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A Family's Request for Complementary Medicine After Patient Brain Death

Arthur Isak Applbaum, PhD, Jon C. Tilburt, MD, MPH, Michael T. Collins, MD, and David Wendler, PhD

John F. Kennedy School of Government and Edmond J. Safra Foundation Center for Ethics, Harvard University, Cambridge, Massachusetts (Dr Applbaum); General Internal Medicine and Biomedical Ethics, Mayo Clinic, Rochester, Minnesota (Dr Tilburt); Skeletal Clinical Studies Unit, Cranial Facial and Skeletal Diseases Branch, National Institutes of Dental and Craniofacial Research, Bethesda, Maryland (Dr Collins); and Department of Bioethics, National Institutes of Health Clinical Center, Bethesda, Maryland (Dr Wendler).

Abstract

A 19-year-old woman living with relatives in the United States who was admitted for elective cranial surgery for complications related to a congenital disorder developed an acute intracranial hemorrhage 10 days after surgery. The patient was declared dead following repeat negative apnea tests. The patient's father requested that the treating team administer an unverified traditional medicinal substance to the patient. Because of the unusual nature of this request, the treating team called an ethics consultation. The present article reviews this case and discusses other cases that share key features to determine whether and when it is appropriate to accommodate requests for interventions on patients who have been declared dead.

CASE PRESENTATION

DR COLLINS: Ms R was a 19-year-old woman who was living with relatives in the United States for the past several years, while her parents continued to live abroad. The patient was admitted for elective cranial surgery related to complications of a genetic syndrome. Ms R spoke English well and was able to provide consent for the surgery.

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Corresponding Author: David Wendler, PhD, Department of Bioethics, 1C-119, Bldg 10, National Institutes of Health, Bethesda, MD 20892 (dwendler@cc.nih.gov).

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Study concept and design: Applbaum, Wendler.

Acquisition of data: Tilburt, Collins.

Analysis and interpretation of data: Applbaum, Collins.

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Following a successful neurosurgical procedure, the patient was doing well until 10 days after surgery when she complained of acute, severe headache and rapidly became unresponsive. She was transferred to the intensive care unit (ICU) where cranial computed tomographic scanning revealed an intracranial hemorrhage. An attempt by interventional radiology to identify and thrombose the bleeding vessel was aborted due to hemodynamic instability. The patient was then taken to the operating room where the bleeding was controlled. The patient's clinical status did not subsequently improve and she remained unresponsive while on mechanical ventilation. Examination was consistent with brain death and following repeated apnea tests, the patient was declared dead. Because her parents had not seen her in a long time and had no chance to say good-bye, she was returned to the ICU and kept on the ventilator, pending arrival of her parents.

The patient's father, who held her durable power of attorney for health care, arrived within 24 hours of the declaration of death. Her mother was to arrive the following day. The father requested that the ventilator be continued and asked the treating team to administer a purported traditional Chinese medicinal substance to the patient. The father explained that the substance is often used in his native country for a range of conditions, including coma. He asked the treating team to combine "the best of Western and Eastern medicine" to benefit his daughter. After several conversations with the father, it remained unclear in what ways he thought the substance might be beneficial. Ms R's relatives in the United States supported the father's request. In response to the unusual nature of this request, the treating team called an ethics consultation to consider whether to administer the substance for 2 or 3 days while maintaining the patient on the ventilator.

DISCUSSION

DR APPLBAUM: Ethics cases often are evaluated by weighing or balancing the considerations that count in favor and against the proposed course of action and its alternatives. Here, a different approach, what might be called the method of analytic isolation, will be pursued.¹ By considering hypothetical variations on the actual case, one reasons from clear cases to more difficult ones in an attempt to identify the principles that are doing the critical work in one's moral judgments. A first, overarching variation is to suppose, until explicitly modified but of course contrary to fact, that none of the proposed ways of treating this patient are particularly costly, either in material resources or in effort on the part of the medical and nursing staff.

Imagine that this young patient on the ventilator was conscious and was being treated with a conventional drug that had some prospect of medical benefit, and she clearly wanted to remain on the ventilator and continue treatment. Surely she should continue to be treated and not removed from the ventilator.

