Human rights, ethics and the medical profession

Dirceu Greco 1, James Welsh 2

Abstract
In this paper we try to sketch out the major ethical challenges, failures and complexities in implementing ethical medicine in times of political and social turmoil – but also in more stable times. We begin with the aftermath of Nazi medicine in the first half of the 20th century. The behaviour of the Nazi doctors included crimes against humanity that were also found in other states and political systems, including democracies. Receiving much less publicity (and virtually no accountability), the medical experiments carried out on a smaller scale by Japanese doctors during World War II taught also painful lessons. Other countries have also experienced genocide though with less medical involvement. But breaches of bioethics have also been documented in societies and institutions not afflicted by war or by genocidal government policy. We should thoroughly reflect on the situations depicted here, which occurred during the Nazi regime and elsewhere even in more stable times, to help make sure they are never repeated.


Resumen
Derechos humanos, ética y práctica médica
Este artículo trata de los principales desafíos éticos, los fracasos y las complejidades en la implementación de la medicina ética en tiempos de agitación política y social, y también en tiempos más estables. Comenzamos con las secuelas de la medicina nazi en la primera mitad del siglo XX. El comportamiento de los médicos nazis incluyó delitos evidentes contra la humanidad que también sucedían en otros países y sistemas políticos, incluyendo democracias como la de Estados Unidos. Los experimentos médicos llevados a cabo en una escala más pequeña por los médicos japoneses durante la Segunda Guerra Mundial recibieron menos publicidad (y prácticamente nada de rendición de cuentas), aunque también tienen lecciones dolorosas. Otros países también han experimentado genocidios, aunque con menos participación médica. Sin embargo, infracciones de la bioética también se han documentado en sociedades e instituciones no afectadas por la guerra o por políticas gubernamentales genocidas. Deberíamos reflexionar profundamente sobre las atrocidades descritas en este texto, que ocurrieron durante el régimen nazi y en otras situaciones en tiempos de estabilidad, para asegurarnos de que nunca más se repitan.


1. PhD dirceugreco@gmail.com – Universidade Federal de Minas Gerais (UFMG), Belo Horizonte/MG, Brasil 2. PhD jwelsh@amnesty.org – London School of Tropical Medicine & Hygiene, Londres/Inglaterra.

Correspondência

Declaram não haver conflitos de interesse.
Nazi abuses and their aftermath

The atrocities committed, encouraged and permitted by the Nazis against European Jewry and other minorities were an outrage and beyond comparison in their planning and ruthlessness. There is no definitive figure for the number of deaths during the Nazi period. It has been estimated that between 5.1 million to 6.2 million Jews were killed or perished from starvation and disease in ghettos and camps. And this does not account for all the pain inflicted on the survivors and their families.

Around 100,000 men were arrested as homosexuals during the Nazi period, some of whom were interned in concentration camps where many died. In addition, other ethnic groups, political activists and mentally disabled people were killed.

During World War II, about 200,000 ‘Gypsies’ [Roma] were killed throughout Europe by Nazi Germany and allies solely on the basis of their ethnicity and imputed “inferiority” between 1939 and 1941, approximately 100,000 German citizens were either sterilized or killed because they were physically deformed, diagnosed with emotional illnesses, or considered mentally impaired. In total, some 5 million non-Jewish victims died under Nazi rule.

Remembering what happened during the Nazi period is of utmost importance as it will help lower the risks of delegating it as a half-forgotten abuse from the past, a horror from a period of war and an abuse by a specific government in a specific time. It will also help to open our eyes to the unacceptable participation of the medical profession before and during the Second World War in Germany and in occupied territories/countries and to the risks of this behavior ever happening again.

Nazism: First steps on the slippery slope

According to Hanauske-Abel, support by doctors for the German military did not start with Nazism. A manifesto in support of German militarism was signed by notable public figures from medicine, science and the arts in 1914. Those who were critical of this (such as the physician Georg Nicolai) faced hostility. Nicolai escaped imprisonment and went into exile in South America (ironically the destination later chosen by some of the Nazi doctors) where he lived for the rest of his life. In January 1933 – before Hitler came to power – around 7% of doctors were already members of the Nazi party. By 1942, around half of all doctors were members compared to 7% of teachers.

Prior to the war, the German medical profession participated in the forced sterilization of between 200,000-350,000 mentally and physically disabled individuals and was a determinant actor in the “euthanasia” of men, women and even children vaguely defined as mentally ill. A programme of elimination of those regarded as “life unworthy of life” [Lebensunwertes Leben] began in 1939 and up to 200,000 people were subsequently murdered under this programme.

