Difficulties of Determining Death: 
What Should We Do About the ‘Dead Donor Rule’?

Introduction

My task is to offer a critical overview of the difficulties of determining death in the context of vital organ procurement and to consider the ethical implications of either maintaining the Dead Donor Rule (DDR) or pursuing alternative ways to obtain vital organs for transplantation.

As we approach this topic, it is important to keep in mind the widespread, perhaps universal, fear of a premature, mistaken declaration of death. Historically, this was expressed in the fear of being buried alive as well as the fear of burying others alive. For example, Edgar Allan Poe, the 19th century originator of the detective story and author of horror stories, among other kinds of works, wrote a story entitled The Premature Burial. For Poe this topic was a long-standing fascination and even obsession, based on tales he had heard or read about people being buried or entombed alive. It appears in at least a half-dozen of his stories. The Premature Burial itself was probably inspired by the publicity surrounding the exhibition of a ‘life-preserving coffin’ at a fair in New York City in 1843:

To be buried while alive is, beyond question, the most terrific of [the] extremes which has ever fallen to the lot of mere mortality. That it has frequently, very frequently, so fallen will scarcely be denied by those who think. The boundaries which divide Life from Death, are at best shadowy and vague. Who shall say where the one ends, and where the other begins?
We know that there are diseases in which occur total cessations of all the apparent functions of vitality, and yet in which these cessations are merely suspensions, properly so called. They are only temporary pauses in the incomprehensible mechanism. A certain period elapses, and some unseen mysterious principle again sets in motion the magic pinions and the wizard wheels. The silver cord was not forever loosed, nor the golden bowl irreparably broken. But where, meantime, was the soul?¹

Now, long after the development of technologies that can help us better determine who is on which side of the boundary dividing life from death, fears remain, often in the context of organ procurement.

Modern day versions of Poe’s horror story often focus on the removal of organs following a mistaken declaration of death. Following is an alarming story that comes from a state and federal investigation of a 2009 case at St. Joseph’s Hospital in Syracuse, New York—the federal investigative report was not made public until 2013. In this case, doctors were about to remove organs from a 41-year-old woman, Colleen Burns, who had already been declared dead but who suddenly opened her eyes under the bright lights of the operating room. Many physicians, nurses, and others made a series of mistakes that led to this fiasco, beginning with the failure to adequately address what had brought her to the hospital (a drug overdose and its effects). Then error on error landed her in the operating room for the removal of her organs. These compounded errors, at least five or six, included insufficient testing to ensure that the drugs had cleared her system, too few brain scans, lack of attention and response to a nurse’s suggestion that the woman was still alive, and a failure to examine other signs, such as curled toes and respirator resistance. When hospital personnel informed the family that Ms. Burns was dead (brain dead), the family authorized the removal of life support systems and donation of her organs for transplantation. Later, reviewing the records, an outside physician noted that the woman had been given a sedative “to the point that she would be non-reactive”: “If you have to sedate them or give them pain medication, they’re not brain dead and you shouldn’t be harvesting their organs.”²

For all these mistakes, the hospital was fined only $6,000.00—perhaps because it appeared that the woman was not harmed. She committed suicide sixteen months later, but there appears to be no connection between her suicide and the hospital’s earlier egregious mistakes. Ms. Burns’ mother indicated that her daughter was already so depressed that this incident “really didn’t make any difference to her”.

It is easy to view this case as a failure to adhere to established protocols for determining brain death before making a declaration of death and removing organs. Such a failure indicates the need for better professional education about determining death by neurological standards. Not surprisingly, the state ordered the hospital to hire a consultant neurologist to educate its staff on brain death criteria. But suppose, as many have argued, that these criteria are themselves unsound and the entire conception of brain death is deeply flawed. If so, then it is not simply a matter of educating physicians and other health professionals so they can more reliably apply these criteria. Patients may be wrongly declared dead in violation of the Dead Donor Rule even when established protocol is carefully followed. If the neurological standards for determining death and the underlying conception of brain death are flawed, how should this affect organ procurement, including the process and content of informed consent to donation (as provided in this case by Ms. Burns’ mother)?