Now suppose that her physician concludes that continued drug treatment is a clear case of physiological futility, but the conscious, competent patient asks for 1 more trial of medication. By using a clear case of physiological futility, we can avoid debate over the usefulness of a broader concept of futility that includes threshold judgments about probabilities and qualitative assessments of benefit, or whether the broader concept of futility is best understood as a descriptive determination that delivers normative conclusions or one that has normative judgments built in.^{2,3}

Physicians generally should not agree to requests for clearly futile treatments, even when cost is not an issue, because doing so undermines medical professionalism and the supportable claims to expert authority of medical science. The physician is not an all-purpose technical extension of the patient's will and interests, but a professional committed to the good of health

and the relief of suffering by the application of the medical sciences using sound clinical judgment. The terms of a physician's service are properly regulated by the ideals of medicine, reflectively endorsed and broadly conceived. Although the proper practice of medicine will be subject to lively and creative contestation along various frontiers, a physician with professional integrity is permitted, and sometimes required, to refuse to provide requested service that falls far short of medicine's regulative ideals as currently understood.

Respect for the autonomy of the patient requires that a competent patient or her surrogate be allowed to refuse almost all treatments (with some exceptions for refusals that harm others), but such respect does not require the physician to administer all possible treatments. This distinction is underappreciated. No reasonable construal of the demands of patient autonomy or self-governance extends without regard for the legitimate claims of a physician's self-governance. In the service of autonomy, a patient is entitled to be informed of treatment options and of disagreements in professional judgments, and is always free to transfer one's care to another willing clinician. But patients are not entitled to treatment that the treating physician judges to be bad medicine.

Treatments that provide no benefit at all (for example, laevo-mandelonitrile-beta-glucuronoside, commonly known as Laetrile), impose risks of harm that clearly outweigh the benefits (fenfluramine-phentermin, commonly known as Fen-Phen), provide benefits that are not related to health broadly understood (performance-enhancing drugs for athletes), provide benefits that require lack of transparency for their efficacy (placebos), or provide benefits only to third parties (calming a frantic parent by treating a child's viral infection with antibiotics) are all treatments that, in some way and to some extent, fall short of the regulative ideals of medicine. Patients are not entitled to such treatments under a claim of autonomy and the physician ordinarily has strong reasons to refuse. This is so, even if the requested treatment is not costly in resources or effort. Practicing medicine in a way that conflicts with or undermines its regulative ideals either is a violation of commitments a physician already has made or is a failure on the part of the physician to have made the proper commitments. Either way, the physician's professional integrity is at stake.

Compassionate futility at the deathbed, however, seems to be an easily containable exception to the general objection to futile treatment. A good physician treats a patient's suffering and fear as well as the patient's body. If another course of treatment is necessary to assure the patient that every effort has been made, it would be reasonable to agree, even though the extra effort is on strict biological criteria one step past reasonable. Although the clinician is not morally required to administer futile treatments, there are conditions under which futile treatment does not conflict with medicine's ideals, and so is permissible. Alternatively, rather than considering this example an exception from the general objection to futile treatment, one could deny its futility. Although the treatment is physiologically ineffective, it offers important psychological benefits. Either way, if by assumption another round of treatment would be neither costly nor lengthy, the physician ordinarily should accommodate the patient's request.

How should the clinician respond if the patient were competent and said, "I know I am about to die, and in my culture, there is a certain kind of ritual cleansing required in preparation for death that I cannot do myself. I believe that the migration of my soul to the afterlife depends on this preparation. Could the nursing staff help me wash myself to prepare for death?"

Suppose that no relative or cleric can arrive in time to perform the requisite ablutions. Suppose as well that the ritual does not require for its spiritual efficacy that the washer share the meanings that adherents attach to the act, so that the clinical staff is not called upon to endorse the patient's religious tradition. As long as the staff involved has no conscientious objection to doing so and performance of the washing does not detract substantially from their clinical

obligations, they ordinarily should accommodate such a request. Health professionals are not strictly obligated to do so, because the request falls outside the bounds of medical and nursing care, but neither does the request conflict with or undermine any of the ends or ideals of medicine and nursing. If a clinician could compassionately help a patient fulfill a religious duty in this way and if doing so did not violate that clinician's own religious or moral commitments, it would be the decent thing to do.

