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Epidemiology of Brain Death in Pediatric Intensive Care Units in the United States

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IMPORTANCE Guidelines for declaration of brain death in children were revised in 2011 by the Society of Critical Care Medicine, American Academy of Pediatrics, and Child Neurology Society. Despite widespread medical, legal, and ethical acceptance, ongoing controversies exist with regard to the concept of brain death and the procedures for its determination.

OBJECTIVES To determine the epidemiology and clinical characteristics of pediatric patients declared brain dead in the United States.

DESIGN, SETTING, AND PARTICIPANTS This study involved the abstraction of all patient deaths from the Virtual Pediatric Systems national multicenter database between January 1, 2012, and June 30, 2017. All patients who died in pediatric intensive care units (PICUs) were included.

MAIN OUTCOMES AND MEASURES Patient demographics, preillness developmental status, severity of illness, cause of death, PICU medical and physical length of stay, and organ donation status, as well as comparison between patients who were declared brain dead vs those who sustained cardiovascular or cardiopulmonary death.

RESULTS Of the 15 344 patients who died, 3170 (20.7%) were declared brain dead; 1861 of these patients (58.7%) were male, and 1401 (44.2%) were between 2 and 12 years of age. There was a linear association between PICU size and number of patients declared brain dead per year, with an increase of 4.27 patients (95% CI, 3.46-5.08) per 1000-patient increase in discharges ($P < .001$). The median (interquartile range) of patients declared brain dead per year ranged from 1 (0-3) in smaller PICUs (defined as those with <500 discharges per year) to 10 (7-15) for larger PICUs (those with 2000-4000 discharges per year). The most common causative mechanisms of brain death were hypoxic-ischemic injury owing to cardiac arrest (1672 of 3170 [52.7%]), shock and/or respiratory arrest without cardiac arrest (399 of 3170 [12.6%]), and traumatic brain injury (634 of 3170 [20.0%]). Most patients declared brain dead (681 of 807 [84.4%]) did not have preexisting neurological dysfunction. Patients who were organ donors (1568 of 3144 [49.9%]) remained in the PICU longer after declaration of brain death compared with those who were not donors (median [interquartile range], 29 [6-41] hours vs 4 [1-8] hours; $P < .001$).

CONCLUSIONS AND RELEVANCE Brain death occurred in one-fifth of PICU deaths. Most children declared brain dead had no preexisting neurological dysfunction and had an acute hypoxic-ischemic or traumatic brain injury. Brain death determinations are infrequent, even in large PICUs, emphasizing the importance of ongoing education for medical professionals and standardization of protocols to ensure diagnostic accuracy and consistency.

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In the United States, the Uniform Determination of Death Act defines death in the following way: "an individual who has sustained either (1) irreversible cessation of circulatory and respiratory functions (ie, cardiovascular or cardiopulmonary death) or (2) irreversible cessation of all functions of the entire brain, including the brain stem (ie, death by neurologic criteria or brain death) is dead."[1,2] The Uniform Determination of Death Act or a similar statute has been adopted in all states.[3] Guidelines for the determination of brain death in children were published by the American Academy of Pediatrics in 1987 and then revised in 2011 by the same organization in conjunction with the Child Neurology Society and the Society of Critical Care Medicine.[4-6] In the United States, brain death is exclusively diagnosed in intensive care unit (ICU) settings owing to the need for mechanical ventilatory support. Based on 2 small studies, the estimated prevalence of brain death is approximately 15% of deaths in large academic US pediatric intensive care units (PICUs).[7,8]

Despite widespread medical, legal, and ethical acceptance, ongoing controversies exist with regard to the concept of brain death and procedures for its determination.[9-12] A quality improvement summit convened by the American Academy of Neurology to address contemporary concerns associated with brain death determination established a set of goals to improve public trust in the brain death determination process.[13] Work toward those goals, including the development of training resources, unifying policies, and standardizing protocols, relies on a more complete understanding of contemporary epidemiology of brain death in children in the United States.

We have therefore conducted this detailed analysis of the epidemiology and clinical characteristics of children declared brain dead in a large national multiinstitutional and geographically diverse PICU database. The identification of the demographics and clinical characteristics of children who are declared brain dead will help define where further research and educational resources may be needed to guide both health care professionals and the public in managing these clinically and socially challenging cases.

