



Ethics of Approaching Parents for Pediatric Donation After Circulatory Death

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Abstract

Purpose of Review DCD is expanding, and with this expansion, there are emerging ethical issues involved in approaching the parents of a child for DCD. This paper will address those issues.

Recent Findings The ethical issue that has received the most focus recently regarding pediatric DCD is the duration of the waiting period, after death declaration but prior to organ recovery, to ensure lack of autoresuscitation. A growing body of literature exists investigating autoresuscitation, thus providing a little more insight into the process of death determination.

Summary Pediatric DCD involves both the organ donor and the donor family. Informed consent for organ donation is obtained using the best interest model in pediatrics. Full disclosure of the process of DCD is essential to equip parents to make the best decision for their child. Additionally, the clinician must be prepared to explain the process to the families and honestly answer questions they might have about the process of their child's death and organ recovery.

Keywords Pediatric donation after circulatory death · Pediatric organ donor · Withdrawal of life sustaining therapy · Informed consent · Death determination · Autoresuscitation

Introduction

The past few years have continued to see an ever-widening gap between the number of organ donors and the number of patients awaiting an organ transplant. This shortage of organs is seen more dramatically in pediatrics where patients are smaller, leading to size limitations with transplants. Currently, there are just over 1900 pediatric patients less than 17 years of age awaiting an organ transplant [1]. In 2018, there were a total of 875 organ donors under the age of 17 years [1]. A patient must expire prior to becoming an organ donor. The Uniform Determination of Death Act, written into law in 1981, states that 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 brainstem, is dead, and that a determination of death must be made in accordance with accepted medical standards [2]. Thus, in order to become an organ donor, a patient must either meet criteria for neurological death, commonly referred to as brain death, or become an organ donor through a process known as donation after circulatory death (DCD). It is paramount that organ recovery does not result in the patient's death, thereby following the Dead Donor Rule (DDR) which is an internationally accepted ethical norm. DCD utilization has increased dramatically over the past 25 years, with adult donors leading in numbers but an increase has also been noted in pediatrics. In 2018, there were 133 DCD donors under the age of 17 years while a mere 10 years prior, there were only 73 DCD donors under the age of 17 years [1]. This increased utilization of DCD has the potential to increase the pediatric donor pool. As well, increased utilization requires good clinician understanding of the processes and implications, both clinical and ethical, which accompany DCD. Importantly in pediatrics, there also needs to be special attention towards the approach, communication, and education of parents of potential DCD donors.

Although DCD has only seemingly recently become an accepted and adopted method to donate organs, it is important to realize that the first organ donors were DCD donors. The

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first kidney and liver transplants in the 1950s and even the first heart transplant in 1967 were performed from organs obtained from donors who were declared dead based on cardiorespiratory criteria. Neurological criteria for death was only beginning to be established in 1968 when the Harvard ad hoc committee published their report on neurologic death [3]. Now that there exist criteria to declare neurologic death, this is the method by which most organs are recovered as organs can be recovered and transplanted from someone who, although legally dead, still has circulatory function and thus adequate tissue and organ oxygenation. Because DCD relies on cessation of cardiorespiratory function, there does run a risk of these organs sustaining some ischemic damage prior to organ recovery.

DCD Process

Prior to exploring the ethical implications that surround DCD, it is important to first understand the process and the steps involved (Fig. 1). Eligibility for DCD requires that a patient has sustained a catastrophic neurologic insult with little to no hope of recovery of brain function. It is important to note that these patients do not meet criteria for neurologic death. After

discussion with the family and the medical team, a decision is then made to withdraw life sustaining therapies (WLST) and at that time usually a do not resuscitate (DNR) order is placed in the chart.

As an example, consider a previously healthy 6-year-old who is admitted to the Pediatric Intensive Care Unit (PICU) following a drowning event and subsequent cardiopulmonary arrest at the scene with ultimate return of spontaneous circulation following aggressive resuscitation by medical personnel. Following a period of stabilization and constant reassessment in the PICU, the medical team determines that the hypoxic injury sustained to her brain is so severe that she has no hope of a meaningful recovery. Importantly, the medical team also notes that she does not meet criteria for neurologic death as she still has irregular but spontaneous respirations noted. Following numerous discussions with the family, they decide that although their daughter does not meet criteria for neurologic death, she is no longer the same 6-year-old girl they previously had and they do not wish her to have a life attached to ventilators and tube feeding. They decide that WLST is in her best interest. This example highlights the type of patient who would be a candidate for DCD; one that suffered a catastrophic neurologic insult but ultimately did not progress to neurologic death.

