

NEGOTIATING AMBIGUITIES IN LIFE AND DEATH

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It might not seem obvious that distinguishing life from death is a difficult task, but careful analysis reveals ambiguities at both the beginning and end of life. This paper contrasts the biological and philosophical defenses of brain death with the discussion surrounding the ethics of abortion and the research uses of human embryos. In the following pages, I detail the evolution of brain death as a biological and philosophical concept and compare this to the parallel ambiguity and controversy that surrounds the beginning of life. I draw out the inconsistencies between the two approaches: despite the presence of several reasonable philosophical and biological critiques, brain death is defined rigidly by a single legally enforceable definition, whereas the bioethical and legal world has given more tolerance to the multiple philosophical and ethical conclusions consistent with the ambiguous biology at the beginning of life. In addition, there has been a much more public debate around the biology, ethics, and morality at the beginning of life, especially regarding abortion and the uses of stem cells. In this paper, I argue that brain death deserves a similarly honest and shared debate.

Redefining Death

Death is not a social construct. It is one of the inescapable biological facts that unite all life forms. The designation of “brain death,” however, is a product of modern medicine. Before the advent of life support and other technologies, death was recognized by the cessation of cardiac and respiratory functions (President’s Council on Bioethics 2008, 1). However, when South African surgeon Christian Barnard performed the world’s first successful heart transplant in 1967, it became increasingly important to define the moment of death as precisely as possible (Lock 2002, 88). After circulation ceases, organ perfusion stops and the possibility of a successful organ donation is all but zero. Patients with “total brain failure” (also referred to those in “irreversible, unresponsive comas”) could be the optimal organ donors: they had lost all brain function, but life support technology could maintain organ perfusion until the transplant team was ready to retrieve the organs. There has long been consensus, however, that it is immoral to take organs from a living donor – this is known as the ‘dead donor rule’ (Bernat 2014). Thus, in order for these patients with “total brain failure” to become organ donors, they needed to be declared dead. For perhaps

the first time in medical history, there was a practical impetus to reconsider and elaborate on the definition of death.

Shortly after Barnard's surgery, Dr. Henry K. Beecher, a renowned anesthesiologist at Harvard Medical School, petitioned the school to convene a group to discuss the ethical issues surrounding these "hopelessly unconscious" patients (Lock 2002, 89). The group, known as the Ad Hoc Committee of Harvard Medical School to Examine the Definition of Brain Death, published a report in the *Journal of the American Medical Association* entitled, "A Definition of Irreversible Coma." The report argues for a redefinition of death that encompasses those people in irreversible comas. One of the reasons for the new definition is that "obsolete criteria for the definition of death can lead to controversy in obtaining organs for transplantation" (Ad Hoc Committee of the Harvard Medical School 1968, 1). From its very origin, the concept of brain death has been intimately linked to organ donation.¹

This conclusion was largely endorsed by academic medicine but there remained no consensus on how to diagnose the condition (Lock 2002, 104). By the eighties, there were six different legal statutes regarding brain death in the United States and it was becoming evident that a more consistent policy was necessary (Pallis 1990). President Reagan established a commission to clarify this debate and refine and update the criteria put forth by the Harvard group, with the goal of coming up with guidance that could be codified legally. The commission did not change the Harvard group's central conclusion and put forth the following as their concluding recommendation:

Uniform Determination of Death Act

An individual who has sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all function 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 for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 2]

The group, drawing on both biological and philosophical premises, concluded that "death is the moment at which the body's physiological system ceases to constitute an integrated whole. Even if life continues

¹ The report's other reason for this new definition was equally pragmatic, stating that patients in irreversible comas (with beating hearts but irreversible brain damage) could place an undue burden on families and hospitals.

in individual cells or organs, life of the organism as a whole requires complex integration, and without the latter, a person cannot properly be regarded as alive” (President’s Commission 1981, 33). The report was successful as a matter of public policy: 45 states have formally adopted the Uniform Determination of Death Act and the remaining five have recognized it through judicial opinion (Magnus, Wilfond, & Caplan 2014; National Conference of Commissioners of Uniform State Laws 1981). Brain death was now a medical and legal entity. Today the diagnosis of brain death (also known as “total brain failure”) involves meeting four criteria: 1) the patient is in a unresponsive coma, 2) there is no immediate history of hypothermia, poisoning, drug intoxication or potential metabolic cause of coma (as these conditions are often transient and can mimic the effects of total brain failure), 3) the patient demonstrates no brain stem reflexes (such as the gag reflex, the cough reflex, and certain eye movements) and 4) the patient shows no drive to breathe (President’s Council 2008).

