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PHILOSOPHICAL EXPLORATION

When Brain Death Belies Belief

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Abstract The case of Jahi McMath has reignited a discussion concerning how society should define death. Despite pronouncing McMath brain dead based on the American Academy of Neurology criteria, the court ordered continued mechanical ventilation to accommodate the family's religious beliefs. Recent case law suggests that the potential for a successful challenge to the neurologic criteria of death provisions of the Uniform Determination of Death Act are greater than ever in the majority of states that have passed religious freedom legislation. As well, because standard ethical claims regarding brain death are either patently untrue or subject to legitimate dispute, those whose beliefs do not comport with the brain death standard should be able to reject it.

Keywords Brain death · Religious freedom · Free exercise clause · Jahi McMath · Uniform Determination of Death Act

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The McMath Case

On December 9, 2013, Children's Hospital Oakland admitted 13-year-old Jahi McMath in order to undergo an adenotonsillectomy procedure. Following surgery, she was transferred to the pediatric intensive care unit. According to McMath's mother, Jahi bled significantly from her mouth postsurgery. She then suffered cardiac arrest, but remained in coma after successful resuscitation. Three days later, two hospital physicians declared McMath brain dead. At the family's request, three additional physicians who were not affiliated with Children's Hospital examined McMath and confirmed that she met the brain death criteria.

The hospital provided McMath's family with time to gather family members around her bedside to say their final goodbyes in accordance with the California Health and Safety Code §1254.4 requirement to provide next of kin with a "reasonably brief period of accommodation" prior to discontinuing cardiopulmonary support of a brain dead patient. On December 19, 2013, 1 week after the declaration of brain death, the hospital advised McMath's mother that it intended to discontinue ventilation. McMath's mother disputed the determination of brain death and commenced legal proceedings (see Winkfield v. Children's Hospital Oakland et al. 2013). On December 20, 2013, the Alameda County Superior Court granted a temporary restraining order that required the hospital to continue to treat McMath until further order of the court. As well, the presiding judge, Evelio Grillo, required the hospital to locate one of an identified group of acceptable independent physicians to verify or refute the medical diagnosis of brain death.

On December 23, 2013, the court extended the temporary restraining order to December 30, 2013. The next day, the court-appointed independent physician, Dr. Paul Fisher, confirmed that McMath met the criteria for brain death and the court declared her to be legally deceased. Despite this verification of the hospital's diagnosis, Judge Grillo extended the temporary restraining order for an additional week since McMath's family claimed that it was arranging to move her to a medical facility in New York. On January 3, 2014, the hospital and McMath's mother reached a settlement in which the hospital agreed to release McMath to her mother's care. Two days later, after the Alameda County Coroner issued, but did not publicly release a death certificate for McMath, McMath's family moved her to New Jersey, the only state that recognizes a religious exemption to brain death diagnoses. She remains there on life support more than 2 years later. McMath's lawyer has brought an application to have her death certificate declared invalid based on evidence of intact brain structure and intracranial blood flow.

In the aftermath of the case, academics and clinicians have focused primarily on the degree to which brain death equates with biological death, and whether it constitutes good public policy. Some scholars attributed the McMath controversy, which garnered significant media attention, to the public's misunderstanding of brain death. Numerous bioethicists acknowledge that brain death and biological death are not identical. Brain dead humans have functioning vital organs, continue to digest and excrete, grow and develop, and can even reproduce. Many see the brain death concept as necessary to facilitate the donation of viable organs while concurrently deeming the donor legally dead. Some also argue that, despite some biological functioning, a brain dead person is "as good as dead" since recovery of consciousness is either impossible or extremely unlikely (see, for example, Bernat and Larriviere 2014). However, this is a normative claim regarding which lives have value and ought to be preserved rather than a mere diagnosis, which may conflict with personal beliefs that death does not occur until circulation and respiration have irreversibly ceased.

While most of the academic literature that was published in the aftermath of the McMath case has focused on the validity of the brain death diagnosis, analysts have paid less attention to the right of the individual to reject the concept of brain death on religious or secular grounds. From a medical standpoint, at the time that the Court declared Jahi McMath dead, there was no clinical evidence before the court that she failed to meet the brain death criteria. What makes the McMath case particularly unique is that even after Judge Grillo ruled that the young girl was unequivocally brain dead, he extended the restraining order that prevented the hospital from removing her from life support. Yet, if McMath was dead in the eyes of the law and the medical community, such an extension seems inappropriate. The only apparent basis for doing so was to accommodate her family's belief that McMath was not biologically dead based on religious grounds even though California law has no provision for such an exemption.

