Part I

Rights of persons
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Bioethics, health law, and human rights can be viewed either as distinct areas of study and advocacy, or as interrelated areas that not only overlap, but have synergistic energy that can be concentrated to produce social change and promote social justice. This chapter introduces a way to think about this interrelationship and applies it to real-world cases.

2.1 Theory

Bioethics, health law, and human rights are overlapping and interrelated in ways that are not always either articulated or understood. Rather than antagonistically competing for their own influence, these fields can most constructively be viewed as complementary and synergistic. Thus, for example, human rights strongly support the medical ethics principle of informed consent, and medical ethics supports the human rights concept of the right to health. Human rights are universal and as such apply to all humans; they also articulate governmental obligations, and as such, focus on states. Health law is jurisdictional, and is the result of a political process in a particular country – which may or may not be the result of a country signing a particular treaty, obligating it to implement certain domestic law. Bioethics, especially its subcategory of medical ethics, defines the obligations of physicians when treating patients, and can also define a physician’s obligations when working for the state (usually seen as the domain of human rights).

Health law, bioethics, and human rights can be thought of as three different species of spiders that spin overlapping webs, the overlap becoming the strongest and most robust ‘net.’ The overlap of their webs can be observed with special clarity in the conduct of international research trials, especially those sponsored by rich countries and conducted in resource-poor countries. Other examples include the failure of the United Nations to take responsibility for introducing cholera in Haiti during their earthquake relief efforts, and the continued force-feeding of hunger strikers at the US military prison at Guantánamo. An even more striking example in the US is the abject failure of the government (and many physicians) to even acknowledge the internationally recognized ‘right to health,’ and to take effective steps to combat its components of hunger, homelessness, and lack of access to basic medical care (Universal Declaration of Human Rights 1948, article 25; UN Economic and Social Council 2000).
Physicians in the US and around the world have roundly condemned violations of medical ethics and human rights, including force-feeding at Guantánamo. That the practice nonetheless continues illustrates a major paradox with both medical ethics and human rights: both are widely supported in theory, but governments can (and do) ignore both when they think it is in their self-interest to do so. One reason often posited for the failure of governments to take human rights and medical ethics more seriously, and to incorporate them into their domestic law, is their inability to agree upon their origins and authority. It seems most reasonable to conclude that contemporary human rights and contemporary bioethics were born together in the aftermath of World War II (WWII). WWII produced the International Military Tribunal at Nuremberg (which articulated the Principles of International Law Recognized in the Charter of the Nuremberg Tribunal and in the Judgment of the Tribunal 1950 (Nuremberg Principles)), the subsequent Trials of War Criminals before the Nuremberg Military Tribunals under Control Council Law No. 10 (which articulated the Nuremberg Code 1947 – and can be seen as the first bioethics trial), and the founding of the United Nations (UN). The UN quickly adopted the Universal Declaration of Human Rights (UDHR) in 1948, and soon thereafter the Geneva Convention Relative to the Protection of Civilian Persons in Time of War (Fourth Geneva Convention) 1949 (Geneva Convention).

2.1.1 Human rights and Nuremberg

There was a series of attempts to define and champion human rights before Nuremberg. Thomas Aquinas taught that human rights came from God, but that man could discover the content of this ‘natural law’ through reason. Kant grounded rights on the notion of human dignity and taught that they were universal (Robertson 2000: 33). The revolutions in the US and France were both based on concepts of human rights. In the case of the former, the Declaration of Independence 1776 proclaimed that ‘all men are created equal and endowed by their creator with certain inalienable rights, including life, liberty, and the pursuit of happiness.’ The Bill of Rights 1791 also defined areas of a citizen’s life the government could not invade, including rights of free speech, religion, and the press. The French Declaration of the Rights of Man and the Citizen 1789 proclaimed 17 specific rights as ‘the natural, inalienable and sacred rights of man’ (pre-amble). Jeremy Bentham objected to the French list, arguing that there was no such thing as a natural right, but that they were all created by the law of the country (Robertson 2000: 11–12). Bentham’s view that rights are created by governments through law, and thus can and do vary from country to country, continues to have adherents today. Nonetheless, it seems correct to say that the most common view is that humans are special. Human rights are seen as inherent in what it means to be human, and are thus sometimes described simply as the ‘birthright’ of a human newborn (Morsink 2009: 46).

