Brain Death at Fifty: Exploring Consensus, Controversy, and Contexts

BY ROBERT D. TRUOG, NANCY BERLINGER, RACHEL L. ZACHARAS, AND MILDRED Z. SOLOMON

This special report is published in commemoration of the fiftieth anniversary of the “Report of the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death,” a landmark document that proposed a new way to define death, with implications that advanced the field of organ transplantation. This remarkable success notwithstanding, the concept has raised lasting questions about what it means to be dead. Is death defined in terms of the biological failure of the organisms to maintain integrated functioning? Can death be declared on the basis of severe neurological injury even when biological functions remain intact? Is death essentially a social construct that can be defined in different ways, based on human judgment? These issues, and more, are discussed and debated in this report by leading experts in the field, many of whom have been engaged with the topic for decades.

Until the mid-twentieth century, death was defined in terms of the failure of three critical organ systems: circulatory, respiratory, and neurological. In other words, a person was dead when found to be nonresponsive and without pulse or spontaneous respiration. The diagnosis was simplified by the fact that the loss of any one of these functions quickly led to the loss of the other two. Sudden cardiac arrest quickly led to unconsciousness and respiratory arrest, whereas massive head injury led to loss of respiration and subsequent cardiac arrest.

Two developments in the 1950s changed all this. First was the invention of mechanical ventilation supported by an intensive care unit. Where previously the loss of the three vital functions had been essentially simultaneous, mechanical ventilation made it possible to maintain respiration and circulation in a person who otherwise would have perished quickly from a brain injury that caused loss of spontaneous respiration. This development raised concern about the inappropriate use of ICU beds and ventilators for patients with brain injuries from which recovery was unlikely or impossible. The second development was organ transplantation. Organ transplantation usually requires the availability of “living” organs from bodies deemed to be “dead.” Patients determined to be dead by neurologic criteria and who have consented to organ donation via advance directive or whose surrogates have consensually been the ideal source of such organs, since death is declared while the organs are being kept alive by a ventilator and a beating heart.

The Harvard report on brain death. By the mid-1960s, many organizations around the world began to contemplate the concept of “brain death.” In the United States, this effort was led by Henry Beecher at Harvard Medical School, resulting in the publication of the 1968 Harvard report to determine brain death. Early responses to the report were varied and often passionate. A 1971 Hastings Center task force generally endorsed the call for a means to determine death by neurological criteria but did not reach consensus on all points. Some commentators felt that the question was a philosophical one, not one that could be settled by medical facts alone, and argued for going further than the Harvard report, by accepting the loss of higher brain function as a sufficient criterion to define death.1 Hans Jonas agreed that life support could be withdrawn from persons permanently unconscious, but criticized the Harvard committee for labeling such persons dead.2 In this essay set, we have invited Robert Veatch and Gary Balckin each to offer his reflections on the motivations and work of this seminal committee.

What is brain death? The Harvard report proposed a set of tests for determining when a patient is brain-dead, and in broad outline these tests are similar to those we use today.3 They have three components. First, they confirm that the patient is unconscious, that is, that there is no evidence that the person can perceive or respond to any stimuli. Second, they demonstrate the loss of key brainstem functions, the most important of which are the respiratory centers that drive spontaneous respiration. Third, they demonstrate that the condition is permanent by ruling out any potentially reversible conditions, such as drug intoxication or hypothermia. Conceptually, therefore, brain death can be thought of as “permanent apneic unconsciousness.”

Year after year, there are media reports about patients who have been diagnosed as “brain-dead” and who have apparently experienced miraculous recoveries. In every case, careful examination of the evidence has shown these reports to be false. To date, there has never been a case in which brain death was correctly diagnosed and the patient subsequently recovered any neurological function whatsoever.4 (This is why Alan Shewmon’s assertions in the Jahi McMath case, described below, will be so important if they are found to be correct.) Unfortunately, the term “brain-dead” has acquired a colloquial meaning, representing any sort of impairment of neurological functioning, from a severe brain injury or disorder of consciousness to a temporary lapse of memory. And even experienced reporters and editors may confuse brain death with other neurological states following brain injury. Inaccurate use of the term “brain dead” has contributed to public misunderstanding of this neurological state.

