Intersect, Vol 18, No. 1 (2024)

Reconsidering Consent on Brain Death Examination

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Abstract

By medical definition, brain death refers to ”the irreversible loss of all functions of the brain” (Goila and Pawar, 2009, 8). Although brain death has been under US legislative approval since 1981, heightened legal disputes and criticism from bioethicists have brought renewed interest in brain death examination (Starr et al., 2024). Some individuals claim that the current protocol for conducting brain death examination has been developed incautiously, driven by an exaggeration of practical benefits without sufficient consideration of ethical implications. In light of these issues, we argue that performing brain death examination without consent is unethical. To support our assertion, we investigate the faulty application of implied consent, potential medical inaccuracies of the procedure, and the need to problematize taking epistemic authority as an absolute judgment. The danger of utilitarian bias and the dead donor rule are analyzed to refute primary rationales for conducting brain death examinations without consent. As a culmination of these findings, we proactively address how consent can be ethically obtained with respect to the affected patient and family. Ultimately, we argue that establishing a policy of consent will ensure that a patient’s autonomy and well-being are protected in an era of rapidly developing medical technology and policy.

Background

With the development of advanced technologies such as ventilators and feeding tubes, it is possible to sustain biological processes even when the brain ceases to function (Biel and Durrant, 2020, 2). During the late 20th century, this astonishing phenomenon raised several questions concerning the traditional cardiopulmonary definition of death, which requires a spontaneous cessation of lung or heart activity for a formal declaration of death (Sarbey, 2016, 743-744). In 1968, the Harvard Medical School proposed a new striking definition of death. Termed as *irreversible coma or brain death*, this standard equated an irreversible loss of brain activity with legal death (Harvard Medical School, 1968, 337). While this proposition was significantly criticized for the lack of thorough justification, the concept of recognizing the disintegration of the brain as the legal death of a human being attracted the attention of medical and legislative institutions (Sarbey, 2016, 744).

Thirteen years following the Harvard Medical School's proposal, the "total brain" criterion was presented by the US President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. This criterion "define[d] death as the death of the entire brain of a person" (Sarbey, 2016, 744). Through the Uniform Determination Death Act, this "total brain" definition was implemented in the United States's legislation (Keeley et al., 2009, 7; Sarbey 2016, 744). Most countries, with the exception of a few such as Egypt and India, now authorize brain death as legal death with explicit guidelines (Wijdicks, 2023, 20; Wahlster et al., 2015, 1878).

The primary method of brain death examination consists of a neurological exam and an apnea test. If the patient shows confounding symptoms such as poisoning or hypothermia, ancillary tests are used instead. Ancillary tests recognized by the AAN include "EEG [(electroencephalogram)], nuclear scans, transcranial Doppler (TCD) ultrasonography, and cerebral angiography" (Biel and Durrant, 2020, 3).The primary method of brain death examination consists of a neurological exam and an apnea test. If the patient shows confounding symptoms such as poisoning or hypothermia, ancillary tests are used instead. Ancillary tests recognized by the AAN include "EEG [(electroencephalogram)], nuclear scans, transcranial Doppler (TCD) ultrasonography, and cerebral angiography" (Biel and Durrant, 2020, 3).

While brain death examination has been implemented across the US, the AAN does not mandate consent for physicians to perform the examination (Lewis, 2017, 505). To maximize viable organ donations and conserve intensive care unit (ICU) resources, doctors will immediately proceed with brain death examination on a patient suspected of the condition (Muramoto, 2016, 9). Once the brain death exam yields a positive result, the patient is legally and indisputably dead. Unless the patient is an organ donor, doctors immediately remove life support (Muramoto, 2016, 2).

Several recent investigations and studies concerning brain death examination have questioned the current protocol of not requiring consent.

We argue that performing brain death examinations without consent is unethical. Physicians and medical institutions should obtain consent to examine by inquiring about a critically ill patient's preference in advance or receiving proxy consent from a legally approved delegate (e.g. a family member). The first section of the paper will address the principles of consent, explaining why the current protocol of conducting brain death examination without obtaining permission is founded on a flawed application of implied consent.

Introduction

Brain death is a complex subject rooted in biology, ethics, and policy. The choice to proceed with brain death examination is supported by the argument that brain death leads to the death of the entire body—"Somatic death closely follows the declaration of brain death. Despite all efforts to maintain the donor's circulation, irreversible cardiac arrest usually occurs within 48 to 72 hours of brain death…" (Soifer and Gelb, 1989, 815-816). However, unexpected cases of prolonged survival after brain death and recurrent discoveries of flaws in the procedure have led to the emergence of ethical concerns.

