

Critical analysis of three arguments against consent requirement for the diagnosis of brain death ¹

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Abstract

In modern hospitals in developed countries, deaths are determined usually after a prearranged schedule of resuscitative efforts. By default, death is diagnosed and determined after “full code” or after the failure of intensive resuscitation. In end-of-life contexts, however, various degrees of less-than-full resuscitation and sometimes no resuscitation are allowed after the consent and shared decision-making of the patient and/or surrogates. The determination of brain death is a unique exception in these contexts because such an end-of-life care plan is usually not offered until after brain death is declared. This essay analyzes and critiques three arguments for denying the family and/or surrogate a chance to consent to or forego the diagnostic protocol of brain death and choose an alternative end-of-life plan. First, opponents of consent for the determination of brain death argue that presenting it as a selectable end-of-life plan undermines the integrity of death determination. The second argument is that it is inconsistent to allow foregoing the determination of brain death when the determination of circulatory death is non-negotiable. The third argument is that allowing the patient/surrogate to forego the determination of brain death would jeopardize the fair and appropriate utilization of intensive care resources and potentially reduce organ donor pools. After closer conceptual examinations of these three arguments, this essay concludes that these arguments are conceptually and morally problematic.

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It defends an alternative patient-centered end-of-life care plan based on consent and shared decision-making.

Keywords: Brain death, Informed consent, Shared decision-making, End-of-life care, Palliative care, Futility, Organ donation

1. Introduction

Introducing consent and shared decision-making before the diagnosis of brain death or death by neurologic criteria (BD/DNC) has become increasingly controversial in view of publicized cases of allegedly unauthorized diagnosis of BD/DNC.² Over the past several years, different arguments to reject consent before diagnosing BD/DNC have been published,³ while others have

² Lewis, A., & Greer, D. (2018). Medicolegal complications of apnoea testing for determination of brain death. *J Bioeth Inq*, 15(3), 417-428.; Lewis, A. (2018). Contentious ethical and legal aspects of determination of brain death. *Semin Neurol*, 38(5), 576-582.; Berkowitz, I., & Garrett, J.R. (2020). Legal and ethical considerations for requiring consent for apnea testing in brain death determination. *Am J Bioeth*, 20(6), 4-16. A highly publicized case of unconsented diagnosis is the case of Jahi McMath from the state of California. In December 2013, this 13 year-old female sustained severe hypoxic/anoxic encephalopathy as a complication of pharyngeal surgery. Two neurologists independently diagnosed BD/DNC. According to the court filing, the hospital administration pressured the family to agree to donate organs and disconnect the patient from life support without clear explanation, let alone consent or explanation about the test for BD/DNC. The parents were only informed about the results of two EEG tests. They did not understand why the hospital wanted to remove her life support and pressured them to sign the consent form for organ donation. In response, the chief physician told them, 'What is it you don't understand? She is dead, dead, dead, dead!' The parents refused to accept the diagnosis, and transferred the patient to another facility and then an apartment in New Jersey where she was supported by a home ventilator until 2018 when she had the final cardiac arrest. (See Plaintiff's Complaint for Damages for Medical Malpractice at 23-24, *Winkfield v. Rosen*, No RG 15760730. Cal. Super. Ct. filed March 2, 2015)

³ Lewis, A., & Greer, D. (2017). POINT: Should informed consent be required for apnea testing in patients with suspected brain death? No. *Chest*, 152(4), 700-702.; Russell, J.A., Epstein, L., Greer, D., Kirschen, M., Rubin, M., & Lewis, A. (2019). Brain death, the determination of brain death, and member guidance for brain death accommodation requests: AAN position statement. *Neurology*. doi:10.1212/wnl.0000000000006750.; Greer, D., Shemie, S.D., Lewis, A., Torrance, S., Varelas, P.,...Sung, G. (2020). Determination of brain death/death by neurologic criteria: the world brain death project. *JAMA*, 324(11), 1078-1097.; Lewis, A., & Pope, T.M. (2017). Physician power to declare death by neurologic criteria threatened. *Neurocrit Care*, 26(3), 446-449.

argued that the procedure of diagnosis as a whole, or more specifically the apnea test, should be done after informed consent like any other major medical intervention.⁴

One argument against the consent requirement before diagnosing BD/DNC is that death has never been diagnosed after consent, and why should BD/DNC be treated differently, particularly since it is legally and morally no different from circulatory death or death by circulatory criteria (CD/DCC)? However, critics argue that the procedure used to diagnose BD/DNC is morally no different from other medical interventions that commonly require informed consent. Why should the diagnostic procedure of BD/DNC be treated differently from other medical procedures? Arguments on both sides seem to converge on whether the diagnosis of BD/DNC should be treated as an exception from other procedures at the end of life (for opponents of consent) or from other procedures of death determination (for proponents of consent).

Opponents of the consent requirement present three major justifications for denying the family/surrogate's participation in end-of-life decision-making. First, they argue that treating the diagnosis of BD/DNC as a selectable option would undermine the integrity of the entire practice of BD/DNC.⁵ I call this the "integrity argument." Their reasoning is that the diagnosis of BD/DNC is a legally authorized and required practice of physicians. Therefore, allowing the family/surrogate to object to and forego this practice can undermine its integrity.