The Dead Donor Rule (DDR)

The Dead Donor Rule (DDR), as John Robertson sees it, “is a centerpiece of the social order’s commitment [including the medical profession’s commitment] to respect persons and human life”. It also serves as the ‘ethical linchpin’ for the system of voluntary organ donation, based on trust.

The DDR is both permissive and restrictive. It allows us to take vital organs from dead persons with their consent or their next of kin’s consent. But it also prohibits taking vital organs from living persons, even with their consent: We may not kill people in order to take their organs, and we may not kill people in the process of taking their organs.

The DDR and its operation presuppose that it is possible to determine the status of persons as living or dead and that, in contrast to Poe’s concern, the line between life and death can be reliably drawn for purposes of removing vital organs for transplantation. Being on one side or the other of the line affects people’s legal and moral status. If people are dead, they cannot be harmed—vital organ removal does not set back their interests (in Joel Feinberg’s language). A declaration of death by appropriate medical personnel is a speech act, performative speech, which changes an individual’s moral and/or legal status. The physician or physicians (as authorized by law) can declare or pronounce death (after determining that it has occurred). In describing (or putatively describing) a biological reality, this speech act assigns an individual to a particular status—that of a dead person—and thus alters the structure of the legal/moral rights of and obligations to that individual. A wide variety of actions can follow a declaration of death, from burial to payment of life insurance. The declaration of death also serves a gate-keeping function for organ donation: Post-mortem removal of vital organs for transplantation now becomes a possibility, assuming appropriate consent.

When it became possible in the mid-1950s to transplant organs, kidneys could be transplanted from living donors, and vital organs could be removed for transplantation from dead individuals, who at the time were declared dead by conventional cardiopulmonary standards. By the mid-to late 1960s, there was interest in increasing the number of potential organ donors and improving the viability of donated organs by redefining death or updating the criteria for determining death to include brain-oriented formulations. International conversations among physicians and scientists, with some input from other professionals, led to the development of the concept of brain death and criteria and measurements for determining when it occurs.

An important milestone in this process was the 1968 report of the Harvard committee to examine “the definition of brain death”, which offered a “new criterion for death” (irreversible coma). It identified two reasons for a new definition and criteria, growing out of recent technological developments. One reason focused on the care of patients: “Improvements in resuscitative and supportive measures have led to increased efforts to save those who are desperately injured,” sometimes with “only partial success” and major and irreversible brain damage, creating great burdens for patients, their families, and hospitals, as well as for others in need of hospital beds.

The second reason focused on the way “obsolete criteria for the definition of death can lead to controversy in obtaining organs for transplantation”. This reason, stated gingerly in the report, was discussed among members of the Harvard committee and others in more provocative ways: “Can society afford to lose organs that are now being buried?” Clearly, there was also an interest, as Martin Pernick puts it, in “defending the entire medical profession against the public perception that transplant surgeons were organ-stealing killers”. This second reason presupposed the Dead Donor Rule—we can only remove vital organs from deceased individuals. Hence, it is
important to have brain death and other criteria for determining when death occurs. We will examine this reason in detail below.

The first reason concerned what can be called the Dead Patient Rule. At the time, many felt that we needed “a ‘dead patient rule’ for turning off mechanical ventilators”. However, we soon overcame that limitation and set standards and procedures for determining when it is ethically justifiable to withhold or withdraw ventilators and other medical technologies from dying (though not yet dead) patients. Many bioethicists in early 1970s expected, as Robert Veatch has noted, to continue wrangling for a long time about decisions to withhold or withdraw medical procedures in order to let patients die. By contrast, many thought—and I was one of them—that the determination of death in general and for deceased organ donation in particular was more or less settled, perhaps because it seemed to rest on a biological foundation identified and agreed upon by scientists and physicians.

However, in some countries, such as the U.S., the standards and procedures for withholding and withdrawing life-prolonging treatments now enjoy a wider consensus and have greater stability than do the standards and procedures for determining death in the context of deceased organ donation. Indeed, we now face a crisis about the Dead Donor Rule in part because of difficulties in determining death, with the resultant uncertainty about whether we are in fact killing people to take their organs or through taking their organs.

I will use two major poets to partially frame this discussion, and I will return to these frames later. Seamus Heaney described the task of the poet as “undeceiving the world” and in the Four Quartets T. S. Eliot observed that “human kind cannot bear very much reality.” These themes bear on the ethics of proposals to address problems in the DDR.

