Recent ethical literature on organ donation in the United States focuses on the reality that there are far more patients on a waiting list for a transplant than there are donors. It is estimated that there are approximately 170,000 people living today in the United States who are recipients of an organ donation, yet as many as 7,000 patients die annually because there are not enough organs available. It may be of interest to note that the 2007 Organ Procurement and Transplantation Network reports that in 2006 the increase in the number of living donors was lower than in any previous year. That year saw a 6% increase in deceased donors, but only a 2% increase from living donors. Not surprisingly, the ethical literature looks at the ethical issues related to increasing the availability of organs from deceased donors. This has resulted in a good deal of ethical discussion about the definition of death, who should be considered to be dead, why they should be thought to be dead, and whether or not it even matters if a person is dead in the procurement of vital organs. These questions are the focus of this analysis.

Defining the moment of death

The importance of an informative and practical definition of death is grounded in the traditional belief that before vital organs can be retrieved from a person, that person must first be known to be dead. This has come to be known as the ‘dead donor rule:’ a person must be dead to be a donor of vital organs. The standard definition of death in use since before the 1960s spoke of the permanent and irreversible cessation of cardiac and pulmonary activity. The definition is descriptive of what death looks like so that it can be recognized. Once recognized, decisions about what can be done with the person’s body can be made, including vital organ retrieval. When someone had permanent loss of cardio/pulmonary function, it could be determined that the person was dead and their vital organs retrieved.

An early challenge to the cardio/pulmonary definition came with the development and widespread use of CPR in the 1960s. With CPR a heart could sometimes be restarted, raising the prospect that if a heart stopped but could be restarted, the person was not dead — at least not yet — because the cessation was not clinically irreversible. Concern about irreversible cessation of the heart was part of the discussion in 1967 when Dr. Christian Barnard performed the first heart transplant in South Africa. Much controversy resulted at that time over questions as to whether the donor was in fact dead when his heart was procured precisely because it was restarted in the recipient. By the standard descriptive definition the donor was not technically dead; the dead donor rule had been violated.

The ability to restart cardio/pulmonary function made necessary a hermeneutical nuance with the standard definition: irreversible cessation has come to be understood not as physiological irreversibility, which may not exist, but as ethical and legal irreversibility. That is, when there is no ethical or legal obligation to attempt to rescue someone with cardio/pulmonary resuscitation (CPR), the cessation is ‘ethically’ or ‘legally’ permanent, even if not physiologically permanent. It is, therefore, not necessary to attempt CPR in every instance in order to determine physiological permanence of cessation, and it is permissible to restart cardio and/or pulmonary function in a donation recipient. A person is dead when there is no legal or ethical obligation to respond to cardio/pulmonary cessation that is not followed by spontaneous resuscitation. Such persons are dead, and hence may be donors of vital organs according to the dead donor rule.

A second challenge to the standard descriptive definition of death came from those patients who suffered severe neurological damage and seemed to look alive only because they were attached to life-sustaining machines. The Harvard Medical School offered a resolution to this problem in 1968 by expanding the definition of death to include what

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has come to be known as “brain death.” This definition of death was incorporated into the Uniform Determination of Death Act in 1981. In this new context, death can be defined as the irreversible cessation of all brain activity, including the cortex (higher brain) and the brain stem, irrespective of cardio/pulmonary function. As with the more traditional definition, the definition of brain death is also a descriptive or informational definition – it gives the information needed to know whether someone is alive and whether that person may be envisioned as an organ donor under the dead donor rule. With both the cardio/pulmonary and brain function definitions for death, death can be determined, and the dead donor rule preserved in the retrieval of vital organs from donors.

Challenges to a descriptive definition of death — being ‘dead for the purpose of’

As early as 1975, before the brain death definition was incorporated into the Uniform Determination of Death Act, and since, the narrowness of the brain death definition has been challenged. An early and continuing leading writer on the subject is Robert Veatch. In a 1975 article, Veatch called for a definition of death that allows simply for the irreversible loss of the ‘higher brain,’ the cortex, as a definition of death. This change would allow more people to be understood as being dead and, therefore, available as donors of vital organs under the dead donor rule.