The ‘natural’ versus government-defined (positive law) dichotomy could not survive World War II. The horrors of mass murders, the Holocaust, torture, slavery, and arbitrary detention, all ‘legal’ under the positive law of Germany, were universally condemned as violations of the customary/natural ‘law of nations.’ At Nuremberg, many acts were judged as war crimes and ‘crimes against humanity,’ crimes that no government could lawfully authorize, including murder, torture, slavery, and arbitrary detention (Alston and Goodman 2013: 126). All of these can be rightfully categorized as ‘negative’ human rights, as in the right not to be murdered, tortured, enslaved, or treated as a research subject without informed consent. The most important human rights documents, including the Universal Declaration of Human Rights, the International Covenant on Civil and Political Rights 1966 (ICCPR), and the International Covenant on Economic, Social and Cultural Rights 1966 (ICESCR) are all direct products of World War II. The same can be said about the most important humanitarian treaty, the Geneva Convention and the Nuremberg
Principles, which were established in the major war crimes trial (the International Military Tribunal) of the Nazi leaders after World War II. The Nuremberg Principles made it clear that there are such things as war crimes and crimes against humanity (including murder, torture, and slavery); that individuals and not just states can be held criminally accountable for committing these crimes; and that it is not a defense for an individual to claim he was ‘just obeying orders’ or following the law of his country (Principles I, IV, VI). The rapid growth of international human rights law in reaction to the horrors of World War II has been profound in both human rights law and humanitarian law.

2.1.2 Humanitarian law

Humanitarian law is the formal term used to denote the law of war, especially that which pertains to rules restraining the worst impulses of the armies of warring states. The law of war is generally divided into two parts: (1) laws relating to the prevention of war (primary prevention) by discouraging going to war in the first place (jus ad bellum); and (2) laws relating to what may be thought of as secondary prevention, rules for the conduct of war, especially rules to protect civilians (jus in bello) (Grodin et al. 2013: 264).

Because war is so terrible it has, at least since Roman times, required justification, usually set forth in a version of the just war doctrine. This doctrine requires that war be waged under a public authority, be instigated either for self-defense, or to punish a grievous injury, and be pursued only to achieve the just ends, not for vengeance (Grodin et al. 2013: 264). What constitutes self-defense has been open to some interpretation, but notions of ‘preemptive war,’ designed to respond to a future threat, have no just war pedigree. Nations need not wait until they are attacked to defend themselves, but an attack must be imminent and unstoppable by other means to justify initiating a self-defense war.

Jus in bello rules, rules that limit the destructiveness of an inherently destructive activity, may seem strange, even counterproductive, since they may make war appear less horrible than it is. Nonetheless, prohibiting the mass slaughter of civilians has been a central tenet of the laws of war at least since the Thirty Years War (1618–48) and the work of Dutch jurist Hugo Grotius. Before that time, murder, rape, and pillage were seen as acceptable, even necessary, consequences of war.

The Convention (II) with Respect to the Laws and Customs of War on Land and Its Annex: Regulations Concerning the Laws and Customs of War on Land 1899 and the Convention (IV) Respecting the Laws and Customs of War on Land and Its Annex: Regulations Concerning the Laws and Customs of War on Land 1907 (collectively referred to as the Hague Conventions), established before World War I, specifically apply to land warfare and prohibit, among other things, ‘the attack or bombardment of towns, villages, habitation or buildings which are not defended’ (Convention (II), article 25). The post-World War I League of Nations was singularly ineffective in preventing World War II, and the Hague Conventions were systematically ignored during the war, which included both the slaughter of civilians by Germany and the Soviet Union, but also the firebombing of German and Japanese cities by the US, and even the use of atomic weapons on Hiroshima and Nagasaki.

The killing of millions of civilians during World War II, as well as the deaths of millions of prisoners of war, led to the Geneva Conventions of 1949 and their two additional protocols of 1977. Occupying powers are obliged to protect nonmilitary persons and places, and to make sure that the civilian population is provided with food and medical supplies as well as ‘clothing, bedding, means of shelter, and other supplies essential to the survival of the civilian population’ (Protocol Additional to the Geneva Conventions of August 12 1949, and relating to the Protection of Victims of International Armed Conflicts (Protocol I) 1977, article 69). Common article 3 of the
Geneva Conventions, common to all four of the conventions, sets the minimum standard for all conflicts, and prohibits not only torture, but also cruel, inhuman, or degrading treatment of all prisoners of war. Its operative section, which applies to all persons ‘taking no active part in the hostilities’ for whatever reason (including injury and detention), ensures that these persons ‘shall in all circumstances be treated humanely,’ by prohibiting the following acts at all times:

(a) violence to life and person, in particular murder of all kinds, mutilation, cruel treatment and torture;
(b) taking of hostages;
(c) outrages upon personal dignity, in particular, humiliating and degrading treatment.

(Geneva Conventions, article 3)

The results of these efforts to protect civilian populations and members of the armed forces who have been captured or have ‘laid down their arms,’ have, at best, been mixed, as can be seen in the wars in Iraq, Afghanistan, the Congo, and Syria over the past decade. The attempt to develop a ‘permanent Nuremberg’ tribunal, now known as the International Criminal Court – formally established in 2000 – has great potential. Unfortunately, the United States has not ratified the treaty that established it, due primarily to concerns about trying its own soldiers in an international court and post-9/11 politics.

