Case Study

Jahi McMath and the Ethics of the Brain Death Standard

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Abstract: How does one account for "the discrepancy" between the evidence of total and irreversible brain death and the current evidence of recovered brain function? This is the question that is raised by recent legal action in the case of 13-year old Jahi McMath, certified dead on the basis of neurological criteria but maintained in mechanical ventilation and medical/nursing care since then at the insistence of the parents who claim she is alive. In this brief discussion, the medical and legal issues are reviewed. Here the argument is advanced that this is not a case that means there should be a re-evaluation of the neurological criteria for determination of brain death. Instead, this case is to be understood as the exception that proves the rule.

Case Scenario: In late 2013, then 13-year old Jahi McMath underwent complicated throat surgery, suffered severe blood loss that lead to an anoxic-ischemic event, and was declared "brain dead" while a patient at Children's Hospital in Oakland California (USA). She was pronounced "dead" on the basis of brain death (neurological) criteria valid in the State of California. Jahi's parents and loved ones objected to the declaration of death because of what they believed to be the presence of cardiopulmonary function; and they requested that Jahi be kept on a respirator with tracheotomy performed for prospective transfer to another hospital and nasogastric tube inserted for feeding and nutritional support to her body.

The latter procedures were refused by the hospital medical staff because of the declaration of brain death and likewise not supported by court judgment, despite a series of intervening court injunctions not to withdraw mechanical ventilation. In what has turned out to be a totally unique case, the family of Jahi insisted that, despite the medical evidence and professional judgments of numerous physicians and specialists in neurology, the young girl is alive and, therefore, deserving of continued medical and nursing care.

Despite the issuance of a death certificate, Jahi's "body" was "transferred with the permission of the coroner to be taken out of state," the family then moving her to a facility in the State of New Jersey that was willing to accept Jahi as an in-patient for the purpose of continued medical and nursing care. After

approximately eight months in this facility, Jahi was transferred to a home environment in that state, where she continues to receive what the family has determined to be acceptable medical/nursing care.

Christopher B. Nolan, legal counsel for the family, has now, one year later, filed a petition (a "Writ of Error Coram Nobis") in the Superior Court of California, County of Alameda, seeking reversal of the judicial determination of brain death.1 Based on evidence and testimony before it at the time one year earlier, the Court determined that McMath "met the standard and criteria to be determined brain dead." This meant that the Court affirmed the professional medical judgment and diagnosis, which concluded that McMath suffered "total and irreversible cessation of all neurologic activity, including the brain stem." Key to this assessment is the judgment that the cessation is understood to be both total and irreversible.

In the intervening time (01 September and 26 September 2014), Jahi's parents permitted additional testing to assess Jahi's brain structure and function. Accordingly, Dr. D. Alan Shewmon, Professor Emeritus of Neurology and Pediatrics (with board certifications in pediatrics, neurology, and electroencephalography and recently retired), from the David Geffen School of Medicine of the University of California at Los Angeles, submitted legal testimony on 03 October 2014 in support of the petition to reverse the judgment of brain death.2 Referencing "MRI/MRA studies, records, and reports, as well as viewing two videos of Jahi McMath moving her body parts (foot and arm) following her mother's commands," and also accounting for "discussions with Dr. Calixto Machado, a world renowned expert on brain death" and Dr. Philip DeFina, "a neuroscientist with the International Brain Research Foundation," Dr. Shewmon has found sufficient reason to assert "unequivocally" that Jahi "does not [in October 2014] fulfill diagnostic criteria for brain death."

Attorney Nolan asserts in his petition before the Court that independent medical judgment and "objectively verifiable diagnostic measurements" now allow for the conclusion that the claim of total and irreversible cessation of brain function in Jahi that was the basis of the declaration of death is to be construed as an error in fact. Indeed, Nolan asserts furthermore, "What may have appeared to be fact was actually prediction which has turned out to be wrong." As far as Nolan is concerned, Jahi's family has succeeded in keeping Jahi "alive" to date, in which case the Court must now provide legal remedy for its "flawed, unjust" judgment of death and correct the legal record.

