

Lessons from the Case of Jahi McMath

BY ROBERT D. TRUOG

The experience of Jahi McMath was, first and foremost, a terrible tragedy for her and her family. A healthy girl underwent elective surgery and was left with a profound brain injury that led to the diagnosis of brain death. But beyond this sad story, the case has also raised challenging uncertainties about one of the most profound existential questions that we can ask: how do we know whether someone is alive or dead?

As an introduction to the essays that follow, by Alan Shewmon and Michele Goodwin,¹ I will provide some background to the case.² The story, however, is actually two parallel narratives—one about the role of brain functioning in the definition of death, and the other about the influence of race, class, and culture in the way that health care is experienced in the United States today. I will focus on the former.

On December 9, 2013, Jahi McMath underwent complex pharyngeal surgery for obstructive sleep apnea at Oakland Children's Hospital. Postoperatively she was transferred to the pediatric intensive care unit for close observation. Later that evening, she began to spit up blood, and eventually suffered a massive hemorrhage. She had a cardiac arrest. She was resuscitated with return of spontaneous circulation, but with significant hypoxic injury to her brain.

Two days later, the chief of neurology performed an examination and an electroencephalogram (EEG), both of which indicated the diagnosis of brain death. Hospital policy required that the test be confirmed by a second

physician; this was done the following day, and she was officially declared to be brain-dead on December 12.

As is customary in such cases, the family was given a couple of days to absorb the trauma of the circumstances and to decide whether to consider organ donation. On December 15, the hospital told the family that the ventilator would be removed the following morning. The family, very angry about how they felt they had been treated, retained an attorney, and the hospital agreed to continue with ventilation temporarily.

The judge asked for an exam by a physician from another hospital, so the chief of child neurology at Stanford repeated the exam and also performed a cerebral blood flow study. Both the exam and the study confirmed the diagnosis. At this point, the judge ruled that McMath was legally dead. Nevertheless, the family and the hospital reached an unusual agreement for her body to be released to her mother, with continuation of the ventilator and intravenous fluids.

On January 3, 2014, the coroner issued a death certificate, dated December 12, the day that the second, confirmatory test was performed. On January 5, McMath was released from Oakland Children's and transported to a hospital in New Jersey. She was transferred to New Jersey specifically because that is the only state with a law that prohibits the determination of death by neurological criteria when this would violate the personal religious beliefs of the individual. The state also has a law that prohibits payers from denying coverage to individuals based on their personal religious beliefs regarding brain death.

She was later discharged from the hospital and spent most of the next four years in an apartment in New Jersey. She had no spontaneous respiration, required a ventilator to breathe, and was administered tube feedings

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Perhaps Jahi McMath actually improved somewhat, rising a little on the spectrum of brain injury. In so doing, she would have crossed the bright legal line we have drawn between the living and the dead.

for nutrition. She continued to grow, began having menstrual periods, and was relatively stable but for a few intercurrent hospitalizations. In 2018, she reportedly developed liver failure and had exploratory surgery for unexplained bleeding. When more surgery was proposed, her mother chose to “let her go,” and on June 22, 2018, Jahi died in the hospital, surrounded by her family. At the time of this writing, she has two death certificates. The California certificate indicates that she died on December 13, 2013; the New Jersey certificate states that she died on June 22, 2018, with liver failure and hypoxic brain injury as the causes of death.

Alan Shewmon details in his essay that he personally examined McMath and has reviewed numerous video tapes and medical records related to her case. It is his opinion that, prior to her cardiac arrest in June 2018, she no longer met the criteria for brain death and was actually in a minimally conscious state.³

McMath’s case is striking in at least two ways. First, how can it be that a person diagnosed as dead by qualified physicians continued to live, at least in a biological sense, more than four years after a death certificate was issued? While prolonged biological survival has been documented in many other cases of brain death (in one case for more than twenty years), no other cases provoked either the me-

dia notoriety or the legal attention of the McMath case. Second, the diagnosis of brain death has been considered irreversible; in fact, there has never been a case of a person correctly diagnosed as brain-dead who improved to the point that the person no longer fulfilled the diagnostic criteria. If Shewmon’s allegations are correct, this case could have momentous implications for how we think about this diagnosis going forward.

In the remainder of this essay, I will offer a hypothesis that could, perhaps, explain both of these remarkable aspects of the McMath case.⁴ The hypothesis is based on differences in how we distinguish between biological and legal categories. The law tends to prefer to draw bright-line distinctions between categories, whereas biological categories tend to fall along a spectrum, without sharp distinctions.

