

**CASE AND COMMENTARY****How Should Physicians Manage Organ Donation after the Circulatory Determination of Death in Patients with Extremely Poor Neurological Prognosis?**

Commentary by James L. Bernat, MD and Nathaniel M. Robbins, MD

**Abstract**

Organ donation after the circulatory determination of death (DCDD) accounts for a growing percentage of deceased organ donations. Although hospital DCDD protocols stipulate donor death determination, some do not adhere to national guidelines that require mechanical, not electrical, asystole. Surrogate decisions to withdraw life-sustaining therapy should be separated from decisions to donate organs. Donor families should be given sufficient information about the DCDD protocol and its impact on the dying process to provide informed consent, and donors should be given proper palliative care during dying. An unresolved ethical question is whether and how donor consent should be seen as authorizing manipulation of a living donor during the dying process solely for the benefit of the organ recipient.

**Case**

Jenna is a 21-year-old woman involved in a motor vehicle accident. She suffers severe head trauma and is emergently intubated at the scene by emergency medical services personnel who immediately transport her to the nearest level I trauma center. Jenna remains comatose for several days in the intensive care unit (ICU) without any signs of neurologic recovery. Scans of her brain revealed signs of severe cortical injury, but a neurologic exam suggests that some brain stem reflexes still remain. Her devastated family members understand her very poor prognosis and inquire about organ donation, as Jenna was listed as an organ donor and had been very active in promoting organ donation. They feel strongly that donation is what she would want.

Because Jenna does not meet criteria for brain death, the medical team members discuss cardiac death with her family and review the specifics of the protocol with them. In order to meet criteria for cardiac death, Jenna would be taken to the operating room where she would be extubated and her vital signs monitored and timed closely for the next hour. If, within that hour, her heart were to stop beating and remain stopped for 5 minutes, it would be considered irreversible cardiac death and thus organ procurement would begin immediately. If, however, after an hour Jenna's heart continued to beat, she would no

longer be eligible to be an organ donor as prolonged ischemia would render her organs unusable, and instead she would be taken back to the ICU and receive hospice care. Her family members do not want her to suffer, and they are reassured by her physicians that regardless of whether her organs can be procured and donated, her comfort will be their highest priority. That being said, they are hopeful that she will be able to donate her organs, both so that something hopeful might come from such an immense tragedy and to honor and uphold Jenna's own very clear wishes to be an organ donor.

In the operating room, Jenna is extubated with Dr. K, the medical intensivist overseeing the process. Her breathing continues initially for about 25 minutes and then becomes progressively slower. The team watches as her oxygen saturations begin to dwindle. At about 45 minutes postextubation, Jenna's oxygen saturations drop dramatically. Her heart continues to beat, though slowly. At 52 minutes and 35 seconds, the monitors show asystole, the complete cessation of electrical activity of the heart. A timer is started. One minute passes followed by 2, then 3, then, "What was that?" one of the technicians asks, staring at the heart monitor. A small blip on the rhythm strip had appeared on the screen for less than 1 second. "I think I might have bumped the table," says a nurse. "It's probably just artifact," she adds, turning to Dr. K. Staring at the clock, Dr. K knows that if he counts that small quiver on the screen as a heartbeat, then there will not be enough time left to restart the clock and for Jenna to remain asystolic for the designated 5 minutes. In other words, if it's counted as a heartbeat, Jenna would be sent to the ICU, likely die within minutes of leaving the operating room, and her organs would no longer be viable for donation.

Dr. K considers whether to count it.

