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INFANT BRAIN DEATH: SOME COMMENTS

T.S. ELLIS, III*

Brain death\(^1\) is a thoroughly modern concept.\(^2\) Not until the 1960's did it come into common parlance. It was the child of advances in resuscitative techniques, including chiefly the development of mechanical respirators and various therapies to restart and regulate heartbeat and maintain blood pressure. By the 1960's, medical science had achieved the remarkable ability to maintain the respiration and heartbeat of a patient who in the past would have been thought dead. Such a patient had irreversibly lost any ability to breathe without mechanical or artificial assistance. Moreover, this patient would never awaken, react to any stimuli, or recover any cognitive or cortical function. The question then naturally arose—is such a patient alive or living?

This question was not only vexing, it was urgent. Signifi-

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1. “Brain death” as used here is the irreversible state of total absence of brain function, both cortex and stem. In this state, there is no spontaneous respiration and absent a mechanical respirator, breathing would cease, as would heart function soon thereafter. The term “brain death,” then, is to be sharply distinguished from “cerebral death,” with which it is often confused. Cerebral death connotes the state, sometimes reversible, of persistent coma, absence of cortex function, but with some remaining brainstem function, including respiration. See In re Quinlan, 70 N.J. 10, 355 A.2d 647, cert. denied sub nom Garger v. New Jersey, 429 U.S. 922 (1976). For a judicial statement of the brain death-cerebral death distinction, see In re Conroy, 98 N.J. 321, 486 A.2d 1209 (1985).

2. Until modern times, determination of death has been based chiefly on the absence of heart and respiratory function. Reliance on the absence of breathing or heartbeat as a sign of death was sometimes unreliable with the result that history records a number of apparently spontaneous resurrections. Even as late as the last two decades, press accounts can be found of persons prematurely declared dead on a cardio-pulmonary basis awakening or reviving. See A.E. WALKER, CEREBRAL DEATH 168-69 (1981). In the nineteenth century, the cardio-pulmonary standard for determination of death was thought by some to be sufficiently unreliable so that they requested that they be wounded or mutilated before burial to ensure that they were dead. Some persons were buried in coffins outfitted with devices designed to ring a bell above earth in the event of any movement of the corpse’s chest. These bizarre precautions do not seem so outlandish in light of the many accounts of live burials that appeared in the literature in the nineteenth century. Id. at 6-7.
cant pressures mounted for an answer, including an awareness that maintaining patients in this state often served to increase the anguish suffered by family and loved ones and involved the expenditure of enormous resources, both public and private. Moreover, uncertainty over the legal status of such patients was a major obstacle to transplantation medicine. All of this led in 1968 to the publication of certain criteria by the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death. These criteria, simply stated, held that a patient with a permanently nonfunctioning brain, stem and cortex, was dead, not just brain dead, but simply dead. The problem was to define this state. According to the Harvard group, a patient with no spontaneous respiration or elicitable reflexes, who is deeply comatose with total unawareness of external stimuli and who has an isoelectric (flat) electroencephalogram, was dead.

The publication of the Harvard criteria was a major impetus for further debate, and ultimately, for legislative action. In the 1970's, many states amended their statutory definitions of death to include, in some fashion, the brain death concept. Most states now have statutory definitions of death

3. See Wasmuth, The Medical, Legal & Ethical Considerations of Human Organ Transplantations, 11 WM. & MARY L. REV. 636 (1970); Comment, The Criteria For Determining Death in Vital Organ Transplants — A Medico-Legal Dilemma, 38 MO. L. REV. 220 (1973). For a vivid illustration of the impact of the doubt then existing concerning the legal status of brain death, see Tucker’s Adm’t v. Lower, No. 2831 (Circuit Court for the City of Richmond, Va. 1972). There, transplant surgeons removed the heart and kidneys from an adult patient who, by today’s brain death criteria, was legally dead. In the absence of family members, consent for the organ removal was obtained from an assistant medical examiner. The decedent’s estate sued the surgeons for wrongful death and, in the absence of a statutory or legally established definition of brain death, the judge felt compelled to submit the case to the jury which, after about an hour’s deliberation, returned a verdict in defendants’ favor.


