# Neuroethics of death in the United States

Mikaela Sifuentes

University of Texas Health Science Center at San Antonio

Department of Pharmacology

San Antonio, TX

United States of America

Email: sifuentesmm@uthscsa.edu

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By Mikaela Sifuentes

The search for a universal definition of death is a relatively new objective in human history, framed by complex biological, technological, and socio-political factors. While it is widely understood that "life" and "death" describe inverse states of being, what separates these two states has been vigorously debated by scientists, ethicists, and theologians. Far from merely an academic distinction, the definition of death has implications that extend to end-of-life healthcare, organ transplantation, and inheritance law. This review explores the historical and current definitions of death in the United States, the role of technological advances, and the resultant social and legal applications.

## Definitions of Death

Primary to the debate about the specific definitions of death is the deliberation over whether death is a singular event or a continuous process. If a process, death could be defined as an irreversible, progressive loss of an organism's function to live. If this is the case, the cessation of a pulse or brain activity may merely be a *sign* of a point of no return in the process of death. This also implies that there may be different "degrees" of death as it progresses, which may reflect the distinctions between *cardiopulmonary*, *cortical*, and *whole brain* death, which are expanded upon below. On the other hand, were death a singular event in time, this would mean that death is the exact moment at which life has ceased. With this understanding, there is no room for degrees of life or death. Rather than signaling death, the loss of functions (i.e. heartbeat, breathing) *is* death in itself. This distinction is generally supported by religions that hold a concept of a soul, which is either wholly present or absent in a body, without any gradation between the two states. Legally, the determination of the continuous or singular nature of death was decided in *Thomas vs Anderson* (1950)(1), when a California District Court of Appeal ruled that "death is not a continuous event;" rather, it "is an event that takes place at a precise time."

Traditionally, death has been defined as the irreversible cessation of cardiopulmonary functions, evidenced by the permanent absence of a spontaneous heartbeat and breathing. **Cardiopulmonary death**, sometimes known as "clinical death," had previously been a clearly-defined moment with little ambiguity. Although early forms of artificial respiration existed, they were primarily restricted to manually-operated devices used for short-term emergencies. Therefore, before the invention of the mechanical artificial ventilator, cardiopulmonary death closely coincided with the tissue death of the rest of the human body, whereupon all vital functions have clearly ceased and the onset of decay can be observed. Even so, studies had confirmed that certain tissues of the body die more quickly than others after cardiac arrest, leaving open the possibility that an apparent single event of bodily death could be teased apart into separate processes. Legally, the single cardiopulmonary definition of death persisted until the 1980s, when alternative definitions were incorporated into law. According to *Black's Law Dictionary* (first published in 1891)(2), which was referenced in two critical end-of-life legal

disputes in the 1950s, death was defined as the "total stoppage of the circulation of the blood." This can be contrasted with *apoplexy*, which was described as a "failure of consciousness," a "suspension of voluntary motion," and "suspension of the cerebrum," but distinct from death itself. However, advances in neurosurgery and artificial respiration were already subverting this definition of death by the early 20th century.

Even before the widespread use of mechanical ventilation (sometimes generally referred to as "artificial life support" today), the classic definition of death was challenged by observations recorded by surgeons in rare circumstances. While operating on a patient in 1908, neurosurgeon Harvey Cushing became one of the first physicians to document brain death. After the surgery, the patient suddenly ceased breathing, and emergency artificial respiration was induced manually. Cushing attempted to revive the patient through multiple methods, even using an early form of electrical brain stimulation, but the patient did not recover. Cushing noted that the patient lacked any apparent sensory or motor function, response to noxious stimuli, or cerebral blood flow, observations that would support a contemporary diagnosis of brain death. After 36 hours of attempting to rescue the patient, Cushing concluded that despite the persistent beating of the patient's heart, mental and autonomic respiratory function of the brain had irreversibly ceased. In a final effort to restore breathing, Cushing ordered the injection of adrenaline, after which the patient spasmed and the heartbeat finally stopped. This spared Cushing the responsibility of deciding whether a patient failing the cardiopulmonary criteria for death was nonetheless already deceased, a dilemma that doctors at the time undoubtedly faced, yet remained undocumented.(3) It was not until mechanical means of artificial respiration was widely used in medical care that the dissociation of cardiac, respiratory, and cognitive function at the end of life would be extensively discussed.

It eventually became apparent that the traditional definition of death was insufficient to describe the reality observed in practice. The first successful surgery using mechanical cardiopulmonary bypass (called a "mechanical heart") was conducted in 1952, significantly removing the heartbeat as a necessary and sufficient sign of life. This led to a pressing bioethical question: if a patient without a heartbeat could be living, could a patient with a heartbeat be dead? As artificial means of preserving cardiopulmonary function became more widely used, more doctors came across observations similar to that of Cushing – that the heart seemed to be able to outlive a patient's cognitive abilities. This irreversible loss of cognition was linked to brain function in the cerebral cortex, which could sometimes be disconnected or damaged following stroke or trauma. This would be evident from the patient's permanent loss of voluntary responses, language comprehension, and activity in the cerebral cortex, symptoms of a condition that came to be known as **cortical** or **neocortical death**.

