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‘Brain Death,’ Organ Donation, and Presumed Consent*

Consent Cannot Be Presumed because ‘Brain
Death’ Is Not True Death

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Abstract

The marked decline in organ donation in Germany in recent years has once again brought the debate on the opt-out policy into the spotlight of German politics. Until now, Germany has remained one of the few European countries where the opt-in system for ‘postmortem’ organ donation is still in force. In mid-2018, however, the Health Minister, Jens Spahn, proposed a bill to change the current opt-in to an opt-out system in order to increase the supply of transplant organs. This bill is to be decided by the Bundestag in the coming months of this year (2019). The current debate in Germany on organ donation legislation effectively touches not just on the controversial concept of presumed consent (the basis for the opt-out policy) but also on the intractable ‘brain death’ controversy, because the bulk of alleged ‘postmortem’ organs are removed from brain-dead donors. The analysis in this paper demonstrates that presumed consent, as it is being practiced currently, is not a consent but a fiction. *Presumed consent (and therefore, the opt-out system) would be valid only if the public were to be fully informed about the factual reality of what ‘brain death’ truly is.* A review of the historical events, and the manuscript-drafts of the Harvard Report, brings to light the inherent utilitarian link between the interests of transplantation and the introduction of ‘brain death’ in 1968. ‘Brain death’ is not true death but a medico-legal construct whereby deeply comatose patients (deemed to be in irreversible coma) are declared

dead so that organs can be legally removed. Therefore, before introducing any opt-out legislation on organ donation, the State must first fulfill its duty to inform its citizens that they would not be dead yet when organ procurement begins, and that, in fact, they would be killed by the process.

Zusammenfassung

Hirntod, Organspende und die angenommene Zustimmung – Eine Zustimmung kann nicht angenommen werden, da der „Hirntod“ nicht der wirkliche Tod ist

Der deutliche Rückgang der Organspenden in Deutschland in den letzten Jahren hat die Debatte über die Widerspruchsregelung (Opt-out-Regelung) wieder ins Blickfeld der deutschen Politik gerückt. Bislang ist Deutschland eines der wenigen europäischen Länder geblieben, in denen das Einwilligungssystem (Opt-in-System) für die „postmortale“ Organspende noch in Kraft ist.

Mitte 2018 schlug der Gesundheitsminister Jens Spahn jedoch, einen Gesetzentwurf zur Änderung des derzeitigen Einwilligungssystems (Opt-in) in ein Widerspruchssystem (Opt-out) vor. Hierdurch soll eine Erhöhung der Organspenden erreicht werden. Über diesen Gesetzentwurf soll der Bundestag in den kommenden Monaten dieses Jahres (2019) entscheiden. Die aktuelle Debatte in Deutschland über das Organspendengesetz berührt nicht nur das unstrittene Konzept der angenommenen Zustimmung (die Grundlage für die Widerspruchsregelung), sondern auch die hartnäckige Kontroverse

um den „Hirntod“, da der Großteil der angeblichen „postmortalen“ Organe aus hirntoten Spendern entfernt wird. Die Analyse in diesem Aufsatz zeigt, dass die angenommene Zustimmung, wie sie derzeit praktiziert wird, keine echte Zustimmung, sondern eine bloße Fiktion ist. *Die angenommene Zustimmung (und damit das Widerspruchssystem) wären nur dann gerechtfertigt, wenn die Öffentlichkeit umfassend über die tatsächliche Realität des „Hirntod“ informiert würde.* Ein Rückblick auf die historischen Ereignisse und die Manuskriptentwürfe des Harvard Reports zeigen den inhärenten utilitaristischen Zusammenhang zwischen den Interessen an Organtransplantationen und der Einführung des „Hirntods“ im Jahr 1968.

Der „Hirntod“ ist nicht der wirkliche Tod, sondern ein medizinisch-rechtliches Konstrukt. Durch dieses medizinisch-rechtliche Konstrukt werden die tiefkomatösen Patienten (die als irreversibel gelten) für tot erklärt, damit ihre Organe legal entfernt werden können. Bevor der Staat eine Widerspruchsgesetzgebung (Opt-out- Gesetzgebung) für die Organspende einführt, muss er daher zunächst seine Informationspflicht erfüllen: Der Staat muss also seine Bürger darüber informieren, dass sie als Organspender noch nicht tot sein werden, sondern erst durch den Prozess der Organentnahme getötet werden.

1 Introduction

The debate on organ donation-transplantation once again returned to the spotlight of sociopolitical life in Germany when, at the beginning of September 2018, Jens Spahn, the Health Minister, introduced a draft bill in order to push Germany to “change its laws on organ donation and adopt an opt-out scheme to increase the number of organs available for transplantation.”¹ The reason for Spahn’s intervention is self-evident: the persistent decline in organ donation in Germany. According to the data on ‘postmortem’ organ donation from the *Deutsche Stiftung Organtransplantation* (German Organ Transplantation Foundation),² the number of organ donors has dropped from 1296 donors in 2010 to only 797 in 2017 (i.e., from 15.9 to 10.4 donors per million inhabitants), which in turn resulted in 1500

¹“German Health Minister Calls for Opt-out Organ Donation,” Deutsche Welle <http://www.webcitation.org/76mIdDER0>.

²The term ‘postmortem’ is written with quotation marks because, as will be shown further in this paper, the ‘brain death’ paradigm for the determination of death (and thus, the source of ‘postmortem’ organ donation in Germany) has been proven to be seriously flawed as it contradicts the reality of biological (medical) evidence, the sound tenets of philosophical anthropology, and the principles of holistic contemporary biophilosophy. For an exhaustive treatment on the indefensibility of ‘brain death,’ see Doyen Nguyen, *The New Definitions of Death for Organ Donation: A Multidisciplinary Analysis from the Perspective of Christian Ethics* (Bern: Peter Lang, 2018). Similarly, the term ‘brain death’ is also written with quotation marks, because it is a condition in which, in the great majority of cases, neither the patient nor his or her brain is dead.

fewer life-saving organ transplants in 2017 than in 2010.³ Furthermore, in spite of 2,594 transplants performed in 2017, there were still 10,000 patients on the waiting-list as of the end of August 2018.⁴ The draft bill introduced by Spahn was approved by the German federal government at the end of October 2018. At this writing, whether or not the bill will become law depends on the decision of the *Bundestag* (the German federal parliament) in 2019.⁵

Similar to other developed countries, the main source of organ donation in Germany consists of heart-beating donors, i.e., individuals pronounced dead based on neurological criteria, also referred to as the ‘brain death’ paradigm. However, ‘brain death,’ despite its worldwide acceptance as a legal policy, has been the subject of unrelenting controversy since its inception such that today “doubt [regarding ‘brain death’] has become an international consensus.”⁶

Nevertheless, according to the current opt-in policy for organ donation in Germany, before any organ donation can take place in Germany, the following must happen:

- A patient must have severe, irreversible brain damage

³Kevin Schulte et al., “Decline in Organ Donation in Germany,” *Deutsches Ärzteblatt International* 115, no. 27-28 (2018): 463-468, 463.

⁴Alice Tidey, “Germany Debates Opt-out System for Organ Donations,” Euronews <http://www.webcitation.org/76mm5arUd>.

⁵Alexander Pearson, “Germany Proposes Law to Increase Organ Transplants,” *Deutsche Welle* <http://www.webcitation.org/76mmb403O>.

⁶E. Christian Brugger, “Are Brain Dead Individuals Dead? Grounds for Reasonable Doubt,” *Journal of Medicine and Philosophy* 41, no. 3 (2016): 335.

and be considered a potential organ donor.

- The treating physician must recognize this situation in timely fashion and report it to the DSO [*Deutsche Stiftung Organtransplantation*].
- The patient's irreversible loss of brain function must be ascertained and documented.
- The patient must truly be suitable for organ donation.
- Consent to organ donation must be present.⁷

Germany is not the only country to struggle with the chronic shortfall of human organs for transplantation. The widening gap between demand and supply, which results from a combination of complex factors, has remained a problematic issue in many developed countries, some of which (e.g., Austria, Belgium, and France) have sought to expand the donor pool by means of opt-out legislation.⁸ If the bill proposed by Spahn is passed by the *Bundestag* in 2019, organ donation in Germany will switch from its current opt-in policy (which requires explicit consent) to an opt-out system, frequently also referred to as presumed

⁷Schulte et al., "Decline in Organ Donation in Germany," 465.

⁸See M. J. Mehlman, "Presumed Consent to Organ Donation: A Reevaluation," *Health Matrix* 1, no. 1 (1991): 31-66, 40-42; Kenneth Gundle, "Presumed Consent: An International Comparison and Possibilities for Change in the United States," *Cambridge Quarterly of Healthcare Ethics* 14, no. 1 (2005): 113-118.

consent. Independent of the ‘brain death’ controversy, presumed consent is itself also a subject of serious debate, however.⁹

In other words, the current debate on organ donation in Germany touches on both the ‘brain death’ and presumed consent controversies at once, which in turn raises two separate yet interrelated ethical questions. The first question is: can consent be presumed? Stated differently, is presumed consent indeed a consent, or is it a fiction? The second and more important question is: are brain-dead donors dead? Stated differently, is ‘brain death’ true human death, the biological manifestation of which is the loss of somatic integration, or is it a construct for the purpose of organ transplantation? In examining both of these issues, the aim of this paper is two-fold. First, the paper will show that, regardless of its practical benefits to organ donation-transplantation, presumed consent (the basis for the opt-out legislation) raises a whole host of difficulties. In particular, it is philosophically indefensible because it is nothing more than a hypothetical consent, and therefore, not a consent as such. Second, the paper will show

⁹There is ample literature in this regard, especially because of the protracted debated on presumed consent in the United Kingdom. See, for instance, I. Kennedy et al., “The Case for ‘Presumed Consent’ in Organ Donation,” *The Lancet* 351, no. 9116 (1998): 1650-1652; S. Bramhall, “Presumed Consent for Organ Donation: A Case Against,” *Annals of The Royal College of Surgeons England* 93, no. 4 (2011): 270-272. In the United Kingdom, an opt-out legislation was contemplated in 2008, subsequently rejected, but now it has been brought back into consideration again. See “Organ Donation (Deemed Consent) Bill 2017-19,” UK Parliament <http://www.webcitation.org/76mnN8aUm>.

that, in addition to its known biological inaccuracies and philosophical incoherences,¹⁰ 'brain death' since its inception has been a construct designed to serve the ends of transplantation. The paper thus seeks to bring to light the utilitarian character of both the opt-out policy and the 'brain death' paradigm with respect to its genesis. If they are combined together and act synergistically, what would be the moral consequences to the society even if, for the time being, such consequences still remain carefully hidden from the general public?

2 On Consent in Organ Donation

On the one hand, it has been hailed that "organ and tissue donation to others symbolizes the greatest goodness of a person – the capacity to make other's lives better."¹¹ In this regard, a vigorous appeal to noble charity and solidarity, frequently in conjunction with the use of the catchphrase 'the gift of life,' has been one of the most common strategies for promoting organ donation.¹² The Catholic

¹⁰See Nguyen, *The New Definitions of Death for Organ Donation*.

¹¹J. Savulescu, "Death, Us and Our Bodies: Personal Reflections," *Journal of Medical Ethics* 29, no. 3 (2003): 127-130, 128. Note, however, that the Savulescu is also a firm advocate of organ donation euthanasia as a measure to increase the supply of transplant organs. See Dominic Wilkinson and Julian Savulescu, "Should We Allow Organ Donation Euthanasia? Alternatives for Maximizing the Number and Quality of Organs for Transplantation," *Bioethics* 26, no. 1 (2012): 32-48.