2.1.3 Human rights law and the Universal Declaration of Human Rights

The Charter of the United Nations, signed by the 50 original member nations in 1945, spells out the goals of the UN. The first two are ‘to save succeeding generations from the scourge of war … and to reaffirm faith in fundamental human rights, in the dignity and worth of the individual person, in the equal rights of men and women and of nations large and small’ (Charter of the United Nations, preamble). After the Charter was signed, the adoption of an international bill of rights, complete with legal authority, proceeded in three steps: a declaration, two treaties, and an implementation measure (Alston and Goodman 2013: 139).

The Universal Declaration of Human Rights ‘marked a new chapter in a history that began with the great charters of humanity’s first rights moment in the seventeenth and eighteenth centuries’ (Glendon 2001: xvii), notably the British Bill of Rights 1689, the US Declaration of Independence, and the French Declaration of the Rights of Man and the Citizen. In 1946, the UN established the Commission on Human Rights, which held its first meeting in January 1947 to create an international bill of rights. Eleanor Roosevelt was the chairperson. Other members included the head of the Chinese delegation, Peng Chun Chang, Lebanon’s Charles Malik, France’s René Cassin, Canada’s John Humphrey, and India’s Hansa Mehta. Altogether, 16 member states were represented on the Commission. The Commission had input both from its members and other groups. Perhaps most significantly, the United Nations Educational, Scientific and Cultural Organization (UNESCO) philosophers’ committee gathered input from around the world on human rights, including perspectives from Chinese, Islamic, Hindu and other traditions. A remarkable consensus on what should be considered a human right emerged when people as diverse as Mohandas Gandhi, Pierre Teilhard de Chardin, Benedetto Croce, and Aldous Huxley (Glendon 2001: 51) were among those who provided input. But, as Mary Ann Glendon observed:

… they harbored no illusions about how deep the agreement they had discovered went. Maritain liked to tell the story of how a visitor at one meeting expressed astonishment that
champions of violently opposed ideologies had been able to agree on a list of fundamental rights. The man was told: ‘Yes, we agree about the rights but on condition no one asks us why.’ (2001: 77)

The rights listed in the Universal Declaration of Human Rights were seen as rights that in practice no one would oppose, rather than as growing out of any particular foundational philosophy of the world. The UDHR was adopted without dissent by the General Assembly of the United Nations on December 10, 1948. Some of its articles are noteworthy, as highlighted by Figure 2.1.

The status of the UDHR was very much like that of the US Declaration of Independence, i.e. it was a statement of what its signers believed should be included in the notion of human rights – a statement of belief and aspiration, with no enforcement mechanism or status as international human rights law. This took the development and ratification of a treaty, in this case two treaties (Donnelly 2003: 23). The names of the two subsequently developed treaties well describe their content, the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights. The division of human rights into two treaties has been most persuasively attributed to the competing ideologies in the Cold War. The US and its allies were firmly in favor of the former, but not willing to adopt the latter; similarly, the Soviet Union was in favor of the latter, but not of the former. The treaties were promulgated in 1966, adopted in 1976, and by 2012 each of them had been ratified by 150 (of approximately 200) countries (Alston and Goodman 2013: 141–2 and 282).

More specifically, the rights articulated in articles 1 to 21 can be categorized as ‘civil and political rights,’ such as ‘the right to life, liberty and security of person’ (Universal Declaration of Human Rights). The rights articulated in articles 22 to 27 can be categorized as ‘economic, social, and cultural,’ such as rights to education, health, and social security (Universal Declaration of Human Rights). Article 25, of course, has special interest to public health and bioethics practitioners as it articulates the right to health (Universal Declaration of Human Rights). It also contains a recurring theme in international human rights that motherhood and childhood merit special care. Because the government must spend money to support political rights as well, such as protecting people’s right to life and physical security, developing a judicial system, and treating people equally, the traditional distinction between negative and positive rights has lost much of its appeal. Most modern commentators discuss human rights in the context of state obligations instead. Specifically, when a country ratifies a treaty, including the two Covenants, the government undertakes the obligation or duty to ‘respect, protect, and fulfill’ the rights articulated in the treaty.

Respect requires that the government itself not violate the rights; protection requires that the government passes laws and otherwise prohibits private parties from violating the rights, and fulfillment requires the government to undertake an affirmative obligation to actualize the rights. This latter step can involve setting up a school system, a healthcare system, and an infrastructure system for food, shelter, sanitation, and clean water. Because many governments that adopted the two Covenants do not currently have the financial resources to implement all of the economic and social rights, the requirement is that they move in the direction of implementation by ‘progressively realizing’ the rights to the extent of their ability (Annas 2010: 191).