Three Practices of Post-Mortem Organ Removal for Transplantation

The crisis about the DDR arises in three different contexts and practices of obtaining deceased donor organs. Each raises somewhat different problems, but all three face significant challenges, on the grounds that they usually or often violate the DDR or that we cannot know with enough certainty that they are not violating that rule.

According to the Uniform Determination of Death Act, “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,” as determined by the application of “accepted medical standards”. This act has been adopted in some form throughout much of the U.S., and states that have not explicitly adopted it through legislation generally operate with both standards for determining death.

Donation after Neurological Determination of Death (DNDD)

Most transplanted organs come from brain dead donors, as determined by neurological standards. A large number of kidneys in some countries—for instance, the U.S. and Japan—come from living donors, but most kidneys and all vital organs—hearts, livers, and lungs (except for portions of livers or lungs)—come from donors who are declared dead, usually by neurological standards.

As of August 2013, available statistics indicated that since 1988 in the U.S., there had been just over 283,000 organ donors—just over 124,000 were living donors, while more than 158,000 were deceased donors. Most were declared dead by neurological standards, and all were deemed to meet the Dead Donor Rule. Over that same twenty-five-year period, these donations enabled about

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575,000 organ transplants. Just over 124,000 organs, mainly kidneys, came from living donors, and over 450,000 organs came from deceased donors—deceased donors usually provide more than one organ (in the U.S., an average of under three per donor). These data have been drawn from the data provided by the Organ Procurement and Transplantation Network (OPTN). For updated data, see http://optn.transplant.hrsa.gov/latestData/rptData.asp


President’s Council on Bioethics, Controversies in the Determination of Death, p. 90.


Donation after Circulatory Determination of Death (DCDD)

Cardiopulmonary or circulatory standards were used in post-mortem organ procurement before the development of brain death criteria. Over the last twenty years or so, these standards have emerged again, alongside neurological standards, because of the severe, persistent shortage of organs for transplantation. However, special difficulties arise when we incorporate cardiopulmonary or circulatory standards into the practice of organ procurement, especially because of the need to obtain the organs quickly before they are compromised and often to start measures to preserve organs before death has been declared.

I will use the language of ‘donation after circulatory determination of death’ (DCDD) instead of ‘donation after cardiac death’ (DCD) because the DCDD’s focus on the circulatory standard for determining death is less confusing and more informative. There are two kinds of DCDD—controlled and uncontrolled. In controlled DCDD, the patient (perhaps through an advance directive or living will) or the patient’s family makes a decision to stop treatments so the patient can die; hence, the patient’s death is expected. After this decision to terminate treatments, the appropriate

13 These data have been drawn from the data provided by the Organ Procurement and Transplantation Network (OPTN). For updated data, see http://optn.transplant.hrsa.gov/latestData/rptData.asp


16 President’s Council on Bioethics, Controversies in the Determination of Death, p. 90.

medical personnel make an inquiry about willingness to donate. No effort is made to resuscitate
the dying patient. By contrast, in uncontrolled DCDD, the individual’s death is not expected; he or
she suffers a cardiac event and resuscitative efforts are undertaken but are unsuccessful.

I will start with controlled donation after circulatory determination of death (cDCDD). Earlier,
for instance, in the original Pittsburgh protocol, such donors were called ‘non-heart-beating donors’
(as distinguished from ‘heart-beating donors’ in DNDD). Over the last decade, there has been an
increase in number of cases of cDCDD in the U.S.: from 87 to 848 donors each year. They now
constitute slightly over 10% of the deceased organ donations each year. The U.K. and Australia saw
substantial increases in cDCDD over the last decade and now more than one third of all deceased organ donors
in those countries come from cDCDD.

Following are some difficulties of and challenges to cDCDD. A general attack came from medical sociologist Renee Fox who described the early Pittsburgh protocol for non-heart-beating donors as “an ignoble form of cannibalism”, which is irreverent as well as medically and ethically problematic. More specific criticisms, from various sources, include:

- Conceptual problems: in cDCDD ‘irreversible’ has been interpreted to mean ‘permanent’
because of the decision not to provide resuscitation. Hence, resuscitation will not be performed in contrast to cannot be performed.

