



Consent for Conducting Evaluations to Determine Death by Neurologic Criteria: a Legally Permissible and Ethically Required Approach to Addressing Current Controversies

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Abstract

Ethical and legal questions persist in the bioethics and clinical communities surrounding the determination of death by neurologic criteria (DNC). Among challenges to the determination of DNC are questions about the physician's role in the process. Once the exam is performed, if the patient meets criteria, the patient-physician relationship terminates. Whether informed consent is required to perform the exam, however, is a subject of ongoing controversy. Recent court cases also consider whether informed consent should occur prior to the determination of DNC. Those who argue against consent suggest that physicians have an obligation to determine death and the examination for DNC is required to make this determination. Those who support obtaining informed consent prior to the examination argue that informed consent is required prior to any examination, treatment, or test, following principles of biomedical ethics. This paper reflects on the existing debate about whether consent is necessary, ultimately concluding that is legally permissible and ethically required.

Keywords Brain death · Death by neurologic criteria · Informed consent · Apnea test · Organ donation · Public trust

Introduction

Half a century following development of criteria to determine death by neurologic criteria (DNC) [1•], ethical and legal questions persist in the clinical and bioethics communities surrounding the concept of DNC. Recent court cases raise the question of the role of informed consent in making a determination of DNC [2•, 3•]. This question is rooted in (1) complexities of the criteria for determining DNC, (2) concerns over the potentially chilling effects on organ donation of limiting DNC, (3) worries about allocation of scarce resources given hypothetical resource utilization by patients who meet

DNC, and (4) fundamental questions about the role and obligations of clinicians in determining death, being stewards of health care resources, and maintaining the integrity of the patient-physician relationship. Situating the discussion in these contextual considerations, this paper reflects on an existing debate about whether consent is unnecessary or required to determine DNC. Ultimately, it concludes that consent is legally permissible and ethically required, offers additional justifications for obtaining consent, and calls for further inquiry to understand how to implement a consent process in a way that balances fundamental patient interests with important social interests.

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The Evolution of the DNC Determination and Its Controversies

Historical Context of the Development of Determination of DNC

Medical advances in the mid-twentieth century such as mechanical ventilation and defibrillation made it possible to indefinitely sustain the lives of individuals who would

otherwise die or never regain consciousness. The medical community struggled with how to conceptualize the status of patients who had limited interaction with the environment but whose essential functions were maintained only through life-sustaining technologies. Concurrently, the medical community realized the potential for successful organ donation with the first kidney transplant in 1954 and the first heart transplant in 1967 [4, 5]. To move forward successfully and ethically with organ transplantation would require conditions consistent with the dead donor rule—the emerging ethical concept that an individual ought to be dead prior to the removal of organs such that organ removal did not *cause* death—and that would permit continued perfusion of organs prior to their removal to increase the likelihood of successful transplant [6, 7, 8•, 9•].

In this context, the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death convened and published their landmark report in 1968 [10••]. They generated a novel definition of death by neurologic criteria. Patients in an irreversible coma with “no discernable central nervous system activity,” including reflexes, spontaneous ventilation, and EEG activity could be diagnosed as brain dead. The Committee justified this new definition by noting that, “The burden is great on patients who suffer permanent loss of intellect, on their families, on the hospitals, and on those in need of hospital beds already occupied by these comatose patients.” Additionally, they stated that, “Obsolete criteria for the definition of death can lead to controversy in obtaining organs for transplantation” [10••]. Notably, both motivations offered by the Committee—responsible resource utilization and ethically acceptable conditions for organ donation—were to achieve socially valuable goods, rather than providing scientific or patient-centered reasons for the new definition of death [11•].

Efforts to reach consensus on DNC from a legal perspective resulted in the 1980 Uniform Determination of Death Act (UDDA) [12]. The UDDA states, “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.” The UDDA made available a legal framework for determination of DNC that was ultimately enacted by all 50 states in some manner, whether through statutes or court cases. While the majority of states adopted the UDDA in its entirety, others adopted variations. Three states require reasonable accommodation of patient beliefs, and New Jersey permits religious objection to DNC [13•]. Differences in state legislation may represent differences in acceptance of DNC as death, reflecting any number of the current challenges to DNC.

