

VIEWPOINT

Defining Death—Making Sense of the Case of Jahi McMath

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Clearly distinguishing between the living and the dead is an essential function in any society, necessary for determining when people may be buried, when their wills may be executed, when efforts to keep them alive may be terminated, and when they may donate their organs, among other issues. The recent and ongoing case of Jahi McMath has raised some doubts about how this distinction is made in the United States.¹⁻³

Jahi McMath is currently a 17-year-old girl who experienced a massive hemorrhage after a complex tonsillectomy in 2013, leaving her brain-dead. Her family refused to accept the diagnosis and she was transferred to New Jersey, which by law prohibits physicians from declaring death by neurologic criteria when this would violate the religious beliefs of the patient. Now, more than 4 years after she was issued a death certificate in California, she is being kept biologically alive in an apartment in New Jersey, supported by a ventilator, tube feedings, and supplemental hormones. She has continued to grow and develop, even progressing through puberty. Her case has led many to wonder: How is it that society can consider a growing adolescent, albeit one with a devastating brain injury who needs a ventilator to

status on their 18th birthday, with virtually all of the rights, privileges, and obligations of adulthood. Yet from a biological or psychological perspective, not much has typically changed from the day before. Similarly, people are considered legally blind when their eyesight is 20/200 or worse, although visual loss usually is not all-or-none but rather occurs across a continuous spectrum of severity.

Failure to appreciate the difference between bright legal lines and the continuous spectrum of biological functioning underlies the confusion over Jahi McMath. Clinicians sometimes care for severely brain-injured children who are functioning slightly above the line that defines brain death. Many of these patients are in a vegetative state; some are ventilator dependent but do not meet all of the requirements of the diagnosis of brain death. These patients are legally alive, they are treated with life support when they become ill, and they may survive for many years. It should be no surprise then, that an individual like Jahi McMath, a patient who is functioning just below that line, may be biologically very similar to these patients and likewise may—with the necessary medical support—live for many years.

If this is the case, why are there not more patients like Jahi McMath? The answer is that the diagnosis of brain death functions as a self-fulfilling prophecy. In almost all cases, the diagnosis of brain death is quickly followed by removal of the ventilator or by organ donation, which invariably leads to cardiorespiratory death. But if life support is continued, patients like McMath may live for many years (the longest reported case of survival after careful determination of brain death is more than 20 years^{6,7}).

Cases like that of Jahi McMath cause great angst because they seem to cast doubt on the ability of the medical profession to distinguish between the living and the dead. The confusion disappears, however, with the recognition that law and biology function differently. The law necessarily depends on bright-line determinations to standardize many important societal distinctions, such as when a person becomes an adult, when a person is blind, and when a person is dead.

However, failure to appreciate this distinction has also led to some factually inaccurate comments from prominent bioethicists about the McMath case (“There isn’t any likelihood that she’s gonna survive very long,” “She is going to start to decompose,” and “You can’t really feed a corpse”). Comments like these, in the face of clear evidence to the contrary, erode the confidence of the public in the truthfulness and candor of the medical profession.

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breathe, to be “dead” in any commonsense meaning of the term?

To make sense of the case of Jahi McMath, it is important to examine the relationship between biology and law in medical practice. All brain injury can be described in terms of a spectrum of severity. The state termed “brain death” is near the very bottom of that spectrum, representing the loss of most—but not necessarily all—of the functions of the brain. This point on the spectrum is characterized by “irreversible apneic coma,” that is, the patient’s brain injury is severe enough to render him or her permanently unconscious and ventilator dependent.⁴ The Uniform Determination of Death Act (UDDA), adopted in 1981, draws a bright line at this point on the spectrum, such that patients functioning below that line are legally dead and those functioning above that line are legally alive.⁵

Although legal definitions are typically defined by bright lines, biology tends to be continuous. Consider, for example, that all citizens acquire a completely new legal

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The UDDA has served its purpose well. By drawing a bright line at the level of permanent unconsciousness and ventilator dependence, the UDDA has defined when a person should be considered dead, making it permissible for the person to be an organ donor if they wish and making it permissible for the health care system to refuse to continue to provide the patient with life support. Like many other legal bright lines, it is a social construction based on biological reality but not completely defined by it. Although the line is necessarily somewhat arbitrary, it represents a meaningful threshold, which over several decades has had widespread societal acceptance.

As with many other laws, decisions need to be made about how to treat those who hold religious or principled objections to the legal standard. In the case of brain death, New Jersey has carved out a religious exemption, and some other states require that these objections be given "reasonable accommodation."² But it would be a mistake to believe that the case of Jahi McMath and others like it present a fundamental challenge to the diagnosis of death by neurologic criteria. All that is required is more clarity about how the continuous nature of biological functioning is translated into the requirements of the law.

ARTICLE INFORMATION

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