

Published in final edited form as:

JS C Med Assoc. 2011 August; 107(4): 146–149.

### BRAIN DEATH, CARDIAC DEATH, AND THE DEAD DONOR **RULE**

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> Everyone knows what "brain dead" means: a person whose brain no longer works is brain dead. The term is used so frequently and in so many different contexts that we should not be surprised that two thirds of people incorrectly believe that someone who is brain dead is not legally dead, and more than half believe that a comatose patient is brain dead. Such misunderstandings and confusions make it easy to comprehend why there is still a good deal of controversy about the relationship between determination of death and organ donation. At a more fundamental level, however, there is good reason to question the logic and rationality of our current definitions of death and related concepts, such as the so-called "Dead Donor Rule" (DDR), which lies at the heart of current organ procurement policy.<sup>2</sup> The controversy surrounding these issues has become heated enough that clinicians should understand the basis of the controversy and how it might affect their practices.

I will make several points in this discussion: When we pronounce individuals dead by neurological criteria, they are not really dead. When we pronounce individuals dead by neurological criteria, they are not really dead.

### **BACKGROUND**

The era of clinical organ transplantation began in 1954 when Joseph Murray transplanted a kidney from one identical twin into another. Liver and heart transplantation, both of which require organs that could be obtained only from people who are already dead, became realities, respectively, in 1963 (Thomas Starzl) and 1967 (Christiaan Barnard). Survival rates after both liver and heart transplantation remained low until the introduction of cyclosporine in 1980. This drug, in combination with existing less effective immunosuppressive drugs, markedly increased survival rates and led to rapid expansion of the organ transplantation field. This, in turn, generated demand for increasing numbers of organs, especially from dead individuals, producing a paradox: "the need for both a living body and a dead donor." The groundwork required to resolve this paradox had been laid in 1968 by Henry Beecher and the Harvard Ad Hoc Committee's proposal that a person could be diagnosed as dead when there was irreversible cessation of the function of the entire brain.<sup>4</sup> This status has since become known as brain death, and has been codified in the law of every state by their adoption of the Uniform Determination of Death Act (UDDA) after its promulgation in 1981:

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.

There is only one kind of death — when one is dead, one is dead — but death can be determined in the two different ways described in the law. A brain dead individual who is warm and pink with heart beating and lungs ventilating is just as dead, legally, as an individual whose body has turned cold after the heart has permanently stopped beating.

The DDR is the formalization of the widely held belief that it is wrong to kill one person to save the life of another, leading to the conclusion that people should already be dead before vital organs are removed, an act that would certainly kill them. The DDR is neither a law nor a regulation — it is a description of an ethical norm: an organ donor must be dead before vital organs are removed. The UDDA in combination with the DDR assures patients, families, physicians, and other health professionals that a patient who is brain dead is in fact dead, making removal of organs for life-saving transplantation legally and ethically acceptable.

### **BRAIN DEAD DONORS ARE NOT REALLY DEAD**

The current system has been in effect for over 30 years, and seems to be working satisfactorily. Yet, there remains considerable controversy about the validity of the DDR, to the point that some have recommended that the DDR be abandoned.<sup>5</sup> First, the diagnosis of brain death may be unreliable. Many patients who meet all the criteria for brain death do not in fact have "irreversible cessation of all functions of the entire brain," because some of the brain stem's homeostatic functions remain, such as temperature control and water and electrolyte balance.<sup>6</sup> To counter this observation, some argue that not all the functions of the brain need to be lost for a patient to be dead, only those that are critical to maintaining integration of the body functions; loss of these critical functions will inevitably lead over hours or days to cardiac arrest, even with continuing intensive life-support.<sup>7</sup> Yet, even though this is often true, the bodies of some patients who meet all the criteria for brain death can survive for many years with all their bodily functions intact except for consciousness and brain stem reflexes.<sup>8</sup>

### DONORS AFTER CARDIAC DEATH ARE NOT REALLY DEAD

Over the past 15 years, as the shortage of organs for transplantation has become more acute, there has been an increasing emphasis on donation after cardiac death (DCD). Patients who have severe brain injuries but who are not brain dead may still be organ donors if the patient, by advance directive, or the patient's family decides that life support should be withdrawn. After that decision is made, consent for organ donation is obtained. The patient is brought to the operating room, life support is withdrawn, and when the heart stops after a few minutes to an hour without ventilation or other support, the physician observes the patient for a few minutes to ensure that the heart does not start beating again spontaneously. If there continues to be no circulation for 2–5 minutes, the physician pronounces the patient dead. At this point, the transplant team enters the operating room and removes organs, usually the kidneys and liver, from the now dead patient.<sup>9</sup>