Controversies Over the Determination of DNC Under the UDDA

Following the development of DNC, several ongoing ethical and legal dilemmas persist [14•]. These include concerns over the adequacy of the definition’s “bright line” requirement for complete cessation of all brain functions and ambiguity about whether diagnostic evaluations meet these criteria, questions about whether neuroendocrine dysfunction ought to be required to determine DNC, arguments about whether DNC is a social or biologic construct, potentially not accepted by certain minority groups who have equal moral relevance to majority groups, and possible confusion or objection to the notion that DNC may be useful as a legal fiction to permit pursuit of other socially valuable goals but is not really death [14, 15•, 16•, 17•, 18•]. Ross and Veatch have argued that one solution to the ambiguity is to permit families to choose what definition of death aligns with their own beliefs and values [19•, 20•].

Professional guidelines also reflect the challenges of determining DNC. The American Academy of Neurology 2010 adult guidelines comment that although there are no reports of recovery following a determination of DNC, complexities remain in determining the safest techniques for apnea testing. These guidelines also acknowledge that there is insufficient evidence about the utility of newer ancillary testing to confirm DNC [21]. Despite widespread acceptance of DNC, in 2011, the Society for Critical Care Medicine Section on Neurology, American Academy of Pediatrics, and Child Neurology Society updated their guidelines on pediatric DNC to in order to diminish widespread variation in the determination of DNC in pediatrics [22]. These professional societies also highlight the importance of physicians in providing support and guidance to the family.

Contextualizing the Physician’s Role in DNC Determinations

Amidst challenges to the determination of DNC are underlying questions about the physician’s role and obligation in performing the exam. While the UDDA provides circulatory and neurologic criteria by which a physician *can* diagnose death, it does not mandate the determination of death by either criterion. Physicians must also balance a fiduciary duty to promote the best interests of their patients with their roles as stewards over medical resources. Once a patient is determined to be dead, fiduciary responsibilities toward the patient end. Yet, whether informed consent is required to perform the exam that ultimately terminates the patient-physician fiduciary relationship is a subject of ongoing controversy.

Considering Informed Consent as a Response to Existing Controversies

Historical Context of Informed Consent in the Medical Profession

The concept of informed consent has its early origins in common law cases under a framework of assault and battery, recognizing that examination of the body alone requires consent, even if no intervention occurs. See Fig. 1 for a timeline from these early cases to the current issues. In one of the first cases, a court considered whether a woman who claimed a work-related injury could be required to undergo a surgical examination requested for diagnostic purposes by the surgeon without consent in order to determine the extent of injury. The court held that “No right is held more sacred or is more carefully guarded by the common law than the right of every individual to the possession and control of his own person, free from all restraint or interference of others unless by clear and unquestionable authority of law,” citing Judge Cooley who wrote, “The right to one’s person may be said to be a right of complete immunity; to be let alone” [23]. *Mohr v. Williams* established the need for consent for *any* contact between a physician and patient, holding that “every person has a right to complete immunity of his person from physical interference of others, except in so far as contact may be necessary under the general doctrine of privilege; and any unauthorized touching of the person of another...constitutes an assault and battery” [24]. The sentiment was echoed in the contemporaneous landmark case *Schloendorff v. Society of New York Hospital*, with that court holding that “every human being of adult years and sound mind has a right to determine what shall be done with his own body” [25]. Following these cases’ grounding consent in respect for the body, the term “informed consent” first appeared in a 1957 case broadening the concept to include considerations of appropriate disclosure [26]. The American Medical Association’s Code of Medical Ethics guidance on informed consent highlights that informed consent is required for diagnostic procedures as well [27].

Informed Consent for the DNC Evaluation

Whether consent is required for the DNC exam or its component parts is a matter of current legal and ethical debate. Some argue that physicians have a duty to declare death when present and that consent is not required to make this determination [28•]. Others maintain that DNC evaluation—and apnea testing in particular—is a diagnostic procedure, requiring informed consent [29•]. A series of court cases have led to different conclusions about the need for consent [1•].

Prior to reviewing existing cases and arguments regarding consent, a brief discussion of the apnea test is warranted, as this component of the DNC evaluation generates the most

controversy over the potential need for consent due to risks associated with its performance. The apnea test may be performed with a few variations, all of which require that a number of physiological parameters be met. Induction of hypercapnia is, by definition, required in apnea testing. This physiologic derangement may have implications for a patient with brain injury. Goudreau et al. report that approximately 25% of apnea tests were associated with cardiovascular events—most commonly hypotension—with an increase in events when patients did not strictly meet prerequisite criteria [30]. Other studies have reported complications in up to two-thirds of patients, including hypotension, acidosis, hypoxemia, and even barotrauma and pneumothorax [31–33]. Recent studies counter that the apnea test remains safe if performed according to guidelines, though controversy endures [34, 35].

