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Robert D. Truog & Franklin G. Miller

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Target Article

Changing the Conversation About Brain Death

Robert D. Truog, Boston Children's Hospital and Harvard Medical School
Franklin G. Miller, National Institutes of Health

We seek to change the conversation about brain death by highlighting the distinction between brain death as a biological concept versus brain death as a legal status. The fact that brain death does not cohere with any biologically plausible definition of death has been known for decades. Nevertheless, this fact has not threatened the acceptance of brain death as a legal status that permits individuals to be treated as if they are dead. The similarities between “legally dead” and “legally blind” demonstrate how we may legitimately choose bright-line legal definitions that do not cohere with biological reality. Not only does this distinction bring conceptual coherence to the conversation about brain death, but it has practical implications as well. Once brain death is recognized as a social construction not grounded in biological reality, we create the possibility of changing the social construction in ways that may better serve both organ donors and recipients alike.

Keywords: brain death, dead donor rule, definition of death, health policy, organ donation, organ transplantation

Two recent cases have reignited an ongoing conversation about the concept of brain death. Jahi McMath is a 14-year-old who suffered devastating neurological damage following complications from a tonsillectomy. She met criteria for the diagnosis of brain death, but continues to survive at an undisclosed location with the aid of mechanical ventilation and tube feedings. Marlise Munoz was a 33-year-old woman who was 14 weeks pregnant when she sustained severe brain injury from a pulmonary embolism. She also met established neurological criteria for the diagnosis of death, and was sustained on life support despite objections from her family that this was not treatment she would have wanted, based on a state law requiring that life support not be terminated if a woman is pregnant (Gostin 2014; Magnus, Wilfond, and Caplan 2014).

In commenting on these cases and the topic in general, we are interested in changing the conversation about brain death by recognizing that there are important and relevant distinctions between brain death as a biological concept and brain death as a legal status.

An important fact is that the clinical criteria for brain death are widely accepted as legal criteria for death, not only in the United States but also in many countries around the world. There are some legal exceptions, such as in New Jersey, where death may not be declared upon the basis of neurological criteria when this would violate the personal religious beliefs or moral convictions of that individual (Olick 1991). Even so, these are notable primarily as exceptions to the general rule.

Another important fact is that the clinical criteria for brain death do not coincide with a biological definition of death. The arguments supporting this claim have been made many times over the past several decades and have never been refuted. For readers who are not familiar with them, we summarize them here.

Scientific interest in the definition of life has a long history, going back at least to Claude Bernard in the 1850s. In the 1920s, Walter Cannon developed the concept of homeostasis, defined as the property of living organisms to maintain a stable internal environment through energy-consuming processes that maintain integrated functioning. Death occurs at the moment when this integrated functioning of the organism as a whole is irreversibly lost. This conceptual definition of life applies across the biological spectrum, from single-celled organisms to plants and animals (Cannon 1932; Korein 1978; Macklem and Seely 2010). In 1981 the U.S. President's Commission affirmed this definition, and took the stance that the state of “brain death” was consistent with this biological understanding of death, on the basis that the functioning of the brain is necessary for the integrated functioning of the organism as a whole (President's Commission 1981).

Over the past several decades, however, we have learned that this is not scientifically correct. Incontrovertible evidence has been developed that those individuals who meet diagnostic criteria for brain death can continue to live and maintain integrated functions indefinitely with the aid of mechanical ventilation. These include

circulation, digestion, excretion of waste products, temperature control, wound healing, fighting infections, and even continued growth and development (Shewmon 1998; 2001). Aside from some minor details, this array of organismic functioning in brain-dead patients is similar to that of ventilator-dependent patients with high cervical quadriplegia, who also can live for years despite the near total physiological separation of the brain from the body (Shewmon 1999). While consciousness is intact in the latter, the loss of consciousness in the former does not make them biologically dead. And while both are ventilator dependent, dependence upon life support is no more relevant to whether one is living or dead for these patients than it is for those who require dialysis or a pacemaker.