¹²See Nguyen, *The New Definitions of Death for Organ Donation*, 516.

Church, especially through the words of Pope John Paul II, also sees organ donation as a new way for man to make a sincere gift of himself and fulfill his “constitutive calling to love and communion.”¹³ Moreover, in the eyes of the Pope, the gift of a vital organ donated after death gives the donors the possibility “to project beyond death their vocation to love.”¹⁴ The same teaching is found in the Catechism which states: “Organ donation after death is a noble and meritorious act and is to be encouraged as an expression of generous solidarity.”¹⁵ At the same time, however, Catholic moral tradition also emphasizes that ‘post-mortem’ organ donation “is not morally acceptable if the donor or his proxy has not given explicit consent.”¹⁶

On the other hand, as pointed out by Sneddon, it cannot be denied that at the very core of organ donation, “the most fundamental reason to acquire organs at all is utility. If people could not benefit from available organs, or if we were unable to use organs to help people, then we would not have such practices.”¹⁷ This rationale of utility is operative in every legal system which regulates the pro-

¹³John Paul II, “To Participants of the First International Congress of the Society for Organ Sharing (20 June 1991)” http://w2.vatican.va/content/john-paul-ii/en/speeches/1991/june/documents/hf_jp-ii_spe_19910620_trapianti.html (accessed 04/05/2015), no. 3.

¹⁴Ibid., no. 4.

¹⁵*Catechism of the Catholic Church* (Vatican City: Libreria Editrice Vaticana, 2003), no. 2296.

¹⁶Ibid.

¹⁷Andrew Sneddon, “Consent and the Acquisition of Organs for Transplantation,” *HEC Forum* 21, no. 1 (2009): 55-69, 55.

curement of 'postmortem' transplant organs, irrespective of whether it follows the opt-in or opt-out policy. The first is based on explicit consent; the second, on presumed consent. For the sake of clarity, the 'brain death' controversy, which will be treated in section 3, is bracketed out from the discussion on consent presented below.

In countries which follow the opt-in legislation such as Germany and the United States, the basic rule is that the procurement of 'postmortem' organs can be performed if there is explicit permission on the part of the patient who, during life, has agreed to organ donation. This is reflected in such documents as the donor registration card, driver's license, or some other form of advanced directive. In the absence of any such explicit decision, no organ removal can take place unless the patient's family or a person whom the patient had designated as a proxy, consents to donate the patient's 'postmortem' organs. In contrast, under a presumed consent legislation, the newly deceased (namely, the brain-dead patient) whose organs are deemed suitable for organ harvesting is automatically considered to be a donor unless he or she had registered his or her objection to opt-out from organ donation. In the absence of any such explicit objection, it is presumed that the individual would have allowed the removal of his or her 'postmortem' organs. In other words, in the pure opt-out policy, the default when the patient had not made any decision during his life, is to proceed with organ removal whereas in the opt-in system, the default is not to proceed. In real life, the practice of opt-out policies varies between countries, ranging from 'hard' to 'soft' depending on the extent to which the views of the relatives are taken into account

when the donor had not registered his or her objections.¹⁸ According to the argument of supporters of opt-out legislation, presumed consent “mak[es] it easier for the family not to oppose donation and free[s] them of any responsibility or remorse,” whereas the opt-in policy puts the burden of the responsibility on the family, already distraught by the death of their loved ones.¹⁹

2.1 The Personalistic norm, the Ethical Foundation of Consent

From an ethical viewpoint, the term ‘consent’ refers to the act of giving a permission, an approval, or an agreement. To be valid, a consent must be given freely, without coercion or deception. Consent necessarily presupposes a moral agent with sufficient mental capacity to give it. The notion of consent in organ donation is derived from the practice of informed consent in other medical fields, either those which involve diagnostic or therapeutic procedures to be performed on patients, or clinical research involving human subjects.

The notion of consent is founded on the ethical principle of respect for persons which is an expression of the person-

¹⁸An example of ‘soft’ opt-out policy is Italy, where organ removal can proceed once it has been ascertained that the family does not object. An example of ‘hard’ opt-out policy is Austria where relatives have no say at all. See Kennedy et al., “The Case for ‘Presumed Consent’ in Organ Donation,” 1650.

¹⁹Constantinos Simillis, “Do We Need to Change the Legislation to a System of Presumed Consent to Address Organ Shortage?,” *Medicine, Science and the Law* 50, no. 2 (2010): 84-94, 89.

alistic norm. This norm, operative in all spheres of human life, "states that the person is the kind of good which does not admit of use and cannot be treated as an object of use and as such the means to an end . . . [Stated differently,] the person is a good towards which the only proper and adequate attitude is love."²⁰ When applied to the realm of medicine and science, the personalistic norm basically means that the interests of individuals prevail over those of science and society. Here, it is worth recalling that, already in 1845, Max Simon, a French physician, emphasized this ethical position in the following words: "one cannot not stress this principle enough: the most indigent patient, even as the most useless to society, cannot be subjected to experiments that could endanger his life. Perish rather science than such principle!" [my translation].²¹ It may be argued that this ethical position does not apply to organ donation since it is not a medical experiment on human subjects, but rather a 'postmortem' procedure. However, such an argument would be valid only if 'brain death' criteria were both empirically (biologically) and theoretically (philosophically) sound, which they are not, as has been amply proven in the published literature.

The same insistence on the personalistic ethical principle

²⁰Karol Wojtyła (John Paul II), *Love and Responsibility*, trans., H. T. Willetts (New York: Farrar, Straus, Giroux, 1981), 41.

²¹Max Simon, *Déontologie Médicale Ou des Devoirs et des Droits des Médecins Dans L'état Actuel De La Civilisation* (Paris: Baillière, 1845), 337. The original French text reads: "*nous ne saurions trop le répéter, le malade le plus obscure, le plus inutile à la société même, ne sauraient être soumis à des expériences qui mettraient évidemment sa vie en péril: périsse la science plutôt qu'un tel principe!*"

is echoed in the teaching of the Catholic Church, notably, through the insightful words of Pope Pius XII. In his 1952 Address to the First International Congress on the Histopathology of the Nervous System, Pius XII taught three important points: (i) science is not the highest value to which all other values should be subordinated; (ii) the human person is not ordained to be an object of utility to the society; on the contrary, the community is to be there for man, instead; and (iii) man is not the absolute master but only the steward of nature, including his own body; hence, he cannot freely dispose of himself as he pleases.²² This means no one, not even the individual him- or herself, “may treat either his or her body, or the organs as property that can be taken and distributed at will.”²³ This is one of the reasons why the Church insists that explicit consent (understood in the sense of informed consent) is required

²²See Pius XII, “Discours aux Participants au Congrès International d’Histopathologie du Système Nerveux (14 Septembre 1952)” http://w2.vatican.va/content/pius-xii/fr/speeches/1952/documents/hf_p-xii_spe_19520914_istopatologia.html (accessed 01/17/2018). The Pope’s original statement in French is as follows: “*la science n’est pas la valeur la plus haute, à laquelle tous les autres ordres de valeurs – ou dans un même ordre de valeur, toutes les valeurs particulières – seraient soumises. [...] L’homme dans son être personnel n’est pas ordonné en fin de compte à l’utilité de la société, mais au contraire, la communauté est là pour l’homme. [...] En ce qui concerne le patient, il n’est pas maître absolu de lui-même, de son corps, de son esprit. Il ne peut donc disposer librement de lui-même comme il lui plait.*”

²³Nicanor Austriaco, “Presumed Consent for Organ Procurement: A Violation of the Rule of Informed Consent?,” *National Catholic Bioethics Quarterly* 9, no. 2 (2009): 245-252, 248.

in 'postmortem' organ donation.

Independent of the Church's teaching, the principle of respect for persons has also been the cornerstone and foundation of secular medical ethics. As pointed out by Harris, respect for persons entails both: (i) respect for autonomy and, therefore, respect of the patient's autonomous choices; and (ii) concern for his or her welfare.²⁴ This last dimension reflects the known principles of beneficence and non-maleficence with respect to the consenting subject, both of which cohere with the principle *primum non nocere* of the Hippocratic Oath.

2.2 The Lack of Transparent Disclosure to the Public about 'Brain Death'

At first glance, it seems that both the opt-in and opt out systems uphold the respect for persons since, as Hartogh points out, "systems of both types purport to respect the decision of the deceased person, whether his decision is to donate or to refuse donation, or to hand over the decision to his relatives (or to some other person [who acts as a proxy])."²⁵ As shown below, a close look at the practice of organ donation reveals that respect for persons is lacking in both systems.

That both opt-in and opt-out systems respect the decision of the deceased person (or, alternatively, of the family or

²⁴See John Harris, "Consent and End of Life Decisions," *Journal of Medical Ethics* 29, no. 1 (2003): 10-15, 10.

²⁵Govert den Hartogh, "Can Consent Be Presumed?," *Journal of Applied Philosophy* 28, no. 3 (2011): 295-307, 295.

the proxy) necessarily presupposes that people have been substantially and honestly informed about all the crucially relevant facts regarding organ donation such that they can have an adequate understanding of the consequences of their decisions. In this regard, the crucial question that must be considered is the following: in the current practice of organ donation, how much of the relevant information about 'brain death' has been provided to the public at large? Put differently, do individuals in the opt-in system who have agreed to the 'postmortem' removal of their organs, and individuals in the opt-out system who have not registered their refusal to donate, understand what the state of 'brain death' is? Have they been provided sufficient information to know that 'brain death' is not death as ordinarily understood, i.e., not in the sense as when one speaks of the death of a family pet? The answer to this question is 'no' because even in the purported informed consent of the opt-in policy for organ donation,

“For most people, the understanding about organ donation is limited to the consent forms filled in at their state Department of Motor Vehicles, or online at their regional Organ Procurement Organization websites. The information provided on such websites is unidimensional, geared toward promoting donation and reinforcing consent. In particular, there is no mentioning of any other options for end-of-life care (e.g., hospice). In that sense, it is difficult to say that the average lay person is fully informed when he/she signs the informed consent

for organ donation after death.”²⁶

The above remark is confirmed by the study by Woien et al. who, in a survey of 60 Organ Procurement Organizations (OPO) in the United States which handle online organ donation registration, found that:

“The disclosure on OPO Web sites and in on-line consent forms lacked pertinent information required for informed enrollment for deceased organ donation. [...] The Web sites predominantly provide positive reinforcement and promotional information rather than the transparent disclosure of the organ donation process.”²⁷

Similarly, in the United Kingdom where the government is transitioning from the existing opt-in to an opt-out policy, it has been found that:

“The process of registration with the ODR [Organ Donor Register] falls well short of that required to establish informed consent. The educational materials associated with the ODR consist of information designed to encourage donation, with no mention of possible negative consequences of participation in donation.”²⁸

²⁶Nguyen, *The New Definitions of Death for Organ Donation*, 7, footnote 19.

²⁷Sandra Woien et al., “Organ Procurement Organizations Internet Enrollment for Organ Donation: Abandoning Informed Consent,” *BMC Medical Ethics* 7, (2006): 14.

