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## Ethical Implications of the Legal Definition of Brain Death in Light of Modern Technological Advancements

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### Cover Page Footnote

I thank Crystal LHote for assisting me throughout the editing process and Adam Weaver for encouraging me to publish my work. I also thank the Saint Michael's College community for their undying support over the last four years.

# Ethical Implications of the Legal Definition of Brain Death in Light of Modern Technological Advancements

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## **Abstract**

Modern medical advancements in resuscitation and life support shifted the idea of death from a cardio-respiratory view to that of a neurocentric view. As a result, the irreversible loss of brain function in both the brainstem and cerebral cortex became known as brain death. Soon thereafter, guidelines for determining brain death (BD) were defined under law. According to policy, one is considered brain dead if they have no brainstem reflexes, a lack of cerebral blood flow, and an absence of cerebral electrical activity. If one is pronounced brain dead, it is legal to remove them from life support. However, in all but two states, the brain death diagnosis is final, and an individual and/or their surrogate cannot refute the diagnosis if it is against their personal or religious beliefs. Despite the fact that the legal definition of BD is necessary in light of technological advancements, the updated definition does not leave room for individual autonomy in select cases. The definition of BD was written by intellectuals that consider death to be the loss of higher order functioning, rather than the absence of both mind and body function. Even though advance directives provide individuals with the freedom to express their wishes regarding medical treatment, BD is an official diagnosis with little room for negotiation. Due to the fact that current technology cannot reverse severe brain damage and that death is now assessed on a graded scale, an individual and/or their surrogate should have the right to determine at what point they are no longer alive.

*Keywords:* Brain Death, Whole Brain, Brainstem, Bioethics, Medical Ethics

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## **Introduction**

Both clinical and ancillary tests are used to determine brain death, the irreversible loss of brain function in both the brainstem and cerebral cortex. If a patient is not considered brain dead, there are other diagnoses used to categorize the severity of the damage, such as a vegetative state, minimally conscious state, or locked in syndrome. This has led to several ethical concerns regarding misdiagnosis and the removal of life support. In all but two states, the individual or their surrogate cannot refute the brain death diagnosis if it is against their personal or religious beliefs. Even though the legal definition of BD is necessary considering medical and technological advancements, the updated definition does not leave room for necessary individual autonomy in select cases. This essay will provide background on disagreements in diagnosing BD, the legal definition of BD, and the neuroanatomy of BD, in order to clearly describe case studies that highlight the ethical concerns of brain death. It will conclude with a discussion of pluralism and how this pertains to BD, emphasizing the importance of encompassing diverse perspectives within the brain death diagnosis.

## **Background**

*“Are we defined by when we live and die, if death can be prolonged?” (Koch, 2019).*

Prior to the 1950's, death was determined by the lack of a heartbeat. After Bjørn Ibsen invented the positive pressure mechanical ventilator in 1953, the idea of death shifted from a cardio-respiratory view to that of a neurocentric view because the heart and lungs could be resuscitated and sustained without sufficient brain function (Laureys, 2005; Machado, 2010). Without respiration and/or circulation, the heart and lungs stop functioning, blood stops flowing to the brain, consciousness and electrocortical activity are lost within seconds, and apoptosis and

necrosis, cell and tissue death, immediately follow (Vrselja, 2019). Since technology could not improve neurological function if anoxia occurred for too long or if brain damage was too severe, the theory of brain death emerged, which equates human death to the irreversible loss of brain function (Laureys, 2005).

