The recent widely publicized cases of two young women kept on life support despite being declared brain dead have highlighted concerns about whether physicians, hospital leaders and the public fully understand the term “brain death” and whether physicians are effectively communicating what it means to patients’ families.

Experts say poor communication can contribute to serious public relations and legal problems for hospitals, as it did in these two cases. One case involves a pregnant woman, raising unique issues because at least a dozen states have laws restricting the ability of healthcare providers to end life support for terminally ill pregnant women, regardless of the wishes of the patient or the family.

“Patients and even some doctors are mixed up about the proper use of concepts like coma, brain death and persistent vegetative state,” said Art Caplan, a professor of bioethics at NYU Langone Medical Center, New York. As a result, he said the terms are often communicated to patients’ families in ways that are confusing and misleading. “I think doctors should simply say, ‘Susie is dead’ and shouldn’t use the term brain death.” Otherwise, he added, families may think their loved one’s “brain has died but the body may come back.”

Michael Silhol, a Dallas healthcare attorney and former board member of the American Health Lawyers Association, said hospitals should develop specific policies on how to engage patients’ families in discussing withdrawal of life support for brain-dead patients or transferring the patient to a different facility.

Neurologists and neurosurgeons differ in how they deliver the news to families that their loved one is brain dead, said Dr. James Bernat, a neurology professor at Dartmouth-Hitchcock Medical Center, Lebanon, N.H. Some say straight out that the patient is brain dead and treatment will be stopped, while others give the family time to accept the loss before discontinuing life support. But doctors should never provide false hope if they have determined brain death. “In the case of brain dead, there is no hope,” Bernat said.

Brain death occurs when all brainstem reflexes have stopped working, according to the American Academy of Neurology. Once those functions are gone, a human being is considered dead in all 50 states, both medically and legally. The only way to keep a brain-dead patient “alive” is through intensive life support, including ventilator care, which is what the two brain-dead young women are receiving.

When delivering news of brain death, physicians face the dual challenge of clearly conveying its irreversibility and that life support will be removed, while remaining compassionate and giving the family time to comprehend the loss. It’s a different conversation from explaining that a patient is in a coma, a vegetative state, or a minimally conscious state. Patients in these states remain alive because parts of their brain still function, though they may or may not be able to breathe independently.

In Texas, a young pregnant woman, Marlise Munoz, 33, who worked as a paramedic, was declared brain dead at the John Peter Smith Hospital in Fort Worth at 14 weeks of gestation. But the hospital refused to remove her from respirators, citing a Texas law that prohibits the withdrawal of life-sustaining treatment from a pregnant patient. Last week, her husband, Erick, filed suit to force the hospital to take his wife off life support.

In California, the family of Jahi McMath, 13, fought to keep her on life support at the Children’s Hospital & Research Center in Oakland despite her being declared brain dead following complications from tonsil surgery. The hospital refused, and on Jan. 5, per court order, the family transferred the girl to an undisclosed facility in another state. Some bioethicists have called the facility’s acceptance of McMath “crazy” and “irresponsible.”

Caplan said the only variability in laws governing brain death involves pregnant patients. There have been brain-dead mothers whose fetuses have survived to term, though no one can be sure how badly damaged the fetus might be before delivery.

In the Munoz case, though, a court may make the decision about whether to keep the young woman on life support.

“Having been in a similar position, I may have done the same thing as the John Peter Smith Hospital did,” said Silhol, who formerly served as general counsel for Parkland Hospital in Dallas. “In this case, there is a conflict between the laws. The hospital is in a no-win situation. No other state with the pregnancy statute has had to resolve this issue from what I know, so others will be looking to see what the Texas court decides.”

Caplan urges physicians and hospital staff to communicate the terrible news to families gently but firmly. “We like believing in miracles, that’s just one of the cultural facts about Americans,” he said. “But hospitals have authority to stop treating the dead. If you’re going to try to accommodate a family so they accept the fact that their loved one has died, you have to set firm limits on how that’s going to happen.”

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