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Quote to note

"Integrity without knowledge is weak and useless, and knowledge without integrity is dangerous and dreadful."

— Samuel Johnson

Inside

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Medical ethics during war

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Contrary to popular belief, military medical personnel are not angels in white who grace the battlefield solely to save men and women from the ravages of battle. Instead, they are an integral part of their nation's war-making machine, and although medicine dedicates itself to saving lives, the lives they save during war are principally those whose job it is to kill others. Medicine during war is not above the fray but, in many senses, a driving force behind it. This awareness alone creates a dilemma for a profession that lives by the axiom *Do no harm.*

In a civilian setting, medical professionals focus on the interests of their patients whose well-being is the proper subject of medical care. In a military setting, however, "patients," that is, military service personnel, are not an end in themselves but a means to protect vital national interests. As a result, the goal of military medicine is twofold: First, maintain the fitness of soldiers so they can effectively fulfill their duties and second, treat the wounded so they can continue to fight. Military medicine is not even about saving lives per se, but of "salvaging" the maximum number of soldiers and returning them to duty. This pushes the well-being of any individual patient into the background. The eye of military medicine, like that of the military in general, is always on *raison d'etat*: the interests of the state. All this has significant effects on patient rights and medical ethics during war.

Patient rights: Medical ethics in peace is different from military medical ethics during war. Consider, for example, three common rights firmly entrenched in modern bioethics: informed consent, confidentiality and the right to die with dignity. Soldiers have little of these rights. The right to informed consent also means the right to refuse treatment. But may soldiers refuse standard medical treatment such as vaccinations or care for common illnesses? The answer is usually no. Refusal to accept care crucial for them to perform their duties is grounds for disciplinary action. Nor do soldiers have the right to keep otherwise private information confidential, if this information is necessary for military purposes. The same is true of their right to die. Unless severely wounded and without any chance to return to battle, the duty to soldier on overrides a serviceperson's right to die. Under these conditions, soldiers must accept medical treatment. Who then looks out for their welfare? Well, doctors do, but they are constantly juggling the interests of their patients and the interests of the state. This makes military medicine, particularly during war, far more paternalistic than civilian medicine. Patient autonomy does not entirely disappear but is often set aside for other considerations.

Asymmetrical war and medical ethics: As armed conflict changes from conventional war between two similarly armed nations that abide by international law to so-called asymmetrical war between states and sub-state actors (guerrilla groups, lawless regimes or well-armed ethnic groups), military medicine faces even harder dilemmas. In these non-traditional wars, nations or coalitions of states (like NATO) inter-

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vene to prevent massacres of innocent civilians and restore political stability (the former Yugoslavia), fight states sponsoring terrorism (Afghanistan), suppress insurgency (Iraq) or settle political disputes violently (Israel and the Palestinians). As they do so, military medical workers must treat the wounded and use their medical expertise to assist the military directly by providing care to local civilians, building weapons and assisting in interrogation.

Medical programs for local civilians: Caring for civilian populations can present a difficult dilemma for medical personnel. During the Vietnam War, for example, the idea of "medical stability operations" garnered widespread support. Eager to gain the backing of the South Vietnamese people, U.S. officials hoped to use medical care to win "hearts and minds." Medical care for civilians became an important part of nation building. It not only could significantly improve a people's well-being but might also strengthen support for the South Vietnamese government. Should medical professionals use their expertise in this way? Although some think not, the answer really turns on the policies medicine is supporting. In Vietnam, the United States was propping up a corrupt and unpopular regime and this alone should have given physicians (and anyone else) pause about using medicine for political purposes. In other instances, however, medical stability operations in South America or other nations in Southeast Asia may, indeed, help fledgling regimes win the loyalty of those living in a country splintered by tribal loyalties. Medicine can serve an important political function, but it demands that nurses, physicians and medics understand the cause they and their country are supporting.

