

Should the Brain Death Exam With Apnea Test Require Surrogate Informed Consent? Yes

The UDDA Revision Series

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The ethical and legal case for requiring surrogate informed consent before conducting an apnea test to diagnose death by neurologic criteria is grounded in 2 simple and unimpeachable premises:

1. Apnea testing is a *medical procedure*, one that increases the risk of significant iatrogenic harm.
2. Patients and surrogates have a broad and well-recognized *right to refuse unwanted medical procedures*.¹

This remarkably clear and compelling case—which we have defended at length elsewhere^{1,2}—is, nonetheless, not universally recognized across legal jurisdictions and clinical practice. Indeed, our position often meets substantive opposition, so it is worth responding to 4 primary objections.

Objection 1: Apnea Testing Is Not “Medical Treatment” and as Such Is Not Accompanied by a Right of Refusal

The right of refusal is not limited to medical treatment. Ethical consistency and long-standing legal precedent support the right to refuse *diagnostic* procedures.^{3,4} For example, patients and surrogates have the right to refuse treatment of leukemia and *also* to refuse a bone marrow biopsy to diagnose leukemia in the first place.²

Objection 2: Apnea Testing Is Part of Routine Medical Care Encompassed by General Consent

The right of refusal is not relinquished through general consent to treatment (or even by prior explicit consent to a procedure). Legally authorized surrogates can *withdraw* consent at any point. Moreover, “in terms of existential significance to patients and families, apnea testing and the wider brain death evaluation are about as far away from procedures like blood pressure or body temperature checks as one can get.”^{1,2} Clinicians should approach this evaluation with the gravity that it deserves and invite surrogates to understand, consent to, and even be present for apnea testing.

Objection 3: Surrogate Informed Consent Is Not Required Because Apnea Testing Carries No Risk of Significant Harm to Patients

Informed consent for medical procedures varies according to the nature and magnitude of potential risks and complications. Procedures without consequential risks—such as venipuncture—do not require *explicit* consent while procedures with the potential for serious adverse effects do. The apnea test falls closer to the latter than the former.¹ Serious complications

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do arise in apnea testing, often related to hypercarbia or mechanical complications accompanying the procedure. These complications include hypoxemia, hypotension, arrhythmias, hemodynamic instability, cardiac arrest, tension pneumothorax, interstitial emphysema, and pneumomediastinum. Although adherence to brain death guidelines reduces their incidence, these potential complications, nevertheless, remain relevant.^{5,6} Indeed, the physiologic changes produced during apnea testing—especially hypercarbia and possible hypotension—contradict standard management goals for patients in coma secondary to severe head injury, hypoxic ischemic injury, stroke, or cerebral hemorrhage. In these patients, strict blood pressure control is mandatory. Hypercarbia must be avoided to prevent cerebrovascular vasodilation that might increase intracranial pressure possibly aggravating cerebral ischemia. These perturbations increase the risk that patients with serious brain injuries (but not brain dead) *before conducting the apnea test* could be left brain dead *after and as a consequence* of it.^{1,2}

This insidious phenomenon has been described in detail in the work by Coimbra on the global ischemic penumbra. According to Coimbra,⁷ a patient appearing brain dead on clinical examination after a catastrophic injury may still retain areas of brain tissue perfused with sparse levels of blood flow. The global ischemic penumbra occurs when this blood flow is insufficient to permit function but adequate to avoid permanent necrosis. This phenomenon may explain the preservation of substantial (MRI-confirmed) brain tissue in the case of Jahi McMath, a child appropriately declared dead by clinical neurologic criteria and supportive ancillary testing, who, nonetheless, was maintained on ventilator support for several years and subsequently demonstrated motor responses to commands.⁸ Conducting apnea testing in a neurologically devastated patient risks hypercarbia and cerebral ischemia that could be the *coupe de grace* in the progression from severe (but not irreversible) brain damage to permanent brain death.