Since 1981, three states have made amendments upon the initial Uniform Determination of Death Act. In New York, hospitals are required to accommodate religious or moral objections to brain death. This has been clarified in court proceedings to mean waiting at least seven days before discontinuing life support if families object (thus allowing families to find another facility that will continue support). California has a similar law though it requires hospitals to adopt a policy of a “reasonably brief period of accommodation” for any objection, religious or otherwise. The period of accommodation is defined as the time necessary to gather family and next of kin at the bedside. Finally, New Jersey has a categorical exception for religious objection: if families object to the declaration of brain death on religious grounds, a physician cannot declare a patient dead by neurological criteria and brain-dead individuals may be permitted to remain indefinitely supported (Burkle & Pope 2015). In every other state, the designation of brain death functions no differently than when a patient is declared dead on the basis of cardio-respiratory criteria, the “traditional” definition. Treated as an objective medical fact, there is no rationale to allow for any objections to the designation of brain death.

Current clinical and legal guidelines surrounding brain death do not reflect the complex evolution of brain death as a medical and legal entity. Much of the clinical guidance is designed to mitigate and

mask the ambiguity between what a brain dead individual looks like (well-perfused, warm skin, with a beating heart) and what we expect a dead body to appear like (grey, “lifeless,” with no heartbeat or pulse) The Hastings Center Guidelines for Decisions on Life-Sustaining Treatment and Care Near the End of Life warns that: “clinicians caring for grieving families must be careful both to clarify that death by neurological criteria *is* death – that the patient has already died” (Berlinger, Jennings & Wold 2013, 2). The report further reminds clinicians that “the declaration of death does not require the consent of a surrogate or another person” and that “terms such as ‘life support’ or the suggestion that the patient is being ‘kept alive by machines’ should be avoided in this context, as unclear or inaccurate language may lead loved ones to conclude that the patient is still alive” (Berlinger, Jennings & Wold 2013, 4).

Biological and Philosophical Defenses of Brain Death

The 1981 Presidential Commission made the first sophisticated biophilosophical argument for brain death when they defended it biologically under the rationale of “bodily integration.” As the report stated, if a “brain dead” patient could no longer integrate his or her bodily functions, he or she was biologically dead (President’s Commission 1981, 33). However, in the years following the publication of this report, an increasing amount of evidence appeared that individuals who meet criteria for brain death could maintain integrated functions – such as circulation, digestion, wound healing and even continued growth and development. In some cases, it seemed these processes could continue indefinitely with the aid of mechanical ventilation (Shewmon 1998, 1999, 2001; Truog and Miller 2014). This new evidence weakened the biophilosophical argument that supported the 1981 group’s conclusions.

As a response, in 2008 a new Presidential commission released a report that reexamined brain death. The 2008 report acknowledges the new evidence of continued bodily integration in individuals declared as brain dead, writing 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 total brain failure can still be alive, at least in some cases” (President’s Council 2008, 57). The 2008 committee agreed with the 1981 group that death occurs at the moment of which “wholeness” of the body is lost. They disputed the previous group’s conclusion, however, that the loss of somatic (‘bodily’) integration

was evidence that the organism was no longer a whole. The 2008 group offers a “more compelling account of wholeness:” “determining whether an organism remains a *whole* depends on recognizing the persistence or cessation of the fundamental *vital* work of a living organism” (President’s Council 2008, 59-60). They further clarify that this “vital” work depends on three fundamental capacities: 1) “an openness to the world” (evidenced by receptivity to stimuli and signals), 2) “the ability to act upon the world to obtain selectively what it needs”, and 3) “the basic felt need that drives an organism to act as it must, to obtain what it needs and what its openness reveals to be available” (President’s Council 2008, 61). While this report defended brain death in entirely new terms (incorporating new biological evidence and a new philosophical concept of ‘vital work’), there was no change in clinical practice or legal guidelines. The singular definition (without any mechanisms to accept alternative conclusions) remained.