Non-lethal weapons: The same caveat holds true when we consider weapons development. Until very recently, physicians had nothing to offer weapons designers whose arms depended almost exclusively on high explosives. But that is changing. As warfare turns asymmetrical, strong states find that their military might is limited because their enemies mingle among the civilian population. To fight under these circumstances, large armies require the means to repel large crowds, protect facilities and isolate insurgents without causing widespread civilian casualties. To do this, policymakers are turning to non-lethal weapons that employ chemical agents and sound or radar waves to incapacitate an enemy temporarily. These "medicalized" weapons require medical expertise to answer an array of questions: What "portals of entry" (eyes, ears, skin, lungs) best allow chemicals to anesthetize the human body? What dosages of which chemical agents will render a person unconscious without killing him? What audio frequency will cause convulsions and nausea? What intensity and kind of electromagnetic waves will cause an excruciating pain without burning human skin? Answers to this last question were central to the development of the U.S. Army's Active Denial System (ADS), a non-lethal weapon that repulses an enemy force with millimeter waves that stimulate nerve endings just below the surface of the skin to "produce a heat sensation that forces targeted individuals to flee the beam within seconds."[1] The ADS is due for deployment in Iraq to control crowds, provide checkpoint security and protect U.S. installations.

These weapons raise medical questions that require standard research and testing protocols. Medical personnel and medical knowledge are crucial to ensure that these weapons are effective and non-lethal. Should physicians help develop these weapons? Many say no: "Medical professionals," warns the U.S. Army's textbook on military medical ethics, "ought to stay in the business of healing and not hurting, which includes not participating in or contributing to weapons research and development."[2] But the question is not so easily decided when it comes to non-lethal weapons, which are not harmless. They cause pain, unconsciousness and, under the less than ideal conditions on the battlefield, sometimes death. But if they save a significant number of civilian lives, shouldn't physicians lend their expertise and help build these weapons?

Interrogational torture: Torture poses a similar, but more difficult, question. Although many people try to distinguish between torture, ill treatment and aggressive interrogation, all agree that each harms interrogees. This debate is heated and perhaps intractable, but if we assume that rough and painful questioning is justifiable because it saves many innocent lives, then the question of medical involvement is the same: Should doctors lend their expertise to interrogation? As we ask this, it is important to understand what doctors do in interrogation facilities. By most accounts, physicians provide routine care for detainees before, during and after interrogation, certify their fitness to withstand questioning and, sometimes, help interrogators tailor their techniques to specific suspects. The question of medical participation is not simple. One must not forget that those aiding torture cause significant harm, albeit indirectly. This alone may be sufficient to condemn anyone who plays a role in interrogation. But if one accepts the need for aggressive interrogation in certain, exceptional cases, then there are no grounds for excluding physicians and other medical personnel from doing their part.

Whether one condones interrogational torture depends on many things. One has to accept that no other means are available to save lives. One has to believe that interrogation techniques like covering a suspect's head with a filthy hood, forcing him to sit or stand in painful stress positions and/or listen to powerfully loud music are qualitatively different from severe beatings, genital mutilation, burning or electric shock. One has to be able to draw a meaningful distinction between serial murderers, brutal rapists and sadistic pedophiles (whom no one thinks to torture) and terrorists (whom many people think are fair game). One must be convinced that interrogational torture is effective and that the long-term effects on liberty and freedom fall before the near-term benefit of saving many lives. These, too, are hard decisions to make. But once the decision is made to torture terror suspects, then there is no reason to leave the job to someone else and exempt health care professionals.

Medical professionals and the state: Does all this mean that during war doctors and nurses should put themselves at the service of the state unconditionally? Of course not. On the contrary, it means that medical professionals, like any concerned citizens, must examine the justice of the war they are fighting. There are many responses a person can make when their country goes to war. Most often, they go along with what their country requires, resting assured that they are protecting vital national interests or fighting for the rights and well-being of others threatened by terror or genocide. Medicine, like any other profession, may have to work at the state's behest. This may mean aiding medical stability operations, contribut-

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Ask the ethicist:

When consent to serve as a research subject is not informed

Question: A 58-year-old woman with widely metastatic malignant melanoma continued to progress despite aggressive chemotherapy. Her oncologist explained to her that no therapy was known to be effective in this setting. The oncologist offered her the opportunity to serve as a research subject in a Phase I clinical trial of an innovative chemotherapeutic agent as part of a multi-center trial. He explained that as a subject in a Phase I study, she would be used to determine the toxicity and dosage of chemotherapy but that it was unlikely to help her. He provided her a detailed consent form to read but she declined to read it, explaining that she felt she had no real choice in the matter because she would die without treatment and this trial represented her only chance. Her oncologist wondered if her consent was valid or if this circumstance represented implicit coercion because she was so desperate and had already agreed to participate irrespective of risks. How would you advise the oncologist?

