




# Does the Uniform Determination of Death Act Need to Be Revised?

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## Abstract

Prompted by concerns raised by the rise in litigations, which challenge the legal status of brain death (BD), Lewis and colleagues recently proposed a revision of the Uniform Determination of Death Act (UDDA). The revision consists of (i) narrowing down the definition of BD to the loss of specific brain functions, namely those functions that can be assessed on bedside neurological examination; (ii) requiring that the determination of BD must be in accordance with the specific guidelines designated in the revision; and (iii) eliminating the necessity for obtaining consent prior to performing the tests for BD determination. By analyzing Lewis and colleagues' revision, this article shows that this revision is fraught with difficulties. Therefore, this article also proposes two approaches for an ethical revision of the UDDA; the first is in accordance with scientific realism and Christian anthropology, while the second is grounded in trust and respect for persons. If the UDDA is to be revised, then it should be based on sound ethical principles in order to resolve the ongoing BD controversies and rebuild public trust.

**Summary:** This article critically examines the recent revision of the Uniform Determination of Death Act (UDDA) advanced by Lewis and colleagues. The revision only further reinforces the status quo of brain death without taking into account the root cause of the litigations and controversies about the declaration of death by neurological criteria. In view of this deficiency, this article offers two approaches to revising the UDDA, both of which are founded on sound moral principles.

## Keywords

Brain death, Ethical revision of the Uniform Determination of Death Act, Informed consent, Legal definition of death, Religious exemption

The declaration of “death by neurological criteria” (DNC)—also referred to as brain death (BD), understood in the sense of whole BD, and not in the sense of brain stem death or higher BD—is an established medicolegal practice throughout the United States and in many countries worldwide. Nevertheless, BD has remained a matter of controversy ever since its inception. In recent years, the heated contention has moved from academic circles into the courtrooms, as more families of patients declared brain-dead have become emboldened to file lawsuits challenging the legitimacy of DNC.<sup>1</sup> As Pope (2018, S46) points out, “leading medical professional societies and organ procurement organizations are deeply concerned that these challenges are eroding public trust in the concept of brain death.”

Prompted by such concerns, the American Academy of Neurology (AAN) Ethics, Law, and Humanities Committee convened a summit in October 2016 attended by representatives from medical stakeholder societies with professional interest in BD, such as the AAN, the Society of Critical Care Medicine (SCCM), and the Child Neurology Society (CNS),

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among others (Lewis et al. 2018).<sup>2</sup> In addition to reaffirming the validity of DNC and, in particular, the validity of the AAN guidelines for BD determination in adults,<sup>3</sup> one of the key goals formulated by the summit was to “advocate for a consistent legal approach to brain death determination in all 50 states” (Lewis et al. 2018, 46). This is made manifest in the recent proposal of a revision of the Uniform Determination of Death Act (UDDA) authored by a subgroup of the scholars who published the summit report (Lewis et al. 2019; Lewis, Bonnie, and Pope 2020).<sup>4</sup>

Such insistence for a revision of the UDDA raises two interrelated questions: (i) is there a need to modify the UDDA? and (ii) is the revision of the UDDA formulated by Lewis and colleagues ethically sound, especially from the perspective of Catholic physicians? To answer these questions, this article will critically examine both the proposed Revised Uniform Determination of Death Act (RUDDA) and the argumentation that undergirds it.

## BD and the UDDA—A Brief Historical Background

Since the 1968 publication of the report of the Harvard Ad Hoc Committee, which “define[s] irreversible coma as a new criterion for death” (Harvard Medical School 1968), DNC has gained worldwide practice especially following its highest endorsement in 1981 by the President’s Commission (1981) for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. The task of the Commission was essentially twofold:

- (i) to provide a conceptual rationale for DNC. In this regard, the Commission basically adopted *in toto* the thesis originally articulated by Bernat, Culver, and Gert (1981), according to which the brain is the central somatic integrator, that is, the critical system responsible for the functioning and life of the organism as a whole (Bernat 2002, 325).
- (ii) to develop a uniform definition of death articulated in terms of a model-statute, the UDDA, in order to eliminate the problematic “patchwork pattern of conflicting new [DNC] and old [cardiorespiratory] methods” of establishing death across the USA (Pernick 1999, 8). The UDDA, which confers a legal status to DNC, states:

functions, or (2) irreversible cessation of all functions of the entire brain, including the brain stem, is dead. A determination of death must be made in accordance with accepted medical standards. (President’s Commission 1981, 2)

All fifty states have since adopted the UDDA although not every state replicates word-for-word the complete language of the UDDA (Lewis, Cahn-Fuller, and Caplan 2017, 116–17). Notwithstanding variations in the legal language among the states, every state has incorporated DNC into its definition of death, whether by statutory law, rules and regulations, or judicial decision (Nikas, Bordlee, and Moreira 2016, 237; Lewis, Cahn-Fuller, and Caplan 2017, 116). Effectively, BD is legal death—*uniformly* across the USA—on a par with traditional cardiorespiratory death. There are two most notable variations, however: (i) the law in New Jersey includes a categorical religious exemption from BD;<sup>5</sup> this was the result of a “hard-fought battle [...] on the part of the Jewish communities” (Kahn 2016, 1551); and (ii) in the case of BD during pregnancy, the laws in twelve states (Alabama, Idaho, Indiana, Kansas, Kentucky, Michigan, Missouri, South Carolina, Texas, Utah, Washington, and Wisconsin) “automatically invalidate a woman’s advance directive [against receiving life support] regardless of the gestational age or state of health of the unborn child” (Nikas, Bordlee, and Moreira 2016, 248).

Globally, the interventions of governmental legislatures and authoritative bodies have succeeded in bringing about a (seemingly) widespread public acceptance of DNC.<sup>6</sup> Yet, the controversy about its scientific and philosophical validity persists. Among the reasons for such persistence, three are worth mentioning. First, within a decade after the promulgation of the UDDA, it was discovered that many brain-dead patients, that is, those who met all the bedside diagnostic tests for BD, continued to manifest certain brain functions, in particular: (a) persistent function of the hypothalamo–pituitary axis, namely the production of antidiuretic hormone (ADH), and (b) cortical activity demonstrated on electroencephalogram recordings.<sup>7</sup> Second, and more importantly, it also came to light that a significant number of brain-dead individuals, who for some reason did not become organ donors, continued to survive for longer periods than the expected maximum “few days” (President’s Commission 1981, 17; Soifer and Gelb 1989, 815–16).<sup>8</sup> Thus, since the publication of Shewmon’s (1998a, 1998b, 2001) articles analyzing such cases of survivors with

An individual who has sustained either (1) irreversible cessation of circulatory and respiratory

“chronic BD,” the bioethical debate over DNC has steadily intensified. Third, ever since the introduction of DNC into clinical practice, the primary source of transplanted organs is brain-dead donors, which in turn implies an inseparable link between BD and organ donation-transplantation.<sup>9</sup> In this regard, the general public is typically uninformed about BD and its implications (Nair-Collins 2018, S43). Nevertheless, the occasional news of brain-dead patients who narrowly escaped the procedure of organ explantation and subsequently recovered neurologically (Nguyen 2016, 260; Kompanje 2013) have rendered the public circumspect about BD. This is made manifest in the increasing frequency of families’ objections both to the use of neurological criteria and to the discontinuation of life support after the declaration of BD,<sup>10</sup> along with the ensuing rising incidence of legal disputes.<sup>11</sup>