Key Points

Question What are the epidemiology and clinical characteristics of patients declared brain dead in US pediatric intensive care units (PICUs)?

Findings In a national database study of 15 344 patients who died in PICUs, brain death occurred in 20.7% of pediatric deaths, primarily in children without preexisting neurological dysfunction and from an acute hypoxic-ischemic injury (52.7%) or brain injury (20.0%). There was a linear association between pediatric intensive care unit size and number of patients declared brain dead per year.

Meaning Brain death evaluations are performed infrequently, even in large pediatric intensive care units, emphasizing the importance of physician education and protocol standardization to ensure diagnostic accuracy and consistency.

Methods

We abstracted all patient deaths from the Virtual Pediatric Systems (VPS) national multicenter database between January 1, 2012 and June 30, 2017. The VPS database is a web-based database using standardized clinical data definitions, data quality control, and data analysis. It was developed by a partnership between Children's Hospital Association and Children's Hospital Los Angeles.[14] The VPS database uses a prospective observational cohort of consecutive PICU admissions from a diverse set of hospitals caring for critically ill children in the United States. Data are collected by trained staff, with quality validation performed by individual sites and VPS. The interrater reliability in the VPS database is consistently more than 95%.[14] This study was deemed to be exempt by the Children's Hospital of Philadelphia institutional review board because it was conducted using deidentified data from deceased children.

Patient demographics including age, sex, race, discharge year, trauma status, outcome (ie, survived or died), length of stay (LOS), and organ donation status, as well as all diagnoses (based on *International Classification of Diseases, Ninth Revision* [*ICD-9*] codes) relevant to the PICU stay, were mandatory data fields for all patients. Patients were classified as dying a cardiovascular or cardiopulmonary death death vs brain death. Length of stay was reported in both medical (ie, time from PICU admission to documented declaration of death) and physical (ie, time from PICU admission until the deceased patient was documented as physically discharged from the PICU) terms. The Pediatric Index of Mortality was calculated at PICU admission and represented severity of illness for each patient.[15] We used the Pediatric Cerebral Performance Category (PCPC) as a metric of preillness developmental status.[16] Preillness was defined as prior to the hospitalization in which the patient died. The PCPC is an optional data element for collection in VPS. Data associated with donation after cardiac death were not available for this study. The size of PICUs was based on number of patient discharges per year (<500, 500-999, 1000-1499, 1500-1999, and 2000-4000).[17,18]

Nurses who were certified in VPS data abstraction determined the primary cause of each patient's brain injury based on their diagnosis codes and assigned it to 1 of 7 categories: cardiac arrest, traumatic brain injury (TBI), shock and/or respiratory failure without cardiac arrest, central nervous system infection (eg, meningitis, encephalitis, abscess), brain neoplasm, vascular condition (eg, stroke, hemorrhage, aneurysm, arteriovenous malformation), and other (eg, ventriculoperitoneal shunt malfunction, diabetic ketoacidosis, ingestion, hepatic encephalopathy). A secondary diagnosis was assigned if available and relevant. If cardiac arrest occurred, it was assigned as the primary diagnosis. For example, if a patient sustained both a cardiac arrest and TBI, cardiac arrest was listed as the primary diagnosis and TBI as the secondary diagnosis.

