American Bioethics and Human Rights: The End of All Our Exploring

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In his compelling novel *Blindness*, José Saramago tells us about victims stricken by a contagious form of blindness who were quarantined and came to see themselves as pigs, dogs, and “lame crabs.” Of course, they were all human beings – although unable to perceive themselves, or others, as members of the human community. The disciplines of bioethics, health law, and human rights are likewise all members of the broad human rights community, although at times none of them may be able to see the homologies, even when responding to a specific health challenge.

The boundaries between bioethics, health law, and human rights are permeable, and border crossings, including crossings by blind practitioners, are common. Two working hypotheses form the intellectual framework of this article: we can more effectively address the major health issues of our day if we harmonize all three disciplines; and American bioethics can be reborn as a global force by accepting its Nuremberg roots and actively engaging in a health and human rights agenda. That these disciplines have often viewed each other with suspicion or simple ignorance tells us only about the past. They are most constructively viewed as integral symbiotic parts of an organic whole.

A review of the subject matter generally seen as contained in the bioethics vessel and how they have been addressed in recent years underscores the close relationship between bioethics and human rights, especially as they are used in the new field of health and human rights, but more generally in the nongovernmental organization community, the developing world, and the academic community. Is the interest in globalization, public health, and human rights completely novel for American bioethics, or is it in fact a natural development in a field whose origins have been mostly misunderstood or suppressed? My tentative conclusion is that the evidence supports the latter view.

Both American bioethics and international human rights were born from World War II, the Holocaust, and the Nuremberg tribunals. While the Doctors’ Trial was only a part of Nuremberg and the new field of international human rights law, I believe it is accurate to conclude that the trial itself marked the birth of American bioethics. At the Doctors’ Trial, American judges articulated the Nuremberg Code of human experimentation based on the arguments of American prosecutors, and American physicians served as both consultant to the prosecution and expert witness in helping the court to articulate the code.¹

Reaching this conclusion after exploring the variety

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of topics in this essay suggests T.S. Eliot’s fabled lines from *Little Gidding*:

We shall not cease from exploration
And the end of all our exploring
Will be to arrive where we started
And know the place for the first time.

It is coincidental, but fitting nonetheless, that T.S. Eliot composed these lines during World War II when he was a night fire-watcher during the fire bombings of London. World War II was the crucible in which both human rights and bioethics were forged, and they have been related by blood ever since. Recognizing and nourishing this birth relationship will permit American bioethics to break free from its focus, if not obsession, with the doctor-patient relationship and medical technology and to cross our own border to become a global force for health and human rights – not as an imperialistic project, but to learn from and work with other cultures, countries, and activists.

In reflecting on the principled foundation of his philosophy, Descartes adopted a model from nature: “Philosophy as a whole is like a tree whose roots are metaphysics, whose trunk is physics, and whose branches, which issue from this trunk, are all the other sciences.” Of the sciences themselves, Descartes identified three principal ones, “medicine, mechanics, and morals.” The fruits of this tree, Descartes went on to note, will only be culled from “the extremities of the branches” and what they will turn out to be may not be known until they actually appear.

The tree metaphor works here as well. The human rights tree took root and was nourished in the blood and ashes of World War II and the Holocaust. Its roots are in universal law and human dignity, both of which apply to all humans by virtue of their humanity, and which were articulated at the trial of the major Nazi war criminals at Nuremberg. The trunk of this human rights tree is made up of the Nuremberg Principles, the Charter of the United Nations, and Universal Declaration of Human Rights. The branches are the major human activities needed to bring the human rights outlined in the Declaration to fruition. One of these branches is bioethics, and other branches include health law, international law, treaties, humanitarian law, corporate law, and corporate ethics. Science, technology, and economic development can also be seen as branches. The fruits of each branch will, of course, vary, some nourishing the mind, some the soul, and some the body.

Although the World War II origin of American bioethics seems obvious at the beginning of the 21st century, mainstream bioethics historians may continue to prefer seeing American bioethics as a 1960s-70s response to medical paternalism made more powerful by medical technology, especially organ transplantation and mechanical ventilation. Moreover, there was an active program to bury the Nazi past and distance American medicine and American bioethics from Nazi medicine for fear it would be somehow tarnished by it. The best known example is probably Henry Beecher—sometimes himself credited with getting American bioethics started with his 1966 essay in the New England Journal of Medicine that catalogued unethical experiments. Beecher was also a leader in drafting the Helsinki Declaration on human research—which he saw as a way to “save” medical research from becoming dominated by the Nuremberg Code. Nuremberg was also on the minds of Daniel Callahan and the founders of the Hastings Center, and they held a major program on its implications for bioethics. But, as described by Arthur Caplan (who himself sponsored a similar program a decade later, in 1989), there were many reasons for American bioethics to suppress its birth, most notably the sheer unprecedented scale of immorality of the Nazi doctors, and potential guilt by association, especially in the research enterprise. Although he does not use the phrase in his book on the subject, I recall Caplan saying at this meeting, “bioethics was born from the ashes of the Holocaust.”