To administer a traditional remedy on the request of a conscious, competent, dying patient in some respects is like giving physiologically futile conventional care to alleviate a patient's anxiety and in other respects is like performing a ritual washing to accommodate a cultural or religious practice. From the perspective of the patient, of course, there is a third possibility—the remedy is a physiologically beneficial medicine. This discussion supposes that the clinician has no good reason to share such a belief. If there were such reasons, the clinician should not judge the treatment to be futile.

Either way, in treating the whole person, medical professionals may choose to respond to a patient's need in at least some unconventional ways. The medical staff has no obligation to administer the substance and there are countervailing considerations that tell against the practice. Ordinarily, clinicians should refuse to administer a substance that may be toxic to the patient or others, and if this is an unknown substance of uncertain purity, that may be reason enough to refuse allowing it in the hospital. But let us assume, perhaps contrary to fact, that the substance in question is known to be a sterile, harmless herbal preparation. If one grants that the compassionate use of a traditional remedy at the deathbed is a sufficiently clear exception to the futility objection on the grounds that it does not contradict or lead to a general undermining of the regulative ideals of medicine, then again, it would be decent to acquiesce. Not everything that a physician does for a patient has to have a strictly medical purpose.

Suppose now that the patient is alive but unconscious and by advance directive she has asked to be kept on the ventilator and given a traditional remedy, or a member of her family holding a health care proxy and exercising substituted judgment asks the same. Remember that we have assumed there are no countervailing resource considerations. To accommodate her still is not unreasonable. Although she no longer is capable of suffering if the physician refuses, we show respect for her by respecting her prior autonomous will, either by following the content of her directive or by deferring to the decisions of those persons she chose to make decisions for her. Also, when family is involved, health professionals sometimes can attend to their suffering, anxiety, fear, or guilt by deferring to the prior will of an unconscious patient.

In contrast, now suppose that the patient is a corpse without heartbeat whose chest is rising and falling because she is still attached to the ventilator. But her advance directive or her health care surrogate, believing that she is not dead and can be cured or believing that she is dead but can be brought back to life, demands that she be kept on the ventilator and administered a traditional remedy. This crosses the bounds of reasonable accommodation to farce. To initiate medical treatment on a dead body is a farce because actions express meanings in addition to having consequences, and no physician committed to the regulative ideals of medicine can sincerely endorse what such treatment expresses. The patient is dead and any right she may have had to direct and control how she is treated by physicians and nurses ceases with her death. Her prior will controls, within limits, the disposition of her assets and remains, but it cannot control whether she is considered dead or alive. She could have entered into a contract or extracted a promise from her physician to treat her corpse with medicines, or her surrogate may have done so. But unless such treatment provides medical benefits for others, as in the case of an organ donor or a pregnant woman, it would be a violation of professional integrity for a physician to offer or provide service on such terms.

What if the medical staff were asked, either by advance directive or by the family, to prepare for burial in a certain way a corpse recognized by all to be dead? Perhaps, in parallel to the hypothetical case above, the patient's religion holds that the dead body needs to be ritually cleansed in order for the soul to embark on its journey. In the first instance, of course, this is the duty of an undertaker or a cleric, and ordinarily the only responsibility of the medical staff after death is to transfer custody of the body to such a person in a dignified and timely way. So suppose that the tradition requires that the washing be done immediately after death, and those who ordinarily would perform this ceremony cannot arrive in time. Unlike the case of administering curative treatments to a dead body, this is not a medical farce, and so not a violation of professional integrity. It falls outside of the staff's professional responsibilities, but not outside of the bounds of human kindness. If the nurses (for it would be the nurses) have no conscientious objection on their own religious or moral grounds, this is a kindness they may volunteer to do.

In a variation closer to the actual case presented, suppose a patient on a ventilator is dead by brain death criteria, but there is an advance directive asking that she not be declared dead under the circumstances, or a family member, acting under a durable power of attorney, asks that she not be declared dead. How should the medical case team respond?

