would clearly prohibit randomization to placebo. The commitment to individual well-being entails that the investigator treat the research subject simultaneously as a patient. In practice, such a standard does not require that researchers give each woman the best therapy available anywhere in the world. But it does require that researchers studying transmission rates also treat the patient (woman and infant) in a manner designed to reduce transmission.

—Deborah Hellman


Biology, Consciousness, and the Definition of Death

When does a human life end? This question used to be answered quite easily. According to the traditional standard, which has only recently been questioned, a human being is dead when her heart and lungs have irreversibly ceased to function. In some cases, permanent loss of consciousness may precede cardiopulmonary failure. But the interval between these two events has typically been a matter of hours or days, and the traditional standard regards only the latter event as definitive.

Today, however, the development of mechanical respirators, electronic pacemakers, and other medical technologies has created the possibility of a greater temporal separation between various system failures—a patient may lose consciousness a decade or more before his heart and lungs fail, for example. Meanwhile, interest in the availability of transplantable organs has provided an incentive not to delay unnecessarily in determining that a person has died. (Current law, it need hardly be said, embraces the so-called “dead-donor rule”: organs necessary for life may not be procured before donors are dead, since the removal of such organs would otherwise cause death—that is, kill the donors—violating laws against homicide.)

Two landmark reports helped to generate a movement away from exclusive reliance on the traditional standard: the 1968 report of the Harvard Medical School Ad Hoc Committee and a 1981 presidential commission report, Defining Death. This second document included what became the Uniform Determination of Death Act (UDDA). Today all fifty states and the District of Columbia follow the UDDA in recognizing whole-brain death—irreversible cessation of all functions of the entire brain—as a legal standard of death. The UDDA doesn’t jettison the cardiopulmonary standard, however. Instead, it holds that death occurs whenever either standard (whichever applies first) is met. One important consequence of this change is that an individual can be legally dead even if her cardiopulmonary system continues to function. If a patient’s entire brain is nonfunctioning, so that breathing and heartbeat are maintained only by artificial life-supports, that patient meets the whole-brain standard of death.

Some philosophers and scientists have argued that the whole-brain standard does not go far enough. Several leading authors on the subject have advocated a higher-brain standard, according to which death is the irreversible cessation of the capacity for consciousness. This standard is often met prior to whole-brain death, which includes death of the brainstem—that part of the brain which allows spontaneous respiration and heartbeat but is insufficient for consciousness. Thus, a
A Biological Perspective

One way to approach the issue of defining death is to consider it from a biological perspective. The concept of death applies not only to humans, but also to nonhuman animals and plants; it is a biological fact that all organisms live and die. In asking what death is, then, it seems logical to ask what is common to all instances of death. The answer will provide the core meaning of the term “death.”

What happens when a human, dog, squid, bee, or tulip dies? In each case, the organism breaks down in a fundamental way. Particular systems may break down before others, and the events from the first major system failure to eventual putrefaction clearly involve a process. But somewhere in the continuum that includes both dying and disintegration, the organism as a whole ceases to function. Charles Culver and Bernard Gert have helpfully defined death as “the permanent cessation of functioning of the organism as a whole.” The phrase “organism as a whole” does not mean literally the entire organism (since loss of a limb or spleen, say, is compatible with life); it refers to the integrated functioning of most or all of the important subsystems (organ subsystems, in the case of all but the most primitive animals). This, roughly, is the core meaning of “death” as seen from a biological perspective.

Both of the currently recognized standards of death are arguably compatible with this organismic concept. Under the cardiopulmonary standard, death occurs when a patient’s heart and lungs have permanently ceased to function—that is to say, when they no longer support each other or other organ systems. Under the whole-brain standard, a patient is dead when her brainstem no longer orchestrates her vital functions. In either case, the appeal is to the role of a particular organ or system in the functioning of the organism as a whole.

In contrast, the higher-brain standard is clearly not compatible with the organismic concept of death. Consider a patient in a permanent vegetative state. Her mind is gone, but her brainstem continues to function. Her heart beats spontaneously, maintaining normal blood pressure. Body temperature continues to be regulated, and other organ systems function as usual. From a biological standpoint, it would appear that this organism continues to function as a whole, despite her permanent unconsciousness. Thus, from this standpoint, the higher-brain standard of death appears incorrect. It must receive support from a different perspective, to which we now turn.

A Person-Based Perspective

Higher-brain theorists contend that human death cannot be adequately understood by assimilating it to organismic death in general. This claim can be defended in two different ways.

First, it might be argued that there is no core meaning shared by all correct applications of the term “death.” The various uses of the term, on this view, bear only a “family resemblance” to one another. In a family, a certain characteristic feature (e.g., above-average height) may be shared by most but not all members, while another common feature (e.g., brown eyes) is shared by a different set of family members, and so on, without any single, definable family “look” being shared by all. Similarly, there might be no essence common to the deaths of all organisms that can be invoked in an effort to illuminate human death.

