



The conceptual injustice of the brain death standard

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Abstract

Family disputes over the diagnosis of brain death have caused much controversy in the bioethics literature over the conceptual validity of the brain death standard. Given the tenuous status of brain death as death, it is pragmatically fruitful to reframe intractable debates about the metaphysical nature of brain death as meta-linguistic disputes about its conceptual deployment. This new framework leaves the metaphysical debate open and brings into focus the social functions that are served by deploying the concept of brain death. In doing so, it highlights the epistemic injustice of medicolegal authorities that force people to uniformly accept brain death as a diagnosis of death based on normative considerations of institutional interests, such as saving hospital resources and organ supplies, rather than empirical evidence of brain death as death, which is insufficient at best and nonexistent at worst. In light of this injustice, I propose the rejection of the uniform standard of brain death in favor of a choice-based system that respects families' individualized views of death.

Keywords Brain death · Death · Clinical ethics · Conceptual engineering · Epistemic injustice · Neuroethics

Introduction

The case of Jahi McMath stirred great controversy in the medical and bioethics community over the legitimacy of the brain death standard. Shortly after a complex pharyngeal surgery, Jahi suffered from a massive hemorrhage and a cardiac arrest that caused significant damage to her brain [1]. Two physicians determined that she met the diagnostic criteria for brain death, defined by law as the “irreversible cessation of all functions of the entire brain,” and Jahi’s parents were told to take her off her ventilator [2]. However, the family refused to accept that Jahi was dead, and legally challenged her brain death determination before transferring her to a hospital in New Jersey, which uniquely permits exemptions to the brain death criteria [3].

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Jahi spent the next four years in New Jersey, where her body continued to grow and develop until she developed liver failure and was eventually taken off her ventilator. The case of Jahi McMath is just one of multiple controversies in recent years in which brain dead declared patients' families resist the neurological diagnosis of death and file lawsuits to prevent hospitals from discontinuing life support [4–6]. Families cite beliefs, some of them religious, that their loved ones should not be determined dead if their heart is still beating, regardless of their lack of brain activity [7]. Given the contentious nature of the determination of death, the medicolegal community ought to ask: what is the conceptual basis for brain death, and is it worth keeping? In this paper, I argue that the brain death standard is a conceptual construct that promulgates epistemic and pragmatic injustices, which can be ameliorated by instituting a choice-based determination of death instead.

Defining brain death

Determining death

Death is an intuitive concept for most people. One can usually determine when animals fall prey to predators and die, when characters die on screen, or when people die from injury or disease outside of the hospital. However, a medical setting where patients often exist in a gray area between our intuitive grasps of life and death demands a more precise standard of determination. Traditionally, death has been determined by a cardiopulmonary standard (or a circulatory standard), which entails the irreversible failure of a person's heart and lung functions [8]. Recent developments in medical technology and techniques, such as ventilators and cardiopulmonary resuscitation (CPR), have allowed clinicians to restore these functions in patients who experience cardiopulmonary arrest, but it also created ambiguities in determining whether the patient is still alive [9]. During the interval after cardiopulmonary arrest in which resuscitative efforts are administered, the patient's brain functions may cease due to oxygen deprivation such that even if their cardiopulmonary functions are intact as in a living person, they would be permanently unconscious and immobile, just like a dead person.

In 1968, the Ad Hoc Committee of Harvard Medical School proposed a new, neurological criterion for determining death, which entails the permanent failure of brain functions that results in loss of consciousness, movement, breathing and reflexes [10]. They cited two reasons for developing this new criterion: (1) it relieves the great burden of “permanent loss of intellect” on patients, families and resource-strained hospitals, and (2) it avoids controversy for clinicians obtaining organs for transplantation from brain dead patients [10, p. 1]. Thirteen years later, the President's Commission promulgated the Uniform Determination of Death Act (UDDA), which legally sanctioned brain death as death entailed by the “complete absence of all functions of the entire brain, including the brainstem” [2]. In what is otherwise known as the whole-brain standard, the UDDA's neurological criteria has since been adopted by 38 states to provide a legal basis for brain death. However, there exists

significant limitations and contradictions in the brain death standard that seem to undermine its conceptual legitimacy.

