Controversy and Consensus on Pediatric Donation After Cardiac Death: Ethical Issues and Institutional Process

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ABSTRACT
Donation after cardiac death (DCD) remains controversial in some pediatric institutions. An evidence-based, consensus-building approach to setting institutional policy about DCD can address the controversy openly and identify common ground. To resolve an extended internal debate regarding DCD policy at Children's Hospital Boston, a multidisciplinary task force was commissioned to engage in fact finding and deliberations about clinical and ethical issues in pediatric DCD, and attempt to reach consensus regarding the development of a protocol for pediatric DCD. Issues examined included values and attitudes of staff, families, and the public; number of possible candidates for DCD at the hospital; risks and benefits for child donors and their families; and research needs. Consensus was reached on a set of foundational ethical principles for pediatric DCD. With assistance from the local organ procurement organization (OPO), the task force developed a protocol for pediatric kidney DCD which most members believed could meet all the requirements of the foundational ethical principles. Complete consensus on the use of the protocol was not reached; however, almost all members supported initiation of kidney DCD for older pediatric patients who had wished to be organ donors. The hospital has implemented the protocol on this limited basis and established a process for considering proposals to expand the eligible donor population and include other organs.

Donation after cardiac death (DCD) is offered in an increasing number of US hospitals, but it remains particularly controversial in pediatric institutions. Because of children's vulnerability, including their inability to speak for themselves, special safeguards have been developed for their protection in many areas of clinical care and research. Policies and procedures developed for the care of adults frequently require modification to be appropriate for children. Since DCD involves changes in the end-of-life care of a living child, as well as postmortem donation of the child's organs—and since most children cannot competently choose donation or consent to the associated changes in medical care on their own behalf—special protections for children as prospective donors are needed.

At Children's Hospital Boston (CHB), many staff members wished to make DCD available for families who might find solace in donation when their children died. At the same time, some staff were reluctant to institute a DCD protocol because of ethical concerns for the protection of seriously ill children. Often the same staff members held both values and were simply uncertain whether pediatric DCD could be managed in a way that was compatible with both. In an effort to develop consensus about DCD within the institution, a 17-member, multidisciplinary, hospital-wide task force was appointed to assess what was known about pediatric DCD, to consider both clinical and ethical issues, and to make a recommendation for hospital policy. After nearly 2 years of frequent meetings, detailed review, and debate of issues surrounding DCD, the task force did not reach consensus on all issues; however, it produced an evidence base to inform hospital policy, agreed on ethical guidelines, developed a premortem protocol specifically designed for pediatric kidney DCD, and found common ground in support of DCD for a particular subset of patient-donors.

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ETHICAL CONTROVERSIDIES

Why is DCD so controversial in our hospital and some other pediatric institutions? There are at least three major reasons: greater uncertainty in neurological prognosis for children, greater difficulty in meeting consent requirements, and absence of data from which to predict important patient care outcomes. For example, since children’s brains are more resilient than those of adults, it can be more difficult to predict accurately whether a child’s severe neurological injury is irreversible. Such a prediction is usually the basis for decisions to withdraw life support in patients who would be eligible for DCD. There is concern that a desire to donate organs could lead to premature decisions to withdraw life support from a child who might have recovered meaningful brain function.

Perhaps the most complex of the controversies at our hospital revolved around informed consent. DCD involves a potential conflict in priorities between the end-of-life care of the donor and the preservation of organs for recipients. This conflict is minimized when the donor is a competent adult who wants to become a donor, and especially (though this is rare) when he or she can give informed consent to premortem interventions aimed at organ preservation. In those cases, the donor’s and recipients’ interests can be aligned. The same can be true when the donor is a mature or legally emancipated minor. When the donor is a young child, however, such “first-person” consent is not possible. Parents ordinarily can provide a proxy consent for donation, but in DCD the situation is more complicated than in donation after brain death, because the donation procedure encompasses the medical care of a living (albeit imminently dying) child. When patient care is involved, the standard ethical and legal criteria for proxy consent require parents to make their decisions on the basis of either “substituted judgment” (their view of what their mature child would have chosen for him- or herself) or the “best interests of the child” (for younger children). The “best interests” standard has drawn serious criticism, and limited exceptions have been recognized in other contexts, such as consent for children’s participation in research studies that cannot offer direct benefit to them. Its proper role in cases of extreme neurological injury has also been questioned. Nonetheless, it remains a powerful and long-respected safeguard for vulnerable patients.