Response: A sad story, not rare in medicine: A dying woman asks to enroll in a clinical trial without being informed of its risks, believing it to embody her only hope to avert otherwise inevitable death. Troubled that her consent might not be valid and that circumstances might coerce her, her oncologist asks for advice.

At first glance, the questions seem so simple that they hardly bear serious scrutiny. The patient's "consent" is transparently invalid, since even the weakest formulation of informed consent requires disclosure and acceptance of risk. Coercion, by definition, implies that one person use an irresistible threat to compel another to act against her will. Unless we take the notion of the grim reaper literally, no such person and no such threat exist in this case. Circumstances may limit choices tragically, but they cannot coerce. And even though the threat of non-enrollment might be manipulative, it is not coercive if it is not used to compel her to act against her will, but rather to grant her wishes—even if those wishes are not in her best interest.

Thus reassured, our oncologist-researcher might now feel tempted to accede. He might rationalize enrolling an eager subject as an act of beneficent manipulation and proceed with disclosure of risk, to fulfill his legal and ethical obligation. But he remains appropriately hesitant, for at least two good reasons. First, as a matter of principle, disclosure and lack of coercion are necessary, but not sufficient to ensure informed consent. Second, he has qualms about his dual role as physician and as researcher, recognizing that as a matter of professional obligation, his primary job is to take care of his patient, even if doing so means ending up with a smaller number of research subjects.

In *A History and Theory of Informed Consent*, Faden and Beauchamp argue that informed consent comprises four elements: divulgation, lack of coercion, comprehension and autonomous authorization.[1] They maintain that substantially autonomous action cannot occur in the absence of the first three conditions. In the present case, even a thoroughly read and understood 30-page NIH-approved consent form is doomed to fail, because our patient seems to lack comprehension, not merely of the nature of Phase I trials—which are not intended to be therapeutic—but of her own condition. Refractory metastatic melanoma is invariably fatal, and anyone who enters a clinical trial under the assumption that this is not the case does so under false pretenses. That she would enter the trial voluntarily and that she has been informed of its risks is still not enough to generate true informed consent if she does not comprehend her own condition and the promise (or lack thereof) of the trial in light of that condition.

Early in my career, Dr. Balfour Mount, who brought hospice to North America in the early 1970s, told me something important he had been told by Dame Cicely Saunders a few years before: "A bedpan thrown at you is not to be reacted to. It is to be interpreted." A desperate act is a cry for help, and when a patient makes an unreasonable or irrational demand, her physician's duty is not to satisfy it, but to ask why it is being made.

A desperate demand is an expression of suffering—not merely a reaction to incurable disease, but what Cassell[2] might call a response to the impending disintegration of a person. That our colleague has asked for help suggests that he feels both uncomfortable and ill-equipped to work this out alone. This is as it should be. Moments of existential crisis call for all the resources a system can summon: psychologists, social workers, grief counselors and chaplains, nurses, family members, friends—the list is endless.

The most important piece of advice we can give him is to call on those resources, to explore the request, to find its meaning and to help his patient cope with a reality that threatens to overwhelm her. The outcome may well be that she will enroll in the trial. But perhaps she will decide to spend her last days quietly with loved ones at home, or to take a final vacation to the Côte d'Azur. Unless our colleague finds a way to ask and discover what she really wants, his job will remain at least half undone.

Outcome: The patient enrolled in the Phase I trial and died two months later. □

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The legal column:

The fed's role in public health emergencies

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The time has come for Americans to prepare to federalize our nation's response to public health emergencies. I said that exactly the way I intended. We should be prepared, when the occasion arises, to empower the federal government to respond quickly and seamlessly at the first recognition of a large-scale public health emergency.

