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A Biophilosophical Approach to the Determination of Brain Death

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> Technical and clinical developments have raised challenging questions about the concept and practice of brain death, culminating in recent calls for revision of the Uniform Determination of Death Act (UDDA), which established a whole brain standard for neurologic death. Proposed changes range from abandoning the concept of brain death altogether to suggesting that current clinical practice simply should be codified as the legal standard for determining death by neurologic criteria (even while acknowledging that significant functions of the whole brain might persist). We propose a middle ground, clarifying why whole brain death is a conceptually sound standard for declaring death, and offering procedural suggestions for increasing certainty that this standard has been met. Our approach recognizes that whole brain death is a functional, not merely anatomic, determination, and incorporates an understanding of the difficulties inherent in making empirical judgments in medicine. We conclude that whole brain death is the most defensible standard for determining neurologic death-philosophically, biologically, and CHEST 2024; 165(4):959-966 socially-and ought to be maintained.

KEY WORDS: bioethics; brain death; death determination; ethics

In the 1980s, in the wake of the Harvard Ad Hoc Committee's report and the work of the President's Commission, the Uniform Law Commission, in conjunction with the American Medical Association and the American Bar Association, proposed the UDDA, establishing the legal notion of "whole brain death."¹⁻⁴ As the model statute put it, brain death could be determined by "the irreversible cessation of the functions of the entire brain, including the brainstem."⁵

The statute was adopted by 37 states and the District of Columbia, and led to legal recognition of brain death in the remaining states, accomplishing exactly what a uniform law is supposed to do: codifying a widely agreed-upon approach.^{6,7} Although it did not define death, the UDDA unified brain death with the traditional cardiorespiratory approach to death as two standards for determining death under a single concept. Most observers accepted this law because it was compatible with an underlying metaphysical definition of death as the point at which an organism has ceased to exist as an integrated whole.^{1,3,4,8,9} Supporting this view, it was noted that individuals determined to be whole brain dead were physiologically unstable, and it was said that these bodies could not be supported for

ABBREVIATIONS: UDDA = Uniform Determination of Death Act AFFILIATIONS: From the Kennedy Institute of Ethics (D. P. S.), Pellegrino Center for Clinical Bioethics (D. P. S., A. H. R., J. G., and G. K. D.), the Department of Medicine (D. P. S. and A. H. R.), the Department of Philosophy (D. P. S.), and the Department of Neurology (C. S. T. and J. G.), Georgetown University, Washington, DC; Essentia Health (C. A. D.); and the University of North Dakota School of Medicine and Health Sciences (C. A. D.), Grand Forks, ND.

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more than a few weeks.^{1,4,10-17} Other observers subscribed to a so-called "higher brain" definition of death—holding that the irreversible loss of consciousness meant the death of the person, and advocating that such loss of consciousness should be made the legal standard for determining brain death.^{18,19} Although the UDDA was not completely satisfying to such observers, it was not inconsistent with their view. Any patient who met the legal criteria for whole brain death would also, by definition, meet the standard of higher brain death. Moreover, based on their poor prognosis, life-sustaining therapies could still be discontinued for those who had less than whole brain destruction, so higher brain death advocates were accommodated.

The model statute thus codified a workable truce among competing conceptions of death. The genius of the simplicity of the UDDA was that the law simply names the two standards and is silent about definitions, permitting a socio-legal solution to deeper metaphysical disagreements.

Cracks Appear in the Ethical, Legal, and Medical Consensus

Subsequent to 1981, testing for indicators of whole brain death were pared down—the requirement of an EEG was dropped, and the time before a repeat confirmatory examination was shortened (and eventually eliminated). All that came to be deemed necessary to determine that the whole brain had ceased to function was a set of three clinical criteria: irreversible unresponsiveness, apnea, and the absence of brainstem reflexes.²⁰ The capacities of intensive care also improved, and the numbers of people declared brain dead increased over this period, thereby supplying organs for burgeoning transplantation programs.²¹

Concomitantly, a number of cases arose that challenged the notion of whole brain death.²² First came case reports of pregnancies carried to term by women declared whole brain dead.²³ Then came sporadic case reports of individuals persisting for months—or even years—after the declaration of brain death, a phenomenon dubbed, ironically, "chronic brain death."^{22,24} The issue rose to national prominence with the case of Jahi McMath. Jahi was a young girl declared brain dead in California, whose family moved her to New Jersey (which has a religious exemption clause in its brain death statute), where she persisted for 4 years, even undergoing puberty.^{25,26} These cases appear to undermine both (1) the understanding that the whole brain has been destroyed in patients meeting the current clinical criteria for brain death, and (2) the philosophical idea that these individuals have ceased to exist as integrated wholes.

