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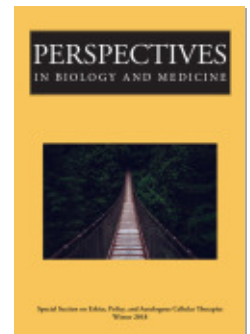
"I Sleep, But My Heart Is Awake": *Negotiating marginal states in life and death*

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“I SLEEP, BUT MY HEART IS AWAKE”

negotiating marginal states in life and death

MARGARET C. HAYDEN* AND STEPHEN D. BROWN*†

ABSTRACT This article compares a six-week fetus to a brain-dead boy to illustrate multiple inconsistencies and flaws in various prominent frameworks for determination of death by neurological criteria (“brain death”). The authors critically examine the biological and normative assumptions that distinguish these ethically ambiguous “marginal states” at the beginning and end of life and find no consistent biological or ethical criteria that coherently define the fetus as alive and the boy as dead. The authors note important contradictions in how medicine, bioethics, and society treat these marginal states, despite their striking biological and philosophical similarities, and conclude that these contradictions are ultimately untenable. They propose that rigid societal policy regarding brain death be abandoned in favor of more permissive policy that resembles those governing actions at the beginning of life, such as around abortion and embryonic stem cell research.

IN THE OUTPATIENT ULTRASOUND SUITE OF A MAJOR urban medical center, the mood is somber. A young woman lies tense and anxious. Pregnant for the first time, she has experienced early first-trimester bleeding. The radiologist relates the

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ultrasound findings: there has been a small hemorrhage, but there is a six-week-size fetus with normal cardiac activity. Translation: the baby is alive! The woman quietly sobs, happy but apprehensive.

Across the drive, in the main hospital building, a young boy lies unresponsively comatose in the Pediatric Intensive Care Unit (ICU). He was hit by a car while riding his bicycle. He is relying on a ventilator to breath, but his cardiovascular system is supporting itself. After a series of tests that demonstrate absent brainstem reflexes and no respiratory drive after a carbon dioxide challenge, the ICU physician speaks to his exhausted parents: the boy’s heart is working on its own, but his brain is not functioning. Translation: the boy is dead. His parents are devastated.

At first glance, the fetus and the boy seem to have little in common. The former possesses full potential for a complete life; the latter possesses none. This distinction is not just the product of philosophical deliberation or commonsense judgment, it is codified in medical practice guidelines. If an embryo measuring greater than seven millimeters demonstrates cardiac activity, it is alive; if not, it is dead (ACR 2017). While the evidence base that supports this determination has been questioned (Jeve et al. 2011), cardiac activity nonetheless remains the only objective physiologic criterion in determining life from death in the six-week fetus. The distinction between life and death in this case is independent of the presence of a functioning nervous system. Indeed, the first electrical brain activity does not usually occur until day 40 to 43 of life (Gazzaniga 2005). On the other hand, despite the fact that the boy’s heart is beating spontaneously, he is dead according to multi-society professional consensus and the Uniform Determination of Death Act (UDDA), precisely because his nervous system, and particularly his brain, is nonfunctional (Nakagawa 2011; NCCUSL 1981). The UDDA, which is accepted for both adults and children, defines death by neurological criteria as the “irreversible cessation of all functions of the entire brain, including the brainstem” (Wijdicks et al. 2010, 1191). While the boy’s heart still beats, he is irreversibly comatose, has no reflexes, and exhibits no drive to breathe. Therefore, established medical convention holds him as dead. According to medical and legal standards, the fetus and the boy could not be more different.

Despite this fact, the six-week fetus and the boy share a peculiar similarity: neither possesses consciousness, but both have spontaneously beating hearts. Both, it would seem, could echo the voice of the rapt, young lover in the Song of Songs: “I sleep, but my heart is awake.” The similarities go deeper. Within the limits of available scientific understanding, neither possesses any coherently functional neurological apparatus (Gazzaniga 2005). Some small degree of spontaneous neural activity may exist in both the six-week fetus and the brain-dead boy, but neither generates basic reflexes (Gazzaniga 2005; Wijdicks et al. 2010). We have thus come to a paradoxical set of circumstances. At the one end of the spectrum, a human life form—the early gestation fetus—does not require neurological function to be recognized as “living,” but at the other end of the spectrum—a brain-

dead boy—the absence of neurological function is defined as death. If both the six-week fetus and the brain-dead boy completely lack a functional neurological apparatus, yet both possess normal cardiac activity, what reasonable grounds exist to consider one alive and the other dead?