### **Commentary**

The practice of organ donation after the circulatory determination of death (DCDD) is increasing in frequency throughout the United States, Canada, and many European countries. This increase results from a greater interest of families of dying patients in donating organs and from the spread of hospital DCDD programs.<sup>1</sup> In the United States, Canada, and the United Kingdom, only "controlled" DCDD is practiced. In controlled DCDD, potential donors are ICU patients dependent on tracheal positive-pressure ventilation, usually because of profound brain damage, whose lawful surrogate decision makers have decided to withdraw life-sustaining therapy (LST) to allow them to die but have requested that they be organ donors after death. By aligning the timing of withdrawal of LST and subsequent circulatory death determination with the readiness of the transplantation surgical staff, the DCDD protocol allows for rapid recovery of organs, usually the kidneys and liver, and occasionally others, before the onset of ischemic organ injury.<sup>2</sup>

In several European countries, the accepted practice is “uncontrolled” DCDD, in which prospective donors are patients who sustained a sudden primary cardiac or respiratory arrest from which they could not be resuscitated. These patients are declared dead and, if deemed to be suitable organ donors, are then intubated, ventilated, and placed on a mechanical chest compression device to maintain oxygenation and circulation prior to organ donation.<sup>3</sup> Trials of these protocols in the United States have failed largely because of the inability to obtain informed consent for donation from a lawful surrogate decision maker in the setting of a sudden unexpected death, usually occurring outside the hospital.<sup>4,5</sup> Uncontrolled DCDD protocols have been conducted most successfully in Spain where the prevailing presumed consent law provides [automatic consent](#) for organ donation unless the potential donor previously had opted out.<sup>6</sup>

This case offers several discussion points centered on the proper management of a prospective DCDD donor, informed consent for DCDD, and the death determination of the donor. In the United States, individual medical centers and organ procurement organizations draft their own DCDD protocols, including the standards for death determination, which often vary, sometimes significantly.<sup>2</sup> Nevertheless, there are accepted general principles<sup>7</sup> and national guidelines<sup>8</sup> that should inform the design of DCDD protocols and improve the uniformity of death determination procedures. In our commentary, we show how the management of the case departs in several ways from established DCDD principles and guidelines, and we discuss several practical and ethical challenges posed by the case.

### **Determining Prognosis and Appropriate Treatment**

The 21-year-old-woman in coma several days following a severe traumatic brain injury (TBI) was said to have a very poor prognosis. However, this prognosis could be overstated because young TBI patients with some brain stem function can occasionally make significant functional recovery.<sup>9</sup> Neurointensivists caring for her must be careful to pronounce a rigorous evidence-based prognosis. The absence of brain stem functioning is an important element in an early prognostic score, often indicating if the patient had undergone uncal transtentorial herniation, which heralds irreversible brain stem damage. It is incumbent on neurointensivists to be confident of a poor prognosis when making decisions to withdraw LST after the first several days following a TBI in a young person to avoid creating a self-fulfilling prophecy.<sup>10</sup> Clarity of [physician communication](#) is essential and a numeric estimate of prognosis on the basis of outcome studies is helpful to avoid family members understanding a different account than physicians think they have presented.<sup>11</sup>

In this case, we were surprised to note that family members began discussing organ donation before discussing their level of certainty that, because of her poor prognosis, Jenna would wish to have LST discontinued and die. Although withdrawal of LST is a prerequisite for controlled DCDD, there is a strong consensus in the medical, ethics, and

organ donation communities that the decision to be an organ donor should be uncoupled from and never drive the decision to withdraw LST.<sup>12</sup> The obvious reason for uncoupling the two considerations is that the instrumental benefit of organ donation should not determine the treatment of the potential donor. The decision to withdraw LST must be made on the basis of determining and following the patient's personal values and preferences to the extent that they can be known. Advance directives can be useful to provide first-person expressed wishes but are unlikely to have been executed by a previously healthy 21-year-old woman and are not mentioned in the case report.