Brain death: a defective concept?

There are several practical reasons for regarding brain death as a defective concept in typifying death. Firstly, medical practices do not comport with the UDDA's legislative definition, creating discordance between theoretical and in-practice assessments of brain death. Clinicians determine brain death by testing for unconsciousness, apnea (i.e., loss of breathing) and the irreversibility of both states, which can be collectively called a state of "irreversible apneic unconsciousness" [11, p. 2139]. However, this is not the same as the irreversible cessation of *all* functions of the *entire* brain, as specified by the UDDA. Numerous patients who meet the clinical criteria of brain death demonstrate continued hypothalamic functions of their brains, which facilitates biological growth, sexual maturation and even the gestation of a fetus [12, 13]. Secondly, there are significant practical limitations to the bedside methods used to determine 'irreversible' states of unconsciousness, with recent studies demonstrating that up to 40% of patients with disorders of consciousness are being misdiagnosed to a lower level of consciousness [14]. Given that legally, many brain dead declared patients still retain certain neurological functions and their state of unconsciousness cannot be reliably ascertained, the medicolegal category of brain death rests on empirically tenuous grounds.

Even if the UDDA was revised to define brain death as 'irreversible apneic unconsciousness,' it does not capture an inclusive view of death. Western rationalist philosophy and its location of personhood in the brain as the "seat of rational thoughts" supports the notion that permanent loss of brain functions indicates the death of the person [15, p. 217]. In contrast, Eastern philosophy and religions do not dichotomize the body and the rational mind, but rather emphasize the importance of the physical body as a whole, which may contribute to the public rejection of brain death in some Eastern societies [16]. For example, the diagnosis of brain death conflicts with holistic conceptualizations of the body and soul in Japan, which invokes public reluctance towards acknowledgement of brain death as 'true death' [17]. Studies also demonstrate that fewer people in Japan and China support brain death as an appropriate standard for human death than in Western countries such as the United States or France due to competing cultural conceptions of death [15]. However, these beliefs are not just limited to citizens of non-Western countries, as exemplified by Jahi's mother who "didn't understand how Jahi could be dead when her skin was still warm and soft and she occasionally moved her arms, ankles, and hips" [3, p. 5]. Given the practical deficits in operationalizing the diagnosis of brain death and its preclusion of many people's intuitive understanding of death as a whole-body phenomenon, why might medicolegal authorities continue to uphold such a controversial concept?

Death as joint-carving or role-playing?

In order to examine why brain death continues to be upheld, we must first assess the conceptual nature of death. Some might argue that when labeling someone or something as “dead,” one attempts to make metaphysically true claims about whether the organism is *actually* dead. Medical professionals ascertain the moment of death by measuring heart rate, brain waves, or the level of carbon dioxide in a patient’s blood, which serve as empirical proxies that determine when the patient reaches the metaphysical plane of death. However, this view of ‘death’ as carving at a precise joint in nature does not comport with the reality of brain death determination. The UDDA provides no reasoning nor evidentiary support for how brain death tracks the “reality” of death, and the American Academy of Neurology (AAN) merely calls it an “implicit position of the UDDA that death is a biological reality that may result from the irreversible injury to the heart and the brain” [18, p. 231]. In other words, brain dead declared patients are dead because they are dead. The Harvard Ad Hoc Committee is the only authority that provides non-circular reasoning for developing a criterion for brain death, which was identified earlier in this essay as (1) relieving the burdens of care on families and resource-strained hospitals and (2) allowing clinicians to procure organs from brain dead individuals. However, these are normative reasons that appeal to caregiving burdens, hospital resources and organ transplantation, rather than scientific evidence of the underlying metaphysical event of death.

