

Summary: Ethics for Lunch, 16 March, 2021

Issues of Trust in Declaration of Death by Neurologic Criteria and How to Navigate the Challenges

<https://youtu.be/IGnaJMsqWkg>

Panelists: Mark Hughes, MD, MA; April Sharp, MD; Adam Schiavi, MD, PhD, MS; Renita Somerville, LCSW-C; Anna Noguchi, BSN, RN; Rev. John Ponnala, MA, BD, BCC

The March 2021 Ethics for Lunch focused on the issues of trust and challenges faced by the neurology and interdisciplinary teams in working with patients who meet criteria for neurological death. Panelists addressed the growing concerns about brain death within the community and how the social, political, and historical realities of racism contribute to distrust about the diagnosis. The panel shared their views and expertise on how to gain trust and navigate through the brain death testing process.

The summary of discussion on the case study:

1. Determination of brain death is defined as the absence of neurologic function with a known irreversible cause of coma. The clinical diagnosis is comprised of two clinical exams separated by at least 6 hours in adults and 12 to 24 hours in the pediatric population. This includes absence of brainstem reflexes, absence of motor reflexes, and the presence of apnea. Exam is completed via a standardized protocol.
2. The first exam establishes the absence of neurologic function; the second exam is confirmatory and establishes that this is an irreversible finding/determination.
3. If there are concerns with exam findings or questions about the validity of the exam for any reason, then ancillary testing can be used to support the clinical diagnosis. Ancillary testing cannot be used as a substitute for a clinical exam. Spinal reflexes are a common complicating factor in brain death determination. These are reflexes where the nerves and signals only go through the spinal cord and not the brain. Spinal reflexes can be spontaneous or produced by a stimulus. They are not an uncommon finding in a patient with a brain injury. Spinal reflexes can be very complex movements and very confusing for families.
4. In all cases of potential brain death, it is important for the clinical team to be open and straightforward with the family early on. The conversation typically begins with explaining the injury and why the team is concerned that the injury will impact the neurologic function. It is important not to introduce the idea of brain death too early as the clinical picture may be dynamic in the first 24 hours. It is of utmost importance to use plain language when talking about the idea of brain death. Clinicians should frame the conversation with the patient's family that the clinical team is looking for the presence of brain function, and if they do not see that, then it means that the family's

loved one is unfortunately dead. The conversation and language then transition to talking about how the organs are being sustained via machines.

5. These cases of acute trauma in previously healthy individuals pose difficulties in developing a trusting relationship with the family. Given the suddenness of the trauma and the short period of time for the determination of death to be made, it can be challenging for the team to have these conversations effectively.
6. Whenever the situation is complicated, the responsibility of certifying and diagnosing the death of a person should not fall on one individual--especially an individual who is trying to build a trusting relationship with the family.
 - a. The declaration process should be transparent and as straightforward as possible. Determination of death when the heart is still beating and the lungs are still ventilating does not make sense to most people in an instinctual way. If there is anything that is not by the book or is out of place, then the relationship with the family can be damaged, leading to mistrust.
 - b. The best practice is to utilize the systemic resources of interdisciplinary teams for assessment and guidance in accordance with hospital policy to provide institutional backing and establish rapport with the family.
7. Another source of distrust in the brain death diagnosis process occurs with families from minority communities stemming from historical events. As a result of these events, individuals from these communities come in with an established mistrust for the hospital and the care team, Historical events include:
 - a. The Tuskegee Syphilis Study, in which poor illiterate African American men were subjected to an experiment studying the natural history of syphilis despite the introduction of penicillin in the 1940's.
 - b. Henrietta Lacks' experience, in which her cancer cells were taken without her consent.
 - c. The Compost study done in this community where researchers wanted to see how to treat lead paint poisoning among children in the community. Researchers dispersed lead impregnated compost in the yards of African American families without their consent.
8. When families come in to the hospital with established distrust and disbelief, this may be perceived by the ICU team as the family being difficult, disagreeable, angry, or noncompliant. This can in turn make these families feel judged and stigmatized by the providers, and this perpetuates further distrust.
 - a. Strategies to build trust between the medical team and family include: building a trusting relationship with at least one family member; holding structured family meetings with clear, simple communication; and being mindful of not sending mixed messages.

- b. When the family sees things that they view as signs of life (e.g., spinal movements, a heartbeat, feeling warm to the touch), it is important to ensure that team members are clear about how to interpret these signs.
- 9. When families come present with anger, denial, and/or bargaining, it is important to recognize that they could be grieving.
- 10. After a family meeting or goals of care conversation, it is crucial to be present with the family and assess how the information landed with them. Often the family will ask follow-up questions that will illuminate their level of understanding of the grim prognosis.
 - a. Clinicians should take time when possible to create a space that encourages any and all questions that the family may have. It is helpful to gain an understanding of how the information presented to the family during the meeting was actually interpreted by the family.
 - b. The goal is always being to provide the best care possible to the patient and their family. The clinical team should validate the family's fears and frustrations. This information should be shared with the rest of the clinical team to allow for collaboration in creating the best pathway moving forward. Actions could include giving the family more space, having a follow-up meeting with the ICU team to answer questions, and/or getting a consulting service to answer more specific questions, if needed.
- 11. In helping these families navigate the difficult waters of race, culture, belief, and faith, it is appropriate to acknowledge their experience of loss and their feelings of anger, resentment, anxiety, panic, loneliness, and abandonment. The clinical team must address all these factors in order to help the family understand and accept their loss.

References:

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