Brain injury expert says important changes still needed to legal definition of death despite reform pause

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After surveying the views expressed by 41 advocacy, medical, and transplant-focused organizations on the Uniform Determination of Death

Act, a brain injury expert is calling for much-needed reforms to the legal definition of death in the United States. The recently announced pause by the Uniform Law Commission, which is spearheading revisions, is disappointing, the expert notes, but should not permanently stall practical fixes to longstanding problems with the Death Act.

"This study shows that most medical organizations support revisions of the Uniform Determination of Death Act to align the legal description of the neurological criteria for death with medical standards," said Ariane Lewis, MD, a neurocritical care specialist and professor in the Departments of Neurology and Neurosurgery at NYU Grossman School of Medicine.

Specifically, Lewis argues, the legal description for death needs to reflect medical guidelines, which do not require that loss of hormone function be considered when declaring someone brain dead. Moreover, Lewis says, the Death Act must be revised to include legal guidance for health care providers about what to do when a family objects to stopping mechanically assisted breathing for a relative who is already brain dead. The act, for example, should clarify when and for how long, if not indefinitely, a person can be kept on a ventilator after brain death if a family objects to it being removed.

Lewis says her survey results showed that 34 organizations (83%) favored revisions to the Death Act. However, she acknowledges that views about how to revise it varied. Some religious organizations and patient advocacy groups were opposed to using loss of brain function as a criteria for declaring death, favoring instead the traditional definition of death as having occurred after the heart stops beating.

Lewis, who also serves as director of neurocritical care at NYU Langone Health, has already shared her survey results and perspective with the commission, whose work to amend the Death Act was suspended in late

September. Lewis has been one of 100 observers working with the commission for the past three years on revisions to the statute.

Publishing in the journal *Neurocritical Care* online Oct. 25, the study involved a detailed review of the comments and viewpoints submitted to the commission between January and July 2023 by 41 organizations impacted by the Death Act.

Historically, a person was considered dead when their heart stopped beating and they could no longer breathe on their own. Technological advances in mechanical ventilation have changed that, allowing people, in some cases, to keep breathing after they had suffered catastrophic brain injuries leading to coma, and had lost the nerve function needed for them to breathe on their own. Such cases led in 1981 to the U.S. Uniform Determination of Death Act, which defined death as either the irreversible cessation of all brain or cardiopulmonary functions. This definition was adopted by all American states as the legal basis for declaring a person dead.

The act, however, failed to specify the medical tests needed to determine whether someone was dead. Furthermore, a small number of states allow families to voice objections on religious grounds. This includes some Orthodox Jews, Muslims, and Catholics who equate withdrawal of mechanical ventilation to euthanasia, even after a person has been declared brain dead. Dozens of lawsuits have been filed against health care facilities by families wishing to keep a relative, who has already been declared brain dead, on mechanical ventilation indefinitely.

Citing the need for more legal guidance for physicians, Lewis is calling on the commission to accept international and national medical standards for death by neurological criteria. Among these are guidelines published by the American Academy of Neurology, Society of Critical Care Medicine, American Academy of Pediatrics, and Child Neurology

Society, none of which require the loss of hormone function when declaring someone brain dead.

Lewis points out the loss of "all functions of the entire brain," which could also cover cessation of hormone secretion, is included in the act's definition of death. However, such loss of hormone function is not needed to be declared dead by brain criteria using current medical standards.

The Death Act's definition, Lewis argues, is not only too broad, but it is also impractical because there is currently no medically established standard for measuring whether and when hormone secretion from the brain has stopped. Thus, she says, the act should be clarified to specify what brain functions must be lost in order to declare someone legally dead, recognizing that loss of hormone secretion should not be among the criteria.

Another study finding was that patient advocacy groups favored revisions to the act that require family consent before discontinuing mechanical ventilation after a person is declared dead. Medical organizations, Lewis says, are opposed to this position.

"The results of this survey show that while stakeholders support revisions to the Death Act, medical organizations and patient advocacy groups are deeply divided on the approach to do this," said Lewis. With prospects for consensus slim and the commission's efforts paused as a result, Lewis concludes that "without revisions to the law, it remains unclear what tests are required for declaring someone brain dead, and physicians and the public do not have legal guidance about how to resolve conflicts when families object to death by brain criteria."

More information: Perspectives of Medical Organizations, Organ Procurement Organizations and Advocacy Organizations about Revising

the Uniform Determination of Death Act, *Neurocritical Care* (2023).

Provided by NYU Langone Health