The Uniform Determination of Death Act. Following publication of the 1968 Harvard report, the concept of brain death slowly gained traction. Kansas became the first state to adopt the criteria in 1970. Over the rest of that decade, many states developed criteria in a patchwork and inconsistent fashion, making it possible to be legally alive in one state and legally declared dead in another. To resolve this confusion, in 1981 the President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research was formed to develop model legislation. Reflecting much state law, Alex Capron, the executive director of the commission, writes in this special report about the work of the commission and what it accomplished.

The Uniform Determination of Death Act, proposed by the President’s Commission and now adopted in some form by all fifty states, reads:

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

The UDDA specifies two different criteria for determining death: cardiopulmonary criteria and neurological criteria. These two criteria map onto the two main pathways for organ donation. In the brain death pathway, death is determined on the basis of neurological criteria, and the patient is declared dead while still on the ventilator and while the organs are being perfused and oxygenated. This permits the retrieval of all vital organs (heart, lungs, kidneys, liver, small bowel, and pancreas) under optimal conditions. In the donation after circulatory determination of death (DCDD) pathway, typically, patients who have suffered a devastating neurological injury but who do not meet criteria for brain death have life support withdrawn in a controlled fashion.7 They are then observed for the onset of pulselessness, which must occur within about an hour for the organs to be usable. Once pulselessness occurs, they are observed for an additional five minutes to be sure that the heart will not start again on its own (autoresuscitation). If this does not occur, they are declared dead and organ procurement begins. In this pathway, the organs are exposed to at least several minutes of hypoxic or ischemic injury, so typically only the organs usable for transplantation are the kidneys.

Are brain-dead donors dead? Much of the controversy about brain death since 1981 has revolved around the question of whether it is a manifestation of biological death.
Early responses to the 1968 Harvard report on brain death were varied and often passionate.
James Bernat has been the leading defender of this view. His original argument was that brain death quickly leads to the loss of functioning of the organism as a whole, such that brain death literally results in the disintegration of the body, regardless of the degree of medical support provided. This has been the primary criticism of this view and has developed a series of cases showing that the bodies of patients diagnosed as brain-death do not necessarily “disintegrate,” so long as they are provided with mechanical ventilation and tube feedings. His work indicates that such patients may retain integrated functioning, including growth and development, wound healing, infection fighting, and gestation of a pregnancy, such that some of these patients may continue to have biological survival for many years. Bernat acknowledges many of Shannon’s main arguments in this essay, but in this special report offers a modified argument for why brain death represents the loss of functioning of the organism as a whole. Shannon reviews the main elements of his critique of brain death and offers some thoughts about how these problems can be resolved.

Are DCDD donors dead? The central arguments in this area focus on Bernat’s distinction between the concepts of permanence and irreversibility. Permanence is understood as a situation that will progress to irreversibility in the absence of an attempt to reanimate it. “Irreversibility” implies that the situation cannot be reversed even if attempts are made to do so. In the context of DCDD, where death is declared five minutes after the onset of pulselessness, no one disputes the fact that at least some donors could be reanimated if such attempts were to be attempted. James Bernat argues that this area of concern is irrelevant on several grounds, most notably because all hospitalized patients in this situation are declared death by irreversible cardiac failure orders (meaning reanimation would not be attempted) and there is no evidence that reanimation can ever occur beyond five minutes. An offshoot of this argument concerns the grounds for why the permanence standard is conceptually flawed and, therefore, why we cannot assume that DCDD organ donors are dead at the time their organs are procured.

In the United States, DCDD protocols have largely been used only when life support is withdrawn in a controlled manner and with the consent of the patient’s surrogate. Some European health care systems have been experimenting with a more aggressive form of DCDD, where patients who have experienced unexpected cardiopulmonary arrest out of the hospital are enrolled in protocols to preserve their organs for transplantation once emergency response physicians determine that their chance for survival is nil. Iván Ortega-Deballon and David Rodríguez-Arias examine one of the fundamental ethical issues of this approach: with patients who suffer cardiac arrest outside of the hospital, when it is acceptable to stop trying to save the life of the patient and shift the purpose of the resuscitation to saving the patients for transplantation? Why does it matter? In response to the views that neither brain-dead nor DCDD organ donors are “really” dead, some scholars have argued that the problem is not with the criteria themselves but with the understanding of the purpose of the so-called dead donor rule, which requires that donors be dead before their organs are procured. Three scholars address this issue: David Magnus offers the bedrock ethical commitment of the transplantation enterprise. He points out that, regardless of the validity of the ethical arguments, any violation of the rule would be considered voluntary euthanasia, currently prohibited in the United States.