According to DNC proponents, however, “brain death is widely regarded as the prime example of a formerly contentious bioethical and biophilosophical issue that *has been resolved to the point of widespread public consensus*, [as evidenced] in the enactment of effective and well-accepted brain death laws and policies throughout the world” (Bernat 2006, 40, emphasis added). The question, however, is: how genuine is this alleged public consensus? A public consensus, in the full sense of the word, implies that the legislation of DNC should have been preceded by open public debates, using an informative, unbiased, and open approach to engage the participation of the public at large. Ironically, however, no such open public debate was carried out. Instead, DNC was grandfathered in as a law, without engaging the participation of the public. Given that the public at large has been left uninformed and essentially excluded from the decision-making process, on an issue (death itself) which touches every member of the society, it cannot be said that the public consensus boasted by BD advocates is a genuine consensus. Rather, it is a *consensus imposed by the law*, that is, by the presence of more or less uniform laws in every state of the United States permitting physicians to declare DNC. In a way, this has given BD a rather privileged status as compared to other contentious bioethical issues (such as abortion, physician-assisted death, or euthanasia) that have not achieved a similar uniform legal status in the United States.

The law, in general, remains impervious to critics and opposition. Thus, the ongoing opposition to BD, as manifested in the increased numbers of scholarly anti-BD articles over the last two to three decades, has not made any impact on lawmakers. Consequently, “the law concerning brain death has

remained stable for decades” (Pope 2018, S46). Thus, from the perspective of BD advocates, the growing resistance to BD on the part of families and resulting increase in lawsuits (especially since the McMath case in 2013) has much to do with their misunderstanding or confusion about BD (Burkle, Sharp, and Wijdicks 2014).<sup>12</sup> Such (alleged) confusion has been attributed to the “variation in the verbiage of state laws” (Lewis, Cahn-Fuller, and Caplan 2017, 121), the variability in the practice and determination of DNC between different institutions (Greer et al. 2008; Ghoshal and Greer 2015),<sup>13</sup> and the variability in the management of family objections to BD testing or removal of life support (Lewis et al. 2019, 14–16). According to BD proponents, such multifaceted variability leading to the public distrust in DNC ultimately has its source in the deficiencies of the UDDA itself (Lewis, Cahn-Fuller, and Caplan 2017; Lewis et al. 2019; Lewis, Bonnie, and Pope 2020), and the needed remedy is national uniformity, both in the clinical setting and in the language of the law across the country.<sup>14</sup> This is why, the goals embraced at the 2016 summit organized by the AAN aim not only in “the development of systems to ensure that brain death determination is consistent and accurate” (Lewis et al. 2018, 425), namely, through educational initiatives and credentialing programs, but also in advocating a revision of the law regarding BD, that is, the revision of the UDDA itself.

## Critical Analysis of the Arguments for the Revision of the UDDA

Recently, Lewis and colleagues proposed a revised UDDA (RUDDA) in order “to legally standardize death declaration around the country” (Lewis, Bonnie, and Pope 2020, 143) which, according to their assessment, is necessary because the existing UDDA is deficient on the following four counts (Lewis et al. 2019, 16–20; Lewis, Bonnie, and Pope 2020):

- (1) The UDDA does not delineate any particular set of specific brain functions which, when irreversibly lost, is considered to indicate BD. Rather, according to its wording, BD legally signifies and, therefore, requires the “irreversible cessation of all functions of the entire brain, including the brain stem” (President’s Commission 1981, 2).
- (2) The UDDA does not specify which accepted medical standards (i.e., the technical medical requirements) are legally authoritative for establishing death. It only states that

“a determination of death must be made in accordance with accepted medical standards” (President’s Commission 1981, 2).

- (3) The UDDA gives no indication whether or not consent needs to be obtained from families or surrogates prior to BD determination.
- (4) The UDDA provides no instructions on how to handle religious objections to the withdrawal of life support after DNC.

The last two remarks of Lewis and colleagues regarding the UDDA are basically correct. It is doubtful, however, whether the first two items can be counted as deficiencies of the UDDA. Both regard the technical aspects of determining death that pertain to the responsibility and prerogative of the medical profession, and not of legislators. Just as “the Church does not make technical decisions” on the determination of death (John Paul II 2000, no. 5.2), so the law should not either. It is thus appropriate that the final sentence of the UDDA reads the way it does, that “a determination of death must be made in accordance with accepted medical standards.”

The RUDDA advanced by Lewis and colleagues addresses only the first three of the four items listed above. As will be shown below, the formulation of their RUDDA and the arguments to justify it present several difficulties, especially with respect to scientific realism and the tenets of sound anthropology.

### Revising and Narrowing the Legal Definition of BD

In their RUDDA, Lewis and colleagues change the UDDA statutory definition of BD, the “irreversible cessation of *all* functions of the entire brain, including the brain stem” (President’s Commission 1981, 2, emphasis added), by deleting the term “*all*” and replacing it with a set of specific neurological signs which, according to DNC proponents, constitute the sufficient requirements for the diagnosis of BD. The RUDDA legal definition of BD thus reads as follows: “irreversible cessation of functions of the entire brain, including the brainstem, *leading to unresponsive coma with loss of capacity for consciousness, brainstem areflexia and the inability to breathe spontaneously*” (Lewis et al. 2019, 18, table 2; Lewis, Bonnie, and Pope 2020, 144, table, emphasis original). Such a statutory definition of BD, which descends to the level of particular medical signs and symptoms, is problematic, however.

As explained by the President’s Commission, the discourse about death encompasses four interrelated levels which move hierarchically from the general to

the particular, that is, from the abstract philosophical level to the concrete procedural level as follows (President’s Commission 1981, 55–56):

- (1) the level of the basic concept of death; an example of this is the conceptual definition death as the loss of the integration of the organism as a whole;
- (2) the level of the general physiological standards whereby death is defined in terms of organ systems;
- (3) the level of the operational criteria, that is, a set of specific medical signs (e.g., loss of consciousness, absence of brain stem reflexes and of spontaneous respiration) to “further define what is meant by the general physiological standards” (President’s Commission 1981, 56);
- (4) the level of the specific tests and procedures to established that the operational criteria are met.

According to the President’s Commission, the formulation of a statutory definition of death necessitates a balanced approach, so that it would be neither an abstract definition at the basic conceptual level nor a technical definition at the operational level or lower. This is why the Commission formulated the UDDA statutory definition of death at the level of general physiological standards. More importantly, and as pointed out by the Commission, the task of a statute is to articulate general standards and not “operational criteria (which are better left to medical bodies to establish)” (President’s Commission 1981, 56), especially since such operational criteria (and, therefore, the tests and procedures) can change over time.<sup>15</sup> In other words, that the four levels described above are ordered hierarchically (from the general to the particular) means that the operational criteria established by medical bodies (i.e., the medical standard(s) such as the AAN guidelines for the determination of BD) should be such that they satisfy the legal definition of death articulated in the UDDA and not the other way around.

In contrast to the UDDA, the legal definition of death in the RUDDA is formulated at the operational level. Lewis and colleagues argue that this approach is warranted because the language of the UDDA, namely, that its clause “all functions of the entire brain,” does not match the accepted medical standards (Lewis et al. 2019, 17).<sup>16</sup> In other words, the authors change the language of the law to make it satisfy the current medical guidelines (the operational criteria) for the determination of DNC. Such

an approach, which stands in sharp contrast to the Commission's approach, amounts to doing violence to the nature of the law itself, however.