A third major concern is the dearth of research on several questions of central importance in evaluating the effects of DCD on the care of dying children and their families. How many minutes after acirculation is it necessary to wait before declaring death in a child? Research on this topic (for patients of any age), though urged by the Institute of Medicine more than a decade ago, has not been forthcoming. How will DCD affect the care of children and their families at the time of the donor’s death, and how will families’ grief be affected over time by the fact that they did or did not choose to participate? Only anecdotal evidence is available to date. Will offering DCD for the relatively small number of medically eligible children have any effect on the overall provision of ICU care to seriously ill children? We are aware of no studies addressing this issue. Yet each of these questions is fundamental to the goals and professional responsibilities of a pediatric hospital and its clinical staff.

A PARTIAL CONSENSUS

Despite the need for information and competing patient-care concerns, the task force reached a partial consensus that offering DCD could be consistent with the hospital’s mission if a protocol could be developed that would meet eight foundational ethical conditions:

1. Each child will be an appropriate candidate for withdrawal of life support under circumstances not involving the prospect of organ donation.
2. The withdrawal of life support process will be consistent with established practices at CHB, and there will be no physical harm, suffering, or hastening of death to the child by the DCD process/protocol. The withdrawal of life support will be conducted in a compassionate and sensitive fashion that respects and preserves the human dignity of the patient.
3. There will be rigorous oversight of protocol development and the subsequent implementation. Resources will be made available to ensure independent oversight and monitoring of the DCD process and outcomes, with controls and authority established to prevent conflicts of interest, variance from the established protocol, and violations of any of these eight foundational criteria.
4. CHB will work with the New England Organ Bank (NEOB) to find mutually agreeable ways of proceeding with DCD, but the implementation of the protocol will not alter the quality of care in the ICU or the trust of families that the welfare of their child is their and the staff’s paramount concern. DCD will be an option for some families, but none will be pressured to see organ donation as an obligation or expectation.
5. Participating families will give genuine informed consent which includes a statement that parents can change their mind at any time in the process. They will be informed of (i) the differences between the orchestration and experience of death, for both their child and themselves, if their child is going to be a DCD donor or not, and (ii) other facts likely to make a difference in their decision (eg, the likelihood of the organs going to another child).
6. The child will clearly be dead, which implies no potential for cognition before organ removal takes place, and our criteria for declaring death, including
"Taking into account the mission of Children's Hospital Boston as a whole, the hospital should adopt a DCD protocol:

... for all possible candidates, including small children and infants"

... only for competent adults and mature or emancipated minors who have signed donor cards or entered their names in a donor registry"

our concept of "irreversibility," will be ethically and medically justifiable.

7. Diversity in religious, cultural, and personal values will be respected. Staff who object to DCD may avoid participation.

8. There will be no extra financial costs to the family from DCD participation.

The task force then developed a DCD kidney protocol that was tailored to meeting these criteria. Specific safeguards were included in the protocol to address each ethical concern. As a result, most members of the task force supported the protocol; however, the group was polarized as to the appropriateness of DCD for younger children or those who had not themselves chosen to be organ donors. Figure 1 indicates the positions of the 17 task force members when asked to represent their views on a 100-mm line ranging from complete disagreement to complete agreement with alternative policy statements regarding the age of the donor child.

A WAY FORWARD

On the recommendation of the DCD task force, our institution has adopted the following approach to moving forward with DCD. First, we will offer DCD at least for the group of patients whose interests most clearly are served by the option to donate: competent adults and mature or emancipated minors who have indicated their desire to be organ donors by completing a donor card or entering their names in a donor registry. We will implement the protocol developed by the task force, beginning with kidney donation. In starting from this position of solid staff support, our primary emphasis will be on doing DCD well for the eligible patients and building positive experiences for our patients, families, and staff.

We view the implementation phase as very important and have developed a specific DCD advisory group to ensure safeguards are followed, staff are supported, and proposed exceptions to the protocol are addressed immediately. Education for all involved staff is a priority, following which feedback regarding the implementation will be sought. Simulation training with the protocol is under development. Community opinion has also been sought with a presentation of DCD and the protocol to the Harvard Community Ethics Consortium. Finally, collaborative relationships with our local organ procurement organization (OPO) must be maintained and fostered.

Consideration is being given to expanding the protocol to additional organs (e.g., the liver) which can be procured successfully with the same safeguards in place, and to including other patient populations as consistent with the 8 foundational conditions and supported by our staff. Further evaluation of critical questions surrounding the time of death is being conducted, based on initial findings by the task force. In addition, we will work with other pediatric institutions to build the research database needed to answer crucial questions about the process and outcomes of DCD for donors and their families. It is hoped that a national consensus will emerge that can inform DCD policy in all institutions that care for children and youth.

REFERENCES