A common example is how we distinguish between the categories of “adult” and “minor.” For most legal purposes, the distinction is drawn as a bright line on a person’s eighteenth birthday, when a person typically acquires most of the rights, privileges, and obligations of being an adult. From a biological or psychological perspective, of course, growth in maturity and judgment occur along a continuum. People are typically not much different on their eighteenth birthday from what they were like the day before. But while this sharp legal distinction is necessarily some-

Figure 1. The Biology of Brain Injury

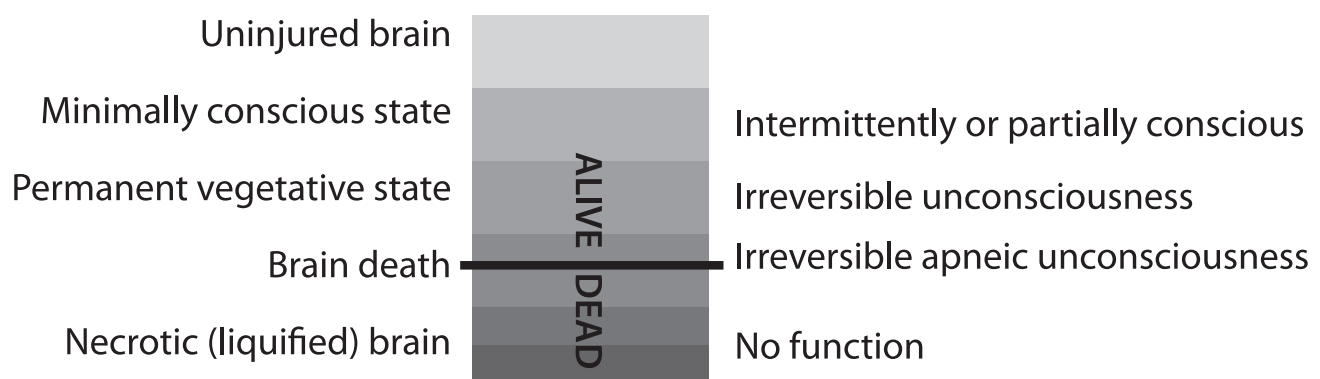
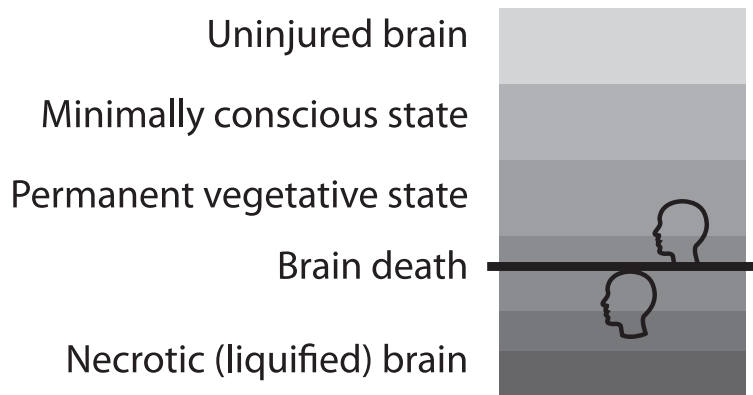


Figure 2. Brain Injury and Somatic Survival



what arbitrary, it is nevertheless reasonable and meaningful. It is better, for example, than drawing the line at the age of seven or thirty.

Brain injury also occurs along a biological spectrum. As illustrated in figure 1, at one end of the spectrum is an uninjured brain, and points along that spectrum represent the minimally conscious state (where consciousness is only partially or intermittently present) and the permanent vegetative state (where consciousness is permanently lost). Near the bottom of the spectrum is brain death, in which most, but not necessarily all, of the brain's functions have been lost. At the very bottom is a brain that has liquified or been replaced by fibrous tissue and has no function at all.

In the 1950s and '60s, discussion began about whether patients below a certain point on this spectrum could be regarded as "dead." In 1981, the Uniform Definition of Death Act drew a bright line at the point where the person was considered to be permanently unconscious, without brainstem reflexes, and without any neurologically driven respiration. Hence, the UDDA drew a bright legal line at this point across the continuous biological spectrum of brain injury.

This hypothesis is only a model, and as the aphorism goes, all models are false; some models are useful. This model is certainly false to the extent that it represents a simplification of the complex neurological reality of brain injury. Nevertheless, I suggest it may be useful in understanding certain aspects of the McMath case.

In my practice as a pediatric intensive care physician, I care for children with all levels of brain injury. Some are like the patient represented in figure 2 who has profound brain injury but is just above the line that we call brain death. Patients like this are alive. Sometimes their parents choose to withdraw life support and allow them to die, based on their poor quality of life and prognosis, but often their parents choose to continue with life support. These

children may live at home or in chronic care facilities, and they typically require intermittent hospitalizations to be treated for pneumonia or other intercurrent problems. But they may live for many years.

Other children are just below the line. That appears to have been the case with McMath. These children are legally dead. We do not offer continued life support beyond a few days at most, to give parents a chance to decide whether to donate their child's organs for transplantation. Yet aside from their brain injury, these children are often biologically quite similar to those who are just above the line. If the unusual decision is made to continue with life support, as in the McMath case, it should be no surprise that they, too, have the potential to live biologically for many years.⁵

Given that patients diagnosed as brain-dead may have prolonged biological survival, why are cases like that of McMath relatively uncommon? The answer lies in the fact that the diagnosis is almost always a self-fulfilling prophesy. In almost every case, once the diagnosis is made, life support is terminated, whether or not the parents decide to donate the child's organs for transplantation. Even when families disagree with termination of life support, they are typically overridden, since brain death is legal death in almost every state. (Only New Jersey permits families to refuse indefinitely to have their family member diagnosed as dead by neurological criteria.)