The 2008 President’s Council’s conclusion is elaborated upon and defended biophilosophically by James Bernat in a 2014 paper in the American Journal of Bioethics. Bernat believes “that the strongest justification for the brain death concept is not the integration rationale [the thesis of the 1981 group] but the cessation of the organism as a whole” (2014, 5). He attempts to elaborate on the committee’s discussion of what “wholeness” entails (beyond the vital work definition), relying on a 2009 paper by Bonelli et al.: “The Philosophical Considerations on Brain Death and The Concept of the Organism as a Whole.” Bonelli et al. argue that all living things exhibit four criteria: 1) dynamics (essential life processes such as metabolism, growth, pulse, respiration, etc.), 2) integration (that life processes derive from mutual interaction of parts), 3) coordination (the interaction of parts is kept constant within a certain order), 4) immanency (that the above 3 categories are inherent and spring from life) (Bonelli, Prat, & Bonelli 2009, 4). They further argue that an additional four criteria distinguish living beings from other life forms: 1) completion (the organism is not a component part of another living entity), 2) indivisibility (the organism cannot be divided into more than one living being), 3) self-reference (the observable life processes serve the self-preservation of the whole, even at the expense of the parts), and 4) identity (the living being remains one and the same throughout life) (Bonelli, Prat, & Bonelli 2009, 4-5). Under Bonelli et al.’s classification, a sperm cell is alive (it demonstrates dynamics, integration, coordination,

and immanency) but it is not a living being because it does not form a “specifically integrated whole” (Bonelli, Prat, & Bonelli 2009, 2). Citing Bonelli et al., Bernat concludes his defense of the 2008 Presidential Council’s report: “The brain dead human organism has irreversibly lost its totality, completion, indivisibility, self-reference and identity. It can no longer ever again function as a whole and therefore is dead” (Bernat 2014, 6). This work represents the current biophilosophical framework for understanding and defending brain death as the biological and philosophical equivalent to death by irreversible cessation of circulatory and respiratory systems.

The 2008 Presidential Council’s conclusion and Bernat’s and Bonelli et al.’s elaborations have not gone unquestioned. Michael Nair-Collins issued a particularly potent critique of the “mainstream medical literature on death” arguing that it has not demonstrated the traits normally associated with a scientific investigation, such as “making empirically testable and falsifiable claims, a commitment to evidence and logic over authoritative assertion, or a willingness to revive hypotheses and theories in light of new evidence” (Nair-Collins 2015, 2). He argues that the traditional thinking on brain death is better represented not as scientific inquiry, but as “excessive ad hoc revisions whose sole purpose is to protect the core claims from empirical refutations, an unwillingness to modify its claims in the face of clearly recalcitrant evidence, and appeals to authority rather than evidence” (Nair-Collins 2015, 3). Nair-Collins sees the alternative justifications in the 1981 and 2008 Presidential reports as exemplary of ad hoc revision. He insinuates that the Presidential Council knew what outcome they wanted (the continued legitimacy and legality of brain death) and created a rationale that would lead to that conclusion. This, he claims, is far from scientific methodology.

Robert Truog and Franklin Miller also argue forcefully that brain death criteria do not correspond to any authentic conception of biological death. They agree with the 1981 Presidential Commission that “death occurs at the moment when this integrated functioning of the organism as a whole is irreversibly lost” (Truog & Miller 2014, 9), but they disagree that brain death is the moment at which this occurs. Truog and Miller do not endorse the 2008 redefinition of wholeness around “vital work” or Bonelli et al.’s criteria. They ask if vital work include consciousness. If so, then why are patients in persistent

vegetative states not classified as dead?² Does vital work then mean other functions besides consciousness? If so, Truog and Miller are not convinced that patients diagnosed as brain dead lack those functions. In practice, Truog and Miller are not against current organ donation policy. They see brain death as a “legal fiction” – in the same way as someone who is declared legally blind may not meet the full biological definition of blindness, but is “close enough” for all legal and public policy reasons (Truog & Miller 2004, 10).