The Potential for a Legal Challenge to Brain Death

Twenty-six years ago, successfully challenging the legal definition of death on religious grounds was unfathomable. The US Supreme Court had rendered its decision in *Employment Division, Department of Human Resources v. Smith* (1990). The court held that neutral laws of general applicability that fetter the exercise of religious freedom were not unconstitutional provided that they were not specifically aimed at curtailing religious freedom. Since the stipulation in section 1 of the US Uniform Determination of Death Act of 1981 (1993/1997) ("UDDA") that "irreversible cessation of all functions of the entire brain, including the brain stem" constitutes death was not intended to specifically restrain religious belief, it would have been difficult to argue that state laws based on the UDDA violated the Free Exercise Clause of the First Amendment, which reads, "Congress shall make no law…prohibiting the free exercise thereof [i.e., of religion]".

However, the legal landscape and public attitudes toward diversity, which influence the courts, have changed dramatically since the *Smith* decision. Today, the success of such a religious freedom challenge to the brain death standard is conceivable given the judiciary's recent trend toward favoring autonomy, and statutes that protect the exercise of religion even if the law involved is of general application. Yet, to fully understand the potential for a successful legal challenge to the UDDA definition of death, which all states have adopted with slight variation, it is first necessary to understand how religious freedom claims have evolved under United States law.

Constitutional Claims Concerning the Free Exercise of Religion

The Supreme Court first interpreted the Free Exercise Clause in the 1878 case of *Reynolds v. U.S* (1878). The defendant, George Reynolds, who was secretary to Brigham Young, was indicted under a federal anti-bigamy statute for having multiple wives. Reynolds argued that this law violated his right to freely exercise his religious beliefs since he had a faith-based duty to practice polygamy. The Supreme Court confirmed that the Free Exercise Clause guaranteed religious freedom, but found that although this constitutional provision encompassed religious opinion, it did not protect actions that violated social duties or undermined good order. The Court further denied that polygamy was within the purview of the First Amendment since the practice "has always been odious among the

northern and western nations of Europe." (164). The court expressed concern that if it granted a religious exemption for polygamy, it "would permit every citizen to become a law unto himself." (164). Twelve years later in *Davis v. Beason* (1890), the Supreme Court reaffirmed its narrow interpretation of the Free Exercise clause. It upheld an Idaho statute that prevented bigamists and polygamists from voting or holding property since the "free exercise of religion…must be subordinate to the criminal laws of the country…" (333).

The Supreme Court's interpretation of the Free Exercise Clause changed dramatically in the case of *Sherbert v. Verner* (1963). The plaintiff was a member of the Seventh-day Adventist Church whose employment was terminated because she refused to work on Saturdays due to her religious beliefs. Sherbert applied for unemployment benefits, but the South Carolina Employment Security Commission denied her claim because she was not considered to be available for employment due to her refusal to work on Saturdays. In response, Sherbert initiated a legal action against the Commission in which she argued that her constitutional right to freely exercise her religious beliefs had been violated. The Supreme Court implemented a four-pronged test to determine whether a law withstood a constitutional challenge based on the Free Exercise Clause:

1. for a claimant to succeed, his or her religious belief had to be sincere;
2. the government provision that impeded the exercise of the religious belief had to be a substantial burden;
3. even if there was a substantial burden, the provision would still be upheld if it served a compelling state interest; and
4. even if there was a compelling state interest, the provision had to pursue that interest in a manner that was the least restrictive to the exercise of the religious belief in question.

The Court held that South Carolina's refusal to pay unemployment benefits to Sherbert was a substantial burden on the exercise of her sincere religious beliefs and that the state's interest in preventing fraudulent claims for benefits based on the potential for feigned religious beliefs was not compelling. Citing *Thomas v. Collins* (1945), the Court defined compelling state interests narrowly, stating that "only the gravest abuses, endangering paramount interests" (530) would justify limitations on exercising religious beliefs.

The *Sherbert* test would remain the law of the land until the aforementioned *Smith* case in 1990. In that case, the plaintiffs, Smith and Black, were Native American counselors at an Oregon drug rehabilitation clinic who were fired because they had consumed peyote, a hallucinogenic drug, at a religious ceremony. Under criminal law, the possession of peyote constituted a felony. Because their employment was terminated due to this alleged misconduct, the state denied Smith and Black's claims for unemployment compensation. In response, the two commenced legal action against the state Department of Human Resources claiming that their rights to freely exercise their religious beliefs had been violated.

