Ethics in Neuroscience: 
Mind Over Matter?

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In this paper, I propose to address an old problem in a contemporary context. The old problem is justifying decisions that hasten the deaths of persons with severe brain injury who are, by definition, incapable of deciding for themselves. The modern context is a developing insistence that medical decisions be evidence-based and cost-effective.

In important respects, the old problem is more taxing than that of physician-assisted suicide. Would-be suicides are usually competent and demonstrably suffering, but here the focus is on persons who are neither competent nor discernibly suffering. Indeed, it is persons with strong emotional ties to the brain-injured who are the most evident sufferers.

My particular concern is whether neurologists and neuroscience can offer special insights to those mulling decisions that will hasten death, be they families or primary caregivers. Note that I said “special insights, not just information about diagnosis and prognosis. I presume that neurologists can accurately characterize brain injury and that their opinions on this matter can be helpful to those who face hard choices about whether to withhold or withdraw treatment. But does expert knowledge of the human brain lend peculiar authority to neurologists’ opinions about such ultimate questions? Can neurologists say when consciousness is gone forever -- even if they can’t exactly define what consciousness is? Can they characterize pain and suffering in one who can neither speak nor move? Can they define an appropriate allocation of societal resources for such persons? Even if we suspect neurologists’ opinions on such matters are not rigorously derived, are these opinions nonetheless entitled to extra weight because they issue from experts in brain science?

All this rhetoric should not be interpreted
as a heresy against neurologists and neuroscience. My intent, rather, is to open an inquiry into the roles of experts and formalism in decisions that may occasion the deaths of severely brain-injured persons whose wishes are unknown or undetermined. To set the stage for the inquiry, I will highlight two recent position statements of the American Academy of Neurology and review various ethical and legal justifications for hastening the deaths of persons with severe brain injuries. This account should serve to highlight some of the difficulties and ambiguities that may arise. I will then probe the relevance and reliability of neurological opinions for decisions about care of the severely brain-injured and will close with some reflections on how much process is needed to ensure clinically accurate and ethically sensitive decisions.

Decisions that Hasten Death

A. Positions of the American Academy of Neurology

The American Academy of Neurology is the world’s largest assemblage of neurologists; its membership also includes many nonphysician neuroscientists and a few psychiatrists. In recent years, the Academy has spoken out on two high-profile issues relating to care of persons with catastrophic brain injury. These statements, cast in ethical tones, rest on certain assumptions about neurologists’ capacity to generate reliable information about the scope and outcome of brain injury. The first statement considers care of persons in a persistent vegetative state (PVS). The second statement deals with the ethics of taking organs from living anencephalic infants for transplantation. The former emphasizes consciousness as the touchstone of decision making, while the latter underscores the sanctity of human life.

1. The Persistent Vegetative State (PVS)

Adopted by the executive board in 1989, the Academy’s statement asserts that PVS is diagnosable by clinical criteria with a “high degree of medical certainty” and that persons in a PVS are “completely unconscious” and therefore unable to experience pain or suffering. Once PVS has been “reliably diagnosed,” and it is “clear that the patient would not want further medical treatment,” it is deemed ethical to withdraw all treatment if the patient’s family concurs. Artificial nutrition and hydration are included within the rubric of medical treatment, and the Academy’s statement explicitly declares that there is no medically or ethically significant distinction between withholding and withdrawing treatment.

2. Infants with anencephaly

Here the focus is on the status of anencephalic infants as living persons. They are presumed to be alive if their hearts are still beating, despite the facts they are unresponsive and require ventilators and other aggressive treatment to sustain vital nonneurologic functions. The Academy invokes the “dead donor” rule set forth in the Uniform Anatomical Gift Act to support the position that it is unethical to remove organs for transplantation from anencephalic infants who are not brain dead. That the infants are unconscious, that they have little prospect of survival for more than a few days and no hope of attaining sentience, are not seen as pivotal concerns. Indeed, when the American Medical Association recently declared that use of organs of anencephalics for transplantation is ethical, the Academy — along with other organizations — pressured the AMA to reverse its stand. The central
argument was that the “dead donor” rule precluded removal of organs or tissues before cardiac standstill occurred. Moreover, the national press quoted one Academy member as saying that the issue of recovery of consciousness in infants with anencephaly is “unresolved.” In the legal sphere, the Florida Supreme Court has taken a similar tack, finding that an anencephalic child was not brain dead and barring organ transplantation agreed to by the child’s parents.

3. *Inconsistent positions?* On one level, the two Academy statements appear inconsistent. Thus, it is thought ethical to end the lives of persons in a PVS because they will never regain “consciousness” but unethical to remove the life-sustaining organs of anencephalic infants, unconsciousness notwithstanding. Observable anencephaly, however, may be a better predictor of permanent unconsciousness than bedside neurologic evaluations or neuroimaging studies. Persons in PVS often open and move their eyes, utter sounds and move their limbs spontaneously or after stimulation, behaviors that pose difficulties for examiners trying to assess whether a scintilla of awareness is present.

Still, the inconsistency may be more apparent than real. The frank instrumentalism of taking organs from anencephalic infants to benefit other infants with better prospects may simply be too coarse to bear, no matter how severely afflicted the “donor” or how urgent the need for transplantable organs. Moreover, creating a precedent for taking transplantable organs from the severely brain injured arguably opens the door to intrusions on other helpless humans whose lives are thought not worth living and thus subject to claims for the “greater good.” These concerns about a slippery slope could just as well apply to persons who are permanently unconscious, however: Hastening the deaths of persons in PVS could greatly ease the burden on families or on a public saddled with escalating health care costs.

