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REVIEW

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# Brain death as a moral definition and an act of love: the tale of Moon, Nehviel and Fate

Nereo ZAMPERETTI <sup>1</sup>, Marco VERGANO <sup>2</sup>, Nicola LATRONICO <sup>3, 4, 5 \*</sup>

<sup>1</sup>Unit of Palliative Care, AULSS 8 Berica, Vicenza, Italy; <sup>2</sup>Department of Anaesthesia, Intensive Care and Emergency, S. Giovanni Bosco Hospital, Turin, Italy; <sup>3</sup>Department of Medical and Surgical Specialties, Radiological Sciences and Public Health, University of Brescia, Brescia, Italy; <sup>4</sup>Department of Anesthesia, Intensive Care and Emergency, Spedali Civili University Hospital, Brescia, Italy; <sup>5</sup>Alessandra Bono University Research Center on Long Term Outcome (LOTO) in Survivors of Critical Illness, University of Brescia, Brescia, Italy

\*Corresponding author: Nicola Latronico, Department of Anesthesia, Intensive Care and Emergency, ASST Spedali Civili University Hospital, Piazzale Ospedali Civili 1, 251223 Brescia, Italy. E-mail: [nicola.latronico@unibs.it](mailto:nicola.latronico@unibs.it)

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## ABSTRACT

The vital status of people with a destroyed brain is one of the most discussed topics in medical literature. According to the current legal narrative, people whose brain is destroyed *are* dead. Nevertheless, a clear biological rationale to support with certainty such a narrative is still lacking. The purported rationale of the “the brain as the central integrator of the body” has proven to be biologically untenable. Persons with a destroyed brain can be maintained viable for long periods of time, showing clear signs of good biological integration. This fact stirs up a continuous seething of heated discussions among scholars, and generates uncertainty among lay people, loss of trust towards the medical community, and highly controversial cases in the media. To try to settle this unresolved situation, we propose a moral narrative, according to which people whose brain is destroyed *should be considered as* dead. Defining those people as biologically dead is impossible. Their clinical condition is neither life nor death; it is something in between, an artifice created by modern medicine. Yet, we can well state that the irreversible loss of all brain functions is a clinically and scientifically useful point of no return in the process of dying which can guide sound decisions. Through a personal reinterpretation of the myth of Orpheus and Eurydice, we would like to show that the choice to consider people with a destroyed brain as dead is a sound moral decision and an act of love.

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The concept of brain death is deeply rooted in western societies and has gained wide social acceptance. Nevertheless, as Alexander Capron elegantly stated, brain death remains “*well settled, yet still unresolved*.”<sup>1</sup> This is also probably due to the fact that, as Shewmon pointed out, “*Brain death as death began as a utilitarian legislative decree and has remained a conclusion in search of a justification*.”<sup>2</sup> After more than 50 years, a plausible rationale for maintaining the legal narrative of brain death (so that people whose brain is destroyed are dead) is still

lacking. In this paper, we propose a different narrative, a moral one, so that people whose brain is destroyed should be considered as dead.

### The traditional narrative about brain death

The current public narrative about brain death originated after the first heart transplantation, which took place in Cape Town (South Africa, 1967) thanks to favorable legal and political circumstances. Remarkably, “*legal authori-*

ties had left the definition of death imprecise, and... if a doctor so deemed, death of the brain was legally acceptable as evidence of death" (Barnard 1987).<sup>3</sup> At that time, no shared official definition existed about the vital status of individuals with a destroyed brain.

The surgical operation had enormous resonance and triggered a spirit of emulation worldwide.

*"In the 15 months after the initial human heart transplant, 118 heart allografts were performed in 116 patients in 18 different countries by some 40 different surgeons. In the same period, about 50 liver transplants were performed. Of all heart transplants done between 1968 and 1975, 37 percent took place in 1968."*<sup>4</sup>

The need for clear rules was evident and urgent. The Harvard Committee first convened on 14 March 1968. A great dilemma became evident as a choice had to be made between a moral option (people whose brain is destroyed should be considered as dead) versus a legal option (people whose brain is destroyed are dead).