David Rodríguez-Arias and Michael Naz-Collins explore these issues from the opposite perspective—that we have a fundamental obligation to inform the public about whether our practices conform with the dead donor rule while at the same time pointing out ways in which the DRR may work against the interest of patients who wish to be donors. They also discuss data that they believe show that the public is much less concerned about maintaining the DRR than health care professionals may assume.

Brain death, public policy, and the law. Debates about whether organ donors are dead have premised a biological understanding of what it means to be dead. While we commonly think about death in biological terms—the death of the body—human death means more than the death of the biological organism. When a person dies, their esophagus disappears, and others’ experiences of them change. Those who continue to live mourn the loss of more than a body. So some scholars have questioned why we privilege a purely biological understanding of death. Instead, they argue that death is experienced as both a biological and a social process, involving rituals such as funerals, a period of mourning, the reference to a surviving spouse as a “widow” or “widower,” and other social roles. Death is understood as an event with many other sequelae. Therefore, the definition of death should reflect both biological and social factors. In addition, under what conditions all patients, or some groups may not hold the same values concerning when death occurs.

Along these lines, Thaddeus Pope provides a comprehensive review of the legal status of brain death, pointing out that the number of legal challenges has been rapidly increasing in recent years. Seema Shah examines the legal theories undergirding the condition of brain death and considers the connotations of the characterization of brain death as a “legal fiction” and whether “legal status” is a better way to capture where brain death lies in relation to other neurological states. Laine Ross argues that individuals should be allowed to choose their own definition of death within a range of options. Courteney Campbell explores how religion and culture shape our experience of personal identity and death. Arthur Caplan offers the perspective of a bioethicist who has long observed debates over the end of continuation of life, arguing for how these issues should be viewed in context.

Much of the controversy about brain death since 1981 has revolved around the question of whether it is a manifestation of biological death.

One of us (Robert Truog) provides the background to the case. Alan Shewmon is a neurologist who examined McMath and reviewed her medical records, as well as videos made by her family recording movements that they and Shewmon perceive as purposeful. He offers provocative evidence that he believes shows she was not dead at the time he examined her, raising questions about whether the medical community may not always be in agreement as to whether diagnostic criteria need be modified to assure irreversible death. Finally, Michele Goodwin examines how race, class, and cultural considerations shape how we interpret the interpersonal and legal conflicts in cases such as this and how to improve the outcomes of these cases going forward.

James Bernat has been the leading defender of this view. His original argument was that brain death quickly leads to the loss of functioning of the organism as a whole, such that brain death literally results in the disintegration of the body, regardless of the degree of medical support provided. This has been the primary critique of this view and has developed a series of cases showing that the brains of patients diagnosed as brain-dead do not necessarily “disintegrate,” so long as they are provided with mechanical ventilation and tube feedings. His work indicates that such patients may retain integrated functioning, including growth and development, wound healing, infection fighting, and gestation of a pregnancy, such that some of these patients may continue to have biological survival for many years. Bernat acknowledges many of Shewmon’s main points, but he believes that this special report offers a modified argument for why brain death never represents the loss of functioning of the organism as a whole. Shewmon reviews the main elements of his critique of brain death and offers some thoughts about how these problems can be resolved.

Are DCDD donors dead? The central arguments in this area focus on Bernat’s distinction between the concepts of permanence and irreversibility. Permanence is understood as a situation that will progress to irreversibility in the absence of an attempt to reverse it. “Irreversibility” implies that the situation cannot be reversed even if attempts are made to do so. In the context of DCDD, where death is declared five minutes after the onset of pulselessness, no one disputes the fact that at least some donors could be resuscitated. This was to be attempted. James Bernat argues that this area of consensus is irrelevant on several grounds, most notably because all hospitalized patients in this situation have do-not-resuscitation orders (meaning resuscitation would not be attempted) and there is no evidence that resuscitation can ever occur beyond five minutes. Ar-tificially prolonging the course for why the permanent death standard is conceptually flawed and, therefore, why we cannot assume that DCDD organ donors are dead at the time their organs are procured.

