



Consent for determination of death by neurologic criteria in Canada: an analysis of legal and ethical authorities, and consensus-based working group recommendations

Le consentement pour la détermination du décès selon des critères neurologiques au Canada : analyse de la jurisprudence et des considérations éthiques, et recommandations consensuelles du groupe de travail

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Received: 30 June 2022 / Revised: 13 December 2022 / Accepted: 15 December 2022 / Published online: 2 May 2023

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Abstract *This article addresses the following question: should physicians obtain consent from the patient (through an advance directive) or their surrogate decision-maker to perform the assessments, evaluations, or tests necessary to determine whether death has occurred according to neurologic criteria? While legal bodies have not yet provided a definitive answer, significant legal and ethical authority holds that clinicians are not required to obtain family consent before making a death determination by neurologic criteria. There is a near consensus among available professional guidelines, statutes, and court decisions. Moreover, prevailing practice does not require consent to test for brain death. While arguments for requiring consent have some validity, proponents cannot surmount weightier considerations against imposing a consent requirement. Nevertheless, even though clinicians and hospitals may not be legally required to obtain*

consent, they should still notify families about their intent to determine death by neurologic criteria and offer temporary reasonable accommodations when feasible. This article was developed with the legal/ethics working group of the project, A Brain-Based Definition of Death and Criteria for its Determination After Arrest of Circulation or Neurologic Function in Canada developed in collaboration with the Canadian Critical Care Society, Canadian Blood Services, and the Canadian Medical Association. The article is meant to provide support and context for this project and is not intended to specifically advise physicians on legal risk, which in any event is likely jurisdiction dependent because of provincial or territorial variation in the laws. The article first reviews and analyzes ethical and legal authorities. It then offers consensus-based recommendations regarding consent for determination of death by neurologic criteria in Canada.

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Résumé *Cet article répond à la question suivante : les médecins doivent-ils obtenir le consentement du patient (au moyen d'une directive médicale anticipée) ou de son mandataire spécial pour réaliser les examens, évaluations ou tests nécessaires pour déterminer si le décès est survenu selon des critères neurologiques? Bien que les organes juridiques n'aient pas encore fourni de réponse définitive, selon la jurisprudence et l'éthique, les cliniciens ne sont pas tenus d'obtenir le consentement de la famille avant de procéder à une détermination de décès selon des critères neurologiques. Il y a un quasi-consensus dans les lignes directrices professionnelles, les lois et les décisions*

judiciaires disponibles. De plus, la pratique courante n'exige pas le consentement pour procéder aux examens permettant de déterminer une mort cérébrale. Bien que les arguments en faveur de l'exigence d'un consentement aient une certaine validité, leurs défenseurs ne peuvent pas surmonter des considérations plus importantes contre l'imposition d'une exigence de consentement. Néanmoins, même si les cliniciens et les hôpitaux ne sont peut-être pas légalement tenus d'obtenir le consentement, ils devraient tout de même aviser les familles de leur intention de déterminer le décès selon des critères neurologiques et offrir des aménagements raisonnables temporaires lorsque cela est possible. Cet article a été mis au point en collaboration avec le groupe de travail sur les questions légales et éthiques du projet de Définition uniformisée de la mort cérébrale et de critères fondés sur des données probantes pour sa détermination au Canada et développé avec la Société canadienne de soins intensifs, la Société canadienne du sang et l'Association médicale canadienne. Cet article vise à étayer et fournir un contexte au projet et ne vise pas à conseiller spécifiquement les médecins sur le risque juridique qui, de toute façon, varie probablement en raison des différences légales provinciales et territoriales. L'article commence par passer en revue et analyser la jurisprudence et les considérations éthiques. Il propose ensuite des recommandations consensuelles concernant le consentement pour la détermination du décès selon des critères neurologiques au Canada.

Keywords accommodation · apnea test · brain death · informed consent · law

This article addresses the following question: must physicians obtain consent from the patient (through an advance directive) or their surrogate decision-maker to perform the assessments, evaluations, or tests necessary to determine whether death has occurred according to neurologic criteria? While legal bodies have not yet provided a definitive answer, significant legal and ethical authority holds that clinicians are not required to obtain family consent before making a determination of death by neurologic criteria (DNC).

There is a near consensus among available professional guidelines, statutes, and court decisions. Moreover, prevailing practice does not require consent to test for brain death. Accordingly, increasingly vocal proponents of a consent requirement bear a heavy burden to overcome the presumptive legitimacy of the *status quo*. While their arguments have some validity, proponents cannot surmount weightier considerations against imposing a consent requirement. Nevertheless, even though clinicians and

hospitals may not be legally required to obtain consent, they should still notify families about their intent to determine death by neurologic criteria and offer temporary reasonable accommodations when feasible.

Methods

An interprofessional and multidisciplinary expert committee was assembled both 1) to review and analyze legal and ethical authorities and 2) to develop consensus-based recommendations on DNC consent requirements using an iterative process. The overall project, *A Brain-Based Definition of Death and Criteria for its Determination After Arrest of Circulation or Neurologic Function in Canada* (BBDD), developed in collaboration with the Canadian Critical Care Society, Canadian Blood Services, and the Canadian Medical Association, organized five guideline development groups: 1) neurologic criteria; 2) ancillary testing; 3) circulatory criteria; 4) stakeholder engagement; and, 5) legal/ethics. The legal/ethics group was diverse and represented a breadth of disciplines, including critical care medicine, pediatric medicine, bioethics, and law.

