



## A Legal Fiction with Real Consequences

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definition of death as the irreversible end of personal experiencing and interacting, deeming the ongoing integrated functioning of the organism (and the spontaneity of heartbeat) to be irrelevant because of ventilatory and other support (Gervais 1986).

Any criterion for determining death presupposes an answer to the question: What is so essentially significant to human life that its irreversible loss is death? People differ in their answer to this question. Despite this, people can accept the use of the brain-death criterion for determining death either because they agree with the consciousness-based concept of death underlying it, or because they consider the combination of irreversible unconsciousness and the necessity of perpetual mechanical support to be death. For others, a conscience clause in a determination of death statute would enable people to clarify their wishes concerning life-sustaining treatment and organ donation in the event of brain death.

When the President's Commission constructed its arguments in 1981, it insisted that the irreversible loss of the integrated functioning of the organism as a whole was the single unified concept of death that legitimated the use of the brain death criterion and the traditional use of the cardiopulmonary criterion (TC). Many of us now agree that brain death does not fulfill this concept of death, and some of us believe brain death reflects a different understanding of human death (Gervais 1986). In my view, the first big error in the promotion of brain death as death was the failure to acknowledge that implicit in the adoption of the BDC was a different definition of human death.

The BDC directly diagnoses that relevant parts of the brain are destroyed, treating ongoing heart and lung functioning as irrelevant to the determination. As traditionally applied in preventilator times, the TC directly diagnoses that the heart and lungs have irreversibly ceased to function. A person is dead, but according to a different concept of death, in the two cases. But in both cases, the person is irreversibly unconscious—a point relevant to the practices of controlled and uncontrolled donation after cardiac death (cDCD and uDCD). These practices occur while cardiac function remains reversible and without knowledge of the status of the brain, thus departing from both concepts of death. I assume that most people considering declaring themselves organ donors assume that they

would be dead (and therefore irreversibly unconscious) during organ procurement. Since there is no guarantee of this under current practice, cDCD and uDCD should only be done as exceptions to the Dead Donor Rule, under a living donation approach that assures anesthesia.

I favor this approach to cDCD and uDCD because it enables these practices to continue but does not exacerbate and perpetuate what Frank Miller has rightly called the “crisis of incoherence” that has plagued the definition of death debate since the adoption of the brain death criterion. Current cDCD and uDCD practices have deepened the crisis. DCD donation can only be coherently addressed as an expansion of living donation, and ironically, only then will adequate protections for these donors be potentially assured. Potential donors/surrogates should be invited, in a value-neutral way uncharacteristic of current organ procurement practices, to consider living donation through a process of full disclosure and fully informed consent to the multiple, complex modifications in end-of-life best practices DCD requires. I believe that controlled exceptions to the Dead Donor Rule can afford donors and their loved ones greater autonomy and protection from potential harms.

Technological support of the human organism has forced the normative question on us: What should we consider human death to be? What biological/functional changes signify the end of a life? As a standard of coherence, “biological plausibility” returns us to using the traditional heart and lung criteria in the old-fashioned way. Since the public has not questioned the plausibility of considering brain death to be death, it seems wrong to attack it for reasons of biological implausibility. It also seems wrong to assert, as a biological fact, that brain death is death. It is a statement that is the conclusion of both metaphysical and normative reflection (Gervais 2014). ■

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# A Legal Fiction with Real Consequences

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In “Changing the Conversation About Brain Death,” Truog and Miller (2014) summarize doubts that have been

expressed for decades about whole brain death, and argue forcefully that brain death is not equivalent to biological

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death, but is rather a legal fiction. From its inception to its widespread acceptance as a definition of legal death, brain death has played a vital, positive social role in allowing the procurement of lifesaving organs, while at the same time protecting potential organ donors from harm. Despite these salutary effects, the legal fiction of brain death prompts ethical concern when it is treated as a social, biological, and legal fact, to the detriment of patients and families. Most families opt to withdraw life support from patients following a diagnosis of brain death, but a small minority do not, and they suffer the adverse consequences of dissenting from the legal fiction.

### COERCION AND DENIAL OF HEALTH INSURANCE

Health insurance coverage is premised on the “medical necessity” of the treatment of injury and illness to improve a patient’s condition (Anderson, Vernaglia, and Morrigan 2007). Under ordinary circumstances, coverage ceases upon the legal death of an individual. But under ordinary circumstances—and unlike brain death—legal and biological death coincide. Treating a corpse would surely fail to improve its condition. But the relatively minimal care required to maintain life in the brain-dead patient—in many cases, little more than artificial nutrition and hydration (ANH), and ventilation—is no less a “medical necessity” than life support for a high cervical quadriplegic or a permanently vegetative patient. The condition of the quadriplegic or the vegetative patient is also unlikely to be improved by the provision of life-sustaining treatment. Continued insurance coverage, like continuing medical care, is in such cases premised on its necessity for maintaining life. Numerous cases in the literature point to the utility of life support for the brain dead, who can be maintained in a physiologically healthy condition for many years (Shewmon 1998).