Can this model or hypothesis potentially help to make sense out of Shewmon's claim that McMath no longer met the criteria for brain death? Here again, I think that seeing brain injury as occurring along a spectrum can be helpful. Brain injury is not necessarily static: sometimes patients with severe brain injury get better; sometimes they get worse. We now know of many well-documented cases of patients who were diagnosed as being in a permanent vegetative state and, over a period of years, improved to being in a minimally conscious state.⁶ Could this same phenomenon occur further down the spectrum? Perhaps McMath actually improved somewhat, rising a little on the spectrum of brain injury. This would not seem to be surprising in itself. But what makes this conceptually important would be that, in so doing, she would have crossed the bright legal line we have drawn between the living and the dead.

My own view is that we should recognize and accept this for what it is. No diagnoses in medicine are infallible. Diseases are not static. A patient may meet the diagnostic criteria for a condition at one point in time but not at a future point in time. Like the decision that individuals would attain the legal age of majority on their eighteenth birthday, the UDDA's drawing of a bright legal line at a point

on the spectrum of brain injury was necessarily somewhat arbitrary but nevertheless reasonable and meaningful. This line defines the point at which we allow patients to donate their organs, and where we have no obligation to sustain them on life support. Since 1981, it has had the support of the overwhelming majority of the population and has facilitated our programs of organ procurement and transplantation, which have saved many thousands of lives. Hopefully the model presented here may help to explain some of the apparent paradoxes presented by the case of Jahi McMath.

1. D. Alan Shewmon, “The Case of Jahi McMath: A Neurologist’s View,” and M. Goodwin, “Revisiting Death: Implicit Bias and the Case of Jahi McMath,” both in *Defining Death: Organ Transplantation and the Fifty-Year Legacy of the Harvard Report on Brain Death*, special report, *Hastings Center Report* 48, no. 6 (2018): S74-S76 and S77-S80, respectively.

2. T. M. Pope, “Brain Death Forsaken: Growing Conflict and New Legal Challenges,” *Journal of Legal Medicine* 37 (2017): 265-324, at 301; R. Aviv, “The Death Debate,” *The New Yorker*, February 5, 2018, p. 30-41.

3. D. A. Shewmon, “The Case of Jahi McMath: A Neurologist’s View,” *Defining Death: Organ Transplantation and the Fifty-Year Legacy of the Harvard Report on Brain Death*, special report, *Hastings Center Report* 48, no. 6 (2018): S74-S76.

4. This section of the essay expands upon comments made in an earlier article: R. D. Truog, “Defining Death-Making Sense of the Case of Jahi McMath,” *Journal of the American Medical Association* 319 (2018): 1859-60.

5. D. A. Shewmon, “Chronic ‘Brain Death’—Meta-analysis and Conceptual Consequences,” *Neurology* 51 (1998): 1538-45.

6. J. J. Fins, *Rights Come to Mind: Brain Injury, Ethics, and the Struggle for Consciousness* (New York: Cambridge University Press, 2015); J. T. Giacino et al, “The Minimally Conscious State: Definition and Diagnostic Criteria,” *Neurology* 58 (2002): 349-53.

The Case of Jahi McMath: *A Neurologist's View*

BY D. ALAN SHEWMON

From the start, I followed the case of Jahi McMath with great interest through the news media. In December 2013, she clearly fulfilled the diagnostic criteria for brain death. By early January, the media were reporting that multiple bodily systems were deteriorating and that cardiovascular collapse was imminent, an inevitable trajectory for a corpse on a ventilator.¹ One of her physicians testified thus to the court,² and a neurointensivist commentator explained the same to the newspapers.³ The deterioration was held up as proof that her body was no longer an “organism as a whole” but a collection of organs and tissues that were literally disintegrating.

As a neurologist with a special interest in chronic brain death, I was later not surprised to learn that, after she was flown to New Jersey, where she became statutorily resuscitated and was treated as a comatose patient, Jahi's condition quickly improved. In retrospect, the multisystem deterioration attributed to death was actually due to four weeks of no nutrition and untreated thyroid and adrenal insufficiency. With tube feedings and hormone replacement, she stabilized to the point of being discharged to an apartment, where she remained for nearly four more years, cared for by family and round-the-clock nurses.

When it became clear in early 2014 that Jahi could have a potentially long survival, I approached her family through their lawyer, thinking that her case fit perfectly with the series of chronic brain death cases that I had earlier published.⁴ Around the same time, her family began to report that she sometimes responded to simple mo-

tor commands. I shared the general skepticism regarding these reports, assuming that the family was in denial and was misinterpreting spinal myoclonus (a rapid, involuntary twitch generated by the spinal cord) as volitional.

The family had noticed that when Jahi's heart rate was above eighty beats per minute, she was more likely to respond, as though the heart rate reflected some sort of inner level of arousal. So they began to make video recordings of command-response sessions at such times. I have been privileged to be entrusted with copies of these recordings, sixty in total, forty-eight of which proved suitable for assessing alleged responsiveness. They span a two-year period and last from thirteen seconds to twelve minutes each, for a total duration of ninety-seven minutes. All have been certified by a forensic video expert as unaltered.

The first thing that struck me was that the great majority of the alleged responses were not spinal myoclonus. In fact, they did not resemble any type of spontaneous, involuntary movement described in patients paralyzed from high spinal cord lesions. Most involved discrete body parts and were slower than myoclonus. Others involved more than one body part or a sequence of movements lasting several seconds.