DIFFERENTIATING LIFE FROM DEATH

It may be that the boy's neurologic function is permanently or irreversibly absent, while the fetus's is not. This logic would help to create a clear line for determining that a fetus is indeed living when meaningfully coherent neurologic function commences and reflexes first appear (at approximately 8–10 weeks) (Gazzaniga 2005). What then to think of the six-week fetus with a heartbeat but no neurological activity? Perhaps a meaningful difference is that the six-week fetus possesses full potential to develop not only complete neurological function, but also consciousness and personhood, while the brain-dead boy does not. Proponents of “higher brain” conceptions of death variably identify consciousness and personal identity as critical features of living humans and equate the absence of such features with lack of personhood and even death—or, at least, a loss of moral standing equivalent to death (Green and Wilker 1980; Veatch and Ross 2015). In this formulation, for example, the boy would be considered dead even if he were in a persistent vegetative state (PVS) with some brain stem reflexes intact. Both those who see organized, coherent, if even elemental, neurological activity and those who view higher brain function (or consciousness) as key to distinguishing life from death would have to see the six-week fetus as dead, unless they viewed its potential capacity for future consciousness or identity as conferring some sort of enhanced moral standing that superseded other determinations. This may be fair enough, but the challenge lies in demarcating the earliest stage at which such potential capacity becomes ethically actionable. A sperm, for example, carries such potential. So does a freshly fertilized in vitro ovum that possesses neither neurologic nor cardiac activity.

Ultimately, any conception that holds brain function as a metric for distinguishing life from death requires some further biological foundation to discern the different statuses of brain-dead individuals and six-week fetuses. Perhaps we might argue that the fetus and newly formed embryo possess biological characteristics of “living” organisms that both a brain-dead boy and a sperm cell lack. To explore this possibility, it is instructive to review the conclusions of the 2008 President's Council on Bioethics which took up the question of defining brain death and determined that not all functions of the entire brain needed to be absent to make a determination of death by neurological criteria. The Council determined that what distinguished living organisms from dead organisms is the ability to conduct “vital work,” defined as “the work of self-preservation, achieved through the organism's need driven commerce with the surrounding

world” (60). This depends on the ability of organisms to recognize and respond to “a basic felt need that drives [them] to act as [they] must” and “act upon the world to obtain selectively what [they] need” (61). The Council argues that an individual who is diagnosed as dead on the basis of neurological criteria lacks such capacities. An individual in PVS is not dead, according to the Council, because he or she maintains some receptivity and responsiveness to the external environment. However, unlike the individual in PVS, it is difficult to conclude that a six-week fetus that lacks any coherent neural activity manifests any more “openness to its surrounding world” than the brain-dead boy. Per the Council’s criteria, the early gestation fetus would have to be considered dead.

Defenders of the President’s Council’s conclusions have offered additional properties of living entities to clarify the biological underpinning of brain death. James Bernat (2014), for example, draws upon a thesis by Bonelli, Prat, and Bonelli (2009) that all living entities, or “life forms,” exhibit four basic properties: (1) dynamics (essential life processes such as metabolism, growth, pulse, and respiration); (2) integration (that life processes derive from mutual interaction of parts); (3) coordination (the interaction of parts is kept constant within a certain order); and (4) immanency (that the previous three categories are inherent to and spring from the life form). Using these criteria, both the brain-dead boy and the fetus would qualify as “life forms.” Their spontaneously beating hearts and related circulatory function are evidence of their capacity for dynamics, integration, coordination, and immanency.

Bernat draws further upon Bonelli and colleagues to argue that what distinguishes “life forms,” such as brain-dead individuals, from “unified whole organisms” is the presence or absence of four additional characteristics: (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). Under the Bonelli classification, a sperm cell is alive (it demonstrates dynamics, integration, coordination, and immanency), but it is not a living organism because it does not form a “specifically integrated whole” (Bonelli, Prat, and Bonelli 2009, 2). Bernat (2014) argues that the brain-dead individual also lacks these characteristics and is unable to function as a whole organism; therefore, while it may technically be a “life form,” it is no longer a living organism.