Consider the criteria for death in more detail. Throughout the United States, either the irreversible cessation of circulatory and respiratory function or the irreversible cessation of the functioning of the entire brain is sufficient to determine death. These may not be the most sound criteria on philosophical or biological grounds.⁴ One may hold that death comes more readily, with the permanent loss of consciousness, or less readily, only when the heart has stopped beating. But whole brain death is part of the common, public standard. One is free to hold that the law is mistaken, but one is not free to choose one's own criterion of death and expect others to act on it. Although some advocate for personal choice in criteria of death, what follows argues against such a position.

A court case, *Crobons v Wisconsin National Life Insurance Company and Wyant*, shows why it is important to have a commonly shared public rendering of death.^{5,6} Mr Crobans, a resident of Michigan, was on life support after suffering a massive stroke. Crobans' business partner, Wyant, owned a \$100 000 insurance policy on the life of Crobans that named Mrs Crobans as beneficiary. On September 12, 1982, Crobans' physician wrote in the chart "neuro-examination consistent with brain death."⁵

Because Mrs Crobans was reluctant to accept her husband's death, the physician agreed to postpone the disconnection of life support. Upon hearing of the brain death of his partner, on September 13, Wyant hurried to make himself the beneficiary of the policy. On September 14, Crobans was disconnected from life support and declared dead.

Wyant, as owner of the policy, was entitled to change the beneficiary as long as Crobans was alive. When, then, did Crobans die? The Michigan Death Act specifies a brain death criterion, but Wyant argued that the purpose of the act was to provide liability protection to transplant surgeons, and so the brain death criterion applied only in transplant cases; for insurance purposes, the older heartbeat criterion governed. The most plausible construal of Wyant's position is that, apart from transplantation, patients and families may choose which death criterion to use. Mrs Crobans was still refusing the brain death criterion on September 13, and therefore that made it the case that Mr Crobans was still alive when Wyant named himself beneficiary.

Federal district and appellate courts rejected Wyant's claim. "The plain language of the statute requires that the method of determining death, prescribed under the act, 'shall be used for all purposes in this state including the trials of civil and criminal cases.'"⁶ In Michigan, brain

death is death for everyone and for all purposes, and does not turn on an individual's intentions or beliefs.

To have different criteria of death for different purposes, or to let the choice of criteria turn on the intentions or beliefs of the dying, is not necessarily incoherent. If the correct criterion of death is not simply a scientific or metaphysical fact but rather a practical, normative judgment that supervenes on such facts, then in principle the criteria of death within some range can be plural or intention-dependent and laws reflecting that could be written.

For instance, New Jersey does not permit death to be declared on neurological criteria if it would "violate the personal religious beliefs of the individual."⁷ Similarly, New York requires that hospitals make "reasonable accommodations" to those persons who object to brain death criteria.⁸ But to give up on a common and public rendering of death, as New Jersey and to some extent New York have done, is a spectacularly bad idea. Whether prosecutors may charge assailants with murder should not turn on the religious beliefs or advance directives of their victims, and it is a counsel of confusion for someone to be alive for life insurance companies but dead for health insurance companies.

Put more generally, when the interests and obligations of third parties are affected, and others are called upon to take important action or shoulder significant burdens, a common and public rendering of the time of death is needed. Members of a political society may collectively choose one criterion or another, or collectively agree that death is a process, not a moment, and set up special rules for the dying. An individual, including no doubt many individual physicians, may hold that the public standards are mistaken and continue to believe that there is an important moral difference between cold corpses and perfused brain dead bodies on ventilators.⁹ But it cannot simply be up to an individual to decide for others when that individual should be treated as alive and when that individual should be treated as dead. Therefore, there are limits on how much accommodation clinicians may or must make to families or patients whose cultural traditions disagree with the publicly rendered criteria of death.

Consider now the final counterfactual variation. Continue to suppose that treatment in the ICU is not costly, but otherwise take the facts of the case as they are: the parents of a patient who has been declared dead ask to keep her on the ventilator and initiate a trial of a traditional remedy. The request can be separated into 2 parts: a request not to withdraw treatment (the ventilator) and a request to initiate treatment (the traditional remedy).

