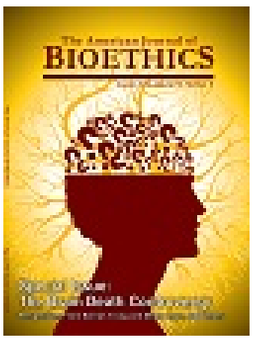

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Target Article

Whither Brain Death?

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The publicity surrounding the recent McMath and Muñoz cases has rekindled public interest in brain death: the familiar term for human death determination by showing the irreversible cessation of clinical brain functions. The concept of brain death was developed decades ago to permit withdrawal of therapy in hopeless cases and to permit organ donation. It has become widely established medical practice, and laws permit it in all U.S. jurisdictions. Brain death has a biophilosophical justification as a standard for determining human death but remains poorly understood by the public and by health professionals. The current controversies over brain death are largely restricted to the academy, but some practitioners express ambivalence over whether brain death is equivalent to human death. Brain death remains an accepted and sound concept, but more work is necessary to establish its biophilosophical justification and to educate health professionals and the public.

Keywords: brain death, death, definition of death, organ transplantation

Brain death is back in the news with the coincidental juxtaposition of two highly publicized, controversial, and tragic cases. The teenaged Jahi McMath was diagnosed as brain dead following throat surgery but her parents refused to accept the diagnosis and insisted upon continued treatment (Magnus, Wilfond, and Caplan 2014). The pregnant Marlise Muñoz was diagnosed as brain dead but the Texas hospital in which she was admitted insisted on continuing ventilator treatment against the wishes of her family by claiming that regulations in the Texas Health and Safety Code mandated treatment in pregnancy for the welfare of the fetus (Ecker 2014). For those of us who have been engaged in scholarly debates over brain death for decades, and had seen public controversies subside as its acceptance rose, their sudden re-ignition was disorienting. Yet, given the persisting misunderstanding of vegetative state and brain death by the public, and the ambivalence over brain death expressed by some professionals, recurring controversies might have been predictable.

Brain death is the familiar name for the determination of human death by showing the irreversible cessation of the brain's clinical functions. There is wide agreement that "brain death" is a misleading term because it wrongly implies that only the brain dies and that there is more than one kind of death—rather than that there is more than one way to determine death. Its unfortunate name alone further aggravates public confusion over its meaning. Yet because past attempts have been unsuccessful in replacing other ingrained but poorly chosen names of medical syndromes with more accurate newly coined terms (e.g., replacing "vegetative state" with "unresponsive wakefulness syndrome" as advocated by Laureys et al. 2010), the term "brain death" is probably not going to be retired soon. Users of the term "brain death," however, should use it correctly.

THE CURRENT STATE OF BRAIN DEATH

Brain death has evolved from an instrumental to a biophilosophical concept. It emerged in the 1950s contemporaneously with the development of tracheal positive-pressure mechanical ventilation and the rise of organ transplantation. First called *coma dépassé* (irretrievable coma) by Mollaret and Goulon (1959), it was given its modern clinical criteria and familiar name in a landmark report in the *Journal of the American Medical Association* in 1968 (Ad Hoc Committee 1968). Its use by physicians to determine death has now become accepted throughout the developed and developing world and many countries have enshrined it into public laws (Wijdicks 2002). Brain death was first developed to permit withdrawal of ventilator support in hopeless cases before laws and practices permitted that action, and to facilitate organ donation (Giacomini 1997). Now that withdrawal of life-sustaining therapy has become accepted practice, brain death declaration is performed most commonly to permit organ donation.

From its origins, brain death also has had critics who claimed it was unscientific, illogical, or a legal fiction contrived to facilitate organ donation (Miller and Truog 2012). But despite the vigor and longevity of the arguments opposing it, and the logic and rigor of some critiques (especially those of Shewmon 2001; 2009; 2010), the opponents have been unsuccessful in catalyzing a public movement sufficient to change medical practices or public laws.

