Ethical Challenges to Neurological Criteria for Death

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When is a person dead? This question has significance in the Catholic understanding of organ transplants from donors, both living and dead, and to recipients, because it frames our Catholic approach to how to best care for all involved.

Before 1954, the answer was clear: A person is dead when they are not breathing and when their heart is not working. This is known as the cardio-pulmonary determination of death. It remains the standard definition for deciding when someone is dead and the most frequently used criterion for death. Most of us will likely be declared dead by this definition.

But, for some context, we need to take a short historical journey before we return to this question of whether the cardio-pulmonary definition alone is sufficient for determining whether someone is dead.[1] In 1954, the cardio-pulmonary definition was challenged, indirectly and unexpectedly. That was the year that human organ transplantation was first successful at Peter Bent Brigham Hospital in Boston where Dr. Joseph Murray successfully transplanted a kidney between two twins.[2]

It is easy to see how transplants can be a great good. In this historical case, a living donor gave an organ to someone in need. To be specific, most humans have two kidneys. So, they can still live with only one kidney. But quickly after this kidney transplant, a Catholic moral question emerged about how such a donation could be moral.

Catholic theology prohibits the mutilation of the human body. Mutilation is any intervention that inhibits or destroys the healthy functioning of the human body. If we are created in the image of God, and our creation as embodied persons is good, we do not have license to destroy something that is healthy and functional.

So, how can someone donate an organ to another person when that organ is healthy and functions for the person who wants to give it to others? At first glance, participating in live organ transplantation would seem to suggest that we are doing something moral by gifting an organ. However, at the same time, it would seem like doing something immoral by denying ourselves the use of that same organ.

How can we measure this choice? Pope Pius XII addressed this question shortly after the first kidney transplant. His response, in the context of corneal transplants, was that organ donation should be understood as an intent to be charitable, rather than as an intent to mutilate.[3] Those who give organs in these circumstances do not intend to diminish themselves; rather, they seek to help those in need.

Successful kidney transplantation opened a door. Kidneys were the first transplants, but other organs quickly followed. Today, there are multiple organs that can be successfully transplanted. Furthermore, there are multiple circumstances today that define death due to recent medical advancements. As the clinical techniques for transplanta-

tion became perfected, the questions shifted from whether transplants were ethical (which most conceded that they were) to more pragmatic concerns about the source of organs that could be transplanted. There were, and still are, more persons who need transplants than there are donors.[4]

Another factor in this conversation is that in the late 1950s and early 1960s, medicine became much better at treating, if not curing, what were once immediately fatal (acute) conditions. As intensive care medicine evolved, some organ system functions could be wholly provided or significantly improved by adding technology (for example, through mechanical ventilation, hemodialysis, etc.). Patients who would have died in earlier times from acute conditions were now "surviving," or more accurately, were in a state of temporary stability from death. It is fair to say that the lived experience of many of those patients was not what we would consider to be ordinary life. At best, for some, it was a suspension, rather than a cessation, of the process of death. In other cases, of course, the advances in technology for chronic illnesses significantly improved lives.

So, the success of organ transplantation and the existence of this population of patients led to a discussion at Harvard Medical School. The practical question was whether these patients, who were sustained only because of technological intervention, were really alive or dead. Was a patient who was maintained by machines but had no brain activity truly alive? What if only some parts of their brain were not functioning, and was this nonfunctioning temporary or permanent? How would death be defined if patients were perfused and respirated by machines? If these patients were being artificially maintained, could they actually be dead? And, if they were dead, could they be a source of organs to assist the living? These were the questions surrounding the advances in transplantation medicine.

The Ad Hoc Committee of Harvard Medical School to Examine the Definition of Brain Death questioned whether the cardio-pulmonary definition of death was sufficient to determine all circumstances of death. In 1968, this committee recommended that neurological criteria be accepted to determine death, in addition to cardio-pulmonary criteria. This led to "brain death," as it is popularly known, or, more accurately, to "the determination of death by neurological criteria."

