and A. Steinberg, "Dissociation Between the Wishes of Terminally Ill Parents and Decisions by Their Offspring," *Journal of the American Geriatric Society*, 41, no. 6 (1993): 599-604.

28. See Memorandum by Dr. David Lamb, House of Lords, *Select Committee on Medical Ethics*, 1993-94 Session, Vol. III, Minutes of Oral Evidence (London: HMSO, 1994): at 133; Ulrich, *supra* note 4, at 190.

29. Schneiderman and Jecker, *Wrong Medicine*, *supra* note 24, at 97; L.J. Schneiderman, N.S. Jecker, and A.R. Jonsen, "Medical Futility: Its Meaning and Ethical Implications," *Annual International Medicine*, 112 (1990): 949-954; L.J. Schneiderman, K. Faber-Langendoen, and N.S. Jecker, "Beyond Futility to an Ethic of Care," *American Journal of Medicine*, 86 (1994): 110-114.

30. R.D. Truog, A.S. Brett, and J. Frader, "The Problem with Futility," *N. Engl. J. Med.*, 326, no. 23 (1992): at 1561. For further criticism of Schneiderman et al.; see G.G. Griener, "The Physician's Authority to Withhold Futile Treatment," *Journal of Medicine and Philosophy*, 20 (1995): 216-218.

31. J.D. Lantos, P.A. Singer, R.M. Walker et al., "The Illusion of Futility in Clinical Practice," *American Journal of Medicine*, 87 (July 1989): 81-83.

32. Council on Ethical and Judicial Affairs, American Medical Association, "Medical Futility in End-of-Life Care," *JAMA*, 281, no. 10 (1999): 938-940.

33. Rubin, *supra* note 23, at 115-117.

34. J.F. Childress, *Practical Reasoning in Bioethics* (Bloom-

ington, Indiana: Indiana University Press, 1997): at 163. For a contrasting view, see N.S. Jecker, "Is Refusal of Futile Treatment Unjustified Paternalism?," *Journal of Clinical Ethics*, 6, no. 2 (1995): 133-137.

35. Rubin, *supra* note 23, at 20. For further analysis, see *In re Conservatorship of Wanglie*, No. PX-91-283 (Minn. Dist. Ct., June 28, 1991, reviewed in 16 [1] MPDLR 46).

36. S. Ashwal et al., "The Persistent Vegetative State in Children: Report of the Child Neurology Society Ethics Committee," *Annals of Neurology*, 32 (1992): 570-576; H.S. Levin et al., "Vegetative State after Closed Head Injury: A Traumatic Data Bank," *Archives of Neurology*, 48 (1991): 580-585; W.F.M. Arts et al., "Unexpected Improvement after Prolonged Post-traumatic Vegetative State," *Journal of Neurology, Neurosurgery, and Psychiatry*, 48 (1985): 1300-1303; L. Sazbon et al., "Course and Outcome of Patients in Vegetative State of Nontraumatic Aetiology," *Journal of Neurology, Neurosurgery, and Psychiatry*, 56 (1993): 407-409; K. Andrews, "Vegetative State—Background and Ethics," *Journal of the Royal Society of Medicine*, 90 (November 1997): at 594.

37. *Airedale NHS v. Bland*, 1 All ER 821, 826 (1993).

38. South Australian Voluntary Euthanasia Society, *DID YOU KNOW? The Principle of Double Effect SAVES*, Fact Sheet No. 23 (October 1997), E-mail: metty@ozemail.com.au.

39. Joseph Boyle wrote extensively on this topic. See, e.g., J.M. Boyle Jr., "Toward Understanding the Principle of Double Effect," *Ethics*, 90 (July 1980): 527-538, and "Who Is Entitled to Double Effect?" *The Journal of Medicine and Philosophy*, 16 (1991): 475-494. See also the testimony of Dr. Walter R. Hunter before the Committee on the Judiciary (June 24, 1999) <<http://www.house.gov/judiciary/hunt0624.htm>>; F.M. Kamm, "Physician-Assisted Suicide, the Doctrine of Double Effect, and the Ground of Value," *Ethics*, 109, 3 (1999): 586-591; C.F. McKhann, *A Time to Die: The Place for Physician Assistance* (New Haven, Connecticut: Yale University Press, 1999): 102-106.