One might argue that the risks of the evaluation for DNC are not clinically significant in a patient with such severe injury that DNC is likely. However, they are conceptually important in considering whether consent ought to be required. Acidosis, hypoxemia, or a drop in cerebral perfusion pressure may at least theoretically worsen an injured brain in a patient who is not yet brain dead. Further, the possibility that these risks associated with the evaluation may actually contribute to the state for which the exam evaluates makes the evaluation for DNC conceptually distinct from the evaluation for death by circulatory criteria. This distinction is relevant to previously articulated arguments against consent.

Cases Concerning Consent for DNC

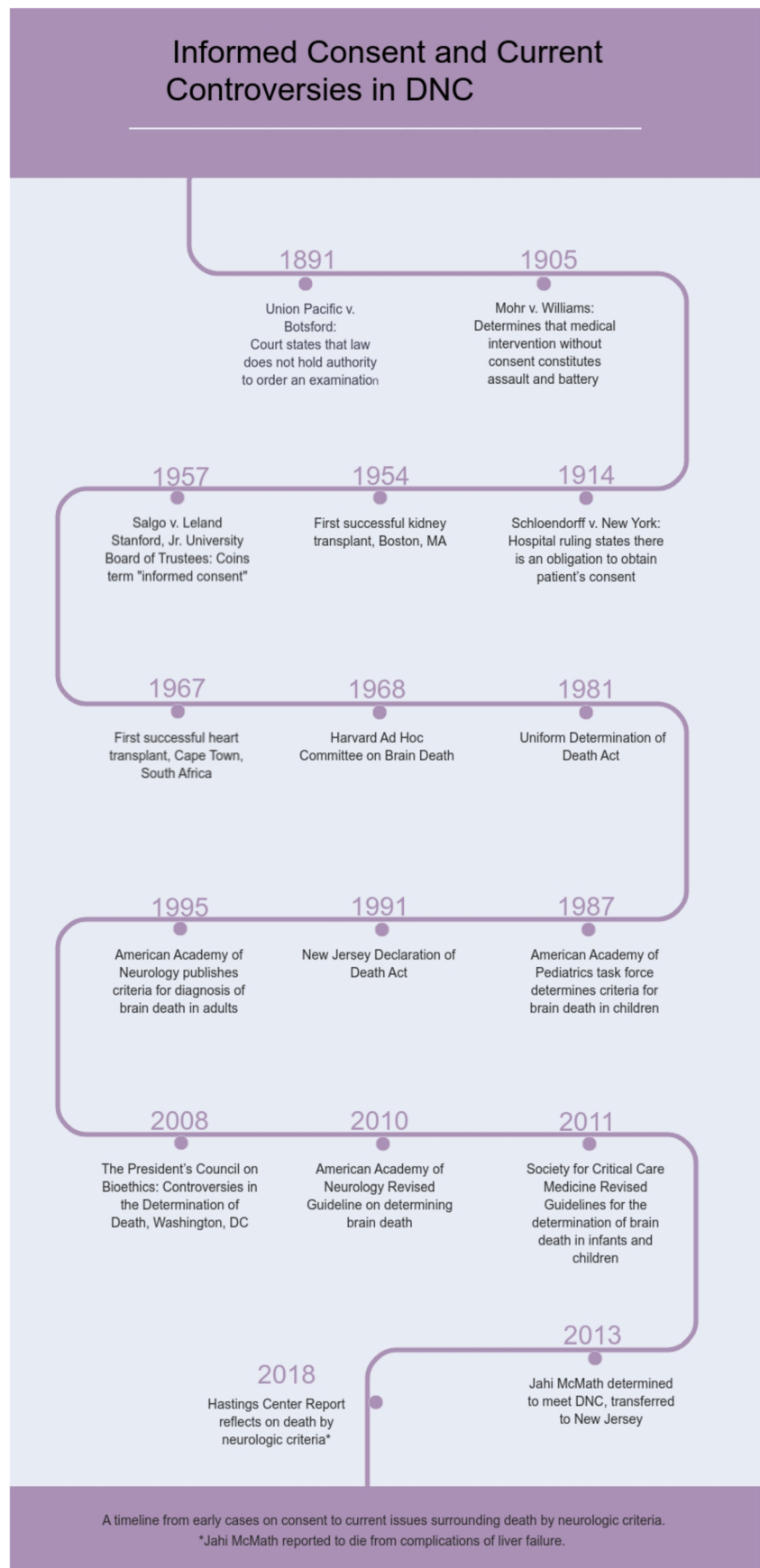
Three cases have come before courts whose holdings suggest a need for consent for the DNC evaluation.

