

# Rapid Public Health Policy Response Project



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School of Public Health and Health Services

## Diagnosing Death: Why does it remain “well settled and persistently unresolved”<sup>1</sup>?

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### **About this Paper**

For 10 days after a 12-year-old boy had been declared dead by physicians, he lay in an intensive-care unit of Children's National Medical Center, sustained by drugs and a ventilator. His Orthodox Jewish parents insisted that, according to religious law, the boy remained alive because his heart continued to beat. District of Columbia law said he did not.

Statutes on the books of every U.S. state consider a person to be dead when all functions of the brain, including the brain stem, have irreversibly ceased, and clinical criteria for diagnosing death on this basis are well established. Nonetheless, there is continued debate, especially in religious, philosophical and bioethics contexts, about how, or even if, brain death should be defined.

This paper reviews current law, the debate over a statutory "conscience clause" that allows cessation of cardiopulmonary function to be the sole basis of a declaration of death, and the impact of the discussion on organ transplantation.

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### **About the Rapid Health Policy Response Project**

The Rapid Health Policy Response Project of the School of Public Health and Health Services at The George Washington University presents data and other background information on breaking public health stories. The goal is to educate the public, policymakers, legislators, health care providers, the media and others in order to promote informed decisionmaking.

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# Diagnosing Death: Why does it remain “well settled and persistently unresolved”<sup>1</sup>?

Motl Brody was pronounced dead by physicians on Nov. 4, 2008. For the next 10 days, the 12-year-old boy lay in an intensive-care unit of Children’s National Medical Center, his heart function sustained by pharmaceuticals and his breathing made possible by a ventilator.

According to the legal standards accepted in every U.S. state, a complete absence of brain function meant that Motl was dead. But his family, Orthodox Jews, argued that as long as his heart continued to beat, Motl remained alive and the hospital should continue to treat him.<sup>2</sup>

Despite the continued use of medical procedures, Motl’s heart and lungs stopped functioning on Nov. 15. The case became the most recent to call attention to the complexities of determining when death occurs, and offers an opportunity for health care providers, legislators, and the general public to discuss these issues in the interest of promoting sound policymaking.

## An emerging definition

Until the mechanical ventilator was invented in the 1950s, there was little reason to separate the concepts of neurological and cardiovascular death. Total cessation of brain function led swiftly to heart failure and conversely, the absence of heart function destroyed the brain. But as technology became available to maintain respiratory function and to restart the heart, social policy and ethical considerations became as central as biology in determining when death occurs.

A brief overview of human physiology is in order. While the division is by no means absolute, the *cerebrum* of the brain, whose outer shell is the cortex, largely controls the “higher” functions of human life, including consciousness, thought, feeling and memory. The *cerebellum* controls sensory and motor functions and the *brain stem* is in charge of the most basic life-sustaining functions, including respiration, blood pressure, swallowing, and the sleep-wake cycle. We do not require thought to make our hearts beat – as long as the heart is adequately oxygenated (either because an individual retains respiratory function, or is attached to artificial breathing devices) and free of other defects, it is generally capable of pumping blood through the body.<sup>3</sup>

Four decades ago, a Harvard Medical School *ad hoc* committee published a landmark paper presenting a set of neurologic criteria intended to define “irreversible coma as a new criterion for death.”<sup>4</sup> Far from resolving the issue, the report triggered broad debate in the 1970s and 1980s as to the extent of the brain damage necessary to assert that death had occurred even if cardiovascular capacity remained.

- ▶ One camp, the so-called “*neo-corticalists*,” argued that a person is dead if loss of consciousness cannot be reversed, regardless of the brain stem’s capacity to sustain automatic functions.

- ▶ An alternative, based on the “*whole-brain standard*,” asserted that death occurred when all functions of the entire brain, including those of the brain stem, were irreversibly lost. This was the view ultimately adopted in a landmark 1981 report by the President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research.<sup>3</sup>

The “whole-brain standard” was incorporated into the Uniform Determination of Death Act, a statute drafted by the National Conference of Commissioners on Uniform State Laws<sup>5</sup> and adopted by most U.S. states and territories.<sup>6</sup> The language, recommended and approved by the American Medical Association and the American Bar Association, states:

An individual who has sustained either (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.

