

HEALTH

At Issue in 2 Wrenching Cases: What to Do After the Brain Dies

By **BENEDICT CAREY** and **DENISE GRADY** JAN. 9, 2014

In one way, the cases are polar opposites: the parents of Jahi McMath in Oakland, Calif., have fought to keep their daughter connected to a ventilator, while the parents and husband of Marlise Muñoz in Fort Worth, Tex., want desperately to turn the machine off. In another way, the cases are identical: both families have been shocked to learn that a loved one was declared brain-dead — and that hospital officials defied the family’s wishes for treatment.

Their wrenching stories raise questions about how brain death is determined, and who has the right to decide how such patients are treated.

“These cases are quite different from those we’ve known in the past,” like Karen Ann Quinlan, Nancy Cruzan or Terri Schiavo, said Dr. Joseph J. Fins, director of the medical ethics division at NewYork-Presbyterian/Weill Cornell hospital. He explained: “Those patients could all breathe without a ventilator. They were in a vegetative state, not brain-dead, and that distinction makes all the difference.”

A person who has received a brain-death diagnosis cannot breathe on his or her own and is legally dead, in all 50 states. In two states, New York and New Jersey, hospitals must take into account the family’s religious or moral views in deciding how to proceed in such cases. In all others, including California and Texas, hospitals are not required to consult the family in how to terminate care.

Doctors at Children’s Hospital in Oakland pronounced Jahi, 13, brain-dead on Dec. 12. She developed complications after surgery for sleep apnea and lost a large amount of blood. Ms. Muñoz, 33, got the diagnosis at John Peter Smith

Hospital after she collapsed from a blood clot when she was 14 weeks pregnant. The hospital, citing a state law, refuses to remove the ventilator because it would harm the fetus, now in its 20th week.

The two cases are poignant in part because of a biological quirk of the body: The patients' hearts continue to beat. Hearts have their own pacemaker, and with ventilation, the heart can continue to beat for days, even up to a week. But with more aggressive care, it can last months and longer after brain death, experts say, depending on the health of the patient and how much treatment is provided.

That ventilation saved the fetus in the Muñoz case, and probably in the nick of time, said Dr. R. Phillips Heine, director of maternal and fetal medicine at Duke University's medical school. The diminished blood flow to the fetus when the mother collapsed — she is thought to have been passed out for about an hour before receiving care — “may lead to adverse effects over time, but we have no way to predict that,” Dr. Heine said.

A prolonged heartbeat has created the perception of life for Jahi's family, while for Ms. Muñoz's relatives it represents a denial of the right to die.

“The way I've described this state is that a part of the organism is still alive, obviously, but the organism as a whole — the human being — is gone,” said Dr. James L. Bernat, the Louis and Ruth Frank professor of Neuroscience at Dartmouth's medical school.

Diagnosing a brain as “dead” is a matter of determining the function of its most primitive area, the brain stem. The brain stem, the plug of neural tissue at the base where the spinal cord enters the skull, is the body's plant manager, sustaining systems like muscle tone, metabolic equilibrium and ventilation.

Testing its function requires some expertise, because people with severe brain injuries are often unresponsive and appear brain-dead when they are not. A coma, for instance, is an unresponsive state that often represents a period of recovery for the brain stem and other areas. People generally emerge from a coma within two to three weeks after their injury. If they do not, they may enter a vegetative state, in which the brain stem is functioning but higher brain areas are shut down, or what is called a minimally conscious state — in which a patient is

occasionally responsive, but not predictably. People who emerge from a vegetative state are thought to pass through a minimally conscious stage before becoming consciously aware.

To determine brain death, four elements are needed, experts said. First, the doctor must rule out other possible explanations for the unresponsive state, like anesthesia, diabetic coma or hypothermia. An injury must also be established, like a blow to the head or blood loss.

Doctors then test the function of so-called cranial nerves, including one that runs to the eye and activates blinking; another in the throat that causes gagging; and a third in the inner ear that allows the eyes to focus on an object when the head is moving. Each of these engages the brain stem. If touching the person's cornea with a Q-tip does not trigger a blink, or touching the back of the throat brings no gagging, the brain stem is either out of commission or close to it.

The last step is called an apnea test. To perform this, doctors allow the carbon dioxide level to slowly increase in the patient's blood; once the concentration reaches a certain threshold, anyone with a partly functional brain stem will wheeze for breath. This is the true litmus test for brain death, and it can take about 20 minutes, during which doctors must not leave the room even for a moment, said Dr. Panayiotis N. Varelas, director of the neuroscience intensive care unit at Henry Ford Hospital in Detroit.

“If the patient tries to breathe, you abort the test immediately and say the patient is not brain-dead,” Dr. Varelas said.

The exact timing of these tests, and the number of times they are done — some doctors perform them all once; others do so twice, separated by a number of hours — vary from hospital to hospital, surveys have found. But botched cases are very rare, experts said; people diagnosed with brain death do not come back.

Under New York and New Jersey laws, people can prolong the provision of oxygen to keep a person's heart beating for religious or moral reasons. But elsewhere, “life support” is superfluous, if there is no life to support. In that context, the McMath and Munoz cases are different, said Dr. Fins, who is working on a book titled “Rights Come to Mind: Brain Injury, Ethics and the Struggle for Consciousness.”

The parents of Jahi McMath “are hoping their daughter will recover and asking to reverse a decision that isn’t under human control,” he said. “In the Muñoz case, the family is asking to reverse a decision that is under human control, and has to do with whether the mother would want to be a mother under these circumstances.”

Correction: January 9, 2014

An earlier version of this article referred incorrectly to the apnea test. The level of carbon dioxide in the patient’s blood is allowed to increase; it is not given through the ventilator.

Correction: January 10, 2014

An earlier version of a picture caption with this article misidentified the man in the white shirt to the left of Nailah Winkfield, the mother of Jahi McMath. He is Marvin Winkfield, not Omari Sealy, and he is Jahi’s stepfather, not her uncle. An earlier version of this correction included the same error.

Correction: January 11, 2014

An article on Friday about brain death and what the diagnosis means misstated the date on which Jahi McMath was declared brain-dead following complications from surgery at Children’s Hospital Oakland. She underwent surgery on Dec. 9 and was declared brain-dead on Dec. 12, not on Dec. 9.

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