

Robert S. Olick, Eli A. Braun, and Joel Potash, "Accommodating Religious and Moral Objections to Neurological Death," *The Journal of Clinical Ethics* 20, no. 2 (Summer 2009): 183-91.

Accommodating Religious and Moral Objections to Neurological Death

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It is widely accepted both in medical circles and in society at large that a patient is dead when she or he has irreversibly lost (1) all cardio-respiratory functions or (2) all functions of the entire brain, including the brain stem (also known as whole brain death, neurological death, or death by neurological criteria). Yet this consensus, embraced in law across the 50 states, has not settled public debate over the determination of death. Controversy persists about the timing of death, the conceptual coherence of competing "definitions" of death, the historical connection between emergence of the whole-brain standard and the need for transplantable organs, and the implications of different definitions for end-of-life care.¹ Two leading journals have recently devoted symposia to these and other issues related to the determination of death.² In December 2008, the President's Council on Bioethics released a white paper critical of the prevailing formulation of the whole-brain death standard.³

Largely absent from the debate has been the place of a conscience clause in patient care and public policy. Nationwide adoption of the Uniform Determination of Death Act, or some variant of that model law, has embraced the view that societal interests in a uniform standard of death — including certainty about an individual's legal and moral status, appropriate death rituals, and rules governing property, insurance, social security, and other legal arrangements — are too important to allow individuals to opt-out of and reject neurological criteria for determination of death. Two states, New York and New Jersey, share this commitment to a uniform standard for determination of death, but have concluded that societal interests in uniformity should sometimes yield to and *reasonably accommodate* a patient's religious or moral objection to being determined dead on the basis of neurological criteria.⁴

Here we report on a case in New York that presented the question: What does reasonable accommodation mean? We present the case and place the issues in the context of New York law. We then discuss the disagreement that ensued between family members and healthcare professionals regarding continuation of treatment.

In late 2005, the New York State Department of Health (DOH) updated its guidance on the determination of brain death and the meaning of its regulations, first adopted nearly 20 years earlier. The DOH iterated the state's interest in a uniform approach to whether an individual is legally alive or dead. It reaffirmed the obligation of reasonable accommodation of the individual's wish to opt-out of neurological criteria for deter-

mination of one's own death. The DOH called on all hospitals in the state to review and, if necessary, revise their policies. We go on to discuss the shaping of hospital policy concerning reasonable accommodation of objection to neurological death in the context of the DOH guidance and note some policy lessons that emerged from the case we present.

CASE SUMMARY: "I DON'T BELIEVE IN BRAIN DEATH"

GF was a 52-year-old patient admitted to the neurosurgery intensive care unit (ICU) for sudden subarachnoid hemorrhage. Two nights prior to admission, GF did not feel well and had a headache. The next day GF was less responsive than usual and somewhat combative. GF's spouse brought GF to the emergency room. GF was intubated, attached to mechanical ventilation, and sedated to allow for computed tomography (CT) scan of the head. The scan revealed a profuse subarachnoid hemorrhage and a small right-sided subdural hematoma. Emergency ventriculostomy for cerebrospinal fluid diversion was performed. GF was unconscious after surgery. Further workup with a CT angiogram showed an aneurysm of the right internal carotid artery. GF was taken back to the operating room, the aneurysm was clipped, and a bone flap was created for decompression of the brain. Nevertheless, intracranial pressure continued to increase and GF never regained consciousness.

When the patient's spouse expressed concern about GF's rapid heart rate, a covering neurosurgeon suggested that a further operation to decompress the brain might slow the patient's heart rate, even if it was unlikely to reverse the patient's coma. In an effort to show compassion, the neurosurgeon added that the patient's heart was "strong." The patient's spouse then requested a surgical decompression of the brain, but the primary neurosurgeon refused to perform it. He noted fixed dilated pupils, absent corneal reflex, lack of motor response to stimulation, and the absence of any breathing over the ventilator. He suspected neurological death and recommended the diagnosis be clinically confirmed. Even if GF was not dead by neurological criteria, the neurosurgeon believed further decompression would not benefit GF and might subject GF to harm.