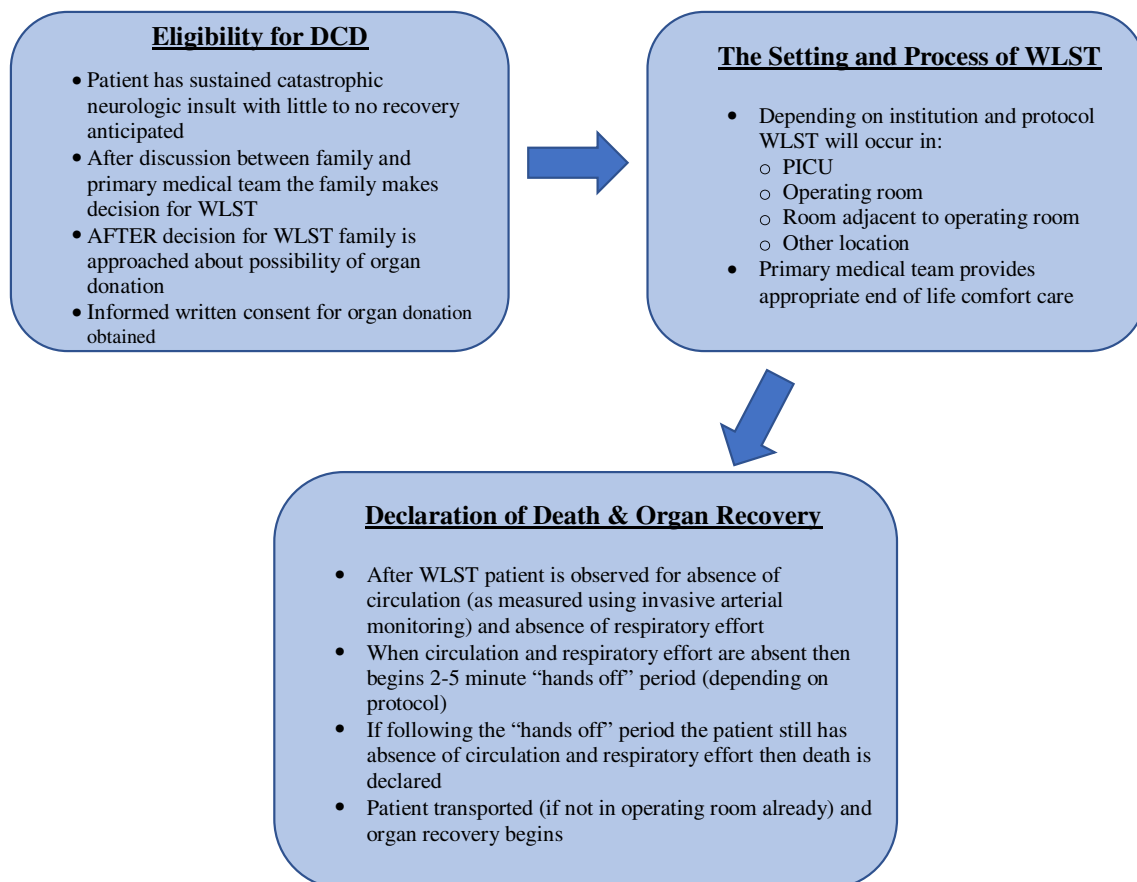


Fig. 1 Processes and considerations involved in pediatric DCD

Depending on the institution, then a trained requestor will approach the family and introduce the options for organ donation. It is mandated by law that every family of a deceased or soon to be deceased individual is approached regarding organ donation [4]. What is paramount in this discussion is that there is clear separation between the medical team caring for the patient and the team approaching the family regarding donation, this is termed “decoupling”. Following this discussion, then informed written consent is obtained from the family. The setting for WLST is variable dependent on the protocol for each institution but normally occurs either in the PICU or the operating room. During WLST, the primary medical team provides standard end of life care. Once there is absence of circulation and respiratory effort, then death is declared and a 2–5-min “hands off” period begins. The duration of the “hands off” period is protocol dependent and can vary. After this time if circulation and respiratory effort remain absent, then the patient is declared dead and taken for organ recovery. Most protocols require declaration of death within 60 to 90 min of WLST to ensure that the organs that are recovered have not sustained significant warm ischemic injury. If the patient does not die within the allotted time, then they are no longer a donor candidate and end of life comfort care continues and the patient may require transfer back to the PICU.

DCD is endorsed by numerous medical societies including the American Academy of Pediatrics, Society of Critical Care Medicine and the Institute of Medicine [4–6]. However, despite these endorsements and its increased utilization, there remain some ethical concerns over the practice, with some of these concerns more specific to pediatric DCD. These include obtaining informed consent for a pediatric DCD donor, approaching the family of a potential DCD donor and how death is determined in DCD. This review will focus on these ethical dilemmas as they relate to pediatric DCD.

Ethical Issues to Consider Regarding Pediatric DCD

Informed Consent

The doctrine of informed consent is a key ethical pillar by which a patient’s autonomy is recognized and respected. Children and adolescents cannot give informed consent as they are not recognized as having full autonomy. There are exceptions for informed consent in pediatrics and these include emancipated minors and mature minors. For this reason, the best interest standard is utilized widely, in which parents make decisions on behalf of their child, considering their special relationship with the child. And this decision is considered, in most cases, to be in the best interest of the child [7]. It is a rare scenario in which a child has discussed their prior desire to be an organ donor, although it has occurred as