It should also be noted that since the development of the UDHR, almost 100 new countries have been formed, many of which have adopted at least some of the provisions of the two treaties into their own constitutions. In these countries, the treaties are not just a matter of international human rights law, but have the full force of the highest level of domestic law as well. In countries where the treaty provisions are part of their national constitutions, including India and South Africa, courts have consistently insisted they be enforced (Annas 2005: 59–67). Human rights
PREAMBLE
Whereas recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world,
Whereas disregard and contempt for human rights have resulted in barbarous acts which have outraged the conscience of mankind, and the advent of a world in which human beings shall enjoy freedom of speech and belief and freedom from fear and want has been proclaimed as the highest aspiration of the common people . . .

ARTICLE 1
All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood.

ARTICLE 2
Everyone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind, such as race, color, sex, language, religion, political or other opinion, national or social origin, property, birth or other status . . .

ARTICLE 3
Everyone has the right to life, liberty and security of person.

ARTICLE 4
No one shall be held in slavery or servitude; slavery and the slave trade shall be prohibited in all their forms.

ARTICLE 5
No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment.

ARTICLE 6
Everyone has the right to recognition everywhere as a person before the law.

ARTICLE 7
All are equal before the law and are entitled without any discrimination to equal protection of the law. All are entitled to equal protection against any discrimination in violation of this Declaration and against any incitement to such discrimination.

ARTICLE 8
Everyone has the right to an effective remedy by the competent national tribunals for acts violating the fundamental rights granted him by the constitution or by law.

ARTICLE 9
No one shall be subjected to arbitrary arrest, detention or exile . . .

ARTICLE 18
Everyone has the right to freedom of thought, conscience and religion; this right includes freedom to change his religion or belief, and freedom, either alone or in community with others and in public or private, to manifest his religion or belief in teaching, practice, worship and observance.

ARTICLE 19
Everyone has the right to freedom of opinion and expression; this right includes freedom to hold opinions without interference and to seek, receive and impart information and ideas through any media and regardless of frontiers.

Figure 2.1 Extracts from the Universal Declaration of Human Rights
were codified in Europe following the UDHR with the adoption of the *European Convention on Human Rights* 1950, and equipped with its own enforcement mechanism, the European Court of Human Rights. The United States, on the other hand, adopted only the *International Covenant on Civil and Political Rights*. Even in this context, the US generally insists it can only be enforced by the courts in a way that is consistent with its *Constitution* 1787 – which remains the highest law in the US.

### 2.1.4 Bioethics and human rights

Contemporary bioethics can be usefully thought of as having been born at the Doctors’ Trial in Nuremberg in which Nazi physicians were called to answer for crimes of murder and torture committed under the guise of human experimentation (Annas and Grodin 1992: 3). The US judges who presided over the first of 12 subsequent trials (i.e. following the International Military Tribunal which had judges not only from the US, but also from Britain, France, and the Soviet Union as well), articulated the *Nuremberg Code*, not only the first comprehensive code of
conduct regarding human experimentation, but also the first to clearly articulate the requirement of informed consent of the research subject (Annas and Grodin 1992: 2; Perley 1992: 151).

After adopting the Universal Declaration on the Human Genome and Human Rights 1997 (Lenoir 1997: 31), and the International Declaration on Human Genetic Data 2003, UNESCO took on the project of developing an international declaration on bioethics. This project, which involved 180 nations, eventually sought to combine human rights and bioethics into a single declaration, the Universal Declaration on Bioethics and Human Rights, adopted in 2005. The purpose of the Declaration is primarily to guide states, individuals, and corporations in dealing with issues of medicine and human research. Its principles are set forth in article 3:

1. Human dignity, human rights and fundamental freedoms are to be fully respected.
2. The interests and welfare of the individual should have priority over the sole interest of science or society.

(Declaration of Malta)

The declaration is especially strong on consent, equality, privacy, and non-discrimination, and it has been praised for setting an international standard that applies basic human rights principles to bioethics (Adorno 2007: 152–3). On the other hand, it has been argued that many of the principles are overly vague and generalized (e.g. ‘Appropriate assessment and adequate management of risk related to medicine, life sciences and associated technologies should be promoted’ (Universal Declaration on Bioethics and Human Rights, article 20) (Macpherson 2007: 588). The World Health Organization (WHO) also objected to UNESCO’s development and promulgation of the Declaration, arguing that health and health-related regulation should be left to the WHO. Of course, there are private organizations that have also promulgated ethical rules that can be seen as human rights declarations as well, perhaps, most notably, the World Medical Association’s (WMA) Declaration of Malta on Hunger Strikers 1991 (Declaration of Malta) which, as noted at the beginning of this chapter, prohibits the force-feeding of hunger strikers by physicians, even when the physicians are working for the military or the prison. It is especially noteworthy to see private medical organizations, like the WMA, explicitly adopt human rights language in their declarations of medical ethics.