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Long-standing attempts also have failed to change the accepted "whole-brain" criterion of death to the "higher-brain" criterion requiring only the loss of consciousness and cognition (Veatch 2005). After its endorsement by the U.S. President's Commission in 1981, subsequent high-level policy reviews by a conference co-sponsored by the Institute of Medicine (Youngner, Arnold, and Schapiro 1999) and an analysis by the U.S. President's Council on Bioethics (2008) found that, despite acknowledged shortcomings in its theoretical justification, brain death remained a coherent, workable, and successful public policy.

Current debates over brain death are largely restricted to the academy; most physicians who pronounce brain death in daily practice are unaware of them. Medical groups have produced practice standards for determining brain death that are accepted widely (Nakagawa et al. 2011; Wijdicks et al. 2010). The principal debates about brain death within the medical community concern only technical details (Bernat 2013a). Yet because academic disputes continue, nonclinical scholars who participate in conferences and publish critical analyses often develop a different impression of the current status of brain death than do medical practitioners.

Even within the academy, the hottest area of controversy in death determination in organ donors, ironically, is not over brain death but rather over the standards for the circulatory determination of death (Bernat 2013a). The principal dispute concerns whether an organ donor is truly dead at the moment death is usually declared—in most protocols at five minutes following complete circulatory cessation—at a point when circulatory cessation is permanent but may not be irreversible yet (Bernat 2013b). This nagging question has dogged the practice of organ donation after the circulatory determination of death since its inception (Lynn 1993), but appears to bother physicians more than patients' family members. In my clinical experience, family members of patients nearly always consider the patient dead at the moment of heartbeat cessation. Tellingly, a recent international survey showed that physicians expressed greater confidence in the accuracy of brain death determinations than in circulatory death determinations (Rodriguez-Arias et al. 2013). This opinion is justified, given that the circulatory–respiratory tests of death are valid only because they lead to fulfilling the more fundamental brain criterion (Bernat, Culver, and Gert 1982).

Despite persistent academic disputes, the widespread acceptance of brain death by physicians and its enshrinement in public laws might be interpreted as showing a high degree of public satisfaction with it. However, this apparent unanimity masks a latent level of confusion and ambivalence about brain death that surfaces in surveys and when individual cases, like those of McMath and Muñoz, come to public attention. The Teresa Schiavo case in 2005 showed the public's misunderstanding of states of brain damage. She had lived for 15 years in a vegetative state when a highly publicized controversy erupted highlighting the dispute among her family members over whether she wished to continue to receive hydration and nutrition by gastrostomy tube keeping her alive or to have it discontinued and die (Hook and Mueller 2005). An analysis of news media reports of her case (Racine et al. 2008) showed that some journalists confused the vegetative state with brain death, despite the fact that no physicians examining Mrs. Schiavo or courts ruling on her case ever stated she was brain dead.

Why does public misunderstanding of brain death persist? Is it simply a knowledge deficit that could be amenable to education or is there a more fundamental ambivalence over the concept? One obvious barrier is that brain-dead patients do not appear dead: It is contrary to experience to call a patient dead who continues to have heartbeat, circulation, and visceral organ functioning. Yet the widespread acceptance of brain death has been driven by its intuitive appeal and instrumental value in organ donation. These features led to the enactment of laws and the establishment of medical practices permitting physicians to use brain death as a determination of death a decade before rigorous biophilosophical arguments were offered to justify the equivalence of brain death with human death (Belkin 2003).

Public misconceptions over brain death should be amenable to education. By analogy, people ignorant of the clinical characteristics of the vegetative state who observe the affected patient's eyes open, close, and move may understandably but wrongly assume that these abilities imply awareness of self and environment. Once people understand that wakefulness and awareness are separate capacities, they then can understand that eye opening and movement do not necessarily indicate awareness in a vegetative patient (Giacino et al. 2014). Similarly, when one understands the concept that the irreversible cessation of clinical brain functions indicates the death of the person, despite the fact that the majority of observable parts of the person remain alive supported by machines, it becomes easier to accept why physicians consider the person dead.

AN ANALYSIS OF DEATH

Those who accept brain death have varying levels of understanding of why brain-dead patients are dead. The most common level is intuitive. To many people, it seems logical that patients whose brain functions have totally and irreversibly ceased comprise a qualitatively different state than those who continue to possess at least some brain functions because the brain is the master organ, the seat of consciousness, and the source of human characteristics and behavior. The intuitive level creates a sufficient degree of understanding for most people to accept brain death despite possessing only a vague and inchoate concept.

