"BRAIN DEATH", AUTONOMY AND THE FUTURE OF ORGAN TRANSPLANTATION

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Abstract. Autonomy and its companion, informed consent is regarded as fundamental in contemporary medical ethics. Still, the individuals are deprived of the possibility to make a genuinely informed choice with respect to organ donation in the event of "brain death". It can be easily argued, scientifically speaking, that the status of the "brain dead" patients is that of living beings, able to process nutrients and drugs and even to harbour and nourish their progeny into the womb. A philosophical, not scientific distinction between the "un-meaningful" lives of the "brain dead" and "meaningful" human life underlines the "brain death" concept. Yet, the public is told that the "brain dead" are dead, i. e. lacking life. Not only that this situation collides with the principle of autonomy, but it also poses a risk for public trust in organ transplantation. It is obvious that people have certain expectancies from health care professionals and the decision makers, and finding out about such inconsistences might drive the public reject organ transplantation, with the recourse to the "brain death" concept ultimately leading to the aggravation of the organ shortage, instead of the alleviation that it was expected to bring.

Keywords: autonomy; brain death; organ transplantation; public trust in health care

Muerte cerebral, autonomía y el futuro del trasplante de órganos

Resumen: La autonomía y su manifestación en el consentimiento informado es considerada fundamental en la ética médica contemporánea. Sin embargo, a los individuos se les priva de la posibilidad de realizar una elección informada genuina cuando se trata de donación de órganos en el caso de "muerte cerebral". Puede fácilmente argumentarse, científicamente hablando, que el estatuto de paciente con "muerte cerebral" es el de un ser vivo, capaz de procesar nutrientes y fármacos, incluso mantener y nutrir la progenie en el útero. El concepto de "muerte cerebral" está basado en una distinción filosófica, no científica, entre la vida "sin significado" del que tiene el "cerebro muerto" y la vida "con sentido". Sin embargo, a las personas se les dice que las personas con el "cerebro muerto" están muertas, carecen de vida. Esta situación no solamente colisiona con el principio de autonomía, sino que también supone un riesgo para la confianza pública en el trasplante de órganos. Es obvio que las personas tienen ciertas expectativas acerca de la toma de decisiones de los profesionales de la salud, y el conocer tales inconsistencias podría llevar a que las personas rechacen el trasplante de órganos con el "muerte cerebral", conduciendo a la agravación en el bajo suministro de órganos, en vez del alivio que se espera conseguir.

Palabras clave: autonomía, muerte cerebral, trasplante de órganos, confianza pública en el cuidado de la salud

"Morte cerebral", autonomia e o futuro do transplante de orgãos

Resumo: Autonomia e seu complemento, consentimento informado, são considerados como fundamentais em ética médica contemporânea. Ainda assim, as pessoas são privadas da possibilidade de fazer uma escolha informada genuína com respeito à doação de órgãos no caso de "morte cerebral". Pode ser facilmente argumentável, cientificamente falando, que a condição de pacientes com "morte cerebral" é a de seres vivos, capazes de processar nutrientes e medicamentos, e mesmo de abrigar e nutrir sua descendência no útero. Uma distinção filosófica, não científica, entre a vida "sem sentido" da "morte cerebral" e a vida humana "significativa" enfatiza o conceito de "morte cerebral". Contudo, ao público é dito que os com "morte cerebral" estão mortos, isto é, sem vida. Esta situação não apenas colide com o princípio da autonomia como também constitui um risco para a confiança pública no transplante de órgãos. É óbvio que as pessoas tem certas expectativas sobre os profissionais de cuidados à saúde e os que tomam decisões, e encontrar tais inconsistências pode levar o público a rejeitar o transplante de órgãos, com a utilização do conceito de "morte cerebral" levando, em última instância, ao agravamento da escassez de órgãos ao invés da atenuação que era esperada trazer.

Palavras-chave: autonomia, morte cerebral, transplante de órgãos, confiança pública em cuidados à saúde

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Introduction

Contemporary Bioethics promotes autonomy as one of the fundamental principles. Still, autonomy² is hampered when the individuals are deprived of the possibility to make a genuinely informed choice with respect to organ donation in the event of "brain death". From a scientific perspective it can be easily argued that the claim that the "brain dead" are lacking life fails basic examination. Even some of the promoters of the "brain death" construct sustain that it should be openly admitted that these subjects are alive - yet "dead enough to donate" (1:148). Still, the larger public continues to be told that "brain death" is true death, i.e. lack of life, and so people's option regarding organ donation in such circumstances relies upon an induced false belief.

