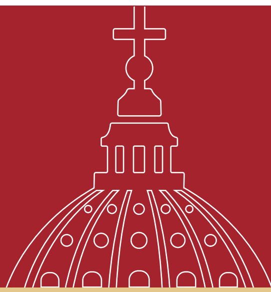

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Also in this issue: "The Problem with Human Composting," by Dawn Turpin

DEATH AND TAXES NO MORE: THE NEURORESPIRATORY PROPOSAL AND THE UDDA

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It is well known that patients who meet the clinical criteria for brain death can go through puberty and even gestate pregnancies.[1] Calling such patients brain dead seems to defy common sense. If a patient is dead, how can she grow and give birth?

In 1981, the Uniform Law Commission published the Uniform Determination of Death Act (UDDA) with the support of the American Medical Association and the American Bar Association. This model statute was accepted and approved by all 50 States and the District of Columbia.[2] It states:

> An individual who has sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessations 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.[3]

Sometime later, the American Academy of Neurology (AAN) developed practice guidelines to test for whole brain death. Unfortunately, this only truly tests for partial brain death.[4] It is not that the clinical criteria used are bad; they are just incomplete. They do not test for neuroendocrine function which is vital for self-integration of the human being. From such criteria have arisen cases like those mentioned above, which have been termed "chronic brain death." This issue came to national attention when the family of a young girl, Jahi McMath, refused to accept the diagnosis and ultimately had to move to a state that supported a religious exemption for brain death. She lived for another four years, undergoing puberty, before she died of liver failure.[5]

How could such a thing happen? Though Jahi had a significant injury to her brain, she was not whole-brain dead. She had persistent neuroendocrine function, which is how she was able to go through puberty. The part of the brain responsible for this function, the hypothalamus, controls many functions necessary for self-integration, such as salt-water balance, temperature control, blood pressure, and sleep.[6] Because of her case and many others, there has been a lot of speculation about the legitimacy of brain death and our ability to detect it.[7]

"Fixing" the Problem

In 2021, the Uniform Law Commission met to see if they could "fix" the problem of brain death by re-evaluating the UDDA.[8] After much debate they proposed abandoning whole brain death for a definition of brain death aligned with the inadequate clinical criteria, the same practice guidelines responsible for the "chronic brain dead" patients. They believe that "dead enough" is good enough to be declared legally dead and become an organ donor. This neurorespiratory proposal states:

> An individual who has sustained either (a) permanent cessation of circulatory and respiratory functions, or; (b) permanent coma, permanent cessation of spontaneous respiratory functions, and permanent loss of brainstem reflexes, is dead. A determination of death must be made in accordance with accepted medical standards.

The wording is almost identical to a proposal published by many official observers in *Neurology* and seems to carry the support of the AAN.[9]

Many observers have speculated why this would be an acceptable solution. It ignores why the chronic brain dead patients exist and codifies testing that does not do what it is supposed to do. The law states that the patient must be whole brain dead to be legally dead. Currently, the practice of medicine is in violation of the law. (Recall, the clinical criteria do not test for whole-brain death but rather partial-brain death.) Professionals in the medical field are worried about potential lawsuits if they continue to follow the recommendations of the AAN.[10] Logically, if a medical test, or in this case a group of tests, performs poorly when diagnosing a disease, the testing should be improved. Changing the definition of a disease to validate a test turns the result into a false positive.[11]

The strong support and acceptance for this proposal could also be related to societal trends to deny objective reality. Death is seen by many as a consensus and not a fact.[12] Death is a "legal fiction."[13] This is truly alarming, as it allows an individual or group to decide when a patient is "dead enough" to lose all rights under the law and his or her health insurance.

Additionally, it is also possible that such a change is related to the misunderstanding of the nature of the human being. In the law and in medicine the belief about people is that we are minds accidentally inhabiting bodies and not embodied persons.[14] Such a dualist understanding of the human being is in stark contrast to what John Paul II taught in his *Theology of the Body*.[15] Society often associates human dignity with the ability to exercise one's autonomy, and people who cannot do so might as well be dead.[16]

Another issue is that if the clinical criteria were expanded to test for whole brain death, the number of available organs for donation would decrease.[17] The Catholic Church teaches that organ donation is a great gift, but as Pope Benedict stated quite clearly, it can only occur "*ex cadavere.*"[18] However, whether someone is dead is an entirely separate issue from whether he or she is are an organ donor. Furthermore, Catholic social teaching holds that you may not abandon a higher good for a lesser one.[19] Even if donating organs is appropriate for the common good, violating a patient's intrinsic human dignity is not allowed, even to achieve that very laudable end.

Others have talked about the burden on society that such patients impose.[20] Society oftentimes has viewed the value of life in