If we extrapolate these criteria to a six-week fetus, it is difficult to conclude that Bernat or Bonelli and colleagues would see the fetus as a living organism. A fetus might not be considered to have achieved completion until it reaches the threshold of viability or even until the moment of birth. Applying the “identity” criterion to a fetus evokes the classic “acorn versus tree” debate: some might see embryos and early-stage fetuses as categorically different entities from human be-

ings, despite their developmental continuity, just as acorns are physically and biologically distinct from oak trees (Sandel 2004; Thompson 1971). Others would argue that, unlike acorns, all human life forms are imbued with the same inherent qualities regardless of developmental stage, and that therefore embryos possess genuine human identity and moral value (George and Lee 2004). Regardless, it seems difficult to claim that the Bernat/Bonelli framework could characterize the fetus as biologically “living” in a way that the brain-dead boy is not. To accept the President’s Council’s or Bernat/Bonelli’s conceptions of life and death, one would have to conclude either that the human fetus is no more “living” than a sperm cell, or it is dead, to at least the point of viability, if not later.

ALTERNATIVE CONCEPTIONS OF LIVING ORGANISMS

The concept of an “organism” has been subject to extensive historical revision and contemporary debate in biology and philosophy. Many others could recognize within the fetus or even much younger embryo properties of living “organisms” that are not included within the Bernat/Bonelli criteria. These include an entity’s capacity to transact exchanges between its inner mechanisms and its external environment, its possession of an organized metabolism, and its demonstration of internally integrated physiological function (Cheung 2010; Shewmon 2001; Truog and Miller 2014; Wolfe 2010). Other potential properties include the possession of heterogeneous and specialized parts, a variety of internal organs and diverse organic molecules, and the capacity for growth and development, reproduction, self-repair, metabolism, and environmental adaptations (Koshland 2002; Pradeu 2010; Truog and Miller 2014). If we would grant, as some do, that an organism requires a cluster of these functions, but does not have to possess all of them, and that a cluster of such processes might characterize living organisms such as bacteria and distinguish them from non-organisms such as viruses (or sperm cells), then the fetus is indeed as alive as any other entity that possesses such qualities yet lacks a neurological apparatus, including, certainly, the brain-dead boy.

In essence, those who accept the concept of neurologically determined death must adhere to a restrictive set of biological criteria that fail to account for generally established properties of organisms. Indeed, critics of the determination of death by neurological criteria have argued persuasively that no such criteria are sufficient to define an individual as dead so long as the individual’s ongoing internal processes permit meaningfully integrated physiologic function. They have pointed to numerous compelling examples, including ongoing circulation, digestion, wound healing, and even continued growth and development in individuals who have met criteria for brain death (Shewmon 1998, 1999, 2001; Truog and Miller 2014). The fetus again shares some of these integrative functions with the brain-dead boy. No reasonable criteria exist that define the fetus as alive and the

boy as dead. Any of the formulations of brain death put forth by the UDDA, President’s Council, or Bernat/Bonelli would also declare the six-week fetus as dead. Some may hold that the human species is so distinct that born individuals merit a definition of life and death that is different from the rest of the biological universe and that does not apply to the human fetus. But this, of course, is a philosophical rather than biological distinction.

PARADOXICAL SOCIETAL TREATMENT FOR SIMILARLY MARGINAL STATES

Despite their apparent differences, the fetus and the brain-dead boy with the beating heart share many parallels. Their understood neurological function is such that both would be defined as dead according to almost any conventionally accepted criteria for neurological determination of death in humans (granting that empirical limitations preclude confident clinical declaration of brain death in neonates before 37 weeks, and no criteria have been established for six-week fetuses). On the other hand, they are both alive if we recognize that living organisms are self-contained entities that possess a cluster of identified properties that permit integrative physiologic function. Either way, both occupy what Robert Veatch (2015) has called a “marginal state” (307), a space at the threshold of life and death where concrete biological properties engender philosophical ambiguity, and where no consensus exists about when or how—or even why—full moral status as a human being is deserved.

Here enters another set of paradoxical circumstances. These marginal states, so similar in their biological properties and ethical ambiguity, are treated differently by medicine and society. While medicine considers the fetus with the beating heart unequivocally alive, society recognizes that divergent moral and religious beliefs exist about the significance of that life, and individuals are currently permitted latitude in making their own decisions about the status of the fetus and the pregnancy. The early gestation fetus is subject to a patchwork of state regulations and protections, which, by federal mandate, variably balance the values and preferences of the pregnant woman against the states’ obligations to uphold the inherent moral value of the fetus (*Planned Parenthood of Southeastern Pa. v. Casey*, 505 US 883 (1992)). Although their liberties in this regard have been threatened, women in all states continue to have the legal authority to ask a physician to terminate the life of that fetus directly. At the same time, the fetus is subject to stringent federal research protections under the Code of Federal Regulations (45 CFR 46.204), with concerted protections extended to even younger embryos *in vitro*.

