Why brain death is considered death and why there should be no confusion

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ABSTRACT

Neurologic determination of brain death is a complex assessment that may be misunderstood by nonspecialists and families. Recent guidelines clarify how to proceed with such an examination and are available to physicians, with the time of death in adults and children being determined by the last defining test—the apnea test. This core principle in neurology has been challenged recently in court and resulted in an unprecedented continuation of care in a 13-year-old child declared dead. This review comments on the medical, legal, and ethical quandaries introduced by this case and highlights the major elements of consensus on matters related to brain death that have been forged over 3 decades of sustained medical and societal debate. A clear appreciation by physicians and the public of the diagnostic determination of death following loss of brain function will help to prevent similar conflicts from occurring in the future. *Neurology*® 2014;83:1464–1469

GLOSSARY

NCCUSL = National Conference of Commissioners on Uniform State Laws; **TRO** = temporary restraining order; **UDDA** = Uniform Determination of Death Act.

The tragic case of a 13-year-old Oakland, California, child (Jahi McMath) who was declared dead on December 12, 2013, following complications of a tonsillectomy, adenoidectomy, and redundant sinus tissue removal, recently pitted family members, lawyers, and the hospital against each other as they struggled to resolve continuing support. Children's Hospital & Research Center Oakland (hereafter referred to as the hospital) claimed that Jahi was legally dead following 2 assessments by its medical staff (one neurologist and one pediatric intensivist). As the child was dead, the hospital maintained that it was no longer obligated to continue providing medical care at the family's request. The family, by contrast, claimed that their child was not dead because she had a continually beating heart and was moving in response to touch. They demanded that the hospital continue to provide medical care, including ventilatory support, in hopes that she might recover. The family also maintained that the hospital's failure to provide the requested medical care to Jahi was disrespectful of her and her family's religious values.

This case led to a legal quagmire and generated considerable public interest. To assist physicians and others in responding to questions about this exceptional case, we present an analysis of the pertinent medical, legal, and ethical issues raised. Our analysis is based on public information, including court records, media reports, and relevant medical literature.

The diagnosis of brain death. Acute catastrophic brain injury involving both hemispheres of the brain rarely leads to brain death. That would require loss of brainstem function and typically is a consequence of a massive hemispheric lesion compressing and damaging the mesencephalon, pons, and medulla oblongata. As a result of its natural resilience, the brainstem rarely stops functioning completely. This fundamental neurologic principle of the brainstem to be the last structure to lose function has been known for centuries and even to Jean-Martin Charcot, one of the founders of neurology, who said it was the last structure to die.

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Once brainstem function is lost, breathing stops first and the heart soon thereafter. If in the acute phase the patient can be intubated, placed on a mechanical ventilator, sufficiently oxygenated, fluid resuscitated, and vasopressors and vasopressin added, this agonal sequence can potentially be prevented. Once an untreatable catastrophic neurologic structural injury has been proven while in this supported state, recovery does not occur and there is no known effective medical or surgical intervention. Irreversibility is determined by absent motor responses, loss of all brainstem reflexes, and apnea after a CO₂ challenge and not by further waiting. After this state is reached, blood pressure is unstable and often relentlessly declining despite efforts to stabilize it. Cardiac arrhythmias appear and typically multisystem injury as a result of a widespread inflammatory response and intravascular coagulation occurs. Support measures are complex, often fail, and the ability to maintain a brain dead body is virtually impossible. There is no disagreement that brain death is a distinct clinical neurologic state and different from all other manifestations of acute or prolonged coma. For example, the clinical findings in brain death are different from those of comatose patients, where patients eventually may be able to breathe on their own and when some or all brainstem reflexes are preserved. In the medical judgment of practicing neurointensivists, neurosurgeons, and all neurologic and neurosurgical societies and academies throughout the world, brain death constitutes death of the person.

Clear standards for determining pediatric brain death were established by a multidisciplinary task force more than 25 years ago. These consensus standards have been widely adopted and have been revisited by the Society of Critical Care Medicine, the American Academy of Pediatrics, and the Child Neurology Society.¹ The most current pediatric guideline recommends 2 examinations 12 hours apart by 2 different attending physicians in children 1 year or older. This is different from adult brain death guidelines, which require only one full examination (with optional confirmation by another physician).² Whether a waiting interval in children is needed or even rational has been debated.³

The medical details surrounding Jahi McMath are not known to us but the description of the neurologic examination of the court-appointed neurologist shows a full neurologic examination, apnea test, isoelectric EEG, and a nuclear scan with no demonstrable uptake.

Now, months after this determination, Jahi McMath is still supported by artificial means. Because brain death leads to terminal cardiac arrhythmias in the overwhelming number of patients, this is remarkable, but not exclusive of a diagnosis of brain death.