The arguments of Lewis and colleagues reveal the real reason why "the RUDDA delineates the specific functions of the brain that must be lost in DNC" (Lewis, Bonnie, and Pope 2020, 143). Such delineation effectively excludes the presence of persistent neuroendocrine function (the secretion of ADH and other pituitary hormones) from being recognized as evidence of continued brain functioning in brain-dead patients. The approach of Lewis and colleagues mirrors that of Bernat (1998, 18) who, two decades ago, in the wake of the finding of persistent ADH secretion in brain-dead patients, argued that the definition of BD means "the irreversible cessation of all *clinical* functions of the entire brain" rather than "the irreversible cessation of all functions of the entire brain." Bernat used the term "clinical functions" to refer solely to those brain functions that can be assessed on bedside neurological examination. According to Bernat (1999, 88), ADH secretion does not count as a clinical function "because its presence or absence is not assessed or detected on a usual clinical examination and requires a laboratory test for diagnosis." Similarly, the AAN guidelines, according to which the presence of "normal blood pressure and absence of diabetes insipidus are compatible with brain death" (Wijdicks 1995, 1007), also discount the critical role of ADH in the maintenance of water electrolytes homeostasis and hemodynamic stability. In the same vein, Lewis and colleagues (2019) argue that since the accepted medical standards do not require the evaluation of hypothalamic-pituitary function, the language of their RUDDA will bring the law in line with medical standards (p. 18). Such a move will close the existing gap between the legal and the medical criteria for BD, that is, between the UDDA and the medical guidelines (in particular, the AAN guidelines). In this regard, the following statement made by Pope (2017) is revealing:

To make the medical criteria as rigorous as the UDDA demands would be expensive and time consuming. And it would probably adversely impact rates of organ procurement. Therefore, it is far more feasible to bring the law into line with current medical practice than bring medical practice into line with the law. (p. 307)

Such a move will also eliminate the occurrence of future lawsuits challenging the declaration of DNC

on the basis of persistent pituitary/hypothalamic/hormonal function. A case in point in this regard was the McMath case in which the plaintiffs contended that the declaration of death was erroneous, on the grounds that McMath had continuing neuroendocrine function as evidenced by her pubertal changes.

To further strengthen their argument, Lewis and colleagues (2019) also assert that

The authors of the UDDA do not appear to have intended the phrase "all functions of the entire brain" to encompass functions of the pituitary gland and hypothalamus; in their 188-page report, they mentioned "coma" 120 times, "brainstem" 22 times, and "apnea" nine times. But not once did the Commission mention any terms to describe pituitary/hypothalamic/hormonal function. (p. 17)

The above argument is rather specious, however. The terms "coma," "brain stem," and "apnea" were mentioned because they were the known signs of BD which have been described since the publication of the Harvard Report in 1968. The Commission mentioned nothing about the hypothalamic-pituitary function simply because, at the time of the publication of its report in 1981, it was not yet discovered that significant numbers of brain-dead patients would demonstrate persistent neuroendocrine function.

### *Specifying the Identity of Accepted Medical Standards*

According to BD advocates, the UDDA clause "in accordance with accepted medical standards" (President's Commission 1981, 2) generates confusion because it does not specify which standards constitute the "accepted medical standards" nor does it indicate "what professional body or bodies are responsible for identifying the 'accepted medical standards'" (Lewis et al. 2019, 14). As such, this UDDA clause is deemed responsible for "the lack of uniformity in the medical standards used to determine DNC" (Lewis, Bonnie, and Pope 2020, 143). Citing the Hailu case, Lewis and colleagues also argue that this clause can give rise to litigations over BD determination whereby one medical standard (e.g., the original Harvard standard) is put against another standard (e.g., the AAN guidelines).<sup>17</sup> The authors thus replace the existing UDDA clause with their RUDDA wordings, specifying the identity of the accepted medical standards as follows:

A determination of death must be made in accordance with the applicable guidelines set forth in (1) “Evidence-based guideline update: determining brain death in adults: report of the quality standards subcommittee of the American Academy of Neurology,” published June 8, 2010, by the American Academy of Neurology, or (2) “Guidelines for the determination of brain death in infants and children: an update of the 1987 task force recommendations,” published January 27, 2012 by the Society of Critical Care Medicine [SCCM], American Academy of Pediatrics [AAP] and Child Neurology Society [CNS], or (3) subsequent revisions of these guidelines that are recognized by the Board of Medicine to be accepted medical standards. (emphasis original; Lewis et al. 2019, 17, table 2; Lewis, Bonnie, and Pope 2020, 144, table)

Given that BD proponents have attributed families’ resistance to DNC and the ensuing rise in lawsuits to the variability in BD policies among hospitals, it appears that the above wording of the RUDDA aims at enforcing, via the power of the law, an absolute and uniform compliance to the AAN and SCCM/AAP/CNS guidelines throughout the United States. Lewis and colleagues (2019) also insist that state “legislatures should refer explicitly to these standards by name in statutes about death” (p. 19) by citing the 2019 revised BD statute in Nevada as a model. In Nevada, subsequent to the Hailu case in 2015, the state law regarding BD determination was revised to refer explicitly to the AAN and SCCM/AAP/CNS guidelines as the required standards for BD determination in adults and children, respectively (Nevada Revised Statute 2019). In addition, the Nevada statute also makes provisions for the acceptance of any future revisions of these standards.<sup>18</sup> In a similar manner, Lewis and colleagues also include in their RUDDA a mechanism (a better one than that used in the Nevada revised BD statute) for the acceptance of future revisions of the AAN and SCCM/AAP/CNS guidelines, by delegating to an administrative agency, the Board of Medicine, the authority to review and approve such revisions as needed.

What effectively takes place in the above strategy is that the language of the law governing the determination of BD throughout the United States can be made to change, as needed, in accordance with the changes of the AAN and SCCM/AAP/CNS guidelines. Does it not seem that the RUDDA permits the law to be manipulated and become subservient to the

medical guidelines/standards? Here, it is worth noting that (i) the AAN guidelines were established and promoted by (leading) members of the AAN, (ii) at the 2016 summit, the validity of the AAN guidelines was reaffirmed by the AAN itself and other medical stakeholders in BD determination, and (iii) the RUDDA endorsing the AAN guidelines is authored by (leading) members of the AAN.

A more important question that should be raised is the following: is it ethical for a national (or universal) statutory law regarding BD to explicitly prescribe a particular medical standard as the accepted medical standard when its guidelines contradict the reality of the phenomenon of death? Such is the case with the AAN guidelines (Nguyen 2019, 302–304). Scientifically and empirically speaking, “death is a biological phenomenon [which] appl[ies] equally to related species” (Culver and Gert 1982, 182). It follows, therefore, that “the constellation of biological signs indicative of human death is no different from that seen in the death of other types of mammals,” such as the death of a cat or a dog (Nguyen 2019, 302). Whereas the Harvard standard requires the complete silence of the nervous system (Harvard Medical School 1968, 338),<sup>19</sup> the AAN guidelines affirm that the presence of a whole host of clinical signs, such as profuse sweating, blushing, tachycardia, sudden increase in blood pressure, motor stretch reflexes, Babinski reflex, and spontaneous movements of the limbs, is compatible with death (Wijdicks 1995, 1007). In other words, the change from the Harvard standard to the AAN guidelines is a *post hoc* move in order to exclude those functions that are preserved in brain-dead patients as irrelevant, which then makes it possible to uphold the claim that BD is death (Nguyen 2019, 298–302; Nair-Collins 2015, 74). With its assertion that the presence of neuroendocrine function, reflexes, and spontaneous movements is compatible with death, the AAN standard contradicts both scientific realism and the tenets of sound anthropology, in particular, Christian anthropology as held and taught by the Catholic Church (Nguyen 2019).

