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ORIGINAL RESEARCH

The Case for Reasonable Accommodation of Conscientious Objections to Declarations of Brain Death

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Abstract Since its inception in 1968, the concept of whole-brain death has been contentious, and four decades on, controversy concerning the validity and coherence of whole-brain death continues unabated. Although whole-brain death is legally recognized and medically entrenched in the United States and elsewhere, there is reasonable disagreement among physicians, philosophers, and the public concerning whether brain death is really equivalent to death as it has been traditionally understood. A handful of states have acknowledged this plurality of viewpoints and enacted "conscience clauses" that require "reasonable accommodation" of religious and moral objections to the determination of death by neurological criteria. This paper argues for the universal adoption of "reasonable accommodation" policies using the New Jersey statute as a model, in light of both the ongoing controversy and the recent case of Jahi McMath, a child whose family raised religious objections to a declaration of brain death. Public policies that accommodate reasonable, divergent viewpoints concerning death provide a practical and compassionate way to resolve those conflicts that are the most urgent, painful, and difficult to reconcile.

Keywords Brain death · Death · Conscientious objection · Reasonable accommodation

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Introduction

All fifty states in the United States of America have adopted into law two criteria for declaring death, in accordance with the criteria found in the Uniform Determination of Death Act: neurological criteria for whole-brain death, that is, the irreversible loss of all functions of the entire brain, including the brainstem, and circulatory-respiratory criteria, that is, the irreversible loss of all circulatory and respiratory functions.[1] Persons meeting the criteria for either definition of death are considered legally dead. Whole-brain death is a well-entrenched legal and medical orthodoxy, but it is not universally accepted by patients or their families. Several religious traditions and sects, among them Orthodox Judaism, Buddhism,[2]

[1] The international picture is more diverse. Most European countries have adopted a whole-brain death standard for declaring death, although the United Kingdom has a brainstem standard. Numerous countries have no laws defining the criteria for death or do not legally recognize neurological criteria. In some Asian countries, such as Japan and Singapore, the concept of brain death remains highly controversial.

[2] The Buddhist understanding of death is that it occurs when the body is bereft of three things: vitality, heat, and consciousness. There is some controversy over how these traditional indicators track with modern medical concepts, but many Buddhists, especially Japanese Buddhists, reject the criterion of brain death (Keown 2005). Many religions, including Buddhism, Confucianism, and Hinduism, are without centralized authorities or leaders to pronounce doctrine, making diverse interpretations possible. Several Islamic countries have accepted whole-brain death or brainstem death, but there is no international consensus on how brain death must be interpreted under Islamic law, and some Muslim juridical bodies reject brain death altogether (Padela, Arozullah, and Moosa 2013).

and some Native American traditions, do not recognize brain death as death but do accept the traditional circulatory-respiratory definition of death. While families and surrogates decide to withdraw life support in the majority of cases of brain death, when irresolvable conflicts arise between families and healthcare providers concerning such declarations of death, they require the intervention of the courts and attract much media attention. These controversies point to the need for recognition and accommodation of conscientious objections to whole-brain death, yet only a handful of states have legislated such "conscience clauses," which require "reasonable accommodation" of moral and/or religious objections to whole-brain death. Of those, only New Jersey specifically mandates that healthcare providers use circulatory-respiratory criteria for declaring death when patients or their families object to whole-brain death.

This paper will argue for universal adoption of reasonable accommodation policies modelled on New Jersey's statute. First, I'll assess whether there is reasonable disagreement when it comes to whole-brain death by examining current medical and philosophical controversies concerning the determination of death. Next, I'll discuss the Jahi McMath case, in which the family of a teenaged girl in California raised religious objections to a declaration of death by neurological criteria. I'll then examine existing "reasonable accommodation" policies in California, New York, and New Jersey, and consider how "reasonable accommodation" in defining death might be interpreted by looking at the "reasonable person" standard and federal laws that mandate "reasonable accommodation" in other contexts, and also consider the question of to whom reasonable accommodation applies. I'll then consider what definitions of death might be *prima facie* reasonable and merit accommodation. Finally, I'll show why reasonable accommodation is needed, and how a conscience clause modelled on New Jersey's statute can respect plurality and diversity, avoid conflicts over the determination of death, and have other ethically significant salutary effects as well.

Is There Reasonable Disagreement About Whole-Brain Death?

