

Socially Situated Brain Death

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FROM THE EDITOR

Why Should We See Brain Death as Socially Situated?

Ariane Lewis, MD and Thaddeus M. Pope, JD, PhD

There are 2 ways to determine death: (1) by irreversible cessation of circulatory and respiratory functions or (2) by irreversible cessation of all functions of the entire brain. While physicians have used circulatory and respiratory criteria for centuries, they only started using neurological criteria in 1968.¹ Since then, key ethical questions concerning brain death have become “well settled” and yet have remained “persistently unresolved.”²

This theme issue of the *AMA Journal of Ethics* examines growing ethical, social, and legal complexities of determining and declaring death by neurological criteria. There are few questions in health care ethics more fundamental than whether a patient is alive or dead. Therefore, it is disconcerting to witness escalating uncertainty and variability surrounding 5 consequential questions. Three concern the identity and legitimacy of medical criteria for determining brain death. Two concern patient management and family decision making.

First, can we confidently identify the **generally accepted clinical standards** for brain death? Unfortunately, there is significant variability from state to state and from hospital to hospital.³ These differences concern (a) physician qualifications, (b) the number of physicians required to perform a brain death evaluation, (c) prerequisites for a brain death evaluation, (d) clinical evaluation performance, and (e) use of ancillary tests. Without uniformity and consistency, a patient who is determined dead at Hospital A might be determined alive at Hospital B. Such incoherence threatens to undermine public trust and confidence.⁴

Second, assuming we can identify accepted clinical standards, do these standards actually **correspond to death**? Patients who are found to be dead using generally accepted standards for death by neurological criteria continue to exhibit some bodily functions (including, in some cases, hypothalamic activity) prior to discontinuation of ventilator support.⁵ Thus, brain death is not a scientific discovery but rather a socially situated diagnosis.

Third, do generally accepted clinical standards for brain death **correspond to legal death**? Because the Uniform Determination of Death Act requires irreversible cessation of “all” functions of the “entire” brain,⁶ yet because hypothalamic function can persist, a gap exists between clinical standards and the more demanding legal standard.⁷ This question continues to be addressed in state and federal courts.⁸

Fourth, must clinicians **obtain consent to evaluate** a patient for brain death? On one hand, since consent is not required for diagnosing death by circulatory and respiratory criteria, one might ask, Why should it “be required for determination of death by neurological criteria?”⁹ On the other hand, consent is required before clinical procedures, and apnea testing—part of the brain death determination—has some risks.¹⁰

Fifth, should **religious objections** to brain death be honored? Organ support is typically withdrawn after brain death. Some people feel that neurological criteria for death conflict with their religious views.¹¹ What should clinicians do when a family member says a patient would have had religious objections to brain death? Should organ support be continued until death by circulatory and respiratory criteria?

Contributors to this theme issue consider these and other clinical, ethical, social, and cultural questions about brain death.

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CASE AND COMMENTARY: PEER-REVIEWED ARTICLE

What Should We Do When Families Refuse Testing for Brain Death?

Robert D. Truog, MD, MA, Wynne Morrison, MD, MBE and Matthew Kirschen, MD, PhD

Abstract

Two commentaries respond to a case about apnea testing to confirm death by neurologic criteria.

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Case

BJ is a 10-year-old who was pulled from a pool. He was intubated in the field by emergency medical technicians. Cardiopulmonary resuscitation was performed for 30 minutes before his heart started beating again. Upon arrival in an emergency department, BJ was unresponsive, with sluggishly reactive pupils, but no other brain stem reflexes. After being admitted to the pediatric intensive care unit (PICU), BJ was minimally over-breathing the ventilator. Sedated and cooled to 33 °C for 24 hours, BJ was then gradually rewarmed over the next 24 hours. Three days after rewarming and discontinuation of sedation, BJ did not over-breathe the ventilator and remained comatose with no brain stem reflexes. After another 3 days, BJ's condition did not improve.

Eight days after BJ's admission to the PICU, Dr F obtained a cranial computed tomography scan that showed diffuse sulcal and cisternal effacement, loss of gray-white borders, and herniation. Dr F now explains to BJ's parents that BJ is probably "brain dead" and that the next step in BJ's care is to perform a clinical examination to look for evidence of brain activity. Dr F further explains that patients with no signs of brain activity are taken off the ventilator to see whether they breathe spontaneously. Although BJ's parents are upset, they express understanding and agreement with Dr F's assessment plan.

Dr F performs the clinical assessment in accordance with the Society of Critical Care Medicine, American Academy of Pediatrics, and Child Neurology Society 2011 standards¹ and concludes that BJ is comatose with no brain stem reflexes. With BJ's parents at the bedside, Dr F performs an apnea test, regarded as a critical part of a

brain death diagnosis examination,² and finds that BJ does not breathe, despite a rise in carbon dioxide partial pressure to 110 mm Hg.

BJ's parents express concern that BJ looked uncomfortable being off the ventilator during the apnea test. Dr F responds, however, that the apnea test results³ suggest that BJ is brain dead and that the exam and the apnea test must be repeated to confirm this conclusion. BJ's parents state that they've read online that apnea testing can be dangerous, emphasize that they never consented to an apnea test, and reiterate that they refuse to allow the apnea test to be repeated.

Dr F wonders how to proceed.

Commentary 1

by Robert D. Truog, MD, MA

As a pediatric intensive care physician and anesthesiologist, I have diagnosed brain death more times than I can remember, and I have been in Dr F's shoes on many occasions. Based on this experience, I have come to believe that the medical profession has not been truthful with patients and families about the **meaning of brain death**. Drawing from the well-known case of Jahi McMath, the medical literature, and my own experience, I have suggestions for how we can communicate more honestly and effectively with patients and families. I will also offer some concrete advice that I would give to Dr F about how to proceed.

Jahi McMath

Jahi McMath was a healthy 13-year-old when she underwent pharyngeal surgery for obstructive sleep apnea.⁴ That evening, she began spitting up blood. This progressed to a massive hemorrhage and cardiac arrest. She was successfully resuscitated but suffered severe hypoxic brain injury and was diagnosed as brain dead 3 days later.

For readers unfamiliar with what patients who are brain dead look like, it is likely that Jahi looked very similar to other sick children in the intensive care unit (ICU): her eyes were closed, she did not respond to her mother's voice, and she needed a ventilator to breathe. Visually, it would not seem unreasonable for Jahi's mother to question why clinicians were telling her that Jahi was dead; other children in the ICU that looked just like Jahi were getting better. Nevertheless, when Jahi's mother asked about the discrepancy between what she saw and what she was being told, one clinician allegedly responded, "What is it that you don't understand? She's dead, dead, dead."⁵ This response seemed to imply that Jahi's mother was simply unable to understand what was obvious to everyone else. In fact, however, Jahi's mother was perceiving the situation clearly. Let me explain why.

Origins of the Concept of Brain Death

Brain death was standardized in US law in 1980 with the Uniform Determination of Death Act (UDDA). The UDDA provides 2 pathways for diagnosing biological death: (1) the irreversible loss of cardiorespiratory function (how most people die) or (2) the irreversible loss of all functions of the entire brain (a way of dying that can only happen when patients are being mechanically ventilated in an ICU). Its framers were very careful to state that they were not "redefining" death.^{6,7} Death was, they insisted, characterized biologically as irreversible loss of integrated functioning of the organism as a whole. Scientifically, death is fundamentally the same across the biological spectrum; we speak

of dead animals, dead plants, and dead people. Death is always followed by disintegration and putrefaction. Dust to dust.

The reason brain death is just an alternative way of diagnosing biological death, Bernat et al explained, was because the diagnosis was invariably and quickly followed by disintegration of the body.⁷ Use of a ventilator could slow the process down, but only temporarily. Even with mechanical life support, they claimed, the heart would stop and a body would begin to decompose within a week or two.⁷

These concepts have been taught to physicians ever since the UDDA was introduced. One international expert on brain death recently affirmed: physicians “globally ... now invariably equate brain death with death and do not distinguish it biologically from cardiac arrest.”⁸ New guidelines on brain death from the American Academy of Neurology also consider “death to be a ‘unitary phenomenon’ regardless of causation, resulting from either irreversible failure of brain or circulatory function.”⁹ When the physician asked Jahi’s mother, “What is it that you don’t understand?,” he was expressing what he, and I, and most physicians have been trained to believe: brain death is biological death, just as cardiorespiratory arrest is death. But there is a problem with this view: it is wrong.

Traditional Understanding of Brain Death

Evidence of why this prominently accepted view of death is wrong comes primarily from the work of a pediatric neurologist, Alan Shewmon. Over the years, he has meticulously documented dozens of cases of prolonged biological survival after a diagnosis of brain death.¹⁰ One of the most dramatic cases involved a young boy diagnosed as brain dead from bacterial meningitis at the age of 4, who was supported with a ventilator and tube feedings for 20 years before succumbing to cardiac arrest and biological death. At autopsy, he had a completely calcified brain. No neural tissue could be identified, grossly or microscopically.¹¹ As counterintuitive as it might seem, the biological truth is that the body does not need a brain in order to maintain integrated functioning.

Perhaps this should not be surprising. Across the biological spectrum, many organisms survive with only rudimentary nervous systems. While a human brain might be what makes human life worth living, it is not necessary for sustaining biological life. Cases of prolonged biological survival after a diagnosis of brain death happen regularly. Jahi McMath survived for almost 5 years—supported with tube feedings, mechanical ventilation, and occasional hospitalization. She lived with her family in their apartment, where she grew and went through puberty.^{4,5} More recently, a woman was found to be 9 weeks pregnant after she was pronounced brain dead following a traffic accident.¹² After several months in the ICU, she vaginally delivered a healthy baby boy and then, remarkably, also donated organs for transplantation. It simply defies the laws of biology to think that any organism could give birth to offspring several months after being biologically dead. It may not be surprising at all, however, if we recognize that she was alive during that time, albeit with a severe and nonrecoverable brain injury.

One might ask why these cases are not more common. One answer is that a diagnosis of brain death is almost always a self-fulfilling prophesy. That is, once testing is complete, a physician completes a death certificate, and the patient’s family can then choose to donate their loved one’s organs or terminate ventilation, pathways that both lead rapidly to biological death. Most families have no desire to prolong the biological life of a loved one who will never recover consciousness. But in the rare cases in which

families refuse to accept a brain death diagnosis and mechanical ventilation is continued, we should not be surprised when prolonged biological survival is the outcome.

Explaining What Death Is

If brain death is not biological death, then what is it? Brain death unquestionably involves an exceedingly severe brain injury. Although there is some debate (beyond the scope of this article), most neurologists believe that brain death represents a state of irreversible apneic unconsciousness. In other words, when a patient is correctly diagnosed as brain dead, we can be highly confident—even if not absolutely certain—that a brain-dead patient will never regain consciousness or be able to breathe on their own. So, how should Dr F explain this to BJ's parents? Let me suggest 3 approaches that I think could be helpful.

First, I would advise Dr F to remain nonconfrontational and to make every effort to understand the situation from the family's perspective. Specifically, I would explore whether family members are objecting to the diagnosis itself or instead taking a confrontational stance out of anger related to other aspects of their care. In the McMath case, for example, the parents primarily were angry because they believed that Jahi had not received appropriate care and that the hospital was not forthcoming in explaining what happened.^{4,5} People of color are often distrustful of doctors and hospitals—and for good reason, since our health care system has a long history of racial injustice. At a later time, Jahi's mother stated: "If her brain is jelly, we are going to have to accept that. I don't think people should live on that way. If they're gone, they're gone."⁵ In other words, had Jahi's family been treated honestly and with respect at the beginning, it's not clear that the family would have objected to the diagnosis of brain death. I would encourage Dr F to explore this possibility in the most compassionate way possible.

Second, if the family is truly objecting to the diagnosis of brain death, I would explore the reasons for their position. Of the many families that I have worked with that have refused testing for and diagnosis of brain death, I can remember only 2 cases in which the objection was based on deeply held religious beliefs. In all of the other cases, the parents were grieving and struggling to come to grips with the fact that their child had sustained a devastating brain injury, recovery from which was impossible. Objecting to the diagnosis or the testing was the only way they could put off the inevitable and avoid having to face the sad truth of their loss. In almost all cases, giving family members a few days to grieve, to allow the facts to sink in, and to receive the support of other family members, friends, social workers, and spiritual counselors will be sufficient to help them to accept the diagnosis. Most families don't want to sustain the life of a loved one who will never wake up, any more than clinicians want to participate in care that is essentially futile. I would therefore advise Dr F to work with his colleagues and the hospital administration to give the family a few days, knowing that in most cases time will resolve the conflict without confrontation.

Third, what should we do when the refusal of the family is not just denial or an expression of complicated grief but stems from deeply held moral or religious objections to the diagnosis of death by neurological criteria? It is widely known that some branches of Orthodox Judaism hold that as long as breathing is occurring (even if it requires a ventilator), then the patient is alive. In my mind, there is nothing illogical or inherently unreasonable about this position. How should we respond?

I'm not sure of my own views on this subject. On one hand, we know that New Jersey has had a religious exemption to the determination of death by neurological criteria for over 25 years.¹³ To my knowledge, there is no evidence that this law has affected the utilization of ICU beds or the donation of organs for transplantation in any significant way. If we can respect individual religious beliefs without significant impact on others, I think there is a strong presumption that we should do so.

On the other hand, our government is not obligated to **respect all religious beliefs**. Many Mormons believe polygamy is ethical and a part of their religion, and yet polygamy is illegal and not tolerated in the United States. I do not think it would be unreasonable for the government to hold that ICU care for patients who are almost certainly never going to wake up is a misuse of the health care system, regardless of whether or not the family can pay for the services. Brain death is legal death in our society, and I can understand the logic of simply telling families that this is the law and that they must comply. Since I think it could be ethically justifiable to either defer to the family's religious beliefs or to overrule them, I would support whatever position was taken by existing state law and hospital policies. I would suggest that Dr F do the same.

Conclusion

Devastating brain injuries that lead to the diagnosis of brain death are always tragic. This tragedy is further compounded when families find themselves in opposition to the doctors and nurses who are caring for them at a time when they are grieving the unexpected loss of a loved one. As I have described in this paper, I believe we wrongly and needlessly compound these problems by not being honest with families about the meaning of brain death. I have also outlined 3 strategies for compassionately but effectively addressing objections to the diagnosis: exploring sources of the family's anger and distress that may be unrelated to the diagnosis; being as accommodating as possible in giving the family time to grieve and to come to acceptance of the situation; and considering how to respond to families who hold deep religious views about the diagnosis of death by neurological criteria. Responding to families' religious objections is the least common but probably the most difficult scenario, and I think arguments in favor of deferring to the family or overriding their demands can both be supported.

Commentary 2

by Wynne Morrison, MD, MBE and Matthew Kirschen, MD, PhD

Before discussing the "right" way to approach the case presented, it is important to acknowledge how horribly sad it is—devastating for this family, tragic for the child, and emotional for the clinical team. While our discussion will focus on areas of disagreement among the parties involved, all are connected as unwilling witnesses in this unimaginable situation.

When a patient has suffered a catastrophic brain injury that is complete and irreversible, the appropriate next step in the patient's care is to determine if the patient meets criteria for death by neurological criteria (DNC).¹⁴ Some have argued that there is a medical duty to make this determination and therefore permission should not be sought from surrogate decision makers to initiate the evaluation.¹⁵ Others have argued that respect for varied cultures within a pluralistic society mandates that surrogates be allowed to refuse the DNC evaluation if they do not accept the concept of using neurologic criteria to determine death.¹⁶

Risks of Apnea Testing

The apnea test is of particular concern because of its risks, which include hypoxemia, hypotension, and arrhythmias. These risks are low, especially if standardized protocols—including preoxygenation—are followed.^{17,18,19} If hypoxemia or hypotension occur during apnea testing, stability is usually rapidly achieved by aborting the test.²⁰ For patients judged to be at high risk of cardiopulmonary decompensation during apnea testing, ancillary testing can be substituted to support the clinician's DNC determination.^{14,21}

We contend that these risks are similar to the risks of other procedures in critical care for which separate consent is not typically sought (eg, titrating vasoactive infusions, adjusting ventilators, transporting patients for diagnostic studies). For many such interventions in medicine, clinicians simply discuss the need for the intervention with the patient or family, answer questions, and proceed. The “informing” component is present, but the “consent” looks much more like tacit agreement or nonobjection.