A first ethical issue underlying brain death examination is the incentive for organ donation. Since brain-dead patients sustain circulation and respiration through the aid of life support, they are optimal organ donors. These individuals are often eligible to donate organs and tissues such as the intestine, lungs, heart, cartilage, skin, and cornea (Westphal et al., 2016, 234). Given the profound organ scarcity in modern medicine, brain death examination is often endorsed by policymakers and hospital administrators to increase organ availability. However, practical benefits have overpowered ethical evaluation of the procedure, and there is a pressing need to re-examine the protocol for brain death examination.

The second, and most important, ethical issue is patient consent. In the US, current legislation does not require obtaining patient consent before conducting brain death examination. According to the American Academy of Neurology (ANN), physicians have the authority to examine brain death despite refusal from patients or their families (Balucani et al., 2024). We argue that performing brain death examination without consent is unethical. This argument will be presented through a six-part literature review: principles of consent, potential medical inaccuracies, doctor's epistemic authority, a refutation of opposing arguments, an extension of the argument to family members, and additional considerations on how consent should be obtained.

Before proceeding with the argument, two clarifications must be made. First, our argument concerns requiring *consent* for brain death examination, and the *option* to opt out of brain death examination, but does not mandate that all families *must* reject the procedure. Therefore, the benefits of conducting brain death examination including eliminating the emotional and financial burden of continuing life support are taken into account. Both the choice for and against brain death examination are respected. Secondly, a discussion of *who* provides consent (e.g. patient or family) is not a concern in our argument. Instead, we argue that consent should be obtained regardless of manner. Whether consent is acquired from the patient in the form of advanced directives, proxy consent from a family member, or any other legally authorized substitute for the patient is not discussed in this paper.

1: Principles of Consent

Requiring a patient or family's authorization before conducting brain death examination is supported by several clarifications on the principles of consent. Two forms of consent are practiced in modern medicine—*informed (or expressed)* consent and implied consent—and the current protocol of conducting brain death examination without explicitly obtaining consent is founded on the latter. Informed consent, which can be expressed verbally or in written form, involves the patient explicitly being asked for permission to perform a specific procedure or examination after being provided with adequate information. On the other hand, implied consent is when permission is not separately and explicitly requested because the physician assumes from present circumstances that the given procedure accords with the patient's desires (Kakar et al., 2014, 69; Cole, 2012, 550). This principle of implied consent is used to justify the current protocol of not acquiring the patient's permission before assessing for brain death. However, a more thorough investigation of implied consent reveals that it is an unsuitable approach to brain death examination.

In a study investigating how implied consent is understood among nurses, one nurse explained that in general, explicit consent is unnecessary because "most people come into the hospital with the expectation that certain things are going to be done (Cole, 2012, 551)." The reasoning behind implied consent is since the patient's decision to seek medical help reflects their wish to improve health, subsequent actions taken by physicians to aid in that objective do not require explicit permission. While it may be tempting to see consent as a clear-cut decision and assume that permission is only necessary in the initial stages of medical care, the truth is that consent is a blurred principle. As medical sociologists have been re-examining the nature of the patient-doctor relationship, a new concept of a dynamic relationship has been proposed. As explained by Siegler, the patient-doctor relationship "is a dynamic model and is always in flux…Patients and physicians must achieve accommodations repeatedly, even regarding the same basic conditions for which the original accommodation was concluded" (Siegler, 1981, 62). Siegler highlights that the patient's agreement to enter into a relationship with a doctor does not imply that the patient will agree with the doctor's every decision. For instance, a cardiac patient's decision to visit a physician does not imply that the patient concurs with the physician's proposal for angiography or surgery (Siegler, 1981, 63). In a truly ethical and effective relationship, consent must be repeatedly sought for each step taken within the treatment process, which also applies to the moments before a patient's brain death. Thus, to ensure ethical medical conduct for the entire duration of the patient-doctor relationship, the physician must seek consent before conducting brain death examination.