Veatch has suggested that people who want to be organ donors upon their death should be able to choose between higher brain, whole brain, or cardiopulmonary definitions of death. Patients should be able to choose the definition that best fits their desire to be a donor as well as their own particular religious, cultural, or personal beliefs. What is important to note is that this discussion is not about a definition of death per se, a definition that allows us to know when someone is dead, but about creating a definition of death that will allow a greater number of organ donations. The definition is less about a description of the moment of death than it is about defining someone as being dead for the purpose of retrieving vital organs. In theory, someone could be understood to be dead according to one of Veatch’s three different criteria of personal choice. Each criterion could make someone ‘sufficiently dead,’ or to use the expression of Jay Baruch, ‘dead enough’ to be a deceased donor.

Because of the change of context from a definition of death per se to an understanding of who is ‘dead enough’ to be a donor, we also see a change in the nature of the definition itself. It is no longer descriptive and informational. The definition is now utilitarian, giving a definition of the patient’s usefulness or availability as an organ donor. The definition is not meant to say what death itself looks like, but to say if it is possible to consider someone as an organ donor. Under this scenario, it would be possible to have two patients with exactly the same neurological devastation in the same ICU, one who is ‘dead enough’ to be a vital organ donor because he or she wanted to be such, and the other who is not ‘sufficiently dead,’ because perhaps their religious tradition prohibits organ donation. The dead donor rule is preserved, but the definition of who is dead becomes highly situational and utilitarian.

Not being dead at all — giving up the dead donor rule

The debate about whether someone can be considered dead for the purpose of being an organ donor is only one part of the discussion. In 2003, Elysa R. Koppleman proposed that donation of vital organs need not be restricted to deceased donors, and hence any definition of death is not especially important. Such donations she argues should be allowed from living patients with irretrievably lost higher brain function; i.e., people who are permanently unconscious. Koppleman’s ethical justification for this is that such a donation, and the patient’s subsequent death, would be done only when it was consistent with the donor’s particular history and interest.

Veatch, commenting on Koppleman’s 2003 article, notes that she is offering the same policies for organ procurement that he would like to see. The difference is that Veatch views the donor as dead and so the dead donor rule is preserved, whereas Koppleman abandons the dead donor rule and hence sees many of the same donors as alive. The chief point of disagreement is whether or not the patient should be understood as being dead. They do agree on a utilitarian policy that sees the clinical state of the patient (dead because of neurological devastation or alive with neurological devastation) as being defined for the purposes of organ donation.

Although they agree on who can be a donor, even if they
disagree on whether or not that donor is dead, they do not agree on the same strategy for increasing the number of organ donations, and this is insightful. Veatch claims that doing away with the dead donor rule, as Koppleman suggests, would require too many legal changes and weaken societal prohibitions on killing. He concludes it would be easier and less controversial to simply change the definition of death so more people fit the dead donor rule as a way of procuring more deceased donations. That, it seems to me, reveals a clearly utilitarian approach toward increasing the number of organ donations.

Robert Truong offers an interesting twist to this discussion in articles in 2003 and 2008. He writes that ultimately whether the patient is considered dead for the purposes of donation, as Veatch says, or alive but available for the purposes of donation, as Koppleman says, is not important. Instead, what is needed is simply a correct understanding of the ethical principles of nonmaleficence and autonomy in the allowance of all donations. Nonmaleficence holds, when applied to organ donation, that no one be harmed in the taking of their organs. From this principle, Truong concludes that we may take these vital organs from patients who are neurologically devastated or imminently dying. Such patients it seems, whether we think of them as dead or alive, cannot be harmed by the loss of their heart, lungs, kidneys, livers, pancreas, etc. Autonomy holds that we need patient consent, and that all we need is patient consent. As long as there is proper consent to the donation, everything that does not harm is permissible. Again, whether or not the patient is technically dead or alive is not determinative.