Since its inception, the concept of brain death has been contentious, and pronouncements of the impending death of brain death have been frequent. While whole-brain death is decidedly a matter of settled law, both in the United States and elsewhere, the matter has hardly been settled from a medical, moral, or philosophical standpoint.

Brain death is deeply counterintuitive and defies traditional, common-sense notions of life and death. The heart beats spontaneously, maintaining circulation in the brain-dead patient. With mechanical ventilation, respiration (that is, the exchange of oxygen and carbon dioxide) also continues. Indeed, "brain dead" persons are routinely kept on "life support" to maintain healthy, viable organs for transplant. Their bodies exhibit physiological stress responses to incisions made for organ retrieval. The brain dead "corpse" remains warm to the touch, it can move spontaneously, and many essential biological functions (digestion, waste excretion, homeostasis, thermoregulation, hormonal and immunological functions, spinal reflexes, etc.) can continue. Wounds develop and heal. Although in most cases the brain dead individual continues to "live" for a matter of days or weeks, longer survivals have been documented (Shewmon 1998). In rare cases, brain dead children have remained alive for years with minimal intervention, exhibiting both proportional growth and sexual maturation.[3] There are several cases in the literature of brain-dead pregnant women who were maintained on life support and gestated living fetuses (Miller and Truog 2009). It defies more than common sense to claim that a dead woman can gestate and give birth to a living infant.[4]

In 1968, the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death developed criteria for determining death in

[3] It is certainly contentious to refer to "life support" for a brain dead individual or to call that individual "alive," but such references will be made throughout this paper, to acknowledge that the medical and moral status of these patients is in dispute. It would be question-begging to simply call them "dead" and deny that they are receiving life support. "Physiological support" is an available alternative term, one that perhaps captures the dualistic proposition that the bodies of these patients are alive, but not their minds. However, "life support" is the more common terminology, used extensively, for example, in the President's Council white paper (President's Council 2008).

[4] In a 2014 case in Texas, a pregnant woman, Marlise Muñoz, was declared brain dead, but kept on life support to preserve the life of her unborn fetus. Her family objected, citing her wishes not to be kept alive in such a condition. The hospital in the case cited a Texas law that prohibits the withdrawal of life support from pregnant women. The family sued; a district court sided with the family and ordered the withdrawal of life support, noting that the law did not apply to the deceased, but only to living pregnant women (see *Erick Muñoz v. John Peter Smith Hospital*).

response to two developments in medicine: advances in intensive care that could maintain life in individuals with brain injuries resulting in irreversible coma, and improvements in the success of organ transplantation. By establishing a new way of being dead, the committee effectively killed two birds with one stone: life support could be legally withdrawn from hopeless cases, and an obstacle to procuring organs from heart-beating donors was removed. Indeed, the committee justified the neurological determination of death by citing these instrumental reasons, while declining to explain why brain death actually constituted death (Ad Hoc Committee 1968).

The latter task was taken up by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research in 1981, in its report *Defining Death* (President's Commission 1981). The commission's report laid the groundwork for the Uniform Determination of Death Act and established uniform diagnostic criteria for determining death, both of which led to the entrenchment of whole-brain death in law and medicine. The commission defined death as the moment when there is a loss of "integrative unity of the organism as a whole," and argued that the brain is a central integrator of the whole organism. When the entire brain ceases to function, so does the organism, and the "dis-integrated" organism is thus dead. The commission concluded that brain death and "ordinary death" are physiologically identical states, although the equivalence is "masked" in brain death by artificial life support, which creates the mere appearance of continuing life.

Shewmon called the Commission's reasoning into question, arguing that most integrative functions of the body are not brain-mediated (Shewmon 2001). Moreover, the diagnostic criteria for whole-brain death do not establish the absence of somatically integrative brain function, but rather "loss of consciousness, of cranial nerve functions and of spontaneous breathing" (Shewmon 2001, 465). While the Commission bolstered its conclusion by claiming that brain dead bodies inexorably and imminently deteriorate to cardiovascular collapse within a few days, this is less proof that brain death is a *diagnosis* of actual death than that it is a *prognosis* of imminent death. But even the imminence of death may be greatly exaggerated. Shewmon collected data on more than one hundred cases of survival in brain death exceeding a week, with one case of survival exceeding fourteen years ("and still going" at the time, although that patient succumbed to cardiac arrest after twenty years). Notably, many of the shorter duration survivals involved withdrawal of life support as the terminal event (Shewmon 1998).