In the United States, DCDD protocols have largely been used only when life support is withdrawn in a controlled manner and with the consent of the patient’s surrogate. Some European health care systems have been experimenting with a more aggressive form of DCDD, where patients who have experienced unexpected cardiopulmonary arrest out of the hospital are enrolled in protocols to preserve their organs for transplantation once emergency response physicians determine that their chance for survival is nil. Iván Ortega-Deballon and David Rodriguez-Arias examine one of the fundamental ethical issues of this approach: with patients who suffer cardiac arrest outside of the hospital, when is it acceptable to stop trying to save the life of the patient and shift the purpose of the resuscitation to saving the organs for transplantation? Why does it matter? In response to the views that neither brain-dead nor DCDD organ donors are “really” dead, some scholars have argued that the problem is not with the criteria themselves, but with the underlying assumptions of the so-called dead donor rule, which requires that donors be dead before their organs are procured. Three scholars address this issue. David Magnus describes how building a bedrock ethical commitment of the transplantation enterprise. He points out that, regardless of the validity of the ethical arguments, any violation of the rule would be considered voluntary euthanasia, currently prohibited in the United States.

David Rodriguez-Arias and Michael Naim-Collins explore these issues from the perspective of the donor’s own concern. They believe we have a fundamental obligation to inform the public about whether our practices conform with the DNR while at the same time pointing out ways in which the DNR may work against the interest of patients who wish to be donors. They also discuss data that they believe show that the public is much less concerned about maintaining the DNR than health care professionals may assume.

Brain death, public policy, and the law. Debates about whether organ donors are dead have assumed a biological understanding of what it means to be dead. While we commonly think about death in biological terms—the death of the body—brain death means more than the death of the biological organism. When a person dies, their essence disappears, and others’ experiences of them change. Those who continue to live mourn the loss of more than a body. So some scholars have questioned why we privilege a purely biological understanding of death. Instead, they argue that death is experienced as both a biological and a social process, involving rituals such as funerals, a period of mourning, the reference to a surviving spouse as a “widow” or “widower,” and the issuance of a death certificate, among many other sequalae. Therefore, the definition of death should reflect both biological and social factors because they consider death to be a social construct.

Along these lines, Thaddeus Pope provides a comprehensive review of the legal status of brain death, pointing out that the number of legal challenges has been rapidly increasing in recent years. Seema Shah examines the legal theories underlying the condition of brain death and considers the connotations of the characterization of brain death as a “legal fiction” and whether “legal status” should be a clearer way to capture where brain death lies in relation to other neurological states. Laine Ross argues that individuals should be allowed to choose their own definition of death within a range of options. Courtenay Campbell explores how religion and culture shape our experience of personal identity and death. Arthur Caplan offers a perspective of a bioethicist who has long observed debates over the end of continuation of life, arguing for how these issues should be viewed in context.

The future. A recent cover of Science magazine featured chimp that had been genetically engineered to remove the immune system. He claims that the opponents are using them as a source of organs for xenotransplantation into humans. The development of virtually inexhaustible sources of transplantable organs, through xenotransplantation or other technologies, would make most of the areas of controversy and concern covered in this report irrelevant, by eliminating the need for human donors to serve as a source of transplantable organs. Two essays in this issue explore various facets of the new challenges that these advances would bring. Lesley Sharp argues for how we should think about the “other” animals involved in the xenotransplantation enterprise, and Sheila Jasani critically examines these advances through the lens of societal participation and consent, suggesting mechanisms for assuring societal involvement in scientific developments that will surely fundamentally change the ways that we view life, death, and our own humanity.

The case of Jahi McMath. Among the many recent challenges to the concept of brain death, the case of Jahi McMath has certainly received the most attention. McMath was an adolescent girl who sustained severe neurological injury following complications from surgery in December 2013.8 McMath was an adolescent girl who sustained severe neurological injury.8 Her family refused to accept the diagnosis, and after a legal battle they were able to take custody of her body and move her to New Jersey, whose brain-death statute permits families to object to this determination and, further, permits the enrollment of the patient in state-funded Medicaid to cover long-term services and supports.9 Much of the controversy about brain death since 1981 has revolved around the question of whether it is a manifestation of biological death.

One of us (Robert Truog) provides the background to the case. Alan Shewmon is a neurologist who examined McMath and reviewed her medical records, as well as videos made by her family recording movements that they and Shewmon perceive as purposeful. He offers provocative evidence that he believes shows she was not dead at the time he examined her, raising questions about whether the medical staffs may not always be in direct contact with the patient in situ. Furthermore, the diagnostic criteria need to be modified to assure irreversibility. Finally, Michele Goodwin examines how race, class, and cultural considerations shape how we interpret the interpersonal and legal conflicts in cases such as this and how to improve the outcomes of these cases going forward.