²⁸Dale Gardiner and Robert Sparrow, “Not Dead Yet: Controlled

Put bluntly, the OPO and ODR function more as advertisements at the service of organ transplantation rather than as “reliable sources of information about the relevant facts surrounding the organ donation process.”²⁹ Thus, under the opt-in system, the lack of transparent disclosure of the crucially pertinent information concerning ‘brain death’ and organ harvesting leads people to give explicit consent without substantial understanding of the issue at hand. Hence, their explicit consent is *de facto* not an informed consent. Likewise, under presumed consent (opt-out) legislation, the same lack of transparency deprives people from the possibility of registering their objection to donating organs. Where can they find, without great difficulty, the information that, if they were to be declared brain-dead: (i) their heart would still continue to beat spontaneously, (ii) they may still retain some brain activity, in particular, the production of antidiuretic hormone by the posterior pituitary–hypothalamus axis,³⁰ (iii) very likely, they would still have spontaneous movements and spinal reflexes,³¹ and (iv) there would be increased heart rate and

Non-Heart-Beating Organ Donation, Consent, and the Dead Donor Rule,” *Cambridge Quarterly of Healthcare Ethics* 19, no. 1 (2010): 17-26, 22.

²⁹Mike Nair-Collins, “Death, Brain Death, and the Limits of Science: Why the Whole-Brain Concept of Death Is a Flawed Public Policy,” *The Journal of Law, Medicine & Ethics* 38, no. 3 (2010): 667-683, 678.

³⁰See Amir Halevy and Baruch Brody, “Brain Death: Reconciling Definitions, Criteria, and Tests,” *Annals of Internal Medicine* 119, no. 6 (1993).

³¹See Gustavo Saposnik, Vincenzo S. Basile, and G. Bryan Young, “Movements in Brain Death: A Systematic Review,” *Canadian*

blood pressure in reaction to skin incision and sternotomy at the time of organ removal?³² Without important information of this kind, people will not see why they need to take time to register their objection to donating their organs 'postmortem.' In the unforeseen case of being declared brain-dead, they would fall into the *default* category, except in the 'soft' opt-out system where the family is allowed to express their objection.

Where the family is involved because of the absence of any explicit decision on the part of the brain-dead patient, it is unlikely that the relatives are provided the crucially relevant information about 'brain death' and organ removal. The reason for this is at least threefold. First, the complexity of the 'brain death' controversy is such that "many physicians do not understand the conceptual difficulties, inadequacies, and fallacious reasoning surrounding the brain death doctrine;"³³ hence it is doubtful that they

Journal of Neurological Sciences 36, no. 2 (2009): 154-160. According to this review, the occurrence of spontaneous movements and reflexes can be observed in 75-80% of brain-dead patients, especially during the first 24-72 after the declaration of 'brain death.' Reflexes can occur in response to some painful or noxious stimuli (including hypoxia or hypotension during the apnea test). Movements range from simple reflexes such as deep tendon reflexes and plantar flexor response, to complex movements, the most dramatic of which is the Lazarus sign.

³²See Randall C. Wetzel et al., "Hemodynamic Responses in Brain Dead Organ Donor Patients," *Anesthesia and Analgesia* 64, no. 2 (1985): 125-128; Eelco F. M. Wijdicks, "Determining Brain Death in Adults," *Neurology* 45, no. 5 (1995): 1003-1011.

³³Nair-Collins, "Death, Brain Death, and the Limits of Science," 677.

can explain the matter clearly to the family. Second, it cannot be expected that transplant coordinators, OPO personnel, or pro-‘brain death’ physicians (if they happen to handle the care of severely brain injured, deeply comatose patients) would offer the family an unbiased picture on ‘brain death’ and organ donation. Rather, in all likelihood, they will seek to skillfully persuade the distraught family into consenting to the removal of the organs of the brain-dead person. The relatives see that their loved one (connected to a ventilator and receiving pharmacological support) is warm and pink, with the heart still beating; yet, at the same time they are told, with no uncertainty, that their loved one is already dead. Their experience is one of cognitive dissonance which further compounds their grief and distress. It is in such vulnerable moments that the request for organ retrieval is posed to the relatives. Incorporated in the request is a subtle nudging strategy which invariably appeals to noble charity and solidarity, along with the exhortation that organ donation is “a way of finding meaning in death [by] mak[ing] the best of a tragic situation,³⁴” and that the family “can [find] consolation in the fact that some concrete good has come of their loss.”³⁵ A third but not less significant reason for the lack of

³⁴Dick Teresi, *The Undead: Organ Harvesting, the Ice-Water Test, Beating-Heart Cadavers—How Medicine Is Blurring the Line between Life and Death* (New York: Vintage Books, 2012), 144.

³⁵James DuBois, “Avoiding Common Pitfalls in the Determination of Death,” *National Catholic Bioethics Quarterly* 7, no. 3 (2007): 545-559, 558. Elsewhere, DuBois also argues against the need for transparency. See James M. DuBois, “The Ethics of Creating and Responding to Doubts About Death Criteria,” *Journal of Medicine*

transparency are the benefits (e.g., research grants) offered to medical institutions and hospitals which promote organ donation-transplantation.³⁶

To sum up, in the current climate of organ donation, the lack of transparent disclosure of the crucial information about 'brain death' to the public at large basically interferes with people's ability to act as autonomous agents. Put simply, it directly contradicts respect for autonomy and, therefore, the personalistic norm. Moreover, the *default* is far worse in the opt-out than the opt-in system since, in the absence any clear decision of the individual during life, the former proceeds with organ removal whereas the latter does not. What then is the motive why so many European countries have adopted the opt-out legislation? Even more important, however, is the following question: if, as shown above, explicit consents (whether from the donors or their families) for organ removal under the opt-in legislation are not informed consent, then in what way can presumed consent qualify as a consent? Or put simply, is the concept of presumed consent defensible?

and Philosophy 35, no. 3 (2010): 365-380.

³⁶In this regard, it is of note that in Germany, the bill drafted by Spahn, the Health Minister, includes the plan that "some 1.300 hospitals where transplantations are performed would receive a higher remuneration." See Pearson, "Germany Proposes Law to Increase Organ Transplants."

2.3 On Presumed Consent: Why Consent for Organ Procurement Cannot Be Presumed

At first glance, the idea of presumed consent seems to be commendable because it seeks to reduce the loss of lives of patients on the waiting list who could have been saved through organ transplantation. For the sake of the argument, let us take the term ‘postmortem’ for what it literally means, that is, after death. This in turn requires that one must consider what death is.

2.3.1 Pope Pius XII’s Teaching on Postmortem Organ Donation

Metaphysically speaking, a human person is the union of body and soul. Death is the metaphysical event marked by the separation of the soul from the body which now becomes a corpse (a cadaver). To be specific, a cadaver, precisely because it is a non-ensouled body, is a body in name only, just as the eyes of the statue of a person are eyes in name only.³⁷ Thus, a cadaver, a dead ‘body,’ does not have the status of a person but rather, that of a *res* (a thing, an object). From a purely physicalist perspective, which sees the corpse only in terms of its material composition, this is true. A *res* is not a bearer of rights or a member of the moral human community to whom certain

³⁷See Aristotle, *De Anima: Books II and III (with Passages from Book I)*, trans., David W. Hamlyn (Oxford: Clarendon Press, 2002), 412b4-6.

protections apply, namely, "the prohibition of autopsies, burial, or cremation while still biologically living."³⁸

However, does this mean that it can be eviscerated without the permission of the individual (while still alive) or of the relatives now in charge of his mortal remains? Here, the insightful teaching of the Catholic Church, expressed through the words of Pope Pius XII in one of his discourses in 1952, sheds light on why a human corpse deserves to be treated differently from an animal corpse. The Pope stated: "the [dead] body was the abode of a spiritual and immortal soul, [it was] an essential and constitutive part of a human person whose dignity it shared; something of that dignity still remains in it" [my translation].³⁹ In other words, a human dead body has an intrinsic moral and religious dimension attached to it. This is why, as Pius XII reiterated in the conclusion of the same discourse, doctors cannot just extract organs from the deceased for therapeutic (i.e., transplantation) purposes as they please, without taking into account the rights of those in charge of the body of the deceased,⁴⁰ that is, without informed consent. It should

³⁸Nair-Collins, "Death, Brain Death, and the Limits of Science," 668.

³⁹Pius XII, "Discours à L'association des Donneurs De Cornée Et à L'union Italienne des Aveugles (14 May 1956)" http://w2.vatican.va/content/pius-xii/fr/speeches/1956/documents/hf_p-xii_spe_19560514_cornea.html (accessed 01/17/2018). The original French text reads: "*Le corps était la demeure d'une âme spirituelle et immortelle, partie constitutive essentielle d'une personne humaine dont il partageait la dignité; quelque chose de cette dignité s'attache encore à lui.*"

⁴⁰Ibid. At the end of his address, Pius XII stated in French: "*En*

be noted here that the teaching of Pope Pius XII reflects a deep understanding of human psychology, recognizing the fact that most cultures and religions have always treated the dead with reverence, that is, as ends in themselves, rather than as means to an end. As attested to by Baumann et al.,

“Even under a regimen of presumed consent many families feel naturally entitled to defend their dying or dead loved one’s physical and spiritual interests and speak on his or her behalf. Certainly, posthumous harm could occur when the patient’s own wishes or values are not looked for, are disregarded or not respected. Moreover, families also can be harmed, especially by overlooking the affective or family bond by denying them the right to express, honour and put into practice the values of their departed beloved. So, presumed consent is often viewed by families with much suspicion.”⁴¹

ce qui concerne l’enlèvement de parties du corps d’un défunt à des fins thérapeutiques, on ne peut pas permettre au médecin de traiter le cadavre comme il le veut. [...] Il faut aussi prendre en considération les droits et les devoirs de ceux à qui incombe la charge du corps du défunt. Finalement, il faut respecter les exigences de la morale naturelle, qui défend de considérer et de traiter le cadavre de l’homme simplement comme une chose ou comme celui d’un animal.”

⁴¹Antoine Baumann et al., “Talking About Patient’s Values and Posthumous Organ Donation,” *Intensive Care Medicine* 41, no. 8 (2015): 1516.

2.3.2 The Utilitarian and Presumptuous Character of Presumed Consent

Corresponding to the above metaphysical understanding of human death is the ordinary common sense understanding of death which recognizes that, in its concrete manifestation,

“Death is a biological phenomenon and should apply equally to related species. When we talk of the death of a human being, we mean the same thing as we do when we talk of the death of a dog or a cat. This is supported by our ordinary use of the term death, and by law and tradition. It is also in accord with social and religious practices and is not likely to be affected by future changes in technology.”⁴²

If indeed the ongoing debate about 'postmortem' organ donation refers to death understood in its ordinary sense as stated in the above-quoted passage, and if one also brackets out (or is unaware of) the above-mentioned teaching of the Church, then one may think that the idea endorsed by advocates of opt-out legislation makes good sense. From their perspective, when a person dies, his or her dead 'body' is a *res*; the organs are no longer useful to that person, but they can save the lives of patients with organ failure; therefore, 'postmortem' organs must be made available in a way

⁴²Charles M. Culver and Bernard Gert, *Philosophy in Medicine: Conceptual and Ethical Issues in Medicine and Psychiatry* (New York: Oxford University Press, 1982), 182.

that maximizes the benefits of living patients awaiting organ transplants. In this vein, some ethicists have even argued that the refusal to donate one's 'postmortem' organs, thereby wasting them through burial or cremation at the cost of other people's lives, is effectively "morally unacceptable" because it puts the interests of the dead above those of living persons.⁴³

It is thus clear that the fundamental premise upon which rests other various arguments for presumed consent legislation, is the utilitarian motive that "any measure that increases the supply of organ transplantation is a good thing."⁴⁴ This is why advocates of the opt-out policy frequently appeal to studies which compare the organ donation-transplantation between opt-in and opt-out countries, showing that the presumed consent legislation is associated with a higher rate of organ donation.⁴⁵ This does not mean, however, that there is a causal relationship between pre-

⁴³H. E. Emson, "Editorials: It Is Immoral to Require Consent for Cadaver Organ Donation," *Journal of Medical Ethics* 29, no. 3 (2003): 125-127, 127. See also John Harris, "Organ Procurement: Dead Interests, Living Needs," *Journal of Medical Ethics* 29, no. 3 (2003): 130-134.