The current structure of "bottom-up" response to naturally occurring or bioterrorist-induced public health emergencies has been built on and around our traditional local-state-federal public health infrastructure. It is largely a political artifact of a time when most public health problems were local in nature. Whether this adequately serves our public health needs is a separate and severable debate. But what we have learned through the last decade of near- and actual large-scale disasters is more than troubling. The overlapping responsibilities among public health, first-response and law enforcement agencies have proven to be cumbersome and inadequate. In even the most straightforward tasks, such as providing temporary food and shelter for disaster victims, we struggle not for resources, but for coordination and concerted direction. Federal officials, bound by their traditional role, await the request of state officials, who react only after local efforts prove to be inadequate.

For some types of public health problems, that bottom-up schema may be sufficient. But what will happen when the stakes are much higher, as they will be when some deadly variant of avian influenza arrives? How well will the existing network of public health agencies perform if we ever must identify and isolate people who may have been exposed to a fast-moving and highly infectious disease? Can our current public health infrastructure make and enforce *those* kinds of decisions fast enough to make them effective?

Consult any person or agency who has evaluated our current circumstances or our recent experience with disaster response. No one concludes that we are adequately prepared for a serious, multijurisdictional public health emergency.

Since September 2001 there have been a series of new federal laws concerning bioterrorism and public health security, various reports outlining what the federal government will and will not do, and follow-up assessments of their implementation. These efforts, however, have focused largely on national security in the larger sense and have subsumed public health preparedness into the activities of an array of agencies concerned with homeland defense. There have been some new federal resources for state and local public health agencies, but nothing commensurate with their new responsibilities, and surely not enough to enhance their emergency response capabilities sufficiently. To the contrary, most public health experts believe that the net result of these recent federal efforts has been a step backwards for both their traditional public health activities and their level of emergency preparedness.

Just as critically, all of these federal efforts have continued to build on the bottom-up paradigm. The federal government continues to insist that its role in public health matters, even in large-scale emergencies, is supportive and secondary to that of the state and local public health agencies. That role makes sense only involving problems that are state and local in their dimensions. The next Spanish flu, the next terrorist-introduced toxin, the next SARS may become a national problem.

We need a national response. No amount of interagency coordination and planning—the new buzzwords of public health policy—will prepare us properly or adequately. What we need now is to prepare the capacity for a direct federal response when circumstances warrant it.

Consider the following the essential elements of a remedial proposal. The public health surveillance apparatus of the federal government should be upgraded and restructured from its current, largely advisory role to make it primarily responsible for real-time identification of emergent public health problems. Then the president should be empowered to declare a temporary, national public health emergency, much like the governors of most states are currently empowered to do (and as strictly confined as those emergency powers are, or, at least, *should be*). That emergency declaration should empower a single agency, preferably headed by a visible, publicly recognizable and highly credible official. All these elements should be part of a single, highly publicized and heavily debated statutory enactment—not buried in an omnibus legislative package or part of a claim by the federal executive of extraordinary power. As with all important legislation, the details are critical: e.g., the exact definition of what is or is not an "emergency" trigger. These statutory details should be confronted and resolved before, not after, the law is changed.

The specific changes in federal statutory and administrative laws that will be required to achieve these objectives are as diverse as the options for their implementation. Some could be implemented without any remedial legislation. But none of the existing federal public health agencies is currently empowered or structured to do all of what I have outlined. Perhaps as importantly, no part of the existing federal public health apparatus has the necessary mindset. The institutional culture of those agencies must change, as well as the rest of the executive branch of the federal government, for all this to work.

The creation of a legal scheme that empowers the federal government to assume command of state and local public health resources will encounter political resistance. The key to overcoming that resistance will be exactly what it should be in political controversy: convincing enough Americans that the potential threat is great enough to warrant such an extraordinary redistribution of power. Frankly, I don't think that will be difficult.