Furthermore, conducting brain death examination without the patient's explicit authorization is founded on ignorance towards the principle of risk. To decide whether or not implied consent can be applied, physicians must consider the procedure's level of risk (Balucani et al., 2024). If the risk associated with the procedure is high, the principle of implied consent does not apply, and doctors must receive explicit consent from the patient or their family. In the words of Adithya and Jamin, "high-risk medical procedures require informed consent, even though in an emergency the main priority is life saving measures" (Adithya and Jamin, 2022, 5). Several factors of brain death examination deem it a "high-risk medical procedure" that is unsuitable to conduct under implied consent. For instance, the apnea test presents the possibility of "hemodynamic or pulmonary compromise…complications include hypotension, hypoxemia, arrhythmia, barotrauma, or cardiac arrest" (Spears et al., 2022, 5). Furthermore, researchers strongly suggest that patients are accompanied by medical professionals equipped with potential medications when undergoing the apnea test due to the possibility of grave complications. Statistics show that 1.6 to 4.8% of apnea tests are terminated due to suspicion of medical hazards (Spears et al., 2022, 5). Along with the harms associated with the apnea test, various forms of ancillary testing present the possibility of serious complications. For example, because angiography (a common form of ancillary testing for brain death examination) requires contrast solution to be administered deep into the heart (Biel and Durrant et al., 2020, 5), it can result in complications such as "cerebral infarction, contrast-induced allergy, and angio-site hematoma or infection" (Nam et al., 2022, 335). Furthermore, because cerebral angiography involves inserting catheters into the blood vessels leading to the brain, it can disturb blood clots and result in thromboembolism. Catheters also present the danger of cerebral infarction because they can "damage the endothelial atherosclerotic plaque or cause dissection of the intima" (Nam et al., 2022, 337). Due to the plethora of such life-threatening complications, it is clear that brain death examination is a "high-risk medical procedure" where implied consent does not apply

While the given analysis is sufficient to justify that brain death examination is a risky procedure unfit for implied consent, this argument can be further extended by analyzing two features of brain death that make complications particularly intolerable. First of all, candidates for brain death examinations are critically ill. They are scrutinously monitored in the ICU as even minimal contamination or disturbance to the body can be devastating. If brain death examination is required for all patients, responsibility must be acquiesced for when a critical patient undergoes an invasive brain death examination and suffers the detrimental side effects, and receives a negative result. Secondly, the side effects of brain death examination are exceptionally reprehensible because the examination in itself is not necessary. According to the US Federal Policy for the Protection of Human Subjects, "...risks to subjects are reasonable in relation to anticipated benefits" (Weijer, 2000, 344). For procedures necessary to aid the patient's health, risks are acceptable. For example, doctors proceed with cardiopulmonary resuscitation (CPR) despite the possibility of the compressions breaking the patient's ribs because the procedure is needed to support the patient's cardiac viability (Van Wijck et al., 2023, 1331). On the other hand, brain death examination does not benefit the patient's health in any way—the only diagnosis that the examination can provide is a declaration of death, an ultimate decision with no possible treatment. It is not worth risking the injurious side effects of a brain death examination when it by no means contributes to the patient's well-being. Due to these particular features of brain death examination, the significance of complications is further exacerbated, evidently demonstrating that the examination is a high-risk procedure unsuitable to conduct under implied consent.

Another critical misunderstanding that has been used to justify exempting brain death examination from consent is that individuals going through the procedure are deceased and no longer have autonomy—the dead are no longer living human beings with legal rights. However, suspicion of brain death does not directly translate to a legal death. The patient is not officially declared dead until after the brain death examination has yielded a positive result. The decision on whether or not to conduct brain death testing is made before such declaration, thus the patient is still a living human being whose autonomy must be respected (Balucani et al., 2024). With this understanding, consent must be obtained before conducting brain death examination. In addition to ethical discussion on the principles of consent, an examination of the potential medical inaccuracies of brain death examination, which will be discussed in the following section, reveals that obtaining permission is necessary before conducting the examination.

2: Potential Medical Inaccuracies

The legacy of inaccuracies in brain death examination carries several implications that deem performing the procedure without obtaining consent a severely unethical act. Particularly, the ancillary tests used for brain death examination have received extensive criticism (Biel and Durrant et al., 2020, 3). While ancillary testing may not seem as significant as the primary method of examination, the accuracy of ancillary testing must still be examined as the plethora of confounding factors require doctors to opt for the ancillary procedure more often than anticipated. Common confounding factors for the primary protocol of brain death examination include severe facial injury or hormone imbalance (Biel and Durrant et al., 2020, 3). These are frequent conditions in critically ill patients, especially those who are suspected of brain death.

Various forms of ancillary testing have been proven to present serious limitations. For example, the “digital subtraction cerebral angiogram” may result in discrepancies depending on how the contrast solution was administered into the patient’s bloodstream (Biel and Durrant et al., 2020, 2). Furthermore, “brain radionuclide imaging,” another form of ancillary testing that relies on administering radioisotopes into the patients’ system, may yield different results as patients absorb radioisotopes at various speeds (Biel and Durrant et al., 2020, 5). Finally, the electroencephalogram also faces limitations as the electrodes fail to test the region below the cerebral cortex to maximum accuracy. Nearby machines in the ICU may also disrupt the measurement of the electric current, further obfuscating results (Biel and Durrant et al., 2020, 5). These evident shortcomings of ancillary testing demonstrate that precision for brain death examination cannot be ensured.

