Background on Death by Neurologic Criteria Standards and Practice

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Medical Standards on Determination of Death by Neurologic Criteria:

- The 2010 American Academy of Neurology (AAN) standard and the 2011 Society of Critical Care Medicine (SCCM)/American Academy of Pediatrics (AAP)/Child Neurology Society (CNS) standard on determination of death by neurologic criteria are considered the "accepted medical standards" in the USA by multiple medical societies
- Since the publication of the first pediatric standard in 1987 and the original AAN standard in 1995, no other medical societies in the USA have produced competing standards on determination of death by neurologic criteria
- The AAN is working in conjunction with SCCM/AAP/CNS to produce an updated standard on determination of death by neurologic criteria
- The AAN recognizes that institutional standards deviate from the AAN standards and intends to work with an appropriate regulatory authority, such as the Joint Commission, to improve consistency once new standards have been published

Content of Medical Standards on Determination of Death by Neurologic Criteria:

- There is no preset observation time prior to commencing an evaluation for determination of death by neurologic criteria, but the evaluation should only be performed once prerequisites, including exclusion of confounding conditions and identification of the etiology for the patient's condition, are met
- The clinical evaluation determines if the patient is comatose and has absence of the following brainstem reflexes: pupillary/corneal/oculocephalic/oculovestibular/gag/cough reflexes
    - Note that the oculocardiac reflex and the atropine test are two other ways to evaluate brainstem function which are not included in these standards or most other standards around the world (the oculocardiac reflex is mentioned in 13% of standards around the world and the atropine test is mentioned in 6% of standards around the world)
- If the clinical evaluation shows no evidence of brain function, the ventilator is discontinued so an apnea test can be performed to determine if the patient is able to breathe spontaneously in the setting of a carbon dioxide challenge (the carbon dioxide rises in the blood when they are off of the ventilator and this should trigger the medulla, the base of the brain, to cause them to breathe if they are able to do so)
- The aforementioned standards require one clinical evaluation and apnea test in adults and two in children

- If the full clinical evaluation is completed and a patient is found to be comatose, have absent brainstem reflexes and inability to breathe spontaneously, death is declared
- If a portion of the clinical evaluation or apnea test cannot be performed, an ancillary test is performed to evaluate for blood flow to the brain or electrical activity in the brain
- The standards do not require evaluation of the hypothalamus/pituitary gland and it has been estimated that 10-91% of patients who meet the conditions established in the standards continue to secrete antidiuretic hormone from the hypothalamus

Current Practice and Guidance from the AAN with Regards to Obtaining Consent Before an Evaluation for Determination of Death by Neurologic Criteria:

- 78% of adult neurologists in the USA who completed a 2015 survey performed by the AAN strongly or somewhat disagreed that physicians should obtain consent from a patient's family before performing an evaluation for determination of death by neurologic criteria
- 72% of pediatric neurologists and intensivists in the USA who completed a 2016 survey believed it was not necessary to obtain consent before performing an evaluation for determination of death by neurologic criteria
- "The AAN believes that its members have both the moral authority and professional responsibility, when lawful, to perform a brain death evaluation including apnea testing, after informing a patient's loved ones or lawful surrogates of that intention, but without obligation to obtain informed consent. This position is analogous to the authority and responsibility historically granted to the medical profession to determine circulatory death without the requirement for additional informed consent."

Steps after Determination of Death by Neurologic Criteria:

- Hospitals are required to notify Organ Procurement Organizations about patients being evaluated for determination of death by neurologic criteria and patients who will be declared dead based on cessation of circulation and respiration after treatment is withdrawn
- Organ Procurement Organizations work with the healthcare team to determine the appropriateness of speaking to families about donation
- 42% of adult neurologists in the USA who completed a 2015 survey performed by the AAN believed it is necessary to obtain permission from a patient's family to discontinue organ support after determination of death by neurologic criteria (47% believed this is not necessary and 11% were neutral)
- 42% of pediatric neurologists and intensivists in the USA who completed a 2016 survey believed it is necessary to obtain permission from a patient's family to discontinue organ support after determination of death by neurologic criteria (45% believed this is not necessary and 13% were neutral)

Clinician Experience and Guidance from the AAN on Objections to Determination of Death by Neurologic Criteria:

- 47% of adult neurologists in the USA who completed a 2015 survey performed by the AAN have been asked to continue organ support after determination of death by neurologic criteria outside of organ donation
- 61% of pediatric neurologists and intensivists in the USA who completed a 2016 survey have been asked to continue organ support after determination of death by neurologic criteria outside of organ donation
- In both surveys, objections were attributed to religious beliefs, moral beliefs, belief the patient could regain neurologic function, lack of acceptance that the patient was dead because their heart was beating, desire to await arrival of additional family members prior to discontinuation of organ support, desire to delay the decision about organ donation, desire to continue receiving social security benefits, perception that acceptance of death meant giving up
- "The AAN desires to provide lawful guidance for its members faced with requests for accommodation. These requests include objections to brain death determination or the withdrawal of organ-sustaining technology. The AAN strives to achieve reconciliation of the positions all stakeholders without undermining the professional responsibility of neurologists acting in the best interest of their patients. The AAN is respectful of and sympathetic toward requests for limited accommodation based on reasonable and sincere social, moral, cultural and religious considerations, recognizing that beliefs vary not only between but within religions, and understanding that such requests must be based on the values of the patient and not those of loved ones or other surrogate decision makers. At the same time, the AAN acknowledges that there is no ethical obligation to provide medical treatment to a deceased person. In the United States, with the exception of New Jersey, there is no legal obligation to provide indefinite accommodation with continued application of organ-sustaining technology organ sustaining technology to the deceased. The AAN recognizes the potential for harm to the patient, the family, or other patients and the healthcare team from indefinite accommodation. These potential harms include mistreatment of the newly dead, deprivation of dignity, provision of false hope with resultant distrust, prolongation of the grieving process, undermining of the professional responsibility of the physician to achieve a timely and accurate diagnosis, and an anticipated societal harm arising from a negotiated and inconsistent standard of death. The AAN encourages members to include provisions for management of requests for accommodation in institutional brain death protocols addressing the conditions and time frame for accommodation. Despite its respect for cultural and religious perspectives, and its empathy for grieving loved ones, the AAN endorses the implicit position of the UDDA that death is a biological reality that may result from irreversible injury to the heart or brain. Accordingly, the AAN believes that death should be determined by criteria that can be objectively and uniformly assessed in order to demonstrate irreversible loss of circulatory or whole brain function, as supported by the President's Commission. Physicians are uniquely qualified and authorized by their training, experience and licensure to determine that death has occurred by either a circulatory or neurological mechanism, and are professionally obligated to make this determination in a timely and accurate manner… The AAN suggests that when requests for indefinite accommodation occur, all authorized stakeholders in the welfare of the patient, including members of the medical team and designated administrative or legal institutional officials should be kept apprised of the situation. Involvement of others with recognized mediating skills, including clergy members, mental health professionals, palliative care or ethics

consultants, should be considered. The AAN recognizes that when attempts to reconcile disputes pertaining to indefinite accommodation fail, transfer of an individual to another facility, when lawful and feasible, represents a measure of last resort. The AAN recognizes that when attempts to reconcile disputes pertaining to indefinite accommodation fail, unilateral withdrawal of organ sustaining technology (other than in pregnant females) over the objection of loved ones is acceptable, when supported by law and institutional policy, and represents a measure of last resort."