
The Public's Right to Accurate and Transparent Information about Brain Death and Organ Transplantation

BY MICHAEL NAIR-COLLINS

I believe that the organ transplantation enterprise is morally flawed. Allow me to explain why. “Brain-dead” donors are the primary source of solid vital organs, and the transplantation enterprise emphasizes that such donors are dead before organs are removed—or in other words that the dead donor rule (DDR) is followed. However, individuals meeting standard diagnostic criteria for brain death—unresponsiveness, brainstem areflexia, and apnea—are still living, from a physiological perspective. Therefore, removing vital organs from a heart-beating, mechanically ventilated donor is lethal. But neither donors nor surrogates nor the public in general are typically informed of this obviously relevant information. Therefore, donors or surrogates do not provide valid consent for a lethal medical procedure. This is a serious moral failing on the part of the transplant community. To address this concern, I advocate for accurate and fully transparent communication of information to the public to allow for an informed civic dialogue about the ethics and legality of lethal organ procurement. Furthermore, I advocate that systems be put in place by the transplant community to allow for valid consent for lethal organ procurement.

One might respond by defending the validity of brain death as a standard for death. David Magnus has argued that brain death truly is death.¹ His defense of this claim is rooted in certain metaphysical presuppositions, that we cannot “carve nature at its joints,” but rather, that there is an ineliminable element of choice involved in

the construction of biological categories, which must take into account the purposes for which the category is defined. That is, death is a social construction, a choice to be made. Choosing the diagnostic category of brain death as death is appropriate, he argues, because it matches up with most people’s intuitions about when the “person” has ceased to exist and because it allows unilateral ventilator withdrawal and organ procurement to continue while remaining consistent with the DDR.

I think Magnus is mistaken in his background metaphysics. I agree that no human practice is value free, including science, and that identifying natural ontological categories is a messy and complex, value-laden endeavor. But this doesn’t imply that the science of physiology cannot yield a physiological understanding of death. It can. Space precludes further discussion of this; I want only to flag it here.² The more salient problem with Magnus’s view is that it leads to the same practical conclusion as mine. Namely, if how to define death is a choice, then whose choice is it? Surely it is not my choice, nor solely the choice of those able to participate in socially and politically influential gatherings (nor was it solely the choice of those able to participate in the deliberations of the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death, fifty years ago). The determination of death is a fundamental question for all human societies, and it will affect all of us. This issue draws on long cultural traditions, and on deep philosophical, religious, and political worldviews and value systems. Everyone has the right and the ability to participate in informed dialogue about how we ought to define death. Thus, if identifying when death occurs is a choice, then the choice is properly one for all of us, not an elite few. Therefore, this first response to my critique

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The transplant community should put systems in place to allow for valid consent for lethal organ procurement.

yields essentially the same practical conclusion: it is time for transparency and open dialogue about brain death.

Magnus has replied to this line of reasoning with an analogy to the nosology of viral illness. Clinicians don't need to have lengthy discussions with their patients about the complexities of nosology when presumptively treating the flu, he notes, so why would they need to do this for death?³ But the analogy is spurious. We do not write laws defining who does or does not have the flu; one's deep religious values are not implicated by actions we take on the presumption that one does or does not have the flu; there are no legal challenges to the diagnosis of the flu, yet there is a growing number of legal challenges to the neurological determination of death. Death is far more important than the flu.

One of Magnus's criteria for an ideal boundary to select between life and death is that it must make organ procurement possible while remaining consistent with the DDR. But this cannot be an a priori criterion for choosing what death is. The DDR is supposed to function as a constraint on medical practice. It provides (allegedly but not in reality) a hard line that may not be crossed: if the patient is not dead, then vital organs may not be removed. But if the DDR is to function as a constraint, and if death is a choice, then the choice of what should count as death cannot be determined by the practical requirements of organ procurement itself; otherwise, the DDR is no constraint at all.

A second response to my critique is to defend the validity of brain death as a standard for death, but to do so from a biological perspective, as James Bernat does.⁴ On this idea, death is not merely a social construction. There is a biological reality to death, and patients meeting diagnostic criteria for brain death are in fact biologically dead bodies: they are corpses, despite the fact that they do not appear to be. The problem with this response is that it isn't true.

Space again precludes a lengthy treatment of these issues; however, the case can be made quite simply.⁵ Drawing on work by Alan Shewmon, imagine two patients.⁶ Patient A is in the intensive care unit with metastatic brain cancer and is unresponsive, apneic, and ventilated, with a preserved corneal blink reflex. She is in septic shock, is on pressor medication, and has multisystem organ failure. She is dying, but no one would suggest that she is already dead. Patient B meets the criteria for brain death, is on home

ventilation, is absorbing nutrition through the gastrointestinal system, has no need for a pressor agent, and is physiologically stable. Indeed, patient B is growing, sexually maturing, and healing from infections such as pneumonia or from wounds such as phlebotomy punctures. No richly detailed or complex biological theory of death is needed to see the obvious truth: patient B is physiologically living. Whatever biological life and death are, if patient B is physiologically more stable than patient A, whom everyone acknowledges is alive, then patient B is alive. The transplant enterprise does not disclose this obviously relevant fact when seeking "consent" for organs; hence valid consent is not obtained for a lethal medical procedure.