⁴ Truog, R.D., & Tasker, R.C. (2017). COUNTERPOINT: Should informed consent be required for apnea testing in patients with suspected brain death? Yes. *Chest*, 152(4), 702-704.; Berkowitz & Garrett, *op. cit.* note 1.; Rodriguez-Arias, D., Molina-Perez, A., & Diaz-Cobacho, G. (2020). Death determination and clinicians' epistemic authority. *Am J Bioeth*, 20(6), 44-47.; Johnson, L. (2020). Restoring trust and requiring consent in death by neurological criteria. *Am J Bioeth*, 20(6), 33-35.; Michael Jackson, B. (2020). Informed consent for apnea testing: meeting the standard of care. *Am J Bioeth*, 20(6), 49-51.; Yanke, G., Rady, M., Verheijde, J., & McGregor, J. (2020). Apnea testing is medical treatment requiring informed consent. *Am J Bioeth*, 20(6), 22-24.

⁵ Lewis, A., Bonnie, R., & Pope, T. (2020). Is there a right to delay determination of death by neurologic criteria? *JAMA Neurol*, 77(11), 1347-1348.; Greer et al., Supplement 12. *op. cit.* note 2.

Second, they argue that the diagnosis of CD/DCC does not require consent, and if the diagnosis of BD/DNC requires consent, the consent requirement is applied inconsistently across different death diagnoses. They argue that if CD/DCC is diagnosed without consent, then BD/DNC should also be diagnosed without consent.⁶ I call this argument the “symmetry argument” because it requires symmetry between CD/DCC and BD/DNC regarding consent.

The third argument is focused on resource allocation and two types of resources are involved: intensive life-sustaining treatment (LST) and transplantable organs. By foregoing BD/DNC, the patient may require more utilization of intensive LST such as ventilators and ICU beds and may not be able to donate vital organs.⁷ I call this the “utilitarian argument.”

Proponents of consent have replied that the procedure of BD/DNC, particularly the apnea test, should be no different from any other therapeutic and diagnostic procedures that involve risks such as potentially increasing intracranial pressure, and like any other medical tests, false positive, false negative, and procedure errors.⁸ In addition, some have argued that patients should be allowed to decline unwanted medical diagnoses. BD/DNC can be one such diagnosis for some patients.⁹ In response, opponents seem agreeable to some sort of accommodation, at least for religious objections.¹⁰

⁶ Russell et al., *op. cit.* note 2; Lewis et al. *op. cit.* note 4; Greer et al., *op. cit.* note 4.

⁷ Bhagat, D., & Lewis, A. (2020). The case against solicitation of consent for apnea testing. *Am J Bioeth*, 20(6), 20-22; Greer et al., *op. cit.* note 4.

⁸ See note 3.

⁹ Muramoto, O. (2016). Informed consent for the diagnosis of brain death: a conceptual argument. *Philos Ethics Humanit Med*, 11(1), 8. doi:10.1186/s13010-016-0042-4; Paquette, E., Frader, J., Shah, S., Tasker, R.C., & Truog, R. (2020). Beyond the apnea test: an argument to broaden the requirement for consent to the entire brain death evaluation. *Am J Bioeth*, 20(6), 17-19.

¹⁰ Greer et al., *op. cit.* note 2.

This essay conceptually analyzes the three arguments against the consent requirement for the diagnosis of BD/DNC from the perspective of proponents. Agreeing with opponents, I show that there is no justification for treating BD/DNC differently from other deaths in hospitals. However, disagreeing with opponents, I argue that most in-hospital deaths in modern hospitals in developed countries are subject to advance care planning and shared decision-making, which includes consent about how death will be determined. BD/DNC should be no exception. Most importantly, it is not death per se that families/surrogates are consenting to or declining, but the interventions that are necessary to diagnose death. Each death determination in hospitals involves different interventions and procedures. The family/surrogate would like to have the option to decline one procedure and choose an alternative.

Before the main discussion below, I briefly introduce three background premises on which I base my arguments. First, my discussion strictly follows the definition of death as given by the Uniform Determination of Death Act.

An individual who has sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain stem, is dead. A determination of death must be made in accordance with accepted medical standards.¹¹

This is adopted in the entire United States (U.S.) with minor modifications by each state, and similar definitions are also adopted in the United Kingdom (U.K.), most of the Commonwealth Nations, and many other European countries. (Difference between “whole brain”

¹¹ Uniform Determination of Death Act. 1980. 12A U.L.A. 781. Available from: <https://www.uniformlaws.org/HigherLogic/System/DownloadDocumentFile.ashx?DocumentFileKey=341343fa-1efe-706c-043a-9290fdcf909>

(U.S.) versus “brain-stem” (U.K.) has negligible practical significance). Hereafter I call this one-death-two-criteria doctrine for more general application outside the U.S. This essay has no intention to dispute this definition. However, two important concepts in this definition are critical in the following discussion. First, the one-death-two-criteria doctrine gives no priority to one criterion over the other. If one is unavailable, using the other does not violate this definition. Second, both criteria stipulate the requirement to establish the irreversibility of the cessation of the functions, not a temporary cessation.

