

# Determining Brain Death: Will Scientific Certainty Get Us There?

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## Introduction

In his address to the 18<sup>th</sup> International Congress of the Transplantation Society, Pope John Paul II said that in acknowledgement of the unique dignity of the human person, vital organs which occur singly can only be removed from a person after the person's death.<sup>1</sup> To do otherwise would intentionally cause the person's death. He admitted that his assertion gives rise to one of the more debated issues in contemporary bioethics and in the minds of concerned persons – the problem of ascertaining the moment of death. He stated:

In this regard, it is helpful to recall that *the death of the person* is a single event, consisting in the total disintegration of that unitary and integrated whole that is the personal self. It results from the separation of the life-principle (or soul) from the corporal reality of the person. The death of the person, understood in this primary sense, is an event which *no scientific technique or empirical method can identify directly.*<sup>2</sup>

In his address, the Pope asserted that the complete and irreversible cessation of all brain activity, if rigorously applied, is a morally certain way of determining death. Despite this statement and others that support the current neurological conception of death, the debate continues.

Death has never had a precise clinical determination. Throughout history, criteria have ranged from signs of decomposition to primitive assessments of ceased cardiopulmonary function (such as using a mirror to determine the presence of breathing).<sup>3</sup> Clinical determinations were not questioned on philosophical or theological grounds, but out of concern for public safety and premature pronouncement of death (decomposition risked infectious disease and primitive cardiopulmonary assessments risked premature burial). Emphasis on more definitive clinical criteria evolved over time as a way to help minimize these risks and, in modern times, as a means to declare a patient dead for organ donation.

The modern development of the concept of brain death, on the other hand, has raised broader questions concerning the

relationship between clinical criteria and the meaning of death. The concern does not arise out of fear that the patient might unexpectedly recover; a 2010 study found no evidence of neurological recovery in patients diagnosed as brain dead between 1996 and 2009.<sup>4</sup> The concern arises out of fear that we may be pronouncing persons and harvesting organs their organs when they are not *really* dead.

### The Debate

'Brain death' originated in the 1950s and 60s when medical technology created a new class of patients for whom circulation and respiration could be artificially maintained despite a complete lack of neurological function. In 1959, the term coma dépassé (beyond coma) was coined to describe 12 comatose patients with flat EEGs who had lost consciousness, brainstem reflexes, and spontaneous respiration, yet whose circulation and respiration could be maintained artificially.<sup>5</sup> In 1968, the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death issued a report that set out a new brain-based set of criteria for determining death. The criteria included a permanent loss of all brain functions, from consciousness to primitive brainstem reflexes.<sup>6</sup>

In 1981, the President's Bioethics Commission, in drafting a uniform determination of death act, outlined two definitions of death: irreversible cessation of circulatory and respiratory functions; and irreversible cessation of all functions of the entire brain, including the

brainstem.<sup>7</sup> The new uniform determination of death law did not outline, however, an unequivocal definition of clinical testing, including indications, procedures, and validity and reproducibility of neurological tests.<sup>8</sup> In 1995, these clinical questions were addressed by the American Academy of Neurology (AAN), which published a set of practice parameters to help clinically determine brain death in adults.<sup>9</sup>

Until recently the rationale for brain death was that the brain represented an irreversible loss of integration of the person as a whole because it was the primary integrator and mediator of somatic functioning.<sup>10</sup> Evidence now suggests that many integrated functions of the body are not brain-mediated and many integrative functions of the brain do not incorporate vital functions of the body.<sup>11</sup> Brain dead patients on mechanical ventilation, for example, maintain their own digestion, hormonal balance, wound healing, and even, in some cases, gestation of a fetus. Some have suggested that patients diagnosed as brain dead remain alive in virtually every sense except for the loss of neurological function.<sup>12</sup>

In 2008 the President's Council on Bioethics published a white paper entitled "Controversies in the Determination of Death."<sup>13</sup> The council abandoned the idea that the brain was the integrator and mediator of somatic function, but they did not abandon the concept of brain death. Rather, the council moved to an elementary biological concept of an

organism's being, not just its pathophysiological functioning. The white paper mentioned the following as fundamental capacities of a living organism: 1) openness to the world, receptivity to stimuli from the surrounding environment; 2) an ability to act upon the world to obtain what is needed, and; 3) a basic drive that causes the organism to act. The council stated that these capacities were mutually supporting and included the inner drive for spontaneous breathing (thereby not including coma or PVS patients in the definition of death).

