

EDITOR'S NOTE

Given the impact of DCD on health care organizations, we believe it is important to share the variety of perspectives on this issue with our readers. It is our hope that the following three articles will help shape the way Catholic health care organizations develop their approach to DCD.

Back to Basics: Examining the Assumptions of Donation after Cardiac Death

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IN THE LAST SEVERAL YEARS, hospitals have experienced more and more encouragement from organ procurement organizations (OPOs) and others to adopt protocols to facilitate the procurement of organs from patients who are seriously and irreversibly brain-injured but not brain dead. This encouragement has been constant from the OPOs for at least a decade. The difference now is that policy-making organizations, such as the Health Resources and Services Administration (HRSA) and the Joint Commission, have inaugurated a cascade of support for the procurement of organs under conditions of controlled cardiac death. The main attitude underlying these directives and policies can be summed up this way: Increase the donor pool because transplants save lives.

Ordinarily, policy set at a national level reflects either prevailing political interests or a settled consensus of opinion. In the 1970s, the lowering of the speed limit to 55 mph probably did not reflect a general public feeling about the right speed to drive on a freeway. What it did reflect was a decision on the part of lawmakers to lower freeway mortality and save oil, both of which were national political interests. The 1991 Patient Self-Determination Act, on the other hand, probably did reflect a general public consensus that it was appropriate for persons to express in advance any desire they had to limit the lengths to which medicine might go to sustain their lives, particularly under dire circumstances.

In the case of donation after cardiac death (DCD), it would be comforting to believe that the push toward wide-

spread adoption of DCD policies stems from agreement among most people that on the whole, there is a duty to save lives by donating one's organs if one is irreversibly brain damaged and uninterested in prolonging one's life under those circumstances. But we have no evidence of such a consensus, or even of public awareness of DCD, much less a public conviction about it. Nor is there evidence that some sinister or benign political interest is really behind the push. The absence of either motivation makes the widespread regulatory support of DCD puzzling, except for one thing. The technology of organ donation has been successful, and the more we widen the group of people on whom it is therapeutically tried, the more successful it is. This sets up a presumption in its favor.

But sometimes a presumption discourages the examination of assumptions. In this article, I suggest that the examination of three fundamental assumptions is precisely what is called for on the subject of DCD. If we are to wholeheartedly embrace such a change in the manner of securing organs for transplant, we should do it with a deep understanding of the ideas that undergird the change, and we should be as transparent in our public conversation about those ideas as possible.

Assumption 1: *There is an organ shortage. When hospitals do not have DCD protocols, transplant candidates die needlessly.*

The literature on organ donation typically begins with a statement of the number of candidates suitable for organ transplantation, followed by a dramatically smaller number

of organs available for transplant. These candidates have conditions resulting in the life-threatening deterioration of a kidney, liver, lung, pancreas or heart. In the end stages of their disease, they will die without effective treatment. No treatment is as effective as organ transplant for these patients (although even a transplant is not 100 percent certain and not without side effects). The shorthand for this state of affairs is that these patients will “die waiting” with the implication that it is therefore our obligation to try to increase the pool of organs for transplantation so that more of these patients can be saved.

Another way to look at this situation, however, is to compare it to the early quandaries about the removal of life-sustaining treatment. The *Quinlan* Court, for example, went to some trouble to assert that it was not the removal of life support that caused the death of someone, but her underlying disease. In the same way, it is not the lack of a transplantable organ that causes the death of someone who “dies waiting,” but the underlying disease. This is not to say that we shouldn’t try to increase the donor pool. Indeed, some will find it a duty. It is simply to remind us that both medicine and human life have limits, and that increasing the pool, although a laudable goal, must be done in an ethically reflective way, characterized by the same features as other ethical decisions—respect for persons, beneficence, justice, an honest telling of the truth, informed consent.

The number of diseases and the severity of disease, for which transplantation is now the indicated treatment, has grown dramatically in recent years and may be expected to continue. When the candidate list grows, we must realize that not everyone who might benefit from a transplant will get one. It is a hard fact but a real one. This kind of understanding might lead to a more balanced view of all organ donations, including DCD, and could situate the good of organ transplantation more rationally within other health care goods.

Assumption 2: *DCD is essentially the same as the already accepted procedure(s) for procuring organs for transplantation, and therefore it is uncontroversial.*

In an effort to help people embrace the new DCD protocols, OPOs have stressed that DCD is simply a return to an earlier and accepted form for determination of death. In the old days, the thinking goes, we knew someone was dead and declared them such by noticing and confirming

the absence of breath and pulse, evidence that the heart had stopped. Then came the determination of death by neurological criteria — in essence, using signals (or lack thereof) from the brain, rather than from the heart, to declare someone dead. The reason for this move toward neurological criteria was twofold. First, with the rise in use of the technology for mechanical ventilation, the cessation of heart and lung function was effectively camouflaged, so it was harder to declare some people dead the old-fashioned way. Second, the desire to improve outcomes in the relatively new procedure of organ transplantation meant that deterioration of organs under conditions of “uncontrolled” or spontaneous cardiac death should be minimized. These two combined to produce, in 1968, criteria for determining death using neurological measures. This greatly increased the number of organs suitable for transplantation, because the time gap between the cessation of blood flow and the procurement of the organ during which the organ’s quality diminished was eliminated.