In light of ongoing criticism of whole-brain death and clinical data that cast considerable doubt on the rationale put forth by the commission's report, a 2008 white paper by the President's Council on Bioethics revisited the brain death controversy and sought to establish a new rationale for equating brain death with death. The council stated that "total brain failure can continue to serve as a criterion for declaring death—not because it necessarily indicates complete loss of integrated somatic functioning, but because it is a sign that this organism can no longer engage in the essential work that defines living things" (President's Council 2008, 64). That essential work includes "self-preservation" and "need-driven commerce with the surrounding world." Breathing and consciousness are the two critical ways that this commerce is conducted, according to the council. The council argues that merely being unconscious (such as are persons in a coma or vegetative state) or merely being ventilator-dependent (such as are persons with high level spinal cord damage) is not sufficient for being dead, but being both unconscious and unable to breathe is. Thus, the ventilator-dependent, unconscious individual in total brain failure is dead.

Critics were quick to point out that, by this line of reasoning, anyone in a coma would be considered dead. Shah and Miller characterize the council's reasoning as "fallacious" and as offering no explanation for why persons who lack both consciousness and the ability to breathe unassisted are dead when other biological functions are being maintained (Shah and Miller 2010, 550). Miller and Truog argue that since neither unconsciousness nor lack of spontaneous breathing alone constitute being dead, the conclusion that having both characteristics constitutes death is "a *non sequitur*" (Miller and Truog 2009, 189). Indeed, while being unconscious and not breathing are surely *necessary* conditions of being dead, they are just as surely not *sufficient*, even when taken together, as there are decidedly living individuals who are unconscious, and who cannot breathe spontaneously. By the council's reasoning, a high cervical quadriplegic in a persistent vegetative state is dead despite evidence to the contrary.

In changing its terminology from whole-brain death to "total brain failure," the council also departs from uniform statutory definitions of whole-brain death as

"the irreversible cessation of all functions of the entire brain, including the brain stem," noting that islands of functioning brain tissue and minimal brain function may persist in the "brain dead" individual. This is consistent with earlier attempts by some whole-brain death defenders to argue that what matters is the "permanent cessation of the critical functions" of the brain (Bernat 1998, 18), which allows, for example, for hypothalamic functioning and continuing EEG activity in the dead brain. This interpretation departs from the statutory definition of whole-brain death. Such "fudging of the law" (Shah and Miller 2010, 549) *may* be consistent with the Uniform Determination of Death Act's statutory requirement that physicians make the determination of death *in accordance with accepted medical standards*, but declaring that whole-brain death is equivalent to death "is not a fudge, but an outright fiction" (Shah and Miller 2010, 549). It is, to be sure, a convenient fiction, but one beset by inconvenient truths.

It is little wonder that the tongue must be tied in knots to speak of the "brain dead." The council refers to the "brain dead" patient as a "heart-beating cadaver" exhibiting "something like health," with a mechanical ventilator "in essence, ventilating a corpse–albeit one that in many ways does not look like a corpse" (President's Council 2008, 3). It is difficult, in the face of medical evidence and common sense, to maintain that brain death is really, truly death, but there is ample evidence that whole-brain death is not even really, truly indicative of a completely dead brain (cf. Shewmon 2001; Halevy 2001; Halevy and Brody 1993; Truog 2007). Neurohormonal function, cortical function, and even (rarely) sleep patterns measured by EEG, as well as evidence of preserved brain stem function have been documented in the brain dead (Halevy 2001).[5] Brain dead "corpses," then, don't merely appear to be alive by exhibiting *bodily* functions associated with the living, but by evincing neurological activity as well, making whole-brain death, at least, a misnomer. As Engelhardt succinctly puts it, brain dead bodies "appear to be alive because they are in fact alive" (Engelhardt 1986, 209).

[5] While isolated functions do not add up to a brain that functions as an integrated whole or one capable of sustaining consciousness, their presence might preclude a determination of "irreversible loss of all functions of the entire brain," which is the language used in the UDDA. Importantly, if areas of the brain continue to function, even as isolated islands, that would plausibly imply a brain that is not biologically dead.