These views concerning the maintenance of integrated functioning were affirmed in 2008 by the President's Council on Bioethics in its book *Controversies in the Determination of Death*, when the council concluded that "If being alive as a biological organism requires being a whole that is more than the mere sum of its parts, then it would be difficult to deny that the body of a patient with total brain failure [the council's term for "brain death"] can still be alive, at least in some cases" (President's Council on Bioethics 2008, 57). We now know that integrated functioning is an emergent property of organisms, and is not dependent upon an integrating organ like the brain.

Nevertheless, the President's Council argued that bodies with "total brain failure" should be seen as biologically dead because they allegedly cease to perform "the vital work" of the organism as a whole. This view, however, cannot withstand critical scrutiny. If by "vital work" the council meant the functions associated with consciousness, then the council's definition would classify patients in a persistent vegetative state as dead, a position the council rejects. If by "vital work" the council meant functions other than those associated with consciousness, then patients diagnosed as brain dead may retain the entire range of these functions, as discussed earlier.

Other theories for justifying brain death have been proposed. Some, for example, have defended the view that we should have a specific definition of death for human beings based upon the irreversible loss of the capacity for consciousness (Veatch 1993). This is a defensible view, given the centrality of consciousness to meaningful existence, but has never gained traction since it depends on certain controversial metaphysical commitments and again would categorically define patients in a persistent vegetative state as being dead.

In short, we contend it is simply a fact that the legal definition of death, as defined by neurological criteria, does not correspond with a biological definition of death. Again, while this view has circulated for decades, supporters of brain death continue to endorse the erroneous dogma that the "brain dead" are biologically dead. Why might this be? One possibility is that they believe that professional adherence to the brain death dogma is necessary to sustain the lifesaving practice of vital organ transplantation. This practice relies on "the dead donor rule," under

which it is considered legal and ethical to procure vital organs only from donors who are deemed dead by medical professionals in light of a biological conception of death (Bernat 2013; Miller and Truog 2008; Robertson 1999; Truog and Miller 2008; Truog, Miller, and Halpern 2013;).

Recently, the article "Accepting Brain Death" was published in *The New England Journal of Medicine* in response to the cases just cited (Magnus et al. 2014). The authors correctly observed that brain death is widely accepted as legal death, with thousands of patients declared brain dead each year, and with many of these donating multiple organs that save the lives of thousands of others with life-threatening organ failure. Clearly, there is something to be said for "accepting" brain death and supporting the status quo.

Accepting brain death as legal death does not preclude us, however, from critically examining the biological meaning of the concept. If we agree that brain death is not biological death, but is legal death, then the concept can best be described as a "legal fiction." Readers may assume that use of the word "fiction" in this context is pejorative, but that is not the case. Legal fictions serve a very legitimate role in society, by facilitating important social functions, particularly in situations where the necessary function may not entirely conform to the material facts.

We have discussed how legal fictions apply to the definition of death in more detail elsewhere (Shah and Miller 2010; Shah, Truog, and Miller 2011), but the relevance of the approach can be appreciated by considering the concept of "legally blind." By law, anyone who has visual acuity of less than 20/200 is considered to be legally blind. We of course recognize that not all of these individuals are biologically blind. But there are many advantages to categorizing them as legally blind, in terms of drawing a bright line at a point where a number of important social decisions may be made, such as whether they qualify for certain types of disability support, or whether they are allowed to have a driver's license. Put colloquially, persons whose vision is less than 20/200 are "close enough" to being blind that, for all legal purposes, we can consider them to be blind.

The analogy to viewing brain death as legal death but not biological death should be obvious. While not biologically dead, their profound degree of neurological impairment has led to the view that, for all legal purposes, they can be treated as if they are dead. Furthermore, a survey of the history of "brain death" suggests that the concept of brain death may have been at least implicitly intended as a legal fiction from the very beginning.