Inconsistencies and misrepresentations have accompanied the "brain death" concept for the past fifty years. Prior to the 1968 Harvard Report(2), "comatose individuals who have no discernible central nervous system activity" (2:85) were considered alive and taken care of as such. After the Harvard Report the same individuals with the same characteristics should be considered dead - even though still taken care of, in view of organ retrieval. Suddenly A was no longer identical with A, a typical violation of the law of identity leading to the informal logical fallacy known as equivocation. Following Harvard, illogicality kept finding its way into state documents. The Uniform Determination of Death Act proclaims 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" (3:2). One can easily notice that "brain dead" subjects are alive and dead at the same time, i. e. alive according to criterion 1, and dead according to criterion 2.

Many states came to accommodate the "brain death" criterion of death into their legislation, consequently designing the legal frame allowing organ harvesting from "brain dead" donors. Once pronounced "legally dead" it becomes legal to perform invasive surgery in view of the removal of their vital organs, which would be considered criminal if performed on a living patient. It should be mentioned that "brain death" diagnosis kept differing from state to state and period to period. The pertinent remark that Levin and Whyte made 30 years ago, namely that "Clinical criteria make it possible to be brain dead in one country and not in another" (4:852) proved to be perpetually valid (5-7). To this day one can be dead into one jurisdiction and alive in another, alive today and dead tomorrow, not because of a change of medical condition, but due to variability in brain death diagnosis criteria and practice. Efforts were made towards establishing universal guidelines for the determination of death(8,9)still the issue remains unsolved. An interesting point is that Japan, for example, relegated the responsibility at the individual level – let the individual decide whether he/she should be treated as alive or as dead and an organ donor in the event of "brain death" (10). Deciding who is dead curiously becomes a matter of choice, and so does whether vital organs removal from a heart beating individual should be punished as infliction of grievous bodily harm ultimately leading to the death of the victim, or praised as an achievement of medical art. Nevertheless, even if "brain death" criteria and practices would be adopted into an international standardized form they would finally do nothing more than confirming the fact that the subject does correspond to the condition called "brain death", formally accepted as a legal criterion of death. The fallacy embedded into the Harvard Report would still be there and transforming it into an *argumentum ad populum* by universal acceptance of certain standards in diagnosis would not correct it.

As it shall be shown in the following, the scientific arguments demonstrating that the "brain dead" are not dead, i. e. lacking life are basic, easy to perceive and in the nowadays globalized world would be also easy to disseminate. Public's awareness of the inconsistencies of the "brain death" concept might rise. Obviously people have certain expectancies from health care professionals and the decision makers in health care, and finding out that they are no strangers to confusion in their discourse on "brain death" might have

² It can be argued that the other fundamental principles are also contradicted by organ removal from "brain dead" donors, but this will not constitute the object of the present paper.

undesirable consequences in the long term.

Standards of care for the dead

Nutrients and liquids are administered to the "brain dead" and waste is eliminated by their organism(11), a fact which requires a huge number of processes taking place into the cells into a coordinated manner and is numbered by Biology among the fundamental traits of the living. An entity that assimilates nutrients and water and produces urine and perspiration is by no means dead – the dead consume nutrients and water only in legends and horror movies.

"Brain dead" subjects also receive lots of drugs, as they are treated for all consequences of their brain injuries and any other conditions till the day their organs are removed. They are administered vasopressors, hormones, diuretics, electrolytes, antibiotics a. o. according to the practical experience accumulated in "brain dead" donors care(12,13). Scientifically speaking, it is beyond doubt that dead bodies do not react to drugs and use them so that to maintain physiological parameters - drugs have to be uptaken by the cells and dealt with adequately, molecules to be actively fabricated in order to build the proper response and express it. It should also be mentioned that sustained treatment becomes necessary due to the systemic reactions developed by the "brain dead" individual's organism - which is therefore biologically reactive, i. e. not dead - in response to brain injuries (14).