Regardless of consistency, the Academy’s positions reveal an enduring tension about what version of life merits the greatest protection. Is it mind in the form of human consciousness or matter in the form of a detectably functioning human brain? To display this tension in another way, I turn to some justifications that ethicists, scholars and courts have tendered for decisions that hasten the deaths of persons with severe brain injuries. I will then revisit the matter of the Academy’s consistency of viewpoint, and take a closer look at neurologists’ role in deliberations about hastening the deaths of the severely brain-injured. An important goal of this strategy will be to underscore the limits of neurological expertise.

B. Justifying decisions to remove life support

1. *“Neocortical death”* Several years ago, law professor David Smith proposed that the law treat irreversible loss of cognitive (“neocortical”) functions of the brain as the equivalent of brain death. His proposal rested in part on a postulated capacity of positron emission tomography (PET), a complex neuroimaging technology, to provide objective proof that the neocortex is nonfunctional. Although Smith’s proposal has not attracted wide support, it nevertheless emphasizes just how close a permanent vegetative state is to brain death. Indeed the proposal challenges those who accept the notion of brain death to articulate
why the polity should draw a bright line between the two states of unawareness.

A simple response to the challenge is that, in the present state of the neurologic art, a diagnosis of brain death is substantially more secure than a diagnosis of neocortical death. A variant of this response is that the attempt to define life in terms of level of awareness risks indeterminacy. Arguably there are so many conceptual difficulties inherent in defining human consciousness that its presence or absence should not be used as a decisional criterion. It may be easier to assign moral centrality to the status of the human brainstem. If the brainstem is functioning, a person can breathe and maintain a heartbeat, and is therefore alive. Once the brainstem ceases to function, however, cardiac and respiratory functions soon cease as well. In this construct, it is not the mind that takes priority, but matter, symbolized by a human form and enough brainstem function to sustain other vital organs.

2. Permanent Unconsciousness If the public views consciousness as the central attribute of human life, it may accept the notion that an unconscious person, however defined, has a diminished claim to ethical and legal protections. Several judicial rulings are consistent with this conclusion. Beginning with the ruling in the Quinlan case some 20 years ago, several courts have concluded that the public interest in protecting life wanes as the degree of neurologic impairment increases. The U.S. Supreme Court recently reiterated this view by declaring that the federal constitution protects the right ("liberty") of a permanently unconscious person to opt for removal of life support. The U.S. Congress, while professing a dedication to protecting severely impaired newborns from death-hastening decisions by parents and caregivers, created an exception for neonates who are "irreversibly comatose," and the American Medical Association has joined the American Academy of Neurology in asserting ethical endorsement for removing life support from permanently unconscious patients.

When death-hastening actions have been challenged as unlawful homicides, courts have offered two sorts of justifications. One is that the actions are justifiable because they protect the exercise of fundamental rights or liberties; the other is that the actions are not a legal "cause" of death since they merely allow a fatal illness to run its natural course.

3. Autonomous Choice For those who hold that permanent unconsciousness alone does not justify hastening death, invoking the autonomy principle may supply an added measure of persuasion. The crux of the Cruzan litigation was not whether Nancy Cruzan was permanently unconscious. About that there was little argument. Rather, the central issue was whether ending life support was consistent with her wishes. The high court upheld a Missouri supreme court ruling that required "clear and convincing" proof of her preference to decline artificial feeding as a prerequisite for authorizing removal of her feeding tube, and it was not until her parents assembled such proof that removal of the tube was permitted.

Courts in New York, Massachusetts and, more recently, Michigan have taken a similar approach, and the Academy of Neurology's statement on PVS indicates that removal of life support is ethical only "when it is clear that the patient would not want further medical treatment." In other words, under a decisional standard that emphasizes autonomous choice, proof of permanent
unconsciousness is but a step to the threshold. A further requirement is proof that the person would prefer to end life. An unambiguous advance directive may suffice in this respect, as might oral statements to family or friends if they are explicit enough.

It may be impossible to determine the autonomous preferences of permanently unconscious individuals. In this circumstance, the doctrine of substituted judgment offers a way of implementing the autonomy principle. The doctrine assumes that appropriate proxies can be found to exercise choices the brain-injured individuals would have made if capable of deciding for themselves. Appropriate proxies may include family members, significant others and court-appointed guardians. To secure legal immunity, the proxies sometimes seek advance judicial approval for actions that may hasten death. Even if substituted decision making is thought generally appropriate, concerns about the slippery slope may limit its application. Many persons with severe brain damage retain some detectable awareness but are patently incompetent to make any health care decisions, much less a decision as momentous as opting for death. Their families, attending physicians and other caregivers may all agree that it is wrong to sustain their lives, and families may be able to offer persuasive reasons why they are appropriate proxies to make such a choice. But if proof of unconsciousness is a condition for invoking the substituted judgment principle, suitable proxies may question their authority to act if there is any evidence of residual awareness.

At first blush, it would seem that advance directives, such as a living will or the appointment of a health care proxy, should eliminate any need to invoke the substituted judgment doctrine. Various studies, however, reveal that most persons do not execute advance directives and that, even if they do, caregivers may be unaware of them. Even if an advance directive exists, it may be denied operative effect.