Many people within and without government may properly fear that any effort to achieve these objectives will violate federalism, the implicit constitutional principle that protects the integrity and autonomy of the states, and other constitutional limits on federal action. There are legitimate constitutional concerns that govern the struc-

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Ethics and the humanities:

In the land of pain

By Alphonse Daudet
New York: Knopf, 2002, 112 pages

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In 1891 the French novelist and playwright Alphonse Daudet wrote, "Doctors are very poor at discerning things. When a patient says to them, 'I've noticed that an egg taken in the morning on an empty stomach brought relief on such-and-such a day,' they note the observation, but issue the same prescription as for all their patients." Daudet had a lot of experience with doctors. He contracted syphilis at the age of 17, soon after arriving in Paris to start his literary career. More than two decades later, he suffered from tabes dorsalis, a form of tertiary syphilis that progressively destroys the structures of the dorsal column of the spinal cord, leading to lower extremity ataxia, muscle atrophy and intractable neuropathic pain. From the early 1880s until his death in 1897, Daudet sought help from the leading neurologists of his day, including J. M. Charcot and C. E. Brown-Séquard, but he came to believe that none of these doctors were interested in his experience as a patient. He wrote, for example, that the famous Charcot, who frequently sent patients to the mineral baths at Lamalou, had never personally visited the place to see how his patients were doing.

Daudet tried all sorts of therapy, including mashed bulls' testicles and elixir of guinea pig. Nothing worked, with the exception of large quantities of morphine and chloral hydrate, which made his life bearable. Daudet also coped with his intractable pain by writing about it. He planned to write a complete memoir of his life with pain, but by the time of his death in 1897, he hadn't gotten farther than 60-odd pages of notes and reflections. The English author Julian Barnes has translated and collected these fragments into a small jewel of a book called *In the Land of Pain.*

The title is illustrative. Those who suffer from chronic pain live in a different country from those who are well, and they gradually find themselves speaking a language that others don't understand. At first Daudet describes details of his discomfort, but soon realizes how repetitive and boring this is to his friends. "Pain is always new to the sufferer," he writes, "but loses its originality for those around him. Everyone will get used to it, except me." Daudet finds himself living in a new country where pain is pervasive: "Pain finds its way everywhere, into my vision, my feelings, my sense of judgment; it's an infiltration."

One of the more depressing aspects of medicine today is the fact that doctors are still "very poor at discerning things," at least when it comes to pain. I get a knot in the pit of my stomach whenever I hear a resident discussing whether a patient's pain is "real" or "imaginary," or making a cynical comment about drug-seeking behavior, especially when the resident herself has prescribed a grossly inadequate course of analgesia. Some of my colleagues believe that a person has to appear anguished on the outside to be experiencing severe pain on the inside. And others get exasperated with patients who report more pain than their condition warrants—according to the doctor—and tell them, "You're overreacting" or "It's all in your head." When I hear this, I want to shake the doctor by his shoulders and yell, "Of course it is! All pain, no matter what causes it, is in the head. Where else could it be?"

In the Land of Pain illustrates that chronic pain sufferers can live calm, productive lives despite constant agony. Daudet continued writing, publishing and socializing until the end of his life, even though near the beginning of his journal he wrote, "My friends, the ship is sinking, I'm going down, holed below the water line." At the same time, the author's strength, compassion and humor shine in his little book. He emerges as a generous person, who was well loved by his contemporaries. But what if you were his doctor? Would your assessment be different? You might accuse Daudet of exaggerating his pain since he doesn't appear desperate. Yes, you might say, he clearly has tabes, but why does he need to take that much morphine?