In exceptional cases, prolonged support is possible as long as oxygenation, circulation, nutrition, and treatment of multiple medical complications is provided.

The legal conflict. Due to the underlying conflict between the hospital and Jahi McMath's family, the case was brought before the Alameda California Superior County Court in December 2013. Judge Evilio Grillo issued a temporary restraining order (TRO) stopping the hospital from disconnecting her ventilator. He also appointed an independent physician (a pediatric neuro-oncologist from Stanford University), Dr. Paul Graham Fisher, to reevaluate Jahi. Dr. Fisher confirmed the girl's status as brain dead, stating in his report that there was "irreversible brain injury and now complete absence of cerebral function and complete absence of brainstem function, child meets all criteria for brain death, by professional societies and state of California."⁴ With this additional independent confirmation, Judge Grillo ordered that the hospital could remove ventilator support but not until December 30 (18 days after the hospital's original diagnosis of death) in order to allow the family time to seek out other institutions for care.

Hours before the December 30 deadline, Judge Grillo issued another restraining order again stopping the hospital from removing support and giving the family until January 7, 2014, to make arrangements for her transfer. As a stipulation for transfer, the hospital lawyer and administrators required clearance from the county coroner that a dead body could be removed and transferred from their hospital. Although the hospital refused to allow either their surgical staff or outside medical staff to perform a tracheostomy and feeding tube placement necessary for her transfer to a long-term care facility, to our knowledge the hospital did not place restrictions on the family's access to the body, which remained in a monitored hospital bed throughout this time.

On January 3, 2014, some 22 days after the original diagnosis of death, Judge Grillo announced that the family and hospital had come to a partial agreement.⁵ The agreement specified that an outside medical team could remove Jahi McMath from the hospital and that her mother would take full responsibility for her body during its relocation to another facility. Under this agreement, Jahi's family would have approximately 3 days to coordinate this relocation process, and if they were unable to make the necessary arrangements during that period, the hospital could remove the ventilator supporting her body.

Judge Grillo denied the family's request to compel the hospital or an outside physician to insert feeding and breathing tubes to facilitate the relocation.⁵ The agreement also required the Alameda County coroner

to sign a document accepting Jahi McMath's body prior to its release to her mother. On January 3, 2014, the coroner issued a death certificate stating that Jahi died on December 12, the day that doctors originally declared her dead. On January 6, Jahi's parents removed her body from the hospital with assistance from an ambulance service.⁴

Legal basis and history of brain death. The legal definition of death was traditionally viewed as the cessation of cardiopulmonary function.

As medical advances were made, most notably in the areas of ventilatory support and transplantation medicine, there became an interest in and need for more accurately defining death by neurologic criteria.⁶ In 1968, a physician-led committee out of Harvard Medical School published a paper titled "A definition of irreversible coma," concluding that patients who meet criteria for a certain type of severe brain injury may be pronounced dead before cardiopulmonary cessation occurs.⁷ State legislatures during that time also considered amending their statutes to recognize this changing trend. Kansas became the first state to define brain death as a legal death standard by statute in 1970.⁶ Concern soon arose, however, over the lack of consistency in both the legal definition of death used within each statute as well as between those statutes originating among differing states.⁷

Due to the changing environment already recognized by state legislatures, in 1981 the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research published *Defining Death: Medical, Legal and Ethical Issues in the Determination of Death*.⁸ The goal of the commission was to analyze the changing definitions of death that had already been actuated in state statutes such as Kansas and others. Following extensive evaluation of the information presented before them as well as that existing in the biomedical literature, the Commission proposed a statute receptive to legal, medical, religious, and policy concerns yet providing uniformity in its definition of death. In their report, they proposed a uniform statute for determining death by either "irreversible cessation of circulatory and respiratory functions" or "irreversible cessation of all functions of the entire brain, including the brainstem."⁶⁻⁸

The Commission's suggestion was endorsed by the American Medical Association, the American Bar Association, and the National Conference of Commissioners on Uniform State Laws (NCCUSL). The NCCUSL published this statute under the name Uniform Determination of Death Act (UDDA) and worked to get it passed in states and jurisdictions across the United States. The UDDA has since been adopted in all 50 states by statute or case law,

although in certain states it has been passed into law in a modified form.^{7,9} While not all US jurisdictions have adopted the literal wording of the UDDA, they all contain some legal acknowledgment of a brain-based standard of death.^{7,10}

Both New Jersey and New York provide for exceptions from traditional brain death standards in situations of religious belief conflict.^{6,9} The New Jersey statute requires that a physician shall not declare an individual dead on the basis of neurologic criteria when they have reasons to believe "that such a declaration would violate the personal religious beliefs of the individual."¹¹ Instead, when this is the case, "death shall be declared...solely upon the basis of cardio-respiratory criteria."¹¹

