

# Organ Donation in Pediatric Patients with Severe Anoxic Brain Injury

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## Abstract

Anoxic brain injury in children is a rare and devastating occurrence. Families are shocked by the unexpected nature of their child's neurologic injury, which may be the result of a sudden and prolonged cardiac arrest. Organ donation in these children is subject to much discussion and controversy. Recently, we encountered three pediatric patients with anoxic brain damage who progressed to brain death within a few days of admission. Pediatric palliative care was involved from the time of arrival to the hospital in all the patients. The team served as a critical conduit to support families and helped in managing end-of-life decisions including organ donation. All three families consented to organ donation. We discuss here the patients, the palliative care involvement, and the factors responsible for successful donation.

**Keywords:** Organ donation, pediatric intensive care, pediatric palliative care

## INTRODUCTION

There is a persistent mismatch between the supply of and demand for transplantable organs worldwide, resulting in deaths of individuals on the waiting list. The decision – making process of parents to donate organs of their deceased child with anoxic brain injury is very traumatic and difficult. It is greatly influenced by delay in initiation of brain death protocols to deal with the shock, their expectations from the health care professionals during the pre- donation period and early involvement of the palliative care team. The team counsels and supports the family emotionally and spiritually.

We present patients who were admitted with severe anoxic brain injury and discuss the invaluable role played by the pediatric palliative care team both for successful organ donation and in supporting the bereaved parents.

## CASE REPORTS

### Case 1

A 17 year old girl was admitted to our Pediatric Intensive Care Unit (PICU) after a cardiac arrest at home from a heroin overdose. There was return of spontaneous circulation after resuscitation efforts by emergency medical services. However, on admission, she had minimal cranial nerve

activity. She was managed with maximal medical therapy. On the 3<sup>rd</sup> day, she lost complete brain stem functions and was declared brain dead.

### Case 2

An 11 year old boy was admitted to PICU after he hanged himself in his bedroom. On arrival, he had no cranial nerve activity. On the second hospital day, all brain electrical activity was lost and he developed central diabetes insipidus. He was declared brain dead on the third hospital day.

### Case 3

A 17 year old girl with known pulmonary arteriovenous malformations (Osler–Weber–Rendu disease) was admitted with hemoptysis. After admission, she had a massive bout of hemoptysis leading to profound and refractory hypoxemia. She suffered a cardiac arrest for which she underwent extracorporeal membrane oxygenation. On stabilization, she had minimal brain activity and was subsequently declared brain dead.

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## DISCUSSION

The overall mortality rate in PICU across US teaching hospitals is around 5% that is well below the adult critical care units. While the mortality rate in children has nearly halved, the mode of death in the PICU has been proportionally same over the past two decades.<sup>[1]</sup> The causes of decrease in mortality are likely due to the quality of care and more permissive admission criteria. The number of medically suitable patients who die within 2 h of planned withdrawal of life-sustaining therapy is nearly six times higher than the actual organ donors. The loss is due to delayed referral until at the time of or after planned withdrawal of life-sustaining therapy.<sup>[2,3]</sup>

Currently, more than 119,000 people are on the organ transplant waiting list, of which approximately 2000 are children under the age of 18.<sup>[4]</sup> The number of children on the transplant waiting list far exceeds the available pediatric organs.<sup>[5]</sup> The general public has good understanding of organ donation; however, only half of the family members approached are agreeable to donating the organs of their deceased child. This illustrates the critical need for early conversation about organ donation with the family of a brain-dead child.

Despite the dire need for organs, there are only few studies that have assessed the factors that influence decision-making process.<sup>[6,7]</sup> Decision-making at the end of life for children is the most traumatic and difficult experience families will ever encounter. The profound responsibility for counseling lies in the hand of the clinicians who care for them.<sup>[1,7,8]</sup> The palliative care team's role is invaluable to address the medical, psychological, social, and spiritual concerns of families and to empower them in making decisions.<sup>[9,10]</sup>

Counseling allows the parents of brain dead children time to reflect to deal with the imminent shock before being approached by the organ donor network.<sup>[7,8,10]</sup> The context in which the information was shared, including sensitivity with attention to emotional needs, was the greatest impact factors in prior studies. Physician's attitudes including comfort in discussing brain death in a sensitive and timely manner have historically increased the success rate of consent for organ donation.<sup>[11]</sup> Delay in initiating brain death protocols appears to increase the willingness to participate and thereby increase the rates of donation.<sup>[6-8]</sup> In these studies, the authors concluded that the family members had time to deal with the initial shock of the trauma without dealing with the additional stress of a decision regarding organ donation. Privacy within the PICU along with a noncramped waiting area away from the PICU where families could talk, discuss, and cry were mentioned as a great need in such situations.<sup>[10]</sup>