- Short waiting time: One problem for many practitioners is the short waiting time—2–5
minutes after cardiac arrest before organ recovery. This time, which is supposedly long
enough to avoid the possibility of autoresuscitation, is a matter of concern for a number of
clinicians—are these individuals really dead?

- Effect on end-of-life care: Concerns have been raised about possible compromises in the
quality of end-of-life care, for instance, in ante-mortem interventions, some of which may
cause discomfort or hasten death.

Even though cDCDD programs are developing and expanding in the U.S., several medical asso-
ciations and professionals, even when somewhat supportive, have registered these and other
concerns. Some critics have called for a moratorium on cDCDD programs, particularly those
involving children. Running through these concerns and criticisms is a worry that cDCDD circumvents the Dead Donor Rule.

Similar concerns, criticisms, and worries also plague uncontrolled donation following circu-
latory determination of death. In uDCDD, the individual’s death is not planned or expected; a
person, often outside the hospital, suffers a cardiac event and resuscitation is unsuccessful. Proto-
cols vary. One in New York City requires 30 minutes of vigorous resuscitative efforts, by well-
trained emergency technicians, under on-line direction from a physician. Once the point of futility
is reached, efforts are stopped and death is declared. Organ preservation efforts do not begin for
15–20 minutes while “consent to donate is verified and the police and medical examiner clear the
body for removal.” Spanish protocols do not involve declaring death at the scene, but only at the
hospital. Hence, it is possible to wait to ask the family. Given the opt-out system in Spain, it is
legitimate to take some measures to prepare the body for donation before the family is asked.

Some uDCDD programs are quite successful—for instance, Spain and France have increased
rates of transplantation with good outcomes. (Incidentally, Spain accepts uDCDD but not cDCDD,
whereas the U.S. has accepted cDCDD but mainly has pilot programs in uDCDD—these differ-
ences reflect a variety of social, cultural, and historical factors.) The 2006 Institute of Medicine

19 Scott D. Halpern et al., “Estimated Supply of Organ Donors After Circulatory Determin-
ation of Death: A Population-Based Cohort Study”, Research Letter, Journal of the American


21 Renee Fox, “An Ignoble Form of Cannibalism: Reflections on the Pittsburgh Protocol for Procuring Organs from Non-Heart-Beating Cadavers”, Kennedy Institute of
Ethics Journal 3, no. 2 (June 1993): 231–239.

22 For a defense of the standard of permanence, see several works by James L. Bernat, singly or with others. Among these is Bernat, “On Noncongruence between the Concept and Determination of

23 See, for example, the Committee on Bioethics, American Academy of Pediatrics, “Ethical Controversies in Organ Donation After Circu-


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report, *Organ Donation: Opportunities for Action*, identified uDCDD as a promising way to increase the supply of transplantable organs, perhaps providing as many as 22,000 additional organ donation opportunities in the U.S. But so far there has been little progress in implementing uDCDD in the U.S.

Following are some difficulties of and challenges to uDCDD. Critics charge that weak tests are used and do not guarantee irreversibility, while proponents insist that “there is actual, demonstrated irreversibility of cardiac, respiratory, and spontaneous circulatory function” and thus conformity with the Dead Donor Rule. Critics further contend that irreversibility cannot be established until the exhaustion of all possible resuscitative measures, because there is evidence of recovery following unconventional resuscitation measures. Hence some of those who become donors in uDCDD could have been saved.

uDCDD doesn’t meet the ‘permanence’ standard of cDCDD regarding ‘circulatory function’ when there are efforts, after the determination of death, to institute artificial circulation—by using chest compressions, ventilation, and extracorporeal membrane oxygenation (ECMO). These individuals, some say, become ‘undead, thereby invalidating the previous circulatory determination of death. But defenders respond that the restoration is far below normal physiologic range. (Some recommend that if ECMO is used, an intra-aortic balloon should be inserted to prevent meaningful circulation to heart and brain.) Issues of trust also arise in the cessation of futile resuscitative efforts in order to commence organ preservation and procurement efforts. Still another criticism is that uDCDD requires a very heavy investment of resources and diverts resources from rescue efforts to organ retrieval.