In the 2006 *Shively v. Wesley Medical Center* case, a Kansas court declined a hospital request to perform a DNC evaluation over the family’s objection, finding no basis for such an order in a case involving a 2-year-old near-drowning victim whose clinical exam progressed to being consistent with DNC [36].

In 2016, a Montana court more directly addressed the issue in *In the Matter of the Guardianship of A.C.* when a 6-year-old drowning victim had clinical symptoms of herniation and the family consented to the first exam but refused the second [37]. The mother reported that the words “brain death” were not used, invalidating the first consent. The court held that the state’s UDDA did not mandate that providers conduct an exam and that the apnea examination is a medical procedure, preserving the individual’s right to choose or refuse.

In the same year, California considered a case of a high school near drowning victim in *Pierce v. Loma Linda*. A family raised concerns about the apnea test causing harm and refused the exam, requested an external independent neurologic evaluation, and continued management until an evaluation was performed. The court issued a temporary restraining

Fig. 1 Informed consent and current controversies in DNC



order granting their request [38]. In each case, the court would not allow evaluation for DNC in the setting of the family refusing consent for evaluation, setting precedent requiring consent in these jurisdictions.

Two courts have denied family refusals of DNC determinations that raise the question of consent without directly addressing it.

In 2006, another Kansas court heard *In the Interest of Minor Michael J Todd v University of Kansas Medical Center*, the case of a 14-year-old who sustained an accidental gunshot injury and underwent an evaluation for DNC confirmed by an intensivist, neurologist, and neurosurgeon [39–41]. The family raised concerns about hospital motivations related to organ donation [41]. They requested a temporary restraining order for an independent evaluation, stating that the exam was done incorrectly, which the court granted and subsequently reversed after the examination was performed. Because the order was not reversed until after the family request was met, it is unclear whether this case supports or refutes the need for consent.

A 2011 Georgia case *Hawkins v. DeKalb* involved a pregnant 18-year-old woman who sustained head trauma and spent months with a clinical exam consistent with DNC until after delivery when two clinical exams confirmed DNC and the hospital discontinued life-sustaining therapies [42]. The mother sued the hospital on multiple theories, including breach of contract and wrongful death. She claimed that although she signed a general treatment consent permitting the hospital to perform necessary examinations, the consent also stated she had control over advanced directives and they did not obtain consent to remove life-sustaining therapies. She also claimed that she did not provide consent for brain death evaluation. The court stated that failure to provide consent for either of these did not *cause* death and therefore denied her claim because the lack of consent could not be used to justify the type of claim upon which she requested recovery. The court acknowledged that “an evidentiary dispute may have arisen as to the issue of consent” but that based on the theory she requested recovery was inapplicable and not addressed.

A 2016 Virginia court, hearing *Lawson v. VCU*, expressly denied refusal of a DNC evaluation, suggesting that family consent to evaluation is not required. When a 2-year-old with anoxic injury secondary to choking developed clinical signs of DNC, the family raised concerns about the apnea test and requested transfer but an accepting facility could not be found. The family refused DNC evaluation on religious grounds but the court subsequently issued an order to perform the exam [43–47].

In a current case in Illinois, *Cassaro v. Friedman*, the court will consider a case of anoxic injury secondary to a suspected accidental drug overdose. Two DNC evaluations were consistent with DNC within the first 20 h of presentation. The patient reportedly desired organ donation, authorized by his father, who was present while the mother was returning from out of

state, but reports being available [48]. The mother claims the father should not have been the sole decision maker and consent was not obtained for performing the DNC evaluation. The case is pending.

Table 1 catalogs existing cases. Cases generally involved otherwise healthy pediatric patients who experienced unexpected injury. Several parents raised specific concerns about risks of apnea testing. The presence of some EEG activity, even when subsequent EEGs showed no activity, was troublesome. Two cases included concerns about organ donation.

