Can Pediatricians Define and Apply the Concept of Brain Death?

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ABSTRACT. *Objective.* **We sought to determine pediatric residents' and attending physicians' ability to define brain death, their ability to apply this standard of death to a clinical scenario, and their knowledge regarding the legal necessity of confirmatory testing when determining death by brain criteria. We compared resident and attending self-confidence at discussing brain death with their ability to define brain death and apply this concept to a clinical scenario.**

Methodology. **A questionnaire was sent to 136 residents, postgraduate years 1 through 3, at four accredited pediatric training programs in the United States. Participation was tracked by return address. One follow-up request for participation was made. A similar procedure was followed for 140 faculty pediatricians at two of the institutions.**

Demographic information including level of training, subspecialty training, training program, and formal ethics training was collected. Respondents defined brain death, interpreted a clinical scenario, and stated whether confirmatory testing is legally required to determine death by brain criteria. Respondents rated their confidence at explaining brain death to a patient's family on a scale from 1 to 5.

Results. **Eighty-seven percent (118/136) of resident surveys were returned. Thirty-six percent (42/118) of the residents correctly defined brain death. Forty-three percent (51/118) of residents correctly interpreted the clinical scenario. Fifty-five percent (65/118) of the residents correctly recognized that brain death could be determined without a confirmatory test. Residents who correctly defined brain death were as confident as those who did not (2.8 ± 1 vs 1.5 ± 1). Residents who correctly interpreted the clinical scenario were as confident as those who did not (2.6 ± 1 vs 1.9 ± 0.9).**

Eighty percent (112/140) of attending physician surveys were returned. Thirty-nine percent (44/112) of attending physicians correctly defined brain death. Fifty-three percent (59/112) correctly interpreted the clinical scenario. Fifty-eight percent (65/112) recognized that brain death can be diagnosed without confirmatory testing. All pediatric intensivists (n = 12) correctly answered all three questions. Their performance was significantly better than other pediatricians. Attendings who correctly defined brain death were more confident than those who did not (4.2 ± 1 vs 1.1 ± 0.9). Attendings who correctly interpreted the clinical scenario were more confident than those who did not (3.8 ± 1.2 vs 2.2 ± 1.2).

Conclusions. **Pediatric residents and attendings have difficulty defining and applying the concept of brain death. This concept is difficult to grasp and internalize for many pediatricians. To ensure that critical decisions are made by knowledgeable physicians and well-informed families, more effective educational strategies need to be identified.** *Pediatrics* **1999;103(6). URL: http://www.pediatrics.org/cgi/content/full/103/6/e82;** ***infants, children, pediatric intensive care unit, brain death, medical education, residents, medical ethics.***

ABBREVIATION. PICU, pediatric intensive care unit.

The concept of defining death by brain criteria was first formally proposed in 1969, by the Ad Hoc Committee of the Harvard Medical School and subsequently supported by the influential President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research.[1] Improvements in resuscitative and supportive technology had resulted in a subset of critically ill patients whose hearts continued to beat despite a completely and irreversibly damaged brain. In addition to diagnosing death by traditional cardiorespiratory criteria, the Ad Hoc Committee recommended that irreversible loss of cortical and brainstem function be considered a new standard for determining death.[2]

Determining death through brain criteria is utilized throughout the United States. Many states have enacted legislation based on the Uniform Determination of Death Act, which considers death by brain and cardiorespiratory standards as legally equivalent.[3] No state has adopted legislation that stipulates the specific criteria by which a doctor must declare patients dead by cardiorespiratory or brain standards. Appropriately, these decisions are left to the physician's discretion within evolving standards of care.

Despite the broad use of brain criteria for determining death, the concept remains confusing to many health professionals. Youngner described doctors' and nurses' substantial difficulty defining and applying the concept of brain death in adult patients.[4] No data exists regarding pediatricians' knowledge of death by brain criteria.

Sophisticated critical care sometimes allows physicians to support visceral organ function in the face of devastating neurologic injury, making an understanding of death by brain criteria pertinent to the practice of contemporary pediatric medicine. Many children die each year waiting for donor organs to become available. The accurate determination of

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death is necessary to provide appropriate information to a patient's family, to prevent unnecessary medical interventions in dead patients, and to maximize the supply of donor organs. Pediatric primary care providers, as well as specialists who routinely care for critically ill children, should understand this concept of death.

In this project, we sought to determine pediatric residents' and attending physicians' ability to define brain death, their ability to apply this standard of death to a clinical scenario, and their knowledge regarding the legal necessity of confirmatory testing (cerebral angiography, electroencephalogram, nuclear blood flow study, etc) when determining death by brain criteria. We compared resident and attending self-confidence at discussing brain death with their ability to define brain death and apply this concept to a clinical scenario.