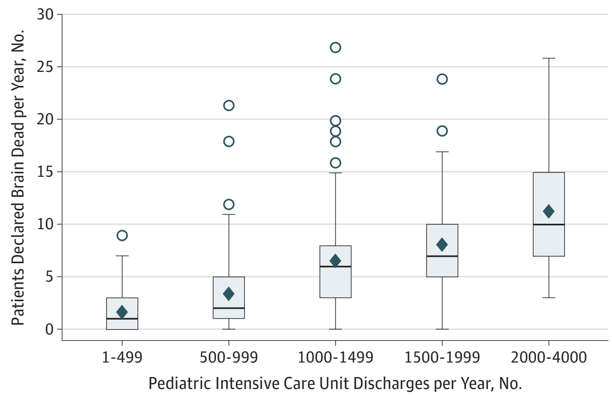
Statistical analyses were performed using SAS version 9.4 (SAS Institute). A Cochran-Armitage trend test assessed the percentage of patients declared brain dead across the 5-year study period. We conducted linear mixed models to examine the association between the number of patients declared brain dead and PICU size. Random intercepts and slopes accounted for cluster (ie, hospital-specific) outcomes in the number of brain deaths over the study period, as well as slight variation in the association between PICU size and brain death between hospitals. The PICU medical LOS variable was compared by brain death causative mechanism using the Kruskal-Wallis test. The Wilcoxon rank sum test was used for post hoc pairwise comparison between each pair of causative mechanisms, and *P* values were adjusted using the false discovery rate method. Presence of preexisting developmental disability (defined as a PCPC level >1) was compared between different brain death causative mechanism using the χ^2 test. Physical LOSs of patients who were organ donors and those of patients who were not organ donors were compared using the Wilcoxon rank sum test. We compared factors associated with whether patients declared brain dead who were not organ donors (n = 1567) who had had physical LOSs longer than 48 hours after declaration, including age, race, cause of brain injury, and whether they were declared dead in states with legal accommodations for religious objections to brain death (ie, California, Illinois, New Jersey, and New York), using χ^2 or Fisher exact tests. Multivariable logistic regression with random intercepts was fitted to further adjust for confounding and within-hospital clustering.[9,19]

To better understand the demographics of brain death, we compared the cohort declared brain dead with patients who were declared dead by cardiovascular or cardiopulmonary criteria. Comparisons between patients declared brain dead and cardiovascular or cardiopulmonary death were performed with χ^2 or Wilcoxon rank sum tests for nominal and continuous variables, respectively. Post hoc analysis of the χ^2 test for variables with more than 2 levels was conducted using the standardized residual test to identify categories driving the significant associations, with absolute value greater than 3 considered to be significant deviation.[20] Kaplan-Meier plots and the log-rank test were used to determine the difference in medical LOSs for the cohorts declared brain dead and those who sustained cardiovascular or cardiopulmonary death.

Results

A total of 3170 of the 15 344 patients (21%) who died in 145 PICUs during this 5-year period were declared brain dead. The percentage of patients declared brain dead per year varied over time to a minimal degree (2012, 459 of 2369 [19.4%]; 2013, 463 of 2502 [18.5%]; 2014, 506 of 2689 [18.8%]; 2015, 611 of 2639 [23.2%]; 2016, 609 of 2709 [22.5%]; 2017, 496 of 2315 [21.4%]; *P* < .001). The median number of patients declared brain dead per year ranged from 1 (interquartile range [IQR], 0-3) for smaller PICUs (defined as those with <500 discharges per year) to 10 (7-15) for larger PICUs (defined as those with 2000-4000 discharges per year; **Figure 1**). There was a linear association between PICU size and number of patients declared brain dead per year, with an increase of 4.27 patients (95% CI, 3.46-5.08; *P* < .001) per 1000-patient increase in discharged patients.

Figure 1. Number of Brain Death Cases by Pediatric Intensive Care Unit Size



Pediatric intensive care unit size was determined by the number of patients discharged per year. Horizonal lines within each box represent medians and diamonds represent means.

The most common primary causes of brain injury leading to brain death were hypoxic-ischemic injury from cardiac arrest (1672 [52.7%]), shock and/or respiratory failure without cardiac arrest (399 [12.6%]), and TBI (634 [20.0%]) (**Table 1**). A total of 975 patients (30.8%) declared brain dead had sustained a TBI, but 341 also had cardiac arrests and therefore were assigned to the primary diagnosis category of cardiac arrest. Medical LOSs varied by the causative mechanism of brain death (cardiac arrest, 2.5 [IQR, 1.6-3.9] days; TBI, 2.0 [95% CI, 1.3-3.6] days; shock and/or respiratory failure without cardiac arrest, 3.0 [95% CI, 1.9-5.8] days; vascular conditions, 2.8 [95% CI, 1.7-5.0] days; central nervous system infection, 2.8 [1.8-6.1] days; brain neoplasm, 3.4 [95% CI, 1.8-7.8] days; other, 3.5 [95% CI, 2.1-5.9] days; *P* < .001; Table 1). Medical LOSs was shortest for patients declared brain dead owing to TBI (median [IQR], 2.0 [1.3-3.6] days; *P* < .001). Most patients declared brain dead (671 of 807 [84.4%]) were categorized as normal on the preillness PCPC scale (**Table 2**). Patients declared brain dead who had preexisting neurological dysfunction by PCPC assessment (PCPC level >1) were more likely than those with normal PCPC to have had shock and/or respiratory arrest without cardiac arrest (25 [19.8%] vs. 61 [9.0%]; standardized residual, 3.64), brain neoplasm (7 [5.6%] vs 9 [1.3%]; standardized residual, 3.13), or other causative mechanism (13 [10.3%] vs 22 [3.2%]; standardizedresidual, 3.59), including ventricular shunt malfunction, cancer, diabetic ketoacidosis, or liver failure that led to brain death (*P* < .001). There was no difference in medical LOSs for patients declared brain dead with and without developmental disabilities.