Legislation/Guidance Addressing Consent

Two states provide legislative or administrative guidance that negate the need for consent. Nevada legislation specifically requires determination be made in accordance with guidance provided by the American Academy of Neurology. Consent is not required and life-sustaining therapy must be removed within 24 h of determination of DNC, with exceptions for pregnant individuals or organ donors [49]. New York guidelines state that consent need not be obtained but requests based on religious or moral objections for reasonable accommodations should be referred to staff, and if objections are made to invasive ancillary tests, the medical team should consult counsel and ethics committees [50].

Arguments for and Against Consent

Argument That Consent Is Unnecessary

Greer and Lewis argue that consent is not required for DNC evaluations [28••, 51••]. They maintain that physicians have an obligation to determine death and conducting an evaluation is required to make this determination. They suggest that risks associated with the apnea test do not mandate consent because the exam does not pose material risk to the patient, and reasonable physicians do not need to obtain consent when there is no material risk. While they concede that there are risks to the apnea test, they note that studies suggest these can be mitigated with guideline adherence. They also acknowledge a theoretical risk of harm from rise in PaCO₂ but contend that the risk is not clinically meaningful because of the severity of the patient’s injury prior to DNC evaluation. They add that less than 10% of individuals will breathe during the apnea test when the remainder of the DNC evaluation is consistent with DNC [51••]. Furthermore, they assert that the patient’s surrogate should not be permitted to choose whether or not the exam should occur because “it is unethical to allow a negotiated standard for death and to treat patients who may be dead by neurologic criteria differently than by cardiopulmonary criteria” [28••]. Because consent is not required to determine death by cardiopulmonary criteria, they argue that it should not be required to determine DNC.

Table 1 Court cases considering consent for determination of DNC

Court case	State (year)	Is consent required?	Case description
Shively v. Wesley Medical Center	KS (2006)	Yes	<i>Case description from hospital brief to appellate court requesting reversal of lower court decision.</i> Two-year-old Brett Shively had a near-drowning accident with cardiac arrest. He was resuscitated in the emergency room and progressed to lose pupillary responses, developed diabetes insipidus, and had an unresponsive electroencephalogram (EEG). An initial neurologic evaluation without apnea examination was consistent with brain death. The medical team recommended a full “brain viability examination.” The family refused consent and ultimately obtained a temporary restraining order. The court declined the hospital’s request to perform the evaluation over the family’s objection, stating that the “basis for such an order is not clear.” A discharge plan was developed and Brett was discharged home. The hospital filed for appeal. The appeal was dismissed as moot, leaving lower court findings in place.
In the Matter of the Guardianship of A.C., a minor	MT (2016)	Yes	<i>Case description from court order denying second exam.</i> Six-year-old Allen Callaway had a submersion injury with cardiac arrest. When concern for herniation and brain death evolved, the medical team sought consent for and performed an initial brain death evaluation. The mother reports that when she provided consent, she was told that Allen’s care would not change as a result. She also reports that the words “brain death” were not used, arguing that she provided consent without full understanding. During the apnea evaluation, the patient’s father reported that the exam caused pain, stress, and physical harm. The family refused a second evaluation, and the court considered whether it was in Allen’s best interests to perform a second examination, ultimately finding that it was not. A tracheostomy and G-tube were placed. The court also ruled that (1) Montana’s Uniform Declaration of Death Act does not mandate that providers conduct a brain death evaluation and that (2) the apnea examination is a medical procedure, falling under an individual’s right to choose or refuse medical treatment.
Pierce v. Loma Linda	CA (2016)	Yes	<i>Case description from mother’s court petition for temporary restraining order and the temporary restraining order.</i> High-school student Alex Pierce had a near drowning. He underwent CPR by fire rescue and was taken to a local hospital then transferred to Loma Linda. He initially had brain activity on EEG and was reportedly moving extremities and opening his eyes. He subsequently developed seizures which were treated and then, the medical team informed the family that they were going to perform an initial brain death evaluation after Alex’s clinical examination changed. The family reported concern about the examination itself, specifically the apnea test, causing harm to Alex, requested an examination by an independent provider with EEG, and continued management until that time. A temporary restraining order was issued precluding any apnea testing or removal or withholding of any medical treatment, requiring continued management and an independent evaluation.
In the Interest of Minor Michael J Todd v University of KS Medical Center	KS (2006)	Unclear	<i>Case description from mother’s court petition, hospital court petition and media.</i> 14-year-old Michael Todd sustained an accidental gunshot injury to his neck. He was taken to an initial hospital and the following day at a referral facility was diagnosed as brain dead, confirmed by an intensivist, neurologist, and neurosurgeon. The mother petitioned for a temporary restraining order, requesting an independent examination and contending the examination was not performed correctly. A temporary restraining order was issued and subsequently reversed after an independent examination was done by a physician identified by the family. As the order was not reversed until an exam was completed by a provider chosen by the family, it is not clear whether the court required consent or not. The mother also reported concern about a potential motivation to remove Michael’s organs for donation.
Hawkins v. DeKalb	GA (2011)	Unclear	<i>Case description from judicial opinion.</i> 18-year-old Tara Hawkins suffered head trauma. She was pregnant and hospitalized for several months with declining neurologic function. Her exam was consistent with brain death, although an apnea test was not performed for months because of concern for the fetus. After delivery, two neurologic examinations were consistent with brain death. The patient’s family had been told after the first examination that, if the second examination was consistent with brain death, mechanical ventilation would not be reinstated. After the second examination, life sustaining therapies were discontinued. The mother sued the hospital on multiple theories, including breach of contract and wrongful death. She claimed that although she signed a general treatment consent that the medical team could perform examinations they deemed necessary, the consent also stated that she had control over advanced directives and they did not obtain her consent to remove life-sustaining therapies. She also claimed that she did not provide consent for brain death testing. The