⁴⁴Kennedy et al., "The Case for 'Presumed Consent' in Organ Donation," 1650.

⁴⁵See *ibid.* See also, Alberto Abadie and Sebastien Gay, "The Impact of Presumed Consent Legislation on Cadaveric Organ Donation: A Cross-Country Study," *Journal of Health Economics* 25, no. 4 (2006): 599-620; Firat Bilgel, "The Impact of Presumed Consent Laws and Institutions on Deceased Organ Donation," *The European Journal of Health Economics* 13, no. 1 (2012): 29-38; Zeynep Burcu Ugur, "Does Presumed Consent Save Lives? Evidence from Europe," *Health Economics* 24, no. 12 (2015): 1560-1572.

sumed consent and increased donation, since such studies often do not take into account "complementary and/or supportive factors that could be attributed alongside introduction of presumed consent (e.g., publicity campaigns, organizational change, [and] infrastructural support)."⁴⁶ A case in point in this regard is Spain where the opt-out legislation, introduced in 1979, has nevertheless remained dormant as evidenced by the absence of an opt-out registry.⁴⁷ As Murphy and colleagues point out, the "Spanish law is a theoretical presumed consent, but in practice the system is 'opt-in.'"⁴⁸

Spain's record of being the country with the highest rate of organ donation (34-35 per million inhabitants) obtained primarily from brain-dead donors, relies primarily on infrastructural measures, especially transplant coordinators, most of whom are intensive care physicians or anesthesiologists charged with the special task of identifying potential donors.⁴⁹ Under such a practice, however, what is the likelihood that a severely brain-injured and deeply comatose patient would be left to progress to a stage where he or she would be declared brain-dead instead of receiving aggressive neuro-intensive care which could bring him or her to

⁴⁶Adnan Sharif, "Presumed Consent Will Not Automatically Lead to Increased Organ Donation," *Kidney International* 94, no. 2 (2018): 249-251, 249.

⁴⁷See Paul Murphy, Rafael Matesanz, and John Fabre, "Presumed Consent Is Unnecessary," *British Medical Journal* 341, no. 7779 (2010): 922-924.

⁴⁸*Ibid.*, 922.

⁴⁹See Rafael Matesanz, "Factors Influencing the Adaptation of the Spanish Model of Organ Donation," *Transplant International* 16, no. 10 (2003): 737.

recovery, even if partial? It would be naïve to think that a physician who is pro-‘brain death’ will handle the severely brain-injured, deeply comatose patient in the same way as a physician who is not.⁵⁰ For the patient, his or her outcome – life or death – may come down to whether he or she “is anticipated as a potential organ donor or whether he or she is viewed as a patient who deserves the maximum therapeutic intervention with a view to full recovery.”⁵¹

Advocates of opt-out legislation also appeal to the data of poll surveys which have indicated that the public supports organ donation. In the United States, the well-known Gallup survey in 1993 showed that 69% Americans were favorable to donating their organs ‘postmortem,’ yet only 28% actually indicated their explicit consent on their donor card or driver’s license.⁵² The same phenomenon is observed in Germany where, in the 2014 survey by the *Bundeszentrale für gesundheitliche Aufklärung* (Federal Center for Health Education) 71.0% of the respondents indicated they would donate their organs, whereas only one

⁵⁰An example of this sad truth is Coimbra’s account of a 15 year-old brain injured female patient who was declared brain-dead without having received aggressive neuro-intensive therapy during the precious 48-72 hour time window after the initial injury. See Cicero G. Coimbra, “Are “Brain Dead” (or “Brain-Stem Dead”) Patients Neurologically Recoverable?,” in *Finis Vitae: “Brain Death” Is Not True Death*, ed. Roberto De Mattei and Byrne Paul A. (Oregon, Ohio: Life Guardian Foundation, 2009), 313-314.

⁵¹Doyen Nguyen, “Brain Death and True Patient Care,” *Linacre Quarterly* 83, no. 3 (2016): 263.

⁵²“Gallup Poll Surveys Views on Organ Donation,” *Nephrology News & Issues* 7, no. 5 (1993): 16.

third of them carry an organ donor card.⁵³ Similarly in the United Kingdom, “over 80% of the adult population say they would definitely, or would consider, donating their organs, but only 37% of the population have registered as donors on the NHS [National Health Service] Organ Donor Register.”⁵⁴ On the basis of this kind of data, it has been argued that opt-out legislation would improve organ donation rates and reflect better the wishes of the society because presumed consent is grounded in “the recognition of the *unexpressed* but autonomous will of most members of society. [. . . Hence], it would be safe to assume that people who have not registered an objection want to donate their organs.”⁵⁵ Such an argument is seriously flawed, because it is based on the false assumption that, because most people approve organ donation, one may presume that they actually want to donate their organs. Such an assumption is unfounded as it overlooks several common sense facts

⁵³E. Tackmann and S. Dettmer, “Akzeptanz Der Postmortalen Organspende in Deutschland,” *Der Anaesthesist* 67, no. 2 (2018): 118-125.

⁵⁴“The Opt-out System,” NHS <https://www.organdonation.nhs.uk/supporting-my-decision/the-opt-out-system/> (accessed 01/07/2019). After this paper was accepted for publication, the UK voted to change to an opt-out system effective spring 2020 and has changed their website. Similar data can be found in Simillis, “Do We Need to Change the Legislation to a System of Presumed Consent to Address Organ Shortage?,” 89.

⁵⁵F. Moustarah, “Organ Procurement: Let’s Presume Consent,” *Canadian Medical Association Journal* 158, no. 2 (1998): 231-234, 232. See also, V. English and A. Sommerville, “Presumed Consent for Transplantation: A Dead Issue after Alder Hey?,” *Journal of Medical Ethics* 29, no. 3 (2003): 147-152, 150.

of life, such as: (i) polls can be inaccurate since what a person gives as a response to a survey does not warrant that he or she will act that way; (ii) the large gap between the support for organ donation and the actual registration to donate may very well indicate ambivalence, doubt and reluctance more than anything else on the part of those who have not registered.⁵⁶ Thus, it is rather presumptuous for supporters of an opt-out policy to assert that “it is permissible to use the organs of someone who did not opt out, because they have – by their silence – actually consented.”⁵⁷

2.3.3 The Deceptive Character of Presumed Consent in Organ Donation

The logic of presumed consent in organ donation totally differs from that used in emergency settings where informed consent cannot be obtained but life-saving procedures need to be initiated on the patient. It is morally right to proceed, however, because life-saving interventions under emergency conditions are “always governed by the principle of ‘the best interests’ of the patient, not some third party.”⁵⁸ Since

⁵⁶G. C. Webster, “Presumed Consent? Let’s Not Be Presumptuous!” *Canadian Medical Association Journal* 159, no. 2 (1998): 135. See also, T. Tottoczko, “Presumed Consent: What Does It Mean?” *Transplantation Proceedings* 35, no. 3 (2003): 1195-1197, 1196; Hartogh, “Can Consent Be Presumed?,” 299.

⁵⁷B. Saunders, “Opt-out Organ Donation without Presumptions,” *Journal of Medical Ethics* 38, no. 2 (2012): 69.

⁵⁸M. D. Dominic Bell, “The UK Human Tissue Act and Consent: Surrendering a Fundamental Principle to Transplantation Needs?,” *Journal of Medical Ethics* 32, no. 5 (2006): 283-284.

life is universally recognized by mankind as the highest good in the created world, it can be safely presume that the patient in question would have consented explicitly to have life-saving procedures performed on him or her. Thus, life-saving intervention is the paradigmatic exception in which the notion of presumed consent applies for the sake of the welfare of the person whose consent is being presumed.⁵⁹ Such is, however, not the case with organ retrieval which serves the interests of some anonymous potential recipients rather than the welfare of those (i.e., the brain-dead patients) whose consent are being presumed. As such, presumed consent contradicts the principle of beneficence which is part and parcel with the notion of consent itself.⁶⁰

Most importantly, the notion of presumed consent for organ donation is philosophically indefensible, precisely because consent, properly understood, refers not to an intention or "a disposition to prefer or wish or desire that action be done . . . [but rather] a public act of authorization."⁶¹ Most arguments for opt-out legislation invariably rest on the interpretation of consent as intention or disposition.⁶² This is a false understanding of consent, however, because an intention or disposition for a certain preference (in this

⁵⁹See Mike Collins, "Consent for Organ Retrieval Cannot Be Presumed," *HEC Forum* 21, no. 1 (2009): 71-106, 80-81.

⁶⁰See the discussion at the end of section 2.1.

⁶¹Hartogh, "Can Consent Be Presumed?," 296. See also, Saunders, "Opt-out Organ Donation without Presumptions," 71.

⁶²The usual claim is that the opt-out policy fulfills the wish of most people to donate since surveys have shown that most people support organ donation. See footnotes 49-51.

case, to donate one's organs) is first-person knowledge or a mental state which no other party can have access to. The individual him- or herself must explicitly make it known to another person. Hence, consent is an action and not a mental state. This is why:

“The presumption of consent does not mean that it can be safely assumed that consent has been given. [...] It only means that it can be assumed that people would consent under hypothetical circumstances. But hypothetical consent is no consent, anymore than false money is money, a potential donor (or person) is a donor (or person), or a shadow cabinet is a cabinet. Therefore presumed consent [for organ retrieval] is a fiction.”⁶³

If presumed consent is a fiction, then to adopt it as a policy and pass it as if were equivalent to actual consent would be ethically deceitful to the public. This would further compound the moral issues associated with the ‘brain death’ paradigm which currently supplies the bulk of transplant organs. Indeed, as to be shown below, the reality of what ‘brain death’ truly is, is the very reason why presumed consent legislation cannot be accepted.

⁶³Hartogh, “Can Consent Be Presumed?,” 299.

3 Organ Transplantation, the Direct Cause of the Genesis of 'Brain Death'

A common argument advanced by scholars who not only support opt-out legislation but also recommend automatic "routine recovery of cadaveric organs" (i.e., mandatory organ donation), is the following: the necessity for obtaining consent applies only to the living and not to the dead because consent is designed to foster a person's moral autonomy and protect him or her from harm and exploitation; but a corpse has neither autonomy nor interests, and therefore it cannot be harmed.⁶⁴ Scholars supporting opt-out legislation and/or mandatory donation use the terms 'cadaver' and 'cadaveric organs' in reference to 'brain-dead' donors without giving any consideration to the protracted and heated controversy about 'brain death.' In other words, such scholars treat the patient as really dead when he or she is declared brain dead. But is 'brain death' truly death, that is, death as it understood in the ordinary sense of the term?⁶⁵

The answer to the above question is a resounding "no."

⁶⁴See Aaron Spital and James S. Taylor, "Routine Recovery: An Ethical Plan for Greatly Increasing the Supply of Transplantable Organs," *Current Opinion in Organ Transplantation* 13, no. 2 (2008): 202-206, 203; Aaron Spital and James Stacey Taylor, "Routine Recovery of Cadaveric Organs," *Kidney International* 94, no. 5 (2018): 1023; Sneddon, "Consent and the Acquisition of Organs for Transplantation," 65-66.