Today many healthcare and public health advocates use ‘the right to health’ to demand decent healthcare worldwide (Ruger 2010: 1). Likewise, human rights are almost always at the forefront of arguments about the wars in Iraq, Afghanistan, and Syria. Bearing witness to the slaughter in all of these (and other) countries, it is easy to become cynical and disenchanted with human rights. David Kennedy catalogs the major critiques of human rights, noting how they limit other emancipatory possibilities, frame problems and solutions too narrowly, overgeneralize and become unduly abstract, and express a Western liberalism; human rights promises more than it can deliver, and the UN human rights bureaucracy is itself part of the problem (2004). In his words:

The generation that built the human rights movement focused its attention on the ways in which evil people in evil societies could be identified and restrained. More acute now is how good people, well-intentioned people in good societies, can go wrong, can entrench and support the very things they have learned to denounce.

(Kennedy 2004: 35)
Philosophers both support and contest the existence of human rights (Sen 1985; Etzioni 2010). Allan Gewirth has, for example, argued that agency or action is the common subject of all morality and practice, and human rights are found in the basic freedom and wellbeing necessary for human agency (1978: 229; 1979: 1156). He also distinguishes three types of human rights: basic rights which safeguard one’s very existence; nonsubtractive rights, which are required to fulfill the capacity for purposive agency; and additive rights which provide the requisites for developing one’s capabilities (Gewirth 1985). Alasdair McIntyre, on the other hand, insists human rights do not exist in the real world any more than other mythological creatures such as unicorns and witches (MacIntyre 1988: 83; Walters 2003).

In the real world, however, the philosophical and legalistic debates are mostly beside the point. As Joseph Kunz observed more than 60 years ago in regard to the UDHR, ‘[i]n the field of human rights … it is necessary to avoid the Scylla of a pessimistic cynicism and the Charybdis of mere wishful thinking and superficial optimism’ (1949: 320). With specific application to bioethics, ‘no other language than rights language seems as suitable for global health advocacy. All people have (inherent) human rights by definition, and people with rights can demand change, not just beg for it’ (Annas 2010: 191).

2.2 Illustrations from the US

2.2.1 Law and medicine

Medical care in 2013 is unrecognizable from what it was in 1813, and no nineteenth-century physician would be at home in a modern hospital. A nineteenth-century lawyer, however, would be completely at home in a contemporary courtroom, as would a present-day lawyer transported back to the early nineteenth century. Although slavery was still legal and women did not yet have the right to vote, the US Supreme Court was the highest court in the land, and the US Constitution and its Bill of Rights would be familiar, as would the jury and the common law system adopted from England.

Over the past two centuries, the discipline of medical jurisprudence – the application of medical knowledge to the needs of justice – has been renamed legal medicine (including forensic science), and applying the law to medicine has expanded from medical law to health law. Legal procedures and courtrooms have changed little, but there have been almost as many changes in the application of law to medicine over the past 200 years as there have been changes in the practice of medicine. Health law’s intimate relationship with medical ethics also has a strong precedent. Thomas Percival’s original title for his 1803 Medical Ethics text, which has been described as ‘the most influential treatise on medical ethics in the past two centuries’ (Beauchamp and Childress 2001: 31), was Medical Jurisprudence (Percival 1803). More than half of Percival’s text specifically addresses ‘professional duties … which require a knowledge of law’ (Percival 1803: xiv and 61). Medicolegal expert David Paul Brown argued more than 100 years ago that both professions needed to understand the other, saying: ‘[a] doctor who knows nothing of law and a lawyer who knows nothing of medicine, are deficient in essential requisites of their respective professions’ (Channing 1860: 233).

A court case from England in the mid-eighteenth century illustrates that the law’s concern with human experimentation by physicians did not begin at Nuremberg. The celebrated case of Slater v. Baker and Stapleton was decided in England in 1767 (95 Eng. Rep. 860 (Slater)). Slater had broken his leg, it had not healed well, and he had sought treatment from another physician, a surgeon named Baker, and an apothecary named Stapleton. They broke the leg again and set
it in ‘a heavy steel thing that had teeth’ to stretch it, with a poor result. Slater sued them, and three surgeons testified that the ‘steel thing’ should not have been used. The jury awarded Slater £500 (approximately £60,000 today), and the defendants appealed. The appeals court affirmed the award, saying that a radical experiment could itself be considered malpractice, at least in the absence of the patient’s consent. In the Court’s words:

This was the first experiment made with this new instrument; and although the defendants in general may be as skillful in their respective professions as any two gentlemen in England, yet the Court cannot help saying that in this particular case they have acted ignorantly and unskilfully, contrary to the known rule and usage of surgeons.

(Slater 1767, p. 863)

Even this is not the first legal mention of consent in the context of experimentation. Rather it follows, as noted by medical historian and ethicist Robert Baker:

It dates to the very first law regulating health professionals in the British colonies, the Duke of York’s Law of 1665. The law states in relevant part, that ‘no physician … [may engage in experimental surgery or medicine] … upon or toward the body of any … without the … consent of the patient or patients if they be mentis compotes, much less contrary to such consent.

