

WHEN IS DEATH?

Anxiety over being buried alive dates back centuries. Roman author Pliny the Elder remarked: "Such is the condition of humanity, and so uncertain is men's judgment, that they cannot determine even death itself." The New Testament told of Jesus raising the beggar Lazarus from the dead. (In modern times dozens of cases have been reported of a so-called "Lazarus Syndrome" - spontaneous return of normal heart rhythm after failed attempts at cardiopulmonary resuscitation.) Even Maimonides cited a case of a man who revived three days after apparent death.

Lively debate continued for centuries and, in particular, the 19th century was obsessed by reports of inadvertent burials alive. Other than holding a feather or a mirror next to the nose, doctors had few means of certifying death except for visible decay and the press was quick to sensationalize any mistakes. Sometimes bells were tied to a cadaver's limbs that could be heard if they began to move in the coffin.

During the Enlightenment, some Jewish doctors encountered a troubling dilemma since their religious tradition required burial as soon as possible as a sign of respect. In 1612 Abraham Portoleone of Mantua in his will admonished his sons against burying him until 72 hours had elapsed. He wrote, "our sainted fathers were eager to hasten burial but do not marvel at what I ask for for not all scholars agree with one another." In 1787 Dr. Markus Herz of Berlin published a pamphlet titled "On the premature burial of Jews" in which he agreed with a recently passed civil law that required waiting three days before internment lest an error be made. Dr. Herz asked, "Would it not be advisable to discontinue this practice and follow the example of our ethical and enlightened neighbors who watch over their dead for at least several days before burial?" Nevertheless, when Markus Herz died in 1803, he was buried promptly in a Jewish cemetery - with no bells attached."

In 1844 Edgar Allen Poe wrote a short story titled "The Premature Burial" in which the narrator who suffers from severe cataplexy has an abnormal fear of being buried alive. After describing several recent instances of premature burials, he explained that "the stifling lack of air and fear of death combine with claustrophobia, darkness, and silence to form a terrifying ordeal that does not occur anywhere else on Earth." The narrator relates:

To be buried while still alive is, beyond question, the most terrific extreme which has ever fallen to the lot of mere mortality. That it has frequently, very frequently, so fallen will scarcely be denied by those who think. The boundaries which divide Life from Death are at best shadowy and vague. Who shall say where the one ends, and where the other begins?

After “a distressing experience” in his own family, a 19th century English social reformer William Tebb dedicated himself to stamping out the scourge of “death-counterfeits.” By his estimate, in England and Wales alone some twenty-seven hundred people were annually “consigned to a living death...The thought of suffocation in a coffin is more terrible than that of torture on the rack, or burning at the stake ... When we neglect precautions against a fate so terrible, our tears are little less than hypocrisy and our mourning is a mockery.” And in 1896 William Tebb founded the London Association for the Prevention of Premature Burial.

All of this preceded the advent of modern diagnostic technology which should have resolved the problem once and for all, but in some respects has only muddied the waters. By the 1980s one could stop breathing, even have their heart stop beating, yet artificially be kept alive long enough that viable tissue could be transplanted from newly dead donors. Because there weren't enough fresh hearts, lungs, kidneys and corneas that could be harvested, it became a practical matter to determine exactly when a potential candidate was legally dead.

THE HARVARD CRITERIA

Determination of death by strictly neurological criteria as an alternative to cardio-respiratory failure was first proposed in 1968 by a special committee at Harvard Medical School. They were concerned that obsolete criteria for defining death can lead to controversy in obtaining organs for transplantation and concluded that a diagnosis of brain death required irreversible, cessation of all functions of the *entire* brain. In 1981 the Harvard plan was adopted with some modifications into a model state law called the Uniform Determination of Death Act (UDDA.) It was approved by the National Conference of Commissioners on Uniform State Laws in cooperation with the American Medical Association, the American Bar Association and the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research and, in due time, was adopted by most states albeit with a few variations.