Seeking “Permission” Is Problematic

In our practice, we approach discussions about the determination of DNC—including apnea testing—as information sharing rather than decision making. We prepare the family members early for the range of possible outcomes from catastrophic brain injury, including death. We assure them—by both words and actions—that we are doing everything possible to facilitate recovery and prevent secondary brain injury. We use *aligning language* by explaining that if the outcome is a severe but nonfatal brain injury, “we” (family and team both) will have difficult decisions to make about whether to continue technological support. However, if the patient is determined to be dead by neurologic criteria, there is no need to make further decisions, as there is no indication to continue technological support.

When performing an evaluation for DNC, we inform the family that we are conducting a comprehensive and protocolized examination (with checklist in hand) to look for any sign of neurological function. By allowing families to be present for the examination and apnea test, we hope to give them an appreciation of the patient's lack of response to the varied stimuli. We have had family members afterwards say, “We saw how hard you tried.”

We do not usually ask family members if they *want* us to do the exam. How could anyone ever want such a thing? We explain that it is the medically appropriate time to do it, inform them about the process in an accessible way as best we can, and proceed. In that sense, we argue that *consent* is not necessary for the neurological examination or apnea test but that *informing* is mandatory. And just as we don't ask permission for the evaluation, we also do not ask permission to stop technological supports after the DNC determination. We simply explain that it is the appropriate next step.

Responding to Objections

The case presented offers a different dilemma, however. This family is actively objecting to performance of the apnea test. We hope to avoid such situations, but it is not always possible. While we don't ask a family for permission to initiate the DNC evaluation, it is altogether different to override an active objection.

If we can't talk the family through why the evaluation is important, we pause. If the case is one of preexisting, culturally consistent objections to the concept of DNC, we involve

clinical and administrative leaders, as well as ethics and legal consultants, to determine a unified approach before deciding whether to proceed with an evaluation despite objections. Slowing things down can allow time for the medical team and family to listen to each other and hopefully agree on a common approach.²² Team members may struggle if they feel they are providing **nonbeneficial care** and may need support. If it is the safety of the apnea test itself that concerns the family, then an ancillary test can be substituted.

For some medical choices, one path is clearly more appropriate than others.²³ In this case, determining whether the patient fulfills criteria for DNC is clearly the standard; avoiding the evaluation will not return the patient to health in the long run. We shouldn't offer choices that don't make medical sense.²⁴ And yet, at the same time, we believe that overriding active objections should never be done lightly.

Some would argue that these 2 positions are contradictory. We claim, instead, that they are both patient and family centered. Many families would indeed prefer not to be given a choice about initiating a process that could confirm their child has died. We have worked with families who initially objected to the evaluation but later expressed relief when it was explained that difficult decisions would be out of their hands if death was determined. The medical teams should be guides on this path, not bulldozers.

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Dr Truog serves as a paid consultant on data safety monitoring committees for Sanofi and Covance and Dr Morrison is the Children's Hospital of Philadelphia's liaison to the regional organ procurement organization and in that capacity has spoken at several conferences. Dr Kirschen had no conflicts of interest to disclose.

The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental. The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

CASE AND COMMENTARY: PEER-REVIEWED ARTICLE

How Should Clinicians Respond When Patients' Loved Ones Do Not See "Brain Death" as Death?

Rabbi Jason Weiner, DBioethics and Rabbi Charles Sheer, MA, BCC

Abstract

Two commentaries respond to a case. Each considers religious or cultural values that sometimes conflict with medical standards of practice or law. These conflicts frequently occur at the end of life when stress and tensions are high and, if not handled carefully, can escalate and cause tremendous pain.

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Case

NK is a 32-year-old man who lost consciousness after having a severe headache. His wife, SK, called an ambulance. NK was intubated in the field by emergency medical technicians and brought to the hospital. NK's admission cranial computed tomography (CT) scan showed subarachnoid hemorrhage¹ and severe hydrocephalus with intraventricular hemorrhage. Twenty-four hours later, NK remains comatose with no brain stem reflexes.

Dr T explains to SK that NK is probably "brain dead." SK responds, "We are Orthodox Jews,² so we do not believe that death happens until the heart stops." Dr T explains that the next step is to determine whether NK has any brain activity. SK agrees to allow Dr T to examine her husband and clarifies, "Regardless of what you find, my husband is alive until his heart stops,³ so we will continue to keep him on the machines until then."

Dr T wonders how to respond.

Commentary 1

by Rabbi Jason Weiner, DBioethics

Religious or cultural values sometimes conflict with medical standards of practice or law. These conflicts frequently occur at the end of life when stress and tensions are high and, if not handled carefully, can escalate and cause tremendous pain. As the rabbi of a large medical center with a significant Orthodox Jewish population, I have frequently

supported both Orthodox families and our medical staff's attempts to sensitively navigate brain death diagnosis, which isn't accepted as the definition of death by many Orthodox Jews.⁴ Although each situation is unique and must be handled on a case-by-case basis, by listening, engaging religious leadership, supporting hospital staff, and practicing cultural humility, clinicians can often identify a care plan for patients who are brain dead that is sensitive to both medical standards of practice and personal religious and cultural values.

Mitigating Conflict

Listen first. Regarding the case under discussion, I would encourage Dr T to start by listening carefully to the family, expressing empathy and respect for their outlook, and affirming that their perspective is important and that team members will try their best to accommodate it insofar as possible. The hospital's reasonable accommodation policy should be reviewed (if it has one and, if not, one should be developed). The first goal must be to establish trust and a positive working relationship. Orthodox or not, everyone needs time to process such a shock. Furthermore, being treated with compassion by health care clinicians can be very beneficial,⁵ especially for people who find themselves in situations like the one in this case.⁶ Once the brain death testing, as well as confirmatory testing (which is often required by Jewish law⁷), is completed, more time will have passed—which hopefully will help the family to become more amenable to discussion—and the results of the testing might be relevant for helping the family and their rabbi determine next steps.

Involve religious leadership. If all testing confirms the brain death diagnosis, and if the family members remain adamant that they do not accept this as the definition of death and thus request ongoing mechanical support, then the next phase of care for the family begins. The family should continue to be listened to and shown compassion. Their rabbi, as well as supportive professionals within the hospital, such as a chaplain who is familiar with the religious needs of the Orthodox community, should be included in discussions.

It is crucial for medical practitioners to establish a collaborative, trusting relationship with the family's rabbinic leadership. Within Orthodoxy, rabbinic leadership often plays a strong role in decision making due to the central role that Jewish law plays in all decision making (not just medical decision making). The hospital's chaplaincy often has a relationship with local rabbinic leadership and can **serve as an important liaison** by helping to explain rabbinic rulings to the hospital staff and, conversely, the medical culture to the rabbinic leadership.

Support hospital staff. Some hospital staff members might become distressed by the prospect of continuing interventions for a body that they consider to be a corpse. They should receive emotional support, and some should be excused from caring for the patient if they are not comfortable doing so. In addition to being the right thing to do and preventing burnout, supporting staff can help mitigate potential escalation of conflict between frustrated health care clinicians and families.

Practice cultural humility. For those remaining on the care team, it becomes essential to reiterate the importance of cultural humility and the fact that defining life and death are philosophical concepts, not just medical criteria. Family members might not see the status of the patient in the same way that the medical team does, so insisting that they frame everything within the standard medical worldview will not only come across as

disrespectful but also make effective communication impossible. A different worldview should not automatically render someone “difficult” or maladaptive. It is crucial also to remember that family members might still be shocked or experiencing severe anticipatory grief and are turning to their community and religion—as they do for all major decisions—as a source of guidance and support.

Coming to a compromise. Once a reasonable amount of time has been allowed—“reasonable” in my experience being a few days, as brain dead patients’ hearts often stop on their own after a few days though this sometimes takes longer, especially in younger patients—and the family has been shown compassion, understanding, and emotional support, if there is still no clinical change, institutional pressure to remove life-sustaining technologies might begin to build, as well as stress and anxiety. At this phase, we usually attempt to figure out a compromise approach as we move toward a resolution.

While decisions are made on a case-by-case basis, taking various crucial details into account, most rabbinic leaders are reasonable and can help find a workable approach. For example, while those who interpret Jewish law as not accepting neurological criteria for determining death will generally not permit active **withdrawal of life support**, they often permit withholding increased interventions. This exception is based partially on the distinction that Jewish law makes between “withholding” and “withdrawing.” Jewish law sometimes permits withholding life-prolonging interventions in dying patients since it is passive.⁸ However, Jewish law considers stopping therapy to be the performance of an action. Thus, while terminal extubation will rarely be permitted, there are times when rabbis will permit not adding any new medical interventions, not increasing vent settings in the face of pulmonary decline, or not engaging in chest compressions when the heart stops. Sometimes they will also allow some medications, eg, vasopressors, to run out and not be refilled. This approach, which can be very helpful, is sometimes referred to as do not escalate (DNE). DNE recognizes the desire not to actively hasten the demise of the body but also allows for the cessation of biological functioning to occur in a more natural way. This approach often allows families to feel less culpable in their loved one’s death and that they have maintained their integrity in adhering to Jewish law while caring for a family member.

Conclusion

If compassion, trust, and a positive working relationship have been established from the outset, conflict is much more likely to be mitigated than in situations when that relationship has not been developed. Respectful and compassionate interactions in cases such as this go a long way toward building strong relationships with the communities from which such patients come. This trust and mutual respect take time to build, and it is thus essential for medical leadership to give staff and families the time necessary to establish such rapport.

Commentary 2

By Rabbi Charles Sheer, MA, BCC

This case illustrates how culture or religion might countermand a physician’s diagnosis, even regarding death. In fact, SK’s refusal to accept death by neurological criteria (DNC) affects the entire health care institution. SK’s instruction to “keep him on the machines” affects nursing and other staff who suffer moral distress when assigned to care for what they might consider to be a cadaver. Her rejection also has substantial financial

implications. Like most trauma patients, NK is in an intensive care unit (ICU). The steep tab for the room, physician and staff, medications, and so on is not medically mandated. The hospital cannot legally bill these costs and will probably have to absorb them. NK's hospitalization entails a violation of the ethical principle of justice: the equitable distribution of resources and services.

Despite all of the above considerations, no hospital wishes to gain the reputation of being insensitive to the religious or cultural needs of its client community or of having refused to care for a patient. Given the impact a case such as the one described above might have on community relations, hospitals' public affairs and legal departments often become involved. The nub of the issue is not science or the role of the physician. The challenge is whether a health care institution can remain true to its commitment to evidence-based practice while respecting patients' right to allow their cultural values to play a determining role in their lives. This essay recommends the establishment of a special committee to address such challenges. Composed of individuals trained in conflict resolution and cultural competency, the committee would relieve clinical staff of cases that require special skills, language, and emotional openness. This special committee could bridge the gap between family and institution by its presence, experience, and skill.

Jewish Law and Death

Cultural competency, which emerged from the nursing profession,⁹ is now an established element of modern medicine. Most clinicians would know that when SK rejects DNC, she does so in accordance with a Jewish definition of death with a long pedigree. The sources that underlie that definition go back almost 2 millennia, and they are too extensive to present here.¹⁰ One classical talmudic case deals with a collapsed building under which a person is presumed to be buried. The rescuer is mandated to uncover the person's body to ascertain whether the party is still alive.¹⁰ The texts and commentaries present various areas of the torso to be revealed: the heart, mid-section (stomach area), or the diaphragm. What emerges from these sources is that death is identified with the cessation of cardiopulmonary function. It is only in the last half-century, after the development of positive-pressure ventilation, that medicine identified a neurological cause of death. Although brain death is an accepted definition of death, it continues to be controversial on scientific as well as philosophical grounds.^{10,11}

Since Jewish law is driven by textual precedent, the status of DNC has been a source of much dispute. Indeed, the "brain death debate" is arguably the most contentious and the most discussed topic in contemporary Jewish medical ethics.¹⁰ To complicate matters, the position on DNC within the Orthodox world has shifted in recent decades. For over 3 decades, the mainline Orthodox rabbinical organization, the Rabbinical Council of America (RCA), adhered to the decision of Rabbi Moshe Feinstein, as was stated on the RCA website: "In accord with the ruling of Harav Hagaon Moshe Feinstein ... and of the chief rabbinate of Israel, brain stem death, together with other accepted neurological criteria, fully meets the standards of halacha [Jewish law] for determining death."¹² In 2010, the RCA rescinded its prior position on brain death and, in a 110-page study,¹³ enjoined each rabbi to resolve this decision individually on behalf of each inquirer.

Dr T's conflict with the patient's wife in our case is real, complex, and severely tests the mettle of the institution. Although a hospital might tout its commitment to cultural competency, cases such as this one can place an excessive burden on health care

institutions. Absent clear directions from in-house policy, medical agencies, or government, many institutions handle such cases awkwardly.

Family Liaison Committee

I propose that institutions respond to DNC denial by convening, from the moment of its discovery, a forum for communication with the family that is serious, transparent, and ongoing, similar to **disclosure and apology programs**.¹⁴ When medical errors occur, the relationship between institution and family can be sustained even though the hospital was at fault. Specific actions, such as responding promptly after a medical error, issuing a sincere apology, and assuming responsibility, can effectively diffuse even contentious and litigious contexts.¹⁵ When such responses are put in place, the relationship between the family and the health care institution is maintained and the number of lawsuits is reduced.¹⁶ The research regarding medical errors attests that thoughtful management and communication are effective tools to foster good patient relations. I propose that hospitals appropriate these methods when confronted with DNC denial.

Hospitals should establish a family liaison committee (FLC) that would spring into action upon the request of the attending physician after a family objects to a DNC determination. Its members might include a physician, nurse, social worker or case manager, and chaplain, as appropriate. Its objectives would be as follows:

- To establish the FLC as the forum for communication with the family, including regular patient status updates and family meetings (to which the family rabbi might be invited);
- To explicate the clinical services to be provided, as determined with the attending physician;
- To define the time frame during which the patient can remain on the unit and receive the above-indicated services.

At the initial meeting, the FLC would review extant institutional protocols (if any) or established legal mandates. In states where some form of “**reasonable accommodation**” is mandated—New York, New Jersey, Illinois, and California¹⁷—the FLC would orchestrate the patient’s treatment accordingly. Thus, in New York State, where hospitals are required to have written policies defining “reasonable accommodation” for a patient’s or surrogate’s religious or moral objection to DNC,¹⁷ the FLC would explicate what the established arrangements are. Having a written document would enable the group to present what the hospital is prepared to do. The heavy lifting—at least, in terms of defining what will be extended to such a patient—has been done. In New Jersey, where a DNC cannot be determined on behalf of a patient who is known to reject DNC,¹⁸ the FLC would inform the family that, in accordance with state law and hospital policy, the clinical staff will not seek to determine DNC.

The FLC’s task entails a delicate balancing act. In one ethics committee consult on a case similar to that of NK, a colleague asked me, “What medical school did that rabbi get his degree from?” I understood her objection and what stimulated it. But I imagine a physician of this mindset would be challenged to negotiate empathetically and effectively with the family. Only when the FLC truly understands the cultural context of the family’s rejection of DNC and communicates transparently and consistently with the family can conflict and discord can be minimized.

Accommodating a Request for Time

The time frame is usually the most important and challenging issue. In the event that the family requests time for leave-taking or to enable a relative from outside the area to arrive, the accommodation period would be a day or two. Few hospitals are unwilling to make this accommodation. Families who object to DNC for religious reasons, however, tend to desire an open-ended delay¹⁹ because a termination of mechanical respiration is viewed as “pulling the plug.” Thus, in New Jersey, which has a large Hassidic population, the law sets no time limit for mechanical respiration after determination of DNC.