GF's spouse requested that treatment continue, stating that their religion recognized only the absence of heartbeat as death. The spouse said, "We don't believe in brain death; I don't want to go there." Recalling the covering neurosurgeon's statements, GF's spouse maintained that the patient's heart would remain strong if the increased pressure in the brain was relieved, and opposed any alternative procedure, including completion of the hospital's protocol to determine brain death. The patient had not left written evidence of treatment preferences and had not appointed a healthcare proxy. There was no do-not-resuscitate (DNR) order or organ donor card. The primary neurosurgeon called an ethics consult. A meeting was arranged with the ethics consultant, the spouse, and the neurosurgeon. After discussion of the likelihood of whole-brain death and the futility of further treatment, the spouse stated that GF's heartbeat indicated that the soul had not left the body and that GF was therefore alive. The spouse abruptly left the room, and the ethics consultant raised the following questions:

1. What would the patient want?
2. Does the patient share the religious beliefs of the spouse?
3. Could their religious beliefs be clarified with the help of clergy?
4. Should the medical team proceed with the hospital's protocol for determining brain death over the objections of the spouse?
5. If the spouse is merely denying death, what is a reasonable time to allow for acceptance?
6. If no brain-death determination is done and the patient is legally alive, is a surgical decompression indicated?
7. Can a family member insist on continued ventilation for the patient?
8. Should a DNR order be placed over the spouse's objection?
9. Would the opinion of a second neurosurgeon help resolve the disagreement?

A number of these questions were presented at a second conference that included the patient's spouse, son, sister-in-law, and attorney, as well as a chaplain of the patient's faith. Also present were the primary neurosurgeon, the ethics consultant, and representatives from nursing staff, nursing administration, social work, and hospital counsel. The family

raised the possibility that GF be transferred to another hospital to prolong treatment, but yielded when told that other area hospitals would not accept a patient in GF's condition. Following this conference, the family met privately with their attorney and chaplain, after which they accepted that GF would not recover and likely was "legally dead." They relented on their previous request for surgical decompression, agreed to allow the neurosurgeon to proceed with the determination of neurological death, and consented to the placement of a DNR order. Without recognizing whole-brain death as the end of life, the family agreed to withdraw treatment if GF met neurological criteria for cessation of brain function. Because the family conference with their attorney and chaplain were private and confidential, we were not privy to further explanation of the family's change of mind.

BACKGROUND: NEW YORK STATE LAW

In 1987 New York became the first state to legally embrace an obligation to acknowledge and accommodate a patient's objection to a determination of death based on neurological criteria when that objection is founded on religious or moral grounds. Under DOH regulations, all hospitals in the state must have written policies for determining death by neurological criteria, including "a procedure for the reasonable accommodation of the individual's religious or moral objection to the determination as expressed by the individual, or by the next of kin or other person closest to the individual."⁵

The DOH regulations embraced the 1986 recommendations of the New York State Task Force on Life and the Law (the Task Force), constituted in the executive branch of government under the DOH. The regulations legitimated whole-brain death as a legal standard of death, and resolved any lingering confusion in the aftermath of New York's 1984 *Eulo* decision, which recognized the brain-death standard in a criminal case.⁶ Under the regulations, death "shall be deemed to have occurred" and "official time of death" noted at the conclusion of all examinations and confirmatory tests. Until this confirmation, the patient is legally alive. Before making a final determination, hospitals are to notify family members or others close to the patient that the determination of death "will soon be completed." This is when the patient's family is most likely to voice an objection to neurological criteria for determining death.

If the family objects, how should the medical staff proceed? The regulations offer little guidance regarding what constitutes *reasonable accommodation* of the patient's beliefs and values. Uniform clinical standards for determining neurological death are mandated, but there is no prescribed manner of accommodating conscientious objection. Consistent with the Task Force's recommendation that there be no formal legal exception to neurological death, New York law does not establish a specific and enforceable right to continued interventions and care following determination of death.⁷ Thus, the meaning of accommodation and its ethical parameters are subject to interpretation and may vary across New York hospitals.

