Difficult choices seem all the more unfair when death suddenly strikes the young or the pregnant. The recent stories of three young women, two who were pregnant and all of whom were determined to be dead by neurologic criteria, have revived discussions of the ethics of end-of-life care, including self-determination, substituted judgment and other competing interests. Despite important differences in fact and circumstance, these stories provide rich context for contemporary discussions of autonomy, definitions of death, and even the role of financial cost in making decisions regarding end-of-life care.

The Stories.

Marlise Muñoz was a 33 year-old paramedic who was determined to be dead by brain function criteria but, it appears, not formally declared dead, two days after collapsing on her kitchen floor. She was 14 weeks pregnant at the time of her death. The hospital, a public county hospital near Fort Worth in Texas, refused the family’s request to end “life-sustaining treatment” on the grounds that state law prohibited the cessation of life-support to a pregnant woman. The Muñoz family successfully fought the hospital’s decision to continue treatment because the court held the law in question did not apply to persons already dead.

In Victoria, British Columbia, 32 year-old Robyn Benson lay in a hospital, dead by brain function criteria from a cerebral hemorrhage and pregnant with a 22-week fetus. With the consent and support of Robyn’s husband Dylan and family, the hospital administered treatment and support necessary to bring the fetus to term. The 27-week-old fetus was delivered by Caesarean section on February 8. Through his blog and website, Dylan Benson is raising funds to cover the expenses related to the burial of his wife, delivery of his son, and child-rearing.

Following surgery on her tonsils, Jahi McMath, a 13-year-old girl in Oakland, California, suffered complications that led her doctors to declare her dead by brain function criteria last December. Children’s Hospital Oakland informed the family, and the coroner issued a death certificate. The McMath family refused consent to terminate life support based on religious and observational belief that Jahi is not dead. A court-ordered mediation ended with an agreement to transfer the body to a long-term care facility amenable to the continuation of the treatment requested by the family. On January 5, the hospital reportedly released the body to the coroner’s office, which then released the body to the custody of Jahi’s mother. The family continues efforts to raise the funds necessary to cover expenses and sustain current levels of support.

Death.

The stories of Mrs. Muñoz, Mrs. Benson, and Miss McMath all involve determination of death and the end of life. In each instance, physicians determined that the patient was dead by brain function criteria. The McMath family rejected the declaration of death citing, in addition to religious convictions, witnessed behavior and physical responses as evidence that she is alive. Amid memories of Terri Schiavo, who existed for years in a persistent vegetative state before her death, the more recent tragedies have raised questions about the “types” of death.
The determination of when death occurs has evolved to meet advances in medical knowledge and cultural norms. The traditional determination applies when in ordinary medical judgment cardiopulmonary function has irreversibly ceased. This clinical criterion does not apply when a patient is supported by mechanical ventilation; instead, criteria developed by the American Academy of Neurology (AAN) are more appropriate. The AAN criteria, when competently applied, prevent a false positive determination that death has occurred, i.e., wrongly labelling a patient dead when the patient is still alive. Both cardiopulmonary and brain function criteria support the clinical judgment that there is cessation of all spontaneous activity in the brain and brain stem, from which such autonomic functions as ventilation, heart rate, and alertness originate. The condition is unlike Permanent Vegetative State (PVS), an irreversible loss of awareness in which the patient is still alive. Patients in PVS are sometimes referred to as “virtually dead,” which is both inaccurate and confusing.

Pregnancy.

The shared point of interest in the stories of Ms. Muñoz and Ms. Benson is the complexity added by pregnancy. The concept of the fetus as a potential citizen is the subject of extraordinary controversy in ethics, law, religion and politics. The point of gestation at which the state may justify action to protect that potential life over the objections of an adult citizen varies by state and country. In refusing the Muñoz family’s request to stop medical intervention, the Texas hospital cited the fetal protection provision of the state law applicable to advance directives. (See text box.) Despite agreement by all parties that the fetus was not viable, the hospital interpreted the statute as establishing for government a definitive role in the decision to end “life sustaining treatment” in a pregnant patient. The court disagreed and, during the hearing that preceded the order, noted that the statute did not apply to a dead patient and that the fetus was within the gestational age range during which abortion is legal in Texas. Mrs. Muñoz, if alive, could act legally to end the pregnancy; consequently, her husband could represent her interests in death without undue state interference. The Muñoz story suggests that a woman’s ability to legally end pregnancy under less extraordinary circumstances should inform the propriety of state intervention when the woman is dead by brain function criteria.
Regardless of state intervention, the analysis of ethical considerations in decisions involving mechanical and pharmacologic support for the brain-dead-yet-pregnant body is complicated. Reported outcomes for continued pregnancies of about 14 weeks in a cadaver are very poor, which means that such intervention should be considered experimental: the outcome cannot be reliably predicted.\textsuperscript{11} The outcomes for continued pregnancy in a cadaver for a fetus around 22 weeks gestation are better but, given the small numbers, the outcome cannot be reliably predicted.\textsuperscript{12} When an experiment is performed for the benefit of an individual patient, the fetal patient in this case, innovation occurs.\textsuperscript{13} The emerging standard is that clinical innovation should undergo prospective review and approval for its scientific, clinical, and ethical justification.\textsuperscript{14} There is no ethical obligation to continue pregnancy in a cadaver. A decision to continue pregnancy in a cadaver should not rest solely on the request of the father of the fetal patient or other family members.