I do not think objective criteria can be defined for an “appropriate” time period that can be set. Once the hospital establishes its willingness to offer an accommodation, the FLC would be responsible to set the time period, considering such issues as the prior medical state of the patient, the suddenness of the patient’s traumatic event, and the patient’s age. A range of a few days to a week would demonstrate the hospital’s appreciation for the religious position of the patient. Respect for the cultural background of patients warrants a meaningful accommodation. One advantage of having an established committee is that it would develop experience in gauging what proposed time frames mean to families and communities who do not accept DNC. What was experienced as a “meaningful” response to a previous request for ongoing maintenance?

Communicating With Families

During its discussions with the family, the FLC should use language that is unambiguous. Dr T’s comment “that NK is probably brain dead” is not helpful. No family wants to be informed that its loved one is “probably” deceased. What Dr T should have said is that confirmatory testing needs to be done to establish the patient’s status.

Although the FLC should be respectful of the family’s religious position, it should use language that is consistent with the diagnosis. In general, the term *brain death* should not be used. It might imply to the patient’s family that the brain is not functioning, but the patient is alive. Such language gives a duplicitous message to the family.²⁰ Similarly, referring to mechanical respiration as “life support” and using the term *withdrawal of care* implies that the patient is alive. References should be to the service rendered by the device (mechanical respiration) and not its alleged function (life support). All staff—especially nurses—should be coached to use terminology consistent with the hospital’s assignment of DNC status to the patient.

During initial meetings with the family, the FLC might introduce the possibility of a transfer either to a non-ICU floor (if medically possible) or to another institution. If the family wishes an open-ended accommodation, the hospital might present its acceptable time frame and, at the same time, offer to undertake a search to identify a receptive transfer institution. The hospital should play an active role, thereby demonstrating its commitment to the patient.

Possible Objections

One might counter that the attending physician, not an FLC, should determine any post-DNC service; after all, this person is responsible for the patient. I would agree with this objection in cases in which the attending physician or the family deem it vital that the former play a role on the FLC. Although I have argued that the hospital advances the treatment of the case with a predesignated team of individuals trained—and with the knowledge—to develop a service plan and to negotiate it with the family, the wishes of

family and the physician should determine the process. Effectiveness is the primary objective of this proposal. If these principals wish to maintain the active role of the physician, so be it.

Another objection to this proposal is that an FLC could confuse families who already have difficulty understanding the role and standing of the diverse medical services involved in patient care. True, the attending physician, the department chair, or the nurse manager could play the negotiating role. However, the case of NK requires negotiating skills in an emotionally charged context and with the unusual objective of determining a plan that runs counter to what Dr T just ordered. Can Dr T shift on a dime, to now effectively work with the family to set in motion a plan that runs counter to the diagnosis? Is it prudent for the hospital to assign this complex task to an attending physician, without knowing his or her temperament and skills in such delicate negotiations?

What is most compelling about an FLC is that it brings a sense of gravitas to the negotiation with the family. When the FLC introduces itself as the hospital's "official" response to a rejection of DNC, the implication is clear: the hospital deems this issue worthy of formal institutional treatment. The patient is crucial, and a special committee has been appointed to oversee the painful case. The FLC allows the attending physician to focus on the diagnosis, and if a family rejects the DNC determination, another group assumes the negotiation task on behalf of the institution. Its designation within the hospital system grants it special standing to develop a plan that, hopefully, will be adopted by the hospital—and the family—as the *modus operandi*.

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CASE AND COMMENTARY: PEER-REVIEWED ARTICLE

Should a Patient Who Is Pregnant and Brain Dead Receive Life Support, Despite Objection From Her Appointed Surrogate?

Daniel Sperling, SJD

Abstract

This article considers whether and when a physician is obligated to offer life support to the point of fetal viability to a patient who is brain dead and pregnant. Lack of ethical, legal, and clinical consensus about best practice in managing this kind of case; a poor clinical evidence base; and the fact that offering life support violates the patient's autonomy and human dignity, as expressed in her advance directive, are sources of ethical, legal, and clinical complexity analyzed here.

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Case

BR is a 28-year-old woman in Nevada who is 10 weeks pregnant. She was comatose on arrival to the emergency department and found to have a ruptured arteriovenous malformation (AVM), a tangle of vessels in the brain. BR had right corneal and gag reflexes and was over-breathing the ventilator. Due to the severity of her condition, BR's care team deferred treating her AVM¹ to see if she would improve neurologically. They placed an external ventricular drain in BR's head, and after 2 days, bright red blood filled the drain. A repeat scan showed that her AVM had re-bled.

Upon examination, BR no longer has any evidence of brain activity. Dr N, the attending physician, determines her to be dead using the American Academy of Neurology 2010 standards.^{2,3} After discussion with a hospital administrator, Dr N tells BR's husband, J, that BR's organs will continue to be perfused since Nevada's Uniform Determination of Death Act states that organ support will not be withheld or withdrawn from a pregnant woman if it is "probable that the fetus will develop to the point of live birth with continued application of organ-sustaining treatment."⁴

J objects, "My wife has an advance directive stating she does not want to depend on machines to stay alive, so it would be disrespectful to her to have machines keep her alive for the sake of the baby's reliance on her organs. As hard as it is," J confesses, "I don't feel right using my wife's body as an incubator if she's not alive."

Feeling sympathy for J's views and an obligation to comply with state law, Dr N wonders how to respond.

Commentary

Brain death during pregnancy is an exceedingly rare event but one that has significant practical, ethical, and legal implications.⁵ In this case, BR, a pregnant woman, has been determined to be brain dead. The medical practitioners want to follow the local law, which mandates artificially maintaining the somatic functions of a woman in her stage of pregnancy. BR's husband feels that maintaining BR on machines is disrespectful and in violation of her wishes expressed in an advance directive, which states that she does not want life support. Hence, what is being proposed is continuing organ support for a person who is dead, with the intent to hopefully allow the fetus to complete gestation and be delivered, despite the mother's wishes seemingly to the contrary. The medical team is thus confronted with an ethical and professional dilemma, which is complicated by limited clinical data and legal challenges.

Ethical Analysis

Respect for bodily autonomy. Professional organizations, such as the American College of Obstetricians and Gynecologists and the International Federation of Gynecology and Obstetrics, hold that respecting the rights of the pregnant woman who is the primary patient should take precedence over the delivery of the fetus in ethical deliberations whenever legally possible.^{5,6} One might argue that keeping BR under life support against her previously expressed wishes would amount to objectifying her and treating her as a consumable body.⁷ Seen this way, a woman serves as a mere means to preserve life, especially if she is kept on life support against her wishes in the early stages of pregnancy when the fetus is less likely to survive and hence the **state's interest in the life of the fetus** should not override the woman's right to personal autonomy and dignity.⁶ Moreover, subjecting BR to life support against her wishes would undermine her constitutional right to make effective decisions about her own body.⁸ It would also violate her right to bodily integrity⁹ and the physicians' duty to treat her in a respectful and humane way,¹⁰ including when she is (a) dead (patient).¹¹

Right to refuse treatment. In addition, ignoring a woman's previously expressed wish not to be dependent on life support just because she is pregnant infringes on her elementary right to **refuse medical treatment** or any form of medical intervention,¹² thereby treating her unjustly and unfairly. Such a practice should therefore be regarded discriminatory.¹² In the context of this case, it also violates her constitutional right to privacy and to terminate pregnancy, more specifically.⁸

Respect for symbolic existence. In addition, one can argue that if mechanical ventilation violates a previously living pregnant woman's right to personal autonomy and a brain-dead pregnant woman's right to respect and human dignity, it affects her symbolic existence, since being viewed as a "ventilated corpse" shapes the way she is perceived and imagined by others. In this respect, the violation of one's right not to be perceived in disrespectful ways by others applies following the death of a person as much as it applies while she is alive.¹³ Moreover, promoting actions to save the life of a fetus in the face of death reflects a troubling shift from accepting the symbolic continuity of the dead woman with the living woman to re-initiating the woman's "real" life through some potential life.¹⁴

Best interests of the child. Maintaining BR on life-support until delivery—if indeed a successful pregnancy can be assured—is a deliberate act of planned orphanhood. One should question whether it is in the best interest of a child to live in and serve as the memory of her dead and artificially maintained mother.¹⁵ Although there is little research examining the effect of such a practice on the well-being of the future child, it is argued in the case of **posthumous reproduction** that extensive psychological counseling should take place¹⁶ and that due consideration must be given to the psychological well-being of the future child.

Interests of the father. Other than the rights and interests of the brain-dead pregnant woman and the fetus, this case also raises concerns as to the role of BR's husband in advancing BR's interests. A challenging component of this case involves the views and interests of BR's husband as the father of this fetus. It can be argued that the decision as to whether to continue to maintain BR on life support for the best interest of the fetus should be determined with reference to the patient about whom the decision is made—namely, BR—regardless of other parties' interests in that decision. Assuming there are 2 patients in this case (BR and the fetus), the father may be called upon to reflect upon the best course of action pertaining to their interests and not his own.¹¹ In this case, BR's interests seem to correspond to BR's previous wish not to be artificially maintained under life support.

Clinical Evidence

The ethical challenges discussed above are complicated by limited clinical data pertaining to cases of brain death during pregnancy. It is reasonable to argue that, in principle, the woman's rights and interests should be subordinated to those of the fetus only when there is a realistic prospect of fetus survival and possibly only when a fetus' survival entails tolerable complications, illness, or disability. While reports of such cases are limited, some important insights can still be made.

First, because there is limited experience with and scarce reporting of cases, there is no consensus as to the best practice to manage such cases.¹⁷ A 2016 review of brain death protocols in US hospitals revealed that the vast majority of them (93.8%) offer no guidance about fetal management following maternal brain death.¹⁸ More disturbingly, 99% of them do not refer to the person who is responsible for making decisions for the fetus.¹⁸

Second, evidence suggests that the effectiveness of maintaining a brain-dead pregnant woman on life support to allow continued fetal development depends on the gestational age and physiological health of the fetus—specifically, lung maturity—at the time of brain death. Most documented cases show that gestation could be prolonged for 14 to 45 days (2-6 weeks).¹⁹ A literature review of 30 cases published between 1982 and 2010 revealed that only 12 resulted in the delivery of viable infants.²⁰ These data should call into question the assumption that the state might be acting to promote the interest of potential life when the potential for life might not be significantly high, given the early stage of pregnancy during which the medical intervention would have to take place.

Legal Challenge

While the ethical analysis and the clinical data discussed in this article lead to the conclusion that the previously expressed wishes of BR should be upheld, with the result that life support would be discontinued, such an action allegedly goes against Nevada state law. BR's case therefore not only reflects a situation in which the law cannot be

supported on moral and ethical grounds, but also serves as an example of the more general phenomenon in which the law's interference with and shaping of bioethical issues results in serious threats to important interests reflected in these issues.²¹

It could be argued that, while the purpose of this law is to preserve life and protect the state's interest in the fetus, it does not extend to maintaining a pregnancy over the objections of the patient and her family members. Yet the Nevada law characterizes the determination of death as well as the management of death during pregnancy as a clinical decision, thereby ignoring the doctrine of informed consent and the ethical duty to respect the patient and her beliefs.²² One can further argue that the rationale for this law is to provide procedural and substantive rules for making treatment decisions when there are no previous directives from the patient or her guardian. This is not the case here.

An additional argument raised in a similar case falling under a comparable law in Texas holds that while the language of such a law may seem mandatory, the law nonetheless does not force medical practitioners to act in accordance with it.²³ By this reasoning, health care practitioners may choose not to comply with this law. In such a case, their only sanction is that they will be denied legal immunity that could have been secured had they followed the law. However, if physicians enforce BR's previous directive to not maintain her under life support, they might still enjoy legal immunity under state law and case law upholding the legal validity of advance directives more generally, assuming such laws do not hold constitutionally valid exceptions.

For these reasons, it is argued here, as it has been argued in a more detailed analysis elsewhere,²⁴ that if the pregnant woman gave explicit directions about foregoing life support in case of loss of competency, physicians should follow her instructions—especially if the fetus is in its first or second trimester—and no state interest in protecting potential life should apply before that time. Any law that specifies otherwise might not be justified under reasonable ethical or constitutional analysis.

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MEDICAL EDUCATION: PEER-REVIEWED ARTICLE

How Educators Can Help Prevent False Brain Death Diagnoses

Farah Fourcand, MD and Diana M. Barratt, MD, MPH

Abstract

It is critical for brain death diagnosis to be accurate. Although standardized guidelines and institutional protocols for brain death determination exist, for many physicians, lack of understanding about brain death leads to confusion and muddles interactions with patients' loved ones at the end of life. Using a case-based approach, this article demonstrates what tends to go wrong in erroneous brain death diagnoses and clarifies what physicians and educators should do to help avoid these errors.

Uncertainty About Brain Death

Consciousness, a state of awareness of self and environment, requires arousal and cognition.¹ In coma, there is an absence of awareness of self and environment, even when the patient is vigorously stimulated.¹ According to the Uniform Determination of Death Act, which was proposed in 1980 by the National Conference of Commissioners on Uniform State Laws in cooperation with the American Medical Association and the American Bar Association, an individual who has sustained "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."² The American Academy of Neurology has since established and reaffirmed standards for determination of brain death.^{3,4} Determination of brain death in the pediatric population is currently based on separate guidelines from the Society of Critical Care Medicine, the American Academy of Pediatrics, and the Child Neurology Society.⁵ There are no instances in which a patient has regained consciousness after brain death was determined according to these standards.

Nevertheless, confusion exists among physicians regarding definitions of and distinctions among brain death, coma, **persistent vegetative state, and minimally conscious state**.⁶ Prognostic uncertainty also exists in the latter 3 states.¹ In this article, a false diagnosis of brain death in an adult patient will be presented to provide clinical context for the American Academy of Neurology brain death criteria with the aim of demystifying identification of distinct levels of consciousness (see Table 1), highlighting confounding variables in diagnosing brain death, and instilling diagnostic confidence in physicians.

Table 1. Disorders of Consciousness and Their Corresponding Diagnostic Criteria

Disorders of Consciousness	Diagnostic Criteria
Minimally Conscious State ⁷	<ul style="list-style-type: none">● Some definite, albeit inconsistent, awareness of self or environment.● Patients may intermittently respond purposefully to external stimuli, such as following commands or reacting to noxious stimuli.● Patients may track, hold an object, or mouth words.
Unresponsive Wakefulness Syndrome, ⁸ Formerly Vegetative State ⁹	<ul style="list-style-type: none">● Spontaneous eye opening occurs and sleep-wake cycles are present.● Patients may yawn, make facial movements, and breathe independently.● Although patients may respond nonpurposefully to external stimuli, there is no definite evidence of awareness of self or surroundings.● Within the first 28 days after injury, physicians must avoid suggesting that these patients have a universally poor prognosis,⁶ as patients may progress to minimally conscious state or even recover to the point at which they function independently.● Persistent vegetative state indicates the unresponsive wakefulness syndrome or vegetative state has lasted longer than 1 month.● Permanent vegetative state (3 months after nontraumatic injury and 12 months after traumatic injury) implies irreversibility.
Comatose State ^{10,11}	<ul style="list-style-type: none">● Absence of consciousness, absence of awareness of self or environment, and no response to external stimuli.● Sleep-wake cycles are absent (eyes remain continuously closed).● Some brain stem reflexes may be present, and mechanical ventilation may be required.● Prognosis is highly variable and dependent upon clinical circumstances.
Brain Death ^{3,4,10}	<ul style="list-style-type: none">● Characterized by coma, irreversible cessation of all cortical function, brain stem areflexia, and the inability to breathe spontaneously.● Brain death must be diagnosed according to accepted medical standards. It is primarily a clinical diagnosis augmented by ancillary testing. Brain death mimics must be excluded and prerequisites for brain death examination must be met.^{3,4,10}

Case

A 64-year-old man with a history of end-stage renal disease, chronic obstructive pulmonary disease (COPD), surgical pupils, and failure to thrive was found unresponsive by his family. The family had seen him in his usual state of health 2 days earlier. Emergency medical services staff intubated him in the field and brought him to a community teaching hospital. The patient had missed 2 dialysis sessions due to the holidays. Laboratory evaluation revealed severe electrolyte disturbances, necessitating

urgent dialysis. Head computed tomography (CT) scan showed no evidence of intracranial hemorrhage or large strokes. The patient was admitted to the medical intensive care unit (ICU). After dialysis, the electrolytes normalized.