In December 2004, the DOH empaneled a study group to review and update state guidelines for diagnosing brain death. The panel's December 2005 report responded to concerns that policy and practice in the determination of neurological death were not uniform across the state. The new guidelines directed that hospitals establish rules for privileging physicians who are qualified to determine brain death. (For example, our hospital requires attendings to be residency or fellowship trained in critical care, neurosurgery, emergency medicine, or several other relevant specialties.) The guidelines also clarified rules for notifying next of kin or others close to the patient, and ensured conformity with the most recent American Academy of Neurology guidelines for clinical examinations and tests.⁸ They reiterated that hospital policies must provide for reasonable accommodation. Here the panel expanded upon the 1987 regulations. The study group stated that "policies may include specific accommodations, such as the continuation of artificial respiration under certain circumstances, as well as guidance on limits to accommodation." It suggested that deliberations on individual cases of accommodation may include clergy, ethics consultants, and conflict mediators. The document also asserted that a family's psychological denial of death does not count as a religious or moral objection and is not protected by New York's conscience clause.⁹

These statements are helpful; they answer some important questions. But the guidelines, essentially commentary without force of law, left a number of unanswered questions. Significantly, the regulations and

the guidance document offer no clear rule for how long ventilatory and other support is to be continued for a patient who meets the criteria for neurological death, nor do they address who bears financial responsibility for care provided during the period of accommodation. It is unclear whether accommodation is triggered upon completion of the necessary examinations and confirmatory tests that mark the "official" time of death, or also encompasses delay in confirming the diagnosis at the family's request. Extant New York law delegates to hospitals the task of parsing these and other questions and defining what is reasonable in the process of accommodating religious and moral objections.

DISSENT FROM CONSENSUS: OBJECTIONS TO NEUROLOGICAL DEATH

While most religions and cultural traditions accept neurological criteria for determination of death,¹⁰ opposition to whole-brain death has existed since emergence of the standard. We will briefly describe the best-known and most widely discussed objections to neurological criteria for determination of death: those found in some segments of the Orthodox Jewish faith and in some segments of Japanese society. Rejection of neurological criteria has also been reported among some Roman Catholics, some evangelical Protestants, some Islamic scholars, and some Native Americans.¹¹ When an objection is asserted, the healthcare team should explore the reasons for the opposition. The primary task of the team, however, is to evaluate the sincerity of the objection, not its conformity with official or widely held positions within the patient's faith or culture.

A minority of Orthodox Jewish authorities, citing Talmudic (Tractate Yomah 85a) and Biblical (Genesis 7:22) passages,¹² hold that the presence of any breath, whether spontaneous or mechanically sustained, signifies life.¹³ As stated by one author, "one whose heart still beats, still lives" and "it would be an act of murder to disconnect [a patient] from a respirator."¹⁴ Most Orthodox Jews, however, accept neurological death as death, holding that only spontaneous breath, without dependence on a ventilator, should be considered life.¹⁵ In 1988, the Chief Rabbinate of Israel effectively sanctioned neurological criteria when it approved heart transplantation.¹⁶ Outside Orthodoxy, both the Jewish Reform Movement and the Conservative Movement recognize neurological criteria for determining death.¹⁷

Many trace the roots of the Japanese debate to an unsuccessful transplant by Dr. Jiro Wada in 1968. Wada transplanted the heart of a young drowning victim, whom Wada himself had declared brain dead, to a patient who may not have needed it. The recipient died three months later.¹⁸ This episode fueled deep distrust of the nascent field of transplantation and of the medical establishment, and sparked fears that neurological criteria for determining death would be used to prematurely pronounce death to procure viable organs. The Japan Medical Association accepted neurological criteria for determining death 20 years after the Wada incident, but the Japanese did not pass legislation officially recognizing neurological criteria until 1997.¹⁹

Deep-seated social, cultural, and religious beliefs have played a critical role in the Japanese debate. Some Japanese "think of the 'heart' rather than the brain as the seat of life and personality."²⁰ Others believe life cannot be centered in any organ and humans are "completely integrated mind-body units."²¹ These views, grounded in Buddhist and Shinto traditions, reject the essential link between life and the brain posited by the concept of neurological death and the underlying Western "Cartesian" paradigm that separates mind and body.²² In one vivid example, one Japanese kidney recipient claimed to have "lost his mind," saying, "My body is no longer mine."²³

