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POLICY FORUM

Determining Brain Death—No Room for Error

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Brain death is a uniquely modern, largely hospital-based phenomenon. Without mechanical ventilation, the cessation of brain function leads quickly and inevitably to apnea and cardiac arrest, but with it, patients may be kept in the ICU with an intact heartbeat and circulation, thereby preserving other bodily functions for some time. First described by Mollaret and Goulon over 50 years ago [1], the concept of brain death (BD) has evolved to become a standard widely accepted by clinical, ethical, and legal authorities as an alternative to cardiorespiratory death. Despite its canonization across the United States, however, BD remains an amorphous and unfamiliar concept to most of the public and even to many within the health care profession.

In fact, recent data show that BD policies are still remarkably heterogeneous, even amongst some of the nation's most vaunted medical institutions [2]. If death (much like its obverse, birth) is to be viewed in the traditional manner as a singular, unambiguous event—one about which it is possible to make an objective evaluation, complete with time and date—should such variability in its declaration be acceptable? If not, should action be taken to improve matters? Doing nothing to address such inconsistencies tacitly endorses a system in which a given patient might be declared brain-dead by one hospital, but not dead by that of another facility across the street or across state lines.

We argue that urgent attention must be given to consistent application and regular review of our adopted medical and legal standards—a position which we believe will serve to strengthen research and facilitate ongoing ethical debate surrounding BD. The reasons for such standardization are many, but should include ensuring accuracy in such an irreversible declaration, securing equitable treatment under the law, and allaying public suspicion and misunderstanding about BD determination.

A Brief History of Brain Death

The development of BD as a medicolegal paradigm is a direct result of two important advances in twentieth-century medicine: the adoption of the mechanical ventilator in treatment of critical illness and the advent of successful organ transplantation.

The “iron lung,” an artifact of the poliomyelitis epidemic, gave rise to a new category of illness—first described as *coma-depasse* in 23 patients who survived on the ventilator despite the lack of any respiratory effort [1]. An ad hoc committee of

Harvard Medical School proposed the first clinical definition of such an “irreversible coma” in 1968. This diagnostic framework, shown to be feasible in a 1977 prospective trial of 503 comatose patients [3], together with the dead-donor rule (vital organs should only be taken only from dead patients) [4] and growing demand for organ transplantation, propelled brain death into the legal arena. The need for standardization led to the 1981 Uniform Determination of Death Act (UDDA), which quickly became the legal precedent for the subsequent passage of state laws throughout the country. The UDDA states that

an individual who has sustained

1. irreversible cessation of circulatory and respiratory functions, or
2. irreversible cessation of all functions of the entire brain, including the brain stem

is dead. A determination of death must be made in accordance with *accepted medical standards* [5].

The first systematic attempt to establish such standard practice parameters was not made until the American Academy of Neurology’s 1995 guidelines were issued [6]; an update was published in mid-2010 [7].

Variability in Policy and Procedures

The concise language of the UDDA is the key to the persistent variability in brain death policy. Firstly, it clearly defines whole brain death as legally equivalent to cardiorespiratory death. Yet, while the latter is an easily recognizable state intimately known to all health care workers as a defining moment of the human condition, the former is a much less frequently encountered state. It is palpably different from cardiorespiratory death at the bedside, often evoking discomfort and questions from even the most astute and well-meaning practitioner, questions which take on added urgency due to the finality of the diagnosis. What is the best procedure for proving cessation of all brain function? How does one confirm irreversible injury? Who should examine the patient, how many times, and over what interval?

Answers to these questions exist, but can vary with the source consulted. Do the “accepted medical standards” to which the UDDA refers truly exist? Should one first consult local hospital policy? What if that policy conflicts with national guidelines? What if no policy exists? Can apnea testing always be justified, given that it may put the patient at increased risk for hypotension and arrhythmia and allow serum carbon dioxide concentrations to increase, potentially raising intracranial pressure to lethal levels [8-10]? In cases of disagreement (e.g., about which confirmatory test to perform in any given patient who is a poor candidate for apnea testing), who adjudicates? The law is silent on these and a host of other questions, ultimately leaving it up to states, organizations, and individual physicians to decide what is meant by “accepted medical standards.” Yet, studies have repeatedly shown lack of procedural consensus [2, 11] even after the publication of the AAN guidelines [6, 12].

The most recent such study evaluated BD policies of the neurology and neurosurgery programs named by *U.S. News and World Report* as the top 50 in the U.S.[2]. Out of 41 respondent hospitals, three did not even have a BD policy. Among the remaining 38, the authors reported tremendous variability in each step of the BD evaluation process recommended by the AAN. The qualifications of the examiner, how many exams and at what intervals, what clinical prerequisites should be met, how the apnea test should be conducted, and what ancillary tests could be ordered in what specific situations all varied extensively. As an example, 11 different minimum temperatures were quoted as the threshold above which the BD exam could be initiated. These findings may represent merely the tip of the iceberg, since we might suspect that even more variability exists in less prominent and nonacademic hospitals.