The committee debated two definitions of death by neurological criteria: whole brain death and higher brain death. The choice was whether death is determined by when the entire brain ceases to function or whether the "thinking" or "higher parts" of the brain are not functioning. Their recommendation was that whole brain death was the better standard. The whole brain standard was that brain death was defined, in the words of the Harvard Committee, as the "irreversible cessation of all functioning of the entire brain."[5]

Once the Harvard definition became the clinical, and, largely, legal standard, there have been challenges to it. The threshold of "the irreversible cessation of all functions of the entire brain" is a high standard. It is fair to say that there are some clinical circumstances in which this cannot be immediately determined, particularly when patients are maintained by artificial means.[6]

EXAMINING OTHER DEFINITIONS OF BRAIN DEATH

Dr. Robert Truog of Harvard Medical School has been a persistent critic of the whole brain definition since the early 1990s. In his view, the choice should have been the "higher brain standard." He points to a number of clinical criteria that do not meet the whole brain standard. His principal arguments are that many clinically brain-dead patients maintain hypothalamic endocrine function, which would indicate that the whole brain is not dead. Second, he argues that many persons maintain cerebral electrical activity. Third, some patients retain evidence of environmental responsiveness. Fourth, the brain is physiologically defined as the central nervous system, and many clinically brain-dead patients retain central nervous system activity in the form of spinal reflexes.[7] Many of these concerns persist today.

Surprisingly, a few Catholic authors are now aligning with Truog in his argument. In particular, there are some who are now advancing the argument that any hypothalamic function means that whole brain death has not occurred, in a statement called "Catholics United on Brain Death and Organ Donation: A Call to Action."[8]

The hypothalamus is a neuroendocrine interface that is situated near the center of the brain. As some authors describe it, the hypothalamus "is a high-level sensory integration and motor output area that maintains homeostasis by controlling

endocrine, autonomic and somatic behavior."[9] However, its functioning is not part of the determination of death by neurological criteria, according to the Ad Hoc Harvard Committee.

There are perhaps two reasons for this. First, with synthetic hormones substituting for a nonworking hypothalamus, it is possible to live for a short time without a hypothalamus. So, its absence, or its presence, does not necessarily invalidate the current criteria. Second, although a hypothalamus may continue to "work" for a time after the Harvard criteria have been met, this does not necessarily constitute "life."

The clinical tests of the Ad Hoc Harvard Committee for the determination of death by neurological criteria do not have any "replaceable" functions, like hypothalamic activity. The tests assess whether the person reacts to physical stimuli that would indicate brain activity. They focus on three points: coma, brainstem areflexia and apnea. None of these conditions can be replaced by other therapies.

As noted earlier, even when there is a positive confirmation of brain death, there are some bodily functions that will continue to work for a time, including, for example, some cell growth.

The neurological determination of whole brain death does not mean that the human body will not function after that judgment. As death is a process, rather than a fixed point in time, it means that the neurological determination of death is a clinical judgment that the process of the disintegration of the person and their body is irreversible. So hypothalamic function after whole brain determination is not necessarily a negation of the definition of whole brain death.

QUESTIONS AROUND DETERMINATION OF DEATH

Lately, because of this discussion about hypothalamic function, as well as others, there have been challenges to the Uniform Determination of Death Act (UDDA) definition at the Uniform Law Commission. The Uniform Law Commission established a committee in 2021 to offer recommendations for five questions:

1. Should the term "irreversible" be replaced by the term "permanent"?

2. Is the absence of hypothalamic-pituitary-axis-induced antidiuretic hormone secretion included in "all functions of the entire brain"? If so, how can we reconcile the fact that this is not tested in the medical standards for the determination of death by neurologic criteria published by the American Academy of Neurology, the Society of Critical Care Medicine, American Academy of Pediatrics and Child Neurology Society?

3. What are the accepted medical standards for the determination of death?

4. Is consent needed to determine death?

5. How should objections to the use of neurologic criteria to declare death be handled?[10]

The formation of this committee highlighted continuing discussions among clinicians, bioethicists, theologians and philosophers on the nuances of determining death. It is clear that the original Harvard and UDDA criteria are challenged by some anomalous cases in which persons have met the criteria for death by neurological criteria, yet still persist for a time. The committee formed by the Uniform Law Commission paused its deliberations in 2023 because it could not reach consensus.[11]

Given the history of the criteria and its application, there are three possible responses to the continued use of the criteria. First, one could argue that the criteria are generally applicable and are acceptable for the vast majority of instances when a medical decision needs to be made. So, therefore, no change is needed. Secondly, one could argue that additional criteria could be added to the present definition to test hypothalamic function and cerebral blood flow to have greater certainty that all function of the entire brain has ceased. Third, one could adopt the U.K./Truog criteria which focuses on higher brain function.

In assessing these three possibilities, we should also question the expectation of certainty in determining death. From a Catholic perspective, we cannot conflate moral certainty with absolute medical certainty, which, clinically, is something that is rare. Often, clinicians have to rely on their best judgment in complex cases.