At the very beginning, the moral option was followed. The report of the Harvard Commission defining "irreversible coma as a new criterion for death" was published in the *Journal of the American Medical Association* on 5 August 1968. It begins as follows: *"Our primary purpose is to define irreversible coma as a new criterion for death. There are two reasons why there is a need for a definition: 1) improvement in resuscitative and supportive measures have led to increased efforts to save those who are desperately injured. Sometimes these efforts have only a partial success so that the result is an individual whose heart continues to beat but whose brain is irreversibly damaged. The burden is great on patients who suffer permanent loss of intellect, on their families, on the hospitals, and on those in need of hospital beds already occupied by these comatose patients. 2) Obsolete criteria for the definition of death can lead to controversy in obtaining organs for transplantation."*<sup>5</sup>

As Singer outlined,<sup>6</sup> the reasons adduced are much more moral (the burden on patients, families and society and the need of vital organs) than scientific. This is directly confirmed by what Henry Beecher, chairman of the Harvard Committee, stated in 1971: *"At whatever level we choose to call death, it is an arbitrary decision. Death of the heart? The hair still grows. Death of the brain? The heart may still beat. The need is to choose an irreversible state where the brain no longer functions. It is best to choose a level where, although the brain is dead, usefulness of other organs is still present. This we have tried to make clear in what we have called the new definition of death. (...). Here*

*we arbitrarily accept as death, destruction of one part of the body; but it is the supreme part, the brain. Death of the heart also represents destruction of one part of the body; other parts still function (...). Dying is a continuous process; while death may occur at a discrete time, we are not able to pinpoint it."*<sup>7</sup>

The Committee's reasoning seems to have been the following: brain death is a process in which it is possible to identify a moment when patients are irreversibly "sufficiently dead" in order to forgo life support and to retrieve vital organs. This is clearly a moral proposal, and such it remains even if criteria used to define when that moral view applies is a scientific matter.

Yet, in the following years, the legal option prevailed, most probably because it seemed much more workable. In 1981, Bernat proposed a purported scientific rationale for equating the death of the brain with the death of the person, the theory of "the brain as the central integrator of the body": the irreversible loss of all intracranial functions legitimately corresponds to the biological death of the individual because the brain is the somatic integrative unit. In other words, after the death of the brain, the body is no longer an integrated organism but a mere and rapidly disintegrating collection of organs which have forever lost the capacity to function as a coordinated whole: *"Death is the permanent cessation of functioning of the organism as a whole. (...) The criterion of permanent loss of functioning of the entire brain is perfectly correlated with the permanent cessation of functioning of the organism as a whole because the brain is necessary for the functioning of the organism as a whole. It integrates, generates, interrelates, and controls complex bodily activities. A patient on a ventilator with a totally destroyed brain is merely a group of artificially maintained subsystems since the organism as a whole has ceased to function."*<sup>8</sup>

In 1981, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research officially sanctioned its use and acceptance, acknowledging the "primary organ" concept according to which the cardiorespiratory functions are mere prerequisites for the brain function: *"On this view, the heart and lungs are not important as basic prerequisites to continue life but rather because the irreversible cessation of their functions shows that the brain had ceased functioning. (...) The "primary organ" view would be satisfied with a statute that contained only a single standard - the irreversible cessation of all functions of the entire brain. Nevertheless, as a practical matter, the view is also compatible with a statute establishing irreversible cessation of respiration*

and circulation as an alternative standard, since it is inherent in this view that the loss of spontaneous breathing and heartbeat are surrogates for the loss of brain function.”<sup>9</sup>

In this sense, the Uniform Determination of Death Act (UDDA) acknowledged that “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.”<sup>10</sup>

The consequent definition of death, based on neurological criteria, has since been incorporated in the guidelines and laws of many countries worldwide, including the Italian legislation where death is defined as the irreversible cessation of all brain functions.