The paper concluded that ultimately death is a philosophical question, not one that can be answered by biological facts alone, and admitted that certain biological activities in cells and tissues remain for some time throughout the body even after many would agree that a body had become a corpse.<sup>14</sup> The 2008 white paper has not settled the debate.<sup>15</sup> Criticisms today remain the same. To critics, processes such as digestion, immune response, and the presence of certain neural hormones in brain death patients are examples of the fundamental capacities defined by the 2008 council.<sup>16</sup>

The debate has now become so centered on pathophysiology, some authors are now referring to decapitated bodies and chickens running after having their heads cut off as evidence, or lack thereof, of an organism's life.<sup>17</sup> Consequently, some have asked whether it is time to abandon the concept of brain death and the dead donor rule entirely.<sup>18</sup> Many ask whether

it is more appropriate to argue that brain death is so devastating as to allow organ donation, even though the person is not technically dead until after the organs are harvested,<sup>19</sup> a consequential argument that contradicts Pope John Paul's address.

### Will Scientific Certainty Get Us There?

Debates that try to definitively draw the line are susceptible to the continuum fallacy, and I wonder if that is not what has happened in the debate on brain death. A continuum fallacy says that you cannot draw qualitative conclusions about an issue when you cannot make definitive quantitative distinctions.<sup>20</sup> One famous example is facial hair. Although most, if not everyone, admits to a clear distinction between clean-shaven faces, whiskers, and beards, it is impossible to determine the exact length or number of hairs to determine the difference. A continuum fallacy asserts that because it is impossible to determine the exact point at which a person crosses over from whiskers to a beard, then we can never look at a person and say that his whiskers have *really* become a beard.

Defining death as an exact moment biologically is much like trying to determine the exact amount of facial hair a person must have in order to have a beard instead of whiskers. Biologically, the human body is made of systems, organs, tissue, and cells that often act independently. One can always ask which ones and how many must cease to function before a person is considered dead from a strict biological perspective.

Ultimately death is a theological and philosophical concept supported by biological data, not defined by it. Pope John Paul II spoke to this difference in his address when he said:

Yet human experience shows that once death occurs *certain biological signs inevitably follow*, which medicine has learnt to recognize with increasing precision. In this sense, the "criteria" for ascertaining death used by medicine today should not be understood as the technical-scientific determination of the *exact moment* of a person's death, but as a scientifically secure means of identifying *the biological signs that a person has indeed died*.<sup>21</sup>

Most of the brain death debate confuses this difference. Critics of brain death try to match the technical-scientific moment of determining death with a scientifically secure means for assuring that a person has died, and claim that a moral determination of death cannot be made without making this perfect match.

Admittedly, there are still concerns about brain death, mirroring the call of the Pope to be rigorous in its determination. Concerns include accuracy of tests, misdiagnosis, and uniformity in practice patterns.<sup>22</sup> For example, the aforementioned 2010 study reported that there is insufficient evidence to determine the comparative safety of techniques used for apnea testing, the minimally acceptable observation period to ensure

that neurologic functions have ceased irreversibly, or if newer ancillary tests accurately confirm brain death.<sup>23</sup> Data also suggests a pattern of non-uniformity in practice patterns, including techniques for testing brainstem function, whether and how to perform apnea testing, and whether or which confirmatory electrophysiologic or neuroimaging tests are used.<sup>24</sup> Such concerns and inconsistency can raise anxiety about whether patients undergoing such tests are *really* dead. These questions regard clinical accuracy and uniformity, but can become easily confused with philosophical and theological conceptions of death.

The brain death debate has refined these clinical criteria and practice parameters over time; this refinement needs to continue. Institutions may want to review their brain death policies to ensure that they are consistent with the current AAN guidelines and that staff are comfortable following them. Also institutions may want to address how they approach and support families when the diagnosis is made, and how conflicts will be resolved. Although families may not understand the technical debates surrounding brain death, they intuitively ask the same questions about continued biological functioning, a warm body, a beating heart, etc. Efforts to educate and minimize confusion can be helpful.