This petition for reversal is quite extraordinary both as a matter of law and as a review of a medical certification of death in this patient. However, there is an epistemological assessment here that needs clarification. It is one thing to declare an error in fact and another to assert that a determination of brain death is to be construed as a prediction. A declaration of brain death is a consequence of a medical diagnosis and judgment issued according to both medical and legal criteria. It requires independent confirmation according to those criteria, to assure as high probability as is reasonable on the facts in question. The court-appointed neurologist in this case concurred with the physicians of record that Jahi indeed met the State of California's neurological criteria for the determination of brain death. Under no

circumstances, either medically or legally, would a declaration of death and a certification of death with disposition of the "body" to the office of the coroner be issued were it construed by anyone as a "prediction." Hence, Nolan's statement is entirely problematic both as a statement evaluated from the point of law and from the point of clinical judgment.

If the evaluation of facts is grounded in a different set of facts, then there is no prediction involved at all. It is simply a matter of a medical evaluation and clinical judgment differently grounded. Thus, in contrast to Nolan, Dr. Shewmon opines that the available evidence, i.e., the evidence available at least 10 months after the initial declaration of death, "proves that she is not brain dead, not even comatose, but very severely disabled." In other words, despite this severe disability, Jahi can today be diagnosed to be "conscious" and, therefore, "responsive" (the latter evidence contrary to one of "the cardinal parameters" required in the determination of brain death). Dr. Shewmon is clear in his clinical judgment that "spinal reflex" (as an alternative causal explanation for motion in Jahi's body) is ruled out—"the quality" of Jahi's movements have "the appearance of volition," are "reliably reproducible," and "do not occur at random" as would be expected in a spinal reflex motion.

Additionally, Dr. Shewmon remarks on the assessment of Jahi's "heart rate variability," which is such as to provide "objective corroborating evidence that Jahi not only has spontaneous modulation of heart rate by the autonomic nervous system (such variability should be completely absent in brain death), but even more impressively that her heart rate changes in response to her mother's voice." Dr. Shewmon accounts it as "hard evidence of auditory processing by the brain, if not also of registering of the emotional valence of those auditory signals and frank conscious awareness of them, and it is not a matter of interpretation." Further, citing nursing records, Dr. Shewmon underscores the fact of presence of brain function given that Jahi has had two menstrual periods: "The female menstrual cycle involves hormonal interaction between the hypothalamus (part of the brain), the pituitary gland, and the ovaries. Corpses do not menstruate. Neither do corpses undergo sexual maturation." These facts indicate that Jahi has brain function. Hence, argues Dr. Shewmon: "Hypothalamic function is a brain function, and California's statutory definition of death by neurological criteria requires irreversible absence of all brain functions, so even apart from her responsiveness, she would not fulfill the statutory definition of death on the basis of hypothalamic function." Dr. Shewmon is careful to clarify that he does not imply "that her hypothalamus is functioning normally: it is not. The point is that there is some preserved hypothalamic function, and a rather remarkable one at that)."

Given the additional evidence of a low-voltage EEG rather than an isoelectric (flat) EEG reading, and accounting for "some obviously artifactual waveforms," Dr. Shewmon opines, "there appears to be genuine electrocerebral activity…" This does not mean that the medical judgment given a year ago was in error as to the facts contributing to the determination of death. Rather, "with the passage of time," Dr. Shewmon judges, Jahi's "brain has recovered the ability to generate electrical activity, in parallel with its

recovery of ability to respond to commands." An MR angiogram supports the assessment that there is intracranial blood flow, in which case her brain has not succumbed to necrosis or liquefaction; on the contrary, "much of it is structurally intact."

This claim of brain "recovery," however, places the previous determination of death at Children's Hospital in California in question on the issue of whether Jahi's brain suffered "total" and "irreversible" brain damage. Hence does Dr. Shewmon remind that, "A dead brain cannot spontaneously recover electrical function," in which case the implication is clear that Jahi's brain was not totally and irreversibly dead at the time the medical declaration of death was given nearly a year ago. In other words, were Jahi today located physically in a health care facility in the State of California, there is sufficient medically relevant evidence such that the criteria for brain death would not be met, in which case there would be no medical declaration of death issued on the basis of neurological criteria. Therefore, there is both medical and legal basis for reversal of a declaration of death. Such is the current claim of Jahi's family.