Brain death (BD) assumes that the brain is the critical organ for human life and that death is determined by neurological criteria (Laureys, 2005; Shewmon, 1998). Calixto Machado, an esteemed neurologist from Cuba, stated that the National Commission for the Determination and Certification of Death in Cuba accepted the neurological view of death, and stated that death can be determined by either cardio-circulatory and/or respiratory criterion (if death occurs outside of the intensive care unit (ICU)), or by irreversible loss of brain function (if on life support). Death can be identified by lack of respiration, lack of circulatory function, absence of muscle contractions, coldness (*algor mortis*), rigidity (*rigor mortis*), permanent loss of brain function, and decomposition (Machado, 2010). The different diagnoses of death are interrelated; prolonged cessation of breathing and heartrate will eventually cause brain death (Machado, 2010). When diagnosing death, it is essential to prove irreversibility of body and/or brain function. Following this standard of permanence, there have been no cases in which a brain-dead patient has miraculously woken up (Laureys, 2005). Few medical advancements have been made to improve neurological conditions and it is still highly unlikely that patients who suffer from severe anoxic or traumatic brain injuries will regain function (Schiff *et al.*, 2002). Consequently, there is debate over which brain regions need to be severely and irreversibly damaged in order to meet the requirements of brain death.

There are three different definitions or formulations for brain centered death: neocortical, brainstem, and whole brain death (Laureys, 2005). Firstly, neocortical or human-centered death

defines death as the permanent loss of consciousness and human characteristics. This is caused by irreversible damage to the cerebral cortex, the brain region necessary for higher order functions such as thought and social interaction (Laureys, 2005). According to this theory, those that are in a vegetative state are dead. As a result, this theory is not widely accepted (Laureys, 2005). Secondly, the brainstem formulation defines death as the absence of all brainstem functions, which includes ocular reflexes, gag reflexes, and respiration. This definition is accepted by many neurologists because the brainstem is necessary for autonomic functions and the relay of information to the cerebral cortex; one cannot function if their brain lacks this communication (Laureys, 2005). However, this definition argues that patients with localized lesions to the brainstem are brain dead despite possible activity in the thalami and cerebral cortex, two regions that likely enable consciousness. In fact, there have been numerous cases where patients have been conscious despite damage to the brainstem (Laureys, 2005). Finally, the whole brain formulation requires that there is irreversible damage to the entire brain. This definition is the most widely accepted model because it includes absence of brainstem function and lack of conscious awareness. Conversely, some neurologists argue that this definition is not sufficient for death because many brain-dead patients and patients in permanent vegetative states have some residual brain activity. Currently, according to the neurologist Steven Laureys, “the most accepted definition of death is ‘the permanent cessation of the critical functions of the organism as a whole,’” because no specific definition of death has been entirely agreed upon (2005). Even though a consistent definition of brain death (BD) is necessary considering modern medical advancements, there are numerous ethical and legal concerns of using BD as a medical standard, as it is a rigid diagnosis that does not always consider an individual’s own understanding of death. Assuming that the physician’s medical assessment of the severity of the

brain damage is well-regarded, belief that death as the cessation of neocortical functioning, as well as death being the final stoppage of cardio-respiratory functioning, are equally relevant conceptions of death.

### **What is brain death?**

#### *Legal definition of brain death*

Henry Beecher called the ad hoc Harvard Committee of the Harvard Medical school in 1968 to define irreversible coma as the new criterion for death following the invention of the ventilator and the development of organ transplantation (Beecher, 1968). Prior to the ad hoc Harvard Committee, law in the United States assumed that death was determined by physicians, and that death was simply the absence of vital signs (Beecher, 1968). An accepted definition of irreversible coma was necessary for organ transplantation because it would reduce controversy over procuring organs for donation (Beecher, 1968). Additionally, Beecher argued that maintaining a patient in an irreversible condition was both unfair to the individual and to their families because it would cause unnecessary emotional and financial stress (Beecher, 1968). It would also be unfair to hospitals, as maintaining a brain-dead patient on life support would use hospital space and resources that could have otherwise been devoted to patients with treatable conditions. As a result, the committee stated that any organ with irreversible damage is dead, including the brain. If it can be proven that a patient has permanent loss of autonomic reflexes, voluntary movements, spontaneous breathing, response to stimuli, electrocortical activity, and conscious awareness, they are in an irreversible coma and their organs can be used for transplantation (Beecher, 1968).