Half (1568 of 3144 [49.9%]) of patients declared brain dead became organ donors. Patients who were organ donors physically stayed in the PICU longer after declaration of brain death compared with those who were not donors (median [IQR], 29 [6-41] vs 4 [1-8] hours; *P* < .001). Forty-three patients declard brain dead (2.7%) who were not organ donors were documented as physically present in the PICU more than 48 hours after declaration of brain death, and 11 patients (0.7%) were

Table 1. Causative Mechanisms of Brain Injury Leading to Brain Death

Causative Mechanisms	Prevalence, No. (%)
Total	3170 (100)
Cardiac arrest	1672 (52.7)
Trauma	383 (12.1)
Asphyxiation, asthma, or noninfectious respiratory failure	265 (8.4)
Drowning	193 (6.1)
Infection or sepsis	155 (4.9)
Poisoning, including by carbon monoxide	60 (1.9)
Neurovascular condition	60 (1.9)
Congenital heart disease, cardiomyopathy, or myocarditis	33 (1.0)
Brain tumor	16 (0.5)
Hepatic failure	15 (0.5)
Anaphylaxis	14 (0.4)
Ventricular shunt malfunction	11 (0.3)
Diabetic ketoacidosis	3 (0.1)
Traumatic brain injury	634 (20.0)
Motor vehicle accident	236 (7.4)
Suspected abusive trauma	155 (4.9)
Firearm-associated injury	59 (1.9)
Falls	23 (0.7)
Shock and/or respiratory failure without cardiac arrest	399 (12.6)
Asphyxiation, asthma, or noninfectious respiratory failure	99 (3.1)
Infection or sepsis	93 (2.9)
Drowning	72 (2.3)
Trauma	22 (0.7)
Poisoning	14 (0.4)
Congenital heart disease, cardiomyopathy, or myocarditis	11 (0.3)
Neurovascular condition	4 (0.1)
Vascular conditions	163 (5.1)
Intraparenchymal hemorrhage	84 (2.6)
Ischemic stroke	28 (0.9)
Arteriovenous malformation	24 (0.8)
Nontraumatic subarachnoid hemorrhage, subdural hematoma, or epidural hemorrhage	18 (0.6)
Venous sinus thrombosis	3 (0.1)
Central nervous system infection	104 (3.3)
Brain neoplasm	54 (1.7)
Other	144 (4.5)
Ventricular shunt malfunction	25 (0.8)
Hepatic failure	9 (0.3)
Cancer outside the nervous system	9 (0.3)
Diabetic ketoacidosis	7 (0.2)
Medical length of stay, median (IQR), d	
Total	2.54 (1.6-4.2)
Cardiac arrest	2.5 (1.6-3.9)
Traumatic brain injury	2.0 (1.3-3.6)
Shock and/or respiratory failure without cardiac arrest	3.0 (1.9-5.8)
Vascular conditions	2.8 (1.7-5.0)
Central nervous system infection	2.8 (1.8-6.1)
Brain neoplasm	3.4 (1.8-7.8)
Other	3.5 (2.1-5.9)

documented as physically present in the PICU more than 5 days after declaration of brain death. Seventeen of 43 patients (40%) who were documented as physically present in the PICU more than 48 hours after declaration of brain death were declared dead in a US state with accommodation laws for religious objection to brain death, whereas only 337 of 1533 patients (22.0%; $P < .01$) declared brain dead who were not organ donors with physical LOSs shorter than 48 hours were from these states. Physical LOSs of more than 5 days after declaration of brain death was not significantly different in US states with religious accommodations (2 of 11 [18.2%] vs 352 of 1565 [22.5%]; $P > .99$). The odds of a patient with a physical LOSs more than 48 hours after declaration of brain death being from an accommodation state remained significant (OR, 4.28 [95% CI, 1.59-11.49]; $P = .004$) after adjusting for age, race, and cause of brain injury. African American patients were also more likely to have a physical LOSs greater than 48 hours after declaration compared with white patients (OR, 4.07 [95% CI, 1.49-11.15]; $P = .006$) on adjusted analysis.

