American College of Physicians
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June 7, 2023

Uniform Law Commission
Determination of Death Committee
The Honorable Samuel Thumma, Chair
Eric Weeks, Vice Chair
Professor Nita Farahany, Reporter
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Chicago, IL 60602
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Dear Uniform Law Commission Determination of Death Committee Chair Samuel Thumma, Vice Chair Eric Weeks, Professor Nita Farahany and Members:

On behalf of the American College of Physicians (ACP), I am writing to share comments regarding updating of the Uniform Determination of Death Act (UDDA). We very much appreciate the work of your Committee on this complex topic.

ACP is the largest medical specialty organization and the second-largest physician membership society in the United States. ACP members include 160,000 internal medicine physicians (internists), related subspecialists, and medical students. Internal medicine physicians are specialists who apply scientific knowledge and clinical expertise to the diagnosis, treatment, and compassionate care of adults across the spectrum from health to complex illness. Standards for the determination of death, of course, are of critical importance to our patients, our patients' families, and us.

We are concerned about your June 9, 2023 informal session draft, and about what we had been hearing and reading in press coverage about your deliberations, as well as proposals from observers to your group and others in medical journals. These competing proposals included everything from eliminating brain death as a standard to favoring neurorespiratory criteria (which are asserted to be merely a standardization of the neurological determination of death, but which in reality redefine death itself). Also of concern is the extent to which issues of organ transplantation and organ availability seem to be influencing efforts to modify the UDDA. While revisiting the more than 40-year-old UDDA is clearly indicated, ACP urges caution in any revisions. How death is determined raises profound ethical issues and has implications for patients, families, and for public trust in physicians, the medical profession, and health care. Honesty, transparency, respect, and integrity in how death is determined and communicated must govern any revisions to the UDDA.

ACP Policy

ACP supports maintaining circulatory death and whole brain (neurological) death standards for determining death as separate, independent standards.

The current UDDA-- and the ACP *Ethics Manual*-- state two independent standards, that death is to be determined as either circulatory/respiratory death *or* neurological death. Circulatory/respiratory functions and brain functions are biologically related (e.g., at the level of the brainstem, which controls respiration and circulatory functions, and because the heart and lungs support the brain), but conceptually distinct. Evidently the 1981 UDDA authors considered but rejected the idea that circulatory death was only death because it led to brain death. We agree.

ACP recommends one modification to the UDDA: to replace the word "irreversible" with "permanent" in clause (1) to read that "An individual who has sustained either (1) ~~irreversible~~ permanent cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain stem, is dead. A determination of death must be made in accordance with accepted medical standards."

Use of the term irreversible in both standards causes confusion. "Irreversible" is understood to describe circumstances in which physiological functions cannot resume because it is not biologically possible. "Permanent" means either circumstances in which physiological function cannot resume (i.e., is irreversible) or those in which function will not resume (e.g., because resuscitation, though possible, will not be pursued out of respect for the patient's preferences). When a patient with an order not to be resuscitated arrests, that patient *could* be resuscitated but is not (consistent with appropriate medical decision making). The heart has not stopped irreversibly, but it has stopped permanently. Permanent and irreversible are not synonyms here. Advances in life-sustaining therapies and patient rights mean permanent is the more accurate and appropriate term.

"Irreversible," however, remains the best term regarding brain death. Legal, ethical, and medical standards for determining brain death include the requirement that the loss of brain functions be irreversible (i.e., that reversible causes of the patient's medical condition be ruled out). Critically, using permanent for brain death would inappropriately allow determinations of death when hypothermia or drug intoxication, for example, are reversible.

Therefore, ACP supports what your draft revision identifies as Option 1 (containing your style committee edits) and with our one-word change described above, to read:

Section 3. Determination of Death
(a) An individual is dead if the individual has sustained:
(1) ~~irreversible~~ permanent cessation of circulatory and respiratory functions; or
(2) irreversible cessation of all functions of the entire brain, including the brain stem.
(b) A determination of death must be made in accordance with accepted medical standards.

ACP opposes your revision Option 2.

ACP supports retaining the whole brain standard, the "irreversible cessation of all functions of the entire brain," for determining death according to neurological criteria and opposes so called "higher brain" function standards. While some countries determine death according to loss of "higher brain" functions, ACP opposes revising the UDDA in this manner.