⁶⁵See the block quote corresponding to footnote 42.

Numerous publications have already demonstrated that ‘brain death’ does violence to both the reality of the empirical medical evidence and the sound tenets of philosophical anthropology founded on classical Aristotelian-Thomistic metaphysics.⁶⁶ Even Bernat, the staunchest defender of

⁶⁶See for instance, Nair-Collins, “Death, Brain Death, and the Limits of Science.”; Nguyen, *The New Definitions of Death for Organ Donation*; Doyen Nguyen, “A Holistic Understanding of Death: Ontological and Medical Considerations,” *Diametros* 55, (2018): 44-62; Nicanor Austriaco, “Is the Brain-Dead Patient Really Dead?,” *Studia Moralia* 41, (2003): 277-308; Nicanor Austriaco, “The Brain Dead Patient Is Still Sentient: A Further Reply to Patrick Lee and Germain Grisez,” *Journal of Medicine and Philosophy* 41, no. 3 (2016): 315-328; Paul A. Byrne, Sean O’Reilly, and Paul M. Quay, “Brain Death – an Opposing Viewpoint,” *Journal of the American Medical Association* 242, no. 18 (1979): 1985-1990; Richard H. Bulzacchelli, “The Diagnosis of Death and the Irreducibility of the Human Person,” *Linacre Quarterly* 80, no. 1 (2013): 39-55; Halevy and Brody, “Brain Death: Reconciling Definitions, Criteria, and Tests.”; Ari Joffe, “Are Recent Defences of the Brain Death Concept Adequate?,” *Bioethics* 24, no. 2 (2010): 47-53; David Albert Jones, “Metaphysical Misgivings About Brain Death,” in *Beyond Brain Death: The Case against Brain Based Criteria for Human Death*, ed. Michael Potts, Paul A. Byrne, and Richard G. Nilges (Dordrecht: Kluwer Academic Publishers, 2000), 91-119; Mohamed Y. Rady and Joseph L. Verheijde, “Brain-Dead Patients Are Not Cadavers: The Need to Revise the Definition of Death in Muslim Communities,” *HealthCare Ethics Committee Forum: An Interprofessional Journal on Healthcare Institutions’ Ethical and Legal Issues* 25, no. 1 (2013): 25-45; Josef Seifert, “Is ‘Brain Death’ Actually Death? A Critique of Redefining Man’s Death in Terms of ‘Brain Death’,” in *The Determination of Brain Death and Its Relationship to Human Death, 10-14 December 1989*, ed. Robert J White, Heinz Angstwurm, and Ignacio Carrasco de Paula (Vatican City: Pontificia Academia Scientiarum, 1992), 95-143; Josef Seifert, “On ‘Brain Death’ in Brief: Philosophical

'brain death' has to acknowledge that the 'brain death' paradigm is flawed.⁶⁷ He nevertheless argues that it remains an optimal public policy for the organ procurement enterprise because "in the real world of public policy on biological issues, we must frequently make compromises or approximations to achieve acceptable practices and laws."⁶⁸ Bernat's own words clearly reflect the utilitarian ends of the 'brain death' paradigm.

It is not the purpose of this paper to reiterate in detail the biological inaccuracies and conceptual flaws inherent in the 'brain death' paradigm. Suffice it to indicate, however, as attested in the passage below, that even intensivists (i.e., intensive care physicians) and anesthesiologists who are proponents of organ donation-transplantation recognize that,

Arguments against Equating It with Actual Death and Responses to "Arguments" in Favour of Such an Equation," in *Finis Vitae: "Brain Death" Is Not True Death*, ed. Roberto De Mattei and Byrne Paul A. (Oregon, Ohio: Life Guardian Foundation, 2009), 205-226; D. Alan Shewmon, "Chronic 'Brain Death': Meta-Analysis and Conceptual Consequences," *Neurology* 51, no. 6 (1998): 1538-1545; Robert M. Veatch, "Killing by Organ Procurement: Brain-Based Death and Legal Fictions," *Journal of Medicine and Philosophy* 40, no. 3 (2015): 289-311; D. Alan Shewmon, "The Brain and Somatic Integration: Insights into the Standard Biological Rationale for Equating 'Brain Death' with Death," *Journal of Medicine and Philosophy* 26, no. 5 (2001): 457-478; D. Alan Shewmon, "You Only Die Once: Why Brain Death Is Not the Death of a Human Being; a Reply to Nicholas Tonti-Filippini," *Communio* 39, (2012): 422-494.

⁶⁷James L. Bernat, "The Whole-Brain Concept of Death Remains Optimum Public Policy," *Journal of Law, Medicine & Ethics* 34, no. 1 (2006): 41.

⁶⁸Ibid.

“The bare fact that many brain-dead patients can continue to perform a variety of integrative functions over indefinite time periods, including maintaining body temperature, persistent and adequate hypothalamic hormonal function, regulating salt and water homeostasis, digesting administered food, healing wounds, increase of infection markers and healing infections, stress responses to bodily interventions such as surgery and gestating fetuses in pregnant brain-dead women, makes some wonder whether a brain-dead patient is as ‘dead’ as the doctors say. [...] It is very difficult to see a ‘brain-dead’ pregnant woman, in whose womb a fetus grows over a time period for 2–3 months after the determination of brain death, as ‘a cadaver.’ *There are just too many signs of life. Declaring these patients ‘dead’ solely on the basis of ‘a definition’ seems to contradict our common sense of what it is to be alive* [italics added].”⁶⁹

The above-described clinical reality has been amply reported in the published literature on ‘brain death’ showing the irrefutable empirical evidence that brain-dead patients are not dead. Most notable in this regard is Shewmon’s large collection of well-documented cases of chronic ‘brain death’ survivors, one of whom survived for 20 years after

⁶⁹Erwin J. O. Kompanje and Yorick J. de Groot, “Sounding Board: Is Mandatory Recovery of Organs for Transplantation Acceptable?,” *Intensive Care Medicine* 41, no. 10 (2015): 1836-1837, 1837.

having been diagnosed brain-dead at age 4.⁷⁰ There have been other cases since then, especially the recent famous case of Jahi McMath.⁷¹ Added to this are cases in which the patient (usually a young healthy teenager or young adult in deep coma due to severe traumatic brain injury) was assessed to be brain-dead, but who then somehow 'miraculously' recovered shortly before the scheduled organ harvesting and, as a result, narrowly escaped the lethal ordeal.⁷² Ironically, cases like these bring to mind Edgar Allan Poe's short horror story on *The Premature Burial*.⁷³

Thus, it is rather evident as pointed out by Kompanje that "without the needs of transplantation medicine, 'brain

⁷⁰See Shewmon, "Chronic 'Brain Death': Meta-Analysis and Conceptual Consequences"; D. Alan Shewmon, "'Brainstem Death,' 'Brain Death' and Death: A Critical Re-Evaluation of the Purported Equivalence," *Issues in Law & Medicine* 14, no. 2 (1998): 125-145.

⁷¹Very briefly, Jahi fulfilled the criteria for the determination of whole 'brain death' in December 2013 at age 13. Subsequently in mid-2014, she no longer fulfilled those criteria, that is, she was no longer brain-dead. This was attested by repeated laboratory studies and confirmed by four expert neurologists, including Alan Shewmon, and Calixto Machado (a 'brain death' proponent). For a detailed summary of this case, see Doyen Nguyen, *Why the Thomistic Defense of 'Brain Death' is not Thomistic: an Analysis from the Perspectives of Classical Metaphysics and Contemporary Biophilosophy*, *The Thomist*, in press, footnote 27. See also D. Shewmon, "Truly Reconciling the Case of Jahi McMath," *Neurocritical Care* 29, no. 2 (2018): 165-170.

⁷²See Nguyen, "Brain Death and True Patient Care," 260. See also, Erwin J. O. Kompanje, "Prognostication in Neurocritical Care: Just Crystal Ball Gazing?," *Neurocritical Care* 19, no. 3 (2013): 267-268.

⁷³Edgar Allan Poe, *Complete Stories and Poems of Edgar Allan Poe* (Garden City, N.Y.: Doubleday, 1966), 261.

death as death' would not exist at all."⁷⁴ Yet 'brain death' proponents have insisted that the introduction of the 'brain death' paradigm into clinical practice was not prompted by organ transplantation but, rather, that it "owed its origin to the development of intensive care."⁷⁵ In particular, Diring and Wijdicks, in defense of the Harvard Committee, have claimed "that the Ad Hoc Harvard Committee was primarily concerned with futility of care. [...] Facilitating transplantation was not a major objective [of the Harvard Report]. Organ donation as a potential consequence of this comatose state was not mentioned."⁷⁶ In the discussion which follows below, it will be shown that these claims are not true, and that indeed 'brain death,' from its very inception (i.e., even before the publication of the Harvard Report)⁷⁷ has been specifically designed for the utilitarian purpose of obtaining fresh and viable organs for the transplantation enterprise. The evidence presented below is of two types: (i) external evidence, that is, the external events which led up to the formation of the Ad Hoc Harvard Committee, and (ii) more importantly, the internal evidence which was part and parcel of the genesis of the

⁷⁴Kompanje and de Groot, "Sounding Board: Is Mandatory Recovery of Organs for Transplantation Acceptable?," 1837.

⁷⁵Calixto Machado, Julius Korein, and Yazmina Ferrer, "The Concept of Brain Death Did Not Evolve to Benefit Organ Transplants," *Journal of Medical Ethics* 33, no. 4 (2007): 197-200, 197.

⁷⁶Michael N. Diring and Eelco F. M. Wijdicks, "Brain Death in Historical Perspective," in *Brain Death*, ed. Eelco F. M. Wijdicks (Philadelphia: Lippincott Williams & Wilkins, 2001), 5-27, 13.

⁷⁷See Ad Hoc Committee of the Harvard Medical School, "A Definition of Irreversible Coma," *Journal of the American Medical Association* 205, no. 6 (1968): 337-340.

Harvard report itself.

3.1 Key External Events Leading up to the Formation of the Ad Hoc Harvard Committee

Three notable events set the stage for the Harvard Committee 'brain death' proposal: (a) the 1959 paper of two French neurologists, Mollaret and Goulon, (b) the 1966 Ciba Foundation symposium in London, and (c) the first heart transplants carried out by Barnard in 1967.

3.1.1 Mollaret and Goulon '*le coma dépassé*' (irreversible coma)

In 1959, Mollaret and Goulon, reported a series of 23 patients with a 'new' type of coma characterized by complete unresponsiveness to any stimuli, absence of brainstem reflexes, lack of spontaneous breathing, muscle hypotonia, rapid progression of cardiovascular collapse, diabetes insipidus, altered thermoregulation, and a flat electroencephalogram which remained so until cardiac arrest. The authors designated this condition by the name '*le coma dépassé*.'⁷⁸ The same identical clinical features were to be described by the Ad Hoc Harvard Committee in 1968 as irreversible coma. In this regard, it is interesting to note that the Committee made no reference to the work Mollaret and Goulon

⁷⁸Pierre Mollaret and Maurice Goulon, "Le Coma Dépassé (Mémoire Préliminaire)," *Revue Neurologique* 101, (1959): 3-15.

even though its members knew of the work, in particular Raymond Adams who “frequently spoke to Mollaret.”⁷⁹

The crucial difference between Mollaret and Goulon’s work and the Harvard report is that the former did not presume *le coma dépassé* (irreversible coma) to be true death whereas the latter did, as stated in its opening sentence: “*Our primary purpose is to define irreversible coma as a new criterion for death* [italics added].”⁸⁰ Indeed, when Mollaret was asked the question “do we have the right to discontinue life support measures in the name of criteria which claim to draw a valid dividing line between life and death?” his answer was, “facing these unfortunate patients who fulfill the criteria of what we have called *le coma dépassé*, I have not yet been able nor wanted to accept the *pollice verso* [thumb down] sign” [my translation].⁸¹ The contrast between the action of Mollaret and Goulon and that of the Harvard Committee with respect to the same

⁷⁹Eelco F. M. Wijdeveld, “The Neurologist and Harvard Criteria for Brain Death,” *Neurology* 61, no. 7 (2003): 970-976, 972.