At about that same time, I was a fledgling physician in New Jersey and the UDDA seemed sensible to me - as it probably was to most physicians. However, I soon learned that things weren't so simple. I recall that I once had a female patient in her 40s who suffered a massive pulmonary embolism that caused such severe cerebral anoxia that she fulfilled the recently described neurologic criteria for "brain death." I gently asked her grief-stricken husband whether he'd be willing to donate her organs and although he was inclined to agree, first he'd have to consult his rabbi. They belonged to an Orthodox congregation in Paramus and, to my surprise, their rabbi's response was categorically no! He insisted that according to Jewish Law (*halacha*) death can only be declared when breathing has stopped.

Back then, some four decades ago, most Orthodox rabbis didn't recognize the brain death concept and because this woman was being mechanically breathed she wasn't dead enough! Although her husband was conflicted, eventually he agreed to permit organ donation since the tragedy at least might be used to help others. Arrangements were made, the respirator was turned off, multiple organs were harvested and later the woman's family received many letters of thanks from grateful recipients.

Of course rabbis were not the only ones troubled by these modern ideas. For some people emphasis should focus more on what is life than what is death. They argued that permanent loss of higher brain function - the ability to think, what makes us "human" - was intolerable. Without the capacity to think life wasn't "worth" living. Others insisted on cessation of "whole-brain" function - not only the cerebral cortex but also the brain stem that controls vegetative functions.

DEATH AS AN OPTION

In 1985 I was appointed to New Jersey's newly formed Bioethics Commission which functioned for about six years until government funding was eliminated. Brain death was among the issues we discussed and I soon learned that everyone didn't understand things the way I did. After a representative of an Orthodox Jewish organization (Agudath Yisrael) made a persuasive argument, we agreed that although the definition of death should be rooted in scientific knowledge, life vs. death decisions also represent a societal choice that sometimes might be influenced by religion.

As a result of these discussions, the statute that was passed by New Jersey's legislature in 1991 contained a unique exemption: "Death cannot be declared "in violation of an individual's religious beliefs." A physician should not declare someone dead on the basis of brain death if he or she, "has reason to believe...that it would violate the personal religious beliefs of the individual." In effect, death became a legal *option* in New Jersey. (In addition to Orthodox Jewish concerns, some Buddhists, Native Americans, and evangelical Protestants believe that someone is alive as long as their heart is beating.)

After New Jersey passed its law, religious exemptions to death by neurologic criteria occurred very infrequently in the state. A survey of hospitals during the five year period between 2012 and 2016 turned up more than thirty cases of religious exemption, about half for Orthodox Jewish families. No requests for exemption were denied and during this same period there were 801 brain death donors in New Jersey. The same year that New Jersey passed its brain death statute, New York State's highest court also adopted a religious exemption but it was through case law rather than statute and required only "reasonable accommodation" (24-72 hours) of personal beliefs.

Although the UDDA was intended to provide a comprehensive and medically sound basis for determining death in all situations, in later years the concept came under scrutiny and was the focus of legal challenges. Consider the case of Yechezkel Nakar who in 2017 while at New York Presbyterian Hospital was diagnosed as brain dead. The hospital then issued a death certificate over the objections of his orthodox Jewish family. Nakar was transferred to different hospital where he received medical support for another 21 days until he met traditional diagnostic criteria. His wife filed a lawsuit in Brooklyn Supreme Court seeking to rescind the death certificate, presumably in order to make him eligible for insurance coverage for the intervening three weeks between brain death and cardiopulmonary death. In January 2019 the court ruled in favor of Nakar's family. (Incidentally, New Jersey's brain death law provides for continuation of health insurance coverage when there is a religious exemption.)

Like New York State, California and Illinois also require hospitals only to make "reasonable accommodations" to families' objections but it's not a blanket exemption as in New Jersey. In practice, most hospitals usually continue physiological support for a further 24 hours after declaring brain death. In New York this allows time for families to transfer the patient to New Jersey should they wish to

do so. Indeed, living corpses even have been flown in from much further - and not only Orthodox Jewish corpses.

