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Bodily Integrity and Informed Choice in Times of War and Terror

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Introduction

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By George J. Annas

Law is the dominant force behind American medical ethics, and has been for at least the past half-century. That lawyers and judges, rather than physicians, have set the agenda for medical ethics in the United States is a bit surprising to many in the field of medical ethics, but it should not be. Medicine has historically been based on paternalism. The Hippocratic physician was obligated to act in the best interests of the patient—as the physician judged those interests—and to "do no harm." American law, on the other hand, is based on liberty and justice, principles that, among other things, led to the law's adoption of the doctrine of informed consent—better termed informed choice—under which individuals make the ultimate decision about what, if anything, will be done to their bodies. All of the articles in this issue make that central point from a remarkable variety of perspectives.

The question of when the law assumed the dominant role in defining ethical medical practice can be debated, but my nomination is at the "Doctors' Trial" at Nuremberg. The end of World War II was marked by the birth of the international human rights movement, the formation of the United Nations, and the adoption of the Universal Declaration of Human Rights. The "Doctors' Trial" was an important piece of this picture. U.S. judges, presiding under military jurisdiction in Nuremberg, Germany, found fifteen Nazi physicians guilty of war crimes and crimes against humanity for their actions in conducting or authorizing lethal and torturous medical experiments on concentration camp inmates. More importantly, the court articulated what has come to be called the Nuremberg Code, which sets forth the legal requirements for human experimentation. The most significant provision is the first of ten: "The voluntary consent of the human subject is absolutely essential . . . the person involved should have the legal capacity to give consent; should be so situated as to be able to exercise free power of choice, without intervention of any element of force, fraud, deceit, duress, overreaching, or other ulterior form of constraint or coercion; and should have sufficient knowledge and comprehension of the elements of the subject matter involved as to enable him to make an understanding and enlightened decision. . . "

The 1948 Universal Declaration of Human Rights (UDHR) declares bodily integrity central to both human rights and human dignity, providing in Article 5, for example, that "No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment." Most physicians, of course, do not view human experimentation as torture, but the treaty that followed the declaration, the International Covenant on Civil and Political Rights, made the link unmistakable by adding an additional sentence to the UDHR's Article 5 in its Article 7: "No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his free consent to medical or scientific experimentation." This is, of course, now a fundamental precept of international human rights law. Moreover, under the treaty, Article 7 is nonderogable, even "in time of public emergency which threatens the life of the nation."

In the United States, our courts later adopted and applied the doctrine of informed consent to the therapeutic as well as the research setting, reversing the Hippocratic ethic by placing choice in the hands of patients rather than physicians. As pivotal as the doctrine of informed choice is now to both law and medical ethics, its application in some circumstances remains contested, as Robyn S. Shapiro discusses in her overview of the controversy surrounding the payment of living donors for solid organs. Lawyers continue to be called upon to advocate for their clients whose right to bodily integrity has been ignored or abused. Moreover, physicians sometimes have affirmative obligations to act to help their patients that reliance on informed consent alone cannot resolve. Kathryn L. Tucker, for example, accurately describes the epidemic of untreated pain as a "human rights tragedy." She could as accurately have described physicians' failure to treat their patients' pain and suffering as torture. It is a scandal that the medical profession ignores such widespread suffering, and it will likely take vigorous legal action to change medical practice in this realm. Similarly, Shawna L. Parks correctly notes that institutionalizing juvenile offenders should require that they be provided basic mental health care. Susan Berke Fogel and Lourdes A. Rivera demonstrate how religious guidelines can frustrate and prevent good medical care, and why lawyers should insist that when the two are in conflict, "the medical needs of the patient must prevail."

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step—the document needs to be both readable and effective in communicating information in order to obtain a truly *informed* consent. A host of other factors—design, cultural relevance, format, length, density, and style—all enter into the question of the document's potential for effective communication.