Truog and Miller aver that “drawing the line for insurance coverage at the level of brain death may seem somewhat arbitrary.” While it is true that in law, lines are often drawn at arbitrary points—for example, the age of legal majority—the reason is generally that legal lines must be distinct, and so do not always correspond to fuzzy realities. Denial of insurance for brain-dead patients is arbitrary because the definition of brain death is itself plagued by fuzzy and arbitrary distinctions. By law, brain death is the irreversible cessation of the functions of the *entire* brain, including the brainstem. While someone who has been declared brain dead is by definition legally dead, some persons meeting standard diagnostic criteria for brain death continue to exhibit not only bodily functions (e.g. growth, healing, pregnancy, circulation, excretion, etc.), but some neurological functions as well (Halevy 2001; Shewmon 2001). They are not merely exceptions to the rule, and “all physicians who diagnose brain death know that many patients . . . continue to have physiologically significant brain functions” (Truog and Miller 2014, 11). There is scant ethical justification for denying coverage to

a living patient on life support, even one at “the extreme end of the spectrum of neurological injury” (Truog and Miller 2014, 12), when other neurologically injured persons, including those who require far greater medical intervention, are covered. Consistency and justice minimally require that anyone not satisfying the statutory requirements for brain death—and there would be many—should remain eligible for health insurance coverage.<sup>1</sup>

That it is arbitrary and inconsistent is but one objection to the denial of insurance coverage for brain-dead patients. It also has a potentially coercive effect, particularly for families with limited financial resources who may not be able to pay for ongoing care. This raises important concerns about justice, especially if families who object to a declaration of brain death are coerced into accepting the withdrawal of life support because they cannot pay for care, or lack the knowledge or resources to fight a legal battle.<sup>2</sup> Given the potential for coercion, and the lack of consistent justification for denial, the prevailing standard of providing insurance coverage for living, severely brain-injured patients should include the brain dead.

### INSTRUMENTALIZING THE BRAIN DEAD

Brain-dead patients are routinely and without controversy maintained on life support when they are organ donors, in order to preserve the viability of their organs for transplant. Nondonor patients, on the other hand, can be threatened—as Jahi McMath and her family were—with the unilateral, involuntary withdrawal of life support. Jahi McMath is a California girl who suffered severe hypoxic brain injury as a result of postsurgical blood loss, and was declared brain dead. Her family objected on religious grounds, and has consistently maintained that their belief is that death occurs only when the heart stops beating. As with most brain-dead patients, Jahi’s heart beats spontaneously, and she has been maintained on life support since December 2013. Her family took Oakland Children’s Hospital to court to prevent the withdrawal of life support.

When a nondonor is treated as a loiterer in the intensive care unit (ICU), it fosters the suspicion that brain-dead patients are viewed instrumentally, and not worthy of medical care and life support in their own right. Reifying this suspicion fuels the perception of discrimination, and increases mistrust of the medical community. Surveys of potential organ donors reveal that many fear that their willingness to donate will result in substandard or less aggressive medical treatment and a premature,

1. The state of New Jersey, in addition to requiring the use of circulatory-respiratory criteria for death when there is a religious objection to neurological criteria, does not permit denial of insurance coverage. It is unique in doing so.

2. Hospitals, unable to bill third-party insurers for the care of “dead” patients, have a financial conflict of interest that could incentivize them to press the issue of withdrawing life support.

preventable death (D'Alessandro, Peltier, and Dahl 2011; Newton 2011). Given the chronic shortage of lifesaving organs, that the involuntary withdrawal of life support from nondonor patients might sow public distrust and discourage organ donation is itself an important practical reason to avoid it. When access to life support is contingent on the donor status of the patient, it also raises troubling ethical concerns about allocation of health care resources, conflicts of interest for health care providers, and the abandonment of patients.

### PATERNALISM: ADDING INSULT TO INJURY

McMath's family was subjected to a strong dose of paternalism, with doctors and hospital representatives publicly referring to their child as "a deceased person" and a "dead body," when neither was factually or medically accurate (BBC 2013). Many bioethicists joined the chorus, calling the family deluded and crazy, while also paternalistically expressing concern about the emotional and financial toll on Jahi's parents (*Los Angeles Times* Staff 2014). The hospital took the charade of death so far as to release the child—still breathing with a ventilator—to the county coroner, who then turned Jahi over to her family for ongoing care. The hospital treated Jahi as neither a patient nor a "dead body"; living patients are not sent to the morgue, and dead bodies are not actively ventilated. Contrary to the hospital's stated conviction that their child had died, Jahi's family was not shown the forbearance and sympathy customary for distressed families. It is neither ethical nor decent to heap such abuse on a grieving family, and the legal fiction of brain death should not be employed to justify such paternalistic and unseemly maltreatment. Two guiding precepts of ethical medicine are respect for the autonomy of patients and their surrogates, and nonmaleficence. At minimum, these principles constrain us from using the legal fiction of brain death to treat patients as if they are uncontroversially biologically and socially dead, or to neglect the duty to treat them and their families with compassion.

### REWRITING THE FICTION

Medical, philosophical, and religious dissent from the whole brain death orthodoxy has persisted for decades. Truog and Miller are right that it is time to change the conversation. A new conversation can begin by acknowledging that in a pluralistic society there are diverse viewpoints on contentious and deeply important matters, and few matters in human existence have the cultural,

social, spiritual, and personal weight of death. That the legal fiction has been informally rewritten to include patients who do not exactly fit legal criteria tells us we can rewrite it to accommodate other endings as well, out of respect for those whose convictions lead them to reject a neurological definition of death.

It remains a legal necessity to determine death by neurological criteria to permit the harvesting of vital organs for transplant from patients with beating hearts. But death by legal fiat has been reified, and it is treated as a settled medical, biological, and social fact that the brain-dead, contrary to common sense and tradition, are simply dead. While it is important to recognize the instrumental value of a neurological definition of death, it is equally important not to wield it to instrumentalize persons, and to justify viewing those declared brain dead as either organ donors who exist only to serve others, or as mere corpses to whom we owe nothing. ■

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