### Problems with the traditional narrative

The situation seemed well-assessed and workable. Perhaps, as Peter Singer observed, such a situation was profitable for all: “The redefinition of death in terms of brain death went through so smoothly because it did not harm the brain-dead patients and it benefited everyone else: the families of brain-dead patients, the hospitals, the transplant surgeons, people needing transplants, people who worried that they might one day be kept on a respirator after their brain had died, taxpayers and the government.”<sup>6</sup>

This happened because – in individuals with a destroyed brain – biological death is a self-fulfilling prophecy: it usually follows the diagnosis, either from ventilator withdrawal or from organ donation. Yet problems emerged in situations in which there were good reasons to maintain the intensive supports. In fact, when organ support is maintained, prolonged biological maintenance is possible with good somatic integration. This typically happens when total brain destruction is diagnosed in pregnant women (and intensive supports are maintained in order to carry forward a pregnancy) or in children (when parents do not accept a death diagnosis). As Truog pointed out, “when functions such as breathing and nutrition are medically supported, the brain is not essential for maintaining biological integration and functioning.”<sup>11</sup>

Interestingly, Shewmon collected “161 documented survivals of at least 1 week, approximately 67 at least 2 weeks, approximately 32 at least 4 weeks, approximately 15 at least 2 months, and 7 at least 6 months”, in patients diagnosed as brain dead (the longest survivals being up to 14.5 years).<sup>12</sup>

Powner and Bernstein reported 10 cases of brain-dead

pregnant mothers: “The longest period of support was 107 days, from 15 to 32 weeks of gestation. Two mothers also became organ donors. Recurrent infections, thermolability, and other complications common to prolonged ICU care were encountered. All infants survived. One had congenital abnormalities caused by phenytoin use by the mother. When followed, all others developed within normal growth and mental variables.”<sup>13</sup>

A more recent review also demonstrates that BD pregnant mothers can be maintained vital for quite long periods of time and give birth to healthy babies – a fact that can be considered a good sign of sufficient somatic integration: “In 35 cases of brain death in pregnancy at a mean gestation age of 20 weeks, maternal somatic support aimed at maximizing perinatal outcome lasted for about 7 weeks, with 77% of neonates being born alive and 85% of these infants having a normal outcome at 20 months of life.”<sup>14</sup>

It is difficult to think that a woman who is able to carry a pregnancy forward for weeks and give birth to a healthy newborn is biologically dead (a dis-integrated organism).

As for the case of children with a destroyed brain, the most significant story is the one of TK. The heart of TK stopped beating in January 2004, more than twenty years after a diagnosis of brain death was made. In all that time, life-sustaining treatments were maintained because his family refused the BD diagnosis. At the autopsy, no neural elements were recognizable grossly or microscopically.<sup>15</sup> Certainly, some form of somatic integration was present.

More recently, in December 2013, 13-year-old Jahi McMath was declared brain dead in California. The BD diagnosis was first made by the attending clinicians, and repeated two weeks later by Paul Fisher, the chief of pediatric neurology at Stanford Children’s Hospital. Fisher repeated the standard brain-death exam and performed a radionuclide cerebral-blood-flow study; he confirmed the hospital’s conclusion. The diagnosis was therefore surely correct, according to the current practice, yet her family refused to accept the declaration of death because – from their perspective – death does not occur until the heart stops beating. Moreover, they demanded public acknowledgement of such a refusal.<sup>16</sup> They transferred Jahi to New Jersey, the only US state where religious exemption to the definition of death based on neurological criteria is allowed. There, her heart continued to beat in her body until June 2018, when her family accepted to forgo vital support. In the nearly 5 years since the initial declaration of brain death, Jahi had developed puberty, but remained with no brainstem reflexes or respiratory drive, so mechanically ventilated for the whole period. A formal BD testing was

never repeated. This even led some authors to question the accuracy of the initial diagnosis.<sup>17</sup>

There have been many other similar episodes in the US,<sup>18</sup> causing suffering to families and confusion among the general public.

