

## **Defining death: Getting it wrong for all the right reasons**

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### **Abstract:**

The Uniform Determination of Death Act defines death as either the irreversible cessation of all circulatory and respiratory functions or of all functions of the entire brain. As a matter of scientific fact, many patients declared dead for purposes of organ donation do not meet this legal requirement. In addition, many of these patients have not lost “the integrated functioning of the organism as a whole,” a scientific standard that defines life across the entire biological spectrum, not just in humans. As such, current practices violate the implicit ethical and legal principle known as the “dead donor rule,” which states that vital organs may never be removed from patients before they are dead.

I claim that while current practices of organ procurement do cause the death of the patient, they are nevertheless ethical because 1) they are performed with the patient’s or surrogates’ consent (principle of respect for autonomy), and 2) they do not harm or set back the interests of the patient (principle of nonmaleficence). While the ideal long-term solution is to reframe the ethics of vital organ donation in terms of these principles rather than the dead donor rule, a more practical short-term solution may be to conceptualize current approaches to defining death as socially acceptable “legal fictions,” acknowledging that they are not biologically valid. Not only would this solution create a more honest and transparent public policy, but it would save lives by increasing both the quantity and the quality of organs available for transplantation.

## Defining death: Getting it wrong for all the right reasons

The Dead-Donor Rule, or DDR, is a principle that has been an implicit ethical and legal requirement in the procurement of organs since the beginning of the transplantation enterprise in the 1960s.<sup>1</sup> The rule has been expressed in various formulations, including: 1) vital organs for transplantation may only be procured from patients who are dead, or 2) physicians may not cause death when procuring vital organs for transplantation. The rule does not exist literally in the law, but rather is understood to be an implication of existing laws and ethical standards related to homicide.

This article is divided into two parts. The first part advances an argument that is purely scientific in nature, and relies only on careful examination of the biological facts about patients currently diagnosed as dead for purposes of organ donation. I will conclude that many patients currently deemed to be legally dead for purposes of organ donation are not, in fact, dead by any scientific or biological standard. If this claim is correct, then it follows that our current practices of organ procurement do not conform with the DDR.

While the majority of experts and commentators on the subject argue that we should not abandon the DDR, it is important to be clear that unless this claim can be shown to be false, then there is no way that we can continue our current practices in organ procurement and continue to hold allegiance to the DDR. Again, I want to emphasize that this argument does not depend upon any ethical or value assumptions, but rather is a narrow scientific argument that the biological claims made by others over the years cannot withstand critical scrutiny.

In the second part, I explore the options that are available to us, if indeed the claim made in the first part is correct. One option, of course, would be to confirm the authority of the DDR and to stop procuring organs from individuals that we have previously considered to be deceased. This option would have tragic consequences, resulting in the premature death of thousands of patients each year from failure to receive a life-saving organ, as well as failure to honor the altruistic requests of many individuals to donate their organs to others when they are no longer in need of them.

A second option, which I will argue is the best long-term solution, is to reconsider the ethical and legal foundations of organ procurement, and explore whether it may be ethically and legally permissible for patients to donate vital organs before they are dead, provided certain other requirements are met. For example, I propose that individuals who will not be harmed by organ procurement and who have given permission for this procedure should be permitted to donate, even if at the time of organ procurement they are not yet dead. In addition to other implications which will be explored, this approach would legitimate our current approach to organ procurement.

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<sup>1</sup> J.A. Robertson, *The dead donor rule*, 29 (6) Hastings Ctr. Rep. 6 (1999)

A third option, which may be the best short-term solution, is to acknowledge the discordance between our scientific understanding of death and our current legal requirements for the diagnosis of death. This approach would frame our current criterion for determining death as a "legal fiction," and would also legitimate our current practices, while recognizing that the legal requirements for determining death do not necessarily conform with scientific reality.

Finally, we have the option of simply ignoring the problem, and choosing to "muddle through." At the present time, this would seem to be the preferred choice of the medical profession and perhaps of society in general. While it has the obvious advantage of allowing a life-saving practice to continue, it has a number of practical and ethical drawbacks as well, which will be explored.

### **Historical and Conceptual Background**

The modern age of organ procurement and transplantation from deceased donors can be traced to December 3, 1967, when Christian Barnard performed the first heart transplant in Cape Town, South Africa.<sup>2</sup> Almost lost in the headlines about this remarkable medical advance was the question of whether the donor was dead at the time his heart was removed for transplantation.

The relevance of this question was not lost upon Henry Beecher, an anesthesiologist at Harvard Medical School, who saw it is a key issue to be resolved if organ transplantation was to continue to develop. He immediately sought the support of the Dean to appoint an "Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death," which he chaired.<sup>3</sup> The paper from the Committee, titled "A Definition of Irreversible Coma," suggested that the diagnosis of "irreversible coma" could perhaps be considered a new way of defining death. If so, then procuring organs from patients with devastating brain injury, such as the donor in Cape Town, could be seen as being in compliance with the DDR. Unfortunately, Beecher and his colleagues did not actually provide any scientific, philosophical, or logical justification for why the state of "irreversible coma" could be equated with "death." Indeed, in my opinion, such a justification does not exist.

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<sup>2</sup> C.N. Barnard, *The operation: A human cardiac transplant: An interim report of a successful operation performed at Groote Schuur Hospital, Cape Town*, 41 S. African Med. J. 1271 (1967); C.N. Barnard, *Reflections on the first heart transplant*, 72 S. African Med. J. 19 (December 5 1987)

<sup>3</sup> Ad Hoc Comm. of the Harvard Med. Sch., *A definition of irreversible coma, Report of the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death*, 205 (6) J. of the Am. Med. Ass'n. 337 (1968)

Despite these ambiguities, in 1980 Kansas became the first state to adopt the Harvard criteria into law as a definition of death. Several other states followed in the next few years, creating the awkward situation where it was possible for a patient to be alive in one state and dead in another.<sup>4</sup> In 1981, the Uniform Conference of Commissioners on Uniform State Laws approved the Uniform Definition of Death Act (UDDA), which has since been adopted by legislation or case law in all 50 states.<sup>5</sup> The UDDA states:

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

In other words, the UDDA specifies two different ways for determining death. These correspond with the two main pathways for organ procurement currently in use (Figure 1). Both are predicated upon the DDR, i.e., each pathway corresponds to one of the alternative ways for determining death. In the Brain Death Pathway, death is determined on the basis of the irreversible loss of all brain function, whereas in the Donation after Circulatory Death (DCD) pathway, death is determined on the basis of the irreversible loss of circulatory function. In patients diagnosed as brain-dead, the organs are perfused with oxygenated blood from the heart right up until the time when they are infused with cold preservative fluid. This pathway therefore yields organs in the best possible condition, since they suffer minimal ischemic injury from lack of blood flow or oxygenation. In this pathway, organs of all types can be procured, including the heart, lungs, liver, kidneys, pancreas, bowel and more. The DCD protocol, on the other hand, requires the surgical team to wait 2-5 minutes (depending on the hospital protocol) after the patient loses a pulse (to be sure that the loss of pulse is "irreversible") before organ procurement can begin. This exposes the organs to some degree of ischemic injury, and as a practical matter, only kidneys can typically be procured in this way. In addition, these kidneys are at some greater risk of failure compared with kidneys obtained from brain-dead donors.<sup>6</sup>

### **Part 1: Are brain-dead or DCD donors known to be dead at the time their organs are procured?**

#### Brain-dead donors

The UDDA requires that "A determination of death must be made in accordance with accepted medical standards." At the same time that the UDDA was adopted, an article was published in the Journal of the American Medical Association (JAMA) describing the

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<sup>4</sup> President's Comm'n., *Defining Death: A Report on the Medical, Legal, and Ethical Issues in the Determination of Death*, Gov't. Printing Office Washington, D.C. (1981)

<sup>5</sup> Id.