Robert Veatch, another prominent bioethicist, also disagrees that brain death is a form of true, biological death. He concurs with Truog and Miller: “there is no doubt that, if the word *death* is to retain a singular, biological meaning, the defenders of the circulatory or somatic position (including Miller and Truog) must be right” (Veatch 2015, 297). Veatch, however, is less interested in limiting the term *death* to those cases and more focused on elaborating the social, moral, and legal uses of the term. Veatch understands death to be primarily a sociological term – one applied to human beings who no longer have full moral standing in our human community – rather than a biological fact. Patients diagnosed as brain dead could be declared dead not because of an inherent biological truth, but because we as a human community have deemed them to not have full moral standing. Even if it is possible to say in the case of total brain failure that there is still a living being biologically, Veatch and his supporters conclude that there is no living being in any sense that is important for public policy (Veatch 2015, 298). In fact, Veatch would label patients with profoundly disordered consciousness, such as those in in a persistent vegetative state, but without total brain failure, as dead.

The 2008 Presidential Council recognizes that the controversy surrounding brain death “cannot be settled by appealing exclusively to clinical or pathophysiological facts” (President’s Council 2008, 49). However, they give little credence to any of the doubts raised by Miller, Truog, Veatch, or others (which were well known before the 2008 report). The commission dismisses the idea that “death should be treated merely as a legal construct or as a matter of social agreement” as Veatch might argue for and

² Persistent vegetative state (PVS) is defined as a wakeful unconscious state that lasts longer than a few weeks. Patients in PVS may exhibit signs of wakefulness like eye movements, spontaneous movement, or groaning.

concludes that the “current neurological standard for declaring death, grounded in a careful analysis of total brain failure, is biologically and philosophically defensible” (President’s Council 2008, 89). They do not acknowledge that the very concept of brain death was first introduced (by the Ad Hoc Committee of 1968) as somewhat of a social agreement to resolve issues surrounding organ donation. Convinced by the new bio-philosophical rationale, the Council recommends no change to the Uniform Declaration of Death Act put forth by the 1981 Commission. Thus, despite vigorous debate within the bioethical world and the existence of multiple plausible philosophical conclusions, in all but three states (New York, New Jersey, and California) brain death is treated as an objective and uncontested medical ruling.

Ambiguities at the Beginning of Life

In many ways, the ambiguities and ethical complexities surrounding end of life designations are paralleled in the medical-ethical-legal debate that occurs around the beginning of life. The question of when exactly life begins has been front and center in debates around the morality and legality of abortion and the research uses of human embryos. There remain clinically relevant biological uncertainties. The American College of Radiologists (2009) advises that embryonic demise may be diagnosed in an embryo of ≥ 7 mm without cardiac activity, but these guidelines are based on two papers with a combined sample size of just 47, a startlingly small size for the basis of decision as significant as the diagnosis of miscarriage (Bourne 2012). Motivated by inconsistent criteria, Jevé et al. undertook the first systemic review of the evidence behind diagnostic criteria for miscarriage in 2011, but the paucity of quality studies hampered the analysis. Jevé et al. were unable to recommend any specific standards for embryonic demise and concluded that further studies were “urgently required.” Confirming embryonic life, it appears, can be just as clinically ambiguous as defining the moment of death at the end of life.

The ethical debates regarding research uses of human embryos ask what marks the beginning of human life. Some argue that this occurs at the moment of fertilization, when the sperm and the egg fuse. Others argue that the embryo becomes human when the primitive streak forms and nervous system begins to develop (around 14 days of development) (President’s Council 2004, 80). For others, the threshold may be at some later date, perhaps viability outside the womb. These debates depend on biological arguments

(When does cardiac activity begin? When does the ability to perceive pain develop?) and different philosophical conceptions of when life (and human life specifically) begins and how one's moral status changes throughout the course of development. The discussion on brain death also features biological ambiguities and differing philosophical conclusions. According to the 2008 Presidential Council on Bioethics, these could largely be resolved by its criterion of wholeness, which was further elaborated by Bonelli et al. Since life and death are two ends of the same state, one would expect that a sound, defensible philosophical interpretation of brain death could also be used to illuminate ambiguities around the beginning of life. If Bonelli et al.'s concept of wholeness defines death, what does it say about the beginning of life?

