

Ethics For Lunch – February 20, 2024

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"Navigating the Ethical and Cultural Challenges in Neurological End-of-Life Care"

The February Ethics for Lunch presented the case of a 52 year old man who was initially brought into the hospital unidentified with severe brain injury. After his identity was determined, his adult children served as his surrogate decision makers. His children were informed that he would not have any meaningful improvement in his neurologic status. His neurologic exam worsened, and he met criteria for death by neurologic criteria. He was Fundamentalist Christian from India, and his children objected to brain death testing, because they only believe in death by circulatory criteria. Plus, they felt that as long as their father was on supportive measures like mechanical ventilation, there was a chance of a miracle occurring. Other family members voiced similar sentiments.

Summary points:

1. Families may need to be educated about the difference between coma, persistent vegetative state, minimally conscious state, and dead by neurologic criteria (brain death). Terminology should be precise and consistent.
 - Coma means the absence of consciousness and patients can be in a coma for a variety of reasons (intoxication, brain injury, medically induced). With a coma, there are signs that there is still some brain function intact. Patients in coma may recover.
2. The healthcare team should cultivate mutual understanding with the family of the patient's condition. Families may need to be told more than once for information to sink in.
3. Clinicians should be good listeners when conversing with a patient's family members—listening for what's behind any questions the family poses and where they are coming from.
4. It is critical to build trust between the health care team and family.
 - A family advocate bridges the gap between the health care team and families—building trust and providing emotional and spiritual support for both the patient and their family.
 - A social worker tries to see the situation from the family's perspective (humanize the patient, learning their values, culture, and family dynamics) and can provide space for the family to process the information they are getting from the team. That can provide context to understand why a family may react a certain way.
5. The concept of brain death arose due the emergence of mechanical ventilators—the body's organs can persist even though the brain is completely damaged.
6. The goals in caring for a patient with a devastating neurologic injury are to limit harm to the patient, trying to benefit them, and trying to be just and equitable across all patients.
7. Testing for death by neurologic criteria is more a prognostic test than a diagnostic test. As such, it is not a test for which the family needs to give informed consent.
 - Unlike checking for pulse and respirations (which are instantaneous) in death by cardiopulmonary criteria, testing for death by neurologic criteria is a process requiring several steps. Families may not be familiar with all of the tests that need to be done.
 - Families may be invited to witness the testing so they can see the results themselves
8. According to the United States Uniform Determination of Death Act (UDDA) of 1980, "An individual who has sustained either (1) irreversible 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."

- According to the UDDA, “all functions of the entire brain” is interpreted as permanent loss of function of the brain as a whole, including the brainstem, resulting in (1) coma, (2) brainstem areflexia, and (3) apnea in the setting of an adequate stimulus.
 - Some implication of the definition of death by neurologic criteria is that a person can be pulseless on ECMO and be alive, and a person can be dead with a beating heart.
9. The brain is the center of who a person is—their memories, their purposefulness, their emotions. So when there is irreversible cessation of brain activity, then the person has died.
 10. When explaining the concept of brain death to a family, it is important to look for body language clues as to whether they are understanding the information. Families can also be overwhelmed with the information, and it may be important to follow up with them one-on-one after a family meeting to ask open-ended questions.
 11. “Irreversibility” of loss of consciousness is known by the fact that no patient who has met the criteria for brain death has ever regained consciousness.
 12. It is important to have precision in the language that is used:
 - e.g., when talking about death by neurologic criteria, it is “removal of supportive measures,” not “withdrawal of life support.”
 - e.g., the physician should not say “We believe the patient is dead,” but rather “Our suspicion is that the patient is dead and we need to do the confirmatory testing.”
 13. When addressing religious aspects, one should never make assumptions about what the patient or family believes based on the type of religion they belong to.
 - It is better to be open-ended in asking them about their particular beliefs and values.
 - Sometimes it can be helpful to bring in a spiritual leader from their faith community to help in building trust and explaining how the medical aspect intersects with their values.
 - If a family is hoping for a miracle, the team could join them in that wish while also recommending going forward with appropriate testing.
 14. It is important to get training in communication skills so these family meetings can go well.
 - Clinicians need to minimize harms to families in how they explain these concepts
 15. Clinicians must follow the standard of care in their jurisdiction in performing prognostic testing.
 - New Jersey provides an exception for religious reasons for determination of death by neurologic criteria. Families wishing to transfer the patient to New Jersey have to coordinate the transfer and privately pay for the transportation before death is declared.
 16. There can be some flexibility in the timing of the testing (e.g., waiting for a loved one to be present), but there are concerns of fairness in the allocation of resources, knowing that there may be other critically ill patients who need an ICU bed.
 - Clarity in the process also respects the integrity and well-being of the clinicians on the team who may have moral distress when there is deviation from the standard of care.
 17. After death by neurologic criteria, there is the possibility of pursuing organ donation either because the patient gave first person consent when they were alive or the next of kin authorizes donation if the patient never made a decision about donation.
 - If a patient did designate themselves an organ donor, the next of kin cannot go against that decision. They would have to demonstrate that the patient had changed their mind about being an organ donor.
 - The organ procurement organization is responsible for approaching the family about organ donation. They also address funeral homes, counseling support, and help with the grieving process.

References:

1. Lewis, A., Kirschen, M. P., & Greer, D. (2023). The 2023 AAN/AAP/CNS/SCCM Pediatric and Adult Brain Death/Death by Neurologic Criteria Consensus Practice Guideline: A Comparison With the 2010 and 2011 Guidelines. *Neurology. Clinical practice*, 13(6), e200189
2. Greer, D. M., et al. (2023). Pediatric and Adult Brain Death/Death by Neurologic Criteria Consensus Guideline. *Neurology*, 101(24), 1112–1132.