In short, there are serious on-going controversies about the determination of death in each of these three practices of organ procurement—DNDD, cDCDD, and uDCDD. Hence, it is fair to say that the Dead Donor Rule faces a crisis in part because of the difficulties of determining death and the uncertainties about whether the donor is actually dead when the organs are removed.

What Should We Do about the Dead Donor Rule?

Given this crisis, what should we do about the DDR, which presupposes that we are able to draw a clear line between life and death? What are the ethical implications of different approaches to the DDR in transplantation medicine, and which policies, laws, and practices should we adopt?

Truth or consequences?

Let’s start with ‘truth or consequences’, the title of Dan Brock’s article reflecting on his experiences as a philosopher on the staff of the President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. There is often a tension between what we might call truth, as understood in an academic seminar, and formulating ethically acceptable and feasible public policies, all things considered, in the particular circumstances. Yet the latter is and should be the primary concern in public policy. (Incidentally, my experience on bodies advising governmental policy makers on organ transplantation and other matters is similar.)

Brock was on the staff of President’s Commission in the early 1980s, when it was developing a major and influential report on *Deciding to Forego Life-Sustaining Treatment*. It had become commonplace at the time to say that it is permissible to allow patients to die, to let nature take its course, as long as we do not kill them. Philosophically, Brock held a different view—that the dif-
ference between killing and allowing to die “is not in itself morally important, and that stopping life-sustaining treatment is often killing, though justified killing.” Brock’s view was not held—and was even sharply rejected—by the majority of the members of the President’s Commission. Suppose, in the name of truth, Brock could have ‘undeceived’ these commissioners, convincing them that there is no sharp distinction between allowing to die and killing, and that letting die is killing. That likely would have had very unfortunate effects.

The commissioners probably would not have said, “Letting die is the same as killing and we should permit both of them.” Instead, they probably would have said, “Letting die is just as bad as killing, and we shouldn’t permit either of them.” Such a conclusion would have produced bad consequences for many patients at the end of their lives. It would have deprived them of their exercise of autonomy and required them to undergo treatments they wanted to refuse. Patients would have been wronged as well as harmed. In short, ‘undeceiving’ the commissioners would probably have had terrible effects in the real world.

Now what should we do about the dead donor rule? In discussing several possible options, I should note that some of these options might apply only to one or two of the three practices of deceased organ procurement rather than to all of them.

Option 1: Abandon the rule and institute an alternative: living vital organ donation.

Many who propose that we abandon the DDR do so because of the difficulties of determining death. Others apparently would support an alternative approach—living vital organ donation—even if the line between life and death could be reliably drawn. However, the latter thinkers also point to the difficulties in determining death to buttress their arguments. Among the several opponents of the DDR, Frank Miller and Robert Truog have written a number of important and powerful articles and an excellent book Death, Dying, and Organ Transplantation: Reconstructing Medical Ethics at the End of Life that take this approach.36

They insist that the DDR “does no genuine moral work in current practices of vital organ donation because ‘brain-dead’ donors remain alive and donors under DCDD protocols are not known to be dead at the time organs are procured.” Hence, we “should be working toward honestly facing the fact that currently we are procuring vital organs from patients who are not known to be dead and that it is ethically legitimate and desirable to do so.” According to Miller and Truog, where there are valid decisions to stop life-sustaining treatment and where there is consent to donation, we should be able to use vital organs from these living-though-dying persons. We do not harm them (because they will be dead shortly, in any event); and we have their or their family’s consent. “The absence of harm plus appropriate consent legitimate vital organ donation.” (112) The upshot is that DDR “must be abandoned”. (114) “The ethics of withdrawing LST [life-sustaining treatment], recognizing that this causes death, underlies the justification for vital organ donation from still-living patients.” (115)

The Miller/Truog approach fails to connect with the public’s (and medical professionals’) moral beliefs, symbols, values, and practices, including religious ones, which largely mesh with and support the DDR. If the Miller/Truog position were to be adopted by policy-makers, its consequences would likely be disastrous for organ donation and transplantation. Consent to deceased organ donation, particularly by families, and medical participation in obtaining and transplanting organs often hinge on the beliefs, symbols, and values represented in the DDR. In short, this way of ‘undeceiving the world’ could be disastrous for many potential recipients of donated organs—because many in the public and medical and health professions ‘cannot bear very much reality’, if indeed what is argued is reality.
37 See also ROBERT TRUOG, "Brain Death—Too Flawed to Endure, Too Ingrained to Abandon", American Journal of Law, Medicine & Ethics 35, no. 2 (Summer 2007): 273–81.