The legal/ethics group formed four smaller working groups focused on more specific questions, including consent for DNC (commonly known as “brain death testing”). That group first reviewed primary source legal databases in Canada, the USA, and the UK for statutes, regulations, court cases, and other agency and tribunal materials, following up with involved attorneys to obtain non-public records. The group then used a range of databases (including PubMed, Scopus, and Westlaw) to identify known relevant literature, including journals with a focus in medicine, critical care, bioethics, and law. The group reviewed this literature, sourced their endnote references through a “snowballing procedure,” and identified and reviewed further materials. The group deemed this broad approach appropriate because this document relies heavily on theoretical analysis informed by available research data. The group also reviewed existing policies of key medical organizations.

The group then developed the content of the recommendations in this article through an 18-month iterative discussion-based consensus process consisting of videoconferencing meetings, webinars, and electronic correspondence. A writing committee drafted the recommendations, which the working group members then reviewed on multiple occasions and revised. The article was further modified through a deliberative discussion process by the full project panel. This article is meant to provide support and context for the BBDD project and is not meant to specifically advise physicians on legal risk, which in any event is likely jurisdiction dependent because of provincial or territorial variation in the laws.

Growing conflict over death determination by neurologic criteria testing

Most reported conflicts over brain death in Canada concern clinician duties to continue somatic support after DNC.¹ In these cases, clinicians have already performed the requisite evaluation and testing, and have already determined that the patients were dead. Nevertheless, the patients' families objected to withdrawing organ-sustaining treatment such as mechanical ventilation.²

But increasingly, DNC conflicts concern not only post-determination treatment but also predetermination testing. This testing is designed to confirm permanent cessation of brain function characterized by: 1) absence of any form of consciousness, 2) absence of brainstem reflexes, and 3) absence of the capacity to breathe shown by formal apnea testing.³ Families object to this testing for various reasons, including: 1) distrust, 2) hope that the patient will regain neurologic function, 3) grief, 4) regret, and 5) religious or moral reasons.⁴

Among other Canadian tribunals, the Ontario Superior Court of Justice has adjudicated several "objection to testing" disputes over the past five years.^{5–7} And this is just the tip of an iceberg representing many more bedside conflicts in Canadian hospitals that did not escalate to courts or tribunals.⁸ Moreover, just as recent cases question whether there is a duty to accommodate requests to continue somatic support after DNC, commentators increasingly ask whether there is a parallel duty to accommodate requests before DNC, namely requests to abstain from (or at least delay) DNC.^{9–13}

Determination of death by neurologic criteria constitutes a set of medical interventions that would ordinarily require consent

The DNC process includes interacting with the patient's body and altering the patient's treatment. These are the types of medical interventions for which consent is normally legally required. Most published court judgements, guidelines, and commentary on consent for DNC focus on the apnea test. But the type of test is immaterial to the analysis. From a legal perspective, the analysis would be the same for apnea testing, for ancillary testing, and even for the bedside clinical exam. Clinicians have a *prima facie* (at first view) duty to obtain consent before administering any diagnostic or therapeutic intervention.

Under constitutional law, common law, statutory law, regulatory law, and standards of practice from provincial colleges of physicians and surgeons; clinicians have a *prima facie* duty to obtain consent. They may not treat or

diagnose patients without consent either from the patient or, if the patient is incapacitated, from their surrogate decision-maker. When clinicians suspect a patient of having suffered brain death, clinicians must administer either an apnea test or an ancillary test to confirm. Because these tests are invasive, clinicians have a *prima facie* duty to obtain consent.

Constitutional law

A patient's right to be free from unwanted interference is constitutionally grounded in section 7 of the Canadian Charter of Rights and Freedoms, which guarantees the right to life, liberty, and security of the person.¹⁴ The Supreme Court of Canada has also observed that "The requirement for informed consent is rooted in the concepts of an individual's right to bodily integrity and respect for patient autonomy."¹⁵ Legislation addressing consent to treatment must be consistent with the Charter, and the common law is to be developed in line with Charter values.¹⁶

Common law

In addition to constitutional principles, at common law, clinicians must obtain a patient's consent for the administration of medical treatment.^{15,17–19} Failing to obtain consent is medical battery.²⁰ The Canadian Medical Protective Association observes, "Physicians may do nothing to or for a patient without valid consent."²¹ A clinician commits battery when they physically interfere with a patient's bodily integrity without consent.²²

Statutory law

In addition to constitutional and common law principles, most Canadian provinces have legislatively codified the clinician's *prima facie* duty to obtain consent.^{23–25} For example, the Ontario Health Care Consent Act (HCCA) requires that clinicians "shall not administer" treatment unless they have the consent of the person or the person's surrogate decision-maker.²³ How these statutes apply to DNC depends on how that testing fits the statutory language. Is DNC testing "health care," "treatment," "examination," or "assessment?" While the statutes link the duty to obtain consent to "treatment" and "health care," the statutes define those terms broadly. Therefore, the *prima facie* (at first view) duty is triggered for a wide range of clinician conduct.

Regulatory law

Many provinces not only have enacted statutes addressing professional misconduct but also have promulgated regulations under those statutes. Many of these regulations also address consent, for example, prohibiting clinicians from “performing a professional service for which consent is required by law without consent.”²⁶

Standards of practice

In addition to constitutional principles, common law, statutory law, and regulatory law, the conduct of physicians is set by provincial colleges of physicians and surgeons.²⁷ Every college has rules regarding consent. For example, in Alberta, the College of Physicians and Surgeons Standards of Practice state, “A regulated member must obtain a patient’s informed consent prior to an examination, assessment, treatment, or procedure.”²⁸

Exceptions to the consent requirement apply to death determination by neurologic criteria

While DNC constitutes a set of medical interventions that would ordinarily require consent, that is not the end of the analysis. There are statutory exceptions to this *prima facie* duty that probably apply to DNC. Moreover, because “accepted medical standards” for DNC do not require consent, there is probably also a common law exception to the *prima facie* duty to obtain consent.^{5,7,29–31} Beyond Canadian statutory and common law authorities, we can look to the USA and the UK for guidance. USA and UK laws similarly carve out an exception, excusing clinicians from a *prima facie* duty to get consent for DNC.