described by Hoover et al. in which interviews with parents of children who were DCD donors made the decision to donate in order to “honor their child’s preference” [8]. More likely the wishes of the child regarding organ donation are unknown as they are not eligible for listing on donor registry’s and would not have a donor card. Thus, when considering the decision a parent makes on behalf of their child regarding organ donation, most would consider the benefits and risks that the decision might incur on the child. In the case of organ donation, there seems to be no direct, physical, benefit to the donor but rather a direct benefit to the organ recipient. While this is true, people cite that most organ donors are acting on behalf of an intrinsic altruistic hope that they can help others when they choose to be an organ donor. Can this hold true for children as well? It is not known at exactly what age someone develops an understanding of altruism; however, some people truly question whether a child is capable of understanding such a concept and as such would organ donation be what they would truly want [9]. Regardless of our direct knowledge of a child’s appreciation and desire for altruism, it is nearly impossible to know if a child, when posed the question, would want to be an organ donor. But the family is best poised to make this decision given their intimate and close relationship with the child over the years as well as considering the values and culture of the family as a whole. As such, it is important that regardless of the decision to become a DCD donor or not, that the parental decision regarding organ donation for their child be respected. Through doing this, we are able to respect the parental role as guardian and decision maker for a child and indirectly then respect the burgeoning autonomy of the child.

Another aspect of obtaining informed consent for DCD from the parents of a child is that of full disclosure about the process and potential outcomes. Parents must be informed that following declaration of death, organ recovery will immediately occur. Although some may view this as a burden on parents, limiting their time with their now deceased child, alternatively for those families who feel donation, is very important; it will likely help with grieving and closure. Regardless the medical team cannot anticipate in what fashion the family will need to grieve and as such it is important to provide families of potential DCD donors with the facts regarding the process. Parents must also be informed that at any time, they can change their mind and stop the DCD process. As well, many families who agree to DCD anticipate that donation will definitely occur. It is important to ensure that the family knows the time limitations regarding DCD and that if the child does not die within a certain amount of time, then donation is no longer an option and standard comfort care will continue and may even require transfer of the patient back to the PICU. This is important because some parents have described their child’s inability to ultimately donate due to not dying within an allotted time as a “second loss” or that it

heightened the pain of an already devastating loss [10]. In the process of obtaining informed consent from parents regarding DCD, it is important to ensure that parents are provided with information and support, and feel as though they have made the right choice, one in their child's best interest, to pursue DCD.