In the end, many would argue that organ donation is the primary driver to maintaining the conception of death by neurological criteria.<sup>25</sup> Recent efforts to implement organ donation by cardiac

death (DCD) protocols have likely increased awareness and concerns around determining death prematurely, and have undoubtedly given renewed attention to brain death.<sup>26</sup> In my opinion, however, the concept of brain death does not serve organ transplantation only. It is also supports families facing loved ones who have been diagnosed brain dead, regardless of whether they will donate the person's organs.

Not long ago I counseled a family with the brain death of their loved one – a woman in her early 20s who reached the state of brain death due to complications from H1N1. In this case, the diagnosis of brain death did not facilitate organ donation (the family refused donation), but the diagnosis did help support the family in their loss and grieving. I and others explained to the family that the young girl's condition was different than a coma, PVS, or other impaired neurological state. These other states show some signs of response to the environmental or somatic regulation – such as spontaneous breathing. Unlike these other states, no one has ever 'recovered' from brain death.

Ultimately we told the family that their loved one had died. In the end, the family did not feel as if they were making a decision to “pull the plug” or were somehow “not giving her every chance at life”, which are common sentiments from loved ones facing end-of-life decisions. Rather, much of the family began grieving over her body even before we disconnected artificial respiration (we did

not refer to it as life-sustaining treatment as not to confuse the family that we were sustaining their loved one's life).

This may be where debate concerning clinical criteria and the meaning of death arises, practically speaking. Although the Catholic tradition on brain death and its implication for Catholic hospitals is clear, other religious traditions may approach the issue differently. The family I counseled did not object on religious grounds, but others may.

Accommodations to these different beliefs should be made after discussions about the true teachings of that religion and after their real applicability to the concept of neurological death are clarified with religious experts.

There may never be a perfect match between the moral determination of death and the clinical criteria used to support that determination. That does not mean that a line should not be drawn. Brain death is not just a determination that supports the dead donor protocol and organ donation. It also supports families facing a loved one's death by helping illustrate the reality of the patient's condition versus other more commonly known diagnoses (i.e., coma, PVS), and aids them in their ability to face the finality of that diagnosis.

Resources:

<sup>1</sup> Pope John Paul II, "Address of the Holy Father John Paul II to the 18<sup>th</sup> International Congress of the Transplantation Society." [http://www.vatican.va/holy\\_father/john\\_paul\\_ii/sp\\_eches/2000/jul-sep/documents/hf\\_jp-ii\\_spe\\_20000829\\_transplants\\_en.html](http://www.vatican.va/holy_father/john_paul_ii/sp_eches/2000/jul-sep/documents/hf_jp-ii_spe_20000829_transplants_en.html) Last access on August 26<sup>th</sup>, 2010.

<sup>2</sup> Ibid.

<sup>3</sup> J.N. Kirkpatrick, K.D. Beasley, and A. Caplan, "Death is Just Not What is Used to Be," *Cambridge Quarterly of Healthcare Ethics*, 19, 2010: 7-16.

<sup>4</sup> E.F.M. Wijdicks, P.N. Varelas, G.S. Gronseth, and D.M. Greer, "Evidence-Based Guideline Update: Determining Brain Death in Adults," *American Academy of Neurology*, 74, 2010:1911-18.

<sup>5</sup> P. Mollaret and M. Goulon, "Le coma dépassé (mémoire préliminaire)," *Revue de Neurologie (Paris)*, 101,1959: 3-5.

<sup>6</sup> Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death, "A Definition of Irreversible Coma," *JAMA*, 205 (6) 1968: 337-40.

<sup>7</sup> President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, "Defining Death: A Report on the Medical, Legal, and Ethical Issues in the Determination of Death," Washington, D.C.: Government Printing Office, 1981.

<sup>8</sup> E.F.M. Wijdicks, "Determining Brain Death in Adults," *Neurology*, 45, 1995:1003-11.

<sup>9</sup> The Quality Standards Subcommittee of the American Academy of Neurology, "Practice Parameters for Determining Brain Death in Adults (summary statement)," *Neurology*, 45, 1995:1012-14.