⁸⁰Ad Hoc Committee of the Harvard Medical School, “A Definition of Irreversible Coma,” 337.

⁸¹In the original French, the question to Mollaret was: “*A-t-on le droit d’arrêter la réanimation au nom des critères prétendant tracer une frontière valable entre la vie et la mort?*” Mollaret then answered: “*Devant ces malheureux, qui réalisent ces états que nous avons individualisés sous le terme de «comas dépassés», [...] je n’ai encore pu, ni voulu, consentir le geste du pollice verso.*” Pierre Mollaret, “La Réanimation Respiratoire à L’hôpital Claude Bernard,” *Acquisitions Médicales Récentes* 13, (1959): 5-21, quoted in Göran Settergren, “Brain Death: An Important Paradigm Shift in the 20th Century,” *Acta Anaesthesiologica Scandinavica* 47, no. 9 (2003): 1053-1058, 1057-1058.

phenomenon of irreversible coma raises the following serious question (see section 3.3): does changing the definition of death change the phenomenon of death into what we want it to be?

3.1.2 The Ciba Foundation Symposium on Ethics in Medical Progress

During the 1960s, "the burgeoning field of organ transplantation unleashed a strong desire to expand the recipient pool."⁸² Yet there were several impediments, notably the limited availability of living related donors and the poor quality of organs from cadaveric donors.⁸³ Thus, at the 1966 international symposium on *Ethics in Medical Progress: With Special Reference to Transplantation* sponsored by the Ciba Foundation in London, one of the main issues on the agenda concerned the definition of death. As pointed out by Rothman, "the issue needed to be confronted in order to increase the efficacy of the transplant procedure,"⁸⁴ especially since with the traditional determination for death, the kidneys (and other organs) deteriorate rapidly when deprived of blood supply upon the cessation of circulation due to cardiopulmonary arrest. Here, it should be noted that prior to 1968,

"[The] definitions of death found in various med-

⁸²Diringer and Wijdicks, "Brain Death in Historical Perspective," 6.

⁸³Ibid., 7.

⁸⁴David J. Rothman, *Strangers at the Bedside: A History of How Law and Bioethics Transformed Medical Decision Making* (New York: Aldine de Gruyter, 2003), 156.

ical dictionaries and cyclopedias revolve around one central theme: the *cessation of all vital functions of the human body*. In formulating the criteria for determining death, these traditional medical definitions do not isolate the function of any one organ; rather, they emphasize the total stoppage of all vital bodily functions, [...] as evidenced by absence of heart-beat and respiration, [...] beyond the possibility of resuscitation. These classical medical definitions of death give no special significance to the vital function of the brain, [rather, they] place *the definition of death on an integrated basis*, stressing the idea of total stoppage of bodily functions [italics added].”⁸⁵

In other words, the above passage indicates that the traditional definition of death, which corresponds to the ordinary sense of death, reflects a holistic vision of human beings in which the human person is not reduced to the mind, and then further reduced from the mind to the brain.

At the above mentioned Ciba Foundation-funded symposium, intense discussions were held concerning the issue of equating *le coma dépassé* with death for the purpose of organ procurement. As the terminology ‘brain death’

⁸⁵William F. Arnet, “The Criteria for Determining Death in Vital Organ Transplants—a Medical-Legal Dilemma,” *Missouri Law Review* 38, no. 2 (1973): 220-234, 221-222. Among the dictionaries and encyclopedias referred to by Arnet are the 1951 edition of Blackiston’s New Gould Medical Dictionary, and the 1965 edition of Dorland’s Illustrated Medical Dictionary.

or 'brain-dead donor' was not yet invented, labels such as 'heart-lung preparations' or the oxymoron terminology 'living cadavers' were used to refer to such potential donors.⁸⁶ In particular, based on Mollaret and Goulon's article, the Belgian surgeon Guy Alexandre advanced five neurological criteria for death which he had already applied since June 1963 on "patients with head injuries, whose hearts had not stopped, to do kidney transplantations."⁸⁷ There were participants favorable to Alexandre's proposal for 'brain death,' although they would not have it applied to themselves or their family members.⁸⁸ The one person who endorsed Alexandre's idea most enthusiastically was Joseph Murray, a future member of the Harvard Ad Hoc Committee. "Those criteria are excellent," he stated, "this is the kind of formulation that we will need before we can approach the legal profession."⁸⁹

However, there was also strong opposition against Alexandre's approach as several participants, in refuting the above statement of Murray, affirmed that "if a patient has a heartbeat he cannot be regarded as a cadaver." In particular, David Daube, a professor in Civil Law, reiterated

⁸⁶"General Discussion," in *Ethics in Medical Progress: With Special Reference to Transplantation*, ed. G. E. W. Wolstenholme and Maeve O'Connor (Boston: Little Brown and Company, 1966), 155, 158.

⁸⁷G. P. J. Alexandre, "From the Early Days of Human Kidney Allotransplantation to Prospective Xenotransplantation" <http://www.webcitation.org/76nnBGNe1>.

⁸⁸"General Discussion," *Ethics in Medical Progress*, 153.

⁸⁹Joseph E. Murray, "Organ Transplantation: The Practical Possibilities," in *Ethics in Medical Progress: With Special Reference to Transplantation*, ed. G. E. W. Wolstenholme and M. O'Connor (Boston: Little Brown and Company, 1966), 69.

that,

“Under the classical definition of death, which should not be lightly discarded, an irreversibly unconscious person whose life depends on a machine is still alive. The doctor may be right to stop the machine and let him die. But until death occurs, interference with his body is illicit: it is not a corpse.”⁹⁰

Thus, the Ciba Symposium closed without reaching any agreement whether death should be redefined or not. The symposium itself was clear evidence, however, that the interests of organ transplantation played a causal role in the subsequent ‘reclassification’ of irreversible coma as death through the clever invention of a new name, ‘brain death.’

3.1.3 Barnard’s ‘Sensational’ Heart Transplantation

The movement toward redefining the criteria for death, which had begun with the need for better quality kidneys, took an accelerated turn with heart transplantation. The close temporal sequence between the Harvard Committee and Barnard’s pioneering heart transplant cannot be considered a mere coincidence. On December 3, 1967, in Cape Town, Christiaan Barnard conducted the first heart transplant taken from a young woman already declared dead

⁹⁰David Daube, “Transplantation: Acceptability of Procedures and the Required Legal Sanctions,” in *Ethics in Medical Progress: With Special Reference to Transplantation*, ed. G. E. W. Wolstenholme and M. O’Connor (Boston: Little Brown and Company, 1966), 191.

(albeit with a beating heart) by a neurosurgeon.⁹¹ In order to avoid the criticism that he had killed the donor, Barnard did not remove her heart until the electrocardiogram had shown no activity for 5 minutes.⁹² Although the recipient "died 18 days later from extensive bilateral pneumonia," this limited success was hailed throughout the world as a major medical triumph;⁹³ thus allowing Barnard to proceed with a second heart transplant within less than a month. The second recipient lived for 18 months, with a questionable quality of life, however. Precisely because heart transplants had become a reality, "medicine [urgently] needed a new standard of death, specifically *brain death*, to determine when organs could be removed from a still-living body [italics original]."⁹⁴ As a result, on January 4, 1968, Robert Ebert, the dean of Harvard Medical School approved the formation of an ad hoc committee in response to an earlier request from Henry Beecher.⁹⁵ According to

⁹¹Michael A. DeVita, Snyder James V., and Ake Grenvik, "History of Organ Donation by Patients with Cardiac Death," *Kennedy Institute of Ethics Journal* 3, no. 2 (1993): 118.

⁹²Christiaan N. Barnard, "The Operation. A Human Cardiac Transplant: An Interim Report of a Successful Operation Performed at Groote Schuur Hospital, Cape Town," *South African Medical Journal = Suid-Afrikaanse tydskrif vir geneeskunde* 41, no. 48 (1967).

⁹³Raymond Hoffenberg, "Christiaan Barnard: His First Transplants and Their Impact on Concepts of Death," *British Medical Journal* 323, no. 7327 (2001): 1478-1480, 1478.

⁹⁴Gregory E. Pence, *Classic Cases in Medical Ethics Accounts of Cases That Have Shaped Medical Ethics, with Philosophical, Legal, and Historical Backgrounds* (Boston: McGraw-Hill, 2004), 44.

⁹⁵On October 30, 1967, Beecher wrote to the dean of Harvard Medical School, Robert Ebert: "Both Dr. Murray and I think the time

the dean's letter, the purpose of the Harvard Committee is to study "the ethical problems created by the hopelessly unconscious man [...] and] the necessity of giving further consideration of brain death [...] since] many of the ethical problems of transplantation and other developing areas of medicine hinge on appropriate definition."⁹⁶

3.2 The Genesis of the Harvard Report

The Harvard Committee consisted of 13 members including one lawyer, one historian, one theologian (a Presbyterian minister), and ten physicians with expertise in transplantation, neurology, neurosurgery, public health, and anesthesiology (Beecher, the chairman of the Committee).⁹⁷ The Committee worked swiftly behind closed doors from March through June and completed its work with the sixth

has come for a further consideration of the definition of death. Every major hospital has patients stacked up waiting for suitable donors." Note that the dean did not reply to Beecher immediately; the response only came after the news of Barnard's acclaimed heart transplant. Beecher's letter to dean Ebert is part of the 'Beecher manuscripts' preserved at the Francis Countway Library of Medicine at Harvard. Currently the records are closed to the public; they are made available only to certain selected people. Beecher's letter is quoted in Rothman, *Strangers at the Bedside: A History of How Law and Bioethics Transformed Medical Decision Making*, 160-161.

⁹⁶Quoted in Wijdicks, "The Neurologist and Harvard Criteria for Brain Death," 972.

⁹⁷In the original publication of the Harvard Committee's report in 1968, the names of the Committee members were not made available. The reprint of the article, which appeared in the *International Anesthesiology Clinics* 45, no. 4 (2007): 113-119, listed all 13 members.

and final draft submitted to the dean on June 25, 1968.⁹⁸ It received immediate publication on August 5, 1968.

3.2.1 The Harvard Committee's Alleged Justifications for Identifying Irreversible Coma ('Brain Death') with Death

The Committee stated the reason for its work in the very first paragraph of the report as follows:

"Our primary purpose is to define irreversible coma as a new criterion for death. There are two reasons why there is need for a definition: (1) Improvements in resuscitative and supportive measures have led to increased efforts to save those who are desperately injured. Sometimes these efforts have only 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* [italics added]."⁹⁹

⁹⁸Mita Giacomini, "A Change of Heart and a Change of Mind? Technology and the Redefinition of Death in 1968," *Social Science & Medicine* 44, no. 10 (1997): 1465-1482.

⁹⁹Ad Hoc Committee of the Harvard Medical School, "A Definition of Irreversible Coma," 337.