Forty-eight hours after admission, the patient was not following commands and remained ventilator dependent. An internal medicine resident performed a neurological examination. There was no spontaneous movement of the extremities, nor was there reaction to noxious stimuli applied to the nail beds. The nurse reported only a weak cough with tracheal suctioning. The ICU team ordered a brain magnetic resonance image, which showed small chronic and acute cerebral strokes. The ICU team informed the family that the patient had poor neurological reserve from strokes, which explained his comatose state.

When the nurse reported that the patient no longer had cough or gag reflexes, the internal medicine resident performed another examination. Based on the hospital's brain death policy, a nonneurologist could diagnose brain death. The resident performed the oculovestibular reflex test unsupervised and informed the team there was no response. Since the patient retained CO₂ due to his COPD, apnea testing could not be performed. The family was informed that he was brain dead but that an ancillary test would be performed for confirmation. Due to a series of errors, the patient received thiamine and ammonia level tests instead of an electroencephalogram. He also received a CT scan of the cervical spine intended for another patient with a similar name. The patient was found to have a critically high ammonia level, severely low thiamine level, and subacute C1-C2 fracture with cord compression. Additionally, it was discovered that the patient had received intermittent sedation.

The team **informed the family** that the patient was not brain dead. The patient was given thiamine supplementation and lactulose, resulting in an improvement in his mental status. The neurosurgeon stated that the patient's cervical spinal cord injury would not benefit from steroids or decompressive surgery at that late point in time. Neurology and palliative medicine were also consulted. It was determined that his high cervical spinal cord injury would make him ventilator dependent. A decision was made to withdraw artificial support and the case was discussed at the morbidity and mortality conference.

Table 2. American Academy of Neurology's Checklist for Determination of Brain Death Applied to the Case^a

Prerequisites (All Must Be Checked)

- Irreversible coma with a known cause. *The patient had hyperammonemia due to missing 2 dialysis sessions and thiamine deficiency in the setting of failure to thrive. Both are potentially reversible causes of coma.*

 - Brain imaging explains coma. *Although the patient had small cerebral infarcts, these were not sufficient to result in coma. Structural lesions that cause impairment of consciousness must involve the reticular activating system (above the level of the mid-pons) or its projections—the bilateral thalami or large areas of the bilateral cerebral hemispheres.*

 - No CNS depressant drug effect. *The patient was receiving intermittent sedation. Brain death cannot be determined in the presence of CNS drug effects.*

 - No residual paralytics. *The patient was not given paralytics.*

 - No severe electrolyte, acid-base, or endocrine abnormality. *Although the patient's severe electrolyte disturbances resolved after dialysis, his hyperammonemia and thiamine deficiency were discovered after he was diagnosed as brain dead. Even in the event that a cause of irreversible injury, such as malignant*
-

cerebral edema secondary to stroke, were known, reversal of these abnormalities prior to brain death evaluation would be necessary.

“Normothermia or mild hypothermia (core temperature > 36 °C).” *The patient was normothermic. In cases in which hypothermia or targeted temperature management protocol is used (ie, postcardiac arrest, malignant cerebral edema, subarachnoid hemorrhage), neurological assessment during the rewarming phase is highly variable and could be done prematurely.*

“Systolic blood pressure ≥ 100 mm Hg” with or without the use of vasopressors. *The patient was normotensive without vasopressors.*

“No spontaneous respirations.” *The patient did not have spontaneous respirations secondary to a high cervical spine injury, and respiratory drive was hindered by other factors.*

Examination (All Must Be Checked)

No pupillary responses to bright light. *Although pupillary responses are relatively resistant to metabolic coma, the patient’s pupils were postsurgical. In a patient with postsurgical pupils, the pupillary reflex cannot be properly evaluated, warranting ancillary testing.*

No corneal reflexes. *The patient’s history of ocular surgery could result in loss of corneal reflexes.*

No oculoccephalic reflexes. *This test should not have been performed on this patient, due to his cervical spinal cord injury.*

No oculovestibular reflexes. *This test was performed by the internal medicine resident, who was unsupervised.*

No response to noxious stimuli at the temporal-mandibular joint or supraorbital nerve. *Although this test was not performed, it could have detected a response (grimace) in this patient to noxious stimuli to the face.*

No gag reflexes. *The sedation could have inhibited the patient’s gag reflex.*

No cough response to tracheal suctioning. *The sedation could have inhibited the patient’s cough response.*

No motor response “to noxious stimuli in all 4 limbs.” *The patient’s high cervical spinal cord injury could have prevented him from detecting the noxious stimuli as well as moving his extremities in response.*

Apnea Testing

In addition to not meeting the above prerequisites for determination of brain death, this patient had contraindications to apnea testing—parenchymal lung disease/CO₂ retention AND a high cervical spinal cord lesion, which contributed to lack of spontaneous respirations.

Ancillary Testing

Ancillary testing (EEG, TCD, cerebral angiogram, HMPAO SPECT) is to be ordered only if the clinical examination cannot be fully performed due to patient factors or if apnea testing is inconclusive or aborted. *In this case, the patient did not meet prerequisites for determination of brain death. However, if he had met prerequisites, ancillary testing would have been necessary because pupillary and corneal responses were untestable due to ocular surgery and apnea testing was contraindicated due to COPD and high cervical spinal cord lesion.*

Adapted from Wijdicks EFM, Varelas PN, Gronseth GS, Greer DM; American Academy of Neurology.³

^a Commentary relevant to patient in italics.

Case Discussion

Most of the prerequisites for the determination of brain death³ (see Table 2) are meant to exclude brain death mimics, such as hypothermia,¹² drug intoxications,^{12,13} Guillain-Barré syndrome,¹² locked-in syndrome,¹⁴ and metabolic encephalopathies, including electrolyte, acid-base, or endocrine disturbances.¹² In the preceding case, a number of the prerequisites for the determination of brain death were not met. The patient had metabolic causes of encephalopathy (including hyperammonemia and thiamine deficiency¹⁵) and had been sedated. Although he had small cerebral strokes, his stroke burden was insufficient to result in coma. Structural lesions that cause impairment of

consciousness must involve the reticular activating system (above the level of the mid-pons) or its projections—the bilateral thalamic or large areas of the bilateral cerebral hemispheres.¹⁶

A clinical diagnosis of brain death was not possible because a number of the brain stem reflexes and other responses were not testable. Prior ocular surgery can inhibit both pupillary light responses and corneal reflexes.¹⁷ In a patient with a cervical spinal cord injury, oculocephalic reflexes should not be tested. In addition, the sedation could have inhibited the patient's gag and cough reflexes. His lack of response to noxious stimuli in all 4 limbs could have been due to both his cervical spinal cord injury and the sedation. Despite the cervical spinal cord injury, he might have responded to noxious stimuli of the head—had this test been performed.^{12,18}

In addition to the patient not meeting prerequisites for determination of brain death, there were 2 contraindications to apnea testing—parenchymal lung disease/CO₂ retention and high cervical spinal cord injury.¹⁸ If he had met the prerequisites, ancillary testing would have been necessary to diagnose brain death, because some brain stem reflex tests and the apnea test could not be performed.³ The case illustrates a **series of errors** that led to a false determination of brain death. Unfortunately, this case might not represent an isolated event. In a survey of physicians who perform brain death examinations, only 25% reported compliance with current practice guidelines, with most relying on clinical practice and hospital policies.¹⁹

Recommendations

Although the diagnosis of brain death³ and prognosis of neurological recovery after brain injury¹¹ are well-defined in the literature, hospital policies in the United States for the determination of brain death are highly variable and often not in line with current practice guidelines.^{20,21} Without the safety net of standardized guidelines, false diagnoses of brain death are more likely to occur. Rather than a top-down approach, a more fail-safe method of ensuring appropriate diagnoses of brain death might well come from early education of future physicians and continuing education of physicians in practice.

Undergraduate and graduate medical education, as well as continuing medical education, should include instruction on the disorders of consciousness—brain death, coma, vegetative state, and minimally conscious state. In undergraduate medical education, simulation-based education on brain death diagnosis has been employed at several institutions, including New York University (NYU) Grossman School of Medicine²² and Florida International University (FIU) Herbert Wertheim College of Medicine.²³ After implementation of a workshop and simulation, investigators at NYU Grossman found significant improvements in medical knowledge of brain death, comfort in performing a brain death examination, and comfort in counseling a family member.²² Investigators at FIU Herbert Wertheim found that implementation of a coma/brain death simulation translated into better medical student performance in real clinical settings.²³ There were significant improvements in documentation of focused history, accuracy of brain death examinations, high-yield reviews of the medical record, family counseling, and conflict resolution in actual coma patients compared to historical controls.²³

In graduate medical education, similar improvements were seen with training. Investigators at Loyola University Medical Center found that simulation-based education improved incoming neurology residents' postintervention brain death examination,

apnea testing, and family discussion.²⁴ Investigators at Yale University School of Medicine evaluated physician competency in determination of brain death after simulation-based training at different levels of experience (from resident to attending physician) and among different specialties, both neurological and nonneurological.²⁵ Even among neurologists and neurosurgeons, posttest scores were significantly higher than pretest scores.²⁵

In recent years, the American Academy of Neurology's Ethics, Law, and Humanities Committee has convened a multisociety quality improvement summit to cultivate a united front in reaffirming the validity of current standards of brain death determination, developing regulatory systems that ensure consistent and accurate brain death determinations, and responding to biopsychosocial factors that influence public trust.²⁶ With regard to engendering public trust, the committee recommended uniform criteria for death determination in both children and adults, nationwide consistency in medical and legal communities' management of brain death similar to that of cardiopulmonary death, and community-based improvement in health literacy. To ensure that such measures are taken, a regulatory authority analogous to the Joint Commission that reviews hospital protocols during stroke center certification was recommended.^{26,27} The committee also acknowledged that a grassroots approach is needed to make significant change in the primary education and consistent reeducation of physicians through simulation-based credentialing programs.^{26,27}

In parallel to credentialing bodies that provide advanced cardiac life support training,²⁸ clinicians allowed by local law to perform brain death examinations should be required to demonstrate competency. The Neurocritical Care Society provides a brain death determination course to standardize brain death diagnosis. This course aims to educate clinicians on matters similar to those outlined in the analysis of the case—brain death prerequisites, brain death examination, pitfalls and barriers that arise during the process of brain death determination, interdisciplinary communication, and family dynamics.²⁹

Over 50 years after a Harvard ad hoc committee first introduced criteria for the determination of brain death in the United States,³⁰ progress towards the evidence-based practice of brain death determination has made formidable strides, with the aforementioned limitations. Similar to public mistrust of brain death determination, young physicians regard neurology as overly complex, a term coined “neurophobia.”³¹ As our understanding of brain death and disorders of consciousness evolves and as we seek to cultivate empowered doctors in training, knowledgeable physicians in practice, and trusted institutions abiding by evidence-based, standardized guidelines, it is fundamental to success that we concurrently rethink how we approach neurosciences in medical education as whole.

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HEALTH LAW

Reexamining the Flawed Legal Basis of the “Dead Donor Rule” as a Foundation for Organ Donation Policy

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Abstract

The legal basis of what’s known as the “dead donor rule” (DDR), which requires that donors must be dead according to legal criteria, is rooted in physicians’ fears of civil and criminal liability for participating in organ retrieval and donation. This article suggests that one reason to revisit the DDR is to help illuminate possible legal ways to retrieve and donate organs. Specifically, this article considers one of these: medically justifiable homicide, which is legally and ethically distinct from murder and wrongful death.

Origins

Organ donation in modern medicine is governed by a straightforward ethical norm: that before the retrieval of any vital organs (eg, the heart), a donor must first be dead, ie, “patients must be declared dead before the removal of any vital organs for transplantation,”¹ a requirement known as the dead donor rule (DDR). While this mandate is simple and seems logical on its face, in practice the DDR is a problematic doctrine in need of reform. In recent years, scholars have noted the quandaries that the rule has created: it has expanded the definition of biological death (eg, by inclusion of “brain death”)² and has precluded some terminal patients (eg, those with neurodegenerative diseases like amyotrophic lateral sclerosis, or ALS) from donating their organs.³

The weakness of the DDR stems from its presumed ethical and legal justifications and the key problems they attempt to solve. One ethical justification is designed to protect vulnerable people from being “sacrificed” or “killed” for their organs.⁴ An additional ethical rationale, which reflects the perspective of physicians, is that the Hippocratic Oath forbids physicians from harming or killing their patients; hence, the DDR acts as a safeguard to ensure that ethical medical practice prohibits the deliberate killing of patients.⁴ The legal basis—that dead donors must be legally dead—is equally important and compelling in understanding the rule’s rationale. The legal basis, which is meant to protect physicians, is rooted in organ transplant physicians’ fear of being held civilly and criminally liable for killing a patient. By better understanding the legal basis of the DDR and its implications, alternative solutions can be explored that might enable physicians to legally participate in organ donation outside of the DDR.

Legal Basis

Physicians' anxiety about being prosecuted for being involved in the organ procurement process was evident in the 1970s, when the legality of organ procurement from brain-dead patients—ie, those patients with an “irreversible loss of all functions of the brain, including the brain stem”⁵—was at the forefront of medicolegal discussions. As Roger Leng notes, “[t]he real crux of the problem lies with the responsibilities and potential liabilities of the medical profession,” because transplant surgeons are in a “legal vacuum” and are “unsure” whether the actions they take (ie, procurement of organs from a brain-dead patient) are “risking criminal and civil liability.”⁶ This anxiety was a response to the fact that brain death was an accepted medical definition of death but was not yet a recognized legal definition of death in most jurisdictions. Additionally, when legal issues of organ donation were first being debated in the 1960s, the French National Council of the Order of Physicians noted the risk of homicide that physicians procuring organs faced and opined that “declaring first that the subject [the potential organ donor] is dead” is preferable “from a legal point of view, because the death is declared before organ procurement,” thus eliminating legal risk.⁷

Fear of legal liability is a valid concern for any physician involved in the withdrawal of life-sustaining measures in patients who are in a chronic **state of unconsciousness** (eg, comatose state, persistent vegetative state, brain dead), although the risk of legal liability is particularly heightened for transplant surgeons. For example, in the famed Karen Quinlan case (1976), some physicians rejected participating in any withdrawal of life-sustaining measures for Quinlan, as she was in a vegetative state and not brain dead (ie, Quinlan did not suffer “total brain death”—cerebrum plus brain stem—but “cerebral death”), because they were fearful of criminal and civil liability for withdrawing life-sustaining treatment from a patient who, by all known criteria, biological or legal, was deemed living.⁸ However, physicians who remove the life-sustaining measures have a possible legal defense in that their withdrawing treatment is an “omission” and not a “positive act,” and “omission to act can be the basis for homicide liability only where there is a clear duty to act.”⁹ By contrast, transplant surgeons have to **proceed with extreme caution**, as their interventions are a “positive act” akin to a “surgical assault”; if brain-dead patients are deemed legally alive, “there is little a transplant surgeon can do to avoid possible criminal liability short of waiting until the donor’s plug had been pulled and the heart has stopped,”⁹ ie, waiting until the donor was determined legally dead by common law cardiopulmonary death. Therefore, the DDR solved an immediate conundrum confronting worried physicians: simply deem brain-dead donors as also legally dead. Then any organ procurement process involving such donors cannot be the cause of death; any criminal (eg, murder, manslaughter) or civil (eg, wrongful death, malpractice) claims are functionally impossible. However, as noted earlier, the simplicity of this rule creates other problems.

