

Why Brain Death Is Death

Fran Lowry | September 19, 2014

In the final weeks of December 2013, Jahi McMath, a 13-year-old girl from Oakland, California, went into Children's Hospital & Research Center Oakland for a tonsillectomy, adenoidectomy, and removal of redundant sinus tissue.

Tragically, complications ensued. Jahi was declared legally dead on December 12, 2013, following 2 assessments by the hospital's neurologist and pediatric intensivist. The family requested that her care continue, but the hospital maintained that it was no longer obligated to continue providing medical care as the child was dead.

Today, Jahi continues to receive care at a facility (name and location undisclosed) that agreed to take her after Children's Hospital released her body. The facility has fitted Jahi with a feeding tube, and her mother gives her a weekly manicure and pedicure.

There is a [Facebook page](#) where people can write encouraging messages for Jahi's family and for Jahi herself. Supporters of Jahi declare that her brain may improve. That is still her mother's hope.

As of this writing, there have been 26,444 "Likes" since Jahi's mother joined Facebook on December 17, 2013, 5 days after her daughter was declared brain dead.

The case has garnered widespread media attention and has led to a "legal quagmire," Christopher M. Burkle, MD, JD, and his colleagues from Mayo Clinic, Rochester, Minnesota, write in a review [published online](#) September 12 in *Neurology*.

The Mayo Clinic physicians decided to analyze the pertinent medical, legal, and ethical issues raised by the McMath case to help doctors and others respond to questions about brain death.

Brain death is irreversible and determined by absent motor responses, loss of all brainstem reflexes, and apnea after a CO₂ challenge. It is not determined by further waiting. Support measures often fail and the ability to maintain a brain-dead body is "virtually impossible," Dr. Burkle and his colleagues write.

They add that brain death is a distinct clinical neurologic state and is different from all other manifestations of acute or prolonged coma, where patients may eventually 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," they write.

Standards for determining pediatric brain death were established more than 25 years ago and have been adopted and revisited by the Society of Critical Care Medicine, the American Academy of Pediatrics, and the Child Neurology Society. The diagnosis, in a [guideline released in 2011](#), requires 2 examinations, 12 hours apart, by 2 different attending physicians in children 1 year or older.

[Adult brain death diagnosis](#), on the other hand, requires just 1 full examination, with optional confirmation by another physician.

Dr. Burkle and colleagues acknowledge that they do not know the exact medical details surrounding Jahi McMath, but they do have access to the description of the neurologic examination of the court-appointed neurologist. That examination shows a full neurologic examination, apnea test, isoelectric electroencephalography, and a nuclear scan with no demonstrable uptake.

The fact that Jahi is still supported by artificial means, although remarkable, is 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," they write.

Jahi was declared dead by the hospital, and 18 days later, the Alameda County Superior Court judge upheld the declaration, agreeing that Jahi's medical condition met the definition set out by California's Uniform Determination of Death Act.

That Act states that an individual who has sustained either irreversible cessation of circulatory and respiratory functions or irreversible cessation of all functions of the entire brain, including the brain stem, is dead.

The judge also gave Jahi's family time to find another facility and mandated that the hospital continue ventilator support until that time.

Dr. Burkle and colleagues write that this case highlights the need for neurologic determinations of death and state laws on the matter to be 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," they write.

They add that there is a strong consensus about brain death as a result of decades of discussion 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 we encourage our colleagues in critical care, neurosciences, and biomedical ethics to engage patients and local communities about matters related to brain death," they conclude.

Difficult Reality

Writing in an [accompanying editorial](#), James L. Bernat, MD, from Dartmouth-Hitchcock Medical Center, Lebanon, New Hampshire, and Dan Larriviere, MD, JD, from Ochsner Medical Center, New Orleans, Louisiana, agree that brain death remains poorly understood, not only by the public but by health professionals.

"I agree with the statements the authors made and do not have any significant disagreements, other than to point out to readers that there are scholars, physicians, lawyers, philosophers, theologians, and others who oppose brain death, even though it is generally accepted and has been the law of the land, and, in many physicians' minds, is uncontroversial," Dr. Bernat told Medscape Medical News.

The reality of brain death can be very difficult for families to come to terms with, he said.

"There are counterintuitive aspects to brain death because the patient's heart is still beating, blood is circulating. Patients do not look like they are dead in terms of the traditional understanding of what a dead body looks like. That is one factor that can make brain death hard to understand," Dr. Bernat noted.

"The second is that many cases of brain death are from traumatic brain injury, for example in a young person. They go from being in superb health one moment to being in this condition the next moment and that's very hard to accept.

"The third aspect is that there is confusion about the term 'brain death.' It's not a good term, it is misleading. Many people confuse it with coma and they have read newspaper accounts of people believed to be in an irreversible coma who recover, and that adds to the scepticism or gives them hope that their loved one will simply recover. That does not happen if the diagnosis of brain death has been made accurately," Dr. Bernat said.

The proper term for brain death would be "death determined by the absence of brain function," Dr. Bernat suggested.

"This would be to show that it is death, it isn't just that the brain is dead, but that the person is dead. But there is no clear way to say it short-hand. All of the clearer descriptions are a sentence or a long phrase, so brain death has caught on as a short name. It's in the vernacular, so it's not something that is going to go away."

Explaining that a loved one is brain dead to a family can be difficult and requires sensitivity and compassion on the part of the health professional delivering the news, Dr. Bernat said.

"These are poignant and emotional conversations and often take place over time. It isn't something that you just swoop in and say, and then leave. It requires reinforcement and questions and answers, calmly and compassionately," he said.

"The points that need to be communicated are that it's hopeless, irreversible, and that there is no benefit for any type of treatment. It's accepted as death in the law and it offers an opportunity for organ donation."

The possibility of organ donation should be raised but carefully, he added.

"There is a lot of discussion about the optimal way to do that. The opportunity for organ donation provides a transcendent good that many family members feel is very meaningful. The fact that their loved one's death would contribute to the survival of another person can be sustaining. But one needs to make sure that organ donation is not driving the brain death determination. It is a very difficult communication, and something that I think requires a lot of experience to do well," Dr. Bernat said.

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