<sup>10</sup> A. Joffe, "Are Recent Defenses of the Brain Death Concept Adequate?" *Bioethics*, 24 (2), 2010: 47-53.

<sup>11</sup> D.A. Shewmon, "The Brain and Somatic Integration: Insights into the Standard Biological Rationale for Equating 'Brain Death' with Death." *Journal of Medicine & Philosophy*, 26 (5), 2001: 457-78.

<sup>12</sup> F.G. Miller and R. D. Truog, "Rethinking the Ethics of Vital Organ Donations," *Hastings Center Report*, 38(6), 2008:36-46.

<sup>13</sup> President's Council on Bioethics, "Controversies in the Determination of Death," Washington, D.C.: Government Printing Office, 2008.

<sup>14</sup> Ibid.

<sup>15</sup> D. A. Shewmon, "Brain Death: Can It Be Resuscitated?" *Issues in Law & Medicine*, 25(1), 2009:3-12.

<sup>16</sup> F. G. Miller and R. D. Truog, "The Incoherence of Determining Death by Neurological Criteria: A Commentary on Controversies in the Determination of Death, A White Paper by the President's Council on Bioethics," *Kennedy Institute of Ethics Journal*, 19(2), 2009:185-93.

<sup>17</sup> Ibid., pp. 397-99. J. P. Lizza, "Commentary on 'The Incoherence of Determining Death by Neurological Criteria,'" *Kennedy Institute of Ethics Journal*, 19(4): 393-5.

<sup>18</sup> R. D. Truog, "Is it Time to Abandon Brain Death?" *Hastings Center Report*, 27(1),1997.

<sup>19</sup> M. Potts, "A Requiem for Whole Brain Death: A Response to D. Alan Shewmon's 'The Brain and Somatic Integration,'" *Journal of Medicine & Philosophy*, 26(5), 2001: 479-91. R. D. Truog and V. M. Robinson, "Role of Brain Death and the Dead-Donor Rule in the Ethics of Organ Transplantation," *Critical Care Medicine*, 31, 2003: 2391-96. R. M. Veatch, "Abandon the Dead Donor Rule or Change the Definition of Death?" *Kennedy Institute of Ethics*, 14, 2004: 261-76. G. Boniolo, "Death and Transplantation: Let's Try to Get Things Methodically Straight," *Bioethics*, 21, 2007: 32-40. R. D. Truog and F. G. Miller, "The Dead Donor Rule and Organ Transplantation," pp. 674-5.

<sup>20</sup> Wikipedia. "Continuum Fallacy." [http://en.wikipedia.org/wiki/Continuum\\_fallacy](http://en.wikipedia.org/wiki/Continuum_fallacy) Last accessed on August 25<sup>th</sup>, 2010.

<sup>21</sup> Pope John Paul II, "Address of the Holy Father John Paul II to the 18<sup>th</sup> International Congress of the Transplantation Society."

<sup>22</sup> E. F. M. Wijdicks, "The Diagnosis of Brain Death," pp. 215-21.

<sup>23</sup> Quality Standards Subcommittee of the American Academy of Neurology, "Evidence-Based Guideline Update: Determining Brain Death in Adults," pp. 1911-18.

<sup>24</sup> D. M. Greer, P. H. Varelas, S. Haque and E. F.M. Wijidicks, "Variability of Brain Death Determination Guidelines in Leading US Neurologic Institutions," pp. 284-9. J. L. Bernat, "How Can We Achieve Uniformity in Brain Death Determinations?" *Neurology*, 70, 2008: 252-3.

<sup>25</sup> J.D. Banja, "Are Brain Dead Patients *Really* Dead?" *The Journal of Head Trauma Rehabilitation*, 24(2), 2009:141-44.

<sup>26</sup> J. L. Bernat, "The Boundaries of Organ Donation after Circulatory Death," *New England Journal of Medicine*, 359(7), 2008: 669-71. G. F. Burke, "A Non-Heart Beating Donor Protocol," *Ethics & Medics*, 2000, 25(4): 1-3. T. S. Huddle, M. A. Schwartz, F. A. Bailey and M. A. Bos, "Death, Organ Transplantation and Medical Practice." *Philosophy, Ethics, and Humanities in Medicine*, 3: 5.