The lawful surrogate first must determine what type of treatment Jenna would have wished to have in this circumstance and then follow it. If the surrogate does not know Jenna's expressed wishes but knows something about Jenna's values and treatment preferences, the surrogate can apply the substituted judgment standard to try to reproduce a decision that Jenna would have made were she capable of deciding. If the surrogate does not know Jenna's values and treatment preferences or expressed wishes, he or she can use the best interest standard to try to weigh prospective benefits against prospective burdens of therapy. Given the family members' claim that Jenna wanted to be an organ donor, perhaps they assumed that, in this situation, she also would have wanted withdrawal of LST to allow her to die. But this omitted step is absolutely essential and should not be glossed over. Ideally, Jenna's physicians first should have asked her lawful surrogate decision maker if Jenna would have wished to receive further life-sustaining therapy given her prognosis. If she would not, then they could raise the option of her serving as an organ donor after the circulatory determination of death.

### **Determination of Death**

The case repeatedly uses the outmoded phrase "cardiac death." Although this phrase, like "nonheart-beating" organ donor, was formerly accepted, over the past 12 years or so it has been replaced by the phrase "circulatory death." The rationale for this change in terminology is that all death statutes in the United States, which are modeled after the Uniform Determination of Death Act (approved by the National Conference of Commissioners on Uniform State Laws in 1981) use the phrase "cessation of circulatory and respiratory functions" to underscore that the absence of circulation determines death, not the absence of cardiac function.<sup>8</sup> Although the heart usually is the source of circulation, other sources include cardiopulmonary resuscitation (CPR), heart-lung machines, and extracorporeal membrane oxygenation (ECMO). These technologies can provide circulation and support life when the heart is stopped or even surgically absent. What counts in a death determination therefore is the cessation of circulation. That is why the word "cardiac" has been replaced by "circulatory" in the acronym DCDD.<sup>2,9,13</sup>

The physicians declaring death in this case apparently required electrical asystole as proof of circulatory death, which is why the presence of the questionable blip on the electrocardiographic monitor created such a problem. But in 2005, a national consensus

was reached within the DCDD community of intensivists and organ donation professionals that electrical asystole, while establishing complete cessation of circulation, is unnecessary, and mechanical asystole constitutes sufficient evidence of circulatory cessation.<sup>7</sup> Thus, pulseless electrical cardiac activity, a common type of mechanical asystole, is considered circulatory cessation. The consensus holds that DCDD protocols for donor death determination should require only mechanical asystole and not electrical asystole as was demanded in this case. Residual electrical activity within the cardiac conduction system that does not generate a cardiac contraction producing circulation therefore is irrelevant to death determination. There might be a few hospitals whose DCDD protocols require electrical asystole for death determination, but the majority do not. If Dr. K.'s hospital protocol complies with currently accepted standards for circulatory death determination, the presence of the questionable electrocardiographic blip in this case would not have been an issue.

The protocol in this case describes a strict adherence to a 60-minute interval after death declaration in which DCDD is permitted. Although it is true that many planned cases of DCDD cannot be conducted because the patient does not die within the time interval after death declaration permitted by the protocol, there are no national guidelines on this time limit and it varies among transplant centers.<sup>7</sup> Many centers respect a 60-minute limit,<sup>7</sup> but some use 90 minutes and others even longer depending upon the preferences of the organ transplantation team. The time limit is stipulated not simply because transplanted organ health declines with longer dying intervals. Rather, it exists because the surgical staff members in the operating room remain scrubbed, gowned, gloved, and ready to procure organs and, as a logistical matter, they cannot wait indefinitely for the potential donor to die. Therefore, each medical center delineates a time limit after extubation based on its own resources such that, if the prospective donor remains alive, the donation is cancelled.<sup>7</sup> In any event, the time limit is not an absolute cutoff (as suggested in this case) and can be negotiated in each case with the transplantation team. If Dr. K.'s hospital still followed an electrical asystole death determination standard, a longer observation period would be necessary in the presence of uncertainty about death determination, as in this case.