The Supreme Court held that the *Sherbert* test only applied in situations involving individualized government assessment of claims rather than laws of general applicability, such as criminal laws. The Court held that a right of free exercise does not obviate an individual's obligation to comply with neutral laws of general applicability. Therefore, such laws are valid even if they do not serve a compelling government interest. The Smith case marked a return to the Court's original, narrow interpretation of the Free Exercise Clause in *Reynolds v. U.S* (1878).

In response to the unpopular *Smith* decision, the federal legislature enacted the *Religious Freedom Restoration Act* (1993) ("RFRA"), which attempted to reinstate the *Sherbert* test. It provided that "government shall not substantially burden a person's

exercise of religion even if the burden results from a rule of general applicability" unless it can demonstrate that the burden "is in furtherance of a compelling government interest" and "is the least restrictive means of furthering that compelling government interest" (§2000bb-1). However, the reinstatement of the *Sherbert* test was short-lived. In the case of *City of Boerne v. Flores* (1997), the Supreme Court held that RFRA exceeded Congress' power. While it is true that the Free Exercise Clause is applicable to states by its incorporation into the fourteenth amendment and the amendment itself provides Congress with the "power to enforce, by appropriate legislation, [that amendment's] provisions", the Supreme Court held that "legislation which alters the meaning of the Free Exercise Clause cannot be said to be enforcing the Clause" (519). Although the ruling prevented Congress from imposing RFRA on states, the statute was later held to be constitutional with respect to federal laws (*Gonzales v. O Centro Espirita Beneficente Uniao do Vegetal* 2006). In response to these developments, approximately 30 states have either enacted legislation with content similar to RFRA or have been subject to court decisions that interpreted state constitutional provisions as requiring a strict scrutiny approach to denying religious freedom (Eilperin 2014).

In the decision of *Burwell v. Hobby Lobby Stores, Inc.* (2014), the Supreme Court considered whether certain provisions of the Patient Protection and Affordable Care Act (2010) violated RFRA. In assessing whether RFRA applies to federal laws that regulate closely held for-profit corporations, the Court held that RFRA is not necessarily tied to a pre-*Smith* interpretation of the Free Exercise Clause. In its submissions in *Burwell*, the United States Department of Health and Human Services argued that RFRA essentially codified the pre-*Smith* cases that interpreted the Free Exercise Clause, none of which implied that corporations had free exercise rights. However, the Supreme Court rejected this argument and held that "exercise of religion" should be interpreted more broadly than as a mere return to pre-1990s case law. The Court noted that following *Boerne*, Congress amended the definition of "exercise of religion" so that it did not reference the First Amendment and instead defined it as including "any exercise of religion, whether or not compelled by, or central to, a system of religious belief" (Religious Land Use & Institutional Persons Act, 2000, s. 2000cc-5(7)(A)). Moreover, Congress directed that these provisions "be construed in favor of a broad protection of religious exercise, to the maximum extent permitted by the terms of this chapter and the Constitution." (2762). The Supreme Court stated that RFRA goes "far beyond what this Court has held is constitutionally required" (2767) in terms of protecting religious liberty. This represents the broadest interpretation of the free exercise of religion that the USA has ever witnessed.

Brain Death, Religious Freedom, and the Legal Landscape

In light of the current legal landscape, what are the prospects for challenging the neurologic criteria of death provisions in the UDDA on grounds of religious freedom? In states that have not enacted an RFRA equivalent statute or do not have state constitutional provisions that require strict scrutiny, a challenge to the provision that allows physicians to pronounce someone dead based on a diagnosis of brain death would be subject to the narrow interpretation of the Free Exercise Clause reflected in the *Smith* decision. Because UDDA provisions constitute a neutral law of general applicability that do not specifically target a religious practice, a challenge to the brain death conception would likely fail. However, in order to reconcile its decision with past case law in which the Supreme Court

affirmed Free Exercise Clause challenges to laws of general applicability, the *Smith* court did state that such laws could be successful if some other constitutional right, in addition to the right of free exercise of religion, was also involved (881). In brain death cases, one could argue that the rights to life and liberty contained in the Due Process Clause of the 14th Amendment would fulfill this requirement. This would raise the interesting legal and moral issue of whether or not someone who is declared brain dead has life or liberty interests that can be violated. Even if the patient's advocates could convince the Court that a *prima facie* due process violation had occurred, they would face the difficult task of satisfying the 14th Amendment requirement that the right of a brain dead patient to have his or her life artificially prolonged was "deeply rooted in the nation's history" (*Washington v. Glucksberg* 1997).