I surveyed some of Jahi's nurses, who unanimously attested that such movements did not occur spontaneously. In the videos, nonmyoclonic movements indeed occurred rarely during baseline periods. The frequency of movements was much greater during periods of command and coaxing than at baseline. Also, the latency between command and next movement was much shorter than would be expected by chance. The anatomical specificity between command and next movement was striking and difficult to explain away by chance. After countless hours studying the videos and taking a devil's

D. Alan Shewmon, “The Case of Jahi McMath: A Neurologist's View,” *Defining Death: Organ Transplantation and the Fifty-Year Legacy of the Harvard Report on Brain Death*, special report, *Hastings Center Report* 48, no. 6 (2018): S74-S76. DOI: 10.1002/hast.962

Based on the compelling video evidence and the gross structural preservation of Jahi's brain in the 2014 MRI scan, I am convinced that, from early 2014, she was in a "minimally conscious state."

advocate approach at every step, I cannot escape the conclusion that the alleged responses were genuine.

Some videos seem to demonstrate a surprising degree of comprehension. For example: extending the thumb upward after previously flexing it and being told to move it *up* instead; or making a stronger repeat arm movement when told to "move it harder"; or, after a previous motor response when the digits and hand remained tense, relaxing them quickly upon being told to relax them; or moving the middle finger consistently when asked which is the "eff you" finger or other circumlocutions. These demonstrations were not cherry-picked coincidences of spontaneous movements because such movements never occurred during baseline periods.

According to her mother, Jahi's periods of responsiveness occurred on average about three times per week and lasted several minutes to half an hour at a time. It is therefore unlikely that she would have exhibited responsiveness during a randomly timed examination. When I examined her on December 2, 2014, she was in fact unresponsive to commands; she also exhibited no brain-stem reflexes and did not breathe over the ventilator or during twenty seconds off it. (A formal apnea test was not possible in the apartment, nor would it have been permitted.) This is why the video evidence is so important: it compellingly places Jahi in the category of "minimally conscious state."⁵

To shed light on the structural and functional state of Jahi's brain, she was transported on September 26, 2014, to Rutgers University Hospital for magnetic resonance imaging, an MR angiogram and venogram, electroencephalogram (EEG), and multimodal evoked potentials. The MRI showed extensive damage to the cerebral white matter and mid- to lower brain stem but surprising preservation of the internal and surface anatomy of the cerebral and cerebellar hemispheres, with relatively little atrophy.⁶ This contrasted markedly with the MRI or CT scans of chronic brain-dead patients, which have consistently shown the totally liquefied brain to have been replaced by a chaotic jumble of membranes, fluids, and calcifications.

Jahi's MR angiogram and venogram showed no signal related to blood flow within the brain substance, but these techniques are not sensitive enough to detect low flow. From the extent of structural preservation, one can infer

that, although Jahi's cerebral blood flow was markedly reduced, there must never have been a time when it was completely absent, or else her brain would have undergone total liquefaction, as in the cases of chronic brain death. Likewise, at the time of a radionuclide scan performed on December 23, 2013, cerebral blood flow must have been reduced to a level below the scan's resolution, too low to support synaptic function but enough to prevent tissue necrosis. This is the range called the "ischemic penumbra," well known in the stroke field and hypothesized by Cicero Coimbra to occur globally as a mathematical necessity during the progression from normal to no flow in the pathogenesis of brain death.⁷ Jahi's case may be the first indirect confirmation of Coimbra's hypothesis.⁸ False positivity of the brain death diagnostic criteria and of "confirmatory" blood flow tests is not unprecedented.⁹ ("False positivity" here means that, despite her 2013 fulfillment of the diagnostic criteria for brain death [which by definition includes irreversible apneic coma], she did not remain irreversibly comatose.)

The behavioral evidence for intermittent responsiveness is difficult to reconcile with the neurophysiological tests at Rutgers. The EEG was isoelectric, and the evoked potentials showed no responses. The discrepancy can be approached in one of two ways: either we can give priority to the tests, concluding that Jahi could not possibly have been conscious or capable of hearing and that the videos should simply be disregarded, or we give priority to the behavioral evidence, concluding that there must be something about the tests in her case that we do not understand and that makes them unreliable as indicators of total and permanent brain nonfunction.

The visual and somatosensory evoked potential results are hardly surprising and imply nothing about capacity for hearing, consciousness, or voluntary movement. Regarding the brain-stem auditory evoked potential, the click stimulus has a frequency content above that of the human voice; hence, audiologists regard it as an inadequate tool to assess hearing. Absence of wave I, which is generated peripherally, can be due not only to absence of electrical signals in the acoustic nerve but also to asynchrony of signals. Indeed, hearing can be preserved following acoustic neuroma surgery despite absence of all waves.¹⁰ EEGs reflect the electri-

cal activity of only the portion of cortex directly below the scalp. Consciousness, hearing, and even functional vision can be present in children with congenital absence of cortex and an essentially flat EEG.¹¹ Moreover, if Jahi's responsiveness was intermittent, then her EEG activity might also have been intermittent. Indeed, Calixto Machado and colleagues found electrocerebral activity on EEGs performed at other times in Jahi's apartment.¹² (They also found heart-rate-variability evidence of responsiveness to her mother's voice.)