38 See Committee on Bioethics, American Academy of Pediatrics, "Ethical Controversies in Organ Donation After Circulatory Death".


Option 2: Accept the ascribed status of death in deceased organ donation as a legal fiction that preserves the DDR at least for the time being.

MILLER and TRUOG recognize the possible negative effects of immediately abandoning the DDR. In short, they seem to hold that “human kind cannot [at least yet] bear very much reality.” Hence, they propose an alternative: Maintain the DDR as a legal fiction, as a temporary measure, until the public matures enough to face reality. ‘Undeceiving’ involves education about the legal fiction.37

In proposing that we view the DDR as a ‘legal fiction’, MILLER and TRUOG want to evacuate its ‘moral force’, depriving it of any ‘inherent ethical significance’. It does have ‘ethical significance’ as a rule within a larger set of ethical principles, some consequentialist, some deontological. Even though in theory we should drop the DDR, this is practically ‘difficult to achieve’—again, without harmful consequences. Thus, MILLER and TRUOG view their “legal fictions approach as a halfway house in the evolution of medical ethics and the law”—“halfway to abandoning the dead donor rule.” It is a “temporary expedient”, a “pragmatic compromise”, a “progressive” step in the direction of “greater transparency”. It “weakens the link between the ethics of organ transplantation and standards for determining death”. (171)

This legal fictions approach may be a way for critics of the DDR to assign it some temporary instrumental value, without ceasing efforts to abandon it over time. But to make the DDR transparent as a fiction would probably have negative effects similar to those of Option 1 above—though perhaps less dramatic and extensive. Of course, this is an empirical question. In my judgment, MILLER and TRUOG again fail to attend adequately to the moral beliefs, including those in major religious traditions, which would have an impact; these are moral beliefs that it is wrong to kill people in order to take their organs. (MILLER and TRUOG suggest that we need more surveys of beliefs as well as additional educational efforts.)

They further argue that “in a liberal democracy, public policy supported by the law permits practices that some find deeply objectionable.” (149) While that is true, one intended function of the DDR is to provide a basis for trust so people will voluntarily donate organs for transplantation. Parallel to BROCK’s situation, if MILLER and TRUOG were to convince policy makers and others of the legal fictions approach, there would probably be resistance to deceased organ donation, particularly by families, because this would amount morally to killing their loved ones, whether in DNDD or in DCDD. Many medical practitioners would probably feel the same way—this is already evident in the responses of many physicians and others to cDCDD.38

Actually, what MILLER and TRUOG propose would not differ greatly from current practices of selecting donors of vital organs, but the interpretation of the DDR as a ‘legal fiction’, in all probability, would contribute to the de-legitimation of deceased organ donation and would be accompanied by a decline in organ donors as well as a reluctance of many physicians, nurses, and other professionals to participate in the process of organ procurement and transplantation.

Option 3: Retain DDR with expanded individual/familial choices of conceptions and criteria of death.

Another approach, represented in ROBERT VEATCH’s writings, maintains the DDR but opens the range of possibilities for determining death. Two states, New York and New Jersey, have set a conventional approach to death but accommodate religious and moral objections to being declared dead by neurological standards.39 Hence, people can choose to be declared dead by cardiopulmonary standards if they wish rather than by neurological standards.

One advantage of this option is that it allows individual choice (and, where the individual has not chosen, familial choice) of the conception of death and hence, at least, of neurological or
circulatory standards for determining death. Veatch draws a distinction between the value questions involved in setting a definition of death at the conceptual level and the technical questions, such as how to test for signs of life, that necessarily involve medical expertise. The value questions should be in the domain of ‘religious/philosophical/policy choice’, not medical science.\(^\text{40}\) Given the value diversity in liberal pluralistic societies, recognizing a plurality of value-laden definitions of death is an appropriate step. However, rather than “letting a hundred flowers bloom”, as China’s Chairman MAO put it, Veatch proposes that the society set a ‘default definition’—probably, whole brain death—and then grant individuals a reasonable range of options in conceptions of death. Expanding to an unlimited range would create public health, societal, and ethical problems.

