Brain death is a neurological condition on which much can be said and theorized. A recent book *Death Before Dying*—with its *contradictio in terminis* title—puts some of the disputes on what could be called ‘the neurology of death’ into historical perspective. Belkin is a psychiatrist from New York University Langone Medical Centre who has a PhD in the history of science. During his psychiatry residency more than 20 years ago, he personally dissected the ‘Beecher papers’: the collected correspondence and drafts from the Harvard Medical School Ad Hoc Committee set up to examine the definition of brain death. To gain a fuller perspective, he also interviewed many neurologists and other physicians, including members of the Harvard Committee (the ‘brain death architects’ as he calls them). In *Death before Dying*, Belkin provides a good insight into the deliberations of the Committee and, more speculatively, places the Harvard criteria of brain death and its prior deliberation into the early history of medical ethics.

The book takes a broad sweep, has many asides and dense prose, particularly when Belkin posits that ‘the explosive growth of bioethics was a response to a loss of faith in the pragmatism of the medical point of view, of the thought style and structure of medical knowledge as a source of values’. It leans heavily on personal remembrances by neurologists of the day and, although this can sometimes give a skewed one-sided view, it also produces a plethora of anecdotes and sentiments. Ultimately, the book is about Henry Beecher, the Committee and the Law, but also on how coma became better understood and the aforementioned emerging role of bioethics. This work is an exploration of, in essence, a very simple neurological finding generating all sorts of vexed questions and sophistical arguments. Belkin does much right in this relevant historical work.

Belkin debunks several myths. Many bioethicists have attacked the Harvard committee for focusing on issues related to organ transplantation, but Belkin argues clearly that there is a lack of justification for this claim. He exposes the misrepresentation of the presence of a transplant surgeon and transplant nephrologist on the Harvard committee. Many bioethicists have claimed that this indicated a desire to facilitate transplantation, and some even suggested that these transplant physicians may have reduced the length of the observation period required after a decision on death and transplantation eligibility. However, this argument—the self-serving role of the transplant physicians—has been disputed multiple times and has largely disappeared from the discussion (see also Wijdicks, 2003).

Belkin opens the book with the discussions of the Harvard committee regarding Beecher’s crusade over what to do with these ‘hopelessly comatose patients’. Beecher’s editorial in the *New England Journal* was titled ‘Ethical problems created by the hopelessly unconscious patient’ and addressed the futility of care of these individuals. Beecher went on to stress that ‘death of the brain is death indeed, even though the heart continues to beat’ (Beecher, 1968). The committee he brought together was all inclusive in its representation of specialties and consisted of Raymond Adams (neurology), Clifford Barger (physiology), William Curran (law), Derek Denny Brown (neurology), Dana Farnsworth (public health), Jordi Folch-Pi (biochemistry), Everett Mendelson (history), John Merrill (transplant nephrology), Joseph Murray (transplant surgery), Ralph Potter (social ethics), Robert Schwab (neurology) and William Sweet (neurosurgery).

Most of the preparatory work that went on before the committee started to draft the manuscript was performed by the neurologist Robert Schwab, and he can be credited with providing a more detailed description of an isoelectric EEG in brain death and for merging the EEG into diagnostic criteria. The criteria which would allow the physician to indicate that the patient was dead...
were (i) absence of spontaneous respiration for 30 min; (ii) no tendon reflexes of any type; (iii) no pupillary reflexes; (iv) absence of oculocardiac reflex (eyeball pressure slowing heart rate); and (v) 30 min of isoelectric EEG. Some of these criteria made it in the final document, others did not.

Belkin allows the reader to review the (surviving) drafts of the Harvard committee. The document in its first draft had only three headings (no movement or breathing, no reflexes and flat EEG). Adams later added ‘unreceptivity’ and ‘unresponsivity’. Adams, in his interview with his biographer (Laureno, 2009), felt that simply the term ‘no reflexes’ would be sufficient; but to his credit he also substantially improved the next draft with further details on brainstem reflexes. The centrality of the brainstem was undoubtedly recognized, but it did not reach the prominence it deserved. When re-reading these drafts and this book, I cannot escape the feeling that there was some struggle to distinguish irreversible coma from brain death and perhaps not all committee members had a complete grasp of these differences. And, as we will see later, most neurologists and neurosurgeons in the USA soon turned their eyes above the tentorium and towards the hemispheres. Not the neurosurgeon Sweet, however, who continued to argue that all was needed was no brainstem (he confided to Belkin that the others ‘did beat on me’).