In the majority of states that do have RFRA equivalent provisions, the prospects for a successful challenge to the brain death standard based on religious grounds are much brighter. Under the *Sherbert* test, a claimant would need to establish that his or her religious belief that someone is alive until the heart stops beating is sincere and that the UDDA provision concerning brain death substantially burdens the exercise of this religious belief. The "sincerity of belief" standard requires that the religion belief system occupy a meaningful place in the life of the claimant (*US v. Seeger* 1965). Courts must limit their inquiry to whether or not the belief is sincerely held and cannot evaluate the truth of the religious beliefs (*U.S. v. Ballard* 1944). In the McMath case, the Court did not question the sincerity of McMath's family's religious belief in the denial of brain death even though such a belief is principally limited to a small minority of the population (i.e., some Orthodox Jews, Buddhists, Muslims, Native Americans, and Shinto sects) (Pope 2015). However, as mentioned previously, religious exercise under RFRA is interpreted very broadly to include actions that are not compelled by, or central to, a system of religious belief. This suggests that a Christian who held a spiritual belief that death did not occur until the heart stops beating is entitled to the free exercise of this belief even if it is not considered part of Christian doctrine.

Once a believer's sincerity is established, requiring someone to accept brain death as legal death against his or her religious beliefs creates a substantial burden on free exercise rights. Thus, in order to uphold the brain death standard, states with RFRA-like provisions would have to demonstrate that there is a compelling state interest that justifies the burden on a person's religious belief. Commonly cited interests that states could raise include promoting the uniformity of the brain death standard across states (Delaney 2010) and maintaining the integrity of the medical profession, which would be jeopardized by requiring hospitals to treat patients that are dead (Luce 2015). While promoting legal uniformity across states is a laudable goal, it does not seem sufficiently compelling to justify the infringement of religious freedom. After all, many legal standards vary from state-to-state, including the RFRA provisions. In fact, there is already variation in the brain death standard among states with New Jersey providing a religious exception to the determination of death by neurologic criteria and California, Illinois, and New York requiring hospitals to reasonably accommodate religious objections to brain death (Pope 2015).

It is also important to note that while the UDDA provisions standardize the definition of death in all 50 states, subject to the exceptions mentioned above, it does not specify a uniform means of diagnosing brain death. Though the UDDA does state that declarations of death should be made in accordance with accepted medical standards, it is not clear what those standards are. The most likely candidate would be the American Academy of Neurology ("AAN") guidelines. However, in the recent case of *In re Guardianship of*

Hailu (2015), the Nevada Supreme Court expressed doubt as to whether the AAN provisions are an accepted medical standard.

The *Hailu* case also highlights the fact that accepted medical standards may vary from state-to-state despite the UDDA. The Nevada Supreme Court stated that it is necessary to determine what the accepted medical standards are *in Nevada* and considered legislative intent to determine what this might be (12). Thus, despite a uniform definition of death, the brain death standard could still be applied differently in certain states, which undermines claims of uniformity. While standardizing the determination of death across states is a worthy aim, the UDDA does not accomplish this, and even if it did, that aim does not meet the Supreme Court's stringent requirement that the religious exception to a compelling state interest would endanger paramount interests.

Medical integrity may fair better as a potential compelling state interest that would justify upholding the UDDA brain death standard. Although Jahi McMath's family managed to find care givers that would treat the brain dead teenager, health care professionals commonly declare that being forced to treat a dead patient contravenes their ethical principles. Setting aside the issue of whether or not the patient is actually dead considering that biological functions continue, a government's interest in maintaining the integrity of the medical profession has not been particularly definitive in court cases involving a patient's autonomy rights. In *Cruzan v. Director, Missouri Dept. of Health* (1990), the Supreme Court listed four state interests in case law relating to medical treatment, including the integrity of the medical profession. However, the Court specified that, of these, a state's interest in preserving life is paramount. Despite this, the Court held that a patient has a right to refuse medical treatment regardless of these state interests. Seven years later in *Washington v. Glucksberg* (1997), the Supreme Court refused to extend Due Process Clause rights to include the recognition of a terminal patient's right to physician-assisted suicide. While the Court declined to weigh the six different state interests it discussed, it did say that physician-assisted suicide is inconsistent with the physician's role as a healer. The Court emphasized the importance of not blurring the line between healing and harming, and maintaining trust in the doctor-patient relationship (731), both of which factors are absent in brain death cases.

