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## MEDICINE AND SOCIETY: PEER-REVIEWED ARTICLE

### What Does the Public Need to Know About Brain Death?

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#### Abstract

Brain death differs from traditional circulatory death, and understanding how it differs is important. Public awareness of brain death is based largely on inaccurate media representations, common examples of which are described here. The purpose of this article is to motivate lay understanding of brain death by tracing key moments in the history of how we've come to define and recognize brain death as death. This article also considers criticisms of brain death and rebuttals to those criticisms.

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#### Introduction

Public awareness of brain death is based largely on inaccurate media representations. In this article, I first review common examples of misrepresentation of brain death in the media. I then discuss historical aspects of the development of brain death criteria, review various criticisms voiced about the concept both after its introduction and to date, and discuss arguments in support of the concept of brain death. Lastly, ongoing efforts to address the most recent debates concerning brain death are discussed.

#### What Does the Public Know About Brain Death?

Portrayal of **medical topics in the media** provides public education and affects perceptions of and formation of opinions on these topics.<sup>1,2</sup> An analysis of media coverage of “brain death” prior to 2016 revealed that misinformation was presented in 72% of articles.<sup>3</sup> Imprecise use of medical terms and misrepresentation of brain death as a state of life or a form of neurological impairment rather than a form of death were the most common errors.<sup>3</sup> In this study and another one based on newspaper articles published between 2005 and 2009, the actual medical meaning of the term *brain death* was explained in less than 4% of articles.<sup>3,4</sup> Brain death as a prerequisite for organ donation (ie, patients who are declared brain dead are potential candidates for organ donation) was mentioned in less than a third of articles.<sup>3,4</sup> Similarly, portrayal of brain death in film and television is misleading, with a complete understanding of brain death presented in only 13% of productions.<sup>5</sup> Furthermore, *brain dead* is used colloquially,

often to refer to a person or action considered thoughtless.<sup>4</sup> Examples of misinformation and imprecise use of brain death terminology are shown in the Table.

**Table.** Examples of Misinformation and Misrepresentation of Brain Death in Media

Type of Misinformation	Example	Source
Misleading information on brain death vs severe brain injury without delivery of complete definitions	“‘Hand of God’ Wakes Brain-Injured Girl From Coma”	<i>USA Today</i> <sup>6</sup> (05/13/2015)
Brain death not classified as death and instead referred to as “life support” or an “alive” state	“Mom Loses Battle to Keep Brain-Dead Baby on Life Support”	<i>USA Today</i> <sup>7</sup> (07/23/2014)
Failure to clarify that brain death equals legal death, including not mentioning the time of death	“That evening Mrs. Cregan was declared brain-dead. The family had her respirator disconnected the next morning, and she died almost immediately”	<i>New York Times</i> <sup>8</sup> (04/24/2005)
Implying scientific diagnosis of brain death without provision of details	“Husband Celebrates Miracle as ‘Brain Dead’ Wife Wakes Up in Hospital”	<i>Fox News</i> <sup>9</sup> (05/11/2011)
Colloquial use of brain death terminology	“Emmanuel Macron warns Europe: NATO is becoming brain-dead”	<i>Economist</i> <sup>10</sup> (11/07/2019)

Lack of adequate public education on brain death is further evidenced in studies of public understanding. For example, a survey of Ohio residents revealed that over 98% of respondents had heard of the term *brain death*, but only one-third believed that someone who was brain dead was legally dead, and over half classified coma as death instead.<sup>11</sup> An extensive literature review on public understanding of the dead-donor rule for organ donation revealed that there is a general lack of understanding of both biological and legal facts of brain death, as well as of the relation of brain death to organ donation.<sup>12</sup> Even among family members of patients who had been determined to be brain dead, only 28% could correctly define brain death.<sup>13</sup>