Individual physicians may vary still further in how they conduct and interpret evaluations [13, 14], an observation borne out in our personal experience. Common errors include failure to adequately establish the presence of a biologically plausible cause leading to irreversible whole brain death, inadequate screening for confounding substances, and performance of a confirmatory test prior to a proper clinical exam and apnea test. In one memorable case, a consulting physician had already “declared” BD and communicated this finding to the family when an astute colleague realized, upon re-examination, that the patient had not been off all sedation when initially examined. After propofol was stopped for a reasonable period, brain stem reflexes were once more detectable, which led to a change in diagnosis and confusion and distrust on the part of the agonized family. A primary goal of BD determination should be to drastically minimize (if not eliminate altogether) such false positives. As the above example illustrates, the absence of a more rigorous approach to such assessment may unacceptably compromise the accuracy of diagnosis in the irreversible determination of life and death.

Nonstandardization at the state level adds to the confusion. Although state laws are generally similar, having largely been modeled after the UDDA, significant differences persist. For example, regarding the number and qualifications of examiners, Virginia requires that 2 examiners be involved—one a specialist in neurology, neurosurgery or encephalography—while in Georgia, a single exam by any physician or registered nurse will do [15]. The statutes in New York and New Jersey require physicians to consider accommodating family wishes to continue mechanical ventilation for patients declared dead by neurological criteria, if the requests are made on religious grounds. Given the number of legal proceedings that may be affected by the timing and declaration of death (e.g., prosecution, insurance claims, organ donation), such variation undermines the idea of equal protection under the law.

Based on the reported variability in BD determination and the poor quality of empirical clinical evidence in support of current recommendations, some have voiced valid ethical concerns about the reliability, internal consistency, and even the necessity of the concept of BD [16]. A detailed review of such arguments is beyond

the scope of this paper, but it is worthwhile to note that the new evidence-based AAN guideline update published in June 2010 [7] attempts to address some of these common ethical and technical questions while promoting “uniformity in diagnosis.” For example, after careful review of the literature, it found that *when AAN guidelines for determining brain death were properly followed*, no person meeting such criteria has ever been reported to recover neurological function.

This puts to rest one major concern about equating brain death and cardiorespiratory death and could help to combat the cynical belief that the idea of brain death was invented to provide transplantable organs for a worldwide donation-transplantation “industry.” Such patient and family misconceptions [17] may be attenuated by a more uniform approach to the determination of BD, helping to reassure families of its credibility and rigor.

Towards Standardization

Nearly 30 years after the Uniform Determination of Death Act, and 15 years after the initial American Academy of Neurology guidelines, continued variability in the determination of BD from state to state, hospital to hospital, and, most likely, physician to physician undermines the validity of the concept in the minds of practitioners and the public alike [18]. We agree with other authors who have argued that the time has come for the adoption of a national standard [15, 19] regarding the minimum procedural requirements necessary for a determination of death by neurological criteria.

A national consensus panel representing expert opinion and knowledge of the published literature should meet regularly to review and revise national standards as necessary, given the ever-evolving state of medical science and technology. It is noteworthy, for instance, that 4 out of 5 recommendations in the recently published AAN guidelines update are level U (data inadequate or conflicting, given current knowledge) and only one is level C (possibly effective, ineffective, or harmful for the given condition in the specified population), underscoring the ongoing need for more research [7]. Accountability for the implementation of such a national standard would make the most sense at the hospital level, and an existing accrediting body such as the Joint Commission would be well-positioned to ensure compliance.

Standards and policies are only the first step, however. One way to maximize such implementation might be a certification process for those who want to be involved in the assessment of these patients at this crucial moment. A concerted educational effort, followed by simulation and a certification test, much like Advanced Cardiac or Trauma Life Support training (1- or 2-day courses that train health care professionals to successfully resuscitate patients in cardiac arrest or those who have undergone stroke or severe trauma), would create a cadre of health care practitioners proficient in BD evaluations, who could be a strong source of support for implementation of the guidelines. The development and implementation of bedside checklists could reinforce such learning while further reducing errors of omission.

We should expect and welcome ongoing debate regarding the definition of death and some have argued that, in a pluralistic society, multiple definitions should be allowed to coexist [20]. In fact, in the Japanese Transplantation Law and the New Jersey Death Declaration Law, a patient's right to accept or reject the concept of death by neurological criteria is legally preserved. We should eschew pluralism, however, when it comes to evaluating patients. A standardized, rigorous approach to BD determination is something that we owe our patients and their families—for in such a diagnosis, there is no room for correcting mistakes.

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