<sup>6</sup> Non-Heart-Beating Organ Transplantation: Practice and Protocols. Inst. of Med. (2000)

testing that constituted "accepted medical standards" for determining brain death.<sup>7</sup> Although these standards have evolved over the years, the core elements have not changed. In most cases, the testing can be done at the bedside by physical exam and without specialized equipment.<sup>8</sup>

The law requires that the patient has the irreversible loss of *all* functions of the *entire* brain, including the brain stem. To fulfill the requirements, the examining physician first shows that the patient is unconscious by testing to see if the patient responds to verbal commands or painful stimuli. Function of the brain stem is tested by examining several brainstem reflexes, including whether the pupils react to light and whether the patient coughs or gags with stimulation to the back of the throat. A key element of the testing, known as the apnea test, examines whether the patient makes any effort to breathe when the ventilator is turned off and carbon dioxide is allowed to build up in the patient's blood. Finally, if no brain functioning is detected by this battery of tests, investigations are performed to show that this loss of function is irreversible, i.e., that there is a plausible explanation for what caused the injury, and that various reversible conditions have been ruled out, such as a drug overdose.

Even at the time of publication of the UDDA and the guidelines in JAMA, the medical community was aware that there were significant discrepancies between what the law required and what the diagnostic testing demonstrated.<sup>9</sup> In short, it was clear that the diagnostic testing examined only a few select functions of the brain, and that many patients diagnosed as brain dead actually retained functions that were not a part of the diagnostic battery. For example, many such patients continue to maintain temperature regulation, clearly an important brain function. Others continue to control fluid and salt homeostasis through the regulated secretion of hypothalamic hormones. More controversially, some patients continue to have brainwave activity, although it is not clear whether this activity actually represents brain "function." And finally many patients show an increase in heart rate and blood pressure at the time of skin incision for organ procurement, although whether this represents the perception of pain or merely reflex activity at the level of the spinal cord is not clear. In any case, there is no disagreement in the medical profession, then or now, that the current clinical criteria for the diagnosis of brain death do not meet the letter of the law.

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<sup>7</sup> Guidelines for the determination of death, 246 J. of the Am. Med. Ass'n. 2184 (1981)

<sup>8</sup> E.F.M. Wijdicks; The diagnosis of brain death; 344 New England J. of Med. 1215 (2001); E.F. Wijdicks, P.N. Varelas, G.S. Gronseth, D.M. Greer, and Am. Acad. of Neurology, Evidence-based guideline update: determining brain death in adults: report of the Quality Standards Subcommittee of the American Academy of Neurology, 74 (23) Neurology 1911 (2010)

<sup>9</sup> A. Halevy and B. Brody, *Brain death: Reconciling definitions, criteria, and tests*, 119 Annals of Internal Med. 519 (1993); R.D. Truog, *Is it time to abandon brain death?*, 27 (1) Hastings Ctr. Rep. 29-37 (1997); R.D. Truog, *Brain death-Too flawed to endure, too ingrained to abandon*, 35 (2) J. of Law, Med., and Ethics 273 (2007)

Professor James Bernat, a distinguished neurologist at Dartmouth University, was one of the first to recognize this discrepancy between the law and the clinical diagnostic criteria. In the same year that the UDDA and the JAMA article were published, Bernat and colleagues wrote a seminal paper that they hoped would resolve the discrepancies between the requirements of the law and the clinical findings as well as provide reassurance that “brain death” is really “death.” The paper, titled "On the Definition and Criteria of Death" built upon a scientific tradition going back to the 1800s about the conceptual distinction between life and death.<sup>10</sup> They wrote, “We define death as the permanent cessation of functioning of the organism as a whole.”<sup>11</sup> Building upon the work of renowned physicians and physiologists, from Claude Bernard in France in the 1860s through Walter Cannon at Harvard in the 1920s (who coined the term homeostasis), they elaborated upon the theme that life and death can be understood in terms of thermodynamic concepts. In other words, living organisms are distinguished from the inanimate world by their use of energy consuming processes to oppose entropic forces and maintain internal homeostasis. Throughout life, living organisms use nutrients to generate the energy required to maintain the complex organization and myriad molecular and cellular interactions that constitute life. Once these energy consuming processes stop, we return to the “dust” of the inanimate world. This scientific definition of life can be applied across the entire biological spectrum, from single celled organisms like amoebas, to plants like trees and flowers, and to animals like insects and human beings.

While dying is a “process,” there is a “moment” when a point-of-no-return is crossed and where no resuscitative efforts can be effective at restoring the organism to a state of homeostasis.<sup>12</sup> This is the moment of death. In any given case, it may be difficult to know when this moment occurs (for example, people who drown in freezing cold water can sometimes be resuscitated several hours after they have stopped breathing). Under normal circumstances, however, it seems to be very rare that patients can be resuscitated after more than 10-15 minutes of pulselessness. Hence, while the moment of death is metaphysically precise, determining this moment may be epistemologically difficult.

In their paper, Bernat and colleagues use this framework to explain why "brain death" is really the death of the organism: “The criterion for cessation of the functioning of the organism as a whole is permanent loss of functioning of the entire brain... because the brain is necessary for the functioning of the organism as a whole.”<sup>13</sup> The idea here, in

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<sup>10</sup> J.L. Bernat, C.M. Culver, & B. Gert, *On the definition and criterion of death*, 94 *Annals of Internal Med.* 389 (1981)

<sup>11</sup> *Id.* at 390.