The Harvard Criteria were published in the Journal of the American Medical Association on 5 August 1968 (Anonymous, 1968). The manuscript was light on exclusion criteria apart from hypothermia and barbiturate overdose, other circumstances such as major organ dysfunction were not specifically mentioned and the confounders seemed like an afterthought. Five brainstem reflexes would have to be tested, but there was no testing for apnoea other than disconnection of the ventilator for 3 min (without oxygen provision or testing using a CO2 challenge). The paper also specifically mentioned for the first time that the brain death determination should be delinked from transplantation.

How these criteria worked in practice has remained unknown and Belkin unearths a survey several years later that revealed that more than 1 in 4 US physicians would not turn off the ventilator in cases of suspected brain death. However, interest in the topic would not wane, to put it mildly, and what came later was arguably far more consequential (and perhaps even explosive).

The EEG remained central in the assessment of these catastrophically injured patients. In what historically can be considered an addendum to the main document, Adams and Jequier emphasized, in a paper 1 year later, that brain death was a clinical diagnosis and that physicians should not rely on EEG. ‘The physician that would permit such a crucial decision be made by a machine, ingenious as it might be, leaves himself (and his patient) in a highly vulnerable position’ (Adams and Jequier, 1969).

That did not minimize the importance of the EEG in the USA and most early papers on brain death included EEG descriptions. One of the most influential was by Silverman and associates. This paper contained data on 2650 isoelectric EEGs. A survey suggested that most neurologists believed that any EEG activity indicated a patient could potentially survive. There was uncertainty over how long EEG activity had to be absent for the state to be considered permanent and this became the impetus for the US collaborative study (Silverman, 1970), in which patients were examined regularly and repeatedly. The study demonstrated that comatose patients with no apparent breathing and isoelectric EEGs died from cardiac arrest. One of the other main conclusions of the US collaborative study was that autopsy data could neither prove nor disprove the accuracy of clinical examination. No such prospective studies have been performed in other countries. However, in the UK, Jennett and Glege (1981) published an article on 609 patients in three neurosurgical intensive care units in Cambridge, Glasgow and Swansea. In 326 patients, ventilation was continued and the heart stopped within days. Jennett also validated brain death by looking at 1003 surviving patients with traumatic head injury and found none with a combination of apnoea, fixed pupils, absent eye movements and other unresponsiveness (Jennett and Glege, 1981).

The US collaborative study has been criticized for lack of data and possible confounders; moreover, many of the examinations of the brainstem and of whether there was breathing effort were incomplete (Collaborative study, 1997). The US collaborative study identified the need to test for brainstem reflexes but felt that a confirmatory test, either electrophysiologically or by blood flow, was necessary to define brain death. The study also elaborated on the term ‘brain death’ and suggested that death should be defined as death by cardiorespiratory criteria or by neurological criteria rather than with the terms cardiac death, cerebral death or brain death. Korein later suggested that ‘cerebral death’ was best defined as loss of function of the supratentorial part of the brain, again placing less emphasis on the brainstem. The major critique of the US collaborative study has been that the investigators had more interest in pathology, flow studies and the use of neuropathology as a definitive test for brain death, and did not specifically focus on clinical examination. This line of thinking has unfortunately not disappeared completely, and indeed physicians are still searching for the ultimate laboratory test of brain death and accepting brain death only when there is demonstrably absent intracranial circulation or an isoelectric EEG (Wijdicks, 2002).

The US collaborative study became a model for the President’s Commission report. That, in itself, was a model for legislation on defining death. The President’s Commission on Ethical Issues in Medicine and Biomedical and Behavioral Research published guidelines in 1981 (President’s commission, 1981). The Commission attempted to develop criteria that (i) eliminated error in classifying a living individual as dead; (ii) allowed as few errors as possible in classifying a dead body as alive; (iii) allowed a determination to be made without unreasonable delay; and (iv) were explicit, adaptable, and accessible to verification. Brain death was defined as the ‘irreversible cessation of all [clinically ascertainable] function of the entire brain including the brainstem’. The report led to the Uniform Determination of Death Act (UDDA). The Commission concluded that ‘it is not necessary—indeed it would be a mistake—to enshrine any particular medical criteria, or any requirements for procedure or review, as part of the statute’.