"Brain dead" donors are continuously monitored and specific physiological targets are set – a "brain dead" should exhibit a heart rate of 60-120/min, systolic blood pressure of 100-160 mmHg, and an urine output of 50-100 ml/hr(*11*). It is easy to notice that these parameters are perfectly suitable for living individuals, which leads to the conclusion that either the "brain dead" are very much alive or ... the majority of people are in fact walking dead.

Women in "brain death" can be assisted for months, till they give birth(15). For biologists it is crystal clear that cadavers cannot go on with their own living processes – and so they become cadavers – let alone contribute to the living processes of another organism, growing inside them. Actually, the case of "brain dead" mothers points out that at least some of the "brain dead" subjects can be assisted for much longer than currently in general use, which leaves utilitarian reasons (i. e. organ retrieval and/or lessening of the burden they represent) as the only basis for early withdrawal of support in "brain dead" patients who are still reacting to care.

The "life support" argument

Some claim that the "brain dead" exhibit a misleading "alive" appearance due to the fact that the machines they are connected to make them breathe, but such assertions are utterly unscientific. Obviously, what is called "life support" cannot give life or maintain it forcefully – if it could, then nobody would have died anymore in contemporary times! "Life support" can only help *living* organisms to cope with their state of illness. Ventilators fill the lungs with air, but a dead organism would not be able to transport the oxygen provided to the cells and use it(16) as it would neither be able to perform all other typical for the living processes that take place at the cellular and subcellular level and are all needed, besides the oxygen supply, in order for the heart to keep beating(17). Aerobic metabolism decreases in "brain dead" but it does not cease and can be restored to adequate levels by hormone therapy(18), which became part of current organ donor management.

When death does occur, cessation of all processes characteristic for the living organism leads to a series of post mortem changes that are not present in "brain dead" individuals. Those changes are rigor mortis (stiffening, due to locking of contractile proteins in the muscles deprived of ATP), livor mortis (due to absence of circulation followed by gravitational settling of the blood in the lower portion of the body), *algor mortis* (cadaveric body cooling, different from the treatable hypothermia experienced by the "brain dead"), and decomposition (rotting of the body, with blue-dark green discoloration, gaseous distension, degradation of tissues, ultimately followed by dissolution of bodily structures)(19). Most post mortem changes follow the moment of death within a few hours and should be observable in all "brain dead" individuals. As for decomposition, its onset is detectable within one to three days and it should have been observed stage by stage, down to dissolution in pregnant "brain dead" women that have been assisted for months.

Speaking of assisted vital functions, pacemaker patients and those in need of dialysis are individuals whose abnormal functioning of some vital organs would lead to death unless assisted by the adequate devices – if the "brain dead" should be considered dead because they depend on machines, an obvious logical question would be if pacemaker bearers and dialysis patients should also be pronounced dead and eventually have their organs harvested.

Still, what is the public told about brain death and "brain dead" donors? "Brain death is permanent and irreversible. It is a legal definition of death. However, the vital organs such as the heart, lungs, liver, pancreas and kidneys can be kept viable for a few days if supported by artificial or mechanical support" (20:91 under "What does brain death mean?"); "Though there is irreversible loss of all brain function and the patient is clinically and legally dead, the appearance of life continues. This is only because of a breathing machine (ventilator), which is an artificial means for delivering enough oxygen to the heart to keep it beating" (21: 94); "Remember that your loved one is already legally dead and removing the ventilator does not cause death. Saying goodbye to a loved one who is brain dead is a very difficult experience. Your loved one may look as if he or she is only sleeping. The ventilator fills the lungs with air. The heart monitors may indicate that the heart is still beating. Your loved one may be warm to the touch and have color in the face. But, in fact, your loved one is dead" (22:6). Also, "Once a person is declared brain dead, families are not asked to 'pull the plug' or to take someone 'off of life support' because such actions would be impossible: the person they love has already died" (23:91 under "No One 'Pulls the Plug"). Indeed, the family is not asked to take the donor off life support as it is the job of a member of the transplantation team to do that.

Surgery, not autopsy

As already mentioned above brain injury consequences are to be kept under control and "target perioperative cardiopulmonary parameters in multiorgan donors" (24:135) should be met. The organ harvesting procedures imply anaesthesia, monitoring, and support – the donor is operated on and preparations such as small dissections and cannulations are made for the extraction of organs, whilst "the donor's heart so far has continued beating spontaneously and maintained circulation of all organs" (25:93 under "Donor operation"), circulation that will be discontinued by clamping of the aorta. The heart is removed first, followed by lungs, liver, pancreas, intestine, kidneys a.s.o.