The UDDA requires "irreversible" cessation of circulatory and respiratory functions, yet, under the circumstances of DCD, clearly the heart has not irreversibly arrested, as cardiopulmonary resuscitation ordinarily can restore cardiac function after an arrest of 10–15 minutes or longer. To avoid violating the DDR, it has been argued that a suitable substitute for the term "irreversible" is "permanent," and if there is no intention to revive the heart, then the absence of function is permanent and the patient can be pronounced dead. <sup>10</sup> The only reason this rhetorical device is needed is to satisfy the DDR — if there were no

DDR, semantic manipulation would not be necessary. Moreover, if there were no DDR, organ donation would still be ethical because the decision to remove life support was made appropriately and consent for organ donation was properly obtained.

### WITHDRAWING LIFE SUPPORT CAUSES DEATH

Ever since the New Jersey Supreme Court's decision in the Karen Ann Quinlan case in 1976, a generally accepted ethical norm is that withdrawal of life support does not cause the patient's death, rather, withdrawing life support allows the patient to die — it is the disease that causes the patient's death, not the physician. Yet, this view cannot be correct, because the agent that is the proximate cause of the patient's death is the physician. Miller and Truog illustrate this by hypothesizing two patients who are in identical clinical situations; both are ventilator-dependent. One patient is disconnected from the ventilator by someone who wants to kill the patient, and the other is disconnected by a physician responding to the patient's request to remove unwanted end-of-life technology. It is patently inconsistent to claim that in the first case, death was caused by the person who disconnected the ventilator (thus being guilty of murder), yet in the second case, the death was not caused by the physician who disconnected, but by the disease. There is obviously an enormous moral difference between the two acts, but the agent causing death in both cases is the person who withdrew support.

Although withdrawal of life support (not the patient's disease) causes death, it is not a legally or morally culpable act. The claim that if withdrawing life support causes death, it is unethical is a non sequitur because the central issue here is not causation, but is the overriding principle of respect for the patient's autonomy. The principle of self-determination as it applies to one's own body has long been recognized in U.S. law. The right of self-determination can be exercised by a competent person directly or through an advance directive, or by a proxy appointed by the patient or a legally authorized surrogate agent. This process is firmly established in ethics and law, and is not altered or undermined by recognizing that withdrawal of life support is the cause of death. Thus, the physician who withdraws life-support causes the patient's death, but is neither legally nor morally culpable.

## RECOVERING VITAL ORGANS FROM THE NEARLY DEAD IS ETHICALLY ACCEPTABLE

If brain dead patients are near death but not really dead, recovering vital organs is nevertheless ethically well-grounded. Since 1968, the diagnosis of brain death has been understood to validate both withdrawal of life support and recovery of vital organs, and this does not change at all when brain dead individuals are understood to be in a state of irreversible coma, although still alive — they still satisfy the conditions of the UDDA. Given valid consent for withdrawing life support and for organ donation, if it is acceptable to cause a brain dead patient's death by withdrawing life support, then it logically must be acceptable to cause the patient's death by recovery of vital organs before withdrawal of life support. The cause of death is irrelevant because the ethics of self-determination and informed consent that underlies withdrawal of life support are of paramount importance.

In the case of DCD, the same rationale is valid if the patient is near death and supported by artificial ventilation. If the patient or her proxy-surrogate decision maker exercises the right of self-determination by first consenting to withdrawal of life support and then consenting to recovery of vital organs, a chain of events is set in motion that causes the death of the patient. No harm or wrong is done to the patient or to others by this chain of events, so they should not be seen as a criminal act.

The facts that brain dead patients are not really dead before organs are recovered and that DCD donors are imminently dying but not yet dead means that current practices of organ donation from both brain dead and DCD donors are not consistent with the DDR, yet these practices are ethically and legally well-grounded. Once this is recognized and accepted, the DDR, being neither a statute nor a regulation, can be discarded and physicians need not feel as though they are ethically or legally at fault.

### A HIGHER BRAIN STANDARD OF DEATH

Clearly, the DDR is incoherent with respect to brain death as currently defined. It could be could be saved as ethical policy, however, by changing the standard from the UDDA's "irreversible cessation of all functions of the entire brain, including the brain stem" to a higher brain standard, that is, to permanent loss of consciousness, without requiring loss of brain stem function. The single biggest problem with this move, however, is that a higher brain definition of death is no less counterintuitive than the whole brain definition. For example, patients in a persistent vegetative state would fall into this category because they are permanently unconscious, but they breath spontaneously, do not require artificial ventilation, have normal bodily functions, and have wake-sleep cycles in which the eyes remain open in a state of apparent wakefulness and close during what appears to be sleep. These patients do not even vaguely resemble a state of death.