Statutory exceptions to the *prima facie* duty in Ontario

While there is inadequate space to analyze the need for consent in each of Canada’s thirteen provinces and territories, it is appropriate to examine the legal requirements for consent in Ontario. Ontario is Canada’s largest province, home to more than one-third of the national population. And it is the jurisdiction where 13 of 15 DNC cases have reached courts or tribunals.²

At first glance, the Ontario HCCA seems to categorically require consent by mandating that health practitioners “shall not administer” treatment unless they have the consent of the person or the person’s surrogate decision-maker (§ 10).²³ This requirement appears to apply to DNC, because section 2 of the HCCA defines “treatment” so broadly, as “anything that is done for diagnostic ... or other health-related purpose.”

Determination of death by neurologic criteria seems to fit this definition because it is done for a “diagnostic” purpose. It is a process to determine the nature and circumstances of the patient’s comatose state. So, the Ontario HCCA states a general rule: clinicians may not administer treatment without consent. Treatment includes diagnostic testing. And diagnostic testing includes DNC testing.

But the HCCA makes several exceptions to this general rule. The statute specifically excludes a range of clinician-patient interactions from the definition of “treatment,” including certain evaluations for a diagnostic purpose. Most notable is the exclusion of “assessment or examination of a person to determine the *general nature* of the person’s condition” (§ 2(1) [emphasis added]).^{23,28} Death determination by neurologic criteria seems to fit within this exception. A determination of whether the patient is dead or alive is an assessment to determine the “general nature” of that person’s condition. If this exception applies, then DNC testing is not “treatment” under the Ontario HCCA, and clinicians would have no legal duty under the Ontario HCCA to obtain consent for DNC testing.

In short, while the Ontario HCCA imposes a broad consent requirement for treatment, those “assessments” or “examinations” designed to determine the “general nature” of the patient’s condition are not treatment. So, they fall outside the Ontario HCCA’s general requirement that consent be obtained for treatment. Since DNC testing seems to be just such an assessment or examination, the Ontario HCCA probably does not require consent for DNC.

McKITTY v. HAYANI (ONTARIO SUPERIOR COURT OF JUSTICE 2017)

In 2017, the Ontario Superior Court of Justice ruled that the Ontario HCCA did *not* require consent for DNC. In the Taquisha McKitty case, Justice Shaw ruled that: “Dr. Baker shall perform the tests necessary to determine if Taquisha meets the neurologic criteria for death ... including the apnea testing.”^{6,7}

Justice Shaw explained that “per section 2(1) of the Health Care Consent Act, this is an assessment and not treatment and *consent of the SDM* [surrogate decision-maker] *is not required*” (emphasis added).^{6,7} By concluding that DNC testing does not constitute “treatment,” the court held that the Ontario HCCA does not require consent for DNC. The court’s description of the apnea test as an “assessment” shows that the court was applying the “general nature” exception to the definition of “treatment.”

McKitty v. Hayani is the only court ruling in Canada to directly address the DNC consent question. But its

precedential value is unclear. The court made this ruling before the final hearing that resulted in its Reasons for Decision. The court issued this order in a brief endorsement that was unpublished and not part of the final judgement. While the Ontario Court of Appeal later issued a decision in this case, it focused on constitutional questions unrelated to the consent question.³² On the other hand, “just because it is not published does not mean it is not valid or important in the courts.”³³

MORLANI v. HADDARA (ONTARIO SUPERIOR COURT OF JUSTICE 2021)

The Ontario Superior Court of Justice next confronted the DNC consent question in late 2021.⁵ In the *Morlani v. Haddara* case, the mother of a 29-yr-old patient objected to DNC testing. The patient’s mother filed a petition with the Consent and Capacity Board (CCB). But clinicians said that they would proceed with testing anyway. Consequently, the patient’s mother sought an injunction from the court to prohibit clinicians from proceeding until the CCB could adjudicate.

While the court granted the injunction, it carefully avoided ruling on the merits.⁵ It explained that, for jurisdictional reasons, the substantive question of whether DNC testing is “treatment” under the Ontario HCCA should be answered by the CCB, not by the court (although CCB decisions may be subsequently appealed to the court under section 80 of the Ontario HCCA). In 2013, the Supreme Court of Canada held that under the Ontario HCCA, disputes “over matters of consent to medical treatment” must be resolved by the CCB, “an independent, quasi-judicial body with specialized jurisdiction” (para. 28).¹⁵ The patient died (on circulatory criteria) before either the CCB or the Ontario Superior Court of Justice could rule on the merits and answer that question.³⁴

E.B. (ONTARIO CONSENT AND CAPACITY BOARD 2005)

While only the *McKitty v. Hayani* and *Morlani v. Haddara* cases directly concerned the question of consent for DNC, other non-DNC cases are somewhat analogous. For example, in *E.B.*, the Ontario CCB held that “routine checking of ... vital signs” is not treatment and therefore does not require consent.³⁵ This reinforces the *McKitty v. Hayani* ruling that “general nature” assessments are not treatment and do not require consent. *E.B.* concerned taking the patient’s blood pressure. The CCB noted that was a “common diagnostic tool” for which consent is not required.

While blood pressure testing is clearly less invasive than DNC, the case provides guidance on how to interpret the “general nature” exception in the Ontario HCCA. Death

determination by neurologic criteria testing is also a paradigmatic form of checking “vital” signs. Like blood pressure testing, DNC testing is probably not “treatment” and therefore probably does not require consent under the HCCA. Alternatively, *E.B.* could be understood as a case of “implied consent.” By seeking and presenting for health care services, the patient already consented to this sort of evaluation. Therefore, clinicians have no legal obligation to seek a separate, explicit oral or written consent at the time of this diagnostic intervention.