In applying the four criteria of living beings (completion, indivisibility, self-reference, and identity) to a 12-week-old fetus, it is difficult to conclude that a fetus is indeed a living being. It is hard to argue that a fetus can be thought of having "completion." For most of its development, the fetus is entirely dependent on its mother. The American Congress of Obstetricians and Gynecologists (ACOG) reject the notion that the fetus should be treated as a separate and independent entity from its mother. The ACOG statement (2005) cites the danger of treating the fetus as a separate and complete patient as the dismissal of the needs and interests of the mother as a patient and moral agent in her own right. Prominent bioethicists such as Anne Lyerly, Margaret Little and Ruth Faden also concur that it is inappropriate to think of the fetus as a separate patient when its environment "is the body of an autonomous agent" (Lyerly, Little, and Faden 2008, 43). It's hard to make a case not just for how the fetus is "not part of a whole," but also why it should be treated as such. Under Bonelli et al.'s framework, a fetus might not be considered to have completion (and thus be a fully living being) until it reaches the threshold of viability or even until the moment of birth.

Embryos may also fail to meet several of the other criteria for living beings. It's possible for embryos to spontaneously twin in the first 14 days following fertilization (President's Council 2004, 79). Thus these early embryos are unlikely to meet Bonelli et al.'s "indivisibility" criterion. The "identity" criterion is especially contentious in the debate around the status of embryo as a human being. Bonelli et

al. define identity as “the fact that a living being remains one and the same through the passage of time” (Bonelli, Prat, & Bonelli 2009, 5). Some bioethicists and philosophers, notably Judith Jarvis Thompson (1971) and Michael Sandel (2004), categorically reject the idea. Sandel and Thompson acknowledge that every human being begins life as an embryo, but they do not see that as proving that embryos are persons and make a useful analogy (proposed by Thompson and elaborated upon by Sandel): “although every oak tree was once an acorn, it does not follow that acorns are oak trees, or that I should treat the loss of an acorn eaten by a squirrel in my front yard as the same kind of loss as the death of an oak tree felled by a storm. Despite their development continuity, acorns and oak trees are different kinds of things” (Sandel 2004, 208). To Sandel and Thompson, embryos are to acorns as persons are to oak trees – categorically different entities. According to this logic, embryos would fail to meet the Bonelli et al. identity criterion. Others, of course, disagree. Robert George and Patrick Lee (2004) argue that humans value oak trees because of their magnificence. We do not value the small sapling (or acorn) as much as we value the grand mature oak tree. This, they argue, is different than how we value and see human beings, which depends on intrinsic qualities and not accidental traits like size, age, or IQ (or magnificence). George and Lee see embryos as human beings, already imbued with intrinsic qualities that we value in humans, and thus deserving the same moral treatment we give to other humans. There are sophisticated arguments on both sides of the debate regarding the moral status of embryos. Bonelli et al.’s criteria provide no clear answer to this complexity and ambiguity.

In bioethics and philosophy there are equally rigorous debates about the moral status of embryos and the beginning of life as there are about definitions of death. The President’s Council of Bioethics took up the question of the ethics of research on human embryos in 2004 when they published a report entitled *Monitoring Stem Cell Research*. Whereas the 2008 Presidential Council’s brain death report concluded with a forceful endorsement of a single interpretation, this Council took a very different tack. It concludes that: “the policy debates over stem cell research that have led to the creation of this Council continue; they, and other debates on related topics, are unlikely to go away anytime soon. Our hope is that our work will help to make these debates richer, fairer, and better informed” (2004, 19) and later conclude:

Strong and powerfully argued views have been presented ... For now, neither side to the debate seems close to fully persuading the other of the truth it thinks it sees. But the rich and growing ethical debates do suggest the possibility of progress toward greater understanding of the issues, and toward more informed public decision-making, as all parties to the deliberation appreciate better just what is at stake, not only for them or their opponents, but indeed for all of us. [President's Council on Bioethics 2004, 97]

In response to controversy and contentiousness, the Council opted for tolerating ambiguity and uncertainty rather than endorsing a single dictate. This has important practical considerations. There is no equivalent to the Uniform Determination of Death Act in the beginning of life. With regards to research using human embryos, the 2004 Presidential Council allowed for some degree of nuanced compromise in distinguishing between whether embryo research should be permitted and how it should be funded. Similar tolerance (amidst ongoing debate) is permitted in current abortion law, under which fetuses that fall below the threshold of viability are not granted full moral standing as persons, although it is recognized that they merit some measure of respect and protection (Planned Parenthood of Southeastern Pa. vs. Casey 1992). States are permitted to apply certain restrictions according to their conceptions of what the fetus is, and pregnant patients are permitted to view and act upon their 12-week embryo in any number of ways.