The second premise is that a patient in the hospital is considered alive until proven dead. This is a self-evident and platitudinous ethical principle, which nevertheless is often ignored when a patient is in a border zone between life and death, such as being *suspected* to be brain dead but not yet proven by a formal testing. I call this premise the “alive-until-proven-dead principle” hereafter.¹²

The third in the preamble is that the "opponents" I am discussing is mostly a large group of authors affiliated with the World Brain Death Project (WBDP).¹³ The practice of brain death determination varies considerably around the world, and some or all of the current discussion may not apply to some localities. The WBDP is a project, originated in 2020 in the U.S. but represented by an international panel of experts, to standardize the worldwide practice of brain

¹² This principle does not pertain to out-of-hospital deaths. Sometimes death is determined when a person is missing in an environment incompatible with life, such as being inside a completely burned house or a sunken ship in the deep sea, even without direct evidence.

¹³ Greer et al., *op. cit.* note 2.

death determination through expert consensus. The proposed guidelines are similar to the current U.S. guidelines published by the American Academy of Neurology.¹⁴

In what follows, the first three sections will critique each of the three arguments listed above. In the fourth section, I propose an alternative patient-centered approach that incorporates shared decisions on organ donation, palliative care, and the procedure of death determination, which are all interdependent. The goal of this essay is to provide a conceptual counterpoint to the widely published arguments for denying consent and shared decision-making in the diagnosis of BD/DNC, which can become a worldwide standard.

2. The integrity argument

Physicians are legally authorized and obligated to diagnose and determine death. Death determination has many ramifications for patients, their families, and society. It is essential for the process of probate, burial and cremation, and vital statistics, to name a few. If the determination of death can be modified according to the wishes of the patient or family, the integrity of this legally authorized act might be undermined.

Nevertheless, in the few jurisdictions where patients have long been legally able to forego BD/DNC for religious or personal reasons, such as New Jersey and Japan, there have been no reports that the integrity of death determination has been significantly compromised.¹⁵ Here, it seems critical to separate two related but distinct practices: the legal determination of death and the clinical diagnosis of BD/DNC or CD/DCC. Even if the pluralism of the definition of death in

¹⁴ Russell et al., *op. cit.* note 2.

¹⁵ Son, R.G., & Setta, S.M. (2018). Frequency of use of the religious exemption in New Jersey cases of determination of brain death. *BMC Med Ethics*, 19(1), 76. doi:10.1186/s12910-018-0315-0.; Bagheri, A. (2007). Individual choice in the definition of death. *J Med Ethics*, 33(3), 146-149.

one society might create confusion, consent to the method to diagnose death may not. The following two cases illustrate the wide variations in death diagnoses in contemporary medicine.

Patient A was in hospital for recovery from orthopedic surgery. He had an unexpected sudden cardiac arrest and the code team was called to resuscitate him. After 30 minutes of intensive resuscitation failed, the patient's cardiac standstill was confirmed by electrocardiogram for a further 10 minutes. Subsequently, the physician in charge diagnosed CD/DCC, determined that Patient A had deceased, and certified the time, cause, and manner of death.

Patient B was known to her primary doctor as having end-stage cardiac failure for several months and being taken care of at home. As expected, she died of cardiac arrest at home and her husband called her primary doctor, who diagnosed CD/DCC and determined her death over the phone, using the time her husband told him. The cause and manner of death were self-evident and certified accordingly.

Both Patient A's and B's deaths were properly diagnosed, determined, and certified, but the method of diagnosis was entirely different: Patient A's death was diagnosed after intense and prolonged resuscitative effort and CD/DCC was confirmed by electrocardiogram. Thirty minutes of intense cardiopulmonary resuscitation (CPR) is considered sufficient to diagnose the irreversibility of the cessation of the heart,¹⁶ which is the legal definition of CD/DCC. By contrast Patient B was diagnosed indirectly, resuscitative effort was never initiated, and the

¹⁶ Gordon, L., Pasquier, M., Brugger, H., & Paal, P. (2020). Autoresuscitation (Lazarus phenomenon) after termination of cardiopulmonary resuscitation - a scoping review. *Scand J Trauma Resusc Emerg Med*, 28(1), 14. doi:10.1186/s13049-019-0685-4

patient was never examined. This is acceptable because the underlying condition was well known to the physician and this natural death was expected.

The physician could have asked Patient B's husband to bring her to the hospital for a full physical examination to confirm the irreversibility of the cessation of the circulatory system and undergo an electrocardiogram, but it was considered unnecessary in light of the circumstances and shared decision-making. In this case, the patient and surrogate had decided how death would be diagnosed—no resuscitation, transfer, and test.

There are many different methods of diagnosing death. The legal duty of a physician is to diagnose and determine death using one of these methods, but the selection of the method depends on the context in which the patient and physician find themselves. As the above examples illustrate, incorporating the patient or family/surrogate's wishes regarding procedures does not undermine the integrity of death determination. Diagnosing BD/DNC and CD/DCC involves very different tests in hospital. If one test is unavailable for various logistical, technical, or other reasons, including refusal by the family/surrogate, choosing an alternative does not compromise the integrity of death determination.