Table 1 (continued)

Court case	State (year)	Is consent required?	Case description
Lawson vs. VCU	VA (2016)	No	<p>court stated that failure to provide consent for either of these did not <i>cause</i> death and therefore denied her claim because the lack of consent could not be used to justify the type of claim upon which she requested recovery. The court acknowledged that “an evidentiary dispute may have arisen as to the issue of consent” but that based on the theory she requested recovery was not applicable and not addressed.</p> <p><i>Case description from multiple plaintiff and defendant motions and court order.</i> 2-year-old Miranda Lawson suffered anoxic brain injury after choking. She had progressive neurologic decline, and brain death testing was discussed. The parents obtained a temporary restraining order not to perform an evaluation, citing concerns about harm from the apnea test in particular and requesting 14 days accommodation for transfer to another facility based on a law requiring such time for transfer if a medical team refused treatment a family believed necessary. Several facilities would not accept the patient. After one hearing in the case, in which the hospital reports that it was decided that the examination could proceed, the family provided a handwritten note at the time the team attempted to perform the brain death evaluation that they opposed the exam based on religious grounds. The court subsequently issued an order to proceed with the apnea test.</p>
Cassaro v. Friedman	IL (2016)	Pending	<p><i>Case description from complaint filed by patient's mother.</i> 22-year-old Randall, a former active duty marine with substance use, suffered a cardiac arrest likely secondary to accidental drug overdose. He was admitted to an intensive care unit and, according to the complaint, the following events occurred within a day of admission. A cooling protocol was initiated. Seizure-like activity subsequently developed. An initial EEG was abnormal and a subsequent one showed electrocerebral silence. Two brain death evaluations including apnea testing were performed. Brain death was declared. The patient was a designated organ donor and the organs were procured. The patient's father and fiancé were making decisions at bedside; the mother was returning from out of state. The complaint states that consent was not obtained for performing the brain death exam and was inappropriately obtained from the patient's father solely for other health care actions. The case is ongoing.</p>

Greer and Lewis' argument that consent is unnecessary raises at least three serious concerns. First, their claim that the exam does not pose material risk is questionable as some would disagree regarding what constitutes material risk. It is difficult to know a priori which 10% of individuals might breathe on the evaluation, rendering them not brain dead, and at theoretical risk for having a rise in PaCO₂ that could impact that state by performing the evaluation. Even as Greer and Lewis claim that “by definition, a patient being evaluated for brain death has suffered a neurologic injury with no hope for recovery” [51•], those who do breathe do not meet criteria for DNC. It is impossible to know whether they will have any additional recovery at that time. For some, breathing alone constitutes significant enough quality of life to maintain. Second, as Truog and Tasker counter, general principles of biomedical ethics do not support the claim that consent is not required when physicians believe there is no material risk [52]. As they describe, consent is required for any medical evaluation or intervention unless an exception exists, based on respect for autonomy [53•]. Finally, their conclusion that consent ought not be required because it is not required to diagnose death by cardiopulmonary criteria neglects a morally relevant distinction between the two types of evaluation.