New York's statute requires hospitals to "establish and implement a written policy regarding determination of death."¹² This includes "[a] procedure for the reasonable accommodation of the individual's religious or moral objection to the determination as expressed by the individual or by the next of kin or other person closest to the individual."¹²

Since the UDDA was set forth, it has successfully weathered a number of criticisms and reassessments of neurologic standards for determining death.⁷ The latest reevaluation of the definition of death from a federal oversight perspective took place in 2008, when the US President's Council on Bioethics¹³ published their report continuing to endorse the concept that total "brain failure" serves as a criterion for declaring death.⁷ After "careful consideration to contending positions" of the "clinical and ethical validity of the neurologic standard" of death, the council concluded that this standard of death remained valid.⁷

The presence and uniformity of laws defining death (including brain death) have been adopted and widely accepted. They have offered a framework for organ donation practices as well as helping to mitigate disputes involving medical malpractice, family estate planning, life insurance benefits, and homicide charges.^{9,14}

Legal perspectives on the McMath controversy. As early as 18 days after the hospital had diagnosed Jahi McMath as dead, the Alameda County Superior Court judge held that the child was in fact dead. After confirmation by an independent physician, Judge Grillo agreed that Jahi's medical condition met the definition set out by California's Uniform Determination of Death Act, which states in part "[a]n individual who has sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain stem, is dead."¹⁵ While California's statute does not contain a religious exception, the judge in this case provided Jahi's parents

considerable time to pursue opportunities to have her body transferred to another facility. The amount of time is significant given the moral and professional burdens on health care providers to support a body that has been declared dead.

As discussed above, Judge Grillo entered a TRO requiring that the hospital continue ventilator support until Jahi's parents were given time to explore options for transfer. Because TROs significantly deprive the opposing party of freedom, they are reserved for situations in which the filing party is facing irreparable harm, no other legal form of remedy is available, and a substantial likelihood of success of winning a case on the merits exists.¹⁶ The court must balance the potential hardship to the opposing party as well as any impact on the public following their decision.¹⁶

Judge Grillo delivered a total of 3 TROs during the course of this legal conflict, including his first allotting time for an independent physician to examine Jahi. Following independent medical confirmation of death, the family's likely success of succeeding on the merits dwindled.¹⁷ The importance of an irreparable harm suffered without an adequate remedy under law (e.g., monetary award would not suffice for family-perceived "lost life") may have in turn influenced his decision. Allowing the parents more time to seek out a facility willing to provide care that the hospital had refused might offer such relief. But such irreparable harm became moot once the court established that Jahi McMath was dead.

We are then left with the court's balancing of public interest in denying or granting such an order. The conflict surrounding Jahi was well-publicized by both the media and the family's attorney. Whether the public's knowledge of and possible confusion surrounding this case had ripened the environment for a public debate on the issue of brain death as death is unknown. What is clear and not in question in this case, however, is that under California statutory law Jahi McMath was legally dead on December 12, 2013.

Ethical perspectives on the McMath controversy. Much of the public interest in this case and corresponding media coverage focused on questions about the extent to which the hospital and its physicians may have abandoned Jahi McMath or otherwise treated her and her family in a disrespectful manner. In considering those questions, it is important to consider what would constitute a reasonable response to Jahi's family's request to continue medical care following the declaration of death by neurologic criteria. In particular, questions can be asked about the extent to which the hospital should have provided the family with additional time to grieve and identify another medical

facility that would accept her following the pronouncement of her death.

To our knowledge, no clinical guidelines have been developed for the purpose of determining how much time should be afforded to families for the purpose of grieving at the bedside following a declaration of death in the hospital. This likely reflects the great diversity of needs that grieving families have in such circumstances, as well as differing clinical settings in which death may occur (e.g., intensive care units, hospital nursing floors, hospital-based hospice units). When patients die in intensive care units, it is reasonable to expect that their bodies will be removed from those bed spaces within a few hours due to the need for other patients to receive the heavily monitored care available in those units. On rare occasions, it may be permissible for hospitals to depart from this general practice in order to balance competing moral imperatives. For example, appeals to beneficence or social justice may support short-term extensions of care following a declaration of death by neurologic criteria as a way to support grieving families or facilitate grieving rituals that are responsive to the cultural or religious needs of some families. In remarkable situations where a family member is in transit from a distant location or is otherwise unavailable for a short time, for example, a hospital facility may elect to continue providing limited care to an individual who has been declared dead.