For example, suppose that I, while undeniably competent, execute a detailed advance directive. In it I assert that, in the event a qualified physician determines I have Alzheimer's disease, I prefer a do-not-resuscitate order and the withholding of treatments that might extend my life, such as antibiotics or ventilators. Here my autonomous choice is clear. My physicians may have concluded that I have Alzheimer’s disease and that no treatment will alter its course. But if my proxies or caregivers believe I am not suffering when the diagnosis is reached, concerns about the present authenticity of my request, or more general concerns about sanctity of life or slippery slopes, may cause them to override what was a competent and heartfelt expression of choice when I made it. I may then be left to endure years of what I have unambiguously defined for myself as an intolerable existence, all in sharp violation of the autonomy principle.

4. The beneficence principle Physicians' ethical obligations encompass offering potentially beneficial treatments and withholding unhelpful or harmful treatments. For the severely brain-injured, the small universe of helpful treatments includes measures that sustain vegetative functions (e.g. ventilators, feeding tubes) while any
healing of the brain occurs. At some point, however, these treatments may serve only to sustain life while offering no comfort or hope of neurologic improvement. The treatments would not be overtly harmful unless they caused detectable pain or suffering, but neither would they be palliative in the sense of improving personal well-being. Classifying them as “beneficial” to the afflicted person is therefore highly problematic.

Proxies and caregivers could rationally conclude that severely impaired life is better than no life at all. For them, the beneficence principle would require that life support be continued. But they also could determine, with comparable rationality, that life with severe brain injury is worse than no life at all, or that both states are indistinguishably grim. They might then conclude that hastening death is compatible with a beneficence-oriented ethical standard.

Law can be less forgiving than ethics here. One example is the Cruzan litigation. Nancy Cruzan’s parents were convinced that they were doing the right thing for their daughter by requesting removal of her feeding tube. But Missouri law, as upheld by the Supreme Court, made the parents’ calculus of benefits and burdens irrelevant. No matter that Nancy was thought to be permanently unconscious. What counted most was her wishes. If they were not discernible, removal of her feeding tube would be unlawful, no matter how compelling the evidence that her quality of life was abysmal or that her parents adjudged her continued survival as more burdensome to her than beneficial. Similarly, in Martin v Major, considerable evidence indicated that a conscious but severely impaired man would have preferred death to his existing state, and a hospital bioethics committee had determined that removing life support was ethical. But because his wife and guardian could not prove that he had precisely addressed his present predicament while competent, the Michigan supreme court rejected her request for authorization to remove his feeding tube.

There is no presumption in law to the effect that, absent contrary evidence, a person with catastrophic brain damage will opt for death. Indeed, the presumption is just the opposite. The formula proposed by the New Jersey Supreme Court in the Conroy case, however, bespeaks a judicial willingness to allow caregivers to apply an objectively oriented benefit/burden analysis where subjective preferences are undiscernible. Even here, however, the court defined a cognizable burden in terms of intractable pain, emphasizing the need to establish that a neurologically impaired individual is actually suffering. For the unconscious or barely conscious person, proving subjective experience, such as suffering, represents a nearly insuperable hurdle.

5. Utilitarian calculus The social costs of caring for individuals with advanced brain disease are large and incremental. Evolving public health measures and medical advances assure a continuing graying of the population, and a proportion of these elders will inevitably suffer age-related neurodegenerative disorders and neurological complications of systemic illness. Moreover, over the near term at least, medical treatments are likely to be more successful in prolonging lifespans than in countering the ravages of severe brain disease. At some point, therefore, the polity will squarely face questions as to whether it should expend its resources on measures that only prolong gravely impaired lives at
great expense without measurably affecting the quality of those lives.

In these circumstances, policy makers may feel pressured to formulate guidelines that contemplate limiting care for some brain-injured persons. The preferences of brain-injured individuals or their proxies may then become, if not irrelevant, a matter of secondary concern. An example of things to come might be the Oregon Medicaid program. Under its prioritized schedule of condition-treatment pairs, for example, costs of treatments adjudged to have little or no potential for reversing serious afflictions are not reimbursable; this category includes lifesustaining care for persons in PVS. Oregon law does not explicitly bar life-support for those in PVS. It merely relieves the state Medicaid program of any obligation to pay for such ostensibly futile care, leaving the responsibility for payment to families and other citizens -- if they wish to continue care.

Translating these utilitarian considerations into ethical or legal guides for care of the severely brain-injured is touchy at best. In a democratic society, citizens are empowered to expend their resources as they deem fit. The United States already spends billions on health care each year and can probably afford to expend even more if citizens agree to endure sacrifice in the form of higher taxes or reduced spending on other social programs. Still, our legal system offers no constitutional entitlement to health care. Moreover, the majority of citizens seemingly accept the facts that millions of their fellows lack access to essential health services, and that -- true to the tenets of a market economy -- relative wealth will determine the amount and quality of medical care that individuals receive.

In this cultural setting, it is not difficult to envision a growing societal tolerance for scaling back on care for the severely brain-injured, especially those who require large and continuing expenditures of public funds. A straightforward ethical justification for rationing of this sort is that health care resources are finite and must be expended where they do the most good. Under this principle, the severely brain-injured would have a weak claim on a share of such "finite" resources since they have so little to gain from treatment. Whatever claim they have would seem to rest on the notion that all human lives have intrinsic worth, regardless of severity of neurological impairment, and that an ethical society will expend a decent minimum of resources to sustain the lives of all its citizens.

The limits of neurological expertise

A. What version of life is at stake?

The American Academy of Neurology's statements about persons in PVS and infants with anencephaly exemplify contrasting versions of life. The PVS statement emphasizes consciousness as the status that confers special value on human life, while the anencephaly statement argues for protecting nonsentient human life from actions that would end that life, even with altruistic intentions.