40. Compare "When Doctors Might Kill Their Patients," *British Medical Journal*, 318 (1999): 1431-1432. Further information on this and related issues is available from Hon. Secretary, SAVES, P.O. Box 2151, Kent Town, SA 5071, Australia.

41. For general discussions concerning the progressive neuromuscular disease, Amyotrophic Lateral Sclerosis (ALS) and assisted suicide, see *N. Engl. J. Med.* (October 1998).

42. (T.A.) 1141/90 *Benjamin Eyal v. Dr. Nachman Willensky and Others*, 51(3) P.M. 187, 192.

43. Opening Motion (T.A.) 1141/1990 *Benjamin Eyal v. Lichtenstaedter Hospital* 1991(3) P.M. at 194.

44. Opening Motion (T.A.) 1141/1990 *Benjamin Eyal v. Lichtenstaedter Hospital* 1991(3) P.M. at 87. For other similar cases, see (B.S.) 1030/95 *Israel Gilad v. Soroka Medical Center and Others* (October 23, 1995); Opening Motion (T.A.) 2339 and 2242/95 *A.A. and Y. S. v. Kupat Holim and State of Israel* (January 11, 1996); Opening Motion (T.A.) 2242/95 *Eitay Arad v. Kupat Holim and State of Israel* (October 1, 1998). In the *Arad* case, Judge Talgam emphasized that the starting point must be the dignity of the patient, not the hesitancy of the doctor.

45. Sue Rodriguez also suffered from amyotrophic lateral sclerosis. She publicly expressed a desire to have a physician assist her in ending her life at a time of her choosing when she herself would be unable to do so, rather than wait helplessly to die by suffocation or choking. Ms. Rodriguez sought to challenge the Criminal Code of Canada's prohibition on assisted suicide on the grounds that it violated the country's Charter of Rights and Freedoms. Her appeal was rejected by the Supreme Court of Canada in a 5 (Sopinka, La Forest, Gonthier, Iacobucci, and Major) to 4

(McLachlin, L'Heureaux-Dube, Lamer, and Cory) landmark decision. The court said that it did not want to intervene in this delicate public matter; it deferred to the legislature to change the law if such a change was deemed needed. See *Sue Rodriguez v. The Attorney General of Canada*, File No. 23476 (September 1993). I benefited from a discussion with the Honorable Justice Ian Binnie, the Honorable Justice Peter de C. Cory, and the Honorable Justice Frank Iacobucci of the Supreme Court of Canada (September 28, 1998). See also E. Kluge, "Doctors, Death and Sue Rodriguez," *Canadian Medical Association Journal*, 148, no. 6 (1993): 1015-1017.

46. T. Quill, R. Dresser, and D. Brock, "The Rule of Double Effect—A Critique of Its Role in End-of-Life Decision Making," *N. Engl. J. Med.*, 337 (1997): 1768-1771. See also the correspondence on the rule of double effect in *N. Engl. J. Med.*, 338, no. 19 (1998): 1389-1390.

47. Report of the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death, "A Definition of Irreversible Coma," *JAMA* (August 1968): 337-340.

48. S.J. Youngner et al., "'Brain Death' and Organ Retrieval. A Cross-sectional Survey of Knowledge and Concepts among Health Professionals," *JAMA*, 261, no.15 (April 1989): 2205-2210.

49. D. Wikler and A.J. Weisbard, "Appropriate Confusion over 'Brain Death,'" *JAMA*, 261, no. 15 (1989): at 2246.

50. One anonymous peer reviewer at the *Journal of Law, Medicine & Ethics* noted that brain death is not only used for purposes of transplantation. There are cases in which the family's wish for continued treatment or the patient's advance directive depends upon whether brain death has been determined. Many patients in this category, due to age, infectious disease (e.g., HIV), or other criteria, are not suitable organ donors.