All this was perpetrated with the help and support of the legal and health systems. And deceit was part of the process to convince public opinion of its correctness. The language used to speak of mass murder was aseptic and intended to mislead both the German public and the victims of Nazi policies. Terms such as “hygiene” were applied to society thus conflating public health with programmed racism.

Eugenics in Nazi Germany

The term “eugenics” was first described in 1883 by the English polymath, Francis Galton. The spirit of eugenics – the science of the improvement of the human race by better breeding – formed the title of a booklet published by Henry Davenport, a US advocate of the practice. Edwin Black has pointed to the adoption of eugenics in the USA, noting: Throughout the first six decades of the twentieth century, hundreds of Americans and untold numbers of others were not permitted to continue their families by reproducing. Selected because of their ancestry, national origin, race or religion, they were forcibly sterilized, wrongly committed to mental institutions where they died in great numbers.

Racism too, was not far from the minds of the eugenicists. According to Robert Yerkes, the darker peoples of Southern Europe and the Slavs of Eastern Europe are less intelligent than the fair peoples of Western and Northern Europe and the negro lies at the bottom of the scale of intelligence. Harry Hamilton Laughlin, director of the Eugenics Record Office in the United States, compared human racial crossing with mongrelisation in the animal world and argued that immigrants from Southern and Eastern Europe, especially Jews, were racially so different from, and genetically so inferior to, the current American population that any racial mixture would be deleterious. The psychologist, Adolf Jost, argued...
that if the state demanded the sacrifice of thousands of individuals in wartime, it had the same “right” in times of peace to demand the sacrifice of the impaired and non-productive, who were draining the state of its resources.  

In 1931, two years before Hitler’s assumption of power, Dr. Fritz Lenz, first professor of eugenics at the University of Munich, claimed that: Hitler is the first politician with truly wide influence who has recognized that the central mission of all politics is race hygiene and who will actively support this mission. Within a decade, Hitler had translated that “support” to the development of a programme. The T4 Programme was named after the Chancellery offices at Tiergartenstrasse 4 in Berlin, where records of disabled people were examined by experts who decided whether individuals should live or die.

Those selected to die were murdered by injection or by gas inhalation in “shower rooms” in at least six “euthanasia” centres. According to Dr. Heinrich Bunke, chief physician at the Bernberg Centre, he accepted the invitation to join the T4 Programme as a physician because: it provided the opportunity to collaborate with experienced professors, to do scientific work, and to complete my education.

Nazi involuntary “euthanasia” had nothing to do with “mercy killing” as it had never been a compassionate act. Rather it was a bogus pseudo-scientific and economic theory stemming from notions of racial “hygiene”. The Nazis destroyed “life unworthy of life” (lebensunwertes Leben) as they termed it, not as an act of mercy, but as part of a strategy to murder that part of the population they considered to be inferior.

It may be considered that the most important and grave contribution of medicine to Nazism was in a wider perspective: in incorporating eugenics as an idea of medicine; in legitimizing eugenics as medical doctrine; in providing a scientific veneer to sterilization and murder. It thus made a significant contribution to legitimize Nazi practices, helping the regime to be seen as scientifically oriented and making murder appear to be a legitimate scientific event. German medicine was not a victim of Nazism – rather it might be considered as a partner and co-inventor of violent practices in the cause of the defence of the race and its “purification”.

Telford Taylor, chief of counsel for the prosecution at Nuremberg, described the physicians who were tried and convicted of murder in the following terms: The defendants (...) are charged with murders, tortures and other atrocities committed in the name of medical science (...) These defendants did not kill in hot blood, nor for personal enrichment. Some of them may be sadists (...) but they are not all perverts. They are not ignorant men. Most of them are trained physicians and some of them are distinguished scientists. Yet these defendants, all of whom were fully able to comprehend the nature of their acts, and most of whom were exceptionally qualified to form a moral and professional judgment in this respect, are responsible for wholesale murder and unspeakably cruel tortures.

Seidelman and Moe have drawn attention to the numerous references in the scientific literature citing papers written by doctors who worked within the Nazi scientific framework. The question of what to do with findings derived from unethical research has been the subject of discussion with no consensus arising from debates. Pross has charted the failings and successes in attempts to de-Nazify institutions after World War II.

Doctors have been involved in many forms of abuse but the example of Germany is so powerful that it might lead us to underplay the medical role in a series of contemporary human rights questions that reflect both major attacks on the physical and mental integrity of victims, and also abuses of medical ethics that can have the same effect. This comes up very clearly in a range of situations, both in research and also in prisons, immigration, mental health, gender and sexual rights and in the so-called “war on terror” or global security issues. These are discussed as follows.