The option of conscientious objection to brain death has received support from religious groups, such as Orthodox Jews, Buddhists, and Native Americans, among others, who favor a cardiopulmonary conception. From Veatch’s standpoint, this option should also include a higher-brain conception of death for those who might prefer it, as Veatch himself does. This is “the humane, respectful, fair, and pragmatic solution.”\(^\text{41}\)

Even if a range of tolerable views is established, both professionals and the public will still have to face the difficulties and challenges, already identified, of determining death in the context of organ donation. People’s choice of one or more standards over others will need to be adequately informed, and this will entail fuller disclosure of the problems we have already identified in the three major approaches to obtaining organs from deceased individuals. The difficulties of interpreting and applying the standards will remain, whichever standards individuals and families select. Furthermore, medical professionals will have to decide whether they are comfortable participating in organ removal and transplantation based on any or all of the tolerable standards. Some of these points also apply to the fourth option and will be further developed below.

Option 4: Retain and strengthen the DDR and ethically improve its operation.

Given the deep and widespread uncertainties about and challenges to the Dead Donor Rule, in part because of the difficulties of determining the ‘dead donor’, there are serious ethical concerns about our social and medical practices of obtaining organs for transplantation. I propose we retain the rule and seriously consider, not only with professional groups but also through public engagement, how best to sustain the DDR, by improved conceptual, scientific, clinical, and other work and by enhanced ethical practices. This entails attention to both truth and consequences, to ‘undeceiving the world’ and also helping human kind—the public and the professionals—‘bear reality’.

One indispensable condition is improving the process of informed consent. What kind of consent do we want from whom for what? Too often we have been satisfied with a very weak, watered-down version of consent for post-mortem organ donation in both opt-in and opt-out systems. In general, these systems do not require the kind and level of disclosure of information expected in much of medicine and research. Nor do these systems probe potential donors’ understanding. For living organ donation, consistent with standards elsewhere in medicine and in research, the process of voluntary, informed consent should include (1) disclosure of information to a person (a) who is deemed to be competent to decide, (b) an assessment of his or her comprehension or understanding, and (4) determination of the voluntariness of his or her decision.\(^\text{42}\)

Some of these components are missing or seriously diluted in much, perhaps most, deceased organ donation in both opt-out and opt-in countries. For instance, in the U.S. little information is disclosed for first-person consent to deceased organ donation. This consent often occurs when a
A person is getting a driver’s license from a state department of motor vehicles. Only limited information is disclosed in that context, and there is no real opportunity for individuals to inquire more broadly and deeply into what’s at stake in making the decision. Specifically, there is no disclosure that a person might be declared dead by either neurological or circulatory standards—only that organs will be removed after death. And no information is provided about the difficulties and challenges of determining death in the three different practices we have examined. Perhaps the process is a little better when families decide, but there is no reason to believe it is adequate. In any event, consent to ‘deceased organ donation’ without further specification is probably not informed consent because of the different practices of determining death, each with its own difficulties and uncertainties.

Why do we have such inadequately informed consent for deceased organ donation? Perhaps because of the common view that the line between life and death can be clearly drawn, the determination of death is a purely objective matter, and the dead body cannot be harmed. But this approach to consent is problematic in view of the known difficulties and challenges to ways of determining death in the context of organ donation. Whether first-person or family consent, whether opt in or opt out, more information about relevant uncertainties and doubts is needed to ensure prospective donors’ understanding and, hence, their adequately informed choice. As matters now stand, fewer than 56% of pediatricians in one survey thought that physicians are being truthful about the death of patients in DCDD.

Beyond these points, how much and what kind of information should be disclosed? In my judgment, disclosure should be guided by the baseline of what reasonable people would want to know, augmented by what particular potential donors want to know. However, determining what reasonable people want to know is not easy. Conversation is needed, and focus groups can be instructive, along with other ways to engage the public.