51. R.D. Truog, "Organ Transplantation without Brain Death," in R. Cohen-Almagor, ed., *Medical Ethics at the Dawn of the 21st Century* (New York: New York Academy of Sciences, 2000): 229-239.

52. R.D. Truog, "Is It Time to Abandon Brain Death?" *Hastings Center Report*, 27, no. 1 (1997): at 30.

53. D.J. Self and E. Davenport, "Measurement of Moral Development in Medicine," *Cambridge Quarterly of Healthcare Ethics*, 5, no. 2 (Spring 1996): 269-277; D.J. Self, D.C. Baldwin Jr., and F.D. Wolinsky, "Evaluation of Teaching Medical Ethics by an Assessment of Moral Reasoning," *Medical Education*, 26 (1992): 178-184; S. Holm et al., "Changes in Moral Reasoning and the Teaching of Medical Ethics," *Medical Education*, 29 (1995): 420-423; T.J. Sheehan et al., "Moral Judgment as a Predictor of Clinical Performance," *Evaluation & The Health Professions*, 3 (1980): 394-404.

54. H.S. Perkins, C.M.A. Geppert, and H.P. Hazuda, "Challenges in Teaching Ethics in Medical Schools," *American Journal of the Medical Sciences*, 319, no. 5 (2000).

55. D.J. Self, D.C. Baldwin Jr., and M. Olivarez, "Teaching Medical Ethics to First-Year Students by Using Film Discussion to Develop Moral Reasoning," *Academic Medicine*, 68 (1993): 383-385.

56. Lantos argues that in the literature genre, the openness of the format and the relative intellectual marginality of the discipline allow questions to be raised about doctors and medicine, healing and illness, suffering and dying, that cannot be raised in any other discourse. Literature is thus *avant garde* in raising these issues and beginning to question the patently messianic vision of medicine as a sort of secular salvation. See J. Lantos, "Open Heart" (Shiva M'Horu), in R. Cohen-Almagor, ed., *Medical Ethics at the Dawn of the 21st Century* (New York: New York Academy of Sciences, 2000): 41-51.

57. In the Yale curriculum for Ethical and Humanistic Medicine, students and residents watch each other role play clinical tasks such as obtaining informed consent, delivering bad news, and discussing "do not resuscitate" orders. Students compare the techniques that they observe and perform, then discuss practical suggestions specific to each interactional skill. E. Fox, R.M. Arnold, and B. Brody, "Medical Ethics Education: Past, Present, and Future," *Academic Medicine*, 70, no. 9 (1995): 761-769, at 763. See also J.W. Tysinger et al., "Teaching Ethics Using Small-group, Problem-based Learning," *Journal of Medical Ethics*, 23, no. 5 (1997): 315-318; E.D. Pellegrino, M. Siegler, and P.A. Singer, "Teaching Clinical Ethics," *Journal of Clinical Ethics*, 1, no. 3 (Fall 1990): 175-180; P. Hebert et al., "Evaluating Ethical Sensitivity in Medical Students: Using Vignettes as an Instrument," *Journal of Medical Ethics*, 16, no. 3 (1990): 141-145.

58. T. Hope and K.W.M. Fulford, "The Oxford Practice Skills Project: Teaching Ethics, Law and Communication Skills to Clinical Medical Students," *Journal of Medical Ethics*, 20 (1994): 229-234; R.A. Hope, K.W.M. Fulford, and A. Yates, *The Oxford Practice Skills Course* (Oxford: Oxford University Press, 1996); F. Baylis and J. Downie, "Ethics Education for Canadian Medical Students," *Academic Medicine*, 66, no. 7 (1991): 413-414; A. Browne, M. Broudo, and V. Sweeney, "Results of a Survey on Undergraduate Ethics Education in Canadian Medical Schools," Division of Bio-Medical Ethics, University of British Columbia (working paper).