Although the distinction between withdrawing and withholding treatment does not always make a moral difference in end-of-life care, here there is a moral asymmetry between not disconnecting and initiating. When taking positive action to treat a dead body, it is hard to rebut certain presumptions about intentions and reasons. The burden is on the clinician to explain why the action does not express either endorsement of futile treatment or rejection of the brain death criterion. But a short delay in disconnecting does not immediately express endorsement of futile treatment or rejection of brain death, so does not immediately implicate the clinician's professional integrity. When it comes to attributing intentions and reasons to an agent, inaction usually has more degrees of freedom than action.

Physicians may attend to human suffering in somewhat unconventional ways. The parents are not patients in the care of this physician, so there are limits to what can be reasonably expected in this regard. Also, there is reason to worry that delaying the disconnection of the dead from ventilators unintentionally undermines the practical acceptance of the brain death criterion. To be clear, it is practical, not epistemic acceptance that is sought. If parents, on reflection and deliberation with clinicians, continue to believe that a child declared dead by brain death criteria is still alive, it is both insulting and unnecessary for medical authorities or institutions to insist that they are mistaken. All the clinician can reasonably expect is that the parents reconcile

themselves to the consequences, tragic from their perspective, of not having the authority to command professional caregivers and public institutions to act in accordance with their private beliefs. But a sensitive physician ought to be able to find a decent interval that steers between shock and denial. So, as long as we maintain the assumption that maintaining a patient in the ICU is neither costly nor burdensome, disconnecting the body from the ventilator may be delayed for a short while, as is commonly done, to allow the family to come to terms with the death. Similarly, if the patient, while alive, sought reassurance from her physician that the withdrawal of care be delayed, such reassurance, within limits, could be given to comfort the dying, and once given, should be respected. This is not the same as deferring to a patient's chosen criterion of death. That is not a matter of individual choice controlled by an advance directive or by medical surrogates.

As for initiating the traditional remedy, the answer depends on whether the action is more like helping someone perform a religious ritual over a dead body or more like administering futile medical treatment to a dead body, and this may turn on subtle interpretations of the meanings given to the practice. The medical staff may, at its discretion, accommodate the performance of a religious ritual. Her physician can act as if she is alive for religious purposes, because this does not ask the clinicians to endorse a criterion of death that is contrary to the publicly and professionally accepted one. But the medical staff ordinarily should not participate in what amounts to a medical farce by engaging in what necessarily is the futile medical treatment of a dead body, even if this would bring comfort to the family or, in anticipation, to the dying, and even if the family's reason for believing that the remedy is medically efficacious has a religious or cultural ground.

An important lesson of this case is that, when confronted with patients who make unconventional requests that are grounded in cultural or religious practices or beliefs unfamiliar to the physician, it is important for the physician to understand what reasons underpin the request.^{9–11} In this case, does the family reject the brain death criterion on religious grounds? Does the request simply reflect temporary reluctance to accept bad news, and not principled rejection of the criterion? Do they accept the criterion but are uncertain whether its conditions have been satisfied in this case? Is the traditional preparation believed to be spiritually efficacious or physically efficacious? If physically efficacious, is the remedy believed to be medicine that operates within natural laws, a ritual or magical preparation that operates in a supernatural realm, or do they not make such distinctions? A sensitive and nuanced understanding of why patients and their families seek unconventional treatment is valuable in at least 2 ways: the clinician will have more sound grounds on which to make accommodation decisions at the boundaries of good medical care, and the clinician may discover that the underlying concerns are not what they appear to be on the surface and can be met in ways that fall well within the boundaries of good medical care.

Up to this point, the hypothetical variations have assumed that treatment is not costly. But care in the ICU is quite costly in 2 ways. First, a 3-day stay in the ICU is very expensive monetarily—according to internal hospital estimates, on the order of \$9000 to \$18 000 in direct marginal costs before considering the cost of infrastructure and overhead. Second, an ICU patient requires around-the-clock devotion of time, energy, and concern from nurses and physicians. Even if the family reimburses the federal government for the entire monetary cost of care, the medical staff may still have a complaint: they are being asked to devote themselves to a purpose that falls outside of their professional commitments and that in part undermines those commitments. They signed up for the care of patients, and they are being tasked with the care of corpses. So a complete assessment of this case must include the burdens that the continued treatment of a dead body puts on both the public's resources and the medical staff.