Another construction of the integrity argument is that hospitals have the right to determine whether patients are alive or dead; therefore, patients have no right to refuse death determination.¹⁷ However, a closer look reveals that much like many other decisions in clinical ethics, this issue comes down to context. In most situations, BD/DNC does not occur suddenly. Physicians know that a patient is approaching BD/DNC hours or days beforehand. It is essential that the family/surrogate be involved in important decisions before such a diagnosis becomes

¹⁷ Lewis & Pope, *op. cit.* note 2.

necessary. If a care team initiates appropriate end-of-life counseling and gives the family/surrogate a transparent explanation of the patient's approaching death, including the signs and symptoms of BD, and presents all end-of-life care options available, they might formulate a mutually acceptable course of action.¹⁸

If physicians truly cannot tell whether a patient is alive or dead—(e.g., if the patient is extremely hypothermic or under the influence of sedatives)—they should presume that the patient is alive and worthy of full moral respect following the alive-until-proven-dead principle as mentioned in the Introduction. The family/surrogate should be informed of the status of the patient and full treatment be continued while exploring available options.

When a patient is identified as a candidate for a BD/DNC diagnosis and physicians and the hospital want to proceed to the diagnostic protocol, the guidelines for BD/DNC emphasize that further restorative treatment and LST must be futile.¹⁹ In other words, the prognosis is almost certainly death, neurological or circulatory, or in the unlikely case of survival, the patient will suffer from the worst case of neurologic disability. Further restorative and life-sustaining therapies do not achieve the intended goals. This is the prerequisite before diagnosing BD/DNC recommended by the authors of the guidelines.

At the same time, the recognition of futility normally means the starting point of end-of-life care planning. The goals of care shift from aggressive restorative treatment and LST to comfort measures and dignified death. The patient is now at the junction between a palliative care path and the diagnostic procedure of BD/DNC. Opponents of consent for BD/DNC often argue that

¹⁸ A tragic result of the lack of this preemptive care planning is well exemplified in the case of Jahi McMath. See note 1.

¹⁹ Wijdicks, E.F. (2015). Brain death guidelines explained. *Semin Neurol*, 35(2), 105-115.

when a patient is identified as a candidate for a BD/DNC diagnosis, there is no choice but to proceed to the diagnostic procedure.²⁰ Contrary to their assertion, an important alternative path is to transition to palliative care. Additionally, as will be discussed later, different methods of organ donation are other decisive factors.

Compassionate end-of-life counseling, leading to an agreeable plan for limiting/withdrawing LST (WLST), has been conducted by intensivists for decades,²¹ and it is the mode of death in the majority of patients who die after admission to the ICU. There is no reason to exclude those who are approaching BD/DNC from palliative care options.

3. The symmetry argument

The symmetry argument goes as follows: as long as consent is not required for CD/DCC, it is inconsistent for the entire practice of death determination to require consent for BD/DNC. Opponents of consent insist that CD/DCC and BD/DNC must be symmetrical with regard to the consent requirement.

However, there is no legal, medical, or logical reason that these two practices must be symmetrical. If test A for the diagnosis of condition X does not require consent, it does not logically follow that test B for the same condition X does not require consent. For example, colon cancer can be diagnosed either by an endoscopy or a stool test, but it does not follow logically or medically that the two tests must have the same consent requirement. The current

²⁰ Lewis & Greer, *op. cit.* note 1; Lewis & Greer, *op. cit.* note 2.

²¹ Prendergast, T.J., & Luce, J.M. (1997). Increasing incidence of withholding and withdrawal of life support from the critically ill. *Am J Respir Crit Care Med*, 155(1), 15-20; Cook, D., Rocker, G., Marshall, J., Sjøkvist, P., Dodek, P., ... Guyatt, G. (2003). Withdrawal of mechanical ventilation in anticipation of death in the intensive care unit. *N Engl J Med*, 349(12), 1123-1132.

one-death-two-criteria doctrine of the definition of death only requires that physicians determine a unitary phenomenon of death by either circulatory or neurologic criteria. All clinical details differ between these two criteria.

Informed consent aims to protect the patient's autonomous choice,²² in this case through advance directives or the family/surrogate. When there is no substantial choice, informed consent is moot. Conversely whenever there are relevantly important choices for the patient, consent is morally required. Ordinarily CD/DCC gives no choice, particularly under uncontrolled circumstances outside the hospital, and consent for its diagnosis is inconsequential. By contrast, there are several end-of-life options to choose from when death occurs in the controlled environment of advanced hospitals.

In fact, almost every death in a modern hospital is planned and chosen in one way or another because LST measures are comprehensively implemented. As mentioned earlier, the default choice is so-called "full code," which means a patient receives the maximum efforts to avert death and sustain life at almost any cost. Under full code, death may not be diagnosed until CPR to reverse circulatory and respiratory arrest is deemed a failure. When respiration stops, intubation, mechanical ventilation, and sometimes extracorporeal membrane oxygenation are used. In case of devastating brain injury (DBI), intracranial pressure is monitored and adjusted and therapeutic hypothermia and sedation are often used. Only after all these efforts fail is death usually diagnosed. However, when any of these efforts do not seem to achieve the goals of care in end-of-life contexts, physicians employ an alternative "limited code," "no code," or do-not-resuscitate (DNR) order usually as a shared decision with the patient or family/surrogate. In short,

²² Beauchamp T.L., Childress, J.F.. (2009) Respect for autonomy. In: Beauchamp T.L., Childress, J.F. *Principles of Biomedical Ethics (6th ed.)* (pp. 99-148). New York: Oxford University Press.

virtually every patient in contemporary advanced hospitals has some form of end-of-life plan. Although some of these are improvised according to the rapidly changing clinical context, such plans should in principle reflect the autonomous wishes of the patient and their family/surrogate.