<sup>12</sup> L.R. Kass, *Death as an event: a commentary on Robert Morison*, 173 (3998) *Sci.* 698 (1971)

<sup>13</sup> Bernat, Culver, & Gert, *supra* Note 10 at 391

other words, is that the brain functions as a "central command center" for the body, such that when the body loses the controlling influence of the brain, the body simply disintegrates. As the authors explain, "Destruction of the brain produces apnea and generalized vasodilatation; in all cases, despite the most aggressive support, the adult heart stops within one week, and that of the child within 2 weeks."<sup>14</sup>

When this paper was written in 1981, Bernat's analysis was almost certainly correct. At that time, patients diagnosed as brain-dead rapidly progressed to cardiac arrest, despite the best efforts of clinicians to keep them alive. The problem, however, is that Bernat's claim is no longer true. Today, patients diagnosed as brain dead can live, not just for days or weeks, but for many years.<sup>15</sup>

What has changed? The change can best be understood by comparing brain death with high cervical quadriplegia, which can be caused by accidents involving transection of the spinal cord high in the neck (as in the case of the actor Christopher Reeve). Both brain death and high cervical quadriplegia involve the physiological separation of the brain from the body (ignoring some details). When the body no longer has the controlling and modulating influence of the brain, basic physiological parameters, such as heart rate and blood pressure, become wildly unstable. This phenomenon is known as "spinal shock," and in 1981 patients with either spinal shock or brain death would rarely survive their acute injury.<sup>16</sup>

In recent decades, however, intensive care units have become much more capable and sophisticated at controlling these physiological functions. Although patients with either of these conditions can initially be very unstable and tenuous, with adequate support in the ICU the body is often able to regain equilibrium, and the person may go on to live for many years.

While it is no not uncommon for patients with high cervical quadriplegia to live for years, most patients diagnosed as brain dead die within a short time of their injury, either because 1) they become organ donors, 2) because their families choose to withdraw life support, or 3) because physicians insist upon removal of life support because the patient meets the legal criteria for death.

In most cases there is no conflict between the clinicians and family members around these decisions. No one diagnosed as brain dead has ever recovered consciousness, even to the most minimal degree, and generally family members have no more interest

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<sup>14</sup> Id. at 392

<sup>15</sup> D.A. Shewmon, *Chronic "brain death"- Meta-analysis and conceptual consequences*, 51 (6) *Neurology* 1538 (1998)

<sup>16</sup> Id.; D.A. Shewmon, *The brain and somatic integration: insights into the standard biological rationale for equating "brain death" with death*, 26 (5) *J. of Med. and Philosophy* 457 (2001)

in maintaining life support under these conditions than clinicians have in providing it. Nevertheless, on rare occasions families may refuse to have life-support withdrawn. In one well-documented case, a child who was diagnosed as brain-dead at the age of three lived at home on a ventilator for more than 20 years, fed through a feeding tube placed in his stomach. An autopsy performed after he died showed that his brain had become an amorphous calcified mass – there was no evidence of any brain cells at all.<sup>17</sup> Cases like these demonstrate clearly that the body does not need the brain in order to maintain the integrated functioning that is diagnostic of life. While our brains are indeed necessary for consciousness, personhood, and all of the things that make life worth living, they are not necessary for life itself or our continued existence. In this basic sense, we are not dissimilar from trees and other organisms that maintain complex integrated functioning in the absence of a brain.

This paradox – that a person considered legally dead could live for many years – captured the American media for much of 2014. Jahi McMath was a 14-year-old girl at the time she had massive postoperative bleeding following a surgical procedure at Oakland Children's Hospital.<sup>18</sup> She was diagnosed as brain dead in December 2013, and a death certificate was completed and filed. The hospital informed her parents that she was legally dead and that they were going to remove her from the ventilator and send her to the hospital morgue. The parents disagreed, insisting upon continued treatment. The family was severely criticized by leading bioethicists, one stating: "Their thinking must be disordered, from a medical point of view. . . . There is a word for this: crazy." Others cited the now disproven view that the bodies of these patients disintegrate when the controlling influence of the brain is lost. "Her body," according to one bioethicist, "will start to break down and decay."<sup>19</sup>

As it has turned out, none of this came to pass. Jahi McMath was eventually transferred to a rehabilitation center in New Jersey (New Jersey allows families to opt out of the diagnosis of brain death; New York offers less protection, requiring only that such families receive "reasonable accommodation."<sup>20</sup> Upon her arrival, the facility stated on

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<sup>17</sup> D.A. Shewmon, *Chronic "brain death": meta-analysis and conceptual consequences*, 51 (6) *Neurology* 1538 (1998); D.A. Shewmon, *Spinal shock and brain death: somatic pathophysiological equivalence and implications for the integrative-unity rationale*, 37 (5) *Spinal Cord* 313 (1999); S. Repertinger, W.P. Fitzgibbons, M.F. Omojola, & R.A. Brumback, *Long survival following bacterial meningitis-associated brain destruction*, 21 (7) *J. of Child Neurology* 591 (2006)

<sup>18</sup> R.D. Truog and F.G. Miller, *The meaning of brain death: a different view*, 174 (8) *JAMA Intern Med* 1215 (2014); D.C. Magnus, B.S. Wilfond, & A.L. Caplan, *Accepting brain death*, 370 (10) *New England J. of Med.* 891 (2014)

<sup>19</sup> L. Szabo, *Ethicists criticize treatment of brain-dead patients*, *Nat'l. Catholic Rep.*, Jan. 10 2014

<sup>20</sup> R.S. Olick, E.A. Braun, & J. Potash, *Accommodating religious and moral objections to neurological death*, 20 (2) *J of Clinical Ethics* 183 (2009); R.S. Olick, *Brain death, religious*



their website that “This child has been defined as a deceased person, yet she has all of the functional attributes of a living person despite her brain injury.”<sup>21</sup>

According to accounts on the web, she continues to survive, and has subsequently been transferred to a home care facility where she continues to grow and develop, supported only with a ventilator and tube feedings.<sup>22</sup> According to reports from some neurologists, she has also gone through puberty and begun to menstruate.<sup>23</sup> In criticizing the efforts of her parents to keep her alive, one prominent bioethicist quipped “You can’t really feed a corpse”<sup>24</sup>. This is correct, of course, but given that McMath and other brain-dead patients can not only be fed, but can digest the food, excrete wastes, and grow and develop, he was unwittingly undermining his own position.

Another type of case that illustrates how brain-dead patients may retain integrated functioning involves the tragic stories of women who become brain-dead during pregnancy. Judging from reports in the media, these cases arise at least several times a year.<sup>25</sup> Typically, the family is given a choice of terminating life support or of continuing to keep the woman alive until after the birth of the baby (although in one unusual case a judge required continued treatment of the woman against the objections of her husband because of his belief that Texas law prohibited the withdrawal of life support from a pregnant woman.<sup>26</sup> Certainly the capacity of a woman to gestate a fetus for up to several months until delivery could be taken to be the *sine qua non* of integrated functioning.