A.D. v. M.O.M. (ONTARIO HEALTH PROFESSIONS APPEAL AND REVIEW BOARD 2018)

Other Ontario authority is in accord. The Health Professions Appeal and Review Board (HPARB) is an independent adjudicative agency that reviews decisions made by the Inquiries, Complaints and Reports Committees (ICRC) of the self-regulating health professions colleges in Ontario. In 2018, it reviewed a complaint about the professional conduct of a physician performing a DNC exam for a teenager hit by a car.³⁶

The physician “delayed a formal assessment of brain function first by three days and then by one more day.” She did this even though “usual practice” was to conduct the exam as soon as brain death is suspected. The physician was comfortable delaying the brain function assessment because of the family’s “tremendous suffering.” The physician wanted to give the family “time to adjust and accept the reality of the situation.” Nevertheless, the family complained that the physician failed to show “integrity, respect, and compassion.” The HPARB found that the ICRC’s investigation was adequate and that its decision declining to refer for discipline was reasonable.³⁶

SUMMARY OF THE ONTARIO HEALTH CARE CONSENT ACT

Despite the guidance offered by the previous cases, some may be concerned about the extent to which the Ontario HCCA displaces broad common law duties to obtain consent. These concerns are likely misplaced. An examination of the statute suggests that the Legislative Assembly intended to displace the common law except where specifically “saved.” For example, the intent of the Ontario HCCA is to provide “rules ... that apply consistently” for the health care context (§ 1(a)).²³ Elsewhere, the Ontario HCCA clarifies that “this Act does not affect [a certain] common law duty” (§ 7).²³ There would be no need to preserve those duties unless the Ontario HCCA otherwise displaced common law duties. Moreover, expert commentators conclude that the Ontario HCCA displaces the common law duties concerning consent for treatment.³⁷

Statutory exceptions to the prima facie duty in British Columbia

While Ontario law has most extensively discussed whether consent is required for DNC testing, the law in other Canadian jurisdictions looks similar. Like the Ontario HCCA, the British Columbia (BC) Health Care (Consent) and Care Facility (Admission) Act first states a general rule: “A health care provider must not provide any health care to an adult without the adult’s consent.”²⁴ Second, like the Ontario HCCA, the BC law carves out exceptions to this general rule that may cover DNC.

One exception provides that (1) “a health care provider may undertake triage or another kind of *preliminary examination*, treatment, or diagnosis ... without [consent]” if (2) the individual or her surrogate decision-maker indicates that they “want to be provided with health care” (emphasis added).²⁴ This exception is grounded in logic and common sense. After all, it would be absurd to permit individuals to demand health care services, yet prohibit the very assessments required to determine whether those health care services were appropriate.

This exception for “preliminary examinations” probably applies to DNC testing. First, determining whether the patient is dead or alive is a threshold question, fundamental to determining the patient’s treatment plan. Second, the family objecting to DNC testing invariably wants the hospital to continue somatic support. Therefore, both preconditions for the exception seem to be satisfied. In short, since the surrogate decision-maker wants the patient “provided with health care,” clinicians “may undertake ... preliminary examinations.”

Statutory exceptions to the prima facie duty in Nova Scotia

Like the Ontario and BC statutes, the relevant statute in Nova Scotia (NS) seems to reach the same result. While it does not make an exception specific to DNC, other exceptions seem to cover it. As in other jurisdictions, the general default rule seems categorical: “No person ... shall receive treatment unless he consents to such treatment.”²⁵ But like Ontario and BC, NS provides that presentation for treatment constitutes consent for basic assessments and examinations. One NS health system policy provides: “Presentation at a PCHA [Pictou County Health Authority] treatment facility for provision of services ... constitutes implied consent for ordinary diagnostic and treatment measures.”³⁸

Common law exceptions

The previous section showed that (at least) several provincial statutes carve out various kinds of exceptions to the *prima facie* duty to obtain consent that probably apply to DNC. In addition, clinician and hospital duties to report deaths under Vital Statistics or Organ Transplantation laws and regulations may imply a duty to perform death determination evaluation in a timely manner. While these statutory authorities and the cases interpreting them (especially *McKitty v. Hayani* and *Morlani v. Haddara*) are most dispositive, the common law also probably carves out an exception to the *prima facie* duty to obtain consent that is reinforced by DNC statutes in many provinces.

DEFERENCE TO THE MEDICAL PROFESSION

The law on DNC defers and delegates substantial responsibility to the medical profession.³⁹ First, in three provinces or territories with legislated definitions of death “the fact of death must be determined in accordance with *accepted medical practice*” (emphasis added).^{40–42} Second, in six of eight provinces or territories with no legislated definition of death, statutes state that “the fact of death must be determined ... in accordance with *accepted medical practice*” (emphasis added).^{43–48} While some of these statutes address DNC only for purposes of organ transplantation, the thrust is that the details on DNC are left out of the law and delegated to the medical profession. That discretion is not wholly unfettered; it is unclear whether “accepted medical practice” refers to the tests to perform as opposed to procedural issues like consent.