Whether such explanations account for the discrepancy between Jahi's test results at Rutgers and the evidence for intermittent responsiveness, I do not pretend to know. The point is merely that such tests are not absolute and do not justify ignoring compelling behavioral evidence. Brain death is a clinical diagnosis. Ancillary tests can support clinical evidence *for* brain death, but they cannot trump clinical evidence *against* brain death. At the very least, in a question as weighty as life versus death, the benefit of the doubt should be given.

Space does not permit more than cursory mention that, after becoming officially brain-dead, Jahi underwent pubertal development, including three documented menstrual periods. This indicates some degree of hypothalamic function, which is not considered by official protocols as relevant to the diagnosis of brain death but is surely relevant to the "functioning of the organism as a whole" and hence should qualify as a "brain function" in the eyes of statutory law.

Jahi passed away on June 22, 2018, from abdominal complications unrelated to her neurologic condition. While independent expert evaluation of her apparent intermittent responsiveness is no longer possible, neuropathologic examination of her brain is pending, as of this writing.

Based on the compelling video evidence and the gross structural preservation of her brain in the 2014 MRI scan, I am convinced that, from early 2014, Jahi McMath was in a "minimally conscious state." Her case challenges the claimed infallibility of diagnostic criteria for brain death

and supports the hypothesis that global ischemic penumbra can mimic both clinical brain death as well as absent blood flow on radionuclide scans.¹³

1. A. Bloomekatz, "'Inevitable': As Jahi McMath Deteriorates, Brain-Death Case Nears End," *Los Angeles Times*, January 9, 2014.
2. H. Flori, "Supplemental Declaration Opposing Petitioner's Request for Court Order Compelling Children's Hospital to Perform Tracheostomy and Insert Gastrointestinal Tube," U.S. District Court, Northern District of California, January 7, 2014, 4:13-cv-05993-SBA.
3. T. Collins and L. Leff, "Experts: Clock Ticking for CA 'Brain Dead' Teen," *Associated Press*, January 6, 2014.
4. D. A. Shewmon, "Chronic 'Brain Death': Meta-analysis and Conceptual Consequences," *Neurology* 51, no. 6 (1998): 1538-45.
5. J. T. Giacino et al., "The Minimally Conscious State: Definition and Diagnostic Criteria," *Neurology* 58, no. 3 (2002): 349-53; J. T. Giacino, "The Vegetative and Minimally Conscious States: Consensus-Based Criteria for Establishing Diagnosis and Prognosis," *NeuroRehabilitation* 19, no. 4 (2004): 293-8; T. Bayne, J. Hohwy, and A. M. Owen, "Reforming the Taxonomy in Disorders of Consciousness," *Annals of Neurology* 82, no. 6 (2017): 866-72.
6. C. Machado et al., "A Reason for Care in the Clinical Evaluation of Function on the Spectrum of Consciousness," *Functional Neurology, Rehabilitation, and Ergonomics* 7, no. 4 (2018): 43-53.
7. C. G. Coimbra, "Implications of Ischemic Penumbra for the Diagnosis of Brain Death," *Brazilian Journal of Medical and Biological Research* 32, no. 12 (1999): 1479-87.
8. D. A. Shewmon, "Truly Reconciling the Case of Jahi McMath," *Neurocritical Care* 29, no. 2 (2018): 165-70.
9. A. L. Dalle Ave and J. L. Bernat, "Inconsistencies between the Criterion and Tests for Brain Death," *Journal of Intensive Care Medicine* (2018): doi:10.1177/0885066618784268; D. A. Shewmon, "False-Positive Diagnosis of Brain Death following the Pediatric Guidelines: Case Report and Discussion," *Journal of Child Neurology* 32, no. 14 (2017): 1104-17.
10. J. B. Roberson, Jr., L. E. Jackson, and J. R. McAuley, "Acoustic Neuroma Surgery: Absent Auditory Brainstem Response Does Not Contraindicate Attempted Hearing Preservation," *Laryngoscope* 109, no. 6 (1999): 904-10.
11. D. A. Shewmon, G. L. Holmes, and P. A. Byrne, "Consciousness in Congenitally Decorticate Children: 'Developmental Vegetative State' as Self-Fulfilling Prophecy," *Developmental Medicine & Child Neurology* 41, no. 6 (1999): 364-74.
12. Machado et al., "A Reason for Care."
13. Shewmon, "Truly Reconciling."

Revisiting Death:

Implicit Bias and the Case of Jahi McMath

BY MICHELE GOODWIN

For nearly five years, bioethicists and neurologists debated whether Jahi McMath, an African American teenager from Oakland, California, was alive or dead. However, on June 22, 2018, following complications associated with liver failure, her body gave way, succumbing to the conditions that had rendered her unable to speak, walk, see, eat, breathe independently, or use her arms and legs. After her body finally shut down, Jahi's parents laid her to rest. According to the family's attorney, Christopher Dolan, McMath's death certificate lists her cause of death as a result of hepatic liver failure.