Medical experiments in Japan during World War II

Receiving much less publicity and subject to virtually no accountability were the medical experiments carried out by Japanese physicians and researchers in Unit 731 in the city of Harbin in occupied Chinese territory. Between 1937 and 1945 this unit undertook abusive, unethical and criminal medical “research” including vivisection, deliberate infection, exposure to cold and radiation of prisoners, mostly Chinese. More than 200,000 prisoners died there. Although Japan has issued general statements of apology for behaviour during World War II – the peaceful Japan of today is sincerely remorseful and striving to atone for past mistakes – there has been no specific apology for Unit 731.
Genocide and violation of human rights of vulnerable individuals in the post-Nazi era

Mass killings did not end with the defeat of the Nazi military machine in 1945. Disrespect and violations of human rights have occurred and still occur in countries not at war. They may happen in the name of science or for “public protection”, e.g., unlawful confinement of people with mental illness or of those who are socially marginalised. In some cases prisoners are included in medical research without respect for medical ethics – particularly the right to consent 24.

Cambodia

In 1975, the Khmer Rouge under Pol Pot took power in Phnom Penh. Approximately 2 million citizens died between 1975 and 1979 when Vietnamese military intervention ended Khmer Rouge rule. These crimes had a context – between 1970 and 1974, approximately 750,000 Cambodians died as a result of bombing by US B-52 aircraft, that dropped napalm and dart cluster-bombs to destroy suspected Vietnamese forces traveling through Cambodian territory. A consequence of this bombing campaign was to assist the Khmer Rouge led by Pol Pot to take power with his promise to fight the Vietnamese National Liberation Front (known by opponents as the ‘Viet nam Cong San’ [Viet Cong or Vietnamese communists]) 25.

Rwanda

From April to July 1994 (100 days) an estimated 500,000 – 1 million Tutsi and moderate Hutu were killed by members of the Hutu majority. The principal weapons were machetes and knives. The victims constituted approximately 20% of Rwanda’s population 26. The response of the United Nations and individual members of the international community was subsequently criticised for being late and insufficient. The government that subsequently came to power in the traumatised country was itself criticised for human rights failings 27, although it broadly maintained the support of the population.

Bosnia

As the former Yugoslavia broke up in the early 1990s, territories that had been part of Yugoslavia came into conflict. Under the policies of Serbia led by Slobodan Milosevic and Republika Srpska, the breakaway Serbian territory of Bosnia led by Dr. Radovan Karadžić, some 100,000 people were killed in Bosnia-Herzegovina. Like the Nazis’ “cleansing” Europe of Jews, the Serbs’ aim was the removal (“ethnic cleansing”) of any Bosniak [Bosnian Muslim] or Croat in territory held or claimed by the Serbs. However, significantly, they were not dedicated to the physical elimination of Bosnians by policy and did not construct a killing machine in the Nazi style. Nevertheless, in July 1992, when the first international press reports and photos were published, they evoked memories of the horror of the Holocaust 50 years earlier. Despite public outrage, the international community still refused to intervene during the first few years of the conflict 28.

The mass killings in Rwanda and Former Yugoslavia gave rise to Special Ad Hoc Tribunals established by resolutions of the Security Council of the United Nations. The International Tribunal for the Prosecution of Persons Responsible for Serious Violations of International Humanitarian Law Committed in the Territory of the Former Yugoslavia since 1991, known, more commonly as the International Criminal Tribunal for the former Yugoslavia (ICTY), is a body of the United Nations established to prosecute serious crimes committed during the wars in the former Yugoslavia, and to try their perpetrators. The tribunal is located in The Hague, Netherlands, and has jurisdiction over grave breaches of the Geneva Conventions, violations of the laws or customs of war, genocide, and crimes against humanity, committed in Former Yugoslavia since 1991.

A similar ad hoc tribunal was created to deal with crimes in Rwanda. The International Tribunal for the Prosecution of Persons Responsible for Genocide and Other Serious Violations of International Humanitarian Law Committed in the Territory of Rwanda and Rwandan Citizens Responsible for Genocide and Other Such Violations Committed in the Territory of Neighbouring States, between 1 January 1994 and 31 December 1994, known more commonly, as the International Criminal Tribunal for Rwanda (ICTR), was established in November 1994.

Ethics and human rights violation of vulnerable individuals: Failing institutions

Not all abuses of basic rights are carried out by dictators, violent military officers or brutal criminals. Some occur as a result of practices and procedures that have been followed within institutions over many years.