### **Palliative Care of the Organ Donor**

The case does not mention donor palliative care during dying from LST withdrawal. There is a clear consensus among critical care and organ donor professionals that, during dying, DCDD donors should receive the same type of palliative care that nondonors receive after LST is withdrawn.<sup>8</sup> Typically, DCDD donor palliative care in dying includes the judicious administration of opioid and benzodiazepine drugs to prevent possible suffering.<sup>14</sup> Only when this palliative care is ordered and administered can Jenna's critical care physicians remain confident that they have fulfilled their promise that "her comfort will be their highest priority." The process of organ retrieval should not interfere with the

dying patient's medical care unless premortem interventions using catheters or drugs are prescribed for organ survival benefit.

### **Informed Consent for Organ Donation**

Additional ethical issues raised in this case include the standards of informed consent for organ donation, including the permissible manipulation of the dying donor for the health of the procured organ. The consent issue encompasses 2 questions that physicians should explain to surrogates: how death occurs in prospective DCDD donors and how organ procurement impacts the dying process. There is evidence that surrogate consent for DCDD currently is inadequate because surveyed surrogates lack an understanding of the process of dying and the impact of donation.<sup>15</sup> Surrogates and other family members deserve to know that withdrawal of LST will be conducted by the patient's critical care physician in the same way as he or she would do in a nondonation situation.<sup>16</sup> But, in this case, for efficiency of donation, the withdrawal of LST will be performed in or near the operating room. In some centers, it is performed in the ICU and immediately following death declaration, the deceased patient is rushed to the operating room for organ procurement. In either location, many DCDD programs permit family members to remain present during extubation and death determination if they wish.

During the consent process, surrogates and family members need to be reassured that the same palliative measures during dying will be ordered as in withdrawal of LST in nondonation circumstances. They should be told that, after extubation, the patient's inadequate respiratory drive will produce respiratory failure, which will induce cardiac arrest within a relatively short time because of progressive hypoxemia. To allow the patient to die, no CPR or other circulatory or respiratory support will be attempted and, by protocol, death will be declared after a full 5 minutes of circulatory and respiratory arrest. Family members also need to be told that there is a reasonable chance that the patient will not die during the prescribed time interval after withdrawal of LST and, if that happens, donation will be cancelled for logistical reasons and the patient returned to the ICU.<sup>2</sup>

The consent process also should include the issue of permissible manipulation of the dying donor for the health of the procured organ. Permissible interventions vary among DCDD programs and remain a controversial subject with wide practice variations.<sup>2,17</sup> Proponents of allowing donor interventions for the health of the organ argue that the donor will die anyway and therefore cannot be harmed significantly and that, furthermore, premortem treatment with catheters, drugs, and fluids might improve donor organ health and therefore the chances of normal functioning of the organ once transplanted.<sup>18</sup> Advocates further claim that because the organ donor wishes to donate and these techniques will lead to more successful transplantation, their use is thereby following the donor's wishes. Opponents argue that it is wrong, even with donor or surrogate consent, to manipulate the living donor or to interfere with the donor's dying

process because it violates the principle of nonmaleficence; although the organ recipient might benefit, the donor does not.<sup>19</sup>

One national guideline proscribes the use of systemic ECMO on the recently deceased donor both because of the invasiveness of ECMO catheter insertion into the living donor and because ECMO in the deceased donor could retroactively negate the preceding death determination by re-establishing circulation to the brain, thereby preventing brain infarction.<sup>8</sup> Some scholars believe that valid donor or surrogate informed consent for premortem interventions adequately resolves the issue of harm from donor manipulation, but others disagree.<sup>17</sup> In any event, it is incumbent on physicians following DCDD protocols to fully explain to surrogates what, if any, premortem and postmortem interventions are planned and to seek surrogates' informed consent.

### **Summary**

The determination of death of DCDD organ donors is an important element in DCDD protocols that requires scrupulous compliance by physicians declaring death. Hospitals should institute DCDD protocols that follow current terminology and accepted technical guidelines, unlike those depicted in several aspects of this case. Physicians should prescribe proper palliative care to the donor during dying. Patients or surrogates should provide valid informed consent for organ donation based on an understanding of the exact plan and procedure for terminal palliative care, donor organ support intervention, death determination, and organ donation.