Moreover, it is difficult to reconcile the RUDDA definition of BD, the “irreversible cessation of functions of the *entire* brain, including the brainstem” (Lewis, Bonnie, and Pope 2020, 144, table, emphasis added) with the AAN and SCCM/AAP/CNS guidelines which the RUDDA explicitly designate as the accepted medical standards. The 2010 AAN guidelines specifically state, “in adults, ancillary tests are not needed for the clinical diagnosis of brain death and cannot replace a neurologic examination” (Wijdicks et al. 2010, 1916). Likewise the 2012 SCCM/

AAP/CNS guidelines for determining BD in infants and children state that “ancillary studies (electroencephalogram and radionuclide cerebral blood flow) are not required to establish brain death and are not a substitute for the neurologic examination” (Nakagawa et al. 2011, 2139; Nakagawa et al. 2012, 573). Put simply, according to these guidelines, DNC can be declared solely on the basis of bedside neurological examination, as the confirmatory tests of BD have been made optional. The bedside examination consists only of clinical tests for brain stem functions, however. In what way then does the absence of brain stem functions alone fulfill the RUDDA requirement of “irreversible cessation of the functions of the entire brain”? Indeed, “without the [required] use of ancillary tests, the determination of the US-based ‘whole brain death’ is *identical* to that of the UK-based ‘brainstem death’ [BSD]” (Nguyen 2016, 262). Defenders of BD in the United States, namely Bernat, have amply criticized the BSD formulation (Bernat 2002, 338; Bernat 2006, 39).

### *Eliminating the Need to Obtain Informed Consent for BD Testing*

A merit of the RUDDA is that it brings to the fore the question of whether or not informed consent should be obtained from families or surrogates before performing the neurological examination to establish BD. The cornerstone test of the bedside examination for establishing DNC is the apnea test. The question thus comes down to whether or not consent is required for apnea testing. According to DNC proponents, the fact that the UDDA and most state legislatures are silent on this issue of consent has been one of the reasons contributing to legal confusion and the rise in litigations (Pope 2018, S47; Lewis et al. 2019, 14, 19).

Lewis and colleagues argue that consent is not required because (i) according to the view of most clinicians,<sup>20</sup> the determination of death is not a medical procedure: BD is legal death, on a par with death determined by the traditional cardiopulmonary criteria, and (ii) because consent is not obtained for the latter, then it should not be required for the former (Lewis et al. 2019, 15; Lewis and Greer 2017b, 700). In addition, it has been argued that a requirement for consent would effectively let families opt out of DNC, which, in turn, causes unnecessary burden to hospital resources since the patients cannot be declared dead and will remain on life support until cardiopulmonary arrest (Pope 2018, S47–48; Lewis and Greer 2017c, 705).

The above arguments belong to the pragmatic-utilitarian order, however. Since the question of

consent concerns primarily apnea testing, what needs to be addressed, instead, is whether or not the apnea test is safe to severely brain-injured, “irreversibly” comatose patients. The topic of informed consent is beyond the scope of this article; suffice it to say, however, the higher the risks of a procedure and the lower its benefits to the patient, the more necessary it is to obtain informed consent. “Apnea testing is, by definition, a medically nonbeneficial procedure” (Truog and Tasker 2017b, 706), because it is the cornerstone test for declaring a patient dead by neurological criteria.

In the apnea test, the patient, while being oxygenated via a catheter down the endotracheal tube, is removed from the ventilator for eight to ten minutes to let the arterial partial pressure of carbon dioxide (PaCO<sub>2</sub>) rise above 60 mmHg or at least 20 mmHg above the baseline (Joffe, Anton, and Duff 2010, 1435; Wijdicks et al. 2010, 1916). If no inspiratory efforts are observed, the patient is considered apneic.

The apnea test, in addition to the fact that it has never been validated, not even before the introduction of BD by the Ad Hoc Harvard Committee, is not without harmful risks. While recognizing that apnea testing can produce complications such as cardiopulmonary arrest, arrhythmias, hypotension, hypoxemia, pneumothorax, or pneumoperitoneum, DNC proponents nevertheless consider the apnea test to be a safe and simple procedure when carried out in compliance with the guidelines prescribed by the AAN and SCCM/AAP/CNS (Lewis and Greer 2017b, 701; Wijdicks et al. 2008, 1243). A more insidious and serious complication which may not manifest itself immediately during apnea testing, and which BD proponents seem to have overlooked, is the deleterious effect of acute hypercarbia, that is, a sudden increase in the arterial partial pressure of carbon dioxide (PaCO<sub>2</sub>). In this regard, it is worth noting that in neurointensive care, hypercarbia is absolutely avoided because it can lead to cerebral vasodilation and increased intracranial pressure (ICP; Mongardon et al. 2011, 6 of 11; Tibballs 2010, 476). Of note is that neither ICP nor the rate of increase in PaCO<sub>2</sub>, which is unpredictable, is monitored during apnea testing (Tibballs 2010, 475; Roth et al. 2015, 1208). As described below, a rise in PaCO<sub>2</sub> in the setting of severe brain injury can trigger a vicious cycle:

The injured brain has decreased tolerance to CO<sub>2</sub>, such that even a minor increase in PaCO<sub>2</sub> can aggravate the existing brain edema. Cerebral ischemia, brain edema, and increased ICP

mutually affect one another, resulting in a vicious cycle. Brain edema leads to increased ICP, which in turn causes compression of the cerebral vasculature resulting in further reduction of CBF [cerebral blood flow]. With hypoperfusion, there is decreased oxygen to brain tissue and concomitant accumulation of CO<sub>2</sub>, resulting in intracellular metabolic stress, increased membrane permeability, and worsening edema. (Nguyen 2016, 266)

In a nutshell, a sudden rise in PaCO<sub>2</sub> can result in (i) additional brain injury as the above-described vicious cycle can convert those areas of the brain in ischemic penumbra which are still viable to irreversibly injured, nonrecoverable brain (Joffe, Anton, and Duff 2010, 1437), and (ii) worsening ICP, which can lead to herniation. These adverse neurological effects are not hypothetical, especially since the finding of a significant increase in ICP during apnea testing has been confirmed in a recent study (Roth et al. 2015, 1211, table 3). This study documents a rise in ICP during the apnea test in thirteen of the sixteen instances. Thus, as Truog and Tasker (2017a) point out,

[the] changes in cerebral hemodynamics and hydrodynamics [due to induced acute hypercarbia] may not result in an immediately recognized complication, but may cause secondary injury such that patients who do not meet the criteria for brain death on initial testing might subsequently be made brain dead as a result of the testing. Since the test is performed *before* it is known that the patient is brain dead, the risk here is that a test intended to determine whether a patient is dead may, in fact, cause death. (p. 703, emphasis original)

In addition, from the perspective of a layperson, it is rather anti-intuitive, if not even illogical; that an already injured, compromised, or weakened organ system is subjected to a procedure that challenges it. The question raised by the layperson is this: if a patient with angina at rest is not to be challenged with a stress test while experiencing angina, then why is a patient with a severely injured brain to be challenged with an apnea test? This alone means that families and surrogates should be given the opportunity to be informed and make a decision. Given the adverse neurological effects of apnea testing and its lack of benefit to the patient, it cannot be assumed that families' consent could be a tacit or presumed consent either. It is thus disconcerting that the

RUDDA of Lewis and colleagues dismisses the requirement for informed consent prior to BD testing.