When death is anticipated in such scenarios, organ donation also comes into play for end-of-life decisions. Because the method of death determination and method of organ procurement are often linked, a patient's donor status can influence how death is determined. For example, heart-beating donation (HBD) usually requires BD/DNC, whereas CD/DCC might be sufficient for non-heart-beating donation (NHBD).

Contrary to the symmetry argument that CD/DCC does not afford consent, the diagnostic protocol of CD/DCC requires explicit consent before NHBD or donation after controlled circulatory determination of death (cDCDD). Such a controlled CD/DCC occurs usually in an operating room, under close medical monitoring after withdrawing the ventilator. This withdrawal by physicians brings on respiratory and cardiac arrest, hence "controlled." By consent, testing for the irreversibility of cardiac arrest, a part of the criteria for CD/DCC, is foregone except for a brief stand-off period.

If we conceptually analyze the symmetry argument further, we realize that a form of symmetry between BD/DNC and CD/DCC indeed exists already, though it is quite different from that argued by the opponents. Whether BD/DNC or CD/DCC, if deaths occur in the controlled environment of hospitals, they occur under physicians' volitional control. Just as CD/DCC is diagnosed only after intense testing for irreversibility, i.e. failed CPR, (or no testing for irreversibility by opt-out consent in DNR cases and cDCDD), BD/DNC is diagnosed only after intense efforts to prevent circulatory arrest by maintaining intense LST. Otherwise, the

patient would have died of uncontrollable circulatory collapse, a common consequence of BD/DNC. That is why a DNR order and the diagnostic procedure of BD/DNC cannot coexist simultaneously in one patient.

In contrast to controlled deaths in hospitals, deaths occurring outside hospitals (or sometimes in the emergency department) are often beyond physicians' control. Such uncontrolled deaths are not limited to CD/DCC. Uncontrolled BD/DNC occurs within several minutes of brain and systemic circulatory arrest, resulting in the same clinical manifestation and pathophysiology of controlled BD/DNC. The so-called "death triad"—apneic coma, brainstem areflexia, and systemic circulatory arrest—are the traditional signs used to diagnose death. To diagnose uncontrolled BD/DNC, most physicians confirm brainstem areflexia by testing an absent papillary reflex to light (paralysis of the second and third cranial nerves), often with an absent corneal reflex (paralysis of the fifth and seventh cranial nerves). Along with apneic coma (absolute absence of response and respiration), signs of uncontrolled BD/DNC are incorporated in the traditional diagnosis of death. This is the basic idea of "brainstem death," the unified definition of death in the U.K., which is the irreversible loss of the capacity for consciousness and capacity to breathe attributed to the irreversible cessation of brainstem functions or circulatory arrest.²³ In this way, the traditional determination of death indeed includes the diagnosis of uncontrolled BD/DNC. The irreversibility requirement is fulfilled by the fact that

²³ The Academy of Medical Royal Colleges. (2008) *A code of practice for the diagnosis and confirmation of death. A report of the Academy of Medical Royal Colleges*. Retrieved from <https://www.aomrc.org.uk/reports-guidance/ukdec-reports-and-guidance/code-practice-diagnosis-confirmation-death/>

the brain circulation along with the systemic circulation has permanently stopped without elaborate testing.²⁴

When deaths occur beyond physicians' control, consent is moot regardless of BD/DNC or CD/DCC because there is no alternative. By contrast, when deaths occur under physicians' volitional control, consent, or at least shared decision-making, is morally required because physicians can always act otherwise. In this way, BD/DNC and CD/DCC have a "symmetrical" consent requirement. Both BD/DNC and CD/DCC require consent or shared decision-making if they occur under physicians' volitional control. The problem of the symmetry argument used to deny consent for the diagnosis of BD/DNC is that it compares controlled BD/DNC within physicians' control with uncontrolled CD/DCC beyond physicians' control, and they argue that because uncontrolled CD/DCC does not require consent, controlled BD/DNC should not. They simply compare incomparables. By reviewing the morally salient reasons for the consent requirement for both CD/DCC and BD/DNC, we can conclude that consent is required for controlled BD/DNC *regardless* of the symmetry argument. The requirement for symmetry was invented only to deny the consent requirement for BD/DNC and has no deep moral significance.

4. The utilitarian argument

Opponents of consent for BD/DNC suggest that if we allow patients' families/surrogates to forego the diagnosis of BD/DNC, patients will continue to receive intensive ICU treatment for a condition that is likely BD. They argue that we can eliminate this waste of ICU resources by

²⁴ Gardiner, D., McGee, A., & Bernat, J.L. (2020). Permanent brain arrest as the sole criterion of death in systemic circulatory arrest. *Anaesthesia*, 75(9), 1223–1228.

unilaterally diagnosing BD/DNC.²⁵ This argument poses a binary choice: either diagnosing BD/DNC or perpetual futile care.