Medical acceptance comprises a second level of understanding. Physicians and others with scientific

sophistication may accept brain death as a consequence of their greater understanding of the role of the brain in the functioning of the human organism. Such people may see the absence of consciousness, cognition, breathing, circulatory control, and centrally controlled homeostasis as tantamount to death because what functions remain are supported by mechanical devices and human intervention. They may consider such patients suitable for organ donation and "as good as dead" even if they remain undecided over whether they are truly dead.

Justifying the equivalence of brain death and human death as a result of a rigorous biophilosophical analysis comprises the deepest level of understanding. This level may be reached by conducting an analysis that studies the concept of the human organism and the meaning of death in our technological era in which organs and organ subsystems, particularly circulation and respiration, can be maintained in modern intensive care units. Biophilosophical analyses of death leading to the conclusion that brain death represents human death have been proposed by Korein (1978; 1997), the President's Commission (1981), Culver, Gert, and me (Bernat, Culver, and Gert 1981, 1982), Shewmon (1985), the President's Council (2008), and Bonelli, Prat, and Bonelli (2009), among others. Despite the insights of these analyses, the biophilosophical justification of brain death remains incomplete.

Biophilosophical analyses of death usually follow a format proposed first by Capron and Kass (1972) of clarifying the concept of death before identifying the means to assess whether it has occurred. My colleagues and I followed this approach in our sequential analysis proceeding from the conceptual to the tangible (Bernat et al. 1981; 1982). We proposed a four-step analysis: (1) agreeing on the conditions for the analysis: a set of assumptions framing the arguments that I later called the paradigm of death; (2) the philosophical task of identifying the definition of death: the ordinary meaning of "death" that was used correctly but that has been rendered ambiguous by medical technology; (3) the philosophical and medical task of choosing a criterion of death: that general standard that shows that the definition has been fulfilled by being both necessary and sufficient for death; and (4) the medical task of choosing medical tests that show that the criterion has been fulfilled.

Our stepwise analysis has the virtue of pinpointing areas of disagreement. Even many scholars who disagree with specific elements of our analysis concur that our analytical method is the standard approach to studying the problem (Shewmon 2010). Yet some scholars have rejected it by arguing that one can endorse brain death without first defining death because a unitary definition of death is impossible (Chiong 2005). In previous works, I have defended the elements of the paradigm, the definition, and the criterion of death, and responded to critiques of those elements (Bernat 1998; 2002; 2006). Here I discuss the rationale for the definition and criterion of death for which the criticism led the President's Council (2008) to reexamine the validity of brain death.

THE RATIONALES OF INTEGRATION AND THE ORGANISM AS A WHOLE

In a series of penetrating articles, Shewmon, who previously was a strong proponent of brain death before becoming its most influential critic (see his explanation in Shewmon 1997), attacked it on several grounds, but none more effectively than over the rationale of bodily integration (Shewmon 2001; 2010; Shewmon and Shewmon 2004). In early works defending brain death, the President's Commission (1981) and my colleagues and I (Bernat et al. 1981) cited the essential function of the brain in integrating and coordinating various bodily functions. We also cited the fact, which then was true, that technology could not succeed in maintaining a person's heartbeat and circulation for more than a few days after brain death occurred; thus, the integrating and controlling functions served by the brain were essential to life and therefore counted as a critical function of the organism as a whole. This claim became known as the integration rationale for brain death.

Shewmon later showed that many elements of bodily integration are executed by structures other than the brain, such as the spinal cord (Shewmon 1999), and thus the integrating capacity of the brain could not be cited to justify the equivalence of brain death and human death. Shewmon's analysis was sufficiently persuasive that the President's Council's decision to restudy the subject appears to have been stimulated principally by a need to respond to his critique. The President's Council concurred with Shewmon that the integration rationale was inadequate and offered a new rationale for brain death, namely, the irreversible inability to "carry out the fundamental work of a living organism," including "a fundamental openness to the surrounding environment as well as the capacity and drive to act on this environment on his or her own behalf" (President's Council 2008). Shewmon, who testified before the council, remained unconvinced by its new rationale and concluded that the rationale suffered from the same flaw as the integration rationale that the council replaced (Shewmon 2009).