The deliberations surrounding the definition of death are largely distinct from those relating to “death with dignity” and “the right to die,” which frequently have dominated public discussions in recent years. The flashpoint cases of Karen Ann Quinlan, Nancy Ann Cruzan and, much more recently, Terry Schiavo, involved people in “persistent vegetative states” who retained brain stem function. By law, they were alive. Indeed, after Quinlan’s parents won their battle to disconnect their daughter from a ventilator, she continued to breathe on her own for almost a decade without ever regaining consciousness. Schiavo’s open eyes and her ability to move and occasionally smile were evidence of brain stem activity, although not of cognitive awareness.<sup>7</sup>

The issues involving Motl Brody are very different. The boy was not in a persistent vegetative state. He was, by accepted brain-death criteria and the rule of law, dead. In theory, the hospital had no obligation to seek court sanction for discontinuing treatment. Yet the definition of death is, as one scholar wrote in a *New England Journal of Medicine* editorial, “well settled and persistently unresolved.”<sup>1</sup>

### Controversy remains

Clinical criteria for diagnosing death on the basis of absent brain function are well established, requiring “not only a series of careful neurologic tests but also the establishment of the cause of coma, the ascertainment of irreversibility, the resolution of any misleading clinical neurologic signs, the recognition of possible confounding factors, the interpretation of the findings on neuroimaging, and the performance of any confirmatory laboratory tests that are deemed necessary.”<sup>8</sup>

These criteria are widely accepted, and represent “only a minor evolution”<sup>1</sup> from guidelines advanced by the Harvard *ad hoc* committee in 1968,<sup>4</sup> by the President’s Commission in 1981<sup>3</sup> and by the American Academy of Neurology in 1995.<sup>9</sup>

But if the law and clinical practice suggest a consensus has been established, bioethics, philosophy, and religion do not. There is often uncertainty within a family as well, where it can

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be profoundly disquieting to be told that a loved one whose body retains its warmth and color is nonetheless dead. Certain clinical findings add to the complexity:

- ▶ The medical literature reports cases in which mechanical means were used to circulate blood for months in patients who met the definition of whole-brain death, and the bodies of pregnant women have been maintained long enough for fetal gestation.<sup>10</sup>
- ▶ Some individuals without brain function continue to maintain a degree of organ and tissue capacity, with demonstrated ability to eliminate wastes, maintain body temperature, heal wounds, fight infections, and mature sexually.<sup>10</sup>
- ▶ Residual brain function has been recorded in patients who meet standard clinical tests for whole-brain death — in particular, there may be evidence of continued electroencephalographic activity and hypothalamic functioning.<sup>11</sup>

These findings have helped to stir unease with the whole-brain approach to determining death and used to support two alternatives:

- ▶ ***A return to the cardiovascular standard:*** As in the case of Motl Brody, some question the concept of “brain death” entirely, and suggest that circulatory and respiratory function should once again become the sole criteria for death.
- ▶ ***Absence of higher-brain function:*** The “higher-brain” standard defines death as “the irreversible cessation of the capacity of consciousness.”<sup>12</sup> This formulation is built around the concept that consciousness, cognition and social interaction are so fundamental to what it means to be human that life cannot exist without them.

To date, neither construct has led to significant changes in state laws governing brain death.

### Is a conscience clause appropriate?

The lack of consensus on an ontological issue as profound as when death occurs – across cultures and religions, and even among those who share many religious beliefs – is no surprise. There is not, for example, agreement within the Jewish community, or even among Orthodox Jews, about the appropriate medical definition of death.<sup>13</sup>

Rather than seeking to resolve conceptual disagreements, it may be more appropriate to acknowledge that any definition will inevitably “involve a tradeoff between individual autonomy and governmental interests in uniformity and efficiency.” A more useful question, suggests ethicist Karen Grandstrand Gervais, may be: “What concept of death ought to be written into public policy as the default concept of death?”<sup>14</sup>

Framing the definition of death as a matter of societal decisionmaking, rather than a biological absolute, allows the possibility of making exceptions for personal beliefs. The President’s Commission specifically advised against this, stating that a “conscience clause,” which would permit “an individual (or family members, where the individual is incompetent) to specify the standard to be used for determining his or her death based upon personal or religious beliefs ... has no place in a statute on the determination of death.”<sup>3</sup>

Death, said the Commission, is a *fact* when either the cardiac or brain criteria are met. It did, however, acknowledge the need for some flexibility in the actions to be taken in light of that fact (such as maintaining the body on a respirator until organs can be removed for transplant, or withholding religious pronouncement of death until blood flow ceases).