As mentioned earlier, they omit other important end-of-life pathways including DNR with palliative care and alternative possibilities of organ donation without diagnosing BD/DNC. These end-of-life options are interdependent. For example, if the plan is to diagnose BD/DNC, the patient cannot be allowed dying with a DNR in the palliative plan simply because the heart must be always functional through the completion of the diagnostic procedure of BD/DNC, as discussed in the third section above. A patient who wants to donate the heart with the best chance for successful transplantation should be diagnosed also with BD/DNC before CD happens. Urgent but careful planning is critical at this juncture.

Opponents of consent may not deny the importance of such a care conference, but they do deny families/surrogates the right to forego the diagnosis of BD/DNC (with possible exceptions of religious objections). However, this begs the question: if eliminating the futile use of intensive care resources is an important reason behind their denial of consent, why do they continue fully aggressive LST through the diagnosis of BD/DNC and thereafter until the donor status of the deceased is clarified? As mentioned in the Section 2, the guidelines of BD/DNC presume that further LST is determined futile before proceeding to the diagnostic protocol of BD/DNC. Why do they not allow some family/surrogates to forego BD/DNC and choose palliative care options like other patients facing end-of-life futility?

This is where the second utilitarian reason for opposing to the consent for the diagnosis of BD/DNC matters, and that is organ donation. HBD is predominantly the best source of

²⁵ Bhagat & Lewis, *op. cit.* note 6.

transplantable organs, and those who die of BD/DNC are highly sought-after by organ procurement organizations (OPOs). American hospitals are required to notify OPOs when potential donors are identified. This is not considered a violation of patient's confidentiality even if it is done without the consent of the family/surrogate. In fact, there is a long tradition that organ donation is requested only after death is pronounced. Therefore it is difficult, if not impossible, to discuss organ donation in conjunction with the method of diagnosing death.

Opponents of consent before diagnosing BD/DNC recommends:

... an assessment for determination of BD/DNC be made in *all persons* with devastating brain injuries who are believed to potentially meet criteria for BD/DNC, *regardless of whether they are potential organ donors* (emphasis added).²⁶

In other words, they recommend diagnosing BD/DNC without the knowledge of donor status of the patient. If we want to maximize the number of potential donors, it seems most efficient to test everybody who might meet the diagnostic criteria of BD/DNC regardless of their donor status. However, even if it might maximize the donors for HBD, it would preclude people who do not want to donate, cannot donate, or who have different end-of-life plans a chance to choose an alternative care plan, simply because these pathways cannot coexist in the very same patient who is about to undergo the diagnostic protocol of BD/DNC. These options must be decided prior to the decision to proceed to the diagnosis of BD/DNC.

Admittedly, there are good reasons to avoid considering organ donation before death declaration. Knowledge of donor status can implicitly bias life-sustaining efforts to suit this status and can influence the patient's family's perception, correctly or incorrectly, that the care is

²⁶ Greer et al *op. cit.* note 2.

geared toward organ procurement, not the patient's best interests. Treating every patient approaching BD/DNC blindly as an organ donor by default may lead to an increase in donation rates.

An important and closely related debate is whether organ donation requires consent from the donor or organs can be procured routinely unless an explicit objection was registered by the deceased. One could argue that if organs can be procured without consent, then BD/DNC can also be diagnosed without consent because organs are in the best condition from those who die of BD/DNC. Likewise, if the patient is known to be a consented donor, it might be interpreted that he/she would have consented to a BD/DNC diagnosis as part of the donation procedure.

Nevertheless, there is a critical moral difference between consenting to the diagnostic procedure of BD/DNC and consenting to organ procurement: the former is an antemortem procedure, whereas the latter is a postmortem procedure.²⁷ They carry different moral weight. It is conceivable that many would care much less about what is done to their dead body without consent than their still-living body without consent.

Opponents of the consent seem to leave this difference undisclosed and proceed to the diagnostic protocol of BD/DNC before discussing and planning the next steps, including organ donation and/or WLST. Proponents of consent find this morally problematic because, as discussed above, the patient is deprived of the chance to choose one of several distinct and mutually exclusive antemortem pathways, including continuing LST with eventual CD/DCC with palliative care with/without NHBD and WLST, BD/DNC with/without HBD, and

²⁷ Opponents of consent assert that the procedure for BD/DNC is not a medical procedure because "there is no person left to treat." In other words, they consider a candidate for BD/DNC as an already dead "no person." See Bhagat & Lewis, *op. cit.* note 6. Opponents consciously or unconsciously violate the alive-until-proven-dead principle.

immediate WLST. Precluding the family/surrogate from selecting one of these options while the patient is still alive could constitute a violation of the patient's moral status and rights.

5. Alternative patient-centered approach to BD/DNC and organ donation

I suggest that an opposite approach—one that is transparent and patient-centered—would ameliorate the concerns about the violation of patient's antemortem moral status and organ donation. First, compassionate end-of-life counseling should be initiated upon admission to the ICU and organ donation is discussed along with permission for the diagnostic protocol of BD/DNC as the necessary first step for HBD. At the latest, when the futility of further LST and restorative treatment is established as a presumption before diagnosing BD/DNC, end-of-life counseling should be completed including the possibility of organ donation and/or palliative care.