A third response is to acknowledge that brain death is not biological death but to further claim that the *person*, or human being, has ceased to exist upon irreversible unconsciousness, as Robert Veatch and many others argue.⁷ The problem with this response is that it is a non sequitur. Although many academics find it compelling to understand personhood or moral status in terms of consciousness, that's not the point. The point is that everyone else in society has the right to make up their own mind about whether they think this particularly Western vision of the self, or moral status, is compelling or not.

Fourth, one might respond that the sorts of changes I propose may plausibly lead to bad outcomes—namely, to lower organ donation rates. This concern yields a classic truth-or-consequences problem. The side of "truth" argues for broad disclosure, complete transparency, and public discussion allowing valid consent. But this may result in fewer human organs available for transplant. On the side of "consequences," one might argue that brain death works just fine in practice (even though it's got some theoretical problems), so we should not take chances that might decrease organ transplants and hence lead to more deaths.

In any truth-or-consequences problem, truth already starts with a presumption in its favor. No evidence or argument is needed to sway the case in favor of truth because that is the starting point. However, the duty to be honest might be overridden by significantly harmful consequences. Thus, if there were strong evidence that taking steps in the direction of greater transparency would cause significant harms of sufficient magnitude and likelihood, then a case might be made that harmful consequences outweigh

the presumptive duty of truthfulness. This makes plain the proper role of empirical evidence of public opinion in this debate: to assist in deciding whether the presumption in favor of truth should be overridden.

Along with colleagues, I recently developed a survey to assess U.S. residents' views on organ donation if it were described as causing the biological death of a patient in irreversible coma.⁸ The results do not provide strong evidence that highly significant harms would occur from efforts at greater transparency. Instead, respondents' support for organ donation was strong, and remained strong even when organ procurement was described as causing the death of an irreversibly comatose donor. Clearly, the presumption in favor of transparency has not been defeated.

Finally, the main response to my critique of organ transplantation is consequentialist: organ transplantation saves and improves lives. In that vein, it is important to understand how many patients are affected by organ transplantation: there were around 34,000 transplants in the United States in 2016.⁹ It is difficult to estimate the total cost of organ transplantation, but Medicare expenditures in 2014, excluding all other payers, and *excluding costs of transplant failure*, were over \$6.1 billion.¹⁰ Thus, in comparison with other aspects of the U.S. health care and social welfare systems, organ transplantation has a minimal impact on the number of lives saved or improved, and it is highly expensive. Appealing to the good consequences of organ transplantation in an attempt to justify the lack of transparency, if not outright obfuscation on which the transplantation enterprise rests, is not a very compelling argument. There are better things that the bioethics community could stake its claim on protecting or advocating, such as universal health care or universal access to healthy food and clean water.

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1. D. C. Magnus, "A Defense of the Dead Donor Rule," *Defining Death: Organ Transplantation and the Fifty-Year Legacy of the Harvard Report on Brain Death*, special report, *Hastings Center Report* 48, no. 6 (2018): S36-S38.

2. I discuss the role of facts and values in a biological theory of death in M. Nair-Collins, "A Biological Theory of Death: Characterization, Justification, and Implications," *Diametros* 55 (2018): 27-43.

3. Magnus proposed this analogy during discussion at the "Defining Death: Organ Transplantation and the 50-Year Legacy of the Harvard Report on Brain Death," which took place at Harvard Medical School, in Boston, April 11-13, 2018.

4. J. Bernat, "A Conceptual Justification for Brain Death," *Defining Death: Organ Transplantation and the Fifty-Year Legacy of the Harvard Report on Brain Death*, special report, *Hastings Center Report* 48, no. 6 (2018): S19-S21.

5. But see M. Nair-Collins and F. G. Miller, "Do the 'Brain Dead' Merely Appear to Be Alive?," *Journal of Medical Ethics* 43 (2017): 747-53.

6. D. A. Shewmon, "Constructing the Death Elephant: A Synthetic Paradigm Shift for the Definition, Criteria, and Tests for Death," *Journal of Medicine and Philosophy* 35 (2010): 256-98.

7. See Robert M. Veatch's essay in this collection: "Would a Responsible Person Now Accept the 1968 Harvard Brain Death Report? A Short History of Brain Death," *Defining Death: Organ Transplantation and the Fifty-Year Legacy of the Harvard Report on Brain Death*, special report, *Hastings Center Report* 48, no. 6 (2018): S6-S9.

8. M. Nair-Collins, S. R. Green, and A. R. Sutin, "Abandoning the Dead Donor Rule? A National Survey of Public Views on Death and Organ Donation," *Journal of Medical Ethics* 41 (2015): 297-302.

9. United Network for Organ Sharing, <https://unos.org/>.

10. M. A. Schnitzler et al, "OPTN/SRTR 2016 Annual Data Report: Economics," *American Journal of Transplantation* 18, S1 (2018): 464-503. The Medicare estimate of \$6.1 billion was derived by summing the total calendar-year Medicare costs of each class of organ recipient for 2014 (that is, kidney plus pancreas and so on). These costs are found in tables 5, 10, 15, 20, 25, and 30. This estimate is based on single-year expenditures paid by Medicare alone, excluding other payers, and excluding all costs incurred after transplant failure. Furthermore, this should not be construed as an estimate of the cost of roughly 34,000 transplants alone; instead, this cross-sectional single-year estimate includes initial transplantation cost for those individuals who received a transplant in 2014 (for which Medicare was the payer), as well as follow-up costs for individuals who received a transplant prior to 2014. See the full article for more detailed information.