The source of American bioethics can be read in the biographies of almost all of the founders of American bioethics and its current leaders. But the history of American bioethics is rooted in the Nazi concentration camp in another way as well. Historians are correct to see American bioethics in the late 1960s and early 1970s as fundamentally a reaction to powerful new medical technologies in the hands of medical paternalists who disregarded the wishes of their patients. Thus, the major strategy to combat this unaccountable power was to empower patients with the doctrine of informed consent (sometimes called autonomy, and put under the broader rubric of respect for persons). This is perfectly reasonable. But it is unreasonable to want to distance yourself so much from your origins to miss the fact that Nazi physicians who performed experiments in the concentration camps did so in an impersonal, industrial manner on people they saw as subhuman, and were unaccountable in the exercise of their power over their subjects.
The first response of the American judges to the horror of the Nazi doctors was to articulate, in the first precept of the Nuremberg Code, the doctrine of informed consent. The modern doctrine of informed consent was not born either of U.S. health law in 1972, or of American bioethics shortly thereafter, but at Nuremberg in 1947. American bioethicists have spent so much energy denying their origins that they have produced a misleading account of their central doctrine as well. The American judges at Nuremberg were also comfortable crossing borders, especially the border between American medical ethics (what we now know as bioethics) and international law.

As in any organic whole, the boundaries between these related fields are easily crossed. The collapsing of other boundaries in human rights discourse suggests how a more integrative model might be built. In the brief history of human rights, for example, there have been three great divisions—all of which have been effectively breached (although attempts to police these borders persist). These are the divisions between positive and negative rights, between public and private actors, and between state internal affairs and matters of universal concern.10

The positive/negative distinction has been seen more and more as a difference in degree rather than kind. This is because positive government action is required even to ensure so-called negative rights such as the right to be left alone, the right to vote, freedom of speech, and the right to trial by jury. All of these negative rights actually require the government to do something positive—such as setting up a police and court system, and making legal counsel available to the accused. Of course, in the arena of positive rights, like the right to food, shelter, jobs, and health care, governments will be required to expend more resources to fulfill these rights. But resources will have to be expended to fulfill both types. In the language of contemporary human rights, governments don’t simply have the obligation to act or not to act; but rather have obligations regarding all rights to respect rights themselves, to protect citizens in the exercise of rights, and to promote and fulfill rights. Of course, not all governments can fulfill economic rights immediately because of financial constraints, and international law suggests that governments must work toward the “progressive realization” of these rights within the limits of their resources.

A similar analysis can be made of the distinction between private and public. Individuals cannot be free to commit crimes in the privacy of their homes; the law has jurisdiction in both the public and private sphere. And although international law has traditionally focused solely on the relationships between governments (and between a government and its people), private actors, like transnational corporations, have more recently been seen as having so many direct relationships with governments, who often act explicitly to protect their interests, that they should be seen as a fit subject for international human rights. Similarly, although historically the boundary of a country protected it from interference with its “internal affairs,” the world today will not always now simply stand by and watch as countries engage in massive human rights abuses (as the world did in Rwanda), but may rather, as in Bosnia, intervene to prevent major human rights abuses.

In human rights work entirely new entities, termed nongovernmental organizations or simply NGOs, have sprung up and become the leading forces for change in the world. A notable health-related example is Médecins sans Frontières (MSF), a humanitarian-human rights organization founded on the belief that human rights transcend national borders and thus human rights workers cannot be constrained by borders, but should cross them when necessary. As Renée Fox describes it, over the years the le droit d’ingérence (the right to interfere) has been displaced with an even more activist le devoir d’ingérence (the duty to interfere).11 This concept, of course, takes human rights to be universal and sees globalization as a potential force for good. This physician organization thus redefines medical ethics as physician action to protect human rights, blending these two fields and treating law as subordinate to the claims of human rights. In this regard, MSF itself can be seen as one of the first health and human rights fruits of our human rights tree. Other notable physician NGOs include Physicians for Human Rights, International Physicians for the Prevention of Nuclear War, and Global Lawyers and Physicians.12