METHODS

A 29-item questionnaire was sent to 136 residents, postgraduate years 1 through 3, at four accredited pediatric training programs in the United States between June 1996 and July 1997. Participation was tracked by return address. One follow-up request for participation was made if the questionnaire was not completed in 4 weeks. Questionnaires were rendered anonymous on receipt. Cover letters accompanying the questionnaires stated that participation was voluntary and identified the survey as a research tool. A similar procedure was followed for 140 faculty pediatricians at two of the institutions. Necessity for informed consent was waived by the relevant institutional review boards.

Demographic information including level of training, subspecialty training, training program, and formal ethics training was collected.

Ability to Define Brain Death

Respondents were presented with the following question and multiple choice answers.

What brain functions must be lost for a person to be declared dead by brain criteria?

a. irreversible loss of all cortical brain function
b. irreversible loss of all brain function including cortex and brainstem
c. varies by state
d. don't know

We considered "b" to be the correct answer.

Clinical Scenario

Respondents were presented with the following clinical scenario, question, and multiple choice answers.

A 5-year-old girl is found on the bottom of a pool. She is initially pulseless and apneic. She is aggressively resuscitated. One week into her pediatric intensive care unit stay she has no corneal, cough, or gag reflexes. She does not respond to painful stimuli. There is no nystagmus in response to cold caloric testing. Two minutes into an apnea test she takes one ineffectual breath. Her examination has not changed in 2 days.
Based on these findings, you could reasonably:

a. extubate her with her parents' approval
b. order a brain blood flow study
c. extubate her against her parents wishes
d. declare her dead by brain criteria

We considered "a" to be the correct answer. Answer "a" represents the most common mode of death in the pediatric intensive care unit (PICU).[5,6] Answer "d" is incorrect because the patient breathes during an apnea test and is not dead by brain criteria. Answer "b" is incorrect because confirmatory testing for brain death is not indicated unless the physical examination supports the diagnosis. Answer "c" is incorrect because withdrawing support from a patient in opposition to the surrogate decision-maker's wishes is inappropriate in this circumstance.

Confirmatory Testing

Respondents were presented with the following yes/no question.

Does the law require confirmatory testing for death by brain criteria?

yes no

We considered "no" to be the correct answer. No legislation exists that dictates the methods by which physicians determine irreversible loss of cortical and brainstem function (although institutions and professional organizations may have standards in this regard).[7–10]

Self-Confidence at Discussing Brain Death

Respondents were presented with the following question.

How confident are you in your ability to explain brain death to a patient's family? (circle)

not confident very confident
1 2 3 4 5

This data was treated as continuous.

Statistics

Descriptive statistics were used for demographic data. χ^2 and Fisher's Exact tests were used to analyze categorical data. Group t tests were used to analyze continuous data. Statistical significance was set a priori at $P < .05$.

RESULTS

Residents

Eighty-seven percent (118/136) of resident surveys were returned. Demographics regarding response rate, training program, level of training, and formal ethics education are presented in Table 1.

Thirty-six percent (42/118) of the residents correctly defined brain death. Twenty percent (24/118) of the residents answered "a," 25% (30/118) answered "c," and 19% (22/118) answered "d." The ability to identify the appropriate definition of brain death was not statistically associated with level of training (χ^2, $P = .34$), training program (χ^2, $P = .20$), or formal ethics education (χ^2, $P = .97$).

Forty-three percent (51/118) of residents correctly interpreted the clinical scenario. Forty percent (47/118) answered "b," 0.85% (1/118) answered "c," and 16% (19/118) answered "d." Fifty percent (42/84) of the residents who reported having formal ethics education correctly interpreted the clinical scenario versus 26% (9/34) of residents who did not report ethics education (Fisher's exact test, $P < .05$). Ability to interpret the clinical scenario was not statistically associated with level of training (χ^2, $P = .64$) or training program (χ^2, $P = .65$).

Thirty-eight percent (16/42) of residents who correctly defined brain death were able to correctly interpret the clinical scenario. Forty-six percent (35/76) of residents who incorrectly defined brain death were able to correctly interpret the clinical scenario. A correct definition of brain death was not statistically associated with an ability to correctly interpret the clinical scenario (χ^2, $P = .40$).