The report of the Ad Hoc Harvard Committee in 1968 made a scientific claim about diagnosing the state of "irreversible coma," but offered no scientific or conceptual reason for why this should be considered death (Ad Hoc Committee of the Harvard Medical School 1968). The Uniform Determination of Death Act, which is the basis for the state laws that define brain dead patients as legally dead, requires "the complete absence of all functions of the entire brain, including the brainstem" (President's

Commission 1981). All physicians who diagnose brain death know that many patients who fully meet the medical criteria for brain death continue to have physiologically significant brain functions, including both hormonal regulation and temperature control (Halevy and Brody 1993; Truog 1997; 2007), yet this fact has never threatened the legal status of these patients, even though they do not fulfill the statutory requirements. When it became clear that the central justification for brain death—the loss of integrated functioning of the organism as a whole—was not scientifically valid, few expressed concern about whether public policy around declaring death needed to be reconsidered. At multiple points in the history of the concept of brain death, the legal fiction has been at least implicitly affirmed despite divergence from the scientific facts. While the article “Accepting Brain Death” did not explicitly endorse a legal fictions approach, it suggested that brain death is better seen as a concept rooted in social consensus about the appropriate way to respond to individuals with irreversible apneic coma than as an understanding of biological death.

Bending biological reality to serve perceived public policy needs has not been limited to the diagnosis of brain death. Donation after circulatory determination of death, or DCD, has likewise suffered from criticism about whether the donors are biologically dead after between 2 and 5 minutes of pulselessness, as required by most protocols (Marquis 2010; Bernat, Truog, and Miller 2010). Bernat has advanced the argument that since the loss of circulation in these patients is permanent and will soon become irreversible, it is acceptable to treat them as if the loss is irreversible at an earlier point in time (Bernat 2013; Bernat et al. 2010). From a biological and conceptual perspective, this shift clearly confuses a prognosis (dying) with a diagnosis (dead), yet the lack of a biological rationale for this position has not hindered its widespread endorsement in policy statements and guidelines. Here again, the focus has been on assigning a desired legal status to these donors, rather than on correctly classifying their biological status.

In our view, the criteria for determining death by both neurological and circulatory criteria have ignored biological reality and conceptual coherence in pursuit of fulfilling an important social function—being able to define people as dead while they are still physiologically in a state where their organs can be used for transplantation, that is, a state where the organs are biologically alive and the body is deemed to be dead. From a public policy perspective this may be reasonable, all things considered. People who are declared dead by neurological criteria and circulatory criteria are, in a sense, “as good as dead,” since patients who are declared brain dead will never regain consciousness and DCD donors will be biologically dead within a short time regardless of whether they are organ donors.

Some readers may see the distinction we are making between biological death and legal death as a merely theoretical exercise in conceptual clarity. In our view, however,

this distinction is also practically important, for several reasons. First, the purpose of legal fictions is to enable important social functions. Since legal fictions are, by definition, social constructions, it follows that they can be modified if and when an alternative approach would better serve that function. We have argued elsewhere that the dead donor rule is not the best foundational principle for guiding the ethics of organ donation. Instead, we see it as derivative from a more fundamental principle, that patients who donate organs should not be harmed or wronged by doing so (Miller and Truog 2012).

Requiring that patients be biologically dead before organ removal is one way of assuring that they will not be harmed or wronged; however, organs from patients who are biologically dead are not suitable for organ donation. In view of being in a state of irreversible apneic coma, the “brain dead” have lost any personally meaningful life; accordingly, they cannot be harmed or wronged by procurement of their organs while their hearts remain beating. Moreover, the fact that life-sustaining treatment would be stopped in almost all cases in the absence of organ procurement further supports the stance that these individuals are not harmed or wronged by organ donation. In sum, we fully support the current retrieval of organs from patients declared dead by neurological or circulatory criteria—not because they are biologically dead (they are not), but because they are not harmed or wronged by the donation. Whether valid consent is being obtained for vital organ donation is a complex question that we touch on briefly below.