Quandaries

There is a need to reexamine the DDR and its foundation, as the ethical norm itself, while attempting to safeguard vulnerable people and protect physicians, creates 2 notable problems: (1) it shifts the definition of death; and (2) it does not allow some terminally ill patients who wish to donate their organs a way to do so.

Definition of death. The era of multi-organ transplant procurement began in the 1960s and witnessed “competing interests between those who need organs and those who have them.”⁷ Thus, the impetus for brain death understood as both a medical and legal definition of death was the substantial need for organs; indeed, it is still the case that

the “demand for organs far exceeds the supply.”¹⁰ Donation after **circulatory death determination** is not preferred, as this manner of death tends to render “organs unusable”; indeed, nearly one-third of circulatory death donors “end up unable to donate.”³ However, organs from a donor who is brain dead are optimal for donation, as the organs can be procured before “circulatory arrest” and hence have no “anoxic damage.”⁷ In 1968, the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death released its report, in which it “defined irreversible coma [with no central nervous system activity] as a new criterion for death,” ie, brain death.¹¹ With what became known as the “Harvard criteria”¹² for determining permanent loss of brain functions, medicine embraced brain death as another medically valid definition of death in addition to cardiorespiratory death and immediately “transformed the nature of transplantation,”³ as a brain-dead patient presented an ideal medically viable organ donor: one deemed medically dead but still possessing organs optimal for donation.

Following changes in technology and medicine’s new definition of death, the law began to follow suit. The traditional common law definition of death was cardiorespiratory, ie, “the cessation of circulatory and respiratory functions as evidenced by the absence of heartbeat, pulse, and respiration.”¹³ But in 1980, a model law known as the Uniform Determination of Death Act (UDDA)¹⁴ was created in response to “modern advances in life-saving technology,”¹⁵ bringing to a head the legal crisis regarding the definition of death. The UDDA codifies the traditional common law basis of death, ie, the “total failure of the cardiorespiratory system,” while additionally codifying the “determination of death based upon irreversible loss of all brain functions,” ie, total brain death as opposed to partial brain death or persistent vegetative state.¹⁵ Either determination of death in the UDDA—cardiorespiratory or brain death—suffices to determine that an individual is legally dead. Most states today have adopted the UDDA and codified some of its language.¹⁶ While “medicolegal variations” between states exist that have caused some confusion and lack of uniformity among jurisdictions,¹⁷ all states “have some form of legal recognition for a neurological standard of death.”¹⁰ Of course, the legal benefit of the states codifying the notion of brain death into law was that it squared the medical and legal definitions of death and mitigated transplant physicians’ risk of criminal or civil liability. As brain death became a legal standard of death along with the established cardiorespiratory standard, it allowed for transplant surgeons to practice without risk of liability.

Although the evolution of the definition of death to include brain death would likely have occurred irrespective of the demand for organs, the inclusion of brain death as a part of death’s definition, in both the medical and legal sense, created a pragmatic shortcut to persuade the public and health professionals that organ procurement was legally and morally safe.⁷ In actuality, determining death has no shortcut; it is a complicated task. As Arthur Caplan argues, death is a “biological process, not an event,” and “biological facts are not sufficient to ensure absolute precision.”¹⁸ Hence, in its essence, death can only be viewed as a “normative concept” that “evolves” over time, reshaped by societal values and the acquisition of knowledge.¹⁸ But in the decades since its acceptance, brain death has become dogma, defended vigorously by academics and professionals alike. This adherence has blunted perception and forward thinking about death, reinforcing brain death as legal death, as the DDR demands. As Robert Truog and Franklin Miller wisely note: “By insisting that the key question was whether brain death is really death, the bioethics community seemed to have missed an opportunity to raise the level of discussion to a much more relevant plane.”²

Limiting terminally ill patients. The other problem created by the DDR is that it precludes organ donation by some terminally ill patients who wish to donate. In her piece examining the evolving ethics of organ donation, Lisa Rosenbaum outlines one such example—a patient with ALS who wanted to donate his organs prior to his death.³ Because the terminal patient (at near death) was still alive, adherence to the DDR precluded him from donating his organs, as the only way his organs could be donated successfully was via “imminent death donation,” whereby a terminal patient (with capacity and consent) donates organs before withdrawal of life-sustaining measures.³ The ALS patient petitioned for “imminent death donation,” but the procedure was vetoed by hospital lawyers who were concerned about legal liability, and the patient ultimately died unable to donate any of his organs, as his organs were unusable at the time of death.³ Recent stories like this one have highlighted a misgiving about the DDR, in that it forecloses other possible organ donation scenarios that might still have an ethically sound basis.

Reexamination

According to Truog and Miller, what the DDR has wrought is the “gerrymandering [of] the definition of death to carefully conform with conditions that are most favorable for transplantation,” which has enabled “unnecessary and unsupportable revisions of the definition of death.”¹ The solution to the quandaries that the DDR raises comes from an examination into the foundations of the norm itself. There is a need to revisit the DDR’s justifications, both ethical and legal. With regard to the ethical justification, Truog and Miller note that it may be “perfectly ethical to remove vital organs for transplantation” from patients deemed dead via neurological criteria (ie, brain dead), but the “reason it is ethical cannot be that we are convinced they are really dead.”¹ Truog and Miller argue that the key to ethical organ procurement is consent of the patient and that “with such consent, there is no harm or wrong done in retrieving vital organs before death.”¹ Robert Sade also focuses on autonomy as key: “The cause of death [ie, whether by the withdrawal of life support or not] is irrelevant because the ethics of self-determination and informed consent that underlies withdrawal of life support are of paramount importance.”¹⁹ Indeed, as Sade argues, the organ procurement system already accounts for valid consent and conflicts of interest; from an ethical standpoint, “the DDR serves no necessary protective purpose.”¹⁹ If, in its essence, the DDR’s ethical justification is unnecessary to safeguard ethical practice, then perhaps the rule’s legal basis may lay claim for why the norm persists.

While the DDR has protected physicians (notably transplant surgeons) from legal liability, it need not be the only way to legally protect them; the law might adapt to allow physicians to perform vital organ donation on a living person. Alternative legal methods can be created, such as a legally permissible or defensible form of homicide for specific situations, like “imminent death donation” of a terminally ill patient or “live donation prior to planned withdrawal” of a brain-dead patient, both implemented in a manner upholding patient autonomy with valid informed consent. Of course, permissible forms of homicide are not unprecedented; the law has carved out valid exceptions, such as common-law self-defense and (in some regions of the world) euthanasia. The DDR functioned as a shortcut to any deeper analysis of whether a homicide is justifiable or not, thus eliminating the question in an effort to embrace a simple solution while also providing maximal protection for the physician. However, the time to reopen legal analysis of medically justifiable homicide is here. Transplant physicians can be protected from criminal and civil liability in ways other than simply first deeming the donor dead; the law can find more creative and pragmatic solutions.

Conclusion

The time has come to reexamine the DDR. While the rule has served a useful purpose—increasing organ donation and ensuring some ethical and legal standards to protect patients and physicians—it is not the only possible option. While some bioethicists maintain that the public is supportive of the DDR (ie, most people don't want to see a person murdered for organs) and fear that its abolishment would diminish organ procurement,²⁰ reality presents a different story. Recent studies have shown that the public is strongly supportive of organ donation “in the scenario of irreversible coma with organ removal causing death.”²⁰ Reflecting on these studies, Nair Collins et al note that while “some scholars have suggested that the idea of abandoning the DDR is out of touch with mainstream opinion, the results of the survey challenge this claim.”²⁰ Forming a new ethical and legal justification for vital organ donation would allow society to dispense with the “legal fiction”² that brain death is the same as the biological death of the entire human being and adopt other legal methods—grounded in the reality of the complexity of and murkiness inherent in death's definition—that may still encourage organ donation and protect physicians.

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AMA CODE SAYS

AMA Code of Medical Ethics' Opinions About End-of-Life Care and Death

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Abstract

Death determination is fraught with clinical, cultural, and ethics questions. This article considers relevant history that informs the AMA Code of Medical Ethics opinions about neurological criteria for death.

From Heart to Brain

Diagnosing death became significantly more complex as science revealed more about physiological relationships between the brain and body. The mainstream clinical consensus up to the early 1960s was that a patient died upon cessation of cardiopulmonary function, as indicated by absence of a palpable pulse or, later, by absence of a pulse discernible via stethoscope.¹ In the late 19th century, physicians reported observations about relationships between brain function and other critical bodily functions, notably respiration.² By the 1950s, failing critical cardiopulmonary function could be supported by innovations, such as positive-pressure ventilation,³ which gave rise to new philosophical and clinical questions about the nature and scope of medicine's role in patients' transitions from life to death. Through the 1960s, the connection between the cessation of critical bodily functions and of brain function became clearer from a neurological perspective,² and, in 1968, the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death introduced *brain death* as a legitimate definition of death.⁴

Guidance

Patients, however, are generally not concerned with what constitutes death from neurological or cardiopulmonary standpoints. More often, patients want to know whether, after a lifesaving intervention, they'll walk, talk, be awake, be able to do what they care about doing, and be able to interact with people they care about. For patients, diagnoses tend to matter less than their visions of their future experience of illness and treatment. Even for patients who want "everything done," the physiological dimension of exceptional circumstances is rarely specified. "Do everything, unless I meet criteria for cardiopulmonary death," for example, is not a commonly articulated wish. These realities of patients' experiences underscore the importance of advance care planning and end-of-life decision making; guidance on these subjects is offered in the American Medical Association (AMA) Code of Medical Ethics opinions related to death.

Opinion 5.1, "Advance Care Planning," encourages physicians and patients to consider goals of care and to plan "in advance for decisions about care in the event of a life-

threatening illness or injury.”⁵ The purpose of advance care planning is to generate discussion among patients, their surrogate decision makers, their loved ones, and health professionals about patient values and preferences that should inform the clinical dimensions of EOL care and death. Physicians are encouraged to “be sensitive to each patient’s individual situations and preferences” and to consider factors that could affect patients’ decision making, such as “culture, faith traditions, and life experience.”⁵ Physicians can also use advance care planning time “to address patients’ concerns and expectations and clarify misunderstandings individuals may have about specific medical conditions or interventions.”⁵

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POLICY FORUM: PEER-REVIEWED ARTICLE

Inconsistency in Brain Death Determination Should Not Be Tolerated

Erin Barnes, MD and David Greer MD, MA

Abstract

Since it was proposed in 1980, the Uniform Determination of Death Act has provided the legal basis for determination of death by neurological criteria. The act contains language that allows for acceptable medical standards to be used to determine death. Since 1995, the American Academy of Neurology has provided guidelines for brain death determination (revised in 2010), but nationwide adherence to these guidelines has been incomplete. This variability could lead to misdiagnosis and erosion of public trust in this important medical practice. Physicians must work together as a profession to push for uniformity and accuracy in death diagnosis.

Defining Brain Death

Although the concept of death is as old as life itself, the concept of brain death is a relatively young one. Only in the mid-20th century did technology advance to the point of allowing for organ support in the event that brain function ceased. With the advent of mechanical ventilation, artificial nutrition, and the modern intensive care unit, patients who suffered an irreversible intracranial catastrophe could continue to have their other organs supported and maintained. In 1968, a committee of physicians from Harvard Medical School published a report titled “A Definition of Irreversible Coma.”¹ In 1980, the **Uniform Determination of Death Act (UDDA)** was proposed in order to establish a legal and uniform definition of death—determined by “acceptable medical standards”—that was “clear and socially accepted,” with the intention of its being adopted in every US jurisdiction.^{2,3} This model statute provided the legal basis for death by neurological criteria, stating that an individual could now be determined to be dead if they had sustained “irreversible cessation of all functions of the entire brain, including the brain stem.”² What “acceptable medical standards” meant was left to be determined by the medical community, leading to the creation of societal guidelines in subsequent years.

Following the Harvard report and the UDDA, in 1995, the American Academy of Neurology (AAN) provided consensus practice parameters for the determination of death by neurological criteria in adults.⁴ These guidelines stated that brain death has occurred when “the irreversible loss of function of the brain, including the brain stem,” has been determined by the demonstration of complete loss of consciousness (coma), brain stem

reflexes, and the independent capacity for ventilatory drive (apnea) in the absence of any factors that imply possible reversibility.⁴ Since their introduction in 1995, the AAN guidelines for the diagnosis of brain death have been widely used; however, studies of institutional protocols for determining brain death have shown considerable variability, both within the United States and the world at large.^{5,6,7,8} These inconsistencies in brain death protocols could sow doubt among members of the public and be a potential source of legal exposure. It is intuitively incoherent to think that a person could be dead in one US state but, according to a different protocol, not be dead in a neighboring state. We first discuss how prominent variability in determination of brain death is before discussing why variability matters and what can be done about it.

Variations in AAN Guideline Adherence

The designation of “acceptable medical standards” to determine death in the UDDA allows for those standards to be set nationally, regionally, or locally.² Perhaps as a result, variability exists in protocols for brain death determination in the United States, both among leading hospitals and among all hospitals at large. While this variability seems desirable in that it allows for flexibility based on available equipment and specialists as well as changing medical knowledge, the UDDA has created a scenario in which variability in practice is possible. In 2008, a study of the top 50 hospitals in neurology and neurosurgery in the United States (according to the 2006 *US News and World Report*) showed wide variability in adherence to the current societal guidelines at the time, the 1995 AAN practice parameters.⁵ Protocols varied from the guidelines in respect to all 3 pillars of the clinical diagnosis of brain death—coma diagnosis, absence of all cranial nerve reflexes, and apnea.⁵ Notably, only 63% of reviewed protocols required an established cause of brain death, and only 55% specified the absence of sedatives and paralytics.⁵ Regarding the clinical examination, only 27% of protocols specified that no spontaneous respirations should be present, and only 18% required the absence of a jaw jerk reflex.⁵ Apnea testing had the greatest variation from the guidelines, including acceptable cut-off values for core temperature at the time of testing and whether an arterial blood gas was obtained prior to testing.⁵ Obsolete or incompletely vetted ancillary tests were included in some protocols, including the use of unapproved tests such as computed tomography angiography and magnetic resonance imaging, and there was a lack of consensus on how many clinical examinations were required as well as the minimum wait time between exams.⁵ Strikingly, there was also a lack of clarity regarding who could make the diagnosis of brain death, as less than half of protocols stipulated involvement of a neurosciences specialist, and, in some instances, resident physicians could make the determination.⁵

Updated AAN Practice Parameters

The variability found in the 2008 study prompted an update to the AAN practice parameters in 2010 in hopes of bringing about more uniformity in brain death determination—or at least in the protocols for such.⁹ These guidelines were specifically designed to be more readily incorporated into hospital protocols, with a checklist and specific instructions on how to meticulously perform much of the cranial nerve and apnea testing.⁹

Despite the 2010 update, significant variability remains in hospital policies across the United States.^{6,8} A follow-up study in 2016 reviewed 492 US hospital policies on brain death declaration.⁶ This study again found wide variability in compliance with practice guidelines, especially in the areas of prerequisites for testing, clinical examination, and apnea testing.⁶ Notably, this paper found that only 43.1% of policies specifically required

an attending physician to make the diagnosis of brain death.⁶ In 2017, Wang et al analyzed protocols from the top 50 hospitals in neurology and neurosurgery in the United States (according to the 2015 *US News and World Report*) for comparison to the 2008 study.⁸ Poor compliance with specific clinical examination techniques persisted, but overall there was improvement in concordance with the 2010 practice parameters, driven by better specification of prerequisites to testing, use of recommended ancillary testing, and performance of apnea testing.⁸ Despite some encouraging progress, however, variability persists, which could lead to significant negative consequences.

The developments over the past half century in defining and determining brain death are summarized in the Table.