## Two Approaches for an Ethical Revision of the Uniform Declaration of Death Act

To summarize, the RUDDA formulation of Lewis and colleagues poses three major difficulties:

- (i) The RUDDA reduces the definition of BD to a specific set of brain functions to match those functions that can be assessed on bedside determination of BD. Because this is a *post hoc* move, hidden in the RUDDA is a *petitio principii* (a type of circular reasoning in which the premise already contains the conclusion); this is brought to light by putting the RUDDA in the form of a syllogism:

*Major premise:* BD consists in a loss of the capacity for consciousness, brain stem areflexia, and an inability to breathe spontaneously.

*Minor premise:* the patient is comatose, has no brain stem reflexes, and fails the apnea test.

*Conclusion:* therefore, the patient is brain-dead.

- (ii) The RUDDA designates as accepted medical standards the current guidelines which do not exactly fulfill the RUDDA's own requirement of "the *entire* brain" nor do they correspond to the reality of the phenomenon of death.
- (iii) The RUDDA, by not requiring consent for BD determination (apnea testing), preempts the possibility for families to be informed and make a decision. Yet, DNC advocates have repeatedly stated that the public at large is uninformed and confused about BD and needs to become more informed.

As seen in the above critical analysis, the common thread which runs through the arguments to justify the RUDDA has to do with the recent rise in litigations over DNC, some of which have attracted considerable media attention.<sup>21</sup> This is why the RUDDA (put forth by BD proponents) is formulated the way it is—a formulation in which the legal language is manipulated to descend to the operational level and lower in order to (i) match the medical guidelines (which contradict the reality of the



phenomenon of death) advocated by BD proponents, and (ii) make these guidelines a uniform medicolegal practice throughout the United States. In a democratic country with cultural/religious pluralism like the United States, would such an approach not be considered as rather unilateral and heavy-handed, especially when it takes away from families and surrogates the possibility of making an informed decision prior to the determination of DNC? It seems that, from the perspective of BD proponents, “it is more important that the applicable rule be settled than that it be settled right” in order to achieve legal certainty and uniformity with regard to BD (Pope 2018, S46).<sup>22</sup>

It is common for DNC advocates to attribute litigations over BD (which basically reflect the public distrust in DNC) to the variability in the language among state BD laws and the variability among BD policies. What is overlooked, however, is that families’ resistance to both the BD diagnosis and the request for organ donation which quickly follows it—a resistance that can lead to lawsuits—is caused by the very fact that their loved ones, though declared dead, still look very much alive. The skin is warm and pink, the heart is beating, and the patient is making urine—these are some of the signs of life that any layperson can recognize. Yet, the family members are assured repeatedly that the patient is already dead and that what they see is “artificial life,” a term which implies that the patient only appears alive because the ventilator and various pharmacologic agents mask the usual signs of death (cold and gray, and rigor mortis, among others). The family, however, can intuit that what they are told cannot be true, for if it were, then connecting the ventilator and administering medications to a cold, gray, and rigid corpse would make it appear warm, pink, and supple.

As already pointed out by several scholars, including those who support organ donation, patients who meet all the diagnostic tests for BD (including the ancillary tests) “share many more features with living persons than they do with” a cold and gray corpse (Truog 2004, 357).<sup>23</sup> As irrefutably demonstrated in Shewmon’s work, brain-dead patients manifest a whole host of somatically integrative functions. These functions continue to work together holistically in an integrated and complex way to stave off entropy, maintain homeostatic stability, and keep the body in a continuous interaction with its environment, such as through assimilating nutrients and oxygen and excreting waste and carbon dioxide (Shewmon 2001, 467–71). In a nutshell, it is the empirical evidence of BD itself which explains why

“despite several decades of pedagogical effort on the part of official medicine, many health care professionals, including those involved in transplantation, [...], and the lay public remain unconvinced, at least subliminally, that BD is *really* death” (Shewmon 2001, 459, emphasis original). In other words, at the root of the unrelenting BD controversies, both in academia and in the courts, are the inherent incoherence of the BD paradigm, both at the empirical and conceptual levels. Any amendment of the UDDA, if it is to be ethically acceptable, cannot sidestep this most serious issue that patients declared dead by neurological criteria are still alive, however close to death’s door they might be.

### The First Approach

In the view of this article, there are two main approaches to articulate an ethically revised UDDA (ERUDDA). The first proposed approach, which may be referred to as ERUDDA1, is to formulate the legal definition of death in such a way that it reflects the reality of the phenomenon of death as observed in warm-blooded mammals to which the human species belongs. In other words, “when we talk of the death of a human being, we mean the same thing as we do when we talk of the death of a dog or a cat” (Culver and Gert 1982, 182). Thus, the amended formulation would affirm that death is a biological phenomenon characterized by the *cessation of all vital functions* of the body *beyond all possibility of resuscitation*, as manifested by the combined cessation of heartbeat, circulation, and respiration, and the complete silence of the whole nervous system (brain and spinal cord). In that way, the legal definition of death would be formulated on an integrative basis, without giving primacy to any particular organ system. Conceptually, such a definition would reflect a holistic vision of human beings in which no organ is the central somatic integrator controlling all other organs or organ systems. Such a definition would be, therefore, in accord with the axiomatic principle that the organic whole is greater than the sum of its parts and that no part (be it the brain, the heart or the lungs), however noble it might be, can account for the organic whole. More importantly, such a holistic definition of death would also be in accord with the fundamental tenets of Christian anthropology as held and taught by the Catholic Church.

At this point, the question that is often raised is the following: is the BD paradigm not also in accord with Catholic teaching? In this regard, the National Catholic Bioethics Center (2015) affirms in its 2015 *Brain Death FAQ* document that the

“neurological criteria are compatible with Catholic teaching that a human being is a substantial union of body and rational soul. The complete and irreversible loss of all brain function may be taken as a reasonable indicator that the rational soul is no longer present.” This affirmation is based primarily on the following statement of Pope St. John Paul II (2000): “It can be said that the [neurological] criterion adopted in more recent times for ascertaining the fact of death, namely the complete and irreversible cessation of all brain activity, if rigorously applied, does not seem to conflict with the essential elements of a sound anthropology” (no. 5.3). Catholic defenders of DNC have interpreted this statement as the pope’s definitive approval of BD or as his affirmation of the compatibility of BD with Church teaching. It should be noted immediately, however, that (i) the pope’s phrasing is in conditional terms, as explicitly indicated by the use of the conjunction “if,” and (ii) his statement is carefully nuanced by the use of “does not seem to conflict,” instead of simply affirming that the BD criterion does not conflict with Church teaching.<sup>24</sup>