Consider, for example, a story broadcast on NBC News in February 2014. They reported that “A 32-year-old Canadian woman who had been declared brain dead in December and kept on life support for six weeks died on Sunday soon after giving birth to a baby

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*freedom, and public policy: New Jersey’s landmark legislative initiative*, 1 (4) Kennedy Inst. of Ethics J. 275 (1991)

<sup>21</sup> B.A. Rich, *Structuring conversations on the fact and fiction of brain death*, 14 (8) Am. J. of Bioethics 31 (2014)

<sup>22</sup> M. Malkin, *All life matters- 14 year old Jahi McMath defies ‘experts’*, [http://www.noozhawk.com/article/michelle\\_malkin\\_all\\_life\\_matters\\_14\\_year\\_old\\_jahi\\_mcmath\\_20141228](http://www.noozhawk.com/article/michelle_malkin_all_life_matters_14_year_old_jahi_mcmath_20141228) (accessed Dec. 30 2014)

<sup>23</sup> See Declarations of Drs. Calixto Machado and Alan Shewmon dated October 3, 2014, <http://www.thaddeuspope.com/futilitycases.html> (accessed Dec. 30 2014)

<sup>24</sup> L. Szabo, *supra* note 19

<sup>25</sup> A. Lane, A. Westbrook, D. Grady, R. O’Connor, T.J. Counihan, B. Marsh, & J.G. Laffey, *Maternal brain death: medical, ethical, & legal issues*, 2004 Intensive Care Med. ; D.J. Powner & I.M. Bernstein, *Extended somatic support for pregnant women after brain death*, 31 (4) Critical Care Med. 1241 (2003)

<sup>26</sup> J.L. Ecker, *Death in pregnancy—An American tragedy*, 370 (10) New England J. of Med. 889 (2014)

boy.”<sup>27</sup> Yet according to the “traditionally correct” understanding of brain death, the story should have reported that “A-32 year-old Canadian woman who had been a dead corpse for six weeks gave birth on Sunday to a baby boy.” I know of no instance where journalists have reported on these cases using the “traditionally correct” language, and I suspect they do not do so because language suggesting the dead people can give birth to babies would sound completely implausible, even ridiculous. And it sounds that way because, indeed, it is.

Critical care clinicians often comment on the paradoxical observation that brain-dead patients are sometimes the “healthiest” appearing patients in the ICU. Once they stabilize from spinal shock, they can have all the elements of normal functioning with the exception of consciousness and the ability to breathe and eat on their own. They circulate, respire, digest food and excrete waste products, grow and develop, control their temperature, heal wounds, fight infections, and can even reproduce through the production of sperm and ova and the ability to gestate a fetus.

Two potential objections to this argument are worth considering at this point. First, many observers of the Jahi McMath case believe it is irrelevant whether she is alive or dead. They ask, “Even if a person is alive in some technical sense, why would anyone who was irreversibly unconscious and who will never have the ability to interact with the world in any meaningful way want to live like that?” This is a good question, and can be addressed in two ways. First, we must not confuse the question of whether someone is dead with the question of whether a life is worth living. Although these two questions may collapse together for many people in cases like these, they are fundamentally distinct. The first is a question of biological reality, the second is a question of values.

This being said, many philosophers, most notably Bob Veatch at Georgetown University, have advanced the view that patients who are irreversibly unconscious should be considered dead, since they have lost the intrinsic features of personhood.<sup>28</sup> This argument defines death in moral terms rather than ontological language, and while I cannot do justice to it here, it is compelling and philosophically sound. This position is known as the “higher brain criterion,” and it differs from the “whole brain criterion” as represented by the UDDA in that it focuses on destruction of only the higher brain structures that support consciousness and excludes the brainstem structures that support vegetative functions like breathing.

Although the “higher brain criterion” is philosophically sound, it suffers from many practical and public policy concerns. First, at a practical level, the precise neurological substrates for consciousness are not known, and there is a great deal of controversy in

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<sup>27</sup> J. Gordon, *Brain-dead Canadian woman dies after baby boy born*, Reuters, Feb. 11 2014

<sup>28</sup> R.M. Veatch, *The whole-brain-oriented concept of death. An outmoded philosophical formulation*, 3 J. of Thanatology 13 (1975)

the field about whether and how the absence of consciousness can be correctly diagnosed.<sup>29</sup> Second, at a public policy level, there is no consensus in our country that the absence of consciousness can be equated with the death of the person. Although most observers agreed that Terri Schiavo was irreversibly unconscious (and her autopsy proved that this was certainly the case,<sup>30</sup> public figures at the highest levels of government insisted that it was not acceptable to allow her to die, let alone consider her to be already dead.<sup>31</sup>

The second objection to the argument that I will consider is the view that even though patients like Jahi McMath may be biologically alive, they are ventilator dependent, and this artificial form of life support is merely "masking" their death. One of the criteria for the diagnosis of brain death is apnea, that is, the complete absence of any respiratory drive to breathe. As such, when the ventilator is withdrawn, these patients make no respiratory effort and suffer cardiac arrest and death within minutes. But does it make sense to say that people who are completely dependent upon a form of life support be considered dead simply because they would be dead if that life support were removed? Consider patients who require dialysis or a cardiac pacemaker to sustain life. Absent continued use of this life support, they will die. Certainly, we cannot say that they are already dead. Consider also that patients with high cervical quadriplegia – like Christopher Reeve – may live for many years despite the fact that they are completely dependent upon mechanical ventilation, in exactly the same way as patients diagnosed with brain death. Again, it is clear that dependence upon life support cannot be a reason for considering a person to be dead. The question is *whether* the necessary physiological functions – such as respiration, circulation, and hormonal regulation – are being performed, not *how* they are being performed.<sup>32</sup>

These concerns about brain death have been discussed in hundreds of books and articles in academic journals, newspapers, and magazines for decades. But the issues were taken to a new level in 2008 when the President's Council on Bioethics took up the question of brain death in its book "Controversies in the Determination of Death."<sup>33</sup> The

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<sup>29</sup> A.M. Owen, M.R. Coleman, M. Boly, M.H. Davis, S. Laureys, & J.D. Pickard, *Detecting awareness in the vegetative state*, 313 (5792) *Science* 1402 (2006); M.M. Monti, A. Vanhaudenhuyse, M.R. Coleman, M. Boly, J.D. Pickard, L. Tshibanda, A.M. Owen, & S. Laureys, *Willful Modulation of Brain Activity in Disorders of Consciousness*, 2010 *New England J. of Med.*

<sup>30</sup> F. Charatan, Autopsy supports claim that Schiavo was in a persistent vegetative state, 330 (7506) *BMJ* 1467 (2005)

<sup>31</sup> G.J. Annas, "Culture of Life" politics at the bedside—the case of Terri Schiavo, 352 (16) *New England J. of Med.* 1710 (2005)

<sup>32</sup> F.G. Miller & R.D. Truog, *Rethinking the ethics of vital organ donation*, 38 (6) *Hastings Ctr. Rep.* 38 (2008); Bernat, Culver, & Gert, *supra* Note 10

<sup>33</sup> The President's Council on Bioethics, *Controversies in the determination of death: A white paper of the President's Council on Bioethics*, (2008)

Council, formed under the Bush administration, included 18 eminent scholars from multiple disciplines, including a neurosurgeon. The chairman of the Council at the time was Dr. Edmund Pellegrino, one of the founding leaders of the field of bioethics.