I believe that the strongest justification for the brain death concept is not the integration rationale but the cessation of the organism as a whole. The organism as a whole is a biophilosophical concept first developed in a monograph in 1916 by the biologist Jacques Loeb. The organism as a whole refers not to the whole organism (the sum of its parts) but rather to those functions greater than the sum of its parts: the emergent functions that become manifest when normally functioning organ ensembles work in concert (Clayton and Kauffman 2006). These emergent functions serve the organism as a whole at the expense of the organism's parts and epitomize the unity and wholeness of the organism and the necessary interrelatedness of its parts. Human conscious awareness is the most exquisite and ineffable example of such a function.

My colleagues and I argued that the definition of death that is implicit in our ordinary use of the word in our technological era, in which organ subsystems can be

maintained, is the irreversible cessation of the organism as a whole (Bernat et al. 1981). The essence of the concept of the cessation of the organism as a whole is the distinction between the life of the organism and the technologically supported life of parts of the organism in an intensive care unit. The brain-dead patient is dead because the organism as a whole has ceased, though obviously many parts of the human organism remain alive because of technological support of ventilation and circulation.

Admittedly, the concept of the organism as a whole remains vague and would benefit from further biophilosophical analysis. Bonelli and colleagues (2009) made an important step in that direction in an infrequently cited article. They observed that all life forms have a delimited unity that is characterized by four criteria: (1) dynamics, or signs of life, such as metabolism, regeneration, growth, and propagation; (2) integration, the requirement that the life process derives from the mutual interaction of its component parts; (3) coordination, the requirement that the interaction of the component parts is maintained within a certain order; and (4) immanency, the requirement that the preceding characteristics originate from and are intrinsic to the life form.

Bonelli and colleagues then identified four criteria that make a life form a unified whole organism: (1) completion, the requirement that an organism is not a component part of another living entity but is itself an intrinsically independent and completed whole; (2) indivisibility, the condition of intrinsic unity that no organism can be divided into more than one living organism—and if such a division occurs and the organism survives, the completed organism must reside in one of the divided parts; (3) self-reference or auto-finality, the characteristic that the observable life processes and functions of the component parts serve the self-preservation of the whole, even at the expense of the survival of its parts, because the health and survival of the living whole is the primary end in itself; and (4) identity, the circumstance that, despite incremental changes in form and the loss or gain of certain component parts (that even could eventually result in the exchange of all component atoms), the living being remains one and the same throughout life (Bonelli et al. 2009).

Bonelli and colleagues concluded that the death of an organism is the loss of these four characteristics that render an organism no longer capable of functioning as a whole. They point out that in higher animal species, with the irreversible cessation of all functions of the entire brain (brain death), the organism has permanently lost the capacity to function as a whole and therefore is dead. The organism has lost immanency because its life processes no longer spring from itself but result from external intensive care support. The organism has lost auto-finality because whatever control over the component organ subsystem parts that remains now is directed at the level of the surviving parts and no longer at the whole. The organism has lost self-reference because the continued functioning of its parts no longer supports to the function of the whole. The organism has lost completeness and indivisibility because its separate component parts and subsystems no longer belong to each other and no longer constitute a whole (Bonelli et al. 2009).

In our contemporary technological era in which skilled critical care physicians using advanced technology can maintain the life of component parts of organisms outside of or inside the body, the continued life of the organism has been wrongly attributed to the technologically supported life of many of its component parts. The essence of the death of a person is the irreversible cessation of the functioning of the human organism as a whole. The brain-dead human organism has irreversibly lost its totality, completion, indivisibility, self-reference, and identity. It no longer can ever again function as a whole and therefore is dead.