Yet, according to the state of California, Jahi was no longer alive as of 2014—despite her parents' adamant claims to the contrary. On January 3 of that year, after a fateful tonsillectomy, a coroner issued Jahi's parents a certificate declaring her dead. The coroner reached the same conclusion that doctors and nurses at Oakland Children's Hospital and a judge had only weeks before: Jahi would never wake up, return to school, or resume life as she had known it before her surgery. Jahi's family claims that, to underscore this point, one of the doctors at Oakland Children's Hospital, where she was treated and declared dead, "pounded his fist on the table, saying, 'She's dead, dead, dead.'"¹

A chorus of bioethicists reached a similar conclusion and almost as emphatically. Arthur Caplan, the founding head of the Division of Medical Ethics at NYU School of Medicine, and David Magnus, a professor in medicine and biomedical ethics at Stanford, put it this way, Jahi may seem "life-like," but "it does not change

the facts" that she is dead.² Laurence McCullough, a distinguished emeritus professor of medicine and medical ethics at Baylor College of Medicine, concurred. As he told one reporter for the *Los Angeles Times*, "[H]er body will start to break down and decay. It's a matter of when, not whether."³ Caplan similarly warned, "She is going to start to decompose,"⁴ and he told reporters that "[t]o keep Jahi's body on machines is ethically wrong because definitive brain death is death and maintaining a corpse by artificial means is only slowing the inevitable decay and collapse of bodily remains."⁵ That was four years before the family eventually decided to discontinue life-sustaining treatment, and while Jahi appeared to be in a state of deep sleep, she never decomposed.

Jahi's family, a growing number of advocates, and some physicians struggled with these assessments. They questioned, how can she be dead? She was warm to the touch. Her skin was moist, and she menstruated. How can these signs of life amount to death?

Dead or Alive May Not Be the Right Question

Jahi McMath's case is far more nuanced than what appears on the surface—and only part of that has anything to do with definitional standards of death. After all, brain death (or death by any standard) is not the predictable outcome of a tonsillectomy, especially in children. In the United States, the morbidity rate associated with the procedure is roughly one death in fifteen thousand cases due to anesthesia complications, airway obstruction, or bleeding. That is, death might occur in 0.0066 percent of cases of tonsillectomies. The risk of mortality increases due to postoperative bleeding, but only in 2 to 4 percent of cases. So what went wrong in

Michele Goodwin, "Revisiting Death: Implicit Bias and the Case of Jahi McMath," *Defining Death: Organ Transplantation and the Fifty-Year Legacy of the Harvard Report on Brain Death*, special report, *Hastings Center Report* 48, no. 6 (2018): S77-S80. DOI: 10.1002/hast.963

this case, and to what extent does it have anything to do with brain death?

Rachel Aviv, a reporter for *The New Yorker*, wrote a detailed account of the family's experience in her 2018 article "What Does It Mean to Die?"⁶ Aviv reports that Jahi pleaded with her mother to cancel the surgery.⁷ Jahi questioned whether the doctor was properly prepared to operate on her. She asked her doctor, Frederick Rosen, how many times he had performed the surgery and whether he had enough sleep the night before. Rosen assured Jahi that he was well prepared to perform the tonsillectomy and that he had done the procedure hundreds of times.

Despite Jahi's protests, her mother, Nailah Winkfield, believed the procedure would offer the teen a better quality of life by allowing her to sleep more comfortably and cure her loud snoring. Jahi's snoring was so loud that it dashed hopes of slumber parties. Jahi suffered from sleep apnea and as a result was experiencing fatigue. The lack of sleep and compounding fatigue compromised her concentration and ability to focus in classes. Her mother thought the procedure would address these concerns because tonsillectomies are indicated as appropriate medical interventions in such cases.

Winkfield did not anticipate that, hours after the surgery, her daughter's bleeding would be so severe as to saturate the gauze packing her nose or fill a two-hundred-milliliter basin with blood. This was not normal following a tonsillectomy. And while Rosen, who performed the surgery, indicated in his medical records that there might be some risk of hemorrhaging because Jahi's right carotid artery was in close proximity to the pharynx, it appears that medical technicians responsible for the postoperative care and recovery did not register this important point in their medical records. Instead, one nurse urged Jahi to relax more and stop coughing.

As Jahi's medical gown absorbed more blood, a doctor "instructed the nurse on duty not to change [it]" so that he could assess how much blood she was losing that way.⁸ Jahi's mother questioned whether her daughter was receiving the standard and quality of care her daughter deserved given the circumstances. In response to the family's expressed concerns, one nurse wrote in Jahi's medical chart that physicians were aware of Jahi's unusual bleeding, but that "there would be no immediate intervention from ENT or Surgery."⁹ It is unclear whether doctors chose not to intervene because Rosen had left for the day or for some other reason.

Winkfield and her husband, Marvin, Jahi's stepfather, begged hospital staff to pay attention to Jahi's worsening condition. They believed she was losing too much blood. They were right. As Jahi's mom told Rachel Aviv, "[N]o one was listening to us, and I can't prove it, but I feel in

my heart: if Jahi was a little white girl, I feel we would have gotten a little more help and attention."¹⁰

Finally, in tears, Winkfield phoned her mother, Sandra Chatman, a nurse who worked for thirty years in a surgical center. Jahi's grandmother came as soon as she could. Upon arriving at Oakland Children's Hospital, she urged doctors to respond more aggressively to Jahi's hemorrhaging. It appears her pleas went unaddressed.