Two subsequent cases concerning abortion legislation also involved the government interest in maintaining the integrity of the medical profession. In *Gonzales v. Carthart* (2007), the Supreme Court upheld a federal ban on "partial-birth" abortions based on the government interest in avoiding fetal pain and medical integrity. In *Isaacson v. Horne* (2013), the Ninth Circuit Court of Appeals held that Arizona's statute that prohibited abortions at 20 weeks gestation was unconstitutional because it deprived a woman of the choice to terminate her pregnancy when the fetus was not yet viable. Although the state argued that it had the same interests in mind as were held to be decisive in *Gonzales*, the Court did not find this persuasive in *Isaacson* and the Supreme Court refused to review the decision.

Based on this line of precedent, it is debatable whether a state's interest in maintaining the integrity of the medical professional is sufficiently compelling in the context of a person's right to define death in accordance with religious tenets. Except in relation to physician-assisted suicide, which involves terminating rather than prolonging biological functioning, the interest has not been particularly forceful. The professional integrity argument is also undermined by the fact that physicians routinely provide medical care to those who are declared brain dead in order to facilitate organ donation. This often includes providing nutrition and hormonal support treatment in order to maintain organ quality until procurement for transplantation occurs, which recognized medical associations and

societies endorse (Kotloff et al. 2015). Such care may continue for days. Also, a US survey found that 85 % of physicians would find it "very or somewhat appropriate to comply with the family's request to continue life-sustaining treatment" based on a religious objection to the concept of brain death (Ayeh et al. 2016). The lack of the medical community's concern over this treatment of those considered dead under the UDDA suggests that the integrity of the medical profession is not impugned and that this interest is not sufficiently compelling to override the exercise of religious beliefs.

If the RFRA protects religious liberty far beyond what the Constitution requires, as the Supreme Court stated in *Hobby Lobby*, the religious view that death does not occur until the heart stops beating seems paramount to potential compelling interests. As well, given that the *Cruzan* Court held that a state's interest in preserving life is of the utmost importance, the fact that those who are declared brain dead may still function biologically may aid the position of the person asserting a religious rights claim. Of course, the pendulum of religious freedom rights may swing again to a narrower interpretation of the Free Exercise Clause, and a change in the composition of a highly divided Supreme Court could greatly alter the prospects for a challenge to the UDDA definition of death. However, given the current legal landscape, such a challenge has a better chance of success than it has ever had in the past.

The Normative Case for a Brain Death Exemption

Whether or not a constitutional challenge to the neurological criteria of death provisions of the UDDA on grounds of religious freedom would be successful is one issue. A separate issue is whether a religious exemption *should* be granted. This normative question has been peripheral to the academic debates that have resurfaced in the aftermath of the McMath case. However, the normative issues are very important for the viability of the religious exemption since society typically holds that certain spiritual claims be based in truth, or at least not be obviously false. Thus, a constitutional claim based on freedom of religion that rejected cardio-pulmonary death as biological death would likely fail since it does not conform with our scientific knowledge that the irreversible cessation of blood circulation and breathing does, in fact, constitute death. If it is a fact that brain death is likewise equivalent to biological death, then a religious claim that denies this is problematic.

Those who support the neurological criteria of death found in the UDDA make several factual and normative claims concerning the brain death standard that, if true, could undermine the religious view that brain death is not akin to human death. These include the following assertions: (1) Someone who is brain dead is biologically dead, or, in the alternative, he or she is "as good as dead"; (2) the brain death standard is an uncontroversial, factual reflection of scientific reality; and (3) the brain dead cannot be harmed. We will argue that because all of these claims are either patently untrue or subject to legitimate dispute, those whose beliefs do not comport with the brain death standard should be able to reject it.

Brain Death and Biological Death are Distinct

Historically, neurologists regarded brain death as biological death since it represented the irreversible loss of integrated functioning of the human body (President's Commission 1981). However, in the face of evidence that the body's integrated functions, including

circulation, growth, and healing, are not brain-mediated (Shewmon 2001) and that those declared brain dead may continue to exhibit somatic integrative unity (Verheijde et al. 2009), this position is not supported. This becomes problematic for brain death standard proponents since if a brain dead patient is biologically alive, then declaring him or her dead must be based on a judgment regarding what constitutes personhood and what gives a biologically functioning human being value and moral standing. However, this is not a scientific assessment. Rather, it is a moral determination that should be aided by an appeal to the scientific facts, but must ultimately be addressed as a normative rather than a merely medical issue.