Dr. Shewmon, however, makes a statement that is contrary to attorney Nolan's claim that the original declaration of death is to be considered a mere prediction: "Clearly, Jahi is not currently brain dead. Yet I have no doubt that at the time of her original diagnosis, she fulfilled AAN [American Academy of Neurologists] diagnostic criteria, correctly and rigorously applied by the several doctors who independently made the diagnosis then." Thus, one cannot conclude that the physicians in the case at Children's Hospital are by any means either morally or legally blameworthy for errors in medical judgment. After all, as Dr. Shewmon reminds, "That diagnosis was even backed up by two ancillary tests: an EEG that was reportedly isoelectric and a radionuclide scan that reportedly showed no intracranial blood flow."

The foregoing assessment presents a medical conundrum: How does one account for "the discrepancy" between the evidence of total and irreversible brain death and the current evidence of recovered brain function. Dr. Shewmon proposes one plausible explanation: "(1) the standard clinical diagnostic criteria are not as absolutely, 100% reliable as commonly believed, and (2) radionuclide blood flow studies are not sensitive enough to distinguish no flow from low flow—in technical terminology, from ischemic-penumbra-level flow, i.e., flow that is too low to support brain functioning but just enough to maintain tissue viability."

Discussion: This is a hypothesis, and it is at this point unclear how this might be falsified except insofar as additional testing might be done to evaluate as carefully as might be done with the latest technology what is the functional status of Jahi's brain, and thereby how this may translate to determinations of "conscious" responsiveness. That said, it is important, as a matter of scientific assessment, that no one should expect "absolute, 100% reliability" in any medical judgment and assorted technological evidence given for such functional analyses and determinations of brain death.

Neurological criteria aim to yield medical judgments that are admittedly inductive rather than necessarily certain. This means that we have determinations of brain death and certifications of death on that basis issued with "high probability" rather than with certainty. Was it not for the unusual circumstances in which Jahi's family insisted on continued medical/nursing care and support of Jahi's body? There would be nothing at issue today whether Jahi is "alive" and "conscious" and thus meriting the court's reversal of the declaration of death. This is not a case that means there should be a re-evaluation of the neurological criteria for determination of brain death.

On the contrary, this is very much a case of "the exception proving the rule" (in the Latin, "Exceptio probat regulam in casibus non exceptis"). Both medical practitioners and the courts are permitted discretionary judgment on the basis of the evidence available at the time a judgment is to be issued. Richard Holton3 has written concerning the point of the maxim, re-stating it to say, "Exception (i.e., the fact of excepting) proves (establishes) the rule in the case not excepted." Thus, some explain the maxim to mean that while one may be able to point to an exception to the rule "the rule still stands; and furthermore, that, rather than undermining the rule, the exception serves to confirm it." How can this be so? Holton clarifies:

This second claim may seem paradoxical, but it should not, once it is realized that what does the confirming is not the exception itself, but rather the fact that we judge it to be an exception; and that what is confirmed is not the rule itself, but rather the fact that we judge it to be a rule. To treat something as an exception is not to treat it as a counterexample that refutes the existence of the rule. Rather it is to treat it as special, and so to concede the rule from which it is excepted.

What is important here is to recognize that "the rule" that counts in a case such as that of Jahi McMath is a set of neurological criteria, all of which when applied yield empirical evidence incomplete and subject to error, these criteria together thus counting as the equivalent of a defeasible rule (to use Holton's term here)—i.e., a rule "to which exceptions can be made without rejection."

References

1. Latasha Winkfield v Children's Hospital & Research Center, Case No. PR13-707598, "Declaration of Christopher B. Nolan in Support of Plaintiff's Writ of Error Coram Nobis and Request for Reveres [sic] of Judicial Determination of Brain Death of Jahi McMath," Superior Court of California, Country of Alameda, 03 October 2014.

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3. Holton, R. The Exception Proves the Rule. The Journal of Political Philosophy, 2010; 18(4):369-388.http://onlinelibrary.wiley.com/doi/10.1111/j.1467-9760.2009.00358.x/abstract, accessed 16 November 2014.