Thinking about Thresholds

Both embryos and individuals with total brain failure exist in thresholds that exist at the beginning and end of life. Veatch describes this as a “marginal” state, where it is not clear when or how full moral status is deserved: “at the margins, some biological entities are not assigned this full moral status by at least some people. The embryo and the respiring human with a dead brain are marginal in this way” (Veatch 2015, 307). However, the medical world and society at large have dealt with these parallel marginal states differently. The 2008 report on brain death by the President's Council on Bioethics resolves the debate by an inflexible decision that total brain failure represents the biological death of the human being because the wholeness of the organism is lost (and it fails to meet criteria of completion, indivisibility, self-reference, and identity). Yet, if we apply these four criteria to the other marginal state – that at the beginning of life – it indicates that embryos up until a certain stage are not full living beings.

Nevertheless, the 2004 Presidential Commission convened to investigate the ethical uses of human embryos make no mention of any “vital work” or “wholeness criteria” and in fact does not endorse a single dictate. What can we make of these differences?

The differing tactics and conclusions of the two Presidential Council reports represent two ways to deal with the difficult moral and biological ambiguity posed by these marginal events. Even the 2008 Council does not dispute this complexity, writing that “in patients with total brain failure, the transition from living body to corpse is in some measure a mystery” (President’s Council 2008, 53). The 2008 Council is also well aware of the role of philosophy in these debates, acknowledging that these questions cannot be resolved by purely clinical or biological facts. However, in the face of this uncertainty and the necessity of some value-laden decisions, the Council still endorses a single conclusion, which via its connection to the Universal Determination of Death Act, has the power of law. There is no immediate avenue for dispute or public discussion. Bioethicist David Magnus argues that medicine should retain authority to define death because “the law and ethics have long recognized that deferring to medical expertise regarding the diagnosis of brain death is the most reasonable way to manage the process of dying” (Magnus 2014, 894). He cites no evidence for this conclusion, however. It is also possible that the medical world has used the authority of science and biology to keep the discussion out of the public realm and to deny the inherent ambiguity of threshold states. Compared to the discourse about brain death, which has been largely within the domain of bioethics and academic journals, the dialogue about when life begins has been much more public. The results have left inconsistencies laws regulating abortion—making it hard for providers and patients to know what are their obligations, rights, and limitations. However, for all its messiness, this debate has also yielded a tolerance for multiple conclusions that is not found in the mainstream discussion of brain death. A woman may choose to see her 12-week fetus as a fully human baby, but she may also choose to abort the pregnancy. Today in medical and legal practices, tolerance (albeit of varying degrees) is permitted amidst the biological and moral ambiguity of the beginning of life. Individuals are given permission to act according to their own values and beliefs. This

is in stark contrast to decisions about total brain failure, where individual moral and religious beliefs are permitted little discretion.

Given that defining the thresholds of life and death is inherently a value-laden activity, messy public debates and greater deference to individual beliefs may be the only fair solution. In a pluralistic society, there are a myriad of opinions about where lines are drawn between life and death in these marginal states and about whom, in Veatch's terminology, is granted "full moral standing." The report issued by 2008 Presidential Council on brain death obliquely acknowledges the criticisms of brain death skeptics, but it nevertheless reaffirms the status quo and shows little tolerance of alternative philosophical conclusions. There is a danger in using the authority of science to mask moral and ethical conclusions. One does not need to believe that brain death is true biological death in order to endorse current organ donation practices. Truog and Miller for example, "fully support the current retrieval of organs from patients declared dead by neurological or circulatory criteria – not because they are biologically dead (they are not), but because they are not harmed or wronged by the donation" (Truog and Miller 2014, 11). This may be a valid defense for brain death – but if that is the case, the debate should revolve around whether these patients are harmed by the donation, or more broadly, whether the utilitarian benefits of organ donation outweigh the potential harms, and not about biological facts of life and death. If the defense of brain death is really in the vein of Truog and Miller's "legal fiction" line of reasoning, to cast it in biological terms is to rob the public of a chance to debate and reckon over our shared values in these difficult cases.