Daudet calls his pain an "unwanted guest," to whom he should give "no special attention." At another point he writes about "the ingenious efforts a disease makes in order to survive." The writer never questions his enemy's ultimate victory, but neither does he turn in upon himself. He remains a source of joy to others, especially his family, as indicated in this note: "I only know one thing, and that is to shout to my children, 'Long live life!' But it's hard to do so while I am ripped apart by pain." Only late in his reflections does Daudet mix desolation with endurance, "I've passed the stage where illness brings any advantage or helps you understand things; also the stage where it sours your life, puts a harshness in your voice, makes every cogwheel shriek…"

Why is chronic pain so challenging for doctors to treat? I think it makes our moral cogwheels shriek, too. They get so clogged up with questions about the threat of addiction, or the possibility of being conned, that they resist the patient's suffering, rather than responding with smooth compassion. Alphonse Daudet's little book invites us to loosen up and live for a short while, at least, in the land of pain. Maybe that will help us become better at discerning things. □

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ture of any federal effort of this sort and the manner in which it is implemented. In particular, as a general proposition, even when enacting laws that are otherwise within its constitutional authority, Congress cannot directly compel a state to enact or administer a federal regulatory program. On the other hand, Congress can, in essence, "buy" compliance with federal mandates. If preparation for a declaration of public health emergency and for carrying out federal directives should one ever be declared is (a) financed with a sufficient level of federal funds, and (b) tied to the states' receipt of other federal public health funding, both the political and the constitutional concerns should be addressable. Indeed, the states' willingness to participate would be largely determined by the level of federal funding, as it properly should be.

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Dialogue:

Patients with chronic states of impaired consciousness

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It has been estimated that there are 2.5 to 6.5 million American patients with chronic states of impaired consciousness (PCSIC).[1] Many, perhaps most, are "warehoused" in chronic care facilities where "custodial" care is provided and the opportunities for neurological reassessment are rarely offered and infrequently provided.[1–3] There is both lay and professional resignation to the belief that the accosted brain heals poorly if at all. That neither the passage of time nor medical intervention will result in the return of meaningful awareness or communication, let alone productivity, is a widely accepted dogma. Only the most resolute of family members and newspaper tabloids retain or offer hope.

This pessimism is based on the cruel statistics of the permanent vegetative state (PVS) and the historical belief that most if not all PCSIC deserve the PVS designation. PVS victims, that is, those without evidence of sentience one year after traumatic and three months after non-traumatic brain injury, have no chance of meaningful cognitive recovery.[4]

We have learned from the Terry Wallis case that all patients who suffer from chronically impaired states of consciousness do not remain vegetative.[3] How large is this population? Do these individuals, deemed minimally conscious, represent a minority or as many as the 30–40% of PCSIC as suggested?[2] Are there interventions that may positively influence the natural history of these less afflicted individuals?[5] If so, will either the individual or society benefit by their identification and treatment? Many unanswered questions remain germane to PCSIC that leave both the medically sapient and medically naïve unsettled.

The concept of a minimally conscious state (MCS) was introduced in 2002 in an attempt to promote awareness and proper categorization of a subgroup of PCSIC.[6, 7] These patients have presumably sustained lesser injury to their brains, or they have a greater capacity for recovery than their PVS counterparts. The implication is of course a more optimistic natural history, one that is potentially more amenable to medical intervention. What is the natural history of MCS patients? Do those with brain injury lapse immediately into MCS or is there a continuum from coma to PVS to MCS? If the latter is true, how is the family to know whether their loved one is in a hopeless PVS or whether they should continue years of care because he or she might evolve into a MCS?

The behavioral repertoire of the MCS patient includes reactions that implicate retention or resumption of at least partial, intermittent awareness of self and environment.[7, 8] This may manifest as reproducible behaviors such as relevant response to command; meaningful spontaneous gestured, visual or verbal reactions; and purposeful movements or behavioral responses that are clearly responsive to a relevant stimulus and not simply reflexive in nature. The problem with this bedside standard is self-evident to anyone who has spent any time in an intensive care unit. Patient reactions that are reflexive are frequently misinterpreted by hopeful families as being consciously responsive. In contrast, true responses that are ephemeral in nature and witnessed only by families are readily dismissed by skeptical health care workers.

One strategic approach to an ethical consultation is to gather and consider three different informational domains: (1) the medical facts, (2) the patient's beliefs and (3) both the perspectives of and impact upon other interested parties, including family, health care institutions and society as a whole. Examination of Dr. Fins's recommendations regarding the minimally conscious state and deep-brain stimulation (DBS), the placement of a pacemaker attached to stimulating electrodes within the thalamus, can be approached with a similar construct.