Second, it might be argued that even if there is a core meaning of “death” applying to all organisms, a reconstruction of the term may be justified in the human case. Sometimes the original meaning of a term is justifiably extended or reshaped to fit certain practical interests or changing circumstances. The original meaning of “conversation,” for example, may have required that two individuals be able to hear or at least see each other. But the rapid exchange made possible at great distances by e-mail seems to justify applying the term “conversation” in this context. Perhaps a reconstruction of the term “death” is justified in its application to the special case of human beings.

From the present perspective, then, the core-meaning argument does not settle the question of the nature of human death. A more promising approach, on this view, is to take seriously the fact that we are not only organisms; we are also persons. According to one promi-
nent argument for the higher-brain standard, the capacity for consciousness is essential to persons—essential in the strict philosophical sense of being necessary: Any being lacking this capacity is not a person. It follows that when someone permanently loses the capacity for consciousness, there is no longer a person associated with the body. The person who was, is no more—that is to say, she is dead. Thus, the argument goes, human death is captured by the higher-brain standard.

While this essentialist argument may represent the most prominent case for the higher-brain view, there is also an important value-based alternative, which runs as follows. Human persons value consciousness as necessary for any meaningful existence. When we permanently lose consciousness, we lose all possibility of such an existence: We can no longer think or feel, enjoy relationships with loved ones, pursue projects, or act at all. When we no longer know we exist, there is no point to existing; when we are not aware of life, life has no meaning for us. Because human beings regard consciousness as a precondition for all meaning and value, the permanent loss of the capacity for consciousness is rightly regarded as human death.

Problems with the Person-Based Approach

We have seen that human death can be conceptualized from a biological perspective and from a person-based perspective, with only the latter supporting the higher-brain standard. Can we reasonably select between these two approaches? The case for favoring the biological concept of death begins with a critique of the person-based approach.

First of all, it is an approach that faces certain unsolvable tensions. Here is one example. Since human beings are organisms as well as persons, the concept of organismic death clearly applies in the human case. (This, I should say, is a fact acknowledged by some higher-brain theorists, even though it undermines the “family resemblance” thesis.) As we have seen, however, permanent unconsciousness is not definitive of organismic death. Thus, if the higher-brain standard is correct, then in PVS cases there are two deaths—one of the person and a later death of the organism—for a single human being. This is somewhat odd, since we are accustomed to believing that there is just one death associated with every human being. The oddity is reflected in the phraseology of Tristam Engelhardt, a higher-brain theorist, who describes the permanently unconscious as “biologically living corpses.”

A difficulty that faces the essentialist argument in particular concerns its appeal to the concept of a person. The capacity for consciousness is held to be necessary for personhood. But this capacity cannot be sufficient, since many animals that clearly are not persons (e.g., other mammals, birds) have the capacity for consciousness, too. So what other capacities are necessary? The philosophical tradition that requires consciousness for personhood traces back at least to Locke, who held that persons also possess the traits of self-awareness over time and rationality. This tradition, recently championed by Derek Parfit, consistently requires some psychological capacities beyond mere consciousness to distinguish persons from such conscious nonpersons as gerbils and blue jays. Thus Parfit holds that a person must be “self-conscious, aware of its identity and continued existence over time,” while Engelhardt states that “[w]hat distinguishes persons is their capacity to be self-conscious, rational, and concerned with worthiness of blame and praise.” (It may be tempting to say that a person is any Homo sapiens with the capacity for consciousness. But this move has been consistently rejected as chauvinistic; we may reasonably ask whether individuals outside our species—such as Homo erectus, the Great Apes, the computer HAL in 2001, and God—were or are persons.)

Where is the problem? The essentialist argument assumes not just that persons are essentially beings with the capacity for consciousness, but also that we are essentially (necessarily) persons. Without this second assumption, one could hold that we continue to exist, to live, after losing personhood (including the capacity for consciousness)—the very point that the higher-brain theorists wish to deny. Now the assumption that we are essentially persons, combined with the point that personhood requires psychological capacities in addition to consciousness (say, rationality and self-awareness), has a peculiar implication. Since newborns lack the psychological capacities in question, newborns are, strictly speaking, not persons (even if we often casually refer to them as persons). But if we are essentially persons, meaning we cannot exist as nonpersons, then we did not exist as newborns; the newborns in question were our organismic predecessors. This is a strange result, since we all believe that we were born.

The greatest difficulty with the essentialist argument is that the way it reasons about death is pernicious. By assuming that we are essentially persons, and defining death as loss of personhood, the argument logically invites an expansion of those humans to be counted as dead. Again, analyses of personhood standardly require more than the capacity for consciousness, so the present line of reasoning suggests that some highly subnormal
yet conscious human beings—for example, the most severely demented individuals—are actually dead.