In addition to the numerous limitations of ancillary testing, the accuracy of brain death is further hindered as certain conditions are likely to be misinterpreted as brain death. For example, major intoxication is one of the most prevalent brain death imitators. While some claim that major intoxication can be ruled out through testing light reactivity in the pupils, even this function may be lost in severe cases of barbiturate poisoning (Sullivan et al., 2012, 2). A significant example of such a case is a middle-aged woman who became unconscious due to Baclofen poisoning. Doctors determined that she was brain dead and began arrangements for organ donation. However, the patient was indeed not brain dead and was narrowly saved from an inaccurate diagnosis when she began to show physical movement on the fifth day of being hospitalized (Sullivan et al., 2012, 1). This case demonstrates that false positives are a legitimate concern in brain death examinations, adding to the argument regarding the possibility of inaccurate results from the procedure.

It is an uncontested principle that decisions regarding death must be performed flawlessly in all possible cases (Balucani et al., 2024). While other medical procedures such as therapeutic surgery or treatment may have resources to restore the patient's health after a medical error, death is an ultimate diagnosis. Once brain death has been declared and life support is removed, the patient has no prospect of survival. The absolute nature of brain death examination implies that inaccuracies should be taken with utmost sensitivity. It is ethically intolerable that an examination with such a conspicuous reputation of unreliability is mandated on all suspected patients.

3: Doctor's Epistemic Authority

Those who support conducting brain death examinations without obtaining consent emphasize a doctor's epistemic authority—the authority that a doctor possesses due to their prevailing medical expertise and scholarship (Applbaum, 2017, 209). These researchers claim that doctors decide to conduct brain death examinations under the discernment developed by years of professional training, thus their expertise must be trusted. While epistemic authority is not to be neglected, using this principle to justify conducting brain death examination without consent is questionable. This is due to evidence of many physicians' incompetence in performing brain death examinations and the inflated emphasis on the clinical definition of health, which will be discussed below.

To begin with, several sources draw light on medical professionals' lack of ability to accurately perform brain death examinations. According to a study by Braksick et al. in which 68 physicians were tested on their competence of the AAN brain death determination protocol, only 25% obtained a sufficient score. 10.3% of respondents failed to include the apnea test, one of the most fundamental components of the procedure (Braksick et al., 2019, 888). Additionally, the case of Jahi McMath—a teenage girl who continued to receive life support for five years after her family's tenacious resolution to reject the brain death diagnosis—clearly illustrates that brain death examination remains an ambiguous practice among medical professionals (Shewmon and Salamon, 2021, 457). Neurologist Dr. Alan Shewmon supported the family's rejection of the positive brain death diagnosis as an angiogram and EEG scanning showed both circulation and electrical viability in the brain. On the other hand, neurologist Dr. Paul Fisher claimed that McMath's positive brain death diagnosis was accurate according to his clinical examination of her brain (Lewis and Greer, 2017, 507). The prevalent disagreement among medical professionals demonstrates that competency and standardization of the brain death examination procedure have not been sufficiently established.

Although supporters of the current protocol of brain death examination argue that the procedure has "perfect diagnostic accuracy," this is only true because of the impossibility of corroboration in the procedure. While cardiopulmonary death is accompanied by tangible data such as the flatlining of an electrocardiogram or a sharply declining heart rate, brain death does not come with such confirmatory evidence. Since the patient is immediately declared a corpse once the brain death examination returns to be positive, there is no opportunity to corroborate the accuracy of the procedure—there are no "objective laboratory tests, independent retrospective case review, or pathological investigation[s]" (Muramoto, 2016, 7). If there is no chance to question the validity of the procedure, it is only possible that errors will not be found (Muramoto, 2016, 7). Even the statistics from Braksick et al. which have been used to demonstrate physicians' incapability to perform brain death examination relied on inquiring the physicians themselves on how they performed the procedure, not on independent investigations (Braksick et al., 2019, 889). Therefore, the "perfect diagnostic accuracy" does not mean that there have been no mistakes in brain death examinations, it simply means that there have been no discovered mistakes due to the impossibility of verification.