Instead of explicitly acknowledging the normative component of the brain death standard, the President's Council on Bioethics (2008) simply chose to re-define brain death. The Council acknowledged that in the absence of sufficient clinical and pathophysiological evidence, it was no longer tenable to assert that brain death was equivalent to biological death. To remedy this dilemma, the Council postulated a new philosophical underpinning of the concept of brain death, arguing that brain death does equate with human death because it represents the "cessation of the fundamental vital *work* [their emphasis] of a living organism—the work of self-preservation, achieved through the organism's need-driven commerce with the surrounding world." (President's Council on Bioethics 2008, 60). This vital work requires "receptivity to stimuli", "the ability to act upon the world to obtain selectively what it needs", and "the basic felt need to act as it must [and] obtain what it needs" (President's Council on Bioethics 2008, 61). By defining brain death in this manner, the Council was able to justify the rationale for why someone in a persistent vegetative state ("PVS") who meets this newly defined threshold is indeed alive, but someone declared brain dead does not.

Whereas the proposition that the brain mediates integrated functioning of the body is a factual assertion, the replacement notion of "vital work" is value-laden. For some reason, the President's Council believes that the PVS patient's ability to swallow liquid, or have sleep and wake cycles, constitutes vital work (President's Council on Bioethics 2008, 61), but a brain dead patient's ability to digest, grow, fight infections, and give birth does not. This dividing line between life and death certainly requires better justification than the Council's report provides.

Neurologists and bioethicists that support the neurologic standard of death are in essence claiming that although someone who is brain dead may not be biologically dead, he or she is "as good as dead". However, such an assertion exits the realm of the mere diagnostic and, instead, opens the door to the normative. While the medical community can provide the expertise and information necessary to fully understand the issue, it does not have a monopoly on determining the value of the lives of those without self-consciousness and bleak prognoses. Determining what a human's "vital work" should be or what constitutes being "as good as dead" is a conversation that should involve those outside the medical community and is arguably open to individual interpretation and choice, particularly when someone rejects the brain death concept. In the realm of the normative, a person may hold a religious or secular view that a patient that is biologically functioning has moral worth and should be afforded medical care. The fact that the brain death standard has significant normative content entails providing people with all of the available medical facts and allowing them to make the appropriate decisions. A patient's family's informed consent requires that medical practitioners provide all relevant information. This can include an opinion regarding the permanence of the patient's state and the very poor prognosis, but it should not, as Paris et al. (2014) suggest, simply involve informing the family that the brain dead patient is

dead so that there is no decision to make. This is disingenuous and substitutes the physician's value judgments regarding personhood for those of the patient and family who may have different conceptions of what constitutes death. Though this honest approach may have an adverse impact on organ donation in some circumstances, a medical community that is less than completely forthright with stakeholders could undermine and pose an even greater threat to the organ donation regime.

The Controversy Surrounding the Brain Death Standard

The claim by some that the brain death standard is simply an uncontroversial reflection of established neurology seems more and more untenable as the debate over the concept in the academic literature continues unabated. Still, there are physicians and bioethicists who continue to hold this position. As recent as 2014, Magnus, Wilfond, and Caplan asserted that "Brain death is now clearly defined by the neurological community…, standards for diagnosis are in place, and it is established by law" (893). Similarly, Burkle et al. (2014) have stated that "neurologic determinations of death and state laws concerning these matters are clear and unambiguous." They posit that the controversy over brain death is something that the media has fostered due to its misunderstanding of the concept and suggest that we need public education in order to prevent cases like McMath from reoccurring.

Yet, the controversy over the brain death standard is not simply a matter of the public being ignorant of the medical facts. It extends to legal and medical experts as well. Contrary to what Magnus et al. state, the concept of brain death is not clearly defined within the neurological community and its diagnosis is still subject to veritable legal disputes. While those authors point to the American Academy of Neurology's ("AAN") brain death guidelines as the accepted medical and legal standard, the Nevada Supreme Court recently questioned this in the aforementioned *Hailu* case.

In that case, Aden Hailu, a 20-year-old woman, attended St. Mary's Regional Medical Center in Reno, Nevada and complained of abdominal pain. During an exploratory laparotomy, she suffered an anoxic brain injury and remained in coma. The hospital conducted three EEG tests in the 2 weeks following the surgery that showed brain functioning; however, when the hospital performed an apnea test in the following month, Hailu's failure to breathe on her own led to a diagnosis of brain death. When Hailu's father refused to consent to the removal of life support and sought judicial relief, the District Court held that St. Mary's properly followed the AAN guidelines for determining brain death and refused to grant a restraining order against the hospital. However, on appeal, the Nevada Supreme Court held that it is not clear that the AAN guidelines are "accepted medical standards" under the UDDA. The Court particularly highlighted the fact that the guidelines do not require a confirmatory EEG test even though the AAN's own brain death study found that 84 % of actual brain death determinations include EEG testing. It also noted that in adopting the UDDA provisions into law in Nevada, the legislature made it clear that one of its key purposes was to ensure that there was absolutely no electrical activity in the brain prior to a declaration of death based on neurologic criteria. On November 16, 2015, the Nevada Supreme Court remanded the case to the District Court to hear more expert evidence concerning whether or not the AAN guidelines constitute "accepted medical standards", but the content of the judgment certainly casts doubt on the contention that the brain death standard is clearly defined. After Aden Hailu met the

criteria for cardio-pulmonary death in January 2016, the legal case became moot and the status of the AAN standard remains uncertain.