Compared with the 12 174 cases of documented cardiopulmonary death over the same period, patients declared brain dead were more likely to be male (1861 [58.7%] vs 6855 [56.3%]; $P = .02$), 2 to 12 years old (1401 [44.2%] vs 3773 [31.0%]; $P < .001$; standardized residual, 14.01), and African American (675 [21.3%] vs 1974 [16.2%]; $P < .001$; standardized residual, 6.74; **Table 3**). Patients declared brain dead were more likely than those with cardiovascular death to have sustained trauma (1285 [40.5%] vs 1355 [11.1%]; $P < .001$), more likely to have a higher severity of illness at PICU admission (Pediatric Index of Mortality score: patients declared brain dead, 61 [IQR, 16-87] points; patients with cardiovascular death, 7 [IQR, 3-32] points; $P < .001$), and less likely to have abnormal preillness neurological dysfunction by PCPC assessment (126 [15.6%] vs 1288 [42.0%], $P < .001$; Table 3). Patients declared brain dead were more likely than those with cardiopulmonary or cardiovascular death to have fixed and dilated pupils on PICU admission (1869 of 3170 [59.0%] vs 2091 of 12 174 [17.2%]; $P < .001$). This group of patients also had a shorter duration between PICU admission and death (median [IQR] medical LOSs, 2.5 [1.6-4.2] vs 4.5 [1.1-15.4] days; $P < .001$; **Figure 2**).

Discussion

This large multicenter national pediatric critical care epidemiologic investigation establishes that 21% of PICU deaths were owing to death by neurologic criteria (also known as brain death) rather than cardiopulmonary death. Brain death occurred primarily in previously healthy children either from an acute hypoxic-ischemic insult owing to cardiac arrest, shock and/or respiratory arrest, or TBI. These patients were severely ill on PICU admission and had a median time from admission to brain death determination of 2.5 days. For individual PICUs, diagnosing brain death is uncommon; it occurs fewer than 5 times a year in smaller units (<500 patients per year) and a median of 10 times a year in larger units (2000-4000 patients per year).

Table 2. Causative Mechanism of Brain Death Based on Preillness Neurologic Status, per Pediatric Cerebral Performance Category

Causative Mechanism	Preillness Neurologic Status, No. (%)				
	Normal	Mild Disability	Moderate Disability	Severe Disability	Coma or Vegetative State
Cardiac arrest	368 (84.4)	23 (5.3)	22 (5.0)	21 (4.8)	2 (0.5)
Traumatic brain injury	155 (98.7)	2 (1.3)	0	0	0
Shock and/or respiratory failure without cardiac arrest	61 (71)	8 (9)	6 (7)	10 (12)	1 (1)
Vascular	36 (84)	1 (2)	4 (9)	2 (5)	0
Other	22 (63)	5 (14)	2 (6)	6 (17)	0
Central nervous system infection	30 (88)	0	2 (6)	2 (6)	0
Brain neoplasm	9 (56)	1 (6)	1 (6)	3 (19)	2 (13)
Total	681 (84.4)	40 (5.0)	37 (4.6)	44 (5.5)	5 (0.6)

Preillness neurologic status levels are as per the Pediatric Cerebral Performance Category, with normal being level 1; mild disability, level 2; moderate disability, level 3; severe disability, level 4; and a coma or vegetative state, level 5.