Although physicians have been at times unreliable in their performance of brain death examination, patients place heavy trust in them and do not actively consider possible flaws in the physician's competency when making decisions concerning their treatment. When investigating consent for individuals in medical trials, Corrigan noted that "subjects' explicit or implicit trust in expert systems prevail, and there is very little evidence of a conscious challenge to expert opinion…" (Corrigan, 2003, 781). In the words of the patients in Corrigan's study, one was "sure [that doctors] are not going to give me anything that will do me any lasting damage" and "thought it has got to be pretty safe for them to be allowed to do it" (Corrigan, 2003, 779). While trust in professionals is necessary for effective medical practice, doctors must be aware that patients may have faulty understandings of their true proficiency. Although patients may be confident in the reliability of the procedure, the reality is that there is a possibility of error. It is unethical for doctors to perform, let alone *require*, brain death examination while being aware of the patient's misunderstanding of the doctor's medical competency. Thus, it is necessary that physicians not only ask for consent to perform brain death examinations but also fully inform patients of the possible errors in the procedure.

As outlined, there is a plethora of evidence to demonstrate that not all physicians are capable of performing brain death examination accurately, thus it is unethical to enforce the procedure on unwilling patients. However, even if one assumes that all physicians can perform brain death examination with perfect accuracy, this does not mean that the physician's decision to conduct brain death examination must always be followed. A doctor's epistemic authority lies on the assumption that the clinically right decision—that is, the decision that would be considered right when interpreted by the criteria of modern science and medicine—is the ultimately right decision to make. However, modern bioethicists have heavily questioned this assumption. This challenge to epistemic authority is well explained when Siegler presents the hypothetical case of a ballet dancer being dissatisfied with a new doctor who flawlessly manages her asthma. The dancer wished to return to her old doctor who, despite not being able to achieve complete mastery over her condition, did not use steroid medications that negatively impacted her muscular agility and ability to perform (Siegler, 1981, 58-59). While the clinically right decision would be to perfectly eliminate the condition, this example illustrates that this may not be the correct goal—in this case, the best answer would be to provide a version of health that satisfies the patient.

Siegler's argument which challenges the doctor's absolute clinical authority can be supported by analysis from Blaxter's book, *Health*, where she questions the assumption that health is limited to one clinical definition. According to Blaxter, health is defined differently for everyone: some may define it as the optimal functioning of the body, the absence of disease, or even as divergence (e.g. being fitter than the average adult) (Blaxter, 2010, 4-8). While it is important to consider universal medical standards, the current perception overemphasizes the clinical definition of health, and the patient's perspective is overlooked. As the perception of health may vary according to each patient's values, doctors must try to accommodate each patient and the version of health they desire to have or maintain, striving to equally consider the clinical perception and the patient's perspective. For example, a patient who defines health as the optimal functioning of the body would consent to brain death examination as they would see no purpose in having a body incapable of performing any biological processes. On the other hand, a patient who defines health as survival would reject brain death examination since their goal would be to remain alive for as long as possible, no matter how poor their cognitive and physical state is. Due to the need to consider these various perspectives, epistemic authority should not be the ultimate answer for medical decisions. In the case of a brain death examination, the patient's perception of health can only be respected when doctors allow other actors to take part in the decision-making process, following the patient or family's choice to refuse the examination.

4: Refutation (Organ Donation & ICU Turnover)

While there are several arguments to support requiring consent for brain death examination, the rationale from the opposing side is also important to address. The following section will provide a refutation of the two primary arguments for exempting brain death examination from consent: maximizing organ supply and increasing ICU turnover. To begin with, the severity of the organ scarcity crisis is dominantly used to justify conducting brain death examinations without the patient's permission. In 2021, there were 27,000 deaths from being unable to receive a donation (Spuentrup, 2023, 2), and as of March 2024, more than 103,000 patients needed organ donations in the US alone (U.S. Department of Health & Human Services, 2024). If brain death examination is conducted for all suspected patients without consent, more patients will be declared legally dead before cardio-respiratory death, and thus availability for organ donations will increase (Clarke, 2016, 2053). From the perspective of public health officials or medical institutions that favor utilitarianism—a maximal benefit for the greatest quantity of people—this is a highly appealing choice.