When evaluating for cardiopulmonary determination of death, there is no risk that the evaluation for pulselessness will lead to pulselessness. However, as noted above, risks of the apnea evaluation include the potential for the examination to induce the state it seeks to find, making the two criteria for death conceptually distinct and potentially undermining this justification against obtaining consent.

Argument That Consent Is Required

Truog and Tasker conversely purport that informed consent is required prior to initiating *any* medical treatment, test, or examination, based on principles of biomedical ethics [29•, 51•]. They acknowledge that some may contend that general treatment consents implicitly or explicitly permit necessary assessments. However, they maintain that even if such consent is in place, if there is reason to believe that some may object to a particular test or procedure, it is the duty of the physician to disclose information about it to the family and to give them the opportunity to decline. They offer three justifications. First, they outline two types of risk with the apnea evaluation including (1) several cardiopulmonary complications, with hemodynamic instability found in a significant percentage of

patients in whom the test is performed and (2) the potential for increased intracranial pressure when performing the examination as described above. Second, they note that the New Jersey experience, where an exemption exists, does not support concerns about intensive care units being unduly burdened by caring for brain dead patients [54, 55]. Finally, they claim that religious and conscientious objections to DNC, including international disagreement on whether the concept of DNC is a coherent concept of death, ought to be respected.

Troug and Tasker make a compelling argument to require consent based on fundamental principles of biomedical ethics. Their description of the New Jersey experience addresses one of the key worries of the initial Harvard Committee and suggests this will not be a significant concern. And, they raise an important third justification recognizing the need to be sensitive to the needs and values of *all* patients. Indeed, their arguments support that, from an ethical standpoint, consent ought to be required, but this would reflect a meaningful change in current practice as we understand it and bears additional discussion and study.

Consent Is—at Minimal—Permissible

Whether consent will be required by law remains to be settled, few cases have grappled with the actual question of whether consent is required, as many cases in which the issue has been raised have not required the court to directly answer it. Some courts opine that this question is best settled as a matter of public policy. Legislation requiring or denying a need for consent could more directly address the issue, such as in Nevada. Legislation has the potential to undermine public trust, however, if it is not grounded in broad public discourse [53].

Further, while law may provide the basis upon which physicians *must* act, ethically, more may be required. Minimally, consent is *permissible* in accordance with “acceptable medical standards,” under the UDDA. In addition to the reasons offered by Truog and Tasker, several additional ethical considerations justify obtaining consent prior to a DNC evaluation.

First, failure to obtain consent could undermine trust in the patient-physician relationship, particularly for individuals from social, religious, or cultural minority backgrounds, threatening principles of justice and non-maleficence. Shared decision making (SDM) implements the ethical principles underlying informed consent and facilitates optimal decision-making but depends heavily on how the medical team understands family beliefs, values, and preferences. Cultural differences affect how patients receive and value information, express emotion, and perceive trust [56, 57, 58, 59]. Assumptions and biases about what is understood or prioritized threaten optimal SDM, particularly when cultural differences exist, as described in the well-publicized Jahi McMath case concerning DNC [57, 58, 60]. Claims that the need for uniform criteria to define death justify violation of minority

cultural beliefs or values to perform evaluations without consent require further empirical, philosophical, and legal inquiry [51, 61, 62, 63, 64].

Second, prior to a determination of death, a patient—a moral agent—whose interests are represented by surrogate decision makers still exists. Performing an evaluation without consent threatens the moral agency of the not-yet-declared dead patient. The argument that performing the examination is necessary to determine the status and whether obligations exist is potentially flawed because it presumes a status that has not yet been determined, and a status which subsequently leads to loss of the exercise of moral agency. It is important to note here that agency in this situation is expressed through a surrogate, who may be motivated differently than the patient and not directly reflect their values. But, parents are generally best situated to represent their child’s growing agency and are given discretion to raise their children in line with parental values and preferences. The fact that parents may base decisions in faith or religious beliefs should not discount their role or undermine the moral status of their child *prior* to knowing that the child meets DNC.