5. The report recognized that the validity of these criteria as an indication of irreversible brain death depended upon excluding hypothermia and drugs as causes of the coma. Id. at 338.


that include brain death and the concept of such legislation has been widely endorsed. A recent major event in the de-

8. For a list of states with statutory definitions of brain death, see A.E. Walker, supra note 2, at 154-55. Typical statutes provide alternative definitions of death, one based on cardiopulmonary criteria and the other on brain death. See statutes cited supra note 7. This dual definition has been criticized by commentators on the ground that inconsistencies are possible. For example, the time of death might differ depending upon whether cardiac or brain criteria are used or conceivably it might lead to a misunderstanding that a person could be dead for one purpose, such as transplantation, but alive for other purposes if alternative definitions exist. See Capron & Kass, supra note 6.


The concept of brain death has also generated debate in various civil contexts. Dority v. Superior Court, 145 Cal. App. 3d 273, 193 Cal. Rptr. 288 (1983) (court decided guardian could order removal of life support systems from brain dead infant in case where parents accused of child abuse apparently opposed life support system removal in order to escape liability for homicide); Janus v. Tarasewicz, 135 Ill. App. 3d 936, 482 N.E.2d 418 (1985) (brain death concept used in connection with question as to which of two Tylenol poisoning victims died first for purposes of insurance policy survivorship clause); In re Bowman, 94 Wash. 2d 407, 617 P.2d 781 (1980) (court affirmed application of brain death criteria to five-year-old, stating that patient was dead notwithstanding artificial maintenance of heartbeat and respiration after brain death); In re Haymer, 115 Ill. App. 3d 349, 450 N.E.2d 940 (1983) (court held seven-month-old patient on mechanical ventilation was brain dead and hence legally dead as of
Development of the brain death concept occurred in 1981 when the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research endorsed the concept and outlined specific, now widely accepted criteria.\(^\text{10}\)

Given that brain death is now widely accepted as a way to define death, what then is the problem in this context with infants? Put simply, the concept of brain death, and specifically its definitional criteria, were developed from, and based chiefly on, data and knowledge about adults and others, not infants. There is, as it happens, a substantial body of data and knowledge concerning brain death in adults and children over five years of age.\(^\text{11}\) By contrast, infant brain physiology is less well understood and there is, understandably perhaps, less data available.\(^\text{12}\) A substantial body of medical opinion holds that infant brains may be more resilient, more resistant to insults leading to an irreversible cessation of brain activity.\(^\text{13}\) Indeed, there is some evidence to suggest that some infants who exhibit the adult brain death criteria may not be in an irreversible state.\(^\text{14}\) In one reported instance, a neonate

that time and not as of the subsequent date on which somatic death occurred after removal of the ventilator).

12. See, e.g., Holzman, Curless, Sfakianakis, Ajmonemarsan & Montes, Radionuclide Cerebral Profusion Sestigraphy in Determination of Brain Death in Children, 33 Neurology 1027 (1983); Rowland, Donnelly, Jackson & Jamroz, Brain Death in the Pediatric Intensive Care Unit, 137 Am. J. Disease Childhood 547 (1983). This point has also received judicial recognition. See Lovato v. District Court, 198 Colo. 419, 601 P.2d 1072 (Colo. 1979) (court affirmed removal of life support devices from brain dead 17-month-old abuse victim; doctors testified that clinical and laboratory criteria for pediatric brain death diagnosis are less certain).
awakened and recovered after exhibiting electrocerebral silence and other signs typically thought to establish brain death in adults.\textsuperscript{18} For all these reasons, the 1981 President’s Commission recommended that “Physicians should be particularly cautious in applying neurologic criteria to determine death in children younger than five years.”\textsuperscript{16}

Mindful of the doubt concerning the applicability of adult brain death criteria to small children, especially infants and neonates, the Child Neurology Society\textsuperscript{17} has laudably undertaken to study this issue with an eye toward publishing criteria specific to small children, infants and neonates. A draft of brain death criteria for children entitled “Task Force on Brain Death in Children” [Task Force] has recently been circulated by a Committee of the Society and it is the purpose of this article to make some general observations on this important effort.\textsuperscript{18} First, a brief description is appropriate.