I am convinced, after my ten years of work in this case, that if a research institution focuses its efforts on developing an informed consent document that communicates information and choices to the proposed human subject as effectively as possible, the atmosphere surrounding enrollment in biomedical research studies will tend to be noncoercive, as required under the federal regulations. I believe that the converse of that proposition is equally true: that a complex and difficult-to-understand informed consent document is conducive to a coercive atmosphere in the enrollment process in biomedical research. The document itself is coercive, intentionally or not, when it is unduly long, complex, and incomprehensible. This type of document sends a message to proposed human subjects that they have no meaningful role in the process because it is something that can be understood only by people with greater knowledge than they possess. Conversely, when the institution engages in a studied attempt to communicate effectively and does that as well as possible under the circumstances, in a written document or a videotape, the proposed human subject and all those involved are immediately put on notice that there is a meaningful role for the human in this process. That role involves adequately understanding described choices and knowingly and voluntarily making those choices.

The focus on the effectiveness of communication resulting from this lawsuit is a healthy one that ultimately will benefit both the biomedical research industry and proposed subjects of human research. To further advance the efficacy of the informed consent process, we must provide opportunity for feedback from the actual subjects of human research and recognize that their participation and input is valuable and necessary.

Stephen F. Hanlon manages Holland & Knight's Community Services Team, which provides legal representation to people, groups, and causes that otherwise could not afford it. His major civil rights work has included challenges to high-stakes testing; challenges to indigent defense systems; housing, employment and AIDS discrimination; death penalty litigation; voting rights; and unconsented medical experimentation. Robyn S. Shapiro is a partner in Michael Best & Friedrich LLP. She has represented clients with respect to bioethics issues, medical staff matters, health information privacy, informed consent, regulatory and licensing matters, and employment and other business issues. She is the director of the Bioethics Center at the Medical College of Wisconsin.

From the Chair

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the subject. As such, it may well implicate at least one international instrument that speaks to the obligations of physicians. The U.N. Principles of Medical Ethics Relevant to the Protection of Prisoners Against Torture state:

> It is a contravention of medical ethics for health personnel, particularly physicians . . . [t]o apply their knowledge and skills in order to assist in the interrogation of prisoners and detainees in a manner that may adversely affect the physical or mental health or condition of such prisoners or detainees and which is not in accordance with the relevant international instruments.

The responsibility for curbing such practices ought not to rest with the medical profession alone. But until existing ethical prohibitions are enforced by state medical boards or given legal force and effect, the state will always find willing accomplices to administer truth serum to detainees, psychotropic drugs to prisoners deemed not competent to be executed, and lethal cocktails to those who are.

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Looking at informed consent directly, Stephen F. Hanlon and Robyn S. Shapiro argue persuasively that there is more at stake in human experimentation than physical injury: such experimentation without consent is also an affront to human dignity, and courts should recognize a dignitary harm even in the absence of physical harm when informed consent is not obtained. The Nazis showed us the extreme physicians could go to in the service of the state. Kathy Swedlow helps us understand that when physicians act as agents of the state to involuntarily medicate a death row inmate so that person (certainly not a "patient") can be executed, the drugging can meet neither the legal requirement of informed consent nor the Hippocratic injunction to "do no harm." And Thomas May reminds us that soldiers are people too. Although soldiers may relinquish their right to refuse medical treatment upon enlisting, they retain, as all humans do, their right to refuse to be subjects of human experiments—and so retain their right to refuse experimental or investigational drugs and vaccines, even in wartime. The Nuremberg Code is, after all, a wartime document and made no exceptions for informed consent for either war or the soldiers assigned to fight it.

It should go without saying (but, of course, it doesn't) that civilians retain all of their rights to bodily integrity, even during war and times of domestic emergencies, and that under no circumstances should civilians be subjected to forced vaccination or other bodily invasions—even those deemed "necessary" by military, medical, or public health officials. Human rights lawyers should resist current proposals to grant public health officials the power over the bodies of civilians during a bioterrorist attack or other public emergency. Such proposals are not only destructive of basic human rights, they are counterproductive in that they replace a medical and public health system based on truthful communication and trust with one based on fear and arbitrary power. Terrorism by others is no excuse for torture by us.

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