There is a good reason for this: death is and will likely remain a metaphysically elusive concept. Different cultural communities and religious groups have distinct conceptions about the nature of death and there is no empirically verifiable standard that can authenticate one conception over the others [19–21]. These varied perspectives address not just the physiological component of biological death, but also a metaphysical component concerning the death of the person as a whole. As such, definitions of death often rely on conceptions about personhood, personal identity, and other related metaphysical properties that evade empirical verification and are conceptually difficult to reconcile [22, 23]. Furthermore, in the case of brain death, the current diagnostic methods and tools for determining irreversible states of unconsciousness are unable to make precise assessments of death. The conceptual elusiveness of death may be caused by the metaphysical ambiguity of death, and the multi-faceted nature of its many definitions across time and cultures suggests that it could be characterized as a cluster of many different characteristics, none of which are independently necessary and sufficient for an organism to be dead [24]. For example, Chiong proposes that the property of being dead involves a cluster of characteristics (e.g. lack of consciousness, absence of spontaneous vital functions, ability to decay, etc.), none of which are necessary and sufficient by themselves, but all of which can contribute to an organism being dead [12]. In addition to these physical and behavioral characteristics, the patient and family’s philosophical, cultural, and religious conceptions of death also play a critical role in determining death. Given this incredible diversity of factors, the project of paring down a single definition of death is so complex that operationalizing an empirical undertaking to ‘discover’ the solution

to this problem would be extremely difficult, if not entirely impossible. Instead of committing oneself to such a metaphysically insurmountable task, one might better understand the concept of death in terms of its socio-functional roles, while leaving it open to a plurality of people's reality-tracking concepts of death (e.g., the cessation of one's heart, loss of consciousness or departure of the soul).

To have better conversations about brain death as a legitimate medicolegal category, one should frame these disagreements as metalinguistic disputes about which contexts justify the deployment of the concept of death. It is important to note that framing this dispute as a matter of metalinguistic usage does not reduce it to a semantic squabble, as Plunkett and Sundell argue that disagreements about "which concept should play a functional role... concerns matters of how we navigate our decisions to treat others, what to hold each other responsible for doing, and how to live more generally" [25, p. 20]. Thus, instead of engaging in an empirically futile task of 'discovering' the conceptual boundaries of death, one can adopt a more fruitful framework for understanding how this debate retains normative substance despite its metaphysical uncertainty. This is a matter of conceptual ethics, in which one must determine how the concept of death ought to be deployed or improved in terms of the functional roles it plays in society, which in turn helps people to coordinate and organize their lives together [26]. Therefore, the analysis of death and its typified categories ought to focus on how it enables people to perform important social functions such as gathering the family, withdrawing life-support, grieving, procuring organs and performing burial rituals [27]. Some proponents of brain death might happily agree with this functionalist view of death to argue that brain death as a construct allows one to fulfill important social needs, such as increasing the availability of transplanted organs from brain dead donors [28]. In the following section, I will demonstrate how this argument neglects the way in which the current deployment of brain death prevents families from using death to fulfill other socially important functions.

Before concluding this section, I would like to address an opposing assertion that death reflects a natural reality, which should not be framed merely in terms of normative or social concerns [29]. After all, when applying the terms 'death' or 'dead' to an organism, one seems to pick out an underlying reality about a being's existential and biological state, even if one cannot pinpoint the exact moment or nature of its death. Unlike social kinds such as gender and race, it seems that death should not be treated as an arbitrary social construct but rather something that can be empirically verified, if imperfectly. However, my argument does not seek to define death as a social construct, nor does it depend on whether death is a social construct or a natural reality. Rather, I seek to highlight how the conceptual application of 'death' through constructed medicolegal criteria such as 'brain death' relies on normative considerations which ought to be interrogated. I adopt Thomasson's pragmatic approach to conceptual ethics, which recognizes that normative conceptual choices should be responsive to empirical discoveries without further committing to their metaphysical vindications [30]. So, although empirical procedures for determining brain death can help us understand what features are relevant for the diagnosis, they themselves do not serve as metaphysical justifications for treating someone with irreversible apneic unconsciousness as a dead person. Instead, they are used to

further normative goals, such as (1) relieving caregiving burdens from families and hospitals and (2) increasing organ transplantation rates.