Although the severity of the organ scarcity crisis should not be neglected, two points of refutation—the danger of utilitarian bias and the dead donor rule—demonstrate that enforcing brain death examinations is not the correct way to address this crisis. To begin with, the decision to require brain death examination to maximize organ donations comes from a contextually developed utilitarian partiality. In other words, most brain death decisions are made in the ICU, where the dominant ethos of healthcare providers is "rooted in the belief that [the purpose of] ICU treatment is to eliminate the immediate threat to life" (Siewiera et al., 2014, 56). While the principle of saving lives may seem suitable for the ICU, one must be aware that this principle is applied not by only keeping a single patient in mind, but by attempting to balance the needs of all the patients in the ICU. To the medical professional, the objective of saving lives is not exclusively applied to one patient but is rather viewed from the holistic perspective of aiding all the patients housed in the unit. This situation is well illustrated by Corrigan, who quotes a surgeon from his study on informed consent: "...all patients like to feel that you have got their best interests, their personal best interests at heart, which you have. But…I am actually looking at a broader picture, as well, of which they are only part of that picture…." (Corrigan, 2003, 781). This dominant utilitarian mindset in medical institutions to save the lives of many, compounded with the benefit that brain death examination holds to organ donation, makes physicians and public health officials more likely to favor declaring the death of one patient to save the lives of multiple. This partiality presents even graver implications when physicians are authorized to conduct brain death examinations without obtaining the patient's consent. For example, when brain death examination is allowed without consent, doctors are incentivized to conduct brain death examinations even when brain death is slightly suspected as a quicker declaration of death allows higher viability and quality of organ donations. This presents a high possibility of performing invasive brain death examinations on patients who are not actually brain dead, or even worse, drawing hasty conclusions and declaring false deaths. This warning against overemphasizing utility is well expressed by Fins: "Although the definition of brain death serves great instrumental value, we should be careful not to be blinded by its utility in 'cadaveric' organ donation or decisions to withdraw life-sustaining therapy" (Fins, 1995, 36). Thus, doctors and public health officials must be wary of this unconscious emphasis they place on saving lives and maximizing organ utility, and the current protocol of conducting brain death examination without obtaining the patient's permission must be reconsidered.

Secondly, mandating brain death examination is an unsuitable solution for the organ scarcity crisis according to the dead donor rule, the universal principle on organ donation which states that "organ procurement itself must not cause the death of the donor" (Organ Procurement & Transplantation Network, 2016, 9). Death should lead to organ donation, not the other way around. While the dead donor rule prevents doctors from deliberately perpetrating the death of a patient to obtain their organs, the same proposition can be applied to the current protocol of conducting brain death examinations without obtaining the patient's consent. Enforcing brain death examination on unwilling patients for the sole purpose of procuring organs implies organ donation leading to death—the immoral sequence prohibited by the dead donor rule. The immorality of this system is exacerbated by the consistent history of unreliability in brain death examination: endangering a patient with an inaccurate diagnosis of death to procure their organs is unacceptable. To prevent this deeply unethical act, patients who disagree with brain death examination must be given the choice to refuse.

In addition to the need for organ donations, another argument for exempting brain death examination from consent concerns the resources of the ICU. If brain-dead patients can immediately be declared legally dead, valuable medical resources such as ICU beds, ventilators, and medical equipment can be saved for patients who have a more hopeful prognosis (Muramoto, 2016, 10). Those who endorse this position argue that hospitals should not be misusing precious medical resources on those who are deceased—"hospitals are facilities for the living" (Lewis and Greer, 2017, 506). However, as with the argument for organ donation, conducting brain death examination without obtaining the patient's consent is a flawed solution to conserve medical resources. As outlined in the introduction, if a patient is truly brain-dead, they will soon die by cardiac death. According to the US President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, "even with extraordinary medical care, [brain dead patients] cannot be sustained indefinitely…typically, no longer than several days"

(Muramoto, 2016, 5). Ultimately, the choice to reject a brain death examination will only delay the declaration of death by a couple of days. If brain death examinations are being conducted for the sole purpose of slightly increasing ICU turnover at the cost of threatening the morals and emotional well-being of countless families, it is unnecessary. While the value of ICU equipment and concerns regarding medical scarcity should not be ignored, it is clear that the cost-benefit balance of conducting brain death examinations without obtaining the patient's consent should be re-evaluated.

5: Familial Implications of Brain Death Examination

It is a frequent circumstance in which patients are not conscious, preventing them from declaring their consent for brain death examination. This requires the involvement of a substitute, such as a family member, to express permission in lieu of the patient. As outlined in the introduction, this paper does not favor a certain party providing consent for brain death examination. The following analysis regarding family is not presented to argue that family members should be given the authority to decide on brain death examination. Rather, familial implications are analyzed to support the main argument that obtaining consent must be required for brain death examination by extending the benefits of doing so to more actors. Through the analysis of familial well-being, narrative identity, and religious customs, the following section will elaborate on why exempting brain death examination from consent is a deeply unethical act.