(2013: 233–4)

From these doctor–patient relationship cases, the law (and bioethics) expanded their reach and, following World War II, were often seen in each other’s company. Of particular note is the increasing application of health law to the field of international human rights, including the right to health, the regulation of research on human subjects, and the physician’s role in war and civil conflict. Physicians and lawyers now work together in US-based organizations such as Physicians for Human Rights and Global Lawyers and Physicians. When working separately, medical associations, including the British Medical Association and the WMA, rather than legal associations, deserve much of the credit for the growth of the international ‘health and human rights’ arena. Both law and medicine are critical tools for improving health and wellbeing on a global level, and each profession is more effective when the two work together.

2.2.2 The human right to health

The US healthcare system is not a model for any other country. Where in the world, for example, is there any country (other than the US) where its citizens have the distinct impression that all human beings as such are entitled to any and all treatments and services necessary for the maintenance of health and life, no matter what the cost? Where in the world (other than the US) do we experience a ceaselessly proliferating list of highly expensive, marginally effective treatments for diseases? Where in the world (other than the US) do we expect our health system to provide certain drugs, no matter how experimental or expensive, to forestall death and improve health? And where in the world (other than the US) do we expect, as a matter of right, (access to) the latest developments in open heart surgery, chemotherapy, and cosmetic psychopharmacology? Because American bioethics is grounded in a uniquely dysfunctional healthcare system, it does not travel well. That is why it is extremely unlikely that any country (other than the oil-rich UAE) would model their healthcare system on ours, or that any country would model their bioethics on ours.
We need a model other than the US, one which is dominated by a hyper-individualist market model that is fueled by an almost hysterical fear of death, to define the content of the right to health. In this regard we at least seem to agree on some fundamental points regarding the right to health: rights are not self-enforcing; rights require definition (and in the case of ‘progressive realization’ in resource-poor nations, benchmarks to measure progression); and an unbounded right to health care (which is part of the right to health), whether or not it includes a ‘laundry list,’ would be fiscally unsustainable, even in the US (Moses et al. 2013). It is worth reviewing a few characteristics of the international human right to health.

Rights are set forth in brief and general language in the UDHR and the treaties, though not restricted to these documents. Rights are explicated by the very bodies the treaties established, within which experts and special groups can be formed to do so. In terms of the ‘right to health,’ General Comment No. 14 of the UN Committee on Economic, Social and Cultural Rights (the body set up to help implement the International Covenant on Economic, Social and Cultural Rights) explains a state’s obligation to respect, protect, and fulfill the right to health:

34. … States are under obligation to respect the right to health by, inter alia, refraining from denying or limiting equal access for all persons …; and abstaining from imposing discriminatory practices as State policy …

35. Obligations to protect include, inter alia, the duties of States to adopt legislation or to take other measures to ensure equal access to health care and health-related services provided by third parties; …

36. The obligation to fulfill requires States parties, inter alia, to give sufficient recognition to the right to health in the national political and legal systems, preferably by way of legislative implementation, and to adopt a national health policy with a detailed plan for realizing the right to health. States must ensure provision of health care, including immunization programs against the major infectious diseases and ensure equal access for all to the underlying determinants of health, such as nutritionally safe food and potable drinking water, basic sanitation and adequate housing and living conditions … provide for sexual and reproductive health services.

(UN Committee on Economic, Social and Cultural Rights 2000, paras 34–36)

American bioethicists, like American healthcare, have generally ignored the right to health. In the past three decades, for example, American bioethicists have learned virtually nothing about the right to health, and this is a major limitation of the field. A related problem is that in a US-centric bioethics, the right, when it is discussed, is most often referred to simply as a ‘right to healthcare,’ whereas in the human rights world, it is the ‘right to health.’ On the other hand, there are major issues involving resource allocation and identifying who gets to make allocation decisions (Fink 2013). There is no ‘limitless right to health’ or healthcare any more than there is a limitless right to anything, including liberty, free speech, religious freedom, or free press. As the South African nevirapine case illustrates, when a country adopts the right to health as a constitutional right, its courts have the ability to define and enforce it (Annas 2005: 60–1). Nonetheless, there are also major weaknesses in relying on courts to enforce health rights:

[T]he focus in a courtroom struggle is likely to be narrow, involving specific medical interventions such as chronic kidney dialysis or nevirapine. Should nevirapine not turn out to be the drug of choice … the [court] opinion will not help HIV-positive patients to obtain care.
George J. Annas

The HIV/AIDS epidemic demands a comprehensive treatment and prevention strategy, including education, adequate nutrition, clean water, and gender equality.

(Annas 2005: 67)

2.1.3 American bioethics and freedom from torture and inhuman treatment

That the US has consistently and openly violated the fundamental human right to be free from torture is remarkable. Freedom from torture is one of the most basic human rights of all. Identified by the International Military Tribunal in 1946 as a war crime and a crime against humanity, it was given prominence as a human right in the Nuremberg Doctors’ Trial, the UDHR, the ICCPR, and the Geneva Conventions, and it carries its own federal criminal statute, as well as dedicated treaty, the Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment 1984 (UN General Assembly) (Convention Against Torture).