A higher brain definition of death also carries a great deal of diagnostic uncertainty, as new sophisticated technologies have shown unsuspected cognitive function in patients believed to be permanently unconscious. <sup>12</sup> Moreover, there have been major advances in recent years in treating brain injuries, which could eventually lead to the recovery of some such patients. <sup>13</sup> There seems to be no sense in which a patient who is "permanently unconscious" could be understood to be "dead." A higher brain standard of death would provide no more solid support for the DDR than does the whole brain standard.

# IS ABANDONMENT OF THE DDR FEASIBLE? CLAIMS AND COUNTERCLAIMS

The DDR is needed as a safeguard against removal of organs prematurely under the pressure of increasing the number of organs available for transplantation. In answer to this, it is not the DDR that prevents such abuses, rather, the real safeguards are three requirements that are currently in effect: a valid decision to withdraw life support in patients who are near death, valid consent of the patient or the patient's proxy/surrogate, and no conflicts of interest in the consent process, that is, no member of the transplant team may participate in caring for potential donors or obtain consent for donation. These conditions are already part of the organ procurement system, with or without the DDR. The DDR serves no necessary protective purpose.

Public trust in the organ donation and transplantation system requires certain assurances, such as: withdrawal of life support does not cause a patient's death but is simply allowing the patient to die; brain death is identical to circulatory death; and cessation of cardiac function in DCD donors is irreversible, so is consistent with actual death. All of these alleged requirements for public trust are fictional. If it were true that public trust would be undermined without them (with the consequence of decreased organ donation), the DDR arguably should be retained. In fact, however, there is no objective evidence that public trust requires belief in these evasions, but there is suggestive evidence to the contrary. For example, it is well known that some patients who have been declared dead by neurological criteria continue to have some residual brain function, therefore are not legally dead, yet there has been no public outcry against donation, suggesting that donation by patients who

are not dead but are nearly dead is acceptable to many if not most people. <sup>14</sup> Moreover, there is some direct evidence for this: in one survey, a substantial number of respondents would allow donation of organs even when they knew that the dying donor was not actually dead. <sup>1</sup>

### CONCLUSION

The rationale for abandoning the DDR has radical theoretical implications: the physician who withdraws life support causes the patient's death (not the underlying disease), brain death does not constitute death of a person, and surgeons recover organs from DCD donors who are dying, not actually dead. Practically, however, repealing the DDR has but a few implications. The only change in organ donation by brain dead organ donors would be the absence of declaration of death before organs are recovered. In DCD donation, there would be no declaration of death before organs are recovered, which would do away with the sometimes lengthy delays while waiting for cardiac arrest and then waiting for declaration of death, resulting in shorter warm ischemic times and healthier organs for transplantation. It might also expand the organ donor pool by adding back the donors who fail the current time requirements for pronouncing death.

We do not know whether abandoning the DDR would lead to an overall increase or a decrease in organ donors — there are no data one way or the other. But that is a secondary issue. The main purpose in leaving it behind is to honor and pursue truth. The same reason leads us to require physicians to be honest and forthcoming in dealing with patients and to discipline physicians who give false, deceptive, or misleading testimony on a judicial witness stand. Once physicians understand that brain dead and DCD donors are not really dead, they could claim otherwise only at the cost of undermining integrity and diminishing character.

The driving force behind rejecting the DDR is the ethical norm that physicians should not cause the death of a patient. Yet, we do exactly that when we ethically and justifiably withdraw life support at the request of the patient or proxy-surrogate, or when we remove organs from brain dead or DCD donors who are not actually dead. Once we recognize that the ethical prohibition against physicians causing death of a patient is not absolute and that the guiding principles are respect for patients' self-determination and voluntary informed consent, we can withdraw life support in intensive care units and recover organs from consenting donors without appeal to the DDR and its underlying fictions. Abandoning the DDR will eliminate all of the public's and health care professionals' confusion and misunderstanding about definitions of death and deciding when someone is dead. We could then return to the traditional single standard of death that is well understood by everyone: the irreversible absence of circulation.

### **ABBREVIATIONS**

**DCD** Donation after Cardiac Death

**DDR** Dead Donor Rule

**UDDA** Uniform Determination of Death Act

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