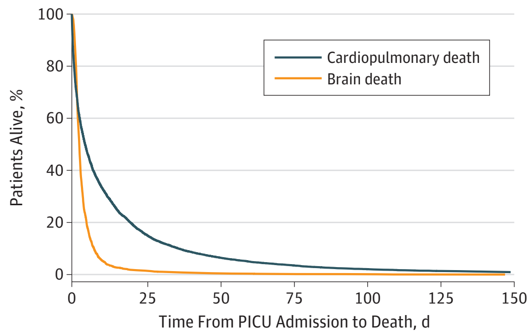
Table 3. Comparison of Demographics Between Patients Declared Brain Dead and Patients Who Sustained Cardiopulmonary Death

Characteristic	No. (%)		*P* Value
	Brain Death (n = 3170)	Cardiopulmonary Death (n = 12 174)	
Sex			
Female	1309 (41.3)	5317 (43.7)	.02
Male	1861 (58.7)	6855 (56.3)	
Age, y			
<2	1061 (33.5)	5532 (45.4)	<.001
2-12	1401 (44.2)	3773 (31.0)	
≥13	708 (22.3)	2869 (23.6)	
Race/ethnicity			
White	1225 (38.6)	5094 (41.8)	<.001
Black/African American	675 (21.3)	1974 (16.2)	
Hispanic/Latino	479 (15.1)	1815 (14.9)	
Asian/Indian/Pacific Islander	90 (2.8)	441 (3.6)	
American Indian/Alaska Native	27 (0.9)	87 (0.7)	
Other/mixed/unspecified	674 (21.3)	2763 (22.7)	
Trauma			
Yes	1285 (40.5)	1355 (11.1)	<.001
No	1885 (59.5)	10819 (88.9)	
Preillness neurologic status disability level[a]			
Total patients with scores	807	1780	<.001
Normal	681 (84.4)	422 (13.8)	
Mild	40 (5.0)	455 (14.8)	
Moderate	37 (4.6)	392 (12.8)	
Severe	44 (5.5)	19 (0.6)	
Coma or vegetative state	5 (0.6)	5317 (43.7)	
Severity of illness			
Pediatric Index of Mortality score	61 [16-87]	7 [3-32]	<.001

[a] Per Pediatric Cerebral Performance Category.

Most patients declared brain dead (84.4%) in this study had relatively normal preillness neurologic status, which is similar to other studies.[7,21] Compared with children with cardiopulmonary death, the children declared brain dead were more likely to be male, 2 to 12 years old, and African American. The incidence of trauma was higher in children declared brain dead, which likely contributed to the male predominance. Compared with white children, African American children were more likely to be declared dead by neurologic criteria than cardiopulmonary criteria. Others have speculated about possible cultural and/or religious perspectives that may influence the likelihood of withholding or withdrawing life-sustaining therapies by African American families (resulting in categorization as cardiopulmonary death), and perhaps a de-

Figure 2. Kaplan-Meier Curve Showing Time From Pediatric Intensive Care Unit Admission to Death



No. at risk

Cardiopulmonary death	12 079	1883	800	432	254	166	112
Brain death	3144	46	15	7	4	1	0

The medical length of stay is shown for patients who died from brain death (yellow line) or cardiopulmonary death (black line). Because patients who had cardiopulmonary death had medical lengths of stay longer than 400 days, the maximum time from PICU admission to death was limited to 150 days to highlight the differences between the patient groups at the earlier points. A total of 121 patients had missing medical length of stay data.

sire to wait for the certainty of brain death before removing organ support.[22]

In this cohort, the median time from PICU admission to death of 2.5 days was similar to previous reports.[7,8] Taking into account the recommended 12-hour observation period between brain death examinations, the initial brain death evaluation likely began approximately 36 to 48 hours after PICU admission, which conforms to the current guideline recommendation that the assessment for absence of all neurologic function after acute brain injury be deferred for 24 hours or longer.[4] Patients who were declared brain dead were more severely ill on PICU admission and had shorter LOSs than those patients who died by cardiopulmonary death. Most children declared brain dead sustained their severe brain injury by mechanisms suggesting that an event had occurred immediately prior to their hospitalization (Table 1). Conversely, patients with comorbid conditions and evolving multisystem organ failure from other causes, such as sepsis, acute respiratory distress syndrome, and heart failure, may have undergone more prolonged attempts to stabilize cardiopulmonary function and thus had a longer LOS prior to cardiopulmonary death.