The two statements thus illustrate a problem that can emerge when neuroscience is invoked in formulating ethical justifications for conduct that hastens death. Certainly neurologists and neuroscience can describe severity and prognosis of brain injury, but such data are dispositive only if society agrees that the level of neurological function determines how much ethical and legal protection is due to its brain-damaged citizens. If such a consensus exists,
neurological opinions are crucially important; if these opinions are that important, they
deserve the most rigorous scrutiny.

1. Consciousness as the central value

Without attempting to define consciousness, the Academy's statement about PVS asserts
that permanent unconsciousness can be reliably diagnosed. Subsequent published work tends to support this assertion.
Especially noteworthy is a two-part report in the prestigious New England Journal of Medicine that extensively reviews existing knowledge about PVS.30

Two kinds of evidence underlie the confidence expressed by the Academy. One derives from accumulated observations of experienced neurological clinicians applying established criteria for the diagnosis of PVS,31 coupled with studies indicating that individuals vegetative for longer than one year rarely regain detectable awareness. The other kind of evidence comprises brain-imaging studies during life and post-mortem neuropathological studies. The imaging studies have demonstrated that persons with a clinical diagnosis of PVS have striking reductions in blood flow and metabolic activity in regions of the brain thought to subserve consciousness.32 Autopsy studies have revealed extensive structural damage in these same regions.33

Assume for the moment that PVS can be reliably diagnosed using methods of neurology and neuroscience. How might neurologists utilize that information to aid proxies in making decisions about life support? For example, can neurologists adequately communicate what it is like to be unconscious? Can they confidently assure proxies that persons whose eyes are open and who occasionally utter sounds experience neither pain nor pleasure? More concretely, can they predict with reasonable accuracy how long a person in PVS will survive? Many neurologists can, of course, draw upon their own experience to relate the travails of long-term care for persons with overwhelming neurological impairments. But this information seems rather tangential to the larger question of whether permanent unconsciousness justifies proxies in opting to hasten death.

Viewed from that perspective, the role of neurological opinion in cases of adults in PVS is narrow but pivotal -- narrow because the core ethical issues must ultimately be resolved by others; pivotal because without a reliable diagnosis of permanent unconsciousness, those issues may not be ripe for discussion.

Neurological opinions may be even less important where debate centers on whether to end life support for brain-injured persons with rudimentary awareness. For example, suppose the wife of a man with advanced Alzheimer's disease asks his physician to remove his feeding tube, relying on conversations she had with her husband when he was sentient. A neurologist's confirmation that he is profoundly demented and that no treatment will alter the course of his disease is irrelevant if permanent unconsciousness is the only justification for hastening death. Even if it is lawful to remove life support from a barely conscious person, moreover, a neurologist's opinion about the rightness of removal would not qualify as expert knowledge. Suppose that a neurologist believes it is unethical to remove a feeding tube from a barely conscious person. To the assertion that the neurologist's personal ethical views are irrelevant, the response might be that participating in removal of the feeding tube would contravene the position statement of the American Academy of Neurology on
PVS, violate a basic societal commitment to protecting human life, offend against professional ethical injunctions to do no harm, or infringe upon strongly held personal beliefs.

These are compelling arguments, akin to those voiced by physicians and their organizations in contemporary debates about physician-assisted suicide, but they do not derive from neuroscience and call for no expertise peculiar to neurologists. They are essentially pleas to respect the sanctity of life in the face of potent pressures to ease the lot of caregivers or to reduce social costs of futile or cost-inefficient care. Certainly these arguments could justify a neurologist’s refusal to participate in removal of a feeding tube from a barely conscious person. But they do not constitute an expert opinion on the issue of whether the tube ought to be removed.

If identifying permanent unconsciousness is indeed the principal contribution neurologists can make to deliberations about ending life support, the reliability of neurological opinion is of great moment. As noted earlier, there is an apparent consensus that the vegetative state is diagnosable and that its prognosis is determinable.

Although consensus about diagnosability of PVS seems secure, there is some fraying over prognosis. The authors of the comprehensive study in the New England Journal of Medicine concluded that recovery of consciousness in adults vegetative for more than one year is “exceedingly rare.”34 The few persons reported to have regained consciousness -- including a woman who had been vegetative for 36 months -- had severe neurologic impairments. A more recent case report in the same journal described a woman who regained consciousness after 17 months in a vegetative state caused by traumatic brain injury.35 The authors estimated that the incidence of recovery of awareness after one year in a vegetative state may be as high as 14 percent, a much higher figure than suggested by the larger paper.

If the accuracy of prognosis at one year is indeed this uncertain, what kind of opinion can today’s neurologists offer families, courts or ethics committees? The available data would easily support an opinion that an adult who has been vegetative for one year probably will not regain consciousness. The data might even satisfy the more stringent legal standard of “clear and convincing” proof. But they do not appear to meet the exacting standard of moral certainty inherent in the legal standard of “beyond a reasonable doubt.”36 However, a neurologist could testify with moral certainty that, even if consciousness returns, residual neurological disability will be significant and independent living impossible.

It is difficult to decide whether decision makers will or should be persuaded by an opinion based on less than moral certainty. If the prevailing ethical view is that level of neurologic function is a valid determinant of the level of care, one could argue that decision makers should accept opinions based on the sort of probabilities physicians customarily apply in clinical practice.

Few clinical decisions rest on moral certainty, of course; clinicians usually employ a less exacting standard. Yet where the result of a decision can be to cause or hasten death, proxy decision makers may insist that a neurological opinion derive from something close to moral certainty. Other proxies might take into account the certainty that the vegetative individual who regains consciousness will remain significantly impaired and may therefore tolerate some
degree of prognostic uncertainty about return of consciousness. Nevertheless, the
fact that a decision could hasten death ensures an enduring concern on the part of
proxies that predictions of outcome are accurate.