We are not familiar with situations in which new medical interventions have been provided to deceased patients for an extended period of time such as was requested by Jahi's family.¹⁸ This is appropriate, as intentionally providing medical care to a deceased person may compromise the professional integrity of physicians. Doing so also may foster misconceptions about the deceased patient's status as dead, detract from the care of living patients, and create significant moral distress for medical professionals. Hospitals that accommodate a family's request to extend the provision of care to a deceased person must weigh these risks against their commitment to supporting the moral integrity of their physicians, with each unique case being evaluated individually to determine what is ethically permissible.

With respect to Jahi McMath, it would appear that continuing medical treatment for several months following the declaration of her death is inconsistent with medical expectations in these circumstances and that the family's requests for additional care following her death were properly rejected by her caregivers. The Medical Ethics Committee for the hospital explicitly considered this issue and concluded that continuing to provide medical support for Jahi for several weeks following the determination that she was dead was medically inappropriate. The Ethics

Committee also expressed concerns that accommodating the family's requests raised "significant concerns of justice and fairness" and could establish "a troubling precedent for the future."¹⁷

Although a recent commentator on this case has proposed that families with the financial means to continue to maintain a deceased individual's body should be allowed to do so,¹⁹ such a position assumes that the integrity of medical professionals is not compromised in such circumstances. No medical objectives are achieved by adopting this approach and to the extent that physicians are not mere technicians who provide forms of care on demand, regardless of the circumstances or need, we reject this position as falling outside the scope of conventional thinking about the management of a deceased patient's body following a declaration of death. We also note that adopting such a position would create significant potential for disparities in the treatment of dying patients, a matter of profound importance in reassuring the public that all hospitalized patients are treated in a respectful manner, regardless of their financial means.

Also relevant to the case involving Jahi McMath are questions about the support of her family during a time of intense suffering and grief. The events that led to her death are tragic and the suffering of her family should be acknowledged and addressed by her caregivers. Providing emotional and spiritual support to families when it is sought following the death of a loved one is a key element of providing quality care. Offering supportive care to a family becomes inappropriate, however, when it creates misunderstandings about the deceased patient's medical history or status as a deceased person.

It is noteworthy that the Medical Ethics Committee for the hospital acknowledged this tension, citing a 2009 report from the President's Council on Bioethics, which concluded that in such situations "It is time to pay the deceased our respects, to mourn their passing—and to do so in the presence of, and with careful regard for, their mortal remains."^{7,17} The Ethics Committee went on to acknowledge the importance of tending to the needs of caregivers in such circumstances as well, writing that "The committee feels great compassion for the care team and the moral distress they are experiencing as a result of being asked by the family and compelled by the court to provide interventions that are against their ethical principles and professional training."¹⁷ In cases where there is a significant and unusually long period of time between the declaration of death and the removal of medical support, the potential for misunderstandings to arise about the patient's legal status is greatly magnified, both within the family and among care providers. Although difficult, that transition cannot be extended over a period of weeks without

compromising the integrity of medical professionals and creating confusion among others.

We applaud the Medical Ethics Committee for the care with which they appear to have handled this situation. Although there were numerous practical complications introduced by the court's order to postpone the removal of medical support for Jahi McMath, the Committee thoughtfully applied well-established ethical principles of professional integrity and respect for persons in this circumstance. As with the medical and legal perspectives reviewed above, here too there is little disagreement concerning the core ethical principles that apply to the McMath case and that should be used to guide clinical decision-making.

DISCUSSION With the important caveat that we have not been able to scrutinize the medical details of this case, which has become a matter of public record very quickly and amid much fanfare, we suggest that this situation further confirms that neurologic determinations of death and state laws concerning these matters are clear and unambiguous. Many patients, family members, and the public at large remain confused about the differences between brain death (death) and other neurologic disorders such as coma or persistent vegetative state. Although some commentators and members of the media have sought to create controversy in this situation, there is none, as a strong and well-established consensus regarding brain death has been forged from decades of sustained discussions in medicine, law, and ethics. If there is a lesson to be learned from this case, it is that there is greater need to communicate this consensus to members of the public and to those who report medical news. An informed public is the best defense against unanticipated outcry in aberrant cases such as this and thus we encourage our colleagues in critical care, neurosciences, and biomedical ethics to engage patients and local communities about matters related to brain death.

AUTHOR CONTRIBUTIONS

Christopher Monfils Burkle: drafting/revising the manuscript, study concept or design, analysis or interpretation of data, accepts responsibility for conduct of research and final approval. Richard R. Sharp: drafting/revising the manuscript, study concept or design, analysis or interpretation of data, accepts responsibility for conduct of research and final approval. Eelco F.M. Wijdicks: drafting/revising the manuscript, study concept or design, accepts responsibility for conduct of research and final approval, study supervision.

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