Because, as citizens, we respect the freedom and autonomy of others, we need a good reason to impose the views of the majority on minorities. Ordinarily, we should take a tolerant and accommodating view of differences in value and belief.¹² We cannot do without a shared public rendering of death, but we should allow individuals the liberty to act on contrary understandings of death as long as important third parties and important other stakes are not involved. This is why, in the hypothetical scenarios above, requests for futile treatment, traditional treatment, and ritual treatment could be accommodated when they are not burdensome in monetary costs or affronts to the professional commitments of the medical staff. But accommodation has its limits. One limit is clear—it is unreasonable to devote substantial public resources and professional energies to the care of a body that, on public and professional criteria, is dead, and this is so even when the religious tradition of the deceased considers the body to be alive. When these burdens are small, perhaps accommodation is optional. But when these burdens are considerable—and a few days in the ICU is considerable—the medical staff not only is entitled to say no, but it must say no.

Ms R should have been disconnected from life support at the time that brain death was established. Instead, the medical staff initially planned to keep her on the ventilator for the 2 days or so that it would take for both of her parents to arrive from abroad and have “a chance to say good-bye.” This is a common practice that looks like minimal decency in particular instances but has 2 unfortunate consequences—a material delay is a mistaken waste of the public’s resources, and it has the general effect of perpetuating the view that brain death is not real death. If the asymmetry drawn earlier between not withdrawing treatment and initiating treatment holds, the physician need not run to the ventilator switch under pain of being taken for a brain death denier. Inaction admits more degrees of interpretive freedom. But unlike the low-cost hypotheticals considered above, time in the ICU is very costly both monetarily and in the professional effort of caregivers, and so cost becomes a binding constraint. When costs are at issue, a delay of more than a few hours seems excessive.

Nonetheless, once the decision had been made to keep her on a ventilator until the arrival of both of her parents, administering the traditional remedy while waiting for the second parent would not at the margin be costly in resources. If one construes the administration of the traditional remedy as a religious ritual, and not as futile medicine, the integrity of medical practice would not be undermined, and so it would not be wrong to accommodate the father’s request while waiting for the mother’s arrival.

Such a construal, however, is strained. An interpretation that entertains the traditional remedy as religious ritual poses the case in its most interesting form, and such cases no doubt occur. Although not all that one would want to know about this case is known, on the basis of the facts presented this interpretation is implausible. In the end, the actual case is best considered from the family’s perspective as a request for what it hopes is the medically efficacious treatment of a living patient by combining “the best of Western and Eastern medicine.” From the physician’s perspective, there is little choice but to view compliance with such a request as the medically futile treatment of a dead body. On this reading of the case, the traditional remedy should not be administered at all.

CASE REVISITED

The treating team wanted to respect the family’s cultural values and recognized that administration of the traditional medication posed no risks to the (dead) patient. In addition, the clinical team thought that a limited administration would help the family come to terms with the patient’s death. The ethics consultation team concluded that “given the psychological benefits to the family ... and the absence of risk to the patient” (since she was dead), it was

permissible for the team to accommodate the family's request so long as clear time limits were in place (2–3 days maximum).

In light of these recommendations, the team agreed to administer the substance and maintain the patient on the ventilator for 48 hours. Three days after the declaration of death, the family requested additional administration of traditional therapy, but this request was denied. A time for withdrawal of support was selected by the family to coincide with optimal timing according to Eastern mystical charts, a ritual was performed at the bedside, and at the selected hour support was withdrawn.

CONCLUSION

This case exemplifies the challenges in handling cross-cultural ethical conflicts in modern medicine. During a time when much attention is being directed toward improving clinicians' cultural competence, this case study illustrates the importance of explicitly discussing how health care professionals can work with patients whose health beliefs, practices, and values may be unfamiliar, recognizing that accommodation has limits when it comes with real costs to others and society.

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