The question *Is there reasonable disagreement about whole-brain death?* can be answered in the affirmative. Although the orthodox medical and legal position is that whole-brain death is death, there remains considerable and reasonable disagreement and doubt about defining death by neurological criteria.

The Jahi McMath Case

On December 9, 2013, thirteen-year-old Jahi McMath underwent surgery for obstructive sleep apnea at Children's Hospital & Research Center Oakland. She suffered post-surgical complications, including significant blood loss, and went into cardiac arrest, resulting in a devastating anoxic neurological injury. Three days later the hospital declared Jahi brain dead and moved to withdraw ventilatory support. Her family strenuously objected. They professed to believe, as devout Christians, that so long as Jahi's heart continued to beat, she was alive. Jahi's mother Nailah Winkfield said: "Her heart is beating, her blood is flowing. She moves when I go near her and talk to her. That's not a dead person" (Onishi 2014, ¶6).

The hospital issued a death certificate listing December 12, 2013 as the date of death. The Winkfields took the hospital to court to stop the unilateral withdrawal of ventilation, which they characterized as an attempt to kill their child (Fields 2013). The family requested that the hospital perform a tracheostomy and gastrostomy to surgically implant breathing and feeding tubes so that Jahi could be transferred to another facility for ongoing care. The hospital refused, with the chief of paediatrics stating that "Children's Hospital Oakland does not believe that performing surgical procedures on the body of a deceased person is an appropriate medical practice" (Ford 2013, ¶18). Nor would the hospital permit an unaffiliated surgeon to perform the surgeries. Superior Court Judge Evelio Grillo issued an injunction barring the withdrawal of ventilatory support and allowed the family time to find another facility but did not order the hospital to perform the requested surgeries. On January 5, 2014, the hospital released Jahi's body—still breathing and attached to a ventilator—to the Alameda County coroner, who then released her to the family. Jahi was moved to a facility in New Jersey for continuing care. She is reportedly now residing and receiving care in the family home in New Jersey (Lupkin 2014).

Reasonable Accommodation and Whole-Brain Death

In accordance with the Uniform Determination of Death Act, California law defines death as "either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain stem" (Cal. HSC. Code §7180). California's law, like many state laws, declares that an individual satisfying either the criteria for whole-brain death or circulatory-respiratory death "is dead." Some jurisdictions, such as New Jersey, state that the person "shall be declared dead," while others, such as Georgia, seem to leave more to the discretion of providers by stating that "A person may be pronounced dead" (Georgia, O.G.C.A. §31-10-16).

California's Accommodations & Brain Death Act, enacted in 2009, mandates a "reasonably brief period of accommodation" of the family or next of kin following death, defined as "an amount of time afforded to gather family or next of kin at the patient's bedside" (Cal. HSC. Code 1254.4). During such time, only existing cardiopulmonary support must be provided, but not artificial nutrition and hydration or other medical care. If a patient's family or surrogate decision-maker objects to the determination of death by neurological criteria or

> voices any special religious or cultural practices and concerns of the patient or the patient's family surrounding the issue of death by reason of irreversible cessation of all functions of the entire brain of the patient, the hospital shall make reasonable efforts to accommodate those religious and cultural practices and concerns… in determining what is reasonable, a hospital shall consider the needs of other patients and prospective patients in urgent need of care (Cal. HSC. Code §1254.4).

Aside from requiring that existing cardiopulmonary support be continued until such time as the family is able to gather at the bedside of the "deceased," California's law does not provide explicit guidance as to what reasonable accommodation requires. Specific policies are thus left to the discretion of hospitals and providers.

New York and New Jersey also have statutes mandating reasonable accommodation in disputes concerning declarations of death by neurological criteria. Both states passed these laws to accommodate religious objections to brain death on the part of Orthodox Jews and other religious groups.[6] New York's law requires hospitals to establish written procedures for the reasonable accommodation of religious or moral objections to brain death (10 NYCRR §400.16), but does not mandate what those procedures or policies must be (NYSDOH 2011). The New York City Health and Hospitals Corporation Ethics Network interprets the law to mean that religious and moral objections "should be respected to the extent of making an effort at reasonable accommodation," which might include a "short, specified period of time" during which ventilation, nutrition and hydration, and other medical support might be continued, but not "that the now dead individual must continue to be treated as a patient" (HHC Ethics, ¶4).