The ad hoc Harvard Committee report was a foundational recommendation that influenced the medical field for decades; however, it was not law until the 1981 President's

commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research wrote the Uniform Determination of Death Act (UDDA) (Garret *et al.*, 2018; Truog *et al.*, 2018). The UDDA states that death is either permanent stoppage of cardiorespiratory function or irreversible damage to the cerebral cortex and brainstem (Truog *et al.*, 2018). It defines death as “the lack of functioning as an integrated whole,” (Truog *et al.*, 2018). Every state in the U.S. has agreed to the general definition of death as described by the UDDA, with some variation in their requirements for determining BD. This act made it legal to remove life support from patients with irreversible brain damage and improved the organ donation process. There is now an average of 8,000 donors annually, each with the capacity to save eight lives (Truog *et al.*, 2018).

The 1981 President’s Committee did not define required medical criteria for determining BD. Subsequently, in 1995 and again in 2010, the American Academy of Neurology (AAN) published standards for the medical community regarding brain death (Garret *et al.*, 2018; Wijdicks *et al.*, 2010). They stated that before testing the patients for BD, all central nervous system depressant drugs must be withdrawn, all neuromuscular blocking agents must be removed, and a normal body temperature and normal blood pressure must be maintained (warming blankets can be used as needed). To clinically assess BD, the physicians must check for lack of responsiveness to all stimuli and for the absence of all brainstem reflexes (Wijdicks *et al.*, 2010). It is most critical to check for apnea, or the inability to voluntarily breathe. The AAN stated that when performing the apnea test, the ventilator can be falsely read; it is best to turn off the ventilator entirely to observe any spontaneous attempts at breathing. The AAN also listed five ancillary tests for cerebral circulation and electrical activity that are acceptable for diagnosing BD when more than the clinical diagnosis is required. These include cerebral



angiography (CA), electroencephalography (EEG), Transcranial Doppler (TCD), the Nuclear Medicine Perfusion Test (NMPT), and somatosensory evoked potentials (Garret *et al.*, 2018). In the 2010 update, the AAN added magnetic resonance imaging (MRI) and magnetic resonance angiography (MRA) as new ancillary tests to accurately identify BD. The AAN also stated that there was not enough evidence to suggest a minimum observation period of patients before officially diagnosing BD (Wijdicks *et al.*, 2010). Using AAN guidelines, there have been no known instances of neurological recovery after BD has been clinically diagnosed (Walter *et al.*, 2018).

### *Neuroanatomy of brain death*

The BD diagnosis of death is only applied to patients in intensive care units maintained on life support (Machado, 2010). Patients outside of the ICU are pronounced dead due to a lack of respiration or pulse, whereas patients that have been resuscitated have to be assessed for irreversible brain damage. BD is physically caused by a lesion to the brain, a traumatic brain injury (TBI), anoxia, a hemorrhage, or a stroke. BD is physiologically caused by an increase in intracranial pressure (ICP), which is characterized by inflammation or swelling in the brain that follows a brain lesion or loss of cardiorespiratory function. If the intracranial pressure passes the mean arterial pressure (the individual's average blood pressure during a cardiac cycle) due to bleeding in the brain, swelling from injury, or lack of oxygen, blood flow is restricted (Machado, 2010). ICP triggers laminar necrosis, or the death of neurons in the cerebral cortex, due to a lack of oxygen and glucose (Schiff *et al.*, 2002). The absence of cerebral blood flow (CBF) in BD patients causes the brain to slowly disintegrate, a phenomenon known as "respirator brain". Occasionally, infants with flexible skulls and TBI patients with part of their skull removed have preserved CBF and see a decrease in swelling (Machado, 2010). In these cases, brain death can

still occur due to an internal lesion that causes a reduction in brain oxygen (Machado, 2010).

Asystole, or stoppage of the heart, is imminent in all BD patients.