Their analysis essentially followed the argument I have outlined above, concluding that "If being alive as a biological organism requires being a whole that is more than the mere sum of its parts, then it would be difficult to deny that the body of a patient with [brain death] can still be alive, at least in some cases."<sup>34</sup> They went on to state that "The reason that these somatically integrative activities continue... is that the brain is not the integrator of the body's many and varied functions... no single structure in the body plays the role of an indispensable integrator. Integration, rather, is an emergent property of the whole organism..."<sup>35</sup>

This conclusion from the Council was remarkable in that it completely undermined a foundational assumption of organ donation and transplantation, namely, that brain-dead organ donors are dead and that procuring their organs adheres with the DDR. As one might imagine, however, allowing such a radical conclusion to stand could have had a devastating impact upon the entire field of organ transplantation, and potentially cost the lives of many patients who would die prematurely for lack of a transplantable organ. So while acknowledging that all of the prior scholarship in support of the concept of brain death was flawed, the Council proposed an entirely new argument for why brain death represents the death of the human organism, replacing the term "brain death" with the new concept of "total brain failure."

To be alive, according to the Council, organisms must be able to perform the "vital work" of the organism as a whole, and in particular must satisfy three criteria:

- receptivity to stimuli and signals from the surrounding environment,
- the ability to act upon the world to obtain selectively what it needs,
- the basic felt need that drives the organism to act as it must, to obtain what it needs.<sup>36</sup>

The report has received surprisingly little response or commentary, but my colleagues and I have a difficult time even understanding what these three criteria mean.<sup>37</sup> If by "vital work" the Council meant the functions associated with consciousness, then the Council's definition would classify patients in a persistent vegetative state as dead, a position the Council specifically rejected. If by "vital work" the Council meant functions other than those associated with consciousness, then patients diagnosed as brain dead may retain the entire range of these functions, as discussed earlier. In short, I am

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<sup>34</sup> Id. at 57

<sup>35</sup> Id. at 40

<sup>36</sup> Id. at 61

<sup>37</sup> F.G. Miller & 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*, 19 92) Kennedy Inst. Ethics J. 185-93 (2009)

skeptical about the Council's new formulation, and it remains to be seen whether this will be adopted as a convincing new justification for the concept of brain death.

To briefly summarize the argument to this point, the concept of brain death describes a patient who may still be alive, but who is severely neurologically injured and will never regain consciousness or breathe without a ventilator. As such, our practice of procuring organs from these patients routinely violates the DDR.

### DCD Donors

Figure 1 shows the two pathways to organ donation. The discussion above has covered the pathway on the left, the brain death pathway, and I will now turn to the pathway on the right, the DCD pathway.<sup>38</sup> DCD donation is typically performed with patients who have suffered severe neurological injury, but injury less severe than that required for the diagnosis of brain death. In order to satisfy the DDR, these patients have life-support – typically the ventilator – withdrawn in a controlled fashion. Depending on hospital protocol, this may be done in the ICU, or the patient may be transported to the operating room for the procedure. In either case, once life support is withdrawn the patient is carefully observed for cardiac arrest and the loss of circulation, as determined with echocardiography by the absence of cardiac ejection or with an arterial catheter by the absence of pulsatility. Generally this must occur within the first 60 minutes after the withdrawal of life support, since if the dying process is prolonged beyond this window it is presumed that the organs have suffered too much ischemic injury to be transplantable. If, however, the patient does become pulseless within this window, then the patient enters the so-called "hands off" or "death watch" portion of the process, where the patient is observed for an interval of between 2 and 5 minutes (depending upon the hospital protocol) to determine whether the heart will start again on its own (autoresuscitation). At the end of that interval, if the patient remains pulseless, the patient is declared dead, and surgical organ procurement begins.

As discussed above, the moment of death occurs at the time when the energy consuming processes of the body diminish to a "point of no return," where the entropic forces pushing towards disorganization and disintegration can no longer be overcome. There is no disagreement among medical experts that many patients have not reached this "point of no return" after only 2-5 minutes of pulselessness, since patients who are not organ donors are frequently successfully resuscitated after being pulseless for this length of time. While acknowledging this point, Professor Bernat has proposed that in the case of organ procurement the concept of "permanence" is a valid proxy for the

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<sup>38</sup> Non-Heart-Beating Organ Transplantation: Practice and Protocols, *supra* note 6; J.L. Bernat, et. al., *Report of a National Conference on Donation after cardiac death*, 6 (2) Am J Transplant 281-291 (2006)

concept of "irreversibility."<sup>39</sup> As he describes it, since no efforts will be made to attempt resuscitation in these patients, and since autoresuscitation has never been observed in any patient who has been pulseless for two minutes or more,<sup>40</sup> these patients are "permanently pulseless," and may therefore be treated as if their pulselessness is irreversible.

Two types of objection can be raised to this proposal.<sup>41</sup> First, it represents a category mistake, in that it confuses the state of "dying" (the condition of pulselessness *will become* irreversible) with the state of "dead" (the condition of pulselessness *is* irreversible). In other words, it confuses a prognosis with a diagnosis.

The second objection is that it makes the state of being "dead" contingent upon the intentions of the caregivers who are present. Two examples make this point:

Case 1: A young man suffers cardiac arrest while playing basketball. Paramedics are called, but no one initiates CPR. The paramedics arrive two minutes later, initiate resuscitation, and the patient survives.

Case 2: A young man has suffered severe neurological injury following a car accident. He is a candidate for DCD donation, and has been pulseless for two minutes following withdrawal of life support. He is deemed to be dead and his organs are removed for transplantation.

Both of these patients are in an identical physiological state after two minutes of pulselessness. In Case 1, the patient is still considered to be alive at this time, but in Case 2 the patient is considered to be dead. If being alive or dead is a state of nature independent of whether caregivers intend to attempt resuscitation, then these cases present a logical contradiction.

Furthermore, in Case 2 above, imagine that when the patient is declared dead after two minutes of pulselessness the patient's wife, who has been at the bedside during the process, suddenly changes her mind and demands that an attempt be made to resuscitate the patient. Imagine that the care team accedes to this demand, and are successful (not an unlikely possibility). What can we say but that the patient has been

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<sup>39</sup> J.L. Bernat, *How the Distinction between "Irreversible" and "Permanent" Illuminates Circulatory-Respiratory Death Determination*, 35 (June) J. Med. Philosophy 242 (2010)

<sup>40</sup> Hornby, L. Hornby, & S.D. Shemie, *A systematic review of autoresuscitation after cardiac arrest*, 38 (5) Critical Care Medicine 1246 (2010)

<sup>41</sup> R.D. Truog & F.G. Miller, *Counterpoint: are donors after circulatory death really dead, and does it matter? No and not really.*, 138 (1) Chest 16-18 (2010); J.L. Bernat, *Point: are donors after circulatory death really dead, and does it matter? Yes and yes*, 138 (1) Chest 13-6 (2010); D. Marquis, *Are DCD donors dead?*, 40 (3) Hastings Ctr. Rep. 24 (2010)

raised from the dead? In the absence of miracles, most consider death to be an irreversible state. Again, this appears to present a logical contradiction.

