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#### **PATIENT CARE**

# **Pediatric Organ Donation Following Neurological Determination** of Death: A Perspective and Review of Current Guidelines

## Jeff F Zhang BS\*

Jacobs School of Medicine and Biomedical Sciences, University at Buffalo, Buffalo, New York, USA

\*Corresponding author: Jeff Zhang, Jacobs School of Medicine and Biomedical Sciences, 955 Main Street, University at Buffalo, Buffalo, New York, USA



#### Abstract

Organ donation in pediatric patients following brain death is a difficult process, fraught with both emotional and logistical challenges. However, due to the relative infrequency in which pediatric brain death occurs, the possibility for organ donation from this patient population can be of extraordinary benefit and lifesaving for other pediatric patients suffering from organ failure. This paper reviews the case of a 15-month old infant who developed death by neurological criteria following Streptococcal meningitis infection and outlines the process by which organ donation occurs in hospitals in the United States for all patients in general and for pediatric patients in particular.

#### **Keywords**

Brain death, End-of-life care, Neurology, Organ donation, Pediatrics, PICU

### Introduction

Compared to adult patients, brain death in pediatric patients is a fairly rare occurrence. It has been estimated that brain death accounts for 2.06% of hospital deaths, with only 7.71% of those patients being under the age of 18 [1]. The most common cause of brain death in pediatric patients is cardiac arrest, with trauma, respiratory failure, drowning, and infection less common causes [2]. Due to the infrequency of brain death in pediatric patients, the possibility of organ donation in these patients can provide an invaluable and lifesaving opportunity for other children suffering from organ failure. However, due to rarity of cases, the complex process by which pediatric organ donation occurs is often difficult to navigate by inexperienced hospital systems and fraught with both emotional and

logistical challenges.

In this paper, I will present the case of a 15-month old infant who developed death by neurological criteria following Streptococcal meningitis infection. I will then review organ donation protocols in the United States, for all patients in general and for pediatric patients in particular.

### **Case Presentation**

The patient was a 15-month old, term-born, infant with no significant past medical history who presented to the emergency department with fever and lethargy over the prior four days. He had initially been admitted three days ago and diagnosed with Streptococcal meningitis. Following initial stabilization, the patient was discharged and given a prescription for antibiotics, but the parents admitted they were never given to the patient due to problems with their insurance and obtaining the medications. Over the past 24 hours, he became progressively lethargic and his mother reported he developed nystagmus and a rash over his trunk. He was then brought to the emergency department, where he was intubated, given one dose each of Ceftriaxone, Vancomycin, and Ativan, and started on 230mL of normal saline and 100mL of 5% dextrose. Lab work at that time was significant for glucose low at 58, leukocytes (WBC) elevated at 11,700 (neutrophils 53.4%), aspartate aminotransferase (AST) 283, alanine aminotransferase (ALT) 71, alkaline phosphatase 194, and consumptive coagulopathy with platelets at 43,000. Due to the patient's worsening condition, he was transferred to the pediatric intensive care unit (PICU).

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Upon admission to the PICU, the patient was judged to be in septic shock and started on Norepinephrine and fluids for blood pressure stabilization, continued on vancomycin and cefepime antibiotics, and had blood, tracheal, urine, and cerebrospinal fluid (CSF) samples drawn for culturation. Plasmapheresis was initiated to correct thrombocytopenia caused by consumptive coagulopathy. Neurological exam noted minimal responses to stimuli with hypertonia and hyperreflexia appreciated on physical examination. CT scan on admission showed loss of gray-white differentiation; follow-up MRI showed signs of cerebritis, diffusion abnormalities, and ventricular enlargement. External ventricular drain (EVD) placement was inserted on the third day of hospitalization. However, despite therapy, the patient's condition continued to deteriorate and he never regained consciousness after hospital admission.

Following multiple meetings with the patient's family regarding his poor prognosis, the parents decided to withdraw care and initiate comfort measures only on day eleven of hospitalization. The parents also expressed an interest in organ donation and consultations between the PICU, cardiology, neurology, and neurosurgery teams with an external organ procurement organization (OPO) were begun. Due to the inability of the attending physicians to guarantee that the patient would expire during organ retrieval within a timeframe compatible with the OPO's operating policies (specified to be within 1-2 hours following withdrawal of life support and placement in the OR), the family was consulted again and decided to decline proceeding with organ donation due to concerns of causing prolonged patient suffering prior to expiration. Two days following this discussion, the patient's EVD was removed and the patient was extubated. Fentanyl was started and the patient was given multiple boluses of Morphine at increasing doses due to signs of discomfort over the following hours. The patient developed dyspnea and eventually progressed to asystole late in the night and was declared dead at 10:53 PM. The patients refused further medical examination postmortem.