It has been documented long ago (26-28) that the "brain dead" donors can display during surgery increase in the blood pressure, tachycardia, perspiration, lacrimation, and muscular movements, reactions perfectly coherent with what Biology describes as the acute stress response (a. k. a. "the fight-or-flight response"), perfectly suitable for a living subject submitted to extremely invasive procedures. They may also perform rather extensive actions, disrupting the harvesting procedure: "The donor has just moved his right arm and is lifting his right thigh from the stretcher. The panic spreads among the nurses, but some doctors also appear perplexed; the anesthesiologist spends at least 15 min calming tempers in the operating room. He protests loudly, excitedly waving a piece of paper—the death certificate— and then he explains more calmly that all examinations and tests have established the cerebral death of the man" (29:47-48); and a second testimony, about another "brain dead" donor: "All vascular structures emerging from the heart were isolated and encircled, and just when the ascending aorta was clamped, the donor moved and delivered with his left arm a powerful punch to the abdomen of my assistant. After a moment of hesitation, the aortic clamp was released, and the blood flow was resumed in the aorta; the donor was still movingthis time his right leg. With a thousand thoughts in my mind, seconds felt like hours. The glazed look in the scrub nurse's eyes and the echoing nurses excited words, somebody screams that this is a desperate act of a man against the donation. The abdominal surgeon appears extremely resolute and exclaims, "clamped the aorta, we start the perfusion," and in an automatic way, I do the same, without hiding my anxiety and nervousness" (29:48).

One might wonder what would have happened if the "brain dead" donor's punch caused some serious injury – would the police have had to file a report on "battery by a dead individual"? Probably not, as the offender was legally dead, at the time of the offence. However, since such reactivity on behalf of supposedly dead subjects might rise doubt, anaesthetists are instructed to deprive the "brain dead" of the possibility to manifest their capacity to react: "Faced with the knowledge of the persistence of higher brain and spinal function in some donors, the inability to test the reticular formation directly and the dramatic perioperative haemodynamic changes that occur, sedation and analgesia should be given with muscle relaxation for organ donation. It is imperative that public confidence is maintained in the transplant programme" (30:106). Indeed, it was documented that due to the spontaneous reactions of the "brain dead", nurses may come to question organ retrieval from such donors: "One disquieting issue for nurses in this study was lack of confidence that the patient was actually dead. Nurses reported patients reacting when moved and questioning why patients 'required pain medication' if they were in fact dead" (31:433).

The restless dead

The various types of movements - some stimulusprovoked and other spontaneous - observed in "brain dead" individuals are listed in literature as deep tendon reflexes, plantar withdrawal, plantar flexor responses, abdominal reflexes, neck-arm flexion, neck-hip flexion, neck abdominal reflex, tendon reflexes in the upper and lower extremities, extension-pronation arm reflex (extension and pronation of the arm and forearm in response to cutaneous stimulation), undulating toe reflex, triple flexion response, the Lazarus sign (that may include shoulder adduction, moving of the arms towards the chest and of the hands to the neck and lower extremity movements), leg movements mimicking leg movement during sleep, eyelid opening and closing, spontaneous low frequency respiratory-like movements(32), fasciculations (muscle twitches)(33), head turning(34), and other.

It was claimed that the many types of movements present in "brain dead" individuals are all purely reflex (i. e. not voluntary and oriented), originating from the spinal cord. But, reactivity and the ability to move characterize the living, again requiring myriads of processes to take place within the cells and into the body as a whole. Dead organisms should not respond to stimuli by stimulus-provoked movements, or perform spontaneous movements - not to mention that the presence of reflexes should invalidate the brain death diagnostic by definition(35). Yet, the practical solution to that obvious lack of coherence was not invalidation of the "brain death" diagnostic in subjects exhibiting movements but postulating that movements are compatible with the "brain death" diagnostic, which gets to be literally postulated, and expanded ad libitum: "Although by definition the diagnosis of brain death requires the irreversible loss of cerebral function, including the brainstem, it appears that all functions are not immediately lost. Several functions including complex spinal automatisms have been reported in patients with brain death and these spinal reflexes can be maintained for up to several hours or days" (33:2377); "Although spontaneous and reflex spinal movements may be present during the first 24 hours, they do not invalidate the diagnosis. The nature of these movements may be elucidated via electrophysiological, functional imaging, or blood flow studies, leading in future to the development of a standardized protocol. Given the myriad of practical and legal implications revolving around the diagnosis of BD, our purpose is to alert the health care community about the various types of movements that can be accepted in these circumstances without invalidating the diagnosis" (32:159).