2. Life as the central value In its resolution about anencephaly and organ
transplantation, the Academy declared that anencephalic infants are living persons
because they are not brain dead; therefore, ending their lives by removing vital organs
for transplantation is unethical.\textsuperscript{37} In this respect, the Academy’s statement defines life
in the anencephalic neonate in the negative: absence of proof of medically defined brain
death.

In surviving anencephalics, residual though impaired brainstem activity may
support enough cardiorespiratory function to allow survival in intensive care units for days
to weeks.\textsuperscript{38} Rarely, as in the case of Baby K,\textsuperscript{39} the brainstem will function well enough
to allow longer survival. By contrast, despite a reduced life expectancy, individuals
in PVS commonly survive for many years in nursing homes or extended care facilities.\textsuperscript{40}
Unlike anencephalic infants who are visibly deformed and ordinarily require respirators
to survive, those in PVS usually have a normal body habitus, and do not require respirators (They do, however, require feeding tubes.)

The Academy regards both anencephalic infants and individuals in PVS as living.
Although both are unconscious because the anatomical substrate for consciousness is
deemed absent, neither meet generally accepted criteria for brain death until their
brainstems cease to function. In the case of anencephalic infants, that usually occurs
within hours or days, no matter how aggressively they are treated. Their
compromised brainstems usually do not support longer survival. In PVS, brainstem
failure (i.e., brain death) ordinarily occurs as a secondary phenomenon after
nonneurologic diseases develop (e.g., pneumonia, sepsis). In either case, however,
removal of nutritional support causes death by starvation or dehydration.

Do these observations imply that the neurological definition of human life reduces
to an intact brainstem, or at least one that works well enough to sustain other vital
functions? If simply not being brain-dead supplies an anencephalic infant’s life with
protected moral status, then what the polity needs from neurologists and neuroscience is
reliable opinion about whether anencephalic infants are or are not dead by neurologic
criteria. Opinions about levels of consciousness or predictions about outcome are irrelevant.

Suppose, however, that the ethical issue is whether to sacrifice the already doomed
lives of anencephalic infants in order to save the lives of children with better prospects.
Neurologists could offer defensible expert opinions that the infants are and will remain
unconscious, are likely to die soon and are unlikely to suffer during surgical removal of
their organs by transplant surgeons. Such opinions could obviously be useful to those
weighing the legal\textsuperscript{41} and ethical\textsuperscript{42} propriety of taking organs of living anencephalic infants
for purposes of transplantation.

Neurologists’ opinions about matters other than the neurologic status of
anencephalic infants have less evident relevance. Thus, concerns about slippery
slopes to euthanasia, excessive instrumentalism and the symbolic devaluation
of impaired lives do not call for illumination by neurologists or neuroscience. Such
concerns are ultimately political in the sense
that they challenge citizens to take a somewhat flexible view of "life." The concept that death occurs when the brain ceases to function has been widely adopted in the United States, and powerful arguments have been made to expand the concept of death to include permanent unconsciousness and anencephaly. Even if these arguments fail to persuade because of inadequate empirical support or for ideological reasons, they avoid the obfuscation that can accompany efforts to calibrate levels of care to level of neurological function.

B. Principled consistency?

I have suggested that the American Academy of Neurology has taken inconsistent positions in its statements about individuals in PVS and anencephalic infants. For individuals in PVS, the salient ethical justification for hastening death, according to the Academy, is that they are permanently unconscious. For anencephalic infants, however, the Academy holds that their status as living humans bars removal of vital organs for purposes of transplantation, notwithstanding the fact that they are unconscious and highly likely to remain so. In the one case, an action that results in death (removal of a feeding tube or ventilator) is permissible; in the other, an action with similar consequences is not. Both categories of persons are alive, and both are forever unconscious. Yet for purposes of "ethical" decision making, unconsciousness justifies death in one case but not the other. Why?

Several possible answers present themselves. Perhaps the simplest is that the Uniform Anatomical Gift Act, which regulates organ transplantations, requires that heart-beating donors be brain dead before their organs can be removed. Since anencephalic infants are not brain dead, removing their organs would be unlawful -- and hence unethical. Another transparent answer is that surgically removing organs with foreknowledge that death will immediately follow is unacceptably coarse and barely distinguishable from a lethal injection. This reality contrasts sharply with the slow, quiet death that follows removal of a feeding tube from a person in PVS. Moreover, surgery would cause death directly, while removing life support can be seen as allowing nature to take its course.

A third distinction derives from the status of anencephalics as infants, a class of persons traditionally treated with special legal and ethical solicitude. Thus, while it might be acceptable to cause the death of an unconscious adult, the same is not true for an unconscious infant. Finally, slippery slope concerns may call for special caution where the explicit purpose of hastening death is not to benefit the afflicted persons, but others. Allowing removal of organs from anencephalic infants arguably could open the door to harvesting of organs or tissues from other vulnerable individuals, including those in PVS.

While these justifications for treating adults in PVS differently from anencephalic infants are credible, I don't regard them as compelling from an ethical perspective. Granted, it would violate the UAGA to remove organs from a heart-beating anencephalic infant. But suppose there were no such law. Would it then be ethical to take their organs for transplantation?