Fifty-five percent (65/118) of the residents correctly recognized that brain death could be deter-

TABLE 1. Resident and Attending Demographics

Resident demographics (n = 118)		
a) Training program	Region of United States	Response rate (%)
Institution A	West	46/50 (92%)
Institution B	Mid-Atlantic	32/36 (89%)
Institution C	Mid-West	29/36 (81%)
Institution D	New England	11/14 (79%)
b) Level of training		
Postgraduate year 1	47	
Postgraduate year 2	34	
Postgraduate year 3	37	
c) Formal ethics education		
Yes	84	
No	31	
Attending demographics (n = 112)		
a) Training program	Region of United States	Response rate (%)
Institution A	West	81/97 (84%)
Institution B	Mid-Atlantic	31/43 (72%)
b) Subspecialty		
Pediatric intensive care	12	
Neurology	7	
General pediatrics	21	
Neonatology	14	
Other subspecialty	58	
c) Formal ethics education		
Yes	33	
No	79	

mined without a confirmatory test. Knowledge regarding the necessity of confirmatory testing was not statistically associated with level of training (χ^2, P = .47), training program (χ^2, P = .20), or formal ethics education training (χ^2, P = .50).

Self-rated confidence was not significantly different in residents who were able to correctly define brain death (n = 42) and those who did not (n = 76) (2.8 ± 1 vs 1.5 ± 1, $P > .05$). Self-rated confidence was not significantly different in residents who were able to correctly interpret the clinical scenario (n = 51) and those who did not (n = 67) (2.6 ± 1 vs 1.9 ± 0.9, $P > .05$).

Attending Physicians

Eighty percent (112/140) of attending physician surveys were returned. Demographic information regarding response rate, training program, subspecialty, and formal ethics education are presented in Table 1.

Thirty-nine percent (44/112) of attending physicians correctly defined brain death. Twenty percent (22/112) of the attending physicians answered "a," 20.5% (23/112) answered "c," and 20.5% (23/112) answered "d."

One hundred percent (12/12) of pediatric intensive care physicians were able to correctly define brain death as compared with 43% (3/7) of pediatric neurologists, 43% (6/14) of neonatologists, 33% (7/21) of general pediatricians, and 43% (25/58) of other pediatric subspecialists (χ^2, $P < .01$). The ability to correctly define brain death was not statistically associated with training program (χ^2, P = .72),or formal ethics education (χ^2, P = .68).

Fifty-three percent (59/112) of attending physicians correctly interpreted the clinical scenario. Twenty-six percent (29/112) of the attending physicians answered "b," 19.6% (22/112) answered "c," and 0.85% (1/112) answered "d." One hundred percent (12/12) of pediatric intensivists were able to correctly interpret the clinical scenario as compared with 86% (6/7) of pediatric neurologists, 36% (5/14) of neonatologists, 52% (11/21) of general pediatricians, and 43% (25/58) of other pediatric subspecialists (χ^2, $P < .01$). The ability to correctly interpret the clinical scenario was not statistically associated with training program (χ^2, P = .26), or formal ethics education (χ^2, P = .33).

Sixty-four percent (28/44) of attending physicians who correctly defined brain death were able to correctly interpret the clinical scenario. Forty-six percent (31/68) of attending physicians who incorrectly defined brain death were able to correctly interpret the clinical scenario. A correct definition of brain death was not statistically associated with an ability to correctly interpret the clinical scenario (χ^2, P = .07).

Fifty-eight percent (65/112) of attending physicians recognized that brain death could be diagnosed without a confirmatory test. One hundred percent (12/12) of pediatric intensivists recognized that brain death could be diagnosed without a confirmatory test as compared with 86% (6/7) of pediatric neurologists, 64% (9/14) of neonatologists, 48% (10/21) of general pediatricians, and 48% (28/58) of other pediatric subspecialists (χ^2, $P < .01$). Knowledge regarding the necessity of confirmatory testing was not statistically associated with training program (χ^2, P = .09), or formal ethics education (χ^2, P = .37).

Self-rated confidence was significantly greater in attending physicians who were able to correctly define brain death (n = 44) versus those who did not (n = 68) (4.2 ± 1 vs 1.1 ± 0.9, $P < .001$). Self-rated confidence was significantly greater in attending physicians who were able to correctly interpret the clinical scenario (n = 59) versus those who did not (n = 53) (3.8 ± 1.2 vs 2.2 ± 1.2, $P < .001$).

DISCUSSION

This study represents an attempt to quantify the ability of pediatric residents and academic attending physicians to define and apply the concept of death by brain criteria, while recording their self-rated confidence at discussing this diagnosis with a patient's family. The questionnaire format is artificial and does not reflect the knowledge, judgment, and skill of physicians confronted by actual patients and clinical scenarios. Although our questions are narrow and do not do justice to the richness of a real case, we suspect that the additional nuances of a critically ill patient may add confusion, not clarification, to most physicians' thinking.

In our study, pediatric residents and attendings had difficulty correctly recognizing the definition of brain death. Death by brain criteria is not so new or so complex that physicians should not have a clear understanding of this concept. In part, the explanation may be that many physicians do not believe that patients without whole brain function are "really dead."[4] Many physicians may find the cardiorespiratory or "higher brain" standards of death to be more conceptually appealing.