Palliative care interventions from the early stages of admission to the ICU are shown to reduce the cost and length of stay without increasing mortality.²⁸ Compassionate communication with transparent information can lead families/surrogates to make better informed decisions and resolve futile care in an amicable way through shared decision-making.²⁹ This approach is much

²⁸ Aslakson, R., Cheng, J., Vollenweider, D., Galusca, D., Smith, T., & Pronovost, P.J. (2014). Evidence-based palliative care in the intensive care unit: a systematic review of interventions. *J Palliat Med*, 17(2), 219-235; Kyeremanteng, K., Gagnon, L.P., Thavorn, K., Heyland, D., & D'Egidio, G. (2018). The impact of palliative care consultation in the ICU on length of stay: a systematic review and cost evaluation. *J Intensive Care Med*, 33(6), 346-353.

²⁹ Truog, R.D., Campbell, M.L., Curtis, J.R., Haas, C.E., Luce, J.M.,... Kaufman, D.C. (2008). Recommendations for end-of-life care in the intensive care unit: a consensus statement by the American College of Critical Care Medicine. *Crit Care Med*, 36(3), 953-963.; Levin, T.T., Moreno, B., Silvester, W., & Kissane, D.W. (2010). End-of-life communication in the intensive care unit. *Gen Hosp Psychiatry*, 32(4), 433-442.; Virdun, C., Luckett, T., Davidson, P.M., & Phillips, J. (2015). Dying in the hospital setting: a systematic review of quantitative studies identifying the elements of end-of-life care that patients and their families rank as being most important. *Palliat Med*, 29(9), 774-796.

more ethical and humane than unconsented and unconditional testing of BD/DNC using “physician power,” as promoted by opponents of consent.³⁰

Moreover, by reducing unnecessary diagnoses of BD/DNC and organ-sustaining treatment from non-donors after a BD/DNC diagnosis, healthcare resources are preserved. This waste of resources through unnecessary testing is ironic because one of the main goals of diagnosing BD/DNC is supposedly to preserve healthcare resources. The logistics of performing the procedure of BD/DNC is burdensome for small hospitals. In most countries outside the U.S., multiple procedures by multiple physicians are required. In Germany, for example, where two physicians are required to diagnose BD/DNC, only 26% of small hospitals can do it on their own without asking for help from specialists in larger hospitals. Hence, logistics alone can reduce the number of patients who undergo BD/DNC protocols.³¹

Nevertheless, there may still be cases in which BD/DNC diagnoses are necessitated by clinical contexts, even if the patient is not an organ donor. For example, some families may not be convinced of the futility of LSTs until BD/DNC has been diagnosed and death thus becomes an established fact. It may be necessary to include BD/DNC diagnoses in end-of-life care options in such cases, even if the patient is not a donor.³² Consent should be obtained before diagnosing

³⁰ Lewis & Pope, *op. cit.* note 2. As seen in the Jahi McMath case, such an authoritarian approach only hardens the opposition to BD/DNC, even when the family had never established any fixed belief about it before (see note 1). Instead of authoritarianism, the focus of discussion should be how to bring closure in a manner that suits best for the patient rather than jumping to the final BD testing or WLST. Comfort measures and dignity usually become the top priority in most cases, and de-escalation of treatment followed by slow transition to palliative care eventuates. Of course, that does not lead to immediate WLST, but during this transition, BD testing may become one of the options to bring closure for the family.

³¹ Formanek, M., & Schoffski, O. (2010). Difficulties with the organ donation process in small hospitals in Germany. *Transplant Proc.*, 42(5), 1445-1448.

³² See also note 29.

BD/DNC, however, for the final removal of organ-sustaining treatment, with an agreed-upon time delay after the declaration of death, unless the family/surrogate changes their mind regarding organ donation. This consent effectively precludes indefinite organ support after non-donors' diagnoses of BD/DNC. Some families also insist on “everything” being done to keep their loved ones alive, and do not accept any de-escalation of LST. Such cases are always challenging, particularly in resource-intensive ICUs. They should be treated no differently from other cases in which the family does not accept the transition to comfort care and insists on medically futile interventions. Patient and compassionate end-of-life communication along with multi-disciplinary support teams can usually facilitate the transition from de-escalation to limiting LST.

Contrary to the traditional strategy of not bringing up the issue of organ donation before death declaration, more open and transparent end-of-life strategies that incorporate organ donation as an integral part of end-of-life care for patients with DBI are gaining momentum in different parts of the world.³³ Several countries with high donation activities, such as Spain,³⁴ the United Kingdom,³⁵ the Netherlands,³⁶ France, Australia, and New Zealand,³⁷ have developed

³³ Achieving Comprehensive Coordination in Organ Donation throughout the European Union- ACCORD Joint Action Work Package 5 — Increasing the collaboration between donor transplant coordinators and intensive care professionals. Final report. 2015. Retrieved from http://www.accord-ja.eu/sites/default/files/download_documents/ACCORD_WP_5_ICU_%26_DTC_Collaboration_FINAL_REPORT.pdf; Manara, A., Procaccio, F., & Dominguez-Gil, B. (2019). Expanding the pool of deceased organ donors: the ICU and beyond. *Intensive Care Med*, 45(3), 357-360.

³⁴ Dominguez-Gil, B., Coll, E., Elizalde, J., Herrero, J.E., Pont, T., ... Matesanz, R. (2017). Expanding the donor pool through intensive care to facilitate organ donation: results of a Spanish multicenter study. *Transplantation*, 101(8), e265-e272.

