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Death's Troubled Relationship With the Law

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Abstract

Death's legal definition must be responsive to advances in technology, and it must delineate between life and death. But where to draw the line is difficult to determine. Death's current legal definition requires irreversible cessation of cardiorespiratory function or irreversible cessation of all brain function. But technology can often restore some brain functions without restoring consciousness, so brain death is often diagnosed without the irreversibility requirement being met. This article argues that the law should be updated to require *permanent* cessation, not *irreversible* cessation and that medicine should be transparent about what *permanent* means.

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Introduction

Death's legal definition must continue to be responsive to advances in medical technology. To be practical and ethical, it must delineate when an individual no longer has and cannot reacquire any meaningful functions or life qualities, when loved ones can begin shaping their lives without the individual, and when clinicians are relieved of their duty to provide care. Agreeing on the absence of meaningful life qualities is challenging, however. Death's definition has shifted to accommodate medicine's increasing capacity to restore life qualities that we can all agree are meaningful, such as the ability to consciously and intentionally interact with the world.[1] Individuals who in a different era would have been considered dead are sometimes "returnable."[2] However, breathing and circulation—"life-like" qualities—that used to be good indicators of the presence of more meaningful life qualities have become less reliable. Respiration and circulation can now be performed artificially. Thus, defining death remains difficult. Can a definition capture when meaningful life qualities are completely gone and unrestorable? Should it try to define what qualities of life are meaningful?

This article will first explain how the current medical practice of diagnosing death pursuant to the standard of permanent cessation of function does not comport with the legal definition of death, which requires irreversible cessation. It will then support

changing the law to replace the irreversibility standard with the permanence standard as long as death diagnoses can be justified in terms of the outcomes that forgone attempts to restore function would have produced and are made according to consistent criteria. Next, this article acknowledges different perspectives regarding what life qualities should be considered meaningful and suggests that respecting different perspectives does not require indefinitely maintaining organ support for individuals who will never again be aware or awake. It concludes by recommending that the standards for brain death determination be periodically examined and refined according to new evidence and that the care team's understanding of meaningful life qualities be made transparent to the patient's family and friends.

Defining Death Based on Permanence

Traditionally, breathing and pulse cessation defined death.[3] In the 1950s, ventilators and defibrillators began routinely reversing breathing and pulse cessation. But some patients for whom circulation and respiration can be restarted will never regain consciousness. The 1968 Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death described criteria for identifying those in an irreversible coma as dead, including loss of brain stem reflexes.[4] During the 1970s, these criteria were adopted by states in patchwork fashion until the development of the Uniform Determination of Death Act (UDDA) in 1980, a model law since adopted by most states,[5] which states:

> An individual who has sustained either:
> (1) irreversible cessation of circulatory and respiratory functions, or
> (2) irreversible cessation 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.[6,7]

Irreversibility sets a high bar. Many people who are determined to be dead according to accepted medical standards could receive interventions that would restore some minimal biological function. Although such people would not meaningfully recover with interventions, they would not technically meet the law's irreversibility standard. James Bernat has attempted to reconcile medical practice with the law by suggesting that *irreversibility*—that a function that has stopped cannot be restarted—be replaced with *permanence*—that a function that has stopped will not restart on its own and no intervention will be undertaken to restart it.[8] The permanence standard implies that interventions will not be implemented because they will not restore any meaningful life quality. If such a practice can be justified, at minimum, the definition of death should be updated to replace the irreversibility standard with the permanence standard.

Deciding When Continued Interventions Are Not Warranted

Justifying the permanence standard requires certainty that choosing not to attempt to restart organ functions would not be fruitful in restoring meaningful life qualities. The final part of the UDDA—that a determination of death must be made in accordance with accepted medical standards—assumes that standard death examinations can accurately establish when a person with ceased function will not benefit from the intervention's attempt to restart the function. The variability in standards for determining brain death[9] and in how long to wait after circulatory death before procuring organs[10] do not inspire confidence in our ability to agree on this moment.

Even the American Academy of Neurology's (AAN's) rigorous standards for diagnosing death by neurologic criteria might need examination. In a rare case in which AAN standards were used to diagnose death but the patient remained on organ support,

months later it was questioned whether the patient's condition was consistent with brain death because the patient's brain retained some function.[11] It has been suggested that the standard brain death tests performed were not sensitive enough to detect the patient's low brain blood flow.[12] Such a case draws attention to the UDDA's intentional abstention from prescribing standards for death examination, which enables the standard for cessation of function to remain up-to-date as medical technology advances.[13] If our *current* medical standards do not accurately predict when a person has lost all brain function, then perhaps they need to be updated. A recent effort has been made involving relevant international professional societies to update recommendations for the determination of brain death, which may help to provide the needed accuracy.[14]

Improving trust in medical practice is critical to public acceptance of determinations of death. Medical discrimination against minority and vulnerable populations is not merely a thing of the past. Research suggests that African Americans still more often receive inadequate or inappropriate care[15] and, perhaps due to their resulting distrust, are more likely to request life-prolonging care.[16] These facts might appear to weaken support for substituting the permanence standard for the irreversibility standard, as clinician bias might influence which patients to remove from support and which patients with ceased function will not have meaningful life qualities restored by intervention.