Table. Sentinel Publications in Brain Death Determination

Publication	Year	Key Features of Brain Death or Its Determination
“A Definition of Irreversible Coma” ¹	1968	<ul style="list-style-type: none"> • Unreceptivity and unresponsivity • No movements or breathing • No reflexes (including deep tendon and spinally mediated) • Flat EEG • Need to exclude hypothermia and presence of central nervous system depressants
UDDA ²	1980	<ul style="list-style-type: none"> • Defined death as “an individual with either irreversible cessation of circulatory and respiratory functions, or 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” • Ancillary testing optional, including EEG or blood flow testing • Peripheral nervous system activity and spinal cord reflexes are not inconsistent with brain death diagnosis • Cause of the coma should be established and sufficient to account for loss of functions • Specifies exclusion of sedation, hypothermia, neuromuscular blockade, and shock • Special caution advised in determination of brain death in children
AAN Practice Parameters ⁴	1995	<ul style="list-style-type: none"> • Specified brain stem reflexes to be tested and how to perform testing, including acceptable pupillary size (4-9 mm), testing for pain response in the cranium, absent jaw jerk reflex, and others • Specified a method for performing apnea testing • Recommended optional confirmatory testing (conventional angiography, EEG, transcranial doppler ultrasonography, technetium-99m HMPAO nuclear scan, and SSEPs)

		<ul style="list-style-type: none"> • Provided a standard for documentation of testing in the medical record • Recommended a repeat neurological examination; discussed that 6-hour waiting period between repeat neurological examination is reasonable but that interval is arbitrary
AAN Practice Parameters ⁹	2010	<ul style="list-style-type: none"> • SSEPs no longer recommended as an ancillary test • Provided a checklist to diagnose brain death • Provided in-depth instructions for performance of each step of clinical examination and apnea testing • Provided more guidance on documentation (eg, time of death is the time arterial Pco₂ reached target value)

Abbreviations: AAN, American Academy of Neurology; EEG, electroencephalogram; HMPAO, hexamethylpropyleneamineoxime; SSEP, somatosensory evoked potentials; UDDA, Uniform Determination of Death Act.

Why Variation Matters

Variability in the diagnosis of brain death has the potential to lead to misdiagnosis. Even in the clearest circumstances, families may have difficulty accepting a diagnosis of brain death when they see their loved one's heart still beating and feel their body warm to the touch. Public trust in the process of brain death determination is integral to enabling physicians to bridge the gap between diagnosis and perception and to help families understand what it means for their loved one to be not only brain dead, but also legally dead with no hope for recovery of any brain function. If the medical profession cannot achieve rigorous, disciplined brain death testing in accordance with accepted guidelines for the determination of brain death on a national scale, confusion and doubt may ensue, leading to **erosion of public trust**. In the event of organ donation, lack of public trust becomes even more ethically concerning. If we cannot promise robust and 100% accurate diagnosis of brain death, we cannot in good faith counsel families about organ donation, as to do so would violate the dead donor rule.¹⁰ It should be noted, however, that there have been no legitimate, unconfounded false positive cases of a patient declared dead by neurological criteria according to the practice parameters put forth by the AAN.⁹ Conversely, failing to diagnose a patient as brain dead (who is dead) might give family members false hope that the patient might recover, prolong their grief, and cause undue pain to all involved. In any case, in order for brain death testing to be effective, the guidelines must be followed.

Recommendations

A variety of reasons may exist as to why the AAN practice parameters have not been uniformly incorporated into hospital protocols nationally. First, the wording of the UDDA allows for determination of death to be based on medically acceptable standards at a national, regional, or local level, which provides legal room for variations in policies and procedures. Second, a significant time investment must be made by clinicians at all hospitals to champion updating practices to meet accepted standards of care and to help train clinicians in the most modern techniques and approaches. Third, without the pressure of regulatory bodies, the calculus at many of these institutions may be that the protocols currently in place are appropriate and sufficient, or "good enough." In light of this unfortunate reality—and until outside pressures change—the burden of **responsibility falls on practitioners** to push their own institutions to adopt guidelines for best practice in order to ensure a uniformly accurate diagnosis of brain death.

Efforts are underway to outline the differences that exist in brain death determination both in the United States and worldwide and to develop clearer and more unified practice parameters to ensure correct determination as close to 100% of the time as possible. These efforts include new practice parameters from the AAN, currently under development, which will merge adult and pediatric guidance into one document. National accreditation bodies could be a key ally in ensuring that proper policies are in place at the hospital level, and even revision of the UDDA might be a necessary step. Such a revision would optimally address what are the appropriate medical standards; clarify what is meant by “all functions of the entire brain, including the brain stem”²; address the issue of whether consent for testing is necessary; and address how to handle objections to termination of organ support after brain death determination.¹¹ Finally, ensuring that proper determination of brain death is occurring will require in-depth and meticulous efforts by hospitals. The Neurocritical Care Society has developed a Brain Death Toolkit,¹² which includes a sample brain death policy (including a checklist) that can be amended for use in an individual hospital, as well as a new training and certification course, which will help ensure that the practice of brain death determination is sound. Combating our current complacency with variability will require these and other ongoing local, national, and global efforts to ensure that the medical community moves toward more uniform and consistently accurate diagnosis of brain death.

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POLICY FORUM: PEER-REVIEWED ARTICLE

Guidance for Physicians Who Wish to Influence Policy Development on Determination of Death by Neurologic Criteria

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Abstract

Physicians have a long-standing obligation to consider social implications of their practice and its potential influences on health policy. One example of a practice's influence on policy is determining death by neurologic criteria. By lobbying policymakers, maintaining their diagnostic skills, participating in national medical societies, and contributing to robust discourse, physicians can positively influence practice and policy about death determination by neurologic criteria.

Physicians' Roles in Health Policy

Since the establishment of the Hippocratic School, physicians have endeavored to treat and prevent illness. The American Medical Association (AMA) *Code of Medical Ethics* continues this tradition in Opinion 8.11, "Health Promotion and Preventive Care," which states: "While a physician's role tends to focus on diagnosing and treating illness once it occurs, physicians also have a professional commitment to prevent disease and promote health and well-being for their patients and the community."¹

Physicians hold positions of respect in society and are a trusted group to inform health care policy development. A 2009 Gallup poll revealed that 73% of Americans had confidence in physician recommendations for health care reform, while only 34% and 42% of Americans had confidence in Republican and Democratic congressional leaders, respectively.² Indeed, trust in the integrity of physicians remains high; however, trust in leadership of the medical profession has declined significantly since the 1960s.³

However, the increasing complexity of health care in the 21st century seemingly poses barriers to physicians' shaping of health policy. Profound changes have occurred in professional reimbursement, resource allocation, and pharmaceutical marketing and development, as well as in financial support for research. Furthermore, the digital revolution has enabled increased attention to quality and safety, regulation compliance, and clinical documentation integrity. While all of these demands have increased the quality of care delivered, they likely have contributed to burnout in health care, as performance expectations grow out of proportion to increased efficiency in workflow. Meanwhile, the ethical dimensions of practice have become more complex, as scientific advances push the boundaries of what is achievable while some consumers increasingly

desire more involvement in their health care decisions. The combination of increasing demands on physicians and increasingly complex clinical, social, and ethical questions leaves physicians with deficits of both time and knowledge that prevent them from attempting to influence health policy through traditional lobbying efforts. Nevertheless, by maintaining excellence in diagnostic skills, participating in national medical societies, and contributing to a robust discourse, physicians can have a positive influence on public policy.

Lobbying

The traditional approach to influencing public policy is to correspond with policy creators, just as any private citizen can. The AMA has offered guidance on how individual physicians can communicate with congressional representatives through letter writing, emails, phone calls, and personal visits.⁴ Such approaches have been shown to be effective and commonplace, with a 2000 survey of legislative assistants to congressional members estimating that approximately 29 000 personal meetings between physicians and legislative assistants occur annually, at which meetings issues such as reimbursement, managed care, and research concerns are discussed.⁵ While lobbying is commonly considered to be an influencer of public policy, several other approaches should be considered, which will be explored in the remainder of this paper with a focus on policy for determination of death by neurologic criteria.

Maintaining Standard of Care

Support for physicians and the positions for which they advocate are based on public trust. This trust is earned by an evidence-based approach to clinical care, maintenance of competency, and physicians' putting their fiduciary responsibility to their patients and community over their own potential personal gain.⁶ Even with extensive training, however, physicians still commit diagnostic errors. The higher the risk of an incorrect diagnosis, the more time, effort, and attention should be devoted to reducing the risk of misdiagnosis. Physicians should be very cognizant of the fact that a patient who has endured a devastating neurologic injury not amenable to correction can still be negatively impacted by their decisions and determinations. The finality of a diagnosis of death by neurologic criteria does **not allow room for error**. A determination of death changes the calculus of risk and benefit for the patient, and the family might endure additional psychological distress after an already tragic event if a diagnosis is not made correctly or according to professional standards.

Misdiagnosis of death reduces public trust in the ability of medicine to accurately determine death. We never know how even one misstep might reverberate through the community and have a long-lasting impact. Repeated experiences might have a greater cumulative effect and eventually lead policymakers to believe that changes in the law are needed to address limitations in practice. Therefore, the first step in positively influencing public policy regarding brain death determination is to pursue excellence in clinical practice and to avoid misdiagnoses.

Many tools are available to avoid a misdiagnosis of death. Following established recommendations by the American Academy of Neurology⁷ will increase fidelity in diagnosis of brain death as well as mitigate public perception that criteria for determining death are arbitrary. Check lists and templates (such as those available from the Neurocritical Care Society Brain Death Toolkit⁸) can help ensure that all essential clinical criteria are given appropriate consideration in the determination of brain death. Furthermore, all physicians need to have the integrity to self-assess whether their

experience in determining death is sufficiently frequent and their training sufficiently up-to-date that they will be able to make an accurate brain death determination. Physicians must maintain their professional integrity, and shortcuts that might reduce the accuracy of the diagnosis should be avoided.

Professional Advocacy

Physicians can influence policy through participation in professional societies. Membership in a professional society is for the purpose of not only improving knowledge and skills, but also ensuring that members are beholden to a code of behavior guiding the execution of those skills. In addition to peer accountability, society participation includes the benefit of continuing education, networking with current and future colleagues, and opportunities to share experiences and opinions on topics for which consensus might not have been reached or is breaking down. While individuals might believe they have a limited voice on the national stage, medical societies often develop specific committees focused on advocating for changes in public policy, such as the American College of Physicians Health and Public Policy Committee.⁹ **Society advocacy** reduces the chance that any singular political motivation is at the heart of a position and ensures that concern for the public welfare is the motivating factor for engagement. Professional societies depend on the volunteerism of their members for committee service, presentations, and contribution to position papers. State medical societies also perform a similar role, as laws regarding determination of death by neurologic criteria are often state based.

Partner With Stakeholders

A healthy discourse in the medical literature on what requires further development and incorporation into society position statements is essential to the development of public policy. Although policymakers can choose the position papers and data that support their agenda, physicians ought still to endeavor to honestly discuss and explore various perspectives, including empirically supported claims. Reading the medical literature, responding with letters to the editor, and initiating discussions at national conferences all constitute participation in the discourse, which can influence not only policy changes but also public opinion if consensus opinions find their way into news media.

Determination of death by neurologic criteria has garnered much attention from the academic world. Academics, however, have a tendency to work in their own “silo,” which is a very ineffective approach for complex issues addressed on a national scale. It would be a grave error to assume that one group has the only voice that matters and that other voices can be dismissed. Neither a purely empirical approach nor a philosophical discussion of the underpinnings of death are adequate to complete our understanding of neurologic criteria. Physicians who determine death by neurologic criteria should both be familiar with and contribute to the scientific knowledge base as well as legal and philosophical arguments about neurologic criteria for determination of death. Likewise, lawyers and ethicists should become familiar with clinicians’ experience. I would argue that the best approach is for authors from different fields to collaborate on manuscripts to create a more robust discourse. Consideration of controversial or dissenting opinions is essential to the development of a thorough understanding of and consensus on neurologic criteria that are logically consistent and have practical application.

Conclusions

Physicians can choose among many different approaches to interact with policy leaders to positively influence understanding of brain death and motivate efforts to standardize

neurologic criteria for determining it. While all physicians should be aiming for error-free determinations of death, some might pursue legislative lobbying, advocate through professional societies, or contribute to the ethical and clinical literatures. Other physicians might choose to spend a significant portion or even all of their later careers in public policy roles.¹⁰ Regardless of the approach taken, all physicians have obligations to consider how their activities affect their colleagues, institutions, patients, and society as a whole.

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POLICY FORUM: PEER-REVIEWED ARTICLE

What Should We Do About the Mismatch Between the Legal Criteria for Death and How Brain Death Is Diagnosed?

Nathaniel M. Robbins, MD and James L. Bernat, MD

Abstract

Mismatch between whole-brain death criteria embedded in statutes and accepted tests physicians use to diagnose brain death have clinical and ethical implications that could undermine public trust in death pronouncements. We consider merits and drawbacks of 4 ways to address this problem.

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Legal and Clinical Mismatch

In 1980, the Uniform Determination of Death Act (UDDA) defined death (“brain death”) as “irreversible cessation of all functions of the entire brain, including the brain stem ... in accordance with accepted medical standards.”^{1,2} Whole-brain criteria of death have since been adopted in all 50 states.³ Although the American Academy of Neurology (AAN) and other organizations have outlined “accepted medical standards” for determining brain death (BD) by neurological criteria,^{4,5,6} controversy is ongoing because testing pursuant to these standards can only approximate BD as codified in law.^{7,8}

Several recent high-profile cases have highlighted this mismatch,⁷ although they are not unique.⁹ This mismatch has reignited controversy among BD experts,¹⁰ spawned lay misunderstanding,¹¹ and could threaten public trust in physicians, their BD diagnoses, or BD as a concept. Addressing conceptual, ethical, and practical implications of this mismatch requires that physicians recognize BD as currently defined and the difficulties of assessing function loss “irreversibility” in the “entire brain.”^{1,2} After discussing these difficulties, we offer 4 solutions for reconciling the mismatch: loosening the whole-brain criterion of death, requiring more stringent testing for diagnosing brain death, acknowledging the incongruence between the concept of death and its bedside determination, and the first 2 solutions in combination.

Irreversible Cessation

One reason for the mismatch between medical and legal standards for determining BD is that accepted medical standards cannot determine irreversible cessation. Function

loss *irreversibility* was recently reaffirmed as a legal requirement for death when a prisoner who was resuscitated after circulatory arrest argued (unsuccessfully and in court) that his life sentence already had been served.¹² Although broad religious, ethical, clinical, and legal consensus exists that death is irreversible and final, in practice, **recognizing exactly when life transitions to death** is not so easy.^{13,14} Circulatory death (CD) is currently diagnosed operationally, based on permanence; the function loss irreversibility criterion is fulfilled and fulfillable only when resuscitation is abandoned or life-sustaining measures are withdrawn.¹⁵ Physicians have always relied on permanent cessation of circulation and respiration to determine death without needing to prove function loss irreversibility—and, as we discuss in relation to BD, proving irreversibility is a problem, because prevailing tests rely on permanent cessation.¹⁵

Hypoxic brain tissue invariably becomes functionally quiescent before it is irreversibly destroyed.⁸ BD examination cross-sectionally evaluates function but cannot distinguish between a “stunned,” quiescent brain and an irreversibly damaged brain.⁸ The clinical term *ischemic penumbra* refers to a brain that is hypoperfused (ie, deprived of sufficient oxygenated blood) and nonfunctional but potentially salvageable; hypoperfusion is a well-recognized state of perilesional neurons in patients with acute ischemic stroke, one that can confound BD diagnosis.^{7,8,16,17,18} Technological advances further blur the line between quiescent and dead brain. For example, it was recently demonstrated that some cellular activity in pig brains can be restored several hours postmortem.¹⁹ Although metabolically active brain cells do not necessarily mean that a brain is living and “proof of demise of every neuron is not required to demonstrate irreversible loss of whole brain function,”²⁰ cellular restoration is one reason function loss irreversibility is **hard to confirm clinically**.