So, to assess the three responses, we could continue to accept the present definition, with the understanding that there will inevitably be some cases, like Jahi McMath, in which the criteria are met, but do not provide absolute certainty that the person is dead. We could also redefine the criteria to include new tests. Weighing the choice between continuing to accept the present criteria or revising them must take into account the effect

such a revision will have on public confidence in the organ procurement system. Catholic ethicists would still reject the higher brain standard, which is the third option.

Having acknowledged that discussion, I believe that it is accurate to say that the majority of those who are involved in the clinical and theological application of the present criteria for the determination of death by neurological criteria would not take the position of the signatories of "Catholics United on Brain Death and Organ Donation: A Call to Action," which is to say that the present criteria are fatally flawed. Many well-regarded clinicians, bioethicists, theologians and philosophers were asked to sign, and they declined. More representative Catholic views on the determination of death by neurological criteria can be found in other statements.[12]

Based on Catholic ethics tradition and ongoing consideration related to these issues, I think the consensus is that some take the position that the present criteria have moral, if not absolute clinical, certainty, while others would say we should try to address the rare cases with heightened tests.

NURTURING A GENUINE CULTURE OF LIFE

In conclusion, the legal definition of determining death by neurological criteria is now more than 40 years old. In that time, clinical practice has shown that it has largely been an effective means of diagnosing death. The body of knowledge related to medicine is always increasing,[13] and skilled clinicians make the best determinations they can with the information available to them.

Having said that, it is important to acknowledge that there are still some issues that require continued scientific and theological discussion. The theological and clinical discussion about the certainty of criteria to establish death by neurological criteria is important, but nuanced. At the same time, however, it is premature to reject the Harvard criteria and to call for Catholics to not donate organs (as urged by "A Call to Action" signatories). As St. John Paul II has written, one way of nurturing a genuine culture of life "is the donation of organs, performed in an ethically acceptable manner, with a view to offering a chance of health and even of life itself to the sick who sometimes have no other hope."[14]

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NOTES

1. The history of transplantation is very detailed and includes animal and human models. For some background, please see: Clyde F. Barker and James F. Markmann, "Historical Overview of Transplantation," *Cold Spring Harbor Perspectives in Medicine* 3, no. 4 (April 2013): https://doi.org/10.1101/cshperspect.a014977.
2. Alvin Powell, "A Transplant Makes History," *The Harvard Gazette*, September 22, 2011, https://news.harvard.edu/gazette/story/2011/09/a-transplant-makes-history/.
3. Pius XII to the Italian Union for The Blind, "Comment on Corneal Transplants," *Acta Apostolicae Sedis*, May 14, 1956; Also, see John Paul II on transplants: Pope John Paul II, "Address of the Holy Father John Paul II to the 18th International Congress of the Transplantation Society," The Holy See, August 29, 2000, https://www.vatican.va/content/john-paul-ii/en/speeches/2000/jul-sep/documents/hf_jp-ii_spe_20000829_transplants.html.
4. See the following source, which lists on its homepage the number of people who need an organ and the number of donations that they have available for those recipients: "Actions to Strengthen the U.S. Organ Donation and Transplant System," Unified Network for Organ Sharing, https://unos.org/transplant/improve-organ-donation-and-transplant-system/.
5. See the following source (requires paid access). The criteria were supported by specific physical challenges to determine if different parts of the brain were functional. An example of the present criteria is the American Academy of Neurology guidelines: "Pediatric and Adult Brain Death/Death by Neurologic Criteria Consensus Guideline," American Academy of Neurology, October 2023, https://www.health.ny.gov/professionals/hospital_administrator/determining_brain_death/docs/aan_brain_death_guidelines.pdf.
"A Definition of Irreversible Coma: Report of the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death," *JAMA* 205, no. 6 (August 5, 1968): 337–340, https://doi.org/10.1001/jama.1968.03140320031009.
After Harvard Medical School published its criteria, the Uniform Law Commission (https://www.uniformlaws.org/home) adopted the Uniform Determination of Death Act in 1980, 12 years later. For background, this organization works to draft common language for state laws so that there is consistency in language and application for common legal issues. Presently, 39 states, plus the District of Columbia and the U.S. Virgin Islands, have adopted common language on death by neurological criteria, based on the Harvard

Committee's criteria. Those states that do not adopt the "common language" do so because of accommodations from constituents in those states. For example, in New York, statutory exceptions from determining death by neurological criteria have been heavily influenced by Orthodox Jewish leaders, who think that the criteria are in conflict with their own beliefs about death.