Third, obtaining consent has the potential to lessen complicated grief for a family whose child may either fulfill DNC or who may be sustained in a way not previously imagined by the family. In pediatrics, we generally respect that parents can best identify the most acceptable quality of life for their child and permit wide latitude in choices to sustain life with the use of the same invasive technologies when children have severe injury that limits any meaningful neurologic function but do not meet DNC. Wightman describes a relational potential standard to explain how parents express their loving and caring relationships with their children through such decisions [65]. Performing an evaluation for DNC without consent, which would lead to discontinuation of organ-sustaining therapies in a child who may function no differently than a child who breathes once during an apnea evaluation, may discount these deep relationships and further complicate grief.

Finally, obtaining consent may lessen moral distress for care providers. As a Montana court has supported, the UDDA does not mandate that providers determine DNC [37]. Cases in which families have refused DNC determinations undoubtedly also place moral distress on medical teams. Some of this distress relates to the continued care of patients for whom the medical team feels there is nothing left to offer. But, distress may also relate to the extreme efforts made to convince families to move forward with evaluations they refuse. If consents was required and providers felt less compelled to “force” an evaluation, moral distress may lessen. This is an area that bears further empirical study.

Obtaining consent for the DNC evaluation would be a change from what we know about current practice, as the majority of respondents in a survey of neurologists reported that they strongly or somewhat disagreed with obtaining

consent prior to a DNC evaluation [65•]. There is limited information about perspectives regarding consent in the pediatric setting specifically and from the perspective of intensive care providers. But, with limited knowledge and significant legal challenges to the concept of DNC, there are compelling reasons to consider consent, particularly in a pediatric setting.

Conclusions

The determination of DNC faces continued ethical and legal challenges, with families often rejecting the evaluation for DNC or the determination itself. More discourse is needed about DNC generally, within the clinical community, ethics community, and with the public. In the interim, obtaining consent prior to performing the exam, particularly in pediatrics may be most ethically justified and best preserve trust and relationships with families. For many families, navigating end-of-life decision-making is challenging and requires different approaches to facilitate optimal decision-making. It is therefore important to consider what type of consent is sufficient to proceed with an examination that will not further burden the decision-making process.

Clinicians facing challenging situations in communicating with families around the determination of DNC should approach such situations bearing in mind that many questions regarding the necessity for consent and how to obtain it still require further research. Clinicians undoubtedly will need to stay informed about the changes to the law as management of challenges to the determination of DNC remains an evolving area of ethical and legal discourse. However, some practical guidance under the current landscape may help clinicians in navigating these dilemmas. One approach in such situations is to afford families time. As the Montana court stated, while the Uniform Declaration of Death Act permits a mechanism by which physicians can declare DNC, the law does not mandate that these examinations be performed, and current guidance provides *minimum* time frames between conducting examinations to determine DNC. Maximum time frames are not stipulated. Affording families who struggle with the determination of DNC time may allow them to come to resolution of conflict with the medical team. A second approach clinicians can take is to recognize that while consent for brain death evaluations ultimately may not be required, under current legal standards, it is at least permissible. Requesting consent prior to performing an exam can help clinicians to avoid future conflict if a family refuses the ultimate determination of DNC. More work needs to be done to develop model language to use in such scenarios, with attention to the multiple possible functions of consent. In the meantime, clinicians should disclose what they believe a family would reasonably want to know about an evaluation for DNC and, if a family refuses consent, recognize that the exam need not be performed.

In thinking about how to implement consent, the research context offers a useful framework to conceptualize the multiple functions a meaningful consent process offers. In addition to promoting autonomy, consent can promote transparency, patient values and welfare in the patient-physician relationship, and—in the policy context—promotes trust and integrity [66•]. To meet these goals, dialog must involve providers who perform DNC evaluations as well as patients and families representing diverse viewpoints. Concerns about chilling effects on organ donation and use of resources will undoubtedly be part of these conversations. Yet, these worries cannot overshadow the importance of public engagement and transparency in determining the optimal way to align equally valuable social goals—truthful communication that respects the diverse values, interests and perspectives of families, and maintaining trust in organ donation. Ongoing empirical, conceptual, legal research and public dialogue are needed to inform how providers discuss DNC with families, learn diverse perspectives about whether and how consent can promote respect for families while not undermining the social value of determining DNC and provide guidance in challenging cases.

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Compliance With Ethical Standards

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Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

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