Since 9/11, US physicians have been implicated over and over again in torture, abusive interrogations, force-feeding prison hunger strikers, and falsifying death certificates of prisoners (Task Force 2013). Nonetheless, the premier US bioethics organization, the President’s Council on Bioethics, has only once mentioned torture by physicians in the context of condemning the force-feeding of a political prisoner by physicians in a Soviet prison camp more than 30 years ago (Bukovsky 2003: 218–19). This failure is shameful, but helps explain why ending force-feeding by physicians (a violation of the Geneva Conventions’ common article 3 and the Declaration of Malta) has so far been impossible (Annas et al. 2013).

2.3 Current controversies suggesting convergence

An ongoing dispute involving the United Nations (and the meaning of both accountability for harm caused in delivering disaster relief and the right to health) helps us appreciate the interrelationships among health law, bioethics, and human rights, and how, used together, they increase the chances of benefiting both individuals and populations.

Shortly after the devastating 2010 earthquake in Haiti, the region experienced a deadly cholera epidemic that afflicted more than 600,000 people, killing more than 8,000 of them. It is now well-documented that this epidemic was caused by infected United Nations peacekeeping forces who were deployed from Nepal to join other UN troops in Haiti to aid in the relief effort. These troops were based in Meye, near the capital of Port-au-Prince, on a tributary of Haiti’s largest river, the Artibonite River, a major source of water for drinking and cooking. The troops from Nepal, an area in which cholera is endemic, brought the disease with them, and it spread quickly from their camp via the river. The United Nations denies any responsibility for the tragedy to this day, claiming, among other things, immunity based on its Charter. A 2013 report from the Yale Law School challenges the position of the UN, and uses health law, medical ethics, and human rights language to assert that the UN must take responsibility for the cholera epidemic and for preventing future epidemics of cholera in Haiti (Transnational Development Clinic et al. 2013).

First, the Yale researchers argue that the UN is in violation of the law. Specific language in the UN Charter and the Convention on the Privileges and Immunities of the United Nations 1946 limits immunity to those instances ‘necessary for the exercise of its functions and the fulfillment of its purposes’ (UN Charter, article 104). Moreover, even in these areas, article 29 of the Convention on the Privileges and Immunities provides that the UN ‘shall make provisions for appropriate modes of settlement of disputes.’ This has been interpreted as requiring the UN to establish a
‘claims commission’ to adjudicate claims for damages caused by UN personnel, including peacekeepers (Transnational Development Clinic et al. 2013: 5). The UN has yet to establish such a claims commission to hear the claims of the Haitian cholera victims.

Second, drawing from principles in the ‘Code of Conduct for the International Red Cross and Red Crescent Movement and Non-Governmental Organizations (NGOs) in Disaster Relief’ (International Federation of Red Cross and Red Crescent Societies and International Committee of the Red Cross (ICRC) 1994), the Yale Group notes the ICRC’s incorporation of a fundamental principle of medical ethics into their Code: ‘commitment to the “do no harm principle”’ (Transnational Development Clinic et al. 2013: 4). In the Yale Group’s view, this bioethics principle does not just apply to physicians, but to all humanitarian relief operations and personnel. In the report’s words, the UN’s ‘introduction of cholera into Haiti violated the do no harm principle of humanitarian intervention. The do no harm principle includes an obligation to not expose individuals to physical hazards, violence, or other rights abuse, including disease’ (Transnational Development Clinic et al. 2013: 47). This principle was violated ‘by introducing an epidemic disease into a major waterway used by a vulnerable population, leading to severe illness and death for many Haitians’ (Transnational Development Clinic et al. 2013: 47).

Third, and perhaps the strongest argument, the Yale report points out the UN failed to honor its own human rights obligations set forth in foundational UN treaties, including the ICCPR and the ICESCR. The report identifies the UN’s failure to respect the right to water, which includes access to safe drinking water and sanitation. Safe drinking water is defined as water ‘free from micro-organisms … that constitute a threat to a person’s health’ (Transnational Development Clinic et al. 2013: 38). Likewise, the UN fell short of respecting the right to health ‘by failing to prevent the introduction of cholera into Haiti’ (Transnational Development Clinic et al. 2013: 39). This created a public health crisis in Haiti, which directly interfered with the country’s ability to ‘comply with its own obligations under the human right to health’ (Transnational Development Clinic et al. 2013: 38, 39, 51). Combining principles from law, ethics, and human rights makes the recommendations of the Yale Group much more compelling than had their report relied on any one of these sources alone. Nonetheless, debate continues and it is uncertain whether the UN will accept its moral and legal responsibilities for this incident.