The concept never reached wide medical or legal application. In one key decision, *Smith vs. Smith* (1958)(4), the idea of a cortical death was outright rejected. The case involved a husband and wife who sustained extensive injuries during an automobile accident, after which the husband immediately died. The wife was transported, unconscious, to a hospital, where she died 17 days later without having ever regained consciousness. In the subsequent dispute over

the couple's estate, it was argued that both people "lost their power to will at the same instant, and that their demise as earthly human beings occurred at the same time." Referring to *Black's Law Dictionary*, the court ruled that given the current definition of death, the woman could not be considered deceased until her heart stopped beating, and it refused to consider the plaintiff's offer of evidence to the contrary.

Today, the term "cortical death" has been replaced with the diagnosis of a persistent or permanent vegetative state (PVS). A vegetative state is described as one of "complete unawareness of the self and the environment, accompanied by sleep-wake cycles, with either complete or partial preservation of hypothalamic and brainstem autonomic functions." Extensive observation of the patient reveals "no evidence of psychological awareness or the capacity to engage in learned behavior." The differences between a vegetative state, a persistent vegetative state, and a permanent vegetative state lies in the length of time and the certainty of prognosis. A vegetative state that extends for more than a week may be described as "persistent" with uncertainty of recovery, whereas a vegetative state that continues for years with a high degree of certainty that the patient will never recover can be called "permanent."(5) In-depth study of patients in a PVS is complicated by a lack of a clear universal diagnostic criteria. Recently, the American Congress of Rehabilitative Medicine published a report analyzing 13 different behavioral assessment scales for disorders of consciousness, highlighting major diagnostic limitations.(6) In 1994, the Multi-Society Task Force on PVS published a consensus statement on the most recent knowledge of the medical aspects of PVS. In it, the authors urged the abandonment of the term "neocortical death," as it does not represent a distinct medical entity.

Despite the lack of support for a neocortical basis for death, there was a growing consensus among physicians for another neurological basis for death: that total, permanent brain failure could effectively be identified as the end of a patient's natural life. This concept was termed **brain stem** or **whole brain death**. In 1968, the ad hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death published a landmark article in the *Journal of the American Medical Association*, which proposed the "irreversible coma" as the new definition of death.(7) Under this condition, the patient is nonresponsive, exhibiting no spontaneous breathing, has failed tests for brainstem reflexes, and elicits a flat electroencephalogram recording. The committee recommended that if these tests confirmed the patient to have "no discernable central nervous system activity" after 24 hours without change, the patient may be declared deceased. Despite a building scientific consensus supporting a whole brain definition of death, the idea did not gain widespread implementation until 1981, when the Uniform Determination of Death Act was created by the National Conference of Commissioners on Uniform State Laws, which set the stage for incorporating whole brain failure as a legal definition of death nationwide.

## Role of Technology

The expansion of technology in the biomedical field has been a forceful driver for reevaluating accepted definitions of death, and will likely continue to be as the biotechnical field

advances. The invention of the mechanical ventilator opened up a world of possibilities of recovery for countless patients, but it also created an apparent limbo, where some patients could linger for months or even years between life and death. This issue was complicated further by the introduction of the cardiopulmonary bypass, which further separated the three human functions that were thought to be indicative of life: breathing, blood circulation, and thought. As medical technology became more refined, scientists documented new distinctions between life, death, and different states of consciousness, which must each be evaluated to determine a responsible and ethical course of treatment. The development of imaging technology and other detection tools has both helped to study these distinctions and complicate it further. While this technology can be extremely valuable for diagnosing patients and studying different states of consciousness, it is also critical to fully understand the limitations of the technology to avoid misinterpreting the data. Faulty interpretation can lead to the formation of false expectations of recovery, or worse, withdrawing care from a patient for which recovery is still possible. Fortunately, imaging techniques have successfully been used to reduce misdiagnoses like that of unrecognized "locked-in" syndrome, in which a patient remains cognitively aware after a brain injury, but they have lost control of voluntary movements and can appear to be in a vegetative state. In this case, technology can be used to observe intact cognitive networks that would have gone undetected by behavioral assessment alone.(8)