Whether or not we agree with Miller, Truog, or Veatch, their sophisticated criticisms of brain death are provocative in that they show that reasonable differences of opinion exist regarding the validity of brain death. It follows then that different decisions about end of life can be reasonable according to an individual's preferences and values. Some individuals will likely be comfortable with the utilitarian conclusion that brain dead individuals are "close enough" to dead to be counted as such. In a society as diverse as ours, however, it's unlikely that feeling would ever be unanimous. The brain death debate is informed by biology, but depends on ethical and moral decisions. This is not, then, a discussion that can

be answered unilaterally by a single committee. In a democracy, the public deserves to be part of an honest discussion, involving both biological facts and philosophical values, about how we should decide to define the boundaries of human life. This already happens in the realm of the beginning of life. What would it look like if we were to allow a more public discussion of brain death or created policy that was more tolerant of alternative philosophical conclusions? Veatch sees two possible solutions to resolve the brain death controversy: “One is to continue to insist on the biological or somatic definition and accept the fiction that current brain death criteria satisfy that definition. That option is linguistically sloppy and probably dishonest. The other option is to acknowledge that there is now a second, moral, and public policy use of the term that is to be used alongside the more traditional biological use” (Veatch 2015, 310). If doctors acknowledge brain death represents this second, moral and public policy use of the term, there is little defense of not fostering a more public debate and creating mechanisms to accommodate alternative philosophical and moral conclusions.

What would this look like practically? There are, of course, some stark distinctions. It will never be biologically or morally acceptable to label a conscious human being as dead. Yet in marginal cases (as with brain death), if we were to treat end of life more like how we treat the marginality at the beginning of life, a more public debate and a greater tolerance for alternative conclusions might result. This could look like more legislation resembling the laws in New York and California, where reasonable accommodations are granted to families who disagree with the neurological criteria of death, or New Jersey, where outright objections are allowed. Perhaps no practical change in policy would result, but there would be increasing transparency regarding the more utilitarian reasons for supporting brain death. This might recognize brain death as a “legal fiction” (as Truog and Miller argue) or just as a moral or public policy use of the term rather than a purely biological definition (as Veatch might contend). While the outcome may be unclear, brain death deserves a fuller and more public debate than it has received. Life and death are biological events, but the way in which we draw the lines between these transitions is influenced by morality and ethics. In debates around the beginning of life there has been more willingness to face these moral and philosophical questions head on. The result hasn’t always been pretty, or even just, but it may be the most

honest approach in a pluralistic and democratic society. In 1969, Dr. Henry K. Beecher, the original convener of the 1968 Harvard Ad Hoc Commission and an early proponent of brain death, wrote that he was doubtful whether “we as a medical society have yet achieved enough emotional and sociologic maturity to handle this question [of brain death] boldly” (Beecher 1969, 1071). For Beecher, a bold approach likely resembled a uniform dictate (as the 2008 Presidential Council concludes). However, in the face of biological and ethical ambiguity, what may be bolder, and certainly requires more emotional and sociologic maturity, is to convene an open and honest public discussion and exploration of our shared values in defining the thresholds between life and death.