The conceptual injustice of brain death

Brain death as institutionalized fiction

“Legal fiction” is a term that has been used to describe brain death (without pejorative intention) as a type of legal construct that is treated as true in order to perform legitimate social functions [31, p. 10]. For example, ‘legal blindness’ is a type of legal fiction that categorizes people with extremely impaired vision but are not biologically blind as *legally* blind in order to subject to them to legal requirements about driving or grant them certain disability support. Similarly, I argue that brain death is a type of conceptual fiction, broadly construed as a construct that is treated as true for the sake of furthering certain social functions. Furthermore, as an institutionalized conceptual fiction, it serves as both a medical and legal fiction to serve the interests of medicolegal institutions.

Firstly, brain death is a form of medical fiction imposed upon the public to serve moral and pragmatic functions that benefit healthcare institutions. The field of medicine has a history of touting biomedical models as immutable descriptions of reality rather than medicalized constructs that aid diagnosis, such as with biomedical models of disability and psychiatric phenomena [32]. Brain death falls into this pattern of medicalization; even though it is not a clinically ‘discovered’ fact-of-the-matter about death, it is implicitly treated as such by medical professionals when presenting the diagnosis to families. Upon further investigation, it becomes apparent that the brain death standard plays several functional roles that are important for healthcare institutions. The first is the scarce hospital resources such as beds and ventilators that are purportedly freed up once patients are declared brain dead and thus no longer in need of care. The second function is a kind of moral assurance for clinicians who are required to withdraw life-sustaining treatment and perform surgeries on patients to procure their organs. If an individual in a state of irreversible apneic unconsciousness is instead declared brain dead, the care team avoids the moral distress that may result from withdrawing treatment and procuring organs from a patient who would otherwise be considered alive. Brain death is also a useful legal fiction because it legally allows clinicians to procure organs from brain dead patients via the dead-donor rule, which stipulates that a person must be declared dead before removing life-sustaining organs for transplantation [33]. Allowing clinicians to declare patients brain dead enables them to procure organs from individuals whose bodies are more optimal for donation because they have not suffered the anoxic injury of circulatory arrest, and it also protects them from the legal liability of ‘killing’ a living patient for their organs.

Despite its medical, legal, and social benefits, the brain death standard relies on a conceptual fiction that can also cause great harm to families of brain dead declared patients. The AAN states that physicians have a moral responsibility to declare an irreversibly unconscious individual brain dead so that they can avoid giving false

hope and prevent a prolonged grieving process for the family [18]. However, many families who resist the brain death diagnosis seem to experience the exact opposite phenomenon, in which they become emotionally distraught, legally pressured, and financially exhausted by their efforts to challenge the fictional construct of brain death [3–6]. For these families, registering someone as ‘dead’ performs other kinds of social functions such as giving up on their loved one, accepting the loss of their soul, or acting as if they are no longer deserving of treatment. Thus, the imposition of a brain death diagnosis forces families into circumstances that they do not perceive to be appropriate for ‘death’ to be conceptually deployed, which breaks their trust in a medical system already embroiled in controversies of paternalism, medical racism and disregard for patient voices [34]. On the other hand, transferring Jahi to a hospital with exemptions to the brain death criteria allowed the McMath family to keep their daughter alive according to their personal convictions about life and death. Over time, even the care team at the New Jersey hospital warmed up to support and congratulate Jahi for “gathering the strength and commitment to move a foot or a finger” [3, p. 30]. The benefits of having brain death perform institutionally valuable functions should not come at a cost to patients’ families who hold different beliefs about what functional roles death performs for them; this constitutes an instance of conceptual injustice that ought to be corrected.