The Ontario Superior Court of Justice recently observed, “According to the jurisprudence and legislation in Ontario and throughout Canada it *falls to the medical profession* to establish the medical guidelines or practices to determine death” (emphasis added).⁷ “[D]eath ... is determined by physicians in accordance with accepted medical practice” (para. 41).⁷ In the same matter, the Court of Appeal for Ontario confirmed that both the common law and relevant statutes “leave the determination of death to the standards of medical practice.”³² While the court clarified that this deference is not unlimited, the law has accepted medical practice because it “provide[s] a sound answer to the question of how to determine whether a person has died” (para. 28).³²

At the same time, the Court of Appeal also said that “the determination of legal death is not simply, or even primarily, a medical or biological question. The question of who the law recognizes as a human being – entitled to all of the benefits and protections of the law – cannot be answered by medical knowledge alone” (para. 29).³²

In short, Canadian law extends deference to the medical profession in relation to the tests and biological markers for DNC. In our view, other aspects of procedures for DNC such as timing, notification of families, explanations of procedures, and the question of consent are less clearly a biomedical matter, but are also part of medical practice. Since it is not medical practice to obtain consent to DNC, one could argue that “accepted medical practice” as broadly understood does not require consent, and neither do laws deferring to that accepted medical practice. This view is supported by the implications of insisting on consent to DNC testing. If the medical profession is unable to conduct basic assessments of a patient’s condition, it will be unable to determine appropriate care, and providing care without that knowledge is unlikely to be accepted medical practice.

ACCEPTED MEDICAL STANDARDS DO NOT REQUIRE CONSENT

The accepted medical practice for DNC used by physicians throughout Canada is set out in previous (2006) guidelines published in the *Canadian Medical Association Journal* (para. 53).³⁰ While those guidelines do not address the need for consent, custom and practice do.

There is ample evidence of this practice. For example, in several reported cases, clinicians performed DNC testing despite an injunction. In the *Morlani v. Haddara* case clinicians planned to conduct testing despite objections of the family.⁵ And expert evidence in that case indicates that DNC testing is customarily done without consent. Other cases also show that clinicians proceed to conduct tests despite objections.³¹ Clinician surveys and professional society guidelines further confirm that the accepted medical standard is to conduct DNC testing without seeking consent.³¹ Consistent with these prior guidelines and practice, the 2023 Guidelines in this Special Issue of the *Journal* state, “Consent for DNC testing should neither be required nor requested.”³

SUMMARY OF COMMON LAW

Canadian law defers and delegates to the medical profession the task of establishing the tests for DNC, arguably including matters like whether to obtain consent. It is unclear whether the statutory phrase “accepted medical practice” applies just to the tests or also to matters like consent. Nevertheless, the customary approach does not require consent for DNC, and pragmatic necessity supports this approach.

Exceptions to the prima facie duty in the USA and UK

The previous sections show that Canadian judicial and legislative authorities hold that consent is probably not required for DNC. To bolster the point, we can look to USA authorities for guidance. First, the general rules for medical consent are much the same in Canada and the USA.⁴⁹ Second, Canadian courts have previously looked to USA law in cases relating to DNC. For example, the Ontario Superior Court of Justice devotes five pages of its *McKitty v. Hayani* decision to reviewing USA jurisprudence on DNC.⁷

USA legislatures, agencies, and courts have repeatedly addressed the question of consent for DNC testing. The overwhelmingly consistent position is that consent is *not* required. This is confirmed by the United States Uniform Determination of Death Act (UDDA) itself, by other statutes and regulations, and by a growing number of court decisions.^{50,51} Recent court decisions in the UK similarly confirm that consent is not required for DNC.^{52,53}

Ethical analysis of consent

Even if clinicians have no legal duty to obtain consent for DNC, it is still appropriate to ask whether that should be the case. Even if we already know what the rules are, we should be prepared to offer explanations and justifications for what the rule *ought* to be.

Arguments for requiring consent

Proponents of a consent requirement for DNC typically assert one or more of the following five arguments.

UNRELIABILITY AND SELF-FULFILLING PROPHECY

Some advocates for requiring consent charge that the apnea test does not measure what it purports to measure. It is an unreliable test.⁵⁴ For example, Rodríguez-Arias *et al.* question the very validity of the apnea test.⁵⁵ An even stronger version of this argument charges that the apnea test not only fails to determine death, but even *causes* it.⁵⁶ Joffe argues that clinicians should not perform the apnea test even with consent because the test is contraindicated, serves no diagnostic purpose, and produces a self-fulfilling prophecy.⁵⁷

SIGNIFICANT RISKS FROM APNEA TESTING

Other advocates for requiring consent are not ready to abandon the apnea test altogether. Nonetheless, they are concerned about potential iatrogenic harm. One

commentator observes that “Most discussions on informed consent for [DNC] focus on the safety issue of the apnea test.”⁵⁸ Unlike ancillary testing, the apnea test imposes significant risks with no countervailing benefit to the patient. Indeed, these risks may be enhanced by variability in how the apnea test is conducted.^{54,59–62} Proponents for requiring consent charge that the apnea test is not in the patient’s best interest, or at least it is a value-laden judgement balancing risks and benefits that is theirs to make.⁶¹

RELIGION- AND CONSCIENCE-BASED OBJECTIONS

Some advocates for requiring consent do not focus on the diagnostic accuracy or risks of the apnea test. Instead, they defend a consent requirement to respect religion. For example, in a 2016 Virginia case, the parents of two-year-old Miranda Grace Lawson physically blocked clinicians from performing the apnea test and gave them a handwritten note: “We are Christians, and it is against our religious beliefs to remove the ventilator.”⁶³ Unlike arguments concerning unreliability and risks, this argument addresses not only the apnea test, but also ancillary testing and the clinical exam.