LIFE AFTER DEATH

In 2013 Jahi McMath a thirteen year old Christian girl living in Oakland California suffered brain damage during or just after throat surgery for sleep apnea but her parents refused to accept a diagnosis of brain death. In retrospect, they may have been correct and she actually was in a persistent vegetative state. After many months of medical-legal impasse, her body was flown to New Jersey. In total Jahi McMath survived for almost five years, during most of the time being cared for at home, and continued to grow and develop with the onset of menarche. When her parents celebrated her 15th birthday they said "Our little sleeping beauty is doing good" - meaning that occasionally she moved a limb - they claimed on command; more likely it was only a reflex. But in June 2018 she developed internal bleeding due to kidney and liver failure and doctors removed her from life support, finally allowing her to die by anyone's standards.

There've been several other cases of prolonged biologic life after neurological death. In 1998 pediatrician Alan Shewmon at UCLA claimed that he'd found 175 cases of somatic survival of a brain dead body that lasted at least a week; 28 cases for longer than a month, 17 cases longer than two months and 4 cases more than a year. Between 2005 and 2013, the ethics consultation service at the Cleveland Clinic reported thirteen requests for continued physiological support for a brain-dead patient. (Of these cases, three families cited their Orthodox Jewish faith, one referenced belief in God and another named their Islamic faith, reasons for the others were not stated.)

THE APNEA TEST

As ever more complex array of diagnostic tests have been employed to measure brain activity - encephalograms, CT, MRI and PET scans, the so-called apnea test has emerged as the gold standard - even superseding feathers and mirrors. In it the comatose patient is removed from the ventilator for about ten minutes during which time the concentration of carbon dioxide in the blood slowly rises. Because CO₂ is a potent stimulus to respiration, if despite significant elevation there's no measurable effort to breathe than apnea is considered irreversible. Of course, every medical test has a trade-off between sensitivity and specificity but death is unique in that it demands 100% specificity and 0% chance of a false-positive error. The apnea test is no exception; moreover, the test itself actually can be damaging to the brain.

A JEWISH PERSPECTIVE

The traditional codifiers of Jewish law ruled that the primary test in determining whether a person is alive or dead involved the nose. This is based on a Biblical verse, “All in whose nostrils was the breath of the spirit of life” (Genesis 7:22), which implies that the “breath of the spirit of life” is what defines life. Although the Talmud doesn’t directly discuss the matter, the question of determining death was addressed indirectly in a parable about what to do when a building collapses on Shabbat and it’s uncertain if anyone alive is trapped underneath. Because of the principle of *pikuach nefesh*, in which saving a life takes priority over all else, the Talmud permits violating Shabbat in order to determine if anyone is alive under the rubble. It then asks which area of the victim’s body one must examine to determine if he or she is alive or dead? The favored option was to uncover the buried victim from above until reaching the nose, seemingly indicating that the rescuer must look for signs of breathing.

One of my sons is a rabbi who for many years has served on the Law and Standards Committee of the Conservative movement that considers difficult theological issues and establishes guidelines. It seemed to him that the apnea test was a perfect compromise between Jewish tradition and the current state of medical expertise and in 2004 the Conservative movement approved the proposal that permanent cessation of respiration as established by the apnea test met the traditional standard of Jewish law.

Gradually Orthodox rabbis have come around on this issue in order to save lives. For example, in Israel the percentage of organ donations had been lower than in most other countries until in 1986 the Chief Rabbinate approved of brain death, at least in principle. However, religious objections continued until 2009 when modifications of the law were made to require proof that spontaneous breathing had irreversibly ceased. Breathing was a measurable result of brain stem function - or was it?

NOT SO FAST

Although the whole brain death standard has been widely accepted, the issue continued to generate controversy. It has been reported that some people may meet all diagnostic criteria of brain death, including the apnea test, and yet retain some brain stem functions. Apparently certain upper spinal cord injuries can prevent breathing yet the ventilator-dependent victim can remain conscious and very much alive. Moreover, as exemplified by the Jahi McMath case, the body is capable of sustaining certain biologic activities even absent a functional brain

By now most theologic and philosophic objectors have been at least partially appeased, but many believe that further clarification is called for - semantically as well as medically. A recent review of the subject concluded the following:

Until the UDDA or individual state laws are revised, lawsuits are likely to continue because current tests do not fulfill the language of the law. The challenge provides an opportunity to clarify the meaning of brain death, better educate the public about the diagnosis, and improve the tests to make them safe and reliable as possible.

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