By changing the conversation around brain death, and honestly acknowledging that patients diagnosed as brain dead are not biologically dead but are considered to be legally dead for reasons of public policy, we open up the discussion to whether modifications of this legal fiction may actually better serve public needs. Consider, for example, the fact that for most DCD donations only the kidneys are procured for transplant, since the other organs typically have suffered too much ischemic injury during the time from stopping life support to cardiac arrest and after the 2–5 minutes of pulselessness required by most DCD protocols. Given that these patients or their surrogates have expressed a desire to donate organs, and given that these patients have chosen to forego continuation of life-sustaining treatment in anticipation of death, what would be unethical about allowing patients to choose to have their organs removed under anesthesia before stopping life support and thus obviating ischemic damage to the organs? By acknowledging that our definitions of death are legal fictions, we open up the possibility for considering alternatives to the dead donor rule, especially for those who would personally choose to donate in this way. Not only would this approach yield more and better organs for transplantation, but it would permit the desires of the donor to be more completely fulfilled.

Changing the conversation around brain death would also change the misleading rhetoric applied to cases like those of Jahi McMath and Marlise Muñoz. One of the

most ironic features of these cases was that in one instance the physicians were insisting on terminating life support for a brain-dead patient, and in the other the physicians were insisting on continuing it. In both cases, however, prominent bioethicists expressed outrage about the way these patients were treated, mostly because the decision makers in each case seemed to be rejecting the notion that the patients were biologically dead (Szabo 2014). In questioning why the family members might want to continue with life-sustaining treatment, one commented that “Their thinking must be disordered, from a medical point of view. . . . There is a word for this: crazy.” Given the biological facts of the matter, “from a medical point of view” we would say that McMath’s parents were far from crazy in believing their daughter to still be biologically alive.

Furthermore, some of the comments from respected bioethicists were factually questionable. One claimed that Jahi’s body was inevitably deteriorating, and that “her body will start to break down and decay.” However, it is not generally the case that the bodies of brain-dead patients inevitably break down and decay. In fact, after an initial period of instability, some brain-dead patients can live for long periods of time, even years. As noted earlier, this is not dissimilar to patients with high cervical quadriplegia, who have a diminished life expectancy but may live for quite some time. Another prominent bioethicist insisted that Jahi McMath was dead because “You can’t really feed a corpse” (Szabo 2014). Of course he is correct, but given that brain-dead patients not only can be fed, but can digest the food, excrete wastes, and grow and develop, he has unwittingly made our point for us.

The case of Marlise Muñoz raised a different set of issues. There are numerous reports in the literature of pregnant women who have been declared “brain dead” and who have gestated a fetus for weeks or even months. In our view, this is just one more dramatic example of how “brain-dead” patients are, in fact, capable of complex integrated functioning. Nevertheless, one bioethicist described this as a “pregnancy in a cadaver” (Szabo 2014). We were surprised that so much of the discussion turned on the question of whether she was a person or a cadaver. In our view, the much more fundamental and ethically important question is whether and when the state has the right to force unwanted treatment on a woman because she is pregnant (Ecker 2014). If her brain injury had been slightly less severe, such that her prognosis was a persistent vegetative state and not brain death, surely the same issues about forced treatment against her wishes would have been just as relevant. By insisting that the key question was whether brain death is really death, the bioethics community seemed to have missed an opportunity to raise the level of discussion to a much more relevant plane.

