

LETTERS

And She's Not Only Merely Dead, She's Really Mostly Sincerely Dead

To the Editor: D. Alan Shewmon's work over the last decade has clearly awakened the bioethics community from its dogmatic slumbers. Easy acceptance of the "somatic integration" rationale for equating the condition known as total brain failure with death of the human being is, after Shewmon, a thing of the past. In "Brain Death: Can It Be Resuscitated?" (Mar-Apr 2009), he has made yet another valuable contribution to the debate, providing a close and critical reading of the President's Council's white paper, "Controversies in the Determination of Death." Shewmon asserts that the council's effort is "brave but flawed." Having been involved in the production of the white paper as lead staff researcher and writer, I believe that he is mistaken on a number of points. (All opinions expressed here are mine alone.)

Shewmon's account of the historical foundations of this controversy is far too one-sided. He rightly points out that the initial equation of "irreversible coma" with human death was made without a developed philosophical defense and with an eye to practical consequences that would follow from a new standard. But a more balanced historical account would also note that the condition in question—also revealingly called "coma dépassé," or "beyond coma"—was recognized by neurologists and others as a *case apart* from all other brain injuries discovered in ventilator-dependent patients. Eelco Wijdick's 2003 historical study of the Harvard Committee's work gives a more nuanced picture, pointing out that "neurologists in the committee knew too well that brain death represented a unique comatose state that could be clearly delineated from other neurologic states." Regardless of the practical context, the task of interpreting this unique state in a way that does justice to the permanent and profound degree of its sufferers' incapacitation had to be taken up.

The "position two" argument in the white paper can be understood as an attempt to provide such an interpretation. It should be noted that this is a more modest way of reflecting on this issue than the "definition-criteria-test" approach that other commentators have followed. The council did not propose a "definition" of death from which a criterion for judging whether someone has died should follow as a logical consequence. Rather, the council keeps its efforts closer to the ground—closer to the reality of the patient and the experience of those who confront the puzzling state of "brain death" in someone they love. Paying close attention to the phenomenon itself—and not to various philosophical devices that have piled up over the years—the white paper encourages us to ask: "What is so unique about this state?" and "Do the phenomena that differentiate this condition have any resonance with the way of being that distinguishes the living from the dead?"

The patient who has suffered total brain failure is closed off from the world, and this closure will never be overcome; not even the very limited recovery that a patient in a persistent vegetative state achieves can be hoped for. The marks of this closure are complete coma—unresponsiveness to pain, to light, and so on—and complete termination of the drive to breathe. Does closure of this sort have any significance to an organism? Here is where the council's discussion of an organism's fundamental, defining work is useful. Openness to the world and the power and drive to interact at the whole organism level is what makes a living thing what it is. "Integration" was certainly never the point. After all, a complex machine is integrated: when assembled and functional, it is more than the sum of its parts. But it is not alive.

Shewmon reasonably asks why breathing and minimal awareness should be singled out as signs of an organism's life and interaction with its environment. He suggests that the council's argument would have difficulty accounting for the embryo, which is alive but does not breathe. According to the council's argument, however, it is not breathing *as such* that is the fundamental work of an organism, but rather its purpose-driven interaction with the world to support the metabolic mode of being. Breathing is one way that this deeper sort of work manifests in higher organisms beyond the embryonic state. Simpler organisms (an amoeba, for instance) and higher organisms at early stages of development do not manifest the fundamental powers of awareness, appetite, and engagement in the same way, and so in these cases, we would have to look for other signs to judge whether each is alive or dead.

It is difficult to discern what policy steps would follow from Shewmon's position. At the end of his review he suggests providing more information about the issue to potential donors so that consent can be more informed. This is a laudable suggestion, but it seems to imply a circumvention of the dead donor rule if one really believes that the patients in question are not dead. To put the point baldly: if, as Shewmon believes, the patient is alive, no amount of information provided prior to consent will make the patient dead.

If one is looking for a logically airtight account of why total brain failure is an adequate standard for judging human death, one is likely to be disappointed. The words of William Osler, though uttered in a different context, ring true here: "Medicine is a science of uncertainty and an art of probabilities." But this does not mean that all answers to the tough quandaries posed by modern medicine are equally valid. The President's Council's white paper shows that the neurological standard for death is far from a mere social construct. It is a biologically well-grounded response to the lived phenomenon of the "brain dead" patient.

Alan Rubenstein

Former Senior Consultant to the President's Council on Bioethics

Visiting Scholar, Carleton College

To the Editor: Alan Shewmon's critique of the President's Council's new rationale for accepting total brain failure as a criterion for the determination of death is dead on. The council's white paper leaves us begging for an explanation of why the combined irreversible loss of the "drive" and "felt need" to breathe and consciously interact with the environment prevents a human organism from existing as a whole. This is especially true when the council admits that the 1981 President's Commission was mistaken in its view that total brain failure necessarily results in a human organism's loss of internal somatic integration. If human organisms with total brain failure can maintain internal somatic integration with the help of artificial support for years, why should the fact that these individuals require artificial support to breathe determine whether they are living organisms? The lack of spontaneous respiration in many other patients does not make them dead or no longer "organisms as a whole." Thus, Shewmon correctly maintains that a living organism may persist without a functioning brain.

The problem with Shewmon's view, however, is that the same could be said about an artificially sustained, decapitated human organism (admittedly a hypothetical case, but not a preposterous one). Most, if not all, of the somatic integration that he points to as evidence that the artificially sustained, whole-brain-dead (in other words, physiologically decapitated) human organism is alive could conceivably be present in an artificially sustained,

physically decapitated human organism. However, if anything entails one's death, decapitation certainly does, despite whatever artificial support may be given to sustain one's decapitated body as an integrated organism. Thus, if we are willing to accept decapitation as death, we should also be willing to accept physiological decapitation (total brain failure) as death.