Objection 4: Requiring Surrogate Informed Consent Will Induce Many Refusals, Draining Scarce Health Care Resources (e.g., Intensive Care Unit Beds and Transplantable Organs) and Causing Clinician Moral Distress

We find evidence for these concerns to be lacking.^{2,9,10} Indeed, we argue that “there are good reasons to believe that the opposite would be the overall effect”² of a robust shared decision-making process that fosters trust and respect for diverse views of death.^{2,11} Regardless, claims about “the greater good” do not invalidate duties to respect bedrock individual rights to refuse unwanted procedures.² The practice of informed consent always introduces the possibility of treatment refusals that clinicians may dislike. Surrogates deserve no less of an

opportunity for informed consent “when deciding whether the rationale for apnea testing outweighs its potential risks.”²

Conclusion

The ethical and legal case for requiring surrogate informed consent before apnea testing is clear, consistent, and compelling. Resistance to it stems more from institutional and ideologic inertia and the professional self-interest of clinicians and health care institutions than from any deficiencies in the position itself. Surrogate informed consent is more than a formal obligation; it also is an *opportunity* for clinicians to recognize the limitations of health care and reorient their practice within a rich, dynamic, ongoing, and genuinely patient-centered process of shared decision making.² Clinicians must engage with surrogates early and often to understand their values and concerns, build trust with the clinical team, and promote education and informed decision making when determining and revising goals of care.² We would recommend that clinicians welcome and invite family presence during the brain death examination to help surrogates better appreciate and understand the patient’s condition and prognosis.^{1,2} Standardizing this practice only further strengthens the case for a thorough process of informing surrogates of “the purpose, methodology, and potential risks of the procedure” before “seeking their explicit consent for clinicians to perform and surrogates to be present for the examination.”^{2,12}

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Jeremy Garrett, PhD	Children’s Mercy Bioethics Center, Children’s Mercy, Kansas City, MO	Drafting/revision of the manuscript for content, including medical writing for content; study concept or design

References

1. Berkowitz I, Garrett JR. Legal and ethical considerations for requiring consent for apnea testing in brain death determination. *Am J Bioeth.* 2020;20(6):4-16.

2. Garrett JR, Berkowitz I. Response to Open Peer Commentaries "Rethinking the ethical, legal and clinical foundations of informed consent and shared decision-making for brain death determination." *Am J Bioeth.* 2020;20(6):W1-W5.
3. Yanke G, Rady MY, Verheijde J, McGregor J. Apnea testing is medical treatment requiring informed consent. *Am J Bioeth.* 2020;20(6):22-24.
4. Paquette E, Frader J, Shah S, Tasker R, Truog R. Beyond the apnea test: an argument to broaden the requirement for consent to the entire brain death evaluation. *Am J Bioeth.* 2020;20(6):17-19.
5. Busl KM, Lewis A, Varelas PN. Apnea testing for the determination of brain death: a systematic scoping review. *Neurocrit Care.* 2021;34(2):608-620.
6. Datar S, Fugate J, Rabinstein A, Couillard P, Wijidicks EF. Completing the apnea test: decline in complications. *Neurocrit Care.* 2014;21(3):392-396.
7. Coimbra CG. Implications of ischemic penumbra for the diagnosis of brain death. *Braz J Med Biol Res.* 1999;32(12):1479-1487.
8. Shewmon DA, Salamon N. The MRI of Jahi McMath and its implications for the global ischemic penumbra hypothesis. *J Child Neuro.* 2022;37(1):35-42.
9. Son RG, Setta SM. Frequency of use of the religious exemption in New Jersey cases of determination of brain death. *BMC Med Ethics.* 2018;19(1):76.
10. Alsultan MA. Utilization of intensive care units' beds occupied by brain-dead patients. *Saudi J Kidney Dis Transpl.* 2011;22(3):444-447.
11. Johnson L, Syd M. Restoring trust and requiring consent in death by neurological criteria. *Am J Bioeth.* 2020;20(6):33-35.
12. Lazaridis C. Accommodating apnea testing: not death determination refusal. *Am J Bioeth.* 2020;20(6):47-49.

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