I generally support the view that it is ethical for parents of dying or gravely impaired infants to refuse treatments that might extend life without improving neurological outcome. But authorizing surgery that would itself end life seems
intuitively different. Still, drawing ethical conclusions about death-hastening actions based primarily on the method chosen seems questionable. Both surgical removal of vital organs and removal of a feeding tube will cause death. One is faster and cruder than the other, but the result is the same. And since the affected individual involved is by definition unconscious, neither action evokes pain or suffering. Thus, it seems no more or less ethical to cause death in an anencephalic child by surgery than to cause death in an adult in PVS by removing a feeding tube. Similarly, I can discern no weighty ethical distinction between the value of life or sentience in an infant with anencephaly or an adult in PVS.

If we are to take slippery slope arguments seriously, I share Schauer's reservations about arguments divorced from empirical reality44 - - they seem to play out similarly for both anencephalic infants and individuals in PVS. If the public devalues the lives of persons in either category for purely instrumental reasons, the results are equally threatening. The threat derives from a construct that explicitly keys the level of ethical and legal protection to the level of neurological function. The line between consciousness and unconsciousness can be hard to draw, and predictions of outcome after brain injury are not as reliable as we might like to think. Thus, accepting permanent unconsciousness as a justification for hastening death entails accepting a very small but still discernible risk of error.

Oversight of decisions that hasten death

As a participant in many discussions about how much care to provide severely brain-injured persons, I have always been struck by the essential conservatism of the deliberations. By that I mean the powerful reluctance of participants to choose or recommend an action that will hasten death. Some may believe that the reluctance derives from fear of adverse legal consequences. However, my perception has been that the greater concern derives from religious or other strongly held personal views about the sanctity of human life, no matter how devastated, and a gnawing uncertainty about whether it is ever justifiable to hasten another's death. Evidence that a brain-injured person is unequivocally and irremediably suffering sometimes tips the scales in favor of a life-ending decision, as does a firmly held belief that the person will never regain consciousness. Otherwise, doubts are likely to be resolved in favor of continuing life support, even where all concerned regard this option as largely nonbeneficent or futile.

A. Slippery slopes

Courts -- supported by a large body of ethical opinion -- have already ruled that the state must respect the autonomous choice of severely brain-injured persons to decline life support.45 If the courts go further and empower proxies to hasten death where evidence of autonomous choice is ambiguous or altogether lacking, via the doctrine of substituted judgment or some other principle, the wall of protection for vulnerable brain-injured persons might begin to erode.46 The result, in a worst case scenario, would be a growing public tolerance for applying utilitarian or economic principles to choices about care, divorced from a concern about the welfare of the afflicted individuals.

B. Regulation
One way to avoid such dangers -- short of an outright ban on decisions that hasten death -- is to legislate protective measures. Legislation might specify which categories of brain injury qualify for removal of life support and mandate a set of procedures that must be followed by proxies and caregivers.

An example of such legislation is the New York statute concerning do-not-resuscitate orders. The law establishes categories of persons for whom do-not-resuscitate orders can be written, including those who are permanently unconscious or dying of "terminal" illnesses, and prescribes steps that must be followed to validate the orders.

A second example is existing federal child protection legislation that encourages states to monitor and regulate treatment of severely impaired infants. This law aims to constrain precipitous decisions by requiring physicians to determine that an infant’s neurological impairment is indeed severe and irremediable before care is removed. It also limits the range of choices parents can make and pressures health care institutions to establish intramural oversight of decisions to withhold or withdraw treatment. Thus, for example, parents are allowed to opt for removal of a respirator from an irreversibly comatose infant but not for removal of “appropriate” fluids and nutrition.

Moreover, both physicians and parents are enjoined to demonstrate to overseers that continued life-support is “futile” or “inhumane,” terms that can be subject to wide interpretation.

C. Toward deregulation

Obviously, laws such as these can deter proxies and attending clinicians from agreeing to hasten the deaths of some individuals with severe brain injury. Less obvious, however, is whether this degree of intrusiveness is needed to deter unjustifiable conduct.

1. Identifying appropriate proxies

Where close family members or others with strong emotional ties are available to speak for a severely brain-injured person, the need to involve outsiders in decisions about care is debatable. Unless proxies have transparent conflicts of interest, I think it unlikely their decisions about care will be less respectful of human life than those of ethics committees, courts or other formal overseers. I recognize, of course, that many believe that such “objective” overseers are essential. They are arguably better able to weigh potentially confusing information about diagnosis, prognosis and therapeutic alternatives and to withstand coercive pressures from attending physicians or their “expert” consultants.

2. Influence of neurologists as consultants

Of all potential threats to decisional integrity, the one that most concerns me is the weight attached to neurological opinions. Regardless of the consistency of its statements about care of persons in PVS and anencephalic infants, the American Academy of Neurology has adopted a conservative stance with respect to decisions that hasten the deaths of persons with severe brain injury. Only those who meet existing criteria for brain death or permanent unconsciousness would qualify for such decisions. Moreover, if permanent unconsciousness is the pivot, removal of life support is appropriate only for those who have somehow indicated a preference for this option. Accordingly, even if neurologists’ predictions of the permanence of PVS do not meet the test of moral certainty, they are likely to derive from the best available
objective measures and a sensitivity to the ethical dimensions of decisions about life support. Moreover, in the setting of the Academy's statements about PVS and anencephaly, neurologists are unlikely to support life-ending decisions for the brain-injured simply because they harbor personal doubts about the value or wisdom of continuing life support. The risk therefore seems small that they will exert coercive pressures on families and primary caregivers in the direction of hastening death.