On the one hand, the Committee's opening statement appears candid and forthright, assuring the reader that its first concern is the burden posed by the 'irreversibly' comatose patients to themselves and their families, and that this concern precedes the need to free up some beds in the intensive care unit. Organ transplantation, so it seems, was not the main impetus for the Committee's definitional effort; only two references were made to transplant / transplantation in the entire report.

On the other hand, to advance irreversible coma (now with the novel label 'brain death') as the new criterion for the determination of death necessarily requires a philosophical rationale to explain why a patient in *coma dépassé* should be considered dead. Yet, as noted by various critics, no conceptual justification was provided in the Harvard Committee's report.¹⁰⁰ A *post hoc* philosophical rationale was not to come until the intervention of the President's Commission in 1981. The two justifications presented in the opening paragraph pertain solely to the pragmatic and utilitarian order. However, are they sufficiently credible to

¹⁰⁰See Giacomini, "A Change of Heart and a Change of Mind? Technology and the Redefinition of Death in 1968," 1465-1482, 1477-1478; Martin S. Pernick, "Brain Death in a Cultural Context: The Reconstruction of Death, 1967-1981," in *The Definition of Death: Contemporary Controversies*, ed. Stuart J. Youngner, Robert M. Arnold, and Renie Schapiro (Baltimore: Johns Hopkins University Press, 1999), 3-33, 9-12; Josef Seifert, "Is 'Brain Death' Actually Death?," *Monist: An International Quarterly Journal of General Philosophical Inquiry* 76, no. 2 (1993): 175-202, 177-178; Robert M. Veatch, "Defining Death Anew: Technical and Ethical Problems," in *Ethical Issues in Death and Dying*, ed. Tom L. Beauchamp and Seymour Perlin (Englewood Cliffs, N.J.: Prentice-Hall, 1978), 18-38, 20.

account for the necessity of introducing a new definition of death, that of identifying *le coma dépassé* with death?

First, it is difficult to see how the burden which patients in irreversible coma pose to themselves, their families, and hospital resources, could have required that a new definition of death be established. As Hans Jonas points out, the question is not whether the deeply comatose patient is dead, but rather how should such a patient be dealt with, that is, whether or not to discontinue the extraordinary measures of artificial life support and let the patient die naturally. Hence, "no redefinition of death is needed [... but rather] a redefinition of the physician's presumed duty to prolong life under all circumstances."¹⁰¹ Most importantly, the decision to take the patient off life support must not be motivated by organ donation. Only then, and assuming that other ethical and medical prerequisites are met, one might accept that irreversible coma "is in itself sufficient ground to discontinue the extraordinary means of life support. Yet this does not necessitate calling this state death."¹⁰² Already before 1968, it had been part of the long-standing (though informal) medical tradition to quietly disconnect the ventilators of patients whose conditions were deemed terminal or irreversible, and to let the dying patient progress to natural death which would soon follow.¹⁰³ Such a practice proves that "the discontinu-

¹⁰¹Hans Jonas, "Against the Stream: Comments on the Definition and Redefinition of Death," in *Ethical Issues in Death and Dying*, ed. Tom L. Beauchamp and Seymour Perlin (Englewood Cliffs, N.J.: Prentice-Hall, 1978), 51-59, 55.

¹⁰²Seifert, "Is 'Brain Death' Actually Death?," 178.

¹⁰³Margaret M. Lock, *Twice Dead: Organ Transplants and the Re-*

ation of extraordinary means of life-support (artificial respirators, etc.) could be justified without maintaining that irreversible breakdown of brain function is identical with death.”¹⁰⁴ Furthermore, the Church’s teaching, namely the address of Pope Pius XII to anesthesiologists, also confirms that there is no absolute moral obligation to prolong at all cost the life of an irreversibly comatose patient whose clinical status steadily deteriorates.¹⁰⁵ Once natural death takes place in such patients, the need to free up ICU beds becomes a non-issue.

The Committee’s second justification states that the “*obsolete criteria for the definition of death can lead to controversy in obtaining organs for transplantation* [italics added].”¹⁰⁶ It is unclear which controversy the Committee was referring to, since prior to 1968 transplant kidneys were taken either from related living donors or from individuals whose death was declared according to the traditional cardiopulmonary standard (could the latter be the obsolete criteria from the Committee’s viewpoint?) which at the time was the only accepted criterion of death. Thus, it seems that the only possible controversy which the Harvard

invention of Death (Berkeley: University of California Press, 2002), 103.

¹⁰⁴Josef Seifert, “Brain Death and Euthanasia,” in *Beyond Brain Death: The Case against Brain Based Criteria for Human Death*, ed. Michael Potts, Paul A. Byrne, and Richard G. Nilges (Dordrecht, Netherlands: Kluwer Academic Publishers, 2000), 201-227, 206.

¹⁰⁵Pius XII, “Address to an International Congress of Anesthesiologists (24 November 1957),” *L’Osservatore Romano*, November 25-26 1957.

¹⁰⁶Ad Hoc Committee of the Harvard Medical School, “A Definition of Irreversible Coma,” 337.

Report alluded to would be if organs were harvested prior to true death, since such an intervention would amount to killing the patient by vivisection and, therefore, violates the Dead Donor Rule. The tacit, unwritten Dead Donor Rule stipulates that vital organs can only be taken from dead people and that "organ retrieval itself cannot cause death."¹⁰⁷ The only way to circumvent the Dead Donor Rule is to have a new criterion for determining death such that procurement of vital organs does not leave physicians open to the charge of murder. In brief, no controversy existed that needed to be resolved by the introduction of the 'brain-death' paradigm. Rather, by introducing it, the Harvard Committee created a controversy which has been unrelenting ever since.

The above brief analysis shows that neither of the two justifications can account for the alleged necessity to make *le coma dépassé* the new definition of death. Indeed, the true, first and foremost justification cannot be immediately found in the Harvard Report itself, but rather in the draft documents of the report and the correspondence between the members of the Committee during the drafting of the report.

3.2.2 The Harvard Committee's True Justification for Identifying Irreversible Coma ('Brain Death') with Death

The Harvard Committee manifested its true reason for re-defining irreversible coma as a new criterion of death not

¹⁰⁷John A. Robertson, "The Dead Donor Rule," *The Hastings Center Report* 29, no. 6 (1999): 6-14, 6.

only in the drafts of the Harvard report but also in the way the Committee carried out its work. In addition, it is interesting to note the biased composition of the Committee: at least six of the ten physicians (specializing in neurology, neurosurgery, renal transplantation, and anesthesiology) were brain death proponents, while there were none to represent the position of the traditional cardiopulmonary death criteria.¹⁰⁸ That the Committee “was not a deliberative body” was recognized by its own theologian-member Ralph Porter.¹⁰⁹ How the Committee carried out its work was also revealing: it worked behind closed doors and in a great hurry from March through June 1968. As pointed out by Giacomini, who analyzed the “Committee’s drafts, memos, and work in progress,”¹¹⁰

“The Committee’s hurried work behind closed doors expropriated the question from a host of outside parties who might not keep the interests of transplantation close at heart, among them the news media, the courts. [...] A timely statement would ward off legal challenges to transplantation, and Harvard’s successful production of the “first” statement would preempt any competing groups’ claims to authority in

¹⁰⁸Teresi, *The Undead: Organ Harvesting, the Ice-Water Test, Beating-Heart Cadavers—How Medicine Is Blurring the Line between Life and Death*, 132.

¹⁰⁹Quoted in Wijdicks, “The Neurologist and Harvard Criteria for Brain Death,” 975.

¹¹⁰The Committee’s drafts, memos, and work in progress are all part of the ‘Beecher manuscripts’ preserved at the Francis Countway Library of Medicine at Harvard (see footnote 95 above).

the area. [...] The urgency clearly was *not* on account of the clinical problem of the "hopelessly unconscious patient," who by 1968 had existed uneventfully in hospitals for years [*italics in original*]."¹¹¹

The language in the drafts of the Harvard report and the memos between the Committee members constitute the clearest and most important evidence showing that the need for fresh and viable organs is the very cause to bring about the birth of 'brain death.' This evidence, accessible only to a few selected scholars and not to the public, reveals the centrality of organ transplantation as the true impetus for the Committee's work. For instance, in one of his correspondences to Beecher in late 1967 regarding organs, Murray wrote:

"The next question posed by your manuscript, namely, 'Can society afford to lose organs that are now being buried?' is the most important one of all. Patients are stacked up in every hospital in Boston and all over the world waiting for suitable donor kidneys. At the same time patients are being brought in dead to emergency wards and potentially useful kidneys are being discarded."¹¹²

¹¹¹Giacomini, "A Change of Heart and a Change of Mind? Technology and the Redefinition of Death in 1968," 1475.

¹¹²Quoted in Wijdicks, "The Neurologist and Harvard Criteria for Brain Death," 972.

Likewise, the necessity of ‘brain death’ for the advancement of organ transplantation was explicitly expressed in several of the manuscript drafts, of which some of the key passages are quoted by Giacomini. For instance, in the conclusion of the first draft of April 11, 1968, we read the following:

“The question before this committee cannot be simply to define brain death. This would not advance the cause of organ transplantation since it would not cope with the essential issue of when the surgical team is authorized – legally, morally, and medically – in removing a vital organ.”¹¹³

In other words, the ‘brain death’ paradigm had to be carefully constructed in such a way that it would serve a two-fold purpose. As pointed out by Pernick, one of the medical historians who had access to the ‘Beecher manuscripts,’ the Harvard Committee and Beecher, its chairman, sought “not only to promote organ donation, but also to protect the profession against transplantation’s critics, [. . . namely] against the public perception that transplant surgeons were organ-stealing killers.”¹¹⁴

A similar pragmatic and utilitarian language is found in the subsequent drafts. The principal causal role of organ transplantation in the genesis of ‘brain death’ is undeniable

¹¹³Quoted in Giacomini, “A Change of Heart and a Change of Mind? Technology and the Redefinition of Death in 1968,” 1474.

¹¹⁴Pernick, “Brain Death in a Cultural Context: The Reconstruction of Death,” 1967-1981, 9.

in the following passage from the manuscript draft of June 3rd, 1968:

“With increased experience and knowledge and development in the field of transplantation, there is great need for the tissues and organs of the hopelessly comatose in order to restore to health those who are still salvageable.”¹¹⁵

The language contained in the manuscript-drafts of the Harvard report thus clearly indicates that which dean Ebert himself recognized, namely that Beecher and the Committee “wish to redefine death in order to make viable organs more readily available.”¹¹⁶ In the final report, the language of the earlier drafts was toned down and replaced with the phrasing of the dean, who suggested that it would be better to indicate that “obsolete criteria for the definition of death can lead to controversy in obtaining organs for transplantation.”¹¹⁷ This statement of the dean stands as the secondary reason (stated in the opening paragraph of the Harvard report) for the Committee’s introduction of ‘brain death’ as a new criterion of death. In other words, organ transplantation, the very reason which had been all along the driving force behind the Committee’s intense endeavor, was now given a muted expression in the final report. In

¹¹⁵Quoted in Giacomini, “A Change of Heart and a Change of Mind? Technology and the Redefinition of Death in 1968,” 1475.

¹¹⁶Quoted in *ibid.* and in Pernick, “Brain Death in a Cultural Context: The Reconstruction of Death, 1967-1981,” 9.

¹¹⁷Quoted in Giacomini, “A Change of Heart and a Change of Mind? Technology and the Redefinition of Death in 1968,” 1474.

that way, it was made to appear as something of minimal importance.