*The impact of clinical and ancillary tests on the definition of death*

People generally agree with the concept of brain death but not on how to best determine it due to the controversy over the different definitions of BD (Walter *et al.*, 2018). Some physicians and neurologists are dissatisfied with clinical tests because occasionally patients diagnosed with BD have residual activity and do not meet whole-brain criteria. Dalle Ave and Bernat analyzed case studies in which BD patients had signs of remaining cortical activity. In one review of 39 cases, BD patients had indications of blood flow in their hypothalamus because of residual ADH secretion. They also found numerous cases in which some patients could still regulate their body temperature, a function that is regularly absent in BD patients (2018). In another study of 17 patients, 1/3 of the individuals still had blood flow in the basal ganglia, thalamus, and/or brainstem despite irreversible damage to most of the brain, indicating some remaining brain function. Dalle Ave and Bernat also found a case of a BD patient that had spontaneous breathing after removal of the ventilator; however, the case described was of a two-year-old boy that died after the ventilator was removed for the second time (2018). Additionally, in 40-50% of the reviewed BD cases, patients had complex spontaneous movements triggered by hyperactivity in the spinal cord. Dalle Ave and Bernat suggested that this could be because of a partially functioning brainstem, seizures, or undetected cerebral function (2018). A study by Kim *et al.* supported this finding. They observed 500 BD patients in order to determine the rate of recurrence of spontaneous movements and found that 80 of the patients had reflexive activity. The most common movements were the extensor planar response (extension and fanning toes) and the tonic neck reflex (head turned to one side with an extended arm while the other arm and

leg are flexed). They determined that spontaneous reflexes were more common when BD was caused by hypoxia, and that spontaneous movements were not rare (2017). Despite findings that some BD patients had residual cortical functioning, the clinical tests did not medically misdiagnose BD. The patients were in an irreversible condition and were considered brain dead.

There is more disagreement over the necessity and accuracy of ancillary testing than clinical testing. In considering the brainstem death criteria, ancillary testing is not always essential because a lack of brainstem reflexes and apnea are irreversible symptoms that typically signify brain death (Walter *et al.*, 2018). A patient with a damaged brainstem but an active EEG recording and “well-preserved cortical visual evoked potentials” would be diagnosed as brain dead. However, an active EEG could indicate that the individual has residual conscious awareness. This suggests that the brainstem formulation is not the most accurate definition of brain death because a conscious individual cannot be legally defined as brain dead. As a result of this problem, Europe created stricter diagnostic codes and now requires an inactive EEG and/or the absence of circulation on a CA test (Walter *et al.*, 2018). The medical community also debates whether the location of the primary brain lesion is significant in diagnosing BD. According to Walter *et al.*, the AAN stated that brain lesions to the supratentorial and infratentorial brain regions are not different, and that a patient diagnosed as brainstem dead is legally dead. The supratentorial region consists of the cerebrum and includes the two brain hemispheres, while the infratentorial region contains the cerebellum. The loss of brainstem function does not necessarily mean that the connection to the supratentorial region or function of the supratentorial region has been lost (Walter *et al.*, 2018). This indicates that the brainstem definition is not entirely sufficient in diagnosing BD because the location of the lesion cannot accurately determine brain death.

On the other hand, the whole brain formulation is challenged by ancillary testing because BD patients can have residual pockets of cortical activity, which can be seen on EEG recordings. Dalle Ave and Bernat ask, “Why should the brain criterion of death require the cessation of all brain functions, but not all activities?” (2018). They suggest creating more flexible whole brain death requirements, as brain dead patients can have a variety of relevant and/or extraneous residual cerebral activity and reflexive movements (Dalle Ave & Bernat, 2018). Generally, the whole brain definition is accepted despite residual functioning because islands of cortical activity are not sufficient for conscious awareness and damage is still irreversible. In some cases, patients that are in an irreversible condition have significant cortical activity. These patients cannot be diagnosed as brain dead using the whole brain definition. The physician has to determine if the lack of cortical functioning is substantial enough to constitute as BD; if not, patients could be in a vegetative or minimally conscious state.

*Other diagnoses of severe brain damage: alternatives to brain death*

Unresponsive wakefulness syndrome, or vegetative state (VS), is defined as “wakefulness without awareness,” (Laureys, 2005). There are two categories of vegetative states: persistent vegetative states, which can be reversible, or permanent vegetative states, which are likely irreversible (Multi-Society Task Force, 1994 a). A patient diagnosed with unresponsive wakefulness syndrome, or a persistent vegetative state, is awake and unconscious for more than a month. The Multi-Society Task Force on PVS (persistent vegetative state), assigned in 1991, stated that symptoms of VS included total unawareness of the self and the environment, no voluntary movements, no response to language, and no voluntary response to sensory stimuli. Unlike brain dead patients, those in vegetative states have preserved sleep/wake cycles, some hypothalamic function, and residual brainstem function, including cranial nerve and spinal

reflexes. They often do not need the ventilator to survive (Laureys *et al.*, 2002; Multi-Society Task Force, 1994 a; Schiff *et al.*, 2002).