The primary strength of this study is that, to our knowledge, it describes the largest cohort of pediatric patients declared brain dead reported to date. Additionally, the VPS database represents PICUs that are variable in size, geographic location, and populations served. Prior studies have reported the proportion of patients declared brain dead among all PICU deaths as 11% to 30%,[21,23-27] with 2 recent small studies[7,8] from large academic PICUs reporting 13% to 16%. Each of these studies contained only 30 to 35 patients declared brain dead, in contrast to the 3170 patients declared brain dead in this study.

Several high-profile cases from the news media describe situations where patients declared brain dead remain physiologically supported after declaration of death.[10,11] We therefore investigated the time between documented brain death determination and documentation of the patient's body physically leaving the PICU to indirectly estimate the frequency these situations. As expected, patients declared brain dead who were organ donors stayed in the PICU longer after declaration of death than those patients who were not donors. This was likely to facilitate the diagnostics necessary for organ donation, secure recipients, travel for procurement teams, and operating room preparedness. Patients declared brain dead who were not organ donors were documented to physically leave the PICU a median of 4 hours after death.

Among the 150 institutions included in this cohort over 5 years, 43 children declared brain dead who were not organ donors (2.7% of all such children) were documented to be physically discharged from the PICU more than 48 hours after documentation of brain death. Only 11 patients in this group (0.7%) were documented as leaving the PICU more than 5 days after documentation of brain death. We have no information to specify reasons for the delays, which could range from allowing for travel time for family members (especially if a parent is in another country, such as with a military deployment), time for legal proceedings if a family objected to the concept of brain death, to simply documentation errors in times and dates in the database.[28] African American patients were more likely to remain physically in the intensive care unit more than 48 hours after declaration of death, which could reflect a need for more time to accept the diagnosis. Notably, a recent survey[29] showed that more than half of pediatric neurologists and critical care physicians have been asked to continue organ support after brain death determination by families, who most commonly believed that their child could regain neurologic function.

Religious beliefs have been cited as the reason for requesting continuation of organ support in legal proceedings.[30] However, physicians report that continued organ support is commonly requested because of the belief that a patient declared brain dead can regain neurological function or a lack of acceptance that a person can be dead if the heart is still beating.[29,31] Interestingly, 40% of the patients physically discharged from the PICU more than 48 hours after documentation of brain death were from 1 of the 4 states with statutes providing accommodation for patients with religious objections to brain death; in contrast, only 22% of patients declared brain dead who were not organ donors with a physical LOS less than 48 hours were from these states. Perhaps accommodation for religious objections influenced the percentage of patients with longer LOS after brain death declaration in these states. New Jersey is the only state in which brain death cannot be declared if it will violate the patient's personal religious beliefs, whereas practitioners and hospitals in the other 3 states are required to make reasonable efforts to accommodate patient's religious beliefs.

These results indicated that smaller PICUs perform brain death determinations fewer than 5 times a year, and larger PICUs only 10 times a year. Brain death determination, like any medical procedure, requires training and practice to ensure accuracy and consistency. Even with published practice guidelines and informational sites, such as the Brain Death Toolkit from the Neurocritical Care Society, variability in practice for pediatric brain death declaration still exists.[32,33] Graduating PICU fellows performed a median of 5 brain death examinations throughout their training, and about 60% felt that they received enough instruction on performing the brain death examination and could do so independently.[34] The infrequency of these patients' circumstances underscores the importance of adhering to guidelines, standardized checklist use, and consistent, clear language with families.[29,33]

Limitations

This study has limitations, some of which are intrinsic to any study using large data sets. There could be miscoding or variability in coding practice across institutions, particularly for diagnosis codes. This may have influenced subcategorization. We were unable to obtain information about donation after cardiac death for patients with cardiopulmonary death. We were also unable to determine whether the brain injury that led to brain death occurred prior to or during PICU admission. Lack of the data on organ-donor eligibility in this database made it impossible to determine consent rates. Additionally, many participating institutions have separate pediatric cardiac intensive care units and some of the cardiac intensive care unitsare not included in the VPS database. This likely skewed these findings toward patients without congenital heart disease.

Conclusions

In this analysis, brain death accounted for one-fifth of PICU deaths. Even in large PICUs, brain death evaluations are performed infrequently. Physician education, standardization of brain death protocols, and the use of precise, consistent language are important to ensure the integrity of brain death determination.

ARTICLE INFORMATION

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