The key to understanding the discrepancy between the UDDA and these cases is that current testing confirms only the lack of function of the brainstem and cortex, and simply *infers* the loss of function of the rest of the brain. In particular, hypothalamic function is not assessed, and appears to persist in an undetermined number of individuals declared whole brain dead by current testing standards.²⁷ The hypothalamus is a physiologically vital but anatomically complicated entity, consisting of a diverse collection of nuclei that are dynamically interactive with intracerebral innervation and the blood supply.²⁸ Hypothalamic function may not cease on brain herniation.²⁹ In most (if not all) of the cases deemed "chronic brain death," the explanation for the persistence of bodily function seems to be that hypothalamic function is preserved.²⁷ Moreover, recent evidence supports that in some cases, the activity of deep brain structures not only can persist after profound insult, but may subserve a pattern of key neurologic functions that could even contribute to some form of consciousness.³⁰

These historical, clinical, neurophysiologic, and neuroanatomic observations are important to bear in mind when considering whether and how to alter our approach to the concept of brain death.

How to Proceed?

So much hangs on the declaration of death that it is important to be as certain and uniform as possible. Legal rights, burial, insurance matters, inheritance, marriage, organ transplantation, and more depend on the declaration of death.³¹ Some, therefore, have advocated abandoning the idea of brain death altogether.^{32,33} Others have proposed codifying current brain death testing as a "legal fiction," holding such people to be dead as a matter of social consensus even though it is a state less than sufficient for determining biological death.³⁴⁻³⁷ A third approach, which we advocate, would be to deepen the philosophical account of brain death and expand testing to confirm the cessation of other critical brain functions besides conscious responsiveness, breathing, and cranial nerves.³⁸

Why We Should Not Abandon Brain Death

We argue that it is not necessary to abandon the concept of brain death. Medical practice requires certainty in the determination of death in a moral sense, not a mathematical sense. Some have, for instance, suggested that only putrefaction is a certain indicator of death.³⁹ That is impractical as a medical standard for determining death. Furthermore, those who advocate cardiopulmonary death as the sole standard of death have overgeneralized from the case reports regarding "chronic brain death."^{40,41} One must be careful to distinguish between false-positive determinations that the whole brain, including the hypothalamus, has ceased to function, and the falsity of the idea that individuals who are whole brain dead are dead. As we will argue below, the idea that brain death is biophilosophically defensible as death is not undermined by the cases of "chronic brain death."

Why Brain Death Should Not Be Cast as a Legal Fiction

Some neurologists and bioethicists have called for simply codifying current testing methods for brain death as a legal fiction. This "neurorespiratory" approach, in essence, stipulates that an individual who cannot think, cannot breathe, and cannot blink should be declared dead as an agreed-upon legal matter, and treated as such, even though not truly biologically dead. They argue that cases of "chronic brain death" prove that we have been dishonest with the public and that simply stipulating that the patient is permanently unconscious, apneic, and lacking brainstem reflexes, and informing the public that this is what we mean by the term brain *dead* is more honest and transparent.⁴² Some have argued, more forthrightly, that such individuals are at least "good as dead," so we might as well call them dead.⁴³⁻⁴⁵ However, this approach is deeply flawed.

First, it is unscientific. When tests do not meet standards, we typically improve the tests and do not lower the standards. If we now understand that critical brain functions can persist after current testing protocols, science suggests that we admit we were wrong and not insist that we were right, substituting our testing protocols for the truth. Some have dismissed hypothalamic function as merely extraneous activity, or even denied that the hypothalamus is part of the brain.^{34,35,37,46,47} Such assertions are physiologically and anatomically false.⁴⁸ Hypothalamic function is critical to life, and all anatomy textbooks classify the hypothalamus as part of the brain.