Pallis—who with Jennett can be considered the pioneer of brain death criteria in the UK—famously commented that the committee was giving the impression that it sought to identify ‘death of
the whole brain' rather than 'death of the brain as a whole' (Pallis and Harley, 1996; Wijdicks, 2012). The UK position has always been that once the brainstem reflexes are lost and there is demonstrable apnoea, the situation is irreversible; and demonstration of the extent of cortical injury that produced the damage in the first place—and thus an EEG—are not absolutely necessary. The importance of the brainstem had been recognized a century before and even Duret said (citing Charcot) that ‘En effet, le bulbe réiste le plus longtemps. C'est l'ultimum moriens des centres nerveux’.

Neurologists had known for many years that the brainstem was the final neuronal structure to cease functioning in a catastrophic neurological injury, or as eloquently stated by Pallis, ‘the infratentorial repercussion of supratentorial lesion’ (Pallis and Harley, 1996). The mere fact that most patients with a catastrophic neurological injury do not lose all brainstem reflexes points to its natural resilience. The exquisite importance of the brainstem, not only in defining life or death, is already clear from its anatomical importance in the evolution of species with many of our ancestors living with a brainstem alone. Moreover, the thinking brain (hemispheres) cannot function without a brainstem input. The brainstem can function without the thinking brain and quite well. However, it would take many decades for physicians to understand (and accept) this fundamental observation. For a long time physicians believed that despite loss of brainstem function, some cognition or awareness could nevertheless be present in patients left unable to express themselves; this created the need to demonstrate loss of all neuronal function through absence of intracranial circulation or absence of electrical activity as the only permissible proof of brain death (Wijdicks, 2002). Notably, the Conference of Medical and Royal Colleges in the UK later changed brain death into brainstem death, again emphasizing the importance of the brainstem (Conference of Medical Royal Colleges and Faculties of the United Kingdom, 1976).

As expected, alternative neurological criteria have been developed throughout the world, although most were modelled on the US version (Wijdicks, 2002). Substantial differences have been noted in the use and requirement of confirmatory tests, the number of physicians needed, how the apnoea test should be performed, and the length of the observation period needed between two tests. Over the years, multiple levels of complexity have been introduced by multiple countries. A consensus will be difficult, and uniform rules for brain death determination may now be unrealistic—there are too many opinions and too many cultures and values in a global world. Notwithstanding these hurdles, I cannot see why we cannot come up with a consensus that emphasizes simplicity and loss of brainstem function (Wijdicks, 2011).

The final—perhaps most compelling—part of Belkin’s book is on what he calls ‘the conceptional turn’, in which bioethicists posit that the definition of death does not rely on medical judgement, but on philosophical and other conceptional categories. This opened up thought experiments and what Belkin calls ‘hypothetical creativity’. And then there were the prefixes—whole and higher. These pseudo over-precise additions always looked unimportant to me but they created a fundamentally different discussion in the USA. Belkin’s book is also very clear on how discussion in the USA deteriorated with a plethora of terminology. When reading Belkin’s book you can feel disagreement brewing and experts coming out of obscurity. He admirably recounts this history of days gone by.

In my study, I have a shelf with recent books on dying, brain death, death, definition of death and the ethics of organ donation. When you look closely you might be surprised to even find titles such as Beyond Brain Death, Twice dead, The undead. ‘Why is this so?’ you may ask. What is this fascination? Is there a new concern? Are physicians doing something wrong? Are we wrongly declaring a patient brain dead? Are we pretending that we know that a patient is dead when we do not? Are we drawing the wrong lines in the sand?

Some thinkers believe that a patient who fulfills the clinical criteria for brain death may not be dead, but rather an irreversibly comatose patient supported by medical technology. They consider this neurological condition an open question and controversial. None will be satisfied with calling it death—no matter how hard you try. Others—virtually all practitioners in this field and their professional societies—have come to realize that when all brainstem reflexes are gone—and nothing else can explain it—it is irreversible and it is the end of it. But these are complex times in medicine. Perhaps long-term support of a brain dead body could be possible, but who would even think of that? No, that is an unfaceable situation. No, it is not alive. It reminds me of a bumper sticker that said ‘organ donors live longer’.

The members of the Harvard Committee can look back with satisfaction and accomplishment. Not perfect, but in 1968 they were very close to a simple assessment. It would take until 1995 for the American Academy of Neurology to clear the way to simplicity just as Pallis and Jennett intended. The debate is long over and there is so little else to be said. But it will not stop the writing of books on the supposed fallacy of brain death and I may need to reserve another shelf. Perhaps I should stop reading them.

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References