While vitally important, transparency and public engagement are also badly neglected. Neither has been featured in the development of the conceptions and criteria of death that provide content for the Dead Donor Rule. The Harvard criteria were featured on the front page of *The New York Times* in 1968 but, for the most part, this report “did not foster a public debate.” Instead, there was widespread deference to the medical profession. Similarly, some professional and interprofessional discussion, but only limited public discussion, has accompanied the development of cDCDD protocols. Furthermore, policies on uDCDD in Spain and France “were introduced and implemented without previous societal consensus or transparency.” In the U.S., efforts have been made to engage public officials and the public about the recent pilot program of uDCDD in New York City and the earlier one in Washington D.C. Overall, the record of transparency and public engagement is at best spotty, at worst woefully unsatisfactory.

Earlier, I observed that in the U.S. and several other countries, there was movement beyond the so-called Dead Patient Rule (under which a patient had to be dead before mechanical ventilation could be stopped) to a substantial consensus about standards and procedures for stopping medical treatments of dying-but-not-yet-dead patients in order to allow them to die. In the U.S., this occurred over time, with widespread participation by the public as well as by clinicians, ethicists, governmental advisory bodies, policy makers, and the like. Legal decisions by the courts were also important, and they often resulted from citizens’ challenges. There are serious doubts that today’s ‘political and social climate’ will allow a similar process for the Dead Donor Rule and the criteria involved in DNDD, cDCDD, and uDCDD. One defender of the rule finds it hard to imagine “how public deliberation might proceed explicitly to consider whether to retain the incoherencies and obfuscations in the current criteria for death determination.”


44 Beauchamp and Childress, *Principles of Biomedical Ethics*, 7th edn., Chapter 4.


46 Robert M. Arnold and Stuart J. Youngner (guest editors), Special Issue: ‘Ethical, Psychosocial, and Public Policy Implications of Procuring Organs from Non-Heart-Beating Donors’, *Kennedy Institute of Ethics Journal* 3, no. 2 (June 1993).

47 Rodríguez-Arias et al., “Casting Light and Doubt on Uncontrolled DCDD Protocols”, p. 27.


49 Rodríguez-Arias et al., “Casting Light and Doubt on Uncontrolled DCDD Protocols”, p. 29.

in my judgment, one of the most urgent, immediate tasks is to figure out how to engage the public in open, transparent, and productive ways. As David Rodríguez-Arias and colleagues rightly emphasize, avoiding such discussions “may lead to an increased inconsistency, rationalization, and obfuscation that could feed public distrust and, ultimately impede the goal everyone seems to want—more organs to save and improve more lives.”  

It is obvious that organ donation and transplantation depend on public trust—after all, members of the public donate the organs needed for transplantation. In addition to being ethically problematic, silence about or obfuscation of the difficulties and uncertainties in determining death will probably not sustain public trust in the long run. Even though there are rumblings of unease as well as explicit concerns among healthcare professionals, especially about some DCDD protocols, there has been a notable lack of public outrage or even public disquiet. However, this does not count as passive acceptance, given the dearth of transparency.

In conclusion, this fourth option involves maintaining and strengthening the Dead Donor Rule by further conceptual and scientific work on determining death and by ensuring its ethical interpretation and application. The major ethical concerns are not identical across the three major practices of obtaining organs for transplantation—DNDD, cDCDD, and uDCDD—or across different countries, which have not adopted these practices at the same rate or to the same extent. For each practice, transparency and public engagement and fuller disclosure of information to ensure donors’ adequately informed consent are essential, along with measures to eliminate or control conflicts of interest and to safeguard conscientious refusals by healthcare professionals who object to participation in one or more of these practices.

It is also crucial that debates about the Dead Donor Rule and its implications for practices of obtaining organs be morally serious, rather than forms of academic gamesmanship—after all, these are matters of life and death. We cannot totally separate truth and consequences. And while we seek to ‘undeceive’ the public, through transparency, public engagement, and disclosure of information to prospective donors, we need, at the same time, to help the public as well as healthcare professionals ‘bear reality’. All this won’t be easy.

51 Rodríguez-Arias et al., “Casting Light and Doubt on Uncontrolled DCDD Protocols”, p. 29.


53 Several variations across different countries have been noted in the text. Here I should also add that practices of DCDD are “virtually non-existent” in Germany and Portugal, among other countries. See Manara, Murphy, and O’Callaghan, “Donation after Circulatory Death”, p. 1110.