New Jersey's law is the only one in the United States to mandate that if a patient objects on religious grounds to neurological criteria for determining death, then death "shall be declared and the time of death fixed, solely upon the cardio-respiratory criteria" (NJ L.1991, c.90, s.5 26:6A-5). That is, when there is a religious objection to the use of neurological criteria, the patient is not considered legally dead unless and until there is an irreversible cessation of all circulatory and respiratory function. Moreover, the law prohibits health insurance providers from denying coverage on the basis of brain death when there is a religious objection, thus removing the potential for financial conflicts of interest for hospitals and financial coercion of families facing decisions concerning the withdrawal of life support (Johnson 2014). New Jersey's law, unlike New York's and California's, specifically privileges *religious* objections, but not other conscientious objections. Despite this omission, its provisions are uniquely and genuinely accommodating of conscientious differences in the determination of death.

What Is a Reasonable Accommodation?

I turn now to the question of what can be considered a *reasonable* accommodation. Reasonable accommodation requirements have been enacted into U.S. federal law in two noteworthy contexts: in Title VII of the 1964 Civil Rights Act, referencing reasonable accommodation

[6] Illinois has a limited accommodation law that requires hospitals to "take into account the patient's religious beliefs" when documenting time of death (210 ILCS 85/6.23). Like New Jersey's law, the Illinois statute exclusively privileges religious beliefs.

of religion, and in the Americans with Disabilities Act (ADA), requiring employers to accommodate disabled employees. Additionally, the "reasonable person" standard is commonly employed in tort and criminal law to define what is reasonably expected or required by considering the standards of a hypothetical informed, impartial, reasonable person.

The courts have interpreted Title VII of the 1964 Civil Rights Act as defining reasonable accommodation of religion as not imposing more than "de minimus costs" upon an employer (Schuchman 1998). The ADA imposes stricter guidelines, although these remain open to interpretation (and litigation): an accommodation is reasonable if it "seems reasonable on its face, i.e. ordinarily or in the run of cases" and if it "appears to be 'feasible' or 'plausible'" (U.S. Equal Employment Opportunity Commission [USEEOC] 2002, ¶9). The limit on what is reasonable is what would cause "undue hardship" to an employer, meaning "significant difficulty or expense … [or] unduly extensive, substantial, or disruptive, or those that would fundamentally alter the nature or operation of the business" (USEEOC 2002, ¶15).

As discussed above, one of the initial motives and justifications for establishing whole-brain death as a definition of death was to avoid having persons in irreversible comas being maintained indefinitely in intensive care units (ICU). It is worth considering, then, if having brain dead patients in hospitals would result in "undue hardship" or be unduly "disruptive, or … fundamentally alter the nature or operation of the business" of hospitals. The life support required by most brain-dead patients is minimal by ICU standards: ventilation and artificial nutrition and hydration. Moreover, the "chronically brain dead," like Jahi McMath, reside in nursing homes or the family home, with minimal nursing care. The burdens of maintaining life support, then, would not fall primarily on hospitals or ICUs; that care would appear plausible and feasible in that these patients do not require special or unusual care not provided to other categories of patients; it's prima facie reasonable, assuming that the patient is not truly dead (which is precisely the matter under dispute).

The ADA establishes a fairly high bar for what must be considered an *unreasonable* accommodation. It is plausible that what is reasonable, on this interpretation, approximates the vague but useful "reasonable person" standard in common law.

Sibley defined the "reasonable" in this light, as adopting the point of view which is "a *standard* one," with the standard being "the point of view of an informed, impartial, sympathetic spectator *C*" (Sibley 1953, 559). To be reasonable "is equivalent to being willing to settle disputes as *C* would settle them" (Sibley 1953, 559). That interpretation is consistent with the way reasonable accommodation under ADA has been interpreted and the way it is used in tort and criminal cases, and it's applicable in disputes concerning the definition of death. Reasonable accommodation in defining death can be viewed in light of what a reasonable, informed, impartial, and (ideally) sympathetic person would consider to be reasonable. In light of reasonable disagreement about the definition of death, as well as the generally resource-modest needs of the "brain dead," an impartial, informed, and reasonable person would view accommodation of conscientious objections to brain death as a reasonable policy.

Who Must Be Reasonable?