Nonetheless, at least two states — New York and New Jersey — have conscience clauses in their statutes:

- ▶ The New Jersey law states that an individual will not be declared dead on the basis of neurological criteria if the physician has reason to believe “that such a declaration would violate the personal religious beliefs of the individual.” In those cases, the pronouncement would be made only on the basis of cardiopulmonary criteria.<sup>15</sup>
- ▶ The New York regulation places the burden of choosing the appropriate standard on the hospital, mandating that each hospital implement a written policy that includes a “procedure for the reasonable accommodation of the individual’s religious or moral objection” to a determination based on whole-brain criteria.<sup>16</sup>

The Japanese model is also worth noting. Following considerable national debate, Japan passed an organ transplantation law in 1997 allowing people to state, on a donor card, their preference for being declared dead on the basis of either brain death or traditional cardiopulmonary criteria.<sup>17</sup>

All of these approaches have their critics. Alex Capron, an ethicist at the University of Southern California, has complained about what he calls “the bifurcated legal standard for determining death.”<sup>18</sup> The New Jersey law raises First Amendment issues, with commentators objecting to the privilege it accords religious beliefs, rather than secular moral principles. The New York law has been criticized for its lack of specificity.<sup>19</sup>

But conscience clauses elevate the role of personal choice and, as doubt stirs about what has, at times, seemed to be a largely settled question, they are getting further attention. Robert Veatch, director and professor of medical ethics at the Kennedy Institute of Ethics at Georgetown University, has urged that individuals be permitted “to choose their own definition of death based on their religious and philosophical convictions,” as long as such definitions “avoid violating the rights of others and avoid creating insurmountable social problems for the rest of society.”<sup>20</sup>

### **Brain death and organ transplantation: an uneasy relationship**

The brain death debate is inextricably tied to the issue of organ transplantation. Organs, which remain in critically short supply, quickly become unsuitable when an individual loses respiratory and circulatory capacity. The best donors, therefore, are typically those in whom cardiopulmonary function can be maintained after brain function has ceased.

The ethical pillar of transplantation, however, is the “dead donor” rule, which states that an individual must be dead before organs are removed. Some scholars have argued that the definition of death is being “gerrymandered” to meet that standard.<sup>21</sup>

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This is not a new concern. The criteria of “irreversible coma” developed by the Harvard *ad hoc* committee was criticized as a utilitarian attempt to advance the field of organ transplantation, rather than to grapple with the profound conceptual questions about the nature of human identity.<sup>22</sup> In addition, the fear that a different standard of death might be applied to gravely ill patients willing to become organ donors has surfaced ever since it became medically feasible to harvest and reuse organs.<sup>3</sup>

If we were willing to consider “organ donation without brain death,” writes one scholar, “we could obviate the need to find ever more creative ways of supporting this beleaguered concept.”<sup>23</sup> Rather than harvesting organs only after an individual has been declared brain dead — or when all cardiac function has ceased, a claim with its own controversies and complexities<sup>24</sup> — this framework would emphasize informed consent as the mechanism for moving forward.

But it would not resolve all conflicts. As the President’s Commission emphasized, an appropriate determination of death is essential not only to facilitate organ transplantation but “to render appropriate care to patients and to replace artificial support with more fitting and respectful behavior when a patient has become a dead body.”<sup>3</sup> The Motl Brody case, and Children’s National Medical Center’s effort to seek court sanction for measures that already had a clear legal basis, highlight the delicacy of the issue.

Broader public debate may be called for, similar to that which occurred in Japan prior to passage of the law allowing citizens to choose their preferred criteria for death. Philosopher Masahiro Morioka writes: “In North America and in some European countries, the debate was restricted to the medical and bioethical spheres, and the views of ordinary people were not necessarily reflected. Why does Japan have the policy it does? In my view, it is because the country held a prolonged nationwide debate.”<sup>25</sup>

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