Brazil: Barbacena, Minas Gerais

Between 1930 and 1960, 60,000 Brazilians, mostly black, were killed in a single mental hospital,
the Hospital Colônia de Barbacena. They were killed not by firearms, or gas chamber, but by starvation, cold, and infections. They were epileptics, alcoholics, homosexuals, prostitutes, girls who got pregnant by their employers or fathers, uncles, brothers and stepfathers, women confined by their husbands, women who had lost their virginity before marriage; and their deaths, of course, were not caused by mental illness. A hospital registry detailed the sale of 1,853 corpses to medical schools to be used in anatomy classes. An Italian psychiatrist, who visited the institution in the late 1970s, classified it as a concentration camp. The institution was closed down in 1980 and turned into a museum.

USA: New York. Willowbrook State School

Willowbrook was an institution for “mentally defective” children on Staten Island, New York. In 1965, U.S. Senator Robert Kennedy visited the Willowbrook institution unannounced. He later declared that the wards were less comfortable and cheerful than the cage in which we put animals in the zoo. In 1972, reporter Geraldo Rivera’s television documentary on this institution showed how disabled children were kept there in conditions of deplorable neglect, in an unhealthy and filthy place. He later documented his findings in a book.

The unacceptable sanitary conditions at Willowbrook facilitated the dissemination of many parasitic and infectious illnesses, including hepatitis A and B, and became the focus of infectious diseases research, which was subsequently criticized as breaching medical ethics. Between 1956 and 1972, research at Willowbrook aimed at defining the differences between infectious hepatitis types A and B. As part of this research, mentally disabled children were exposed to preparations containing the hepatitis virus. Beecher wrote that parents gave consent for the intramuscular injection or oral administration of the virus, but nothing is said regarding what they were told concerning the appreciable hazards involved. According to Rothman, experiments that build upon social deprivation are likely to manipulate the consent of the subjects. The researchers contended that the inherent risk of hepatitis was high and that controlled infection would yield benefits outweighing the risks. The institution was closed down in 1987 after a process of de-institutionalisation had been undertaken. The social deprivation, which consists of the many correlated factors that contribute to social exclusion, mentioned by Rothman was clearly the case for both the Willowbrook and Tuskegee studies.

Other human medical research

It may be subtler today but, in certain regions and in certain conditions, the breaches of and disrespect for human rights can be just as bad. It has to be acknowledged that making decisions about medical testing can be a difficult balancing of potential beneficial outcomes, potential harm to the test population, and possible harm to the reputation of the researchers themselves, particularly where there is growing public pressure to “do something” about particular diseases (such as HIV or Ebola) and while there is simultaneously scepticism about drug companies and international research. Openness, transparency and community consultation/participation are other important factors in mounting a successful and ethical research programme. It should be also mentioned that the inclusion of ethical disciplines in the undergraduate school curricula of health-related professions may help the establishment of sound ethics in both clinical and research practices.

The Tuskegee syphilis study (1932-1972), Alabama, USA

The study was conducted by the US Public Health Service to examine the natural history of syphilis among 600 poor black cotton sharecroppers in Macon County, Alabama; 399 had contracted syphilis prior to the trial and 201 did not have the disease. Subjects received free medical care, meals, and free burial insurance, for participating in the study. However, subjects did not provide informed consent; they were never told they had syphilis, they were denied access to penicillin when it became widely available in mid-1940’s.

Disclosure in the press in 1972 was decisive to the discontinuation of the experiment. It led to the 1979 Belmont Report and to the establishment of the United States Office for Human Research Protections (OHRP). In 1997, 25 years after the end of the study, a public apology ceremony was hosted by President Clinton at the White House.

The syphilis inoculation experiments in Guatemala

Information about these experiments was uncovered by Susan Reverby in 2005 while researching the Tuskegee syphilis study. From 1946 to 1948, the U.S. Public Health Service and the Pan American Sanitary Bureau, with Guatemalan government agencies, conducted experiments exposing people to syphilis, gonorrhoea or chancroid. The objective
was to determine the effect of penicillin in the prevention and treatment of venereal diseases.

The researchers paid prostitutes infected with syphilis to have sex with prisoners. In addition, soldiers, prostitutes, prisoners, and patients with mental disorders were infected by direct inoculation. All subjects were infected without their informed consent. In total, it was reported 32 gonorrhoea experiments, 17 syphilis experiments, and one chancroid experiment were conducted, involving 1,308 people including commercial sex workers, soldiers, prisoners, and psychiatric patients. The ages of subjects ranged from 10 to 72 years, with an average in the 1920s. Of that group, approximately only half (678 individuals) can be documented as receiving some form of treatment, but completion of treatment was documented for only 26% of subjects.