There remains a question as to whom "reasonable accommodation" applies. It seems quite clear, from the language of the existing laws, that the accommodations must be made by hospitals and healthcare providers, not patients or families. That is, hospitals and healthcare providers are charged with being "reasonable" in accommodating patients and families, as opposed to families and patients being enjoined to "be reasonable" or act "reasonably" in their views of death, or to accommodate the views of healthcare providers. However, when the law declines to mandate what counts as both reasonable and an accommodation, hospitals can meet their minimal legal obligations in such a way that they can effectively force patients or families to capitulate to the standards of reasonableness dictated by the hospitals. If providers and hospitals are under no obligation to allow for an alternative definition of death, they can pay little more than lip service to "reasonable accommodation," and families and patients have little choice but to acquiesce. That was certainly evident in the Jahi McMath case, where, following the hospital's declaration of death, a death certificate was issued, and the child's still-breathing "corpse" was released to the coroner rather than her family. These are not practices enacted when patients are alive. Since Jahi McMath was declared medically and legally dead and, under California law, she "is dead," it can hardly be said that the family's views regarding the definition of death were

accommodated at all. The sole accommodation afforded the family, per court order, paradoxically *supports* their contention that Jahi is *not* dead: she remained on ventilatory support before, during, and after she was transferred to the coroner, a practice that is hardly standard when dealing with cadavers.[7] Finally, if providers can unilaterally withdraw life support, their will when it comes to determining death becomes self-fulfilling prophecy, since withdrawal of ventilatory support will eventually but inevitably result in circulatory-respiratory death.

What Definitions of Death Can Be Reasonably Accommodated?

Four decades on, controversy concerning the validity and coherence of whole-brain death continues unabated, and the matter will not be laid to rest any time soon. Currently, three broad conceptions of death are most widely endorsed: circulatory-respiratory death (cf. Shewmon 2001; Truog 2007); whole-brain death (cf. Bernat 1998 and 2005; Capron 2001; Wijdicks 2002), and higher-brain death (cf. Veatch 2005).[8] Higher-brain death is not currently accepted in U.S. law, although in cases where patients have permanently lost consciousness and suffered the equivalent of "higher-brain death," it is not unusual (nor illegal) for life support to be withdrawn by surrogates or per advance directive. That is, there may be wide (although surely not universal) consensus that "higher-brain death" is close enough.[9] Studies show that among the general public, there remains considerable uncertainty about brain death. Siminoff, Burant, and Youngner found that only 40.3 per cent of survey respondents thought people declared brain dead were actually dead, while a higher percentage believed them to be not dead but "as good as dead" (2004, 2330). A not insignificant minority (16.3 per cent) believe that brain-dead persons are alive (Siminof, Burant and Youngner 2004). Larue et al. (2013) found that when more detailed information about brain-dead patients is provided (e.g. that the heart beats, that there are spinal reflexes, and EEG activity), respondents are less likely to equate brain death with death, and public buy-in of brain death falls to between 20 per cent and 30 per cent. If one aggregates the medical and philosophical dissenters, and the public, the whole-brain-death position, although entrenched, may well be a minority one (Veatch 2014).

There is a decided lack of consensus concerning the definition of death, but it is certain that objections to whole-brain death can be based on genuine, deeply held, and deeply important moral and/or religious convictions. There is an evident need for tolerance and accommodation of such conscientious objections to declarations of death by neurological criteria. That is not to say that every objection to a specific declaration of death is either reasonable or based on deeply held moral or religious convictions. Anticipating just such cases, the New York accommodation law differentiates between objections based on moral/religious convictions, and those based on grief, psychological denial, or other factors. The latter do not invoke the requirement of "reasonable accommodation," although the guidelines encourage "sensitivity to these concerns" (New York State Department of Health 2011, 4). Whether this would include objections based solely on epistemic scepticism concerning the definition of whole-brain death is an interesting and important question, but New York's guidelines suggest that such objections might be rebuffed because they are neither morally nor religiously based. Nonetheless, one might easily have genuine moral objections to treating a living person as a corpse based on a flawed or faulty definition of death.

Moral and religious objections do not exhaust the possibilities for what might be considered *reasonable* objections to a declaration of death by neurological criteria. Given historical racism and cultural insensitivity towards marginalized groups, including persons with disabilities, as well as concerns about medical malpractice and negligence, some individuals, families, and

[7] While brain dead organ donors are routinely maintained on life support to preserve the viability of organs, they are never transferred to the coroner in that condition. Organ procurement necessarily and unquestionably leads to death by both neurological and circulatory-respiratory criteria.