The AAN recently defended clinical standards for diagnosing BD in prognostic rather than in conceptual terms, stating that it was “unaware of any cases in which compliant application of the Brain Death Guidelines led to inaccurate determination of death with return of any brain function.”²⁰ Yet confidence in this assertion is limited because accepted standards for diagnosing BD have not been rigorously tested. Patients who meet BD criteria are almost always withdrawn from cardiopulmonary support, which ensures function loss irreversibility.⁸ Cardiopulmonary support was continued in Jahi McMath’s case, however.^{7,8} Independent physicians appropriately declared her to be BD by accepted medical standards, but months later she reportedly demonstrated some preserved brain functions. If some of her brain functions really were preserved, her case seems to illustrate the limited specificity of BD diagnostic tests.^{7,8} Despite being controversial,²¹ the McMath case is important since opportunities to longitudinally follow a patient after a BD diagnosis are few.^{7,8}

Whole Brain Function

In states that have adopted the UDDA, BD determination mandates the “irreversible cessation of all functions of the entire brain, including the brain stem ... in accordance with accepted medical standards.”^{1,2} However, accepted diagnostic tests only enable a physician to examine a patient’s motoric responses, which are controlled by the brain stem.^{22,24} Clinical examination must demonstrate apnea, cranial nerve areflexia, and unresponsiveness caused by an irreversible pathology, excluding mimicking and potentially reversible conditions.^{4,5,23} But “super locked-in patients” with completely destroyed brain stem efferent pathways could appear brain dead, despite preserved consciousness or afferent olfactory and visual pathways, analogous to vegetative patients who demonstrate subclinical awareness when carefully interrogated.^{23,25,26,27,28}

Although brain stem destruction damages the reticular activating system, presumably causing unconsciousness, this effect is not currently empirically verifiable.^{29,30}

Other examples illustrating the mismatch between accepted medical standards for diagnosing BD and the whole-brain criterion of BD codified in law are patients diagnosed as brain dead per accepted medical standards but who retain neurohormonal functions, such as vasopressin release, which requires an intact neurosecretory hypothalamus.^{7,31,32} McMath, for example, reportedly underwent menarche and pubertal development⁷ and showed signs of autonomic environmental reactivity.^{8,33} Even patients who otherwise meet criteria for BD can have cerebral activity revealed on an electroencephalogram (EEG),^{34,35} and though EEG activity does not necessarily indicate “meaningful” brain function, it probably reflects subclinical cognition.^{36,37}

Early BD proponents assumed that brain tissue disintegration invariably followed BD diagnosis.^{2,9,38,39} Liquefaction can follow total brain infarction eventually, but patients diagnosed as brain dead by current tests often have grossly intact brain tissue at autopsy.^{40,41} McMath’s magnetic resonance image reportedly showed some areas of preserved brain tissue 9 months after the initial insult.^{8,17,33} Other authors note frequent persistence of patients’ cerebral electrical activity and blood flow despite a BD diagnosis, particularly following infratentorial injuries.⁴² Although preserved brain structure and blood flow do not necessarily imply preserved function, it seems clear that (1) many nonmotoric brain functions, including higher-order and afferent functions, are difficult to interrogate without an intact brain stem; (2) many young brain-dead patients have sustained blood circulation for long periods after a BD diagnosis; and (3) persistent hormonal and autonomic functions seem to contradict a BD diagnosis according to the UDDA’s requirement, even when diagnosed appropriately per accepted medical standards.

Saying What We Mean, Meaning What We Say

We and others have argued that “all functions of the entire brain”^{1,2} is best interpreted as the functioning of the brain-as-a-whole or the core function of the brain, rather than as the persistence of a single or even each individual brain function.^{38,43} Defenders of the functioning of the brain-as-a-whole concept argue that the apparent mismatch posed by persistent hypothalamic or autonomic activity, for example, stems from misinterpreting “all functions of the entire brain.” But persistence of a single noncritical brain function does not indicate that the function of the brain-as-a-whole has irreversibly ceased.

Despite being widely accepted for decades, the brain-as-a-whole concept remains vague and challenging to defend.^{43,44} Conceptions of the brain’s role as a control center or “somatic integrator” have been criticized because many vital body functions operate independently or in parallel with the brain.^{45,46} Other authors, including us, have emphasized that critical functions, such as cardiorespiratory circulation or consciousness, define the-brain-as-a-whole.⁴³ The President’s Council on Bioethics’ 2008 report suggests that “the work of self-preservation” performed by the brain should be regarded as central.⁴⁵

Yet none of these brain-as-a-whole refinements seem to adequately rebut important criticisms or clarify responses to key clinical and ethical questions: Which specific functions are essential for life? Why are critical functions found in the spinal cord or elsewhere regarded as less important?^{14,44} Why should autonomic and hormonal

functions not be regarded as key parts of “the work of self-preservation”⁴⁵? Proposed brain-as-a-whole definitions seem superficially reasonable but, to date, no necessary and sufficient criteria have been formulated to define life or death of an organism as a whole.

Reconciliation

Although the UDDA requires “irreversible cessation of all functions of the entire brain” to diagnose BD,^{1,2} as just discussed, accepted medical standards are only achievable through physicians’ use of currently available diagnostic tests, which do not assess function loss irreversibility or brain functions other than motor responses and respiration. This mismatch between legal criteria and what’s achievable via currently available tests for diagnosing BD means that false-positive diagnoses of BD are possible in cases of low but not absent brain perfusion or brain stem destruction. How should this mismatch be reconciled?

We propose 3 options: improving testing, amending the UDDA, or accepting the inevitability of mismatch.⁴⁷

Improving testing. To preserve the UDDA, testing standards must be tightened. Mandating **repeat examinations** after a minimal-interval waiting period might help.⁴⁸ Many experts recommend this strategy in certain cases (eg, primary brain stem injuries),²³ and this strategy would apply when hypoperfusion mimics function loss irreversibility. One limitation of this strategy is that the duration of an interval that would sufficiently ensure brain function cessation irreversibility remains unknown. Prolonged waiting is not feasible or desirable for many reasons, including fewer patients qualifying as organ donors.⁴⁹

Another strategy for improving tests would be to mandate ancillary testing to assess whole-brain function more comprehensively. A drawback of this strategy, however, is that ancillary tests are expensive, not always available, and can generate false positives and false negatives.²³ Another method—universal perfusion scanning—also might not eliminate the mismatch between accepted standards for diagnosing BD and the whole-brain criterion of death, because viable brain tissue might survive below commonly accepted neuroimaging detection thresholds.^{7,8,16} Even future technological advances that expand our understanding of consciousness or render today’s ancillary tests obsolete might not help clearly distinguish live patients from dead ones. Thus, it seems reasonable to conclude that testing for whole-brain function will evolve and that establishing enduring standards that render tolerance for ambiguity unnecessary will be challenging, if not impossible.

Amend the UDDA. A second strategy is to amend the UDDA to align it more closely with clinical practice. Since death is difficult to define¹⁴ and since transitions from living, to dying, to death resemble a continuum more than they resemble the binary concept currently enshrined in law,⁵⁰ amendment would be reasonable. One option would be to define BD in terms of cessation of function of the brain-as-a-whole, although a lack of tests for measuring functioning of the brain-as-a-whole^{7,38} remains. Another option would be to define BD in terms of *brain stem death*, as in the UK.⁵¹ This definition would address the mismatch, but practical and philosophical problems would remain for patients who retain consciousness or a quiescent, potentially revivable brain, despite absence of evidence of brain stem function.⁸

Accept mismatch. A third strategy involves preserving BD as defined in the UDDA, while accepting that tests for BD offer only approximations of BD. Death is irreversible by definition, but physicians have always relied on permanent cessation of circulation and respiration to determine death without needing to prove function loss irreversibility.¹⁵ Death can be viewed as a process on a continuum that has important clinical and ethical dimensions, but legally BD is a discrete event.^{13,14,50}

Since it might be impossible to conclusively demonstrate irreversibility and loss of all brain functions, acknowledging the limitations of accepted standards is more intellectually honest and might help overcome public misperceptions and mistrust.^{11,50} A risk is that accepting the mismatch means accepting that some patients' BD diagnoses will probably be wrong.^{10,14,15,52,53} However, it comports with current declarations of CD, which is routinely diagnosed based on permanent cessation of function (ie, resuscitation attempts either are not attempted or have failed and been aborted), not on biologic irreversibility.¹⁵

A Fourth Strategy?

Revising both legal criteria for BD and diagnostic capacity to assess BD might be the best way to address the mismatch between the two. Doing so might help respond to current public skepticism and lack of understanding of BD^{54,55,56,57} and acknowledge lay tendencies to care more about prognosis than abstractions.^{54,57,58,59} Such a change could obfuscate determinations of a time of death and require a refinement of the **dead donor rule**,⁶⁰ which expresses general clinical and ethical consensus that a person must be dead before their organs can be retrieved. When one acknowledges that current testing can only imperfectly approximate BD, the question of whether to abandon the dead donor rule will also need to be carefully considered.^{60,61,62,63}

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MEDICINE AND SOCIETY: PEER-REVIEWED ARTICLE

What Does the Public Need to Know About Brain Death?

Katharina M. Busl, MD, MS

Abstract

Brain death differs from traditional circulatory death, and understanding how it differs is important. Public awareness of brain death is based largely on inaccurate media representations, common examples of which are described here. The purpose of this article is to motivate lay understanding of brain death by tracing key moments in the history of how we've come to define and recognize brain death as death. This article also considers criticisms of brain death and rebuttals to those criticisms.

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Introduction

Public awareness of brain death is based largely on inaccurate media representations. In this article, I first review common examples of misrepresentation of brain death in the media. I then discuss historical aspects of the development of brain death criteria, review various criticisms voiced about the concept both after its introduction and to date, and discuss arguments in support of the concept of brain death. Lastly, ongoing efforts to address the most recent debates concerning brain death are discussed.

What Does the Public Know About Brain Death?

Portrayal of **medical topics in the media** provides public education and affects perceptions of and formation of opinions on these topics.^{1,2} An analysis of media coverage of “brain death” prior to 2016 revealed that misinformation was presented in 72% of articles.³ Imprecise use of medical terms and misrepresentation of brain death as a state of life or a form of neurological impairment rather than a form of death were the most common errors.³ In this study and another one based on newspaper articles published between 2005 and 2009, the actual medical meaning of the term *brain death* was explained in less than 4% of articles.^{3,4} Brain death as a prerequisite for organ donation (ie, patients who are declared brain dead are potential candidates for organ donation) was mentioned in less than a third of articles.^{3,4} Similarly, portrayal of brain death in film and television is misleading, with a complete understanding of brain death presented in only 13% of productions.⁵ Furthermore, *brain dead* is used colloquially,

often to refer to a person or action considered thoughtless.⁴ Examples of misinformation and imprecise use of brain death terminology are shown in the Table.

Table. Examples of Misinformation and Misrepresentation of Brain Death in Media

Type of Misinformation	Example	Source
Misleading information on brain death vs severe brain injury without delivery of complete definitions	“‘Hand of God’ Wakes Brain-Injured Girl From Coma”	<i>USA Today</i> ⁶ (05/13/2015)
Brain death not classified as death and instead referred to as “life support” or an “alive” state	“Mom Loses Battle to Keep Brain-Dead Baby on Life Support”	<i>USA Today</i> ⁷ (07/23/2014)
Failure to clarify that brain death equals legal death, including not mentioning the time of death	“That evening Mrs. Cregan was declared brain-dead. The family had her respirator disconnected the next morning, and she died almost immediately”	<i>New York Times</i> ⁸ (04/24/2005)
Implying scientific diagnosis of brain death without provision of details	“Husband Celebrates Miracle as ‘Brain Dead’ Wife Wakes Up in Hospital”	<i>Fox News</i> ⁹ (05/11/2011)
Colloquial use of brain death terminology	“Emmanuel Macron warns Europe: NATO is becoming brain-dead”	<i>Economist</i> ¹⁰ (11/07/2019)

Lack of adequate public education on brain death is further evidenced in studies of public understanding. For example, a survey of Ohio residents revealed that over 98% of respondents had heard of the term *brain death*, but only one-third believed that someone who was brain dead was legally dead, and over half classified coma as death instead.¹¹ An extensive literature review on public understanding of the dead-donor rule for organ donation revealed that there is a general lack of understanding of both biological and legal facts of brain death, as well as of the relation of brain death to organ donation.¹² Even among family members of patients who had been determined to be brain dead, only 28% could correctly define brain death.¹³

Historical Development of Determination of Death by Brain Death Criteria

“Death” in the case of irreversible coma. Traditionally, the moment when death occurred was marked by the cessation of heartbeat and respiration.¹⁴ But technological advances during the 1950s and 1960s, including the invention of positive-pressure mechanical ventilation,¹⁵ advances in intensive care medicine, and the first successful heart transplantation in 1967,¹⁶ called for a new conception of death. The questions these developments raised was whether patients with incurable, catastrophic brain damage should be artificially maintained with the aid of a respirator. Accordingly, in 1968, the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death published the original criteria for brain death, consisting of (1) unreceptivity and unresponsivity; (2) absence of movement, breathing, and reflexes; and (3) a flat

encephalogram in the absence of confounding factors that was unchanged at an interval of 24 hours or later.¹⁷ Despite the increasing recognition that irreversibly brain-damaged patients maintained by intensive care measures could **donate organs**, given developments in transplantation, the Harvard Committee was focused on a definition of brain death rather than on organ procurement.¹⁸ Their working criteria of brain death were initiated by the medical-ethical question of the right to die in the setting of irreversible coma. While focusing on medical criteria, the report also included consideration of legal cases that had questioned the time of death in irreversibly brain-injured individuals.¹⁷

Equivalence of brain death and traditional death. In 1980, brain death as a form of death was incorporated into the Uniform Determination of Death Act (UDDA),¹⁹ a recommended statute legalizing brain death (defined as “irreversible cessation of all functions of the entire brain”) as death equal to cardiorespiratory death. In 1981, a report by the President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, entitled *Defining Death: Medical, Legal, and Ethical Issues in the Determination of Death*, defined irreversible cessation of all brain function and loss of the integrative functioning of the organism as the main criterion of brain death, arguing that the brain is the body’s central integrator, without which the body inevitably would disintegrate even if supported by machines.²⁰ Brain death was accepted by the medical community as a form of death equivalent to traditional cardiorespiratory death, the difference being that a brain-dead person supported by a machine lacked the traditional visual signs of death.

An exact diagnosis of brain death. Medical **criteria for determination of brain death** were put forward by the American Academy of Neurology (AAN) in 1995 and updated in 2010.^{21,22} The AAN defined brain death as “irreversible cessation of all functions of the entire brain, including the brain stem.”^{21,22} Prior to determining brain death, the underlying reasons for coma, absence of brain stem reflexes, and apnea need to be understood. The diagnosis of brain death is thus primarily clinical. No other tests are required if the full clinical examination, including an apnea test, are completely and conclusively performed. If this examination cannot be accomplished (for example, in the setting of severe trauma to the face that precludes examination of eyes, pupils, cornea, and ears), confirmatory tests (eg, neuroimaging) are necessary. A clinical determination of brain death implies legal death.²³

Criticism of the Concept of Brain Death

Criticism of the concept of brain death immediately arose within both the medical and the philosophical-ethical community^{24,25} when the original criteria were introduced, because it is difficult to come to terms with a concept of death that abandons our long-cherished idea of a sensual perception of death and an exact point in time when death occurs. Even in the Harvard report, the difference between the previously sole criterion of cardiac death with visible cessation of heartbeat and respiration—and hence a visibly defined time point of death—and the lack of such signs with brain death, was recognized.¹⁷ Debates began about whether it was appropriate to accept brain death as death.²⁵

Philosophical-ethical objections. Philosophical-ethical objections to the concept of brain death were first prominently put forward by the philosopher Hans Jonas. He was concerned about the possibility that brain death might be used as a means of pragmatically redefining death, thereby freeing patients, their relatives, and medical

resources from the burden of an indefinitely prolonged coma and increasing the supply of organs for donation,²⁴ a criticism that has persisted.²⁶ A similar point of ethical criticism is that stopping life support might mean ending a human life for utilitarian reasons by regarding brain death as a convenient redefinition of death for the purposes of transplantation medicine.²⁷

Neurophysiological objections. Decisive for a revision of the understanding of brain death as equal to circulatory death was the recognition that neither complete bodily disintegration nor cessation of heartbeat necessarily ensue after brain death.²⁸ With refined artificial support, brain-dead bodies are able to maintain a series of functions, such as wound healing, gestation of a fetus, and sexual maturation—sometimes for long periods of time.²⁹ On this basis, the conclusion was drawn, especially by Shewmon, one of the most prominent critics, that brain death cannot simply be equated with circulatory death.²⁸

Solutions to the Understanding of Brain Death

Regulatory: abandoning the concept of brain death or developing a new rationale.