Four main categories were identified that influenced families' ability to agree or decline donation and their perspective of the decision-making process: knowledge of the deceased donation wish, views of the extended family, giving meaning to the death, and events that occurred in the hospital before the death of the child.<sup>[7,11]</sup>

Prior knowledge of a donation wish was thought to be an important factor in the decision-making process. Rates of adult organ donation and transplantation have increased steadily in the US and Canada, over the past decade due to increase in donation after circulatory death.<sup>[2]</sup> The reason for such success is mostly due to prior donation wish, but there is, however, no such data in children. An interesting fact noted in one study was that those with donor designation on their drivers permit were not more likely to become donors.<sup>[6]</sup> Donation wish or autonomy (the right of self-determination) does not hold for children, because they lack capacity; hence, we respect their wishes based on the best interest of the child as determined by the surrogate decision-maker, usually parents or a family member.<sup>[12]</sup>

In hospital care, including involvement of palliative care in collaboration with intensivists to counsel families to facilitate decision-making, were crucial to understand the emotional needs. This has demonstrated to greatly impact donation decision-making.<sup>[7,11]</sup> Further, familiarity with the professional who formally asked for donation was associated with better outcomes.<sup>[6]</sup> Parents of children hospitalized for longer period before death had time to understand and process the information.<sup>[6]</sup> A collaborative approach between palliative care team, intensivists, and organ procurement officers is the need of the hour and is often a lengthy process. Studies have revealed that families who did not donate reported that their decision was influenced by poor communication and the fact that not enough was done to save the life of the deceased child. Cultural barriers, negative views of other family members, and lack of knowledge about the donation process were other compounding factors. One study of nondonor families mentioned that few parents in their survey said that they were afraid that doctors would declare death too soon if they consented and others said that it may lead to prolongation of life in the ventilator and thereby delay the child's funeral.<sup>[13]</sup> Some parents also had the misconception that they would not be able to have an open casket.<sup>[11]</sup> Another study reported that incentives to increase organ donation in the form of cash payments or rewarded gifting was not effective.<sup>[11]</sup>

More than 1850 pediatric transplants were performed in 2016, with studies highlighting excellent clinical outcomes and quality of life for many patients.<sup>[4]</sup> Increasing organ recovery allows for more pediatric transplants and fewer pediatric waitlist deaths.<sup>[14]</sup> Despite the favorable outcomes, scarcity of donated organs continues to be the primary limiting factor in pediatric transplantation.<sup>[6]</sup> There is increased utilization of pediatric grafts by pediatric recipients and is likely a result of change in network allocation protocols. Children with end-stage liver disease had a scoring system and a regional sharing of pediatric donor livers was implemented. Policy changes were also enforced to give children organs from deceased donors <35 of years. Size matching is an important component of organ donation with techniques such as split, reduced liver grafts increasing the pediatric recipient pool and decreasing waiting times.<sup>[14]</sup>

The bereavement support ranging from opportunity to lay down with the deceased, offering legacy such as hand and footprints, and the presence of spiritual counselors made positive impact for consent for donation.<sup>[7]</sup> It was suggested that the presence of a chaplain in the transplant team can actually facilitate the organ donation in addition to supporting families who have faith or no particular faith.<sup>[10]</sup> Following the declaration of death, families should be supported until they leave the hospital and follow-up calls should be made at regular intervals including referral to bereavement support groups. The bereavement care given to the families was much valued and remembered. Organ donation without palliative care service increases the risk of suboptimal end-of-life care and complicated bereavement.<sup>[12]</sup>

Lastly, all ethical principles apply in organ donation. Ethically, the act of recovery of organs does not cause any harm in a dead donor (nonmaleficence). Beneficence – the principle of doing good – is projected here as the potential donors, and families were given the opportunity to provide them comfort and knowing there is a meaning behind the death to save another individual. Justice is fair allocation of resources, when a person dying on an organ transplant list has the right to access life-saving organs from someone one who can no longer use them.<sup>[15]</sup>

### Summary

The impact of early referral and involvement of pediatric palliative care providers in children with acute, severe anoxic-ischemic encephalopathy is crucial. The decision to donate organs is the direct result of honest communication, timeliness, sensitivity, and the satisfaction of care that was received for the child. Deployment of the multidisciplinary members to support families during this traumatic time helps in the bereavement process.

### Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent forms. In the form the patient(s) has/have given his/her/their consent for his/her/their images and other clinical information to be reported in the journal. The patients understand that their names and initials will not be published

and due efforts will be made to conceal their identity, but anonymity cannot be guaranteed.

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### Conflicts of interest

There are no conflicts of interest.

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