Second, this reconceptualization of brain death may miss important aspects of brain function and deter

scientific progress. By only testing the brainstem and the cortex, we already may be missing important residual brain functions. The subcortical gray matter integrates arousal, motor, sensory, and autonomic functions, which are intimately intertwined. Moreover, groups of neuronal and glial cells can reestablish nodes and networked substrates and patterns of activity in response to particular conditions and states of the brain.⁴⁹ The presence of normal hypothalamic function is highly suggestive of at least thalamic function, and failure to test for hypothalamic function thus leaves open the question of whether there is persistent subcortical cognitive function.^{50,51} Consciousness is not measured directly. The clinical examination can only demonstrate unresponsiveness.⁵² Testing should ensure that enough of the function of the brain has been lost that alternate neural integration pathways and connections would not sustain any form of consciousness. Codifying only the absence of brainstem and cortical functions as death dismisses important aspects of brain activity that we do not yet fully understand.

Third, it is asserted that such a "neurorespiratory" approach is not metaphysical. In fact, however, it would enshrine in law an implicit metaphysical conception that is unacceptable to large swaths of the population.^{1,53-55} What seems most important to proponents of the neurorespiratory approach is the loss of conscious responsiveness⁵⁶; all that is additionally required to be considered dead, effectively, is the inability to breathe. This represents a quasi-higher brain death standard and will be rejected by all those who would refute the mind/ body dualism implicit in this notion of death.

Fourth, this approach makes death a "social construct" rather than an objective biological fact. If anything ought not be a social construct, it is death. Death ought to have an objective biological meaning.^{1,3,4,17,57-61} These proposals logically entail the idiosyncratic notion that death, for humans, has two distinct meanings—a biological cardiopulmonary meaning and a socially constructed neurologic meaning. By contrast, the current UDDA implies that these are two standards for determining death under one meaning (loss of integration). The idea that there is only one underlying meaning of death makes more sense. Moreover, casting brain death as a social construct divorces the notion of human death from the death of other organisms and is biologically implausible.

Fifth, this approach is at odds with the commonsense judgment that a patient like Jahi McMath was still alive

when she was moved to New Jersey. The neurorespiratory approach would force physicians to tell the families of patients like Jahi that they simply do not understand reality as well as doctors do. The message would be that what the family actually witnessed, the facts that Jahi persisted for 4 years and underwent puberty, were merely manifestations of unorganized, purposeless biological activity. The implication would be that the family was simple and ignorant and that doctors have access to a less apparent, but purportedly "real" truth, according to which she was dead the whole time. This line of argument is a hard sell to the plain person of common sense and is redolent of medical paternalism.

Sixth, adding an option for religious or moral objection to the neurorespiratory approach does not solve the issue. Families might not understand the difference between neurorespiratory death and whole brain death without significant education. They will simply be told that their loved one is brain dead and not even be aware of the subtleties, or of any right they might be granted to object. Conversely, were all families to be made fully aware and truly informed, one would find very large numbers of people objecting, and that would create needless conflict and chaos.

Finally, this legal fiction approach will lead to *less* uniformity rather than more. Were the neurorespiratory view encoded in a revised UDDA, certain states would adopt it, but many would not, and other, more conservative states might be motivated to make stricter standards for brain death or eliminate brain death altogether. Even advocates for the neurorespiratory approach, such as Thaddeus Pope, acknowledge that such an outcome is likely.⁶² If the axiomatic purpose of a Uniform Law Commission is to make laws more uniform across states, the codification of this approach in a model law will have the opposite effect. Uniform laws should reflect a broad consensus and not attempt to impose uniformity where no consensus exists.

The Biophilosophical Alternative

Between eliminating brain death altogether and turning brain death into a legal fiction lies a middle ground. The medical profession and society can join together to clarify why, properly understood, whole brain death should still count as a way of correctly determining that death has occurred, and then proceed to improve testing to reduce or eliminate the false-positive rate.

First, whole brain death does not require proof of the necrosis of every neuron and glial cell. What matters is that all the functions of the brain necessary for the persistence of the patient as an individuated, integrated organism have been irrevocably lost.