### Historical Development of Determination of Death by Brain Death Criteria

*“Death” in the case of irreversible coma.* Traditionally, the moment when death occurred was marked by the cessation of heartbeat and respiration.<sup>14</sup> But technological advances during the 1950s and 1960s, including the invention of positive-pressure mechanical ventilation,<sup>15</sup> advances in intensive care medicine, and the first successful heart transplantation in 1967,<sup>16</sup> called for a new conception of death. The questions these developments raised was whether patients with incurable, catastrophic brain damage should be artificially maintained with the aid of a respirator. Accordingly, in 1968, the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death published the original criteria for brain death, consisting of (1) unresponsiveness and unresponsivity; (2) absence of movement, breathing, and reflexes; and (3) a flat

encephalogram in the absence of confounding factors that was unchanged at an interval of 24 hours or later.<sup>17</sup> Despite the increasing recognition that irreversibly brain-damaged patients maintained by intensive care measures could **donate organs**, given developments in transplantation, the Harvard Committee was focused on a definition of brain death rather than on organ procurement.<sup>18</sup> Their working criteria of brain death were initiated by the medical-ethical question of the right to die in the setting of irreversible coma. While focusing on medical criteria, the report also included consideration of legal cases that had questioned the time of death in irreversibly brain-injured individuals.<sup>17</sup>

*Equivalence of brain death and traditional death.* In 1980, brain death as a form of death was incorporated into the Uniform Determination of Death Act (UDDA),<sup>19</sup> a recommended statute legalizing brain death (defined as “irreversible cessation of all functions of the entire brain”) as death equal to cardiorespiratory death. In 1981, a report by the President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, entitled *Defining Death: Medical, Legal, and Ethical Issues in the Determination of Death*, defined irreversible cessation of all brain function and loss of the integrative functioning of the organism as the main criterion of brain death, arguing that the brain is the body’s central integrator, without which the body inevitably would disintegrate even if supported by machines.<sup>20</sup> Brain death was accepted by the medical community as a form of death equivalent to traditional cardiorespiratory death, the difference being that a brain-dead person supported by a machine lacked the traditional visual signs of death.

*An exact diagnosis of brain death.* Medical **criteria for determination of brain death** were put forward by the American Academy of Neurology (AAN) in 1995 and updated in 2010.<sup>21,22</sup> The AAN defined brain death as “irreversible cessation of all functions of the entire brain, including the brain stem.”<sup>21,22</sup> Prior to determining brain death, the underlying reasons for coma, absence of brain stem reflexes, and apnea need to be understood. The diagnosis of brain death is thus primarily clinical. No other tests are required if the full clinical examination, including an apnea test, are completely and conclusively performed. If this examination cannot be accomplished (for example, in the setting of severe trauma to the face that precludes examination of eyes, pupils, cornea, and ears), confirmatory tests (eg, neuroimaging) are necessary. A clinical determination of brain death implies legal death.<sup>23</sup>

### **Criticism of the Concept of Brain Death**

Criticism of the concept of brain death immediately arose within both the medical and the philosophical-ethical community<sup>24,25</sup> when the original criteria were introduced, because it is difficult to come to terms with a concept of death that abandons our long-cherished idea of a sensual perception of death and an exact point in time when death occurs. Even in the Harvard report, the difference between the previously sole criterion of cardiac death with visible cessation of heartbeat and respiration—and hence a visibly defined time point of death—and the lack of such signs with brain death, was recognized.<sup>17</sup> Debates began about whether it was appropriate to accept brain death as death.<sup>25</sup>

*Philosophical-ethical objections.* Philosophical-ethical objections to the concept of brain death were first prominently put forward by the philosopher Hans Jonas. He was concerned about the possibility that brain death might be used as a means of pragmatically redefining death, thereby freeing patients, their relatives, and medical

resources from the burden of an indefinitely prolonged coma and increasing the supply of organs for donation,<sup>24</sup> a criticism that has persisted.<sup>26</sup> A similar point of ethical criticism is that stopping life support might mean ending a human life for utilitarian reasons by regarding brain death as a convenient redefinition of death for the purposes of transplantation medicine.<sup>27</sup>