**The cost.**

The implementation of the Affordable Care Act in the U.S. has encouraged the search for analyses of patterns in the use of healthcare resources that can increase efficiency and improve patient outcomes. As structural incentives and economic realities motivate providers and policymakers to identify models to improve quality as the means to manage costs responsibly, patients remain motivated to be cost-conscious. Fears of crushing medical debt are not yet the stuff of distant history. Fear of financial ruin motivates decisions to accept or reject medical treatment. What of the person who refuses medical treatment primarily to avoid leaving his family in debt? What of someone who wants to be “kept alive,” no matter what? At what point do patient autonomy and bodily integrity yield to fears about the financial health of surviving family and ethical responsibilities to manage scarce resources toward possibility of medical benefit? From what distance should society judge the decision? Who should bear the burden of expense and what does the legitimacy of the cost question in decisions about end-of-life care suggest about social attitudes, norms or sensibilities about affordability and human life?

The question of who should or would bear the costs of extreme medical interventions has followed the controversies that surround the McMath, Muñoz, and even the Benson story. In the case of Marlise Muñoz, the hospital released the body after nearly two months of expensive medical intervention. Where, as here, the provider administered costly treatment to a person

In the now-famous case of Karen Ann Quinlan, who lived in a persistent vegetative state after experiencing respiratory failure and irreversible brain damage, the hospital and treating physicians cited threats of criminal prosecution in refusing the family’s wishes to remove the ventilator.\textsuperscript{1} In granting the order protecting the providers from criminal prosecution, the New Jersey Supreme Court acknowledged the state’s interest in protecting the life of its citizens but also the right of the adult citizen to refuse or avoid indefinite use of artificial means of life support.
declared legally dead over the family’s objection, the apportionment of costs is not obvious. Assuming that the hospital seeks to recover the cost of the additional treatment, the extent of the family’s private insurance coverage is unclear. The private insurance industry traditionally resists covering the cost of medical treatment deemed unnecessary. In the event that the hospital, a county facility, absorbs the cost, then the ultimate payers are the taxpayers.

Cost was cited often as a concern throughout the McMath controversy. The hospital cited the responsible use of finite resources as a partial basis for its objection to administer medical treatment to the dead. The McMath case, an example of one hospital’s response to a family’s refusal to acknowledge death, illustrates the ethical considerations involved when the family’s inability or unwillingness to acknowledge death conflicts with the providers’ ethical responsibility not to squander medical resources by imposing treatment without prospect of medical benefit. Most jurisdictions within the United States do not impose on the provider a duty to continue artificial or extraordinary medical means of life support on a patient with no reasonable expectation of recovery.

As a separate point, the McMath story unfolded in California, where the law arguably creates an incentive to act in perversion of the ethics that commonly apply. Passed by the California State Legislature in 1975, the Medical Injury Compensation Reform Act (MICRA) places a $250,000 cap on non-economic damages from medical negligence. Legal observers note the hospital could face a verdict for economic damages substantially higher than the cap if Ms. McMath remained on a ventilator, because the jury could assess the cost to continue to care for her medical needs and her future lost wages due to her inability to work. Ms. McMath’s death would limit the amount recoverable to $250,000, even if a jury determined that a larger amount would more fairly compensate the family.

**Conclusion.**

A series of remarkable tragedies have captured the public’s attention, sentiment and ire regarding the determination of death and the continuation of pregnancy in a cadaver. By turns similar and distinct, together the stories illustrate ethical issues at the heart of end-of-life treatment decisions involving the young, or the young and pregnant. With the possible exception of the Muñoz case, none stands to upend bioethics or established medical practice regarding the continuation or cessation of life support to a person declared brain dead, or dead. Providers must not only respect the autonomy of the patient and family but also recognize any applicable legal limits on autonomy. The courts have not ruled on the constitutionality of the exclusion of pregnant women with terminal or irreversibly conditions for the provisions of the Texas Advance Directives Act.

The provider and, where the hospital is publicly funded, perhaps the state retain an ethical responsibility to manage the use of scarce medical resources. The duty not to waste medical resources must be tempered by the family’s decisions about treatment. Aside from judgments
about waste, the extraordinary cost of medical life support raises ethical concerns about the role of financial debt in balancing values involved in decisions to continue or end support.

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1 The title paraphrases a quote by British urban artist Banksy: “I mean, they say you die twice. One time when you stop breathing and a second time, a bit later on, when somebody says your name for the last time.”
2 Tex. Health & Safety Code §§166.001, et seq. Section 166.049 of the Advance Directives Act states that “[a] person may not withdraw or withhold life-sustaining treatment under this subchapter from a pregnant patient.”
3 The hospital terminated treatment on January 26, 60 days after Muñoz met the criteria for brain death on November 28, 2013.
6 The state has an interest in the preservation of the life of its citizens.
12 Id.
15 Grillo’s order and def.’s brief. See, for example, American Medical Association (AMA), Opinion 9.0652 – Physician Stewardship of Health Care Resources, AMA Code of Medical Ethics (Nov. 2012), avail. at http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/opinion90652.page. A provider may extend or alter the timeframe to allow the family time to adjust to the situation without running afoul of ethical responsibility to the patient and others to whom a duty is owed.
16 In a case involving the family’s refusal to consent to withdraw life support based on Islamic doctrine and observation, the Canadian Supreme Court recently held that Ontario’s Health Care Consent Act did not allow the hospital to limit or remove the consideration of the family’s involvement in legally-mandated proceedings before an independent ethics tribunal. Cuthbertson v. Rasouli, 2013 SCC 53 (2013).