Brain death as structural gaslighting

The harms incurred by families who resist the brain death diagnosis stem from the epistemic injustice perpetrated by medicolegal authorities through a form of structural gaslighting. Medicine has a troubled history with epistemic injustice, in which patients and families’ testimonies, interpretations, and voices are downplayed or denigrated by healthcare professionals who enjoy epistemic privilege by virtue of their training and expertise [35]. The structure of contemporary healthcare practice empowers physicians to assess and decide which testimonies to receive and act upon, which has historically enabled them to dismiss psychiatric patients’ experiences or discount reports of pain from patients of color [36]. Structural gaslighting is a closely related phenomenon, which describes “any conceptual work that functions to obscure the nonaccidental connections between structures of oppression and the patterns of harm that they produce and license” [37, p. 734]. In the case of brain death, hospitals and medicolegal professionals abuse their structurally bestowed epistemic privilege to force people into accepting a uniform definition of death. This constitutes a type of structural gaslighting, since lay folks are made to think that their resistance to brain death contradicts some empirically verified justification for the metaphysical reality of brain death as death. For example, the chief medical officer of the hospital that Jahi was initially admitted to refused the family’s request for a feeding tube because it would only add to the “illusion that she is not dead” [3, p. 7]. However, no such empirical justification for brain death exists that would warrant such dismissal of the family’s belief in Jahi’s continued life. Although clinicians often have legitimate epistemic access to medical knowledge that lend credence to their decisions, *the diagnosis of brain death creates a skewed dynamic in which*

the clinician makes an overriding metaphysical determination of death that families erroneously perceive to be supported by scientific expertise. However, a growing number of people are realizing that brain death is not a scientifically discovered category, but a constructed concept deployed to further institutional interests in increasing organ donations and freeing up hospital resources. Unfortunately, few families feel that they can defy the structural power of medicolegal authority and are eventually forced to accept the neurologic determination of death.¹

A social justice ameliorative project

Having identified the harms that arise from the brain death standard, I propose a two-part ameliorative project that seeks to conceptually engineer death in a way that respects people's personal views of death. Imposing brain death as a universal neurological criterion should not come at the cost of depriving people of their choice in what they determine to be death. First, I propose a revision to the diagnostic criteria for death that operates under a choice-based system that accounts for each patient and family's personal convictions about death [44]. This ameliorates the structural injustices perpetuated by physicians who override families' resistance to brain death by creating the conceptual space for different metaphysical definitions of death to coexist. One example of such a 'case for choice' would be Lazaridis and Ross's proposal for an opt-out system in which families are given the choice to opt-out of the neurologic criteria for death and conform only to the cardiopulmonary standard, or default to keeping both [45]. They also discuss a non-exhaustible range of different standards, including the organismic inability to resist entropy and maintain homeostasis, the irreversible cessation of all brainstem functions, and the irreversible loss of capacity for consciousness. The pluralistic use of such criteria ensures that families' choices can be regulated within certain bounds of plausible standards while also allowing them the freedom to make a personal choice about determining death. Furthermore, clinicians can proactively elicit and accommodate patients' and families' beliefs about death and inform them of their options in order to work cooperatively towards a criteria of death that would best conform to their beliefs

¹ One might wonder if the circulatory criteria for death could also be perceived as promulgating conceptual injustice. Although the full conceptual analysis of and debate over circulatory death as death remains outside the scope of this paper, there is indeed tenuity in determining the 'irreversible' cessation of circulatory functions (e.g. does reperfusion of the heart after declaration of circulatory death for organ procurement count as the irreversible cessation of circulatory functions?) [38–40]. One could argue that the determination of circulatory death is subject to patients' decisions to refuse chest compressions, extracorporeal membrane oxygenation (ECMO) and other normative reasons (often less related to ulterior institutional motives), thus making circulatory death a conceptual fiction. Regardless of the one's views about circulatory death as fiction, circulatory death is widely accepted and less controversial than brain death, which has faced opposition from many families who have been wrongfully led to believe that their refusal to accept brain death is unscientific and medically untenable [3, 41–43]. The unique harms incurred by these families who have been forced to remove life-sustaining treatment from loved ones they believe were alive makes the application of conceptual injustice particular to the imposition of the brain death standard.