The discussion that follows to address the question raised above is a brief summary of Nguyen’s critical analysis of John Paul II’s (2000) Address (Nguyen 2017, 2018, 241–346). The pope’s statement, which reflects his moral judgment about the use of the neurological criteria, rests on several presuppositions or conditions, all of which must be fulfilled if the conclusion (i.e., the pope’s judgment) is to follow. It was presupposed by the pope that the BD criterion had been established by “clearly determined parameters commonly held by the international scientific community” (John Paul II 2000, no. 5.1). The parameters in question refer to the diagnostic tests for the determination of BD. A diagnostic test is considered to be “clearly determined” only if it has gone through rigorous validation prior to its introduction into clinical practice. Yet, none of the tests for BD have been validated, neither before the publication of the Harvard Report nor thereafter. It was also presupposed by the pope that the parameters are “commonly held” worldwide. This presupposition has been falsified, however, by the factual reality (which DNC advocates themselves have admitted) that there exists no global consensus, but a wide variability in the practice and determination of BD, instead (Wijdicks 2002; Greer et al. 2008, 287). If there is no consensus in the diagnostic parameters, then how can the BD criterion be rigorously applied as stipulated by the pope? Moreover, it is known that many patients “who satisfy all the standard clinical tests for whole brain death [ . . . ] have

not lost all of the integrative functions of the brain. The most important example is neurohormonal regulation” (Brody 1999, 73). This means that the standard diagnostic parameters are inadequate to establish “the irreversible cessation of all functions of the entire brain, including the brain stem (President’s Commission 1981, 2). No amount of rigorous application can compensate for such inherent inadequacy. “If the diagnostic criteria are insufficient to establish the complete and irreversible loss of all brain activity, then in what way can they secure adequate moral certainty” (Nguyen 2018, 471–72) to declare the patient/donor dead and proceed with organ harvesting?

Most importantly, it was presupposed by the pope that the BD criterion “does not seem to conflict with the elements of a sound anthropology” (John Paul II 2000, no. 5.3). The anthropology the pope was alluding to is the Church’s anthropology which rests on Aristotelian-Thomistichylomorphism, according to which man is the substantial union of matter (body) and form (soul), and

The first principle by which the body lives is the soul. And as life appears through various operations in different degrees of living things, that whereby we primarily perform each of all these vital actions is the soul. For the soul is the primary principle of our nourishment, sensation, and local movement; and likewise of our understanding (Thomas Aquinas 1947, ST I, q. 76, a. 1).

In other words, the human soul is that which accounts for all the operations of life: vegetative, sensorimotor, and rational. The separation of the soul from the body at death results in somatic disintegration (John Paul II 2000, no. 4.2) and, therefore, the loss of all vegetative, sensorimotor, and cognitive functions. It has been claimed that BD is death *simpliciter* (Battro et al. 2008, 5), that is, “the complete and irreversible loss of all brain function may be taken as a reasonable indicator that the rational soul is no longer present” (National Catholic Bioethics Center 2015). This raises the following question, however: what then is the principle that accounts for the persistence of numerous integrative vegetative functions, as well as frequent occurrence of various reflexes and spontaneous movements, repeatedly reported in brain-dead patients (Shewmon 2001, 467–71; Saposnik et al. 2000)? Here, it is worth recalling that, according to the AAN guidelines, persistent secretion of ADH, the occurrence profuse sweating, tachycardia, and sudden rise in

blood pressure at the time of laparotomy for organ removal, as well as the occurrence of a whole host of spontaneous movements and reflexes of the limbs (deemed to be of spinal origin), are all compatible with the diagnosis of BD (Wijdicks 1995, 1007). Is the presence of numerous complex vegetative functions not a manifestation of the vegetative power of the soul and is the occurrence of reflexes and spontaneous movements not a manifestation of the sensorimotor power of the same soul?<sup>25</sup> In what way then can it be said that the BD criterion is compatible with the Church's anthropology? "The Church does not make technical decisions, [nevertheless she has the] duty of comparing the data offered by medical science with the Christian understanding of the unity of the person" (John Paul II 2000, no. 5.2). The medical data in this case are the AAN guidelines already promulgated since 1995. It is thus rather puzzling why the pope's 2000 Address did not take into consideration such a crucial piece of medical data.

The fundamental conceptual difference between the BD paradigm and the holistic formulation or definition of death is the following: the former claims that the brain as the organ without which the human person is dead (Bernat, Culver, and Gert 1981, 391–92; Bernat 1984, 48)—a claim which contradicts the axiomatic principle that no part can account for the organic whole. In contrast, the latter acknowledges that what keeps the body integrated and alive is the human soul, such that when the soul leaves the body, "no part of the body retains its proper function" (Thomas Aquinas 1947, ST I, q. 76, a. 8); this is referred to in modern medical terminology as the irreversible cessation of all vital bodily functions beyond all possibility of resuscitation. Without the soul as its principle of life and integration, the corpse immediately succumbs to the natural process of disintegration and putrefaction, that is, "the process of unstoppable increasing entropy [...] which no technological intervention can reverse" (Nguyen 2019, 303–04).

The above-described holistic, integrative definition of death, which is in accord with both scientific realism and Christian anthropology, is basically the same definition as that used prior to the introduction of BD in 1968. It has been referred to as death determined by cardiopulmonary (or cardiorespiratory) criteria. The terminology "cardiopulmonary" can be misleading, however, as it does not convey the full picture of the irreversible cessation of *all* vital functions beyond all possibility of resuscitation.

To adopt the above-described holistic definition of death would effectively eliminate BD from clinical practice, and with it, 80 percent to 90 percent of

all organ transplantation (and essentially, 100 percent of unpaired vital organ transplantation, namely, the heart). Some may consider that this is too high a price to pay for an ethically flawless legal definition of death. In other words, realistically speaking, can the integrative definition of death be implemented to replace the existing UDDA? Given that current Western society, of which the United States is a leading example, is governed more by pragmatic and utilitarian values than by genuine moral values (especially, those concerning the sacredness of human life), the answer is sadly "no."

### The Second Approach

Therefore, in the second proposed approach for articulating the ERUDDA (ERUDDA2), the current bifurcated legal definition of death in the UDDA would be left unchanged. The clinical practice of BD determination would continue. However, precisely because BD does not correspond to the reality of death, and because it is inextricably connected to organ donation-transplantation, the approach in ERUDDA2 would be one that recognizes the families' "right to accurate and transparent information about brain death and organ transplantation" (Nair-Collins 2018, S43). This approach is based on the fact that medicine is a moral activity and requires trust as its foundation. Hand in hand with trust is respect for persons.

As pointed out by Pellegrino and Thomasma (1981, 24), "medicine is [...] a moral activity, since it operates through a personal interrelationship in which physician and patient [or the patient's family or surrogate] are co-participants. [...] The patient is not a passive subject to which a technique is applied." The doctor–patient relationship has inherent elements of inequality especially in knowledge and skill. The patient and/or his family/surrogate nevertheless trust the physician "to enable and empower them to make their own choice based on the most reliable facts" (Pellegrino and Thomasma 1993, 74). Indeed, both the inherent inequality in the doctor–patient relationship and the vulnerable state of the patient (and of his family/surrogate) are sufficient reasons which *de facto* impose moral obligations on the health professional to disclose everything that is relevant and necessary for the patient (or family/surrogate) to make an informed decision (Pellegrino and Thomasma 1993, 42), especially when it concerns a test or procedure which some patients may refuse. A relationship built on trust also entails a mutual respect for each other's personal moral values. In other words, in medical

practice, health professionals cannot disregard the personal values (whether religious or cultural beliefs) of the patients or families/surrogates.