RESPECT FOR PERSONS

Some advocates for requiring consent argue that it shows respect for the person.¹¹ Paquette *et al.* argue that the justification for seeking consent lies in respect for the moral status and agency of the person. Therefore, they argue that informed consent is required not only for the apnea test but also for all other aspects of the evaluation for DNC.⁶⁴

RACE AND TRUST

Conflicts over DNC are reported to occur disproportionately with families from racialized communities. A lack of trust between racialized persons and the medical community is often cited as the reason.⁶⁵ When clinicians proceed to make DNC without consent, that further damages already fragile trust.⁶⁶ Johnson contends that consent is important because it preserves trust with historically marginalized and exploited communities.⁶⁰ Paquette *et al.* argue that seeking consent lessens complicated grief and preserves trust.⁶⁴

Arguments against requiring consent

Commentators opposed to a consent requirement for DNC typically assert one or more of the following six arguments.

PRIMA FACIE DUTY NOT EVEN TRIGGERED

Opponents to requiring consent contend that the *prima facie* duty to obtain consent is never triggered in the first place because the apnea test is not “treatment.” For example, in court cases, hospitals have successfully argued that the apnea test is not “health care” requiring consent.⁶³ Instead, the apnea test is just an assessment or evaluation. Therefore, neither the right to consent nor the right to refuse apply.^{67–69} Hester argues that the apnea test is not itself health care, but rather a means to determine whether health care is appropriate.⁶⁹ Bertino and Potter compare DNC with assessing a patient’s decision-making capacity.⁷⁰

NEED TO ANSWER FUNDAMENTAL QUESTIONS

Even if there is a *prima facie* duty to get consent, opponents to requiring consent contend that presumption is outweighed by the unique and special importance of DNC. Ascertaining whether a patient is alive, or dead, is the most fundamental aspect of providing medical care.^{62,71} Indeed, some professional societies like the American Academy of Neurology (AAN) say not only “may” clinicians test without consent but also they have a “responsibility” to do so.⁷²

Clinicians are obliged to provide appropriate care based on an accurate diagnosis. Accordingly, Vercler and Laventhal argue that physicians may unilaterally perform the apnea test, because they have a fundamental responsibility to determine the suitability of technological interventions that they administer.⁷³ Hester similarly argues that physicians must determine where their professional obligations point.⁶⁹ Furthermore, clinicians must confirm that an individual is eligible for health care services. Otherwise, they may commit fraud by billing for services that are not “medically necessary.”

INTEGRITY OF THE MEDICAL PROFESSION

Once clinicians have determined that a patient is dead, they generally have no ongoing duty to “treat” that patient.⁷⁴ Accordingly, after DNC, clinicians will stop somatic support like mechanical ventilation either immediately or after a brief period of reasonable accommodation. But some families seek to avoid this result by refusing to allow clinicians to perform DNC. Without “determination,” there can be no declaration or pronouncement of death.

Courts have balanced the integrity of the medical profession against patient rights for decades.^{75,76} And when it comes to consent for DNC, preserving the integrity of the medical profession weighs heavily. Many scholars and professional societies have published accounts of the

goods internal to the practice of medicine, including: 1) prevention and/or treatment of disease and illness; 2) restoration of health; 3) relief of pain and/or suffering; 4) healing through the therapeutic encounter; and 5) sustainment, preservation, protection, or prolongation of life. None of these goals is furthered by forgoing DNC. Furthermore, forcing clinicians to act contrary to professional standards causes moral distress.⁷⁷ This is especially difficult for nurses and ancillary staff who spend more time with these patients. Moral distress is linked to problems with retention, absenteeism, and even care quality.

STEWARDSHIP OF SCARCE RESOURCES

The need to answer fundamental questions and the need to preserve the integrity of the medical profession are not the only reasons to perform DNC. Hospitals also need to know whether patients are alive or dead to facilitate appropriate triage of clinician time and material resources.⁷⁸ Clinicians must be good stewards of scarce resources like intensive care unit (ICU) beds.⁵⁸ For example, the American Medical Association Code of Ethics provides, “This obligation requires physicians to be prudent stewards of the shared societal resources with which they are entrusted” (§ 11.1.2).

A consent requirement would permit families to indefinitely prevent the determination, and therefore, the declaration of death. This would cause a misallocation of scarce resources. Hospitals are “not places to maintain the dead.”⁷⁹ Some commentators’ reference the COVID-19 pandemic to illustrate distributive justice arguments about wasting scarce ICU resources on the dead when other living patients with significant prospects for benefit are denied those same resources.⁶⁸ Because ICUs are often full, these distributive justice concerns weigh heavy even without a pandemic surge.

Admittedly, an inability to perform DNC is not always an obstacle to withdrawing ICU treatment such as mechanical ventilation. For example, California and Texas hospitals regularly withdraw life-sustaining treatment from living patients over the objections of the patient’s legally authorized decision-maker.^{80,81} But this is not permitted in Ontario and many other jurisdictions.¹⁵

SYMMETRY AND HARMONY WITH DEATH BY CIRCULATORY-RESPIRATORY CRITERIA

In addition to the forgoing arguments, opponents to requiring consent argue that omitting consent fits with adjacent and analogous rules. First, since consent for determining death is not required on one prong of the UDDA, it should not be required for determining death on

the other prong.^{12,79} In other words, consent is not required for determining “irreversible cessation of circulatory and respiratory functions.” Therefore, consent should similarly not be required for determining “irreversible cessation of all functions of the entire brain.”

Among others, the AAN argues that the rule for DNC should mirror the rule for determining death by circulatory-respiratory criteria. The AAN supports its position that there is “no obligation” to obtain consent for DNC by showing that position “is *analogous* to the authority and responsibility historically granted to the medical profession to determine death by circulatory criteria without the requirement for additional informed consent” (emphasis added).⁷²

This argument from symmetry and harmony can be pushed even further. When performing cardiopulmonary resuscitation, chest compressions are critical to maintaining blood flow and ventilation until spontaneous circulation is restored. Compressions are regularly interrupted or paused to check for pulse and rhythms.^{82–84} While guidelines recommend minimizing these interruptions, they are not only permitted but even recommended. Interrupting chest compressions to check pulse is associated with poorer outcomes. Yet, clinicians do not seek consent to conduct this non-risk-free diagnostic test. Analogously, clinicians should not need consent to conduct DNC.