Redefining the stimulus-provoked movements of the "brain dead" as "brain death-associated reflexes" and their spontaneous movements as "brain death-associated automatisms" that "do not contradict the diagnosis of death" came also as an option, in total agreement with the 1968 Harvard Committee's spirit of unscientific redefinition and postulation that apparently tends to imprint everything related to "brain death" ever since: "In the setting of brain death, we propose using the terms brain death-associated reflexes and brain death-associated automatisms. This terminology is clinically useful because all movements reported in brain dead bodies can be placed in one of these two categories. Furthermore, it does not imply a particular mechanism, which remains speculative in some cases. Although primarily descriptive, these terms have important implications. Brain death-associated reflexes are stimulus provoked movements that do not contradict the diagnosis of death. Such movements may or may not be present during life. Thus, subsets of these reflexes include muscle stretch reflexes, abdominal reflexes, and plantar flexion. Likewise, brain death-associated automatisms are spontaneous movements that do not contradict the diagnosis of death" (36:125).

Into the context, some assert that on one hand physicians should be aware of "reflex movements that can occur in braindead patients" (37:589) so that the diagnosis of brain death is not delayed or disputed and on the other hand that "brain death should be undertaken with circumspection, particularly when related to organ transplantation" (37:590). But, what is left of "circumspection" when doctors are openly suggested to postulate diagnostics and expand them so that to accommodate elements that should contradict those diagnostics by definition? The astonishingly unscientific idea that the dead could actually move, so manifesting the ... reflex activity of their dead bodies seems to be creatively assisted so that it obliterates the objective alternative, namely that the "brain death" diagnostic might prove inappropriate in nearly half(32) of the [erroneously considered] "brain dead" donors, which should preclude organ harvesting from all those subjects.

"Dead enough to donate"

Some of the promoters of the "brain death" concept are not claiming anymore that "brain dead" individuals are inanimate organisms, but openly support the utilitarian thesis that "brain-dead patients are dead enough to donate their organs" (38:110).

A distinction between the existence of the "brain dead" and what should be separately regarded as "human" existence was introduced, in order to justify why the "brain dead" should be viewed as mere organ sources: "The concept of brain death was first described in the medical literature in 1959, and was an attempt to separate the cessation of meaningful neurological function from the cessation of cardiorespiratory function. The rationale for this distinction was that the former represented human existence, while the latter was viewed simply as biological existence" (5:532). The Harvard criteria are regarded as defining "the end of meaningful human life" (39:344), mandating cessation of the "un-meaningful" life of the "brain dead" individual in favour of those considered to be still living the "meaningful" version. Obviously, such distinction is by no means scientific, but philosophical. Philosophy left aside, what persists is a cynical proclamation of the fact that the "brain dead" do have life - a fact that should be obviously incompatible with organ removal, at least from a classical ethics viewpoint. Under these circumstances, some advocate for abandoning the "dead donor rule", in order to "honor and pursue truth" (1:148), as "Once physicians understand that brain dead and DCD donors are not really dead, they could claim otherwise only at the cost of undermining integrity and diminishing character"(1:148) and propose that we should openly move to allowing organ removal not only from dead individuals but also from dying patients, for the benefit of all parties involved: "The driving force behind rejecting the DDR is the ethical norm that physicians should not cause the death of a patient. Yet, we do exactly that when we ethically and justifiably withdraw life support at the request of the patient or proxy-surrogate, or when we remove organs from brain dead or DCD donors who are not actually dead. Once we recognize that the ethical prohibition against physicians causing death of a patient is not absolute and that the guiding principles are respect for patients' self-determination and voluntary informed consent, we can withdraw life support in intensive care units and recover organs from consenting donors without appeal to the DDR and its underlying fictions. Abandoning the DDR will eliminate all of the public's and health care professionals' confusion and misunderstanding about definitions of death and deciding when someone is dead" (1:148).