The above fundamental concepts are applicable to the case of a deeply comatose patient with severe brain injury, soon to be declared dead by neurological criteria. The choice in question concerns the criteria to be used for the determination of death: the traditional cardiopulmonary criteria versus the BD criteria, which require apnea testing. As co-participants in the doctor–patient relationship, families or surrogates cannot be treated as passive subjects. Rather, they have the right to decide and make a choice between the cardiorespiratory and the neurological criteria. To make an informed decision, they need to be given truthful information about BD and apnea testing. As discussed earlier, the nature of the apnea test itself warrants that informed consent be obtained from families or surrogates. Thus, the first way to articulate ERUDDA2 (ERUDDA2a) would be to add a clause into the existing UDDA, to remind the medical community that, because BD determination entails a medical procedure (the apnea test), informed consent must be obtained beforehand. In this way, families are given the possibility to opt out of the determination of DNC.

Another way to articulate ERUDDA2 (ERUDDA2b) is to take into consideration that “millions of Americans have religious objections to brain death” (Pope 2017, 316). Traditionally, the religious groups objecting to BD include Japanese Shinto, Native Americans, Buddhists, Muslims, and Orthodox Jews. Today, however, as the public grows more wary about BD and its connection to organ transplantation, “even Christians are asserting such objections” (Pope 2018, S48). Among the litigations over BD, there have been claims on the grounds of religious exemptions. Ironically, hospitals in most states do not accommodate religious objections, such that once the patient is declared brain-dead, any family request for “prolonged” life support is usually denied. In three states (California, Illinois, and New York), the law instructs hospitals to provide reasonable accommodations at the clinicians’ discretion, which invariably mean limited and short-term accommodations (Pope 2017, 317). As mentioned earlier, the only exception to this sad state of affairs is the New Jersey statute (New Jersey Revised Statute 2013), which includes a categorical religious exemption from the declaration of DNC (see Note 5). If this has been enacted in New Jersey, then why can it not be implemented in the rest of the United States? Without a religious exemption, declaring

death on the basis of BD amounts to a serious violation of strongly held religious (or cultural) beliefs. Thus, the ERUDDA2b would amend the UDDA by including a categorical religious exemption similar to that in the New Jersey statute. Such a move would be in full accordance with the First Amendment, which guarantees the free exercise of religion. Better yet, it would not be unreasonable to expand the religious exemption to become an exemption based on objection of conscience.

A third way to articulate ERUDDA2 would be to follow the model of the law in Japan where “families are given a choice about whether to have death defined by neurologic or by cardiorespiratory criteria” (Truog and Tasker 2017a, 703). In practice, however, the declaration of death on the basis of BD is used only when organ donation is to be performed (Japan Organ Transplant Network 2019). In essence, this third way is rather similar to ERUDDA2b described above.

The characteristic feature of ERUDDA2 is that it involves families’ decision-making. In this regard, even DNC proponents have admitted that much of the public still remains uninformed about BD. Without adequate information on the most salient (and controversial) aspects of BD, how would families be able to make an informed decision? Very often, the determination of DNC is accompanied with a request for the consent to organ donation. Yet, the key relevant information that “removing vital organs from a heart-beating, mechanically ventilated donor is lethal” has been kept undisclosed to families, surrogates, and donors [while they were still alive] (Nair-Collins 2018, S43).<sup>26</sup> In particular, the websites of organ procurement organizations, where a person can enroll in deceased organ donation, “do not fulfill the necessary requirements for informed consent. The websites predominantly provide positive reinforcement and promotional information rather than the transparent disclosure of the organ donation process” (Woien et al. 2006, 1 of 9). In view of this lack of disclosure, it would be necessary that ERUDDA2 be accompanied by a nationwide diffusion of accurate and transparent information about BD and organ donation.

A possible criticism to ERUDDA2 is that the inclusion of specific clauses specifying religious (or conscience-based) exemptions and/or the requirement for informed consent to BD testing would add some lengthy legal verbiage to the existing UDDA formulation. This is mitigated, however, by the fact that ERUDDA2 promotes respect for persons and honest, transparent informed dialogue. It may be also objected that this approach, because

it entails an accurate and truthful disclosure about BD to donors, families, surrogates, and the general public, would lead to the undesirable consequence of lower organ donation rates. But, if medicine is a moral activity founded on trust, then should not truth takes precedence in order to regain public trust? It remains to be seen whether transparent disclosure would adversely affect organ donation rates. According to Nair-Collins, this might not occur since, in a national survey of public views on death and organ donation, 61 percent of 985 respondents “agreed that they would donate in the scenario of irreversible coma with organ removal causing death” (Nair-Collins, Green, and Sutin 2015, 297).

## Conclusion

Does the UDDA need to be revised? The answer to this question is “yes, it does, but not in the way that Lewis and colleagues formulate their RUDDA.” As shown in this article, the RUDDA basically seeks to further strengthen the status quo of BD nationwide, by manipulating the legal language in a way that would suppress opposition to BD. Given that the RUDDA of Lewis and colleagues sidesteps the core issue which lies at the heart of BD controversies, namely, the inherent incoherence of BD, both at the empirical and conceptual levels, this article has presented two approaches for an ethical revision of the UDDA. In the first approach (ERUDDA1), which takes place at the level of general physiological standards (as recommended and chosen by the President’s Commission), the legal definition of death is modified to reflect the reality of the phenomenon of death and, therefore, is in full accordance with the tenets of sound anthropology. In the second approach (ERUDDA2), because it leaves the current legal definition of death unchanged, the ERUDDA includes specifications that allow patients, families, or surrogates to exercise their right to make a decision with regard to BD by (i) respecting their personal religious, cultural, or moral convictions and (ii) providing accessible accurate and transparent information about BD. Both ERUDDA1 and ERUDDA2 rest on sound moral principles. The implementation of either form of the ERUDDA would resolve many, if not all, of the ongoing controversies and litigations over DNC. It would also achieve absolute legal uniformity nationwide, which the RUDDA of Lewis and colleagues seeks to impose. More importantly, either form of the ERUDDA would rebuild the public trust in the medical profession.


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## Notes

1. Some of these lawsuits came to the attention of the media, in particular, the Hailu case in Nevada, and the McMath and Stinson cases in California.
2. The summit included representatives from the American Academy of Neurology (AAN), American College of Radiology, American Neurological Association, American Society of Neuroradiology, Child Neurology Society (CNS), Neurocritical Care Society, and Society of Critical Care Medicine (SCCM).
3. The AAN guidelines for the determination of brain death (BD) in adults was published in 1995 and updated in 2010 (Wijdicks 1995; Wijdicks et al. 2010).
4. The paper of Lewis and colleagues published in the *Annals of Internal Medicine* is a summary of their longer article published in the *Journal of Law, Medicine & Ethics*.
5. The New Jersey Declaration of Death Act, enacted since 1991, exempts a patient from being declared dead on the basis of the neurological criteria. The relevant sections of the statute read: “The death of an individual shall not be declared upon the basis of neurological criteria [ . . . ] when such a declaration should violate the personal religious beliefs or moral convictions of that individual, and when that fact has been communicated to, or should, reasonably be known by, the licensed physician authorized to declare death. In such cases, death shall be declared and the time of death fixed, solely upon the basis of traditional cardio-respiratory criteria” (New Jersey Revised Statute 2013).
6. Most of the authoritative bodies which have endorsed death by neurological criteria (DNC) are medical organizations, including the American Medical Association, the American College of Chest Physicians, the American Academy of Pediatrics (AAP), and the medical societies mentioned in Note 2. Of the nonmedical bodies which have also accepted DNC, the most prestigious is the Pontifical Academy of Sciences; the pronouncements of this consultative body to the Holy See have no magisterial weight, however.