### **References**

1. Bernat JL. Life or death for the dead-donor rule? *N Engl J Med.* 2013;369(14):1289-1291.
2. Morrissey PE, Monaco AP. Donation after circulatory death: current practices, ongoing challenges, and potential improvements. *Transplantation.* 2014;97(3):258-264.
3. Rodríguez-Arias D, Deballon IO. Protocols for uncontrolled donation after circulatory death. *Lancet.* 2012;379(9823):1275-1276.
4. Munjal KG, Wall SP, Goldfrank LR, Gilbert A, Kaufman BJ, Dubler NN; New York City uDCDD Study Group. A rationale in support of uncontrolled donation after circulatory determination of death. *Hastings Cent Rep.* 2013;43(1):19-26.
5. Kirby J. Is there a particular ethical practice and policy space in North America for uncontrolled kidney donation after circulatory death? *J Law Med Ethics.* 2017;45(1):142-148.
6. Rodríguez-Arias D, Wright L, Paredes D. Success factors and ethical challenges of the Spanish Model of organ donation. *Lancet.* 2010;376(9746):1109-1112.
7. Bernat JL, D'Alessandro AM, Port FK, et al. Report of a national conference on donation after cardiac death. *Am J Transplant.* 2006;6(2):281-291.

8. Bernat JL, Capron AM, Bleck TP, et al. The circulatory-respiratory determination of death in organ donation. *Crit Care Med.* 2010;38(3):963-970.
9. Steyerberg EW, Mushkudiani N, Perel P, et al. Predicting outcome after traumatic brain injury: development and international validation of prognostic scores based on admission characteristics. *PLoS Med.* 2008;5(8):e165. doi:10.1371/journal.pmed.0050165.
10. Souter MJ, Blissitt PA, Blosser S, et al. Recommendations for the critical care management of devastating brain injury: prognostication, ethical and psychosocial management: a position statement for healthcare professionals from the Neurocritical Care Society. *Neurocrit Care.* 2015;23(1):4-13.
11. Quinn T, Moskowitz J, Khan MW, et al. What families need and physicians deliver: contrasting communication preferences between surrogate decision-makers and physicians during outcome prognostication in critically ill TBI patients. *Neurocrit Care.* 2017;27(2):154-162.
12. Childress JF. Organ donation after circulatory determination of death: lessons and unresolved controversies. *J Law Med Ethics.* 2008;36(4):766-771, 610.
13. Gries CJ, White DB, Truog RD, et al; American Thoracic Society Health Policy Committee. An official American Thoracic Society/International Society for Heart and Lung Transplantation/Society of Critical Care Medicine/Association of Organ and Procurement Organizations/United Network of Organ Sharing Statement: ethical and policy considerations in organ donation after circulatory determination of death. *Am J Respir Crit Care Med.* 2013;188(1):103-109.
14. O'Hara C, Tamburro RF, Ceneviva GD. Dexmedetomidine for sedation during withdrawal of support. *Palliat Care.* 2015;9:15-18.
15. Overby KJ, Weinstein MS, Fiester A. Addressing consent issues in donation after circulatory determination of death. *Am J Bioeth.* 2015;15(8):3-9.
16. Bernat JL. Harmonizing standards for death determination in DCDD. *Am J Bioeth.* 2015;15(8):10-12.
17. Bernat JL. Controversies in defining and determining death in critical care. *Nat Rev Neurol.* 2013;9(3):164-173.
18. Magliocca JF, Magee JC, Rowe SA, et al. Extracorporeal support for organ donation after cardiac death effectively expands the donor pool. *J Trauma.* 2005;58(6):1095-1101.
19. Dalle Ave AL, Bernat JL. Uncontrolled donation after the circulatory determination of death [published online ahead of print December 21, 2016]. *J Intensive Care Med.* doi:10.1177/0885066616682200.

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