Within about two hours of arriving at the hospital, Chatman noticed that Jahi's oxygen saturation had dropped precipitously and alerted medical staff members responsible for Jahi's care. She was intubated, placed on a ventilator, and for two and a half hours, medical staff members worked to restore her heartbeat. Three days after her operation, following a spate of tests that determined she lacked a gag reflex, responsiveness to light, and other cognitive functions, a clinician of Oakland Children's Hospital declared her brain-dead.

The Politics of Health Care

It has been a mistake in the bioethics community to approach Jahi McMath's case merely as a study of brain death—despite its significance for contemporary debate and analysis on that topic. That is, while Jahi McMath's condition provides a compelling study for analyzing brain death, to ignore the underlying medical treatment, which resulted in her dire status, is not only a folly but also renders her an object. Arguably, circumscribing Jahi McMath's life status to a question of brain death fails to acknowledge and respond to a chronic, if uncomfortable, bioethics problem in American health care—namely, racial bias and unequal treatment, both real and perceived.

On any given day in the United States, disparities in the quality of health care and health outcomes for people of color in comparison to whites are evidenced in American hospitals and clinics. As decades of research show, these disparities are not entirely explained by differences in patient education, insurance status, employment, income, expressed preference for treatments, and severity of disease. Instead, compelling research indicates that, even for African Americans able to gain access to health care services and navigate institutional nuances, disparities persist across a broad range of services, including diagnostic screening and general medical care, mental health diagnosis and treatment, pain management, HIV-related care, and treatments for cancer, heart disease, diabetes, and kidney disease.¹¹ Among other things, research documenting health disparities reminds us that despite the desegregation of health care, race and ethnicity still matter in defining Americans' health experiences.

Landmark empirical research reveals enduring racial disparities in medicine that include higher rates of mor-

Circumscribing Jahi McMath's life status to a question of brain death fails to acknowledge and respond to a chronic, if uncomfortable, bioethics problem in American health care: racial bias and unequal treatment, both real and perceived.

bidity across numerous sectors for black Americans, ranging from pregnancy to heart failure.¹² The negative side of these disparities are experienced by black children as well as adults. What accounts for this? One theory is implicit bias. Examples of implicit bias may be observed at the macro and micro levels. At the macro level, the effects of implicit biases can be seen in the disparate geographic locations of medical facilities, affecting treatment options for inner city and rural Americans versus wealthier urban dwellers. Implicit biases also operate at the micro level. Well-meaning medical providers may exercise implicit (and explicit) biases that with overlying time constraints prohibit thoughtful consideration of unconscious opinions and objective determinants. As such, objective evidence may be missed in favor of cognitive shortcuts, population-based heuristics, and social categorizations. The problem is that cognitive shortcuts often form the basis for diagnostic judgments, medical decision-making, and recommendations regarding treatment.

The nagging questions for Jahi's family were whether race, class, or social status played a role in the quality of care the teen received. Could the family's socioeconomic status have predetermined Jahi's treatment? After all, but for Jahi's grandmother's alerting doctors about her falling oxygen levels, would the hospital's medical staff even have noticed their patient's distressed condition? When Jahi's grandmother asked one physician, "Why aren't you guys seeing about my granddaughter?" she noticed that he was "frowned up with his arms crossed."¹³ To her, "[i]t was like he thought we were dirt."¹⁴

These are the types of concerns unpacked in copious detail by researchers such as Harriet Washington, author of the much acclaimed *Medical Apartheid*,¹⁵ and Dayna Bowen Matthew, a health law professor at the University of Virginia and author of *Just Medicine: A Cure for Racial Inequality in American Healthcare*.¹⁶ Matthew argues that well over 84,000 people of color die each year due to unjust, unfair, and avoidable differences in the quantity and quality of care received compared to white counterparts.¹⁷

Numerous studies echo their concerns.¹⁸ A 2016 study revealed alarming, racially biased, and stereotyped views about the differences between blacks and whites among medical students and residents.¹⁹ The study included a group of 222 white medical students at the University of

Virginia, and the findings, though deeply troubling, are important in advancing nuanced discourse on racial bias in medical understanding and treatment. The investigators "examine[d] whether . . . racial bias is related to false beliefs about biological differences."²⁰

According to the authors, white medical students and residents harbored race-biased views about blacks and, as a result, made "less accurate treatment recommendations."²¹ Even more disquieting were the antiquated views about racial difference that first- and second-year medical students harbored. Many believed that black Americans age more slowly than their white counterparts, that their nerve endings are less sensitive, and even that blood coagulation is different between blacks and whites.²² An alarming percentage thought that blacks have thicker skin than white Americans and that they have "denser, stronger bones than whites."²³ Such misperceptions and stereotypic views about biological differences should not necessarily be attributed to racial animus, but are important to acknowledge in order to understand the medical experiences of black patients, improve medical delivery generally, and specifically address the critical gaps in the quality and quantity of care black patients receive.