One technological hot topic which has been associated with diagnoses of death is organ transplantation. The first successful human kidney transplant was performed in 1954, generating hope for patients suffering from failing organs. Ordinary people now had the option to donate their organs after they died, but with an unclear definition of death, the life-saving breakthrough quickly became a controversial topic regarding end-of-life care. The main factor limiting the capacity of organ transplantation technology to save lives is the availability of suitable donors with functional quality organs. While it is uncontroversial to accept organs donated by patients who have ceased cardiopulmonary function, it is often difficult to retrieve these organs before deterioration has already begun to affect the body. Therefore, there is a high demand for organs from patients who are dependent on artificial life support at or shortly prior to the time of death. Two donation procedures cause concern among patient advocates. The first procedure is donation after a diagnosis of brain death, also known as a "beating heart" donation. In this case, the patient has been assessed and confirmed as brain dead, while cardiopulmonary function is maintained artificially. The second procedure is donation after cardiac death, which follows the withdrawal of artificial care from a consenting terminally ill patient. In this case a patient that has *not* been diagnosed as brain dead can opt to refuse life support (as specified in a living will or by family consent). Under doctor supervision, the patient is withdrawn from support and cardiac death can be declared after blood flow has ceased for a designated period of time. In both of these donation circumstances, advocate groups have expressed concern that a declaration of death may not be made in the patient's best interests, but rather to meet a demand for healthy organ donations. These concerns can be addressed by following recommended guidelines for determining death, increasing transparency and communication with patients' family members,

combating myths about organ donation, and emphasizing the benefits of creating a living will before a debilitating injury occurs.

Another emerging area of technology that could impact current concepts of death is that of suspended animation. Hypothermia has long been used as a tool to reduce tissue damage resulting from cardiac arrest and stroke because it drastically slows down metabolism in the body's cells. However, scientists have been exploring the possibility of bypassing lethal incidents by "supercooling" patients and treating their injuries while they remain in a frozen state. This sort of procedure, if implemented in humans, can add further confusion to the distinctions between life, death, and disordered consciousness, since the patients will temporarily exhibit no classical signs of life while cooled. Failure to emerge from a suspended animated state may also complicate the diagnosis of death, organ donation, and "do not resuscitate" orders.(9)

Beyond the technologies that we can identify today as influential on our understanding of death, it is likely that advances in new techniques or entirely new technology could revolutionize the field. Bioprosthetics offers the possible dilemma we may face when bodily function (i.e. spontaneous breathing, voluntary thought) may forever be preserved as long as failing tissue can be replaced, thus removing the possibility of death. Transplantation of tissue associated with consciousness and identity (such as cerebral transplantation) may not only introduce a question of where in the body personhood lies, but also how it may be artificially modified, and whether any degree of modification can result in a de facto death of the human organism. These developments need to be continuously assessed with up-to-date information in order to reach a uniform consensus on ethical decisions in circumstances resulting from these procedures.

**Medical and Legal Practice**

Although clinical observations challenging the acceptance of cardiopulmonary death were recorded in the early 20th century, it wasn't until the 1950s that the concept of death came to be debated in law. Despite being regarded as a critical bioethical issue today, the first key decisions on the definition of death were over inheritance law, where determining the moment of death can have a major impact on estate transfer. In both *Thomas vs Anderson* (1950) and *Smith vs Smith* (1958), it was claimed that despite a different declared time of death, the deceased had perished at the same time, a claim that was rejected by the court. Both courts cited *Black's Legal Dictionary*, which defined death as the moment in time at which cardiopulmonary functions ceased.

In medical practice, decisions regarding the declaration of death and end-of-life care were typically made on a case-by-case basis, and outcomes heavily relied on the professional opinion of the physician and the wishes of patients' family members. The first public discussion of the ethics of a possible neurological definition of death wasn't until 1959, when French neurologists Pierre Mollaret and Maurice Goullon described a permanent "coma-like" state in patients as being not *barely alive*, but rather *already dead*.(10) The issue was addressed formally by the 1968 report of the ad hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death, titled *A Definition of Irreversible Coma*.(7) The report proposed that death be

defined as the total lack of discernable central nervous system activity, combined with the absence of spontaneous breathing and complete unawareness of the self or external stimuli. The electroencephalogram, which was first used on a human subject in 1924, was also proposed as a useful tool for the diagnosis of death. Using this definition of death, a patient on artificial respiration could be declared dead, after which mechanical ventilation could be terminated.

In 1978, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research was congressionally mandated to advise the government on how to address bioethical issues. This commission released the report *Defining Death* in 1981(11), which clarified that two definitions of death were equally valid: the irreversible cessation of heart and lung functions ***or*** the irreversible loss of "all functions of the entire brain." The report also recommended that these definitions be implemented into uniform state laws. This directly led to an update of the ambiguous Uniform Brain Death Act of 1978, which was replaced with the Uniform Determination of Death Act of 1981. The act was created by the National Conference of Commissioners on Uniform State laws, in collaboration with the American Medical Association and the American Bar Association, and incorporated the findings of the President's Commission report into a guideline that could be modified and adopted on a state-by-state basis. Today, the act has been adopted by all 50 states, although some variations in implementation exist between states.