In some ethical/moral systems there might be no problem if organs are harvested from a dying person who expressed his/her informed consent for organ removal before death occurs, in the event of illness or injuries that might be incompatible with long term survival. But, as already shown above the public is systematically misguided with respect to "brain death" - which is presented as genuine lack of life – and therefore deprived of making a genuinely informed choice. In present, those who give consent for organ removal in the event of "brain death" are misled in their option and actually express a technically invalid consent, based upon the induced false believe that the "brain dead" are truly dead: "A key point is that individuals are not able to understand the issues, and therefore cannot give informed consent to organ donation, if they do not receive accurate information about the procedure. They should know that, in current practice, most organs for transplant are taken from "brain dead" individuals who are not dead in the sense that their circulation and respiration have ceased, or that their brains are really and truly dead. They should be aware that the diagnosis of "brain death" is not soundly based or universally accepted, and that there are serious questions about its constituting the death of the person" (40:408).

An aspect that remains to be established is how many of the health care practitioners and decision makers mislead the public on purpose and how many do that sincerely believing that the "brain dead" are mere cadavers. Dolus, or fault would be the legal question, if organ removal in the case of "brain death" would have constituted the object of – let us take the liberty of using a movie scenario artifice here – a contract between the state and the donating individual. The main problem would however be that it might be too late for those who consented to organ removal to bring before the court an action for annulment.

The long-term damage

Continuing to harvest organs from "brain dead" donors under the pretext that they are dead, i. e. lacking life, in spite of all scientific evidence that proves the opposite might lead to undermining of public trust in the medical profession and the decision structures. In the long run, not only that human physiology would not change, and the above mentioned arguments would persist and be always at hand for anyone, but also more and more "inappropriate" stories involving "brain dead" patients strongly reacting to the invasive procedures they are subjected to in the operating room can be expected to accumulate. In these circumstances, it can be anticipated that the public becomes legitimately suspicious and reject organ transplantation in principle.

Conclusive remarks

Unfortunately, nowadays those who agree to organ removal in the event of "brain death" express in fact a technically invalid consent, based upon the induced false believe that the "brain dead" are lacking life. Scientifically speaking, "brain dead" subjects are not deprived of life³. They are deeply injured individuals who are actually killed during the organ harvesting procedure when their circulation is discontinued and they are deadly wounded by removal of the heart - and maybe it is worth mentioning that the Harvard Report initially spoke about them as "desperately injured" (2:85). Philosophically speaking, they were labelled by some as subjects leading an un-meaningful life who should necessarily "help" those living the meaningful version of human existence. However, the public is misled about the scientific aspects and forced to accept the philosophical conclusions by games of words that become the basis for life and death decisions, either taken for oneself or in the even thornier situation of acting as a surrogate decision maker. Such assault on individuals' autonomy into a world that restlessly discourses about "rights" and the "four principles of medical ethics" is pretty astonishing.

The fact that many doctors accept the "brain death" construct without scrutiny, even though such scrutiny would require knowledge pertaining to basic training, common to professionals in Biology and Medicine is also surprising. One would expect that matters of life and death be approached with more scrupulousness, if not as well with more reverence. As for the utilitarian approach to medicine, even if there should be room under the sun for it, too, it definitely should not be forced upon the others or its values be imposed by deceitful means.

³ As a biologist, I was very surprised by how unscientific could the basis of the claim that the "brain dead" are dead be – and it should be mentioned that the dozens of life scientists enrolled in master's degree and human resources development programs that I encounter as a Bioethics teacher are habitually equally surprised.

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Not only that the principle of autonomy is at stake here, but so might also be the public trust in health care in general and in organ transplantation in particular. People are naturally reluctant to being deceived and being deceived about life and death is no small matter. It is not unreasonable to anticipate that if the fact that there is no case for the claim that the "brain dead" are dead, scientifically speaking and that the turn in defining death was essentially philosophical in nature becomes evident for the public we might consequently face strong rejection of organ transplantation, the recourse to the "brain death" concept ultimately leading to aggravation of the organ shortage, instead of the alleviation that it was expected to bring.

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Received: July 6, 2018. Accepted: September 12, 2018