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 media 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

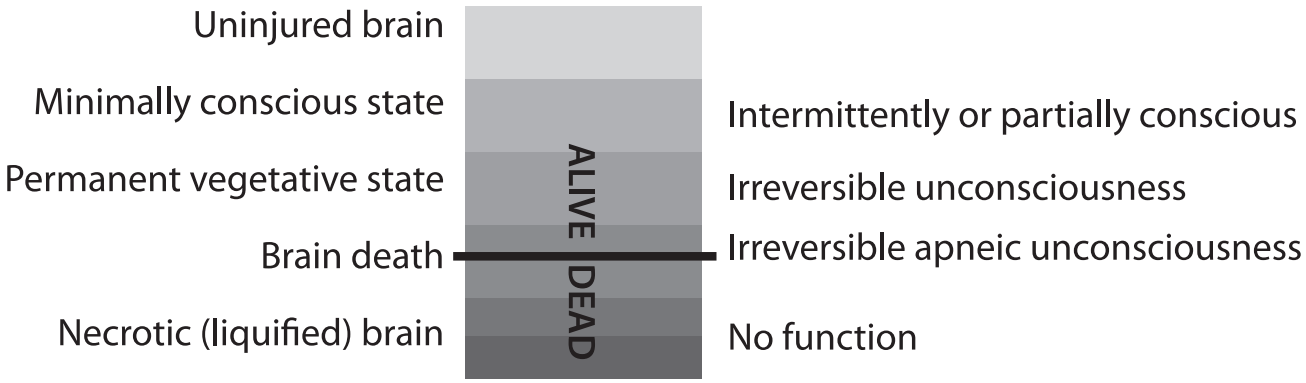
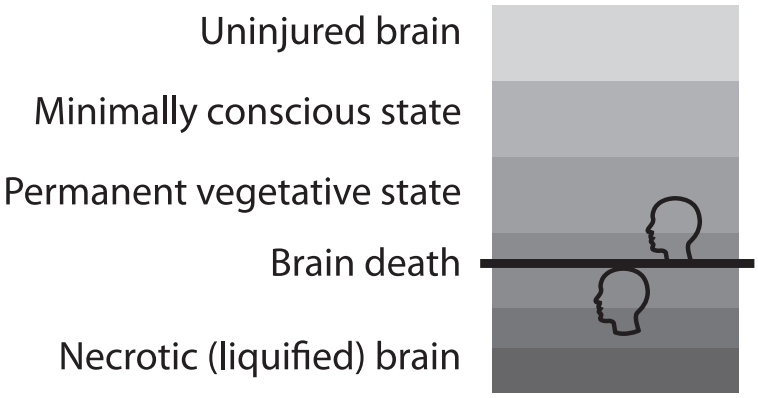


Figure 2. Brain Injury and Somatic Survival



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.