To begin with, the examination of brain death without consent fails to consider familial well-being, violating the principle of "patient- and family-centered medical care" (Muramoto, 2016, 2). When confronted with troubling circumstances such as critical illness in a loved one, family members experience significant mental and emotional turmoil. These emotional complications include depression from overwhelming grief, guilt due to not being able to restore the health of their loved one, and even psychosomatic complications that can result from psychological affliction. Distress from conflict among family members is also a prominent possibility as individuals may have various opinions on sensitive end-of-life decisions (Akdeniz et al., 2021, 1). Before declaring death, physicians follow "patient- and family-centered medical care" to help families cope with these complex emotions (Muramoto, 2016, 2). However, familial care is no longer possible once the brain death examination is conducted and yields a positive result. The patient is officially declared dead, therefore regulations requiring the consideration of their well-being and that of their family members no longer apply (Muramoto, 2016, 2). If brain death examination is immediately conducted on suspected patients without obtaining consent, families are left with severe emotional distress and no proper system of support. While some may argue that complex emotions regarding a family member's death are not exclusive to end-of-life circumstances but rather begin at the onset of critical illness, research shows that many families fail to confront the potential loss of their loved one until the moment arrives: "It is so, that partly, relatives have not yet confronted themselves with the situation, that has been known for a long time (Laryionava et al., 2018, 4)." Researchers have termed family members as "second patients" due to the immense importance of ensuring their well-being in end-of-life care. In the words of a nurse interviewed for a study on end-of-life decisions for cancer patients, "...it is important to take care of relatives just like patients, like a sick person" (Laryionava et al., 2018, 4). With this significant emphasis that has been placed on aiding the well-being of the family, consent must be obtained before performing brain death examinations to ensure provision for the family's emotional and psychological needs.

Furthermore, the exemption of brain death examination from consent fails to consider the implications of a patient's death on the family's narrative identity. Contemporary research demonstrates that death should not only be seen as a biological event but also as a social and psychological event. Philosopher Dr. Tomasini defines social death as "a relational or narrative change that happens as a consequence [of the biological death]" (Tomasini, 2017, 13). The "narrative" identity discussed here is defined as an individual's story of their own self constructed by combining a reinterpretation of previous memories and a visualization of their perceived future (McAdams and McLean, 2013, 233). This narrative identity is deeply related to how an individual perceives themselves, and what they believe is most crucial to expressing their identity (DeGrazia, 2012, 8). From a purely biological perspective, death only affects the deceased patient. Conversely, from the perspective of social death and narrative identity, the effect of death extends beyond the deceased individual. For example, the death of a husband impacts the relational identity of his wife as she becomes a widow (Tomasini, 2017, 14). This relational alteration requires a significant adaptation in the wife's narrative identity: in the absence of a husband who likely has significantly impacted and characterized the past decades of her life, his death implies a need to reconstruct how she perceives herself. Family members should be given sufficient time to process this time in their lives that is burdened with not only grief but also a need to redefine their own identity. However, the current protocol mandates a brain death examination which is “often performed as soon as it is suspected” under the motivation to maximize viable organ donations and conserve ICU resources (Muramoto, 2016, 5). Such a rushed procedure forces a death onto a family without providing them with adequate time to process and adjust to new changes. With this understanding of social death and narrative identity, consent should be an integral part of the brain death examination procedure.

Furthermore, conducting brain death examinations without consent violates the principle of respect for religious customs. This issue is clearly illustrated by the case of Yechezkel Nazar, an elderly man who was announced dead after a brain death examination was conducted while his family was away for a Jewish holy day (Biel and Durrant, 2020, 7). After their return, the family filed a lawsuit against the hospital for examination without their consent. The family claimed that they needed counseling from a rabbi concerning the death, however, they had been unable to contact the rabbi due to the Jewish holiday (Sarah Nakar v. New York, 2019, 3). Accepting and comprehending the death of a loved one is a complex process, often requiring consultation with outside sources such as pastors and therapists. In addition to the need for theological counseling, many religions stipulate various decisions that must be made and ceremonies that must be held before death. For example, Hinduism states that it is favorable to donate the patient’s possessions to charity or religious institutions before death. Christians may want to be anointed by a minister, and in Judaism, it is desirable to pray the Shema (the confirmation of faith) before the moment of death (St Nicholas Hospice Care, 2020, 4-9). For a medical professional to conduct a brain death examination without consent is a severe violation of religious respect, neglecting to consider preparations that a family must make before sending off a loved one in a way that holds to their religious beliefs.