What makes Hoffman's study so deeply compelling is that the concerns it addresses are not new. Over fifteen years after the publication of the Institute of Medicine's groundbreaking study *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, disparate treatment persists.²⁴ In that detailed study and account of racial biases, the authors found that even when accounting for socioeconomic factors, "race and ethnicity remain significant predictors of the quality of health care received."²⁵ Sadly, one of the few areas where black patients received "more" care than whites is amputations. Black patients are nearly twice as likely to have a limb excised from their bodies than are their white counterparts.²⁶

Implicit Bias and Medicine: A System Problem

For now, bioethicists should struggle not only with the question of brain death in Jahi's case but also with the underlying, arguably broader social implications of what her medical treatment and experience represented. Very likely, Winkfield and her family relocated Jahi to New Jersey

because they lost trust in her California medical providers. Likely, Jahi's family were flustered with a medical system that systemically ignores the vulnerable—particularly black Americans. Sadly, it is a system where stereotypes persist, and on too many matrixes blacks will receive less care and less quality of care than their white counterparts. Very likely, these experiences keep Winkfield adamantly disbelieving doctors' assessments of Jahi's status.

Jahi's case is about much more than the definition of brain death. As John Paris, a professor emeritus of bioethics wrote, "The historic mistrust of African Americans toward the medical community was on full display at community organized demonstrations outside Oakland Children's Hospital," where Jahi was treated.²⁷ Paris reminds readers that "accusations were made that the hospital disrespected the family, portrayed the parents as 'ignorant,' and 'wanted a quick end to Jahi's life' to limit malpractice costs."²⁸

Even while the McMath case inextricably involves sociolegal and cultural implications about race, sex, and the politics of health care, important lessons may be learned and insights gleaned from this tragedy. Namely, the practice of beneficence and social justice in medicine are not new concepts, but fundamental principles in bioethics that should be fastened to medical delivery. It is not novel to conclude that even if death were the unavoidable outcome in a high-risk case (Jahi's sleep apnea case was never described as such), patients and their families deserve to be treated with dignity and respect. For the foregoing reasons, Jahi's medical experience as well as her family's interactions with health care providers could serve as a case study in quality of care and implicit bias—not simply in brain death.

1. R. Aviv, "What Does It Mean to Die?," *The New Yorker*, February 5, 2018.

2. A. Caplan and D. Magnus, "Brain Death Really Is Death," *Time*, January 3, 2014.

3. Los Angeles Times Staff, "Jahi McMath: Expert Criticizes Keeping Girl on Ventilator," *Los Angeles Times*, January 13, 2014.

4. L. Szabo, "Ethicists Criticize Treatment of Teen, Texas Patient," *USA Today*, January 9, 2014, last updated January 10, 2014.

5. A. Caplan, "The Case against Care for Those Who Are Brain Dead," *Newsday*, January 9, 2014.

6. R. Aviv, "What Does It Mean to Die?"

7. Ibid.

8. Ibid.

9. Ibid.

10. Ibid.

11. M. van Ryn and S. S. Fu, "Paved with Good Intentions: Do Public Health and Human Service Providers Contribute to Race/Ethnic Disparities in Health," *American Journal of Public Health* 93, no. 2 (2003): 248-55; Council on Ethical and Judicial Affairs, "Black-White Disparities in Health Care," *Journal of the American Medical Association* 263 (1990): 2344-46; see Institute of Medicine, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* (Washington, D.C.: National Academies Press, 2003).

12. Centers for Disease Control, "Heart Disease Death Rates among Blacks and Whites Aged \geq 35 Years—United States, 1968-2015," March 30, 2018, at <https://www.cdc.gov/mmwr/volumes/67/ss/ss6705a1.html>; N. Martin, "Black Mothers Keep Dying after Giving Birth. Shalon Irving's Story Explains Why," National Public Radio, December 7, 2018.

13. R. Aviv, "What Does It Mean to Die?"

14. Ibid.

15. H. Washington, *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present* (New York: Harlem Moon Broadway Books, 2007).

16. D. B. Matthew, *Just Medicine: A Cure for Racial Inequality in American Health Care* (New York: New York University Press, 2015).

17. Ibid.

18. K. O. Anderson, C. R. Green, and R. Payne, "Racial and Ethnic Disparities in Pain: Causes and Consequences of Unequal Care," *Journal of Pain* 10 no. 12 (2009): 1187-1204; H. P. Freeman and R. Payne, "Racial Injustice in Health Care," *New England Journal of Medicine* 342 (2000): 1045-47; M. K. Goyal et al., "Racial Disparities in Pain Management of Children with Appendicitis in Emergency Departments," *JAMA Pediatrics* 169, no. 11 (2015): 996-1002.

19. K. M. Hoffman et al., "Racial Bias in Pain Assessment and Treatment Recommendations, and False Beliefs about Biological Differences between Blacks and Whites," *Proceedings of the National Academy of Sciences of the United States of America* 113 (2016): 4296-4301.

20. Ibid.

21. Ibid.

22. Ibid., at 4298.

23. Ibid.

24. Institute of Medicine, *Unequal Treatment*.

25. Ibid.

26. Ibid., at 74.

27. J. J. Paris et al., "'Brain Death,' 'Dead,' and Parental Denial," *Cambridge Quarterly* 23 (2014): 371-82, at 371, 378.

28. Ibid.

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