However, the move from cardiac death to brain death to facilitate the transplant of organs came at the expense of the general public’s understanding. Brain death is not uncontroversial or well-understood. In fact, according to one study, less than half of the American public understands that neurological criteria are legitimately used to determine the death of a potential organ donor.¹ Anyone who works in an emergency department or ICU has experienced a family’s disbelief when told that their loved one is “brain dead.” This is in part due to the fact that often these deaths are the result of sudden trauma in an otherwise healthy young person, where the coping mechanism of denial enters the picture. It is also due to the fact that a very seriously ill person looks about the same on a mechanical ventilator as a brain dead body. In fact, hospital personnel are sometimes a little confused as well, as evidenced by the number of times we tell families their loved one is brain dead and then *ask* if we can remove “life support.”

Embedded in the assumption that DCD is just a variation on an accepted theme are two other assumptions. One is that brain death is generally understood and accepted, which as we see above, it is not. The other is that old-fashioned cardiac death is not relevantly different from cardiac death under controlled circumstances. The counterargument—that DCD *is* different — is more difficult to make since it turns on the question of what makes something relevantly different. It is true that the means of determining death are the

same; it is the absence of pulse and breath that count as signs of death. But the circumstances under which the death occurs are vastly different. In the earlier case, death was an accomplished fact. Whether witnessed or not, there was nothing that could be done to reverse it. Death came to the patient uninvited, and it served no particular end.

In the case of DCD, cardiac death is not immediately inevitable. This is precisely what recommends it for transplantation purposes: we resist death by mechanical ventilation and then we decide to stop resisting, and the time elapsed between this decision and surgery to get the organ is short. Death is invited, by the justifiable decision to limit life-sustaining treatment in a severely brain-damaged patient, and it serves the end of organ transplantation. Neither its invitational status nor its service to the (good) end of organ transplantation necessarily makes DCD ethically suspect. But it does make it different. This is why suggesting that DCD is a “simple return” to earlier criteria seems disingenuous. It is also why the adoption of DCD protocols should only be done with serious regard to the opinion of the community the hospital serves and the experience of organ donation there in general. Such protocols should also be accompanied by transparent informed consent procedures that stress the real features, risks, and alternatives of the procedure.

Assumption 3: *The language of organ donation is neutral.*

How we describe or frame something shapes our further judgments about it. In an unfortunate appropriation of an agricultural term, the early word for taking an organ from a dead body was *harvest*. Granted, this term was coined in the same utilitarian mentality that gave us *salvageable* patients and *pulling the plug* on life support, but for a while at least, *harvest* was uncontested. When we realized how impersonal and callous *harvest* could sound, we changed the word to organ *procurement*. In this terminology, *procure* is a fancy way of saying “get.” This terminology lives in the acronym for regional transplant networks, also called organ procurement organizations, or OPOs.

Now transplant advocates have further improved the language, at right about the same time as DCD protocols have come into sharper view. In an effort to link the work of organ transplantation to the good works of saving, recycling and loss prevention, what used to be called organ *harvest* and then organ *procurement* has now become organ

recovery, as though the burial of a potentially transplantable organ in the body of its original owner would be a loss.² Getting the organ for transplantation has become, in the minds of some, the default, with any other disposition of the organ regrettable.

It may be unrealistic to hope that the general public can be any better informed about DCD than they are presently about brain death and organ donation, which is to say, not very informed. But given the inadequately analyzed assumptions underlying DCD, the subtle shift in language that marginalizes those who might wish to be buried with all their component parts, and the support DCD is enjoying from regulatory agencies like HRSA, at least a place should be preserved for patients and hospitals that might not be so enthusiastic about it in light of their other values. This is best accomplished by keeping DCD as optional as possible.³ The Joint Commission recognized this when they recently issued a clarification of their standard regarding DCD, which originally seemed to suggest that hospitals were required to adopt policies allowing DCD. Now the commission and all their surveyors recognize that what is more helpful is to expect that hospitals will justify their position on DCD and make that position clear.⁴ Furthermore, it would be wise to continue the present practice of allowing DCD to be considered only if family members raise it, rather than suggest or allow the OPOs, which have vested interests, to “educate” the families of potential candidates about it.

Finally, some of the public is already distrustful of the motivations of hospitals and practitioners in limiting life-saving treatment. Groups who have historically been denied equal treatment or equal access to treatment have just cause to be resentful of that fact. Presuming that DCD is in everyone’s best interest risks further alienating this public. We should not move in the direction of institutional or individual default to DCD without regard for them.

NOTES

1. Telephone communication with James DuBois, author of the study, July 17, 2007.
2. Unfortunately, this has resulted in sentences that are somewhat unintelligible, such as, from one DCD policy, “The patient is allowed to die in a way that facilitates recovery.”
3. “Keeping it optional” includes keeping DCD institutionally optional.
4. Telephone conference call with Paul Schyve and others from the Joint Commission, February 7, 2007.