3. Minimal intrusiveness Assume for the moment that the following propositions are defensible: First, neurologists' predictions of outcome of severe brain injury are generally trustworthy. Second, neurologists will take a conservative approach when formulating opinions that could lead to a decision to hasten the death of a person with severe brain injury. Third, those with strong emotional ties to brain-injured persons are unlikely to choose to hasten death for nonbeneficent reasons.

If these propositions are indeed correct, I submit there is scant need for a regulatory approach that involves administrative rules and institutional monitors, such as that envisioned in the federal child abuse law or in various proposals for formalized oversight. Moreover, I would argue that health care institutions' oversight ought to be no more than minimally intrusive. By minimally intrusive, I mean that institutions should do no more than require a neurological "second opinion" about diagnosis and prognosis and a determination by the relevant health care team that the proxies are the appropriate decision makers. Proxies and attending physicians would have discretion to seek an "ethics consultation," a hearing before an ethics committee, or mediation by clergy or others. But there should be no mandates for such steps or other formal regulatory oversight. From my perspective, this approach would not increase the prospects of medically or ethically unjustifiable decisions and could substantially reduce the burden on caregivers, families and health care institutions.

4. The risks of minimalism I recognize the concern that a minimally intrusive approach is dangerously lax, unlawful or both. Arguably it could allow self-preferring proxies to make unconscionable decisions. Or it could remove a check on the accuracy and reliability of opinions of neurological consultants, some of whom could be inept, uncaring or disparaging of the view that even nonsentient life is precious. Or it may tread beyond the ambit of protected conduct that the judiciary has created for death-hastening decisions.

Cogent as these criticisms may seem, I remain unpersuaded. They imply that proxies, attending physicians or neurological consultants will, if oversight is minimal, sometimes act selfishly, nonbeneficently or in contempt of core social values. I concede that empirical evidence is lacking to support a presumption of altruism. But I also know of no empirical evidence to justify presuming that appropriate proxies of the severely brain-injured will rank their own interests above those of persons they represent. Moreover, even if proxies are basely motivated, it is difficult to envision situations where attending physicians or consulting neurologists would find it in their own self-interest to conspire with proxies to hasten the deaths of brain-injured persons. Certainly involved physicians might conclude that continuing treatment is futile in some sense. But that hardly justifies an assumption of nonbeneficence on their part.
Proxies’ justifications for their choices may differ from those which a popular majority or court of law would find most compelling. But that does not mean that the proxies’ motives must be nonaltruistic. Similarly, the fact that an attending physician or consulting neurologist has doubts about whether nonsentient life should be sustained does not mean that the physicians will misrepresent medical data or attempt to impose their own views.

Only where physicians distort advice or opinions to suit their personal preferences or ideology would there be reason to question their conduct. It seems unlikely that physicians would behave in this way. But, in any event, these hypothetical abuses could be contained by requiring a second opinion.

If a “deregulatory” stance is adopted, deliberations about care of the severely brain-damaged will still proceed in the shadow of law and an array of ethical pronouncements, ensuring that participants in the deliberations will be ever mindful that a “wrong” decision may trigger legal or regulatory inquiry. Thus, even if they are tempted to act in self-preferring or unprofessional ways, the lurking prospect of later litigation or censure should operate as a powerful deterrent.

5. Formal immunity for decisions to hasten death. Ironically, the court that decided the case of Karen Quinlan believed it was fear of legal or professional sanction that inhibited her attending neurologist from doing the “right” thing: removing the respirator it assumed was sustaining vegetative life.51 The court did not credit the physician’s assertion that his reluctance stemmed from medical and ethical concerns. The court thereupon proposed a process for making such decisions that, if followed, would provide legal immunity for proxies and physicians. This case began a fascination with the idea of creating a formalized process to generate sounder decisions than those achievable through the traditional medical model of ad hoc deliberations among families and caregivers with input from knowledgeable consultants.

To the extent that a mandated process may encourage fuller deliberations among proxies and physicians, it could be useful. But, in my view, a process that adds participants and formality only diffuses responsibility for difficult decisions without improving prospects for better outcomes in the ethical sense. Group-think and debate about abstract principles are poor substitutes for highly charged deliberations among those most powerfully affected by whatever choice is made: families, significant others, primary caregivers. Ultimately, I am confident that proxies and attending physicians, informed by neurologists who can distinguish what they know about brain injury from what they believe about the value of impaired life, are as likely to make “right” decisions in these hard cases as are courts or committees -- and at considerably less social cost.

Having ventured onto this limb, I do not propose to saw it off by suggesting that proxies and physicians who operate in this hypothetically deregulated environment should receive advance assurance of legal immunity for their actions. There may already be a sort of de facto immunity for those who make demonstrably compassionate decisions. Nevertheless, I believe that withholding formal immunity will promote the sort of deliberations needed to reach closure in these often profoundly difficult matters.

Elements underlying the posited de facto immunity include judicial recognition that
the “right to die” has constitutional dimensions, legislation and judicial rulings that countenance withholding or withdrawing life support from irreversibly comatose or terminally ill persons, an existing legal presumption that families will act in the best interests of their own, and a professional ethos that biases physicians’ decisions toward preserving life. In this context, public prosecutors or private individuals will seldom have an incentive to challenge an ostensibly beneficent decision to hasten death. Thus, the absence of formal immunity probably does not put those who make such decisions at significant legal risk.