Now that these cases have largely been resolved, it is worth reflecting on what was at stake. Some commentators suggested that those who oppose the view that brain death is biological death “threaten to undermine decades of law,

medicine, and ethics” (Magnus et al. 2014, 1). This sweeping claim needs to be critically examined. First is the fear that animated the Harvard Ad Hoc Committee in 1968, that without brain death, intensive care units (ICUs) would be full of neurologically devastated patients and we would not have room for others in need. While that perspective may have had some validity then, it makes no sense now. The majority of deaths in ICUs today follow the withdrawal of life support from patients who are not brain dead, based on the patient’s poor prognosis. The vast majority of patients and families no more desire the use of life support when hopes for a meaningful recovery are lost than physicians and nurses desire to provide it. There is no evidence to support the fear that substantial numbers of families of brain dead patients would insist on continued treatment if brain death were not recognized as biological death.

If the conversation about brain death in the United States were changed to recognize the distinction between biological death and legal death, the McMath and Muñoz cases would likely have been handled very much the same, but for different reasons. Recognizing their condition as legal death could well justify refusal to comply with a family’s demand to provide continued treatment in the hospital setting and at the expense of the state or an insurance company. Yet the fact that patients such as Jahi McMath remain alive, though in an irreversible apneic coma, supports clinicians making reasonable accommodations to facilitate transfer to a long-term care facility when families insist on maintaining treatment. Given that “brain death” does not signify biological death but is merely the extreme end of the spectrum of neurological injury, drawing the line for insurance coverage at the level of brain death may seem somewhat arbitrary. But for practical purposes we often draw lines at meaningful but nevertheless arbitrary points, such as when we grant all of the privileges of adulthood to persons on their 18th birthday.

On the other hand, if we changed the conversation about brain death, bioethicists might not have felt compelled to so studiously refer to these patients as “cadavers” and “corpses.” Their insistence in emphasizing this counterintuitive (and factually incorrect) terminology recalls the line from Shakespeare’s *Hamlet* that “The lady doth protest too much.” In any case, in the immediate aftermath of many news stories where bioethicists recited the dogma that brain death is biological death, it is telling that NBC News published a story claiming that “A 32-year-old Canadian woman who had been declared brain dead in December and kept on life support for six weeks died on Sunday soon after giving birth to a baby boy” (Gordon 2014). Even after all of the careful coaching by bioethicists, sophisticated news services still seem to have a hard time believing that a baby can be born to a woman who has been dead for six weeks. So do we.

Organ donation was not an issue in either of the two recent cases in the news; however, it is reasonable to

speculate that bioethicists endorsed the brain death dogma, and insisted that the brain dead are no different than lifeless corpses, with an eye to maintaining the established rationale for vital organ donation from heart-beating donors. We are doubtful that public support for transplantation depends on a belief that brain dead donors are biologically dead. In any case, in a democracy the public are entitled to an honest conversation about the scientific facts relevant to public policies.

One of the costs of lack of transparency about the reality of brain death is compromise of the process of informed consent for vital organ donation. Many individuals certify that they choose to be organ donors when applying for or renewing drivers' licenses. These declarations of prospective consent typically simply ask individuals to indicate whether they choose to be organ donors if they are dead. No information is supplied about the nature of brain death. Changing the conversation among bioethicists and other professionals is the first step in becoming honest with the public about what it means to be deemed dead in accordance with neurological criteria and why it is appropriate to procure organs from individuals who are legally but not biologically dead.

We realize that our views run against mainstream thought in bioethics, and we welcome those who will challenge our claims and point out where they need to be amended or abandoned. But we ask that the challenges to our position be based on the merits of the case, and not simply on insistence that the public good of organ transplantation depends upon maintaining an unsupportable view about the biology of brain death. What is the role of bioethics, if not to clarify complex issues and help society to understand them in ways that reflect the scientific facts and promote the development of sound public policy? The time has come to change the conversation about brain death, and live up to the obligations we have to both the medical profession and society at large.

DISCLAIMER

The opinions expressed are the views of the authors and do not necessarily reflect the policy of the National Institutes of Health, the Public Health Service, or the U.S. Department of Health and Human Services. ■

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