Controversies during the turn of the century highlighted a need for fresh evaluations of the science and ethics of accepted definitions of death. In 2001, President George W. Bush issued an executive order to create the President's Council on Bioethics to succeed the National Bioethics Advisory Committee of the Clinton administration. The President's Council reviewed the 1981 report and published their findings in *Controversies in the Determination of Death* in 2008.(12) The report cited growing concerns about the "clinical and ethical validity of the neurological standard," with critics claiming that it was both too restrictive and too liberal. The council ultimately concluded that the neurological standard of irreversible, whole brain failure as a definition of death remains valid.

Since then, most evaluations of the definitions of death confirm this conclusion. In 2010, the Quality Standards Subcommittee of the American Academy of Neurology published "Evidence-based guideline update: Determining brain death in adults," which reviewed the literature concerning whole brain death.(13) The publication supported the whole brain death definition, noting that there was not a single incident of a patient recovering from a standardized clinical diagnosis. The subcommittee also recommended a standard set of procedures in diagnosing brain death.

## Role of Religion

Religion plays a major role in the social understanding, acceptance, and implementation of ethical issues. In the United States, major religious authorities have been responsive to the ongoing discussion of the bioethical concerns surrounding end-of-life care.

The Roman Catholic Church, representing a little over 20% of the American population, was an early contributor to the debates surrounding the definition of death. In 1957, when the idea of a neurological basis for death was beginning to gain traction, Pope Pius XII addressed the International Congress of Anesthesiologists in a speech titled *The Prolongation of Life*. In it, Pius clarified the obligations of doctors to use "ordinary means" to preserve life, and he acknowledged that determining the exact moment of death in severely brain damaged patients is not "within the competence of the Church," but that doctors have the responsibility to act according to facts and reason. In 1985 and 1989, interdisciplinary working groups from the Pontifical Academy of Sciences met and defined death as the spiritual separation of the body from the "soul," which is evidenced by clinical signs of either irreversible cardiopulmonary arrest or the permanent loss of all brain function, confirmed by a physician according to accepted medical standards. (Scripta Varia 83 1989) Church doctrine concerning the soul is a significant factor in shaping the religious perspective on the definition of death. With the concept of the soul being an indivisible source of life, death is a moment of separation that can only happen once. Any spontaneous ordered function of the whole human body is evidence that the soul has not yet left the body. Therefore, from the Catholic perspective death cannot be declared until "the functions of the entire encephalon have been irreversibly lost, including those of the encephalic trunk, which governs the cardio-respiratory function."(14)

Other religions with sizeable populations in the United States share an ethical stance similar to that of the Catholic Church, recognizing the scientific consensus on the validity of brain death while maintaining the importance of extracorporeal aspects of life in accordance with doctrine. In 1969, during the First World Meeting on the Transplantation of Organs, representatives of the Catholic, Protestant, Jewish, and Muslim faiths gathered to discuss the implications of transplant technologies in the context of religious teaching. During the meeting, the groups reached a consensus to accept the clinical diagnosis of brain death. Other representative religious organizations in the United States have made public statements on this perspective. The National Association of Evangelicals, representing about 25% of the American population, affirmed the Uniform Determination of Death Act, with two definitions of death.(15) The Rabbinical Council of America, representing approximately 2% of the American population, remains divided on whether brain death criteria fulfills the *halakhic* (Jewish law and tradition) definition of death and takes no official position on the matter.(16) Within the religion of Islam, which is followed by <1% of the U.S. population, the concept of brain death accepted by multiple Islamic authorities, including the Islamic Medical Association of North America.(17) Although these religious groups consist of heterogeneous populations with diverse communal and personal perspectives on the definition of death, the official positions taken by religious authorities remains a significant source of influence on ethical decision-making and the understanding of death by the public.

## Conclusions

The task of determining a clear definition of death is a complicated endeavor because it attempts to fit a complex array of biological functions into neat distinctions that meet the needs of human society. Definitions of death have a profound impact on the way we handle the ethics of agency, identity, technology, and healthcare, and thus must reflect the impact of societal factors as well as biological evidence. Additionally, the process of dying involves bodily functions that are not easily measured, such as consciousness, leaving room for change as our technological capabilities reveal new ways to assess these components. The emergence of new technologies has historically exposed weaknesses in our ability to adequately distinguish death from similar disordered conditions, and even as we learn more about the physiological changes that occur during death, we uncover information that presents us with new dilemmas. Therefore, it is necessary for scientists to continue to review and validate current methods for defining death while considering future ethical issues that may arise from advances in life-saving technology.

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