By comparison, little latitude is extended to decisions that might be made for the boy with irreversible cessation of total brain function, despite the fact that he is so physiologically similar to the fetus. Given that state law (with limited

exceptions) recognizes brain death as legal death, the boy may not be treated as anything but dead, despite the existence of reasonable alternative conceptions of death. Parental objections to the declaration of death would hold no standing, even if their objections were based on well-articulated moral, religious, or even scientific beliefs. Interestingly, a child in PVS would be treated more like a fetus. That child would be considered very much alive, subject to a strong measure of societal regulations and protections, but with deference paid to the values and preferences of the parents, who would be permitted to withdraw care in many states and institutions (Garros, Rosychuk, and Cox 2003).

Despite the presence of several reasonable alternative philosophical and biological conceptions addressing the ambiguous marginal state at the end of life, brain death is defined rigidly by a single legally enforceable definition. On the other hand, the bioethical and legal worlds have demonstrated tolerance for the multiple philosophical and ethical conclusions that exist around a similarly ambiguous marginal state at the beginning of life. Much more public debate has consequently been permitted around beginning of life ambiguities, particularly regarding abortion and the uses of stem cells. At issue is whether these differences are defensible. Do reasonable grounds exist to justify the latitude given to decisions regarding the fetus and the restricted decision-making permitted around the brain-dead boy?

HISTORICAL PERSPECTIVES

To address these questions, it is worth reviewing the normative proceedings that have informed current standards over time. The concept of “brain death” emerged with the development of life-sustaining technologies and organ transplantation in the 1960s, which brought with them a new utilitarian rationale to define the moment of death as precisely as possible (Lock 2002). Patients who had lost whole brain function were seen as potentially optimal organ donors, because the new “life support” technology could maintain organ perfusion until the moment of retrieval. However, because of a well-accepted tenet holding it immoral to remove life-sustaining organs from a living donor (the “dead donor rule”), such patients needed to be declared dead before they could serve as donors (Truog and Robinson 2003). In 1968, Harvard Medical School convened a committee to discuss the ethical issues surrounding these “hopelessly unconscious” patients (Lock 2002, 89). The group published a report arguing for a redefinition of death that encompassed individuals in irreversible comas, premised upon a utilitarian rationale: to prevent the new technology from placing undue burdens upon families and medical institutions, and in large part, to permit procurement of the organs of the individuals who were now reclassified as dead (Ad Hoc Committee of the Harvard Medical School 1968). From its very origin, the concept of brain death has been grounded in utilitarian logic and inextricably linked to organ donation.

The Ad Hoc Committee’s conclusion was formalized and codified in 1981 by a Presidential Commission that produced the UDDA (President’s Commission 1981). As a public policy matter, the Presidential Commission report was successful: 45 states have formally adopted the UDDA, and the remaining five have recognized it through judicial opinion (Magnus, Wilfond, and Caplan 2014; NCCUSL 1981). Brain death has become a medical and legal entity that is incontestable in most states in the United States. A few states (New York, California, and Illinois) permit limited accommodations for religious or moral objections to brain death. Only one state, New Jersey, has a categorical exception for religious objections: 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 and 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 the more traditional cardiorespiratory criteria.

It is striking that current clinical guidelines do not acknowledge the evolution of brain death and its utilitarian underpinning. The Hastings Center, for example, does not allow for any claims of ambiguity in the diagnosis. It advises clinicians to clarify for grieving families that “death by neurological criteria *is* death—that the patient has already died” (Berlinger, Jennings, and Wolf 2013, 2) and to avoid language such as “life support.” No provisions permit any objections to the designation of brain death. A concept rooted as much in philosophy as in biology is now treated as an objective medical fact.

In stark comparison, policies regarding “marginal states” at the beginning of life explicitly acknowledge the existing ambiguities and openly validate the liberty of both individuals and states to their own subjective interpretation of medical facts. Pluralistic philosophical alternatives at the beginning of life are incorporated directly into policy. Current abortion law in the US, for example, is defined by the seminal 1992 US Supreme Court case, *Planned Parenthood of Southeastern Pa. v. Casey*, which recognized that fetuses at any developmental stage below viability have an intrinsic moral value that is open to good-faith differences. Early gestational age fetuses may merit some measure of respect and protection, although not full moral standing as persons. States are permitted to act according to their particular conceptions to apply certain restrictions on the pregnant woman’s liberties, even at early stages of development, so long as the restrictions do not present an undue burden in access to termination, up to the point of viability. Pregnant patients are permitted to view and act upon their moral and religious beliefs to treat early gestation fetuses in any number of ways. A patchwork of public policy around this sphere has resulted, and practices are highly variable. For example, while abortion is currently recognized as a constitutional right, 43 states prohibit abortions after a specified point in gestation (typically seen as viability), 32 states prohibit use of state funds except when the women’s life is in

danger or the pregnancy is a result of rape or incest (for which federal funding is available), and 17 states mandate some form of counseling before a woman is given an abortion (Guttmacher Institute 2016).