before a life-threatening event occurs. If the patient is in a state of irreversible apneic unconsciousness without prior expressed conditions for a death diagnosis, clinicians should turn to families or surrogates using similar protocols for other substituted medical decisions, such as continuing life-sustaining treatment for patients in a vegetative state. For unrepresented, irreversibly unconscious patients without prior information about their beliefs about death, a default definition of death may be necessary. Empirical evidence regarding people's preferences in defining death may shed further light on this issue, but until then, hospitals should adopt the 'safest' definition of death that would protect highly vulnerable patients, respect their personhood, provide appropriate care, prevent undue biases and avoid conflicts of interest, as outlined in the multi-society statement on treating unrepresented patients from the American Thoracic Society and the American Geriatric Society [46]. Adopting the circulatory criteria of death as a default definition may cause an ICU bed and resources to be taken up by a patient who would have considered themselves brain dead for a few days to weeks. However, adopting the brain death standard as default may cause a clinician to commit the grave moral error of withdrawing treatment from someone who would have considered themselves alive, if irreversibly unconscious. Neither outcome is desirable, but in this non-ideal situation where the hospital cannot be 'death-neutral,' circulatory death as the default standard better situates the clinician to make decisions that protect their highly vulnerable patient without compromising with financial or institutional interests to save resources. Hospitals and clinicians should ensure that patients have earlier conversations about their values and beliefs about death with their providers so that these non-ideal decision-making scenarios do not arise.

Secondly, the dead-donor rule ought to be revised to legally permit exceptions for organ donors who are irreversibly unconscious but not declared dead [33]. This 'living-donor' exception enables families to allow for their loved one's organs to be donated without having to commit to the fictionalized notion that they are dead. Revising the dead-donor rule is a natural consequence of reexamining death as a relevant ethical issue in procuring organs. Truog and Miller argue that the patient's consent, rather than the tenuous determination of their death, is the key to ethical organ procurement, as death is not only definitionally elusive but also not considered an ethical barrier to many other medical decisions in critical settings, such as the withdrawal of ventilators [47]. Other critics of the dead-donor rule have similarly argued that respect for patient's wishes for organ donation should be prioritized over the inadequate and sometimes contradictory methods of declaring the "irreversible" cessation of heart, lung, and brain functions [48–50]. Most recently, debates about a new organ transplant protocol reperfusing the heart of an organ donor after circulatory death (termed normothermic regional perfusion) once again recapitulate seemingly intractable arguments about whether a patient is 'truly' dead: a problem that can be solved with a 'living-donor' revision that allows clinicians to focus on the relevant ethical issue of the patient's consent for organ procurement [40, 51].

I now test my proposal against Podosky's criteria for successful social justice ameliorative projects to prove its conceptual and pragmatic merits in advancing social justice goals [52]. Firstly, Podosky asserts that it must be possible to deliberately implement a conceptual engineering proposal in large communities by

asserting control over the conceptual change. Given that the proposed improvement is the acceptance of multiple death-concepts within the medical setting, this requirement can be achieved by implementing procedures for clinicians to have conversations with their patients about determining their own death. These conversations may take place around the time that advance care planning, code status, and end-of-life preferences are often discussed, and ideally well before the patient experiences a critical illness. Clinicians can frame the medical decision by offering neutral descriptions of circulatory and brain death (e.g. the irreversible cessation of heart and lung function, or brain functions) and solicit the families' understanding about what they or the patient believes constitute death. The clinician should follow the same practices as advance care and code status discussions by not imposing their own views about death on families, providing relevant medical knowledge and exploring patients' values and beliefs in relation to defining death. Hospitals can formalize this process by modifying death forms and advance directives to include brain death and circulatory death as separate options that clinicians can select and document based on patient and family beliefs. Although not everyone may consistently adhere to the guidelines in practice, the process should be transparent enough so that we can scrutinize and correct those who do not follow the procedures.

