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The Death Debate: Penumbra Conundrum

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"*The Death Debate*": Penumbra Conundrum

A thirteen-year-old girl has unexpected bleeding following a tonsillectomy. She suffers a cardiac arrest within hours after the procedure. A two-and-a-half-hour resuscitation effort results in restoration of spontaneous circulation but also evidence of a severe neurologic injury. In her article *The Death Debate*, Rachel Aviv chronicles the four-year story, so far, of Jahi McMath as an example of troubling shortcomings in the concept and application of the determination of death by neurologic criteria ("brain death").[1] This balanced and compelling account and analysis points out philosophical and ethical concerns dating from the original efforts to establish brain death guidelines and legislation. Aviv also reviews other cases where the established brain death criteria have been questioned along with a proposed pathophysiologic explanation. She challenges the reliability of the clinical exam criteria as well as what are referred to as confirmatory tests.

This review of the Aviv article includes perspective and advice for application from the viewpoint of an intensivist clinician also fellowship-trained in palliative medicine. While not an exhaustive review of the voluminous literature pertaining to the topics raised in the article and this essay, key references are cited enabling the interested reader to get started with a more thorough review.

The clinicians caring for Jahi made a clinical diagnosis (coma, lack of brainstem reflexes, lack of spontaneous respiratory effort with apnea testing) of brain death two days after the cardiac arrest event. Electroencephalography was isoelectric. Family spokespersons, prominently her mother and grandmother, questioned these findings and the idea of brain death. The family also had concerns about the pre-arrest care and monitoring. Communication between the clinicians and family was stormy and adversarial. The family quickly obtained legal representation.

A court-ordered neurology consultant confirmed the previous exam findings and ordered a cerebral-blood-flow evaluation (radionuclide scan). It showed no blood flow in the brain. A

death certificate was issued 24 days into her hospitalization. Jahi was then transferred cross-country to a hospital willing to continue the support measures. Nine months into her course, Magnetic Resonance Imaging revealed "…the brainstem nearly destroyed and the nerve fibers connecting the right and left hemispheres barely recognizable…But large areas of her cerebrum…were structurally intact." During the ensuing months, Jahi remained on mechanical ventilatory support and artificial nutrition. She did not awaken but observations by the family and a subsequent neurology consultant questioned the presence of volitional responses to command (moving a finger or toe). This neurologist, two years after the cardiac arrest event, described her as "an extremely disabled but very much alive teenage girl."

Palliative clinicians commonly provide consultation for critically ill unresponsive patients with post cardiac arrest hypoxic ischemic encephalopathy (CA-HIE).[2] The usual task is to communicate with patient spokesperson(s) for shared decision-making to establish goals of care and consider intervention preferences. There is considerable literature, notably in a state of evolution considering the nearly universal embrace of therapeutic hypothermia for unresponsive patients following resuscitation from cardiac arrest, regarding the assessment of CA-HIE patients with regards to mortality and the likelihood of functional recovery.[3-7] This is ordinarily in the context of what is recognized as a variably severe neurologic injury but not meeting the criteria for brain death. A recent systematic review and meta-analysis of this point reported that brain death was diagnosed in 5.4% of 22,744 patients with CA-HIE after conventional (as opposed to extracorporeal) cardiopulmonary resuscitation.[8] Over half of these patients meeting brain death criteria became heartbeating organ donors. The diagnosis of brain death was made in a range of 1-6 days after the resuscitation effort.

The Uniform Determination of Death Act, drafted in 1981 by a President's Commission study on brain death, was used as a model by all states of the United States to establish their own legislation regarding the declaration of death.[9,10] For those who recall working in the intensive care environment during that era, traditional teaching was that patients meeting the clinical criteria for brain death could only be maintained for a brief period even with aggressive supportive efforts. Examples were not uncommon for such clinicians. The case of Jahia MacMath, and a handful of others described by Aviv, dispute this teaching by demonstrating

months to years of survival with basic critical care level support (invasive positive pressure ventilation and artificial nutrition/hydration).[11,12] The description of Jahia MacMath's early evaluations conform with a rigorous standard for the accepted diagnosis of brain death.[13] Likewise, the findings detailed to negate the original diagnosis are convincing. While her cognitive function is at best profoundly impaired, her bodily functions have maintained or been maintained for an extended time interval.