Minimally conscious state (MCS) is another consequence of brain damage. MCS patients are awake with some conscious awareness and typically have severe cognitive and physical disabilities. It is “the most severe form of neurological disability in a conscious patient,” (Wijdicks, 2006). Assuming that consciousness is on a graded scale, the difference between VS and MCS is slight and subjective. VS patients possibly have residual conscious awareness at the subcortical level, whereas MCS patients have more obvious evidence of conscious awareness at the neurological or behavioral level. Not everyone believes that MCS is a valid diagnosis, but if it is accepted, MCS is more common than VS (Wijdicks, 2006). Accurately diagnosing VS and MCS is important because it determines treatment for the individuals. Patients in permanent vegetative states can be removed from life support, whereas MCS patients cannot have treatment withdrawn.

Locked-in syndrome (LIS) directly opposes the brainstem death formulation and is crucial to the brain death definition debate. As previously mentioned, some patients that meet the brainstem death diagnosis because of a large infratentorial lesion and lack of motor skills still have active EEG recordings (Walter *et al.*, 2018). These brainstem dead patients may have retained conscious awareness but are “locked-in” their bodies. They are often quadriplegic and nonverbal and may have an impaired memory or other cognitive disabilities (Walter *et al.*, 2018).

### **Ethical implications of diagnosing brain damage and death**

Despite attempting to categorize brain damage in order to reduce ambiguity of treatment proceedings and the removal of life support, the lines between different states of consciousness are oftentimes blurred. Some BD patients have residual islands of function, albeit minimal, while

many VS patients likely have some preserved consciousness at various levels. What is the impact of possibly misdiagnosing the severity of brain damage? The following cases are pivotal examples of when the medical establishment's definition of death conflicted with the individual's and/or their family's conception, highlighting the necessity of pluralism and individual autonomy in defining death.

The reporter Rachel Aviv described the case of Jahi McMath, a 13-year-old girl from California, who went to the hospital in 2013 to have her tonsils removed. After Jahi's surgery, she began having complications. Despite excessively bleeding from her nose and mouth and extremely low blood oxygen levels, the hospital said that the family did not need to worry. A few hours later, her heart stopped, and Jahi suffered from severe hypoxic injuries. Despite reviving her heart, she was pronounced brain dead two days later (Aviv, 2018). Since California follows the UDDA definition of BD, Jahi was legally declared dead and her ventilator had to be removed within a few days. Her family felt that the hospital was rushing to pull her off of life support and that they were being discriminated against because of their race, particularly since the hospital did not respond to their concerns about Jahi's condition immediately following the surgery. The family argued that being forced to remove the ventilator was a violation of their rights, despite the BD diagnosis. This case immediately gained media attention. Right-to-life activist groups provided the family with the money to transport Jahi to a hospital in New Jersey, the only state besides New York where families can reject the BD diagnosis if it clashes with personal beliefs (Aviv, 2018). Nailah, Jahi's mother, argued that Jahi had previously expressed that she would want to be kept on a ventilator if she were ever in this situation.

After a period of recovery, Jahi began to show some possible signs of residual brain function and conscious awareness. Firstly, Jahi began menstruating. According to Calixto

Machado, if this were to be true, her hypothalamus needed to have residual function. On a brain scan, he found that even though Jahi had no brainstem, she had intact regions of her cerebrum. If she were truly brain dead, her entire brain would have disintegrated due to a lack of CBF.