Abandoning the brain death concept²⁰ and returning to the concept of cardiac death would imply a medical-ethical dilemma with more far-reaching implications than the introduction of the concept of brain death itself. It would mean giving up to a large extent the progress and standards achieved in modern intensive care and transplantation medicine—a setback hardly to be imagined—and it would be ethically highly questionable. First, it could expose irreversibly brain-injured patients to conditions necessary to sustain organism functions (ie, mechanical respiration) and refuse them the right to die if not explicitly stated in predetermined living wills. Second, a reduced ability to donate organs for transplantation would mean that patients whose lives could be saved by the organ of a brain-dead patient who had declared a wish to donate while alive would be doomed to die due to a moral evaluation concerning the expanded concept of death.

A 2008 White Paper by the President's Council on Bioethics about the controversies over brain death³⁰ recognized the need to continually educate the public, respond to the evolving neurological standard, and clarify the relationship between determination of death and organ procurement. The 2 options up for debate—loosening the standard for determining death or abandoning the dead-donor rule (which demands that vital organs should only be taken from persons who are dead)—were both deemed unjustifiable and consequently rejected,³⁰ although the need to reexamine ideas and practices was recognized in light of technological and scientific advances.

Solutions on a philosophical-ethical basis. There are a number of suggestions for resolving debate over the equivalence of brain death with death. One approach is to focus attention on the death of a human being by understanding death not only as a biological event but also as an irreversible loss of the characteristics that define personhood, such as personality, identity, culture, religion, obligations to family and community, legal rights, and lifelong values.³¹ The absence of these capacities represents a condition in which the organism as a whole can no longer perform the work that is characteristic of a living human being.^{32,33} A diagnosis of brain death is determined by a permanent loss of the overarching neurological center that guides both physical and mental functions of a human, which means that the basis for personal being-in-the-world is irreversibly and irrevocably gone and hence that brain death equals death.³²

A second approach is recognizing that death no longer represents one single standard. Scientific and technical developments support broadening the definition of death, which, in many instances, represents a process with shifting boundaries rather than an event. Such a broadening of the definition of death occurred with the introduction of brain death and is supported by the recent survival of a 6-hour cardiac arrest.³⁴ Brain death is hence to be understood as a social construct in the dual sense of normative death, which occurs at “the onset of permanent cessation of functioning of the organism as a whole,” and ontological death, which occurs at “the onset of irreversible cessation” of the characteristics of the organism as a living human being.³³

Conclusion and Ongoing Developments

Brain death is a well-founded and widely accepted concept. However, **controversies persist** and often reach the public eye, which creates confusion and insecurity,³⁵ and misleading information in the media is common.³ Although major differences between and within countries exist in the procedures for diagnosing brain death,³⁶ efforts are under way to (1) establish uniform criteria, (2) develop systems to ensure that brain death determination is consistent and accurate, (3) respond to objections to determination of death by neurological criteria, and (4) improve public trust in brain death determination.^{37,38} The major conceptual debate—whether it is adequate to justify brain death as equivalent to traditional human death²⁸—will likely persist, as brain death is a social construct and, as such, will always be subject to criticism. But a return to a simple dichotomy of dead or alive is no longer justifiable. Death has evolved to have a broader meaning, of which brain death is a part.

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MEDICINE AND SOCIETY: PEER-REVIEWED ARTICLE

Death's Troubled Relationship With the Law

Brendan Parent, JD and Angela Turi

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 death⁹ and in how long to wait after circulatory death before procuring organs¹⁰ 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 care¹⁵ 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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MEDICINE AND SOCIETY: PEER-REVIEWED ARTICLE

Bringing Dying Out of the Hospital's Closet

Helen Stanton Chapple, PhD, RN, MSN, MA

Abstract

Why is the transition from “living” to “dying” not socially marked in the same way that death is marked? This question is addressed using classical anthropological theory, which highlights the significance of liminality, the transitional period during a rite of passage. Seriously ill and dying patients are subject to social vulnerabilities as they approach the end of life. Clinicians’ awareness of these factors may improve their patients’ care.

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Marking the Transitions of Life

Social norms develop partly to maintain communal cohesion in the face of potential disruption and change. We mark events that signify major life transitions (eg, weddings, funerals)—and even seasonal shifts—because they affect us collectively. We respond by spending time and treasure on gatherings, gifts, cards, and appropriate décor. These trappings are important not because they are functional in themselves, but because their mutually held meanings anchor us as a group of fellow humans. They provide reassurance as we navigate the uncertainties of life.

Rituals and traditions form around individual life changes that are clearly identifiable and have sufficient impact on the community at large. van Gennep famously described rites of passage that facilitate individual movement from one social category to another (eg, single to married).^{1,2} These rituals enable the group to formally acknowledge the change and to instantiate individuals in their new social roles.^{1,2} A key feature of such movement within the social body is the phenomenon of liminality, a point when the individual has left one category but has not yet crossed the threshold to the new one. In this liminal space, the individual has no clear place in the social system. She is neither one thing nor the other, while combining aspects of both.³

Clinicians often observe hospitalized patients whose condition seems to be shifting from “living” to “dying.” For those participating in the patient’s clinical journey, this transition is critically important. But it attracts virtually no social notice in the patient’s larger

world. Why should this be true? Several reasons are possible: (1) seriously ill hospitalized patients are already separated from their communities, their social roles suspended; (2) often the signposts of their current condition are inconsistent (eg, lab values improve despite increasing weakness); and (3) unlike the finality of death, the dying situation is stigmatized and does not abrade the larger social order enough to require a symbol-laden adjustment. I explore each of these facets in turn and discuss why marking the transition from living to dying would serve an instrumental purpose for clinicians even when it seems not to call for a specific response from the community at large.

Dying Is a Space of Seclusion

Turner teaches us that the in-betweenness of liminality is a place of social seclusion.³ Seriously ill patients occupy such a space. For now, they have no role in the social order, making them “structurally invisible.”³ They are literally stripped, devoid of the personal effects that signal who they are in the world. For society to notice them under these circumstances would be to violate their dignity. Likewise, their indeterminate status makes persons in transition potentially contaminating to society.⁴

To be in a liminal state renders individuals unclassifiable. When the social body cannot easily categorize its members, it becomes confused. Anomalous persons can pose a threat to the social order.⁵ Even in quotidian life, dying is felt to be private, exempt from public intrusion, and somehow untoward. When some public figures’ dying situations have been publicly acknowledged, such as those of John McCain and Barbara Bush, broad-based close scrutiny is rarely welcome.

Dying Is Difficult to Identify

Because US culture prizes rescue and medical advances, identifying the transition between living and dying for patients with serious illness becomes ever more challenging. What patient circumstances would signal to onlookers that the patient has crossed over from living to dying? Prognostic tools are legion but largely unreliable.^{6,7} **Medical advances and reimbursement** for them encourage “almost limitless uncertainty”⁸ about dying situations that continues to expand.⁹ Misidentification occurs as well. It is difficult for clinicians to acknowledge that persons who can look us in the eye could actually be dying. By the same token, many unresponsive patients, made so by their injuries or clinical interventions, can yet be fully restored to sentience if they are given time to heal or their sedation is reversed. Evidence of interactive cognitive activity can be powerful and potentially misleading for both families and clinicians.

Dying Is Not a Classification to Be Conferred Quickly, Due to Its Stigma

To call a patient *dying* demeans the patient who finds herself in a place designed as a bulwark against death. It is to make her “other” than “us,” something that clinicians are usually reluctant to do in the beginning. Furthermore, to do so can erode clinicians’ belief not only in their ability to **rescue persons from imminent death**, but also in the illusion of their own unlimited futures.¹⁰ Outside the hospital, dying is not a status that almost anyone openly embraces. And why should they? In polite society, dying and death are off the table as acceptable conversational topics, much like sex and personal income.¹¹

Marking certain life transitions is critical for maintaining the social order. As mentioned above, due to stigma, the suspension of critically ill patients’ social roles, and inconsistent signposts of their current condition, the transition of hospitalized patients

from living to dying does not merit communal attention. The public would be resistant to its proclamation. But for those in the clinical setting who are directly affected by the dying process, noticing and responding to it can have important instrumental uses.

Patients' Dual Liminality and Clinician Pain

As it happens, we can identify 2 distinct areas of liminality that relate to the transition from living to dying and from dying to death in a hospitalized patient. The first occurs when the patient is undergoing active diagnosis and treatment for serious illness, but she is not showing a decisive response. The second occurs later, when the clinicians name the patient's condition as dying.

For clinicians, the first of these liminal spaces is the most difficult. If a seriously ill but rescuable patient does not respond to the application of advanced interventions fairly promptly, clinicians see her as having entered an indeterminate space. While the larger society is oblivious, clinicians must face full on the ambiguity she represents. As the uncertainty persists over time, urgency mounts to resolve it. When liminality and uncertainty seem unending, so does the discomfort they bring.

Clinicians recognize this space as awkward, even if they cannot articulate the source of their discomfort. Often, they ascribe it to patient suffering,¹² regardless of whether the patient is actually in pain, and time's passage exacerbates their unease. They may call the care plan "futile" and doubt the wisdom of resource allocation. Moral distress is common. Once enough time has passed, this "ritual of intensification" reaches a tipping point and clinicians can determine that the patient is dying.¹³

At this point, a significant shift in orientation and in the care plan itself occurs. The team may discuss withdrawal of life support with the family, make a referral to palliative care or hospice, or write a do-not-resuscitate (DNR) order. In the eyes of the clinicians, the patient has completed a transition to the category of "unrescuable." To designate her as dying rescues the clinicians from the pain of liminality by surrounding the patient with a clear category.

Yet, in truth, the patient has entered a new area of liminality. The clinicians are relieved by the opportunity to enact a more appropriate care plan. But the patient's vulnerability as a liminal person persists. She officially embodies death in a place dedicated to its diminution. To be deemed unrescuable—indeed, dying—therefore puts the dying but still-living patient in some peril. Her new category enables her needs specifically as a dying patient to receive attention. But the agendas of others who "need the bed" for higher-status, rescuable patients can create conflict. Outside of hospice or palliative care, hospitalized dying patients may receive inconsistent or unstandardized care for which hospitals are not set up to hold themselves accountable.⁸

Bring Dying Out of the Closet

With an official acknowledgement of dying from the team, the new category becomes discussable among all the participants, with what Glaser and Strauss describe as "open awareness" and McQuellon and Cowan describe as "entering mortal time."^{14,15} Dying can come out of the hospital's closet. At no time will the clinicians have another opportunity to optimize the dying process for this patient and this family, to make it as meaningful for them as possible. If such open communication leads to a plan to withdraw life support interventions, clinicians (including social workers and chaplains) can help families honor the life that has been lived and mark the significance of its end.

Openness about the procedure, sharing of pictures and stories, opportunities for prayer, along with a visibly **comfortable patient** are helpful components of this process. It is important for clinicians to prepare families by sharing the unknowable facts, such as how the patient will react to the withdrawal and how much time will pass between the withdrawal and death. Families need assurance that any patient distress will be promptly managed and that the patient will be allowed to take as much time as she needs—death will not be hastened.¹⁶ Discrete “markers” of dying, such as a DNR order in the chart, may be less important than listening to the patient and the family and helping them orchestrate—and make the most of—the critical present in this moment.¹⁰

But because the hospital is organized around rescue as its most important task, its culture may regard an official designation of dying as an opportunity for closing down or minimizing involvement, perhaps of reassigning staff. Clinicians may see the withdrawal of life support as an opportunity to administer opioids without restraint in order to limit the patient’s—or the family’s or their own—suffering.¹⁷ Patients and families may fear abandonment by their physicians as a result of lack of closure.¹⁸

What is ethically important here is to notice the possibility for openness and social inclusion as clinicians reinterpret the patient’s condition. Acknowledging this countercultural liminal territory can clear the way to preparation, customization, and reaffirmation of the patient’s importance to those around her. The important ethical considerations in the transitions from living to dying to death include establishing consensus and full communication regarding the transition, enabling the comfortable patient to take her own time, and facilitating best practices concerning the dying process.

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ART OF MEDICINE

A Hidden Pandemic

Antonio Yaghy, MD, Lauren A. Dalvin, MD, and Carol L. Shields, MD

Abstract

By March of 2020, the COVID-19 pandemic had changed our lives. Shadowing this pandemic is another one that adversely affects clinicians' educations and well-being. This article features a digital photo painting and commentary.

Effects on Education

The 2020 pandemic changed the way health profession schools around the world teach knowledge and skills needed to become qualified clinicians. Most medical schools, for example, offer preclinical courses exclusively online.¹ But virtual learning solutions have limitations for clinical skill building: interactions between students and real patients is irreplaceable. With shortages of personal protective equipment, clinicians are left in dire need of protection, so it was a difficult but necessary decision to temporarily suspend bedside teaching until we achieve substantial decreases in new COVID-19 case numbers per day. Despite easing some shortages in personal protective equipment, this decision to replace real-world, live, on-site, human-to-human interactions with patients and their loved ones with virtual, online learning has led to loss of opportunities to directly model human dimensions of patient care.

Effects on Residency and Fellowship Training

Most programs, especially surgical specialty training programs, have been disrupted. Despite a surge in telehealth encounters to maintain patient access to care,² resident physicians and fellows lost opportunities to learn procedures and gain experience when the number of elective surgical procedures plummeted to prepare space for COVID-19 patients.³ Accredited programs are consequently challenged to assess their trainees' skill development and preparedness to enter independent practice.³ Moreover, lack of social contact among trainees due to physical distancing and in-person conference cancellations also makes educational and patient care experiences less fulfilling.

Effects on Clinicians' Well-Being

Several reports have assessed the pandemic's influences on clinicians' well-being.^{4,5,6} Psychological burdens of feeling overwhelmed, overworked, emotionally drained from losing patients or colleagues, and fearful of contracting the SARS-CoV-2 virus affect everyone, particularly nurses and physicians, who have frequent contact with patients.⁴ Before the pandemic's start, the **burnout rate** among in-training and practicing

physicians already exceeded 50%⁷ and is expected to increase.^{5,6} Witnessing patients' deaths, losing colleagues to the disease, and social isolation at and outside work are also painful. Emotional distress also affects clinicians who are not directly involved in COVID-19 patient care and can accompany the **moral distress** of not being able to provide care, perhaps due to unavailability of telehealth, travel restrictions, or elective procedure deferral.

Figure. *Uncertainty in Her Eyes*, by Antonio Yaghy



Media

Digital photo-painting.

The woman in the image represents any clinician during pandemic times: a nurse who's self-quarantining in her basement or garage out of fear of being an asymptomatic carrier who could transmit the virus to her loved ones, a medical student hoping to diagnose a patient, a resident on call, a fellow examining patients, or an attending physician in an intensive care unit. Two bars represent **physical distancing** that alone can negatively influence mental health. Although the woman is wearing a mask, one might easily recognize uncertainty and worry in her eyes.

This image not only seeks to raise awareness of the COVID-19 pandemic's effects on clinicians, but also serves as a call to imminently address the insufficiency of clinicians' personal protective equipment supplies and their overall well-being. National support is required for developing and integrating wellness programs that provide resources to help clinicians cope with pandemic-induced stress. Yet small actions can make big differences: be kind and acknowledge that we're all in this together. Although smiles on mouths behind masks aren't visible, sometimes smiles delivered with intention, sincerity, and compassion can be expressed with our eyes and be discernible.

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