[8] There are others, including the "brain stem death" standard used in the United Kingdom and Commonwealth (National Health Service 2012) and the "loss of consciousness" standard (Machado 2007).

[9] The salient question is: "Close enough for what?" Even if we considered someone in higher-brain death to be dead, or mostly dead, or as good as dead, or lacking personhood, it seems unlikely that we'd bury or cremate a body with a beating heart. There is some sympathy, however, for using these unfortunates as organ donors, and some commentators (cf. Truog 2007) have proposed that the dead donor rule be abandoned to allow organ donation by those who are only *mostly* dead. There would appear to be some public sympathy for such a move (see Siminoff, Burant, and Youngner 2004).

communities might have other reasons to doubt or distrust a diagnosis of brain death. There may well be cases where those concerns warrant accommodation as conscientious objections. Whether such concerns could effectively be resolved by reasonable accommodation statutes is an important question, although it is one that will be set aside for now.

Objections to *all* definitions of death would not be reasonable, nor would it be reasonable to deny that a cold, decaying corpse in rigor mortis is dead. Such objections and denials would surely fail to satisfy the "reasonable person" test, and would also result in unacceptable burdens to healthcare facilities, and potentially create public health hazards. We would not want ICU beds filled with literally decaying corpses. Neither would we want people claiming to be dead and insisting upon being treated as dead (e.g., someone with the Cotard delusion). Some definitions of death, then, might violate the rights of others, or create serious social burdens that would be unreasonable, which gives society a valid cause to reject them.

There is a limit, then, to what can reasonably be accommodated when it comes to defining death. At present, there are two medically and legally accepted standards for determining and declaring death: whole-brain death and circulatory-respiratory death. If both of these standards are medically and legally accepted, then they are surely considered *equally* reasonable standards for determining and declaring death. Thus, either definition of death can be reasonably accommodated under reasonable accommodation statutes. That is, if one definition is objectionable on the basis of moral or religious conviction, but the other is acceptable, there is nothing unreasonable about using the other definition, since it is medically and legally sound and reasonable. It is clearly the case that the circulatory-respiratory definition of death is time-tested, uncontroversial, and enjoys near universal recognition and acceptance under law, in medical practice, and by reasonable, informed people. A body irreversibly lacking circulation or respiration is uncontroversially dead.[10] Whether other definitions of death might be accorded similar privileged legal status and invoke accommodation—higher-brain death is a likely candidate for inclusion—is an important question, but also one to be set aside for now. It suffices, for the present discussion, to have arrived upon at least *one* universally acceptable definition of death, and one other legally/medically accepted (although medically and philosophically contentious) definition.

[10] There is an interesting and lively debate concerning the *timing* of death by the circulatory/respiratory standard, particularly in the context of donation after cardiac death (DCD). In DCD organ donors, death by irreversible cessation of circulatory-respiratory function is declared shortly after the heart stops—when it might still be *possible* to resuscitate the donor—in order to preserve the viability of organs for transplant. What is not controversial is that a body lacking circulation and respiration will be dead after some relatively short but imprecise interval, unlike brain dead bodies.

The Case for Reasonable Accommodation

There exists reasonable disagreement about the adequacy, coherence, and validity of whole-brain death. Well-informed, reasonable people dissent from the whole-brain-death orthodoxy, and there is compelling evidence that brain death is not death as it has been long and commonly understood. Brain death is counter-intuitive, defies common sense, and runs counter to the religious beliefs of many people in a number of religions that, taken together, represent a significant segment of the world's population. Genuine conscientious objections to declarations of death using neurological criteria in the United States must too frequently be adjudicated in court at considerable cost to families, healthcare providers, and taxpayers. These disputes also cause significant and prolonged emotional distress to families already struggling with the loss of a loved one.

The stakes are extremely high in disputes concerning declarations of brain death and the definition of death because the debate is, in essence, over the moral status of a human being. To declare that someone is dead is to say they are no longer a person with full moral and legal rights and no longer entitled to the care they would receive if we considered them to be living members of the moral community. The debate is, then, a moral debate that will not be resolved by science alone. No technological advance, no brain scan, or neurological test will settle the matter once and for all. Similarly, laws that endorse whole-brain death as death will not settle the matter, especially in those parts of the world like North America and Europe that are increasingly heterogeneous and home to people of diverse religious and cultural traditions and moral convictions. In a pluralistic society, consensus will not be forged or forced by either law or medicine when it comes to the definition of death.