Against the above arguments that families must be given sufficient time to manage emotional well-being, changes in narrative identity, and religious customs, some may question why these considerations are exclusive to brain death. Death is usually an unexpected and sudden event where it is impossible to account for all of these factors. For example, an individual can die in hours due to unexpected deterioration of a critical disease, or even in a matter of seconds if they experience a heart attack or are in a fatal accident. While this is true, it is important to delineate brain death examination from such inevitable cases of death. The rationale for brain death examination is that because the brain is the central organ that regulates and initiates all biological functions, death of the brain will inevitably lead to the death of the patient as they will not be able to sustain essential somatic processes (President's Commission, 1981, 5). Brain death does not mean immediate death, but rather is a standard created to *quicken* the declaration of death by equating a *precursory condition* of death to the legal death itself. Although we must accept that a family may never have *perfectly* enough time to prepare, this does not mean that physicians should not give their best efforts to provide adequate time. Thus, a physician must not enforce a brain death examination to quicken the declaration of death on families who do not desire it, but should rather respect families who oppose the examination by adopting a model of consent.

6: Additional Considerations

While the preceding sections have established that consent must be required for brain death examination, it is also necessary to delineate how this consent must be obtained. Informed consent requires that patients not only be given sufficient information about the proposed medical intervention but also be capable of comprehending that information to make a legitimately autonomous choice (Shah et al., 2023). For example, even if a child or mentally incompetent individual is given information about a medical intervention, physicians would not acknowledge their consent because they are incapable of *understanding* the information.

Despite the need for a thorough understanding of the procedure, brain death is an exceedingly difficult concept for patients and families to comprehend as the event is virtually intangible to the layperson (Muramoto, 2016, 8). While cardio-respiratory death is usually accompanied by distinct signs such as the ceasing of the heartbeat or a violent convulsion, brain death does not come with any of these physical signs. The preceding step of brain death, severe brain injury, looks almost identical to brain death itself—the patient is unconscious, while life support is still running (Goila and Pawar, 2009, 7). This intangibility of brain death makes it a significantly challenging concept for families to accept. This perplexity of brain death is also demonstrated by the case of Jahi McMath outlined earlier. McMath's exceptional situation led the public to question the legitimacy of brain death. In the words of Muramoto, "...the public continue[d] to wonder: If the machine can support her for more than 2 years in this condition, how is this condition the same as the traditional death, which no machine can even stop?" (Muramoto, 2016, 6). The stark contrast between McMath's state if her family would have accepted brain death (McMath being legally and physically dead) and McMath's state after her family's resolution to continue life support (McMath being ventilated in her bed, her heart still beating and her lungs still breathing) was a clear conundrum to many

In addition to the prevalent confusion surrounding brain death examination, the risk of allowing the procedure with insufficient understanding is particularly severe due to its unquestionable and irreversible nature. As explained previously, "a positive [brain death] result entails an immediate and incontestable legal death…almost no recourse is left to the family to reverse this determination" (Muramoto, 2016, 8). Once the brain death examination begins, the family no longer has an option to turn back. For families who may be unsure of their understanding and conviction in brain death examination, this irrevocable nature of the procedure makes it a serious concern.

With these considerations, medical professionals must provide sufficient explanation on brain death examination and confirm a family's understanding of the information before obtaining consent. This process will involve the physician providing a thorough justification of why brain death constitutes a legitimate death, a detailed description of the protocol that will follow a positive result, and absolute transparency of the potential inaccuracies and risks of the examination. Once this information has been delivered, the physician must test the patient's understanding. This should not be a simple question of "Do you understand?" as some patients may fear humiliation or shame from admitting their inability to comprehend the information. Rather, the "teach-back" method in which physicians ask patients to "put the information in their own words" is more effective for confirming a patient's comprehension and has been supported by organizations such as the National Quality Forum (Graham and Brookey, 2008, 68). By following such protocol, doctors can ensure that the consent they have obtained accurately represents the patient's true desires.

Conclusion

The current system of conducting brain death examination without a patient's permission is founded on a faulty understanding of consent, neglect of medical inaccuracies, and disproportionate emphasis on the doctor's epistemic authority. An analysis of the utilitarian bias and dead donor rule also demonstrates that exempting the examination from consent is not an appropriate solution to addressing organ donation scarcity. To ensure ethical implementation of the brain death examination, patients must be given their long-due right to consent. Considering this argument, suggestions for future research include addressing cases of negative brain death examination results and investigating explanations of the examination that can be better comprehended by families. Furthermore, analyzing the actors most suitable for providing consent on behalf of brain-dead patients in the absence of advanced directives would significantly contribute to this discussion. With these steps, the ethical treatment of patients can be preserved amidst the modern evolution of medical practice.

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