What are the medical issues? Can the MCS be reliably distinguished from PVS by either bedside or functional imaging methodology?[9, 10] If so, will current or future technologies allow reasonably accurate prediction of the natural history of any individual patient?[11, 12]

Autonomy maintains its preeminent role among all of our culture's ethical principles. A large proportion of PCSIC have never exercised this autonomy, having avoided the pre-morbid inclination to contemplate or share their attitudes. Once injured, were they able to speak for themselves, would they accede to or reject interventions such as DBS knowing that the outcome might improve awareness but potentially detract from their quality of life? In this setting, is a best interest or substituted judgment standard of decision-making provided by a surrogate adequate to overcome any benefit of the doubt in this regard?

Arguably, the most difficult ethical issue to resolve in individual cases and the one most problematic regarding potential intervention in MCS patients is that of distributional ethics. Is it in society's best interest to spend its limited health care dollars on deep brain stimulators in MCS patients before we know that these expenditures will be in both an individual's and society's best interest? In theory, our medical payment system will serve as an effective checks and balances system. Presumably, routine placement of DBS in MCS patients will not occur until there is an evidence-based mandate to do so.

As reinforced by the Terri Schiavo case, however, medicine is not immune to the influence of politics and public opinion. Our checks and balances system is not fail-safe. It is conceivable that the potential pressure applied by families of those currently sequestered in chronic care facilities would act as a catalyst to promote an unwarranted standard of care of unproven efficacy and uncertain consequence. The wholesale removal of silicon breast implants, stem cell treatments for breast cancer, and the provision of long-term antibiotics for "chronic Lyme disease" are notable, large-scale and contemporary examples where public pressure has triumphed over science and reason.

Dr. Fins and colleagues, as advocates for PCSIC, have drawn our attention to the existence of MCS patients, their potential for at least partial recovery, and the hope that medical intervention might expedite and improve upon the quality of their future lives. By doing so, they have, as with most new information, furnished us with more questions than answers. These questions must be particularly daunting to the lay public who have recently been given mixed messages that patients such as Schiavo will never recover, but that others with nearly identical phenotypes like Terry Wallis

may wake up and talk some 19 years after injury.[3] How can society reconcile this apparent contradiction?

One can only hope that the groundbreaking work done by Dr. Fins and colleagues will translate into future research, better care and better outcomes for PCSIC. Until such time that we can predict the likelihood and extent of meaningful recovery in an individual patient with some measure of accuracy, DBS and similar interventions should be restricted to research settings. There, we can hopefully learn how to identify those with prognostic promise accurately, define their natural histories and assess their long-term outcomes, both with and without novel interventions. □

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Response: I appreciate Dr. Russell's comments on my essay[1] and hope my response productively engages the journal's readers. Before responding to his important question about distributive justice, I'll start with his title, "Patients with Chronic States of Impaired Consciousness" (PCSIC) and why I *oppose* this categorization.

While it is true that such patients exist, it is not helpful to clump them together under a single rubric. This consolidation of diagnostic categories is counterproductive: distinguishing between the permanent vegetative state and the minimally conscious state (MCS) is essential. The point of my earlier article was to further distinguish between patients with impaired consciousness, not to conflate them.

Although both the permanent vegetative state and MCS are "chronic states of impaired consciousness" the former is immutable and the latter potentially elastic, as illustrated by Terry Wallis and other patients. A "chronic" moniker may erroneously imply permanence for MCS, doing a disservice to those whose brain states—and functional status—can evolve.