Many would argue, and I agree, that there may be no ethical reason why patients should not be allowed to donate organs after two minutes of pulselessness, before the organs have suffered too much ischemic injury to be transplantable. The point of these thought experiments, however, is to show that if DCD donation is ethically acceptable, it is justified by reasons other than the claim that these patients are known to be dead at the time their organs are removed. The idea that DCD donation may be ethically justified despite the fact that it may violate the DDR will be discussed later.

To summarize the paper up to this point, my intention has been to critique the claims that brain dead patients and DCD donors are known to be dead at the time of organ procurement. This critique is grounded entirely upon the scientific facts of the matter and commonsense logic; it does not depend upon any value judgments or ethical assumptions.

Some might disagree, and argue that to assume that death is purely a biological phenomenon is itself a value-laden assumption. They might argue that it is perfectly coherent to conceive of death as the departure of the soul from the body or the loss of personhood, however that may be defined. I do not disagree with this view, but none of these alternative concepts lie within the expertise of science or the medical profession. Yet throughout the history of organ transplantation, society has insisted upon a definition of death that is grounded in scientific principles. The UDDA, for example, specifically asserts that : “A determination of death must be made in accordance with accepted medical standards.” If society chooses to adopt an understanding of death grounded in a non-scientific epistemology, then many options are possible. But if the ethical and legal principles governing organ donation must be rooted in science, then the analysis here suggests that organ donors are not, at least in many cases, known to be dead at the time of organ procurement, and that our routine practices of organ donation are in violation of the DDR.

## **Part 2: Where do we go from here?**

If one accepts the central claim of Part 1 of this paper, then what are our options for moving forward? In answering this question, the arguments must leave the realm of purely scientific and logical considerations, and engage in value commitments and ethical assumptions. Four options will be considered.

### Option #1: Cease to perform organ procurement and transplantation as we know it.

Most critics of the ideas presented here have focused their objections on why we must not abandon the DDR.<sup>42</sup> They insist that adherence to the DDR is necessary to continue the life-saving transplantation programs that exist in this country and around the world. But this misses the point emphasized earlier. Unless convincing objections can be made to the argument presented in Part 1 of this manuscript – and to date none have been given – then we are violating the DDR every day with our current practices. It is not possible to accept the arguments presented in Part 1 and to insist upon allegiance to the DDR.<sup>43</sup>

The authors of the President's Council report in 2008 took this very seriously. They wrote "*If indeed it is the case that there is no solid scientific or philosophical rationale for the current 'whole brain standard,' then the only ethical course is to stop procuring organs from heart beating individuals*" (italics in original).<sup>44</sup> They avoided this conclusion only by proposing an entirely new justification for brain death, with the limitations and conceptual problems discussed above. The Council was also quite skeptical of the argument that DCD donors could be considered to be dead based on the concept of "permanence" rather than "irreversibility," but the Council deferred making a final judgment about DCD donation in the absence of further consideration.

Unless convincing arguments can be shown to support why brain-dead and DCD donors are dead at the time of organ procurement, however, then we are simply left with the choice of either ceasing to perform organ procurement as we know it, or finding an alternative option.

### Option #2: Reconsider the ethical and legal foundations of organ procurement.

The status of the DDR as a foundational principle for organ procurement is most easily recognized through historical hindsight, that is, it appears to have been an assumption that was adopted by the transplantation community from what they probably saw as the "obvious" implications of the law and ethics concerning homicide. And indeed, there is an undeniable wisdom contained in the dead donor rule, namely, that it would be

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<sup>42</sup> J.L. Bernat. *Life or death for the dead-donor rule?* 369 (14) New England J. of Med. 1289 (2013); J.A. Robertson, *Should we scrap the dead donor rule?*, 14 (8) Am. J. of Bioethics 52 (2014)

<sup>43</sup> R.D. Truog & Miller, *supra* note 32; R.D. Truog & F. G. Miller, *The dead donor rule and organ transplantation*, 359 (7) New England J. of Med. 674 (2008); R.D. Truog, F.G. Miller, & S.D. Halpern, *The dead-donor rule and the future of organ donation*, 369 (14) New England J. of Med. 1287 (2013)

<sup>44</sup> The President's Council on Bioethics, *Controversies in the determination of death: A white paper of the President's Council on Bioethics*, (2008) at 12



wrong to harm someone in the process of procuring organs for transplantation, and making sure patients are dead before we remove their organs would seem to be an important safeguard in making sure we do not harm them. But in examining the matter more deeply, we can ask whether death is always a *necessary* condition for protecting potential organ donors from harm?

Consider, for example, the case of a 43-year-old man with high cervical quadriplegia who has been living with this condition for several years, dependent upon mechanical ventilation. After long deliberation and counseling, he has decided that he wants to terminate ventilator support and be permitted to die. He understands that death will occur within minutes of the ventilator being withdrawn. He also has a strong desire to donate as many of his organs in the best condition possible.

Currently, his only option for organ donation is to be a DCD donor. Aside from the concerns described above about whether he will actually be dead at the time organ procurement begins, his donation will most likely be limited to his kidneys, and even those will have sustained some ischemic injury prior to procurement.

But consider an alternative, in which he is anesthetized, and as part of the dying process he is able to donate multiple organs (lungs, heart, liver, kidneys, pancreas, bowel, etc.) and all in the best condition possible without ischemic injury. This would be performed entirely at the patient's request and with his permission, and would maximally respect his desire to save as many lives as possible in the process of his dying. His decision to terminate ventilator support has guaranteed his imminent death, but the manner in which his death occurs completely determines whether he can be an organ donor and both the quality and quantity of the organs that can be procured. By allowing him the option to donate all of his organs under anesthesia, is there any plausible way that we can say that he has been harmed?

In my own experience, I participated in the care of a young girl named Jaiden who suffered devastating neurological injury from strangulation after her parka was caught in the blades of the snowblower. She did not fulfill brain death criteria, so her parents asked if she could be a DCD donor. Donation was attempted, but she did not develop cardiac arrest within the 60 minute window described above. As a result, the donation attempt was aborted, and she died in the ICU several hours later. Her parents experienced these events as a "second loss," the first obviously being the devastating death of their daughter, but the second being the loss of the opportunity to donate organs and salvage some meaning from an otherwise tragic situation.

Her story was described by Dr. Darshak Sanghavi, a pediatric cardiologist and journalist for the New York Times Magazine.<sup>45</sup> He wrote that her father "Paul has some difficulty understanding why, if Jaiden was going to die anyway, she could not have been put

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<sup>45</sup> D. Sanghavi, *When does death start?*, New York Times Magazine Dec. 20 2009

under general anesthesia, undergone surgery to donate her organs, and then been declared dead.” In their interview, Dr. Sanghavi explained but this could not have been done because it would have violated the DDR. Her father responded, “There was no chance at all that our daughter was going to survive... I can follow the ethicist’s argument, but it seems totally ludicrous.”