As a matter of fact, in December 2008, the President's Council on Bioethics published a white paper ("Controversies in the determination of death") in which the neurological standard is carefully re-examined<sup>19</sup> and the theory of the brain as the central integrator of the body is definitively abandoned. In particular, the paper admits that: "*there is some degree of somatically integrated activity that persists in the bodies of patients who have been declared dead according to the neurological standard. [...] This point deserves emphasis because [...] the claim that the body of a patient diagnosed with 'whole brain death' is a mere 'group of artificially maintained subsystems' was repeated often enough to become established in the United States as the standard rationale for equating total brain failure with human death: patients with this condition are dead because the systems of the body do not work together in an integrated way. [...] The reason that these somatically integrative activities continue [...] is that the brain is not the integrator of the body's many and varied functions (p. 39-40).*"

### Towards a new narrative

Nowadays, after more than 50 years and in the absence of a clear biological rationale to define with certainty the vital status of people with an irreversibly destroyed brain, the legal option appears untenable. The recurrence of situations of people who are maintained viable for a long time (even years) after a diagnosis of death made on the basis of neurological criteria forces us towards a different narrative. In 2004, we proposed to abandon the term "brain death" and go back to the old term of irreversible apneic coma, which does not involve the presumption of diagnosing the person's biological death: "*A simple alternative could be to revert to the original term of 'irreversible coma' or, more precisely, 'irreversible apneic coma' (IAC), understood not as equivalent to death, but as describing a particular condition in which life support should be legitimately forgone and organs can be retrieved from consenting patients.*"<sup>20</sup>

This suggestion was recently echoed by Truog, who proposed the term "irreversible apneic unconsciousness". He stated: "*The medical profession is always going to be better off, in the long run, if we speak honestly and truth-*

*fully about what we know.*"<sup>11</sup> Irreversible coma is a more precise term however, as it can be easily described as an eye-closed unresponsive state without any inference to the loss of consciousness, whose definition would raise yet another major epistemic problem as we don't yet have highly specific methods for diagnosing irreversible loss of consciousness.<sup>21</sup>

We suggest abandoning the dichotomy between life and death, as diagnosing "brain death" within our current concepts of life and death is impossible. When we want to describe the process of dying of a person whose brain is destroyed, we are somehow confronted with a spectrum of decreasing biological viability which goes from full life (just before the brain injury) to the certain completion of the process of dying (after irreversible asystole). Choosing the death of the brain as a pinpoint, we choose a specific moment in which the dying process is irreversibly and sufficiently advanced (even if not completed). We argue that such a clinical condition is neither life nor death, as these states are usually understood; it is something in between, a state artificially created by high-technology medicine in which we do not know what life and death really are. We cannot claim that this state is equal to death. However, we may state that irreversible apneic coma (brain death) is a clinically and scientifically useful "point of no return" within the dying process: an event that can guide clinical, moral, and social decisions.

We believe that the time has come to change the public narrative about this clinical condition, returning to the moral option.

The short story that follows is a personal reinterpretation of the myth of Orpheus and Eurydice, a poetic representation of the condition of those whose brain is irreversibly destroyed.

### In the name of love

*Moon was a girl of extraordinary beauty. She fell in love with Nehviel, a musician who could play the lyre to such perfection that he was able to charm all living things and even stones and rivers with his music; no-one could resist his melody.*

*Moon and Nehviel lived happily for many years.*

*One day, Moon fell over and hit her head. She lay on her bed for three days and eventually died. When Nehviel heard her last breath, he desperately decided to save her: "Departing souls leave our world at sunset, when they cross the Last River. If I catch her before night, before she reaches the Death side, I'll save her."*

*Nehviel ran as fast as he could, but the river was far away and the road was very long.*

*He kept running and running.*

*The day had started to fade when he finally saw the river, which was still far from him.*

*The river was wide, and a thick dark mist hid the view of the opposite bank.*

*He felt exhausted, but he caught sight of the departing souls lined up on the shore. Every one of them was getting into a small boat and sitting down, then the boats left immediately and disappeared into that cold fog.*

*He ran even faster. Daylight was vanishing.*

*Nehviel saw Moon near the river, and yelled her name. She did not seem to hear his voice.*