The second philosophical clarification required to preserve the notion of whole brain death is subtle but important. Organisms are not merely entities that can be integrated; they are substantially *self*-integrating.^{38,63,64} This is the only refinement that needs to be made to the biophilosophical account of death that was implicit at the time of enactment of the original UDDA. Moreover, this view will even account for those rare cases in which an individual, accurately determined to be brain dead by current criteria, and apparently lacking intrinsic hypothalamic function, sometimes can persist for a bit more than days to weeks with enormous supportive efforts to substitute for the lost hypothalamic function. They might be *integrate-able* for a brief period, but they have ceased to exist as individual, whole, substantially self-integrating organisms.

Organisms, to be the kinds of things that they are (ie, living things), manifest a high degree of persistence (anti-entropy), unity, and relative autonomy.^{38,57,60} Of course, this autonomy is constrained (organisms are always dependent on the environment), but living organisms integrate their own functions and maintain their own homeostasis. When they have irrevocably lost their relatively autonomous capacity to persist as unified entities (ie, have lost their capacity to be substantially self-integrating), they can be determined to be dead. Of course, a judgment is required to determine how much self-integrating capacity must be lost, but such a judgment should be grounded in biophilosophical considerations, not social consensus. Medicine is both practical and scientific. Medicine needs an underlying rationale for the *determination* of death. With the conception we propose, death means the same thing in all species, and it can be determined by both cardiopulmonary and whole brain standards for humans. Such an understanding of death also has commonsense appeal: it should be relatively apparent to the plain person that a human being who has ceased to exist as a self-unifying whole organism can be declared dead and not merely "good as dead." Moreover, such an understanding would count as death for the vast majority of the population, of all philosophical and religious beliefs, and therefore is the most politically and culturally unifying conception.

Self-Integrative Function, Not Anatomy

The determination that an individual is whole brain dead is *functional*, not anatomical. We are not arguing

that every neuron must be dead, but that the organism must have substantially and irrevocably lost the functions of the brain that are critical to the organism's persistence as a relatively autonomous, unified whole its ability to be substantially self-integrating. Our view differs from the President's Council notion of the "vital work" the brain performs for the organism as a whole.⁵³ They privilege respiration as that "vital work," while we require the loss not just of consciousness and respiration, but also the loss of cerebro-somatic homeostatic integration to judge that the organism has ceased to exist as a self-integrating whole.

We are not arguing that patients who are whole brain dead have lost *all* integration, persistence, unity, and autonomy. In an individual who is truly whole brain dead, subsystems (eg, cellular metabolism and many individual organ functions) persist. But the organism has lost its self-integrating capacity—its relatively autonomous ability to persist as a unified whole.³⁸

What we are arguing is that, at a certain point of dependence on artificial means of treatment, the organism becomes a non-organismal, medically supported, biological entity and can be determined to be dead. This threshold is reached when the locus of integration and persistence of the organism is no longer the organism itself but the humans who are tending to it.³⁸ We argue that when an advanced organism such as a human being, because of injury or insult to its brain, has irreversibly lost the capacity for consciousness, has irreversibly lost the capacity for initiating and maintaining respiration, no longer responds reflexively to visual or auditory stimuli, no longer maintains a homeostatic temperature or allostatically responsive BP and heart rate, and no longer can sustain its own its own neuroendocrine activities, such as sodium balance, growth, metabolism, and sexual and reproductive functions, without external support, that individual can be determined to be dead. In such cases, that organism has irrevocably lost its unity, its ability to persist, and its relative autonomy, and has therefore ceased to exist as a unified, substantially self-integrating whole organism. That is to say, that being can be declared dead.

We are not arguing that the brain is the "master integrator" of the organism, but instead that it is a vital component for embodied self-integration. The brain's normal manner of function entails integrating its own neural network activities as crucial to central, embodied integration of the organism as a whole.⁶⁵ In higher

mammals such as human beings, many of the most critical, significant, integrative functions of the organism have become localizable to the brain. Mind-body integration, respiratory integration, and many fundamental homeostatic processes such as regulation of body temperature, endocrine, and autonomic activity are focal to cerebral networks. When all of these have ceased, the organism can no longer reasonably be construed to be substantially *self*-integrating, even if many of these functions can (with enormous effort and for a limited time) be artificially sustained.