The introductory section of the Task Force begins by noting that the concept of brain death is well-established and accepted legally and morally. It makes clear that brain death as used in the document means not reversible cerebral death, but an irreversible loss of all brain function from which “somatic death will invariably follow despite all medical efforts.”\textsuperscript{19}

Importantly, the Task Force introduction affirms the validity of the brain death concept as applied to children. Equally importantly, it then goes on to acknowledge that adult brain death criteria may not be adequate for some children. Additional, pediatrically-oriented testing may be necessary. In the words of the Task Force introduction,

[B]rain death as a medical event is a valid concept in chil-
dren of all ages. The physical (neurological) examination criteria of brain death are identical in children and adult patients. These examination criteria are necessary, but not sufficient, in confirming brain death in children. Laboratory testing is necessary and requires a specific pediatric orientation.20

It is the proper selection and interpretation of additional tests that are the principal focus of the Task Force draft. This is no easy task, given that "most laboratory tests have limitations in younger patients."21 Chief among the tests with limitations in children is the electroencephalogram,22 but it is by no means the only test so limited.23 Understandably, therefore, the major effort of Task Force members is directed to investigating which tests can and should be used to eliminate ambiguity in determining brain death in pediatric patients.

The brain death criteria24 proposed by the Task Force are as follows:

1. Absence, at the time of assessment, of hypothermia, hypotension, and drugs, toxins and/or metabolic derangements capable of simulating brain death.
2. Coma. Complete loss of consciousness, vocalization or volitional activity.
3. Flaccid tone and absence of spontaneous or induced movements, excluding spinal cord events such as reflex withdrawal or myoclonus.
4. No cerebral function as defined by ancillary testing.
5. No brainstem function as defined by:
   a. Midposition or fully dilated pupils which do not respond to light.
   b. Absence of eye movements, including oculocephalic and vestibular movements induced

20. Id.
21. Id.
22. See Ashwal & Schneider, Failure of Electroencephalography to Diagnose Brain Death in Comatose Children, 60 ANNALS NEUROLOGY 512 (1979); Green and Lauber, Recovery of Young Children After ECS, 35 J. NEUROLOGY, NEUROSURGERY & PSYCHIATRY 103 (1972).
24. As in the case of the Harvard criteria, the reliability of the criteria as indications of brain death depends upon excluding hypothermia and drugs as causes of the coma. See Task Force, supra note 18, at 2.
by head turning or caloric stimulation.

c. Absence of movement of bulbar musculature including facial and oropharyngeal muscles. The corneal, sucking, and rooting reflexes are absent.

d. Absence of respiratory movements.

e. Ancillary testing must not refute the absence of brainstem function.

It is in the "ancillary testing," items 4 and 5e, that the pediatric brain death criteria differs from that applicable to adults. And it is with this ancillary testing—the applicability to children and the need for special interpretation—that the remaining pages of the Task Force are chiefly concerned. Finally, it is important to note that the current (November 26, 1985) draft specifies that the criteria should be met for a 24-hour period for patients over one year old (including, presumably, adults) and for a full 48 hours for infants between six and twelve months old. Significantly, the Task Force notes that insufficient data exists to document the reliability of the criteria for infants younger than six months. With this summary description of the Task Force draft, we turn next to some specific observations.

MORAL AND ETHICAL CONSIDERATIONS

The Task Force draft claims moral neutrality for its criteria. It states that "[B]rain death is a medical event definable by scientific criteria independent of moral and ethical considerations." On one view, this is nothing more than a definitional statement, as innocuous as it is obvious. On this view, brain death, like pneumonia or whooping cough, is a medical condition that exists or not—whatever one's moral views.

A second view is broader in focus; it sees, in terms of consequences to a patient, a sharp distinction between definitions of pneumonia and those of brain death. On this view, therefore, far from being independent of moral and ethical considerations, the Task Force brain death definition is manifestly driven by a clear moral premise. That premise, simply put, is that it is right to declare as dead those persons who lose total brain function, cortex and stem, because, on the basis of current knowledge, such a state is always irreversible and invariably followed by somatic death notwithstanding ex-