Even within the medical community, the brain death criteria are not consistently applied. Ghoshal and Greer (2015) analyzed four different studies of brain death declarations from 2002 to 2011, which found major inconsistencies regarding how hospitals applied brain death guidelines, what tests were performed, the qualifications of the examiners that conducted the tests, and the time frame between separate examinations. The most recent of these studies (Shappell et al. 2013), which involved chart reviews of 226 patients in 68 hospitals, found that only 44.7 % of the brain death determinations met AAN practice parameters. This is also consistent with Greer et al.'s (2016) report that brain death determination policies in the US hospitals vary widely and very often fail to meet the AAN guideline requirements.

These studies distract from the core problem of the serious scientific and legal flaws with the AAN standard itself by claiming that the problem is inadequate physician training regarding the proper application of the brain death guidelines. Based on a 2010 survey, Joffe et al. (2012) found that "American neurologists do not have a consistent rationale for accepting [brain death] as death, nor a clear understanding of diagnostic tests for [brain death]" (8). The authors acknowledge that patients declared brain dead may have poor quality of life, but suggest that this is a value judgment based on a patient's prognosis rather than a diagnosis of death. Even advocates of the neurologic criteria of death acknowledge that there is some ambivalence over the standard (Bernat 2014) and concede that it is not "grounded in biological reality" (Truog and Miller 2014, 9) since brain death and biological death are not equivalent.

Part of the problem stems from the fact that so little is understood about how the brain functions and how consciousness emerges from it. Fins (2015) equates the current state of neurology with the historical diagnosis of infectious diseases prior to the discovery of germ theory. Just as the use of fever curves was a primitive tool for categorizing disease, he argues that today's neuroimaging technologies "do more to deepen the mysteries of the mind than to resolve them" (41) and that "brain states remain descriptive, not explanatory categories based on knowledge of the actual physiology that produces the condition" (40). Though Fins (1995) emphasizes our limited knowledge concerning those brain injuries that are less severe than brain death and accepts the brain death standard, he does recognize its normative component and recommends that religious and secular perspectives that reject brain death should be accommodated. Kahn (2016) also argued in support of the reasonableness of accommodating religious and secular objections to the concept of brain death and posited that there is a "need for deep and careful consideration of matter pertaining to the intersection of religion and medicine" (1558).

We posit that the imposition of the brain death standard overestimates our current epistemic position regarding the brain and human consciousness. Contemporary neuroscientific research has raised serious questions about the extent to which we are able to accurately assess and measure the capacity for consciousness in the severely injured human brain. There is indirect evidence of a potentially high error rate that results from employing the AAN guidelines as a standard given a finding that 60 % of 41 brain dead patients examined on autopsy had normal or minimal damage to the brainstem due to ischemia (i.e., a restriction of blood supply to the area) (Wijdicks and Pfeifer 2008). In addition, patients can meet the criteria for a determination of brain death (i.e., unresponsiveness, the absence of brainstem motor reflexes, and lack of spontaneous breathing), but still maintain some neurological function (Nair-Collins 2010). Even when other confirmatory tests, such as electroencephalography, bispectral index, and somatosensory evoked potentials, are used

to confirm a brain death determination made in accordance with the AAN guidelines, there are multiple reports of neural activity even immediately after circulatory and cardiac death (Peterson et al. 2014). Thus, more research is required in order to determine whether these neurological findings are consistent with a determination of death and whether human consciousness is actually irreversibly absent in the brain dead patient. Because time delays with respect to the brain dead adversely impact the viability of their organs for donation purposes, these issues have been underexplored.

The Brain Dead can be Harmed

Proponents of the neurologic criteria of death often argue that even if brain death is not equivalent to biological death, the patient no longer has interests (Magnus et al. 2014) and lacks the capacity to experience harm, though this latter criterion also applies to the PVS patient (Robertson 2014). However, the contention that the brain dead cannot be harmed is typically assumed rather than argued. Yet, our intuitions often lead us to the opposite conclusion that even if the agent is biologically dead, he or she can be harmed in a variety of ways. For example, a person could fail to dispose of a deceased's personal property in accordance with her testamentary provisions. Likewise, one could promise to take care of a dying person's young children and then harm his interests by failing to do so postmortem. One could also unfairly disparage the deceased's reputation and harm him further. If it is true that one can harm the dead, then it seems just as true that one could harm the brain dead even if they do not experience the harm.