References

- American Congress of Obstetricians and Gynecologists. 2005. Maternal Decision Making, Ethics, and the Law. ACOG Committee Opinion No. 321. American College of Obstetricians and Gynecologists. *Obstetrics and Gynecology* 2005 (106): 1127-37.
- American College of Radiologists. 2009. First trimester bleeding. American College of Radiologists (ACR) appropriateness criteria, originated 1996, updated in 2012. Available at <http://acsearch.acr.org/docs/69360/narrative/>
- Ad Hoc Committee of the Harvard Medical School. 1968. A definition of irreversible coma. Report of the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death. *Journal of the American Medical Association* 205(6): 337-340.
- Beecher, H.K. 1969. After the "Definition of Irreversible Coma." *New England Journal of Medicine* 281 (19): 1070-1071.
- Berlinger, N., B. Jennings, and S. M. Wolf. 2013. Guidelines for the Determination of Death. In: *The Hastings Center Guidelines for decisions on life-sustaining treatment and care near the end of life: revised and expanded second edition*. Oxford: Oxford University Press.
- Bernat, J.L. 2013. Life or death for the dead-donor rule? *New England Journal of Medicine* 369(14): 1289-1291.
- Bernat, J. 2014. Whither Brain Death? *The American Journal of Bioethics* 14(8): 3-8.
- Bonelli, R.M, E.H. Prat and J. Bonelli. 2009. *Philosophical Considerations on Brain Death and The Concept of the Organism as a Whole*. *Psychiatric Danubina* 21(1): 3-8.
- Bourne, T. and Bottomley, C. 2012. When is a pregnancy nonviable and what criteria should be used to define miscarriage? *Fertility and Sterility* 98(5): 1091-1096.
- Burkle, C.M. and T.M. Pope. 2015. Brain Death: Legal Obligations and the Courts. *Seminars in Neurology* 35(2): 174-179.
- George, R.P. and P. Lee. 2004. Acorns and Embryos. *The New Atlantis* 7: 90-100.
- Jeve, Y., R. Rana, A. Bhide, S. Thangaratinam. 2011. Accuracy of first-trimester ultrasound in the diagnosis of early embryonic demise: a systematic review. *Ultrasound in Obstetrics & Gynecology* 38(5): 489-496.
- Lock, M. 2002. *Twice Dead: Organ Transplants and the Reinvention of Death*. Berkeley, CA: University of California Press.
- Lyerly, A. D., M.O. Little, and R. F. Faden. 2008. A Critique of the 'Fetus as Patient.' *The American Journal of Bioethics* 8(7): 42-44.
- Magnus, D.C., B.S. Wilfond, and A.L. Caplan. 2014. Accepting brain death. *New England Journal of Medicine* 370(10): 891-894.

- Nair-Collins, M. 2015. Taking Science Serious in the Debate on Death and Organ Transplantation. *Hastings Center Report* 45(6): 38-48.
- National Conference of Commissioners on Uniform State Laws. Uniform Determination of Death Act, 1981 (<http://www.uniformlaws.org/shared/docs/determination%20of%20death/udda80.pdf>).
- Pallis, C. 1990. Brainstem Death. In *Handbook of Clinical Neurology*, vol. 57, edited by P.J Vinken and G.W. Bruyn, 441-496. Amsterdam: Elsevier.
- Planned Parenthood of Southeastern Pa. vs Casey. 505 US 883 (1992). Supreme Court of the United States.
- President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. 1981. *Defining death: Medical, legal, and ethical issues in the determination of death*. Washington, DC: U.S. Government Printing Office.
- President's Council on Bioethics. 2004. *Monitoring Stem Cell Research*. Washington, DC: President's Council on Bioethics.
- President's Council on Bioethics. 2008. *Controversies in the determination of death: A white paper of the President's Council on Bioethics*. Washington, DC: President's Council on Bioethics.
- Sandel, M. 2004. Embryo Ethics – The Moral Logic of Stem-Cell Research. *The New England Journal of Medicine* 351(3): 207-209.
- Shewmon, D.A. 1998. Chornic “brain death” – Meta-analysis and conceptual consequences. *Neurology* 51(6): 1538-1545.
- Shewmon, D.A. 1999. Spinal shock and brain death: Somatic pathophysiological equivalent and implications for the integrative unity rationale. *Spinal Cord* 37(5): 313-324.
- Shewmon, D.A. 2001. The brain and somatic integration: Insights into the standard biological rationale for equating “brain death” with death. *Journal of Medicine and Philosophy* 26(5); 457-478.
- Thompson, J. J. 1971. A Defense of Abortion. *Philosophy and Public Affairs* 1(1); 47-66.
- Truog, R.D. and F.G. Miller. 2014. Changing the Conversation about Brain Death. *The American Journal of Bioethics* 14(8): 9-14.
- Veatch, Robert. 2015. Killing by Organ Procurement: Brain-Based Death and Legal Fictions. *Journal of Medicine and Philosophy* 40(3): 289-311.