Components of Parental Approach for DCD

Although informed consent from the parents is required for pediatric DCD, it is important for the medical team to consider the actual parental approach for obtaining this consent. As stated earlier, there needs to be separation between the medical team caring for the child and the individual approaching the parents for donation. This is termed “decoupling”. To prevent conflicts of interest, the decision to WLST should be separate from the decision to attempt to donate organs [5, 8, 11•, 12, 13]. Additionally, when considering the approach to families regarding DCD, it is inappropriate for the medical team to decide if the family should be approached about donation, as the law mandates that everyone must be given the opportunity to be an organ donor [4]. One study of staff perspectives regarding pediatric DCD demonstrated that medical providers were concerned with bringing up DCD unless the family initiated it [9]. While alternatively others felt like not providing the option to the family because the medical team did not feel it was appropriate would leave a family with regret if they had in fact wanted to donate [9]. By approaching all parents regarding pediatric DCD, regardless of the opinion of the medical providers, autonomy of the family and patient are respected.

Declaration of Death

Finally, an additional aspect of DCD, both pediatric and adult, that has stirred ethical controversy is the determination of death during the process of DCD. As stated earlier, the UDDA requires *irreversible* cessation of circulatory and respiratory function. There is no way to know the exact moment when these functions become irreversible. The “hands off” period used during DCD protocols acts as a proposed safety mechanism to ensure that these functions will not return, as the patient is monitored for evidence of autoresuscitation. Autoresuscitation is the spontaneous return of cardiac activity and circulation. Case reports have demonstrated that in pediatrics, following failed attempts at resuscitation, not simply WLST, that autoresuscitation has not been observed to occur beyond 2 min [14••]. While autoresuscitation can be used to provide the medical team with some assurance that cardiorespiratory function will not resume, it does little to ensure that the patient has lost ALL neurologic function and importantly the ability to still feel pain at time of organ recovery. This has become a

recent topic of interest among bioethicists and clinicians as there is no definitive data to provide guidance on this matter. Veatch states that there is no reason to believe that brain function is lost at the exact moment autoresuscitation is ruled out [15••]. This fear resonates even within the medical community as surveys done with pediatric intensivists and pediatric intensive care nurses have both demonstrated up to 11% of respondents fearing that the DCD donor may feel pain during organ recovery [16, 17]. Very few studies have looked at EEG tracings during WLST in the context of DCD, to better understand this growing concern further studies are warranted [18, 19]. While these concerns may prompt robust discussions among intensivists and bioethicists, it is important that the providers caring for possible DCD donors be aware of this as parents might ask questions such as “will my child feel pain during organ recovery” and “how can you be sure that my child has died”. As a pediatric practitioner, your job is not only to provide direct medical care to the child but also to support the parents and family through such a difficult time and an important component of that support is honesty and empathy in your communication with them.

Conclusion

Pediatric DCD is gaining wider acceptance and being more broadly utilized since its reintroduction. Because of this, it is important for medical providers to be cognizant of some of the ethical issues surrounding pediatric DCD. These include the process of obtaining informed consent from the parents of the child and providing them with accurate and honest information so that they can make a decision grounded in the best interest of their child regarding organ donation. As well, the parental approach regarding DCD should be thoughtfully considered from ensuring that there is decoupling of medical care and request for organ donation to not allowing individual providers' thoughts regarding what a certain family may want regarding organ donation to tarnish their opportunity to allow their child to become an organ donor. Finally, the process of death determination is fraught with ethical concerns, primarily surrounding the specifics of the DCD protocol to ensure the child has died prior to organ recovery. The death of a child is undoubtedly the hardest thing a family can go through and it is important that medical providers be well versed in their ability to communicate prognosis and end of life choices including WLST and the opportunity for organ donation. Ensuring that parents are provided with these choices during such a difficult time is important, because ultimately it is the parents that will have to live on with both the memory and absence of their deceased child.

Compliance with Ethical Standards

Conflict of Interest Ahmeneh Ghavam declares no conflict of interest.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

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