There is also a factual error underlying Dr. Russell's nosology. Citing my *Nature Reviews Neuroscience* essay,[2] he misrepresents that, "It has been estimated that there are 2.5 to 6.5 million American patients with chronic states of impaired consciousness." I wrote, "In the United States alone, TBI [traumatic brain injury] alone has an incidence of 1.5 to 2.0 million people per year with an overall prevalence of 2.5–6.5 million people with permanent impairment."[2] Although disorders of consciousness are included in this aggregate number, the vast majority of injuries are less severe. Moreover, etiologies other than TBI can be causative. U.S. estimates for the vegetative state are 40 to 168 per million people[3] with MCS prevalence estimated at 45,000 to 250,000, assuming a 10-year life expectancy.[4]

Dr. Russell's point about distributive justice is well taken. Deep brain stimulation (DBS) for impaired consciousness remains investigational. Our group reported on a single subject and have repeatedly cautioned against fostering a therapeutic misconception.[5, 6] Clinical trials at multiple levels need to be completed to achieve an evidence-based consensus about safety and efficacy before DBS is deemed therapeutic.[7]

In the meantime, I advocate temperance about prematurely invoking cost constraints. Such ill-timed critiques could short-circuit a promising neuropalliative intervention for some of society's most desperately injured members and paradoxically foreclose findings of cost-effectiveness that might be demonstrated when its costs are systematically weighed against what is so callously described as "custodial care." □

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[1]Fins JJ. The minimally conscious state: ethics and diagnostic nosology. *Lahey Clin Med Eth* 2007;14(3): 1–5.

[2]Fins JJ. Constructing an ethical stereotaxy for severe brain injury: balancing risks, benefits and access. *Nat Rev Neurosci* 2003;4: 323–327.

[3]Beaumont JG and Kenealy PM. Incidence and prevalence of the vegetative and minimally conscious state. *Neuropsychol Rehabil* 2005;15: 184–9.

[4]Fins JJ, Master MG, Gerber LM and Giacino JT. The minimally conscious state: a diagnosis in search of an epidemiology. *Arch Neurol* 2007; 64(10): 1400–1405.

[5]Schiff ND, Giacino JT, Kalmar K, et al. Behavioral improvements with thalamic stimulation after severe traumatic brain injury. *Nature* 2007;448: 600–603.

[6]Schiff ND and Fins JJ. Deep brain stimulation and cognition: moving from animal to patient. *Curr Opin Neurol* 2007;20(6): 638–642.

[7]Fins JJ. Deep brain stimulation: ethical issues in clinical practice and neurosurgical research. In Krames E, Peckham PH and Rezai A, ed. *Textbook of Neuromodulation.* London: Elsevier; in press.

Legal*—continued from page 5*

I am not proposing the complete federalization of public health, but rather a preparation to federalize public health efforts on a temporary basis when the threat is great enough. I am not calling for the public health equivalent of martial law or the suspension of civil rights or giving any executive official any extraordinary power.

I am proposing that we create a federal statutorily proscribed scheme that properly balances individual and collective concerns, respects the separation of private and public domains, and properly distributes legislative and executive discretion. What I am calling for is extraordinary in one sense: It is a call to federalize one function of the public health infrastructure that heretofore has been delegated primarily to the state and local governments, which they have demonstrated they cannot fulfill under extraordinary circumstances. There are simply some potential, public

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Ethics during war—*continued from page 2*

ing to weapons development and, in exceptional cases, facilitating interrogation. At the same time, however, all citizens have a humanitarian obligation to examine the justice of the policies that their state demands they serve. This ethical duty far exceeds their professional or civic responsibilities. When states fail the test of justice, then all citizens—whether doctors, lawyers, plumbers or common laborers—have an overriding obligation to protest, disobey and do their utmost to frustrate national policy. □

[1]Gross M. *Bioethics and Armed Conflict: Moral Dilemmas of Medicine and War.* Cambridge, MA: MIT Press, 2006.

[2]Frisina ME. Medical ethics in military biomedical research. In: *Textbooks in Military Medicine, Military Medical Ethics*, Volume II, Chapter 18 (Washington, DC: Department of Defense, Office of The Surgeon General, U.S. Army, Borden Institute, 2003):545.

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health emergencies—perhaps they may never actually occur—for which direct federal action will be required.

Like many Americans, I watched in horror in 2005 as local, state and, in particular, federal officials embarrassed the nation during the response to Hurricane Katrina. I have no illusions that making something federal makes its better. But I do believe that one structural barrier to improving our collective response to disasters and other public health emergencies of such dimensions is the way in which authority is distributed throughout and across our governing institutions. Obviously, we need other changes as well. ■

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