Cessation of cerebral blood flow following cardiac arrest leads to an ischemic penumbra, an area of acutely injured tissue. In the case of CA-HIE this involves the entire brain, a "stunned" brain. Depending on the duration of absent flow, the extent of secondary injury related to reperfusion and other factors, and preexisting damage due to prior insults, the injured penumbra has a greater or lesser chance of recovering function.[14-16] The concept of whole brain death means that the acute injury is so long and so severe that the entire ischemic penumbra is irreversibly damaged. In a pathobiological phenomenon involving a gradient of dysfunction, an attempt to categorize the process into a binary outcome, dead or not dead in this case, is destined to be imperfect. While a threshold can be assigned at a given point in time for distinguishing a binary outcome, this will not always be a final outcome. The inherent variability of biologic processes collides with the clinical and legal concept of brain death.[17-24] The explanation offered for the Jahia MacMath story involves a severe acute injury, severe enough to result initially in the deficits we call brain death. However, with time, and perhaps abetted by the resilient physiology of a teenage brain, some recovery of function occurred. Does this mean that brain death is reversible?

This question, and others, constitute the conundrum(s) of the title:

Are our testing protocols, and the timing of them, overly sensitive while lacking specificity?

Is this risk of false-positives underrecognized?

Can and should the current protocols be modified to improve the specificity while maintaining an appropriate level of sensitivity?

Should the current legal status of brain death be modified or abolished with corollary revisions in the guidelines for organ donation?

Should attention to the potential for symptom distress in the patient with a brain death diagnosis be included in management protocols?

Absent answers to these questions, palliative clinicians must still respond to today's consult request. Providing consultation for goal-setting and intervention options for the CA-HIE patient with severe neurologic injury, and those close to her, calls upon the clinical and communication skills of a palliative specialist. Meticulous holistic evaluation, correlation of underlying pathophysiology with clinical findings, and application of these clinical findings to formulate a prognostic assessment form the basis for clinician participation in a shared decision-making process. Shared decision-making combines the factors just detailed with patient/spokesperson(s) perspective on life pattern and values to arrive at a consensus plan. The following observations with recommendations are offered as advice to consider for application in our everyday work with CA-HIE patients. Hopefully, they are consistent with providing conscientious care while acknowledging the issues raised in the article.

Quality Matters. Decision-making for most CA-HIE patients revolves around assessment and prognostication regarding significant neurologic injury, but not brain death. In most of these cases a goal-setting discussion depends primarily on the likelihood of cognitive recovery. In a distinct minority, criteria for the diagnosis of brain death are met. The brain death scenario often leads to a decision-making discussion dominated by an announcement rather than a discussion of values and choices. This would be appropriate if the diagnosis of brain death were reliable and discrete. An alternative approach is to view the brain death diagnosis as the far end of a spectrum of severity and prognostic implication, as well as at present the starting point for consideration of heartbeating organ donation.[25,26] The negative prediction for a recovery of interactive living is included in the discussion. A value-laden quality of life consideration is in the picture. This would include the possibility, more likely with certain patient characteristics such as younger age and lower comorbidity burden, of extended preservation with support of non-sentient bodily functions. A decision for withdrawal of

support expecting death and a preference for organ donation, if feasible, can be coordinated under current protocols in either scenario.

Body-Centric Viewpoint. When acting as a surrogate for a CA-HIE patient with significant neurologic injury up to and including a clinical diagnosis of brain death another distinct minority, of spokespersons, espouse a value of life in the context of bodily function equal to or greater than the brain component. This value system may go along with certain ethnic, cultural, or religious traditions – or not. Such a perspective can be appreciated as a different "way of knowing." [27,28] Awareness of and respect for this body-centric view may not improve what is likely to be a difficult clinical challenge but at least will improve the effectiveness of communication.

Goals First, Then Organ Donation. The Kantian categorical imperative is recommended as a guiding principle for the intersection of end-of-life decision-making and consideration of organ donation. A person is an end unto themselves, rather than a means to an end.[29] The benefit that can accrue to another person(s) after successful organ transplantation is not part of the decision-making process regarding goal-setting and intervention preferences for a CA-HIE patient. If, based on the values of the person with CA-HIE, a spokesperson chooses to not continue intervention based on anticipated mortality and quality of life consequences then a discussion of the organ donation option can ensue. This pertains, under current procedures, to the CA-HIE patient with or without a diagnosis of brain death. If organ donation considerations are relevant then the difference would be in the mode of organ harvesting, heartbeating donor or donation after cardiac death.[30] It is well recognized that those left behind, including the spokesperson(s), may derive solace from the tremendous gift of organ donation. However, it should, if necessary explicitly, be recognized as a sequela rather than a component of the primary decision.

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