*Neurophysiological objections.* Decisive for a revision of the understanding of brain death as equal to circulatory death was the recognition that neither complete bodily disintegration nor cessation of heartbeat necessarily ensue after brain death.<sup>28</sup> With refined artificial support, brain-dead bodies are able to maintain a series of functions, such as wound healing, gestation of a fetus, and sexual maturation—sometimes for long periods of time.<sup>29</sup> On this basis, the conclusion was drawn, especially by Shewmon, one of the most prominent critics, that brain death cannot simply be equated with circulatory death.<sup>28</sup>

### **Solutions to the Understanding of Brain Death**

*Regulatory: abandoning the concept of brain death or developing a new rationale.* Abandoning the brain death concept<sup>20</sup> and returning to the concept of cardiac death would imply a medical-ethical dilemma with more far-reaching implications than the introduction of the concept of brain death itself. It would mean giving up to a large extent the progress and standards achieved in modern intensive care and transplantation medicine—a setback hardly to be imagined—and it would be ethically highly questionable. First, it could expose irreversibly brain-injured patients to conditions necessary to sustain organism functions (ie, mechanical respiration) and refuse them the right to die if not explicitly stated in predetermined living wills. Second, a reduced ability to donate organs for transplantation would mean that patients whose lives could be saved by the organ of a brain-dead patient who had declared a wish to donate while alive would be doomed to die due to a moral evaluation concerning the expanded concept of death.

A 2008 White Paper by the President's Council on Bioethics about the controversies over brain death<sup>30</sup> recognized the need to continually educate the public, respond to the evolving neurological standard, and clarify the relationship between determination of death and organ procurement. The 2 options up for debate—loosening the standard for determining death or abandoning the dead-donor rule (which demands that vital organs should only be taken from persons who are dead)—were both deemed unjustifiable and consequently rejected,<sup>30</sup> although the need to reexamine ideas and practices was recognized in light of technological and scientific advances.

*Solutions on a philosophical-ethical basis.* There are a number of suggestions for resolving debate over the equivalence of brain death with death. One approach is to focus attention on the death of a human being by understanding death not only as a biological event but also as an irreversible loss of the characteristics that define personhood, such as personality, identity, culture, religion, obligations to family and community, legal rights, and lifelong values.<sup>31</sup> The absence of these capacities represents a condition in which the organism as a whole can no longer perform the work that is characteristic of a living human being.<sup>32,33</sup> A diagnosis of brain death is determined by a permanent loss of the overarching neurological center that guides both physical and mental functions of a human, which means that the basis for personal being-in-the-world is irreversibly and irrevocably gone and hence that brain death equals death.<sup>32</sup>

A second approach is recognizing that death no longer represents one single standard. Scientific and technical developments support broadening the definition of death, which, in many instances, represents a process with shifting boundaries rather than an event. Such a broadening of the definition of death occurred with the introduction of brain death and is supported by the recent survival of a 6-hour cardiac arrest.<sup>34</sup> Brain death is hence to be understood as a social construct in the dual sense of normative death, which occurs at “the onset of permanent cessation of functioning of the organism as a whole,” and ontological death, which occurs at “the onset of irreversible cessation” of the characteristics of the organism as a living human being.<sup>33</sup>

### Conclusion and Ongoing Developments

Brain death is a well-founded and widely accepted concept. However, **controversies persist** and often reach the public eye, which creates confusion and insecurity,<sup>35</sup> and misleading information in the media is common.<sup>3</sup> Although major differences between and within countries exist in the procedures for diagnosing brain death,<sup>36</sup> efforts are under way to (1) establish uniform criteria, (2) develop systems to ensure that brain death determination is consistent and accurate, (3) respond to objections to determination of death by neurological criteria, and (4) improve public trust in brain death determination.<sup>37,38</sup> The major conceptual debate—whether it is adequate to justify brain death as equivalent to traditional human death<sup>28</sup>—will likely persist, as brain death is a social construct and, as such, will always be subject to criticism. But a return to a simple dichotomy of dead or alive is no longer justifiable. Death has evolved to have a broader meaning, of which brain death is a part.

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