There is still considerable public confusion about "brain death." Both healthcare professionals and the lay public at times confuse neurological death with persistent vegetative state. In one recent study, fewer than half of respondents classified brain-dead patients as "dead," instead characterizing patients as "as good as dead" (43 percent) or "alive" (16 percent).²⁴ These findings parallel an earlier study of physicians and nurses likely to be involved in organ procurement, in which only 35 percent accurately identified the legal and medical criteria for determining death.²⁵ This confusion might contribute to reservations about neurological criteria of death or to a "vitalist" view such as, "If I am still breathing on a ventilator I am still alive,"

whether grounded in secular or religious views of what is essential to life. Concerns that physicians will prioritize care of organs over care for patients, reminiscent of the Japanese debate, remain relevant today.²⁶

As discussed below, New York's conscience clause is intended to honor patients' religious or moral convictions. As suggested earlier, we understand this rubric to include "cultural" convictions. The healthcare team's primary task is to assess the sincerity of patients' objections, not conformity with official positions of patients' faith. In GF's case, the ethics consultant and other members of the healthcare team concluded that although the family's objection was out of keeping with official tenets of the patient's faith, theirs was indeed a genuine expression of religious or moral belief. How then should the healthcare team proceed to respect the patient's values?

DEFINING REASONABLE ACCOMMODATION AND REVISITING HOSPITAL POLICY

As noted earlier, the 2005 DOH guidelines required all New York hospitals to review their policies on neurological death. In response to this mandate, our hospital formed a work group, composed of members of the hospital administration, physicians, and the chair of the ethics committee, who acted as liaison between the work group and the ethics committee. Since much of the policy addressed matters that were essentially clinical and well-settled, the ethics committee's charge was to focus predominantly (although not exclusively) on articulating an ethically acceptable and shared understanding of what "reasonable accommodation" means. The ethics committee had extensive and vigorous discussions of the policy over the course of several months.

Extant hospital policy provided that the attending physician bears responsibility for informing the patient's family of the pending determination of death. The policy went on to suggest, but not require, consultation with the ethics committee, social services, chaplaincy, or administration, "If the family is unable to accept a certification of death by neurological criteria." Key parameters for this conversation with the family were established by the policy's 24-hour rule: "A reasonable amount of time, not to exceed 24 hours, will be allowed to resolve religious, moral, or ethical objections to a declaration of brain death by neurological criteria." After this time, the policy authorized cessation of treatment and supportive services, such as intensive care, medications, and artificial nutrition and hydration.

The meaning and implications of the 24-hour accommodation rule were the focal issues in our deliberations. For those who maintained that neurological death is death, and that there is no obligation to treat a dead body, the 24-hour window represented an appropriate compromise, perhaps based on the care and respect owed to the family, more than on the patient's beliefs. Others pointed out that accommodation honors the patient's values and beliefs, and rests on the patient's conceptual understanding that a person is not dead if the heart is beating and the lungs are moving.

GF's family defined death as the point at which the soul leaves the body, which for them meant when the heart stops beating. Disagreement about accommodation was not resolved within 24 hours in GF's case.

This suggested that for both conceptual and practical reasons, the 24-hour rule was flawed, particularly so when framed to give healthcare providers authority to discontinue supportive services after this time. The ethics committee recommended to the work group that the policy simply state that a reasonable amount of time be allowed for accommodation, and that the limiting phrase "not to exceed 24 hours" be deleted. This was intended to allow a flexible approach to accommodation on a case-by-case basis.

In response, the work group proposed a flexible approach of a different sort. The next draft retained the 24-hour rule, but added the language "unless a longer time frame is expressly approved by Hospital Administration." The propriety of putting hospital administration, including hospital counsel, in this role triggered another debate in the ethics committee. Many felt that this approach unduly "legalized" the determination of death and associated patient care. It would put hospital administration in the position of directing physicians to continue or not continue supportive treatment — and force physicians to choose whether to comply. Further discussion revealed that hospital administration merely wanted to be notified if a rare case of objection to neurological criteria arose in the hospital, but did not necessarily want to be in the position of decision

maker. The final compromise, incorporated into the revised policy, provides that hospital administration shall be notified when a family objects to a determination of death based on neurological criteria. The 24-hour limitation was removed. The policy states that supportive services, including intensive care, medications, blood products, artificial nutrition or hydration, and a private duty nurse at the hospital's expense, may be discontinued after a reasonable time. What constitutes a "reasonable time" is intentionally left undefined. Involving the ethics consult service, social services, and spiritual care is recommended, but not required.