In addition there are physiologic inconsistencies in the determination of death by brain criteria. Many brain dead patients still have some brain function, usually neurohumoral.[11] In one study, less than half of brain dead children have diabetes insipidus.[12] Some patients who fulfill physical examination criteria still have some minimal electrical activity on their electroencephalogram.[13] Death is a clinical, not a pathologic, diagnosis. As Truog said, "the criterion of whole-brain death is only an approximation".[11] This approximation may contribute to cognitive dissonance and clinical confusion.

New arguments question the necessity of adhering to a strict whole brain definition of brain.[11,14] Some scholars have suggested that defining brain death as irreversible loss of all cortical and brainstem function is too restrictive. A cortical or higher brain definition of brain death (that is irreversible loss of higher brain function but not necessarily brainstem function), reflects the opinion that such patients have lost identity as a person, and therefore should be considered dead. The higher brain definition also would allow many patients from whom support is withdrawn to donate organs[11] and thus could substantially increase the number of donor organs. It may be that the conceptual challenges of the whole brain standard of death illustrated in this debate are reflected in physicians' limited grasp of this important concept.

Our clinical scenario involves decision-making around the withdrawal of support, now the most common mode of death in the PICU.[5] We have noted in our clinical practice that distinguishing between a brain dead and severely brain injured patient can be confusing to residents and attending pediatricians. Patients who are dead by brain criteria are either maintained on mechanical ventilation to preserve their potential as an organ donor or support is discontinued. Respiratory effort, even in the absence of other neurologic function, disqualifies a patient as an organ donor unless there is a nonheart beating donor program at the institution in question.[15]

Pediatric residents and attendings had difficulty interpreting the clinical scenario. Pediatric residents and attendings who correctly defined brain death were no more likely to correctly interpret the clinical scenario than their peers who did not. We believe this lack of concordance represents poor internalization of the concept of brain death.

Brain death may be diagnosed by two neurologic exams, including apnea testing, separated in time. To diagnose brain death, the patient must have a diagnosis compatible with the clinical situation and may not be hypotensive, hypothermic, or sedated. Just over half of the residents and faculty recognized that confirmatory testing beyond the physical examination is not a legal necessity.

More than one task force and many individual hospitals have proposed guidelines for the mechanics of diagnosing brain death in children.[8,9,10] Recommendations regarding the necessity, timing, and choice of confirmatory tests varies from guideline to guideline. Clinically, physicians diagnose brain death in a variety of ways.[16] Most states have adopted the Uniform Determination of Death Act, which recognizes neurologic criteria for death but does not stipulate how a physician should make this determination. Although many institutions have guidelines for diagnosing brain death that include confirmatory testing, no state has legislation that demands confirmatory testing. Published guidelines and local institutional rules undoubtedly add to physician confusion regarding the legal necessity of confirmatory testing.

We found that increasing resident seniority (level of training) did not improve performance at defining brain death, interpreting the clinical scenario, or understanding whether confirmatory testing is necessary. This suggests that effective teaching is not occurring as residents progress through their training programs. We found that resident pediatricians' inability to correctly define brain death or interpret the clinical scenario was not associated with a lower level of confidence in discussing brain death with a patient's family.

Fortunately, attendings who were able to correctly define brain death and interpret the clinical scenario were more confident than their peers who could not. Concordance between confidence and objective knowledge about brain death improved with experience and responsibility. Overconfidence in knowledge or ability is a source of problems in medicine.

Issues surrounding the end of life often are included in medical ethics curricula. Self-reported ethics education was associated only with improved resident performance at interpreting the clinical scenario. If ethics education is an appropriate forum to teach about brain death, more effective educational strategies need to be identified and used.

The training program was not associated with improved resident or attending performance. This is of particular interest as no two training pro-

grams or academic faculties are identical in their clinical or educational emphasis. Similar results from programs that differ in terms of size and geography, suggest that confusion regarding brain death is common.

Most clinical decisions regarding brain death are made in the PICU. The pediatric intensivists' responses were consistent and correct. Surprisingly, less than half of the pediatric neurologists correctly defined brain death. As pediatric medicine becomes increasingly subspecialized, clinical knowledge and experience may be increasingly partitioned. Nonintensivists confront issues surrounding brain death infrequently. A primary care physician's involvement in the care of a critically ill child provides comfort to the family and longitudinal perspective to the critical care specialist. It is incumbent on subspecialists to communicate effectively with primary care providers about the determination of death, to facilitate their effective involvement in clinical decision-making.

A clear understanding of brain death is imperative when providing comprehensive pediatric intensive care. Rational and consistent decision-making regarding organ donation, organ procurement, and withdrawal of support all depend on the ability to define and apply the concept of brain death. Inappropriate or unnecessary interventions may be minimized by enhanced education regarding death by brain criteria, ensuring that critical decisions are made by knowledgeable physicians and well-informed families.

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