BRAIN DEATH AS PUBLIC POLICY

In the United States, brain death must be judged to be a successful public policy (Bernat 2006). We have enacted nearly uniform laws permitting its determination as a legal standard of death in every state (Beresford 1999). Medical societies have produced uniform clinical practice guidelines that are widely accepted in the medical community, if not always followed assiduously (Greer et al. 2008). The national program of deceased organ donation continues to use brain dead donors as its principal source of organs, though the percentage of donors after the circulatory determination of death is increasing (Bernat 2013c). Our organ donation program is popular and accepted well by the public. It, too, succeeds as public policy except for the organ shortage crisis and the growing disproportion between available organ donors and needy recipient patients. Despite areas of scholarly skepticism, there has been no sustained public outcry to question or abandon the practice of brain death. Although the number of brain death declarations appears to be decreasing, it is not as a result of controversy, but because of improvements in the treatment of brain injuries and because surrogate decision makers of severely brain-damaged patients make decisions to withdraw life-sustaining therapy from them earlier in their course before they progress to brain death (Kramer et al. 2013).

Despite its success as a policy, some professionals and laypersons feel malaise over brain death. One source of their discomfort is their sense that brain death is a contrived legal fiction to permit the benefits of organ donation. A legal fiction in this context is a purposeful manipulation of biological reality to achieve a societally desirable goal. Legal blindness is a good example. Everyone knows that most people who are declared legally blind have profound visual loss but are not truly blind. Our society created the nonbiological category of legal blindness to allow people with severe visual impairment to qualify for the same benefits as people who are totally blind, though we acknowledge that they are not fully blind. Taylor (1997) and Shaw and Miller (2010) cited this example to analogize our

acceptance of brain death, arguing that we all know that brain-dead patients are not really dead but, as a society, we have created the legal fictional category of brain death to thereby reap the societal benefits of organ donation.

What insights into the success of brain death as a public policy can we glean from the McMath and the Muñoz cases? The McMath family members' refusal to recognize brain death and their insistence upon continued ventilator treatment cited religious reasons. Their lack of trust in the hospital and physicians appeared to be an additional factor. Of course, there have been numerous prior young brain-dead patients whose families insisted on continued treatment. In the McMath case, however, the family also had an unrealistic expectation of treatment, claiming that they believed Jahi McMath would recover fully. This case illustrates the counterintuitive nature of calling a person with heartbeat and circulation dead, and represents a poignant reminder of the difficulties families have in accepting the finality of such a tragic outcome.

The Muñoz case highlights the uncertainty of some professionals about the legal status of brain death. The hospital attorneys insisted that the Texas Health and Safety Code provision requiring continued treatment of brain-damaged pregnant women applied to this woman despite her brain death diagnosis. Most commentators argued that the law required continued treatment to keep living brain-damaged women alive until their baby could be born, but that the law did not apply to dead women (Gostin 2014). Nevertheless, the hospital stood firm in asserting its legal duty to continue treatment. It took a judge's ruling on the family's lawsuit against the hospital to clarify that the law in question did not apply to brain-dead women, and to order the hospital to discontinue her treatment because she was dead. It remains unclear to what extent the hospital attorneys' conservative legal advice resulted from their ambivalence over the legal status of brain death and how much resulted from their uncertainty over the requirements of Texas law. Nationwide, there has been no wavering whatsoever in the firm legal status of brain death in numerous state court rulings in which the issue has been litigated (Burkle, Schipper, and Wijdicks 2011).

One obvious conclusion to redress the mismatch between brain death as a successful public policy and the confusion and malaise over it is the need for improved public education. Survey data continue to reveal misunderstandings about the meaning of brain death by the public (Siminoff, Burant, and Youngner 2004). When poignant cases—like those of McMath and Muñoz—capture public attention, journalists reporting on them have a unique opportunity to educate the public and to correct their misconceptions. Journalists should not squander this educational moment by instead emphasizing the sensationalistic aspects of the family dispute, as unfortunately was done during much of the press reporting in 2005 on Teresa Schiavo (Bernat 2008).

Recent surveys also reveal deficits in health professionals' understanding of brain death (Joffe et al. 2012) that should be amenable to education. The American Academy of Neurology is conducting a program to improve professional education about brain death and the World Congress of Neurology is discussing one. But because surveys of physicians also show that an independent source of professional angst results from the uncertainty over the validity of the concept of brain death (Joffe et al. 2012), more biophilosophical work remains to be accomplished to solidify the conceptual foundation of brain death to better convince skeptics why they are justified in regarding brain dead patients as dead. Capron's apt but ironic summary of its status in 2001 remains true today: Brain death is "well settled yet still unresolved" (Capron 2001). ■

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