25. Id. at 1.
26. Id.
27. Id. (emphasis added).
traordinary medical efforts.

The underlying moral view here is that dying is a process and that brain death, as currently defined, is a point where the process has become irreversible no matter what life support efforts are invoked. It is the irreversibility of the condition and dying process and the inevitability of somatic death that are the moral and ethical hallmarks of the brain death definition. The second view concedes that the Task Force draft is correct in asserting that brain death is an event “definable by scientific criteria.” But according to this view, the definition of the event and the selection of the appropriate scientific criteria must be (and are) based on a moral choice, namely that the irreversibility of brain death as defined and the inevitability (fairly imminently) of somatic death justify declaring a person with this condition as dead for any purpose, including termination of all medical support efforts and use of organs for transplants. Indeed, on this moral view, recognition of brain death as death for all purposes may be a positive duty, an obligation. Continuation of extraordinary medical efforts on a brain dead person is seen, on this view, as prolonging death, not life, thereby causing unnecessary anguish to family and loved ones, wasting scarce medical resources and potentially jeopardizing organ transplant viability.

The important aspect of the Task Force’s moral premise is its exclusion of quality of life considerations. This is as surely correct as it is consistent with current law. Decisions concerning whether death has occurred should never turn on anyone’s assessment or opinion of the quality or value of future life likely to be experienced by the patient.

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28. *Id.*
29. Perfusion of some organs may be impaired by long-term respirator maintenance. Note, however, that there may be circumstances where life support systems should be retained even after brain death occurs. This might be true, for example, with a patient in the late stages of pregnancy so that the fetus can survive to viability. See A.E. Walker, *supra* note 2, at 184-85.
30. Current decisional law correctly equates total brain death with death and recognizes that this state is distinguishable from comas and persistent vegetative states. The latter state is life, not death, for only a portion of the brain is dead; some brain function remains. And this is true no matter how bleak the prospects or how miserable the future quality of life may be. See, e.g., *In re* Torres, 357 N.W.2d 332 (Minn. 1984); *In re* Conroy, 98 N.J. 321, 486 A.2d 1209 (1985).
31. In certain circumstances, however, the law grants competent, live patients or their legal guardians or representatives the right to refuse fur-
In sum, the moral basis of the Task Force criteria seems both clear and clearly correct. To see the criteria, as the Task Force draft does, as "independent of moral and ethical considerations" may be too narrow a focus for some because it fails to see that appropriate scientific criteria can only be selected by reference to moral criteria. For adherents of this view, the moral questions are (i) at what point in the dying process is it acceptable to cease life-sustaining efforts, and (ii) what degree of certainty is acceptable in determining whether this point has been reached? In any event, it is doubtful whether the purpose of the Task Force is served by language which invites debate over whether the brain death definition and criteria are morally neutral. Thus, elimination from the statement that the brain death definition is independent of moral considerations would improve the draft. Worth noting here, though, is that the Task Force's brain death definition and criteria derive from sound moral and settled legal bases.

Physicians As Lawmakers

The importance of the Task Force effort should not be underestimated. It is, in effect, a lawmaking effort. Brain death statutes, as they exist in most states, confer on physicians the power to prescribe how brain death is to be determined. Let me explain. Brain death statutes typically make no distinction between infants and adults; the standard—"irreversible cessation of all functions of the entire brain"—applies equally to both groups. The brain death
ter extraordinary care to sustain a life lacking in quality. This right is typically grounded in the constitutional right to privacy. See In re Barry, 445 So. 2d 365 (Fla. Dist. Ct. App. 1984) (parents granted right to authorize removal of 10-month-old infant's life support systems where the child was in permanent vegetative state with more than 90% brain function permanently lost and life expectancy in this state of no more than two years); Satz v. Perlmutter, 362 So. 2d 160 (Fla. Dist. Ct. App. 1978), aff'd 379 So. 2d 359 (Fla. 1980) (respirator removal authorized as desired by competent, terminally ill, 73-year-old man); In re LHR, 253 Ga. 439, 321 S.E.2d 716 (1984) (parents or legal guardians permitted to order removal of life support systems from terminally ill infant in chronic vegetative state with no hope of recovering cognitive function); Superintendent of Belchertown v. Saikewicz, 373 Mass. 728, 370 N.E.2d 417 (1977) (authorization to withhold chemotherapy from incompetent, profoundly retarded, terminally ill 67-year-old man); In re Torres, 357 N.W.2d 332 (Minn. 1984); In re Quinlan, 70 N.J. 10, 355 A.2d 647, cert. denied sub nom Garger v. New Jersey, 429 U.S. 922 (1976).