New York's conscience exception is based on the values and wishes of the patient, not those of the family. A recent case report in this journal, involving disagreement in an Orthodox Jewish family about their dying father's wishes for end-of-life care, illustrates that at times it may be difficult to clearly distinguish a patient's religious convictions from those of family members.²⁷ The same may be said of secular moral beliefs. Healthcare providers should be attentive to the possibility that families may seek to clothe a patient's objection in religious garb; perhaps because of familiarity with the state's conscience clause or the belief that religious values are due greater respect. Some may attribute their own religious or cultural values (or the strength of those values) to the patient. Consulting with clergy can assist all concerned to clarify their values and convictions, separate their own beliefs from those of the patient, and understand whether the patient's values are in keeping with the official positions of their faith. Still, it bears emphasis that respect for conscience means that the patient's personal convictions that reject neurological death count, even if the teachings of his or her faith accept neurological death as death.

In some cases, family members may be angered by the lack of successful medical treatment, be unwilling to "give up," dispute the diagnosis, cling to hopes of recovery, or be overwhelmed by the perhaps sudden loss of a loved one. In the face of uncertainty or denial about death, families may not be prepared to address decisions about burial, cremation, or planning a funeral. Discussion of organ donation may raise questions about the hospital's commitment to patient-centered care that is respectful of the patient's wishes. We believe that the thoughtful and compassionate involvement of clergy, social workers, ethics consultants, and others can resolve most dilemmas. Education about neurological death may be especially helpful in addressing misunderstandings that do not rest on a different conception of when death occurs. In conversation with families, we should be mindful that those who have not accepted neurological death may simply find it difficult to understand that, with technological support, neurologically dead patients assimilate nutrients, excrete waste, maintain body temperature (albeit subnormal) and are warm to the touch, but are not alive. Although there is no legal obligation to accommodate the values and beliefs of family members, we believe there is an ethical obligation to work with and support them (sometimes characterized as "treating the family"). This may mean delaying withdrawal of ventilatory and other support for a short time. Simply withdrawing support over the family's objection can spark a legal battle, to the detriment of all parties.²⁸

To reject a rule that measures the duty of accommodation in days or hours does not render this obligation open-ended and indefinite. For an adult patient on ventilator support who has irreversibly lost all brain functions, cardiorespiratory death usually occurs within a matter of days of the diagnosis of neurological death. In rare cases, the heart may continue beating for a week or more.²⁹ Those who object to neurological death are at the same time choosing the traditional standard of cardiorespiratory death (not a personalized definition of death). As noted earlier, however, there is no legal right to insist that death be determined on this basis. (By contrast, New Jersey law does create such a right, stating that the time of death is to be fixed upon irreversible cessation of cardiorespiratory functions.) We believe that a reasonable period of accommodation, after which all support should be removed, will emerge under the circumstances of the case; most often this will be a matter of days, not weeks. To better utilize resources and limit costs, hospitals may provide care outside the ICU or in a step-down unit, and may provide only such minimal interventions as are necessary to support cardiac function after neurological death. In the rare case when resources are truly scarce, all interventions should be withdrawn in favor of other patients who need and will benefit from the ICU bed, ventilator, or other intervention. In a given case, these further considerations may serve to mark off the boundaries of reasonableness in accommodating conscientious objection to neurological death.

ADDITIONAL CONCERNS

Two additional issues emerged in our policy discussions. First, who should pay for care delivered during the period of accommodation? Second, may healthcare professionals decline to care for a brain-dead patient during the period of accommodation on the grounds doing so violates their own conscientious values and convictions?

Health insurance policies do not ordinarily cover care provided after the determination of death.³⁰ This care can amount to thousands of dollars. The New York regulations "encourage respect and, whenever possible, an effort to accommodate those patients and their families," but do not address the question of payment.³¹ As far as we are aware, New York law does not obligate insurance coverage for care provided to accommodate conscientious objection following determination of neurological death. Absent third-party coverage, and if the family lacks the means to pay, we believe the hospital should assume responsibility for these costs as charity care. The hospital should avoid suggesting that it will "send the family a bill," as this could intimidate a family into surrendering its objection.