As my colleague Frank Miller and I proposed in our book,<sup>46</sup> a coherent ethical and legal foundation for organ procurement can be built upon the ethical principles of nonmaleficence (do no harm) and respect for autonomy (consent). These same principles are currently the ones used to guide the practice of living organ donation, such as when a person volunteers to donate a kidney to a relative. Transplant teams have well-developed protocols in place to make sure that the decision of the living donor is entirely voluntary, and that potential harms to the donor are minimized as much as possible. Furthermore, when potential donors have an underlying medical condition that would place them at risk for either the procedure itself or for the development of renal failure following the removal of one kidney, the transplant team may decide to not allow the individual to go forward with the donation.

In essence, we propose extending the same principles to a different class of "living donors," that is, those who are imminently dying (as in DCD donors) or those who are irreversibly unconscious (as in brain-dead donors). Not only would this legitimate current practices of organ procurement, but it could also increase the number and quality of organs procured, as in the case of the man with cervical quadriplegia described above. Clearly, safeguards would need to be put into place, and oversight would need to be necessary to make sure that the safeguards are observed, just as is the case with living donation today. Our proposal raises many other issues, of course, and we refer the reader to our book for a more complete discussion of this approach.

Before moving on, however, I will address an objection voiced by several colleagues who reject our views. They wrote: “Some critics of brain death seek to abandon the dead-donor rule. Whatever one thinks of the arguments for that as a philosophical position, it is far out of touch with current medical and legal standards and public opinion.”<sup>47</sup> The view that alternatives to the DDR are simply non-starters in the court of public opinion is frequently espoused and taken to be "obviously" true.

Yet the data do not support this claim. To cite one particularly rigorous study, Nair-Collins and colleagues recently surveyed over 1000 adults in the United States.<sup>48</sup> They were presented with the case of Jason, who "has been in a very bad car accident." Without using the term "brain death," they described his clinical condition as fulfilling all

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<sup>46</sup> F.G. Miller & R.D. Truog, *Death, Dying, and Organ Transplantation* (2012)

<sup>47</sup> Magnus, Wilfond, & Caplan at 3, *supra* Note 18 at 3

<sup>48</sup> M. Nair-Collins, S.R. Green, & A.R. Sutin, *Abandoning the dead donor rule? A national survey of public views on death and organ donation*, 2014 J Med. Ethics

of the criteria for brain death (irreversible unconsciousness, ventilator dependence, etc.), but described him as being biologically alive. Although the case clearly states that he is alive and that organ donation would result in his death, 71% of the survey respondents agreed that "It should be legal for patients such as Jason to donate organs," 70% agreed that "Doctors should be allowed to remove organs from patients like Jason, assuming consent," and 67% stated that "I would want to donate my organs, if I was in a scenario just like Jason's." Data like these have all of the limitations associated with survey research, and certainly a significant minority of respondents did not agree with the statements in the survey, but this study and others like it convincingly refute the view that consideration of alternatives to the DDR is "far out of touch" with public opinion.<sup>49</sup>

### Option #3: Brain death as a legal fiction.

The notion that the legal status of an entity does not necessarily correspond with its biological status has an interesting history. In the 1893 case of *Nix v Hedden*, the US Supreme Court considered whether the tomato is a fruit or a vegetable.<sup>50</sup> At that time, a tax was levied on the importation of all vegetables from the West Indies. Tomato growers in the Caribbean argued that they should be exempt from the tax, since tomatoes are a fruit. In delivering the unanimous opinion of the court, Horace Gray wrote: "Botanically speaking, tomatoes are the fruit of a vine... But in the common language of the people, these are vegetables." The idea that legal status does not necessarily need to accord with biological status has interesting implications for how we define life versus death.

Seema Shah, Franklin Miller and I have explored these possibilities in some detail, building upon the conception of "legal fictions" as developed the literature.<sup>51</sup> Several different types of legal fictions are potentially applicable to the definition of death.

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<sup>49</sup> L.A. Siminoff, C. Burant, & S.J. Youngner, *Death and organ procurement: public beliefs and attitudes*, 14 (3) Kennedy Inst. of Ethics J. 217-234 (2004); T.C. Schmidt, *The Ohio study in light of national data and clinical experience*, 14 (3) Kennedy Inst. of Ethics J. 235-240 (2004)

<sup>50</sup> M.B. Green & D. Wikler, *Brain death and personal identity*, 9 Philosophy and Pub. Affairs 105-133 (1980); C.M. Rick, *The tomato*, 239 (2) Scientific Am. 76-86 (1978)

<sup>51</sup> S.K. Shah, R.D. Truog, & F.G. Miller, *Death and legal fictions*, 37 (12) J. of Medical Ethics 719 (2011); S.K. Shah & F.G. Miller, *Can we handle the truth? Legal fictions in the determination of death*, 36 (4) American J of Law and Med. 540 (2010); R.A. Charo, *Dusk, dawn, and defining death: Legal classifications and biological categories*. In: S.J. Youngner, R.M. Arnold, & R. Schapiro, eds. *The Definition of Death: Contemporary Controversies*. Baltimore: The Johns Hopkins University Press; 1999.

For example, "bright line fictions" refer to situations where legally distinct categories are created by drawing a bright line at a specific point on a continuum. One good example of a "bright line fiction" is the concept of legally blind. Any individual with visual acuity less than 20/200 is considered to be legally blind, despite the fact that from a biological perspective many of them retain the capacity for sight, however limited. This legal classification comes along with some rights (e.g., eligibility for disability benefits) as well as restrictions (e.g., prohibitions around driving). While the category of legally blind does not completely correspond with the category of biologically blind, it nevertheless functions as a very useful concept in law and society.

How might the idea of a "bright line fiction" apply to the concept of brain death? If one imagines neurological disability as occurring across a continuous spectrum, with neurological normality at one end and the complete absence of any neural activity at the other, then one might conceive of brain death as the bright line drawn where the neurological injury is sufficient to eliminate a constellation of functions including consciousness, respiratory drive, and certain brainstem reflexes, but not necessarily all brain activity or function. The problem with this analogy, however, is that we now know that any degree of neurological injury, no matter how severe, is compatible with continued life of the human organism.

Another type of legal fiction, that of a "status fiction," could be more applicable to the concept of brain death. Status fictions, like the fiction that a corporation is a person, are fictions that treat A as if it were B because they are relevantly similar for determining what law should apply to them. Such legal fictions can be helpful, such as in determining in what state or court a corporation can be sued and, more controversially, how a corporation can contribute money to a political campaign; and some can be inappropriate, such as using the analogy to give corporations the right to vote. In this regard, brain death can be conceived as a status fiction that does not accord with biological reality, since many would regard these patients as being "as good as dead," given their irreversible loss of consciousness, dependence upon life support, etc.