SYMMETRY AND HARMONY WITH ACCOMMODATIONS

A second argument from symmetry and harmony focuses on accommodations. Since we disallow families from circumventing declaration of death in other ways, we should disallow it here too. With a consent requirement, families could prevent the declaration of death not because of any specific right to opt out (as in New Jersey),⁷⁴ but simply because they can prevent the prerequisite. In other words, while families have no right to object to the “declaration” of death, they could achieve a practically identical result by objecting to the “determination” of death. In short, if we disallow objections to declaration (or pronouncement) of death, then we should similarly disallow objections to determination of death.

REBUTTAL POINTS

In addition to their own six arguments against consent for DNC, opponents to requiring consent also rebut the arguments of proponents. For example, several authors argue that the risks from apnea testing are neither as common nor as serious as consent proponents suggest.^{58,67,68} When properly conducted, the risks are minimal.

Weighing pro and con arguments

While clinicians must normally obtain informed consent before administering tests and procedures, significant legal and ethical authority supports a DNC exception to this requirement, weighing toward not requiring consent. Consent proponents bear the burden of presenting dispositive reasons why the *status quo* is inadequate and should be replaced. But their arguments do not clearly outweigh the compelling policy reasons not to require consent. Especially compelling are distributive justice concerns.

Notification and reasonable accommodation

Even if clinicians might be able to legally proceed with DNC without consent (or even over family objections), this does not mean that they should immediately do so. Clinicians and hospitals should consider family wishes. This typically entails two duties: 1) notifying family of the intent to perform an evaluation for DNC, and 2) making reasonable accommodations to delay testing. While clinicians might not need to obtain consent because they need permission, there are other reasons to consult with families, including resolving mistrust and permitting them to process the event.

Family notification

Since the earliest days of DNC, courts have held that clinicians should apprise the family.^{85,86} Even if there is no “decision” for families to make, clinicians should still consult with families.⁸⁷ In some jurisdictions, this is required in law, in professional guidelines, and as a matter of custom and practice.

Laws in some states in the USA specifically require family notification of the intent to perform an evaluation for DNC. For example, New York law provides that the facility must “make diligent efforts to *notify* the patient’s surrogate decision-maker that the process for determining brain death is underway” (emphasis added).⁸⁸ New Jersey guidelines similarly provide that “the exam should commence *following notification* of surrogate decision makers” (emphasis added).⁸⁹ Florida requires that the “next of kin of the patient shall be *notified* as soon as practicable of the procedures to determine death” (emphasis added).⁹⁰

Beyond laws, broadly endorsed standards also recommend notification.⁸ For example, the World Brain Death Project recommendations are supported by 33 medical societies and five world federations.⁹¹ They provide, “It is recommended that reasonable efforts

should be made to *notify* a person’s next-of-kin before performing a brain death/death by neurologic criteria determination” (emphasis added).⁸⁶ Similarly, the AAN advises that clinicians “perform a brain death evaluation including apnea testing only “*after informing* a patient’s loved ones or lawful surrogates of that intention” (emphasis added).⁷²

The Society of Critical Care Medicine/American Academy of Pediatrics/Child Neurology Society pediatric standards make similar recommendations: “Physicians are obligated to provide support and guidance for families ... permitting families to *be present* during the evaluation can help them understand that their child has died” (emphasis added).⁹² Obviously, permitting the family to observe determination requires informing them.⁹³ Moreover, even when not specifically required, prevailing custom and practice involve notifying the family that the evaluation will be conducted. Even if their consent is not required, respect and compassion dictate that the family be informed.

Reasonable accommodation in delaying testing

To some degree, notifying families of the intent to perform an evaluation for DNC entails some reasonable accommodation and delay. After all, a key point of notification is to permit the family to gather and say goodbye. For example, hospitals may delay testing to permit the family time to process the situation, to explore transfer options, or even to observe the evaluation.⁹⁴ But reasonable accommodation often goes beyond this. Clinicians regularly *delay* testing to be compassionate and respectful. This is evidenced both by professional society standards and by custom and practice.

While the World Brain Death Project recommends against requiring consent, it recommends reasonable accommodation to objections. Indeed, the World Brain Death Project makes two separate recommendations on this point:

“It is suggested that, in the setting of a request to either forgo a brain death/death by neurologic criteria examination ... a family should be provided with a *finite period* of time to seek to arrange transfer to another facility (should they wish to do so) and the health care team should speak to a potential accepting institution if requested to do so (emphasis added).⁹¹ It is recommended that attempts should be made to *handle requests* to either forgo a brain death/death by neurologic criteria examination ... within a given hospital system before turning to the legal system (emphasis added).”⁹¹

Other professional societies also recommend reasonable accommodation. For example, a widely respected set of

guidelines from the Hastings Center supports accommodating requests to delay DNC.⁹⁵ Notably, these delays are finite and short-term, typically lasting just hours or days.