Of equal importance to the moral debate concerning brain death is that the fundamental ethical principles of

autonomy and respect for persons may be violated when minority viewpoints are not tolerated or are simply overridden by the orthodox majority opinion. When patients suffer grave neurological injuries that leave them permanently incapacitated, it is left to their surrogates and families to act on their behalf and exercise their rights and autonomy by proxy. This is true whether the patient is neurologically "dead," or in a permanent vegetative state, or suffers from a progressive neurodegenerative disease. Potentially, the autonomy of the proxy and the proxy-mediated autonomy of the patient are both violated when the right of moral or religious conscience is not respected in a declaration of death. Such a scenario has parallels to contested cases of withdrawal of life support and the involuntary imposition of life support against the patient's or proxy's wishes. Moreover, just as forcing treatment for the benefit of the patient is paternalistic, withdrawing it against the wishes of the family that acts on behalf of the patient represents a paternalistic imposition of medical opinion and will that fails to respect both the patient and her family.

For humans, few experiences have the cultural, social, spiritual, and personal gravity of death. Declarations of death are not merely medical or legal affairs, and in the brain death controversy it is strikingly evident how medical/legal death and the social and moral death of a person can come apart. This coming apart creates a situation that is not tenable, for a person cannot be both dead and not dead. But reifying a legal declaration of death can have profound social and moral consequences, including a denial of personhood and a change of status from rights-bearing human being to corpse. Such a grave dehumanization is the result when it is considered a settled fact that a person with a "dead" brain is a mere corpse to whom no consideration is due.

The optimal solution is a compromise, one that does not scrap the currently accepted definitions of circulatory-respiratory death and whole-brain death, but rather permits conscientious objections to declarations of brain death through reasonable accommodation statutes. The optimal solution should not create or accept a situation of complete cultural or ethical relativism in which any and all definitions of death are equally valid and endorsed by law and public policy. Indeed, the two existing definitions of death should suffice, for they already include the most viable, least controversial, alternative to brain death. Circulatory-respiratory death is a legally and medically sound, reasonable definition of death, and one that enjoys near universal acceptance across cultures and religions. It can reasonably be accommodated as an alternative to brain death, and, as I have argued, it would be unreasonable and unethical to *refuse* to accommodate it.

A conscience clause modelled on New Jersey's reasonable accommodation statute, but amended to recognize all conscientious (and not exclusively religious) objections to declarations of brain death, would provide several important benefits if universally adopted. It would recognize that there is legitimate and reasonable disagreement about the definition of death and respect social, cultural, moral, and religious diversity and the range of reasonable viewpoints that exist in a pluralistic society. It would also provide a remedy that does not force capitulation on the part of patients and families, does not set a time limit on accommodation, and would require genuine and sincere accommodation by healthcare providers. It would mark a reasonable limit on what is to be accommodated, by mandating that the universally accepted circulatory-respiratory standard be substituted when whole-brain death is objectionable on conscientious grounds, and unlike New York's and California's statutes, it would provide explicit guidance for healthcare providers on both the extent and the limits of accommodation. Finally, by prohibiting denial of health insurance coverage for brain-dead patients, it would relieve some of the coercive economic pressures faced by families making decisions about the provision of life support and remove some potential financial conflicts of interest for healthcare providers.

It is the decent and compassionate thing to allow a grieving family to be reconciled with the loss of a loved one on terms they can accept, without the threat of medical neglect or unilateral withdrawal of life support. Whether Jahi McMath is alive or dead may be in dispute, but there is no question that a family has lost a beloved child, a child who will never again be as she once was. Children's Hospital Oakland used its time and resources to fight McMath's family in court and repeatedly and publicly referred to the child as "a deceased person" and a "dead body" (BBC 2013). But if Jahi had "died" in New Jersey instead of California, she would still be alive, both in the eyes of her family and under the law.

The controversies over brain death are unlikely to be resolved in the near future, but adopting public policies that accommodate reasonable, divergent viewpoints concerning death provides a practical and compassionate

way to resolve conflicts that are urgent, painful, and resistant to reconciliation.

Compliance With Ethical Standards

Disclosure of Competing Interests and Funding None.

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