Finally, a third type of legal fiction, that of an "anticipatory fiction," could be applicable to the determination of death. These are fictions that treat A as if it were B because A will imminently become B. For example, if a contract is imminently about to be breached, the law may treat it as if it has already been breached, in order to avoid the harm that may come from allowing it to be actually breached. Such an approach may be applicable to DCD organ donors, in that it may be legally permissible to treat them as if they are dead, since they will imminently become dead, and doing so avoids the harms that would follow from allowing them to actually become dead, such as the loss of their organs for transplantation.

The primary disadvantage of using a legal fictions approach to the determination of death is that legal fictions are generally transparent to society and to those who are involved. Everyone understands that corporations are not really people. In the case of

organ transplantation, however, the public has been reassured for decades that death is determined on the basis of sound scientific principles. Publically acknowledging that potential organ donors are declared dead on the basis of a "legal fiction," no matter how well justified, is not likely to be well received by at least certain segments of the population.

On the other hand, evidence such as the data discussed above suggest that the public may view the ethics of organ procurement through a different lens than the dead-donor rule, and may see other considerations, such as the permission of the donor and whether the donor is imminently dying or is irreversibly unconscious, as being the ethically determinative factors. In this case, framing the determination of death in terms of legal fictions may be useful as a "baby step" towards opening the discussion about the medical and ethical standards for organ procurement, and creating a dialogue about how to create policies that are both scientifically sound as well as ethically and legally acceptable.

#### Option #4: "Muddle through"

Finally, the option that seems to be the preference of most of those in the medical profession and the transplantation community is to simply ignore the problem and to muddle through.

The major consideration in favor of this view is that the transplantation enterprise is working relatively well. Outside of academic papers like this one, few individuals are raising concerns about how death is diagnosed for purposes of organ donation. Although data suggest that the majority of Americans are willing to entertain alternatives to the DDR, there are undoubtedly many in the country who view the DDR to be a necessary and nonnegotiable prerequisite for organ donation, and who would refuse to participate in the process – and encourage others to do the same – were they to believe there were any reason to suspect that organs were being procured from patients before they are dead.

In addition to those who would oppose alternatives to the DDR on religious or philosophical grounds, we know that some segments of our society, most notably those including individuals from disadvantaged or minority backgrounds, have great distrust for the medical system. They are concerned that doctors may "give up" on some patients in order to obtain their organs, and they may believe that available organs are channeled to the privileged few. Many are concerned that open discussion about the controversies discussed here would likely only fuel this mistrust.

Finally, scientific progress itself may actually make this a moot debate. For example, in the next decade or two the immunological barriers to xenotransplantation may be overcome, and we may have a virtually limitless supply of transplantable organs available from pigs. Alternatively, it may become possible at some point in the future to

grow replacement organs from a patient's own stem cells. Either of these possibilities, or others perhaps not yet imagined, may eliminate the need to procure organs from human beings at all. In this event, the motive to declare patients brain-dead would disappear, and decisions to continue or withdraw life support would be based entirely and solely upon patient-centered factors such as quality of life and religious or value-based commitments. One might imagine a time in the not-too-distant future when the index of textbooks of medicine would not even include an entry for "brain death," since medicine would no longer have a need for this socially constructed definition of death.

While acknowledging all of these concerns and considerations, there are at least three costs associated with maintaining a lack of honesty and transparency with the public. First, one very practical drawback is that the current constraints significantly limit both the quality and the quantity of organs available. Rates of organ donation from both brain-dead donors and living donors have stagnated in recent years, and the most promising avenue for growth is from patients who are currently possible DCD donors. As discussed above, DCD donation is typically limited to procurement of kidneys.

According to one analysis, of the more than 1 million US deaths that occur in institutions annually, only about 1% are eligible to donate through the two pathways described above. But if even 5% of the remaining patients were deemed potential donors by virtue of being either imminently dying or irreversibly unconscious, and if 58% of them agreed to donate their organs (i.e., the current consent rate for donation), then there could be a six-fold increase in the number of potential organ donors. Furthermore, if the protocols no longer required the patients to be pulseless for 2-5 minutes (in order to satisfy the DDR) then the number of transplantable organs would increase several-fold and the quality of the organs would increase as well.<sup>52</sup> Another analysis also predicted a similar increase in available organs if the imposed period of ischemia were removed.<sup>53</sup> In other words, the DDR imposes a burden of ischemic injury on the organs that severely limits the utility of DCD donation. In comparison to the principles of nonmaleficence and autonomy that we have proposed, the DDR does nothing to reduce harm or to protect their autonomy further. By reducing these burdens and not requiring the organs to undergo a period of ischemia, the organ shortage that currently exists could be dramatically reduced or even eliminated.

Second, lack of transparency about of determining death in organ procurement could be seen as a serious compromise in the process of obtaining informed consent for organ donation. Many individuals certify that they choose to be organ donors when applying for or renewing drivers' licenses. These declarations of prospective consent typically simply ask individuals to indicate whether they choose to be organ donors if they are

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<sup>52</sup> Cochrane, T. I., *Wanted, dead or alive*, 39 (3) Hastings Ctr. Rep. 5, author reply 6. (2009)

<sup>53</sup> R.M. Sade & A Boan, *The paradox of the dead donor rule: increasing death on the waiting list*, 14 (8) American J. of Bioethics 21 (2014)

dead. No information is supplied about the nature of brain death or the process of DCD donation.

Finally, perhaps the greatest drawback to muddling through is the impact that this decision would have on the integrity of the scientific enterprise and its relationship to society. One of the hallmarks of the scientific method is a commitment to follow the truth wherever it may lead. Scientists are trained to be continually critical of their own results and those of others, to constantly question the status quo, and to continually look for the ways in which their assumptions might be wrong. This stance has not only been essential to ensuring that unfounded beliefs are discarded and that knowledge and practice continue to advance, but also to secure the trust and support of the public in their willingness to promote the scientific enterprise. The unwillingness of the medical profession to engage in transparent and open dialogue with the public about the scientific facts relevant to declaring death in the context of organ donation is a significant breach of this implicit contract of trust between the scientific community and the society it serves.

Thomas Kuhn's views about the structure of scientific revolutions may have some relevance to the controversies described here.<sup>54</sup> Kuhn hypothesized that dominant scientific paradigms can withstand and absorb anomalies and conflicting data up to a certain critical threshold, but beyond that point they are vulnerable to a wholesale revision that shifts the entire foundation of thought. Whether we decide to use "legal fictions" as baby steps to help us move to this new foundation of understanding, or whether we engage the public directly, I believe this open dialogue is not to be feared but to be welcomed, and that this conversation will lead to a more honest and transparent understanding of the ethics of organ transplantation, one that will better serve both the medical profession and society in the decades to come.

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<sup>54</sup> T. Kuhn, *The Structure of Scientific Revolutions* (1962)

# Figure 1: Two Pathways to Organ Donation