Besides menstruation, Jahi had other evidence of residual brain function. Her heartrate would increase in response to her mother's voice and decrease to soft music, and she had possible deliberate movements following her mother's commands. Jahi would also supposedly squeeze her mother's hand as a way of indicating yes (Aviv, 2018). Many neurologists considered this to be luck or chance, but Alan Shewmon felt that Jahi could possibly be in a minimally conscious state. After reviewing Jahi's movements, he supported the idea that some of her movements were voluntary (Aviv, 2018).

The bioethicist Robert Truog stated that he was disappointed with the medical community for being more concerned with adhering to the BD definition of death than acknowledging the family's wishes. He also reported that African Americans are more likely than Caucasian families to ask for treatment to be prolonged because they do not receive as much medical attention and therefore struggle to believe the BD diagnosis; the hospital should have taken this into consideration (Aviv, 2018). Additionally, he stated that if BD patients can live for years on a ventilator, they could very well be in a VS or MCS. Truog does not agree with the view that brain death is equal to human death; however, he still believes that BD is a necessary diagnosis because BD patients will never regain their full, conscious selves. BD allows families to move forward with the removal of medical treatment, and it prevents controversy over organ transplantation (Powell, 2018). Another bioethicist Alan Weisbard, who served on the 1981 President's Commission, argues that the definition of brain death was written by people that highly value their intellect. He feels that they did not consider religions or people that value the

body as much as the mind (Aviv, 2018). For many, severe loss of brain function feels as though it is death; for others, the individual is still alive until the body dies. Jahi McMath's body died June 22, 2018. The family was frustrated that they had to legally battle with the state of California to change her death certificate from 2013 to 2018, the year they felt she truly died. They were also upset that they could not continue treatment in California, as their wish was to maintain Jahi on life support in their home (Goldschmidt, 2018). According to law, maintaining Jahi's body was illegal, as the state defined her body as a corpse. This emphasizes the need for more states to allow families to reject the BD diagnosis if it is against their personal or religious beliefs.

Another significant case is that of Terry Wallis, who started to speak nineteen years after being diagnosed in a vegetative state. Neurologists imaged his brain and found signs of "possible axonal regrowth." A PET scan also indicated an increase in cerebral metabolism over time (Wijdicks, 2006). Even though the media claimed that Wallis was a miracle, his improvements should not have been surprising. He was likely misdiagnosed and was in an MCS soon after the injury (Wijdicks, 2006). His family had the legal right to maintain his body on artificial nutrition and hydration, as he was diagnosed as vegetative rather than brain dead. They felt that Terry was very much alive despite significantly reduced cortical functioning, and they were able to act on these beliefs.

A third critical case is that of Terri Schiavo, who was in a vegetative state after a cardiac arrest. She had a sleep/wake cycle and gag reflex, but no high-order functioning (Quill, 2005). There was an extensive legal battle between her parents and husband over whether it was acceptable to remove artificial nutrition and hydration. Her parents believed that her movements were intentional, even though her husband and most neurologists disagreed. After multiple



instances of treatment withdrawal and reinstatement while the case was trialed, the Florida Supreme Court eventually sided with her husband. It was determined that Terri did not want to live in a VS, and that because three years of therapy did not improve her condition, her state was irreversible. Treatment was finally removed, and Terri died of dehydration a few days later. Some physicians still wonder if Schiavo was misdiagnosed like Terry Wallis. However, Schiavo was examined by seven different neurologists, whereas Wallis was not. It is unclear if in another ten years, Schiavo would have recovered residual function (Annas, 2005; Wijdicks, 2006). In 2010, Laureys *et al.* proposed the name unresponsive wakefulness syndrome for people in vegetative states in order to reduce possible misdiagnosis, as the VS diagnosis could possibly hinder physicians from seeing signs of consciousness (2010). Changing the name of the diagnosis in the medical field could improve care for severely disabled patients.