Secondly, it must be possible to bring about change to extant social categories. Again, by revising the classification of death to accommodate a plurality of death diagnoses, society can reinforce the deconstruction of brain death as a natural kind and help the public understand the normative nature of medically determining death. The possibility of this goal is demonstrated by the many cases of families opposing the concept of brain death as death, thus indicating that at least some members of the public are amenable to the conceptual engineering of death [3, 41–43].

Thirdly, the conceptual engineering proposal should be adopted for the right reasons. There are at least three moral motivations for adopting this project: (1) to mitigate the epistemic injustices and pragmatic harms that result from structurally gaslighting families who are resistant to brain death; (2) to obtain more robust consent from families before declaring their loved ones dead; (3) to cultivate physician–patient–family relationships that are founded on trust, care and respect for individualized notions of death [53]. Podosky's fourth and final condition for a successful social justice ameliorative project is that the project fulfills the first three conditions without producing harmful consequences. A response to this condition warrants a section of its own, which I will address by answering pragmatic objections to my proposal.

Answering objections

Objection 1: decreased organ donations and increased resource depletion

Some proponents of brain death might argue that my proposal would not only cause families to abandon the neurological criteria for death *en masse*, but also create a significant drop in organ donation rates. After all, who would permit their loved one's organs to be donated if they are no longer considered dead? The picture

painted by the brain death proponent is a world in which intensive care units (ICU) overflow with irreversibly unconscious patients and organ donations plummet as families refuse to let their loved ones go. However, this does not seem to be the case for New Jersey, the only U.S. state that currently permits exemptions to the brain death criteria. Despite the fact that they allow families to reject brain death on religious grounds, they do not uniquely suffer from ICU overflow, and their organ donation rates are comparable to other states with similar population sizes [54–56]. Furthermore, surveys of public opinion demonstrate that most people are willing to donate their organs if they are in an irreversible coma, even if they are told that organ removal would cause their death and violate the dead-donor rule [57]. In fact, people's distrust in the brain death criteria correlates with less favorable attitudes towards organ donation, indicating the need for healthcare professionals to work more transparently with their patients about diagnosing their death if they want to encourage organ donations [58].

Despite these findings, some critics may continue to hold concerns that a nationwide change in death policy can have chilling effects on organ donation and burden hospital resources, perhaps with many more families holding onto their loved ones than in New Jersey. *However, the burden of proof is on the critics to promulgate evidence that choice-pluralism will lead to organ shortages and resource burdens: a claim that has yet to be substantively supported.* The diagnosis of brain death is rare, at around 2% of deaths in the United States, and of the likely minority of families who would keep the patient alive in an irreversible coma and withhold organ donation, most of their loved ones would eventually succumb to cardiovascular collapse in several days or weeks [59–62]. Given the statistical minority of families who would continue indefinite treatment, the evidence for widespread organ shortage and resource burden upon revising the determination of death criteria is unsubstantiated at best, and the improbable risk of such deleterious consequences is and should be outweighed by the conceptually and pragmatically ameliorative effects in allowing patients the freedom to define their own death.

Objection 2: a living-donor exception permits killing people for their organs

Regarding exceptions to the dead-donor rule, some scholars have argued that taking organs from people who are not declared dead is morally impermissible and contrary to the nature of medicine [63]. If patients are not declared dead before their organs are procured, the clinician would essentially be killing a living patient, which constitutes an immoral use of medical power. However, the purpose of the living donor exception is not to permit the nefarious killing of patients for their organs, but rather to allow patients to consent to organ procurement (and their subsequent death) without forcing them or their families to accept brain death as death. As argued in this article, the question of whether a patient is 'truly' dead before organ procurement is conceptually obscure and secondary to the salient ethical matter of respecting the patient's wishes for organ donation upon neurological devastation, *even if* it would cause their death. The moral calculus to weigh the conceptual and pragmatic benefits of donating organs after massive and irreversible neurological injury against the