Whole brain determination of death is based in an "unambiguous and fundamental biological model" not a social construct or value judgment. It is more amenable to clinical testing than the mysterious phenomenon of higher-level consciousness and is a firmer foundation for the determination of death. Recognizing the distinction between molecular activity within individual cells and clinical brain functions, it does not require (and never has required) cessation of all "cellular activity." This accepted standard also reflects the fact that no single brain function uniquely indicates the presence of life, and it minimizes the likelihood that an individual could be wrongly determined to be brain dead.

ACP recommends that the medical tests used for determining death align with standards of death determination, not vice versa, and that the language of the UDDA that "A determination of death must be made in accordance with accepted medical standards" be maintained as is without changes.

Determining death requires clinical examination. The UDDA says that death should be determined "in accordance with accepted medical standards" but intentionally did not specify which tests must be used. Tests used to determine death must align with the standards-- as a medical matter, not as a legal requirement.

Importantly, as the President's Commission and UDDA drafters recognized, clinical and scientific tests used to determine death do not define death; instead, they confirm it. Technology is constantly changing; new ancillary tests to confirm death have and will be developed. But this does not mean every test must be used for every individual patient. Medical judgment is required, just as ancillary tests already play an important role in some but not all determinations of death (e.g., when facial trauma prevents pupillary examination, or neuromuscular disease complicates reflex testing).

The standards for determining death should not be changed to accommodate testing approaches; instead, testing should be more sensitive and specific to meet the standards for determination of death. This issue is not unique to the determination of death. When a test is inaccurate (e.g., as some early COVID-19 tests were), the appropriate response is to improve the test, not alter the definition of health or illness. In some cases of the determination of death, additional tests in accordance with medical standards will be necessary. The fewer or less stringent the criteria used for determining death, the greater the likelihood for falsely determining a patient to be dead.

Contrary to some current proposals, good reasons exist for medical standards not to be made legal requirements, especially since new tests can emerge and be adopted. Making current tests the legal standard means defining death by how it is determined; instead, the standards for determination of death should dictate which tests are developed and used. In addition, this reflects the clinical judgment and unique expertise of medicine, which is characterized by a

"specialized body of knowledge" that is learned and shared over time, and by its commitment to putting patients first.

Lastly, determination of death is a distinct issue from organ transplantation. Criteria for determining death should not be governed by organ transplantation needs.

Given the connection between how death is determined and organ transplantation, there is risk that determination of death will be driven, explicitly or implicitly, by interest in obtaining organs for transplantation. Maintaining separation is critical for avoiding potential conflicts of interest and for preserving trust in the standards by which death is determined, as well as trust in the organ transplantation system.

Conclusion

The stakes here are very high. Trust in health care has been challenged by the COVID-19 pandemic and persists-- perhaps more than ever-- today. Getting this right is essential to maintaining trust in physicians and in the medical profession at death and caring for our patients throughout their lives. Ironically, major changes in the UDDA like adopting a neurorespiratory standard are not only wrong in our view, they could make such a "uniform law" encourage less rather than more uniformity, leading to many states not adopting a revised law. In fact, some states might even adopt more stringent criteria for determining death. Moreover, a neurorespiratory approach sends a message that death is not a biological reality, and seems to have resulted in the Committee proposing "accommodations"-- which compound the problem and will lead to more variability and less uniformity. In a March 2023 *JAMA* article on the determination of brain death, Robert Truog, MD observed that problematic issues related to the UDDA "have not been overwhelming in either their number or their impact, and practice under the current UDDA has been generally well-accepted by the public for more than 40 years." We agree. A major revision is not indicated.

In summary, ACP supports: 1) maintenance in the UDDA of the two current independent standards of determining death, cardiopulmonary and neurological; 2) one clarification to the UDDA, substituting permanent for irreversible only with respect to the cardiopulmonary standard; 3) maintenance of the whole brain death standard; 4) alignment of medical testing with the standards, not the other way around; and 5) complete separation of issues regarding the determination of death from issues around organ transplantation. We also believe educational efforts for health professionals, patients, and the public on these issues would be useful.

We hope our comments are helpful.

Sincerely,

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Chair, Ethics, Professionalism and Human Rights Committee
American College of Physicians