Guantánamo Bay Prison provides a vastly different context for the convergence of law, ethics, and human rights. In 2013, Sondra Crosby and I commented on the ongoing hunger strike by at least 100 of the 166 remaining prisoners and the strategy of using military physicians to ‘break’ the hunger strike by force-feeding (Annas et al. 2013: 101–3).

As we noted, force-feeding competent hunger strikers is a violation of basic principles of medical ethics and is not a matter of serious dispute. The American Medical Association (AMA) has appropriately taken a leadership role on behalf of the profession, writing to the Secretary of Defense that ‘forced feeding of [competent] detainees violates core ethical values of the medical profession’ (Lazarus 2013). Similarly the US Constitution Project’s bipartisan Task Force on Detainee Treatment concluded in April 2013 that ‘forced feeding of detainees [at Guantánamo] is a form of abuse that must end,’ and urged the US to ‘adopt standards of care, policies, and procedures regarding detainees engaged in hunger strikes that are in keeping with established medical, professional and ethical care standards’ (Constitution Project’s Task Force on Detainee Treatment 2013: 36). Another report issued in 2013 also combined law, bioethics, and human rights to call for an end to physician participation in the interrogation and torture of prisoners at Guantánamo, terming such action ‘a violation of medical ethics and international [human rights] conventions’ (Task Force 2013: 1).

The medical ethics standard for physician involvement in hunger strikes has probably been best articulated by the World Medical Association in its Declaration of Malta on Hunger Strikers.
The Declaration of Malta is meant to have the same ethical effect as the Declaration of Helsinki 1964. Physicians can no more ethically force-feed competent hunger strikers than conduct research on competent human subjects without informed consent (Annas et al. 2013: 102). The Declaration of Malta’s bottom line couldn’t be clearer: ‘[f]orcing feeding [of competent hunger strikers] is never ethically acceptable’ (WMA 1991).

Hunger striking is a political activity to protest against terms of detention or prison conditions, not a medical condition. The fact that hunger strikers develop medical problems that need attention and may worsen does not make hunger striking itself a medical problem. Nonetheless, at Guantánamo, prison officials consistently seek to medicalize hunger strikers by asserting that they are ‘suicidal’ and must be force-fed to prevent self-harm and ‘save lives’ (Annas et al. 2013: 102). The Department of Defense’s (DOD) 2006 Medical ‘Instruction’ states specifically that ‘[i]n the case of a hunger strike, attempted suicide, or other attempted serious self-harm, medical treatment or intervention may be directed without the consent of the detainee to prevent death or serious harm’ (DOD 2006: 5). This policy mistakenly conflates hunger striking with suicide. Hunger strikers are not attempting to commit suicide. Rather, they are willing to risk, or even accept, death if their demands are not met. Their goal is not to die, but to have perceived injustices addressed. The motivation is similar to that of a free living person who finds kidney dialysis intolerable and discontinues it knowing he will die. This refusal of treatment with the awareness that death will soon follow is not suicide according to both the US Supreme Court and international medical ethics (Annas et al. 2013: 102).

Law and medical ethics here are consistent with basic human rights, and examining all three simultaneously is much more likely to produce a reasonable and responsible policy than looking at any one of them in isolation. In this instance, using all three sources of guidance helps us to recognize that force feeding a competent person is not the practice of medicine, it is aggravated assault. Military physicians are no more entitled to betray medical ethics than military lawyers are entitled to betray the US Constitution or military chaplains are entitled to betray their religion.

2.4 Conclusion

Ongoing controversies at Guantánamo, the deadly continuing war in Syria with the slaughter and starvation of civilians, as well as wars across the globe caution us not to expect too much even from a synthesis and symbiotic activism fueled by a belief in law, ethics, and human rights working together. Nor is despair a credible strategy for human betterment. We should leverage bioethics, law, and human rights in creative ways in which the whole can be made greater than the sum of its parts. This will require active citizens putting pressure on their governments to honor human rights and the rule of law. But it will also require legal and medical professionals to take their professions seriously and to actively support their colleagues when they are pressured to abandon medical ethics in favor of short-term political or military gains. Transnational professions can benefit both themselves and humanity by fostering human rights. They are much more likely to do so if human rights are viewed as supportive of their own professional ethics, and their actions in fulfillment of their ethics are in turn supported by the law.

References


**Legislation**

*Bill of Rights* 1689 (UK).
*Bill of Rights* 1971 (US).
*Constitution of the United States* 1787 (US).
*Declaration of Independence* 1776 (US).
*Declaration of the Rights of Man and the Citizen* 1789 (France).

**International conventions, treaties and declarations**

*Convention (II) with Respect to the Laws and Customs of War on Land and Its Annex: Regulations Concerning the Laws and Customs of War on Land* 1899.
*Convention (IV) Respecting the Laws and Customs of War on Land and Its Annex: Regulations Concerning the Laws and Customs of War on Land* 1907.
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*World Medical Association 1964, Declaration of Helsinki – Ethical Principles for Medical Research Involving Human Subjects.*

**Cases**