Globally, boundaries are being breached even as the world paradoxically splinters into more and more countries. Nonetheless, as daunting and discouraging as many of the contemporary challenges are, especially those related to global terrorism, the coming of the posthuman, and provision of basic health care to everyone, the Universal Declaration of Human Rights (UDHR) really does provide the world with an agenda and a philosophy. The centrality of the UDHR to bioethics is well-recognized internationally. As put concisely in a 2003 report of the International Bioethics Committee of UNESCO: "modern bioethics is indisputably founded on the pedestal of the values enshrined in the Universal Declaration of Human Rights."13 The world’s one remaining superpower and empire builder, the United States, has yet to embrace the UDHR—even though it was drafted under the able direction of Eleanor Roosevelt— and has even turned itself into an object of fear and distrust around the world in the wake of our "preemptive war" in Iraq. This war, allegedly
fought because of the threat of terrorism, has also added a new dimension to bioethics discourse.

Before the war on terror, the paradigm that most American bioethicists, especially those on President Bush’s Council of Bioethics, worried about was Huxley’s Brave New World – a world in which human would be commodified and stratified, and one in which they would give up all of their dignity and self-respect for security and recreational drugs and sex. It was a world of bioethics and health law. What is evident is that human rights activists are more likely to provide nourishment to the human rights tree than bioethics theorists or health law scholars.

Salman Rushdie also had border crossings on his mind when he reflected on the meaning of 9/11 in his collection entitled Step Across This Line. He ends his reflections by noting that “We are living, I believe, in a frontier time, one of the great hinge periods in human history, in which great changes are coming about at great speed.” On the plus side he lists the end of the cold war, the Internet, and the completion of the Human Genome Project; on the minus a “new kind of war against new kinds of enemies fighting with terrible new weapons.”

In human rights work entirely new entities, termed nongovernmental organizations or simply NGOs, have sprung up and become the leading forces for change in the world. The changes we will adopt are not preordained, and Rushdie quite properly notes that “the frontier both shapes our character and tests our mettle.” He is also right to wonder whether as we stand on this frontier if we will regress into barbarism ourselves or “as custodians of freedom and the occupants of the privileged lands of plenty, go on trying to increase freedom and decrease injustice?” A globalized American bioethics, infused with human rights, would have to pursue global justice.

In another post 9/11 reflection, José Saramago astutely agrees that what our world needs most of all is justice, “a justice that is a companion in our daily doings, a justice for which just’ is most exactly and strictly synonymous with ‘ethical,’ a justice as indispensable to happiness of the spirit as food for the body is indispensable to life.”

Saramago has in mind not only a justice “practiced in the courts whenever so required by law” but more, “a justice that manifests itself as an inescapable moral imperative...”

Where do we find the embodiment of this universal justice that is required by law and nourished by ethics and moral imperatives? In Saramago’s words “we already have a readily understandable code of practical application for this justice, a code embodied for the past fifty years in the Universal Declaration of Human Rights, those thirty essential, basic rights...in terms of the integrity of its principles and the clarity of its objectives, the Universal Declaration of Human Rights, just as it is now worded and without changing a single comma, could replace to advantage the platforms of every political party on Earth...”

This is powerful language and clear eyed: Saramago is no romantic seeking a new Eden, but a realist who understands that without a human rights-focused action by both individuals and governments, “the mouse...
of human rights will implacably be eaten by the cat of economic globalization." Saramago's implicit assertion is that law, ethics and human rights are all of a piece – and that justice cannot be obtained for humans without all three components.

American bioethics was born with international human rights law – and these branches of the human rights tree are much more likely to yield fruit, especially in areas like the right to health and rights in health, if their practitioners work together organically to fulfill the promise of its trunk, the Universal Declaration of Human Rights.