*He saw her approaching a boat, and shouted even louder. She did not stop or turn to him.*

*He saw her getting into a boat, which left silently and swiftly on the black water.*

*Nehviel fell to his knees, breathless. He grasped his lyre and began to play all his desperate grief.*

*As the music spread in the still air, the current stopped flowing, the darkness ceased to loom and the boat stood still at the edge of the haze.*

*He exulted, "She is safe".*

*"She's not", the voice of Fate echoed in the air.*

*"I can reach her!"*

*"Too late. She is too far."*

*"I can swim to her."*

*"You should stop playing. And then the boat would continue on its journey."*

*"Moon will swim back to me."*

*"Moon cannot come back. Her eyes are gazing at her destination, at Death's bank."*

*"But the boat has stopped."*

*"You can halt the stream, the boat and even time - but you cannot reverse her fate."*

*Nehviel stood up, full of anguish, but still playing his lyre.*

*"She's not gone. The night has not come yet", he cried.*

*"But the day is already over."*

*"The moon has not risen."*

*"But the sun has already set."*

*"It will rise again tomorrow."*

*"Only if you let it go now. But tomorrow Moon will be gone forever."*

*"The boat has not reached Death's bank."*

*"True. But she has already left Life's shore."*

*"Moon is alive."*

*"No, no longer."*

*"I can see her crouching in the bow of the boat."*

*"She has the shape and the substance of the living, but she has already lost her thoughts, desires and memories. Most of all, the vital breath will never again pass through her lips into her breast. She has travelled too far across the River and she will never come back."*

*"Is she dead?"*

*"Perhaps not yet."*

*"No longer alive but not yet dead?"*

*"You are keeping her midway."*

*"So what can I do?"*

*"You can play your lyre for her for a little while longer, and grieve and moan. And then let her go."*

*"I am not sure I can do it."*

*"Then you can play as long as you have breath, and hold her in the middle of the river. Mourning forever is useless though, and keeping her there is cruel. She already belongs to Death's world now."*

*"How can I decide?"*

*"Your choice is a matter of love."*

*"It is! And I love her so much."*

*"Then let her go, because leaving is her wish and her destiny. It is not a human's fate to live forever."*

*Nehviel knelt down again, speechless.*

*He played a last song for his love. Then he put his harp down on the ground and let her go on her way.*

*"I have nothing left to remember her by" he murmured, while she slowly faded away into the mist.*

*"Perhaps you do have something. Look."*

*The little boat had reappeared from the cold fog and was slowly approaching the bank. It seemed empty, but when it came nearer Nehviel saw it contained some little sealed jars.*

*"What are these?" he asked.*

*"Departing souls sometimes leave behind something they do not need, for the sake of those who remain."*

*"These jars?"*

*"In that little one she left her eyes; give them to a girl who's longing to see the love in the face of her loved one and the joy in the eyes of her child. The twin jars on the left contain her kidneys; give them to somebody who has still a long journey in his life and not enough hope. That slightly larger one holds her liver; give it to a man who needs courage and determination for a bigger dream. In the other one, she put her lungs; give them to a man who is yearning for a long run in the spring breeze on the ocean shore with his girlfriend. The last one contains her heart; give it to somebody who loves life so much that his heart does not have enough strength."*

*Nehviel stood firm, thoughtful. “And for me?” he asked at last.*

*“The only things you really own are those you’ve given to someone in need.”*

*“What do you mean?”*

*“Moon had to go, as was her destiny. You let her leave and she will always be with you. Others have great dreams but are hampered by life. You can help them by giving them what Moon asked you to share out; those people need these things, not you. If you keep them, they’ll get spoiled. Loving those who are in need is the only way you have to love her.”*

*Nehviel nodded. He put the little jars in his haversack, then picked up his lyre and went away to honour Moon’s wishes.*

### Conclusions

Letting people die after suffering devastating brain injury with irreversible apneic coma is a moral decision and ultimately an act of love towards the person. This is the sense of our tale of Moon, Nehviel and Fate – three names which are the anagram of “In the name of love”.

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