#### Discussion

The decision to donate a child's organs following their untimely death is one of the most heart-wrenching decisions a parent can make. Yet it can also be one of the most fulfilling and gratifying, and bring families a sense of closure knowing that their child's legacy will live on in the good that such a donation is be able to do for others. It is estimated that every nine minutes, a new patient is added to the national transplant waiting list, and that seventeen people die every day while waiting for a transplant [3]. Donated organs may include the heart, lungs, kidneys, liver, and pancreas; additional tissues include bones, ligaments, tendons, intestines, heart valves, and corneas. A single donor can save the lives of up to eight other individuals awaiting organ transplantation and donated tissues can benefit up to 75 others [3].

Organ donation in the United States follows the informal principle of the "Dead Donor Rule," which stipulates that organ retrieval can only occur in patients who have been legally declared dead due to complete cessation of either circulatory function (cardiac death) or neural activity (brain death). The concept of brain death has been historically controversial, but over the past 30 years, multiple medical organizations and international regulatory agencies has reached a consensus to define brain death as the irreversible cessation of cerebral and brainstem function resulting in the complete loss of consciousness, spontaneous movement, cranial nerve function, and respiratory drive [4]. Before a determination of brain death can formally be made, patients undergoing evaluation for brain death must be worked up to rule out any potentially reversible causes for neurological impairment, including metabolic dysfunction, toxicosis, over sedation, hypothermia, or hypotension. Proper neurological evaluation is crucial for the organ donation process due to the fact that, in the US, over 92% of transplantable organs are recovered as "donations after neurologic determination of death" (DNDD) [5]. This means of donation is preferred over "donations after cardiac determination of death" (DCDD) due to multiple studies demonstrating that DNDD is correlated with improved graft survival and transplant outcomes, likely resulting from the preservation of circulatory function and organ perfusion up until the moment of operative retrieval [4].

In order to declare brain death in a child, two separate clinical exams must occur at specified time intervals: at least 24 hours between evaluations for neonates and at least 12 hours between evaluations for children older than one month [6]. The physiological consequences following brain death are complex and multifaceted, and therapeutic management must be carefully undertaken in order to maintain organ integrity. Posterior pituitary dysfunction can lead to hormonal insufficiency, resulting in the development of central diabetes insipidus and hypovolemia which must be managed with fluid resuscitation and vasopressin administration [7]. Dysregulation of the autonomic nervous system can cause cardiovascular instability, requiring inotropic and vasopressor therapy to preserve circulation to potential donor organs [7]; compensatory measures including extracorporeal oxygen support and dialysis for fluid removal should be prepared in anticipation of potential cardiac arrest [7]. Lung injury secondary to neurogenic pulmonary edema can decrease the viability of lung tissue for donation and should be managed with diuretics, protective ventilation, patient positioning, and suctioning [7]. Progression of neural excitotoxic damage can eventually lead to necrosis of the parasympathetic nuclei in the medulla, resulting in the development of an "autonomic storm" of unregulated catecholamine release [8], with subsequent sympathetic exhaustion and catecholamine depletion precipitating rapid declines in heart rate, blood pressure, and myocardial contractility.<sup>9</sup> Such complications must be managed immediately with compensatory therapy and medications in order to prevent end organ ischemia and allow for the organ donation process to proceed as planned.

Following the expressed interest of the patient's family in pursuing organ donation, an initial evaluation is made to judge organ function and suitability, as well as to screen for viral infections and other immunological concerns. Information related to the patient's height, weight, and blood type is used to determine appropriate candidates for subsequent (and often immediate) transplantation following organ recovery. The process of organ retrieval then proceeds in stages with clear, defined roles for all providers involved to ensure a coordinated plan of action, and, when possible, with accommodations made to address the wishes and concerns of the patient's family. An operating room is made available and prepared to receive the patient, withdraw life support, and provide comfort measures prior to initiation of the organ recovery process. Declaration of death occurs when circulation stops and does not spontaneously restart after a waiting period of between two to five minutes-the criteria for circulatory failure. All OPOs in the United States observe the principle of "delayed cessation of circulation," which stipulates that a patient is no longer considered a candidate for organ donation if he/she does not develop circulatory failure within a predetermined time interval (usually between one to two hours) following withdrawal of life support. In the case of our patient, a preemptive determination was made that our patient was unlikely to expire within the one to two hours required by the OPO associated with our hospital, and therefore the patient was not deemed eligible to begin the process of organ donation. Once circulatory death is declared, the organ procurement process must proceed immediately to reduce the risk of ischemic damage which could compromise organ function. Organs are retrieved in sequential order according to tissue sensitivity to hypoxia; generally, the heart and lungs are removed first, then the liver and kidneys [10]. Following successful retrieval, recovered organs are exsanguinated and perfused with a hypothermic preservative solution, and then transported on ice to a hospital where a recipient is awaiting their transplantation procedure.

While pediatric organ donation can be a way to bring comfort and healing to a family undergoing the tragedy of losing their child, the process can also prove to be an emotionally challenging one. Throughout the process, physicians must remain empathetic and proceed with the organ recovery process in a manner that reassures the family that the patient's dignity is respected at every step along the way. When performed in a professional manner and with compassion, physicians can find themselves as facilitators of a family's healing process, as organ donation becomes a means by which family members are able to transform the pain of losing a child into a feeling of fulfillment that the legacy of their child is able to live on in another.

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