Few laws elevate these recommendations into legal duties. Indeed, New York law is unique in requiring that hospitals have a “procedure for reasonable accommodation of the individual’s religious or moral objections to the *determination*” (emphasis added).⁹⁶ A court recently interpreted this law in the case of *Yechezkel Nakar*.⁹⁷ New York-Presbyterian Hospital/Columbia University Irving Medical Center conducted a clinical evaluation for DNC on Mr. Nakar and wanted to perform an apnea test. But Mr. Nakar’s family objected on religious grounds and wanted to consult with their rabbi. Despite these objections, the hospital proceeded to complete the DNC. The court held that since there “was no immediate need to declare Mr. Nakar brain dead, it was not reasonable for respondents to take such action.” Instead, “it would have been reasonable for [the hospital] to accommodate [the family’s] objections by delaying.” The court ordered the hospital to vacate the death certificate.⁹⁷

Beyond professional society guidelines and legal requirements, most hospitals already regularly afford accommodations to families. While most discussion of accommodation focuses on time *after* determination and declaration (so families have an opportunity to gather and say goodbye), hospitals also offer accommodations *before* determination.⁹⁸ Among other evidence, court cases in the USA indicate that clinicians regularly offer brief accommodations of 24–72 hr.¹²

Several Canadian court cases indicate that Canadian clinicians also delay testing to accommodate family wishes.^{99,100} For example, in the above-referenced (*cf.* section *A.D. v. M.O.M.*) case of an Ontario hospital suspecting brain death in a teenager hit by a car crossing the street, clinicians “delayed a formal assessment of brain function first by three days and then by one more day.”³⁶ They delayed DNC even though “usual practice” was to conduct the exam as soon as brain death is suspected. While the family later brought a complaint, the college found that the physician did not breach professional duties of respect and compassion. Indeed, delaying the DNC showed “integrity, respect, and compassion” to allow the family “time to adjust and accept the reality of the situation.”³⁶

While only four jurisdictions in the USA legally mandate reasonable accommodation *after* DNC, this is commonly afforded in almost all jurisdictions.⁷⁴ In fact, it is probably the standard of care. If hospitals accommodate families after death, then they should also accommodate families *before* death. Nevertheless, note that these accommodations are almost always definite, not

indefinite. Accordingly, hospitals should clarify both the reasons for and the duration of pre-DNC accommodation.

As discussed above, the typical form of accommodation is a short-term delay before performing the evaluation for DNC. Reasonable accommodation can also take other forms. Another accommodation might be changing the components of the evaluation. Lazaridis argues that while clinicians need not obtain consent, they must respect “legally protected conscientious objections,” by doing ancillary testing instead of apnea testing.¹⁰¹

Practice recommendations

The following five recommendations regarding consent for DNC are consistent with the law, professional society guidelines, and accepted medical standards. The sequence of these recommendations corresponds to when they would arise chronologically.

1. **Family notification:** Clinicians and hospitals should make reasonable efforts to notify a person’s family before performing tests for DNC (brain death). When appropriate, clinicians and hospitals should not only notify the family but also invite them to observe the evaluation and testing.
2. **Consent probably not required:** Clinicians probably do not need consent to perform the clinical evaluation, apnea testing, or ancillary testing for DNC. Clinicians should not be required to seek consent for these procedures.
3. **Rules on consent:** Legislation, regulations, judicial formulations, executive orders, decrees, or legal guidelines should clarify that clinicians are not legally obligated to obtain consent before performing the clinical evaluation, apnea testing, or ancillary testing for DNC.
4. **Managing objections:** When a family asks clinicians to forgo or to delay DNC, clinicians should seek guidance and support from their ethics committee, risk management, hospital administration, and/or legal counsel.
5. **Reasonable accommodation:** Hospital policies should clarify the grounds for and extent to which the hospital may offer reasonable accommodations such as briefly delaying DNC.

Conclusion

Significant legal and ethical authorities support not requiring consent for DNC. Therefore, clinicians probably do not and should not have a legal duty to

obtain informed consent or any other consent before conducting DNC tests. There is no “decision” or “choice” for families to make. Clinicians should still notify families that they will perform the evaluation. Family acquiescence or silence to this announcement constitutes assent. When families do not assent, hospitals should offer short-term accommodation when appropriate. Health care institutions should have policies for managing and accommodating objections.

Author contributions *Thaddeus M. Pope, Jennifer A. Chandler, and Michael Hartwick* conceived the project. *Thaddeus M. Pope* wrote the first draft of the manuscript. All authors contributed to key arguments and perspectives included in this paper and reviewed relevant sections and drafts. The paper was written by the authors on behalf of the legal/ethics working group of the project, *A Brain-Based Definition of Death and Criteria for its Determination After Arrest of Circulation or Neurologic Function in Canada* developed in collaboration with the Canadian Critical Care Society, Canadian Blood Services, and the Canadian Medical Association.

Acknowledgments The authors express their sincere appreciation for the coordination, support, and guidance provided throughout this project, especially the contributions of Lindsay Wilson and Sylvia Torrance.

Disclosures Professor Pope served on the Uniform Law Commission study committee and serves on the drafting committee for the United States Uniform Determination of Death Act. He regularly receives honoraria for speaking on this and related topics at universities, hospitals, and professional societies.

Funding statement This work was conducted as part of the project entitled, “A Brain-Based Definition of Death and Criteria for Its Determination After Arrest of Circulation or Neurologic Function in Canada,” made possible through a financial contribution from Health Canada through the Organ Donation and Transplantation Collaborative and developed in collaboration with the Canadian Critical Care Society, Canadian Blood Services, and the Canadian Medical Association. The views expressed herein do not necessarily represent the views of Health Canada, the Canadian Critical Care Society, Canadian Blood Services, or the Canadian Medical Association. Professor Chandler holds the Bertram Loeb Chair in Organ and Tissue Donation at the University of Ottawa. Professor Pope’s work was supported by a 2021 Fulbright Canada award to serve as the Research Chair in Health Law, Policy, and Ethics at the University of Ottawa. He completed another significant portion of this work during a 2022 Brocher Foundation research residency.

Editorial responsibility This submission was handled by Dr. James L. Bernat, Guest Editor, *Canadian Journal of Anesthesia/Journal canadien d’anesthésie*.

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