It is both interesting and telling that two more recent presidential commissions tasked with making recommendations around brain death policy and around human embryonic stem cell research took very different approaches to resolving their respective ethical challenges. The 2008 President's Council on Bioethics that tackled brain death concluded with a forceful endorsement of a single interpretation about when death occurs. In contradistinction, the 2004 President's Council that addressed stem cell research validated the legitimacy of numerous conceptions of when human life begins and how moral status changes throughout the course of development. It took the position that there is no single biological truth that could be used to mandate specific actions, and it acknowledged that it was unlikely that such a unifying resolution would be reached anytime soon, asserting that even when biological facts about embryological development are unambiguous, they are not "decisive morally" (75). The Council instead aspired to "the possibility of progress toward greater understanding of the issues, and toward more informed public decision-making" (97).

TREATING MARGINAL STATES SIMILARLY AT THE BEGINNING AND END OF LIFE

Compared to the 2008 President's Council, the 2004 President's Council drew the opposite conclusions around bio-philosophical questions that, as we have seen, are essentially equivalent at the beginning and end of life. Rather than imposing one view where many exist, the 2004 Council opted for tolerating ambiguity and uncertainty. Both the bioethics community and society at large have, thus far, declined to offer singular normative policy-oriented declarations equivalent to the UDDA for the beginning of life. In comparison to brain death policy, regulations at the beginning of life have avoided ultimatums and left room for debate and discussion at state and national levels. This has generated sometimes messy practical uncertainties and inconsistencies, but also a more fluid and open debate than has occurred with brain death policy.

The 2008 President's Council that defends the concept of neurologically determined death acknowledges that, at least for some, the transition from life to death is not always clear: "In patients with total brain failure, the transition from living body to corpse is in some measure a mystery" (53). The Council is well aware of the role of philosophy in these debates, acknowledging that these questions cannot be resolved by purely clinical or biological facts. Rather than endorse policy that incorporates the uncertainties that confound precise definitions at the margins of human life and death, the Council achieves its end by dismissing them. It thus becomes a major challenge to reconcile and maintain the divergent

conclusions of the consultative bodies to the US government regarding policy at the beginning and end of life. However, it is important to do so, because these conclusions are, essentially, proxies for the current ways in which society addresses the related practical issues, such as organ transplantation, abortion, and stem cell research. If they cannot be reconciled, one or the other set of recommendations must be abandoned as intellectually inconsistent.

CONCLUSION

In comparing a six-week fetus to a brain-dead boy, we have argued here that there is no coherent framework that satisfactorily establishes a brain-dead boy as dead and a six-week fetus as alive. Current policies that adhere to the UDDA and its treatment of brain death are based upon structurally unsound biophilosophical premises that are untenable if extrapolated to the beginning of life. Given that laws regarding neurologically determined death are fundamentally premised on utilitarian grounds, if they are to remain intact, they must ultimately be defended using a more transparent utilitarian rationale that claims, in effect, that the benefits of current policies are useful and important to society in a way that would not be useful if a singular moral view of the fetus held sway. Its proponents would have to argue that important societal objectives are met by allowing pluralism for views about fetuses and embryos, but not for those who are brain-dead. We would welcome such an effort, but predict that these claims would be open to various counterclaims of reasonable legitimacy, and that no consensus would be readily forthcoming.

Until one is, we would argue that the more pluralistic approach taken with the fetus be adopted for the brain-dead boy, with allowances made for individuals to apply their own moral calculus to these marginal states. We argue this not for any utilitarian rationale, but because it is more intellectually honest. While not a utilitarian argument, it does point to one: if rigid societal policy is premised upon an intellectually unstable argument and imposed upon those who carry legitimate alternative beliefs, the application of that policy becomes an arbitrary application of power that constrains the liberties of those with reasonable objections. For many in a pluralistic society, protecting such liberties would be an important utilitarian counterweight to the priorities espoused by proponents of current standards for brain death.

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