determination for both infants and adults must be made, according to most statutes, "in accordance with accepted medical standards"33 or on the basis of "the ordinary standards of medical practice."34 What differs then with respect to adults and infants is not the standard, but precisely how it is determined whether the standard is met. And this is ascertained by reference to accepted medical standards. Such standards would presumably include the Task Force criteria when ultimately published. Thus, the final results of the Task Force effort are likely to be the statutory standard for pediatric brain death determinations. Physicians engaged in the Task Force undertaking and those likely to be affected by it should be aware of this.35 For those engaged in the undertaking, the statutory delegation of standard-setting power should encourage them to do their best to canvas the profession and ensure a reasonable consensus.

Given that most courts are likely to accept the Task Force criteria as the legal standard to be met in declaring pediatric brain death, one might ask whether the criteria apply only to well-equipped tertiary care centers or to community hospitals as well. The question arises because of the sophistication of various ancillary tests that may be used to diagnose or confirm pediatric brain death. Contrast angiography, nuclear flow scanning, evoked potentials, ultrasound and doppler flow studies and electroencephalography all require some equipment and expertise not found in many hospitals outside major tertiary care centers. As a practical matter, therefore, the criteria cannot be used at hospitals without this equipment or expertise in those special cases where the criteria would require or indicate their use. In such an instance, it may be necessary to transfer the patient to an appropriate major medical facility in order to comply with the criteria and reach a confident pediatric brain death conclusion.36 On

33. Id.
34. VA. CODE § 54-325.7 (1979).
35. Indeed, we should all bear this in mind for what has been statutorily delegated to physicians is more than the power to set mere abstract technical standards. It is, rather, the power to set technical standards which have important moral content and consequences. The public should be aware of the moral bases of whatever standards are set and debate them for the proper decisionmaker, ultimately, on what circumstances justify a declaration of death is the body politic, not doctors, lawyers or judges. See T. Ellis, Letting Defective Babies Die: Who Decides?, 7 AM. J. LAW & MED. 393 (1982).
36. In this regard, it is important to note that the Task Force, states explicitly that the criteria outlined "are the most rigorous in order to avoid
the other hand, in some instances, it may be possible to diagnose brain death largely on the basis of clinical criteria and without the aid of any especially sophisticated ancillary tests. If so, it may be useful for the Task Force to consider addressing this problem specifically so that physicians without the sophisticated equipment or expertise required for certain ancillary tests may know with some specificity under what circumstances they may satisfactorily reach a conclusion of pediatric brain death using the Task Force criteria.

Another issue of some importance given the likely legal effect of the criteria is the question surrounding their application with respect to infants under six months of age. Ancillary tests for such infants have not been validated. They may be applicable, but only with caution.37 The Task Force may wish to consider making more explicit how the criteria should be used with respect to infants younger than six months of age, including what kinds of ancillary testing might be required in various cases.38 If, as seems clear, insufficient data exists with respect to the ancillary tests, studies should be proposed or recommended to determine which of the ancillary tests are most reliable for these infants and what the clinical criteria should be for these infants if they are different from the criteria for older children.

**Conclusion**

Determining brain death in very young children is as knotty a problem as it is an important one. We are all indebted to the Task Force members for their effort in this regard. We owe them our support and our careful and thoughtful criticism of their work as it progresses to a final draft. At the same time, lawyers would do well to consider some legal issues that may arise in connection with these criteria, includ-
ing whether a physician must consult with a family member before ordering the termination of life support activities with respect to an infant who is brain dead under the criteria and hence under an applicable statute. Surely prudence and sensitivity dictate that the family be consulted, but circumstances may not always permit this to occur and there is, of course, always the possibility that the family may wish to continue life support activities even though the patient is brain dead. There may be certain circumstances in which the family does not accept the brain death diagnosis and requests additional ancillary tests. In this instance, physicians need to know whether they are legally (as well as ethically) bound to perform these tests even though they are not medically indicated. In this area as in others, advances in medical science challenge doctors and lawyers to join together in solving difficult medical, moral and legal questions.