To prevent the influence of clinician bias on death determinations, standards for determining death must be universally applied. Achieving universality might require reexamination of both death diagnosis criteria and standards for confirming their application—a practice update consistent with the UDDA clause requiring death to be determined according to accepted medical standards,[6,7] which can change. However, not revising the irreversibility standard of the UDDA would mean that medicine's continuing to follow the permanence standard contravenes the letter of the law. Doing so can perpetuate distrust in a medical system that does not wait until function has irreversibly ceased to diagnose death despite the legal requirement, does not usually make this incongruity explicit to patients and families, and justifies the omission by assuming its own trustworthiness in knowing when people are actually dead.

Opting instead to make practice more in line with the irreversibility standard—ie, only diagnosing patients as dead when function cannot be restarted, despite technological interventions—would likely perpetuate false hope of recovery by refusing to diagnose as dead patients who will never reacquire meaningful life qualities and would result in unjust distribution of medical resources.

Challenges of Capturing Meaningful Life Qualities in a Definition of Death

The question remains whether the loss of *all* brain function is required for irretrievable loss of all meaningful life qualities. Some have proposed moving to a definition of death that only requires loss of higher brain function,[17] recognizing that only the cerebrum enables consciousness. This definition implies that though other parts of the brain control "lower" bodily functions, such functions alone are not sufficient to constitute meaningful life qualities. The United Kingdom's definition requires only brain stem death, which focuses on the loss of consciousness and spontaneous respiration.[18] Medicine and the law often allow for patients (through advance directives) and their families to decide that persistent vegetative state (awake but not aware) and coma (neither awake nor aware) warrant continued care,[19] which implies that such states could be considered valuable. Family members often rearrange their lives to keep a

persistently unconscious loved one integrated into the family. It can be argued that families benefit from these relationships.

Using this logic, why draw the line at cessation of all brain function for determination of brain death? Some receive value just from a loved one's life-like qualities of breathing, heartbeat, and other bodily functions. Should they not be allowed to maintain such relationships and thus decide that death has not occurred absent all brain activity? If this value is contingent on hope of recovery (held by some but not all family members in these cases), continuing care of a body with permanent cessation of all brain function is misleading and perpetuates false hope. These cases can be differentiated from persistent vegetative state (PVS) cases because, although extraordinarily rare, there are cases of individuals recovering from PVS.[20] Allowing hope for recovery for PVS patients is not unequivocally immoral. Then there are some who, for religious or other reasons, believe that a person is only dead when the heart stops beating and that to remove circulatory support constitutes killing. Should such beliefs not be accommodated by death's definition, as New Jersey's Declaration of Death Act does?[21]

Nevertheless, continuing care for bodies accurately determined dead by neurologic criteria might deprive other patients of valuable resources. Although loved ones must be respected, they cannot be allowed sole discretion on defining the line between life and death. Some states, such as California and New York, provide "reasonable accommodation" after death diagnosis[22,23] by allowing relatives time to say goodbye prior to withdrawing support. Such additions to the law might both be respectful of diverse beliefs and facilitate better outcomes for health care institutions by preventing legal challenges from families who felt disrespected during a traumatic time.

Conclusion

Some argue that replacing the irreversibility with the permanence standard is "gerrymandering the definition of death,"[24] which implies that the goal of updating the definition of death is to serve other ends, such as procuring more organs for transplant, with the result that some people might be diagnosed as dead too hastily. This concern is invalid if the permanence standard can be rigorously applied; function will not restart on its own, and interventions will not be attempted because they would not restore meaningful life qualities. A rigorous permanence standard requires that we can agree, after function has ceased, when interventions will not lead to benefit. Shewmon, a pediatric neurologist, suggests that we have, in fact, 2 definitions of death that entail different death behaviors. Normative death—when we all agree the patient has died and decide to move on—and ontological death—when all function has irreversibly ceased.[25] Requiring 2 definitions implies that we cannot agree when interventions are unable to lead to benefit and that we might be guilty of using circular logic to justify the permanence standard: *How do you know the patient is dead? Because interventions won't help. Why won't interventions help? Because the patient is dead*.[26]

Although medicine might not be able to determine the exact moment when meaningful life qualities are unrestorable, clinical evidence should be sufficient to maintain a single, reliable—yet responsive—death definition. To avoid perpetuating false hope and unjust distribution of resources, normative and ontological definitions must be concordant. When we agree the patient is dead—based on function cessation and the latest comprehensive evidence regarding when attempting to restore function will not lead to benefit—the individual is, in fact, dead. Laws for death determination must draw lines

informed by practice and ethics, even when they cannot precisely separate death from life.

The legal line between life and death must continue to be adaptable to medical advances but be more definite than requiring that death be diagnosed in accordance with undefined "accepted medical standards."[5,6] We need reliable standards for knowing when all meaningful functions have ceased, which should likely be those promulgated by the AAN, the American Academy of Pediatrics, the Child Neurology Society, and the Society of Critical Care Medicine,[27] assuming these organizations are willing to revisit their standards when the need arises.

The UDDA, when updated to reflect the permanence standard, can provide a useful legal process in addition to a line between life and death. A legal process is authoritative when everyone to whom it applies—and death applies to all—agree to the terms. Codifying the permanence standard means medicine must be honest with patients, their families, and itself about why, when function has ceased or will cease, interventions will not be attempted. What life qualities could interventions restore after functions have ceased and will not restart on their own? Should these be considered meaningful? Although this transparency might allow more room for argument, it respects the rights of patients and families to receive information. Families should not be able to object to the discontinuation of care if evidence supports the inability of that care to restore more than life-like qualities, but such objections are less likely to arise if families feel respected.

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