A response
James McCartney writing in 2004 offered a critique of Koppleman’s abandonment of the dead donor rule, but his critique is applicable to the positions of Veatch and Truong as well. He doubts, purely as a practical matter, whether Koppleman’s goal of procuring more organs by doing away with the ‘dead donor rule’ and taking organs from some living patients, can succeed if the general public senses that there is ambiguity about whether the donor needs to be dead first. One might make the same critique of Veatch’s suggestion that one might be able to be ‘dead enough’ for purposes of vital organ donation if people could choose between higher brain, whole-brain, and cardiopulmonary definitions of death.

For my part, I hold ethical concerns about a shift from an informational and descriptive definition of death, a definition that tells us if one is dead, to a utilitarian definition, a definition that tells us if one is sufficiently dead or dead enough ‘for the purposes of’ organ donation. There is a critical need to increase the number of organs for donation, but such a utilitarian approach is to me hubris. Death is the ultimate existential moment of being, after which we materially cease to be. Death defies purposefulness — death per se is never for the purposes of something else. When we die we simply cease to be in this world. Whatever our religious or spiritual beliefs about what does or does not come after death, death itself is the end of our material being in this world. It is possible that some good may come out of one’s death, such as saving lives by donating organs. Death per se, however, is not death for that purpose; people do not die in order that organs might help others live, even if their death is ordered in such a way as to provide for that donation as in organ donation after cardiac death. Death is the end of physical life — what we do with that end is another matter.

A predominantly utilitarian approach to defining death, or procuring organs from the living, raises for me a concern about the slippery slope: Where does such an approach to ‘being dead for the purposes of’ lead? If it can be that a patient is dead for the purposes of organ donation, might they also be able to be dead for other purposes, such as research? I can only imagine the medical strides we could make if we were able to declare people in a permanent vegetative state legally dead for the purposes of research. Once we decide someone can be dead for the purposes of one social good, I am not sure of the criteria to be used to decide if they are dead for the purposes of some other social good.

Finally, this approach, particularly as presented by Truong, over-plays I think the role of consent in ethical analysis. For many ethicists and clinicians, it seems consent is the determining factor in defining the moral status of an action. If the patient or appropriate surrogate has consented and the procurement is not harmful to the patient, death notwithstanding (Truong), then organ procurement is by definition permissible, whether it is a matter of considering this particular person dead (Veatch) or taking the organ when the person is by definition still living (Koppleman). In fact,
consent is not nearly so powerful ethically. Consent in the ethical tradition is a permission to do what is right; it does not make what is done right. Consent is not, like Double Effect, a principle of justification that allows in a particular situation what is otherwise ethically questionable or prohibited. Consent merely allows one to act on an otherwise good option; it does not make the option per se to be ethically good.

Conclusion

“Knowing when death has come, along with what can and should be done before and after it has arrived, has always been a problem for humankind, to one degree or another.”16 The 1981 report of the Presidential Commission determined that one is dead in circumstances of irreversibly lost cardiac and respiratory function and/or irreversible loss of total brain function.17 Moving from these descriptive definitions to a utilitarian definition seems to me to open the door to approaches to definitions of death that have more to do with the procurement of organs than with knowing when a loved one has died, and the time to grieve has arrived. With Hans Jonas in 1974, and to a large degree with the President’s Council on Bioethics in 2009, I challenge the undue precision of our definition of death, and its application to the social need for organs.18 With my colleague Art Caplan, I agree that “people are getting nervous that we’re pushing the standard of death in order to get organs. The public is afraid that surgeons in search of organs for transplant will bend the definition of death to get them.”19

A descriptive, informational definition of death, irrespective of its usefulness for obtaining organs for donation and transplant, seems to me to be the most ethical approach to understanding and diagnosing the moment of death.

NOTES

6. Because brain activity, unlike cardio/pulmonary activity, cannot be resuscitated, irreversibility is both physiological and ethical/legal.