Nevertheless, any astute reader can see through the veil of the revised and guarded language in the final report that the real justification for identifying irreversible coma with death is none other than the interests of the transplantation enterprise. Put bluntly, the introduction of 'brain death' allow surgeons to remove organs from patients with irreversible coma without risking to be accused of homicide or euthanasia.¹¹⁸ Even Peter Singer, whose utilitarian philosophical outlook is well known, affirms that "the brain death criterion of death is nothing other than a convenient fiction."¹¹⁹ This view is corroborated by many other scholars.¹²⁰

In summary, the historical evidence, both external (see section 3.1) and internal, proves the close intrinsic link between organ transplantation and the genesis of 'brain death.' This was further corroborated by Beecher's own

¹¹⁸See Seifert, "Is 'Brain Death' Actually Death?," 178; Seifert, "Brain Death and Euthanasia," 206.

¹¹⁹Peter Singer, "Is the Sanctity of Life Ethic Terminally Ill?," in *Bioethics: An Anthology*, ed. Helga Kuhse and Peter Singer (Malden, MA: Blackwell, 2006), 344-353, 347.

¹²⁰See for instance Don Marquis, "Death as a Legal Fiction," *The American Journal of Bioethics* 14, no. 8 (2014): 28-29; S. K. Shah and F. G. Miller, "Can We Handle the Truth? Legal Fictions in the Determination of Death," *American Journal of Law and Medicine* 36, no. 4 (2010): 540-585; Seema K. Shah, Robert D. Truog, and Franklin G. Miller, "Death and Legal Fictions," *Journal of Medical Ethics* 37, no. 12 (2011): 719-722; Ben A. Rich, "Structuring Conversations on the Fact and Fiction of Brain Death," *The American Journal of Bioethics* 14, no. 8 (2014): 31-33.

statement that, it is not only a waste of resources to keep the hopelessly unconscious patient on the ventilator, but society cannot "continue to condone the discard of [their] tissues and organs [...] when they could be used to restore the otherwise hopelessly ill but still salvageable individual."¹²¹ For Beecher, "at whatever level we choose to call death, it is an arbitrary decision. [...] It is best to choose a level where, although the brain is dead, usefulness of other organs is still present."¹²² Beecher's position thus fit squarely with secular utilitarianism.

3.3 Does Changing the Definition of Death Change the Reality of the Phenomenon of Death?

The above historical account of the genesis of 'brain death' shows that the hurried endeavor of the Harvard Committee came down to a clever exercise of deception and manipulation of the term 'death.' It is not unreasonable to think that the Committee knew that the public at large has always understood death in the ordinary common sense of the term whereby the phenomenon of death in a human person, biologically speaking, is no different from the death of a pet cat or dog. To achieve its purpose, however, the

¹²¹Henry K. Beecher, "Ethical Problems Created by the Hopelessly Unconscious Patient," *New England Journal of Medicine* 278, no. 26 (1968): 1425-1430, 1427.

¹²²Henry K. Beecher and Henry I. Dorr, "The New Definition of Death: Some Opposing Views," *Internationale Zeitschrift für klinische Pharmakologie, Therapie, und Toxikologie* 5, no. 2 (1971): 120-124, 120.

Committee chose to use the same term ‘death’ to designate a totally different phenomenon, as if the phenomenon of death and that of irreversible coma could be conflated together.

Medicine belongs to the field of empirical sciences in which the operative cornerstone principle is scientific realism. As Nguyen points out,

“Realism demands that our concepts (along with the language we use to formulate those concepts) correspond as closely as possible to the reality outside our mind. Therefore, if a scientific thesis is not supported by empirical evidence, then it must be abandoned, or if possible, substantially revised to reflect reality.”¹²³

Applying the principle of scientific realism to the controversy of ‘brain death’ means that we must, first and foremost, acknowledge that life and death are natural biological phenomena, and as such, they are mind-independent phenomena which are not “open to revision or stipulation.”¹²⁴ The task of medical science is “to discover, describe, and explain the features or properties of each phenomenon” and, in the process, distinguish one from the other.¹²⁵ Both life and death are universal phenomena, and within a genus of species – namely the genus of warm blooded mammals – the signs of life (and conversely the

¹²³Nguyen, *The New Definitions of Death for Organ Donation*, 260.

¹²⁴Nair-Collins, “Death, Brain Death, and the Limits of Science,” 671.

¹²⁵Nguyen, *The New Definitions of Death for Organ Donation*, 260.

signs of death) are the same across species. Over millennia man has discovered the constellation of signs which characterizes the phenomenon of death, and which is encapsulated in the medical term 'the traditional cardiopulmonary criterion of death.' It should be noted, however, that this term does not refer just to the cessation of heartbeat and respiration, since the definition of death prior to the 1968 introduction of 'brain death' does not rest on the function of any one organ, but instead "emphasize[s] the total stoppage of all vital bodily functions."¹²⁶

Language, on the other hand, is a product of the human mind and social convention. As such, language can evolve and change; nevertheless such a change cannot be arbitrary but must conform to the above-mentioned principle of realism. In other words, arbitrarily "changing the meanings of terms does not change the world to which those terms refer."¹²⁷ In this regard, precisely because death is a biological, mind-independent phenomenon,

"Changing the meaning or definition of death (word or concept) – that is, changing the criterion for determining death to make it correspond to something else – does not and cannot alter the nature of biological death (phenomenon). Conflating words or concepts with external reality as if the latter could be manip-

¹²⁶ Arnet, "The Criteria for Determining Death in Vital Organ Transplants – a Medical-Legal Dilemma," 221. See the block quote corresponding to footnote 85.

¹²⁷ Nair-Collins, "Death, Brain Death, and the Limits of Science," 670.

ulated by manipulating the former, can only result in epistemic confusion.”¹²⁸

Thus, changing or stretching the definition of the term ‘death’ such that it also encompasses the phenomenon of irreversible coma, and changing the meaning of the term ‘irreversible coma’ such that it becomes a new criterion of death, come down to merely a manipulation of language and concepts – a manipulation which does violence to the principle of realism because those two phenomena remain unchanged, as they differ from one another as day and night. A side-by-side comparison made by Truog and Robinson between: (i) living patients, (ii) brain-dead patients and, (iii) the cadavers of patients whose death is determined according to the traditional criterion, shows the following: brain-dead patients share many features of the living – such as heart-beating, perfusion, functioning vital organs, capacity of reproducing – none of which is manifested in the group of cadavers.¹²⁹ The only feature which the brain-dead group shares with the group of traditional-death cadavers is the absence of the capacity for consciousness.

Put bluntly, redefining irreversible coma (the term) as death, and labelling it as ‘brain death’ does not change the reality of irreversible coma (the phenomenon), for indeed one can only be in a state of coma if one is still alive. What the severely brain-injured, deeply comatose patient

¹²⁸Nguyen, *The New Definitions of Death for Organ Donation*, 261.

¹²⁹See Robert Truog and Walter Robinson, “Role of Brain Death and the Dead-Donor Rule in the Ethics of Organ Transplantation,” *Critical Care Medicine* 31, no. 9 (2003): 2391-2396, 2392 (table 1).

needs and deserves is to be promptly given the state-of-the-art modalities of brain-targeted therapy necessary for the acute management of severe brain injury.¹³⁰ Instead, more often than not, such patients (especially if they are young, and constitutionally healthy before the severe brain injury), are declared brain-dead within 24-48 hours of hospital admission and quickly sent to organ-removal surgery.

4 Conclusion

In addressing the current debate on the possible opt-out legislation for organ donation in Germany, this paper has undertaken a detailed examination of both the issue of presumed consent (the basis for the opt-out legislation) and the problem of 'brain death' together, primarily because the latter is a major source of supply of organ transplants. As demonstrated in the paper, the common thread between 'brain death' and an "opt-out policy" is the ethics of utilitarianism. Another no less important common characteristic between the two is the lack of transparency. With regard to 'brain death,' the notable lack of transparency has been present since its inception, i.e., during the preparatory phase of the Harvard report.

Since the introduction of the Harvard Report, "government and professional organizations and advocacy groups have mischaracterized organ donation as donation after death to make it palatable to the general public."¹³¹ Nor-

¹³⁰See Nguyen, "Brain Death and True Patient Care," 270-272.

¹³¹Joseph L. Verheijde et al., "Legislation of Presumed Consent for End-of-Life Organ Donation in the United Kingdom (UK): Under-

mally, after a patient is declared dead in the intensive care unit, the customary procedure includes “turning off the machines, removing the various lines and tubes, and sending the [dead body] to the appropriate place in the hospital – the morgue.”¹³² In contrast, when a potential donor is declared dead according to the ‘brain death’ criterion,

“Monitoring and intervention continue at maximal levels in order to protect and preserve organs. Health professionals must adhere to detailed instructions defining the specific physiologic and technical indexes for optimal organ perfusion, hydration, diuresis, and avoidance of infection. Should the ‘patient’ have a cardiac arrest, even resuscitation is considered essential.”¹³³

The above passage leads to this very simple question: if ‘brain death’ is death, then “which undertaker would be willing to proceed with funeral procedures [...] on individuals with the diagnosis of ‘whole brain death’ prior to the removal of their organs?”¹³⁴

The lack of transparency, or more precisely stated, the continuing deception of the ‘brain death’ paradigm is one

mining Values in a Multicultural Society,” *Clinics* 63, no. 3 (2008): 297-300, 297.

¹³²Stuart J. Youngner et al., “Psychosocial and Ethical Implications of Organ Retrieval,” *The New England Journal of Medicine* 313, no. 5 (1985): 321-324, 321.

¹³³Ibid.

¹³⁴Doyen Nguyen, “Death: The Loss of Life-Constitutive Integration,” *Diametros*, early view, September 30, 2018 (2018) <http://www.webcitation.org/76ntFwu9W>.

of main reasons why it still remains a highly contentious issue, with opposition mounting from various quarters including, medicine, philosophy, social sciences, as well as in the lay press. Such lack of transparency has been further compounded by the clever use of the emotionally charged terminology "saving lives" or the "gift of life" which conveys the powerful image of life. Certainly, saving the lives of patients whose organs have failed is in itself a good act. But can one justify doing evil – removing vital organs from deeply comatose patients (in so-called irreversible coma) – in order to achieve good?

That both 'brain death' and the current practice of consent (especially presumed consent) in organ donation lack transparency, is not something surprising, however. Both touch the core of the interests of organ transplantation. As Tottoczko points out, for a presumed consent to be valid, it "must be based on the proof or well-founded assumption that the person had been properly informed about the consequences of his or her decision. [In other words], consent can be 'presumed' only when people were properly informed and also given a genuine opportunity to opt out."¹³⁵ This necessarily means that people "would need to be informed of the fact that they would not be dead when organ recovery begins, that they would be killed by the process."¹³⁶ Put simply, organ donation in 'brain death' is not 'postmortem' organ donation, precisely because "organ donation procedures begin before death."¹³⁷ If men for

¹³⁵Tottoczko, "Presumed Consent: What Does It Mean?," 1196.

¹³⁶Collins, "Consent for Organ Retrieval Cannot Be Presumed," 97.

¹³⁷Verheijde et al., "Legislation of Presumed Consent for End-of-Life Organ Donation in the United Kingdom," 298.

millennia have feared to be thought dead while still alive, as illustrated in Poe's short story *The Premature Burial*, then would people not think twice before being subjected to vivisection, let alone volunteering themselves for such a procedure? Moreover, what would happen to the multibillion dollar (or Euro) transplantation enterprise if the public were to learn the truth that the alleged organ donation after death is actually the donation of vital organs before death?