But—as Shewmon correctly points out—consideration of the strictly biological notion of what it means to be an integrated organism cannot justify the claim that one has died in such cases, so an alternative rationale is needed. Fortunately, since the start of the debate over neurological criteria for determining death, there has been a more sensible rationale—the destruction of the psychophysical integrity of the human being that occurs when the potential for consciousness and every other mental function is lost due to catastrophic injury to the brain. Indeed, I think that this is the real reason so many of us have been willing to accept brain death as death. While in principle this would lead to classifying individuals in a permanent vegetative state as dead, we currently lack the diagnostic and prognostic ability to reliably determine when irreversible amentia occurs across the spectrum of PVS cases. We should therefore retain the current whole-brain neurological criterion for determining death, not because individuals who satisfy it are necessarily no longer living organisms as the President's Council claims, but because these individuals have irreversibly lost the potential for any type of mental life.

John P. Lizza

Kutztown University
of Pennsylvania

To the Editor: D. Alan Shewmon praises the white paper written by the President's Council on Bioethics as “a breath of fresh air in a number of respects.” Among them, in Shewmon's view, is that “The council upholds the Kantian prohibition against using human beings merely as means to an end and not also as ends in themselves . . . thereby excluding any relaxation of the ‘dead donor rule.’”

This exaltation of Kant on behalf of the dead donor rule—whether by Shewmon or the council or both—manifests badly oversimplified Kantian ethics. Yes, we should not hover over impending corpses as though they were fields of transplantable organs, and the dead donor rule, paired with a conservative (in other words, not too early) determination of an individual's death, has a role in holding us back from that. But the Kantian principle of not using human beings merely as means to an end is grounded in a deeper, positive injunction to treat the person as an end in herself, as the distinctive moral agent that at bottom she is. It is this moral agency—the capacity to be bound by and to respond to the categorical imperative—that lies at the core of Kantian convictions about dignity and equality.

The orientation of organ donation then expands: it is important not just to prevent the dying person from being harvested as a mere resource, but to allow that person, as the moral agent she is, to determine what goes on. The dead donor rule in its simple, unmodified form thus comes into question. Why may not a competent person near death make her organs available by “lethal removal” if that is likely the only effective way of getting them to recipients? Robert Truog, among others, has suggested abandoning the dead donor rule at the same time as he urges us to move back to cardiorespiratory determination of death.

For any Kantian, this question put to advocates of an unmodified dead donor rule is powerful: really, *you* are going to tell *me*—a rational moral agent who laudably cares about my body's capacity for great good—that I cannot donate my organs a shade before death, before they deteriorate into disuse? And if you have the temerity to tell me that, at least, please, don't claim to be treating me as an end in myself.

Let's-be-cautious arguments for a less permissive determination of death than brain-stem death may well find support in Kantian dignity of the individual. That dignity does not necessarily support an unqualified dead donor rule that is impervious to donor consent. When the council invokes classic moral themes such as the Kantian dignity of the individual uncritically, we in the wider bioethics community should not praise it for doing so.

Paul T. Menzel

Pacific Lutheran University

D. Alan Shewmon replies:

Alan Rubenstein highlights the crux of the debate over “brain death” or “total brain failure.” It boils down to whether the original term “coma dépassé” represented an insight or an exaggeration; also to whether the “uniqueness” of total brain failure is anything more than that of any extreme of a spectrum.

Total brain failure's supposed uniqueness is actually contradicted by its heterogeneity. Some cases have diabetes insipidus; others do not. Many exhibit cardiovascular instability, but some do not. Some have widespread multiorgan damage, while others have pure brain pathology. Some of the former are what I call “dead brain-dead,” whereas many of the latter have every logical right to the same vital status as irreversibly comatose and apneic patients who have some residual brainstem reflex and are by legal and medical standards alive. Total brain failure is also pathologically heterogeneous. Some even debate what “total” means (or should mean) in “total brain failure.”

But even when brain failure is truly “total,” why is this not simply the extreme in the spectrum of coma, rather than something beyond it? The example of the embryo should not be so quickly dismissed. As Rubenstein indicates, we must look for other signs to judge its life/death status: namely, the antientropic dynamics underlying self-maintenance and self-development. In this respect, total brain failure patients with holistic properties resemble embryos, in that their survival depends on connection via “tube” with a “maternal ICU.” If a postnatal organism cannot do something it is supposed to do by nature, this is called a disability. Why should the internal criteria that categorize embryos as alive not apply also to total brain failure patients, with unconsciousness and apnea constituting disabilities? Position two is a laudable attempt to rescue brain death, but time will tell how convinced the rest of the world will be.

Potential donors have a right to know that there is serious debate over whether they will be dead at the time of organ extraction. So do families of total brain failure patients approached by procurement representatives. Informed consent means nothing if it does not include such information. The quotation from Osler about uncertainty applies to most of medicine, but not to the diagnosis of death, where there is no ethical room for false positive diagnoses.

John Lizza's analogy with decapitation has been raised by many, including me. Space does not permit elaborating, except to refer to my book chapter, “Mental Disconnect: ‘Physiological Decapitation’ as a Heuristic for Understanding ‘Brain Death’” (in M. Sanchez Sorondo, ed., *The Signs of Death*, Vatican City: Pontificia Academia Scientiarum, Scripta Varia 110, 2007, 292-333). In essence, the thought experiment does not shed physiological light