The value-based alternative to the essentialist argument also has its vulnerabilities. First, in its effort to define meaninglessness as death, it conflates two concepts whose distinctness cannot simply be erased by definitional fiat. One might agree that a future of permanent unconsciousness would be devoid of meaning and value, but that doesn’t show that one wouldn’t be alive in such a state. The higher-brain theorist might reply that, even so, the fact that existing in a permanently unconscious state would be meaningless is sufficient reason to regard that state as death. But this, too, turns out to be a pernicious way to argue. For while it is reasonable to think that a meaningful existence requires the capacity for consciousness, it is no less reasonable to hold that the former requires a modicum of self-awareness and some ability to socialize with others (or at least the prospect of developing these, as with newborns). The fact that some severely disabled individuals are neither self-aware nor able to socialize casts doubt on this whole way of thinking about life and death.

Finally, any effort to base a standard for human death on “our” values confronts the problem of value pluralism. While liberal intellectuals, and perhaps a majority of Americans, are likely to regard a future of permanent unconsciousness as meaningless, many people—some of them religious fundamentalists—would disagree. For the dissenters, biological life in PVS or permanent coma is at least life and therefore valuable (perhaps infinitely so). For at least some of these people, such a state is meaningful because it is a gift from God, a gift that must not be thrown away through active killing—or defined away with a new definition of death.

Definitions and Policy

Since the higher-brain standard might be viewed as a basis for enacting liberal policies regarding end-of-life medical care and organ donation, rejecting this
standard may seem tantamount to embracing conservative policies. This is not so.

It is firmly established, both in case law and in medical ethics, that competent adult patients have the right to refuse life-supporting medical treatments, even artificial nutrition and hydration. By the same token, an appropriate surrogate can refuse life-supports on behalf of the legally incompetent if there is sufficient reason to believe the patient would have refused treatment in the present circumstances. Because of this broad legal and moral right to refuse treatment, life-supports that are unwanted or are considered unhelpful—including life-supports for permanently unconscious patients—can be terminated without first declaring the patient dead.

What if a family or another surrogate requests life-supports for a patient who has become permanently unconscious? Would not honoring such requests necessitate major expenditures on care that many people believe to be futile? It would, but the public need not fund such care. While there are compelling arguments for the thesis that society should ensure all citizens access to health care (an obligation our society sadly fails to meet), there is no support for the claim that the public must fund all desired care. What is owed is some basic package of health care benefits, and it is reasonable to include in such a publicly funded package only care that everyone can agree is beneficial. Thus, treatment that is arguably futile, including life-supports for the permanently unconscious, need not be covered.

On the other hand, if a patient’s family is willing to pay for such care, or subscribes to a private insurance scheme that covers it, it should be provided (at least if there is no shortage of available hospital beds and other critical supplies). In such a case, the family or insurance company does not consider the treatment futile—no doubt because it successfully prolongs the patient’s life (which the family or insurance company considers a substantial benefit) without causing any suffering.

Rejecting the higher-brain standard entails neither forcing patients to have treatment they don’t want or need, nor making the public pay for care that many consider futile. But since permanent unconsciousness often precedes death as determined by an organismic standard (whole-brain or cardiopulmonary), doesn’t rejecting the higher-brain approach mean that we must often delay before procuring donor organs?

Not necessarily, because in principle this issue can be addressed at another level. Without adopting the higher-brain standard, we could obtain organs from the permanently unconscious if we allowed an exception to the dead-donor rule in this sort of case. However, permitting any exception to the rule would provoke legitimate slippery-slope concerns. That is, if we were to allow one exception, predictably there would be pressures—economic and otherwise—to make additional exceptions.

How one reacts to this prospect depends both on one’s ethical judgments about such possible exceptions and on one’s degree of trust in the medical profession, legislators, and the broader public. I, for one, am not inclined to abandon the dead-donor rule, even for a class of patients who are permanently unconscious. However, prospective organ donors can already (through advance medical directives, for example) refuse life-supports, including nutrition and hydration. This means that even if we retain the dead-donor rule, the practical loss of rejecting the higher-brain standard of death—not getting some organs quite as soon as we otherwise might—is very modest indeed. And as we have seen, several considerations, both conceptual and pragmatic, favor this position.

—David DeGrazia
THE NATIONAL COMMISSION
ON CIVIC RENEWAL

Under the auspices of the National Commission on Civic Renewal, scholars from across the country have written a series of working papers on civil society, focusing on the role of civil associations and social movements in American democracy. The first ten papers were distributed to Commission members last summer and are still available to the general public. In addition, members of the Institute for Philosophy and Public Policy have now contributed papers of their own to the series, and so has Kathleen D. McCarthy of the Center for the Study of Philanthropy, Graduate Center, City University of New York.

To see summaries of the working papers, please consult the Commission's Web site. To order copies, please write to the Commission's offices at the Institute.

The National Commission on Civil Renewal and its associated research activities have been funded through a generous grant from the Public Policy Program of the Pew Charitable Trusts.

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