Improving Testing Today

Given the current state of clinical knowledge, the key question becomes how to be reasonably certain that the brain's functions have actually ceased. There are several alternatives. One simple way to do this would be to add evidence of hypothalamic dysfunction to the clinical testing.^{66,67} There might be alternatives such as forms of neuroimaging that provide more detailed visualization of blood flow or neural node and network activity. 68-71 Another might be improving electrical monitoring devices to detect activity in the subcortical gray matter.⁷² The best means is a matter for neuroscientists and neurologists to discuss and debate. Prospective studies of deep gray matter or hypothalamic function in individuals declared brain dead would help. Perhaps such research could suggest improved, simple, and reliable bedside clinical tests.

Given the current state of medical science, we would argue that reasonable certainty can be achieved now by adding testing for diabetes insipidus to the current clinical triad of lack of conscious responsiveness, apnea, and absent brainstem reflexes. In fact, a close examination of case reports alleging that the bodies of some "chronically brain dead" patients who were said to have lacked intrinsic hypothalamic function but were capable of persisting for extended periods reveals they actually had relatively intact hypothalamic function. Moreover, were they to have persisted only because of extrinsic hormonal support, they would not have been truly self-integrating. Even the patient T. K., who at autopsy was reported to have had no identified neuronal tissue, had MRI findings that revealed blood flow to the hypothalamus; he did not develop diabetes insipidus until just before he was declared dead by the cardiopulmonary standard.²⁴ It was his persistent hypothalamic function that enabled him to remain selfintegrated for over 20 years. We can be reasonably certain that patients who irreversibly lack conscious

responsiveness, spontaneous respiratory drive, and brainstem reflexes, and also have diabetes insipidus, are no longer self-integrating organisms and can be declared dead.

Potential Objections and Rebuttals

Some might suggest that our view, which makes it more difficult to be determined to be brain dead, imposes an undue burden on patients, forcing them to continue what may be viewed as futile treatment. This is a misunderstanding. We are not asserting that patients cannot forgo life-sustaining treatments in the setting of severe brain injury short of whole brain death. We fully support appropriate decisions to withhold or withdraw life-sustaining treatments from such patients. We only argue that they cannot be considered candidates for the procurement of organs while their hearts are still beating, because they have not been determined to be whole brain dead and therefore cannot be treated as cadavers.

Others could argue that our proposal will decrease the number of patients who are brain dead and therefore limit organ donation.⁷³ We have several replies to this. First, not all individuals who are brain dead are candidates for organ donation; our view has implications for treating such individuals as well. Second, the need for organs for transplant should not determine how patients are declared dead. This is unsound ethically and philosophically. Third, invoking such an argument only reinforces the fear that many patients have that brain death is a construct created merely to procure organs for transplantation.⁷⁴⁻⁷⁶ Any stance that reinforces such a suggestion will only increase public distrust and could potentially limit public willingness to donate organs. Fourth, the option of organ donation after circulatory determination of death remains open to such patients. Even cardiac transplantation is now being performed successfully using hearts donated after the determination of death by circulatory criteria.77

Still others might argue that our position is no less arbitrary than neurorespiratory criteria. We would argue, however, that our conception is not merely stipulative, but is based on a philosophically justified concept of death rooted in biological reality. The biophilosophical approach we advocate is not arbitrary. The fact that one has to accept less than 100% certitude that a set of tests are done correctly and that these tests accurately reflect the dysfunction of the whole brain does not mean that the underlying reality, death, is subjective. Rather it means that all judgments about objective reality are fallible, and that in practical judgments, one requires not mathematical certainty, but only enough certainty to be able to justify one's actions (a standard sometimes referred to as moral or prudential certainty).⁷⁸⁻⁸⁰ We judge that our recommendations meet the standard of moral certainty in the determination of whole brain death.

Conclusions

We conclude that, among all proposals for brain death, whole brain death remains the most philosophically defensible, biologically plausible, and sociopolitically acceptable standard, and for these reasons, ought to be maintained. Given the state of medical science today, the mismatch between this standard and current clinical testing can best be bridged by expanding clinical testing to include evidence for the loss of functions that typically map to the hypothalamic region of the brain. In this way, we can be more certain than we now are that the whole brain has ceased to function, and thereby avoid false-positive determinations of death that can occur using existing neurological criteria. Medicine owes patients and their families greater certitude, and not legal fictions, both in the articulation of care and in the determination that a human being is dead.

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