However, whether or not posthumous harm is possible is contentious. In order to argue that the dead can be harmed, it is necessary to overcome two hurdles: the experience problem and the problem of the subject (Sperling 2008). The *experience problem* is that it is difficult to explain how a person can be harmed if he or she does not experience the harm. This forms the implied basis for why many academics assume that the brain dead cannot be harmed. However, knowing about or experiencing a harm is not a necessary condition for being harmed. For instance, if someone slanders another person's reputation, but the person who was slandered is unaware of it and the defamation never impacts her experiences, we still feel as if she has been harmed despite not discovering it (Portmore 2007).

The *problem of the subject* is that it is unclear who is being harmed posthumously since the deceased no longer exists. Feinberg (1984) argued that it is the ante-mortem person that suffers harm even though the harm occurs postmortem since the person held interests that would eventually be defeated regardless of knowledge. Luper (2004) correctly criticized this view since in order for an event to harm us, if must affect us at some time. Yet, a person cannot be causally impacted by an event before it occurs, since this would result in backwards causation.

More recently, Luper (2013), who was historically one of the principal critics of posthumous harm, has argued that what he calls "strategic preferentialism" allows for the possibility of retroactive harm without backwards causation. Strategic preferentialism holds that if a person desires to accomplish an achievement that is essential to his or her life plan, and if that achievement is realized, even postmortem, then it is intrinsically good for her; if it is not realized, it is intrinsically bad for her. The view relies on an account of welfare that maintains that it is intrinsically good for us to get what we want. If strategic preferentialism is sound and a person's aim to only be declared dead on the basis of

circulatory and respiratory criteria constitutes an achievement desire, then a subsequent diagnosis of brain death against the person's ante-mortem wishes would be intrinsically harmful to her.

Even if strategic preferentialism is not a valid reply to the posthumous harm problem, there are other, less contentious bases for believing that harm occurs when someone is declared legally dead contrary to his or her beliefs. For example, if people routinely exhibited no respect for the dead and engaged in activities, such as grave robbery, it would be odd to say that no harm occurs since the dead are no longer self-conscious. Society as a whole would be harmed if its citizens consistently acted with disrespect for the dead. Surviving family members would suffer from observing the fate of their deceased loved ones. Those still living would worry about how they would be treated upon death and whether their wishes concerning the disposition of their assets and the care of their children would be fulfilled. Thus, even if there is no posthumous harm for the deceased, there is for the survivors and those who contemplate their eventual demise.

Similarly, a diagnosis of brain death that is inconsistent with the beliefs of the patient will harm the family members who share the same conception of death. While it may be unlikely that the living worry about whether or not their beliefs concerning brain death will be respected since the likelihood of the occurrence is rare, we should desire a society that respects the religious differences of its citizens when issues concerning divergent values arise.

Conclusion

If brain death was simply an uncontroversial diagnosis consistent with biological death, then religious and secular objections to the standard would be unfounded. However, this is not the case. What it means to be alive or dead is not always definitive. Instead of acknowledging this, our legal system has chosen to draw a line between people in similar states of consciousness and declare some of them to be living and others to be dead. Though this distinction is not completely arbitrary, it does involve value judgments that are subject to criticism. Because brain death has a normative component, we should consider permitting different conceptions of death that reflect and accept the divergent views of a pluralistic society. If the concept of brain death serves the public policy goal of realizing the benefits of organ donation, then it should also be modified to allow people to follow their religious beliefs and personal values when the medical facts are in dispute.

As the courts continue to face cases in which families reject the concept of brain death, the likelihood of a challenge to the standard based on a RFRA-based claim of religious freedom is increasing. In the wake of *Hobby Lobby*, the Supreme Court has interpreted the right to the free exercise of religion more broadly than at any time in the US history. With a very liberal interpretation of religious freedom and ongoing concerns with the brain death standard, the prospects for a successful challenge to the UDDA definition of death are greater than ever in the majority of states that have passed religious freedom legislation.

Compliance with Ethical Standards

Conflict of interest Mr. Yanke, Dr. Rady, and Dr. Verheijde all declare that they have no conflict of interest.

Ethical Approval This article does not contain any studies with human participants or animals performed by any of the authors.

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