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References
3. Jonathan Mann has also suggested the human rights tree model, with the UDHR as a trunk, although without including either bioethics or health law: "The Universal Declaration can be thought of as the trunk of the human rights tree, with the UN Charter as its roots. The two major branches, the two major International Covenants on Civil and Political Rights, and on Economic, Social and Cultural Rights, emerge from and expand upon the trunk with further elaboration through many important treaties and declarations." J. Mann, "Human Rights and AIDS: The Future of the Pandemic," reprinted in J. Mann et al., Health and Human Rights: A Reader (New York: Routledge, 1999): at 223.
9. A rewriting of the intellectual history of American bioethics is beyond the scope of this essay, but my guess is that virtually anywhere one begins to dig in American bioethics, one will end with World War II. The best known examples are from two of the fields intellectual founders: Jay Katz and Hans Jonas. Both were born in Germany and had family members killed in the Holocaust, and the bioethics-related writings of both grew out of their reflections on the war and the concentration camps. Jay Katz, for example, published what is still the leading text on human experimentation in 1972 (Experimentation with Human Beings [New York: Russell Sage, 1972]), and the Nuremberg Doctors' Trial was central to this collection of primary sources. His star student, and assistant in this project, Alex Capron, went on to be a leader in American bioethics himself, and I don't think it's an accident (although he may) that he is currently the ethicist for one of the major "health and human rights" organizations in the world, the World Health Organization. Jay Katz himself was a member of two major U.S. bioethics panels that examined scandals: the Tuskegee Study Panel in 1972, and the President's Advisory Council of Human Radiation Experiments (1994-95). The Nuremberg Code was the centerpiece of the latter report – although attempts to distance bioethics from it continued. See supra note 7. Hans Jonas was, of course, extremely prolific. His bioethics was also much broader than just medicine, but included the entire biosphere. Nonetheless, it was grounded in the Holocaust and the dehumanization of Auschwitz, where his mother was murdered. It is no accident that his own star pupil is now the head of America's bioethics council, Leon Kass.
colleague Judith Swazey, she has accused American bioethics of being based on "Anglo-American analytic philosophical thought and its presuppositions," an impoverished and skewed expression of our society's cultural tradition." Tom Beauchamp (co-author with James Childress of the leading theoretical text on American bioethics, Principles of Biomedical Ethics, 5th ed., (New York: Oxford University Press, 2001) recently described the Fox/Swazey thesis as "surprisingly influential," although given the isolation of American bioethics from the rest of the world, no surprise is warranted. T.L. Beauchamp, "Does Ethical Theory Have a Future in Bioethics?" Journal of Law, Medicine & Ethics 32 (2004): 209-217. Fox and Swazey have had more uncomplimentary things to say about American bioethics. For example, "if bioethics is...more than medical...if it is an indicator of the general state of American ideas, values, and beliefs...then there is every reason to be worried about who we are, what we have become, what we know, and where we are going in a greatly changed and changing society and world." R.C. Fox and J.P. Swazey, Medical Morality is not Bioethics: Medical Ethics in China and the United States, Perspectives in Biology and Medicine 27 (1984): 336-60. And on the narrow focus of American bioethics, "One of the most urgent value questions...unexplored in bioethics is whether as poverty, homelessness, and lack of access to health care increase in our affluent country, it is justifiable for American society to be devoting so much of its intellectual energy and human and financial resources to the replacement of human organs." R.C. Fox and J.P. Swazey, "Leaving the Field," Hastings Center Report 22, no. 5 (1992): 9-15.

12. My colleague Michael Grodin and I followed up our conference on the 50th anniversary of the Nuremberg Code at the Holocaust Memorial Museum by founding our own physician NGO - but combining it with lawyers as well: Global Lawyers and Physicians. See <www.glphr.org> for details.

13. International Bioethics Committee, Report of the ICO on the Possibility of Elaborating a Universal Instrument on Bioethics, UNESCO, Paris, June 13, 2002:at 1. My own view on the question of whether to draft a universal bioethics declaration is that the Universal Declaration of Human Rights already serves this purpose, and that we cannot do better. It is more constructive to put international efforts into instruments aimed at specific bioethics problems areas, such as genetics. I agree, for example, with the spirit of the statement of former IBC chair, Ryuichi Ida of Japan, who noted of UNESCO's Universal Declaration on the Human Genome and Human Rights that it "has its place in the series of international instruments for the protection of human rights in the same way as the 1948 Universal Declaration of Human Rights, whose force is today universally recognized. The UNESCO declaration represents an extension of human rights protection to the field of biological sciences." Edmund Pellegrino has also strongly endorsed the centrality of the UDHR to medical ethics in the context of revelations about how physicians were used to torture under the Iraq dictatorship.

National and international medical associations must examine more closely the implications of becoming instruments of anything other than the healing purposes for which the profession is ordained. This issue will be critical for democratic as for despotic regimes, and it must become a global issue if the United Nations' Universal Declaration of Human Rights is to maintain significance. With such powerful tools advances in biotechnology that could be used for torture - in hand, will the medical profession remain a moral enterprise even in the face of threatening emergencies? E.D. Pellegrino, "Medical Ethics Suborned by Tyranny and War."