6. In years past, there have been several cases where the criteria for the determination of brain death have been questioned. One case to be highlighted is Jahi McMath. This 13-year-old girl was declared brain dead on December 12, 2013, after a hemorrhagic complication following complex oropharyngeal surgery. Although she was declared dead by neurological criteria in California, her mother transferred her care to New Jersey, which recognized a religious exemption to neurological criteria. She subsequently underwent menarche. So, her experience represents a challenge to the Harvard criteria. D. Alan Shewmon and Noriko Salamon, "The Extraordinary Case of Jahi McMath," *Perspectives in Biology and Medicine* 64, no. 4 (2021): https://doi.org/10.1353/pbm.2021.0036.

7. Dr. R.D. Truog and Dr. J.C. Fackler, "Rethinking Brain Death," *Critical Care Medicine* 20, no. 12 (December 1992): https://doi.org/10.1097/00003246-199212000-00018. While I do not agree with Truog on his criteria, I do see a point in his resistance. The Ad Hoc Committee at Harvard saw death as a point in time. If the criteria are present, one is dead, and if all the criteria are not there, one is alive. In opposition to the committee, I would suggest that death is a process. Usually, it is immediate. However, for some people, the process of dying is a slower one of moving toward the criteria. I think that the question is whether there is disintegration in the body. I think that the clinical tests for the determination of death by neurological criteria affirm that the process has started, even if it is not immediately completed.

8. Dr. Joseph M. Eble, John A. Di Camillo, and Peter J. Colosi, "Catholics United on Brain Death and Organ Donation: A Call to Action," Catholic Culture, February 27, 2024, https://www.catholicculture.org/culture/library/view.cfm?recnum=12731; "Integrity in the Determination of Brain Death: Recent Challenges and Next Steps," The National Catholic Bioethics Center, April 11, 2024, https://static1.squarespace.com/static/5e3ada1a6a2e8d6a131d1dcd/t/661802bbc44c0135b4f86639/1712849595809/Integity+in+the+Determination+of+Brain+Death.pdf.

9. William Young, "Overview of the Endocrine System," Merck Manual, April 2022, https://www.merckmanuals.com/professional/endocrine-and-metabolic-disorders/principles-of-endocrinology/overview-of-the-endocrine-system. To make the point again, a positive diagnosis of whole brain death does not mean that some parts of the human body cannot continue to function for some time.
Also, see: Matthew H. Bear; Vamsi Reddy, and Pradeep C. Bollu, "Neuroanatomy, Hypothalamus," Statpearls, October 2022, https://www.ncbi.nlm.nih.gov/books/NBK525993/.

10. Ariane Lewis, "The Uniform Determination of Death Act is Being Revised," *Neurocritical Care* 36, no. 2 (April 2022): 335-338, https://doi.org/10.1007/s12028-021-01439-2. It is beyond the scope of this essay to explore all these questions. They are, however, important.

11. "Perspectives of Medical Organizations, Organ Procurement Organizations, and Advocacy Organizations About Revising the Uniform Determination of Death Act (UDDA)," *Neurocritical Care* 39, no. 2 (October 26, 2023): https://link.springer.com/article/10.1007/s12028-023-01872-5.

12. Daniel Sulmasy et al., "A Biophilosophical Approach to Brain Death," *Chest* 165, no. 4 (April 2024): 959-966, https://doi.org/10.1016/j.chest.2023.12.011; Jason Eberl et al., "The Danger of Turning 'Brain Death' and Organ Donation into Culture War Issues," *America: The Jesuit Review*, April 18, 2024, https://www.americamagazine.org/faith/2024/04/18/brain-death-organ-donation-catholic-catechism-247725.

13. As one example of how the body of knowledge changes, this article published online shortly before *Health Progress* went to print: William R. Sanders et al., "Recovery Potential in Patients Who Died After Withdrawal of Life-Sustaining Treatment: A TRACK-TBI Propensity Score Analysis," *Journal of Neurotrauma* (May 13, 2024): https://www.liebertpub.com/doi/10.1089/neu.2024.0014.

14. Pope John Paul II, *Evangelium Vitae*, section 86, https://www.vatican.va/content/john-paul-ii/en/encyclicals/documents/hf_jp-ii_enc_25031995_evangelium-vitae.html.

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