

1. Mark your confusion.
2. Show evidence of a close reading.
3. Write a 1+ page reflection

Ethicists criticize treatment of teen, Texas patient

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The cases of two young women — a California teen and a pregnant Texas mother, both on ventilators after devastating injuries — have shone a spotlight on difficult end-of-life issues, which can be especially painful when tragedy leads a previously healthy person to be declared brain dead. In both cases, families disagree with the way that hospitals have treated their loved ones. The teen's family wants her kept on the ventilator; the Texas mom's husband wants his wife's ventilator removed.

The stories of Jahi McMath, 13, and Marlise Munoz, 33, are complicated not just by grief, but by the public's lack of understanding of the medical possibilities for people with little to no brain activity, says Arthur Caplan, head of the division of bioethics at NYU Langone Medical Center in New York City.

The California child, McMath, was pronounced brain-dead by the coroner's office, after suffering rare complications from a Dec. 9 tonsillectomy. Unlike patients in a vegetative state, who have some brain activity, people declared brain-dead are no longer alive, says Laurence McCullough, a professor at the Center for Medical Ethics and Health Policy at Baylor College of Medicine in Houston. The term "brain death" simply refers to the method of determining death, he says. By moving the lungs up and down, a ventilator can "give the appearance of life," Caplan says. That also can stimulate a heartbeat. Once the machines are disconnected, however, breathing and circulation stop.

Jahi's parents, unwilling to disconnect her from machines that keep her heart beating artificially, have transferred their daughter from Children's Hospital Oakland to an unnamed facility, where she has had one tube inserted in her throat and another into her stomach to pump in nutrition. The family's attorney, Christopher Dolan, says Children's Hospital made it more difficult for Jahi's family's to process her loss.

"If the facility had been more compassionate and less aggressive and had realized that you don't do this to somebody at Christmas, maybe the family would have had more time to process this," Dolan says. "This is the same hospital that they think made an error with their child, who was then rushing them out the door. They thought the hospital had let them down. ... They just need some time."

The family, who are Christian, is still hoping for a miracle, Dolan says. He acknowledged that he has been criticized for giving the family false hope.

"Is that unethical? Then is church unethical?" Dolan asked in an interview. "A huge part of our nation on the 25th of December was praying to a baby who was born as a miracle, who healed people as a miracle and who died and was resurrected as a miracle."

Jahi's condition is very different from that of Terri Schiavo, who died in 2005 after years in a permanent vegetative state, McCullough says. Although Schiavo had limited brain functioning, she was alive. Decisions about Schiavo's health care were far less clear-cut than those involving Jahi, Caplan says. Only Schiavo's brain stem — the lower part of the brain that controls basic functions such as breathing and swallowing — was active. She did not need a ventilator, because she could breathe on her own. But she could not think, feel, sense or be aware, Caplan says. Because Schiavo's family disagreed about what her wishes would have been, they fought a lengthy court battle over whether to remove her feeding tube. Her husband eventually prevailed. The feeding tube was removed, and she died two weeks later.

In Texas, Munoz suffered an apparent blood clot in her lungs in November, when she was 14 weeks pregnant. Although her husband describes her as brain-dead, the hospital refuses to remove her from a ventilator. In media reports, Erick Munoz has said that his wife didn't wish to be kept alive artificially and would have wanted to be taken off a ventilator.

John Peter Smith Hospital has characterized the woman's condition differently, saying Munoz is in "serious condition in the intensive care unit."

Since only living people can be described as seriously ill, the hospital's description implies that Munoz is alive, not brain-dead, McCullough says. Hospital officials have said that they are following Texas law,

which states that a person may not withdraw or withhold life-sustaining treatment from a pregnant patient. If Munoz is alive but unconscious, McCullough says the hospital shouldn't be blamed for taking the legally cautious approach of keeping her on life support. According to the Uniform Determination of Death Act, adopted by most states, death is defined as "irreversible cessation of circulatory and respiratory functions" or "irreversible cessation of all functions of the entire brain, including the brain stem."

There are no ethical issues in the care of someone who has been declared brain-dead, because the patient is now a corpse, McCullough says. In Jahi's case, "orders should have been immediately written to discontinue all life support," says McCullough, who has no personal knowledge of Jahi's case. "The family should have been allowed to spend some time with the body if they wished. And then her body should have been sent to the morgue. That is straightforward. There is no ethical debate about that."

Both Caplan and McCullough were critical of the unnamed medical facility that agreed to put Jahi's body on a ventilator. "What could they be thinking?" McCullough says. "Their thinking must be disordered, from a medical point of view. ... There is a word for this: crazy."

Caplan agrees: "You can't really feed a corpse."

McCullough says he worries about the emotional, spiritual and financial damage that the parents will suffer. "Insurance doesn't pay for dead people," he says. He also worries about the psychological effect of seeing the girl's body, which is already said to be deteriorating, continue to break down. "Are there some living cells in the body? Not all the cells die at once. It takes time. But her body will start to break down and decay. It's a matter of when, not whether."

Jahi's new doctors are "trying to ventilate and otherwise treat a corpse," Caplan said. "She is going to start to decompose."

Dolan says that Jahi's family understands that her body could deteriorate. "They're not blind to these realities," Dolan says. "The mom has said that if her daughter is decaying, if she is suffering, that she will pull the vent."

The case of Munoz, the Texas mother, is very different if she is, as her husband claims, brain-dead.

In that case, "you have a pregnancy in a cadaver," McCullough says. "Then the law no longer applies." If Munoz is dead, and the hospital wishes to continue ventilation to save her fetus, that is considered a medical experiment, and should undergo careful consideration by a committee of experts, McCullough says. "In desperate cases, you respond with very careful thought and deliberation," says McCullough, who chairs the fetal therapy board at Texas Children's Hospital.

Given that Munoz suffered a loss of oxygen to her brain because of the clot, the fetus may also have suffered grievous harm, as well, Caplan says. "You probably have a fetus who is terribly devastated," Caplan says. "I do think the family's wishes should be honored."

At this point, Munoz's fetus is not viable, says McCullough, noting that infants are generally not considered viable — or able to survive with full medical support — until the 24th week of a 40-week pregnancy. Caplan says the Texas legislature needs to rewrite its law, which he describes as overly broad. As it's written, Caplan says, the law says "you can't have a living will if you are pregnant, even one day pregnant."

Possible responses:

- Do you agree or disagree with Jahi's family's decision to keep her on a ventilator? Explain.
- Do you agree or disagree with Marlise Munoz's husband to take her off the ventilator? Explain.
- Who should have final decision on whether to "pull the plug" on a brain-dead patient? Explain.