The case of Terri Schiavo was also crucial to the debate about the removal of life support. It challenged who had surrogacy rights and the rights of disabled people. In this case, it was ruled that the spouse had the final say as a surrogate (Quill, 2005). The biggest problem with surrogacy is that proxy decisions are not always correct. If possible, individual choices need to be made very clear (Laureys, 2005). In respect to individual rights, the Congressman Thomas DeLay argued that Terri Schiavo was handicapped, and her right's as a disabled person needed to be protected. Many people argued that physicians and families should always err on the side of life. Additionally, they stated that the quality of life of disabled patients is severely undervalued. Even though they require support from others to live, they are "still very much alive," (Laureys, 2005; Truog *et al.*, 2018). On the other hand, erring on the side of life can actually hinder individual autonomy. Since it had been determined that Terri Schiavo did not want to live in a PVS, her right to choice was more important than her families conception of life and death

(Annas, 2005). Her husband had the final decision as a surrogate, and he chose to withdraw artificial nutrition and hydration because it was determined that her condition was permanent, and he believed that his wife would not want to be maintained in that state. From a religious perspective, Pope Pius XII addressed the preservation of life in a 1957 address. He stated that it is not unethical to withdraw ventilation or other treatment if the patient has terminal, irreversible brain damage. However, he also stated that it is immoral to withdraw artificial nutrition and hydration and allow VS patients to starve to death. He argued for the preservation of life at all costs unless hopeless (Griese, 1987). Following these guidelines, it was immoral for Terri Schiavo to die of dehydration and starvation. However, since she had previously expressed desire to not be maintained in that condition, it should not be considered unethical to withdraw her treatment. According to neurologists, her condition was hopeless. Even though her family and her religion believed that she should have been maintained on life support, her husband, her individual wishes, and the law, sided with the removal of her treatment.

### **The importance of pluralism**

Pluralism is a political philosophy that believes in the coexistence of diversity and varied perspectives. These case studies reflect the nature of pluralism because each individual had a different quantity of brain damage and therefore a different diagnosis. However, the results of each case depended on both the medical diagnosis and/or the individual's conception of death. The difference between these cases is in the amount of individual autonomy permissible by law regarding their individual beliefs. Terry Wallis was legally maintained on life support in a vegetative state and Terri Schiavo was legally removed after extensive court battles, whereas Jahi McMath and her family were told to abide by the medical diagnosis rather than by their personal beliefs. Their conception of death was overlooked. This poses the question: should the

brain death definition be loosened to better encompass a broader definition of death? A clear objection to this notion is that this is not practical. Organ transplantation relies on the brain death diagnosis, and BD is necessary to reduce controversy. Additionally, hospitals may not always have the space and equipment to maintain an individual in an irreversible condition. However, even though this is a complex problem without a simple solution, it is essential to be receptive to a broader conception of death. Death as defined by the individual should include lack of cardio-respiratory functioning, lack of cerebral functioning, and should even extend to the lack of complex higher order functioning, should an individual choose. If one believes they are dead based on their individual conception of death, removal of treatment should be ethical, just as it should be allowed for families to maintain a loved one on life support if they reject the BD diagnosis. This in no way diminishes the importance of the physician's assessment; rather, it suggests including both the medical diagnosis and individual beliefs in order to expand one's autonomy over their life and death.

The concept of brain death is complex and laced with ethical concerns. Even though brain death aids in organ transplantation, protects families from prolonged grief, and saves the hospitals space and money, tests for determining BD still leave some room for error, particularly in respect to measuring levels of consciousness. Once BD was defined by the UDDA using the ad hoc Harvard Committee guidelines, and the AAN outlined medical procedures for determining BD, this concept became less controversial. However, despite the best legal efforts, the individual conception of death is still limited. In respect to the different formulations of BD, the whole brain, brainstem, and neocortical definitions do not accurately describe every BD patient. As of now, it is best to follow the clinical guidelines for determining whole brain death even though patients with whole brain death may have some residual functioning because it

leaves less room for error in diagnosis. With that being said, even though BD is a necessary medical standard, it is important to recognize that it is a highly complex and variable issue. Without a clear understanding of consciousness and neuronal plasticity, diagnosing brain death or other (such as VS or MCS) is highly variable. This highlights the concern about the rigidity of the brain death definition, while also emphasizing its importance. In conclusion, it is necessary to include an array of perspectives when considering the brain death diagnosis, even though it may be difficult, because death is not black and white. Just as determining brain damage and consciousness is on a graded scale, death is equally ambivalent.

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