A commission set up by US President Obama evaluated thousands of documents and declared it “a shameful piece of medical history”. The report speculates that it is likely that the Guatemalan sites were chosen specifically because they would be “out of public view in the United States and beyond the reach of our laws and research norms” 39. Moreover, subjects may have been viewed as powerless and easily available and local authorities were not merely cooperative but enthusiastic partners 40.

Many people applauded the Obama administration for giving more visibility to it. However even if today’s research is not as infamous as the Guatemala experiment, the pharmaceutical industry is still testing drugs unethically on poor, vulnerable and exploitable populations in the developing world 41.

HIV vertical transmission studies
In the mid-1990s it was established by trials in the USA that vertical transmission of HIV from mother to child could effectively be prevented by administration of zidovudine to the pregnant mother and then to the mother and infant 42. The problem in transferring this regimen to developing world settings was the cost, and research that involved shorter and cheaper drug protocols together with a placebo cohort was proposed. These studies received strong criticism on ethical grounds 43,44, and the ensuing discussion reflected in modifications on the Declaration of Helsinki, especially in relation to the 2000 and 2008 versions.

Angell drew parallels with the Tuskegee research. She listed the ethical violations, which were multiple: subjects did not provide informed consent; they were denied the best known treatment; the study was continued even after highly effective treatment became available. She concluded: The justifications for the HIV vertical transmission studies financed by the US are reminiscent of those for the Tuskegee study: Women in the Third World would not receive antiretroviral treatment anyway, so the investigators are simply observing what would happen to the subjects’ infants if there were no study 47.

Some of those involved in the research rejected the criticisms arguing that the cost factor, the lack of existing systematic treatment, the fact that the trials did not impose additional risks on the placebo group, and that the research had been approved by relevant ethics committees made it acceptable 48.

Cambodia: Controversy over testing of sex workers
Tenofovir pre-exposure prophylaxis trials with a high-risk sex worker population ended after activists protested they were unethical. But were they? As with mother to child HIV prevention trials before, and Ebola crisis medical care after, the tenofovir trials in Cambodia caused controversy. In this event, the trials ended amid protests by non-governmental organizations. The primary reasons cited for the demonstrations included alleged inadequate prevention counselling by the study investigators, a lack of pre- and post-test HIV counselling, and the non-provision of medical services and insurance for those who seroconverted during the study or experienced adverse events related to the trial drug 49. These premature terminations and others led to considerable reflection on the need not only for sound protocols but also for clear and timely communication with the public including via the media 50,51.

West Africa
The pressures imposed by Ebola arose from the imbalance between the rapidly increasing scale of the epidemic and the lack of properly tested potential medicines. In the early days of the epidemic, a candidate, although untested, drug preparation (Zmapp) was available, but in tiny quantities. It was used when foreign medical workers became infected 52. This immediately exposed the tension between “privileging” foreign white medical staff with new drugs versus the view (and we paraphrase Dr. Paul R. Wolpe) that if the first people (to receive doses of ZMapp) would have been Liberian, headlines would have screamed, that the ‘experimental’ drug was tested on poor Africans 53.

As drug trial protocols were debated there arose a difference of opinion between those
advocating traditional random controlled trials and those who believed that the crisis would not permit the luxury of a traditional approach. At time of writing, some of these issues are being overtaken by the significant containment of the Ebola epidemic though they will still need to be addressed.

Final considerations

There are no simple answers to the many situations of human rights abuse depicted here, but a common denominator has to do with situations of vulnerability, powerlessness, discrimination, and oppression of “non-citizens”. How can one explain the fact that often people, seem to, just accept different forms of aggression and denial of their human rights? What happened during the Nazi regime is one example. One explanation may be what Foucault said about the docile body: one that may be subjected, used, transformed and improved. And this docile body can only be achieved through strict regimen of disciplinary acts.

If people are docile, it should be easy to control and rule over them. Foucault proposed that methods, which made possible the meticulous control of the operations of the body, which assured the constant subjection of its forces and imposed upon them a relation of docility-utility, might be called disciplines. With the control of individuals, the masses are then controlled.

Looking at abuses from the side of the perpetrator, the Milgram experiments of the 1960s on “obedience to authority” arguably demonstrated that humans will carry out abusive acts if instructed to do so by someone in authority. They are now recognised to be based on unethical deception of the subjects (who were told the research focused on learning by a “subject” who, in fact, was an actor) and similar experiments could no longer be carried out. The studies have, nevertheless, been hugely influential.

These insights may partially explain how societies can be contained and even participate in atrocious deeds.

Today, in the second decade of the 21st Century, the levels of violence and abuse of human rights make it very clear we still have a long way to go to reach stable and rights-based societies. Health professionals have an important role in tackling these abuses.

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