³⁵ Rivers, J., Manara, A.R., Thomas, I., & Derrick, E. (2020). Impact of a devastating brain injury pathway on outcomes, resources, and organ donation: 3 years' experience in a regional neurosciences ICU. *Neurocrit Care*, 33(1), 165-172.

programs that link the diagnosis of BD/DNC and other end-of-life options in the ICU to organ donation, and donation is treated as part of a more comprehensive end-of-life care plan for patients with DBI. Administrative details differ from program to program, but one feature is common: they offer many different options, including HBD, NHBD, WLST and comfort care, and the diagnosis of BD/DNC and cDCDD (where this practice is available). They incorporate the values and preferences of the patient/family/surrogate, and final pathways are agreed upon as a shared decision.

In Spain's Intensive Care to Facilitate Organ Donation program, informed consent to participate in the program includes the family's understanding that its measures aim to preserve the patient's organs until BD/DNC, there is no therapeutic aim, and the comfort of the patient is paramount. The family also understands that BD/DNC usually occurs within 24 to 72 hours but may take longer or even not occur, and the patient may ultimately not be a suitable organ donor.³⁸ At least in the Netherlands, the diagnostic procedure of BD/DNC starts after the family/surrogate has consented to organ donation.³⁹

³⁶ Witjes, M., Kotsopoulos, A., Otterspoor, L., Herold, I., Simons, K.S.,... Farid Abdo, W. (2019). The implementation of a multidisciplinary approach for potential organ donors in the emergency department. *Transplantation*, 103(11), 2359-2365.

³⁷ Melville, A., Kolt, G., Anderson, D., Mitropoulos, J., & Pilcher, D. (2017). Admission to intensive care for palliative care or potential organ donation: demographics, circumstances, outcomes, and resource use. *Crit Care Med*, 45(10), e1050-e1059.

³⁸ Martinez-Soba, F., Perez-Villares, J., Martinez-Camarero, L., Lara, R., Monzon, J.L.,... Dominguez-Gil, B. (2019). Intensive care to facilitate organ donation: a report on the experience of 2 Spanish centers with a common protocol. *Transplantation*, 103(3), 558-564.

³⁹ Witjes, M., Kruijff, P., Haase-Kromwijk, B., van der Hoeven, J.G., Jansen, N., & Abdo, W.F. (2019). Physician experiences with communicating organ donation with the relatives: a Dutch nationwide evaluation on factors that influence consent rates. *Neurocrit Care*, 31(2), 357-364.

Needless to say, all these end-of-life discussions and decisions must happen *before* death is declared. Opponents of the consent requirement effectively preclude such end-of-life care planning because families/surrogates of "all persons with devastating brain injuries who are believed to potentially meet criteria for BD/DNC"⁴⁰ are given no right to voice their preferences in the diagnosis of BD/DNC, controlled CD/DCC, organ donation, or palliative care and WLST until BD/DNC has been diagnosed.

6. Conclusion

Whether CD/DCC or BD/DNC, how death is determined is closely linked with individualized end-of-life care plans. The diagnosis of BD/DNC should be offered as one of several critically important end-of-life options before the protocol starts, including HBD, NHBD, and limiting LST or WLST. The unconsented and unconditional diagnosis of BD/DNC, as promoted by opponents of consent, is morally unacceptable because once the preparation for the BD/DNC protocol is initiated without consent, these end-of-life options become no longer available for family/surrogate because the BD/DNC protocol and other end-of-life plans are mutually incompatible.

When a patient is approaching BD/DNC, the family/surrogate should be offered a multi-disciplinary and transparent end-of-life care conference first. With a full range of emotional, spiritual, and logistical end-of-life support during the most difficult time for families/surrogates, the medical eligibility and patient's wishes and preferences for organ donation are respectfully evaluated. If organ donation is out of the question, by choice or medical contraindication, the diagnosis of BD is optional and palliative end-of-life care should be tailored to suit each patient.

⁴⁰ Greer et al *op. cit.* note 2.

The discussion could include various degrees of limiting LSTs, replacing them with comfort measures, leading to the withdrawal of mechanical ventilation and organ support. Meanwhile, the plan can be flexibly and compassionately adjusted to the grieving process of the family/surrogate.

If a patient is a medically eligible and consenting heart-beating donor, by advance directive or by family/surrogate, the need to go through the diagnostic protocol of BD/DNC is discussed and consent should be obtained before proceeding. Alternatively, the possibility of NHBD without BD/DNC can also be discussed, whenever feasible. If the family/surrogate requests to proceed to diagnose BD/DNC while undecided on organ donation, the diagnostic protocol can be performed with a full understanding of the consequences of a positive diagnosis.

I submit that such an end-of-life care plan can achieve the two goals of the current practice of diagnosing BD—procuring transplantable organs and saving ICU resources—while upholding the fundamental moral principle of respect for autonomy and the doctrine of informed consent in end-of-life care. Actively encouraging the family/surrogate to deliberate on the preferences and values of the dying relative from early on can maximize the number of willing potential donors to convert to actual donors, while saving ICU resources by eliminating unnecessary diagnoses of BD/DNC and organ support of non-donors. This can also reduce requests for indefinite organ support after a positive diagnosis of BD/DNC and lawsuits against an unauthorized diagnosis of BD/DNC.