59. M. Parle, P. Maguire, and C. Heaven, "The Development of a Training Model to Improve Health Professionals' Skills, Self-Efficacy and Outcome Expectancies When Communicating With Cancer Patients," *Social Science & Medicine*, 44, no. 2 (1997): 231-240; K. Szauter, E. Boisubain, and M. Levetown, "Teaching Professionalism in Medical Grand Rounds," *Academic Medicine*, 74, no. 5 (1999): 581-582; K.M. Markakis et al., "The Path to Professionalism: Cultivating Humanistic Values and Attitudes in Residency Training," *Academic Medicine*, 75, no. 2 (2000): 141-149.

60. See, for example, D.J. Self, F.D. Wolinsky, and D.C. Baldwin Jr., "The Effect of Teaching Medical Ethics on Medical Students' Moral Reasoning," *Academic Medicine*, 64 (1989): 755-759.

61. D.P. Sulmasy et al., "Medical House Officers' Knowledge, Attitudes and Confidence Regarding Medical Ethics," *Archives of*

Internal Medicine, 150 (1990): 2509-2513; D.P. Sulmasy et al., "A Randomized Trial of Ethics Education for Medical House Officers," *Journal of Medical Ethics*, 19, no. 3 (1993): 157-163; D.P. Sulmasy and E.S. Marx, "Ethics Education for Medical House Officers: Long-Term Improvements in Knowledge and Confidence," *Journal of Medical Ethics*, 23 (1997): 88-92.

62. N.S. Wenger, L. Honghu, and J.R. Lieberman, "Teaching Medical Ethics to Orthopaedic Surgery Residents," *Journal of Bone and Joint Surgery*, 80A, no. 8 (1998): 1125-1131.

63. S. Wear, *Informed Consent, Patient Autonomy and Clinician Beneficence within Health Care* (Washington, D.C.: Georgetown University Press, 1998): at 61.

64. W.B. Carter et al., "Outcome-Based Doctor-Patient Interaction Analysis," *Medical Care*, 20 (1982): 550-566; J.A. Hall, D.L. Roter, and N.R. Katz, "Meta-Analysis of Correlates of Provider Behavior in Medical Encounters," *Medical Care*, 26 (1988): 657-675; P.D. Cleary and B.J. McNeil, "Patient Satisfaction as an Indicator of Quality of Care," *Inquiry*, 25 (1988): 25-36; L.G. Frederickson, "Exploring Information-Exchange in Consultation: The Patients' View of Performance and Outcomes," *Patient Education and Counseling*, 25 (1995): 237-246; D.L. Roter et al., "Communication Patterns of Primary Care Physicians," *JAMA*, 277 (1997): 350-356.

65. See J. Garcia, L.D. Gruppen, and C.M. Grum, "A Program to Elucidate Differences in Medical Students' Communication Skills," *Academic Medicine*, 72, no. 5 (1997): 427-428; J.B. Brown et al., "Effect of Clinician Communication Skills Training on Patient Satisfaction," *Annals of Internal Medicine*, 131 (1999): 822-829, at 826.

66. Brown et al., *supra* note 65, at 828-829.

67. I.S. Switankowsky, *A New Paradigm for Informed Consent* (Lanham, Maryland: University Press of America, 1998): at 105. See also E.J. Cassell, *Talking with Patients*, vol. I, II (Cambridge, Massachusetts: MIT Press, 1985).

68. J. Katz, *The Silent World of Doctor and Patient* (New York: The Free Press, 1984): 4-5, 207-229.

69. Ulrich, *supra* note 4, at 9.

70. W. Levinson, "In Context: Physician-Patient Communication and Managed Care," *Journal of Medical Practice Management*, 14, no. 5 (1999): 226-30.

71. Wear, *supra* note 63, at 179.