A potential advantage of withholding legal immunity is that a residual uncertainty about the legal consequences of decisions to hasten death will ensure careful attention to neurological opinions about diagnosis and prognosis. Proxies are thus likely to seek second neurological opinions even if they are not mandated, and consultants themselves will be acutely mindful of the need for accuracy. For example, when asked to predict outcome of a person with a diagnosis of PVS, an informed and reasonably risk-averse neurologist could be expected to disclose the small but finite possibility of some return of awareness. It would then fall to proxies and attending physicians to decide whether the highly uncertain benefits of continuing life support for the severely brain-injured outweigh the burdens of continuing care. I expect that doubts on this score would virtually always be resolved in favor of continuing life support. While this decision could result in what some might see as a cost-inefficient use of finite medical resources, it is faithful to societal interests in preserving life and protecting vulnerable persons from harm at the hands of others.

Refusing to grant advance immunity for decisions to hasten death also may allay concerns about slippery slopes. Were it to becomes a rule of law that immunity attaches to good faith actions that hasten death for a particular class of persons (e.g., those who are permanently unconscious) if a specified process is observed, an increasing number of persons in that class could become vulnerable once knowledge of the process spread. Again recall the concern of the New Jersey court in *Quinlan* that her physician did not remove her ventilator because of fear of legal sanctions. By offering a way to avoid these sanctions, the court arguably opened the door for decisions to remove life support from other similarly situated persons. It is also conceivable that once a process is created for removing life support from one class of severely brain-injured persons, the polity could choose to extend it to other classes of impaired persons.
Conclusions

Whatever decisional model is chosen, its overriding purpose should be to ensure that decisions to hasten death rest on rigorously determined clinical data and unsullied respect for human life. Participants in these decisions may have different versions of the life they prefer to protect and may need to negotiate about this issue. Eventually they may reach a consensus that enables them to decide whether to extend or shorten that life. Predictably the shape of the consensus will vary among proxy decision makers. Some will agree that preserving the conscious mind has the highest priority, while others may attach pivotal importance to protecting human existence, no matter how diminished. Experts in neurology and neuroscience can inform their deliberations. But ultimately neither they nor any tribunal are better suited to achieve an ethically satisfying outcome than are those most intimately familiar with the afflicted persons.
NOTES

1. See B. Jennet and F. Plum, "Persistent Vegetative State after Brain Damage," _Lancet_ 1 (1972): 734-737 (describing the clinical phenomenon of wakefulness without awareness in which eyes are open and move but responsiveness is limited to primitive movements of limbs and speech is absent; the inference is that the cerebral cortex is nonfunctional).


4. Resolution of Executive Board of American Academy of Neurology, July 8, 1995, copy on file with author. The resolution states, in part, that "anencephalic infants should not serve as multiorgan donors unless they are brain dead."


9. See D. E. Levy, J. J. Sdtis, D. A. Rottenberg et al., "Differences in Cerebral Blood Flow and Glucose Utilization in Vegetative versus Locked-in Patients," _Annals of Neurology_ 22 (1987): 673-682. The authors found that cerebral blood flow and metabolism in PVS patients were drastically lower than in paralyzed but awake patients with locked-in syndrome, lending support to the view that the neocortex is nonfunctional in PVS.


14. See Child Abuse Prevention and Treatment Act, U.S. Code Annotated section 5102, as amended. This legislation defines child abuse to include the withholding of "medically indicated treatment" for "life-threatening conditions." The term "medically indicated" is defined to include "appropriate nutrition, hydration and medication... likely to be effective in ameliorating or correcting all such conditions." Except for "appropriate" nutrition, hydration and medication, the statute does not cover treatment of infants who are "chronically ill and irreversibly comatose," or situations in which treatment could be construed as "futile" or "inhumane." Interpretation of such a complex statute poses formidable difficulties for those involved in neonatal care. See, e.g., R. T. Truog, A. S. Brett and J. Frader, "The Problem with Futility," New England Journal of Medicine 326 (1992): 1650-1653.


20. Martin v Major, 538 NW 2d 399 (MI 1995).

21. Executive Board of the American Academy of Neurology, "Certain Aspects of the Care and Management of the Persistent Vegetative State Patient."

22. See In re Quinlan, 70 NJ 10, 355 A 2d 647.


31. Jennett and Plum, "Persistent Vegetative State after Brain Damage."

32. Levy et al., "Vegetative versus Locked-in Patients."


36. See Council Report, "Persistent Vegetative State and the Decision to Withdraw or Withhold Life Support." The report states that diagnosis of permanent unconsciousness for purposes of treatment removal ought to be “beyond doubt.”


38. Medical Task Force on Anencephaly, "The Infant with Anencephaly."


40. Multi-Society Task Force, "Medical Aspects of the Persistent Vegetative State."


(emphasizing that anencephalic infants with beating hearts do not satisfy current criteria for brain death).


45. Cruzan v Director, 497 US 261 (1990); Rhoden, "Litigating Life and Death"; Beresford, "Legal Aspects of Termination of Treatment Decisions."


49. See Rhoden, "Litigating Life and Death," arguing for a rebuttable presumption that decisions by families to end life support are ethically correct; Lindgren, "Death by Default," providing survey data that indicates overwhelming public preference for allowing families and physicians to be primary decision makers. See also U.S. v University Hospital, 729 F 2d 144 (2d Circuit 1984), emphasizing the central role of parents of severely impaired neonates and their physicians in decisions about life-sustaining medical treatment.


51. In re Quinlan.

52. In re Quinlan, Cruzan v Director; see also Compassion in Dying (fundamental liberty); Quill v Vacco, 1996 WL 148605 (2d Cir 1996) (due process implicated).

53. Rhoden, "Litigating Life and Death."

54. Ibid.; Lindgren, "Death by Default."

55. In re Quinlan.