harm of dying from organ procurement is one that patients ought to make for themselves. The living donor exception is a legislative solution that grants patients the autonomy to stay true to their beliefs about death and avoid having particular conceptions about 'true' death imposed upon them. The rule also helps clinicians avoid needless conflicts with families about their beliefs about death, and instead focus on clarifying their beliefs and granting moral respect to patients' expressed desires to donate their organs when they fall below a certain threshold of lively existence [64]. For example, the neurological criteria for brain death can still be used as a threshold to permit organ donation from patients whose brains are irreversibly damaged without actually diagnosing them as dead. There is no diagnostic difference between procuring organs from brain dead declared patients or patients with irreversible apneic unconsciousness, since both meet the same diagnostic criteria that allows for organ donation. However, the latter diagnosis avoids the conceptual fiction and epistemic injustice that may occur with the former option's insistence on calling the patient dead.²

Objection 3: lack of a unified definition of death decreases trust in the healthcare system

Finally, one might object that accommodating pluralistic conceptions of death may lead to the potential for abuse, and that the lack of a unified standard for determining death would ultimately decrease people's trust in the healthcare system. The first concern is that if patients lack prior expressed preferences for their death diagnosis, having clinicians consult with their families creates the potential for ill-willed family members to diagnose an earlier or later death to further their personal interests. However, this is not an issue that is unique to diagnosing death, but a worry about surrogate decision-making in general, which ought to be addressed with a robust theoretical and pragmatic framework to ensure that surrogates act in the patient's best interest. Furthermore, families' choices in diagnosing death would still be limited to a certain (albeit expanded) range of testable criteria to ensure that they are not completely arbitrary or unreasonable according to medical standards.

The second concern is that the variability in determining death undermines public trust in healthcare institutions' ability to make consistent judgments. However, worries about inconsistency should be directed towards the current variability in a patient's death diagnosis between different states, as well as between different

² If there is no diagnostic distinction, one might argue in favor of defaulting to a circulatory criterion of death and abolishing the dead-donor rule, which means that the diagnosis of brain death would never have to come into play for families to consider organ donation. However, this criteria excludes the beliefs of families who do believe in brain death and organ donation after death, and who would be forced to accept the conceptual mistruth that they are donating the organs of their 'living' loved one whom doctors refuse to declare (brain) dead: a process that will be as equally absurd, offensive, and traumatic as it is for families who are gaslit into believing their permanently unconscious loved ones are dead. Thus, the purpose of choice in the determination of death is not just a practical-legal matter, but also a socio-ethical and conceptual matter about respecting patients' and families' decisions to mark closure and choose how certain 'death-functions' are triggered, whether they be based on circulatory death or brain death.

hospitals and clinicians who practice varying protocols for brain death diagnosis [65, 66]. Even with the UDDA's attempt to provide a uniform standard of brain death, medical societies encourage practices that seem to actively contradict those legal standards by allowing for the preservation of hypothalamic functions in brain dead declared patients [18, 67]. This has led to absurd consequences for patients like Jahi who are considered dead in one state but alive in another. The solution is not to impose a uniform standard of death for all people across the country, but rather to ensure the consistency of death diagnosis for each individual across different states according to their personal beliefs. Public trust is ultimately gained by giving patients the agency to conceptualize their own standards of death regardless of their state residence, rather than forcing everyone into accepting the conceptual fiction of brain death.

Conclusion

Despite the growing recognition within the medical community about the conceptual tenuity of brain death, many hospitals, medical societies, and healthcare professionals have doubled down on the pragmatic benefits of keeping it as a medicolegal and philosophical category of death. Increasing organ availability and decreasing burdens on hospitals are framed as critical functions that may be fulfilled by brain death, but it does not justify the epistemic oppression and structural gaslighting of families who pose legitimate challenges to the diagnosis. The current bioethics literature does not adequately explore the conceptual injustices that underlie the controversy of brain death, and framing the debate as a metalinguistic dispute over which 'death-functions' to prioritize reveals the domination of institutionally valued functions over the people's valued functions. By offering an ameliorative project that can rectify these epistemic injustices and democratize the process of death-determination, I hope to provide a useful solution for lawmakers and clinicians as they reckon with growing public misgivings about brain death as a fictional concept.

Declarations

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