7. For a more detailed discussion on this issue, see Nguyen (2019).
8. According to the Commission, “in adults who have experienced irreversible cessation of the functions of the entire brain, [...] the heart usually stops within two to ten days.” Similarly, Soifer and Gelb (1989, 815–16) state: “Somatic death closely follows the declaration of brain death. Despite all efforts to maintain the donor’s circulation, irreversible cardiac arrest usually occurs within 48 to 72 hours of brain death in adults, although it may take as long as 10 days in children. Indeed, general acceptance of the concept of brain death depended on this close temporal association between brain death and cardiac arrest.”
9. Wijdicks, a leading advocate of DNC, freely admitted this during the 2006 Conference “The Signs of Death” organized by the Pontifical Academy of Sciences. Wijdicks stated: “The diagnosis of brain death is driven by whether there is a transplantation programme or whether there are transplantation surgeons. I do not think brain death examination now, in practice, would have much of any meaning if it were not for the sake of transplantation” (Sorondo 2007, 50).
10. In a recent survey of 938 members of the AAN, nearly half of the 201 respondents reported that they had encountered families’ resistance to the declaration of BD. In response to a hypothetical scenario in which the family requests continued life support after the declaration of BD, 48 percent of the respondents indicated that they would accept such a request so as to avoid litigation (Lewis et al. 2016).
11. Details about legal disputes over BD can be found in Pope (2020).
12. In discussing the McMath case, Burkle, Sharp, and Wijdicks (2014) asserted the following:

this situation further confirms that neurologic determinations of death and state laws concerning these matters are clear and unambiguous. Many patients, family members, and the public at large remain confused about the differences between brain death (death) and other neurologic disorders. [...] Although some commentators and members of the media have sought to create controversy in this situation, there is none, as a strong and well-established consensus regarding brain death has been forged from decades of sustained discussions in medicine, law, and ethics. If there is a lesson to be learned from this case, it is that there is greater need to communicate this consensus to members of the public and to those who report medical news. (p. 1468)

13. In a 2008 survey of the top fifty institutions for neurology and neurosurgery in the United States, variability was found in several areas, from the number of examinations, the type of healthcare professional responsible for BD determination, the use of ancillary testing, to the apnea test, “an area with the greatest possibilities for inaccuracy” (Greer et al. 2008, 288). An updated

- survey of the same fifty institutions in 2015 revealed better uniformity in BD determination. Nevertheless, in the area of apnea testing, “the specifics of the testing technique varied widely across institutions” (Wang et al. 2017, 565).
14. Several pro-BD scholars have expressed the call for such standardization (see, for instance, Choi et al. 2008; Bartscher and Varelas 2010; Lewis, Cahn-Fuller, and Caplan 2017).
  15. The operational criteria for the determination of BD have undergone several modifications, evolving from the original Harvard criterion to the currently practiced AAN guidelines (see the detailed discussion in Nguyen 2019).
  16. In the language of Lewis and colleagues, the phrase “accepted medical standards” refers to both the AAN guidelines for adults and the guidelines for pediatric patients (referred to as the SCCM/AAP/CNS standard) which was published in 1987 and updated in 2012 by the SCCM, AAP, and CNS. They are the guidelines accepted by the AAN and medical stakeholders in BD determination (the names of which are mentioned in Note 2).
  17. In the Hailu case, the declaration of BD was based on the 2010 AAN guidelines. The state Supreme Court of Nevada was not convinced, however, that the 2010 AAN guidelines were the “accepted medical standard,” having replaced the original Harvard criteria (Lewis, Cahn-Fuller, and Caplan 2017, 115–16; Lewis et al. 2019, 14; Lewis, Bonnie, and Pope 2020, 143).
  18. The revised BD statute of Nevada specifies that BD determinations must be

in accordance with the applicable guidelines set forth in: (1) ‘Evidence-based Guideline Update: Determining Brain Death in Adults: report of the Quality Standards Subcommittee of the American Academy of Neurology,’ published June 8, 2010, by the American Academy of Neurology, or any subsequent revisions approved by the American Academy of Neurology or its successor organization; or (2) ‘Guidelines for the Determination of Brain Death in Infants and Children: An update of the 1987 Task Force Recommendations,’ published January 27, 2012 by the Pediatric Section of the SCCM, or any subsequent revisions approved by the Pediatric Section of the SCCM or its successor organization. (Nevada Revised Statute 2019)

19. The Harvard report specifically states “no spontaneous muscular movements” and “as a rule, the stretch tendon reflexes cannot be elicited.” (Harvard Medical School 1968, 338)
20. This assertion is based on two surveys in which 78 percent of 201 adult neurologists and 72 percent of 197 pediatric intensivists and neurologists consider that consent for BD determination is not needed (Lewis et al. 2016, 828; Lewis et al. 2017, e917).
21. Such concern about litigation over BD is quite apparent in some of the recent publications from pro-BD

- scholars (see Lewis and Greer 2017a; Lewis, Cahn-Fuller, and Caplan 2017; Lewis et al. 2018; Lewis, Bonnie, and Pope 2020; Pope 2018).
22. The statement made by Justice Louis Brandeis, “in most matters it is more important that the applicable rule of law be settled than that it be settled right,” was quoted by Pope, one of the co-authors of the RUDDA. According to Pope, although “the law concerning BD has remained stable for decades,” recent legal challenges have upset this stability and “destroyed uniformity.” For this reason, Pope advocates the need for legal certainty and uniformity regarding the legal status of BD.
  23. See also, Youngner et al. (1985, 321); Nair-Collins (2010, 671); Kompanje and de Groot (2015).
  24. The nuanced language of John Paul II should guard us from interpreting his statement as if it were a plain affirmation that the BD criterion does not conflict (and, therefore, is compatible) with the Church’s anthropology. The phrasing “does not seem to conflict” implies that his presupposition, that the “BD paradigm is not inconsistent with the Church’s anthropology, only *seems* to be true according to [his] judgment based on the knowledge that he had around the time of his address” (Nguyen 2017, 163).
  25. It is not uncommon for DNC defenders to argue that the BD patient has died, but the “corpse” still appears alive because of the prowess of medical technology (the ventilator and pharmacological agents). However, such a claim contradicts the principle of proportionate causality, according to which, what is present in the effect must also be present in its cause. In what way can the ventilator, which has only a simple power of insufflation, be capable of causing gas exchange, which takes place in the lungs and throughout the body, and of maintaining homeostasis, body temperature, circulation, digestion, and myriads of other integrative functions (Accad 2015, 224)? If the ventilator can make the BD “corpse” to appear alive, then logically, “if one connects the ventilator to the corpse of a person whose death was determined by the traditional criteria, then one would expect the ventilator [ . . . ] to give the appearance of life in a dead entity. As intuited by common sense, this will not happen, however” (Nguyen 2017, 161).
  26. The case of Elijah Smith in 2013 illustrates this point: the patient had registered himself as an organ donor when applying for his driver’s license. When he suffered an accident and was declared brain-dead, his parents, who were not against organ donation, wanted mechanical ventilation discontinued prior to organ removal. Neither the parents nor the patient knew that organ donation in BD takes place while the donor remains on a ventilator and with a beating heart (Nair-Collins 2015, 78).
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