As it turned out, who bore the cost of care during the period of accommodation was not an issue in GF's case. Because GF's spouse objected to confirmation of brain death, the medical team delayed completing the hospital's protocol for determining death. In the meantime, since death had not been declared, GF's insurance covered the cost of care, and if no ethics consultation had been called, it may have continued to do so until GF's heart failed. Once neurological death was clinically confirmed, all supportive treatment was removed. The clinical determination of whole-brain death occurred several days after the primary neurosurgeon first suspected brain death.

This delay in confirming neurological death departs from customary practice. It left uncertain GF's status as alive or dead, arguably involved treating a patient without an accurate diagnosis, and may have added to the family's confusion and allowed unrealistic expectations, leading them to believe that GF might be able to feel pain despite being neurologically dead. Although our response was intended to honor the patient's conscientious objection and to respect the spouse's refusal to consent to further examination for this purpose, it also resulted in increasing the costs of care and extending insurance coverage to cover these costs. For these reasons, accommodation should not proceed without a formal determination of death. New York's silence on the matter of insurance coverage contributed to the uncertainty in GF's case, and arguably created an incentive to delay confirmation of neurological death.

Currently, only our sister state of New Jersey requires that insurance coverage continue during the period of accommodation,³² a strong commitment to respect for a patient's conscientious objection. New Jersey fixes the time of death when the patient meets cardiorespiratory criteria, keeping insurance in place for a patient who is still legally alive during the period of accommodation (continued ventilation is not postmortem care).³³ To follow this example would require a change in New York law. (In cases of organ donation, the costs of care that are provided to a donor-patient to preserve the viability of his or her organs following determination of neurological death typically are covered through the local organ procurement organization, but this rule rests on a different rationale — the interests of the recipient, not those of the donor-patient.)

Most physicians, nurses, and others who provide critical care embrace the view that neurological death is death, as a matter of medical and scientific fact. Others may find accommodation an unwarranted exception to a sound public policy grounded in medical consensus, or may believe that resources supporting a dead body are better used for the living. In a recent publicized controversy, a Massachusetts hospital departed from its past practice of accommodating such objections (although there is no legal obligation to do so in Massachusetts) because staff insisted that treatment of a decaying body was inhumane. The hospital withdrew life support, despite the family's protest, and subsequently prevailed in a lawsuit brought by the family.³⁴

Healthcare providers who reject the rationale for accommodation may assert that it is not reasonable, is medically futile, or there is no professional obligation to treat a dead patient.³⁵ Physicians and other health-

care providers have a well-established ethical and legal right of professional conscience, provided its exercise is grounded in sincerely held values and convictions. A recent study of physicians' attitudes toward three legal but ethically controversial practices — terminal sedation, abortion, and prescribing adolescents birth control absent parental approval — found that some physicians (18 percent of those surveyed) believe that a physician who objects has no obligation to refer the patient elsewhere.³⁶ We believe that a physician or nurse who objects to continuing treatment during the period of accommodation has a duty to transfer care of the neurologically dead patient. This obligation parallels the approach to respect for professional conscience set forth in many advance directive laws across the U.S., pursuant to which providers may transfer care to a colleague when complying with a patient's refusal of life support presents a genuine conflict, but may not abandon the dying patient. As evidenced by the Massachusetts case, the possibility remains that the law will be asked to intervene in cases of unresolved disagreement on the meaning of reasonable accommodation.

CONCLUSION

GF's case presents the question, What constitutes reasonable accommodation of a patient's religious or moral objection to being declared dead on the basis of neurological criteria? As it happens, the case arose in temporal proximity to the New York State Department of Health's call to reexamine and update hospital policies on determination of neurological death. The guiding lesson is that, in the absence of comprehensive legal rules governing reasonable accommodation, institutional policies concerning respect for conscientious objection should avoid defining reasonableness strictly in terms of days or hours of continued support. Policies should establish an elastic framework sensitive to the conscientious beliefs of the patient, the burdens on family at a time of great loss, and professional commitments of healthcare providers. An important area for future study is a qualitative review of whether the policies and experience of New York hospitals reveal a consistent or uniform approach to the meaning of reasonable accommodation.

MASKING THE CASE

Our presentation modifies certain facts and details of the original case. Information that might identify the patient and family, including religious faith, was masked. The family was not asked for their consent in the writing of this article.

NOTES

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